Autism and Child Psychopathology Series
Series Editor: Johnny L. Matson

Justin B. Leaf
Joseph H. Cihon
Julia L. Ferguson
Peter F. Gerhardt
Editors

Handbook of Quality of Life for Individuals with Autism Spectrum Disorder

Springer

Autism and Child Psychopathology Series

Series Editor

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Brief Overview

The purpose of this series is to advance knowledge in the broad multidisciplinary fields of autism and various forms of psychopathology (e.g., anxiety and depression). Volumes synthesize research on a range of rapidly expanding topics on assessment, treatment, and etiology.

Description

The **Autism and Child Psychopathology Series** explores a wide range of research and professional methods, procedures, and theories used to enhance positive development and outcomes across the lifespan. Developments in education, medicine, psychology, and applied behavior analysis as well as child and adolescent development across home, school, hospital, and community settings are the focus of this series. Series volumes are both authored and edited, and they provide critical reviews of evidence-based methods. As such, these books serve as a critical reference source for researchers and professionals who deal with developmental disorders and disabilities, most notably autism, intellectual disabilities, challenging behaviors, anxiety, depression, ADHD, developmental coordination disorder, communication disorders, and other common childhood problems. The series addresses important mental health and development difficulties that children and youth, their caregivers, and the professionals who treat them must face. Each volume in the series provides an analysis of methods and procedures that may assist in effectively treating these developmental problems.

Justin B. Leaf • Joseph H. Cihon
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Handbook of Quality of Life for Individuals with Autism Spectrum Disorder

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To all those we have had the honor to serve in the past, those who have shaped our current practices, and those we hope to serve in the future with more effective, compassionate, and progressive practices.

Preface

In the United States of America, recent prevalence rates of an individual receiving a diagnosis of autism spectrum disorder (ASD) is 1 in every 44 children, with similar prevalence rates worldwide. The diagnostic criteria for a formal diagnosis of ASD consists of social communication deficits and the presence of repetitive or restrictive behaviors. Additionally, autistics/individuals diagnosed with ASD may have qualitative impairments in cognition, play, and adaptive behaviors. Additionally, autistics/individuals diagnosed with ASD may display aggression and engage in self-injurious behavior. Current estimates indicate there will be approximately 70,000 autistics/individuals diagnosed with ASD who will become adults each year.

It is important to note that individuals do not outgrow their diagnosis; it does not simply go away as one becomes an adult. Therefore, professionals, parents, and autistics/individuals diagnosed with ASD must have resources related to adulthood. Unfortunately, the preponderance of research and resources available (e.g., curriculum books) are made for younger children. Given the increase in prevalence rates and the growing number of autistic adults, the editors of this book came together to develop a handbook on topics specifically related to autistic adults/adults diagnosed with ASD that we hope becomes a valuable resource to professionals, caregivers, educators, and autistic adults. We hope you will find it both interesting and of use in your practice.

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Handbook of Quality of Life for Individuals with Autism Spectrum Disorder: An Introduction

Justin B. Leaf, Joseph H. Cihon, Julia L. Ferguson, and Peter F. Gerhardt

Autism spectrum disorder (ASD) is a lifelong disorder that is defined by impairments in social communication and displaying restricted and/or repetitive behaviors (American Psychiatric Association, 2013). It has also been documented that autistics/individuals diagnosed with ASD engage in aggression (Fitzpatrick et al., 2016), self-injury (Blanchard et al., 2021), pica (Fields et al., 2021), and/or elopement (Anderson et al., 2012). Researchers have also shown that individuals with a diagnosis of ASD have high level of comorbidity with anxiety (Nimmo-Smith et al., 2020), attention-deficit/hyperactivity disorder (Avni et al., 2018), depression (Uljarević et al., 2020), seizures (Matson & Neal, 2009), and tic disorder (Guttmann-Steinmetz et al., 2010). Current prevalence rates indicate that 1 in every 54 children will receive a formal diagnosis of ASD (Maenner et al., 2020).

Children do not outgrow their diagnosis of ASD as they become adults. Simply put, ASD does not just go away. Thus, professionals, parents, and autistics/individuals diagnosed with ASD must have resources related to adulthood. This is especially true with the number of adults who have a diagnosis with ASD. Autism Speaks estimated that 70,000 ASD adolescents will age into adulthood each year (Autism Speaks, n.d.) and that in the next 10 years up to 1,116,000 teens will become adults. These numbers are likely to continue to grow.

Despite being a lifelong disorder, there are great disparities in the research and resources available for autistic/children diagnosed with ASD (i.e., preschool to high school) and autistics/individuals diagnosed with ASD in adulthood. The preponderance of research related to ASD is geared toward younger children (e.g., Reichow et al., 2018). Furthermore, although there are an increasing number of agencies providing intervention for autistics/individuals diagnosed with ASD, the vast majority specialize or focus on services for younger children. Insurance laws/mandates are also mostly written for autistics/individuals diagnosed with ASD under the age of 21 years, leaving many without a viable funding source to receive valuable intervention.

Several professionals have been warning about this disparity and the need to mitigate this inequality in research, clinical practice, and funding resources. For example, Gerhardt and Lainer (2011) stated, “a looming crisis of unprecedented magnitude for adults with autism, their families, and the ill-prepared and underfunded adult service system charged with meeting their needs”

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(p. 37). Roux et al. (2015) referred to what happens to autistics/individuals diagnosed with ASD after they no longer receive special education services as “falling off a cliff” (p. 8). Other professionals, parents, and autistic adults have described various topics as it relates to ASD and ways to improve the lives of autistic adults (e.g., Mason et al., 2018). Although the discussion of adulthood and ASD has increased over the years, more resources are desperately needed. Together the editors came together in an effort to develop a comprehensive handbook on topics related to autistic adults/adults diagnosed with ASD that would be a valuable resource to professionals, caregivers, educators, and autistic adults. This handbook is made up of eight parts.

Part I: Some Perspectives

A hallmark of applied behavior analysis (ABA) has been the inclusion of consumers in the selection of goals and procedures and the direct assessment of the social validity of our goals, procedures, and outcomes (Wolf, 1978). In fact, it can be argued that social validity may be considered the 8th dimension of ABA. The editors of this book also believe it is imperative to include our autistic clients throughout the process of intervention, to learn from them, to change and alter our interventions accordingly, and to grow from these experiences. As such, this handbook begins with a chapter dedicated to the autistic adult perspective.

Specifically, the first chapter in this part includes an interview with several autistic adults. The interview includes questions about their perspectives on autism, ABA, and the relationship of ABA and ASD. These reflections offer a valuable resource to any reader interested in an autistic perspective. Although it is a valuable resource, we do want to caution that this chapter provides perspectives from those interviewed and, as a result, should not be viewed as representative of all autistics/individuals diagnosed with ASD.

The second chapter provides a mother’s perspective regarding her experience with her son’s diagnosis of ASD. Similar to the value of listening and learning from autistic adults, there is also substantial value in listening to the perspective of caregivers. The message in this chapter is powerful, and all professionals should read and reflect on it prior to working with any autistic/individual diagnosed with ASD. Nonetheless, it is important to note that this chapter provides only one unique perspective, and the readers are encouraged to seek out and learn from other perspectives as well.

The final chapter in this part is about family and relationships. This is another important read for practitioners as family dynamics plays a major factor in providing quality intervention.

Part II: Some Challenges

The second part of this handbook includes chapters that contain topics that are essential to autistic adults. Each chapter is authored by experts in the field with respect to each topic. The second part begins with a chapter discussing common psychiatric comorbidities for autistic adults. This chapter is likely to be informative to many practitioners providing services for autistic adults and/or living with an adult who has a comorbid diagnosis. The next chapter takes the reader into autism and the court system. This chapter provides an in-depth overview of every step of the court system process and provides helpful information to help prevent our clients from having to face the brutal realties of the court system.

Part III: Some Important Transitions

The third part of this handbook is dedicated to transitions and education. The first two chapters of this part are important resources to assist in planning for the transition into adulthood. The challenges related to medical and educational transitions have been largely neglected, and resources for practitioners and families are limited. As such, these chapters were designed to help fill this resource gap. The final chapter in this part discusses variables related to success in college and university settings for autistic adults.

This chapter provides many great insights into how students diagnosed with ASD can be more successful in obtaining a higher education degree.

Part IV: Living Arrangement Considerations

The fourth part of this handbook provides an insight and discussion of living arrangements for autistic adults. Finding appropriate, safe, humane, and a least restrictive living environment is often a major challenge for autistic adults and their families. The two chapters in this part are authored by professionals with a wealth of experience related to different living situations for autistic adults. Their experience provides the readers with essential information to assist in finding the most appropriate living environment and other important variables to consider when designing or selecting a living arrangement.

Part V: Cultural Competence, Dignity, and Ethics

The fifth part of this handbook involves important topics that should always be part of the conversation when discussing services and care for autistic adults: cultural competence, dignity, ethics, and respect. Professionals are going to provide services for clients with different cultures, genders, ethnicities, religious beliefs, and values. It is essential that professionals continue to learn and educate themselves on these areas and many others related to cultural competence, dignity, and ethics. The first chapter in this part provides an essential discussion on cultural humility and competence from leaders in the field. The second chapter in this part discusses how to help ensure professionals provide ethical, humane, and compassionate intervention so that clients are treated with dignity and respect. This chapter is vital as society has not always treated people with disabilities in a dignified manner. To continue to improve our science and our clinical practice, we have to continue to grow ethically, and these chapters are a vital part of the handbook.

Part VI: Comprehensive Intervention

The next part of this handbook provides a broad overview of comprehensive interventions for autistic adults/adults diagnosed with ASD. To date, the standard intervention for autistics/individuals diagnosed with ASD has been those based upon the principles of ABA. There have been thousands of studies that have demonstrated the effectiveness of ABA-based procedures and interventions (e.g., Smith, 2012), and several reports indicated that those procedures and interventions meet the requirements to be considered an evidence-based practice (National Autism Center, 2015). As such, the first chapter in this part provides an overview of how this gold standard in intervention relates to autistic adults/adults diagnosed with ASD.

Although, the evidence of the effectiveness of ABA-based procedures and interventions is clear, much of the research is conducted with younger learners. Nonetheless, receiving quality early intervention can greatly improve the quality of the lives for autistic adults (Howlin et al., 2004). Therefore, the second chapter in this part discusses the importance of early intervention as well as considerations when implementing early intervention and how they relate to outcomes in adulthood.

The next chapter in this part describes functional analyses and the treatment of problem behavior of autistic adults/adults diagnosed with ASD. Functional behavior assessment and functional analysis are some of the most published research areas in the field of ABA and autism (Beavers et al., 2013). A functional, behavioral approach to problem behavior is imperative and has a wealth of research to support the effectiveness of this approach over others. This chapter provides insight related to functional behavior assessment and functional analysis with autistic adults/adults diagnosed with ASD.

The final chapter in this part discusses how pharmacological interventions can be effectively implemented with adults diagnosed with ASD. Medications and pharmacological interventions are often prescribed by medical doctors attending to their adult patients with ASD. This chapter provides an overview of common pharmacological interventions and describes the strengths and limitations of what we currently know about pharmacological interventions and their effects for autistic adults.

Part VII: Effective Methods to Teach Essential Skills

The largest part of the handbook consists of six chapters discussing meaningful goals, curriculum, and approaches to develop meaningful and essential repertoires. This part begins with a chapter dedicated to a discussion on the components of meaningful curriculum and the importance of an emphasis on meaningful, socially valid goals. This chapter is a critical read for all practitioners interested in teaching skills that are applied, meaningful, and functional.

The next three chapters highlight specific skill areas. The first of these three chapters in this part discusses the importance of leisure and adaptive skills. Teaching leisure and adaptive skills is likely one indication of a quality program as they are related directly to a person functioning in their environment and engaging in behaviors that make them happy. The next chapter discusses the importance of and methods to develop social skills for autistic adults/adults diagnosed with ASD. The development of social skills can lead to reports of a higher quality of life and decreased reports of negative outcomes (e.g., depression; Schlitz et al., 2018). It is often difficult to know what and how to teach specific social behaviors, two areas this chapter helps the practitioner navigate. The final of these three chapters discusses skills related to obtaining and maintaining gainful employment. Another factor of having a high quality of life is being employed in a job or profession that you love. Unfortunately, this is not the reality for too many autistic adults/adults diagnosed with ASD (Ohl et al., 2017). This chapter provides useful information on how we can help autistic adults/adults diagnosed with ASD obtain and maintain gainful, enjoyable employment.

The final two chapters in this part discusses friendships, dating, and sexuality. All adults, regardless of a diagnosis, should be able to make choices related to who will and will not be a friend and if they even want friends. This would involve developing the skills necessary to make these choices and to develop and maintain meaningful friendships. Furthermore, all adults should be empowered and have the skills to determine if they are interested in dating and developing sexual relationships. These two chapters provide an in-depth discussion related to these often overlooked topics and are an essential part of this handbook.

Part VIII: The Present and Future

The final part of this handbook is dedicated to current outcomes for autistic adults/adults diagnosed with ASD and future directions related to research and practice. This part begins with a detailed evaluation of current outcomes for autistic adults/adults diagnosed with ASD. The next two chapters provide research and practice suggestions for researchers, practitioners, parents, and autistic adults/adults diagnosed with ASD. The recommendations from these two chapters can help ensure that the outcomes for autistic adults/adults diagnosed with ASD continue to improve.

Summary

We want to thank all the authors for their invaluable contributions to this handbook. Taken collectively, we believe this handbook provides a much-needed resource for autistic adults/adults diagnosed with ASD and anyone providing services for autistic adults/adults diagnosed with ASD. We hope that consumers of this handbook enjoy the handbook as much as we enjoyed organizing and editing it and are able to incorporate the contents of it into their practice and research. Finally, we hope that our field continues to progress so autistic adults/adults diagnosed with ASD can continue to access quality behavior services and live the high-quality lives they desire, and deserve, to live. At the end of the day, as behavior analysts our job is to, quite simply, change someone's life for the better. We know how to change behavior. That's the easy part. The hard part is changing behavior in such a way the lives of all involved are improved.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Association. https://doi.org/10.1176/appi.books.9780890425596

Anderson, C., Law, K., Daniels, A., Rice, C., Mandell, D. S., Hagopian, L., & Law, P. A. (2012). Occurrence and family impact of elopement in children with autism spectrum disorders. *Pediatrics, 130*(5), 870–877. https://doi.org/10.1542/peds.2012-0762

Autism Speaks. (n.d.) *Autism statistics and facts*. https://www.autismspeaks.org/autism-statistics-asd

Avni, E., Ben-Itzchak, E., & Zachor, D. A. (2018). The presence of comorbid ADHD and anxiety symptoms in autism spectrum disorder: Clinical presentation and predictors. *Frontiers in Psychiatry, 9*. https://doi.org/10.3389/fpsyt.2018.00717

Beavers, G. A., Iwata, B. A., & Lerman, D. C. (2013). Thirty years of research on the functional analysis of problem behavior. *Journal of Applied Behavior Analysis, 46*(1), 1–21. https://doi.org/10.1002/jaba.30

Blanchard, A., Chihuri, S., DiGuiseppi, C. G., & Li, G. (2021). Risk of self-harm in children and adults with autism spectrum disorder: A systematic review and meta-analysis. *JAMA Network Open, 4*(10), e2130272. https://doi.org/10.1001/jamanetworkopen.2021.30272

Brush, B. (Writer), & Dinner, M. (Director). (1993, May 12). Independence Day (Season 6, Episode 22). [TV series episode]. In B. Brush, M. Dinner, C. Black, & N. Marlens (Executive Producers), *Wonder years*. The Black-Marlens Company; New World Television.

Fields, V. L., Soke, G. N., Reynolds, A., Tian, L. H., Wiggins, L., Maenner, M., DiGuiseppi, C., Kral, T. V. E., Hightshoe, K., & Schieve, L. A. (2021). Pica, autism, and other disabilities. *Pediatrics, 147*(2), e20200462. https://doi.org/10.1542/peds.2020-0462

Fitzpatrick, S. E., Srivorakiat, L., Wink, L. K., Pedapati, E. V., & Erickson, C. A. (2016). Aggression in autism spectrum disorder: Presentation and treatment options. *Neuropsychiatric Disease and Treatment, 12*, 1525–1538. https://doi.org/10.2147/NDT.S84585

Gerhardt, P. F., & Lainer, I. (2011). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy, 41*, 37–45. https://doi.org/10.1007/s10879-010-9160-2

Guttmann-Steinmetz, S., Gadow, K. D., DeVincent, C. J., & Crowell, J. (2010). Anxiety symptoms in boys with autism spectrum disorder, attention-deficit hyperactivity disorder, or chronic multiple tic disorder and community controls. *Journal of Autism and Developmental Disorders, 40*, 1006–1016. https://doi.org/10.1007/s10803-010-0950-x

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212–229. https://doi.org/10.1111/j.1469-7610.2004.00215.x

Maenner, M. J., Shaw, K. A., Baio, J., Washington, A., Patrick, M., DiRienzo, M., Christensen, D. L., Wiggins, L. D., Pettygrove, S., Andrews, J. G., Lopez, M., Hudson, A., Baroud, T., Schwenk, Y., White, T., Rosenberg, C. R., Lee, L., Harrington, R. A., Hutson, M., et al. (2020). Prevalence of autism spectrum disorder among children aged 8 years – Autism and developmental disabilities monitoring network, 11 sites, United States, 2016. *MMWR Surveillance Summary, 69*(SS-4), 1–12. https://doi.org/10.15585/mmwr.ss6904a1

Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research, 11*(8), 1138–1147. https://doi.org/10.1002/aur.1965

Matson, J. L., & Neal, D. (2009). Seizures and epilepsy and their relationship to autism spectrum disorders. *Research in Autism Spectrum Disorders, 3*(4), 999–1005. https://doi.org/10.1016/j.rasd.2009.06.003

National Autism Center. (2015). *Findings and conclusions: National standards project, phase 2*. Author.

Nimmo-Smith, V., Heuvelman, H., Dalman, C., Lundberg, M., Idring, S., Carpenter, P., Magnusson, C., & Rai, D. (2020). Anxiety disorders in adutls with autism spectrum disorder: A population-based study. *Journal of Autism and Developmental Disorders, 50*(1), 308–318. https://doi.org/10.1007/s10803-019-04234-3

Ohl, A., Sheff, M. G., Small, S., Nguyen, J., Paskor, K., & Zanjirian, A. (2017). Predictors of employment status among adults with autism spectrum disorder. *Work, 56*(2), 345–355. https://doi.org/10.3233/WOR-172492

Reichow, B., Hume, K., Barton, E. E., & Boyd, B. A. (2018). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database Systematic Review, 5*, CD009260. https://doi.org/10.1002/14651858.CD009260.pub3

Roux, A. M., Shattuck, P., Rast, J. E., Rava, B. A., & Anderson, K. A. (2015). *National autism indicators report: Transition into young adulthood*. A.J. Drexel Autism Institute, Drexel University.

Schlitz, H. K., McVey, A. J., Dolan, B. K., Willar, K. S., Pleiss, S., Karst, J. S., Carson, A. M., Caiozzo, C., Vogt, E. M., Yund, B. D., & Van Hecke, A. V. (2018). Changes in depressive symptoms among adolescents with ASD completing the PEERS® social skills intervention. *Journa, of Autism and Developmental Disorders, 48*, 834–843. https://doi.org/10.1007/s10803-017-3396-6

Smith, T. (2012). Evolution of research on interventions for individuals with autism spectrum disorder:

Implications for behavior analysts. *Behavior Analyst, 35*(1), 101–113. https://doi.org/10.1007/BF03392269

Uljarević, M., Hedley, D., Rose-Foley, K., Magiati, I., Cai, R. Y., Dissanayake, C., Richdale, A., & Trollor, J. (2020). Anxiety and depression from adolescence to old age in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 50*, 3155–3165. https://doi.org/10.1007/s10803-019-04084-z

Wolf, M. M. (1978). Social validity: The case for subjective measurement or how applied behavior analysis is finding its heart. *Journal of Applied Behavior Analysis, 11*(2), 203–214. https://doi.org/10.1901/jaba.1978.11-203

Part I

Some Perspectives

2 Applied Behavior Analysis: Autistic Adult Perspectives

Amanda N. Kelly and Christiana Colon

Introduction

In our journey of speaking with autistic adults, we had the opportunity to learn a little about each of them, including their experiences receiving applied behavior analysis (ABA) services in their youth. Most of the individuals we interviewed received these services as ABA was first becoming available in the USA. Due in large part to parent advocates, insurance mandates began providing meaningful access to ABA services. The first state to pass an autism insurance mandate, which allowed access to ABA services, was Indiana in 2001. It would be another 18 years before the remaining 49 states also enacted meaningful autism insurance reform. The individuals we interviewed may have been among the first to receive ABA services, helping pave the way for more standardized practices. While there are numerous demonstrations on the effectiveness of ABA, these are often presented as data points on a graph. Our goal with this chapter is to connect these data points with the individuals whose data they represent, and to allow these individuals the opportunity to share with a wide audience, firsthand their perspectives.

Interviewees

Participants for this chapter were recruited through direct contact with former clients as well as reaching out to friends and colleagues, primarily through social media posts. To participate, individuals must have a confirmed diagnosis of an autism spectrum disorder. They must also have received ABA services directly. Two of the participants interviewed met one, but not both criteria, and therefore were not included in this chapter summary, though we valued learning their perspectives.

Eleven individuals were contacted for potential inclusion in this project. As noted earlier, two of the individuals did not receive ABA services; therefore their interviews are not included. Additionally, three other participants expressed interest, but did not schedule interviews. Therefore, the stories and perspectives on the following pages reflect the experiences of six autistic adults: one who identifies as female and five who identify as male. Ages of the participants range from 18 to 30 years. Of the six individuals, five are Caucasian and one is Black. Interviews included individuals who live in Massachusetts, Florida, Hawaii, Indiana, Morocco, and Virginia. Participants from outside the USA were sought, by reaching out to colleagues in India, Kenya, Japan, and the Philippines; however we were unable to locate autistic adults who received ABA services in those regions of the world. This

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is likely a direct reflection that most countries, aside from the USA, do not have insurance coverage or mandates, resulting in a lack of available providers in those areas. All individuals chose to have their first names associated with their responses; none of the participants requested for pseudonyms to be used.

Written and recorded verbal consent was obtained for each participant. For three of the six participants, (i.e., Meghan, Brad, and Luke), their legal caregivers (mothers) were present to help facilitate portions of the interview. In all situations, both consent and assent were sought and obtained. Two of the six participants were former clients, who had received ABA services by one interviewer 7–10 years prior to the interviews.

Regarding saying “autistic” or “a person with autism,” interviewees generally stated they did not have a preference. One participant replied, “I’m probably just on the autism spectrum.” Another participant elaborated by noting, “I’m actually fine with either. I understand why this question is being asked, that I know. Depending on the group or the individual in question. This can be a fiercely debated topic. But for me, personally, it has never once bothered me when I refer to myself as both.” For the purposes of this chapter, we have incorporated both interchangeably. This is done with the intention to show respect to everyone’s preferences and to allow the reader to choose for themselves.

Interviewers

Interviews were conducted by two separate individuals.

Dr. Amanda N. Kelly is a PhD-level behavior analyst and licensed elementary education teacher who has been practicing in the fields of behavior analysis and education for over 20 years. Dr. Kelly has practiced behavior analysis in Massachusetts, Hawaii, and Florida. Dr. Kelly identifies as a Caucasian female and is in her early 40s.

Christiana Colon is a masters level behavior analyst who has been practicing in the field of behavior analysis for 5 years. Christiana has practiced behavior analysis primarily in Florida. Christiana identifies as a Hispanic female in her early 30s.

Procedure

Questions for the interviews were developed by the interviewers. The intention was to ask each interviewee the same set of questions, which occurred for most questions. There were a few occasions where a question may have been omitted, due to the flow of the conversation. All interviews were conducted using ZOOM, a virtual platform. Interviews ranged from 22 to 56 min, averaging 47 min per interview. Interviews were uploaded to Otter.ai, a transcription application. Each transcription was reviewed by the respective interviewer to ensure accuracy of the translation.

Question One: Can You Tell Us a Little Bit About Yourself?

Meghan (Age 18)

I’m friendly, kind, nice, and energetic and hopeful. I’m a hard worker. I used to do that. [Mother: Do you want to tell Amanda some of the things you like?]. I go to high school. In 12th grade this year. [Mother: What kind of stuff do you study?]. English, math, science, and I do cooking. That’s so great. [Mother: What do you want to study after high school?]. I think I will study something. I want to be a chef, I really do. [Mother: What do you do for work?]. I work at Walgreens. I don’t know what else to do. I just stock shelves and do the candy. And it’s interesting. Clean, like clean windows and something like that. [Interviewer: How long have you been working there?]. I’ve been working at Walgreens from four to eight. [Mother: That’s when your shift is. But let’s see, in September/October it will be two years.]. Yeah, I guess you’re right.

Eli (Age 27)

I'm Eli. I'm 27. High functioning on the autism spectrum, currently I'm in an online master's program for disability studies at CUNY School of Professional Studies. Once I graduate, policy making is the goal. I wanted to get into policy making. I don't know how it works exactly, but they said the professors will tell you how to get into it and stuff.

Luke (Age 21)

I was born this way and then I have it when I was like three or two. Okay, I got it around two at what's that called? Rochester, Minnesota.

Brad (Age 30)

Well, I'm currently 30 years old. I am on the spectrum. And, what else? I'm going on 11 years at Goodwill. I do what's known as purging. I used to do textiles, you know, clothes. And every piece of clothing has a color tag on it. And like, for example, red, green, blue, yellow, etc., and one particular color is 50% off and they rotate every week. And what else? In the following week, the same color. That's where I come in. I take them off the shelf and put them in a salvage box. And later on, they're taken to the outlet store. [Interviewer: So, you live in Indiana. Have you lived there your whole life?]. Pretty much, I was born in San Jose, California. And I moved to Indiana when I was like, three or four. Like around like, four. Yeah, I was like really young when we first moved here, and we also spent a year and nine months in Massachusetts.

Taylor (Age 30)

My name is Taylor, I'm 30 years old. I was diagnosed with autism when I was about 4 years old. I went through ABA, from diagnosis until I was about 11–12 years old. And then from there, I received school-based assistance interventions, however you wish to frame that. From there, I graduated high school, graduated college; I became a practitioner in the field as a behavior technician, from 2016 till the summer of this year, when I moved to Morocco, and now I am a professor at a university.

Dash (Age 20)

I'm humble. I'm creative sometimes – when it comes to my hobbies, and everything else I try to do my best. I live here in Virginia. This is kind of a new warm climate. I kind of like warm and grassy plains lakes, so it's quite peaceful. It makes me happy. It's not like Colorado where it's all dry and really humid. Now that place is something else. But I'd say that as for me as a person, I'm not too complex. If you get to know me well, I can be a blast to hang out with.

Question Two: What Does Your Autism Mean to You? If You Were Talking to a Friend Who Didn't Know About Autism, What Would You Tell Them About Autism?

Meghan

It's someone who can be. [Mother: Do you have a hard time finding people to play with?]. Yeah, somebody will play with me sometimes when I was a big kid. But, when we play games, we play together. Like, let's see. [Mother: Are there good things or bad things about your autism? Or both?]. Good. Both of them is autism. [Mother: What do you think is good about it?]. Well, what was good about it is when they are friendly and kind. [Mother: You are friendly and kind. What is bad about it?]. What's bad about it is when you have been bullied. [Mother: Well, you haven't been bullied really, have you?]. No. [Mother: How about at school? Does it make some things hard at school?]. Yeah, people get upset sometimes when they have a hard time. [What do you think is worse: having autism or having epilepsy?]. Epilepsy. [Mother: Because you don't like having…]. Seizures, like when I wear my watch the other day. You know the red thing that spins around so much, that's how I know I have a seizure. [Mother: And you don't want one.]. NO.

Eli

Well, I know I have some capacities, but I also have strengths. I knew I never like, met the full criteria. So sometimes I thought "was I or was I not?" I think I always had bits and traits of it. But I think everybody's a little different with everything.

Brad

Well, it's basically just a simple disability. And like, I do have some, like weaknesses because of my autism. Like, for example, I have a hard time dealing with loudness, like, at concerts or sporting events …And my love for ceiling fans is part of my autism. And I think you (looks to his mother) told me that people with autism, like, have different interests. [Mother: Yeah, special interests. We don't call them obsessions, we call them interests, a lot of times.] I'm not the only one. Because I'm part of a whole community on Facebook that also likes ceiling fans. [Interviewer: It's so fun, what you can find on Facebook. One of my groups is about clouds that I that I follow on Facebook. It's called the Cloud Appreciation Society because I have a special interest in clouds. I didn't know there was one about ceiling fans.]

Taylor

So, throughout my life I've had an interesting dialogue with my autism, of course. I know that even with this concept in the community, it can be one of contention to where the idea of the spectrum or functionality and things like that is a fiercely contested concept in the community. But not just simply in the community, but also in some practitioners' circles of behavioral health as well. I actually worked with some clinicians that have varying views on it. So, when I was diagnosed for the first 10 years of my life, I was low to medium functional range. Especially on the social aspect of it. There were some living skills and issues that I had issues with. But that was actually something my parents did a lot to help me with. I often find that a lot of times there's fellow people with autism or people on the spectrum who tend to fall onto one of two things. They either fight against it or they end up trying to live with it. But it just depends really on their outlook, and factors affecting their life. To use a modern, more cultural sense of it, it's kind of like in Avengers: Endgame with Bruce Banner and the Hulk, where he kind of said that instead of treating the Hulk as like a disease or something and to get rid of it….instead the solution is to actually try to live to coexist with it. And that is what I have found to be the most helpful thing for me, and my autism is that the less I fought against it in the sense of using it either as an identifier or using it as a way to connect with other people or using it as a way to help my life.

Dash

Well for me the positives – it allows me to be creative and think about as much things as possible. Sometimes I can over analyze things, but when I do, it can be a positive. But sometimes I can say stuff that doesn't make any sense, but I try to put meanings into it. Like my art. My art is a part of my autism. It allows me to be creative and somewhat humorous, unintentionally. It makes me forgetful too and sometimes slow, slower at understanding some things but yeah, I would say I'm somewhat proud to have autism. It hasn't been a bad thing so far. It is somewhat fun to have. Benefits? You get to daydream a lot. Outside, you forget a lot of things when you get sidetracked by that daydream.

Question Three: What Are Your Hobbies or Interests? What Do You Like to Do?

Meghan

Yoga, reading. Mm hmm. Is singing also a hobby? [Mother: Singing is also a hobby.]. Yeah. I do that. [Mother: Do you play any instruments?]. I play the piano and I do think I know a lot of instruments.

Eli

Music, writing blogs online, TV shows, and hanging with friends as well.

Luke

I studied about history for a while. I used to be volunteering for the Civil Patrol from 17 to 21. But I heard they have ages from 12 to 21. But I just started at 17 and then I finished at 21. [Interviewer: You did that for 4 years. I remembered that you were doing some of that. What was that like?]. They have like aircrafts, and you've got to do some tests about it. And then they do like some exercise. They do push-ups and sit ups and stretching without reaching. [Interviewer: Did you enjoy it?]. Yeah. And then me and my cadet mates, we just run on a road, walk, run for like, an hour or so.

Brad

I have had this obsession ever since I was really little: ceiling fans. I kind of fix them up. I get extra parts as needed. [Mother: Yeah. So, you'll take an old ceiling fan and clean it up, make sure all the screws match, put light kits on them, you know, just kind of restore them. And then he'll go and sell them or trade them]. [Interviewer: What kinds of things do you like to do? Anything outside? Any other activities that you like to do?]. I like going to movies, like at theaters. I usually go to like comedy and family movies. I don't like horror movies; they are too much for me. The other thing I like to do out of the house is like mini golf, bowling, and new restaurants. And a couple of things that I enjoy but I'm more new to is archery. You know, like shooting a bow? Oh, yeah and axe throwing. [Interviewer: Oh, I've done that. Yeah, it's a lot of fun. It's also a workout!].

Dash

Well, my art. A lot of people whenever they see my art, they usually compare it to something of high standard. "Like your characters look like something from SpongeBob or the Simpsons or Mega Man." One guy said, my art could be tattoo art. I could be a tattoo artist. Right now, I'm just trying to start off small like, I started the (online) account, maybe I could sell a few t-shirts and make a profit out of that. Right now, I've been in college and so far, it's been somewhat mixed. I'm trying to do game design, which is also my second thing to do, like turn my art into an actual product that people can play and enjoy. But outside of that my art has been doing fine. I've been improving. It's not like the simple stick figures that I drew like when I was in kindergarten. I barely drew stick figures back then. But uh, I would say it improved from 2014 to like, right where we are, where I am right now.

Taylor

Oh, wow. (laughs). So I actually don't normally talk about this a whole lot. But I am a gamer. I do like playing video games. But I also prefer to study things; I prefer to read about things, look into things. Find more, learn more and more about things. In a sense, I can honestly say I've never stopped being a student. Except instead of being a student of this or that, or whatever, I find myself being more of a student of the world, just trying to learn as much as I can. So, video games, watching movies, watching YouTube videos, studying, and researching things. Just kind of keeping a tab of what's going on in the world, just trying to be as informed about what's going on in the world as I can. Even of course, before COVID before everything else, I found it to work best to just be aware and be up to date about what's going on in the world. Another thing that actually happened as of last year is that I converted to Islam. Nothing to do with me moving to Morocco, but just as kind of a theological awakening. So, part of my time is also devoted to following the religion and those religious studies. But a lot of it is just interacting with others, learning more about the world, having some free time to do this, that, and the other fun stuff. But a lot of times I try to utilize my free time in my hobbies, to better myself in one way, shape, or form. So, as I've come to explain to people as I've viewed myself as a constant, ongoing project, because that's how I've been able to help both perfect my autism but also as a way to become a better Taylor.

Question Four: What Is ABA to You?

Meghan

ABA is like something that, like, when you think they look like ABA. I think about what ABA is. [Mother: Do you know?]. Hmm, I don't know. [Mother: It's kind of the way you learned stuff.]. It was the kind of way I learned stuff? [Mother: I don't know how much of it you still have at school. I don't think you have very much.]. What do you mean? [Mother: When you were little you used to have it all the time. That's how you learned everything.]. Yeah, I just know different stuff in there. I just studied real hard and I'm a big kid now...I remember the stuff we used to do. [Mother: Do you remember Robyn and Amanda came sometimes?]. I don't really remember. [Mother: Do you remember we learned how to cross the street?]. Yes. I have to know how to be safe and you know safety is an important lesson. [Mother: Yes, it is. Safety is an important lesson. Do you remember Girl Scouts?]. When I was younger, I was in Girl Scouts. [Mother: Do you remember how they helped at Girl Scouts?]. Yeah. [Mother: What kinds of things did you need help with? Did you sometimes have trouble with some of the arts and crafts?]. Yeah, like just putting those little beads on that stick. Then, I had trouble tying it to make it a necklace or bracelet or something.

Eli

Um, it's learning and its behavior. And it's trying to figure out why someone or an animal does something like if it's reinforced and how to assess and change it.

Luke

Trying to make them independent or maybe they might need help some more or maybe, I'm not sure if they can do anything on their own actually. [Interviewer: You were talking a little bit about having RBTs go with you. Can you explain? What's an RBT?]. Registered Behavior Technician. Because I work with them for like 40 h. [Interviewer: What kinds of things did they work on or help you with?]. Trying to make sure if I do anything correctly. I was working at a grocery store for a while and then I was bagging everything at once. And then you know, some customers are okay. And some are not, but I was going to put bubble gum in the same bag, but he told me no bag. Well, that was one customer. [Interviewer: So, you had RBTs that went to work with you as well?]. Yeah, I'm okay with RBTs.

Taylor

Behavior Analysis is the application of behavioral health, but it is also the perfected science of trying to help individuals with autism learn the necessary life skills in order to help them become functioning members of society. It is something that is constantly being worked on to become a better science. People sometimes don't understand that Behavioral Health is a science that is nearly 100 years old. But it's common practice, the one we've come to know as applied behavior analysis did not come into effect until the advent of the BACB around the early 2000s, spit ballpark 2000 to 2003. Before that we had very loose defined, loosely affiliated behavioral health practices. So, I view behavioral health as a still growing process, a science that is still trying to better itself and is still in its early days in terms of practice.

Dash

ABA, I don't know how to describe it. Maybe it's like, for years it's been very helpful. It taught me the basic functions of how to like… well, function, like run a household by yourself. Like I remember, we were teaching ourselves how to like, do the dishes. Right now, I'm great at doing the dishes. Somewhat amateur-ish, but still great. The other thing I remember was we did art. We basically did like communication skills and career goals. I remember the best times we had. We were teaching ourselves like, what was appropriate and what was not appropriate.

Question Five: How Old You Were When You Received ABA?

Meghan

I'm 18 years old, remember? [Mother: Right. You think it was probably around the time you left Middle School?]. I think I just left Middle School and went straight to High School. [Mother: You had home ABA. Once you got to High School, we used it for extracurriculars at school like drama and chorus. And so, we used your hours for that. Do you remember?]. Yeah. Now, my whole entire body is big, huh ma? [Mother: I'm trying to remember who used to go with you. Katrina.]. Yeah. You know, Katrina came to school yesterday. [Mother: I know. She's still your BCBA [Board Certified Behavior Analyst]. You just don't see her that much.]. Yeah, I guess.

Eli

I was 4 and I had services for 6 months. It was 40 h a week in my home and in the playroom. My parents were the first in Nassau County (New York) to win a lawsuit against our school district to receive it. And then by the time I was four and a half, I learned how to talk. It was only like one school at the time that was offering ABA. I didn't even get into that program until I was in fourth grade. And by then, I was at a private school for bright kids and verbal, so she had to say I didn't need it. And I think my mom got off the phone crying about it. And she was glad I didn't wait for them because it took all those years.

Luke

When I was 18? I'm not even sure. Yeah, I think it was 18. So, I'm not sure. Wait a minute, give me a second. I had [analyst name] when I actually when I was 17. And then I had [RBT name] when I was 18 and then [RBT name] when I was 19 and I have [RBT name] when I'm 21.

Brad

[Mother: Currently, Brad gets 9 h of ABA a week. Most of his ABA services, or really all of them, happen now in the community.]. Well, I used to go to [name of center] only once a week. And I learned a few things. I learned how to cook in the oven and use the stovetop. I learned how to converse with people better. I learned how to use Uber. [Mother: I mean, we taught him how to cook in the center, but a lot of his services right now are in the community. And he started ABA, when he was about 13. Well, you know it was when I started at [name of center] and it was just kind of like, "Oh, there's like ABA." He was doing fairly well in school, and he did graduate with a diploma. It took you [looking at Brad] a little extra time, but you did get a diploma. But, once I got involved with [name of center] and the services were available, that's kind of how Brad got started with ABA. That was, you know, 17 years ago. It's much more accessible now. At the time, we were the only center in the state. And, you know, we didn't have...well insurance was barely covering it then.].

Taylor

It was from when I was 4 years old up until 11–12 years old. The thing was, during that time, I had moved between Michigan, Nashville, and Washington state and all in that order. So, by the time I had moved to Washington, the in-school treatments, or behavioral health services that I was receiving in school had started to fade away. My 504, especially by the time I got into middle school, was loosely held in place. And then by my freshman year of high school, it was completely eliminated. During that time, I had lived in three different states. And my degree of services honestly varied between having times where I would actually be taken out of class, to work with a specialist, to having a specialist help me to class, to just simply having time, like additional study time or additional test time. So, varying degrees, depending on the school I was at, and the state I was living in.

Dash

I was like 13 or 14 years old, back in Hawaii, back in the beautiful, luscious place called Hawaii. It was a good place. It was a good day. It was a good day.

Question Six: Did You Find the Services You Received Valuable? Do You Feel They Benefited You?

Meghan

Yeah, yes, I do think that. I think I had fun with them.

Eli

Yeah, I did, because it helped me speak and look at people. And actually, after I finished it, one of the school psychologists re-evaluated me and originally didn't think I was on the spectrum anymore, although I think I always had traits, but I just know I came a really long way from that.

Luke

When I get to 30, I can work at the airport. [Interviewer: You want to work at the airport?]. Yeah, like checking out tickets. [Interviewer: You set your goal for 30, that's awesome. You're going to the Honolulu airport, or you think you're going to leave?]. Here. Before you work there, you got to take tests like Safeway, right? [Interviewer: Probably, I don't know.]. [Mother: He was asking if he was going to be able to get RBT services. Remember (looking to Luke) you wanted to know if you'd get them at what age?]. I don't know. [Mother: Remember? You said you were going to be 30. You wanted to know if you were going to get help when you're at the airport. Right?]. Yeah. [Mother: So, he's asking for help and already thinking of the future. And you wanted to know if you can get RBT help when you're at the airport. And so, I said, "Yeah, maybe they'd help him learn his job and then be on their way".]. [Interviewer: That's right. The idea with ABA is that you want to get the help to do the things you want to do. And then you want to get to a place where you don't need that help anymore. But when we're trying to learn new things, it makes sense that we'd still have help. When we first passed that law, Luke's Law, it stopped at age 15, or 14, I don't remember. Do you? Because you had just turned 15, I think. Now there's no age cap that is stopping people from getting services. So again, because of the great work that you did, the work that you did with your mom and with Emma.].

Taylor

In a sense, yes. As I try to explain it, even though I was receiving services towards the end of the "Wild, Wild West" which was the beginnings of behavioral health, it created a good foundation for me, and my parents gave me a foundation to succeed. It helped my parents and me progress, because if I didn't have those years, I am unsure if my parents would have had the tools and skills to help me to that degree.

Dash

In memory, well yes. So, generally yes. Again, it was very great, like letting me learn all the basics and doing basic stuff, like cleaning your room, doing dishes, doing the bathroom. Like basically doing all the stuff that your mom would basically tell you. Like back then, I struggled a little, a lot. Right now, I do them occasionally. Actually, I don't do it occasionally. I do a lot, like because, well you know, like I know the good and bad things that'll happen if we do these things. Like if you don't do your room, if you don't clean your room, you know, your mom's going to fuss at you. And if you don't brush your teeth, you're going to have cavities all over your body.

Question Seven: Are There Things That Occurred During Your Time with ABA Services You Wish You Could Change? Is There Anything You Didn't Like?

Meghan

I didn't like the boat speeding across makes me seasick. [Mother: Riding on a boat? Ok. I think she's asking more about when people used to come to the house or go to the school program with you. Did you ever think those people were in your way or were you happy to have them?]. Oh, I'm happy to have them.

Eli

I'm not really sure.

Luke

[Mother: I know you didn't want to work with [RBT name] anymore. What was one of the things that [RBT name] used to do that was upsetting to you?]. He was trying to help me. [Mother: But didn't you know how to do some of those things? Was he kind of over helpful?]. Yeah. Well, he was trying to make sure if I can do it right.

Taylor

What I received was not common practice. In a sense I would've wished to receive the services that I do as a practitioner. That way it would've been fluid, and something consistently done regardless of where I lived. I was in some ways subjected to some unethical stuff. I was one time locked into a storage closet. I was one time held down because of the severity of my behaviors and aggression and other behaviors I engaged in. Of course, I would have liked different approaches to that but again c'est la vie. Truth be told that it's hard for me to say because I want to say I would do a lot of what I had done as a behavioral technician.

Dash

I don't remember a single thing. Like I said, they're doing a great job. I was the one that was the problem, kind of. I wish I could have paid attention more.

Question Eight: Are There Things You Were Taught That You Wish You Weren't Taught?

Eli

Not that I could think of.

Luke

Trying to make sure if I can do things on my own before helping.

Taylor

My autism has blocked out 70–80% of my memory of those years. I wish I was taught something that I could've retained and would've stuck besides from a general toleration of instruction. For example, one of the few memories I have was from one of these workers teaching me how to write. I say, if you see my handwriting, you need an Egyptologist, someone who studied ancient Chinese calligraphy and maybe someone who studied some Mandarin (laughs). Learning better handwriting would've been beneficial. Or even like, one of the things that even in today's practice that isn't agreed upon or a standard of services is whether you can teach life skills. There is this constant back and forth tug of war between providers and payers about whether or not this is something we should cover or not cover. If they would have provided this, if this would have been covered, then my dental record would be some triple digit percentage better (laughs) than what it is now. Because, aside from my parents, no one worked with me on it.

Dash

Well, when I think (name of center) was a bad and not a good place. Then there were two guys. I think their names were Connor and Keegan. Like until then, they were the reason I will go there. They were the reason, because then we could hang out. They were the most unique people I've ever met. Like, if I can see them today, again, I would be very happy to see them. Like I used to have best friends, but like they're the ones that seem to be somewhat on my levels, like, kind of. They seemed like they had a lot of inside jokes amongst each other.

Question Nine: What Would You Tell Other Autistic Individuals with Autism About ABA?

Eli

It's usually done as an early intervention for autism, but it's used for other things too. It's just based on positive reinforcement and teaching new skills. And that I had it when I was little too and that it helped me talk.

Luke

That they should get ABA. Make sure they didn't do some stuff and then make sure they didn't do anything and then, and um, and then maybe they can be on their own or not, depends how that is.

Brad

Well, I would just tell them that (name of center) is a big help, and I would highly recommend it.

Taylor

A part of the blowback we're receiving about the services is because other people have been harassed online about "how we can keep doing this therapy, it's torture etc." Most of the individuals that are considered self-advocates with autism and hellishly against behavioral health… most of them are about my age and I would tell them "Look what you went through in treatment and what I went through is not what's practiced today. It's standardized and based on a code of ethics. Even though the BACB does not enforce this as much as it could, most of the practices are enforcing this code at the ground level with no qualms on calling someone out based on this code." I explain to them it's not the same. You may hear about the horror stories that you hear online but that's the minority. It's something it's pointed out because it's the exception, because if it was the norm, you wouldn't feel the need to point it out. I try to relate to them via experience. First, I hear them out, then I relate to them, then give my explanation on where I understand where they're coming from but to understand that it's not the same. What we went through is in the past but not the present.

Dash

Join this, you need it! Okay, maybe not that blunt. But I have something to say, but I don't know how to say it (pause) – like please for the sake of your future and for others, join. Join now! It's been a really great help. I'm pretty sure of it.

Question Ten: Do You Still Have Contact with Any of Your Teachers or Therapists?

Meghan

A dozen teachers. [Mother: You still talk to a lot of them, right?]. Yes. [Mother: Do you remember who you still talk to besides Amanda?]. Oh, Miss Dawson. [Mother: That's your teacher now. Who do you do exercises with everyday online?]. Mrs. Bruin. [Mother: Mrs. Bruin. Her second-grade teacher teaches an exercise group and Meghan signs up every month. And there is Ms. Ross sometimes.]. Yes, on Facebook. [Mother: Oh, how about your favorite from middle school? Who's your favorite teacher in middle school?]. Mr. Robert. [Mother: Do you still see him?]. I can see him again. [Mother: Yup, you do see him at the High School, but you're not in his class?]. Oh, right.

Eli

Yeah, most of them, I think through Facebook.

Luke

My favorite was two teachers I had in ninth grade and one in tenth grade. I'm okay with them. And this other teacher, the third one, I'm okay with them. The other teacher I had was okay, but other teachers I do not like.

Brad

No, not really. [Mother: Some on Facebook?]. Yeah, well some on Facebook.

Taylor

No, I do not. That's mostly because by the time I stopped and worked around becoming a self-advocate, I couldn't remember who helped me in that time.

Dash

I wish I could still talk to them. I had a great one back in Colorado. His name was Mr. Mark. He was the one, like you, that helped me snap back into reality, to make sure that I actually do my stuff. And also like to just do your work and not be lazy. Do work first and play later. That's the type of work he was giving me, and it worked.

Question Eleven: Were There Any Therapists You Didn't Like That You Remember? What Were They Like?

Luke

"You have to do this, do that." But, yeah, but I can do it if I want to. Or not that I want to, but I can. [Mother: Meaning you could do it already?] Yes.

Eli

It was such a long time ago. I think I remember more of the speech. I was much older at that point.

Taylor

Characteristic wise, you could tell when someone is honing it in and in it to win it. You can tell who's there for a paycheck. Those who truly had heart or had a family member who had a similar disability. You can tell when someone was actually wanting to do this because they earnestly wanted to help. They were willing to do whatever it took to get through to you and that they wanted to help you. I honestly knew who was there to help me and who wasn't. In that way, I was able to know who I could trust and work with. In my professional experience, I could say the same things with colleagues. I could tell who went to school and took the time to dedicate it to the field and the individuals that were helping versus someone who read a couple things online and felt "Oh hey I can do this" and didn't have the right skills to do it.

Dash

Nope. I don't think so. I don't think I disliked anyone.

Question Twelve: Do You Have Friends or People You Know That Had ABA? Did They Share a Similar Experience?

Meghan

Yeah. Like any old people? [Mother: No, like people that come to their house to help them, like they do for Matty (her brother). You know how Amy comes for Matty?]. Yeah. [Mother: Do any of your other friends have that?]. Tori, yeah Tori does. [Mother: Remember you used to go to her house to have playdates when she used to have her services?]. Yes. [Mother: Who else has home services? Collin?]. Collin, yes. [Mother: Both Collins.]. Two Collins (laughter).

Eli

I'm trying to remember. I may have known someone I went to, like middle and high school with that may have had it when he was younger. I'm trying to remember who else? Oh, and I think there was a girl too, that I remember that had it when she was younger, too. I think they did have positive experiences. Although the guy I knew, he said his brother had it. And he goes, "Oh, it just made him respond like a parrot." I think he said that on Facebook. It was probably because the therapist wasn't well trained.

Luke

No, I don't think so.

Taylor

Yes. I am friends with several advocates. They both have had it and are the two I talk to the most. Travis is one of the few advocates that is continuously reaching out to the state legislature and constantly is getting denied to still continue to receive services due to an age cap. Same for my other friend.

Dash

My best friend, but my original best friend, Patrick used to have it. I think he had autism. I think I could be wrong.

Question Thirteen: Is There Anything Else You Would Like Us to Know That We Haven't Covered?

Meghan

I still want to learn about how to keep my head up tall.

Dash

Ah, I don't think so. Right now. Is there anything you would like to add?

Brad

[Interviewer: If you have you have any questions or anything that you want me to add, you can let me know, now or later, you have my email.]. [Mother: Would you be ok if Amanda wanted to do a follow-up interview with you with more questions?]. Sure, when? [Mother: Oh, you know? Just in case.]. Oh, okay.

Eli

Um, well, I was also thinking about ABA because I did internships and research as well. And I'm finding that although discrete trials can be effective for each child, some kids are learning faster just with the mands and like the [name of preschool], I feel like a lot of other places will just use both. I kind of think they should just use whatever they're learning fastest from, not that there's anything wrong with doing discrete trial training with each child, but…like to try to mand first, but if they're still distracted then they go "they need 40 hours or 30 hours of therapy." And sort of individualize it like that. I think therapists also find what helps them like some people like getting the attention first and then doing some of the mands. So, let's do that first, and then see which way they're learning best from and do that intervention. It's all ABA anyway.

Luke

I have to go to work at Safeway now. [Interviewer: Okay, I don't want you to be late. I do want to say that because of you, Luke, moms and dads who don't have the money or who need the money for other things – or moms and moms or tutus (Hawaiian for grandmother) and uncles – they get help, right?]. Yeah. [Interviewer: Just like when we go to the doctor and get our glasses, or we go to the dentist. You have your health insurance now that pays for "Luke's Law." Children could not get ABA in Hawaii, through their health insurance, and you changed all of that. YOU made that so much better for everybody.]. Yeah, okay, thanks.

Taylor

Nope, that's about it. Other than that, I have worked with [Dr.] Amanda [Kelly] and networked with her. I've worked with [Dr.] Gina Green and tried my best to be a resource to help be an advocate to help improve ABA services from an availability standpoint and on trying to progress it along. Trying to bridge the gap of the neurological divide.

3

A Parent's Perspective on Life with a Side of Autism

Mary Rosswurm

I was sitting on the couch exhausted. It was late. The TV hummed low in the background. I was zoned out, awash in its blue light. I felt beat up, like the day had pushed me around and left me battered and bruised. Like every other day, I had done my best to balance the demands of everyone I needed to answer to in my life: my family, my employees, my board of directors, and the parents of the children I serve at LittleStar ABA Therapy. My job is making people happy and offering hope and change through behavior-based therapy. I also remember a distinct thought running through my head, a little electrical buzzing above all the white noise of the news or whatever random rerun I was ignoring.

I cannot make one more decision today.

As if on cue, Brad, my young adult son with autism appeared in the doorway. I love Brad with my whole heart. He makes me laugh. I'm proud of him. Honestly, I guess it's sort of a cliché, but I really do feel Brad has made me a better person. But also like many tired parents, I silently willed him not to talk to me. Not because I didn't want to hear from him, because I didn't want to hear from anyone. He had a simple question.

"Can I have some Cheez-Its?"

Normally, I would've said no because it was so late. But tonight? The very last thing I wanted to do was get into a fight with him over crackers. So, instead, I took a quiet little inhale, "Sure. Knock yourself out." In my mind, I phrased it a little differently: "Eat the whole fuckin' box. I don't care."

He headed to the kitchen, happy to get a snack, blissfully unaware of my inner monologue. I stayed put, happy to reinforce the behavior of him asking nicely. No standoff needed. Everybody won.

Being the parent of an adult with autism doesn't mean I need to be a drill sergeant. It means I'm in a rhythm of making a series of tiny decisions where I balance Brad's needs with mine and our family's. Early in his life, each one of those decisions felt heavy. The stakes were always high. Because in addition to those small moments, my head was swimming with the not so tiny decisions. In the back of my mind, running like a computer program were the "big ones."

Will Brad ever talk? How will he make friends? Will he learn how to make eye contact? What if he ends up stuck in his own little world? Will he ever hug me or tell me he loves me?

Maybe your head is full of similar questions right now. Sharing my experience as the parent of an adult with autism will include some practical advice. It wouldn't do much good to simply tell you about the present, the easy moments, without explaining how I got here. So, I'll share a little bit of my story, as well as Brad's. I also want to touch briefly on the future. What does adulthood look like for people with autism after their parents or caretakers pass away and what kind of changes might make brighter futures for them?

Since 2004, I've had the privilege of seeing hundreds of families come through LittleStar, of which, I am currently the CEO. When others

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couldn't offer me the information I needed a quarter century ago, I dove into the topic headfirst. Autism became my career path, out of pain, passion, and necessity. That experience will be peppered throughout this chapter.

But before any of that, I want to tell you this. Because I believe it's the most valuable takeaway. It's what I wish someone would've told me. If you're the parent of a young child with autism, especially if you're the parent of a child with autism who was recently diagnosed, I need you to know one thing right now; you will be happy again.

Your life will not be permanently occupied with therapy appointments, Internet searches, and mountains of paperwork. Your mind will not be constantly running and full of questions and fears. This moment won't consume you forever. In fact, someday, sooner than you think, you will have a life with a *side* of autism, not a full plate of autism.

I know you have questions. For example, which information should you trust? How do you know when to follow your gut against the advice of the experts? Are they *really* experts? Should you listen to them or other parents you know who have a child with autism? In the beginning, it's dizzying. Especially for your child whose every minute counts. It's a marathon, not a sprint. Drink your Gatorade.

I'll share as much as I can here. But over the years, as your child grows up, you will too. Eventually, it'll all be Cheez-Its. Those little moments where you don't have to think twice because you know *exactly* which battles to fight and when to surrender.

Speaking of Knowing Exactly What to Do

I remember the exact moment I realized just how heavy a load I was carrying. It took something big for me to realize. Really big. In 2011, when Brad was 21 years old, we discovered he had a brain tumor. It started as headaches. It progressed to a sore neck. Eventually, he started throwing up. Those are the three classic signs of a brain tumor. That's how I knew.

We went to the emergency room on a Thursday. Brain scans clearly showed something was off. He had surgery on a Tuesday. The diagnosis was swift. The plan was clear. They needed to operate and follow up with chemo and radiation. I never had to think twice about his treatment. They told me what it was going to be, down to the last detail.

It didn't really click for me until a couple years later. I was talking to a parent in my office at LittleStar. I was telling her about the benefits of intensive ABA therapy. She was talking me through the many options she'd been given by others, about all the investigating she'd done before she could make up her mind on her son's treatment. That's when it hit me. With Brad's brain tumor, it all seemed so simple. Brad got sick. He went to the doctor, who referred him to more doctors. They conferred, came to a consensus, and Brad was treated fast and with ongoing checkups, still to this day. As I listened to her, some thoughts occurred to me: *Wait a minute, I'm the parent, not the doctor. Why am I the one to decide how to treat Brad's autism? This is crazy. They laid out a step-by-step plan for his brain tumor, yet parents are left on their own to put their child's autism treatment plan together.*

Nobody said, "Your son has a brain tumor, go home, do some research, and figure it out for yourself." With autism, everything had been left to me. Most parents end up in similar situations. Suddenly, you're responsible for coming up with your child's treatment plan. The doctor will give you some options to investigate, such as calling your local school district, perhaps starting ABA therapy, speech therapy, and/or occupational therapy. Often, you'll find the providers you speak to will have differing opinions.

Thankfully, we made it through the brain tumor, although we're still dealing with it 10 years later. But that experience offered such a stark comparison to everything I'd experienced with his autism diagnosis and in the years following. Imagine a brain tumor feeling…easy. Why is autism treated so differently in the medical community? Especially as diagnoses are increasing at such a rapid rate. The CDC website has many statistics that prove this. Around 1990, the year Brad was born, a range of 2–7 kids per 1000 were diagnosed with autism. In 2016, a similar study of 8-year-old children in 11 communities showed a prevalence rate of 1 in 54 (Maenner et al., 2020). That's a big jump in a small amount of time. We've gotten good at diagnosing autism, but the treatment protocol hasn't changed much. It's still largely left up to the parents to decide how to treat their child's autism.

We now know that behavior interventions are the gold standard of autism treatment. Doctors are beginning to say, "Yeah, you should get some intense ABA therapy." But largely, the collective experience still involves parents leaving that first meeting without a treatment plan in place, without specific recommendations, and left to piece their child's treatment together. Frankly, it feels like being pushed off a cliff. I'll tell you about my cliff later.

To a Widely Varying Audience

To anyone reading this who isn't the parent of a child with autism, I believe there are valuable takeaways here for you too. Maybe you're a practitioner, physician, extended relative, teacher, speech therapist, friend, neighbor, or maybe you just love somebody with autism. At this point, everybody knows someone with autism. For you, I have something incredibly helpful. Hopefully you'll get some perspective, but I also hope you take away an increased sense of empathy.

You've heard the famous quote about walking a mile in another man's shoes. You might've even heard the phrase, "To understand a man, you need to walk a mile in his moccasins." While this quote is often incorrectly attributed to various Native American tribes, it comes from a famous poem by Mary T. Lathrap (1895) entitled *Judge Softly*

.Pray, don't find fault with the man that limps,
Or stumbles along the road.
Unless you have worn the moccasins he wears,
Or stumbled beneath the same load.
There may be tears in his soles that hurt
Though hidden away from view.
The burden he bears placed on your back
May cause you to stumble and fall, too.
Don't sneer at the man who is down today
Unless you have felt the same blow
That caused his fall or felt the shame
That only the fallen know.
You may be strong, but still the blows
That were his, unknown to you in the same way,
May cause you to stagger and fall, too.
Don't be too harsh with the man that sins.
Or pelt him with words, or stone, or disdain.
Unless you are sure you have no sins of your own,
And it's only wisdom and love that your heart contains.
For you know if the tempter's voice
Should whisper as soft to you,
As it did to him when he went astray,
It might cause you to falter, too.
Just walk a mile in his moccasins
Before you abuse, criticize and accuse.
If just for one hour, you could find a way
To see through his eyes, instead of your own muse.
I believe you'd be surprised to see
That you've been blind and narrow-minded, even unkind.
There are people on reservations and in the ghettos
Who have so little hope, and too much worry on their minds.
Brother, there but for the grace of God go you and I.
Just for a moment, slip into his mind and traditions
And see the world through his spirit and eyes
Before you cast a stone or falsely judge his conditions.
Remember to walk a mile in his moccasins
And remember the lessons of humanity taught to you by your elders.
We will be known forever by the tracks we leave
In other people's lives, our kindnesses and generosity.
Take the time to walk a mile in his moccasins.

Great sentiment, right? But what does it mean? I'm sure you get the gist. A mile might be a measurement, but it can feel incredibly different depending on the terrain and who is doing the walking. If you take a hundred people and give them a hundred different miles, they'll have wildly varying experiences. A mile in the snow and ice means wearing a coat and winter boots. That wouldn't be an effective strategy for someone who needs to walk a mile in the desert or the forest.

If you're not a parent of a child with autism, I want to encourage you to be sensitive to the journeys these parents are on. Each family has their own set of circumstances, which could include varying economic standings, their careers, how much support they have from extended family, how close they are to certain doctors and providers, and on and on. Probably the most important part of their journey involves where their child falls on the spectrum.

Why the Differences Matter

You've heard this before. You know this. Autism is a spectrum. As a phrase, it's now blended into our collective vocabulary. People throw it around casually. Maybe it even makes them feel like an expert. But what does it mean? It's important to define what it means to me, because my experience comes from my very specific perspective. It has everything to do with where my son is on the spectrum. But it also has to do with the vast autism symptoms of the individuals I've met during my career.

The best way I know how to describe the spectrum is with comparisons. Many people end up diagnosed with diabetes. Some only need diet and exercise to manage it; others need insulin. Unfortunately, many people are also diagnosed with cancer. Some of them are labeled as being in stage four; others are in stage one. Not to mention the many types of cancer that behave differently depending on where they present in the body. Even though the patients have the same overarching condition, such as diabetes, you wouldn't treat a Type I and a Type II the same. They would have different needs, protocols, and medications. And nobody would argue with that.

However, many people with autism are out in the world, advocating for themselves. They're saying, "We're fine. You don't need to fix us. We don't need to be cured." Of course, they are, and of course they don't. They have theory of mind and are functioning well in society. But they may not speak for the person who lives with symptoms that lead them to bang their head on the floor 300 times a day, has no functional communication, and needs 24/7 care.

Arguing for simple acceptance as a point of view about a disorder with a broad ranging spectrum is a big swing. It would be like a community of diabetes patients saying they don't think anyone should have insulin because *they* don't need it. "You should just control your diabetes with diet and exercise, like we do." Sounds funny, doesn't it? But that's exactly what's happening in the autism community right now.

If you're a self-advocate, that's wonderful. In this chapter, when I share stories about treatments both valid and invalid, maybe those stories won't apply to you. I'm talking about the people who sometimes can't tell you if they're thirsty or their stomach hurts, if they're hungry or they have a toothache. The people who can't tell you if they're being bullied or molested.

Should somebody like Elon Musk be able to speak for a person with autism who has self-injurious behaviors? What about those who have no sense of personal safety and will wander away? Or those who won't answer to their name? No, because Elon's mile is different than the mile of somebody with moderate to severe autism.

My Story and Brad's Story

Brad has two diagnoses. Tuberous Sclerosis Complex (TSC) is a neurological condition where in about seventy percent of cases, autism ends up being associated. At 4 months, he began to have seizures. We started going through testing. At 6 months, we took him to the hospital. That's when the x-rays and scans began. They pointed out little spots on his brain.

He was formally diagnosed at about 9 months. After that, we were sort of on the lookout for autism. By age two, he was diagnosed with autistic tendencies. By four, he had a full-blown autism diagnosis. So, for me, it wasn't a shock. I was prepared. In our day-to-day life, at that point, autism took front and center. The other diagnosis fell away until the brain tumor years later.

It's easy to talk about it factually, but I still remember going to see the doctor at UC San Francisco the day of Brad's formal TSC diagnosis. We had Brad in a stroller that was laid flat. He was on all fours, rocking back and forth. More like revving, like a tiny little anthropomorphized car. I remember thinking maybe that meant he was going to start to crawl soon. I knew he was behind the curve developmentally. Most babies sit up at 4 or 5 months. At 9 months, he still wasn't.

That day, the doctor was compassionate, but matter of fact. He didn't sugar coat anything. He was an older man in his sixties. Every doctor has a sense of authority, but he especially projected a sense of finality as he summarized his thought. Everything leading up to his point was a blur, but I remember the takeaway clearly. He recommended institutionalization for my 9-month-old baby. It almost felt like he was arguing for it. The message was clear; we shouldn't expect much from our son. We should put him away somewhere and go on and live our lives.

He wasn't trying to be cruel. He was trying to set expectations. In a strange way, I'm grateful. He prepared me for the permanence of Brad's disability. But his recommendation? It felt wrong. I was only 24 years old, but I told him my gut feeling. Even though Brad wasn't crawling or sitting up on his own, I could see the light in his eyes. I could see my infant working things out.

"I'm not putting my baby in an institution."

When we got home, Brad dropped his pacifier. When I cleaned it off and gave it back to him, I put it in his mouth the wrong way intentionally. Brad turned it around immediately. He flipped it with his tiny hands, putting it back in his mouth the right way. I pointed this out to my husband at the time, "See? I know he can learn."

As I was holding Brad, we collapsed into each other's arms. We both cried. We were just told that our baby was going to be severely and profoundly intellectually impaired. I knew it wasn't true. This was the cliff moment. A doctor had just shoved us off the edge. We knew some of what he said was true, but the only alternative was one we weren't willing to take. Because it wasn't right. The doctor that day knew only what the available research could tell him up to that point. But I knew my son.

I wanted to hear something more definitive. Anything other than a basic shrug of the shoulders and a very elaborate version of, "Well, then I don't know what to tell you." Tell me something with a clear prognosis, not one now and one I may get a couple years down the road. I had no idea what to aim for or expect.

The next day, I went to the library. I scanned through microfiche. Remember, this was 1991. I browsed through old books I could tell nobody had touched for years. They weren't worth checking out because they contained such little information. Honest to God, my only point of reference for autism was *Rain Man*. The tiny little bit of information I got from the library was so bad, it told me that the outlook and prognosis for my son was not very sunny. In fact, according to what I read, it felt downright grim. I left the library feeling like my life was over. Like I'd never be happy again and Brad and I would be followed by a black cloud forever.

On top of all that, we were still dealing with the seizures. Once a day, we had to give Brad a shot that helped control them. Giving my baby a shot every single day that made him cry, sticking a needle in his perfect little chubby thigh, and being afraid he would start to associate me with pain was all too much. Oh, and I also had a 3-year-old at the time.

I felt sad. I was in shock. I was just trying to make sense of something we were told was going to happen but hadn't happened yet. I also didn't know to what extent it was going to happen. How intellectually impaired was he going to be? I was trying to trust what I felt to be true with my maternal instincts. At the same time, I was worrying the doctors were right.

My husband worked for an airline. I had the same routine every night. I'd make dinner for everyone. He'd leave around nine. I'd get the kids to bed. I'd clean up the kitchen, tidy the kid's playroom, do the laundry, and I swear time would stop. It felt like everything took an eternity. Everything became difficult and heavy. Frankly, I was scared, lost, and alone. Even though I couldn't sleep, I stayed in bed. I shut down.

Then something magical happened. Something simple. My mom came to visit unannounced. She was in her mid-fifties. She was 5′ 8″, slim, and an extrovert. Her hair was short, and she frosted her naturally wavy locks. In fact, she was adventurous with her hair color. Not that she'd have pink or blue hair, but she wasn't stuck on one color. She was still young and could never decide if she was a blonde, a redhead, or a brunette, so she chose each of them depending on her mood. She had a classic style, loved fashion, but wasn't afraid to experiment either. She was a lady through and through.

She grew up an only child, lost her father at a young age, and became a nurse – eventually becoming a hospital administrator. All that to say, she was a natural caretaker. Our phone conversations had clued her in, even though I was doing my best impression of a mom holding it together. My tone was off. She drove from where she lived, an hour away because she knew something was wrong. When she arrived, the kids weren't dressed. The house was a mess, and I was in bed in the middle of the day. Honestly, the odds are pretty good that I hadn't showered in a while.

She tended to the kids. They were happy to see her. At first, I was excited. I thought maybe she came to take care of them so I could stay in bed and cry. Instead, she gave me the talk, but gently. She sat on the edge of my bed and brushed the hair out of my face as I sobbed.

"You have to get up and out of bed. You have two kids to take care of, whatever happened with Brad, this is the hand that life has dealt you. You have two choices. You can feel sorry for yourself, or you can go out and do the best you can for Brad and get him everything he needs so he can be the best Brad he can be. What are you gonna do?"

I remember answering meekly, "Well, I guess I'm gonna go and try to get Brad the best so he can be his best." I wanted to stay in bed and feel sorry for myself, but I knew the right answer. The only real choice she gave me was the right answer.

Mom replied, "Okay. What do we need to do first?" She understood. She had sympathy. But she knew the best thing was to get started, right away. Sure, we both had hopes. We thought maybe he'd grow out of it. We didn't know what we know now. But it was time to get back to the research. Make the phone calls. There was no Autism Speaks. There was a very small Tuberous Sclerosis Foundation, but mostly made up of volunteers trying to raise money for research. There was nobody I knew to call who could give me advice. I had to figure this out on my own.

I got him enrolled into infant stimulation classes, speech therapy, occupational therapy, and physical therapy. I focused on getting him to appointments. Monday through Thursday involved long drives. That was my life in those early days, getting Brad back and forth. All while living the rest of my life with my husband and 3-year-old, while trying to run a house, making sure dinner was on the table, laundry was clean, and food was in the refrigerator. All the things a parent does.

My plate was comedically overfilled. Messily overfilled. It was slippery pasta falling off the sides. Not even necessarily relating to autism, but just having a child who wasn't hitting the recommended milestones felt frustrating. I was 24 years old and hanging on for dear life. My husband worked hard; he went to work and made sure we had health insurance and as much financial stability as we could have. Brad's dad was very present. Just because I felt alone doesn't mean I was alone. He had his grief and stress, too. He was a good dad, kind, patient, and loving.

I thought a lot about the spots they showed me on his brain scans, those tiny little pinpoints. I could picture myself just placing my finger on his brain, scraping them away. Why can't I just do *that*? But I couldn't. I couldn't fix this. Here's what I could do. Watch his therapy.

The therapists would sit with him and cheerfully coach him on what looked like play, but what was really developing skills. They had a toy. It was a yellow plastic pot with a blue lid. It came filled with fake shiny vegetables. "Okay, put it in the pot," they'd say, referring to broccoli or a carrot. They repeated this over and over. Put the vegetables in the pot, one by one. Fill it up. Dump it out. Do it again. *That* was something I could do. Buy that toy and do what I saw them do at home.

I could watch these therapists, who were much older than me, and I could repeat everything they were doing. The speech therapists, occupational therapists, physical therapists, and the lady who ran the infant stimulation classes. I could go home and do everything they did with Brad. Bringing these exercises into my home helped me regain a deep-seated, much-needed sense of control. Finally, I could *do* something.

Brad didn't have to wait for a weekly appointment anymore. I continued his therapy at home. Not just with a pot of vegetables, but with all kinds of objects and actions. I could cheer him on when he performed whatever action I asked him to do. I could cheerfully say, "Yay!" and celebrate every small victory. I didn't have to stand on the sidelines and just let this happen to me. I could teach him and help him acquire skills faster.

This set me on the path to becoming a speech therapist, which eventually led me to LittleStar. But along the way, everything was moment by moment. It wasn't a neat and clean movie montage. I didn't get everything together in a linear fashion. I needed breaks. And sometimes, the breaks weren't even breaks. Because something else was emerging during this time. Anxiety.

I still remember the first time I tried to have a personal day. Mom stayed with the kids, and I went somewhere that made me happy, where everything was sorted and organized. I went to Macy's. I wanted to get out of my head for a little while and into the world, back to something I loved and enjoyed, shopping. Even though we didn't have a lot of money, I loved cruising the cosmetic counters and asking for samples, smelling all the pretty jars, sitting in a chair, and having someone play with my makeup.

It was a nice escape at first. Then I rode the escalator down to the children's section. Racks of neatly pressed little clothes in primary colors. Everything in its place, just as I had imagined. Only here, that feeling of comfort suddenly and mysteriously began to slip away. The walls closed in. It was as if all the little hangers began to clack together, like someone was pushing them too close. The clothes multiplied. I lost my breath. I began to sweat. My pulse quickened. I wanted to jump out of my skin. I'd never experienced this feeling before and genuinely believed I was having a heart attack. It was not pleasant. I needed to get outside, fast. I needed to be in a bigger space with the cool air and the sunshine and then, I needed to get home. To my safe space.

I don't know if I really ran or if I just felt like I was fleeing. For all I know, nobody noticed. I didn't connect the dots at the time, but in retrospect, this was very clearly stress trying to leave my body. This was the first of many panic attacks that would stay with me for a long time. As of writing this, I'm still dealing with them. My anxiety comes and goes like waves on a shore. It's an old familiar feeling, an unwelcomed acquaintance.

Another great word for this feeling is dread, the fear of the unknown. It's tied up in every bad moment. Parents of kids with autism are often left wondering what will happen to their child when they pass away. Is my kid going to end up in a home? What kind will it be? Who will check on them when I'm gone? I believe this is a problem we can solve long term as a community, but I didn't have access to that hope back then in the early times. We'll get to that later.

On Dealing with Outside Perspectives

In the beginning, for me, there were no outside perspectives other than doctors and therapists. As Brad grew, I inevitably heard from parents who weren't in our community. There were a lot of theories on how I needed to discipline Brad more intensely. Like that would help.

I didn't even have a community until around 2004, when I joined LittleStar. That's when I started to hear more internal opinions as I found other autism parents. These were tough to parse through too. Even 17 years ago, there was much less consensus on what autism was and how to treat it. Because of that timeline, I have a different perspective than parents who have children getting diagnosed now. Even parents going through this 10 years ago heard very different information, but at least for them there was still an autism community. You're somewhere on your own timeline. You'll hear a lot of advice, too. The best gift you can give yourself is to learn how to be a savvy consumer, how to find out what's scientifically valid and what's bunk. I have some questions you can use as metrics.

1. Are you being told that one particular person is the only one who can do a specific treatment with your child? If so, run the other way. Any type of treatment should be replicable. There isn't just one doctor on the planet who can do a heart transplant. The process exists and has been as close to perfected as possible. Any treatment you seek for your child should meet the same standard.
2. Is the science they're sharing peer reviewed? A lot of people will make wild claims. Some will go as far as (basically) touting magic powers. Put on your investigator hat. In fact, there's several places where you can begin to fact check some of the claims you'll hear. One I trust is: www.asatonline.org. Anybody can go to this website, search for therapies, learn what they are, what the research is, etc. It can save you countless hours of feeling like you need to know and understand every therapy you hear about.
3. Finally, ask yourself, will this help lessen my child's autism symptoms or will it just be fun and enjoyable for them? Many therapies claim to work wonders. Maybe for some, they do. But if you're on a limited budget, like most of us are, it's important to learn the difference in creating happiness and enjoyment versus something that will lessen the symptoms of autism. Ideally, you'll be able to do both. Take, for example, dolphin therapy. Your kid might think it's fun. That's great. Nobody is going to argue that fun is bad for any child. If you can afford it and it makes them happy, go for it. Equine therapy? Again, maybe your child will love it, but will it help remediate or lessen the symptoms of autism? No. It'll make them happy and be fun, but it won't reduce their repetitive stereotypical behavior, difficulties with social interaction, or communication skills in general. Being with a horse isn't going to help them make better eye contact.

Try to make a direct correlation to the area that needs progress with the help you're seeking. Nobody says, "You've just been diagnosed with cancer? Go get a horse!" Yet I hear that repeatedly after a new family comes to LittleStar for the first time. Dear America, stop telling everyone with autism to ride a horse. Horses are great. But they don't fix autism.

Pilates is good for me. I enjoy it. I've been doing it since 2011. It's therapeutic. But it's not a treatment for any medical condition I might have.

In more sinister corners of the Internet, you'll find even worse. These are places full of parent testimonials. You have therapies that are proven to cause harm. Chelation is dangerous. Simply put, don't do it. Kids have died. PhDs and MDs have gone through this information with a fine-tooth comb, and it's currently considered unsafe. In this case, please make the wisest decision. Be wary of parent testimonials. You don't know if they're being paid for it. You don't know what other treatments their child is doing. Stay with the science.

In a broader sense, there are two approaches I see parents take repeatedly that leave them stuck in a loop of diminishing returns. I have names for these.

The Shotgun Blast Approach

We see this all the time. The shotgun blast approach is exactly what it sounds like. It's when parents decide to try everything they can think of all at once. They may simultaneously change their child's diet, enroll them in equine therapy, and start supplements.

They do all this in addition to ABA Therapy and occupational therapy. The child begins to make progress. That's good. But how do you know what's creating the change? If you start five things at once, you won't know what's truly working. That's bad.

Often, we see parents credit the easiest changes for any real progress. Frankly, from my perspective, we'll often be hard at work for a year on intensive ABA. We'll just be approaching a breakthrough. The parents will say, "Oh, I just took sugar out of my kid's diet! It's working. Taking the sugar away has made him talk!"

No. It's been the therapy he's been in for a year. Cutting sugar out is good, but that's not what creates long-term change. Wanting to try everything you can is understandable. Your child's just been diagnosed. You've heard a lot about early intervention, and you just want to make the most of their time. So, you try everything. You go all in.

When you get a bladder infection, you visit your doctor. He doesn't put you on three antibiotics all at once. You start with one and see if it works. If it doesn't, you go back, and try another. The doctor repeats this until they find the right medication. In the meantime, maybe they test for other factors that may have led to the infection and do some general detective work. But they don't throw every treatment known to cure bladder infections at you all at once. Think of your child's autism in the same way.

A better plan is to choose one strategy at a time, try that and that alone for at least 2 to 3 months, and see if it works for your child. When you take the slow and steady approach, you can really make the decision about whether a treatment is working. You can lay a foundation. Then, you can add to that, bringing in something else that may support what's already working. Aim for buildable.

The No Stone Left Unturned Approach

We know ABA works. But every now and then, something new will appear. The immediate reflex for parents is to ask, "Do I need to try that for my child? He's at a certain level and I know where he needs to make progress. But what if this new thing is *the one thing* that will make him talk?"

It's optimistic. I understand the temptation. We all wonder if there's going to be a magical moment. The desire to live out that story is a strong pull. I've seen this with sand therapy, hyperbaric chambers, expensive supplements, chelation, or whatever is shiny and new.

The danger here is the potential for wasted time and money. Not to mention the way introducing new treatments to established plans may even interfere with current progress. Returning to the list of questions here is important. What does the research say? Are you willing to wait until there is research to prove its merits? Even waiting to see if a new treatment is still around in 6 months could be smart. Don't get addicted to the next great miracle promise. It means you're always chasing something. And here's a hint: if insurance doesn't pay for it, it may not have strong scientific backing behind it yet. While you're chasing these new therapies, your child could be losing time in the one therapy that is proven to work, ABA. You may have all the money in the world, but you only have 24 h in the day, just like everybody else. Always consider, what's the best use of your child's time?

Culturally, we're obsessed with quick fixes. I'm no different. But the way I fall to it, the stakes are low. Can I just be embarrassingly honest? I'm always looking for the mascara that's going to change my life. I've tried them all. Even though I have my favorite brands, I must keep trying anything new that comes out. It's a compulsion, but a harmless one. I keep thinking I'm going to find something better. But spending 36 dollars on a new tube of high-end mascara doesn't really cost me anything in the long run. I can even call it self-care. It's fun. It's a hobby. It's not wasting my child's time.

We all live in a "no stone left unturned" mindset. We can upgrade almost anything we want, at any time. I could find a salon that could turn me into a blonde today. If we don't like our spouse, we get a divorce. Want blue eyes? Pop in some contacts. Do you feel like your breasts are too small? You can get bigger ones. That's fine for you. Those changes are easy. Unfortunately, autism isn't that easy to change.

It may sound silly to compare these superficial changes to different autism treatments. But the psychological temptations we face and how we respond to them have a high impact on our kids. Fads come and go. But we know that behavior-based interventions are currently the best treatments with the best results in lessening symptoms of autism. They teach new behaviors and decrease unwanted behaviors. We know this. But so many parents are on a never-ending quest for something easier.

Right now, even the most hopeful research is being spent on finding out what causes autism. Maybe someday, hopefully someday soon, we'll know what it is. But there isn't currently a pill that can simply cure it. It's not a bladder infection.

This is the dirty little secret of the autism community; people want a cure, and they'll do anything to get it. If we need to accept autism, we need to accept it for what it currently is, and that's something for which there is no cure. Autism is a disability. Even reading that may feel upsetting. I understand. But focusing on what's real and what works can not only offer you peace, it can also keep you grounded in what's best for your child.

Hooray for Hollywood

In addition to expert opinions from well-meaning strangers, friends, and family, you'll need to develop a thick skin against them and pop culture. I want to start this section with some good news/bad news. Your child is probably not going to grow up to be *The Good Doctor*. That's good because frankly, he's a little boring. That's bad because it means you might need to get comfortable with relinquishing what I like to call, the genius fantasy.

I don't want to be shocking or controversial, but did you know that sometimes Hollywood gets it wrong? I know. Like I said – shocking. But there is so much relief in giving up the glossy TV fantasy of what autism looks like in adults.

First, there aren't a lot of Hollywood portrayals of autism. So, the odds are stacked against them to begin with, hardly seems fair. Among that small selection, mostly the high end of the spectrum is represented. We see characters who are less symptomatic, like Max Braverman from *Parenthood*.

We can forgive movies and television though. It's their job to romanticize and glamourize life. People want to see the human spirit being unconquerable. We want to watch stories that make us feel like we can accomplish anything. It's why the movie version of *Rain Man* had special mathematical skills (Yes, he was based on a real person, but the movie chose to highlight very specific qualities of his.). It's why *The Good Doctor* has a photographic memory. We want the superpowers.

We want to see the autism, but we don't want to feel bad about it. Most fictional characters with autism are high functioning while in reality, most people on the spectrum are moderately to severely impacted. Hopefully there will be more realistic portrayals of autism on TV or in movies soon. I do worry about the average person's perception of autism and how it might affect the community of families who live with it every day.

You've learned that empathy matters, that the spectrum is incredibly broad, that you need to vet opinions and discard most media portrayals. What else lies ahead on the road to being the parent of an adult with autism? Get ready, it's exciting…more of the same paperwork we've been filling out since our child first got diagnosed.

The Practicals

I only have so many pages here, so I'll try to keep most of these points short. Think of this as a list of things you can begin to think about, a sort of primer.

1. You're likely eligible for Medicaid. Will it involve the aforementioned paperwork? Yes. Could it be life changing and worth it? Also, yes. It's not for the faint of heart, a few times

a year I must sit through what I lovingly call the Brad Still Has Autism meeting. It's a formality. There are two types of Medicaid. One is based on income; the other is based on disability. As soon as your child gets diagnosed with autism, they will be eligible for Medicaid. Sign up for it right away. When your child turns 18 years old, they may qualify for Medicaid based on their income. Don't put it off, you'll be glad you have it.

2. Look into a special needs trust fund for your child. There's a systemization to this process than can set them up for a well-funded future. Just know the option exists and can bring you great peace of mind. You'll need a special needs attorney for this.
3. Be prepared for therapies to change as your child grows. That may sound like a no-brainer. But they'll progress in their skillset and need to move on and learn new skills, just like all people do. A lot of parents seem unprepared for this until they settle into the rhythm of steady change that can only come with years of experience. I want you to know that change is always coming, even in therapy. Make peace with it. It's usually good.

   Focus on therapy that's medically necessary that most insurance companies will pay for. If you narrow your lens, you'll feel less overwhelmed by the possibilities. Learn the word "reauthorization" too. It'll come in handy.
4. You'll get greater results from most therapies if you stay consistent with them at home and in the community. Just like when Brad was little and I recreated his therapy at home and he made faster progress because of it, the same is true for adults.
5. ABA is for everyone. Somewhere along the way, it got the reputation as being something for kids with behavioral issues. It's for any child who is behind their typical peers. They work on learning new skills and unlearning unwanted skills. It's really that simple and it helps. Am I biased? Sure. But I'm biased because I've seen years of results.
6. Be prepared to have to obtain guardianship of your child when they turn 18 years old. This process will involve a special needs attorney and will take some time, so it's something you'll want to start looking at around the time they're 16 or 17 years old.
7. If your child attends public school, you'll quickly learn about IEPs. You can always reach out to an advocate if you feel like your school is not providing an appropriate education.
8. Right now, you might be immersed in childhood and adolescent issues. But one thing to always keep in mind is this; your child will only be a child for 18 years. They'll be a grownup for *a lot* longer than that. Everything you do now is to prepare them for adulthood, which hopefully is 60 years or more. Get them into therapy as early as you can so they can be prepared for the most independent adulthood possible.

You don't have to learn this all at once. Just make a mental note of what's been mentioned here. When it's time to dive in, you'll know because it'll be a topic you're facing personally.

Taking the D Out of PTSD

Those tips are designed to help your entire family. But what about you? What about the stress and anxiety of raising a child with autism? If your child is an adult, you may be very familiar with this topic. If your child is still young, you might want to prepare yourself for what could be coming. By now, you know how my anxiety started. What you don't know yet, is that it still continues. The progression was so intense, that at one point, I literally thought I was going crazy.

Turns out, I wasn't and I'm not alone. Recent research done in Australia (Stewart et al., 2020) showed that nearly one in five parents of children with autism had PTSD. Symptoms seemed more likely in parents who have children with self-harming or aggressive behaviors. In the same study, although parents of typically developing children may have symptoms of PTSD, they did not meet the clinical criteria for a PTSD diagnosis. Post-Traumatic Stress Disorder or Generalized

Anxiety Disorder are things you'd expect to find in a soldier returning from war, but anyone who experiences trauma can encounter them.

Our bodies need to deal with stress. They're alerting us to danger to protect us. It's an ancient biological system and frankly, it works. The word disorder feels out of place to me. Our bodies aren't responding to stress in a disordered way. They're responding appropriately. Therapy and medications can help. You may need them. But the biggest gift you could give yourself when dealing with anxiety is acceptance.

Accept that there's nothing wrong with you. Anxiety is not a character flaw. You are under constant stress that most people aren't, so give yourself grace. Just as you shouldn't chase your tail searching for a miracle fix for your child, you also *don't need fixing*. You need care.

You wouldn't say to a soldier, "You're home from war, get over it." PTSD and anxiety may stick around for them, and it could be the same for you. Don't be mad at your body. Treat yourself the same way you would if you contracted any other illness. Seek treatment, adapt, and move forward. Don't be hard on yourself. Don't second guess yourself. You're not going crazy. You are not less lovable or less worthy than anyone else. You don't need to beat yourself up. Show yourself the same compassion you'd show to a returning soldier or a loved one dealing with any type of medical diagnosis.

In a way you're fighting your own little war. But your tour of duty lasts a lifetime. You may never have any problems with this. I hope you don't. But if you do, remember there are a lot of people out there dealing with these issues. If you can, talk to other parents who are familiar with your very specific autism-related challenges or seek therapy.

On Peers

Speaking of reaching out to peers, our kids need theirs just as much as we need ours. Can I tell you something I hear over and over from parents that drives me batty? (Don't feel bad if you've said it too, it's sort of in the invisible handbook of *Things That Other People Tell Us* that's magically delivered to you along with your kid's diagnosis. It's right after the chapter titled *Hey, Let's Try Equine Therapy* and just before *Cutting Out Gluten Solves EVERYTHING*.)

I can't tell you how often I hear a new parent say, "I should probably enroll my child in public school so they can be around their typical peers." We know from studies that kids with autism don't learn from their typical peers (Wolfberg et al., 2012). Wolfberg et al. (2012) found children with autism face distinct challenges in social and imaginary play. Without explicit support, they are likely to remain isolated from peers and the consistent interactive play that encourages developmental growth. They have their entire life to be around typical peers. What they need right now is good, intensive therapy. Most children with autism don't have imitation skills, which is how typical children learn. You often see children mimicking dad shaving or mom vacuuming. There's a reason why kitchen playsets, toy cars, and pretend phones are popular toys. If being with typical peers helped, we'd just…do that. Unfortunately, it's not that simple.

Beyond that, what *really* defines a peer? Is it simply age? I consider people my peers when they share my interests or experiences, when we get along, and especially when we choose each other. It's insulting to think two people with disabilities having a friendship isn't as good as a disabled person having a friendship with a "typical" person.

My son is an individual. He likes to go swimming and watching comedies. He can rattle off Chuck Norris facts like nobody's business. He's hysterical and he makes laugh out loud. He's not a big animal person, but he absolutely loves his dogs. Sports aren't his favorite; he'd take city life over country life any day. People with disabilities have just as many likes and dislikes as anyone else.

For example, he loves ceiling fans. It's been a "special interest" for him for as long as he can remember. He likes to take pictures of them and catalogue them. He's not the only one. He found other people with and without autism who love ceiling fans. The Internet isn't all bad. Those are his peers.

On Community

What do you get when you group a bunch of peers together? You get a community. This experience is sort of built-in during childhood because of school, therapy, and services that are more readily available to children. But it can be a challenge when they hit adulthood as many of the services disappear.

Here on Team Autism, not only do we need to work to provide them with community when they're young, we also need to plan for their future. That entails finding people that will accept and embrace them after we're gone, for example, places of employment and somewhere to call home.

Right now, the movement for community often looks like shared living situations. Maybe you're familiar with this practice. If you're not, it's common to find a home in a residential neighborhood that's been earmarked as a group home for adults with disabilities. There's typically a support worker present in the home, 24 hours a day.

The roommates in these situations may have different disabilities, but they're frequently seen as simply being the same. They're seen as a number. The match is made superficially, based on the fact that there's a bed to fill and they need to be a certain gender. Ability, preferences, personality – none of that is considered. In addition to that, there's such a shortage of adult living options that some parents just have to take the first available option, whether it's the right fit for their child or not.

Even though these group homes are in subdivisions, (the community) you don't often find that these folks are being invited to the neighborhood barbecues. Even though they live in a community of typical people, they're generally isolated. They may have each other, but they're still set apart.

When it comes to having each other, I put that in loose terms. What are the odds you would get along with roommates who were chosen for you because of a random commonality? Being thrown into a house with three other people because you all have a disability doesn't automatically make you best friends. You might not even like each other.

Residents in these situations are often forced to attend group activities together, even when they may not want to. If Johnny wants to go to Bible Study on a Tuesday night, the whole house may need to attend because there's only one support worker to go around and nobody can be left at home alone. To be blunt, I don't think that's very fair. I don't recommend abandoning the model altogether. But I do recommend reexamining it and reframing it as just one possible choice. Maybe this works perfectly fine for some people, but there's no such thing as a one-size-fits-all solution.

I am suggesting we consider personalities, preferences, and commonalities. People with disabilities should be treated as the individuals they are.

Let's say that in the best-case scenario, everyone clicks and gets along. Their differences become their strengths. That would be great, but it's unlikely. Now imagine a community where there was more access to everything. Where there were more people and more choices, from the food, activities, to entertainment options, it would be great to simulate something closer to a college dorm. This model is already in practice in many retirement homes. When run by good people, it works.

We put 100 senior citizens into beautiful retirement homes just like this, where they're allowed to come and go as they please, have guests, enjoy their apartments, cook their own food, or eat in the dining hall. It's like living on a beautiful cruise ship. It's where many of us hope to retire and end up someday. It's considered perfectly normal, respectful, and dignified. But, if we tried to do the same thing with 100 people with disabilities, they'd call it an institution. Wealthy people could privately pay to have their son or daughter live in a community like this, but anybody who had to depend on Medicaid funding would never have access to a place like this.

Medicaid wouldn't pay for it…because they'd think of it as an institution.

Access to variety and options can create meaningful friendships for anyone. But it could be life-changing for a person with a disability who just doesn't have the opportunity to be near others that are like them, their true peers. Imagine a place where parents of children with disabilities *also* had a strong sense of community. You'd have a robust community of residents, parents, and support workers to share the load. That would certainly ease the greatest fear of any parent of a child with a disability.

What will happen to my child after I die? Who will take care of them?

This community would. Now imagine a world where there were enough of these communities that adults with autism who couldn't live independently even had a choice of properties. I'm not saying it's the only option that could work, but it would be a vast improvement.

We want to be able to call a group of friends on a Tuesday night and go to the movies if we want. That's living. I'd love to believe we could open our hearts and minds as a society to make room and carry out plans so people with disabilities can do the same.

Let's tweak the model of what we call an institution. Let's change it. Let's create beautiful places to live where people can be protected from fraud and abuse, but also have, yes, I'm gonna say it again, choices, variety, and access. It's a tall order. But it's something parents of adults with autism think about a lot. I know I'd feel better if someone were working on it. That's probably the next big hurdle for autism parents. We like to choose where we live based on our preferences. Our children should be afforded the same.

Outro

So let's talk about Cheez-Its. You do not have to be the world's champion parent all the time. There's no such thing as a perfect parent anyway. It's okay to pick your battles, and it's definitely okay to avoid circular arguments with your kid, at any age. Especially when the stakes are so low.

Sometimes you can just say, "You know what? You're happy. I'm happy. We don't need to fight over Cheez Its." Depending on what kind of day you had, you might even want to say, "You know what? Eat the whole fuckin' box." And that's okay too.

References

Maenner, M. J., Shaw Kelly, A., Baio, J., Washington, A., Patrick, M., DiRienzo, M., Christensen, D. L., Wiggins, L. D., Pettygrove, S., Andrews, J. G., Lopez, M., Hudson, A., Baroud, T., Schwenk, Y., White, T., Robinson Rosenberg, C., Lee, L.-C., Harrington, R. A., Huston, M., …, Dietz, P. M. (2020). *Prevalence of autism spectrum disorder among children aged 8 years – Autism and developmental disabilities monitoring network, 11 sites, United States, 2016*. https://www.cdc.gov/mmwr/volumes/69/ss/ss6904a1.htm?s_cid=ss6904a1_w

Milson, J. (1895). *"Judge Softly" or "walk a mile in his moccasins" – By Mary T. Lathrap*. James Milson – Writing & Things. Retrieved October 9, 2021, from https://jamesmilson.com/about-the-blog/judge-softly-or-walk-a-mile-in-his-moccasins-by-mary-t-lathrap/

Stewart, M., Schnabel, A., Hallford, D. J., McGillivray, J. A., Forbes, D., Foster, M., Shandley, K., Gardam, M., & Austin, D. W. (2020). Challenging child behaviours positively predict symptoms of posttraumatic stress disorder in parents of children with autism spectrum disorder and rare diseases. *Research in Autism Spectrum Disorders, 69*. https://doi.org/10.1016/j.rasd.2019.101467

Wolfberg, P., Bottema-Beutel, K., & DeWitt, M. (2012). Including children with autism in social and imaginary play with typical peers: Integrated play groups model. *American Journal of Play, 5*(1).

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Family Relationships and Individuals with Autism

Kate Fiske and Amanda Austin

For any family, a child's transition to adulthood is a time of considerable adjustment. Parents who have grown accustomed to the routine, regular care their child once required may be both relieved and anxious about their child's newfound independence and ability to navigate new challenges—college, employment, adult relationships—without daily parental guidance. While this is a time of considerable transition, it is also one that most parents expect and anticipate as they raise their child. Children aging into adulthood is as much a rite of passage for parents as it is for the children, often marked by increased parental freedom, opportunity to focus on themselves and their pursuits, more focused time with their partner, as well as a time to watch what their children accomplish on their own. Though young adult siblings often experience a period of increased distance from one another as they explore their new independence, they may enjoy increased closeness in later adulthood (Neyer, 2002) when their age difference is not as evident and commonalities in experiences are easier to identify.

When an adolescent has autism spectrum disorder (ASD), the transition into adulthood will look considerably different for families as the "launching stage" that is so frequently associated with that time is either postponed or permanently placed on hold (Krauss et al., 2005; Marsack & Perry, 2018). While parents of neurotypical children may grapple with the "empty nest" that often results with their child's transition to adulthood, parents of children with ASD may face a significantly different challenge. Individuals with ASD are the least likely to live independently when compared to young adults with other types of disability (Anderson et al., 2014). Even those adults who are able to live independently may require significant support from their family (Marsack & Perry, 2018), with parents and siblings sharing stories of heightened involvement to ensure the success of the individual with autism in social, university, and employment settings (Fiske, 2017).

Furthermore, many parents and siblings must consider events long past young adulthood; parents have to worry about their own mortality and its resulting impact on their child's future in a way that most parents do not. Siblings are acutely aware of the future, too. Sibling relationships are often the longest-lasting relationships that people experience (Carter et al., 2020; Cicirelli, 1995; Goetting, 1986; White, 2001), and as such

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siblings are positioned to provide care and support to their brother or sister with ASD throughout adulthood. The care that siblings provide to their brother or sister throughout their lives will uniquely influence the normative events they experience as well as their relationship with their brother, sister, and other family members.

Despite the significance of family relationships in the care of adults with ASD, research primarily focuses on the experiences of family members of young children and adolescents. Furthermore, of the available research on family members of adults, a relatively limited body examines the experiences of siblings despite the increasing role they may take during their brother or sister's adulthood. In the current chapter, we draw on the early research on the experiences of parents and siblings of young children and adolescents with ASD, but also synthesize the research that has emerged examining the perspectives of these family members as they provide care for an adult family member with ASD. This growing body of knowledge about the experiences of parents and siblings has important implications for practitioners who support this unique of group of family members and provides direction for the field for both research and clinical practice.

Parenting a Child with ASD

The course of parenting is significantly altered when a child is diagnosed with ASD. Research has closely examined the impact of the diagnosis on the well-being of parents over time and examined the factors that can affect a parent's adjustment to their child's diagnosis. Parents can experience a range of emotions at the time of diagnosis, including anger, guilt, and grief (Fiske, 2017). Parents of adult children can often recollect the exact moment that they learned their child was diagnosed with ASD with astounding clarity; the emotions associated with that event and the subsequent grief they experienced can bring a parent to tears decades later. Parents of children with ASD often reflect on the experience of diagnosis by likening it to a death in their family. They recall the hopes and dreams that they had for their child as an infant and toddler, and how the resulting loss of those dreams—often coupled with the actual loss of skills in their child—resulted in extreme grief (Fiske, 2017). The grief and emotions they experience at the time of diagnosis remain and may resurge as the child ages and the parent is reminded of the long-term nature of the child's diagnosis, such as at birthdays and specific ages that typically are associated with normative milestones such as graduation from high school (Fiske, 2017).

Parents of children with ASD also experience significant stress, at levels higher than virtually any other parenting group, and report higher levels of anxiety and depression than do parents of children with other disabilities (Abbeduto et al., 2004; Bouma & Schweitzer, 1990; Bromley et al., 2004; Donovan, 1988; Hartley et al., 2012; Moes et al., 1992; Olsson & Hwang, 2001; Rao & Beidel, 2009; Yamada et al., 2007). The stress levels of parents are strongly related to the symptoms of ASD. Parents whose children exhibit more significant social skills deficits or communication challenges report higher stress (Davis & Carter, 2008), and parents often reflect on how the difficulty understanding their child's wants and needs is frustrating and heartbreaking for them (Fiske, 2017). Even more significantly, research has repeatedly demonstrated that the strongest driver of parenting stress is the child's level of challenging behavior (Abbeduto et al., 2004; Olsson & Hwang, 2001). Parents who have a child with challenging behavior will be unsurprised by this finding. When a child engages in high levels of challenging behavior, the family's life is incredibly disrupted and limited. Parents who have a child with challenging behavior have significant concern for not only the well-being of their child, but also for themselves and other children in the home. The family routine may revolve around preventing the occurrence of challenging behavior, and family trips into the community for leisure activities may be impossible. Furthermore, families may have difficulty finding care for a child with significant challenging behavior, such that parents receive little relief from their time at home.

The increased care required for a child with ASD means that parents may struggle to balance other aspects of their life successfully. Parents may elect to reduce their time in the workforce entirely, changing the trajectory of their career significantly (Cidav et al., 2012). The financial impacts of raising a child with ASD are enormous (Buescher et al., 2014). Furthermore, raising a child with ASD has a considerable impact on the parents' relationships. Though some parents report that their child's diagnosis has strengthened their relationship with their partner (Fiske, 2017), research finds that parents of children with ASD report a higher level of conflict in their marriages (Brobst et al., 2009) and, in some studies, a higher rate of divorce (Hartley et al., 2010). Parents of children with ASD have limited social support because of the increased need for childcare and also the small pool of parents who will understand their experience. Research has clearly demonstrated that parents' perception of the amount of support they receive from others significantly impacts the stress that they report, in that greater perceived support is associated with decreased parental stress (Benson, 2012).

The bulk of the research on parents' experiences focuses on the experiences of parents of young children and adolescents. Significantly less research has examined the experiences of parents of adults with ASD, consistent with the limited focus on autism in adults with ASD. However, a small body of research has emerged that illuminates how the experiences of parents with ASD may shift as their child ages and as new responsibilities and concerns arise for parents, beginning with parents' experiences of planning for their child's transition to adulthood.

Planning for Adulthood

For most parents of children with ASD, the path to adulthood is a concern long before their child reaches the age of 18 years. Recommendations to parents suggest that they should begin transition planning, or planning for their child's transition into adulthood, in early adolescence (Holtz et al., 2006). Parents report considerable concern about the future when they have a child with ASD, noting more worries about employment, living options, and social opportunities than do parents of children with other disabilities such as Down syndrome, cerebral palsy, or a learning disability (Blacher et al., 2010). The focus of their concern covers the range of adult outcomes that will be affected by the diagnosis of autism. Parents of adolescents and young adults with ASD report concerns about their child's relationships in adulthood (Cheak-Zamora et al., 2015), which could include both development of friendships with others their age, or about challenges that may arise in dating as the adult pursues romantic relationships with others. Parents whose children are college-bound report concerns about the transition to college (Cheak-Zamora et al., 2015), with parents bemoaning the difficulty in finding appropriate supports for their children as they move to a setting that requires a much higher degree of independence than previous school settings.

For adults who will not attend college, or for those who will pursue a career after graduation, parents express frustration with the employment options for their child. Taylor and Seltzer (2011) found that only 18% of individuals with ASD had competitive or supported employment upon graduating from the school system. Shattuck et al. (2012) found that participation in employment increased as adults aged, with those more than 10 years out from graduation reporting the highest engagement in employment opportunities. However, the authors also reported significant disparities in access to opportunities for families of color, with Hispanic and African American individuals reporting lower levels of employment and educational opportunities. Low-income families also reported lower engagement in paid employment or college as compared to other families (Shattuck et al., 2012).

Many parents report that jobs that are interesting or motivating for their children are not attainable because their child does not possess the skills (e.g., social, vocational) or independence to be hired for them, and the jobs that remain may be well-suited for their child's skills but are not motivating, such as janitorial tasks

(Cheak-Zamora et al., 2015). Employment concerns are amplified when children are unmotivated to seek opportunities, or when undeveloped skills are not addressed sufficiently through vocational training. Parents may indicate that their child's employment was secured through the parents' networking, rather than through vocational skills training, which puts a tremendous onus on parents during these transitional years (Cheak-Zamora et al., 2015).

Resoundingly, parents express fear about the unmet needs of their child, but at the same time struggle with future planning (Dillenburger & McKerr, 2011). Herrema et al. (2017a) found that over 75% of family members reported weekly worry that the adult with autism would not be sufficiently cared for in the future, and over 60% reported that the adult was not at all prepared for their future. A stark reality emerges with an examination of family preparation for the future. Among 120 relatives of adults with ASD, only 44% of family members had begun to plan for the adult's future, with 28% of families indicating that they did not know where to start in that planning process (Herrema et al., 2017a). Alarmingly, the extent to which parents perceived their child as unprepared for the future significantly affected their well-being, increasing anxiety and depression. Notably, the extent to which caregivers had actually prepared for the future did not impact their well-being: the far-reaching concern was their perception of their child's preparedness (Herrema et al., 2017b).

Relatedly, an interesting line of research has examined the role of uncertainty in the levels of stress experienced by caregivers. As one might imagine, the level of uncertainty for a parent of a child with ASD is high. From the time of diagnosis, the child's future becomes a question mark, and the parent may have little ability to predict outcomes for their child. This uncertainty persists into adulthood and is affected by the points just discussed: uncertainty about education, employment, and care for the adult over time. Parents who are tolerant of this uncertainty may fare better than parents who are intolerant. Preliminary research indicates that 80% of parents of adults with ASD experience a level of intolerance to uncertainty that is similar to that of individuals with anxiety disorders (Herrema et al., 2017b). Levels of intolerance are highly related to family members' reports of worry, depression, anxiety, and stress, even after accounting for other variables such as the level of challenging behavior and the adult's preparedness for the future (Herrema et al., 2017b).

While parents of adults report that their biggest concern for the future is their child's happiness, the next most frequent concerns are where the adult will live and who will look after them as the parents and the child age (Herrema et al., 2017a). Practitioners who recognize the intensive caregiving responsibilities of aging parents and the difficult decisions they must make about the care of the adult child will be better able to provide support for parents during this time.

Caring for an Adult with ASD

Just as the needs of young children with ASD will vary based on their skills, the support needs of adults with ASD will vary, and perhaps even more considerably than in childhood. Normatively, we expect that parents of children will provide a considerable level of care for them. However, depending on the skills of the adult with ASD, parents of adults may still provide a level of care similar to that which they provided when their child was young. Other parents may have children who can live and work independently as adults. This variation in outcome for individuals with ASD has a drastic impact on the daily lives and well-being of parents, resulting in a range of experiences.

Overall, parents report providing less care for their child with ASD in adulthood than in childhood or adolescence, specifically with regard to the legal responsibility they have for their child and the extent to which they have to help them with self-care, facilitate interactions in the community, and provide companionship to their child (Shivers et al., 2017). However, the proportion of individuals with ASD who remain at home with their parents is staggering. The reported proportion of adults with ASD who live at home varies from 60% to 80% in the research (Herrema et al., 2017b; Shattuck et al., 2012). Some research indicates that this percentage drops to ¼ to 1/3 of individuals in their 30s (Seltzer et al., 2000 as cited in Krauss et al., 2005), but the reliance on parents well into adulthood is clear.

Parents whose children remain home with them into adulthood will face many of the same concerns they did when their child was young. Certainly, some parents may have less responsibility for the child's self-care and other daily living skills as their child ages and becomes more independent. However, others may need to remain in that intensive caregiving role if their child's self-care, home life, and community skills are not developed. When compared to parents of neurotypical adults who co-reside with their parents, parents of adults with autism who live at home report spending a greater proportion of each day on childcare and chores and less time on leisure activities (Smith et al., 2010). As parents age and their adult child grows, the level of assistance they can practically provide may decrease, and the physical support of their child becomes more difficult. Additionally, adults who remain at home may have considerable behavior challenges that limit their inclusion in vocational and community settings. Parents of adults indicate that managing their child's challenging behavior is a primary concern (Dillenburger & McKerr, 2011).

Parents may also find themselves overwhelmed by the prospect of meeting a significant portion of—if not all of—their child's needs for companionship. In a group of 19 adults, parents indicated over 50% had few or no social contacts, including friends (Howlin et al., 2000). Liptak et al. (2011) reported that among adolescents and young adults with ASD, over 50% had not gotten together with a friend in the previous year. In these situations, especially when social skills are so impacted by the diagnosis, parents may feel the need to focus on relationship skills within the family and also scaffold opportunities for social interactions outside of the family. As parents age, they may find themselves not only the primary caregiver for their child, but also the primary source of companionship for their child, fulfilling all social needs (Herrema et al., 2017b). A significant number of parents note the importance of this companionship within their family; nearly 50% of parents whose adult children remain at home valued their companionship and nearly 25% of parents whose children lived outside the home reported that they missed their child (Krauss et al., 2005). However, with the myriad caregiving responsibilities parents take on, the need to provide companionship to their child can be an additional challenge that parents face.

Relatedly, many parents report the impact of their child's diagnosis on their own social relationships. As parents of neurotypical children age, it is expected that their social sphere may broaden without the limitations of child rearing. Parents may be able to leave the house alone for extended periods of time to pursue friendships with others, schedule date nights with partners, and join organizations that will connect them with others. This trajectory may not come to pass for parents whose adult children have autism. Parents whose children remain at home find themselves limited in the time that they can use to engage in these relationships and finding trustworthy respite care options for grown adults with autism can be exceedingly difficult. Parents whose adult children live outside of the home may find that they have difficulty finding other parents with whom they can connect through shared experiences, and that their peers may not understand autism and its impact on the family life and parent (Fiske, 2017). Parents whose lives are significantly impacted by the care they provide for their children, or who are concerned that they cannot provide the level of care their child needs, may consider residential placement for their child. The decision to have the adult with autism leave their childhood home is not one made lightly by parents, and parents may rely on practitioners for support and guidance in weighing the options for care.

Residential Care

For parents whose adult lives are limited by their child co-residing with them, the transition to a residential home may allow parents the time to focus on themselves, other ventures and hobbies, and other members of the family. Additionally, residential care may provide parents the opportunity to more thoroughly enjoy the time they have with their child during visits while the daily care responsibilities fall to staff (Hines et al., 2014). However, for many parents these benefits may be outweighed by concerns about the quality of care their child receives in residential care.

Krauss et al. (2005) surveyed parents whose adult children still co-resided with them, or who had moved into residential care. Parents whose children lived outside the home indicated that they valued the benefits to their child, such as the opportunity to learn new skills in residential care and to have more day-to-day structure than parents could reasonably offer at home. These parents often cited benefits to their own lives, such as greater parental freedom for their own pursuits, calmer home life, and improved relationships with family members such as marital partners or other children. Overall, 90% of parents whose children lived in residential care reported benefits of increased free time, while 45% reported less fatigue following their child's transition to residential care.

These reflections contrasted with those of parents whose children remained at home in adulthood, whose concerns included difficulty managing their child's behavior, the constant caregiving that was required, and the impact that these responsibilities had on parent freedom and activities (Krauss et al., 2005). However, parents whose children remained at home felt "peace of mind" that their child was well cared for at home. While parents whose children lived outside the home reported concerns about their child's safety in a residential home, bringing attention to concerns such as whether staff were well-trained and whether their child appeared well-kept during visits. Important enough to re-state here, parents whose children remained at home also shared how much they valued their child's companionship in the adult years (Krauss et al., 2005).

Unsurprisingly, parents' level of care for and concern about their adult offspring—whether the child remains at home or not—has an effect on their well-being. Practitioners who grasp the unique impact of caring for an adult with ASD and the variables that serve to improve parental well-being will be poised to provide therapeutic support that benefits not only the individual with autism, but also parents.

Parent Mental Health and Well-being

As indicated earlier, parents of children with ASD generally experience levels of stress and emotional distress above and beyond their peers. However, research in the general population tells us that parents experience progressive improvements in their well-being as they age (e.g., Jorm et al., 2005). Researchers attribute this change to general adaptation to parenting challenges and shifts in how parents respond to stressful events as they age, such as decreased time spent worrying (Barker et al., 2011). Such research begs the question of whether this phenomenon occurs for parents of children with ASD.

In general, research does indicate that parental well-being improves as their child ages. Barker et al. (2011) conducted a longitudinal study examining the stress and emotional well-being of a cohort of mothers over time. At the start of the study, older mothers reported lower levels of depression and anxiety than did younger mothers, consistent with past research (i.e., Lounds et al., 2007). Over the 10-year period, depression remained stable while anxiety decreased. The authors warned that these results should be interpreted cautiously given the increases in well-being observed in the general population, but notably both depression and anxiety covaried with adult child behavior across the 10-year period. That is, when parents reported that their child's problem behavior decreased, they also reported lower levels of anxiety and depression. Anxiety also decreased for parents when their child moved out of their childhood home (Barker et al., 2011). These findings are consistent with past research in which parents report decreased stress that corresponds with decreases in the challenging behavior exhibited by their adult child (Lounds et al., 2007) and overall decrease in caregiver burden when their child moves out of the home (Krauss et al., 2005; Seltzer et al., 1997b).

Past research also indicates that parents who perceive greater social support experience lower levels of stress (Benson, 2012), and research to date indicates that the importance of social support holds as children age into adulthood. As when their children were young, parents of adults who report a stronger network of family and friends report higher quality of life and are less burdened by the care for their children (Marsack & Samuel, 2017). Further, parents with smaller social networks report higher levels of anxiety and depression (Barker et al., 2011). Lack of access to social support coupled with decreased time and privacy for access to self-care may exacerbate parental experiences of stress (Marsack & Perry, 2018).

Taken together, these findings indicate clear steps practitioners can take to help ameliorate the mental health concerns of parents of adults with ASD. Before turning to the important clinical implications of these research findings, however, let us first consider the impact autism will have on another important member of the family: the sibling.

Sibling Relationships Over Time

Sibling relationships are unique in the sense that siblings share genes, personal characteristics, and similar upbringings, but despite the many shared experiences the relationship is not one based on choice. Siblings are born into their family and, with few exceptions, remain part of each other's daily life until early adulthood or beyond. Sibling relationships are often characterized by ambivalence, even when both siblings are neurotypical (Hodapp et al., 2017). Stories of sibling rivalry and fierce loyalty to siblings throughout childhood are common, evidencing the broad range of emotions that siblings experience in their relationship with one another. When the sibling relationship involves an individual with ASD, a range of positive and negative feelings is often still present, though the sources and nature of these feelings may vary from those in typical sibling relationships.

Early childhood, for siblings, is marked by an opportunity to learn from and with one another in the context of play. Structured games, sports, and pretend play foster skills such as cooperation, collaboration, and—often—conflict resolution. During childhood, when their knowledge of ASD is still emerging, siblings of individuals with ASD may experience some challenges related to their siblings' play and behavior. Research indicates that young siblings are generally satisfied with their sibling relationships (Rivers & Stoneman, 2003). However, neurotypical siblings may experience frustration regarding their unreciprocated attempts to play with their sibling with ASD (Stoneman, 2001), as well as confusion about behavior such as stereotypy and aggression (Ferraioli & Harris, 2009). Because their brother or sister may not respond as other children might to play initiations, siblings of children with ASD may believe that their brother or sister does not like them. They may also be fearful of their siblings if they are targets of aggressive behaviors (Ferraioli & Harris, 2009). As a result, these relationships may be characterized by less intimacy (Kaminsky & Dewey, 2001), and these siblings may spend less time together than do neurotypical siblings (Knott et al., 1995). Additionally, the sibling with ASD will likely require more parental attention than the neurotypical sibling because of the developmental needs, which can serve as a source of conflict and jealousy in the sibling relationship (Bagenholm & Gillberg, 1991; Hodapp et al., 2017; Howlin, 1988).

As siblings become adolescents, their relationships are reportedly often still positive but begin to change. Siblings of individuals with ASD tend to report less satisfaction with their sibling relationships later in childhood than do younger siblings (Rivers & Stoneman, 2003). This may be explained by a variety of unique concerns related to having a sibling with ASD, most notably the developmental "widening of the gap." When the siblings are younger, they are closer in developmental level, but as they grow older, the neurotypical sibling continues to follow a typical developmental trajectory while the sibling with ASD may make slower developmental gains (McHale et al., 1986). As is expected, the neurotypical sibling will also begin to develop relationships with other peers with whom they may spend more time than their sibling with ASD (Ferraioli & Harris, 2009). At the same time, siblings may also develop a variety of concerns that pose barriers to the sibling relationship, including worry about the family's future (Mascha & Boucher, 2006; McHale et al., 1986), embarrassment about their sibling (Mascha & Boucher, 2006), and perceptions of parental favoritism (McHale et al., 1986).

In adulthood, a variety of factors can complicate and contribute to the quality of the sibling relationship when a sibling has autism. Overall, adult siblings tend to report positive relationships with their brother or sister on the spectrum (Hodapp & Urbano, 2007). In a study of sibling strengths, all but one young adult participant was able to identify at least one strength in their sibling with ASD, and over 50% of young adult participants reported 20 or more strengths (Carter et al., 2020). Adult siblings also report strong feelings of love and protectiveness, as well as responsibility for their brother or sister (Atkin & Tozer, 2014). Some factors have been found to impact the closeness of the sibling relationship. For example, the symptoms of the sibling with ASD may have an influence, with a closer sibling relationship reported in adulthood when the sibling with autism has fewer behavioral problems. Additionally, perceptions held by the neurotypical sibling regarding their role as a sibling can affect the relationship, with siblings who feel more reward in the relationship reporting more closeness (Hodapp & Urbano, 2007).

Feelings of stress and other negative emotions related to the sibling relationship can be exacerbated during adulthood, especially during times when their responsibilities in and outside the family increase and more demands on their time emerge (Hodapp et al., 2017; Mactavish et al., 2007). When asked to reflect on their relationships with their siblings with ASD, some adults report a variety of difficult feelings, such as a sense of loss about not having a typical sibling relationship (Connidis, 1992), sadness and frustration about the limited reciprocity in the relationship (Atkin & Tozer, 2014), and resentment about negative childhood experiences and receiving less parental attention (Hodapp et al., 2017). Many siblings in adulthood also reflect on their role as caretaker for their brother or sister with ASD. Their experiences have important implications for practitioners who work with adults with ASD and interact with caregivers, since siblings may take on the role of caregiver as adults with ASD age.

Siblings as Caretakers

The progression of the sibling relationship from childhood to adulthood is often marked by a transition from a companionship role to a caretaking role (Carter et al., 2020). As children, siblings may begin to take on caretaking tasks for their siblings with ASD, and a younger sibling may take on an "older sibling" role (Ferraioli & Harris, 2009). Over time, siblings may be required to take on more responsibilities at home, such as babysitting their sibling or helping their sibling with daily living tasks. Adult siblings can recall the increased responsibilities and caretaking roles that they held as children and continue to hold as adults (Atkin & Tozer, 2014). This "parentification" of siblings of children with ASD may have positive impacts when the caregiving is focused primarily on the sibling (as opposed to caring for the parents in the family, which is associated with negative outcomes). Adult siblings who report having taken on more caregiving responsibilities for their brother or sister as children also report more positive relationships with their sibling in adulthood (Tomeny et al., 2017a).

As siblings age into adolescence and young adulthood, they develop an increased awareness of and concern about their sibling's future as well as their own future as a sibling of someone with ASD (Bagenholm & Gillberg, 1991). Adolescent siblings may begin to think about what their role may be in caring for their sibling, especially when parents are no longer able to care for the sibling (Harris & Glasberg, 2003). As parents age and become less able to care for the sibling with ASD, the neurotypical sibling often becomes the primary caregiver (Heller & Arnold, 2010). Neurotypical siblings have reported a range of feelings about adopting a caretaking role. Many report that they were expected to take on this role (Bigby, 1997; Brady et al., 2019; Freedman et al., 1997; Greenberg et al., 1999; Griffiths & Unger, 1994; Krauss et al., 1996), and some express reluctance about becoming a formal caregiver (Atkin & Tozer, 2014). Interestingly, and consistent with findings for younger siblings, adults who take on more caregiving responsibilities for their brother or sister in adulthood also report more positive attitudes toward the sibling relationship (Tomeny et al., 2017b).

For siblings whose brothers and sisters require it, they may assume legal guardianship as their brother or sister ages or when parents pass away. However, adult siblings report having limited knowledge of guardianship and its alternatives. One study found that all siblings viewed guardianship as necessary for their brother or sister, and considered alternative plans for the future inappropriate (Brady et al., 2019). Unfortunately, less than half of siblings were able to correctly define guardianship (i.e., making decision based on *legal authority*), and only half knew of alternatives to guardianship. Among the half who knew of alternatives, none were able to explain what the alternatives were. Younger siblings also reported that they were not involved in the guardianship process, and their descriptions of guardianship were based on observations from when their parents went through the initial guardianship process (Brady et al., 2019).

Over 90% of adult siblings report concern about their future with their brother or sister with ASD (Moss et al., 2019) and in many cases, with good reason. Regarding their sibling with ASD, adolescent siblings understand that their sibling may not get married, have a job, or live on their own (Ferraioli & Harris, 2009), and that their brother or sister's inability to achieve these normative life events may have implications for their own futures (Eisenberg et al., 1998; Ferraioli & Harris, 2009). A summary of the impact of caregiving on siblings' life events follows.

Impact of Caregiving on Sibling Life Events

The course of normative events in neurotypical siblings' lives—leaving home, marriage, career, starting a family—can be significantly altered by their roles in the life of their brother or sister with ASD. As siblings transition into young adulthood, they may grapple with leaving home for the first time as they set out for college or employment. While many young adults embrace this new freedom, those who have siblings with ASD may experience more difficulty making such a decision. Siblings who move out of their childhood home report feelings of guilt about leaving their family and feel distant from peers who did not have to consider the same factors when moving away. Faced with these feelings, some siblings decide to live close to their families so they can continue to help with regular caregiving responsibilities, or so they can consistently be part of their brother or sister's life. Others choose not to leave home and have reported that it became increasingly difficult to move out as they grew older due to their awareness of how much their families relied on them to help care for their siblings with ASD. Others choose to move far away to create more distance from their family situations (Atkin & Tozer, 2014).

As siblings consider starting a family, some express concerns about finding a spouse who feels comfortable with the sibling with ASD (Seltzer et al., 1997a). Partners of siblings must learn to understand and tolerate the uncertainty regarding their role in the future of the sibling with ASD, including how often they will provide instrumental support, how close they will need to live to their partner's family, and the potential of becoming a primary caretaker for the sibling with ASD. Numerous studies have found lower rates of marriage (Howlin et al., 2015; Wolfe et al., 2014) and childbearing (Howlin et al., 2015) among individuals who have a sibling with ASD than in the general population. Some siblings may consider how the possibility of transmitting genetics will influence their decision to have children of their own (Ferraioli & Harris, 2009).

Less is known about the impact of the caretaking role on siblings' careers. Adults who have a sibling with ASD are more likely to report that their brother or sister influenced their career choice than are other siblings and may pursue human service careers that in some ways reflect the roles they held in their own family (Martins, 2007). Though research has not examined this question specifically among siblings of individuals with ASD, research on siblings of individuals with mild intellectual deficits indicated that the number of siblings who seek out human service careers is influenced by variables such as how many siblings were in the family, the gender of the neurotypical sibling, and the age of the sibling relative to the brother or sister with intellectual deficits (Taylor & Shivers, 2011).

If siblings take on primary care responsibilities, research has also not evaluated the impact that has on their career advancement. For reference, research indicates that mothers of young children with ASD are more likely to leave the workforce or work part-time to provide care for their child with ASD (Cidav et al., 2012) but that some mothers may have the opportunity to re-enter careers as the child ages (Krauss et al., 2005). Whether similar impacts are seen on siblings in adulthood is unknown, though such effects are likely related to factors such as the skills and behavior of the brother or sister with ASD, whether they co-reside with the neurotypical sibling, how involved the neurotypical sibling is in the oversight of services, and the support the siblings may receive from other family members or service providers.

The caretaking needs of siblings will vary greatly depending on variables related to the dynamics and structure of the family and stand to impact the well-being of the neurotypical sibling. However, their well-being will also be influenced by the skills of the individual with ASD, the general temperament of the sibling, and the unique role that siblings play in childhood and beyond. As with parents, understanding the variables that influence psychosocial outcomes for parents will best position practitioners to provide support for these family members.

Psychosocial Outcomes for Siblings

Across the lifespan, the research on sibling outcomes when a member of the family has autism has been generally mixed. One might not be surprised by the inconsistency in the research, considering the many variables that influence sibling outcomes. First, the individual temperament and resilience of the siblings will account for how siblings adjust to and cope with their experiences with their brother or sister. However, even siblings with similar temperaments may experience different outcomes related to the severity of their brother or sister's autism diagnosis and the communication or behavioral challenges that result. The expectations for sibling involvement and caregiving may vary from family to family and, paired with their parents' coping and well-being, will impact how siblings respond to their unique childhood experiences (Hayden et al., 2019).

Overall, research indicates that most adult siblings who have a brother or sister with ASD function well and without any major psychosocial issues, achieving normative outcomes such as independence in adulthood, employment, and meaningful social relationships (Howlin et al., 2015; Moss et al., 2019). Further, relative to the general population, these siblings have been reported to have increased levels of empathy (Meyer & Holl, 2014; Rivers & Stoneman, 2003; Shivers et al., 2019), compassion, and responsibility (Hodapp et al., 2010; Taunt & Hastings, 2002). They have also been found to have better perspective taking skills and better understand how others think and feel (McHale et al., 2016; Shivers et al., 2019).

On the other hand, some studies report that these siblings have poor adjustment outcomes across the lifespan (Fisman et al., 2000; Rossiter & Sharpe, 2001) and are at an increased risk of having low self-esteem (Rodrigue et al., 1993), poorer relationships (Orsmond & Seltzer, 2007), and internalizing behaviors like anxiety and depression (Rossiter & Sharpe, 2001). Siblings of individuals with Down syndrome have been found to have better health and lower levels of depressive symptoms than siblings of individuals with ASD (Hodapp & Urbano, 2007). Over one-third of these siblings also reported having felt lonely (Bagenholm & Gillberg, 1991), and half recalled seeking counseling to work through feelings of depression, anger, and low self-esteem associated with the past (Atkin & Tozer, 2014).

Practitioners can play an important role in teaching siblings skills and strategies for responding to the unique challenges of being a sibling and coping with the resulting emotions and mental health concerns. In research, outcomes for neurotypical siblings are often related to provision of emotional and social support during childhood, adolescence, and adulthood. For example, one study found that more positive adjustment outcomes in adulthood were strongly associated with sibling use of effective coping strategies rather than the severity of their brother or sister's ASD (Macks & Reeve, 2007), and another found that the use of effective coping strategies was related to positive perceptions of the sibling relationship (Jones et al., 2019). Other studies of adult siblings found that those who had better knowledge of ASD reported more favorable attitudes about their sibling relationship (Atkin & Tozer, 2014; Jones et al., 2019). As in childhood (Tomeny et al., 2019), adult siblings' perceptions of the social support they receive are related to well-being and attitudes about their sibling (Jones et al., 2019; Tomeny et al., 2017b).

With these findings in mind, support services that provide siblings with psychoeducation specific to ASD, coping skills, and social support could significantly influence the well-being of siblings as well as the quality of the relationship with their brother or sister (Jones et al., 2019). Early research among young siblings of individuals with ASD indicate that siblings who participate in support groups that provide psychoeducation on autism, connection with other siblings, and skills to cope with challenging emotions also report outcomes such as decreased symptoms of anxiety and depression, increased coping skills, and increased knowledge about ASD following completion of the group (Kryzak et al., 2015; Jones et al., 2020). Unfortunately, due to relative lack of attention to the needs of adults with ASD and their families in research and clinical work, there is an unmet need among adult siblings for such support.

The provision of support to family members is not solely within the realm of clinical psychologists who can provide or moderate the services described above. Practitioners working directly with the individual with ASD may also be a source of support for family members, including siblings. However, practitioners who work with individuals with ASD and their families frequently express hesitance to engage with siblings. This reluctance likely stems from a lack of skills in working with these family members (Dorr & Virgo, 2010). ASD practitioners rarely receive training in working with families, and even less or no training in working specifically with siblings. The training of these practitioners is typically restricted to the application of behavioral principles to teach individuals with ASD, general information about ASD, and/or following organizational protocols (Atkin & Tozer, 2014). The norms and expectations of the organization in which they work can also influence practitioners' engagement with siblings. Practitioners have expressed that their primary concern is to meet the needs of the person with ASD, they prioritize immediate needs over long-term plans, and they do not believe it is their responsibility to engage with siblings (Atkin & Tozer, 2014).

This lack of practitioner training is often perceived by siblings as a lack of support or interest. Siblings report a lack of confidence when engaging with practitioners, feeling unfairly judged by these practitioners, and feeling the need to be proactive and put themselves forward to become involved with practitioners (Atkin & Tozer, 2014). Commonly, these siblings are not included in transition planning for the sibling with ASD (Heller & Arnold, 2010), and adult siblings have recalled feeling the need to be the ones to initiate discussions with parents about their brother or sister's care (Atkin & Tozer, 2014). Considering the significant caregiving role that many siblings will take on as their brother or sister ages, the importance of building relationships between practitioners and siblings, especially as the siblings age into young adulthood and beyond, cannot be overstated.

Clinical Implications

To address the needs of family members of adults with ASD, the work of professionals must be twofold. First, practitioners must establish supports to meet the needs of parents whose children are currently aging into adulthood, or who are already adults. The amount and quality of services provided directly to individuals with ASD will have a drastic impact on the concerns and well-being of parents and siblings. A majority of family members express concern for their child's future (Herrema et al., 2017a) with regard to their happiness, vocational work, residential care, and guardianship. Parents express fear that their children will not be appropriately cared for, and that they will have unmet needs once the parent is unable to provide for their child. Other chapters in this book will examine the current status of these areas as well as how they may be improved, but professionals should recognize that any improvements in outcome for individuals with ASD will also meaningfully impact parents and siblings.

In addition to work in therapeutic care for adults with ASD, continued development is needed in the area of direct support for families. Recommendations for practitioners in providing guidance, skills training, and social support to family members follow. Practitioners will benefit from training focused on these multiple domains to help them feel equipped to work with families. Across all domains, practitioners should strive to integrate therapeutic skills such as rapport building to build a strong working relationship with family members. Generally speaking, patients in medical settings who perceive practitioners as compassionate—acting from a place of empathy—rate them as more effective (Kraft-Todd et al., 2017) and also have better outcomes (Hojat et al., 2011). In the field of autism treatment, Taylor et al. (2019) found that parents rated behavior analysts as lacking in compassionate skills such as checking in on parents' well-being and understanding parents' experiences raising a child with ASD. Specifically, a significant proportion of parents indicated that their child's behavior analyst did not understand parents' fears and anxieties about the future. Compassionate approaches to family interactions that begin with working to understand the experiences of family members shared in this chapter can improve the quality of interactions with family members. Using the recommendations below, practitioners can greatly influence the family's experience with professionals and reduce feelings of stress related to their involvement in care for the adult with ASD.

Guidance for Families

Increased guidance for family members that serves to help them navigate the transition to adulthood has the potential to decrease anxiety and concern they have about the future of the individual with autism. Because a significant proportion of parents report that they do not know where to start in future planning (Herrema et al., 2017a), events and trainings that help orient families are crucial. For example, a workshop or webinar on estate planning that details and prompts parents to complete the steps they need to take to plan for their child's financial future will help decrease the uncertainty they have in that area.

As adult siblings often become primary caregivers for their brother or sister with ASD once their parents are no longer able to take care of them, a connection between siblings and service providers is essential. Parents are long considered the primary contact for an individual with autism with support needs, and adult siblings share barriers to working with professionals involved with their siblings. Siblings whose role as caregivers will evolve as their brother or sister ages should play significant roles in transition planning. In parallel to the example of a parent workshop above, siblings who attend a workshop on guardianship and/or maintaining a relationship with their sibling in adulthood may feel better prepared for their role in adulthood. Interactions between siblings often serve as a source of frustration, and professional support can help them learn to better facilitate these interactions.

Guidance surrounding the adult transition should not only target families whose children are imminently aging into adulthood. Rather, targeting families of children of all ages will help families better prepare for their child's needs in the area of care, guardianship, vocational planning, and finances. Information about the transition may decrease the stress families experience over time. While providing guidance firsthand is useful, service providers and other professionals should also help parents find these events (e.g., online workshops) and share or summarize them for parents in a digestible way. With the many demands of parenting a child with ASD, many parents may not know where to look for these events or may not have the time to attend them.

Practitioners should take special care to reach families of underrepresented communities with the guidance they provide. Past research indicates less positive outcomes for adults from African American and Hispanic communities, as well as for those from low-income families (Shattuck et al., 2012); workshops and trainings on transition planning should include outreach to these groups and others by both providing support in settings easily accessed by a range of communities and considering the unique needs of cultural groups when providing recommendations. Additionally, practitioners should be aware that many attempts at support for families may not reach parents who do not speak English. The use of interpreters and practitioners who speak other languages should be utilized to ensure that family support services reach all families equitably.

Coping Skills

In addition to educating families about the many elements of the transition to adulthood, many parents and siblings will benefit from coping strategies to help them manage the stress and emotional concerns that arise before, during, and after the transition to adulthood. Approaches that teach family members problem-solving skills to overcome some of the hurdles that they face when planning for adulthood may help alleviate their stress. These problem-solving steps can help parents identify the steps needed to feel more control and security in their child's future. However, in some cases parents may not be able to problem-solve aspects of raising a child with ASD, such as the fact that they cannot predict how successful their child will be as an adult, or the vocational or residential opportunities that may be available to their child as he or she ages.

These challenges return to the difficulty parents have with tolerating uncertainty and the profound effect this lack of tolerance can have on their well-being (Herrema et al., 2017b). Additionally, many parents continue to grapple with grief and other emotions related to their child's diagnosis. For these parents as well as siblings, teaching emotion-focused coping strategies that help them manage their emotions and anxiety about the future may be beneficial. More research on coping strategies is needed to identify the approaches that are most successful in improving well-being of family members. While beyond the scope of the current chapter, therapeutic approaches such as acceptance and commitment therapy and mindfulness-based stress reduction may help family members focus on the present moment non-judgmentally, which has been demonstrated to be effective in managing parent stress (Coyne et al., 2020; Ferraioli & Harris, 2013). Approaches such as these, coupled with problem-focused coping strategies, could meaningfully reduce parenting and sibling stress. Again, by teaching these skills to family members when the child with autism is young may help them better cope with challenges as the child transitions into adulthood.

Reducing Challenging Behavior

From a practical standpoint, research across the lifespan indicates that parent stress and well-being is highly affected by the challenging behavior their child exhibits. Unsurprisingly, and as in childhood, parent stress is alleviated when adult challenging behavior reduces (Lounds et al., 2007). While the provision of services in childhood to reduce these behaviors will help family members as the child ages into adulthood, the field must also be prepared to support and treat adults with ASD who engage in challenging behavior, and to work with family members who must maintain low levels of behavior at home. Additionally, practitioners who provide direct services to children with ASD, and even those who provide parent training, often do not include siblings in their work. Because of the central role siblings may play in their brother or sister's care, siblings should be involved as early as possible—if they choose—in decisions regarding and implementation of the treatment of their siblings with ASD.

Similarly, parents whose children engage in challenging behavior in residential settings may worry that their child will be treated safely and with respect. Qualified professionals who are trained to work effectively with adults on the autism spectrum using evidence-based procedures for behavior reduction are necessary in residential care and other adult service providers. Systemically, a state system that incentivizes and funds the expertise of qualified, trained individuals to work with this adult population is necessary to provide family members peace of mind.

Increasing Social Support

Finally, a step professionals can take to reduce the impact of raising a child with ASD on family well-being is to help parents and siblings develop a strong network of informal social support, or the support received from family and friends. Connecting family members with others who have a same-aged child with autism in the family, but also those whose children are older and can guide them through the transition to adulthood, will offer meaningful support. Professionals may facilitate these connections by orchestrating peer-to-peer to support (Iadarola et al., 2020) or social support groups that offer both opportunities for psychoeducation and connection with other parents or siblings. A benefit of peer-to-peer support is the possibility of connecting family members with others of the same cultural and language background, increasing the culturally appropriate support available for families from underserved communities.

Specifically for siblings, support for siblings in the form of support groups has been demonstrated to be an effective way of building knowledge of ASD, creating peer networks, and improving coping skills (Jones et al., 2020; Kryzak et al., 2015). However, finding such support in adulthood can be challenging. Siblings have expressed a desire for various supports, including psychoeducation, social support, and information about transition planning (Heller & Arnold, 2010) and the development and evaluation of individual and group services that will meet this growing need is necessary.

Family therapists also have a role to play in the work with families of individuals with ASD, especially those who understand the impact autism has on the family dynamic. Therapists who are able to work with couples and families to reduce the level of conflict in their home while raising a child with ASD through adulthood can meaningfully impact the support these family members receive from one another (Solomon & Chung, 2012).

Summary

Research has long supported that the experiences of parents and siblings of individuals with ASD are unique from that of other families and differentially affect family members' well-being. While the bulk of research is among family members of children with ASD, emerging research indicates continued challenges faced by parents and siblings as their family member ages into adulthood. As in all areas of study regarding adults with ASD, the body of research with this population of family members is relatively limited. Continued research in the area of family functioning over time is needed, as well as the family services that are most beneficial in bolstering family well-being. However, the work that has been published indicates logical forms of support practitioners can provide for parents and siblings.

Families will require significant guidance as they attempt to navigate a significant shift in the care model that their child has received since childhood and to adapt to new roles as family dynamics shift over time. Practitioner engagement and involvement will be essential to improve the services adults with ASD receive in residential and community settings, thereby reducing the caregiving burden and concern of family members. Practitioners can provide direction to families on the myriad decisions they must make in the care of the individual with ASD and connect families with social support and coping strategies that may help them manage the complexity of what they face as caregivers. The family-practitioner partnership has always been essential in the care of individuals with ASD, but the importance of the relationship is abundantly evident in the transition to adulthood, where parents and siblings require considerable support and guidance to best provide for their family member with autism over time.

References

Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., Murphy, M. M., & Floyd, F. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or Fragile X syndrome. *American Journal of Mental Retardation, 109*(3), 237–254. https://doi.org/10.1352/0895-8017(2004)109<237:PWACIM>2.0C0;2

Anderson, K. A., Shattuck, P. T., Cooper, B. P., Roux, A. M., & Wagner, M. (2014). Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism, 18*(5), 562–570. https://doi.org/10.1177/1362361313481860

Atkin, K., & Tozer, R. (2014). Personalisation, family relationships and autism: Conceptualising the role of adult siblings. *Journal of Social Work, 14*(3), 225–242. https://doi.org/10.1177/1468017313476453

Bagenholm, A., & Gillberg, C. (1991). Psychosocial effects on siblings of children with autism and mental retardation: A population-based study. *Journal of Mental Deficiency Research, 35*, 291–307. https://doi.org/10.1111/j.1365-2788.1991.tb00403.x

Barker, E. T., Hartley, S. L., Seltzer, M. M., Floyd, F. J., Greenberg, J. S., & Orsmond, G. I. (2011). Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology, 47*(2), 551–561. https://doi.org/10.1037/a0021268

Benson, P. R. (2012). Network characteristics, perceived social support, and psychological adjustment in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 42*(12), 2597–2610. https://doi.org/10.1007/s10803-012-1517-9

Bigby, C. (1997). Parental substitutes? The role of siblings in the lives of older people with intellectual disability. *Journal of Gerontological Social Work, 29*, 3–21. https://doi.org/10.1300/J083v29n01_02

Blacher, J., Kraemer, B., & Howell, E. (2010). Family expectations and transition experiences for young adults with severe disabilities: Does syndrome matter? *Advances in Mental Health and Learning Disabilities, 4*(1), 3–16. https://doi.org/10.5042/amhld.2010.0052

Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology, 46*(6), 722–730. https://doi.org/10.1002/1097-4679(199011)46:6<722::aid-jckp2270460605>3.0.co;2-6

Brady, A. M., Burke, M. M., Landon, T., & Oertle, K. (2019). Siblings of adults with intellectual and developmental disabilities: Their knowledge and perspectives on guardianship and its alternatives. *Journal of Applied Research in Intellectual Disabilities, 32*(5), 1078–1087. https://doi.org/10.1111/jar.12597

Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities, 24*(1), 38–49.

Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism, 8*(4), 409–423.

Buescher, A. V., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatrics, 168*(8), 721–728. https://doi.org/10.1177/1362361304047224

Carter, E. W., Carlton, M. E., & Travers, H. E. (2020). Seeing strengths: Young adults and their siblings with autism or intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 33*, 574–583. https://doi.org/10.1111/jar.12701

Cheak-Zamora, N. C., Teti, M., & First, J. (2015). "Transitions are scary for our kids, and they're scary for us": Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities, 28*(6), 548–560. https://doi.org/10.1111/jar.12150

Cicirelli, V. (1995). *Sibling relationships across the life span*. Plenum Press.

Cidav, Z., Marcus, S. C., & Mandell, D. S. (2012). Implications of childhood autism for parental employment and earnings. *Pediatrics, 129*(4), 617–623. https://doi.org/10.1542/peds.2011-2700

Connidis, I. (1992). Life transitions and the adult sibling tie. *Journal of Marriage and the Family, 54*(4), 972–982. https://doi.org/10.2307/353176

Coyne, L. W., Gould, E. R., Grimaldi, M., Wilson, K. G., Baffuto, G., & Biglan, A. (2020). First things first: Parent psychological flexibility and self-compassion during COVID-19. *Behavior Analysis in Practice*. https://doi.org/10.1007/s40617-020-00435-w

Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders, 38*(7), 1278. https://doi.org/10.1007/s10803-007-0512-z

Dillenberger, K., & McKerr, L. (2011). "How long are we able to go on?" Issues faced by older family caregivers of adults with disabilities. *British Journal of Learning Disabilities, 39*(1), 29–38. https://doi.org/10.1111/j.1468-3156.2010.00613.x

Donovan, A. M. (1988). Family stress and ways of coping with adolescents who have handicaps: Maternal perceptions. *American Journal on Mental Retardation, 92*(6), 502–509.

Dorr, H., & Virgo, L. (2010). *Good practice in involving family carers in your workforce development: The what, why and how*. Mencap.

Eisenberg, L., Baker, B. L., & Blacher, J. (1998). Siblings of children with mental retardation living at home or in residential placement. *Journal of Child Psychology and Psychiatry, 39*, 355–363. https://doi.org/10.1111/1469-7610.00331

Ferraioli, S. J., & Harris, S. L. (2009). The impact of autism on siblings. *Social Work in Mental Health, 8*(1), 41–53.

Ferraioli, S. J., & Harris, S. L. (2013). Comparative effects of mindfulness and skills-based parent training programs for parents of children with autism: Feasibility and preliminary outcome data. *Mindfulness, 4*(2), 89–101. https://doi.org/10.1007/s12671-012-0099-0

Fiske, K. E. (2017). *Autism and the family: Understanding and supporting parents and siblings*. W. W. Norton.

Fisman, S., Wolf, L., Ellison, D., & Freeman, T. (2000). A longitudinal study of siblings of children with chronic disabilities. *The Canadian Journal of Psychiatry, 45*(4), 369–375. https://doi.org/10.1177/070674370004500406

Freedman, R., Krauss, M., & Seltzer, M. (1997). Aging parents' residential plans for adults with mental retardation. *Mental Retardation, 35*, 114–123. https://doi.org/10.1352/0047-6765(1997)035<0114:APRPFA>2.0.C0;2

Goetting, A. (1986). The developmental tasks of siblingship over the lifecycle. *Journal of Marriage and the Family, 48*, 703–714. https://doi.org/10.2307/352563

Greenberg, J. S., Seltzer, M. M., Orsmond, G. I., & Krauss, M. W. (1999). Siblings of adults with mental illness or mental retardation: Current involvement and expectation of future caregiving. *Psychiatric Services, 5*, 1124–1219. https://doi.org/10.1176/ps.50.9.1214

Griffiths, D. L., & Unger, D. G. (1994). Views about planning for the future among parents and siblings of adults with mental retardation. *Family Relations, 43*, 221–227. https://doi.org/10.2307/585326

Harris, S. L., & Glasberg, B. A. (2003). *Siblings of children with autism: A guide for families* (2nd ed.). Woodbine House.

Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology, 24*(4), 449–457. https://doi.org/10.1037/a0019847

Hartley, S. L., Seltzer, M. M., Head, L., & Abbeduto, L. (2012). Psychological well-being in fathers of adolescents and young adults with Down syndrome, Fragile X syndrome, and autism. *Family Relations, 61*(2), 327–342. https://doi.org/10.1111/j.1741-3729.2911.00693.x

Hayden, N. K., Hastings, R. P., Totsika, V., & Langley, E. (2019). A population-based study of the behavioral and emotional adjustment of older siblings of children with and without intellectual disability. *Journal of Abnormal Child Psychology, 47*(8), 1409–1419. https://doi.org/10.1007/s/10802-018-00510-5

Heller, T., & Arnold, C. K. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practice in Intellectual Disabilities, 7*(1), 16–25. https://doi.org/10.1111/j.1741-1130.2010.00243.x

Herrema, R., Garland, D., Osborne, M., Freeston, M., Honey, E., & Rodgers, J. (2017a). Brief Report: What happens when I can no longer support my autistic relative? Worries about the future for family members of autistic adults. *Journal of Autism and Developmental Disorders, 47*(11), 3659–3668. https://doi.org/10.1007/s10803-017-3254-6

Herrema, R., Garland, D., Osborne, M., Freeston, M., Honey, E., & Rodgers, J. (2017b). Mental wellbeing of family members of autistic adults. *Journal of Autism and Developmental Disorders, 47*(11), 3589–3599. https://doi.org/10.1007/s10803-017-3269-z

Hines, M., Balandin, S., & Togher, L. (2014). The stories of older parents of adult sons and daughters with autism: A balancing act. *Journal of Applied Research in Intellectual Disabilities, 27*(2), 163–173. https://doi.org/10.1111/jar.12063

Hodapp, R. M., & Urbano, R. C. (2007). Adult siblings of individuals with Down syndrome versus with autism: Findings from a large-scale US survey. *Journal of Intellectual Disability Research, 51*(12), 1018–1029. https://doi.org/10.1111/j.1365-2788.20007.00994.x

Hodapp, R. M., Urbano, R. C., & Burke, M. M. (2010). Adult female and male siblings of persons with disabilities: Findings from a national survey. *Intellectual and Developmental Disabilities, 48*, 52–62. https://doi.org/10.1352/1934-9556-48.1.52

Hodapp, R. M., Sanderson, K. A., Meskis, S. A., & Casale, E. G. (2017). Adult siblings of persons with intellectual disabilities: Past, present, and future. *International Review of Research in Developmental*

Disabilities, 53, 163–202. https://doi.org/10.1016/bs.irrdd.2017.08.001

Hojat, M., Louis, D. Z., Markham, F. W., Wender, R., Rabinowitz, C., & Gonnella, J. S. (2011). Physicians' empathy and clinical outcomes for diabetic patients. *Academic Medicine, 86*(3), 359–364. https://doi.org/10.1097/ACM.0b013e3182086fe1

Holtz, K. D., Owings, N. M., & Ziegert, A. K. (2006). *Life journey through autism: A guide for transition to adulthood*. Organization for Autism Research.

Howlin, P. (1988). Living with impairment: The effects on children of having an autistic sibling. *Child: Care, Health and Development, 14*, 395–408. https://doi.org/10.1111/j.1365-2214.1988.tb00591.x

Howlin, P., Mawhood, L., & Rutter, M. (2000). Autism and developmental receptive language disorder—A follow-up comparison in early adult life. II: Social, behavioural, and psychiatric outcomes. *Journal of Child Psychology and Psychiatry, 41*(5), 561–578. https://doi.org/10.1111/1469-7610.00643

Howlin, P., Moss, P., Savage, S., Bolton, P., & Rutter, M. (2015). Outcomes in adult life among siblings of individuals with autism. *Journal of Autism and Developmental Disorders, 45*(3), 707–718. https://doi.org/10.1007/s10803-014-2224-5

Iadarola, S., Pellecchia, M., Stahmer, A., Lee, H. S., Hauptman, L., Hassrick, E. M., Crabbe, S., Vejnoska, S., Morgan, E., Nuske, H., Luelmo, P., Friedman, C., Kasari, C., Gulsrud, A., Mandell, D., & Smith, T. (2020). Mind the gap: An intervention to support caregivers with a new autism spectrum disorder diagnosis is feasible and acceptable. *Pilot and Feasibility Studies, 6*(1), 1–13. https://doi.org/10.1186/s40814-020-00662-6

Jones, E. A., Fiani, T., Stewart, J. L., Sheikh, R., Neil, N., & Fienup, D. M. (2019). When one sibling has autism: Adjustment and sibling relationship. *Journal of Child and Family Studies, 28*, 1272–1282.

Jones, E. A., Fiani, T., Stewart, J. L., Neil, N., McHugh, S., & Fienup, D. M. (2020). Randomized controlled trial of a sibling support group: Mental health outcomes for siblings of children with autism. *Autism, 24*(6), 1468–1481. https://doi.org/10.1177/1362361320908979

Jorm, A. F., Windsor, T. D., Dear, K. B. G., Anstey, K. J., Christensen, H., & Rodgers, B. (2005). Age group differences in psychological distress: The role of psychosocial risk factors that vary with age. *Psychological Medicine, 35*(9), 1253. https://doi.org/10.1017/S0033291705004976

Kaminsky, L., & Dewey, D. (2001). Sibling relationships of children with autism. *Journal of Autism and Developmental Disorders, 31*, 399–410. https://doi.org/10.1023/a:1010664603039

Knott, F., Lewis, C., & Williams, T. (1995). Sibling interaction of children with learning disabilities: A comparison of autism and Down's syndrome. *Journal of Child Psychology and Psychiatry, 36*, 965–976. https://doi.org/10.1111/j.1469-7610.1995.tb01343.x

Kraft-Todd, G. T., Reinero, D. A., Kelley, J. M., Heberlein, A. S., Baer, L., & Riess, H. (2017). Empathic nonverbal behavior increases ratings of both warmth and competence in a medical context. *PLoS One, 12*(5), e0177758. https://doi.org/10.1371/journal.pone.0177758

Krauss, M. W., Seltzer, M. M., Gordon, R., & Friedman, D. H. (1996). Binding ties: The roles of adult siblings of persons with mental retardation. *Mental Retardation, 34*, 83–93.

Krauss, M. W., Seltzer, M. M., & Jacobson, H. T. (2005). Adults with autism living at home or in non-family settings: Positive and negative aspects of residential status. *Journal of Intellectual Disability Research, 49*(2), 111–124. https://doi.org/10.1111/j.1365-2788.2004.00599.x

Kryzak, L. A., Cengher, M., Feeley, K. M., Fienup, D. M., & Jones, E. A. (2015). A community support program for children with autism and their typically developing siblings: Initial investigation. *Journal of Intellectual Disabilities, 19*(2), 159–177. https://doi.org/10.1177/1744629514564450

Liptak, G. S., Kennedy, J. A., & Dosa, N. P. (2011). Social participation in a nationally representative sample of older youth and young adults with autism. *Journal of Developmental & Behavioral Pediatrics, 32*(4), 277–283. https://doi.org/10.1097/DBP.0b013e31820b49fc

Lounds, J., Seltzer, M. M., Greenberg, J. S., & Shattuck, P. T. (2007). Transition and change in adolescents and young adults with autism: Longitudinal effects on maternal well-being. *American Journal of Mental Retardation, 112*(6), 401–417. https://doi.org/10.1352/0895-8017(2007)112[401,TACIAA]2.0.CO;2

Macks, R. J., & Reeve, R. E. (2007). The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders, 37*, 1060–1067. https://doi.org/10.1007/s10803-006-0249-0

Mactavish, J. B., MacKay, K. J., Iwasaki, Y., & Betteridge, D. (2007). Family caregivers of individuals with intellectual disability: Perspectives on life quality and the role of vacations. *Journal of Leisure Research, 39*, 127–155. https://doi.org/10.1080/00222216.2007.11950101

Marsack, C. N., & Perry, T. E. (2018). Aging in place in every community: Social exclusion experiences of parents of adult children with autism spectrum disorder. *Research on Aging, 40*(6), 535–557. https://doi.org/10.1177/0164027517717044

Marsack, C. N., & Samuel, P. S. (2017). Mediating effects of social support on quality of life for parents of adults with autism. *Journal of Autism and Developmental Disorders, 47*(8), 2378–2389. https://doi.org/10.1007/s10803-017-3157-6

Martins, M. (2007). *Siblings of individuals with autism: Perceptions of the sibling experience, psychological functioning, and the developmental tasks of young adulthood*. Unpublished doctoral dissertation, Rutgers, The State University of New Jersey, New Brunswick, NJ.

Mascha, K., & Boucher, J. (2006). Preliminary investigation of a qualitative method of examining siblings' experiences of living with a child with ASD. *The British Journal of Developmental Disabilities, 52*(1), 19–28. https://doi.org/10.1179/096979506799103659

McHale, S. M., Sloan, J., & Simeonsson, R. J. (1986). Sibling relationships of children with autistic, mentally retarded, and nonhandicapped brothers and sisters. *Journal of Autism and Developmental Disorders, 16*(4), 399–413. https://doi.org/10.1007/s10803-015-2611-6

McHale, S. M., Updegraff, K. A., & Feinberg, M. E. (2016). Siblings of youth with autism spectrum disorders: Theoretical perspectives on sibling relationships and individual adjustment. *Journal of Autism and Developmental Disorders, 46*, 589–602. https://doi.org/10.1007/s10803-015-2611-6

Meyer, D., & Holl, E. (2014). *The sibling survival guide: Indispensable information for brothers and sisters of adults with disabilities*. Woodbine House.

Moes, D., Koegel, R. L., Schreibman, L., & Loos, L. (1992). Stress profiles for mothers and fathers of children with autism. *Psychological Reports, 71*, 1272–1274.

Moss, P., Eirinaki, V., Savage, S., & Howlin, P. (2019). Growing older with autism – The experiences of adult siblings of individuals with autism. *Research in Autism Spectrum Disorders, 63*(October 2018), 42–51. https://doi.org/10.1016/j.rasd.2018.10.005

Neyer, F. J. (2002). Twin relationships in old age: A developmental perspective. *Journal of Social and Personal Relationships, 19*, 55–177. https://doi.org/10.1177/0265407502192201

Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research, 45*(6), 535–543. https://doi.org/10.1046/j.1365-2788.2001.00372x

Orsmond, G., & Seltzer, M. (2007). Siblings of individuals with autism or Down syndrome: Effects on adult lives. *Journal of Intellectual Disability Research, 51*, 682–696. https://doi.org/10.1111/j.1365-2788.2007.00954.x

Rao, P. A., & Beidel, D. C. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior Modification, 33*(4), 437–451. https://doi.org/10.1177/0145445509336427

Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders, 33*(4), 383–394. https://doi.org/10.1023/a:1025006727395

Rodrigue, J. R., Geffken, G. K., & Morgan, S. B. (1993). Perceived competence and behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders, 23*, 665–674.

Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies, 10*, 65–84. https://doi.org/10.1023/A:1016629500708

Seltzer, M. M., Greenberg, J. S., Krauss, M. W., Gordon, R. M., & Judge, K. (1997a). Siblings of adults with mental retardation or mental illness: Effects on lifestyle and psychological well-being. *Family Relations, 46*, 395–405. https://doi.org/10.2307/585099

Seltzer, M. M., Greenberg, J. S., Krauss, M. W., & Hong, J. (1997b). Predictors and outcomes of the end of co-resident caregiving in aging families of adults with mental retardation or mental illness. *Family Relations, 46*(1), 13. https://doi.org/10.2307/585602

Seltzer, M. M., Krauss, M. W., Orsmond, G. I., & Vestal, C. (2000) Families of adolescents and adults with autism: Uncharted territory. In L. M. Glidden (Ed.) International review of research on mental retardation, Vol. 23 (pp. 267–294). Academic Press.

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics, 129*(6), 1042–1049. https://doi.org/10.1542/peds.2011-2864

Shivers, C. M., Krizova, K., & Lee, G. K. (2017). Types of strain among family members of individuals with autism spectrum disorder across the lifespan. *Research in Developmental Disabilities, 68*(July), 42–51. https://doi.org/10.1016/j.ridd.2017.07.003

Shivers, C. M., Jackson, J. B., & McGregor, C. M. (2019). Functioning among typically developing siblings of individuals with autism spectrum disorder: A meta-analysis. *Clinical Child and Family Psychology Review, 22*(2), 172–196. https://doi.org/10.1007/s10567-018-0269-2

Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*(2), 167–178. https://doi.org/10.1007/s10803-009-0844-y

Solomon, A. H., & Chung, B. (2012). Understanding autism: How family therapists can support parents of children with autism spectrum disorders. *Family Process, 51*(2), 250–264. https://doi.org/10.1111/j.1545-5300.2012.01399.x

Stoneman, Z. (2001). Supporting positive sibling relationships during childhood. *Mental Retardation and Developmental Disabilities Research Reviews, 7*, 134–142.

Taunt, H. M., & Hastings, R. P. (2002). Positive impact of children with developmental disabilities on their families: A preliminary study. *Education and Training in Mental Retardation and Developmental Disabilities, 37*, 410–420.

Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders, 41*(5), 566–574. https://doi.org/10.1007/s10803-010-1070-3

Taylor, J. L., & Shivers, C. M. (2011). Predictors of helping profession choice and volunteerism among siblings of adults with mild intellectual deficits.

American Journal on Intellectual and Developmental Disabilities, 116(4), 263–277. https://doi.org/10.1352/1944-7558-116.3.263

Taylor, B. A., LeBlanc, L. A., & Nosik, M. R. (2019). Compassionate care in behavior analytic treatment: Can outcomes be enhanced by attending to relationships with caregivers? *Behavior Analysis in Practice, 12*(3), 654–666. https://doi.org/10.1007/s40617-018-00289-3

Tomeny, T. S., Barry, T. D., Fair, E. C., & Riley, R. (2017a). Parentification of adult siblings of individuals with autism spectrum disorder. *Journal of Child and Family Studies, 26*(4), 1056–1067. https://doi.org/10.1007/s10826-016-0627-y

Tomeny, T. S., Ellis, B. M., Rankin, J. A., & Barry, T. D. (2017b). Sibling relationship quality and psychosocial outcomes among adult siblings of individuals with autism spectrum disorder and individuals with intellectual disability without autism. *Research in Developmental Disabilities, 62*, 104–114. https://doi.org/10.1016/j.ridd.2017.01.008

Tomeny, T. S., Rankin, J. A., Baker, L. K., Eldred, S. W., & Barry, T. D. (2019). Discrepancy in perceived social support among typically developing siblings of youth with autism spectrum disorder. *Autism, 23*(3), 594–606. https://doi.org/10.1177/1362361318763973

White, L. (2001). Sibling relationships over the life course: A panel analysis. *Journal of Marriage and Family, 63*, 555–568. https://doi.org/10.1111/j.1741-3737.2001.00555.x

Wolfe, B., Song, J., Greenberg, J. S., & Mailick, M. R. (2014). Ripple effects of developmental disabilities and mental illness on nondisabled adult siblings. *Social Science and Medicine, 108*, 1–9. https://doi.org/10.1016/j.socscimed.2014.01.021

Yamada, A., Suzuki, M., Kato, M., Suzuki, M. I. E., Tanaka, S., Shindo, T., Taketani, K., Akechi, T., & Furukawa, T. A. (2007). Emotional distress and its correlates among parents of children with pervasive developmental disorders. *Psychiatry and Clinical Neurosciences, 61*(6), 651–657. https://doi.org/10.1111/j.1440-1819.2007.01736.x

Part II

Some Challenges

5

Psychiatric Comorbidity in Individuals with Autism

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Introduction

Comorbid psychiatric disorders such as intellectual disability (ID), attention-deficit/hyperactivity disorder (ADHD), anxiety disorders, and mood disorders are common among adults with autism spectrum disorder (ASD) (Joshi et al., 2010, 2013; McDougle, 2016). The identification and treatment of comorbid psychiatric disorders is important, since if left untreated, they can cause suffering and limit functioning (Joshi et al., 2013; McDougle, 2016). Furthermore, an untreated psychiatric disorder increases the risk of developing subsequent psychiatric disorders. Although psychiatric comorbidities generally present similarly between adults with ASD and adults without ASD, they often go undiagnosed in the ASD population, and therefore untreated. Reasons for under diagnosis include diagnostic overshadowing (i.e., attributing symptoms of a comorbid psychiatric disorder to ASD), under recognition of how psychiatric comorbidities may present in an adult with ASD, possible cognitive limitations associated with ASD, the individual's reduced ability to communicate or describe psychiatric symptoms, and limited access to psychiatric care (McDougle, 2016).

The diagnosis of a comorbid psychiatric disorder is made on the basis of a comprehensive psychiatric history and mental status examination. When assessing an adult with ASD, it can be helpful to obtain collateral information from the patient's family members or caretakers to inform the diagnosis. This is particularly important if the patient has cognitive or communicative limitations. It is important to note though, that even fully verbal adults with ASD of normal intelligence may have difficulty identifying and describing their mood and emotional state. Because of this, behavioral observations from the patient's family and/or caretakers can help identify and accurately diagnose a comorbid psychiatric disorder. When considering the psychiatric differential diagnosis, it is important to determine the timing of symptom onset, chronicity of the symptoms, situations that exacerbate symptoms, and symptom severity (Thom et al., 2020). The mental status examination should assess for the presence of dysmorphic features indicative of a genetic syndrome, as well as the patient's activity level and affect. A brief cognitive examination, focusing on the patient's memory and basic academic skills should also be conducted.

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Common Comorbid Psychiatric Disorders in Autism Spectrum Disorder

Intellectual Disability

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) defines ID as a disorder beginning in childhood causing deficits in both intellectual and adaptive functioning (American Psychiatric Association, 2013). Intellectual functioning includes reasoning, planning, abstract thinking, problem-solving, making judgments, thinking, and academic and experiential learning, while adaptive functioning includes performing activities of daily living (ADLs) independently, social communication, and other tasks required for independent living (American Psychiatric Association, 2013). Because both intellectual and adaptive functioning are necessary for independent living, a diagnosis of ID may affect the patient's ability to live and function without supports. The DSM-5 specifiers for severity of ID include mild, moderate, severe, and profound. The severity specifiers are based on the level of supports required rather than intelligence quotient (IQ).

According to the DSM-5, the prevalence of ID in the general population is approximately 1%, with 6/1000 having a severe ID (American Psychiatric Association, 2013). The prevalence of ID is elevated in the ASD population. A recent study by the Centers for Disease Control and Prevention (CDC) reported that 38% of children with ASD have a comorbid diagnosis of ID (Baio et al., 2018). An additional 24% of children were found to have borderline intellectual functioning (IQ range, 71–85), and 38% of children were considered to have average or above average intellectual functioning (IQ > 85). Although ASD is four times more prevalent in males compared to females, 46% and 37% of females and males, respectively, had a comorbid diagnosis of ID, suggesting that comorbid ID may be more common in females with ASD.

Making the accurate comorbid diagnosis of ID in a person with ASD may be challenging because impairments in social function, repetitive behaviors, and language may present in each condition independently. ID may also be over diagnosed in persons with ASD who are non-vocal/verbal or minimally vocal/verbal. Approximately half of children with ASD have a higher non-verbal IQ than expected based on their verbal communication deficits (Bal et al., 2016). ASD may also not be accurately diagnosed in those with ID, as most standardized assessment tools including the Autism Diagnostic Observation Schedule and the Autism Diagnostic Interview-Revised are not validated for those with severe or profound ID (Thurm et al., 2019). As a result, appropriate screening for ID in those with ASD, and vice versa, is essential to achieving the correct diagnosis.

Depending on the severity of ASD and ID as well as baseline intellectual and adaptive functioning, individuals may require a range of supports for daily living. Some individuals with comorbid ASD and ID may not achieve independent living and may need to live with family members or caregivers, in group homes/assisted living facilities, or in specialized nursing homes. It is noteworthy that there are also elevated rates of medical comorbidities in those with ASD and ID including epilepsy, constipation, chronic renal failure, heart disease, and nutritional deficiencies (Miot et al., 2019). As a result, chronic care for these individuals may become more complex over the lifespan. No pharmacologic treatments are known to improve intellectual, behavioral, speech, or occupational functioning. Occupational and speech therapies may be used to improve adaptive functioning and should be implemented in a developmentally appropriate manner.

Attention-Deficit/Hyperactivity Disorder

ADHD is a pervasive neurodevelopmental condition characterized by inattention, hyperactivity, and impulse control deficits that interfere with social, academic, and/or occupational functioning (American Psychiatric Association, 2013). There are three subtypes of ADHD as defined in the DSM-5: predominantly inattentive presentation, predominantly hyperactive/impulsive presentation, and combined presentation. Symptoms of inattention include making careless mistakes, difficulty sustaining attention, disorganization, difficulties with listening or completing multi-step tasks, distractibility and forgetfulness, avoidance of tasks requiring sustained attention, and losing things necessary to complete tasks (American Psychiatric Association, 2013). Those with hyperactive/impulsive symptoms struggle with quiet activities, talk excessively, interrupt often, are fidgety and unable to sit still, are "driven by a motor," and may run or climb excessively (American Psychiatric Association, 2013). In order to meet criteria for ADHD, symptoms of inattention and/or hyperactivity/impulsivity must be present before the age of 12 years, persist for at least 6 months, and negatively impact academic, social, or occupational functioning in multiple settings (American Psychiatric Association, 2013). As is the case for many neurodevelopmental disorders, while symptoms of ADHD often persist throughout a person's lifetime, the relative severity of and impairment from symptoms of ADHD may decrease with age (Faraone et al., 2006; Weiss & Hechtman, 1993). Some individuals with ADHD experience substantial improvement of symptoms into adulthood, while others have sustained symptoms into late adulthood (St. Pourcain et al., 2011).

While ADHD and ASD share significant comorbidity, diagnostic criteria did not allow for comorbid diagnoses prior to the current version of the DSM, first published in 2013. As a result, studies investigating this comorbidity are relatively recent. Based on current research, it is reported that 15–25% of youth with ADHD have comorbid ASD and 50–70% with ASD meet criteria for ADHD (Antshel et al., 2016). This is a significantly elevated rate of comorbidity compared to the general population, where ADHD is estimated to affect 5% of the general population (Polanczyk et al., 2007). Elevated comorbidity rates may be related to a 50–70% overlap in contributing genetic factors (Lichtenstein et al., 2010; Rommelse et al., 2011). Both disorders are neurodevelopmental disorders and share other commonalities including a male predominance (Christakou et al., 2013; Thapar et al., 2012), clustering in families, and high prevalence of co-occurring sleep disorders (Cortese et al., 2009; Hvolby, 2015; Richdale & Schreck, 2009). In addition, ADHD and ASD share several core and associated symptoms including language/cognitive delays, social difficulties, and executive dysfunction. Importantly, those with comorbid ASD and ADHD have more severely impaired social and adaptive functioning skills compared to those with ASD alone (Avni et al., 2018).

Making the diagnosis of ADHD in a person with ASD may be challenging, as social impairment, cognitive limitations, inattention, and executive dysfunction commonly occur in both conditions. Agitation and aggression, which are relatively common in ASD, may occur as a result of unmitigated hyperactivity, impulsivity, and decreased frustration tolerance attributable to ADHD. Similarly, the repetitive motor behaviors and restricted interests of ASD may be confused with the hyperactivity and inattention of ADHD, respectively. Because an accurate diagnosis is essential for treatment planning, it is essential to complete a thorough psychiatric evaluation to diagnosis comorbid ADHD when appropriate.

The recommended treatment approach for ADHD is medication management in combination with non-medication approaches (Wolraich et al., 2019). Amphetamines and methylphenidates (stimulants) and non-stimulants such as clonidine and guanfacine (alpha-2 agonists) and atomoxetine (a norepinephrine reuptake inhibitor) have Food and Drug Administration (FDA) approval for the treatment of ADHD in the United States. Stimulants are noted to be highly efficacious in the treatment of ADHD (Wolraich et al., 2019), however, are associated with side effects including appetite suppression, insomnia, anxiety/agitation, and mood alterations. Alpha-2 agonists are generally well tolerated, however may cause sedation and hypotension. Side effects of atomoxetine include headache, nausea, gastrointestinal distress, and dizziness. Psychotropic medications may need to be adjusted and combined to reach maximal benefit. Unfortunately, response rates also tend to be lower and the side effect burden higher in individuals with ADHD and ASD compared to those with ADHD alone (Greenhill et al., 2001) Cognitive treatments, including cognitive remediation therapy (CRT) and cognitive behavioral therapy (CBT), as well as behavioral interventions, may also be helpful (Young et al., 2020).

Tic and Tic-Related Disorders

The DSM-5 defines a tic as a "sudden, rapid, recurrent, nonrhythmic motor movement or vocalization" (American Psychiatric Association, 2013). Tourette's disorder requires the presence of multiple motor tics and at least one vocal tic beginning before the age of 18 years and the persistence of tics for at least 1 year (American Psychiatric Association, 2013). Persistent motor or vocal tic disorders are defined as at least one motor or vocal tic (but not both motor and vocal) beginning before the age of 18 years and persisting for at least 1 year (American Psychiatric Association, 2013). Common motor tics include eye blinking, facial grimacing, nose twitching, and jaw/neck/shoulder/limb movements. Common vocal tics include sniffing, grunting, chirping, and throat clearing. Two features which distinguish tics from other repetitive movements and vocalizations seen in ASD include a premonitory urge and suppressibility. Tics are often preceded by a premonitory urge resembling the need to sneeze and can be volitionally suppressed at the expense of increased inner tension (Du et al., 2010). Although tic phenomenology and distribution are similar between ASD and non-ASD populations, persons with ASD may have decreased awareness of their tics compared to those without ASD (Kahl et al., 2015).

An elevated rate of tics and tic disorders in association with ASD has long been reported. Some of this overlap may relate to common genetic mutations that have been associated with both disorders (Fernandez et al., 2012). Approximately 22–34% of children with ASD also meet criteria for a comorbid tic disorder (either Tourette's disorder or chronic motor tic disorder; Baron-Cohen et al., 1999; Canitano & Vivanti, 2007), compared with 1% of children in the general population who meet criteria for a tic disorder. Increased cognitive impairment has been associated with tics in ASD (Canitano & Vivanti, 2007). Tics usually begin between the ages of 4 to 6 years and peak in severity between the ages of 9 and 14 years before diminishing in late adolescence/early adulthood (Gilbert, 2006). However, tics can remain present in adulthood. A study including 21 adults with ASD without ID demonstrated that 10 of 21 adults (48%) exhibited motor tics during a structured assessment (Kahl et al., 2015). Tic severity and the degree to which they cause embarrassment, pain, or are otherwise disruptive can vary across individuals and also within a single individual, often worsening during periods of stress.

The recommended treatment approach for tics and tic-related disorders will depend on the severity of the tics, how distressing they are, and the degree to which they impair functioning. If they are mild, treatment may be limited to providing psychoeducation about tics to the patient, family, and school/vocational staff in an effort to destigmatize them. In fact, the majority of individuals meeting criteria for tic disorders do not require medications for tic suppression. If the tic disorder is moderate to severe, biological and/or psychosocial treatments may be indicated. The classes of medications commonly used to treat tic disorders include alpha-2 agonists (e.g., clonidine or guanfacine) and antipsychotics (e.g., aripiprazole or risperidone). The potential benefits of these medications must be carefully balanced with the potential risks. Although alpha-2 agonists are generally well tolerated, they may cause hypotension and sedation (Schatzberg & DeBattista, 2015). Antipsychotics are associated with a comparatively higher side effect burden including adverse metabolic effects (e.g., increased appetite, weight gain, hypertension, hyperlipidemia, and hyperglycemia) and rare, but potentially irreversible movement disorders (e.g., tardive dyskinesia) (Schatzberg & DeBattista, 2015). Since the natural course of tics is to typically improve throughout adolescence and early adulthood, it may be possible to reduce or discontinue treatment with medications in adulthood (Leckman, 2012). The type of psychotherapy that has the greatest evidence base for the treatment of tics is habit reversal training. Habit reversal training includes increasing awareness of tics and the premonitory urge to tic in order to eventually develop a competing incompatible response (an action that is incompatible with the tic and is meant to replace it) (Leckman, 2012).

Schizophrenia Spectrum Disorders

The core feature of schizophrenia spectrum disorders including brief psychotic disorder, schizophreniform disorder, and schizophrenia is psychosis. Symptoms of psychosis include hallucinations (i.e., perception of sensory stimuli when there is none), delusions (i.e., fixed false beliefs that are inconsistent with reality and the person's socio-cultural background), and disorganized speech or behavior. Negative symptoms of psychosis including apathy, blunting of affect, reduced social drive, and loss of motivation can also occur. Brief psychotic disorder, schizophreniform disorder, and schizophrenia all share similar clinical features; however, they have different criteria with regard to symptom duration: less than 1 month, less than 6 months, and greater than 6 months, respectively. If symptoms of psychosis persist for 6 months or more, schizophrenia is diagnosed and is generally considered to be a chronic condition. According to the DSM-5, if there is a history of ASD or a communication disorder of childhood, schizophrenia can only be diagnosed if prominent delusions or hallucinations are present (American Psychiatric Association, 2013). While the psychotic symptoms of schizophrenia (i.e., hallucinations, delusions, disorganized speech, and disorganized behavior) typically emerge in late adolescence/early adulthood, prodromal symptoms throughout early adolescence are common and may include anxiety, depression, obsessive-compulsive symptoms, social withdrawal, school refusal, sleep disturbances, and irritability (George et al., 2017).

Whether individuals with ASD are at increased risk for schizophrenia and other psychotic disorders remains unknown. It is estimated that the global prevalence of schizophrenia is approximately 1% (Tandon et al., 2009). A recent meta-analysis concluded that schizophrenia is approximately 3.6 times more common in those with ASD compared to the general population; however additional prevalence studies are needed due to significant variation across studies (Zheng et al., 2018).

There is a significant historical overlap between schizophrenia and ASD. ASD was historically believed to be a childhood manifestation of schizophrenia and was commonly described as "childhood psychosis" or "schizophrenic syndrome of childhood" until 1971 when they were conceptually separated (Kolvin, 1971; Kolvin et al., 1971). This historical relationship is not surprising due to some symptomatic similarities between the two disorders. While they are separate neurodevelopmental disorders, they share several symptoms including communication impairment, sensory processing issues, poor eye contact, social deficits/withdrawal, and cognitive difficulties (Posey et al., 2004). Retrospective studies have also revealed delays in language development, visual-motor coordination, and stereotypic/repetitive behaviors in children who later develop schizophrenia, all of which are also highly characteristic of ASD (Alaghband-Rad et al., 1995; Asarnow et al., 1995). In addition, individuals with ASD who experience high levels of stress may appear thought disordered or paranoid at times, particularly when a change in activity or routine occurs (Berney, 2000). The two disorders also share similar risk factors including heritability, prenatal exposure to infections, and inflammation (Cheung et al., 2010).

Antipsychotics are the main treatment for schizophrenia spectrum disorders. The side effects of antipsychotics may include sedation, metabolic disturbances, digestive problems, akathisia (i.e., inner restlessness with an urge to move) and movement-related side effects such as tremors, muscle rigidity, and parkinsonian-like features and tardive dyskinesia. While the literature on the treatment of comorbid schizophrenia in ASD is limited, a retrospective cohort study including 638 youth with first-episode psychosis demonstrated that those with a comorbid diagnosis of ASD were less likely to respond to treatment with antipsychotics (Downs et al., 2017). If there is concomitant aggression and/or irritability, it may be appropriate to consider the use of risperidone or aripiprazole as they have both been approved by the FDA for the treatment of irritability associated with ASD. Regarding psychotherapies, CBT for psychosis and cognitive enhancement therapies have shown efficacy in helping individuals cope with and identify psychotic symptoms. Individual, group, family, and social skills training may also be of benefit to those with schizophrenia and ASD. Those with severe symptoms and impairment may benefit from Assertive Community Treatment (ACT), an intensive and highly integrated form of community-based mental health care delivery, and may need social and occupational supports as they may not be able to work or live independently.

Catatonia

Catatonia is a severe psychomotor syndrome defined by abnormalities in speech, movement, and behavior (Fink & Taylor, 2009). Catatonia may be due to a medical or psychiatric condition such as a mood or psychotic disorder and is being increasingly reported in persons with ASD. According to the DSM-5 diagnostic criteria, patients must exhibit at least three of the following symptoms to qualify for a diagnosis of catatonia: stupor (no psychomotor activity; not actively relating to environment), catalepsy (passive induction of a posture held against gravity), waxy flexibility (slight, even resistance to repositioning), mutism (no or little verbal response), negativism (opposition or no response to instructions), posturing (spontaneous and active maintenance of a posture against gravity), mannerism (odd, caricature of normal actions), stereotypy (repetitive, abnormally frequent non-purposeful movements), agitation, grimacing, echolalia (mimicking another's speech), and echopraxia (mimicking another's movements; American Psychiatric Association, 2013). The diagnosis of catatonia is complicated in individuals with ASD due to overlapping clinical features including echophenomena, mutism, and stereotypies (Dhossche et al., 2006). Because of this overlap, a departure from baseline symptoms and/or functioning is the key to making this diagnosis. Catatonic symptoms seen more frequently in individuals with ASD include increased slowness affecting movement and verbal responses, difficulty initiating and/or completing actions, increased reliance on prompts, and increased passivity (DeJong et al., 2014). The clinical features that should prompt an evaluation for catatonia in an adult with ASD include a loss of language ability and/or self-care skills, psychomotor "freezing" especially during transitions such as a change in activity or when crossing a threshold, and a change in the person's baseline repetitive motor movements.

Catatonia often begins insidiously, and may follow a waxing and waning course, but can become quite severe and even potentially life threatening, particularly when the symptoms interfere with the basic activities of daily life including attaining adequate food intake. Patients with catatonia may either move so often and quickly or eat so slowly that they lose a substantial amount of weight. The overall prevalence of catatonia in ASD is about 6–17%, with higher rates seen in older adolescents and adults compared to younger children (Billstedt et al., 2005; Ghaziuddin et al., 2012; Wing & Shah, 2000). The average age of onset of catatonia in ASD is 19 years (Ohta et al., 2006). Stress, including environmental stressors (e.g., change in routine, loss of structure), psychological factors (e.g., anxiety, depression), and medical illnesses (e.g., fever, infection), may be a precipitating factor for the development of catatonia in persons with ASD (Shah & Wing, 2006). However, the precise underlying neurobiological mechanisms of catatonia in ASD remain unknown. The literature suggests that untreated catatonia in ASD may become chronic and more difficult to successfully treat (Dhossche et al., 2006).

The main treatment approach for catatonia is biological. There are two primary biological treatments for catatonia, including when treating persons with ASD. The first is to use high dosages of a benzodiazepine such as lorazepam (6–24 mg daily). A "lorazepam challenge," wherein the symptoms of catatonia resolve after a dose of lorazepam is administered, may be used to support the diagnosis of catatonia. The second-line treatment is electroconvulsive therapy (ECT). Electroconvulsive therapy is a procedure done under general anesthesia, in which a brief seizure under close medical supervision is triggered to induce relief of psychiatric symptoms. While the use of ECT in persons with neurodevelopmental disorders remains somewhat controversial (Collins et al., 2012; Dhossche & Stanfill, 2004), a retrospective study has documented its effectiveness in 21 patients with ASD and comorbid catatonia who did not respond to lorazepam (Wachtel, 2019). Indefinite maintenance of either treatment approach is generally needed in persons with ASD (DeJong et al., 2014). Psychosocial interventions for catatonia in ASD should accompany the biological approaches and may include explaining to family members and caregivers that the symptoms are due to a neurobiological process rather than volitionally produced, identifying and reducing sources of psychosocial stress, implementing a system of verbal or physical prompts to complete activities, and developing a structured and predictable routine (Shah & Wing, 2006).

Bipolar and Related Disorders

The DSM-5 defines the bipolar and related disorders as mood disorders characterized by episodes of major depression and either mania or hypomania. Mania is a distinct period of abnormal and persistently elevated, expansive, or irritable mood with increased self-esteem or grandiosity, decreased need for sleep, increased or pressured speech, flight of ideas, increased goal-directed activities, distractibility, psychomotor agitation, impulsivity, and increased pursuit of risky activities (American Psychiatric Association, 2013). In order to meet criteria for a manic episode, the symptoms must persist for at least 1 week, three or more of the aforementioned symptoms must be present, and they must cause severe social and occupational impairment and/or require hospitalization. Psychotic features such as delusions and auditory hallucinations may also be present. Hypomanic episodes are similar to manic episodes, but symptoms only need to be present for 4 days, are not characterized by marked impairment or need for hospitalization, and must not include psychotic symptoms. The diagnostic criteria for bipolar I disorder requires the presence of at least one manic episode, while the diagnostic criteria for bipolar II disorder requires the presence of both one hypomanic episode and one major depressive episode. Cyclothymic disorder is diagnosed if there are fluctuating hypomanic and depressive symptoms within a period of 2 years, but the symptoms do not qualify for the diagnosis of bipolar I or II disorder (American Psychiatric Association, 2013).

A study investigating the lifetime prevalence of bipolar disorder across 11 countries demonstrated an overall lifetime prevalence of 2.4% (Merikangas et al., 2011). With regard to prevalence rates of bipolar disorder in adults with ASD, a few studies have reported generally elevated rates of comorbidity, with central estimates of lifetime prevalence of 5–6% (Skokauskas & Frodl, 2015; Vannucchi et al., 2014). Relatives of patients with ASD are also at increased risk of developing bipolar disorder, with a prevalence of approximately 10% (Vannucchi et al., 2014), which may be related to shared genetics between ASD and bipolar disorder (Lee et al., 2019). Youth with ASD and bipolar disorder also experienced increased rates of comorbid ADHD and obsessive-compulsive disorders (Borue et al., 2016).

Large and systematic studies regarding bipolar disorder in the ASD population are generally lacking and are limited to only a few cross-sectional studies. This is in part due to studies on bipolar disorder excluding patients with ASD and in part due to the lack of rigorous assessment of symptoms of bipolar disorder in patients with ASD. It has been reported that symptoms of bipolar disorder emerge and are expressed somewhat differently in those with ASD than in the general population. Borue et al. (2016) noted that patients with comorbid ASD and bipolar disorder have more mixed (depressive symptoms occurring during manic episodes such as sad mood, social withdrawal, and suicidal ideation) or atypical features (including more irritability, aggression, more frequent distractibility, and racing thoughts). In addition, patients with comorbid ASD and bipolar disorder typically experience an earlier onset of mood symptoms, beginning at approximately 10 years of age compared to 12 years of age in neurotypical controls (Borue et al., 2016). Because of these differences, bipolar disorder is often under-recognized or misdiagnosed as ADHD, psychosis, or personality disorders in patients with ASD (Vannucchi et al., 2014).

While the severity of bipolar disorder symptoms often decrease over time, the early diagnosis and treatment of bipolar disorder in young individuals with ASD may lead to improved clinical outcomes and social functioning, which are more severely impaired in patients with a comorbid diagnosis of ASD and bipolar disorder than ASD alone (Borue et al., 2016). The main treatments for bipolar disorder in the general population include mood stabilizers such as valproic acid, carbamazepine, lamotrigine and lithium, and/or second generation antipsychotics such as risperidone, aripiprazole, olanzapine, quetiapine, cariprazine, asenapine, paliperidone, ziprasidone, and lurasidone (Yatham et al., 2018). There are no double-blind, placebo-controlled trials of medications or studies pertaining specifically to the treatment of bipolar disorder with comorbid ASD. Common side effects associated with mood stabilizers include digestive problems, sedation, renal/liver toxicity, tremors, and electrolyte imbalances. There is also the need for mood stabilizer blood level monitoring to avoid toxicity. Valproic acid has been known to cause neural tube defects among other teratogenic effects and should be used with extreme caution in women of childbearing age. Regarding antipsychotics, possible side effects may include sedation, weight gain, digestive problems, akathisia, and movement-related issues such as tremors, muscle rigidity, parkinsonian-like features, and tardive dyskinesia. Psychoeducation and rehabilitative programs should also be provided and must be modified according to the patient's developmental level (Vannucchi et al., 2014).

Major Depressive Disorder

Major depressive disorder is a mood disorder characterized by a persistent change in mood quality accompanied by changes in thinking, behavior, and physical symptoms that last for at least 2 weeks. According to the DSM-5, to meet criteria for a major depressive episode, the person must experience sad mood most of the day, nearly every day, and/or loss of interest or pleasure for at least 2 weeks as well as at least four other thinking, behavioral, or physical symptoms (American Psychiatric Association, 2013). Thinking patterns that are common in depression include frequent thoughts about guilt, hopelessness, worthlessness, excessive worrying, or death or dying. Behavioral changes include social withdrawal, increased irritability, and decreased interest in formerly pleasurable activities. Physical symptoms of depression include appetite changes, sleep problems, and low energy. There are several aspects of ASD that can make the diagnosis of depression more challenging including associated features of ASD such as difficulty accurately identifying and reporting mood, constricted range of facial expression, sleep problems, and social withdrawal. The lack of specific diagnostic tools to screen for and identify depression in ASD adds to this challenge. Incorporating information from the patient as well as observers (e.g., parents, caregivers, teachers, coworkers) may be helpful to arrive at an accurate diagnosis. Some features of depression that may be more prominent in individuals with ASD and are generally easily observable include increased ASD-related behaviors (e.g., hand flapping or other repetitive motor behaviors), irritability, and self-injurious behaviors (Pezzimenti et al., 2019). There is usually a clear onset of depression and the episodes last on average between 1 and 6 months (Simonoff et al., 2008). Patients who present with mood symptoms should undergo a suicide risk assessment including whether the person has wished they were dead, had thoughts about killing themselves, is actively thinking about killing themselves, has a suicide plan, has access to suicide means, and previous suicide attempts. This detailed risk assessment will allow for treatment planning to decrease risk factors for suicide while increasing protective factors and developing a crisis plan. This is of critical importance in the ASD population, as longitudinal population studies have shown that adolescents and young adults with ASD are more likely to attempt and complete suicide than individuals without ASD (Chen et al., 2017; Kirby et al., 2019).

Major depressive disorder among adults with ASD is highly prevalent. A cross-sectional study including 255 individuals with ASD (14–80 years) demonstrated that 38% of the sample met the cutoff scores for clinically significant depression on standardized self-report measures (Uljarević et al., 2019). Individuals with ASD experience more depression symptoms compared to a neurotypical comparison group across the full adult lifespan (Lever & Geurts, 2016b). Unfortunately, depression is likely underrecognized and undertreated in this population (Chandrasekhar & Sikich, 2015). Similar to the general population, female sex (genetic XX) is a risk factor for major depressive disorder among adults with ASD (Lever & Geurts, 2016b), and anxiety is a common psychiatric comorbidity. The severity of baseline core ASD symptoms is associated with developing depression among adults with ASD (Lever & Geurts, 2016b). The timely identification and treatment of major depressive disorder is essential, as untreated depression can result in worsened core symptoms of ASD and lower levels of educational and vocational functioning. Depression in youth with ASD has been associated with lower general functioning as measured by the Child Global Assessment Scale (CGAS; Mattila et al., 2010). Additionally, comorbid depression has a deleterious effect on employment in adult men with ASD (Sung et al., 2015).

Although the treatment of depression has received significant attention in the general population, studies examining the treatment of depression in adults with ASD are much more limited. In fact, no double-blind, placebo-controlled trials of medications for the treatment of major depressive disorder have been conducted in ASD for any age-group. Therefore, the standard medication approaches to treating major depressive disorder in the general population are generally followed and can be helpful in ameliorating symptoms and restoring functioning. First-line antidepressants used to treat major depressive disorder in the general population include selective serotonin reuptake inhibitors (SSRIs), serotonin norepinephrine reuptake inhibitors (SNRIs), bupropion, and mirtazapine. Common side effects associated with antidepressants include headaches, digestive problems, increased anxiety, and changes in sleep or energy. Individuals with ASD may be more likely to experience adverse effects from SSRIs including behavioral activation, irritability, akathisia (inner restlessness with an urge to move), and sleep disturbance (Chandrasekhar & Sikich, 2015). Because individuals with ASD may have more difficulty communicating side effects, it is important to start antidepressants at low doses and increase the dose slowly to a therapeutic or beneficial dose. If the first antidepressant is poorly tolerated or ineffective, it may be helpful to switch to a different antidepressant. Antidepressants can take several weeks to take effect and generally should be continued for at least 6–12 months after attaining remission from depression in order to prevent a relapse. For those who have experienced more than one episode of depression or a very severe single episode of depression, lifelong maintenance on an antidepressant should be considered.

The most common reason for adults with ASD to seek psychotherapy is for the treatment of depression (Lipinski et al., 2019). Psychotherapies for depression including CBT have been modified for the ASD population. CBT is focused on modifying thinking and behavioral patterns that perpetuate and exacerbate depressed mood. Nine sessions of group CBT resulted in improvement of depression symptoms in individuals with ASD compared to a waitlist control group (McGillivray & Evert, 2014). These improvements were sustained at 3- and 9-month follow-ups (McGillivray & Evert, 2014). Adults with ASD report that modifications to psychotherapy for depression such as written communication and clearly structured sessions are beneficial (Lipinski et al., 2019).

Anxiety Disorders

Anxiety disorders are characterized in the DSM-5 as a group of disorders defined by excessive fear, anxiety, and associated behavioral disturbances that cause distress and impairment (American Psychiatric Association, 2013). Fear is a response to a real or perceived threat and is commonly associated with escape behaviors, thoughts of immediate danger, and a "fight or flight" reaction, while anxiety is anticipation of future threat and commonly characterized by cautious and avoidant behaviors, tension, and vigilance. There are many anxiety disorders outlined in the DSM-5 including selective mutism, separation anxiety disorder, specific phobia, social anxiety disorder, agoraphobia, panic disorder, generalized anxiety disorder (GAD), medication/substance-induced anxiety disorder, and unspecified anxiety disorder. While each of these disorders differs in terms of specific criteria and the target of the fear, they are each associated with excessive fear, anxiety or avoidance, as well as cognitive distortions (American Psychiatric Association, 2013). A recent study by Nimmo-Smith et al. (2020) reported that the prevalence of all anxiety disorders is higher in adults with ASD versus controls at 20.1% and 8.7%, respectively. The authors noted that the most common comorbid anxiety disorders are GAD, social anxiety disorder, panic disorder, and unspecified anxiety. In GAD, the individual experiences excessive and significant worry across many domains that is difficult to control as well as three or more of the following symptoms: restlessness, muscle tension, irritability, sleep disturbances, difficulties concentrating, feeling "on edge," and fatigue over a 6-month period. In social anxiety disorder, there is significant fear and anxiety surrounding social situations relating to a fear of being scrutinized, negatively evaluated by others, embarrassed, rejected, or offensive to others. In panic disorder, one experiences recurrent panic attacks with physical/cognitive symptoms including palpitations, sweating, shortness of breath, chest pain/discomfort, dizziness, numbness, chills, nausea, depersonalization/derealization, feelings of choking, dying, or losing control, and also develops maladaptive behaviors surrounding panic attacks and concern regarding future attacks (American Psychiatric Association, 2013). Unspecified anxiety disorder applies to presentations in which symptoms of an anxiety disorder cause significant distress or impairment but do not meet any specific DSM-5 criteria for another disorder.

Approximately 40% of children with ASD have at least one anxiety disorder (van Steensel et al., 2011), with prevalence appearing to decrease with age towards 20.1% between the ages of 18–27 years (Nimmo-Smith et al., 2020). A large population-based birth cohort study of young adults found that 50% of the individuals with ASD had a comorbid anxiety diagnosis, compared to 22.2% of neurotypical individuals (Kirsch et al., 2019). It has also been reported that the risk for an anxiety disorder in those with ASD without ID is three times higher than in the general population (Mazefsky et al., 2013; Nimmo-Smith et al., 2020). The increased rate of comorbid of anxiety disorders in ASD may be related to the core and associated symptoms of ASD including social difficulties and rejection, behavioral and mental rigidity with intolerance to change, caregiver punishment of behaviors, and limbic dysfunction resulting in emotional dysregulation (Mazefsky et al., 2013; Nimmo-Smith et al., 2020).

Making the diagnosis of an anxiety disorder in those with ASD can be challenging due to the risk of diagnostic overshadowing. For example, symptoms of social anxiety disorder may be ascribed to the core social communication deficits of ASD, and an anxiety disorder may not be considered when a person with ASD is highly agitated/aggressive. Anxiety may also manifest differently in those with ASD compared to the general population. One study demonstrated that 17% of youth with ASD had typical anxiety (symptoms consistent with DSM criteria), while

15% had atypical anxiety (symptoms not consistent with DSM criteria), and 31% had both (Kerns et al., 2014). Examples of atypical anxiety in ASD include anxiety around changes in routine and losing access to restricted interests in the absence of generalized worry, unusual specific fears in the absence of sensory sensitivity (e.g., grocery stores, the radio, babies crying, coughing), social fearfulness without fear of negative evaluation, and compulsive/ritualistic behaviors that are not performed to prevent distress or a feared outcome (Kerns et al., 2014). Increased self-injurious behaviors, mental rigidity, and sensory under or over responsiveness may also occur in patients with comorbid anxiety and ASD (Zaboski & Storch, 2018).

Symptoms of anxiety may remain consistent throughout the lifespan if left untreated (Lenze & Wetherell, 2011). Treatment of anxiety is of high importance in those with ASD as untreated anxiety can cause or worsen depression, aggression, and self-injurious behaviors. Cognitive behavioral therapy has been found to be effective in those with comorbid ASD and anxiety disorders and includes psychoeducation, gradual exposure to the source of anxiety, and cognitive restructuring (Ung et al., 2015). Modifications of CBT for individuals with ASD include concrete behavioral programs, integrating specific interests into psychotherapy, and a broad treatment approach that addresses both anxiety and core ASD symptoms (Zaboski & Storch, 2018). Social skills training may also be effective for social anxiety and communication deficits. No double-blind, placebo-controlled studies to date have addressed the pharmacologic treatment of anxiety in adults with ASD; however, SSRIs (such as fluoxetine, sertraline, citalopram, escitalopram, paroxetine), SNRIs (such as venlafaxine and duloxetine), and buspirone have shown efficacy in treating anxiety in the general population and may be beneficial (Schatzberg & DeBattista, 2015). Common side effects of these medications include headaches, gastrointestinal problems, and fatigue/insomnia. As previously noted, patients with ASD may be more sensitive to SSRI-related side effects. Benzodiazepines have been approved for acute anxiety/panic in adults and children; however they should also be approached with caution as paradoxical reactions including aggression may be more likely in patients with ASD (Marrosu et al., 1987).

Obsessive-Compulsive Disorder

Obsessive-compulsive disorder (OCD) is a psychiatric disorder characterized by obsessions and/or compulsions, where usually both obsessions and compulsions are present. The DSM-5 defines obsessions as recurrent, persistent thoughts, urges, or images that are experienced as intrusive and unwanted, which the individual attempts to ignore, suppress, or neutralize, often causing marked anxiety or distress (American Psychiatric Association, 2013). Compulsions are repetitive behaviors or mental acts that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly in order to prevent or reduce distress but are not connected in a realistic way with the feared outcome (American Psychiatric Association, 2013). There is some extent of overlap between the core symptoms of ASD and OCD, as both disorders typically involve repetitive thoughts and behaviors. Importantly, the repetitive thoughts attributed to ASD are typically self-generated repetitive thoughts pertaining to topics of interest that the individual takes pleasure in pursuing (Klin et al., 2007). These contrast with the distressing, intrusive, unwanted nature of obsessions which are generally experienced as unwanted and unpleasant. Furthermore, a study comparing individuals with ASD to those with OCD found that adults with ASD were less likely to experience thoughts with aggressive, contamination, sexual, religious, symmetry, and somatic content than adults with OCD (McDougle et al., 1995). The repetitive behaviors that comprise core ASD symptomatology are termed stereotypies: non-purposeful, voluntary, bilateral, continuous movements. While stereotypies can serve to relieve intense emotions (e.g., anxiety, anger, excitement) that differ from the baseline emotional state, they are generally non-purposeful and do not serve to relieve anxiety/distress associated with an obsession. Unlike stereotypies, compulsions are goal-directed, purposeful behaviors which are performed with the intent of relieving distress/anxiety. Although it is important to distinguish between ASD and OCD when they represent two clinically discrete conditions, these two diagnoses are not exclusionary, and comorbidity can occur. In cases of true comorbidity, the individual should demonstrate clearly distinguishable compulsions which are linked to obsessions as well as repetitive, ritualistic stereotypies of ASD (Wu et al., 2014).

The true prevalence of comorbid OCD among individuals with ASD is unknown, and limited to some extent by the cognitive and communicative limitations sometimes associated with ASD. These make it difficult to discern whether the individual is experiencing obsessions and to what extent observable behaviors resembling compulsions are linked to obsessions. The literature has suggested that OCD in individuals with ASD may be more refractory than in patients with OCD alone (Pazuniak & Pekrul, 2020). The accurate distinction between ASD, OCD, and ASD co-occurring with OCD has important implications for treatment. Biologically, the gold standard first-line treatment for OCD in the general population is SSRIs. Importantly, SSRIs have not been shown to improve the repetitive behaviors in children and adolescents with ASD (Herscu et al., 2020; King et al., 2009), but may be helpful in reducing obsessions and/or compulsions if comorbid OCD is present. Because individuals with ASD may be more likely to experience SSRI-related side effects, the initial dose should be the lowest possible and uptitration should occur slowly. The gold standard psychotherapy for OCD is exposure and response prevention (ERP) therapy, a form of CBT. Exposure and response prevention therapy has been modified for the ASD population and can be helpful in decreasing obsessions, compulsions, and associated distress. Examples of these modifications include more structured sessions, identifying triggers for dysregulation, incorporation of the patient's preferred interests, increased use of visual aids, greater caregiver involvement, and positive reinforcement.

Posttraumatic Stress Disorder

According to the DSM-5, the diagnostic criteria for posttraumatic stress disorder (PTSD) are met when one has been exposed to actual or threatened death, serious injury, or sexual violence (Criterion A) followed by persistent intrusive symptoms (such as nightmares and flashbacks) pertaining to the traumatic event, avoidance of stimuli associated with the traumatic event, negative alterations of cognition and mood, and marked alterations of arousal and reactivity for 1 month or longer (American Psychiatric Association, 2013). A recent Swedish study demonstrated that the lifetime prevalence of PTSD is higher in adults with ASD compared to controls, at 0.7% and 0.3%, respectively (Nimmo-Smith et al., 2020). The lifetime prevalence of PTSD in the general population in the United States has been reported to be much higher, with a lifetime prevalence rate of 8.7% (American Psychiatric Association, 2013). There are no other studies specifically examining this comorbidity.

Individuals with ASD may perceive their environments differently due to sensory and cognitive differences and often demonstrate significant anxiety with changes in routine, sensory stimuli, and social situations. Rumball et al. (2020) conducted a study to identify the nature of trauma experienced by adults with ASD and the co-occurrence of trauma-related disorders. In this study, 78% of males and 47% of females with ASD reported having experienced a life event that they considered to be traumatic, but which would not be considered a traumatic event based on DSM-5 criteria. The most commonly reported non-DSM-5 traumatic events included bullying, stress associated with social difficulties, abandonment by a significant other, and traumas associated with mental health issues, such as anorexia and emotional breakdowns (Rumball et al., 2020). These events were perceived as more traumatic to those with ASD than the general population. It was noted that both DSM-5 and non-DSM-5 traumatic life events contributed to the development of PTSD symptoms in those with ASD, and that the rate of probable PTSD among the respondents with ASD was significantly higher than the rates of probable PTSD in the trauma-exposed general population (Rumball et al., 2020). A separate study also assessed the perception of traumatic experiences in individuals with ASD, and more than 50% of the respondents identified specific stressful life events that were not included in Criterion A as being traumatic (Taylor & Gotham, 2016). Repeated and prolonged stress from harassment or peer victimization was also postulated to lead to the development of PTSD symptoms in individuals with ASD (Nielsen et al., 2015). It is also noteworthy that children with ASD are 3–4 times more likely to be bullied at school and are also at elevated risk of adverse childhood experiences (Hoover & Kaufman, 2018). Moreover, previous studies have proposed that the core symptoms of ASD could result in an increased risk of PTSD (Rumball et al., 2020).

While the DSM-5 criteria for PTSD restrict the diagnosis to patients who have experienced actual or threatened death, serious injury, or sexual violence, this criterion may be overly restrictive when considering patients with ASD. PTSD may remain undetected in this population if a broader definition of "trauma" is not considered. In the ASD population, a trauma assessment should therefore include self-report with the use of standardized trauma checklists and clinical interviews with a broader definition of a traumatic event. An alternative screening approach may include routinely checking for the presence of core features of PTSD such as intrusive symptoms, hyperarousal, and avoidance.

There are no cross-sectional or randomized controlled trials that evaluate specific treatment recommendations for PTSD in adults with ASD. The SSRIs, sertraline and paroxetine, are the only two psychotropic medications approved by the FDA for the treatment of PTSD in the general population. Prazosin is also commonly prescribed for hyperarousal symptoms including nightmares and flashbacks. Regarding psychotherapies, trauma-focused CBT, a form of CBT aimed at identifying, processing, and reframing negative emotions associated with traumatic events, has been shown to be efficacious in treating trauma-related symptoms and disorders in those with ASD (Peterson et al., 2019).

Anorexia Nervosa

Anorexia nervosa is a serious eating disorder with the highest mortality rate of all psychiatric disorders. Key clinical features of anorexia nervosa include restriction of caloric intake leading to significantly low body weight, intense fear of gaining weight, or persistent behavior that interferes with weight gain, and disturbance in which one's body weight or shape is experienced (American Psychiatric Association, 2013). An etiological and clinical link between anorexia nervosa and ASD was first proposed in 1983 by a Swedish child and adolescent psychiatrist, Dr. Christopher Gillberg (Gillberg, 1983). In a seminal report, Dr. Gillberg noted three important clinical observations. First, he reported the observation that females with anorexia nervosa seemed more likely to have male relatives with ASD. Second, he described how a strong insistence or preference for sameness was a key feature of both disorders. Finally, he noted that many females who were receiving treatment for anorexia nervosa appeared socially aloof and struggled with social relationships. In recent years, there has been renewed interest in understanding the relationship between anorexia nervosa and ASD. Adults with comorbid anorexia nervosa and ASD report that the two disorders are interlinked in complex ways, making recovery more challenging (Kinnaird et al., 2019). For example, rigid, literal, or inflexible thinking styles associated with ASD contribute to fixed routines around food and eating behaviors (Kinnaird et al., 2019). Additionally, some patients reported that disordered eating developed from an initial ASD-related intense interest about healthy eating (Brede et al., 2020). Interestingly, some data suggest that the motivation for food restriction in women with ASD and anorexia may be less related to body weight or shape concerns and more related to the sensory aspects of food or internal sensations associated with eating (Brede et al., 2020).

While the true prevalence of comorbid anorexia nervosa and ASD remains unknown, it is generally understood that ASD is overrepresented in treatment seeking eating disorder populations. One study demonstrated that 23% of women seeking treatment for anorexia nervosa at an inpatient or day-patient eating disorder center met the clinical cutoff for ASD on the Autism Diagnostic Observation Schedule (ADOS-2; Westwood et al., 2017). Patients with comorbid ASD and anorexia nervosa typically have more severe eating disorder symptoms, longer inpatient admissions, and poorer outcomes compared to those with anorexia nervosa alone (Tchanturia et al., 2020; Westwood & Tchanturia, 2017). The prevalence of eating disorders in ASD populations is less well understood. Challenges in fully determining the degree of clinical overlap include the difference in timing of onset and gender-based prevalence of these two disorders. ASD is a neurodevelopmental condition beginning within the first few years of life, with a 4:1 male-to-female ratio. In contrast, anorexia nervosa typically begins in adolescence and is up to ten times more common in women than men.

The general treatment approach for anorexia nervosa begins with a medical assessment and physical examination to determine whether an inpatient medical admission is needed to achieve safe refeeding and weight gain. Immediate medical hospitalization is warranted in patients with a body mass index of less than 15, unstable vital signs, evidence of dehydration, life-threatening electrolyte derangements, acute refusal to eat, or suicidality. While no medications have consistently been shown to increase weight gain in anorexia nervosa in the general population, medications may be helpful in treating psychiatric comorbidities such as anxiety or depression. Psychosocial treatments for anorexia nervosa may include family-based treatment, group therapies, and/or individual therapy. Adults with ASD and comorbid anorexia nervosa note several challenges pertaining to conventional inpatient or day hospital treatment environments including sensory overload, group meals, and menu options that do not account for food-specific sensory sensitivities (Brede et al., 2020). Modifications to psychosocial treatment approaches that patients with these comorbid conditions identify as helpful include increased focus on identifying/describing emotions, taking notes during therapy, occupational therapy support to address organizational difficulties around shopping and cooking, and a longer duration of treatment (Kinnaird et al., 2019). A clinical pathway for the treatment of this comorbidity has been developed by the South London and Maudsley National Health Service Trust Eating Disorders Services (www.peacepathway.org) which emphasizes addressing neglected sensory sensitivities, allowing for a longer time to build a therapeutic relationship, and adopting an individualized and flexible approach (Tchanturia et al., 2020).

Sleep-Wake Disorders

Sleep-wake disorders are defined in the DSM-5 by derangements in sleep quality, timing, and duration that result in discomfort and impairment (American Psychiatric Association, 2013). The most common sleep-wake disorders in adults with ASD are insomnia and circadian-rhythm sleep-wake disorders (Carmassi et al., 2019). In insomnia, there is difficulty in initiating and/or maintaining sleep at least three times per week for a period of 3 months. In circadian rhythm sleep-wake disorders, there is a persistent or recurrent pattern of sleep disturbance due to disruptions of the sleep-wake cycle (American Psychiatric Association, 2013). Disturbances in sleep quality, timing, and duration play a significant role in the onset of medical and psychiatric conditions. Chronic sleep impairments and disorders are associated with serious medical and psychiatric comorbidities including hypertension, cardiovascular disease, diabetes, obesity, anxiety, depression, substance use, and stroke (Colten et al., 2006). Chronic sleep impairment may exacerbate symptoms of ADHD, psychosis, and OCD, and result in memory and attention problems (Schubert et al., 2017; Wajszilber et al., 2018; Waters et al., 2018).

Recent studies have demonstrated that compared to the general population, the prevalence of sleep disturbances is elevated in those with ASD, ranging from 50 to 80% compared to 20–41% of the general population (Mannion & Leader, 2014; Ohayon, 2011). Common sleep disturbances include extended time to sleep onset, lower sleep quality, inability to maintain sleep, early morning awakenings, decreased total sleep time, frequent nighttime awakenings, bedtime resistance, and daytime fatigue (Hohn et al., 2019; Mazzone et al., 2018; Øyane & Bjorvatn, 2005). Studies have also reported that adults with ASD have aberrant sleep architecture compared to people without ASD (Carmassi et al., 2019). The development and exacerbation of sleep disorders in individuals with ASD are likely related to neurobiological changes and genetic mutations present in this population. For instance, the impaired function of neurotransmitters such as serotonin, melatonin, and gamma-aminobutyric acid that have been implicated in ASD are also involved in the control of the sleep-wake cycle (Mazzone et al., 2018). Genes involved in melatonin pathways and circadian rhythms have also been found to be affected in those with ASD (Carmassi et al., 2019). Co-existing medical and psychiatric conditions may also contribute to the disrupted sleep in adults with ASD. For instance, gastrointestinal disorders, which are common among patients with ASD, may cause frequent nighttime awakenings. Seizures may cause sleep impairment, and conversely, impaired sleep is a risk factor for seizures. Comorbid psychiatric conditions such as anxiety disorders and ADHD may also contribute to the development of insomnia. Medications for these illnesses, such as SSRIs and stimulants, may also cause adverse effects that disturb the sleep-wake cycle (Cohen et al., 2014). Social cueing problems (such as lack of understanding as to when to go to sleep), increased sensitivity to blue light, sounds, or white noise are other reasons that sleep may be disturbed in those with ASD (Carmassi et al., 2019).

Disruption of the sleep-wake cycle in ASD can have significant social, sensory, and cognitive effects. Core ASD symptoms and associated maladaptive behaviors, such as tantrums and aggression, have been shown to be aggravated by sleep deprivation (Cohen et al., 2014). Since sleep-wake disorders often do not resolve spontaneously, treatment may need to be pursued in order to ensure appropriate sleep. Firstly, possible underlying medical or psychiatric conditions, if present, should be investigated and treated accordingly, with specific interventions taking sleep into consideration if possible. For example, if depression is present, a sedating medication such as mirtazapine could be prescribed to both treat depression and improve sleep quality. A sleep study may need to be completed to rule out sleep apnea if excessive snoring, cessation of breathing, gasping/breathlessness, and frequent awakenings occur. Obesity, excessive daytime sleepiness, and unusual sleep behaviors are other indications for a sleep study. If comorbid medical or psychiatric conditions have been treated and sleep difficulties persist, a trial of sleep medications may be indicated. Prolonged-release melatonin has been shown to be effective in children and adolescents with ASD and insomnia in a randomized controlled trial (Gringras et al., 2017). Regarding non-pharmacologic management, sleep hygiene and CBT for insomnia, should also be recommended.

Gender Dysphoria

Gender dysphoria in adolescents and adults is defined in the DSM-5 as a marked incongruence between one's expressed or experienced gender and their assigned gender (American Psychiatric Association, 2013). Features of gender dysphoria include a strong desire to be rid of one's primary or secondary sex characteristics due to the marked incongruence with the experienced or expressed gender, to have the sex characteristics of the alternative gender, to be treated as the alternative gender, to be of the alternative gender, and a strong conviction that one has the typical feelings and reactions of the alternative gender. To meet criteria for gender dysphoria, one must have at least two of these features for at least 6 months, and the condition must cause clinically significant impairment (American Psychiatric Association, 2013).

In the general population, the prevalence of self-reported transgender identity ranges from 0.5 to

1.3% in children, adolescents, and adults (Zucker, 2017). Some previous studies have postulated that there is higher prevalence of gender dysphoria in individuals with ASD with prevalence rates of 4–5.4% (Warrier et al., 2020). In addition, a recent study suggested that those with more self-reported autistic traits also experienced higher levels of gender dysphoria in the last 12 months and recalled more gender nonconforming behavior from childhood (Kallitsounaki et al., 2020). Despite this, the association between gender dysphoria and ASD remains unclear due to methodological limitations and future high-quality studies are needed (Turban & van Schalkwyk, 2018).

The diagnosis and treatment of adolescents and adults with ASD and comorbid gender dysphoria or gender nonconforming behavior may present unique challenges because of the social and communication complexities that can occur in patients with ASD. Assessments should therefore be administered and tailored to the patient's level of cognitive and social functioning. Screening for gender dysphoria should include asking a few questions regarding gender identity during the clinical interview. While there are adolescents and adults with ASD who may not behave or dress according to an alternative gender, these individuals may still have persistent feelings of gender dysphoria and should not be excluded from a more comprehensive evaluation for gender dysphoria (Strang et al., 2018). Conversely, some individuals with ASD may behave or dress in a manner that is more typical of the alternative gender, but do not identify as the alternative gender. Therefore, a highly individualized, patient-centered approach to gender exploration and care is needed.

There are no specific treatment recommendations for gender dysphoria in adults with ASD beyond the treatments recommended for the general population where the primary approach to care is gender affirmation. Gender affirmation may include a multidisciplinary care team to provide psychological, social, legal, medical, and/or surgical approaches. Treatment goals for psychotherapy should include the broad goals of enhancing self-awareness, communication skills, and executive function while supporting gender exploration and affirmation. Some patients may also seek gender-affirming medical treatments such as hormonal treatment with estradiol or testosterone and/or surgical treatments.

Substance Use Disorders

Substance use disorders occur when the recurrent use of alcohol and/or drugs causes impairments including health problems, disability, and failure to meet major responsibilities. Physical dependence, which occurs when the person requires increasing quantities of the substance to achieve the desired effect (tolerance) or symptoms of withdrawal when the substance is discontinued, may occur. Additional signs of a substance use disorder include use in larger amounts than intended, unsuccessful attempts to cut down use, spending a great deal of time using substances, cravings, use in situations that are physically hazardous, and continued use despite having a physical or psychological problem that is exacerbated by the substance (American Psychiatric Association, 2013). When screening and assessing for substance use disorders in an individual with ASD, it is important to ask direct and specific questions with regard to substance use patterns, as this information may otherwise not be volunteered. The literature describing substance use disorders in adults with ASD remains limited, and well-designed studies assessing factors that precipitate and perpetuate substance misuse in people with ASD are urgently needed. Initial studies suggest that people with ASD may have unique substance use patterns and motivations to sustain use. One small study reported that participants with Asperger's syndrome and a comorbid substance use disorder reported that substances were used for the purposes of self-medicating symptoms of depression, anxiety, or insomnia as well as to increase confidence and ease of communication in social situations (Clarke et al., 2016). Additionally, those with ASD may be more likely to use substances in isolation rather than with peers (Rengit et al., 2016). Individuals with ASD may also be more susceptible to peer exploitation, increasing the likelihood of engaging in risky behaviors associated with substance use (Isenberg et al., 2019).

While ASD was historically assumed to be associated with decreased risk for developing a substance use disorder, more recent data has indicated that substance use disorders can be a significant problem in this population. A recent large Swedish registry study reported that a diagnosis of ASD increased the risk of a substance-use related problem by two-fold (Butwicka et al., 2017). A separate study assessing psychiatric comorbidity in treatment-seeking adults with ASD demonstrated that one-third of adults with ASD reported symptoms consistent with a substance use disorder, which was the same rate observed in the non-ASD psychiatrically referred population (Joshi et al., 2013).

While very little is known about gold standard treatments for substance use disorders in the ASD population, it is clear that many of the core and associated symptoms of ASD can pose challenges in standard substance use disorders treatment settings (Isenberg et al., 2019). For example, many substance use disorder treatments are group-based. Group therapy may be less suitable for individuals with ASD due to difficulties with self-disclosure, intolerance of ambiguous social interactions, and difficulty with perspective taking (Isenberg et al., 2019; Rengit et al., 2016). An individual psychotherapy that focuses on identifying the patient's treatment goals, addresses one behavior at a time, is flexible in terms of session length, and incorporates occasional family meetings may be a more helpful treatment approach (Rengit et al., 2016). Studies on treatment interventions in adults with ASD are needed. Meanwhile, the standard medication assisted therapies for substance use disorders, such as varenicline or bupropion for smoking cessation; naltrexone or acamprosate for alcohol use disorder; and methadone, naltrexone, or suboxone for opioid use disorder should be offered.

Personality Disorders

Personality disorders are defined in the DSM-5 as an "enduring pattern of inner experience and behavior that deviates markedly from the expectations of the individual's experience" (American Psychiatric Association, 2013) with manifestations in at least two of thoughts, feelings, interpersonal functioning, and impulse control. The pattern of inner experience and behavior must be inflexible and occur across a broad range of situations (American Psychiatric Association, 2013). The DSM-5 defines a total of 10 different personality disorders which are grouped into three clusters. Cluster A personality disorders are characterized by unusual behaviors and include paranoid, schizoid, and schizotypal personality disorders. Cluster B personality disorders are characterized by emotional, dramatic, or erratic behavior and include antisocial, borderline, histrionic, and narcissistic personality disorders. Finally, the Cluster C disorders include avoidant, dependent, and obsessive-compulsive personality disorders and are typified by anxious or fearful personality characteristics. The diagnostic criteria for personality disorders specify that the symptoms must not be better explained by another mental disorder, suggesting that if the symptoms can reasonably be attributed to ASD then a comorbid personality disorder diagnosis should not be made. Importantly though, ASD and personality disorders are not mutually exclusive diagnoses. In fact, it has been hypothesized that characteristics of the neurocognitive profile associated with ASD such as inattention, poor impulse control, and difficulty mentalizing may influence adult personality development (Anckarsäter et al., 2006). Other environmental and psychosocial stressors associated with childhood developmental disorders including higher incidences of sexual abuse, parents' reaction to the ASD diagnosis, and differences in child-parent temperament may also increase vulnerability for developing a personality disorder (Wink et al., 2010). Research on comorbid personality disorders in ASD is currently very limited.

The prevalence rates of comorbid personality disorders in the ASD population are largely unknown and have been minimally studied. Challenges inherent to determining the true degree of comorbidity include overlapping symptom domains such as difficulty with interpersonal relationships and emotion regulation as well as the notion that ASD is classically considered a psychiatric diagnosis of childhood while personality disorders are typically considered adult diagnoses. Primarily adult-trained psychiatrists who are meeting the patient during adulthood and lack information about the person's developmental history may "miss" the diagnosis of ASD when considering a personality disorder diagnosis, while child psychiatrists may struggle to "add" a personality disorder diagnosis when longitudinally treating a person who has a known childhood history of ASD. Two prospective studies which included adults with ASD and normal intellectual functioning assessed that 45% and 62% of these study populations met criteria for a DSM-IV personality disorder on structured clinical interview (Hofvander et al., 2009; Strunz et al., 2015). Both these studies identified that Cluster A and Cluster C personality disorders were the most prevalent personality disorder diagnoses. Strunz et al. (2015) compared the ASD patient group to three comparison groups: narcissistic personality disorder, borderline personality disorder, and nonclinical controls. They found that there was an identifiable pattern of personality traits and pathology specific to ASD that was distinguishable from those seen in the three comparison groups which included lower extraversion, decreased openness to experience, higher inhibition, and higher compulsivity. Personality strengths associated with ASD included honesty, orderliness, and conscientiousness (Strunz et al., 2015).

While the treatment of personality disorders in adults with ASD has not been specifically studied, the main treatment for personality disorders in the general population includes psychosocial interventions. No medications have been approved or demonstrated to be consistently effective for the treatment of personality disorders in the absence of other psychiatric comorbidities such as anxiety or depression. A case series which described the presentation and treatment of three adults with ID and comorbid borderline personality disorder identified several important components of treatment including emphasizing safety, providing consistent care, educating team members about the personality disorder diagnosis, working to help the patient improve self-control, and attempting to minimize medications with a high side effect burden (Wink et al., 2010).

Dementia

Dementia is a disorder characterized by significant and progressive cognitive decline of at least one cognitive domain including attention, executive function, learning and memory, language, perceptual-motor, or social cognition (American Psychiatric Association, 2013). The cognitive deficits must interfere with daily function and be severe enough to affect independence. Common presenting issues that raise concern for dementia include forgetfulness, difficulty remembering new events, trouble handling complex tasks, and word finding problems. Behavioral and psychological symptoms associated with dementia such as sleep problems, agitation, and anxiety become more prominent as the disease progresses. The disorder eventually progresses to complete dependence for all daily activities and may lead to premature death. The most common form of dementia among older adults in the general population is Alzheimer's disease, accounting for 60–80% of all dementia cases. The prevalence of Alzheimer's disease rises exponentially with age and typically begins after the age of 65 years (Mayeux & Stern, 2012). Even among healthy adults, signs of cognitive aging can be observed after 50 years of age, with normative declines in processing speed, attention, executive function, and memory (Roestorf et al., 2019). Unfortunately, since ASD is classically thought of as a childhood neurodevelopmental disorder, very little is known about the characteristics and needs of older adults with ASD (Piven & Rabins, 2011), including the prevalence, presentation, and treatment of dementia.

The prevalence of dementia among older adults with ASD and whether ASD is a risk or protective factor for developing dementia are topics that require further study. A large medical records registry-based study which included 1507 adults with ASD demonstrated that adults with ASD (ages 18 years or older) were 4.4 times more likely to have a diagnosis of dementia compared to age- and sex-matched controls (Croen et al., 2015). A study comparing the neuropsychological profile of 23 adults with ASD (ages 51–83 years) to age-, education-, and intellectual ability-matched controls found that aging more adversely affected attention, visual working memory, and fluency in the ASD group, with similar between-group performances in other cognitive domains such as visual and verbal memory (Geurts & Vissers, 2012). In contrast to these findings, another study assessed the neuropsychological profile of adults with ASD (ages 20–79 years, IQ > 80) and found that the ASD group had typical age-related cognitive characteristics that were either reduced or the same as the comparison group (Lever & Geurts, 2016a). The study authors concluded that ASD may partially protect against an age-related decrease in cognitive functioning. Another group demonstrated that individuals with ASD have increased modulation of cortical excitability, indicative of increased brain plasticity. Since plasticity declines with age and may contribute to age-related cognitive decline, this group similarly hypothesized that individuals with ASD may be protected from age-related cognitive decline and dementia (Oberman & Pascual-Leone, 2014). The increased recognition that ASD is a lifelong condition with specific medical and psychiatric needs coupled with the aging population underscores the importance of better understanding how aging affects cognition in adults with ASD. Clarification of this issue will provide a foundation for studying whether ASD is a risk factor for dementia, how dementia presents in this population, and best treatment practices. As of yet, no studies on the management of dementia or cognitive decline in adults with ASD have been published.

Nonspecific Abnormal Behaviors Associated with ASD

Self-Injurious Behaviors

Self-injurious behaviors (SIBs) such as head banging, self-biting, slapping, and eye-gouging are among the most challenging behaviors among individuals with ASD. These behaviors are seen in up to 50% of young children with ASD and are rated as severe in about 15% of cases (Baghdadli et al., 2003). Adults with ASD and ID display higher levels of SIB than adults with either diagnosis alone (Rojahn et al., 2010). SIBs not only pose the risk of severe tissue injury, but can also impede the development of appropriate social and adaptive skills and often lead to the need for more restrictive placements, such as residential settings (Minshawi et al., 2015).

Because SIB can have multiple causes, even within a single individual, a thorough diagnostic assessment of SIB must systematically evaluate for potential behavioral factors, medical conditions, and psychiatric comorbidities (Minshawi et al., 2015). SIBs should be considered using the behavioral framework of antecedent (environmental factors that influence the behavior), behavior (the problematic SIB), and consequence (outcomes related to the behavior's consequence). A functional behavioral assessment (FBA) can be used to identify the antecedents and consequences of SIB. Four common functions of SIB and other problem behaviors include obtaining social attention, gaining access to tangible items, avoiding or escaping demands, and automatic/sensory stimulation (Iwata et al., 1994). Because SIB may be a manifestation of underlying pain or discomfort, an individual exhibiting SIB should also be carefully evaluated for contributing medical factors (Duerden et al., 2012). Individuals with ASD may engage in self-injury either to signal the location of pain or to activate inhibitory pain pathways (Peebles & Price, 2012). Common medical problems underlying SIB include genetic syndromes, migraines, dental problems, otitis media, gastrointestinal disorders, sleep deprivation, and dysmenorrhea/menopause (Minshawi et al., 2015). A detailed medical history and physical examination should be completed. Finally, psychiatric disorders such as major depressive disorder, catatonia, anxiety disorders, or a psychotic disorder may contribute to SIB (Minshawi et al., 2015).

An integrated behavioral and psychopharmacologic approach may be needed for the treatment of SIB when behavioral intervention has not resulted any significant reduction. Behavioral treatment approaches utilize information obtained from the FBA to modify the identified antecedents and consequences. Examples of antecedent modification include enriching the environment so that the individual has continuous access to highly preferred items, activities, or attention; creating an environment that provides a similar sensory experience to the problem behavior; and interspersing high compliance/simple demands with low compliance/more difficult demands. Examples of consequence modification include withdrawing a negative reinforcer by continuing the demand through the episode of SIB; providing positive reinforcement such as rewards or attention for desired behaviors; and teaching and rewarding appropriate alternative behavior (Minshawi et al., 2015). Psychopharmacologic approaches may be beneficial if behavioral treatment is insufficient or the SIB is severe. If a comorbid psychiatric disorder is present, psychopharmacologic treatments should begin by targeting the comorbid psychiatric disorder since the SIB may resolve once the psychiatric comorbidity is treated. In the absence of an identifiable comorbid psychiatric disorder and no medical disorder is present, a trial of a second generation antipsychotic such as risperidone or aripiprazole may be warranted (Minshawi et al., 2015). Both these medications are FDA-approved for the treatment of irritability in children and adolescents with ASD. Risperidone has been shown to decrease SIB in children with ASD in a large, double-blind placebo-controlled trial (Aman et al., 2002). Naltrexone, an opioid receptor antagonist, has also been investigated for the treatment of SIB with mixed results (Rana et al., 2013).

Aggression

Aggression is defined as verbal (threatening, cursing, yelling) or physical (harming, throwing objects, or biting) behaviors that are threatening or likely to cause harm and is of high clinical significance in those with ASD. Aggression is a common and disruptive symptom associated with ASD, sometimes taking precedence over other core features. Aggression can be exhibited in many forms, frequencies, durations, and intensity in those with ASD (Fitzpatrick et al., 2016). In a study including 1380 children with ASD between the ages of 4–17 years, the prevalence of a history of aggression towards caregivers and non-caregivers was 68% and 49%, respectively, and the prevalence of active aggression in the study towards caregivers and non-caregivers was 56% and 32%, respectively (Kanne & Mazurek, 2011). It was also noted that individuals who are younger, have more repetitive behaviors and social/communication problems, and who come from higher-income families were more likely to engage in aggressive behaviors. There were no associations with gender, intellectual functioning, parental education level, or severity of ASD symptoms (Kanne & Mazurek, 2011). The prevalence of physical aggression has been estimated at 53% in a study of 1584 children and adolescents with ASD (Mazurek et al., 2013); however there are no concrete prevalence rates for adults with ASD. Though aggression is highly undesirable in general, it has been associated with several negative outcomes including decreased quality of life and increased stress for patients, families, and caregivers (Fitzpatrick et al., 2016). Aggression has been shown to cause more significant distress to families than the stress associated with core features of ASD (Hastings et al., 2005). Other negative outcomes of aggression for those with ASD include reduced educational and social support, disturbed social relationships, increased risk of use of physical punishment, and more restrictive school or residential settings (Dagnan & Weston, 2006; Luiselli, 2009).

Similar to SIB, aggression may be caused by, and related to, physical illness, psychiatric disorders, sensory overstimulation, or negative emotions which lead to an exaggerated and inappropriate response. A detailed medical and psychiatric evaluation is warranted to evaluate for possible causes of and triggers associated with aggression, as well as the overall trend of aggression. Treatment begins with identifying and managing comorbid medical or psychiatric illnesses as this may result in resolution of the aggressive behaviors. Similar to the approach for SIB described above, an integrative behavioral and psychopharmacological approach is recommended and more likely to be successful in reducing aggressive behaviors. Functional communication training (FCT) is the process in which one is taught to appropriately communicate requests to gain a desirable outcome rather than to engage in aggressive or inappropriate behaviors. Many reviews and research outcomes have demonstrated that FCT is one of the most commonly used and effective interventions for aggressive behaviors (Braithwaite & Richdale, 2000; Carr & Durand, 1985; Matson et al., 2005). Risperidone was demonstrated to reduce aggression in double-blind, placebo-controlled randomized trial of adults with ASD (McDougle et al., 1998). Other treatments that have been investigated for the treatment of aggression in adults with ASD include propranolol, fluvoxamine, dextromethorphan/quinidine, and vigorous aerobic exercise (Im, 2021).

General Treatment Considerations

While the clinical approach to comorbid psychiatric disorders in adults with ASD is similar to that used in the general population, there are several important biological, psychological, and social considerations to be aware of when treating this population. Biologically, prospective psychopharmacology studies that include adults with ASD are limited. This is an important knowledge gap, as response to medications and adverse effects may differ in the ASD population. Additionally, individuals with ASD are at elevated risk for comorbid medical conditions including epilepsy and gastrointestinal disorders which may manifest with behavioral symptoms. Psychologically, although some psychological and behavioral therapies have shown efficacy in reducing psychiatric symptoms in ASD populations, modifications to therapy are often needed. Commonly encountered challenges of psychotherapy include ID, mental rigidity or inflexibility, decreased mentalizing ability, social anxiety, or inability to identify or communicate emotions. Developmentally appropriate approaches, incorporating routine and/or specific interests into therapy sessions, and focusing on identifying cues/triggers for challenging behavior are techniques that may be of particular benefit. Socially, there are many environmental factors that can impact the presentation and trajectory of psychiatric comorbidities. Adults with ASD vary significantly in terms of their functioning and abilities, ranging from needing major supports to being able to work and live independently, making it important to take a highly individualized approach to ensure that the person's social/familial supports, living environment, and day structure are optimized. Finally, the patient's developmental level, intellectual ability, and capacity to consent to care are additional factors to consider.

Conclusion

Psychiatric comorbidities in adults with ASD are common, yet often underrecognized and underdiagnosed. The identification and diagnosis of psychiatric comorbidities may be complicated in this population due to differences in clinical presentation, diagnostic overshadowing, and cognitive/communicative differences. It is essential to assess for psychiatric comorbidities by conducting a thorough diagnostic evaluation with special attention to how the symptoms relate both to the core symptoms of ASD and the specific individual. Pharmacological and psychotherapeutic treatments can be effective in reducing symptom burden and improving functioning, but further studies are needed.

References

Alaghband-Rad, J., McKenna, K., Gordon, C. T., Albus, K. E., Hamburger, S. D., Rumsey, J. M., Frazier, J. A., Lenane, M. C., & Rapoport, J. L. (1995). Childhood-onset schizophrenia: The severity of premorbid course. *Journal of the American Academy of Child & Adolescent Psychiatry, 34*(10). https://doi.org/10.1097/00004583-199510000-00012

Aman, M. G., De Smedt, G., Derivan, A., Lyons, B., Findling, R. L., & Risperidone Disruptive Behavior Study Group. (2002). Double-blind, placebo-controlled study of risperidone for the treatment of disruptive behaviors in children with subaverage intelligence. *The American Journal of Psychiatry,* *159*(8), 1337–1346. https://doi.org/10.1176/appi.ajp.159.8.1337

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Association.

Anckarsäter, H., Stahlberg, O., Larson, T., Hakansson, C., Jutblad, S. B., Niklasson, L., Nydén, A., Wentz, E., Westergren, S., Cloninger, C. R., Gillberg, C., & Rastam, M. (2006). The impact of ADHD and autism spectrum disorders on temperament, character, and personality development. *The American Journal of Psychiatry, 163*(7), 1239–1244. https://doi.org/10.1176/appi.ajp.163.7.1239

Antshel, K. M., Zhang-James, Y., Wagner, K. E., Ledesma, A., & Faraone, S. V. (2016). An update on the comorbidity of ADHD and ASD: A focus on clinical management. *Expert Review of Neurotherapeutics, 16*(3), 279–293. https://doi.org/10.1586/14737175.2016.1146591

Asarnow, R. F., Brown, W., & Standburg, R. (1995). Children with a schizopherenic disorder: Neurobehavioral studies. *European Archives of Psychiatry and Clinical Neuroscience, 245*(2). https://doi.org/10.1007/BF02190733

Avni, E., Ben-Itzchak, E., & Zachor, D. A. (2018). The presence of comorbid ADHD and anxiety symptoms in autism spectrum disorder: Clinical presentation and predictors. *Frontiers in Psychiatry, 9*. https://doi.org/10.3389/fpsyt.2018.00717

Baghdadli, A., Pascal, C., Grisi, S., & Aussilloux, C. (2003). Risk factors for self-injurious behaviours among 222 young children with autistic disorders. *Journal of Intellectual Disability Research, 47*(8), 622–627. https://doi.org/10.1046/j.1365-2788.2003.00507.x

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., Kurzius-Spencer, M., Zahorodny, W., Robinson, C., Rosenberg, W. T., Durkin, M. S., Imm, P., Nikolaou, L., Yeargin-Allsopp, M., Lee, L.-C., Harrington, R., Lopez, M., Fitzgerald, R. T., … Dowling, N. F. (2018). Prevalence of autism spectrum disorder among children aged 8 years – Autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *MMWR. Surveillance Summaries, 67*(6), 1–23. https://doi.org/10.15585/mmwr.ss6706a1

Bal, V. H., Katz, T., Bishop, S. L., & Krasileva, K. (2016). Understanding definitions of minimally verbal across instruments: Evidence for subgroups within minimally verbal children and adolescents with autism spectrum disorder. *Journal of Child Psychology and Psychiatry, 57*(12), 1424–1433. https://doi.org/10.1111/jcpp.12609

Baron-Cohen, S., Scahill, V. L., Izaguirre, J., Hornsey, H., & Robertson, M. M. (1999). The prevalence of Gilles de la Tourette syndrome in children and adolescents with autism: A large scale study. *Psychological Medicine, 29*(5), 1151–1159. https://doi.org/10.1017/S003329179900896X

Berney, T. P. (2000). Autism – An evolving concept. *British Journal of Psychiatry, 176*(1). https://doi.org/10.1192/bjp.176.1.20

Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: Population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders, 35*(3), 351–360. https://doi.org/10.1007/s10803-005-3302-5

Borue, X., Mazefsky, C., Rooks, B. T., Strober, M., Keller, M. B., Hower, H., Yen, S., Gill, M. K., Diler, R. S., Axelson, D. A., Goldstein, B. I., Goldstein, T. R., Ryan, N., Liao, F., Hunt, J. I., Dickstein, D. P., & Birmaher, B. (2016). Longitudinal course of bipolar disorder in youth with high-functioning autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 55*(12). https://doi.org/10.1016/j.jaac.2016.08.011

Braithwaite, K. L., & Richdale, A. (2000). Functional communication training to replace challenging behaviors across two behavioral outcomes. *Behavioral Interventions, 15*, 21–36. https://doi.org/10.1002/(SICI)1099-078X(200001/03)15:1<21::AID-BIN45>3.0.CO;2-#

Brede, J., Babb, C., Jones, C., Elliott, M., Zanker, C., Tchanturia, K., Serpell, L., Fox, J., & Mandy, W. (2020). "For me, the anorexia is just a symptom, and the cause is the autism": Investigating restrictive eating disorders in autistic women. *Journal of Autism and Developmental Disorders, 50*(12), 4280–4296. https://doi.org/10.1007/s10803-020-04479-3

Butwicka, A., Långström, N., Larsson, H., Lundström, S., Serlachius, E., Almqvist, C., Frisén, L., & Lichtenstein, P. (2017). Increased risk for substance use-related problems in autism Spectrum disorders: A population-based cohort study. *Journal of Autism and Developmental Disorders, 47*(1), 80–89. https://doi.org/10.1007/s10803-016-2914-2

Canitano, R., & Vivanti, G. (2007). Tics and Tourette syndrome in autism spectrum disorders. *Autism, 11*(1), 19–28. https://doi.org/10.1177/1362361307070992

Carmassi, C., Palagini, L., Caruso, D., Masci, I., Nobili, L., Vita, A., & Dell'Osso, L. (2019). Systematic review of sleep disturbances and circadian sleep desynchronization in autism spectrum disorder: Toward an integrative model of a self-reinforcing loop. *Frontiers in Psychiatry, 10*. https://doi.org/10.3389/fpsyt.2019.00366

Carr, E. G., & Durand, V. M. (1985). Reducing behavior problems through functional communication training. *Journal of Applied Behavior Analysis, 18*(2). https://doi.org/10.1901/jaba.1985.18-111

Chandrasekhar, T., & Sikich, L. (2015). Challenges in the diagnosis and treatment of depression in autism spectrum disorders across the lifespan. *Dialogues in Clinical Neuroscience, 17*(2), 219–227.

Chen, M. H., Pan, T. L., Lan, W. H., Hsu, J. W., Huang, K. L., Su, T. P., Li, C. T., Lin, W. C., Wei, H. T., Chen, T. J., & Bai, Y. M. (2017). Risk of suicide attempts among adolescents and young adults with autism spectrum disorder: A nationwide longitudinal follow-up study. *Journal of Clinical Psychiatry, 78*(9), e1174–e1179. Physicians Postgraduate Press Inc. https://doi.org/10.4088/JCP.16m11100

Cheung, C., Yu, K., Fung, G., Leung, M., Wong, C., Li, Q., Sham, P., Chua, S., & McAlonan, G. (2010). Autistic disorders and schizophrenia: Related or remote? An anatomical likelihood estimation. *PLoS One, 5*(8). https://doi.org/10.1371/journal.pone.0012233

Christakou, A., Murphy, C. M., Chantiluke, K., Cubillo, A. I., Smith, A. B., Giampietro, V., Daly, E., Ecker, C., Robertson, D., Murphy, D. G., & Rubia, K. (2013). Disorder-specific functional abnormalities during sustained attention in youth with attention deficit hyperactivity disorder (ADHD) and with autism. *Molecular Psychiatry, 18*(2), 236–244. https://doi.org/10.1038/mp.2011.185

Clarke, T., Tickle, A., & Gillott, A. (2016). Substance use disorder in Asperger syndrome: An investigation into the development and maintenance of substance use disorder by individuals with a diagnosis of Asperger syndrome. *International Journal of Drug Policy, 27*, 154–163. https://doi.org/10.1016/j.drugpo.2015.06.003

Cohen, S., Conduit, R., Lockley, S. W., Rajaratnam, S. M., & Cornish, K. M. (2014). The relationship between sleep and behavior in autism spectrum disorder (ASD): A review. *Journal of Neurodevelopmental Disorders, 6*(1). https://doi.org/10.1186/1866-1955-6-44

Collins, J., Halder, N., & Chaudhry, N. (2012). Use of ECT in patients with an intellectual disability: Review. *The Psychiatrist, 36*(2), 55–60. https://doi.org/10.1192/pb.bp.110.033811

Colten, H. R., Altevogt, B. M., & Institute of Medicine (US) Committee on Sleep Medicine and Research (Eds.). (2006). *Sleep disorders and sleep deprivation: An unmet public health problem*. National Academies Press (US).

Cortese, S., Faraone, S., & v., Konofal, E., & Lecendreux, M. (2009). Sleep in children with attention-deficit/hyperactivity disorder: Meta-analysis of subjective and objective studies. *Journal of the American Academy of Child & Adolescent Psychiatry, 48*(9), 894–908. https://doi.org/10.1097/CHI.0b013e3181ac09c9

Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism, 19*(7), 814–823. https://doi.org/10.1177/1362361315577517

Dagnan, D., & Weston, C. (2006). Physical intervention with people with intellectual disabilities: The influence of cognitive and emotional variables. *Journal of Applied Research in Intellectual Disabilities, 19*(2). https://doi.org/10.1111/j.1468-3148.2005.00262.x

DeJong, H., Bunton, P., & Hare, D. J. (2014). A systematic review of interventions used to treat catatonic symptoms in people with autistic spectrum disorders. *Journal of Autism and Developmental Disorders, 44*(9), 2127–2136. https://doi.org/10.1007/s10803-014-2085-y

Dhossche, D. M., & Stanfill, S. (2004). Could ECT be effective in autism? *Medical Hypotheses, 63*(3), 371–376. https://doi.org/10.1016/j.mehy.2004.03.023

Dhossche, D. M., Shah, A., & Wing, L. (2006). Blueprints for the assessment, treatment, and future study of catatonia in autism spectrum disorders. *International Review of Neurobiology, 72*, 267–284. https://doi.org/10.1016/S0074-7742(05)72016-X

Downs, J. M., Lechler, S., Dean, H., Sears, N., Patel, R., Shetty, H., Simonoff, E., Hotopf, M., Ford, T. J., Diaz-Caneja, C. M., Arango, C., MacCabe, J. H., Hayes, R. D., & Pina-Camacho, L. (2017). The association between comorbid autism spectrum disorders and antipsychotic treatment failure in early-onset psychosis. *The Journal of Clinical Psychiatry, 78*(9), e1233–e1241. https://doi.org/10.4088/jcp.16m11422

Du, J. C., Chiu, T. F., Lee, K. M., Wu, H. L., Yang, Y. C., Hsu, S. Y., Sun, C. S., Hwang, B., & Leckman, J. F. (2010). Tourette syndrome in children: An updated review. *Pediatrics and Neonatology, 51*(5), 255–264). Elsevier (Singapore) Pte Ltd. https://doi.org/10.1016/S1875-9572(10)60050-2

Duerden, E. G., Oatley, H. K., Mak-Fan, K. M., McGrath, P. A., Taylor, M. J., Szatmari, P., & Roberts, S. W. (2012). Risk factors associated with self-injurious behaviors in children and adolescents with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(11), 2460–2470. https://doi.org/10.1007/s10803-012-1497-9

Faraone, S. V., Biederman, J., & Mick, E. (2006). The age-dependent decline of attention deficit hyperactivity disorder: A meta-analysis of follow-up studies. *Psychological Medicine, 36*(2), 159–165. https://doi.org/10.1017/S003329170500471X

Fernandez, T. V., Sanders, S. J., Yurkiewicz, I. R., Ercan-Sencicek, A. G., Kim, Y. S., Fishman, D. O., Raubeson, M. J., Song, Y., Yasuno, K., Ho, W. S. C., Bilguvar, K., Glessner, J., Chu, S. H., Leckman, J. F., King, R. A., Gilbert, D. L., Heiman, G. A., Tischfield, J. A., Hoekstra, P. J., … State, M. W. (2012). Rare copy number variants in tourette syndrome disrupt genes in histaminergic pathways and overlap with autism. *Biological Psychiatry, 71*(5), 392–402. https://doi.org/10.1016/j.biopsych.2011.09.034

Fink, M., & Taylor, M. (2009). *Catatonia: A clinician's guide to diagnosis and treatment*. Cambridge University Press.

Fitzpatrick, S., Erickson, C., Srivorakiat, L., Wink, L., & Pedapati, E. (2016). Aggression in autism spectrum disorder: Presentation and treatment options. *Neuropsychiatric Disease and Treatment*. https://doi.org/10.2147/NDT.S84585

George, M., Maheshwari, S., Chandran, S., Manohar, J. S., & Sathyanarayana Rao, T. S. (2017). Understanding the schizophrenia prodrome. *Indian Journal of Psychiatry, 59*(4), 505–509. https://doi.org/10.4103/psychiatry.IndianJPsychiatry_464_17

Geurts, H. M., & Vissers, M. E. (2012). Elderly with autism: Executive functions and memory. *Journal of*

Autism and Developmental Disorders, 42(5), 665–675. https://doi.org/10.1007/s10803-011-1291-0

Ghaziuddin, N., Dhossche, D., & Marcotte, K. (2012). Retrospective chart review of catatonia in child and adolescent psychiatric patients. *Acta Psychiatrica Scandinavica, 125*(1), 33–38. https://doi.org/10.1111/j.1600-0447.2011.01778.x

Gilbert, D. (2006). Treatment of children and adolescents with tics and Tourette syndrome. *Journal of Child Neurology, 21*(8), 690–700. https://doi.org/10.1177/08830738060210080401

Gillberg, C. (1983). Are autism and anorexia nervosa related? *The British Journal of Psychiatry, 142*, 428. https://doi.org/10.1192/bjp.142.4.428b

Greenhill, L., Swanson, B., Vitiello, B., Davies, M., & Wigal, T. (2001). Impairment and deportment responses to differnet methylphenidate doses in children with ADHD: The MTA titration trial. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*(2), 180–187.

Gringras, P., Nir, T., Breddy, J., Frydman-Marom, A., & Findling, R. L. (2017). Efficacy and safety of pediatric prolonged-release melatonin for insomnia in children with autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 56*(11), 948–957.e4. https://doi.org/10.1016/j.jaac.2017.09.414

Hastings, R. P., Kovshoff, H., Ward, N. J., Espinosa, F. D., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders, 35*(5). https://doi.org/10.1007/s10803-005-0007-8

Herscu, P., Handen, B. L., Arnold, L. E., Snape, M. F., Bregman, J. D., Ginsberg, L., Hendren, R., Kolevzon, A., Melmed, R., Mintz, M., Minshew, N., Sikich, L., Attalla, A., King, B., Owley, T., Childress, A., Chugani, H., Frazier, J., Cartwright, C., & Murphy, T. (2020). The SOFIA study: Negative multi-center study of low dose fluoxetine on repetitive behaviors in children and adolescents with autistic disorder. *Journal of Autism and Developmental Disorders, 50*(9), 3233–3244. https://doi.org/10.1007/s10803-019-04120-y

Hofvander, B., Delorme, R., Chaste, P., Nydén, A., Wentz, E., Ståhlberg, O., Herbrecht, E., Stopin, A., Anckarsäter, H., Gillberg, C., Råstam, M., & Leboyer, M. (2009). Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry, 9*. https://doi.org/10.1186/1471-244X-9-35

Hohn, V. D., de Veld, D. M. J., Mataw, K. J. S., van Someren, E. J. W., & Begeer, S. (2019). Insomnia severity in adults with autism spectrum disorder is associated with sensory hyper-reactivity and social skill impairment. *Journal of Autism and Developmental Disorders, 49*(5). https://doi.org/10.1007/s10803-019-03891-8

Hoover, D. W., & Kaufman, J. (2018). Adverse childhood experiences in children with autism spectrum disorder. *Current Opinion in Psychiatry, 31*(2). https://doi.org/10.1097/YCO.0000000000000390

Hvolby, A. (2015). Associations of sleep disturbance with ADHD: Implications for treatment. *ADHD Attention Deficit and Hyperactivity Disorders, 7*(1), 1–18. https://doi.org/10.1007/s12402-014-0151-0

Im, D. S. (2021). Treatment of aggression in adults with autism spectrum disorder: A review. *Harvard Review of Psychiatry, 29*(1), 35–80. https://doi.org/10.1097/HRP.0000000000000282

Isenberg, B. M., Yule, A. M., McKowen, J. W., Nowinski, L. A., Forchelli, G. A., & Wilens, T. E. (2019). Considerations for treating young people with comorbid autism spectrum disorder and substance use disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 58*(12), 1139–1141). Elsevier Inc. https://doi.org/10.1016/j.jaac.2019.08.467

Iwata, B. A., Dorsey, M. F., Slifer, K. J., Bauman, K. E., & Richman, G. S. (1994). Toward a functional analysis of self-injury. *Journal of Applied Behavior Analysis, 27*(2), 197–209. https://doi.org/10.1901/jaba.1994.27-197

Joshi, G., Petty, C., Wozniak, J., Henin, A., Fried, R., Galdo, M., Kotarski, M., Walls, S., & Biederman, J. (2010). The heavy burden of psychiatric comorbidity in youth with autism spectrum disorders: A large comparative study of a psychiatrically referred population. *Journal of Autism and Developmental Disorders, 40*(11), 1361–1370. https://doi.org/10.1007/s10803-010-0996-9

Joshi, G., Wozniak, J., Petty, C., Martelon, M. K., Fried, R., Bolfek, A., Kotte, A., Stevens, J., Furtak, S. L., Bourgeois, M., Caruso, J., Caron, A., & Biederman, J. (2013). Psychiatric comorbidity and functioning in a clinically referred population of adults with autism spectrum disorders: A comparative study. *Journal of Autism and Developmental Disorders, 43*(6), 1314–1325. https://doi.org/10.1007/s10803-012-1679-5

Kahl, U., Schunke, O., Schöttle, D., David, N., Brandt, V., Bäumer, T., Roessner, V., Münchau, A., & Ganos, C. (2015). Tic phenomenology and tic awareness in adults with autism. *Movement Disorders Clinical Practice, 2*(3), 237–242. https://doi.org/10.1002/mdc3.12154

Kallitsounaki, A., Williams, D. M., & Lind, S. E. (2020). Links between autistic traits, feelings of gender dysphoria, and mentalising ability: Replication and extension of previous findings from the general population. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-020-04626-w

Kanne, S. M., & Mazurek, M. O. (2011). Aggression in children and adolescents with ASD: Prevalence and risk factors. *Journal of Autism and Developmental Disorders, 41*(7). https://doi.org/10.1007/s10803-010-1118-4

Kerns, C. M., Kendall, P. C., Berry, L., Souders, M. C., Franklin, M. E., Schultz, R. T., Miller, J., & Herrington, J. (2014). Traditional and atypical presentations of anxiety in youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 44*(11). https://doi.org/10.1007/s10803-014-2141-7

King, B. H., Hollander, E., Sikich, L., McCracken, J. T., Scahill, L., Bregman, J. D., Donnelly, C. L., Anagnostou, E., Dukes, K., Sullivan, L., Hirtz, D., Wagner, A., & Ritz, L. (2009). Lack of efficacy of citalopram in children with autism spectrum disorders and high levels of repetitive behavior: Citalopram ineffective in children with autism. *Archives of General Psychiatry, 66*(6), 583–590. https://doi.org/10.1001/archgenpsychiatry.2009.30

Kinnaird, E., Norton, C., Stewart, C., & Tchanturia, K. (2019). Same behaviours, different reasons: What do patients with co-occurring anorexia and autism want from treatment? *International Review of Psychiatry, 31*(4), 308–317. https://doi.org/10.1080/09540261.2018.1531831

Kirby, A. V., Bakian, A. V., Zhang, Y., Bilder, D. A., Keeshin, B. R., & Coon, H. (2019). A 20-year study of suicide death in a statewide autism population. *Autism Research, 12*(4), 658–666. https://doi.org/10.1002/aur.2076

Kirsch, A. C., Huebner, A., Mehta, S. Q., Howie, F. R., Weaver, A. L., Myers, S. M., Voigt, R. G., & Katusic, S. K. (2019). Association of comorbid mood and anxiety disorders with autism spectrum disorder. *JAMA Pediatrics, 174*(1), 63–70. Advance Online Publication. https://doi.org/10.1001/jamapediatrics.2019.4368

Klin, A., Danovitch, J. H., Merz, A. B., & Volkmar, F. R. (2007). Circumscribed interests in higher functioning individuals with autism spectrum disorders: An exploratory study. *Research and Practice for Persons with Severe Disabilities, 32*(2), 89–100.

Kolvin, I. (1971). Studies in the childhood psychoses I. Diagnostic criteria and classification. *British Journal of Psychiatry, 118*(545). https://doi.org/10.1192/bjp.118.545.381

Kolvin, I., Ounsted, C., Humphrey, M., & McNay, A. (1971). II. The phenomenology of childhood psychoses. *British Journal of Psychiatry, 118*(545). https://doi.org/10.1192/bjp.118.545.385

Leckman, J. F. (2012). Tic disorders. *BMJ, 5*(344), d7659. https://doi.org/10.1136/bmj.d7659

Lee, P. H., Anttila, V., Won, H., Feng, Y.-C. A., Rosenthal, J., Zhu, Z., Tucker-Drob, E. M., Nivard, M. G., Grotzinger, A. D., Posthuma, D., Wang, M. M.-J., Yu, D., Stahl, E. A., Walters, R. K., Anney, R. J. L., Duncan, L. E., Ge, T., Adolfsson, R., Banaschewski, T., … Smoller, J. W. (2019). Genomic relationships, novel loci, and pleiotropic mechanisms across eight psychiatric disorders. *Cell, 179*(7). https://doi.org/10.1016/j.cell.2019.11.020

Lenze, E. J., & Wetherell, J. L. (2011). A lifespan view of anxiety disorders. *Dialogues in Clinical Neuroscience, 13*(4). https://doi.org/10.31887/DCNS.2011.13.4/elenze

Lever, A. G., & Geurts, H. M. (2016a). Age-related differences in cognition across the adult lifespan in autism spectrum disorder. *Autism Research, 9*(6), 666–676. https://doi.org/10.1002/aur.1545

Lever, A. G., & Geurts, H. M. (2016b). Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(6), 1916–1930. https://doi.org/10.1007/s10803-016-2722-8

Lichtenstein, P., Carlström, E., Råstam, M., Gillberg, C., & Anckarsäter, H. (2010). The genetics of autism spectrum disorders and related neuropsychiatric disorders in childhood. *American Journal of Psychiatry, 167*(11), 1357–1363. https://doi.org/10.1176/appi.ajp.2010.10020223

Lipinski, S., Blanke, E. S., Suenkel, U., & Dziobek, I. (2019). Outpatient psychotherapy for adults with high-functioning autism spectrum condition: Utilization, treatment satisfaction, and preferred modifications. *Journal of Autism and Developmental Disorders, 49*(3), 1154–1168. https://doi.org/10.1007/s10803-018-3797-1

Luiselli, J. K. (2009). Aggression and noncompliance. In J. Matson (Ed.), *Applied behavior analysis for children with autism spectrum disorder* (pp. 175–188). Springer.

Mannion, A., & Leader, G. (2014). Sleep problems in autism spectrum disorder: A literature review. *Review. Journal of Autism and Developmental Disorders, 1*(2). https://doi.org/10.1007/s40489-013-0009-y

Marrosu, F., Marrosu, G., Rachel, M. G., & Biggio, G. (1987). Paradoxical reactions elicited by diazepam in children with classic autism. *Functional Neurology, 2*(3), 355–361. http://europepmc.org/abstract/MED/2826308

Matson, J., Dixon, D., & Matson, M. (2005). Assessing and treating aggression in children and adolescents with developmental disabilities: A 20-year overview. *Educational Psychology, 25*, 151–181. https://doi.org/10.1080/0144341042000301148

Mattila, M. L., Hurtig, T., Haapsamo, H., Jussila, K., Kuusikko-Gauffin, S., Kielinen, M., Linna, S. L., Ebeling, H., Bloigu, R., Joskitt, L., Pauls, D. L., & Moilanen, I. (2010). Comorbid psychiatric disorders associated with asperger syndrome/high-functioning autism: A community- and clinic-based study. *Journal of Autism and Developmental Disorders, 40*(9), 1080–1093. https://doi.org/10.1007/s10803-010-0958-2

Mayeux, R., & Stern, Y. (2012). Epidemiology of Alzheimer disease. *Cold Spring Harbor Perspectives in Medicine, 2*(8). https://doi.org/10.1101/cshperspect.a006239

Mazefsky, C. A., Herrington, J., Siegel, M., Scarpa, A., Maddox, B. B., Scahill, L., & White, S. W. (2013). The role of emotion regulation in autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(7). https://doi.org/10.1016/j.jaac.2013.05.006

Mazurek, M. O., Kanne, S. M., & Wodka, E. L. (2013). Physical aggression in children and adolescents with autism spectrum disorders. *Research in Autism Spectrum Disorders, 7*(3). https://doi.org/10.1016/j.rasd.2012.11.004

Mazzone, L., Postorino, V., Siracusano, M., Riccioni, A., & Curatolo, P. (2018). The relationship between sleep problems, neurobiological alterations, core symptoms of autism spectrum disorder, and psychiatric comorbidities. *Journal of Clinical Medicine, 7*(5). https://doi.org/10.3390/jcm7050102

McDougle, C. J. (2016). *Autism spectrum disorder*. Oxford University Press.

McDougle, C. J., Kresch, L. E., Goodman, W. K., Naylor, S. T., Volkmar, F. R., Cohen, D. J., & Price, L. H. (1995). A case-controlled study of repetitive thoughts and behavior in adults with autistic disorder and obsessive-compulsive disorder. *American Journal of Psychiatry, 152*(5), 772–777. https://doi.org/10.1176/ajp.152.5.772

McDougle, C. J., Holmes, J. P., Carlson, D. C., Pelton, G. H., Cohen, D. J., & Price, L. H. (1998). A double-blind, placebo-controlled study of risperidone in adults with autistic disorder and other pervasive developmental disorders. *Archives of General Psychiatry, 55*(7), 633–641. https://doi.org/10.1001/archpsyc.55.7.633

McGillivray, J. A., & Evert, H. T. (2014). Group cognitive behavioural therapy program shows potential in reducing symptoms of depression and stress among young people with ASD. *Journal of Autism and Developmental Disorders, 44*(8), 2041–2051. https://doi.org/10.1007/s10803-014-2087-9

Merikangas, K. R., Jin, R., He, J. P., Kessler, R. C., Lee, S., Sampson, N. A., Viana, M. C., Andrade, L. H., Hu, C., Karam, E. G., Ladea, M., Medina-Mora, M. E., Ono, Y., Posada-Villa, J., Sagar, R., Wells, J. E., & Zarkov, Z. (2011). Prevalence and correlates of bipolar spectrum disorder in the world mental health survey initiative. *Archives of General Psychiatry, 68*(3), 241–251. https://doi.org/10.1001/archgenpsychiatry.2011.12

Minshawi, N. F., Hurwitz, S., Morriss, D., & McDougle, C. J. (2015). Multidisciplinary assessment and treatment of self-injurious behavior in autism spectrum disorder and intellectual disability: Integration of psychological and biological theory and approach. *Journal of Autism and Developmental Disorders, 45*(6), 1541–1568. https://doi.org/10.1007/s10803-014-2307-3

Miot, S., Akbaraly, T., Michelon, C., Couderc, S., Crepiat, S., Loubersac, J., Picot, M.-C., Pernon, É., Gonnier, V., Jeandel, C., Blain, H., & Baghdadli, A. (2019). Comorbidity burden in adults with autism spectrum disorders and intellectual disabilities – A report from the EFAAR (frailty assessment in ageing adults with autism spectrum and intellectual disabilities) study. *Frontiers in Psychiatry, 10*. https://doi.org/10.3389/fpsyt.2019.00617

Nielsen, M. B., Tangen, T., Idsoe, T., Matthiesen, S. B., & Magerøy, N. (2015). Post-traumatic stress disorder as a consequence of bullying at work and at school. A literature review and meta-analysis. *Aggression and Violent Behavior, 21*, 17–24). Elsevier Ltd. https://doi.org/10.1016/j.avb.2015.01.001

Nimmo-Smith, V., Heuvelman, H., Dalman, C., Lundberg, M., Idring, S., Carpenter, P., Magnusson, C., & Rai, D. (2020). Anxiety disorders in adults with autism spectrum disorder: A population-based study. *Journal of Autism and Developmental Disorders, 50*(1). https://doi.org/10.1007/s10803-019-04234-3

Oberman, L. M., & Pascual-Leone, A. (2014). Hyperplasticity in autism spectrum disorder confers protection from Alzheimer's disease. *Medical Hypotheses, 83*(3), 337–342. https://doi.org/10.1016/j.mehy.2014.06.008

Ohayon, M. M. (2011). Epidemiological overview of sleep disorders in the general population. *Sleep Medicine Research, 2*(1). https://doi.org/10.17241/smr.2011.2.1.1

Ohta, M., Kano, Y., & Nagai, Y. (2006). Catatonia in individuals with autism spectrum disorders in adolescence and early adulthood: A long-term prospective study. *International Review of Neurobiology, 72*, 41–54. https://doi.org/10.1016/S0074-7742(05)72003-1

Øyane, N. M. F., & Bjorvatn, B. (2005). Sleep disturbances in adolescents and young adults with autism and Asperger syndrome. *Autism, 9*(1). https://doi.org/10.1177/1362361305049031

Pazuniak, M., & Pekrul, S. R. (2020). Obsessive–compulsive disorder in autism spectrum disorder across the lifespan. *Psychiatric Clinics of North America, 43*(4), 745–758). W.B. Saunders. https://doi.org/10.1016/j.psc.2020.08.010

Peebles, K. A., & Price, T. J. (2012). Self-injurious behaviour in intellectual disability syndromes: Evidence for aberrant pain signalling as a contributing factor. *Journal of Intellectual Disability Research, 56*(5), 441–452. https://doi.org/10.1111/j.1365-2788.2011.01484.x

Peterson, J. L., Earl, R. K., Fox, E. A., Ma, R., Haidar, G., Pepper, M., Berliner, L., Wallace, A. S., & Bernier, R. A. (2019). Trauma and autism spectrum disorder: Review, proposed treatment adaptations and future directions. *Journal of Child & Adolescent Trauma, 12*(4). https://doi.org/10.1007/s40653-019-00253-5

Pezzimenti, F., Han, G. T., Vasa, R. A., & Gotham, K. (2019). Depression in youth with autism spectrum disorder. *Child and Adolescent Psychiatric Clinics of North America, 28*(3), 397–409). W.B. Saunders. https://doi.org/10.1016/j.chc.2019.02.009

Piven, J., & Rabins, P. (2011). Autism spectrum disorders in older adults: Toward defining a research agenda. *Journal of the American Geriatrics Society, 59*(11), 2151–2155. https://doi.org/10.1111/j.1532-5415.2011.03632.x

Polanczyk, G., de Lima, M. S., Horta, B. L., Biederman, J., & Rohde, L. A. (2007). The worldwide prevalence of ADHD: A systematic review and metaregression analysis. *American Journal of Psychiatry, 164*(6), 942–948. https://doi.org/10.1176/ajp.2007.164.6.942

Posey, D. J., Kem, D. L., Swiezy, N. B., Sweeten, T. L., Wiegand, R. E., & McDougle, C. J. (2004). A pilot study of cycloserine in subjects with autistic disorder. *American Journal of Psychiatry, 161*(11). https://doi.org/10.1176/appi.ajp.161.11.2115

Rana, F., Gormez, A., & Varghese, S. (2013). Pharmacological interventions for self-injurious behaviour in adults with intellectual disabilities. *Cochrane Database of Systematic Reviews, 2013*(4) Wiley. https://doi.org/10.1002/14651858.CD009084.pub2

Rengit, A. C., McKowen, J. W., O'Brien, J., Howe, Y. J., & McDougle, C. J. (2016). Brief report: Autism spectrum disorder and substance use disorder: A review and case study. *Journal of Autism and Developmental Disorders, 46*(7), 2514–2519. https://doi.org/10.1007/s10803-016-2763-z

Richdale, A. L., & Schreck, K. A. (2009). Sleep problems in autism spectrum disorders: Prevalence, nature, & possible biopsychosocial aetiologies. *Sleep Medicine Reviews, 13*(6), 403–411. https://doi.org/10.1016/j.smrv.2009.02.003

Roestorf, A., Bowler, D. M., Deserno, M. K., Howlin, P., Klinger, L., McConachie, H., Parr, J. R., Powell, P., Van Heijst, B. F. C., & Geurts, H. M. (2019). "Older adults with ASD: The consequences of aging." Insights from a series of special interest group meetings held at the International Society for Autism Research 2016–2017. *Research in Autism Spectrum Disorders, 63*, 3–12. https://doi.org/10.1016/j.rasd.2018.08.007

Rojahn, J., Wilkins, J., Matson, J. L., & Boisjoli, J. (2010). A comparison of adults with intellectual disabilities with and without ASD on parallel measures of challenging behaviour: The behavior problems inventory-01 (BPI-01) and autism spectrum disorders-behavior problems for intellectually disabled adults (ASD-BPA). *Journal of Applied Research in Intellectual Disabilities, 23*(2), 179–185. https://doi.org/10.1111/j.1468-3148.2009.00519.x

Rommelse, N. N. J., Geurts, H. M., Franke, B., Buitelaar, J. K., & Hartman, C. A. (2011). A review on cognitive and brain endophenotypes that may be common in autism spectrum disorder and attention-deficit/hyperactivity disorder and facilitate the search for pleiotropic genes. *Neuroscience & Biobehavioral Reviews, 35*(6), 1363–1396. https://doi.org/10.1016/j.neubiorev.2011.02.015

Rumball, F., Happé, F., & Grey, N. (2020). Experience of trauma and PTSD symptoms in autistic adults: Risk of PTSD development following DSM-5 and non-DSM −5 traumatic life events. *Autism Research, 13*(12). https://doi.org/10.1002/aur.2306

Schatzberg, A., & DeBattista, C. (Eds.). (2015). *Manual of clinical psychopharmacology*. American Psychiatric Publishing.

Schubert, J., Coles, M., & Arnedt, J. (2017). Later bedtime is associated with decrements in perceived control of obsessions and compulsions. *Sleep, 40*(suppl_1). https://doi.org/10.1093/sleepj/zsx050.1127

Shah, A., & Wing, L. (2006). Psychological approaches to chronic catatonia-like deterioration in autism Spectrum disorders. *International Review of Neurobiology, 72*, 245–264. https://doi.org/10.1016/S0074-7742(05)72015-8

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*(8), 921–929. https://doi.org/10.1097/CHI.0b013e318179964f

Skokauskas, N., & Frodl, T. (2015). Overlap between autism spectrum disorder and bipolar affective disorder. *Psychopathology, 48*(4). https://doi.org/10.1159/000435787

St. Pourcain, B., Mandy, W. P., Heron, J., Golding, J., Davey Smith, G., & Skuse, D. H. (2011). Links between co-occurring social-communication and hyperactive-inattentive trait trajectories. *Journal of the American Academy of Child & Adolescent Psychiatry, 50*(9), 892–902.e5. https://doi.org/10.1016/j.jaac.2011.05.015

Strang, J. F., Meagher, H., Kenworthy, L., de Vries, A. L. C., Menvielle, E., Leibowitz, S., Janssen, A., Cohen-Kettenis, P., Shumer, D. E., Edwards-Leeper, L., Pleak, R. R., Spack, N., Karasic, D. H., Schreier, H., Balleur, A., Tishelman, A., Ehrensaft, D., Rodnan, L., Kuschner, E. S., … Anthony, L. G. (2018). Initial clinical guidelines for co-occurring autism spectrum disorder and gender dysphoria or incongruence in adolescents. *Journal of Clinical Child & Adolescent Psychology, 47*(1). https://doi.org/10.1080/15374416.2016.1228462

Strunz, S., Westphal, L., Ritter, K., Heuser, I., Dziobek, I., & Roepke, S. (2015). Personality pathology of adults with autism spectrum disorder without accompanying intellectual impairment in comparison to adults with personality disorders. *Journal of Autism and Developmental Disorders, 45*(12), 4026–4038. https://doi.org/10.1007/s10803-014-2183-x

Sung, C., Sánchez, J., Kuo, H. J., Wang, C. C., & Leahy, M. J. (2015). Gender differences in vocational rehabilitation service predictors of successful competitive employment for transition-aged individuals with autism. *Journal of Autism and Developmental Disorders, 45*(10), 3204–3218. https://doi.org/10.1007/s10803-015-2480-z

Tandon, R., Nasrallah, H. A., & Keshavan, M. S. (2009). Schizophrenia, "just the facts" 4. Clinical features and conceptualization. *Schizophrenia Research, 110*(1–3). https://doi.org/10.1016/j.schres.2009.03.005

Taylor, J. L., & Gotham, K. O. (2016). Cumulative life events, traumatic experiences, and psychiatric symptomatology in transition-aged youth with autism spectrum disorder. *Journal of Neurodevelopmental Disorders, 8*(1). https://doi.org/10.1186/s11689-016-9160-y

Tchanturia, K., Smith, K., Glennon, D., & Burhouse, A. (2020). Towards an improved understanding of the anorexia nervosa and autism spectrum comorbidity: PEACE pathway implementation. *Frontiers in Psychiatry, 11*. https://doi.org/10.3389/fpsyt.2020.00640

Thapar, A., Cooper, M., Jefferies, R., & Stergiakouli, E. (2012). What causes attention deficit hyperactivity disorder? *Archives of Disease in Childhood, 97*(3), 260–265. https://doi.org/10.1136/archdischild-2011-300482

Thom, R. P., Keary, C. J., Kramer, G., Nowinski, L. A., & McDougle, C. J. (2020). Psychiatric assessment of social impairment across the lifespan. *Harvard Review of Psychiatry, 28*(3), 159–178). Lippincott Williams and Wilkins. https://doi.org/10.1097/HRP.0000000000000257

Thurm, A., Farmer, C., Salzman, E., Lord, C., & Bishop, S. (2019). State of the field: Differentiating intellectual disability from autism spectrum disorder. *Frontiers in Psychiatry, 10*. https://doi.org/10.3389/fpsyt.2019.00526

Turban, J. L., & van Schalkwyk, G. I. (2018). "Gender dysphoria" and autism spectrum disorder: Is the link real? *Journal of the American Academy of Child and Adolescent Psychiatry, 57*(1), 8–9.e2. https://doi.org/10.1016/j.jaac.2017.08.017

Uljarević, M., Hedley, D., Rose-Foley, K., Magiati, I., Cai, R. Y., Dissanayake, C., Richdale, A., & Trollor, J. (2019). Anxiety and depression from adolescence to old age in autism spectrum disorder. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-019-04084-z

Ung, D., Selles, R., Small, B. J., & Storch, E. A. (2015). A systematic review and meta-analysis of cognitive-behavioral therapy for anxiety in youth with high-functioning autism spectrum disorders. *Child Psychiatry & Human Development, 46*(4). https://doi.org/10.1007/s10578-014-0494-y

van Steensel, F. J. A., Bögels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: A meta-analysis. *Clinical Child and Family Psychology Review, 14*(3). https://doi.org/10.1007/s10567-011-0097-0

Vannucchi, G., Masi, G., Toni, C., Dell'Osso, L., Erfurth, A., & Perugi, G. (2014). Bipolar disorder in adults with Asperger's syndrome: A systematic review. *Journal of Affective Disorders, 168*. https://doi.org/10.1016/j.jad.2014.06.042

Wachtel, L. E. (2019). Treatment of catatonia in autism spectrum disorders. *Acta Psychiatrica Scandinavica, 139*(1), 46–55. https://doi.org/10.1111/acps.12980

Wajszilber, D., Santisteban, J. A., & Gruber, R. (2018). Sleep disorders in patients with ADHD: Impact and management challenges. *Nature and Science of Sleep, 10*. https://doi.org/10.2147/NSS.S163074

Warrier, V., Greenberg, D. M., Weir, E., Buckingham, C., Smith, P., Lai, M.-C., Allison, C., & Baron-Cohen, S. (2020). Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. *Nature Communications, 11*(1). https://doi.org/10.1038/s41467-020-17794-1

Waters, F., Chiu, V., Atkinson, A., & Blom, J. D. (2018). Severe sleep deprivation causes hallucinations and a gradual progression toward psychosis with increasing time awake. *Frontiers in Psychiatry, 9*. https://doi.org/10.3389/fpsyt.2018.00303

Weiss, G., & Hechtman, L. T. (1993). *Hyperactive children have grown up: ADHD in children, adolescents, and adults* (2nd ed.). The Guilford Press.

Westwood, H., & Tchanturia, K. (2017). Autism spectrum disorder in anorexia nervosa: An updated literature review. *Current Psychiatry Reports, 19*(7) Current Medicine Group LLC 1. https://doi.org/10.1007/s11920-017-0791-9

Westwood, H., Mandy, W., & Tchanturia, K. (2017). Clinical evaluation of autistic symptoms in women with anorexia nervosa. *Molecular Autism, 8*(1). https://doi.org/10.1186/s13229-017-0128-x

Wing, L., & Shah, A. (2000). Catatonia in autistic spectrum disorders. *British Journal of Psychiatry, 176*(APR.), 357–362. https://doi.org/10.1192/bjp.176.4.357

Wink, L. K., Erickson, C. A., Chambers, J. E., & McDougle, C. J. (2010). Co-morbid intellectual disability and borderline personality disorder: A case series. *Psychiatry, 73*(3), 277–287. https://doi.org/10.1521/psyc.2010.73.3.277

Wolraich, M. L., Hagan, J. F., Allan, C., et al. (2019). Subcommittee on Children and Adolescents with Attention-Deficit/Hyperactive Disorder. Clinical practice guideline for the diagnosis, evaluation, and treatment of attention-deficit/hyperactivity disorder in children and adolescents. *Pediatrics, 144*(4), e20192528. (2020). *Pediatrics*, *145*(3), e20193997. https://doi.org/10.1542/peds.2019-3997

Wu, M. S., McGuire, J. F., Arnold, E. B., Lewin, A. B., Murphy, T. K., & Storch, E. A. (2014). Psychometric properties of the children's Yale-Brown obsessive compulsive scale in youth with autism spectrum disorders and obsessive-compulsive symptoms. *Child Psychiatry and Human Development, 45*(2), 201–211. https://doi.org/10.1007/s10578-013-0392-8

Yatham, L. N., Kennedy, S. H., Parikh, S. V., Schaffer, A., Bond, D. J., Frey, B. N., Sharma, V., Goldstein, B. I., Rej, S., Beaulieu, S., Alda, M., MacQueen, G., Milev, R. V., Ravindran, A., O'Donovan, C., McIntosh, D., Lam, R. W., Vazquez, G., Kapczinski, F., … Berk, M. (2018). Canadian Network for Mood and Anxiety Treatments (CANMAT) and International Society for Bipolar Disorders (ISBD) 2018 guidelines for the management of patients with bipolar disorder. *Bipolar Disorders, 20*(2), 97–170. https://doi.org/10.1111/bdi.12609

Young, S., Hollingdale, J., Absoud, M., Bolton, P., Branney, P., Colley, W., Craze, E., Dave, M., Deeley, Q., Farrag, E., Gudjonsson, G., Hill, P., Liang, H., Murphy, C., Mackintosh, P., Murin, M., O'Regan, F., Ougrin, D., Rios, P., … Woodhouse, E. (2020). Guidance for identification and treatment of individuals with attention deficit/hyperactivity disorder and autism spectrum disorder based upon expert consensus. *BMC Medicine, 18*(1), 146. https://doi.org/10.1186/s12916-020-01585-y

Zaboski, B. A., & Storch, E. A. (2018). Comorbid autism spectrum disorder and anxiety disorders: A brief review. *Future Neurology, 13*(1). https://doi.org/10.2217/fnl-2017-0030

Zheng, Z., Zheng, P., & Zou, X. (2018). Association between schizophrenia and autism spectrum disorder: A systematic review and meta-analysis. *Autism Research, 11*(8). https://doi.org/10.1002/aur.1977

Zucker, K. J. (2017). Epidemiology of gender dysphoria and transgender identity. *Sexual Health, 14*(5). https://doi.org/10.1071/SH17067

6

Autism Spectrum Disorders and the Criminal Justice System

Elizabeth Kelley and Nick Dubin

The following chapter covers a subject that is uncomfortable for most stakeholders in the field of autism. Surveying autism podcasts, books, and articles by self-advocates and those involved in neurodiversity, one finds very little mention of the problems individuals with autism face when they are ensnared by the criminal justice system. Furthermore, there is even less discussion surrounding best practices of ways to represent individuals with autism once they have entered the criminal justice system.

This lack of coverage is understandable. On the one hand, individuals with autism face a host of issues. Differences in sensory processing, emotional regulation, communication issues, interpersonal relationships, occupational challenges, and motor skills, plus health and hygiene issues (Bishop-Fitzpatrick & Kind 2017; Wrobel, 2003) – all are enough to consume the agenda for most parents and individuals on the autism spectrum. Lack of employment and underemployment continue to remain huge issues, as some estimates are that 80–85% of people on the spectrum fall into that category (Patton, 2019). Recent estimates show the average age someone on the spectrum will live to is 36 years, a truly frightening and almost unbelievable statistic (Kurchak, 2018). In the midst of all this, there is still significant stigma and misunderstanding. Nonetheless, despite these challenges, we feel that the contents of this chapter remain a vitally important and relevant topic. Over the past few years, the mainstream media has begun to understand that the issues faced by people with ASD in the criminal justice system must be addressed (Eisner, 2019; Pasha, 2017; Robison, 2013; Rubin, 2017; Sunderland, 2017). Indeed, many of the aforementioned challenges people with autism have can actually contribute to why they may become involved in the criminal justice system in the first place.

An important note: education and prevention are key to ensuring that the events and scenarios described in this chapter do not come to pass for more individuals with autism. Everyone wants fewer victims and perpetrators, though individuals on the autism spectrum tend to fall into the first category (Copenhaver & Tewksbury, 2019). Many individuals on the autism spectrum are strict rule followers when they know the rules and those rules seem logical. Therefore, it may appear at first glance counterintuitive that strict rule followers can end up in the criminal justice system – but this is often because their behaviors are either misunderstood by the authorities, or the person themselves did not grasp the societal taboos regarding the behavior in question.

This chapter will describe the complete anatomy of a criminal case, from the initial encounter with law enforcement, to the interrogation room, through the bond hearing, through the use of experts, through plea bargaining or dismissal, through resolution including a sentencing hearing.[1]

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[1] In this chapter, we draw liberally from our two books: *Representing People with Autism Spectrum Disorder: A*

J. B. Leaf et al. (eds.), *Handbook of Quality of Life for Individuals with Autism Spectrum Disorder*, Autism and Child Psychopathology Series, https://doi.org/10.1007/978-3-030-98507-3_6

Initial Encounter with Law Enforcement

Persons on the autism spectrum can end up in the criminal justice system for a variety of reasons. Sometimes there is a complicated backstory, and sometimes it is a purely an extempore act, that is, an accidental encounter with patrol officers who misunderstand autistic behavior and construe it as dangerous (Vargas, 2020). One third to one half of all deadly police encounters involve those with a disability (DeGue et al., 2016; Perry & Carter-Long, 2016; Torrey et al., 2013). This is particularly true for African Americans and Latinos with a disability. We often see this problem with juveniles who are sent to juvenile detention for violent outbursts (Treanor, 2018). We strongly support Crisis Intervention Team (CIT) trainings which focus on teaching law enforcement to recognize mental disabilities, de-escalate situations, and recommend trainings where autistic individuals conduct the seminars themselves. Furthermore, we would like to see virtual reality simulators put to use in trainings, which allow officers to be in the shoes of people with autism by giving the trainees the same sensory bombardments and confusing signals autistic people receive in real life. Autistic individuals often get mistaken by police for being high, intoxicated, or purposely non-compliant (Furfaro, 2018). The problem can be compounded when the person is overstimulated from a sensory point of view, leading to what could be perceived by the officer as a "meltdown." If the person is non-vocal or has selective mutism in stressful situations, which is common for those with autism, this exacerbates the problem (Salerno-Ferraro & Schuller, 2020).

The Interrogation Room

We are both concerned that autistic individuals are likely to be taken advantage of by law enforcement during the pre-arrest and post-*Miranda* phases. The National Registry of Exonerations estimated that 69% of those who were later exonerated had a learning disability or an intellectual/cognitive impairment (Johnson et al., 2018). For sexual assault, the number was 12% (Johnson et al., 2018). For child sexual abuse, the number was 11% (Johnson et al., 2018).

It is not difficult to understand how this can happen. Autistic people can be extremely deferential, compliant, and confrontation averse when dealing with authority figures such as the police (O'Sullivan, 2018). Furthermore, the guilt-grabbing tendencies many autistic individuals have due to their strong sense of right and wrong and black/white thinking can cause increased suggestibility and make these individuals much more vulnerable to false confessions once under interrogation (Perske, 2011). Furthermore, we both have noticed, anecdotally, that many interviews by police of autistic individuals blur the line between custodial interrogations where a person is formally under arrest, versus pre-interrogation interviews where a person is technically free to leave. For the autistic person, however, it is not usually clear that they are free to leave. Many of these pre-interrogation interviews take place after a dramatic predawn raid at the person's residence, where police, FBI agents, or Homeland Security agents storm a home with guns drawn and are in the process of conducting a search warrant. While the autistic person is technically not under arrest at that time, the optics of the environment do not give that impression to anyone.

Outside the home, there are usually police cars present with sirens blazing, sometimes from multiple jurisdictions, along with many detectives and officers inside the home collecting evidence. Officers will often isolate the autistic person of interest away from the rest of the family into a "safe room" while the collection of evidence is taking place (Legal Reform for the Intellectually & Developmentally Disabled,

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Practical Guide for Criminal Defense Lawyers, Elizabeth Kelley, ed. (2020); and *Autism Spectrum Disorder, Developmental Disabilities, and the Criminal Justice System: Breaking the Cycle*, Nick Dubin, Jessica Kingsley Publishers, (2021).

2021). For example, during this time, they may bring the autistic person to their bedroom to get them in a more comfortable environment, all designed to get them to talk. Prosecutors and detectives rely on the fact that they can conduct these interviews without *Miranda* warnings as long as they technically do not place an individual under arrest or in custody (Kamisar, 2017). However, many autistic people tend to believe they are in custody in these situations and could never make that distinction, let alone think to ask the question of whether they are in custody in the first place (Goldstein et al., 2003).

We mentioned earlier, we share concerns about the post-*Miranda* phases as well for this population. Goldstein et al. (2003) studied 55 adolescents whose cases had already been adjudicated to see if they comprehended or understood what *Miranda* warnings meant using the *Miranda* Rights Comprehension Instruments II (MRCI-II). Participants were asked to use their written expression skills to demonstrate their knowledge of *Miranda* rights through a series of multiple-choice questions. The results of the study found that those individuals who were cognitively impaired had a difficult time in comprehending *Miranda* rights. But what was perhaps most significant about this study was that individuals who had received any kind of special education were less likely than their general-education counterparts to comprehend *Miranda* Rights. This suggests that the United States is not doing enough to safeguard our responsibilities to those with intellectual and or communication processing disabilities like autism to preserve their rights against self-incrimination. We recommend adopting models like the England and Wales's "Appropriate Adult" program, which safeguards against such abuses (Bath et al., 2015), and bringing in friends-of-the-court when needed.

Bond Hearing/Arraignment

After arrest and interrogation, a bond hearing/arraignment is the next major event in the anatomy of a criminal case for an individual on the autism spectrum, or anyone for that matter (Kelley 2020). After the booking process, the autistic defendant comes before a judicial officer to determine whether they will remain in custody or be released with certain conditions pending trial. Often, lawyers are meeting clients for the first time and have little information about them coming into the hearing. This puts even the most seasoned attorney at a huge disadvantage, especially if they are not informed of the ASD condition of the individual prior to the hearing. A bond hearing may fly by in the blink of an eye timewise, but the consequences of how the judge rules are enormous.

There are three major issues a defense lawyer needs to consider going into this hearing. The first is the circumstances of the case and the client with ASD – meaning the pre-bond interview and report conducted by pretrial services and sent to the judge. This report assesses flight risk, nature of the charges, and prior criminal record. For many autistic people who happen to be first time offenders, this will help to mitigate a higher bond or no bond at all. Many autistic people have clean records, do not have much money, and are not in a position to buy a plane ticket and flee to another country. But many parents we have spoken to have expressed frustration at the fact that they were not allowed to attend the pre-bond interview where important questions are asked of the autistic defendant, such as "Are you feeling suicidal at this time?" Most parents would probably want to tell their children to answer "no" regardless of how they are feeling, so the problem can be more adequately addressed at home with private mental health practitioners skilled in ASD, rather than in jail (A "yes" answer to that question almost guarantees the autistic person will be held in custody). Just like a presentencing report where a probation officer interviews the convicted defendant, an autistic defendant is giving answers in this interview that may be summarized by someone with perhaps little understanding of ASD. The autistic person's demeanor, non-verbal behaviors, and communication differences may all be misinterpreted by the interviewer, whose input is fed to the judicial officer who determines bond. We recommend a defense lawyer attend this interview to interpret behaviors to the interviewer if there is enough notification and time for them to be there.

This leads to the second issue a defense lawyer should consider: behavioral considerations observed by the court. Although the autistic person may be a strong candidtate for pretrial release because of such factors as low risk of flight, low violence risk to the community, unlikelihood of victim intimidation, and strong family supports, this can all be undone by the perceived "attitude" a person with autism displays in court. If this is the first time an autistic individual has ever been arrested, then this will be an extremely foreign environment for the client with autism. Nothing about the proceedings will seem to make sense to them, and it may generate many emotional reactions that may seem inappropriate with what is considered proper courtroom decorum. The court must be educated on what may be perceived as a lack of respect, such as poor eye-contact, twiddling thumbs, or looking disinterested in the proceedings. Conversely, for the client who has the cognitive ability to understand they are in trouble, the nervousness and anxiety an autistic defendant has can produce a hyperactive client who seems to have no impulse control. The courts do not want to release people who cannot control their actions. Of course, the person in question may have perfect impulse control during non-stressful situations, but the distinction between anxiety due to unfamiliar situations and lack of impulse control is something a defense lawyer clearly needs to spell out to the court. Specifically, lawyers may want to limit their clients' testimony at this hearing. Some autistics may want to speak on their behalf (as they are used to doing in life), which may hurt their chances of being released. In the meantime, a lawyer should consider friend-of-the-court options down the road for future status conferences and throughout the case to ease communication issues between the client and the court, if family members are not available.

Finally, and perhaps most importantly, the lawyer should emphasize that jail is the worst possible place for a defendant waiting disposition of a case. The problems are numerous and significant. Many people with ASD will languish while their mental health needs deteriorate, and as a result, will not be in any position to collaborate with their lawyer in an intelligent way (Hess, 2020). Other inmates take advantage of socially naïve inmates without "street cred" and thus they are routinely abused (Hess, 2020). Prison or jail staff lacks patience for those they cannot understand (Allely, 2015). The person with autism may have extreme sensory sensitivities and find the constant noise (e.g., clanging of doors opening and closing), yelling of inmates and staff, fluorescent lights, and smells intolerable. It is not uncommon for individuals with autism to have severe allergies (e.g., Chen et al., 2013), gastrointestinal issues (e.g., McElhanon et al., 2014), and be very picky eaters (e.g., Wallisch et al., 2020). They can also have well-known sleep disturbances (Liu et al., 2006). In essence, putting an autistic person in jail may bring up issues of competency depending on the degree of mental deterioration that takes place if sent to jail – particularly if the autistic inmate lands in solitary confinement due to misunderstood behavior. One of the authors of this paper is familiar with a case in which an individual with ASD deteriorated in solitary confinement to the point that he could no longer collaborate meaningfully with his attorney.

ASD inmates with emotional regulation issues who show their emotions are going to have particular problems because prisoners universally view crying as a sign of weakness (Laws, 2019). Some ASD individuals will stare at others, even though they are usually known for making no eye contact. Because of all these issues, plus others which might be relevant for a particular ASD individual, an attorney needs to fight as hard as possible for the client to be released on their own recognizance, or in the alternative, for a low bond.

Remember that what a defense lawyer may consider a "favorable" condition may not seem at all favorable to the defendant with autism. Many autistic people have been arrested for downloading child pornography due to ease of access (e.g., Rubin, 2017), lack of social opportunities, and the lack of proper sexual education curriculum, among other reasons usually not at all related to pedophilia (Hingsburger et al., 1991). In many jurisdictions, this particular charge makes them statutorily subject to mandatory electronic monitoring if they are lucky enough to be released from custody. But in some instances, electronic monitoring may be completely inappropriate. For example, in one case we are familiar with, electronic monitoring caused a horrible skin rash for a defendant with autism, and the constant sensory buzzing of the low battery on his ankle drove him out of his mind. Finally, out of desperation, he cut the monitor and ran. This was not a dangerous defendant based on his lack of criminal history. Yet he contends that if he were given a less intrusive sensory GPS system to wear (like a wristwatch instead of an ankle monitor), he would not have been forced to take the drastic measures he did. He argues he was not given the Title II ADA accommodations he needed to cope with his autism. As a result of his cutting the monitor, this person has languished in jail for the past 10 months while awaiting trial during Covid-19 for fourth degree criminal sexual conduct, specifically, patting an adult woman on the backside. Simply put, an autistic individual should not languish in jail for this.

Finding Experts

We cannot emphasize this enough: a criminal defense lawyer must retain or request a mental health expert with strong expertise in ASD. Indeed, one of the first things a lawyer needs to do after the bond hearing (if not before) is start thinking about securing a forensic expert. Note, if the accused is being treated, that individual cannot serve as an independent forensic expert because that would constitute a conflict of interest. However, the evaluating expert would likely consult the treatment provider's records.

In terms of retaining or requesting that the court appoint an expert, a lawyer must assess the likely purpose as well as the characteristics of the client in question. Is there an issue of competency where a client has no idea what is going on? Are there strong mitigating factors present that should warrant a departure from the statutory, legislative guidelines? Can the case be taken to trial? Are there pre-trial issues which should be explored such as the impact of the interrogation techniques as they relate to this defendant's ASD?

Before finding the expert, a thorough debriefing with the client and family members should take place. The lawyer should ask family historians for all available records, such as previous Individualized Education Plans (IEPs), 504 plans, medical reports, past diagnoses, school report cards, residential treatment records, and anything else that would be relevant. Ultimately, this should be turned over to the expert.

Typically, referrals for an expert can be found by checking with organizations like the Legal Reform of Intellectually and Developmentally Disabled (LRIDD), The Arc's National Center on Criminal Justice and Disability (NCCJD), or a search of Google Scholar to see both who has written about autism, and if that attorney practices within a given geographical radius.

Once an expert is retained or appointed, that expert will want to interview a range of people who can address the defendant's characteristics including parents, siblings, teachers, co-workers, neighbors, and the like. One of the reasons why this is so important is that it refutes any argument that the prosecutor may raise that the defendant is malingering.

If the defendant is charged with a sexually oriented offense, the expert may want to perform a psychosexual exam on the individual in question to make sure they do not have pedophilic tendencies if a sex crime is the reason for the referral. This is usually done if a prosecutor asks for it, and often they do. This exam is usually scored using a test known as the Abel Assessment, and for individuals with intellectual disabilities – a modified version of the test known as the Abel-Blasingame Assessment System – ABID (Blasingame et al., 2011). The test measures visual reaction time to individuals of all ages. In other words, the time it takes to visually process the picture of a person and then press a button to move on to the next picture. It is assumed the longer a person takes looking at a picture of a person they are sexually attracted to, the more time will go by before they press the button.

The length of time looking at an image is not the only factor used by the scoring and algorithms; there are certain company secrets about the test kept under wraps so people cannot beat the test. However, our concern with measuring visual reaction time as it relates to individuals on the autism spectrum is that the test does not seem to account for other variables related to neurological differences such as sensory integration and sustained attention on a visual stimulus. For example, when taking the Integrated Visual and Auditory (IVA) Continuous Performance Test (CPT), designed to measure visual reaction time, autistic individuals showed significant impairment in their ability to control their response to visual cues (Chien et al., 2014). Another study showed that visual reaction time tends to be prolonged in autistic children and adolescents (Bhakare & Vinchurkar, 2015; keep in mind that prolonged response time would indicate an attraction to a particular age group, using Abel's methodology). Other studies using electrophysiological and behavioral indicators (e.g., audiovisual reaction time tests) of processing visual and audio stimuli have revealed deficits in general audiovisual temporal processing in ASD individuals (Martínez-Sanchis, 2014). Moreover, autistic individuals have consistently shown problems with over-focused attention (Todd et al., 2009) and with shifting visual attention from one stimulus to another (e.g., Tager-Flusberg et al., 2001; Townsend et al., 1996; Wainwright-Sharp & Bryson, 1993). Psychomotor retardation (or slower motoring functioning) can be seen in autistic individuals (Ghaziuddin & Al-Owain, 2013), which may indicate the speed of their visual reaction time to an image. Research is definitive that ASD individuals have difficulties with sensory integration (Roley et al., 2015), and McKeen (2013) believes that, in light of this fact, more research should be conducted on visual reaction time testing with autistic individuals. In short, the issues of slow visual-processing time on a given stimulus could easily be confused by the algorithm of the test as attraction to an age group of people.

In contrast, the Abel-Blasingame Assessment System is the same test, but the pretest makes accommodations for the person with an intellectual disability and is "normed" for a population with an Intellectual Disability. IQ scores are accounted for with the Abel-Blasingame (ABID); unlike the Abel, an IQ test is given prior to the administering of the main test if one is not on file. The ABID goes slowly on pretest questions, allowing testers the processing time they need to respond to the written or oral questions. Visual aids supplant the written word when those prompts are considered helpful. Breaks are built in, and the evaluation occurs over a few days to accommodate the person's attention span. The written questions are at a reading comprehension level of a second grader. Anecdotally, we know of a few autistic individuals who have taken the ABID and have not shown pedophilic tendencies. Obviously, such results can be a huge benefit in a report submitted to a prosecutor and judge. But because the test relies so much on visual processing, sustained attention, and switching attention between one stimulus and another (a well-known weakness for individuals on the autism spectrum; Mackinlay et al., 2006; Rajendran et al., 2011), this test should be utitlized cautiously – unless the individual scores well.

It is vital that experts explain the concept of uneven development of an individual on the spectrum to the court. A person with ASD can perform in a high functioning manner in several areas of developmental but unequally low in others (Heaton et al., 2008; Melling & Swinson, 2016). Lynda Geller (2005) states:

> The uneven development across skills may result in significantly discrepant maturity levels in the same person. Social and emotional maturity may severely lag, but one is expected to behave in a certain way based on age or intellect. So, while development generally marches forward in a more or less predictable manner, emotional regulation for those on the spectrum may be delayed or altered by countless subtle constitutional differences. (p. 2)

The phrase "don't judge a book by its cover" applies here. Simply because someone looks a certain way does not mean that when you scratch below the surface, you will not see something entirely different. Uneven development of cognitive skills is common in individuals on the spectrum. This means some people have built-in areas of their brain that specialize in certain areas of intelligence, but other areas of the brain where there are huge gaps. Autism savants are the most noticeable example of this; other examples are much subtle. Rubie and Akshoomoff (2010) say that individuals on the spectrum have uneven cognitive skills, with “relative strengths in processing visual/nonverbal information, and relative weakness in processing…abstract information” (p. 2). Typically, information that is abstract is not tangible in nature, readily accessible without further explanation or easily learnable unless it has been explicitly taught in a concrete or remedial way to ASD learners. Abstract information which does not come naturally may have been a reason why that ASD person did not pick up on the social signals a woman was trying to send him that said “leave me alone,” and he was charged with stalking. It may have been the reason why a gullible ASD person took the bait of someone taking advantage of them, and got stuck with the charges – not the person who set them up.

Experts also need to explain in great detail that difficulty with understanding what another person is thinking (generally referred to as lack of empathy) does not mean this meets the profile of someone without a conscience. This concept is explained nicely in Simon Baron-Cohen’s (2012) book *The Science of Evil*, in which Baron-Cohen sees autism and psychopathy as opposites on a spectrum.

Finally, the attorney may want to explore the issue of competency. Regarding people with ASD, it should be noted that the mere parroting back of phrases may be attributed to a great memory rather than an intrinsic understanding or the inherent ability to generalize from context to context (Plaisted, 2015). A lawyer has to use their judgment as to whether to proceed down this path because the court may order that the client be “restored” to competency rather than simply dismiss the case. Clients with autism who are inflexible, who insist upon a dismissal of the charges, who are completely unrealistic about the circumstances they are facing, who are unable to anticipate the strategy the other side would use due to deficits in theory of mind, could very well lack competency, even if they are verbally impressive. Lawyers should be careful not to be thrown off by individuals with autism who possess a big vocabulary, and seem smart, but may lack basic social and emotional intelligence.

Although the expert may be hesitant to advocate any specific position and simply report the facts they are given, lawyers should be willing to extrapolate the parts of the report that would best support the conclusion that a probationary sentence or even a diversion program is in the best interests of the person with autism and the community.

Plea Bargaining

A man, we will call John, is a smart autistic young man who graduated near the top of his highschool class. He earned a bachelor’s degree from a well-respected university and had a promising career ahead of him. He likes the feel of different types of silky clothing. He also wears spandex himself and is gender fluid. Additionally, John has delayed social skills. John’s legal problems related to the fact that he had the habit of walking up to women, striking up friendly conversations with them, and then asking if he could touch their clothing. Most of the time women agreed, but on one occasion, John touched the wrong woman. She immediately went to the police and John was detained. Not realizing what he had done wrong, John sat and waited for almost a year in the county jail while his fate was being decided. Eventually, he pleaded to a misdemeanor offense, but it put him on the sex offender registry. Today, John insists that the touch was non-sexual in nature and tactile-sensory seeking. John was not aware that touching a woman to feel her silky clothing would constitute any kind of sexual offense. Again, in his mind, it was a sensory issue. He was not even attracted to the woman. His trial attorneys ignored this issue and encouraged him to plead guilty prematurely, and this landed him on a sex offender registry.

Lawyers representing individuals with ASD may have a difficult time negotiating with prosecutors. The biggest obstacle may be a prosecutor's inability to understand the concept of uneven development for individuals who do not have an IQ that falls at the borderline range or below. From our anecdotal experience, many prosecutors will point to college degrees, jobs obtained, and other life accomplishments as a way to say that this person knew better. However, this overlooks the challenges of daily life confronted by many individuals on the spectrum. Quite possibly, an autistic Ph. D. will have trouble getting past the first interview and will find it difficult to be employed (Shattuck et al., 2012). As mentioned earlier, unemployment falls around 80–85% for this population (Patton, 2019). Those who are employed, may never have been in a romantic relationship, may never have had many or any friends (Orsmond et al., 2013), and still may not have any. Therefore, ASD individuals lack many of the quintessential social learning opportunities throughout childhood and adolescence that their typically developing peers experienced. However, they may also be late bloomers.

During the course of plea bargaining, we also need to reference back to concerns prosecutors may have regarding perceived "lower" empathy levels, perceived stubbornness, and repetitive behavior patterns that may be of concern to them. We must point out that individuals with autism tend to lack *cognitive* empathy (Mazza et al., 2014), which is lack of understanding of how someone is feeling. But individuals with ASD do not often lack *affective* empathy, which is empathetic concern (Bos & Stokes, 2019) – and this is quite different. In other words, lacking cognitive empathy but having affective empathy can be translated by saying, "I see you are feeling something, I just don't know what it is you are feeling. Help me to understand." In contrast, a criminally oriented person with psychopathic attributes lacks affective empathy and this can be summarized as saying, "I know what you are feeling, but I just don't care" (Baron-Cohen & Wheelwright, 2004). This is the main difference between antisocial personal disorder and ASD. Autistic people often care about other people and their feelings (Rogers et al., 2007), but many have a very difficult time intuitively reading those feelings (Frith & Happé, 1994). Concerning perceived "stubbornness," this concern can be overcome when logical and consistent rules and structure are put into place for the person with autism, playing into the natural tendency of autistic individuals to be strict rule followers. To quote Dr. Lynda Geller, "People on the autism spectrum are notoriously law-abiding rule followers, …but if they don't know a rule, they don't follow it" (Wenner Moyer, 2019, para 12).

Although we recognize that in the vast majority of cases diversion will not be given, we are cognizant of the fact that the next best thing is plea to a lesser included offense which includes no incarceration and no sex offender registration. It is important that the lawyer knows what the mandatory minimums are attached to each offense, and in particular, whether the offense triggers mandatory registration in that particular state.

We know of some defendants (as well as family members) who find any kind of plea agreement unacceptable. In their minds, they did not do anything wrong or cannot understand why they are being prosecuted. It may be more challenging for these defendants to take any deal, especially if it involves incarceration. Attorneys are not equipped to provide mental health counseling to defendants facing these situations – all they can do is offer their legal counsel and be encouraging to the person and their family. We should point out that for most autistic people, anything less than a sentence of zero incarceration and zero registration will not be perceived as a "win." Once again, the defense attorney should stress to the prosecutor that sending someone with the developmental emotional and social levels of a child, even though they are chronologically the age of an adult, should be avoided if the person is not a danger to the community and is not at a high risk to reoffend. It is almost certain the person will mentally deteriorate/decompensate in prison and spend much of their time in solitary confinement.

For individuals with intellectual impairments who may be functionally illiterate or need extra support to complete probation successfully, we can already hear some of the objections people may have to a diversionary or probationary sentence. For example, a prosecutor or judge might argue that if they cannot read or comply with conditions, how can they be a good candidate for such a program? But is prison really a better alternative? In prisons, there are unwritten rules and regulations (as well as written rules) that people need to follow in order to survive. Can we honestly say that an individual with ASD would be safer there than the outside world? Would they be safer trying to join a gang, or be left without protection? Would they be safer complying with potentially abusive, unsympathetic correctional staff? Would they be safer in solitary confinement? Will it help them to have their Social Security or Medicaid benefits suspended? Maybe this dilemma requires us to strengthen, at a societal level, the supports we offer to such persons in these situations. A good example of such support is the Criminal Justice Advocacy Program operated by The Arc of New Jersey and an organization like LRIDD.

A final note regarding proposed plea deals: an attorney is ethically required to convey any potential offer to the client. This applies even if the proposed plea is unacceptable or even outrageous in the mind of the accused or their family. In other words, do not shoot the messenger.

Plea Hearing

The lawyer must thoroughly review the waiver of rights form so the client completely understands their constitutional rights, and not just in a rote sense. A lawyer should spend extra time talking to the client on the autism spectrum about decorum, short answers, and non-elaboration. Similarly, the lawyer should spell out in direct terms that every sentence in response to a direct question by the judge that only requires a "yes" or "no" should end with "Your onor." Also, the lawyer should explain to a client before the hearing that they may be remanded after the hearing and prior to sentencing – though we encourage lawyers to strongly argue against this. We recommend having mental health counselors in the room while this discussion between the lawyer and the client is taking place to help the ASD person deal with the sheer volume of emotions this information will generate. A lawyer cannot do this alone. Every collateral consequence that could arise out of this conviction should be explained to the individual and/or their support system. If this includes finding out what the sex offender registry will entail, the lawyer should advise accordingly. A judge will not go into details about the sex offender registry in open court at the plea hearing, other than informing the person that they need to register. This hardly explains the collateral consequences the person will experience in the future. For example, what tier will they be on? Will there be residency restrictions? How often will they have to report to police? Will there be Internet restrictions? Are there going to be travel restrictions for the rest of a person's life?

Mitigation Efforts

Once a plea has been reached, mitigation efforts should immediately go into effect. This begins with the often-overlooked presentence report.

Although technically not a part of mitigation in a typical case, it should be included. A presentence interview is an intense experience for the person who recently pleaded guilty. It can take hours and sometimes last more than one day. It delves into every aspect of a person's life – past and present. A probation officer conducting the interview is going by guidelines and point values set out legislatively in considering what sentence to recommend to the judge, but there are also partly subjective interpretations involved. A probation officer is behaviorally attuned to the interviewee. Are they telling the truth? Are they remorseful? Can they demonstrate their remorse in a verbally eloquent way? These are, of course, all neurotypical standards of behavior the probation officer is using as for these subjective yardsticks. We recommend the lawyer attend all the interviews. Some clients may be intrinsically remorseful but because of their ASD, simply cannot communicate it. This is important because remorse always factors into the guidelines. Lawyers should be prepared to act as para-interpreters – almost the way a deaf person would be accorded a sign language interpreter. It is not fair to send a socially challenged defendant into a setting where their behavior will be judged by a certain set of standards and not be there to explain to the probation officer what the person with ASD is actually feeling if they themselves cannot communicate it. The lawyer can communicate this by referring to forensic reports which highlight the person's propensity to follow rules, conversations the lawyer has had with the ASD defendant, as well the client's life history. A defense lawyer should put everyone in the defendant's life on "red alert" that they may be contacted to talk about their family member or friend to the probation officer. Then when that all-important report comes, lawyers should aggressively challenge the guidelines, if applicable, if point values are off or anything inappropriate was recommended based upon a behavioral misinterpretation.

Next, the lawyer needs to show how and why the person with ASD will be successful on supervision. What steps have they taken since their arrest? This could be as much as attending therapy or being compliant with the conditions of release.

Submitting character letters is also important. Quality letters from people who are aware of the charges and still support the person are invaluable. Finding community members outside the family who can attest to their belief in the ASD person can speak volumes, whether that be a former boss, high school teacher, coach, or any other person without family ties.

Hiring a mitigation specialist is usually thought of only in death penalty cases, but it should not be ruled out in the case of a client with ASD. A mitigation specialist can coordinate the letters, create a mitigation video (depending on evidentiary standards in a jurisdiction), help the lawyer prepare a quality sentencing memorandum, and relate best practices on the strategies that will be in place in the community to ensure the person is successful. Ideally, the mitigation specialist hired would have a solid foundational understanding of ASD.

Sentencing

Frequently, the judge has made up their mind before sentencing. An exception to this may be if the defendant says something out of line in their allocution. The lawyer must ensure this does not happen. If the client plans to read a statement, the lawyer should review it carefully and perhaps help the person to craft it. If the ASD individual has communication challenges, it is wise to assume a conservative posture for this hearing. If, of the other hand, the ASD defendant is capable of expressing remorse and can write a statement that bears eloquence and succinctness, it may help their cause to say something.

The presentencing report usually recommends a classification level or setting for the defendants heading to prison. However, both in the sentencing memorandum and at sentencing – the defense lawyer should try to get the judge to recommend the lowest security facility possible. In the federal system, this is ultimately decided by the Bureau of Prisons (BOP), but the judge's opinion carries significant weight. The type of facility an individual is classified into can sometimes make the difference between life and death. If the individual with ASD has been convicted of a sex crime, such as downloading child pornography, ideally, they would be secluded from the general population and surrounded by inmates convicted of the most similar crimes. One such facility in the federal system is Elkton where approximately 70% of the people in the satellite camp are there for child pornography convictions.

Most people think of sentencing as the moment when a judge pronounces how much time a person will spend in prison or on supervision. But a sentencing hearing is also the time and place that the judge describes the conditions of release to the defendant. A lawyer will have to use their good judgment as to whether any conditions deserve scrutiny and should raise an objection. For example, it has been our experience that group therapy for "sex offenders" can often be extremely distressing for individuals on the spectrum. Attorney Mark Mahoney (2009) gives an example:

> As a condition of his probation that young man was ordered to attend a traditional SOTP. He has said that the stories he hears at his group treatment make him feel nauseous. He does not understand how or why the others in the treatment program did what they did, and he believes that everything that is said as part of his SOTP is the opposite of what he is told by his private psychologists. Overall, he seems to find the traditional SOTP unhelpful and upsetting. Instead of helping him learn appropriate behavior, it is confusing him and placing him in contact with individuals who actually are sexual predators. (p.57)

A lawyer must know if the sentencing judge they are before is known for being reasonable or if such a request at the sentencing hearing would be unwise. Perhaps such a request deserves a separate motion after the incarceration is served. This has to be left to the discretion and experience of the attorney who can read the room and see if it is an importune time to bring something up.

Polygraphs are often a condition for ASD defendants convicted of sexually related crimes after release from prison or on supervised release. Numerous parents have expressed their concern to us about the nature of polygraphs being used on their children. In conjunction with the sensory intrusions such as the blood pressure cuff and skin galvanizers, polygraphers try to get inconclusive subjects to “confess” (FBI Website, 2002), and there is much in the literature on ASD and false confessions (Griego et al., 2019; North et al., 2008).

In addition to all of that information regarding polygraphs, because of the very literal nature that autistic people possess (Wing et al., 2011), ASD individuals might answer the questions differently than neurotypicals would answer them. The logic is like a different language. For example, in the authors’ personal experiences, one person with autism was asked on a polygraph “Have you ever had sex with an animal?” The answer was no, except they had masturbated against a stuffed animal toy and failed that question. We could imagine the same might be true if the person considered anime pornography and was asked if they viewed any pornography.

Lastly, the lawyer of the person with ASD should fight as hard as possible for voluntary surrender. This should be requested in the sentencing memorandum as well.

Prison

We know individuals with ASD who have survived prison and have been released, but not without significant psychological impact. We also know others who have not made it through. One started a fire just so they could be put in solitary confinement (Mesibov & Sreckovic, 2017). Of course, solitary confinement is its own kind of torture (Conley, 2013).

We must emphasize the importance of reviewing prison culture, rules, and decorum before an ASD client enters prison. Think about it: the defendant with ASD did not understand how things worked in the outside world. Are they suddenly going to adopt to a 50-fold more hostile environment instinctively? The answer is, of course, no. They need direct guidance.

All of the challenges faced in jails described in this chapter are present, if not magnified in the prison environment. Additionally, there are further challenges.

First, the number one rule of prison is to mind one’s own business. For example, individuals with ASD who are meek by nature may need to be told to hold their head upright, stand up straight and look proud – even if it does not come naturally. One’s body language and disposition are everything in that setting. If they are in for a sexual offense, make it a cardinal rule that they do not share this voluntarily. If they are asked, it gets tricky. People can look it up or have someone on the outside look it up for them. No one wants to be lied to, but answering yes can also bring problems. This dilemma should be fully explored with professionals who can offer educated answers before entering the prison setting. It is too tricky a question to even answer in this chapter.

Next, encourage defendants with ASD to establish routines. Exercise is good; it gets them away from jail staff inside and gives a little breathing room. Perhaps they will meet some exercise pals in the yard. However, the unfortunate nature of prison is that one has to be careful how much they share about themselves wherever they are – in the yard, in the chow hall, watching TV, on the job, near the laundromat, or in the bunks. The lawyer must review the difference between being "friendly" and being someone's friend. It is very easy to be taken advantage of in prison, and the trusting nature of those with ASD makes this all too possible (Newman et al., 2015). A prison consultant well-versed in the challenges faced by autistic individuals might be helpful.

ASD individuals should be warned never to talk about the amount of money sent by family for their books because they will probably be extorted by other inmates. Also, ASD individuals should shed their childhood identities of being the policeman on the playground by tattling on other kids and admonishing them for breaking the rules. No one wants to acquire the label of "snitch" while in prison.

It is important the lawyer secure a copy of the handbook of the facility before the person is sent there. Make sure the individual understands all the formal rules. Perhaps hire a reputable prison consultant who in conjunction with the lawyer can explain these terms in a way the ASD individual can understand. Be sure to explain the importance of not questioning prison guards' authority at any time while incarcerated. ASD people can make people feel like they are being questioned under deposition if the rules seem illogical or don't make sense, as prison bureaucracy often does not. We would suggest telling individuals with ASD that this is like being in the military and the correctional officers are like drill sergeants; you do what you are told. This is for the individual's own good and survival.

The autistic person might engage in catastrophizing (MacAlister, 2017) before they enter the incarcerated setting. While this is understandable, an autistic person needs to be spoken to like a scientist in this situation: "The odds are you will get through this. It won't be easy, but you will talk every week to Grandma Jane or Mom and Dad. You won't be in here forever. Life will get better on the other side of this."

Caregivers may want to go out of their way to make sure that prescribed medications will be available on a time-scheduled basis. We have heard of stories of autistic people waiting in pill lines in prison and not receiving their medications, or not being able to take their prescribed doses because the prison does not allow certain classes of medications to be given. If parents and caregivers can try to establish contact with prison personnel, this would be ideal. However, this is not always possible.

Probation, Supervision, and the Sex Offender Registry

As improbable as it might sound, prison is not always the biggest hurdle for the individual with ASD. Probation officers (PO) who are not well versed in understanding individuals with autism make the experience very bumpy.

Very simply, a probation officer is like a god. They have the power of life or death over the individual. It takes nothing more than reasonable suspicion on the part of the PO to set up a revocation hearing, which almost always results in revocation back to prison – if that is what the PO wants. We recommend that parents, family members, siblings, spouses, and other support systems form friendly alliances early on in the relationship with the PO, keeping in mind that a PO can change on a moment's notice. Just as was the case with the lawyer explaining autism to the PO conducting the presentence investigation, someone needs to act in that same capacity with the PO during probation, parole, or supervised release. If the PO seems open to reading materials on autism, by all means give them those materials. Do your best to educate this person on the condition, but not in a way that could be perceived as manipulative. The idea is to reassure the PO that this is not a person they are going to have to worry about. After all, they may have 50 or 100 people on their caseload. The individual with autism, however, should scrupulously try to obey all the rules.

It is possible a probationer will have general, as well as special conditions, of supervision.

Special conditions are usually reserved for specific populations like sex offenders, or targeted towards individuals who judges think will have a propensity to violate. Standard special conditions are attending a group sex offender treatment program (SOTP) and the taking of polygraphs. Other special conditions could consist of a curfew, a prohibition against toys in their house (if it is a sex offense), or a prohibition against being around a child without a "responsible" adult present. Another standard "special condition" for most sex offenders is that they cannot watch any pornography including legal, adult pornography. The probation officer is able to know if the person followed this condition by utilizing a polygraph at regular intervals and asking the person directly. Therefore, it is important to review the conditions one by one so the individual on the spectrum can almost recite them by memory.

These conditions can be incredibly intrusive and almost impossible to follow. For instance, one man on probation had a Smart TV, which allowed him to watch Hulu, Netflix, Peacock, HBO Max, and the like. One of the conditions of his release was that he could not possess anything that connected him to the Internet. Upon a surprise inspection, this ASD individual was discovered possessing the Smart TV and was ordered to go back to prison at a revocation hearing. In reality, the person was an individual with an intellectual disability who won this TV at a church raffle and made no connection in his mind between the TV and the Internet. To him, the Internet involved the use of the computer, not a television. But this violation was treated as a strict liability offense. In other words, it did not matter he did not understand the rules. Unfortunately, in the eyes of the PO, he violated the rules and was punished regardless of his comprehension. Therefore, it is imperative that a support system is in place to help the individual navigate this minefield.

The same minefields are found when dealing with the sex offender registry. Each state as well as the federal government has its own set of rules. Most lawyers do not understand them all. Yet if a person on the registry violates them, they risk being sent to prison. Thus, a support system must be in place to help the person with ASD comply with all registry rules. These can include the amount of time a person can physically be present in another state before they have to register, how many times a year a person must register, whether there are residency restrictions, and whether they can petition at a particular point in time (sometimes after 10 years) to be removed from their state's registry. Most municipalities also have officers who regularly make compliance checks to make sure an individual is living where they say they are living. A support system put into place can help the ASD individual understand their constitutional rights in these encounters. We know of situations where police have asked to come in. Unless they have a warrant, they have no right to do that. We would hope an individual with autism who tries to be rule abiding would not let a police officer abuse their power in this situation. Individuals with autism should be taught to politely ask the officers if they have a warrant. If the answer is no, then the person with autism can politely decline the request and know they did not do anything wrong.

Conclusion

We hope this chapter has been informative with regard to a sensitive topic. Thanks to the neurodiversity movement, ASD self-advocates, other concerned individuals like family members, and mental health professionals, society is beginning to recognize that individuals on the spectrum present unique challenges as well as qualities that should be celebrated. Unfortunately, the intersection of ASD and the criminal justice system is not often discussed. We have tried to fill that void with this chapter. We hope you take away from this chapter that ASD individuals have different developmental trajectories, uneven developmental profiles, and social processing difficulties. But we also hope that you will better understand that the criminal justice system tries to place all square pegs through a round hole – and individuals with autism are "square pegs." We have provided alternative strategies to be used with this population – strategies to ensure the fair, equitable, and humane treatment of individuals with autism as they pass through the criminal justice system.

References

Allely, C. S. (2015). Experiences of prison inmates with autism spectrum disorders and the knowledge and understanding of the spectrum amongst prison staff: A review. *Journal of Intellectual Disabilities and Offending Behaviour, 6*(2), 55–67. https://doi.org/10.1108/JIDOB-06-2015-0014

Baron-Cohen, S. (2012). *The science of evil: On empathy and the origins of cruelty*. Basic books.

Baron-Cohen, S., & Wheelwright, S. (2004). The empathy quotient: An investigation of adults with Asperge Syndrome or high functioning autism, and normal sex differences. *Journal of Autism and Developmental Disorders, 34*(2), 163–175. https://doi.org/10.1023/b:jadd.0000022607.19833.00

Bath, C., Bhardwa, B., Jacobson, J., May, T., & Webster, R. (2015). There to help: Ensuring provision of appropriate adults for mentally vulnerable adults detained or interviewed by police. *Irish Journal of Learning Disabilities, 44*(3), 213–224.

Bhakare, P., & Vinchurkar, A. (2015). Study of visual reaction time in autism. *Indian Journal of Medical Research and Pharmaceutical Sciences, 2*(7), 49–51.

Bishop-Fitzpatrick, L., & Kind, A. (2017). A scoping review of health disparities in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*(11), 3380–3391. https://doi.org/10.1007/s10803-017-3251-9

Blasingame, G. D., Abel, G. G., Alan, J., & Wiegel, M. (2011). The utility and psychometric properties of the Abel-Blasingame Assessment System for individuals with intellectual disabilities. *Journal of Mental Health Research in Intellectual Disabilities, 4*(2), 107–132. https://doi.org/10.1080/19315864.2011.593696

Bos, J., & Stokes, M. A. (2019). Cognitive empathy moderates the relationship between affective empathy and wellbeing in adolescents with autism spectrum disorder. *European Journal of Developmental Psychology, 16*(4), 433–446. https://doi.org/10.1080/17405629.2018.1444987

Chen, M. H., Su, T. P., Chen, Y. S., Hsu, J. W., Huang, K. L., Chang, W. H., Chen, T. J., & Bai, Y. M. (2013). Comorbidity of allergic and autoimmune diseases in patients with autism spectrum disorder: A nationwide population-based study. *Research in Autism Spectrum Disorders, 7*(2), 205–212. https://doi.org/10.1016/j.rasd.2012.08.008

Chien, Y. L., Gau, S. S. F., Chiu, Y. N., Tsai, W. C., Shang, C. Y., & Wu, Y. Y. (2014). Impaired sustained attention, focused attention, and vigilance in youths with autistic disorder and Asperger's disorder. *Research in Autism Spectrum Disorders, 8*(7), 881–889.

Conley, A. (2013). Torture in US jails and prisons: An analysis of solitary confinement under International Law. *ICL Journal, 7*(4), 415–453.

Copenhaver, A., & Tewksbury, R. (2019). Interactions between autistic individuals and law enforcement: A mixed-methods exploratory study. *American Journal of Criminal Justice, 44*(2), 309–333. https://doi.org/10.1007/s12103-018-9452-8

DeGue, S., Fowler, K. A., & Calkins, C. (2016). Deaths due to use of lethal force by law enforcement: Findings from the National Violent Death Reporting System, 17 US states, 2009–2012. *American Journal of Preventive Medicine, 51*(5), S173–S187. https://doi.org/10.1016/j.amepre.2016.08.027

Eisner, C. (2019, September 13). *When people with intellectual disabilities are punished, and parents pay the ultimate price.* The Marshall Project. www.themarshallproject.org/2019/09/13/when-people-with-intellectual-disabilities-are-punished-parents-pay-the-price

FBI Website. (2002). *Does the confession criterion in case selection inflate polygraph accuracy stimates?* FBI. https://archives.fbi.gov/archives/about-us/lab/forensic-science-communications/fsc/july2002/krapohl.html

Frith, U., & Happé, F. (1994). Autism: Beyond "theory of mind". *Cognition, 50*(1–3), 115–132. https://doi.org/10.1016/0010-0277(94)90024-8

Furfaro, H. (2018, June 6). *Why police need training to interact with people on the autism spectrum*. Spectrum Magazine. www.spectrumnews.org/features/deep-dive/police-need-training-interact-people-spectrum

Geller, L. (2005). *Emotional regulation and autism spectrum disorders*. Asperger Center for Education and Training. http://aspergercenter.com/articles/Emotional-Regulation-and-Autism-Spectrum.pdf

Ghaziuddin, M., & Al-Owain, M. (2013). Autism spectrum disorders and inborn errors of metabolism: An update. *Pediatric Neurology, 49*(4), 232–236. https://doi.org/10.1016/j.pediatrneurol.2013.05.013

Goldstein, N. E., Condie, L. O., Kalbeitzer, R., Osman, D., & Geier, J. L. (2003). Juvenile offenders' Miranda rights comprehension and self-reported likelihood of offering false confessions. *Assessment, 10*(4), 359–369. https://doi.org/10.1177/1073191103259535

Griego, A. W., Datzman, J. N., Estrada, S. M., & Middlebrook, S. S. (2019). Suggestibility and false memories in relation to intellectual disability and autism spectrum disorder: A meta-analytic review. *Journal of Intellectual Disability Research, 63*(12), 1464–1474. https://doi.org/10.1111/jir.12668

Heaton, P., Williams, K., Cummins, O., & Happé, F. (2008). Autism and pitch processing splinter skills: A group and subgroup analysis. *Autism, 12*(2), 203–219. https://doi.org/10.1177/1362361307085270

Hess, P. (2020, November 11). *Autism behind bars.* Spectrum | Autism Research News. https://www.spectrumnews.org/features/deep-dive/autism-behind-bars/

Hingsburger, D., Griffiths, D., & Quinsey, V. (1991). Detecting counterfeit deviance: Differentiating sexual deviance from sexual inappropriateness. *The Habilitative Mental Healthcare Newsletter, 10*(9), 51–54.

Johnson, S, Blume, J. H., & Hritz, A. (2018). Convictions of innocent people with intellectual disability. *Albany Law Review, 82*(3), 1031–1062.

Kamisar, Y. (2017). The Miranda case fifty years later. *Boston University Law Review, 97*(3), 1293–1307.

Kelley, E. (2020). *Representing people with autism spectrum disorders: A practical guide for criminal defense lawyers*: Chicago, Illinois: American Bar Association.

Kurchak, S. (2018, February 19). *I'm autistic. I just turned 36–The average age when people like me die*. Vox. https://www.vox.com/first-person/2018/2/19/17017976/autism-average-age-death-36-stress

Laws, B. (2019). The return of the suppressed: Exploring how emotional suppression reappears as violence and pain among male and female prisoners. *Punishment & Society, 21*(5), 560–577. https://doi.org/10.1177/1462474518805071

Legal Reform for the Intellectually & Developmentally Disabled. (2021, January 12). *A mother's nightmare*. Legal Reform for the Intellectually & Developmentally Disabled https://lridd.org/a-mothers-nightmare/

Liu, X., Hubbard, J. A., Fabes, R. A., & Adam, J. B. (2006). Sleep disturbances and correlates of children with autism spectrum disorders. *Child Psychiatry and Human Development, 37*(2), 179–191. https://doi.org/10.1007/s10578-006-0028-3

MacAlister, L. (2017, November 22). *Autism and catastrophizing*. National Autistic Society. https://www.autism.org.uk/advice-and-guidance/professional-practice/autism-catastrophising

Mackinlay, R., Charman, T., & Karmiloff-Smith, A. (2006). High functioning children with autism spectrum disorder: A novel test of multitasking. *Brain and Cognition, 61*(1), 14–24. https://doi.org/10.1016/j.bandc.2005.12.006

Mahoney, M. (2009). *Asperger's syndrome and the criminal law: The special case of child pornography*. Harrington & Mahoney. www.harringtonmahoney.com/content/Publications/AspergersSyndromeandtheCriminalLawv26.pdf

Martínez-Sanchis, S. (2014). Neurobiological foundations of multisensory integration in people with autism spectrum disorders: The role of the medial prefrontal cortex. *Frontiers in Human Neuroscience, 8*, 970. https://doi.org/10.3389/fnhum.2014.00970

Mazza, M., Pino, M. C., Mariano, M., Tempesta, D., Ferrara, M., De Berardis, D., Masedu, F., & Valenti, M. (2014). Affective and cognitive empathy in adolescents with autism spectrum disorder. *Frontiers in Human Neuroscience, 8*, 791. https://doi.org/10.3389/fnhum.2014.00791

McElhanon, B. O., McCracken, C., Karpen, S., & Sharp, W. G. (2014). Gastrointestinal symptoms in autism spectrum disorder: A meta-analysis. *Pediatrics, 133*(5), 872–883. https://doi.org/10.1542/peds.2013-3995

McKeen, P. (2013). *The impact of motor skill training on balance, hand-eye coordination and reaction in a group of adults with autism and an intellectual disability*. Unpublished doctoral dissertation, University of Windsor.

Melling, R., & Swinson, J. M. (2016). The relationship between Autism Spectrum Quotient (AQ) and uneven intellectual development in school-age children. *Cogent Psychology, 3*(1), 1149136. https://doi.org/10.1080/23311908.2016.1149136

Mesibov, G., & Sreckovic, M. (2017). Child and juvenile pornography and autism spectrum disorder. In L. A. Dubin & E. Horowitz (Eds.), *Caught in the web of the criminal justice system: Autism, developmental disabilities, and sex offenses* (pp. 69–94). Jessica Kingsley Publishers.

Newman, C., Cashin, A., & Waters, C. (2015). A hermeneutic phenomenological examination of the lived experience of incarceration for those with autism. *Issues in Mental Health Nursing, 36*(8), 632–640. https://doi.org/10.3109/01612840.2015.1014587

North, A. S., Russell, A. J., & Gudjonsson, G. H. (2008). High functioning autism spectrum disorders: An investigation of psychological vulnerabilities during interrogative interview. *The Journal of Forensic Psychiatry & Psychology, 19*(3), 323–334. https://doi.org/10.1080/14789940701871621

O'Sullivan, O. P. (2018). Autism spectrum disorder and criminal responsibility: Historical perspectives, clinical challenges and broader considerations within the criminal justice system. *Irish Journal of Psychological Medicine, 35*(4), 333–339. https://doi.org/10.1017/ipm.2017.13

Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(11), 2710–2719. https://doi.org/10.1007/s10803-013-1833-8

Pasha, S. (2017, August 15). *The U.S. justice system has an autism problem*. The Dallas Morning News. www.dallasnews.com/opinion/commentary/2017/08/15/the-u-s-justice-system-has-an-autism-problem

Patton, E. (2019). Autism, attributions and accommodations: Overcoming barriers and integrating a neurodiverse workforce. *Personnel Review, 48*(4), 915–934. https://doi.org/10.1108/PR-04-2018-0116

Perry, D. M., & Carter-Long, L. (2016). *The Ruderman white paper on media coverage of law enforcement use of force and disability*. Ruderman Foundation.

Perske, R. (2011). Perske's list: False confessions from 75 persons with intellectual disability. *Intellectual and Developmental Disabilities, 49*(5), 365–373. https://doi.org/10.1352/1934-9556-49.5.365

Plaisted, K. C. (2015). Reduced generalization in autism: An alternative to weak central coherence. In J. A. Burack, T. Charman, N. Yirmiya, & P. R. Zelazo (Eds.), *The development of autism: Perspectives from theory and research* (pp. 149–169). Lawrence Erlbaum Associates.

Rajendran, G., Law, A. S., Logie, R. H., Van Der Meulen, M., Fraser, D., & Corley, M. (2011). Investigating multitasking in high-functioning adolescents with autism spectrum disorders using the Virtual Errands Task. *Journal of Autism and Developmental Disorders, 41*(11), 1445–1454. https://doi.org/10.1007/s10803-010-1151-3

Robison, J. (2013, August 6). *Autism and porn: A problem no one talks about.* Psychology Today. www.psychologytoday.com/us/blog/my-life-aspergers/201308/autism-and-porn-problem-no-one-talks-about

Rogers, K., Dziobek, I., Hassenstab, J., Wolf, O. T., & Convit, A. (2007). Who cares? Revisiting empathy in Asperger syndrome. *Journal of Autism and Developmental Disorders, 37*(4), 709–715. https://doi.org/10.1007/s10803-006-0197-8

Roley, S. S., Mailloux, Z., Parham, L. D., Schaaf, R. C., Lane, C. J., & Cermak, S. (2015). Sensory integration and praxis patterns in children with autism. *American Journal of Occupational Therapy, 69*(1), 1–8. https://doi.org/10.5014/ajot.2015.012476

Rubin, A. (2017, May 31). *Downloading a nightmare.* The Marshall Project. www.themarshallproject.org/2017/05/31/downloading-a-nightmare

Ruble, L. A., & Akshoomoff, N. (2010). Autism spectrum disorders: Identification and diagnosis. *Helping children at home and school III: Handouts for families and educators*, S8H9. https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.168.5179&rep=rep1&type=pdf

Salerno-Ferraro, A. C., & Schuller, R. A. (2020). Perspectives from the ASD community on police interactions: Challenges & recommendations. *Research in Developmental Disabilities, 105*, 103732. https://doi.org/10.1016/j.ridd.2020.103732

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics, 129*(6), 1042–1049. https://doi.org/10.1542/peds.2011-2864

Sunderland, M. (2017, September 28). *The autistic children who are labeled as sex offenders*. Vice. www.vice.com/en_us/article/kz7zxa/the-autistic-children-who-are-labeled-as-sex-offenders

Tager-Flusberg, H., Joseph, R., & Folstein, S. (2001). Current directions in research on autism. *Mental Retardation and Developmental Disabilities Research Reviews, 7*, 21–29.

Todd, J., Mills, C., Wilson, A. D., Plumb, M. S., & Mon-Williams, M. A. (2009). Slow motor responses to visual stimuli of low salience in autism. *Journal of Motor Behavior, 41*(5), 419–426.

Torrey, E. F., Kennard, A. D., Eslinger, D. F., Biasotti, M. C., & Fuller, D. A. (2013). *Justifiable homicides by law enforcement officers: What is the role of mental illness*. Treatment Advocacy Center and National Sheriffs' Association. Accessed on 24/11/2020 at www.treatmentadvocacycenter.org/storage/documents/2013-justifiable-homicides.pdf

Townsend, J., Harris, N. S., & Courchesne, E. (1996). Visual attention abnormalities in autism: Delayed orienting to location. *Journal of the International Neuropsychological Society, 2*(6), 541–550. https://doi.org/10.1017/s1355617700001715

Treanor, J. (2018, November 19). *Vegas Lost: "Autism court" helps kids who would otherwise be going to detention centers*. KSNV https://news3lv.com/news/local/vegas-lost-autism-court-helps-kids-who-would-otherwise-be-going-to-detention-centers

Vargas, T. (2020, June 24). *A young black autistic man was sentenced to 50 years for a car crash. Tens of thousands of people are now calling for his freedom*. Washington Post. https://www.washingtonpost.com/local/a-young-black-autistic-man-was-sentenced-to-50-years-for-a-car-crash-tens-of-thousands-of-people-are-now-calling-for-his-freedom/2020/06/24/fabeda1a-b640-11ea-a8da-693df3d7674a_story.html

Wainwright-Sharp, J. A., & Bryson, S. E. (1993). Visual orienting deficits in high-functioning people with autism. *Journal of Autism and Developmental Disorders, 23*(1), 1–13.

Wallisch, A., Nowell, S., & Little, L. (2020). Picky eating in children with autism spectrum disorder (ASD): An examination of behavioral profiles. *American Journal of Occupational Therapy, 74*(4Supplement1), 1. https://doi.org/10.5014/ajot.2020.74S1-PO5126

Wenner Moyer, M. (2019, July 17). *When autistic people commit sexual crimes*. Spectrum | Autism Research News. https://www.spectrumnews.org/features/deep-dive/when-autistic-people-commit-sexual-crimes/

Wing, L., Gould, J., & Gillberg, C. (2011). Autism spectrum disorders in the DSM-V: Better or worse than the DSM-IV? *Research in Developmental Disabilities, 32*(2), 768–773. https://doi.org/10.1016/j.ridd.2010.11.003

Wrobel, M. (2003). *Taking care of myself: A hygiene, puberty and personal curriculum for young people with autism*. Future Horizons.

Part III

Some Important Transitions

7

Transition to Adulthood for Adolescents and Young Adults with Autism: Can We Improve Outcomes?

Peter F. Gerhardt and Shanna N. Bahry

For most neurologically typical people, adulthood represents a time characterized by both age (18 years or older) and some combination of gainful employment, preferred relationships, interpersonal intimacy, family, children, independent travel, leisure alternatives, the management of physical and mental health challenges, and independent living, to name just a few. Adulthood is generally understood as a time of increased responsibility, risk, and, hopefully, reward and pleasure. Adulthood, we have been told, is supposed to be the best time of our lives.

For many adults with autism,[1] however, the definition of adulthood is often abbreviated to simply having attained the chronological age of 18 years and the display of some of the physical features of adulthood (e.g., height, body hair). The difference between the two is pretty stark, given that most autistic adults experience significant challenges across multiple aspects of adult life including accessing employment (Taylor & Seltzer, 2010), continuing school, independent living, socializing, community inclusion and participation (Roux et al. 2015, 2013), and staying healthy (e.g., Walsh et al., 2017), and safe (e.g., Shattuck et al., 2018). Not a particularly promising picture. But why is this?

Over the past 30 years, the field of behavior analytic intervention in ASD has grown increasingly progressive and positive, (e.g., Friman et al., 1998; Leaf et al., 2016, 2017). Significant, socially valid outcomes have been documented in such areas as early intervention (e.g., Reichow, 2012), functional analysis/assessment (e.g., Iwata & Dozier, 2008; Jessel et al., 2016), educational inclusion (e.g., Ferraioli & Harris, 2011), and the acquisition of social skills (Gunning et al., 2019). However, this does not seem to be the case when it comes to the transition of autistic adults to included, engaged, and preferred adult lives, despite the obvious need (e.g., McCollin & Obiakor, 2010).

IDEA and Transition to Adulthood

The transition requirements of the Individuals with Disabilities Education Act – IDEA (2004) deserve a quick discussion. IDEA defines special education transition services as:

> *[…] a coordinated set of activities for a child with a disability that:*
> *(A) is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from*

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[1] *Note: Throughout this document the term "autism" or "autistic" is used to refer to those individuals on the autism spectrum whose degree of cognitive and behavioral involvement would result in a diagnosis of Severity Level 2 or 3 under DSM-V Guidelines (American Psychiatric Association,* 2013).

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> *school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation*
> *(B) is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and*
> *(C) includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation.* (IDEA, 2004. Section 300.43)

While IDEA's transition requirement brings with it the funding and related resources necessary to, potentially, achieve more positive outcomes, funding alone does not appear to be sufficient to guarantee such outcomes. The IDEA transition requirement does, however, provide families, schools, educators, students, etc., with a significant degree of flexibility to meet the needs of a diverse student population, which is a strength. This flexibility is designed to address the needs of students with different and distinct needs, strengths, and challenges but, unfortunately, is focused far more on the process of transition (e.g., coordinated set of activities, results-oriented processes, facilitated movement from school to post-school activities) than it is on the outcomes of that process (e.g., independence, employment, social inclusion, a positive quality-of-life).

Under IDEA, transition services are expected to start no later than the student's 14th birthday, although they may start earlier if deemed appropriate by the IEP team. But is 14 years already too late? Cimera et al. (2013) examined transition outcomes for two matched groups each consisting of 453 youth with autism across 4 years. Students were matched on age, gender (as reported at birth), ethnicity, severity of disability, and the presence of any cooccurring conditions. The authors reported that the group that started transition at 14 years had higher rates of employment, higher wages, and lower cost of services after graduation, than did the comparison group across all 4 years. This is certainly encouraging, but absent any knowledge of what was being taught, how was it being taught, and where was it being taught during transition for each group—the results are less instructive than we would have liked.

But if starting transition earlier is better, it takes no great leap of logic to assume that starting even earlier would, most likely, result in even more positive and significant outcomes for autistic adults. This may be particularly true given that, for typically developing peers, transition to adulthood begins in preschool (Ruddel, n.d.). In other words, given that most of the skills considered important in adulthood are the result of the scaffolding of a series of mastered prerequisite skills, the later the process begins, the fewer prerequisite skills there are upon which to build, and fewer useful adult skills mastered.

For example, McGowan et al. (2017) reported that cooking skills consist of set of physical skills (e.g., chopping, heating, mixing) used in meal preparation, but also include perceptual and conceptual skills, such as how different foods react when cooked. These then serve as the platform for broader skills referred to as food skills (Fordyce-Voorham, 2009) which include meal planning, ingredient shopping, budgeting, healthy eating, etc. For students with autism, skills such as the safe use of knives, how to handle hot items, hand washing, solid and liquid measurement, and basic food storage would, most likely, need to be included. This makes it highly unlikely that this entire set of skills/prerequisites can be acquired, if instruction begins at age 14 years. Going forward, this means that special education teachers, behavior analysts, family members, and members of IEP teams need to take a much longer view of how transition to adulthood works and when it should start if truly meaningful adult skills are to be developed.

Transition to What?

How best to support individuals with autism in positive adult lives is something about which we know less than is desirable (e.g., Perkins & Berkman, 2012). Shattuck et al. (2012a) described the research base in adult services/intervention as both underdeveloped and relatively unformed. In their review of the literature, Bishop-Fitzpatrick et al. (2013) came to a similar conclusion stating, "There is substantial need for the rigorous development and evaluation of psychosocial treatments for adults with ASD" (p. 687). Most recently, Shattuck et al. (2020a, b) reviewed the research on adult programs/services. They reported that the body of research remains small and lacks any unifying conceptual framework or consistent methodological approaches. The authors go on to argue that adult program providers should adopt a life-course-systems-perspective and examine the complex interactions between culture, history, organizations, policies, funding, and families that may directly and indirectly impact service accessibility, delivery, coordination, and effectiveness of services (Shattuck et al., 2020a, b). Unfortunately, this presents a very real challenge as an "end point" is essential to any transition process. Absent an understanding of what services and supports are available post-21, and the potential appropriateness and effectiveness of these services, (e.g., Nadig et al., 2018), developing a functional transition to adulthood plan becomes something of a guess game.

Snell-Rood et al. (2020), for example, conducted a series of focus groups with autistic students, parents, teachers, administrators, adult service providers, and policymakers (10 groups, n = 40). Overall, group participants reported that critical activities associated with the transition process were not reliably implemented. This included such things as nonfunctional goal-setting, ineffective communication, and inadequate involvement of all relevant stakeholders. Post-graduation, these newly minted adults reported struggling to "access necessary services due to inadequate planning, overburdened services, and insufficient accountability for adult service providers" (p. 1164). In what would appear to be something of an understatement, the authors conclude that the "transition from school to the adult world is particularly problematic for those with ASD," and is impacted by myriad "individual, organizational, and policy barriers [that] interfere with a successful transition" (p. 1176).

While ineffective transition practices and policies may help fulfill the legal mandate of the transition requirements of IDEA, adult outcome research (e.g., Anderson et al., 2018; Roux et al., 2015; Shattuck et al., 2018; Wisner-Carlson et al., 2020) indicates that positive transition outcomes are not the norm. While the potential of the IDEA transition requirements remains significant, poor or incomplete implementation has seemingly resulted in newly graduated autistic adults with few of skills needed to live preferred lives characterized by competence, dignity, happiness, and quality.

So while change is obviously needed, change on a systems level is, unfortunately, difficult. Kaufman (1993) noted that systems change within special education would require the profession to, "confront its problems in ways likely to bring truly substantive, lasting change-reform that is radical in that its failure is not highly predictable" (p. 6). Further complicating that is the fact the field of special education has historically been riddled with fads and ineffective techniques, resulting in the power of scientific research and data to be somewhat ignored (Kauffman et al., 2016; Zane, 2005). Not exactly a promising place for a transition age student with autism to find themselves. With that in mind, the following small-scale recommendations for change are put forward for the transition to adulthood process to result in better outcomes for adults on the spectrum:

1. The role of the behavior analyst in the transition process needs to be redefined.
2. Adaptive behavior skills that support independence need to be prioritized.
3. Community-based instruction (CBI) and employment development need to be prioritized.
4. The rest of the world needs to be trained.

Redefining the Role of the Behavior Analyst in the Transition Process

Over the past two decades, the role of the Board Certified Behavior Analyst (BCBA) (www.bacb.com) in the development and implementation of evidence-based educational programming for elementary and middle school-aged learners with autism has become well established (e.g., Alberto et al., 2013). In that position, BCBAs may collaborate with other professionals to identify relevant instructional goals, determine any existing functional environment-behavior relationships, and design evidence-based instructional programs and interventions along with the associated data collection and progress monitoring process (e.g., Shriver, 2019).

But in high schools, the BCBA often functions as, at best, an add-on to the transition process, only asked for input when the student presents with a specific behavior challenge. Some of this may be the result of the different job descriptions and different roles and responsibilities of the BCBA and the special education teacher. Many BCBAs providing services in public schools may be unfamiliar with the roles of their new professional colleagues, as well as the structure, culture, and mandates of schools (VanDerwall & Polling, 2021). At the same time, we would expect established education professionals to be unfamiliar with the role of the BCBA. Max and Lambright (2021), for example, conducted an online survey of a small number of BCBAs regarding their experiences working in American K-12 public schools. The results indicated that, in general, school-based BCBAs had significant challenges establishing treatment fidelity for their students with ASD due to limited time, support, resources, and collaboration with educators and administrators.

In addition, BCBAs working in public high schools may not be involved in the transition process because they lack the necessary training in the transition process, the scope/sequence of transition curriculum, and instruction in the community. This may, in part, be because the Behavior Analysis Certification Board (BACB) does not require its certificants to have any training in either education and/or special education (BACB, 2017) and school administrators hiring BCBAs may not consider it important to prioritize hiring those who do. In a very competitive market (e.g., Dixon, 2014), it may be more a matter of hiring an available BCBA rather than waiting to hire a BCBA with education credentials.

Or, perhaps, because the role of the BCBA in public schools generally focuses on the reduction of challenging behavior rather than on the development of interventions designed to increase transition-related behavior (e.g., Hollins & Peterson, 2021). This represents a significant, systems-wide problem that needs to be addressed moving forward. Behavior analysts come equipped with the knowledge and skills needed to affect change in all behavior, including skill acquisition. These knowledge and skills should be seen as complimentary to those of the special education teacher and neither in competition nor in conflict with them.

Behavioral terminology also appears to play a role in the BCBA's lack of integration into instructional processes in general. For example, McMahon et al. (2021) surveyed 164 US teachers regarding their perception of behavior analytic terminology. In general, participants indicated that non-technical terms were highly preferable to more technical, behavior analytic terminology which BCBAs are trained to use. The exception was "reinforcement," but even then, it was acceptable only when applied to middle or high school students. Conversely, teachers rated intervention-related terms as less socially acceptable for use with younger students. The authors note that this could be due to a persistent belief that young children require an education, not formal intervention (a distinction without a difference).

Another reason may simply be that BCBAs working in high schools view transition programming as outside of their scope of practice and so do not actively advocate for their involvement in the process. Despite that, the high school-based BCBA has an ethical responsibility to work, consult, and collaborate with other multidisciplinary team members to meet the needs of their student/client (e.g., VanDerwall & Poling, 2021). In fact, a reasonable argument can be made that BCBAs working in schools need only look as far as Baer, Stokes, and Risley (1968) to understand why this is the case.

In their seminal article Baer, Wolf, and Risley (1968) identified seven defining dimensions of ABA. These (in brief) include:

1. Applied – Deals with problems of social importance.
2. Behavioral – Deals with objective, measurable behavior or reports that can be validated.
3. Analytic – Requires an objective demonstration that the procedures caused the effect.
4. Technological – Procedures are described well enough that they can be replicated.
5. Conceptually systematic – Arises from a specific and identifiable theoretical base.
6. Effective – Produces strong, socially important effects.
7. Generality – Designed from the outset to operate in new environments and continue after treatment has ended.

All seven dimensions are relevant to effective instructional intervention in ASD across ages, instructional domains, and contexts. However, there are three dimensions that provide BCBAs working in schools with significant guidance with reference to transition programming. These are:

> **A***pplied: Deals with problems of social importance.*
> **G***enerality: Operates in new environments and continues after treatments have ended.*
> **E***ffective: Results in socially important behavior change.*

Taken together, the acronym "*AGE*" provides a clear, concise, and behavior analytic description of BCBAs' ethical role in the transition to adulthood process while, at the same time, defining the overall end goal of the process. To be more specific, AGE conceptualizes the effective transition to adulthood process as: *the identification* of *socially important targets of skill acquisition that are taught in ways that produce strong, socially important effects, by using interventions designed to generalize and maintain skill acquisition targets after formal programming has ended.* This describes clear, practical guidance that is well within the ethical scope of practice for the BCBA interested in contributing to the process of helping an individual successfully "*AGE.*"

The BCBA working in a high school brings both a comprehensive knowledge-base and an array of evidence-based interventions to the transition planning and implementation process. But the extent to which BCBAs are currently welcomed into that process is unknown and should be the target of future research. The absence of such research, however, does provide the BCBA working in a high school with the functional equivalent of a "get out of jail free" card. The field of Applied Behavior Analysis, as noted, offers clear and concise guidance to BCBAs in support of their participation in the transition to adulthood process. Failure to do so would seem to be the professional equivalent of a "sin of omission."

Prioritize Adaptive Behavior Skills That Support Independence

Life in the community requires a complex and diverse set of skills generally subsumed under the heading of adaptive behavior. Adaptive behavior can be defined as those skills or abilities that enable the individual to meet norm-referenced standards of personal independence. Adaptive behavior skills can change as a function of a person's age, environmental demands, and cultural expectations (Heward, 2009). This collection of diverse, yet complementary skills is central to an individual's ability to effectively and independently navigate his or her environment (Mazefsky et al., 2008) and, as such, needs to be prioritized starting at an early age (e.g., Ninci et al., 2015; Meyer et al., 2018). On a very basic level, adaptive behavior skills will get you through times of no academic skills better than academic skills will get you through times of no adaptive behavior skills (Gerhardt & Rodriguez, 2018).

In practice, instruction in activities of daily living skills (ADLs) is often seen as being synonymous with instruction in adaptive behavior. While this is an inexact comparison, both appear associated with more positive adult outcomes. While some research (e.g., Clarke et al., 2021) has found that many of these skills may not maintain in adulthood, other research (e.g., Wise et al., 2020) indicates this may not always be the case. Clearly, additional research is needed in this area.

Adaptive behavior beyond simple daily living skills has received little attention in the autism research literature (Bennett & Dukes, 2014), beyond skills such as personal care/grooming (Wertalik & Kubina, 2017). One reason may be that, unlike the diagnosis of intellectual disability, adaptive behavior deficits are not central to a diagnosis on the autism spectrum and have, until recently, generally not been considered primary targets for intervention or research.

A second reason may be that adaptive behavior competencies generally require a shifting between motor, communication, social, and decision-making skills as a function of changing contexts. Figure 7.1 provides a graphic example of such shifts for the relatively straightforward task of public restroom use. The complexity of adaptive behavior cannot be overstated, making these skills hard to teach and even harder to research well.

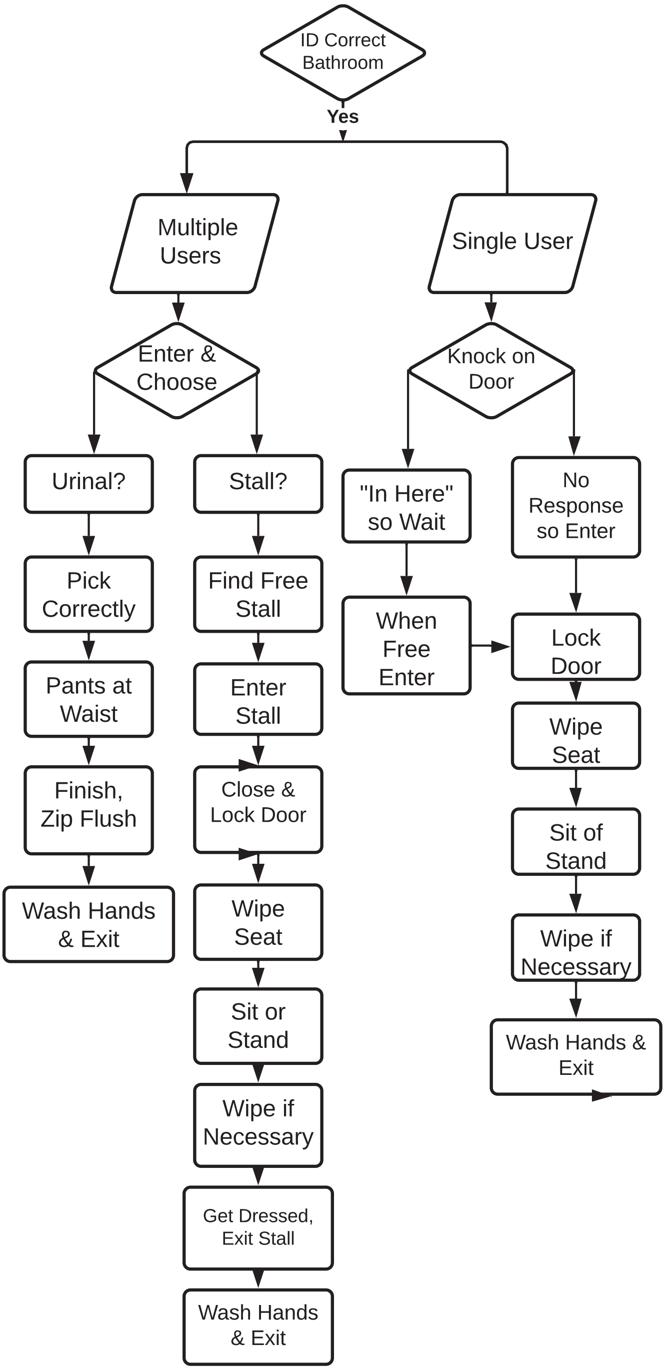
In their overview of adaptive behavior in ASD, Gerhardt et al. (2013) offered an outline of what is programmatically necessary to provide effective adaptive behavior intervention. They argued that effective adaptive behavior intervention requires an understanding of the context and intensity of instruction, and the efficiency and value of the skill in question. In their model, context refers to the environment in which the skill is most likely to be displayed. For example, shopping would need to be taught at the grocery store where the student is likely to shop with his or her family. Intensity refers to the importance of such instruction being provided at a relatively high rate (e.g., daily) to promote skill acquisition. For example, a student would more quickly learn how to buy lunch at a fast food restaurant if instruction was provided daily (at the restaurant), rather than weekly. Efficiency refers to the response effort required for the skill to be acquired. For example, while generally not a preferred task, doing the laundry can be made more efficient/less effortful (and, ideally, less non-preferred) by skipping sorting, washing everything in cold, and using premeasured laundry pods. Non-preferred skills that require significant response effort are unlikely to remain in anyone's repertoire for any length of time. Finally, there is value. The value of any skill is a function of the extent to which the individual in question finds the skill to be of personal interest, utility, or, simply, reinforcing. For example, learning to have lunch delivered by ordering via an application on a smart phone would probably offer more value to the student than would doing laundry, even if done efficiently.

In many ways, the transition to adulthood is the transition to the adaptive behavior necessary to navigate life in the community. It is important to note that the inability of an adult on the spectrum to acquire any number of adaptive behavior competencies does not mean that the potential for a full, fulfilling, enjoyable, and positive adult life is over. What it does mean is that individualized services and personal accommodations designed to close the gap between environmental demands and individual skill deficits need to be available both during transition and on the terminal side of the transition process.

Prioritize Community-Based Instruction (CBI) and Employment Development

Community-based instruction (CBI) requires the provision of effective educational intervention outside of the classroom and in the community. Community-based instruction has been recognized as an evidence-based practice (e.g., Mazzotti et al., 2021) and is associated with improved independence for students with different disability labels post-graduation (Walker et al., 2010). CBI has been shown to be effective in the development of vocational/work skills (e.g., Allen et al., 2010), social skills (e.g., Hernandez & Kulkarni, 2018), safety skills (e.g., Clees & Gast, 1994; Taber et al., 2003), and a variety of adult life skills (e.g., Spooner et al., 2020). McDonnell et al. (1993) examined the impact of CBI on the adaptive behavior repertoire of high school students with an intellectual disability. The frequency with which CBI was pre-

Fig. 7.1 Task analysis of adaptive behavior sequence for "using a public restroom"



sented was a more significant predictor of skills gains than was IQ or the presence/absence of challenging behavior.

How CBI Works

Gerhardt and colleagues (2019) note that the process of identifying and implementing CBI opportunities with learners on the spectrum needs to start early (i.e., no later than 7–8 years of age) with a focus on goals with the greatest relevance to the student and his or her family. The process, in general, goes like this:

1. Identify, with input from the student and their parents, a set of community-based instructional targets for a particular student along with the locations where instruction could be provided.
2. Conduct an observation at the proposed community location at the time instruction is expected to be provided (e.g., Tuesdays at 1:00 PM). This observation should result in:
   (a) A draft task analysis of the instructional target(s).
   (b) The identification of any relevant distractions or potential risks (e.g., busy parking lot; loud PA system; absence of public restrooms; fluorescent lighting; limited cell phone service; easily accessible fire alarm pulls).
   (c) The identification of community members, specific to that environment, who might be able provide ancillary assistance (e.g., store manager, cashier)
3. Based upon the acquired data, develop a plan to implement CBI.
4. Implement CBI. Collect relevant data.
5. Repeat process for subsequent goals.

Calculating the Frequency of Instruction in CBI

After the development of a clearly defined CBI goal, it is often helpful to develop an estimate as to how many instructional opportunities (IO) will be required for the student to acquire the skill. For example:

- If based on student's typical rate of skill acquisition for a similar task, it is estimated that it will take 100 instructional opportunities (i.e., episodes of CBI) for them to master the skill. AND,
- Each CBI instructional opportunity, from leaving school to returning to school, takes 1 h. AND,
- The student has 30 h of instruction/week for 40 weeks/year. AND
- They are expected to acquire the skill in a single school year. THEREFORE:
- 100 instructional opportunities provided across 40 weeks of instruction = 2.5 instructional opportunities/week or, in real world terms, 2–3 opportunities which requiring 2–3 h/week. If the goal is for the student to acquire the skill in 20 weeks, then 5 instructional opportunities will need to be provided each week.

Effectively delivered CBI is central to the provision of effective transition programming for autistic youth and young adults. Despite this, only 4.8% of the autism intervention research published between 2012 and 2017 was community-based (Steinbrenner et al., 2020). This is, of course, problematic. It is essential that autistic youth and adults don't just have a limited number of CBI opportunities but, instead, that they have a transition program that prioritizes repeated opportunities to practice and acquire skills in the community where they are expected to be displayed (e.g., Spooner et al., 2020).

In reality, there are any number of restrictions to the implementation of CBI as part of a comprehensive transition plan within a public school. The first is that the availability, or lack thereof, of student transportation to and from the community often presents a significant barrier. A second restriction is the philosophical administrative adherence to state educational standards in favor of prioritizing CBI. Third, support personnel may lack the skills necessary to provide instruction in the community. Lastly, unfortunately, the educational culture is more concerned with risk avoidance than student independence and instruction in the community is inherently risky. This, obviously, needs to change. However, as long as the goal of transition programming continues to be (1) risk avoidance, and (2) student success in the in the classroom, limited individual progress can be expected.

Employment Development as CBI

In North American society, employment in the typical world is considered a significant hallmark of adulthood. Work is so central to adult lives that most of us spend around a quarter of our lives at work (Warr & Clapperton, 2010). What we do for a living is often considered an indication of status and, by implication, our contribution to society at large. Employment is a direct source of income and provides us with a variety of choices as to where to live, what to buy, and how to make good use of our free time. The workplace is the environment in which many of our primary and secondary social relationships are formed and maintained. Work provides structure and routines and, to a large extent, promotes personal dignity, self-validation, and an individual's overall mental and physical health (Hedley et al., 2017; Hendricks, 2010; Solomon, 2020). Exclusion from employment generally has significant negative implications across most, if not all, domains of adult life.

Despite that, employment rates for adults with autism remain unacceptably low.

In their review of data from the National Longitudinal Transition Survey II (NLTS-II), Shattuck et al. (2012b) found that during the first 6 years after high school, only 55.1% of adults with ASD had ever held paid employment, and the percentage was even lower (50%) if they had transitioned out of high school in the past 2 years. Further, when compared to other disability cohorts, individuals on the autism spectrum had the lowest rates of employment. Burgess and Cimera (2014) evaluated the employment outcomes of transition-aged adults with autism spectrum disorders (ASD) who received vocational rehabilitation (VR) services in the 10 prior years. The results indicated that while the number of adults accessing VR services increased, the percentage of autistic adults who attained employment did not increase. Roux et al. (2015), as a result of their analysis of NLTS-2 data reported, "young adults with autism have a difficult time following high school for almost any outcome you choose - working, continuing school, living independently, socializing and participating in the community, and staying healthy and safe" (p. 8). More recently, Fong et al. (2021), in their review of employment outcomes, noted that only 37% of individuals with autism reported having been employed for 12 months or more 4 years post high school. Further, they noted job loss for these individuals was far more often the result of behavioral and social challenges than it was any specific deficits related to the production/vocational aspect of the job.

The factors associated with these continued poor outcomes remain poorly understood. Chen et al. (2015) reported that social difficulties, employers' negative attitudes, and limited access to needed support services were factors contributing to the inability to obtain and retain employment. As a result of their comprehensive review of the employment literature, Anderson et al. (2021) reported that poor employment outcomes are associated with poor person-environment fit, a lack of comprehensive and integrated services, and uncertainty about the roles of parents (e.g., a tendency of parents to "over support" their son or daughter on the spectrum, thereby increasing dependence and increasing independence).

Poor person-environment fit is a factor reported by a number of researchers (Lai et al., 2020; Pfeiffer et al., 2018; Stewart et al., 2014). Poor person-environment fit or, as it is sometimes called, "job match," is the extent to which a particular job and its associated social, sensory, and physical environments match the personal preferences or neurological needs of the employee. As such, a goal of any reasonable school to work transition process should be to identify the potential environmental barriers and opportunities to employment before graduation on a case-by-case basis. This can most readily be accomplished during transition through a process called job sampling.

Job sampling refers to the practice providing a number of short-term employment training opportunities (i.e., samples) to the transitioning student with autism and then observing and measuring how he or she navigates that particular environment. Does the transition student like to move around or stay seated when working? Do they like to have music on in the background? Do they prefer to work in the morning or in the afternoon? Are they good at high precision tasks (e.g., data entry), rather more gross motor tasks such as stocking shelves? Do they prefer to be part of an active, busy environment or a calm, quiet environment more to their liking? And so on. A central goal of job sampling is the identification of environmental modifications necessary to meet the needs of the learner rather than trying to "fix" the employee with autism to meet the demands of the environment. Person-environment fit appears to be a critical factor in the successful employment of autistic adults.

Train the Rest of the World

Unfortunately, the most significant post-transition barrier to an included, positive life for autistic adults is, sadly, the attitudes and behavior of those of us in the neurotypical community. The provision of community-based instruction, particularly with reference to employment development, is central to the acquisition of the skills necessary for success in post-transition life. This process, however, doesn't just engender behavior change with the transitioning student. Perhaps the more important behavior change is the change that occurs in the behavior of work site supervisors and coworkers, in the behavior of the supermarket cashier and the staff at the aquarium, gym, or frozen yogurt shop, or simply in the behavior of other patrons in the mall food court. When done correctly, CBI and employment help transition an individual from being a coworker with autism to a coworker with a name. That is why it is important to, as part of the transition process, train the rest of the world to the benefits of knowing, working with, and hanging out with someone on the spectrum.

So while the process of training the rest of world is, admittedly, a poorly defined intervention, it is an intervention that requires significant prioritization. Like the rest of transition planning, the reduction of these barriers requires a set of both group and individualized interventions. The diversity of the autism spectrum, which is significant, is actually more of a three-dimensional diversity matrix than it is a two-dimensional spectrum. So while every adult on the spectrum may have the same diagnostic label, everyone with that label is different from everybody else with that label. As such, what would appear to be most potentially beneficial is not additional autism awareness but, instead, the development of a culture of autism acceptance including individualized training about who a new coworker with autism happens to be as a person.

This is not asking a lot. Since the passage of the Americans with Disabilities Act (ADA) in 1990, American society and culture has become increasingly aware of, and comfortable with, the provision of environmental accommodations to persons with physical disabilities. The call to train the rest of the world is simply an extension of that process to include the needs of the neurodiverse community. We have moved beyond a time when a wheelchair user couldn't access most public buildings due to the presence of stairs and the absence of a ramp. The goal now is to figure out what constitutes a ramp for autistic citizens and how do we get it installed wherever it is needed.

Summary

There is much work to be done with regard to the effective, community-based implementation of transition programming and the research that supports it, particularly for autistic adolescents with a co-occurring intellectual disability (e.g., Lord, et al., 2021). As Lord and colleagues (2017) argue, "research that tests interventions to promote achievable independence for autistic adolescents and adults is needed, focusing on outcomes such as employment, meaningful and generalizable social skills, improvement of common co-occurring mental health conditions and broader functioning and well-being" are greatly needed (p. 307).

Obviously, there are a number of other areas of adult life that could, and maybe should, have been discussed as part of transition planning. This might include travel training, the development of age normative leisure skills that function as leisure for the individual, sexuality and sexual safety skills, and so on. The fact is, adulthood is a complex, rewarding, challenging, enjoyable, and frustrating time of life that for many adults with ASD that is, sadly, neither rewarding nor all that enjoyable.

"The mass of men lead lives of quiet desperation," wrote Henry David Thoreau in *Walden* (1854). With a large cohort of young adults with ASD rapidly approaching middle age, and soon thereafter, hitting their proverbial golden years, the fear is that Thoreau may be proved right. The adult service system, as it currently stands, is unprepared to meet the needs of this diverse and complex population (e.g., Goehner, 2011). That is the bad news. The good news is that, today, we have a clearer understanding of the problem and the needs of adults with ASD, and are rapidly generating solutions that go beyond mere funding requests. While additional funding is, of course, necessary, in order to transform lives of quiet desperation into lives of competence, dignity, and quality—creative, collaborative, research-based, cost-effective, and replicable services are needed.

From the very first day a young child with ASD walks through the school door, we, in whatever role we fill, need to be thinking about building a platform of skills for each successive environment leading, ultimately, to a broad base of adaptive and academic skills in support of adult life. Between loving and highly focused parents; educated, caring, and dedicated professionals; talented researchers; entitlement legislation; and involved community members, this young child is, in many ways, resource rich, up until high school graduation. The one resource there will never be enough of though is time. Time is not, and never will be, on the side of the transition student. Effective planning and the maintenance of high expectations is, therefore, our best (and inexhaustible) resource to support an enjoyable, satisfied, safe, and included adult life.Compliance with Ethical StandardsNo funding was received for this manuscript. There were no human participants in this manuscript and therefore we did not need to receive informed consent was obtained from the parents of all individual participants included in the study. We were in accordance with ethical standards of the institutional research committee and with 1964 Helsinki decoration and its later amendments or comparable ethical standards.

References

Alberto, P., Troutman, A. C., & Axe, J. B. (2013). *Applied behavior analysis for teachers*. Pearson.

Allen, K. D., Wallace, D. P., Greene, D. J., Bowen, S. L., & Burke, R. V. (2010). Community-based vocational instruction using videotaped modeling for young adults with autism spectrum disorders performing in air-inflated mascots. *Focus on Autism and Other Developmental Disabilities, 25*, 186–192. https://doi.org/10.1177/1088357610377318

Americans with Disabilities Act of 1990. P.L. 101-336. Equal Employment Opportunity Commission. Regulations of the Americans with Disabilities Act of 1990, July 26, 1991.

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Anderson, K. A., Sosnowy, C., Kuo, A. A., & Shattuck, P. T. (2018). Transition of individuals with autism to adulthood: A review of qualitative studies. *Pediatrics, 141*, S318–S327. https://doi.org/10.1542/peds.2016-4300I

Anderson, C., Butt, C., & Sarsony, C. (2021). Young adults on the autism spectrum and early employment-related experiences: Aspirations and obstacles. *Journal of autism and developmental disorders, 51(1), 88–105.* https://doi.org/10.1007/s10803-020-04513-4

Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis, 1*(1), 91-97. https://doi.org/10.1901/jaba.1968.1-91

Behavior Analyst Certification Board (BACB). (2017). *BCBA/BCaBA task list* (5th ed.). Author.

Bennett, K. D., Dukes, C. A. (2014). Systematic Review of Teaching Daily Living Skills to Adolescents and Adults with Autism Spectrum Disorder. Review Journal of Autism and Developmental Disorders 1, 2–10. https://doi.org/10.1007/s40489-013-0004-3

Bishop-Fitzpatrick, L., Minshew, N. J., & Eack, S. M. (2013). A systematic review of psychosocial interventions for adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders,* ***43***, 687–694. https://doi.org/10.1007/s10803-012-1615-8

Burgess, S., & Cimera, R. E. (2014). Employment outcomes of transition-aged adults with autism spectrum disorders: A state of the states report. *American journal on intellectual and developmental disabilities, 119*, 64–83. https://doi.org/10.1352/1944-7558-119.1.64

Chen, J. L., Leader, G., Sung, C., et al. (2015). Trends in employment for individuals with autism spectrum disorder: A review of the research literature. *Review Journal of Autism and Developmental Disorders, 2*, 115–127. https://doi.org/10.1007/s40489-014-0041-6

Cimera, R. E., Burgess, S., & Wiley, A. (2013). Does providing transition services early enable students with ASD to achieve better vocational outcomes as adults? *Research and Practice for Individuals with Severe Disabilities, 38*, 88–93. https://doi.org/10.2511/027494813807714474

Clarke, E. B., McCauley, J. B., & Lord, C. (2021). Post–high school daily living skills in autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 60*, 978–985. https://doi.org/10.1016/j.jaac.2020.11.008

Clees, T. J., & Gast, D. L. (1994). Social safety skills instruction for individuals with disabilities: A sequential model. *Education and Treatment of Children*, 163–184. https://www.jstor.org/stable/42899351

Dixon, M. R. (2014). The next generation of ABA providers. *Behavior Analysis in Practice, 7*, 145–146. https://doi.org/10.1007/s40617-014-0009-0

Ferraioli, S. J., & Harris, S. L. (2011). Effective educational inclusion of students on the autism spectrum. *Journal of Contemporary Psychotherapy, 41*, 19–28. https://doi.org/10.1007/s10879-010-9156-y

Fong, C. J., Taylor, J., Berdyyeva, A., McClelland, A. M., Murphy, K. M., & Westbrook, J. D. (2021). Interventions for improving employment outcomes for persons with autism spectrum disorders: A systematic review update. *Campbell Systematic Reviews, 17*, 1185–1208. https://doi.org/10.1002/cl2.1185

Fordyce-Voorham, S. (2009). Essential food skills required in a skill-based healthy eating program. *Journal of the Home Economics Institute of Autralia, 16*, 16–20.

Friman, P., Wilson, K. G., & Hayes, S. C. (1998). Behavior analysis of private events is possible, progressive, and nondualistic: A response to lamal. *Journal of Applied Behavior Analysis, 31*, 707. https://doi.org/10.1901/jaba.1998.31-137

Gerhardt, P. F., Zawacki, J., & Satriale, G. (2013). Adaptive behavior in adolescents and adults with autism spectrum disorders. In Gerhardt, P. F. & Crimmins, D. (Eds.) Social Skill and Adaptive Behavior Intervention with Learners with Autism. pp. 159–170. Baltimore.

Gerhardt, P. F., & Rodriguez, A. (2018, May 25). *Adulthood begins in preschool: Identification and intervention with skills that support competent adulthood (Full Day Workshop).* Association for Behavior Analysis International.

Goehner, A. L. (2011). A generation of autism, coming of age. New York Times, 4–13.

Gunning, C., Holloway, J., Fee, B., Breathnach, Ó., Bergin, C. M., Greene, I., & Bheoláin, R. N. (2019). A systematic review of generalization and maintenance outcomes of social skills intervention for preschool children with autism spectrum disorder. *Review Journal of Autism and Developmental Disorders,* ***6***, 1–28. https://doi.org/10.1007/s40489-019-00162-1

Hedley, D., Uljarević, M., & Hedley, D. F. (2017). Employment and living with autism: Personal, social and economic impact. In S. Halder & L. C. Assaf (Eds.), *Inclusion, disability and culture: An ethnographic perspective traversing abilities and challenges* (pp. 295–311). Springer.

Hendricks, D. (2010). Employment and adults with autism spectrum disorders: Challenges and strategies for success. *Journal of Vocational Rehabilitation, 32*, 125–134. https://doi.org/10.3233/JVR-2010-0502

Hernandez, C., & Kulkarni, S. S. (2018). Social skills and students with moderate to severe disabilities: Can community based instruction help? *Journal of the American Academy of Special Education Professionals, 6*, 22.

Heward, W. L. (2009). *Exceptional children: An introduction to special education* (9th ed.). Merrill/Prentice Hall.

Hollins, N., & Peterson, S. (2021). The role of behavior analysts in providing equitable services for clients in public schools. In *A scientific framework for compassion and social justice: Lessons in applied behavior analysis* (p. 16). Routledge

Individuals with Disabilities Education Act (IDEA). (2004). 20 U.S.C. § 1400

Iwata, B. A., & Dozier, C. L. (2008). Clinical application of functional analysis methodology. *Behavior Analysis in Practice, 1*, 3–9. https://doi.org/10.1007/BF03391714

Jessel, J., Hanley, G. P., & Ghaemmaghami, M. (2016). Interview-informed synthesized contingency analyses: Thirty replications and reanalysis. *Journal of Applied Behavior Analysis, 49*, 576–595. https://doi.org/10.1002/jaba.316

Kauffman, J. M., Anastasiou, D., & Maag, J. W. (2016). Special education at the crossroad: An identity crisis and the need for a scientific reconstruction. *Exceptionality*. https://doi.org/10.1080/09362835.2016.1238380

Kaufman, J. M. (1993). How we might achieve the radical reform of special education. *Exceptional Children, 60*, 6–16. https://doi.org/10.1177/001440299306000102

Lai, M. C., Anagnostou, E., Wiznitzer, M., Allison, C., & Baron-Cohen, S. (2020). Evidence-based support for autistic people across the lifespan: Maximising potential, minimising barriers, and optimising the person–environment fit. *The Lancet Neurology, 19*, 434–451. https://doi.org/10.1016/S1474-4422(20)30034-X

Leaf, J. B., Leaf, R., McEachin, J., Taubman, M., Ala'i-Rosales, S., Ross, R., Smith, T., & Weiss, M. J. (2016). Applied behavior analysis is a science and, therefore, progressive. *Journal of Autism and Developmental Disorders, 46*, 720–731. https://doi.org/10.1007/s10803-015-2591-6

Leaf, J. B., Cihon, J. H., Leaf, R., McEachin, J., & Taubman, M. (2017). A progressive approach to discrete trial teaching: Some current guidelines. *International Electronic Journal of Elementary Education*, *9*, 361–372. https://www.iejee.com/index.php/IEJEE/article/view/163

Max, C., & Lambright, N. (2021) Board certified behavior analysts and school fidelity of applied behavior analysis services: Qualitative findings. *International Journal of Developmental Disabilities*. Published Online: 24 May 2021. https://doi.org/10.1080/20473869.2021.1926854

Mazefsky, C. A., Williams, D. L., & Minshew, N. J. (2008). Variability in adaptive behavior in autism: Evidence for the importance of family history. *Journal of Abnormal Child Psychology, 36*, 591–599. https://doi.org/10.1007/s10802-007-9202-8

Mazzotti, V. L., Rowe, D. A., Kwiatek, S., et al. (2021). Secondary transition predictors of postschool success: An update to the research base. *Career Development and Transition for Exceptional Individuals, 44*, 47–64. https://doi.org/10.1177/2165143420959793

McCollin, M. J., & Obiakor, F. E. (2010). Transition: Why it does not work. In F. E. Obiakor, J. P. Bakkem, & F. Rotatori (Eds.), *Current issues and trends in special education: Research, technology, and teacher preparation* (pp. 163–174). Emerald Group Publishing Limited. https://doi.org/10.1108/S0270-4013(2010)0000020013

McDonnell, J., Hardman, M. L., Hightower, J., Keifer-O'Donnell, R., & Drew, C. (1993). Impact of community-based instruction on the development of adaptive behavior of secondary-level students with mental retardation. *American Journal on Mental Retardation, 97*, 575–584.

McGowan, L., Caraher, M., Raats, M., Lavelle, F., Hollywood, L., McDowel, D., Spence, M., McCloat, A., Mooney, E., & Dean, M. (2017). Domestic cooking and food skills: A review. *Critical Reviews in Food Science and Nutrition, 57*, 2412–2431. https://doi.org/10.1080/10408398.2015.1072495

McMahon, M. X. H., Feldberg, Z. R., & Ardoin, S. P. (2021). Behavior analysis goes to school: Teacher acceptability of behavior-analytic language in behavioral consultation. *Behavior Analysis in Practice, 14*, 131–140. https://doi.org/10.1007/s40617-020-00508-w

Meyer, A. T., Powell, P. S., Butera, N., Klinger, M. R., & Klinger, L. G. (2018). Brief report: Developmental trajectories of adaptive behavior in children and adolescents with ASD. *Journal of Autism and Developmental Disorders, 48*, 2870–2878. https://doi.org/10.1007/s10803-018-3538-5

Nadig, A., Flanagan, T., White, K., & Bhatnagar, S. (2018). Results of an an RCT on a transition support program for adults with ASD: Effectis on self-determination and quality of life. *Autism Research, 11*, 1712–1728. https://doi.org/10.1002/aur

Ninci, J., Neely, L. C., Hong, E. R. et al. (2015) Meta-analysis of Single-Case Research on Teaching Functional Living Skills to Individuals with ASD. *Review Journal of Autism and Developmental Disorders, 2, 184–198* https://doi.org/10.1007/s40489-014-0046-1

Perkins, E. A., & Berkman, K. A., (2012). Into the Unknown: Aging with Autism Spectrum Disorders. *American Journal of Intellectual and Developmental Disabilities. 117, 478–496.* https://doi.org/10.1352/1944-7558-117.6.478

Pfeiffer, B., Brusilovskly, E., Davidson, A., & Persch, A. (2018). Impact of person-environment fit on job satisfaction for working adults with autism spectrum disorders. *Journal of Vocational Rehabilitation, 48*, 49–57. https://doi.org/10.3233/JVR-170915

Reichow, B. (2012). Overview of Meta-analyses on early intensive behavioral intervention for young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*, 512–520. https://doi.org/10.1007/s10803-011-1218-9

Roux A. M., Shattuck P. T., Cooper B. P., et al. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 52, 931–939.* https://doi.org/10.1016/j.jaac.2013.05.019. PMID: 23972695; PMCID: PMC3753691.

Roux, A. M., Shattuck, P., Rast, J. E., Rava, J. A., & Anderson, K. A. (2015). *National autism indicators report: Transition into young adulthood*. Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University1028-1037.

Ruddel, C. (n.d.). *Transition begins in preschool*. Work Ability Utah Medicaid Infrastructure Grant Presentation. Accessed on line on 1/2/22 at: https://slideplayer.com/slide/7749973/

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012a). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics, 129, 1042–1049.* https://doi.org/10.1542/peds.2011-2864

Shattuck, P. T., Roux, A. M., Hudson, L. E., Taylor, J. L., Maenner, M. J., & Tran, J. (2012b). Services for adults with autism spectrum disorders. *Canadian Journal of Psychiatry, 57*, 284–291.

Shattuck, P. T., Lau, L., Anderson, K. A., & Kuo, A. A. (2018). A national research agenda for the transition of youth with autism. *Pediatrics, 141*(Supplement 4), S355–S361. https://doi.org/10.1542/peds.2016-4300M

Shattuck, P. T., Rast, J. E., Roux, A. M., Anderson, K. A., Benevides, T., Garfield, T., McGhee Hassrick, E., & Kuo, A. (2020a). *National autism indicators report:*

High school students on the autism spectrum. Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University.

Shattuck, P. T., Garfield, T., Roux, A. M., et al. (2020b). Services for adults with autism spectrum disorder: A systems perspective. *Current Psychiatry Reports, 22*, 13.

Shriver, M. D. (2019). Applied behavior analysis in education: The role of the board certified behavior analyst. In S. G. Little & A. Akin-Little (Eds.), *Behavioral interventions in schools: Evidence-based positive strategies* (pp. 133–142). American Psychological Association. https://doi.org/10.1037/0000126-008

Snell-Rood, C., Ruble, L., Kleinert, H., McGrew, J. H., Adams, M., Rodgers, A., Odom, J., Wong, W. H., & Yu, Y. (2020). Stakeholder perspectives on transition planning, implementation, and outcomes for students with autism spectrum disorder. *Autism: The International Journal of Research and Practice*, *24*(5), 1164–1176. https://doi.org/https://doi.org/10.1177/1362361319894827

Solomon, C. (2020). Autism and employment: Implications for employers and adults with ASD. *Journal of Autism and Developmental Disorders, 50*, 4209–4217. https://doi.org/10.1007/s10803-020-04537-w

Spooner, F., McKissick, B. R., & Reyes, E. (2020). Life skills and community-based instruction. In *Handbook of adolescent transition education for youth with disabilities* (pp. 165–179). Routledge.

Steinbrenner, J. R., Hume, K., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., Szendrey, S., McIntyre, N. S., Yücesoy-Özkan, S., & Savage, M. N. (2020). *Evidence-based practices for children, youth, and young adults with Autism*. The University of North Carolina at Chapel Hill, Frank Porter Graham Child Development Institute, National Clearinghouse on Autism Evidence and Practice Review Team. Accessed online at: https://ncaep.fpg.unc.edu/sites/ncaep.fpg.unc.edu/files/imce/documents/EBP%20Report%202020.pdf

Stewart, D., Law, M., Young, N. L., Forhan, M., Healy, H., Burke-Gaffney, J., & Freeman, M. (2014). Complexities during transitions to adulthood for youth with disabilities: Person–environment interactions. *Disability and Rehabilitation, 36*, 1998–2004. https://doi.org/10.3109/09638288.2014.885994

Taber, T. A., Alberto, P. A., Seltzer, A., & Hughes, M. (2003). Obtaining assistance when lost in the community using cell phones. *Research and Practice for Persons with Severe Disabilities, 28*, 105–116.

Taylor, J. L., & Seltzer, M. M. (2010). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders, 41*, 566–574.

VanDerwall, R., & Poling, A. (2021). Six Useful Websites for Practitioners Working in Schools. *Behavior Analysis in Practice, 14, 264–271.* https://doi.org/10.1007/s40617-020-00505-z

Walker, A. R., Uphold, N. M., Richter, S., & Test, D. W. (2010). Review of the literature on community-based instruction across grade levels. *Education and Training in Autism and Developmental Disabilities*, *45*, 242–267. http://www.jstor.org/stable/23879810

Walsh, C., Jones, B. & Schonwald, A. (2017). Health Care Transition Planning Among Adolescents with Autism Spectrum Disorder. *Journal of Autism Developmental Disorders 47, 980–991.* https://doi.org/10.1007/s10803-016-3020-1

Warr, P. B., & Clapperton, G. (2010). *The joy of work? Jobs, happiness, and you*. Routledge, Taylor & Franics Group.

Wertalik, J. L., Kubina, R. M. (2017). Interventions to Improve Personal Care Skills for Individuals with Autism: A Review of the Literature. *Review Journal of Autism and Developmental Disorders, 4, 50–60 (2017).* https://doi.org/10.1007/s40489-016-0097-6

Wise, E. A., Smith, M. D., & Rabins, P. V. (2020). Correlates of daily functioning in older adults with autism spectrum disorder. *Aging & Mental Health, 24*, 1754–1762. https://doi.org/10.1080/13607863.2019.1647138

Wisner-Carlson, R., Uram, S., & Fils, T. (2020). The transition to adulthood for young people with autism spectrum disorder. *Child and Adolescent Psychiatric Clinics, 28*, 345–358. https://doi.org/10.1016/j.chc.2019.12.002

Zane, T. (2005). Fads in special education: An overview. In R. M. Foxx & J. M. Mulick (Eds.), *Controversial therapies for developmental disabilities* (pp. 197–214). Routledge.

8

Healthcare Transitions for Individuals with Autism

Laura Pickler and Paul Dressler

Introduction

Transition from pediatric to adult care for adolescents and young adults with autism is a multifaceted process that has many components all aimed at maximizing independence and self-advocacy in the areas of health and wellness. People with autism have unique needs and considerations that can make the process challenging, rewarding, and sometimes simply different from other youth. Examples are modifications in office procedures, physical examination approach, enhanced communication strategies, and at times a focus on families or caregivers that is not generally needed with other transitioning youth. Clinicians and other healthcare professionals involved in this part of a young person's life can feel confident that they are making a significant difference in quality of life and well-being for their patients when they acknowledge the differences of this patient population. This chapter will attempt to delineate these differences as well as provide examples and suggestions for how to improve interrelated systems that impact the successfulness of the process within the context of the individual and the communities where they reside.

All youth need a carefully planned transition to adulthood, but this is especially important for youth with autism spectrum disorder as they may be challenged with communication and social relatedness that can make self-advocacy more challenging compared to the general population. In addition, the diversity of abilities noted in people with autism also complicates recommendations for this patient population. When looking at the literature supporting transition best practices for people with autism, it is helpful to remember that autism is a childhood onset developmental disability with a wide spectrum of social, communication, and behavior challenges (https://www.cdc.gov/ncbddd/autism/facts.html). The presence of intellectual disability may or may not exist, further complicating the interpretation of the literature when applying best practices to an individual patient. Additionally, a wide range of genetic conditions are associated with autism or autistic features (https://www.omim.org). A common example is Down syndrome, but there are literally hundreds, if not thousands, of genetic conditions that cause autistic features.

Despite increased interest and need for transition support, according to the 2018–2019 National Survey of Children's Health, only 18% of young adults received services needed for transition, and youth with developmental disabilities were even less likely to receive transition

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planning, which may lead to disparities in healthcare (Cheak-Zamora et al., 2013). Several studies in the literature document this disparity with one study showing that only 34% of women with disabilities received cervical cancer screening and 42% received breast cancer screening (Cobigo et al., 2013). In another study, only 34% of adults with disabilities reported being routinely screened for colorectal cancers (Deroche et al., 2017). The lack of needed screenings could be considered reflective of discomfort among healthcare providers, the absence of medical homes for adults in general, and a failure in the transition process (Hermans & Evenhuis, 2014). At a most basic level, it is a failure of the US healthcare system to provide needed preventative services for vulnerable citizens.

Individuals with autism are at risk for other healthcare disparities that impact health and wellness in addition to a lack of access to primary care services. Adolescents with autism are more likely than age-matched peers to be treated with multiple medications, including psychotropic agents, although they are less likely to have a psychiatrist managing their psychopharmacologic medications (Wee et al., 2013). One study looked at data from the National Survey of Children with Special Health Care Needs and found that 60% of transition-age youth with autism spectrum disorder had two or more diagnosed health or mental health conditions in addition to their autism spectrum disorder (Roux et al., 2015). Another study reported only 24% of adults with developmental disabilities taking psychotropic medications had received psychiatric consultation (Lewis, 2002). These gaps in healthcare quality are concerning and can impact the quality of life for many young adults.

Table 8.1 Tenants of a medical home

Tenants of a medical home
Accessible
Family centered
Continuous
Comprehensive
Coordinated
Compassionate
Culturally effective

Since the 1960s, the idea of a medical home for all patients has been endorsed first by the American Academy of Pediatrics and subsequently recognized by all the major physician specialty associations and the US public health system as the standard of care. Tenants of a medical home are summarized in Table 8.1 (www.aap.org). The medical home model has been shown to be useful in the transition process (Cooley & Sagerman, 2011). It is important to recognize that a medical home is not a specific location, or any one medical clinician, but a system of care that encompasses needed services, coordination of care, and partnerships with patients (and families, as appropriate). Very recently, the American College of Physicians convened a broad group of stakeholders with the purpose of understanding the complexities of transitions of care and making recommendations for how principles of high-value shared care between primary care and specialists can be better implemented across the U.S health system.

The medical community as a whole acknowledges that healthcare is not ideal for many patients, in particular for patients with complex or chronic conditions. The idea of a Quadruple Aim to improve the healthcare system in four broad dimensions is worth mentioning here. The four principles of the Quadruple Aim include enhancing patient experience, improving population health, reducing costs, and protecting the clinician workforce (Bodenheimer & Sinsky, 2014). Individuals with autism can benefit from this increased visibility of gaps in the healthcare system and advocate strongly for improvements in how care is provided by engaging with their providers and their local public health system.

Service Systems that Support People with Autism

Most people, including people with autism, typically need a medical system of care and often do not rely on just one person or clinic to help manage their health needs. It is productive to think about healthcare systems as a team of people with the patient and, if appropriate, their family at the center of the team. Needed services such as primary care, medical specialists, dental care, and mental health services all are accessed in a coordinated way so that optimal health is maintained. If a person is at their physical best, then the other ways they prefer to spend their time are more easily accessible, such as pursuing work, education, recreation, independence, and relationships. There are many barriers to achieving coordinated systems of care in the USA that include knowing what is needed, accessing the needed services, and having a way to pay for it all. This can be quite overwhelming, especially for young adults with autism who have to navigate the health system on their own for the first time. In addition, communities across the country are inconsistent in what is available leading to gaps in care and disparities that are compounded by social determinants of health.

Nationally, steps have been taken in recent years to address the needs and status of people with developmental disabilities across the lifespan. State Title V Programs, Medicaid, the Affordable Care Act (ACA), Social Security/Supplemental Security Income (SSI), Medicare, and civil rights laws like the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA) are critical for people with developmental disabilities, providing benefits, supports, and civil rights protections for their health and well-being (www.thearc.org). However, service systems are largely siloed, uncoordinated, and can be difficult to access. Most systems are not set up to provide direct services but instead serve as gateways to needed services and supports. We describe here some key systems that aid transition to adult life for people with autism including intellectual and developmental disabilities (IDD).

Children and youth with developmental disabilities, which include autism, are covered from birth under the broad authority of the Social Security Act of 1935. Title V of the Social Security Act provides funding to state maternal and child health (MCH) programs, which serve 44 million women and children in the USA (www.amchp.org). In 1989, the Maternal and Child Health Bureau (MCHB) outlined the need to develop population-based systems of care for children and youth with special healthcare needs (CYSHCN) that are family centered, community based, coordinated, and culturally competent. The Medical Home tenants may be recognized in the core language of this guidance. Today, in order to receive federal funds, each state must submit an annual standardized application to the MCHB for the Title V Maternal and Child Health Block Grant Program. Through a comprehensive process that identifies all potential MCH priorities, states and territories conduct surveys and analyze data to determine where they can have the most impact and need the most resources to address local MCH problems and challenges. A formula is used to determine funding allocations based on population size and need (www.amchp.org/AboutTitleV/Documents/Celebrating-the-Legacy.pdf). Virtually all states use these grants to fund programs that provide care coordination for CYSHCN and in some cases provide diagnostic medical services and treatments. This includes making sure youth have access to programs by providing transportation, translation, and other services. Activities that support transition to adult life have become increasingly important priorities for many states.

In 2016, 15 national performance measures (NPMs) were selected to guide a major transformation process in the Title V Program, including one on transition: *Increase the percentage of adolescents with and without special healthcare needs who receive services necessary to make transitions to adult care.* A total of 32 state Title V agencies subsequently selected transition as an NPM for their Five-Year Action Plan. Those plans included a variety of evidence-informed transition strategies and interventions, such as the Six Core Elements of healthcare transition (Got Transition), consumer and healthcare professional education, and interagency transition planning (McManus & Beck, 2017). The National Survey of Children's Health (NSCH), sponsored by the MCHB and redesigned for initial data release in 2017, currently measures annually national and state transition performance among youth with and without special healthcare needs aged 12 through 17 years. Detailed information about NPM performance is available through the Child and Adolescent Health Measurement Initiative (https://www.childhealthdata.org/browse/survey/results?q=7777&r=1).

Another significant piece of legislation is Section 504 of the Rehabilitation Act of 1973, which complements provisions in the Social Security Act (www.dol.gov/oasam/regs/statutes/sec504.htm). These acts and their revisions dictate SSI benefits which many people with IDD receive. Whereas child eligibility is based on a functional assessment, and impairment in two or more life areas is required to qualify, adult eligibility is based on the ability to work. Many young adults with IDD will remain eligible under the adult rules, but some may not and people with autism likely need help navigating this transition. As such, reapplication for SSI benefits at the age of 18 years is a critical transition process for this population.

Schools also play a pivotal role in shaping transition to adulthood for young adults with autism. The IDEA of 2004 states that a primary objective of special education is to "further education, employment, and independent living" (www.law.cornell.edu/uscode/text/20/1400). The law requires schools to provide an Individualized Education Program (IEP) to each student with a disability and mandates transition activities. By 16 years old, the IEP must contain a statement of needed transition services along with a coordinated set of activities that promotes movement from school to post-school life, including post-secondary education, vocational training, adult services, independent living, and/or community participation. Each year, the IEP team must develop, confirm, or update these goals and services (Antosh et al., 2013). For students with chronic medical conditions, Individualized Health Plans (IHPs) help address items such as daily medication, nutritional needs, and instructions for medical emergencies during the school day.

The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), authorized in 1963 and last reauthorized in 2000, provides a number of programs to support individuals with IDD, such as State Councils on Developmental Disabilities and University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDDs) (National Council on Disability, 2011). The Administration on Developmental Disabilities (ADD) is the federal agency responsible for the implementation and administration of the DD Act.

Most recently, growth in the Medicaid program has shifted the system of supports for people with IDD from one that is funded predominantly by state funds to one that is funded predominantly by Medicaid—with joint federal and state funding (Wood et al., 2016). Home and Community-Based Services (HCBS) Waivers are Medicaid programs that provide services in the home for persons who would otherwise require institutional care in a hospital or nursing facility. Without waiver services being delivered in the community, some young adults with autism might not be able to live at home or receive needed supports in the workplace. Waivers provide specific services over and above those in the general Medicaid adult benefits package and are targeted to persons who demonstrate the need for a high level of care. Services typically include items such as personal care assistance, companion services, transportation, therapy, behavioral support, skilled nursing, durable medical equipment, and supported employment services. A care coordinator is assigned to the Medicaid waiver enrollee to assist with access to community services. There is significant variation across states in Medicaid waiver eligibility, and enrollment is typically capped; that is, once enrollment reaches a specified number or dollar threshold, waiting lists are created (Smith et al., 2000).

Other Important Aspects from the Literature to Consider

Broadly speaking, the current literature around healthcare transition has centered around three major themes: (1) current status of transition including barriers and successes, (2) perspectives from different stakeholders around the transition process, and (3) pilot programs seeking to improve transition in clinics or other settings.

Barriers are well documented with some support for interventions that can help people with autism have more successful transitions to adult life.

All transition-age youth require access to appropriate healthcare, and individuals with autism are no exception. While there is an increased need for successful transition, adolescents and adults who have autism spectrum disorder are unlikely to receive transition planning (Cheak-Zamora et al., 2013; McManus et al., 2013; Roux et al., 2015), with one study finding that less than 10% of youth with autism spectrum disorder met the national transition core outcome (Walsh et al., 2017). In particular, individuals who were Hispanic and non-Hispanic Black youth and had family income <400% of the federal poverty level were even less likely to receive transition planning (Cheak-Zamora et al., 2021; Walsh et al., 2017), indicating further disparities within this population. The results of poor transition planning have been assessed by looking at where young adults with autism spectrum disorder are receiving their care. One national study looking at youth aged 16–23 years who have autism spectrum disorder found that as patients aged, they were utilizing outpatient services at a lower rate, while the use of emergency department services remained steady (Nathenson & Zablotsky, 2017). This study also noted that individuals in the Northeast portion of the USA were less likely to see a decline in outpatient utilization than in the South or Midwest (Nathenson & Zablotsky, 2017).

There have been a number of studies looking at perspectives of different stakeholders on the transition process. Many of these studies have helped identify barriers to transition. From the provider perspective, barriers to transition have included the amount of time required for adult providers to manage complex patients in clinic (Dressler et al., 2018; Okumura et al., 2010; Peter et al., 2009), the lack of reimbursement for the increased time spent (Okumura et al., 2010; Peter et al., 2009; Scal et al., 1999), poor knowledge and lack of training about developmental disabilities in adult providers (Bruder et al., 2012; Okumura et al., 2010; Peter et al., 2009; Pickler et al., 2010; Scal et al., 1999), the amount of care coordination beyond just medical concerns (Dressler et al., 2018; Okumura et al., 2010; Scal et al., 1999), lack of adult providers who will accept patients with IDD (Dressler et al., 2018; Okumura et al., 2010; Pickler et al., 2010; Scal et al., 1999), difficulty finding an adult provider who takes the patient's insurance (Dressler et al., 2018, Pickler et al., 2010), and lack of provider knowledge on the transition process (Dressler et al., 2018). From the patient and caregiver perspectives, barriers to transition included poorly coordinated transfer of care (Okumura et al., 2010; Peter et al., 2009; Shanahan et al., 2020), difficulty finding an adult provider who sees adults with developmental disabilities (Kuhlthau et al., 2016; Shanahan et al., 2020), and families and patients not wanting to leave the pediatric setting (Pickler et al., 2010).

There have been a few studies looking at programs to improve the medical transition for youth who have autism spectrum disorder. The second author of this chapter piloted a transition clinic that used a consultative model for youth with an intellectual and/or developmental disability, which included youth with an autism spectrum disorder (Dressler et al., 2018). After the visit, a summary of recommendations and resources was provided to the primary care provider. While youth and families gave positive feedback about the clinic, primary care providers largely did not follow through on the recommendations or resources and cited barriers noted above that prevented them from engaging in the transition process (Dressler et al., 2018). More recently, a group of providers piloted a program based on the Extension for Community Healthcare Outcomes (ECHO) model to improve transition. In this model, primary care providers participated in teleconference sessions with an interdisciplinary team of experts. These sessions were weekly for 1 h over the course of 3 months. The sessions consisted of didactics about transition and opportunities for the primary care providers to present cases. This resulted in improved self-efficacy of primary care providers caring for transition-age youth with autism spectrum disorder (Mazurek et al., 2020). Challenges noted by providers were difficulty engaging in sessions during clinic hours and needing more region/state-specific resources and supports (Cheak-Zamora et al., 2021). To aid in addressing the healthcare gap of adequate numbers of adult primary care providers, a pilot study implemented a targeted curriculum to family practice nurse practitioner students that focused on caring for adults with an autism spectrum disorder. This included didactics, online modules, and experiential care. Results showed improved knowledge and self-efficacy in caring for this patient population among graduates (Dietz & Armstrong-Brine, 2015; Iannuzzi et al., 2019), indicating a possible model for increasing numbers of providers entering the workforce who are ready to care for individuals with autism.

Framework to Guide Medical Transition Initiatives and Intervention

Given the complexity of transition for adolescents and adults with autism, there has been demand for a framework to guide transition at the healthcare system and clinical practice levels. The National Center for Healthcare Transition, Got Transition, is a federally funded program with a number of goals aimed at improving the transition to adult healthcare experience for all youth and young adults. The American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians recently collaborated to produce a clinical report to provide guidance to physicians on key elements of transition based on Got Transition's work (White et al., 2018).

The goals of Got Transition are to

- Coordinate with other federally funded medical homes and financing centers to achieve quality care, decrease costs, and improve patient experience (these key points can be recognized as the triple aim).
- Engage youth, young adults, and families on the importance of a planned transition from pediatric to adult care.
- Strengthen evidence and policy analysis.
- Increase practice/system adaptation of evidence-informed practices for transition to adult healthcare.
- Enhance engagement of key stakeholder organizations in healthcare transition clinical, educational, and policy improvement.
- Update and expand Got Transition's website capability and communication strategies.

Got Transition has put considerable time and effort into establishing Six Core Elements to guide practice improvement for transition. The Six Core Elements of healthcare transition are the backbone of any organized transition effort. They define basic components of a structured transition process and provide customizable sample quality improvement and measurement tools at no cost for each core element. There are three distinct packages to provide specific guidance depending on whether a patient is being served in a pediatric practice, family medicine/med-peds practice, or adult-focused practice. See Table 8.2 for a list of the Six Core Elements. Next, we will provide a case study exemplifying how the Six Core Elements can be used to benefit someone with autism.

Case Example for How Got Transition Resources Are Used

CG is your patient who has multiple stable medical issues that include autism, congenital heart disease, intellectual disability, obstructive sleep apnea, and constipation. She is well cared for by a loving family and is active in her school and the community. Your office has a good working relationship with the family and has helped them with accommodations to maximize CG's health

Table 8.2 Six Core Elements of healthcare transition

Six Core Elements of healthcare transition
Policy—no surprises for the patient or family
Tracking and monitoring—who is ready and where are they in the process?
Readiness assessment—use to help identify opportunities for increased independence
Planning—plan for success
Transfer of care—to a new provider or an adult model of care with the same provider
Transfer completion—close the loop and evaluate satisfaction

and wellness throughout childhood. While you have not had lengthy discussions about growing into adulthood with CG's parents, they have expressed hope for CG to have choices about how she lives her adult life and desire maximum independence. With this goal in mind, you want to help the family prepare for adulthood. Your office has initiated a transition protocol modeled after best practice recommendations from Got Transition, the National Center for Healthcare Transition.

Age 12

At CG's 12-year-old physical appointment, you discuss your office transition policy with the patient and her parents. You emphasize that transition is a process expected to take several years. At this visit, you ask the family to think about their goals for CG into adulthood and begin to engage CG in discussions about growing up in a developmentally appropriate way. A sample transition policy can be found at https://www.gottransition.org/providers/leaving-1.cfm. Your office staff enters CG into your tracking and monitoring system at this visit. A sample registry entry can be viewed at https://www.gottransition.org/providers/leaving-2.cfm.

Age 14

CG and her parents come in to discuss forms needed to be completed by the school nurse at 14 years old. You take the opportunity to initiate transition planning at this visit. You follow guidelines for general adolescent health maintenance guidelines. You encourage the family to explore Person-Centered Planning resources and review your expected timeline for transition. CG and her parents complete a baseline transition readiness assessment at this visit. A sample readiness assessment can be found at https://www.gottransition.org/providers/leaving-3.cfm. Additionally, you flag CG's chart to have your office nurse review specialists currently helping manage CG's care and send a message in the electronic medical record notifying them of the need to initiate transition planning and requesting ongoing communication as they develop their transition plan for CG.

Age 16

Utilizing the transition registry your office uses, your staff flags CG's chart as needing a follow-up visit to prepare for an adult model of care and to discuss transfer to adult specialists. At this visit, you have CG and her parents complete an updated transition readiness assessment and discuss gaps identified with this tool. Additionally, you formalize a transition readiness plan of care, medical summary, and emergency care plan (sample transition-related forms can be found at https://www.gottransition.org/providers/leaving-4.cfm). You encourage the family to make follow-up appointments with all of CG's specialists in order to update their condition-specific transition care plans. You also request that they integrate your medical transition plan of care into CG's educational transition plan and Person-Centered Plan that was developed previously. A major point of discussion at this visit involves helping the family plan for supportive decision-making. They have time to explore options at this point, but you emphasize that at 18 years old, the medical community will expect some documentation of supported decision-making to be provided.

Age 18

CG's parents request a visit with you after she turns 18 to review their documentation for supported decision-making, privacy, assent/consent, self-advocacy, and access to information. You transition to an adult model of care at this visit and make sure to include CG into the discussion. You are sure to document any preferences CG has regarding the plan for adult care/independence, especially with regard to how medical appointments are handled. Specifically, CG wishes to always have a parent present during all portions of the appointment and does not want time on her own with you unless requested. At this visit, you document the transition plans for each of CG's specialists into the chart so that your staff will be aware of when to expect transfers to take place. The optimal timing for transfers of care for all of CG's clinicians is also discussed and documented. CG and her family complete an updated transition readiness summary, and goals to increase independence are reviewed. CG's educational transition plan is also documented in her medical record. Office staff provide resources for the family that include information on keeping insurance into adulthood and self-care management. You update the plan of care, medical summary, and emergency care plan at this visit.

Age 21

Shortly after CG's 21st birthday, the family informs you that CG will be moving to another state in order to participate in secondary education. This will necessitate transfer to an adult primary care practice as well as adult specialists. The family understands that each specialist will conduct their own transfer-of-care process and that the timing of these transfers is independent from your practice. You request that the family come in for a transfer-of-care visit. You update the plan of care, medical summary, and emergency care plan with their input. The family has identified an adult practice to which they want to transfer. You review the transfer-of-care checklist and write a transfer-of-care letter (samples can be found at https://www.gottransition.org/providers/leaving-5.cfm). Copies of the transfer package documents are provided to the family at this visit and will be faxed to the receiving clinician's office (transfer package documents include final transition readiness assessment, plan of care including goals and pending actions, medical summary, emergency care plan, legal decision-making documents, additional important documents you have identified (i.e., health maintenance records, lab and radiology test results, immunization records). You make note of when the appointment with the adult practice is to occur and have your staff fax the entire package in advance. Two days before the patient's first visit with the new practice, you call to be sure the transfer package was received and highlight any pending actions that need to be addressed in a timely fashion. You suggest that the new clinician have the patient complete an updated transition readiness assessment at their first visit to help identify self-management areas that still could be improved. The new adult clinician accesses the readiness assessment and implements their office's new patient processes (scheduling, communication, electronic medical record portal access). They also ensure that they have your office's back line so that any questions can be quickly and efficiently answered. The new adult practice ensures that one or two additional follow-up appointments are scheduled in order to be sure the patient is fully integrated into the practice and that ongoing management of active problems is planned.

Age 22 and Forward

Three to 6 months after the transfer occurs, you have your staff call the family to confirm transfer of responsibility to the adult practice and solicit their feedback on the process of integration into the new adult medical home/specialist clinician practice. Survey examples can be found at https://www.gottransition.org/providers/leaving-6.cfm. You also fax a letter to the new adult clinicians thanking them for accepting your patient, confirming completion of transfer, and offering any consultative help if needed.

Your practice has a continuous quality improvement mindset around transition, and so you periodically evaluate your progress in fully integrating the Six Core Elements of healthcare transition into your practice. Your goal is that all patients receive the same high-quality transition experience. You utilize a tool for this activity. Samples can be found at https://www.gottransition.org/providers/leaving-measure.cfm.

The authors of the Six Core Elements fully recognize that this process takes time as exemplified in this case. The ideal age to begin transition efforts varies between patients; however, the recommended start time is at 12 years of age with a goal of completion soon after the patient's 21st birthday. It is never too late to begin the transition process. While healthcare providers and their teams may perform the bulk of transition work, young adults and their families also should have a high level of engagement in the process to ensure success. See Fig. 8.1 for a timeline illustrating the transition process.

There is evidence measuring the Six Core Elements that shows positive outcomes with their use (Gabriel et al., 2017; Schmidt et al., 2020). Patients were shown to have better self-reported

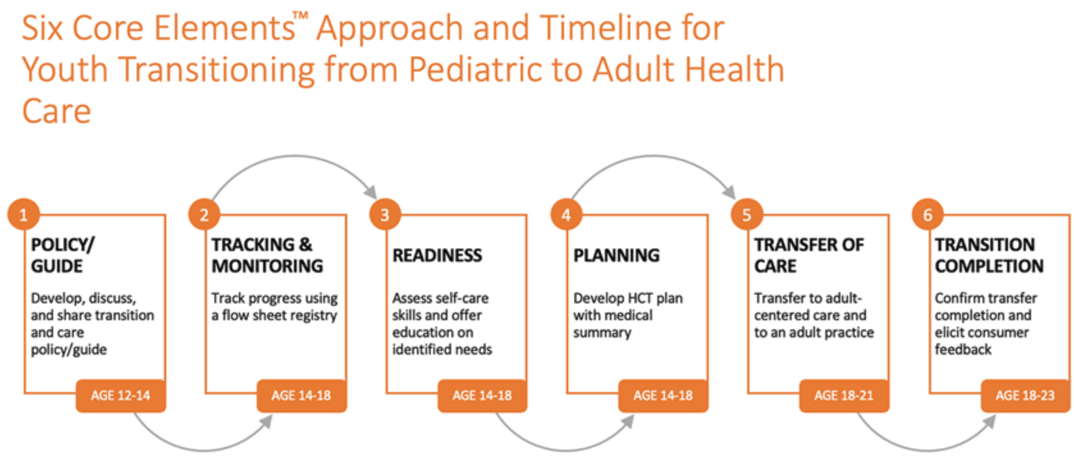

Fig. 8.1 Six Core Elements approach

health, adherence of care, improved disease-specific measures, and improved quality of life. The patient experience was also improved with better satisfaction and a reduction in barriers to care. A decrease in hospital admissions and emergency department visits has also been shown. The reader is highly encouraged to explore practice tailored resources available free of cost online (https://www.gottransition.org/six-core-elements).

Subspecialist Perspective

The second author of this chapter is a developmental-behavioral pediatrician who sees patients in a consultative model. In this clinic, some patients are seen regularly for psychotropic medication management, others are on an annual or biannual basis, and some are only seen one time. Thus, the transition needs in this clinic model vary significantly between patients, and the process will often differ from the primary care example provided above.

For patients who are seen regularly for psychotropic medication management, we start transition preparation early by looking at transition readiness. This includes developing transition plans for interacting with healthcare providers and the healthcare system. The Got Transition Readiness Assessment has been helpful in finding gaps of readiness to address. In addition, there are a number of helpful tools available that are intended to assist people with autism specifically. These are summarized in Table 8.3.

Finding adult partners to accept patients transitioning from pediatric care is a challenge. Since there is no developmental-behavioral specialty for adults, there is no equivalent provider on the adult side for natural partnership in the transition process. Available adult providers are often physicians in adult psychiatry, primary care (e.g., family medicine, med-peds, or internal medicine), or adult neurology. Other barriers are the limited number of providers who accept Medicaid insurance, have an interest in this patient population, and are accepting new patients. When a new provider is identified, we send a transition packet that includes a cover letter summarizing the patient's care, their involvement in clinic, psychotropic medication history in a digestible format, clinic notes, and direct contact information for the pediatric clinician.

Another challenge in the transition process has been family weariness during the process of transferring care. We try to support families by discussing the process early so that no one is caught off guard. Additionally, we aid in the transition process and follow up with families after their initial visit with the adult provider to ensure it is a good fit. The authors of this chapter acknowledge that much of this process is reliant

Table 8.3 Tools specifically available to support individuals with ASD (https://www.gottransition.org/resources-and-research/special-populations.cfm)

Tools specifically available to support individuals with ASD
Autistic Self Advocacy Network (ASAN) found at: https://autisticadvocacy.org/
Transition to Adulthood: A Health Care Guide for Youth and Families by the Autistic Self Advocacy Network found at: https://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-healthcare-toolkit-final.pdf
Transition Tools for Youth and Young Adults with Intellectual Disabilities or Developmental Disabilities (ID/IDD) by the American College of Physicians Council of Subspecialty Societies found at: https://www.acponline.org/system/files/documents/clinical_information/high_value_care/clinician_resources/pediatric_adult_care_transitions/gim_dd/idd_transitions_tools.pdf
Integrating Young Adults with Autism spectrum Disorder into Your Practice: Tips for Adult Health Care Clinicians found at: https://www.gottransition.org/resource/?tips-integrating-yas-autism-into-practice
Making Health Care Transition Work for Youth with Autism: Youth and Parent Perspectives and Resources in partnership with Family Voices and the National Institute of Mental Health found at: https://www.youtube.com/watch?v=F6YGAcNU_Uo

on patients and their families and includes navigating a complex and confusing system. As noted, not all adult providers have experience in managing patients with special needs, including autism spectrum disorder. This adds to the apprehensiveness for families who are transitioning. Acknowledging that it might be challenging to find an adult provider who has experience in autism, we emphasize that finding a provider who is open to collaboration and willing to learn might be a positive experience. We recommend being open-minded when looking for new providers as there is opportunity for the adult clinician to become an expert in a patient over time, which could end up less frustrating for families than trying to find a perfect fit based on board specialty or advertised experience.

Legal Requirements/Supportive Decision-Making

When someone turns 18 years of age, they are considered an adult by law. At that age, all are considered to have the capacity to make decisions in their lives. If someone is not able to make all decisions independently, then supportive decision-making should be considered. The options for this vary widely from state to state. This includes different levels of support and processes to implement these supports.

When considering the level of support that may or may not be needed, it is important to err on the side of the least restrictive option. When certain options, including conservatorship or power of attorney, are put into place, there is a loss of one's rights to make their own decisions. Thus, autonomy of the individual needs to be weighed heavily when determining what supports are needed. Included in this autonomy is the right to decisions that appear to be poor choices. Poor choices are made by many neurotypical adults of all ages, such as poor choices with money, unhealthy eating, or not following doctors' advice. If there is a consistent pattern of poor choices that leads to significant harm and the individual does not understand the consequences, then shared decision-making might be indicated (The Arc of Tennessee, 2008).

There is a newer option for adults who have a developmental disability called supported decision-making (Allen & Pogach, 2019). In this process, the adult identifies a person or persons whom they trust to help them make decisions. Often, an agreement is signed that outlines that supporter's role and what areas they can offer help. Examples include medical, financial, and/or educational decisions. The role of the supporter is to help go through and interpret information for the individual. They are NOT making decisions for the individual. The end decision is made by the individual (The Arc of Tennessee, 2017). It should be noted that this option is fairly new and not available in all states. For more information about specific state law, please see www.supporteddecisionmaking.org.

Conservatorship is described as a legal relationship between a competent adult and an adult who needs help with decision-making. Only the court can establish this relationship. In this relationship, the competent adult is called the conservator. The conservator has the authority to act on behalf of the individual who needs help with decision-making. In Tennessee, a conservator is appointed by the court and acts as an agent of the court for final decision-making. The court order should be specific on what rights are removed from an individual, including medical, financial, and/or choice on living arrangements (The Arc of Tennessee, 2008). As noted, there are differences in conservatorship between states. This relationship removes rights from an individual, and much conversation and consideration need to occur before pursuing this option.

There are other options that allow for shared or supportive decision-making. These will also vary from state to state. Examples include a representative payee who helps with managing money received from the Social Security Administration or a durable power of attorney assigned to an adult to help make decisions in healthcare. This option assumes that the individual asking for help is considered competent at the time the document is signed (The Arc of Tennessee, 2008). There are likely other options available in each state. It is helpful for professionals and families to become familiar with local advocacy groups who will have state-specific information.

Future Directions

Research Opportunities for System Change

As noted above, there have been a number of studies demonstrating inadequate transition from pediatric to adult healthcare services for individuals who have autism spectrum disorder, perspectives from families and providers on the challenges to transition, and some pilot projects looking to improve this process. These studies provide a nice foundation describing the current state of transition. In looking forward, there are several areas to further assess.

It is very important to have clinic models that include both pediatric and adult healthcare providers in the transition process. Specifically, showing that such a model can be feasible for practices to implement in a typical clinic setting is needed. Some of the concerns from providers have been the amount of time (which might not be reimbursed) needed to partake in the transition process (Okumura et al., 2010; Peter et al., 2009; Scal et al., 1999) and the amount of time it takes to manage patients with special needs in clinic (Dressler et al., 2018; Okumura et al., 2010; Peter et al., 2009). Given these concerns, research that helps clarify which clinic resources are needed can help practices better prepare for the transition process, conduct quality improvement for transition in their offices, as well as alleviate some fears if evidence demonstrates that multidisciplinary visits can be done efficiently.

In addition to demonstrating that the transition process can be done efficiently, it is also important to show that transition is in the best interest of the patient and that reimbursement for the clinician allows for sustainability in the system. In order to advocate for appropriate reimbursement, demonstrating that the process works and decreases healthcare costs in the long term is needed. This should include studies that demonstrate a decrease in high-cost health utilization if transition is successful. Measures may include a decrease in visits to the emergency department, hospitalizations, or procedures, which all might have been prevented with appropriate preventative care.

We described the Extension for Community Healthcare Outcomes (ECHO) model and how it was used to increase the self-efficacy of primary care providers who care for transition-age youth with an autism spectrum disorder (Mazurek et al., 2020). This is a promising model. However, pilots were implemented on a national level for practices scattered throughout the country. Being able to establish more regional ECHO hubs is needed to support primary care providers to manage this patient population. This should include demonstrating the ability to recruit enough providers and practices on a regional level to make this model sustainable.

Telehealth

The pandemic starting in 2019 challenged our healthcare system on many levels; however, concerns about infectious disease transmission spawned innovation for how direct patient care is provided. As can be imagined, relationships between clinicians and patients are best accomplished if both the patient and the clinician are able to see each other's faces. These challenges in combination with community restrictions requiring wearing a mask and social distancing necessitated exploring telehealth modalities as a means for providing medical care for people with autism. In addition, some patients with autism are unable to adequately wear a mask on their face, and the already present anxiety around coming to the hospital can be significantly heightened by this practice. Simultaneously, regulatory restrictions that usually did not allow for home-based telehealth services were lifted, and a whole new intervention was born where patients could be in their homes and receive medical services virtually.

We wondered about the utility and pitfalls of telehealth, and so to better understand our patients' views and experience, we performed surveys before and after the delivery of multidisciplinary telehealth appointments for our first 150 patients (Pickler, 2020, unpublished data). Interestingly, more than half of families had prior experience with telehealth (62%) for themselves or another family member. One-third of patients were hesitant to try telehealth, but because they felt that their concerns were urgent, they made an appointment. When asked if they were concerned about receiving the same quality of care via telehealth, half of the respondents indicated that they were neutral or concerned about this possibility.

One day after the appointment, families were again surveyed by phone about their experience. Responses indicated that 98% of families were delighted with their care and they felt that their needs were fully addressed with a telehealth type of appointment. When asked if they felt that an in-person appointment would have provided any additional insights about their child, the results were more mixed. Telehealth is a relatively new way to access healthcare, and most respondents did not have an in-person appointment for comparison. The benefits of not needing to drive to a hospital location and the financial savings when avoiding travel costs outweighed any hesitation for future participation in a digital appointment type for most families.

Conclusions from this small unpublished study are that families are willing to access care using telehealth. For some families, telehealth is preferred and even provides better service than in-person appointments. In particular, patients with autism who experience anxiety when going to a clinic appointment were better served during video visits. Telehealth eliminates the burden of travel, especially for families who live in rural areas. We do have concerns about health disparities and whether or not the use of technology to provide care increases burdens for families who experience financial stress or lack of access to high-speed Internet. Further research is needed to better understand the benefits and challenges of telehealth and how to eliminate the impact on patients whose families experience health disparities.

Clinical Implications and Conclusions

While there has been significant progress for adolescents and young adults experiencing transition to adult care, there is still work to be done. It is well recognized by governmental entities that young adulthood is a time of high risk, especially for adults experiencing health and educational disparities (CDC.gov). A higher level of educational attainment is associated with access to information that allows for better decision-making and improved overall health (Rasberry et al., 2015). An emerging body of evidence is showing that individuals with autism experience increased morbidity and mortality simply because of their autism diagnosis alone (Hirvikoski et al., 2016), but when combined with other well-recognized social determinants of health such as race, ethnicity, culture, gender identity, socioeconomic status, environmental threats, educational inequalities, and access to basic healthcare services, there is even more cause for concern due to the preventable nature of these problems (Eilenberg et al., 2019). A review by Bishop-Fitzpatrick and Kind (2017) looked at health disparities in people with autism and found only nine studies that met their inclusion criteria for being of high quality and none included health disparities or older adults. The need for increased research in the health disparities that impact adults with autism is highlighted in their work. The authors of this chapter wholeheartedly agree with increased emphasis in this area and add their support for urgency in better understanding the barriers that people with autism face so that appropriate interventions can be implemented for these young adults.

The protective or resiliency factors for adults with autism that make a tangible difference in their health and promote wellness have yet to be fully understood (Coppus, 2013). There are opportunities for both primary care clinicians and specialists to focus on quality improvement, and the materials from Got Transition are helpful resources in this regard (McManus et al., 2015; White et al., 2012). Actual transfers of care to the adult system are fraught with opportunities for failure for all youth, but people with autism seem more limited by a lack of providers who have knowledge and interest in the wide spectrum of patients with autism. As mentioned in the introduction, people with autism present with a wide variety of needs that change over time and with intervention in childhood. The specific health needs for people with autism are therefore difficult to study, and healthcare provision guidelines into adulthood are broad. Patients with more significant needs may find resources in specialty clinics like neurology or psychiatry, but these healthcare providers are a limited resource and distribution across communities is unequal. Integrated medicine is emerging into mainstream medical care with increased awareness for what opportunities exist in this field, but research to document what is helpful as well as what is harmful is lacking. Ultimately, in order for the medical system to change for better provision of care for people with autism, patients and their families will need to be at the center of engagement around this issue. Resources to help equip the lay public for this type of high-level engagement do exist but are not universally available. One such highly recommended example is the Family Leadership Training Institute (http://fltiofcolorado.colostate.edu/). It is only with the combined efforts of young adults, their families, healthcare clinicians, researchers, educators, public health professionals, and legislators that significant change can be made.

References

Allen, Z., & Pogach, D. (2019). More states pass supported decision making agreement laws. *Journal of the American Bar Association Commission on Law and Aging, 41*(1), 159–161.

American Academy of Pediatrics. National Resource Center for Patient/Family Centered Medical Home. https://medicalhomeinfo.aap.org/overview/Pages/Whatisthemedicalhome.aspx. Accessed 1-8-21.

Antosh, A. A., Blair, M., Edwards, K., Goode, T., Hewitt, A., & Izzo, M. (2013). *A collaborative interagency, interdisciplinary approach to transition from adolescents to adulthood*. Association of University Centers on Disabilities.

Association of Maternal and Child Health Programs. https://amchp.org. Accessed 1-8-21.

Bishop-Fitzpatrick, L., & Kind, A. (2017). A scoping review of health disparities in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*(11), 3380–3391. https://doi.org/10.1007/s10803-017-3251-9

Bodenheimer, T., & Sinsky, C. (2014). From triple to quadruple aim: Care of the patient requires care of the provider. *Annals of Family Medicine, 12*(6), 573–576. https://doi.org/10.1370/afm.1713

Bruder, M. B., Kerins, G., Mazzarella, C., Sims, J., & Stein, N. (2012). Brief report: The medical care of adults with autism spectrum disorders: Identifying the needs. *Journal of Autism and Developmental Disorders, 42*(11), 2498–2504.

Celebrating the legacy, shaping the future: 75 years of state and federal partnership to improve maternal and child health. Association of Maternal & Child Health Programs. 2010. www.amchp.org/AboutTitleV/Documents/Celebrating-the-Legacy.pdf. Accessed 1-8-21

Centers for Disease Control and Prevention. What is Autism Spectrum Disorder. https://www.cdc.gov/ncbddd/autism/facts.html. Accessed 1-8-21.

Centers for Disease Control and Prevention. Health Disparities Among Youth. https://www.cdc.gov/healthyyouth/disparities/index.htm. Accessed 2-12-21.

Cheak-Zamora, N. C., Yang, X., Farmer, J. E., & Clark, M. (2013). Disparities in transition planning for youth with autism spectrum disorder. *Pediatrics, 131*(3), 447–454.

Cheak-Zamora, N., Farmer, J. G., Crossman, M. K., Malow, B. A., Mazurek, M. O., Kuhlthau, K., & Hess, A. (2021). Provider perspectives on the extension for community healthcare outcomes autism: Transition to adulthood program. *Journal of Developmental and Behavioral Pediatrics: JDBP, 42*(2), 91–100.

Cobigo, V., Ouellette-Kuntz, H., Balogh, R., Rose, R., & Dababnah, S. (2013). Are cervical and breast cancer screening programmes equitable? The case of women with intellectual and developmental disabilities. *Journal of Intellectual Disability Research, 57*(5), 478–488. https://doi.org/10.1111/jir.12035

Cooley, W. C., & Sagerman, P. J. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics, 128*(1), 182–200.

Coppus, A. (2013). People with intellectual disability: What do we know about adulthood and life expectancy? *Developmental Disabilities Research Reviews, 18*(1), 6–16.

Data Resource Center for Child and Adolescent Health. https://www.childhealthdata.org/browse/survey/results?q=7777&r=1. Accessed 1-8-21.

Deroche, C., McDermott, S., Mann, J., & Hardin, J. (2017). Colorectal cancer screening adherence in selected disabilities over 10 years. *American Journal of Preventive Medicine, 52*(6), 735–741. https://doi.org/10.1016/j.amepre.2017.01.005

Dietz, I., & Armstrong-Brine, M. (2015). *Evaluation of current transition models for youth with develop-*

mental disabilities aging out of pediatric practices. Paper presented at the Society for Developmental & Behavioral Pediatrics, Las Vegas, NV.

Dressler, P. B., Nguyen, T. K., Moody, E. J., Friedman, S. L., & Pickler, L. (2018). Use of transition resources by primary care providers for youth with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 56*(1), 56–68.

Eilenberg, J. S., Paff, M., Harrison, A. J., & Long, K. A. (2019). Disparities based on race, ethnicity, and socioeconomic status over the transition to adulthood among adolescents and young adults on the autism spectrum: A systematic review. *Current Psychiatry Reports, 21*(5), 32.

Family Leadership Training Institute of Colorado. http://fltiofcolorado.colostate.edu/. Accessed 2-12-21.

Gabriel, P., McManus, M., Rogers, K., & White, P. (2017). Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review. *The Journal of Pediatrics, 188*, 263–269.

Hermans, H., & Evenhuis, H. M. (2014). Multimorbidity in older adults with intellectual disabilities. *Research in Developmental Disabilities, 35*(4), 776–783.

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry, 208*(3), 232–238.

Iannuzzi, D., Rissmiller, P., Duty, S. M., Feeney, S., Sullivan, M., & Curtin, C. (2019). Addressing a gap in healthcare access for transition-age youth with autism: A pilot educational intervention for family nurse practitioner students. *Journal of Autism and Developmental Disorders, 49*(4), 1493–1504.

Kuhlthau, K. A., Delahaye, J., Erickson-Warfield, M., Shui, A., Crossman, M., & van der Weerd, E. (2016). Health care transition services for youth with autism spectrum disorders: Perspectives of caregivers. *Pediatrics, 137*(Supplement 2), S158–S166.

Lewis, M. (2002). The quality of health care for adults with developmental disabilities. *Public Health Reports, 117*(2), 174–184. https://doi.org/10.1093/phr/117.2.174

Mazurek, M. O., Stobbe, G., Loftin, R., Malow, B. A., Agrawal, M. M., Tapia, M., & Sohl, K. (2020). ECHO autism transition: Enhancing healthcare for adolescents and young adults with autism spectrum disorder. *Autism, 24*(3), 633–644.

McManus, M., & Beck, D. (2017). *Transition to adult health care and state title V program directions: A review of 2017 block grant applications*. Got Transition, The National Alliance to Advance Adolescent Health. www.gottransition.org/resourceGet.cfm?id=431

McManus, M. A., Pollack, L. R., Cooley, W. C., McAllister, J. W., Lotstein, D., Strickland, B., & Mann, M. Y. (2013). Current status of transition preparation among youth with special needs in the United States. *Pediatrics, 131*(6), 1090–1097.

McManus, M. A., White, P., Barbour, A., Downing, B., Hawkins, K., Quion, N., & McAllister, J. W. (2015). Pediatric to adult transition: A quality improvement model for primary care. *Journal of Adolescent Health, 56*(1), 73–78.

Nathenson, R. A., & Zablotsky, B. (2017). The transition to the adult health care system among youths with autism spectrum disorder. *Psychiatric Services, 68*(7), 735–738.

National Council on Disability. www.ncd.gov/publications/2011/Feb142011#toc1. Accessed 1-8-21.

Okumura, M. J., Kerr, E. A., Cabana, M. D., Davis, M. M., Demonner, S., & Heisler, M. (2010). Physician views on barriers to primary care for young adults with childhood-onset chronic disease. *Pediatrics, 125*(4), e748–e754.

Online Mendelian Inheritance of Man Online Catalog of Human Genes and Genetic Disorders. https://www.omim.org/search?index=entry&sort=score+desc%2C+prefix_sort+desc&start=1&limit=10&search=autism. Accessed 6-15-21

Peter, N. G., Forke, C. M., Ginsburg, K. R., & Schwarz, D. F. (2009). Transition from pediatric to adult care: Internists' perspectives. *Pediatrics, 123*(2), 417–423.

Pickler, L. (2020). *Perspectives of families utilizing telehealth*. Unpublished Data.

Pickler, L., Kellar-Guenther, Y., & Goldson, E. (2010). Barriers to transition to adult care for youth with intellectual disabilities. *International Journal of Child and Adolescent Health, 3*(4), 575–584.

Rasberry, C. N., Tiu, G. F., Kann, L., McManus, T., Michael, S. L., Merlo, C. L., Lee, S. M., Bohm, M. K., Annor, F., & Ethier, K. (2015). Health-related behaviors and academic achievement among high school students – United States. *MMWR. Morbidity and Mortality Weekly Report, 66*, 922–927.

Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A., & Anderson, K. A. (2015). *National Autism Indicators Report: Transition into young adulthood*. Life Course Outcomes Research Program, AJ Drexel Autism Institute, Drexel University.

Scal, P., Evans, T., Blozis, S., Okinow, N., & Blum, R. (1999). Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *Journal of Adolescent Health, 24*(4), 259–264.

Schmidt, A., Ilango, S. M., McManus, M. A., Rogers, K. K., & White, P. H. (2020). Outcomes of pediatric to adult health care transition interventions: An updated systematic review. *Journal of Pediatric Nursing, 51*, 92–107.

Shanahan, P., Ollis, L., Balla, K., Patel, R., & Long, K. (2020). Experiences of transition from children's to adult's healthcare services for young people with a neurodevelopmental condition. *Health & Social Care in the Community, 00*, 1–10.

Smith, G., O'Keefe, J., Carpenter, L., Doty, P., Kennedy, G., & Burwell, B. (2000). *Understanding Medicaid home and community services: A primer*. Department of Health and Human Services.

The Arc. Policy and Advocacy Civil Rights. https://www.thearc.org. Accessed 1-8-21.

The Arc of Tennessee. (2008). *Conservatorship and alternatives to conservatorship* [White Paper]. https://www.disabilityrightstn.org/documents/conservatorship_handbook.pdf

The Arc of Tennessee. (2017). *Supported decision-making: Creating a continuum of choice* [White Paper]. https://www.disabilityrightstn.org/getattachment/Resources/March-2017/Supported-Decision-Making-Creating-Continuum-of-C/SDM-White-Paper-FINAL.pdf

The National Alliance to Advance Adolescent Health. (2014). *Got transition*. http://www.gottransition.org/. Accessed 1-8-21.

U.S. Code 1400 Chapter 33 (d) (1) (A). www.law.cornell.edu/uscode/text/20/1400. Accessed 1-8-21.

United States Department of Labor, U.S. Code 701, Title 29. http://www.dol.gov/oasam/regs/statutes/sec504.htm. Accessed 1-8-21.

Walsh, C., Jones, B., & Schonwald, A. (2017). Health care transition planning among adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*(4), 980–991.

Wee, L., Koh, G., Auyong, L., Cheong, A. L., Myo, T. T., Lin, J., Lim, E. M., Tan, S. X., Sundaramurthy, S., Koh, C. W., Ramakrishnan, P., Aariyapillai-Rajagopal, R., Vaidynathan-Selvamuthu, H., & Khin, M. M. (2013). The medical, functional and social challenges faced by older adults with intellectual disability. *Annals of the Academy of Medicine, Singapore, 42*(7), 338–349.

White, P. H., & Cooley, W. C. (2018). Transitions Clinical Report Authoring Group; American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics, 142*(5), e20182587.

White, P. H., McManus, M. A., McAllister, J. W., & Cooley, W. C. (2012). A primary care quality improvement approach to health care transition. *Pediatric Annals, 41*(5), e91–e97.

Wood, D., Edwards, L. R., & Hennen, B. (2016). Health care transition. In I. L. Rubin, J. Merrick, D. E. Greydanus, & D. R. Patel (Eds.), *Health care for people with intellectual and developmental disabilities across the lifespan* (pp. 219–228). Springer.

Issues in Individuals with ASD in Higher Education Environments

9

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Outcomes of Individuals with ASD

By almost any standard one could choose, the outcomes of adult individuals with autism are poor. While educational entitlement is a legal right for children with autism spectrum disorder (ASD), many individuals fall off a service delivery cliff in adulthood. With a paucity of options available for vocational training and few programs geared for people with ASD at the college level, many individuals fall through the cracks (Gerhardt & Lainer, 2011). When this lack of engagement is coupled with aging parents, finite economic resources, and social isolation, the results are sobering. Many individuals with ASD fail to continue to develop skills in adulthood, often because they are unable to find the settings and supports that match their needs.

The deficits associated with ASD are numerous and have been well documented (e.g., restrictive and repetitive movements, social deficits, and communication impairments; American Psychiatric Association, 2013; Cai & Richdale, 2016; Ravizza et al., 2013). These deficits pose many challenges in childhood but are mitigated by widespread availability of services and by intense and individualized intervention (Howard et al., 2014). The extent to which individuals with ASD are prepared for the challenges of adulthood with that intervention is questionable. Often, individuals with ASD remain dependent on low ratios of student-teacher attention that are not available in vocational settings. Work performance may not be adequate for competitive employment. For those who are capable of higher education learning, the options are limited and the supports are few.

In the National Longitudinal Transition Study-2 (Newman et al., 2011), it was reported that about 60% of youth with disabilities attempt postsecondary education. However, only 32% of those with ASD attended postsecondary education schools. The vast majority of individuals with ASD do not even attempt college. Given that individuals with ASD can be motivated to learn, these statistics are concerning.

Furthermore, 21% of individuals with ASD had no employment or education experiences after high school (Newman et al., 2011). Of these individuals, 80% were living at home with their parents. Additionally, 40% reported having no friends, raising worries about severe social isolation. From a mental health perspective, it seems that many individuals with ASD enter adulthood with few connections, little structure, and much less autonomy than adults with other disabilities.

Unemployment and underemployment are also grave concerns, as more than 50% of individuals with ASD do not have paid work after high school (Eaves & Ho, 2008; Howlin et al.

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2014; Shattuck et al., 2012; Taylor & Seltzer, 2011). Of those who did work, most never achieved anything close to full-time status (Eaves & Ho, 2008; Taylor & Seltzer, 2011). Some may even only be able to obtain work in segregated settings such as sheltered workshops (Carter et al., 2012; Hendricks & Wehman, 2009). In addition to the quality of life and mental health consequences that unemployment and underemployment have on the individuals themselves, there are additional negative financial consequences for the families and for society (Järbrink et al., 2007; Krieger et al., 2012; Taylor & Seltzer, 2012). Whittenburg et al. (2019) analyzed employment outcomes for over 4,000 individuals with autism who were transition age and received some vocational rehabilitation services. Predictably, the authors found that as levels of education increased, so did employment rates and weekly wages. Adults with postsecondary education held the highest employment rate (i.e., 68.9%) and earned the highest weekly wage (i.e., $207.80). In terms of underemployment, none of the groups broken down by educational level reached full-time employment; however, those with postsecondary education worked more hours than any other group (i.e., 19.1 h). Comparatively, those who finished high school worked an average of 14.3 h per week and earned $129.08 per week. Hence, these data are concerning from a societal perspective as well as from a humanitarian perspective.

Much has been done to understand how individuals with ASD might be integrated more successfully into employment contexts (Dreaver et al., 2020). Some characteristics of workers with ASD that have been commonly noted as valuable include attention to detail, task focus, passion, loyalty, and dependability (Dreaver et al., 2020). The match between the individual and the job seems to be of central importance. In addition, external supports have been noted as helping individuals to master socially relevant work skills (e.g., personal care, boundaries with others; Dreaver et al., 2020). In addition, adaptive strategies can assist the worker in successfully navigating the demands of the job. For example, the worker may be given strategies to mitigate sensory elements of the environment and to create daily routines for assigned tasks. Other supports that have been suggested include regular check-ins with supervisors, autism training for supervisors, and access to an expert for circumstances requiring more support and problem-solving (Dreaver et al., 2020). In a similar vein, speculation has been made about how to prepare individuals with ASD for college and how to support them once they are there.

In this chapter, we will review the enrollment characteristics of individuals with ASD who pursue higher education, their needs, the supports that are commonly available, and strategies for success. We will also review some program elements that are unique and some special challenges. We will also discuss best practices and areas for future research and program development.

Enrollment Characteristics of People with ASD in Institutions of Higher Education

Many individuals with autism will seek out higher education following the completion of their high school programs. Continued study in a specialized degree may even be appealing for some individuals with autism (compared with high school), as college study allows for a more singularly focused educational experience that aligns with one of the core diagnostic features of autism: restricted areas of interest (Bakker et al., 2019; Viezel et al., 2020). There have been a number of identified predictors for participation in secondary education within the autism community. Chiang et al. (2012) identified family characteristics (e.g., parental expectations, household income), student characteristics (e.g., attending a general education high school, performing at grade level), and the ability to have in-depth transition planning (e.g., including the goal of higher education during transition planning with the student) as predictive of a successful enrollment in secondary education. Seemingly, parental involvement may play the largest role in promoting or inhibiting college success. This could be in the form of support, help, motivation, or even in the setting of expectations (Accardo, 2017).

In a large-scale study of individuals in the United Kingdom, there were a number of interesting disparities between the higher education enrollment characteristics of individuals with ASD and those without (Karola et al., 2016). The rate of individuals with autism who enrolled in higher education was 9–22%, compared to 45% of those without autism. Students with autism were generally younger than those without, and there was a significantly higher proportion of males to females with autism (i.e., a 4:1 ratio) compared to those without autism (i.e., a 1:1 ratio; Karola et al., 2016). There were also identified patterns related to subject choice for those with autism compared to those without. Students with autism were most likely to study computer science, creative arts and design, historical and philosophical studies, and mass communications and less likely to study medicine and dentistry and allied medicine (Karola et al., 2016). In a much smaller sample of 21 individuals and their families from Michigan, all participants (i.e., parents and individuals with autism) rated that they were confident they would attend postsecondary education (Camarena & Sarigiani, 2009). There was a discrepancy between what the mothers of individuals with autism aspired for and their child's or the father's aspirations. Of the interviewed mothers, 45% reported that a vocational or associate degree was most likely; however, 55% said that a 4-year degree would be the goal. One mother phrased her aspirations for her child as "in my dreams … I have no idea whether or not this is realistic" (Camarena & Sarigiani, 2009, p. 7).

Many individuals with autism seek out postsecondary education for the same reasons as their neurotypical peers. Most importantly, they seek higher education in order to gain access to increased job opportunities or in order to join a specific profession that requires a college education (Camarena & Sarigiani, 2009). However, some individuals have also reported that they hope to seek out new friendships and a more independent lifestyle, either living with friends, a roommate, or on their own (Anderson et al., 2016). One high school student reported feeling that college students were less judgmental and that it would be easier to make friends on a campus setting than it had been in high school. Anderson et al. (2016) also found a perceived notion that friendships formed in a college setting were lifelong in comparison to friendships formed in high school. Additionally, many young adults with autism identify a goal for their college experience to be joining social clubs or organizations (Accardo, 2017; Anderson et al., 2016). Some even view that trying new things is part of what makes a successful college experience (Accardo, 2017).

Despite the increase in enrollment over time by students with autism, these students are also at the highest risk of dropping out and failing to complete their college degree. A 2015 study showed that the retention rate for students with a disability is approximately 53% compared to 64% for students without a disability (Sayman, 2015). Barnard-Brak et al. (2010) found that one reason for this disparity could be due to a lack of understanding on the part of faculty and administration of the diverse needs of students with a disability. Students with autism may also be less likely to seek out services to support their needs or may seek these services too late in their college tenure. This critical behavior is vastly different from what is available and provided in primary and secondary schools, where progress is monitored and requests for assistance are solicited. Unlike special education services in elementary and high school, higher education institutions are not required to seek out, identify, and support students with disabilities in the same way (Barnard-Brak et al., 2010).

Many individuals with ASD now seek college experiences, and many are capable of doing so with appropriate accommodations and individualized, embedded supports (Jansen et al., 2017). Given the stark data on outcomes in terms of independence and employment, increasing success in college is an important strategy to build additional career paths. In order to make the college environment more accessible, a variety of needs must be assessed, and individualized supports must be provided.

Needs of Individuals with ASD in Institutions of Higher Education

The issues for individuals with ASD in higher education settings are numerous and are varied. As the rate of postsecondary enrollment for ASD adults continues to rise (Newman et al., 2011), so does the call to address the needs and challenges these students face when joining the historically unchanging climate of higher academia. In some ways, the needs are different from those with other disabilities. As is often the case in autism, strengths of the learners can obscure deficits. Furthermore, the tendency to avoid communicating can be more prominent among this group of students. This makes it difficult to identify needs early in the semester, and it can make it difficult to create a success plan while the class/semester is still salvageable.

The other issue that makes campus life challenging for individuals with ASD is that the major challenges often lie outside of the classroom. While some of these students present as well qualified and capable of meeting the academic demands, just over half of these students are graduating (Sayman, 2015). Clearly, a variety of factors contribute to this statistic.

Even strong high school students often flounder with the transition to college (Anderson et al., 2018, 2020). While the academic demands may not represent a large cognitive leap, there is also often far less structure and support in the assignment of tasks. In college, professors expect students to read the syllabus, track due dates, and proactively reach out when they need assistance. Beyond academics, the expectations for independent living are also daunting. It is not uncommon for individuals with ASD to struggle the most with campus navigation, time and task management, emotional regulation, and social relationship navigation (Grogan, 2015). There may be a variety of social situations that the student was not expecting or is unable to navigate independently. Students may feel isolated if they do not easily make friends and do not have the comfort of living with people who support them (i.e., parents and siblings).

Arguably, one of the most anticipated aspects of the postsecondary experience for new college students is the freedom and flexibility of their schedule. Many college students relish the ability to organize their extracurricular activities around their course load and vice versa, often making modifications with each new semester. However, for a student with autism, this can mean the difference between maturation and attrition.

Case Example

Joshua is 18 years old and is a high school senior and will be a freshman at a local state college in the fall. He has done well with individualized attention in high school and took honors classes. He is more than capable of college level work. Still, his parents are worried. He has never lived away from home. They plan to get him a private room, since his schedule and behavior might irritate a roommate. His parents are worried about his ability to wake up independently on time, his tendency to procrastinate, and his social isolation. They notified the college counselor of these worries and were assured he will be on their radar, but they are not sure it will be enough.

Coming from the structured and predictable nature of the typical high school setting, the type of time and task management skills required at the collegiate level can be a challenging transition for students. The lack of structure in college settings compared to K–12 settings can be problematic during the transition period and can be noticeably lacking in family involvement. Additionally, K–12 settings have fewer academic stressors and can be less socially isolating than college settings (Cai & Richdale, 2016).

In contrast, this unstructured new reality, coupled with the inflexible style of teaching and learning that is common at many institutions, leads to increased difficulty with task completion and time management (Grogan, 2015). Anderson et al. (2020) surveyed 102 college students with autism in Australia and New Zealand and found that one of the most common self-reported concerns at the postsecondary level was the completion of academic tasks. To illustrate, students report struggling with understanding the syllabus and determining which details are most important, navigating the ambiguity of course assignments, and adjusting to the classical teaching and evaluation methods being implemented (Jansen et al., 2017). Even if the syllabus and assignments are understood, students with autism have indicated having a hard time planning out their studies and being able to gauge how much time should be spent on short- and long-term assignments in each course throughout the semester due to the lack of structure and routine (Fabri et al., 2016).

In addition to the grave challenges associated with time and task management, students with autism may find it more difficult to navigate the college campus itself (Longtin, 2014). Although some postsecondary settings have a new student orientation geared at helping incoming students get their bearings as they enter a new setting, it falls short of meeting the needs of ASD students. For example, many new student orientations can include sensory-heavy activities (e.g., band or cheer performances, returning students cheering on new students), which can be extremely aversive and even intolerable for sensory-sensitive individuals with autism. Additionally, these sensory sensitivities can continue to be a stressor for students throughout their duration of study, making general campus navigation a daring feat (Anderson et al., 2018). All considered, one of the biggest reasons why campus navigation can be an arduous task is because of the absent or inadequate transition planning.

Bakker et al. (2019) evaluated the retention of first-year students with ASD in higher education settings by surveying 96 students with autism, 2252 students with other disabilities, and 25,000 students without autism enrolled at a major university. Results showed that one of the areas of need indicated for students with autism was more robust transition planning. One suggestion made was that ASD students visit the college campus they have chosen to attend a few times prior to the start of classes to gain better familiarity with its layout and locations on campus that might be more sensory friendly. Furthermore, it would be helpful to obtain information for various on-campus services (e.g., health center, disability services) prior to the start of the semester, as well as a decision tree to help determine if and when contact with each service may be needed. Without adequate transitioning, students seem to have a more difficult time adjusting to changes in routine, classes, and location of services around campus (Cai & Richdale, 2016).

Emotional regulation among individuals with autism is also a serious concern, as they have been reported to have higher rates of comorbidity and emotional dysregulation than both neurotypical peers and peers with other disabilities (Bakker et al., 2019; Dijkhuis et al., 2020). Difficulties with emotional regulation are often coupled with heightened stress, fewer social supports, and barriers to the utilization of parental support compared to high school settings (Cai & Richdale, 2016; Dijkhuis et al., 2020). Some common emotional concerns include increased feelings of loneliness and isolation, higher stress levels, mood disorders, and suicidal ideation and attempts (Van Hees et al., 2015).

Case Example

Matt is 20 and is a sophomore at a private, small college. He is doing well academically but has hit some rough spots socially. Last semester, he received poor grades from a teacher and was very angry. He had some heated email exchanges with the professor and then decided to meet her in the parking lot as she headed home. In this interaction, he continued to make his same points and was very repetitive and insistent. The teacher later filed a complaint that she felt threatened, and the student is now being sent to a disciplinary hearing. The family is concerned, as there was already a complaint from a student who felt "stalked" when she refused the romantic interest expressed by Matt. He continued to sit near her in the cafeteria, and she often saw him near her, staring at her on campus. The campus police are concerned for the safety of other students and faculty and have issued *stern warnings to Matt. Matt is becoming increasingly despondent about the issues, especially the police involvement, and has become more withdrawn.*

Jackson et al. (2018) designed a cross-sectional study to better understand their range of postsecondary experiences; fifty-six college students with ASD were surveyed to gather insight regarding their academic, mental health, and social needs and experiences. Mental health experiences of interest included history of mental health diagnoses, past or present suicidal behavior, medication history, and symptoms related to anxiety, depression, or stress. More than half of all participants endorsed having a co-occurring diagnosis and taking at least one prescribed medication (Jackson et al., 2018). The mood diagnoses most commonly disclosed included various types of anxiety disorders (i.e., 60.7%), depression (i.e., 35.7%), bipolar disorder (i.e., 5.4%), and panic disorder (i.e., 1.8%). Jackson et al. (2018) concluded that comfort with academic coursework and feelings of loneliness were the two most statistically significant predictors of emotional distress and comorbidity with these mood disorders (Jackson et al., 2018).

Alarmingly, nearly 75% of participants also reported suicidal behavior (i.e., plan, ideation, attempt) in their lifetime, with more than half of the total sample endorsing suicidal ideation within the past year (Jackson et al., 2018). Statistically significant variables associated with increased suicidal behavior were the number of friends, level of academic comfort, reported loneliness, stress, and anxiety-related and depressive symptoms (Jackson et al., 2018). Similar findings were also reported in a 2020 study by Anderson and colleagues assessing the needs and characteristics of university students with autism in Australia. In their survey of 102 students, Anderson et al. (2020) found that students on the autism spectrum presented with significantly higher rates of suicidal ideation and self-harm than their neurotypical peers. Furthermore, Anderson and colleagues indicated that emotionally distressed students were likely not aware of available supports, did not feel available supports met their needs, and demonstrated poor advocacy skills that could potentially help them access novel ones (Anderson et al., 2020).

Case Example

Deandra is a 21-year-old college student who is exceptionally alone. She has tried to join a variety of clubs and activities, but none have resulted in meaningful connections. While she has some "friends" who say hello to her and greet her, she is never invited to meals or to parties. Over time, she has tried less and become more isolated. She now does lots of ordering food in, joining classes synchronously from her room, and letting assignments slide. Her roommates rarely see her, and she is failing a couple of classes.

Some mediators for emotional dysregulation are social support and feelings of connectedness. However, for individuals with autism, a diagnosis characterized by deficits in social communication and interaction, this can present a unique and grueling challenge. While social support and a sense of belonging have been identified as protective factors for college retention and emotional regulation among ASD students (Karola et al., 2016), they report having a difficult time forming and maintaining the social connections necessary for these relationships (Braxton & McClendon, 2001; Dijkhuis et al., 2020). For instance, students must contend with the expectations of a new social landscape and set of social rules, as they are expected to be able to communicate effectively with peers and superiors without support. They are essentially required to learn how to navigate multiple social circles simultaneously; they struggle with picking up on the social cues of their classmates and teachers, connecting with classmates, participating in course discussions, and even knowing when and how to ask questions in class – a problem some refer to as limited interpersonal competence (Dijkhuis et al., 2020; Fabri et al., 2016; Van Hees et al., 2015). Van Hees et al. (2015) corroborated these findings in a study of 23 adults with autism currently enrolled in college. Based on information gathered from participants, results showed that 75% of students felt socially disconnected from their peers on campus, resulting in feelings of loneliness and isolation.

While each of these needs presents its own challenges to students, it is important to keep in mind that many individuals with autism in post-secondary settings are struggling to maneuver these needs simultaneously. Moreover, the needs and outcomes of each often affect the others. For instance, individuals with fewer social supports and emotional regulation skills are more likely to present with poorer time and task management skills. Conversely, poorer academic performance as a result of poor management skills can also exacerbate socioemotional needs. If students are not well equipped or informed enough to seek out the campus support they need, then there is a chance they will soon become a part of the ever-growing attrition statistics.

Commonly Available Supports and Services

The reality of college-based accommodations is that they are starkly different than the educational supports individuals with autism experience in primary and secondary school. Students are no longer protected under the Individuals with Disabilities Education Act (IDEA, 2004), and as such, institutions of higher education are not required to ensure that students have the accommodations needed to be successful. This change in support level can often leave students feeling that they are not receiving all of the support they need. However, there are a number of colleges that have specific programs designed to support students with autism (Viezel et al., 2020), and all colleges that accept students with autism who receive federal financial aid must provide reasonable accommodations and support (Scheef et al., 2019). Thus, more supports are available than one might realize, and it is important to express and advocate for the accommodations that the student requires (Welkowitz & Baker, 2005).

Academic accommodations are commonly available for individuals with disabilities and can include extended deadlines, extra time on exams, provision of lecture notes, separate testing locations, tutors, detailed syllabi with concrete language, and curriculum/coursework modifications. In some cases, a scribe may accompany the learner to take notes. The goal of an academic accommodation is to allow the student to complete the assignment in a manner in which they are most comfortable (Gelbar et al., 2014). A successful accommodation should be paired to the student's skill deficit. For example, Jansen et al. (2017) found that extended deadlines were most frequently used to combat difficulty with flexibility and were used to address global information processing deficits. For students who may take longer with all elements of coursework, such extensions can be very helpful. Jansen et al. also found that the most common accommodation was extended time for tests, and this was described by the students interviewed to be their most highly valued and needed accommodation. This pool of students also indicated that taking exams in a separate location or in a smaller group helped to reduce their stress levels and allowed for more cohesive planning and organizing for exams (Jansen et al., 2017). Academic supports are commonly given and are rated as useful by students with ASD, although more work is needed to specifically identify the most effective strategies and components (Anderson et al., 2019).

Social support services are also provided at the collegiate level. The most frequently reported social supports include supervised social activities, social skills groups, and housing accommodations (Accardo et al., 2019). Supervised social activities can help to bridge the gap and allow students with autism to meet other students with autism as well as forge connections with their peers. One of the sensitive issues in this context is disclosure. Accessing these services necessitates disclosure. This is a highly sensitive and individualized issue. Some individuals may wish to disclose this, and others may feel uncomfortable about it. It is important to note that the individual with ASD must have agency around this decision.

At times, social experiences are also combined with skills training, especially for complex chains of behavior that are necessary on the campus. Supervised social activities could include lunchtime socials, off-campus dinners, taking public transportation into a city, or attending a concert. Social skills groups are also commonly available and can either be therapeutic or non-therapeutic (Barnhill, 2016).

Case Example

Deandra could benefit immensely from a support opportunity like this. She could meet other students who have similar interests, and she would be able to forge meaningful connections through repeated encounters with them at the activities. There would also be a safe place for her to connect with others without leaving her in a vulnerable situation.

One of the biggest transitions for any student is living away from home in a campus setting. Some universities offer a college campus transition program, which allows for students to move into their dorms or university housing anywhere from 3 days to 6 weeks earlier than the rest of the student body. In some programs, this may be done as a summer program a year before entering college as well. For students who arrive early for this special pre-orientation, additional time on campus is spent attending presentations and workshops in order to get oriented to campus life (Accardo et al., 2019; Barnhill, 2016). In a 2019 survey of 23 students with autism who attended a mid-size university, the on-campus transition program was the most preferred support service following academic coaching (Accardo et al., 2019).

In addition to the physical location change of living on campus instead of at home, the expectations of independent living can be overwhelming for students. In a survey of 30 colleges, 80% offered instruction in life skills including laundry, budgeting, and hygiene (Barnhill, 2016). Some institutions of higher education make this a focus during summer intensive orientation programs. In addition to getting to know the campus and attending seminars, there are often lessons in laundry and time management, as these are aspects of independent living that may need more focus (Barnhill, 2016). Even simple tasks such as waking for class might be a new transition for a student who has been woken each morning for high school by their parents.

Counseling services are commonly available to students whose struggles intensify and exceed the social interventions available through residence life initiatives (Francis & Horn, 2017). When individual counseling is needed, it is important to facilitate engagement with the counseling center staff. Both individual and group counseling can help identify areas of need and can assist in developing a plan to address the most pressing concerns. Furthermore, individual counseling allows for the ongoing assessment of the most worrisome symptoms, such as suicidal ideation, lack of initiative, and isolation from the college community.

Case Example

Deandra is in need of assessment and treatment from the counseling center and will likely require continued care to assess and address the intensity of her depression. Weekly goals regarding engagement might help her reverse the course of her current path, and support may help her access other resources.

Matt also could benefit from the counseling center, as he learns to inhibit some of the behaviors that others are finding frightening. Evidence-based strategies could be used to identify appropriate and inappropriate responses and interactions, and the therapist could rehearse more appropriate responses to stressful situations.

Supports Needed but Not Commonly Available

Accardo et al. (2019) interviewed students with autism about what supports they felt they needed that were not provided or were not initially provided to them. One of the common themes was the general idea of not knowing what was available or what students would benefit from. One student interviewed suggested that during the start of the semester, students be provided with an initial consultation with a service center coordinator to explore what accommodations or supports would be beneficial. This ties into the idea that students would benefit from a more personalized approach to their postsecondary education (Accardo et al., 2019). Some students may also be unsure how to identify with their disability without someone coaching them, which can lead to the student being unaware of how to advocate for themselves.

Neurotypical students may also dread the details of registration and course planning. In most colleges, this is associated with anxiety, and there is often a perception of urgent competition for available courses. One must be "ready," having organized options and being able to speedily navigate course registration sites at the time of registration. For individuals with ASD, a common complaint was the ability to plan better at the time of course registration (Accardo et al., 2019). Students indicated that having access to the professors' office hours would influence their decisions about what courses to take based on how it would fit into their academic schedule (Accardo et al., 2019). Students with disabilities are often encouraged to attend office hours to discuss any difficulties they are having with the course or reach out for any extra help that may be available to them. Better outcomes (e.g., better grades, higher retention rates) have been demonstrated to have a correlational relationship with increased communication with faculty (Austin & Peña, 2017). Willey (2000) suggested that students plan realistically when completing their course registration and cautioned against planning back-to-back classes that were not in the same building and not scheduling courses that were outside of the student's typical schedule (e.g., early mornings, late nights). It may be helpful for students to mark drop dates of courses, so as to avoid a negative impact on their grade point average.

During classes, many different issues may impact the student. Some of these are highly idiosyncratic, and some are more universal. In any case, the student must be aware of their own personal vulnerabilities and of the strategies that work best for them. Some requests might be able to be prophylactically made, to avoid negative outcomes. After the semester begins, if sudden changes in routine are upsetting, it may be helpful to ask the professor for advance warning for any changes in the schedule or assignment requirements (Willey, 2000). It may also be helpful to learn where and how the professor will post changes to expectations so that the student can know where to go to get the most up-to-date information about the course.

It is not uncommon for those new to college to seek a community. For an individual with special needs, access to such a community is even more essential. Supports that assist across learners with special needs include physical spaces that provide solace and structure. In an interview of 12 postsecondary students enrolled in a university program, one of the most common themes was a safe location space to meet during the day (Scheef et al., 2019). This is a support that may not be readily available at all universities. Students appreciated having a designated space to complete assignments where the distractions and environmental stimuli were minimal. Alternatively, students also found it helpful to have a designated space to meet with others and play board games or just have a useful social outlet (Scheef et al., 2019).

Strategies for Success

As the enrollment of college students with autism continues to grow, college faculty must continue to adapt and learn how to most effectively teach all students. Feeling supported by faculty members has been identified as a key component for student success, and transversely, students suffer when they feel they cannot seek out help or that a faculty have a reluctance to work with them (Herbert et al., 2014). Naturally, students will also experience an array of responsiveness from various faculty members who have their own history of working with students with disabilities (Herbert et al., 2014).

One framework for supportive faculty-student interactions is a pedagogical approach to responsive teaching, which includes structured scaffolding, differentiated instruction, comprehensive accommodations, and collaborative institutional support (Austin & Peña, 2017). Structured scaffolding has been demonstrated to be effective in helping students with autism. This approach involves taking larger assignments and breaking them down into smaller components with clearly outlined expectations (Austin & Peña, 2017). This method of instruction is credited for enhancing learner outcomes by increasing engagement with course material.

Differentiated instruction involves approaching content material through different methods and approaches such as lectures, discussions, small group projects, and interactive activities. This pedagogical approach allows for a multidimensional learning experience and enhances different learning styles. A responsive approach to differentiated instruction is one in which the professor acknowledges that it is their responsibility to teach the content, but there are many different ways in which this can be approached (Austin & Peña, 2017). This approach could also allow for students to self-select a modality of instruction that would benefit their studies. If the student was aware of their own learning style, they could request an accommodation through their professor for one modality over another.

The use of comprehensive accommodations should focus on the strengths of each individual student and the ways in which they are most capable of succeeding. This approach to education can be seen as "leveling the playing field" in order to give everyone access to an equal education (Austin & Peña, 2017). This does not mean compromising the rigor of the assignment, but rather it allows the student the support to complete the assignment in a way that is meaningful for them. For example, some students might have difficulty writing as a means to demonstrate their mastery of material. They may be permitted to present an uploaded audio file explaining the material. Similarly, a student may have difficulty in a class presentation, especially if comorbid anxiety is an additional diagnosis. Such students might be permitted to pre-record their class presentation and play it for the class.

The final pedagogical approach to responsive teaching is collaborative institutional support. A successful faculty member is often provided support themselves, either from the college's disabilities office or other available avenues that support learners with disabilities (Austin & Peña, 2017). In this way, the instructor can be assisted to identify and implement supports and accommodations that improve the learner's engagement and performance in the class.

While these should be recognized as a good foundational framework, faculty need to make sure that their behavior reflects confidence, understanding, and flexibility in working with students who have a learning or developmental disability. Cawthon & Cole (2010) surveyed 110 students and found only 32% of students indicated that they had interacted with their professors about their learning disability. Most concerningly, students reported a number of obstacles that they encountered when attempting to obtain accommodations or support services, and at the top of the list were professors who were unwilling to accommodate them or were hard to schedule time with (Cawthon & Cole, 2010).

Hsiao et al. (2019) developed a yearlong, five-module faculty development program that helps to create proficiency with working with students with disabilities. Module 1 focused on background information about legislation and support as well as accommodations and how to make environments physically welcoming. This module also highlighted departmental and campus-wide resources that are available for faculty members to access. Module 2 encompassed implications of laws and regulations, the roles and responsibilities of faculty members, students and disability support services, and the components of a reasonable accommodation. This module was led by the director of disability support services, which made this an individualized approach to each institution of higher education. Module 3 was a student panel that focused on characteristics of diverse learners and accommodation strategies. One of the highlighted features

Table 9.1 University support services and accommodations

Type of service	Universities offering the service or accommodation
Support program/comprehensive care team	University of Alabama; Arkansas State University; University of Arkansas; California State University, East Bay; University of Connecticut; Nova Southeastern University; University of Florida; University of North Florida; University of West Florida; Emory University; University of Idaho; Eastern Illinois University; Harper College; Ancilla College; University of Indianapolis; Loras College; Western Kentucky University; Nicholls State University; Towson University; Merrimack College; Eastern Michigan University; Michigan State University; Mississippi State University; University of Missouri – St. Louis; University of Montana; Fairleigh Dickinson University; Ramapo College; Rutgers University; Adelphi University; Daemen College; Iona College; Manhattanville College; New York University; Purchase College; Rochester Institute of Technology; Defiance College; Kent State University; Muskingum University; Ohio University; The Ohio State University; Stark State College; Wright State University; Xavier University; University of Science and Arts; University of Tulsa; Willamette University; Carnegie Mellon University; Drexel University; Eastern University; Edinboro University; Indiana University of Pennsylvania; Kutztown University; Mercyhurst University; Slippery Rock University; St. Joseph's University; West Chester University; York College; Clemson University; Dakota State University; Austin Peay State University; University of Tennessee at Chattanooga; Texas Tech University; University of Houston-Clear Lake; George Mason University; Virginia Tech; Bellevue College; Seattle Central College; Marshall University; Marquette University; St. Norbert College
Peer mentoring	Golden West College; University of Delaware; Nova Southeastern University; University of Florida; Emory University; Harper College; Western Kentucky University; Nicholls State University; Towson University; Merrimack College; Eastern Michigan University; Michigan State University; Mississippi State University; University of Missouri – St. Louis; University of Montana; Ramapo College; Rutgers University; Manhattanville College; Purchase College; Kent State University; The Ohio State University; Drexel University; Edinboro University; Indiana University of Pennsylvania; Kutztown University; Mercyhurst University; Marshall University; St. Norbert College
Organized activities/group programs	Golden West College; Nova Southeastern University; University of Florida; Emory University; Harper College; Ancilla College; University of Indianapolis; Western Kentucky University; Nicholls State University; Towson University; Merrimack College; Eastern Michigan University; Michigan State University; Mississippi State University; University of Missouri – St. Louis; Ramapo College; Rutgers University; Manhattanville College; Purchase College; Rochester Institute of Technology; The Ohio State University; Edinboro University; Mercyhurst University; West Chester University; Marshall University; St. Norbert College
Social skills groups/social skills training	Golden West College; Nova Southeastern University; University of Florida; University of North Florida; University of West Florida; Emory University; Ancilla College; University of Indianapolis; Towson University; Merrimack College; Eastern Michigan University; Michigan State University; Rutgers University; Purchase College; The Ohio State University; Drexel University; Indiana University of Pennsylvania; Mercyhurst University; Marshall University
Career readiness programs/career planning	University of Delaware; University of Florida; University of North Florida; University of West Florida; Emory University; Harper College; Ancilla College; University of Indianapolis; Towson University; Merrimack College; Michigan State University; Mississippi State University; University of Missouri – St. Louis; Ramapo College; Rutgers University; Purchase College; Carnegie Mellon University; Drexel University; Mercyhurst University; West Chester University; St. Norbert College
Life skills programs	Nova Southeastern University; University of Florida; University of North Florida; University of West Florida; Emory University; Ancilla College; Towson University; Eastern Michigan University; Rutgers University; Indiana University of Pennsylvania; West Chester University; Marshall University
Parent support programs	Harper College; Eastern Michigan University; Ramapo College

of this module is the suggestions provided by the student panel for how faculty members can create an inclusive classroom. Module 4 switched to an accessible online learning focus with a month-long online course delivered through the university's learning management system. This module worked through how to create accessible online content for students with disabilities and highlighted resources available to faculty through the learning management system. Finally, Module 5 focused on celebrations, reflections, and moving forward in a focus group-based discussion.

Peer Mentors

Peer mentors in postsecondary education help to support individuals with developmental disabilities across many different domains including learning, working, and socializing. The peer mentoring process is when a mentor guides a mentee through a new role in a new setting by providing modeling, support, and guidance. A peer mentor should help support an individual to complete a task as independently as possible, meeting them at the level of assistance they require (Fisher et al., 2020. Peer mentoring programs also help students to increase their social skills and can make community participation more successful (Gibbons et al., 2018; Harrison et al., 2019). Additionally, these programs are a good model for other community members and may lead to decreased stigmatization and discrimination against people with disabilities (Athamanah et al., 2020; Izzo & Shuman, 2013).

One pedagogical approach for peer mentorship programs is to use a service-learning model. A service-learning approach integrates community service with academic instruction and focuses on personal and professional growth, development of a multicultural experience, and awareness of a multitude of social issues (Gibbons et al., 2018). Some peer mentorship programs offer college students course credit for completing a class on disabilities while mentoring individuals with developmental disabilities. Throughout the course of the semester, students would provide weekly contact with their mentees and could provide both academic and social support based on the need and level of support desired (Izzo & Shuman, 2013). This model has been demonstrated to be most effective when the academic course matches the population with whom the mentor works. Through the hands-on experience of peer mentoring, mentors have been able to engage in self-exploration, which in turn leads to professional and personal growth (Gibbons et al., 2018).

Specific Program Characteristics

There are currently 73 institutions of higher education (i.e., 2-year, 4-year, and secondary support programs) that offer individualized and group support services for individuals on the autism spectrum. Some of the programs are associated with a per semester fee, while others are at no cost to the individual (College Autism Spectrum, n.d.). Table 9.1 shows a summary of the types of services and supports that are provided at each of the 73 institutions of higher education referenced above.

Bridge Programs

A significant mediator for academic success among students with autism in postsecondary settings is proper transition planning (Shattuck et al., 2012; Van Hees et al., 2015). In an effort to close this gap, colleges and universities nationwide have begun to implement bridge programs specifically for students with autism. To illustrate, LeTourneau University (2020) in Texas provides students with a specialized new student orientation, weekly individual and group coaching, ongoing peer mentorship, liaison services to increase access to campus support services, and assistance with understanding campus culture. While this program does prioritize the support and matriculation of its students, it is important to note that participation requires students to pay an additional fee per semester and disclose their autism diagnosis – two factors that could present as barriers to entry for prospective students.

The Bridge to Independence program at Nicholls State University is the first of its kind to be certified in Louisiana by the US Department of Education. The focus of Nicholls' program is to provide support to currently enrolled students with ASD and intellectual disabilities, including having designated peer mentors and academic coaches for students to assist with coursework completion, campus navigation, and social support. Other services include modifications and accommodations to course and diploma requirements, optional social skills seminars, ongoing student check-ins, and liaison support between students and other campus resources as needed (Nicholls State University, 2019).

Pathways, another college bridge program based at Illinois' Aurora University, is unique in its comprehensiveness, as it offers bridge programs to current high school students, newly enrolled college students, and recent graduate students with autism (AU Magazine, 2020). These programs, each unique in their own right, are merely a snapshot of the numerous transition and support programs available to students nationwide. While the services and emphasis of each program differ from the next, they continue to grow in number and breadth. To date, there are 72 college-based bridge and support programs for students with autism across 32 states, in addition to countless college preparation programs offered by non-academic organizations (Brown, 2021).

Transitioning into Higher Education

Individuals with ASD face many challenges as they transition to adulthood. In almost all aspects of life (e.g., independent living, employment, higher education), outcomes are worrisome and can be improved. In many ways, the supports for adults with ASD are elusive. Some programs provide enhanced support, and these are associated with better outcomes.

The solutions, of course, need to be incorporated much earlier into the education of individuals with ASD. Now that more individuals with autism are attending college, the middle and high school years need to be used to focus more on the requisite skills (Gerhardt & Lainer, 2011). Programming to enhance life skills, time management, financial planning, long-term management skills, problem-solving skills, independent travel, and managing a schedule of competing demands independently should all be focused on in middle and high school education. The development of these skills in the high school years can ease the transition to college and program for success in college environments. Many of these skills are not needed in high school, when parents are proximal and independence is limited. Once in college, however, many skills will need to be available that were not necessary in younger years. This extension of transitional planning to include the possibility of higher education experiences should be incorporated as early as possible, as these skills will require years of shaping and development.

In a model of supports aligned for college-bound individuals with ASD, Chickering and Reisser (1969) created three vectors of support that describe how to best create a successful college-bound student. The first behavioral domain is to achieve competency in intellectual skills and expand interpersonal skills (e.g., working cooperatively to reach a goal). The second level is to manage emotions, which emphasizes how to express oneself appropriately no matter the situation. This domain includes self-control and should highlight the need to learn safe behavior, advocacy skills, and an understanding of sexual education. The final vector is moving through autonomy toward independence and should be focused on developing freedom and trusting their own abilities (Chickering & Reisser, 1969).

As with many other challenges associated with ASD, the solutions require coordinated planning, collaboration between instructions and families, and individualized goals (Chiang et al., 2012; Hendricks & Wehman, 2009). Once in college, the need for supports must be assessed so that individuals can be helped to succeed. A broad assessment of skills, including those associated with the navigation of the physical and social environments, is crucial. Ongoing check-ins can identify problems early in development so that proper support can be provided.

Disclosure (to Share or Not to Share)

Research has shown that an individual is less likely to request accommodations when they encounter a faculty member who has a misconception about support needs (Austin & Peña, 2017). In turn, these individuals are less likely to disclose to the faculty member that they have a disability and may need an accommodation (Black et al., 2015; Herbert et al., 2014; Noble & Childers, 2008; Park et al., 2012). This can be a barrier to success for students as they are unable to access the support they need. Additionally, some students may feel that disclosing they have a disability and accessing accommodations is an advantage over their peers. This can fuel the ongoing stigma of having a disability and being treated differently. In order to be viewed as the "same" as their peers, some students may be even more unlikely to disclose their disability to their professors (Squires et al., 2018). Many students have disclosed that they are "anxious for a new beginning" (Herbert et al., 2014, p. 24) and as a result do not choose to use disability services that are available to them.

Other students may feel the desire to challenge themselves and view college as an opportunity to grow and overcome their disability. Some students have reported that turning down accommodations that were provided to them (i.e., note taking and extended time on tests) would force them to advance their skills in these areas (Squires et al., 2018; Van Hees et al., 2015). Without having these services to support them, some learners indicate that they create better, more consistent study habits and are forced to learn better time management skills. Some students indicate that they were proud of themselves for working at the same pace or completing the same assignments as everyone else (Squires et al., 2018; Van Hees et al., 2015). This is certainly a theme throughout the journey of post-secondary education that students want to enhance their independence (Squires et al., 2018).

Family Impact on Success

When families stay involved and support a student through the transition and their continued collegiate life, the outcomes are more successful, and a student with ASD is more likely to be able to complete their degree (Van Hees et al., 2015). One of the key roles that a family member can play in the transition to higher education is to assess how the student adapts and handles different stressful situations or changes to their day-to-day routine (Dallas et al., 2015). While allowing the student to try to handle an issue independently, the family member can help create problem-solving ideas or suggestions to ease the burden of a difficult situation the next time one arises. This model allows the student to have independence while being a safety net of support in case the need arises.

A general theme for research conducted with families who have a student in higher education is to be a level of support that allows the student to be successful, while challenging them to be their own self-advocate and live as independent of a life as wanted (Dallas et al., 2015). Some of the supports that parents felt they could provide to their children could be viewed as more of a "behind-the-scenes" role and could involve tasks such as managing money, paying bills, and managing appointments (Morrison et al., 2009).

Another important factor to consider is the bidirectionality of the relationship between child and parent and what this means to each member of the relationship. For a neurotypical child that is transitioning to college, the relationship between parent and child changes. Some children will report that there is an increase in more "open" communication, feeling "equal" to their parents, and acquiring more independence (Van Hees et al., 2018). This can create complex emotions on the part of parents and children who want these aspirations but are unsure of how to navigate the transition. One area of particular difficulty is the parent's ability to communicate with their child's university, a practice that in primary and secondary education is second nature. Once their child enrolls in a university, there are privacy laws (i.e., transferring the education rights from parents to students) that can leave parents feeling powerless at times (Van Hees et al., 2018). It is important for families to know their rights under the Family Education Rights and Privacy Act (FERPA) and to be able to make an informed decision regarding waivers for college faculty to be able to connect with parents (Francis et al., 2017).

One of the ways parents can conquer this feeling of helplessness is to help students become more self-determined. A shift in mindset from making decisions "for" to making decisions "with" is vital to helping students reach a greater mode of independence. This can be a learning experience for families as well, as they shift into the role of an advisor and help to support decision-making and allowing for their child to face the natural consequences of their actions (Francis et al., 2017).

Case Example

Joshua has trouble with getting up on time; in high school, his parents always set his alarm for him, and if he overslept, they would be there to prompt him to get up and start his day so he did not miss class. As his parents shifted into their new role of supporting and doing things "with" him, they talked to him about how he could have a new backup system that did not involve him. Joshua now has an alarm clock in his room, but he also sets reminders on his smartphone as well.

Availability of Sexual Education Programs

Approximately 58% of adults report being sexually active by the age of 18 years – a figure that jumps to 75% by the time most adults turn 20 years old (Uecker & Regnerus, 2010). While we do not have isolated data on the sexual activity of college students with autism, we can reliably assume that they are seeking to engage in physical relationships at a rate that is similar to their peers. Adults with autism report sexual interests and desires consistent with their neurotypical peers, supporting the need for ASD-informed sexual education programming. Even so, they are often stereotyped as uninterested or incapable of social connection or sexual desire (Schöttle et al., 2017).

Parents of adults with autism also struggle with the decision to sexually educate their children, having to reconcile the fact that their child may present with deficits in some aspects of development yet still have the capacity for mature sexual thoughts and desires (Ruble & Dalrymple, 1993). Moreover, many parents who do provide or intend to provide some form of sexual knowledge to their child question whether they are capable of grasping concepts beyond the biological functions of sex, namely, sexuality, sexual violence, and socially appropriate sexual behavior (Ballan, 2012). As a result, sexual education programs for individuals with autism are likely inadequate or nonexistent. This dearth of sexual education programs, combined with the novel postsecondary challenges previously discussed, can be calamitous for these students. In the next few sections, the implications of deficits in sexual knowledge will be addressed.

The culmination of a lack of exposure to proper sexual education, the social deficits characteristic of autism, and developmentally appropriate level of sexual interest place these individuals at higher risk for sexual victimization and perpetration. Specifically, adults on the spectrum are 2.4 times as likely to experience rape and three times more likely to receive other unwanted sexual advances than their neurotypical counterparts (Brown-Lavoie et al., 2014). Conversely, an increase in one's sexual knowledge has been found to be a mediating factor relative to sexual victimization from others, reducing its risk of occurrence (Brown-Lavoie et al., 2014).

Sutton and colleagues (2013) conducted a pilot study surveying 37 incarcerated males and found that 60% met criteria for ASD, citing that the core deficits of ASD coupled with a limited sexual knowledge place these individuals at greater risk of engagement in socially unacceptable behavior. While these findings are not indicative of all males on the spectrum, it remains important to highlight the extent to which a lack of adequate sexual education information can severely impact an individual's life.

Sexual education is typically taught retroactively, following an instance of inappropriate behavior, rather than as a preventative measure (Ford, 1987). Similarly, Loftin and Hartlage (2015) maintain that intensive sexual education programs addressing the unique needs of individuals with ASD are likely not accessible until an individual has been sexually victimized or has committed a sexual crime, most likely in error. Of the sexual education programs currently available, most emphasize the biological and anatomical perspective of sex but often neglect to stress the sociocultural norms consistent with a consensual, romantic relationship (McCarthy, 2020).

Intersectionality of ASD, Sexual Orientation, and Gender Identity

Historically, members of the LGBTQ+ community have been subjected to severe relentless discrimination and ostracism. LGBTQ+ membership alone is significantly correlated with higher rates of mental health diagnoses, increased disparities in access to healthcare and treatment, and chronically unmet or undertreatment health-related issues. When compounded with an autism diagnosis, the risk for mental health issues and disparities in adequate access to treatment is augmented (Duke, 2011; Hall et al., 2020).

Despite the fact that the literature available on the intersectionality of disability status and sexual orientation or gender identity is relatively nonexistent, recent studies have shown that individuals with ASD are more likely to identify with nonheterosexual and gender-fluid groups than their neurotypical counterparts (George & Stokes, 2018; Glidden et al., 2016). In an effort to better understand their unique experiences, Hillier et al. (2019) conducted a small focus group of adults with autism who identify as members of the LGBTQ+ community. What Hillier et al. gathered from this study was that the intersectionality of LGBTQ+ membership and an autism diagnosis means having to balance two historically oppressed dual identities, navigating multiple minority stressors, increased feelings of isolation, and decreased lack of appropriate services.

These findings highlight the urgent need to create sexual education programs that bring awareness to the distinctive experiences and unmet needs of this dually marginalized group both before and during their postsecondary experience. Gender diversity and healthy sexual functioning should likely be core aspects of the sexual education program, as both have repeatedly been identified as important aspects of psychosocial development. All considered, adequate programming must be relationship oriented and account for core ASD deficits in social interaction and theory of mind, as these skills are foundational in the individual's ability to empathize, understand, and appropriately respond to their partner (Solomon et al., 2019). This should also include a discussion of examples and non-examples regarding when and where certain sexual behaviors are socially acceptable to engage in.

Conclusion

Individuals with ASD are increasingly entering higher education settings. This is encouraging, as it may help to improve the vocational outcomes for these individuals and may increase the chances that they will attain independent living. While many of these individuals have excelled in high school, many will require academic accommodations and strategies designed to support their engagement, productivity, and success. Most will require assistance in adapting to the higher level of independence associated with college. In addition, the social landscape will present novel challenges requiring instruction and support.

Colleges and universities can provide specialized services to these students before entering the setting, during orientation, and while enrolled. Some of the most important supports include structured social experiences, peer mentors, individual counseling, and skill building. Social experiences and peer mentors can reduce isolation and provide social contact that is supported and monitored. Individual counseling allows for continuous assessment of student adaptation, identification of intense needs, and access to professionally mediated problem-solving and social support. Skill building can be done in individual sessions or in group contexts and can ensure that comprehensive attention is given to college-relevant (e.g., time management), social (e.g., communication), and safety (e.g., assertiveness, limit setting, harm reduction) skills.

Special attention must be paid to issues regarding complex social contexts such as dating and sexuality. Emotional regulation skills are also essential to success, as difficulties in this area can lead to negative consequences and social avoidance by others. It is essential that these complex, hidden skills are also targeted for intervention and that individuals are broadly assessed to ensure that these issues are not missed.

It is exciting to see so many individuals with ASD entering higher education settings and to help so many of them realize their potential in this environment. Preparing the faculty and staff to meet the unique needs of these learners is essential to success. Training will ensure that the environment provides scaffolded supports to reduce stress for the students and that faculty are assisted to understand and provide the necessary supports. With careful planning, individualized assessment, and creative supports, these students can thrive and succeed.

References

Accardo, A. L. (2017). College-bound young adults with ASD: Self-reported factors promoting and inhibiting success. *College of Education Faculty Scholarship, 9*, 36–46.

Accardo, A. L., Kuder, S. J., & Woodruff, J. (2019). Accommodations and support services preferred by college students with autism spectrum disorder. *Autism, 23*(3), 574–583. https://doi.org/10.1177/1362361318760490

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Anderson, K. A., McDonald, T. A., Edsall, D., Smith, L. E., & Lounds Taylor, J. (2016). Postsecondary expectations of high school students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 31*(1), 16–26. https://doi.org/10.1177/1088357615610107

Anderson, A. H., Carter, M., & Stephenson, J. (2018). Perspectives of university students with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*(3), 651–665. https://doi.org/10.1007/s10803-017-3257-3

Anderson, A., Stephenson, J., Carter, M., & Carlon, S. (2019). A systematic literature review of empirical research on postsecondary students with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 49*, 1531–1558. https://doi.org/10.1007/s10803-018-3840-2

Anderson, A. H., Carter, M., & Stephenson, J. (2020). An on-line survey of university students with autism spectrum disorder in Australia and New Zealand: characteristics, support satisfaction, and advocacy. *Journal of Autism and Developmental Disorders, 50*(2), 440–454. https://doi.org/10.1007/s10803-019-04259-8

Athamanah, L. S., Fisher, M. H., Sung, C., & Han, J. E. (2020). The experiences and perceptions of college peer mentors interacting with students with intellectual and developmental disabilities. *Research and Practice for Persons with Severe Disabilities, 45*(4), 271–287. https://doi.org/10.1177/1540796920953826

AU Magazine. (2020). *The bridge to hope: Helping students with autism find their path to college and beyond*. Aurora University. https://aurora.edu/pathways/bridge-to-hope.html

Austin, K. S., & Peña, E. V. (2017). Exceptional faculty members who responsively teach students with autism spectrum disorders. *Journal of Postsecondary Education and Disability, 30*(1), 17–32.

Bakker, T., Krabbendamm, L., Bhulai, S., & Begeer, S. (2019). Background and enrollment characteristics of students with autism in higher education. *Research in Autism Spectrum Disorders, 67*, 101424. https://doi.org/10.1016/j.rasd.2019.101424

Ballan, M. S. (2012). Parental perspectives of communication about sexuality in families of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(5), 676–684. https://doi.org/10.1007/s10803-011-1293-y

Barnard-Brak, L., Lechtenberger, D. A., & Lan, W. Y. (2010). Accommodation strategies of college students with disabilities. *Qualitative Report, 15*(2), 411–429. https://doi.org/10.46743/2160-3715/2010.1158

Barnhill, G. P. (2016). Supporting students with Asperger syndrome on college campuses: Current practices. *Focus on Autism and Other Developmental Disabilities, 31*(1), 3–15. https://doi.org/10.1177/1088357614523121

Black, D. R., Weinberg, L. A., & Brodwin, M. G. (2015). Universal design for learning and instruction: Perspectives of students with disabilities in higher education. *Exceptionality Education International, 25*(2), 1–26. https://doi.org/10.5206/eei.v25i2.7723

Braxton, J. M., & McClendon, S. A. (2001). The fostering of social integration and retention through institutional practice. *Journal of College Student Retention:*

Research, Theory & Practice, 3(1), 57–71. https://doi.org/10.2190/RGXJ-U08C-06VB-JK7D

Brown, J. (2021). *College programs*. College Autism Spectrum. https://collegeautismspectrum.com/collegeprograms/

Brown-Lavoie, S. M., Viecili, M. A., & Weiss, J. A. (2014). Sexual knowledge and victimization in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 44*(9), 2185–2196. https://doi.org/10.1007/s10803-014-2093-y

Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher education students with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(1), 31–41. https://doi.org/10.1007/s10803-015-2535-1

Camarena, P. M., & Sarigiani, P. A. (2009). Postsecondary educational aspirations of high-functioning adolescents with autism spectrum disorders and their parents. *Focus on Autism and Other Developmental Disabilities, 24*(2), 115–128. https://doi.org/10.1177/1088357609332675

Carter, E. W., Austin, D., & Trainor, A. A. (2012). Predictors of postschool employment outcomes for young adults with severe disabilities. *Journal of Disability Policy Studies, 23*, 50–63. https://doi.org/10.1177/1044207311414680

Cawthon, S. W., & Cole, E. V. (2010). Secondary students who have a learning disability: Student perspectives on accommodations access and obstacles. *Journal of Postsecondary Education and Disability, 23*(2), 112–128.

Chiang, H. M., Cheung, Y. K., Hickson, L., Xiang, R., & Tsai, L. Y. (2012). Predictive factors of participation in postsecondary education for high school leavers with autism. *Journal of Autism and Developmental Disorders, 42*(5), 685–696. https://doi.org/10.1007/s10803-011-1297-7

Chickering, A. W., & Reisser, L. (1969). *Education and identity* (2nd ed.). Jossey- Bass.

College Autism Spectrum. (n.d.). *College programs*. https://collegeautismspectrum.com/collegeprograms/

Dallas, B. K., Ramisch, J. L., & McGowan, B. (2015). Students with autism spectrum disorder and the role of family in postsecondary settings: A systematic review of the literature. *Journal of Postsecondary Education and Disability, 2*(8), 135–147.

Dijkhuis, R. R., de Sonneville, L., Ziermans, T. B., Staal, W. G., & Swaab, H. (2020). Autism symptoms, executive functioning and academic progress in higher education students. *Journal of Autism and Developmental Disorders, 50*(4), 1353–1363. https://doi.org/10.1007/s10803-019-04267-8

Dreaver, J., Thompson, C., Girdler, S., Adolfsson, M., Black, M. H., & Falkmer, M. (2020). Success factors enabling employment for adults on the autism spectrum from employers' perspective. *Journal of Autism and Developmental Disorders, 50*(5), 1657–1667. https://doi.org/10.1007/s10803-019-03923-3

Duke, T. S. (2011). Lesbian, gay, bisexual, and transgender youth with disabilities: A meta synthesis. *Journal of LGBT Youth, 8*(1), 1–52. https://doi.org/10.1080/19361653.2011.519181

Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*(4), 739–747. https://doi.org/10.1007/s10803-007-0441-x

Fabri, M., Andrews, P., & Pukki, H. (2016). A guide to best practice in supporting higher education students on the autism spectrum—for professionals within and outside of HE. *Autism & Uni- Widening Access to Higher Education for Students on the Autism Spectrum, 28*, 1–28.

Fisher, M. H., Athamanah, L. S., Sung, C., & Josol, C. K. (2020). Applying the self-determination theory to develop a school-to-work peer mentoring programme to promote social inclusion. *Journal of Applied Research in Intellectual Disabilities, 33*(2), 296–309. https://doi.org/10.1111/jar.12673

Ford, A. (1987). Sex education for individuals with autism: Structuring information and opportunities. In D. Cohen & A. Donnellan (Eds.), *Handbook of autism and developmental disorders* (pp. 430–439). Wiley.

Francis, P. C., & Horn, A. C. (2017). Mental health services and counseling services in higher education: An overview of recent research and recommended practices. *Higher Education Policy, 30*(2), 263–277. https://doi.org/10.1057/s41307-016-0036-2

Francis, G. L., Duke, J. M., & Chiu, C. (2017). The college road trip: Supporting college success for students with autism. *Division of Autism and Developmental Disabilities Online Journal, 4*(1), 20–35.

Gelbar, N. W., Smith, I., & Reichow, B. (2014). Systematic review of articles describing experience and supports of individuals with autism enrolled in college and university programs. *Journal of Autism and Developmental Disorders, 44*(10), 2593–2601. https://doi.org/10.1007/s10803-014-2135-5

George, R., & Stokes, M. A. (2018). Gender identity and sexual orientation in autism spectrum disorder. *Autism: The International Journal of Research and Practice, 22*(8), 970–982. https://doi.org/10.1177/1362361317714587

Gerhardt, P. F., & Lainer, I. (2011). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy, 41*, 37–45. https://doi.org/10.1007/s10879-010-9160-2

Gibbons, M., Taylor, A. L., Wheat, L. S., & Szepe, A. (2018). Transformative learning for peer mentors connected to a postsecondary education program for students with intellectual and developmental disabilities. *International Journal of Research on Service-Learning and Community Engagement, 6*(1), 1–13.

Glidden, D., Bouman, W. P., Jones, B. A., & Arcelus, J. (2016). Gender dysphoria and autism spectrum disorder: A systematic review of the literature. *Sexual Medicine Reviews, 4*(1), 3–14. https://doi.org/10.1016/j.sxmr.2015.10.003

Grogan, G. (2015). Supporting students with autism in higher education through teacher educator programs. *SRATE Journal, 24*(2), 8–13.

Hall, J. P., Batza, K., Streed, C. G., Jr., Boyd, B. A., & Kurth, N. K. (2020). Health disparities among sexual and gender minorities with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 50*(8), 3071–3077. https://doi.org/10.1007/s10803-020-04399-2

Harrison, A. J., Bisson, J. B., & Laws, C. B. (2019). Impact of an inclusive postsecondary education program on implicit and explicit attitudes toward intellectual disability. *Intellectual and Developmental Disabilities, 57*(4), 323–336. https://doi.org/10.1352/1934-9556-57.4.323

Hendricks, D. R., & Wehman, P. (2009). Transition from school to adulthood for youth with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 24*(2), 77–88. https://doi.org/10.1177/1088357608329827

Herbert, J. T., Hong, B. S., Byun, S. Y., Welsh, W., Kurz, C. A., & Atkinson, H. A. (2014). Persistence and graduation of college students seeking disability support services. *Journal of Rehabilitation, 80*(1), 22–32.

Hillier, A., Gallop, N., Mendes, E., Tellez, D., Buckingham, A., Nizami, A., & OToole, D. (2019). LGBTQ + and autism spectrum disorder: Experiences and challenges. *International Journal of Transgender Health, 21*(1), 98–110. https://doi.org/10.1080/15532739.2019.1594484

Howard, J. S., Stanislaw, H., Green, G., Sparkman, C. R., & Cohen, H. G. (2014). Comparison of behavior analytic and eclectic early interventions for young children with autism after three years. *Research in Developmental Disabilities, 35*(12), 3326–3334. https://doi.org/10.1016/j.ridd.2014.08.021

Howlin, P., Savage, S., Moss, P., Tempier, A., & Rutter, M. (2014). Cognitive and language skills in adults with autism: A 40-year-follow-up. *Journal of Child Psychology and Psychiatry, 55*(1), 49–58. https://doi.org/10.1111/jcpp.12115

Hsiao, F., Burgstahler, S., Nuss, D., & Doherty, M. (2019). Promoting an accessible learning environment for students with disabilities via faculty development (Practice brief). *Journal of Postsecondary Education and Disability, 32*(1), 91–99.

Individuals with Disabilities Education and Improvement Act. (2004). 20 U.S.C §1400.

Izzo, M. V., & Shuman, A. (2013). Impact of inclusive college programs serving students with intellectual disabilities on disability studies interns and typically enrolled students. *Journal of Postsecondary Education and Disability, 26*(4), 321–335.

Jackson, S., Hart, L., Brown, J. T., & Volkmar, F. R. (2018). Brief report: Self-reported academic, social, and mental health experiences of post-secondary students with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*(3), 643–650. https://doi.org/10.1007/s10803-017-3315-x

Jansen, D., Petry, K., Ceulemans, E., Noens, I., & Baeyens, D. (2017). Functioning and participation problems of students with ASD in higher education: Which reasonable accommodations are effective? *European Journal of Special Needs Education, 32*(1), 71–88. https://doi.org/10.1080/08856257.2016.1254962

Järbrink, K., McCrone, P., Fombonne, E., Zandén, H., & Knapp, M. (2007). Cost-impact of young adults with high functioning autistic spectrum disorder. *Research in Developmental Disabilities, 28*(1), 94–104. https://doi.org/10.1016/j.ridd.2005.11.002

Karola, D., Julie-Ann, J., & Lyn, M. (2016). School's out forever: Postsecondary educational trajectories of students with autism. *Australian Psychologist, 51*(4), 304–315. https://doi.org/10.1111/ap.12228

Krieger, B., Kinébanian, A., Prodinger, B., & Heigl, F. (2012). Becoming a member of the work force: Perceptions of adults with Asperger Syndrome. *Work, 43*(2), 141–157. https://doi.org/10.3233/WOR-2012-1392

LeTourneau University. (2020). *Bridges College Success Program: Academic & social support for student with autism*. LeTourneau University. https://www.letu.edu/student-life/bridges-program.html

Loftin, R. L., & Hartlage, A. S. (2015). Sex education, sexual health, and autism spectrum disorder. *Pediatrics and Therapeutics, 5*(1), 1–6. https://doi.org/10.4172/2161-0665.1000230

Longtin, S. E. (2014). Using the college infrastructure to support students on the autism spectrum. *Journal of Postsecondary Education and Disability, 27*(1), 63–72.

McCarthy, A. (2020, February 14). *CRUSH: Developing a sexual education program for young adults on the autism spectrum*. Boston Children's Hospital.. https://answers.childrenshospital.org/crush-developing-a-sexual-education-program-for-young-adults-on-the-autism-spectrum/

Morrison, J. Q., Sansosti, F. J., & Hadley, W. M. (2009). Parent perceptions of the anticipated needs and expectations for support for their college- bound children with Asperger's Syndrome. *Journal of Postsecondary Education and Disability, 22*(2), 78–87.

Newman, L., Wagner, M., Knockey, A. M., Marder, C., Nagle, K., Shaver, D., & Wei, X. (2011). *The post-high school outcomes of young adults with disabilities up to 8 years after high school: A report from the National Longitudinal Transition Study – 2 (NLTS2). NCSER 2011–3005*. National Center for Special Education Research.

Nicholls State University. (2019). *Bridge to independence*. Nicholls State University. https://www.nicholls.edu/education/support-programs/bridge-to-independence/

Noble, K. D., & Childers, S. A. (2008). A passion for learning: The theory and practice of Optima Match at the University of Washington. *Journal of Advanced Academics, 19*(20), 236–270. https://doi.org/10.4219/jaa-2008-774

Park, H. J., Roberts, K. D., & Stodden, R. (2012). Faculty perspectives on professional development to improve efficacy when teaching students with disabilities. *Journal of Postsecondary Education and Disability, 25*(4), 377–383.

Ravizza, S. M., Solomon, M., Ivry, R. B., & Carter, C. S. (2013). Restricted and repetitive behaviors in autism spectrum disorders: The relationship of attention and motor deficits. *Development and Psychopathology, 25*(3), 773–784. https://doi.org/10.1017/S0954579413000163

Ruble, L. A., & Dalrymple, N. J. (1993). Social/sexual awareness of persons with autism: A parental perspective. *Archives of Sexual Behavior, 22*(3), 229–240. https://doi.org/10.1007/BF01541768

Sayman, D. M. (2015). I still need my security teddy bear: Experiences of an individual with autism spectrum disorder in higher education. *Learning: Assistance Review, 20*(1), 77–98.

Scheef, A. R., McKnight-Lizotte, M., & Gwartney, L. (2019). Supports and resources valued by autistic students enrolled in postsecondary education. *Autism in Adulthood, 1*(3), 1–8. https://doi.org/10.1089/aut.2019.0010

Schöttle, D., Briken, P., Tüscher, O., & Turner, D. (2017). Sexuality in autism: Hypersexual and paraphilic behavior in women and men with high-functioning autism spectrum disorder. *Dialogues in Clinical Neuroscience, 19*(4), 381–393. https://doi.org/10.31887/DCNS.2017.19.4/dschoettle

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with autism spectrum disorder. *Pediatrics, 129*(6), 1042–1049. https://doi.org/10.1542/peds.2011-2864

Solomon, D., Pantalone, D. W., & Faja, S. (2019). Autism and adult sex education: A literature review using the information-motivation-behavioral skills framework. *Sexuality and Disability, 37*(3), 339–351. https://doi.org/10.1007/s11195-019-09591-6

Squires, M. E., Burnell, B. A., McCarty, C., & Schnackenberg, H. (2018). Emerging adults: Perspectives of college students with disabilities. *Journal of Postsecondary Education and Disability, 31*(2), 121–134.

Sutton, L., Hughes, T., Huang, A., Lehman, C., Paserba, D., Talkington, V., Taormina, R., Walters, J., Fenclau, E., & Marshall, S. (2013). Identifying individuals with autism in a state facility for adolescents adjudicated as sexual offenders. *Focus on Autism and Other Developmental Disabilities, 28*(3), 175–183. https://doi.org/10.1177/1088357612462060

Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders, 41*(5), 566–574.

Taylor, J. L., & Seltzer, M. M. (2012). Developing a vocational index for adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(12), 2669–2679. https://doi.org/10.1007/s10803-010-1070-3

Uecker, J. E., & Regnerus, M. D. (2010). Bare market: campus sex ratios, romantic relationships and sexual behavior. *The Sociological Quarterly, 51*(3), 408–435. https://doi.org/10.1111/j.1533-8525.2010.01177.x

Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of Autism and Developmental Disorders, 45*(6), 1673–1688. https://doi.org/10.1007/s10803-014-2324-2

Van Hees, V., Roeyers, H., & De Mol, J. (2018). Students with autism spectrum disorder and their parents in the transition into higher education: Impact on dynamics in the parent-child relationship. *Journal of Autism and Developmental Disorders, 48*(10), 3296–3310.

Viezel, K. D., Williams, E., & Dotson, W. H. (2020). College-based support programs for students with autism. *Focus on Autism and Other Developmental Disorders, 35*(4), 234–245. https://doi.org/10.1177/1088357620954369

Welkowitz, L. A., & Baker, L. J. (2005). Supporting college students with Asperger's syndrome. *Asperger's Syndrome: Intervening in Schools, Clinics, and Communities, 173*, 1–25.

Whittenburg, H. N., Cimera, R. E., & Thoma, C. A. (2019). Comparing employment outcomes of young adults with autism: Does postsecondary educational experience matter? *Journal of Postsecondary Education and Disability, 32*(2), 159–172.

Willey, L. H. (2000). *Pretending to be normal: Living with Asperger's syndrome*. Jessica Kingsley Publishers.

Part IV

Living Arrangement Considerations

Community-Based Residential Options for Adults with Autism and Intellectual Disabilities

10

John M. Guercio

Group Home Settings for Persons with Intellectual Disabilities

The unique place that group homes hold in our society has been a hotly debated topic for many years (Lakin & Stancliffe, 2007). For every opponent of these settings that feel that they are not necessary and that those with disabilities should live at home, there are those supporters that detail how lifesaving these settings have been to their loved ones and how their presence allowed their family members to become better integrated into their home communities. The debate is real, but the fact of the matter is that the history of our mental health system has long battled with ineffective treatment settings and approaches (Lakin & Stancliffe, 2007; Torrey, 2014). Community-based environments for people with intellectual disabilities (IDs) can serve as a strong catalyst to their further blossoming in terms of a variety of skills and experiences that they may not have been exposed to were they to remain in their home setting. As the parents of persons with IDs age, they become more and more incapable of addressing their loved ones' needs as they get older. We read of horror stories all the time where police have found persons with IDs aimlessly roaming the streets of their town. When questioned, it eventually turns out that they found their parent(s) unresponsive in the home and were literally lost as their aging parent passed away and left them with no idea of what to do next. The scenario of parents in their 80s trying to care for children in their 60s should scare all of us. Plans need to be made for those with disabilities to transition into environments that best fit their needs. Most typically developing children leave home around the age of 18 years to pursue either college or work. Why are we still seeing parents in their golden years trying to provide for their children that are aging as well? Our society has set up a system whereby these individuals can have three shifts of fresh staff to take care of them as opposed to leaving these responsibilities to family members that may be ill-equipped to do so. I realize that this may be a controversial statement for many to read, but it is an issue that needs to be addressed so that our population of those with ID can receive the care that they truly need.

The Kennedys and the Deinstitutionalization Movement

It was a September morning in 1939 and Joseph P. Kennedy watched as his political aspirations were being crushed under the wheels of German

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tanks guided by Hitler. He was preoccupied with a number of events, but primarily an issue of the most intimate nature was with his oldest daughter Rosemary who was due to turn 21 years old shortly. Doctors had diagnosed Rosemary with mild mental retardation early in her childhood. This diagnosis placed a great stigma on the powerful political family and eventually set the table for a number of reforms in our mental health system that are still developing to this day (Torrey, 2014). Rosemary appeared to be typically developing to those around her. The Kennedys were fiercely protective of her, and few knew of her challenges. As she grew older, the family placed her in a number of convents to ensure her safety and to take her away from the prying questions that the Kennedys felt would besiege them if others discovered her condition. Joe Kennedy's extreme generosity with the church allowed for this option as Rosemary started to show more behavioral signs of her diagnosis. She received a great deal of attention from her mother Rose, which resulted in her achieving a fourth-grade level in math and a fifth-grade level in English, but her progress plateaued there. Some of the guests at the gatherings hosted by the Kennedys could start to observe the behavioral manifestations of Rosemary's ID.

Rosemary was reported to behave in strange ways around the dinner table wearing a nightgown and engaging in screaming fits that resulted in her wildly pacing the halls of the Kennedy home. She was also reported to have attacked her grandfather at one point when going into one of her rages (Torrey, 2014). The pursuit of political ambition and respectability led to an egregious decision by the family.

The desire to be viewed in a positive light and to avoid any negative evaluations that would arise from Rosemary's ongoing exploits with sexual contact with men and other manic behavior led to a decision that would shape the path that care for the ID population and those with mental illness would take to the present day. This political ambition mixed with the potential fallout from having a family member that society could label as insane led to the decision to seek a lobotomy for Rosemary (Torrey, 2014).

In mid-November of 1941, after administrating a mild sedative to Rosemary, Neurosurgeon James Watts drilled two small holes in the top of her skull and proceeded to insert a knife and sever brain tissue at the site of the holes. The operation was a huge mistake, rendering Rosemary much more disabled than she had been prior to the surgery. In 1948, the Kennedys placed her in St. Coletta's School for Exceptional Children. The facility was run by Franciscan nuns in Wisconsin. Rosemary was now, in effect, out of sight and out of mind. The Kennedys donated a million dollars to St. Coletta's in 1983, and Rosemary remained there until she passed away in 2005 at the age of 86. The tragedy that befell Rosemary was one that demanded reparation. This would eventually come to fruition in 1960 when John F. Kennedy (JFK) was elected to the office of the President of the United States.

The use of congregate living settings in the community is the upshot of President Kennedy's widespread deinstitutionalization movement in the 1960s. The shortcomings of the institutional settings have been well documented. The abuses that took place in our institutional settings for persons with mental illness and developmental disabilities had a checkered past to say the least (Torrey, 2014). Several investigations into the failures of this system have been conducted, the most powerful of which was the President's Panel on Mental Retardation in 1961.

The panel had 27 members and was charged to develop a plan to combat some of the abuses found in the "mental retardation" system up to that time. There was little consensus as to what approaches to take. The committee developed a 200-page report in October of 1962 that included 95 recommendations. One of the most significant developments was the designation of 18 university-affiliated clinical facilities that were to be developed for persons with IDs. The driving force behind this initiative was Eunice Shriver (Shorter, 2000). Eunice was Rosemary's sister and fought tirelessly for the rights of persons with IDs. She would continuously make requests of her brother JFK until she was able to get what she needed for her interest in the promotion of service for those with IDs. JFK had stated that he wanted to give his sister whatever she wanted in order to get her off the phone so that he could get on with the business of government (Shorter, 2000). Eunice shared a level of contempt for psychiatrists as was the case for most family members at the time. The general impression was that psychiatry had done very little for persons with IDs and a new focus and renewed efforts were in order (Gorman, 1976). The contentiousness between the advocates of those with IDs and mental illnesses was entrenched. Much of the ammunition for this discontent was the belief that mental illness was something that people could recover from, while those with an ID could not. This belief that the person with an ID would always be inferior fueled efforts on both sides. The psychiatrists that were caring for Rosemary felt that the Kennedys were being disingenuous by prioritizing ID over mental illness as Rosemary suffered from both issues.

The Death of the Asylum

The Interagency Commission on Mental Health agreed to go forward with an initiative that they viewed would eliminate state mental institutions as they existed at that time within one generation. These efforts were brewing in the midst of the publication of Thomas Szasz's *The Myth of Mental Illness* and Irving Goldman's *Asylums* (Goffman, 1968; Szasz, 1961). Szasz was adamant in his views that mental illness did not exist, and Goffman's contention was that most of the conditions that patients in mental institutions experienced were a result of the deplorable conditions found in those institutions and the process of institutionalization itself (Cresswell, 2008; Mac Suibhne, 2011). The wheels were now set in motion.

President Kennedy stated in his 1963 message to Congress, "if we launch a broad new mental health program now, it will be possible within a decade or two to reduce the number of patients now under custodial care by 50 percent or more" (Torrey, 2014, p. 52). The new legislation had a fatal flaw. The closing of state mental health institutions was the focus. No substantive plans were put into place regarding where the discharged patients would go once they were released. The process had already been set in motion, and the move to the community was imminent.

The Growth of the Residential Community-Based Model

The decline in the population of individuals residing in congregate care institutional settings has decreased significantly over the years. In June of 1977, 207,356 of the approximately 247,780 persons with IDs receiving residential services lived in either public or private institutional settings with more than 16 persons (Prouty et al., 2006). This was an astounding 83.7% of the ID population that were receiving residential services. Fast forward 28 years to June of 2005 and only 67,066 of the 411,215 persons receiving residential services were in congregate-based institutional settings. This number was a much lower 16.3% of those with ID in residential settings (Prouty et al., 2006). During that same span of time, those persons living in group settings in community-based homes increased from 40,424 to 344,152 (see Fig. 10.1). Those with IDs living in nursing home environments decreased by 12,755 persons as well during that span of time. These moves were heralded by the Centers for Disease Control and Prevention (CDC) as laudable events.

The importance of this move to the community is emphasized in the following statement:

> Institutionalization and other forms of congregate care are inconsistent with positive public health policy and practice. They diminish people's opportunities to realize essential features of human well-being: choice, control, ability to establish and pursue personal goals, family, and community interaction, privacy, freedom of association, and the respect of others (National Center on Birth Defects and Developmental Disabilities [NCBDDD], 2003, p. 181).

The support of the federal government was not as vivid in these events as it could have been until the passage of the Americans with Disabilities Act (ADA) in 1990 (Cook, 1991). The Olmstead Act paved the way for these moves to the com-

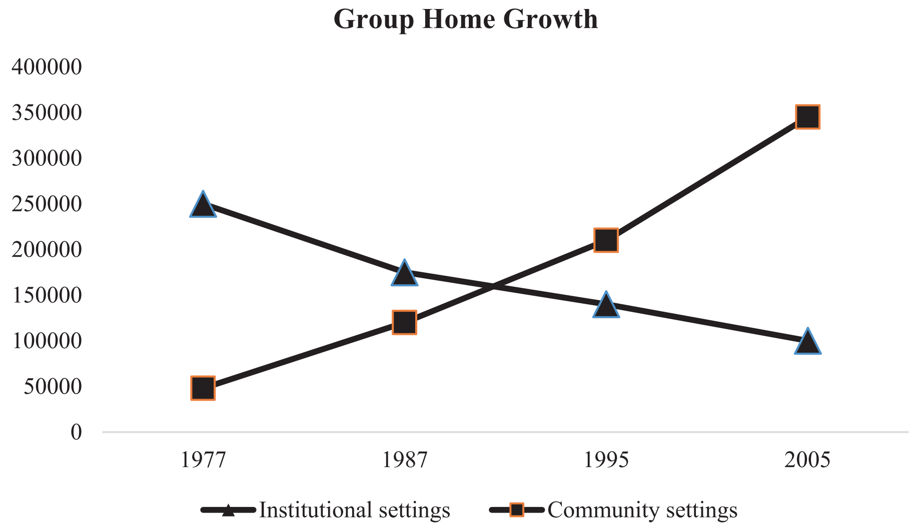

Fig. 10.1 Corresponding rates of those with intellectual disabilities (IDs) in congregate-based institutional settings compared to those living in community-based settings

munity and all of the benefits that would come with them.

In the Olmstead decision, the Supreme Court affirmed that the ADA places the burden on the states to provide services in the most inclusive settings that are possible. This edict brought along with it an obligation to place persons with disabilities in community-based settings when their treatment professional had determined that this would be the best course of action for the person (Butler, 1999). The person with the disability was also empowered with the decision as to whether or not they wanted to live in the identified setting. President Bush signed an Executive Order on June 18, 2001, that acknowledged the Olmstead decision was to help put an end to unjustified isolation or other forms of discrimination based upon a person's disability. The ADA made acts of discrimination against those with an ID prohibited by law and encouraged more community-based living options for persons with disabilities (Lakin & Stancliffe, 2007). The manner in which these living environments are funded is more of a state-based decision-making process.

Individual states are responsible for the design and operation of residential service programs for people with IDs. The federal government then supplements these efforts through Medicaid funds at around 50–76% of the costs of those programs and services. Each of these settings must meet the minimum federal guidelines in order to begin operation as well. The costs of implementing community-based shared living arrangements are far outweighed by the benefits that they provide for those that reside in these settings.

A great deal of research has been conducted related to the efficacy of community-based living arrangements for people with IDs (Harchik & Campbell, 1998). These studies have examined a number of variables related to the health and well-being of those with IDs. These findings continue to underscore the increased personal autonomy, community participation, and increased family contacts that have been observed when people with IDs live in community-based homes as opposed to institutional settings. Persons with IDs that reside in community-based settings are more equipped to participate in the life of the community (Guercio, 2020). Many of these settings are significantly smaller than those of an institutional nature and the result of more community access with less staffing concerns. The increased focus on community-based integration allows for many skills such as grocery shopping, money management, and social skills to be practiced in vivo as opposed to strictly role played and never used in functional ways in functional settings.

Financial Advantages

Families that primarily provide in-home care for their loved ones bear the burden of extensive therapy costs, residential modifications, and a host of other hidden costs that are manifested when these supports are provided in naturalistic settings such as the family home (Lakin & Stancliffe, 2007). The costs to the state of maintaining the status quo of institutional placements bring along with it a financial burden of a different sort. The costs of operating state-run institutional settings are immense (Stancliffe & Lakin, 2005).

Even as state-operated institutions were downsizing, the fixed costs associated with their operation remained. The costs, per person, to operate these institutions actually increased from around $52,077 in 1977 to around $148,000 per person per year as late as 2005 (Lakin et al., 2006). What looked to be a very progressive move on the face of it proved to be less impressive than initially thought. Closing the institutions only shifted the cost to the states. The 74% decrease in state-run facilities' populations from 1977 to 2005 only resulted in a real dollar savings of 24%. Each state is tasked with designing community reintegration as they see fit.

In 2005, approximately 60% of the people residing in state-run institutions lived in one-third of the states (i.e., 17; Lakin & Stancliffe, 2007). These states have traditionally been known as the slowest with respect to their deinstitutionalization efforts (Prouty et al., 2006). As the states have gradually taken over the housing needs of these persons with IDs, the size of the residential community settings has undergone a downsizing.

The percentage of people receiving residential supports in the community in 2005 was 8.5 times greater than when deinstitutionalization efforts were initiated in 1977 (Lakin & Stancliffe, 2007). Many of the initial residential homes placed in the community had from seven to 15 persons in them. This number has decreased to the point that by 2005, the number of community-based residential settings with less than three people in them decreased 21.5 times compared to the 1977 number. That is an increase from 8680 people in 1977 to 184,024 people as of 2005. The huge push to the community was a great move for persons with disabilities as well as a fantastic opportunity for behaviorally based staff training methods to flourish.

Staff Training and Oversight

The implementation of the plans that are put into place by behavioral professionals is the backbone of successful community placements. Reid and Parsons (2002) stated that the

> lack of effective treatment resulting from insufficient program implementation has led to an overreliance on numerous types of medications to sedate or otherwise override the occurrence of challenging behavior. Such medications often have detrimental side effects for individuals with severe disabilities and frequently do not address the actual reasons why people engage in challenging behavior (p. 6).

The group home service model has been referred to by some as the emblem of community-based care (Tossebro et al., 2012). The term has been applied to a diverse set of living arrangements, residents, and support that is provided in the setting. For the purposes of this chapter, we will use the definition put forth by Clement and Bigby (2010), which defines the group home as a living arrangement for between two and six residents where staff support is provided both in the home and in the community for those that live there. Group homes are part of the landscape of ID service provision and are a practical means to implement most of our social policies around services for those with an ID. Quality of life can be addressed in these settings regardless of the functioning level of those that live in them.

In the United Kingdom, a program entitled *Valuing People* exists whereby legal and civil rights independence, choice, and inclusion are primary focuses (Clement & Bigby, 2010). The staff in group home environments are expected to support the persons that live there according to these principles. The focus in setting up these environments has primarily been to provide those with IDs the same opportunities and options that are available for those without an ID and to do so in a way that fosters autonomy and inclusion. The appearance of these settings needs to fit within this philosophical model as well.

The goal of an ordinary house in a typical neighborhood will allow such settings not to be identified as a service establishment. This is a crucial aspect of the group home being able to blend into the community with no outstanding identifiers as to the services that are provided inside. This vision of a typical life just like everyone else's life is the ultimate goal. In order to guide the philosophy that serves as the foundation for group home settings, O'Brien (1987) has proposed five accomplishments that serve as a framework for the behavior of staff working in group home settings (see Table 10.1).

Table 10.1 John O'Brien's five accomplishments. The accomplishments provide a framework for deinstitutionalization and inclusion for persons living in group home settings in the community

Accomplishment	Definition and rationale
Community presence	The sharing of common community sites that define community inclusion and participation
Choice	The experience of autonomy in small daily matters (what to wear, or what to eat) and in more significant matters such as what type of work to pursue, who one lives with, etc.
Competence	The chance to perform functional activities that are part of the person's values with the degree of assistance that is required according to the person's ID
Respect	Holding a valued place among a group of people and valued roles in the life of the community
Community participation	The experience of being included within a network of interpersonal relationships that includes close friends. Without this focus, people with ID tend to be more isolated and restricted. This restriction typically involves only family members and paid supports. As a conduit to increased community inclusion, it is important to provide the opportunity for those typically developing members of the community to interact with those with ID

Behavioral Concerns in Residential Settings

Many of the persons requiring residential supports in the community display unwanted behavior. This behavior can be in the form of verbal threats, noncompliance, property destruction, and/or physical aggression. These issues make it difficult to provide these services in a safe manner that reduces the risk for all involved in the person's care. A recent study underscored the utility of examining aggressive behavior in adults with IDs and the different interventions that have been applied to these problems (Im, 2021).

The strongest evidence to date for efficacy with behavioral issues for adults with IDs (primarily autism) and aggression has been from pharmaceutical means (Im, 2021). Most reviews are biased toward randomized controlled trials, thus excluding a great deal of the behavioral literature due to its focus in single subject design (SSD) methodology. Even given this bias, there is strong evidence to suggest that function-based interventions for adults with IDs and aggression in community settings can be treated using behavioral interventions (Guercio, 2020; Guercio & Cormier, 2015; Singh et al., 2019; Wilson et al., 2015). The prevalence of behavioral issues in residential settings has been documented to demonstrate the increased frequency with which these issues can be displayed.

Guercio and McMorrow (2007) presented a 5-year sample of aggressive behavior that was observed in residential settings for persons with IDs and acquired brain injuries (ABIs). The primary intent of the study was to quantify the levels of aggression that can be observed in residential settings for those that may not be aware of the behavioral needs of adults with residential and

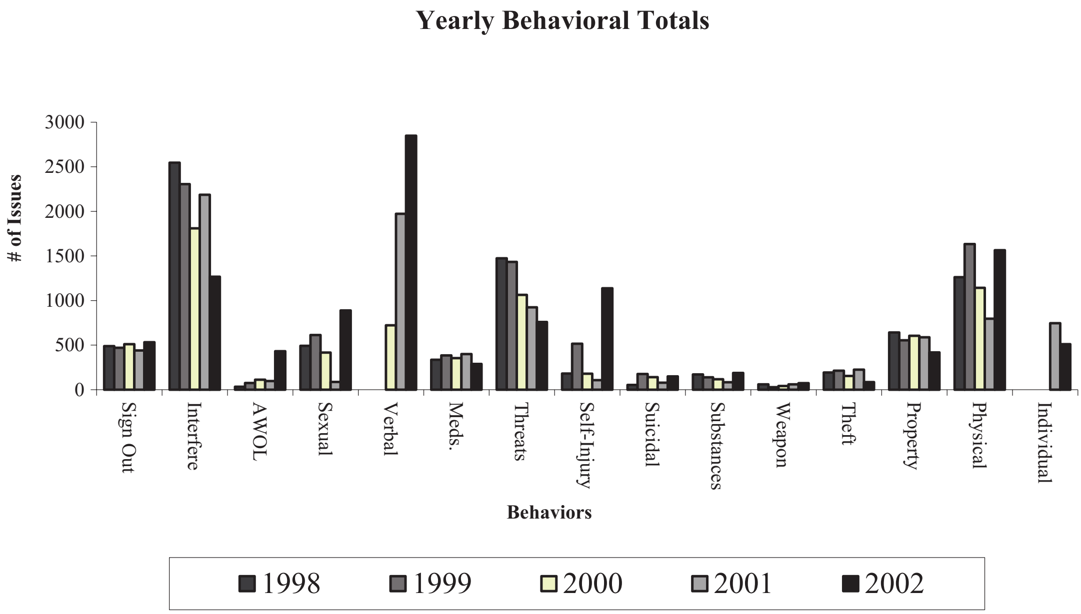

Fig. 10.2 Frequency and types of aggressive behavior manifested by individuals in community-based residential settings. The behavior was recorded yearly from 1998 to 2002 across a sample of 28 adults

Note. **Specifically, note the y axis on this graph. There were upwards of 3000 issues observed per year with respect to some topographies of aggressive behavior. Such challenges call for a strong technology of behavior change in community-based settings in order to produce positive outcomes for the persons served in these settings.**

behavioral needs. Their study examined a population of approximately 28 persons across 5 years. The topographies of aggressive behavior were operationally defined for staff recording and presented across each of the years of the study. The persons involved in the study ranged in age from 20 to 70 years and lived in one of five residential homes. The total computation of the extreme frequency of these issues in residential settings was quite eye opening (see Fig. 10.2).

Staffing Issues in Community-Based Residential Settings

When it comes to services for persons with IDs, support staff play a crucial role. They are the face of the organization, and their efforts represent the agency that employs them (Hatton et al., 1999). The direct support professionals (DSPs) that work in residential settings for persons with ID serve a strong social networking function (Sharrard, 1992). There is no contention to the assertion that working in residential settings where behavioral challenges, staffing concerns, and other issues appear on a daily basis can cause a great deal of stress. Surveys have shown that between 25% and 32.5% of the staff that work in these settings experience heightened levels of stress as a result of their job (Robertson et al., 2005). When these issues occur with staff and they are not addressed adequately, burnout can occur (Jackson & Maslach, 1982). Some of the key signs and symptoms of burnout among staff are exhaustion, poor interaction styles with the persons served, as well as tardiness and absenteeism. Though these symptoms and the burnout that can result can occur in DSP staff that work with persons with IDs, they are much more prevalent in staff that work with persons that display extreme behavioral challenges. Persons that display high-risk aggression and property destruction are those that are more likely to require residential services in the community and require that most of our focus be on providing them the evidence-based services that best serve to maintain their autonomy and minimize the risks that they present. These services are best provided when we instill a strong foundation of staff training that addresses the critical skills that staff will need when working with persons with IDs.

The behavioral literature has done a magnificent job of documenting the importance of staff behavior as it applies to the outcomes for the persons served. Staff training is a crucial area that should undergird the efforts taken to provide quality support in the community for persons with IDs (Ivancic & Heise, 1998; Sturmey, 1998). Given the progress that has been made with deinstitutionalization as detailed above, the focus has been shifting more to how to improve community-based residential services (Harchik & Campbell, 1998; Sundram, 1999).

The discipline of organizational behavior management (OBM) is subsumed under the field of applied behavior analysis (ABA). The principles and applications that are involved in OBM are identical to those applied in the field of ABA, with the caveat that they are applied in different organizational settings. The early period in the evolution of community-based residential living for persons with IDs occurred in the late 1960s and early 1970s. The primary focus during those times was an organizational principle that the type of settings involved were a function of the severity of the person's disability (Hitzing, 1987). Such views narrowed the options for persons with IDs and left them primarily with no alternatives other than larger residential settings with more people per home. As the prevailing attitudes of the times changed in the 1980s, the focus shifted more to client choice and the planning of services centered around personal preferences (Racino & Knoll, 1986).

The term "person centered" started to be used more frequently in the mid-1980s. The options to persons with IDs also broadened around this time as shared living situations, in-home family-based support, and independent supported living (ISL) arrangements started to flower (Racino, 1995). The shift in focus to a more person-centered approach emphasized the ability for the person to choose where they wanted to live, as well as their roommates, with the ongoing support to live out these choices (Bellamy & Horner, 1987). The needs and choices of the person served were now at the forefront as opposed to the availability of services as was found in the old model (Boles et al., 1988). These new living arrangements in the community called for innovations in management and supervision methods that behavior analysis was prepared to address (Harchik & Campbell, 1998).

The field of OBM provided a great deal of guidance as the supervisory skills of staff, interactions with house staff by supervisory staff, and staff's use of teaching strategies were all research fodder for the burgeoning opportunities now available in the community-based supports and staff training arenas. The use of direct observation was very helpful in examining positive and negative feedback and their effects on staff performance. The outcomes of some of these historical studies have proven unequivocally that OBM interventions work in community-based residential settings. Additional findings in the literature underscored that ongoing observation and feedback are crucial to delivering quality residential services. Workshops and trainings alone are ineffective in producing significant behavior change in DSP staff (Guercio, et al., 2005). One fact that is clear is that staff members can be taught effective skills to work in these settings that can generalize to other similar settings (Guercio, et al., 2005; Guercio & Dixon, 2011). The feedback that is provided for staff must be provided on a consistent basis as they perform their daily duties.

Promoting Staff Data Collection Behavior

No residential community-based setting would be complete without state-mandated paperwork and guidelines for how to fill this documentation out. From a behavioral perspective, the most important documentation that takes place in residential services is the behavioral notes and data that are collected on the persons that live in these residences. The most common approach to training staff to complete their daily documentation occurs in lecture-based staff training sessions (Guercio, et al., 2005).

These training sessions are targeted at providing the staff that work in residential settings the skills to fill out the required documentation for their shift. Staff involvement in behavioral programming can be a key catalyst in success for the persons served (Guercio et al., 2005). The majority of traditional staff training is provided in lecture format whereby a supervisor covers all of the material that staff are to retain and requires those that attend the training to fill out attendance sheets verifying their presence. There are typically no posttests or other permanent products to document competence in the tasks that were trained. As a result, many staff do not learn the skills that are being taught, and the end result is a performance deficit that shows up in the future. Competency-based training and feedback are required to get staff to retain the material that is being trained (Guercio et al., 2005).

Traditional lecture-based staff training procedures are not efficacious in communicating to staff what is required from them behaviorally (Campbell, 2007). The staff only tend to retain minimal competency in the trained areas, and it may take weeks or months for performance deficits to show up. By that time, the issues are severe enough that a great deal of valuable information may have been missed. A recent meta-analysis of the required components for effective staff training indicated that mere lecture needs to be only one component of the procedure (van Oorsouw et al., 2009). Basic in-service training was found to be much more effective when in vivo on-the-job efforts were intermingled with the in-service. Verbal and other types of feedback have proven to be strong predictors of behavior change in staff (Daniels & Bailey, 2014). The comorbidity of behavioral problems only exacerbates the need for effective staff training as evidenced by the high levels of staff turnover and burnout that were discussed earlier in this chapter. Effective training can foster more control and expertise for staff as they work with those that may display higher levels of aggressive behavior. The research is clear that high-quality staff training programs help to facilitate increased autonomy, quality of life, and the attainment of personal goals for persons with IDs (Brown et al., 2013). As we shift our focus more to evidence-based interventions for training the staff that work with some of our most vulnerable citizens, it is imperative that we employ methodologies that are proven in the literature (Gormley et al., 2020).

Staff training related to data collection behavior is an area familiar to most behavior analysts. Incorporating the evidence-based practices described above, Guercio et al. (2005) utilized a systematic method of feedback to staff that was related to their completion of designated behavioral data collection across three community-based residential settings. Staff were to complete assigned behavioral incentive plan data on each of the residents in their home. A systematic progression of in-service training, general and specific public posting, and supervisor assignment phases were utilized to increase the data collection behavior in the residential setting. In-service training was found to have minimal effect on the staff's data collection behavior. The public posting intervention showed some deterioration of effect over time as staff became accustomed to the feedback. The most efficacious intervention was the assignment of supervisory staff to ensure that the data were collected on a daily basis. The accountability that this intervention involved produced the most robust effect as the graph below attests (see Fig. 10.3).

Therapeutic Teaching Interactions

Promoting dignity and respect for those that we serve is the cornerstone of quality residential services for persons with IDs. The evolution of the field of psychiatry and ID services is rife with maltreatment and atrocities that have done anything but respect the dignity and promote respect for those that are served. Knowing how to fill out paperwork and take care of the duties around the residence is great, but if these things are done with a poor interaction style, minimal gains can

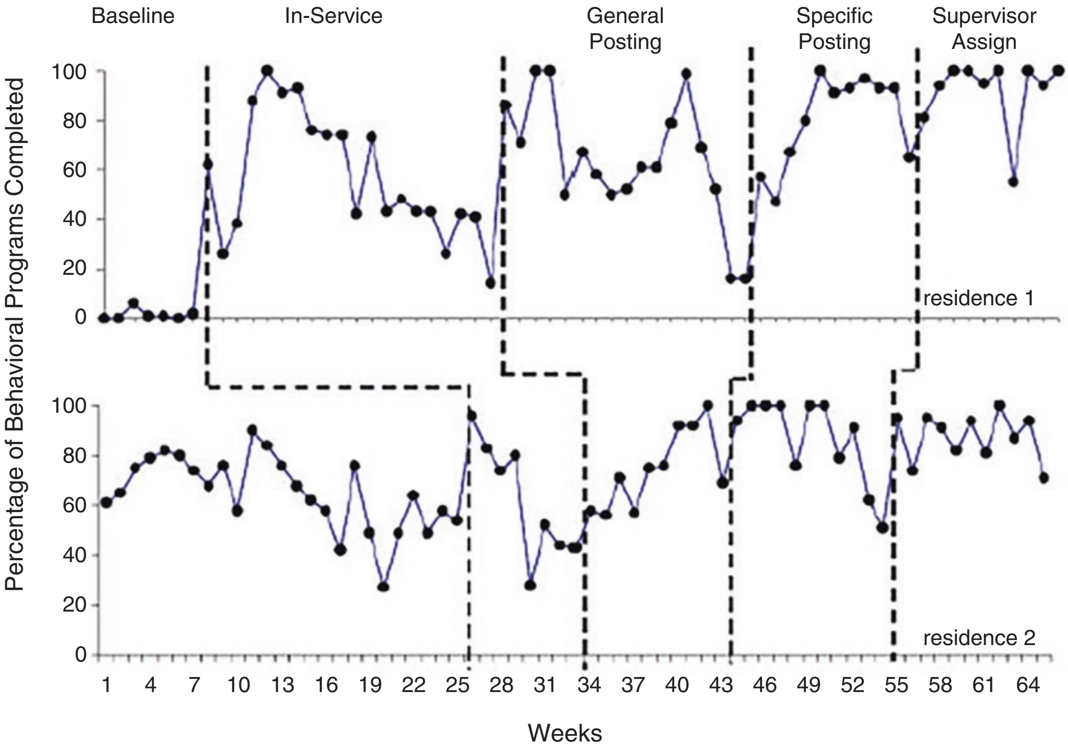

Fig. 10.3 Staff data collection behavior through all of the phases of the study including posting and supervisor assignment

be made for the persons with ID living in the homes staffed by persons with little care or concern for their values (Guercio, 2020). Being able to diffuse a potential problem is the best way to teach staff to better monitor their interaction styles.

There are many examples of staff that attempt to justify their role in an aggressive outburst when questioned as to the cause of the outburst. I have heard several staff state that they just asked the person with an ID to complete a task and they started to display aggressive behavior. What is so often overlooked is the manner in which the request is made. Staff in DSP roles tend to focus excessively on the plans that are written for the people that they serve and the manner in which they try to follow these plans is often heavy handed and confrontational in nature. Dietary guidelines and supervision guidelines are frequently interpreted as rigid rules that must be followed at all costs. An inability to be flexible in these situations and to take the path of least resistance with respect to provoking angry outbursts is a skill that must be taught to all DSP staff in order to maintain a safe and healthy residence. I have observed situations where a medical professional has recommended that the sodium intake of a client be reduced below a certain amount per day. This happens all of the time in residential settings given our parental stance toward putting restrictions in place for persons with IDs in the name of their health. The ironic thing is that their same-age peers that are typically developing are making the same poor choices about nutrition and health with no untoward consequences. Well-intentioned staff will then try to restrict foods or even take foods away from the person if they violate the medical restriction that has been put in place. This is a recipe for disaster as the end result is typically escape-maintained aggressive responding. The promotion of more positive teaching-based interactions is the best way to avoid such aggression.

Guercio and Dixon (2010) employed a survey of supervisors in a residential facility to determine which of the DSP staff that were employed there suffered from interaction style problems. The staff that were identified were then observed for their interactional deficits by way of an operationalized interaction tool that allowed the investigators to quantify, in objective terms, their use of a characteristically positive interaction style. The interaction style training model goes by the acronym PEARLS and is described in Table 10.2 (McMorrow, 2003).

Each of the components of the PEARLS model is scored using a 10-min interval procedure where each of the components is scored during separate 1-min bins of the 10-min interval according to each of the components of the system listed above. The operational definitions for each of the components are included to allow both supervisors and staff the opportunity to quantify the positive interactions that are observed and to give feedback related to particular strengths and weaknesses in the interaction styles of individual staff members.

Observations of the staff members showed that both the frequency and quality of their interactions with residents were well below that of their DSP peers (Guercio & Dixon, 2010). This is typically the case in that decreased effort in maintaining interactions typically produces an interaction style that is devoid of reinforcement for either the DSP or the person with an ID. For these reasons, the frequency and quality of positive interactions have to be targeted in order to facilitate positive teaching-based interaction styles. Video modeling and instruction was then employed to build the interactional skills of the staff.

The efficacy of video-based modeling to facilitate positive interaction styles has been proven to work in situations whereby staff have been resistant to other training methods (Guercio & Dixon, 2010). Video-based models that display all of the elements of the PEARLS interaction system were provided to the staff identified as having poor interaction skills. The provision of video-based samples of their own behavior to the staff serves as a learning tool for them to self-evaluate their skills. Staff interpretation of their own skill sets is very inaccurate, and this was manifested by the high scores that staff tended to give themselves even after watching initial video clips of their behavior. The staff were also required to provide a detailed description of what a good interaction consisted of prior to observing a second video

Table 10.2 Description of the PEARLS interaction model. Each component of the model is described along with descriptions of the behavior involved in each of the components

PEARLS element	Description
Positive	Was the staff member engaging in or initiating positive interactions with the person served? This was measured by a frequency count of the statements that were made by staff during the observation period and scoring them as positive if they were supportive of the person served and included praise or other components that were favorable. Examples of such statements would be “I heard that you had a great day at work today, great job,” or “you performed your cooking routine with very few problems today, congratulations.” some nonexamples that were provided included any directives given that were sarcastic or that delivered negative feedback to the participant such as “what kind of shirt is that? Don’t you know that those colors don’t match? What is wrong with you?”
Early	Did the staff member intervene early enough to avoid a more high-risk behavioral episode? This element of PEARLS was scored as occurring if the staff intervened verbally, gesturally, or physically as the person served started to engage in some of the precursor behaviors to their behavioral chains of aggression. Early responding meant that the staff intervened prior to significant high-risk aggression being displayed. This element was scored as not applicable (N/A) if no issues of inappropriate behavior or aggression were noted. The frequency counts of this element were then displayed as percentages according to the description above
All	Was the staff member interacting with as many of the persons served as possible? This element of PEARLS utilized a formula that looked at the number of persons served that were within a 6-ft radius of the staff member. If the staff member had five persons served within 6 feet of him/her during the observation period but interacted with only two of them, he or she was scored with a 40% for that interval (2/5 × 100 = 40)

(continued)

Table 10.2 (continued)

PEARLS element	Description
Reinforce	Did the staff member provide praise or other forms of reinforcement for displays of appropriate behavior? The reinforce element of PEARLS was similar to the positive element, with the main difference being that reinforce was based upon the staff member's response to the behavior of the person served as opposed to a general statement as described in the positive element. Scoring was the same as described above
Look	Was the staff member looking for opportunities to teach appropriate behavior at every opportunity? The look component recorded instances of staff interaction or statements that provided alternative appropriate response examples to the participant either verbally or through modeling after the display of inappropriate behavior. An example of the look element would be a staff member reviewing appropriate male-female interactions if the participant had made a sexually inappropriate comment or tried to fondle a staff member. Scoring for this element was the same as described above
Speak softly	Did the staff member use a conversationally appropriate tone of voice when interacting with the person served? The speak softly component focused on staff employing tones of voice that were too loud or authoritarian in nature. An example of the speak softly component would be the staff member using a tone of voice that could not be heard in an adjoining room or heard from a distance of at least 15 feet away

that was an exemplar of an appropriate interaction style as defined by the PEARLS model. The staff were given feedback after they scored their own video samples as well as their scoring of the clinical staff exemplar video. The feedback consisted of how their scores differed from the scores of clinical staff based on the operational definitions of the model as outlined above. The staff were also offered in vivo feedback after each interaction and a second opportunity to view a video sample of their interaction style after receiving feedback on their scoring and watching an exemplar video in the previous phases of the study. The results showed that all of the staff in the study significantly improved upon their PEARLS scores as a result of the video scoring, modeling, and feedback (see Fig. 10.4). Now that staff could display these skills, what type of an impact did increased PEARLS scores have on client engagement in functional activities and happiness indices?

The question to be answered was a viable one in that the functional impact of high PEARLS scores on the day-to-day behavior of the persons served was the real purpose of training these skills. In order to answer this question, PEARLS skills were taught to staff across three residential settings. The concomitant behavior of engagement in purposeful activities was measured for the persons with IDs living in these residences. Resident productive activity was patterned after the Group Activity Observation Form described by Reid and Parsons (2002). The scale allowed for discrete descriptions of the residents' behavior during 10-min observation periods:

Purposeful/Adaptive: Activities with a purpose.
Purposeful/Age Inappropriate: Activities associated with a younger age group.
Engaged: Manipulating materials in appropriate ways/exploration.
Nonadaptive: Lack of participation in purposeful activity.
Aggressive/Disruptive: Property destruction/aggression.

Measures of resident happiness were also assessed according to behavioral definitions described by Green and Reid (1996). Happiness was defined as any vocalization or facial expression that would be considered to be an indicator of happiness (e.g., smiling, laughing, yelling while laughing). Unhappiness was defined as any vocalization or facial expression that would be considered to be an indicator of unhappiness (e.g., frowning, crying, grimacing). Neutral was defined as facial expressions that did not fit either of the two categories (Guercio & Dixon, 2011). The results clearly demonstrated the efficacy of teaching positive therapeutic interaction skills and their subsequent impact on purposeful activ-

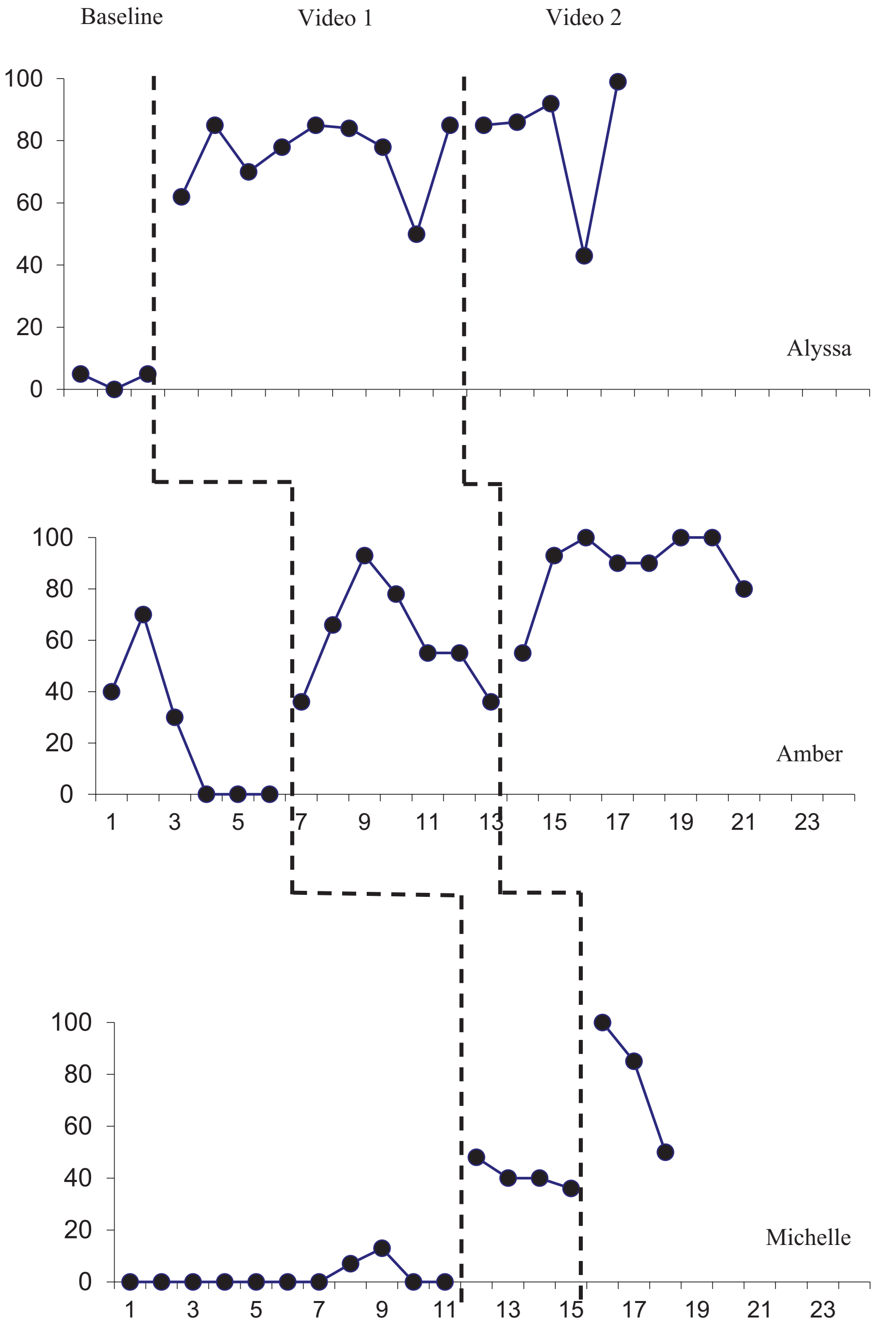

Fig. 10.4 PEARLS interaction scores for the three staff involved in the study. Scores are depicted during each of the phases of video modeling and feedback

ity and the happiness indices of those living in residential settings for adults with IDs. PEARLS behavior was found to increase across all of the phases of the study (see Fig. 10.5). Concomitant increases were also seen in the productive involvement of the residents in the homes where

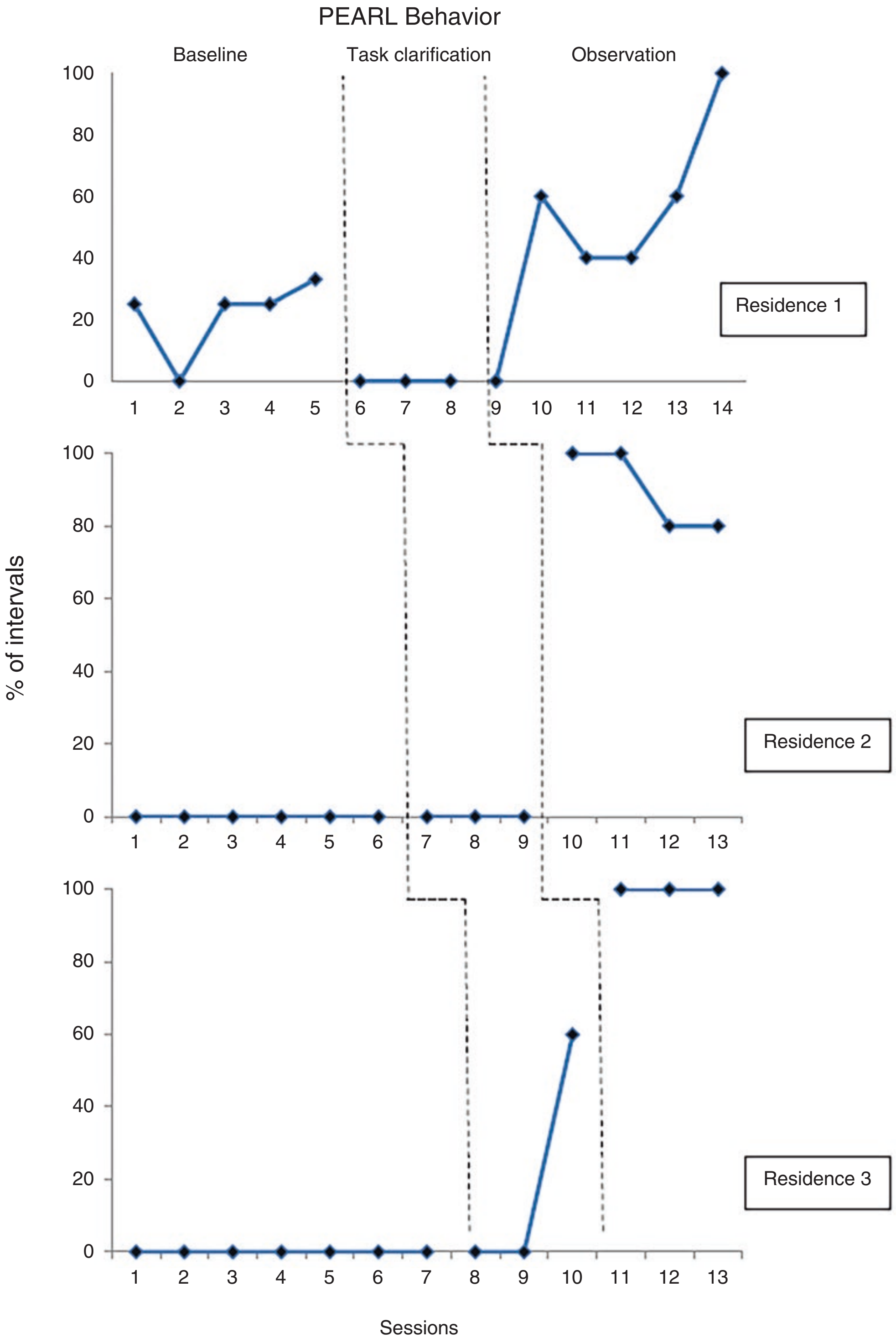

Fig. 10.5 PEARLS interaction scores for the three staff involved in the study. Scores are depicted during each of the phases of video modeling and feedback

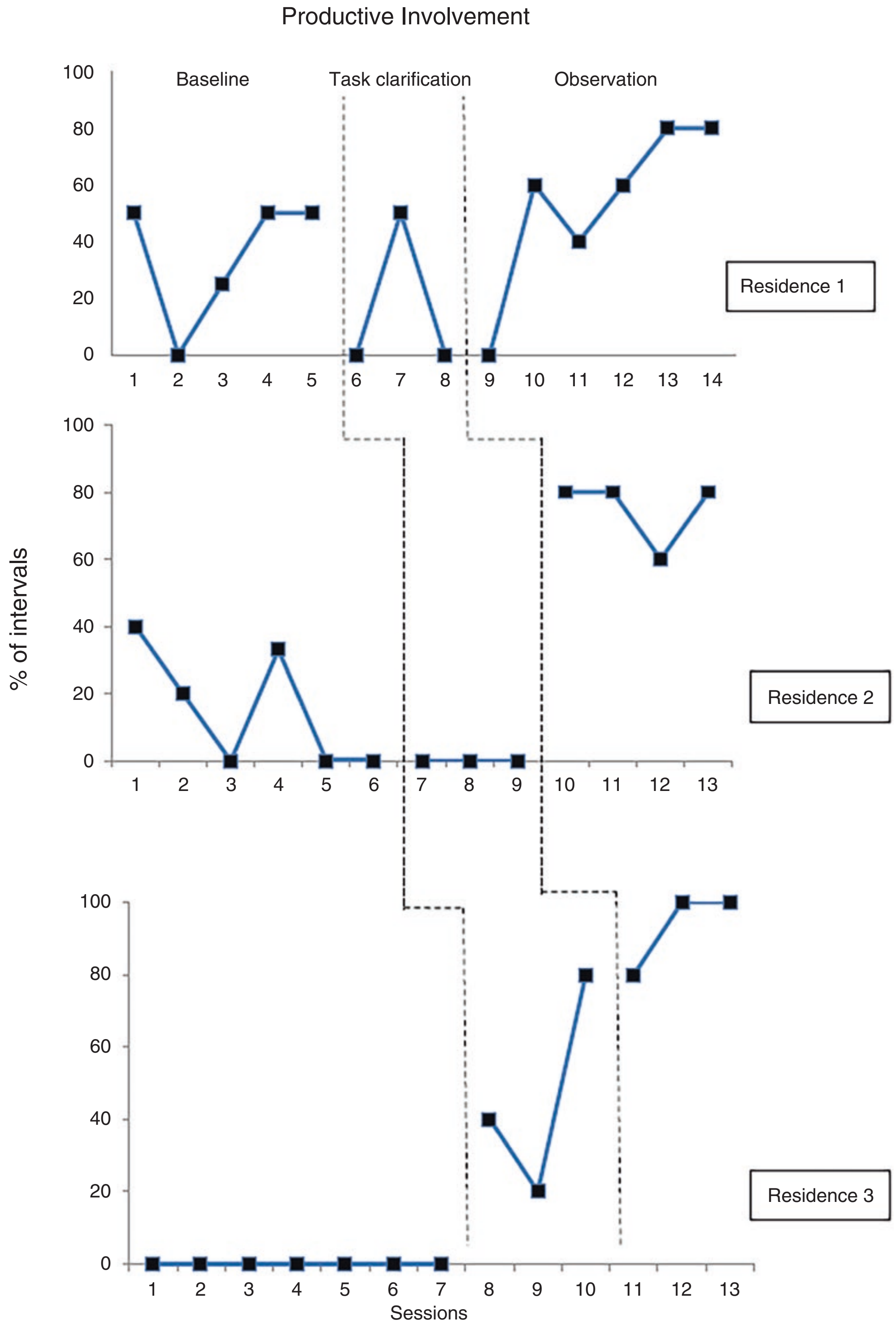

Fig. 10.6 Productive involvement scores for the three staff involved in the study. Scores are depicted during each of the phases of video modeling and feedback

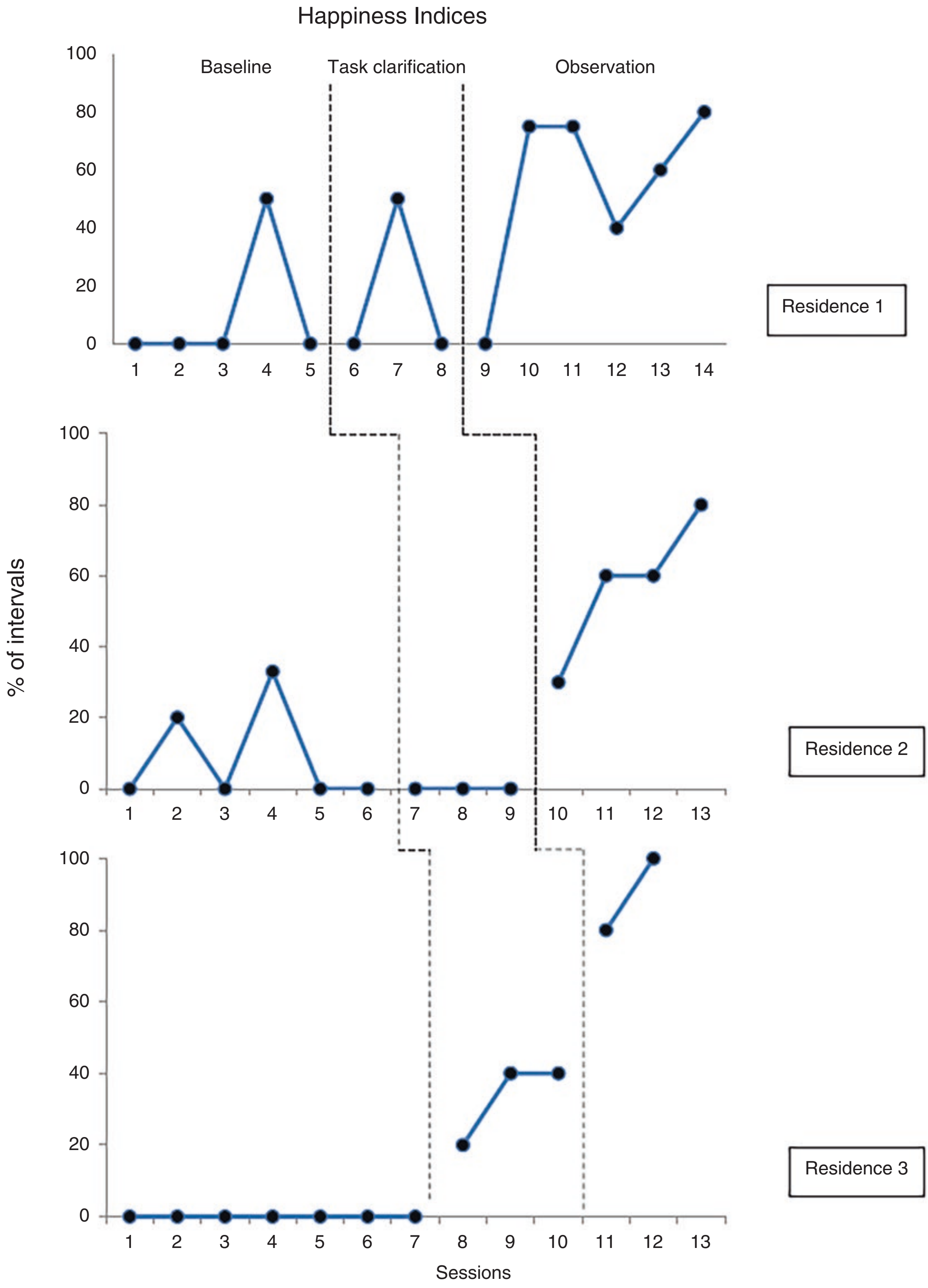

Fig. 10.7 Happiness indices scores for the three staff involved in the study. Scores are depicted during each of the phases of video modeling and feedback

the interventions were initiated (see Fig. 10.6). A very clear impact was also observed with respect to the happiness indices that were observed for the residents in homes where PEARLS scores were the highest (see Fig. 10.7).

Each of the outcomes described above demonstrates the utility of a science of behavior to positively impact socially valid behavioral outcomes in community-based residential settings.

Where Do We Go from Here?

We are many decades out from the mass deinstitutionalization movements of the 1960s. In order to more fully realize President Kennedy's vision for better community-based living options for persons with IDs, we must employ our science of behavior more meticulously to issues that have the greatest impact on persons with special needs. This chapter has illuminated the specific efforts of the field of behavior analysis in general, and OBM in particular, to facilitate improvements in the manner in which staff are trained to provide the critical services that they are charged with providing on a daily basis. We have the technology to do so, we must choose better targets of our services in order to produce more meaningful outcomes.

My core belief is that our focus should be more sharply on the direct care staff that work in community-based residential settings. The behavior of the people that we serve cannot experience the positive gains that clinicians envision unless there is a strong base of DSP staff that are dedicated to their duties and trained to criterion on what these duties entail. We should avoid wasting our time on meaningless training sessions in lecture-based formats at all costs. The literature has taught us that our staff training needs to include performance-based measures. Staff should also be required to demonstrate some minimum measurable competency in order to work in the homes in which they are assigned. We should stop spinning our wheels trying to teach staff behavior that may have little to no influence on socially valid outcomes and increased autonomy. By pinpointing these behavioral issues, we can avoid the inhumanity that was rampant in the institutional settings of the past. We are finally freeing those with IDs from these settings and need to be better prepared to address these issues in settings that are more appropriate for facilitating choice and independence in the communities in which they live. The lives of those that we serve may just depend on it.

References

Bellamy, G. T., & Horner, R. H. (1987). Beyond high school: Residential and employment options after graduation. In M. Snell (Ed.), *Systematic instruction of persons with severe handicaps* (pp. 491–510). Merrill.

Boles, S., Horner, R. H., & Bellamy, G. T. (1988). Implementing transition programs for supported living. In B. L. Ludlow, A. P. Turnbull, & R. Luckasson (Eds.), *Transitions to adult life for people with mental retardation* (pp. 101–117). Paul Brookes.

Brown, I., Hatton, C., & Emerson, E. (2013). Quality of life indicators for individuals with intellectual disabilities: Extending current practice. *Intellectual and Developmental Disabilities, 51*(5), 316–332. https://doi.org/10.1352/1934-9556-51.5.316

Butler, N. S. (1999). In the Most appropriate setting: The rights of mentally disabled individuals under the Americans with Disabilities act in the wake of Olmstead VLC. *Catholic. University Law Review, 49*, 1021.

Campbell, M. (2007). Staff training and challenging behaviour. Who needs it? *Journal of Intellectual Disabilities, 11*(2), 143–156. https://doi.org/10.1177/1744629507076928

Clement, T., & Bigby, C. (2010). *Group homes for people with intellectual disabilities: Encouraging inclusion and participation*. Jessica Kingsley Publishers.

Cook, T. M. (1991). The Americans with Disabilities act: The move to integration. *Temple. Law Review, 64*, 393.

Cresswell, M. (2008). Szasz and his interlocutors: Reconsidering Thomas Szasz's "myth of mental illness" thesis. *Journal for the Theory of Social Behaviour, 38*(1), 23–44. https://doi.org/10.1111/j.1468-5914.2008.00359.x

Daniels, A. C., & Bailey, J. S. (2014). *Performance management: Changing behavior that drives organizational effectiveness*. Aubrey Daniels International.

Goffman, E. (1968). *Asylums: Essays on the social situation of mental patients and other inmates*. Aldine Transaction.

Gorman, M. (1976). Community absorption of the mentally ill: The new challenge. *Community Mental Health Journal, 12*(2), 119–127. https://doi.org/10.1007/BF01411381

Gormley, L., Healy, O., Doherty, A., O'Regan, D., & Grey, I. (2020). Staff training in intellectual and developmental disability settings: A scoping review. *Journal of Developmental and Physical Disabilities, 32*, 187–212. https://doi.org/10.1007/s10882-019-09683-3

Green, C. W., & Reid, D. H. (1996). Defining, validating, and increasing indices of happiness among people with profound multiple disabilities. *Journal of Applied Behavior Analysis, 29*(1), 67–78. https://doi.org/10.1901/jaba.1996.29-67

Guercio, J. M. (2020). *Assessment of adult core competencies: Teaching skills to adults with autism and severe behavioral challenges. Assessment of adult core competencies curriculum (ACCEA) (For clients with extreme aggression)*. Hedgehog Publishers.

Guercio, J. M., & Cormier, R. J. (2015). Blending stimulus fading procedures with forward chaining to address treatment resistance in an adult with an autism spectrum disorder. *Behavior Analysis in Practice, 8*(2), 215–218. https://doi.org/10.1007/s40617-015-0060-5

Guercio, J. M., & Dixon, M. R. (2010). Improving the quality of staff and participant interaction in an acquired brain injury organization. *Journal of Organizational Behavior Management, 30*(1), 49–56. https://doi.org/10.1080/01608060903529780

Guercio, J. M., & Dixon, M. R. (2011). The observer effect and its impact on staff behavior in an acquired brain injury neurobehavioral treatment setting. *Journal of Organizational Behavior Management, 31*(1), 43–54. https://doi.org/10.1080/01608061.2010.520142

Guercio, J. M., & McMorrow, M. J. (2007). *Frequency and types of unwanted behavior exhibited in neurobehavioral rehabilitation*. Unpublished manuscript.

Guercio, J. M., Dixon, M. R., Soldner, J., Shoemaker, Z., Zlomke, K., Root, S., & Small, S. (2005). Enhancing staff performance measures in an acquired brain injury setting: Combating the habituation to organizational behavioral interventions. *Behavioral Interventions, 20*(1), 91–99. https://doi.org/10.1002/bin.174

Harchik, A. E., & Campbell, A. R. (1998). Supporting people with developmental disabilities in their homes in the community: The role of organizational behavior management. *Journal of Organizational Behavior Management, 18*(2–3), 83–101. https://doi.org/10.1300/J075v18n02_05

Hatton, C., Emerson, E., Rivers, M., Mason, H., Mason, L., Swarbrick, R., & Alborz, A. (1999). Factors associated with staff stress and work satisfaction in services for people with intellectual disability. *Journal of Intellectual Disability Research, 43*(4), 253–267. https://doi.org/10.1046/j.1365-2788.1999.00208.x

Hitzing, W. (1987). Community living alternatives for persons with autism and severe behavior problems. In D. J. Cohen & A. Donnellan (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 396–410). Wiley.

Im, D. S. (2021). Treatment of aggression in adults with autism spectrum disorder: A review. *Harvard Review of Psychiatry, 29*(1), 35–80. https://doi.org/10.1097/HRP.0000000000000282

Ivancic, M. T., & Heise, W. J. (1998). Organizational behavior management in large residential organizations: Moving from institutional to client-centered care. *Journal of Organizational Behavior Management, 18*(2–3), 61–82. https://doi.org/10.1300/J075v18n02_04

Jackson, S. E., & Maslach, C. (1982). After-effects of job-related stress: Families as victims. *Journal of Organizational Behavior, 3*(1), 63–77. https://doi.org/10.1002/job.4030030106

Lakin, K. C., & Stancliffe, R. J. (2007). Residential supports for persons with intellectual and developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(2), 151–159. https://doi.org/10.1002/mrdd.20148

Lakin, K. C., Prouty, R., & Coucouvanis, K. (2006). Changing patterns in size of residential settings for persons with intellectual and developmental disability, 1977–2005. *Mental Retardation, 44*(4), 306–309. https://doi.org/10.1352/00476765(2006)44[306:CPISOR]2.0.CO;2

Mac Suibhne, S. (2011). Erving Goffman's asylums 50 years on. *The British Journal of Psychiatry, 198*(1), 1–2. https://doi.org/10.1192/bjp.bp.109.077172

McMorrow, M. J. (2003). *Getting ready to help: A primer on interacting in human service*. Paul Brookes.

National Center on Birth Defects and Developmental Disabilities (NCBDDD). (2003). Chapter 6: Disability and secondary conditions, vision for a decade. In *Healthy people, 2010*. Centers for Disease Control and Prevention.

O'Brien, J. (1987). A guide to life-style planning. In G. T. Bellamy & B. Wilcox (Eds.), *A comprehensive guide to the activities catalog: An alternative curriculum for youths and adults with severe disabilities* (pp. 175–189). Paul H. Brookes.

Prouty, R. W., Smith, G., & Lakin, K. C. (2006). *Residential services for persons with developmental disabilities: Status and trends through 2003*. Research and Training Center on Community Living.

Racino, J. A. (1995). Community living for adults with developmental disabilities: A housing and support approach. *Journal of the Association for Persons with Severe Handicaps, 20*(4), 300–310. https://doi.org/10.1177/154079699602000406

Racino, J. A., & Knoll, J. (1986). Life in the community: Developing non-facility based services. *TASH Newsletter, 12*(9), 6.

Reid, D. H., & Parsons, M. B. (2002). *Working with staff to overcome challenging behavior among people who have severe disabilities: A guide for getting support plans carried out* (Vol. 1). Habilitative Management Consultants.

Robertson, J., Hatton, C., Felce, D., Meek, A., Carr, D., Knapp, M., & Lowe, K. (2005). Staff stress and morale in community-based settings for people with intellectual disabilities and challenging behaviour: A brief report. *Journal of Applied Research in Intellectual Disabilities, 18*(3), 271–277. https://doi.org/10.1111/j.1468-3148.2005.00233.x

Sharrard, H. E. (1992). Feeling the strain: Job stress and satisfaction of direct-care staff in the mental handicap service. *The British Journal of Mental Subnormality, 38*(74), 32–38. https://doi.org/10.1179/bjdd.1992.005

Shorter, E. (2000). *The Kennedy family and the story of mental retardation*. Temple University Press.

Singh, N. N., Lancioni, G. E., Karazsia, B. T., Myers, R. E., Kim, E., Chan, J., & Janson, M. (2019). Surfing the urge: An informal mindfulness practice for the self-management of aggression by adolescents with autism spectrum disorder. *Journal of Contextual Behavioral Science, 12*, 170–177. https://doi.org/10.1016/j.jcbs.2018.10.003

Stancliffe, R. J., & Lakin, K. C. (2005). *Costs and outcomes of community services for people with intellectual disabilities*. Paul H Brookes Publishing.

Sturmey, P. (1998). History and contribution of organizational behavior management to services for persons with developmental disabilities. *Journal of Organizational Behavior Management, 18*(2–3), 7–32. https://doi.org/10.1300/J075v18n02_02

Sundram, C. J. (1999). Pitfalls in the pursuit of life, liberty, and happiness. *Mental Retardation, 37*(1), 62–67. https://doi.org/10.1352/0047-6765(1999)037<0062:PITPOL>2.0.CO;2

Szasz, T. S. (1961). The uses of naming and the origin of the myth of mental illness. *American Psychologist, 16*(2), 59–65. https://doi.org/10.1037/h0040842

Torrey, E. F. (2014). *American psychosis: How the federal government destroyed the mental illness treatment system*. Oxford University Press.

Tøssebro, J., Bonfils, I. S., Teittinen, A., Tideman, M., Traustadottir, R., & Vesala, H. T. (2012). Normalization fifty years beyond—Current trends in the Nordic countries. *Journal of Policy and Practice in Intellectual Disabilities, 9*(2), 134–146. https://doi.org/10.1111/j.1741-1130.2012.00340.x

van Oorsouw, W. M., Embregts, P. J., Bosman, A. M., & Jahoda, A. (2009). Training staff serving clients with intellectual disabilities: A meta-analysis of aspects determining effectiveness. *Research in Developmental Disabilities, 30*(3), 503–511. https://doi.org/10.1016/j.ridd.2008.07.011

Wilson, A. N., Kasson, E. M., Gratz, O., & Guercio, J. M. (2015). Exploring the clinical utility of a stimulus avoidance assessment to enhance a relaxation training model. *Behavior Analysis in Practice, 8*(1), 57–61. https://doi.org/10.1007/s40617-014-0035-y

11

Community Settings and Individuals with Autism

Amy R. Bukszpan and Todd Streff

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that spans a lifetime (Lever et al. 2017). It has become increasingly evident that there are mounting challenges to be faced as those with ASD move from childhood to adolescence and then into adulthood (Dudley et al., 2019; Gerhardt & Lainer, 2011; Perkins & Berkman, 2012; Schott et al., 2021; Shattuck et al., 2012a, b). With estimates of over 48,000 teenagers with ASD turning 18 years old each year (Shattuck et al., 2012b), a further sizable cohort of individuals with ASD aging into their 70s (Perkins & Berkman, 2012), and 1 in 54 children being diagnosed with ASD (Centers for Disease Control and Prevention, 2020), the Centers for Disease Control and Prevention (CDC) warns that these trends should provoke heightened concerns over research and resources for those transitioning to adolescence and on to adulthood (CDC, 2020).

Adults with ASD and those who support them have many alternatives and decisions to manage as they navigate through the barriers they are likely to encounter in their day-to-day living. The authors of this chapter look at two broad aspects: deinstitutionalization and the move to the community and clinical concerns to ensure a high quality of living. Within each of these aspects, there are several factors to consider as we face an increasing number of ASD diagnoses and an aging population of ASD individuals needing services through adulthood. Factors include interventions and trained support to ensure an individual's health and safety, autonomy, and quality of life in the community.

Resnik and Blackburn (2009) noted that of 917 adults aged 19–30 years, only 32% reported still living with their parents or guardians, compared to 58% who indicated living independently, either with or without a spouse or partner. This same review looked at 1652 adults with ASD also, aged 19–30 years, and found that 79% still lived with their parents or guardians, with only 4% reporting living independently and 12% living in a supported residence for individuals with special needs (Resnik & Blackburn, 2009). Further, Hewitt et al. (2017) identified that individuals with ASD had a 42% lower chance of living independently when compared to their peers with developmental disabilities. Even more, Hewitt et al. noted a clear association between the type of living situation and severity of ASD symptoms.

Shattuck et al. (2012b) identified a dearth of research on services for adults and adolescents with ASD. The authors pointed to an "underdeveloped" and "uninformed" field of study and noted that "Extant research does not reflect the

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demographic or impairment heterogeneity of the population, the range of services that adults with autism require to function with purposeful lives in the community, or the need for coordination across services" (Shattuck et al., 2012b, p. 288). With the growing number of adults and adolescents with ASD living in the community, it is incumbent upon practitioners, service providers, and agencies to support these individuals with high-quality, evidence-based practices and interventions which meet their growing needs (Gerhardt & Lainer, 2011; Schott et al., 2021; Shattuck et al., 2012b). This includes evaluating community-based options from access to resources and support services to developing long-lasting social relationships.

With Shattuck et al. (2012b) in mind, this chapter will first seek to briefly review the history of community living in the ASD population and outline a variety of community-based housing options by assessing placements based on the degree of supports and availability and access to the community. Next, this chapter will evaluate indicators for increasing an individual's access to a high quality of life by outlining various concerns relative to community living and provide clinical recommendations for practitioners providing services for clients in these settings.

Part I: Deinstitutionalization and the Move to the Community

Between the 1950s and 1970s, the United States saw a drop from an estimated 560,000 institutionalized individuals to less than 50,000 (Hinshaw, 2007). It was a period marked by widespread deinstitutionalization of psychiatric hospitals and developmental centers with the passing of the Community Mental Health Centers Construction Act in 1963 (Lima et al., 2018). The treatment and housing of individuals with mental health disorders and developmental disabilities moved from large, often state-run, institutions to community-based residences (Leslie et al., 2017). While goals sighted for this transition include the improvement of long-term outcomes for the residents and increased accountability for staff (Mandell, 2017), additional reasons included abolishing inhumane living conditions as well as an increased hope that psychotropic medications would provide adequate resolution to interfering behaviors (Lima et al., 2018). A further reason for deinstitutionalization included reduced cost of care, as funding moved from hospitals to community-based treatment (Lima et al., 2018; Yohanna, 2013).

State-run facilities, such as hospitals and institutions, were to serve not only a housing function for individuals with mental health disorders and developmental disabilities but were also to provide ongoing support services including therapeutic and medical treatment, medication, prevocational and vocational training, employment opportunities, and a built-in community (Yohanna, 2013). However, it became increasingly evident, after a 1970s expose of the filthy, experimental, and inhumane treatment of residents at a state-run school for children with developmental disabilities, that individuals in institutionalized settings, shuttered behind closed doors, out of sight, and out of the mind of many, could easily become victims to squalid conditions, unethical practices, and abuse (Mandell, 2017). Evaluations for alternative funding, the Civil Rights Movement of the 1960s, with calls for the equality and autonomy of marginalized and vulnerable populations, and the response to the publicity of the appalling findings at the state-run school, all moved the mission for deinstitutionalization forward across the United States in the 1970s (Lima et al., 2018).

State Medicaid waiver programs allowed states to cover the costs for the care and support of an individual with disabilities in their home or community rather than a hospital or institutionalized setting (Velott et al., 2016). Initially, Medicaid waivers only covered particularly at-risk individuals who would otherwise be placed in skilled nursing facilities, intermediate care facility, or intermediate care facilitate for the mentally retarded (Miller et al., 1999). However, the passing of the Omnibus Budget Reconciliation Act (OBRA) of 1985 authorized state administrators to utilize Medicaid waivers for home- and community-based services (HCBS). Further, the passing of the *Olmstead* ruling by the Supreme Court in 1999, which mandated that individuals with disabilities receive services in integrated settings, pressed the growth of HCBS and the further movement away from hospital and institutionalized settings (Schott et al., 2021; Velott et al., 2016). By 2010, 47 states were using HCBS waivers to cover the long-term care of over 1.4 million adults and children, with over one-third of those individuals having an intellectual or developmental disability (Velott et al., 2016).

Presently, Medicaid waivers are used to provide a variety of community-based services for individuals across the United States with 2.5 million people receiving services. These services include case management, day care, habilitation, home health care, nursing, personal care, respite care, medication management, training, and transportation (Miller et al., 1999). Unfortunately, due to the growing demand in services and the decentralized nature of individually run state Medicaid waiver programs (Velott et al., 2016), nearly half a million individuals with ASD or other intellectual or developmental disabilities are either on waitlists for Medicaid waivers or waiting for approved Medicaid services (Schott et al., 2021). Thus, even though the Medicaid waiver program markedly helped to reduce the number of individuals with developmental and intellectual disabilities living in institutions, there is growing disparities in services as well.

Transitioning from Institution to Community: A Case Study

Transitioning individuals from an institution to community-based housing options comes with risks, fears, concerns, and barriers. Horn et al. (2013) provided a case study of Tim, a 47-year-old man, diagnosed with severe ASD and profound developmental delays with a history of aggression and property destruction, who, after nearly 7 years of seclusion within an institutionalized placement, transitioned to near-full community inclusion. In their evaluation, Horn et al. noted the transition was prompted by two factors. The first was a legal issue and the second an ethical one. Due to a dropped assault charge, Tim was no longer mandated to the forensic unit of the hospital; thus, he was to transition into the greater hospital ward and then into an appropriate community setting; this was the legal issue. The ethical concern was over a question of quality of life. How could Tim be expected to have anything other than a poor quality of life if he was alone in a locked room for most of his life. Together, these issues drove Tim's initial steps to transition.

Horn et al. (2013) use this case study not only to underscore the successful interventions utilized but also to evaluate staff training, the overall effects of rapport building and developing trust between a client and practitioner, and the ultimate change in staff attitudes toward Tim. By not only considering the rights and success of the individual under care but additionally accounting for the emotions and safety of direct-care staff, Horn et al. (2013) provided an excellent framework for clinical recommendations which we will return to later in this chapter.

Types of Community Settings

Several questions come to mind for anyone on the hunt for a new home or moving out on their own for the first time. Do I want to live in a city or are the suburbs okay? Am I okay with rural housing; driving a distance to get to work, school, medical appointments? What kind of home am I looking for? Single-family dwelling or an apartment? Should I live with roommates, on my own, or do I stay close to home? Can I afford to live here? What type of job can I secure? What will my public benefits (e.g., Supplemental Security Income [SSI] and Social Security Disability Insurance/Disabled [SSDI] Adult Child Benefits) cover? This is a challenge for sure. For the increased number of individuals with ASD reaching adulthood, and their families, seeking housing options comes with even further questions. Additional considerations may include the level of daily support required, degree of access to behavioral or medical health, availability of career and vocational supports, and access to social activities, friends, and family.

While there are a variety of community housing options available for individuals with ASD, these options often lack consistency and a clear framework for selecting, identifying, and evaluating each model (Resnik & Blackburn, 2009). From group homes to independent living, renting a space alone or living with peers, to living with foster parents or ultimately choosing to stay at home with parents, each model should be evaluated based on an individual's needs, values, and reinforcers, as well as for overall safety, access to interventions, and social network. Thompson et al. (2018) found that caregivers regarded the success of their adult child's living arrangements by the degree of individuality of the placement, which involved not only available resources but the style and built of the home as well. Considerations for paying for the residence, state-funded programs, or individual responsibility need also to be planned.

The heterogeneity of ASD creates further problems for selection of the best community-based options for housing as there is truly no one-size-fits-all option. Research indicates that for adults with ASD, intellectual and verbal abilities in childhood are strongly correlated with improved outcomes as adults (Howlin & Magiati, 2017), potentially suggesting less of a need for supports and interventions for these individuals in community living settings. Also, Stuart-Hamilton and Morgan (2011) found that for aging adults with ASD without intellectual disability, maintaining a high quality of life included employment which highlighted fiscal freedom, affording a living situation with greater access to social interactions and the community. However, Zimmerman et al. (2018) noted that the perceived social support of adults diagnosed with high-functioning ASD, which included access to interventions, was also related to improved psychosocial outcomes. Thus, when analyzing options for community-based options, be it housing, employment, or support services, it is important to always take the individual's perspectives into considerations as well as their ultimate goals.

The importance of selecting an appropriate community-based housing option lies in the individual's ability to lead a high-quality life marked by access to reinforcement through the environment. Krauss et al. (2005) set out to identify parental perspectives on adults with ASD living at home or in community-based settings by collecting data from 133 families. Participants all had a son or daughter, aged 22 years or older, with ASD. Of the population, 63% lived in a non-family setting with the remaining living with their parents at home. Outcomes of the study found mothers to have positive and negative perspectives on their adult child living at home or in community. Co-residing with their adult child at home was marked with their child receiving good care and security, as well as indicators of overall happiness. However, negative aspects of living at home involved problems with the family managing their adult child's behaviors, lack of social interactions, limitation of freedom, and concerns over their child's future. Mothers with adult children living in community-based settings also noted a range of both benefits and disadvantages for their children. Benefits included their child learning new skills and building independence, having a greater social life, and making friends, as well as having a more age-appropriate lifestyle. Negatives included challenges over staffing; concerns regarding training, turnover, and communication; and worry regarding the overall quality of care of their child, including their safety, personal hygiene and grooming, and less integration with the family.

Krauss et al. (2005) highlighted the perspectives of parents examining some commonly noted pros and cons of community-based living and why so many parents opt to keep their adult children with ASD living at home. Their study echoes the voices of many other parents of adults who struggle with the urge to ensure the safety and well-being of their adult child but who also seek to maintain a balance in their own lives. Unsurprisingly, there are a high number of adult individuals with ASD who still live at home, co-habituating with their parents, due to the key factors identified in the previous study.

It is reported that young adults with ASD reside with their parents or guardians more often and for longer duration than peers with and without developmental disabilities (Anderson et al., 2014). For these individuals who remain at home, this placement can only last if parents or guardians can provide direct care or ensure supplementary support services for their adult children. Interventions focused on developing activities of daily living, a greater reliance on day services, and a focus on supported employment all become progressively more important in the development of the individual and the ability for the caregiver to maintain care (Autism Society San Francisco Bay Area, 2021).

Discussions surrounding adults with ASD living at home often revolve around the individual's effect on the caregiver and stressors on family resources (Krauss et al., 2005; Marsack-Topolewski et al., 2021; Wong et al., 2020) as well as limited access to services and community access (Schott et al. 2021). However, Krauss et al. (2005) found that for some mothers of adult children with ASD, keeping their children at home and in their care was marked with benefits to the family as well as their sons and daughters. However, perceived caregiver burden does directly affect the ability of a family to care for their adult child with ASD at home and for that individual's ability to access resources in and around the community (Wong et al., 2020).

Caregiver burden and caregiver capacity to provide care both greatly affect the quality of life of an individual living at home with ASD as well as the quality of life of the parent or guardian providing care. Autism severity has been found to be a significant predictor of caregiver burden and to negatively impact the caregiver's quality of life (Stuart & McGrew, 2009). Further, mental health concerns and challenging behaviors are the two most noted forecasters for parental burden (Wong et al., 2020).

Marsack-Topolewski et al. (2021) evaluated parental perceptions of caregiver burden for 320 parents, aged 50–59 years, who had at least one adult child with ASD living at home. Marsack-Topolewski et al. then sought to evaluate whether teaching the skills associated with activities of daily living (ADLs) would reduce the parents' overall, perceived parental burden. The adult children of the participants represented the heterogeneity of adults with ASD living at home with their parents or guardians. Of the participants' children with ASD, 42% had access to some level of employment, including sheltered workshops, a job coach, a full- or part-time job, and referenced friends in the community. Further, Marsack-Topolewski et al. noted that nearly 25% of the participants' children attended public schools, 16% attended university or college programs, and 4.1% attended a vocational training program and that only 11% of parents reported that their adult child with ASD engaged in serious interfering behaviors.

Marsack-Topolewski et al. (2021) analyzed parental burden across 15 items using a Caregiver Burden Inventory (CBI) along with three items from the Caregiver Reaction Assessment (CRA). The CBI and CRA evaluated for items across four categories of parental burden: time dependence, developmental, emotional, and financial. The time dependence burden was related to topics interfering with the parents' time dedicated to such items as helping their adult child to perform daily tasks, needing to always supervise their child, and their child's overall dependency on them for basic functioning. The next category, the developmental burden group, included questions regarding the parents' own personal development and included issues around feelings that they were missing out on in their own life, emotional stress, their social life, and personal expectations. The emotional burden grouping consisted of parents' negative feelings directed toward their adult child with ASD such as feeling ashamed by them, resenting their child, feeling uncomfortable with friends over, and being angry over their own interactions towards their child. Lastly, to measure the financial impact of raising and supporting an adult with ASD in their home, the researchers asked questions over availability of adequate resources and financial strain under the financial burden question classification. The mean score of all four categories represented the total, parental caregiver burden. Overall, Marsack-Topolewski et al. (2021) found that the higher the parental burden score, the greater their adult child's deficits in ADLs.

The results of Marsack-Topolewski et al. (2021) indicated that interventions which focus on developing independence in ADLs can be beneficial to the adult child with ASD and the parents providing care. Parents noted feeling less caregiver burden which can improve the relationships between parents and children and maintain a healthy home life and emotional well-being for both parties. Meanwhile, those adult children with more age-appropriate functioning in ADLs reportedly had increased access to the community, held jobs or job placements, engaged in social interactions, and had friends. This suggests the importance for practitioners to continue to target interventions related to independently engaging in ADLs, even as an individual with ASD ages (Marsack-Topolewski et al., 2021). It further implies that an individual's ability to care for themself is directly related to their access to improved quality of life and potentially less restrictive housing placement with greater access to the community.

The following sections will highlight various models of community living by evaluating each example by its access to the community, availability of resources, and a brief outline for individuals who may be more successful in each setting. Later in the chapter, we will provide clinical recommendations to connect the gaps between appropriate settings and access to suitable services as well as suggestions to practitioners to improved interventions to sustain a high quality of life within community-based settings.

Housing Options

Supervised Group Homes

With 24-h support staff and a focus on promoting skills of independent living for the residents, group homes may be the most restrictive of community housing options. Scattered throughout the community, these homes are relatively small dwellings with no more than eight individuals living in the home at a time, with some homes housing as few as two residents. These community residences are actual homes or apartments, where individuals with disabilities, including ASD, can live with support staff and peers. An agency typically owns the residence itself and provides training to the direct-care staff who treat and aid the residence across multiple facets of their daily tasks. Through direct intervention and individualized programming, support staff work with residents on gaining the appropriate skills to move on to more independent community living, within and beyond the group home. These skills can include activities of daily living such as hygiene, dressing, and grooming. It can also include money management, housekeeping, and home maintenance (Gerhardt & Lainer, 2011).

Some have argued that group homes lack participation and individualization of programming and restrict access to the community (Gerhardt & Lainer, 2011). However, the Teaching-Family Model has been a replicated and successful means of caring for and treating individuals with ASD in community living environments (Fixsen et al., 2007). With its initial implementation in 1967 at Achievement Place (Wolf et al., 1995), a group home for delinquent children, the Teaching-Family Model supports eight ambitions which provide a central focus on how the program cares for, treats, and achieves outcomes for the residents, stakeholders, practitioners, and institution. With an emphasis on ethically appropriate, compassionate, and respectful services with programming that is cost-efficient, effective, individualized, socially valid, and replicable, the Teaching-Family Model has been replicated for well over three decades and has demonstrated success in extensions to community-based and adult applications including individuals with ASD (McClannahan et al., 1984). In fact, in the 15 years after the initial start of Achievement Place, 792 couples trained were to run Teaching-Family group homes with over 303 homes that had opened (Fixsen et al., 2007; Wolf et al., 1995).

With the addition of two other staff, Teaching-Family group homes are led and managed by a married couple referred to as Teaching-Parents. These homes support up to seven individuals with the couple making the group home their permanent residence. These Teaching-Parents are ultimately responsible for the individualized treatment procedures, behavior reduction, and skill acquisition of everyone in the home (Fixsen et al., 2007).

The original Teaching-Family Model was designed to incorporate behavioral contingencies to shape and reinforce appropriate behaviors for a group of troubled youth as an alternative placement to a large, state reform school (Wolf et al., 1995). Teaching-Parents were thus trained to utilize the behavioral principles of motivation and reinforcement using token economies and other extrinsic and intrinsic systems to facilitate behavior change in the boys (Wolf et al., 1995). Currently, the Teaching-Family Model is used to provide individuals with intellectual disabilities a community living experience which incorporates positive behavior supports, employment options, and social development (Teaching-Family Association, 2021).

The Teaching-Family Model represents a potentially beneficial and sustainable model for group homes for individuals with diverse needs (Fixsen et al., 2007). Due to the staffing structure of the Teaching-Parents, there is limited staff turnover, which creates greater opportunity for staff to develop more beneficial and effective relationships with residents and reduces costs related to training and recruitment of a revolving door of incoming staff (Gerhardt & Lainer, 2011).

Cooperative Living

Cooperative living and congregate living arrangements are like group homes. They are relatively small, community-based residences that cater to an autism-friendly life. Trained staff from an agency typically support the inhabitants of the home, which is typically owned by a group of parents, a single parent, a nonprofit entity, or a community group, which creates an LLC (Autism Speaks, 2011). In the case of either cooperative or congregate living arrangements, residents have all the benefits of a group home, such as hired caregivers to aid the residents in their daily tasks at the home, but also the same pitfalls, such as high turnover and undertrained staff.

Supported Living

For an adult with ASD who can live independently in their own home but still requires some level of assistance, supported living arrangements may be most appropriate. Intended as a placement to nurture an individual's engagement and interaction in their community (Resnik & Blackburn, 2009), in this type of setting, individuals may receive support in socialization, planning, personal hygiene, or any other specified area at a significantly lower intensity than those living in a group or cooperative home (Easterseals, 2021). In a supported living model, support services are catered to the individual's unique needs, with service providers who work directly with the individual focusing on target areas (Autism Speaks, 2011). These homes can be individually owned or leased, with some people receiving public funding to supplement their payments (Resnik & Blackburn, 2009).

In one review of residential options for adults living with ASD and other related disorders, four tenets of supported living were outlined (Resnik & Blackburn, 2009). These included availability of support to anyone regardless of the level of support needed, individual-directed planning rather than agency directed, and purposeful planning and small residential groups, which increase access and engagement with the community and community resources (Resnik & Blackburn, 2009).

Independent Living

For anyone, living independently comes with a set of responsibilities and skills: from managing finances, ensuring the trash goes out on Mondays (or is it Tuesdays?) to knowing an appropriate time to go to bed and when to get up. Independent living is much more than mastering a handful list of competencies; it is learning to navigate rather complex and novel experiences by making choices and learning from the consequences of those decisions. It can be simultaneously liberating, frightening, and lonely. For adults with ASD who possess all the necessary skills and knowledge, as well as an integrated support network, independent living is a successful choice. For others, it can be a forced circumstance (Joshi, 2020) due to the passing of the primary caretakers or some other life event.

A Case Study of Independent Living Joshi (2020) provided a review of a 24-year-old adult male, Aakash, who was living independently after the passing of his parents in India. This case study illustrated a few struggles Aakash faced in living on his own and highlights the importance of social support in successful integration in the community. This analysis not only pointed to the evaluation of physical and mental health but also considered the benefits of reciprocal relationships on Aakash's social and spiritual well-being, factoring in the individualization of culture for his successful integration in community living.

Of concern to those around Aakash was his lack of socialization, general hygiene and self-care, cleanliness of his home, understanding the intent of others, and safety. Overall, Aakash overcame these concerns and integrated into the community successfully due to a strong familial, support network, which promoted and reinforced his self-advocacy and fostered his independence. Joshi (2020) noted that Aakash's aunt and uncle were integral in his achievement, checking in on him frequently and often dictating to him what needed to be done. However, Joshi further indicated that Aakash had his own, often strong, opinions, was not often open to other's recommendations unless provided with a rationale, but also sought advice from others. Ultimately, Aakash held a job, went on a vacation, made friends with neighbors, managed his finances, ran his home, shaved regularly, and even participated in health courses to better maintain control over his diabetes. This case study demonstrated the benefits of a caring and engaged network of people working with an individual to ensure their successful integration into the community and access to resources (Joshi, 2020). It further underlined the importance of fostering skills of self-advocacy, problem-solving, and seeking and receiving support for individuals living on their own.

Part II: Clinical Concerns and Ensuring a High Quality of Life

Every person has the right to a high quality of life. Each person's definition of what that life is is likely to be a little different. For one person, it may be the ability to go out and see friends, have a job, or feel secure in their relationships, while for another, it could be cooking a meal, aging gracefully, or knowing they can care for themselves. However, ensuring that individuals with ASD have a high quality of life, and a quality of life they want, can be a challenge for practitioners when individuals live in community settings. A fulfilling quality of life involves many aspects beyond the home, like feeling safe and active within a community. It can be accessing community shopping, knowing where to go, how to get there, and appropriate conduct in each setting. Further, community life is socialization, going out for a movie, watching a ball game, dating, and relationship building. Even more, community life may mean belonging to a church or synagogue, engaging in a community of faith, participating on a team or sports league, and even hanging out at a local bar.

In the United States, control of one's own finances, a sustainable income, and a fulfilling job are all seen as part of a person's overall quality of life, and this should be no different for individuals with ASD (Gerhardt & Lainer, 2011). Assessment for "happiness, health, safety, and community engagement" should be measured for each individual placement (Mandell, 2017 p. 811). Further, interventions that include opportunities for individuals to possess the highest quality of life by means of engaging in a full range of activities (Bishop-Fitzpatrick et al., 2016), which promote the individual's independence and well-being and the "realization of one's full potential in caring out activities at home" (Marcotte et al., 2020, p.101), should be of maximum importance.

According to the US Bureau of Labor Statistics, only 17.9% of individuals with disabilities were employed in 2020. By comparison, 61.8% of individuals without a disability were employed (U.S. Bureau of Labor Statistics, 2020). Reports indicate that of 25-year-olds with ASD, nearly half reported never holding a job (Autism Speaks, 2021). Medicaid waivers are intended to aid in the access of long-term supports to vulnerable populations including individuals with ASD to increase HCBS and, thus, overall indicators of a higher quality of life. Waivers include financial coverage for vocational training, medical assistance, mental health, and physical health care, as well as housing options. However, there is a serious deficit in the number of actual met services for individuals with ASD when compared to those who are approved for waiver services. Further, of the adults with ASD, those with a co-occurring diagnosis of a mental or behavioral concern were more likely to have unmet service needs. Even more, individuals with developmental disabilities, intellectual disabilities, and learning disabilities who noted receiving some services still reported unmet services related to mental or behavioral health, activities of daily living, and employment and vocational training (Schott et al., 2021).

Evaluating the quality of life for individuals with ASD can inform recommendations for community settings including interventions and necessary services. Further, appropriate amounts of quality support can lead to improvements and maintenance of a high quality of life. This can include support around the foundations of daily routines, a partner to shop with, or even a full-time caretaker (Edwards et al., 2018). In a large-scale quality-of-life study, which measured the self-described quality of life of its participants, Mason et al. (2018) evaluated the quality of life for 370 participants with ASD in the United Kingdom. Results indicated that those who reported having a higher quality of life were independently employed and engaged in social relationships but also received assistance from a supportive environment, which included interventions related to activities of daily living, money management, vocation, and social skills. Those who reported lower quality of life feared isolation as they aged and diminished supports.

Challenges to Consider in Delivering Effective Community-Based Services

Community-based services, which include programs that not only foster independence but also focus on providing individuals with a high quality of life, adopt a strategy which weaves employment, independent living, and social engagement. This can incorporate daily programming and direct-care support for cooking, cleaning, and bathing, group or individual social activities, professional guidance for job tasks, and medication management. Securing a high quality of life includes living a life rich in reinforcement with minimal barriers in accessing preferred environments, people, and activities. Additionally, it includes the availability of medical care and an overall sense of safety and security (Bishop-Fitzpatrick et al., 2016). Yet, there are several barriers and challenges to service delivery that must be considered when planning for evidence-based interventions in the community.

This section will review specific challenges to addressing the quality of life of adults with ASD in community settings. It includes an investigation into behavior supports and the prevalence of co-occurring mental health diagnosis, as well as an analysis of safety concerns across everyday skills and concerns around abuse and violence. Considerations toward stigma and collaborating with community organizations are also reviewed including a focus on transportation and access to religious- and faith-based organizations. Barriers around staffing are also discussed.

Behavior Supports and Co-occurring Mental Health Diagnosis

Identifying resources and services that address challenging or maladaptive behaviors and co-occurring mental health conditions should be a priority in promoting successful community living for adults with ASD (Schott et al., 2021). Understanding ways to work with individuals within their communities to address these conditions, such as finding providers, collaborating with case management, and delivering applicable interventions, are all key essentials in maintaining a safe and happy life. While this may present additional challenges for practitioners, it is of high necessity for this group as research has shown considerable support suggesting the association between challenging behaviors in individuals with ASD and mental health problems (Painter et al., 2018).

ASD is associated with behavioral excesses, engaging in repetitive and restricted behaviors, and the presentation of maladaptive behaviors

(Wing & Gould, 1979). Challenging behaviors can include self-injury, aggression, property destruction, and outbursts, which can increasingly interfere with a person's life and can cause harm to themselves or those around them. Even more, these behaviors can restrict access to preferred environments and people and can contribute to an individual's stress and reduced quality of life (Mudford et al., 2008, Prior & Ozonoff, 2007). Consequently, adults with ASD have been found to be up to three times more anxious overall than a comparison group of individuals with intellectual disabilities (Gillott & Standen, 2007).

It is well documented that children with ASD present with challenging behaviors that interfere with everyday activities, restricting their access to people and places (Wing & Gould, 1979). Studies have also demonstrated that increased severity of ASD, with co-occurring intellectual disabilities, increases the severity of challenging behaviors (Lundqvist, 2013; Painter et al., 2018). In an investigation of 106 young adults with ASD, Rattaz et al. (2018) confirmed that individuals with ASD continue to engage in challenging behaviors well into young adulthood and that there was a direct relationship between deficits in language and cognition and the likelihood of challenging behaviors. Additional findings suggested that communication deficits may maintain self-injury, highlighting the importance of ongoing language and communication interventions for adults with ASD.

Of a group of 180 adults diagnosed with ASD, 80.2% were also diagnosed with a comorbid mental health condition, with the majority diagnosed with anxiety disorder or obsessive-compulsive disorder (Bishop-Fitzpatrick et al., 2016). Additionally, in a similar study of 370 adult participants diagnosed with ASD, 70% reported a mental health diagnosis, with anxiety and depression rounding out the most frequently reported disorders (Mason et al., 2018). Schott et al. (2021) identified that of adults with ASD who responded to a survey of individuals on a wait list for HCBS, nearly 53% reported having unmet needs for mental and behavioral services with most co-occurring diagnoses identified as anxiety, depression, and ADHD.

Maddox et al. (2020) interviewed 22 adults with ASD, 44 mental health clinicians, and 11 agency leaders including clinical and executive directors from six community health centers. All three participant groups were asked to identify barriers to services. Of the 22 participants with ASD, 21 reported previously receiving mental health services, underscoring the importance of services for this population. They most often cited obstacles to service delivery consistent of clinicians who failed to understand autism, provided recommendations that were impractical or nonfunctional to their client, client feelings of being underchallenged to make progress, as well as citing being "distracted or distressed" by stimuli in the office (Maddox et al., 2020, p. 923). Clinicians' major barriers to treatment were lack of knowledge about autism, with 43 of 44 clinicians noting they had never received any ASD-specific training. Agency leaders concurred, mentioning that, "limited knowledge about autism leads to poor competence and low confidence working with this population" (Maddox et al., 2020, p. 923).

Maddox et al. (2020) emphasized the need for better informed, educated, and trained mental health professionals for working with individuals with ASD, and they are not alone. Ghaziuddin et al. (2002) called for the expansion of research and interventions in treating depression and ASD, while Lake et al. (2014) called for partnerships between developmental disability agencies and community mental health providers in the training and delivery of services for those with high-functioning ASD.

Community Safety and Abuse

Teaching individuals with ASD to guard themselves against, and identify, unsafe and potentially abusive situations is paramount to successful community living (Gerhardt & Lainer, 2011; Hughes et al., 2020; Miltenberger et al., 1999). Moreover, as adults with disabilities are more at risk for physical, emotional, and sexual violence (Gibbs et al., 2021), it is incumbent that considerations for community engagement come with explicit planning to address these concerns (Hughes et al., 2012). In their review, Mikton et al. (2014) reported identifying limited results on the effectiveness of specific interventions on decreasing and responding to violence toward individuals with disabilities. Yet, Mikton et al. (2014) noted this dearth in research simply reveals the significant gaps in this work and emphasized the efforts which need to be made.

Hughes et al. (2020) studied 170 participants ranging in age from 18 to 67 years, all with some level of intellectual or developmental disability who lived in community settings, with 60% reporting some type of past abuse including nearly 50% reporting emotional abuse, 25% reporting physical abuse, and 21% and 18% reporting sexual and disability-related abuse, respectively. Still Hughes et al. (2020) hypothesized that these percentages were under representative of their participant population, as around 20% indicated they would rather not say if they were victims of abuse or others who indicated that they did not know if they were victims or not (Hughes et al., 2020).

Navigating daily living comes with obstacles related to health and safety. From simply crossing the street, to boiling a pot of water, to getting from point A to point B without getting lost, and then knowing what to do if one should get lost, there is potential for danger in everyday tasks to which most adults rarely give a second thought. However, for adults with ASD who may possess deficits in identifying dangerous scenarios (Gerhardt & Lainer, 2011), the potential for danger adds to the challenges of living a fully independent life. Even more, given recent concerns over interactions with the law enforcement, considerations on how to safely interact with police officers have similarly been noted as an important skill for individuals with ASD to attain (McCleery et al., 2020).

Teaching safety skills is a must for practitioner consideration when supporting adults with ASD in the community and needs to be evaluated based on the specific needs and abilities of the client. This includes an investigation into problem-solving and appropriate responding in high-stress environments, evaluating abilities to assess novel situations, and then understanding and demonstrating the appropriate manner to respond (McCleery et al., 2020).

Collaboration with the Community

As already described in this chapter, community involvement and access must not only encompass appropriate housing, but it must also embrace a holistic approach to community inclusion, which promotes successful employment and participation in a variety of community-based programs (Scheeren & Geurts, 2015). Membership or contributions to community activities like engaging in religious- and faith-based services (Terry, 2015) and neighborhood gardens (Rubin, 2018) have been shown to have increased positive outcomes for individuals with ASD. Inclusive communities and activities can offer adults with ASD a sense of safety and belonging, which some research has shown to increase self-reliance and resilience with the potential to decrease maladaptive behaviors (e.g., Farkas et al., 2020, and Lai & Szatmari, 2019), thus improving the overall quality of life. Limitations, which may affect or restrict community involvement, can include transportation, accessibility, and additional support staff needed to assist the individual throughout their environment (Gerhardt & Lainer, 2011). Yet, the available benefits that community living promotes can far outweigh the potential limitations. With critical evaluation and collaboration with all stakeholders, access can and should be made.

Scheeren and Geurts (2015) completed a systematic review of the research on community integration of individuals with ASD and those with psychotic disorders, noting the discrepancies between the two groups. Scheeren and Geurts noted considerable gaps in the literature on research regarding community inclusion of adolescence and adults with ASD, identifying gaps in the study of the stigma of ASD diagnosis and interventions to reduce stigma around those with ASD. Reduction of this stigma may support greater community inclusion and moves the onus of change away from the individual and toward the community or institution. Interventions, such as adapting typically developing peers’ attitudes toward peers with ASD, have previously demonstrated some success in altering perceptions across adolescent groups (Ranson & Byrne, 2014; Staniland & Byrne, 2013) and may show promise across adult populations.

The presence of faith, spirituality, or religion can also have a significant impact on the everyday quality of the life of a family or individual (Gerhardt & Lainer, 2011). Adults with ASD need to be accepted by their faith communities with access to worship or practice commensurate to their individual spiritual goals. Religious affiliation can cultivate feelings of camaraderie and friendship for individuals with ASD as well as opportunities to access additional social and leisure interactions (Terry, 2015). Further, for adults with ASD, following religious or spiritual practices initiated during childhood offers a comforting and familiar continuity of belief and routine from childhood to adulthood (Gerhardt & Lainer, 2011).

As Terry (2015) pointed out, faith communities have a responsibility to serve all people, but there may be impediments to the wholehearted acceptance of individuals with ASD and their families in some spiritual communities. Central to these barriers are philosophical and attitudinal concerns steeped in fear and an overall lack of training and knowledge of ASD. For spiritual communities to expand their inclusive practices, leadership must commit to expanding their knowledge of ASD as well as their relationships with other community-based organizations that serve this population. Steps to reduce stigma around those with ASD and create learning opportunities must be created. Practitioners should be conscientious of these challenges and work with clients and community organizations to address these inequities.

Simply getting around the community is another challenge adults with ASD may encounter. Where there is no public transportation, accessing community-based services becomes tricky, as therapeutic services may not offer their own transportation. Securing employment without transportation services adds an additional barrier for many with ASD. Further, even if public transportation is an option, travel training to competency must be completed before that individual can journey alone (Anderson & Butt, 2018). Often, travel training encompasses learning bus or train routes, reading, deciphering, and following a schedule, as well as travel safety. It can involve intensive one-on-one training in which direct-care staff accompany an individual in the community on their commute. Additional time may be spent training appropriate social skills for riding in the community as well as interacting with bus drivers, fellow commuters, and law enforcement and knowing what to do when lost (Babka et al., 2009). Options for independent travel can include free transportation offered for individuals with disabilities on the state or county level, where individuals are picked up and driven door-to-door, but those may be available based on location and qualifications (Anderson & Butt, 2018).

With travel as an integral part of inclusion in the community, it is important for practitioners to consider how to teach and support travel skills. Agencies and practitioners should work with local, regional, and state organizations to ensure there are transportation options available for those who require them. But even more, practitioners should consider everyday norms for adults. How did they get to work today, the movies last night, or their girlfriend's place this morning? Did they take an Uber or some other alternative mode of transportation like a scooter or bike? These should all be considered and individualized for the needs of each person.

Car service applications, such as Uber, have become mainstream modes of transportation throughout the United States, and these should be more viable solutions for adults with ASD as ways to navigate throughout the community. Car service applications afford a person the freedom of transit without needing to know the lay of the land. They are often reliable, inexpensive, and relatively quick and accessible and thus can be an auxiliary means of transportation for adults with ASD. Yet, these forms of transportation are not without their challenges as well. Drivers may get lost, need to be reminded about directions, and may benefit for training on more inclusive practices such as direct training regarding passengers with ASD or other disabilities (Scarantino, 2019).

Ongoing Staffing Concerns

It is incumbent upon human service agencies to prepare their staff to work with clients effectively and humanly (Luiselli & Russo, 2005). However, with staff recruitment, training, and retention identified as an ongoing challenge in the delivery of services for adults with ASD (Gerhardt & Lainer, 2011), there can be many challenges to ensuring optimal services are provided. Direct-care providers support individuals with disabilities across a variety of settings and responsibilities. These include cooking meals, leading interventions, travel training and escorting throughout the community, medication management, and countless other tasks that enable individuals in their care to lead independent and full lives. Unfortunately, this realm of human services is plagued by high turnover, while direct-care staff are beset by low wages and poor training (Stone, 2004). It is a clear paradox: the people employed for the most difficult work receive the least amount of support.

Disability advocates and agencies have been sounding the alarm for years that there is a direct support workforce crisis. In 2017, the President's Committee for People with Intellectual Disabilities reported on three decades of obstacles in finding, keeping, and educating staff, calling the problem "untenable" and blaming low wages, poor benefits, limited training, and lack of career advancement possibilities (President's Committee for People with Intellectual Disabilities, 2017).

It has been noted that high staff turnover is related to poor outcomes in clinical services. Kazemi et al. (2015) investigated predictors toward intentions to resign, in which 96 behavior technicians working with individuals with ASD were evaluated, and found evidence that training, supervision, pay, and job satisfaction were the top determinants whether a technician planned to remain on the job or resign. Knowing this, practitioners and agencies need to work together to overcome the challenges around staff turnover to increase competency and ensure the competent continuity of services. As the case study of Tim by Horn et al. (2013) pointed out, staff with greater confidence in their skills, improved rapport with the client, and appropriate support were able to best deliver services to the client. Only through substantial and dedicated training was the staff's behavior then shifted from responses of fear and uncertainty to those of compassion and care. This is a model that must be learned from and modeled, but it takes dedication and agency buy-in from all levels (Luiselli & Russo, 2005).

When individuals with disabilities lived in large group housing, it was often easier to train staff as they were all together located in one area. An agency could plan to send one clinician out to one location: train a shift in the morning, a shift at night, and then the overnight shift; and be done for the day. Same for day habilitation programs and sheltered employment. With the move to smaller gatherings of individuals living together, as opposed to these large hubs, clinicians need to take training to the streets. This creates a unique challenge to the practitioner as more time, effort, and planning need to take place to train all direct-care staff effectively and efficiently. It is also important to consider the training of interventions that are practical to the environment and within a provider's responsibilities in their role and with a client (Wood et al., 2007).

Recommendations for Community-Based Interventions

As evident from the previous sections of this chapter, community settings can present unique challenges to practitioners providing services as well as the individuals receiving services in the community. It is therefore crucial to outline clinical recommendations for providers when practicing with clients to ensure clients reap the full benefits of an established high-quality life.

Marcotte et al. (2020) conducted a systematic review of interventions focused on developing the independence of individuals with ASD. Marcotte et al. identified seven effective interventions out of the 20 articles that met the criteria of adolescent and adult participants with an ASD diagnosis. These interventions included video self-modeling, video modeling, behavioral interventions, video prompting, transition planning, training of the use of a cognitive aid, and social skills groups. A discussion of these findings is a good place to begin, as success at home will ideally lead to success in the community. Afterwards, the section will review critical areas for interventions and provide additional recommendations for treatment. These areas include how to address inappropriate behaviors and improve coordination and access to mental health resources, developing safety skills, and increasing opportunities for socialization and development of leisure skills.

The 20 articles reviewed by Marcotte and colleagues (2020) cover interventions which target activities of daily living and transition skills. They included self-care, social and communication skills, meal preparation, shopping, time management, and the development of leisure activities. Participants in all 20 articles were 14 and older and diagnosed with ASD. Fourteen of the 20 articles in the literature review were split between demonstrating the effectiveness of video prompting and the efficacy of behavioral interventions in developing skills of independence, while another seven focused on the efficacy of behavioral interventions. Let us first consider video prompting.

Video prompting, defined by "video segments presenting a task step by step…used while the person is performing the task in question" (Marcotte et al., 2020, p. 111), proved effective in improving an individual's abilities to complete new tasks and transition to next steps within a task, and results were maintained post intervention when the prompts were removed. Interventions utilizing video prompts were also met with a high level of social validity by participants and other stakeholders. Aldi et al. (2016) confirmed Marcotte and colleagues' (2020) analysis demonstrating the success of two 18-year-old males with ASD in acquiring three skills of daily living using an Apple iPad device and video-modeling prompts.

Correct tools are required to complete a job successfully, but often one tool can complete many tasks. Marcotte et al. (2020) noted that while the effectiveness of an intervention was correlated with the degree of its personalization, the tool to deliver those video prompts was often the same: an iPad or iPad-type device. Tasks related to shopping for groceries on a budget, preparing meals, and developing skills of time management were all taught using these types of devices. These findings suggest that digital devices may be formidable aids for increasing skills of daily living and independence for an individual with diverse programming needs. Further, digital devices are everywhere with people using them for many tasks. Thus, there is little stigma for an individual using their device in the community, as it is a perfectly appropriate means for prompting, organizing, and scheduling.

Marcotte and colleagues (2020) defined behavioral interventions as including strategies in which positive reinforcement was used to teach individuals to acquire new or more appropriate skills. The seven articles highlighted by Marcotte and colleagues demonstrated that behavioral interventions were effective and efficient in teaching tasks such as meal and food preparation, shopping, and travel in the community. Even more, interventions were conducted by caretakers, practitioners, researchers, and peers with ASD, thus establishing the versatility in service delivery.

Consistent with Marcotte et al. (2020), it has been evident for decades now that behavioral interventions are effective for treating a wide range of behaviors for children and adults with ASD and intellectual disabilities, in hospital, residential, and community settings (Allen et al., 1964; Ayllon & Michael, 1959; Wolf et al., 1967). Several of the interventions listed in the following recommendations will fall within the practices informed by applied behavior analysis (ABA), the field of behavioral study which methodically applies the principles of behavior to fostering or reducing responses of social significance for individuals and groups.

Behavior interventions were identified as key elements to thriving programing to foster home-based skills of independence in adults with ASD (Marcotte et al., 2020). This is in accordance with findings related to ABA in that ABA has been effectively used to increase skill acquisition and reduce behavioral excesses in diverse populations across a variety of domains including communication, leisure, activities of daily living, games, sports, and self-help (Yu et al., 2020). ABA is evidenced based and widely recognized as the foremost intervention for the treatment of skill deficits in individuals with ASD (Leaf et al., 2021).

Outcomes of quality ABA interventions are marked by improvements in communication, socialization, adaptive behavior, and IQ scores. Treatment is highly individualized, is adaptable, and provides opportunities for successful integration of adults in their community (Grigorenko et al., 2018). ABA interventions can be delivered in any setting, making therapy flexible, accessible, and appropriate for teaching across communities, environments, and tasks including banks, malls, workplaces, and restaurants (McClannahan et al., 2002). While much of the research in ABA is focused on children with ASD (e.g., Lovaas, 1987; Harris & Delmolino, 2002), there is research to support the use of ABA with geriatric populations (e.g., Burgio & Burgio, 1986), athletics and sports performance of college-age athletes (e.g., Luiselli & Reed, 2015), and adults with ASD (e.g., Bishop-Fitzpatrick et al., 2014; McClanahan et al., 2002). It is therefore supported that interventions utilizing ABA principles and procedures are effective means for developing skills, reducing the probability of behaviors, and training staff and should be used to address service delivery and intervention concerns regarding adults with ASD in the community.

Addressing Interfering Behavior and Access to Mental Health Resources

In the poignant commentary, “The Right to Effective Behavioral Treatment,” Van Houten et al. (1988) asserted that recipients of behavior change services have the right to a therapeutic environment, services in which the overriding goals reflect the individual’s personal welfare, treatment by a component clinician, and programs to teach functional skills. With Maddox et al. (2020) echoing this sentiment across the mental health field, the importance and ethical significance in providing improved services regarding effective interventions to reduce interfering behaviors and increasing mental health resources for adults with ASD is obvious. Early in this chapter, we noted observed discrepancies in unmet services under Medicaid waivers (Schott et al., 2021) as well as unmet services simply due to a lack of qualified providers (Maddox et al., 2020). The recommendations that follow emphasize ways to address challenging behaviors that are cost-effective and align with the sentiment of Van Houten and colleagues. Relevant suggestions on how to integrate community-based mental health services into a viable option for those who require it will also be delivered.

There are many successful ABA-based interventions which address the reduction and replacement of interfering behaviors; the following strategy is used to underscore commonalities for successful interventions based on the qualities of a successful behavior reduction plans.

Research by McClean et al. (2007) suggests that community housing options for individuals with severe interfering behaviors fall victim to the poor treatment of, and response to, problem behaviors. McClean et al. cited inadequate training of crisis management staff, the “absence of effective organizational infrastructure” (p. 282) and competing systems or models of behavior reduction. McClean et al. presented an evaluation of positive behavior support (PBS) as an effective model to reduce and maintain low levels of problem behaviors to address individual client outcomes and challenges of community-based interventions.

Hallmarks of a PBS model include a functional assessment of problem behavior to address the maintaining variables of the interfering behavior, environmental modifications, shaping and altering individual behavioral repertoires through the introduction of new, more appropriate behaviors and, finally, an improved quality of life (McClean et al., 2007). PBS has been used across a wide range of settings and proved successful across populations and providers and reflects core principles of ABA (Carr et al., 1999).

In their research, McClean et al. (2007) implemented PBS across five individuals noted to have "the most severe challenging behaviors in the country" (p. 284).

In their study, McClean et al. (2007) assessed five participants, two women and three men, aged 21 through 38 years, all with intellectual disabilities ranging from mild to severe, living in community settings. Two participants were diagnosed with ASD and comorbid diagnoses of psychosis and depression, while the other three carried the additional diagnoses of rapid cycling mood disorder, cerebral palsy and mood disorder, and paranoid schizophrenia. Four of the five participants were prescribed psychotropic medications for the management of severe behaviors. Of the two participants with ASD, Andrew and Sean, Andrew engaged in aggression in the form of punching, slapping, kicking, and hairpulling, and Sean engaged in self-injury in the form of head banging. Indeed, Sean's head banging was so severe that he required daily wound dressing and numerous x-rays to check for fractures, while Andrew's physical aggression placed staff on work leave due to serious injuries (McClean et al., 2007).

McClean et al.'s (2007) results are a testament to an effective system. After 1 month, all five participants demonstrated behavior reductions to near-zero rates as well as significant decreases across psychiatric symptoms following the introduction of a PBS model. Even more, data on treatment fidelity underscored the successful implementation of behavior plans by crisis staff. Additionally, three of the four participants receiving medications received decreased dosages resulting in an overall medication reduction of 66%. Finally, costs of services per individual dropped by nearly 28% over 18 months. For three individuals, quality-of-life scores showed drastic enhancements from scores below the 1 percentile pre-treatment to above the 50th percentile afterwards as they were able to live either independently or in small group settings.

What is important to note about the previous study (McClean et al., 2007) is the well-rounded success of the program. From staff training to psychiatric collaboration for medication management, there was a holistic approach to treatment permeating the behavior plan. Regardless of the intervention or model, a system-wide integration took place for the improvement of the lives of individuals, which stressed quality indicators for success including medication reduction, less-restrictive housing, and a life with reduced levels of stress (McClean et al., 2007).

The successful integration of mental health services within ASD treatment takes a collaborative approach akin to the one demonstrated across McClean et al. (2007) for behavior reduction. Stakeholders require sufficient training, common goals, and a coordinating body to safeguard practices. Communication between mental health and developmental disability agencies needs to flow freely, with these entities broadening their scope to connect systems and create partnerships and provide referrals rather than working independent of one another in opposing systems. Adults with ASD should be accepted for mental health services without fear of being turned out for developmental disability services instead (Lake et al., 2014). Lastly, mental health practitioners and behavioral health clinicians should work together to provide interventions that are appropriate and functional to the individual, with each party playing an integral role, informed by their scope of practice but shaped by a universal collaborative drive to provide high-quality outcomes to the individual (Maddox et al., 2020).

Teaching Safety Skills

Practitioners and community agencies must work with individuals to create strategies for addressing safety-related challenges. As noted earlier, research indicates that individuals with disabilities are at a disproportionate risk for abuse and violence (Hughes et al., 2012). Therefore, skills that support identifying unsafe environments, responding appropriately when placed in an abusive situation, and taking steps to guard against violence are all critical to an individual's quality of life. There are varying approaches to teaching safety and abuse protection in the literature. Such interventions include utilizing behavioral skills training (BST) to target individual objectives related to safety (Egemo-Helm et al., 2007; Miltenberger et al., 1999), the use of virtual reality (VR) instruments to supply role-play opportunities, and treatment packages focused on groups of behavioral responses (Hughes et al., 2020).

BST has been used to teach a variety of safety skills, which include gun safety (Miltenberger et al., 2009), self-protection skills (Haseltine & Miltenberger, 1990), and sexual abuse prevention (Miltenberger et al., 2009). BST employs the steps of instructions, modeling, rehearsal, and feedback to provide a systematic way to teach individuals appropriate, and often complex, responses to situations (Miltenberger et al., 1999, 2009). Miltenberger et al. (2009) and Haseltine and Miltenberger (1990) both noted the limited effectiveness of the generalization of responses when BST lacked in situ training, finding interventions with an in-situ element augmented the effectiveness of BST and generalization and maintenance of learned skills.

BST with and without in situ elements was used to address sexual abuse prevention in women with intellectual disabilities (Egemo-Helm et al., 2007; Miltenberger et al., 1999). In Miltenberger et al. (1999), six female participants, aged 33–57 years, were all trained to respond appropriately to stimulated sexual abuse appeal and scored across four categories: does or does not engage or comply; indicates “no” or refuses; leaves the situation or seeks support to leave; and reports the event. Results of this study found that the participants all acquired the skills of sexual abuse prevention; however, they did not all generalize to in situ assessments. Egemo-Helm et al. (2007) evaluated teaching the same four points to abuse prevention as outlined in Miltenberger et al. but supplemented the intervention using in situ training scenarios which mimicked natural conditions in which the participants would typically find themselves. Results of the study indicated that all participants gained and maintained the skills of sexual abuse prevention, thus demonstrating the effectiveness of BST with an in situ component.

When using BST to teach skills related to health or safety, clinicians should note the importance of teaching safety strategies in natural environments, creating opportunities for instruction which closely resemble the naturally occurring situations in which the individual may find themself. Additionally, thought should be given to the use of well-trained staff who will be required to behave in threatening or dangerous ways toward the individual receiving treatment. Finally, practitioners must also heed considerations and weigh the risks and benefits to exposing individuals to potentially stressful conditions and whether in situ teaching is appropriate and necessary in teaching the specific safety skill (Egemo-Helm et al., 2007).

Safety awareness and prevention treatment packages are another way to teach safety skills to adults with ASD. An intervention by Hughes et al. (2020) focused on delivering abuse prevention and education through a program called *The Safety Class* (TSC) to both men and women with an intellectual disability living in diverse community-based housing. The treatment was developed with the input and recommendations of individuals with intellectual disabilities participating in local and national community advisory boards. The program included a “cognitive skill-based” (Hughes et al., 2020, p. 304) approach to teaching to develop and expand knowledge on safety and abuse, safety skills, and safety self-efficacy. The TSC intervention program is an eight-session, weekly, in vivo group treatment program with topics on “communication skills, healthy boundaries, nature and types of abuse, relaxation training, respect in relationships, warning signs of abuse, safety in relationships, safety planning, coping with trauma, help seeking, and disability rights” (Hughes et al., 2020, p. 307).

Hughes et al. (2020) demonstrated the importance and effectiveness of teaching safety skills to individuals with intellectual and developmental disabilities. A total of 170 participants took part in the study, with pre- and post-intervention data on an individual’s knowledge of safety and abuse, including communication, safety planning skills, and safety-related self-efficacy. Statistical analysis provided evidence that the TSC treatment model improved participants’ knowledge over time compared to a control group of participants who did not receive the training. Participants rated their training with a high degree of favorability, indicating the classes were good, material was delivered in an understandable way, they would recommend it the course to a friend, and agreed the program would help keep them safe.

There are certainly benefits to the TSC model, as it easily addresses several safety skills across a large group of people, but clinicians should supplement this training with natural setting practice and presentation of learned skills under the conditions in which they may occur. While the results of Hughes et al.' (2020) post-test analysis of the TSC teaching curriculum indicated the participants learned the material, there was no assessment whether individuals would, or did, engage in the appropriate behaviors related to the taught topics of TSC when confronted with a given scenario. Clinicians should practice caution when choosing an intervention model which relies on questionnaires as the main assessment of actual learned behaviors (e.g., Hughes et al., 2020). Like adding in situ training to BST, safety skills training should be augmented with an assessment of learned skills in the contexts in which they occur.

A third intervention strategy clinicians may consider in addressing teaching skills of health and safety to adults with ASD is the use of immersive virtual reality (VR). McCleery et al. (2020) evaluated the feasibility of utilizing VR to teach individuals with ASD aged 12 years and up to navigate the often stressful and challenging behaviors related to interacting appropriately with law enforcement. McCleery et al. noted VR tools to be less expensive and more readily available than previously. Moreover, participants found the intervention favorable and willingly engaged in sessions. Finally, the VR sessions had low dropout rates and involved low and nonserious side effects to treatment.

Immersive VR may be an effective strategy to teaching many skills for adults with ASD including challenging and high-risk situations related to health and safety that may be too unsafe to test in the natural environment. Dixon et al. (2020) used immersive VR to teach children with ASD to identify if it was safe to cross the street, and Goldsmith (2009) evaluated the effectiveness of BST + VR to teach children with ASD, aged 9–13 years, street-crossing skills. Both studies had positive outcomes in the VR assessment. Further, evaluations of using VR as an intervention to address substance abuse disorder in adults (Washburn et al., 2021) as well as addressing improvements in forklift driving (Choi et al., 2020) underline the growing field of use of VR in teaching skills of health and safety for adults.

It should be noted that although BST and VR have been evaluated as tools to specifically address the development of skills related to safety and the reduction of violence and abuse for adults with ASD, both interventions are suitable for potentially teaching a wide array of skills including aspects related to socialization (Miller & Bugnariu, 2016; Miltenberger et al., 2017) and employment and vocational training (Morgan & Wine, 2018; Smith et al., 2015).

Focusing on Opportunities for Socialization and the Development of Leisure Skills

As an adult, socialization, friendships, and romantic relationships are all part of life. So too is the choice to hang out on the couch and watch Netflix all night. Yet, one of the core deficits of ASD is the inability to engage appropriately with others in a social way, which can mean challenges across developing friendships, holding down a job, developing enjoyable and age-appropriate leisure skills, and ultimately full participation in the community. Moreover, research has shown that with increased severity of ASD, there is a corresponding decrease in age-appropriate social responses (Wilkins & Matson, 2009). Therefore, it is critical that practitioners find ways to support adults with ASD in having a rich social life that suits their personal wants and needs, which includes the expansion of leisure activities.

Farley et al. (2018) reviewed social outcomes across a group of 169 adults with ASD. Across the group sample, 75% of the participants lacked any experience dating, with parent informants noting that they often felt their adult child lacked understanding of a romantic relationship with others or that their child had an unrealistic perception of the relationship. Results also indicated that while over 50% of participants spent time in organized groups, a little less than half reported spending time with peers.

The data Farley et al. (2018) collected reflect considerable heterogeneity in responses and personal choices by the individual regarding their own perspectives and quality of life. While friendships and romantic relationships may be important to some, it may not be equally as important to others. Regardless, training and options need to be made available for adults with ASD so they can make informed decisions of how they wish to spend their time and with whom. These may be challenging topics for both trainers and trainees, but learning how to foster romantic relations and training on sexuality, gender, and orientation can be life changing as it can safely guard against abuse as well as open doors to age-appropriate social interactions, acceptance, and long-lasting happiness (Turner et al., 2017).

Participation in leisure skills has been shown to decrease stress and increase the quality of life for adults with ASD (Garcia-Villamisar & Dattilo, 2010). Teaching leisure skills is a critical aspect of any treatment program for individuals with ASD (Garcia-Villamisar & Dattilo, 2011). It helps foster social relationships by building common and shared interests and supports independent living by giving a person a feeling of purpose, intent, and happiness (Finke et al., 2018). Expanding past the known research of teaching leisure skills to children with ASD is important in developing tools which address the unique needs of adults and the range of social and leisure activities.

Studies which investigate systems to teach adults with ASD to increase independence across leisure skills (e.g., Palmen et al., 2011) are a good start to this expansion and provide clinicians with a model for potential interventions. Wilson et al. (2006) present another model of how to evaluate and increase leisure skills of adults with severe disabilities by incorporating appropriate measures of preference and social validity to identify potential leisure activities, which created programmatic buy-in for support staff that is critical when teaching any new skill.

One of the foremost intervention strategies for teaching independent skills is video prompting (Marcotte et al., 2020). Video prompting has been used to teach individuals with developmental disabilities skills of daily living (e.g., Gardner & Wolfe, 2013), transitioning between tasks (e.g., Cihak et al., 2010), communication and social skills (e.g., Mason et al., 2012), and vocational training and employment (e.g., Bross et al., 2020; Rosen et al., 2017). Following this trend, Chan et al. (2013) successfully taught three novel leisure skills to a 35-year-old man with Down syndrome and moderate intellectual disability named Marvin.

Marvin, although not an adult with ASD, can be used as a successful model for intervention. Living at home with his mother, Marvin has limited communication skills, attends a community-based day habilitation program, and works at a sheltered workshop. Chan et al. (2013) set out to teach Marvin three leisure skills: painting, listening to music, and taking digital pictures. Each skill was comprised of several sub-steps. During treatment, video prompting on an iPod was used as a model and prompt for each step of the activity. Verbal cues and least-to-most prompting were used to support errors or delays in responding. During baseline, Marvin demonstrated very few of the skills required to complete the novel leisure tasks. However, after about six sessions of intervention in painting, nine intervention sessions for listening to music, and four sessions of intervention for taking pictures, Marvin completed each leisure activity independently (Chan et al., 2013).

Chan et al. (2013) supported the previous research on the success of video modeling and video prompts, as well as the effectiveness and acceptability of using digital devices such as iPads and iPods as treatment tools. Video prompts and video modeling are sensible options for teaching social and leisure skills for community settings, especially when using a tablet or other digital device. Further recommendations include peers or colleagues to model appropriate behaviors or for the individual to record themselves completing the steps of each task and use themselves as the video models.

Brief Considerations on Staff Training

More training does not always mean more effective treatment. Appropriate training, supervision, and oversight all play important roles in the service delivery and training of direct-care staff who work in community settings. While some evaluations for increasing staff retention and reducing staffing vacancies in residential direct care have included modifications to long successful treatment models like the Teaching-Family Model as well as manipulations of staffing schedules (Strouse et al., 2003), those may not be practical interventions on the individual or practitioner level. More successful training interventions may focus on the job, site, client, or task-specific training with feedback, instruction, modeling, and hands-on, active learning (e.g., Burch et al., 1987; Reed & Henley, 2015). BST and performance- and competency-based training (PCBT) are both perfect examples of training interventions for both preservice and ongoing staff training. As previously outlined, BST is an evidenced-based intervention which successfully trains skills across a variety of topics and populations. PCBT also has a robust history of success in providing excellence in training across groups, measuring competency across performance and delivery feedback until staff reach performance criterion (Reed & Henley, 2015).

While both BST and the PCBT are beneficial to the training of direct-care staff, they can be lengthy and costly (Reid, 2017). Peer training, train-the-trainer models, and pyramidal training are all further ways to increase opportunities to train staff with strained resources and limits to time and access with a director or leadership-level trainer. Additional suggestions would be to incorporate video-modeling and voice-over didactic training with feedback (Reed & Henley, 2015), as well as videoconferencing tools (e.g., Higgins et al., 2017), to provide increased time and occasions to train staff.

Once staff assume a position with clientele, ongoing training and direct supervision must be maintained. Senior-level staff should be held accountable for the ongoing training and procedural integrity of direct-care staff, and overall quality of services should be regularly and systematically reviewed for client progress, happiness, and safety. Staff should be trained to respond to a wide array of client behaviors, nurturing self-assurance and ownership in their role discouraging turnover (Reed & Henley, 2015).

Ongoing in-service training for supervisors and supervisees may also aid in the establishment of an agency-wide training ethic, which supports the ongoing professional development of employees. Incentives to attend and participate in training, like door prizes, meals, and games, may also be conducive in establishing motivation to attend training sessions (Shapiro & Kazemi, 2017). Consequently, these incentives may work to boost morale while reinforcing rapport between supervisors and staff which may counteract turnover.

Direct-care and support staff play a critical role in the delivery of community-based instruction. They are the heavy lifters, the unsung heroes of service delivery. Those that work in residential settings often spend more time with clients than their own families, spending holidays, meals, and birthday celebrations side-by-side with coworkers and clients. They should be trained and cared for as we would any caretaker, addressing their needs individually and with compassion. Agencies and practitioners must invest in effective training programs and practices, collaborate with staff, and ensure generalization of skills. Thus, practitioners should actively pursue feedback from staff on training and seek out staff preferences on the best training modalities for their best outcomes (Shapiro & Kazemi, 2017).

And Now What?

Passing of the Community Mental Health Centers Construction Act in 1963 and the *Olmstead* ruling by the Supreme Court in 1999 were cornerstone decisions to expand community living and funding opportunities for individuals with disabilities. This chapter has highlighted many government, advocacy, professional, and parent groups that have expanded integrated community living opportunities and clinical practices to ensure a higher quality of living for ASD individuals. With an increasing number of ASD diagnoses and an aging population of ASD individuals, the timing of these increased services is needed.

The challenges these initiatives have created are rapidly mounting and we need to continue to push for meaningful legislation, education, research, and support to keep the momentum headed in a positive direction for inclusive housing and services. We need to find resolution for higher pay and effective training methods of direct service personnel that support these individuals. Expansion of employment opportunities that allow great choice, satisfaction, and independence in the natural community they live in is crucial. With these expanded housing, supports, and employment opportunities, we will be able to raise the quality of life for the increasing population demand.

References

Aldi, C., Crigler, A., Kates-Mcelrath, K., Long, B., Smith, H., Rehak, K., & Wilkinson, L. (2016). Examining the effects of video modeling and prompts to teach activities of daily living skills. *Behavior Analysis in Practice, 9*(4), 384–388. https://doi.org/10.1007/s40617-016-0127-y

Allen, K. E., Hart, B., Buell, J. S., Harris, F. R., & Wolf, M. M. (1964). Effects of social reinforcement on isolate behavior of a nursery school child. *Child Development, 35*, 511–518.

Anderson, C., & Butt, C. (2018). Young adults on the autism spectrum: The struggle for appropriate services. *Journal of Autism and Developmental Disorders, 48*(11), 3912–3925. https://doi.org/10.1007/s10803-018-3673-z

Anderson, K. A., Shattuck, P. T., Cooper, B. P., Roux, A. M., & Wagner, M. (2014). Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism: The International Journal of Research and Practice, 18*(5), 562–570. https://doi.org/10.1177/1362361313481860

Autism Society San Francisco Bay Area. (2021). *Overview of current adult autism housing options*. https://www.sfautismsociety.org/housing-options-for-adults-with-autism.html

Autism Speaks (2011). *Guide to Housing and Residential Supports for People With Autism*. https://www.autismspeaks.org/sites/default/files/2018-08/Housing%20Tool%20Kit.pdf https://www.autismspeaks.org/autism-statistics-asd

Autism Speaks. (2021). *Autism statistics and facts*. https://www.autismspeaks.org/autism-statistics-asd

Ayllon, T., & Michael, J. (1959). The psychiatric nurse as a behavioral engineer. *Journal of the Experimental Analysis of Behavior, 2*(4), 323–334. https://doi.org/10.1901/jeab.1959.2-323

Babka, R. J., Cooper, J. F., & Ragland, D. R. (2009). Evaluation of urban travel training for older adults. *Transportation Research Record: Journal of the Transportation Research Board, 2110*(1), 149–154. https://doi.org/10.3141/2110-18

Bishop-Fitzpatrick, L., Minshew, N. J., & Eack, S. M. (2014). A systematic review of psychosocial interventions for adults with autism spectrum disorders. In *Adolescents and adults with autism spectrum disorders* (pp. 315–327). Springer. https://doi.org/10.1007/978-1-4939-0506-5_16

Bishop-Fitzpatrick, L., Hong, J., Smith, L. E., Makuch, R. A., Greenberg, J. S., & Mailick, M. R. (2016). Characterizing objective quality of life and normative outcomes in adults with autism spectrum disorder: An exploratory latent class analysis. *Journal of Autism and Developmental Disorders, 46*(8), 2707–2719. https://doi.org/10.1007/s10803-016-2816-3

Bross, L. A., Travers, J. C., Wills, H. P., Huffman, J. M., Watson, E. K., Morningstar, M. E., & Boyd, B. A. (2020). Effects of video modeling for young adults with autism in community employment settings. *Career Development and Transition for Exceptional Individuals, 43*(4), 209–225. https://doi.org/10.1177/2165143420941488

Burch, M. R., Reiss, M. L., & Bailey, J. S. (1987). A competency-based "hands-on" training package for direct-care staff. *Journal of the Association for Persons with Severe Handicaps, 12*(1), 67–71.

Burgio, L. D., & Burgio, K. L. (1986). Behavioral gerontology: Application of behavioral methods to the problems of older adults. *Journal of Applied Behavior Analysis, 19*(4), 321–328. https://doi.org/10.1901/jaba.1986.19-321

Carr, E. G., Horner, R. H., Turnbull, A. P., Marquis, J. G., McLaughlin, D. M., McAtee, M. L., Smith, C. E., Ryan, K. A., Ruef, M. B., & Doolabh, A. (1999). In D. Braddock (Ed.), *Positive behavior support for people with developmental disabilities: A research synthesis*. American Association on Mental Retardation.

Centers for Disease Control and Prevention. (2020). *Prevalence of autism spectrum disorder among children aged 8 years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016*. Centers for Disease Control and Prevention.

Chan, J. M., Lambdin, L., Van Laarhoven, T., & Johnson, J. W. (2013). Teaching leisure skills to an adult with developmental disabilities using a video prompting intervention package. *Education and Training in Autism and Developmental Disabilities, 48*(3), 412–420. http://www.jstor.org/stable/23880997

Choi, M., Ahn, S., & Seo, J. (2020). VR-based investigation of forklift operator situation awareness for preventing collision accidents. *Accident Analysis and Prevention, 136*. https://doi.org/10.1016/j.aap.2019.105404

Cihak, D., Fahrenkrog, C., Ayres, K. M., & Smith, C. (2010). The use of video modeling via a video iPod and a system of least prompts to improve transitional behaviors for students with autism spectrum disorders in the general education classroom. *Journal of Positive Behavior Interventions, 12*(2), 103–115. https://doi.org/10.1177/1098300709332346

Dixon, D. R., Miyake, C. J., Nohelty, K., Novack, M. N., & Granpeesheh, D. (2020). Evaluation of an immersive virtual reality safety training used to teach pedestrian skills to children with autism spectrum disorder. *Behavior Analysis in Practice, 13*(3), 631–640. https://doi.org/10.1007/s40617-019-00401-1

Dudley, K. M., Klinger, M. R., Meyer, A., Powell, P., & Klinger, L. G. (2019). Understanding service usage and needs for adults with ASD: The importance of living situation. *Journal of Autism and Developmental Disorders, 49*(2), 556–568.

Easterseals. (2021). *Services for adults with autism*. https://www.easterseals.com/our-programs/autism-services/adults-with-autism.html

Edwards, M., Parmenter, T., O'Brien, P., & Brown, R. (2018). Family quality of life and the building of social connections: Practical suggestions for practice and policy. *International Journal of Child, Youth and Family Studies, 9*, 88–106. https://doi.org/10.18357/ijcyfs94201818642

Egemo-Helm, K. R., Miltenberger, R. G., Knudson, P., Finstrom, N., Jostad, C., & Johnson, B. (2007). An evaluation of in situ training to teach sexual abuse prevention skills to women with mental retardation. *Behavioral Interventions, 22*(2), 99–119. https://doi.org/10.1002/bin.234

Farkas, T. N., Mendy, J., & Kargas, N. (2020). Enhancing resilience in autistic adults using community-based participatory research: A novel HRD intervention in employment service provision. *Advances in Developing Human Resources, 22*(4), 370–386. https://doi.org/10.1177/1523422320946293

Farley, M., Cottle, K. J., Bilder, D., Viskochil, J., Coon, H., & McMahon, W. (2018). Mid-life social outcomes for a population-based sample of adults with ASD. *Autism Research, 11*(1), 142–152. https://doi.org/10.1002/aur.1897

Finke, E. H., Hickerson, B. D., & Kremkow, J. M. D. (2018). To be quite honest, if it wasn't for videogames I wouldn't have a social life at all: Motivations of young adults with autism spectrum disorder for playing videogames as leisure. *American Journal of Speech-Language Pathology, 27*(2), 672–689. https://doi.org/10.1044/2017_AJSLP-17-0073

Fixsen, D. L., Blasé, K. A., Timbers, G. D., & Wolf, M. M. (2007). In search of program implementation: 792 replications of the Teaching-Family Model. *The Behavior Analyst Today, 8*(1), 96–110. https://doi.org/10.1037/h0100104

García-Villamisar, D. A., & Dattilo, J. (2010). Effects of a leisure programme on quality of life and stress of individuals with ASD. *Journal of Intellectual Disability Research, 54*(7), 611–619. https://doi.org/10.1111/j.1365-2788.2010.01289.x

Garcia-Villamisar, D., & Dattilo, J. (2011). Social and clinical effects of a leisure program on adults with autism spectrum disorder. *Research in Autism Spectrum Disorders, 5*(1), 246–253. https://doi.org/10.1016/j.rasd.2010.04.006

Gardner, S., & Wolfe, P. (2013). Use of video modeling and video prompting interventions for teaching daily living skills to individuals with autism spectrum disorders: A review. *Research and Practice for Persons with Severe Disabilities, 38*(2), 73–87. https://doi.org/10.2511/027494813807714555

Gerhardt, P. F., & Lainer, I. (2011). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy: On the Cutting Edge of Modern Developments in Psychotherapy, 41*(1), 37–45. https://doi.org/10.1007/s10879-010-9160-2

Ghaziuddin, M., Ghaziuddin, N., & Greden, J. (2002). Depression in persons with autism: Implications for research and clinical care. *Journal of Autism and Developmental Disorders, 32*(4), 299–306. https://doi.org/10.1023/a:1016330802348

Gibbs, V., Hudson, J., Hwang, Y. I., Arnold, S., Trollor, J., & Pellicano, E. (2021). Experiences of physical and sexual violence as reported by autistic adults without intellectual disability: Rate, gender patterns and clinical correlates. *Research in Autism Spectrum Disorders, 89*, 101866. https://doi.org/10.1016/j.rasd.2021.101866

Gillott, A., & Standen, P. J. (2007). Levels of anxiety and sources of stress in adults with autism. *Journal of Intellectual Disabilities, 11*(4), 359–370. https://doi.org/10.1177/1744629507083585

Goldsmith, T. R. (2009). Using virtual reality enhanced behavioral skills training to teach street-crossing skills to children and adolescents with autism spectrum disorders [ProQuest Information & Learning]. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 69*(7–B), 4421.

Grigorenko, E., Torres, S., Lebedeva, E., & Bondar, Y. (2018). Evidence-based interventions for ASD: A focus on applied behavior analysis (ABA) interventions. *Psychology Journal of the Higher School of Economics, 15*, 711–727. https://doi.org/10.17323/1813-8918-2018-4-711-727

Harris, S. L., & Delmolino, L. (2002). Applied behavior analysis: Its application in the treatment of autism and related disorders in young children. *Infants & Young Children, 14*(3), 11–17. https://doi.org/10.1097/00001163-200201000-00006

Haseltine, B., & Miltenberger, R. G. (1990). Teaching self-protection skills to persons with mental retardation. *American Journal of Mental Retardation, 95*(2), 188–197.

Hewitt, A. S., Stancliffe, R. J., Hall-Lande, J., Nord, D., Pettingell, S. L., Hamre, K., & Hallas-Muchow, L. (2017). Characteristics of adults with autism spectrum disorder who use residential services and supports through adult developmental disability services in the United States. *Research in Autism Spectrum Disorders, 34*, 1–9. https://doi.org/10.1016/j.rasd.2016.11.007

Higgins, W. J., Luczynski, K. C., Carroll, R. A., Fisher, W. W., & Mudford, O. C. (2017). Evaluation of a telehealth training package to remotely train staff to conduct a preference assessment. *Journal of Applied Behavior Analysis, 50*(2), 238–251. https://doi.org/10.1002/jaba.370

Hinshaw, S. P. (2007). *The mark of shame: Stigma of mental illness and an agenda for change*. Oxford University Press.

Horn, T., Sunstrum, B., & Kirilo, D. (2013). Facing fear and change: What it took to successfully integrate a patient with autism in seclusion 23/7 into the community after seven years. *International Journal of Mental Health, 42*(2–3), 99–114. https://doi.org/10.2753/IMH0020-7411420206

Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry, 30*(2), 69–76. https://doi.org/10.1097/YCO.0000000000000308

Hughes, K., Bellis, M. A., Jones, L., Wood, S., Bates, G., Eckley, L., McCoy, E., Mikton, C., Shakespeare, T., & Officer, A. (2012). Prevalence and risk of violence against adults with disabilities: A systematic review and meta-analysis of observational studies. *The Lancet, 379*(9826), 1621–1907. https://doi.org/10.1016/S0140-6736(11)61851-5

Hughes, R. B., Robinson-Whelen, S., Davis, L. A., Meadours, J., Kincaid, O., Howard, L., Millin, M., Schwartz, M., & McDonald, K. E. (2020). Evaluation of a safety awareness group program for adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities, 125*(4), 304–317. https://doi.org/10.1352/1944-7558-125.4.304

Joshi, M. (2020). Living alone and with autism. *Journal of Psychosocial Research, 15*(1), 171–180. https://doi.org/10.32381/JPR.2020.15.01.14

Kazemi, E., Shapiro, M., & Kavner, A. (2015). Predictors of intention to turnover in behavior technicians working with individuals with autism spectrum disorder. *Research in Autism Spectrum Disorders, 17*, 106–115. https://doi.org/10.1016/j.rasd.2015.06.012

Krauss, M. W., Seltzer, M. M., & Jacobson, H. T. (2005). Adults with autism living at home or in non-family settings: Positive and negative aspects of residential status. *Journal of Intellectual Disability Research, 49*(2), 111–124. https://doi.org/10.1111/j.1365-2788.2004.00599.x

Lai, M.-C., & Szatmari, P. (2019). Resilience in autism: Research and practice prospects. *Autism, 23*(3), 539–541. https://doi.org/10.1177/1362361319842964

Lake, J. K., Perry, A., & Lunsky, Y. (2014). Mental health services for individuals with high functioning autism spectrum disorder. *Autism Research and Treatment, 2014*, 1–9. https://doi.org/10.1155/2014/502420

Leaf, J. B., Cihon, J. H., Leaf, R., Mceachin, J., Liu, N., Russell, N., Unumb, L., Shapiro, S., & Khosrowshahi, D. (2021). Concerns about ABA-based intervention: An evaluation and recommendations. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-021-05137-y

Leslie, D. L., Iskandarani, K., Dick, A. W., Mandell, D. S., Yu, H., Velott, D., Agbese, E., & Stein, B. D. (2017). The effects of Medicaid home and community-based services waivers on unmet needs among children with autism spectrum disorder. *Medical Care, 55*(1), 57–63. https://doi.org/10.1097/MLR.0000000000000621

Lever, A. G., Ridderinkhof, K. R., Marsman, M., & Geurts, H. M. (2017). Reactive and proactive interference control in adults with autism spectrum disorder across the lifespan. *Developmental Psychology, 53*(2), 379–395. https://doi.org/10.1037/dev0000219

Lima, R. C., Feldman, C., Evans, C., & Block, P. (2018). *Autism policy and advocacy in Brazil and the USA* (pp. 17–52). Springer. https://doi.org/10.1007/978-3-319-93293-4_2

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology, 55*(1), 3–9. https://doi.org/10.1037/0022-006X.55.1.3

Luiselli, J. K., & Reed, D. D. (2015). Chapter 21: Applied behavior analysis and sports performance. In H. S. Roane, J. L. Ringdahl, & T. S. Falcomata (Eds.), *Clinical and organizational applications of applied behavior analysis* (pp. 523–553). Academic. https://doi.org/10.1016/B978-0-12-420249-8.00021-6

Luiselli, J. K., & Russo, D. C. (2005). Clinical peer review: Description of a comprehensive model in behavioral healthcare. *Behavior Modification, 29*(3), 470–487. https://doi.org/10.1177/0145445504273279

Lundqvist, L.-O. (2013). Prevalence and risk markers of behavior problems among adults with intellectual disabilities: A total population study in Örebro County, Sweden. *Research in Developmental Disabilities, 34*(4), 1346–1356. https://doi.org/10.1016/j.ridd.2013.01.010

Maddox, B. B., Crabbe, S., Beidas, R. S., Brookman-Frazee, L., Cannuscio, C. C., Miller, J. S., Nicolaidis, C., & Mandell, D. S. (2020). "I wouldn't know where to start": Perspectives from clinicians, agency leaders, and autistic adults on improving community mental health services for autistic adults. *Autism: The International Journal of Research and Practice, 24*(4), 919–930. https://doi.org/10.1177/1362361319882227

Mandell, D. S. (2017). A house is not a home: The great residential divide in autism care. *Autism, 21*, 810–811. https://doi.org/10.1177/1362361317722101

Marcotte, J., Grandisson, M., Piquemal, C., Boucher, A., Rheault, M. È., & Milot, É. (2020). Supporting independence at home of people with autism spectrum disorder: Literature review. *Canadian Journal of Occupational Therapy. Revue Canadienne D'ergotherapie, 87*(2), 100–116. https://doi.org/10.1177/0008417419890179

Marsack-Topolewski, C. N., Samuel, P. S., & Tarraf, W. (2021). Empirical evaluation of the association between daily living skills of adults with autism and parental caregiver burden. *PLoS One, 16*(1), e0244844. https://doi.org/10.1371/journal.pone.0244844

Mason, R. A., Rispoli, M., Ganz, J. B., Boles, M. B., & Orr, K. (2012). Effects of video modeling on communicative social skills of college students with Asperger syndrome. *Developmental Neurorehabilitation, 15*(6), 425–434. https://doi.org/10.3109/17518423.2012.704530

Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research, 11*(8), 1138–1147. https://doi.org/10.1002/aur.1965

McClannahan, L. E., Krantz, P. J., McGee, G. G., & MacDuff, G. S. (1984). Teaching-family model for autistic children. In W. P. Christian, G. T. Hannah, & T. J. Glahn (Eds.), *Programming effective human services: Strategies for institutional change and client transition* (pp. 383–406). Springer. https://doi.org/10.1007/978-1-4613-2707-3_18

McClannahan, L. E., MacDuff, G. S., & Krantz, P. J. (2002). Behavior analysis and intervention for adults with autism. *Behavior Modification, 26*(1), 9–26. https://doi.org/10.1177/0145445502026001002

McClean, B., Grey, I. M., & McCracken, M. (2007). An evaluation of positive behavioural support for people with very severe challenging behaviours in community-based settings. *Journal of Intellectual Disabilities, 11*(3), 281–301. https://doi.org/10.1177/1744629507080791

McCleery, J. P., Zitter, A., Solórzano, R., Turnacioglu, S., Miller, J. S., Ravindran, V., & Parish, M. J. (2020). Safety and feasibility of an immersive virtual reality intervention program for teaching police interaction skills to adolescents and adults with autism. *Autism Research, 13*(8), 1418–1424. https://doi.org/10.1002/aur.2352

Mikton, C., Maguire, H., & Shakespeare, T. (2014). A systematic review of the effectiveness of interventions to prevent and respond to violence against persons with disabilities. *Journal of Interpersonal Violence, 29*(17), 3207–3226. https://doi.org/10.1177/0886260514534530

Miller, H. L., & Bugnariu, N. L. (2016). Level of immersion in virtual environments impacts the ability to assess and teach social skills in autism spectrum disorder. *Cyberpsychology, Behavior and Social Networking, 19*(4), 246–256. https://doi.org/10.1089/cyber.2014.0682

Miller, N. A., Ramsland, S., & Harrington, C. (1999). Trends and issues in the Medicaid 1915(c) waiver program. *Health Care Financing Review, 20*(4), 139–160.

Miltenberger, R. G., Roberts, J. A., Ellingson, S., Galensky, T., Rapp, J. T., Long, E. S., & Lumley, V. A. (1999). Training and generalization of sexual abuse prevention skills for women with mental retardation. *Journal of Applied Behavior Analysis, 32*(3), 385–388. https://doi.org/10.1901/jaba.1999.32-385

Miltenberger, R., Gross, A., Knudson, P., Bosch, A., Jostad, C., & Breitwieser, C. B. (2009). Evaluating behavioral skills training with and without simulated in situ training for teaching safety skills to children. *Education & Treatment of Children, 32*(1), 63–75. https://doi.org/10.1353/etc.0.0049

Miltenberger, R. G., Zerger, H. M., Novotny, M., & Livingston, C. P. (2017). Behavioral skills training to promote social behavior of individuals with autism. In *Adaptive behavior strategies for individuals with intellectual and developmental disabilities* (pp. 325–342). Springer. https://doi.org/10.1007/978-3-319-62995-7_19

Morgan, C. A., & Wine, B. (2018). Evaluation of behavior skills training for teaching work skills to a student with autism spectrum disorder. *Education & Treatment of Children, 41*(2), 223–232. https://doi.org/10.1353/etc.2018.0009

Mudford, O. C., Arnold-Saritepe, A. M., Phillips, K. J., Locke, J. M., Ho, I. C. S., & Taylor, S. A. (2008). Chapter 9: Challenging behaviors. In J. L. Matson (Ed.), *Clinical assessment and intervention for autism Spectrum disorders* (pp. 267–297). Academic. https://doi.org/10.1016/B978-012373606-2.50011-5

Painter, J., Hastings, R., Ingham, B., Trevithick, L., & Roy, A. (2018). Associations between mental health problems and challenging behavior in adults with intellectual disabilities: A test of the behavioral equivalents hypothesis. *Journal of Mental Health Research in Intellectual Disabilities, 11*(2), 157–172. https://doi.org/10.1080/19315864.2018.1431747

Palmen, A., Didden, R., & Korzilius, H. (2011). An outpatient group training programme for improving leisure lifestyle in high-functioning young adults with ASD: A pilot study. *Developmental Neurorehabilitation, 14*(5), 297–309. https://doi.org/10.3109/17518423.2011.595433

Perkins, E. A., & Berkman, K. A. (2012). Into the unknown: Aging with autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities, 117*(6), 478–496. https://doi.org/10.1352/1944-7558-117.6.478

President's Committee for People with Intellectual Disabilities. (2017). *Report to the President 2017America's direct support workforce crisis: Effects on people with intellectual disabilities, families, communities and the U.S. economy.* Retrieved October 27, 2021, from https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF

Prior, M., & Ozonoff, S. (2007). Psychological factors in autism. In F. R. Volkmar (Ed.), *Autism and pervasive developmental disorders* (pp. 69–128). Cambridge University Press. https://doi.org/10.1017/CBO9780511544446.004

Ranson, N. J., & Byrne, M. K. (2014). Promoting peer acceptance of females with higher-functioning autism in a mainstream education setting: A replication and extension of the effects of an autism anti-stigma program. *Journal of Autism and Developmental Disorders, 44*(11), 2778–2796. https://doi.org/10.1007/s10803-014-2139-1

Rattaz, C., Michelon, C., Munir, K., & Baghdadli, A. (2018). Challenging behaviours at early adulthood in autism spectrum disorders: Topography, risk factors and evolution. *Journal of Intellectual Disability Research, 62*(7), 637–649. https://doi.org/10.1111/jir.12503

Reed, F. D. D., & Henley, A. J. (2015). A survey of staff training and performance management practices: The good, the bad, and the ugly. *Behavior Analysis in Practice, 8*(1), 16–26. https://doi.org/10.1007/s40617-015-0044-5

Reid, D. H. (2017). Competency-based staff training. In J. K. Luiselli (Ed.), *Applied behavior analysis advanced guidebook* (Vol. 2, pp. 21–40). Academic Press. https://doi.org/10.1016/B978-0-12-811122-2.00002-4

Resnik, D. D., & Blackburn, J. (2009). *Opening doors. A discussion of residential options for adults living with autism and related disorders: A collaborative report by the urban land institute Arizona*. Southwest Autism Research & Resources Center and Arizona State University.

Rosen, R., Weiss, P. L., Zancanaro, M., & Gal, E. (2017). Usability of a video modeling computer application for the vocational training of adolescents with autism spectrum disorder. *British Journal of Occupational Therapy, 80*(4), 208–215. https://doi.org/10.1177/0308022616680367

Rubin, A. S. (2018, June 11). Healing impacts of gardening for young adults with ASD. *New directions for young adults*. https://www.ndfya.com/2018/06/11/healing-impacts-of-gardening-for-young-adults-with-asd/

Scarantino, L. (2019, February 5). How Uber can be a positive experience for riders with autism. *The Mighty.* https://themighty.com/2019/02/using-uber-autism/

Scheeren, A. M., & Geurts, H. M. (2015). Research on community integration in autism spectrum disorder: Recommendations from research on psychosis. *Research in Autism Spectrum Disorders, 17*, 1–12. https://doi.org/10.1016/j.rasd.2015.05.001

Schott, W., Nonnemacher, S., & Shea, L. (2021). Service use and unmet needs among adults with autism awaiting home- and community-based Medicaid services. *Journal of Autism and Developmental Disorders, 51*(4), 1188–1200. https://doi.org/10.1007/s10803-020-04593-2

Shapiro, M., & Kazemi, E. (2017). A review of training strategies to teach individuals implementation of behavioral interventions. *Journal of Organizational Behavior Management, 37*(1), 32–62. https://doi.org/10.1080/01608061.2016.1267066

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012a). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics, 129*(6), 1042–1049. https://doi.org/10.1542/peds.2011-2864

Shattuck, P. T., Roux, A. M., Hudson, L. E., Taylor, J. L., Maenner, M. J., & Trani, J.-F. (2012b). Services for adults with an autism spectrum disorder. *The Canadian Journal of Psychiatry, 57*(5), 284–291. https://doi.org/10.1177/070674371205700503

Smith, M. J., Fleming, M. F., Wright, M. A., Losh, M., Humm, L. B., Olsen, D., & Bell, M. D. (2015). Brief report: Vocational outcomes for young adults with autism spectrum disorders at six months after virtual reality job interview training. *Journal of Autism and Developmental Disorders, 45*(10), 3364–3369. https://doi.org/10.1007/s10803-015-2470-1

Staniland, J. J., & Byrne, M. K. (2013). The effects of a multi-component higher-functioning autism anti-stigma program on adolescent boys. *Journal of Autism and Developmental Disorders, 43*(12), 2816–2829. https://doi.org/10.1007/s10803-013-1829-4

Stone, R. I. (2004). The direct care worker: The third rail of home care policy. *Annual Review of Public Health, 25*(1), 521–537. https://doi.org/10.1146/annurev.publhealth.25.102802.124343

Strouse, M. C., Carroll-Hernandez, T. A., Sherman, J. A., & Sheldon, J. B. (2003). Turning over turnover: The evaluation of a staff scheduling system in a community-based program for adults with developmental disabilities. *Journal of Organizational Behavior Management, 23*(2–3), 45–63. https://doi.org/10.1300/J075v23n02_04

Stuart, M., & McGrew, J. H. (2009). Caregiver burden after receiving a diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders, 3*(1), 86–97. https://doi.org/10.1016/j.rasd.2008.04.006

Stuart-Hamilton, I., & Morgan, H. (2011). What happens to people with ASD in middle age and beyond? Report of a preliminary on-line study. *Advances in Mental Health and Intellectual Disabilities, 5*, 22–28.

Teaching-Family Association. (2021). *Hallmarks of a Teaching-Family Model Program.* https://www.teaching-family.org/who-we-are

Terry, K. (2015). A wrinkle in the fold: Inclusion of people with autism spectrum disorders in faith communities. *Social Work & Christianity, 42*(4), 449–469.

Thompson, C., Bölte, S., Falkmer, T., & Girdler, S. (2018). To be understood: Transitioning to adult life for people with autism spectrum disorder. *PLoS One, 13*(3), e0194758. https://doi.org/10.1371/journal.pone.0194758

Turner, D., Briken, P., & Schöttle, D. (2017). Autism-spectrum disorders in adolescence and adulthood: Focus on sexuality. *Current Opinion in Psychiatry, 30*(6), 409–416. https://doi.org/10.1097/YCO.0000000000000369

U.S. Bureau of Labor Statistics. (2020). *Persons with a disability: Barriers to employment, types of assistance, and other labor-related issues summary.* U.S. Bureau of Labor Statistics. Retrieved October 26, 2021, form https://www.bls.gov/news.release/dissup.nr0.htm

Van Houten, R., Axelrod, S., Bailey, J. S., Favell, J. E., Foxx, R. M., Iwata, B. A., & Lovaas, O. I. (1988). The right to effective behavioral treatment. *The Behavior Analyst, 11*(2), 111–114. https://doi.org/10.1007/bf03392464

Velott, D. L., Agbese, E., Mandell, D., Stein, B. D., Dick, A. W., Yu, H., & Leslie, D. L. (2016). Medicaid 1915(c) home- and community-based services waivers for children with autism spectrum disorder. *Autism, 20*(4), 473–482. https://doi.org/10.1177/1362361315590806

Washburn, M., Hagedorn, A., & Moore, S. (2021). Creating virtual reality based interventions for older adults impacted by substance misuse: Safety and design considerations. *Journal of Technology in Human Services*. https://doi.org/10.1080/15228835.2021.1915927

Wilkins, J., & Matson, J. L. (2009). A comparison of social skills profiles in intellectually disabled adults with and without ASD. *Behavior Modification, 33*(2), 143–155. https://doi.org/10.1177/0145445508321880

Wilson, P. G., Reid, D. H., & Green, C. W. (2006). Evaluating and increasing in-home leisure activity among adults with severe disabilities in supported independent living. *Research in Developmental Disabilities, 27*(1), 93–107. https://doi.org/10.1016/j.ridd.2004.11.012

Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders, 9*(1), 11–29. https://doi.org/10.1007/BF01531288

Wolf, M., Risley, T., Johnston, M., Harris, F., & Allen, E. (1967). Application of operant conditioning procedures to the behavior problems of an autistic child: A follow-up and extension. *Behaviour Research and Therapy, 5*(2), 103–111. https://doi.org/10.1016/0005-7967(67)90004-6

Wolf, M., Kirigin, K., Fixsen, D., Blase, K., & Braukmann, C. (1995). The teaching-family model. *Journal of Organizational Behavior Management, 15*, 11–68. https://doi.org/10.1300/J075v15n01_04

Wong, V., McGrew, J., & Ruble, L. (2020). Predicting the outcomes of parents of transition-age youth or young adults with ASD. *Journal of Autism and Developmental Disorders, 50*(8), 2723–2739. https://doi.org/10.1007/s10803-020-04362-1

Wood, A. L., Luiselli, J. K., & Harchik, A. E. (2007). Training instructional skills with paraprofessional service providers at a community-based habilitation setting. *Behavior Modification, 31*(6), 847–855. https://doi.org/10.1177/0145445507302893

Yohanna, D. (2013). Deinstitutionalization of people with mental illness: Causes and consequences. *AMA Journal of Ethics, 15*(10), 886–891. https://doi.org/10.1001/virtualmentor.2013.15.10.mhst1-1310

Yu, Q., Li, E., Li, L., & Liang, W. (2020). Efficacy of interventions based on applied behavior analysis for autism spectrum disorder: A meta-analysis. *Psychiatry Investigation, 17*(5), 432–443. https://doi.org/10.30773/pi.2019.0229

Zimmerman, D., Ownsworth, T., O'Donovan, A., Roberts, J., & Gullo, M. J. (2018). High functioning autism spectrum disorder in adulthood: A systematic review of factors related to psychosocial outcomes. *Journal of Intellectual and Developmental Disability, 43*(1), 2–19. https://doi.org/10.3109/13668250.2016.1262010

Part V

Cultural Competence, Dignity, and Ethics

12

Cultural Humility, a Path to Equity

Patricia Wright and Johanna Murphy

Cultural Humility, a Path to Equity

At school, no matter how many times I referred to the instructions, I invariably made some catastrophic mistake. Often, my mistakes were original, inexplicable, and inconceivable to the teacher. I invented entirely new ways to be wrong, while the other kids all seemed to know exactly what to do. It almost always boiled down to differences in the way we both worked with words. Defending myself, I'd read the teacher's instruction back to her – I took notes obsessively because by middle school, I'd learned that that sort of legalistic defense was my only hope.

Our seventh-grade teacher once planned our entire afternoon around a deductive reasoning lesson. She used a riddle about a blind circus performer, famous for being the shortest man in the world. After achieving worldwide renown in the circus world, he had a lovely cottage built for himself. He'd used the finest all-natural materials to construct his dream home. Friends and acquaintances were shocked when, after a few months, they learned that the man had died by suicide.

The class lesson was to determine his motive for suicide. We should ask her as many questions as it took to compile evidence. She expected we'd use most of the afternoon working toward a hypothesis. I raised my hand first. "Did the house have a stone floor?" "Yes, yes it did." I raised my hand again; breathless, I asked, "Did he kill himself because the stone floor was grinding down his cane and since he was blind and had no one around, it made him think he was getting taller and that he would lose his title as the smallest man in the world?"

Nearly 40 years later, I can still feel the utter disgust in her voice, "Yes, yes, that was it." I'd blown a whole lesson plan and instead of being rewarded for figuring out the answer, the teacher and my classmates were irritated and angry with me.

– Johanna.

Culture has long been described as the social behavior and norms of groups of people. Colloquially, the term "culture" is used to describe a membership among a group of people or to describe something such as a shared cultural experience (Bergey & Kaplan, 2010; Cohen, 2009). Culture can include many things such as knowledge, arts, language laws, customs, and habits (Tylor, 1871). Individuals exhibiting shared knowledge and behaviors form a culture (Ember et al., 2019). For Johanna, the culture of her school was difficult to navigate; she experienced the world differently than her peers.

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Membership in many cultural groups is not easily obtained for people with autism. Adults with autism describe their difficulty in navigating cultural norms across their lifespan (Bailey et al., 2020; Bury et al. 2021; Chen et al., 2017).

Cultural groups form as a collection of individuals who share a core set of beliefs, patterns of behavior, and values (Goode & Dunne, 2004). As cultural groups form, people begin to be identified as members and are welcomed in, or they are excluded or self-exclude from that group (Tajifel, 1974). Johanna was placed in the outgroup in her school as her behavior did not follow the expected cultural norms. Autistic youth and adults report feeling that they are often in the outgroup when in social contexts that include neurotypicals (Crompton et al., 2020; Kapp, 2018).

Valuing and navigating cultural diversity is important as our communities, workplaces, and social environments include an array of diverse cultural groups. Acceptance of differences between genders, races and ethnicities, and religions, although with continued need for improvement, is an expected norm in today's society. Diversity affords us the opportunity to learn from one another and benefit from diverse perspectives. Navigating diverse cultures requires flexibility. Strife exists between cultural groups when one group wants to promote exclusivity and superiority over another group. The in-group assumes superiority largely because the existence of another culture is anathema. Until neurodiversity is recognized and accepted as a culture, this assumption of neurotypical as a universal culture will continue.

Understanding one's own culture and valuing differences is required to facilitate collaboration and cooperation among groups that may hold differing beliefs and norms (DeLisser & Hark, 2010). Valuing, or at a minimum accepting, diversity of gender, race and ethnicity, and religion is an expectation in today's society. Although inclusion has yet to be fully achieved in today's society, there is a general expectation of equity. It is viewed as inappropriate to discriminate and/or engage in biased behaviors related to differences of race, ethnicity, gender, age, and religion. The value of neurodiversity has recently become a category of diversity that has joined in the effort toward equity and inclusion of historically disenfranchised populations. Autistic adults report discriminatory acts ranging from being mocked or taunted in public, active avoidance by neurotypicals, to acts of physical aggression (Jones et al., 2021). Those with neurodiverse conditions, including autism spectrum disorder, are addressing historical and contemporary discriminatory acts. The community of autistics is stating that it is no longer acceptable to engage in discriminatory behaviors, whether systemic, intentional, or unconscious toward those who are neurodiverse (Grinker, 2020; Owren, 2013). Neurodiversity is emerging as a culture that benefits society with unique and valuable characteristics including attention to detail, deep focus, tenacity, integrity, and more.

Through the simple proportionality of neurodiversity within the general population, neurodiverse individuals are a minority. Daily activities including employment, community events, social engagements, and even something as mundane as public transportation require frequent interactions between neurodiverse and neurotypical individuals. Cultural humility is vital to ensure interactions are respectful between the neurodivergent and neurotypical. These cross-cultural interactions can take many forms. Colleagues may be required to navigate a coworking space where a neurodivergent colleague prefers a workspace devoid of visual distraction and their officemate prefers to have the wall space covered with colorful art. A neurotypical direct support professional may be asked to provide instructional support to a person who has conveyed they would like to expand their repertoire of independent leisure skills. Currently, the adult with autism spends a significant portion of time in their rocking chair humming; the neurotypical support worker does not understand why being in a rocking chair and humming is pleasurable and that it may be a leisure activity. These cross-cultural interactions must be respectful of the culture of autism. This does not imply that the shared office should be either devoid of art or full of art or that the adult with autism should spend all of their leisure time humming in a rocking chair, but it does require that everyone involved in these situations not assume the neurotypical perspective is the right and only one.

The dominant culture currently present in society is neurotypical. The power dynamic created by this dominance requires both cultures, but particularly the neurotypical culture, to assess the situation and determine what is appropriate to mediate issues, ensuring cultural supremacy is not being leveraged. Historically, there has been an expectation that neurodiverse individuals should acknowledge culture discrepancies and resolve any discord through adjusting their behavior into a neurotypically normative framework. Given that social and communication deficits are inherent in an autism diagnosis, this puts an extreme burden onto neurodiverse individuals to analyze a social context and then modify their behavior. A culturally humble approach would allow for analysis of the situation by both parties to first discern if any mediation is required and if indeed behavior change is necessary to not place the sole burden on the autistic to determine what is required to ensure harmony between the two cultures.

This power dynamic is particularly important to address when there is already an inherent power imbalance such as a paid professional providing support to an individual with autism. The goal of treatment is not to change a neurodivergent individual to one who presents as typical. The goal of treatment is to improve quality of life. The culture of autism must be respected. Treatment and intervention goals must be carefully evaluated to ensure neurotypical supremacy is not being applied.

Critical Self-Reflection Questions for Practitioners

1. What are your cultural identities that impact your work as a social service professional?
2. How would you define the culture of autism?

The Culture of Autism

The first person I found for my "autism tribe" was someone I first met as a child. A school friend I reconnected with as an adult flat out told me: you are autistic. A lot had happened the previous year or two to prepare me to absorb this information, and I'd had my suspicions, but to hear it from someone who had no ego stake in whether or not I was weird, and who remembered my childhood as well as I did, made it suddenly seem like the most natural explanation in the world.

I've come to suspect that almost everyone I've ever had an instant natural rapport with is probably on the spectrum. There's just a whole different vibe among autistics. Don't get me wrong, I've had plenty of instances of immediately hating the autistic person I just met. There's an instant ease – I assume that it flows from the total absence of the sub-rosa social ranking that's usually present when you meet a neurotypical person. Autistics don't care what you do for a living, who you know, what you look like, or what you earn. We only care that you're interesting.

– Johanna.

People with autism have formed their own cultural identity often coined "the neurodiversity movement," which continues to be defined and refined (den Houting, 2019). Being neurodiverse is a cultural identity. In the simplest sense, the "in neurodiversity group" are those having a diagnosis of autism or other neurodiverse condition, and the "out neurodiversity group" are those without autism or other neurodiverse diagnosis. Autistic adults report that spending time with other autistic people is easier and more comfortable than spending time with neurotypical people, that they are better understood by other autistic people (Crompton et al., 2020). Being in autistic-led spaces, such as the Autscape Conference (a conference developed for and by autistics), is reported to improve a feeling of well-being and belonging by autistic adults (Milton & Sims, 2016).

Proponents of the neurodiversity movement advocate that the inclusion of individuals who are neurodiverse benefits society as they see the world differently and are able to contribute positively to society because of this different perspective. Several historical figures who have greatly contributed to society have been named as having autism including Elon Musk (Itzkoff, 2021), an entrepreneur; Temple Grandin (Grandin & Scariano, 1986), a leading animal scientist; and Dan Aykroyd (Hollow, 2019), a famous actor. Other historical figures including Albert Einstein (James, 2003), Bill Gates (Caplan, 2005), Andy Warhol, (Thorpe, 1999), Charles Darwin (Smith, 2009), and many others, although not formally diagnosed, have all been publicly named as having characteristics of autism. Naming these accomplished professionals is often used to demonstrate how people with autism have been contributing to the betterment of society for centuries.

Elevating a particular subset of the culture of autism, describing the "good" individuals with autism to demonstrate the value of the cultural identity is not dissimilar to the use of "good negro" and "bad negro" descriptions prevalent in racist literature throughout history (Mixon, 1997; Woodson, 1990). A "good negro" was acceptable as they did not vocalize or address racism, working to be accepted and acceptable to the dominant white culture. "Good negroes" also followed the dominant culture through education and behavior in an attempt to neutralize ill-will directed toward them. Neurodiversity acceptance should not be based upon the beneficence to the neurotypical population because of their talents or the ability to perform or their ability to become indistinguishable from their neurotypical peers.

One of the strongest beliefs of the neurodiverse community is that there is no deficiency inherent in having autism, the issue is the societal response to their autistic presentation. This social model of disability posits that the problems disabled people face are the result of social oppression and exclusion, not their individual deficits (Nicolaidis, 2012; Oliver, 2013). The greater disability community has voiced this position of disability with the belief that a person is disabled not by their impairment, but by the failure of their environment to accommodate their needs (Oliver, 1996). The social model has also been seen as a significant tool to combat disability marginalization to rehabilitate the public perception of disability (Dirth & Branscombe, 2017). Indeed, combatting ableism, stereotyping, prejudice, discrimination, and social oppression toward people with disabilities has been a rallying cry of those with disabilities for decades (Bogart & Dunn, 2019).

The neurodiversity movement utilizes this social model of disability. Unlike the medical model that views disability as a problem of self, the social model of disability states that people are disabled by barriers in society, not by an impairment or difference (Goering, 2015). For autistic people, the social model of disability indicates that the lack of acceptance of their differences is indeed a barrier created by society (Woods, 2017).

There are some members of the autism research community and family members of people with autism who do not agree that autism can be wholly subscribed under the social model of disability. Parents of autistic children commonly subscribe to the medical model and engage in treatments to change or cure their children (Chamak, 2008; Ravn et al., 2017) as well as the fields of psychiatry and psychology who assess an individual to ascertain deficits on the basis of behavioral deviations from average (American Psychiatric Association, 2013; Anckarsäter, 2010). The medical model is perceived as most relevant for those on the autism spectrum who have significant care and safety needs that are attributed to their disability or diagnosis of autism spectrum disorder. Some individuals living with autism require the support of others to remain safe and well. For these individuals with higher support needs, the medical model of disability is argued to be relevant (Anistasou & Kauffman, 2013; Baron-Cohen, 2019).

The social model of disability argues that society should welcome diversity and be inclusive of differences as the unique nature of the diverse human condition. The medical model of autism assesses individuals with autism and identifies deficits and differences that need to be rectified to promote a more positive life experience. As with all cultures, there is both agreement and disagreement about what defines this cultural identity (Chapman & Veit, 2020).

Neurodiversity and Culture

The neurodiversity movement is in its early stages of development when measured against other cultural identities such as gender and race. Professionals who are neurotypical, working to support adults with autism, need to engage in critical self-reflection to discern their understanding of neurodiversity culture and their value for diversity to guide any intervention that is developed and implemented for an individual for whom they might be providing service. Mediating these differences should not simply be trying to ensure compliance to a perception of normalcy or promoting the culture of neurotypical. The goal of the intervention is not to remove characteristics of autism; the goal of the intervention is to promote an increase in the person's quality of life. In addition, any intervention should consider not only the person with autism but also the societal barriers that are present that make a person who exhibits characteristics of autism less able to experience success within society. It is not solely the responsibility of the person with autism to change; it is also the responsibility of society to welcome diversity.

Intersectionality

The culture of autism does not occur within a vacuum. Autism intersects with other identities that also have inherent power imbalances such as race and gender. Gender is of particular importance to the autistic community as the diagnosis of autism is more prevalent in individuals who identify as male (Christensen et al., 2018). However, the proportion of females receiving a diagnosis of autism increases with the age in which they receive the diagnosis (Huang et al., 2020). Women with autism report feeling marginalized within the autism community (Cook & Garnett, 2018). Women with autism have created their own autistic spaces to address the power imbalance they feel in autistic spaces that are dominated by men.

The disenfranchisement of racial identities other than white also extends to the autism community. So often the visual representation of autism is of a white, male child. This pictorial narrative has resulted in people of color having inadequate representation and understanding (Onaiwu, 2020). This convergence of oppressions, its intersectionality, must be understood in the autistic community as they significantly affect the inherent power dynamics of a culture.

Critical Self-Reflection Questions for Practitioners

1. Do you agree that autism is a cultural identity? Why or why not?
2. How does your community (e.g., faith community, school) or workplace include people with autism? Is there opportunity to be more inclusive? How?
3. Which is most in line with your belief system, the social model or the medical model of disability? How does this belief impact your work as a professional?

Cultural Humility

As a musician, I feel like the same thing happens to me as happens to music, to sound reproduction itself. I am chopped up and remixed and compressed into unnatural forms that ruin the essential goodness. There are so many questions about source material and recording techniques and format that impact who you wind up being and how you sound. I made a thousand small choices over forty some years to sample, approximate, and re-represent my essential vibrations and to reformat and repackage myself, to be more listenable to others. Vynil to tape, to CD, to mp3, was I still even the same person? I did finally pare down all the noise and present a clean, tidy all *digital package while I was married, and it wound up meaning nothing. It didn't prevent disaster; it didn't keep me safe; it didn't keep me loved. So what would I do now? Go back to the beginning and turn it down to half-speed. What if I ask myself the obvious questions: When were you happiest? When was joy most accessible to you? When did you feel most yourself? What if I paid attention to that instead of all the things I thought I should do or be in order to seem normal? Where is the nuance?*

– Johanna.

To ensure individuals with autism and neurotypicals experience success requires cultural humility. Cultural humility is defined by Tervalon and Murray-Garcia (1998) as a lifelong commitment to self-evaluation and self-critique in order to redress power imbalances and move toward the development of mutually beneficial clinical and advocacy partnerships within communities on behalf of individuals and defined populations. This original research in cultural humility was defined within the medical community and the interaction between medical providers and their patients. There were clear patterns of bias and ineffective treatment when medical providers were delivering care to those of different cultures than they themselves identified (Borkan & Neher, 1991; Brown-Johnson et al., 2020; Ibrahim et al., 2003: Lorié et al., 2017; Pinderhughes, 1989). Cultural competence training educates medical providers about cultural differences; however, it was ineffective as exposure to a culture does not address the need for lifelong learning nor ongoing critical self-reflection. Cultural humility emerged as a model to address these additional needs to promote more effective cross-cultural understanding and more effective treatment within the medical community. Over the last 20 years, cultural humility has been integrated across multiple professions including education (Haynes-Mendez & Engelsmeier, 2020), social work (Bibus & Koh, 2021), school psychology (Fisher et al., 2020), and psychology (Buchanan et al., 2020) and lends itself well to the integration needs of the neurodiverse and neurotypical communities.

The neurotypical community, including the professional social service community that has been designed to support people with autism, is often engaged in positioning their cultural norms as superior over those who are neurodivergent, often placing the burden of social integration entirely on the shoulders of the autistic person. Examples of this cultural supremacy include the goal of treatment of autism to becoming indistinguishable to their typically developing peers (Broderick, 2009) and decreasing or eliminating stereotypy such as hand flapping or repetitive body movements (Boyd et al., 2012), not because these behaviors are physically harmful but solely because society views these behaviors as atypical and therefore not appropriate to exhibit in public (Jaswal and Akhtar, 2019: Kapp et al., 2019).

Cultural humility requires action from both individuals and institutions. Fisher-Borne et al. (2015) provides a model of cultural humility demonstrating the interaction between individuals and institutions in Fig. 12.1. Individuals and institutions must engage in ongoing learning and critical self-reflection to address the inherent power imbalances that exist in today's society. For example, at an individual level, a direct service professional asked to support an adult with autism to learn independent leisure skills must critically evaluate why they perceive it as not appropriate for an adult with autism to spend their leisure time in their room rocking in a rocking chair and humming. Institutionally, the social service provider for whom the direct support professional works must provide professional learning for the direct support professionals regarding the right of choice and the importance of agency for all humans. The social service provider must also institute a process to ensure when goals are selected for adults with autism that the primary consideration is that of the person with autism for whom they are delivering service.

The power imbalance for autistic adults in society is significant. The autism research community is dominated by non-autistic researchers (Pellicano & Stears, 2011). Maras (2021), argues that autistic adults have difficulty obtaining and maintaining employment, not due to a lack of employable skills but because of hiring and onboarding institutional practices that are biased toward those with neurotypical communication skills. The institution of human resources and

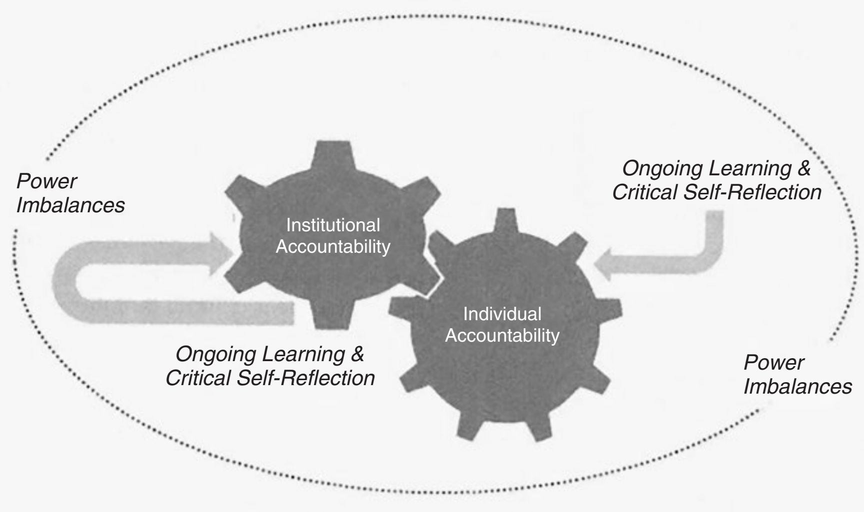

Fig. 12.1 Model of cultural humility. (Fisher-borne et al., 2015)

employer expectations have developed processes that inherently discriminate against people with autism (Pfeiffer et al., 2017; Whetzel, 2014). Interview processes typically demand a high degree of verbal acumen (Civiello, 2009). Ongoing learning and critical self-reflection of the individuals working in human resources must occur to address the imbalance. The suicide rate for adults with autism is higher than that for their neurotypical counterparts (Costa et al., 2020), and autistic adults report difficulty in accessing mental health services and supports (Howlin et al., 2015). The institutions present in mental health organizations and the professionals working within them have not adequately addressed the power imbalances that are precluding adults with autism from adequately accessing mental health services and supports.

There is an inherent power imbalance between the neurodiverse and neurotypical communities. Cultural supremacy has been established, implying that neurotypical standards are preferential and that those with neurodiverse conditions must change to match the preferred neurotypical cultural profile. The social and communication characteristics that result in an autism diagnosis have been historically targeted for remediation in order for the autistic individual to be deemed a success in neurotypical society (Rosales & Whitlow, 2019). This effort to change personal characteristics can have a profoundly negative impact on individuals with autism (Cage et al., 2018). Indeed, this practice also has deleterious effects on the entire culture. Limiting individualism and requiring all members of society to merge into the perceived norm limits learning and decreases the opportunities to profit from diversity of thoughts, beliefs, and actions. Cultural humility requires ongoing action from both the neurodiverse and the neurotypical community. Each member must take action and practice, as individuals and as members of institutions, in order to redress the existing power imbalances and to ensure that all members of the community have equal access to the knowledge, tools, and resources available for success.

Masking

I tried to accommodate the world by wearing earrings, lipstick, makeup, and nail polish. I didn't care for it aesthetically, but what I never knew to say was I can feel the weight of the polish on my nails. It mutes my sense of touch. Lipstick feels like grease, and the feeling never goes away; my lips can't breathe, and the feel of nail polish on my hands eclipses all other sensory *information. Perfume scents, which all the makeup has, make me slightly nauseous. Silky fabrics make my skin crawl. Synthetic fabrics, even sweater knits, make the hairs on the back of my neck stand up. I can't hear anything when I am wearing itchy wool. My limbs were in a constant state of jerk and twitch. Competing sensory input, competing understandings of social interactions leave me in a permanent state of choke that manifests in stumbles because my body and my mind are occupied by opposing forces: everything that feels natural and comfortable to me is everything I shouldn't be. I could be sure of myself, anchor myself in no area, and I was adrift.*

– Johanna.

In an attempt to better align with cultural norms, people with autism engage in masking their autism symptomology. Masking is the conscious or unconscious suppression of natural autistic responses (Pearson & Rose, 2021). Individuals on the spectrum have increasingly reported autistic burnout from masking (Cassidy et al., 2020; Higgins et al., 2021). Burnout is described as intense physical, mental, or emotional exhaustion that results mainly from the cumulative effect of having to navigate a world designed for the neurotypical, a world where subtle language and indirect cues require decoding, where the need to be social is an ongoing stress, and where bright lights and ambient noise induce sensory overload (Raymaker et al., 2020).

Minority stress can take a significant toll on the wellness of a minority culture. When an individual is a member of a stigmatized minority group, the disharmony produced by poorness of fit with the dominant culture results in substantial stress (Allison, 1998; Clark et al., 1999). In communities of color, maintaining one's personal safety in a society that makes wrongful assumptions requires a high level of vigilance; this vigilance is exhausting. In the LGBT community, coming out of the closet can reduce stress and result in a happier, healthier life. For autistic adults, the effort to mask their autistic characteristics and socially camouflage results in exhaustion and threats to self-perception (Hull et al., 2017).

The premise that results in autistic masking is that the neurotypical culture's norms are superior to the neurodiverse culture. Demonstrating savvy social skills is more preferable to the neurotypicals than trying to navigate the social meaning behind the behavior of autistics (Cook et al., 2021). This perceived supremacy requires autistic adults to engage in the emotional effort of masking their autism symptomatology so they too can exist in the dominant culture. This masking comes at a significant personal cost to autistics.

Critical Self-Reflection Questions for Practitioners

1. How do you currently practice culturally humility? What do you do well? On what areas could you improve?
2. What behaviors do you exhibit as a professional that demonstrate cultural humility?
3. How can you address masking when supporting adults with autism?

Applying Cultural Humility

Work/Employment

Work has always been a struggle. I do well and get promoted to some sort of supervisory role in which I implode because I'm bad with people. Bosses tend to like me because I have great ideas and overperform. I have a weird gift for streamlining and reorganizing business processes. I save them time and money. Coworkers and those who report to me tend to dislike me for the very same reasons – the act of streamlining and reorganizing anything irritates people because it involves changing what they've always done and carries the social undercurrent of "you've been doing this the wrong way," which breeds resentment. I can be goal oriented to the point of seeming rude – we don't have time for small talk; we are trying to reach a sales goal. I have no instinct for morale building, because in my world, you simply do your best all of the time.

For years, I believed that the rules we were taught as children were also true for most work scenarios: always do your best; follow the rules *give by your employer. What I realize now is that I was incapable of seeing a much larger picture – as opposed to my neurotypical peers, I have a much narrower sphere of interest and therefore have had an atypical amount of attention and energy to give to work.*

What I've come to understand is that the diplomacy needed in the workplace is bidirectional. Both parties need to understand the possible social implications of their actions, and they must also understand the cognitive biases they bring with them. If I want my distinct developmental trajectory to be seen and validated, I must do the same in return. I should do what isn't instinctual to me: I should include them. I need to exhibit more diplomacy in the area of group relations. For their part, my coworkers should try to understand that my developmental trajectory means that I'm often blind to the importance of group dynamics and that I don't mean to insult them, I just see things from an entirely foreign-to-them perspective.

– Johanna.

Cultural supremacy and its effect on professionals with autism begin from the earliest point of workforce engagement (Hagner & Cooney, 2005; Scott et al., 2017). The typical method of obtaining a job universally benefits individuals with strong neurotypical communication and social skills. The initial phone screening and interview process continues to be widely accepted as a talent acquisition process. Given that the majority of jobs do not require individuals to spontaneously answer questions about which they have no prior preparation or knowledge, this method of hiring seems arbitrary and clearly places autistic candidates at a disadvantage. The mismatch between job responsibilities and how professionals secure employment is a significant barrier for people with autism whose diagnosis ensures social challenges (Maras et al., 2021). The employment difficulties continue for adults with autism when social expectations extend into the work experience.

The social communication requirements of employment extend beyond the initial employment procurement. John, a professional working in the banking industry, shared his experience that demonstrates the ongoing communication and social expectations that employers place on employees and the consequences if an autistic professional does not meet these expectations.

> I loved my first job at the bank. I think I was really good at it, but when I was in the same position for 3 years and watched all of my colleagues get promoted and I never did, I figured there was something wrong with me. Looking back, I now know that the bank manager was promoting "team players." My performance reviews were exemplary for my assigned tasks but also mentioned that I had an opportunity for growth in teaming. I thought that meant that I needed to work harder at getting my group tasks done at work. What teaming really meant was going out after work together for drinks and playing or at least attending the company softball team games. I don't drink, and I don't really like softball, so I didn't even think about doing those things. It wasn't until I moved to another bank within the organization and was rapidly promoted that I realized maybe it wasn't my work performance that kept me from being successful. My current boss and I talked about it, and I realized now I missed how important those social events were to my professional success and that my lack of engagement in social activities made me an outsider to my colleagues. I still don't fully understand how social events have any relevance to my work performance. And I wish my colleagues had been more direct in telling me that my absence at these events was noticed and important to my career success. Nobody tells you about these social rules, but they do judge you by them.

Applying cultural humility to the institution of work would have allowed John's prior boss to engage in critical self-reflection of the power imbalance that she had created, to identify the biases that afforded privilege to employees that participated in outside events like softball games, events that were not at all related to work performance. At an individual level, each employee takes responsibility for ensuring employees from diverse cultures, including the culture of autism, experience equity in the workforce. Equity means everyone receives fair treatment, everyone knows what to expect, and that people have equal access to opportunities (Society for Human Resource Management, n.d.). Equity at work is advantageous for both employees and the employer.

At an institutional level, employers must evaluate their processes and protocols to assess for artificial barriers that discriminate against and exclude autistic people. Discrimination of people with disabilities in the workplace is illegal; however, the discrimination of people with autism is often subtle and requires awareness and cultural humility to acknowledge and remedy these discriminatory practices. John's experience is a great example of the need for institutional critical self-reflection. Equitable promotion practices would have meant that John's supervisor either informed John that engagement in outside events was pivotal for promotion within the company or the employer would acknowledge that outside social activities should have no bearing on promotions and John would have likely been selected for promotion at pace as his colleagues who were performing at his same level.

Friendships and Relationships

Relationships of any kind have largely been a murky concept for me. There was also what I call the "brass ring syndrome." My intense focus on obtaining a partner was spurred as a result of so many years of being told friends and partners was the goal, so I would appear "normal." Having a relationship was a token I was trying to collect to move toward normalcy. I've just turned 50, and I can honestly say that prior to my 40s, I was probably too immature to carry out a serious relationship. I'm deeply embarrassed now by what I now recognize as not just emotional immaturity but emotional blindness of a sort, both in my romantic and friend relationships.

Everyone, my parents, my siblings, my friends, exerted extreme pressure on me to blend in, to fit in, to be like the other girls so that I could make friends and have a happy life. Naturally, acquiring friends or romantic partners became the goal. Friends and romantic partners were tangible proof that I was "normal." I worked toward it constantly.

One trouble was that, trapped in my own self-referential world, I didn't understand a relationship required an almost metallurgical process of alloying two substances. My idea of a relationship was always two distinct units conveniently orbiting each other. I did not know how or why to emotionally open with friends or lovers because the goal had only ever been to obtain them.

After I was diagnosed with and treated for anxiety, I had the emotional room to really evaluate how I related with people. I realized my ability to interact with people was in some very real ways like that of a grade schooler – I felt like I needed permission or instructions. I was always waiting for an adult to step in, someone who had the authority to protect me or to make people behave fairly or be nice. Without even really being aware of it, I often expected friends or lovers to take on that role. Theoretically, that might have been ok if I'd had the adjacent agency to also provide some sort of comfort to them, However, like a young child, I had no sense that I could or should contribute anything back.

I could never understand why nothing worked out: I was doing what I was supposed to do! The understanding came when I was diagnosed with Asperger's and learned about masking. Yes, I was doing "everything right" if the end goal was tricking someone into liking you. However, if I was looking for a real connection, true self to true self, I was doing exactly all the wrong things for all the wrong reasons. It's hard to find a good match when you've been masking yourself for so long that you have no idea what you want in a partner or what you have to offer. It wasn't until I simply quit masking and made myself remember who I was and what I enjoyed before I was pressured into fitting in that I had enough of a sense of self and enough sense of self-worth to see that I could provide real emotional support and value too that I began real, fulfilling relationship.

– Johanna.

Relationships with other people are important for overall well-being. Historically, there has been a misconception that people with autism prefer to be alone and do not want friendships or relationships. Individuals with autism spectrum disorder have a similar level of romantic interest but experience less relationship success and lower satisfaction with romantic relationships (Hancock et al., 2020). As Johanna's story represents, being autistic and navigating the complex social and communication requirements of pursuing and engaging in intimate relationships is challenging (Mogavero & Hsu, 2020).

When one partner is autistic and the other is neurotypical, the relationship is intercultural. Intercultural relationships can take many forms including interracial, interfaith, geographic regions, and between people with autism and people without autism. Intercultural relationships often must navigate different communication patterns (Tili & Barker, 2015), increased societal pressure (Buggs, 2019), and family acceptance (Bell & Hastings, 2015), to name just a few additional barriers to relationship success.

Some autistic adults choose to date, partner, and marry others with autism (Bertilsdotter Rosqvist, 2014). Many couples realize a diagnosis of autism for one of the partners when they are already partnered; indeed, the neurotypical partner is often the person in the relationship pushing for their partner to pursue a diagnosis as they are looking for explanations of what is contributing to challenges in their relationship (Lewis, 2017). Other couples knowingly partner, fully aware that one person is autistic and the other is neurotypical. Every relationship requires communication and compromise, but for couples with one neurotypical and one autistic partner, cultural humility from both parties can address some of the inherent challenges that present themselves.

Home/Community Living

Wendy is an autistic adult who has significant support needs. Wendy moved to a supported apartment as her parents were aging; they and the other people in Wendy's life realized moving might encourage Wendy to not only gain some additional independent living skills but it would also be much easier for Wendy to transition living away from her parents before they passed away. Her support community had the foresight to understand that learning how to live away from her parents would be easier if she was not simultaneously grieving their death. Wendy receives care coordination services from a social service agency. Martha, Wendy's care coordinator, shared this story of Wendy's adjustment to her new home.

> Being in the water is Wendy's favorite place. Her family talks about the swimming pool being a favorite place for her even as a baby, splashing in the water and squealing with joy. Wendy is now 34 and splashing in the pool is still one of her most joyful activities. Fortunately, her apartment building has a pool. The pool is a social place at Wendy's apartment building. Often, there are other residents enjoying the water, swimming laps and enjoying the cool water on a hot day. The professional team supporting Wendy noticed that when she gets into the pool, other residents exit the pool; Wendy watches them leave. Wendy would benefit from making some additional adult social connections with her fellow apartment building residents; she is a social person and likes interacting with others. Wendy doesn't have spoken language; she often moves toward people and looks expectantly into their faces which her staff and family interpret as being interested in others. Her professional staff thought the pool might be a place to connect with other adults, but it has not worked out that way. The other apartment residents seem to be clearing out of the pool when Wendy arrives.

Connecting socially and building a community is important to most adults. The fellow residents in Wendy's apartment building may not become intimate friends, but her support staff felt there needed to be some support offered to the other residents to help them engage with Wendy in a neighborly fashion at the pool. Outside of the pool, Wendy was learning to greet her neighbors with a wave and a smile when they crossed paths in the hallway or in the laundry room. There was discussion among Wendy's direct support professionals and her family about having an informational flyer shared with her neighbors about her, but that was dismissed as it felt extremely impersonal and perhaps even disrespectful as Wendy could not consent to having her personal information shared with strangers in her building.

Employing the concept of cultural humility, the support staff knew that they wanted to support Wendy to learn to share the pool space respectfully but also to address the power imbalance that was resulting in the perceived superiority of the neighbors. There was desire to help the neighbors learn about the benefit that splashing in the pool has for Wendy; it was one of the few places where Wendy experienced pure joy. To achieve these goals, Wendy's support team purchased some aquatic exercise equipment and began to teach Wendy how to use it in the pool to allow for a more discreet splashing experience and to afford Wendy an opportunity to invite her fellow residents to join her in an activity – water aerobics.

Martha, Wendy's care coordinator, shared the success of this modest addition of aquatic exercise equipment to her home.

> Over a period of a few months, Wendy learned how to use the pool exercise equipment to both exercise and get the water splashing she enjoyed. The splashing was contained to a certain area in the pool where Wendy used her equipment. Once Wendy had learned how to use the exercise equipment, a second set was purchased. This material was kept by the side of the pool. When fellow residents would come to the pool environment, Wendy's staff would invite them to use the equipment and would include Wendy in the brief interaction that would occur when another resident chose to use the equipment. This interaction was often just a simple smile and a wave. Over time the interactions became a bit more friendly, and residents began to initiate greeting Wendy outside of the pool and engaging in short social interactions that appeared to bring Wendy pleasure.

Through this simple modification, Wendy and her neighbors engaged in critical self-reflection and ongoing learning to address a power imbalance. Wendy learned how to use aquatic exercise equipment that would control her splashing to a certain zone. The residents in her community learned how to interact with Wendy in a prosocial manner. The cultural superiority that was previously exhibited by the community residents dissipated, and the power imbalance was addressed.

Critical Self-Reflection Questions for Practitioners

1. How can you as a professional deploy cultural humility to promote a more inclusive work or recreation environment?
2. How do you address biases that you observe in your community or at your workplace?
3. What do you perceive to be the biggest barrier to achieve an inclusive society for people with autism?

Conclusion

If I'm honest, I cannot recommend my own personal odyssey learning to bridge the cultural gap between being neurodiverse and the rest of the world. It involves guitars, liquor, and swearing. At some point, I realized that my worst moments were born out of trying to fit in or be who I was supposed to be, and that things went much more smoothly when I just focused on what came naturally to me. I learned to pay attention to the moments where I felt "in flow" socially and worked to dissect what it was that worked.

– Johanna.

Adults with autism are valuable members of our society. Engaging in cultural humility through lifelong learning and critical self-reflection can address the power imbalance between the neurotypical and neurodiverse cultures. The application of cultural humility in our workplaces, communities, and relationships decreases the privilege that is currently experienced by neurotypicals. Autistics have much to contribute to our society. Through mutual diplomacy, differences can be embraced as a strength. No longer do we ask adults with autism to mask their symptoms; each individual is valued for their individual characteristics, and differences are evaluated to discern if there is indeed a need for change or if the perceived difference is simply the dominant paradigm trying to bend each human into normative behavior that promotes comfort for the majority.

References

Allison, K. W. (1998). Stress and oppressed social category membership. In J. K. Swim & C. Stangor (Eds.), *Prejudice: The target's perspective* (pp. 145–170). Academic.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Association. https://doi.org/10.1176/appi.books.9780890425596

Anastasiou, D., & Kauffman, J. M. (2013). The social model of disability: Dichotomy between impairment and disability. *Journal of Medicine & Philosophy, 38*(4), 441–459. https://doi.org/10.1093/jmp/jht026

Anckarsäter, H. (2010). Beyond categorical diagnostics in psychiatry: Scientific and medicolegal implications. *International Journal of Law and Psychiatry, 33*(2), 59–65. https://doi.org/10.1016/j.ijlp.2009.12.001

Bailey, K. M., Frost, K. M., Casagrande, K., & Ingersoll, B. (2020). The relationship between social experience and subjective well-being in autistic college students: A mixed methods study. *Autism: The International Journal of Research & Practice, 24*(5), 1081–1092. https://doi.org/10.1177/1362361319892457

Baron-Cohen, S. (2019). Observations: The concept of neurodiversity is dividing the autism community—It remains controversial—But it doesn't have to be. *Scientific American Blog Network*. Available at: https://blogs.scientificamerican.com/observations/the-concept-of-neurodiversity-is-dividing-the-autism-community/. Accessed 29 Nov 2020.

Bell, G. C., & Hastings, S. O. (2015). Exploring parental approval and disapproval for black and white interracial couples. *Journal of Social Issues, 71*(4), 755–771. https://doi.org/10.1111/josi.12147

Bergey, B. W., & Kaplan, A. (2010). What do social groups have to do with culture? The crucial role of shared experience. *Frontiers in Psychology, 1*, 199. https://doi.org/10.3389/fpsyg.2010.00199

Bertilsdotter Rosqvist, H. (2014). Becoming an 'autistic couple': Narratives of sexuality and couplehood within the swedish autistic self-advocacy movement. *Sexuality & Disability, 32*(3), 351–363. https://doi.org/10.1007/s11195-013-9336-2

Bibus, A. A., & Koh, B. D. (2021). Intercultural humility in social work education. *Journal of Social Work Education, 57*(1), 16–27. https://doi.org/10.1080/10437797.2019.1661925

Bogart, K. R., & Dunn, D. S. (2019). Ableism special issue introduction. *Journal of Social Issues, 75*(3), 650–664. https://doi.org/10.1111/josi.12354

Borkan, J. M., & Neher, J. O. (1991). A developmental model of ethnosensitivity in family practice training. *Family Medicine, 23*(3), 212–217.

Boyd, B., McDonough, S., & Bodfish, J. (2012). Evidence-based behavioral interventions for repetitive behaviors in autism. *Journal of Autism & Developmental Disorders, 42*(6), 1236–1248. https://doi.org/10.1007/s10803-011-1284-z

Broderick, A. A. (2009). Autism, "recovery (to normalcy)," and the politics of hope. *Intellectual & Developmental Disabilities, 47*(4), 263–281. https://doi.org/10.1352/1934-955647.4.263

Brown-Johnson, C., Shankar, M., Taylor, N. K., Safaeinili, N., Shaw, J. G., Winget, M., & Mahoney, M. (2020). "Racial Bias...I'm not sure if it has affected my practice": A qualitative exploration of racial bias in team-based primary care. *Journal of General Internal Medicine, 35*(11), 3395–3397. https://doi.org/10.1007/s11606-020-06219-w

Buchanan, N. T., Rios, D., & Case, K. A. (2020). Intersectional cultural humility: Aligning critical inquiry with critical praxis in psychology. *Women & Therapy, 43*(3/4), 235–243. https://doi.org/10.1080/02703149.2020.1729469

Buggs, S. G. (2019). Color, culture, or cousin? Multiracial Americans and framing boundaries in interracial relationships. *Journal of Marriage & Family, 81*(5), 1221–1236. https://doi.org/10.1111/jomf.12583

Bury, S. M., Flower, R. L., Zulla, R., Nicholas, D. B., & Hedley, D. (2021). Workplace social challenges experienced by employees on the autism Spectrum: An international exploratory study examining employee and supervisor perspectives. *Journal of Autism & Developmental Disorders, 51*(5), 1614–1627. https://doi.org/10.1007/s10803-020-04662-6

Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism & Developmental Disorders, 48*(2), 473–484. https://doi.org/10.1007/s10803-017-3342-7

Caplan, A. (2005, May 31). Would you have allowed Bill Gates to be born? *NBC News*. https://www.nbcnews.com/id/wbna7899821

Cassidy, S. A., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2020). Is camouflaging autistic traits associated with suicidal thoughts and Behaviours? Expanding the interpersonal psychological theory of suicide in an undergraduate student sample. *Journal of Autism & Developmental Disorders, 50*(10), 3638–3648. https://doi.org/10.1007/s10803-019-04323-3

Chamak, B. (2008). Autism and social movements: French parents' associations and international autistic individuals' organizations. *Sociology of Health & Illness, 30*(1), 76–96. https://doi.org/10.1111/j.1467-9566.2007.01053.x

Chapman, R., & Veit, W. (2020). Representing the autism Spectrum. *American Journal of Bioethics, 20*(4), 46–48. https://doi.org/10.1080/15265161.2020.1730495

Chen, Y.-W., Bundy, A. C., Cordier, R., Chien, Y.-L., & Einfeld, S. L. (2017). A cross-cultural exploration of the everyday social participation of individuals with autism spectrum disorders in Australia and Taiwan: An experience sampling study. *Autism: The International Journal of Research & Practice, 21*(2), 231–241. https://doi.org/10.1177/1362361316636756

Christensen, D. L., Braun, K., Baio, J., Bilder, D., Charles, J., Constantino, J. N., Daniels, J., Durkin, M. S., Fitzgerald, R. T., Kurzius-Spencer, M., Lee, L. C., Pettygrove, S., Robinson, C., Schulz, E., Wells, C., Wingate, M. S., Zahorodny, W., & Yeargin-Allsopp, M. (2018). Prevalence and characteristics of autism spectrum disorder among children aged 8 years – Autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *Morbidity and Mortality Weekly Report. Surveillance Summaries (Washington, DC: 2002), 65*(13), 1–23. https://doi.org/10.15585/mmwr.ss6513a1

Civiello, M. (2009). Communication counts in landing a job. *T+D, 63*(2), 82–83.

Clark, R., Anderson, N., Clark, V., & Williams, D. (1999). Racism as a stressor for African Americans: A biopsychosocial model. *American Psychologist, 54*(10), 805–816. https://doi.org/10.1037/0003-066X.54.10.805

Cohen, A. B. (2009). Many forms of culture. *American Psychologist, 64*(3), 194–204. https://doi.org/10.1037/a0015308

Cook, B., & Garnett, M. (Eds.). (2018). *Spectrum women: Walking to the beat of autism*. Jessica Kingsley Publishers.

Cook, J., Crane, L., Hull, L., Bourne, L., & Mandy, W. (2021, June). Self-reported camouflaging behaviours used by autistic adults during everyday social interactions. *Autism*. https://doi.org/10.1177/13623613211026754

Costa, A. P., Loor, C., & Steffgen, G. (2020). Suicidality in adults with autism spectrum disorder: The role of depressive symptomatology, alexithymia, and antidepressants. *Journal of Autism & Developmental Disorders, 50*(10), 3585–3597. https://doi.org/10.1007/s10803-020-04433-3

Crompton, C. J., Hallett, S., Ropar, D., Flynn, E., & Fletcher-Watson, S. (2020). "I never realized everybody felt as happy as I do when I am around autistic people": A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism: The International Journal of Research & Practice, 24*(6), 1438–1448. https://doi.org/10.1177/1362361320908976

DeLisser, H., & Hark, L. (2010). *Achieving cultural competency: A case-based approach to training health professionals*. Wiley, John & Sons, Incorporated.

den Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism: The International Journal of Research & Practice, 23*(2), 271–273. https://doi.org/10.1177/1362361318820762

Dirth, T. P., & Branscombe, N. R. (2017). Disability models affect disability policy support through awareness of structural discrimination. *Journal of Social Issues, 73*(2), 413–442. https://doi.org/10.1111/josi.12224

Ember, C. R., Ember, M., & Peregrine, P. (2019). *Anthropology*. Pearson.

Fisher, E. S., Grapin, S. L., & Shriberg, D. (2020). Cultural humility as a form of social justice: Promising practices for global school psychology training. *School Psychology International, 41*(1), 53–66. https://doi.org/10.1177/0143034319893097

Fisher-Borne, M., Cain, J. M., & Martin, S. L. (2015). From mastery to accountability: Cultural humility as an alternative to cultural competence. *Social Work Education, 34*(2), 165–181. https://doi.org/10.1080/02615479.2014.977244

Goering, S. (2015). Rethinking disability: The social model of disability and chronic disease. *Current Reviews in Musculoskeletal Medicine, 8*(2), 134–138. https://doi.org/10.1007/s12178-015-9273-z

Goode, T. D., & Dunne, C. (2004). *Cultural self-assessment. From the curricula enhancement module series*. National Center for Cultural Competence, Georgetown University Center for Child and Human Development.

Grandin, T., & Scariano, M. (1986). *Emergence, labeled autistic*. Arena Press.

Grinker, R. R. (2020). Autism, "Stigma," disability: A shifting historical terrain. *Current Anthropology, 61*(S21), S55–S67. https://doi.org/10.1086/705748

Hagner, D., & Cooney, B. F. (2005). "I do that for everybody": Supervising employees with autism. *Focus on Autism & Other Developmental Disabilities, 20*(2), 91–97. https://doi.org/10.1177/10883576050200020501

Hancock, G., Stokes, M. A., & Mesibov, G. (2020). Differences in romantic relationship experiences for individuals with an autism spectrum disorder. *Sexuality & Disability, 38*(2), 231–245. https://doi.org/10.1007/s11195-019-09573-8

Haynes-Mendez, K., & Engelsmeier, J. (2020). Cultivating cultural humility in education. *Childhood Education, 96*(3), 22–29. https://doi.org/10.1080/00094056.2020.1766656

Higgins, J. M., Arnold, S. R., Weise, J., Pellicano, E., & Trollor, J. N. (2021). Defining autistic burnout through experts by lived experience: Grounded Delphi method investigating #AutisticBurnout. *Autism: The International Journal of Research & Practice*. Advance online publication. https://doi.org/10.1177/13623613211019858

Hollow, M. (2019, December 18). What's so funny about autism? *New York Times*. https://www.nytimes.com/2019/06/18/well/mind/autism-spectrum-humor-comedy.html

Howlin, P., Arciuli, J., Begeer, S., Brock, J., Clarke, K., Costley, D., di Rita, P., Falkmer, T., Glozier, N., Gray, K., Guastella, A., Horstead, S., Rice, L., Stancliffe, R. J., West, S., Yam, C., & Einfeld, S. (2015). Research on adults with autism spectrum disorder: Roundtable report. *Journal of Intellectual & Developmental Disability, 40*(4), 388–393. https://doi.org/10.3109/13668250.2015.1064343

Huang, Y., Arnold, S. R., Foley, K.-R., & Trollor, J. N. (2020). Diagnosis of autism in adulthood: A scoping review. *Autism: The International Journal of Research & Practice, 24*(6), 1311–1327. https://doi.org/10.1177/1362361320903128

Hull, L., Petrides, K., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017). "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. *Journal of Autism & Developmental Disorders, 47*(8), 2519–2534. https://doi.org/10.1007/s10803-017-3166-5

Ibrahim, S. A., Whittle, J., Bean-Mayberry, B., Kelley, M. E., Good, C., & Conigliaro, J. (2003). Racial/ethnic variations in physician recommendations for cardiac revascularization. *American Journal of Public Health, 93*(10), 1689–1693. https://doi.org/10.2105/AJPH.93.10.1689

Itzkoff, D. (2021, May 18). Elon Musk hosts a mother's day episode of 'Saturday Night Live. *New York Times*.

https://www.nytimes.com/2021/05/09/arts/television/elon-musk-snl.html

James, I. (2003). Singular scientists. *Journal of the Royal Society of Medicine, 96*(1), 36–39. https://doi.org/10.1258/jrsm.96.1.36

Jaswal, V., & Akhtar, N. (2019). Being versus appearing socially uninterested: Challenging assumptions about social motivation in autism. *Behavioral and Brain Sciences, 42*, E82. https://doi.org/10.1017/S0140525X18001826

Jones, S. C., Gordon, C. S., Akram, M., Murphy, N., & Sharkie, F. (2021). Inclusion, exclusion and isolation of autistic people: Community attitudes and autistic people's experiences. *Journal of Autism & Developmental Disorders*. Advance online publication. https://doi.org/10.1007/s10803-021-04998-7

Kapp, S. K. (2018). Social support, well-being, and quality of life among individuals on the autism spectrum. *Pediatrics, 141*(Suppl 4), S362–S368. https://doi.org/10.1542/peds.2016-4300N

Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). "People should be allowed to do what they like": Autistic adults' views and experiences of stimming. *Autism: The International Journal of Research & Practice, 23*(7), 1782–1792. https://doi.org/10.1177/1362361319829628

Lewis, L. F. (2017). "We will never be normal": The experience of discovering a partner has autism spectrum disorder. *Journal of Marital & Family Therapy, 43*(4), 631–643. https://doi.org/10.1111/jmft.12231

Lorié, Á., Reinero, D. A., Phillips, M., Zhang, L., & Riess, H. (2017). Culture and nonverbal expressions of empathy in clinical settings: A systematic review. *Patient Education and Counseling, 100*(3), 411–424. https://doi.org/10.1016/j.pec.2016.09.018

Maras, K., Norris, J. E., Nicholson, J., Heasman, B., Remington, A., & Crane, L. (2021). Ameliorating the disadvantage for autistic job seekers: An initial evaluation of adapted employment interview questions. *Autism: The International Journal of Research & Practice, 25*(4), 1060–1075. https://doi.org/10.1177/1362361320981319

Milton, D., & Sims, T. (2016). How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability & Society, 31*(4), 520–534. https://doi.org/10.1080/09687599.2016.1186529

Mixon, G. (1997). "Good negro—Bad negro": The dynamics of race and class in Atlanta during the era of the 1906 riot. *The Georgia Historical Quarterly, 81*(3), 593–621.

Mogavero, M. C., & Hsu, K. H. (2020). Dating and courtship behaviors among those with autism spectrum disorder. *Sexuality & Disability, 38*(2), 355–364. https://doi.org/10.1007/s11195-019-09565-8

Nicolaidis, C. (2012). What can physicians learn from the neurodiversity movement? *American Medical Association Journal of Ethics, 14*(6), 503–510.

Oliver, M. (1996). *Understanding disability: From theory to practice*. Mackays of Chatham.

Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society, 28*(7), 1024–1026. https://doi.org/10.1080/09687599.2013.818773

Onaiwu, M. G. (2020). "They Don't know, Don't show, or Don't care": Autism's white privilege problem. *Autism in Adulthood, 2*(4), 270–272. https://doi.org/10.1089/aut.2020.0077

Owren, T. (2013). Neurodiversity: Accepting autistic difference. *Learning Disability Practice, 16*(4), 32–37.

Pearson, A., & Rose, K. (2021). A conceptual analysis of autistic masking: Understanding the narrative of stigma and the illusion of choice. *Autism in Adulthood, 3*(1), 52–60. https://doi.org/10.1089/aut.2020.0043

Pellicano, E., & Stears, M. (2011). Bridging autism, science and society: Moving toward an ethically informed approach to autism research. *Autism Research, 4*(4), 271–282. https://doi.org/10.1002/aur.201

Pfeiffer, B., Braun, K., Kinnealey, M., Matczaka, M. D., & Polatajko, H. (2017). Environmental factors impacting work satisfaction and performance for adults with autism spectrum disorders. *Journal of Vocational Rehabilitation, 47*(1), 1–12. https://doi.org/10.3233/JVR-170878

Pinderhughes, E. (1989). *Understanding race, ethnicity and power: The key to efficacy in clinical practice*. Free Press.

Ravn Andersen, E., Bøttcher, L., & Dammeyer, J. (2017). An interview study of why parents conduct intensive ABA home training for their child with autism spectrum disorder. An analysis from the lens of the dialectical disability model. *European Journal of Special Needs Education, 32*(2), 270–286. https://doi.org/10.1080/08856257.2016.1223400

Raymaker, D. R., Teo, R. T., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., Kapp, S. K., Hunter, M., Joyce, I., & Nicolaidis, C. (2020). "Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": Defining autistic burnout. *Autism in Adulthood, 2*(2), 132–143. https://doi.org/10.1089/aut.2019.0079

Rosales, R., & Whitlow, H. (2019). A component analysis of job interview training for young adults with autism spectrum disorder. *Behavioral Interventions, 34*(2), 147–162. https://doi.org/10.1089/aut.2019.0079

Scott, M., Jacob, A., Hendrie, D., Parsons, R., Girdler, S., Falkmer, T., & Falkmer, M. (2017). Employers' perception of the costs and the benefits of hiring individuals with autism spectrum disorder in open employment in Australia. *PLoS One, 12*(5), 1–16. https://doi.org/10.1371/journal.pone.0177607

Smith, R. (2009, February 18). Charles Darwin had autism, leading psychiatrist claims. *The Guardian*. https://www.telegraph.co.uk/news/health/news/4680971/Charles-Darwin-had-autism-leading-psychiatrist-claims.html

Society for Human Resource Management. (n.d.). *Introduction to the human resources discipline of diversity, equity and inclusion.* https://www.shrm.org/resourcesandtools/tools-and-samples/toolkits/pages/introdiversity.aspx

Tajfel, H. (1974). Social identity and intergroup behaviour. *Social Science Information, 13*(2), 65–93. https://doi.org/10.1177/053901847401300204

Tervalon, M., & Murray-Garcia, J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Undeserved, 9*(2), 117–125. https://doi.org/10.1353/hpu.2010.0233

Thorpe, V. (1999, March 13). Was autism the secret of Warhol's art? *The Guardian*. https://www.theguardian.com/uk/1999/mar/14/vanessathorpe.theobserver

Tili, T. R., & Barker, G. G. (2015). Communication in intercultural marriages: Managing cultural differences and conflicts. *Southern Communication Journal, 80*(3), 189–210. https://doi.org/10.1080/1041794X.2015.1023826

Tylor, E. (1871). *Primitive culture* (Vol. 1). J.P. Putnam's Son.

Whetzel, M. (2014). Interviewing tips for applicants with autism spectrum disorder (ASD). *Journal of Vocational Rehabilitation, 40*(2), 155–159.

Woods, R. (2017). Exploring how the social model of disability can be rein-invigorated for autism: In response to Jonathan Levitt. *Disability and Society, 32*(7), 1090–1095. https://doi.org/10.1080/09687599.2017.1328157

Woodson, C. G. 1875–1950. (1990). *The mis-education of the Negro*. Africa World Press.

13

Ethical Considerations and Dignity for Adults with Autism Spectrum Disorders

Melissa L. Olive

In the years between 1990 and 2020, we have seen an explosion of diagnosed cases of autism spectrum disorder (ASD). For example, in the early 1990s, the national rate for ASD was 1 in 10,000 children (Autism and Developmental Disabilities Monitoring Network, 2012). By 2010, it was reportedly 1 in 68 (Developmental Disabilities Monitoring Network Surveillance, 2014). Five years later, in 2017, it was 1 in 40 (Kogan et al., 2018).

Children with ASD grow up. Dietz et al. (2020) reported that the current incidence of adults with ASD is 2.21%, or almost 5.5 million individuals. Roux et al. (2017) noted that we can expect about half a million youth to age into adulthood over the next decade. Not only is the adult system about to be inundated with individuals with ASD, the stage of adulthood in ASD is the one where the least knowledge exists from research (Centers for Medicaid and Medicare Services, 2010; Missouri Autism Guidelines Initiative, 2012; Roux et al., 2017). Moreover, states may grapple with insufficient provider groups who are knowledgeable and experienced providers for adults with ASD (Centers for Medicaid and Medicare Services, 2011).

While many adults with ASD are able to live independently and without behavioral supports, it is unclear what percentage of adults with ASD require behavioral supports. We do know that slightly over half of middle-aged adults with ASD have a severe or profound intellectual disability (Roux et al., 2017). The 2017 National Autism Indicators Report (Roux et al., 2017) focused solely on adults with ASD and more severe challenges, and the results were gloomy. For example, 49% of adults with ASD used six or more services funded by a state Developmental Disabilities (DD) program. These state programs are overwhelmed with need yet lack the funding to meet the demands. In fact, 25% of study participants reported they did not receive all the services they needed. These adults also have comorbidities of other health and behavioral health needs. For example, Vohra et al. (2016) noted that 85% of their sample used at least one psychotropic medical prescription and 75% had 20 or more prescription drug claims in a year. Moreover, about half of adults with ASD had at least one health condition with gastrointestinal issues (GI) being the most common health problem (Rast et al., 2020). However, 77% of adult health-care providers rated their knowledge and skills for providing care to patients with ASD as poor or fair (Zerbo et al., 2015).

It is clear adults with ASD have complex needs (Rast et al., 2020) requiring an array of services which should be coordinated carefully to ensure appropriate service integration and delivery. Given that 46% of adults with ASD

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have significant behavioral challenges (Roux et al., 2017), therapy based on applied behavior analysis (ABA) is just one of many needed services for adults with ASD. The purpose of this chapter is to describe the ethical considerations for behavior analysts when providing ABA-based services for adults with ASD. Of utmost importance is the need to ensure that adults with ASD are treated with "compassion, dignity, and respect" (Behavior Analyst Certification Board, 2020, p. 4.)

The framework for this chapter is based on five components (see Fig. 13.1). First, the Behavior Analyst Certification Board (BACB) Ethics Code for Behavior Analysts (hereafter The Code, 2020) serves as the overall foundation for ethical delivery of services. Second, written informed consent should always be obtained prior to the start of services. Third, funding of services may impact access to appropriate care. Fourth, legal and regulatory matters will vary from state to state, which may also affect access to appropriate care. And finally, all behavior analysis services should be based on sound evidence-based services/practices (EBP).

The Code

The Code is really the foundation for all services provided for adults with ASD by behavior analysts. The most recent Code includes four core principles. These are benefitting others, treating others with compassion, dignity, and respect, behaving with integrity, and ensuring competence. Every aspect of the behavior analytic services for adults with ASD should be based on those four core principles. This is especially true for the need to treat with compassion, dignity, and respect. Behavior analysts serving the adult ASD population must also remember several key points from The Code. These points will be summarized from a process of factors to consider before starting services, considerations during service delivery, and discharge processes (see Fig. 13.2).

Before Services Begin

Prior to serving adults with ASD, the behavior analyst should take care to ensure that adult services fall within their scope of competence (#1.05). Behavior analysts should complete

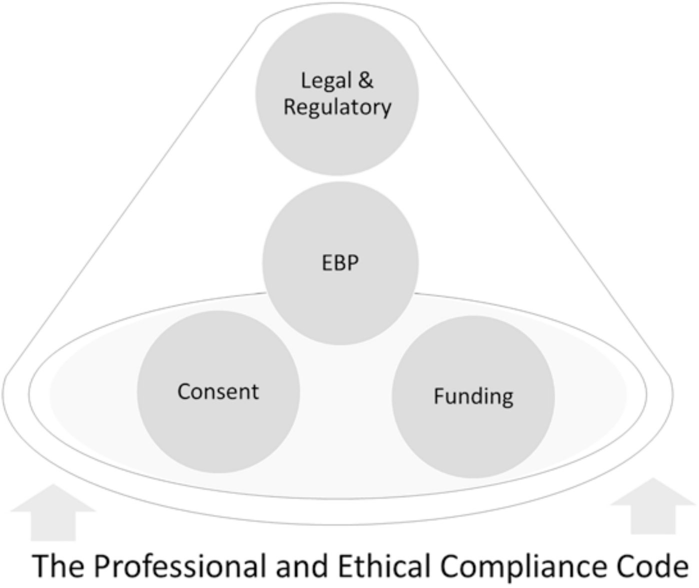

Fig. 13.1 Framework for ethical considerations and dignity

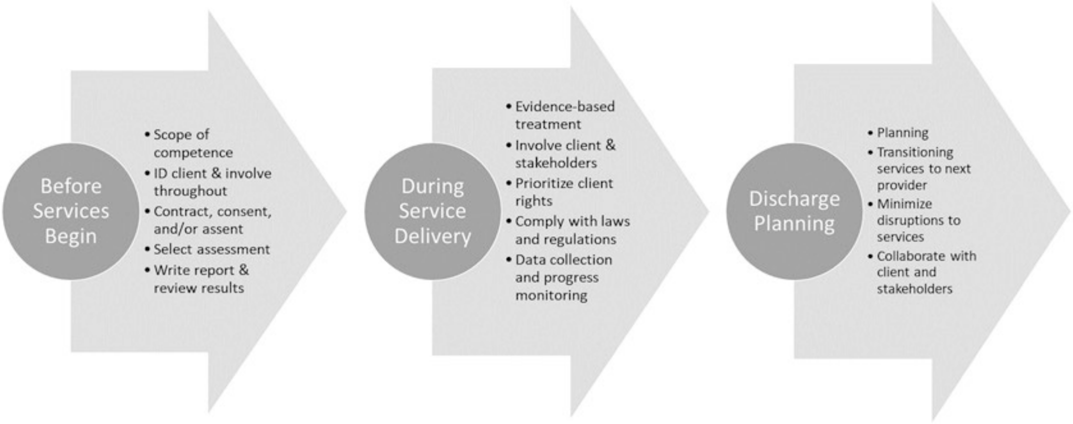

Fig. 13.2 Process of ethical considerations for service delivery

coursework, supervision, and/or mentorship in any new area of services prior to beginning those services (Brodhead et al., 2018). As described previously in this chapter, adults with ASD have very complex needs, and the behavior analyst serving this population should be well-equipped with experience as well as familiarity and expertise with the evidence-based practices for adults with ASD.

When serving adults with ASD, the behavior analyst should first determine who will be the actual client. Behavior analysts should remember that the definition of client may change from time to time depending on location of services, funder, and service type. For example, if the behavior analyst developed a treatment plan for the adult and is monitoring staff while they implement, taking data on fidelity of implementation, and reviewing client progress toward the treatment goals, then it is clear the adult with ASD is the client. On the other hand, if a group home hires the behavior analyst to conduct training for staff who provide residential services to adults with ASD, then the group home staff are the clients. If a family hires the behavior analyst to consult with them on how to remain safe during crisis situations, then the family is the client. The behavior analyst is responsible for identifying who will be the direct recipient of services. The behavior analyst is also responsible for informing all parties when the client changes based on a change in services.

When the client has been identified, the behavior analyst should then document services within a contractual service agreement (#3.04), which would clearly define the behavior analyst's role with relevant parties (#1.04). Next, the behavior analyst should collaborate with stakeholders, but only after receiving written consent (see #3.02 for additional information). The behavior analyst should also obtain consent to collaborate with appropriate stakeholders. In the most recent Code, the BACB added the term "stakeholder" to the glossary. A stakeholder is "An individual, other than the client, who is impacted by and invested in the behavior analyst's services (e.g., parent, caregiver, relative, legally authorized representative, collaborator, employer, agency or institutional representative, licensure board, funder, third-party contractor for services)" (BACB, 2020, p. 8).

Given the documented extent of medical needs reported by adults with ASD (Roux et al., 2017), prior to the initiation of services, the behavior analyst should engage in due diligence to ascertain what role, if any, underlying medical conditions may be playing in the current behavioral challenges (see #2.12). Roux et al. (2017) noted that over half (i.e., 64%) of adults with ASD in their study took medications for behavioral challenges. Moreover, Davignon et al. (2018) noted that adults with ASD were two to three times as likely to have depression or anxiety when compared to adults without ASD. Davignon and colleagues also noted that adults with ASD were far more likely to be diagnosed with schizophrenia, ADHD, epilepsy, or bipolar disorder. Finally, Zerbo et al. (2019) reported that adults with ASD had much higher utilization of health-care services when compared to adults with other disabilities.

In light of the complex medical needs for adults with ASD, behavior analysts should coordinate care with prescribing/treating physicians to determine if medications are necessary or if doses may be modified once appropriate and effective behavior interventions have been put into place (Newhouse-Oisten et al., 2017). Once appropriate permissions have been obtained, the behavior analyst should then plan to coordinate care between and among relevant medical providers as services ensue. This could include sharing progress notes and data to document response to intervention, response to medication changes, and any other relevant data.

Initial and Ongoing Assessment

With each initial assessment and/or re-assessment, behavior analysts should include clients and stakeholders in the assessment process (#2.09). The funding source or state regulations may place restrictions on the amount of time behavior analysts have available to complete appropriate assessments. Nonetheless, behavior analysts will need to engage in due diligence to ensure clients and stakeholders are included in the selection and prioritization of treatment goals.

As part of the assessment process, behavior analysts should “select and design assessments that are conceptually consistent with behavioral principles” (BACB, 2020, p. 12; #2.13). Again, the funding source may attempt to dictate measures to be included in the assessment, but behavior analysts should remain firm in their scientific training and ensure appropriate measures are utilized. Just because the funding source will not reimburse for a functional assessment does not justify the behavior analyst designing a treatment plan without first assessing the function of targeted behavior. At the same time, behavior analysts must also carefully select assessment measures by conducting a risk-benefit analysis to determine which measures are most appropriate for each client (#2.13).

As stated previously, behavior analysts will complete a thorough medical review before services commence. Newhouse-Oisten et al. (2017) noted the assessment may need to be repeated several times until behavior levels are stable. A comprehensive medical review should be completed again with each re-assessment to appropriately assess any medication changes, physical and/or symptom changes, and new diagnoses. Additionally, any sudden change regarding intensity or severity of behavior or resurgence of behavior should be evaluated for any medical change. Newhouse-Oisten et al. provided a list of sample questions to consider when completing assessments for individuals.

Finally, when the assessment is complete, the behavior analyst will summarize assessment procedures and results in writing (#2.13). The behavior analyst should allow time to meet with appropriate parties and explain those assessment results to clients, guardians, and stakeholders (#2.08).

Ethical Decision-Making During Service Delivery

Once behavior analysts have completed the assessment, they will initiate services. The duration of services can range from a few weeks to several years. Therefore, behavior analysts should take extra precaution to ensure their services remain ethical throughout. As summarized in Fig. 13.2, and described above, behavior analysts will want to ensure they select only evidence-based treatments throughout the course of services (#2.14). Behavior analysts are obligated to involve clients and stakeholders throughout the intervention process (#2.09). Due to the variety of funding sources and service delivery options, behavior analysts must remain diligent to comply with all laws and regulations related to their services (#1.02).

The next section of this chapter will focus on the client and stakeholder role throughout services, the need to collect data and document services throughout, the importance of collaboration and consultation throughout services, and the process of designing intervention and modifying interventions over the course of service delivery.

Client and Stakeholder Involvement Throughout

With the pressures of funding limitations, behavior analysts may be faced with the challenge of designing, implementing, and overseeing appropriate services for their clients within budget allowances. However, behavior analysts must prioritize client rights throughout the process (#2.01), and they must act in the best interest of their clients (#1.03, 2.10, 3.01). This may include advocating for increases in funding and/or services (#3.12), increasing collaboration with other providers, increasing guardian involvement, and incorporating staff training. Behavior analysts must also work to ensure their clients remain free from harm (#3.01) throughout the course of services. This includes ensuring that all involved parties are capable of implementing developed plans with fidelity, focusing on intervention strategies to ensure that all risks are minimized (#2.15), and ensuring that interventions have desired outcomes for the individual being treated. If at any time during the course of services, the behavior analyst becomes aware of possible abuse/neglect, they must comply with state regulations regarding mandated reporting.

Data Collection and Progress Monitoring

Throughout the course of intervention, behavior analysts appropriately document services provided (#2.05). First, behavior analysts should document the occurrence of direct and indirect services to the client. This most often occurs in the form of a session note. Session notes should include a variety of information types and will vary based on the funder. At a minimum, session documentation should include client's name, provider's name, service provided, date of service, persons present, summary of session activity, and next steps or actions needed. If indirect services are provided, session notes should be completed so as to document the occurrence of all services. This is especially true for billed indirect services.

Behavior analysts must also select appropriate measurement systems very early in the intervention process. Then behavior analysts must ensure that data are collected and graphed regularly (#2.17). Throughout intervention and at regular intervals (e.g., weekly), behavior analysts summarize the data and use the data to make treatment decisions jointly with the client and/or guardian. Prior to the start of services, behavior analysts indicate the schedule of data analysis and review (#2.16). Depending on consents, behavior analysts may need to regularly share data analysis with appropriate stakeholders. Treatment decisions based on data analysis can include continuing the intervention, modifying the intervention, changing the type of intervention, or terminating services. The data analysis and decision-making are continual throughout the course of intervention (#2.18). It is during this ongoing analysis of data that behavior analysts must also determine if other services or medications are impacting the individual's progress.

Collaboration, Consultation, and Client Involvement

The behavior analyst has many responsibilities when providing services for adults with ASD. Of utmost importance is the need to involve the client and/or guardian throughout the services (#2.09). Additionally, the behavior analyst must collaborate with colleagues (#2.10) and consult with other providers when appropriate (#2.18). It is equally important for other providers to similarly share information about their intervention strategies and outcomes with behavior analysts. Therefore, behavior analysts will find it helpful to establish a system that will promote regular communication between and among the treatment team. Any new intervention or change to the intervention should be described to all parties to be certain that the procedures will not interfere with existing treatment (Newhouse-Oisten et al., 2017). When behavior analysts analyze data and become concerned about other services or medication interfering with the individual's progress, they must take action by reviewing options and discussing services with all involved professionals and clients/guardians.

Designing and Modifying Interventions

Any intervention designed by behavior analysts for adults with ASD must be tailored to the individual and their diverse needs as well as based on individualized assessment data and results (#2.14). Interventions should also be based on evidence-based practices for adults with ASD and conceptually consistent with behavioral principles (#2.14). The plan should also be described in writing and reviewed with team members prior to implementation (#2.16).

Behavior analysts should consider several relevant factors when designing and modifying interventions. For example, they must prioritize reinforcement procedures (#2.14). This could cause challenges if the adult prefers edible reinforcers and the state's Human Rights Committee (HRC) does not approve plans containing edibles. The complexities around HRCs will be discussed more thoroughly later in this chapter. Another challenge is the need to ensure that interventions will maintain under naturalistic conditions. This can be particularly problematic if the individual resides in group care where rates of positive attention or the implementation of other intervention procedures may be limited due to staffing constraints.

When data suggest that a change to the treatment plan is warranted, behavior analysts make changes considering all the elements above. For example, all changes are made in conjunction with the client and/or guardians. The change is discussed with relevant stakeholders to ensure the change will not interfere with other treatments. The change is based on behavioral principles, described in writing, and fully described to team members prior to implementation.

Discharge and Fading Services

Behavior analysts may discontinue behavioral services for a variety of reasons. For example, an individual may complete the outcome of their service such as reducing challenging behavior or acquiring missing skill deficits. On the other hand, the client and/or guardian may elect to discontinue services for numerous reasons. The behavior analyst may elect to discharge the client due to lack of follow-through with the treatment plan or due to interfering services from other providers. Services may also be discontinued due to a lack of progress over a substantial period of time. Regardless of the reason for service discontinuation, behavior analysts have ethical obligations to their clients in terms of planning the discharge (#3.15), transitioning services to the next provider (#3.16), and working to minimize disruptions to services (#3.16). Behavior analysts continue to collaborate with the client and stakeholders throughout the discharge process to ensure a seamless transition.

With The Code serving as a foundation of all behavior analytic services, the next sections of this chapter will focus on other important areas. However, because The Code is the foundation, references to it will continue throughout this chapter.

Written Informed Consent

Under The Code, #2.11, behavior analysts are "responsible for explaining, obtaining, reobtaining, and documenting required informed consent" (BACB, 2020, p. 11). The individual responsible for providing written consent will vary based on the capabilities of the adult with ASD. Specifically, if the adult has a guardian or conservator, that person would be responsible for providing written consent. It is the responsibility of the behavior analyst or their employer to maintain the most recent copies of guardianship/conservatorship to ensure that client rights are always upheld.

If the adult does not have a guardian or conservator, then the adult with ASD would be responsible for providing consent. It is the responsibility of the behavior analyst to ensure that the signing party fully understands the risks and benefits of treatment, the cost of treatment, and any other pertinent information such as where to file a complaint regarding services.

If the individual is represented by a guardian or conservator, the behavior analyst must ensure that the adult with ASD assents to services. Assent is defined as approval, agreement, and/or permission (US Legal, 2021). For an adult with ASD with limited verbal skills, assent would be any behavior that is reasonably interpreted as willingness to participate. Behavior analysts will have a difficult time deciding the next steps if an adult with ASD does not assent to services that are designed to keep them safe. For example, if the adult engages in serious self-injurious behavior (SIB), an intervention is necessary in order to keep them safe. Behavior analysts will need to collaborate with appropriate stakeholders to complete the risk-benefit analysis regarding the continuation of services against the client's wishes.

As a guardian of my adult sibling with ASD and an intellectual disability, he does not assent to regular blood testing that is required to monitor potential side effects of his anticonvulsant medication. Rather than medicating him for blood draws, we utilize a preferred item as a distractor (Davis et al., 2000) resulting in him consuming his favorite food and beverage while simultaneously keeping his arm still with prompts and/or gentle restraint by the phlebotomist.

Behavior analysts should recognize that guardians/conservators and/or clients may remove consent at any time during the course of assessment and treatment. If termination of behavior analytic services places the client in harm's way, behavior analysts may need to collaborate with appropriate stakeholders and/or report risks under their state's mandated reporter laws as described later in this chapter.

Funding of Services

Behavior analysts have the responsibility of understanding the funding sources for behavior analytic services. In some states, services may be covered by health insurance and state Developmental Disability departments or through private pay and/or grants. Each is discussed more thoroughly next.

Health Insurance

In 2001, Indiana mandated coverage of ABA services to individuals with ASD (Autism Speaks, 2021). In 2007, two more states passed mandated coverage. This trend continued until 2019 when all 50 states had passed similar mandates. Each state's mandate varies, however, with regard to limitations such as age and cost caps. Nonetheless, in some states, coverage is mandated for adults with ASD through their health insurance. As such, behavior analysts who provide services funded by health insurance will need to be completely apprised of the funder requirements that accompany those services. This can include requirements for session notes, location of services, amount of supervision of services, and appropriate intervention targets. Just as behavior analysts need to have adult services in their scope of practice, they must also be informed of funder policies. Some funders require specific assessments prior to the commencement of services. Behavior analysts should be acutely aware of their own license restrictions as well as their own scope of practice before administering certain assessments. And as previously described, behavior analysts must utilize evidence-based assessment procedures, so additional assessments may be needed over and above those required by the funder. And finally, health insurance carriers regularly complete audits of rendered services. Unsuccessful audits may lead to costly recoupment of payments and potential fraud investigations, so extreme care and caution should be embraced throughout the course of treatment funded by health insurance.

State DD Services

As Roux et al. (2017) described in their report surveying 29 states, the percentage of state DD users diagnosed with ASD ranged from 6% to 24% while the percentage of individuals in their study with intellectual disability and ASD ranged from 57% to 100%. Interestingly, they noted that 49% of adults with ASD utilized six or more services funded by the DD agency while 89% used three or more services each year. One such service in many states is behavioral support. While not all state DD agencies value the role of the behavior analyst in adult services, some states do allocate funding for behavior analysts. However, when behavior analytic services are available, they are rarely delivered in a tiered approach as described in the Council of Autism Service Providers (2020) ASD guidelines. Most often, services are provided directly to the adult or directly to parents, guardians, caregivers, and/or residential staff. In true tiered services, the frontline technician often receives 40 or more hours of specific training in ABA. However, the parents, guardians, caregivers, and/or residential staff are very unlikely to have received that amount of training in ABA. This lack of training places behavior analysts in a precarious position since they cannot recommend interventions that staff are not trained to implement. Thus, staff training is another needed service, but due to budget deficits, it is unlikely that enough hours of behavior analytic services are available to fully assess, develop treatments, train staff, and monitor intervention effectiveness. Thus, behavior analysts should use care to fully understand the amount of service hours available for their clients. Finally, as described above, regardless of the funding source, behavior analysts will still need to document their services with session notes and data while also analyzing data frequently to ensure progress is being made.

Private Pay and Grant Funding

Individuals may elect to pay for behavior analytic services privately. Few individuals will have the resources available to pay for extensive behavioral supports based on their own or their loved ones' needs. A comprehensive program delivered in a tiered model can easily cost more than $100,000 per year. This exorbitant cost usually leaves individuals purchasing what few services they can afford, which places the behavior analyst in another predicament of determining how much behavior support is required and for how long.

Individuals may not fully understand the need for indirect services, which include writing reports, analyzing data, and modifying treatment plans. Behavior analysts will need to clearly define and describe services upfront to ensure that individuals are aware of all the necessary components of behavior supports. It is not uncommon for parents/guardians to request only technician services without the oversight of a behavior analyst. Parents/guardians may not want to pay for indirect work on the case and may not understand the value of data analysis and program modification.

Individuals may also have access to special grant funding. This funding is often one-time funding and likely for only a few thousand dollars. Behavior analysts should work to meet the special funding requirements while balancing their requirement to be in compliance with The Code. Special grants may limit services to certain types of behavior support or support in specific locations. These grants may also require specific receipts or other documentation of services. Starting services for families with alternate funding will require behavior analysts to be familiar with all funding requirements.

Legal and Regulatory Matters

In addition to funding limitations, behavior analysts will find that legal and regulatory matters vary widely from state to state. The next section of this chapter discusses just a few of the regulations that may impact the ethical delivery of behavior analytic services.

Mandated Reporters

Many states have requirements for the mandated reporting of child abuse and neglect. Some states have similar reporting requirements for adults with disabilities, including adults with

ASD. Behavior analysts will need to make certain that they understand and are in compliance with the reporting requirements in the state(s) where they practice (#3.01). Mandated reporting is often required within a specified window of time from when the behavior analyst became aware of the possible abuse/neglect matter. The time needed to document and follow up with mandated reporting is often not a reimbursable expense. Even so, behavior analysts must remain in compliance.

Human Rights Committees

Each state will have some type of human rights committee (HRC). An HRC reviews human rights issues raised by or on behalf of individuals in DD agencies. The committee is often comprised of physicians, parents, agency employees, and other parties knowledgeable of adults with ASD and other developmental disabilities. While the rules vary from state to state, behavior analysts are responsible for knowing the regulations in the state(s) where they practice (#1.02, #3.01, #3.06). HRCs may have explicit policies regarding the oversight and approval of behavior plans consisting of aversive components, intrusive devices or safety measures, and the use of restrictive consequences. Additionally, behavior analysts may have to attend an HRC meeting to describe and possibly defend the treatment plan they have developed.

Federal Laws and State Laws

Several laws apply to services for adults. It is important for behavior analysts to remember that federal laws apply to all states and that each state will have its own laws and regulations that will need to be followed (#1.02, #3.01, #3.06). Likely, the Civil Rights of Institutionalized Persons Act (CRIPA, 1997) is the most important. Under this law, the attorney general in any state may investigate institutions where adults with ASD reside looking for widespread abuse. The investigations focus on "egregious or flagrant conditions" that limit the adult's rights or privileges. The investigations may also focus on any conditions where the adult "suffered grievous harm … pursuant to a pattern" (CRIPA, 1997, p. 4796). This means that if a behavior analyst develops faulty behavior plans on a recurring basis and those behavior plans result in individuals being harmed or denied their rights, behavior analysts could be held responsible under civil actions. While this law is designed to protect issues related to widespread abuse, nonetheless, behavior analysts should use caution when practicing with adults with ASD. It is of paramount importance that behavior analysts uphold the rights of adults with ASD and that behavior analysts are fully aware of those rights.

The regulations under the US Department of Health and Human Services regulate services provided within most group homes. While the group home organization is responsible for following rules around the residence itself, behavior analysts are responsible for understanding and fully complying with the regulations regarding behavior services, behavior support plans, and human rights matters.

The USA has two disability-specific laws to which individuals must adhere. This includes the Americans with Disabilities Act (ADA, 1990) as well as the Rehabilitation Act of 1973. The ADA is comprised of multiple titles. Under Title 1, Employment, the behavior analyst may need to provide services to ensure that an adult with ASD is fairly employed. Under Title II, State and Local Governments/Transportation/Public Services, the behavior analyst may need to develop support plans so that adults with ASD may access public transportation safely. Under Title III, Public Accommodations, behavior analysts may need to support adults with ASD as they navigate various community facilities and activities. And finally, under Title IV, Telecommunications, behavior analysts may need to support adults with ASD to communicate with others in order to schedule medical appointments and access social services.

Just as the ADA has multiple titles, the Rehabilitation Act also has several sections. Fewer of these sections apply to behavior analysts. Under Sect. 504, any program that receives federal funding must comply. Thus, group homes and other similar entities must comply and refrain from discriminating against individuals with disabilities as they access education, employment, and other services. This discrimination component is also consistent with The Code (#1.08). Finally, Section 508 requires the Federal Government to create accessible websites and other technologies which may result in the behavior analyst developing programs to assist adults with ASD in accessing those websites and services.

Finally, under the Voting Accessibility for the Elderly and Handicapped Act (1973), behavior analysts may need to participate in the development of support plans to ensure that the adult with ASD may access polling places and also appropriately participate in their right to vote.

Evidence-Based Practices

Not only do behavior analysts need to comply with legal and regulatory matters, but they also have a duty to provide effective treatment that is conceptually consistent with behavior analysis and based on scientific evidence (#2.01). Adults with ASD have the right to effective treatment and evidence-based practices (Van Houten et al., 1988). However, the age group of adults with autism is the age group with the least amount of research focus (Centers for Medicaid and Medicare Services, 2010; Roux et al., 2017). In 2010, the Centers for Medicare and Medicaid Services commissioned a report on ASD services. As part of the report, the authors reviewed the research literature for interventions designed for adults with ASD. They found three evidence-based interventions that they defined as “effectiveness as established through peer-reviewed research in scientific journals” (Centers for Medicaid and Medicare Services, 2010, p. 20) while utilizing several scoring criteria. The evidence-based interventions included supported employment, structured teaching, and behavioral packages.

In 2015, the National Autism Center conducted a review of the literature to identify established interventions for individuals with autism. At the time, the workgroup found only 27 articles that met their inclusion criteria for adults with ASD. Their report noted that for adults aged 22 years and older, only one established intervention had been thoroughly researched and had sufficient evidence, defined as, “sufficient evidence is available to confidently determine that an intervention produces favorable outcomes for individuals on the autism spectrum” (National Autism Center, 2015, p. 234). That single intervention is behavioral interventions and includes ABA-based strategies of prompting, extinction, differential reinforcement of incompatible behavior, choice, and functional communication training as well as combined interventions such as prompting plus error correction.

While the limited studies on research for adults with ASD seem sparse, it should be noted that all research may not have been included in the aforementioned review. Specifically, Leaf et al. (2021) completed a review of a similar literature review for children and youth with ASD. Their paper noted a number of limitations of the Evidence-Based Practices for Children and Youth Report (Steinbrenner et al., 2020). These limitations included missing studies, excluding certain designs, and excluding articles with null findings. Leaf et al. also made several pertinent recommendations for behavior analysts. These recommendations included the need for behavior analysts to be objective and practice rational skepticism; continue efforts to educate other professionals and consumers about the importance of experimental control when evaluating research; educate the public on confounding variables, different research designs, and importance of single subject designs; and collaborate on the development of a general consensus for determining evidence-based practices in ABA. Likely most important in their paper is the notion that science is ever evolving, and behavior analysts will need to continue to assess the evidence base particularly as it relates to adults with ASD.

Not only should behavior analysts take care to implement only evidence-based intervention based on principles of behavior analysis, but behavior analysts must also strive to conduct more research focused on adults with ASD. Given the paucity of studies reported in two literature reviews (Centers for Medicaid and Medicare Services, 2010; National Autism Center, 2015), it is essential that behavior analysts focus on including adults with ASD in order to broaden the evidence base of interventions available for this population.

In summary, choosing to provide behavior analytic services to adults with ASD requires much planning and forethought by the behavior analyst. Behavior analysts should remember the framework used to lay out this chapter. Specifically, the BACB Professional and Ethical Compliance Code is the foundation of all services. Thereafter, behavior analysts must (a) obtain informed written consent and assent for all services; (b) understand the role of the funder and how the funder requirements may impact services; (c) thoroughly research the legal and regulatory requirements for services; and (d) use only evidence-based services.

References

Americans With Disabilities Act of 1990, 42 U.S.C. § 12101 *et seq* (1990). https://www.ada.gov/pubs/adastatute08.html

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2008 Principal Investigators, & Centers for Disease Control and Prevention. (2012). Prevalence of autism spectrum disorders – Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. *Morbidity and Mortality Weekly Report. Surveillance Summaries (Washington, DC: 2002), 61*(3), 1–19.

Autism Speaks. (2021). *Autism insurance reform in 50 states*. https://www.autismspeaks.org/state-regulated-health-benefit-plans

Behavior Analyst Certification Board. (2020). *Ethics code for behavior analysts*. Author.

Brodhead, M. T., Cox, S. P., & Quigley, S. P. (2018). *Practical ethics for effective treatment of autism spectrum disorder*. Academic Press.

Centers for Medicaid and Medicare Services. (2010). *Autism spectrum disorders (ASDs) services final report on environmental scan*. https://impaqint.com/sites/default/files/project-reports/Autism_Spectrum_Disorders.pdf

Centers for Medicaid and Medicare Services. (2011). *Report on state services to individuals with autism spectrum disorders (ASD)*. https://www.cms.gov/apps/files/9-state-report.pdf

Civil Rights of Institutionalized Persons, 42 U.S.C. § *et seq* (1997). https://www.govinfo.gov/content/pkg/USCODE-2019-title42/pdf/USCODE-2019-title42-chap21-subchapI-A-sec1997.pdf

Davignon, M. N., Qian, Y., Massolo, M., & Croen, L. A. (2018). Psychiatric and medication conditions in transition-aged individuals with ASD. *Pediatrics, 141*(S4), S335–S345. https://doi.org/10.1542/peds.2016-4300K

Davis, C. A., Reichle, J. E., & Southard, K. L. (2000). High probability requests sequences and a preferred item as a distractor: Increasing successful transitions in children with behavior problems. *Education and Treatment of Children, 23*, 423–440.

Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators, & Centers for Disease Control and Prevention (CDC). (2014). Prevalence of autism spectrum disorder among children aged 8 years - autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report. Surveillance Summaries (Washington, DC: 2002), 63*(2), 1–21.

Dietz, P. M., Rose, C. E., McArthur, D., & Maenner, M. (2020). National and state estimates of adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 50*(12), 4258–4266. https://doi.org/10.1007/s10803-020-04494-4

Kogan, M. D., Vladutiu, C. J., Schieve, L. A., Ghandour, R. M., Blumberg, S. J., Zablotsky, B., Perrin, J. M., Shattuck, K. A., Kuhlthau, K. A., Harwood, R. L., & Lu, M. C. (2018). The prevalence of parent-reported autism spectrum disorder among US children. *Pediatrics, 142*(6). https://doi.org/10.1542/peds.2017-4161

Leaf, J. B., Sato, S. K., Javed, A., Arthur, S. M., Creem, A. N., Cihon, J. H., Ferguson, J. L., & Oppenheim-Leaf, M. L. (2021). The evidence-based practices for children, youth, and young adults with autism report: Concerns and critiques. *Behavioral Interventions, 36*(2), 457–472. https://doi.org/10.1002/bin.1771

Missouri Autism Guidelines Initiative. (2012). *Autism spectrum disorders: Guide to evidence-based intervention*. www.autismguidelines.dmh.mo.gov

National Autism Center. (2015). *Findings and conclusions: National standards project, phase 2*. Author. http://www.autismdiagnostics.com/assets/Resources/NSP2.pdf

Newhouse-Oisten, M. K., Peck, K. M., Conway, A. A., & Frieder, J. E. (2017). Ethical considerations for interdisciplinary collaboration with prescribing professionals. *Behavior Analysis in Practice, 10*(2), 145–153. https://doi.org/10.1007/s40617-017-0184-x

Rast, J. E., Roux, A. M., Anderson, K. A., Croen, L. A., Kuo, A. A., Shea, L. L., & Shattuck, P. T. (2020). *National autism indicators report: Health and health* *care*. https://drexel.edu/~/media/Files/autismoutcomes/publications/NAIR%20Health%202020.ashx

Roux, A. M., Rast, J. E., Anderson, K. A., & Shattuck, P. T. (2017). *National autism indicators reports: Developmental disability services and outcomes in adulthood*. https://drexel.edu/~/media/Files/autismoutcomes/publications/Natl%20Autism%20Indicators%20Report%202017_Final.ashx

Steinbrenner, J. R., Hume, K., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., … Savage, M. N. (2020). *Evidence-based practices for children, youth, and young adults with autism*. The University of North Carolina, Frank Porter Graham Child Development Institute, National Clearinghouse on Autism Evidence and Practice Review Team.

The Council of Autism Service Providers. (2020). *Applied behavior analysis treatment of autism spectrum disorder: Practice guidelines for healthcare funders and managers*. https://casproviders.org/wp-content/uploads/2020/03/ABA-ASD-Practice-Guidelines.pdf

US Legal. (2021, September). *Assent law and legal definition*. https://definitions.uslegal.com/a/assent/

Van Houten, R., Axelrod, S., Bailey, J. S., Favell, J. E., Foxx, R. M., Iwata, B. A., & Lovaas, O. I. (1988). The right to effective behavioral treatment. *Journal of Applied Behavior Analysis, 21*(4), 381–384. https://doi.org/10.1901/jaba.1988.21.381

Vohra, R., Madhavan, S., Sambamoorthi, U., StPeter, C., Poe, S., Dwibedi, N., & Ajmera, M. (2016). Prescription drug use and polypharmacy among Medicaid-enrolled adults with autism: A retrospective cross-sectional analysis. *Drugs-Real World Outcomes, 3*(4), 409–425. https://doi.org/10.1007/s40801-016-0096-z

Voting Accessibility for the Elderly and Handicapped Act. 42 U.S.C. § 98–435 *et seq* (1973).

Zerbo, O., Massolo, M. L., Qian, Y., & Croen, L. A. (2015). A study of physician knowledge and experience with autism in adults in a large integrated healthcare system. *Journal of Autism and Developmental Disorders, 45*(12), 4002–4014. https://doi.org/10.1007/s10803-015-2579-2

Zerbo, O., Qian, Y., Ray, T., Sidney, S., Rich, S., Massolo, M., & Croen, L. A. (2019). Health care service utilization and cost among adults with autism spectrum disorders in a US integrated health care system. *Autism in Adulthood, 1*(1), 27–36. https://doi.org/10.1089/aut.2018.0004

Part VI

Comprehensive Intervention

14

Applied Behavior Analysis: An Overview of ABA-Based Autism Services for Adults

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Services specifically tailored for autistic adults/adults with autism[1] often focus on supported employment skills, community access, initiating and maintaining social relationships, promoting safety, and increasing personal independence through continued acquisition of daily living skills, self-advocacy skills, and any other repertoires that promote optimized autonomy, choice, and personal freedoms. These domains are critically necessary, and many would consider them socially significant, as key concerns for the adult demographic may include general safety, reducing potential for abuse encountered through community-based and daily living assistance, maintaining schedules of preventive medical care, reducing heightened risk of depression and anxiety via social isolation, and overcoming the financial, social, and emotional challenges posed by systemic underemployment (Gerhardt & Lainer, 2011).

A concern for society is insufficient resources for adult services, particularly for those with autism and developmental disabilities (Gerhardt & Lainer, 2011). When this is paired with the rise of prevalence of autism, the result is a generation that has come into adulthood without sufficient resources to support employment, personal freedom, and improved quality of life (Gerhardt & Lainer, 2011). While early intensive behavioral intervention (EIBI), a comprehensive application of early services rooted in the principles of applied behavior analysis (ABA), has demonstrated the potential to teach foundational skills that can successfully prepare children to transition into autonomous adults (e.g., communication repertoires, social interaction, leisure skills, self-management), a generation of autistic adults may have missed an opportunity for early intervention, due to a lack of regional resources and funding (Gerhardt & Lainer, 2011).

Even with the advent of mandated insurance coverage for early intervention, some autistic individuals may not be diagnosed until they are in their teens or early adulthood and again are faced with a dearth of options for support in their transition. While school programs may offer some training programs in independent living skills and vocational training through age 22 years

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[1] While it is standard practice in academic and medical communities to use person-first language (e.g., person with autism), some communities of adult self-advocates (e.g., Autistic Self Advocacy Network, ASAN) have asked that identity-first language be used. In keeping with the inclusion practices of the authors' affiliations, identity-first language will be used throughout this chapter.

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under the Individuals with Disabilities Act (IDEA), extended to age 26 in some states, there is a substantial need for more robust supports post-transition (Smith et al., 2020). Supervision ratios may be suboptimal, tasks may be complex, and social interactions may be highly nuanced. Additionally, performance management is inconsistent from one employer to the next and often involves social cues and consequences that pose a challenge to neurodivergent employees untrained in interpreting those specific cues (Hendricks, 2010). This mismatch of management ratio and style sensitive to the needs of the neurodivergent employee may result in ongoing employment barriers and inconsistent employment status. Currently, unemployment and chronic underemployment are common in autistic adults (Gerhardt & Lainer, 2011).

The gaps illustrated in the above example extend to other areas of social significance to the autistic adult. Reliance on assistance with intimate hygiene (such as in a medically supported assisted living model) leaves an individual vulnerable to higher incidents of abuse, especially in the case of the adult who either is unable to communicate the occurrence of abuse (Thornberry & Olson, 2005) or has no access to community or social relationships with whom to share the information or seek help. Individuals who become lost, engage in wandering, or who otherwise require emergency assistance from first responders may find themselves in a confrontation with first responders if they are unable to communicate clearly or respond to early nuanced cues to deescalate interactions. It has been reported that agencies involved in the criminal justice system do not sufficiently support autistic individuals (Browning & Caulfield, 2011). Difficulty managing community environments, especially those occasional anxiety responses in the general population (e.g., dental and medical appointments; Blomqvist et al., 2014), may lead to avoidance of preventive care and eventually require far more intrusive medical procedures to correct urgent medical concerns. Each of these areas will be discussed further in the chapter.

ABA: An Overview

ABA, as a practice, refers to the application of behavior analytic principles (e.g., shaping, reinforcement) to solve problems of social significance. Methodologies for teaching have been used to impart critical skills to young learners with developmental disabilities (i.e., early intensive behavioral intervention; Reichow et al., 2018), and broader applications of ABA are used to impact systemic behavior change across important societal structures, intersecting with such industries as climate science, workplace safety, organizational management, city planning, community-level social intervention, and criminal justice reform (Beaubrun, 2021; Dixon et al., 2018; Morris, 1980). When applied to autism treatment, there is a substantial volume of evidence demonstrating the efficacy of ABA-based protocols, and, as such, ABA is considered the gold standard in autism treatment (e.g., National Autism Center, 2015; Rosenwasser & Axelrod, 2001; Steinbrenner et al., 2020).

Some Dimensions of Applied Behavior Analysis

In 1968, Baer et al. identified some defining dimensions of ABA; though never claiming to be exhaustive, these dimensions are commonly used to classify procedures and interventions as behavior analytic. The dimensions included applied, behavior, analytic, effective, technological, conceptually systematic, and generality.

Applied is a designation of social significance. Problems addressed by practitioners of ABA should be meaningful to the individuals impacted, as well as contribute to improvement of social systems overall. As a dimension, *behavioral* indicates that ABA is interested in observable, measurable behavior (i.e., what one can do as opposed to what one can say they can do, unless verbal behavior is of interest in which case practitioners of ABA would still be interested in observable, measurable behavior). The designation *analytic* refers to a believable demonstration of a functional relationship between a procedure or intervention and the organism's behavior; said differently, a believable demonstration of experimental control between an independent and dependent variable. *Effective* indicates use of evidence-based practices, resulting in efficient, reliable behavior change. *Technological* refers to a procedural description of the intervention, such that a trained, independent practitioner could replicate the procedure based on its written description. *Conceptually systematic* refers to connecting technological descriptions and observed behavior change to established principles of the science. Finally, *generality* is a reference to the need to ensure that any changes in behavior generalize and maintain across time and contexts. A student should be able to apply learned behaviors across multiple contexts and settings, with multiple social partners, and across a variety of materials; further, the learned skills should be durable and should persist beyond the teaching context, so that they encounter contingencies that are arranged or inherent in novel environments.

Social Significance and Social Validity

In 1978, Wolf published a seminal manuscript published in the *Journal of Applied Behavior Analysis* (JABA) calling for a focus on social validity as part of improving the impact of ongoing dissemination efforts for science. Wolf argued that assessing social acceptance from stakeholders (e.g., clients and their families) would improve the impact and value of the field's contributions overall. Since then, social validity has been a common, though inconsistent, focus of practitioners in ABA (Ferguson & Cihon, 2018).

Most recently, the Behavior Analyst Certification Board's (BACB) Ethics Code for Behavior Analysts (Behavior Analyst Certification Board Board(R), [BACB(R)], 2020), effective January 2022, encourages assessing social validity directly from the client (recipient of service). Historically, consent for treatment has often been received from a client's parent or caregiver, rather than directly from the recipient of services (Hanley, 2010). While seeking social validity ratings via more traditional means (e.g., satisfaction surveys) directly from the client may be particularly challenging in the case of non-speaking individuals with developmental disabilities, emerging literature has offered ways to assess the acceptability of treatment from the client directly, based on their actions during treatment sessions. For example, Hanley and colleagues (2010) and Shillingsburg et al. (2019) incorporated indicators of assent via social approach behaviors into their studies as a means to determine the preferences of non-speaking clients, and these approaches may be interpreted as acceptability of the treatment.

Part of Wolf's (1978) original call was for practitioners of ABA to hold special focus on clients' preferences and treatment acceptance when evaluating the success of interventions. In light of the requirements of the Ethics Code for Behavior Analysts (BACB(R), 2020) and to remain responsive to all stakeholders, practitioners should continue to collect social validity data from the clients' perspective directly through traditional means (e.g., soliciting self-report) and through measurement of correlated behaviors. Examples of these correlated behaviors may include indicating preference for methodology by selecting the correlated treatment room (Hanley, 2010) or demonstrating measurable "social approach" behaviors, such as approaching the behavior technician and remaining in the teaching area (Shillingsburg et al., 2019). Additionally, there is ongoing opportunity to develop new and accurate means of assessing treatment acceptability directly from non-speaking adults.

Ethical Considerations

The Ethics Code for Behavior Analysts (BACB(R), 2020) emphasizes the need for practicing within an individual's scope of competence, upholding interdisciplinary collaboration, and practicing with cultural humility. Practitioners should consider each individual, environment(s), and the treatment team when providing ABA services. It is likely that a behavior analyst, when providing services for an adult, will be a member of a multi-disciplinary team. It is important for all members of a treatment team, including behavior analysts, psychiatrists, general health providers, other therapists, caregivers, guardians, and the patient, to regularly communicate with each other and to be aware of intervention changes made by any member of the treatment team (LaFrance et al., 2019; Newhouse-Oisten et al., 2017).

Per the requirements of the ethics code (BACB, 2020), the team should approach their treatment and recommendations with compassionate care and competence. When possible, the individual receiving services should be included in all discussions and provided opportunities to ask questions and to give input on course of treatment. Information may be provided directly from the individual, parent(s), and/or caregiver(s) (i.e., stakeholders). The team should create a way of communicating with stakeholders and team members; coordination of care should include planning of clinical discussions, sharing of data, and treatment protocols. It is important that practitioners take into consideration their scope of practice, competence, and possible limitations and utilize the additional team members to assist in clinical treatment needs that are outside the area of expertise.

Practitioners should also practice cultural awareness and undertake ongoing professional development to learn how to work within the cultural values and norms of their clients (BACB(R), 2020). Fong et al. (2016) stated awareness of cultural differences and similarities may allow for programmatic modifications that result in more culturally appropriate models of behavior analytic service delivery. Behavior analysts might develop their awareness by learning about a client's cultural needs and views during the intake process, ensuring that program goals are developed consistent with a client's cultural practices. Miller et al. (2019) offered a framework for cultural responsiveness in behavior analysis, recommending that behavior analysts seek exposure to varied cultures, nurture intentional communities of inclusion, and collect data to ensure system-wide improvements in cultural and social justice behavior targets. In order to enhance education and ongoing professional competencies in areas of cultural responsiveness and cultural humility, Najdowski et al. (2021) and Mathur and Rodriguez (2021) developed recommendations for university curricula and post-graduate training competencies.

Long-Term Outcomes and Quality of Life

There are many clinical outcomes that may be tied to an individual's quality of life into adulthood. One indicator is the quality of interpersonal relationships, in the home and community, as well as the ability to autonomously direct leisure and daily schedules. Employment is also highly correlated with quality of life and brings increased independence through financial stability, and a fulfilling career is, for many individuals, closely linked with personal identity and sense of accomplishment (Gerhardt & Lainer, 2011). Overall health is also closely tied to quality-of-life outcomes (Gerhardt & Lainer, 2011), and therefore support services may focus on maximizing the ability to navigate preventive and corrective medical needs, adequate sleep, nutrition, and overall physical fitness. Additionally, maintaining good mental health (under a broader domain of emotional functioning) contributes to overall quality of life (Burgess & Gutstein, 2007). Assessed domains from quality-of-life rating scales may include individual quality of life indicators, family/caregiver domains, financial status, social network, partner relationship, and coping skills (Markowitz et al., 2016).

As autism treatment follows in the footsteps of ambulatory medicine, it is likely that similar regulations and reimbursement models for adult insurance-funded ABA services will emerge. One such model is value-based reimbursement. In this model, providers are reimbursed for services based on a selection of structural, process-based, and clinical/medical outcomes. The

International Consortium for Health Outcomes Measurement (ICHOM) is one entity that supports movement toward value-based payment models, using patient-reported outcome measures (PROMs) as part of a recommended standards set. In 2021, ICHOM released their first standards set for autism services (n.d.). This set includes individual norm- and criterion-referenced assessments to assess multiple critical functioning areas, including communication and social repertoires, sleep and overall physical health, and anxiety; additionally, quality of life is assessed overall. This battery of assessments is designed to guide high-quality treatment toward outcomes deemed as high priority by both treatment recipients and providers. Historically, there has not been consensus in any one industry designating optimal clinical outcomes for any course of treatment. Continued measurement of clinical outcomes, and continued consensus-building within and across treatments, will be a critical step in ensuring optimized quality of life for adults with autism receiving therapeutic and support services, regardless of the funding source.

Domains of Application

The following provides a selection of domains of program focus that are represented in the literature (cited throughout) pertaining to services and interventions for autistic adults.

Language/Communication

Improved functional communication repertoires are critically important for adults with developmental disabilities (Hendricks, 2010; Nepo et al., 2017). The ability to indicate needs, respond to and cooperate with basic directives (e.g., from assisted living personnel or first responders), and self-advocate for choice in service provision are necessary communication skills; individuals with more severely impacted communication repertoires are at higher risk for abuse (Verdugo et al., 1995). Further, communication fluency is a factor in overall quality of life, including social relationships, employment, and independence (Mason et al., 2021).

Of note, many adults may not have vocal-verbal repertoires; this need not be a barrier to effective and fluent communication, but modality selection does have implications for community access. LaRue et al. (2016) recommended a modality selection model for choosing methods of communication for individuals with autism. Selecting a communication modality requires consideration of several factors, including ease of acquisition, intelligibility, and likely success of contacting reinforcement with novel communication partners. For example, sign language may be an appealing option because it does not require any device or materials, and for individuals able to learn complex fine motor responses, the communication is always readily available to them. A limitation of sign language is in the relatively limited percentage of communication partners fluent in sign language. In an emergency, presenting an identification card could potentially access assistance more readily than signing a request for help and personal information. Alternatively, a communication device may be used (e.g., communication app on a smartphone), and the novel communication partner would be more likely to understand the communication; limitations to this modality may include expense, potential social stigma, and reliance on a device separate from the body, potentially limiting access, though, at the time of this writing, carrying a smartphone is almost universal in Western cultures even across socioeconomic status, and therefore likely to be within constant reach.

Social Behavior

Adults with autism are more likely than their same age peers to experience social isolation, including being excluded from social invitations and never visiting or hearing from friends (Orsmond et al., 2013). Literature has found that adults with autism carry about a 40% risk of suffering from anxiety, depression, and other mental health diagnoses (Hollocks et al., 2019); adults with autism are also potentially at higher risk of isolation and suicide (Kõlves et al., 2021). As a result, many programs for adults focus on initiating and maintaining meaningful social connections with peers and family members in order to prevent social isolation.

Some areas of focus relevant to this population may include sexual health and safety, appropriate dating behavior, and Internet safety. In order for adults to engage in prevalent methods of identifying and connecting with romantic partners (i.e., Internet-based dating services, Roth & Gillis, 2015), an understanding of social norms and safety behaviors related to social media and Internet use are appropriate areas for skill development. Additionally, adults may place high value on attending communities of faith (Gerhardt & Lanier, 2011), and repertoires related to navigating transportation, managing schedules, and interacting with community members are supportive of attending faith-based services.

Independence and Community Access

Personal hygiene, grooming, domestic routines, and various self-care skills are critically important areas of focus for the adult population. Grooming and personal hygiene skills may include showering, dental hygiene, hair grooming, applying deodorant, moisturizing, and applying topical medications. Daily self-care activities may include selecting weather-appropriate clothing, preparing nutritious meals, caring for clothing, basic housekeeping, and maintaining a daily activity schedule. Community access skills may include navigating public transportation, completing purchases, and accessing community appointments, as well as leisure activities (e.g., taking a trip to the movies). These skills keep the individual in good health and may increase opportunities for independent living and maximize opportunities for social interaction.

Executive Functioning and Self-Management

One variable correlated to lower quality of life in autistic adults is difficulties with executive functioning skills (de Vries & Geurst, 2015; Wallace et al., 2016). Executive functioning skills, such as those identified in the indices of the Behavior Rating Inventory of Executive Function – Adult Version (BRIEF-A) (Gioia et al., 2002), include inhibition, flexibility, emotional control, self-monitoring, initiation, working memory, planning and organizing, task monitoring, and organization of materials (Wallace et al., 2016). Inhibition refers to the ability to control impulses and is related to planning and goal setting. Flexibility is crucial to navigating unexpected changes to routines and environmental contingencies. Emotional control is a useful interpersonal skill, as well as a necessary skill in many employment environments. Self-monitoring allows the individual to thrive in multiple settings, including the home, community, and workplace. Initiation is necessary for increased independence (Hume et al., 2009), which allows freedom from prompt dependence and relying on others to ensure basic routines are completed. Planning and organizing encompass the skills of anticipating the steps to complete prior to an activity or event. For example, if an adult needs to be at the workplace by 8 am, there are multiple activities that need to be completed prior to that (e.g., eating breakfast, brushing teeth, transportation to work), and the individual needs to be able to plan their morning routine to allow time for each of these tasks.

Employment

Hendricks (2010) outlined the benefits, obstacles, and outcomes of employment for autistic adults. Employment offers an individual financial stability and the ability to pursue their interests. Additionally, employment is correlated with a sense of personal dignity and improved quality of life (Griffiths et al., 2016). There are significant barriers to employment for autistic adults. A primary area of concern is interpersonal interactions, such as those between the employee and their coworkers and/or supervisor (Hendricks, 2010). While each autistic adult presents with different repertoires, as the condition is heterogeneous, there are some common themes in barriers to employment. The types of social skills that may need to be developed for success in the workplace often relate to the more nuanced "soft skills" required to navigate the workplace (Hendricks, 2010). These may include making inferences and generalizing feedback which may affect performance evaluations and even result in termination of employment.

Harmful Behavior

Individuals with ASD are more likely than those diagnosed with other developmental disabilities to engage in challenging behaviors (e.g., harmful or dangerous behaviors such as self-injury, aggression, elopement from the home, and property destruction); these behaviors may emerge during childhood and if untreated are likely to persist into adulthood (Matson & Rivet, 2008). Exhibition of challenging behaviors in adulthood may lead to social isolation, restrictive residential settings, restrictive interventions, and reduced quality of life (Cooper et al., 2019; Emerson et al., 2000). In extreme cases, these behaviors may result in incarceration or institutionalization. Therefore, a primary area of focus for many ABA-based support services is to prevent, reduce, and provide long-term management for harmful behaviors that could result in placement in these more restrictive environments.

ABA-Based Procedures

Evidence-Based Practices

The similarity between the literature and the profile of the client (e.g., accounting for age, severity, comprehensive needs) should be considered when selecting evidence-based teaching strategies. Importantly, much of the literature base on ABA-based treatments includes young participants (i.e., 8 years old and younger), and practitioners should be careful when generalizing these approaches without consulting the adult-focused literature. In a discussion of available supports for adults with autism, Gerhardt and Lainer (2011) identified multiple studies demonstrating effective strategies in supporting issues of social significance, such as modeling, prompting, reinforcement, pivotal response treatment, shaping, relaxation training, chaining, and precision teaching. Additional evidence-based behavior analytic practices for adults with autism include task analysis, activity schedules, visual supports, differential reinforcement of alternative behaviors, prompting, shaping, and positive reinforcement (Hagner & Cooney, 2005). Several of these strategies, and select corresponding studies, are outlined in the following section.

Self-Monitoring/Self-Management

Self-management (or self-monitoring) programs allow the client to become progressively more independent in managing their own routines and behaviors. A self-monitoring procedure typically includes an individual identifying instances of when they engage in the target behavior and self-administering reinforcement (Tiger et al., 2009). This approach has been demonstrated to effectively support adults with autism in vocational practices (Ackerman & Shapiro, 1984; Ninness et al., 1991) and reducing harmful behaviors (Tiger et al., 2009).

Ackerman and Shapiro (1984) evaluated a self-monitoring program to improve independence in the workplace, reducing the need for 1:1 supervision or job support. Five adult participants with intellectual disabilities were taught to self-monitor their work by recording when they had completed each unit of packaging. Following the intervention, the participants had increased their rate of work task completion, and their self-recording achieved high interobserver agreement with the research team (93%).

In another study (Tiger et al., 2009), a 19-year-old diagnosed with Asperger syndrome and severe skin picking successfully reduced self-injury by self-monitoring through a differential reinforcement procedure (i.e., differential reinforcement of other behavior [DRO]). In this study, the initial phase was therapist-monitored; the participant received praise and a ticket (later exchanged for money) for intervals with an absence of skin picking. After extending the intervals to 10 min, the therapist taught the participant to self-monitor the occurrence and non-occurrence of their skin picking behavior and to self-administer tickets for 10-min intervals with an absence of skin picking. Finally, the participant demonstrated the ability to effectively self-monitor at 15-min intervals, in the absence of the therapist, demonstrating that reduction of harmful behavior was under the control of the self-monitored reinforcement contingency, rather than under the stimulus control of the therapist's presence.

Prompting

Prompting is an effective strategy for teaching a myriad of new skills to learners of all ages. Some skills relevant to autistic adults that may be taught by prompting include onsite employment coaching (Gentry et al., 2012), personal hygiene (Probst & Walker, 2017), feminine hygiene (Veazey et al., 2016), household tasks (Sigafoos et al., 2005, 2007), fire safety (Tiong et al., 1992), mealtime behaviors (Anglesea et al., 2008), and community skills (Satriale et al., 2007). There are special considerations for prompting methods when the client is an adult; these include the client's physical size and strength and concerns related to social stigma. It is a matter of social significance to identify less intrusive prompting methods (Satriale et al., 2007; Taylor et al., 2004) to minimize social stigma (Zane et al., 2012).

Satriale et al. (2007) used Bluetooth technology to prompt independent responding in the community setting. The purpose of the study was to reduce the potential social stigma associated with more overt prompts (i.e., physical and gestural) in a community setting. The participant was an autistic 16-year-old male with a history of prompt dependency whose community skills were significantly impacted. All instruction occurred in the natural community setting (i.e., without initial clinic-based teaching), and Bluetooth technology was used to discretely deliver vocal prompts; the prompts were faded over time, and the participant acquired an independent purchasing routine.

The majority of literature demonstrating efficacy of physical prompting is focused on young children as participants. Given the scarcity of evidence for physical prompting as an effective strategy for teaching adults, less intrusive prompting methods may be preferable and have been demonstrated to be effective. The studies referenced in this section demonstrate the efficacy of vocal and model prompts. One method described in several of the studies was video prompting (e.g., Sigafoos et al., 2005, 2007). One identified difficulty with video model prompts was the deterioration of the skill after removal of the prompt (Sigafoos et al., 2005), as gradual fading of the video clips (an effective strategy for promoting independence with more traditional physical and gestural prompts) presented a challenge. In a follow-up study, Sigafoos et al. (2007) were able to successfully remove video prompting following "chunking" of the individual video prompt segments; after the participants (three adult men with developmental disabilities) had learned to successfully respond to each individual video, the videos were then edited together to create a single video of the total task (i.e., video modeling), and the participants were able to successfully complete the task (washing dishes) following the full video. The men were then able to maintain the acquired skill following the removal of the video model entirely.

Video Modeling

Video modeling typically entails a client watching a video of an entire task and then completing that task themselves; this is distinct from video prompting, wherein only one step of the task chain is shown in the video, and the client completes only that step before the next video clip is played (Sigafoos et al., 2007). Video modeling entails playing a brief video clip and then providing the instruction to engage in the activity observed in the clip. This technique may be used to teach social skills and employment skills (Park et al., 2020; Morgan & Salzburg, 1992). Rehfeldt et al. (2003) used a video model (2.5 min in duration) to teach three adult participants to make a sandwich. The video task analysis included 17 steps. Participants were asked to watch the video and then perform the task; all participants learned the target skill and were able to demonstrate the skill, without the video model, at the 1-month follow-up probe.

Considerations in methodology for video modeling include the point of view of the video and the subject. In one approach, a peer model (e.g., a sibling, a parent, the therapist) performs the task in the video. Another approach is video self-modeling (Buggey, 2005), wherein the client themselves is recorded completing the task (as part of a role-play scenario), and the therapist's audio prompts are edited out, such that the edited video becomes the model for teaching independent performance of the skill (Buggey et al., 1999). Alternatively, video may be captured of the client performing pieces of the task correctly over time, with these pieces edited together to create one brief video demonstrating the complete correct response; this approach is most useful for clients who are unable to participate in directed role-play (Buggey, 2005).

Visual Supports and Task Analysis

Visual supports have been used with teens and young adults with autism to teach a variety of repertoires, including video game play (Blum-Dimaya et al., 2010), transitions (Cihak, 2011), and social skills (Hughes et al., 2011), and to reduce self-injury (O'Reilly et al., 2005). Visual supports are concrete stimuli that, paired with or used in place of verbal cues, provide information to learner regarding behavioral expectations, upcoming activities and transitions, or details related to a particular task (Sam & AFIRM Team, 2015).

A common visual support used in ABA-based services is an activity schedule. An activity schedule is a series of pictures or words, each of which provides the discriminative stimulus for completing a task (Rehfeldt, 2002). An activity schedule is a visual representation of a task analysis that a client can learn to follow independently. By teaching the client to follow an activity schedule, they can learn to complete complex tasks and to master a challenging and necessary skill for increased independence at work and at home.

Another intervention based on visual supports is script fading. Hughes et al. (2011) worked with five participants (teens and young adults) who, at baseline, exhibited few social communication initiations with peers. Communication scripts were used to teach participants social initiations (i.e., asking questions); instruction was also provided to peers to serve as communication partners in the generalization phase. Multiple conversation-starters were taught, and peers were taught to offer the communication book to participants for use during generalization probes. In baseline, social initiations were nearly nonexistent; with use of the communication book and with trained peers, participants were able to engage in initiations reportedly in the expected range, using social comparison data. Responses were also reported to maintain at the 6-month probe.

Task analysis is the process of breaking complex tasks into small steps, and chaining is used to join these steps into a full activity. A task analysis is often presented as a pictorial or textual visual support (non-visual presentations of task analysis, such as audio and video prompts, are discussed in the prompting section). Task analysis has been used to teach autistic adults various tasks, including daily living skills, including maintaining a living space, mending clothing, and cleaning (Cronin & Cuvo, 1979; Cuvo et al., 1992; Williams & Cuvo, 1986). In the 1992 study, Cuvo and colleagues worked with 11 adults with learning disabilities and intellectual disabilities to teach community living skills.

Three types of textual task analysis supports were provided to participants, written either generically (i.e., with the end result of the activity listed but without broken down steps), specifically (i.e., including smaller steps in the task), or individualized (i.e., detailing the steps performed incorrectly at assessment). Post-training, participants were able to detail the steps of the target skill (e.g., cleaning an oven) on a written test, with favorable results from participants using either the specific or individualized task analysis.

Behavioral Skills Training

Behavioral skills training (BST, Miltenberger, 2008) is a process of teaching that includes reviewing a protocol, modeling and/or role-playing the procedure, providing feedback during implementation, debriefing to coaching improvement, and repeating the final steps until the learner demonstrates proficiency. BST has been used to teach general safety skills, such as seeking assistance when lost (Bergstrom et al., 2012; Pan-Skadden et al., 2009; Taylor et al., 2004), avoiding abduction (Beck & Miltenberger, 2009; Gunby et al., 2010; Johnson et al., 2006), and escaping a fire (Bigelow et al., 1993).

In 2006, Johnson and colleagues used BST plus in situ training to successfully teach abduction prevention in neuro-typical school children. Previous studies showed that BST was a potentially effective procedure for teaching abduction prevention, though not all children learned the skill (Carroll-Rowan & Miltenberger, 1994) and others who did learn the skill did not maintain the skill over time (Marchand-Martella et al., 1996). Additionally, studies have shown that highly contrived, role-play-only training techniques lack generalization to low frequency, high-stakes events unless training was conducted in real-life settings (Gast et al., 1993; Gunby et al., 2010). Johnson et al. (2006) used BST to teach abduction avoidance repertoires (i.e., saying “no” and running to tell a trusted adult), paired with an in situ training event wherein an adult confederate used a stereotypical abduction lure. Gunby et al. (2010) extended this work by applying the intervention with autistic children. Participants were children with autism who exhibited extensive communication repertoires, but who still showed impacted safety and community skills (Gunby et al., 2010). BST was conducted in a center setting, with in situ abduction probes offered in other areas of the building, outside the building, and in one participant’s neighborhood. The children were taught to say “no,” run from the area to a safe location, and tell a familiar adult immediately about the incident. Abduction probes in novel locations, performed by a confederate (i.e., an unfamiliar adult connected with the study), were conducted before and after BST training. Follow-up probes were conducted 3–7 weeks following initial training. Participants successfully learned the abduction prevention skills and maintained those skills at follow-up.

Although the above-referenced study was conducted with children, community safety skills are critical to adult populations, and similar methods may prove successful in teaching safety repertoires to autistic adults. A difficulty in implementing in situ training with confederates with the adult services population is related to the types of programs targeted for acquisition and reduction. For example, if a client is learning to avoid inappropriate interactions with strangers in a restroom, an in situ training event could result in removal or even arrest for the confederate, making these training approaches challenging to implement.

Functional Communication Training

Functional communication training (FCT) is a treatment approach that typically pairs differential reinforcement of an alternative behavior (i.e., a communication response functionally equivalent to challenging behavior) with extinction of a behavior targeted for reduction (Carr & Durand, 1985). This procedure has been widely validated as an effective method for reducing challenging behaviors (Tiger et al., 2008). As with much of the literature on ABA-based autism interventions, there is a paucity of adult-focused FCT literature, compared with the number of child-focused studies (Gregori et al., 2020); however, high-quality studies have shown FCT to be an effective method for reducing harmful or challenging behavior for autistic adults (Chezan et al., 2014; Schmidt et al., 2014).

In order to implement FCT to reduce challenging behavior, the function of the behavior should be determined (typically via a functional analysis, FA; Tiger et al., 2008), and a functionally alternative communication response should be identified to occasion reinforcement. Simultaneously, occurrences of the challenging behavior no longer receive reinforcement (i.e., extinction is employed). Over time, the schedule of reinforcement for the alternative response is thinned, and in many cases tolerance training is introduced (Tiger et al., 2008). Chezan et al. (2014) implemented an FA procedure and an FCT procedure with three adults with intellectual disabilities. Following acquisition of a functionally equivalent communication response, problem behavior decreased, and participants exhibited the replacement response at follow-up probes.

When working with autistic adults, there may be a greater risk of harm from challenging behavior, particularly in the presence of an extinction burst or increased aggression. In an analysis of 41 data sets from extinction use with participants ages 5–54 years old, Lerman et al. (1999) found that approximately 50% of cases resulted in extinction bursts or increases in aggression. For this reason, careful consideration is warranted in determining whether extinction is necessary, safe, and ethical (Geiger et al., 2010; Manente et al., 2010). Given the safety considerations in working with adults with severe dangerous behaviors, there may be instances in which the safest option is to provide reinforcement for the communication response and to avoid extinction of problem behavior. Emerging literature demonstrating the feasibility and efficacy of this approach (i.e., allowing withdrawal of assent in the form of leaving the work area) has been demonstrated to be effective with child participants (Rajaraman et al., 2021). In the event that extinction is too dangerous to implement, it is recommended to reinforce problem behavior at the lowest possible magnitude, such as providing a reinforcer during an identified precursor behavior (Langdon et al., 2008; Najdowski et al., 2008).

Discussion/Conclusion

ABA-based services are applicable to the needs of the adult population, and multiple effective approaches and packages have been outlined in this chapter. There are, however, barriers to effective delivery of these services. The literature base for ABA-based autism services is mostly focused on younger learners, and behavior analytic literature focusing on the needs of adults is more scarce (Gerhardt & Lainer, 2011). This poses at least two challenges for serving adult populations effectively. First, funding sources may use the smaller percentage of adult-focused studies to suggest that there is insufficient evidence to fund the service for adults. This may be countered by publications that promote the evidence based on age bands (e.g., Steinbrenner et al., 2020) and by increasing contributions to the literature regarding (and ideally including authorship by) autistic adults. It may also be reasonable to expect that the general principles of the science should be applicable to effective practice across populations (i.e., children and adults alike). A second potential issue is the assumption of generalization of methodologies across populations, where explicit literature support is not available. It is important to ensure strategies have been demonstrated to be effective (and replicable) with the population to which they are applied. Although the principles of ABA are universally applicable, specific techniques and treatment plans should be tailored to the needs and considerations of the individual (Manente et al., 2010). The strategies and corresponding studies included in this chapter, therefore, are specific to adults with ASD when applicable. Clinicians should consider their knowledge of the literature and its specific applications to the specific populations they serve to understand their scope of experience and competence and to seek professional development and mentorship accordingly (Brodhead et al., 2018).

References

Ackerman, A. M., & Shapiro, E. S. (1984). Self-monitoring and work productivity with mentally retarded adults. *Journal of Applied Behavior Analysis, 17*(3), 403–407. https://doi.org/10.1901/jaba.1984.17-403

Anglesea, M. M., Hoch, H., & Taylor, B. A. (2008). Reducing rapid eating in teenagers with autism: Use of a pager prompt. *Journal of Applied Behavior Analysis, 41*(1), 107–111. https://doi.org/10.1901/jaba.2008.41-107

Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis, 1*(1), 91–97. https://doi.org/10.1901/jaba.1968.1-91

Beaubrun, M. C. (2021). Urban planning through a behavior analytic lens. In M. Zube & J. Sadavoy (Eds.), *Compassion and social justice in applied behavior analysis: A collection of essays* (pp. 297–301). Routledge.

Beck, K. V., & Miltenberger, R. G. (2009). Evaluation of a commercially available program and in situ training by parents to teach abduction-prevention skills to children. *Journal of Applied Behavior Analysis, 42*(4), 761–772. https://doi.org/10.1901/jaba.2009.42-761

Behavior Analyst Certification Board. (2020). *Ethics code for behavior analysts*. Author.

Bergstrom, R., Najdowski, A. C., & Tarbox, J. (2012). Teaching children with autism to seek help when lost in public. *Journal of Applied Behavior Analysis, 45*(1), 191–195. https://doi.org/10.1901/jaba.2012.45-191

Bigelow, K. M., Huynen, K. B., & Lutzker, J. R. (1993). Using a changing criterion design to teach fire escape to a child with developmental disabilities. *Journal of Developmental and Physical Disabilities, 5*(2), 121–128. https://doi.org/10.1007/BF01045971

Blomqvist, M., Dahllöf, G., & Bejerot, S. (2014). Experiences of dental care and dental anxiety in adults with autism spectrum disorder. *Autism Research and Treatment, 2014*, 238764. https://doi.org/10.1155/2014/238764

Blum-Dimaya, A., Reeve, S. A., Reeve, K. F., & Hoch, H. (2010). Teaching children with autism to play a video game using activity schedules and game-embedded simultaneous video modeling. *Education and Treatment of Children, 33*(3), 351–370. https://doi.org/10.1353/etc.0.0103

Brodhead, M. T., Quigley, S. P., & Wilczynski, S. M. (2018). A call for discussion about scope of competence in behavior analysis. *Behavior Analysis in Practice, 11*(4), 424–435. https://doi.org/10.1007/s40617-018-00303-8

Browning, A., & Caulfield, L. (2011). The prevalence and treatment of people with Asperger's Syndrome in the criminal justice system. *Criminology & Criminal Justice, 11*(2), 165–180. https://doi.org/10.1177/1748895811398455

Buggey, T. (2005). Video self-modeling applications with students with autism spectrum disorder in a small private school setting. *Focus on Autism and Other Developmental Disabilities, 20*(1), 52–63. https://doi.org/10.1177/10883576050200010501

Buggey, T., Toombs, K., Gardener, P., & Cervetti, M. (1999). Training responding behaviors in students with autism: Using videotaped self-modeling. *Journal of Positive Behavior Interventions, 1*(4), 205–214. https://doi.org/10.1177/109830079900100403

Burgess, A. F., & Gutstein, S. E. (2007). Quality of life for people with autism: Raising the standard for evaluating successful outcomes. *Child and Adolescent Mental Health, 12*(2), 80–86. https://doi.org/10.1111/j.1475-3588.2006.00432.x

Carr, E. G., & Durand, V. M. (1985). Reducing behavior problems through functional communication training. *Journal of Applied Behavior Analysis, 18*(2), 111–126. https://doi.org/10.1901/jaba.1985.18-111

Carroll-Rowan, L. A., & Miltenberger, R. G. (1994). A comparison of procedures for teaching abduction prevention to preschoolers. *Education and Treatment of Children, 17*(2), 113–129.

Chezan, L. C., Drasgow, E., & Martin, C. A. (2014). Discrete-trial functional analysis and functional communication training with three adults with intellectual disabilities and problem behavior. *Journal of Behavioral Education, 23*(2), 221–246. https://doi.org/10.1007/s10864-013-9192-2

Cihak, D. F. (2011). Comparing pictorial and video modeling activity schedules during transitions for students with autism spectrum disorders. *Research in Autism Spectrum Disorders, 5*(1), 433–441. https://doi.org/10.1016/j.rasd.2010.06.006

Cooper, J. O., Heron, T. E., & Heward, W. L. (2019). *Applied behavior analysis* (3rd ed.). Pearson Education.

Cronin, K. A., & Cuvo, A. J. (1979). Teaching mending skills to mentally retarded adolescents. *Journal of Applied Behavior Analysis, 12*(3), 401–406. https://doi.org/10.1901/jaba.1979.12-401

Cuvo, A. J., Davis, P. K., O'Reilly, M. F., Mooney, B. M., & Crowley, R. (1992). Promoting stimulus control with textual prompts and performance feedback for persons with mild disabilities. *Journal of Applied Behavior Analysis, 25*(2), 477–489. https://doi.org/10.1901/jaba.1992.25-477

de Vries, M., & Geurts, H. (2015). Influence of autism traits and executive functioning on quality of life in children with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*, 2734–2743. https://doi.org/10.1007/s10803-015-2438-1

Dixon, M. R., Belisle, J., Rehfeldt, R. A., & Root, W. B. (2018). Why we are still not acting to save the world: The upward challenge of a post-Skinnerian behavior science. *Perspectives on Behavior Science, 41*(1), 241–267. https://doi.org/10.1007/s40614-018-0162-9

Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., & Hillery, J. (2000). Treatment and management of challenging behaviours in residential settings. *Journal of Applied Research in Intellectual Disabilities, 13*(4), 197–215. https://doi.org/10.1046/j.1468-3148.2000.00036.x

Ferguson, J. L., & Cihon, J. H. (2018). Social validity. In F. Volkmar (Ed.), *Encyclopedia of autism spectrum disorders*. Springer.

Fong, E., Catagnus, R. M., Brodhead, M. T., Quigley, S., & Field, S. (2016). Developing the cultural awareness skills of behavior analysts. *Behavior Analysis in Practice, 9*(1), 84–94. https://doi.org/10.1007/s40617-016-0111-6

Gast, D., Collins, B., Wolery, M., & Jones, R. (1993). Teaching preschool children with disabilities to respond to the lures of strangers. *Exceptional Children, 59*(4), 301–311. https://doi.org/10.1177/001440299305900403

Geiger, K. B., Carr, J. E., & Leblanc, L. A. (2010). Function-based treatments for escape-maintained problem behavior: A treatment-selection model for practicing behavior analysts. *Behavior Analysis in Practice, 3*(1), 22–32. https://doi.org/10.1007/BF03391755

Gentry, T., Lau, S., Molinelli, A., Fallen, A., & Kriner, A. (2012). The Apple iPod Touch as a vocational support aid for adults with autism: Three case studies. *Journal of Vocational Rehabilitation, 37*(2), 75–85. https://doi.org/10.3233/JVR-2012-0601

Gerhardt, P. F., & Lainer, I. (2011). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy, 41*, 37–45. https://doi.org/10.1007/s10879-010-9160-2

Gioia, G. A., Isquith, P. K., Retzlaff, P. D., & Espy, K. A. (2002). Confirmatory factor analysis of the behavior rating inventory of executive function (BRIEF) in a clinical sample. *Child Neuropsychology, 8*(4), 249–257. https://doi.org/10.1076/chin.8.4.249.13513

Gregori, E., Wendt, O., Gerow, S., Peltier, C., Genc-Tosun, D., Lory, C., & Gold, Z. S. (2020). Functional communication training for adults with autism spectrum disorder: A systematic review and quality appraisal. *Journal of Behavioral Education, 29*, 42–63. https://doi.org/10.1007/s10864-019-09339-4

Griffiths, A. J., Giannantonio, C. M., Hurley-Hanson, A. E., & Cardinal, D. (2016). Autism in the workplace: Assessing the transition needs of young adults with autism spectrum disorder. *Journal of Business and Management, 22*(1), 5–22.

Gunby, K. V., Carr, J. E., & Leblanc, L. A. (2010). Teaching abduction-prevention skills to children with autism. *Journal of Applied Behavior Analysis, 43*(1), 107–112. https://doi.org/10.1901/jaba.2010.43-107

Hagner, D., & Cooney, B. F. (2005). "I do that for everybody": Supervising employees with autism. *Focus on Autism and Other Developmental Disabilities, 20*(2), 91–97. https://doi.org/10.1177/10883576050200020501

Hanley, G. P. (2010). Toward effective and preferred programming: A case for the objective measurement of social validity with recipients of behavior-change programs. *Behavior Analysis in Practice, 3*(1), 13–21. https://doi.org/10.1007/BF03391754

Hendricks, D. (2010). Employment and adults with autism spectrum disorders: Challenges and strategies for success. *Journal of Vocational Rehabilitation, 32*(2), 125–134.

Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: A systematic review and meta-analysis. *Psychological Medicine, 49*(4), 559–572. https://doi.org/10.1017/S0033291718002283

Hughes, C., Golas, M., Cosgriff, J., Brigham, N., Edwards, C., & Cashen, K. (2011). Effects of a social skills intervention among high school students with intellectual disabilities and autism and their general education peers. *Research and Practice for Persons with Severe Disabilities, 36*(1–2), 46–61. https://doi.org/10.2511/rpsd.36.1-2.46

Hume, K., Loftin, R., & Lantz, J. (2009). Increasing independence in autism spectrum disorders: A review of three focused interventions. *Journal of Autism and Developmental Disorders, 39*(9), 1329–1338. https://doi.org/10.1007/s10803-009-0751-2

International Consortium for Health Outcomes Measurement. (n.d.). *ICHOM standard set for autism spectrum disorder*. https://connect.ichom.org/standard-sets/autism-spectrum-disorder/

Johnson, B. M., Miltenberger, R. G., Knudson, P., Egemo-Helm, K., Kelso, P., Jostad, C., & Langley, L. (2006). A preliminary evaluation of two behavioral skills training procedures for teaching abduction-prevention skills to schoolchildren. *Journal of Applied Behavior Analysis, 39*(1), 25–34. https://doi.org/10.1901/jaba.2006.167-04

Kõlves, K., Fitzgerald, C., Nordentoft, M., Wood, S. J., & Erlangsen, A. (2021). Assessment of suicidal behaviors among individuals with autism spectrum disorder in Denmark. *JAMA Network Open, 4*(1), e2033565. https://doi.org/10.1001/jamanetworkopen.2020.33565

LaFrance, D. L., Weiss, M. J., Kazemi, E., Gerenser, J., & Dobres, J. (2019). Multidisciplinary teaming: Enhancing collaboration through increased understanding. *Behavior Analysis in Practice, 12*(3), 709–726. https://doi.org/10.1007/s40617-019-00331-y

Langdon, N. A., Carr, E. G., & Owen-Deschryver, J. S. (2008). Functional analysis of precursors for serious problem behavior and related intervention. *Behavior Modification, 32*(6), 804–827. https://doi.org/10.1177/0145445508317943

LaRue, R. H., Pepa, L., Delmolino, L., Sloman, K. N., Fiske, K., Hansford, A., Liebross, S., & Weiss, M. J.

(2016). A brief assessment for selecting communication modalities for individuals with autism spectrum disorders. *Evidence-Based Communication Assessment and Intervention, 10*(1), 32–43. https://doi.org/10.1080/17489539.2016.1204767

Lerman, D. C., Iwata, B. A., & Wallace, M. D. (1999). Side effects of extinction: Prevalence of bursting and aggression during the treatment of self-injurious behavior. *Journal of Applied Behavior Analysis, 32*(1), 1–8. https://doi.org/10.1901/jaba.1999.32-1

Manente, C. J., Maraventano, J. C., LaRue, R. H., Delmolino, L., & Sloan, D. (2010). Effective behavioral intervention for adults on the autism spectrum: Best practices in functional assessment and treatment development. *The Behavior Analyst Today, 11*(1), 36–48. https://doi.org/10.1037/h0100687

Marchand-Martella, N., Huber, G., Martella, R. C., & Wood, W. S. (1996). Assessing the long-term maintenance of abduction prevention skills by disadvantaged preschools. *Education and Treatment of Children, 19*(1), 55–68.

Markowitz, L. A., Reyes, C., Embacher, R. A., Speer, L. L., Roizen, N., & Frazier, T. W. (2016). Development and psychometric evaluation of a psychosocial quality-of-life questionnaire for individuals with autism and related developmental disorders. *Autism, 20*(7), 832–844. https://doi.org/10.1177/1362361315611382

Mason, D., Capp, S. J., Stewart, G. R., Kempton, M. J., Glaser, K., Howlin, P., & Happé, F. (2021). A meta-analysis of outcome studies of autistic adults: Quantifying effect size, quality, and meta-regression. *Journal of Autism and Developmental Disorders, 51*, 3165–3179. https://doi.org/10.1007/s10803-020-04763-2

Mathur, S. K., & Rodriguez, K. A. (2021). Cultural responsiveness curriculum for behavior analysts: A meaningful step toward social justice. *Behavior Analysis in Practice.* Advance online publication. https://doi.org/10.1007/s40617-021-00579-3

Matson, J. L., & Rivet, T. T. (2008). Characteristics of challenging behaviours in adults with autistic disorder, PDD-NOS, and intellectual disability. *Journal of Intellectual and Developmental Disability, 33*(4), 323–329. https://doi.org/10.1080/13668250802492600

Miller, K. L., Re Cruz, A., & Ala'i-Rosales, S. (2019). Inherent tensions and possibilities: Behavior analysis and cultural responsiveness. *Behavior and Social Issues, 28*, 16–36. https://doi.org/10.1007/s42822-019-00010-1

Miltenberger, R. G. (2008). *Behavior modification: Principles and procedures* (4th ed.). Thompson Wadsworth.

Morgan, R. L., & Salzberg, C. L. (1992). Effects of video-assisted training on employment-related social skills of adults with severe mental retardation. *Journal of Applied Behavior Analysis, 25*(2), 365–383. https://doi.org/10.1901/jaba.1992.25-365

Morris, E. K. (1980). Applied behavior analysis for criminal justice practice: Some current dimensions. *Criminal Justice and Behavior, 7*(2), 131–145. https://doi.org/10.1177/009385488000700201

Najdowski, A. C., Wallace, M. D., Ellsworth, C. L., MacAleese, A. N., & Cleveland, J. M. (2008). Functional analyses and treatment of precursor behavior. *Journal of Applied Behavior Analysis, 41*(1), 97–105. https://doi.org/10.1901/jaba.2008.41-97

Najdowski, A. C., Gharapetian, L., & Jewett, V. (2021). Toward the development of antiracist and multicultural graduate training programs in behavior analysis. *Behavior Analysis in Practice, 14*, 462–477. https://doi.org/10.1007/s40617-020-00504-0

National Autism Center. (2015). *Findings and conclusions: National standards project, phase 2*. Author.

Nepo, K., Tincani, M., Axelrod, S., & Meszaros, L. (2017). iPod Touch® to increase functional communication of adults with autism spectrum disorder and significant intellectual disability. *Focus on Autism and Other Developmental Disabilities, 32*(3), 209–217. https://doi.org/10.1177/1088357615612752

Newhouse-Oisten, M. K., Peck, K. M., Conway, A. A., & Frieder, J. E. (2017). Ethical considerations for interdisciplinary collaboration with prescribing professionals. *Behavior Analysis in Practice, 10*(2), 145–153. https://doi.org/10.1007/s40617-017-0184-x

Ninness, H. A., Fuerst, J., Rutherford, R. D., & Glenn, S. S. (1991). Effects of self-management training and reinforcement on the transfer of improved conduct in the absence of supervision. *Journal of Applied Behavior Analysis, 24*(3), 499–508. https://doi.org/10.1901/jaba.1991.24-499

O'Reilly, M., Sigafoos, J., Lancioni, G., Edrisinha, C., & Andrews, A. (2005). An examination of the effects of a classroom activity schedule on levels of self-injury and engagement for a child with severe autism. *Journal of Autism and Developmental Disorders, 35*(3), 305–311. https://doi.org/10.1007/s10803-005-3294-1

Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(11), 2710–2719. https://doi.org/10.1007/s10803-013-1833-8

Pan-Skadden, J., Wilder, D. A., Sparling, J., Severtson, E., Donaldson, J., Postma, N., Beavers, G., & Neidert, P. (2009). The use of behavioral skills training and in-situ training to teach children to solicit help when lost: A preliminary investigation. *Education and Treatment of Children, 32*(3), 359–370.

Park, J., Bouck, E. C., & Duenas, A. (2020). Using video modeling to teach social skills for employment to youth with intellectual disability. *Career Development and Transition for Exceptional Individuals, 43*(1), 40–52. https://doi.org/10.1177/2165143418810671

Probst, K. M., & Walker, V. L. (2017). Using the system of least prompts to teach personal hygiene skills to a high school student with comorbid visual impairment and autism spectrum disorder. *Journal of Visual Impairment & Blindness, 111*(6), 511–526. https://doi.org/10.1177/0145482X1711100603

Rajaraman, A., Hanley, G. P., Gover, H. C., Staubitz, J. L., Staubitz, J. E., Simcoe, K. M., & Metras, R. (2021). Minimizing escalation by treating dangerous problem behavior Within an enhanced choice model. *Behavior Analysis in Practice.* Advance online publication. https://doi.org/10.1007/s40617-020-00548-2

Rehfeldt, R. A. (2002). A review of McClannahan and Krantz's activity schedules for children with autism: Teaching independent behavior: Toward the inclusion and integration of children with disabilities. *The Behavior Analyst, 25*(1), 103–108.

Rehfeldt, R. A., Dahman, D., Young, A., Cherry, H., & Davis, P. (2003). Teaching a simple meal preparation skill to adults with moderate and severe mental retardation using video modeling. *Behavioral Interventions, 18*(3), 209–218. https://doi.org/10.1002/bin.139

Reichow, B., Hume, K., Barton, E. E., & Boyd, B. A. (2018). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *The Cochrane Database of Systematic Reviews, 5*(5), CD009260. https://doi.org/10.1002/14651858.CD009260.pub3

Rosenwasser, B., & Axelrod, S. (2001). The contributions of applied behavior analysis to the education of people with autism. *Behavior Modification, 25*(5), 671–677. https://doi.org/10.1177/0145445501255001

Roth, M. E., & Gillis, J. M. (2015). "Convenience with the click of a mouse": A survey of adults with autism spectrum disorder on online dating. *Sexuality and Disability, 33*(1), 133–150. https://doi.org/10.1007/s11195-014-9392-2

Sam, A., & AFIRM Team. (2015). *Visual supports*. National Professional Development Center on Autism Spectrum Disorder, FPG Child Development Center, University of North Carolina.

Satriale, M. G., Chance, L., & Nepo, K. (2007). *The use of Bluetooth® technology to prompt independent responding in the community: The reduction of the stigma of prompting*. Poster presentation at ABAI Autism 2009.

Schmidt, J. D., Drasgow, E., Halle, J. W., Martin, C. A., & Bliss, S. A. (2014). Discrete trial functional analysis and functional communication training with three individuals with autism and severe problem behavior. *Journal of Positive Behavior Interventions, 16*(1), 44–55. https://doi.org/10.1177/1098300712470519

Shillingsburg, M. A., Hansen, B., & Wright, M. (2019). Rapport building and instructional fading prior to discrete trial instruction: Moving from child-led play to intensive teaching. *Behavior Modification, 43*(2), 288–306. https://doi.org/10.1177/0145445517751436

Sigafoos, J., O'Reilly, M., Cannella, H., Upadhyaya, M., Edrisinha, C., Lancioni, G. E., Hundley, A., Andrews, A., Garver, C., & Young, D. (2005). Computer-presented video prompting for teaching microwave oven use to three adults with developmental disabilities. *Journal of Behavioral Education, 14*, 189–201. https://doi.org/10.1007/s10864-005-6297-2

Sigafoos, J., O'Reilly, M., Cannella, H., Edrisinha, C., de la Cruz, B., Upadhyaya, M., Lancioni, G. E., Hundley, A., Andrews, A., Garver, C., & Young, D. (2007). Evaluation of a video prompting and fading procedure for teaching dish washing skills to adults with developmental disabilities. *Journal of Behavioral Education, 16*(2), 93–109. https://doi.org/10.1007/s10864-006-9004-z

Smith, M. J., Pinto, R. M., Dawalt, L., Smith, J. D., Sherwood, K., Miles, R., Taylor, J., Hume, K., Dawkins, T., Baker-Ericzén, M., Frazier, T., Humm, L., & Steacy, C. (2020). Using community-engaged methods to adapt virtual reality job-interview training for transition-age youth on the autism spectrum. *Research in Autism Spectrum Disorders, 71*, 101498. https://doi.org/10.1016/j.rasd.2019.101498

Steinbrenner, J. R., Hume, K., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., … Savage, M. N. (2020). *Evidence-based practices for children, youth, and young adults with autism*. The University of North Carolina, Frank Porter Graham Child Development Institute, National Clearinghouse on Autism Evidence and Practice Review Team.

Taylor, B. A., Hughes, C. E., Richard, E., Hoch, H., & Coello, A. R. (2004). Teaching teenagers with autism to seek assistance when lost. *Journal of Applied Behavior Analysis, 37*(1), 79–82. https://doi.org/10.1901/jaba.2004.37-79

Thornberry, C., & Olson, K. (2005). The abuse of individuals with developmental disabilities. *Developmental Disabilities Bulletin, 33*(1–2), 1–19.

Tiger, J. H., Hanley, G. P., & Bruzek, J. (2008). Functional communication training: A review and practical guide. *Behavior Analysis in Practice, 1*(1), 16–23. https://doi.org/10.1007/BF03391716

Tiger, J. H., Fisher, W. W., & Bouxsein, K. J. (2009). Therapist- and self-monitored DRO contingencies as a treatment for the self-injurious skin picking of a young man with Asperger syndrome. *Journal of Applied Behavior Analysis, 42*(2), 315–319. https://doi.org/10.1901/jaba.2009.42-315

Tiong, S. J., Blampied, N. M., & le Grice, B. (1992). Training community-living, intellectually handicapped people in fire safety using video prompting. *Behaviour Change, 9*(2), 65–72.

Veazey, S. E., Valentino, A. L., Low, A. I., McElroy, A. R., & LeBlanc, L. A. (2016). Teaching feminine hygiene skills to young females with autism spectrum disorder and intellectual disability. *Behavior Analysis in Practice, 9*, 184–189. https://doi.org/10.1007/s40617-015-0065-0

Verdugo, M. A., Bermejo, B. G., & Fuertes, J. (1995). The maltreatment of developmentally handicapped children and adolescents. *Child Abuse and Neglect, 19*(2), 205–215. https://doi.org/10.1016/0145-2134(94)00117-d

Wallace, G. L., Kenworthy, L., Pugliese, C. E., Popal, H. S., White, E. I., Brodsky, E., & Martin, A. (2016). Real-world executive functions in adults with autism spectrum disorder: Profiles of impairment and associations with adaptive functioning and co-morbid anxiety and depression. *Journal of Autism and Developmental*

Disorders, 46(3), 1071–1083. https://doi.org/10.1007/s10803-015-2655-7

Williams, G. E., & Cuvo, A. J. (1986). Training apartment upkeep skills to rehabilitation clients: A comparison of task analytic strategies. *Journal of Applied Behavior Analysis, 19*(1), 39–51. https://doi.org/10.1901/jaba.1986.19-39

Wolf, M. M. (1978). Social validity: The case for subjective measurement or how applied behavior analysis is finding its heart. *Journal of Applied Behavior Analysis, 11*(2), 203–214. https://doi.org/10.1901/jaba.1978.11-203

Zane, T., Satriale, G., & Gerhardt, P. (2012). The support of adolescents and adults with autism in the community: How to establish community and life skills that will endure. *Autism Spectrum News, 5*(Spring), 29–30. https://autismspectrumnews.org/the-support-of-adolescents-and-adults-with-autism-in-the-community-how-to-establish-community-and-life-skills-that-will-endure/

The Relationship of Early Intensive Behavioral Intervention and Adulthood for Autistics/Individuals Diagnosed with Autism Spectrum Disorder

Justin B. Leaf, Joseph H. Cihon,
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The education that an autistic child receives when they are young may be an important factor affecting their quality of life when they reach adulthood (Howlin et al., 2004). Reichow (2012) noted, "Collectively, EIBI [Early Intensive Behavioral Intervention] is the comprehensive treatment model for individuals with ASDs with the greatest amount of empirical support…" (p. 518). Other professionals and organizations have long determined that the procedure(s) with the most robust empirical support demonstrating improvements in the overall quality of life for autistics/individuals diagnosed with autism spectrum disorder (ASD) are those based upon the principles of applied behavior analysis (ABA; Eldevik et al., 2009; Howard et al., 2005; Leaf et al., 2008, 2011; New York State Department of Health, 1999; Reichow et al., 2018; Simpson, 2005). Researchers have consistently noted the importance of autistics/individuals diagnosed with ASD receiving EIBI (sometimes referred to as intensive behavioral intervention) as it results in an overall improved quality of life (Eldevik et al., 2009; Howard et al., 2005; Leaf et al., 2011; Lovaas, 1987; Reichow et al., 2018). Additionally, professionals have shown that when autistics/individuals diagnosed with ASD receive EIBI, it can save state and federal governments hundreds of thousands of dollars (Chasson et al., 2007; Jacobson et al., 1998).

The purpose of this chapter is to provide readers with (a) a definition of what constitutes EIBI, (b) a brief overview of the history and research of EIBI, (c) a description of the factors that lead to a quality EIBI, and (d) recommendations for future clinical practice and research. A theme throughout this chapter will be discussing how EIBI is related to positive outcomes for autistic adults/individuals diagnosed with ASD.

Defining EIBI

Although there is no singular agreed upon universal definition of EIBI, there are several key and common components that define EIBI. These components include (a) the age of the child when intervention begins, (b) the intensity of the intervention, (c) the duration of the intervention, (d) intervention procedures based upon the principles of ABA, (e) comprehensive curriculum, (f) implementation by trained professionals, and (g) parent involvement throughout the process.

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Age at Onset

It is critical to note that any autistic/individual diagnosed with ASD can receive intensive behavioral intervention at any age, as evident by this handbook. For example, Roth et al. (2014) reviewed the literature for behavioral interventions for adolescents and adults and found that adolescents and adults benefited from behavioral intervention. Although behavioral intervention is beneficial at any age, there is general agreement that the earlier an autistic/individual diagnosed with ASD begins intervention, the greater the potential outcomes (e.g., Simpson, 2001; Towle et al., 2020).

Even though professionals agree that it is most beneficial to start intervention as early as possible, there is no general agreement on what constitutes "early." This is evident by researchers including a variety of ages when evaluating the effectiveness and/or reporting on EIBI. For example, in a meta-analysis of EIBI studies, Kuppens and Onghena (2012) analyzed the data on participants who received services prior to 10 years old, while Caron et al. (2017) reviewed the literature for studies that included participants that had received EIBI prior to 7 years of age. As suggested by Matson et al. (2012), EIBI could be defined as an autistic/individual diagnosed with ASD receiving behavioral intervention prior to reaching school age (i.e., 12 months to 4 years of age). However, if an autistic/individual diagnosed with ASD still requires behavior support after reaching school age, they should continue to receive intensive behavioral intervention despite their age. Ultimately, regardless of disagreement on what "early" means, there is general agreement that EIBI must occur as young as possible and should continue as needed.

Intensive

In a seminal study on EIBI, Lovaas (1987) reported participants receiving an average of 40 h of behavioral intervention per week. Since this seminal study, there have been various descriptions of what constitutes intensive intervention. Some researchers have described intensive as meaning an autistic/individual diagnosed with ASD receiving ABA services anywhere between 15 and 40 h per week (e.g., Matson et al., 2012; Smith & Iadarola, 2015), 20–30 h per week (e.g., Green et al., 2002), 30–40 h per week (e.g., Green, 1996; Weiss, 1999), and 35–40 h per week (e.g., Cohen et al., 2006). With these different definitions of what constitutes "intensive," it may be difficult to know at which point an intervention is considered EIBI. Nonetheless, research has consistently shown that the more intensive the intervention, the better the outcome for autistics/individuals diagnosed with ASD (e.g., Lovaas, 1987). As such, a safe practice would be describing any comprehensive intervention that occurs for an average of 25–40 h a week as intensive intervention (e.g., Reichow, 2012, 2018). This range is reflective of the importance of individualization to meet the needs of the learner and not based upon a preconceived notion of what is intensive or based upon funding reimbursement.

Duration

Similar to the importance of the intensity of intervention is the duration of intervention. EIBI does not promise quick, drastic changes with minimal effort (unlike some fad treatments). It requires weeks upon weeks, months upon months, and years upon years of intensive intervention. Thus, EIBI commonly occurs for 2 or more years for autistics/individuals diagnosed with ASD. The total duration depends upon multiple variables including but not limited to (a) the need for continuing services, (b) availability of funding, (c) client preference, and (d) availability of staff. According to Jacobson et al. (1998), the range of EIBI is generally anywhere between 2 and 6 years in duration with 3 years being a "reasonable average duration" (p. 225). Although the average may be 3 years, research has shown that a successful duration can be anywhere between 6 and 36 months (Caron et al., 2017). Like the intensity of intervention, the duration of intervention must be individualized to meet the needs of the individual learner.

Behavioral

A third, and essential, component of what constitutes EIBI is that the procedures used within EIBI are based upon the principles of ABA (Klintwall & Eikeseth, 2014). Within this framework, behavior is learned through interactions within the environment. The systematic use of reinforcement and punishment increases the likelihood of desired behaviors and decreases the likelihood of underinsured behaviors, respectively. Within this framework, an interventionist would not implement those procedures/interventions which are not conceptually systematic with ABA (e.g., DIR/Floortime®). Additionally, an interventionist would not implement procedures which have limited or less methodologically sound research (e.g., Social Stories™), interventions that have been identified as a pseudoscience (e.g., Social Thinking; Leaf et al., 2016a, 2018), or procedures that have been identified as an anti-science (e.g., Facilitated Communication/Rapid Prompting Method; Jacobson et al., 1995).

Comprehensive

EIBI must include a comprehensive curriculum. This is important so the intervention can target the development of skills that may be needed across the life span. A comprehensive curriculum is also likely to help the child develop the skills necessary to make informed decisions at later ages and lead to more autonomy and independence. When designing a comprehensive curriculum, it is important to meet the individual needs of each client and avoid using a "one size fits all" approach. Nonetheless, there are likely common themes within a comprehensive curriculum involved in EIBI.

First, EIBI interventionists commonly target the development of learning how to learn behaviors (e.g., Leaf & McEachin, 1999). Learning how to learn behaviors help promote learning in a variety of environments and contexts – enhancing the process of learning. This can include attending, observational learning, identifying and labeling contingencies, and deductive reasoning. Second, comprehensive curriculum within EIBI commonly includes decreasing undesired behavior (e.g., behavior that is harmful to the learner or people in the learner's environment or negatively impacts the learning process). Within EIBI these behaviors may be self-injury, aggression, PICA, elopement, and/or stereotypic/self-stimulatory behaviors. When targeting these undesired behaviors, it is essential that the interventionist identifies functionally related alternative replacement behaviors. It should be noted that an interventionist should not target undesired behavior (e.g., self-stimulatory behavior) simply because of the possibility of social stigmas but, rather, because of the immediate and long-term negative impact it might have for the learners' overall quality of life.

Deficits in social skills is one of the defining characteristics of ASD (American Psychiatric Association, 2013) making targeting the development of social skills common within EIBI. One purpose of teaching social skills is to improve upon current deficits and teach the contingencies involved in various social contexts. Targeting skills in this manner may increase the likelihood that individuals can determine their desired and undesired social contexts and choose how to behave as they age. Common examples of social skills targeted with EIBI may include sharing, turning taking, telling jokes, entering into a game, and engaging in prosocial behavior that leads to friendship development. Relatedly, EIBI commonly involves a focus on the development of communication skills. While there may be many rationales for teaching communication, it should ultimately be done so the autistic/individual diagnosed with ASD can better communicate their wants and needs and understand what is occurring in their environment. Examples of communication skills include imitation, receptive language, matching, expressive language, entering a conversation, and conversation flow.

A fifth area that is commonly concentrated upon in EIBI is the development of adaptive behaviors/self-help skills. These behaviors are taught so that an autistic/individual diagnosed with ASD can better function in their environment. These types of behaviors commonly include toileting, washing hands, brushing teeth, cooking a meal, cleaning up, and laundry. Finally, comprehensive curriculum within EIBI often includes academic skills and pre-vocational skills. These skills include reading, writing, math skills, time management, problem-solving, assembly, sorting, and stacking. These skills are critical so that an autistic/individual diagnosed with ASD can succeed in school and later in their chosen profession.

Trained Interventionists

Implementing behavioral intervention within EIBI is not an easy task. It takes constant analysis of a variety of variables while implementing the most effective procedures for a specific client in a specific context. Thus, it is important that those providing the intervention are thoroughly trained. Interventionists must be trained to implement several procedures and approaches (e.g., discrete trial teaching, behavioral skills training, social skills groups, prompting, shaping) with a high degree of fidelity and quality. That is to say, interventionists must exceed the current minimal standards which have defined the field (Leaf et al., 2020). Direct interventionists (i.e., the individuals directly and regularly implementing procedures with clients) and the supervisors (i.e., the individuals overseeing the curriculum, intervention, and training the direct interventionists) need to have a thorough knowledge of many areas related to ASD and ABA including (a) autism and developmental disabilities, (b) what constitutes evidence-based procedures, (c) the principles of applied behavior analysis, (d) and an understanding of the various procedures that they might have to implement.

Parent/Caregiver Involvement

A final key component of EIBI is parent/caregiver involvement. In the early research on EIBI (e.g., Lovaas, 1987), parents were expected to be part of the team of direct interventionists. Presently, the roles of parents/caregivers within EIBI greatly differ. In general, parents receive training to be knowledgeable about the procedures that are being implemented and receive parent training for any behavior management strategies the caregivers would like to implement in the home. Parents/caregivers should be actively involved in the selection of goals and the course of intervention, and they should provide essential information to the team members and be part of any individualized education planning and yearly assessments. Unlike the early days of the development of EIBI, parents should not have to give up their profession or implement the procedures with their child as the primary interventionist. Nevertheless, parents/caregivers are critical to their child's success from intake to discharge, and their role cannot be understated.

History and Research

EIBI can be traced back to some of the original founders of behaviorism and ABA including innovators such as Thorndike, Pavlov, Watson, Rayner, Jones, Skinner, and Bijou. From these pioneers the technology making effective behavioral intervention possible was born. Wolf et al. (1963) conducted one of the earliest studies to evaluate the effectiveness of behavioral intervention. In this study Wolf et al. implemented several operant conditioning procedures (e.g., extinction, shaping) with a 3-year-old autistic boy named Dickey. Wolf and colleagues' goal was to help Dickey wear his glasses, improve upon his bedtime behavior, and decrease tantrums. The results demonstrated the effectiveness of the operant conditioning procedures for each behavior of interest. This study as well as other seminal studies (e.g., Ayllon & Azrin, 1965; Bijou, 1957; Sherman, 1964) laid the foundation and paved the way for the first empirical evaluation of a comprehensive behavioral intervention for autistics/individuals diagnosed with ASD (i.e., Lovaas et al., 1973).

Lovaas et al. (1973) evaluated the implementation of behavior analytic procedures (e.g., discrete trial teaching, shaping, punishment, task analysis) for 20 autistics/individuals diagnosed with ASD, ages 3–10 years old. Lovaas et al. intended to improve prosocial behavior (e.g., language, play, social behavior) and to decrease the occurrence of aberrant behaviors (i.e., self-stimulation and echolalia). The Stanford Binet Intelligence Quotient Test, Vineland Social Maturity Scores, and other response measures were used to evaluate the effects of the intervention. The results indicated improvements for all 20 participants. Even though the participants showed improvements following behavioral intervention, there was variability in terms of maintenance in that "…follow-up measures recorded 1 to 4 years after treatment indicated that large differences between groups of children were related to the post-treatment environment" (Lovaas et al., 1973, p. 156).

Lovaas et al. (1973) led to one of the most commonly cited studies with respect to EIBI for autistics/individuals diagnosed with ASD (i.e., Lovaas, 1987). Specifically, Lovaas (1987) compared an average of 40 h of direct behavioral intervention per week to an average of 10 h of direct behavioral intervention per week plus other approaches. Thirty-eight children, all under 4 years of age, were quasi-randomly assigned into the two different groups (i.e., intensive and non-intensive group). Nineteen participants received intensive behavioral intervention (e.g., an average of 40 h of formal behavioral intervention per week, parental involvement, and punishment procedures), while another 19 participants received a non-intensive eclectic model of intervention (i.e., an average of 10 h of direct intervention per week plus other interventions). Regardless of the group, the participants received intervention for 2 or more years in multiple settings (e.g., clinic, home, community). The outcomes were divided into three categories (i.e., recovered, aphasic, and autistic) based upon IQ, school placement, and diagnosis. A total of 47%, 42%, and 10% of participants that received the intensive behavioral intervention reached recovered, aphasic, and autistic outcomes, respectively. A total of 0%, 42%, and 58% of participants that received the non-intensive behavioral intervention reached recovered, aphasic, and autistic outcomes, respectively.

McEachin et al. (1993) conducted a 6-year follow-up with the participants from Lovaas (1987). Specifically, McEachin et al. used three different standardized assessments as well as current school placement to examine the long-term effects of the intervention provided in the original Lovaas study. The results of this follow-up study showed that participants that received intensive intervention had an average of 30 points higher on IQ assessments than participants who did not receive intensive intervention. Further, the majority of participant in the intensive group maintained their outcome status. Another major event that occurred in 1993 was the publication of the book *Let Me Hear Your Voice* (Maurice, 1993). This book, written by Catherine Maurice, described her experience raising two autistic children who received EIBI. Maurice's book is commonly credited with the vast increase and acceptance of EIBI for autistics/individuals diagnosed with ASD (Leaf & McEachin, 2016).

Smith et al. (1997) conducted a retrospective analysis of 21 autistics/individuals diagnosed with ASD. This analysis consisted of participants who received intensive treatment (i.e., 30 h of treatment for 2 or more years) to a non-intensive group (i.e., 10 h of treatment for up to 2 years). The results showed that the participants in the intensive group responded better on cognitive assessments and had higher levels of speech after intervention. Weiss (1999) evaluated the effects of EIBI for 20 children diagnosed with ASD. Within this study the participants received 40 h of EIBI per week for 2 years. Participants made positive gains across two assessments (i.e., Childhood Autism Rating Scale and Vineland Adaptive Scale) and reached the mastery criterion for the targeted skills. Smith et al. (2000) evaluated the effects of EIBI. Participants were either in an EIBI group or a parent implemented group. The EIBI group consisted of participants receiving an average of 24.5 h a week for 33 months. The parent implemented group consisted of participants receiving 15–20 h a week for 2 years. Smith et al. (2000) reported that the

EIBI group outperformed children in the parent training group determined by responses on formal assessments (e.g., Merrill-Palmer, Reynell, and Vineland) and responding on various subskills (e.g., visual-spatial, language, academic).

Sallows and Graupner (2005) compared a group of 13 children who received EIBI (i.e., 37 h a week) to a group of 10 children who received parent-implemented behavioral intervention (i.e., 31 h a week). Intervention lasted 3–4 years across the two groups with both groups receiving intervention similar to what was described in Lovaas (1987). Both groups displayed increases in cognition, language, and adaptive skills as measured by formal assessments.

Howard et al. (2005) compared EIBI to an eclectic approach to treatment. In this study, 29 participants received EIBI for 25–40 h per week, 16 participants received an eclectic approach for 25–30 h per week, and 16 participants received an eclectic approach implemented in the public school system for 15 h per week. The results demonstrated that the participants in the EIBI group showed better improvement in IQ, adaptive, and language assessments.

Leaf et al. (2011) provided a programmatic description of a progressive, community-based EIBI program for 64 autistics/individuals diagnosed with ASD. In this report, participants received EIBI for an average of 21 h per week for up to 34 months in the United States, Hong Kong, Australia, or the United Kingdom. Leaf and colleagues found that 39% of participants reached best outcome according to the definition used by Lovaas (1987) and an additional 31% reached best outcome based on an expanded definition (i.e., IQs of 85 or higher, successfully doing grade-level work in full-time general education classrooms and received limited supports). Taken together, 70% of all participants reached a best outcome status after receiving progressive EIBI.

Eikeseth (2012) compared EIBI to treatment as usual for 49 autistics/individuals diagnosed with ASD. Twenty-five participants assigned to the EIBI condition received an average of 24 h per week with intervention that was characterized as the Lovaas model. Twenty-four participants received treatment as usual which consisted of an eclectic approach comprised of sensory motor therapies, TEACCH, augmentative communication, and ABA (3–5 h per week). Following a year of intervention, participants in the EIBI condition made significant improvements when compared to the treatment as usual condition on two formal assessments (i.e., Vineland Adaptive Behavior Scales the Childhood Autism Rating Scale).

Finally, Smith et al. (2021) conducted a long-term follow-up (i.e., 10 years) for participants who received EIBI. Specifically, Smith and colleagues included 19 participants who had EIBI that consisted of 36 h per week of what was described as the Lovaas model, with intervention lasting up to 6.5 years. The results demonstrated that participants maintained their cognitive gains 10 years later, that there was a significant reduction in the symptoms of autism, and that none of the participants acquired any new psychiatric disorders.

Variables to Improve Success

The short- and long-term success of EIBI is dependent upon multiple factors. Some of these factors are outside of the control of the interventionist. For example, the age of onset of the intervention (e.g., Towle et al., 2020), cognitive impairments (e.g., Ben-Itzchak et al., 2014), and the severity of aberrant behavior (e.g., Jang et al., 2011) at the onset of intervention have been correlated with differential outcomes. There are, however, various factors that the interventionist can control and which can result in better outcomes. What follows is a discussion of some of these factors that can lead to positive outcomes for autistic adults. These should not be viewed as listed in order of importance or as exhaustive, but as some factors to consider within EIBI.

A Progressive Approach

It is our contention that EIBI should be provided through a lens of a progressive approach to ABA

(Leaf et al., 2016b). Research has documented the effectiveness of components of a progressive approach (e.g., Cihon et al., 2019, 2020; Leaf et al., 2017) as well as more a comprehensive, progressive intervention (e.g., Leaf et al., 2011). There are several necessary components for EIBI to align with a progressive approach to ABA. Perhaps, the most important component is individualization to help ensure the behavioral intervention meets the needs of each learner. The interventionist does not necessarily implement the same procedure or target the same skills across learners but varies the procedures and goals based upon the strengths and deficits of each learner. This is done in an effort to develop meaningful, functional skills and not to simply check off a box on an assessment.

A second necessary component for EIBI to align with a progressive approach to ABA is that interventionists are permitted to analyze variables in the moment and make moment-to-moment changes as necessary to maximize progress (collectively referred to as clinical judgment; Leaf et al., 2019). The variables assessed are many, ever changing, and include, but are not limited to, (a) the learner's attentiveness, (b) the learner's receptivity to learning, (c) the learner's excitement level (e.g., calm, agitated), (d) the learner's recent and past performance, (e) the learner's current motivation, (f) the learner's verbal and non-verbal behavior, (g) the learner's persistence, (h) the learner's physical health, (i) the learner's emotional health, and (j) the staff's skill level. Each of these, and others, are considered within and across sessions in an effort to maximize progress and provide the most effective, compassionate intervention possible.

A third component that is necessary for EIBI to align with a progressive approach to ABA is that only procedures that are conceptually systematic with ABA and have empirical support are used. While this is a common component of most EIBI, it is a core component of a progressive approach to ABA. Procedures lacking empirical support or that closely resemble or align with pseudoscience or anti-science are not used, regardless of any disclaimers provided by those involved in the intervention. This approach is supported by the many comparisons of eclectic and strictly behavioral interventions that can be found within the literature (e.g., Howard et al., 2005). That is, better outcomes are obtained when the intervention is driven solely by behavior analytic principles and procedures than when it is combined with other approaches (Howard et al., 2005).

Finally, EIBI that aligns with a progressive approach to ABA is humane and compassionate. As previously stated, this approach is individualized for the needs of each learner. Taking each learner's strengths and weaknesses into account helps to ensure the intervention is provided with compassion. Furthermore, EIBI that aligns with a progressive approach to ABA comes from a behavior analytic worldview. Within this worldview, behavior is a product of its circumstances and not the result of some innate dysfunction or abnormality (Cooper et al., 2020). The learner is behaving exactly the way they should be given their learning history and the current context and prevailing contingencies. This places focus on changing the context and contingencies as opposed to changing the learner. Some have argued this offers a "humane and compassionate alternative to the blame-oriented view of problem behavior" (Friman, 2021, p. 637). Additionally, EIBI that aligns with a progressive approach to ABA means working collaboratively with families, other professionals, and autistics/individuals diagnosed with ASD. This means listening to and considering everyone's perspectives that are involved in the intervention perspective.

Meaningful Curriculum

Autism is not a diagnosis of an inability to touch your nose or wave your hands after an interventionist says, "Do this." Rather it is a diagnosis associated with social communication deficits and restricted and repetitive behaviors (American Psychiatric Association, 2013). Other associated deficits include cognitive skills (Frazier et al., 2014), adaptive skills (Gilotty et al., 2002), and presence of aberrant behavior (Matson et al., 2008). Unfortunately, irrelevant, decontextualized skills are commonly targeted within behavior interventions for autistics/individuals diagnosed with ASD (e.g., touching nose, waving hands; Leaf et al., 2016b). The most effective, successful EIBI targets and prioritizes functional, meaningful, applied, and authentic skills. For this to happen, short- and long-term benefits of the targeted skills/goals must be considered as well as any potential risk or short-term discomfort. For example, there are several short- and long-term benefits of developing a generalized matching repertoire such as expedited learning in the short term and better functioning in new environments in the long term. This comes with very little risk or discomfort. In another example, there are few short-term but several long-term benefits of developing compliance with taking medicine. This may also come with discomfort and some levels of risk. In both of these examples, several variables must be taken into consideration to determine the benefits and risks involved to decide the best course of treatment. Ultimately, a meaningful and functional curriculum will lead to younger learners learning important skills that will improve their overall quality of life. Hopefully, these skills will continue to be useful and create more opportunities and choices for the learner in adulthood.

Quality Interventionists

As previously stated, implementing a progressive approach to EIBI can be challenging as the interventionist has to continually analyze variables in the moment, use clinical judgment, and make moment-to-moment changes as necessary to maximize progress. Not only is this enormously difficult, but it can be equally stressful given the high stakes involved in EIBI impacting the clients life. The difficulty involved in and the importance of effective, quality EIBI make it critical that interventionists are highly competent. Unfortunately, standards in the field do not always make this a reality (Leaf et al., 2020). Nonetheless, there are several considerations when considering training for EIBI interventionists.

Interventionists should receive direct training and supervision in the context in which they will work and with the clients with whom they will work. This training should continue until competency in this context is demonstrated. This differs from time-based trainings in which the time spent in training is based on a predetermined number of hours. The time spent in training with competency-based training, on the other hand, is determined by the interventionist's behavior. If the interventionist demonstrates the trained skills quickly, training may end quickly; however, if the interventionist does demonstrate the necessary skills quickly, training will continue until they do so. Even when initial training ends, supervision and advanced training should continue. This helps ensure the maintenance of skills as well as the development of more advanced skills (e.g., clinical judgment). While training in this context has focused on direct interventionists, the same logic applies to those in more supervisory roles. That is, all professionals involved in providing EIBI should be required to demonstrate competency with clients receiving EIBI, and credentials are merely a starting point.

Further, there are a variety of behaviors that are not commonly found in task lists for behavior analytic certification but are critical for professionals involved in providing EIBI. These behaviors include (a) clinical judgment, (b) handling pressure, (c) critical thinking, (d) inspiring others, (e) being a good self-evaluator, (f) assisting others to improve, (g) being a tireless worker, (h) eagerness to learn, (i) accepting and incorporating feedback, (j) compassionate care skills, (k) creativity, (l) handling professional discourse, (m) professional in all areas (e.g., clinic, conferences, social media), and (n) avoiding drama. These behaviors are important for interventionists because they relate to better and quicker skill acquisition and improvement for the learner in the short term which corresponds to positive outcomes in adulthood.

Future Directions

Clinical Practice

Research and clinical practice have long demonstrated the importance of EIBI for autistics/individuals diagnosed with ASD. The outcomes of quality EIBI result in improved quality of life, more autonomy, and increased options in childhood and adulthood. It is also clear that the same outcomes are less likely to occur when autistics/individuals diagnosed with ASD do not receive EIBI. Thus, it is important for autistic/individuals diagnosed with ASD to continue to have access to quality EIBI. There are, however, several recommendations for clinical practice as it relates to EIBI.

First, despite some recent criticisms about the intensive nature of EIBI (e.g., Kupferstein, 2018), it remains important to determine the intensity required for each learner individually. Intensity should not, however, be based upon some a priori assumption number or by third-party payers. For some this may mean more than 40 h per week, while for others it may mean much less than 40 h per week. It should also be noted that there have been several studies that have found positive correlations between the intensity of EIBI and outcomes (e.g., Howlin et al., 2004). That is, the more intensive the intervention, the better the outcomes on a variety of measures (e.g., adaptive behavior, cognitive level, social behavior). Nonetheless, the only determination of the amount of hours should be based upon the learners' individual needs.

Second, and perhaps most related to the topic of this book, interventionists should consider how skills taught within EIBI will impact the recipients of EIBI later in life. It is likely that adolescence and adulthood are not necessarily considered within EIBI, which is understandable. However, planning and preparing for the transition to adolescence and adulthood should begin as early as possible (Roux et al., 2015). This involves reviewing goals to determine their use beyond childhood and childhood contexts. For example, identification of coins and other monies is a common goal in early intervention. Yet many adolescents and adults find themselves using digital methods of payment and money management, which renders the previously taught skill nonfunctional. As such, considering how skills taught within EIBI will impact the recipients later in life may lead the supervisors and interventionists providing EIBI to consider prioritizing the development of skills like how to use debit cards, Apple Pay, and the like.

Third, we suggest the use of a variety of standardized (e.g., the Vineland, Social Skills Improvement System, and Weschler Preschool & Primary Scales of Intelligence) and curricular assessments (e.g., A Work in Progress, Verbal Behavior Milestones Assessment and Placement Program, Assessment of Basic Language and Learning Skills) when developing the curriculum. It is unlikely that one assessment or curriculum book will provide the necessary information to ensure a comprehensive intervention that develops functional, meaningful, applied, and authentic skills. Making use of a variety of assessments helps address the limitations of each assessment as well as assist in communicating progress with the relevant consumers.

Finally, as previously discussed, we encourage the adoption of a progressive approach to ABA as it relates to EIBI. Research has demonstrated the positive effects of such a conceptualization (e.g., Leaf et al., 2011; Lovaas, 1987; McEachin et al., 1993). While this research base is sound and growing, more research will be needed. Nonetheless, the research supports adopting this approach, and the benefits are evident for those providing intervention as well as the recipients of EIBI. Continual adoption of a progressive approach to ABA applied to EIBI will hopefully lead to more effective, quality, compassionate, and humane interventions available for autistics/individuals diagnosed with ASD.

Research

There is a plethora of research documenting the effectiveness of EIBI for autistics/individuals diagnosed with ASD. Despite the large body of research, there are still several areas for additional research that warrant discussion. First, future researchers should compare different approaches to EIBI for autistics/individual diagnosed with ASD. Today there are many different models of EIBI intervention such as the Lovaas model (e.g., Smith, 2013), a progressive approach (e.g., Leaf et al., 2016b), Applied Verbal Behavior (e.g., Sundberg & Michael, 2001), and Comprehensive Application of Behavior Analysis to Schooling (e.g., Healy et al., 2008). Each of these approaches has been demonstrated to be effective for autistics/individuals diagnosed with ASD; however, the conditions under which one may be more effective, efficient, or preferred for specific demographics or contexts remain unknown. Comparative studies would help provide data to make this determination and guide practicing behavior analysts in selecting the best approach for each individual learner.

Second, and similar to previous studies (e.g., McEachin et al., 1993; Smith et al., 2021), researchers should evaluate the long-term maintenance of participants who received EIBI. Previous research has demonstrated that participants who received EIBI maintained their gains after EIBI and continued to succeed in standardized assessments and/or school placement (e.g., McEachin et al., 1993; Smith et al., 2021). Despite these positive findings, there have been some that have voiced concern about the long-term effects of EIBI and behavioral intervention more generally (e.g., Kupferstein, 2018). Continued research evaluating the long-term effects of EIBI will help determine the validity of these concerns as well as how well skills developed in EIBI persist across time. This research will also be helpful in examining which skills developed in EIBI do and do not help promote autonomy in adolescence and adulthood. This data will be invaluable in informing changes, if any, to the skills that are targeted within EIBI.

Conclusion

It is without question that EIBI can result in significant improvements on a variety of measures for autistics/individuals diagnosed with ASD. These improvements occur in childhood and may continue to promote autonomy and options in adolescence and adulthood. As such, it is imperative that autistics/individuals diagnosed with ASD continue to have access to quality, effective, compassionate, and humane EIBI. It is equally important that we continue to improve upon our intervention and capture these changes empirically. Doing so will lead to better EIBI and better outcomes for autistics/individuals diagnosed with ASD.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Ayllon, T., & Azrin, N. H. (1965). The measurement and reinforcement of behavior of psychotics. *Journal of the Experimental Analysis of Behavior, 8*(6), 357–383. https://doi.org/10.1901/jeab.1965.8-357

Ben-Itzchak, E., Watson, L. R., & Zachor, D. A. (2014). Cognitive ability is associated with different outcome trajectories in autism spectrum disorders. *Journal of Autism and Developmental Disorders, 44*(9), 2221–2229. https://doi.org/10.1007/s10803-014-2091-0

Bijou, S. W. (1957). Patterns of reinforcement and resistance to extinction in young children. *Child Development, 28–47*, 54. https://doi.org/10.2307/1125999

Caron, V., Bérubé, A., & Paquet, A. (2017). Implementation evaluation of early intensive behavioral intervention programs for children with autism spectrum disorders: A systematic review of studies in the last decade. *Evaluation and Program Planning, 62*, 1–8. https://doi.org/10.1016/j.evalprogplan.2017.01.004

Chasson, G. S., Harris, G. E., & Neely, W. J. (2007). Cost comparison of early intensive behavioral intervention and special education for children with autism. *Journal of Child and Family Studies, 16*(3), 401–413. https://doi.org/10.1007/s10826-006-9094-1

Cihon, J. H., Ferguson, J. L., Milne, C. M., Leaf, J. B., McEachin, J., & Leaf, R. (2019). A preliminary evaluation of a token economy with a flexible earning requirement. *Behavior Analysis in Practice, 12*(3), 548–556. https://doi.org/10.1007/s40617-018-00316-3

Cihon, J. H., Ferguson, J. L., Leaf, J. B., Milne, C. M., Leaf, R., & McEachin, J. (2020). A randomized clinical trial of three prompting systems to teach tact relations. *Journal of Applied Behavior Analysis, 53*(2), 727–743. https://doi.org/10.1002/jaba.617

Cohen, H., Amerine-Dickens, M., & Smith, T. (2006). Early intensive behavioral treatment: Replication of the UCLA model in a community setting. *Journal of Developmental and Behavioral Pediatrics, 27*(2 Suppl), S145–S155. https://doi.org/10.1097/00004703-200604002-00013

Cooper, J. O., Heron, T. E., & Heward, W. L. (2020). *Applied behavior analysis* (3rd ed.). Pearson.

Eikeseth, S., Klintwall, L., Jahr, E., & Karlsson, P. (2012). Outcome for children with autism receiving early and intensive behavioral intervention in mainstream preschool and kindergarten settings. *Research in Autism*

Spectrum Disorders, 6(2), 829–835. https://doi.org/10.1016/j.rasd.2011.09.002

Eldevik, S., Hastings, R. P., Hughes, J. C., Jahr, E., Eikeseth, S., & Cross, S. (2009). Meta-analysis of early intensive behavioral intervention for children with autism. *Journal of Clinical Child and Adolescent Psychology, 38*(3), 439–450. https://doi.org/10.1080/15374410902851739

Frazier, T. W., Georgiades, S., Bishop, S. L., & Hardan, A. Y. (2014). Behavioral and cognitive characteristics of females and males with autism in the Simons simplex collection. *Journal of the American Academy of Child and Adolescent Psychiatry, 53*(3), 329–240.e3. https://doi.org/10.1016/j.jaac.2013.12.004

Friman, P. C. (2021). There is no such thing as a bad boy: The circumstances view of problem behavior. *Journal of Applied Behavior Analysis, 54*(2), 636–653. https://doi.org/10.1002/jaba.816

Gilotty, L., Kenworthy, L., Sirian, L., Black, D. O., & Wagner, A. E. (2002). Adaptive skills and executive function in autism spectrum disorders. *Child Neuropsychology, 8*(4), 241–248. https://doi.org/10.1076/chin.8.4.241.13504

Green, G. (1996). Early behavioral intervention for autism: What does the research tell us? In C. Maurice, G. Green, & S. C. Luce (Eds.), *Behavioral intervention for young children with autism: A manual for parents and professionals* (pp. 29–44). Pro-Ed.

Green, G., Brennan, L. C., & Fein, D. (2002). Intensive behavioral treatment for a toddler at high risk for autism. *Behavior Modification, 26*(1), 69–102. https://doi.org/10.1177/0145445502026001005

Healy, O., O'Connor, J., Leader, G., & Kenny, N. (2008). Three years of intensive applied behavior analysis: A case study. *Journal of Early and Intensive Behavior Intervention, 5*(1), 4–22. https://doi.org/10.1037/h0100407

Howard, J. S., Sparkman, C. R., Cohen, H. G., Green, G., & Stanislaw, H. (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities, 26*(4), 359–383. https://doi.org/10.1016/j.ridd.2004.09.005

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212–229. https://doi.org/10.1111/j.1469-7610.2004.00215.x

Jacobson, J. W., Mulick, J. A., & Schwartz, A. A. (1995). A history of facilitated communication: Science, pseudoscience, and antiscience science working group on facilitated communication. *American Psychologist, 50*(9), 750–765. https://doi.org/10.1037/0003-066X.50.9.750

Jacobson, J. W., Mulick, J. A., & Green, G. (1998). Cost–benefit estimates for early intensive behavioral intervention for young children with autism – General model and single state case. *Behavioral Interventions, 13*(4), 201–226. https://doi.org/10.1002/(SICI)1099-078X(199811)13:4<201::AID-BIN17>3.0.CO;2-R

Jang, J., Dixon, D. R., Tarbox, J., & Granpeesheh, D. (2011). Symptom severity and challenging behavior in children with ASD. *Research in Autism Spectrum Disorder, 5*(3), 1028–1032. https://doi.org/10.1016/j.rasd.2010.11.008

Klintwall, L., & Eikeseth, S. (2014). Early and intensive behavioral intervention (EIBI) in autism. In V. B. Patel, V. R. Martin, & C. R. Martin (Eds.), *Comprehensive guide to autism* (pp. 117–137). Springer. https://doi.org/10.1007/978-1-4614-4788-7_129

Kupferstein, H. (2018). Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis. *Advance in Autism, 4*, 19–29. https://doi.org/10.1108/aia-08-2017-0016

Kuppens, S., & Onghena, P. (2012). Sequential meta-analysis to determine the sufficiency of cumulative knowledge: The case of early intensive behavioral intervention for children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 6*(1), 168–176. https://doi.org/10.1016/j.rasd.2011.04.002

Leaf, R., & McEachin, J. (1999). *A work in progress: Behavior management strategies and a curriculum for intensive behavioral treatment of autism*. Different Roads to Learning.

Leaf, R., & McEachin, J. (2016). The Lovaas model: Love it or hate it, but first understand it. In R. Roomanczyk & J. McEachin (Eds.), *Comprehensive models of autism spectrum disorder treatment* (pp. 7–43). Springer. https://doi.org/10.1007/978-3-319-40904-7_2

Leaf, R., McEachin, J., & Taubman, M. (2008). *Sense and nonsense in the behavioral treatment of autism: It has to be said*. Different Roads to Learning.

Leaf, R. B., Taubman, M., McEachin, J. J., Leaf, J. B., & Tsuji, K. H. (2011). A program description of a community-based intensive behavioral intervention program for individuals with autism spectrum disorders. *Education and Treatment of Children, 34*(2), 259–285. https://doi.org/10.1353/etc.2011.0012

Leaf, J. B., Kassardjian, A., Oppenheim-Leaf, M. L., Cihon, J. H., Taubman, M., Leaf, R., & McEachin, J. (2016a). Social Thinking®: Science, pseudoscience, or antiscience? *Behavior Analysis in Practice, 9*(2), 152–157. https://doi.org/10.1007/s40617-016-0108-1

Leaf, J. B., Leaf, R., McEachin, J., Taubman, M., Ala'i-Rosales, S., Ross, R. K., Smith, T., & Weiss, M. J. (2016b). Applied behavior analysis is a science and, therefore, progressive. *Journal of Autism and Developmental Disorders, 46*(2), 720–731. https://doi.org/10.1007/s10803-015-2591-6

Leaf, J. B., Leaf, J. A., Milne, C., Taubman, M., Oppenheim-Leaf, M., Torress, N., Townley-Cochran, Leaf, R., McEachin, J., & Yoder, P. (2017). An evaluation of a behaviorally based social skills group for individuals diagnosed with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*, 243–259. https://doi.org/10.1007/s10803-016-2949-4

Leaf, J. B., Cihon, J. H., Ferguson, J. L., Taubman, M., Leaf, R., & McEachin, J. (2018). Social Thinking®, pseudoscientific, not empirically supported, and non-evidence based: A reply to Crooke and Winner.

Behavior Analysis in Practice, 11(4), 456–466. https://doi.org/10.1007/s40617-018-0241-0

Leaf, R., Leaf, J. B., & McEachin, J. (2019). *Clinical judgment*. Different Roads to Learning.

Leaf, J. B., Leaf, R., McEachin, J., Bondy, A., Cihon, J. H., Detrich, R., Eshleman, J., Ferguson, J. L., Foxx, R. M., Freeman, B. J., Gerhardt, P., Glenn, S. S., Miller, M., Milne, C. M., Mountjoy, T., Parker, T., Prtichard, J., Ross, R. K., Saunders, M. S., & Streff, T. (2020). The importance of professional discourse for the continual advancement of practice standards, The RBT® as a case in point. *Journal of Autism and Developmental Disorders, 51*, 1789–1801. https://doi.org/10.1007/s10803-020-04631-z

Lovaas, O. I. (1987). Behavioral treatment and normal education and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology, 55*(1), 3–9. https://doi.org/10.1037/0022-006x.55.1.3

Lovaas, O. I., Koegel, R. L., Simmons, J. Q., & Long, J. (1973). Some generalization and follow-up measures on autistic children in behavior therapy. *Journal of Applied Behavior Analysis, 6*(1), 131–166. https://doi.org/10.1901/jaba.1973.6-131

Matson, J. L., Wilkins, J., & Macken, J. (2008). The relationship of challenging behaviors to severity and symptoms of autism spectrum disorders. *Journal of Mental Health Research in Intellectual Disabilities, 2*(1), 29–44. https://doi.org/10.1080/19315860802611415

Matson, J. L., Tureck, K., Turygin, N., Beighley, J., & Rieske, R. (2012). Trends and topics in early intensive behavioral interventions for toddlers with autism. *Research in Autism Spectrum Disorders, 6*(4), 1412–1417. https://doi.org/10.1016/j.rasd.2012.02.010

Maurice, C. (1993). *Let me hear your voice: A family's triumph over autism*. Fawcett Columbine.

McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation, 97(4), 359–372.*

New York State Department of Health, Consensus Panel. (1999). *Clinical practice guideline: The guideline technical report. Autism/pervasive developmental disorders, assessment and intervention for young children (ages 0–3 years)*. Report 4217. NYS Department of Health.

Reichow, B. (2012). Overview of meta-analyses on early intensive behavioral intervention for young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(4), 512–520. https://doi.org/10.1007/s10803-011-1218-9

Reichow, B., Hume, K., Barton, E. E., & Boyd, B. A. (2018). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews, 2018*(5), CD009260. https://doi.org/10.1002/14651858.cd009260.pub3

Roth, M. E., Gillis, J. M., & DiGennaro-Reed, F. D. (2014). A meta-analysis of behavioral interventions for adolescents and adults with autism spectrum disorders. *Journal of Behavioral Education, 23*, 258–286. https://doi.org/10.1007/s10864-013-9189-x

Roux, A. M., Shattuck, P., Rast, J. E., Rava, B. A., & Anderson, K. A. (2015). *National autism indicators report: Transition into young adulthood*. A.J. Drexel Autism Institute, Drexel University.

Sallows, G. O., & Graupner, T. D. (2005). Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Journal on Mental Retardation, 110*(6), 417–438. https://doi.org/10.1352/0895-8017(2005)110[417:ibtfcw]2.0.co;2

Sherman, J. A. (1964). Modification of nonverbal behavior through reinforcement of related verbal behavior. *Child Development, 35*(3), 717–723. https://doi.org/10.2307/1126497

Simpson, R. L. (2001). ABA and students with autism spectrum disorders: Issues and considerations for effective practice. *Focus on Autism and Other Developmental Disabilities, 16*(2), 68–71. https://doi.org/10.1177/108835760101600202

Simpson, R. L. (2005). Evidence-based practices and students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 20*(3), 140–149. https://doi.org/10.1177/10883576050200030201

Smith, T. (2013). Lovaas institute for early intervention (LIFE). *Behavior Analysis in Practice, 6*(2), 78–79. https://doi.org/10.1007/BF03391807

Smith, T., & Iadarola, S. (2015). Evidence base update for autism spectrum disorder. *Journal of Clinical Child and Adolescent Psychology, 44*(6), 897–922. https://doi.org/10.1080/15374416.2015.1077448

Smith, T., Eikeseth, S., Klevstrand, M., & Lovaas, I. O. (1997). Intensive behavioral treatment for preschoolers with severe mental retardation and pervasive developmental disorder. *American Journal on Mental Retardation, 102*(3), 238–249. https://doi.org/10.1352/0895-8017(1997)102<0238:ibtfpw>2.0.co;2

Smith, T., Groen, A. D., & Wynn, J. W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation, 105*(4), 269–285. https://doi.org/10.1002/9780470755778.ch6

Smith, D. P., Hayward, D. W., Gale, C. M., Eikeseth, S., & Klintwall, L. (2021). Treatment gains from early intensive behavioral intervention (EIBI) are maintained 10 years later. *Behavior Modification, 45*(4), 581–601. https://doi.org/10.1177/0145445519882895

Sundberg, M. L., & Michael, J. (2001). The benefits of Skinner's analysis of verbal behavior for children with autism. *Behavior Modification, 25*(5), 698–724. https://doi.org/10.1177/0145445501255003

Towle, P. O., Patrick, P. A., Ridgard, T., Pham, S., & Marrus, J. (2020). Is earlier better? The relationship between age when starting early intervention and outcomes for children with autism spectrum disorder:

A selective review. *Autism Research and Treatment, 2020*, 7605876. https://doi.org/10.1155/2020/7605876

Weiss, M. J. (1999). Differential rates of skill acquisition and outcomes of early intensive behavioral intervention for autism. *Behavioral Interventions, 14*(1), 3–22. https://doi.org/10.1002/(SICI)1099-078X(199901/03)14:1<3::AID-BIN25>3.0.CO;2-F

Wolf, M., Risley, T., & Mees, H. (1963). Application of operant conditioning procedures to the behaviour problems of an autistic child. *Behavior Research and Therapy, 1*(2–4), 305–312. https://doi.org/10.1016/0005-7967(63)90045-7

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Functional Analysis of Behavioral Challenges with Adults with Autism

Joseph D. Dracobly and Richard G. Smith

Some adults with autism engage in behaviors that, if left unaddressed, can lead to substantial negative impacts on their relationships with others, ability to benefit from educational and therapeutic efforts, health, and overall quality of life (DeVries & Geurts, 2015). Specific behavioral challenges faced by adults with autism may include odd or contextually inappropriate mannerisms, repetitive and/or contextually inappropriate movements or sounds (e.g., stereotypy, echolalia), refusal to participate in or tolerate critical activities (e.g., noncompliance, food refusal), tantrums and other disruptive behavior, property destruction, physical and verbal aggression, and behavior that produces harm to their own body or self-injurious behavior (SIB) (Hong et al., 2018).

These behaviors can diminish the quality of life for individuals with autism and others with whom they interact (e.g., family members, caregivers, teachers; Lecavalier et al., 2006) in a number of ways. Individuals who display unusual, bizarre, or dangerous behaviors may experience serious difficulties in establishing and maintaining social relationships (e.g., Walsh et al., 2013; Weiss et al., 2012). Challenging behaviors have been shown to impair efforts to teach and train academic, self-care, social, and other adaptive skills (e.g., Fox & Emerson, 2001; Pyles et al., 1997). Severe challenging behaviors, such as noncompliance/food refusal, aggression, and SIB, can result in serious health problems, injury and tissue damage to oneself or others, or even death (Sabuncuoglu et al., 2015).

Interventions for challenging behaviors exhibited by individuals with disabilities were among the first reported extensions of behavior science to a societal problem. In fact, several demonstrations of effective behavioral treatments appeared prior to the establishment of the *Journal of Applied Behavior Analysis* in 1968. For example, Teodoro Ayllon and colleagues published a series of analyses in which they demonstrated the utility of behavioral measurement and contingency arrangements in the treatment of an array of problem behaviors in institutional settings (e.g., Ayllon & Michael, 1959). Ayllon and his colleagues used reinforcement, extinction, and punishment procedures to address behavioral challenges including hoarding, bizarre speech, food refusal, and others. Similarly, Montrose Wolf and colleagues used operant conditioning procedures to reduce several forms of severe challenging behavior exhibited by a boy with autism (Wolf et al., 1963, 1967).

These and other early efforts to address challenging behaviors showed that contingency management, guided by an understanding of principles of behavior, could be effective components of habilitative programs for individuals

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with disabilities. Strategies focused primarily on arranging reinforcement contingencies for the absence of problem behaviors, targeting incompatible behaviors for increase and, frequently, implementing punishment contingent on behaviors targeted for decrease. The emphasis was often on creating strong contingencies to compete with problematic behaviors by encouraging clients to “do something else.” This approach came to be known as “behavior modification,” and, although researchers and clinicians frequently reported favorable outcomes, there was little focus on identifying and addressing the underlying causes of the behavioral challenges (Pelios et al., 1999). This general strategy ultimately limited the general effectiveness of behavioral approaches, as interventions sometimes produced mixed outcomes or failed to show maintenance and generalization in real-life settings. Not infrequently, failures of less-intrusive, reinforcement-based treatments led to the use of more intrusive management strategies, including restraint, psychotropic medication, or punishment (Pelios et al.).

Throughout the 1960s and 1970s, the behavior modification approach to treating behavior disorders prevailed. Although several behaviorally oriented researchers and clinicians speculated about the potential role of operant conditioning in creating and maintaining challenging behaviors and some had even incorporated hypotheses about the contingencies that maintained their clients’ problem behaviors into their interventions, almost none attempted to systematically assess those contingencies and to “match” treatment to them. Several publications at the close of the 1970s and into the early 1980s changed all that and heralded a “functional analysis revolution” in applied behavior analysis.

The Functional Analysis Revolution

After nearly 20 years of efforts to understand and address challenging behaviors exhibited by persons with autism and other disabilities, the behavior-analytic literature contained several conceptual analyses of the underlying causes of these behaviors. Researchers described how these behaviors could be maintained by several different contingencies of reinforcement and demonstrated the effectiveness of treatments corresponding to those contingencies. For example, whereas previous efforts to use differential reinforcement to treat behavior disorders depended on choosing a reinforcer that was more powerful and easier to obtain than those associated with the problem behavior (i.e., they needed to “overpower” the unknown factors that motivated problem behavior), researchers began to leverage their hypotheses about the maintaining variables for problem behavior to encourage “better ways” to obtain them, effectively “replacing,” rather than overpowering, previously operative contingencies.

Efforts to understand and address the operant mechanisms underlying problem behaviors were scattered throughout the early literature on applied behavior analysis. For example, Smolev (1971) suggested that problem behaviors could be maintained by various operant contingencies. Some researchers focused on the effects of contingent attention from caregivers, by arranging for extinction of problem behaviors (i.e., attention was no longer presented as a consequence) and reinforcement for other, more appropriate ways to access attention (e.g., Ferster, 1961; Lovaas et al., 1965; Lovaas & Simmons, 1969; Romanczyk & Goren, 1975; Peterson & Peterson, 1968; Weiher & Harman, 1975). Other efforts focused on behavior maintained by escape from aversive contexts or tasks (e.g., Carr et al., 1976; Cautela & Baron, 1977; Jones et al., 1974) and behavior that appeared to be reinforced by its automatically (i.e., non-socially) produced consequences (e.g., Berkson & Mason, 1964; Favell et al., 1982; Rincover & Devaney, 1982).

In 1977, Edward Carr published a seminal review of the extant literature on SIB in which he evaluated several then-current accounts of its causes (Carr, 1977). Carr considered psychodynamic, organic, and operant accounts for SIB, concluding that operant accounts were most consistent with the available data. He divided operant accounts into three broad categories: positively reinforced, negatively reinforced, and self-stimulatory behavior.

Carr's work was immediately recognized as an important contribution to our understanding of SIB and influenced a generation of future researchers who would develop a broad array of procedures designed to assess the operant functions of SIB (and other behavioral challenges) and to evaluate the feasibility of function-based treatments. This "functional analysis revolution" resulted in vast improvements in our understanding of a variety of behavioral challenges including SIB, aggression, property destruction, tantrums, stereotypies, elopement, food refusal, and many other forms of less prevalent behavioral challenges. The functional analytic model has been extended to populations including children and adults with an array of disabilities and syndromes (e.g., intellectual disability, autism, Cornelia de Lange syndrome, Lesch-Nyhan syndrome), typically developing children and adults and non-humans (see Beavers et al., 2013; Hanley et al., 2003). The effectiveness of a functional analytic conception of behavioral challenges has been further validated through legislation requiring that children with disabilities and behavioral challenges who attend public schools have the right to a "functional behavioral assessment" as a part of their comprehensive educational programming (IDEA, 1997).

The Evolution of Functional Assessment Methodologies

Although early researchers had demonstrated that problem behavior could be sensitive to environmental events (e.g., Berkson & Mason, 1964; Carr et al., 1976; Lovaas & Simmons, 1969; Peterson & Peterson, 1968), it was not until the early 1980s that a systematic approach to identify the influence of these environmental events was developed. Among the first researchers to evaluate an empirical methodology for identifying the operant functions of SIB and other behavioral challenges was Brian Iwata, a recently appointed Assistant Professor of Psychology and Psychiatry at the Johns Hopkins School of Medicine. Assigned to a unit serving children with severe behavior disorders and heavily influenced by the work of Carr and other operant practitioners, Iwata developed a systematic process for empirically evaluating the operant functions of SIB, and, in 1982, Iwata and colleagues published a seminal study on an empirical methodology for identifying the variables that maintain problem behavior.

Incorporating Carr's (1977) conceptualization of the operant mechanisms that could maintain SIB, Iwata et al. (1982/1994) designed a series of test conditions to isolate different sources of reinforcement. Using logic similar to allergy testing, Iwata and colleagues exposed participants to a series of conditions, each in isolation, and each designed to test for sensitivity to a specific reinforcement contingency. If, when exposed to antecedent and consequent conditions associated with a specific contingency, SIB was observed at levels above a control condition, then the researchers tentatively concluded that the participant's SIB was sensitive to that form of reinforcement. For example, in the social disapproval condition, the participant was in a room with a therapist and some toys. At the beginning of the session, the therapist told the participant that the therapist had work to do (i.e., a discriminative stimulus [S^D] for the availability of attention) and then stopped talking to the participant and moved across the room (i.e., an establishing operation [EO] for attention). If the participant emitted SIB, the therapist made statements of concern or disapproval and gently touched the participant. If higher measures of SIB were observed in this condition, relative to a control condition, the researchers concluded that SIB was maintained by social positive reinforcement in the form of attention. In an academic demand condition, the therapist presented learning trials to the participant, potentially functioning as aversive stimulation and an EO for escape. If the participant completed a learning trial, the therapist briefly praised the participant and presented the next learning trial. If the participant emitted SIB, the therapist removed the learning materials and stopped asking the participant to complete the learning trials for 30 s. If higher measures of SIB were observed in the academic demand condition, relative to a control condition, the researchers concluded that SIB was maintained by social negative reinforcement in the form of escape from task demands. In an alone condition, participants were in a room with no other people or stimuli. There were no programmed antecedent or consequent events. The purpose of this condition was to determine if SIB would occur in the absence of changes in the social environment. That is, the alone condition was designed to identify automatic reinforcement as a potential maintaining consequence for the participant's SIB.

These test conditions were compared to a control condition, called unstructured play, which was designed to "rule out" the operant accounts assessed in test conditions. In this condition, the participant had continuous access to toys, the therapist provided positive attention and physical contact, and no task demands were presented. By arranging noncontingent and unrestricted access to the consequences that might maintain SIB, the motivation for SIB would be eliminated, and, thus, little or no SIB should be observed. Any SIB occurring in other conditions could then be compared with measures of SIB from the unrestricted play condition to estimate their involvement in maintenance of SIB. These four conditions were presented in a multielement design and then continued until either clear differentiation between at least one test condition and the control condition occurred or there were sustained, undifferentiated patterns of responding across all conditions.

Across the participants, Iwata et al. (1982/1994) observed four distinct response patterns. First, for four of nine participants, there were higher levels of responding in the alone condition, suggesting that their SIB was maintained by some source of automatic reinforcement. Second, for three participants, undifferentiated responding across conditions was observed – also apattern indicating maintenance by automatic reinforcement. Third, for two participants, higher levels of responding occurred in the academic demand condition, indicating their SIB was maintained by social negative reinforcement. Finally, for one participant, higher levels of responding were observed in the social disapproval condition, indicating his behavior was maintained by social positive reinforcement. Taken together, Iwata et al. were able to identify a source of reinforcement for all nine participants' SIB.

Over the next 30 years, hundreds of studies demonstrated the utility of Iwata et al.'s general methodology for assessing the operant function(s) of severe problem behavior. Furthermore, a large body of literature demonstrated that experimental functional analysis (EFA) outcomes could be a foundation for the development of individualized, function-based, and highly effective interventions (e.g., Beavers et al., 2013; Carr & Durand, 1985; Hanley et al., 2003; Iwata et al., 1994).

During this time, several researchers proposed alternative strategies for conducting the EFA process. Extending Iwata et al.'s general methodology of empirical analysis, Carr and colleagues directly manipulated antecedent conditions – but not consequences – in their analysis. For example, in their seminal study on functional communication training (FCT), Carr and Durand (1985) conducted a pretreatment EFA with each participant. In these EFAs, Carr and Durand manipulated two variables – attention and demands – across four conditions. Each session was divided into 30-s trials, which were further divided into 10-s intervals during which the antecedent conditions were presented. In the easy 100 condition, participants were presented with a card-matching task that they had previously mastered and received attention during all 10-s intervals. In the easy 33 condition, the tasks were again those that had been previously mastered, but attention was provided during only 33% of the 10-s intervals. In the difficult 100 condition, the participants were presented with the card-matching task containing cards on which they had made errors on during the pre-EFA task assessment, and the participants received attention during all 10-s intervals. Across all three conditions, problem behavior resulted in the same consequences: therapists either ignored non-dangerous problem behavior, guided the participant back to their seat if they left the table for more than 10 s, or applied restraint for dangerous behavior. Because the consequences were constant across conditions, the determination of function was based on problem behavior occurring in the presence of specific EOs. That is, if they observed higher levels of problem behavior in the difficult 100 condition relative to the easy 100 condition, they concluded that problem behavior was maintained by negative reinforcement in the form of escape from difficult tasks. Likewise, if Carr and Durand observed higher levels of problem behavior in the easy 33 condition relative to the easy 100 condition, they concluded that the problem behavior was maintained by positive reinforcement in the form of attention.

Whereas Carr and Durand (1985) focused on identifying how antecedents influenced problem behavior by systematically manipulating antecedents while holding consequences constant across conditions, an alternative strategy is to manipulate antecedents while allowing naturally occurring consequences to occur. Anderson and Long (2002) were the first to evaluate this tactical innovation, termed a structured descriptive assessment (SDA). The SDA was conducted in the participants' natural environments with their regular caregivers as therapists. Four different antecedent variables were manipulated: attention, tangible items, task demands, and play opportunities. In each condition, the therapist presented the relevant S^D and EO, and, if problem behavior occurred, the therapist was instructed to respond as they normally would. For example, in the attention condition, the therapist talked to the participant for a brief period before the session started and then, at the start of the session, remained present (i.e., S^D) but stopped talking to the participant (i.e., EO). As with Carr and Durand's EFA, higher levels of problem behavior in the presence of a specific set of antecedent variables, relative to the play context, were taken as evidence of the likely maintaining consequence of problem behavior.

Although these antecedent-only, or A-B, EFA approaches have led to successful treatment, there are several issues unique to this approach that likely precluded their widespread adoption. First, EFAs in which only antecedent conditions are systematically manipulated cannot directly evaluate the effects of operant contingencies. Most antecedent influences (Sds and conditioned MOs) acquire their evocative function through pairing with consequences, so by manipulating antecedents only, one assumes the antecedent has sufficient prior pairing to maintain control over behavior – repeatedly over the course of assessment – in the absence of a contingency between the behavior and the consequence. Such persistence of problem behaviors across many trials and sessions in the presence of a systematically arranged extinction contingency seems inconsistent with an operant account of the behavior and suggests that further investigation of (1) the validity of this tactic and/or (2) the functional characteristics of behavior that seems to be evoked by conditions typically associated with social reinforcement (the arranged EOs and S^Ds) but that persists in the absence of the relevant reinforcement contingency.

Another concern with prevalent antecedent EFA strategies is the combination of antecedent variables, thus introducing potential confounds into each test condition. For example, in Carr and Durand's (1985) approach, both attention and task demands are present during each trial, regardless of condition. Therefore, even when responding is differentiated between a test and control condition, it is not clear whether a single variable or multiple variables are responsible for the differentiation.

A similar concern with the SDA involves its uncontrolled consequences. Whereas antecedents are systematically manipulated in an SDA, caregivers are "asked to respond to problem behavior as they typically would" (Anderson & Long, 2002, p. 141). Although this tactic permits some potentially interesting information about the types, schedules, and variability of consequences for problem behavior in the natural environment, it may also obscure assessment results by introducing uncontrolled variability within and across conditions. Alternatively, when a test condition shows differentiation, but variability in consequences is also observed within that condition (e.g., escape from tasks is sometimes provided as a consequence during an attention condition), it is not clear whether responding in that condition is a function of the systematically arranged antecedent events or the uncontrolled and variable consequences delivered by caregivers.

Finally, without a clear understanding of the effects of consequences, several highly effective forms of function-based treatment may not be possible to properly implement and evaluate. Many, if not most, function-based treatments require *knowledge of the type of contingency involved in maintaining problem behavior but also the specific form of its maintaining consequences*. For example, noncontingent reinforcement (NCR) involves time-based delivery of the consequence that maintains problem behavior to reduce the occurrence of problem behavior and other responses in that response class (e.g., Lalli et al., 1997; Richman et al., 2015). Without isolation of the effects of consequences, A-B EFAs may result in, at best, delivery of ineffective NCR or, at worst, delivery of contraindicated NCR (e.g., continued attention delivery for problem behavior maintained by social avoidance). Most other function-based strategies (e.g., DRA, FCT) also require a specific "match" between maintaining consequences and stimuli to be used as reinforcement in order to produce effective and sustainable treatment effects (e.g., Carr & Durand, 1985; Tiger et al., 2009).

Alternative Methodologies: Descriptive Assessment

Following the development of the EFA approach, researchers began evaluating alternative methods that did not involve evoking and potentially reinforcing problem behavior and required less time and resources. Direct observation, long a standard in behavior science, has been evaluated as an alternative to EFA. Descriptive assessment (DA) involves observing and collecting data on a target behavior in the environments in which it typically occurs. Over the years, DAs have taken many forms. The "four function" model classifies four common types of events identified in over 30 years of research as maintaining consequences for challenging behaviors: social positive reinforcement in the form of attention, social positive reinforcement in the form of access to tangible items, social negative reinforcement, and automatic reinforcement. During observation periods, data collectors record instances of the target behavior and then record antecedent events that preceded, and subsequent events that followed, the target behavior (A-B-C analysis). For example, each time a target behavior occurs, data collectors may record antecedents such as the presentation of demands, removal of preferred items, or low levels of attention. Similarly, the data collectors will record events that occurred after the behavior, such as the termination of demands, delivery of preferred items, or the delivery of attention. The total instances of the target behavior and each antecedent and consequent event are then summed. The correlations between the antecedent and consequent events can be compared, with stronger correlations indicating a likely controlling variable (see Pence et al., 2009, for a comparison of different forms of DA with EFAs).

Different types of correlational analyses have been proposed, with the strongest being conditional probability (e.g., Lerman & Iwata, 1993; Vollmer et al., 2001) or lag sequential analyses (e.g., Borrero & Borrero, 2008; Gunter et al., 1993). Each of these analyses provides a quantitative measure of the relation between a given event and problem behavior. In conditional probability analyses, the probability of either antecedent event preceding problem behavior or a consequent event following problem behavior is compared with the unconditional probability of each event. If the conditional probability of the two events exceeds the unconditional probability of each, a behavioral relation is considered present. In lag sequential analyses, a second-by-second or minute-by-minute calculation of conditional probabilities is calculated for each antecedent and consequent event, relative to all instances of behavior. If the conditional probability of an antecedent event increases as the time before problem behavior approaches zero (lag), a behavioral relation is considered present. Likewise, if the conditional probability of a consequent event increases in the seconds after problem behavior (sequential), a behavioral relation is considered present. Although this approach can yield useful information about the environmental events that surround problem behavior, researchers have found this form of descriptive assessment to be limited in identifying actual functional relationships. For example, Thompson and Iwata (2001) found that attention occurred in 80% of intervals following problem behavior, which should strongly suggest attention was the maintaining consequence for problem behavior. However, in a subsequent study, Thompson and Iwata (2007) found that attention was the maintaining consequence for only 3 of 15 problem behaviors (20%). These results suggest that the types of correlations observed in descriptive assessments may be insufficient to infer functional relationships and call into question the general utility of A-B-C recording for identifying the variables that control problem behavior.

A method that combines A-B-C analysis and correlational analyses is the contingency space analysis (CSA; e.g., Martens et al., 2008). In the CSA, one conducts observations similar to those in A-B-C analyses. Specifically, one records the target behavior and a variety of consequent events. The main difference between A-B-C analysis and the CSA is that, in the CSA, one also collects data on non-target behavior that followed the consequences one is measuring. Following observations, one calculates several values: conditional probability of each consequence given the target behavior, the conditional probability of the consequence given all non-target behavior, the unconditional probability of the target behavior, and the unconditional probability of all non-target behavior. These values are then plotted on a graph, with the conditional probability of a consequence given the non-target behavior on the x-axis and the conditional probability of a consequence given the target behavior on the y-axis. One then plots a diagonal line, to bisect the x- and y-axes, which represent the two conditional probabilities being equal. One then plots the conditional probability of each consequence-target behavior and consequence-non-target behavior relation. If a data point for a given consequence appears above the diagonal line, a likely reinforcement relation exists between the target behavior and the consequence. Likewise, if a data point for a given consequence is below the diagonal line, a likely reinforcement relation exists between non-target behavior and the consequence. The primary benefit of the CSA over A-B-C analysis alone and conditional probability analysis alone is the comparison of relations between the target behavior and consequences and the non-target behavior and consequences. For example, a high conditional probability of a consequence given a target behavior could indicate a potential reinforcement contingency. However, this may miss the actual relation – a high conditional probability between any behavior and a consequence. In this case, only the inclusion of the additional conditional probability of the consequence given all non-target behavior would allow for this determination to be made.

Scatterplot Analysis

In a scatterplot analysis, the occurrence of behavioral data is recorded in cells on a grid, typically with hours of the day displayed on the y-axis and consecutive days on the x-axis (e.g., Kahng et al., 1998; Touchette et al., 1985). Different markings are made based on the characteristics of behavior during each observation period. For example, a single occurrence may be recorded using a dot in the cell, a few occurrences may be recorded using slashes in the cell, and many occurrences may be recorded by filling the cell in completely. After several days of having the data entered into the scatterplot, temporal patterns may begin to emerge. Emergent patterns can be correlated with specific environmental events that reliably happen during the time(s) or day(s) with higher levels of problem behavior, and those events that are highly correlated may be suspected as having a functional relation to problem behavior. Although scatterplots are frequently used in practice, Kahng and colleagues found that scatterplots often do not produce outcomes that reveal differentiation through visual analysis (Kahng et al., 1998). To clarify undifferentiated scatterplots, these researchers conducted statistical control analyses of scatterplot data for 15 participants. Results indicated that 12 of 15 data sets were outside of statistical control (i.e., the data sets showed evidence of non-random patterning); however, there are two substantial limitations to this approach. First, a primary benefit of the scatterplot is its ease of implementation and interpretation. If statistical analyses are necessary to identify patterns, a primary benefit of the approach is compromised, and those patterns may be relatively irrelevant in identifying the variables that occasion and maintain problem behavior. Second, because the scatterplot only identifies temporal patterns, there is no mechanism for identifying the specific variables that occurred during the assessment period. If the typical flow of activities in the natural environment is not reasonably stable, differentiation will be compromised, and it is not possible to identify the environmental events present when problem behavior is observed. This can preclude even a strong hypothesis about the functional relation between environmental events and problem behavior. Finally, as Kahng et al. noted, an experimental analysis can be conducted, perhaps multiple times, in the time it typically takes to complete a scatterplot analysis. Although the scatterplot may sometimes identify temporal patterns that could subsequently be assessed to identify environmental influences, it is not, by itself, an efficient or precise method for identifying the variables that maintain problem behavior.

In general, the primary contribution of DA to the functional assessment process appears to be to provide specific information that can subsequently be incorporated into EFA. The general failure of DA to reliably correspond with EFA outcomes (e.g., Pence et al., 2009) suggests that it cannot be used in isolation as the sole source of functional assessment information. However, DA can provide useful information to incorporate into the EFA, such as specific stimuli or persons that may be associated with problem behaviors, particular forms of problem behavior to be assessed, and potential precursor behaviors.

Alternative Methodologies: Anecdotal Assessments

Anecdotal, or indirect, assessments involve obtaining information about the behavior, the individual, and/or the conditions under which the behavior occurs from caregivers, significant others, or even the individual themselves. This information may be obtained using interviews, questionnaires, or rating scales.

Among the first and most widely used anecdotal assessments is the Motivation Assessment Scale (MAS; Durand & Crimmins, 1988). The MAS is a 16-item questionnaire about four common functions of problem behavior – social positive reinforcement in the form of attention, social positive reinforcement in the form of access to tangible items, social negative reinforcement, and automatic reinforcement. Respondents answer each question using a 7-point Likert-type scale, ranging from “never” to “always.” The total score for each functional category is summed, and the highest score(s) indicates the likely function(s). Durand and Crimmins (1988) compared outcomes across two raters, showing high levels of agreement across the two respondents for all participants. They then conducted EFAs with eight participants (two from each of the functional categories). Across the eight participants, the results of EFAs corresponded with results from the respective MAS. That is, for all participants, the EFAs identified the same source of reinforcement as the MAS. Although this study provided initial evidence of the utility of anecdotal assessments, subsequent researchers were often unable to replicate Durand and Crimmins’ findings (e.g., Newton & Sturmey, 1991; Sigafoos et al., 1994; Zarcone et al., 1991). Many of these failures to replicate may have been due to differences in populations and respondents; however, difficulties obtaining high levels of reliability across raters call into question the general utility of the MAS – by itself – as a useful method for functional assessment.

Given mixed outcomes of replication attempts with the MAS, several researchers developed alternative anecdotal assessments (see Sturmey, 1994, for a review). Two of the most frequently cited assessments are the Questions about Behavioral Function (QABF; Matson & Vollmer, 1995) and the Functional Analysis Screening Tool (FAST; Iwata et al., 2013). The QABF is a 25-item item questionnaire that assesses five functional categories: attention (i.e., social positive reinforcement), escape (i.e., social negative reinforcement), nonsocial (i.e., automatic positive reinforcement), physical (i.e., automatic negative reinforcement), and tangible (i.e., social positive reinforcement). Respondents answer questions using a scale of 0 to 3, with 0 representing "Never" and 3 representing "Always." In a comparison of QABF, MAS, and EFA outcomes, Paclawskyj et al. (2001) found that the QABF predicted the outcomes of EFA in 56.3% of cases whereas the MAS predicted the outcomes of EFA in 43.8% of cases. Although the QABF was thus taken as more accurate, agreement with EFA outcomes was only slightly above chance levels – a result also obtained by other researchers (e.g., Koritsas & Iacono, 2013). The FAST has produced slightly better outcomes. The FAST is a 16-item questionnaire that assesses four functional categories: social positive reinforcement (i.e., attention and tangible), social negative reinforcement, automatic positive reinforcement, and automatic negative reinforcement. For each question, respondents answer either "Yes" or "No." Iwata et al. (2013) found that FAST outcomes matched EFA outcomes in 63.8% of cases. Interestingly, the FAST was administered to two respondents for each participant, and when both respondents agreed, the FAST outcomes matched the EFA outcomes in 70.8% of cases. Dracobly et al. (2018) further examined rater agreement for the FAST and found high agreement among pairs of expert respondents (i.e., respondents who were BCBAs, had taken a course in functional assessment, and completed at least one EFA), as well as high levels of correspondence between FAST and EFA outcomes. Specifically, Dracobly et al. found that the FAST outcomes of any one expert matched the EFA outcomes in 90% of cases and, when both experts agreed on the FAST, the outcomes matched those from EFAs in 80% of cases. Although researchers have found the FAST to be a generally more reliable assessment, relative to other anecdotal approaches, its originators recently acknowledged that agreement and predictive validity remained at troublesome levels and cautioned that anecdotal assessment should not be considered "an approximation to an EFA of problem behavior; it is simply one way to gather information" (Iwata et al., 2013, p. 283). Iwata et al. (2013) offered three potential contributions of anecdotal assessment. First, it provides a formalized structure for the EFA information-gathering process; second, results may be helpful in identifying particular stimuli that can subsequently be incorporated into A-B or A-B-C EFA arrangements; and third, when substantial agreement is observed across multiple respondents, it may provide sufficient information to eliminate irrelevant test conditions and thus expedite the EFA process.

The Interview Informed Synthesized Contingency Analysis (IISCA; Hanley et al., 2014) has been proposed as a method for using information gained through anecdotal assessment to identify behaviors, stimuli, and – most importantly – contingencies to be analyzed in an EFA. Researchers have demonstrated that open-ended interviews can be used to identify "synthesized" contingencies, that incorporating synthesized contingencies within a test-control analytic format frequently produces rapid differentiation between test and control conditions, and that interventions based on those outcomes are frequently effective to reduce or eliminate challenging behaviors (Coffey et al., 2020). Synthesized contingencies are arrangements in which antecedents (i.e., S^Ds and MOs) associated with more than one type or form of reinforcement are simultaneously presented and the consequences associated with those antecedents are simultaneously delivered contingent on targeted responses. An example of a test for a synthesized contingency would be if the therapist removed a preferred tangible item (e.g., tablet device, toys) and directed the participant to complete an academic task. If the participant emitted the target behavior, the therapist would reinstate access to the tangible item and withdraw task demands. This test condition is designed to assess the combined effects of positive reinforcement (e.g., restored access to the tangible item) and negative reinforcement (e.g.., escape from task demands) on the behavior of interest. Outcomes are contrasted with those from a matched control condition (e.g., free access to tangible items and no task demands). Proponents of IISCA argue that synthesized contingencies are more representative of natural environments and that, in most cases, isolated contingencies do not maintain challenging behavior; rather, an interactive effect of synthesized contingencies is necessary for behavioral maintenance (Hanley et al., 2014). Critics of IISCA have countered that combining contingencies during assessment increases the risk of "false-positive" outcomes, in which data indicate maintenance of behavior by a synthesized contingency when, in fact, only one contingency was operative (Fisher et al., 2016). In fact, Fisher and colleagues showed that isolated contingencies were sufficient to produce differentiation in three of five EFAs in which IISCA had identified maintaining synthesized contingencies. Thus, the need to frequently combine contingencies during EFA remains a topic for further investigation.

More germane to the current discussion is the use of a structured interview to identify contingencies to be tested during an EFA. There are two potential concerns with the structured interview process. First, because research on IISCA is in its early stages and most investigations have been conducted by its originators, their students, or senior researchers (i.e., a recent review identified 17 IISCA studies, 11 of which were conducted by originators or their students; Coffey et al., 2020) and because administration and interpretation of an open-ended interview require subjective, in-the-moment decisions by the administrator (e.g., tips for administering IISCA indicate that administrators may use their discretion to omit or rephrase questions and to draw conclusions about response class membership, MOs, etc.; Hanley, 2018), it is not yet known whether practitioners are generally able to replicate the level of success reported in current research. That is, the training and history necessary to administer and interpret the open-ended interview are unclear, and the inherent flexibility of the process adds to this concern (it should be noted that, when administered with proper fidelity, the flexibility of open-ended interviewing can produce information that may not be obtained through more structured assessments). Second, although several investigations have shown that synthesized contingencies identified via structured interview produced differentiated EFA outcomes, the possibility of false positives, as described above, limits the extent to which assessment and treatment outcomes can validate the interview. Because the results of structured interviews often support synthesized contingencies, and because false-positive outcomes for synthesized contingencies have been documented (Fisher et al., 2016), the utility of structured interviews to accurately identify operative contingencies may be suspect. That is, if an assessment points toward the involvement of multiple contingencies when only one is operative, an analysis of those contingencies will likely produce a positive outcome (the data will indicate maintenance by the synthesized contingency when, in actuality, only one was operative). This may be compared to an allergy test in which the physician exposes the patient to several potential allergens simultaneously. Although the likelihood of a positive reaction would be greatly increased, it would not be possible to determine whether a single substance or a combination of allergens was responsible for the reaction, and it would not be appropriate to conclude that the results were an interactive effect of all the allergens. Indeed, preliminary replication results showing sensitivity to isolated contingencies for three of five participants for whom interviews had suggested multiple controlling consequences provide empirical evidence of such errors. Although IISCA has generated a great deal of interest and enthusiasm, these results suggest that the open-ended interview component of IISCA should be interpreted with caution as additional extension, replication, and validation occur. One final concern with the IISCA is that the procedures have only been conducted with children. Because this chapter is focused on assessment with adults, we would caution practitioners working with adults when using the IISCA with adults until additional empirical analyses with adults are conducted.

A similar approach to using anecdotal assessment to improve the efficiency of an EFA is the inclusion of multiple respondents in an anecdotal assessment process. As suggested by Iwata et al. (2013), substantial agreement among respondents on anecdotal assessments may provide enough information to omit unnecessary test conditions and, therefore, expedite the EFA process. For example, Smith et al. (2012) recruited 5 direct-care staff to complete MAS and QABF assessments for each of 27 participants, and results were assessed for agreement across respondents and correspondence with EFA outcomes. Overall, Smith et al. obtained at least 80% (i.e., 4/5 respondents) agreement among respondents for 57% of respondent groups with the QABF and 52% of respondent groups with the MAS. Smith et al. further found that, for eight participants for whom at least 80% agreement across raters was obtained on the QABF, MAS, or both, the results of the anecdotal assessments matched the results of the EFA in 100% of cases. Although these results are promising, Smith et al. also observed that, consistent with previous outcomes, agreement on either the MAS or QABF remained just above chance levels. Thus, although anecdotal outcomes matched those from EFAs when agreement is obtained, agreement was obtained for only a little over half of cases. Furthermore, it is not known if agreement among fewer respondents might be sufficient to predict EFA outcomes. In many settings (e.g., schools, worksites), it may be difficult to administer anecdotal assessments to multiple respondents, which would limit its overall utility. Finally, only a handful of published studies have incorporated the Multiple Respondent Anecdotal Assessment (MRAA) as a component of the EFA process; much more research will be needed to determine if it represents a useful advance in pretreatment EFA.

The literature on anecdotal assessment suggests that, although there are substantial concerns that limit the usefulness of anecdotal data, there appear to be conditions under which anecdotal assessments can produce reliable and valid outcomes (e.g., with expert respondents or with multiple respondents). Unfortunately, recent outcomes showing improvements in anecdotal assessment must be considered preliminary and suggestive; additional replications will be needed to further evaluate the utility of different types of anecdotal assessment (e.g., open-ended interview, rating scales) and of potential innovations such as using expert and/or multiple respondents. Thus, pending further research and development, clinicians are well advised to consider anecdotal assessment a component of a more comprehensive functional assessment process and to heed Iwata and Dozier's (2008) admonition against using anecdotal assessments for purposes beyond preliminary information gathering and guidance in designing EFA conditions.

Functional Analysis Procedures: Concerns, Limitations, and Solutions

Although EFA procedures may seem straightforward, there are several important considerations that must be addressed when planning and carrying out an EFA. The behavior analyst must make a series of decisions, which may include specifics of the test and control procedures, the order and format in which conditions will be presented, the schedule of consequences, and arrangement of the "typical" EFA conditions: alone/no interaction, attention, play, and escape. It may often be appropriate or even necessary to individualize features of the EFA based on information obtained from everyday environments (which may be obtained through descriptive or anecdotal assessment). For example, if anecdotal or descriptive evidence suggests that the target behavior is sometimes followed by the delivery of tangible consequences, a tangible condition can be created. Similarly, if divided attention or activity interruption seems to frequently precede target behaviors, these antecedent conditions can be incorporated into relevant test conditions. When specifics of the test and control conditions have been defined, it will be necessary to determine the order and format for presenting conditions. Hammond et al. (2013) showed that a fixed order of conditions can produce rapid and clear EFA outcomes, perhaps because they maximize motivational influences. Another decision that the clinician will encounter is the type and schedule of consequences for problem behavior. At one end of the continuum, no programmed consequences may be used, as in the A-B EFA. More typically, consequences are delivered according to a continuous schedule of reinforcement (FR 1) in which each response produces the consequence. Intermittent schedules may be used to verify the reinforcement effects of a particular consequence (Lovaas & Simmons, 1969) or to simulate schedules observed in the natural environment; however, if an intermittent schedule is selected, it must be understood that problem behavior may occur at increased rates or may escalate in intensity, which could present a substantial safety risk. Finally, one must develop specific arrangements of antecedent conditions corresponding to each test condition. For example, Conners et al. (2000) found that the inclusion of distinct discriminative stimuli for each condition (e.g., different therapists) facilitated more efficient and clear EFA outcomes. The clinician should identify items via a preference assessment to incorporate in the appropriate conditions (e.g., attention, play, tangible) and the specific tasks, requests, or other potentially aversive events to be presented in the test for negative reinforcement. Fortunately, these considerations should not present a major barrier to clinicians – even those with limited expertise – because specific procedures for addressing these matters are well-represented in the behavior-analytic literature and easily replicable. Thus, although developing EFAs requires fluency in behavior-analytic principles and procedures, there are many resources available to guide credentialed practitioners through the process.

Given these considerations, a potential limitation of EFAs is the level of expertise necessary to conduct EFA procedures. Over the past 40 years, a variety of individuals have conducted EFAs and produced clear outcomes (e.g., Ringdahl & Sellers, 2000; Thomason-Sassi et al., 2013), including parents and family members (e.g., Reimers et al., 1993; Umbreit, 1996; Vollmer et al., 1996; Wacker et al., 2013), teachers or trainers (e.g., Bloom et al., 2011; Kodak et al., 2013; Lambert et al., 2013; Watson & Sterling, 1998), and even peers (e.g., Broussard & Northup, 1995; Carr et al., 1996). Thus, there is ample evidence that, although the EFA should be developed and supervised by a certified or licensed behavior analyst, individuals with limited or no expertise in behavior analysis can be easily trained to implement EFA procedures with high levels of fidelity.

Another potential limitation of EFA is that the resources needed to implement EFA may not be available to practitioners. Beyond disciplinary resources to provide guidance on conceptual and procedural matters, EFA requires physical resources, such as space, personnel (e.g., therapists, data collectors), protective equipment, materials to be integrated into test and control conditions (e.g., instructional/training materials, preferred stimuli, data collection supplies), and associated professional supports (e.g., medical personnel, client representation). In fact, much early EFA research was conducted in well-resourced labs and clinics where all relevant expertise and physical resources were readily available, which may have supported the notion that extensive (and expensive) resources must be present to successfully complete the EFA process. However, a substantial amount of subsequent research has shown that it is possible to conduct EFAs in a range of contexts, including homes, offices, schoolrooms, and other "natural" environments, using largely personnel (see above) and materials already present in those environments (e.g., Bloom et al., 2011; Lambert et al., 2013). Because an EFA is designed to simulate conditions in the natural environment that evoke and maintain problem behaviors, it is typically unnecessary and even undesirable to integrate a large amount of external materials or personnel into test or control conditions. In fact, when materials, supplies, and persons that are not typically found in the natural environment are brought into the EFA process, the external validity of EFA outcomes may be compromised. That is, because the purpose of EFA is to identify the variables associated with problem behavior that already occurs in the participant's natural environment, any evidence about the effects of stimuli or conditions that cannot be found in that environment must be interpreted with great caution. Thus, it is usually neither necessary nor desirable to incorporate substantial external resources in test or control arrangements.

Resources for data collection will be required to successfully implement an EFA; however, recent advances in data collection technologies have made such resources readily available. In recent years, many behavioral data collection applications have been developed for use on laptops, cell phones, and tablets. These applications are usually inexpensive (or free) and can easily be programmed to collect, store, and convert EFA data as appropriate for individual cases. The ease of use of many apps can permit the therapist to simultaneously conduct EFA procedures and collect data (although an independent data collector is preferred, if available).

The involvement of other professional personnel from within and without behavior analysis in the functional assessment process is necessary in virtually all cases. When conducting an assessment that is likely to result in the occurrence of behaviors that can result in damage to persons or property, it will be critical to insure proper involvement, consultation, and oversight from a number of parties. The functional assessment process should involve consultation with medical professionals (especially in cases of SIB), peer-review from other behavior analysts, and review and oversight by a human rights representative or committee. Representation from relevant professional disciplines and other stakeholders is critical to ensure protections for both the client and the behavior analyst and in many cases (e.g, when assessing and treating severe behavior disorders) is mandated by state or federal policies and statutes. Behavior analysts should be fluent with all relevant laws, regulations, and policies surrounding the functional assessment process and embrace an interdisciplinary process as they develop and implement functional assessments. These matters are not specific to the functional assessment process and thus should not be considered limitations of functional assessment and EFA specifically, per se; rather, collaboration among stakeholders is best practice in any situation in which severe problematic behaviors are targeted for change.

In summary, EFA requires few physical resources that are not typically present in natural or clinical environments. As with any important behavioral intervention, appropriate behavior-analytic and multi-disciplinary resources will be required; however, these resources are necessitated by the nature of the presenting problems (e.g., behavioral excesses that are sufficiently dangerous, intense, or destructive to require professional intervention), rather than the assessment/treatment methodology. That is, the involvement of a team of trained professionals must be involved in the development, implementation, and evaluation of any course of assessment and treatment for these sorts of behavioral challenges, whether an EFA occurs or not.

An additional concern when conducting EFAs is the amount of time required to conduct an assessment. For example, using common procedures of three test conditions and one control condition, 10-min sessions, and at least three cycles of the four conditions, an EFA would take a minimum of 120 min. If clear differentiation does not occur, the EFA would be continued, resulting in potentially multiple hours or even days to complete the assessment. Because prolonged assessment both delays treatment and increases risk, researchers have evaluated a variety of methods to reduce the duration of time to complete an EFA. Two primary approaches have emerged – the brief experimental functional analysis (e.g., Derby et al., 1992; Northup et al., 1991; see Gardner et al., 2012, for a review) and the latency experimental functional analysis (e.g., Thomason-Sassi et al., 2011; Neidert et al., 2013).

There are several procedural variations of the brief EFA. In one arrangement, an individual is exposed to a single instance of each condition, and sessions are shorter in duration (e.g., 5 min). In another arrangement, a fixed number of sessions per condition is conducted (e.g., two sessions per condition). If differentiation is observed between a test and the control condition, one can immediately begin treatment. If there is not clear differentiation based on overall session values, one may also conduct within-session analyses, such as analyzing data on a minute-by-minute or second-by-second basis (e.g., Henry et al., 2021). For example, responding that occurs primarily at the beginning of the session and then stops may indicate extinction is occurring. Alternatively, responding that persists across the session increases following the onset of the EO and temporarily ceases following the onset of the programmed consequence, which may indicate a reinforcement contingency. The benefit of the brief EFA is that there is, overall, less exposure to environmental events that evoke and maintain problem behavior. For example, if only one session per condition is conducted, the brief EFA would require only 40 min to complete, a threefold decrease compared to a standard EFA with three sessions per condition.

Although the brief EFA requires less time overall, in each session, problem behavior can occur many times, which continues to present risk. The latency EFA presents a time-sensitive alternative. In a latency EFA, a maximum of one instance of problem behavior is "required" per session. That is, as in a standard EFA and brief EFA, at the beginning of test sessions, programmed antecedent events are presented. When the first instance of problem behavior occurs, the programmed consequence is delivered, and the session ends. In the latency EFA, then, the reinforcing consequence(s) for problem behavior is indicated by a lower latency to the first instance of problem behavior. There are two main benefits of the latency EFA relative to the brief EFA. First, the latency EFA could take a similar duration of time as the brief EFA. If one conducts only one session per condition and problem behavior occurs in a test condition in less than the programmed session time (e.g., latency of 2 min), the overall duration of a latency EFA would be 32 min, whereas the overall duration of a brief EFA would be 40 min. In addition to the time reduction, the latency EFA would only evoke and reinforce one instance of problem behavior, whereas the brief EFA would evoke and reinforce many more instances of problem behavior. Second, latency EFAs most commonly involve multiple iterations of each condition. Although this increases the time required to complete the assessment, it allows for detection of across-session patterns and stability of the effects of environmental events while only requiring one instance of problem behavior per session.

Although the brief EFA and the latency EFA are the two primary adaptations of EFA to reduce the time required to complete assessment, there are two other adaptations worthy of mention. An additional method to reduce assessment time is the trial-based EFA (e.g., Bloom et al., 2011; Sigafoos & Saggers, 1995). In a trial-based EFA, sessions are typically 2–6 min. A matched control period is presented either before and after the test period or after the test period. For example, in an attention condition, attention is provided for the first 2 min (i.e., control), attention is then removed (i.e., test) for a maximum of 2 min, and if problem behavior occurs, the test portion stops, and attention is provided for 2 min (i.e., control). The benefit of the trial-based EFA is a reduction in time. With matched controls, only three sessions occur per cycle with a maximum of 4–6 min (i.e., depending on arrangement of test-control or control-test-control). If three cycles are required to obtain differentiation, the total assessment time would be, at most, 36–54 min, as compared to 120 min for a standard EFA.

A final adaptation to reduce assessment duration is a progression through a series of analyses (e.g., Tiger et al., 2009; Vollmer et al., 1995). In this approach, one begins with some form of brief assessment (e.g., single-instance, short-duration brief EFA). If differentiation between a test condition and the control condition occurs, the assessment is complete. If there is no differentiation, one conducts additional analyses. For example, one may conduct a second cycle of all conditions and examine within-session patterns of responding. If there continues to be no differentiation, one may progress to more extended sessions by increasing session duration. If there continues to be no differentiation, one could modify the EFA into a different format (e.g., a trial-based EFA) or conduct a standard EFA. If, at this point, there is no differentiation, one may conduct a screening for automatic reinforcement, such as repeated exposure to an alone or no interaction condition. If behavior does not persist in these contexts, one may then evaluate the social test conditions in a different arrangement, such as a reversal or pairwise design. This is but one example of a progression from brief to extended analyses. The benefit of this approach is the potential for a shorter assessment duration. Even if a standard EFA produces differentiation in three cycles, it is possible that shorter session durations, fewer sessions, or both could have produced that same differentiation. By starting with the brief EFAs, one allows for the shortest EFA possible to identify the reinforcement contingency for problem behavior without sacrificing precision by only using a single EFA arrangement.

Unique Considerations for Adults with Autism

In each of the sections above, we discussed a variety of considerations for conducting EFAs with adults. These considerations are general – they have been found to be effective with a wide variety of populations, including adults with autism. However, there are several unique characteristics of autism that come to bear on the assessment of problem behavior. In general, these characteristics have taken three forms in the assessment of problem behavior of adults with autism: differentiation of subtypes of SIB, the effects of transitions on problem behavior, and the effects of interruptions of ongoing activity on problem behavior.

Subtypes of SIB

SIB has long been a behavior of concern to applied behavior analysts (e.g., Carr, 1977; Corte et al., 1971; Ferster, 1961; Iwata et al., 1982/1994). Since the development of EFA procedures, researchers have reliably found that SIB is most commonly maintained by some form of social reinforcement. However, there remains a substantial percentage of SIB cases for which there is no discernable socially mediated cause. In the assessment of SIB, this most commonly appears when either SIB persists regardless of what occurs in the social environment or when an SIB persists if an individual is left alone. Until recently, these patterns resulted in a determination that SIB was automatically maintained. However, the precise controlling relations was rarely, if ever, specified. For example, for some individuals, SIB may persist due to the sensory stimulation it produces. When that sensory stimulation is blocked or an alternative response produces that sensory stimulation, SIB decreases (e.g., Garcia & Smith, 1999; Roscoe et al., 1998; see Rooker et al., 2018, for a review). More recently, researchers have focused on assessments designed to better delineate different types of automatically reinforced SIB.

In a seminal study, Hagopian et al. (2015) reviewed EFAs conducted with individuals at a specialized program affiliated with a medical school between 1997 and 2012. During this period, they identified 39 individuals with automatically reinforced SIB. They then analyzed each EFA and identified three distinct categories: SIB that occurred at the highest rate in the alone condition and lowest rate in the play (i.e., control) condition, SIB that happened across all conditions at either a high or variable rate, and SIB that involved self-restraint. Hagopian et al. provided several reasons for these classifications. For Subtype 1, a low rate of SIB in the play (i.e., control) condition could indicate that the SIB was sensitive, in some way, to changes in the social environment. However, for Subtype 2, if SIB occurred at a high rate in all conditions and all conditions varied in a similar way, it was unlikely that changes in the immediate social environment could effectively reduce SIB. Finally, for Subtype 3, because the individual was attempting to stop their SIB, a common assumption is that SIB terminates some form of aversive stimulation. In this case, then, the maintaining consequence was a form of negative reinforcement. Taken together, each subtype provided better specificity to the likely source of reinforcement, which would directly affect treatment selection. In a subsequent analysis of all data sets of automatically reinforced SIB published between 1982 and 2015, Hagopian et al. (2017) found that the three subtypes adequately allow for differentiation of treatments, leading to more efficient reductions in SIB.

Interruption of Ongoing Activity and Transitions

Among the core features of autism are restricted interests and repetitive patterns of behavior (American Psychiatric Association, 2013). Often, disruption of these interests or repetitive patterns can occasion problem behavior; researchers have conceptualized this as an issue of transitions (e.g., McCord et al., 2001). That is, the transition from one activity to another occasions the onset of problem behavior. In these situations, researchers have sought to determine if environmental events or features prior to the transition, after the transition, or both produce differential changes in problem behavior. The empirical work on the relation between transitions and problem behavior can be divided into two broad categories: transitions that involve the cessation of a specific activity and transitions from any given activity to another.

Although research on the disruption of ongoing activity has been rather limited, researchers have identified two primary factors relevant to the assessment and treatment of problem behavior occasioned by transitions. The first factor is the direct interruption of ongoing activity. Several researchers have evaluated a unique method for assessing problem behavior occasioned by interruption of ongoing activity: an analysis of symmetrical "do" and "don't" requests (e.g., Adelinis & Hagopian, 1999; Falcomata et al., 2012; Fisher et al., 1998; Hagopian et al., 2007). The purpose of this analysis is to determine whether the primary evocative event is the interruption per se or the instruction to complete an alternative activity. For example, in a "do" condition, a therapist instructs an individual to complete a specific task (e.g., clean a table). In a matched "don't" condition, the therapist makes the materials related to the "do" condition available but only instructs the individual to stop whatever they were doing (e.g., "Stop touching the door"). A higher rate of problem behavior in the "do" condition relative to the "don't" condition suggests a typical social negative reinforcement function – escape from task demands. However, a higher rate of problem behavior in the "don't" condition indicates a different function of problem behavior – continued access to the ongoing activity. This analysis could be particularly important for adults with ASD when designing treatment. Specifically, it would be important to determine if any interruption (e.g., "stop what you're doing") or only specific interruptions (e.g., "do this") occasion problem behavior. Because of the core feature of ASD, restricted interests or repetitive patterns of behavior, one may expect some difficulty with interruptions of highly preferred tasks in which an individual regularly engages. If an interruption produces an increase in the likelihood of problem behavior only when a specific request is made (e.g., to do a specific task), treatment may involve common interventions for escape-maintained problem behavior, such as altering the request requirement or increasing reinforcement for adherence to the request. However, there is an increase in the likelihood of problem behavior anytime a repetitive, highly preferred is interrupted; a subsequent analysis may be necessary, to isolate the features of the interruption that evoke problem behavior. To address this pattern, researchers have focused on an analysis of transitions that precede problem behavior.

The second type of transition analysis is a direct assessment of the influence of specific transitions on the occurrence of problem behavior. These evaluations have focused on two broad categories of transitions: transitions from highly preferred contexts to less preferred contexts and unpredictable transitions. Several studies have evaluated the effects of transitions from one activity to another, conceptualized as either transitions from a highly preferred activity to a less preferred activity (high-low) or rich-to-lean (schedules of reinforcement) transitions (e.g., Castillo et al., 2018; Hagopian et al., 2004; Jessel et al., 2016). Before the EFAs are conducted, researchers identify either a hierarchy of preferred activities (high-low) or relative rates of reinforcement across times and activities. To begin the EFAs, researchers typically establish a pattern of repeated exposure to the highly preferred activity or a rich schedule of reinforcement. Once low rates of problem behavior are established in these contexts, the "test" phase of the EFA begins. During the test phase, an individual is initially exposed to either the high-preference activity or the rich reinforcement schedule. After a fixed period of time, one of two types of changes occurs: completion of the high-preference activity and an instruction to begin low-preference activity or a reduction in the rate of reinforcement. If problem behavior occurs, no programmed consequences are delivered. That is, naturally occurring patterns of reinforcement continue to occur, but no differential response is made contingent on problem behavior. To establish the effects of high-low transitions or rich-lean transitions on problem behavior, the test conditions are compared to control conditions that involve either transitions from one high-preference activity to another high-preference activity or transitions from one rich reinforcement schedule to another rich reinforcement schedule. This cycle then repeats until clear patterns emerge, specifically, higher rates of problem behavior with high-low transitions or rich-lean transitions relative to high-high or rich-rich transitions.

The second type of direct assessment of transitions, analysis of unpredictable transitions, is an emerging procedural variation of EFA (e.g., Brewer et al., 2014; Flannery et al., 1995; Lequia et al., 2012). Similar to the high-low transition analysis, before the EFA begins, a hierarchy of preferred activities is established. To begin the EFA, researchers have then exposed participants to a reliable pattern of activities. Once low rates of problem behavior are established, the test phase of the EFA begins. During the test phase of the EFA, unlike the high-low transition analysis, after the first activity is completed, one gives instructions to start a new activity. These transitions may take several different forms: change from a preferred activity to another preferred activity, change from a preferred activity to a nonpreferred activity, change from a nonpreferred activity to a preferred activity, or change from a nonpreferred activity to another nonpreferred activity. The critical feature of the transition is the absence of a signal for an upcoming transition (e.g., specific period of time elapsing), thus making the transition unpredictable. As with the high-low or rich-to-lean transition EFA, there are no programmed consequences for problem behavior. To establish the effects of unpredictable transitions on problem behavior, test conditions with unpredictable transitions are alternated with control conditions with predictable transitions (e.g., a fixed sequence of transitions). This cycle then repeats until clear patterns emerge, specifically, higher rates of problem behavior following unpredictable transitions relative to predictable transitions.

There is at least one important consideration for conducting transition EFAs. Specifically, one must determine when to conduct a transition EFA instead of a more common EFA with multiple test and control conditions. In many cases, this could involve a relatively straightforward determination: whether problem behavior occurs across a variety of contexts when events in those contexts change. For example, during most days, adults experience many transitions, such as from leisure activities at home to work, work to meals, meals back to work, from work to home, and between leisure activities at home. Each of these transitions involves changes in a variety of features of the environment, often across functional categories. For example, transitioning from leisure activities to work may involve the termination of positive reinforcement from the leisure activities to a context with a high rate of demands. However, the work context may involve other sources of positive reinforcement, such as interaction with co-workers and interaction with specific work tasks. Problem behavior that occurs just before or immediately after the transitions, regardless of transition type, could indicate the need to directly analyze the effects of transitions on problem behavior. However, other patterns of problem behavior can make differentiating the effects of a transition more difficult. Problem behavior that occurs just before or immediately following certain transitions could indicate that *specific* EOs occasion problem behavior - only certain transitions involving certain environmental events are troublesome. In these cases, the most straightforward approach may be to conduct a standard EFA to determine if those specific environmental events (e.g., termination of positive reinforcement from leisure activities or onset of demands at work) influence problem behavior. Only if clear patterns during the standard EFA do not emerge would one then conduct a transition EFA. In either case, an empirical analysis would be the most effective method to isolate the influence of specific variables, transition-related or otherwise.

There are also two important implications of transition EFAs. First, transition EFAs may be more frequently necessary for individuals with autism than for other populations. One of the core features of autism is a preference for regularity or repetition. Much of everyday life consists of changes from one state of affairs to another. For example, in a typical day, one may contact various preferred and non-preferred activities several times, such as transitioning from sleep to breakfast, work to a break, work to a meal, and a meal to work. As individuals age, these routines may become more established. For adults with autism, such routines may be of great benefit because they help establish orderly and predictable transition patterns that accommodate their general preference for regularity and repetition. This congruity between routines and a sensitivity to regularity or repetition, however, may then produce a more pronounced effect when disruptions to transitions (e.g., unpredictable transitions) occur. That is, the strength of the EO may be enhanced because there are three disruptions: (1) interruption of the routine per se, (2) interruption of the transitions, and (3) interruption of reinforcement from those activities. In this context, a typical EFA arrangement would isolate only the effects of a single disruption – the interruption of some ongoing source of reinforcement. Treatment based on such an analysis may not be effective, because the EO produced by the disruption may remain relatively strong. Therefore, knowing that individuals with autism may be more likely to have a preference for regularity or repetition, it would be important to consider the influence of transitions whenever conducting functional assessment and EFAs of problem behavior.

A second important implication of transition EFAs is that the influence of transitions on problem behavior is applicable across a variety of EO and consequence contexts. In standard EFAs, each category of reinforcement is tested in isolation. In each condition, however, there is a programmed transition from an EO to an abolishing operation (AO). That is, an EO is present, and contingent on problem behavior, a putative reinforcer is delivered, thus momentarily presenting an AO. At the end of the presentation, the EO is again presented. One may observe responding in all test conditions and conclude that problem behavior is multiply controlled. However, because the EO-AO transition is present in all conditions, it may be the transitions themselves, rather than the effects of the EOs and AOs that are evoking problem behavior. For example, the AO-EO transition typically involves a change from continuous access to a stimulus to no access to a stimulus. Traditionally, the evocative effect is considered to be produced by the presentation of the EO. However, it is possible that the evocative effect is produced by the transition from a rich reinforcement schedule (AO) to a lean reinforcement schedule (EO). In these cases, one may be able to determine the evocative source by specifically conducting a rich-to-lean transition EFA. This EFA could involve two conditions. In one condition, the standard AO-EO transition could occur: continuous access to no access. In a second condition, a modified AO-EO transition could occur: continuous access to intermittent access (e.g., once every 10 s). Higher levels of problem behavior observed in the continuous to no access condition relative to the continuous to intermittent access condition would indicate problem behavior is evoked by the rich-to-lean transition. Likewise, equal levels of problem behavior across both conditions would indicate problem behavior is sensitive to simply removal of the putative reinforcer. Taken together, analyses of transitions, including unpredictable transitions and rich-to-lean transitions, remain an important consideration for several forms of problem behavior more prevalent in adults with ASD.

Potential Limitations of Functional Analysis

Although the EFA methodology described by Iwata et al. (1982/1994) has been shown to be a remarkably effective to assess the functional properties of behavior across a wide variety of target behaviors, settings, populations, and even species, it is not without limitations. Among potential limitations of EFA described in the literature are risk to participants and others, resources needed to conduct EFAs, the time required to produce stable outcomes, and the expertise needed to conduct procedures and interpret outcomes (c.f., Hanley, 2012; Iwata & Dozier, 2008). These potential limitations have been evaluated in the empirical literature, and several extensions and refinements of EFA methodology have been developed in attempts to resolve them.

Risk to Participants and Others

A frequently cited concern with EFA is that the process involves ongoing exposure to risk to participants and others, especially when the behavior being assessed is severe and dangerous (e.g., Deochand et al., 2020; Kahng et al., 2015; Wiskirchen et al., 2017). The primary concern is that, because a central component of EFA methodology is the presentation of antecedent conditions that are likely to increase the likelihood of problem behavior, the participant (in cases of SIB, elopement, or severe tantrums) and others (in cases of aggression or property destruction) are at elevated risk during session procedures. A related concern is that the consequences arranged for target behaviors in the A-B-C EFA model may serve to further strengthen existing problem behaviors or even condition new operant function(s) for those behaviors.

Iwata et al. (1982/1994) EFA model included several safeguards to reduce potential risks to participants and others. All participants were cleared for participation via a multiple-component process that included Human Subjects Review, medical evaluations and records reviews, establishment of session-termination criteria (e.g., sessions were terminated contingent on the occurrence of a certain number or intensity of responses), immediate medical examination when termination criteria were met, and weekly interdisciplinary team reviews. Reviews of the EFA literature indicate that these safeguards, along with others such as the use of protective equipment (e.g., blocking pads), have been widely adopted as standard components of EFA methodology. Further, although concerns about the safety of EFA seem reasonable, results of an empirical review of 99 EFAs of SIB showed that although rates of SIB were higher during EFA sessions than at other times, both rates and severity of injuries were quite low both within and outside the EFA context (Kahng et al., 2015). Thus, it seems that EFA may be, in general, a relatively safe method for analyzing operant contingencies; however, it remains the case that, when working with participants who present with severe and dangerous behaviors, measures to ensure the safety of all involved in the EFA process should be developed and assessed. Several modifications and extensions of EFA have been developed to address this concern.

Some previously discussed refinements and extensions of the EFA format were developed at least in part to reduce risks associated with the EFA process. For example, A-B manipulations avoid presenting potentially reinforcing consequences for challenging behavior and thus reduce the likelihood of inadvertently strengthening the behavior. As previously described, however, the validity of A-B manipulations may be compromised by the absence of programmed consequences, thus offsetting its potential as an alternative format for reducing risk (Smith & Iwata, 1997). However, refinements designed to reduce the amount of time required for the EFA process, such as time-limited, trial-based, or test-control formats, may reduce risk by minimizing the time in EFA and, thus, participants' exposure to events that evoke and/or reinforce problem behaviors.

Clinicians and researchers have employed protective equipment, including personal restraints, body pads, and padded walls and floors to protect participants from harm from SIB during EFAs. Unfortunately, research outcomes indicate that protective equipment can invalidate the outcomes of EFAs for SIB, decreasing or otherwise altering patterns of SIB such that interpretations were not possible (Borrero et al., 2002; Le & Smith, 2002). Interestingly, a recent investigation of the effects of therapist-worn protective equipment during EFAs of aggression showed that outcomes were identical to EFAs without protective equipment (Oropeza et al., 2018). These mixed results across topographies of challenging behavior suggest that further research will be needed to understand when and what types of protective equipment can be used without compromising EFA outcomes. Clinicians should exercise caution and discretion when integrating protective equipment into plans to reduce risk during EFA.

A promising approach to risk reduction during EFA is to arrange EFA consequences for precursor behavior, rather than severe challenging behavior (Smith & Churchill, 2002). Precursors are behaviors that reliably precede episodes of challenging behavior and may be benign (e.g., manding) or less severe forms of challenging behavior (e.g., moaning or screaming). A precursor functional analysis (PFA) involves identifying precursors via direct observation and the calculation of conditional probabilities indicating a precursor-challenging behavior sequence and arranging EFA consequences for the precursor behavior. Research has demonstrated that (a) precursors are quite common and relatively easy to identify, (b) the results of PFAs frequently correspond with EFAs of challenging behavior, and (c) typically, little or no severe challenging behavior occurs during PFA (Heath & Smith, 2019). Furthermore, responses that already exist in the repertoire and frequently precede more severe behaviors and benign forms of precursors (e.g., mands) seem ideal for use in differential reinforcement of alternative behavior (DRA; Zimmerman & Zimmerman, 1962) or functional communication (FCT; Carr & Durand, 1985; Dracobly & Smith, 2012). Increasingly, researchers and practitioners are incorporating PFAs into their EFA processes (e.g., Hanley, 2018) as a general method for reducing the risks of strengthening severe challenging behaviors and of incurring injury or property damage.

Summary and Recommendations

EFA represents the state of the science for assessing behavioral challenges with persons with autism and intellectual disabilities. The process, designed to reveal the environmental events that evoke and maintain challenging behaviors, has evolved substantially since its inception, with innovations that have improved its effectiveness, efficiency, and safety. It is recognized as best practice by the discipline and has been embraced, and even mandated through policy and legislation, by the larger culture (e.g., IDEA, 1997). That said, many practitioners report implementing only anecdotal or descriptive components of the process, with few actually conducting EFAs (e.g., Oliver et al., 2015; Petursdottir et al., 2010; Roscoe et al., 2015). Efforts should be made to encourage practicing behavior analysts to conduct a comprehensive functional assessment process for all individuals whose behavioral challenges require systematic and programmatic assessment and treatment. As the evidence presented in this chapter demonstrates, recent innovations can be incorporated into the functional assessment process to make it “doable” in virtually any treatment environment.

Within the literature on functional assessment, a trend is emerging in the development of efficient, efficacious, and socially valid EFAs. This approach focuses on using the strengths of each type of functional assessment rather than focusing on one type of assessment only (e.g., Iwata & Dozier, 2008). To begin, we would recommend practitioners gather information from caregivers about the everyday environment. This may be most effectively accomplished by conducting either an open-ended anecdotal assessment (e.g., Hanley et al., 2014) or multiple-respondent anecdotal assessments (e.g., Smith et al., 2012). Starting with anecdotal assessment has two primary benefits. First, one can develop a clear understanding of various parameters of problem behavior, including defining characteristics, relative severity, and relevant contexts. Second, one can assess agreement across caregivers about contexts in which problem behavior is more or less likely. If there are high levels of agreement across caregivers, one may be able to conduct a more efficient EFA by including only those conditions identified through anecdotal assessment as relevant. Once anecdotal assessment has been completed, practitioners should consider conducting some form of descriptive assessment. Purposes of the descriptive assessment would be to observe and refine the definition of problem behavior and to identify items, forms of attention, tasks demands, and the like, for inclusion in an EFA. Finally, once the information from anecdotal and descriptive assessments are collected and analyzed, one can develop an EFA, to empirically test the information obtained from the anecdotal and descriptive assessments. In selecting an EFA, one should consider a variety of factors, including the relative risk involved in evoking and reinforcing problem behavior (consider precursor EFA or latency-based EFA), how many conditions are necessary (consider a test-control EFA), if the EFA must occur in the everyday environment (consider trial-based EFA), and whether problem behavior occurs in context of transitions (consider unpredictable-transition FA or rich-lean transition FA). Once a specific format is selected, practitioners should also consider the general condition arrangements, including the use of isolated and synthesized contingencies and the planned number of sessions (e.g., brief EFAs). Once an EFA is started, practitioners should consider analyzing various aspects of the data in addition to session-summary values, such as within-session patterns, which may reveal orderly patterns between the onset of the EO and problem behavior, or the relation between putative precursors and problem behavior. Doing so may permit practitioners to reduce the overall EFA duration and risk of problem behavior.

With the advent of EFAs, major improvements in clinical services have been accomplished for individuals with ASD. By precisely identifying the variables that influence problem behavior, more precise, efficient, and effective interventions have been developed and validated. Advances and innovations in functional assessment have led to meaningful improvements in the quality of life for adults with ASD (e.g., Alvarez et al., 2014; Bird & Luiselli, 2000). By taking a comprehensive approach to functional assessment that involves using anecdotal and descriptive assessments to inform the design of EFAs, practitioners can improve the likelihood that they assess all potentially relevant variables while also precisely identifying the influence of those variables. Not only does this approach help ensure a valid assessment outcome, but it also allows the EFA-informed treatment to promote meaningful and enduring improvements in the quality of life for adults with ASD.

References

Adelinis, J. D., & Hagopian, L. P. (1999). The use of symmetrical "do" and "don't" requests to interrupt ongoing activities. *Journal of Applied Behavior Analysis, 32*(4), 519–523. https://doi.org/10.1901/jaba.1999.32-519

Álvarez, J. P., Call, N. A., & Lomas Mevers, J. E. (2014). Increasing the social validity of function-based treatments for problem behavior. *Acta de Investigación Psicológica, 4*, 1683–1700. https://doi.org/10.1016/S2007-4719(14)70974-3

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Author.

Anderson, C. M., & Long, E. S. (2002). Use of a structured descriptive assessment methodology to identify variables affecting problem behavior. *Journal of Applied Behavior Analysis, 35*(2), 137–154. https://doi.org/10.1901/jaba.2002.35-137

Ayllon, T., & Michael, J. (1959). The psychiatric nurse as a behavioral engineer. *Journal of the Experimental Analysis of Behavior, 2*(4), 323–334. https://doi.org/10.1901/jeab.1959.2-323

Beavers, G. A., Iwata, B. A., & Lerman, D. C. (2013). Thirty years of research on the functional analysis of problem behavior. *Journal of Applied Behavior Analysis, 46*(1), 1–21. https://doi.org/10.1002/jaba.30

Berkson, G., & Mason, W. A. (1964). Stereotyped behaviors of chimpanzees: Relation to general arousal and alternative activities. *Perceptual and Motor Skills, 19*(2), 635–652. https://doi.org/10.2466/pms.1964.19.2.635

Bird, F. L., & Luiselli, J. K. (2000). Positive behavioral support of adults with developmental disabilities: assessment of long-term adjustment and habilitation following restrictive treatment histories. *Journal of*

Behavior Therapy and Experimental Psychiatry, 31, 5–19.

Bloom, S. E., Iwata, B. A., Fritz, J. N., Roscoe, E. M., & Carreau, A. B. (2011). Classroom application of a trial-based functional analysis. *Journal of Applied Behavior Analysis, 44*(1), 19–31. https://doi.org/10.1901/jaba.2011.44-19

Borrero, C. S., & Borrero, J. C. (2008). Descriptive and experimental analyses of potential precursors to problem behavior. *Journal of Applied Behavior Analysis, 41*(1), 83–96. https://doi.org/10.1901/jaba.2008.41-83

Borrero, J. C., Vollmer, T. R., Wright, C. S., Lerman, D. C., & Kelley, M. E. (2002). Further evaluation of the role of protective equipment in the functional analysis of self-injurious behavior. *Journal of Applied Behavior Analysis, 35*(1), 69–72. https://doi.org/10.1901/jaba.2002.35-69

Brewer, A., Strickland-Cohen, K., Dotson, W., & Williams, D. (2014). Advance notice for transition-related problem behavior: Practice guidelines. *Behavior Analysis in Practice, 7*, 117–125. https://doi.org/10.1007/s40617-014-0014-3

Broussard, C. D., & Northup, J. (1995). An approach to functional assessment and analysis of disruptive behavior in regular education classrooms. *School Psychology Quarterly, 10*(2), 151–164. https://doi.org/10.1037/h0088301

Carr, E. G. (1977). The motivation of self-injurious behavior: A review of some hypotheses. *Psychological Bulletin, 84*(4), 800–816. https://doi.org/10.1037/0033-2909.84.4.800

Carr, E. G., & Durand, V. M. (1985). Reducing behavior problems through functional communication training. *Journal of Applied Behavior Analysis, 18*(2), 111–126. https://doi.org/10.1901/jaba.1985.18-111

Carr, E. G., Newsom, C. D., & Binkoff, J. A. (1976). Stimulus control of self-destructive behavior in a psychotic child. *Journal of Abnormal Child Psychology, 4*, 139–153. https://doi.org/10.1007/BF00916518

Carr, J. E., Taylor, C. C., Wallander, R. J., & Reiss, M. L. (1996). A functional-analytic approach to the diagnosis of a transient tic disorder. *Journal of Behavior Therapy and Experimental Psychiatry, 27*(3), 291–297. https://doi.org/10.1016/s0005-7916(96)00025-0

Castillo, M. I., Clark, D. R., Schaller, E. A., Donaldson, J. M., DeLeon, I. G., & Kahng, S. (2018). Descriptive assessment of problem behavior during transitions of children with intellectual and developmental disabilities. *Journal of Applied Behavior Analysis, 51*(1), 99–117. https://doi.org/10.1002/jaba.430

Cautela, J. R., & Baron, M. G. (1977). Covert conditioning: A theoretical analysis. *Behavior Modification, 1*(3), 351–368. https://doi.org/10.1177/014544557713004

Coffey, A. L., Shawler, L. A., Jessel, J., Nye, M. L., Bain, T. A., & Dorsey, M. (2020). Interview-Informed Synthesized Contingency Analysis (IISCA): Novel interpretations and future directions. *Behavior Analysis in Practice, 13*, 217–225. https://doi.org/10.1007/s40617-019-00348-3

Conners, J., Iwata, B. A., Kahng, S. W., Hanley, G. P., Worsdell, A. S., & Thompson, R. H. (2000). Differential responding in the presence and absence of discriminative stimuli during multielement functional analyses. *Journal of Applied Behavior Analysis, 33*, 299–308. https://doi.org/10.1901/jaba.2000.33-299

Corte, H. E., Wolf, M. M., & Locke, B. J. (1971). A comparison of procedures for eliminating self-injurious behavior of retarded adolescents. *Journal of Applied Behavior Analysis, 4*(3), 201–213. https://doi.org/10.1901/jaba.1971.4-201

de Vries, M., & Geurts, H. (2015). Influence of autism traits and executive functioning on quality of life in children with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*, 2734–2743. https://doi.org/10.1007/s10803-015-2438-1

Deochand, N., Eldridge, R. R., & Peterson, S. M. (2020). Toward the development of a functional analysis risk assessment decision tool. *Behavior Analysis in Practice, 13*, 978–990. https://doi.org/10.1007/s40617-020-00433-y

Derby, K. M., Wacker, D. P., Sasso, G., Steege, M., Northup, J., Cigrand, K., & Asmus, J. (1992). Brief functional assessment techniques to evaluate aberrant behavior in an outpatient setting: a summary of 79 cases. *Journal of Applied Behavior Analysis, 25*(3), 713–721. https://doi.org/10.1901/jaba.1992.25-713

Dracobly, J. D., & Smith, R. G. (2012). Progressing from identification and functional analysis of precursor behavior to treatment of self-injurious behavior. *Journal of Applied Behavior Analysis, 45*(2), 361–374. https://doi.org/10.1901/jaba.2012.45-361

Dracobly, J. D., Dozier, C. L., Briggs, A. M., & Juanico, J. F. (2018). Reliability and validity of indirect assessment outcomes: Experts versus caregivers. *Learning and Motivation, 62*, 77–90. https://doi.org/10.1016/j.lmot.2017.02.007

Durand, V. M., & Crimmins, D. B. (1988). Identifying the variables maintaining self-injurious behavior. *Journal of Autism and Developmental Disorders, 18*, 99–117. https://doi.org/10.1007/BF02211821

Falcomata, T. S., Roane, H. S., Muething, C. S., Stephenson, K. M., & Ing, A. D. (2012). Functional communication training and chained schedules of reinforcement to treat challenging behavior maintained by terminations of activity interruptions. *Behavior Modification, 36*(5), 630–649. https://doi.org/10.1177/0145445511433821

Favell, J. E., McGimsey, J. F., & Schell, R. M. (1982). Treatment of self-injury by providing alternate sensory activities. *Analysis and Intervention in Developmental Disabilities, 2*(1), 83–104. https://doi.org/10.1016/0270-4684(82)90007-6

Ferster, C. B. (1961). Positive reinforcement and behavioral deficits of young children. *Child Development, 32*(3), 437–456. https://doi.org/10.2307/1126210

Fisher, W. W., Adelinis, J. D., Thompson, R. H., Worsdell, A. S., & Zarcone, J. R. (1998). Functional analysis and treatment of destructive behavior maintained by termination of "don't" (and symmetrical "do") requests.

Journal of Applied Behavior Analysis, 31(3), 339–356. https://doi.org/10.1901/jaba.1998.31-339

Fisher, W. W., Greer, B. D., Romani, P. W., Zangrillo, A. N., & Owen, T. M. (2016). Comparisons of synthesized and individual reinforcement contingencies during functional analysis. *Journal of Applied Behavior Analysis, 49*(3), 596–616. https://doi.org/10.1002/jaba.314

Flannery, K. B., O'Neill, R. E., & Horner, R. H. (1995). Including predictability in functional assessment and individual program development. *Education and Treatment of Children, 18*(4), 499–509.

Fox, P., & Emerson, E. (2001). Socially valid outcomes of intervention for people with MR and challenging behavior: Views of different stakeholders. *Journal of Positive Behavior Interventions, 3*(3), 183–189. https://doi.org/10.1177/109830070100300306

Garcia, D., & Smith, R. G. (1999). Using analog baselines to assess the effects of naltrexone on self-injurious behavior. *Research in Developmental Disabilities, 20*(1), 1–21. https://doi.org/10.1016/s0891-4222(98)00028-6

Gardner, A. W., Spencer, T. D., Boelter, E. W., DuBard, M., & Jennett, H. K. (2012). A systematic review of brief functional analysis methodology with typically developing children. *Education and Treatment of Children*, *35*(2), 313–332. http://www.jstor.org/stable/42900159

Gunter, P. L., Denny, R. K., Jack, S. L., Shores, R. E., & Nelson, C. M. (1993). Aversive stimuli in academic interactions between students with serious emotional disturbance and their teachers. *Behavioral Disorders, 18*(4), 265–274. https://doi.org/10.1177/019874299301800405

Hagopian, L. P., Toole, L. M., Long, E. S., Bowman, L. G., & Lieving, G. A. (2004). A comparison of dense-to-lean and fixed lean schedules of alternative reinforcement and extinction. *Journal of Applied Behavior Analysis, 37*, 323–338. https://doi.org/10.1901/jaba.2004.37-323

Hagopian, L. P., Bruzek, J. L., Bowman, L. G., & Jennett, H. K. (2007). Assessment and treatment of problem behavior occasioned by interruption of free-operant behavior. *Journal of Applied Behavior Analysis, 40*(1), 89–103. https://doi.org/10.1901/jaba.2007.63-05

Hagopian, L. P., Rooker, G. W., & Zarcone, J. R. (2015). Delineating subtypes of self-injurious behavior maintained by automatic reinforcement. *Journal of Applied Behavior Analysis, 48*(3), 523–543. https://doi.org/10.1002/jaba.236

Hagopian, L. P., Rooker, G. W., Zarcone, J. R., Bonner, A. C., & Arevalo, A. R. (2017). Further analysis of subtypes of automatically reinforced SIB: A replication and quantitative analysis of published datasets. *Journal of Applied Behavior Analysis, 50*(1), 48–66. https://doi.org/10.1002/jaba.368

Hammond, J. L., Iwata, B. A., Rooker, G. W., Fritz, J. N., & Bloom, S. E. (2013). Effects of fixed versus random condition sequencing during multielement functional analyses. *Journal of Applied Behavior Analysis, 46*(1), 22–30. https://doi.org/10.1002/jaba.7

Hanley, G. P. (2012). Functional assessment of problem behavior: Dispelling myths, overcoming implementation obstacles, and developing new lore. *Behavior Analysis in Practice, 5*, 54–72. https://doi.org/10.1007/BF03391818

Hanley, G. P. (2018, August). *Implementation assistance*. Practical Functional Assessment. https://practicalfunctionalassessment.com/implementation-materials/

Hanley, G. P., Iwata, B. A., & McCord, B. E. (2003). Functional analysis of problem behavior: A review. *Journal of Applied Behavior Analysis, 36*(2), 147–185. https://doi.org/10.1901/jaba.2003.36-147

Hanley, G. P., Jin, C. S., Vanselow, N. R., & Hanratty, L. A. (2014). Producing meaningful improvements in problem behavior of children with autism via synthesized analyses and treatments. *Journal of Applied Behavior Analysis, 47*(1), 16–36. https://doi.org/10.1002/jaba.106

Heath, H., Jr., & Smith, R. G. (2019). Precursor behavior and functional analysis: A brief review. *Journal of Applied Behavior Analysis, 52*(3), 804–810. https://doi.org/10.1002/jaba.571

Henry, J. E., Kelley, M. E., LaRue, R. H., Kettering, T. L., Gadaire, D. M., & Sloman, K. N. (2021). Integration of experimental functional analysis procedural advancements: Progressing from brief to extended experimental analyses. *Journal of Applied Behavior Analysis, 54*(3), 1045–1061. https://doi.org/10.1002/jaba.841

Hong, E., Dixon, D. R., Stevens, E., Burns, C. O., & Linstead, E. (2018). Topography and function of problem behavior in individuals with autism spectrum disorder. *Advances in Neurodevelopmental Disorders, 2*, 206–215. https://doi.org/10.1007/s41252-018-0063-7

Individuals with Disability Education Act Amendments of 1997 [IDEA]. (1997). Retrieved from https://www.congress.gov/105/plaws/publ17/PLAW-105publ17.pdf

Iwata, B. A., & Dozier, C. L. (2008). Clinical application of functional analysis methodology. *Behavior Analysis in Practice, 1*, 3–9. https://doi.org/10.1007/BF03391714

Iwata, B. A., Dorsey, M. F., Slifer, K. J., Bauman, K. E., & Richman, G. S. (1982). Toward a functional analysis of self-injury. *Journal of Applied Behavior Analysis, 27*(2), 197–209. https://doi.org/10.1901/jaba.1994.27-197

Iwata, B. A., Pace, G. M., Dorsey, M. F., Zarcone, J. R., Vollmer, T. R., Smith, R. G., Rodgers, T. A., Lerman, D. C., Shore, B. A., & Mazalesk, J. L. (1994). The functions of self-injurious behavior: An experimental-epidemiological analysis. *Journal of Applied Behavior Analysis, 27*(2), 215–240. https://doi.org/10.1901/jaba.1994.27-215

Iwata, B. A., Deleon, I. G., & Roscoe, E. M. (2013). Reliability and validity of the functional analysis screening tool. *Journal of Applied Behavior Analysis, 46*(1), 271–284. https://doi.org/10.1002/jaba.31

Jessel, J., Hanley, G. P., & Ghaemmaghami, M. (2016). A translational evaluation of transitions. *Journal of Applied Behavior Analysis, 49*(2), 359–376. https://doi.org/10.1002/jaba.283

Jones, F. H., Simmons, J. Q., & Frankel, F. (1974). An extinction procedure for eliminating self-destructive behavior in a 9-year-old autistic girl. *Journal of Autism and Childhood Schizophrenia, 4*, 241–250. https://doi.org/10.1007/BF02115230

Kahng, S., Iwata, B. A., Fischer, S. M., Page, T. J., Treadwell, K. R., Williams, D. E., & Smith, R. G. (1998). Temporal distributions of problem behavior based on scatter plot analysis. *Journal of Applied Behavior Analysis, 31*(4), 593–604. https://doi.org/10.1901/jaba.1998.31-593

Kahng, S., Hausman, N. L., Fisher, A. B., Donaldson, J. M., Cox, J. R., Lugo, M., & Wiskow, K. M. (2015). The safety of functional analyses of self-injurious behavior. *Journal of Applied Behavior Analysis, 48*(1), 107–114. https://doi.org/10.1002/jaba.168

Kodak, T., Fisher, W. W., Paden, A., & Dickes, N. (2013). Evaluation of the utility of a discrete-trial functional analysis in early intervention classrooms. *Journal of Applied Behavior Analysis, 46*(1), 301–306. https://doi.org/10.1002/jaba.2

Koritsas, S., & Iacono, T. (2013). Psychometric comparison of the Motivation Assessment Scale (MAS) and the Questions About Behavioral Function (QABF). *Journal of Intellectual Disability Research, 57*(8), 747–757. https://doi.org/10.1111/jir.12022

Lalli, J. S., Casey, S. D., & Kates, K. (1997). Noncontingent reinforcement as treatment for severe problem behavior: Some procedural variations. *Journal of Applied Behavior Analysis, 30*(1), 127–137. https://doi.org/10.1901/jaba.1997.30-127

Lambert, J. M., Bloom, S. E., Kunnavatana, S. S., Collins, S. D., & Clay, C. J. (2013). Training residential staff to conduct trial-based functional analyses. *Journal of Applied Behavior Analysis, 46*(1), 296–300. https://doi.org/10.1002/jaba.17

Le, D. D., & Smith, R. G. (2002). Functional analysis of self-injury with and without protective equipment. *Journal of Developmental and Physical Disabilities, 14*(3), 277–290. https://doi.org/10.1023/A:1016028522569

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 50*, 172–183. https://doi.org/10.1111/j.1365-2788.2005.00732.x

Lequia, J., Machalicek, W., & Rispoli, M. J. (2012). Effects of activity schedules on challenging behavior exhibited in children with autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders, 6*(1), 480–492. https://doi.org/10.1016/j.rasd.2011.07.008

Lerman, D. C., & Iwata, B. A. (1993). Descriptive and experimental analyses of variables maintaining self-injurious behavior. *Journal of Applied Behavior Analysis, 26*(3), 293–319. https://doi.org/10.1901/jaba.1993.26-293

Lovaas, O. I., & Simmons, J. Q. (1969). Manipulation of self-destruction in three retarded children. *Journal of Applied Behavior Analysis, 2*(3), 143–157. https://doi.org/10.1901/jaba.1969.2-143

Lovaas, O. I., Freitag, G., Gold, V., & Kassorla, I. C. (1965). Experimental studies in childhood schizophrenia: Analysis of self-destructive behavior. *Journal of Experimental Child Psychology, 2*(1), 67–84. https://doi.org/10.1016/0022-0965(65)90016-0

Martens, B. K., Digennaro, F. D., Reed, D. D., Szczech, F. M., & Rosenthal, B. D. (2008). Contingency space analysis: an alternative method for identifying contingent relations from observational data. *Journal of Applied Behavior Analysis, 41*(1), 69–81. https://doi.org/10.1901/jaba.2008.41-69

Matson, J. L., & Vollmer, T. (1995). *Questions About Behavioral Function (QABF)*. Disability Consultants.

McCord, B. E., Thomson, R. J., & Iwata, B. A. (2001). Functional analysis and treatment of self-injury associated with transitions. *Journal of Applied Behavior Analysis, 34*, 195–210. https://doi.org/10.1901/jaba.2001.34-195

Neidert, P. L., Iwata, B. A., Dempsey, C. M., & Thomason-Sassi, J. L. (2013). Latency of response during the functional analysis of elopement. *Journal of Applied Behavior Analysis, 46*(1), 312–316. https://doi.org/10.1002/jaba.11

Newton, J. T., & Sturmey, P. (1991). The Motivation Assessment Scale: Inter-rater reliability and internal consistency in a British sample. *Journal of Mental Deficiency Research, 35*(5), 472–474. https://doi.org/10.1111/j.1365-2788.1991.tb00429.x

Northup, J., Wacker, D., Sasso, G., Steege, M., Cigrand, K., Cook, J., & DeRaad, A. (1991). A brief functional analysis of aggressive and alternative behavior in an outclinic setting. *Journal of Applied Behavior Analysis, 24*(3), 509–522. https://doi.org/10.1901/jaba.1991.24-509

Oliver, A. C., Pratt, L. A., & Normand, M. P. (2015). A survey of functional behavior assessment methods used by behavior analysts in practice. *Journal of Applied Behavior Analysis, 48*, 817–829. https://doi.org/10.1002/jaba.256

Oropeza, M. E., Fritz, J. N., Nissen, M. A., Terrell, A. S., & Phillips, L. A. (2018). Effects of therapist-worn protective equipment during functional analysis of aggression. *Journal of Applied Behavior Analysis, 5*(3), 681–686. https://doi.org/10.1002/jaba.457

Paclawskyj T. R, Matson J. L, Rush K. S, Smalls Y, Vollmer T. R. (2001). Assessment of the convergent validity of the Questions about Behavioral Function (QABF) Scale with analogue functional analysis and the Motivation Assessment Scale. *Journal of Intellectual Disability Research, 45*, 484–494. https://doi.org/10.1046/j.1365–2788.2001.00364.x

Pelios, L., Morren, J., Tesch, D., & Axelrod, S. (1999). The impact of functional analysis methodology on treatment choice for self-injurious and aggressive behavior. *Journal of Applied Behavior Analysis, 32*, 185–195.

Pence, S. T., Roscoe, E. M., Bourret, J. C., & Ahearn, W. H. (2009). Relative contributions of three descriptive methods: Implications for behavioral assessment. *Journal of Applied Behavior Analysis, 42*(2), 425–446. https://doi.org/10.1901/jaba.2009.42-425

Peterson, R. F., & Peterson, L. R. (1968). The use of positive reinforcement in the control of self-destructive behavior in a retarded boy. *Journal of Experimental Child Psychology, 6*(3), 351–360. https://doi.org/10.1016/0022-0965(68)90116-1

Petursdottir, A. I., Esch, J. W., Sautter, R. A., & Stewart, K. K. (2010). Characteristics and hypothesized functions of challenging behavior in a community-based sample. *Education and Training in Autism and Developmental Disabilities*, *45*, 81–93. http://www.jstor.org/stable/23880152

Pyles, D. A., Muniz, K., Cade, A., & Silva, R. (1997). A behavioral diagnostic paradigm for integrating behavior-analytic and psychopharmacological interventions for people with a dual diagnosis. *Research in Developmental Disabilities, 18*(3), 185–214. https://doi.org/10.1016/S0891-4222(97)00003-6

Reimers, T. M., Wacker, D. P., Cooper, L. J., Sasso, G. M., Berg, W. K., & Steege, M. W. (1993). Assessing the functional properties of noncompliant behavior in an outpatient setting. *Child and Family Behavior Therapy, 15*(3), 1–15. https://doi.org/10.1300/J019v15n03_01

Richman, D. M., Barnard-Brak, L., Grubb, L., Bosch, A., & Abby, L. (2015). Meta-analysis of noncontingent reinforcement effects on problem behavior. *Journal of Applied Behavior Analysis, 48*(1), 131–152. https://doi.org/10.1002/jaba.189

Rincover, A., & Devaney, J. (1982). The application of sensory extinction procedures to self-injury. *Analysis and Intervention in Developmental Disabilities, 2*(1), 67–81. https://doi.org/10.1016/0270-4684(82)90006-4

Ringdahl, J. E., & Sellers, J. A. (2000). The effects of different adults as therapists during functional analyses. *Journal of Applied Behavior Analysis, 33*(2), 247–250. https://doi.org/10.1901/jaba.2000.33-247

Romanczyk, R. G., & Goren, E. R. (1975). Severe self-injurious behavior: The problem of clinical control. *Journal of Consulting and Clinical Psychology, 43*(5), 730–739. https://doi.org/10.1037/0022-006X.43.5.730

Rooker, G. W., Bonner, A. C., Dillon, C. M., & Zarcone, J. R. (2018). Behavioral treatment of automatically reinforced SIB: 1982–2015. *Journal of Applied Behavior Analysis, 51*(4), 974–997. https://doi.org/10.1002/jaba.492

Roscoe, E. M., Iwata, B. A., & Goh, H. L. (1998). A comparison of noncontingent reinforcement and sensory extinction as treatments for self-injurious behavior. *Journal of Applied Behavior Analysis, 31*(4), 635–646. https://doi.org/10.1901/jaba.1998.31-635

Roscoe, E. M., Phillips, K. M., Kelly, M. A., Farber, R., & Dube, W. V. (2015). A statewide survey assessing practitioners' use and perceived utility of functional assessment. *Journal of Applied Behavior Analysis, 48*, 830–844. https://doi.org/10.1002/jaba.259

Sabuncuoglu, O., Irmak, M. Y., Demir, N. U., Murat, D., Tumba, C., & Yilmaz, Y. (2015). Sibling death after being thrown from window by brother with autism: Defenestration, an emerging high-risk behavior. *Case Reports in Psychiatry, 2015*, 463694. https://doi.org/10.1155/2015/463694

Sigafoos, J., & Saggers, E. (1995). A discrete-trial approach to the functional analysis of aggressive behaviour in two boys with autism. *Australia & New Zealand Journal of Developmental Disabilities, 20*(4), 287–297. https://doi.org/10.1080/07263869500035621

Sigafoos, J., Kerr, M., & Roberts, D. (1994). Interrater reliability of the Motivation Assessment Scale: Failure to replicate with aggressive behavior. *Research in Developmental Disabilities, 15*(5), 333–342. https://doi.org/10.1016/0891-4222(94)90020-5

Smith, R. G., & Churchill, R. M. (2002). Identification of environmental determinants of behavior disorders through functional analysis of precursor behaviors. *Journal of Applied Behavior Analysis, 35*(2), 125–136. https://doi.org/10.1901/jaba.2002.35-125

Smith, R. G., & Iwata, B. A. (1997). Antecedent influences on behavior disorders. *Journal of Applied Behavior Analysis, 30*(2), 343–375. https://doi.org/10.1901/jaba.1997.30-343

Smith, C. M., Smith, R. G., Dracobly, J. D., & Pace, A. P. (2012). Multiple-respondent anecdotal assessments: An analysis of interrater agreement and correspondence with analogue assessment outcomes. *Journal of Applied Behavior Analysis, 45*(4), 779–795. https://doi.org/10.1901/jaba.2012.45-779

Smolev, S. R. (1971). Use of operant techniques for the modification of self-injurious behavior. *American Journal of Mental Deficiency, 76*(3), 295–305.

Sturmey, P. (1994). Assessing the functions of aberrant behaviors: A review of psychometric instruments. *Journal of Autism and Developmental Disorders, 24*(3), 293–304. https://doi.org/10.1007/BF02172228

Thomason-Sassi, J. L., Iwata, B. A., Neidert, P. L., & Roscoe, E. M. (2011). Response latency as an index of response strength during functional analyses of problem behavior. *Journal of Applied Behavior Analysis, 44*(1), 51–67. https://doi.org/10.1901/jaba.2011.44-51

Thomason-Sassi, J. L., Iwata, B. A., & Fritz, J. N. (2013). Therapist and setting influences on functional analysis outcomes. *Journal of Applied Behavior Analysis, 46*(1), 79–87. https://doi.org/10.1002/jaba.28

Thompson, R. H., & Iwata, B. A. (2001). A descriptive analysis of social consequences following problem behavior. *Journal of Applied Behavior Analysis, 34*(2), 169–178. https://doi.org/10.1901/jaba.2001.34-169

Thompson, R. H., & Iwata, B. A. (2007). A comparison of outcomes from descriptive and functional analyses of problem behavior. *Journal of Applied Behavior Analysis, 40*(2), 333–338. https://doi.org/10.1901/jaba.2007.56-06

Tiger, J. H., Fisher, W. W., Toussaint, K. A., & Kodak, T. (2009). Progressing from initially ambiguous functional analyses: Three case examples. *Research in Developmental Disabilities, 30*(5), 910–926. https://doi.org/10.1016/j.ridd.2009.01.005

Touchette, P. E., MacDonald, R. F., & Langer, S. N. (1985). A scatter plot for identifying stimulus control of problem behavior. *Journal of Applied Behavior Analysis, 18*(4), 343–351. https://doi.org/10.1901/jaba.1985.18-343

Umbreit, J. (1996). Functional analysis of disruptive behavior in an inclusive classroom. *Journal of Early Intervention, 20*(1), 18–29. https://doi.org/10.1177/105381519602000104

Vollmer, T. R., Marcus, B. A., Ringdahl, J. E., & Roane, H. S. (1995). Progressing from brief assessments to extended experimental analyses in the evaluation of aberrant behavior. *Journal of Applied Behavior Analysis, 28*(4), 561–576. https://doi.org/10.1901/jaba.1995.28-561

Vollmer, T. R., Northup, J., Ringdahl, J. E., Leblanc, L. A., & Chauvin, T. M. (1996). Functional analysis of severe tantrums displayed by children with language delays: An outclinic assessment. *Behavior Modification, 20*(1), 97–115. https://doi.org/10.1177/01454455960201005

Vollmer, T. R., Borrero, J. C., Wright, C. S., Van Camp, C., & Lalli, J. S. (2001). Identifying possible contingencies during descriptive analyses of severe behavior disorders. *Journal of Applied Behavior Analysis, 34*(3), 269–287. https://doi.org/10.1901/jaba.2001.34-269

Wacker, D. P., Lee, J. F., Padilla Dalmau, Y. C., Kopelman, T. G., Lindgren, S. D., Kuhle, J., Pelzel, K. E., Dyson, S., Schieltz, K. M., & Waldron, D. B. (2013). Conducting functional communication training via telehealth to reduce the problem behavior of young children with autism. *Journal of Developmental and Physical Disabilities, 25*, 35–48. https://doi.org/10.1007/s10882-012-9314-0

Walsh, C. E., Mulder, E., & Tudor, M. E. (2013). Predictors of parent stress in a sample of children with ASD: Pain, problem behavior, and parental coping. *Research in Autism Spectrum Disorders, 7*(2), 256–264. https://doi.org/10.1016/j.rasd.2012.08.010

Watson, T. S., & Sterling, H. E. (1998). Brief functional analysis and treatment of a vocal tic. *Journal of Applied Behavior Analysis, 31*(3), 471–474. https://doi.org/10.1901/jaba.1998.31-471

Weiher, R. G., & Harman, R. E. (1975). The use of omission training to reduce self-injurious behavior in a retarded child. *Behavior Therapy, 6*(2), 261–268. https://doi.org/10.1016/S0005-7894(75)80151-1

Weiss, J. A., Cappadocia, M. C., MacMullin, J. A., Viecili, M., & Lunsky, Y. (2012). The impact of child problem behaviors of children with ASD on parent mental health: The mediating role of acceptance and empowerment. *Autism, 16*(3), 261–274. https://doi.org/10.1177/1362361311422708

Wiskirchen, R. R., Deochand, N., & Peterson, S. M. (2017). Functional analysis: A need for clinical decision support tools to weigh risks and benefits. *Behavior Analysis: Research and Practice, 17*, 325–333. https://doi.org/10.1037/bar0000088

Wolf, M., Risley, T., Johnston, M., Harris, F., & Allen, E. (1967). Application of operant conditioning procedures to the behavior problems of an autistic child: A follow-up and extension. *Behavior Research and Therapy, 5*(2), 103–111. https://doi.org/10.1016/0005-7967(67)90004-6

Zarcone, J. R., Rodgers, T. A., Iwata, B. A., Rourke, D. A., & Dorsey, M. F. (1991). Reliability analysis of the Motivation Assessment Scale: A failure to replicate. *Research in Developmental Disabilities, 12*(4), 349–360. https://doi.org/10.1016/0891-4222(91)90031-m

Zimmerman, E. H., & Zimmerman, J. (1962). The alteration of behavior in a special classroom situation. *Journal of the Experimental Analysis of Behavior, 5*(1), 59–60. https://doi.org/10.1901/jeab.1962.5-59

17

Pharmacological Interventions for Adults with Autism Spectrum Disorder

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Autism spectrum disorder (ASD) is a heterogeneous neurodevelopmental disorder characterized by restrictive, repetitive patterns of behavior and deficits in social communication and social interaction (American Psychiatric Association, 2013). ASD is common – data from the Autism and Developmental Disabilities Monitoring Network indicated that in 2016, 1 in 54 children met the criteria for being diagnosed with ASD (Maenner et al., 2020). It is also a persistent, lifelong disorder. As with everyone, the behavior of people with autism changes over the course of their lives, so do the challenges they face.

Physicians often prescribe psychotropic drugs – medications intended to improve mood, cognitive status, or overt behavior – to help people with ASD meet these challenges. Two medications, the antipsychotics aripiprazole (Abilify) and risperidone (Risperdal), are approved by the US Food and Drug Administration (FDA) for treating "irritability" in young people (6–17 years of age) with ASD and are widely used for this purpose. Other psychotropic medications are also commonly prescribed for members of this population. The effectiveness of psychotropic medications as a treatment for young people with ASD has generated substantial interest among researchers and scholars. As an example, VanDerwall et al. (2021) recently reviewed the effects of aripiprazole in people with ASD. They found 14 relevant studies and 12 review articles that summarized the research findings.

Although VanDerwall et al. (2021) included studies regardless of the age of participants, the oldest participant in any study was 22 years of age, and most involved only children and adolescents. Given the absence of relevant information, VanDerwall and colleagues emphasized that it is impossible to determine whether age modulates the effects of aripiprazole in people with ASD or to reach data-based conclusions about the effects of the drug in older members of this population.

The tendency of researchers to not include adult participants with ASD in drug research is not limited to studies of aripiprazole. Poling et al. (2017) recently summarized the effects of psychotropic drugs in people with ASD. In describing the limitations of the published research, they wrote: "The effects of psychotropic drugs in people [with ASD] past young adulthood remain to be determined" (Poling et al., 2017, p. 464). In making this point, they referred to a review by Dove et al. (2012), who examined eight studies that examined the effects of psychotropic medications in 13- to 30-year-old people with ASD. Four of the studies were of fair quality and

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four were of low quality. The scarcity of studies and the lack of good quality studies indicate a clear need for more, and better, drug research involving adults with ASD, because members of this population often receive psychotropic drugs.

Given the relative scarcity of research examining the effects of psychotropic drugs in adults with ASD, it is no surprise that many reviews of the psychopharmacology of ASD pay little or no attention to adults. Table 17.1 lists 28 reviews published since 2010 with the drug(s), target symptoms, and age range considered. Half of them considered research involving adults. None of their authors, except for VanDerwall et al. (2021), suggested that age influences the effects of psychotropic drugs in people with ASD.

It may well be that results obtained with children and adolescents with ASD generalize to older people. Even if this is so, the available research has serious limitations. Beginning with Greiner's (1958) plea for good quality studies, researchers have pointed out that drug studies involving people with developmental disabilities, including ASD, often are poorly controlled and of limited scope (e.g., Gadow & Poling, 1986; Matson et al., 2000; Sprague & Werry, 1971).

In Poling et al.'s (2017) review of psychotropic medications for people with ASD, they described several limitations of the available research and explained the significance of these limitations. Those limitations are relevant to what is known about drug effects in *all* people with ASD, including adults. We list them below, with occasional comments pointing out particular relevance to adults. Please see Poling et al. for detailed, general discussion.

1. *There are no long-term studies of the value or adverse effects of drug treatments*. By the time a person with ASD is 50 years of age, that individual may well have received a psychotropic drug every day for three or four decades, but nothing is known about the costs and benefits of such extended exposure.
2. *The probability of gender differences in drug effects has been largely ignored.* It is interesting that Jobski et al. (2017) found that the sex of adults with ASD did not predict overall psychotropic drug use, but there was a difference in the kinds of drugs most often prescribed for men and women. Men more often received antipsychotics and medications identified to treat attention-deficit/hyperactivity disorder (ADHD) than women, whereas women were more likely to be treated with antidepressants and anxiolytics than were men. The factors responsible for this difference merit investigation.
3. *Very little is known about the effects of polypharmacy*.
4. *Drug treatments are rarely compared to other treatments*. Few drug versus drug comparisons have appeared. Comparisons of drug versus nondrug treatments are even rarer.
5. *The effects of combinations of psychotropic medications and non-pharmacological interventions are largely unknown*.
6. *Measures of desired and side effects are often weak.* As evidence, Brugha et al. (2015) reviewed studies that supposedly examined the effects of various interventions on the core symptoms of ASD in adults, including 19 drug studies. They found that measures were inconsistent and often inappropriate, noting: "Use of outcome measures varied with frequent use of non-standardized assessment, very little use of measures designed specifically for individuals with ASD or of instruments focusing on core ASD deficits, such as communication or social functioning" (Brugha et al., 2015, p. 99).
7. *Data analysis is often weak.* In many studies with adults, the clinical significance of drug-induced changes is not considered. Rather, statistical significance revealed via an inferential statistic is the sole evidence of the supposed value of the medication.
8. *The possibility of bias affecting findings is high in many studies.* Research funded by the manufacturers of psychotropic drugs raises this possibility.
9. *Predictors of positive responses to drugs have not been isolated.* When data for individual adults with ASD are reported, there are individual differences in the effects of a medication, but the variables responsible for the

Table 17.1 Published reviews of drug effects (since 2010)

Published reviews	Drug or drug classes	Demographic[a]	Target symptoms[b]
Aman et al. (2014)	Atomoxetine	Children (19 years old or younger)	Hyperactivity
Baribeau and Anagnostou (2013)	Multiple drug agents	Children and adults	Social communication
Bartram et al. (2019)	Aripiprazole	All ages	Irritability
Ching and Pringsheim (2012)	Aripiprazole	Children	Behavioral problems
Dove et al. (2012)	Multiple drug classes	Adolescents and young adults (13–30 years old)	Core symptoms of ASD and comorbid symptoms
Doyle and McDougle (2012)	SRIs and antipsychotics	Children and adults	Core symptoms of ASD and comorbid symptoms
Elbe and Lalani (2012)	Antipsychotics and miscellaneous drug agents	Children and adults	Irritability
Farmer and Aman (2011)	Aripiprazole	Children	Irritability
Frye et al. (2013)	Multiple drug classes	Children	Seizures
Fung et al. (2012)	Aripiprazole	Children (4–18 years old)	Sensory abnormalities
Ghanizadeh (2012)	Atomoxetine	Children and adults	ADHD symptoms
Ghanizadeh et al. (2015)	Aripiprazole	Children and adolescents	Irritability
Guenole et al. (2011)	Melatonin	Children and adolescents	Sleep disturbance
Hirsch and Pringsheim (2016)	Aripiprazole	Children and adults	Behavioral problems
Jenabi et al. (2019)	Multiple drug classes	Children	Sleep disorders
Jobski et al. (2017)	Multiple drug classes	Children and adults	Non-core symptoms of ASD and psychiatric comorbidity
Krishnaswami et al. (2011)	Secretin	Children (12 years old or younger)	Core symptoms of ASD
Maneeton et al. (2018)	Aripiprazole	Children and adolescents	Behavioral disturbances
McPheeters et al. (2011)	Multiple drug classes	Children (12 years old or younger)	Challenging and repetitive behaviors
Mohiuddin and Ghaziuddin (2013)	Multiple drug classes	Children and adults	Hyperactivity, irritability, and aggression
Preti et al. (2014)	Oxytocin	Children and adults	Emotion recognition and eye gaze
Reichow et al. (2013)	Methylphenidate, atomoxetine, and clonidine	Children	ADHD symptoms
Rizzo and Pavone (2016)	Aripiprazole	Children and adolescents	Irritability and aggression
Rossignol and Frye (2014)	Multiple drug agents approved for Alzheimer's disease	Children and adults	Core symptoms of ASD and comorbid symptoms
Roy et al. (2015)	Naltrexone	Children	Core symptoms of ASD and comorbid symptoms
Siegel and Beaulieu (2012)	Alpha-2 agonists and antipsychotics	Children (18 years old and younger)	Core symptoms of ASD and comorbid symptoms
Taylor (2016)	Multiple drug classes	Adults	Behavioral disturbances
VanDerwall et al. (2021)	Aripiprazole	Children and young adults (4-22 years old)	Irritability

[a] Demographics as reported by the authors in the review

[b] Target symptoms and/or areas as reported by the authors in the review

differences are unknown. For example, McDougle et al. (1998) examined the effects of risperidone on the severe aggression of 14 adults with ASD. Eight responded favorably to the drug; six did not. The reason for the difference was unclear.

Despite these limitations, Poling et al. (2017) concluded that research supports three conclusions. They are as follows:

1. *A wide range of medications have been evaluated inadequately.* Very few drugs have been studied in multiple, well-controlled trials using valid outcome measures. This poses a huge problem for physicians searching for evidence-based pharmacological interventions to benefit people with ASD. Huete et al. (2014) clearly described the problem they face: "…psychiatrists are challenged with basing their understanding of medication utility on a less that optimal body of research and more often on case study reports, and sometimes must refer to reported results and clinical trials of medications used in the general population for similar symptoms to guide their decision" (p. 736).
2. *Antipsychotic drugs often reduce challenging behaviors in children and adolescents.* As noted, risperidone and aripiprazole are FDA-approved for this purpose (i.e., treating "irritability"). This is de facto evidence that a panel of experts deemed the data providing evidence of their value compelling.
3. *No drug significantly improves the core symptoms of autism.* Although a well-tolerated medication that produced such an effect would revolutionize the treatment of people with ASD, such a drug is yet to appear.

In fairness, we must point out that some experts are more optimistic in their appraisal of the research literature than are Poling et al. (2017). Ethical and practical restrictions, coupled with very limited funding, make it difficult to conduct well-controlled research involving people with ASD. The results of limited, poorly controlled studies are often all that is available for assessing the value of pharmacological interventions, and experts differ in their willingness to accept the results of such studies. They also differ with respect to the criteria they apply when evaluating whether a study supports meaningful results. This is fine. Anyone interested in the psychopharmacology of ASD should contact multiple sources, such as the reviews listed in Table 17.1, and view all conclusions – including ours – with due skepticism. With that caution in mind, and an overview of the psychopharmacology of ASD as background, we now turn our attention specifically to adults.

Prevalence of Psychotropic Drug Use in Adults with Autism

A small number of studies have examined the prevalence of psychotropic drug use in adults with ASD. Prevalence rates differ substantially across studies, but, overall, their findings suggest that more than half of the members of this population are prescribed at least one psychotropic drug at a given point in time. Jobski et al. (2017) provided a systematic review of the use of psychotropic drugs in patients with ASD and reported a median prevalence level of 41.9% for 21 surveys that primarily involved children. They reported a median prevalence of 61.5% for six surveys that primarily involved adults.

We conducted a literature search to find articles reporting prevalence rates that were published after the review by Jobski et al. (2017). We searched four databases (i.e., *Cochrane Library*, *PubMed*, *Scopus*, and *Web of Science*) using the terms "Autism Spectrum Disorder" AND "Adult" AND "Psychotropic drug." This search produced 114 results. Two of us perused each article, selecting those that reported the prevalence of psychotropic drug use among adults with ASD. Five articles, listed in Table 17.2, reported prevalence. The median prevalence was 59%, with a range of 39–90%. These findings are comparable to the results of the studies summarized by Jobski et al.

In general, the probability that a person with ASD will receive at least one psychoactive drug

Table 17.2 The prevalence of psychotropic drug use in adults with autism

Article	Number of participants	Prevalence (%)
Axmon et al. (2017)	180[a]/7720[b]	50[a]/39[b]
Cvejic et al. (2018)[c]	188	55
Fusar-Poli et al. (2019)[d]	195	59
Nylander et al. (2018)	601	90
Vohra et al. (2016)	1772	85

[a] Participants had dementia
[b] Participants did not have dementia
[c] Data were drawn from a caregiver survey
[d] Eight percent of participants were between 14 and 17 years old

Table 17.3 The prevalence of psychotropic drug polypharmacy in adults with autism

Article	Number of participants	Prevalence (%)
Cvejic et al. (2018)[a]	188	22
Espadas et al. (2020)	83	57
Fusar-Poli et al. (2019)[b]	195	33
Jobski et al. (2017)[c]	>300,000	23[a]
Nylander et al. (2018)	601	75
Taylor (2016)[d]	347	41
Vohra et al. (2016)	1772	19

[a] Median, with range of 5–54%
[b] Data were drawn from a caregiver survey
[c] Eight percent of participants were between 14 and 17 years old
[d] Review article

increases with age, the presence of psychiatric comorbidity, the presence of concomitant intellectual disability (ID), and the occurrence of severe challenging behavior. These factors also appear to increase the probability of polypharmacy. Polypharmacy, which we define as the concurrent administration of two or more psychotropic medications (some researchers require three or more medications), is common when adults with ASD are considered. Jobski et al. (2017) reported a median polypharmacy level of 21.5% in studies primarily including children and 40.6% in those focusing on adults. We examined the articles revealed by our literature search to find those that reported the prevalence of polypharmacy. Seven, listed in Table 17.3, did so. The median prevalence of polypharmacy was 33%, slightly lower than that reported by Jobski et al. with a range of 19–75%.

Psychiatric Comorbidity and Autism in Adulthood

Many children and adolescents with ASD hurt themselves, damage property, have temper tantrums, and do other things that reduce the quality of their lives, limit their freedom and independence, and pose problems for caregivers (Matson & Rivet, 2008; Matson et al., 2011; Minshawi et al., 2014; Summers et al., 2017). Medical professionals frequently view such responses as indications of "irritability," and both aripiprazole and risperidone are FDA-approved for treating irritability in children and adolescents with ASD. "Irritability" is not a disease, and the responses it comprises are often learned operant behavior that often can be treated effectively with non-pharmacological interventions (Poling et al., 2017). Nonetheless, the kinds of behavioral excesses comprised by "irritability" often persist into and sometimes develop during adulthood (Matson & Rivet, 2008).

Studies show that a substantial minority of adults with ASD engage in one or more forms of challenging behavior, including stereotypies, self-injury, temper tantrums, elopement, property destruction, and physical aggression (Matson et al., 2011). The likelihood of such behavior occurring increases when ID accompanies ASD and as ASD severity increases. Psychotropic medications are commonly prescribed to reduce such behaviors (Matson et al., 2011) in adults, as well as in children and adolescents, with ASD.

Psychotropic medications also are widely used to treat psychiatric comorbidities that accompany ASD. There is a substantial level of co-occurring psychiatric disorders in children and adolescents with ASD. It is not clear how comorbidities change across the lifetime, but psychiatric comorbidities are common in adults with ASD (Buck et al., 2014; Esler et al., 2019). Conditions that often occur in combination with ASD in adults are ADHD, mood disorders, and anxiety disorders (e.g., Hofvander et al., 2009; Joshi et al., 2013).

Psychiatric diagnosis is fraught with difficulty regardless of the population being diagnosed, but it is especially hard in people with ASD. This is because symptoms of ASD may overlap with symptoms of other disorders (e.g., ADHD, obsessive compulsive disorder [OCD]) and the communication impairments characteristic of ASD may limit the information (e.g., about thoughts and feelings) available to diagnosticians (Esler et al., 2019). The presence of ID can further challenge diagnosticians. Nonetheless, as noted, when adults with ASD experience problems involving their mood, cognitive status, or overt behavior, those problems often lead to a psychiatric diagnosis.

Psychotropic medications are the primary tool that psychiatrists and other physicians have available for helping people who have problems involving their mood, cognitive status, or overt behavior. Psychiatric diagnosis helps them to choose appropriate medications. If, for example, someone is diagnosed with major depressive disorder (American Psychiatric Association, 2013), a physician is almost certain to prescribe a drug that is FDA-approved for treating depression. More than 20 such medications are available. The choice of a medication is based upon an individual physician's knowledge of and experience with individual drugs, including their side effects and specific indications and contraindications for their use.

Once a drug is selected, the physician selects a starting dose, which is often at the bottom of the suggested therapeutic range. The patient takes the drug for a sufficient period for it to have an effect, and then the severity of depression is assessed and compared to the level evident before treatment started. Standardized measures of severity, such as the Beck's Depression Inventory (Bech et al., 1996), should be used, but clinical judgment and patient self-report are also important and in some cases are used alone. If no significant improvement is evident, the physician is likely to adjust the dose upward. If, again, no gain is evident, the physician is likely to try another antidepressant. This process is typically continued until, ideally, an effective medication is found or it becomes clear that the patient is not going to benefit from a single FDA-approved antidepressant. At that point, some physicians will try a drug that is not FDA-approved, which is an off-label application. Off-label prescribing is an accepted medical practice and is justified when there is sound evidence that the drug is likely to be beneficial.

As examples of an off-label application of a psychotropic drug, both aripiprazole and risperidone are approved to treat irritability in young people (6–17 years of age) with ASD. If a physician sees evidence of irritability in a 20-year-old person with ASD – and the evidence would be the occurrence of challenging behavior – it would be reasonable for the physician to prescribe one of these drugs off-label.

When no single drug produces the desired effect, some physicians will add a second drug to the treatment regimen, so the patient is simultaneously prescribed two psychotropic medications to treat the same condition, depression in our example, which is one form of polypharmacy. Simultaneously prescribing two or more drugs to treat two or more psychiatric conditions, such as a tricyclic antidepressant to treat depression and an antipsychotic to treat schizophrenia, is another form. Decisions regarding the continuation or modification of multi-drug regimens, like those concerning single drugs, should be made based on valid and reliable measures of the conditions being treated. Given the time and resource constraints faced by most practicing physicians, this is easier said than done.

People who come to physicians having problems with mood, cognitive status, or overt behavior, and their advocates when present, want and need help. Drugs are the main tools that physicians can use to help these people. Given this dynamic, patients and advocates are apt to encourage physicians to prescribe drugs, to keep searching for effective medications when initial attempts fail, and to not throw in the towel.

Persistence is a virtue, and there is no doubt that psychotropic drugs benefit many patients, including adults with ASD. But with any treatment modality, it is all too easy to be convinced that an intervention, such as an antidepressant drug, is beneficial, when it is not actually changing the patient in the desired way.

Thompson (2007) provides an insightful discussion of why parents of children with ASD often persist with useless treatments. He notes that the absence of viable alternative treatments, the failure of prior treatments, the presence of small treatment effects, and the failure to systematically measure the problem the treatment is intended to solve are contributing factors. These same factors can influence the decisions that adults with ASD make about the treatments they receive. In many cases, however, such decisions will not be made by the adult with ASD but rather by legal guardians. They, too, are apt to be influenced by factors other than the actual effects of the intervention.

In some cases, there is compelling evidence that a given drug is widely effective in treating a diagnosed condition, so that a physician can treat the disorder with substantial confidence that the treatment will be effective. When drugs are FDA-approved for a particular indication, a panel of experts at the Center for Drug Evaluation and Research agrees that there is sufficient scientific evidence to conclude that the drug is safe and effective for a given use. This is not to say that everyone treated with the drug will derive significant benefits or that the drug is free of adverse effects, but only that the drug's health benefits outweigh its known risks in a given population (US Food and Drug Administration, 2019).

Many drugs currently are FDA-approved for treating named psychiatric disorders in adults, and it is reasonable to assume that they are appropriate for treating adults with ASD diagnosed with these disorders. But two considerations call this assumption into question. One is the imprecision of psychiatric diagnosis, especially when applied to people with ASD. Obsessive-compulsive disorder (OCD) diagnosed in an adult with ASD is not necessarily the same condition as OCD in another adult with respect to manifestations and underlying cause. The other is that the presence of ASD might alter sensitivity to pharmacological interventions. The drug trials upon which FDA approval is based typically do not include people with ASD, and it is not given that the effects observed in other people will generalize to people with ASD. Of course, it is possible that the effects of psychotropic drugs do not differ as a function of the presence or absence of ASD and that psychiatric diagnosis in adults with ASD is accurate enough to not constitute a challenge. The only way to evaluate these possibilities is to consult the research literature and determine what is known about the effects of psychotropic drugs in adults with ASD.

Research Findings

Taylor (2016) provided an exhaustive review of studies examining the effects of psychotropic medications in adults with ASD that were published in the English language between 1985 and 2015. Taylor found and summarized 43 studies. As she classified the drugs, 13 studies examined selective serotonin reuptake inhibitors (i.e., fluoxetine 4, fluvoxamine 2, sertraline 2), two examined the tricyclic antidepressant clomipramine, two examined the serotonin norepinephrine inhibitor venlafaxine, one examined the norepinephrine reuptake inhibitor atomoxetine, one examined the benzodiazepine lorazepam, one examined the azapirone buspirone, one examined the anticonvulsant divalproex sodium, and one examined the psychostimulant methylphenidate. Miscellaneous agents were examined in six studies (i.e., naltrexone 3, clonidine 2, propranolol 1). Antipsychotic drugs were examined in 14 studies (i.e., aripiprazole 5, risperidone 4, clozapine 2, haloperidol 1, lithium 1, paliperidone 1, quetiapine 1).

Taylor (2016) provided information about the research designs of all studies she examined. Randomized between-groups, placebo-controlled studies enrolling a large number of participants, often termed "clinical trials," are typically considered to be the "gold standard" in clinical psychopharmacology, with a pharmacological intervention considered as "evidence-based" when two (or more) such studies demonstrated its value (Reichow et al., 2008). The faith placed in such studies is so great, in fact, that some reviews of drug effects in people with ASD only consider them and exclude other research designs (e.g., Hirsch & Pringsheim, 2016; Maneeton et al., 2018).

There are good reasons for the scarcity of large-N, well-controlled studies of drug effects in adults with autism. Such studies are expensive and there is no ready source of funding. Practical and ethical considerations make such studies difficult to conduct and limit the range of tenable outcome measures. It is hard to access large numbers of adults with ASD, for (unlike, for instance, young people with ASD in school settings) they do not necessarily meet in sizeable groups. They are a protected group, which rightly causes Human Subjects Review Boards to look very carefully at research protocols involving them. Many adults with ASD receive one or more psychotropic medication, which may confound research involving other medications. Finally, limited access to and limited human resources for data collection prevent collecting detailed behavior data for large numbers of participants, especially over long periods of time.

Although not widely accepted in medicine, well-controlled small-N within-subject experiments can yield meaningful information about drug effects. Recognizing this, Reichow et al. (2008) developed a rubric that allows within-subject (which they term "single subject") research designs to be considered in evaluating the evidence base for a particular application of an intervention. Applying the rubric categorizes an intervention as an established evidenced-based practice (EBP), a promising EBP, or not an EBP.

Taylor (2016) applied the rubric developed by Reichou et al. (2008) to determine the status of various psychotropic drugs as EBPs for targeted outcomes in adults with ASD. She concluded that two drugs, risperidone and fluoxetine, are promising EBPs in this population. To be considered a promising EBP as defined by Reichou et al., a drug can be shown to be effective in at least three single-subject studies of at least adequate research report strength meeting the following criteria: (1) conducted by at least two different research teams, (2) conducted in at least two different locations, and (3) total sample size of at least nine different participants across studies. A drug can also be deemed a promising EBP if it is shown to be effective in at least two group experimental design studies of at least adequate research report strength (the studies can be conducted by the same research team in the same location). More rigorous criteria must be met for a drug to be considered as an EBP.

With respect to specific applications for adults with ASD, Taylor (2016) concluded that "only two medications, risperidone and fluoxetine, met Reichow et al.'s (2008) criteria for promising evidence based interventions for reducing irritability and repetitive behaviour associated with ASD in adults" (p. 71). To examine whether studies published after her review elevate any drugs as an established EBP for adults with ASD, we examined all of the articles revealed by our literature search, described previously, and by a search of Google Scholar. Although research examining several drugs appeared, they were not sufficient to elevate any medication to the status of an established EBP. Published studies varied greatly in several respects, and we saw no evidence of a consistent and concerted effort to examine the effects of a particular medication on a significant outcome measure. To provide evidence of the broad and varied range of studies we examined, overviews of nine of them follow.

In 2016, Carminati et al. conducted a randomized, double-blind, placebo-controlled study to investigate the effectiveness of venlafaxine in treating behavioral disorders (i.e., irritability, hyperactivity/noncompliance, overall clinical performance) in 13 adults with ASD. Scores on the Aberrant Behavior Checklist and the Behavior Problems Inventory were the primary dependent variables. This study failed to provide clear evidence of a beneficial effect of venlafaxine, although the authors worked hard to find, via statistical analysis, a beneficial effect of the drug.

Joshi et al. (2016) evaluated memantine hydrochloride for the treatment of core social and cognitive deficits in 18 adults with high-functioning ASD using a prospective, 12-week, open-label trial. They found that memantine treatment significantly reduced scores on the Social Responsiveness Scale-Adult Research Version and Clinical Global Impression-Improvement subscale measures of autism severity. Moreover, the treatment led to significant improvement in ADHD and anxiety symptom severity, nonverbal communication, executive function, and neuropsychological assessment scores. The drug was well-tolerated by participants and was not associated with any serious adverse events. However, the design of the study is inadequate to support strong conclusions.

In a brief report, Olincy et al. (2016) utilized a double-blind placebo-controlled cross-over study to examine the effects of an investigational receptor-specific partial agonist drug (DMXB-A) on the inhibitory functions of the alpha7-nicotinic receptor gene (CHRNA7), in two adults with ASD. Abnormalities in this gene (i.e., CHRNA7) are common among individuals with ASD. They found that DMXB-A altered the biomarker for receptor activity and increased attention, as evidenced by self-reports and scores on the Attention Scale on the Repeatable Battery for the Assessment of Neuropsychological Status.

Umbricht et al. (2017) conducted a randomized, double-blind, placebo-controlled cross-over study, assessing the effects of a single dose of arginine vasopressin receptor 1A antagonist (RG7713) on eye tracking, behavioral and clinical measures of social cognition and communication, and safety and tolerability, in 19 adult males with ASD. Statistically significant effects were limited to improved eye tracking, providing preliminary evidence of a positive effect of RG7713 on social cognition.

In 2017, Quintana and colleagues conducted a randomized controlled trial that examined the effects of two doses of oxytocin administered using a novel Breath Powered intranasal delivery device. Seventeen male adults with ASD participated in the study. They received a randomized sequence of single-dose sessions which consisted of eight international units (IU) oxytocin, 24 IU oxytocin, or placebo, before completing four social-cognitive tasks. The primary outcome measure of “overt emotion salience” found a significant effect, with eight IU of oxytocin increasing overt emotion salience compared to placebo. However, there was no significant increase after 24 IU of oxytocin treatment. No significant effects were found in the remaining measures (reading the mind in the eyes task performance, emotional dot probe, and face morphing). It is not clear how overt emotion salience relates to the core symptoms of ASD, to challenging behavior, or to any psychiatric disorder.

Yamasue et al. (2018) examined the effects of intranasal oxytocin on the core social symptoms of ASD using a randomized clinical trial. One hundred and six adult males with ASD were assigned to either a placebo group or a treatment group. The treatment group received 481 units per day of intranasal oxytocin for a total of 6 weeks. No between-group differences were found on the Autism Diagnostic Observation Schedule reciprocity measure, as both the treatment and placebo groups saw a reduction in scores. Some secondary measures such as the Autism Diagnostic Observation Schedule repetitive behavior measure and the duration of gaze fixation on socially relevant regions were better in the treatment group, but others were not. The frequency of adverse events did not differ between groups. Yamasue et al. concluded that continuous intranasal oxytocin treatment, as administered in the study, could not be recommended as a treatment for the core social symptoms of high-functioning ASD in adult men. However, they did add that there was some evidence that oxytocin could be useful in treating repetitive behavior.

In 2018, Danforth et al. examined the feasibility and safety of 3,4-methylenedioxymethamphet amine (MDMA)-assisted psychotherapy on reduction of social fear and avoidance, characteristics that are common among people with ASD. They conducted a blinded, placebo-controlled pilot study, with 12 adults with ASD who displayed a marked to severe level of anxiety. Danforth et al. found statistical improvement in Liebowitz Social Anxiety Scale scores from baseline to 1 month post-intervention, for the MDMA group, as well as from baseline to the 6-month follow-up.

In 2019, Ballester and colleagues assessed the effectiveness and tolerability of agomelatine as a treatment for sleep problems in adults with both ASD and ID. They conducted a randomized controlled trial with 23 individuals between the ages of 23 and 47 years old, 87% of which were male and all presenting with insomnia symptoms prior to the start of the study. The primary measure was total sleep time, as measured by ambulatory circadian monitoring. Agomelatine treatment was effective in treating insomnia and circadian rhythm sleep problems in the targeted participants, with only mild and transient adverse events. Although not a core symptom of ASD, a challenging behavior, or a psychiatric disorder, sleep disturbance is common in people with ASD and can contribute to other problems, making the results of this study noteworthy.

Bolognani et al. (2019) also used a randomized, double-blind, placebo-controlled study to investigate the effects of balovaptan on the core symptoms of ASD (i.e., socialization and communication deficits), in 223 adult males with ASD. They observed no significant difference in the primary efficacy measure (i.e., Social Responsiveness Scale, second edition). However, balovaptan was associated with improvement in scores on the Vineland-II Adaptive Behavior Scale. Balovaptan is of particular interest because it was developed by Roche specifically as a treatment for ASD. As reported by Fierce Biotech (n.d.-b), animal research suggested that balovaptan, a vasopressin 1a receptor antagonist, could help neurons communicate, an action that might target the core symptoms of ASD. Initial results were promising, but that promise was not realized in a phase 3 clinical trial, which was abandoned early, along with the drug. This pattern of results resembles that observed previously with oxytocin, another neuropeptide.

Finally, Joshi et al. (2020) assessed the short-term tolerability and efficacy of liquid formulation extended-release methylphenidate (MPH-ER) for the treatment of adults with comorbid ADHD and high-functioning ASD. During a 6-week, open-label trial with 15 adults between the ages of 20 and 29 years old (80% male), MPH-ER was administered using a flexible titration schedule. Results indicated that short-term MPH-ER treatment was effective, with a significant improvement in ADHD severity. MPH-ER was also described as well-tolerated, although adverse effects of headache, insomnia, anxiety, and decreased appetite were experienced by 13 of 15 participants. Methylphenidate has been repeatedly shown to be effective in reducing indications of ADHD in other populations, and this study suggests that its values extend to adults with ASD. Unfortunately, the design of the study does not support strong conclusions.

Conclusions

More than four dozen studies of the effects of psychotropic drugs in people with ASD have included adult participants. These studies have examined several different drugs, representing all of the major classes of psychotropic medications and experimental compounds. Unfortunately, the design of most studies renders their results suggestive, but not compelling. There are, however, some points that the research supports. After examining what is known regarding the use of psychotropic drugs to benefit adults with ASD, we reached seven conclusions.

Many Adults with ASD Are Prescribed One or More Psychotropic Drugs

Prevalence values differ substantially across studies, but it is clear that many, perhaps most, adults with ASD receive at least one psychotropic medication and a substantial proportion of medicated individuals receive two or more drugs. The widespread use of such medications suggests that they produce substantial benefits. Critics of psychopharmacology point out that those benefits could take the form of profits for the people who manage or invest in big pharma, the representatives who market psychotropic drugs to physicians, and the physicians who prescribe them.

There is no doubt that the pharmacological industry markets drugs aggressively, sometimes inappropriately, and generates enormous profits. It is not uncommon for new drugs to be introduced with enormous fanfare only to subsequently fall from grace. Aripiprazole is a case in point (VanDerwall et al., 2021). There is reason to be skeptical of big pharma, but we are convinced that the vast majority of physicians are committed to the well-being of their patients and would not consistently prescribe drugs they knew to be useless, let alone harmful. Moreover, research supports the value of some such drugs.

Beneficial Effects Are Reported in Most Studies

In most, but not all, of the drug studies involving adult participants with ASD reviewed by Taylor (2016), and in the subsequent studies we analyzed, some evidence of benefit was provided. This held, regardless of the drug class or specific drug evaluated, the design of the experiment or the outcome measure used. It is fair to state that, at present, there is insufficient evidence to support the use of any drug for any indication in an adult with ASD as an established EBP. But it is unfair to claim that there is no evidence that medications produce beneficial effects; there is such evidence. Moreover, many drugs are FDA-approved for specific indications in the adult population at large. If these indications, namely, psychiatric comorbidities, are present in adults with ASD, their use with these adults is appropriate. But, as noted previously, accurately diagnosing psychiatric disorders in adults with ASD is difficult, especially in individuals with comorbid ID. In addition, it is unclear whether the presence of ASD modulates the effects of psychotropic medications. Given this state of affairs, one can never be confident that a given medication will benefit an adult with ASD who receives it. Careful monitoring of desired and adverse drug effects is the quintessence of appropriate psychotropic drug treatments. This is an important point to which we will return.

There Is No Evidence That Age Influences Drug Effects in People with ASD

Most reviews of the pharmacological treatment of people with ASD emphasize findings with children and adolescents, although some of them include studies with adults. Table 17.1 lists 28 reviews published since 2010. Readers seeking detailed information about the pharmacological treatment of people with ASD should consult these reviews. Given the focus of the present chapter, it is interesting that their authors do not indicate that age modulates the clinical value of psychotropic medications. Although they vary in how strongly they endorse the use of pharmacological interventions for people with ASD, these authors generally agree that there are substantial limitations in the research base, that aripiprazole and risperidone are often useful for reducing challenging behavior, and that medications should be used with caution because of their potential side effects.

As we noted in another review (Poling et al., 2017), however, there are no systematic comparisons of the effects of psychotropic drugs across age groups. Many studies that include adults also include younger people but fail to disaggregate the data as a function of age. Had such disaggregation occurred and a large enough number of patients of different ages been studied, an effect of age might have been revealed. The effects of age also could be examined by comparing drug effects in similar studies that used different age groups, but such studies do not exist. The limited information that is available suggests that age does not strongly influence how people with ASD respond to psychotropic medications, but support for this proposition is decidedly weak. Almost nothing is known about the effects of psychotropic medication in elderly people with ASD. Given the issues associated with geriatric psychopharmacology in the general population (Meyers & Jeste, 2010), this is unfortunate.

It Is Not Clear Whether ASD Modulates the Effects of Psychotropic Drugs

It is not clear because compelling comparisons of the effects of the same doses of drugs on the same outcome measures in similar-aged adults with and without ASD have not appeared. Functional and structural brain characteristics that differ between people who are and who are not diagnosed with ASD underpin the behavioral differences responsible for the diagnosis. As Thompson (2007) points out, "Collectively, the available evidence suggests that the symptoms of ASDs can be traced to dysfunctions in specific brain areas, primarily the amygdala, prefrontal and parietal motor areas (minor neurons), orbitofrontal cortex, fusiform face area, cingulate, basal ganglia, and the two primary speech areas" (p. 37). It is logical to expect these dysfunctions to qualitatively or quantitatively alter the effects of psychotropic drugs and research examining this possibility is merited.

Researchers have made significant progress in determining the genetic and neurochemical mechanisms responsible for ASD (see Crespi, 2019; Marotta et al., 2020). Knowledge of the biological mechanisms responsible for the core symptoms of ASD, as well as the psychiatric disorders and challenging behavior that frequently accompany ASD, might well provide a logical rational basis for pharmacological interventions. Work in this direction is ongoing (Crespi, 2019).

It is noteworthy that two companies, Novartis and Sangamo, recently inked a $75,000,000 deal to work jointly to develop targeted drugs for treating ASD, with up to an additional $720,000,000 available to Sangamo across 3 years if milestones are met (Fierce Biotech, n.d.-a). The two companies will partner to use Sanomo's proprietary genome regulation technology to alter activity in three genes believed to be involved in ASD and ID. Success is far from a given, but, should it occur, it would fundamentally alter the way medications for ASD are designed, their mechanism of action, and, ideally, their benefits for recipients.

All psychotropic drugs can produce side effects, although the nature, likelihood, potential severity, and reversibility of these untoward effects differ across medications. It is possible that the neurological dysfunctions responsible for ASD alter the likelihood and the severity of some medications, although whether this occurs has not been determined.

More, and Better, Research Is Needed

There is much of importance regarding the effects of psychotropic drugs in people with ASD, regardless of their age, that has not been adequately examined. Additional, well-controlled research in several areas is obviously needed. But, as we have also noted, conducting research involving participants with ASD is difficult, and there is little funding to support it. Small-N repeated measures experimental designs, although not generally accepted in medicine, can yield valuable important information about the effects of psychotropic medications (Poling et al., 2010; Weeden et al., 2010). Adopting this approach to research would make it easier to conduct drug studies involving adults with ASD. But it is essential that small-N studies, like traditional clinical trials, be well-controlled, with sound experimental designs, double-blinds, placebo controls, and appropriate outcome measures. Few such studies have occurred and this approach does not appear to be gaining favor.

For the foreseeable future, people with ASD and their caregivers who are seeking benefit from psychotropic drugs can know all there is to know about these medications and still lack important information regarding risks and benefits. The same is true of the physicians who prescribe such medications. Nonetheless, it is clearly evident that, when used appropriately, psychotropic medications significantly benefit many adults with ASD. The key phrase here is "when used appropriately."

EBP for an Individual Constitutes Appropriate Drug Use

We have suggested elsewhere (e.g., Poling, 1994; Poling & Ehrhardt, 1999; Weeden et al., 2010) that the essence of appropriate use of psychotropic drugs entails the following:

1. Ensuring that the goals of treatment are clear and in the client's best interest.
2. Ensuring that treatment decisions are made on the basis of real drug effects.
3. Ensuring that drug therapy is flexible and integrated with non-pharmacological interventions.

Table 17.4 Principles of best practice in psychotropic drug use[a]

1. Before initiating pharmacotherapy, a psychiatric evaluation is completed
2. Before initiating pharmacotherapy, a medical history is obtained, and a medical evaluation is considered when appropriate
3. The prescriber is advised to communicate with other professionals involved with the patient to obtain collateral history and set the stage for monitoring outcomes and side effects during the medication trial
4. The prescriber develops a psychosocial and psychopharmacological treatment plan based on the best available evidence
5. The prescriber develops a plan to monitor the patient, short and long term
6. Prescribers should be cautious when implementing a treatment plan that cannot be appropriately monitored
7. The prescriber provides feedback about the diagnosis and educates the patient and family regarding the patient's diagnosis and the treatment and monitoring plan
8. Complete and document the consent of the parent, or assent of the patient and consent of the parent or other caregiver, before initiating medication treatment and at important points during treatment
9. The assent and consent discussion focuses on the risks and benefits of the proposed and alternative treatments
10. Implement medication trials using an adequate dose and for an adequate duration of treatment
11. The prescriber reassesses the patient if the patient does not respond to the initial medication trial as expected
12. The prescriber needs a clear rationale for using medication combinations
13. Discontinuing medication in children requires a specific plan

[a]These general practices are recommended by the American Academy of Child and Adolescent Psychiatry and reproduced with minor modification from Walkup et al. (2009). Reproduced with permission

In pursuing these objectives, practitioners are behaving in a manner consistent with best practice guidelines. Table 17.4 provides a list of such guidelines, slightly modified from the recommendations of the American Academy of Child and Adolescent Psychiatry (Walkup et al., 2009) for the appropriate use of psychotropic medications in children. Age and the presence of ASD do not alter the fundamentals of appropriate medication use. Following the guidelines listed in Table 17.4 goes far in ensuring that psychotropic medications are used appropriately in adults with ASD.

These guidelines are based on the use of EBPs. Appropriate use of EBPs involves three steps for each individual to be treated. First, the condition to be treated is quantified, which may, but need not, involve assigning a diagnostic label. Second, an intervention, such as a psychotropic medication, for which there is good scientific evidence to support its value in treating that condition, is selected. Third, the effects of that intervention, both desired and adverse, are evaluated in the treated individual, and decisions about subsequent treatment are based on the results of this evaluation.

The third step is the most important one. If it can be shown that receiving a psychotropic medication clearly improves the quality of life of an adult with ASD, then that medication is, for that person, an EBP and, put simply, a good thing. Unfortunately, in everyday situations, it is often hard to adequately determine whether a drug is producing either desired or significant adverse effects. It is generally assumed that neurotypical adults can, in consultation with their physicians, make sound judgments about how a psychotropic medication is affecting them and rationally choose whether to continue, alter, or terminate treatment. Some adults with ASD have the capacity to do likewise, but others do not. In the latter case, special care should be taken to ensure that decisions are based on actual, rather than hoped-for, beneficial effects, a point Thomas Greiner (1958) made more than 40 years ago, when he noted that, when it came to psychotropic medication, children and developmentally disabled people require special protections. Physicians alone are rarely in a position to collect the data needed to fully profile the effects of a psychotropic medication, and it is wise to enlist members of other professions, such as behavior analysts, to assist (see Weeden et al., 2010).

Of course, non-pharmacological alternatives have been shown to be of value for treating challenging behaviors and psychiatric comorbidities, and the doctrine of least restrictive alternatives suggests that they deserve consideration prior to drug treatment. But in many cases, such treatments are not available or have been tried and failed. Psychotropic medications can play a valuable role in the lives of adults with ASD. Because of the risks they pose, they are best used at the lowest dose and for the shortest time possible, but that by no means makes them bad. To borrow a metaphor from Travis Thompson (2007) categorizing psychotropic drugs as “bad” or “good” is as foolish as doing the same for rain. Clearly, both depend on the situation. Rain is bad in the midst of a flood, a blessing in a drought. A psychotropic drug that causes tardive dyskinesia and changes nothing for the better is bad; a drug that relieves suffering is good. Psychotropic drugs are powerful tools that need to be used with care and caution. When they are, they can greatly benefit adults with ASD. Providing psychiatrists and other physicians with appropriate training regarding ASD and the effects of psychotropic drugs in this population, including strategies for evaluating drug effects, would go far in making this happen. Fostering in caregivers and advocates a skeptical, but not cynical, perspective on the use of psychotropic drugs would do the same. If this chapter has helped to foster such an attitude in you, the reader, then our goal in writing is met, and we are pleased.

References

Aman, M. G., Smith, T., Arnold, L. E., Corbett-Dick, P., Tumuluru, R., Hollway, J. A., Hyman, S. L., Mendoza-Burchamm, M., Pan, X., Mruzek, D. W., Lecavalier, L., Levato, L., Silverman, L. B., & Handen, B. (2014). A review of atomoxetine effects in young people with developmental disabilities. *Research in Developmental Disabilities, 35*, 1412–1424. https://doi.org/10.1016/j.ridd.2014.03.006

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Author.

Axmon, A., Kristensson, J., Ahlström, G., & Midlöv, P. (2017). Use of antipsychotics, benzodiazepine derivatives, and dementia medication among older people with intellectual disability and/or autism spectrum disorder and dementia. *Research in Developmental Disabilities, 62*, 50–57. https://doi.org/10.1016/j.ridd.2017.01.001

Ballester, P., Martínez, M. J., Inda, M. D., Javaloyes, A., Richdale, A. L., Muriel, J., Belda, C., Toral, N., Morales, D., Fernández, E., & Peiró, A. M. (2019). Evaluation of agomelatine for the treatment of sleep problems in adults with autism spectrum disorder and co-morbid intellectual disability. *Journal of psychopharmacology (Oxford, England), 33*, 1395–1406. https://doi.org/10.1177/0269881119864968

Baribeau, D. A., & Anagnostou, E. (2013). Social communication is an emerging target for pharmacotherapy in autism spectrum disorder – A review of the literature for potential agents. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 23*, 20–30.

Bartram, L. A., Lozano, J., & Coury, D. L. (2019). Aripiprazole for treating irritability associated with autism spectrum disorders. *Expert Opinion on Pharmacotherapy, 20*, 1421–1427. https://doi.org/10.1080/14656566.2019.1626825

Bech, P., Hamilton, M., & Zung, W. W. K. (1996). *The Bech, Hamilton, and Zung Scales for mood disorders: Screening and listening* (2nd ed.). Springer.

Bolognani, F., Del Valle Rubido, M., Squassante, L., Wandel, C., Derks, M., Murtagh, L., Sevigny, J., Khwaja, O., Umbricht, D., & Fontoura, P. (2019). A phase 2 clinical trial of a vasopressin V1a receptor antagonist shows improved adaptive behaviors in men with autism spectrum disorder. *Science Translational Medicine, 11*, eaat 7838. https://doi.org/10.1126/scitranslmed.aat7838

Brugha, T. S., Doos, L., Tempier, A., Einfeld, S., & Howlin, P. (2015). Outcome measures in intervention trials for adults with autism spectrum disorders: A systematic review of assessments of core autism features and associated emotional and behavioural problems. *Internal Journal of Measures in Psychiatric Research, 24*, 99–115. https://doi.org/10.1002/mpr.1466

Buck, T. R., Viskochil, J., Farley, M., Coon, H., McMahon, W. M., Morgan, J., & Bilder, D. A. (2014). Psychiatric comorbidity and medication use in adults with autism spectrum disorder. *Journal of Autism and*

Developmental Disorders, 44, 3063–3071. https://doi.org/10.1007/s10803-014-2170-2

Carminati, G. G., Gerber, F., Darbellay, B., Kosel, M. M., Deriaz, N., Chabert, J., Fathi, M., Bertschy, G., Ferrero, F., & Carminati, F. (2016). Using venlafaxine to treat behavioral disorders in patients with autism spectrum disorder. *Progress in Neuro-Psychopharmacology & Biological Psychiatry, 65*, 85–95. https://doi.org/10.1016/j.pnpbp.2015.09.002

Ching, H., & Pringsheim, T. (2012). Aripiprazole for autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews, 5*. https://doi.org/10.1002/14651858.CD009043.pub2

Crespi, J. (2019). Comparative psychopharmacology of autism and psychotic-affective disorders suggests new targets for treatment. *Evolution, Medicine, and Public Health, 1*, 149–168. https://doi.org/10.1093/emph/eoz022

Cvejic, R. C., Arnold, S. R. C., Foley, K., & Trollor, J. N. (2018). Neuropsychiatric profile and psychotropic medication use in adults with autism spectrum disorder: Results from the Australian Longitudinal Study of Adults with Autism. *BJPsych Open, 4*, 461–466. https://doi.org/10.1192/bjo.2018.64

Danforth, A. L., Grob, C. S., Struble, C., Feduccia, A. A., Walker, N., Jerome, L., Yazar-Klosinski, B., & Emerson, A. (2018). Reduction in social anxiety after MDMA-assisted psychotherapy with autistic adults: A randomized, double-blind, placebo-controlled pilot study. *Psychopharmacology, 235*, 3137–3148. https://doi.org/10.1007/s00213-018-5010-9

Dove, D., Warren, Z., McPheeters, M. L., Taylor, J. L., Sathe, N. A., & Veenstra-Vander Weele, J. (2012). Medications for adolescents and young adults with autism spectrum disorders: A systematic review. *Pediatrics, 130*, 717–726. https://doi.org/10.1542/peds.2012-0683

Doyle, C. A., & McDougle, C. J. (2012). Pharmacologic treatments for the behavioral symptoms associated with autism spectrum disorders across the lifespan. *Dialogues in Clinical Neuroscience, 14*, 263–279. https://doi.org/10.31887/DCNS.2012.14.3/cdoyle

Elbe, D., & Lalani, Z. (2012). Review of the pharmacotherapy of irritability of autism. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 21*, 130–146.

Esler, A., Hewitt, A., Hall-Lande, J., Pettingell, S. L., & Houseworth, J. (2019). Psychotropic medication use for adults with autism spectrum disorder who receive services and supports through adults developmental disability services in the United States. *Journal of Autism and Developmental Disorders, 49*, 2291–2303. https://doi.org/10.1007/s10803-019-03903-7

Espadas, C., Ballester, P., Londoño, A. C., Almenara, S., Aguilar, V., Belda, C., Pérez, E., & Peiró, A. M. (2020). Multimorbidity and psychotropic polypharmacy among participants with autism spectrum disorder with intellectual disability. *Psychiatry Research, 292*. https://doi.org/10.1016/j.psychres.2020.113321

Farmer, C. A., & Aman, M. G. (2011). Aripiprazole for the treatment of irritability associated with autism. *Expert Opinion on Pharmacotherapy, 12*, 635–640. https://doi.org/10.1517/14656566.2011.557661

Fierce Biotech. (n.d.-a). *Novartis, Sangamo team up on genetic meds for autism in $75M deal*. Downloaded March 2, 2021 from https://www.fiercebiotech.com/biotech/novartis-sangamo-team-up-genetic-meds-for-autism-75m-deal

Fierce Biotech. (n.d.-b). *Special reports: 2 Balovaptan*. Downloaded March 23, 2021 from https://www.fiercebiotech.com/special-report/2-balovaptan-2020-s-top-10-clinical-trial-flops

Frye, R. E., Rossignol, D., Casanova, M. F., Brown, G. L., Martin, V., Edelson, S., Coben, R., Lewine, J., Slattery, J. C., Lau, C., Hardy, P., Fatemi, S. H., Folsom, T. D., MacFabe, D., & Adams, J. B. (2013). A review of traditional and novel treatments for seizures in autism spectrum disorder: Findings from a systematic review and expert panel. *Frontiers in Public Health*. https://doi.org/10.3389/fpubh.2013.00031

Fung, L. K., Chahal, L., Libove, R. A., Bivas, R., & Hardan, A. (2012). A retrospective review of the effectiveness of aripiprazole in the treatment of sensory abnormalities in autism. *Journal of Child and Adolescent Psychopharmacology, 22*, 245–248. https://doi.org/10.1089/cap.2010.0103

Fusar-Poli, L., Brondino, N., Rocchetti, M., Petrosino, B., Arillotta, D., Damiani, S., Provenzani, U., Petrosino, C., Aguglia, E., & Pierluigi, P. (2019). Prevalence and predictors of psychotropic medication use in adolescents and adults with autism spectrum disorder in Italy: A cross-sectional study. *Psychiatry Research, 276*, 203–209. https://doi.org/10.1016/j.psychres.2019.04.013

Gadow, K., & Poling, A. (1986). *Methodological issues in human psychopharmacology*. JAI Press.

Ghanizadeh, A. (2012). Atomoxetine for treating ADHD symptoms in autism: A systematic review. *Journal of Attention Disorders, 17*, 635–640. https://doi.org/10.1177/1087054712443154

Ghanizadeh, A., Tordjman, S., & Jaafari, N. (2015). Aripiprazole for treating irritability in children & adolescents with autism: A systematic review. *Indian Journal of Medical Research, 142*, 269–275. https://doi.org/10.4103/0971-5916.166584

Greiner, T. (1958). Problems in methodology in research with drugs. *American Journal of Mental Deficiency, 64*, 346–352.

Guénolé, F., Godbout, R., Nicolas, A., Franco, P., Claustrat, B., & Baleyte, J. M. (2011). Melatonin for disordered sleep in individuals with autism spectrum disorders: Systematic review and discussion. *Sleep Medicine Reviews, 15*, 379–387. https://doi.org/10.1016/j.smrv.2011.02.001

Hirsch, L. E., & Pringsheim, T. (2016). Aripiprazole for autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews, 6*. https://doi.org/10.1002/14651858.CD009043.pub3

Hofvander, B., Delorme, R., Chaste, P., Nyden, A., Wentz, E., Stahlberg, O., Herbrecht, E., Stopin, A., Anckarsater, H., Gillberg, C., Rastam, M., & Leboyer, M. (2009). Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry, 9*, 35. https://doi.org/10.1186/1471-244X-9-35

Huete, J., Schmidt, J., & Lopez-Arvizu, D. (2014). Behavioral disorders in young children with autism spectrum disorder. In J. Tarbox, D. R. Dixon, P. Sturmey, & J. L. Matson (Eds.), *Handbook of early intervention for autism spectrum disorders* (pp. 717–752). Springer.

Jenabi, E., Ataei, S., & Bashirian, S. (2019). Evaluation of drug interventions for the treatment of sleep disorders in children with autism spectrum disorders: A systematic review. *Korean Journal of Pediatrics, 62*, 405–409. https://doi.org/10.3345/kjp.2019.00668

Jobski, K., Höfer, J., Hoffmann, F., & Bachmann, C. (2017). Use of psychotropic drugs in patients with autism spectrum disorders: A systematic review. *Acta Psychiatrica Scandinavica, 135*, 8–28. https://doi.org/10.1111/acps.12644

Joshi, G., Wozniak, J., Petty, C., Martelon, M. K., Friend, R., Bolfek, A., Kotte, A., Stevens, J., Furtak, S. L., Bourgeois, M., Caruso, J., Caron, A., & Biederman, J. (2013). Psychiatric comorbidity and functioning in a clinically referred population of adults with autism spectrum disorders: A comparative study. *Journal of Autism and Developmental Disorders, 43*, 1314–1325. https://doi.org/10.1007/s10803-012-1679-5

Joshi, G., Wozniak, J., Faraone, S. V., Fried, R., Chan, J., Furtak, S., Grimsley, E., Conroy, K., Kilcullen, J. R., Woodworth, K. Y., & Biederman, J. (2016). A prospective open-label trial of memantine hydrochloride for the treatment of social deficits in intellectually capable adults with autism spectrum disorder. *Journal of Clinical Psychopharmacology, 36*, 262–271. https://doi.org/10.1097/jcp.0000000000000499

Joshi, G., DiSalvo, M., Wozniak, J., Ceranoglu, T. A., Yule, A., Surman, C., Fried, R., Galdo, M., Hoskova, B., Belser, A., & Biederman, J. (2020). A prospective open-label trial of long-acting liquid methylphenidate for the treatment of attention deficit/hyperactivity disorder in intellectually capable adults with autism spectrum disorder. *The World Journal of Biological Psychiatry, 21*, 274–290. https://doi.org/10.1080/15622975.2019.1679392

Krishnaswami, S., McPheeters, M., & Veenstra-Vaderweele, J. (2011). A systematic review of secretin with children with autism spectrum disorders. *Pediatrics, 127*, 1322–1325. https://doi.org/10.1542/peds.2011-0428

Maenner, M. J., Shaw, K. A., Baio, J., Washington, A., Patrick, M., DiRienzo, M., … Dietz, P. M. (2020). Prevalence of autism spectrum disorder among children aged 8 years – Autism and developmental disabilities monitoring network, 11 sites, United States, 2016. *MMWR Surveillance Summaries, 69*, 1–12. https://doi.org/10.15585/mmwr.ss6904a1

Maneeton, N., Maneeton, B., Putthisri, S., Suttajit, S., Likhitsathian, S., & Srisurapanoont, M. (2018). Aripiprazole in acute treatment of children and adolescents with autism spectrum disorder: A systematic review and meta-analysis. *Neuropsychiatric Disease and Treatment, 14*, 3063–3072. https://doi.org/10.2147/ndt.s174622

Marotta, R., Risoleo, M. C., Messina, G., Parisi, L., Carotenuto, M., Vetri, L., & Roccella, M. (2020). The neurochemistry of autism. *Brain Sciences, 10*(3), 63. https://doi.org/10.3390/brainsci10030163

Matson, J. L., & Rivet, T. T. (2008). Characteristics of challenging behaviours in adults with autistic disorder, PDD-NOS, and intellectual disability. *Journal of Intellectual and Developmental Disability, 33*, 323–329. https://doi.org/10.1080/13668250802492600

Matson, J. L., Bamburg, J. W., Mayville, E. A., Pinkston, J., Bielecki, J., Kuhn, D., Smalls, Y., & Logan, J. R. (2000). Psychopharmacology and mental retardation: A 10 year review (1990-1999). *Research in Developmental Disabilities, 21*, 263–296. https://doi.org/10.1016/s0891-4222(00)00042-1

Matson, J. L., Sipes, M., Fodstad, J. C., & Fitzgerald, M. E. (2011). Issues in the management of challenging behaviours of adults with autism spectrum disorders. *CNS Drugs, 25*, 597–606. https://doi.org/10.2165/11591700-000000000-00000

McDougle, C. J., Holmes, J. O., Carlson, R. C., et al. (1998). A double-blind placebo-controlled study of risperidone in adults with autistic disorder and other pervasive developmental disorders. *Archives of General Psychiatry, 55*, 633–641. https://doi.org/10.1001/archpsyc.55.7.633

McPheeters, M. L., Warren, Z., Sathe, N., Bruzek, J. L., Krishnaswami, S., Jerome, R. N., & Veenstra-Vanderwheele, J. (2011). A systematic review of medical treatments for children with autism spectrum disorder. *Pediatrics, 127*, 1312–1321. https://doi.org/10.1542/peds.2011-0427

Meyers, B. S., & Jeste, D. V. (2010). Geriatric psychopharmacology: Evolution of a discipline. *The Journal of Clinical Psychiatry, 71*, 1416–1424. https://doi.org/10.4088/jcp.10r06485gry

Minshawi, N. F., Hurwitz, S., Fodstad, J. C., Biebl, S., Morriss, D. H., & McDougle, C. J. (2014). The association between self-injurious behaviors and autism spectrum disorders. *Psychology Research and Behavior Management, 7*, 125–136. https://doi.org/10.2147/PRBM.S44635

Mohiuddin, S., & Ghaziuddin, M. (2013). Psychopharmacology of autism spectrum disorders: A selective review. *Autism, 17*, 645–654. https://doi.org/10.1177/1362361312453776

Nylander, L., Axmon, A., Björne, P., Ahlström, G., & Gillberg, C. (2018). Older adults with autism spectrum disorders in Sweden: A register study of diagnoses, psychiatric care utilization and psychotropic medication of 601 individuals. *Journal of Autism and Developmental Disorders, 48*, 3076–3085. https://doi.org/10.1007/s10803-018-3567-0

Olincy, A., Blakeley-Smith, A., Johnson, L., Kem, W. R., & Freedman, R. (2016). Brief report: Initial trial of alpha 7-nicotinic receptor stimulation in two adult patients with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*, 3812–2817. https://doi.org/10.1007/s10803-016-2890-6

Poling, A. (1994). Pharmacological treatment of behavioral problems in people with mental retardation: Some ethical considerations. In L. J. Hayes, G. J. Hayes, S. C. Moore, & P. M. Ghezzi (Eds.), *Ethical issues in developmental disabilities* (pp. 149–177). Context Press.

Poling, A., & Ehrhardt, K. (1999). Applied behavior analysis, social validation, and the psychopharmacology of mental retardation. *Mental Retardation and Developmental Disabilities Research Reviews, 5*, 342–347. https://doi.org/10.1002/(SICI)1098-2779(1999)5:4%3C342::AID-MRDD12%3E3.0.CO;2-7

Poling, A., Ehrhardt, K., Wood, A., & Bowerman, R. (2010). Psychopharmacology and behavior analysis in autism treatment. In E. A. Mayville & J. A. Mulick (Eds.), *Behavioral foundations of effective autism treatment* (pp. 257–275). Sloan.

Poling, A., Ehrhardt, K., & Li, A. (2017). Psychotropic medications as treatments for people with autism spectrum disorders. In J. Matson (Ed.), *Handbook of treatments for autism spectrum disorder* (pp. 459–471). Springer.

Preti, A., Melis, M., Siddi, S., Vellante, M., Doneddu, G., & Fadda, R. (2014). Oxytocin and autism: A systematic review of randomized controlled trials. *Journal of Child and Adolescent Psychopharmacology, 24*, 54–68. https://doi.org/10.1089/cap.2013.0040

Quintana, D. S., Westlye, L. T., Hope, S., Nærland, T., Elvsåshagen, T., Dørum, E., Rustan, Ø., Valstad, M., Rezvaya, L., Lishaugen, H., Stensønes, E., Yaqub, S., Smerud, K. T., Mahmoud, R. A., Djupesland, P. G., & Andreassen, O. A. (2017). Dose-dependent social-cognitive effects of intranasal oxytocin delivered with novel breath powered device in adults with autism spectrum disorder: A randomized placebo-controlled double-blind crossover trial. *Translational Psychiatry, 7*, E1136. https://doi.org/10.1038/tp.2017.103

Reichow, B., Volkmar, F. R., & Cicchetti, D. V. (2008). Development of the evaluative method for evaluating and determining evidence-based practices in autism. *Journal of Autism and Developmental Disorders, 38*, 1311–1319. https://doi.org/10.1007/s10803-007-0517-7

Reichow, B., Volkmar, F. R., & Bloch, M. H. (2013). Systematic review and meta-analysis of pharmacological treatment of the symptoms of attention-deficit/hyperactivity disorder in children with pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 43*, 2435–2441. https://doi.org/10.1007/s10803-013-1793-z

Rizzo, R., & Pavone, P. (2016). Aripiprazole for the treatment of irritability and aggression in children and adolescents affected by autism spectrum disorders. *Expert Review of Neurotherapeutics, 16*, 867–874. https://doi.org/10.1080/14737175.2016.1211007

Rossignol, D. A., & Frye, R. E. (2014). The use of medications approved for Alzheimer's disease in autism spectrum disorder: A systematic review. *Frontiers in Pediatrics, 2*, 1–8. https://doi.org/10.3389/2Ffped.2014.00087

Roy, A., Roy, M., Deb, S., Unwin, G., & Roy, A. (2015). Are opioid antagonists effective in attenuating the core symptoms of autism spectrum conditions in children: A systematic review. *Journal of Intellectual Disability Research, 59*, 293–306. https://doi.org/10.1111/jir.12122

Siegel, M., & Beaulieu, A. A. (2012). Psychotropic medications in children with autism spectrum disorders: A systematic review and synthesis for evidence-based practice. *Journal of Autism and Developmental Disorders, 42*, 1592–1605. https://doi.org/10.1007/s10803-011-1399-2

Sprague, R. L., & Werry, J. L. (1971). Methodology of psychopharmacological studies with the retarded. In N. R. Ellis (Ed.), *International review of research in mental retardation* (Vol. 5, pp. 147–219). Academic Press.

Summers, J., Shahrami, A., Cali, S., D'Mello, C., Kako, M., Palikucin-Reljin, A., Savage, M., Shaw, O., & Lunsky, Y. (2017). Self-injury in autism spectrum disorder and intellectual disability: Exploring the role of reactivity to pain and sensory input. *Brain Sciences, 7*, 140. https://doi.org/10.3390/brainsci7110140

Taylor, L. R. (2016). Psychopharmacologic intervention for adults with autism spectrum disorder: A systematic literature review. *Research in Autism Spectrum Disorders, 25*, 58–75. https://doi.org/10.1016/j.rasd.2016.01.011

Thompson, T. (2007). *Making sense of autism*. Paul H. Brookes.

U.S. Food and Drug Administration. (2019). *Development and approval process: Drugs*.

Umbricht, D., Del Valle Rubido, M., Hollander, E., McCracken, J. T., Shic, F., Scahill, L., Noeldeke, J., Boak, L., Khwaja, O., Squassante, L., Grundschober, C., Kletzl, H., & Fontoura, P. (2017). A single dose, randomized, controlled proof-of-mechanism study of a novel vasopressin 1a receptor antagonist (RG7713) in high-functioning adults with autism spectrum disorder. *Neuropsychopharmacology, 42*, 1924. https://doi.org/10.1038/npp.2016.232

VanDerwall, R., Rotta, K., Ehrhardt, K., & Poling, A. (2021). Using aripiprazole to benefit people with autism spectrum disorder: A critical appraisal. *Advances in Neurodevelopmental Disorders, 5*, 1–10. https://doi.org/10.1007/s41252-020-00190-7

Vohra, R., Madhavan, S., Sambamoorthi, U., StPeter, C., Poe, S., Dwibedi, N., & Ajmera, M. (2016). Prescription drug use and polypharmacy among Medicaid-enrolled adults with autism: A retrospective cross-sectional analysis. *Drugs – Real World Outcomes, 3*, 409–425. https://doi.org/10.1007/s40801-016-0096-z

Walkup, J., & the Work Group of Quality Issues. (2009). Practice parameter on the use of psychotropic medication in children and adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry, 48*, 961–973. https://doi.org/10.1097/chi.0b013e3181ae0a08

Weeden, M., Ehrhardt, K., & Poling, A. (2010). Psychotropic drug treatments for people with autism and other developmental disabilities: A primer for practicing behavior analysts. *Behavior Analysis in Practice, 3*, 4–12. https://doi.org/10.1007/2FBF03391753

Yamasue, H., Okada, T., Munesue, T., Juroda, M., Fujioka, T., Uno, Y., Matsumoto, K., Kuwabara, H., Mori, D., Okamoto, Y., Yoshimura, Y., Kawakubo, Y., Arioka, Y., Kojima, M., Yuhi, T., Owada, K., Yassin, W., Kushima, I., Benner, S., … Kosak, H. (2018). Effect of intranasal oxytocin on the core social symptoms of autism spectrum disorder: A randomized clinical trial. *Molecular Psychiatry, 25*, 1849–1858. https://doi.org/10.1038/s41380-018-0097-2

Part VII

Effective Methods to Teach Essential Skills

18

Meaningful Curriculum and Functional Intervention for Adults with Autism

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Overall, individuals with autism spectrum disorder (ASD) have poor outcomes in adulthood when compared to same-aged peers in every area that is typically evaluated, including post-secondary education, employment, living arrangements, social and community participation, access to services, physical and/or mental health, and safety (Roux et al., 2015). Such outcomes have shown little improvement over time (Newman et al., 2010) and are worse than those of adults with other disability labels (e.g., learning disability, speech-language impairment, intellectual disability, and emotional disturbance) (Roux et al., 2015). Every year, approximately 70,000+ teens diagnosed with ASD become adults (Autism Speaks, n.d.) and, in general, are not provided the skills necessary to successfully make this transition to an independent life after high school (Gerhardt & Lainer, 2011). These outcomes pose challenges to individual quality of life, as well as financial and social costs to the family and society at large (Dell'Armo & Tassé, 2018; Farley et al., 2018; Howlin & Magiati, 2017).

Despite the fact that ASD is a lifelong neurodevelopmental disorder that often necessitates supports and services across the lifespan, individuals on the spectrum are typically met with a dramatic drop in available supports upon reaching adulthood, often referred to as falling off a service cliff (Roux et al., 2015). While federal laws require special education and transition services, post-high school, no such mandates currently exist, leaving families to fend for themselves in seeking out appropriate support (Roux et al., 2015). The needs of adult individuals on the spectrum in terms of employment, day, community, and residential services far exceed the resources currently available (Gerhardt & Lainer, 2011). Over the next decade, it is estimated that an additional 707,000–1,116,000 teens will enter the world of adulthood (Autism Speaks, n.d.), only further exacerbating this problem.

Given the current limitations in funding and resources allocated to adult supports (Cimera & Cowan, 2009; US Department of Health and Human Services, 2017), it becomes critical that educational services leading up to, and during, the transition to adulthood focus on the application of meaningful curriculum and use of functional intervention in order to best position each

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individual for success in the rest of their lives. This success may be thought of in terms of three major life goals that neurotypical individuals often have: (a) get a good job, (b) live away from home (even with necessary supports), and (c) be reasonably happy (Ticani & Bondy, 2014). Unfortunately, it seems that a combination of poor preparation leading up to adulthood and the limited access to effective, individualized adult services means that only rarely are these goals a reality. This is true, despite the fact that individuals on the spectrum can and often do make valuable contributions to the communities in which they live and should be afforded access to this opportunity.

What Makes a Curriculum Meaningful?

A meaningful curriculum is one that is individualized, inclusive of the individual's unique needs and interests, and is focused on building independence in current and future environments (Ayres et al., 2011). A meaningful curriculum also assesses an individual's needs and prioritizes programs based on what is most important to their lives. Because outcomes can partially be predicted based on the adaptive behavior repertoires of an individual (Ayres et al., 2011; Dell'Armo & Tassé, 2018; Mazefsky et al., 2008; Mazzotti et al., 2016), a focus on such skills constitutes a potentially meaningful curriculum for many individuals on the spectrum. Adaptive behavior is, essentially, all skills and abilities that allow independent functioning in their day-to-day life (Heward, 2005). According to Tassé et al. (2012), these skills may be thought of in terms of three broad domains including (a) conceptual skills (e.g., language, reading/writing, number, time, money concepts), (b) social skills (e.g., interpersonal skills, friendship, social problem solving, social participation), and (c) practical skills (e.g., self-care skills, daily living skills, health and safety skills). Adaptive skills are "so central to adult life that it would not be an understatement to say that good adaptive behavior skills will get a person through times of no academic skills better than good academic skills will get a person through times of no adaptive behavior" (Gerhardt et al., 2013, p. 167). Adaptive behavior should therefore be a priority in programming starting at a young age and increase in focus as individuals get closer to adulthood.

Obviously, what is meaningful for some is not meaningful for all; as such, practitioners need to take the unique needs of each individual into consideration when confronted with general education standards and medical necessity restrictions. Adherence to the general education curriculum may call practitioners to prioritize goals that have little to no impact on the future lives of individuals; for example, acquiring the ability to identify Saturn when you cannot brush your teeth is not a meaningful outcome (Ayres et al., 2011). While academic skills may be part of a meaningful curriculum for some individuals, others may need to focus more on adaptive behavior competencies instead (although even the more "academic" student still needs to acquire meaningful adaptive skills). A truly individualized curriculum fulfills each individual's right to an appropriate education (Ayres et al., 2011, 2012).

Additionally, insurance companies who fund applied behavior analysis (ABA) services often require that goals meet a standard of "medical necessity," which seemingly limits goal selection to those that address the core deficits of ASD, as defined in DSM-V (i.e., social impairment, language/communication impairment, and respective/restrictive behaviors; American Psychiatric Association, 2013). While these are important targets of intervention, limiting programming to these skills may omit targeting other vital adaptive behavior skills (Gerhardt et al., 2013); this is especially important when considering that individuals with ASD often have greater deficits in adaptive behavior in comparison to the general population (Matthews et al., 2015).

Skill areas in addition to academic skills and those skills specific to the ASD diagnostic criteria that can be considered meaningful include, but are not limited to, self-care/hygiene, dressing, health/safety, cleaning/care of the home, cleaning/care of clothing, mealtime skills, community engagement, self-management, and leisure/recreation. Such inherently complicated skills require intervention that is effective, potentially complex, and socially valid. Interventions based on the principles of ABA (Baer et al., 1968) represent a set of evidence-based strategies that have been demonstrated to increase adaptive behavior skills for older individuals with ASD. This includes, but is not limited to, interventions such as modeling, chaining, shaping, differential reinforcement, token economies, behavioral momentum, self-management, and functional communication training (FCT; Gerhardt & Lainer, 2011).

How to Teach: Effective Interventions for Meaningful Goals

Effective intervention to teach adaptive skills requires considerations in several areas such as (a) the context in which the skill is taught, (b) the intensity with which it is taught, (c) the efficiency of the skill, and (d) its inherent value to the individual learning the skill (Gerhardt et al., 2013). First, because individuals with autism have been shown to have difficulty generalizing skills and maintaining them over time (Arnold-Saritepe et al., 2009; de Marchena et al., 2015; Lovaas et al., 1973), a meaningful curriculum provides intervention in the environment where the skill is most likely to take place (Gerhardt et al., 2013). Skills targeted for acquisition that, on first glance, appear to be meaningful lose that designation when only taught out of the appropriate context (Brown et al., 1976). As such, practitioners cannot solely teach skills in classrooms or clinics and hope for the best. For example, an individual who is taught a purchasing routine to mastery in the classroom will be unlikely to do so in the community, absent any instruction in the community. As individuals get older, the proportion of teaching that should occur in contrived environments (e.g., classrooms, clinics) versus natural environments (i.e., where the skill will ultimately occur) should decrease (Gerhardt et al., 2013). Thinking long term is crucial, as individuals will only be in the classroom or clinic for a finite number of years but will be out in the real world the rest of their lives.

Second, skills must be taught with sufficient intensity to facilitate skill acquisition. As previously stated, many of the adaptive behavior skills that are critical for life outside of the classroom and matter most in adulthood are complicated. Practitioners must ensure that adequate instructional time is provided so sufficient practice opportunities are offered. This is especially important, given that individuals on the spectrum often require repeated opportunities to respond in order to acquire skills (Green, 2001; Lovaas et al., 1973). While simple academic tasks that are taught in the classroom easily allow for many teaching opportunities, this is generally not the case for complex, community-based skills in many programs. Practitioners cannot expect an individual to acquire such complex skills if instruction in the natural learning environment is provided just once a week. Complex, meaningful community-based adaptive behavior skills are attainable, but only if taught with sufficient instruction intensity (i.e., repeated opportunities to respond; Gerhardt et al., 2013).

Third, efficiency, which can be defined as the effort required for a task to be completed (Gerhardt et al., 2013), should be prioritized when developing a meaningful curriculum. Decreasing the response effort necessary to achieve the desired end may increase the likelihood of mastery, especially given that our society is constantly developing new ways to do this for typically developing individuals. For example, it may be much more efficient to teach an individual to use a smartphone application to track a train or subway route and purchase their ticket than to teach memorization of complicated public transportation routes and complex behavior chains required to purchase this ticket in person. Alternatively, it also may be even more efficient to teach the skill of using a rideshare application (e.g., Uber) to get to a desired destination.

Further, it is important to regularly assess individual progress in skill acquisition and make the necessary adaptations to, ideally, increase efficiency and more quickly facilitate mastery of the skill. For example, if an individual is struggling with measuring and pouring in laundry detergent and this is inhibiting full independence, an efficient adaptation would be to use Tide PODS™ instead. Other examples would include using Apple or Google Pay instead of a debit or credit card for purchases in the community, using the "send my location" function on a smart phone when asked, "Where are you?," or microwaving a healthy meal for lunch instead of cooking one from scratch. More efficient alternatives are abundantly available, so given that practitioners have limited time to teach complex adaptive behavior, instructional time should always be maximized.

Finally, a meaningful curriculum allows for balance between teaching high- and low-value skills, in terms of how much these skills matter to the individual learning them or how relevant they are in their everyday lives. A skill that is highly valued is more likely to be maintained over time, so should be prioritized in a meaningful curriculum (Gerhardt et al., 2013). However, low-value skills might also be important if they promote engagement, safety, or enjoyment in an indirect way. For example, showering may be a low-value skill to an individual, but mastery of the skill may lead to decreased body odor/increased neat appearance, which may help promote engagement in social situations or the ability to get and retain a job (which both may be of high value).

What to Teach: Socially Significant Goal Selection

While the procedures used are important, "Despite how evidence-based your interventions are, teaching inconsequential skills well is really no better than teaching essential skills poorly. *What we teach needs to be as important as how we teach*" (Gerhardt, 2008, p. #, emphasis added). Critical skills may be defined as the most impactful intervention targets and generally meet the following criteria: (a) once acquired, they enable the individual to complete a variety of relevant tasks independently and engage in desired activities, (b) they are used with sufficient frequency to remain in the repertoire once they are acquired, and (c) they can be acquired in a reasonable amount of time (Gerhardt & Rodriguez, 2018). McGreevy et al. (2014) outlined what they referred to as "The Essential Eight" (p. 2) which are prime examples of critical skills; these included making requests, waiting, accepting removals, completing required tasks, accepting "no," following directions, completing daily living skills related to health and safety, and tolerating situations related to health and safety. Another critical skill related to safety is the ability to say "No" in the context of an inappropriate request being made (Gerhardt & Rodriguez, 2018).

Critical skills can be identified by their congruence with what is known as the Criterion of Ultimate Functioning (Brown et al., 1976), which is essentially any skill that if the individual does not learn to do for themselves, someone will have to do it for them. Decision-making when choosing which skills to target for an individual on the spectrum should always be done with this criterion in mind. Ideally, a meaningful curriculum will begin targeting critical skills at a young age and increase in complexity across the lifespan. For example, if a terminal goal is to engage in the critical skill of dressing, this would entail closing the door for privacy, independently selecting clothing that is appropriate and preferred, putting on that clothing, and checking their appearance to confirm they look presentable before leaving. Building up to this skill, individuals as young as preschool or elementary age can begin working on tolerating wearing different types of clothing, work on zippering, snapping, buttoning, orienting clothing, or putting on various types of clothing. Upon getting to middle school age, they could begin selecting weather-appropriate clothing, getting dressed with absent supervision from others, doing components of their laundry, or putting clothing away. Upon reaching transition age, the individual may begin working on shopping for their own clothing and independently recognizing when their clothes are dirty and need to be changed (Gerhardt & Rodriguez, 2018). Of course, as previously stated, a meaningful curriculum is highly individualized, and these are only brief examples. However, practitioners should consider creating long-term goals and setting short-term objectives across various stages of the lifespan to ensure that programming is setting the individual up for meaningful outcomes (Bannerman et al., 1990; LaRue et al., 2016).

Choosing the right skills to teach in order to best promote more positive outcomes in adulthood is crucial, and such decisions should always be made with regard to social validity. Social validity, which is defined within the field of ABA as being "judged by someone as having value to society" (Wolf, 1978, p. 11), needs to be integrated into the goals we write, the procedures we use, and the degree of impact our treatments have (Wolf, 1978). Ensuring social validity requires that we seek the input of the individual whenever possible, the family, and society at large. When identifying which skills to target, practitioners are encouraged to take many social validity considerations into account before making any final decisions. For example, Bahry and Gerhardt (2021) identified 20 questions to ask when identifying meaningful goals; these questions span seven instructional considerations, including functionality and independence, long-term considerations, level of risk, enjoyment/community access, practical considerations, social considerations, and family/team considerations. Questions such as these can be asked as a self-assessment tool by the practitioner writing the goals or as part of larger conversation with a team including other practitioners and family members when discussing goal selection. Such questions are also encouraged to be asked by the individual themselves as a self-advocate in contributing to what their curriculum entails.

Intersection of the Individual

A central feature of a meaningful goal or objective is that it presents as meaningful to the person for whom it was written. In other words, meaningful goals require a significantly greater degree of individualization than do non-meaningful goals. This individualization requires a continual assessment of the intersection of the person with their environment along with their preferences, dislikes, and personal idiosyncrasies. For example, a goal for a person to respond with their location to a text sent to their smartphone by a known sender has value as a safety goal but, initially, may have limited meaningfulness. But, if we know that a student loves chocolate cake, beginning instruction by sending them texts telling them where to find a piece of chocolate cake will begin to make the goal more meaningful. Once they consistently respond to those texts, non-cake-related texts would be systematically introduced shifting from a fixed ratio (FR) 1 schedule of reinforcement (meaning reinforcement is provided on a fixed ratio of one, so after every correct response) to an intermittent schedule (Cooper et al., 2020; Ferster & Skinner, 1957). Ultimately, text requests to "tell me where you are" are consistently responded to by the student, as the overall skill is meaningful. Note that in this scenario, the student is not presented with a piece of cake as a potential reinforcer for responding to the text alarm. Instead, the text alarm works to signal the availability of reinforcement contingent on completing the text direction.

Admittedly, that is a fairly simple example of how intersectionality can be used to make goals meaningful. In many cases, particularly with adolescents and adults, the relevant "intersections" may be significantly complex. For example, sticking with the chocolate cake example, it may still be preferred, but it may only be a highly preferred stimulus if (a) mom made the cake, (b) it is eaten with a glass of milk, (c) it is eaten while watching music videos, and (d) it is eaten in the afternoon before going home. The intersection of the individual may be difficult to identify, but by initially isolating potential intersections and collecting data alone and in combination, the challenge is not insurmountable.

Commercially Available Assessments and Curricula: Guides, Not Roadmaps

There are numerous commercially available assessments and curricula that specifically aim to increase adaptive behavior skills that are important to daily life. Some of these available tools include only an assessment component and allow the user to assess a finite number of skills for their presence in the repertoire of the individual. The *Assessment of Functional Living Skills* (AFLS; Partington & Mueller, 2016) and the *Community-Based Skills Assessment* (CSA; Autism Speaks, 2014) are good examples of this type of assessment. Other tools contain both an assessment of a set number of functional skills and suggested methods by which to teach these skills such as lesson plans, task analyses, or a guided order in which skills should be prioritized. Some of these include the *Functional Independent Skills Handbook* (FISH; Killion, 2003), the *Eden Autism Assessment and Curriculum School Series* (Holmes et al., 1990), or *Essential for Living: A Communication, Behavior, and Functional Skills Curriculum, Assessment and Professional Practitioner's Handbook* (EFL; McGreevy et al., 2014).

These tools are beneficial for a number of reasons. Assessments allow the practitioner to determine a baseline level of a set number of skills and use that as a point to measure progress over a treatment period. This is generally necessary, and various funding sources may require a skills assessment during a certain time frame (e.g., annually, bi-annually) in order to demonstrate that the treatment being provided is effective. These tools may also be useful in generating ideas for meaningful goals; the inclusion of a certain skill within a tool may spark an idea for a target that may be very useful to an individual's life that they may not have thought of otherwise. Additionally, methods of teaching included in these tools may be helpful in deciding how a practitioner may teach the skill to the individual they are serving. While these tools can be very useful, simply because a skill is included on the assessment's desirable skills may falsely lead practitioners to assume that all skills included are necessary for all individuals. However, it is important to again remember that what is meaningful for some is not meaningful for all. A truly meaningful program is highly individualized. A practitioner should therefore not choose a skill to target simply because of its presence within a functional skills assessment or curriculum but should instead use clinical judgment to make these decisions on a case-by-case basis (Leaf et al., 2016).

To this end, there are also tools available that do not contain assessment components that survey for the presence or absence of specific skills, but instead provide guidance in how to create a meaningful curriculum for an individual, stressing the importance of individualization. Good examples of this include, but are not limited to, *The Syracuse Community-Referenced Curriculum Guide for Students with Moderate and Severe Disabilities* (Ford et al., 2005) and the *Functional Curriculum for Elementary and Secondary Students with Special Needs (fourth Edition)* (Wehman & Kregel, 2019). These curricula contain components such as decision-making tools to guide individualized goal selection, guidance on objective writing, scope and sequence charts to guide progressive goal writing over time, guidance on logistics of goal selection (e.g., when, where, with whom goals will be targeted), home-school collaboration strategies, decision points for departing from the general curriculum, as well as how to embed adaptive behavior targets into the general curriculum, amongst other idiosyncratic features. Again, the emphasis of such curricula is on the individual, and the purpose is to guide the practitioner to develop programming that is tailored to that specific individual. Such tools, coupled with social validity measures previously discussed, would appear to be particularly useful when developing a meaningful curriculum.

Respectful Intervention

"The more functional skills individuals with disabilities have in their repertoires, the more they can do for themselves, the more privacy, choice and dignity they have and the fewer social, emotional, financially and other pressures they place upon others" (Brown et al., 1979, p. 4). Meaningful curriculum, therefore, lends itself to respectful intervention. Integrating respect into programming involves ensuring that individual rights are not violated. These rights include those that allow for a preferred quality of life and, yes, happiness. This is of particular importance, given that individuals with ASD routinely report lower quality of life than same age, typically developing individuals (Ayres et al., 2018). Targeting goals that matter to the individual and that will play an integral role in their lives as adults promote the potential for improved quality of life. Additionally, much of the outcome data reported at the start of this chapter refer to quality-of-life indicators (e.g., social relationships, employment, integration into the community). Techniques rooted in ABA have demonstrated the ability to operationally define and systematically increase indices of happiness even in individuals with profound multiple disabilities with limited to no communication abilities (Dillon & Carr, 2007; Green et al., 1997; Green & Reid, 1996; Ivancic et al., 1997; Lancioni et al., 2002). On both practical and professionally ethical bases, the fact that tools exist to help identify and promote the acquisition of behaviors associated with improved quality of life supports an argument in favor of meaningful curriculum and intervention.

Respectful intervention promotes dignity and personal liberties for those it serves, imposing the fewest restrictions necessary to maintain safety and facilitate the development of skills (Van Houten et al., 1988). Winett and Winkler (1972) warned against "a rigid preoccupation with order and control and where children are required to be still, to be silent, and to obey" (p. 499); this is of increased importance as individuals age along the lifespan. While individuals have a right to effective treatment targeting the skills necessary to live as independently as possible, this may require instruction and support in exercising these freedoms responsibly (Bannerman et al., 1990). Personal liberties such as the right to choose and refuse and to make decisions about their programming should be afforded to all individuals, starting at a young age and increasing as they get closer to adulthood. These decisions can start out simply, such as what they will have for snack or which task they will work on first, and increase in complexity such as choosing clothing to purchase or which job or volunteer opportunities they will sample.

Embedding the instruction in self-determination skills is an important component of respectful intervention, especially because these skills often do not develop naturally individuals with disabilities (Stancliffe et al., 2000; Wehmeyer et al., 1996). As Wehmeyer and Abery (2013) stated, "Self-determined people are, in essence, actors in their own lives, rather than being acted upon" (p. 399). Such individuals make their own decisions, set their own goals, and create plans to meet these goals (Martin et al., 2019). This critical skill has been shown to improve the likelihood of meaningful outcomes in adulthood, specifically in the areas of employment, postsecondary education, and independent living (Field et al., 1998; Lachapelle et al., 2005; Powers et al., 2012; Wehmeyer & Schwartz, 1997). Self-determined behavior, including choice making, has also been identified as a core dimension of quality of life (Shalock & Verdugo, 2012; Wehmeyer & Abery, 2013). Happiness and, therefore, quality of life are often improved by simply stating what one wants and having that request honored; those able to make choices therefore have the ability to gain access to what they want and avoid what they do not want (Green & Reid, 1996). As such, those with well-established verbal repertoires may be at an advantage to those unable to communicate preferences (either vocally or by way of augmentative or alternative communication modalities). Meaningful curricula should therefore prioritize teaching these skills and, in the meantime, assess various indices of happiness (e.g., smiling, laughing, yelling while smiling) as well as unhappiness (e.g., frowning, crying, yelling without smiling) to determine and honor preferences (Dillon & Carr, 2007; Green & Reid, 1996).

For adults with autism, practitioners need to ensure that the language and behavior used during intervention promote dignity. How practitioners speak to, and about, the individual is central to this process. Minimally, this could involve using language that the individual and/or their family prefers (e.g., person-first vs. diagnosis-first language), refraining from speaking about the individual in front of them, avoiding potentially pejorative language such as "low-functioning," and speaking about people in a normative way (e.g., using respectful language like Ms./Mr. if it is customary in a given context; Reid et al., 2017). Behaving in a way that reflects dignity may involve traveling in a manner that does not suggest superiority (e.g., walking next to opposed to in front of the individual, intermixing staff and individuals with disabilities' seating in a van), avoiding segregating individuals with disabilities from the staff who are supporting them in the community (e.g., staff at one table, individuals with disabilities at another), and supporting a dignified appearance such that it would not reflect poorly on that individual (e.g., clothing that is dirty, private body parts exposed accidentally; Reid et al., 2017).

Similarly, individuals on the spectrum are entitled to the dignity of risk. Appropriate and reasonable risk-taking can, and should be, incorporated into a meaningful curriculum (Perske, 1972). For example, an individual will never be able to acquire the skills necessary to independently navigate throughout the mall if that opportunity is never provided to them under the guise of personal safety. Similarly, not providing instruction in the benefits of cooking healthy meals because the support staff are afraid that they might burn their hand fails to reference the frequency with which typical peers burn themselves during cooking.

Withholding access to risk is a way of infantilizing individuals. As clients grow older and enter adulthood, practitioners need to include instruction in the competencies associated with managing the dignity of risk to whatever extent possible while minimizing the possibility of harm or trauma. Clinical judgment, including an in-depth understanding of the individual's learning history, family concerns and preferences, and individual preferences, should be used to guide these decisions, with input from all team members.

Safety Skills

There are unintended consequences with a more paternalistic versus egalitarian model of supporting adults with disabilities. As previously stated, in the name of safety, caretakers including direct support staff, funding agencies, and guardians often protect the individual on the autism spectrum beyond the point of mitigating risk to nearly eliminating the possibility of risk altogether. The notion that individuals on the autism spectrum require close support, high levels of skill mastery, and demonstration of generalization across several, often arbitrary, environments before being allowed to venture out in the real world may constitute a barrier to respectful intervention. This may place restrictions on basic human rights, which includes the right to reasonable risk. Encountering risk through appropriate assessment is not only a human right but also a useful tool in intervention planning (Perske, 1972).

Ensuring the right to reasonable risk is afforded within a meaningful curriculum and often begins with allowing exposure. An individual cannot be expected to respond safely under novel conditions; however, lack of exposure should not be an excuse to prevent the individual from accessing those conditions. For example, we cannot assume every individual on the autism spectrum would be unsafe using a knife; therefore, preventing knife use based on merely a diagnosis is incredibly restrictive with a weak and inappropriate rationale. Allowing unrestricted access to many potentially dangerous items is not suggested either. Assessment and teaching of the desired skill in some form are necessary (of course, while always ultimately ensuring safety).

In addition to promoting dignity, reasonable risk supports error-based learning, which is an approach to teaching in which the learner has the opportunity to attempt the response, and in the event of an error, the practitioner immediately corrects that error (Ownsworth et al., 2013). Error-based learning can aid in generalization for acquired skills (Ownsworth et al., 2013) and is a fundamental way in which motor skills are acquired (Seidler et al., 2013). For example, drinking from a cup that is too full may result in the error of spilling that drink, but it is a valuable way to learn to adjust that behavior the next time a full cup is encountered. Error-based learning is in contrast to errorless learning, wherein the learner is provided opportunities to engage in correct responding with scaffolding so that they are highly unlikely to make an error (Cooper et al., 2020; Ownsworth et al., 2013). While there are notable outcomes resulting from errorless learning, criticism of the approach includes the lack of generalization of learned skills (Ownsworth et al., 2013, 2017). As such, practitioners should consider the use of error-based learning as an optional approach to teaching safety skills within a meaningful curriculum, as always, using clinical judgment to make such decisions.

If the individual is allowed to explore the contingencies of the environment, they may acquire valuable skills that cannot be taught in a classroom. In situ experiences where safety skills are required can allow the individual to access natural contingencies of reinforcement and punishment and promote generalization. Dixon et al. (2010) conducted a literature review and found that most training methods for teaching safety skills to individuals with developmental disabilities incorporated in situ procedures. However, not all teaching and learning environments are conducive to in situ training for every safety skill, so it may be important to mimic key attributes of the natural environment in order to increase acquisition of the skill with much less risk. This is exemplified in the work of Khan et al. (2021) teaching road safety to children using virtual reality and gamification. As the individual makes reasonable progress, safeguards can be strategically removed so that the individual can access the natural context for the skill increasingly independently. With all safety skill instruction, there may be a need for supervision to control for any significant safety errors. In all cases, the balance between safety and dignity is critical.

While some safety concerns will naturally resolve due to the changing physical characteristics of an aging individual (e.g., a person who does not meet the height requirement for an amusement park ride may reach a safe height to ride the following year), in general, safety skills should be taught as early as possible. This is especially important given the creativity often required to teach these skills and the need to strategically plan for their maintenance and generalization. Additionally, safety skills should be taught at a young age due to the previously mentioned lack of supports and services available in adulthood.

Identifying Safety Goals

Behavior analytic literature provides support for the identification and training of important safety skills such as poison prevention, abduction prevention, and firearm safety (Johnson et al., 2005; Miltenberger, 2008; Morosohk & Miltenberger, 2021; Petit-Frere & Miltenberger, 2021). Thus, safety skills can and should be targeted as part of a truly meaningful curriculum. In identifying safety goals, it is recommended to first consider the safety skills the individual currently exhibits and under what conditions. Decision-making regarding selection of safety skills goals should be made with consideration given to both the probability of the individual needing the skill and the level of risk to the individual if the skill is not in the repertoire. Safety skills that are high probability and high risk should be addressed with urgency, while low-probability, low-risk skills may be less of a priority. For example, pedestrian safety is likely to be a very important skill in urban areas with many crosswalks and sidewalks (i.e., high probability), whereas it may be less relevant in rural areas with less traffic flow (i.e., low probability). In order to determine which safety skills to target for intervention, the practitioner should gather information about the environments the individual frequently contacts or is likely to contact in the future. Assessments and curricula can serve as a guide for selecting skills; however, these skills should be relevant to the goals, common environments, and current supports in place specifically for the individual.

Generally, safety skills are targeted in either a reactive or proactive manner. For example, targeting safe street crossing *after* an individual attempts to cross the street when the “Don’t Walk” sign is lit would constitute a reactive intervention. The same skill targeted proactively could include instruction in recognizing and differentially responding to “Walk/Don’t Walk” signs *before* approaching an actual intersection. Neither way is intrinsically better than the other, and it can often be difficult to predict which safety skills are necessary as a function of the context in which the skill is needed. However, not targeting either strategy should be considered unacceptable; the inclusion of such skills is a crucial component of a meaningful curriculum.

As previously mentioned, social validity must be taken into account at all stages of meaningful curriculum development, including consideration of long-term outcomes. Targeting relevant safety skills is often necessary to achieve these outcomes. For example, if it is determined that the individual enjoys cooking meals and would like to cook for other people, a job description of a chef, identifying the prerequisite skills for culinary classes or speaking with someone who already works in the field may be helpful in identifying meaningful goals. It may also be helpful to explore multiple avenues for this interest; in addition to becoming a chef, an individual who enjoys cooking for others could become a caretaker, volunteer for a meal program, and/or prepare meals for friends and family. Each of these long-term goals will require multiple safety skills to be targeted for acquisition, with some being more important depending on the intended outcome and future responsibilities. It is helpful to work backward from the long-term goal and ask the question, “What is preventing the individual from doing this now?” The answer to this question will dictate the ways in which safety concerns are addressed.

Addressing Safety Concerns

Regarding safety concerns resulting from physical limitations, collaboration with other disciplines is critical to the success of the individual. For example, a person with a physical limitation involving the use of their legs may have difficulty accessing a building where stairs pose both a barrier to the individual and a safety concern to their support team. By seeking consultation from an appropriate specialist, the individual could work to develop the strength and skills necessary to climb the stairs, use assistive technology to climb the stairs, or access accommodations or alternatives for entering the building. For a person with difficulty using a knife due to decreased mobility in their hands, there may be some safety concerns regarding the safe preparation of their meals. Seeking consultation could help to increase mobility in their hands, make modifications to the conditions under which knives are used (e.g., knives are used for slicing medium and large food items that are flat but are not used for dicing), and/or use alternative devices to accomplish the same task (e.g., using a kitchen appliance to chop or dice vegetables instead of a knife).

Additional Considerations

Safety skills are not only about physical preservation of the individual. Safety skills also encompass avoiding financial and/or sexual exploitation as well as knowledge of state and federal laws and human rights. Financial safety skills that may guard against financial exploitation (to the extent possible) may include using a credit card, handling money, as well as being able to sign one’s own name, recognize their signature, and differentiate when to sign a document. The process of receiving a document, reviewing the document for understanding, seeking clarification and/or consultation from a trusted advisor if necessary, and then signing the document may be a manageable and attainable skill when task analyzed. Another important safety skill in the prevention of abuse and exploitation is personal/physical resistance, often called noncompliance. Reinforcing “over-compliance” can put individuals with different disability labels at significantly increased risk for abuse and exploitation (Muccigrosso, 1991). Teaching and honoring consent, assent, and resistance are necessary safety skills for all individuals.

Meaningful Intervention and Challenging Behavior

A high prevalence of challenging behavior exists within the ASD population, specifically with such dangerous behavior as self-injury and aggression. Often these behaviors develop as a result of skill deficits in other areas, such as communication. In a large population-based sample in the United States, self-injurious behavior (SIB) was reported to occur in more than 30% of children with ASD (Soke et al., 2016). Another large sample study found aggression to be reported in approximately one in four individuals with ASD, with a significant association found between aggression and overall cognitive level (IQ; Hill et al., 2014). The display of challenging behavior can, and often does, restrict the activity of adolescents and adults on the spectrum. Community-based instruction (CBI) often gets put on hold, as do job training opportunities because of the presence of challenging behavior. As such, a meaningful curriculum should adequately address these challenges in order to allow for increased skills in other important areas.

Despite having over 60 years of behavior analytic research focusing on the assessment and intervention of challenging behavior (Ala'i-Rosales et al., 2018), the vast majority of this research has been conducted in well-controlled environments with little attention paid to generalization and long-term maintenance. Part of the problem is that research-based approaches to autism in less controlled environments are not accepted as a worthy endeavor within the general research community. The complexity of autism beyond the clinic or classroom (i.e., the real world) does not lend itself well to constrained laboratory investigation. However, research attempting to address this complexity outside the laboratory is often viewed as being of poorer quality and often not published (Singh & Elsabbagh, 2014). This means, unfortunately, that the research base for assessment and intervention in less well-controlled environments such as the individual's home or in the community is lacking.

Further complicating the issue is that there seems to be no agreed upon definition of "in the community." In much of the research on functional behavior assessment (e.g., Dunlap & Kern, 2018), the phrase *in the community* refers to intervention in the classroom, as opposed to in the clinic or other research setting. As such, there exists a significant gap in our understanding as to how to best determine the function of a behavior in less structured environments (e.g., in the community, meaning parks, grocery stores, movie theaters). Research conducted in such real-world environments are needed in order to progress our understanding and ability to intervene effectively in these contexts.

None of this, however, should be understood as being outside the scope of practice of a knowledgeable and skilled behavior analyst. To the contrary, behavior analysis is the only science, and practice, with the potential to effectively and efficiently address this challenge. So, with regard to meaningful intervention with challenging behaviors displayed by adolescents and adults with ASD, a few suggestions/recommendations are offered. Meaningful intervention with challenging behavior:

1. Requires that the observed behavior change results in positive changes to the individual's life. Reductions in the frequency of aggression that does not increase community access or employment opportunities, while important, may not constitute meaningful behavior change.
2. Should, ideally, result in a set of skills that enable the individual to manage their own behavior. This includes, but is not limited to, antecedent strategies such as behavioral relaxation/self-calming, functional communication competencies, context-appropriate refusal skills, the ability to accept delayed reinforcement, curricular modifications congruent with the individual's preferences, and environmental modifications that support greater access to positive reinforcement.
3. Targets only those behaviors that are documented to have a negative impact on the individual's quality of life. All of us engage in stereotypic behavior. The difference lies in our understanding of the social contingencies that govern behavior and our ability to then learn to differentiate between the conditions when we can and cannot engage in stereotypy. Any stereotypy intervention, therefore, should be instructional in nature.

4. Acknowledges each individual's right to be angry, irritated, or annoyed. It is only a problem when anger, irritation, or annoyance presents as aggression or self-injury. What happens before that, however, is potentially reinforceable as behaviors that are, often, low effort and, potentially, incompatible with the display of aggression or self-injury.

Meaningful intervention with challenging behavior is, like meaningful intervention in general, highly individualized and focused on sustainable behavior change in the absence of paid support. While this may present even the most skilled behavior analyst with a significant challenge, not doing so presents the individual in question, with a challenge of greater significance, that is, how to attain a positive quality of life in adulthood.

Future Planning

Long-term planning can be overwhelming and confusing. It is difficult to prioritize goals and challenging to conceptualize big picture goals as manageable skills that can be successfully taught. Adulthood is difficult and complicated, and the skills required to be successful as an adult often include multiple components; any one skill may include social skills, multitasking, communication, and self-help. Additionally, many skills are context-dependent; they require certain behaviors in some settings, but different behaviors in others. Fortunately, there are some strategies to implement in long-term planning that help make these easier.

Plan Ahead

Skills that are complicated and variable do not necessarily take longer to learn than those that are simple and straightforward. Skills that are simple (e.g., putting on a shirt, microwaving a bag of popcorn, checking your email) are usually similarly implemented in a variety of settings, and fairly straightforward to teach. The good news is that bigger, complex skills (e.g., getting ready to leave the house in the morning, making your own meals, applying for a job) are really just made up of several of these smaller skills. Getting ready to leave the house in the morning includes the skill of putting on a shirt independently, microwaving a bag of popcorn for a snack is a steppingstone to microwaving a frozen dinner for a meal, and checking your email is a component of completing an online job application. This makes it important to consider whether the short-term goals that are being taught to the individual are going to contribute to the acquisition of a longer-term goal. If this path is not readily apparent, it may mean that further consideration of the utility of that short-term goal is required. A more proactive approach is to work backward. Consider the best outcome for the individual. Once that has been decided, look at what goals will help the individual achieve those outcomes, and then further break those goals into component skills. Continuing to break skills down into smaller components will eventually bring you to a starting point. That starting point is a meaningful goal.

In further consideration of planning ahead, this process should begin early in the individual's life. It is unclear exactly what the ideal point to begin planning meaningful goals is, but it is likely much earlier than most people think. While many jurisdictions have legislation that outlines when it needs to begin in school, some experts argue that transitioning planning should begin as young as preschool (Gerhardt & Rodriguez, 2018). In some cases, a consideration of where the skill being taught would fit into a bigger goal is a good way to do this.

Using data from the *National Longitudinal Transition Study 2* (NLTS-2), Shogren and Plotner (2012) found that the average age that transition planning began in schools for students with autism was 14.4 years. Additionally, Shogren and Plotner found that the goal "maximize functional independence" (p. 19) was found to be cited in the goals of 57.9% of students with ASD. For 57.1% of students with ASD, a goal of "enhance social/interpersonal relationships and satisfaction" (Shogren &

Plotner, 2012, p. 19) was included in their plans, and only 22.9% had a goal of attend a 2- or 4-year college. Unfortunately, one third of students had an Individualized Education Plan (IEP) that did not link the course of study for the student with their transition goals. Given that meaningful life goals are time-consuming and difficult to attain, it is imperative that all educational and teaching opportunities are maximized by effectively planning ahead.

Person-Centered

As stated earlier in this chapter, integral to successful future planning is the inclusion of the person whose life is being planned. Person-centered planning includes the person's opinion of the life they see as meaningful based on their individual strengths, abilities, aspirations, and preferences (Collings et al., 2019). It has been found that person-centered planning can result in positive outcomes for people with various disabilities (Robertson et al., 2007) and, thus, should be included in long-term planning. Since the active engagement of the individual in person-centered planning generally requires having the ability to make and communicate decisions (Grove & McIntosh, 2005), it is important to target those skills early in an individual's life and to provide many opportunities to practice. Even then, however, alternative methods of determining a student's likes, dislikes, and plans for the future will need to somehow be included.

Flexibility

The last pillar to long-term planning is flexibility. Long-term plans change. It is estimated that young employed individuals (i.e., ages 18–24 years) change jobs an average of 5.7 times in the early stages of their career (US Department of Labor Bureau of Labor Statistics, 2019). According to the Centers for Disease Control and Prevention (CDC), as of 2020, the divorce rate in the United States was almost 50% (CDC, 2021). This means that for a very large proportion of the population, at some point in life, long-term plans changed. People's interests change, they are exposed to new experiences, they meet new people, and so on. While it is important to begin long-term planning early, it is also important to remember that those plans may need some adjusting over time.

Generalization and Maintenance

The last phase in planning meaningful goals and creating a functional intervention is ensuring generalization and maintenance of the skills taught. Generalization occurs when "a broad range of stimuli 'set the occasion for' or evoke a particular behavior" (Mayer et al., 2012, p. 416). This means that a variety of stimuli need to evoke the same response. Consider the example of an individual returning a greeting from another person. The goal is that the individual is able to respond "hi" when a friend says "hi," but also when the friend says, "hey," "what's up," "hi there," "hello," and so on. A similar type of generalization occurs as response generalization, in which case the goal is that in response to a friend saying "hi," the individual can respond with "hey," "hi," "what's up," "hello," etc. Both types of generalization are integral to learning. With all the time and effort that can go into teaching meaningful goals, the utility of these goals is severely limited if they cannot be applied to a broad range of stimuli or responses.

In a pivotal article in 1977, Stokes and Baer outlined strategies to promote generalization. Until this point, generalization was considered to be a largely passive process, one that just happened after a skill was taught. Stokes and Baer outlined nine strategies for generalization that could be utilized including:

1. Train and hope: Do nothing beyond regular teaching to promote generalization. This strategy does not often result in practical generalization (e.g., teach the skill of ordering food in a fast-food restaurant and then go to new fast-food restaurants and hope to see demonstration of the skill there too).

2. Sequential modification: Teach a specific behavior and then assess for generalization. If it does not occur, then teach for generalization (e.g., teach the skill of ordering food in a fast-food restaurant and then go to new fast-food restaurants and hope to see demonstration of the skill there too. If generalization is not seen, then program for the skill in the new fast-food location).
3. Introduce to natural maintaining contingencies: Teach the skill to be maintained by using the items that will occur in the natural environment as reinforcement as opposed to artificial reinforcers (e.g., ordering a treat at a fast-food restaurant as the reinforcer while teaching the skill).
4. Train sufficient exemplars: Use a variety of stimuli in initial teaching (e.g., teach ordering in a variety of fast-food restaurants at the same time).
5. Train loosely: Use loose stimulus control in initial teaching (e.g., teach to order food in variable order, using different methods of payment, etc.).
6. Use indiscriminable contingencies: Use intermittent schedules of reinforcement throughout teaching (e.g., sometimes ordering an ice cream after successful trials, sometimes not ordering an ice cream).
7. Program common stimuli: Look for the commonalities across stimuli and teach those. (e.g., line up to order at the counter, wait for food at the other end of the counter).
8. Mediate generalization: Establish a new response that is likely to be used in other settings as well (e.g., waiting in line to order is likely to be used similarly in other fast-food restaurants, not just the one taught).
9. Train to generalize: Instruct and reinforce instances of demonstrated generalization (e.g., in a new fast-food restaurant reinforcing recognizing where to line up).

Not every strategy will be feasible or effective in each situation, and the most effective method may be a combination of several strategies. When considering the complexity of teaching meaningful skills, as well as the ever-challenging aspect of having enough time to teach everything that is needed, it is extremely important that generalization be targeted appropriately and consistently.

The final factor to consider is maintenance of skill, which can be defined as “a lasting change in behavior” (Cooper et al., 2020, p. 302). This seems to be an obvious concern; skills that do not maintain are no longer of use to the individual. In general, if a skill is programmed so that the demonstration of the skill is maintained by contingencies that are naturally reinforcing in the environment within which the skill will be used, it is likely that that skill will be well maintained (Kohler & Greenwood, 1986; Leaf & McEachin, 1999). Fortunately, meaningful goals often include reinforcement that is likely to occur in the natural environment. Consider the acquisition of a second language. If an individual is taught the language in a contrived environment like a classroom and never has opportunity to use the language outside of that setting, it is likely that, over time, their fluency and accuracy when using language will worsen. Compare that to a situation wherein the individual acquires a new language in an immersive community such as a community where that language is regularly spoken. The lack of opportunity to practice and be naturally reinforced for the use of that language contributes to poor maintenance of the skill. This is important in the selection of meaningful goals as discussed earlier in the chapter; choosing skills that the individual is likely to need often in their environment will help those skills be naturally maintained, and, as such, they are likely to be retained in the individual’s repertoire.

Summary

Personal independence is, for all intents and purposes, the degree of congruence between the skills an individual has acquired over time and those required to navigate the social, communication, safety, and mobility demands of the environment in which they live, work, or play. Most typically developing individuals acquire a majority of these skills through a combination of in vivo modeling, shaping, chaining, trial and error, generalization, and long-term maintenance (among others). Some more "specialized" skills (e.g., riding a bike, playing an instrument, doing the backstroke) may require a degree of formalized instruction, particularly if the goal is for the skill to be displayed at a more proficient level than one's peers. For people with autism, however, that naturalistic combination of processes in a naturalistic context is generally insufficient to acquire even basic skills.

Instruction in skills collectively referred to as adaptive behavior is associated with more positive outcomes in adulthood (Dell'Armo & Tassé, 2018). Adaptive behavior, however, represents an incredibly complex and diverse collection of skills and behavioral competencies, the boundaries of which are defined by the intersection of age in years and the physical, geographic, sociocultural, economic, personal preferences, and health-related demands of the environment. This is at the core of *meaningful curriculum and functional intervention*.

Various aspects of meaningful curriculum and functional intervention have been laid out in some detail earlier in the chapter. However, there is a meaningful curriculum "hack" that has not been discussed, and that is the use of the phrase "in order to." When writing instructional goals as part of a school-based IEP, an insurance-funded treatment plan, or a Medicaid-funded adult program, end the goal with "in order to…" and then complete the sentence.

For example, Bill is a fictional 13-year-old who lives in a rural community. Bill has coexisting diagnoses of autism and an intellectual disability. An instructional goal for Bill may be "Bill will learn to independently ride a 2-wheeled bicycle for a minimum of 60-minutes." Absent additional information, this would appear to be a very time-intensive instructional goal. However, if we add a completed "in order to," we end up with, "Bill will learn to independently ride a 2-wheeled bicycle for a minimum of 60-minutes *in order to join his family on long bike rides and promote a healthy lifestyle as he ages*." This addition explains in plain language why this goal could be considered meaningful to Bill. On the other hand, if Bill had a goal such as "Bill will learn to balance his checkbook using the bank provided ledger and a calculator *in order to*…" In order to what? In order to do something in the most difficult way possible when using an app or downloading an account statement online would provide the same outcome much more quickly and easily. Perhaps more importantly, assume Bill masters the calculator goal, where does he go with that skill next? Does he report a negative balance to a parent? Does he advocate at the bank to correct their error? Or, maybe, he then transfers money from one account to another to cover the deficit? In any case, the addition of "in order to" allows this helpful thought process to begin, the outcome of which may be to further refine goals to make them more meaningful. It is of course not suggested that this is a fool-proof method, neither should it be considered a substitute to the recommendations provided earlier in this chapter. At best, "in order to" is simply a potentially useful goal hack that may be considered.

Effective intervention requires the merge of evidence-based intervention with individualized, meaningful curriculum applied in the context of the complexities in the lives of students and/or clients. While the concept of meaningful curriculum has significant face validity (i.e., it makes sense), the research base in support of this approach can be described as limited. However, until that research is available, it is probably worth repeating that "teaching the wrong skills well is no better than teaching the right skills poorly." As a field, we are proficient at evidence-based skills acquisition. Now we need to be proficient with targeting the right skills.Compliance with Ethical StandardsNo funding was received for this manuscript. There were no human participants in this manuscript, and therefore we did not need to receive informed consent obtained from the parents of all individual participants included in the study. We were in accordance with ethical standards of the Institutional Research Committee and with 1964 Helsinki decoration and its later amendments or comparable ethical standards.

References

Ala'i-Rosales, S., Cihon, J. H., Currier, T., Ferguson, J. L., Leaf, J. B., Leaf, R., McEachin, J., & Weinkauf, S. M. (2018). The big four: Functional assessment research informs preventative behavior analysis. *Behavior Analysis in Practice, 12*(1), 222–234. https://doi.org/10.1007/s40617-018-00291-9

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Publishing. https://doi.org/10.1176/appi.books.9780890425596

Arnold-Saritepe, A., Phillips, K. J., Mudford, O., Rozario, K. A., & Taylor, S. (2009). Generalization and maintenance. In J. Matson (Ed.), *Applied behavior analysis for children with autism spectrum disorders* (pp. 207–224). Springer. https://doi.org/10.1007/978-1-4419-0088-3_12

Autism Speaks. (2014). *Community-based skills assessment (CSA): Developing a personalized transition plan*. https://www.autismspeaks.org/tool-kit/community-based-skills-assessment

Autism Speaks. (n.d.) *Autism statistics and facts.* https://www.autismspeaks.org/autism-statistics-asd

Ayres, K. M., Douglas, K. H., Lowrey, K. A., & Sievers, C. (2011). I can identify Saturn but I can't brush my teeth: What happens when the curricular focus for students with severe disabilities shifts. *Education and Training in Autism and Developmental Disabilities, 46*(1), 11–21.

Ayres, K. M., Douglas, K. H., Lowrey, K. A., & Sievers, C. (2012). The question still remains: What happens when the curricular focus for students with severe disabilities shifts? A reply to Courtade, Spooner, Browder, and Jimenez (2012). *Education and Training in Autism and Developmental Disabilities, 46*(1), 14–22.

Ayres, M., Parr, J. R., Rodgers, J., Mason, D., Avery, L., & Flynn, D. (2018). A systematic review of quality of life of adults on the autism spectrum. *Autism, 22*(7), 774–783. https://doi.org/10.1177/1362361317714988

Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis, 1*(1), 91–97. https://doi.org/10.1901/jaba.1968.1-91

Bahry, S. N., & Gerhardt, P. F. (2021). *Make it meaningful: A practitioner's guide to writing goals that matter.* Manuscript in preparation.

Bannerman, D. J., Sheldon, J. B., Sherman, J. A., & Harchik, A. (1990). Balancing the right to habilitation with the right to personal liberties: The rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behavior Analysis, 23*(1), 79–89. https://doi.org/10.1901/jaba.1990.23-79

Brown, L., Nietupski, J., & Hamre-Nietupski, S. (1976). Criterion of ultimate functioning. In M. A. Thomas (Ed.), *Hey, don't forget about me: Education's investment in the severely, profoundly, and multiply handicapped* (pp. 2–15). The Council for Exceptional Children. Retrieved from https://mn.gov/mnddc/parallels2/pdf/70s/76/76-HDF-CEC.pdf

Brown, L., McLean, B., Nietupski, S. H., Pumpian, I., Certo, N., & Gruenewald, L. (1979). A strategy for developing chronological age appropriate and functional curricular content for adolescents and young adults with significant disabilities. *Journal of Special Education, 13*(1), 81–90. https://doi.org/10.1177/002246697901300113

Centers for Disease Control and Prevention (CDC). (2021, May 4). *Marriage and divorce*. https://www.cdc.gov/nchs/fastats/marriage-divorce

Cimera, R. E., & Cowan, R. J. (2009). The costs of services and employment outcomes achieved by adults with autism in the US. *Autism, 13*(3), 285–302. https://doi.org/10.1177/1362361309103791

Collings, S., Dew, A., & Dowse, L. (2019). 'They need to have walked in our shoes': What people with intellectual disability say about National Disability Insurance Scheme planning. *Journal of Intellectual and Developmental Disability, 44*(1), 1–12. https://doi.org/10.3109/13668250.2017.1287887

Cooper, J. O., Heron, T. E., & Heward, W. L. (2020). *Applied behavior analysis* (3rd ed.). Pearson Education.

de Marchena, A. B., Eigsti, I. M., & Yerys, B. E. (2015). Brief report: Generalization weaknesses in verbally fluent children and adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*(10), 3370–3376. https://doi.org/10.1007/s10803-015-2478-6

Dell'Armo, K. A., & Tassé, M. J. (2018). The role of adaptive behavior and parent expectations in predicting post-school outcomes for young adults with intellectual disability. *Journal of Autism Developmental Disorders, 49*(4), 1638–1651. https://doi.org/10.1007/s10803-018-3857-6

Dillon, C. M., & Carr, J. E. (2007). Assessing indices of happiness and unhappiness in individual with developmental disabilities: A review. *Behavioral Interventions, 22*(3), 229–244. https://doi.org/10.1002/bin.240

Dixon, D. R., Bergstrom, R., Smith, M. N., & Tarbox, J. (2010). A review of research on procedures for teaching safety skills to persons with developmental disabilities. *Research in Developmental Disabilities, 31*(5), 985–994. https://doi.org/10.1016/j.ridd.2010.03.007

Dunlap, G., & Kern, L. (2018). Perspectives on functional (behavioral) assessment. *Behavioral Disorders, 43*(2), 316–321. https://doi.org/10.1177/0198742917746633

Farley, M., Cottle, K. J., Bilder, D., Viskochil, J., Coon, H., & McMahon, W. (2018). Mid-life social outcomes for a population-based sample of adults with ASD. *Autism Resources, 11*(1), 142–152. https://doi.org/10.1002/aur.1897

Ferster, C. B., & Skinner, B. F. (1957). Schedules of reinforcement. *Appleton-Century-Crofts*. https://doi.org/10.1037/10627-000

Field, S., Martin, J., Miller, R., Ward, M., & Wehmeyer, M. (1998). Self-determination for persons with disabilities: A position statement of the Division on Career Development and Transition. *Career Development for Exceptional Individuals, 21*(2), 113–128. https://doi.org/10.1177/088572889802100202

Ford, A., Schnorr, R., Meyer, L., Davern, L., Black, J., & Dempsey, P. (Eds.). (2005). *The Syracuse community-referenced curriculum guide for students with moderate and severe disabilities*. Paul H. Brookes Publishing Co. (Original work published 1989).

Gerhardt, P. F. (2008, March 7). *ABA and effective intervention for older individuals with ASD: Transitioning to competent adulthood* [PowerPoint Slides]. Texas Association for Behavior Analysis, Invited Workshop. Dallas, TX.

Gerhardt, P. F., & Lainer, I. (2011). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy, 41*, 37–45. https://doi.org/10.1007/s10879-010-9160-2

Gerhardt, P. F., & Rodriguez, A., (2018, May 25). *Adulthood begins in preschool: Identification and intervention with skills that support competent adulthood* [PowerPoint Slides]. Association for Behavior Analysis Annual Convention, San Diego, CA.

Gerhardt, P. F., Zawacki, J., & Satriale, G. (2013). Adaptive behavior in adolescents and adults with autism spectrum disorders. In P. F. Gerhardt & D. Crimmins (Eds.), *Social skill and adaptive behavior intervention with learners with autism* (pp. 159–170). Brookes Publishing.

Green, G. (2001). Behavior analytic instruction for learners with autism: Advances in stimulus control technology. *Focus on Autism and Other Developmental Disabilities, 16*(2), 72–85. https://doi.org/10.1177/108835760101600203

Green, C. W., & Reid, D. H. (1996). Defining, validating, and increasing indices of happiness among people with profound multiple disabilities. *Journal of Applied Behavior Analysis, 29*(1), 67–78. https://doi.org/10.1901/jaba.1997.30-217

Green, C. W., Gardner, S. M., & Reid, D. H. (1997). Increasing indices of happiness among people with profound multiple disabilities: A program replication and component analysis. *Journal of Applied Behavior Analysis, 30*(2), 217–228. https://doi.org/10.1901/jaba.1997.30-217

Grove, N., & McIntosh, B. (2005). *Communication for person centered planning*. Foundation for People with Learning Disabilities.

Heward, W. I. (2005). *Exceptional children: An introduction to special education*. Prentice Hall.

Hill, A. P., Zuckerman, K. E., Hagen, A. D., Kriz, D. J., Duvall, S. W., van Santen, J., Nigg, J., Fair, D., & Fombonne, E. (2014). Aggressive behavior problems in children with autism spectrum disorders: Prevalence and correlates in a large clinical sample. *Research in Autism Spectrum Disorders, 8*(9), 1121–1133. https://doi.org/10.1016/j.rasd.2014.05.006

Holmes, A. S., Brooks, M., Finkler, N., & Guadagno, C. (Eds.). (1990). *Eden autism assessment and curriculum school series*. Eden Institute, Inc.

Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry, 30*(2), 69–76. https://doi.org/10.1097/YCO.0000000000000308

Ivancic, M. T., Barrett, G. T., Simonow, A., & Kimberly, A. (1997). A replication to increase happiness indices among some people with profound multiple disabilities. *Research in Developmental Disabilities, 18*(1), 79–89. https://doi.org/10.1016/S0891-4222(96)00039-X

Johnson, B. M., Miltenberger, R. G., Egemo-Helm, K., Jostad, C. M., Flessner, C., & Gatheridge, B. (2005). Evaluation of behavioral skills training for teaching abduction-prevention skills to young children. *Journal of Applied Behavior Analysis, 38*(1), 67–78. https://doi.org/10.1901/jaba.2005.26-04

Khan, N., Muhammad, K., Hussain, T., Nasir, M., Munsif, M., Imran, A. S., & Sajjad, M. (2021). An adaptive game-based learning strategy for children road safety education and practice in virtual space. *Sensors, 21*(11), 3661. https://doi.org/10.3390/s21113661

Killion, W. K. (2003). *Functional independence skills handbook: Assessment and curriculum for individuals with developmental disabilities*. Pro-Ed.

Kohler, F. W., & Greenwood, C. R. (1986). Toward a technology of generalization: The identification of natural contingencies of reinforcement. *The Behavior Analyst, 9*, 19–26. https://doi.org/10.1007/BF03391926

Lachapelle, Y., Wehmeyer, M. L., Haelwyck, M. C., Courbois, Y., Keith, K. D., Schalock, R., & Walsh, P. N. (2005). The relationship between quality of life and self-determination: An international study. *Journal of Intellectual Disability Research, 49*(10), 740–744. https://doi.org/10.1111/j.1365-2788.2005.00743.x

Lancioni, G. E., O'Reilly, M. F., Campodonioc, F., & Mantini, M. (2002). Increasing indices of happiness and positive engagement in persons with profound multiple disabilities. *Journal of Developmental and Physical Disabilities, 14*, 231–237. https://doi.org/10.1023/A:1016020320752

LaRue, R. H., Manente, C. J., Dashow, E., & Sloman, K. N. (2016). Functional skills. In N. N. Singh (Ed.), *Handbook of evidence-based practices in intellectual and developmental disabilities* (pp. 229–239). Springer. https://doi.org/10.1007/978-3-319-26583-4_9

Leaf, R. B., & McEachin, J. J. (1999). *A work in progress: Behavior management strategies and a curriculum for intensive behavioral treatment of autism. Different roads to learning*. NY DRL Books.

Leaf, J. B., Leaf, R., McEachin, J., Taubman, M., Ala'i-Rosales, S., Ross, R. K., Smith, T., & Weiss, M. J. (2016). Applied behavior analysis is a science and, therefore, progressive. *Journal of Autism and Developmental Disorders, 46*(2), 720–731. https://doi.org/10.1007/s10803-015-2591-6

Lovaas, O. I., Koegel, R., Simmons, J. Q., & Long, J. S. (1973). Some generalization and follow-up measures on autistic children in behavior therapy. *Journal of Applied Behavior Analysis, 6*(1), 131–165. https://doi.org/10.1901/jaba.1973.6-131

Martin, J. E., Pulos, J. M., & Sale, P. (2019). Assessing and teaching critical self-determination skills to transition-age youth with disabilities. In P. Wehman & J. Kregel (Eds.), *Functional curriculum for elementary and secondary students with special needs* (4th ed., pp. 53–74). PRO-ED, Inc.

Matthews, N. L., Smith, C. J., Pollard, E., Ober-Reynolds, S., Kirwan, J., & Malligo, A. (2015). Adaptive functioning in autism spectrum disorder during the transition to adulthood. *Journal of Autism and Developmental Disorders, 45*(8), 2349–2360. https://doi.org/10.1007/s10803-015-2400-2

Mayer, G. R., Sulzer-Azaroff, B., & Wallace, M. (2012). *Behavior analysis for lasting change* (2nd ed.). Sloan Publishing.

Mazefsky, C. A., Williams, D. L., & Minshew, N. J. (2008). Variability in adaptive behavior in autism: Evidence for the importance of family history. *Journal of Abnormal Child Psychology, 36*(4), 591–599. https://doi.org/10.1007/s10802-007-9202-8

Mazzotti, V. L., Rowe, D. A., Sinclair, J., Poppen, M., Woods, W. E., & Shearer, M. L. (2016). Predictors of post-school success: A systematic review of NLTS2 secondary analyses. *Career Development and Transition for Exceptional Students, 39*(4), 196–215. https://doi.org/10.1177/2165143415588047

McGreevy, P., Fry, T., & Cornwall, C. (2014). *Essential for living: A communication, behavior and functional skills curriculum, assessment and professional practitioner's handbook for children and adults with moderate-to-severe disabilities*. Patrick McGreevy, Ph.D., P.A.

Miltenberger, R. G. (2008). Teaching safety skills to children: Prevention of firearm injury as an exemplar of best practice in assessment, training, and generalization of safety skills. *Behavior Analysis in Practice, 1*(1), 30–36. https://doi.org/10.1007/BF03391718

Morosohk, E., & Miltenberger, R. (2021). Using generalization-enhanced behavioral skills training to teach poison safety skills to children with autism. *Journal of Autism and Developmental Disorders, 52*(1), 283–290. https://doi.org/10.1007/s10803-021-04938-5

Muccigrosso, L. (1991). Sexual abuse prevention strategies and programs for persons with developmental disabilities. *Sexuality and Disability, 9*, 261–271. https://doi.org/10.1007/BF01102396

Newman, L., Wagner, M., Cameto, R., Knokey, A., & Shaver, D. (2010). *Comparisons across time of the outcomes of youth with disabilities up to 4 years after high school: A report of findings from the National Longitudinal Transition Study (NLTS) and the National Longitudinal Transition Study-2 (NLTS-2)*. SRI International. Retrieved from https://nlts2.sri.com/reports/2010_09/nlts2_report_2010_09_complete.pdf

Ownsworth, T., Fleming, J., Tate, R., Shum, D. H. K., Griffin, J., Schmidt, J., Lane-Brown, A., Kendall, M., & Chevignard, M. (2013). Comparison of error-based and errorless learning for people with severe traumatic brain injury: Study protocol for a randomized control trial. *Trials, 14*, 369. https://doi.org/10.1186/1745-6215-14-369

Ownsworth, T., Fleming, J., Tate, R., Beadle, E., Griffin, J., Kendall, M., Schmidt, J., Lane-Brown, A., Chevignard, M., & Shum, D. H. (2017). Do people with severe traumatic brain injury benefit from making errors? A randomized controlled trial of error-based and errorless learning. *Neurorehabilitation and Neural Repair, 31*(12), 1072–1082.

Partington, J. W., & Mueller, M. M. (2016). *The assessment of functional living skills guide: Essential skills for independence at home, school, and in the community*. Behavior Analysts, and Stimulus Publications.

Perske, R. (1972). The dignity of risk and the mentally retarded. *Mental Retardation, 10*(1), 24–27.

Petit-Frere, P., & Miltenberger, R. G. (2021). Evaluating a modified behavioral skills training procedure for teaching poison prevention skills to children with autism. *Journal of Applied Behavior Analysis, 54*(2), 783–792. https://doi.org/10.1002/jaba.799

Powers, L. E., Geenen, S., Powers, J., Pommier-Satya, S., Turner, A., Dalton, L., & Swank, P. (2012). My life: Effects of a longitudinal, randomized study of self-determination enhancement on the transition outcomes of youth in foster care and special education. *Children and Youth Services Review, 34*, 2179–2187. https://doi.org/10.1016/j.childyouth.2012.07.018

Reid, D. H., Rosswurm, M., & Rotholz, D. A. (2017). No less worthy: Recommendations for behavior analysts treating adults with intellectual and developmental disabilities with dignity. *Behavior Analysis in Practice, 11*(1), 71–79. https://doi.org/10.1007/s40617-017-0203-y

Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krinjin-Kemp, E., Towers, C., Romeo, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P., & Joyce, T. (2007). Person-centered planning: Factors associated with successful outcomes for people with intellectual disabilities. *Journal of Intellectual Disability Research, 51*, 232–243. https://doi.org/10.1111/j.1365-2788.2006.00864.x

Roux, A. M., Shattuck, P., Rast, J. E., Rava, B. A., & Anderson, K. A. (2015). *National autism indicators report: Transition into young adulthood*. A. J. Drexel Autism Institute, Drexel University. Retrieved from https://drexel.edu/autismoutcomes/publications-and-reports/publications/National-Autism-Indicators-Report-Transition-to-Adulthood/

Seidler, R. D., Kwak, Y., Fling, B. W., & Bernard, J. A. (2013). Neurocognitive mechanisms of error-based motor learning. *Advances in Experimental Medicine and Biology, 782*, 39–60. https://doi.org/10.1007/978-1-4614-5465-6_3

Shalock, R. L., & Verdugo, M. A. (2012). *A leadership guide for today's disabilities organizations*. Brookes Publishing.

Shogren, K. A., & Plotner, A. J. (2012). Transition planning for students with intellectual disability, autism, or other disabilities: Data from the National

Longitudinal Transition Study-2. *Intellectual and Developmental Disabilities, 50*(1), 16–30. https://doi.org/10.1352/1934-9556-50.1.16

Singh, I., & Elsabbagh, M. (2014). Autism research beyond the bench. *Autism, 18*(7), 754–755. https://doi.org/10.1177/1362361314548816

Soke, G. N., Rosenberg, S. A., Hamman, R. F., Ringerlin, T., Robinson, C., Carpenter, L., Giarelli, E., Lee, L., Wiggins, L. D., Durkin, M. S., & DiGuiseppi, C. (2016). Brief report: Prevalence of self-injurious behaviors among children with autism spectrum disorder – A population-based study. *Journal of Autism and Developmental Disorders, 46*(11), 3607–3361. https://doi.org/10.1007/s10803-016-2879-1

Stancliffe, R. J., Abery, B. H., & Smith, J. (2000). Personal control and the ecology of community living settings: Beyond living-unit size and type. *American Journal on Mental Retardation, 105*(6), 431–454. https://doi.org/10.1352/0895-8017(2000)105<0431:PCATEO>2.0.CO;2

Stokes, T., & Baer, D. (1977). An implicit technology of generalization. *Journal of Applied Behavior Analysis, 10*(2), 349–367. https://doi.org/10.1901/jaba.1977.10-349

Tassé, M. J., Schalock, R. L., Balboni, G., Bersani, H., Borthwick-Duffy, S. A., Spreat, S., Thissen, D., Widaman, K. F., & Zhang, D. (2012). The construct of adaptive behavior: Its conceptualization, measurement, and use in the field of intellectual disability. *American Journal on Intellectual and Developmental Disabilities, 117*(4), 291–303. https://doi.org/10.1352/1944-7558-117.4.291

Ticani, M., & Bondy, A. (Eds.). (2014). *Autism spectrum disorders in adolescents and adults: Evidence-based and promising interventions*. The Guildford Press.

U.S. Department of Health and Human Services. (2017). *Report to congress: Young adults and transitioning youth with autism spectrum disorder*. Retrieved from https://www.hhs.gov/sites/default/files/2017AutismReport.pdf

U.S. Department of Labor Bureau of Labor Statistics. (2019, August 22). Number of jobs, labor market experience, and earnings growth. *Results from a national longitudinal study*. https://www.bls.gov/news.release/pdf/nlsoy.pdf

Van Houten, R., Axelrod, S., Bailey, J. S., Favell, J. E., Foxx, R. M., Iwata, B. A., & Lovaas, O. I. (1988). The right to effective behavioral treatment. *Journal of Applied Behavior Analysis, 21*(4), 381–384. https://doi.org/10.1901/jaba.1988.21-381

Wehman, P., & Kregel, J. (Eds.). (2019). *Functional curriculum for elementary and secondary students with special needs* (4th ed.). Pro-Ed.

Wehmeyer, M. L., & Abery, B. H. (2013). Self-determination and choice. *Intellectual and Developmental Disabilities, 51*(5), 399–411. https://doi.org/10.1352/1934-9556-51.5.399

Wehmeyer, M. L., & Schwartz, M. (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional Children, 63*(2), 245–255. https://doi.org/10.1177/001440299706300207

Wehmeyer, M. L., Kelchner, K., & Richards, S. (1996). Essential characteristics of self-determined behavior of individuals with mental retardation. *American Journal on Mental Retardation, 100*(6), 632–642.

Winett, R. A., & Winkler, R. C. (1972). Current behavior modification in the classroom: Be still, be quiet, be docile. *Journal of Applied Behavior Analysis, 5*(4), 499–504. https://doi.org/10.1901/jaba.1972.5-499

Wolf, M. M. (1978). Social validity: The case for subjective measurement or how applied behavior analysis is finding its heart. *Journal of Applied Behavior Analysis, 11*(2), 203–214. https://doi.org/10.1901/jaba.1978.11-203

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Leisure and Adaptive Behavior for Individuals with Autism

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Overview

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition that includes persistent deficits in social and communicative functioning and patterns of behavior that are repetitive, circumscribed, and restricted in ways that can significantly undermine overall quality of life for individuals with ASD and their caregivers throughout the lifespan (American Psychiatric Association, 2013). Without access to highly individualized and effective supports, these core deficits inherent with a diagnosis of ASD can diminish the extent to which individuals with ASD ultimately achieve independence across a wide range of contexts (e.g., home, work, transportation, leisure) in adulthood.

The term "adaptive behavior," as it relates to people with disabilities, refers to a multidimensional construct corresponding to the degree to which a person demonstrates the capacity to independently succeed within their environment (Tassé et al., 2012). Adaptive behavior is a central focus of many standardized norm-referenced evaluations used to assess the existence, extent, and nature of individual impairment and/or intellectual/developmental disability. Forms of adaptive behavior can include a person's ability to engage in a wide range of activities of daily living (ADLs; e.g., cooking, personal hygiene, household chores), social and communication skills (receptive and expressive), and many other tasks, activities, and aptitudes considered essential behaviors for handling one's own life (Freeman et al., 1999; Kenworthy et al., 2010; Chang et al., 2013). Other forms of adaptive functioning commonly regarded as essential for living a meaningful adult life include maintaining employment, managing time and money, and engaging in recreational/leisure activities (Bal et al., 2015; Cordier et al., 2017; Dawson et al., 1998).

An individual's overall level of adaptive functioning is typically determined by evaluating the extent that a person performs a variety of ADLs across settings and contexts and is not based on that person's expected and/or unrealized potential to engage in adaptive behavior. While it has been established that the presence or absence of adaptive behavior is generally correlated with cognitive ability among individuals with intellectual disabilities (i.e., higher cognitive ability is often equated with higher levels of adaptive behavior), the connection between cognitive ability and adaptive functioning is often more complicated for individuals with ASD (Farmer et al., 2018). Specifically, individuals with ASD can

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often have substantial gaps in the existence of a variety of adaptive skills even in cases when an individual demonstrates average or above average performance on evaluations of cognitive potential (Bal et al., 2015).

Over the past decade, several studies have documented the pervasive existence of poor outcomes related to overall quality of life resulting from a lack of independent adaptive functioning among adults with ASD. The National Longitudinal Transition Study (2012), which examined outcomes for middle school and high school students with ASD compared to youth with other disabilities, found that only 17% of school-age students with ASD could independently manage activities of daily living compared to 47% of students in all other disability categories (Lipscomb et al., 2017). Similarly, Bal et al. (2015) conducted a multiyear longitudinal examination of the predictors, trajectories, and overall attainment of ADLs for individuals diagnosed with autism between the ages of 2 and 21 years. They found that many younger adults with ASD performed ADLs at a level approximately 5–6 years behind their same-age typically developing peers.

Taheri et al. (2016) compared the social/recreational engagement of three groups of children, adolescents, and young adults aging 3–19 years. They had three groups of participants: (a) ASD with intellectual disability (ID), (b) ID without ASD, and (c) peers without a developmental disability. Taheri et al. found that individuals with developmental disabilities (i.e., ASD with ID and ID without ASD groups) engaged in fewer *social activities* including *social gatherings, participation on sports teams, and other communal activities as compared to their typically developing peers*. The ASD with ID group engaged in the lowest number of social events and recreational activities. Additionally, they reported to have fewer friends than all the other participants in the study. These findings are important in highlighting that individuals with ASD often have gaps in adaptive functioning pertaining to leisure time activities in addition to other areas of daily living. Without access to effective evidence-based intervention targeting the development of adaptive skills, many individuals with ASD are at high risk for poor outcomes throughout adulthood. This may result in an overreliance on family and caregivers to provide support for their daily living needs, which may undermine the quality of life for all involved (Howlin, 2000; Roux et al., 2015; Seltzer et al., 2004).

The prioritization of specific adaptive behaviors for skill acquisition programming for adults with ASD can be challenging, given the potential for there to be substantial gaps across many domains of present adaptive functioning (e.g., self-care, communication, employment, leisure) as well as the wide range and variability of specific adaptive skills/behaviors within each domain. There are several factors that practitioners can consider when identifying adaptive skills deficits to target for intervention and the order in which to target those skills. While many of these factors may be specific to the existing skill deficits, preferences, and support needs of an individual, practitioners should seek to evaluate the potential magnitude of benefit that results from the acquisition of a particular adaptive skill in achieving desirable outcomes for the client (i.e., practitioners should target skills that provide the “biggest bang for the buck”). The acquisition of certain adaptive skills can play a pivotal role in opening access to a variety of subsequent desirable opportunities and outcomes. An example of pivotal adaptive skills could include learning to cook independently, which can increase access and consumption of healthy food and improve overall health, be a critical component of independent living, function as a potential job skill, and be a preferred leisure time activity. Another example is learning independent personal hygiene, which may increase the likelihood of opportunities for social engagement, employment, community inclusion, and improved physical health as well as eliminate the need for caregiver support. A final example is learning to use public transportation or Uber/Lyft, which can increase community accessibility for employment and a variety of leisure activities such as shopping, dining, and fitness.

Leisure Skills as a Crucial Component of Adaptive Functioning

When designing assessments and interventions aimed at encouraging individuals with ASD to establish a solid repertoire of adaptive behavior, it is critical for skill acquisition programming to include a focus on the identification of, and exposure to, preferred activities that an individual can reliably engage in during periods of leisure. Leisure time activities can include anything related to the way that a person chooses to spend their "free time" or periods of time where there is no required behavior (e.g., no one is telling you what you "have to do" or there is no school, work, chores). Leisure behavior can take many forms and can be derived from an almost unlimited offering of interests (e.g., animals, outer space, Disney, trains, superheroes, history, architecture), hobbies (e.g., puzzles, scuba diving, playing an instrument, crafts, gardening, travel, painting), relaxation strategies (e.g., reading, taking a bath, listening to music, meditation, yoga), recreation (e.g., sports, dining, amusement parks, video games, dancing, ingestion of drugs and alcohol), exercise (e.g., running, weight lifting, swimming, splitting wood with an axe), and vocal/motor stereotypy (e.g., twiddling thumbs, humming, foot tapping, whistling, crossing and uncrossing legs). Leisure time behavior can be social or solitary, productive or unproductive, physically/cognitively rigorous or restful, healthy or unhealthy, exciting or passive. Furthermore, it can require a high degree of skill or be accessible to all regardless of prior experience. Finally, it can be dangerous/risky or without risk and in some cases can even transition to being a source of income.

Engagement in adaptive leisure time activities can have numerous benefits, including stress reduction (Bishop-Fitzpatrick et al., 2018), increased inclusion and opportunities for social interaction (Buttimer & Tierney, 2005; Rao et al., 2008), lower likelihood of challenging behavior (Bremer et al., 2016; Matson et al., 2010), and a greater overall quality of life (Rimmer et al., 2007). Participation in leisure activities can provide occasions to interact with others who share common interests and increase access to a variety of opportunities for social engagement. For example, reading can lead to joining a book club, or playing video games can lead to attending different conventions or tournaments providing opportunities for inclusion and social engagement. Whatever the interest, hobby, or activity may be, having established adaptive leisure skills can increase the likelihood of finding opportunities to interact with a compatible group of like-minded individuals who share the same interests.

Current research suggests that participation in social and recreational activities has numerous psychological benefits, such as increased self-esteem when developing meaningful friendships (Rao et al., 2008; Patterson & Pegg, 2009) and decreased social anxiety (Bellini, 2004; Bauminger & Kasari, 2000), and provides an escape from repetitive routines (Caldwell & Gilbert, 1990). Furthermore, studies found that engagement in leisure activities encourages inclusion into the community and decreases overall social isolation and poor physical and psychological health (Buttimer & Tierney, 2005; Eldeniz Cetin & Cay, 2020; Rimmer et al., 2007).

Barriers to the Development of Adaptive Leisure Skills for Adults with ASD

While it has been widely established that the development of adaptive leisure skills can have numerous benefits resulting in a higher quality of life, current research indicates that many autistic adults do not participate in adaptive leisure activities to the same extent as their neurotypical peers (Stacey et al., 2019). Research also demonstrates that as individuals with ASD age into adolescence, participation in physically active forms of recreation and leisure activities (e.g., exercise, sports) decreases and risk of obesity increases (McCoy et al., 2016; Sorenson & Zarrett, 2014). Adolescents with autism are about two times more likely to be obese than adolescents without developmental disabilities (Phillips et al., 2017).

Obesity as a condition by itself has been well established to lead to a range of significant health risks such as physical diseases (e.g., certain cancers, diabetes, hypertension, heart disease, stroke) and a variety of psychological health complications (da Luz et al., 2018).

There are several characteristics related to autism that can contribute to the lack of established adaptive leisure time behavior. These include deficits in communication and social skills (Goldman et al., 2009), difficulty learning through imitation (Williams et al., 2004), a lack of motor development/coordination (Hilton et al., 2012), restricted/circumscribed interests (Turnbull & Turnbull, 1985), and the existence of challenging behavior (Jones et al., 1990). In addition to the characteristics of autism that may impede the acquisition of leisure skills, research also shows that individuals with ASD often have far fewer opportunities to engage in leisure activities as compared to their same-age peers beginning in early childhood and continuing into adulthood (Taheri et al., 2016). Restrictions in access to opportunities to participate in adaptive leisure time activities that exist throughout childhood result in fewer occasions to learn and practice related skills, which can ultimately produce a gradual widening of the gap in adaptive functioning between individuals with autism and their typically developing same-age peers, which persists throughout adulthood.

Deficits in Communication and Social Skills

Communication deficits can create challenges for individuals with ASD who have difficulty understanding vocal and written instructions, have difficulty learning through imitation, and are unable to effectively express their needs and/or advocate for alternate options for communication (Goldman et al., 2009; Williams et al., 2004). These deficits, which are common among people with ASD, result in a greater propensity toward sedentary activities (e.g., watching television or movies, playing video games) as compared to their typically developing peers (Chonchaiya et al., 2011; Must et al., 2015). In particular, the inability to read or comprehend written or spoken rules, guidelines, and messages that are created for the collective safety of people participating in community events may impede an individual's ability to safely participate and potentially lead to dangerous consequences when out in the community.

Deficits in Motor Development

Research suggests that underdeveloped motor skills (i.e., physical strength, agility, balance, coordination) among people with autism may be a primary contributor to a lack of access to and participation in sports and other physical activities (Hilton et al., 2012). Specifically, individuals with ASD can demonstrate challenges with the imitation and performance of gross motor movements involved in running, jumping, and swinging a bat as well as fine motor tasks, such as throwing a ball or darts. Hilton et al. (2012) compared the motor development of individuals on the autism spectrum and their typically developing siblings between the ages of 4 and 21 years from 67 families to evaluate the impact of autism on motor performance. All participants were observed performing various motor skills such as cutting with scissors, imitating movements, running, and throwing a ball. Findings indicated that 83% of the participants with ASD demonstrated below average ability in motor skills, while only 6% of their neurotypical siblings demonstrated below average motor skills. Based on these findings, Hilton et al. concluded that motor impairments may be a core symptom of autism. The potential for a variety of existing deficits in motor development and the need for explicit training to build these skills should be a key consideration for practitioners designing programming to encourage adults with ASD to engage in active forms of leisure time behavior.

Restricted and Repetitive Interests

Restricted interests refer to an abnormal level of intensity of focus corresponding to a specific behavior, topic, or activity. Restricted or circumscribed interests can significantly limit the extent to which individuals with ASD engage in a variety of adaptive leisure activities (Smerbeck, 2019; Turnbull & Turnbull, 1985). Some common concerns related to restricted interests among adults with ASD are that interests may not be “age appropriate” (i.e., an adult frequently engaging in activities typically viewed as only appropriate for young children), that a focus on restrictive interests can take up too much of an individual’s time or money, that restricted interests can become perseverative or obsessive, that restricted access to intense interests can increase anxiety and even evoke challenging behavior, or that intense/repetitive engagement in some restricted interests can be socially stigmatizing, ultimately resulting in even fewer opportunities for social engagement.

Although restricted interests have been viewed as creating a barrier to adaptive functioning to be addressed through intervention, there are many practitioners and adults with ASD who advocate that in some cases an intense focus in a single area or activity can result in a high degree of expertise and subsequent potential social benefit (i.e., connection with others that share the same interest; Smerbeck, 2019). Furthermore, an individual’s interests can often be deeply associated with their personal identity, and practitioners’ attempts to design intervention to diminish someone’s focus on interests that they are passionate about can sometimes be viewed as an attempt to fundamentally change who that person is. For some adults with ASD, the idea of implementing a therapeutic intervention to influence or alter their interests can be equated to an attempt to fundamentally change their personal identity to make them appear more typical (Parsloe, 2015). Consequently, practitioners should always have a commitment to achieving a balance between respecting the interests, preferences, and personal liberties of the clients they are supporting with the need to achieve goals toward greater adaptive functioning and overall quality of life (Bannerman et al., 1990). Practitioners should avoid justifying interventions to address the restrictive interests/behavior of adults with ASD based on what they subjectively or arbitrarily conceive as being typical or appropriate and instead focus on intervening only when there is a clear functional benefit associated with the intended outcome of treatment and/or if the restricted interests result in concerns related to general safety and well-being.

Challenging Behavior

Challenging behavior can refer to any behavior that undermines adaptive functioning regardless of the specific topography of the behavior. While the existence of challenging behavior is not a diagnostic component of autism, the prevalence of problem behavior among individuals with ASD is higher relative to other populations (Didden et al., 2012; Lowe et al., 2007). Common topographies of challenging behavior can include vocal and motor stereotypies, self-injurious behavior (SIB), aggression, property destruction, and elopement. Challenging behavior can represent a physical and/or a social barrier to engagement in adaptive leisure activities and can be cause for concerns about the safety of the individual engaging in problem behavior and those around them, which can then in turn be used as justification for proactively restricting access to future leisure opportunities. Challenging behavior can represent a physical barrier when the behavior is topographically incompatible with the physical requirements for participation in leisure activities (e.g., an individual that engages in high rates of intense motor stereotypy is unable to simultaneously participate in a competitive soccer game). In addition, challenging behavior can be socially stigmatizing and can undermine motivation for individual interest in engagement in leisure activities out of concern that other participants or event organizers may not be accepting and/or supportive when problem behavior occurs.

Some forms of potentially dangerous high-intensity and/or severe challenging behavior can result in event organizers and practitioners choosing to restrict access to opportunities for participation in inclusive leisure activities even when the current rates of responding in problem behavior are consistently near zero levels (e.g., high-intensity/low-frequency SIB, aggression, property destruction). This can result in a complex situation for practitioners attempting to balance the need to maintain overall safety of all community members during inclusive leisure activities, while not infringing upon the rights of individuals with ASD to freely access their communities despite the existence of symptoms of their disability (i.e., challenging behavior).

The recent emergence of advocacy efforts for greater inclusion and acceptance for all people on the spectrum have highlighted the lack of qualified professionals capable of supporting access to inclusive leisure activities for individuals with significant behavioral support needs (Anderson & Butt, 2018). These advocacy efforts have also brought to light the existence of a range of discriminatory practices in restricting access to a variety of community-based opportunities based on the existence of challenging behavior (Jones et al., 2021). In the majority of cases, the existence of challenging behavior among adults with ASD should be viewed as a manifestation of an individual's condition and/or disability. From this perspective, an individual does not make a "choice" to engage in challenging behavior and thus should not be subjected to punitive consequences (i.e., restricted access) merely in response to the perceived potential for the future occurrence of the behavior. Ideally, adults with ASD that engage in challenging behavior should be afforded the same access to inclusive community-based opportunities for leisure as their neurotypical peers as long as resources (e.g., effective behavior intervention plan, proper ratio of highly trained support staff, protective equipment, supportive community) allow for this to be accomplished in a way in which the risk of injury to the individual and other community members can be minimized.

Stereotypy: A Barrier to Leisure Activities or a Form of Adaptive Behavior?

Stereotypy refers to behavior that is repetitive and non-contextual, which can be exhibited in the form of motor movement or vocal expression. While previous research has demonstrated that it is possible for stereotypies to be maintained by a variety of consequences, including access to tangible reinforcement (Ahearn et al., 2003), social reinforcement (Durand & Carr, 1987), and forms of negative reinforcement (Ahearn et al., 2003; Kennedy et al., 2000; Repp et al., 1988), there is evidence to suggest that stereotypy frequently occurs to fulfill an underlying need for automatic reinforcement and/or self-stimulation (Lovaas et al. 1987; Rapp & Vollmer, 2005; Rogers & Ozonoff, 2005). This has resulted in this class of behavior being casually referred to as "stimming." However, the use of this terminology (i.e., "stimming") should be avoided unless the function of stereotypy has been empirically determined to be access to automatic reinforcement (Cunningham & Schreibman, 2008).

The majority of humans engage in some form of stereotypy (e.g., twiddling thumbs, humming, foot tapping, whistling, hair twirling) at varying degrees of frequency/intensity at some point in their lifetime without the need for intervention or having any risk of undermining access to participation in any aspect of their community or their overall quality of life (Cunningham & Schreibman, 2008; Shafer et al., 2017). In contrast, the prevailing trend among practitioners working to support individuals with ASD who exhibit stereotypic behavior has been to generally categorize this behavior as maladaptive and to design therapeutic interventions to reduce and/or eliminate this behavior. While research has gradually recognized limitations in understanding stereotypic behavior (Harrop, 2015), therapeutic interventions remain in demand as many parents and caretakers view stereotypies as visibly stigmatizing (Kinnear et al., 2016; Kapp et al., 2019).

Autism rights activists have increasingly advocated against therapeutic interventions to decrease stereotypies and have defended the rights of adults with autism to engage in stereotypies due to the potential for this behavior to fulfill an underlying need for self-stimulation and/or lead to the relief of internal aversive states such as stress and/or anxiety (Orsini & Smith, 2010; Kapp et al., 2019). An online survey of 100 adults with ASD that examined various reasons for engaging in stereotypies found that 72% of respondents reported that stereotypy was a coping tool to reduce stress, 69% reported that stereotypy helped them to relax, and 57% reported that they needed stereotypy when they were overstimulated. Additionally, about 91% of participants reported that they found stereotypy to be "satisfying," with 72% reporting they had been encouraged to stop engaging in stereotypy through the use of reprimands (Steward, 2015). While these findings make an important contribution to the limited understanding surrounding the potential role and function of stereotypy for adults with ASD, it should be noted that the results of this study should be interpreted with caution as respondents were limited to individuals that had the ability to participate in interviews and focus groups and may not be representative of the views and perspectives of the broader population of adults with ASD.

This raises the following question: Should stereotypy be considered a class of maladaptive behavior in need of therapeutic intervention or an adaptive leisure skill that can provide a variety of benefits? The realization that stereotypy can be beneficial for some individuals has encouraged many practitioners to shift from a perspective that all stereotypy should be completely eliminated to an approach focused on working with adults with ASD to learn to discriminate between situations in which stereotypy might be stigmatizing and problematic and private settings/contexts where engagement in stereotypy is acceptable as a form of adaptive leisure behavior (Crutchfiled et al., 2015; Haley et al., 2010; Shabani et al., 2001). As is the case with any other form of leisure behavior, stereotypy should only be considered adaptive if it is not pervasive across settings and contexts occurring at rates and/or intensity that undermines engagement in other forms of critical adaptive functioning (Gross & Jazaieri, 2014; Jones et al., 1990).

The Consumption of Alcohol and Controlled Substances for Leisure

Various forms of adaptive leisure activities have shown to positively impact the lives of individuals with autism; however, there are many unhealthy or dangerous leisure activities which can become more accessible as individuals enter adulthood. There are a variety of reasons an individual may turn to substance use, such as short-term solutions to common difficulties associated with getting through the day, attainment of peace of mind, daily frustrations, and, more commonly, social engagement (Kronenberg et al., 2014). Although substance use may be viewed as a short-term solution to common difficulties such as physical or psychological well-being (Helverschou et al., 2018), there are many other long-term consequences associated with substance use that can have impactful undesirable outcomes including reduced quality of life, mental health disorders, and premature death resulting from overdoses, accidents, violence, and suicide (Arnevik & Helverschou, 2016).

There are a limited number of studies examining the prevalence of substance use among individuals with ASD, and the findings are equivocal. Arnevik and Helverschou (2016) estimated that 0.7–36% of adults with ASD have a co-occurring substance use disorder. Butwicka et al. (2017) suggested that the overall risk of substance use-related problems for individuals with autism is close to double the risk identified in the neurotypical population, while other studies suggest that substance use may be uncommon and less prevalent among individuals with ASD compared to individuals with other disorders (Arnevik & Helverschou, 2016; Lugo-Marín et al., 2019; Ramos et al., 2013; Sizoo et al., 2010; Santosh & Mijovic, 2006).

Kaltenegger et al. (2021) found that alcohol consumption was lower among individuals with ASD. They evaluated the prevalence of drinking among individuals with and without ASD across three age groups (i.e., ages 15, 18, and 24 years) and found that the risk of adverse outcomes resulting from alcohol consumption was lower for individuals with ASD compared to individuals without ASD. However, Kaltenegger et al. also found that this risk increased with age. Santosh and Mijovic (2006) evaluated substance use in adolescents with ASD ages 12–18 years. They found lower rates of drug and alcohol use in individuals with ASD compared to the control group. While researchers have found that individuals with ASD were less likely to engage in alcohol consumption initially, other findings have suggested that there was a higher risk for accelerated alcohol dependence among adults with ASD if/when they did consume alcohol (De Alwis et al., 2014; Huang et al., 2021). These inconsistent findings may be due in part to limited samples and/or the participants' limited access to/engagement in social opportunities where drinking and substance use are widespread.

Experimentation with alcohol use may first develop in social contexts during adolescence among peers (Chartier et al., 2011) and continue into adulthood. There are certain periods of time in an adult's life in which substance use among peers in social situations might be more common, such as enrollment in postsecondary education. Although it is typical to think of this time as one associated with substance experimentation, many studies that evaluated substance use in adults with ASD did not report education level of the participants (Ressel et al., 2020). Attending university may be a difficult transition for many students, and related challenges may increase the likelihood that these students consume alcohol and other substances to cope.

While universities are mandated to have some type of support for students with disabilities related to the provision of accommodations for accessibility, specific programming and supports for autistic adults in a university setting are often limited. Many universities have ongoing research to evaluate the prevalence of drug and alcohol use among students (Cohn et al., 2011; Neal et al., 2006; Shono et al., 2018; White & Labouvie, 1989), but there is little existing research evaluating these issues specifically relating to adolescents or adults with ASD within the university setting. Although research suggests that there may be an increased risk with this population, there is a critical lack of data on the actual rates of substance use among autistic adults. Without adequate proactive resources to support students with ASD in this highly dynamic and social period of their lives, students may turn to substance use (Adhia et al., 2020).

It is important to consider the risk factors associated with substance use when practitioners are designing programming to support autistic adults in the development of social repertoires. Although alcohol consumption may be a right for many individuals above the local legal age for consumption, an abundance of caution should be exercised in encouraging anyone to adopt the use of alcohol or other substances as a means of socialization. The impairments in functioning and decision-making, resulting from the consumption of alcohol and other controlled substances, can result in a wide range of undesirable legal/punitive consequences that can have serious long-term impacts on the overall success of adults with ASD throughout their lifetime (Helverschou et al., 2018).

Designing High-Quality Programming for Adaptive Leisure Skill Development

Identifying Specific Goals and Objectives for Adaptive Leisure Programming

The existing literature related to the design of effective instructional methods for teaching adaptive leisure skills for people on the spectrum is largely confined to school-age children with ASD (Matson et al., 2012). Additionally, the development of effective adaptive leisure programming for adults with ASD can sometimes be perceived as something that is desirable but not critical or required (i.e., peripheral and/or secondary to other goals related to communication, employment, self-care). This perception can result in a diminished commitment to rigor related to the planning, implementation, and evaluation of programming focused on the development of adaptive leisure skills on behalf of practitioners supporting adults with ASD. Systematic assessment procedures that can be used to reliably identify existing leisure skill deficits, to match an individual's interests/preferences with meaningful leisure activities, and to evaluate social validity, levels of engagement, and indicators of successful outcomes during and following intervention are valuable tools in designing effective programming to encourage the acquisition of adaptive leisure skills. Unfortunately, appropriate assessment tools specific to the needs of adults with ASD are generally lacking as well as core indicators of success that can also contribute to the program development, leading to improved outcomes (Brugha et al., 2015).

The Vineland Adaptive Behavior Scales-Interview Edition (VABS; Sparrow et al., 1984) is a standardized measure that is widely used to evaluate domains such as communication, daily living, and socialization through a semistructured interview with a primary caregiver. The VABS has been used to evaluate the existence of adaptive skills before and after a 12-month leisure program for adults with ASD (Garcia-Villamisar & Dattilo, 2011). The program was designed to identify the strengths and interests of the 20 participants with ASD and support their engagement in a variety of corresponding leisure activities for 2 h per day, 5 days a week. At the conclusion of the study, Garcia-Villamisar and Dattilo (2011) demonstrated a significant improvement in the VABS composite score that focused on measuring the social behavior. They concluded that participation in a program of structured leisure and recreation can have a positive influence on social and communication skill development for adults with autism.

Few existing studies focusing on the acquisition of leisure skills evaluate whether the skills and activities that are taught are actually enjoyable or preferred by the individuals participating in the research. This has resulted in some researchers highlighting the importance of differentiating between the constructs of *enjoyment* and *participation* in leisure activities (Eversole et al., 2016). While exposure to a variety of activities can often result in the development of a preference or enjoyment for a particular activity over time, it is important for practitioners to remember that providing opportunities for adults with ASD to exercise their right to personal liberty and have input and choice related to how their time is spent is equally as important to learning a new leisure skill (Bannerman et al., 1990). According to Bannerman et al. (1990):

> Clients at every functioning level should be given opportunities to make choices in their residential and work settings, within and between scheduled activities. Some clients might only be able to make simple choices initially (e.g., what dessert to eat, when to go to bed). Other clients might learn to make more complicated decisions (e.g., how to spend a workshop paycheck, how to handle a problem with another client). Staff members must be motivated to provide these opportunities for choice. (p. 86)

Generally speaking, increased engagement in an activity occurs when programming prioritizes preference and choice, potentially creating a higher level of self-determination (Kreiner & Flexer, 2009). While there are not established models for the assessment and identification of leisure preferences specifically for adults with ASD, there are several strategies that have been demonstrated to be effective with children that practitioners can adapt for use with adults. Interviews, surveys, and checklists conducted with an individual person about their preferred interests and items/activities that they value, while also soliciting input from family members, teachers, and others who know the individual well, can provide valuable information in the identification of potential adaptive leisure activities and contingencies that can be implemented to increase motivation.

Systematically identifying many potential preferred interests/activities may encourage increased engagement in adaptive leisure skills. Free operant preference assessments, which involve providing free access to potentially preferred items/activities without delivering a demand, providing time limitations, or any other restrictions when engaging in the activity, can be useful for identifying preferred activities or preferences and can be conducted in natural or contrived environments (Toner, 2014). Another approach to systematically identifying leisure preferences can include the implementation of a multiple stimulus without replacement preference assessment (DeLeon & Iwata, 1996). While preference assessments exist to aid in identifying specific preferred items and activities, they provide relatively little information about the design of leisure activities and related instructional strategies that are likely to result in the best outcomes.

The Importance of Prioritizing Physical Activity as a Goal for Adults with ASD

Physical activity (PA; e.g., exercise, sports) is an important part of healthy living and a leisure skill for many people. Engagement in moderate-to-vigorous PA has beneficial effects on cardiovascular health, weight, and cognition (Sorenson & Zarrett, 2014). Additionally, PA has been shown to reduce problem behavior (Bremer et al., 2016) and increase on-task behavior (Reid et al., 1988) for individuals with ASD. Research has shown desirable outcomes for individuals with ASD from engagement in physical activities such as soccer (Cei et al., 2017; Hayward et al., 2016), basketball (Tse & Masters, 2019), aquatic activities (Alaniz et al., 2017; Caputo et al., 2018), martial arts (Bahrami et al., 2012), aerobics (Brand et al., 2015), exergaming (Dickinson & Place, 2014; Hilton et al., 2014), and numerous other activities (Huang et al., 2020). While research clearly supports increased participation in PA for individuals with ASD, the existing studies in this area almost exclusively evaluated the benefits of PA for children.

Research has demonstrated that PA may have positive effects on problem behaviors exhibited by individuals with ASD. The effects of PA have been evaluated on stereotypy (Celiberti et al., 1997; Kern et al., 1984; Prupas & Reid, 2001), aggression (Allison et al., 1991), and SIB (Elliot et al., 1994), making PA an emerging evidence-based practice for addressing challenging behavior (Wong et al., 2015). While this subject has been extensively studied among neurotypical individuals, research related to outcomes resulting from PA for individuals with ASD is sparse (Sowa & Meulenbroek, 2012). Furthermore, the research that does exist related to the outcomes of PA for autistic people overwhelmingly includes studies conducted with children under the age of 16 years, and research evaluating the outcomes for adults with ASD resulting from regular physical activity is generally scarce (Croen et al., 2015).

Evaluating Outcomes from Participation in Leisure and Recreation

When evaluating the outcomes of participation in adaptive leisure and recreation in a meaningful way, measures should include both objective and subjective indicators of success (Lloyd & Auld, 2002). Objective measures assess the quantitative aspects of involvement, such as the frequency, intensity, and number of activities in which an individual participates. Subjective measures assess the qualitative aspects, such as individual satisfaction, enjoyment, and perceived value derived from engagement in adaptive leisure activities. A better understanding of both objective and subjective indicators of leisure and recreation would arm practitioners, caretakers, and adults with ASD with the necessary knowledge to improve upon an often overlooked area.

Indirect assessments, such as questionnaires or structured interviews, are the most utilized leisure and recreation research tools. The Leisure Satisfaction Scale (LSS; Ragheb & Beard, 1980) examines the experiences of adults with ASD across six subscales (i.e., psychological, educational, social, relaxation, physiological, aesthetic). Stacey et al. (2019) used the LSS to evaluate if 249 adults with ASD were satisfied with their leisure experiences in comparison to their neurotypical counterparts. Findings showed lower satisfaction among adults with ASD, indicating a greater need for the assessment of leisure-specific variables that increase enjoyment.

Quality of Life

Participation in leisure and recreation is often used as an indicator of success when measuring quality of life (QoL; Verdugo et al., 2005). QoL is a multidimensional construct defined as an "individual's perception of their position in life in the context of the culture and value systems in which they live and, in their goals, expectations, standards and concerns" (World Health Organization QOL Group, 1995, p. 1405). To our knowledge, no instrument currently exists that has been specifically designed to comprehensively measure QoL of adults with ASD. However, recent research has focused on adapting evaluation tools established for use in evaluating QoL with other disability populations and has demonstrated validity in evaluating QoL among adults with ASD.

The abbreviated version of the World Health Organization's Quality of Life assessment (WHOQoL-BREF; World Health Organization QOL Group, 1998) scores participation in recreation and leisure as a subdomain of environment. This assessment has been used in a wide range of groups including adults on the autism spectrum with adequate validity (Lloyd & Auld, 2002; Moss et al., 2017; Mason et al., 2019). One of the benefits of the WHOQoL-BREF is that it targets an individual's satisfaction rather than making normative assumptions on how the various domains are valued. McConachie et al. (2018) expanded the WHOQoL-BREF to include nine autism-specific questions in an effort to make this evaluation more useful for practitioners supporting people with ASD. The additional items were developed from themes that emerged from a survey of the autism community and included topics related to sensory issues, healthcare access barriers, financial security, and autistic identity (e.g., "Do sensory issues in the environment make it difficult to do things you want to do?"). McConachie et al. (2018) established the rationale for developing systematic approaches for evaluating and addressing the unique needs of people with autism related to outcomes pertaining to QoL.

While there continues to be growing interest in evaluating the QoL of individuals with ASD throughout the lifespan, there is still much to be accomplished in accurately measuring and interpreting indicators of QoL in a meaningful way across the multidimensional needs of adults with ASD (Bal et al., 2018).

Literature Review of Existing Examples of Programming for Leisure Skills Development

There are numerous potential strategies for intervention once targets for instructional programming focused on the development of adaptive leisure skills have been identified. The following section provides an introduction to the existing literature documenting specific approaches to encouraging adults with ASD to engage in a variety of adaptive leisure activities. It is our hope that this review of the existing literature provides a starting point for practitioners looking to develop effective programming for adaptive leisure skill development while also directly highlighting the desperate need for more research related to the identification of effective evidence-based strategies for assessment, intervention, and program evaluation specific to supporting adults on the autism spectrum in this area.

Initially, the term "autism" combined with "adults," "leisure," or "leisure activities" was used to conduct keyword searches of abstracts available in the PsycINFO, EBSCOhost (Academic Search Premier), and Medline databases published between 2010 and 2020. However, this search only yielded a combined total of 33 published studies among the 3 databases, and these studies were not specific to the assessment, intervention, or evaluation of any particular leisure skill area (e.g., exercise, the arts). Rather, articles yielded were primarily case studies, survey studies, or studies focused on the perspectives of parents of individuals with autism and other disabilities.

Following this initial search, we determined that it was necessary to widen our search field to ensure that our search results were representative of the field of existing literature by including search terms representing specific categories of leisure skills. Specifically, we conducted this subsequent review of the existing literature using the search term "autism" combined with "adults," combined with specific terms related to specific leisure activities.

Table 19.1 breaks down the search terms related to each leisure category, subcategories

Table 19.1 Literature review search terms and results

Leisure activity topic	Terms searched with “autism” and “adults”	Total references yield (before evaluated for inclusion)
Physical activity		
Aerobics	“Aerobics,” “aerobic exercise”	2
Aquatics	“Aquatic,” “aquatic exercise,” “aquatic therapy,” “swimming,” “swim”	11
Sports	“Sports,” “soccer,” “tennis,” “basketball”	34
Exercise	“Exercise,” “fitness,” “physical activity”	75
Horseback riding	“Horseback riding,” “equine,” “equine therapy”	6
Martial arts	“Martial arts,” “karate,” “MMA”	4
Exergaming	“Exergaming,” “interactive fitness”	2
Visual arts		
Painting	“Painting” and “art”	1
Drawing	“Drawing” and “art”	7
Sculpture	“Sculpture” or “sculpting” and “art”	0
Performing arts		
Dance	“Dance,” “dance movement therapy”	17
Music	“Music,” “music therapy”	48
Internet/online activities		
Social media	“Social media,” “Facebook,” “twitter,” “Instagram”	39
Online dating	“Online dating,” “online relationship,” “internet dating”	3
Gaming	“Gaming,” “video games,” “online gaming”	34
Hobbies		
Cooking/culinary	“Cooking,” “culinary”	2
Knitting/sewing	“Knit,” “knitting,” “sew,” “sewing”	0
Beekeeping	“Beekeeping”	1
Movies/television	“Movies,” “film,” “television,” “TV,” “motion picture”	62

searched, and the total number of articles that were found.

In total, 345 articles were identified as being relevant to the topic of leisure skills/activities for adults with autism based on the updated search parameters. Once identified, abstracts of the 345 studies were retrieved and reviewed to evaluate if they met the following criteria for inclusion:

1. A majority of the participants (50% ≥) included must have been at least 18 years old at the time of the study.
2. Participants must have had a primary diagnosis of ASD.
3. The study employed an experimental design which evaluated the intervention and/or leisure activity/activities effects on an observable dependent variable (e.g., problem behavior).
4. Results of studies were quantitative.
5. The study was published in a peer-reviewed journal.

After evaluating the abstracts of the 345 studies, 16 of the studies met criteria for inclusion in this review. Of the 329 excluded studies, 93 studies did not meet the age requirement (i.e., they did not include enough adult participants), 85 did not meet the diagnosis requirement, 314 did not meet the experimental design requirement, 9 did not meet the requirement of quantitative results, and 54 did not meet the requirement of being peer-reviewed (e.g., conference papers, dissertations, magazine/newspaper articles). The 16 articles that were identified as meeting the criteria for inclusion were evaluated to discern the relative effects of the given intervention/leisure skill for improving outcomes of the adult participants. In some instances, existing research in a particular area of leisure (e.g., aerobics, aquatics, horseback riding) only included studies that did not yield results within the parameters of the inclusion criteria (e.g., did not demonstrate how the intervention influenced desired outcomes, did not include adults); in these cases, one to two sample studies for each area are still offered with an asterisk (*) to at least provide *some* information for approaches to instruction/intervention within these leisure skill areas that have been reviewed. Table 19.2 summarizes the findings of

Table 19.2 Summary of research studies identified for inclusion

Leisure category	References	Participant age range/ mean	Dependent variables/results
Physical activity			
Aerobics	*Brand et al. (2015)	10 children mean age 10	Performance on a variety of motor skills and parent reports of various patterns of sleep (objective/subjective sleep, sleep schedules, and sleep-related psychological functioning); participation in an individualized aerobic exercise training and motor skills training program resulted in improved specific motor skills and improved objectively assessed sleep on nights following the training interventions compared to nights not preceded by training exercise
	*Elliot et al. (1994)	6 adults Aged 22–41	Problem behavior (e.g., aggression, rocking, vocalizations, stereotypy); vigorous aerobic exercise resulted in reduced significant reduction in problem behaviors for one participant, moderate reduction for three participants, and little to no reduction for two participants
Aquatics	*Alaniz et al. (2017)	7 children Aged 3–7	Water safety skills using the Aquatic Skills Checklist (ASC) and social skills using the Social Skills Improvement System (SSIS) in group sessions; Improvements indicated through mean scores on ASC for water safety skills for all participants. No significant improvements in social skills evaluated using the SSIS
Sports	Azar et al. (2016)	11 adults Mean age 35.5	Intervention involving motor skills training, whole-body exercise, and sports/games for improving motor skills and reaction time; significant improvements in fine/gross motor dexterity following the intervention
	Barak et al. (2019)	50 adults with ID and 19 adults with ASD Mean age 31.8	Game of Life (GOL) soccer initiative (teaching soccer skills along with social skills and health-related behaviors in a series of physical activity programs) for improving fitness and mobility; ASD group showed improvements in the areas of physical fitness and mobility based on results from pre−/posttest measures of specific activities (e.g., soccer skills, chair rising, standing long jump, etc.)
	*Cei et al. (2017)	30 children Aged 6–13	Parent perceptions of psychosocial and motor skills; parents report significant improvement on 6/10 of the soccer skills assessed
	Favoretto et al. (2020)	27 adults Mean age 24.7	Intervention involving an 8-week adapted tennis program (1-h, twice per week) for improving tennis skills; pre−/posttest skills assessments were conducted for specific skills (e.g., forehand, backhand, etc.). Results indicate improvement across tennis skills for most participants
	*Hayward et al. (2016)	18 children Mean age 9.66	Parent perceptions of social skills; total of 64.3% of parents reported improved changes: 50% reported relationship with siblings improved; 14.3% of parents believed it was much improved. 35.7% noted no change
	Szabo (2019)	3 adults Mean age not provided	Acceptance and Commitment Training (ACT) called "Watch Me Try" (didactic modules to promote psychological flexibility model) compared with direct contingency management (DCM; task analysis, modeling, prompting, shaping) to facilitate athletic performance and improve tardiness to practice of young adults with ASD engaged in competitive sports; evaluated using a concurrent multiple-baseline across participants design; all three participants increased on-time attendance, heart rate, and length of falls during practice climbs and improved in competition performance. One improved with DCM alone, while two required ACT intervention
	Yu and Jee (2020)	35 adults Aged 20–29	Comparing the effects of participating in a 12-week exercise program (e.g. games, floorball, basketball, inline skating, etc.) on physical fitness and gross motor function (GMF) between individuals with mild and severe ASD; variables evaluated included body composition, cardiopulmonary fitness, flexibility, muscle strength/ power, GMF; results indicated significant differences between groups in body composition, physical fitness (except muscle strength), locomotion, and object control skills, indicating individuals with severe ASD had more difficulty with the educational exercise program than those with mild ASD

(continued)

Table 19.2 (continued)

Leisure category	References	Participant age range/ mean	Dependent variables/results
Exercise	Bassette et al. (2018)	3 adults Aged 18–21	Use of a multicomponent behavioral intervention (Exercise Buddy application, prompting, changing criteria, reinforcement) to teach functional movement exercises (e.g., squats); all participants increased their ability to perform exercise independently; results generalized to two different community settings
	LaLonde et al. (2014)	4 adults Aged 21–26	Multiple-baseline across participants design with reversal to evaluating behavioral methods (goal-setting, reinforcement) for increasing walking; all participants were able to meet the goal of 10,000 steps per day consistently with reinforcement conditions in place; social validity indicated participants and teacher found the intervention "highly acceptable"
	Savage et al. (2018)	3 adults Aged 20–22	Alternating treatment design comparing different types of praise (e.g., in-person v. technology-delivered [e.g., headphones]) for increasing engagement in physical activity (walking laps); number of laps completed increased for all participants during intervention and mixed results in the choice and generalization conditions
Horseback riding	*Ward et al. (2013)	21 children Mean age 8.1	Gilliam autism rating scale, Second edition (GARS-2) and sensory profile school companion (SPSC) to assess autism characteristics and sensory responses, respectively, completed by parents/teachers; improvements reported related to classroom (e.g., attention) and disruptive behaviors (e.g., stereotypy), social communication, and response to sensory input in the classroom
Martial arts	*Bahrami et al. (2012)	30 children Aged 5–16	GARS-2 – Stereotypy; stereotypy of the intervention group (participated in 14-week Kata training) compared to control group. Intervention group evidenced lower levels of stereotypy compared to control group
Exergaming	Jozkowski and Cermak (2020)	18 adults with ASD and 18 neurotypical (NT) adults Aged 18–25	Six conditions evaluating differences between ASD and NT group for effects exergame (EG) vs. traditional seated video games (TSVG; e.g., TSVG alone, TSVG with partner, tennis EG alone, tennis EG with partner, boxing EG alone, boxing EG with partner) on BMI percentile, perceived exertion, and enjoyment; both groups experienced significantly higher energy expenditure, spend more time, and expressed greater enjoyment engaged in the exergame activities with another person
Visual arts			
Painting	*Kuo and Plavnick (2015)	1 child Aged 3	Reversal design applying antecedent art intervention (1-to-1 instructional lesson prior to large group session) for reducing off-task behavior; antecedent-based individualized activity resulted in improved on-task behavior compared to baseline conditions
Drawing	Darewych et al. (2018)	14 adults Mean age 27.7	Application of *Scribble Drawing*, *Bridge Drawing with Path (BDP), and Future Trip Drawing* art-based assessments for evaluating imagination and symbolic development of drawings; most participants were able to draw concrete symbols from their *Scribble Drawing*, half of the participants were able to depict a bridge or a path symbol using *BDP* (indicating potential deficits in executive functioning), and all but one participant were able to depict a future trip they would like to take, artistically during the *Future Trip Drawing* activity
Performance arts			
Dance	Mastrominico et al. (2018)	73 adolescents and adults Aged 14–52 Mean age 22.5	Randomized control trial evaluating the application of dance movement therapy (DMT) activities (e.g., mirroring techniques) on empathy, measured using the *Cognitive and Emotional Empathy Questionnaire*; results indicated no significant changes in overall empathy between control and intervention groups

Music	Hillier et al. (2011)	22 adolescents and adults Aged 13–29 Mean age 18	Evaluation of a pilot music program (SoundScape) for improving self-esteem, anxiety, and attitudes toward and relationships with peers using pre−/post-questionnaires; SoundScape program met once per week, for 8 weeks, for 90-min sessions led by music education students; content included listening activities, composition with instruments, discussion of compositions, recording, and group projects; following participation in the program, participants self-reported significantly higher self-esteem, lower anxiety, improved attitudes toward peers
	Mateos-Moreno and Atencia-Doña (2013)	8 adults Mean age not provided	Application of combined music and dance movement therapies for evaluating autistic behaviors using the Revised Clinical Scale for Evaluation of Autistic Behavior (ECA-R) following dance/movement and music therapy procedures over 36, 1-h sessions across 17 weeks; results indicated the combination of dance/movement and music therapy are effective for improving autistic behaviors in individuals with severe autism
Internet/online activity			
Social media	Ward et al. (2018)	106 adults Median age 28	Online survey study to understand the use of social media (SM) among adults with ASD with a focus on the relationship between SM use and happiness and the role of the SM platform; participants who use SM platforms self-reported greater subjective happiness than those who did not; those who used Facebook most self-reported greater subjective happiness than those who used Twitter most; results indicate more research needed to evaluate specific qualities of SM platforms that equate to measures of subjective happiness
Online dating	*Roth and Gillis (2015)	17 adults Mean age 29.6	Survey study evaluated participation in, safety precautions using, and future education for online dating among adults with ASD; results indicated approximately half of participants have used online dating services with variable success; safety concerns were the most often reported disadvantages
Gaming	*Mazurek et al. (2015)	58 adults Mean age 20.5	Qualitative interview study meant to examine the preferences and motivations for playing video games; themes most commonly reported were personal enjoyment, perceived benefits of gaming (e.g., social connections, stress reduction), and perceived negative effects of gaming (e.g., addictive, takes time from other important requirements); highest preferred game types were role-playing and action-adventure games
Hobbies			
Cooking/culinary	Mechling et al. (2013)	2 adolescents 2 adults Aged 15–19	Alternating treatments design comparing the effects of commercially available vs. custom video prompts for completing cooking recipes; results indicate custom video prompts were most effective for improving independent responding across all participants
Beekeeping	Sances et al. (2019)	1 adult Age not provided	Application of activity schedule and contingent reinforcement for independent completion of a beehive inspection; results indicated that the activity schedule, reinforcement, and instruction resulted in improvements in independence in completing the beehive inspection
Movies/television	*Kuo et al. (2014)	91 adolescents Mean age 14.8	Survey study exploring how adolescents with ASD and their parents consumed media; results indicated that 78% of adolescents watched 2 h of television per day, while 98% used computers (~5 h per day); participants reported most commonly watching cartoons, played computer or video games, and/or visited websites about video games and anime; a comparison between ASD and NT populations indicated differences in that ASD adolescents watched television with their mothers, whereas NT adolescents watched television with their friends

the literature review to provide a representative sample of existing research related to strategies for designing effective interventions for the development of leisure skills for adults with ASD.

Summary/Discussion of Literature Review

It is important to note that, while thorough, this was not intended to be a wide-sweeping review of all existing literature that could be related to the topic of leisure for adults with autism. One of the primary challenges in conducting a comprehensive review of the existing literature related to the topic of adaptive leisure skills and activities is due to a lack of a universal definition and agreement on the appropriate usage of the term "leisure." As previously discussed, leisure time activities can include anything related to the way that a person chooses to spend their "free time," which results in numerous examples of published research that are relevant to the development, implementation, and evaluation of programming designed to support the acquisition of adaptive leisure behavior even if the authors of the research never explicitly use the term "leisure" to refer to the skills and/or activities that are the targets of intervention/evaluation.

Given that delving deeply into the existing literature related to every possible leisure category/activity was beyond the scope of this chapter, we chose to provide a representative sample of the literature that was discovered. Our findings demonstrate the complexity of conducting a comprehensive review of the literature on this topic and the significant lack of existing literature related to strategies for the development of adaptive leisure skills specific to adults with ASD. Even when using search terms explicitly including the term "adult," 26.96% of the resulting studies were subsequently excluded due to the primary participant group being children. This is further evidence of the great disparity in the number of studies focused on children compared to adults with ASD in this area of research.

Future Directions and Areas in Need of Research

As noted at many points in the current chapter, the literature regarding the assessment and teaching of leisure skills in ASD populations is sparse. Further, what little research that does exist focuses almost exclusively on young children. As such, there are many avenues for research in adults with ASD.

Assessment of Leisure Skills

The route to sound intervention begins with evidence-based assessment procedures. While thinking of the term *assessment*, many of us immediately think of assessments for academic skill deficits or functional assessments for challenging behavior. However, the use of systematic assessments to guide the development of leisure skills is equally important. Despite the importance of these assessments, the literature outlining leisure skill assessments is lacking.

One important area in need of investigation is related to the predictive validity of indirect leisure skill assessments. Most existing leisure skill assessments are indirect in nature. Given the nature of indirect assessment, they generally involve a verbal report of preference, based on the report of the individual or their caregivers. While this may represent a good starting point in the assessment process, these indirect measures may not be a reliable measure of the actual desire to participate in an activity. In addition, indirect assessments have limited utility in individuals with significant communication deficits. As such, there is a clear need for evaluations of the extent to which any of these indirect assessments predict independent engagement in leisure activities.

While direct leisure skill assessments could have utility, relatively few procedures have been investigated for this purpose. While preference assessment procedures have been well-established for identifying potential reinforcers/enjoyable activities, they are not sufficient for identifying activities that individuals will engage with independently and spontaneously. The development of direct leisure skill assessments is of utmost importance. Avenues of research could investigate different classes of leisure activities (e.g., outdoor/physical activities, art, computer-based activities) to determine preference for activities and, perhaps most importantly, evaluate motivation to engage in the activities spontaneously (without prompting from others).

Another deficit in the assessment literature is the limited scope of the existing assessments. As noted above, a simple preference for an activity is not the sole indicator of whether a leisure skill is appropriate. There are a number of key component skills that influence preference for and appropriateness of leisure activities. Skills such as motor skills, social skills, communicative ability, or the presence of challenging behavior can all influence the appropriateness of leisure activities. When these factors are taken into account, it may be possible to "fine-tune" leisure activities and adapt them to the needs of individuals. To this point, there has been little or no research evaluating the impact of these component skills on the success of leisure skill interventions.

Effective Strategies for Teaching Leisure Skills to Adults

While assessment represents a critical area in need of research, the identification of strategies to teach leisure skills to adults with ASD is another area that warrants attention. As noted previously, almost all of the leisure skill research has focused on assessment and intervention for young children with ASD. While training strategies, such as behavioral skills training (BST), have obvious value, adaptations for adults should be outlined as well.

Identifying strategies that minimize the need for intensive staffing and prompting must be a priority. As individuals move beyond the age of educational entitlements, the availability of trained staff to teach important skills (e.g., leisure skills) is usually limited. With fewer resources and a lack of well-trained staff, there is a need for teaching strategies that do not require intensive resources. While it may be possible to use intensive prompting procedures to teach young children how to participate in leisure activities, such as playing a computer game, playing Uno with a peer, or playing basketball, using such prompting procedures may be impractical and/or inappropriate while working with adults.

Related to the above points, there is a need for social validity measures to determine if the skills taught are actually leisure skills. A leisure skill is a skill that should be spontaneously exhibited with no prompting or coercion from another person. In other words, it should be a voluntary choice rather than a task. In many cases, the very skills taught for the purpose of developing a leisure repertoire are indistinguishable from any academic or functional skill that is taught. The true measure of whether a skill is truly a leisure skill is whether an individual chooses to participate in the activity and do so independently. Ideally, studies would incorporate a leisure skill test to determine if the activity would be spontaneously chosen.

Effective Intervention for Severely Impacted Populations with ASD

The support needs of individuals with profound intellectual and multiple disabilities also represent an area in need of sound research. To this point, the existing literature has largely neglected the needs of people who are severely impacted (i.e., severe intellectual disabilities, physical disabilities). This population presents a unique challenge, especially since they often present with motor deficits, social/communicative deficits, and challenging behavior. The presence of these issues should not preclude the assessment and teaching of leisure skills. In fact, they highlight the need for them. The development of leisure skills can compete with the occurrence of rituals and challenging behavior. While leisure skills may look different for this population (activities may need to be brief; they may need to be adapted to meet their physical/communicative needs), they are no less important than with other populations.

Improving Lifespan Outcomes for Adults with ASD Through Adaptive Leisure

The absence of a universal definition for "leisure" and the enormous variability that exists among humans in terms of their leisure time interests and activities presents a significant challenge for the creation of a unified and clear understanding of what should be considered "typical" in terms of outcomes when evaluating adaptive leisure behavior throughout the lifespan and "best practice" in designing programming to support adults with ASD in achieving these outcomes. This chapter has sought to highlight many of the key issues concerning the lack of access and opportunity for individuals with ASD to participate in meaningful and beneficial adaptive leisure time activities. It is well documented that engagement in adaptive leisure behavior has a wide range of benefits in many aspects of an individual's overall quality of life. As such, providing individuals with ASD the resources and opportunities they require to have the chance to participate in the adaptive leisure activities of their choosing should be considered to be an irrevocable personal liberty and a matter of basic human rights to which all should be entitled.

An individual's interests can often be deeply associated with their personal identity, and criticism and/or attempts to design intervention to diminish someone's focus on interests that they are passionate about can sometimes be viewed as an attempt to fundamentally change who that person is. Aside from extreme examples of leisure behavior that undermines engagement in other forms of adaptive behavior, no one (e.g., practitioners, family, caregivers, friends) should be empowered to determine whether an adult with autism's preferred leisure time behavior is too restrictive, not age-appropriate, too stigmatizing, unimportant, or unavailable. Respecting someone for who they are while also encouraging that person to become aware that in some situations and contexts, some of the traits/behavior that they associate with their identity may not result in their being able to achieve all of their individualized lifetime goals is a delicate balance. Practitioners should always have an equal commitment to respecting the interests, preferences, identities, and personal liberties of the clients they are supporting with the need to achieve goals toward greater adaptive functioning and overall quality of life (Bannerman et al., 1990).

References

Adhia, A., Bair-Merritt, M., Broder-Fingert, S., Nunez Pepen, R. A., Suarez-Rocha, A. C., & Rothman, E. F. (2020). The critical lack of data on alcohol and marijuana use by U.S. adolescents with autism spectrum disorder. *Autism in Adulthood, 2*(4), 282–288. https://doi.org/10.1089/aut2019.0051

Ahearn, W. H., Clark, K. M., Gardener, N. C., Chung, B. I., & Dube, W. V. (2003). Persistence of stereotypic behavior: Examining the effects of external reinforcers. *Journal of Applied Behavior Analysis, 36*, 439–448. https://doi.org/10.1901/jaba.2003.36-439

Alaniz, M. L., Rosenberg, S. S., & Beard, N. R. (2017). The effectiveness of aquatic group therapy for improving water safety and social interactions in children with autism spectrum disorder: A pilot program. *Journal of Autism and Developmental Disorders, 47*, 4006–4017. https://doi.org/10.1007/s10803-017-3264-4

Allison, D. B., Basile, V. C., & MacDonald, R. B. (1991). Brief report: Comparative effects of antecedent exercise and lorazepam on the aggressive behavior of an autistic man. *Journal of Autism and Developmental Disorders, 21*, 89–94. https://doi.org/10.1007/BF02207001

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Association.

Anderson, C., & Butt, C. (2018). Young adults on the autism spectrum: The struggle for appropriate services. *Journal of Autism and Developmental Disorders, 48*, 3912–3925. https://doi.org/10.1007/s10803-018-3673-z

Arnevik, E. A., & Helverschou, S. B. (2016). Autism spectrum disorder and co-occurring substance use disorder - A systematic review. *Substance Abuse: Research and Treatment, 10*, 69–75. https://doi.org/10.4137/SART.S39921

Azar, N. R., McKeen, P., Carr, K., Sutherland, C. A., & Horton, S. (2016). Impact of motor skills training in adults with autism spectrum disorder and an intellectual disability. *Journal on Developmental Disabilities, 22*(1), 28.

Bahrami, F., Movahedi, A., Marandi, S. M., & Abedi, A. (2012). Kata techniques training consistently decreases stereotypy in children with autism spectrum disorder. *Research in Developmental Disabilities, 33*(4), 1183–1193. https://doi.org/10.1016/j.ridd.2012.01.018

Bal, V. H., Kim, S., Cheong, D., & Lord, C. (2015). Daily living skills in individuals with autism spectrum disorder from 2 to 21 years of age. *Autism, 19*(7), 774–784. https://doi.org/10.1177/1362361315575840

Bal, V. H., Hendren, R. L., Charman, T., Abbeduto, L., Kasari, C., Klinger, L. G., … Rosenberg, E. (2018). Considerations from the 2017 IMFAR Preconference on measuring meaningful outcomes from school-age to adulthood. *Autism Research, 11*, 1446–1454. https://doi.org/10.1002/aur.2034

Bannerman, D. J., Sheldon, J. B., Sherman, J. A., & Harchik, A. E. (1990). Balancing the right to habilitation with the right to personal liberties: The rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behavior Analysis, 23*(1), 79–89. https://doi.org/10.1901/jaba.1990.23-79

Barak, S., Oz, M., Dagan, N., & Hutzler, Y. (2019). The Game of Life soccer program: Effect on skills, physical fitness and mobility in persons with intellectual disability and autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities, 32*(6), 1401–1411. https://doi.org/10.1111/jar.12620

Bassette, L., Kulwicki, J., Dieringer, S. T., Zoder-Martell, K. A., & Heneisen, R. (2018). The use of a multicomponent behavioral intervention to promote physical activity in adolescents with autism spectrum disorders across inclusive community settings. *Behavior Analysis in Practice, 11*(4), 358–369. https://doi.org/10.10007/s40617-018-00285-7

Bauminger, N., & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child Development, 71*(2), 447–456. https://doi.org/10.1111/1467-8624.00156

Bellini, S. (2004). Social skill deficits and anxiety in high-functioning adolescents with autism Spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 19*(2), 78–85. https://doi.org/10.1177/10883576040190020201

Bishop-Fitzpatrick, L., Mazefsky, C. A., & Eack, S. M. (2018). The combined impact of social support and perceived stress on quality of life in adults with autism spectrum disorder and without intellectual disability. *Autism, 22*(6), 703–711. https://doi.org/10.1177/1362361317703090

Brand, S., Jossen, S., Holsboer-Trachsler, E., Pühse, U., & Gerber, M. (2015). Impact of aerobic exercise on sleep and motor skills in children with autism spectrum disorders—A pilot study. *Neuropsychiatric Disease and Treatment, 11*, 1911–1920. https://doi.org/10.2147/NDT.S85650

Bremer, E., Crozier, M., & Lloyd, M. (2016). A systematic review of the behavioural outcomes following exercise interventions for children and youth with autism spectrum disorder. *Autism, 20*(8), 899–915. https://doi.org/10.1177/1362361315616002

Brugha, T. S., Doos, L., Tempier, A., Einfeld, S., & Howlin, P. (2015). Outcome measures in intervention trials for adults with autism spectrum disorders; a systematic review of assessments of core autism features and associated emotional and behavioural problems. *International Journal of Methods in Psychiatric Research, 24*(2), 99–115. https://doi.org/10.1002/mpr.1466

Buttimer, J., & Tierney, E. (2005). Patterns of leisure participation among adolescents with a mild intellectual disability. *Journal of Intellectual Disabilities, 9*(1), 25–42. https://doi.org/10.1177/1744629505049728

Butwicka, A., Långström, N., Larsson, H., Lundström, S., Serlachius, E., Almqvist, C., … Lichtenstein, P. (2017). Increased risk for substance use-related problems in Autism Spectrum disorders: A population-based cohort study. *Journal of Autism and Developmental Disorders, 47*, 80–89.

Caldwell, L., & Gilbert, A. (1990). Leisure, health, and disability: A review and discussion. *Canadian Journal of Community Mental Health, 9*, 111–122. https://doi.org/10.7870/cjcmh-1990-0022

Caputo, G., Ippolito, G., Mazzotta, M., Sentenza, L., Muzio, M. R., Salzano, S., & Conson, M. (2018). Effectiveness of a multisystem aquatic therapy for children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 48*(6), 1945–1956. https://doi.org/10.1007/s10803-017-3456-y

Cei, A., Franceschi, P., Rosci, M., Sepio, D., & Ruscello, B. (2017). Motor and psychosocial development in children with autism spectrum disorder through soccer. *International Journal of Sport Psychology, 48*(5), 485–507. https://doi.org/10.7352/IJSP.2017.48.485

Celiberti, D. A., Bobo, H. E., Kelly, K. S., Harris, S. L., & Handleman, J. S. (1997). The differential and temporal effects of antecedent exercise on the self-stimulatory behavior of a child with autism. *Research in Developmental Disabilities, 18*, 139–150. https://doi.org/10.1016/s0891-4222(96)00032-7

Chang, F. H., Coster, W. J., & Helfrich, C. A. (2013). Community participation measures for people with disabilities: A systematic review of content from an international classification of functioning, disability and health perspective. *Archives of Physical Medicine and Rehabilitation, 94*(4), 771–781. https://doi.org/10.1016/j.apmr.2012.10.031

Chartier, K. G., Hesselbrock, M. N., & Hesselbrock, V. M. (2011). Alcohol problems in young adults transitioning from adolescence to adulthood: The association with race and gender. *Addictive Behaviors, 36*(3), 167–174. https://doi.org/10.1016/j.addbeh.2010.10.007

Chonchaiya, W., Nuntnarumit, P., & Pruksananonda, C. (2011). Comparison of television viewing between children with autism spectrum disorder and controls. *Acta Peodiatrica, 7*, 1033–1037. https://doi.org/10.1111/j.1651-2227.2011.02166x

Cohn, A. M., Hagman, B. T., Graff, F. S., & Noel, N. E. (2011). Modeling the severity of drinking consequences in first-year college women: An item response theory analysis of the Rutgers alcohol problem index. *Journal of Studies on Alcohol and Drugs, 72*(6), 981–990. https://doi.org/10.15288/jsad.2011.72.981

Cordier, R., Milbourn, B., Martin, R., Buchanan, A., Chung, D., & Speyer, R. (2017). A systematic review evaluating the psychometric properties of measures of social inclusion. *PLoS One, 12*(6). https://doi.org/10.1371/journal.pone.0179109

Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism, 19*(7), 814–823. https://doi.org/10.1177/1362361315577517

Crutchfiled, S. A., Mason, R. A., Chambers, A., Wills, R. A., & Mason, B. A. (2015). Use of a self-monitoring application to reduce stereotypic behavior in adolescents with autism: A preliminary investigation of I-connect. *Journal of Autism and Developmental Disabilities, 45*(5), 1146–1155. https://doi.org/10.1007/s10803-014-2272-x

Cunningham, A. B., & Schreibman, L. (2008). Stereotypy in autism: The importance of function. *Research in Autism Spectrum Disorder, 2*(3), 469–479. https://doi.org/10.1016/j.rasd.2007.09.006

da Luz, F. Q., Hay, P., Touyz, S., & Sainsbury, A. (2018). Obesity with comorbid eating disorder: Associated health risks and treatment approaches. *Nutrients, 10*(7), 1–9. https://doi.org/10.3390/nu10070829

Darewych, O. H., Newton, N. J., & Farrugie, K. W. (2018). Investigating imagination in adults with autism spectrum disorder with art based assessments. *Journal on Developmental Disabilities, 23*(2), 27–36.

Dawson, J. E., Matson, J. L., & Cherry, K. E. (1998). An analysis of maladaptive behaviors in persons with autism, PDD-NOS, and mental retardation. *Research in Developmental Disabilities, 19*(5), 439–448. https://doi.org/10.1016/S0891-4222(98)00016-X

De Alwis, D., Agrawal, A., Reiersen, A. M., Constantino, J. N., Henders, A., Martin, N. G., & Lynskey, M. T. (2014). ADHD symptoms, autistic traits, and substance use and misuse in adult Australian twins. *Journal of Studies on Alcohol and Drugs, 75*(2), 211–221. https://doi.org/10.15288/jsad.2014.75.211

DeLeon, I. G., & Iwata, B. A. (1996). Evaluation of a multiple-stimulus presentation format for assessing reinforcer preferences. *Journal of Applied Behavior Analysis, 29*(4), 519–533. https://doi.org/10.1901/jaba.1996.29-519

Dickinson, K., & Place, M. (2014). A randomized control trial of the impact of the computer-based activity programme upon the fitness of children with autism. *Autism Research and Treatment, 2014*, 1–9. https://doi.org/10.1155/2014/419653

Didden, R., Sturmey, P., Sigafoos, J., Lang, R., O'Reilly, M. F., & Lancioni, G. E. (2012). Nature, prevalence, and characteristics of challenging behavior. In J. L. Matson (Ed.), *Functional assessment for challenging behaviors* (pp. 25–44). Springer Science + Business Media. https://doi.org/10.1007/978-1-4614-3037-7_3

Durand, V. M., & Carr, E. G. (1987). Social influences on "self-stimulatory" behavior: Analysis and treatment application. *Journal of Applied Behavior Analysis, 20*(2), 119–132. https://doi.org/10.1901/jaba.1987.20-119

Eldeniz Cetin, M., & Cay, E. (2020). Examining leisure activity engagement of students with intellectual disability. *International Journal of Educational Methodology, 6*(1), 57–66. https://doi.org/10.12973/ijem.6.1.57

Elliot, R. O., Dobbin, A. R., Rose, G. D., & Soper, H. V. (1994). Vigorous, aerobic exercise versus general motor training activities: Effects on maladaptive and stereotypic behaviors of adults with both autism and mental retardation. *Journal of Autism and Developmental Disorders, 24*(5), 565–576. https://doi.org/10.1007/BF02172138

Eversole, M., Collins, D. M., Karmarkar, A., Colton, L., Quinn, J. P., Karsbaek, R., … Hilton, C. L. (2016). Leisure activity enjoyment of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 46*(1), 10–20. https://doi.org/10.1007/s10803-015-2529-z

Farmer, C., Swineford, L., Swedo, S. E., & Thurm, A. (2018). Classifying and characterizing the development of adaptive behavior in a naturalistic longitudinal study of young children with autism. *Journal of Neurodevelopmental Disorders, 10*(1), 1. https://doi.org/10.1186/s11689-017-9222-9

Favoretto, L., Hutchison, Z., Mowling, C. M., & Pangelinan, M. M. (2020). Improvements in tennis skills in adults with developmental and intellectual disabilities following an 8-week adapted tennis program. *Journal of Motor Learning and Development, 8*(2), 245–261. https://doi.org/10.1123/jmld.2019-0016

Freeman, B. J., Del'Homme, M., Guthrie, D., & Zhang, F. (1999). Vineland adaptive behavior scale scores as a function of age and initial IQ in 210 autistic children. *Journal of Autism and Developmental Disorders, 29*, 379–384. https://doi.org/10.1023/a:1023078827457

Garcia-Villamisar, D., & Dattilo, J. (2011). Social and clinical effects of a leisure program on adults with autism spectrum disorder. *Research in Autism Spectrum Disorders, 5*(1), 246–253. https://doi.org/10.1016/j.rasd.2010.04.006

Goldman, S., Wang, C., Salgado, M. W., Greene, P. E., Kim, M., & Rapin, I. (2009). Motor stereotypies in children with autism and other developmental disorders. *Developmental Medicine and Child Neurology, 51*(1), 30–38. https://doi.org/10.1111/j.1469-8749.2008.03178.x

Gross, J. J., & Jazaieri, H. (2014). Emotion, emotion regulation, and psychopathology: An affective science perspective. *Clinical Psychological Science, 2*, 387–401. https://doi.org/10.1177/2167702614536164

Haley, J. L., Heick, P. F., & Luiselli, J. K. (2010). Use of an antecedent intervention to decrease vocal stereotypy of a student with autism in the general education classroom. *Child & Family Behavior Therapy, 32*(4), 311–321. https://doi.org/10.1080/07317107.2010.515527

Harrop, C. (2015). Evidence-based, parent-mediated interventions for young children with autism spectrum disorder: The case of restricted and repetitive behaviors. *Autism, 19*, 662–672. https://doi.org/10.1177/1362361314545685

Hayward, L. M., Fragala-Pinkham, M., Johnson, K., & Torres, A. (2016). A community-based, adaptive soccer program for children with autism: Design, implementation, and evaluation. *Palaestra, 30*(4), 44–50.

Helverschou, S. B., Steindal, K., Nøttestad, J. A., & Howlin, P. (2018). Personal experiences of the criminal justice system by individuals with autism spectrum disorders. *Autism, 22*(4), 460–468. https://doi.org/10.1177/1362361316685554

Hillier, A., Greher, G., Poto, N., & Dougherty, M. (2011). Positive outcomes following participation in a music intervention for adolescents and young adults on the autism spectrum. *Psychology of Music, 40*(2), 201–215. https://doi.org/10.1177/0305735610386837

Hilton, C. L., Zhang, Y., Whilte, M. R., Klohr, C. L., & Constantino, J. (2012). Motor impairment in sibling pairs concordant and discordant for autism spectrum disorders. *Autism: The International Journal of Research and Practice, 16*(4), 430–441. https://doi.org/10.1177/1362361311423018

Hilton, C. L., Cumpata, K., Klohr, C., Gaetke, S., Artner, A., Johnson, H., & Dobbs, S. (2014). Effects of exergaming on executive function and motor skills in children with autism spectrum disorder: A pilot study. *The American Journal of Occupational Therapy, 68*(1), 57–65. https://doi.org/10.5014/ajot.2014.008664

Howlin, P. (2000). Outcome in adult life for more able individuals with autism or Asperger syndrome. *Autism, 4*(1), 63–83. https://doi.org/10.1177/1362361300004001005

Huang, J., Du, C., Liu, J., & Tan, G. (2020). Meta-analysis on intervention effects of physical activities on children and adolescents with autism. *International Journal of Environmental Research and Public Health, 17*(6), 1950. https://doi.org/10.3390/ijerph17061950

Huang, J. S., Yang, F. C., Chien, W. C., Yeh, T. C., Chung, C. H., Tsai, C. K., … Liang, C. S. (2021). Risk of substance use disorder and its associations with comorbidities and psychotropic agents in patients with autism. *JAMA Pediatrics*, e205371. Advance online publication. https://doi.org/10.1001/jamapediatrics.2020.5371

Jones, R. S. P., Wint, D., & Ellis, N. C. (1990). The social effects of stereotyped behavior. *Journal of Mental Deficiency Research, 34*(3), 261–268. https://doi.org/10.1111/j.1365-2788.1990.tb01537.x

Jones, S. C., Gordon, C. S., Akram, M., Murphy, N., & Sharkie, F. (2021). Inclusion, exclusion and isolation of autistic people: Community attitudes and autistic people's experiences. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-021-04998-7

Jozkowski, A. C., & Cermak, S. A. (2020). Moderating effect of social interaction on enjoyment and perception of physical activity in young adults with autism spectrum disorders. *International Journal of Developmental Disabilities, 66*(3), 222–234. https://doi.org/10.1080/20473869.2019.1567091

Kaltenegger, H. C., Doering, S., Gillberg, C., Wennberg, P., & Lundström, S. (2021). Low prevalence of risk drinking in adolescents and young adults with autism spectrum problems. *Addictive Behaviors, 113*, 106671. https://doi.org/10.1016/j.addbeh.2020.106671

Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russel, G. (2019). People should be allowed to do what they like: Autistic adults' views and experience of stimming. *Autism, 23*(7), 1782–1792. https://doi.org/10.1177/1362361319829628

Kennedy, C. H., Meyer, K. A., Knowles, T., & Shukla, S. (2000). Analyzing the multiple functions of stereotypical behavior for students with autism: Implications for assessment and treatment. *Journal of Applied Behavior Analysis, 33*(4), 559–571. https://doi.org/10.1901/jaba.2000.33-559

Kenworthy, L., Case, L., Harms, M. B., Martin, A., & Wallace, G. L. (2010). Adaptive behavior ratings correlate with symptomatology and IQ among individuals with high-functioning autism spectrum disorders. *Journal of Autism Developmental Disorders, 40*(4), 416–423. https://doi.org/10.1007/s10803-009-0911-4

Kern, L., Koegel, R. L., & Dunlap, G. (1984). The influence of vigorous versus mild exercise on autistic stereotyped behaviors. *Journal of Autism and Developmental Disorders, 14*(1), 57–67. https://doi.org/10.1007/BF02408555

Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders, 46*(3), 942–953. https://doi.org/10.1007/s10803-015-2637-9

Kreiner, J., & Flexer, R. (2009). Assessment of leisure preferences for students with severe developmental disabilities and communication difficulties. *Education and Training in Developmental Disabilities*, 280–288. http://www.jstor.org/stable/24233501

Kronenberg, L. M., Slager-Visscher, K., Goossens, P. J., van den Brink, W., & van Achterberg, T. (2014). Everyday life consequences of substance use in adult patients with a substance use disorder (SUD) and co-occurring attention deficit/hyperactivity disorder (ADHD) or autism spectrum disorder (ASD): A patient's perspective. *BMC Psychiatry, 14*, 264. https://doi.org/10.1186/s12888-014-0264-1

Kuo, N. C., & Plavnick, J. B. (2015). Using an antecedent art intervention to improve the behavior of a child with autism. *Art Therapy, 32*(2), 54–59. https://doi.org/10.1080/07421656.2015.1028312

Kuo, M. H., Orsmond, G. I., Coster, W. J., & Cohn, E. S. (2014). Media use among adolescents with autism spectrum disorder. *Autism, 18*(8), 914–923. https://doi.org/10.1177/1362361313497832

LaLonde, K. B., MacNeill, B. R., Eversole, L. W., Ragotzy, S. P., & Poling, A. (2014). Increasing physical activity in young adults with autism spectrum disorders. *Research in Autism Spectrum Disorders, 8*(12), 1679–1684. https://doi.org/10.1016/j.rasd.2014.09.001

Lipscomb, S., Haimson, J., Liu, A. Y., Burghardt, J., Johnson, D. R., & Thurlow, M. L. (2017). *Preparing for life after high school: The characteristics and* *experiences of youth in special education. Findings from the National Longitudinal Transition Study 2012. Volume 2: Comparisons across disability groups: Full report (NCEE 2017-4018)*. U.S. Department of Education, Institute of Education Sciences, National Center for Education Evaluation and Regional Assistance.

Lloyd, K. M., & Auld, C. J. (2002). The role of leisure in determining quality of life: Issues of content and measurement. *Social Indicators Research, 57*(1), 43–71. https://doi.org/10.1023/A:1013879518210

Lovaas, O. I., Newsom, C., & Hickman, C. (1987). Self-stimulatory behavior and perceptual reinforcement. *Journal of Applied Behavior Analysis, 20*(1), 45–68. https://doi.org/10.1901/jaba.1987.20-45

Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K., & James, W. (2007). Challenging behaviours: Prevalence and topographies. *Journal of Intellectual Disability Research, 51*(8), 625–636. https://doi.org/10.1111/j.1365-2788.2006.00948.x

Lugo-Marín, J., Magán-Maganto, M., Rivero-Santana, A., Cuellar-Pompa, L., Alviani, M., Jenaro-Rio, C., Díez, E., & Canal-Bedia, R. (2019). Prevalence of psychiatric disorders in adults with autism spectrum disorder: A systematic review and meta-analysis. *Research in Autism Spectrum Disorders, 59*, 22–33. https://doi.org/10.1016/j.rasd.2018.12.004

Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., … Parr, J. R. (2019). A systematic review of what barriers and facilitators prevent and enable physical healthcare services access for autistic adults. *Journal of Autism and Developmental Disorders, 49*(8), 3387–3400. https://doi.org/10.1007/s10803-019-04049-2

Mastrominico, A., Fuchs, T., Manders, E., Steffinger, L., Hirjak, D., Sieber, M., Thomas, E., Holzinger, A., Konrad, A., Bopp, N., & Koch, S. C. (2018). Effects of dance movement therapy on adult patients with autism spectrum disorder: A randomized controlled trial. *Behavioral Sciences (Basel, Switzerland), 8*(7), 61. https://doi.org/10.3390/bs8070061

Mateos-Moreno, D., & Atencia-Doña, L. (2013). Effect of a combined dance/movement and music therapy on young adults diagnosed with severe autism. *The Arts in Psychotherapy, 40*(5), 465–472. https://doi.org/10.1016/j.aip.2013.09.004

Matson, J. L., Mahan, S., Hess, J. A., Fodstad, J. C., & Neal, D. (2010). Progression of challenging behaviors in children and adolescents with autism spectrum disorders as measured by the Autism Spectrum Disorders-Problem Behavior for Children (ASD-PBC). *Research in Autism Spectrum Disorders, 4*(3), 400–404. https://doi.org/10.1016/J.Rasd.2009.10.010

Matson, J. L., Hattier, M. A., & Belva, B. (2012). Treating adaptive living skills of persons with autism using applied behavior analysis: A review. *Research in Autism Spectrum Disorders, 6*(1), 271–276. https://doi.org/10.1016/J.Rasd.2011.05.008

Mazurek, M. O., Engelhardt, C. R., & Clark, K. E. (2015). Video games from the perspective of adults with autism spectrum disorder. *Computers in Human Behavior, 51*, 122–130. https://doi.org/10.1016/j.chb.2015.04.062

McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the validity of a qualityof life measure for autistic people. *Journal of Autism and Developmental Disorders, 48*(5), 1596–1611. https://doi.org/10.1007/s10803-017-3402-z

McCoy, S. M., Jakicic, J. M., & Gibbs, B. B. (2016). Comparison of obesity, physical activity, and sedentary behaviors between adolescents with autism spectrum disorders and without. *Journal of Autism and Developmental Disorders, 46*(7), 2317–2326. https://doi.org/10.1007/s10803-016-2762-0

Mechling, L. C., Ayres, K. M., Foster, A. L., & Bryant, K. J. (2013). Comparing the effects of commercially available and custom-made video prompting for teaching cooking skills to high school students with autism. *Remedial and Special Education, 34*(6), 371–383. https://doi.org/10.1177/0741932513494856

Moss, P., Mandy, W., & Howlin, P. (2017). Child and adult factors related to quality of life in adults with autism. *Journal of Autism and Developmental Disorders, 47*(6), 1830–1837. https://doi.org/10.1007/s10803-017-3105-5

Must, A., Philips, S., Curtin, C., & Bandini, L. G. (2015). Barriers to physical activity in children with autism spectrum disorders: Relationship to physical activity and screen time. *Journal of Physical Activity and Health, 12*(4), 529–534. https://doi.org/10.1123/jpah.2013-0271

Neal, D. J., Corbin, W. R., & Fromme, K. (2006). Measurement of alcohol-related consequences among high school and college students: Application of item response models to the Rutgers Alcohol Problem Index. *Psychological Assessment, 18*, 402–414. https://doi.org/10.1037/1040-3590.18.4.402

Noonan, S. K., Haist, F., & Müller, R. A. (2009). Aberrant functional connectivity in autism: Evidence from low-frequency BOLD signal fluctuations. *Brain Research, 1262*, 48–63. https://doi.org/10.1016/j.brainres.2008.12.076

Orsini, M., & Smith, M. (2010). Social movements, knowledge and public policy: The case of autism activism in Canada and the US. *Critical Policy Studies, 4*, 38–57. https://doi.org/10.1080/19460171003714989

Parsloe, S. M. (2015). Discourses of disability, narratives of community: Reclaiming an autistic identity online. *Journal of Applied Communication Research, 43*(3), 336–356. https://doi.org/10.1080/00909882.2015.1052829

Patterson, I., & Pegg, S. (2009). Serious leisure and people with intellectual disabilities: Benefits and opportunities. *Leisure Studies, 28*(4), 387–402. https://doi.org/10.1080/02614360903071688

Phillips, K. L., Schieve, L. A., Visser, S., Boulet, S., Sharma, A. J., Kogan, M., … Yeargin-Allsopp, M. (2017). Prevalence and impact of unhealthy weight in a national sample of US adolescents with autism and other learning and behavioral disabilities. *Maternal* *and Child Health Journal, 18*(8), 1964–1975. https://doi.org/10.1007/s10995-014-1442-y

Prupas, A., & Reid, G. (2001). Effects of exercise frequency on stereotypic behaviors of children with developmental disabilities. *Education and Training in Mental Retardation and Developmental Disabilities, 36*(2), 196–206. http://www.jstor.org/stable/23879735

Ragheb, M. G., & Beard, J. G. (1980). Leisure satisfaction: Concept, theory, and measurement. *Leisure Satisfaction: Concept, Theory, and Measurement*, 329–353.

Ramos, M., Boada, L., Moreno, C., Llorente, C., Romo, J., & Parellada, M. (2013). Attitude and risk of substance use in adolescents diagnosed with Asperger syndrome. *Drug and Alcohol Dependence, 133*(2), 535–540. https://doi.org/10.1016/j.drugalcdep.2013.07.022

Rao, P. A., Beidel, D. C., & Murray, M. J. (2008). Social skills interventions for children with Asperger's syndrome or high-functioning autism: A review and recommendations. *Journal of Autism and Developmental Disorders, 38*(2), 353–361. https://doi.org/10.1007/s10803-007-0402-4

Rapp, J. T., & Vollmer, T. R. (2005). Stereotypy I: A review of behavioral assessment and treatment. *Research in Developmental Disabilities, 26*, 527–547. https://doi.org/10.1016/j.ridd.2004.11.005

Reid, P. R., Factor, D. C., Freeman, N. L., & Sherman, J. (1988). The effects of physical exercise on three autistic and developmentally disordered adolescents. *Therapeutic Recreation Journal, 22*(2), 47–56.

Repp, A. C., Felce, D., & Barton, L. E. (1988). Basing the treatment of stereotypic and self-injurious behaviors on hypotheses of their causes. *Journal of Applied Behavior Analysis, 21*(3), 281–289. https://doi.org/10.1901/Fjaba.1988.21-281

Ressel, M., Thompson, B., Poulin, M.-H., Normand, C. L., Fisher, M. H., Couture, G., & Iarocci, G. (2020). Systematic review of risk and protective factors associated with substance use and abuse in individuals with autism spectrum disorders. *Autism, 24*(4), 899–918. https://doi.org/10.1177/1362361320910963

Rimmer, J., Rowland, J., & Yamaki, K. (2007). Obesity and secondary conditions in adolescents with disabilities: Addressing the needs of an underserved population. *Journal of Adolescent Health, 41*(3), 224–229. https://doi.org/10.1016/j.jadohealth.2007.05.005

Rogers, S. J., & Ozonoff, S. (2005). Annotation: What do we know about sensory dysfunction in autism? A critical review of the empirical evidence. *Journal of Child Psychology and Psychiatry, 46*(12), 1255–1268. https://doi.org/10.1111/j.1469-7610.2005.01431.x

Roth, M. E., & Gillis, J. M. (2015). "Convenience with the click of a mouse": A survey of adults with autism spectrum disorder on online dating. *Sexuality and Disability, 33*(1), 133–150. https://doi.org/10.1007/s11195-014-9392-2

Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A., & Anderson, K. A. (2015). National Autism Indicators report: Transition into young adulthood. In *Life course outcomes research program*. AJ Drexel Autism Institute, Drexel University.

Sances, J., Day-Watkins, J., & Connell, J. E. (2019). Teaching an adult with autism spectrum disorder to use an activity schedule during a vocational beekeeping task. *Behavior Analysis in Practice, 12*(2), 435–439. https://doi.org/10.1007/s40617-018-00306-5

Santosh, P. J., & Mijovic, A. (2006). Does pervasive developmental disorder protect children and adolescents against drug and alcohol use? *European Child & Adolescent Psychiatry, 15*(4), 183–188. https://doi.org/10.1007/s00787-005-0517-0

Savage, M. N., Taber-Doughty, T., Brodhead, M. T., & Bouck, E. C. (2018). Increasing physical activity for adults with autism spectrum disorder: Comparing in-person and technology delivered praise. *Research in Developmental Disabilities, 73*, 115–125. https://doi.org/10.1016/j.ridd.2017.12.019

Seltzer, M. M., Shattuck, P., Abbeduto, L., & Greenberg, J. S. (2004). Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews, 10*(4), 234–247. https://doi.org/10.1002/mrdd.20038

Shabani, D. B., Wilder, D. A., & Flood, W. A. (2001). Reducing stereotypic behavior through discrimination training, differential reinforcement of other behavior, and self-monitoring. *Behavioral Interventions, 16*, 279–286. https://doi.org/10.1002/bin.96

Shafer, R. L., Newell, K. M., Lewis, M. H., & Bodfish, J. W. (2017). A cohesive framework for motor stereotypy in typical and atypical development: The role of sensorimotor integration. *Frontiers in Integrative Neuroscience, 11*, 19. https://doi.org/10.3389/fnint.2017.00019

Shono, Y., Ames, S. L., Edwards, M. C., & Stacy, A. W. (2018). The Rutgers alcohol problem index for adolescent alcohol and drug problems: A comprehensive modern psychometric study. *Journal of Studies on Alcohol and Drugs, 79*(4), 658–663. https://doi.org/10.15288/jsad.2018.79.658

Sizoo, B., van den Brink, W., Koeter, M., Gorissen van Eenige, M., van Wijngaarden-Cremers, P., & van der Gaag, R. J. (2010). Treatment seeking adults with autism or ADHD and co-morbid substance use disorder: Prevalence, risk factors and functional disability. *Drug and Alcohol Dependence, 107*(1), 44–50. https://doi.org/10.1016/j.drugalcdep.2009.09.003

Smerbeck, A. (2019). The survey of favorite interests and activities: Assessing and understanding restricted interests in children with autism spectrum disorder. *Autism, 23*(1), 247–259. https://doi.org/10.1177/1362361317742140

Sorenson, C., & Zarrett, N. (2014). Benefits of physical activity for adolescents with autism spectrum disorder: A comprehensive review. *Review Journal of Autism and Developmental Disorders, 1*(4), 344–353. https://doi.org/10.1007/s40489-014-0027-4

Sowa, M., & Meulenbroek, R. (2012). Effects of physical exercise on autism spectrum disorders: A meta-analysis. *Research in Autism Spectrum Disorders, 6*(1), 46–57. https://doi.org/10.1016/j.rasd.2011.09.001

Sparrow, S., Balla, D. A., & Cicchetti, D. (1984). *Vineland adaptive behavior scales (expanded form)*. American Guidance Service.

Stacey, T.-L., Froude, E. H., Trollor, J., & Foley, K.-R. (2019). Leisure participation and satisfaction in autistic adults and neurotypical adults. *Autism, 23*(4), 993–1004. https://doi.org/10.1177/1362361318791275

Steward, R. L. (2015). *Repetitive stereotyped behaviour or 'stimming': An online survey of 100 people on the autism spectrum*. Paper Presented at the 2015 International Meeting for Autism Research. Retrieved from https://insar.confex.com/insar/2015/webprogram/Paper20115.html

Szabo, T. G. (2019). Acceptance and commitment training for reducing inflexible behaviors in children with autism. *Journal of Contextual Behavioral Science, 12*, 178–188. https://doi.org/10.1016/j.jcbs.2019.03.001

Taheri, A., Perry, A., & Minnes, P. (2016). Examining the social participation of children and adolescents with intellectual disabilities and autism spectrum disorder in relation to peers. *Journal of Intellectual Disability Research, 60*(5), 435–443. https://doi.org/10.1111/jir.12289

Tassé, M. J., Schalock, R. L., Balboni, G., Bersani, H., Borthwick-Duffy, S. A., Spreat, S., … Zhang, D. (2012). The construct of adaptive behavior: Its conceptualization, measurement, and use in the field of intellectual disability. *American Journal on Intellectual and Developmental Disabilities, 117*(4), 291–303. https://doi.org/10.1352/1944-7558-117.4.291

Toner, N. (2014). How do you figure out what motivates your students? *Science in Autism Treatment, 11*(1), 12–14.

Tse, A., & Masters, R. (2019). Improving motor skill acquisition through analogy in children with autism spectrum disorders. *Psychology of Sport & Exercise, 41*, 63–69. https://doi.org/10.1016/j.psychsport.2018.12.002

Turnbull, A. P., & Turnbull, H. R., 3rd. (1985). Developing independence. *Journal of Adolescent Health Care, 6*(2), 108–119. https://doi.org/10.1016/s0197-0070(85)80035-8

Verdugo, M. A., Schalock, R. L., Keith, K. D., & Stancliffe, R. J. (2005). Quality of life and its measurement: Important principles and guidelines. *Journal of Intellectual Disability Research, 49*(10), 707–717. https://doi.org/10.1111/j.1365-2788.2005.00739.x

Ward, S. C., Whalon, K., Rusnak, K., Wndell, K., & Paschall, N. (2013). The association between therapeutic horseback riding and the social communication and sensory reactions of children with autism. *Journal of Autism and Developmental Disorders, 43*(9), 2190–2198. https://doi.org/10.1007/s10803-013-1773-3

Ward, D. M., Dill-Shackleford, K. E., & Mazurek, M. O. (2018). Social media use and happiness in adults with autism spectrum disorder. *Cyberpsychology, Behavior and Social Networking, 21*(3), 205–209. https://doi.org/10.1089/cyber.2017.0331

White, H. R., & Labouvie, E. W. (1989). Towards the assessment of adolescent problem drinking. *Journal of Studies on Alcohol, 50*(1), 30–37. https://doi.org/10.15288/jsa.1989.50.30

Williams, J. H. G., Whiten, A., & Singh, T. (2004). A systematic review of action imitation in autistic spectrum disorder. *Journal of Autism and Developmental Disorders, 34*(3), 285–299. https://doi.org/10.1023/b:jadd.0000029551.56735.3a

Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, S., Brock, M. E., Plavnick, J. B., Fleury, V. P., & Schultz, T. R. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of Autism and Developmental Disorders, 45*(7), 1951–1966. https://doi.org/10.1007/s10803-014-2351-z

World Health Organization QOL Group. (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science and Medicine, 41*, 1403–1409. https://doi.org/10.1016/0277-9536(95)00112-K

World Health Organization QOL Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine, 28*, 551–558. https://doi.org/10.1017/S0033291798006667

Yu, J., & Jee, Y. S. (2020). Educational exercise program affects to physical fitness and gross motor function differently in the severity of autism spectrum disorder. *Journal of Exercise Rehabilitation, 16*(5), 410–417. https://doi.org/10.12965/jer.2040688.344

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Social Behavior and Social Interventions for Adults on the Autism Spectrum

Christine T. Moody and Elizabeth A. Laugeson

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by two clusters of symptoms: deficits in social communication and restricted, repetitive behaviors or interests (APA, 2013). Though onset of symptoms must be present early in development, autism is generally considered a lifelong disorder, with support needs present even in those who achieve more positive outcomes (Fombonne, 2003). Autism is also known for its significant heterogeneity in clinical presentation (Masi et al., 2017), as represented by the oft-quoted statement: "if you've met one person with autism, then you've met one person with autism." Despite the wide spectrum of profiles, some have considered autism to be defined by core disruptions in social information processing, which results in differences in reciprocal social interaction (Pelphrey et al., 2011). Other commonalities within the diversity of autism spectrum may exist as well, all of which are centered around social behaviors. For example, challenges with pragmatic language, or the social use of language (e.g., adjusting conversation to context or person, responding contingently, spontaneously providing information for social purposes), are considered universally present in ASD (Tager-Flusberg et al., 2005). These features may relate to the other diagnostic characteristics and social communication differences, such as difficulties understanding and utilizing nonverbal communication, and struggles developing, maintaining, and understanding relationships (APA, 2013). Finally, although other forms of psychopathology impact some social behaviors, such as flat affect or diminished eye contact (e.g., depression, anxiety, schizophrenia), reduced social reciprocity and interactive behaviors are most distinctive to the social profile of individuals on the autism spectrum (Morrison et al., 2017) and are more impaired than would be expected given the individual's cognitive level (APA, 2013). Ultimately, the importance of social behavior in ASD cannot be understated.

Although much is known about children diagnosed with ASD, including strong empirical support for numerous evidence-based practices and interventions (Odom et al., 2010), research into the development and treatment of ASD across the lifespan into adulthood is much more limited (Howlin & Moss, 2012; Shattuck et al., 2020). In recent years, such research involving autistic adults has garnered increased attention, especially as large cohorts of autistic children are aging into adulthood with significant service needs (Gerhardt & Lainer, 2011). However, there are still extensive and serious gaps in the field, given the historical focus of research and funding on youth populations (Baker-Ericzén et al., 2018a). In particular, development of evidence-

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based treatments for autistic adults continues to be identified as lacking and an ongoing urgent area of need (Lorenc et al., 2018), even though current research has clearly demonstrated that autistic adults exhibit poor outcomes, across multiple domains, including vocational, educational, independence, social functioning (Eaves & Ho, 2008). In understanding these pervasively poor outcomes, social functioning has emerged as an important predictor and mechanism of prognosis. For example, early childhood language skills and joint attention have been identified as specific predictors of adult social functioning (Gillespie-Lynch et al., 2012). In another study, social reciprocity emerged as the strongest predictor of adult outcome (Howlin et al., 2013).

In a review of studies examining outcomes in adulthood for those diagnosed with ASD, Magiati et al. (2014) found that although measures of cognition, language, and autism features remained stable or improved from childhood to adulthood, social functioning in autistic adults was generally very poor. The majority of studies reviewed reported high rates of social isolation and very few friendships or romantic relationships among adults on the autism spectrum, with some evidence indicating that social outcomes worsen across development (Howlin et al., 2013). In a comparison by age, autistic adults were significantly less likely to have a single high-quality friendship than autistic adolescents (Orsmond et al., 2004). Furthermore, autistic adults are at even higher risk than other neurodevelopmental disorder populations for poor social outcomes, such that autistic adults report lower perceived social support than both neurotypical peers and peers with ADHD, especially in relation to support derived from friends (Alvarez-Fernandez et al., 2017). Not surprisingly, this lack of social connection has been connected with high levels of loneliness and depressive symptoms reported by adults on the spectrum (Mazurek, 2014).

Overall, the social outcomes of adults diagnosed with ASD are unfortunately bleak. As youth enter young adulthood, there are significant changes that may contribute to the process of increasing isolation. Specifically, the transition out of high school represents a stark loss in structured opportunities for social interactions, whether through daily interaction with peers in classrooms or the presence of easily accessible extracurricular activities and school community events. Following high school, autistic individuals are more likely than their peers to struggle with maintaining contact with friends as well as seeking out and forming connections to new peer social groups in employment and higher education settings. This net loss of social opportunities has been confirmed through research, with autistic youth showing a significant decline in structured social opportunities immediately after graduating high school but showing no changes in participation in unstructured social activities (Lounds Taylor et al., 2017). Compounding these difficulties in the transition to adulthood, individuals on the autism spectrum also experience what has been deemed the "services cliff" following high school. The services cliff is characterized by a significant decline in access to and use of services, resulting in a rise in unmet service needs across the autism spectrum in young adulthood (Laxman et al., 2019; Shattuck et al., 2011). Further, documented disproportionality has shown that autistic young adults of color and/or from low-income backgrounds are even less likely to successfully access services after the educational entitlement system ends (Shattuck et al., 2011). This loss of supportive services is exacerbated by demands related to novel tasks and roles within adult contexts, such as employment, and increased expectations of independent functioning. In sum, as young people on the autism spectrum transition to adulthood, many lose the formal and informal supports, bolstering their social functioning.

Alternatively, one study did find more positive social outcomes for autistic adults (Farley et al., 2009). This sample was particularly unique due to its high representation of members of the Church of Jesus Christ of the Latter-Day Saints. Study findings suggest that in communities with high levels of support, integration, and community activities, autistic adults can achieve more favorable social outcomes. Further, with the development of new treatments for autistic adults, there is also emerging evidence that interventions can promote improvements in the social functioning of this vulnerable population (Bishop-Fitzpatrick et al., 2013; Laugeson et al., 2015).

Taking these multiple components together, it is clear that social behavior in ASD is a critical area of study across the lifespan. The current chapter aims to summarize what is known about the social behavior of adults diagnosed with ASD, review the importance and impact of social behavior profiles on functional outcomes, and highlight examples from the growing field of available interventions targeting social outcomes in this population.

Social Behavior in Autistic Adults

Social behavior is a broad umbrella term that can be divided into several different dimensions. One common conceptualization of the components of social behavior includes four components: social communication, social cognition, social awareness, and social engagement/motivation. Autistic individuals often exhibit differences in each of these areas across the lifespan. However, as individuals mature and their social contexts change (e.g., from school to work), the implications of such differences can result in clinical presentations and dilemmas unique to each developmental stage. In the sections below, we will focus on presenting research and clinical information relevant to adults on the autism spectrum.

Social Communication

Social communication encompasses a wide range of verbal and nonverbal behaviors, all of which serve a communicative purpose, whether in initiation or response to a social partner. More simply, these behaviors can be thought of as knowing what to say (e.g., responding on topic, complying with social norms) and how to say it (e.g., tone, facial expression) to meet a social goal. Beginning with characteristics of speech and prosody, autistic adults demonstrate significant differences from typically developing adults in their rate, volume, stress/emphasis, and phrasing (i.e., a measure of speech fluency, documenting word repetitions, stuttering, or revising while speaking; Shriberg et al., 2001). In coded observations of role-play conversations, autistic adults were less fluid in their conversational speech, were less likely to ask their partner questions, were rated as demonstrating lower interest in interaction, had fewer instances of integrated eye contact, and displayed more examples of inappropriate or flat affect (Morrison et al., 2017). Additionally, adults on the spectrum may struggle to understand and respond appropriately to figurative or nonliteral language, such as metaphors, hyperbole, and sarcasm due to patterns of concrete thinking (Kalandadze et al., 2018).

In one interesting study design, autistic adults were asked to generate questions they had about “getting along with other people,” which were then addressed collaboratively in a group setting through problem-solving. The questions and responses provided by participants revealed challenges with a number of social communication skills, such as conflict resolution, navigating workplace interactions, getting to know someone better, starting and maintaining conversations, entering group conversations, asking someone on a date, and knowledge of social norms (Sperry & Mesibov, 2005). Beyond general social interactions with peers, specific social contexts in adulthood create unique manifestations of social communication errors. In the work place, such social errors and challenges can manifest as problems with coworkers, due to being too blunt or engaging in “policing” behaviors due to rigid adherence to rules (e.g., reporting a coworker for being late). There are also ramifications for interactions with supervisors, where autistic individuals may be perceived as overly resistant to change, inflexible, or insubordinate. Adults themselves report workplace challenges in making small talk, interacting with clients, and providing constructive feedback (Baldwin & Costley, 2016). Qualitatively, they describe having to work harder to “appear as normal” and learn the “rules” in employment settings (Baldwin & Costley, 2016).

Social Cognition

Social cognition most commonly refers to the ability of individuals to perceive the intentions and internal states of others, including thoughts and emotions. The most prominent social cognitive skill studied in autism is theory of mind, a more technical term for perspective taking abilities, including how others' internal experiences may differ from one's own. Autistic adults show a clear pattern in which social cognition, such as theory of mind and emotion perception, is more impaired than nonsocial cognition, including memory and attention (Velikonja et al., 2019). In individuals on the autism spectrum, neurobiological research has documented consistent differences in the brain structures associated with social cognition, including the amygdala, superior temporal sulcus, and fusiform gyrus (Pelphrey et al., 2004). Interestingly, as adults on the autism spectrum age, some of these social cognition deficits may abate relative to neurotypical adults. One study found that there were less pronounced differences in theory of mind abilities between autistic and neurotypical adults in middle and later adulthood (Lever & Geurts, 2016). However, on a task of emotional perception, *Reading the Mind in the Eyes* (Baron-Cohen et al., 2001), there was a nonsignificant effect of age on performance through adulthood, though the authors noted interesting gender differences in trajectories over time (Pagni et al., 2020).

These social cognitive differences contribute to observed deficits in traditional tasks measuring empathy in adults with ASD (Baron-Cohen & Wheelwright, 2004). However, more nuanced examination shows instead a consistent impairment in cognitive empathy, or the ability to infer others' mental states, and inconsistent findings with respect to emotional empathy, or the ability to share in the emotions of others (Smith, 2009). Several studies have actually found no differences by diagnostic status in emotional empathy (Dziobek et al., 2008) or in physiological reactions to emotional situations (Trimmer et al., 2017). Ultimately, this may suggest that while autistic adults struggle to independently identify and understand others' emotional states, they experience similar levels of concern and sympathy for others.

Importantly, deficits in theory of mind leave autistic adults vulnerable to victimization and being taken advantage of, given their impaired ability to detect deception (i.e., understanding that someone might say something they do not believe; Mathersul et al., 2013). Data bear this risk out, such that autistic adults are more likely than their neurotypical peers to be victimized (Brown-Lavoie et al., 2014). Though other neurodevelopmental disorder populations also have elevated social vulnerability, autistic adults have been found specifically to have lower risk awareness and lower social protection due to diminished social networks and friendships, even when compared to other disability groups (Fisher et al., 2013). In clinical settings, these findings may manifest in adults on the spectrum and their families anecdotally reporting greater incidents of safety concerns and victimization experiences (i.e., financial, sexual) due to such naiveté.

Difficulties in social cognition and perspective-taking may also contribute to inappropriate social behaviors sometimes utilized by autistic adults. For example, research has documented an increased use of inappropriate romantic courtship behaviors by autistic adults, including following or monitoring the activities of their love interest (e.g., pseudo-stalking), choosing inappropriate people of interest (e.g., strangers, celebrities), and persisting in pursuit following a nonresponse or negative response from a desired partner (Stokes et al., 2007). However, importantly, people close to these adults on the autism spectrum (e.g., family members) most often report that the individual is unaware of the inappropriateness of their behaviors and had difficulty understanding that the other person was not interested, suggesting the presence of a deficit in perspective-taking rather than malicious intent (Stokes et al., 2007). This explanation has been confirmed through mediation analysis, showing that theory of mind deficits predicted inappropriate courtship behaviors in autistic adults (Mintah & Parlow, 2018). This study also found that poor theory of mind skills were related to an increased likelihood of interpreting ambiguous interactions as indicators of flirtatious interest. Thus, the authors summarize that the observance of such inappropriate courtship behaviors is likely an unintentional result of misunderstanding and misinterpreting cues (Mintah & Parlow, 2018).

Social Awareness

Social awareness includes skills related to picking up on social cues and being broadly aware of the surrounding social landscape (e.g., visual, auditory information). The basic foundations of social awareness appear to be disrupted in those diagnosed with autism, with a large number of studies documenting that autistic individuals engage in atypical gaze orienting in social interactions and depictions, with decreased attention and priority given to social stimuli (e.g., people, faces; Chevallier et al., 2013; Fletcher-Watson et al., 2009). However, even when attention is directed toward social stimuli, autistic adults may not process the information in a manner facilitating social awareness. For example, one study showed that individuals diagnosed with ASD do not show a typical pattern of brain activation in response to fearful faces looking off to the side, which activated regions associated with danger in typical controls (Zürcher et al., 2013). Although interpretation of cues to deduce others' mental states falls under the domain of social cognition, one's ability to successfully achieve that hinges necessarily on the accurate and timely sensory perception of cues (e.g., seeing changes in facial expression, shifts in body language, orientation of gaze). Such cues in a social interaction or within one's environment may be fleeting, and even minor differences in attention may have significant consequences (Fletcher-Watson et al., 2009). These differences in social awareness likely contribute to common social errors observed in adults with ASD, such as topic perseveration (e.g., not identifying social cues indicating lack of interest) or dominating the conversation (e.g., not noticing social cues that the other person would like to speak). Further, evidence indicates that social stimuli may actually be less distracting to autistic individuals than to neurotypical people (Chevallier et al., 2013), possibly resulting in autistic adults appearing "oblivious" to their social environments.

Finally, despite difficulties in social awareness and understanding others' mental states, autistic adults often do experience subjective feelings of judgment and lack of social acceptance related to their symptoms and behaviors (Kapp et al., 2019a). Research investigating the phenomenon of "camouflaging," in which autistic individuals mask, hide, or otherwise compensate for their autism features in social interactions, has clearly demonstrated their awareness of the need to change one's behavior to achieve various aims (Hull et al., 2017).

Social Engagement and Motivation

Some theorists cite social motivation as the foundational social deficit in ASD that creates cascading effects on ongoing development (Chevallier et al., 2012). Specifically, this theory posits that lack of social motivation results in less social experience, which subsequently leads to differences in social communication and cognition from reduced opportunities to acquire such knowledge. However, the explanation that autistic individuals are not interested in or motivated by social interaction runs counter to many anecdotal observations among clinicians and parents, where forming friendships and romantic relationships is reported as a primary goal and a source of distress when not achieved. The popularity of social skills treatment programs in the community also suggests a desire for social engagement and signifies motivation for improved social connection and acceptance, with the primary barrier being not knowing how to achieve that goal rather than a lack of interest. Subsequent challenges to this theory have posited alternative explanations for behaviors that may appear as lack of social motivation or interest (Kapp et al., 2019b).

In contrast, qualitative analysis of interviews with young adults on the autism spectrum confirms a strong desire for social engagement and efforts to form friendships while acknowledging significant challenges in doing so (Sosnowy et al., 2019). Autistic young adults identified acceptance of atypical behavior and common interests as essential features of successful friendships in adulthood (Sosnowy et al., 2019). Perhaps relatedly, multiple small-scale studies have documented that adults on the spectrum report increased comfort in and preference for social interaction with other adults diagnosed with ASD relative to interaction with neurotypical adults (Morrison et al., 2020; Crompton et al., 2020). In contrast, neurotypical adults expressed preference for continued interaction with other typically developing adults (Morrison et al., 2020). From this lens, it is possible that social engagement in autistic adults may be impacted by dyadic factors beyond the individual, with lack of mutual understanding from both sides (Milton, 2012). This hypothesis is reinforced through data that show adults on the spectrum spend as much time interacting with others as do neurotypical adults (Hintzen et al., 2010). Instead, what does differ is the company they keep during that time, such that autistic individuals spend the majority of their social time with family members, whereas neurotypical adults' social time is more evenly split between family and friends (Hintzen et al., 2010). Consistent with the self-determination theory of social engagement, autistic adults also report the highest levels of intrinsic motivation for interaction in situations where they felt comfortable, accepted, and listened to, which was usually with family members and close friends (Chen et al., 2015). This was in contrast to social interactions with less familiar people, such as coworkers or classmates, where they reported being extrinsically motivated to interact to satisfy external demands (i.e., feeling like they had to; Chen et al., 2015).

Importance of Social Functioning

These differences in and challenges with social behavior have important ramifications for multiple domains of functioning for adults on the autism spectrum, including their ability to develop and maintain meaningful relationships of all kinds, obtain and maintain meaningful employment and postsecondary education, and demonstrate well-being via their mental health and subjective quality of life.

Social Relationships

Several adult outcome studies have reported that more than half of autistic individuals do not have any meaningful, close friendships (Howlin & Moss, 2012; Eaves & Ho, 2008). Compared to other disability groups, autistic adults are least likely to report regular, weekly get-togethers with friends (Newman et al., 2011). Beyond not having close friendships and get-togethers, 28% of autistic adults reportedly had no social contact with peers in the past 12 months – a rate more than three times higher than that of adults with intellectual, learning, or emotional disabilities (Orsmond et al., 2013). Interestingly, one study found that adults on the spectrum participate in community activities, such as classes, clubs, volunteer work, or sports, at comparable rates with other disability groups (Newman et al., 2011). This finding is contrary to the drastic differences in frequency of get-togethers with friends, strongly indicating that adults on the spectrum primarily struggle with skills that promote social connection and ultimately turn acquaintances into friends outside of organized social contexts (e.g., school, church, clubs, sports teams). For example, conversational skills are critical to the development of relationships and have been linked to frequency of social contact and the formation of friendships in autistic adults (Friedman et al., 2019; Orsmond et al., 2013). Clearly, the formation of friendships is not only contingent on access to peers through participation in social activities but also on an ability to engage and connect with those peers in meaningful ways (i.e., conversational exchange).

Autistic adults also report similar levels of interest in having romantic relationships and engaging in sexual activity as their neurotypical peers but are significantly less likely to have romantic involvement (Cheak-Zamora et al., 2019; Hancock et al., 2020). A large study inclusive of over 200 autistic adults identified that social engagement explained the relationship between ASD diagnostic status and difficulties with romantic relationships (Hancock et al., 2020). Two qualitative analyses of factors that enabled or inhibited romantic intimacy in autistic adults found that they specifically benefited from explicit and direct communicative styles and had more difficulty with giving and receiving romantic signals (e.g., flirting, expressing emotion; Sala et al., 2020; Smith et al., 2020). Interestingly, autistic adults also report learning less about sexuality from their peers than did neurotypical adults, likely another manifestation of the social behavioral profile of ASD that interferes with success and satisfaction in this area (Hancock et al., 2020). Of note, accumulating anecdotal and clinical observations in the field have informed recent empirical investigation into the gender identity and sexual orientation of individuals on the spectrum. Findings suggest higher rates of gender dysphoria and lower rates of heterosexual orientation in adults on the autism spectrum (George & Stokes, 2018a, b). Unfortunately, some of the social behaviors of autistic individuals (e.g., specialized interests, concreteness, difficulties with adjusting behavior to context) also contribute to parents' apprehensions in discussing sexuality with their autistic child, which puts these individuals at further disadvantage (Ballan, 2012).

Despite the challenges imbued by social differences, there are also indications that autistic adults can have successful and fulfilling romantic relationships. Indeed, in one recent study with a large sample of autistic adults ($n = 675$), over 50% reported being in a current romantic relationship, with very low levels of dissatisfaction with those relationships (Dewinter et al., 2017). Further, research results suggest that autistic adults may also demonstrate stronger commitment, as evidenced by longer relationship duration (Jobe & White, 2007), and greater honesty in relationships (Russell et al., 2019). Notably, it may be that more recent cohorts of adults on the spectrum are experiencing improved romantic relationship outcomes. Initial adult outcome studies generally observed very low participation in this area, with a review from almost a decade ago showing that more than half of studies reported less than 15% of autistic adults being involved in significant romantic relationships (range 0–38%; Howlin & Moss, 2012). More recently, data suggest much greater proportions of autistic adults have had meaningful romantic relationship experiences (>50%), though the rates are still significantly lower than neurotypical samples (Byers et al., 2013; Dewinter et al., 2017; Strunz et al., 2017).

Professional and Educational Pursuits

Autistic adults are chronically unemployed or underemployed. In two studies of outcomes in the transition to adulthood period, including one using a large national dataset, only 44% of young adults on the spectrum had held any sort of paid job in the immediate years after high school (Eaves & Ho, 2008; Friedman et al., 2019). Those that had a history of paid employment were more likely than the general population to work part-time or very few hours, be overqualified, be paid wages close to or below the minimum wage, and be employed as a casual worker with no ongoing job security or benefits (Baldwin et al., 2014; Eaves & Ho, 2008; Friedman et al., 2019). Similarly, autistic young adults are also less likely to enroll in or complete postsecondary education than their neurotypical peers or other disability groups (Newman et al., 2011), with less than half reporting any higher education participation in the 8 years after high school.

The social functioning of adults diagnosed with ASD is inextricably tied to their professional and educational success. In surveys examining barriers to employment, the most commonly identified factors by autistic adults were difficulties getting past the interview stage and social communication with coworkers or supervisors (Coleman & Adams, 2018; Lorenz et al., 2016). Conversational abilities and social skills have been shown to longitudinally predict vocational success and educational attainment in adults with ASD (Chiang et al., 2013; Friedman et al., 2019; Liptak et al., 2011). In a review of predictors of vocational success, social competence and social support factors were identified across multiple studies (Walsh et al., 2014). As compared to their neurotypical peers, autistic college students report lower levels of belonging, lower quality social relationships, and higher rates of all forms of bullying (e.g., physical, verbal, rumors) and social exclusion (McLeod et al., 2019). In a qualitative study of college students with neurodevelopmental disorders, negative peer interactions were cited as a barrier to success in postsecondary education, but only for those diagnosed with ASD (Bolourian et al., 2018), further underscoring the specificity of significant social challenges for this population. Interestingly, diagnosis disclosure to employers has also been connected with increased likelihood of job obtainment and maintenance (Ohl et al., 2017). Similarly, college students who disclosed their ASD diagnosis to faculty also described finding the process helpful (Bolourian et al., 2018). However, this skill of diagnosis disclosure, in and of itself, can often invoke worry about stigma and require confidence to do so appropriately (Anderson et al., 2017; Bolourian et al., 2018).

Despite these challenges, young adults on the autism spectrum have many strengths that may serve them well in postsecondary education. These include strong technological skills, self-advocacy experiences, persistence, diligence, and strong interests in their subjects of study (Anderson et al., 2017). Similarly, autistic adults often have positive qualities that may be harnessed successfully in the right workplace setting, including dependability, patience for repetitive work, honesty, and specialized interests/knowledge (Solomon, 2020). Unfortunately, employers often hold false beliefs about efficiency and productivity of individuals diagnosed with ASD and are influenced by negative stigma and societal attitudes about ASD (Scott et al., 2017). However, employers who do hire adults on the spectrum often find that the benefits outweigh any costs and evaluate their employees' performance more favorably than expected (Scott et al., 2017).

Mental Health and Quality of Life

The mental health crisis among autistic individuals is pervasive and profound. Research suggests autistic adults are at elevated risk for co-occurring mental health problems, though there is a wide range of prevalence estimates of mental health disorders for this vulnerable population (30–84%; Bishop-Fitzpatrick & Rubenstein, 2019; Howlin & Moss, 2012; Lai et al., 2019). There is mixed evidence regarding whether autistic individuals with co-occurring intellectual disability vary in their rates of co-occurring mental health conditions as compared to autistic individuals without cognitive impairments (Howlin & Moss, 2012), with some evidence suggesting that those without cognitive impairments may be at higher risk for internalizing problems, such as anxiety and depression (Bishop-Fitzpatrick & Rubenstein, 2019). One sample of autistic college students found that most were experiencing loneliness, 74% reported suicidal ideation or behavior in their lifetime, and rates of severe stress were five times greater than a typical college student sample (Jackson et al., 2018). Beyond mental health disorders, autistic adults also report lower quality of life as compared to normative samples (Crane et al., 2019). Arguably, the social difficulties associated with autism play an important role in understanding the incidence of mental health problems and poor well-being in this population. Social support, or the availability of helping relationships, has predicted positive quality of life, well-being, and adaptation following stressors in autistic adults (Bishop-Fitzpatrick et al., 2018; Hedley et al., 2019; Renty & Roeyers, 2007). Beyond friendships, involvement in intimate romantic relationships has also been shown to be protective, relating to improved quality of life across multiple domains (Pearlman-Avnion et al., 2017). Unfortunately, autistic adults who struggle with forming meaningful relationships are less likely to be able to draw upon these supportive resources to bolster their resiliency and well-being.

Adults perceive stigma related to autism features and mental health problems, resulting in a heightened desire to "camouflage" (Crane et al., 2019; Kapp et al., 2019a). However, these camouflaging behaviors come at a high emotional cost, with reports of exhaustion, identity loss, depressive symptoms, and suicidality (Cage & Troxell-Whitman, 2019; Cassidy et al., 2018; Hull et al., 2017). Further, the construct of collective self-esteem, or one's beliefs about how autistic individuals as a group are viewed by society and by oneself, has been linked to personal self-esteem, anxiety, and depressive symptoms in autistic adults (Cooper et al., 2017), further compounding the potential negative effects of perceived stigma. Another socially based barrier to mental health results from the social communication differences characteristic of autism, which, according to autistic adults themselves, interfere with their ability to seek mental health treatment and express internal experiences (Camm-Crosbie et al., 2019). Systems challenges in accessing mental health treatment also exist, such that mental health providers are often ill-equipped to interact with and serve adults on the autism spectrum, due to lack of training, experience, and confidence (Maddox et al., 2020).

Evidence-Based Social Interventions

Given the pervasively poor outcomes seen in adulthood for autistic individuals, the development and dissemination of evidence-based interventions is crucial. However, there is currently a dearth of rigorously tested and widely available treatment options for this population, whose needs will continue to grow exponentially (Gerhardt & Lainer, 2011). Many of the approaches that have been validated in autistic children are either inappropriate for adults (e.g., play-based, early intervention) or have not been adapted to meet their unique needs (e.g., romantic relationships). Among psychosocial interventions, a recent review identified 41 studies over the last 37 years investigating treatments in adult populations (Pallathra et al., 2019). Unfortunately, only 11 of these were randomized control trials (RCTs), considered the gold standard of intervention evaluation. Further, only one of those was rated as having strong methodological quality. In the following section, the current state of the literature with respect to social interventions for autistic adults will be reviewed and examined.

Social Skills Interventions

Although social skills group interventions are not novel forms of treatment for autistic populations, there has been a striking lack of empirical investigation into their efficacy in adulthood. While a recent review of interventions aiming to target social behavior in autistic individuals found 16 studies inclusive of adult participants, only studies examining mindfulness, mental health, and social cognition were included (Ke et al., 2018). Further, methodological rigor was poor among the majority of studies, with several single subject designs and lack of control groups (Ke et al., 2018). Another review identified 12 intervention studies targeting social skills for adults with ASD (Pallathra et al., 2019); however, 6 of these focused on isolated skills, such as increasing question asking (Palmen et al., 2008) or reducing negative statements in conversation (Koegel et al., 2016). Though perhaps effective in achieving improvements in these specific social behaviors, programs with such limited scope are clearly insufficient to address the social needs of autistic adults more broadly. As such, more research investigation into traditionally defined, comprehensive social skills treatments is needed.

Only one comprehensive social skills program for adults on the autism spectrum, known as *PEERS® for Young Adults*, has had multiple RCTs to support its efficacy (Gantman et al., 2012; Laugeson et al., 2015; McVey et al., 2016). *PEERS® for Young Adults* is a 16-week social skills group intervention that focuses on skills related to making and keeping friends, developing and maintaining romantic relationships, and handling conflict and rejection. Topics include conversational skills, peer entry and exiting strategies, nonverbal communication (e.g., assessing interest, acceptance), appropriate use of humor, finding sources of friends, electronic communication, get-togethers, dating, conflict resolution, responding to bullying, and perspective-taking. The results of three RCT studies showed improvements among autistic adults in overall social skills, ASD-related social impairments, social skills knowledge, and social engagement (e.g., number of get-togethers) across self-report and caregiver-report measures (Gantman et al., 2012; Laugeson et al., 2015; McVey et al., 2016). Within individual studies, additional benefits were achieved in the areas of loneliness, empathy, and social anxiety (Gantman et al., 2012; McVey et al., 2016). Essential to the *PEERS® for Young Adults* program is the presence of two groups: one for the adults themselves and a second group for social coaches. Social coaches are important people within the adult's life (e.g., parents, older siblings, life coaches) who agree to participate in the program, learn the same skills, and serve as a support to the adult as they practice and apply skills outside of sessions. Research on the *PEERS®* method in adolescents suggests that additional improvements observed after the end of treatment (e.g., 4 months to 5 years later) may be attributed to the ongoing involvement of such social coaches (Laugeson et al., 2015; Mandelberg et al., 2014). *PEERS® for Young Adults* draws upon the evidence-based methods of instruction for social skills training in autistic individuals across the lifespan, including small group format, inclusion of social coaches, didactic instruction, concrete rules and steps, modeling of skills, opportunities for in-session practice, use of praise, and generalization homework (Moody & Laugeson, 2020).

Although the *PEERS® for Young Adults* program does include instruction on dating skills (e.g., flirting, asking someone on a date, going on dates, dating safety), the primary focus of the intervention is on the development of friendships. Only one program, known as *Ready for Love*, focusing exclusively on romantic relationship social skills has been tested in adults with ASD (Cunningham et al., 2016). The *Ready for Love* intervention produced positive benefits in ASD-related social impairments and empathy more broadly, as well as more targeted benefits in dating skills. Strengths of this study included a relatively large sample size ($n = 39$), given typical sizes of other intervention studies for autistic adults. Though some additional psychoeducation interventions related to sexuality and safety (e.g., anatomy, reproduction, privacy) exist, these were not considered to be targeting social components of romantic relationships (Sala et al., 2019). Additionally, other interventions supporting romantic functioning have begun to be tested in other neurodiverse populations but have yet to be extended to adults on the autism spectrum (Exell et al., 2020). Consequently, there is a strong need for more widespread and accessible intervention programs focused on romantic relationships, dating, and sexuality for autistic adults (Cheak-Zamora et al., 2019).

Employment-Related Interventions

In response to the underemployment and unemployment rates of autistic adults, programs have emerged in order to teach employment-related skills. Initially, most of these programs, summarized by Walsh et al. (2014), focused on direct teaching of vocational hard skills needed for specific jobs, such as photocopying, cleaning, stocking, and customer service. Strategies to teach autistic adults these hard skills included positive reinforcement, video modeling, coaching, and gradual fading of supports as would be seen in techniques derived from the science of applied behavior analysis (ABA). More comprehensive supported employment programs, which most often include job coaching, have also been shown to be effective in enhancing job outcomes in adults on the spectrum (Wehman et al., 2014). Project SEARCH is one of the most extensively tested supported employment skills programs for individuals with disabilities more broadly. However, Project SEARCH has also developed a curriculum with autism-specific supports that has empirical support from a large-scale RCT (Wehman et al., 2019). This RCT was inclusive of autistic adults with or without co-occurring intellectual disability, highlighting its applicability across the wide range of cognitive functioning within the autism spectrum. The program includes a 9-month rotating internship in the last year of high school, which can be up to age 22 for individuals on the spectrum, focused on gaining on-the-job experience with supports to build resumes with past work experience. Project SEARCH + ASD supports also includes social communication instruction using ABA teaching strategies and seamless integration with adult Vocational Rehabilitation service providers to reduce delays to adult services after high school. Over 70% of Project SEARCH participants were engaged in competitive employment at a 1-year follow-up, as compared to only 17% of the control group (Wehman et al., 2019). Project SEARCH also performs better than other "treatment as usual" supported employment models, in terms of cost effectiveness, employment retention, and wage (Schall et al., 2015).

More recent programs have focused less on hard skills and on-the-job coaching as seen in supported employment and more on the soft skills that are identified by autistic individuals and supported by research to be barriers to positive vocational outcomes (Coleman & Adams, 2018; Lorenz et al., 2016). These employment-specific social communication skills include strategies for conversations, negotiation/conflict, offering and asking for assistance, responding to requests, networking, perspective-taking, and working within a team (Baker-Ericzén et al., 2018b; Sung et al., 2019). Many also include additional approaches to support emotion regulation and executive functioning (e.g., goal setting, problem-solving, organizational skills). Similar to the format of social skills groups, these programs often utilize a group format, didactic lessons, positive and negative exemplars, cognitive and behavioral skills practice, and homework assignments. Though all intervention models tested showed evidence of effectiveness in improvement in social communication skills, all were feasibility and pilot studies and were thus limited by small samples ($n<17$) and lack of control groups (Baker-Ericzén et al., 2018b; Sung et al., 2019). An additional study that utilized a less structured discussion of relevant topics (e.g., problem-solving, employment, friendships, perspective-taking) through group leader question prompts also reported on qualitative benefits to social interactions, self-esteem, and job-seeking behaviors (Hillier et al., 2007).

Additionally, there has been a recent surge in short-term, targeted interventions aimed at improving the job interviewing skills of autistic adults (Smith et al., 2021; Strickland et al., 2013). Most often, these programs include a virtual reality training component with complex programming that allows dynamic responding (Burke et al., 2020; Smith et al., 2021). These virtual interactive interview interventions have demonstrated significant positive effects on self-efficacy, confidence, and skills while interviewing (Burke et al., 2020; Smith et al., 2021; Ward & Esposito, 2019). In examining outcomes after 6 months posttreatment, participants who received virtual reality job interview training were more likely to have gained competitive employment (Smith et al., 2015). Secondary analysis of participant data demonstrated that the number of virtual reality practice interviews significantly predicted employment outcome at 6 months, through a mediating effect of live interviewing skills at end of treatment (Smith et al., 2017). Further, these studies demonstrate some methodological strengths not always seen in the adult autism intervention literature, including larger sample sizes ($n = 153$, Burke et al., 2020), use of RCTs with a treatment-as-usual group (Smith et al., 2021), and inclusion of autistic individuals with and without cognitive impairments (Smith et al., 2021).

More informally, a study examining the supervisors of gainfully employed adults on the autism spectrum identified common supervision strategies that bolstered the success of these individuals in the workplace (Hagner & Cooney, 2005). In addition to organizational supports, such as maintaining a consistent schedule, providing structure, tracking workflow, using direct communication, and verifying understanding of instruction, there were also several socially oriented strategies that emerged as supportive in employment settings. These included assisting the autistic employee in learning social rules, norms, and cues on the job, encouraging coworkers to initiate interactions, and assigning one or two other coworkers to provide suggestions and "keep an eye out" for their autistic coworker (Hagner & Cooney, 2005).

Postsecondary Education Interventions

In addition to employment programs, there have been a few programs aimed at promoting positive social adaptation within the postsecondary school environment (Gelbar et al., 2014). One promising program consisted of a 3-day pre-enrollment program in the summer before the fall semester, in which incoming autistic college students were invited to stay in campus housing (Lei et al., 2020). Over the course of several years, a total of 122 students with ASD participated in the research evaluation of the summer program. Participants received academic socialization experience in attending lectures, interacting with faculty, accessing tutoring support, and disclosing diagnoses. Further, participants were given information about social clubs on campus, access to cafeterias for shared meals, and opportunities for informal socialization with other participants. Participants reported satisfaction with the program, within qualitative data suggesting that the program facilitated social connections and mitigated social concerns about entering postsecondary education (Lei et al., 2020).

Emotion Recognition Interventions

Interventions specifically targeting social cognition, such as emotion recognition and theory of mind, have also been tested in autistic adults. Programs have utilized computerized software programs and virtual reality platforms with success to teach social cognitive skills (Golan & Baron-Cohen, 2006; Kandalaft et al., 2013). Adaptations of social cognition interventions for individuals with schizophrenia have also been applied to adults on the spectrum, including a group-based adaptation of the Social Cognition and Interaction Training (SCIT) program (Turner-Brown et al., 2008) and an adaptation of Cognitive Enhancement Therapy (CET), which includes both online neurocognitive training and a structured group class curriculum delivered over 18 months (Eack et al., 2013). Both of these models were effective in improving emotion understanding, and CET demonstrated benefits across multiple other neurocognitive domains (e.g., processing speed, flexibility, organization; Eack et al., 2013). Researchers have also explored the use of oxytocin, administered intranasally, as a physiological mechanism to improve emotion recognition with mixed results (Wieckowski et al. 2020).

Discussion

The current chapter reviewed the scientific knowledge on the social behavior of adults diagnosed with ASD, along with empirically supported interventions for this highly understudied and marginalized population. Consistent with the diagnostic symptoms of the disorder, autistic adults demonstrate distinctive profiles across all major domains of social behavior. As discussed, social behavior and functioning displays reliable connections to the functional outcomes of autistic individuals. However, it is also important to consider that social behavior, especially in autism, does not exist in a vacuum. Instead, there are interactive effects and perpetuating processes. For example, executive and cognitive functioning components, such as processing speed deficits, have also been linked to social communication abilities in adults on the autism spectrum (Haigh et al., 2018). Sensory processing abnormalities may further contribute to differences in social awareness through difficulties filtering out extraneous details, delays in processing of relevant stimuli, and difficulties integrating information from multiple senses (Thye et al., 2018). Further, the greater levels of stress observed in and reported by autistic adults may be one component linked to further exacerbation of social difficulties (Bishop-Fitzpatrick et al., 2015). However, as highlighted in the current chapter, it is also likely that the social challenges experienced by individuals on the spectrum contribute to increased stress and decreased well-being, thus creating a cascading cycle. Given the negative outcomes associated with social skills deficits, targeting social functioning in treatment is one fruitful avenue for clinicians to pursue, with a growing body of evidence suggesting positive benefits, despite methodological limitations in the current literature base (Bishop-Fitzpatrick et al., 2013).

Clinical Implications

As discussed, differences in social behavior and the associated challenges often have harmful impacts on the lives of adults on the autism spectrum. Fortunately, advancements in the field have enhanced understanding of how these social differences manifest and interfere with functioning in adulthood. Although currently limited, the growing body of research supports that psychosocial interventions are effective in improving social outcomes. Taken together, the following clinical implications are considered.

First, thorough clinical assessments of social functioning are essential. In autistic adults, utilization of both self-report and informant-report of social skills and social functioning via validated and normed questionnaires is recommended to guard against limitations due to lack of insight or proxy reporter bias. Further, clinical interviewing surrounding relationships may need to be expanded beyond what is typically indicated for clients with other forms of psychopathology, given deficits in understanding of relationships. For example, deeper inquiry into friendships (e.g., frequency of contact with friends, types of friendships, social engagement activities) and romantic relationships (e.g., dating history, sexual intimacy, assessment of romantic interest, and reciprocity) could both be illuminating avenues of pursuit. Additionally, behavioral observations of social interactions can help clinicians to further understand and assess social functioning, as well as track changes over the course of treatment. Though clinicians frequently note client behaviors throughout the course of a clinical encounter, observation of a more intentional social interaction may have added value.

In addition to assessment, treatment planning to include interventions targeting social behavior for adults on the autism spectrum may be warranted, assuming the adult is socially motivated and interested in receiving these services. Even adults who are presenting to treatment for other mental health challenges, such as depression and anxiety, may benefit from interventions incorporating social components, many of which have been found to be powerful mechanisms of change in mental health symptoms (McVey et al., 2016). However, these interventions must be individualized to the needs of the adult, whether it be skills related to friendships, romantic relationships, or the workplace. Further, the social goals of the adult themselves should be elicited and prioritized to ensure motivation and promote self-advocacy skills. In treatment planning, clinicians may consider integrating social skills lessons into their own work or referring clients to complementary group social skills intervention services, which tend to be the modality with the strongest evidence base for autistic individuals (Laugeson et al., 2015). Close coordination of individual treatment with group services is recommended in order to reinforce and consolidate the skills learned over time. This may be done through acquisition of teaching materials used in group treatment or through consultation with group leaders to facilitate common understanding and reinforcement of skills in individual therapy.

Finally, it is essential that whatever social behaviors are targeted, the skills taught are considered ecologically valid, meaning that skills align with the social behaviors of socially accepted peers (Laugeson & Ellingsen, 2014). Too often, adults (and youth) on the autism spectrum receive ineffective social skills instruction derived on the perceptions and beliefs of adults and providers of what is appropriate behavior in a given situation. Additionally, the involvement of caregivers, family members, and/or close friends may have added benefits in promoting generalization of skills and facilitating practice outside of sessions.

Future Directions

Despite the development of promising new research focusing on autistic adults, a number of limitations exist in the literature. In particular, a primary gap exists within the representativeness of the samples included in the current research. Almost all of the studies cited in the current chapter utilized samples of young or middle-aged adults (e.g., 20–40 years of age). Thus, increased research attention is needed for older adults diagnosed with ASD, including their social behavior profiles and overall outcomes, but also effective treatments and mechanisms to support well-being within this understudied population. Similarly, much of the current literature also draws exclusively from cognitively able adults who would be classified as "Level 1" per the DSM-5, indicating relatively lower support needs. Very few studies have focused specifically on autistic adults with intellectual disability or more substantial support needs, nor has research extensively explored within-spectrum differences in social behavioral presentations and treatment response (e.g., examining IQ as a moderator, comparing groups across the three DSM-5 support-level classifications). Additionally, the current literature has clearly documented the social communicative differences and poor social outcomes observed in autistic adults. However, predictors and correlates of such behaviors and outcomes are less clearly understood and could be an important avenue for future research. Finally, there is a strong need for rigorous testing of social interventions for adults, with larger samples, randomized control designs, replication, and long-term follow-up studies.

Conclusions

In sum, autistic individuals experience unique and pervasive challenges in adulthood, as social demands shift and the availability of supportive services diminishes. Social functioning is an essential factor in these challenges and a prime target for intervention. Though research is limited, current evidence does indicate that adults on the spectrum benefit from psychosocial interventions targeting social behaviors. The development and dissemination of evidence-based practices in this underserved population has the potential to enable autistic adults to reach their potential and showcase their many strengths.

References

Alvarez-Fernandez, S., Brown, H. R., Zhao, Y., Raithel, J. A., Bishop, S. L., Kern, S. B., … Di Martino, A. (2017). Perceived social support in adults with autism spectrum disorder and attention-deficit/hyperactivity disorder. *Autism Research, 10*(5), 866–877. https://doi.org/10.1002/aur.1735

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Publication. https://doi.org/10.1176/appi.books.9780890425596

Anderson, A. H., Stephenson, J., & Carter, M. (2017). A systematic literature review of the experiences and supports of students with autism spectrum disorder in post-secondary education. *Research in Autism Spectrum Disorders, 39*, 33–53. https://doi.org/10.1016/j.rasd.2017.04.002

Baker-Ericzén, M. J., Brookman-Frazee, L., & Brodkin, E. S. (2018a). Accelerating research on treatment and services for transition age youth and adults on the autism spectrum. *Autism, 22*(1), 2–5. https://doi.org/10.1177/1362361317738646

Baker-Ericzén, M. J., Fitch, M. A., Kinnear, M., Jenkins, M. M., Twamley, E. W., Smith, L., … Leon, J. (2018b). Development of the supported employment, comprehensive cognitive enhancement, and social skills program for adults on the autism spectrum: Results of initial study. *Autism, 22*(1), 6–19. https://doi.org/10.1177/1362361317724294

Baldwin, S., & Costley, D. (2016). The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism, 20*(4), 483–495. https://doi.org/10.1177/1362361315590805

Baldwin, S., Costley, D., & Warren, A. (2014). Employment activities and experiences of adults with high-functioning autism and Asperger's disorder. *Journal of Autism and Developmental Disorders, 44*(10), 2440–2449. https://doi.org/10.1007/s10803-014-2112-z

Ballan, M. S. (2012). Parental perspectives of communication about sexuality in families of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(5), 676–684. https://doi.org/10.1007/s10803-011-1293-y

Baron-Cohen, S., & Wheelwright, S. (2004). The empathy quotient: An investigation of adults with Asperger syndrome or high functioning autism, and normal sex differences. *Journal of Autism and Developmental*

Disorders, 34(2), 163–175. https://doi.org/10.1023/b:jadd.0000022607.19833.00

Baron-Cohen, S., Wheelwright, S., Hill, J., Raste, Y., & Plumb, I. (2001). The "Reading the mind in the eyes" test revised version: A study with normal adults, and adults with Asperger syndrome or high-functioning autism. *Journal of Child Psychology and Psychiatry, 42*(2), 241–251. https://doi.org/10.1111/1469-7610.00715

Bishop-Fitzpatrick, L., & Rubenstein, E. (2019). The physical and mental health of middle aged and older adults on the autism spectrum and the impact of intellectual disability. *Research in Autism Spectrum Disorders, 63*, 34–41. https://doi.org/10.1016/j.rasd.2019.01.001

Bishop-Fitzpatrick, L., Minshew, N. J., & Eack, S. M. (2013). A systematic review of psychosocial interventions for adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(3), 687–694. https://doi.org/10.1007/s10803-012-1615-8

Bishop-Fitzpatrick, L., Mazefsky, C. A., Minshew, N. J., & Eack, S. M. (2015). The relationship between stress and social functioning in adults with autism spectrum disorder and without intellectual disability. *Autism Research, 8*(2), 164–173. https://doi.org/10.1002/aur.1433

Bishop-Fitzpatrick, L., Mazefsky, C. A., & Eack, S. M. (2018). The combined impact of social support and perceived stress on quality of life in adults with autism spectrum disorder and without intellectual disability. *Autism, 22*(6), 703–711. https://doi.org/10.1177/1362361317703090

Bolourian, Y., Zeedyk, S. M., Blacher, J. (2018). Autism and the university experience: Narratives from students with neurodevelopmental disorders. *Journal of Autism and Developmental Disorders 48*(10), 3330–3343 https://doi.org/10.1007/s10803-018-3599-5

Brown-Lavoie, S. M., Viecili, M. A., & Weiss, J. A. (2014). Sexual knowledge and victimization in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 44*(9), 2185–2196. https://doi.org/10.1007/s10803-014-2093-y

Burke, S. L., Li, T., Grudzien, A., & Garcia, S. (2020). Brief report: Improving employment interview self-efficacy among adults with autism and other developmental disabilities using virtual interactive training agents (ViTA). *Journal of Autism and Developmental Disorders*, 1–8. https://doi.org/10.1007/s10803-020-04571-8

Byers, E. S., Nichols, S., & Voyer, S. D. (2013). Challenging stereotypes: Sexual functioning of single adults with high functioning autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(11), 2617–2627. https://doi.org/10.1007/s10803-013-1813-z

Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of camouflaging for autistic adults. *Journal of Autism and Developmental Disorders, 49*(5), 1899–1911. https://doi.org/10.1007/s10803-018-03878-x

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism, 23*(6), 1431–1441. https://doi.org/10.1177/1362361318816053

Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism, 9*(1), 1–14. https://doi.org/10.1186/s13229-018-0226-4

Chiang, H., Cheung, Y. K., Li, H., & Tsai, L. Y. (2013) Factors associated with participation in employment for high school leavers with autism. *Journal of Autism and Developmental Disorders, 43*(8), 1832–1842. https://doi.org/10.1007/s10803-012-1734-2

Cheak-Zamora, N. C., Teti, M., Maurer-Batjer, A., O'Connor, K. V., & Randolph, J. K. (2019). Sexual and relationship interest, knowledge, and experiences among adolescents and young adults with autism spectrum disorder. *Archives of Sexual Behavior, 48*(8), 2605–2615. https://doi.org/10.1007/s10508-019-1445-2

Chen, Y. W., Bundy, A. C., Cordier, R., Chien, Y. L., & Einfeld, S. L. (2015). Motivation for everyday social participation in cognitively able individuals with autism spectrum disorder. *Neuropsychiatric Disease and Treatment, 11*, 2699. https://doi.org/10.2147/NDT.S87844

Chevallier, C., Kohls, G., Troiani, V., Brodkin, E. S., & Schultz, R. T. (2012). The social motivation theory of autism. *Trends in Cognitive Sciences, 16*(4), 231–239. https://doi.org/10.1016/j.tics.2012.02.007

Chevallier, C., Huguet, P., Happé, F., George, N., & Conty, L. (2013). Salient social cues are prioritized in autism spectrum disorders despite overall decrease in social attention. *Journal of Autism and Developmental Disorders, 43*(7), 1642–1651. https://doi.org/10.1007/s10803-012-1710-x

Coleman, D. M., & Adams, J. B. (2018). Survey of vocational experiences of adults with autism spectrum disorders, and recommendations on improving their employment. *Journal of Vocational Rehabilitation, 49*(1), 67–78. https://doi.org/10.3233/JVR-180955

Cooper, K., Smith, L. G., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology, 47*(7), 844–854. https://doi.org/10.1002/ejsp.2297

Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2019). 'Something needs to change': Mental health experiences of young autistic adults in England. *Autism, 23*(2), 477–493. https://doi.org/10.1177/1362361318757048

Crompton, C. J., Hallett, S., Ropar, D., Flynn, E., & Fletcher-Watson, S. (2020). 'I never realised everybody felt as happy as I do when I am around autistic people': A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism, 24*(6), 1438–1448. https://doi.org/10.1177/1362361320908976

Cunningham, A., Sperry, L., Brady, M. P., Peluso, P. R., & Pauletti, R. E. (2016). The effects of a romantic relationship treatment option for adults with autism spectrum disorder. *Counseling Outcome Research and Evaluation, 7*(2), 99–110. https://doi.org/10.1177/2150137816668561

Dewinter, J., De Graaf, H., & Begeer, S. (2017). Sexual orientation, gender identity, and romantic relationships in adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47*(9), 2927–2934. https://doi.org/10.1007/s10803-017-3199-9

Dziobek, I., Rogers, K., Fleck, S., Bahnemann, M., Heekeren, H. R., Wolf, O. T., & Convit, A. (2008). Dissociation of cognitive and emotional empathy in adults with Asperger syndrome using the Multifaceted Empathy Test (MET). *Journal of Autism and Developmental Disorders, 38*(3), 464–473. https://doi.org/10.1007/s10803-007-0486-x

Eack, S. M., Greenwald, D. P., Hogarty, S. S., Bahorik, A. L., Litschge, M. Y., Mazefsky, C. A., & Minshew, N. J. (2013). Cognitive enhancement therapy for adults with autism spectrum disorder: Results of an 18-month feasibility study. *Journal of Autism and Developmental Disorders, 43*(12), 2866–2877. https://doi.org/10.1007/s10803-013-1834-7

Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*(4), 739–747. https://doi.org/10.1007/s10803-007-0441-x

Exell, R., Hilari, K., & Behn, N. (2020). Interventions that support adults with brain injuries, learning disabilities and autistic spectrum disorders in dating or romantic relationships: A systematic review. *Disability and Rehabilitation*, 1–14. https://doi.org/10.1080/09638288.2020.1845824

Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., … Coon, H. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research, 2*(2), 109–118. https://doi.org/10.1002/aur.69

Fisher, M. H., Moskowitz, A. L., & Hodapp, R. M. (2013). Differences in social vulnerability among individuals with autism spectrum disorder, Williams syndrome, and Down syndrome. *Research in Autism Spectrum Disorders, 7*(8), 931–937. https://doi.org/10.1016/j.rasd.2013.04.009

Fletcher-Watson, S., Leekam, S. R., Benson, V., Frank, M. C., & Findlay, J. M. (2009). Eye-movements reveal attention to social information in autism spectrum disorder. *Neuropsychologia, 47*(1), 248–257. https://doi.org/10.1016/j.neuropsychologia.2008.07.016

Fombonne, E. (2003). Modern views of autism. *The Canadian Journal of Psychiatry, 48*(8), 503–505. https://doi.org/10.1177/070674370304800801

Friedman, L., Sterling, A., DaWalt, L. S., & Mailick, M. R. (2019). Conversational language is a predictor of vocational independence and friendships in adults with ASD. *Journal of Autism and Developmental Disorders, 49*(10), 4294–4305. https://doi.org/10.1007/s10803-019-04147-1

Gantman, A., Kapp, S. K., Orenski, K., & Laugeson, E. A. (2012). Social skills training for young adults with high-functioning autism spectrum disorders: A randomized controlled pilot study. *Journal of Autism and Developmental Disorders, 42*(6), 1094–1103. https://doi.org/10.1007/s10803-011-1350-6

Gelbar, N. W., Smith, I., & Reichow, B. (2014). Systematic review of articles describing experience and supports of individuals with autism enrolled in college and university programs. *Journal of Autism and Developmental Disorders, 44*(10), 2593–2601. https://doi.org/10.1007/s10803-014-2135-5

George, R., & Stokes, M. A. (2018a). Gender identity and sexual orientation in autism spectrum disorder. *Autism, 22*(8), 970–982. https://doi.org/10.1177/1362361317714587

George, R., & Stokes, M. A. (2018b). Sexual orientation in autism spectrum disorder. *Autism Research, 11*(1), 133–141. https://doi.org/10.1002/aur.1892

Gerhardt, P. F., & Lainer, I. (2011). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy, 41*(1), 37–45. https://doi.org/10.1007/s10879-010-9160-2

Gillespie-Lynch, K., Sepeta, L., Wang, Y., Marshall, S., Gomez, L., Sigman, M., & Hutman, T. (2012). Early childhood predictors of the social competence of adults with autism. *Journal of Autism and Developmental Disorders, 42*(2), 161–174. https://doi.org/10.1007/s10803-011-1222-0

Golan, O., & Baron-Cohen, S. (2006). Systemizing empathy: Teaching adults with Asperger syndrome or high-functioning autism to recognize complex emotions using interactive multimedia. *Development and Psychopathology, 18*(2), 591–617. https://doi.org/10.1017/S0954579406060305

Hagner, D., & Cooney, B. F. (2005). "I do that for everybody": Supervising employees with autism. *Focus on Autism and Other Developmental Disabilities, 20*(2), 91–97.

Haigh, S. M., Walsh, J. A., Mazefsky, C. A., Minshew, N. J., & Eack, S. M. (2018). Processing speed is impaired in adults with autism spectrum disorder, and relates to social communication abilities. *Journal of Autism and Developmental Disorders, 48*(8), 2653–2662. https://doi.org/10.1007/s10803-018-3515-z

Hancock, G., Stokes, M. A., & Mesibov, G. (2020). Differences in romantic relationship experiences for individuals with an autism spectrum disorder. *Sexuality and Disability, 38*(2), 231–245. https://doi.org/10.1007/s11195-019-09573-8

Hedley, D., Uljarević, M., Bury, S. M., & Dissanayake, C. (2019). Predictors of mental health and well-being in employed adults with autism spectrum disorder at 12-month follow-up. *Autism Research, 12*(3), 482–494. https://doi.org/10.1002/aur.2064

Hillier, A., Fish, T., Cloppert, P., & Beversdorf, D. Q. (2007). Outcomes of a social and vocational skills support group for adolescents and young adults on the autism spectrum. *Focus on Autism and Other Developmental Disabilities, 22*(2), 107–115. https://doi.org/10.1177/10883576070220020201

Hintzen, A., Delespaul, P., van Os, J., & Myin-Germeys, I. (2010). Social needs in daily life in adults with pervasive developmental disorders. *Psychiatry Research, 179*(1), 75–80. https://doi.org/10.1016/j.psychres.2010.06.014

Howlin, P., & Moss, P. (2012). Adults with autism spectrum disorders. *The Canadian Journal of Psychiatry, 57*(5), 275–283. https://doi.org/10.1177/070674371205700502

Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid-to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(6), 572–581. https://doi.org/10.1016/j.jaac.2013.02.017

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017). "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders, 47*(8), 2519–2534. https://doi.org/10.1007/s10803-017-3166-5

Jackson, S. L., Hart, L., Brown, J. T., & Volkmar, F. R. (2018). Brief report: Self-reported academic, social, and mental health experiences of post-secondary students with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*(3), 643–650. https://doi.org/10.1007/s10803-017-3315-x

Jobe, L. E., & White, S. W. (2007). Loneliness, social relationships, and a broader autism phenotype in college students. *Personality and Individual Differences, 42*(8), 1479–1489. https://doi.org/10.1016/j.paid.2006.10.021

Lounds Taylor J., Adams R. E., Bishop S. L. (2017) Social participation and its relation to internalizing symptoms among youth with autism spectrum disorder as they transition from high school. *Autism Research, 10*(4), 663–672. https://doi.org/10.1002/aur.1709

Kalandadze, T., Norbury, C., Nærland, T., & Næss, K. A. B. (2018). Figurative language comprehension in individuals with autism spectrum disorder: A meta-analytic review. *Autism, 22*(2), 99–117. https://doi.org/10.1177/1362361316668652

Kandalaft, M. R., Didehbani, N., Krawczyk, D. C., Allen, T. T., & Chapman, S. B. (2013). Virtual reality social cognition training for young adults with high-functioning autism. *Journal of Autism and Developmental Disorders, 43*(1), 34–44. https://doi.org/10.1007/s10803-012-1544-6

Kapp, S. K., Goldknopf, E., Brooks, P. J., Kofner, B., & Hossain, M. (2019a). Expanding the critique of the social motivation theory of autism with participatory and developmental research. *Behavioral and Brain Sciences, 42*. https://doi.org/10.1017/S0140525X18002479

Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019b). 'People should be allowed to do what they like': Autistic adults' views and experiences of stimming. *Autism, 23*(7), 1782–1792. https://doi.org/10.1177/1362361319829628

Ke, F., Whalon, K., & Yun, J. (2018). Social skill interventions for youth and adults with autism spectrum disorder: A systematic review. *Review of Educational Research, 88*(1), 3–42. https://doi.org/10.3102/0034654317740334

Koegel, L. K., Navab, A., Ashbaugh, K., & Koegel, R. L. (2016). Using reframing to reduce negative statements in social conversation for adults with autism spectrum disorder. *Journal of Positive Behavior Interventions, 18*(3), 133–144. https://doi.org/10.1177/1098300715596136

Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., … Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet Psychiatry, 6*(10), 819–829. https://doi.org/10.1016/S2215-0366(19)30289-5

Laugeson, E. A., & Ellingsen, R. (2014). Social skills training for adolescents and adults with autism spectrum disorder. In *Adolescents and adults with autism spectrum disorders* (pp. 61–85). Springer. https://doi.org/10.1007/978-1-4939-0506-5_4

Laugeson, E. A., Gantman, A., Kapp, S. K., Orenski, K., & Ellingsen, R. (2015). A randomized controlled trial to improve social skills in young adults with autism spectrum disorder: The UCLA PEERS® program. *Journal of Autism and Developmental Disorders, 45*(12), 3978–3989. https://doi.org/10.1007/s10803-015-2504-8

Laxman, D. J., Taylor, J. L., DaWalt, L. S., Greenberg, J. S., & Mailick, M. R. (2019). Loss in services precedes high school exit for teens with autism spectrum disorder: A longitudinal study. *Autism Research, 12*(6), 911–921. https://doi.org/10.1002/aur.2113

Lei, J., Calley, S., Brosnan, M., Ashwin, C., & Russell, A. (2020). Evaluation of a transition to university programme for students with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 50*(7), 2397–2411. https://doi.org/10.1007/s10803-018-3776-6

Lever, A. G., & Geurts, H. M. (2016). Age-related differences in cognition across the adult lifespan in autism spectrum disorder. *Autism Research, 9*(6), 666–676. https://doi.org/10.1002/aur.1545

Liptak, G. S., Kennedy, J. A., & Dosa, N. P. (2011). Social participation in a nationally representative sample of older youth and young adults with autism. *Journal of Developmental & Behavioral Pediatrics, 32*(4), 277–283. https://doi.org/10.1097/DBP.0b013e31820b49fc

Lorenc, T., Rodgers, M., Marshall, D., Melton, H., Rees, R., Wright, K., & Sowden, A. (2018). Support for adults with autism spectrum disorder without intellectual impairment: Systematic review. *Autism, 22*(6), 654–668. https://doi.org/10.1177/1362361317698939

Lorenz, T., Frischling, C., Cuadros, R., & Heinitz, K. (2016). Autism and overcoming job barriers: Comparing job-related barriers and possible solutions in and outside of autism-specific employment. *PLoS One, 11*(1), e0147040. https://doi.org/10.1371/journal.pone.0147040

Maddox, B. B., Crabbe, S., Beidas, R. S., Brookman-Frazee, L., Cannuscio, C. C., Miller, J. S., … Mandell, D. S. (2020). "I wouldn't know where to start": Perspectives from clinicians, agency leaders, and autistic adults on improving community mental health services for autistic adults. *Autism, 24*(4), 919–930. https://doi.org/10.1177/1362361319882227

Magiati, I., Tay, X. W., & Howlin, P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review, 34*(1), 73–86. https://doi.org/10.1016/j.cpr.2013.11.002

Mandelberg, J., Laugeson, E. A., Cunningham, T. D., Ellingsen, R., Bates, S., & Frankel, F. (2014). Long-term treatment outcomes for parent-assisted social skills training for adolescents with autism spectrum disorders: The UCLA PEERS program. *Journal of Mental Health Research in Intellectual Disabilities, 7*(1), 45–73. https://doi.org/10.1080/19315864.2012.730600

Masi, A., DeMayo, M. M., Glozier, N., & Guastella, A. J. (2017). An overview of autism spectrum disorder, heterogeneity and treatment options. *Neuroscience Bulletin, 33*(2), 183–193. https://doi.org/10.1007/s12264-017-0100-y

Mathersul, D., McDonald, S., & Rushby, J. A. (2013). Understanding advanced theory of mind and empathy in high-functioning adults with autism spectrum disorder. *Journal of Clinical and Experimental Neuropsychology, 35*(6), 655–668. https://doi.org/10.1080/13803395.2013.809700

Mazurek, M. O. (2014). Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism, 18*(3), 223–232. https://doi.org/10.1177/1362361312474121

McLeod, J. D., Meanwell, E., & Hawbaker, A. (2019). The experiences of college students on the autism spectrum: A comparison to their neurotypical peers. *Journal of Autism and Developmental Disorders, 49*(6), 2320–2336. https://doi.org/10.1007/s10803-019-03910-8

McVey, A. J., Dolan, B. K., Willar, K. S., Pleiss, S., Karst, J. S., Casnar, C. L., … Van Hecke, A. V. (2016). A replication and extension of the PEERS® for young adults social skills intervention: Examining effects on social skills and social anxiety in young adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(12), 3739–3754. https://doi.org/10.1007/s10803-016-2911-5

Milton, D. E. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability & Society, 27*(6), 883–887. https://doi.org/10.1080/09687599.2012.710008

Mintah, K., & Parlow, S. E. (2018). Are you flirting with me? Autistic traits, theory of mind, and inappropriate courtship. *Personality and Individual Differences, 128*, 100–106. https://doi.org/10.1016/J.PAID.2018.02.028

Moody, C. T., & Laugeson, E. A. (2020). Social skills training in autism spectrum disorder across the lifespan. *Child and Adolescent Psychiatric Clinics, 29*(2), 359–371. https://doi.org/10.1016/j.chc.2019.11.001

Morrison, K. E., Pinkham, A. E., Penn, D. L., Kelsven, S., Ludwig, K., & Sasson, N. J. (2017). Distinct profiles of social skill in adults with autism spectrum disorder and schizophrenia. *Autism Research, 10*(5), 878–887. https://doi.org/10.1002/aur.1734

Morrison, K. E., DeBrabander, K. M., Jones, D. R., Faso, D. J., Ackerman, R. A., & Sasson, N. J. (2020). Outcomes of real-world social interaction for autistic adults paired with autistic compared to typically developing partners. *Autism, 24*(5), 1067–1080. https://doi.org/10.1177/1362361319892701

Newman, L., Wagner, M., Knokey, A. M., Marder, C., Nagle, K., Shaver, D., & Wei, X. (2011). The post-high school outcomes of young adults with disabilities up to 8 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2). NCSER 2011–3005. National Center for Special Education Research.

Odom, S. L., Collet-Klingenberg, L., Rogers, S. J., & Hatton, D. D. (2010). Evidence-based practices in interventions for children and youth with autism spectrum disorders. *Preventing School Failure: Alternative Education for Children and Youth, 54*(4), 275–282. https://doi.org/10.1080/10459881003785506

Ohl, A., Grice Sheff, M., Small, S., Nguyen, J., Paskor, K., & Zanjirian, A. (2017). Predictors of employment status among adults with autism spectrum disorder. *Work, 56*(2), 345–355. https://doi.org/10.3233/WOR-172492

Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders, 34*(3), 245–256. https://doi.org/10.1023/b:jadd.0000029547.96610.df

Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(11), 2710–2719. https://doi.org/10.1007/s10803-013-1833-8

Pagni, B. A., Walsh, M. J., Rogers, C., & Braden, B. B. (2020). Social cognition in autism Spectrum disorder across the adult lifespan: Influence of age and sex on reading the mind in the eyes task in a cross-sectional sample. *Frontiers in Integrative Neuroscience, 14*, 50. https://doi.org/10.3389/fnint.2020.571408

Pallathra, A. A., Cordero, L., Wong, K., & Brodkin, E. S. (2019). Psychosocial interventions targeting social functioning in adults on the autism spectrum: A literature review. *Current Psychiatry Reports, 21*(1), 5. https://doi.org/10.1007/s11920-019-0989-0

Palmen, A., Didden, R., & Arts, M. (2008). Improving question asking in high-functioning adolescents with autism spectrum disorders: Effectiveness of small-group training. *Autism, 12*(1), 83–98. https://doi.org/10.1177/1362361307085265

Pearlman-Avnion, S., Cohen, N., & Eldan, A. (2017). Sexual well-being and quality of life among high-functioning adults with autism. *Sexuality and Disability, 35*(3), 279–293. https://doi.org/10.1007/s11195-017-9490-z

Pelphrey, K., Adolphs, R., & Morris, J. P. (2004). Neuroanatomical substrates of social cognition dysfunction in autism. *Mental Retardation and Developmental Disabilities Research Reviews, 10*(4), 259–271. https://doi.org/10.1002/mrdd.20040

Pelphrey, K. A., Shultz, S., Hudac, C. M., & Vander Wyk, B. C. (2011). Research review: Constraining heterogeneity: The social brain and its development in autism spectrum disorder. *Journal of Child Psychology and Psychiatry, 52*(6), 631–644. https://doi.org/10.1007/s10803-006-0268-x

Renty, J., & Roeyers, H. (2007). Individual and marital adaptation in men with autism spectrum disorder and their spouses: The role of social support and coping strategies. *Journal of Autism and Developmental Disorders, 37*(7), 1247–1255.

Russell, G., Kapp, S. K., Elliott, D., Elphick, C., Gwernan-Jones, R., & Owens, C. (2019). Mapping the autistic advantage from the accounts of adults diagnosed with autism: A qualitative study. *Autism in Adulthood, 1*(2), 124–133. https://doi.org/10.1089/aut.2018.0035

Sala, G., Hooley, M., Attwood, T., Mesibov, G. B., & Stokes, M. A. (2019). Autism and intellectual disability: A systematic review of sexuality and relationship education. *Sexuality and Disability, 37*(3), 353–382. https://doi.org/10.1007/s11195-019-09577-4

Sala, G., Hooley, M., & Stokes, M. A. (2020). Romantic intimacy in autism: A qualitative analysis. *Journal of Autism and Developmental Disorders, 50*(11), 4133–4147. https://doi.org/10.1007/s10803-020-04377-8

Schall, C. M., Wehman, P., Brooke, V., Graham, C., McDonough, J., Brooke, A., … Allen, J. (2015). Employment interventions for individuals with ASD: The relative efficacy of supported employment with or without prior Project SEARCH training. *Journal of Autism and Developmental Disorders, 45*(12), 3990–4001. https://doi.org/10.1007/s10803-015-2426-5

Scott, M., Jacob, A., Hendrie, D., Parsons, R., Girdler, S., Falkmer, T., & Falkmer, M. (2017). Employers' perception of the costs and the benefits of hiring individuals with autism spectrum disorder in open employment in Australia. *PLoS One, 12*(5), e0177607. https://doi.org/10.1371/journal.pone.0177607

Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post–high school service use among young adults with an autism spectrum disorder. *Archives of Pediatrics & Adolescent Medicine, 165*(2), 141–146. https://doi.org/10.1001/archpediatrics.2010.279

Shattuck, P. T., Garfield, T., Roux, A. M., Rast, J. E., Anderson, K., Hassrick, E. M., & Kuo, A. (2020). Services for adults with autism spectrum disorder: A systems perspective. *Current Psychiatry Reports, 22*(3), 1–12.

Shriberg, L. D., Paul, R., McSweeny, J. L., Klin, A., Cohen, D. J., & Volkmar, F. R. (2001). Speech and prosody characteristics of adolescents and adults with high-functioning autism and Asperger syndrome. *Journal of Speech, Language, and Hearing Research, 44*(5), 1097–1115. https://doi.org/10.1044/1092-4388(2001/087)

Smith, A. (2009). The empathy imbalance hypothesis of autism: A theoretical approach to cognitive and emotional empathy in autistic development. *The Psychological Record, 59*(3), 489–510.

Smith, M. J., Fleming, M. F., Wright, M. A., Losh, M., Humm, L. B., Olsen, D., & Bell, M. D. (2015). Brief report: Vocational outcomes for young adults with autism spectrum disorders at six months after virtual reality job interview training. *Journal of Autism and Developmental Disorders, 45*(10), 3364–3369. https://doi.org/10.1007/s10803-015-2470-1

Smith, M. J., Smith, J. D., Fleming, M. F., Jordan, N., Brown, C. H., Humm, L., … Bell, M. D. (2017). Mechanism of action for obtaining job offers with virtual reality job interview training. *Psychiatric Services, 68*(7), 747–750. https://doi.org/10.1176/appi.ps.201600217

Smith, R., Netto, J., Gribble, N. C., & Falkmer, M. (2020). 'At the end of the day, it's love': An exploration of relationships in neurodiverse couples. *Journal of Autism and Developmental Disorders*, 1–11. https://doi.org/10.1007/s10803-020-04790-z

Smith, M. J., Sherwood, K., Ross, B., Smith, J. D., DaWalt, L., Bishop, L., … Steacy, C. (2021). Virtual interview training for autistic transition age youth: A randomized controlled feasibility and effectiveness trial. *Autism*, 1362361321989928. https://doi.org/10.1177/1362361321989928

Solomon, C. (2020). Autism and employment: Implications for employers and adults with ASD. *Journal of Autism and Developmental Disorders, 50*, 4209–4217. https://doi.org/10.1007/s10803-020-04537-w

Sosnowy, C., Silverman, C., Shattuck, P., & Garfield, T. (2019). Setbacks and successes: How young adults on the autism spectrum seek friendship. *Autism in Adulthood, 1*(1), 44–51. https://doi.org/10.1089/aut.2018.0009

Sperry, L. A., & Mesibov, G. B. (2005). Perceptions of social challenges of adults with autism spectrum disorder. *Autism, 9*(4), 362–376. https://doi.org/10.1177/1362361305056077

Stokes, M., Newton, N., & Kaur, A. (2007). Stalking, and social and romantic functioning among adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 37*(10), 1969–1986. https://doi.org/10.1007/s10803-006-0344-2

Strickland, D. C., Coles, C. D., & Southern, L. B. (2013). JobTIPS: A transition to employment program for individuals with autism spectrum disorders. *Journal of*

Autism and Developmental Disorders, 43(10), 2472–2483. https://doi.org/10.1007/s10803-013-1800-4

Strunz, S., Schermuck, C., Ballerstein, S., Ahlers, C. J., Dziobek, I., & Roepke, S. (2017). Romantic relationships and relationship satisfaction among adults with Asperger syndrome and high-functioning autism. *Journal of Clinical Psychology, 73*(1), 113–125. https://doi.org/10.1002/jclp.22319

Sung, C., Connor, A., Chen, J., Lin, C. C., Kuo, H. J., & Chun, J. (2019). Development, feasibility, and preliminary efficacy of an employment-related social skills intervention for young adults with high-functioning autism. *Autism, 23*(6), 1542–1553. https://doi.org/10.1177/1362361318801345

Tager-Flusberg, H., Paul, P., & Lord, C. (2005). Language and communication in autism. In F. R. Volkmar, A. Klin, R. Paul, & D. J. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (3rd ed., pp. 335–364). Wiley.

Thye, M. D., Bednarz, H. M., Herringshaw, A. J., Sartin, E. B., & Kana, R. K. (2018). The impact of atypical sensory processing on social impairments in autism spectrum disorder. *Developmental Cognitive Neuroscience, 29*, 151–167. https://doi.org/10.1016/j.dcn.2017.04.010

Trimmer, E., McDonald, S., & Rushby, J. A. (2017). Not knowing what I feel: Emotional empathy in autism spectrum disorders. *Autism, 21*(4), 450–457. https://doi.org/10.1177/1362361316648520

Turner-Brown, L. M., Perry, T. D., Dichter, G. S., Bodfish, J. W., & Penn, D. L. (2008). Brief report: Feasibility of social cognition and interaction training for adults with high functioning autism. *Journal of Autism and Developmental Disorders, 38*(9), 1777–1784. https://doi.org/10.1007/s10803-008-0545-y

Velikonja, T., Fett, A. K., & Velthorst, E. (2019). Patterns of nonsocial and social cognitive functioning in adults with autism spectrum disorder: A systematic review and meta-analysis. *JAMA Psychiatry, 76*(2), 135–151. https://doi.org/10.1001/jamapsychiatry.2018.3645

Walsh, L., Lydon, S., & Healy, O. (2014). Employment and vocational skills among individuals with autism spectrum disorder: Predictors, impact, and interventions. *Review Journal of Autism and Developmental Disorders, 1*(4), 266–275.

Ward, D. M., & Esposito, M. K. (2019). Virtual reality in transition program for adults with autism: Self-efficacy, confidence, and interview skills. *Contemporary School Psychology, 23*(4), 423–431.

Wehman, P. H., Schall, C. M., McDonough, J., Kregel, J., Brooke, V., Molinelli, A., … Thiss, W. (2014). Competitive employment for youth with autism spectrum disorders: Early results from a randomized clinical trial. *Journal of Autism and Developmental Disorders, 44*(3), 487–500. https://doi.org/10.1007/s10803-013-1892-x

Wehman, P., Schall, C., McDonough, J., Sima, A., Brooke, A., Ham, W., … Riehle, E. (2019). Competitive employment for transition-aged youth with significant impact from autism: A multi-site randomized clinical trial. *Journal of Autism and Developmental Disorders*, 1–16. https://doi.org/10.1007/s10803-019-03940-2

Wieckowski, A. T., Flynn, L. T., Richey, J. A., Gracanin, D., & White, S. W. (2020). Measuring change in facial emotion recognition in individuals with autism spectrum disorder: A systematic review. *Autism, 24*(7), 1607–1628. https://doi.org/10.1177/1362361320925334

Zürcher, N. R., Rogier, O., Boshyan, J., Hippolyte, L., Russo, B., Gillberg, N., … Hadjikhani, N. (2013). Perception of social cues of danger in autism spectrum disorders. *PLoS One, 8*(12), e81206. https://doi.org/10.1371/journal.pone.0081206

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Employment and Vocational Skills for Individuals with Autism

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The ability to procure employment represents a critical developmental step in the lives of most people. While we have all experienced frustration with our jobs, employment is a defining activity of adulthood and acts as a protective factor in many key life domains (Schall et al., 2020). In short, employment represents a pivotal step in our development into adulthood.

Gainful employment has many benefits that extend beyond simply receiving a paycheck. Take a moment to consider the social implications of having a job. Employment provides us with an opportunity to develop social relationships with the people with whom we work. These interactions allow us to develop social skills, expand our social network, and feel as though we are a part of a broader community. Gainful employment can also enhance our productivity and provide people with a sense of purpose. The research literature also suggests that employment can have protective effects against poor health (Burgard & Lin, 2013). People who are gainfully employed tend to have fewer health problems than those who are not (Krueger & Burgard, 2011; Rogers et al., 2000). Finally, gainful employment allows us to be financially independent. While we all allocate parts of our salary to basic necessities, such as groceries or rent, earned income can also provide more opportunities to develop leisure skills and recreational interests (e.g., going bowling, traveling).

For most of us, integration into the workforce begins after the conclusion of our educational experience, whether it be graduating from high school or finishing college. While our initial employment experiences are unlikely to be our terminal career goal, most of us can successfully obtain employment. These early employment experiences help us to identify and refine our goals in life and ultimately set us on our career path. Most of us would agree that these employment experiences are pivotal in our development; although we usually take these experiences for granted. While we usually find and sustain employment without much difficulty, employment outcomes for people with autism spectrum disorder (ASD) are generally poor.

Employment Outcomes for People with ASD

The transition from the public school system to adulthood represents a challenging and stressful period for individuals with ASD and their families. Supports and services that were entitlements during their school-age years are no longer available, and families often struggle to identify

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needed resources. This dearth of available resources for individuals transitioning from the school system has colloquially been referred to as the “services cliff” (Roux et al., 2015).

According to the Individuals with Disabilities Education Act (IDEA), the primary purpose of public education is to prepare individuals for employment and community integration after their school years (IDEA, 2004). While the public school system does well in this regard for individuals who are neurotypical, less favorable outcomes are observed for adolescents and adults with an ASD diagnosis (Friedman et al., 2013; Taylor et al., 2015). In fact, estimates indicate that approximately 50–75% of adults with ASD are unemployed (Bush & Tassé, 2017; Howlin et al., 2004).

As discouraging as these statistics are, the outcomes for women and minority groups with ASD and IDD are even worse (Nye-Lengerman, 2017; Qian et al., 2018). Research suggests that women with ASD are 26% less likely to be employed than men with ASD (Nye-Lengerman, 2017). Outcomes of this research have also indicated that Asian/Pacific Islanders and African Americans with ASD are less likely to be employed than their Caucasian peers (Nye-Lengerman, 2017; Qian et al., 2018).

Autistic adults who have been fortunate enough to obtain employment tend to work fewer hours and are paid less than their neurotypical counterparts (Roux et al., 2015). Baldwin et al. (2014) shared the occupational experiences of 130 adults with ASD and detailed the types of jobs that they were able to procure. The large-scale study highlighted the fact that adults with ASD often had an educational level that exceeded their individual work responsibilities. The findings also identified social relationships to be a barrier within the workplace. Regardless of their educational, intellectual, or vocational abilities, adults with ASD are typically underemployed and may find difficulty in maintaining employment once hired (Taylor & Seltzer, 2011).

While experts in the field have articulated the importance of integrating individuals with disabilities into the workforce, the infrastructure to effectively support individuals who have significant support needs in employment settings is lacking. To effectively support this population, an analysis of the barriers contributing to these outcomes is necessary. There are several barriers that need to be overcome to produce successful employment outcomes. Common obstacles include some of the characteristics of ASD that interfere with employment, adequate preparation for employment experiences prior to graduation, and the preparation of employers of individuals with ASD.

Barriers to Employment

There are several factors that contribute to poor employment outcomes for autistic adults. By definition, individuals with ASD often present with characteristics that can interfere with their ability to function in some employment settings. While the degree to which these factors interfere with successful employment outcomes varies, interactional difficulties, comorbid intellectual disability, and behavioral challenges are all variables that have the potential to adversely impact the ability to obtain and retain employment.

Communication Difficulties

Perhaps one of the most significant obstacles for individuals with ASD are the communication deficits that are inherent to the diagnosis. As interaction is a critical skill for many occupations, communication deficits are likely to interfere with the ability to obtain and retain employment. This is particularly problematic as approximately 30% of autistic individuals remain minimally verbal or nonverbal, even after years of intervention (Tager-Flusberg & Kasari, 2013), and many fail to develop functional speech at all (Matson et al., 2010). The presence of communication difficulties clearly limits the range of job opportunities and may interfere with procuring employment. For employment experiences to be successful, accommodations often need to be made to address communication deficits. Commonly used accommodations include the use of augmentative communication devices or sign language.

Social Deficits

Most individuals with ASD present with some degree of social deficits. As with other symptoms of autism, the extent to which social behavior is affected varies from person to person. Autistic people often display difficulty with social-emotional reciprocity, including abnormal social approach. They may be unlikely to share their interests with others and often have difficulty initiating or responding to social interactions (American Psychological Association, 2013). These social deficits may manifest as difficulties with conveying information appropriately, asking too many questions, and challenges with navigating coworker humor (Hurlbutt & Chalmers, 2004). As social interaction is a requirement for many jobs, the inability to communicate fluently and social disinclination (e.g., difficulty looking at or sharing information with others) significantly limit employment opportunities (e.g., customer service). As social deficits can be a limiting factor in obtaining employment, teaching the social skills necessary to navigate work settings is critical (Wehman et al., 2012).

Cognitive Functioning Level

As ASD can manifest in many ways, the prevalence of intellectual disability varies dramatically. A study by the Centers for Disease Control and Prevention (2014) examined records dating back to 2008 and found that 38% of children with ASD had concurrent intellectual disability. The presence of an intellectual disability is another factor that can limit the scope of available employment opportunities for people with ASD. Individuals with significant cognitive impairments often struggle with attending to tasks, have problems with working memory, or lack problem-solving skills (Hill, 2004; Williams et al., 2006). In addition, employment for people with significant intellectual disability would likely require supports (e.g., job coaches, 1:1 aides) for obtaining a job, coaching while on the job, and facilitating social interactions. Such supports are not readily available in most employment settings.

Behavioral Challenges

Many individuals with ASD present with problem behavior that is disruptive or, in some cases, dangerous (Hartley et al., 2008). Common topographies of maladaptive behavior include aggression, self-injurious behavior (SIB), property destruction, and ritualistic/stereotypical behavior. Estimates of the prevalence of maladaptive behavior range widely, but the literature indicates that 30–50% of individuals with ASD present with some form of maladaptive behavior (e.g., Shattuck et al., 2007). Intervention challenges can be amplified in older individuals given the complexity and intensity of the challenging behavior (Borthwick-Duffy, 1994; Rojahn & Schroeder, 1991).

These challenges are not limited to dangerous forms of behavior. People with ASD often present with non-dangerous, situationally inappropriate types of behavior, such as hand flapping or body rocking. While these types of behavior are not dangerous, any form of problem behavior, dangerous or not, may discourage or prevent employers from hiring people with ASD.

Quality of Existing Vocational Preparation

Complicating matters further is the fact that very little research exists for selecting appropriate vocational targets for individuals with special needs. The stated purpose of IDEA (2004) is to “ensure that all children with disabilities have available to them a free appropriate public education (FAPE) and related services designed to meet their unique needs and *prepare them* for further education, *employment*, and independent living” (IDEA, Sec. 300.1(a)). Mounting literature suggests the need for the development of employment placement resources for individuals with ASD (Schaller & Yang, 2005). However, empirically supported assessment tools for this purpose are lacking. In the absence of valid assessment tools, schools and training programs often focus on nonfunctional academics rather than functional skills that will benefit students with ASD after graduation. The unfortunate outcome of these circumstances is inadequate preparation, poor vocational "matching," and, ultimately, employment failure (Barnard et al., 2001; Jennes-Coussens et al., 2006; Muller et al., 2003; Newman et al., 2009).

Preparation of the Workplace

While there are certainly issues that warrant individual intervention, the burden of change should not fall exclusively upon people with ASD and their families. It is arguably more important to prepare workplaces to accommodate individuals with autism rather than the other way around. Given the nature of ASD, the workplace environment may be more amenable to change anyway.

Perhaps the most significant obstacle to overcome is the negative perception of potential employers regarding people with autism. In many cases, employers have limited experience with hiring and working with individuals with disabilities, which may lead to misconceptions and biases (Ju et al., 2013). Morgan and Alexander (2005) surveyed prospective employers regarding the hiring of individuals with developmental disabilities. Potential employers often expressed concerns regarding increased cost, the level of supervision required, lack of productivity, pronounced skill deficits, and difficulties with the termination of employment. Further, Houtenville and Kalargyrou (2012) found that potential employers cited concerns related to safety, attendance, punctuality, appearance, and social skills when considering hiring neurodiverse individuals. However, Lindsay et al. (2018) found business improvements related to hiring individuals with disabilities (including autism) in the areas of profitability (e.g., tax credits, turnover, retention), competitive advantage (e.g., customer loyalty and satisfaction), inclusive work culture, and ability awareness (i.e., for training coworkers of employees with disabilities). Despite this evidence, these negative perceptions persist and warrant intervention.

Perhaps one of the simplest and most effective strategies to prepare the workplace is to educate coworkers about the nature of ASD. For people who are unfamiliar with autism, the population can sometimes seem less social, awkward, or rude. Obviously, these characteristics are not the fault of autistic people, nor should they be expected to behave "normally." Teaching coworkers that a person might be less talkative, make less eye contact, or need quiet working conditions could significantly improve working conditions for both the coworkers and autistic people. Practically speaking, the task of teaching people to tolerate a coworker with autism may be simpler, and perhaps more ethical, than trying to teach a person with autism to behave like their "normal" coworkers.

Another key to preparing the workplace is identifying accommodations that increase the likelihood of success. As is the case with anyone entering the workforce, a proper fit is necessary for job success. Not all people with ASD will thrive in the same kind of settings. People may be sensitive to noise, be adversely affected by crowds, or struggle with the difficulty/complexity of certain tasks. In many cases, these issues may only require simple accommodations (e.g., being able to wear headphones during work or working in a less crowded area).

These barriers, when not properly addressed, often lead to missed opportunities for employment. As challenging as these barriers may be, families are also left to navigate a complex legal landscape to access employment supports as they leave the educational system and move into adulthood.

Legal Issues in Accessing Services

There are many government agencies and programs that exist at the federal, state, and local levels (e.g., Vocational Rehabilitation, Medicaid-

State I/DD Agency, private health insurance, Social Security) that are intended to ensure that all people with disabilities have the opportunity to obtain competitive and integrated employment. Navigating these programs can be difficult to fully comprehend. While most of the primary legislation governing programs and protections related to employment for people with autism and other disabilities ares largely provided by the US federal government, federal legislation often allows for individual state agencies to dictate the specific forms, organization, and extent of the funding, programs, and supports that they provide for employment services and all related rules and regulations on a local level.

Hypothetically, allowing state and local government to design employment assistance programs in ways that are most appropriate for their respective constituents makes sense as there are likely many key differences in the needs of citizens living in different geographic regions of the United States. However, drawbacks to this approach include that there is enormous inconsistency in funding, access to effective services, and outcomes related to employment supports for autistic adults across counties and states and on a national level (Roux et al., 2018). In other words, the landscape of funding for employment programs and corresponding outcomes in one state could be completely different from those in another state. This lack of consistency in the structure and administration of services makes it difficult to conduct a simple evaluation of the overall effectiveness of US programs intended to encourage individuals with disabilities to attain competitive employment.

In many states, available funding for behavior analytic services provided in support of the attainment of employment goals is distributed between federal, state, and local agencies, such as Vocational Rehabilitation, Medicaid, private health insurance, and Social Security. Each of these agencies has their own set of systems, definitions, and requirements for service delivery, documentation, billing, and compliance. Consequently, behavior analysts supporting adults with autism in employment settings need to be fluent in working within multiple complex fee-for-service systems specific to the individual state where the practitioner is providing services. This is in direct contrast to the funding mechanism for practitioners working in school settings where funding is derived primarily from local property taxes and is relatively guaranteed. The added complexity and effort required to secure funding and be fluent in compliance requirements from multiple sources should be a primary consideration for early career practitioners that are contemplating a career working with autistic adults in employment settings.

While many people with a range of disabilities may benefit from the current national approach to providing employment supports, outcomes for adults with autism vary widely across states (Roux et al., 2018), and the vast majority of people on the spectrum continue to be without access to opportunities for competitive employment throughout the United States (Newman et al., 2011).

The Autism Collaboration, Accountability, Research, Education and Support Act (Autism CARES Act), which originally passed into law in 2006, is the primary federal legislation mandating funding specifically for ASD-related services, training, and research. The Autism CARES Act requires that representatives from each of the federal agencies that support research and program efforts relevant to ASD collaborate to compose a comprehensive report to Congress on all federal activities related to youth and young adults with autism and the challenges they face regarding the transition from school-based programs to adult service systems.

State of the Research Regarding Employment and ASD

As noted previously, the existing research regarding employment intervention and outcomes for individuals with ASD remains relatively sparse. While there have been several studies documenting that people with ASD tend to be employed less, there have been few studies outlining what constitutes best practice to improve employment outcomes. Evidence-based vocational assessment methods and effective teaching procedures remain underrepresented in the literature. This section of the chapter is a review of the existing empirical literature to summarize best practice in assessment and intervention for developing vocational skills.

Identifying Vocational Targets

While interest mounts in the area of improved transition planning, selecting appropriate vocational targets to improve outcomes for individuals with ASD remains an area in need of more research. Using assessment to inform instruction improves the efficiency of the training (McCurdy & Cole, 2014). Vocational skill assessments can be used to identify client strengths and deficits that can inform instructional goals. The use of sound assessment procedures to inform intervention is one of the most significant predictors of competitive employment for autistic individuals (Kaya et al., 2016). In recent years, several assessments have emerged to address this need. Most of these assessments have been in the form of questionnaires and rating scales, with relatively few direct vocational assessment measures.

Indirect Vocational Assessment Instruments Indirect vocational assessments represent an important step in identifying employment matches for people with ASD. These assessments are particularly useful for populations with little or no intellectual disability. Their utility may be more limited for heavily impacted populations, as they may not be able to accurately answer content questions in the instruments.

The Autism Work Skills Questionnaire (AWSQ; Gal et al., 2013) is a 78-item, semistructured, work-based assessment designed to create an employment profile for people with ASD. When completing the questionnaire, the participants respond to questions using a 5-point Likert scale on six content domains that include level of independence, work habits, working style, routine daily activities, interpersonal skills, and sensory needs. Gal et al. (2015) compared AWSQ ratings for neurotypical people and individuals with ASD. Gal et al. (2015) found significant differences in the scores between the groups for four of the five main AWSQ domains, suggesting that the AWSQ may be useful in matching individuals with ASD to jobs.

The Self-Directed Search® Form E. Fourth Edition (SDS; Holland et al., 1994) is a self-administered questionnaire based on the belief that there are six personality types: realistic, investigative, artistic, social, enterprising, and conventional. These different personalities are presumed to seek particular work environments. There is preliminary evidence to suggest that the SDS is a quality tool for individuals with learning disabilities and developmental disabilities, as well as those who are unable to read (Murray et al., 2016).

The current resources that are available for vocational selection may, in some cases, be poorly suited for individuals with ASD who are severely impacted and/or nonverbal. A couple notable exceptions are the Reading-Free Vocational Interest Inventory (RFVII-3; Synatchk & Becker, 2020) and the Career Occupational Preference System: Picture Inventory of Careers (COPS-PIC; Knapp-Lee, 2007).

The RFVII-3 is a nonverbal measure of vocational interests for users from Grade 5 through adult. The assessment requires the examinee to select from a variety of pictured work-related activities as a measure of preference. The scores derived from the assessment place the examinee in 1 of 11 professional areas: automotive, building trades, clerical, animal care, food service, patient care, horticulture, housekeeping, personal service, laundry service, and material service. The tool is designed for individuals with learning disabilities and developmental disabilities as well as those who are unable to read.

The COPS-PIC is another nonverbal measure of vocational interests designed for individuals Grade 7 to adult. The COPS-PIC can be used to assess individuals with reading or language difficulties as well as individuals with low academic or career motivation. The assessment requires the examinee to express preferences using pictures of occupational activities. The scores on the assessment are linked to 14 career clusters, including science, technology, outdoor, consumer economics, outdoor, business, clerical, communication, arts, and service.

There are a number of strengths to these indirect vocational assessment models. Perhaps the greatest strength is their ease of use. Most of these assessments can be completed by the individual or their family members in a brief period of time. Indirect assessments also can provide exploratory opportunities to consider employment experiences previously not considered.

While indirect assessments may be viable starting points while planning vocational experiences, their usefulness is limited with individuals with more significant support needs. As indirect assessments are often completed by parents, caretakers, or teachers, they are subject to bias and may not produce reliable results. In addition, indirect reports of work preference may not be reflective of actual preference when presented with the work experiences.

Direct Vocational Assessment Instruments While indirect assessment measures can be a helpful tool for guiding vocational programming, the nature of these tools requires an inference be made that the reported preference for the jobs translates to actual vocational/employment preference. Families and practitioners may forego direct assessments and use trial-and-error job approaches to identify job matches. While these strategies can sometimes be effective, they can also be inefficient, with time and resources wasted.

Situational Assessments Situational assessments involve allowing an individual to sample job experiences in community-based work environments (Inge, 2007; Wehman et al., 2007). In many cases, such assessments can be superior to indirect measures as they allow the job seeker to directly perform the required work tasks. For example, an individual may be given the opportunity to sample several different jobs (e.g., doing janitorial work, delivering mail in an office building, working as a cashier in a grocery store), and data can be collected for engagement (e.g., on-task behavior) and aptitude (i.e., how well they performed). These assessments also allow an individual to express preference for tasks after participating in the activity. Situational assessments are particularly useful for individuals with whom questionnaires or interviews are not appropriate means of obtaining information. Perhaps the main drawback of these assessments is the lost time spent training in unmatched jobs.

Skill-Based Vocational Assessments As an alternative to traditional assessment models, there is some support for skill-based vocational assessments. Using such models may allow practitioners to circumvent the need for job sampling and provide information that may help to tailor multiple jobs to meet the needs of job seekers. LaRue et al. (2019) designed a skill-based vocational assessment that assessed client choice/preference for specific critical dimensions of vocational skills: social vs. nonsocial tasks, complex vs. repetitive tasks, and sedentary vs. mobile tasks. The results from this assessment were used to design a vocational profile for each participant. Each participant was then exposed to *matched* and *unmatched* job experiences based on the results of the assessment. To evaluate differences in performance in matched and unmatched jobs, the investigators monitored work productivity and disruptive behavior. In the final phase, participants were given a choice between completing matched or unmatched jobs. The assessment resulted in varied job profiles across the participants. All the participants performed better (i.e., more on-task, less disruptive behavior) while completing jobs matched to their assessment results. In addition, when participants were allowed to choose between matched and unmatched jobs, they consistently chose to complete jobs that matched their profile results.

Direct vocational assessments represent an important step in designing and matching autistic people with ideal employment outcomes. Exposure to actual job components and identifying the optimal performance characteristics to adapt employment experiences have the potential to greatly improve job retention and satisfaction.

Research on the Skills for Successful Employment

Even when sound assessments are completed to identify good employment matches, skills necessary to obtain and retain employment must be taught. The process often begins with teaching the skills and expectations necessary for completing the job itself. While those skills are an obvious necessity for job success, there is also a need to teach other related skills, such as how to interview for a job and how to navigate workplace interactions (e.g., "soft skills").

Teaching the Skills for the Job We have all had the opportunity to start a new job at some point in our lives. Upon starting the job, we likely required orientation or training to provide us with the skills and knowledge to perform competently. The extent of this training likely depended on a number of factors, such as the complexity of the job and our aptitude for completing specific tasks. We likely benefitted from evidence-based training strategies, such as written job descriptions, watching experts perform the job, and frequent feedback from our trainers/supervisors. There is no reason to expect this to be different for teaching autistic people.

In most cases, a job is not a specific, isolated task. Most jobs are a collection of smaller tasks that we must master to meet expectations. For example, consider a sales associate at a department store. Such a job may require a person to unload and store inventory on shelves in the back of the store, restock items in the front of a store when they are needed, answer questions posed by customers, and operate a cash register. While these skills may be acquired readily with minimal structured training for most people with a diagnosis of ASD, some may require intensive teaching procedures to teach each individual skill.

Behavioral skills training (BST; Sarokoff & Sturmey, 2004) represents an evidence-based strategy for teaching people such skills. BST is a training procedure that includes written/verbal instructions, modeling/role playing, and performance feedback. The combination of these components represents an effective way to teach skills. A voluminous literature exists validating the utility of these strategies for training (for a review, see Kirkpatrick et al., 2019). While most of the BST literature has focused on teaching neurotypical individuals how to implement skills, there is a growing literature on its use to teach critical skills to people with ASD.

In a series of studies by Lerman and colleagues, autistic individuals were taught to implement behavioral programming with autistic children using BST (Lerman et al., 2015; Lerman et al., 2013). In these studies, the trainees were able to acquire teaching skills (i.e., mand training, discrete trial instruction) with BST, which led to corresponding skill acquisition in the young children with whom they were working. In addition, social validity measures indicated that some participants' teaching was indistinguishable from that of trainees without ASD.

Gunn et al. (2017) taught a 22-year-old autistic college student social pragmatic and executive functioning skills using BST. The authors evaluated the use of a coaching program based on the BST model to help the student meet the requirements necessary to pass a practicum course. The primary objective of the coaching sessions was to increase the student's ability to provide high-quality interactions with the children. Results indicated the student increased her rate of verbal interactions and, anecdotally, the quality of her interactions.

The empirical literature has clearly shown that BST is an effective tool for teaching people skills regardless of their diagnosis. There is now an emerging literature demonstrating the utility of these training procedures for teaching autistic adults job skills.

Interview Skills Before entering into any given position, there are introductory skills that must be acquired before progressing into the workforce.

As a foundation to any employment opportunity, an interview may be a necessary first step toward gaining employment. With social communication deficits being one of the core characteristics of ASD, individuals may have difficulty with interview skills that rely heavily on a person's ability to connect to their interviewer while being able to speak to their experiences as related to the current job. Many studies have evaluated the utility of various training procedures to increase interview skills with adolescents and adults with ASD.

In recent years, researchers have used BST to teach job interview skills. For example, Stocco et al. (2017) used BST to teach appropriate question asking and answering, as well as appropriate attending behavior, to five college students during mock interviews. The use of BST led to improvements in the interview behavior across all five participants.

Advances in technology have provided additional avenues for training interview skills. Rosales and Whitlow (2019) used a BST package to teach interview skills to six participants using a web-based platform. In the investigation, the authors used BST to teach commonly asked interview questions using a commercially available training program. The authors found that BST was effective for teaching and improving responses to interview questions. In addition, the improved interview performance generalized to novel interviewers and novel settings and maintained over time.

Strickland et al. (2013) evaluated a web-based curriculum (JobTIPS) to teach interview skills to 22 autistic adolescents between the ages of 16 and 19. The training consisted of theory-of-mind guidance, video modeling, visual supports, and virtual reality practice. In this randomized study, the performance of participants was evaluated in two interviews. Following the first interview, half of the participants received the training, while the other half did not. The results showed that the participants who completed the JobTIPS training demonstrated improved short-term verbal skills, such as content and delivery of the responses to interview questions, as compared to the control group.

Some studies have evaluated the efficacy of virtual reality tools to improve interview skills by providing an interactive and individualized practice environment (Villante et al., 2020; Walker et al., 2016). Virtual reality has been used not only to evaluate interview skills but to improve collaborative skills as well. Zhang et al. (2020) evaluated virtual reality and collaborative virtual environments to attempt to provide additional opportunities for communication and collaboration skills training. The interactions demonstrated in the virtual reality environment reflected interactions with typically developing peers, and results suggest promise for future research. While the technology of virtual reality may be useful, other high-level technological supports have also been used to aid in training, such as robots, to provide assistance during mock interviews while teaching appropriate interview behavior (Kumazaki et al., 2019). As we move toward a world of technological advancements, future research should consider the benefit of incorporating technology into the development and improvement of interview and workplace skills.

Teaching Soft Skills The ability to navigate the social nuances in workplace relationships can be a significant challenge for autistic people. Promoting social communication and collaboration is a key factor in many employment settings. In a pilot study, Connor et al. (2020) evaluated an eight-session work-related social skills training to improve social cognition, social function, and social confidence. The Assistive Soft Skills and Employment Training (ASSET) was adapted from a general soft skills curriculum and focused on communication, attitude and enthusiasm, teamwork, networking, problem-solving and critical thinking, and professionalism through a structured learning approach. The training consisted of 90-min sessions in a group format among 26 adults with ASD. Results indicated improvements across all categories and a reduction in anxiety. Sung et al. (2019) also evaluated the ASSET program with 17 autistic adults. They observed improvements in social functioning, self-confidence, and engagement, as well as larger, impactful indicators of a proper quality of life, such as a sense of belonging.

Grob et al. (2019) implemented a BST training package to teach three autistic adults critical workplace social skills. In this investigation, the authors taught participants social skills, such as responding appropriately to feedback, requesting help, and asking for a task model from the supervisor. Results indicated that the intervention was effective for improving all targeted social skills.

Although there is currently little research on supporting adults with ASD in employment, particularly in reference to improving soft skills, there is a push for evolved systems of support, especially as rates of ASD continue to rise. As we continue to evaluate more suitable methods of supporting adults with ASD in various employment settings, we should also continue to develop support systems for these individuals not only to become generally more employable but to also learn adaption and maintenance skills in the job once they are working.

Identifying the Appropriate Setting

While providing the skills necessary to obtain and retain a job is essential, the employment setting itself is also a critical factor for job success. As autism presents in a variety of different ways, an ideal placement is going to vary from person to person. For example, many people with ASD require no accommodations and have minimal difficulty working alongside neurotypical colleagues in a traditional workplace. On the other hand, there are people with autism who have significant support needs and may require more intensive support, such as job coaches or modifications to their job responsibilities, and are better suited for supported employment experiences or day programs/sheltered workshops. What follows is a description of some of the most common vocational/employment settings for people with ASD.

Competitive Integrated Employment

Competitive integrated employment (CIE) refers to vocational experiences where individuals earn market wages at or above minimum wage (Cimera et al., 2014). People working in CIE settings generally have little or no supplemental support relative to their neurotypical counterparts. CIE is usually the preferred outcome for individuals with disabilities and their families. As such, CIE should be the goal for practitioners working with this population whenever possible. CIE experiences offer many benefits, including greater opportunities for social relationships, improved cognitive functioning, and financial support/freedom (Wehman, et al., 2016).

Supported Employment (SE)

While the goal is usually to attain competitive employment with no additional support, some people with ASD require workplace accommodations for successful outcomes. Supported employment (SE) refers to workplace experiences that have accommodations to maximize the likelihood of success. These accommodations may include having job coaches present to provide support, modifications to job responsibilities, or changes to the physical layout of the workplace. For SE to be effective, the supports need to be individualized to meet the job seeker's needs around all stages of employment and based on observation and data collection (Chen et al., 2014; Garcia-Villamisar et al., 2002; Gerhardt & Lanier, 2010; Scott et al., 2019; Wehman et al., 2017). Although sample sizes are small, and populations limited, the research on SE is promising for both vocational outcomes and non-vocational outcomes such as cognitive performance outside work (Garcia-Villamisar & Hughes, 2007; Scott et al., 2019; Wehman et al., 2012; Wehman et al., 2017). While these supports are present at the start of SE experiences, the long-term goal should be to fade these supports as they become more independent (Nicholas et al., 2015).

Prevocational Settings

While the goal should always be directed at obtaining competitive or supported employment, there are some individuals who do not possess the skills necessary to maintain employment in traditional work settings. In many cases, these individuals need to develop vocational skills in more controlled settings with additional supports, such as day habilitation programs and sheltered workshops.

Adult Day Services or Day Habilitation While there is tremendous variability to how different programs operate, adult day services (ADS) or day habilitation (DH) services often implement vocational and/or prevocational programing both in facility-based settings and in the community. In these programs, job training will often include periods of center-based programming in conjunction with controlled individual or group employment experiences in the community (Gerhardt & Lanier, 2010; Taylor & Seltzer, 2011). ADS/DH programs represent a common model of vocational support for individuals diagnosed with autism; however, the research base supporting the efficacy of such models is not particularly strong with regard to future employment or quality of life outcomes.

Sheltered Workshops Sheltered workshops (SWs) are another form of controlled, prevocational work experience. SWs are often large, congregate facility-based employment programs. In these programs, people with disabilities often complete minimum wage piece work and prevocational skill training (Cimera et al., 2012; Garcia-Villamisar et al., 2002; Gerhardt & Lanier, 2010; Nicholas et al., 2015). As is the case with adult day programs, the literature supporting SWs is not particularly strong. In fact, there is some evidence suggesting that sheltered workshops may have a negative effect on the eventual outcomes of individuals working in the community in terms of pay rate, hours, and overall cost of support services (Cimera et al., 2012). Because research supports that employment outcomes are generally better after SE services, there has been an industry "shift" away from SWs in favor of increased community integration (Nicholas et al., 2015).

Models for Clinical Practice

With the tremendous variability in how ASD presents, what constitutes best practice must be adapted to meet the needs of the individual. Understanding job preference and skill sets through vocational assessments and development of work skills through systematic instruction are crucial components for aiding autistic adults to find appropriate, meaningful, and enjoyable employment opportunities. The need for individualized services and training is imperative for realizing successful employment outcomes (Anderson et al., 2018). What follows is a summary of steps for practitioners and families to take to improve employment outcomes.

Addressing the Barriers to Employment

As noted earlier in the chapter, the associated features of ASD can sometimes interfere with the ability to gain and retain employment. Difficulties with communication, social skills deficits, and repetitive or maladaptive behavior can all become barriers to employment (Howlin & Magiati, 2017; Moss et al., 2017). While systematic intervention is not always necessary, people who are more heavily impacted are likely to need more intensive intervention. With regard to social and communication difficulties, it is important for practitioners to use assessments to identify specific skills in need of intervention. For individuals presenting with challenging behavior, practitioners should use functional behavior assessments to identify factors contributing to its occurrence along with function-based interventions to address these issues.

While it is important to respect individual differences and neurodiversity, the presence of challenging behavior (e.g., aggression, stigmatizing repetitive behavior) or significant social/communication deficits will limit the range of opportunities available. The role of the practitioner should be to provide autistic individuals with the skills they need to allow them to be as independent as possible.

Prepare the Work Environment

As discussed previously, employers and coworkers can sometimes have negative perceptions about people diagnosed with autism (Black, et al., 2019; Hurlbutt & Chalmers, 2004; Unger, 2002). As practitioners supporting this population, we need to take measures to prepare potential work environments to accommodate autistic individuals. This may include providing didactic training to staff and administrators to familiarize them with the needs and characteristics of diverse populations. Preparations could also involve modifying the environment itself to allow autistic individuals to be as successful as possible (e.g., quieter working environments, written instructions for tasks, the presence of job coaches). By preparing the work environment, practitioners can decrease the likelihood of misunderstandings and conflict while creating an accommodating workplace that is individualized to increase the likelihood of success.

Implement Sound Vocational Assessments

We described some encouraging research supporting the use of indirect and direct vocational assessment procedures to create better job matches. Despite their utility, they are used infrequently in applied settings, which likely contribute to poor outcomes. As practitioners, we should be using these measures to account for both aptitude and preference in identifying potential jobs for autistic individuals. Indirect vocational assessments, such as the Autism Work Skills Questionnaire (AWSQ), represent an ideal starting point and could be used to identify potential areas to explore and target for future analysis.

For those more severely impacted or with an intellectual disability, direct vocational assessment procedures may have more utility. These direct vocational assessments might involve exposing the individual to different job experiences (i.e., job sampling) or characteristics of jobs (e.g., whether they prefer working alone or with others) and measuring performance and preference while completing jobs.

Use Sound Training Procedures

Using systematic training procedures, such as BST, represents the most effective way to teach someone to implement a skill. As noted previously, BST includes providing instructions (written and/or verbal), modeling and role playing, and performance feedback. The combination of these training procedures has been shown to be incredibly effective across a variety of populations. While the use of BST to teach specific job skills is important, it is equally important to use BST to train associated skills, such as interviewing skills and the skills necessary to navigate social interactions in the workplace.

Upon the acquisition of these skills, practitioners should take measures to fade themselves from the environment to allow for independent responding. While having supports in place is desirable in the early stages of training, the presence of support staff can be costly and stigmatizing. The ability to work independently is likely to open up opportunities for this population (e.g., competitive integrated employment).

Select the Appropriate Setting

When identifying appropriate employment environments, families and practitioners must consider several logistical factors to ensure success. CIE should always be the goal. However, the support needs of this population are quite variable. While many are capable of CIE, there are others that have more significant support needs and are better suited for part-time employment or prevocational training. The wrong placement is likely to lead to failure and can have long-term detrimental effects on individuals, their families, and employers.

When possible, families and practitioners should seek employment partnerships in familiar, accessible environments. An often-overlooked factor in promoting successful employment opportunities is access to transportation. Research has indicated autistic individuals experience many obstacles when attempting to procure transportation to and from work (Lubin & Feeley, 2016). To the extent that it is possible, families and practitioners should identify job sites that are easily accessible (i.e., close to home) and/or have easy access to affordable public transportation.

Assess and Monitor Outcomes

To ensure the success of the people we support, it is important to monitor their employment outcomes. In doing so, it allows practitioners to calibrate interventions for the individuals with whom we work, and it represents a mechanism for feedback for our practices. Outcomes can be measured at the level of the individual and at the program level.

Monitoring individual outcomes may be the most direct way that we can evaluate our effectiveness. Relevant dependent variables might include information about pay rate, promotions, and the duration of employment. For individuals with more significant support needs, we might measure work productivity, on-task behavior, the presence of interfering behavior, and the need for prompting from support staff. Such measures could yield valuable information for refining interventions and improving employment outcomes.

There are several ways to monitor program outcomes. Direct outcome measures found in the literature include prolonged employment/job stability/retention rates, wages, intervention hours required to secure employment, type of job (e.g., manual or unskilled), and comparisons of income with expenditure (Brooke et al., 2018; Howlin et al., 2000; Ohl et al., 2017; Roux et al., 2013; Wehman et al., 2016; Wilczynski et al., 2013). Indirect outcome measures include questionnaires of job satisfaction (Alcock & Howlin, 2003), relationships with employer (Nicholas et al., 2018; Ohl et al., 2017), level of job support (Nicholas et al., 2018; Ohl et al., 2017), and social demands (Hurlbutt & Chalmers, 2004).

As support needs often vary greatly from person to person with autistic adults, supports to program for outcomes of independence in adulthood will also vary greatly. Some autistic adults may have advanced college degrees, have driver's licenses, and live independently, while some may require significant support needs in adaptive/functional living skills, engage in problem behavior, and/or have little to no vocal communicative abilities. As autistic individuals age into adulthood, it is important to consider that (a) their support needs do not magically disappear upon turning 21 years old and (b) the behavioral approaches applied to promote successful outcomes should occur within the natural environment. Further, when considering the individualized supports required, we consider what needs to be altered: the individual or the environment. When applying behavioral interventions for prevention of problem behaviors that interfere with community inclusion, practitioners should consider what changes to the physical characteristics of the environment could result in improved behavioral outcomes (Horner et al., 2002). Through this use of "environmental engineering" (Horner et al., 2002, p. 425), the focus of intervention shifts from fitting individuals into certain environments to modification of environments to fit the needs of the people within it. This is applicable in a number of community-based environments and especially relevant when considering vocational opportunities for adults on the autism spectrum.

- Hannah: Hannah is a 24-year-old woman with a diagnosis of ASD. She has above-average intelligence (IQ = 125). Hannah has shown preference and aptitude for computer programming. She has a job working for a software company in a large office with cubicles. A service provider may check in daily or weekly to identify any concerns. Otherwise, Hannah can transport herself to and from work independently, earn a paycheck, and have meaningful social relationships with her coworkers.

- Fred: Fred is a 27-year-old autistic man. He has an IQ of 80 and has some minor social deficits (e.g., difficulty sustaining conversations). While he does not have any major behavioral issues, he does engage in some motor stereotypy (i.e., flicking his fingers repeatedly). He has a paid, part-time position with a local cleaning company that provides janitorial services in office buildings after hours. There is an aide that supports Fred during working hours. The aide transports Fred to and from work and helps him to set up materials before starting his shift. The aide then stands back to let Fred work independently.
- Evan: Evan is a 31-year-old autistic male. Evan has severe intellectual disability (IQ is unmeasurable) and minimal communication ability. In addition, Evan presents with intermittent yet severe maladaptive behavior (e.g., aggression, self-injury). Problem behavior is most likely to occur during difficult work tasks and transitions. Evan spends most of his time in an adult day program that works on prevocational and developing leisure skills. Evan volunteers at a local charity organization for a few days a week with staff support. Responsibilities include sorting donated items and hanging clothing on racks. An aide is always present to ensure that Evan remains on task and to implement a behavior intervention plan.

You can see that the work circumstances for the adults in each of these examples are completely different. What is important to note is that each of these scenarios may represent the optimal outcome for the adult represented. The key is for practitioners to individualize intervention strategies to find the best fit.

Areas of Need for Future Research

As autistic adults are generally underrepresented in clinical research, there are many areas in need of investigation. While there is an obvious need to advance state-of-the-art interventions, it is also critical to evaluate existing strategies and develop ways to implement the procedures in low-resource settings. In addition, the research that does exist often does not find its way into clinical practice. Bridging this research to practice gap is critical for improving employment outcomes for people diagnosed with autism.

While the literature on the assessment and treatment of maladaptive behavior is well developed in younger populations, modifications tailored to the needs of adults are understudied. As any form of problem behavior in the workplace is likely to result in termination, strategies for addressing these issues are of paramount importance. The complexity and intensity of problem behavior, coupled with increases in strength and stature, can make problem behavior unmanageable in adults. Models of assessment that minimize the occurrence of challenging behavior need to be developed and refined. Some encouraging models of assessment, such as trial-based functional analyses (Bloom et al., 2011; LaRue et al., 2010) and latency-based functional analyses (Thomason-Sassi et al., 2011), have utility in older populations. As challenging behavior can often be more dangerous in adults, there is a need to evaluate intervention models that prevent their occurrence, such as fixed time schedules of reinforcement (e.g., Vollmer et al., 1993) and functional communication training (Carr & Durand, 1985), while minimizing the need for the implementation of extinction.

As noted earlier in the chapter, several vocational assessments have emerged to assist in identifying employment placements. While many of these assessments appear to have face validity, the extent to which these tools lead to successful employment outcomes remains unclear. There is a clear need for research linking vocational assessment results to long-term outcomes in employment settings.

While some vocational assessment tools have been developed for autistic populations, people who are severely impacted (e.g., those who present with comorbid intellectual disability and/or are nonverbal) remain underrepresented in the literature. To this point, most vocational assessments have had limited applicability for autistic people with severe communication deficits. Some preliminary research outlining direct vocational assessment procedures are encouraging, but more solutions for this at-risk population are needed.

Related to the above points, there is also a need for research evaluating the effects of job preference on long-term outcomes. While many of the existing vocational assessments are designed to predict jobs that an individual may have the skills necessary to perform, job preference is rarely explored. As most of us can attest, having the ability to perform a task well is not necessarily a reliable indicator of our preference for it. The extent to which one's preference for a job affects long-term outcomes represents an important area to be explored.

While the literature outlining effective training practices is fairly well developed in neurotypical populations, studies evaluating their use with adults diagnosed with ASD are sparse. Future research could verify the effectiveness of these procedures for teaching job skills to autistic populations. Technological modifications to training components also represent an important area for future research. For example, the use of video modeling for training vocational skills could allow for training in the absence of job coaches, which could be a cost-effective, less-intrusive training alternative. As noted earlier, there have been some preliminary investigations into training interviewing skills and the conversational skills necessary to navigate the workplace. These lines of research are in their infancy and warrant more attention.

The inevitable outcome of these lines of research will undoubtedly show that the design of employment experiences needs to be individualized. Successful employment will result from sound vocational assessments, individualized teaching strategies designed for older learners, and adequate preparation of the workplace to accommodate the needs of this population. While programs serve as models to achieve this successfully, there is a need for program evaluation research to determine what predicts the best outcomes.

Clinical Implications

As noted at the start of this chapter, obtaining employment represents a critical developmental step in the progression to adulthood. While the traditional educational experience adequately prepares neurotypical people to join the workforce, outcomes for people diagnosed with ASD tend to be less favorable. The fact that the vast majority of people with ASD are unemployed is a clear evidence of this.

These failures lead to several undesirable outcomes. If we do not adequately prepare autistic people for employment, they are more likely to become isolated and less likely to be integrated with their community and are more likely to experience health problems. Perhaps most importantly, failure to adequately prepare people to join the workforce deprives autistic adults of their ability to become independent. Without gainful employment, it becomes less likely that people can afford to live on their own, can afford to travel, or have opportunities to participate in social activities.

While the empirical literature on the topic remains sparse, the research that does exist highlights the importance of individualized intervention. Addressing the barriers that are likely to interfere with employment, using systematic vocational assessments, using sound training procedures, and preparing the workplace to accommodate autistic coworkers can lead to improved outcomes for this population.

References

Alcock, J., & Howlin, P. (2003). *An evaluation of prospects supported employment service for individuals with Asperger syndrome*. Report to the UK Department for Work and Pensions.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Publishing.

Anderson, C., Lupfer, A., & Shattuck, P. T. (2018). Barriers to receipt of services for young adults with autism. *Pediatrics, 141*(Supp 4), S300–S305. https://doi.org/10.1542/peds.2016-4300G

Baldwin, S., Costley, D., & Warren, A. (2014). Employment activities and experiences of adults with high-functioning autism and Asperger's disorder. *Journal of Autism and Developmental Disorders, 44*, 2440–2449. https://doi.org/10.1007/s10803-014-2112-z

Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). *Ignored or ineligible: The reality for adults with autistic spectrum disorders* (The National Autistic Society Report for National Autism Week). NAS.

Black, M. H., Mahdi, S., Milbourn, B., Thompson, C., D'Angelo, A., Ström, E., Falkmer, M., Falkmer, T., Lerner, M., Halladay, A., Gerber, A., Esposito, C., Girdler, S., & Bölte, S. (2019). Perspectives of key stakeholders on employment of autistic adults across the United States, Australia, and Sweden. *Autism Research: Official Journal of the International Society for Autism Research, 12*(11), 1648–1662. https://doi.org/10.1002/aur.2167

Bloom, S. E., Iwata, B. A., Fritz, J. N., Roscoe, E. M., & Carreau, A. B. (2011). Classroom application of a trial-based functional analysis. *Journal of Applied Behavior Analysis, 44*(1), 19–31. https://doi.org/10.1901/jaba.2011.44-19

Borthwick-Duffy, S. A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology, 62*(1), 17–27. https://doi.org/10.1037//0022-006x.62.1.17

Brooke, V., Brooke, A. M., Schall, C., Wehman, P., McDonough, J., Thompson, K., & Smith, J. (2018). Employees with autism spectrum disorder achieving long-term employment success: A retrospective review of employment retention and intervention. *Research and Practice for Persons with Severe Disabilities, 43*(3), 181–193. https://doi.org/10.1177/1540796918783202

Burgard, S. A., & Lin, K. Y. (2013). Bad jobs, bad health? How work and working conditions contribute to health disparities. *The American Behavioral Scientist, 57*(8), 1105–1127. https://doi.org/10.1177/0002764213487347

Bush, K. L., & Tassé, M. J. (2017). Employment and choice-making for adults with intellectual disability, autism, and down syndrome. *Research in Developmental Disabilities, 65*, 23–34. https://doi.org/10.1016/j.ridd.2017.04.004

Carr, E. G., & Durand, V. M. (1985). Reducing behavior problems through functional communication training. *Journal of Applied Behavior Analysis, 18*(2), 111–126. https://doi.org/10.1901/jaba.1985.18-111

Centers for Disease Control and Prevention. (2014, March 28). Prevalence of autism spectrum disorder among children aged 8 years – Autism and developmental disabilities monitoring network, 11 Sites, United States, 2010. *Surveillance Summaries, 63*(SS02), 1–21.

Chen, J., Leader, G., Sung, C., & Leahy, M. (2014). Trends in employment for individuals with autism spectrum disorder: A review of the research literature. *Review Journal of Autism and Developmental Disorders, 2*, 115–127. https://doi.org/10.1007/s40489-014-0041-6

Cimera, R. E., Wehman, P., West, M., & Burgess, S. (2012). Do sheltered workshops enhance employment outcomes for adults with autism spectrum disorder? *Autism: The International Journal of Research and Practice, 16*(1), 87–94. https://doi.org/10.1177/1362361311408129

Cimera, R. E., Burgess, S., & Bedesem, P. L. (2014). Does providing transition services by age 14 produce better vocational outcomes for students with intellectual disability? *Research and Practice for Persons with Severe Disabilities, 39*(1), 47–54. https://doi.org/10.1177/1540796914534633

Connor, A., Sung, C., Strain, A., Zeng, S., & Fabrizi, S. (2020). Building skills, confidence, and wellness: Psychosocial effects of soft skills training for young adults with autism. *Journal of Autism and Developmental Disorders, 50*(6), 2064–2076. https://doi.org/10.1007/s10803-019-03962-w

Friedman, N. D., Warfield, M. E., & Parish, S. L. (2013). Transition to adulthood for individuals with autism spectrum disorder: Current issues and future perspectives. *Neuropsychiatry, 3*(2), 181–192. https://doi.org/10.2217/npy.13.13

Gal, E., Ben Meir, A., & Katz, N. (2013). Development and reliability of the Autism Work Skills Questionnaire (AWSQ). *American Journal of Occupational Therapy, 67*(1), e1–e5. https://doi.org/10.5014/ajot.2013.005066

Gal, E., Landes, E., & Katz, N. (2015). Work performance skills in adults with and without high functioning autism spectrum disorders (HFASD). *Research in Autism Spectrum Disorders, 10*, 71–77. https://doi.org/10.1016/j.rasd.2014.10.011

García-Villamisar, D., & Hughes, C. (2007). Supported employment improves cognitive performance in adults with autism. *Journal of Intellectual Disability Research, 51*(2), 142–150. https://doi.org/10.1111/j.1365-2788.2006.00854.x

García-Villamisar, D., Wehman, P., & Navarro, M. D. (2002). Changes in the quality of autistic people's life that work in supported and sheltered employment. A 5-year follow-up study. *Journal of Vocational Rehabilitation, 17*(4), 309–312.

Gerhardt, P., & Lainer, I. (2010). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy, 41*(1), 37–45. https://doi.org/10.1007/s10879-010-9160-2

Grob, C. M., Lerman, D. C., Langlinais, C. A., & Villante, N. K. (2019). Assessing and teaching job-related social skills to adults with autism spectrum disorder. *Journal of Applied Behavior Analysis, 52*(1), 150–172. https://doi.org/10.1002/jaba.503

Gunn, S. L., Sellers, T. P., & Lignugaris/Kraft, B. (2017). Application of coaching and Behavioral Skills Training during a preschool practicum with a college student with autism spectrum disorder. *Clinical Case Studies, 16*(4), 275–294. https://doi.org/10.1177/1534650117692673

Hartley, S. L., Sikora, D. M., & McCoy, R. (2008). Prevalence and risk factors of maladaptive behaviour in young children with Autistic Disorder. *Journal of Intellectual Disability Research, 52*(10), 819–829. https://doi.org/10.1089/aut.2019.0058

Hill, E. L. (2004). Executive dysfunction in autism. *Trends in Cognitive Sciences, 8*(1), 26–32. https://doi.org/10.1016/j.tics.2003.11.003

Holland, J. L., Powell, A., & Fritzsche, B. (1994). *SDS professional user's guide*. Psychological Assessment Resources, Inc.

Horner, R. H., Carr, E. G., Strain, P. S., Todd, A. W., & Reed, H. K. (2002). Problem behavior interventions for young children with autism: A research synthesis. *Journal of Autism and Developmental Disorders, 32*(5), 423–446. https://doi.org/10.1023/a:1020593922901

Houtenville, A., & Kalargyrou, V. (2012). People with disabilities: Employers' perspectives on recruitment practices, strategies, and challenges in leisure and hospitality. *Cornell Hospitality Quarterly, 53*(1), 40–52. https://doi.org/10.1177/1938965511424151

Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry, 30*(2), 69–76. https://doi.org/10.1097/YCO.0000000000000308

Howlin, P., Mawhood, L. M., & Rutter, M. (2000). Autism and developmental receptive language disorder: A follow-up comparison in early adult life: II. Social, behavioural and psychiatric outcomes. *Journal of Child Psychology and Psychiatry, 41*(5), 561–578. https://doi.org/10.1111/1469-7610.00643

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45*(2), 212–229. https://doi.org/10.1111/j.1469-7610.2004.00215.x

Hurlbutt, K., & Chalmers, L. (2004). Adults with autism speak out: Perceptions of their life experiences. *Focus on Autism and Other Developmental Disabilities, 17*(2), 103–111. https://doi.org/10.1177/10883576020170020501

Individuals With Disabilities Education Act, 20 U.S.C. § 1400 (2004).

Inge, K. (2007). *Q and a on customized employment: Workplace supports (technical brief)*. Virginia Commonwealth University Rehabilitation Research and Training Center.

Jennes-Coussens, M., Magill-Evans, J., & Koning, C. (2006). The quality of life of young men with Asperger syndrome: A brief report. *Autism, 10*(4), 403–414. https://doi.org/10.1177/1362361306064432

Ju, S., Roberts, E., & Zhang, D. (2013). Employer attitudes toward workers with disabilities: A review of research in the past decade. *Journal of Vocational Rehabilitation, 38*(2), 113–123. https://doi.org/10.3233/JVR-130625

Kaya, C., Chan, D., Rumrill, P., Hartman, E., Wehman, P., Iwanga, K., Pai, C., & Avellone, L. (2016). Vocational rehabilitation services and competitive employment for transition-age youth with autism spectrum disorders. *Journal of Vocational Rehabilitation, 45*(1), 73–83. https://doi.org/10.3233/JVR-160812

Kirkpatrick, M., Akers, J., & Rivera, G. (2019). Use of behavioral skills training with teachers: A systematic review. *Journal of Behavioral Education, 28*, 344–361. https://doi.org/10.1007/s10864-019-09322-z

Knapp-Lee, L. (2007). *COPS-PIC*. EdITS, Inc.

Krueger, P. M., & Burgard, S. A. (2011). Income, occupations and work. In R. G. Rogers & E. M. Crimmins (Eds.), *International handbook of adult mortality* (pp. 263–288). Springer.

Kumazaki, H., Muramatsu, T., Yoshikawa, Y., Corbett, B. A., Matsumoto, Y., Higashida, H., Yuhi, T., Ishiguro, H., Mimura, M., & Kikuchi, M. (2019). Job interview training targeting nonverbal communication using an android robot for individuals with autism spectrum disorder. *Autism, 23*(6), 1586–1595. https://doi.org/10.1177/1362361319827134

LaRue, R. H., Lenard, K., Weiss, M. J., Bamond, M., Palmieri, M., & Kelley, M. E. (2010). Comparison of traditional and trial-based methodologies for conducting functional analyses. *Research in Developmental Disabilities, 31*(2), 480–487. https://doi.org/10.1016/j.ridd.2009.10.020

LaRue, R. H., Maraventano, J. C., Budge, J. L., & Frischmann, T. (2019). Matching vocational aptitude and employment choice for adolescents and adults with ASD. *Behavior Analysis in Practice, 13*(3), 618–630. https://doi.org/10.1007/s40617-019-00398-7

Lerman, D. C., Hawkins, L., Hoffman, R., & Caccavale, M. (2013). Training adults with an autism spectrum disorder to conduct discrete-trial training for young children with autism: A pilot study. *Journal of Applied Behavior Analysis, 46*(2), 465–478. https://doi.org/10.1002/jaba.50

Lerman, D. C., Hawkins, L., Hillman, C., Shireman, M., & Nissen, M. A. (2015). Adults with autism spectrum disorder as behavior technicians for young children with autism: Outcomes of a behavioral skills training program. *Journal of Applied Behavior Analysis, 48*(2), 233–256. https://doi.org/10.1002/jaba.196

Lindsay, S., Cagliostro, E., Albarico, M., Mortaji, N., & Karon, L. (2018). A systematic review of the benefits of hiring people with disabilities. *Journal of Occupational Rehabilitation, 28*(4), 634–655. https://doi.org. https://doi.org/10.1007/s10926-018-9756-z

Lubin, A., & Feeley, C. (2016). Transportation issues of adults on the autism spectrum: Findings from focus group discussions. *Transportation Research Record: Journal of the Research Board, 2542*(1), 1–8. https://doi.org/10.3141/2542-01

Matson, J. L., Mahan, S., Kozlowski, A. M., & Shoemaker, M. (2010). Developmental milestones in toddlers with autistic disorder, pervasive developmental disorder-not otherwise specified and atypical development. *Developmental Neurorehabilitation, 13*(4), 239–247. https://doi.org/10.3109/17518423.2010.481299

McCurdy, E. E., & Cole, C. L. (2014). Use of a peer support intervention for promoting academic engagement of students with autism in general education settings. *Journal of Autism and Developmental*

Disorders, 44(4), 883–893. https://doi.org/10.1007/s10803-013-1941-5

Morgan, R. L., & Alexander, M. (2005). The employer's perception: Employment of individuals with developmental disabilities. *Journal of Vocational Rehabilitation, 23*(1), 39–49.

Moss, P., Mandy, W., & Howlin, P. (2017). Child and adult factors related to quality of life in adults with autism. *Journal of Autism and Developmental Disorders, 47*(6), 1830–1837. https://doi.org/10.1007/s10803-017-3105-5

Muller, E., Schuler, A., Burton, B. B., & Yates, G. B. (2003). Meeting the vocational support needs of individuals with Asperger Syndrome and other autism spectrum disabilities. *Journal of Vocational Rehabilitation, 18*, 163–175.

Murray, N., Hatfield, M., Falkmer, M., & Falkmer, T. (2016). Evaluation of career planning tools for use with individuals with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders, 23*, 188–202. https://doi.org/10.1016/j.rasd.2015.12.007

Newman, L., Wagner, M., Cameto, R., Knokey, A., & Shaver, D. (2009). *Comparisons across time of the outcomes of youth with disabilities up to 4 years after high school: A report of findings from the National Longitudinal Transition Study (NLTS) and the National Longitudinal Transition Study-2 (NLTS2)*. IES National Center for Special Education Research.

Newman, L., Wagner, M., Knokey, A. M., Marder, C., Nagle, K., Shaver, D., Wei, X., Cameto, R., Contreras, E., Ferguson, K., Greene, S., & Schwarting, M. (2011). *The post-high school outcomes of young adults with disabilities up to 8 years after high school: A report from the National Longitudinal Transition Study-2 (NLTS2)* (NCSER 2011-3005). SRI International.

Nicholas, D. B., Attridge, M., Zwaigenbaum, L., & Clarke, M. (2015). Vocational support approaches in autism spectrum disorder: A synthesis review of the literature. *Autism, 19*(2), 235–245. https://doi.org/10.1177/1362361313516548

Nicholas, D. B., Zwaigenbaum, L., Zwicker, J., Clarke, M. E., Lamsal, R., Stoddart, K. P., Carroll, C., Muskat, B., Spoelstra, M., & Lowe, K. (2018). Evaluation of employment-support services for adults with autism spectrum disorder. *Autism, 22*(6), 693–702. https://doi.org/10.1177/1362361317702507

Nye-Lengerman, K. (2017). Vocational rehabilitation service usage and outcomes for individuals with autism spectrum disorder. *Research in Autism Spectrum Disorders, 41–42*, 39–50. https://doi.org/10.1016/j.rasd.2017.08.003

Ohl, A., Grice Sheff, M., Small, S., Nguyen, J., Paskor, K., & Zanjirian, A. (2017). Predictors of employment status among adults with autism spectrum disorder. *Work, 56*(2), 345–355. https://doi.org/10.3233/WOR-172492

Qian, X., Papay, C., Chaxiong, P., & Johnson, D. R. (2018). Literature review of employment outcomes for adults with intellectual and developmental disability. *International Review of Research in Developmental Disabilities, 55*, 213–266. https://doi.org/10.1016/bs.irrdd.2018.08.006

Rogers, R. G., Hummer, R. A., & Nam, C. (2000). *Living and dying in the U.S.A.: Behavioral, health, and social differentials of adult mortality*. Academic.

Rojahn, J., & Schroeder, S. R. (1991). Behavioral assessment. In J. L. Matson & J. A. Mulick (Eds.), *Handbook of mental retardation* (2nd ed., pp. 240–259). Pergamon Press.

Rosales, R., & Whitlow, H. (2019). A component analysis of job interview training for young adults with autism spectrum disorder. *Behavioral Interventions, 34*(2), 147–162. https://doi.org/10.1002/bin.1658

Roux, A. M., Shattuck, P. T., Cooper, B. P., Anderson, K. A., Wagner, M., & Narendorf, S. C. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 52*(9), 931–939. https://doi.org/10.1016/j.jaac.2013.05.019

Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A., & Anderson, K. A. (2015). *National Autism Indicators Report: Transition into Young adulthood*. Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.

Roux, A. M., Rast, J. E., & Shattuck, P. T. (2018). State-level variation in Vocational Rehabilitation service use and related outcomes among transition-age youth on the autism spectrum. *Journal of Autism and Developmental Disorders, 50*(7), 2449–2461. https://doi.org/10.1007/s10803-018-3793-5

Sarokoff, R. A., & Sturmey, P. (2004). The effects of behavioral skills training on staff implementation of discrete-trial teaching. *Journal of Applied Behavior Analysis, 37*(4), 535–538. https://doi.org/10.1901/jaba.2004.37-535

Schall, C., Wehman, P., Avellone, L., & Taylor, J. P. (2020). Competitive integrated employment for youth and adults with autism: Findings from a scoping review. *Child and Adolescent Psychiatric Clinics of North America, 29*(2), 373–397. https://doi.org/10.1016/j.chc.2019.12.001

Schaller, J., & Yang, N. K. (2005). Competitive employment for people with autism: Correlates of successful closure in competitive and supported employment. *Rehabilitation Counseling Bulletin, 49*(1), 4–16. https://doi.org/10.1177/00343552050490010201

Scott, M., Milbourn, B., Falkmer, M., Black, M., Bölte, S., Halladay, A., Lerner, J., Lounds Taylor, J., & Girdler, S. (2019). Factors impacting employment for people with autism spectrum disorder: A scoping review. *Autism, 23*(4), 869–901. https://doi.org/10.1177/1362361318787789

Shattuck, P. T., Seltzer, M., Greenberg, J. S., Orsmond, G. I., Bolt, D., Kring, S., Lounds, J., & Lord, C. (2007). Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of Autism Developmental*

Disorders, 37(9), 1735–1747. https://doi.org/10.1007/s10803-006-0307-7

Stocco, C. S., Thompson, R. H., Hart, J. M., & Soriano, H. L. (2017). Improving the interview skills of college students using behavioral skills training. *Journal of Applied Behavior Analysis, 50*(3), 495–510. https://doi.org/10.1002/jaba.385

Strickland, D. C., Coles, C. D., & Southern, L. B. (2013). JobTIPS: A transition to employment program for individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(10), 2472–2483. https://doi.org/10.1007/s10803-013-1800-4

Sung, C., Connor, A., Chen, J., Lin, C. C., Kuo, H. J., & Chun, J. (2019). Development, feasibility, and preliminary efficacy of an employment-related social skills intervention for young adults with high-functioning autism. *Autism, 23*(6), 1542–1553. https://doi.org/10.1177/1362361318801345

Synatchk & Becker. (2020). *The Reading-free vocational interest inventory* (3rd ed.). Pro-Ed.

Tager-Flusberg, H., & Kasari, C. (2013). Minimally verbal school-aged children with autism: The neglected end of the spectrum. *Autism Research, 6*(6), 468–478. https://doi.org/10.1002/aur.1329

Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders, 41*(5), 566–574. https://doi.org/10.1007/s10803-010-1070-3

Taylor, J. L., Henninger, N. A., & Mailick, M. R. (2015). Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ. *Autism, 19*(7), 785–793. https://doi.org/10.1177/1362361315585643

Thomason-Sassi, J. L., Iwata, B. A., Neidert, P. L., & Roscoe, E. M. (2011). Response latency as an index of response strength during functional analyses of problem behavior. *Journal of Applied Behavior Analysis, 44*(1), 51–67. https://doi.org/10.1901/jaba.2011.44-51

Unger, D. D. (2002). Employers' attitudes toward persons with disabilities in the workforce: Myths or realities? *Focus on Autism and Other Developmental Disabilities, 17*(1), 2–10. https://doi.org/10.1177/108835760201700101

Villante, N. K., Lerman, D. C., Som, S., & Hunt, J. C. (2020). Teaching adults with developmental disabilities to problem solve using electronic flowcharts in a simulated vocational setting. *Journal of Applied Behavior Analysis, 54*(3), 1199–1219. https://doi.org/10.1002/jaba.786

Vollmer, T. R., Iwata, B. A., Zarcone, J. R., Smith, R. G., & Mazaleski, J. L. (1993). The role of attention in the treatment of attention-maintained self-injurious behavior: Noncontingent reinforcement and differential reinforcement of other behavior. *Journal of Applied Behavior Analysis, 26*(1), 9–21. https://doi.org/10.1901/jaba.1993.26-9

Walker, Z., Vasquez, E., & Wienke, W. (2016). The impact of simulated interviews for individuals with intellectual disability. *Journal of Educational Technology & Society, 19*(1), 76–88.

Wehman, P., Targett, P., & Young, C. (2007). Off to work for individuals with autism: A supported employment approach. *Autism Advocate, 46*, 54–58. https://doi.org/10.2511/027494812804153606

Wehman, P., Lau, S., Molinelli, A., Brooke, V., Thompson, K., Moore, C., & West, M. (2012). Supported employment for young adults with autism spectrum disorder: Preliminary data. *Research and Practice for Persons with Severe Disabilities, 37*(3), 160–169. https://doi.org/10.2511/027494812804153606

Wehman, P., Brooke, V., Brooke, A. M., Ham, W., Schall, C., McDonough, J., et al. (2016). Employment for adults with autism spectrum disorders: A retrospective review of a customized employment approach. *Research in Developmental Disabilities, 53–54*, 61–72. https://doi.org/10.1016/j.ridd.2016.01.015

Wehman, P., Schall, C. M., McDonough, J., Graham, C., Brooke, V., Riehle, J. E., Brooke, A., Ham, W., Lau, S., Allen, J., & Avellone, L. (2017). Effects of an employer-based intervention on employment outcomes for youth with significant support needs due to autism. *Autism: The International Journal of Research and Practice, 21*(3), 276–290. https://doi.org/10.1177/1362361316635826

Wilczynski, S. M., Trammell, B., & Clarke, L. S. (2013). Improving employment outcomes among adolescents and adults on the autism spectrum. *Psychology in the Schools, 50*(9), 876–887. https://doi.org/10.1002/pits.21718

Williams, D. L., Goldstein, G., & Minshew, N. J. (2006). The profile of memory function in children with autism. *Neuropsychology, 20*(1), 21–29. https://doi.org/10.1037/0894-4105.20.1.21

Zhang, L., Weitlauf, A. S., Amat, A. Z., Swanson, A., Warren, Z. E., & Sarkar, N. (2020). Assessing social communication and collaboration in autism spectrum disorder using intelligent collaborative virtual environments. *Journal of Autism and Developmental Disorders, 50*(1), 199–211. https://doi.org/10.1007/s10803-019-04246-z

22

Friendships and Social Relationships of Autistic Individuals Across the Lifespan: A Focus on Often-Overlooked Autistic Women

Katharine Figueroa, Lauren Baczewski, and Connie Kasari

Humans are a social, collaborative species, and therefore social relationships are the fabric of our society. Society is a culmination of individuals and communities, and relationships are critical for our individual psychological and physical health across the lifespan. Research shows that the presence of high-quality social relationships predicts better physical and mental health (Yang et al., 2016). More specifically, an individual's cardiovascular health, stress responses, sleep, immune systems, and cognitive health can all be positively affected by having friends and negatively affected by their absence (Cole et al., 2015; Griffin et al., 2019; Holt-Lunstad et al., 2007; Lee & Goldstein, 2016; Seeman et al., 2001). Friends can ameliorate social exclusion and rejection at school, improving mental health (Peters et al., 2011). In one study, college freshman with and without healthy self-esteem had their depression reduced by social support (Cohen et al., 1986). Results of another study show that older adults participating in social or community activities are more likely to report better health (Sirven & Debrand, 2008). Unsurprisingly, those with stronger social connections tend to live longer than those who do not have those relationships (Holt-Lunstad et al., 2015). Given how important social relationships are to a healthier, longer, and fulfilling life, what are the experiences of people who have less access to social relationships or live with the misconception that they do not desire relationships to begin with?

Autism is a developmental condition characterized by challenges in social functioning and communication, with ranging symptoms, characteristics, and severity (American Psychiatric Association, 2013). Additionally, many individuals with autism may engage in repetitive behaviors (Leekam et al., 2011), avoid eye contact (Hadjikhani et al., 2017), and have alexithymia (i.e., difficulty identifying emotions; Poquérusse et al., 2018). These are only a few examples of "autistic" behaviors that can impact social interactions, as they may be considered socially disruptive by others or incorrectly perceived as evidence of antisocial inclinations from the autistic person. In fact, behaviors of autistic individuals are often described in the literature as signaling less desire for social connections or

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relationships (Jaswal & Akhtar, 2019), but research that centers the experiences of autistic participants provides a different perspective. When asked about their preferences for social interaction and connection, autistic individuals are similar to their neurotypical peers in seeking social relationships that are meaningful and long-lasting (Bargiela et al., 2016; Bauminger & Kasari, 2000; Cresswell et al., 2019; Daniel & Billingsley, 2010; Sedgewick et al., 2019b; Sinclair, 2010). Due to differences in social cognition, autistic people find maintaining, fostering, and navigating these relationships to be challenging (Müller et al., 2008) and subsequently report having fewer friendships than their neurotypical counterparts (Dean et al., 2014). Autistics may have different preferences and approaches to their social relationships, often preferring to connect with others in small groups rather than one-on-one and to share activities rather than engage in emotional bonding via conversation (Calder et al., 2013; Kuo et al., 2013; Orsmond et al., 2004; Petrina et al., 2014). Some research has looked into autistic people's friendships from their own perspective, with results illustrating the need to reconceptualize how autistic friendship is defined to include diverse first-hand experiences (Sosnowy et al., 2019). More research is needed to understand how to effectively support autistic people in developing the types of meaningful social relationships they seek.

How can we most effectively help those with autism find fulfilling and long-lasting relationships? There are many supports available for individuals with autism that aim to strengthen or provide new social skills, improve understanding of social cues, and allow people to have an easier time navigating social expectations and situations. However, not all autistic individuals are identified and diagnosed early enough to receive such programs or supports due to a myriad of reasons, including the phenomenon known as "camouflaging." Camouflaging has been described as the conscious and/or unconscious mimicry of neurotypical behaviors (Bargiela et al., 2016) that otherwise would not come naturally to the individual, which can lead to that person experiencing delays in receiving an autism diagnosis and thus remaining unsupported. Autistic women in particular experience camouflaging at a higher rate than their male counterparts (Cassidy et al., 2018; Hull et al., 2020; Lai et al., 2017; Schuck et al., 2019). Societal expectations of women (Cage & Troxell-Whitman, 2019; Dean et al., 2017) as well as diagnostically unaccounted-for differences in female presentation of autism (Dean et al., 2014) may also be contributing factors. This greater propensity for camouflaging may partially explain why women often receive autism diagnoses later in life (Begeer et al., 2013; Lehnhardt et al., 2016). In addition to delayed diagnosis and less access to supports, camouflaging can also have a negative impact on friendship and relationship formation for autistic individuals. Camouflaging can lead the autistic person to feel that their friendships and relationships are less genuine and that their social partners lack an accurate understanding of who they truly are (Hull et al., 2017). Many autistic individuals report that camouflaging affects their feelings of closeness to their friend or social partner (Hull et al., 2017), illustrating the potential negative impact of masking on friendship formation and development.

There is evidence to suggest that autistic people interact in a way best understood by other autistic people compared to neurotypicals (Crompton et al., 2020b) who may struggle to understand the autistic person's social cues and mental states (Edey et al., 2016; Sheppard et al., 2016). As a result, the friendships of autistic and neurotypical people may face challenges with mutual empathy in the sense that a neurotypical individual may struggle to understand an autistic individual's viewpoint and vice versa (Milton, 2012). This is not to say there is a lack of empathy on either person's side. Instead, this dilemma may be attributed to the double empathy theory (Milton, 2012), which posits that having different neurological and life experiences can make autistic and neurotypical individuals' understandings and *knowledgeable* empathy of each other more difficult. Milton notes that autistic individuals may have the empathetic advantage as they are more exposed to neurotypicals' viewpoints: "... many autistic people have indeed gained a greater level of insight into (non-autistic) society, and more than vice versa, perhaps due to the need to survive and potentially thrive in a (non-autistic) culture" (Milton, 2012, p. 886).

Despite the unique social challenges and societal stigma that autistic individuals face, friendship is desired, beneficial, and *possible* for them. Both autistic and non-autistic people can receive the same benefits and protective factors from healthy friendship, and autistic people should be given the extra support needed to increase their opportunities to connect with others in their own way and to promote satisfaction within their friendships.

The chapter that follows reviews the literature on autistic individuals' social relationships across childhood, adolescence, and adulthood. We review different types of social relationships (e.g., siblings, friends, romantic partners) across the lifespan for autistic individuals. In each section, we focus on autistic women's social relationships in particular, because there is less known about their experiences and unique dynamics when it comes to diagnosis and relationships. After reviewing the literature on social relationships across the lifespan for autistic individuals, we briefly examine the impact of social camouflaging on relationships, mental health, and loneliness, which are all interconnected. We examine extant interventions that aim to support the social relationships of autistic individuals and point to gaps in available treatment and research. Finally, we conclude with implications for future research and social relationship interventions.

Family Relationships

The Role of Family Support

Positive relationships with family are important for well-being across one's lifespan (Merz et al., 2009; Umberson & Montez, 2010). Due to the long-lasting duration of many family relationships, family members may have a larger impact on an individual's life than friends and/or intimate partners. In fact, the quality of family relationships is a greater predictor of aging health than the quality of intimate partnerships (Woods et al., 2020). While high-quality friendships contribute to an individual's well-being, friendships may not completely replace the benefit gained from positive family relationships. Even among individuals with a highly positive friend relationship, more positive familial relationships were associated with better health and self-esteem (Fuller-Iglesias et al., 2013). This may be because long-lasting friendships, as well as intimate relationships, are often dependent upon the emotional content of the relationship, whereas familial relationships and support may be less conditional. In this way, family relationships may play a unique and more constant or enduring role in an individual's social support system.

The stability of familial relationships can be particularly supportive for those who may struggle with social communication skills, which is often the case for people with autism. Autistic individuals often have difficulty understanding others' emotions and navigating the complex social milieu of friendships. These include challenges in interpreting social cues (Jellema et al., 2009; Morrison et al., 2019), identifying emotions on faces (Baron-Cohen et al., 1997), tone of voice (Golan et al., 2007), sarcasm (Persicke et al., 2013), and social mistakes (Baron-Cohen et al., 1999). These findings illustrate some of the difficulties autistic individuals may have in regard to navigating complex social cues and emotions. Familial relationships may therefore be particularly important in the life of an autistic person for their lesser foundation on emotional value and exchanges compared to other relationships. Fostering relationships that typically do not require as steep emotional prerequisites for support to be provided, family members become an essential and impactful resource for autistic individuals who struggle with emotional aspects of relationships. Given that individuals with autism experience more physical and mental health challenges (Graham Holmes et al., 2020) and greater loneliness than their non-autistic peers (Ee et al., 2019), family support is critical.

In particular sibling relationships are often an individual's longest-lasting family relationship because of co-occurring lifespans. Siblings (especially older siblings) offer a social example to their autistic siblings that can be beneficial in developing social skills and potential friendships (Ben-Itzchak et al., 2019; Rum et al., 2021). Beyond the scope of this chapter, an emerging area of research is on social skills development of autistic children from sibling relationships. Across both future research and interventions in this area, more self-reporting from autistic children about their experiences and relationships is sorely needed, as much of the current literature only takes into account parental and non-autistic sibling views and perspectives.

Summary and Future Directions

Familial relationships can serve as substantial sources of social support for autistic individuals across the lifespan. Having siblings confers an advantage for autistic individuals, especially those who have older siblings. The presence of a sibling provides autistic children with multiple advantages such as greater prosocial practice and behaviors, a larger family network of support, and potential long-lasting friendship. More longitudinal studies that examine how different types of family relationships change across time are especially needed, as they may point to meaningful periods when intervention would be most efficacious. Finally, significant efforts toward measuring inclusive samples for future studies must be made for the following populations: minority, lower-income, nonverbal, and women.

Friendships

Friendships are important to both autistic people and neurotypicals alike, though the former may experience different and additional challenges when it comes to forming and maintaining such relationships (Mazurek, 2014). When examining the peer relationships of individuals with autism, it is critical to consider the role of gender and age. The friendships of autistic women, in particular, are grossly understudied. However, the limited research on this topic suggests that there are notable differences in socialization and autism presentation across an autistic female's lifespan compared to autistic males that are significant to autistic females' social network quality, their reality of belated diagnosis, and mental health challenges related to camouflage. These unique distinctions play a significant role and should be factored into future interventions and supports for better and more effective outcomes for autistic women's social lives and their quality of life. This section will describe the friendships of autistic children, adolescents, and adults, with a special focus on gender differences at each of these developmental stages.

Understanding Autistic Friendships and Loneliness: Childhood

Friendships are an integral contributor to a child's social development. For example, having more friends is correlated with greater child prosocial skills (Gest et al., 2001; Ladd, 2005). Children's social play behavior and language skills can also improve with increased social interactions with peers (Rogers, 2000; Wolfberg & Schuler, 1993). Social play behavior and language skills have been shown to predict higher academic achievement and less risk of later adjustment problems (Brendgen et al., 2005; Middleton et al., 1986). Therefore, the presence and quality of friendships in a child's life can have a lasting impact on their development across time.

Autistic children without co-occurring intellectual disability report interest in having friends (Bauminger & Kasari, 2000) and in socializing with their peers (Bauminger et al., 2008). Like neurotypical children, autistic children prefer to and mostly socialize with same-gender friends (Dean et al., 2014). Compared to their non-autistic counterparts, autistic children tend to have fewer friends (Taheri et al., 2016), less reciprocated friendships (Rotheram-Fuller et al., 2010), and friendships of a lower quality (Bauminger & Kasari, 2000). On average, autistic children often report feeling greater loneliness compared to their non-autistic peers while also having a less complete understanding of loneliness during childhood (Bauminger & Kasari, 2000). As Bauminger and Kasari (2000) noted in their study, this experience of loneliness importantly indicates both a motivation for having social relationships and recognition of the value of friendships by the autistic child, but their interpretation of loneliness is also unique. Two types of loneliness were identified by children in the study: (1) emotional loneliness (feelings of sadness and emptiness) and (2) social cognitive loneliness (lack of an available social group, social exclusion, or being alone). Autistic children mostly defined loneliness as being alone, while non-autistic children defined loneliness as both being alone and feeling sad (Bauminger & Kasari, 2000). Autistic children may therefore understand loneliness by comparing their social experiences to others or by reflecting on their own past social experiences (tactics not requiring emotional evaluation or understanding), which indicates autistic children may conceptualize loneliness through a purely social cognitive lens (Bauminger & Kasari, 2000).

Despite their apparent lesser quantity and quality of friendships, both autistic children and their selected friends (with or without ASD) report high levels of friendship satisfaction (Petrina et al., 2017). Autistic and neurotypical groups of mental-aged matched children have similar expectations for their friendships, with one exception: the autistic group has more expectation that their friendships will include expressing care for one another (Bottema-Beutel et al., 2019). Thus, in many ways, autistic children have the same general expectations for their friendships as neurotypical children, even if they may conceptualize the experience of loneliness, or lack of friendship, differently. Future research should expand knowledge on differences in children's actual and self-perceived friendship quality, loneliness, and the association between expectations and friendship quality for autistic children as well as develop tools to help autistic children better understand and self-identify the emotional dimension of loneliness.

While acknowledging the myriad benefits of social interactions for autistic children, it is important to remember the child's individual needs as well. There are times when they may genuinely want something different from socializing or to be alone, although one must consider developmental considerations of children's understanding. Results of a study showed that adults were active in supporting their autistic children's friendships, but this could sometimes contradict with the children's desires (Calder et al., 2013). Autistic individuals' perspectives on their friendships and goals are needed and should be included when deciding the methods and timing of intervention.

Gender Differences in the Friendships of Autistic Children

Both autistic male and female children tend to have fewer relationships and higher social exclusion compared to their neurotypical same-gender counterparts (Dean et al., 2014). In comparison to autistic male children, autistic female children often have more friends than autistic boys (Dean et al., 2014). This discrepancy may be partially due to autistic girls often experiencing less "visible" social exclusion compared to their male counterparts. Autistic girls often experience being "socially overlooked," and their social rejection is at times less recognized as they may physically be near peers but not engaging or interacting with the group, whereas autistic boys often experience more overt social rejection resulting in physical isolation from peers, which may be easier to visually identify in social spaces (Dean et al., 2014, 2017). Another contributing factor is the implication that female children with autism may have more developed social skills than male children with autism, visible in their higher scores on the Friendship Questionnaire, albeit still less so than their neurotypical counterparts (Head et al., 2014). Future research should seek to deepen understanding on the aspects of the female social landscape that allows the social challenges of many autistic girls to go overlooked. Studies should also prioritize including self-report from autistic girls in relation to their social experiences and preferences in their friendships. As there are impactful gender differences in presentation among the autistic population, the aim should be to develop better criteria and tools for diagnosing autism among female and nonbinary gender groups and supporting individuals accordingly.

Understanding Autistic Friendships: Adolescence

As autistic children enter adolescence, they face a myriad of new "unwritten" rules that govern social interactions and exchanges. In entering this new developmental stage, friendships become increasingly important and impactful, and securing and maintaining friendships can become increasingly challenging for many. Research conducted with autistic adolescents reports that many young people experience both greater loneliness and poorer friendship quality than their non-autistic counterparts (Locke et al., 2010). Additionally, while both adolescents and children with ASD have reported higher levels of loneliness compared to ADHD and nonclinical control groups, this difference did not become statistically significant until adolescence, when desires for social interactions also increased (though still lower than other groups; Deckers et al., 2017). Autistic adolescents' higher levels of reported loneliness compared to non-autistic individuals and younger autistic children may be reflective of the increased social demands of adolescence as well as the increased importance of peers during this time. Adolescence presents a new social landscape, one in which many choose to spend a significant amount of time socializing and talking to friends (Larson & Seepersad, 2003; Raffaelli & Duckett, 1989). Yet many autistic adolescents appear to spend more time performing solitary activities and less time doing social activities than their neurotypical peers (Orsmond & Kuo, 2011). Results of the same study also showed that, when not alone, autistic adolescents spend the most time in the company of their parents or paid professionals (Orsmond & Kuo, 2011). Some autistic adolescents may not have substantial opportunities to interact with their peers or may choose to spend more time with family or alone due to social anxiety or other factors (Orsmond & Kuo, 2011). Social anxiety and behavioral avoidance may increase with age among autistic adolescents but decrease with age among neurotypical adolescents (Kuusikko et al., 2008). All these factors may play a role in autistic adolescents' abilities to seek out and establish friendships. The notable increase in social anxiety and avoidant behaviors may be especially detrimental to friendship opportunity, and future programs and interventions should buffer and strengthen supports in these target areas during adolescence. Secondly, social skills training, when desired by the adolescent, can help them connect and secure relationships with peers and feel less alone.

Gender Differences in the Friendships of Autistic Adolescents

Research suggests that autistic adolescent females may be, on average, more socially motivated than their autistic male counterparts (Sedgewick et al., 2016). Autistic adolescent girls report finding social interactions to be both important and difficult (Cook et al., 2018; Foggo & Webster, 2017), and they most frequently have conversations with their friends rather than participating in shared activities like their autistic male peers (Kuo et al., 2013). Similar to their neurotypical agemates, many autistic female adolescents report having one or two close friends and desire friends who are trustworthy, supportive, and respectful (Foggo & Webster, 2017). In contrast to their neurotypical female counterparts, autistic young women tend not to have a wider circle of casual friends (Sedgewick et al., 2019b). In particular, managing disagreements and adapting to changing social situations are two elements of friendship that autistic girls report struggling with the most, making them conflict avoidant (Foggo & Webster, 2017; Sedgewick et al., 2019b). These specific challenges with friendships may explain why autistic female adolescents report more relational conflict in their friendships compared to both autistic male adolescents and neurotypical adolescents of all genders (Sedgewick et al., 2016). In a study interviewing ten females diagnosed with autism, participants reported that building and maintaining friendships became increasingly difficult during adolescence, prompting them to use camouflaging strategies (e.g., masking and imitation) to manage social situations (Tierney et al., 2016). These firsthand descriptions suggest that adolescence is a transition point into the use of *intentional and self-aware* camouflaging for some autistic females. For these reasons, all autistic adolescents (including autistic young women in particular) may benefit from support around conflict resolution and general relationship management skills during this developmental stage. These skills will be fundamentally helpful as these adolescents seek out and maintain their friendships. The use of coping strategies such as camouflaging in the face of social challenges should also be assessed in this period for every individual. Interventions and supports should equip adolescents with alternative coping techniques beyond camouflaging and have systems in place to protect against the potential adverse impact of camouflaging on autistic adolescents' mental health.

Understanding Autistic Friendships: Adulthood

Autistic adults generally have fewer reciprocated social relationships (Orsmond et al., 2013) and a greater desire for more friends (Finke et al., 2019) compared to the general population. Many autistic adults report that they find their relationships with neurotypicals to be less comfortable than their friendships with other neurodivergent people (Crompton et al., 2020a; Sosnowy et al., 2019). This preference for friendships with other fellow autistic adults may be attributable to the double empathy theory (Milton, 2012), which posits that it may be difficult for both neurotypical and neurodivergent people to understand and have empathy toward individuals with different neural landscapes and thus different experiences of the world. Autistic adults tend to be perceived more negatively than their neurotypical peers during first impressions (Cage & Burton, 2019; Sasson et al., 2017). Though interestingly, these first impressions became more positive when autistic individuals were labeled as having autism, implying a possible positive impact of diagnosis disclosure when creating first impressions (Sasson et al., 2017). Future studies should examine the relationship between diagnostic disclosure and friendship formation as well as measure the impact of stigma in both the presence and absence of disclosure of autism.

Gender Differences in the Friendships of Autistic Adults

As for the gender differences of autistic women's friendships, interestingly, they report experiencing boosted happiness and confidence in their adult relationships compared to adolescence (Sedgewick et al., 2019a). Autistic females tend to have friendships based on emotional sharing like neurotypical women (Kuo et al., 2013) but are more likely to prefer greater physical distance from conversation partners and/or friends compared to non-autistic women (Finke et al., 2019). Similar to autistic adolescents, autistic female adults face unique social landscape challenges, including more subtle social cues and female peers who may be less accepting of social mistakes and differences (Bargiela et al., 2016). When it comes to first impressions, autistic women are rated as having a better first impression than autistic adult males (Cage & Burton, 2019; Sasson et al., 2017), which perhaps could give them a slight advantage in friendship formation. Further studies are needed to assess what role, if any, first impressions play on friendship formations for autistic female-identifying adults.

Ultimately, the forming of friendships and other social relationships is critically important to most autistic people, both developmentally and emotionally. Yet many autistic individuals, adult and youth alike, struggle with creating and navigating friendships and so would benefit from social supportive programming. Despite challenges with friendship interactions, autistic individuals have unique social needs just as their neurotypical counterparts do. Future research in this area could examine the unique struggles and experiences of autistic females in relation to conflict, and social support programs should provide specific tools that help autistic women navigate the expectations and nuances of the female social landscape. Importantly, many autistic individuals identify with a more expansive gender expression beyond "female" or "male." Although recent research has begun to explore the experiences of gender nonconforming and/or gender diverse autistic individuals (Strang et al., 2018, 2019), much more research is needed in this area, particularly research that includes trans and gender diverse individuals in the research process. Finally, because of the substantial variance across autistic individuals, it is important that social programs and interventions attempt to understand and incorporate the unique experience of the person with whom they are working. Events and supports should be tailored to the unique needs of the autistic people they intend to serve—and to do so, programs would benefit from partnering with their local autistic adolescent and young adult communities to learn about the types of social programming they seek.

Romantic Relationships

Contrary to early research that conflated autism's challenges in social-emotional expression with romantic apathy and asexuality of persons with autism, it is the modern consensus that most individuals with autism are interested in securing intimate romantic relationships (Bennett et al., 2018; Byers et al., 2013; Hancock et al., 2020; Haracopos & Pedersen, 1992; Kellaher, 2015; Strunz et al., 2017). Furthermore, studies show no noticeable difference in the sexual interests of females (Pecora et al., 2019) or males (Dewinter et al., 2015) with autism when compared to their neurotypical, same-gendered counterparts. There are a myriad of possible health benefits that result from the presence of positive romantic relationships (Grewen et al., 2003; King & Reis, 2012). Positive romantic relationships and mental health also can promote each other, yet relationships have a stronger impact on mental health than vice versa (Braithwaite & Holt-Lunstad, 2017). And for autistic people, who on average have higher rates of both medical and psychiatric diseases than the general population (Croen et al., 2015), experiencing loving romantic relationships could be a possible protective factor for their quality of life and well-being.

Autistics and neurotypicals alike desire fulfilling, meaningful romantic relationships. When asked to describe important features of their romantic relationships, adults with ASD and those without ASD mention similar elements, including the presence of communication, self and mutual respect, sharing, and similarity, and that maintaining and strengthening a relationship is a work in progress (Sala et al., 2020). Although there are many common elements to the desired relationships of autistic and neurotypical adults, there are also some important differences.

Individuals with ASD report a need for direct and concise communication from their partners, whereas neurotypicals place less emphasis on explicit communication and more on body language (Sala et al., 2020). Additionally, many autistic individuals report that having partners that experience similar challenges or lived experiences (e.g., being autistic, neurodiverse, having social anxiety) helps them relate to their partner, whereas these shared experiences are seemingly less essential or important to neurotypicals (Sala et al., 2020). Research shows that autistic individuals who have partners who also have ASD report greater relationship satisfaction than those with neurotypical partners (Strunz et al., 2017). This finding may be explained by autistics' preferences for direct communication, which may contradict neurotypical expectations for more subtle flirting behavior (e.g., innuendo, body language). At the same time, some neurotypical partners may relish the directness of their autistic partners as it stands in contrast with the indirect communication practiced in many dating experiences (Hode, 2014). Although there are many important contributors to the success of romantic relationships, it may be critical for many with ASD to find relationships with those that can best understand their lived experience.

For some autistic individuals, finding potential romantic partners and entering an intimate relationship can be anxiety-provoking and stressful. Many individuals with ASD report having less opportunities and greater anxiety to meet potential partners, having shorter relationship spans, and experiencing greater concern over their ability to build and sustain future relationships (Hancock et al., 2020). The association between relationship difficulties and ASD diagnosis is partly explained by differences in peer social engagement (Hancock et al., 2020). Research in this area suggests that autistic individuals may have difficulty engaging with their peers due to differences in social skills, preferences, and anxiety (Chang et al., 2012). Fewer opportunities to meaningfully engage with peers may contribute to challenges in finding a well-matched potential partner. As a result, programs that seek to support the relationship development of autistic individuals should consider ways to build social self-confidence and increase opportunities for peer interaction.

The Role of Camouflage in Loneliness, Depression, and Friendships in Autism

Within the realm of friendships, camouflaging (or masking of autistic traits to conform to neurotypical standards) and resultant mental health concerns can exacerbate the already isolating social experiences of many autistic individuals, particularly for girls and women (Cassidy et al., 2018; Hull et al., 2020; Lai et al., 2017; Schuck et al., 2019). As a population, many autistic people already have fewer friendships with less reciprocity, which can directly lead to greater rates of loneliness (Mazurek, 2014). Social difficulties are related to higher rates of mental health challenges among autistic adults (Dow et al., 2021), and depression may be a byproduct of one's inability to get their social needs met and form close relationships (Smith & White, 2020). Camouflaging may mediate or explain the relationship between social stressors and mental health issues like depression and anxiety for autistic people (Cage et al., 2018).

Individuals with autism are four times more likely than their neurotypical counterparts to have depression in their lifetime (Hudson et al., 2019); and females with autism experience anxiety and depression statistically more often than males (Lai et al., 2019; Mandy et al., 2012; Oswald et al., 2016; Solomon et al., 2012). More camouflaging of one's autistic traits is associated with lower sense of belonging and a greater risk of lifetime suicidality (Cassidy et al., 2020). Taken together, these studies show the impact of camouflaging on mental health outcomes and the pervasive psychological challenges that many autistic individuals face. To support autistic individuals' mental well-being and the development of supportive friendships, existing social skills programs should consider the mental toll of camouflaging. Current programs should also be modified to take into consideration the method by which individuals with autism are asked to "adapt behaviorally to neurotypical standards" and whether it is worthwhile to the individual in question and their mental well-being. Greater screening efforts for depression and other mental health challenges among the autistic population are needed, and we need to increase opportunities for autistic individuals to connect with neurodivergent communities in which they can be their truest selves.

Access to a community that autistic individuals can identify with (and the social relationships and better self-understanding it offers) can be delayed by camouflaging and subsequent missed diagnosis. For autistic women in particular, a missed autism diagnosis often denies them the opportunity to connect to an inclusive and supportive network of neurodivergent or likeminded individuals (Bargiela et al., 2016). Undiagnosed autistic women are more likely to attribute their social challenges to their personal flaws (inspiring negative self-concept and isolated feelings) rather than traits they have in common with the autistic community (Hickey et al., 2018; Hurlbutt & Chalmers, 2002; Kanfiszer et al., 2017; Leedham et al., 2020; Portway & Johnson, 2005; Webster & Garvis, 2017). Earlier diagnosis and increasing opportunities for social connection that do not pressure camouflaging would be beneficial to both autistic individuals' mental health and social fulfillment.

Interventions and Supports for Friendships and Social Relationships in Autism

Evidence-based programs designed to support the social relationships of autistic individuals are limited. When it comes to friendship skills specifically, the Program for the Education and Enrichment of Relational Skills (PEERS) remains one of the only widely available evidence-based friendship training programs for adolescents and adults with autism (Yamada et al., 2020). Adolescents enrolled in PEERS show significant improvements in self-reported social skills knowledge and social responsiveness; however, data on whether or not individuals acquire friendships or maintain those relationships is unknown. There have been several trials evaluating the PEERS program with participants aged 11–17 (Laugeson et al., 2009, 2012; Schohl et al., 2014; Yoo et al., 2014) and 18–24 (Gantman et al., 2012; Laugeson et al., 2015; McVey et al., 2016), all showing improvements in social skills knowledge, but no data on friendships per se. Results of a small pilot study also showed PEERS to be effective within a community setting (Hill et al., 2017). The PEERS program continues to be widely adopted both within and outside the United States using the same outcome measures on self-reported social skills knowledge (Yamada et al., 2020).

Other social skills programs have also been demonstrated to be effective, and many have been implemented in community settings, such as schools. Remaking Recess is an intervention that has been situated in schools and shown improvements in peer engagement and connections to peers based on peer report, teacher report, and observations at school (Kretzmann et al., 2015; Shih et al., 2019). In these studies, autistic students indicate other students in their classrooms who are their friends and get reports from their classmates as to whether they are their friends. Reciprocity in friendships can be tracked. Other school-based social skills interventions also offer support in the school setting for the development of peer relationships and reciprocity of friendships (Kasari et al., 2016). In most cases, reciprocity of friendships has not been improved as a result of interventions, but more friend nominations from classmates have been found from neurotypical students to autistic students. It may be that autistic students have a harder time recognizing the friend potential of other students in their classes (Kasari et al., 2012).

Future intervention efforts must consider the heterogeneity of autism, and programs that offer individualized supports may be most impactful. For both behavioral and pharmaceutical treatment approaches, a greater use of objective measures of treatment response (e.g., biomarkers) may lead to a greater understanding of autistic subgroups, leading to personalized treatment options (Masi et al., 2017). A recent systematic review of group social skills interventions highlights other gaps where future treatment efforts should be focused. Many existing intervention approaches have substantial limitations, including potential publication bias exaggerating true effects, small effects reported by parents and no effects reported by teachers, and improved social knowledge, not behavior, being the source of self-reported effects (Gates et al., 2017). For future research, more large and well-controlled studies using greater scope of outcome measures should be conducted to uncover how effective social skills interventions may be and for whom they are most supportive. Additionally, while group interventions have their place, more personalized intervention approaches (in general and for social skills) that account for the heterogeneous nature of autism ought to be developed and examined.

Interventions Targeting Social Anxiety: Cognitive Behavioral Therapy Approaches

Social anxiety is a significant barrier to socialization for individuals with autism, and thus several socially focused intervention approaches aim to provide supports around anxiety. In children with autism, greater social anxiety is associated with lower assertive and responsible social skills

(Chang et al., 2012). Because social anxiety can contribute to additional social challenges among children with ASD, it should be a common target for intervention. Both standard cognitive behavioral therapy (CBT) and especially CBT adapted for autism (e.g., Behavioral Interventions for Anxiety in Children with Autism; BIACA) are effective in reducing parent-reported anxiety symptoms (Wood et al., 2020). Similar results have been found regarding the impact of CBT that targets anxiety for adolescents and adults. For example, the Multimodal Anxiety and Social Skills Intervention (MASSI) program targeted co-occurring anxiety and social skills challenges through individual therapy, group sessions, and parent coaching (White et al., 2013). For adults with ASD (i.e., 18 males), participation in group CBT for social interaction anxiety was found to decrease both anxiety and avoidance of social situations post-intervention, with participants' feedback being generally positive (Spain et al., 2017). Additionally, results of modified CBT for social anxiety and social functioning in young adults with ASD showed overall positive outcomes, most notably decreased social anxiety symptoms, increased social motivation, and less restricted interests and repetitive behaviors along with strong satisfaction with the program by participants (Bemmer et al., 2021). While reduction in social anxiety may ultimately benefit the greater development of friendships and even romantic relationships for autistic individuals, friendships have not been an outcome of these studies.

Social Programming for Autistic Women

In line with the idea of interventions targeting subgroups within autism, female-targeted interventions and supports that deliver social skills training would be an important resource for girls, given the gender-specific experiences within and outside of autism. However, there are very few programs for social skills available for girls, with even less evidence to assess their efficacy. One such program is Girls Night Out, a social skills and self-care program at the University of Kansas Medical Center tailored to support girls and young women (10–19 years old) with autism. A recent study (i.e., Jamison & Schuttler, 2017) was the first of its kind to evaluate Girls Night Out, which supports autistic females across 4 years. Results showed that the Girls Night Out program produced significant increases in self-reported social competence, self-perception, and well-being for participants (Jamison & Schuttler, 2017). While this is promising for developing future gender-specific intervention models supporting social skills and relationships for women, it is important to note that the Girls Night Out program is costly ($500 for 8–10 weekly 2-h sessions for kids; $600 for 10–12 weekly 2-h sessions for teens), which limits its access to those who can afford it. It is critical that social support programs are equally accessible to all who may desire to enroll, especially to autistic individuals that are economically disadvantaged.

Another notable social program for autistic women (15–60 years old) is "Under Our Wing." This program is unique in that it both is a peer-led mentoring project and is designed by autistic women. Features included training in mentoring skills, networking, business start-up, creativity, information technology skills, self-care, confidence, and team building. While there is no published evidence of its efficacy, there is an ongoing third-party evaluation by Yolanda Gibb from Durham University. The "Under Our Wing" program and other peer-led social programs need more testing using rigorous research designs (e.g., randomized controlled trials) in order to assess their efficacy and effectiveness in improving social outcomes for autistic individuals and particularly improvement in social relationships such as friendships. Preliminary results of the current evaluation show that a majority of participants reported increased confidence, better sense of self and identity, and self-esteem (Stewart, 2019). These preliminary results are an important first step, but additional studies are needed to assess the program's ability to impact desired outcomes and particularly relationships with others.

A paper presented at the International Society for Autism Research (INSAR) conference underscores the need for social programs that promote self-determination skills and autism identity, which correlate with physical and mental health and quality of life (McDonald et al., 2019). Indeed, this peer-led model seems to reflect the value and need for autism experts. Findings of a survey showed that autistic participants had greater scientific knowledge on autism, were more likely to describe autism experientially or neutrally, and reported lower stigma along with their family members, implying that adults with autism should be recognized as autism experts and involved more in autism research as partners (Gillespie-Lynch et al., 2017). Similar to the structure of "Under Our Wing," autism experts should be helping in both developing and facilitating social skills interventions.

In summary, many more programs for females with autism as well as studies on these women's outcomes and experiences are needed to determine the efficacy of gender-specific programs. And finally, more autistic peer-led programs (in general and for women specifically) should be created to offer peer support for mental health and well-being for a group at well-known risk of poorer mental health.

Conclusion

Friends

While most individuals with ASD express a desire for friendships, their experience with friendships overall is lacking when compared to the general population and may often be qualified as more isolating, lonely, and confusing. Besides a similar preference for same-gendered friends, there are also pertinent gender differences in social expectations and socialization for autistic individuals, with autistic boys' and girls' social experiences aligning more closely with their same-gendered neurotypical counterparts. For example, females are tasked with navigating the nuanced nature of girls' social "rules," while male friendships are often based around shared activities. Autistic women often struggle with relational conflict, which can lead to difficulties in their friendships. Autistic adult women's experiences with relationship satisfaction undergo a transition across the life course with high levels of friendship satisfaction reported in childhood, lower satisfaction in adolescence (a difficult period of great change and increased social and self-awareness), and reported notable improvements in relationship satisfaction as adults (likely having learned from prior social and relationship experiences).

Romantic Partners

Autistic people's needs for social relationships extend beyond friendships to romantic relationships as well, seeking most of the same things in romantic relationships as neurotypicals, but with a greater preference for direct communication with partners. Again, they also face similar issues of less relationship experiences (often of shorter duration), greater loneliness, and fewer relationship opportunities. As was also true for friendships, adolescents and adults of both genders on the spectrum express more satisfaction in romantic relationships with other neurodivergent individuals as they can relate more to their partner—something that can be explained by the double empathy theory. Diverse gender identities and sexual orientations are common among the autistic population, especially for autistic females, which necessitates improved LGBTQ+ inclusive sexual education that is adapted for individuals with ASD.

Mental Health Related to Social Relationships

When discussing the social lives of autistic people, the role of their mental health (both an acting influence and potential byproduct of their social relationships) cannot be ignored. There are many notable mental health comorbidities with autism, including depression, anxiety, and suicidality. Camouflaging may be experienced by all individuals with autism, but it is more likely among females because of multiple interrelational factors. For example, female socialization has different demands that promote the need for camouflaging, autistic females often have greater social motivation, and society may perceive women with autistic behaviors differently than men. One significant consequence of camouflaging is postponed or lack of an autism diagnosis, which strips affected individuals from clinical supports, stronger self-identity, and a greater autistic community and social network of like-minded peers.

Social Skills and Interventions

It is clear that group social skills training interventions can help autistic individuals improve their social knowledge and overall social skills and communication, proving to be a steppingstone to greater opportunities and relationships. However, most intervention programs do not measure change in friendships or relationships other than parent report. While school-based interventions report more peer connections as a result of intervention, specific change in friendship reciprocity is harder to obtain (Kasari et al., 2012, 2016; Shih et al., 2019). Additionally, girls may benefit greatly from peer groups focusing on their gender-specific needs. The integration of autism expertise (from autistic individuals themselves) in interventions and programs is critically needed.

Evident Gaps and Areas for Future Research

Mental Health/Camouflage: Research and Services

Perhaps one of the greatest gaps in the development of friendship relationships is failure to examine mental health needs and, vice versa, how friendship difficulties may exacerbate mental health issues. Despite autistic individuals' high susceptibility to mental health risks (e.g., depression, anxiety, suicidality), modern mental health services do not adequately discover or diagnose camouflaged individuals with autism. Camouflaging or "masking oneself" (i.e., disguised behaviors for better social outcomes) also contributes to poor mental health in this population, and more services need to address both its impact on social ability and the nature of interventions that utilizes training "to behave more neurotypically." In this way, greater propensity for camouflaging may also contribute to autistic women's larger rates of mental health issues. Better training and diagnostic measures to "find" camouflaged individuals as well as emphasis on providing autism-safe social opportunities for connecting with others without a need to camouflage one's autistic traits should be implemented (for more rewarding socialization and relationships).

Social Skills Training and Interventions

When it comes to social skills training and relationship supports to help autistic individuals navigate socially, group social skills interventions are common, but more evidence of their efficacy is needed especially as related to relationship outcomes. Programs specifically catering to autistic women and their specific issues are few, but recent examples (i.e., Under Our Wing) show promise for a peer-led mentoring model. Greater options for interventions would prove beneficial, as well as having more developed and enacted using autistic expertise (via individuals who themselves have autism), and a focus on friendships or relationship quality as an outcome.

Overarching Demographics Gap

While there has been a recent increase in studies focused on autistic women, there is still more that needs to be researched, particularly around camouflaging and how to not miss girls who could utilize supports they would otherwise miss never being diagnosed. Research also pools from overwhelmingly White participants, those without intellectual disability, and those with middle-to-high incomes, which does not accurately reflect the autistic population's demographics. There needs to be more inclusive studies on minority populations in general and minority women specifically who are disadvantaged by a lack of studies that reflect their needs and identify relevant supports.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Association. https://doi.org/10.1176/appi.books.9780890425596

Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders, 46*(10), 3281–3294. https://doi.org/10.1007/s10803-016-2872-8

Baron-Cohen, S., Jolliffe, T., Mortimore, C., & Robertson, M. (1997). Another advanced test of theory of mind: Evidence from very high functioning adults with autism or Asperger syndrome. *Journal of Child Psychology and Psychiatry, 38*(7), 813–822. https://doi.org/10.1111/j.1469-7610.1997.tb01599.x

Baron-Cohen, S., O'riordan, M., Stone, V., Jones, R., & Plaisted, K. (1999). Recognition of faux pas by normally developing children and children with Asperger syndrome or high-functioning autism. *Journal of Autism and Developmental Disorders, 29*(5), 407–418. https://doi.org/10.1023/A:1023035012436

Bauminger, N., & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child Development, 71*(2), 447–456. https://doi.org/10.1111/1467-8624.00156

Bauminger, N., Solomon, M., Aviezer, A., Heung, K., Gazit, L., Brown, J., & Rogers, S. J. (2008). Children with autism and their friends: A multidimensional study of friendship in high-functioning autism spectrum disorder. *Journal of Abnormal Child Psychology, 36*(2), 135–150. https://doi.org/10.1007/s10802-007-9156-x

Begeer, S., Mandell, D., Wijnker-Holmes, B., Venderbosch, S., Rem, D., Stekelenburg, F., & Koot, H. M. (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(5), 1151–1156. https://doi.org/10.1007/s10803-012-1656-z

Bemmer, E. R., Boulton, K. A., Thomas, E. E., Larke, B., Lah, S., Hickie, I. B., & Guastella, A. J. (2021). Modified CBT for social anxiety and social functioning in young adults with autism spectrum disorder. *Molecular Autism, 12*(1), 1–15. https://doi.org/10.1186/s13229-021-00418-w

Ben-Itzchak, E., Nachshon, N., & Zachor, D. A. (2019). Having siblings is associated with better social functioning in autism spectrum disorder. *Journal of Abnormal Child Psychology, 47*(5), 921–931. https://doi.org/10.1007/s10802-018-0473-z

Bennett, M., Webster, A. A., Goodall, E., & Rowland, S. (2018). *Life on the autism spectrum: Translating myths and misconceptions into positive futures*. Springer. https://doi.org/10.1007/978-981-13-3359-0

Bottema-Beutel, K., Malloy, C., Cuda, J., Kim, S. Y., & MacEvoy, J. P. (2019). Friendship expectations may be similar for mental age-matched children with autism spectrum disorder and typically developing children. *Journal of Autism and Developmental Disorders, 49*(10), 4346–4354. https://doi.org/10.1007/s10803-019-04141-7

Braithwaite, S., & Holt-Lunstad, J. (2017). Romantic relationships and mental health. *Current Opinion in Psychology, 13*, 120–125. https://doi.org/10.1016/j.copsyc.2016.04.001

Brendgen, M., Wanner, B., Morin, A. J., & Vitaro, F. (2005). Relations with parents and with peers, temperament, and trajectories of depressed mood during early adolescence. *Journal of Abnormal Child Psychology, 33*(5), 579–594. https://doi.org/10.1007/s10802-005-6739-2

Byers, E. S., Nichols, S., Voyer, S. D., & Reilly, G. (2013). Sexual well-being of a community sample of high-functioning adults on the autism spectrum who have been in a romantic relationship. *Autism, 17*(4), 418–433. https://doi.org/10.1177/1362361311431950

Cage, E., & Burton, H. (2019). Gender differences in the first impressions of autistic adults. *Autism Research, 12*(10), 1495–1504. https://doi.org/10.1002/aur.2191

Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of camouflaging for autistic adults. *Journal of Autism and Developmental Disorders, 49*(5), 1899–1911. https://doi.org/10.1007/s10803-018-03878-x

Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders, 48*(2), 473–484. https://doi.org/10.1007/s10803-017-3342-7

Calder, L., Hill, V., & Pellicano, E. (2013). 'Sometimes I want to play by myself': Understanding what friendship means to children with autism in mainstream primary schools. *Autism, 17*(3), 296–316. https://doi.org/10.1177/1362361312467866

Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism, 9*(1), 1–14. https://doi.org/10.1186/s13229-018-0226-4

Cassidy, S. A., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2020). Is camouflaging autistic traits associated with suicidal thoughts and behaviours? Expanding the interpersonal psychological theory of suicide in an undergraduate student sample. *Journal of Autism and Developmental Disorders, 50*(10), 3638–3648. https://doi.org/10.1007/s10803-019-04323-3

Chang, Y. C., Quan, J., & Wood, J. J. (2012). Effects of anxiety disorder severity on social functioning in children with autism spectrum disorders. *Journal of*

Developmental and Physical Disabilities, 24(3), 235–245. https://doi.org/10.1007/s10882-012-9268-2

Cohen, S., Sherrod, D. R., & Clark, M. S. (1986). Social skills and the stress-protective role of social support. *Journal of Personality and Social Psychology, 50*(5), 963. https://doi.org/10.1037//0022-3514.50.5.963

Cole, S. W., Capitanio, J. P., Chun, K., Arevalo, J. M., Ma, J., & Cacioppo, J. T. (2015). Myeloid differentiation architecture of leukocyte transcriptome dynamics in perceived social isolation. *Proceedings of the National Academy of Sciences, 112*(49), 15142–15147. https://doi.org/10.1073/pnas.1514249112

Cook, A., Ogden, J., & Winstone, N. (2018). Friendship motivations, challenges and the role of masking for girls with autism in contrasting school settings. *European Journal of Special Needs Education, 33*(3), 302–315. https://doi.org/10.1080/08856257.2017.1312797

Cresswell, L., Hinch, R., & Cage, E. (2019). The experiences of peer relationships amongst autistic adolescents: A systematic review of the qualitative evidence. *Research in Autism Spectrum Disorders, 61*, 45–60. https://doi.org/10.1016/j.rasd.2019.01.003

Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism, 19*(7), 814–823. https://doi.org/10.1177/1362361315577517

Crompton, C. J., Hallett, S., Ropar, D., Flynn, E., & Fletcher-Watson, S. (2020a). 'I never realised everybody felt as happy as I do when I am around autistic people': A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism, 24*(6), 1438–1448. https://doi.org/10.1177/1362361320908976

Crompton, C. J., Ropar, D., Evans-Williams, C. V., Flynn, E. G., & Fletcher-Watson, S. (2020b). Autistic peer-to-peer information transfer is highly effective. *Autism, 24*(7), 1704–1712. https://doi.org/10.1177/1362361320919286

Daniel, L. S., & Billingsley, B. S. (2010). What boys with an autism spectrum disorder say about establishing and maintaining friendships. *Focus on Autism and Other Developmental Disabilities, 25*(4), 220–229. https://doi.org/10.1177/1088357610378290

Dean, M., Kasari, C., Shih, W., Frankel, F., Whitney, R., Landa, R., Lord, C., Orlich, F., King, B., & Harwood, R. (2014). The peer relationships of girls with ASD at school: Comparison to boys and girls with and without ASD. *Journal of Child Psychology and Psychiatry, 55*(11), 1218–1225. https://doi.org/10.1111/jcpp.12242

Dean, M., Harwood, R., & Kasari, C. (2017). The art of camouflage: Gender differences in the social behaviors of girls and boys with autism spectrum disorder. *Autism, 21*(6), 678–689. https://doi.org/10.1177/1362361316671845

Deckers, A., Muris, P., & Roelofs, J. (2017). Being on your own or feeling lonely? Loneliness and other social variables in youths with autism spectrum disorders. *Child Psychiatry & Human Development, 48*(5), 828–839. https://doi.org/10.1007/s10578-016-0707-7

Dewinter, J., Vermeiren, R., Vanwesenbeeck, I., Lobbestael, J., & Van Nieuwenhuizen, C. (2015). Sexuality in adolescent boys with autism spectrum disorder: Self-reported behaviours and attitudes. *Journal of Autism and Developmental Disorders, 45*(3), 731–741. https://doi.org/10.1007/s10803-014-2226-3

Dow, D., Morgan, L., Hooker, J. L., Michaels, M. S., Joiner, T. E., Woods, J., & Wetherby, A. M. (2021). Anxiety, depression, and the interpersonal theory of suicide in a community sample of adults with autism spectrum disorder. *Archives of Suicide Research, 25*(2), 297–314. https://doi.org/10.1080/13811118.2019.1678537

Edey, R., Cook, J., Brewer, R., Johnson, M. H., Bird, G., & Press, C. (2016). Interaction takes two: Typical adults exhibit mind-blindness towards those with autism spectrum disorder. *Journal of Abnormal Psychology, 125*(7), 879. https://doi.org/10.1037/abn0000199

Ee, D., Hwang, Y. I., Reppermund, S., Srasuebkul, P., Trollor, J. N., Foley, K. R., & Arnold, S. R. (2019). Loneliness in adults on the autism spectrum. *Autism in Adulthood, 1*(3), 182–193. https://doi.org/10.1089/aut.2018.0038

Finke, E. H., McCarthy, J. H., & Sarver, N. A. (2019). Self-perception of friendship style: Young adults with and without autism spectrum disorder. *Autism & Developmental Language Impairments, 4*, 2396941519855390. https://doi.org/10.1177/2396941519855390

Foggo, R. S. V., & Webster, A. A. (2017). Understanding the social experiences of adolescent females on the autism spectrum. *Research in Autism Spectrum Disorders, 35*, 74–85. https://doi.org/10.1016/j.rasd.2016.11.006

Fuller-Iglesias, H. R., Webster, N. J., & Antonucci, T. C. (2013). Adult family relationships in the context of friendship. *Research in Human Development, 10*(2), 184–203. https://doi.org/10.1080/15427609.2013.786562

Gantman, A., Kapp, S. K., Orenski, K., & Laugeson, E. A. (2012). Social skills training for young adults with high-functioning autism spectrum disorders: A randomized controlled pilot study. *Journal of Autism and Developmental Disorders, 42*(6), 1094–1103. https://doi.org/10.1007/s10803-011-1350-6

Gates, J. A., Kang, E., & Lerner, M. D. (2017). Efficacy of group social skills interventions for youth with autism spectrum disorder: A systematic review and meta-analysis. *Clinical Psychology Review, 52*, 164–181. https://doi.org/10.1016/j.cpr.2017.01.006

Gest, S. D., Graham-Bermann, S. A., & Hartup, W. W. (2001). Peer experience: Common and unique features of number of friendships, social network centrality, and sociometric status. *Social Development, 10*(1), 23–40. https://doi.org/10.1111/1467-9507.00146

Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose expertise is it? Evidence for autistic adults as critical autism experts. *Frontiers in Psychology, 8*, 438. https://doi.org/10.3389/fpsyg.2017.00438

Golan, O., Baron-Cohen, S., Hill, J. J., & Rutherford, M. D. (2007). The 'Reading the Mind in the Voice' test-revised: A study of complex emotion recognition in adults with and without autism spectrum conditions. *Journal of Autism and Developmental Disorders, 37*(6), 1096–1106. https://doi.org/10.1007/s10803-006-0252-5

Graham Holmes, L., Zampella, C. J., Clements, C., McCleery, J. P., Maddox, B. B., Parish-Morris, J., Udhnani, M. D., Schultz, R. T., & Miller, J. S. (2020). A lifespan approach to patient-reported outcomes and quality of life for people on the autism spectrum. *Autism Research, 13*(6), 970–987. https://doi.org/10.1002/aur.2275

Grewen, K. M., Anderson, B. J., Girdler, S. S., & Light, K. C. (2003). Warm partner contact is related to lower cardiovascular reactivity. *Behavioral Medicine, 29*(3), 123–130. https://doi.org/10.1080/08964280309596065

Griffin, S., Williams, B., Ravyts, S., Dzierzewski, J., & Rybarczyk, B. (2019). Loneliness predicts reductions in sleep quality in older Americans. *Innovation in Aging, 3*(Suppl 1), S529. https://doi.org/10.1093/geroni/igz038.1946

Hadjikhani, N., Johnels, J. Å., Zürcher, N. R., Lassalle, A., Guillon, Q., Hippolyte, L., Billstedt, E., Ward, N., Lemonnier, E., & Gillberg, C. (2017). Look me in the eyes: Constraining gaze in the eye-region provokes abnormally high subcortical activation in autism. *Scientific Reports, 7*(1), 1–7. https://doi.org/10.1038/s41598-017-03378-5

Hancock, G., Stokes, M. A., & Mesibov, G. (2020). Differences in romantic relationship experiences for individuals with an autism spectrum disorder. *Sexuality and Disability, 38*(2), 231–245. https://doi.org/10.1007/s11195-019-09573-8

Haracopos, D., & Pedersen, L. (1992). *Sexuality and autism. A nationwide survey in Denmark*. Unpublished manuscript.

Head, A. M., McGillivray, J. A., & Stokes, M. A. (2014). Gender differences in emotionality and sociability in children with autism spectrum disorders. *Molecular Autism, 5*(1), 1–9. https://doi.org/10.1186/2040-2392-5-19

Hickey, A., Crabtree, J., & Stott, J. (2018). 'Suddenly the first fifty years of my life made sense': Experiences of older people with autism. *Autism, 22*(3), 357–367. https://doi.org/10.1177/1362361316680914

Hill, T. L., Gray, S. A., Baker, C. N., Boggs, K., Carey, E., Johnson, C., Kamps, J. L., & Varela, R. E. (2017). A pilot study examining the effectiveness of the PEERS program on social skills and anxiety in adolescents with autism spectrum disorder. *Journal of Developmental and Physical Disabilities, 29*(5), 797–808. https://doi.org/10.1007/s10882-017-9557-x

Hode, M. G. (2014). Just another Aspie/NT love story: A narrative inquiry into neurologically-mixed romantic relationships. *Interpersona: An International Journal on Personal Relationships, 8*(1), 70–84. https://doi.org/10.5964/ijpr.v8i1.123

Holt-Lunstad, J., Uchino, B. N., Smith, T. W., & Hicks, A. (2007). On the importance of relationship quality: The impact of ambivalence in friendships on cardiovascular functioning. *Annals of Behavioral Medicine, 33*(3), 278–290. https://doi.org/10.1007/bf02879910

Holt-Lunstad, J., Smith, T. B., Baker, M., Harris, T., & Stephenson, D. (2015). Loneliness and social isolation as risk factors for mortality: A meta-analytic review. *Perspectives on Psychological Science, 10*(2), 227–237. https://doi.org/10.1177/1745691614568352

Hudson, C. C., Hall, L., & Harkness, K. L. (2019). Prevalence of depressive disorders in individuals with autism spectrum disorder: A meta-analysis. *Journal of Abnormal Child Psychology, 47*(1), 165–175. https://doi.org/10.1007/s10802-018-0402-1

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017). "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders, 47*(8), 2519–2534. https://doi.org/10.1007/s10803-017-3166-5

Hull, L., Lai, M. C., Baron-Cohen, S., Allison, C., Smith, P., Petrides, K. V., & Mandy, W. (2020). Gender differences in self-reported camouflaging in autistic and non-autistic adults. *Autism, 24*(2), 352–363. https://doi.org/10.1177/1362361319864804

Hurlbutt, K., & Chalmers, L. (2002). Adults with autism speak out: Perceptions of their life experiences. *Focus on Autism and Other Developmental Disabilities, 17*(2), 103–111. https://doi.org/10.1177/10883576020170020501

Jamison, T. R., & Schuttler, J. O. (2017). Overview and preliminary evidence for a social skills and self-care curriculum for adolescent females with autism: The girls night out model. *Journal of Autism and Developmental Disorders, 47*(1), 110–125. https://doi.org/10.1007/s10803-016-2939-6

Jaswal, V. K., & Akhtar, N. (2019). Being versus appearing socially uninterested: Challenging assumptions about social motivation in autism. *Behavioral and Brain Sciences, 42*. https://doi.org/10.1017/s0140525x18001826

Jellema, T., Lorteije, J., van Rijn, S., van t'Wout, M., de Haan, E., van Engeland, H., & Kemner, C. (2009). Involuntary interpretation of social cues is compromised in autism spectrum disorders. *Autism Research, 2*(4), 192–204. https://doi.org/10.1002/aur.83

Kanfiszer, L., Davies, F., & Collins, S. (2017). 'I was just so different': The experiences of women diagnosed with an autism spectrum disorder in adulthood in relation to gender and social relationships. *Autism, 21*(6), 661–669. https://doi.org/10.1177/1362361316687987

Kasari, C., Rotheram-Fuller, E., Locke, J., & Gulsrud, A. (2012). Making the connection: Randomized controlled trial of social skills at school for children with autism spectrum disorders. *Journal of Child Psychology and Psychiatry, 53*(4), 431–439. https://doi.org/10.1111/j.1469-7610.2011.02493.x

Kasari, C., Dean, M., Kretzmann, M., Shih, W., Orlich, F., Whitney, R., Landa, R., Lord, C., & King, B. (2016). Children with autism spectrum disorder and social skills groups at school: A randomized trial comparing intervention approach and peer composition. *Journal of Child Psychology and Psychiatry, 57*(2), 171–179. https://doi.org/10.1111/jcpp.12460

Kellaher, D. C. (2015). Sexual behavior and autism spectrum disorders: An update and discussion. *Current Psychiatry Reports, 17*(4), 25. https://doi.org/10.1007/s11920-015-0562-4

King, K. B., & Reis, H. T. (2012). Marriage and long-term survival after coronary artery bypass grafting. *Health Psychology, 31*(1), 55. https://doi.org/10.1037/a0025061

Kretzmann, M., Shih, W., & Kasari, C. (2015). Improving peer engagement of children with autism on the school playground: A randomized controlled trial. *Behavior Therapy, 46*(1), 20–28. https://doi.org/10.1016/j.beth.2014.03.006

Kuo, M. H., Orsmond, G. I., Cohn, E. S., & Coster, W. J. (2013). Friendship characteristics and activity patterns of adolescents with an autism spectrum disorder. *Autism, 17*(4), 481–500. https://doi.org/10.1177/1362361311416380

Kuusikko, S., Pollock-Wurman, R., Jussila, K., Carter, A. S., Mattila, M. L., Ebeling, H., Pauls, D. L., & Moilanen, I. (2008). Social anxiety in high-functioning children and adolescents with autism and Asperger syndrome. *Journal of Autism and Developmental Disorders, 38*(9), 1697–1709. https://doi.org/10.1007/s10803-008-0555-9

Ladd, G. W. (2005). *Children's peer relations and social competence: A century of progress*. Yale University Press.

Lai, M. C., Lombardo, M. V., Ruigrok, A. N., Chakrabarti, B., Auyeung, B., Szatmari, P., Happé, F., Baron-Cohen, S., & MRC AIMS Consortium. (2017). Quantifying and exploring camouflaging in men and women with autism. *Autism, 21*(6), 690–702. https://doi.org/10.1177/1362361316671012

Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet Psychiatry, 6*(10), 819–829. https://doi.org/10.1016/S2215-0366(19)30289-5

Larson, R., & Seepersad, S. (2003). Adolescents' leisure time in the United States: Partying, sports, and the American experiment. *New Directions for Child and Adolescent Development, 99*, 53–64. https://doi.org/10.1002/cd.66

Laugeson, E. A., Frankel, F., Mogil, C., & Dillon, A. R. (2009). Parent-assisted social skills training to improve friendships in teens with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 39*(4), 596–606. https://doi.org/10.1007/s10803-008-0664-5

Laugeson, E. A., Frankel, F., Gantman, A., Dillon, A. R., & Mogil, C. (2012). Evidence-based social skills training for adolescents with autism spectrum disorders: The UCLA PEERS program. *Journal of Autism and Developmental Disorders, 42*(6), 1025–1036. https://doi.org/10.1007/s10803-011-1339-1

Laugeson, E. A., Gantman, A., Kapp, S. K., Orenski, K., & Ellingsen, R. (2015). A randomized controlled trial to improve social skills in young adults with autism spectrum disorder: The UCLA PEERS® program. *Journal of Autism and Developmental Disorders, 45*(12), 3978–3989. https://doi.org/10.1007/s10803-015-2504-8

Lee, C. Y. S., & Goldstein, S. E. (2016). Loneliness, stress, and social support in young adulthood: Does the source of support matter? *Journal of Youth and Adolescence, 45*(3), 568–580. https://doi.org/10.1007/s10964-015-0395-9

Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism, 24*(1), 135–146. https://doi.org/10.1177/1362361319853442

Leekam, S. R., Prior, M. R., & Uljarevic, M. (2011). Restricted and repetitive behaviors in autism spectrum disorders: A review of research in the last decade. *Psychological Bulletin, 137*(4), 562. https://doi.org/10.1037/a0023341

Lehnhardt, F. G., Falter, C. M., Gawronski, A., Pfeiffer, K., Tepest, R., Franklin, J., & Vogeley, K. (2016). Sex-related cognitive profile in autism spectrum disorders diagnosed late in life: Implications for the female autistic phenotype. *Journal of Autism and Developmental Disorders, 46*(1), 139–154. https://doi.org/10.1007/s10803-015-2558-7

Locke, J., Ishijima, E. H., Kasari, C., & London, N. (2010). Loneliness, friendship quality and the social networks of adolescents with high-functioning autism in an inclusive school setting. *Journal of Research in Special Educational Needs, 10*(2), 74–81. https://doi.org/10.1111/j.1471-3802.2010.01148.x

Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012). Sex differences in autism spectrum disorder: Evidence from a large sample of children and adolescents. *Journal of Autism and Developmental Disorders, 42*(7), 1304–1313. https://doi.org/10.1007/s10803-011-1356-0

Masi, A., DeMayo, M. M., Glozier, N., & Guastella, A. J. (2017). An overview of autism spectrum disorder, heterogeneity and treatment options. *Neuroscience Bulletin, 33*(2), 183–193. https://doi.org/10.1007/s12264-017-0100-y

Mazurek, M. O. (2014). Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism, 18*(3), 223–232. https://doi.org/10.1177/1362361312474121

McDonald, T. A. M., Fan, R., Ye, F., Boursolulian, J., & Malow, B. A. (2019). *Physical and psychological health and quality of life in adults with autism: Role of self-determination and autism identity*. Presented at International Society for Autism Research (INSAR), Montreal, Canada.

McVey, A. J., Dolan, B. K., Willar, K. S., Pleiss, S., Karst, J. S., Casnar, C. L., Caiozzo, C., Vogt, E. M., Gordon, N. S., & Van Hecke, A. V. (2016). A replication and extension of the PEERS® for young adults social skills intervention: Examining effects on social skills and social anxiety in young adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(12), 3739–3754. https://doi.org/10.1007/s10803-016-2911-5

Merz, E. M., Consedine, N. S., Schulze, H. J., & Schuengel, C. (2009). Wellbeing of adult children and ageing parents: Associations with intergenerational support and relationship quality. *Aging and Society, 29*(5), 783. https://doi.org/10.1017/S0144686X09008514

Middleton, H., Zollinger, J., & Keene, R. (1986). Popular peers as change agents for the socially neglected child in the classroom. *Journal of School Psychology, 24*(4), 343–350. https://doi.org/10.1016/0022-4405(86)90022-1

Milton, D. E. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability & Society, 27*(6), 883–887. https://doi.org/10.1080/09687599.2012.710008

Morrison, K. E., Pinkham, A. E., Kelsven, S., Ludwig, K., Penn, D. L., & Sasson, N. J. (2019). Psychometric evaluation of social cognitive measures for adults with autism. *Autism Research, 12*(5), 766–778. https://doi.org/10.1002/aur.2084

Müller, E., Schuler, A., & Yates, G. B. (2008). Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism, 12*(2), 173–190. https://doi.org/10.1177/1362361307086664

Orsmond, G. I., & Kuo, H. Y. (2011). The daily lives of adolescents with an autism spectrum disorder: Discretionary time use and activity partners. *Autism, 15*(5), 579–599. https://doi.org/10.1177/1362361310386503

Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders, 34*(3), 245–256. https://doi.org/10.1023/b:jadd.0000029547.96610.df

Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(11), 2710–2719. https://doi.org/10.1007/s10803-013-1833-8

Oswald, T. M., Winter-Messiers, M. A., Gibson, B., Schmidt, A. M., Herr, C. M., & Solomon, M. (2016). Sex differences in internalizing problems during adolescence in autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(2), 624–636. https://doi.org/10.1007/s10803-015-2608-1

Pecora, L. A., Hancock, G. I., Mesibov, G. B., & Stokes, M. A. (2019). Characterising the sexuality and sexual experiences of autistic females. *Journal of Autism and Developmental Disorders, 49*(12), 4834–4846. https://doi.org/10.1007/s10803-019-04204-9

Persicke, A., Tarbox, J., Ranick, J., & Clair, M. S. (2013). Teaching children with autism to detect and respond to sarcasm. *Research in Autism Spectrum Disorders, 7*(1), 193–198. https://doi.org/10.1016/j.rasd.2012.08.005

Peters, E., Riksen-Walraven, J. M., Cillessen, A. H., & de Weerth, C. (2011). Peer rejection and HPA activity in middle childhood: Friendship makes a difference. *Child Development, 82*(6), 1906–1920. https://doi.org/10.1111/j.1467-8624.2011.01647.x

Petrina, N., Carter, M., & Stephenson, J. (2014). The nature of friendship in children with autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders, 8*(2), 111–126. https://doi.org/10.1016/j.rasd.2013.10.016

Petrina, N., Carter, M., Stephenson, J., & Sweller, N. (2017). Friendship satisfaction in children with autism spectrum disorder and nominated friends. *Journal of Autism and Developmental Disorders, 47*(2), 384–392. https://doi.org/10.1007/s10803-016-2970-7

Poquérusse, J., Pastore, L., Dellantonio, S., & Esposito, G. (2018). Alexithymia and autism spectrum disorder: A complex relationship. *Frontiers in Psychology, 9*, 1196. https://doi.org/10.3389/fpsyg.2018.01196

Portway, S. M., & Johnson, B. (2005). Do you know I have Asperger's syndrome? Risks of a non-obvious disability. *Health, Risk & Society, 7*(1), 73–83. https://doi.org/10.1080/09500830500042086

Raffaelli, M., & Duckett, E. (1989). "We were just talking...": Conversations in early adolescence. *Journal of Youth and Adolescence, 18*(6), 567–582. https://doi.org/10.1007/BF02139074

Rogers, S. J. (2000). Interventions that facilitate socialization in children with autism. *Journal of Autism and Developmental Disorders, 30*(5), 399–409. https://doi.org/10.1023/A:1005543321840

Rotheram-Fuller, E., Kasari, C., Chamberlain, B., & Locke, J. (2010). Social involvement of children with autism spectrum disorders in elementary school classrooms. *Journal of Child Psychology and Psychiatry, 51*(11), 1227–1234. https://doi.org/10.1111/j.1469-7610.2010.02289.x

Rum, Y., Zachor, D. A., & Dromi, E. (2021). Prosocial behaviors of children with autism spectrum disorder (ASD) during interactions with their typically developing siblings. *International Journal of Behavioral Development, 45*(4), 293–298. https://doi.org/10.1177/0165025420971042

Sala, G., Hooley, M., & Stokes, M. A. (2020). Romantic intimacy in autism: A qualitative analysis. *Journal of Autism and Developmental Disorders, 50*(11), 4133–4147. https://doi.org/10.1007/s10803-020-04377-8

Sasson, N. J., Faso, D. J., Nugent, J., Lovell, S., Kennedy, D. P., & Grossman, R. B. (2017). Neurotypical peers are less willing to interact with those with autism based on thin slice judgments. *Scientific Reports, 7*(1), 1–10. https://doi.org/10.1038/srep40700

Schohl, K. A., Van Hecke, A. V., Carson, A. M., Dolan, B., Karst, J., & Stevens, S. (2014). A replication and extension of the PEERS intervention: Examining effects on social skills and social anxiety in adolescents with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 44*(3), 532–545. https://doi.org/10.1007/s10803-013-1900-1

Schuck, R. K., Flores, R. E., & Fung, L. K. (2019). Brief report: Sex/gender differences in symptomology and camouflaging in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 49*(6), 2597–2604. https://doi.org/10.1007/s10803-019-03998-y

Sedgewick, F., Hill, V., Yates, R., Pickering, L., & Pellicano, E. (2016). Gender differences in the social motivation and friendship experiences of autistic and non-autistic adolescents. *Journal of Autism and Developmental Disorders, 46*(4), 1297–1306. https://doi.org/10.1007/s10803-015-2669-1

Sedgewick, F., Crane, L., Hill, V., & Pellicano, E. (2019a). Friends and lovers: The relationships of autistic and neurotypical women. *Autism in Adulthood, 1*(2), 112–123. https://doi.org/10.1089/aut.2018.0028

Sedgewick, F., Hill, V., & Pellicano, E. (2019b). 'It's different for girls': Gender differences in the friendships and conflict of autistic and neurotypical adolescents. *Autism, 23*(5), 1119–1132. https://doi.org/10.1177/1362361318794930

Seeman, T. E., Lusignolo, T. M., Albert, M., & Berkman, L. (2001). Social relationships, social support, and patterns of cognitive aging in healthy, high-functioning older adults: MacArthur studies of successful aging. *Health Psychology, 20*(4), 243. https://doi.org/10.1037//0278-6133.20.4.243

Sheppard, E., Pillai, D., Wong, G. T. L., Ropar, D., & Mitchell, P. (2016). How easy is it to read the minds of people with autism spectrum disorder? *Journal of Autism and Developmental Disorders, 46*(4), 1247–1254. https://doi.org/10.1007/s10803-015-2662-8

Shih, W., Dean, M., Kretzmann, M., Locke, J., Senturk, D., Mandell, D. S., Smith, T., & Kasari, C. (2019). Remaking recess intervention for improving peer interactions at school for children with autism spectrum disorder: Multisite randomized trial. *School Psychology Review, 48*(2), 133–144. https://doi.org/10.17105/SPR-2017-0113.V48-2

Sinclair, J. (2010). Being autistic together. *Disability Studies Quarterly, 30*(1). https://doi.org/10.18061/dsq.v30i1.1075

Sirven, N., & Debrand, T. (2008). Social participation and healthy aging: An international comparison using SHARE data. *Social Science & Medicine, 67*(12), 2017–2026. https://doi.org/10.1016/j.socscimed.2008.09.056

Smith, I. C., & White, S. W. (2020). Socio-emotional determinants of depressive symptoms in adolescents and adults with autism spectrum disorder: A systematic review. *Autism, 24*(4), 995–1010. https://doi.org/10.1177/1362361320908101

Solomon, M., Miller, M., Taylor, S. L., Hinshaw, S. P., & Carter, C. S. (2012). Autism symptoms and internalizing psychopathology in girls and boys with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(1), 48–59. https://doi.org/10.1007/s10803-011-1215-z

Sosnowy, C., Silverman, C., Shattuck, P., & Garfield, T. (2019). Setbacks and successes: How young adults on the autism spectrum seek friendship. *Autism in Adulthood, 1*(1), 44–51. https://doi.org/10.1089/aut.2018.0009

Spain, D., Blainey, S. H., & Vaillancourt, K. (2017). Group cognitive behaviour therapy (CBT) for social interaction anxiety in adults with autism spectrum disorders (ASD). *Research in Autism Spectrum Disorders, 41*, 20–30. https://doi.org/10.1016/j.rasd.2017.07.005

Stewart, C. (2019). *Creating a route to the building of self-identity, confidence and inclusion for autistic women and girls: The Under Our Wing peer-mentoring project*. Scottish Autism Network. https://swanscotland.org/wp-content/uploads/2019/10/100705-SA-AE-Swan-Poster-A0_2.pdf

Strang, J. F., Powers, M. D., Knauss, M., Sibarium, E., Leibowitz, S. F., Kenworthy, L., Sadikova, E., Wyss, S., Willing, L., Caplan, R., Pervez, N., Nowak, J., Gohari, D., Gomez-Lobo, V., Call, D., & Anthony, L. G. (2018). "They thought it was an obsession": Trajectories and perspectives of autistic transgender and gender-diverse adolescents. *Journal of Autism and Developmental Disorders, 48*(12), 4039–4055. https://doi.org/10.1007/s10803-018-3723-6

Strang, J. F., Klomp, S. E., Caplan, R., Griffin, A. D., Anthony, L. G., Harris, M. C., Graham, E. K., Knauss, M., & van der Miesen, A. I. (2019). Community-based participatory design for research that impacts the lives of transgender and/or gender-diverse autistic and/or neurodiverse people. *Clinical Practice in Pediatric Psychology, 7*(4), 396. https://doi.org/10.1037/cpp0000310

Strunz, S., Schermuck, C., Ballerstein, S., Ahlers, C. J., Dziobek, I., & Roepke, S. (2017). Romantic relationships and relationship satisfaction among adults with Asperger syndrome and high-functioning autism. *Journal of Clinical Psychology, 73*(1), 113–125. https://doi.org/10.1002/jclp.22319

Taheri, A., Perry, A., & Minnes, P. (2016). Examining the social participation of children and adolescents with intellectual disabilities and autism spectrum disorder in relation to peers. *Journal of Intellectual Disability Research, 60*(5), 435–443. https://doi.org/10.1111/jir.12289

Tierney, S., Burns, J., & Kilbey, E. (2016). Looking behind the mask: Social coping strategies of girls on the autistic spectrum. *Research in Autism Spectrum Disorders, 23*, 73–83. https://doi.org/10.1016/j.rasd.2015.11.013

Umberson, D., & Montez, J. K. (2010). Social relationships and health: A flashpoint for health policy. *Journal of Health and Social Behavior, 51*(1_suppl), S54–S66. https://doi.org/10.1177/0022146510383501

Webster, A. A., & Garvis, S. (2017). The importance of critical life moments: An explorative study of successful women with autism spectrum disorder. *Autism, 21*(6), 670–677. https://doi.org/10.1177/1362361316677719

White, S. W., Ollendick, T., Albano, A. M., Oswald, D., Johnson, C., Southam-Gerow, M. A., Kim, I., & Scahill, L. (2013). Randomized controlled trial: Multimodal anxiety and social skill intervention for adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(2), 382–394. https://doi.org/10.1007/s10803-012-1577-x

Wolfberg, P. J., & Schuler, A. L. (1993). Integrated play groups: A model for promoting the social and cognitive dimensions of play in children with autism. *Journal of Autism and Developmental Disorders, 23*(3), 467–489. https://doi.org/10.1007/BF01046051

Wood, J. J., Kendall, P. C., Wood, K. S., Kerns, C. M., Seltzer, M., Small, B. J., Lewin, A. B., & Storch, E. A. (2020). Cognitive behavioral treatments for anxiety in children with autism spectrum disorder: A randomized clinical trial. *JAMA Psychiatry, 77*(5), 474–483. https://doi.org/10.1001/jamapsychiatry.2019.4160

Woods, S. B., Priest, J. B., & Roberson, P. N. (2020). Family versus intimate partners: Estimating who matters more for health in a 20-year longitudinal study. *Journal of Family Psychology, 34*(2), 247. https://doi.org/10.1037/fam0000600

Yamada, T., Miura, Y., Oi, M., Akatsuka, N., Tanaka, K., Tsukidate, N., Tomoka, Y., Okuno, H., Nakanishi, M., Taniike, M., Mohri, I., & Laugeson, E. A. (2020). Examining the treatment efficacy of PEERS in Japan: Improving social skills among adolescents with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 50*(3), 976–997. https://doi.org/10.1007/s10803-019-04325-1

Yang, Y. C., Boen, C., Gerken, K., Li, T., Schorpp, K., & Harris, K. M. (2016). Social relationships and physiological determinants of longevity across the human life span. *Proceedings of the National Academy of Sciences, 113*(3), 578–583. https://doi.org/10.1073/pnas.1511085112

Yoo, H. J., Bahn, G., Cho, I. H., Kim, E. K., Kim, J. H., Min, J. W., Lee, W. H., Seo, J. S., Jun, S. S., Bong, G., Cho, S., Shin, M. S., Kim, B. N., Kim, J. W., Park, S., & Laugeson, E. A. (2014). A randomized controlled trial of the Korean version of the PEERS® parent-assisted social skills training program for teens with ASD. *Autism Research, 7*(1), 145–161. https://doi.org/10.1002/aur.1354

23

Sexuality and Sexuality Education with Individuals with Autism: What You Should Know But Probably Don't

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A note about terminology used in the following chapter. Multiple terms are used to identify individuals on the autism spectrum. These include, but are not limited to, autistic, individual on the autism spectrum, intellectual and developmental disability (IDD), and learner on the spectrum. There is no hidden meaning in our choice of label other than our judgment as to the best construction of the sentence or paragraph. Throughout the chapter, the terms "services" and "supports" are used. Services refers to an actual service (e.g., respite, school, adult day program) being provided to the individual. The term "supports," on the other hand, refers to how the professionals providing these services interact with the person on the spectrum to help achieve the person's desired goal. Amy Gravino, an author on this chapter and an autistic adult, recalls being present at her own Individualized Education Plan (IEP) meetings as a child, yet never being asked to share her thoughts about the quality of the educational services she was receiving. So, while Amy may have been provided with appropriate educational services, the quality of her supports fell far short of what should be expected.

Human sexuality is biologically, emotionally, socially, behaviorally, and societally complex. Sexuality education is, unfortunately, the controversial offshoot of that complexity and the only way for us humans to make any sense out of this natural life experience. Even before we are born, we are sexual beings and the result of, in the vast majority of cases, some act of sexual behavior (Institute of Health, 2001). Sexuality, however, is not to be confused with gender and sexual orientation – or having sex, for that matter – which are all different things. One's sexuality is more about who you are as a person than it is about to whom you are sexually attracted. While sexuality is currently understood to be fluid in nature, there seems to be no consensus on the definition or meaning of sexual fluidity (Diamond et al., 2020).

Sexual behavior is, on one level, just behavior. But it is behavior that is constrained by religious and societal norms, personal and family values, cultural restrictions and freedoms, and an (usually) arcane set of legal prohibitions, to name just a few. Add to this the challenges of being an autistic youth on the spectrum who is struggling to understand sexuality through a neurodiverse lens with little in the way of accurate information, support, or effective instruction. Under

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these conditions, the odds on the occurrence of errors, social misunderstandings, the display of socially offensive behavior, or social stigmatization is, most likely, significantly greater than the odds in favor of obtaining sexual competence and sexual satisfaction.

Sexuality and Disability: A Very Brief History

American society's acceptance of the sexuality of people with various disability labels has, historically, been dismal at best and hostile at worst. Historically, disabled individuals were seen as something less than a whole person, and, as such, any display of individual sexuality was seen as unacceptable and generally punished (Richards et al., 2006). Individuals with IDDs were randomly sterilized, confined to their home, excluded from marriage, or placed in state-run institutions where they were segregated by gender to prevent them from having sex and reproducing (Gomez, 2012; Kempton & Kahn, 1991). While gender-based segregation may have reduced the risk of pregnancy, it would seemingly have increased the potential for same-sex physical intimacy given it was the only possible outlet for sexual expression.

Between approximately 1880 and 1940, American politicians were broadly promoting the philosophy of eugenics (i.e., genetic breeding to improve the bloodline of the best and brightest the country had to offer; e.g., Allen, 1997). There was a growing belief across the country that "mentally defective" persons were genetically loaded toward criminality and promiscuity and were a drain on society (e.g., Goddard, 1912). So, this societal ill needed to be addressed. By 1963, this resulted in eugenics laws being passed in 28 states. The vast majority of their laws legalized compulsory (i.e., forced) sterilization (Stein & Dillenburger, 2017). According to Richards et al. (2006), "between 1907 and 1957 some 60,000 Americans were sterilized without their consent, many without their knowledge" (p. 96).

Carrie Buck's story is illustrative of the personal impact of the eugenics movement (e.g., Cohen, 2016). Carrie Buck was an 18-year-old woman when she was committed to the Virginia State Colony for Epileptics and Feebleminded. As Carrie was considered a feeble-minded woman who was also the daughter of a feeble-minded mother (also in the Colony involuntarily) and the mother of an illegitimate feeble-minded child, the Superintendent of the Colony petitioned the Commonwealth of Virginia to allow her surgical sterilization. The case eventually landed on docket of the US Supreme Court. In a decision written by Justice Oliver Wendell Holmes Jr., the Court found, "It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind." Holmes infamously concluded, "three generations of imbeciles are enough" (Buck v. Bell, 1927).

We would note that several relevant facts were omitted from the papers provided to the Court. These included that Carrie was initially committed to the institution by her foster parents after the birth of her child out of wedlock, her child was not the result of promiscuity but of rape by the son of her foster parents, and Carrie was not feeble-minded even by the standards of the day. Despite this, the Supreme Court's decision in Buck v. Bell remains in the books. It has never been challenged.

The 1960s and 1970s saw the dawn of the Disability Rights Movement and the birth of the sexuality revolution. The Disability Rights Movement set out to change the predominant perception of people with disabilities as being incompetent, helpless, immobile, asexual, and incapable of taking charge of their own lives. This involved challenging the medical model of disability where people were viewed, and labeled, according to the sum of their inabilities with little, if any, attention to abilities or potential (Sabatello, 2013). Instead, it was argued, more attention should be paid to strengths, talents, interests, and the impact of the disability in the context of where a person lives, works, and plays. In other words, the person inside the label.

The Disability Rights Movement did not, it seems, significantly impact the autistic community until after the publication of DSM-IV (American Psychiatric Association, 1994). The DSM-IV codified, the diagnosis of Asperger syndrome as being part of the autism spectrum. For the first time, this set the groundwork for the development of a "Culture of Asperger's," the boundaries and norms of which were identified by the members of the culture itself. At the same time, there was a growing revolution in computer technology inclusive of the Internet (Bagatelle, 2020) which could bring members of this culture together from distant locations. There was now a segment of the autistic community who could, and would, readily speak for themselves and who had access to similar individuals via Internet groups to advocate for public recognition of autistic rights.

Beginning in the 1960s, the sexual revolution was a social movement that challenged traditional sexual values, roles, and behavior. This process, to be certain, continues today. At the core of the sexual revolution was the de-stigmatization, if not normalization, of premarital sex, masturbation, polyamory, access to contraception, and LBGTQ+ sexual identities. Unfortunately, the sexual revolution does not seem to have made any substantial inroads into the lives of adults with various disability labels, but it is a topic in great need of further study.

For example, many adults today likely view masturbation as an appropriate, desirable, and private act. But that shift in attitude does not seem to have readily permeated into the lives of people with IDDs. Mann and Travers (2020) reviewed the literature on interventions designed to address "inappropriate" masturbation as displayed by individuals with IDDs. They reported that the studies they found "primarily used consequence strategies, instructional interventions, or packaged interventions to reduce inappropriate masturbation and related behavior" (p. 214). The earlier the study, the more likely it was to rely on punishment-based interventions. Conversely, in his review of the behavior analytic research on strategies to teach appropriate masturbation to adult men with IDD, Cicero (2018) found that over the past 30 years, there has not been a single, peer-reviewed study on the provision of evidence-based instruction to teach effective and efficient masturbation to males with IDD. Similarly, the question of how to respectfully teach effective and efficient masturbation to women with IDD also remains unstudied at this point and may present with a different set of challenges.

The sexual revolution's ability to change societal beliefs with regard to the sexuality and sexual behavior of consenting adults has been a long and often contentious process. Unfortunately, this has also been a process that has, perhaps unintentionally, excluded individuals with diverse disability labels. Members of the disability community, not surprisingly, stress this needs to change. Hennessy (2016) has called for a new sexual revolution, specifically addressing the needs of people with disabilities noting that they, like everyone else, love, lust, and feel desire. Tepper (2000) argued that "societal attitudes toward people with disabilities have largely served to quiet both personal and political discussion on sexual pleasure" (p. 285).

There is still a long way to go. In 2006, Richards et al. wrote that individuals with IDDs have, historically, been viewed as sexually deviant, prone to criminality, asexual, and problematic to society. While there have, arguably, been areas of improvement over the last five decades (e.g., the sexuality behavior of individuals with IDDs is not typically punished), the continued perception of adults with IDDs as perpetual children, irrespective of their age, still lingers with substantial, negative consequences.

The Right to Sexuality

Clearly, a shift in attitude toward sexuality education for persons with a disability needs to occur. The natural tendency of parents is to protect their children from any potential sources of harm, and the harm that may potentially arise from engaging in unprotected sexual activity is no less frightening. For some parents, sexual behavior may signal the possibility of physical harm (e.g., sexually transmitted diseases, infections), emotional distress, heartache, unwanted pregnancy, and sometimes just a reminder of the immediacy of adulthood. As such, the instinct to protect their children from such experiences is understandable but may also be unintentionally harmful. In 1990, Diane Bannerman and her colleagues published an article discussing the rights of adults with disabilities to access habilitation, in contrast to their right to make poor choices. Bannerman et al. argue that most adults have the right to make choices in life that may prioritize personal liberties but be unproductive or potentially unhealthy (e.g., eating too many doughnuts, watching sitcoms). Bannerman and colleagues outlined the importance of balancing the right to habilitation with the right to make choices in life for people with disabilities, emphasizing the importance of teaching clients to "exercise their freedoms responsibly" (Bannerman et al., 1990, p. 86). In the consideration of personal liberties, sexual behavior is likely of high importance to many adults.

Historically, not only were people on the autism spectrum denied their rights to sexual autonomy, it has also been the perspective of many that adults on the autism spectrum are disinterested in sexual activity or simply do not develop sexually (Gill, 2015). It has since been realized that people with autism do in fact develop sexually and represent the spectrum of sexuality that is seen in other populations (Gill, 2015). That is, people with autism may be hetero-, homo-, bi-, or asexual. People on the spectrum may be cisgender, transgender, or genderfluid. They may be interested in monogamous, polygamous, or polyamorous relationships. People with autism may have several kinks or none at all (Carley, 2021). While sexual behavior is not quite the same as eating too many doughnuts, the same principles of responsible freedom apply. It is incredibly important that people with autism have the opportunity to have the same experiences and opportunities as others to develop sexually, including experiences that shape personal preferences and sense of self.

Bannerman et al. (1990) discussed this as a need to "exercise freedoms responsibly" (p. 86). This means it is incumbent upon those that provide teaching, education, and support to people on the autism spectrum to set the occasion for responsible engagement in sexual behavior. Teachers and other educators, behavior analysts, and parents need to ensure individuals with autism spectrum disorder (ASD) have access to comprehensive sex education, as well as effective teaching methodology. Access to sex education is considered a human right by the World Health Organization (UNESCO, 2021). While methods informed by applied behavior analysis (ABA) are often used to teach skills to people with ASD, it is important to remember that behavior analysts have the responsibility to provide intervention that is applied (i.e., useful) (Baer et al., 1968), socially valid (Wolf, 1978) and delivered in the context of a program designed to teach functional life skills (Van Houten et al., 1988). Clearly personal autonomy related to sexuality meets all of these areas of responsibility and, as such, should be a priority for behavior analysts and other evidence-based clinicians.

In order to manage the responsibility of sexual behavior, it is important that demonstration of skills in health and hygiene, communication, social interactions, self-advocacy, legal issues, and many more be ensured, across a variety of settings, situations, and interaction types. However, it remains important to consider that, within typical development, sexual behavior is rarely an easily mastered skill; it is unlikely that most adolescents and young adults feel very confident with their initial forays into dating and sex. Even the most responsible young adults have stumbles with sexual experiences, awkward dates, nervous encounters, and difficulty in conversation about sex. Adolescents and adults on the autism spectrum are not spared these difficulties and should be supported within, not denied the opportunity.

What Do We Think We Know?

Much of what we understand to be true about sexuality and ASD is the result of surveys (e.g., how many people report doing "x") or qualitative research. Intervention research, on the other hand, is rarer and, so, less informative. At least some of the gap in our understanding of sexuality and sexual behavior in ASD stems from a general lack of understanding about sexuality in general. Even as sex and sexuality permeate almost every aspect of our lives, there are any number of fundamental questions that remain unstudied and, therefore, unanswered (Pfaus et al., 2014). One reason, as noted by Irvine (2014), may be that sexuality research is generally regarded as socially necessary, but, at the same time, "sex researcher" carries with it something of a negative stigma. This results in limited federal funding for sex research (Epstein, 2006) and fewer young researchers entering the field in the first place. Even if one's research is funded, outlets for resulting publications may be limited given the potential for controversy.

Having said that, there are a few things we know with some confidence regarding sexuality and ASD. Kelleher (2015), in her summary of the sexuality research, noted that adults diagnosed with autism 1 (i.e., limited if any, cognitive involvement) appear similar to their typical peers in terms of sexual interest. While this group may know the basic language of sexuality, this does not seem to generalize to the actual display of the corresponding behavior. This, unfortunately, means that when it comes to sexual safety, vocal-verbal responses tend not be predictive of the display of safety-related behavior (for more people than just those with ASD).

Parchomiuk (2019) postulated that the development of a competent repertoire of social, social/sexual, and sexual safety skills in autistic individuals may, in part, be the result of issues associated with being autistic. For example, difficulties in understanding social rules/social boundaries or in understanding non-verbal communication may effectively limit one's access to the type of learning experiences that are readily and repeatedly accessed by typical peers. This may be particularly impactful given that nearly all sexual behavior is social behavior and, as social behavior, varies as a function of its physical and social context. For example, how long should you make eye contact with someone you just met? How long is too long? How short is too short? At what point does social eye contact become creepy and make the listener uncomfortable? This is just a basic example. You can easily extrapolate this process to more complex topographies of sexual behavior and identify many of the potential social challenges embedded in each.

There appears to be a greater diversity of sexual expression as reported by adults on the spectrum, somewhat more so for women, including higher reported rates of asexuality, bisexuality, gay, lesbian, and gender dysphoria (i.e., trans) and lower reported rates of heterosexuality (e.g., George & Stokes, 2018; Percora et al., 2020; Turner et al., 2017). George and Stokes (2018) go on to state that the "sexual attractions and behaviors of individuals on the autism spectrum are as diverse as the spectrum itself" (p. 139). One possible explanation for the differences identified between adults on the spectrum and their typical peers with regard to LGBTQ+ identity is that adults on the spectrum were simply more honest in their responses. Whatever the reason, it is important to increase awareness about the diversity of sexual and gender expression in ASD to educators, behavioral analysts, medical professionals, family members, and support staff so as to provide truly individualized care and support when necessary.

The final area about which we know something is, unfortunately, sexual abuse. Because sexuality abuse tends to be underreported in typical populations and individuals on the spectrum tend not to be good self-reporters (Carbajal & Praetorius, 2020), it seems reasonable to assume that current prevalence estimates are probably low. Recent research, (e.g., Kenny et al., 2021) on the prevalence of sexual abuse with children and adolescents on the spectrum indicates a rate 2–3 higher than their typical peers. Mandell et al. (2005) reported that 16.6% of children with autism in their study had been sexually abused, as reported by their support staff. Brown-Lavoie et al. (2014) reported that 78% of their respondents with ASD reported at least one instance of sexual victimization, compared to 47.4% of comparison group. According to Graham Holmes et al. (2020), 6.4% of youth with autism in their survey had a documented history of sexual abuse, and 14.5% were bullied by peers for lack of sexual knowledge. Sala et al. (2020) found that autistic women reported higher levels of unwanted sexual contact than did their typical peers and are at a three times greater risk to experience sexual coercion than are men on the spectrum.

But here is the thing; in some ways, the numbers do not matter as a single incident of sexual abuse is too much if it is your child (or you have a working moral compass). Historically, professionals have tended to rely on a strategy of "supervision and protection" rather than one of evidence-based interventions in support of personal skill development. Supervision and protection, however, should be seen as something of an interim strategy as it fails to protect against the most likely perpetrator of sexual abuse (e.g., someone known to the person; Dube & Hebert, 1988).

Sexuality Education

In their annual report, the Sexuality Information and Education Council of the United States (SIECUS, 2021) noted that general education sex education is a patchwork of laws, ideologies, and accurate and inaccurate information across the United States. For example, in the United States:

- Only **29** states and the District of Columbia mandate sex education.
- **Thirty-five** states require schools to stress abstinence education.
- Just **16** states require instruction on condoms or contraception.
- **Fifteen** states do not require sex education to be any of the following: age-appropriate, medically accurate, culturally responsive, or evidence-based/evidence-informed.
- Only **nine** states require sex education to include information on consent.
- Only **eight** states require culturally responsive sex education.
- Just **seven** states have policies that include affirming sexual orientation instruction on LGBQT identities or discussion of sexual health for LGBQT youth.
- **Nine** states explicitly require instruction that discriminates against LGBTQ people.

- ***Source****: Sex Ed State Law and Policy Chart: SIECUS State Profiles 2021.* https://siecus.org/wp-content/uploads/2021/12/2021-Sex-Ed-State-Law-and-Policy-Chart-3.pdf

Not surprisingly, then, is the fact that research on what constitutes appropriate and effective sex education for persons on the autism spectrum is not all that encouraging (e.g., Davies et al., 2021; McDonalds & Fleming, 2016). This is despite the fact that individuals with ASD have a right and need for accurate, timely, and effective sex education. Graham Holmes et al. (2020) surveyed the parents of 298 youth with autism, 8–12 years of age with 52.7% of the sample assigned male at birth and 47.3% were assigned female at birth. Almost 40% of the sample had not received any sex education in school or from a community provider. For individuals with ASD and ID, the percentage jumped to 60.9%.

Sala et al. (2019) conducted a systematic review of peer-reviewed articles on sex education and IDD published between 1980 and 2018. A total of 33 studies were identified. While many of the studies demonstrated positive outcomes, many were:

> …broad in their stated aims, used non-validated outcome measures and provided insufficient statistical information to calculate effect size. [ ] most studies did not include details of community consultation, stakeholder input or prior needs assessment in designing the intervention [and] were of a weak quality in relation to sample bias, study design, data collection, and lack of evaluation of intervention integrity. (Sala et al., 2019, p. 376)

Solomon et al. (2019) reviewed the existing literature on sex education and individuals with ASD using an information-motivation-behavior (IMB) skills framework. IMB is a well-established model frequently employed in behavioral health/risk reduction research. The central theme emerging from Solomon and colleagues' research is that autistic individuals vary significantly in their personal needs regarding sexual health, dating, and relationships. Solomon et al. concluded that "sexual education curricula are only beginning to be developed for people on the autism spectrum" (p. 363).

As noted by Solomon et al. (2019), a valid criticism of the sex education tools and curricula available for use with (or by) individuals with ASD is that specific needs of the individual are poorly addressed. This is a substantial issue given the diversity that defines the autism spectrum. A second concern is that much of what constitutes sex education in ASD is knowledge-based (e.g., completing quizzes or worksheets) instead of based on behavior skills training (BST) to allow for the acquisition of the actual skills (e.g., Davies et al., 2021; Sala et al., 2019). In other words, successful outcomes are more often based on verbal responses to questions rather than on the display of an actual, relevant skill or skill set. And lastly, there appears to be more of an emphasis on social engagement across studies rather than on the acquisition of potentially useful sexuality safety skills.

Additional Considerations

The path to sexual autonomy for persons with disabilities, and specifically autism, has been horrendous, and it is incumbent upon parents of those on the spectrum, clinicians, and society overall to move forward in a positive and respectful manner. While the Disability Rights Movement has seemingly excluded sexual rights overall, there are particular needs related to sexuality for those on the autism spectrum. The social-communication components of the diagnostic criteria for autism (American Psychiatric Association, 2013) mean navigation of social situations may be difficult, and interpretation of innuendo and non-verbal communication can be challenging. Repetitive behavior and restricted interests can lead to perseveration and increased impulsivity. As such, in order to respect the sexual autonomy and rights of individuals with autism, specific sex education must be made available and accessible.

For a person involved in a relationship (sexual or otherwise), a parent of someone involved in a relationship, or a person trying to teach someone about relationships, relationships and sex are complicated. Beyond formal education, there are some additional considerations that are important.

Considerations for Parents of People on the Spectrum

1. Think ahead, probably farther than initially expected. Goals related to sexuality are often complex and thus may take a lot of teaching. Gerhardt (2012) recommends a 5-year rule wherein parents should set teaching goals based on where they expect their child's need to be in 5 years (i.e., if a child is 10 years old, a parent should be considering goals for a 15-year-old). Additionally, it has been found that parents tend to underestimate their child's sexual experiences (DeWinter et al., 2016). This perpetuates a cycle of crisis responsivity in regard to education. A proactive approach is important to ensure increased autonomy and reduced risk of harm.
2. Be direct and clear in discussions and teaching about sexuality. People with autism may have difficulty with inferences, unclear language, innuendo, ambiguity, or insinuation (Myles et al., 2014) and benefit from clear, concise, direct language. So, use the real words for whatever it is you may be describing/teaching. Neither penis nor vagina is a dirty word, and both are much better than "peepee" or "hooha" or whatever may be typical in your family. While this may not be the most natural or even comfortable way for you to address sexuality, it will ensure much greater understanding.
3. Safety behaviors must be taught and not assumed. Every person has different experiences in life, different preferences, and different opportunities. This means that while some risks are universal (e.g., everyone needs to learn about consent, birth control), teaching should also focus on the specific behaviors that individual will require in the specific situations they are more likely to encounter. This

may require individualization of experiences and risks to be directly applicable to each person. Additionally, safety skills should be taught in a variety of settings and situations and practiced often to ensure generalization and maintenance (see Stokes & Baer, 1977, for further discussion of generalization and maintenance procedures). Many unsafe situations have a low frequency of occurrence but high risk of harm. Because they are situations often not encountered frequently, a regular maintenance check of safety skills is required.

4. Good sexual health means that people have opportunities to have safe, personally satisfying, and non-coercive sexual experiences they desire, if they desire (Glasier et al., 2006). Unfortunately, as previously noted, the prevalence of sexual abuse and sexual victimization/coercion with individuals on the spectrum is unacceptably high due, at least in part, to a lack of education regarding what constitutes a safe and healthy relationship and what skills are required (Girardi et al., 2020). While space prohibits a comprehensive review of the safety skill literature (e.g., Tekin-Iftar et al., 2020), a few basic sexual safety skills should be noted including functional noncompliance, independent self-care, and discrimination skills:
   (a) **Functional noncompliance** – The field of behavior analytic education and intervention is very proficient at shaping compliance, particularly with younger learners on the spectrum (e.g., Radley & Dart, 2016). Compliance of this nature is generally understood as a prerequisite skill to future skill acquisition. However, indiscriminate compliance to adult direction runs counter to the promotion of sexual health (e.g., Sandoval-Norton, & Shkedy, 2019; see also Gorycki et al., 2020). Though not usually thought of this way, the ability to say “no” to a direction, request, or situation is actually a safety skill that is in nearly everyone’s repertoire. Teaching young learners under what conditions they should use their functional “no” response builds in a degree of protection for later in life.
   (b) **Independent self-care** – The extent to which a learner on the spectrum is able to independently toilet, shower, dress/undress, get ready for bed, and wake themselves up significantly reduces the need for any adult (family member or otherwise) to provide assistance in completing these intimate self-care activities.
   (c) **Discrimination skills** – A critical sexual safety skill is the ability to discriminate between safe and unsafe situations and people. For example, if they are not yet independently toileting, learners with ASD are typically taught to accept help/training in the bathroom from any available staff. While there may be some value in this initially, the need to identify who can, and who cannot, provide them with assistance in the bathroom, showering or dressing, is a critical sexual safety skill. It is important to note that whenever staff leave and new staff are hired, the learner will need to be taught whatever discrimination “rules” apply to new staff.

Considerations for Educators

1. People on the autism spectrum are individuals with as wide a range of sexual interests as those not on the spectrum (Carley, 2021). Making assumptions about preference, interests, curiosities, or experiences when goal setting and teaching is restrictive and potentially offensive. Sexuality for many people includes an element of exploration; while some preferences may be easy to identify, others may need some trying-it-out. Additionally, what an individual wants at any moment is dynamic and changing (Cooper et al., 2007), and sexual preferences and desires are no different. Preference changes under certain conditions are impacted by deprivation, satiation, and experiences, and overall preferences tend to change over time; most people have vastly different sexual preferences in middle age than they do as adolescents. It should be expected that this applies similarly on the spectrum as well, and education should reflect

this level of individualization. It is also important to ensure that education includes an emphasis on self-advocacy, in terms of ensuring a functional "no" response for safety reasons as well as skills related to advocating for their own preferences.

2. Be aware of the law and ensure teaching explicitly covers local laws regarding sexuality. Laws around sexual acts vary by region, and people with autism can be vulnerable to both victims and, often unknowingly, perpetrators of unlawful sexual behavior (Mandell et al., 2005). Explicit education and ensuring understanding of lawful (and unlawful) acts are essential.
3. What looks like sexual behavior is not always sexual behavior. For example, if a student sticks her hand down the front of her pants and attempts to physically masturbate, that is probably a sexual behavior. However, sticking a hand down one's pants is also a very good way to gain staff attention or terminate a task or non-preferred activity. If that is the case, the behavior in question is not sexual and so needs to be addressed differentially.
4. Be attentive to teaching strategies. Teaching about sexuality can utilize many of the same teaching strategies that may be effective in other domains, for example, if the individual learns well when they have a chance to practice a skill using behavioral skills training or a teaching interaction procedure would work well (see Leaf et al., 2020, for further description of teaching methods). If the learner requires a visual prompt, this should be incorporated. Clinicians and educators should be aware that verbal reports may not be indicative of future behavior (Northup, 2000), and as such careful consideration should be given to stimulus control and maintaining contingencies.

Considerations for Adults on the Spectrum

1. Not everyone in the world is who they say they are and not all people are good. It can be very helpful to have a typical friend you can turn to to ask for help. This could be a family member, a support staff, or someone you know from elsewhere. The important thing is that they understand you and have your best interests in mind.
2. There are potential legal consequences to behavioral missteps. Extended eye contact, repetitive questioning, and touching someone to get their attention, for example, can all be regarded as sexually inappropriate behavior by the receiver. While there is research on training of police and other first responders in recognizing and understanding autism, (e.g., Railey et al., 2020), there does not appear to be much in the way of teaching autistic people how to safely interact with police which is a significant gap in our knowledge base.
3. The Internet, TV, and movies are not necessarily good guides for relationships. Online pornography is a bad guide to relationships.
4. Only you get to decide what your sexuality/gender identity is and what your feelings about relationships are. If you are having difficulty dealing with how others try to perceive or identify you, you should seek help.
5. Everyone has difficulty in this area. We are all learning and stumbling along.

Summary

The complexity of human sexuality, particularly when integrated with the complexity of living life on the autism spectrum, presents a variety of challenges to helping people on the spectrum attain satisfying sex lives (whatever that might mean) in which they are safe from abuse (or, more accurately, as safe as anyone really can be) and free from social misunderstanding. But complexity is not an excuse to avoid providing sexuality education.

Historically, people with autism and other disabilities have had their sexuality ignored, denied, or punished for "their own good." To this day, research on how and when to teach such a basic sexual behavior as masturbation is missing from our canon. While we do not have a good handle on the development and effective delivery of a truly comprehensive sexuality education curricula, we do know how to teach individual skills quite well (except, apparently, masturbation). The time has passed for parents, clinicians, educators, and society at large to recognize the autistic individual's right to own sexuality and to push for such instruction and support.

As with many areas of the research, research on sexuality has often failed to incorporate the desires, needs, thoughts, and recommendations of individuals on the spectrum. Dewinter et al. (2020) cite this as a failure to develop a stakeholder-informed research agenda. Using a nominal research technique, the research needs and priorities of the autistic community were solicited. Research priorities that were identified included:

1. Improving support and interventions that promoted sexual health and satisfying sexual experiences and relationships.
2. How to best support and promote sexual well-being.
3. How to prevent sexual victimization and, conversely, sexual offending.
4. How do autistic individuals experience and navigate sexuality across the lifespan?
5. What are the experiences and needs of the LGBTQ+-identifying individuals?
6. Finally, how do sexuality and relationships develop in autistic individuals with lower levels of intellectual functioning?

These are all very big questions that, for the most part, pertain more to individuals with an autism 1 diagnosis than those with an autism 2 or autism 3 diagnosis. This discrepancy based on the diversity within the autism spectrum is, in our opinion, likely the biggest challenge we face as we look toward the future. On the one hand, there is a significant need for research into, for example, how best to teach a 10-year-old cisgender female how to make her preferences for feminine hygiene products known to her family or support staff. On the other hand, there is a significant need for research into supporting the needs of the autistic LGBTQ+ community including the need, and right, to have a satisfying sex life.

That gap seems insurmountably wide, particularly, since it all falls under the (now, unfortunately, somewhat generic) diagnosis of ASD. And maybe it is. But perhaps the solution is that future researchers in sexuality and autism consistently and clearly define who the participants in the study were and whether their findings can extend beyond that cohort. And if not, then recommend additional avenues of research to, potentially, validate the findings as being germane to other cohorts on the spectrum.

Sexuality is central to how typical adults define themselves from early adolescence through adulthood. Sexuality is more about who we are as a person than who we may choose to sleep with. At the same time, personal sexuality continues to be little understood and, in some quarters, stigmatized or even forbidden. This despite the fact that sexuality plays a bigger role in determining the quality of our lives than does what we do for a living or where we live (but not more than how long of a commute to work you have). The challenge, therefore, is to prioritize this aspect of adult life for adolescents and adults on the spectrum, to whatever extent possible, and not consider sexuality education and support something to implement once an individual has engaged in sexual behavior that is deemed inappropriate, offensive, or potentially dangerous (Griffiths, 1999).

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References

Allen, G. E. (1997). The social and economic origins of genetic determinism: A case history of the American Eugenics Movement, 1900–1940 and its lessons for today. *Genetica, 99*, 77–88. https://doi.org/10.1007/BF02259511

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Author.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Author.

Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis, 1*(1), 91–97. https://doi.org/10.1901/jaba.1968.1-91

Bagatelle, N. (2020). From cure to community: Transforming notions of autism. *Ethos, 38*, 33–55. https://doi.org/10.1111/j.1548-1352.2009.01080.x

Bannerman, D. J., Sheldon, J. B., Sherman, J. A., & Harchik, A. E. (1990). Balancing the right to habilitation with the right to personal liberties: The rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behavior Analysis, 23*(1), 79–89. https://doi.org/10.1901/jaba.1990.23-79

Brown-Lavoie, S., Viecili, M. A., & Weiss, J. A. (2014). Sexual knowledge and victimization in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 44*, 2185–2196. https://doi.org/10.1007/s10803-014-2093-y

Buck v. Bell. (1927). 274 U.S. 200, 47 S.Ct. 584.

Carbajal, J., & Praetorius, R. T. (2020). How does autism affect the processing of child sexual abuse trauma? *Journal of Human Services: Training, Research, and Practice., 5*, 1–27.

Carley, M. J. (2021). *The book of happy, positive, and confident sex for adults on the autism spectrum…and beyond!* Neurodiversity Press.

Cicero, F. R. (2018). Shaping effective masturbation in persons with developmental disabilities: A review of the literature. *Sexuality and Disability, 37*, 91–108. https://doi.org/10.1007/s11195-018-9551-y

Cohen, A. (2016). *Imbeciles: The Supreme Court, American Eugenics, and the Sterilization of Carrie Buck*. Penguin Books.

Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied behavior analysis* (2nd ed.). Pearson Education.

Davies, A. W., Balter, S., van Rhijn, T., Spracklin, J., Maich, K., & Soud, R. (2021). Sexuality education for children and youth with autism spectrum disorder in Canada. *Intervention in School and Clinic*. Advance online publication. https://doi.org/10.1177/10534512211051068

Dewinter, J., Vermeiren, R., Vanwesenbeeck, I., & Nieuwenhuizen, C. V. (2016). Parental awareness of sexual experience in adolescent boys with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 46*(2), 713–719. https://doi.org/10.1007/s10803-015-2622-3

Dewinter, J., van der Miesen, A. I. R., & Holmes, L. G. (2020). INSAR special interest group report: Stakeholder perspectives on priorities for future research on autism, sexuality, and intimate relationships. *Autism Research, 13*(8), 1248–1257. https://doi.org/10.1002/aur.2340

Diamond, L. M., Alley, J., Dickenson, J., & Blair, K. L. (2020). Who counts as sexually fluid? Comparing four different types of sexual fluidity in women. *Archives of Sexual Behavior, 49*(7), 2389–2403. https://doi.org/10.1007/s10508-019-01565-1

Dube, R., & Hebert, M. (1988). Sexual abuse of children under 12-years of age: A review of 511 cases. *Child Abuse and Neglect, 12*, 321–330. https://doi.org/10.1016/0145-2134(88)90045-2

Epstein, S. (2006). The new attack on sexuality research: Morality and the politics of knowledge production. *Sexuality Research & Social Policy, 3*, 1–12. https://doi.org/10.1525/srsp.2006.3.1.01

George, R., & Stokes, M. (2018). Sexual orientation in autism spectrum disorder. *Autism Research, 11*, 133–141. https://doi.org/10.1002/aur.1892

Gerhardt, P. F. (2012, April 14). *Sexuality instruction and learners with ASD: What behavior analysts need to know.* APBA conference, Tampa FL, United States.

Gill, M. (2015). *Already doing it: Intellectual disability and sexual agency*. University of Minnesota Press.

Girardi, A., Curran, M. S., & Snyder, B. L. (2020). Healthy intimate relationships and the adult with autism. *Journal of the American Psychiatric Nurses Association, 27*, 405–414. https://doi.org/10.1177/1078390320949923

Glasier, A., Gülmezoglu, A. M., Schmid, G. P., Moreno, C. G., & Van Look, P. F. A. (2006). Sexual and reproductive health: A matter of life and death. *The Lancet, 368*, 1595–1607. https://doi.org/10.1016/s0140-6736(06)69478-6

Goddard, H. H. (1912). *The Kallikak family: A study in the heredity of feeble-mindedness*. MacMillan Co. https://doi.org/10.1037/10949-000

Gomez, M. T. (2012). The S words: Sexuality, sensuality, sexual expression, and people with intellectual disabilities. *Sexuality and Disability, 30*, 237–245. https://doi.org/10.1007/s11195-011-9250-4

Gorycki, K. A., Ruppel, P. R., Zane, T., & Navalta, C. P. (2020). Is long-term ABA therapy abusive: A response to Sandoval-Norton and Shkedy. *Cogent Psychology, 7*(1). https://doi.org/10.1080/23311908.2020.1823615

Graham Holmes, L., Shattuck, P. T., Nilssen, R., Strassberg, D. S., & Himle, M. B. (2020). Sexual and reproductive health service utilization and sexuality for teens on the autism spectrum. *Journal of Developmental & Behavioral Pediatrics, 41*, 667–679. https://doi.org/10.1097/DBP.0000000000000838

Griffiths, D. (1999). Sexuality and people with developmental disabilities: Mythconceptions and facts. In I. Brown & M. Percy (Eds.), *Developmental disabilities in Ontario* (pp. 443–452). Front Porch Publishers.

Hennessy, A. (2016, June 26). The disabled community still waits for our 1960s sexual revolution. *The Guardian.* Accessed on 12 December 2021 at https://www.theguardian.com/global-development-professionals-network/2016/jun/26/the-disabled-community-still-wait-for-our-1960s-sexual-revolution

Institute of Medicine (US) Committee on Understanding the Biology of Sex and Gender Differences. (2001). In T. M. Wizemann & M. L. Pardue (Eds.), *Exploring the* *biological contributions to human health: Does sex matter?* National Academies Press.

Irvine, J. M. (2014). Is sexuality research 'dirty work'? Institutionalized stigma in the production of sexual knowledge. *Sexualities, 17*, 5–6. https://doi.org/10.1177/1363460713516338

Kellaher, D. C. (2015). Sexual behavior and autism Spectrum disorders: An update and discussion. *Current Psychiatry Reports, 17*, 25. https://doi.org/10.1007/s11920-015-0562-4

Kempton, W., & Kahn, E. (1991). Sexuality and people with intellectual disabilities: A historical perspective. *Sexuality and Disability, 9*, 93–111. https://doi.org/10.1007/BF01101735

Kenny, M. C., Crocco, C., & Long, H. (2021). Parents' plans to communicate about sexuality and child sexual abuse with their children with autism spectrum disorder. *Sexuality and Disability, 39*, 357–375. https://doi.org/10.1007/s11195-020-09636-1

Leaf, J. B., Milne, C. M., Leaf, J. A., Rafuse, J., Cihon, J. H., Ferguson, J. L., Oppenheim-Leaf, M. L., Leaf, R., McEachin, J., & Mountjoy, T. (2020). *The autism partnership method: Social skills groups*. Different Roads to Learning.

Mandell, D., Walrathc, C., Manteuffeld, B., Sgrod, G., & Pinto-Martin, J. (2005). The prevalence and correlates of abuse among children with autism served in comprehensive community-based mental health settings. *Child Abuse and Neglect, 29*, 1359–1372. https://doi.org/10.1007/s10803-014-2093-y

Mann, L. E., & Travers, J. C. (2020). A systematic review of interventions to address inappropriate masturbation for individuals with autism spectrum disorder or other developmental disabilities. *Review Journal of Autism and Developmental Disorders, 7*, 205–218. https://doi.org/10.1007/s40489-019-00192-9

McDaniels, B., & Fleming, A. (2016). Sexuality education and intellectual disability: Time to address the challenge. *Sexuality and Disability, 34*, 215–225. https://doi.org/10.1007/s11195-016-9427-y

Myles, B., Coffin, A., Owens, D., & Yantes, C. (2014). Characteristics of adults with high-functioning autism spectrum disorders. In M. Tincani & A. Bondy (Eds.), *Autism spectrum disorders in adolescents and adults: Evidence-based and promising interventions* (pp. 3–23). The Guilford Press.

Northup, J. (2000). Further evaluation of the accuracy of reinforcer surveys: A systematic replication. *Journal of Applied Behavior Analysis, 33*(3), 335–338. https://doi.org/10.1901/jaba.2000.33-335

Parchomiuk, M. (2019). Sexuality of persons with autistic spectrum disorders (ASD). *Sexuality and Disability, 37*, 259–274. https://doi.org/10.1007/s11195-018-9534-z

Percora, L. A., Hooley, M., Sperry, L. M., Mesibov, G. B., & Stokes, M. A. (2020). Sexuality and gender issues in individuals with autism spectrum disorder. *Child and Adolescent Psychiatry Clinics, 29*, 543–556. https://doi.org/10.1016/j.chc.2020.02.007

Pfaus, J. G., Scdedpkowski, L. A., Marson, L., & Georgiadis, J. R. (2014). Biology of the sexual response. In D. L. Tolman & L. M. Diamond (Eds.), *APA handbook of sexuality and psychology* (pp. 145–204). American Psychology Association.

Radley, K. C., & Dart, E. H. (2016). Antecedent strategies to promote children's and adolescents' compliance with adult requests: A review of the literature. *Clinical Child and Family Psychology Review, 19*, 39–54. https://doi.org/10.1007/s10567-015-0197-3

Railey, K. S., Love, A. M. A., & Campbell, J. M. (2020). Systematic review of law enforcement training related to autism spectrum disorder. *Focus on Autism and Other Developmental Disabilities, 35*, 221–233. https://doi.org/10.1177/1088357620922152

Richards, D., Miodrag, N., & Watson, S. L. (2006). Sexuality and developmental disability: Obstacles to healthy sexuality throughout the lifespan. *Developmental Disabilities Bulletin, 34*(1–2), 137–155.

Sabatello, M. (2013). A short history of the international disability rights movement. In M. Sabatello & M. Schulze (Eds.), *Human rights and disability advocacy*. University of Pennsylvania Press.

Sala, G., Hooley, M., Attwood, T., Mesibov, G. B., & Stokes, M. A. (2019). Autism and intellectual disability: A systematic review of sexuality and relationship education. *Sexuality and Disability, 37*, 353–382. https://doi.org/10.1007/s11195-019-09577-4

Sala, G., Pecora, L., Hooley, M., Stokes, & Mark, A. (2020). As diverse as the spectrum itself: Trends in sexuality, gender, and autism. *Current Developmental Disorders Reports, 7*, 59–68. https://doi.org/10.1007/s40474-020-00190-1

Sandoval-Norton, A. H., & Shkedy, G. (2019). How much compliance is too much compliance: Is long-term ABA therapy abuse? *Cogent Psychology, 6*(1). https://doi.org/10.1080/23311908.2019.1641258

Sexuality Information and Education Center of the United States. (2021). *Sex Ed State Law and Policy Chart: SIECUS State Profiles 2021*. Author. Accessed online on 20 December 2021 at https://siecus.org/wp-content/uploads/2021/12/2021-Sex-Ed-State-Law-and-Policy-Chart-3.pdf

Solomon, D., Pantalone, D. W., & Faja, S. (2019). Autism and adult sex education: A literature review using the information-motivation-behavioral skills framework. *Sexuality and Disability, 37*, 339–351. https://doi.org/10.1007/s11195-019-09591-6

Stein, S., & Dillenburger. (2017). Ethics in sexual behavior assessment and support for people with intellectual disability. *International Journal on Disability and Human Development, 16*, 11–17.

Stokes, T. F., & Baer, D. M. (1977). An implicit technology of generalization. *Journal of Applied Behavior Analysis, 10*(2), 349–367. https://doi.org/10.1901/jaba.1977.10-349

Tekin-Iftar, E., Olcay, S., Sirin, N., Bilmez, H., Degirmenci, H. D., & Collins, B. C. (2020). Systematic review of safety skill interventions for individuals with autism spectrum disorder. *The*

Journal of Special Education, 54, 239–250. https://doi.org/10.1177/0022466920918247

Tepper, M. S. (2000). Sexuality and disability: The missing discourse of pleasure. *Sexuality and Disability, 18*, 283–290.

Turner, D., Briken, P., & Schottle, D. (2017). Autism-spectrum disorders in adolescence and adulthood: Focus on sexuality. *Current Opinion in Psychiatry, 30*, 409–416. https://doi.org/10.1097/YCO.0000000000000369

UNESCO. (2021). *Comprehensive sexuality education: A foundation for life and love campaign.* United nations educational, scientific, and cultural organization. Retrieved from 28 December 2021 https://en.unesco.org/themes/education-health-and-well-being/cse-campaign

Van Houten, R., Axelrod, S., Bailey, J. S., Favell, J. E., Foxx, R. M., Iwata, B. A., & Lovaas, O. I. (1988). The right to effective behavioral treatment. *Journal of Applied Behavior Analysis, 21*(4), 381–384.

Wolf, M. M. (1978). Social validity: The case for subjective measurement or how applied behavior analysis is finding its heart. *Journal of Applied Behavior Analysis, 11*(2), 203–214. https://doi.org/10.1901/jaba.1978.11-203

Part VIII

The Present and Future

24

Measuring Outcomes for Adults with Autism Spectrum Disorders: Historical Perspectives and Hope for the Future

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Let us face it, historically, discussions regarding outcomes for adults with autism spectrum disorder (ASD) have not been easy. The topic is often bleak, describing a poor outlook based on factors that failed to consider an array of potential perspectives (Howlin & Magiati, 2017). But when we examine these outcomes by including considerations from family members, peers, employers, and autistic adults themselves, these conversations may become easier and more optimistic, revealing improved outcomes for adults with ASD because of the growth of new practices over the past 40 years (Bishop-Fitzpatrick et al., 2016).

The last 40 years have seen a shift from the institutionalized placement and care of individuals with disabilities to the inclusion of individuals with disabilities into the communities they live (Leslie et al., 2017). The deinstitutionalization of individuals with disabilities was driven by multiple factors, including the passing of the Community Mental Health Centers Construction Act in 1963 (also known as the Mental Retardation Facilities and Construction Act, Public Law 88–164, and the Mental Retardation and Community Mental Health Centers Construction Act in 1963) (Lima et al., 2018) and the Olmstead ruling of 1999 (Schott et al., 2021). Prior to this shift in the community inclusion of individuals with disabilities, researchers measured outcomes for institutionalized individuals based on rating scores on a scale from *good* to *very poor* with social and communicative abilities as the primary indicators for success (Rutter et al., 1967). There was a high level of variability in these criteria, and individual outcomes often looked bleak due to this narrow approach (Henninger & Taylor, 2013). But this approach to analyzing and evaluating outcomes for individuals with developmental disabilities, especially adults, is myopic. As we know from various outcome studies (e.g., Farley et al., 2018; Marriage et al., 2009; Oakley et al., 2021), outcomes vary greatly from person to person, informant to informant, based on the individual's and their caretaker's perspectives, values, and goals. Therefore, adult outcomes must be assessed and evaluated on the individual level, accounting for variability within a person's experience, their individual desires, in conjunction with standardized assessments such as the Vineland Adaptive Behavior Scales (Carter et al., 1998) or the Social Responsiveness Scale (Brugha et al., 2015).

As deinstitutionalization progressed over the last 50 years, the number of patients in state-run facilities significantly dropped, and a greater number of adults with ASD began living and working in a variety of community settings, indicating that successful outcomes with adults affected by ASD can, and should, look very different than previ-

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ously viewed (Burgess & Gutstein, 2007; Leslie et al., 2017). As the National Council on Disability (NCD) states on their website, “Closing institutions is about developing strong and inclusive community supports and allowing people to have control over how they live their lives” (National Council on Disability, 2012). Thus, any discussion about outcomes must encompass this new, and evolving, landscape.

This chapter seeks to survey the historical approaches to evaluating outcome measures for adults diagnosed with ASD and then moves on to highlight alternative perspectives to adult outcomes as the reporting and viewpoints shift from researchers toward caregivers and individuals. We seek to explore how deinstitutionalization and early intervention altered the possibilities for individuals affected by ASD and how this then further changes how we evaluate outcomes. Further, we explore caregiver perspectives on raising and supporting an adult with ASD and the evolving indicators of success from their unique point of view. From there, we examine outcomes on the individual level and delve into self-determinism and person-centered planning, two key elements which have critically reshaped the conversation over adult outcomes in recent years. These interrelated aspects are fundamental to an individual’s ownership over their own life and will be examined in terms of the shifting attention to the rights of individuals to guide their own futures.

Historical Perspectives on Outcome Measures

Historically, adults diagnosed with ASD were considered to have deficient or substandard outcomes (Ruble & Dalrymple, 1996). The tools used to measure these indicators were often vague and unreliable (Henninger & Taylor, 2013). Researchers from the late 1960s through the early 2000s used terms like “poor” or “good” to describe overall adult outcomes, with most adults falling within the poor category (Mason et al., 2021). This approach to evaluating outcomes for adults affected by ASD was notably used by Leo Kanner (1971) in describing outcomes from a 28-year follow-up study examining results for a group of 11 individuals. In his follow-up study, Kanner (1971) remarked that only 2 of the 11 original participants demonstrated success, with success being measured as adults who lived under the care of their family members and engaged in communication skills respectable enough for employment, social interactions, and community activities. Kanner (1971) further remarked that 4 of the 11 participants represented the poorest outcomes in which they continued to live at institutions and displayed significantly reduced communication skills. These types of outcome studies were first introduced by Rutter et al. (1967) as they sought to set criteria for individuals who, at the time, were referred to as having infantile psychosis and who demonstrated “abnormalities that were autistic in typed” (p. 1186). It was after Rutter et al. that these criteria were more readily adapted to adults with ASD as outcome indicators (Henninger & Taylor, 2013).

Rutter et al. (1967) used terms such as “good,” “fair,” “poor,” and “very poor” to set criteria when studying the outcomes of 63 adults in their study. Good outcomes were considered if an individual lived at close to age-appropriate normal life, which included living outside of an institution, gainful employment, and engaging in typical social interactions. Individuals with fair outcomes were those who made some social and educational progress but continued to demonstrate deficits in interpersonal relationships and engaged in inappropriate behaviors. Lastly, individuals who fell in the poor to very poor outcome categories were individuals who were marked by stark deficits or maladaptive behaviors that they were deemed unable to lead independent lives. Differentiation between those in the poor and very poor categories meant that the poor group had some potential for social progress and improvement while the very poor had none. The results from the sample demonstrated that 14% of individuals had good outcomes and 61% had poor or very poor (Rutter et al., 1967).

In 1987, Gillberg and Steffenberg applied this classification system to 46 individuals over the age of 16 years who were previously diagnosed with infantile autism or autistic-like conditions but added a new sub-category between "fair" and "poor" addressing "restricted but acceptable" behaviors. This additional criterion "restricted but acceptable" was the first step in 20 years to expand outcome measures for adults with ASD. This is notable as Gillberg and Steffenberg expected to see better outcomes with the introduction of this new criterion, which they believed, addressed the acceptance of certain behaviors in specific contexts with certain people. Unfortunately, this was not the case as outcomes from their study still followed similar patterns as those seen in the previous studies with 59% of individuals investigated having a poor to very poor outcome. Later in 2005, Billstedt and colleagues expanded further on Rutter et al.' (1967) work by building five outcome measures with more heterogenetic qualifications which included employment or vocational training, residential situations, diagnosis of comorbid disorders, obvious or significant disabilities, and significant barriers to communication. While this sought to expand criteria and look further at individualization, it was still based on vague data, and even under these new criteria, outcomes were still categorized as predominantly poor or very poor (Henninger & Taylor, 2013).

For the following 30 years, outcome measures for adults with ASD were measured through the lens of the previously outlined process (Mason et al., 2021). It was not until the late 2000s that a shift in outlook began to occur. These changes reflected the mounting effects of deinstitutionalization and early intervention, adults with ASD now living in a variety of community settings and the widely seen and felt results from those who had received childhood therapeutic interventions (Henninger & Taylor, 2013). These two elements helped force the discussion of outcomes to move from researcher-driven and ambiguous criteria to individually focused and more explicit. Here the beginnings of environmental fit and individualization began to take root in the context of an individual's success.

One notable change that occurred was targeted outcome definitions for social functioning (Farley et al., 2018). New measurements included building and sustaining meaningful relationships, engaging in competitive employment, and considering independent living placements (Mason et al., 2018). Additionally, we began to see a swing from what makes for good institutional behavior change to what matters most to an individual's happiness and achievement in their optimal environment. A second noteworthy change that occurred during this time is a fundamental alteration in the research, steering away from outcome evaluations and moving toward quality-of-life discussions (e.g., Burgess & Gutstein, 2007; McCauley et al., 2020; Tavernor et al., 2013). These studies focus on social relationships, friendship, community inclusion, and independence (Howlin et al., 2000) and include a qualitative analysis from individuals studied in evaluating their own interventions (Tavernor et al., 2013).

Researchers evaluating outcome measures of adults with ASD have noted that intellectual and communication functioning can be strong indicators for success and improved overall quality of life in adults with autism (McClannahan et al., 2002) with increased opportunities for gainful employment, social relationships, and independent living (Marcotte et al., 2020). Conversely, autism severity, linked to reductions in communication and social relationships, has been used to predict poorer outcomes for adults and children with ASD (Howlin & Magiati, 2017). However, some researchers (e.g., Billstedt et al., 2011) noted that outcome assessments needed to analyze how well the individual fits into an "Autism-Friendly Environment" (p. 7), citing that it is not about the person being accepted into their environment but finding suitable environments that are most appropriate for the individual. These researchers urge a more comprehensive evaluation of outcomes that should include an analysis of most supportive and least restrictive environments.

Further, research has noted that variables which include educated caregivers or support staff, structured education, vocational training, or employment which fits the motivation and personality of the individual, plus customized treatment or interventions, work to improve predictors for an improved quality of life and can lead to more successful outcomes and greater independence (McClannahan et al., 2002). These recommendations transfer the viewpoint of adult indicators for success away from the dichotomy of poor or good based on an individual's functioning level to a more varied perspective accounting for the variability of each individual and their supporting environment. Billstedt et al. (2011) reevaluated a previous participant sample from their 2005 (Billstedt et al., 2005) study in which they failed to account for an individual's fit and happiness in the environment. In the 2005 study, results indicated that 78% of the samples were categorized with poor or very poor outcomes (Billstedt et al., 2011). However, upon revision of the outcome measures under the updated guidance from 2011, 62% of the adults met good or very good criteria (Billstedt et al., 2011).

While discussing subjective indicators for overall happiness, fit, and well-being may run contrary to the training of quantitative researchers, it is undeniable that these elements need to be considered alongside standardized assessments when examining the intricacies of a human's life. Notably, the validity in outcome criteria made up the bulk of the criticisms of the early research on adult outcomes, remarking that academic achievement, IQ scores, and statistical assessments do not fully present a picture of an individual's success as an adult (Bishop-Fitzpatrick et al., 2016; Burgess & Gutstein, 2007; McCauley et al., 2020). As seen in Billstedt et al. (2011), there is much more to the examination of adult outcomes than an individual's level of severity or level of independence. The remaining portions of this chapter will venture into these more subjective concerns. Let us now look at how caregivers' perspectives and treatment options inform their evaluation of outcomes, as well as reflect upon the changing landscape of self-advocacy, education, and employment to assess how individuals themselves can play an active role in shaping their own lives and therefore outcomes.

Caregivers of Adults with ASD

It has been well-documented that families of children with ASD experience higher levels of stress as compared to families of typically developing children (Hoffman et al., 2009), children with Down syndrome or intellectual disability (Abbeduto et al., 2004), fetal alcohol syndrome (Watson et al., 2013), or other disabilities (Brobst et al., 2009). Specifically, the core deficits associated with ASD such as social communication impairments, restrictive and repetitive patterns of behavior, and disruptive behaviors along with the severity of these symptoms have been found to be the greatest factors that contribute to stress for families of children with ASD (Ekas & Whitman, 2010; Hayes & Watson, 2013; Lecavalier et al., 2006). Parents of children with ASD have reported needing to make significant adjustments in their careers to allow time for caregiving duties, a general lack of spontaneity in their family life, and a decline in the development of their own personal social lives (Meirsschaut et al., 2010). For practitioners who serve children with ASD and their families, understanding and empathizing with each family's unique and potentially stressful life are critically important steps to foster rapport building and collaborative development of effective and individualized programming (Rodger et al., 2008; Stanford et al., 2020).

There is some research investigating stress levels and the subsequent impact of behavioral intervention on families of young children with ASD (e.g., McGrew & Keyes, 2014; Strauss et al., 2012). McGrew and Keyes (2014) assessed the caregiver burden and marital adjustment of mothers of children with ASD within 6 months of diagnosis and again 1 year later. The findings suggested that female caregivers were functioning at the same level 1 year after the diagnosis; however, a positive change with one assessed variable was caregivers reporting an increase in perceived provider support over time. Additionally, research in Early Intensive Behavioral Intervention (EIBI) has found that including parents in treatment can lead to improvements with child behavior and the intensive and consistent parent training and supervision led to parental treatment fidelity which led to children's overall improvement (Strauss et al., 2012). These results are promising for parents of young children with ASD; however, since autism is a lifelong disability (Centers for Disease Control and Prevention [CDC], 2020), individuals with ASD often require caregiver assistance for their entire life span (Matson & Rivet, 2008). Interventions focused on improving social communication, adaptive functioning, and the reduction of maladaptive behaviors continue to increase in accessibility for individuals with ASD, but it remains challenging to obtain these services post high school (Gerhardt & Lainer, 2011). As a direct consequence of the lack of support, caregivers may be faced with financial, emotional, and developmental burdens when caring for their adult children with ASD (Marsack-Topolewski et al., 2021; Marsack-Topolewski & Church, 2019).

Personal Perspectives

The impact caregiver burden has on quality of life has been assessed by surveying and interviewing parents of adults with ASD (Marsack-Topolewski & Church, 2019). Marsack-Topolewski and Church adapted the Caregiver Burden Inventory (CBI), a scale used to measure caregivers' perception of burden related to caring for individuals diagnosed with Alzheimer's disease (Novak & Guest, 1989), and tailored it for use in their study for parents of adults with ASD. The adapted CBI contained 15 items from 3 domains (i.e., time dependence, developmental, and emotional burden) as these were deemed to be significant to caregivers of adults with ASD. Marsack-Topolewski and Church found that developmental burden, or the feeling of caregivers being out of sync in development with their peers, was found to have a statistically significant negative impact on parents' quality of life. To address the developmental burden, the researchers suggested that practitioners working with parents of adults with ASD should focus client programming on developing independence in daily living skills while also encouraging and facilitating opportunities for caregivers to participate in social interactions with other caregivers or groups (Marsack-Topolewski & Church, 2019).

In many cases, it is likely that parents and caregivers of adults with ASD have dedicated a sizable portion of their lives focused on the educational, developmental, and behavioral needs of their children (Marsack-Topolewski & Church, 2019; Matson & Rivet, 2008). Caregivers assume an even greater burden when their children age out of high school, as support and resources for adults with disabilities remain to be scarce (Bishop-Fitzpatrick et al., 2013; Gerhardt & Lainer, 2011; Shattuck et al., 2007). Given this unfortunate reality, we felt it was necessary to speak with caregivers of individuals with ASD and hear their journey raising a child with autism from childhood to young adulthood. We had the opportunity to speak to two women who are parents of young adults with ASD as well as each being intimately involved in the autism community throughout the world. Summaries of these interviews follow as a notable reflection of the perspectives caretakers have in raising children with ASD to young adulthood. The pseudonyms of Anne and Bethany are used in the following caregiver accounts to preserve the confidentiality of the caregivers, their children, and their families.

Anne's Story

Anne has a 20-year-old son who was first diagnosed with ASD at age 3. Access to appropriate supports and services in her area was difficult to come by, and Anne spent an exceptional amount of time researching interventions and strategies that would support her son's education and development. Despite her hard-fought and valiant efforts across countless years to secure applied behavior analysis (ABA) services for her child, Anne was unable to obtain services in her state and ultimately took matters into her own hands by becoming her son's educator. Moreover, to this day, Anne continues to hire, train, and pay for behavioral support for her son privately. While her son now has a job caring for horses, he also has a one-on-one aid, trained in ABA, who supports him throughout the day. Furthermore, Anne expressed that while ABA therapy is critical in improving outcomes for individuals with ASD, her experience with her son demonstrated that the school system possessed ignorance involving incorporating ABA services as well as resistance in adopting a scientific approach to solving problems. Anne additionally voiced wanting to have a plan in place for her son that includes access to ABA services should she and her husband no longer be able to take care of him.

As Anne discussed, there is an unfortunate reality in obtaining appropriate, adequate, and necessary services for adults with disabilities – securing access tends to either be extremely challenging or impossible in most cases (Murphy et al., 2016; Shattuck et al., 2011). It is often the case that individuals may receive services when their behavior is at a level that is highly unmanageable, engaging in self-injury or severe aggression, and in those instances, they may be placed in institutions (Manente et al., 2010). Further, when parents or caregivers choose to become their child's teacher, in many instances, like in this caregiver's case, they become fantastic ABA interventionists who help facilitate meaningful progress for their child. While this progress should be celebrated, it may result in further exclusion from obtaining services because their child is not engaging in severe challenging behavior, an unfortunate paradox.

Bethany's Story

Bethany is the mother of three boys, two of whom are on the autism spectrum. The first son has been receiving intensive ABA services for numerous years and today, at 19 years old, has a full-time program of approximately 35 hours a week and continues to make clinically significant progress. While Bethany notes that her son has learned numerous skills and has tremendous work potential for certain types of employment, she further expressed fear that employers would be uncomfortable in employing him should they see him engage in self-injury while on the job. Bethany stressed that while her son may engage in minimal instances of self-injury, there are still some occasions in which he will engage in these behaviors, and the chance that they may occur, at work, is troubling for her to consider. These concerns are echoed by employers when surveyed, stating that employees with ASD can often be skillful at their job which is valued but the challenges that interactions with people and behavior problems can have present a barrier for long-term employment and reduction of intensive support (Schall, 2010).

Despite these challenges and fears, this caregiver recounted a story of when her son was 14 years old and attended an ABA program over the summer. During the initial intake meeting, the ABA team asked for his employment plan to which she responded, "He's 14," explaining that she was shocked that the team was expecting an employment plan. Over the course of the summer, her son was able to work in the community with the assistance of his ABA team, and this experience shed light on the need to focus on employment training much earlier in the life of an individual with ASD. This program had well-established partnerships within the community and was properly set up to run an effective vocational training program for their clients. She recognized the program being exceptional in that regard; however, in many areas of the United States, it is rare that vocational training starts early (Lounds Taylor et al., 2012; Walsh et al., 2014).

Social validity is the extent to which stakeholders find intervention procedures appropriate and the effects of treatment to be important (Wolf, 1978). One caregiver shared her experience of collaborating with her son's ABA team to develop programs to teach him leisure skills so that he can occupy himself during "downtime." The team was able to successfully teach him to play turn-taking board games, which was appreciated. However, the caregiver is still concerned regarding her son's leisure activities as his deficits persist when left alone. This is now an area of concern that the family would like to address through their son's ABA program. When programming encompasses stakeholders' desires and feedback, it ultimately creates consumer buy-in, develops rapport, and can lead to meaningful outcomes.

The ideas, experiences, and advice shared by both caregivers are invaluable and thought-provoking for both caregivers of individuals with ASD and practitioners who serve the population. Although their stories are representative of just two sets of families, they paint a picture of the challenges associated with obtaining services and the need for comprehensive interventions that are appropriate and are focused on socially valid outcomes. ABA-based interventions tend to be focused on objective measurement as a means of treatment and program evaluation; however, when evaluating the matters of social validity, there appears to be a burgeoning need for subjective measurement as well.

What Practitioners Can Do

Social Validity

As it has become increasingly apparent that the best treatment outcomes are achieved through the inclusion and collaboration of consumers (Bowman et al., 2021), there must be a concerted effort toward the recruitment of feedback from all stakeholders (Wolf, 1978). Methods for assessing social validity include having consumers complete questionnaires and comparing treatment outcomes with behavioral norms (Carr et al., 1999). While the validity of subjective measurement may be debatable, it has been well-established that including the input and involvement of stakeholders not only leads to better treatment outcomes but is the best practice in ABA (Fawcett, 1991; Strain et al., 2012). While notable concerns over subjective measurement in ABA include reliability of personal statements and the replication and recordability of observable events (Wolf, 1978), when developing intervention plans, it is important to consider each stakeholder's values, skills, goals, and stressors (Slocum et al., 2014) as the success of plan implementation is heavily dependent on these factors (Hickey et al., 2018). Practitioners should arrange opportunities for ongoing and consistent collaboration and feedback from caregivers regarding behavioral programming while bearing in mind the daily challenges caregivers of adults with ASD face.

Compassionate Care

As detailed earlier in this section, caregivers of adults with ASD are faced with persistent and considerable stressors on an ongoing basis. When practitioners are given the opportunity to serve a family of an adult with ASD, it is necessary to consider the pervasiveness and intensity how these challenges affect the family day to day and to incorporate compassionate practices as part of the collaborative process. Rohrer et al. (2021) and Taylor et al. (2019) are both formable articles which outline both recommendations and checklists for how practitioners can improve compassion and collaboration in their work and are both highly recommended for further insight on this topic. A case for how a clinician may engage in compassionate care when interacting with a client may go as follows. A parent may express frustration that her adult son is not making the treatment gains that were expected. A behavior analyst demonstrating compassion would empathically listen to the parent, take the parent's perspective, and acknowledge the parent's feelings. The behavior analyst then takes the additional step to alter treatment goals so that they teach to the son's deficits and the mother's concerns and thus works to both improve the outcomes of the son and resolve the parent's overall frustration (Taylor et al., 2019). This deliberate and active act of compassion can lead to the development of trust which in turn may allow the behavior analyst to highlight the treatment gains that have been met thus far and open the dialogue for continued gains.

Outcomes Dictated by Individuals

It is imperative that outcome-related discussions are in general driven by individuals with ASD, for them to have a critical role in guiding the planning and treatment process. Camm-Crosbie et al. (2019) conducted a survey that found that adults with a diagnosis of ASD indicated that they had difficulty accessing treatment for mental health services and that understanding and support for mental health needs, including thoughts of suicide, were alarmingly lacking. With the consideration that adults with a diagnosis of ASD are at a higher risk for a mental health crisis (Camm-Crosbie et al., 2019), it is imperative that goals that are meaningful to the individual are developed, and the most effective treatment is selected. Furthermore, processes have emerged that call for the increasing role of adults developing their own goals. Two movements or processes worth mentioning include self-determination and person-centered planning.

In short, self-determination is the process of exercising autonomy to make choices or decisions about one's own life (Erwin et al., 2009). Similarly, person-centered planning is a process that includes several key components such as: (a) centering the individual with a disability; (b) incorporating other key individuals in the life of the focus person; (c) considering the individual's strengths, interests, talents, and values; and (d) developing an action plan consistent with those values (Flannery et al., 2000; Holburn et al., 2000). When compared to one another, self-determination is an inevitable result of a person-centered planning process. Presently, these two processes have even been incorporated into federal regulations pertaining to Medicaid-funded services for people with disabilities (Medicaid, n.d.). Thus, self-determination and person-centered planning are two critical processes that guide outcome-oriented discussions for adults with ASD.

Within a person-centered planning approach, some key outcomes to consider include involvement in community activities, preferred leisure activities, employment goals, social outcomes, living arrangements, and essential daily living skills. For example, if an adult with ASD has an interest in working at a local fisherman shop, specific vocational goals can be outlined in accordance with their preferences. Similarly, some adults with ASD may hope to participate in specific community activities of interest such as a cooking club or an art group. Other individuals may even want to enhance their social skills to improve friendships or intimate relationships. Adults may even formulate certain safety or emotional regulation goals. Further, adults may communicate the desired outcomes as it relates to where they want to live, who they want to live with, and how much support they desire within their preferred residential setting.

Developing Outcomes

To develop these goals or outcomes, several different formal or informal methods can be employed. For example, for some individuals, informal interviews can be conducted with adults with ASD. This may involve asking direct questions about preferences as well as short-term and long-term goals (Tullis & Seaman-Tullis, 2019). Other processes may involve more formalized methods that involve multi-step, mapping of preferences, or even direct assessments (Reid et al., 1999). For adults who may have difficulties with communication, adult-driven approaches may even include observing affect, while the person of focus engages with certain activities, and then developing outcomes based on activities associated with positive affect (Luiselli, 2017).

Additionally, outcomes driven by adults may require a shifting of priorities from traditional academic goals that were a focus when school aged to more functional alternatives. Though academic and functional are not necessarily antonymous or incompatible, functional goals are typically practical or immediately relevant skills for the individual (Dell'Armo & Tassé, 2019). As follows, adult-directed outcomes may involve a lesser emphasis on reading or math skills and a greater emphasis on community safety or self-care skills. Moreover, functional goals are more likely to facilitate community integration as well as progress that is meaningful to the individual with ASD. Additionally, considerations for goals to be developed that assist adults with navigating complex topics, such as sexuality (Mann & Travers, 2019), friendships (DaWalt et al., 2019), and accessing healthcare (Burke et al., 2010), should include the individual with a diagnosis of ASD, so that goals that are being targeted are meaningful and applicable to the individual's contextual circumstances and values.

Notably, some of these methods involve a level of subjectivity that may be uncomfortable for practitioners, particularly those focused on objective outcomes. As Wolf (1978) outlined, measures related to the appropriateness of goals, procedures, and outcomes (i.e., social validity) invariably rely on subjective responses. However, these subjective measures ensure that outcomes are salient to the individuals and others in their direct circle of support. While several different methods have been developed to assess social validity in the past several decades, including more formal instruments with rating scales, further research is still needed on how to best formulate outcomes that are beneficial for adults with ASD (Carter & Wheeler, 2019).

Some Considerations

The role of adults in selecting their own goals cannot be overemphasized. At the same time, certain ethical dilemmas do arise relative to balancing autonomy or individual rights with the right to an effective, habilitative environment. How do caregivers and professionals proceed when individuals make choices that are counter-habilitative? Are there circumstances that may necessitate compromising personal liberties? For adults who are more impacted by their disability, what does person-centered planning or self-determination look like? (For a detailed discussion on balancing personal rights with habilitation, see Bannerman et al. 1990; Van Houten et al. 1988.)

Bannerman et al. (1990) made several recommendations in their seminal article that are worth re-mentioning here. It is important to note that these recommendations apply to all individuals with disabilities, regardless of the severity of their disability. First, individuals' preferences should be emphasized when considering on which skills to focus. Second, individuals with disabilities should be involved in the decision-making process as it relates to outcomes or goals. Third, choice-making skills should be taught. Fourth, individuals should be given the opportunity to make choices throughout their daily activities. Overall, adults with ASD play a central role in dictating their own goals, and it is the responsibility of caregivers and professionals to facilitate choice and independence throughout the planning and treatment process.

Optimism for the Future

The Advancement and Outcomes of Behavior Interventions

Since the groundbreaking publication of Dr. Ivar Lovaas' EIBI research in both the 1970s and then the late 1980s (e.g., Lovaas et al., 1973; Lovaas, 1987), EIBI has been classified as a comprehensive, intensive intervention with overwhelmingly positive results (Peters-Scheffer et al., 2011). Despite the success of the UCLA Young Autism Project, and the many studies published confirming its effectiveness since, EIBI has not gone without criticism (Healy & Lydo, 2013). Some past and current criticisms of EIBI include its rigidity, underdeveloped generalization programming, and a more flexible, dynamic approach (Gruson-Wood, 2016). In response, researchers have championed for the use of more progressive approaches to ABA and other behavior interventions alike (e.g., Leaf et al., 2016b, 2020). For instance, progressive models of discrete trial teaching (DTT), often used in conjunction with EIBI, utilize more naturalized discriminative stimuli, emphasize stimulus generalization, and incorporate more environmental distractors in teaching (Koegel et al., 1999; Leaf et al., 2016a; Princiotta & Goldstein, 2013; Rogers, 2016).

Similarly, Leaf et al. (2016a) advocated for a progressive approach to ABA. They posited that conventional approaches to ABA are often more static and characteristically rule-governed, lacking the flexibility needed in an intervention claiming to focus on social contingencies. A progressive approach, on the other hand, encourages the use of clinical judgment rather than standalone protocols to more successful target socially relevant conditions. Even though documented outcomes have confirmed the effectiveness of a progressive approach to ABA (e.g., Leaf et al., 2016a, b, 2018), there remains an unmet need to operationally define and individualize our outcome criteria as technologically as we do our interventions.

Changes to Outcome Criteria in Adults with ASD

One way we have sought to improve the outcome evaluation process has been by broadening the inclusion criteria to allow for more individualization while also being more standardized with our methods of measurement. Preliminary adult outcome data was often criticized for its lack of specificity and validity (Bishop-Fitzpatrick et al., 2016). As a result, many researchers have worked to formulate outcome measures in a more clear and personalized manner (Farley et al., 2018). Outcome criteria for adults with ASD have historically been based on developmental milestones characteristic of neurotypical adults (i.e., living alone, having a career, marriage, home ownership). These long-standing societal expectations for emerging adulthood have started changing, leading to similar changes in how we measure outcomes for adults with ASD (Henninger & Taylor, 2013). In addition to this sociocultural shift in adult expectations, a focus on more specific refinement of outcome criteria is happening within behavior-analytic research. Definitions of success are now incorporating more subjective goals, personal preferences and characteristics, and an evaluation of outcomes based on person-environment fit (Henninger & Taylor, 2013; Ruble & Dalrymple, 1996; Slocum et al., 2014). For instance, an individual living in a residential home with a part-time job may evaluate their current circumstances positively based on their own perception of independence. As illustrated, subjective definitions for independence, self-reported quality of life, and personal circumstances are becoming more common outcome indicators.

The Importance of Validity on Social Impact

The individual and their personal contextual factors should determine what is and is not of socially significance (Ruble & Dalrymple, 1996). While Slocum et al. (2014) acknowledge our ability as behavior analysts to create and implement effective programs at the individual level, they retort that a broad social impact cannot be achieved until we are making changes at scales of social importance and across broader socially significant settings. This requires expansion of utility research, normalizing the evaluation of social validity, and emphasizing compassionate care as a standard practice (Slocum et al., 2014; Taylor et al., 2019; Wolf, 1978).

It goes without saying that it is important to demonstrate experimental control in research. A critique presented by Slocum et al. (2014), however, stated that an overly strict adherence to functional control can jeopardize the external validity of our findings if taken too far. Slocum's response to this criticism was to expand research, demonstrating treatment utility and generalization outcomes. A growing body of qualitative research evaluating autism in adolescence and adulthood is on the rise outside the field of behavior analysis (Anderson et al., 2018). With studies examining the views of adolescents with ASD on their education (Fayette & Bond, 2018), adults with autism on their involvement with music (Allen et al., 2009), and lived experiences of those with autism from youth to adulthood (DePape & Lindsay, 2016), there are emerging and existing models for evaluating interventions, developing treatment, and respecting personal experience to improve outcomes for those with ASD (e.g., Landon et al., 2016). Further, the need for more standardized social validity measures is long overdue (Ferguson et al., 2019) and essential for collaboration between parties, and evaluation of treatment outcomes should be utilized to improve the quality of life and the measurement of outcomes, for adults.

Compassionate Care as a Clinical Standard

Research has demonstrated that interpersonal collaboration between clients and providers leads to more positive treatment outcomes. Consequently, effective collaboration means that clinicians must demonstrate compassionate care as a clinical standard. Compassionate care, defined here as the integration of perspective taking, active listening, and empathic responding, is an important part of the therapeutic alliance. It facilitates an environment that encourages ongoing collaboration and interpersonal learning. To behave compassionately means clinicians must engage with their clients, responding with interventions and strategies that both respect the client's personal preferences and fall in suit with clinical and ethical training (Slocum et al., 2014; Taylor et al., 2019). Clinical methods may only be as successful as far as they are deemed meaningful and socially appropriate by our clients and compatible with other aspects of the individuals' environment (Baer et al., 1968).

With all forms of science, evolution is inevitable. As the landscape of autism-related treatment continues to grow throughout the years, so do our confidence in the advancement in the field of behavior analysis. While we reflect on the historical triumphs of past ABA researchers, we hold in parallel the urgent, communal call to action to carry the scientific torch forward in both research and practice – this is where our optimism for the future lies.

References

Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, down syndrome, or fragile X syndrome. *American Journal on Mental Retardation, 109*(3), 237–254. https://doi.org/10.1352/08958017(2004)109<237:PWACIM>2.0.CO;2

Allen, R., Hill, E., & Heaton, P. (2009). 'Hath charms to soothe …': An exploratory study of how high-functioning adults with ASD experience music. *Autism, 13*(1), 21–41. https://doi.org/10.1177/1362361307098511

Anderson, K. A., Sosnowy, C., Kuo, A. A., & Shattuck, P. T. (2018). Transition of individuals with autism to adulthood: A review of qualitative studies. *Pediatrics, 141*(Supplement 4), S318–S327. https://doi.org/10.1542/peds.2016-4300i

Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis, 1*(1), 91.

Bannerman, D. J., Sheldon, J. B., Sherman, J. A., & Harchik, A. E. (1990). Balancing the right to habilitation with the right to personal liberties: The rights of people with developmental disabilities to eat too many doughnuts and take a nap. *Journal of Applied Behavior Analysis, 23*(1), 79–89. https://doi.org/10.1901/jaba.1990.23-79

Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: Population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders, 35*(3), 351–360. https://doi.org/10.1007/s10803-005-3302-5

Billstedt, E., Gillberg, I, C., & Gillberg, C. (2011). Aspects of quality of life in adults diagnosed with autism in childhood. *Autism 15*(1), 7–20 https://doi.org/10.1177/1362361309346066

Bishop-Fitzpatrick, L., Minshew, N. J., & Eack, S. M. (2013). A systematic review of psychosocial interventions for adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(3), 687–694. https://doi.org/10.1007/s10803-012-1615-8

Bishop-Fitzpatrick, L., Hong, J., Smith, L. E., Makuch, R. A., Greenberg, J. S., & Mailick, M. R. (2016). Characterizing objective quality of life and normative outcomes in adults with autism spectrum disorder: An exploratory latent class analysis. *Journal of Autism and Developmental Disorders, 46*(8), 2707–2719. https://doi.org/10.1007/s10803-016-2816-3

Bowman, K. S., Suarez, V. D., & Weiss, M. J. (2021). Standards for interprofessional collaboration in the treatment of individuals with autism. *Behavior Analysis in Practice*. https://doi.org/10.1007/s40617-021-00560-0

Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities, 24*(1), 38–49. https://doi.org/10.1177/1088357608323699

Brugha, T. S., Doos, L., Tempier, A., Einfeld, S., & Howlin, P. (2015). Outcome measures in intervention trials for adults with autism spectrum disorders; a systematic review of assessments of core autism features and associated emotional and behavioural problems. *International Journal of Methods in Psychiatric*

Research, 24(2), 99–115. https://doi.org/10.1002/mpr.1466

Burgess, A. F., & Gutstein, S. E. (2007). Quality of life for people with autism: Raising the standard for evaluating successful outcomes. *Child and Adolescent Mental Health, 12*(2), 80–86. https://doi.org/10.1111/j.1475-3588.2006.00432.x

Burke, L. M., Kalpakjian, C. Z., Smith, Y. R., & Quint, E. H. (2010). Gynecologic issues of adolescents with Down syndrome, autism, and cerebral palsy. *Journal of Pediatric and Adolescent Gynecology, 23*(1), 11–15. https://doi.org/10.1016/j.jpag.2009.04.005

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism, 23*(6), 1431–1441. https://doi.org/10.1177/1362361318816053

Carr, J. E., Austin, J. L., Britton, L. N., Kellum, K. K., & Bailey, J. S. (1999). An assessment of social validity trends in applied behavior analysis. *Behavioral Interventions, 14*(4), 223–231. https://doi.org/10.1002/(SICI)1099-078X(199910/12)14:4<223::AIDBIN37>3.0.CO;2-Y

Carter, S. L., & Wheeler, J. J. (2019). *The social validity manual: Subjective evaluation of interventions* (2nd ed.). Academic.

Carter, A. S., Volkmar, F. R., Sparrow, S. S., Wang, J.-J., Lord, C., Dawson, G., Fombonne, E., Loveland, K., Mesibov, G., & Schopler, E. (1998). The Vineland Adaptive Behavior Scales: Supplementary norms for individuals with autism. *Journal of Autism and Developmental Disorders, 28*(4), 287–302. https://doi.org/10.1023/A:1026056518470

Centers for Disease Control and Prevention. (2020, March 25). *What is autism spectrum disorder*. https://www.cdc.gov/ncbddd/autism/facts.html

DaWalt, L. S., Usher, L. V., Greenberg, J. S., & Mailick, M. R. (2019). Friendships and social participation as markers of quality of life of adolescents and adults with fragile X syndrome and autism. *Autism, 23*(2), 383–393. https://doi.org/10.1177/1362361317709202

Dell'Armo, K. A., & Tassé, M. J. (2019). The role of adaptive behavior and parent expectations in predicting post-school outcomes for young adults with intellectual disability. *Journal of Autism and Developmental Disorders, 49*(4), 1638–1651. https://doi.org/10.1007/s10803-018-3857-6

DePape, A. M., & Lindsay, S. (2016). Lived experiences from the perspective of individuals with autism spectrum disorder: A qualitative meta-synthesis. *Focus on Autism and Other Developmental Disabilities, 31*(1), 60–71. https://doi.org/10.1177/1088357615587504

Ekas, N., & Whitman, T. L. (2010). Autism symptom topography and maternal socioemotional functioning. *American Journal on Intellectual and Developmental Disabilities, 115*(3), 234–249. https://doi.org/10.1352/1944-7558-115.3.234

Erwin, E. J., Brotherson, M. J., Palmer, S. B., Cook, C. C., Weigel, C. J., & Summers, J. A. (2009). How to promote self determination for young children with disabilities: Evidenced-based strategies for early childhood practitioners and families. *Young Exceptional Children, 12*(2), 27.

Farley, M., Cottle, K. J., Bilder, D., Viskochil, J., Coon, H., & McMahon, W. (2018). Mid-life social outcomes for a population-based sample of adults with ASD. *Autism Research, 11*(1), 142–152.

Fawcett, S. B. (1991). Social validity: A note on methodology. *Journal of Applied Behavior Analysis, 24*(2), 235–239. https://doi.org/10.1901/jaba.1991.24-23537

Fayette, R., & Bond, C. (2018). A systematic literature review of qualitative research methods for eliciting the views of young people with ASD about their educational experiences. *European Journal of Special Needs Education, 33*(3), 349–365. https://doi.org/10.1080/08856257.2017.1314111

Ferguson, J. L., Cihon, J. H., Leaf, J. B., Van Meter, S. M., McEachin, J., & Leaf, R. (2019). Assessment of social validity trends in the journal of applied behavior analysis. *European Journal of Behavior Analysis, 20*(1), 146–157. https://doi.org/10.1080/15021149.2018.1534771

Flannery, K. B., Newton, S., Horner, R. H., Slovic, R., Blumberg, R., & Ard, W. R. (2000). The impact of person centered planning on the content and organization of individual supports. *Career Development for Exceptional Individuals, 23*(2), 123–137. https://doi.org/10.1177/088572880002300202

Gerhardt, P. F., & Lainer, I. (2011). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy, 41*, 37–45. https://doi.org/10.1007/s10879-010-9160-2

Gillberg, C., & Steffenburg, S. (1987). Outcome and prognostic factors in infantile autism and similar conditions: A population-based study of 46 cases followed through puberty. *Journal of Autism and Developmental Disorders, 17*(2), 273–287. https://doi.org/10.1007/BF01495061

Gruson-Wood, J. F. (2016). Autism, expert discourses, and subjectification: A critical examination of applied behavioural therapies. *Studies in Social Justice, 10*(1), 38–58. https://doi.org/10.26522/ssj.v10i1.1331

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*, 629–642. https://doi.org/10.1007/s10803-012-1604-y

Healy, O., & Lydo, S. (2013). *Early intensive behavioural intervention in autism spectrum disorders*. InTech. https://doi.org/10.5772/54274

Henninger, N. A., & Taylor, J. L. (2013). Outcomes in adults with autism spectrum disorders: A historical perspective. *Autism, 17*(1), 103–116. https://doi.org/10.1177/1362361312441266

Hickey, G., McGilloway, S., O'Brien, M., Leckey, Y., Devlin, M., & Donnelly, M. (2018). Strengthening stakeholder buy-in and engagement for successful exploration and installation: A case study of the development of an area-wide, evidence-based prevention and early intervention strategy. *Children and Youth Services Review, 91*, 185–195. https://doi.org/10.1016/j.childyouth.2018.06.008

Hoffman, C. D., Sweeney, D. P., Hodge, D., Lopez-Wagner, M. C., & Looney, L. (2009). Parenting stress and closeness: Mothers of typically developing children and mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 24*(3), 178–787. https://doi.org/10.1177/1088357609338715

Holburn, S., Jacobson, J. W., Vietze, P. M., Schwartz, A. A., & Sersen, E. (2000). Quantifying the process and outcomes of person-centered planning. *American Journal of Mental Retardation, 105*(5), 402–416. https://doi.org/10.1352/0898017(2000)105<0402:QTPAOO>2.0.CO;2

Howlin, P., & Magiati, I. (2017). Autism spectrum disorder. *Current Opinion in Psychiatry, 30*(2), 69–76. https://doi.org/10.1097/YCO.0000000000000308

Howlin, P., Mawhood, L., & Rutter, M. (2000). Autism and developmental receptive language disorder—a follow-up comparison in early adult life. II: Social behavioural and psychiatric outcomes. *Journal of Child Psychology and Psychiatry, 41*(5), 561–578. https://doi.org/10.1111/1469-7610.00643

Kanner, L. (1971). Follow-up study of eleven autistic children originally reported in 1943. *Journal of Autism and Childhood Schizophrenia, 1*(2), 119–145. https://doi.org/10.1007/BF01537953

Koegel, L. K., Koegel, R. L., Harrower, J. K., & Carter, C. M. (1999). Pivotal response intervention I: Overview of approach. *Journal of the Association for Persons with Severe Handicaps, 24*(3), 174–185. https://doi.org/10.2511/rpsd.24.3.174

Landon, J., Shepherd, D., & Lodhia, V. (2016). A qualitative study of noise sensitivity in adults with autism spectrum disorder. *Research in Autism Spectrum Disorders, 32*, 43–52. https://doi.org/10.1016/j.rasd.2016.08.005

Leaf, J. B., Cihon, J. H., Leaf, R., McEachin, J., & Taubman, M. (2016a). A progressive approach to discrete trial teaching: Some current guidelines. *International Electronic Journal of Elementary Education, 9*(2), 361–372. Retrieved from https://www.iejee.com/index.php/IEJEE/article/view/163

Leaf, J. B., Leaf, R., McEachin, J., Taubman, M., Ala'i-Rosales, S., Ross, R. K., Smith, T., & Weiss, M. J. (2016b). Applied behavior analysis is a science and, therefore, progressive. *Journal of Autism and Developmental Disorders, 46*(2), 720–731. https://doi.org/10.1007/s10803-015-2591-6

Leaf, J. B., Leaf, R., McEachin, J., & Cihon, J. H. (2018). Progressive applied behavior analysis. In F. Volkmar (Ed.), *Encyclopedia of autism spectrum disorders*. Springer. https://doi.org/10.1007/978-1-4614-6435-8_102239-1

Leaf, J. B., Cihon, J. H., Ferguson, J. L., Milne, C. M., Leaf, R., & McEachin, J. (2020). Advances in our understanding of behavioral intervention: 1980 to 2020 for individuals diagnosed with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-020-04481-9

Lecavalier, L., Leone, S., & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 50*, 172–183. https://doi.org/10.1111/j.1365-2788.2005.00732.x

Leslie, D. L., Iskandarani, K., Dick, A. W., Mandell, D. S., Yu, H., Velott, D., Agbese, E., & Stein, B. D. (2017). The effects of Medicaid home and community-based services waivers on unmet needs among children with autism spectrum disorder. *Medical Care, 55*(1), 57–63. https://doi.org/10.1097/MLR.0000000000000621

Lima, R. C., Feldman, C., Evans, C., & Block, P. (2018). *Autism policy and advocacy in Brazil and the USA* (pp. 17–52). https://doi.org/10.1007/978-3-319-93293-4_2

Lounds Taylor, J., McPheeters, M. L., Sathe, N. A., Dove, D., Veenstra-VanderWeele, J., & Warren, Z. (2012). A systematic review of vocational interventions for young adults with autism spectrum disorders. *Pediatrics, 130*(3), 531–538. https://doi.org/10.1542/peds.2012-0682

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology, 55*(1), 3–9. https://doi.org/10.1037//0022-006x.55.1.3

Lovaas, O. I., Koegel, R., Simmons, J. Q., & Long, J. S. (1973). Some generalization and follow up measures on autistic children in behavior therapy 1. *Journal of Applied Behavior Analysis, 6*(1), 131–165.

Luiselli, J. K. (2017). Exercise, leisure, and physical well-being. In K. Shogren, M. Wehmeyer, & N. Singh (Eds.), *Handbook of positive psychology in intellectual and developmental disabilities* (Springer Series on Child and Family Studies). Springer. https://doi.org/10.1007/978-3-319-59066-0_12

Manente, C. J., Maraventano, J. C., LaRue, R. H., Delmolino, L., & Sloan, D. (2010). Effective behavioral intervention for adults on the autism spectrum: Best practices in functional assessment and treatment development. *The Behavior Analyst Today, 11*(1), 36–48.

Mann, L. E., & Travers, J. C. (2019). A systematic review of interventions to address inappropriate masturbation for individuals with autism spectrum disorder or other developmental disabilities. *Review Journal of Autism and Developmental Disorders*, 1–14. https://doi.org/10.1007/s40489-019-00192-9

Marcotte, J., Grandisson, M., Piquemal, C., Boucher, A., Rheault, M. È., & Milot, É. (2020). Supporting independence at home of people with autism spectrum disorder: Literature review. *Canadian Journal of Occupational Therapy. Revue canadienne d'ergothérapie, 87*(2), 100–116. https://doi.org/10.1177/0008417419890179

Marriage, S., Wolverton, A., & Marriage, K. (2009). Autism spectrum disorder grown up: A chart review of adult functioning. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 18*(4), 322.

Marsack-Topolewski, C. N., & Church, H. L. (2019). Impact of caregiver burden on quality of life for parents of adult children with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities, 124*(2), 145–156. https://doi.org/10.1352/1944-7558-124.2.145

Marsack-Topolewski, C. N., Samuel, P. S., & Tarraf, W. (2021). Empirical evaluation of the association between daily living skills of adults with autism and parental caregiver burden. *PLoS One, 16*(1), e0244844. https://doi.org/10.1371/journal.pone.0244844

Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research, 11*(8), 1138–1147. https://doi.org/10.1002/aur.1965

Mason, D., Capp, S. J., Stewart, G. R., Kempton, M. J., Glaser, K., Howlin, P., & Happé, F. (2021). A meta-analysis of outcome studies of autistic adults: Quantifying effect size, quality, and meta-regression. *Journal of Autism and Developmental Disorders, 51*(9), 3165–3179. https://doi.org/10.1007/s10803-020-04763-2

Matson, J. L., & Rivet, T. T. (2008). Characteristics of challenging behaviours in adults with autistic disorder, PDD-NOS, and intellectual disability. *Journal of Intellectual and Developmental Disabilities, 33*(4), 323–329. https://doi.org/10.1080/13668250802492600

McCauley, J. B., Pickles, A., Huerta, M., & Lord, C. (2020). Defining positive outcomes in more and less cognitively able autistic adults. *Autism Research, 13*(9), 1548–1560. https://doi.org/10.1002/aur.2359

McClannahan, L. E., MacDuff, G. S., & Krantz, P. J. (2002). Behavior analysis and intervention for adults with autism. *Behavior Modification, 26*(1), 9–26. https://doi.org/10.1177/0145445502026001002

McGrew, J. H., & Keyes, M. L. (2014). Caregiver stress during the first year after diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders, 8*, 1373–1385. https://doi.org/10.1016/j.rasd.2014.07.011

Medicaid. (n.d.). *Self-directed services*. https://www.medicaid.gov/medicaid/long-term-services-supports/self-directed-services/index.html

Meirsschaut, M., Roeyers, H., & Warreyn, P. (2010). Parenting in families with a child with autism spectrum disorder and a typically developing child: Mothers' experiences and cognitions. *Research in Autism Spectrum Disorders, 4*, 661–669. https://doi.org/10.1016/j.rasd.2010.01.002

Murphy, C. M., Wilson, C. E., Robertson, D. M., Ecker, C., Daly, E. M., Hammond, N., Galanopoulos, A., Dud, I., Murphy, D. G., & McAlonan, G. M. (2016). Autism spectrum disorder in adults: Diagnosis, management, and health services development. *Neuropsychiatric Disease and Treatment, 12*, 1669–1686. https://doi.org/10.2147/ndt.s65455

Novak, M., & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *The Gerontologist, 29*(6), 798–803. https://doi.org/10.1093/geront/29.6.798

Oakley, B. F., Tillmann, J., Ahmad, J., Crawley, D., San José Cáceres, A., Holt, R., Charman, T., Banaschewski, T., Buitelaar, J., & Simonoff, E. (2021). How do core autism traits and associated symptoms relate to quality of life? Findings from the Longitudinal European Autism Project. *Autism, 25*(2), 389–404.

Peters-Scheffer, N., Didden, R., Korzilius, H., & Sturmey, P. (2011). A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 5*(1), 60–69. https://doi.org/10.1016/j.rasd.2010.03.011

Princiotta, D., & Goldstein, S. (2013). Early start Denver model: An intervention for young children with autism spectrum disorders. In S. Goldstein & J. A. Naglieri (Eds.), *Interventions for autism spectrum disorders: Translating science into practice* (pp. 59–73). Springer. https://doi.org/10.1007/978-1-4614-5301-7_4

Reid, D. H., Everson, J. M., & Green, C. W. (1999). A systematic evaluation of preferences identified through person-centered planning for people with profound multiple disabilities. *Journal of Applied Behavior Analysis, 32*(4), 467–477. https://doi.org/10.1901/jaba.1999.32-467

Rodger, S., Keen, D., Braithwaite, M., & Cook, S. (2008). Mothers' satisfaction with a home based early intervention programme for children with ASD. *Journal of Applied Research in Intellectual Disabilities, 21*(2), 174–182. https://doi.org/10.1111/j.1468-3148.2007.00393.x

Rogers, S. (2016). Early start Denver model. In *Comprehensive models of autism spectrum disorder treatment* (pp. 45–62). Springer.

Rohrer, J. L., Marshall, K. B., Suzio, C., & Weiss, M. J. (2021). Soft skills: The case for compassionate approaches or how behavior analysis keeps finding its heart. *Behavior Analysis in Practice*. https://doi.org/10.1007/s40617-021-00563-x

Ruble, L. A., & Dalrymple, N. J. (1996). An alternative view of outcome in autism. *Focus on Autism and Other Developmental Disabilities, 11*(1), 3–14. https://doi.org/10.1177/108835769601100102

Rutter, M., Greenfeld, D., & Lockyer, L. (1967). A five to fifteen year follow-up study of infantile psychosis. II. Social and behavioural outcome. *The British Journal of Psychiatry, 113*(504), 1183–1199. https://doi.org/10.1192/bjp.113.504.1183

Schall, C. M. (2010). Positive behavior support: Supporting adults with autism spectrum disorders in the workplace. *Journal of Vocational Rehabilitation, 32*, 109–115. Retrieved https://worksupport.com/documents/JVRautismSchall_behavior.pdf

Schott, W., Nonnemacher, S., & Shea, L. (2021). Service use and unmet needs among adults with autism awaiting home- and community-based Medicaid services. *Journal of Autism and Developmental*

Disorders, 51(4), 1188–1200. https://doi.org/10.1007/s10803-02004593-2

Shattuck, P. T., Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., Bolt, D., Kring, S., Lounds, J., & Lord, C. (2007). Change in autism symptoms and maladaptive behavior in adolescents and adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 37*(9), 1735–1747. https://doi.org/10.1007/s10803-006-0307-7

Shattuck, P. T., Magner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post high school service use among young adults with autism spectrum disorder. *Archives of Pediatrics & Adolescent Medicine, 165*(2), 141–146. https://doi.org/10.1001/archpediatrics.2010.279

Slocum, T. A., Detrich, R., Wilczynski, S. M., Spencer, T. D., Lewis, T., & Wolfe, K. (2014). The evidence-based practice of applied behavior analysis. *The Behavior Analyst, 37*(1), 41–56. https://doi.org/10.1007/s40614-014-0005-2

Stanford, C. E., Totsika, V., & Hastings, R. P. (2020). 'Above and beyond': The perceptions of mothers of children with autism about 'good practice' by professionals and services. *Research in Autism Spectrum Disorders, 77*, 101615. https://doi.org/10.1016/j.rasd.2020.101615

Strain, P. S., Barton, E. E., & Dunlap, G. (2012). Lessons learned about the utility of social validity. *Education and Treatment of Children, 35*(2), 183–200. https://doi.org/10.1353/etc.2012.0007

Strauss, K., Vicari, S., Valeri, G., D'Elia, L., Arima, S., & Fava, L. (2012). Parent inclusion in early intensive behavioral intervention: The influence of parental stress, parent treatment fidelity and parent-mediated generalization of behavior targets on child outcomes. *Research in Developmental Disabilities, 33*(2), 688–703. https://doi.org/10.1016/j.ridd.2011.11.008

Tavernor, L., Barron, E., Rodgers, J., & McConachie, H. (2013). Finding out what matters: Validity of quality of life measurement in young people with ASD. *Child: Care, Health and Development, 39*(4), 592–601. https://doi.org/10.1111/j.1365-2214.2012.01377.x

Taylor, B. A., LeBlanc, L. A., & Nosik, M. R. (2019). Compassionate care in behavior analytic treatment: Can outcomes be enhanced by attending to relationships with caregivers? *Behavior Analysis in Practice, 12*(3), 654–666. https://doi.org/10.1007/s40617-018-00289-3

Tullis, C. A., & Seaman-Tullis, R. L. (2019). Incorporating preference assessment into transition planning for people with autism spectrum disorder. *Behavior Analysis in Practice, 12*(3), 727–733. https://doi.org/10.1007/s40617-019-00353-6

Van Houten, R., Axelrod, S., Bailey, J. S., Favell, J. E., Foxx, R. M., Iwata, B. A., & Lovaas, O. I. (1988). The right to effective behavioral treatment. *Journal of Applied Behavior Analysis, 21*(4), 381–384. https://doi.org/10.1901/jaba.1988.21-381

Walsh, L., Lydon, S., & Healy, O. (2014). Employment and vocational skills among individuals with autism spectrum disorder: Predictors, impact, and interventions. *Review Journal of Autism and Developmental Disorders, 1*, 266–275. https://doi.org/10.1007/s40489-0140024-7

Watson, S. L., Harding, K. D., & Hayes, S. A. (2013). Autism spectrum disorder and fetal alcohol spectrum disorder. Part 1: A comparison of parenting stress. *Journal of Intellectual & Developmental Disability, 38*(2), 95–104. https://doi.org/10.3109/13668250.2013.788136

Wolf, M. M. (1978). Social validity: The case for subjective measurement or how applied behavior analysis is finding its heart. *Journal of Applied Behavior Analysis, 11*(2), 203–214. https://doi.org/10.1901/jaba.1978.11-203

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On Predicting the Future: Recommendations for the Field of ABA in Supporting Adults with ASD

Peter F. Gerhardt, Shanna N. Bahry, Brian Mason, and Maria Sasaki Solis

What does the future hold for autistic adults across the age and ability spectrum? Absent the sudden development of an ability to see into the future or one of us stumbling upon the secret of time travel, the only way to even attempt to answer that question is to offer up our vision for what we hope will be the future for adults with autism, and the role the science of applied behavior analysis (ABA) will play in that future. Even then, given the diversity that defines the autism spectrum, and the myriad applications and, at times, misapplications, of ABA-based interventions, we may, at best, only be able to speculate about what the future holds for a relatively narrow cohort of autistic adults at a defined time in their lives. Does not seem all that promising, does it?

Maybe not, but there is still a good reason to try. Lewis Carroll (1865) in *Alice's Adventures in Wonderland* has the following exchange take place between Alice and the Cheshire Cat:

> "Would you tell me, please, which way I ought to go from here?"
>
> "That depends a good deal on where you want to get to," said the Cat.
>
> "I don't much care where—" said Alice.
>
> "Then it doesn't matter which way you go," said the Cat.
>
> "—so long as I get SOMEWHERE," Alice added as an explanation.
>
> "Oh, you're sure to do that," said the Cat, "if you only walk long enough." (p. 76–77).

This exchange has since been paraphrased (and repeatedly "memed") to "If you don't know where you're going, any road will get you there." In other words, having an idea as to what a field's future should look like is necessary to make even incremental progress toward that future. With that in mind, we have identified what we consider to be a short set of highly desirable and reasonably attainable recommendations for shaping the future of the field of ABA to best support adults on the autism spectrum. These recommendations include (a) the application of increasingly progressive ABA-based interventions and supports that are person-focused, comprehensive, and tied to improved quality of life in both current and future environments; (b) the development of strategies for inclusion that go beyond physical inclusion and are implemented across the lifespan; (c) the continuing professionalization of the field of adult services to increase staff retention/motivate long-lasting career paths and justify funding sources; and (d) further research to support the use of ABA-based interventions for adolescents and adults with ASD to inform

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programming and support the use of ABA-based interventions in older learners.

Person-Focused, Progressive ABA-Based Interventions for Improved Quality of Life

In order for ABA-based interventions to improve the quality of life for autistic adults, the field needs to apply increasingly progressive ABA-based processes (Leaf et al., 2016) and interventions that are person-focused and comprehensive. Let us take a minute and break this down a bit. Person-focused refers to the idea that the entire program of behavioral intervention needs to be designed around a single person and target the strengths and interests of that person while creatively addressing the impact of skill deficits. Not easy to do, and certainly not contained anywhere in the Behavior Analytic Certification Board (BACB) Task List (BACB, 2017), but critical, nonetheless. Person-focused interventions are critical because quality of life (QoL) is highly idiosyncratic and changes across the lifespan of each individual. In general, QoL has been reported as lower for individuals on the spectrum than it is for their typical peers (Ayres et al., 2018). The use of QoL as an outcome measure requires a recognition that the interactions between the different parts of our lives equate to the totality of our lives and define the features of a whole, fully realized life (Roux et al., 2015). Isolated skills acquired out of the natural context and displayed only when directed (e.g., "John, time to do your laundry") probably contribute little to the whole of one's life. While the mix of these parts may be different for each person, the interactions between preferred social relationships, desirable living environment, preferred employment, financial security, level of education, ability to make choices, and exercise control over these choices, and our physical and mental health come together to define, at least in part, one's QoL (see Dell'Armo & Tassé, 2019; Kirby et al., 2016; Moss et al., 2017; Roux et al., 2015).

To effectively individualize treatment to promote unique improvements in QoL, intervention must be comprehensive and include targets that are related to often neglected aspects of adult life (Gerhardt & Lainer, 2011). Full participation in some of these areas (e.g., independence, self-management, sexuality, personal safety, time management, self-advocacy) may require the acquisition of complex discrimination and decision-making skills requiring these aspects to be targeted early and often to ensure acquisition to whatever level possible (e.g., Gerhardt et al., 2013). While it is true across all skill domains, for these neglected aspects of transition, measures of social validity are of particular importance to ensure significant and valued behavior change (Schwartz & Baer, 1991; Wolf, 1978).

To that end, when working with adults on the spectrum, competent behavior analysts will need to ask:

- What does this person want to do?
- What life experiences, positive and negative, may impact how interventions are to be developed and implemented?
- What makes this person happy? Sad? Angry?
- What behavioral idiosyncrasies are highly valued by this person?
- How does this person most effectively communicate?
- What are this person's preferred environmental conditions?
- And so on….

As stated earlier, there is a significant need for a greater emphasis on the use of progressive behavior analytic processes. Leaf et al. (2016) defined progressive behavior analysis as an approach to intervention that is structured, yet flexible, and contingent upon, and responsive to, socially valid [*adult*] progress. The need to produce analysts who are not just tool users is emphasized in the progressive approach (Leaf et al., 2016). So, instead of rigid adherence to skills assessments and published curricula to drive programming, the progressive behavior analyst endeavors to have the person on spectrum, independent of where they are on the spectrum, tell them what they need or want. This is not to say that the use of assessments and established curricula is inherently bad. Assessments and established curricula can be quite helpful but should never be the only source of information to guide intervention. Truly person-focused programming aimed at improving quality of life will be highly individualized and should not be constrained to the skills contained within any one tool.

In order to teach the extensive and complex skills that are necessary to live as independent an adult life as possible, there may need to be some sacrifice of treatment integrity which would be made up for by the gain in social validity. Behavior analysts will need to be comfortable with utilizing teaching procedures that go beyond simple discrete trial teaching while sitting at desk to teaching in far less controlled environments (see Gerhardt & Lainer, 2011; Gerhardt et al., 2013; Leaf et al., 2016) across the community, using interventions such as chaining (e.g., Lambert et al., 2016), modeling (e.g., Allen et al., 2010), shaping (e.g., Shabani & Fisher, 2006), differential reinforcement (e.g., Sigafoos et al., 2009), and readily accessible and practical technology-based resources such as smartphones (e.g., Walsh et al., 2017). Many of these procedures may be more age-appropriate for older individuals as well (e.g., physical prompting may be widely accepted for a 3-year-old, but not a 13-year-old).

Progressive behavior analysts, as Leaf et al. (2016) noted, analyze behavior and environment interactions on a moment-by-moment basis. In teaching complex skills needed in adulthood, this may mean the use of more context-driven reinforcement (e.g., adding a preferred item to the shopping cart when wrapping up grocery shopping) and adapting to the readily changing, unpredictable nature of community-based instruction. Progressive behavior analysts are, "shaped by clear goal specification, knowledge of principles, scientific method, and current environmental contingencies, instead of rigid adherence to unresponsive protocols" (Leaf et al., 2016, p. 721). With respect to approaching adulthood, this necessitates practitioners being open to changing procedures and skills targets when sufficient progress is not being made in order to maximize skill acquisition and promote the best outcomes.

Only by adopting a more progressive behavior analytic perspective when working with individuals with autism will long-term outcomes for adults improve. But why would the field move in that direction in the first place? The answer is simple. Quality ABA-based intervention is characterized by the resulting outcomes. As increasing numbers of behavior analysts adopt a progressive behavior analytic orientation and practice, the potential for more positive outcomes increases. Contingent on progressive, evidence-based behavior analytic practice, positive outcomes will become more common, and the positive reinforcement (including economic reinforcement) will increase. The strength of our outcomes mirrors the strengths of our science which will, moving forward, drive broader adoption.

Strategies for Inclusion Across the Lifespan

Like many features in our lives, terminology is important and is influenced by our past learning history, current reinforcement, and complex interactions of verbal behavior. The terms integration and inclusion are often found in discussions of a path forward for individuals with autism. When we search for a formal definition as our guide, the Oxford Dictionary online defines inclusion as "the fact or policy of providing equal opportunities and resources for people who might otherwise not get them, for example people who are *disabled* or belong to minority groups" (Oxford Learner's Dictionary, n.d.). The Merriam-Webster Dictionary online adds: "the act or practice of including and accommodating people who have historically been excluded (as because of their race, gender, sexuality, or ability)" (Merriam-Webster, n.d.)

However, the current interpretation of the term inclusion and the practices involved currently fall far short of the true vision of equal opportunity and understanding for those living with autism (Schall et al., 2015). Inclusion has often been interpreted as a physical act and has included having those with a disability seated in the same space or joining into the same activities as typical peers. This interpretation places the responsibility upon the individual to demonstrate enough of the required skills to, in effect, earn social inclusion. It remains vital that our practices move away from a narrow interpretation of what it means to be integrated into society. Integration may be legislated and operationalized, but true inclusion requires a shift in responsibility away from the individual to make this happen. This means new ways of teaching, systematic removal of barriers, creatively developing work opportunities, and rightfully giving a voice and decision-making opportunities to those with ASD. With these goals, the responsibility of inclusion is upon the community to learn the skills, adopt practices, and provide supports for individuals on the autism spectrum.

Jung et al. (2019) emphasized that any movement to inclusion starts with a vision. Having a vision of inclusive communities, workplaces, and educational systems allows the programmatic focus to remain on the goal of living, learning, and working together. Absent such a vision, the process is at risk of a series of never-ending policy revisions or partial measures (Jung et al., 2019). Within any workplace, organization, or educational system, processes will change, staff turnover will occur, and new priorities will emerge that may interfere with existing inclusion procedures, but the accepted vision will remain. Kotter (2012) noted that vision is essential to motivating people to take action in a coordinated manner all headed in the right direction independent of the environmental context. This vision requires inclusion efforts in the classroom, workplace, and community.

Inclusion Efforts in the Classroom

Discussion about the need and benefits of inclusion for adolescents and adults with ASD and other disabilities has been going on for many decades (Mesibov & Shea, 1996; Schopler & Bristol, 1980; Stainback & Stainback 1984; Strain, 1983). In the early 1990s, researchers (e.g., Jordan & Powell, 1994; McGee et al., 1993; Myles et al., 1993) were investigating ways by which the field of education could move toward inclusion by "mainstreaming" students (McGregor, 1997). At the same time, there was an emergent literature calling for a move-away from the "expert model" where there is a single point of authority/information and an inflexible hierarchy below that to a more collaborative approach (McGregor, 1997). However, advocates, families, and clinicians have been arguing just as long for opportunities for *meaningful inclusion* (i.e., inclusion across multiple aspects of education and that does not focus on changing the individual with a disability). Much of this advocacy has largely been in isolated pockets (Lima et al., 2018; Ward & Meyer, 1999). While these efforts are to be applauded, society continues to come up short in meeting the goal of inclusion. For example, the Individuals with Disabilities Education Improvement Act of 2004 (IDEA, 2004) requires that students are given access to the general education curriculum, to the extent possible, in order to promote inclusion and equal opportunity. While some advocate that it is the right of individuals with disabilities to have this access (see Courtade et al., 2012), targeting general education curriculum should not be done at the expense of targeting skills that will improve independent functioning in adulthood and increase quality of life (Ayres et al., 2011; Ayres et al., 2012).

Central to this recommendation is that well-intended efforts to promote the inclusion of persons with autism do not, unintentionally, cause distress. Comprehensive school/educational inclusion is a complex process requiring more than just the provision of a "Velcro-aide"[1] in the classroom. Previous research (e.g., Able et al., 2014; Corkum et al., 2014; LeBlanc et al., 2009) has found that school staff often lack knowledge about the specific characteristics and needs of students with autism and the practices that effectively support these students in inclu-

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[1] "Velcro-aide" is an unofficial special education term referring to an in-school 1:1 aide who never leaves the side of their assigned student.

sive education settings and so many may be reluctant to even make the attempt. Recent reports (e.g., Rowley et al., 2012) indicate an unacceptably high prevalence of bullying and social isolation in some inclusive environments. Comprehensive, socially valid, school-based inclusion is a complex process requiring the professionals involved to monitor myriad variables and conditions. The long-term benefits, however, would seem to make this a worthwhile effort.

Workplace Inclusion and Adults with ASD

Workplaces have been slow to adopt inclusive practices that support adults with autism and other neurodivergent individuals to meaningfully contribute to a workplace (Hendricks, 2010). While many employers may be knowledgeable about the parameters and benefits of providing reasonable accommodations to new hires with physical challenges, they are far less knowledgeable about what constitutes a reasonable accommodation for a potential neurodivergent hire. While adults on the spectrum are far less likely to be employed than neurotypicals, for those who have found employment, there is a tendency for them to be paid less than even other employees with disabilities, work less hours, have inconsistent benefits, and work in positions that are often below their actual ability and carry little in the way of status (e.g., an adult with a bachelor's degree stocking and collecting carts in the supermarket parking lot; Alverson & Yamamoto, 2017; Burgess & Cimera, 2014; Lee et al., 2018; Roux et al., 2015).

A recent review of workplace inclusion practice by Santuzzi et al. (2021) brings to light an important consideration with respect to the act of disclosure in our understanding of workforce participation. Although new hires may be encouraged by their family, support staff, or advocates to complete self-disclosure forms, new employees may be reluctant to disclose their disability label or diagnosis. Working with employers to reduce the stigma that may be associated with disclosure and provide a richer understanding of inclusion among its employees will ideally improve the comfort of those making the self-disclosure (Santuzzi et al., 2021). This is just one of a number of potential barriers to workplace inclusion that will require sensitivity and foresight to address.

How well workplace leaders understand ASD in general is a predictor of successful employment for autistic adults (Bowman, 2020). Increased knowledge of, and familiarity with, autism by co-workers has been shown to improve communication, facilitate positive relationships, and minimize conflict (e.g., Nicholas et al., 2018). This should not be surprising, as the same positive impact can be seen in schools when teachers understand the diverse needs for their students with autism (Hayes et al., 2013; Webster & De Boer, 2019). In the workplace, studies (Harmuth et al., 2018); Nicholas et al., 2018; Wehman et al., 2016) have shown that job coaches and mentoring systems are both effective forms of on-the-job training and improve socialization between all employees. For example, Nicholas et al. (2018) studied a unique approach of building an ecosystem to support an individual in competitive employment. A core component of the ecosystem includes employer engagement in understanding ASD, using accommodations appropriately, and leading all employees to support the work. The ecosystem model also prioritized employment readiness skills and prior exposure to work, two important indicators of successful employment.

Community Inclusion

In the community at large, there is a need to expand beyond compliance with legislation (e.g., Americans with Disabilities Act; ADA, 1990) and instead be exposed to potentially reinforcing contingencies and environmental cues that may evoke behavior that promotes inclusionary practice. If we combine a guiding vision with evidence-based practices, movement toward the goal for inclusion should become increasingly likely. Although significantly more complex than school or employment inclusion, much of the structure used to establish inclusive practices in those environments can, ideally, be applied to the greater community. One challenge, however, is what may be accommodating for one adult on the spectrum may be distracting or disorienting for another. For example, inclusionary practices for adults with autism in public spaces might begin with the provision of designated "quiet spaces," rocking chairs, and single-stall bathrooms and the absence of fluorescent lighting or chemical smells. However, what is aversive to one individual may be unnoticed or even pleasant by another. This means that attempts to simply add universal accommodations into any number of aspects of community living will likely fail. True community inclusion will likely be a more gradual process that looks a little bit different for each adult.

Continuing Professionalization of the Field of Adult Services

When graduating from school and beginning adulthood, a neurotypical individual expects this to be the most interesting, challenging, invigorating, infuriating, emotional, risky, and passionate time of their lives. However, an adult on the spectrum transitions into a adult system that is generally not set up to adequately support them across a multi-faceted adulthood. When they do receive support, their direct support professional likely only had to provide a valid driver's license, pass a criminal background check, and sit through 2–4 weeks of state-mandated training to be hired. Nobody, it seems, goes to college to work with adults on the spectrum. Nobody. However, if you want to work with children with autism in any decision-making capacity, it will require an earned master's degree in either special education, speech and language pathology, occupational therapy, applied behavior analysis, or some related field (e.g., Best Accredited Colleges, 2021). To be sure, there are pockets of excellence in adult services in, most likely, all 50 states. But they tend to be small and somewhat quiet and tend not to conduct or publish research, leaving them to continue with the work they do without a lot of fanfare. Again, nobody goes to college to work with adults with autism. The field is simply not seen as a career path to, well, anywhere.

Generally speaking, the field of adult services is at a considerable disadvantage when it comes to supporting individuals on the spectrum. Adult services are generally funded at the level far less than are educational services (e.g., Autism Speaks, n.d.-a, b; IDEA, 2004), creating a wide disparity in resources and staffing, leaving countless individuals either unsupported or undersupported (Gerhardt & Lainer, 2011; Roux et al., 2015). In 2017, the President's Committee for People with Intellectual Disabilities (PCPID) identified the adult services direct support workforce crisis and its collateral effects on people with intellectual disabilities, families, communities, and the economy, as the most pressing issue facing this group in the United States. In this report, the PCPID (2017) stated, "The direct support workforce and the service system that supports it are in a crisis that will result in catastrophic outcomes for people with ID and their families unless significant and immediate responses are implemented" (p. 8). Allocation of funding and resources to increase the workforce that supports the ASD population into adulthood is a critical concern for the future of the field of ABA in its efforts to support individuals on the spectrum.

Among the issues related to supporting the workforce cited by the PCPID (2017) were (a) low wages; (b) growing demand for services due to the growth and aging of the US population; (c) demographics shifts resulting in fewer people moving into the direct support personnel (DSP) workforce; (d) low wages, poor access to health insurance, and lack of paid time off or other benefits; (e) high stress; (e) insufficient training and preparation for DSP roles; and (f) lack of professional recognition and status for skilled DSPs. These issues are critical to the successful future of adults on the autism spectrum and can be thought of as a roadmap to fixing the system that supports them.

The Behavior Health Center of Excellence (BHCOE®) recently released its ABA Compensation and Turnover Report (BHCOE, 2021), which reported that between the years

2018 and 2020, turnover steadily increased (increases of 8.5% for direct care staff, 2.5% for supervisor staff, and 13% for clinical directors). The primary reason cited for turnover for direct care and supervisory ABA staff was voluntary departure (BHCOE, 2021). For DSPs working with adults with intellectual and developmental disabilities (IDD), the numbers are even worse (Friedman, 2021). The turnover rate for DSPs is considerably higher, with estimates ranging from 30% to 70% turnover a year. For DSPs who left their positions after only 6 months, factors included wages, no paid time off or health insurance, high staff vacancy rates, and low staff sizes, leaving the cycle of turnover to perpetuate (Friedman, 2021).

Staffing issues are exacerbated by the fact that many human service professions employ essential workers who do not get reprieve even during extreme situations such as a global pandemic. Although data for 2021 are not yet available as of this writing, it would not be surprising to see the extent to which COVID-19 pandemic and subsequent national labor shortage has exacerbated the staffing crisis in the field. Jimenez-Gomez et al. (2021) reported a snapshot of the impact of COVID-19 on the ABA workforce and noted that job insecurity, decreased productivity, and increased burnout compromised the ability of behavior analysts to provide effective services for clients.

Recruiting and retaining excellent support personnel will help ensure excellent adult services. In the United States, occupational prestige (e.g., Treiman, 1977) represents an arbitrary ranking of a job based on that job's perceived worthiness by others. In US News and World Report's 2021 List of 100 Best Jobs (US News, 2021), neither adult service provider nor DSP made the list, but speech therapist (i.e., #7) and occupational therapist (i.e., #19) did, as well as massage therapist (i.e., #58) and nail technician (i.e., #68). This is something that can be changed. ABA is a science that is highly effective at changing human behavior and even contains a subspecialty that focuses on the behavior of people in the workplace based on modification of environmental variables (Bucklin et al., 2000; OBM Network, 2021). Friedman (2021) noted that adult services agencies can improve DSP retention (and the subsequent health, safety, and security of adults with IDD) by providing ongoing, relevant staff development opportunities to DSPs. Establishing a field of intervention, support, and services that is equitably paid and professionally respected and can attract some of the most talented, energetic, and forward-thinking candidates that might otherwise go elsewhere should be a central tenant of any vision for the future.

Ultimately, society needs to show that they care about adults on the spectrum by adequately and equitably funding the necessary services and supports. This might require us to shed more light on the current reality of adult services (in other words, the ghost of Christmas yet to be). Otherwise, even those who work to educate children with autism will remain blissfully unaware of the unfortunate state of adult services and supports once people age out of school. It is imperative that autistic adults are not allowed to slip through the cracks of the system and be even less visible to society than they might otherwise be. If the governmental and societal will is there, resources can be allocated to better support adult services, starting with supporting these individuals with adequately trained professionals on a career path with long-term dedication to the field. There may be many ways to secure adequate funding to support this endeavor. For example, state Medicaid reimbursement rates can be increased, allowing for an increase in wages, and ideally health insurance coverage might also be made more widely available to support behavior analytic services across the lifespan, without limitations based on age (see Autism Speaks, n.d.-a, b). With further professionalization of the field, the crisis facing services for adults on the spectrum should ideally be resolvable.

Further Research to Support the Use of ABA in Adolescents and Adults with ASD

Finally, additional research is needed to support the use of ABA-based interventions with adolescents and adults with ASD to inform evidence-based programming and practice. A prevailing myth in autism intervention is the existence of an "expiration date" on the utility and effectiveness of intervention based on the principles of ABA. The persistence of this myth can potentially be understood as an unexpected consequence of Lovaas (1987) where 47% of the autistic children in the study achieved "normal intelligence and educational funding" (p. 1) as the result of intensive behavior analytic intervention. The media and the field of behavior analysis itself have broadly promoted this study (e.g., according to Google Scholar, it has been cited over 4900 times since its publication), leaving many outside of behavior analysis (e.g., teachers, funding sources, families, general public) to believe that ABA-based intervention is primarily useful with young children on the spectrum. Because there is not similar large-scale, randomized control trial research showing that autistic teens and/or adults can achieve similar outcomes from their peers when provided with intensive behavior analytic intervention, the value of ABA-based intervention for them is viewed as limited by those outside of the field. The problem is, this perspective is flawed. The goal of evidenced-based, behavior analytic intervention with older individuals is not now, nor has it ever been, to "fix" the person with ASD and/or to make them indistinguishable from their peers. The goal of person-focused, progressive behavior analytic intervention is, or should be, to change behavior in a way that results in greater opportunities for the individual in question to have an increasingly positive, individually determined, QoL (Schwartz & Baer, 1991; Schwarz & Kelly, 2021; Wolf, 1978). This goal does not expire at an arbitrary age.

While the body of behavior analytic research addressing the needs of children with ASD is, admittedly, larger and more sophisticated (Howlin, 2021; Leaf et al., 2021), there is a growing interest and subsequent body of research targeting community, social, and adaptive behavior competencies with adults on the spectrum (e.g., Anderson & Carr, 2021; Gerhardt et al., 2014; LaRue et al., 2020; Tincani & Bondy, 2014). This is, unfortunately, a somewhat recent phenomenon. Additionally, current research on older learners on the spectrum may suffer from design flaws that require additional research to mediate in order to develop a comprehensive and useful research base (Shattuck et al., 2020). These methodological issues should be taken into consideration in future research. Research funding also needs to be appropriately allocated to areas across the lifespan. Of note, in their examination of funded ASD research, the Interagency Autism Coordinating Committee noted that as of 2016, only 2% of research was dedicated to examining how to best meet the needs of people with ASD as they progress into and through adulthood (IACC, 2019). This disparity clearly needs to be remediated.

With regard to services for adults with ASD, there is a significant need to research the effectiveness of ABA-based intervention that is more progressive, person-focused, context relevant, and collaborative, and that results in truly socially significant outcomes. Additionally, future research should further identify what specific skills or abilities are critical to promoting improved outcomes and what behavioral excesses may limit community participation. Input from autistic adults, caregivers, other professionals, and community members should be collected to help inform what skills are truly necessary and should be prioritized. Finally, in order to make a large impact on the vast world of adulthood and promote expansion and dissemination across disciplines, large-scale, longitudinal studies (e.g., the NLT-2, see Roux et al., 2015) and randomized control trials are likely necessary (Smith, 2013). Such research will be highly beneficial in advocating for more substantial funding and resources to support older individuals on the autism spectrum. These findings, most importantly, then need to be translated into common practice.

Conclusion

The future we envision for adults with autism will not happen on its own. Collectively, autistic adolescents and adults, their family members, educators, behavior analysts, other professionals, funders, employers, and the community at large will need to identify the goals, develop the policies, and implement the processes that will, eventually, form the basis for that future. This will not be an easy process, but it is a worthwhile and necessary one. At the heart of all of this, in our opinion, is the application of increasingly progressive ABA-based interventions and support that are person-focused, comprehensive, and committed to improving quality of life in the supported individual's present and future. Along with this, we believe strategies need to be developed to support inclusion across classrooms, workplaces, and community settings that are implemented across an individual's lifespan. Third, and arguably most importantly, we argue for the continued professionalization of the field of adult services. The failure to professionalize the field of adult services will, unfortunately, make advancements in other areas, somewhat moot. The current state of DSP retention in adult services is, sadly, a reflection of how society at large values adults with ASD and/or IDD, and that must change. Finally, we suggest that further research supporting the use of ABA-based interventions for older learners will inform programming and help in advocating for additional research to help support this underserved population. We maintain that these recommendations are needed to ensure progress and maintain integrity in the overall vision of the future.

Despite the need for improvement in the aforementioned areas, we remain optimistic about the future of programs and services for autistic adults across the ability spectrum. This book itself is a good example of why. The focus on QoL, the diversity of topics, and the experience and expertise of the authors are good indicators of the growing interest in how best to meet the needs of autistic adults. In addition, there is a growing recognition, on the part of the professional community, of the need to improve our ability to partner with our students, adult clients, and their families to develop meaningful goals with the potential to contribute to an overall positive QoL. The final reason? In many ways, positive outcomes for autistic adults are limited more by our lack of vision as to what is possible than almost any other obstacle. The only person who should be able to decide what they can and cannot do is the person themself. Far too many opportunities are left on the table when we say things like, "They won't be able to do that." Whether you are right or wrong is not the point. The point is, when you partner with people, it is no longer just your decision to make. In short, no one can predict the future for adults with autism; however, we can do our best to help by first establishing a vision for what we hope that future will be, including how the science of applied behavior analysis will play a role in securing that future.

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References

Able, S., Sreckovic, M. A., Schultz, T. A., Garwood, J. D., & Sherman, J. (2014). Views from the trenches: Teacher and student supports needed for full inclusion of students with ASD. *Teacher Education and Special Education, 38*, 44–57. https://doi.org/10.1177/0888406414558096

Allen, K. D., Wallace, D. P., Greene, D. J., Bowen, S. L., & Burke, R. V. (2010). Community-based vocational instruction using videotaped modeling for young adults with autism spectrum disorders performing in air-inflated mascots. *Focus on Autism and Other Developmental Disabilities, 25*, 186–192.

Alverson, C. Y., & Yamamoto, S. H. (2017). Employment outcomes of vocational rehabilitation clients with autism spectrum disorders. *Career Development and Transition for Exceptional Individuals, 40*(3), 144–155. https://doi.org/10.1177/2165143416629366

Americans With Disabilities Act of 1990, 42 U.S.C. § 12101 et seq. (1990). https://www.ada.gov/pubs/adastatute08.htm

Anderson, A., & Carr, M. (2021). Applied behaviour analysis for autism: Evidence, issues, and implementation barriers. *Current Developmental Disorders Report*. Advance Online Publication. https://doi.org/10.1007/s40474-021-00237-x

Autism Speaks. (n.d.-a). *Autism statistics and facts*. https://www.autismspeaks.org/autism-statistics-asd.

Autism Speaks. (n.d.-b). *State regulated health benefits.* https://www.autismspeaks.org/state-regulated-health-benefit-plans

Ayres, K. M., Douglas, K. H., Lowrey, K. A., & Sievers, C. (2011). I can identify Saturn but I can't brush my teeth: What happens when the curricular focus for students with severe disabilities shifts. *Education and Training in Autism and Developmental Disabilities, 46*(1), 11–21. http://www.dddcec.org

Ayres, K. M., Lowrey, K. A., Douglas, K. H., & Sievers, C. (2012). The question still remains: What happens when the curricular focus for students with severe disabilities shifts? A reply to Courtade, Spooner, Browder, and Jimenez (2012). *Education and Training in Autism and Developmental Disabilities, 47*(1), 14–22. http://www.jstor.org/stable/23880558

Ayres, M., Parr, J. R., Rodgers, J., Mason, D., Avery, L., & Flynn, D. (2018). A systematic review of quality of life of adults on the autism spectrum. *Autism, 22*(7), 774–783. https://doi.org/10.1177/1362361317714988

Behavior Analyst Certification Board (BACB). (2017). *BCBA task list* (5th ed.). https://www.bacb.com/wp-content/uploads/2020/08/BCBA-task-list-5th-ed-211019.pdf

Behavioral Health Center of Excellence (BHCOE). (2021). *2021 ABA compensation & turnover report*. Retrieved December 21, 2021, from https://www.bhcoe.org/project/2021-aba-compensation-and-turnover-report/

Best Accredited Colleges. (2021). *Careers in Autism Education: Job Options and Education Requirements.* Retrieved December 22, 2021, from https://bestaccreditedcolleges.org/articles/careers-in-autism-education-job-options-and-education-requirements.html

Bowman, A. D. (2020). What we know about employers' perspectives on successfully integrating adults with autism spectrum disorders in the workplace. *International Journal of Psychiatry Research, 3*(1), 1–4. https://doi.org/10.33425/2641-4317.1054

Bucklin, B. R., Alvero, A. M., Dickinson, A. M., Austin, J., & Jackson, A. K. (2000). Industrial-organizational psychology and organizational behavior management. *Journal of Organizational Behavior Management, 20*(2), 27–75. https://doi.org/10.1300/J075v20n02_03

Burgess, S., & Cimera, R. E. (2014). Employment outcomes of transition-aged adults with autism spectrum disorders: A state of the States report. *American Journal on Intellectual and Developmental Disabilities, 119*(1), 64–83. https://doi.org/10.1352/1944-7558-119.1.64

Corkum, P., Bryson, S. E., Smith, I. M., Giffin, C., Hume, K., & Power, A. (2014). Professional development needs for educators working with children with autism spectrum disorders in inclusive school environments. *Exceptionality, 24*, 33–47. https://doi.org/10.5206/eei.v24i1.7709

Courtade, G., Spooner, F., Browder, D., & Jimenez, B. (2012). Seven reasons to promote standards-based instruction for students with severe disabilities: A reply to Ayres, Lowrey, Douglas, & Sievers (2011). *Education and Training in Autism and Developmental Disabilities, 47*(1), 3–13. http://www.jstor.org/stable/23880557

Dell'Armo, K. A., & Tassé, M. J. (2019). The role of adaptive behavior and parent expectations in predicting post-school outcomes for young adults with intellectual disability. *Journal of Autism and Developmental Disorders, 49*(4), 1638–1651. https://doi.org/10.1007/s10803-018-3857-6

Friedman, C. (2021). The impact of direct support professional turnover on the health and safety of people with intellectual and developmental disabilities. *Inclusion, 9*, 63–73. https://doi.org/10.1352/2326-6988-9.1.63

Gerhardt, P. F., & Lainer, I. (2011). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy, 41*, 37–45. https://doi.org/10.1007/s10879-010-9160-2

Gerhardt, P. F., Zawacki, J., & Satriale, G. (2013). Adaptive behavior in adolescents and adults with autism spectrum disorders. In P. F. Gerhardt & D. Crimmins (Eds.), *Social skill and adaptive behavior intervention with learners with autism* (pp. 159–170). Brookes Publishing.

Gerhardt, P. F., Garcia, M. F., & Foglia, A. (2014). Skill-building interventions for adolescents and adults. In M. Tincani & A. Bondy (Eds.), *Autism Spectrum disorders in adolescents and adults* (pp. 164–181). The Guilford Press.

Harmuth, E., Silletta, E., Bailey, A., Adams, T., Beck, C., & Barbic, S. P. (2018). Barriers and facilitators to employment for adults with autism: A scoping review. *Annals of International Occupational Therapy, 1*, 31–40.

Hayes, J. A., Baylot Casey, L., Williamson, R., Black, T., & Winsor, D. (2013). Educators' readiness to teach children with autism spectrum disorder in an inclusive classroom. *The Researcher, 25*, 67–78. https://www.nrmera.org/wp/content/uploads/2016/02/Researcherv25n1Hayes_et-al.pdf

Hendricks, D. (2010). Employment and adults with autism spectrum disorders: Challenges and strategies for success. *Journal of Vocational Rehabilitation, 32*(2), 125–134. https://doi.org/10.3233/JVR-2010-0502

Howlin, P. (2021). Adults with autism: Changes in understanding since DSM-111. *Journal of Autism and Developmental Disorders, 51*, 4291–4308. https://doi.org/10.1007/s10803-020-04847-z

Individuals with Disabilities Education Act (IDEA), 20 U.S.C. § 1400. (2004). Retrieved December 22, 2021, from https://sites.ed.gov/idea/statute-chapter-33/subchapter-i/1400

Jimenez-Gomez, C., Sawhney, G., & Albert, K. M. (2021). Impact of COVID-19 on the applied behavior analysis workforce: Comparison across remote and nonremote workers. *Behavior Analysis in Practice, 14*(4), 1–10. Advance online publication. https://doi.org/10.1007/s40617-021-00625-0

Jordan, R. R., & Powell, S. D. (1994). Whose curriculum? Critical notes on integration and entitlement. *European Journal of Special Needs Education, 9*(1), 27–39. https://doi.org/10.1080/0885625940090103

Jung, L. A., Frey, N., Fisher, D., & Kroener, J. (2019). *Your students, my students, our students: Rethinking equitable and inclusive classrooms*. ASCD.

Kirby, A. V., Baranek, G. T., & Fox, L. (2016). Longitudinal predictors of outcomes for adults with autism spectrum disorder: Systematic review. *OTJR: Occupation, Participation and Health, 36*(2), 55–64. https://doi.org/10.1177/1539449216650182

Kotter, J. L. (2012). *Leading change*. Harvard Business Review Press.

Lambert, J. M., Copeland, B. A., Karp, E. L., Finley, C. I., Houchins-Juarez, N. J., & Ledford, J. R. (2016). Chaining functional basketball sequences (with embedded conditional discriminations) in an adolescent with autism. *Behavior Analysis in Practice, 9*(3), 199–210. https://doi.org/10.1007/s40617-016-0125-0

LaRue, R. H., Maraventano, J. C., Budge, J. L., & Frischman, T. (2020). Matching vocational aptitude and employment choice for adolescents and adults with ASD. *Behavior Analysis in Practice, 13*, 618–630. https://doi.org/10.1007/s40617-019-00398-7

Leaf, J. B., Leaf, R., McEachin, J., Taubman, M., Ala'i-Rosales, S., Ross, R. K., Smith, T., & Weiss, M. J. (2016). Applied behavior analysis is a science and, therefore, progressive. *Journal of Autism and Developmental Disorders, 46*, 720–731. https://doi.org/10.1007/s10803-015-2591-6

Leaf, J. B., Cihon, J. H., Ferguson, J. L., Milne, C. M., Leaf, R., & McEachin, J. (2021). Advances in our understanding of behavioral intervention: 1980 to 2020 for individuals diagnosed with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 51*, 4395–4410. https://doi.org/10.1007/s10803-020-04481-9

LeBlanc, L., Richardson, W., & Burns, K. A. (2009). Autism spectrum disorder and the inclusive classroom: Effective training to enhance knowledge of ASD and evidence-based practices. *Teacher Education and Special Education, 32*, 166–179.

Lee, G. K., Chun, J., Hama, H., & Carter, E. W. (2018). Review of transition and vocational interventions for youth and adults with autism spectrum disorder. *Review Journal of Autism and Developmental Disorders, 5*(3), 268–284.

Lima, R. C., Feldman, C., Evans, C., & Block, P. (2018). Autism policy and advocacy in Brazil and the USA. In *Autism in translation* (pp. 17–52). Palgrave Macmillan. https://doi.org/10.1007/978-3-319-93293-4_2

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology, 55*(1), 3–9. https://doi.org/10.1037/0022-006X.55.1.3

McGee, G. G., Paradis, T., & Feldman, R. S. (1993). Free effects of integration on levels of autistic behavior. *Topics in Early Childhood Special Education, 13*(1), 57–67. https://doi.org/10.1177/027112149301300107

McGregor, G. (1997). Introduction to special issue on inclusion. *Education and Treatment of Children, 20*(1), 1–6. http://www.jstor.org/stable/42940547

Merriam-Webster. (n.d.). *Inclusion*. In Merriam-Webster.com dictionary. Retrieved December 27, 2021, from https://www.merriam-webster.com/dictionary/inclusion

Mesibov, G. B., & Shea, V. (1996). Full inclusion and students with autism. *Journal of Autism and Developmental Disorders, 26*(3), 337–346. https://doi.org/10.1007/BF02172478

Moss, P., Mandy, W., & Howlin, P. (2017). Child and adult factors related to quality of life in adults with autism. *Journal of Autism and Developmental Disorders, 47*, 1830–1837. https://doi.org/10.1007/s10803-017-3105-5

Myles, B. S., Simpson, R. L., Ormsbee, C. K., & Erickson, C. (1993). Integrating preschool children with autism with their normally developing peers: Research findings and best practices recommendations. *Focus on Autistic Behavior, 8*(5), 1–19. https://doi.org/10.1177/108835769300800501

Nicholas, D. B., Mitchell, W., Dudley, C., Clarke, M., & Zulla, R. (2018). An ecosystem approach to employment and autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*, 264–275. https://doi.org/10.1007/s10803-017-3351-6

OBM Network. (2021). *What is OBM?*. Retrieved December 21, 2021, from http://obmnetwork.com/what-is-obm/

Office of Autism Research Coordination, National Institute of Mental Health, on behalf of the Interagency Autism Coordinating Committee (IACC). (2019, January). *2016 IACC autism Spectrum disorder research portfolio analysis report.* Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee, https://iacc.hhs.gov/portfolio-analysis/2016/index.shtml

Oxford Learner's Dictionary. (n.d.). *Inclusion*. In Oxford Learner's Dictionary.com dictionary. Retrieved December 27, 2021, from https://www.oxfordlearnersdictionaries.com/us/definition/english/inclusion

President's Council on Intellectual and Developmental Disabilities. (2017). *America's direct support workplace crisis: Effects on people with intellectual disabilities, families, and communities and the US economy*. Author.

Roux, A. M., Shattuck, P., Rast, J. E., Rava, B. A., & Anderson, K. A. (2015). *National autism indicators report: Transition into young adulthood*. A.J. Drexel Autism Institute, Drexel University.

Rowley, E., Chandler, S., Baird, G., Simonoff, E., Pickles, A., Loucas, T., & Charman, T. (2012). The experience of friendship, victimization and bullying in children with an autism spectrum disorder: Associations with child characteristics and school placement. *Research in Autism Spectrum Disorders, 6*(3), 1126–1134. https://doi.org/10.1016/j.rasd.2012.03.004

Santuzzi, A. M., Martinez, J. J., & Keating, R. T. (2021). The benefits of inclusion for disability measurement in the workplace. *Equality, Diversity and Inclusion.* Online ahead-of-print. https://doi.org/10.1108/EDI-06-2020-0167

Schall, C. M., Wehman, P., Brooke, V., Graham, C., McDonough, J., Brooke, A., Ham, W., Rounds, R., Lau, S., & Allen, J. (2015). Employment interventions for individuals with ASD: The relative efficacy of supported employment with or without prior project SEARCH training. *Journal of Autism and Developmental Disorders, 45*, 3990–4001. https://doi.org/10.1007/s10803-015-2426-5

Schopler, E., & Bristol, M. (1980). *Autistic children in public school*. ERIC Clearinghouse on Handicapped and Gifted Children. The Council for Exceptional Children. https://files.eric.ed.gov/fulltext/ED197577.pdf

Schwartz, I. S., & Baer, D. M. (1991). Social validity assessments: Is current practice state of the art? *Journal of Applied Behavior Analysis, 24*(2), 189–204. https://doi.org/10.1901/jaba.1991.24-189

Schwarz, I. S., & Kelly, E. M. (2021). Quality of life for people with disabilities: Why applied behavior analysts should consider this a primary dependent variable. *Research and Practice for Persons with Severe Disabilities, 46*, 159–172. https://doi.org/10.1177/15407969211033629

Shabani, D. B., & Fisher, W. W. (2006). Stimulus fading and differential reinforcement for the treatment of needle phobia in a youth with autism. *Journal of Applied Behavior Analysis, 39*(4), 449–452. https://doi.org/10.1901/jaba.2006.30-05

Shattuck, P., Roux, A. M., Hudson, L. E., Taylor, J. L., Maenner, M. J., & Trani, J. (2020). Services for adults with autism spectrum disorders. *Canadian Journal of Psychiatry, 57*, 284–291. https://doi.org/10.1007/s11920-020-1136-7

Sigafoos, J., Green, V. A., Payne, D., O'Reilly, M. F., & Lancioni, G. E. (2009). A classroom-based antecedent intervention reduces obsessive-repetitive behavior in an adolescent with autism. *Clinical Case Studies, 8*(1), 3–13. https://doi.org/10.1177/1534650108327475

Smith, T. (2013). What is evidence-based behavior analysis? *The Behavior Analyst, 36*, 7–33. https://doi.org/10.1007/BF03392290

Stainback, W., & Stainback, S. (1984). A rationale for the merger of special and regular education. *Exceptional Children, 51*(2), 102–111. https://doi.org/10.1177/001440298405100201

Strain, P. S. (1983). Generalization of autistic children's social behavior change: Effects of developmentally integrated and segregated settings. *Analysis and Intervention in Developmental Disabilities, 3*(1), 23–34. https://doi.org/10.1016/0270-4684(83)90024-1

Ticani, M., & Bondy, A. (Eds.). (2014). *Autism Spectrum disorders in adolescents and adults: Evidence-based and promising interventions*. The Guildford Press.

Treiman, D. J. (1977). *Occupational prestige in comparative perspective*. Academic.

U.S. News. (2021). *100 Best Jobs*. Retrieved December 22, 2021, from https://money.usnews.com/careers/best-jobs/rankings/the-100-best-jobs

Walsh, E., Holloway, J., McCoy, A., & Lydon, H. (2017). Technology-aided interventions for employment skills in adults with autism spectrum disorder: A systematic review. *Review Journal of Autism and Developmental Disorders, 4*, 12–25. https://doi.org/10.1007/s40489-016-0093-x

Ward, M. J., & Meyer, R. N. (1999). Self-determination for people with developmental disabilities and autism: Two self-advocates' perspectives. *Focus on Autism and Other Developmental Disabilities, 14*(3), 133–139. https://doi.org/10.1177/108835769901400302

Webster, R., & De Boer, A. (2019). Teaching assistants: Their role in the inclusion, education and achievement of pupils with special educational needs. *European Journal of Special Needs Education, 34*, 404–407. https://doi.org/10.1080/08856257.2019.1615746

Wehman, P., Brooke, V., Brooke, A. M., Ham, W., Schall, C., McDonough, J., … Avellone, L. (2016). Employment for adults with autism spectrum disorders: A retrospective review of a customized employment approach. *Research in Developmental Disabilities, 53*, 61–72.

Wolf, M. M. (1978). Social validity: The case for subjective measurement or how applied behavior analysis is finding its heart. *Journal of Applied Behavior Analysis, 11*(2), 203–214. https://doi.org/10.1901/jaba.1978.11-203

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Recommendations for Behavioral Research in Supporting Adults Diagnosed with ASD

Justin B. Leaf, Joseph H. Cihon, Julia L. Ferguson, and Peter F. Gerhardt

It has been reported that approximately 70,000 autistics/individuals diagnosed with autism spectrum disorder (ASD) transition from school-based services into adulthood every year (Autism Speaks, n.d.). Autism Speaks further estimates that within the next decade up to 1,116,000 teens with an autism diagnosis will become adults (Autism Speaks, n.d.). Taken together, the number of autistics/individuals diagnosed with ASD transitioning into adulthood within our society is ever increasing. This increase is but one reason why it is essential for members of society and the helping professions to understand various topics (e.g., post-secondary education, dating sexuality, living in the community) that directly affect autistic adults. It is one of the reasons we conceptualized this handbook in the first place.

As we read each chapter from our esteemed colleagues, we were struck in amazement of the work that has already been in efforts to support autistic adults. Reading about the work on teaching leisure and adaptive behavior (Manente et al., 2022), improving social behaviors (Moody & Laugeson, 2022), creating employment opportunities and maintaining employment (LaRue et al., 2022), and decreasing maladaptive behavior (Dracobly & Smith, 2022) provides behavior analysts and other members of the helping professions with excellent resources to teach and maintain valuable skills. Chapters discussing healthcare transitions (Pickler & Dressler, 2022), post-secondary education (Volpe et al., 2022), the court systems (Kelley, 2022), and family relationships (Fiske & Austin, 2022) provide behavior analysts and other members of the helping professions with valuable information to help support autistics/individuals diagnosed with ASD across a wide variety of contexts and transitions through adolescence and adulthood. These chapters have inspired the us and we hope they inspire the readers of this handbook as well.

Although we are inspired by the impressive work highlighted in this handbook, it also highlights that the research and clinical practice related to supporting autistic adults is lacking when compared to what exists for younger autistics/individuals diagnosed with ASD. Unfortunately, this is also consistent with previous analyses (e.g., Farley et al., 2018; Howlin & Iliana, 2017; King et al., 2020; Lord et al., 2020). Fortunately, Gerhardt et al. (2022) provided a wonderful resource providing clinical recommendations related to supporting adult autistics/individuals diagnosed with ASD. When positing areas of future research related to sup-

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porting autistic adults, however, one word comes to mind: *more*. We need *more* research that includes autistic adults, we need *more* individuals involved in conducting this research, and we need *more* funding dedicated to autistic adults. Fruitful areas for future research in supporting adult autistics/individuals diagnosed with ASD seem limitless. Nevertheless, the purpose of this chapter is to provide some suggestions for areas of research related to supporting autistic adults that we, the editors of the handbook, feel are imperative.

Happiness and Quality of Life

If asked what they want for their children when they grow up, most parents would likely include happiness somewhere in their response. We hope that all practicing behavior analysts and those in the helping professions share this vision – we want our clients to be happy and have a high quality of life (QoL). Happy with the friendships that they develop, happy with the job(s) they choose, happy with their living arrangements, and happy with their hobbies. Although this is a desire of many parents, practicing behavior analysts, and those in the helping professions, the research on this area is lacking, and there are several possible areas for future research that warrant discussion.

First, there is no generally agreed-upon definition or behavioral account (i.e., operational definition) of QoL. Ayres et al. (2018) relied on the World Health Organization's definition of QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns..." (p. 1). While the World Health Organization is a reputable organization, and some may adopt this definition, its breadth and use within behavior analytic research are limited. It is unclear how things like friendships, job placement, hobbies, language development, adaptive behaviors, sexuality, dating, relationships, and leisure skills fit into this definition or affect "an individual's perception of their position in life…" (Ayres et al., 2018, p. 1). Behavior analysts are uniquely situated with our feet planted firmly in the natural sciences; our emphasis on the measurement of overt behavior and our conceptualization of verbal behavior can assist in the development of a behavioral account of QoL. As such, we recommend behavior analysts examine the conditions under which various autistic individuals from diverse backgrounds and cultures indicate a high QoL has been achieved. These conditions can be cumulated and examined for commonalities and important contextual variables. This will help lead to a behavioral, operational, and measurable account of QoL that can then be examined and tested within the empirical literature.

Following preliminary work on developing and examining more behavioral accounts and definitions of QoL, efforts can be allocated into the development of QoL assessments. Although some QoL assessments may already be established (e.g., Quality of Life Index [Ferrans & Powers, 1984], Quality of Life Scales [Flannagan, 1982]), many rely upon self-report (e.g., Mosteller & Falotico-Taylor, 1989) and/or are not autism specific. While there is value in data generated via self-report, there are numerous variables that can affect the validity and objectivity of self-reported measures (Cooper et al., 2020; Howard & Dailey, 1979; Kazdin, 2011). Observable and objective data offer several benefits over data generated via self-report, and the development of future QoL assessments should strive to include observable and objective measures whenever possible. Furthermore, previously developed QoL assessments will not have benefited from preliminary work on developing and examining more behavioral accounts of QoL. The development of more objective QoL assessments should include involvement from various individuals from diverse backgrounds and cultures. These assessments should be evaluated for external and internal validity within the empirical literature. It is our hope that these efforts will lead to a stronger focus on efforts to improve and continually assess autistic clients' QoL across contexts and ages.

Finally, and most importantly, the development of high-quality, objective QoL assessments can assist in research examining methods to improve the QoL for adult autistics/individuals diagnosed with ASD. Recent meta-analyses have shown that autistic adults score lower on measures of QoL than neurotypical adults (e.g., Ayres et al., 2018). This finding should be alarming to any practicing behavior analyst and those in the helping professions. Future research efforts must be allocated to addressing this disparity in QoL measures. These efforts can include experimental evaluations of teaching methods, goals, supports, and other contextual variables and how theses variables affect QoL measures and outcomes for autistic individuals. This research should begin with single-case experimental designs to examine contextual differences across individuals, especially while efforts in developing culturally responsive, individualized QoL assessment are occurring. It will also be important for this research to move, when possible, into larger-scale studies to help inform large-scale efforts to assess and improve QoL measures for autistic adults.

Long-Term Outcomes

Interventions based upon the principles of applied behavior analysis (ABA) for autistics/individuals diagnosed with ASD have been demonstrated to be effective for over 50 years (Leaf et al., 2021a). This research has led to multiple organizations (e.g., Autism Speaks, Association for Behavior Analysis International, United States Surgeon General, National Institute of Mental Health, American Psychological Association) recognizing behavioral intervention as the most effective intervention and/or standard in treatment for autistics/individuals diagnosed with ASD. Despite the research and organizational support and endorsement, some have questioned, or noted concern, with what they see as the long-term effects of ABA-based interventions for autistics/individuals diagnosed with ASD (e.g., Bascom, 2014; Devita-Raeburn, 2016; Holcomb, 2021; Latimer, 2019; Lynch, 2019; Ram, 2020; Rossi, 2021; Sequenzia, 2016). While much concern is presented with anecdotal reports and little empirically sound research (Gorycki et al., 2020; Leaf et al., 2018), it cannot be discounted and should motivate future research efforts.[1] As such, another recommended area of future research that is necessary and should be ongoing is evaluating the long-term outcomes with autistics/individuals diagnosed with ASD who received early intensive behavioral intervention at a young age.

Future research evaluating the long-term effects of ABA-based intervention could include comparing groups of autistics/individuals diagnosed with ASD who have and have not received ABA-based intervention across a variety of measures, one of which being QoL. While to most behavior analysts, ABA refers to one of the three branches of the science of behavior analysis (Baer et al., 1968, 1987), within some communities the term *ABA* has become synonymous with autism intervention, discrete trial teaching, Lovaas (Leaf et al., 2021b), and numerous other meanings. As such, it will be essential for the duration, intensity, and components of the ABA-based intervention within this research to be adequately described. Failing to do so will make identifying any differences in long-term outcomes with those autistics/individuals diagnosed with ASD who have and have not received ABA-based intervention difficult, if not impossible. This research should also include objective measures, where possible, of desirable (e.g., QoL, friendships, employment, education) and undesirable dependent variables (e.g., trauma, anxiety, stress, masking). This research will be essential in providing empirical evidence to inform if and what changes are necessary within ABA-based intervention for autistics/individuals diagnosed with ASD to improve the desired long-term outcomes and avoid undesirable outcomes.

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[1] As Leaf et al. (2018) noted, "Even with the tremendous success of ABA-based interventions for individuals diagnosed with ASD, it is important to frequently assess the acceptability of our interventions. Those within the field should take every accusation that ABA-based interventions could be potentially traumatic for the individuals receiving those interventions seriously" (p. 127).

Evidence-Based ABA-Based Interventions for Autistic Adults

As previously noted, there has been over 50 years of research on behavioral intervention as it relates to supporting autistics/individuals diagnosed with ASD (Leaf et al., 2021a). Researchers have found procedures and methods such as discrete trial teaching (e.g., Shillingsburg et al., 2014), incidental teaching (e.g., Hart & Risley, 1980), behavioral skills training (e.g., Miltenberger, 2008), the teaching interaction procedure (Cihon et al., 2017), video modeling (e.g., Ezzedine et al., 2020), script and script fading (e.g., Garcia-Albea et al., 2014), prompting (e.g., Cihon et al., 2020), and social skills groups (e.g., Leaf et al., 2017) to be highly effective for developing important skills with autistics/individuals diagnosed with ASD. However, the preponderance of these studies has been conducted with the participation of younger autistics/individuals diagnosed with ASD with autistic adolescents and adults being vastly underrepresented (Gerhardt & Lainer, 2011). While the behavioral principles responsible for the effectiveness of the aforementioned procedures and methods (e.g., reinforcement, punishment, stimulus control) are generalizable across and within populations, future research should strive to include autistic adolescents and adults as participants.

We also recommend that future behavioral research with autistic adolescents and adults strives to have members of the participants' community implementing the methods of the research, as opposed to the researchers themselves. This more closely aligns to early behavior analytic research (e.g., Ayllon & Michael, 1959) and will help increase the likelihood of the generalization and maintenance of the observed effects of the research (Stokes & Baer, 1977). This research should also include the assessment of social validity (Wolf, 1978) at all stages. When possible, researchers should include the participants in the conceptualization of the research question, the selection of dependent and independent variable(s), as well as the ratings of the results of the research upon completion.

Research examining the effectiveness of well-established ABA-based methods and procedures with autistic adolescents and adults should involve the use of single-case experimental designs (e.g., multiple baseline) as well as group designs (e.g., randomized clinical trials). Single-case experimental designs will be essential in demonstrating and establishing internal validity and allowing examination of individual differences. Following the establishment of a body of literature using single-case experimental designs, group designs can be employed in efforts to improve external validity and examine the generality of ABA-based methods and procedures with a larger number of autistic adolescents and adults. Furthermore, group designs are more commonly accepted by the scientific community and society at large and may be useful in influencing decisions related to funding for behavior analytic services.

As research examining the effectiveness of well-established ABA-based methods and procedures with autistic adolescents and adults progresses, it may be fruitful to conduct comparative research (Holcombe et al., 1994). This research should involve comparing two or more established ABA-based methods and procedures to determine the relative efficiency and effectiveness of the different methods and procedures. It will be essential that this research includes well-described methods, contexts, and participant demographics. Each of these variables will be essential in determining the conditions under which one procedure or method may be more or less effective and efficient than another. It is also essential that this research involves social validity measures that assess the participants' preferences across the procedures and methods examined. It may be the case that one procedure is more effective but less preferred than another procedure that is less effective but more preferred. It is not enough that our procedures and methods are effective; they must also be acceptable and preferred to the greatest extent possible.

Applied, Functional, and Meaningful Skills

Another area in which future research efforts should be allocated is in the examination and development of applied, functional, and meaningful skills. While there have been numerous studies that have documented the effectiveness of various ABA-based methods and procedures to develop a variety of skills with autistics/individuals diagnosed with ASD, there has been disagreement and discussion about the importance of these skills (e.g., Ayres et al., 2011; Gerhardt & Lainer, 2011). This point is exacerbated when it relates to adolescents and adults diagnosed with ASD. For example, researchers have demonstrated effective methods to develop on-topic conversation (e.g., Leaf et al., 2017), sharing (e.g., Kamps et al., 1992), sorting (e.g., Farber et al., 2016), and vocational skills (e.g., Villante et al., 2021). These and other skills may be important to any individual, but they are far less nuanced than other important skills for adolescents and adults (e.g., developing and maintaining friendships, developing and maintaining intimate relationships, dating, hanging out at a bar). We encourage researchers to start exploring methods to teach more complex and meaningful skills in the environmental and social context where the skills are most likely to be needed and of use, for autistics/individuals diagnosed with ASD. Teaching these skills will be difficult to operationally define and may require a combination of various teaching methods (e.g., the teaching interaction procedure; Cihon et al., 2017), but this is ultimately an empirical question in need of further research.

Conclusion

Some have noted the dearth of behavior analytic research for adult autistics/individuals diagnosed with ASD (Gerhardt & Lainer, 2011). The lack of behavior analytic research on this topic can be viewed as insurmountable by some. We suggest it be viewed as motivation and a goal to overcome. It may seem daunting, but we have the tools at our disposal, and the impact this research will have for so many cannot be overstated. We believe that the recommendations provided here are actionable steps to help address this ongoing problem. It should be noted that the recommendations provided here should not be viewed as an exhaustive to-do list for researchers. Rather, these recommendations should be viewed a starting point and a motivational tool for additional work to evaluate the application of ABA-based interventions for autistic adults.

References

Autism Speaks. (n.d.) *Autism statistics and facts*. https://www.autismspeaks.org/autism-statistics-asd

Ayllon, T., & Michael, J. (1959). The psychiatric nurse as a behavioral engineer. *Journal of the Experimental Analysis of Behavior, 2*(4), 323–334. https://doi.org/10.1901/jeab.1959.2-323

Ayres, K. M., Lowrey, K. A., Douglas, K. H., & Sievers, C. (2011). I can identify Saturn but I can't brush my teeth: What happens when the curricular focus for students with severe disabilities shifts. *Education and Training in Mental Retardation, 46*(1), 11–21. https://doi.org/10.2307/23880027

Ayres, M., Parr, J. R., Rodgers, J., Mason, D., Avery, L., & Flynn, D. (2018). A systematic review of quality of life of adults on the autism spectrum. *Autism, 22*(7), 774–783. https://doi.org/10.1177/1362361317714988

Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis, 1*(1), 91–97. https://doi.org/10.1901/jaba.1968.1-91

Baer, D. M., Wolf, M. M., & Risley, T. R. (1987). Some still-current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis, 20*(4), 313–327. https://doi.org/10.1901/jaba.1987.20-313

Bascom, J. (2014, March 24). *Quiet hands*. http://neuroqueer.blogspot.com/2014/03/quiet-hands-by-julia-bascom.html

Cihon, J. H., Weinkauf, S., & Taubman, M. (2017). Using the teaching interaction procedure to teach social skills for individuals diagnosed with autism spectrum disorder. In J. B. Leaf (Ed.), *Handbook of social skills and autism spectrum disorder* (pp. 313–324). Springer. https://doi.org/10.1007/978-3-319-62995-7

Cihon, J. H., Ferguson, J. L., Leaf, J. B., Milne, C. M., Leaf, R., & McEachin, J. (2020). A randomized clinical trial of three prompting systems to teach tact relations. *Journal of Applied Behavior Analysis, 53*(2), 727–743. https://doi.org/10.1002/jaba.617

Cooper, J. O., Heron, T. E., & Heward, W. L. (2020). *Applied behavior analysis* (3rd ed.). Pearson.

Devita-Raeburn, E. (2016, August 11). *Is the most common therapy for autism cruel?* https://www.theatlantic.com/health/archive/2016/08/aba-autism-controversy/495272/

Dracobly, J. D., & Smith, R. G. (2022). Functional analysis of behavioral challenges with adults with autism. In J. B. Leaf, J. H. Cihon, J. L. Ferguson, & P. F. Gerhardt (Eds.), *Handbook of quality of life for individuals with autism spectrum disorder*. Springer.

Ezzedine, E. W., DeBar, R. M., Reeve, S. A., & Townsend, D. B. (2020). Using video modeling to teach play comments to dyads with ASD. *Journal of Applied Behavior Analysis, 53*(2), 767–781. https://doi.org/10.1002/jaba.621

Farber, R. S., Dube, W. V., & Dickson, C. A. (2016). A sorting-to-matching method to teach compound matching to sample. *Journal of Applied Behavior Analysis, 49*(2), 294–307. https://doi.org/10.1002/jaba.290

Farley, M., Cottle, K. J., Bilder, D., Viskochil, J., Coon, H., & McMahon, W. (2018). Mid-life social outcomes for a population-based sample of adults with ASD. *Autism Research: Official Journal of the International Society for Autism Research, 11*(1), 142–152. https://doi.org/10.1002/aur.1897

Ferrans, C. E., & Powers, M. (1984). *Quality of life index*. Author.

Fiske, K., & Austin, A. (2022). Family relationships and individuals with autism. In J. B. Leaf, J. H. Cihon, J. L. Ferguson, & P. F. Gerhardt (Eds.), *Handbook of quality of life for individuals with autism spectrum disorder*. Springer.

Flannagan, J. C. (1982). Measurement of quality of life: Current state of the art. *Archives of Physical Medicine and Rehabilitation, 63*(2), 56–59.

Garcia-Albea, E., Reeve, S. A., Brothers, K. J., & Reeve, K. F. (2014). Using audio script fading and multiple-exemplar training to increase vocal interactions in children with autism. *Journal of Applied Behavior Analysis, 47*(2), 325–343. https://doi.org/10.1002/jaba.125

Gerhardt, P. F., & Lainer, I. (2011). Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy, 41*, 37–45. https://doi.org/10.1007/s10879-010-9160-2

Gerhardt, P. F., Bahry, S. N., Mason, B., & Solis, M. S. (2022). On predicting the future: Recommendations for the field of ABA in supporting adults with ASD. In J. B. Leaf, J. H. Cihon, J. L. Ferguson, & P. F. Gerhardt (Eds.), *Handbook of quality of life for individuals with autism spectrum disorder*. Springer.

Gorycki, K. A., Ruppel, P. R., Zane, T., & Navalta, C. P. (2020). Is long-term ABA therapy abusive: A response to Sandoval-Norton and Shkedy. *Cogent Psychology, 7*(1). https://doi.org/10.1080/23311908.2020.1823615

Hart, B., & Risley, T. R. (1980). In vivo language intervention: Unanticipated general effects. *Journal of Applied Behavior Analysis, 13*(3), 407–432. https://doi.org/10.1901/jaba.1980.13-407

Holcomb, M. (2021, May 30). *A too-short, very incomplete introduction to masking: The practice, effectiveness, costs and ethics of performing neurotypically* [Conference symposium]. Applied Behavior Analysis International 47th Annual Conference. https://www.abainternational.org/events/program-details/event-detail.aspx?sid=72969&by=ByArea#s194A_0

Holcombe, A., Wolery, M., & Gast, D. L. (1994). Comparative single-subject research: description of designs and discussion of problems. *Topics in Early Childhood Special Education, 14*(1), 119–145. https://doi.org/10.1177/027112149401400111

Howard, G. S., & Dailey, P. R. (1979). Response-shift bias: A source of contamination of self-report measures. *Journal of Applied Psychology, 64*(2), 144–150. https://doi.org/10.1177/0193841X8000400105

Howlin, P., & Iliana, M. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry, 30*(2), 69–76. https://doi.org/10.1097/YCO.0000000000000308

Kamps, D. M., Leonard, B. R., Vernon, S., Dugan, E. P., Delquadri, J. C., Gershon, B., Wade, L., & Folk, L. (1992). Teaching social skills to students with autism to increase peer interactions in an integrated first-grade classroom. *Journal of Applied Behavior Analysis, 25*(2), 281–288. https://doi.org/10.1901/jaba.1992.25-281

Kazdin, A. E. (2011). *Single-case research designs: Methods for clinical and applied settings*. Oxford University Press.

Kelley, E. (2022). Autism spectrum disorders and the criminal justice system. In J. B. Leaf, J. H. Cihon, J. L. Ferguson, & P. F. Gerhardt (Eds.), *Handbook of quality of life for individuals with autism spectrum disorder*. Springer.

King, C., Merrick, H., & Couteur, A. L. (2020). How should we support young people with ASD and mental health problems as they navigate the transition to adult life including access to adult healthcare services. *Epidemiology and Psychiatric Sciences, 29*(90), 1–5. https://doi.org/10.1017/S2045796019000830

LaRue, R. H., Manente, C. J., Maraventano, J. C., Budge, J., Butler, C., Hoffman, M. R., & Kahng, S. (2022). Employment and vocational skills for individuals with autism. In J. B. Leaf, J. H. Cihon, J. L. Ferguson, & P. F. Gerhardt (Eds.), *Handbook of quality of life for individuals with autism spectrum disorder*. Springer.

Latimer, O. (2019, August 31). *International day of protest against ABA: Gentle ABA is still abuse.* https://www.asparenting.com/international-day-of-protest-against-aba-gentle-aba-is-still-abuse/?fbclid=IwAR20N45D5RE0B6vD6GjWIQGJP8ulSMPCfPCu9q9NBaqEHQTjQAVSXJAAJ4I

Leaf, J. B., Leaf, J. A., Milne, C., Taubman, M., Oppenheim-Leaf, M., Torres, N., Townley-Cochran, D., Leaf, R., McEachin, J., & Yoder, P. (2017). An evaluation of a behaviorally based social skills group for individuals diagnosed with autism spectrum disorder. *Journal of Autism and Developmental*

Disorders, 47(2), 243–259. https://doi.org/10.1007/s10803-016-2949-4

Leaf, J. B., Ross, R. K., Cihon, J. H., & Weiss, M. J. (2018). Evaluating Kupferstein's claims of the relationship of behavioral intervention to PTSS for individuals with autism. *Advances in Autism, 4*(3), 122–129. https://doi.org/10.1108/aia-02-2018-0007

Leaf, J. B., Cihon, J. H., Ferguson, J. L., Milne, C. M., Leaf, R., & McEachin, J. (2021a). Advances in our understanding of behavioral intervention: 1980 to 2020 for individuals diagnosed with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 51*(12), 4395–4410. https://doi.org/10.1007/s10803-020-04481-9

Leaf, J. B., Cihon, J. H., Leaf, R., McEachin, J., Liu, N., Russell, N., Unumb, L., Shapiro, S., & Khosrowshahi, D. (2021b). Concerns about aba-based intervention: An evaluation and recommendations. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-021-05137-y

Lord, C., McCauley, J. B., Pepa, L. A., Huerta, M., & Pickles, A. (2020). Work, living, and the pursuit of happiness: Vocational and psychosocial outcomes for young adults with autism. *Autism: The International Journal of Research and Practice, 24*(7), 1691–1703. https://doi.org/10.1177/1362361320919246

Lynch, C. L. (2019, March 28). *Invisible abuse: ABA and the things only autistic people can see.* https://neuroclastic.com/2019/03/28/invisible-abuse-aba-and-the-things-only-autistic-people-can-see/

Manente, C. J., LaRue, R. H., Maraventano, J. C., Butler, C., Budge, J., Scarpa, C., & Kahng, S. (2022). Leisure and adaptive behavior for individuals with autism. In J. B. Leaf, J. H. Cihon, J. L. Ferguson, & P. F. Gerhardt (Eds.), *Handbook of quality of life for individuals with autism spectrum disorder*. Springer.

Miltenberger, R. G. (2008). Teaching safety skills to children: Prevention of firearm injury as an exemplar of best practice in assessment, training, and generalization of safety skills. *Behavior Analysis in Practice, 1*(1), 30–36. https://doi.org/10.1007/BF03391718

Moody, C. T., & Laugeson, E. A. (2022). Social behavior and social interventions for adults with ASD. In J. B. Leaf, J. H. Cihon, J. L. Ferguson, & P. F. Gerhardt (Eds.), *Handbook of quality of life for individuals with autism spectrum disorder*. Springer.

Mosteller, F., & Falotico-Taylor, J. (1989). *Quality of life and technology assessment*. National Academy Press.

Pickler, L., & Dressler, P. (2022). Healthcare transition for individuals with autism. In J. B. Leaf, J. H. Cihon, J. L. Ferguson, & P. F. Gerhardt (Eds.), *Handbook of quality of life for individuals with autism spectrum disorder*. Springer.

Ram, J. (2020, June 2). *I am a disillusioned BCBA: Autistics are right about ABA*. https://neuroclastic.com/2020/06/02/i-am-a-disillusioned-bcba-autistics-are-right-about-aba/

Rossi, R. (2021, May 30). *Checking blind spots: Navigating neurotypical standards of social skills as it relates to neurodivergent clients* [Conference symposium]. Applied Behavior Analysis International 47th Annual Conference. https://www.abainternational.org/events/program-details/event-detail.aspx?sid=72969&by=ByArea#s194A_0

Sequenzia, A. (2016, April 27). *Autistic conversion therapy.* https://awnnetwork.org/autistic-conversion-therapy/?fbclid=IwAR1KVUN-h6qJ6paWxAwX2H22PH8ApGHQJqG9F4arjzWKrZVNh7Z9cp5GBJ4

Shillingsburg, M. A., Bowen, C. N., Valentino, A. L., & Pierce, L. E. (2014). Mands for information using "who?" and "which?" in the presence of establishing and abolishing operations. *Journal of Applied Behavior Analysis, 47*(1), 136–150. https://doi.org/10.1002/jaba.101

Stokes, T. F., & Baer, D. M. (1977). An implicit technology of generalization. *Journal of Applied Behavior Analysis, 10*(2), 349–367. https://doi.org/10.1901/jaba.1977.10-349

Villante, N. K., Lerman, D. C., Som, S., & Hunt, J. C. (2021). Teaching adults with developmental disabilities to problem solve using electronic flowcharts in a simulated vocational setting. *Journal of Applied Behavior Analysis, 54*(3), 1199–1219. https://doi.org/10.1002/jaba.786

Volpe, S., Weiss, M. J., & Boone, V. (2022). Issues in individuals with ASD in higher education environments. In J. B. Leaf, J. H. Cihon, J. L. Ferguson, & P. F. Gerhardt (Eds.), *Handbook of quality of life for individuals with autism spectrum disorder*. Springer.

Wolf, M. M. (1978). Social validity: The case for subjective measurement or how applied behavior analysis is finding its heart. *Journal of Applied Behavior Analysis, 11*(2), 203–214. https://doi.org/10.1901/jaba.1978.11-203

Correction to: Community-Based Residential Options for Adults with Autism and Intellectual Disabilities

John M. Guercio

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The original version of this book was published with an incorrect representation of Fig. 10.4 which has now been corrected.

The updated original version of this chapter can be found at
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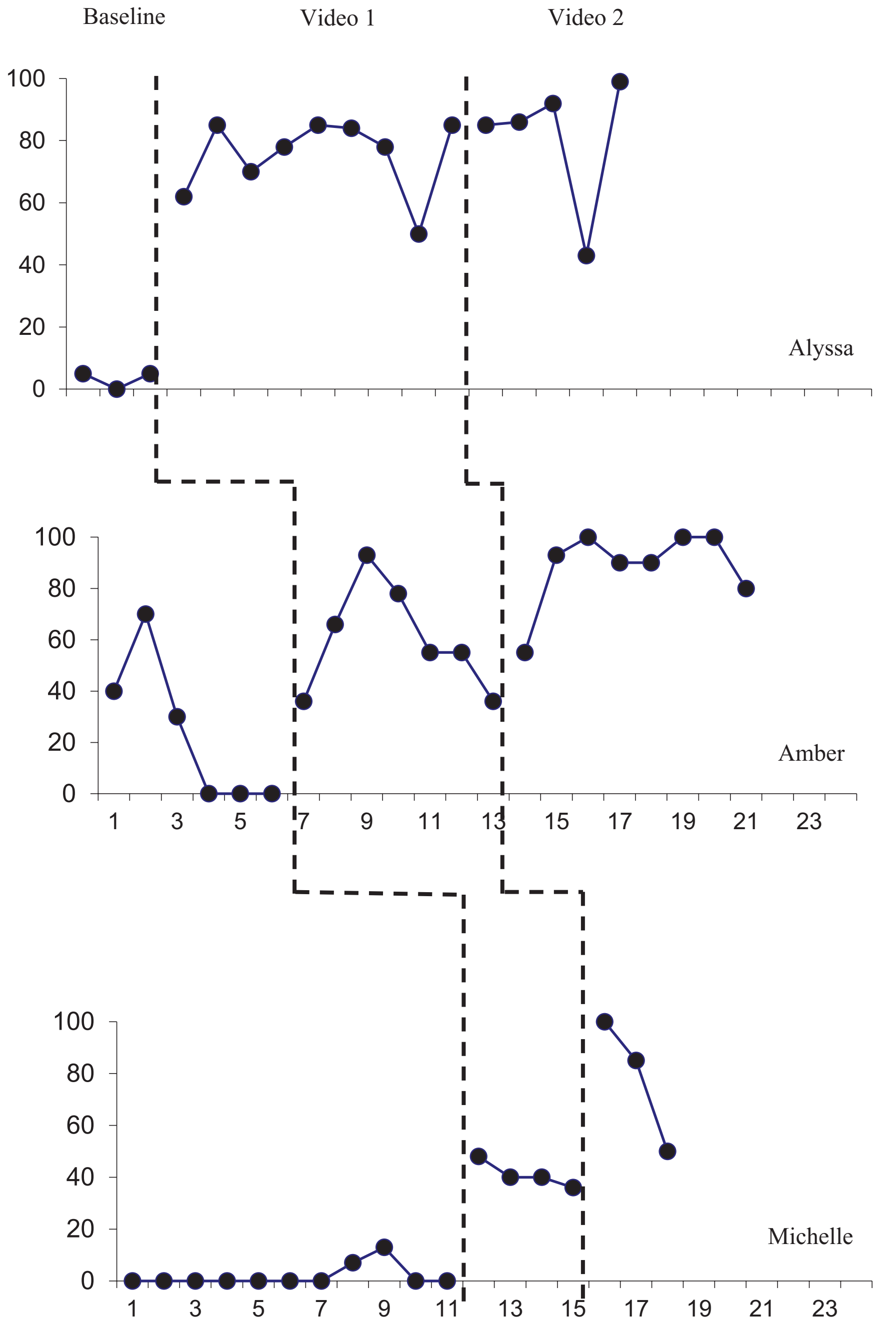

Fig. 10.4 PEARLS interaction scores for the three staff involved in the study. Scores are depicted during each of the phases of video modeling and feedback

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