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Michael Siller · Lindee Morgan
Editors

Handbook of Parent-Implemented Interventions for Very Young Children with Autism

Springer

Autism and Child Psychopathology Series

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ISSN 2192-922X ISSN 2192-9238 (electronic)
Autism and Child Psychopathology Series
ISBN 978-3-319-90992-9 ISBN 978-3-319-90994-3 (eBook)
https://doi.org/10.1007/978-3-319-90994-3

Library of Congress Control Number: 2018947420

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Printed on acid-free paper

This Springer imprint is published by the registered company Springer Nature Switzerland AG
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

Für die Eltern von Sebastian

Foreword

Over recent decades, there has been a dramatic increase in knowledge regarding the early course of autism spectrum disorders (ASD) as well as a proliferation of evidence-based interventions that have been shown to improve the lives of children with ASD and their families. Knowledge regarding the early course of ASD has informed early screening and detection efforts, such that several measures are available to conduct general population screening designed to identify children at high risk for ASD as early as 12 months of age. Moreover, understandings regarding the heterogeneity of the early course of ASD, with respect to both symptom variation and age at onset, have led to calls for repeated ASD screenings as well as the use of screeners to identify broader developmental and behavioral challenges. Further, there have been major advances in early diagnosis, both in relation to the availability of appropriate diagnostic instruments and the formal recognition that children who evidence impairment based on the presence of multiple ASD symptoms, but do not yet meet full criteria (i.e., may meet criteria for the new Zero to Three DC: 0–5 Early Atypical Autism Spectrum Disorder diagnosis), should receive existing evidence-supported treatments. In addition, there is now consensus that children as young as 12–14 months of age can meet full criteria for ASD. Finally, there has been a dramatic increase in the empirical evidence supporting naturalistic, developmental approaches to child ASD interventions that approach parents as collaborators and critical caring decision-makers. Yet, consistent with expected lags from innovation to dissemination, systems of care have not kept pace with scientific understanding regarding screening, early diagnosis, or intervention science.

Drs. Siller and Morgan have compiled a unique and important edited volume that is likely to shorten the gap between scientific innovation and dissemination to systems of care serving diverse children with ASD and their families around the world. This book is rich in both conceptual frameworks and practical tools for providing family-centered, inclusive services in a wide range of early intervention service systems. Appropriate for clinicians and clinical researchers, the chapters are authored by the world's leading clinical scientists and innovators – the experts who have developed and evaluated new early identification and intervention methods and approaches for children with ASD and their families. Moreover, while grounded in both empirical evidence and strong conceptual models of development, family systems, adult learning, multiple aspects of diversity, and stigmatization, authors synthesize their lived experience as scientists and clinicians committed to supporting children with ASD and their families to offer specific practical suggestions on a broad range of topics central to effective practice and research, including the following: monitoring and discussing concerns with parents and other family members; using behavioral and motivational strategies to promote children's social communication; joining with parents as collaborators; motivating and empowering parents to become active, self-reflective, and engaged learners who are poised to address children's goals within the context of daily routines; and supporting family well-being (e.g., mindfulness and promoting social connection). In addition, this compilation goes further to address the use of technology (e.g., video feedback, telehealth) to advance dissemination efforts as well as offer specific recommendations for pursuing and evaluating implementation and dissemination work in early intervention systems of care. The range of empirically supported early screening and therapeutic interventions presented to enhance children's development and family well-being and the possibility of expanding evidence-based services in existing service networks as well as in underdeveloped, underresourced communities should offer a sense of optimism and hope for the field and for parents raising young children with ASD. With great pleasure, I encourage everyone involved in early identification and intervention services for young children with ASD to read this book!

Boston, MA, USA Alice Carter

Preface

In 2006, the American Academy of Pediatrics published a groundbreaking policy statement on early identification of children with developmental delays. Specific recommendations for surveillance and screening of autism spectrum disorders (ASD) were published as clinical practice guidelines in 2007. According to these guidelines, all children (independent of known risk factors or parental concerns) should be screened for ASD using formal screening tests administered during pediatric well-child visits at 18 and 24 months. Given the heated debate between advocates and policy-makers about funding for early intervention services, these clinical practice guidelines underscored the need for rigorous early intervention research for toddlers, younger than 24 months, at "high risk" for ASD.

Between 2007 and 2010, Autism Speaks funded seven research studies, testing the efficacy of parent-mediated interventions for toddlers at "high risk" for ASD. Because this research was novel and aimed to chart new territory, the Autism Speaks Toddler Treatment Network (ASTTN) was formed to provide an infrastructure for ongoing communication between the key investigators of these seven research studies. From the beginning, the principal investigator of an eighth research study, funded through other sources, was invited to join the network. The ASTTN was initially codirected by Sally Rogers and Michael Siller and involved 26 investigators who met regularly during bimonthly conference calls and annual meetings. Since 2010, the ASTTN was opened to researchers beyond the initial network and continued to hold annual conferences, coordinated by a planning committee that was led, among others, by Lindee Morgan and Lauren Turner-Brown. Initially, the network focused primarily on methodological issues, including diagnostic inclusion criteria for toddlers, measures of treatment fidelity in parent-mediated interventions, shared baseline and outcome measures, and analytic techniques for identifying moderators and mediators of treatment efficacy.

Aside from these questions of research methodology, the ASTTN also provided a context to learn about the eight experimental, parent-mediated interventions that were being developed and tested across the network. Since the investigators of the ASTTN represented a range of different disciplines (e.g., early childhood education, clinical or developmental psychology, speech-language pathology, occupational therapy, and behavior analysis), we learned to speak and understand each other's terminology. Further, by discussing our experiences, we learned about the possibilities and challenges of implementing parent-mediated interventions to support families and promote learning in toddlers with autism. Most importantly, we witnessed an emerging consensus about the essential components of effective interventions for young children with autism. This emerging consensus was first articulated under the moniker of Naturalistic Developmental Behavioral Interventions (NDBI; Schreibman et al., 2015) and includes strategies such as child choice, environmental arrangement, natural reinforcement, balanced turn taking, contingent imitation, and broadening the child's attentional focus. The current volume is an attempt to present this consensus, as it relates specifically to parent-mediated interventions for young children with autism. Most of the chapters are authored by original or current members of the ASTTN.

Obviously, our pursuit of the essential components of parent-mediated interventions for young children with autism will continue in the future. As discussed in Chap. 1, any universal conclusions about the efficacy of parent-mediated interventions are complicated by the fact that a broad range of approaches has been developed and tested. At the same time, it is the heterogeneity of intervention approaches that gave rise to the emerging consensus that is presented in this volume.

Atlanta, GA, USA

Michael Siller
Lindee Morgan

Reference

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Acknowledgments

I wish to acknowledge my ongoing debt to my first clinical supervisor, Roland Wittig, who helped me discover the continuity between collaborative play and linguistic dialogue; to my doctoral mentor, Marian Sigman, whose seminal research continues to inspire many authors in this volume and whose wisdom and friendship I miss dearly to this day; to Alice Carter, Sally Rogers, and Ami Klin, who have generously supported and guided my work throughout the last decade; and to Lindee Morgan, my wonderful partner, companion, and collaborator.

Michael Siller

I would like to express my gratitude to Amy Wetherby for teaching me so many skills but mostly, how to remain family-centered, even in the context of rigorous research; to my former colleagues at the Florida State University Autism Institute – friends and life guides, every one of you; and to my dearest companion in both work and play, Michael Siller.

Lindee Morgan

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Lindee Morgan, Ph.D., CCC-SLP, is Assistant Professor of Pediatrics at the Emory University School of Medicine and codirects (with Dr. Michael Siller) the Education Sciences Research Core as well as the Preschool Education Lab at Marcus Autism Center, Children's Healthcare of Atlanta. Dr. Lindee Morgan completed her Ph.D. in Communication Disorders at Florida State University in 2002. Prior to joining the faculty at Emory in 2016, she served as the Director of the Center for Autism and Related Disabilities and the Associate Director of Implementation in the Autism Institute at the Florida State University College of Medicine. Her primary clinical/scholarly focus is intervention, largely classroom-based, for individuals with autism spectrum disorder (ASD). Her research has focused on investigating treatments to improve active engagement, social communication, and other relevant outcomes for individuals with autism across the life span. She is a developer of the Autism Navigator, a unique collection of web-based tools and courses designed to bridge the gap between science and community practice. Dr. Morgan is one of the four authors of the Autism/Communication Navigator for Early Intervention Providers and is currently collaborating with colleagues at Florida State University to develop Autism Navigator for Kindergarten Classrooms. Her articles have been published in a number of leading journals including *Pediatrics*, the *Journal of Child Psychology and Psychiatry*, and the *Journal of Autism and Developmental Disorders*.

1

Systematic Review of Research Evaluating Parent-Mediated Interventions for Young Children with Autism: Years 2013 to 2015

Michael Siller and Lindee Morgan

Abstract

The last decade has witnessed a tremendous increase in rigorous intervention research in autism, particularly studies evaluating parent-mediated interventions. In 2011 and 2014, the Agency for Healthcare Research and Quality (AHRQ) published a pair of systematic literature reviews of studies evaluating the efficacy/effectiveness of behavioral interventions, including parent-mediated approaches. However, these reviews have not adequately incorporated articles published in 2013 and thereafter. Using the same methods and criteria to identify published articles providing adequate evidence as the original AHRQ reports, the current literature review update identified twenty additional studies, published between 2013 and 2015. All studies used controlled group designs to evaluate parent-mediated interventions for young children with autism. The current chapter reviews the results of these 20 studies and discusses whether the available evidence (defined broadly in terms of quality, quantity, and consistency) is sufficient to confidently determine that parent-mediated intervention approaches are effective for increasing children's language/communication and cognitive abilities, reducing autism symptoms, and supporting the parents' use of development-enhancing parenting practices.

The last decade has witnessed a tremendous increase in rigorous intervention research in autism, particularly studies evaluating parent-mediated interventions. Efforts to systematically review this rapidly growing evidence base have been published by the Agency for Healthcare Research and Quality (Warren et al., 2011; Weitlauf et al., 2014), the Cochrane Database of Systematic Reviews (Oono, Honey, & McConachie, 2013), the National Standards Project (National Autism Center, 2015), the National Professional Development Center (Wong et al., 2013), as well as various academic journals (Beaudoin, Sébire, & Couture, 2014; Zwaigenbaum et al., 2015). Systematic literature reviews differ from each other in their methodology (e.g., study selection criteria related to children's ages and characteristics of the research design) and the nature of the interventions being evaluated (e.g., parent-mediated approaches,

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_1

behavioral intervention approaches). Further, one important limitation of any systematic effort to evaluate a highly active field of investigation is that new evidence emerges rapidly, and key conclusions can age rather quickly. In fact, the publication deadlines for studies to be included in the above-cited reviews ranged between June 2010 and December 2013. Given delayed indexing in bibliographic databases, available literature reviews have not adequately incorporated articles published in 2013 and thereafter.

The current chapter reports the results of a systematic review of intervention research published between 2012 and 2015. While the methodology of this literature review and key conclusions about the efficacy of parent-mediated interventions are summarized in this chapter, detailed methods and results are available upon request from the first author (M.S.).

Agency for Healthcare Research and Quality (AHRQ) Review of Behavioral Interventions for Children with Autism Spectrum Disorder

In 2011 and 2014, AHRQ published a pair of systematic literature reviews of studies evaluating the efficacy/effectiveness of behavioral interventions for children with autism spectrum disorder (ASD; Warren et al., 2011; Weitlauf et al., 2014). These literature reviews distinguished three kinds of behavioral intervention approaches: (1) *ABA-Based Early Intensive Behavioral and Developmental Approaches*, (2) *Behavioral and Developmental Early Intervention-Parent Training*, and (3) *Play-/Interaction-Focused Intervention Approaches* (Table 1.1). These three intervention approaches can be represented along two orthogonal dimensions:

1. Whether the intervention is primarily implemented by a clinician or the child's parent (i.e., clinician-mediated vs. parent-mediated)
2. Whether the intervention is implemented during many hours per week, targeting multiple outcome domains, as compared to interventions that are implemented with relatively low intensity, focusing on a smaller number of outcomes (i.e., comprehensive vs. focused).

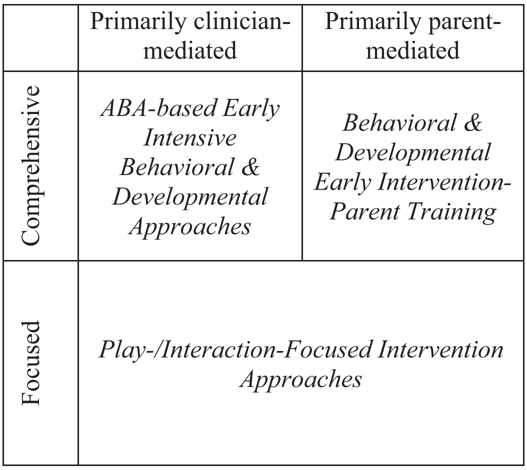
A graphical representation of these two dimensions, and how they relate to the three AHRQ categories of behavioral interventions, is presented in Fig. 1.1.

Parent involvement, education, training, or coaching (i.e., parent-mediated interventions) plays an important role across all three kinds of behavioral intervention approaches. Although *ABA-Based Early Intensive Behavioral and Developmental Approaches* involve many hours of clinician-delivered intervention, parent involvement is considered to be a crucial component of most comprehensive intervention programs for young children with ASD. Examples include the UCLA/Lovaas Model (Lovaas, 1987), the Learning Experiences and Alternative Program (LEAP; Boyd et al., 2014), and the Early Start Denver Model (ESDM; Dawson et al., 2010). Similarly, many of the *Play-/Interaction-Focused Intervention Approaches* such as the Joint Attention Symbolic Play Emotion Regulation (JASPER; Kasari, Lawton et al., 2014) program, Focused Playtime Intervention (Siller, Hutman, & Sigman, 2013), or Reciprocal Imitation Training (Ingersoll & Gergans, 2007) have been implemented by training, educating, or coaching parents.

The methodology used to complete the AHRQ literature reviews (Warren et al., 2011; Weitlauf et al., 2014) involved three phases: (1) identification of published studies providing adequate evidence, (2) Study Quality Assessment, and (3) determination of Strength of Evidence grades. The first phase consisted of a sequence of bibliographic database searches, abstract review, and full-text review and identified 45 and 67 behavioral intervention studies for the 2011 and 2014 literature reviews, respectively. Criteria used to determine whether an article provided adequate evidence about the efficacy/effectiveness of an intervention approach included (a) participants ages 2–12 diagnosed with ASD or 0–2 at risk for ASD diagnosis, (b) at least 10 individuals with ASD (or at risk) in the target age range, and (c) the study used a controlled group design (e.g., randomized controlled trial, prospective

Table 1.1 Three categories of behavioral interventions included in the 2014 Report of the Agency for Healthcare Research and Quality (AHRQ)

ABA-Based Early Intensive Behavioral and Developmental Approaches
Intervention strategies are derived from applied behavior analysis (ABA). The goal of ABA is to teach new skills, promote generalization of these skills, and reduce challenging behaviors with systematic reinforcement
Use of high-intensity (i.e., many hours per week, one-on-one) instruction
Approaches differ substantially in terms of their structure (i.e., intensity, duration, parent component), approach (i.e., discrete trial, developmental), and setting (i.e., home, clinic, classroom)
Specific approaches that were considered in the 2014 AHRQ Review include manualized approaches and more eclectically defined and delivered approaches. Examples include (1) UCLA/Lovaas (Eikeseth, Klintwall, Jahr, & Karlsson, 2012; Peters-Scheffer, Didden, Mulders, & Korzilius, 2010) (relies heavily on one-on-one therapy sessions during which a trained therapist uses discrete trial teaching with a child to practice target skills), (2) Learning Experiences and Alternative Program (LEAP; Strain & Bovey, 2011) (incorporates a range of strategies, including peer-mediated social skills training, incidental teaching, pivotal response training, picture exchange communication system (PECS), and positive behavior support), and (3) Early Start Denver Model (ESDM; Dawson et al., 2010) (blends ABA principles with developmental and relationship-based approaches for young children)
Behavioral and Developmental Early Intervention-Parent Training
Parent training approaches that use principles of behavioral learning to focus on key pivotal behaviors rather than global improvements
May focus on social communication skills or specific behaviors, such as initiating activities
Individual approaches vary in terms of approach, scope, and intensity Specific approaches that were considered in the 2014 AHRQ Review include (1) Pivotal Response Training (PRT; Schreibman & Stahmer, 2013), (2) Hanen's "More Than Words" (HMTW; Carter et al., 2011), (3) Parent delivery – Early Start Denver Model (P-ESDM; Rogers et al., 2012), (4) Milton and Ethel Harris Research Initiative Treatment (MEHRIT; Casenhiser et al., 2013): Parent-administered DIR/Floortime, and (5) Preschool Autism Communication Trial (PACT; Green et al., 2010)
Play-/Interaction-Focused Intervention Approaches
Use interactions between children and parents or clinician to affect outcomes such as imitation or joint attention skills or the ability of the child to engage in symbolic play
Specific approaches that were considered in the 2014 AHRQ Review include (1) Joint Attention Symbolic Play Emotion Regulation (JASPER; Kasari et al., 2010), (2) Focused Playtime Intervention (FPI; Siller et al., 2013), (3) Reciprocal Imitation Training (RIT; Ingersoll, 2010, 2012), and (4) Joint Attention Mediated Learning (Schertz et al., 2013)



	Primarily clinician-mediated	Primarily parent-mediated
Comprehensive	*ABA-based Early Intensive Behavioral & Developmental Approaches*	*Behavioral & Developmental Early Intervention-Parent Training*
Focused	*Play-/Interaction-Focused Intervention Approaches*	

Fig. 1.1 Graphical representation of two intervention dimensions (i.e., clinician-mediated vs. parent-mediated, and focused vs. comprehensive) and how they relate to the three categories of behavioral interventions included in the 2014 Report of the Agency for Healthcare Research and Quality (AHRQ)

and retrospective cohort study, and nonrandomized controlled trial). The latter criterion is particularly noteworthy, since studies using single-subject research designs did not meet the threshold for providing "adequate evidence" for this literature review.

Once studies providing adequate evidence about the efficacy/effectiveness of a behavioral intervention approach were identified, study quality was assessed by evaluating each studies' methodological rigor. This assessment considered various study characteristics including the study design, diagnostic approach, participant ascertainment, intervention delivery, outcome measurement, and analysis approach. While the Study Quality Assessment was completed separately for each study, the Strength of Evidence grades were determined based on a qualitative synthesis of the entire body of research. Thus, Strength of Evidence was determined with regard

Table 1.2 Strength of Evidence grades assigned in the 2014 Report of the Agency for Healthcare Research and Quality (AHRQ)

Strength of Evidence grade	Description
High	High confidence that the evidence reflects the true effect. Further research is unlikely to change estimates.
Moderate	Moderate confidence that the evidence reflects the true effect. Further research may change our confidence in the estimate of effect and may change the estimate.
Low	Low confidence that the evidence reflects the true effect. Further research is likely to change confidence in the estimate of effect and is also likely to change the estimate.
Insufficient	Evidence is either unavailable or does not permit a conclusion.

to important, global questions. For example: Are *Behavioral and Developmental Early Intervention-Parent Training* approaches effective for increasing language/communication outcomes? How confident are we that these effects will be stable in light of future research? "Strength of evidence describes the adequacy of the current research, both in terms of quantity and quality, as well as the degree to which the entire body of current research provides a consistent and precise estimate of effect" (p.15, Weitlauf et al., 2014). For each global review question, four Strength of Evidence grades were assigned (Table 1.2).

A summary of the global questions evaluated, as well as the Strength of Evidence grades assigned in the 2014 AHRQ report, is provided in Table 1.3. For most of the evaluated global questions, the Strength of Evidence was graded as "low," indicating "low confidence that the evidence reflects the true effect." Only three intervention effects were graded as "moderate." That is, the literature review revealed moderate confidence that *ABA-Based Early Intensive Behavioral and Developmental Interventions* are associated with improvements in IQ/cognitive abilities as well as language/communication skills. Similarly, the literature review revealed moderate confidence that *Play-/Interaction-Based Interventions* are associated with improvements in joint attention. With regard to *Behavioral and Developmental Early Intervention-Parent Training*, the AHRQ review revealed "low" confidence in positive treatment effects on symptom severity and language/communication outcomes, as well as no effect on IQ/cognitive outcomes.

Table 1.3 Summary of the broad questions evaluated and the Strength of Evidence grades included in the 2014 Report of the Agency for Healthcare Research and Quality (AHRQ)

Outcome	2014 AHRQ report
ABA-based Early Intensive Behavioral and Developmental Interventions	
IQ/cognitive abilities	Medium for positive effect
Adaptive behavior	Low for positive effect
Symptom severity	Low for positive effect
Language/communication	Medium for positive effect
Social skills/social behavior	Low for positive effect
Behavioral and Developmental Early Intervention-Parent Training	
IQ/cognitive abilities	Low for no effect
Symptom severity	Low for positive effect
Language/communication	Low for positive effect
Play-/Interaction-Based Interventions	
Joint attention	Medium for positive effect
Play skills	Low for positive effect
Language/communication	Low for positive effect
Social skills	Low for positive effect

Does Recent Evidence Change our Confidence in the Efficacy/Effectiveness of Parent-Mediated Interventions?

As emphasized above, all three categories of behavioral intervention approaches evaluated in the AHRQ reports (Warren et al., 2011; Weitlauf et al., 2014) include parent-mediated intervention strategies. However, for comprehensive, clinician-delivered intervention approaches (i.e., *ABA-Based Early Intensive Behavioral and*

Developmental Interventions), the added value of including parent-mediated intervention components has not been fully quantified. Thus, the most direct evidence about the efficacy of parent-mediated interventions comes from *Behavioral and Developmental Early Intervention-Parent Training*, as well as parent-mediated focused interventions included among *Play-/Interaction-Based Interventions.*

To the largest extent possible, the current literature review update used the same methods and criteria to identify published articles providing adequate evidence as the original AHRQ reports (Warren et al., 2011; Weitlauf et al., 2014). One important exception is that the current literature review update was limited to interventions for younger children and only included samples of children with ASD (or at risk) who were 6 years or younger at baseline (the original AHRQ reports included samples of children who were 12 years or younger). Inter-rater reliability on the study selection process between the 2014 AHRQ review and the current review update was calculated based on articles published in 2012, revealing excellent agreement between the two reviews (*kappa* = 0.89). The review deadline for the current update was October 2015.

The current literature review update identified 49 articles that were published between 2012 and 2015 and were not included in the AHRQ 2014 review. These 49 articles reported on 47 unique research studies. For 6 of these 47 unique research studies, previous publications on the same research samples were identified (Carter et al., 2011; Casenhiser, Shanker, & Stieben, 2013; Dawson et al., 2010, 2012; Green et al., 2010; Kasari, Freeman, & Paparella, 2006; Kasari, Gulsrud, Freeman, Paparella, & Hellemann, 2012; Kasari, Paparella, Freeman, & Jahromi, 2008; Siller et al., 2013; Yoder & Stone, 2006a, 2006b).

Among the 47 studies with newly published data, 30 reported on intervention approaches that were exclusively parent-mediated. Of these, nine evaluated comprehensive intervention approaches (i.e., *Behavioral and Developmental Early Intervention-Parent Training*) and eleven evaluated play−/interaction-based, focused, parent-mediated approaches (i.e., *Play-/Interaction-Based Interventions*). Finally, the literature review update identified ten parent-mediated intervention studies that did not fit into either of these two categories and will not be discussed in the current chapter. Of these ten studies, four evaluated interventions for high-risk infants (Baranek et al., 2015; Green et al., 2013; Green et al., 2015; Rogers et al., 2014), three evaluated interventions targeting challenging behaviors or sleep (Bearss et al., 2015; Grahame et al., 2015; Johnson et al., 2013), and three evaluated interventions that did not directly address child outcomes and focused instead on improving parent knowledge and well-being (Feinberg et al., 2014; Suzuki et al., 2014; Zhang, Yan, Du, & Liu, 2014). While these studies do not fit into the scope of the current chapter, some of these topics are examined in-depth elsewhere in this volume including Part I (Chaps. 2, 3, and 4 discuss interventions for infants at high risk for autism) and Part IV (Chap. 18 discusses self-help for parents of children with autism). The following sections of this introductory chapter provide a summary of evidence from this updated review of the literature specific to parent-mediated interventions, both comprehensive and focused.

Newer Evidence About Comprehensive, Parent-Mediated Intervention Approaches

Improvements in language/communication Siller and Sigman (2002, 2008) published the first pair of prospective longitudinal studies to show that responsive parental behaviors reliably predict long-term (16-year!) language gains in children with ASD. This finding, which has since been replicated by several research groups (e.g., Adamson, Bakeman, Deckner, & Romski, 2009; Baker, Messinger, Lyons, & Gantz, 2010; McDuffie & Yoder, 2010; Perryman et al., 2013; Warren, Brady, Sterling, Fleming, & Marquis, 2010), provided an important impetus to research evaluating parent-mediated interventions in ASD. Despite this correlational evidence, the 2014 AHRQ review (Weitlauf et al., 2014) failed to demonstrate a consistent treatment effect of comprehensive parent-mediated interventions (i.e., *Behavioral and Developmental Early Intervention-Parent Training)* on children's communication/language outcomes. Although the 2014 AHRQ review identified several studies that reported significant treatment effects on communication/language outcomes (e.g., Aldred, Green, Emsley, & McConachie, 2012; Roberts et al., 2011; Strauss et al., 2012), it was concluded that the studies' methodology (e.g., intervention approach, nature of the control group, outcome measure) was too variable to conclude with confidence that the evidence reflects a true and consistent treatment effect (i.e., Strength of Evidence grade: low for positive effect).

Of the nine comprehensive, parent-mediated intervention studies identified in the current literature update (Table 1.4), only one study (Wetherby et al., 2014) reported a significant treatment effect on a standardized, clinician-administered measure of children's language abilities. In this study, the treatment effect was evident for children's receptive, but not expressive language abilities. In addition, two studies showed significant treatment effects on measures derived from language samples collected during parent-child interaction (Casenhiser, Binns, McGill, Morderer, & Shanker, 2015; Hardan et al., 2015), and three studies showed significant treatment effects on parent-reported communication/language abilities (Green et al., 2010; Hardan et al., 2015; Pickles et al., 2015; Stadnick, Stahmer, & Bookman-Frazee, 2015).

Conclusions:

- Standardized, clinician-administered measures of language/communication evidence two important strengths, when used in research evaluating parent-mediated interventions. First, compared to the intervention context, standardized measures capture children's language/communication abilities at a fairly high level of generalization (i.e., different setting, materials, interactive partner). Second, when used in the context of a randomized clinical trial, clinician-administered measures allow the concealment of children's group assignment. However, given characteristic difficulties with generalization, standardized, clinician-administered outcome measures set a very high bar when evaluating the impact of parent-mediated interventions on language/communication outcomes in children with autism. Moreover, standardized language measures typically focus on gains in vocabulary and language structure, rather than spontaneous, communicative, and functional language use typically targeted in parent-mediated interventions.
- Although responsive parental behaviors are commonly observed in the context of parent-child play interactions, language learning occurs across many daily routines including caretaking, the completion of household chores, and community outings. Arguably, Wetherby et al. (2014) revealed the strongest treatment effects on language/communication because parents were provided with the supports necessary to embed intervention strategies across different kinds of daily routines.
- Responsiveness-based intervention strategies may be most effective in promoting children's early language milestones. That is, Carter et al. (2011) reported that children with relatively low object interest at baseline showed larger treatment-related gains in communication/language in response to a responsiveness-based intervention, compared to children with higher object interest.

Improvements in autism symptoms The AHRQ 2014 review also identified several studies evaluating comprehensive parent-mediated intervention approaches that report significant treatment-related reductions in ASD symptoms (Aldred et al., 2012; Landa & Kalb, 2012; Strauss et al., 2012). Again, it is the studies' heterogeneity of intervention approaches, sample characteristics, outcome measures, and findings that "makes it difficult to meaningfully compare outcomes across studies" (p. 85; Weitlauf et al., 2014). Overall, the AHRQ 2014 report concluded that there was "low" confidence that the evidence in support of a treatment effect of comprehensive, parent-mediated interventions on ASD

Table 1.4 Comprehensive parent-mediated intervention studies identified for the current literature review update

Author	Design	N	Age	Brand/type	Intensity
Carter et al. (2011), Lieberman-Betz et al. (2014)	Multi-site randomized controlled trial	32	21.1 (2.7)	Hanen's "More than Words" (HMTW)	~11 sessions over 5 months
Casenhiser et al. (2013, 2015)	Single-site randomized controlled trial	25	42.5 (8.8)	Milton and Ethel Harris Research Initiative (MEHRIT)/ Developmental Individual Relationship-Based (DIR)	~52 sessions over 12 months
Green et al. (2010), Pickles et al. (2015)	Multi-site randomized controlled trial	77	45 (26–60)	Preschool Autism Communication Trial (PACT)	~19 sessions over 12 months
Hardan et al. (2015)	Single-site randomized controlled trial	25	49.2 (14.4)	Pivotal Response Treatment (PRT)	~12 sessions over 3 months
Solomon et al. (2014)	Multi-site randomized controlled trial	64	49.9 (10.4)	Play Project/ Developmental Individualized Relationship-Based (DIR)	~12 sessions over 12 months
Stadnick et al. (2015)	Quasi-experiment	16	46.8 (25.9)	Project ImPACT	~12 sessions over 3 months
Tonge et al. (2014)	Single-site randomized controlled trial	35	46 (8)	Parent Education and Behavior Management	~ 20 sessions over 5 months
Welterlin et al. (2012)	Single-site randomized controlled trial	10	30.2 (3.6)	Home TEACCHing Program/ TEACCH	~12 sessions over 3 months
Wetherby et al. (2014)	Multi-site randomized controlled trial	42	19.6 (1.9)	Early Social Interaction/ Social Communication, Emotional Regulation, Transactional Supports (SCERTS)	~ 104 sessions over 9 months

symptom severity reveals a true (e.g., consistent) treatment effect.

None of the nine comprehensive, parent-mediated intervention studies identified in the current literature update (Table 1.4) reported adequate evidence to show significant treatment-related reductions on symptom severity scores derived from a standardized diagnostic measure (e.g., Autism Diagnostic Observation Schedule, ADOS, Lord et al., 2012). Preliminary evidence suggesting a treatment effect on ADOS classifications was reported by Solomon, VanEgeren, Mahoney, Huber, and Zimmerman (2014); however, due to methodological concerns, the authors state that "the improvements in autism symptomatology (…) must be viewed very cautiously" (p. 483). Short of changes on measures derived from standardized diagnostic measures, several studies revealed treatment effects on observational measures of specific symptom domains. For example, Wetherby et al. (2014) reported a significant treatment effect on the Social Composite of the Communication and Symbolic Behavior Scales (CSBS, Wetherby & Prizant, 2002). Similarly, several authors reported significant treatment-related gains on social communication behaviors observed during parent-child interaction (Green et al., 2010; Casenhiser et al., 2013, 2015; Solomon et al., 2014). Importantly, Pickles et al. (2015) reported that 61–80% of the (nonsignificant) treatment effect on ADOS social communication scores was mediated by gains in child initiations observed during parent-child interaction. Finally, two studies reported significant treatment effects on parent-reported measures of social communication and socialization (Green et al., 2010; Wetherby et al., 2014).

Conclusions:

- Studies identified in the current literature review update provide little evidence to suggest that comprehensive, parent-mediated interventions have a true and consistent treatment effect on global measures of symptom severity, derived from standardized diagnostic instruments (e.g., ADOS).

- Several studies have revealed significant treatment effects on symptom levels in the social domain. Measures to capture social outcomes vary across studies, both in content (e.g., social initiation, social communication, socialization) and method of data collection (i.e., clinical assessment, observation of parent-child interaction, parent report). This methodological heterogeneity limits the general conclusions that can be drawn.
- Future research would benefit greatly from behavioral measures of children's social symptoms that can feasibly be administered to diverse samples; that effectively capture aspects of children's social attention, comprehension, and motivation; and that are related to the etiology of autism (i.e., endophenotypes). Current advances in eye-tracking of dynamic social stimuli bear great promise in this regard (Rice, Moriuchi, Jones, & Klin, 2012; Swanson & Siller, 2013).

Improvements in cognitive abilities/IQ The AHRQ 2014 review (Weitlauf et al., 2014) found that most studies evaluating comprehensive, parent-mediated interventions do not find a significant treatment effect on children's cognitive abilities/IQ. Of the nine studies evaluated for the current literature review update, at least four studies evaluated treatment outcomes using a standardized assessment of cognitive abilities (e.g., the Mullen Scales of Early Learning; Psychoeducation Profile-Revised), and no evidence was provided to suggest that comprehensive, parent-mediated interventions are associated with treatment effects in cognitive abilities/IQ (Solomon et al., 2014; Tonge, Brereton, Kiomall, Mackinnon, & Rinehart, 2014; Welterlin, Turner-Brown, Harris, Mesibov, & Delmolino, 2012; Wetherby et al., 2014).

Conclusions:

- Although it is not unreasonable to assume that shorter-term gains in language/communication abilities and reductions in autism symptoms will increase children's access to learning opportunities, leading to longer-term increases in cognitive abilities/IQ, this cascade of treatment effects has little empirical evidence to date.

Improvements in patterns of parent-child interaction One outcome domain that was not addressed in the AHRQ 2014 review (Weitlauf et al., 2014) concerns the extent to which comprehensive, parent-mediated interventions improve patterns of parent-child interaction, specifically the use of development-enhancing parental strategies. Recent years have witnessed an emerging consensus around evidence-based, development-enhancing intervention strategies. This consensus has been articulated under the moniker of Naturalistic Developmental Behavioral Interventions (NDBI; Schreibman et al., 2015) and includes strategies such as child choice, environmental arrangement, natural reinforcement, balanced turn taking, contingent imitation, and broadening the child's attentional focus. Although there are currently no universal fidelity measures to capture these development-enhancing intervention strategies, most of the nine comprehensive, parent-mediated intervention studies identified in the current literature update (Table 1.4) measured changes in parental behaviors and strategies. For example, Hardan et al. (2015) used prespecified fidelity criteria derived from Pivotal Response Treatment, demonstrating that parents were able to learn and implement the intervention strategies with high accuracy. Similarly, three studies used observational fidelity scales capturing a range of intervention strategies (Casenhiser et al., 2013, 2015; Solomon et al., 2014; Stadnick et al., 2015), demonstrating significant increases in parental use of these strategies over the course of the intervention. Finally, two studies used measures of parental responsiveness (Carter et al., 2011; Green et al., 2010), demonstrating treatment effects on this measure.

Conclusions:

- Comprehensive, parent-mediated interventions are effective for increasing a range of development-enhancing parental behaviors and intervention strategies. Although different intervention approaches target and measure different parental behaviors, an emerging consensus has been articulated under the moniker of NDBI.

- To date, only one comprehensive, parent-mediated intervention study has investigated whether the parents' use of NDBI strategies mediates the relation between treatment and child outcome. That is, a clinical trial of the PACT intervention reported that the parents' synchronous responses to the child partially mediated gains in social communication (Pickles et al., 2015).
- Future research would benefit greatly from a universal fidelity measure that evaluates the extent to which parents implement key, evidence-based intervention strategies, as summarized under the NDBI moniker (Schreibman et al., 2015).

Newer Evidence About Focused, Play-/Interaction-Based, Parent-Mediated Intervention Approaches

Improvements in language/communication The 2014 AHRQ report identified three *Play-/Interaction-Based Interventions* that reported significant treatment effects on communication outcomes (Kasari et al., 2008; Schertz, Odom, Baggett, & Sideris, 2013; Venker, McDuffie, Weismer, & Abbeduto, 2012). Kasari et al. (2008) evaluated the efficacy of a clinician-implemented JASPER intervention and found significant treatment-related gains in children's expressive, but not receptive, language outcomes. Evaluating a joint attention parent-mediated intervention, Schertz et al. (2013) reported significant treatment effects on a standardized measure of receptive language, as well as parent-reported communication skills (i.e., Vineland Adaptive Behavior Scales, VABS; Sparrow, Cicchetti, & Balla, 2005). Finally, evaluating a parent-mediated intervention targeting the parents' verbal responsiveness, Venker et al. (2012) reported a significant treatment effect on an observational measure of children's communication, demonstrating increases in prompted, but not spontaneous, communicative acts. Based on this limited evidence, the 2014 AHRQ review concluded that there was low evidence supporting a positive effect of *Play-/Interaction-Based Interventions* on children's language/communication outcomes.

Of the eleven focused, parent-mediated intervention studies identified in the current literature update (Table 1.5), six evaluated treatment-related gains in spoken communication/language (Ginn, Clionsky, Eyberg, Warner-Metzger, & Abner, 2015; Kasari, Siller et al., 2014; Kasari, Gulsrud, Paparella, Hellemann, & Berry, 2015; Siller et al., 2013; Siller, Swanson, Gerber, Hutman, & Sigman, 2014; Thompson, McFerran, & Gold, 2014; Woo, Donnelly, Steinberg-Epstein, & Leon, 2015). Of these six studies, only one study reported a significant treatment effect on children's receptive, but not expressive, language skills evaluated using a standardized, examiner-administered measure (Woo et al., 2015). In addition, Siller et al. (2013) found that children's expressive language abilities at baseline moderated subsequent treatment-related gains in expressive language. For preschoolers who entered the program with delayed expressive language skills (i.e., skills associated with children below 12 months of age, $n = 24$), results showed a significant, medium-to-large treatment effect that accounted for approximately 25% of the variance in children's subsequent language gains. A comparable treatment effect was not found for children who entered the study with more advanced language skills.

Conclusions:

- The only focused, parent-mediated intervention study that identified a significant treatment effect on children's language abilities (i.e., receptive language) evaluated an intervention designed to enrich children's sensorimotor experience (Woo et al., 2015). The intervention was delivered by email, and parents were instructed to implement two daily sessions (15–30 min) for 6 months. Given the intervention's low intensity (at least in terms of clinician time), a significant treatment

Table 1.5 Focused parent-mediated intervention studies identified for the current literature review update

Carr et al. (2016), Kasari, Lawton, et al. (2014)	Multi-site randomized controlled trial	60	41.9 (10.0)	Joint Attention Structured Play Emotion Regulation (JASPER)	~24 sessions over 3 months
Chiang et al. (2016)	Quasi-experiment	18	35.9 (8.6)	Joint Attention Structured Play Emotion Regulation (JASPER)	~20 sessions over 8 weeks
Ginn et al. (2015)	Single-site randomized controlled trial	15	51.6 (14.4)	Child-Directed Interaction Training (CDIT)/ Parent Child Interaction Training (PCIT)	~8 sessions over 2.5 months
Kasari et al. (2015)	Single-site randomized controlled trial	43	30.7 (3.5)	Joint Attention Structured Play Emotion Regulation (JASPER)	~20 sessions over 2.5 months
Kasari, Siller, et al. (2014)	Multi-site randomized controlled trial	32	22.2 (4.2)	Focused Playtime Intervention (FPI)	~12 sessions over 3 months
Poslawsky et al. (2015)	Single-site randomized controlled trial	40	42.2 (9.0)	Video Interaction to promote Pos. Parenting (VIPP)	~ 5 sessions over 3 months
Sanefuji and Ohgami (2013)	Single-site randomized controlled trial	8	54 (34–71)	Contingent imitation	~ 1 session
Siller et al. (2013, 2014)	Single-site randomized controlled trial	36	58.3 (12.7)	Focused Playtime Intervention (FPI)	~12 sessions over 3 months
Silva and Schalock (2013)	Quasi-experiment	97	46.8 (13.2)	Qigong Sensory Treatment	~ 21 sessions over 5 months
Thompson et al. (2014)	Single-site randomized controlled trial	12	44 (6)	Family-centered music therapy (FCMT)	~16 sessions over 4 months
Woo et al. (2015)	Single-site randomized controlled trial	28	57.6 (13.2)	Sensorimotor exercises	~ 1 session/ 13 contacts over 6 months

effect on children's receptive language abilities is surprising and may be attributed to several methodological weaknesses of the research design. Most importantly, less than half of the families randomized to the experimental group completed the intervention protocol and were included in the data analyses. Thus, a certain amount of intensity in terms of clinician time, as well as a focus on intervention strategies that parents can implement across multiple natural routines (Wetherby et al., 2014), may be necessary to affect generalized language gains.

- Consistent with developmental theory and research evaluating comprehensive, parent-mediated interventions (Carter et al., 2011), findings presented by Siller et al. (2013) suggest that responsiveness-based parent-mediated interventions may be most effective at facilitating children's earliest language milestones.

Improvements in autism symptoms In evaluating the effect of *Play-/Interaction-Based Interventions* on autism symptoms, the AHRQ 2014 report addressed three specific symptom domains: joint attention, play/imitation skills, and social skills.

Improvements in joint attention The AHRQ 2014 review identified nine intervention studies that incorporated play- or interaction-based strategies to target joint attention outcomes (Weitlauf et al., 2014). Based on this body of literature, the authors noted consistent evidence to suggest that *Play-/Interaction-Based Interventions* increase joint attention outcomes. Despite this consistent evidence, the authors rated the Strength of

Evidence as moderate because (1) the duration of effects is unclear and (2) participants in most studies were also receiving other early intervention and disentangling effects is difficult. In light of the current focus, it is also noteworthy that only two of these studies evaluated parent-mediated interventions (Kasari, Gulsrud, Wong, Kwon, & Locke, 2010; Schertz et al., 2013). Both studies reported significant treatment effect on children's responsiveness to other's bids for joint attention that were maintained over a 2–12-month follow-up period. Treatment effects on children's initiations of joint attention were not statistically significant.

Of the eleven focused, parent-mediated intervention studies identified in the current literature update (Table 1.5), five studies investigated treatment effects on joint attention outcomes (Carr et al., 2016; Chiang, Chu, & Lee, 2016; Kasari et al., 2015; Kasari, Lawton, et al., 2014; Kasari, Siller, et al., 2014; Poslawsky et al., 2015). Out of these five studies, two reported significant treatment effects on joint attention outcomes evaluated using the Early Social Communication Scale (Mundy, Sigman, Ungerer, & Sherman, 1986), a structured, examiner-administered observational measure of nonverbal communication. Kasari, Lawton, et al. (2014) evaluated a parent-mediated intervention based on JASPER, reporting a significant treatment effect on children's initiations of joint attention between baseline and exit. This treatment effect was not maintained during a 3-month follow-up. Similarly, Poslawsky et al. (2015) reported a conditional treatment effect of a video-feedback intervention to promote positive parenting adapted to autism (VIPP-AUTI) on child initiations of joint attention, moderated by school attendance. That is, the intervention effectively increased joint attention outcomes, but only for children who were not attending school.

Improvements in play skills and imitation The 2014 AHRQ report identified several *Play-/Interaction-Based Interventions* that reported significant treatment effects on children's functional and symbolic play (Kasari et al., 2006; Kasari et al., 2010; Murdock & Hobbs, 2011; Wong, 2013) and imitation skills (Ingersoll, 2010, 2012). Based on this small and somewhat inconsistent body of literature, the 2014 AHRQ report concluded that there is low confidence in a positive effect of *Play-/Interaction-Based Interventions* on play/imitation outcomes. Again, only one of the above-mentioned studies tested the efficacy of a parent-mediated intervention on this symptom domain (Kasari et al., 2010).

Of the eleven focused, parent-mediated intervention studies identified in the current literature update (Table 1.5), four studies reported outcome measures of functional/symbolic play (Carr et al., 2016; Kasari et al., 2015; Kasari, Lawton, et al., 2014; Poslawsky et al., 2015) or imitation skills (Sanefuji & Ohgami, 2013). Kasari et al. (2015) reported a significant treatment effect on the frequency of functional play acts as well as the overall play level between baseline and exit, but treatment effects were not maintained at follow-up. Similarly, Kasari, Lawton, et al. (2014) and Carr et al. (2016) reported significant treatment effect on the diversity of symbolic play acts, but only for children who showed at least one symbolic play act at study entry. Finally, Sanefuji and Ohgami (2013) reported that parent-mediated contingent imitation intervention significantly improved children's imitative abilities.

Improvements in social abilities The 2014 AHRQ report identified five studies that effectively increased children's social engagement (i.e., joint engagement, shared positive affect) with teachers (Lawton & Kasari, 2012; Wong, 2013) or parents (Kaale, Smith, & Sponheim, 2012; Kasari et al., 2010). Based on this evidence, the 2014 AHRQ review concluded that there was low evidence supporting a positive effect of *Play-/Interaction-Based Interventions* on social skills.

Of the eleven focused, parent-mediated intervention studies identified in the current literature update (Table 51.), three studies found that parent-mediated JASPER increased children's observed joint engagement during parent-child interaction (Carr et al., 2016; Chiang et al., 2016; Kasari et al., 2015; Kasari, Lawton, et al., 2014). In addition, Siller et al. (2014) reported a significant treatment effect on children's attachment-related behaviors (both, observed during a brief separation-reunion episode and evaluated using a parent-report questionnaire). This is the first clinical trial to demonstrate that responsiveness-based interventions can enhance the attachment-related behaviors of children with autism, a finding that has previously been shown for other high-risk populations (Heinicke et al., 1999; Heinicke, Fineman, Ponce, & Guthrie, 2001; Juffer, Bakermans-Kranenburg, & van IJzendoorn, 2008; Powell, Cooper, Hoffman, & Marvin, 2007; van der Boom, 1994, 1995). In addition, two studies reported significant treatment effects on parent-reported measures of social/emotional awareness and functioning (Ginn et al., 2015; Thompson et al., 2014).

Conclusions:

- Focused, parent-mediated interventions can improve core autism symptoms, including joint attention, functional/symbolic play, and imitation. Given differences in intervention and measurement approach, findings are somewhat inconsistent and the duration of effects is unclear.
- Several clinician-administered, semi-structured observational measures have been used to evaluate gains in joint attention, play skills, and imitation (e.g., Early Social Communication Scale, Mundy et al., 1986; Communication and Symbolic Behavior Scales, Wetherby & Prizant, 2002; Structured Play Assessment, Ungerer & Sigman, 1981; Motor Imitation Scale, Motor Imitation Scale, Stone, Ousley, & Littleford, 1997). In the context of clinical trials, clinician-administered measures allow the concealment of children's group assignment. However, age norms are typically not available for these measures (e.g., the CSBS is normed for children up to 24 months), making the longer-term impact on core deficits difficult to evaluate.
- Focused, parent-mediated interventions can improve children's social engagement during interactions with the caregiver, including markers of the relationship quality (i.e., attachment-related child behaviors). Since play-based interactions between parent and child often provide the context for both, intervention and measurement, the degree of generalization implicit in these measures is limited.

Improvements in pattern of parent-child interaction Consistent with the literature on comprehensive, parent-mediated interventions (i.e., *Behavioral and Developmental Early Intervention-Parent Training)*, focused interventions also provide support that parents can effectively learn and implement a broad range of intervention strategies, aiming to promote their children's social communication skills. Of the eleven focused, parent-mediated intervention studies identified in the current literature update (Table 1.5), two used prespecified criteria for parent fidelity of implementation, demonstrating that 50% of parents demonstrated skill mastery of implementing intervention strategies derived from parent-child interaction therapy (Ginn et al., 2015) and 75% of parents demonstrated complete fidelity in implementing Qigong massage therapy (Silva & Schalock, 2013). In addition, four studies reported significant treatment effects on a range of development-enhancing intervention strategies, including non-intrusiveness, positive following, and responsive communication (Ginn et al., 2015; Kasari, Siller, et al., 2014; Poslawsky et al., 2015; Siller et al., 2013; Siller et al., 2014).

Conclusions:

- Consistent with results from research evaluating comprehensive, parent-mediated interventions, focused interventions have also been shown to increase a range of development-enhancing parental behaviors and intervention strategies. Although heterogeneous measures are used, underlying concepts relate to child choice, environmental arrangement, natural reinforcement, balanced turn taking, contingent imitation, and broadening the child's attentional focus (i.e., NDBI).
- Above, we cited a comprehensive, parent-mediated intervention study that showed that parents' synchronous responses to the child partially mediated gains in social communication (Pickles et al., 2015). Similarly, results

from a clinical trial of parent-mediated JASPER (a focused, parent-mediated intervention) found that parents' use of mirrored pacing mediated subsequent treatment gains in joint engagement (Gulsrud, Hellemann, Shire, & Kasari, 2016). Both measures of synchronous responsiveness and mirrored pacing emphasize the parents' ability to respond to and elaborate on the child's focus of attention, interest, and play actions.

General Conclusions About the Efficacy of Parent-Mediated Interventions

The 2013 Cochrane review and meta-analysis of clinical trials "did not find statistical evidence of gains from parent-mediated approaches in most of the primary outcomes assessed" (p. 2, Oono et al., 2013). That is, evidence of treatment effects on most aspects of language and communication, including child initiations observed during parent-child interaction, was "largely inconclusive and inconsistent across studies" (p. 2). In contrast, the Cochrane report revealed strong and consistent treatment effects on patterns of parent-child interaction (i.e., shared attention, parent synchrony) and some suggestive evidence of improvements in language comprehension and reductions in autism symptoms. These overall conclusions about intervention efficacy are consistent with those of a similar literature review of parent-mediated interventions for children under 3 years of age (Beaudoin et al., 2014), as well as the AHRQ reviews discussed in detail above (Warren et al., 2011; Weitlauf et al., 2014).

The conclusions drawn in the 2013 Cochrane report were based on 17 clinical trials of parent-mediated interventions published before August 2012. The current literature review discussed an additional 20 studies published between 2012 and October 2015. Despite some differences in study selection methods, 17 of the 20 studies[1] identified for the current literature review update were randomized clinical trials, effectively doubling the amount of evidence available in 2013. Despite this exponential increase in the number rigorous studies evaluating the efficacy of parent-mediated interventions in autism, the dominant characteristic of this body of literature continues to be its heterogeneity – heterogeneity of outcome measures, participant characteristics, and intervention strategies (i.e., structure, content, approach). In the following section, we will briefly discuss three general conclusions from this literature review update and refer the reader to corresponding chapters of the Handbook where related issues are discussed in greater detail.

Generalization of intervention outcomes The primary question addressed in the 2013 Cochrane review (Oono et al., 2013) was whether the available evidence (defined broadly in terms of quality, quantity, and consistency) is sufficient to confidently determine that a given intervention approach produces favorable outcomes. In contrast, the 2014 AHRQ review aimed to answer more specific questions about the interventions' impact on specific outcome domains. For example: Is the given intervention approach effective for increasing children's language/communication outcomes? Results from the current literature review update highlight the importance of organizing outcome measures not only by outcome domain, but also the degree of similarity between the intervention and assessment context. That is, meaningful learning implies that a skill that is acquired in one setting (i.e., the intervention setting) can be applied in another setting (i.e., the assessment setting). Similarly, meaningful learning implies that a skill that is acquired in a certain way (e.g., with a certain material or interactive partner) can be applied in a different way (e.g., with different materials or interactive partners). When presenting the primary results of a clinical trial evaluating the PACT intervention, Green et al. (2010) concluded very eloquently that the generalization of the intervention effect was attenuated across interaction and context. That is, results revealed significant treatment

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[1] Earlier publications on 3 of the 20 studies identified for the current literature review update were also included in the Cochrane report (Carter et al., 2011; Green et al., 2010; Siller et al., 2013).

effects on outcome measures that were more proximal to the intervention, including measures of parent and child communication observed during parent-child interaction. In contrast, treatment effects on outcome measures that were more distal to the intervention including measures of social communication skills assessed during interactions with an assessor or observed in children's natural school environment were smaller and nonsignificant.

At this point, we do not have a quantitative way to represent the degree of generalization that is necessary in order to apply a skill that is acquired in one way (i.e., in accordance with the intervention procedures) and assessed in another (i.e., as part of the outcome assessment). In the absence of such a quantitative representation, the conclusions we can draw from a systematic review of the literature are limited in several ways. First, the interpretation of each outcome measure changes depending on the nature of the evaluated intervention. This complicates the comparison between different kinds of interventions. For example, consider an intervention that is implemented by a clinician and uses a structured teaching approach where skills are broken down into separate components and taught one at a time using behavioral learning principles (e.g., Discrete Trial Training; Lovaas, 1987). In the context of such an intervention, a clinician-administered, standardized test of cognitive abilities evidences many similarities with the intervention procedures and should be interpreted as a relatively proximal outcome measure. That is, intervention and assessment activities are typically administered at a table, target discrete, decontextualized skills; focus on basic cognitive functions such as matching, imitation, and responding to prompts; and involve a clinician that implements behavioral principals to elicit specific child behaviors. In contrast, the same assessment should be interpreted as a relatively distal outcome measure when used to evaluate a parent-mediated intervention that is implemented in the context of natural family routines and focuses on social communication outcomes.

Second, the attenuation of intervention effects across interaction and context described by Green et al. (2010) for the PACT intervention reveals a pattern that is consistent across the literature on parent-mediated interventions more broadly. Arguably, interventions that are more successful at achieving more generalized outcomes are those that are implemented over longer durations, involve more hours of clinician time, and are implemented across multiple natural family routines (Wetherby et al., 2014). The likely association between the intensity of a parent-mediated intervention and the degree of generalization in children's learning outcomes raises questions about the cost-effectiveness relationship, including "how much generalization" you can reasonably expect from a short-term, parent-mediated intervention. Eighteen of the 20 parent-mediated intervention studies included in the current literature review update involved fewer than 25 intervention sessions and were implemented over a period less than 12 months.

Finally, a quantitative way to represent the degree of generalization between intervention and assessment would facilitate the integration of evidence from studies using a controlled group design and studies using single-subject research. That is, single-subject research is generally more suitable for evaluating more proximal as compared to more distal intervention outcomes.

Supporting diverse parents During the last decade, intervention research in autism has started to recognize that not all children benefit from interventions in the same way. For example, results from the current literature review update suggest that responsiveness-based parent-mediated interventions may be most effective for children with autism who have limited language skills (Siller et al., 2013) or limited object interest (Carter et al., 2011). Along the same lines, Part I of this volume (Chaps. 2, 3, and 4) explores the role of child age on the implementation and efficacy of parent-mediated interventions. Specifically, the authors describe current research on interventions for infants at high risk for autism and discuss how their needs, and those of their families, can be met in the context of parent-mediated interventions.

Arguably the most robust finding from the current literature review update is that, on average, parents can be effectively taught to implement a broad range of intervention strategies. However, the emerging evidence also suggests that not all parents acquire the same level of proficiency in using the targeted strategies, maintain the use of these strategies over time, and implement the acquired strategies with sufficient intensity to affect children's longer-term outcomes. Research on parent-mediated interventions in autism is only beginning to systematically identify parent or family characteristics that predict parent buy-in or treatment efficacy. Results from several studies suggest that higher baseline levels of self-reported parenting stress are related to smaller gains from parent-mediated interventions (see Chaps. 2 and 10; Osborne, McHugh, Saunders, & Reed, 2008; Robbins, Dunlap, & Plienis, 1991; Stadnick et al., 2015). However, other research suggests that a certain level of parenting stress increases (rather than reduces) parent implementation of intervention strategies during everyday interactions and routines. That is, Alquraini and Mahoney (2015) found that high levels of parenting stress enhance the extent to which treatment-related gains in maternal responsiveness lead to improvements in child development. In addition to this emerging literature on the role of parenting stress, Siller et al. (2013) reported that parents who were better able to describe their child's experience and behaviors in a complex, open, and accepting way are more likely to benefit from an intervention based on parent coaching, compared to parents who find it more difficult to engage in such conversations about their child. As discussed in detail in Chap. 12, current parent coaching approaches are based on the recognition that (1) parents have an intimate knowledge of the child's abilities, challenges, and typical performance; (2) parents understand the child's and the family's daily routines, environments, and culture; and (3) parents have ideas about the goals they would like to accomplish for their child, themselves, and as a family. Not all parents may be equally prepared to engage in such conversations about their child. Interestingly, results presented by Siller et al. (2018) suggest that the parents' capacity for reflection and self-evaluation can be effectively increased in the context of parent coaching. Part II of this volume focuses on a broad range of individual differences between parents of children with autism, discussing strategies to support parents who experience financial hardship and poverty (Chap. 5 and 7), cultural differences and stigma (Chap. 6), and cognitions/emotions that may make it difficult to fully engage in parent coaching (Chap. 8).

Differences and similarities between parent-mediated intervention approaches Parent-mediated intervention approaches in autism have been developed, and are implemented, by professionals with training across many disciplines, including early childhood education, clinical or developmental psychology, speech-language pathology, and behavior analysis, holding a range of professional licenses, degrees, or certifications. Further, available interventions differ from each other in their approach (e.g., theoretical framework, terminology), content (e.g., targeted family routines, learning outcomes, adult-learning strategies), and structure (e.g., number of weekly, clinician-implemented sessions, duration of the intervention period, training, and experience of the interventionists). Given the existing heterogeneity of intervention approaches, broad statements about the efficacy/effectiveness of parent-mediated interventions are not intellectually satisfying or useful in practice. What would be more helpful is a greater understanding of the active ingredients that are shared across different approaches and responsible for increases in child development and parent learning. Further, it would be useful to have access to tools to effectively monitor the implementation of these active ingredients (i.e., fidelity measures) and to measure proximal outcomes to ensure that child and parent learning is impacted as predicted. Part VI and Part VII of this handbook discuss the implementation science perspective on parent-mediated interventions in greater detail. This includes strategies for supporting families across the globe

(Chaps. 22, 23, and 24), as well as successful initiatives to support the community implementation of parent-mediated intervention strategies in the USA (Chaps. 25, 26, 27, and 28).

One distinction that was operationalized by Rogers and Vismara (2008), and applied in the 2014 AHRQ review concerns the distinction between comprehensive (i.e., interventions that are implemented during many hours per week, targeting multiple outcome domains) and focused intervention approaches (i.e., interventions that are implemented with relatively low intensity, focusing on a smaller number of outcomes). As discussed above, the current literature review supports the notion that parent-mediated interventions that are implemented over longer durations involve more hours of clinician time and are implemented across multiple natural family routines (Wetherby et al., 2014) and are more likely to produce generalized learning outcomes, compared to interventions that are more focused and short-term. However, in the context of parent-mediated interventions, a clear distinction between focused and comprehensive approaches proves to be difficult. First, many parent-mediated interventions emphasize the integration of learning outcomes across multiple developmental domains (e.g., social, play, language). Second, the intensity of a parent-mediated intervention is not only defined in terms of clinician hours but also the intensity with which parents implement the intervention during daily routines, as well as how many daily routines are directly targeted by the intervention.

Our ability to draw empirical conclusions about active ingredients from this heterogeneous body of literature is limited by the fact that (1) few studies directly compare different parent-mediated intervention approaches to each other and (2) most studies have relatively small sample sizes, providing limited statistical power to test hypotheses about mediators and moderators of intervention efficacy. This being said, the last decade has witnessed an emerging consensus about active ingredients of effective interventions (Schreibman et al., 2015). The current Handbook aims to capture this emerging consensus.

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Part I

Supporting Families of Infants at High-Risk for Autism

2

Supporting Families of Infants At-Risk for ASD Identified Through Community Screening and Surveillance

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Abstract

Screening tools have given us the opportunity to identify risk symptoms of autism spectrum disorder (ASD) in infants prior to the full expression of symptoms when a definitive diagnosis can be made. Identification of ASD risk via community screening and surveillance is particularly important for the estimated 89% of infants without known genetic risk factors (such as an older sibling with ASD) who will eventually be diagnosed with ASD. Based on the application of a transactional model of development to infants at-risk for ASD, parent-implemented very early interventions have the potential to attenuate the expression of ASD symptoms in these infants and improve outcomes. In this chapter, we will (1) discuss what is known about identification of infants who are at-risk for ASD through community screening, (2) highlight the research to date examining use of parent-implemented very early interventions for infants who were identified as at-risk for ASD via community screening, and (3) offer insight into some of the advantages and obstacles in intervening with this population based on our own research experiences and those of our colleagues who have done similar work.

Introduction

Currently, we have the capability of identifying many children who are at significant risk for autism spectrum disorder (ASD) during infancy. One opportunity for doing so is focusing on infants who have an older sibling with ASD. We know these infant siblings have about a 20% chance of eventually being diagnosed with ASD as well (Constantino, Zhang, Frazier, Abbacchi, & Law, 2010; Ozonoff et al., 2011), and most parents of children with ASD are aware that the infant siblings of these children have a higher risk of ASD. This early awareness of an infant's risk for ASD can bring both anxiety and opportunities. Families that include infants as well as one

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_2

or more children already diagnosed with ASD can benefit from supports that recognize these factors, as discussed in Chap. 3. However, given that only an estimated 11% of children with ASD are members of multiplex families (Constantino et al., 2010), there is a large population of at-risk infants who cannot be identified based on familial risk.

We now have parent-report screening tools with some utility for identifying infants at-risk for ASD as young as 6–12 months old, allowing for very early identification of at least some of the 89% of children with no known familial risk who will eventually be diagnosed with ASD. In most cases, however, fully expressed diagnostic symptoms of ASD are not observed by the end of the first year of life (Ozonoff, Heung, Byrd, Hansen, & Hertz-Picciotto, 2008); therefore, definitive diagnoses are rarely made this early, even in cases where infants are known to be at-risk. A key question then becomes, are there benefits for both identifying these at-risk children before conclusive diagnoses can be made and connecting them with community resources?

The purpose of this chapter is to examine the opportunities and challenges related to parent-implemented very early intervention (PIVEI) for infants (i.e., under 18 months of age) known to be at-risk for ASD, prior to the time that definitive diagnoses can be provided. Further, our focus is on infants who are identified in the community via screening or surveillance rather than on those who are identified based on having an older sibling with ASD.

Theoretical Foundations

Theoretically, intervening during the first year and a half of life, before the full expression of ASD symptoms, could have important impacts on brain and behavioral development. In particular, due to the rapidity of changes in neural networking during this time period and the high level of neural plasticity, interventions to promote key or "pivotal" behaviors (e.g., joint engagement of infants and caregivers) during this time may contribute to normalization of neural development, establish more typical developmental trajectories across behavioral domains, and ameliorate ASD symptoms or even prevent the appearance of some symptoms.

The transactional model (Barnlund, 1970; Sameroff, 1983) describes the dynamic interchange of child and environmental factors impacting development over time. According to the transactional model, an infant's development is dependent on the environment in which that development occurs as well as exposure to different people who provide practice for more complex future interactions between children and adults. In infancy, the child's primary interactions are in the home environment with their parents, who model and scaffold social communication and self-regulation during daily living tasks such as diapering and feeding. In line with the transactional model, parent responsiveness to young children has demonstrated long-term positive effects on language, social-emotional, and academic outcomes in children with and without disabilities (Evans & Porter, 2009; Gulsrud, Jahromi, & Kasari, 2010, Kaiser et al., 1996; Mahoney & Powell, 1988; Kim & Mahoney, 2005).

Also consistent with the transactional model, infant and child variables influence parent responses and interaction strategies (Barnett, Gustafsson, Deng, Mills-Koonce, & Cox, 2012; Yoder & Warren, 2001). Early sensory-regulatory difficulties (e.g., hyporesponsiveness to salient stimuli) as well as social communication difficulties (e.g., limited shared interest in objects) in infants may directly impact parent responsiveness and/or offer parents fewer opportunities to respond to their child. For example, some infants with ASD will vocalize less and use a reduced amount of canonical babbling (e.g., "baba," "dada") (Patten et al., 2014) in their first year of life, which likely will alter the quantity and/or quality of responses from caregivers (Gros-Louis, West, Goldstein, & King, 2006; Warlaumont, Richards, Gilkerson, & Oller, 2014). The effects of transactional difficulties in early interaction and engagement between parents and infants are hypothesized to be cascading, such that having fewer opportunities to practice these skills in infancy will reduce engagement in social interactions during the school years, thus broadening the gap even further over time (Leezenbaum, Campbell, Butler, & Iverson, 2014). For example, Parker and Asher (1993) found that children with early social communication deficits had fewer friendships when compared with peers who were competent social communicators, and lack of friends was predictive of poorer emotional well-being over time. Moreover, early social communication deficits have been found to predict poorer outcomes in employment and relationships in adulthood (Howlin, Moss, Savage, & Rutter, 2013).

Another example of the cascading effects of transactions that begin during infancy is demonstrated by the early co-regulation of interactions between parents and infants. Co-regulation is the process of anticipating responses of another person and adjusting reactions according to what has already taken place within an interaction such that the exchange can continue (Fogel, 1993). Co-regulation between mothers and 6-month-old infants has been linked to later positive developmental outcomes, play engagement, and secure infant attachment (Evans & Porter, 2009). Secure infant attachment is a critical outcome of these co-regulated parent-infant interactions because it is associated with self-regulation in the areas of social self-control and attentional impulsivity in elementary school (Drake, Belsky, & Fearon, 2014). Thus, early breakdowns in co-regulation between parents and infants, such as those that may occur when infants have unusual social or sensory responses (e.g., an infant looking at the ceiling fan while his mother tries to play peek-a-boo) may have long-term effects on infant self-regulation.

The importance of transactions between genetic risk for ASD and environmental factors that shape the development of neural circuitry during the child's early experiences is emphasized in neurodevelopmental theories. Dawson (2008) proposed a developmental model of risk factors in ASD. Consistent with the transactional model, Dawson suggested that the child's interactions with parents and his or her early social environment are pivotal to the emergence of social brain circuitry necessary for future social communication success. According to Dawson, biological risk factors contribute to the child's behavioral deficits, which further trigger risk processes that may iteratively impact development over time; however, the neural plasticity present in infancy provides an opportunity for early intervention to target the transactions between the parent and infant, which may alter these risk processes and guide the brain circuits toward more typical patterns to improve outcomes. Figure 2.1 illustrates the importance of early identification of behavioral ASD symptoms via screening and surveillance and the potential effects of

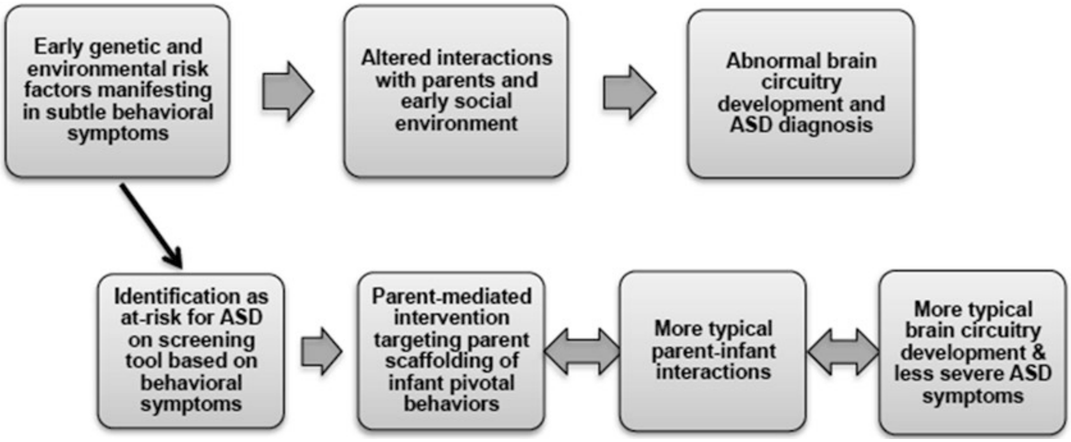

Fig. 2.1 Developmental model of risk and outcome in ASD, with and without parent-mediated very early intervention. (Modified from Dawson, 2008)

intervening at this critical stage of brain development before ASD symptoms have fully manifested.

Identifying Infants and Young Toddlers Through Community Surveillance or Screening

To fully evaluate the potential benefits and challenges of scaling up programs of PIVEI for community-identified children, we must first consider the strategies for identifying infants who are at-risk for ASD as well as the outcomes of implementing these identification strategies. A considerable literature related to early screening for ASD has developed since the seminal publications reporting on screening 18-month-olds using the Checklist for Autism in Toddlers (CHAT) (Baron-Cohen et al., 1996; Baron-Cohen, Allen, & Gillberg, 1992). Building on that work, most of the literature reports on screening toddlers at 18 months of age or older and, even in cases where some younger toddlers are included, the results for younger toddlers rarely are disaggregated from the results for older toddlers. Relevant to this chapter, however, studies on a few screening tools or surveillance strategies have reported data more specific to identifying children in community samples based on ASD-related symptoms detectable prior to 18 months.

Within the studies focused on identifying infants at-risk for ASD that are relevant to our discussion of PIVEI, we will highlight four important themes. First, systematic screening or surveillance for early symptoms of ASD can identify infants who are at an elevated risk of a later diagnosis of ASD. That is, the prevalence in the US population currently is estimated at 1 in 68 at age 8 years (Autism and Developmental Disabilities Monitoring Network, 2014), or about 1.5% of the population. In comparison, 17.4% of 12-month-old infants identified as at-risk via screening by community primary healthcare providers with the Infant-Toddler Checklist (ITC, Wetherby & Prizant, 2002) were eventually diagnosed with autism (Pierce et al., 2011). This value, representing the number of "true positives" divided by the number of "true positives plus false positives" on a screening tool, is called the positive predictive value (PPV). Notably, the ITC was developed as a screener intended to detect young children at-risk for a range of communication and language problems rather than designed to be specific to ASD. The PPV for the First Year Inventory (Baranek, Watson, Crais, & Reznick, 2003; Reznick, Baranek, Reavis, Watson, & Crais, 2007), a screening tool designed specifically to identify 12-month-old infants at-risk for ASD, was estimated to be 31% in a community sample (Turner-Brown, Baranek, Reznick, Watson, & Crais, 2013). A study of the Early Screening of Autistic Traits (ESAT) questionnaire (Dietz, Swinkels, van Daalen, van Engeland, & Buitelaar, 2006), used to screen 14–15-month-olds in a community sample, found a PPV of 25%, although the method used for this screening study involved a 2-step process wherein children were "prescreened" by a primary care provider using only 4 questions and then referred for a 14-item screening with the ESAT if any of the initial 4 questions were failed. The reported PPV reflects diagnostic outcomes relative to the second step of the screening process with the 14-item ESAT. Although these PPVs may seem low on an absolute scale, it is important to remember that PPVs are affected by the base rate of the condition that is the target of the screening. All other factors being equal, the PPV decreases as base rates decrease. And despite the increase in prevalence of ASD in recent years, the current US prevalence estimate of about 1.5% is relatively low compared to, for example, the prevalence of any developmental disability, recently estimated at about 15% in the USA (Boyle et al., 2011).

A second important theme in the literature on early screening for ASD is closely related to the above discussion of the utility of ASD screening tools and surveillance programs for identifying infants at-risk for ASD. Importantly, many of the infants identified through community-based programs who are "false positives" in terms of an eventual diagnosis of ASD nevertheless go on to exhibit other developmental problems. Given the larger base rate in the population for any developmental disability compared to the base rate for ASD specifically, it perhaps is unsurprising that the positive predictive value (PPV) of ASD screening tools for detecting a broader range of developmental concerns tend to be considerably higher than the PPVs for ASD. For instance, the PPV at 12 months for the ITC in detecting children later identified with a broad range of developmental problems (ASD, language disabilities, other developmental disabilities) was 75% (Pierce et al., 2011); similarly, the PPV for the first year inventory (FYI) at 12 months for detecting children identified with a broader range of developmental problems or concerns at age 3 years was estimated at 85% (Turner-Brown et al., 2013), and the PPV for the ESAT for broader developmental problems was 100% (Dietz et al., 2006). Thus, in interpreting screening results for parents or in considering referrals for assessment or the initiation of PIVEI with infants who fail ASD screenings, primary care providers and clinicians should take into account the very high likelihood that these infants will exhibit some developmental problems by the time they are 3–4 years of age, even if they are not ever diagnosed with ASD.

A third theme in studies of community screening or surveillance for the purpose of early identification of infants at-risk for ASD is that these methods will miss large numbers of children who will eventually be diagnosed with ASD. This theme is related to the "sensitivity" of early screening for ASD, or the proportion of all individuals with a condition who are detected by a screening tool (i.e., the "true positives"/"true positives plus false negatives"). There are several possible explanations for missed cases. These include potential issues with the screening tool itself (e.g., failing to have items on the screener that accurately reflect early ASD symptoms, or having items about behaviors that are difficult for parents or others to report reliably), as well as the fact that the onset of the symptoms of ASD varies from child to child, such that some infants who will be eventually diagnosed with ASD may not exhibit many symptoms during their first year and a half or so of life (Ozonoff et al., 2008). This implies that, unless future ASD screening tools for infants are much more sensitive than our current tools, universal screening in infancy would need to be followed with universal screenings during the toddler period in order to maximize early identification of children who will be diagnosed with ASD.

A final important theme in studies of community screening or surveillance for early identification of infants at-risk for ASD is that many children are lost to follow-up. In the literature on very early screening and surveillance for ASD, definitive diagnoses for children identified before 18 months of age as at-risk were typically not provided until the children were 2-and-a-half to 4 years of age (Barbaro, Ridgway, & Dissanayake, 2011; Dietz et al., 2006; Pierce et al., 2011; Turner-Brown et al., 2013). Such gaps between the times when heightened risk for ASD can be identified and definitive diagnoses are provided undoubtedly account in part for children lost to follow-up; however, several studies make clear that many children and families are lost to follow-up almost immediately. Potential reasons include that primary care providers may not refer a child who has failed an ASD screener for further assessment, parents may not respond to attempts to contact them to schedule follow-up assessments, parents may decline developmental assessments of their children despite a failed screening, or contact information for a family may change even within a relatively short period of time following the screening. This situation places limits on our confidence in current findings pertaining to the reliability and validity of the early screening tools or surveillance strategies. It also draws attention to the need to address implementation challenges in the research-to-practice continuum if we are to realize the full potential impact of efforts to detect infants at-risk for ASD.

Practice guidelines of the American Academy of Pediatrics (AAP) (Myers & Johnson, 2007) recommend routinely screening for ASD at 18 and 24 months of age, and recent evidence suggests that many primary care providers are doing some screening for ASD even if they are not fully adhering to the AAP guidelines (Self, Parham, & Rajagopalan, 2015). The AAP guidelines further recommend surveillance for ASD (along with other developmental concerns) at every well-child visit starting in infancy; but at this point, routine screening for ASD earlier than 18 months of age is not usual practice. In a qualitative study using focus group methodology, our team found that pediatric healthcare providers had reservations about implementing ASD screenings before 18 months; among other concerns, they wanted to avoid over-referring and creating anxiety for parents, especially without assurances that appropriate diagnostic and intervention services would be readily available in the community (Crais et al., 2014). In our intervention research studies, in the course of referring 13–15-month-olds who screened at-risk for ASD to community services, our observation is that most families who pursue assessment of their infants in order to determine their eligibility for the state's early intervention program have received developmental assessments of their children's language, cognitive, motor, and adaptive skills, but diagnoses of ASD, if warranted, have typically not been given until close to the child's second birthday or later. Research on the stability of early ASD diagnoses has yielded somewhat mixed findings. Several studies have reported that when clinicians feel confident about diagnosing ASD in infants and toddlers, even those as young as 12 months of age, diagnoses are quite stable (Barbaro & Dissanayake, 2010; Chawarska, Klin, Paul, & Volkmar, 2007; Guthrie, Swineford, Nottke, & Wetherby, 2013; Ozonoff et al., 2015). Other studies, however, have reported less stability in terms of children being diagnosed with ASD as toddlers but not in a subsequent assessment (Kleinman et al., 2008; Turner & Stone, 2007; Worley, Matson, Mahan, Kozlowski, & Neal, 2011).

Also important in working with families of at-risk infants is the stability of a clinical determination that the child does not yet show symptoms that warrant an ASD diagnosis. In a large (n = 418) recent study of infant siblings of children with ASD, substantial numbers of those not diagnosed with ASD as younger toddlers (e.g., 18 months) met the criteria as older toddlers (24 months) or preschoolers (36 months) (Ozonoff et al., 2015). Specifically, 44 children were identified with ASD at 18 months, but the total diagnosed with ASD swelled to 79 at 24 months and to 110 at 36 months. The extent to which the same phenomenon might be observed in infants identified as at-risk for ASD prior to 18 months of age based on community screening or surveillance for behavioral symptoms of ASD has not been rigorously evaluated, but it seems probable that these infants also will meet the full criteria for an ASD diagnosis in increasing numbers as they grow older.

Studies of PIVEI with Infants At-Risk for ASD

As described above, initiating interventions with at-risk infants before the symptoms of ASD are fully expressed could theoretically be an efficient and effective strategy for improving long-term developmental and adaptive outcomes as well as reducing the severity of autism-related symptoms. Recently, these conceptual arguments have prompted empirical studies of PIVEI with at-risk infants and young toddlers. The few studies published thus far, however, vary in a number of ways, including (a) the criteria for considering an infant or toddler at-risk, (b) the ages of children, (c) the ways that children were identified and recruited, and (d) the specifics of the interventions tested. Although these variations make it challenging to synthesize the limited current evidence across studies, they are advantageous in highlighting complex issues related to PIVEI for at-risk infants that deserve attention in translating between research and practice.

Our intentional focus is on PIVEI with infants identified as at-risk for ASD based on community screening and surveillance, with the interventions initiated prior to the time a clinical diagnosis is provided. We will discuss potential factors that may impact the appropriateness and efficacy of different components of PIVEI programs for families of these infants, who often wait for a year or more following their awareness of ASD risk symptoms for diagnostic clarity.

Using a single-case experimental design, Koegel and colleagues (Koegel, Singh, Koegel, Hollingsworth, & Bradshaw, 2014) studied the effects of modified Pivotal Response Treatment on three infants (4, 7, and 9 months old, respectively) with low levels of social engagement. In all three cases, parents had concerns about their infants, which were confirmed by a pediatrician or developmental specialist and also via an intake screening at the facility where the study was conducted. The intervention sessions were conducted at home for 1 h per week, for 4, 6, and 12 weeks for the three children, respectively. Parents were coached to first engage the infant socially during activities the infant had been observed to prefer (as indicated by some display of positive affect) and then to intersperse social engagement strategies during activities that were initially "neutral" in terms of the infant's affective response. Parents were asked to implement the intervention strategies on a daily basis and as frequently as possible. The intervention was effective in increasing all three infants' positive affect and decreasing their avoidance of eye contact during interactions with their parents and also had a collateral impact on the percentage of the time each infant responded to his or her name. These gains were maintained over 2–6-month follow-up periods (see Chap. 4).

A second study (Rogers et al., 2014) was a pilot investigation of the "Infant Start" version of the Early Start Denver Model parent curriculum with 7 infants ranging in age from 7 to 15 months. Four of the seven infants were recruited through a study of infant siblings of children with ASD, and the remaining three were referred by their parents or someone else in the community due to concerns about early symptoms. The researchers confirmed the presence of early ASD symptoms with observational measures, but a diagnosis was not required. Using the Infant Start curriculum, therapists coached parents across 12 weekly, 1-h clinic sessions to engage their infants in social activities; use vocalizations, gestures, and eye gaze to communicate; and play with objects in more diverse and functional ways. The intervention proved feasible in that therapists had high fidelity scores, and parents showed significant improvements in their fidelity scores from the beginning to the end of the 12-week program. The program also garnered high average parent satisfaction ratings. Infants were followed to 36 months of age, with the researchers considering the trajectories of comparison groups created from extant longitudinal data as well as a group of infants whose parents declined referrals into the intervention study. The outcomes for the infants who received PIVEI were particularly promising in the areas of reduced later symptoms of ASD and improved verbal skills.

A third published study of PIVEI with community-identified infants at-risk for ASD reports on a small randomized controlled trial by our group (Baranek et al., 2015), which served as a preliminary evaluation of "adapted responsive teaching" or ART. ART represents an adaptation of responsive teaching (Mahoney & MacDonald, 2007). ART retains the general approach of responsive teaching in that interventionists coach parents in the use of a range of "responsive strategies" (e.g., "play face-to-face games without toys," "follow my child's lead," "translate my child's actions, feelings, and intentions into words") to promote "pivotal behaviors" ("social play," "imitation," "exploration," "adaptability and coping"). Adaptations to responsive teaching incorporated into ART included reducing the pivotal behavior categories to two broad domains of social communication and sensory regulation and choosing pivotal behaviors best aligned with these two domains. This adaptation involved adding pivotal behavior content in the sensory-regulation domain, as well as adding responsive strategies appropriate for this domain. We removed any language from the original responsive teaching materials for parents that referred to a child's disability, so that they would be suitable for at-risk infants prior to any diagnosis, and we used ART as a home-based intervention, whereas responsive teaching had been delivered more frequently in a clinical setting. The planned intensity of ART is 30 sessions of 1 h each over a 6-month period of time. Figure 2.2 provides a model for ART.

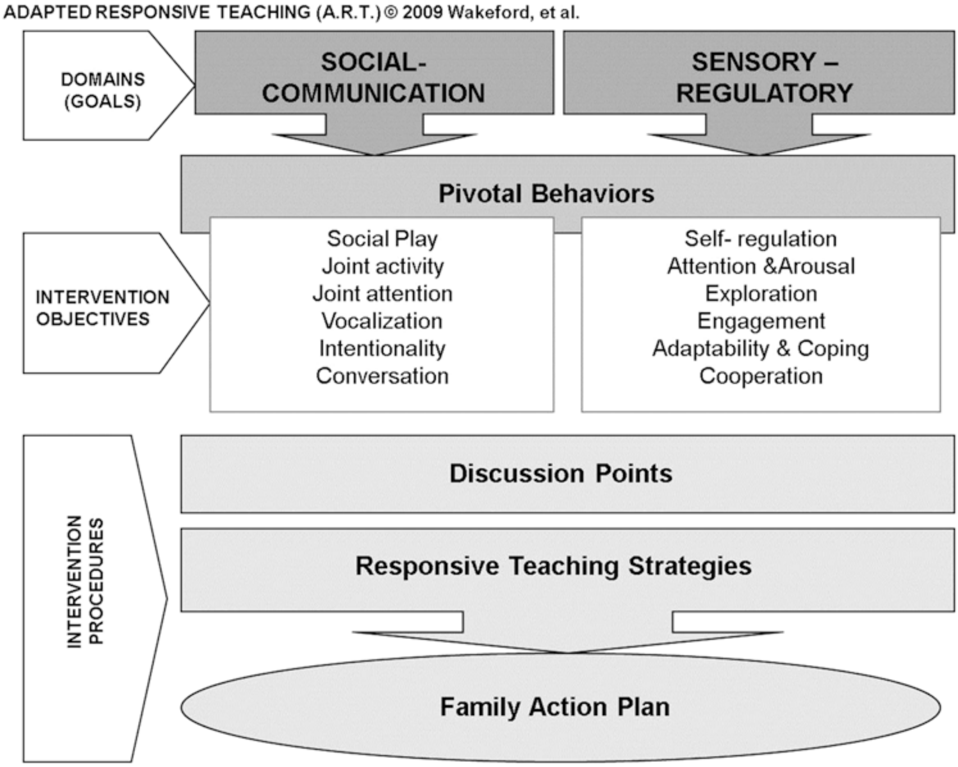

Fig. 2.2 Model for adapted responsive teaching. (Adapted from Mahoney & Macdonald, 2007)

To recruit families to participate in the study, we mailed the FYI (Baranek et al., 2003) to families in our catchment area based on public birth records indicating they had an infant within 2 weeks of turning a year old. The 18 infants enrolled in this initial study of ART scored at-risk for ASD on the FYI (see Turner-Brown et al., 2013), with the additional requirement that at least some ASD risk symptoms were observed at the pre-intervention assessment, which occurred when the infants were around 15 months of age. Families of eligible infants were randomized to an ART group or a control condition called "referral to early intervention and monitoring" (REIM) and assessed at three time points, pre-treatment, immediately posttreatment, and follow-up. Main effects were found such that infants in the ART group improved more than those in the REIM group in receptive language, social adaptive skills, and sensory hyporesponsiveness. Furthermore, parents who were in the ART group showed improved parental interaction styles as evidenced by less directive behaviors. Between-group differences in some outcomes were larger immediately posttreatment and attenuated by the 6-month follow-up assessment. Growth trajectories of the ART group tended to become slightly less steep, whereas the growth trajectories of the REIM group became steeper. We were not able to determine whether the "catching up" we observed in the REIM group was due to maturational changes or to their participation in more intensive community early intervention services than the ART group, which was especially salient between the posttest and follow-up assessments.

More recently, we completed a larger study of ART in which 87 families were randomized to ART or REIM groups (Watson et al., 2017). The methods for this study were closely aligned with those of Baranek et al. (2015), except that in the larger study, we used the FYI scores alone to confirm that infants met our at-risk criterion for study eligibility, whereas in Baranek et al., we imposed stricter eligibility requirements of confirming risk indicators in the pretest assessment. In addition, we did not include a follow-up assessment in the design of the larger study.

Findings from the larger trial contrasted with Baranek et al. in that they provided limited support for main effects of ART on child outcomes of primary interest in the social communication and sensory-regulatory domains. The most striking positive findings in the larger study were that ART had main effects on parent responsiveness and parent affect, with parents in the ART group showing more responsiveness and positive affect in interactions with their infants at posttest than those in the REIM group. Specifically, parents in the ART group showed significant improvements on both a coded measure reflecting parent verbal and nonverbal behaviors that followed into the infant's focus of attention ($d = 0.62$) and on the Maternal Behavior Rating Scale (Mahoney, Powell, & Finger, 1986) Responsiveness subscale ($d = 0.46$) and Affect subscale ($d = 0.75$). Although the specific aspects of parent interaction style that were affected varied between the two studies of ART, reducing parent directiveness in Baranek et al. (2015) and increasing responsiveness and affect in Watson et al. (2017), arguably these findings represent intervention impacts on a broader latent construct reflecting more positive parenting styles. In addition, although we did not see main effects of ART on our primary infant outcomes, there was evidence that changes in parent responsiveness mediated outcomes for the majority of infant outcome measures, including several tapping the social communication and sensory-regulatory behaviors that were targeted most directly by ART. We also examined two potential moderators of infant outcomes: the infants' initial nonverbal cognitive level and parent scores on the Parental Stress Scale (Berry & Jones, 1995). We did not find evidence that the infants' initial nonverbal cognitive level moderated the intervention effects on any of our outcome measures, nor did we find that parent stress was a moderator of effects on most of the infant outcomes. However, parental stress did moderate two secondary infant outcomes: Mullen Scales of Early Learning Visual Reception scores (Mullen, 1995) and Vineland Adaptive Behavior Scales Daily Living scores (Sparrow, Cicchetti, & Balla, 2005). The pattern of findings was that infants whose parent showed lower scores on the factor of parenting burden and higher scores on parenting reward improved more if they were in the ART group, whereas infants whose parents showed the opposite pattern either showed no differential change related to group (for Visual Reception scores) or improved more in the REIM group (for Daily Living Skills). Taken together, our findings suggest that, whereas more research is required to fully understand the reasons that parental responsive strategies are associated with infant outcomes, interventions targeting parent responsiveness are promising models for PIVEI.

Despite the many differences in these four studies of PIVEI with infants showing symptoms that place them at-risk for later diagnoses of ASD, they share some commonalities in intervention goals (e.g., increasing the infants' social engagement and positive affect) as well as the key commonality of being parent-implemented. Also, even though the Rogers et al. intervention sessions took place in a clinic and the other studies in the home setting, all four studies describe some focus on helping parents plan to embed "therapeutic" activities within their routine daily activities. The total number of intervention sessions varied rather widely across the studies, but another commonality was that the weekly amount of professional contact with a given family was in the range of 1–2 h per week. In other words, the amount of a professional's weekly time devoted to coaching caregivers is fairly minimal. Thus, all of these intervention programs assume that parents and other caregivers are integrating work on the infant's goals into daily routines such that the infant benefits from many interactions beyond the ones that occur when the interventionist and family are together.

Issues Related to PIVEI for Infants At-Risk for ASD

Early forays into a new area of research on PIVEI for infants identified as at-risk for ASD through community screening and surveillance, such as the studies described above, provoke consideration of issues that are both similar to and different from issues pertaining to ASD intervention research and practice with infant siblings of children with ASD or with toddlers or preschoolers. As discussed in detail in Chap. 3, parents who have an older child diagnosed with ASD may be more anxious and/or more vigilant about the development of their younger infant than is the case for families who are having their first child, or families without a history of ASD. Thus, it is conceivable that families who already have a child with ASD may more readily “buy into” the idea of doing PIVEI with their infant, particularly if they have already seen behaviors in the infant that concern them, compared to families who learn about their infant’s risk through community screening. However, other factors in families who have an older child with ASD may reduce the extent to which they would invest in PIVEI with an infant. For example, some families have heavy demands on their time, energy, and budgets trying to meet the needs of an older child or children already diagnosed with ASD; in this situation, PIVEI with an infant who may never be diagnosed with ASD may seem like less of a priority than in families who are confronting the possibility that their infant is at-risk for autism for the first time.

It also is worthwhile to consider the similarities and differences between families who develop concerns or learn through screening or surveillance that their 12- to 18-month-old infant is showing some early ASD symptoms, compared to families who reach this point when their child is 18–24 months (the ages when a child is more likely to be screened in the USA) or older. As reviewed earlier in this chapter, there are strong theoretical arguments for “the earlier the better” in relation to PIVEI. In general, however, the earlier families become aware of their infant’s or toddler’s symptoms of ASD, the longer they will wait before a definitive diagnosis is made. This prolonged period can bring its own set of challenges, such as making it hard for individual family members to reach the same conclusion that the infant may have ASD or another developmental disability that is not yet fully expressed.

This issue is highlighted in a qualitative study (Freuler et al., 2014) following up on families who had participated in the Baranek et al. (2015) efficacy study. One of the themes that emerged from interviews with these families was summarized as “getting dad on board,” based on the recurring reflection by mothers that the fathers either did not share their initial concerns or favored a “wait and see” approach over pursuing early intervention. In fact, one father himself said, “I just thought everything will be okay. Everything works out.”

Another challenge related to earlier identification of ASD risk is that, in general, the younger the child is when first identified as having symptoms of ASD, the less certainty there will be about the eventual diagnostic outcome. For example, the PPVs for identifying children who are “true positives” for ASD are lower for screening tools used with infants than for the M-CHAT-R/F used with toddlers at 18 and 24 months. Adding further support to this point, a study using the original M-CHAT showed that the PPV for ASD was much lower for 16- to 23-month-old toddlers than for 24- to 30-month-olds. Research indicates that it is fairly common for physicians not to refer infants and young toddlers for further assessment even when they have observed symptoms themselves, or the child has failed a screening (Crais et al., 2014; Niehus & Lord, 2006; Pierce et al., 2011). In fact, in the focus group study we completed with primary care providers (Crais et al., 2014), physicians described that they sometimes “overruled” the results of a positive ASD screening based on their own clinical opinion that the child was not showing symptoms that would warrant further assessment. Although this may be valid in some cases, there is evidence that systematic screening has greater utility for early identification of children with developmental disabilities than surveillance alone (Guevara et al., 2013; Thomas, Cotton, Pan, & Ratliff-Schaub, 2012) and that well-informed professionals will nevertheless miss symptoms of ASD in brief observations (Gabrielson et al., 2015). Another recent study confirms that, compared to parents of children with other developmental delays/disorders, parents of children with ASD have concerns earlier and raise these concerns with their child's health care provider earlier, but that they are more likely to receive passive or reassuring responses from the health care provider and less likely to receive proactive responses than parents of children with other developmental concerns (Zuckerman, Lindly, & Sinche, 2015). Further, when providers responded proactively, the gaps between initial parent concerns and diagnosis of ASD were shorter than when providers responded passively or with reassurance.

The tendency of physicians to respond passively or reassuringly to parents' early concerns about ASD symptoms likely contributed to another theme that emerged from the family interviews of ART intervention study participants (Freuler et al., 2014); this theme was "working against all odds." Many of the comments that contributed to this theme related to difficulty that the parents had in getting validation of their concerns or the screening results from their child's pediatrician, extended family members, or early intervention professionals in some cases. For example, one mother reported, "He's (pediatrician) more relying on his observations during exams than talking with the parents about their concerns." Another mother commented that, "... if we had not gotten into the study, by now we would have heard 'no' so many times that we would have given up trying to get anybody to sort of see what we were seeing."

Based on our experiences with the FYI, parents who learn their infants are at-risk for ASD right after the first birthday can experience heightened anxiety, and for some families who are vulnerable for other reasons (e.g., parent with pre-existing clinical depression), this knowledge may harm family functioning and quality of life. On the other hand, families whose children were screened with the FYI and who participated in our studies of ART, even when assigned to the REIM group, have expressed their gratitude for the early information about their infant's symptoms, so they could start early to pursue information, intervention, and other resources for their child (Freuler et al., 2014). In fact, about two-thirds of the parents who consented to participate in our larger RCT had expressed some type of concern about their infant's development in response to two open-ended questions on the FYI, so for these families, learning the results of the FYI screening may have served to validate their concerns. On the other hand, we also have encountered families who indicate directly or indirectly that they are not concerned about their infant's development even though he/she failed the FYI screening. The indirect evidence comes from the large proportion of parents whose infants failed the FYI that did not respond to three attempts to contact them or declined an initial assessment of their child (39% of the 280 infants who failed the FYI screening). The direct evidence comes from a number of cases of infants seen for initial assessments about whom our assessment team expressed concerns verbally and in a written report, but whose parents continued to voice a lack of concern. These were more likely to be families whose infants scored within or above the normal range on standardized tests of development than those whose infants scored below the normal range. But we also have had the experience of parents of infants with initially low scores on developmental assessments seeing strong improvements in aspects of their child's development such as in language and then assuming the child is catching up in his or her development (and therefore not in need of intervention), even though the child shows continuing unusual or challenging behaviors associated with risk of ASD.

Among other reasons, these issues are important because they may influence the motivation and commitment of a family to enroll in studies of PIVEI, or to enroll in community EI services, and to consistently implement PIVEI. In parent-implemented interventions with infants and toddlers with or at-risk for ASD, the theories of change explicitly or implicitly involve some mediating variable(s) related to changes in parental behavior. But, it is difficult to know the quality or intensity with which any measured changes in parental behavior are manifested at times when parents are not being observed by research team members. Even when programs are designed so that therapeutic interactions with a child can be integrated into typical family routines, each of the PIVEIs reviewed requires that caregivers change their interaction styles and/or add new routines. They also require that families become more conscious of what their infant is doing and keep the infant engaged appropriately with his or her environment, especially with the social environment. We concur with Wallace and Rogers (2010) that one challenge in research on PIVEI and its practice is to ensure that the intensity of intervention, in terms of the frequency of high-quality learning opportunities the child has throughout the day, is sufficient to yield an effect. The guideline of 25 h per week of active engagement (National Research Council, 2001) is largely based on older literature on early intensive behavioral interventions with children with ASD, which were quite different from contemporary PIVEI programs. We have not yet solved the problem of how to measure the intensity of PIVEI, which is a formidable barrier to being able to accumulate evidence on what intensity is needed to impact child outcomes.

Implications for Future Research, Policy, and Practice

The emerging findings on PIVEI are encouraging overall. Especially salient among the studies of PIVEI we have discussed in this chapter and studies of parent-mediated interventions with toddlers at high risk for or diagnosed with ASD is that parent-implemented interventions have been associated with positive changes in parent interaction strategies as well as some child outcomes, at least in the short-term. Studies have been insufficient in duration to judge potential long-term effects of PIVEI; that is, the transactional model we described earlier predicts that changes in parent interaction styles in the short-term will lead to more optimal parent-child transactions, with hypothesized cascading effects on child developmental outcomes in the long-term. Thus, despite the lack of main effects on short-term child outcomes in our larger RCT of ART, the theory of change suggested by the transactional model along with the number of positive findings from our studies and those of others suggests that continued research on PIVEI may generate knowledge that will have an important impact on outcomes for infants showing early symptoms of ASD and on their families as well.

Future research can advance our understanding of PIVEI with more nuanced investigations of the “active ingredients” and mechanisms of change of different PIVEI approaches, as well as examinations of why PIVEI does not have the expected effect in all cases. For example, it may be that a given PIVEI is well-designed with respect to the targeted infant behaviors, but fails to provide parents with strategies they find acceptable or feasible. Or, an intervention may specify sound child goals and parent strategies, but may not provide for a sufficient length or amount of professional support for families such that parents are able to continue scaffolding the child’s progress once professional support is reduced or withdrawn.

Another implication from our findings that initial parenting stress moderated the effects of ART on some infant outcomes (Watson et al., 2017) is that, as has long been recognized in other areas of intervention research, we should not expect a single intervention approach to be effective for all children and families. Two decades ago, Guralnick (1993) advocated that early intervention researchers move beyond efficacy studies focusing on main effects to a “second generation” of early intervention research that would elucidate connections among program components, child and family characteristics, and outcomes. In the larger body of research on interventions for children with ASD, research remains largely in the “first generation” (Stahmer, Schreibman, & Cunningham, 2011). And research on PIVEI for infants at-risk for ASD has just begun. Designing studies early on to answer not only questions about main effects but also the types of second-generation questions that Guralnick proposed will yield extremely helpful information for practitioners and parents considering the most appropriate intervention approach for a particular infant who is at-risk for ASD.

The research issues above imply that we need to vastly expand PIVEI research. Engaging parents and early intervention professionals in the development and refinement of PIVEI approaches may be one productive strategy to arriving at intervention models that can be scaled up effectively (Stahmer, Brookman-Frazee, Lee, & Searcy, 2011). Due to the generally limited diversity in race, ethnicity, language, and educational and socioeconomic backgrounds of participants in intervention studies, and the importance of understanding whether these factors impact outcomes in PIVEI, one important goal is to engage with more diverse communities in future research. We also endorse the idea that varied research methods are necessary if we are to gain insights on these complex research questions, including qualitative and mixed methods, single-case experimental designs, RCTs designed and powered for moderator and mediator analysis, and quasi-experimental designs such as regression discontinuity designs. Exploratory analyses of data collected in efficacy trials of PIVEI also should be undertaken, as these analyses could provide additional opportunities to identify the characteristics of infants and families who respond to, or do not respond to, a given intervention. PIVEI research also would benefit from some early collaborative efforts to identify a small set of key outcome measures, thereby enhancing our ability to synthesize information across studies as we build an evidence base.

Needless to say, high-quality research on a sufficient scale to realize the potential of PIVEI to positively impact people's lives and improve public health will require funding, in a context of many important, competing priorities. Strategies to effectively advocate for the importance of PIVEI research warrant some consideration. Typically, families who are active in disability advocacy groups have older children who already have diagnoses, often for years. These families have legitimate concerns about the relative paucity of research on interventions for older children, adolescents, and adults with ASD or other disabilities; their concerns are deservedly influencing the national research agenda. Understandably, early intervention and PIVEI research may not be a high priority for parent advocacy groups or self-advocates, because at the time families would be involved in PIVEI, they likely would not yet be involved in advocacy groups. Thus, researchers need to not only engage with families who are the intended consumers of PIVEI but also with the advocacy groups that these families may be turning to in the future.

In considering policy implications of PIVEI research, it is important to keep in mind that the context of policy-making in this area will vary widely from country to country and even among governmental units, agencies, and professional organizations operating in the same country. Within the USA, for example, the accumulated evidence on the quality of available screening tools and the benefits of universal screening for ASD in 18- to 30-month-old children was recently deemed insufficient to support a national recommendation (Siu & the US Preventive Services Task Force, 2016), yet practice guidelines of the American Academy of Pediatrics have been in place for almost 10 years recommending universal screening at 18 and 24 months, with surveillance at every well-child visit (Johnson & Myers, 2007). Many advocacy groups and professionals have expressed strong disagreement with the USPSTF conclusions, stemming from the evidence and outcomes considered or not considered, and the underlying assumptions affecting how existing evidence was interpreted (Coury, 2015; Mandell & Mandy, 2015). Thus, there is a lack of consensus on the appropriate public health policy related to early screening for ASD and, by implication, to PIVEI.

In this context, and given that research on PIVEI is in its own nascent period, we lack convincing empirical support for a policy that universal screening for ASD should begin as early as 9–12 months. On the other hand, a recent cost-effectiveness analysis for Ontario, Canada, that examined PIVEI (using either the Early Start Denver Model intensive treatment program of 20 h per week of clinician-provided intervention or the less intensive parent-implemented version of this model) found that either version of PIVEI would have favorable cost-effectiveness ratios to age 65, compared to the current practice in Ontario of providing early intensive behavior intervention only to moderately to severely impaired children already diagnosed with ASD, typically at 4 years or later (Penner et al., 2015). As we look ahead to maximizing the relevance of research to policy, this study highlights the need to include policy-relevant outcomes such as cost-benefit analyses in future PIVEI studies.

Another policy relevant to any future scaling up of PIVEI is that, at least in most states in the USA, being at-risk for ASD in and of itself currently will not qualify a child for public early intervention services. Although many infants identified as at-risk for ASD will meet other eligibility criteria for early intervention, such as showing significant developmental delays in at least some developmental domains, a substantial number of the infants in our intervention studies did not meet our state's early intervention eligibility criteria. Thus, along with lowering the age of screening, modifying eligibility criteria for early intervention is likely another area in which policies will need to be changed to make PIVEI widely available to infants and families who may benefit from it. We envision that ongoing and future PIVEI research will have implications for policy decisions on issues such as the recommended age for beginning universal screening for ASD and expanding eligibility criteria for early intervention, as we gain insights into (a) how to design effective and scalable PIVEI programs, (b) the long-range outcomes for children and families who participate in PIVEI, and (c) the cost-effectiveness of these programs.

Supporting Families of Infants At-Risk for ASD Today

Although PIVEI research is itself in the "infancy" stage, it nevertheless has some implications for current practice. Even if universal screening for ASD does not occur until 18 months or later, or does not occur at all, many parents of infants who will later be diagnosed with ASD have concerns about their development and will mention concerns to their child's healthcare provider. Given the evidence that a proactive response to such parental concerns will lead to an earlier diagnosis (Zuckerman et al., 2015), and the frustrations expressed by families when their concerns are not validated (Freuler et al., 2014), one practice implication is that healthcare providers should be prepared to offer an appropriate screening for infants whose parents raise concerns about ASD and/or should refer these infants for developmental assessments based on their parents' concerns. That is, when a parent already has concerns that he or she is willing to voice to the healthcare provider, a response that indicates respect for those concerns is warranted. Even if parents cannot get a definitive diagnosis at the time they first have concerns, professionals with expertise in young children with ASD and other developmental disabilities can nevertheless provide information on potential developmental concerns, determine eligibility for early intervention services, and make appropriate recommendations for intervention.

The responsibility for initial action on parental concerns will generally fall to the family's healthcare provider, as the professional parents are most likely to turn to with concerns about their child's development. This responsibility is consistent with the concept of the "medical home" advanced by the American Academy of Pediatrics several decades ago, and now embraced by multiple medical associations, as represented by the Patient-Centered Primary Care Collaborative [www.pcpcc.org]. The principles of the medical home include being accountable for patient-centered, comprehensive, and coordinated care that is accessible to patients and committed to quality and safety. The principles do not mean that all healthcare services (including behavioral healthcare) will be provided by the primary care provider, but rather that the medical home is accountable for helping patients find the resources they need and for coordinating care across varied community services that could address the patients' needs. For infants and young children, the accountability clearly includes developmental surveillance and screening, along with appropriate referrals (e.g., to early intervention services in the community) and follow-up to determine if the family has been able to access needed services (Adams, Tapia,, & the Council on Children with Disabilities, 2013; Johnson & Myers, 2007). We concur with Brian and colleagues (Chap. 3) that families of children with

ASD benefit from service navigators who are thoroughly knowledgeable about complex service systems for individuals with developmental disabilities. However, an initial challenge for families of infants at-risk for ASD is to "get the ball rolling" (Freuler et al., 2014), and this is the point at which the actions of primary care providers can facilitate or hinder the process.

Even primary care providers embracing these principles of the medical home often feel inadequately prepared to effectively identify and serve infants and toddlers at-risk for ASD or other developmental disorders and their families (Crais et al., 2014; Finke, Drager, & Ash, 2010; Self et al., 2015) and self-identify a need for continuing education opportunities as well as better preprofessional preparation (e.g., required rotations in developmental and behavioral pediatrics, hands-on training with screening tools) to enhance their knowledge and skills in this area (Self et al., 2015). Particularly for families who are having early concerns about an infant's development, knowledgeable primary care providers can play key roles. Recognizing that ASD may be difficult to diagnose or rule out in infants who display symptoms, the primary care provider can counsel parents who find themselves in a period of ambiguity even after referral for a developmental evaluation, guide families in finding appropriate intervention services, and advocate for the family and child to receive services they need in a timely manner.

Primary care providers may be reluctant to discuss the possibility that an infant or toddler has ASD due to concerns about alarming parents when the providers themselves are not certain about the diagnosis. In this regard, it is important to remember that many of these parents have concerns about aspects of their infant's development as early as 12 months of age (based on our experience in community screening with the FYI), although they may not be thinking about the possibility of ASD. In addition, qualitative and anecdotal evidence provides reassurance that parents report many positive feelings about the benefits of learning their infant is at-risk for ASD or other developmental problems and about the benefits of PIVEI for them and their infants (e.g., Freuler et al., 2014). At the same time, it is important that primary care providers and others who talk with parents of infants at-risk for ASD recognize most families likely will enter a period of increased anxiety and stress as they learn about their infant's risk, seek more information and clarity about the infant's condition, and try to find ways to help their infant. In addition, some families already may be struggling to cope with other stressors unrelated to their infant's risk and thus may be particularly in need of supports designed to promote the well-being of the family. Thus, conversations between professionals and parents of infants at-risk for ASD should include ongoing discussion of the needs of the parents and family.

Another concern expressed by primary care providers is that if they identify and refer families for services, the families may not be able to get a diagnosis or access intervention services for their infant. Inarguably, available services and waiting periods to access services will vary widely from one community to another. However, declining to refer at-risk infants and toddlers for services obscures the true level of need for evaluation and early intervention services within the community, deprives parents of the opportunity to advocate on behalf of themselves and their children, and underrepresents the need for services for this population to policymakers. Our recent study of ART illustrates that early identification of infants at-risk for ASD can facilitate the entry of these infants into early intervention even in the absence of an ASD diagnosis. In that study, only 12 of the 87 randomized infants were getting early intervention services before randomization at around 14 months of age; 27 additional infants enrolled in community early intervention services while they were participating in the study (between the ages of ~14 and 22 months). Although some of the infants may have been referred to early intervention through other channels even in the absence of our study, our past experience has been that it is relatively rare for children in our state who are later diagnosed with ASD to have started early intervention services before the age of 2 years.

However, there is also a potential burden for a minority of families who will learn their infant is at-risk for ASD or other developmental disabilities and seek early intervention services, only to be told that their child is not eligible for services. These families may then enter a period of "anxious waiting" for more clarity on their child's diagnostic and developmental status. Again, an informed primary care provider can provide support to these families by not dismissing their ongoing concerns, but rather scheduling an appointment to see the child again in another few months and re-referring the child for a developmental evaluation if concerns continue. If primary care providers understand that ASD can be especially difficult to diagnose in infants and toddlers who are showing relatively typical motor, cognitive, and language development (and therefore not qualifying for early intervention services), they may be more likely to take such actions.

Our emphasis on the important role that primary care providers can and should play in facilitating early identification and early intervention for infants and toddlers at-risk for ASD is balanced by a recognition that many children will not have a medical home. This is particularly likely to be the case among traditionally underserved groups. Thus, additional strategies are required to reduce current disparities in the age of identification of ASD and access to early intervention services. These could include in-service training for child care providers on raising concerns with parents, screening for ASD, and referring families to developmental centers or early intervention programs for further assessment; developing public service announcements with early intervention agency contact information for parents who may be concerned about their infants' development; publicizing links to online screening tools that parents can complete; having information and screening booths at community events attracting diverse families of young children; and using social media to increase awareness of ASD symptoms and resources for families who have concerns. Images and communication should reflect the cultural and linguistic diversity of the community. To succeed in such extended efforts to increase awareness of risk signs of ASD in infants and toddlers and provide families with access to services, some component of the service delivery system must accept the responsibility for implementing them. Public early intervention programs would seem to be a logical choice, but the resources of these programs are often stretched thin. Thus, advocacy for additional resources likely will be needed before existing programs can take on more proactive roles in early identification of infants and toddlers at-risk for ASD.

Conclusions

We have strong theoretical arguments for the putative advantages of initiating interventions with infants and toddlers at-risk for ASD prior to diagnosis, but thus far have only a handful of studies on PIVEI. Each of the PIVEI approaches we have described in this chapter has been associated with some positive outcomes for parents or children or both, so although none has a strong evidence base, they are reasonable options to explore. Practitioners certainly can draw from the larger evidence base on parent-mediated interventions with "older" toddlers who already have been diagnosed with ASD, but should keep in mind that these intervention models may not completely fit the needs of families who have infants at-risk for ASD. Excitement about the potential positive impact of PIVEI on the outcomes of infants at-risk for ASD will undoubtedly drive additional research. This chapter has considered the promise of such early interventions in conjunction with some of the challenges with the aim of stimulating creative conceptual thinking and practical problem-solving that can be applied to research and practice with this population of infants and their families.

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3

Supporting the Families of High-Risk Infants Who Have an Older Sibling with ASD: Collaboration, Consultation, and Care

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Abstract

This chapter explores the unique experiences of families parenting an infant or toddler with emerging developmental concerns, while also parenting an older child with autism spectrum disorder (ASD). We consider this within the context of the literature regarding parenting a child with ASD and the current state of knowledge about sibling recurrence risk and early signs of emerging ASD in infants and toddlers. The majority of this chapter is written from the perspective of a clinical research team with many years of experience garnered through a longitudinal 'infant sibling study'. From this perspective, informed by ongoing conversations with families, we reflect on the processes by which parents navigate through the push and pull of closely observing their young child for the emergence of developmental differences, and we describe a collaborative model of monitoring and discussing concerns with families, the importance of appreciating families' perspectives, and the joint process by which families may be best supported. We provide a brief overview of practical supports such as early intervention, advocacy, and family navigation and highlight the importance of helping caregivers find time and resources to take care of their own personal needs. This chapter concludes with a first-person account of this unique period in one family's life.

Introduction

Parenting a child with autism spectrum disorder (ASD) carries with it unique challenges, joys, and unanticipated opportunities. Parents of children with ASD report increased stress (Estes

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_3

et al., 2009; Osborne, Mchugh, Saunders, & Reed, 2008), depression and anxiety (e.g. Estes et al., 2009; Hayes & Watson, 2013), and marital discord (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001), as well as reduced time for family activities (Hutton & Caron, 2005). Increased financial burden (Kogan et al., 2008) is associated with both reduced parental employment and intervention costs (Orsmond, Lin, & Seltzer, 2007). Orsmond et al. (2007) reported increased depressive and anxiety symptoms and lower family adaptability and cohesion in mothers caring for a child with ASD and another child with a disability. These findings highlight the potential for cumulative effects on parenting strain when families have more than one child with ASD. Given sibling recurrence rates for ASD of 10–25% (Constantino, Zhang, Frazier, Abbacchi, & Law, 2010; Grønborg, Schendel, & Parner, 2013; Ozonoff et al., 2011; Zwaigenbaum et al., 2012), many families are faced with the challenge of raising multiple children with ASD. Moreover, in addition to ASD risk, other developmental differences characterize many non-ASD siblings (e.g. Charman et al., 2016; Georgiades et al., 2013; Messinger et al., 2013), such as subclinical ASD-like traits (i.e. the broader autism phenotype (BAP; Piven & Palmer, 1999; Szatmari et al., 2000) and various learning (e.g. Drumm, Bryson, Zwaigenbaum, & Brian, 2015) and mental health challenges (Orsmond et al., 2007).

Resiliency has also been described in families of children with ASD, in the form of increased family cohesion, adopting a new world view, personal strength, empathy, and finding meaning or spirituality (Bayat, 2007). Positive reflections from parents of children with developmental disabilities including ASD highlight gaining an increased understanding of ‘the world of disabilities’, a unique love for their unique child (e.g. ‘I love my child as he is’), personal or family enrichment (increased compassion, tolerance, patience), learning to appreciate the little things in life, and increased spirituality and marital cohesion (King et al., 2006; Myers, Mackintosh, & Goin-Kochel, 2009). Feelings of control, hopefulness, and empowerment have been highlighted as factors that contribute to positive adaptation (King et al., 2006). Practitioners will increasingly need to find effective ways to support these families and foster their resilience. This will require gaining a deeper understanding of parents’ experiences as they navigate, both individually and as a family unit, through the emergence of symptoms of possible ASD and related developmental concerns in their young infant.

Despite some commonalities among caregiving for children with a range of special healthcare and developmental challenges, the uniqueness of the parenting experience for caregivers of children with ASD has been raised in the literature, leading to a heightened interest in the lived experiences of these families. A small handful of first-hand accounts of the experience of caring for a child with ASD have emerged in the past decade (e.g. DeGrace, 2004; Myers et al., 2009; Nicholas, Zwaigenbaum, Roberts, & Mckeever, 2013), but this work is still nascent. A recent investigation of mothers’ lived experience parenting a child with ASD reveals a range of challenges beginning as early as the *first recognition of signs of concern* (usually in the first years of life; Nicholas et al., 2013). Often, very early concerns are dismissed by professionals, leaving parents to monitor their child’s development on their own, while feelings of distress, uncertainty, and worry grow. Reflecting on this very important time in the development of the child, and his or her relationships within the family, the urgency of supporting families through these early stages becomes paramount.

Research on Early Signs of ASD in Infants and Toddlers

The past decade has yielded a substantial body of research focused on characterizing the very early development of younger siblings of children with ASD through longitudinal study designs (e.g. see Jones, Gliga, Bedford, Charman, & Johnson, 2014 for a review). This longitudinal ‘high-risk’ design (now characterized by work from Baby Siblings Research Consortium; BSRC) was initially premised upon emerging evidence that early signs predictive of ASD could be detected well before diagnoses were typically made in the community (i.e. around age 4; Daniels & Mandell, 2014). Early work was motivated by emerging evidence from retrospective parent reports and first birthday video tapes (e.g. Baranek, 1999; Osterling & Dawson, 1994) that demonstrated the presence of observable behavioural differences early in development in babies who had later received an ASD diagnosis. The primary objective of the longitudinal high-risk sibling design was to systematically characterize early symptom emergence *prospectively* in order to increase our understanding of the developmental cascade of ASD. The goal was, ultimately, to support early identification and intervention at the earliest time possible in the hopes of reducing impairment and improving outcomes. Although there is a potentially rich source of information about the unique experiences of families parenting more than one child with ASD (i.e. 'multiplex' families), this specific line of inquiry remains under-developed.

As the field has evolved over the past decade, researchers have gained a fuller understanding of very early behavioural signs of ASD 'risk' in young babies and toddlers. We have now reached a point at which early behavioural signs predictive of ASD can sometimes be identified within the first 6–9 months of life (e.g. Sacrey et al., 2015, 2016) and are often detected by 12–18 months of age in younger siblings of children with ASD (e.g. see Jones et al., 2014 review). However, as we learn more about risk markers very early in development, we have come to learn that early signs of 'risk' are often just that – signs of *risk*. As we make strides towards earlier identification, we also face increased uncertainty. For example, while very good diagnostic stability exists for ASD diagnoses made in younger siblings as early as 18–24 months of age (Ozonoff et al., 2015; Zwaigenbaum et al., 2015), diagnostic stability below 18 months has not been well established. This presents practitioners with the unique challenge of sharing early *concerns* with families, while acknowledging some degree of uncertainty about what those signs mean with respect to longer term outcomes. For many practitioners and families, this inherent uncertainty can be daunting, but it is essential to find ways to navigate through it collaboratively in order to support children and their families.

Findings from our group and others (Ozonoff et al., 2015; Zwaigenbaum et al., 2015) demonstrate relatively good stability of diagnosis as early as 18–24 months and good predictive validity of instruments like the Autism Observation Scale for Infants (AOSI), in detecting risk at 12 months (Bryson & Zwaigenbaum, 2014). Notably, however, sensitivity is considerably lower, even in cohorts that are followed very carefully in longitudinal studies – in other words, not all cases of ASD are detected at these early time points. In most cases, children with ASD who were not identified at earlier time points (not deemed to have ASD or with lower indices of concern for ASD) have milder symptoms and are higher functioning than those cases detected earlier. In many cases, however, there are some early indicators of risk prior to a diagnosis being confirmed. What this means is that it can be very difficult for a clinician to conclude that a high-risk sibling, showing some early developmental differences, is 'out of the woods' for a diagnosis; these children should be monitored carefully over time (see Charman et al., 2016; Zwaigenbaum et al., 2015). Sensitivity increases considerably by age 3, but there is a small number of high-risk siblings who are not diagnosed until later (e.g. see Brian et al., 2015). In these cases, developmental concerns or differences have almost always been noted by age 3, but symptoms have remained subthreshold. Such findings highlight the importance of following some children into middle childhood, if subthreshold concerns persist.

Parents' Responses to Emerging Concerns: Reflections from a Clinical Research Team

Recent findings from our longitudinal sibling study reveal that this unique group of parents is often able to identify concerns, as young as 6 months of age, that predict ASD outcomes in their infants (Sacrey et al., 2015, 2016). Yet to be systematically examined, however, is the parental experience of detecting such concerns so early in their child's development and how the opportunity for discussion of these concerns with a practitioner influences that experience. In longitudinal research designs with high-risk siblings, parents may have the opportunity to raise concerns or 'bounce them off' a professional in order to gauge whether their level of concern is consistent with that of the practitioner. However, in most cases in which younger siblings of children with ASD are not being followed systematically, parents may be left wondering and worrying in isolation, as many clinical providers do not yet feel equipped to identify ASD-related concerns in the first year of life – many families continue to report that they have been counselled to 'wait and see' before taking any action.

Our combined experience with the families we have followed through our longitudinal clinical research cohort (e.g. Bryson et al., 2007; Zwaigenbaum et al., 2005) has provided a rich context in which to gain some insights into families' journeys through the emergence of early developmental concerns in a young child. Recognizing that our reflections most likely only represent a fraction of the families' actual experiences, we do not wish to imply that the following is an exhaustive set. Rather, we offer the main themes identified through ongoing conversations with families as their children develop and concerns emerge. Moreover, we have not identified a consistent linear passage through any particular 'stages'; instead, different reactions appear to ebb and flow, evolving over time and in myriad different configurations across families and individual family members. Themes include the expression of *relief* about being 'believed' by a professional, which may stand in contrast to a family's experiences with their older child – see Freuler et al. (2014)'s description of families working 'against all odds' to have their concerns considered; *action-orientation (or urgency)* in the form of seeking intervention strategies and referrals for community supports as soon as possible; *hopefulness* or feelings of optimism that earlier detection will lead to earlier intervention and thus the potential for optimal outcomes; *exhaustion* at the prospect of 'going through it all again'; *disbelief* –particularly when the emerging symptoms differ from those of the older child; *anger* towards the professionals for detecting or discussing these signs; and *despair* at the realization that already fragile emotional, personal, and family resources will need to be stretched further. Particularly unique among this group of parents is a sense of *comfort* or *familiarity* with ASD that is rarely seen in families receiving a diagnosis for their first affected child – it would seem that some families in our high-risk sibling cohort have settled into an understanding of ASD and feel relatively well-equipped to manage ASD again in a subsequent child. Moreover, some families do not view ASD as devastating and see their children in a more positive light, with strengths and challenges like everyone else; these feelings may lead more readily to a sense of *acceptance* and may bolster resiliency. Increased *vigilance* may also be unique to this group of parents – they already know the symptoms that characterize ASD and may watch closely for these signs in a younger child almost from birth. In many families, different caregivers may not be experiencing the same levels of concern, readiness to discuss concerns, or acceptance, only adding to tensions within the family. Parenting experiences vary in countless ways, and research has only begun to explore them. Of particular interest to our team are the factors that contribute to parents' *resilience and coping* when faced with early signs of ASD in a subsequent child. A deeper understanding of how these factors interact to influence the experience of each caregiver, as well as the family unit, will assist clinicians in supporting families along their journey. One of the most important considerations may be finding the right fit to support each family's unique set of needs and strengths and their current ability or readiness to address their child's developmental differences. For instance, families with an 'action-oriented' perspective may be supported best by access to early intervention services or developmental strategies to use immediately at home with their baby. The past few years have seen a groundswell in interventions designed specifically for infants/toddlers at risk for or with early signs of ASD (e.g. Rogers et al., 2012; Kasari et al., 2014; Wetherby et al., 2014; Baranek et al., 2015; Green et al., 2015; Brian, Smith, Roberts, Zwaigenbaum, & Bryson, 2016; Brian, Smith, Zwaigenbaum, & Bryson, 2017); such programmes often use parent-mediated approaches, with or without therapist-delivered components. In our clinical and research roles, we have found it easier to raise concerns with families in the context of being able to offer very early ASD-specific strategies, recommendations, or direct access to intervention; moreover, our impression is that access to such intervention makes it easier for some parents, as they have something positive to focus on, which can result in increased hopefulness. Parent-mediated interventions, in particular, have the potential to increase parents' feelings of empowerment and efficacy (Schertz, Odom, Baggett, & Sideris, 2013; Brian et al., 2017), which may serve to foster resiliency.

Conversely, parents who are primarily experiencing 'disbelief' or 'exhaustion' may need more time to process the clinician's concerns before being able to mobilize and/or embrace intervention. Such parents may be best supported by a slower pace, increased empathy, and follow-up care to help them get through their initial difficulties moving towards seeking intervention. Care must be taken in such cases to avoid making families feel guilty if they are not able to embrace such opportunities immediately.

Collaboration, Openness, and Hope

Parents who enrol in high-risk infant sibling studies are a unique and often highly vigilant group. These parents are usually aware of the recurrence risk to subsequent children, and in many cases report enrolling in the study in order to have their baby's development monitored carefully over time, typically with the goal, if warranted, of intervening as early as possible. Families grow to trust their clinical research team and demonstrate increasing comfort with the team over repeated visits. In our model, families are asked at each visit to highlight any of their own concerns that have emerged since the previous visit. The lead clinician or senior clinical research staff members typically discuss any emerging concerns with families and encourage parents to comment on the observations of the staff either to concur or provide counter-examples of behaviours being discussed. Early in our work with high-risk siblings, our clinical-research team (together with the larger clinical and research community) had less familiarity with the manifestation of ASD in infants and toddlers, and this was often reflected in reluctance to share very early concerns with families in order to prevent undue burden. However, in response to direct feedback from families, and as the research evidence has mounted, we have come to learn that the best approach with the vast majority of families is to adopt an open and collaborative relationship with parents in order to help them navigate the experience of watching developmental concerns emerge. In ambiguous cases, we have found it important to remain very open with families about the degree of uncertainty, while highlighting both the concerns we observe as well as the skills and behaviours that increase our uncertainty. Many families have expressed that they value this open approach; however, it also bears emphasizing that the ambiguity inherent in such situations may also be a source of distress for some parents.

The importance of dedicating adequate time and attention to discussing concerns with families cannot be over-stated. Creating a calm, comfortable (non-rushed/unpressured) environment, listening carefully to parents and giving due consideration both to their concerning and positive observations, are all essential. Indeed, it is typically best to begin these conversations by first asking parents whether they have any concerns or questions rather than the clinician taking the lead; in this and related discussions, it is often helpful to distinguish between isolated symptoms/signs (which can occur in siblings who do not go on to receive an ASD diagnosis) and the full syndrome/disorder. Some families may be aware of the research literature on high-risk siblings, and it is often important to help parents understand the level of evidence and what a particular risk factor means in terms of predictive power. Moreover, it is critical to focus on the individual child and highlight the limitations of making child-specific predictions based on group-level evidence (https://www.autismspeaks.org/family-services/tool-kits).

When parents are asked to reflect on their life with a child with ASD, they identify both negative effects such as unique stressors and positive impacts such as feelings of enrichment, compassion, patience, and joy (Myers et al., 2009). Together with feelings of control, hopefulness, and empowerment (e.g., King et al., 2006), positive attributions likely play a central role in fostering a family's resiliency and coping when raising a child with ASD. In discussing emerging concerns with families, it is essential to also discuss a child's strengths and help parents reflect on the unique joys and perspectives that the individual child brings to their life. The description of a child with ASD as 'my greatest joy and my greatest heartache' (Myers et al., 2009) exemplifies the complexity of parents' experiences. Highlighting a child's strengths and unique personality, and their special relationship with family members, may serve to foster a family's sense of hopefulness, thus bolstering their ability to adapt positively to concerns that are being raised.

Parental Reference Point

Parents of high-risk siblings are uniquely familiar with ASD and the behavioural manifestations that contribute to a diagnosis and may use the older sibling with ASD as a reference point in interpreting their younger child's development (e.g. see Drumm et al., 2015; Zwaigenbaum et al., 2015). When the younger child appears to have milder or fewer symptoms than the older sibling, parents may have difficulty believing or accepting that the younger child is also showing symptoms of ASD. Many parents interpret 'atypical' behaviours exhibited by the younger sibling as merely 'copying' their sibling with ASD. Although no systematic studies have evaluated this phenomenon, clinical experience suggests that this is rarely an adequate explanation, particularly when the behaviour occurs frequently, persists over time, and appears self-motivating for the child. In cases where a younger sibling may 'explore' a behaviour modelled by their sibling, this exploration is typically short-lived and the behaviour is not usually maintained.

Conversely, parents may recognize behaviours that 'look like' ASD in their younger child and interpret them as definitive sings of ASD. In cases where a diagnosis of ASD is not clinically supported, it can be helpful to share with parents that siblings will often exhibit *some of* the behaviours seen in ASD without meeting full criteria for a diagnosis (either now or in the future). The concept of the 'broader autism phenotype' (or BAP, described above) can help some families understand that siblings without ASD may have overlapping behaviours in common with their identified sibling (e.g. social communication challenges (Georgiades et al., 2013), difficult temperament (Garon et al., 2009)). Again, it can be helpful to highlight the distinction between isolated symptoms and the full syndrome. Although not well established in the literature, this is likely explained, at least in part, by shared genetics between siblings; this explanation may be helpful for families who are experiencing distress related to the expression of one or two isolated behaviours that lead them to conclude their younger child has ASD. Regardless, it is important to remind families that ASD is defined by a constellation of multiple behaviours and developmental atypicalities that hang together and evolve over time to result in a diagnosis. To date, no isolated, single 'red flag' has been identified as a reliable predictor of ASD in high-risk sibling samples (e.g. Chawarska et al., 2014).

The Promise of Early Intervention

Our group and others have become increasingly interested in the impact on the family of very early intervention for infants and toddlers showing early risk markers for ASD. As the field moves to ever earlier detection of risk, considerable efforts have been made, with some promising findings, to develop interventions that are focused on early developmental needs of increasingly younger children in the face of risk, even before diagnosis is confirmed (e.g. Chaps. 2 and 4; Baranek et al., 2015; Brian et al., 2017; Koegel, Singh, Koegel, Hollingsworth, & Bradshaw, 2014; Rogers, Estes, et al., 2012; Rogers et al., 2014). The vast majority of such emerging infant and toddler interventions have adopted a naturalistic developmentally and behaviourally based approach (coined naturalistic developmental behavioural interventions, 'NDBIs' (Schreibman et al., 2015)), and many have a parent-mediated component in which parents are taught strategies to enhance their child's development in everyday situations. An advantage of NDBI models, as applied to parent-mediated programmes, is that caregivers do not have to take on the unnatural role of 'therapist' (e.g. see Siller, Hutman, & Sigman, 2013), which can add stressors to the parent-child relationship. Instead, many such models emphasize or directly target the natural parent-child relationship and aim to foster interactions that do not 'feel like' therapy and reportedly feel more natural to families. A recent qualitative exploration of families' lived experiences in such a parent-mediated early intervention programme for toddlers with emerging or diagnosed ASD revealed positive attributions about both parent and child skill acquisition and feelings of 'ease' and comfort with the strategies. Most importantly, parents reported increased feelings of empowerment and hopefulness for their child's future (Fenwick et al., 2014). Schertz and colleagues (Schertz, Baker, Hurwitz, & Benner, 2011) have made a call for toddler interventions that are truly family-centred in that they directly support the family's ability to foster their children's development, thus promoting 'family confidence and competence' (p. 18), which are associated with reduced stress. Family-centred approaches are now emerging in the literature and in community programmes.

Considering the whole family, with a focus on both negative and positive impacts, is essential as this field moves forward. For example, future research on parent-mediated programmes needs to consider the impact on family members other than the caregiver and child who are the focus of the programme (e.g. what strategies work best to help other caregivers and siblings feel like they are a part of the process rather than feeling excluded?). Careful consideration also needs to be given to families in which a child's gains may be minimal despite considerable parental effort and the possible feelings of pressure placed on families who are not able to commit to undertaking such programmes. It is essential to weigh the possibility of parental feelings of empowerment with the possible feelings of undue responsibility for a child's progress. Clinicians will need to find sensitive ways to provide encouragement and support for parental involvement, while avoiding placing pressure on parents if caregiver-mediated approaches are not a good fit for their family.

With the exception of one recent study (Freuler et al., 2014), very little research has systematically explored the experiences of parents with babies identified through community screening as being 'at risk' for ASD. Based on a positive screen at 1 year of age, parents were invited to participate in an intervention trial of parent-mediated Adaptive Responsive Teaching (Baranek et al., 2015) and were subsequently interviewed regarding their experiences in the programme (Freuler et al., 2014). Themes of 'working against all odds' to have concerns heard by professionals, the 'value of the personal relationship' with professionals, and an eagerness to 'get the ball rolling' were highlighted. Themes also included 'getting dad on board', which underscores the importance of recognizing that different caregivers may be experiencing very different levels of concern and/or acceptance in the face of emerging symptoms. Vastly discrepant reactions emerged from parents who were randomized into an immediate intervention group (describing this as a 'win-win' experience) versus those receiving community services ('navigating amidst ambiguity'). This study reveals a unique set of circumstances that characterize the experience of having an at-risk baby identified through community screening and the subsequent journey into the world of early intervention. Recent years have seen a push towards earlier detection of risk and earlier access to intervention, and perhaps secondary prevention, particularly with high-risk babies. Experts in the field are now in a position to help policymakers appreciate the potential for very early intervention, initiated in response to signs of risk (but often before a diagnosis can be confirmed), to improve child and family outcomes and reduce the economic burden in the long run (Penner et al., 2015).

Practical Supports for Families

Many families need very practical supports to help them navigate through a complex service delivery system (i.e. 'navigating amidst ambiguity'; Freuler et al., 2014). Some centres that conduct diagnostic assessments for ASD provide 'family navigators', a role that has been promoted and encouraged by Autism Speaks through their Autism Treatment Network. However, for the most part, such supports are available only once a diagnosis is confirmed (and only rarely even at that point). In the face of *risk* (vs. confirmed diagnosis), the 'system' may be poorly defined and even more difficult to navigate. Although considerable differences exist across regions, most communities have generic early intervention (infant development/early years) programmes for babies aged 0–3 years with any developmental concerns, and specialized child care placements may be available. Accessing supports through these programmes is often an important first step for families with infants or toddlers displaying developmental concerns. Through such programmes, children may be able to access support for speech and language development, occupational therapy, and other non-ASD-specific services while being monitored for the emergence of ASD. Increasingly, infant siblings of children with ASD are being viewed as a 'high-risk' group by community infant development programmes, some of which have defined pathways for screening and early intervention specifically for these infants (e.g. Infant and Child Development Services Peel, Ontario, Canada; http://www.icd-speel.ca/about-us). However, this is by no means a consistent approach across countries and different regions. Parents and professionals need to work together to advocate further for resources to support high-risk infant siblings and their families through similar mechanisms.

While most families with an older child with ASD have 'been through the system' with their older child, it must not be assumed that they need less support around coping or accessing supports for their younger child. If several years have elapsed, many components of the early intervention system are likely to have changed, and in cases where families are newcomers, they may not have had experience with the early intervention systems where they now live. Moreover, when faced with the potential stressors associated with detection of developmental challenges in a subsequent child, families may not have the emotional, financial, and other necessary resources to navigate the system on their own. Supports around advocacy may be useful in promoting parents' sense of control and efficacy as they navigate the service system. Autism Speaks has developed an advocacy tool kit (https://www.autismspeaks.org/family-services/tool-kits), and advocacy coaching has been included in some parent-mediated intervention programmes (e.g. Siller et al., 2013). The provision of advocacy workshops within the community will likely go a long way to supporting families in the future.

In our experience it has been essential to make ourselves available to families for consultation both as they navigate the community services system and as they monitor their baby's development. Regardless of the context in which a family is being followed, it is critical that some level of ongoing support is made available so they feel that they have someone they can go to, whom they trust, as their feelings of concern ebb and flow and their own emotional needs manifest. Professionals need to be encouraged to really listen to parents' concerns and partner with them in monitoring their child's development over time, as long as any concerns persist.

Taking Care of Yourself

Most parents of toddlers need to be reminded and supported to dedicate some time and resources to taking care of themselves. This is often harder and yet even more important for families of children with special needs, particularly in the case of more than one child with such needs. Many parents have shared with us that they do not feel they have the 'luxury' of prioritizing their own needs, or feel guilty if they do take any time for themselves. Parents need to be supported to acknowledge that their own mental health and coping lay the foundation for their ability to support their children. In some cases, parents may need to find ways for even a very brief break in the midst of a busy day (e.g. stopping to sit down and have a cup of tea), which may involve reprioritizing other perceived household priorities. This can sometimes be as simple as helping a parent give themselves 'permission' to take a break and leave the cleaning for another day. In other cases, parents may need professional support, in the form of individual or couples' counselling, to manage the stressors they are experiencing. Although parent-mediated interventions are generally viewed favourably by parents (e.g. Fenwick et al., 2014; Freuler et al., 2014; Siller et al., 2013), several programmes have added a specific learning module about 'taking care of yourself' (e.g. Brian et al., 2016; Rogers, Dawson, & Vismara, 2012). This may be essential to ensure that parents are not feeling overwhelmed by the demands associated with such programmes.

A Parent's Perspective

For 8 years I believed that having a second child receive an autism diagnosis would be easier than the first one. After all, I already knew what I was doing. It took all of 10 seconds to prove me wrong. To my surprise, it was actually much harder the second time around.

My first son Harrison was diagnosed with autism at the age of 3. I took him to the paediatrician shortly after his second birthday with concerns about his language and social development. I thought he may benefit from a preschool programme. His doctor agreed and told me she was concerned that he may be showing signs of autism. She referred him to a developmental paediatrician and the waiting began. For a year I waited for him to be assessed. During that year my surprise at her conclusion gave way to determination to get him all the help he deserved. With her help I got him into preschool and he began to receive speech therapy. But I wanted so much more for him, and that required a diagnosis. By the time he was assessed by a developmental paediatrician, I was very anxious to get an autism diagnosis. His current and future services depended on it. When he was diagnosed I was flooded with relief – now he would have everything he needs!

When Harrison was 10, I was blessed with another baby boy. From day 1 I watched him like a hawk. I enrolled him in the Baby Sibling Study as an extra precaution. There would be no waiting for an assessment this time around; I felt that I was on top of things.

Little Lee was a joyful baby. He would sit in his baby chair and babble with me while I did chores; he smiled at me and offered lots of affection and eye contact. His Baby Sibling assessments were going well. Around a year old, he developed a habit of banging his head when he was angry; he had a high-energy demeanour and was more social with myself than with others, especially in public. But he was starting to try and talk and was able to count to ten; I felt confident in his development.

At his 18-month Baby Sibling assessment, things didn't go as planned. I watched him point out to the assessor every number in the room, even when that wasn't what he should have been doing. What a smart baby! A future mathematician! I expected feedback would be pretty standard just like the other visits. But then it all changed. The assessor mentioned that his language was less developed than expected, that his eye contact was fleeting, and that he was unusually interested in numbers. She said many more things and she said them kindly. But I don't remember any of them. I remember another staff member coming into the room with some paperwork. I remember that the baby was angry and wanted to go home. But I don't remember anything else she said to me that day. I just remember that I knew in that moment that everything was about to change again.

I hadn't seen it coming like I had the first time. How could I have missed it? She picked it up after spending just a few hours with him. I felt such guilt and confusion. I had just been through a very difficult divorce; the kids and I were finally settling into our new normal. Now I knew that soon enough our new normal would become the old normal and we would have to transition all over again. How could I parent two autistic children? I was going to be outnumbered.

The next day the assessor called me. She had seen how confused I was and how surprised by the outcome of his assessment. She wanted to go over the results again with me. This was not a diagnosis, but only some concerns and reason to watch him closely. He would be assessed again at 21 months and I would have more answers at that time. In the meantime she wanted me to register him for speech therapy and daycare, and she wanted me to try not to worry and just enjoy him. She stressed how important it was that I take care of myself. Her empathy was like a life preserver in a stormy sea, she gave me something to hold onto, a way to keep my head above the water. One way or the other we would be okay.

The next 3 months were a blur of worry and anticipation. Some days I was able to convince myself that there was no way he would receive an autism diagnosis. Other days all I could do was breathe and hope that if he was on the spectrum, at least it would be mild. Everything he did looked different to me now; I was looking at him through autism-coloured lenses and I interpreted every move he made.

During that time I applied to and interviewed for a very exciting full-time job; one that would be a huge step in my professional life. As I interviewed I couldn't shake the thought that it was possibly pointless. If he was diagnosed, there's no way I could commit to working full-time. That was hard enough to manage with just one child on the spectrum.

By the time we arrived for his evaluation at 21 months, I was pretty sure I knew what I was going to hear. His head banging behaviour continued to escalate and his language development wasn't picking up speed. I saw more and more behaviours that pointed towards autism. A few hours later, I heard exactly what I was expecting to hear; he is on the autism spectrum. The news did not surprise me, but my own reaction did. There was no relief this time around, no feeling of accomplishment. There was only dread. I knew what the next few days, weeks, months, and years had in store for me. I knew that autism was once again going to become the only full-time job I had. I knew exactly what I was getting myself into.

I didn't want to be there in that room hearing those words. I didn't want to keep moving forward. I wanted to be back to not knowing. I wanted to hit pause or, even better, rewind. I was entering the grieving period all over again, and I did not choose this journey.

On the bus ride home that day, I took a photo of him with my phone. I carefully examined his little face. It was the same face I had kissed that morning. He was the same boy I walked into the room with and the same one I will raise to be the best man he can be. I will let myself grieve the 'normal' that I have once again left behind. I will allow myself some anger and disappointment as I travel forward. I will once again accept help and kindness from those in the profession of autism, as I navigate his path towards his full potential. I will do what I need to do, to help him be the best that he can be.

Acknowledgements Our group has been conducting baby sibling research since 1999, with funding support from Autism Speaks, Autism Speaks Canada, Canadian Institutes of Health Research, NeuroDevNet, SickKids Foundation, Simons Foundation, the Sinneave Family Foundation, the Craig Foundation, the Joan and Jack Craig Chair in Autism Research (SB, IMS), and the Stollery Children's Hospital Foundation Chair in Autism Research (LZ). We are tremendously grateful for our highly committed research staff and trainees who have supported us in supporting the families in our research. Finally, we wish to thank all the dedicated families who have shared their children, their time, and their stories with us over many years – this work would not be possible without them.

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Adapting Pivotal Response Treatment to Support the Families of High-Risk Infants

Jessica Bradshaw and Lynn Koegel

Abstract

Pivotal response treatment (PRT) is a comprehensive, evidence-based treatment model for individuals with autism spectrum disorder. This chapter will detail the development of PRT and introduce the basic behavioral and motivational strategies used to enhance social engagement, language, and play for young children with ASD. PRT has traditionally relied upon "parent training" or "parent education" as an integral component of intervention, and research studies focused on the parent-training components of PRT will be described. We also provide a rationale for earlier intervention to improve prognosis and enhance developmental gains for individuals with ASD. Thus, this chapter will address the justification and methods for adapting PRT for families of high-risk infants under 24 months of age and describe how a naturalistic, developmental, behavioral approach that targets social motivation is ideally suited for infant intervention. Preliminary research presented here suggests that the motivational strategies of PRT can be effective for improving social engagement and social communication for infants within the first two years of life.

Pivotal Response Treatment to Support Families of High-Risk Children and Those with a Diagnosis of Autism Spectrum Disorder

Pivotal response treatment (PRT) is a naturalistic, developmental, behavioral intervention that was developed to improve motivation in children with autism spectrum disorder, consequently accelerating learning and triggering widespread gains. To target the pivotal area of motivation for children with ASD, a specific set of strategies is implemented as a package during teaching opportunities. These strategies can be applied throughout the child's waking hours within natural settings and daily routines. Initial research on PRT focused on expressive communication (Koegel, O'Dell, & Koegel, 1987), but subsequent studies showed that the strategies are effective across a wide range of developmental domains. Importantly, research demonstrated

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_4

that when targeting pivotal areas, widespread collateral gains in other untargeted areas were observed (e.g., Koegel & Koegel, 1995; Koegel, Koegel, Harrower, & Carter, 1999; Mundy, Sigman, & Kasari, 1990; Schreibman, Stahmer, & Pierce, 1996). Thus, intervention proved to be more efficient and effective when motivational components were included. The end goal of PRT is to provide an intervention that will result in improvements in a broad number of behaviors in a natural setting and provide young children with autism the tools to learn skills in language, socialization, and academics that are necessary to lead meaningful, independent lives.

PRT is based on behavior modification approaches that were originally developed to decrease disruptive behaviors and improve social and communicative functioning for children with ASD (Lovaas, Koegel, Simmons, & Long, 1973; Lovaas, Schreibman, & Koegel, 1974). These initial studies of PRT demonstrated significant improvements in the children's behavior by using discrete trials and rewarding appropriate behavior (e.g., Lovaas, 1977). This type of research uses a standard "ABC" behavioral format in which an *antecedent* is presented, the child responds with a target *behavior*, and a *consequence* is provided to reinforce that behavior. Table 4.1 demonstrates an example of how discrete trial training (DTT) may be used to teach a child colors.

This paradigm is similar to teaching strategies that are commonly used in the classroom, wherein children are seated at desks or tables and can receive stickers or verbal reinforcement when they respond correctly to a teacher's question. The reinforcement method in which stickers or tokens are provided for correct or good behavior, and can then later be exchanged for a reward or prize, is called a "token economy" and is commonly used with typically developing children and even adults. However, early work in autism treatment suggested that the motivation of typically developing children appears to differ from that of children with ASD (Koegel & Egel, 1979). Young children are generally motivated to learn in order to get social reinforcement from teachers and parents; yet social motivation is diminished in young children with ASD. The use of a token economy system that required children with ASD to work for favorite objects or activities was effective for teaching discrete skills in discrete settings. However it was quickly apparent that this discrete trial, behavioral approach (sometimes referred to simply as an "applied behavior analysis" or the "ABA" approach) lacked effectiveness in promoting generalization and maintenance of learned skills. That is, children with autism were acquiring new skills, but many did not maintain over time and were not generalizable to different settings or different behaviors.

PRT was developed to overcome some of these challenges and carries a few basic underlying tenets. First, parent education is a necessary component in the education of children with autism. Research shows that parents are not only helpful in implementing intervention for children with ASD but that parents are in fact an essential piece of the entire intervention process. Without their active involvement, their child's gains are unlikely to generalize or maintain (Koegel, Glahn, & Nieminen, 1978). Second, intervention must be implemented in natural settings using child-preferred materials and activities that are found in those settings. Artificial settings do not result in the level of generalization and maintenance that occurs when inclusive settings

Table 4.1 Example of traditional discrete trial training to teach colors

Setting	Antecedent	Behavior	Consequence
The child and clinician sit across from each other at a table. The clinician has a reinforcer that the child likes, such as a treat or toy.	The clinician shows the child the treat or toy so he knows what he is working for. The clinician holds up a flash card with a yellow box on it and asks the child "what color?" while pointing to the yellow box.	The child correctly responds with "yellow."	The clinician says "good, yellow!," hands the child a sticker, and says "two more stickers and you get to earn your treat." The next trial is presented.

with naturally occurring stimuli are used (Koegel, O'Dell, & Koegel, 1987). Third, a focus on improving the individual with autism's motivation will accelerate learning and decrease frustration and disruptive avoidance and escape behaviors. It was observed that while using structured ABA procedures, children continued to have difficulty *rapidly* acquiring skills and they appeared to lack motivation to learn during intervention sessions. These challenges precipitated a line of research focused on using naturalistic methods to target underlying features of autism, such as motivation. Studies began to focus on procedures to strengthen the response-reinforcer relationship (Koegel & Egel, 1979; Williams, Koegel, & Egel, 1981). The thought was that the children may be experiencing "learned helplessness," which occurs when there is a perceived absence of control over the response-consequence contingency, and subsequently an individual may stop trying or exhibit very low rates of responding (Seligman, 1972). To counteract this phenomenon, steps to motivate the individual were put in place. A number of individual areas were researched with the end goal of improving "motivation," defined as improving children's responsiveness, correct responding, and positive affect. In other words, by using strategies to improve motivation, collateral gains would be observed in multiple areas. Motivation would be the first pivotal behavior and the defining component in pivotal response treatment. It was hypothesized that motivation could be measured by changes in children's affect. Affect in terms of enthusiasm, happiness, and interest became a critical measure in the initial intervention research leading to the development of PRT.

This new theoretical paradigm was tested by combining a general "ABA" stimulus-response-consequence framework with newly developed strategies for presenting teaching trials. A variety of systematic procedures were incorporated into both the presentation of the stimulus items (i.e., antecedent) and the reinforcement provided subsequent to the desired behavior (i.e., consequence). These antecedent and consequence strategies were developed to improve motivation, thus accelerating learning, improving affect, and decreasing disruptive behavior. Importantly, the target behaviors remained the same (e.g., language), while the treatment delivery method was altered in order to incorporate the motivational components. These modifications to the traditional ABA framework for teaching skills to children with ASD formed the earliest foundation for the development of pivotal response treatment. The general motivational procedures are described below.

Child Choice Child choice or following the child's lead makes an enormous difference in child responsiveness. Instead of using flash cards or arbitrary items that are usually uninteresting to the child, child-preferred items are identified and incorporated into treatment. This means that if the child is more motivated when playing on the swings, then intervention is moved to the playground. Implementing treatment in the child's natural environment using child choice greatly increases the likelihood of generalization. Many studies document the importance of child choice in regard to responsiveness and engagement (e.g., Carter, 2001; Dunlap, 1994).

Interspersal of Acquisition and Maintenance Tasks Acquisition tasks are targeted areas the child has not yet learned, and maintenance tasks are tasks the child has already mastered. Research shows that treatment targeting exclusively acquisition tasks results in increased child frustration and task avoidance. However, when previously learned tasks are interspersed with acquisition tasks, children learn faster and exhibit greater enthusiasm, happiness, and interest (Dunlap, 1984).

Task Variation Closely related to task interspersal is task variation. Instead of repeatedly presenting the same target tasks until mastered, varying the tasks with other activities results in faster learning (Dunlap, 1984; Winterling, Dunlap, & O'Neill, 1987). Such variation, as opposed to massed practice, has similar results to the interspersal of maintenance and acquisition tasks in regard to reducing disruptive behavior and increasing the rapidity of skill acquisition (Winterling et al., 1987).

Consequences Child choice ties nicely into the presentation of the reinforcer. When items that the child finds enjoyable are used in the intervention, the task becomes inherently rewarding, and the contingent provision of the preferred item is then naturally reinforcing.

Natural Reinforcers In contrast to providing rewards that are unrelated to the task, reinforcers that are directly and functionally related to the task result in accelerated learning. If the child chooses the activity or item, then it can be provided contingent upon a correct response. Such natural rewards allow the child to more easily understand the response-consequence relationship. It also enhances generalization of skills as the child is likely to request preferred items or activities outside of intervention as well.

Rewarding Attempts Rather than using a strict-shaping paradigm, common in behavioral intervention, children are rewarded for all genuine attempts. This is especially important for children having difficulty learning first words. When the child's attempts are rewarded, regardless of how close the pronunciation is to the adult word, the children learn words faster than when each response is equal to or better than the previous (Koegel, O'Dell, & Dunlap, 1988).

The individual components described above were combined into a treatment package that was initially investigated for teaching first words and language to children with ASD. The first study published using this package focused on expressive verbal communication (Koegel et al., 1987). Participants in this early study were young children with autism who were minimally verbal, despite participating in intensive structured ABA programs. However, incorporation of motivational strategies resulted in rapid generalized gains in imitative and spontaneous utterances across all children. This treatment package of motivational procedures (previously called the natural language paradigm or NLP, now called pivotal response treatment) has demonstrated effectiveness in several developmental domains, such as play (Pierce & Schreibman, 1995; Stahmer, 1995), social initiations (Koegel, Carter, & Koegel, 2003), socialization in schools (Robinson, 2011), and academics (Koegel, Singh, & Koegel, 2010). Table 4.2 presents an overview of PRT components and treatment examples for caregivers.

The PRT package has been shown to be more effective than treatment as usual or structured ABA intervention in several single-subject design studies as well as randomized clinical trials (Mohammadzaheri, Koegel, Rezaee, & Rafiee, 2014). Research shows that compared to a traditional ABA format, teaching parents PRT leads to increased positive parent-child interactions, evidenced by increased positive communication style, increased parent happiness and interest, and reduced parent stress (Koegel, Bimbela, & Schreibman, 1996). This is important as stress levels of parents of children with autism are generally exceedingly high (Estes et al., 2009; Moes, Koegel, Schreibman, & Loos, 1992). Reduction of parent stress should be a key ingredient to any parent-implemented intervention and will likely lead to more frequent implementation of treatment strategies. PRT is designed to be play-based, naturalistic, and easily incorporated into daily routines. This ease of implementation along with improvements in affect fits nicely within a transactional model wherein both parents and their children may benefit from each other's enjoyment, thereby reducing stress.

This leads us to consider the importance of the earliest possible onset of intervention for reducing parent stress, increasing motivation, and improving child communication while ameliorating potentially proliferating difficulties in order to help the child move toward an optimal developmental trajectory. PRT was originally developed as an early intervention for pre- and elementary school-aged children, focusing on improving social communication and motivation following diagnosis. Recently, however, the age of diagnosis has decreased to 18–24 months of age, and community screeners are available to help identify high-risk infants in the first year of

Table 4.2 Core components of pivotal response treatment for teaching intentional communication

PRT component	Description	Intervention procedure and parent-implemented examples *Target behavior: intentional vocalizations*
Child choice	Follow the child's lead in selection of task stimulus and reinforcement items and activities	Prior to starting intervention, parents should watch their play to see what is interesting to him or her *Example*: You notice your child is interested in putting items in the shape sorter
Shared control	Control of the stimulus items is shared with the parent and the child	The parent takes turns with items while sharing control of the stimulus items with the child *Example*: You take most of the shapes while letting your child have the sorter. This allows both you and your child to have some control over the activity, but your child must interact with you to continue the activity
Child attention	Gain the child's attention before providing a prompt or another opportunity for communication	The parent gets the child's attention before presenting the opportunity *Example*: You get down on the floor with your child and hold up a shape while ensuring the child is looking at either you or the shape before presenting the prompt "star" as a language opportunity
Clear opportunity	The communication opportunity is clear and concise	The opportunity should be clear and concise such that the child understands what the parent is asking *Example*: Keep language short when providing a communication opportunity. Instead of saying "oh I see you want the star, here it is, do you want the star?," simply state "star" while holding up the item. This way your child knows exactly what to do in order to communicate
Interspersal of maintenance and acquisition tasks	Provide opportunities for already-mastered skills the majority of the time while incorporating a new skill every few trials	The parent mixes up easy and difficult tasks *Example*: Your child is very good at saying "star" while looking at the star. You will always reinforce these good words (maintenance skill) while holding out for a more sophisticated method of communication, such as saying "star" while making eye contact with you (acquisition skill) about every 3–5 trials (more or less depending on the child's level of motivation)
Contingent reinforcement	Provide reinforcement immediately after the desired behavior	The child gets the reward right away to connect the response with the consequence *Example*: Give your child the shape as quickly as possible after he or she says the word or a good attempt. This rapid and contingent response will strengthen the response-reinforcer relationship
Natural reinforcement	The reinforcer should be directly related to the response (child's target behavior)	The parent should find a reward that is intrinsically related to the target behavior *Example*: Once the child says "star" or attempts to vocalize or say another shape, the shape he or she said should be given to the child
Reinforce attempts	Attempts to produce the target behavior should be reinforced	Good trying should always be rewarded *Example*: If your child is just beginning to make intentional vocalizations, any good attempts to vocalize for the purpose of communicating should be reinforced. If you prompt for "triangle" and the child says "ti-ga" while showing good effort and attention, this attempt should be immediately reinforced

life, prior to the full manifestation of ASD symptoms (see Chap. 2). Further, parental concerns about ASD may be present several years prior to a formal diagnosis of ASD, in some cases as early as 4–6 months of age (see Chap. 3; Koegel, Singh, Koegel, Hollingsworth, & Bradshaw, 2013). Other chapters in this section have also presented empirical and theoretical arguments for the critical importance and benefits of supporting families of high-risk infants before a confirmed diagnosis is possible. This work has motivated new research in adapting PRT to enrich social engagement and communication opportunities for high-risk infants in the first 2 years of life. That is, although a formal diagnosis may not occur prior to the point in time when expressive words are expected (around 12–16 months), preliminary research suggests that symptoms of social avoidance, lack of social responsiveness, and reduced social communication can be addressed (see Bradshaw, Steiner, Gengoux, & Koegel, 2015, for review). As such, families and interventionists can work together to intervene at the earliest possible time to improve the infant's developmental trajectory.

For example, social communication and play are among the building blocks for later-developing, more sophisticated language and social skills. Social engagement emerges at as young as 2 months of age when infants begin to exhibit reciprocal social smiling with caregivers. This behavior sets off a cascade of mutually reinforcing social interactions that develop into a social-communicative repertoire consisting of gaze shifting, gestures, and language. In contrast, infants and toddlers with ASD do not show this typical trajectory of social-communicative development. Prospective and retrospective studies of infants later diagnosed with ASD have identified infant behaviors and behavioral symptoms between 6 and 24 months of age that deviate significantly from those of typically developing infants (e.g., Baranek, 1999; Clifford & Dissanayake, 2008; Macari et al., 2012; Maestro et al., 2002; Osterling & Dawson, 1994; Ozonoff et al., 2010; Shic, Macari, & Chawarska, 2014; Watson, Crais, Baranek, Dykstra, & Wilson, 2013; Werner, Dawson, Osterling, & Dinno, 2000). By 9–12 months of age, infants with ASD may exhibit an increasing number of behavioral atypicalities, including reduced eye contact, failure to orient to name, reduced social smiling, abnormal affect, fewer gestures, lower activity levels, and longer duration orienting to objects (see Boyd, Odom, Humphreys, & Sam, 2010, and Zwaigenbaum et al., 2005, for review). Overall, research to date has documented early prodromal features of ASD in infancy and suggests that these behaviors intensify in the second year of life. Thus, earlier onset of intervention is related to improved developmental trajectories for infants with ASD (Rogers et al., 2012), and treatment during the first year of life may be pivotal for optimal outcomes (Koegel, Koegel, Ashbaugh, & Bradshaw, 2014).

Adapting Pivotal Response Treatment to Support Families Before Diagnosis

Consider the social-communicative profile for typically developing infants during the first year of life. The emergence of social referencing includes the use of eye gaze, facial expression, and gestures for the purpose of sharing and requesting. Babbling transforms into functional vocalizations and primitive word approximations. A direct application of the original PRT strategies that focused on teaching first words (Koegel et al., 1987) and language (Koegel, Koegel, & Surratt, 1992) would not be completely appropriate for prelinguistic infants in the first year. However specific PRT components that have been shown to improve motivation by using a classical conditioning paradigm in the natural environment may be well-suited for treatment of infants beginning to demonstrate a lack of social engagement and social-communicative difficulties. In this context, foundational skills that provide a scaffold for first words and language development, such as eye contact, gestures, and intentional vocalizations, can be addressed. While the treatment targets are different for PRT with infants, the theoretical foundation and motivational principles central to PRT remain the same. Developmental considerations for adapting parent-implemented PRT for use with infants are described below.

Social Motivation

Socialization and language difficulties are among the core deficits of individuals with ASD. The motivational strategies of PRT, as described above, provide a practical framework that allows for a sustained, enjoyable parent-child interaction, while behavioral strategies serve to provide appropriate opportunities for communication and reinforcement. The adaptation of pivotal response treatment for use with infants is an organic extension given its naturalistic methodology and focus on motivation. Some researchers have postulated that social motivation is at the core of social deficits observed in individuals with ASD (Dawson, 2008; Koegel, Valdez-Menchaca, & Koegel, 1994). From a developmental perspective, this decreased social motivation may stem from, or at least manifest as, diminished interest in social interactions in infancy. Early parent-infant social interactions provide the necessary context for language learning, and decreased attention and interest in social interactions in infancy could have a critical impact on social-communicative development (Bradshaw, 2015). In the first 6 months of life, infants with typical social development enjoy face-to-face interactions with a caregiver. Around 6 months, infants become increasingly object-focused and gradually choose to engage in triadic interactions in which they shift gaze between objects and a caregiver (Bakeman & Adamson, 1984). Early referential exchanges allow caregivers to label objects and engage in a language- and object-embedded social interaction. These socially motivated joint attention episodes provide a context for promoting language development (see Mundy & Newell, 2007). Thus, PRT for infants in the first year of life focuses on increasing motivation to engage in a social interaction with a caregiver. We hypothesize that increasing attention to caregivers as well as positive affect during parent-infant interactions will create an inherently more reinforcing exchange that will improve social motivation and generate widespread gains in social communication in the first years of life (Fig. 4.1).

Treatment Targets

As mentioned previously, social-communicative abilities are just emerging in the first years of life. An infant's communicative repertoire consists primarily of nonverbal behaviors such as gestures, facial expression, and eye gaze, as well as communicative vocalizations and word approximations. An initial assessment of the infant's current social-communicative functioning using standardized assessment can determine delays compared to established norms of chronologically age-matched peers. Such assessments might include the Communication and Symbolic Behavior Scales (CSBS: Wetherby & Prizant, 2002), Mullen Scales of Early Learning (Mullen, 1995), Bayley Scales of Infant Development (Bayley, 2006), and MacArthur Communicative Development Inventory (Fenson et al., 1993). Additional assessments provide quantitative information about frequency and quality of social-communicative behaviors as well as ASD symptoms: the Early Social Communication

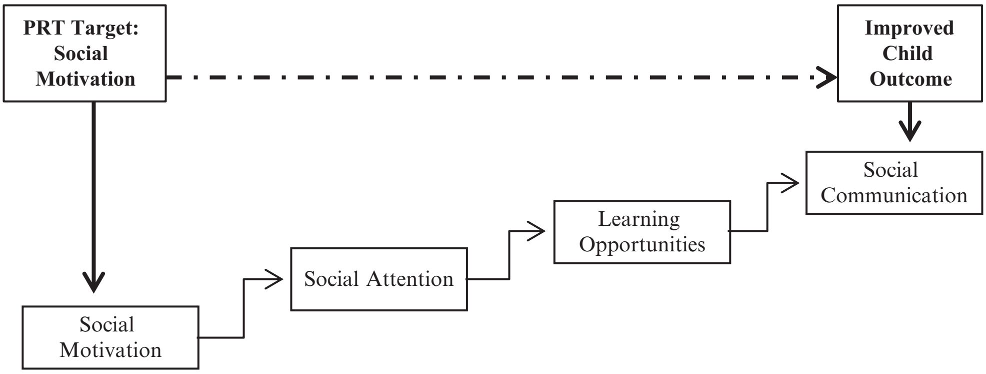

Fig. 4.1 Theoretical model for targeting social engagement in infancy. PRT strategies work to create more motivating social interactions for infants. As infants become more socially motivated, and thus prefer to engage in social interactions, they will spend more time attending to social features in the environment, which will increase learning opportunities embedded in social interactions and ultimately improve social-communicative skills

Scales (ESCS: Mundy et al., 2003); the Autism Diagnostic Observation Schedule, Toddler Module (ADOS: Rutter, DiLavore, Risi, Gotham, & Bishop, 2012); and the Autism Observation Scale for Infants (AOSI: Bryson, Zwaigenbaum, McDermott, Rombough, & Brian, 2008). For younger infants who exhibit variability in behavior, gathering observational data over a period of several days or weeks can be helpful in determining stability of perceived deficits (Bradshaw, Koegel, & Koegel, 2012). Treatment targets should then be selected considering both the child's developmental skill level and chronological age. For example, 24-month-old infants should be engaging in pretend play and saying two- to four-word phrases. If a 24-month-infant with or at risk for ASD is exhibiting cause-and-effect play and is not communicating using vocalizations or gestures, treatment should be modified appropriately; treatment targets might include simple functional play and communication using gestures and intentional vocalizations. A focus on developmental precursors supports the emergence of skills and enhances developmental gains. For example, the development of initiating joint attention, a skill that occurs developmentally earlier than expressive verbal communication, is associated with advanced language skills in children with and without ASD (e.g., Mundy, Sigman, & Kasari, 1990). Similarly, treatment for infants younger than 12 months might include social engagement and heightened positive affect during face-to-face play, as social smiling has been associated with enhanced social responsivity and social initiations (Bradshaw, 2015; Parlade et al., 2009).

Self-Regulation

Infants have fewer capacities to self-regulate and often require caregiver support to assist in self-soothing. For example, infants in the first year of life show less awareness of social or task demands, and social exchanges are grounded in immediate motivations and perceptual stimuli, whereas 12- to 18-month-olds regulate their physical and emotional state based on social context (Kopp, 1982). In contrast, cognitive achievements of representational thinking and recall memory allow for self-control, observed through active behavioral compliance, by 2 years of age (Kopp, 1982). An understanding of the neurobehavioral organization of the infant informs approach to treatment in the first years of life. Intensity should be adjusted appropriately, and physiological state (e.g., sleepy, fussy) must be weighed more heavily than older children in decisions about treatment implementation. This is well suited for the naturalistic approach of PRT in which treatment can (and should) be implemented by caregivers on an ongoing basis and throughout daily routines. Parents should also be taught how to read their infant's cues related to behavioral state so as to provide a maximally positive and reinforcing social interaction. An infant's capacity to learn and respond is significantly related to behavioral state, and so intervention for younger infants should be implemented during appropriate times (Wolff, 1987). Although optimally motivating social interactions are encouraged, breaks in social interaction should be provided as necessary to maintain an optimal state for learning.

Parent Education and Coaching

Parent education is a critical piece of PRT for young children and infants with or at risk for ASD. The importance of implementation throughout daily routines and activities, the need for continued support in social-communicative skills, and developmentally appropriate stranger anxiety in young infants implore a parent-education and parent-implementation model. Research has shown that parents can master the motivational strategies of PRT and incorporate them into daily routines with a 5-day, 25 h parent-education program (Koegel, Symon, & Koegel, 2002). These gains proved to be long-lasting for at least up to 1 year post-intervention. Importantly, parents were also observed to exhibit more positive affect and interest when interacting with their children and also showed reductions in (untargeted) stress. A follow-up study showed that parents who learned PRT through this brief, high-intensity training program were able to train other significant caregivers to fidelity in the implementation of PRT with their child (Symon, 2005). Parent education has also been shown to be effective in improving language across contexts for parents of minimally verbal children with ASD younger than 3 years old (Koegel, Bruinsma, & Koegel, 2006; Bradshaw, Koegel, & Koegel, 2017). These studies showed improvements in the number of words produced expressively and vocabulary diversity from pre- to post-intervention during naturalistic language samples. Across all children, expressive language improvements ranged from 16 to 200 total words uttered with some children using 3–93 unique words. Additionally, parents corroborated the positive outcomes, reporting large increases in functional expressive words their children produced on the Vineland Adaptive Behavior Scales, Communication Domain (Sparrow, Cicchetti, & Balla, 2005). The feasibility and effectiveness of PRT parent-education programs have been independently replicated at other sites, outside of the original development research laboratories of PRT (e.g., Coolican, Smith, & Bryson, 2010). Group parent training of PRT has also been developed, demonstrating significant improvements in parent fidelity of implementation and child expressive language after 10 weeks (Gengoux et al., 2015; Minjarez, Williams, Mercier, & Hardan, 2011). Together, this research suggests that the motivational and behavioral strategies of PRT are feasible for parents to learn and train others in a relatively brief period of time and are effective for improving social communication in young children with ASD.

Research has also examined specific features of parent-education programs that decrease parent stress and enhance parent satisfaction and gains. Steiner (2011) examined the effect of a strength-based approach to parent training, which compared deficit-based statements to strength-based statements during coaching sessions. During the strength-based condition, the interventionist made statements that highlighted the child's strengths, for example, "It seems like he has a lot of interests, that's a good sign. One way to get his attention is..." This was compared to the deficit condition in which statements were made related to the child's area of weakness, such as "It seems like it is hard to get his attention. One way to get his attention is..." Results demonstrated that the strength-based approach improved parent affect and enhanced parent-child interactions during parent coaching sessions not only compared to the deficit-based approach but also compared to pre-treatment interactions. Importantly, this suggests that parent-implemented intervention using a strength-based approach during feedback sessions may effectively help *decrease*, rather than induce, parent stress.

Modifications of PRT parent training can also lead to enhanced gains in socialization. For instance, Vernon, Koegel, Dauterman, and Stolen (2012) extended the motivational concept of *child choice* by embedding a social component into the child's interests throughout intervention. In a traditional PRT paradigm for a child whose preferred activities included jumping on a trampoline, the child would be reinforced for saying the word "jump" by allowing her to jump on a trampoline. Using the socially embedded PRT paradigm, a social component would be embedded within the reinforcement, so the adult may jump *with* the child on the trampoline. In this way, the reinforcement comes from the adult jumping with the child rather than the trampoline itself, making social interaction a part of the preferred activity. Results of this study showed rapid gains in both parent acquisition of the teaching procedures and child behaviors. As expected in traditional and socially embedded PRT frameworks, all children showed substantial improvements in verbal initiations. Additionally, children in socially embedded PRT spent greater proportions of time making eye contact with their caregiver and showing positive affect. Moreover, parent-child interactions drastically improved in respect to increased synchronous engagement as well as parent positive affect.

Strategies for Parent Coaching

Introduction of the Topic Sessions can begin with a check-in about the previous week, questions about concepts learned thus far, specific problem areas related to implementation of PRT strategies, and gains the child has made. Praise for caregivers should be provided for any examples of implementing the procedures or generating creative ideas for eliciting communication from their child. Attempts should be made to incorporate any problem areas or questions into the session for that day. PRT strategies can be explained to the parent with the child playing nearby while providing examples specific to their child. For example, a clinician introduction to child choice might be “Right now, Jackson is playing with the animal puzzle and it’s great that he’s so interested in the pieces. It also looks like instead of putting the puzzle pieces in, he prefers stacking the puzzle pieces and knocking them down. We can follow his lead by joining in his play and helping him stack and knock them down, and we can even have him make a vocalization or word attempt before he stacks every third puzzle piece. If we instead try to get him to put the pieces in the puzzle board, this would not be following his lead.” This initial introduction of the PRT strategy can remain relatively brief followed by clinician modeling where the clinician models how to use the strategy of child choice with Jackson.

Modeling As the clinician models the strategy, she can provide narration of her actions and explain rationale for particular decisions. For example, “So I’m joining him in stacking the pieces, making sure to not be too intrusive and not interrupting his play, but still making sure that he exhibits the target behavior of using expressive words. You see that I first tried to knock down the tower too early. I knocked it down before all the pieces were stacked and he seemed to get a little frustrated with me. I’m glad he communicated his frustration and it is great that he is still sticking with the activity! So now I’m going to continue to follow his lead by allowing him to stack all the pieces before knocking over the tower. This is great because we have more opportunities to have him try and talk for the pieces. We will discuss at a later session how to make his play a little bit more flexible. But right now, let’s just focus on following his lead.” The clinician here is using several skills that deserve mention. First, she acknowledged that she had made a mistake in following the child’s lead, highlighting that even expert clinicians can misread child cues and cause frustration. Second, she utilized a strength-based approach by commending his interest in the puzzle, reframing his frustration as a method of communication, and praising his maintenance of motivation to engage in the activity. The clinician then ended with a reminder of the topic for the day – child choice.

Listening to Parent Concerns The clinician might then incorporate some of the parent’s concerns into the topic for that day. For example, “You mentioned that Jackson had a hard time when you joined his play this week and would often choose to play something else. Why don’t we try to make this interaction more motivating for the both of you by adding a fun element to the animal puzzle? I’ve seen him enjoy animal books before when you make the animal noises, which is fantastic. Why don’t you try incorporating some of the animal noises, which he loves, into this puzzle game? Since he is already making verbal attempts to name many of the items, this would be a nice way to add to his repertoire of words.” At this point, the clinician would encourage the parent to try using the child choice strategy, while the clinician observes and provides feedback. We think of parent education as a practice-with-feedback process rather than learning through didactics, and so the rest of the session is spent interweaving practice, feedback, modeling, and discussion. The session then ends with a summary of the topic, a few statements about what the parent and child did well in the session, instructions for what to practice in the upcoming week, and troubleshooting as necessary.

Implementation of PRT for Families with High-Risk Infants

Preliminary research suggests that beginning intervention in the first year or two of life, when social engagement and social-communicative challenges are just emerging, can have a greater impact on prognosis and developmental outcome (Koegel, 2000; Rogers et al., 2012). Several studies have documented how parent implementation of PRT strategies for toddlers with ASD can lead to rapid and widespread gains. Implementation of parent-mediated interventions for high-risk infants, however, carries unique challenges. These challenges have been addressed in previous chapters, so here we focus on how pivotal response treatment is especially suited for parent-implemented intervention in infancy and present examples of how it can be implemented for 6- to 24-month-old high-risk infants to increase social engagement, improve nonverbal and verbal expressive communication, and decrease autism symptomology. The remainder of this chapter will provide strategies and examples for how to adapt PRT for use with high-risk infants, based on both chronological age and developmental level. We start with using PRT to teach first words to older infants (15–24 months) who are already showing basic nonverbal communicative attempts but who have yet to use consistent verbal communication (Bradshaw, Koegel, & Koegel, 2017). We then describe modifications made to PRT for improving nonverbal intentional communication, such as eye contact and gestures, for infants who are not yet exhibiting any social-communicative attempts. And finally, we describe how to use motivational PRT strategies to promote positive social engagement for our youngest infants between 6 and 9 months old. Examples of essential PRT strategies for promoting social engagement and communication in high-risk infants are displayed in Tables 4.3 and 4.4.

PRT Strategies for Teaching High-Risk Infants' First Words

PRT strategies for improving verbal communication in high-risk infants in the second year of life require few modifications from the traditional PRT paradigm and use the fundamental PRT structure of providing a language opportunity, waiting for a response, and reinforcing the desired behavior (Bradshaw, Koegel, & Koegel, 2017; Bradshaw, Steiner, et al., 2015; Steiner, Gengoux, Klin, & Chawarska, 2013).

Provide a Language Opportunity Caregivers can easily embed infant-preferred activities and provide communication opportunities throughout daily routines and during play. Caregivers can wait to give their infant a highly preferred item until he or she provides some indication of intentional communication. Providing opportunities can be an easy part of any household activity by simply placing highly preferred items "in sight, out of reach" so the child has more opportunities to communicate, for example, placing a favorite toy on a high shelf or a favorite snack in a tightly sealed, clear container. However, verbal prompting for a language attempt may not be the most effective way to teach older infants their first words. In more challenging cases, verbal routines during motivating activities can work especially well. Common verbal routines include "ready, set...go" or "one, two...three." A caregiver can provide an opportunity by first modeling the entire verbal routine and then pausing in anticipation of the last part of the routine as in "ready, set...." This rhythmic strategy builds behavioral momentum during a

Table 4.3 Pivotal response treatment strategies for improving intentional communication. Suggested age: 12–24 months

Suggested target behaviors	Modified PRT component	Example
Eye contact and gaze shifting Gestures Vocalizations First words	Hierarchical prompting	Incorporate physical prompts, model prompts, and open-ended prompts as necessary based on the infant's skill level
	Reinforce attempts	Reinforcing attempts is a key component of traditional PRT; however working with infants who are just beginning to learn communication requires parents to reinforce *any* approximation of the desired behavior
	Interspersal of maintenance and acquisition tasks	Parents and clinicians may choose to intersperse fewer acquisition tasks for infants in order to provide more opportunities for infants to solidify already-learned skills

Table 4.4 Pivotal response treatment strategies for improving intentional communication. Suggested age: 6–12 months

Suggested target behaviors	Modified PRT component	Description
Looking to caregiver Positive affect	Child choice	Identify what type of face-to-face play and social interaction the infant enjoys and incorporate those activities into play as often as possible. Learn to identify the infant's cues for self-regulation and disengagement
	Task variation	Vary the activity often when interacting with the infant to maintain social engagement and prevent disengagement
	Interspersal of neutral and preferred activities	Gradually intersperse neutral activities with highly preferred social activities to generalize positive social engagement to social interaction rather than to specific activities

highly motivating activity. Similar strategies can be used with favorite songs or animal sounds. Many children with ASD begin to communicate when their parent pauses in the middle of singing a favorite song. For example, a caregiver can start singing "twinkle, twinkle, little..." and then pause so that the infant can continue with an approximation of the word "star" or any vocalization at all.

Provide Natural Contingent Reinforcement Natural reinforcement involves a direct and natural relation between language and reinforcement. If the child's motivating activity is getting tickled, a caregiver could reinforce any attempt of the word "tickle" by tickling contingently following the child's response. This direct relation between the infant's communicative attempt and reinforcement also promotes skill generalization.

Reinforce Attempts Communication emerges gradually. At 12–18 months, we do not expect infants to say their first word perfectly, and so we do not expect infants and toddlers with or at risk for ASD to say their first words perfectly either. In fact, caregivers and clinicians may first focus on intentional communication rather than accurate or precise utterances. For example, when a child reaches for her doll and says "ah," a caregiver can model the correct form of the word "doll" while immediately reinforcing the communication attempt by handing her the doll. Prompting the child for the correct word "doll" and waiting for a more accurate response runs the risk of losing the child's motivation to communicate.

Supporting Families to Improve Nonverbal Intentional Communication in High-Risk Infants

Prior to saying first words, infants exhibit prelinguistic intentional communication, including sharing enjoyment by looking from an object to the caregiver or pointing to an object of interest. These nonverbal communication skills begin to emerge between 9 and 12 months, and high-risk infants have been reported to exhibit diminished quantity and quality of nonverbal communication. Pivotal response treatment has also been adapted to improve prelinguistic intentional communication in high-risk infants (e.g., Steiner et al., 2013). The following modified PRT strategies can be taught to parents of high-risk infants who are not yet exhibiting intentional communication: child choice, clear opportunities, interspersal of maintenance and acquisition tasks, immediate and contingent reinforcement, natural reinforcement, and reinforcing attempts. In contrast to traditional PRT models in which verbal communication is the primary focus of intervention, PRT can be adapted to target prelinguistic forms of social communication for infants as young as 12 months old, such as pointing, giving, showing, and other gestures.

As in traditional PRT, intervention is implemented during infant-preferred activities and tasks, such as peekaboo with a blanket. Clear opportunities are provided by first engaging the child in a highly engaging routine. For example, a caregiver may build a routine with the following sequence: (1) caregiver places the blanket over the child and says "Where's Abby? Where is she? I think I see her…”; (2) caregiver pulls off the blanket, places the blanket on the ground, and says “peekaboo!” followed by tickling; and (3) caregiver says “let’s play again!” This routine has an easily identifiable beginning and end, which helps to build anticipation and maintain engagement but also serves as a *clear opportunity* for the infant to initiate a communicative attempt: the activity has suddenly stopped and the blanket is on the floor, leaving the infant to vocalize, gesture (give or point), or shift gaze from the blanket to the caregiver in order to continue the interaction. It also incorporates a rewarding social interaction, while also using an object (blanket) that can be used to teach a giving gesture.

As in verbal language, prompting strategies can be used if the infant is not yet demonstrating a target behavior, such as a give gesture. In their study of adapting PRT for high-risk 12-month-old infants, Steiner et al. (2013) utilized prompts that were organized into a hierarchy such that a *physical prompt* was the highest level (most supportive), followed by a *model prompt*, and an *open-ended prompt* at the lowest level (least supportive). Using this method, if a behavior is difficult to elicit, a clinician, or second caregiver, may begin with the most supportive prompt – physical prompting. In our blanket peekaboo example, a parent coach or second caregiver may sit behind the infant and physically prompt Abby using the give gesture by putting the blanket in Abby’s hand and guiding her hand toward her mother. This, of course, would be immediately followed by the caregiver putting the blanket over Abby and reinitiating the peekaboo routine in order to reinforce the “give” gesture. Moving up in the prompt hierarchy, model prompts are defined as the parent modeling the target behavior, for example, demonstrating a point to elicit a point from the infant or saying “more” to elicit an infant vocalization. Finally, the least supportive prompt is the open-ended prompt in which a parent would elicit a response from the infant without modeling, for example, asking, “What do you want?”

It is beneficial to create opportunities for activities in which the caregiver or clinician can easily join into the activity and engage with the infant. For example, some infants can become overly fixated on cause-and-effect objects, e.g., a toy telephone, in which interruption of the activity for the purpose of presenting a communication opportunity may elicit frustration. Clinicians and parents may choose to avoid such activities. Additionally, infants in early intervention may not have developed functional play, and so clinicians and caregivers may choose to incorporate learning opportunities into activities that involve food or physical play (e.g., tickling). Early learners can become easily frustrated with continued presentation of difficult tasks, and thus it is important to intersperse easy, already-mastered tasks, with new, more difficult tasks. For example, if an infant consistently gives objects to a caregiver to request but only occasionally pairs this behavior with eye contact, a caregiver might wait for the integration of these two behaviors once every five to seven trials.

Supporting Families to Improve Social Engagement in Very Young Infants

In the first year of life, infants engage in reciprocal, highly affective face-to-face dyadic interactions with a caregiver. These very early social interactions are critical for learning social contingencies, developing effective self-regulation, and acquiring later communicative competencies (Feldman, 2007). In an effort to address parental concerns about a lack of infant social responsivity and social engagement early in life, we have adapted PRT strategies to focus on improving positive social engagement during face-to-face play for very young high-risk infants. The larger developmental domain addressed is social engagement, and potential target behaviors to focus on include increasing the frequency of social smiling and eye contact during the interaction. PRT for very young infants focuses on improving positive affect and eye gaze during face-to-face play with a caregiver and incorporates three key motivational strategies adapted from the traditional PRT paradigm: child choice, task variation, and interspersal of neutral and preferred activities.

Child Choice Child choice refers to incorporating activities or items that are motivating to the child, or infant in this case. Infant-preferred activities are identified through systematic evaluation of the infant's interest and affect during parent-infant interactions. A clinician observes multiple parent-infant interactions in which the parent is utilizing multiple activities and strategies to try and engage their infant. These simple observations of the infant's play preferences in a naturalistic setting can illuminate the contexts in which he or she will be most motivated to interact. Each activity is then categorized as *preferred*, activities in which the infant exhibits indications of enjoyment such as high positive affect and eye contact; *neutral*, activities in which the infant appears to passively accept the activity without indication of wanting the interaction to continue or cease; or *not preferred*, activities in which the infant exhibits dislike for the activity such as gaze aversion combined with negative affect. Although infants use gaze aversion to self-regulate their arousal during highly stimulating activities, gaze aversion accompanied with negative affect likely reflects a non-preferred activity. In our research with high-risk infants exhibiting very early concern for ASD, these initial assessments of parent-infant interactions revealed that the motivational property of the interaction appeared to be constrained by specific activities rather than generalized to social interactions, in contrast to typically developing infants who exhibit consistently positive social affect with their caregiver regardless of activity. The goal of PRT for very young high-risk infants therefore is to expand their social engagement to a variety of social activities with their caregiver, thus potentially transferring their activity-centered engagement to a social-centered engagement.

Task Variation During parent-infant interactions, parents are taught how to read their infants' cues and vary the activity frequently, thus consistently providing novel activities and maintaining social engagement. Although looking away during social interaction serves as a self-regulatory behavior for young infants, potential cues for infant social disengagement included prolonged looking away accompanied with negative affect and a trend of decreasing affect over several seconds. Thus, varying the enjoyable activities before the infant satiates is important.

Reinforcement To increase social motivation in such young infants, this intervention relies on a classical conditioning paradigm in which parents *become* the preferred activity. This is in contrast to a traditional operant conditioning paradigm in which natural reinforcers are provided contingent upon appropriate communicative responding. Again, the goal here is to make the parent and the social interaction as reinforcing as possible and to condition the child to associate the parents' interactions with the positive and enjoyable activities.

Intersperse Acquisition and Maintenance Activities Once an infant is exhibiting high levels of social engagement, including making eye contact and smiling, throughout the preferred activities for three consecutive sessions, neutral activities are incorporated. That is, the activities that had previously been considered neutral are gradually and systematically incorporated into the rotation of the preferred play activities. As the infant begins to demonstrate improved affect with the neutral activity, another is added, and so on, until all of the parent-infant activities that were presented in the initial assessment period are incorporated into play. An emphasis on reading infant cues and providing highly rewarding activities will help to improve the parent's understanding of his or her infant's individual preferences and communicative style, thus increasing the likelihood of increasingly contingent and rewarding social interactions for at-risk infants and their parents.

Summary

The overarching goal in adapting parent-implemented PRT for high-risk infants before an ASD diagnosis is to help caregivers understand typical social-communicative development, discern concerning behaviors, and learn basic motivational and behavioral strategies for improving social engagement and communication. It should be noted that infant behaviors can be unstable in the first year of life and vary greatly. Assessing for stable patterns of difficulties with socialization is important, so that other natural environmental factors (such as fatigue) are not erroneously evaluated as an at-risk symptom. However, a strength of beginning intervention during infancy is that the interventions are not as labor intensive as those needed in the preschool years and beyond. Emerging studies suggest that parents can be taught strategies in a relatively short period of time and that the bulk of the intervention hours can be implemented by parents throughout the infant's waking hours. This cost and time efficiency supports the use of adapting interventions for families with high-risk infants. Although teaching first words and language has historically been among the first steps in using PRT for young children with ASD, this target seems inappropriate for high-risk infants younger than 12 months who do not yet have a diagnosis and may be inappropriate for older infants who are not yet demonstrating prelinguistic communication. In adapting PRT for high-risk infants, we had to develop new, appropriate target areas for young infants and early learners. We found that working to improve the positive affect and social attention during social interactions, as well as teaching nonverbal intentional communication, led to observable gains and parent satisfaction. The core theoretical underpinning of PRT – to improve social motivation – remains the same in working with high-risk infants, but the strategies and intervention goals are slightly modified to address developmental stage.

The transition from working with children with a diagnosis of ASD to teaching PRT to parents of high-risk infants carries unique challenges. For example, learning that an infant is at risk for social-communicative impairments can induce parent stress and anxiety, and clinicians should be provided tools to help reduce parental anxiety while promoting self-efficacy and confidence. Research suggests that interventions, such as PRT, that can be implemented during play and daily routines reduce parent stress when compared to other strategies that require the parent to take time out of the day to implement drill-type activities (Koegel et al., 1996). Although clinician-parent alliances are important in all forms of parent-mediated interventions, we have learned that this is an especially important aspect of adapting PRT for high-risk infants. Given the high levels of stress accompanied with uncertainty of their infant's outcome, clinicians who are compassionate while also focusing on parent coaching of PRT procedures are most successful. Further, outcomes will be improved if parents are considered as valuable and important team members when developing goals and implementing intervention programs (Brookman-Frazee & Koegel, 2004). Parents should be both recognized and respected as experts relating to their own infant. As well, families' cultural and socioeconomic variables and values should be considered during parent-education programs (Baker & George, 2013; Santarelli, Koegel, Casas, & Koegel, 2001). Consistent recognition and celebration of parent and infant strengths are essential for creating a positive environment and promoting optimal learning and development (Steiner, Koegel, Koegel, & Ence, 2012).

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Part II

Supporting Families with Diverse Parenting Practices, Cognitions, and Emotions

Financial Hardship and Parenting Stress in Families with Young Children with Autism: Opportunities for Preventive Intervention

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Abstract

Children under age 6 years are especially likely to live in households facing serious financial hardship, and economic strain can increase the amount of stress experienced by parents of young children. Parenting stress and financial hardship are especially salient to families with young children with autism spectrum disorder (ASD). This chapter utilizes Conger and Conger's (J Marriage Fam 64:361–373, 2002) family stress model to conceptualize how financial hardship and parenting stress can exacerbate behavior problems among at-risk young children. The chapter also summarizes the literature on financial hardship and parenting stress among families with young children with ASD. The chapter concludes with a discussion of screening and intervention strategies to support low-income families with young children with ASD. An established preventive intervention for low-income families with young children is described. The chapter presents possible modifications to this preventive intervention approach to address the psychosocial needs of economically insecure families with young children with ASD.

Financial Hardship and Parenting Stress in Families with Young Children with Autism: Opportunities for Preventive Intervention

Parenting young children is challenging, and these challenges can be exacerbated by several factors including parenting stress and financial strain. Furthermore, financial strain and parenting stress are linked within families, with financial hardship and economic pressure each playing a role in heightening parents' emotional distress, difficulties with parenting, and children's risk for subsequent maladjustment (Conger & Conger, 2002). Financial hardship is prevalent among families with young children, and children under age 6 years are more likely to live in households facing serious financial hard-

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_5

ship than older children or adults. Based on a recent estimate, 48% of young children in the United States live in families classified as “low-income” (family income less than 200% of the federal poverty threshold), and 25% of young children live in families classified as “poor” (family income below the federal poverty threshold; Jiang, Ekono, & Skinner, 2015). These statistics translate to approximately 11.1 million young children living in low-income families in the United States.

Parenting stress and financial hardship are especially salient to families with young children with autism spectrum disorders (ASD). The prevalence of ASD, recently estimated as 1 in 68 children (Autism and Developmental Disabilities Monitoring Network, 2014), is similar in lower-income and higher-income populations (Boyle et al., 2011). This means that the population of children with ASD residing within low-income households in the United States is likely to be well over 150,000. In addition, many families who had been economically secure will experience financial hardships due to increased costs and other ramifications of the ASD diagnosis. Given the relatively high likelihood that families with young children with ASD will experience financial hardship and associated family stressors, it is important to understand and address the unique psychosocial needs of these families. In this chapter, we utilize Conger and Conger’s (2002) family stress model to conceptualize how financial hardship and parenting stress can exacerbate behavior problems among at-risk young children, including children with ASD. Then, we summarize the literature on financial hardship, factors that often co-occur with low socioeconomic status, and parenting stress among families with young children with ASD. We conclude with a discussion of interventions geared toward supporting low-income families with children at-risk for serious behavior problems. In particular, we describe how an efficacious preventive intervention for low-income families could be adapted to address the psychosocial needs of economically insecure families with young children with ASD.

The Family Stress Model

The family stress model (FSM) was developed by Rand Conger, Katherine Conger, and their colleagues to explain the influences of financial hardship on the lives of rural families facing the economic crisis in agriculture that occurred in the Midwestern United States during the 1980s (Conger, Conger, & Martin, 2010; Conger & Elder Jr., 1994). The FSM posits that financial hardship and resulting economic pressure negatively impact child adjustment via influences on parents’ and other caregivers’ emotions and behaviors. Parents’ negative emotions and problematic relationships that stem from economic stressors adversely affect their parenting strategies, leading to behavioral difficulties among their offspring (Conger & Donnellan, 2007). The FSM was initially validated in longitudinal research with rural parents and adolescents in Iowa (Conger & Conger, 2002). For the most part, subsequent tests of the FSM in other populations have provided evidence that this model is applicable to families with children in different age ranges and across several ethnic, racial, and cultural groups. These follow-up studies of the FSM have focused on several specific populations, including African-American families with school-age children (Conger et al., 2002), Mexican American families with fifth graders (Parke et al., 2004), and low-income families with toddler-aged children in New Orleans, many of whom were impacted by Hurricane Katrina (Scaramella, Sohr-Preston, Callahan, & Mirabile, 2008).

Two modifications and extensions of the FSM are noteworthy. First, the notion of resilience has been incorporated into the FSM because biological, psychological, and social factors might either compensate for or buffer against the negative influence of economic hardship on family processes (Conger & Conger, 2002). For example, in the Congers’ sample of rural families in Iowa, high levels of support within the marital relationship attenuated the link between economic pressure and emotional distress (Conger, Rueter, & Elder, 1999). Second, Conger and Donnellan (2007) proposed an interactionist model of the role of socioeconomic conditions on human development that melds social causation perspectives like the FSM and the family investment model (FIM) with social selection perspectives. Similar to the FSM, the FIM posits that families with more economic resources can make greater investments in their children's growth and learning whereas families with fewer resources focus on immediate family needs. Social selection perspectives focus on the idea that connections between socioeconomic factors and children's developmental outcomes may be due to underlying characteristics like personality traits or intelligence. The interactionist model melds the social causation and social selection perspectives by positing that parents' characteristics emanating from their own childhood and adolescence impact the family's socioeconomic conditions (consistent with the social selection process) but that the family's socioeconomic conditions also impact family stress and investment in their children (consistent with the social causation process).

The FSM and the associated interactionist perspective can be applied to processes that unfold within families who have young children with ASD. As is the case with the rural families from Iowa and the cultural minority groups who have been the focus of much of the FSM research, families with young children with ASD are vulnerable to economic pressure resulting from financial hardship. Arguably, these families are particularly at-risk because they have young children and because seeking and receiving adequate treatment for ASD can have significant time and financial costs. Regardless of the source of the strain, financial hardship within families with children with ASD can set in motion a cascade of negative effects in the family that may undermine parenting and exacerbate behavior problems within these already vulnerable children. However, these families might also have important sources of resilience that could compensate for or buffer against the financial hardship. We are not aware of studies that have fully evaluated the FSM in families with young children with ASD, but the following sections provide summaries of what is known about financial hardship and parenting stress among families who have children with ASD.

Financial Hardship

Financial hardship is a fairly common experience among families of children with ASD. In some situations, parenting a child with ASD may contribute to new financial hardships that did not exist prior to the ASD diagnosis. A recent estimate from three national data sets places the annual costs of caring for a child with ASD at $17,081 when tabulating costs for education, health care, therapy, and other services (Lavelle et al., 2014). Although most of these costs are not paid directly by parents, utilizing medical interventions for autism such as medications and having unreimbursed out-of-pocket expenses predicts the likelihood that families experience financial problems (Sharpe & Baker, 2007). In addition, families with lower incomes are especially likely to report financial problems due to autism and related conditions. Caring for a child with ASD can negatively impact the caregivers' employment status and earnings, and these effects are often especially profound for mothers (Baker & Drapela, 2010). On average, mothers of children with ASD earn 35% less than mothers of children with other health issues and 56% less than mothers of typically developing children (Cidav, Marcus, & Mandell, 2012). Fortunately, early intervention can mitigate some of the financial strain and help improve behavioral skills, but families facing new financial hardships often struggle to gain access to necessary support resources.

In other situations, economic stressors may predate the ASD diagnosis (i.e., in cases where children were born into families living in poverty), and this scenario poses unique challenges for identification and treatment. For example, children with ASD who come from lower income or racial/ethnic minority families are more likely to be diagnosed later and to be underdiagnosed (Roux et al., 2012). In many cases, these families are coping with other risk factors that tend to co-occur with low income, and these risk factors may exacerbate family stress and associated child behavior problems. Some of these poverty cofactors include residential and relationship instability, single parenthood, teen parenthood, and low levels of parental education. In studies of young children without ASD, the presence of poverty cofactors such as these predicts behavior problems even after accounting for the impact of family income on behavior problems (e.g., Ackerman, Schoff, Levinson, Youngstrom, & Izard, 1999). In addition, cumulative risk research shows that, as the number of poverty cofactors accumulates, child behavior problems increase (Evans, Li, & Whipple, 2013). During early childhood, higher levels of cumulative risk lead to behavior problems by undermining parent responsivity (Trentacosta et al., 2008), a process that fits with the core mechanisms outlined in the FSM. Moreover, a recent study reports that higher levels of cumulative risk during infancy are linked with difficulties in toddlers' development of self and social cognitive skills such as joint attention and self-recognition, an association that seems to stem from the finding that mothers facing more poverty-related risk factors exhibit lower levels of parenting responsivity (Wade, Moore, Astington, Frampton, & Jenkins, 2015). Although the Wade et al. study focused on a normative sample of children, the findings may have implications for the ASD population because genetically driven social cognitive deficits associated with ASD might be worsened by poverty cofactors that undermine parental responsivity and heighten family stress.

Negative effects of low income and poverty cofactors on family functioning and child adjustment have also been documented among families with children with ASD. In secondary analyses based on data collected in the large, population-based Millenium Cohort Study in the United Kingdom, Midouhas, Yogaratnam, Flouri, and Charman (2013) found that families of children with ASD have higher levels of household chaos and socioeconomic disadvantage than families of children without ASD. Moreover, higher levels of poverty among families of children with ASD are associated with symptoms of psychopathology (conduct problems and emotional problems) above and beyond intellectual ability of the child and low birthweight. In addition, in these analyses, mothers of children with ASD exhibit less maternal warmth, a factor that explains the relationship between poverty and broad psychopathology (Midouhas et al., 2013). Conversely, more maternal warmth predicts fewer conduct problems and less hyperactivity, whereas household chaos predicts more conduct problems (Midouhas et al., 2013).

Similarly, in other research, Flouri, Midouhas, Charman, and Sarmadi (2015) found that children with ASD and comorbid ADHD are at high risk for emotional problems but only if they are from socioeconomically disadvantaged families. The authors conclude that this is likely the result of the accumulation of risk factors. Taken together, results from these studies suggest that poverty and associated contextual risk factors like household chaos and less-optimal parenting quality contribute to behavioral problems in children with ASD. These contextual risk factors may be important targets for preventive intervention designed to mitigate the risk of escalating behavior problems among young children with ASD.

Parenting Stress

Parenting stress is a multifaceted construct that includes parents' negative emotional responses to stressors in the home, their negative views of their children, and their tendency to engage in harsh reactive parenting practices (Deater-Deckard, 2004). Parenting stress is a robust correlate of parents' broader well-being (e.g., Lavee, Sharlin, & Katz, 1996), and it may play a crucial role in exacerbating behavior problems among young children with ASD. Longitudinal research suggests that parenting stress declines across early childhood, with the highest levels of stress observed during toddlerhood (Williford, Calkins, & Keane, 2007). This developmental progression of parenting stress coincides with the normative trajectory of behavior problems that tends to peak during toddlerhood and declines during the preschool period. There are also individual differences in parenting stress across families, and higher levels of parenting stress are associated with more behavior problems and less social competence during early childhood (Anthony et al., 2005). Moreover, the association between parenting stress and child behavioral maladjustment is at least somewhat distinct from the association between observed parenting behavior and children's maladjustment.

The notion of parenting stress is especially germane to families of young children with ASD. This is because deficits in social interaction and communication are characteristic of the disorder and may heighten parenting stress. Learning of the child's diagnosis can be difficult for parents and is often the first major struggle, but autism is a lifelong condition that can lead to chronically elevated stress among parents and caregivers throughout the lifespan (Karst & Van Hecke, 2012). Results from a meta-analytic review confirm that parenting stress is quite common among parents of children with ASD (Hayes & Watson, 2013). Mothers of children with ASD report significantly higher levels of parenting stress than mothers of typically developing children (Brobst, Clopton, & Hendrick, 2008; Davis & Carter, 2008; Kiani, Reza, & Hashjin, 2014; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013; Phetrasuwan & Shandor Miles, 2009; Quintero & McIntyre, 2010; Rao & Beidel, 2009), children with Down syndrome (Dabrowska & Pisula, 2010; Eisenhower, Baker, & Blacher, 2005), children with developmental delay without autism (Estes et al., 2009), and children with chronic physical health conditions (Gupta, 2007). From the perspective of the FSM, parenting stress may be a key factor among families raising a child with ASD because it links financial hardship and other socioeconomic stressors often encountered by these families with their child's elevated behavior problems. However, we are not aware of studies that have formally tested this association in a population with ASD.

Although research indicates that the severity of the child's autism is predictive of parents' elevated stress levels (Benson & Karlof, 2009), numerous other studies also suggest that this stress is the result of the sometimes intense behavior problems that are common among children with ASD (Abbeduto et al., 2004; Blacher & McIntyre, 2006; Brobst et al., 2008; Estes et al., 2009; Hastings et al., 2005). In a study of families raising children with ASD, children's negative behavioral symptoms are the primary source of parenting stress for mothers, and mothers who report more parenting stress also report more depressive symptoms and lower levels of maternal well-being (Phetrasuwan & Shandor Miles, 2009). Contrasting results are reported by Eisenhower et al. (2005), however. In that study, mothers of children with autism report the highest levels of parenting stress relative to mothers of typically developing children or children with other disabilities even after controlling for children's behavior problems and current cognitive skills.

Poorer well-being among parents of children with ASD extends beyond parenting stress. For example, parents of young children recently diagnosed with ASD report more daily parenting hassles than parents of preschoolers without ASD (Quintero & McIntyre, 2010). They also have more parent-child relationship problems and higher levels of depressive symptoms (Davis & Carter, 2008). Notably, the most consistent predictor of these parental problems is the extent of the child's delays or deficits in social relatedness. In other research, mothers and fathers of children with ASD report three and five times more anxiety and depression, compared to norms for the general adult population (Bitsika, Sharpley, & Bell, 2013). Moreover, the pervasive nature of the defining features of autism makes it especially likely that it will have a significant impact on the lives of the individuals caring for children with ASD in multiple ways. As detailed previously, the strain associated with parenting a child with ASD may disrupt caregiver roles and undermine family relationships, as well as straining financial resources and putting constraints on work and leisure time (Glasberg, Martins, & Harris, 2006; Gray, 1998). Moreover, parents of children with ASD are more likely to experience social isolation and spousal relationship problems, especially if they also lack social support or utilize escape-avoidance coping strategies, such as avoiding others, hoping for miracles, or denying the reality of the situation (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001).

Despite experiencing substantial stress and poorer psychosocial well-being, parents of children with ASD often show markers of positive adjustment and resilience. For example, mothers of children with ASD report that they have positive relationships with their children in the sense that they do not lack emotional closeness with them or exhibit cold patterns of parent-child interaction (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009). In fact, mothers of children with ASD are more likely to report a close relationship with their child and better coping with parenting tasks than parents of children without ASD (Montes & Halterman, 2007). According to Koegel et al. (1992), the main differences between families of children with ASD and other families are that the families of children with ASD, regardless of children's age or functioning level, or the families' geographical location or cultural orientation, have more concerns regarding the well-being of their child in the future, their child's level of cognitive impairment and ability to function independently, and the likelihood that their child will be accepted in the community. These concerns translate into a greater need for parents to obtain intervention services for their child, which can be very expensive and place great financial strain on families of children with ASD.

Interventions to Support Low-Income Families

It is widely agreed that early screening and family-based intervention are effective ways to reduce morbidity and the lifetime costs associated with ASD (Corsello, 2005). Unfortunately, low-income families often face more barriers to receiving these kinds of services than their higher-income counterparts. The American Academy of Pediatrics (AAP) recently called for universal autism screening so that at-risk children can be identified in a timely way and receive appropriate services (Johnson & Myers, 2007). Despite this recommendation, young children in the United States from impoverished backgrounds face barriers to access to screening. Their families might also be less likely to engage in clinical services for ASD or participate in evidence-based treatments. For example, low-income families of children with ASD are less likely to participate in support groups (Mandell & Salzer, 2007). Unfortunately, little is known about the impact of socioeconomic stressors on participation in evidence-based treatments for ASD because research samples tend to be homogenous (Rogers & Vismara, 2008). Furthermore, studies of parent-mediated treatments for ASD have not considered the role of parent sociodemographic characteristics as moderators of the effectiveness of treatment (Lang, Machalicek, Rispoli, & Regester, 2009).

Studies of behavioral parent training among families who have young children with other behavioral and developmental disorders provide evidence that socioeconomic factors impact treatment engagement and treatment effectiveness. For example, low socioeconomic status and minority group membership predict treatment non-completion during behavioral parent training for young children with oppositional defiant disorder (Lavigne et al., 2010). A recent study of young children with developmental delays also reported that families with higher levels of cumulative risk are more likely to drop out of behavioral parent training (Bagner & Graziano, 2012). Regarding treatment outcomes, a meta-analysis of parent training shows that socioeconomically disadvantaged families tend to benefit from parent training immediately following treatment, at least when child behavior problems were severe (Leijten, Raaijmakers, Orobio de Castro, & Matthys, 2013). However, disadvantaged families benefit less from parent training at follow-up assessments, leading the authors to recommend continued support following intervention for these families. Overall, the evidence suggests that novel and nontraditional approaches to developmental screening and intervention may be warranted to meet the needs of socioeconomically disadvantaged families parenting a child with ASD.

To address the issue of reduced access to screening, Roux and colleagues launched an innovative 2-1-1 Los Angeles County Developmental Screening Project (2-1-1 LA Project; Roux et al., 2012). A primary goal of the project was to provide telephone-based developmental and autism screening to underserved low-income, ethnically diverse children living in the greater Los Angeles metropolitan area. Children were screened for autism using the Modified Checklist for Autism in Toddlers (M-CHAT) and for developmental delays using the Parents' Evaluation of Developmental Status (PEDS). The results of their telephone screening show that a sizable number of underserved children living in poverty are indeed at heightened risk for developmental delays including ASD, indicating need for further evaluation and referral for services. Specifically, over a fourth of the sample (28.2%) were deemed to be at high risk for developmental delay, and over half (56%) were considered to be at moderate-to-high risk. Moreover, of the 1605 children screened for ASD using the M-CHAT, 21.2% were at heightened risk for ASD, although this study did not use the M-CHAT follow-up interview that increases this tool's utility (Robins et al., 2014). Fortunately, the investigators were able to provide follow-up care for the majority of children in their sample, which included referral for diagnostic services, enrichment programs (e.g., early childhood education), and intervention services. The finding from the 2-1-1 LA Project suggest that nontraditional approaches to developmental screening may be warranted in reaching and identifying underserved children at-risk for developmental problems.

Family-based interventions have also been adapted to meet the needs of low-income families with children with ASD. Although there is growing evidence that evidence-based family interventions are effective in improving the cognitive functioning (i.e., IQ, language, and social communication skills) and adaptive behavior of young children with ASD (e.g., Kasari, Gulsrud, Freeman, Paparell, & Helleman, 2012; Landa, Holman, O'Neill, & Stuart, 2011), the efficacy of such interventions for children with ASD from low-resourced families is less well established. To address this gap, Kasari and colleagues conducted a randomized control trial (RCT) to compare the efficacy of two short-term (3-month) interventions for 112 preschool-aged children with ASD and their low-income and/or Medicaid-eligible families. Families were randomly assigned to one of the two interventions (a group-based caregiver education intervention and an individualized caregiver-mediated intervention). The targeted outcomes included core deficits described for children with ASD: joint play (social engagement), joint attention skills, and symbolic play. These outcomes were assessed at three time points: pretest, posttest, and 3 months posttest.

Among their many findings, Kasari et al. (2014) provide compelling evidence for the efficacy of caregiver-mediated intervention for young children with ASD from low-resourced families. Although all children showed improvements in their joint engagement with others and their ability to initiate joint attention with a social partner, children in the caregiver-mediated intervention group exhibited significantly greater improvement in these skills. Moreover, children in the caregiver-mediated intervention were more likely to maintain gains in joint engagement over time (however, children in both groups maintained their gains in initiating joint attention skills). With regard to play skills, children in the caregiver-mediated intervention group exhibited greater improvement in symbolic (but not functional) play skills than children in the caregiver education intervention. Kasari and colleagues suggest that further work is needed to evaluate whether low-income children with ASD generalize these gains to other areas of functioning or maintain these skills over a longer period of time.

The intervention conducted by Kasari and colleagues provides an excellent example of relatively straightforward adaptations to established caregiver-mediated intervention approaches to meet the needs of low-income families. Specifically, the interventions were delivered in the families' homes and neighborhoods, and efforts were made to adapt to families' schedules by conducting sessions at night or on the weekend. In addition, the intervention sessions centered around everyday activities in the home setting that were identified by families as important. Although this approach goes a long way toward meeting the needs of low-income families of young children with ASD, additional therapeutic efforts could focus on offering support for the financial hardship, parenting stress, and associated concerns that often occur in these vulnerable families. These additional efforts would address the recent call to integrate aspects of parent and family functioning into treatments for ASD (Karst & Van Hecke, 2012). The remainder of this chapter describes the Family Check-Up (Dishion et al., 2008), a family-based intervention approach that could be adapted to meet the unique needs of families of young children with ASD.

The Family Check-Up

The Family Check-Up (FCU) model was originally developed to assist youth and their families during the transition to adolescence (Dishion & Kavanagh, 2003). The FCU has since been adapted for several other populations, including low-income families with toddler-aged children (Shaw, Dishion, Supplee, Gardner, & Arnds, 2006). The FCU for toddlers is a home visitation program that combines an emphasis on parenting and the family context that is often found in other home visiting programs for infants (e.g., the Nurse-Family Partnership; Olds, 2006) with a focus on problem behaviors that often occur during the "terrible twos." The FCU is led by a parent consultant; these consultants are typically masters-level mental health professionals with training in child development and parenting interventions.

The FCU involves at least three sessions that typically take place in the family's home. The first session is called the "get-to-know-you" visit where rapport is established between the parent consultant and the child's caregivers. The child's caregivers are asked to share information about their family and their child, including strengths and concerns. The second session is a formal assessment of multiple aspects of the family context, such as family well-being, parenting, and the child's temperament and behavior. Each aspect being assessed includes multiple subdomains. For example, subdomains within the family well-being domain include daily hassles, parental emotional well-being, parenting confidence, and the quality of the relationship between the child's parents and their significant others. For each subdomain, the family's score is classified along an axis ranging from "strength" to "needs attention" based on established norms for the measures. The third session is focused on providing feedback to the parents based on the findings from the assessment session. During this session, the parent consultant uses techniques informed by motivational interviewing (Miller & Rollnick, 2002) to enhance parents' motivation to address areas of functioning that are classified as needing attention or that the parent identifies as areas of concern. The parent consultant also guides caregivers in setting goals and addressing barriers to meeting goals. In some cases, additional visits with the parent consultant are scheduled to help parents meet their goals. For instance, additional visits might provide training to help parents address problematic child behaviors or address aspects of parental psychosocial functioning that could interfere with effective caregiving, such as a low level of social support, parental depression, or conflict between caregivers. The FCU is informed by a health-maintenance model of prevention, and parent consultants continue to visit families on a yearly basis using similar procedures.

Two RCTs provide evidence for the efficacy of the FCU among low-income families with a toddler-aged child. For both trials, mothers and their toddlers were recruited from the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), and families receiving the FCU were compared to demographically similar families in a no-treatment control condition. The first trial was conducted in Pittsburgh, PA, and the sample was limited to families with toddler-aged boys. The results of the first trial show that, relative to families in the control condition, families in the FCU group exhibited improvements in parental involvement and positive parenting and a reduction in child conduct problems after the first 2 years of the program (Gardner, Shaw, Dishion, Burton, & Supplee, 2007; Shaw et al., 2006). The second trial included families of boy or girl toddlers recruited from multiple sites (Charlottesville, VA, Eugene, OR, and Pittsburgh, PA). The results of the second trial also show that the FCU is linked to reductions in multiple forms of child behavior problems, including conduct, emotional, and co-occurring problems. However, the magnitude of the effect size for the reduction in problem behaviors was relatively modest ($d = 0.23$; Dishion et al., 2008). Furthermore, FCU effects on problem behavior were mediated by decreased maternal depression and increased positive parenting (Shaw, Connell, Dishion, Wilson, & Gardner, 2009). What is striking is that both trials led to reductions in child behavior problems even though families randomized to the FCU condition averaged less than four sessions per year.

Subsequent investigations of data collected in the FCU multisite trial have focused on moderators of treatment outcomes and longer-term impacts. The FCU was equally effective for families facing several poverty cofactors such as young parenthood (Gardner et al., 2009). In addition, the program was more effective for families with less educated parents. Follow-up of this sample into elementary school has documented parent-reported reductions in oppositional behavior problems from age 2 through 5 years and teacher-reported reductions in these behavior problems at age 7.5 years for children in the FCU group (Dishion et al., 2014). Moreover, children from intervention families who engaged in multiple check-ups across early childhood showed the steepest declines in oppositional behavior. When children were in elementary school, families in the FCU group also reported more use of formal (e.g., mental health counseling) and informal (e.g., help from relatives) services than families in the control group, and this effect was especially apparent among the families with the lowest socioeconomic status (Leijten et al., 2015). The investigators attribute this effect to the FCU's emphasis on enhancing family members' awareness of the difficulties they are facing and increasing their motivation to seek help in the community.

In summary, the FCU is a time- and cost-effective prevention program targeting child behavior problems and the family context that has been shown to be effective with multiple populations, including low-income families with toddlers. The rigorous research on the FCU supports its classification by the US Department of Health and Human Services as one of seventeen evidence-based early childhood home visiting service models (Avellar et al., 2014). Because the FCU is a flexible approach, it would be relatively straightforward to adapt this approach to meet the diverse needs of low-income families with young children with ASD. Families could be identified for the FCU at the time of the ASD diagnosis or soon thereafter, and a mental health professional (the parent consultant) could meet with the family to establish rapport and assess domains relevant to coping with the ASD diagnosis. These domains could include the family's financial resources, sources of social support, the parents' stress and broader well-being, as well as aspects of the child's functioning, including behavior problems. Then, the parent consultant could meet with the family on a separate occasion to share feedback on the family's functioning within these domains compared to established norms. Each family would have a unique profile of strengths and domains that merit further attention, and sources of strength could be highlighted by the consultant as resources for the family to build upon. Strategies from motivational interviewing could be utilized by the parent consultant to help the parents identify goals to address domains that merit attention. For example, if parenting stress is elevated, the parent consultant could help the parents explore how elevated stress may undermine their efforts to help their child, and the consultant and parents could work together to identify goals related to alleviating stress.

An adaptation of the FCU for families with young children with ASD could also be geared toward helping families explore the pros and cons of the various available treatment options for ASD based on the family's unique profile of strengths and areas of concern. This approach would fit with the recent emphasis on integrating aspects of parent and family functioning into treatments for ASD, and it would also help families process the potentially overwhelming array of treatment approaches (Karst & Van Hecke, 2012). As noted above, because the FCU is informed by a health-maintenance model of prevention, parent consultants continue to visit families on a yearly basis. For families with young children with ASD, the yearly check-up could be especially helpful as parents, the child, and other family members continue to adapt to the diagnosis and face additional transitions and stressors.

Summary and Conclusion

The family stress model describes how financial hardship impacts parents' functioning and children's maladjustment, and the processes leading from hardship to difficulties within the family milieu are especially salient to at-risk families with young children. Moreover, financial hardship and parenting stress are especially common among families with young children with ASD. Research is needed to elucidate how hardship and stress unfold from before the first symptoms of ASD emerge through the point of the ASD diagnosis and subsequent adaptation to the diagnosis. Moreover, modifications are needed to screening and intervention approaches to better meet the needs of low-income families with young children with ASD. Prevention approaches such as the Family Check-Up could be adapted to meet these families' needs. Providing such services could improve families' functioning and help them to better meet the needs of young children with ASD.

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6

Culture, Stigma, and Intersectionality: Toward Equitable Parent-Practitioner Relationships in Early Childhood Special Education

Susan D. Holloway, Shana R. Cohen, and Irenka Domínguez-Pareto

Abstract

Parental involvement in the selection and implementation of children's educational services is one of the most important tenets of the Individuals with Disabilities Education Act. However, parental involvement may be less welcome and less effectively supported in families from non-dominant groups (i.e., those with lower social status as a result of their race, ethnicity, social class, or immigrant status) compared to those with more resources. In this chapter, we explore several important conceptual tools related to diversity and stigmatization that support families' equitable access to special education services for their young children. After reviewing how culture has typically been defined in the field of early childhood special education (ECSE), we introduce the critical sociocultural perspective and describe its clear implications for more effective parent-practitioner relations. We subsequently explore the notions of individual and institutional stigma, and show how early childhood practitioners can identify stigmatizing experiences that children with disabilities and their parents may have encountered. We then address the experience of families who are stigmatized for additional reasons other than the disability status of a family member, showing how children and families are located at the intersection of overlapping social identities rather than situated within a single homogenous racial, ethnic, or gender category. We conclude the chapter with specific suggestions for service providers to assist them in addressing stigmatization of individuals with autism, particularly those who are members of non-dominant groups, in the hope of moving the field of ECSE closer to its promise of a free, appropriate, public education for all.

Parental involvement in the selection and implementation of children's educational services is one of the most important tenets of the Individuals with Disabilities Education Act (IDEA) (Trainor, 2010b; Turnbull, 2005). However, this emphasis on parents' advocacy has disadvantaged parents

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_6

whose lack of economic, social, and educational resources diminishes their access to special education systems or whose prior experiences have eroded their trust in the efficacy of the services (Kalyanpur & Harry, 1999; Trainor, 2010a; Valle, 2009, 2011; Wang, Mannan, Poston, Turnbull, & Summers, 2004). Parents' ability to be effective advocates can also be hindered by unwarranted and inaccurate stereotypes that practitioners may hold regarding a family's sociocultural background (Domínguez-Pareto, 2015; Ong-Dean, 2009).

As a consequence of these social dynamics, parental involvement may be less welcome and less effectively supported in families from non-dominant groups (i.e., those with lower social status as a result of their race, ethnicity, social class, or immigrant status) compared to those with more resources (Baquedano-López, Alexander, & Hernandez, 2013; Cooper, Riehl, & Hasan, 2010; Lightfoot, 2004). For example, the *Los Angeles Times* reported that in 2010 the California Developmental Services Department spent an average of $11,723 per child on White children but only $7,634 on Latinos and $6,593 on Black children (Zarembo, 2012), a disparity that can only be understood by attending to the ways in which services are dependent on racial/ethnic and class status. These disparities persist despite the formation of a Senate Select Committee to address the issue of inequitable state funding (Leigh, Grosse, Cassady, Melnikow, & Hertz-Picciotto, 2016).

In this chapter, we explain some important conceptual tools that support productive reflection regarding issues of cultural diversity and equitable access to services. Toward that end we introduce three sensitizing concepts – culture, stigma, and intersectionality – and illustrate how these concepts can help early childhood special educators design and implement more equitable and effective practices for families from diverse sociocultural backgrounds rearing young children with ASD. Our goal in introducing these ideas is to engage the readers in a dialogue to stimulate reflexivity, the practice of reflecting on one's own practice and sociocultural position (Bourdieu & Wacquant, 1992; Giddens, 1991).

We begin with a discussion of how culture has typically been defined in the field of early childhood special education (ECSE) and introduce an alternative, more nuanced approach that has clear implications for effective parent-practitioner relations. We then describe the concepts of stigma and intersectionality, and explore how these notions can help ECSE professionals understand the experiences of families from non-dominant groups who care for a child with ASD. We conclude the chapter with specific suggestions for addressing stigmatization toward members of non-dominant groups in the hope of moving the field of ECSE closer to its promise of a free, appropriate, public education for all (Free Appropriate Public Education under Section 504, 2010).

Understanding Culture: The Perils of a Conventional Approach

In the past four or five decades, the field of ECSE has increasingly focused on understanding the diverse cultural pathways traveled by families caring for a child diagnosed with ASD or other intellectual disabilities. However, the conception of culture often endorsed in this literature has unintentionally resulted in a number of misrepresentations and distortions. One significant problem has been a tendency to make essentializing overgeneralizations about particular groups. The term "essentializing" refers to "the assumption that a group has one or more defining features characteristic of all group members" (Gjerde, 2004, p. 142). In this conventional approach, the individuals within a particular ethnic, racial, or geographical group are all assumed to hold similar values and to engage in common activities "because of their culture." This approach is problematic for several reasons. For one thing, it relies on stereotypes rather than acknowledging the wide diversity among individuals and across particular subgroups in terms of language, histories, and ideologies. So, for example, Mexicans are frequently described as "family-oriented" and therefore assumed to be supported by a large network of loving and attentive relatives, when the reality is far more complex (Abrego, 2014; Baca Zinn & Wells, 2005; Cohen, Holloway, Domínguez-Pareto, & Kuppermann, 2013). Ultimately, this tendency to make assumptions about a family member's beliefs or behaviors based solely on membership in a particular sociocultural group can draw a practitioner's attention away from the family's actual experiences and the sources of support they may have as well as ones they may lack.

Another problematic aspect of this essentializing approach is that it often leads members of non-dominant groups to assume that only other groups "have culture." If ECSE practitioners are encouraged to think in terms of sweeping generalizations about groups other than their own, and if they themselves are members of a dominant group that is not described in a similarly stereotypical way, it can be difficult for them to recognize that their own community also shares certain beliefs or practices that are culturally constructed. As a consequence, these practitioners may promote their own ways of thinking, doing, and talking as the "normal" or "common sense" ways without reflecting on the socially constructed nature of all human practices (Geertz, 1983). This is particularly true if an educator's position is in agreement with current early intervention treatments as well as the accepted language and beliefs of those in the early intervention field. Without denying the contribution of scientific knowledge and evidence to the effectiveness of treatments, we note that professional ways of thinking and organizing the world are also socioculturally constructed and are subject to historical change (Foucault, 1972; Grinker, 2007; Kalyanpur & Harry, 1999). In any case, we would argue that practitioners can be more effective if they are careful to recognize the beliefs and practices that are available and salient to members of their own sociocultural group(s) (Derman-Sparks & Ramsey, 2011).

A third drawback of the conventional approach to culture is that it positions each individual as a member of a single culture and ignores the fact that everyone participates in "multiple cultural categories" (Gjerde, 2004, p. 144). For example, in addition to being of Mexican origin, a parent may participate in other sociocultural contexts where members share strongly held beliefs and common practices, whether it be a religious group, an activist organization, or an occupational setting. Furthermore, a person's participation in various cultural settings typically changes over time, leading to concomitant changes in beliefs and practices. For example, a parent may pick up skills or perspectives from working in her child's preschool setting that she later implements in rearing a younger sibling. In that case, it would be important for an early interventionist to appreciate the ways in which the parent's earlier exposure to the ECSE milieu contributes to the approach that she may now take toward intervention.

Last, these conventional perspectives on culture often construe customs as "age-old" and unchanging, not recognizing that individuals adapt cultural practices to respond to opportunities or barriers that parents and children are encountering in their daily lives. For instance, suppose a Mexican immigrant parent is reluctant to let her toddler participate in a group setting that offers an opportunity for peer social interaction. A conventional approach to culture may lead a case manager to worry that this child is being deprived of this opportunity because of a "traditional" Mexican belief that children should interact with family members instead of strangers. But the reality may be far more complex. If the family lives in a dangerous neighborhood, for example, the parent may decide that it would be safer to encourage interaction between the young child and her cousins who live nearby rather than participate in the program. The parent herself may regret that the child is missing a good opportunity to play with same-age peers in a group setting but draws upon her cultural knowledge to find a safer way of supporting her child's social skills in her particular environment. A case manager who reflects on trade-offs in a situation such as this may see the wisdom of the parent's solution rather than blame her actions on "cultural" beliefs.

A Critical Sociocultural Approach to "Culture"

> Imagine cultural pathways themselves as consisting of cultural activities that we "step" into – engage in – and walk alongside throughout life. (Weisner, 2002, p. 276)

> Sociocultural understandings move from an understanding of culture as something that ethnic groups share to culture as systems of meanings and practices that evolve between families, the medical and service community, and larger political, social and economic worlds. (Skinner & Weisner, 2007, p. 310)

To conceptualize culture in a way that avoids the pitfalls described in the previous section, we sketch out a critical sociocultural approach to working with socioculturally diverse families. The fundamental elements of this approach are introduced in the quotations at the beginning of this section. First, and possibly most important, we call attention to culture as systems of meaning that are constructed when individuals participate in common activities over time (Nasir & Hand, 2006). In other words, people who engage in common activities are thereby constructing and reconstructing the norms, meanings, and perspectives that constitute culture (Lave & Wenger, 1991; Wenger, 1998). These authors maintain that culture is "transmitted" not by handing down "lore" from one generation to the next but through the ongoing actions of participants. As a result of their activity in the community, new members move from being peripheral "apprentices" to full participants able to access the language, ideology, and values of the community. By taking a critical sociocultural approach, ECSE practitioners can develop more nuanced understandings of families from diverse communities than they might if they relied on global, "essentializing" ideas about culture.

In addition to facilitating a clearer understanding of families' cultural practices, the critical sociocultural approach is also a powerful way to understand the "culture" of the ECSE system. As Lave and Wenger (1991) discuss, this idea of "community of practice" applies to professional participants in institutional settings like schools or hospitals who interact with each other over time to create acknowledged routines, specialized language, and associated beliefs and values. Although Kalyanpur and Harry (1999) made this point many years ago about the "culture" of special education, it has not, in our view, received the attention it deserves. ECSE professionals are cultural insiders who share certain familiar ways of talking, thinking, and doing. As cultural insiders, it is easy for professionals to take for granted that these customary practices are "normal" or "natural" rather than community-specific. ECSE cultural insiders may be less aware of the effort and time it takes for parents or other outsiders to acquire the "shared repertoire" used by members of the ECSE culture (Wenger, 1998). Moreover, if early childhood special education is seen as a community of practice co-constructed by practitioners and families, it becomes clear how important it is to acknowledge and build on parents' knowledge, skills, and values.

While the notion of a "community" may initially seem to convey an image of harmony and equality, communities of practice do not necessarily allow access to all who wish to participate nor do they assign the same status to all members of the community. Rather, individuals within communities of practice are associated with differential access to power and social status, even in groups that purport to be nonhierarchical, group-oriented, or "collectivistic" (Holloway, 2010). Professionals who view a particular cultural practice as a departure from what is "right" or "normal" may find it difficult to engage with families from groups that are associated with that practice (e.g., Lightfoot, 2004; Valencia & Black, 2002). For instance, a parent whose interactions with educators are perceived as overly confrontational during an IEP meeting may be perceived by an ECSE practitioner as being a disrespectful or incapable advocate (Lareau & Munoz, 2012; McHatton & Correa, 2005), and these difficult interactions may impede the parent from accessing services to which the family is entitled (Domínguez-Pareto, 2015; Ong-Dean, 2009).

Practitioners sensitive to power inequalities between parents and ECSE practitioners can ask themselves various questions throughout the intervention process. *How do I expect parents to communicate their opinions? How much have I tried to listen to other people's points of view? Are there parents I feel more connected to than others? If so, are there class, race, and other background characteristics that we share? If so, what can I do to learn more about those I feel less connected to?* By engaging in self-interrogation, ECSE practitioners can become more conscious of the subtle but powerful messages concerning social status and membership that may be conveyed by cultural "insiders" to "outsiders."

Another powerful implication of using a critical sociocultural approach is that it helps us understand that parents are not simply enacting "traditional" values and practices. Rather, they also have agency, and as agentic, self-reflective individuals, they can also modify cultural practices of child-rearing (Shore, 1996). As we saw earlier in the example of the mother who came up with an alternative to support her toddler's social skills, parents are continually adapting cultural practices in light of the resources they have access to and the daily challenges they experience. In particular, low-income parents from non-dominant groups often use creative and powerful methods to ensure their children's survival and to achieve institutional transformation in the face of many challenges (Collins, 1994). While the work of practitioners is often focused on the development of very specific child competencies, and justifiably so, parents' actions in this regard can be best appreciated when an interventionist recognizes the full scope of powerful, time-consuming, and essential "motherwork" that goes into being an effective parent.

ECSE practitioners who acknowledge parental agency may better understand why a parent may choose not to accept recommended practices. By acknowledging that a practice may conflict with other culturally constructed values or with conditions in the local context, practitioners may also better understand how and why parents within the same community sometimes engage in divergent practices. Again, it is apparent that effective practice involves taking the time to listen to parents' perceptions and to understand their rationale for the decisions and choices they have made.

In order to understand fully the experiences of socioculturally diverse families within the ECSE system, we now turn to the concept of stigmatization. In particular, we seek to describe how stigmatization of ASD is expressed in variable ways toward families depending on their membership in particular sociocultural groups as well as how it is differentially stigmatized within socioculturally diverse communities.

Understanding Stigma: Enacted and Structural Stigmatization

> …autism is really two illnesses. It's all the symptoms we are familiar with, plus the stigma and exclusion that society attaches to it… The paradox is that handicaps that are invisible can actually create more burden, stigma, and shame than those that are easily seen…. (Grinker, 2007, pp. 68–69)

The notion of stigma refers to the assignment by society of inferior status and negative regard to individuals or groups with particular conditions or attributes (Goffman, 1963; Link & Phelan, 2001). Stigma is not a characteristic of the individual but a process by which individuals and societies devalue others and discriminate against them. Individuals experience explicit stigmatization, also referred to as enacted stigmatization, through overt discrimination as well as avoidance or shunning. In spite of significant advances in public understanding of intellectual disabilities, families of children with ASD still confront enacted stigmatization, often on a daily basis. Because their condition is "invisible," individuals with autism and their families are subjected to enacted stigmatization to a greater degree than individuals with visible disabilities such as a physical impairment that requires the use of a wheelchair. In the course of conducting our research, we have spoken with many parents of children with ASD about their feelings of isolation and anger when strangers, friends, or family avoid their child or make accusatory or shaming comments about the child's behavior (Cohen et al., 2013; Cohen & Miguel, 2018; Domínguez-

Pareto, 2014). Not surprisingly, caregivers of children with disabilities who feel stigmatized are more likely to experience emotional distress, social isolation, depression, and suicidal thoughts than those who do not feel stigmatized (Gray, 1993; Green, Davis, Karshmer, Marsh, & Straight, 2005).

A second type of stigma, structural stigma, refers to societal-level conditions and institutional policies that constrain the opportunities, resources, and well-being of those who are stigmatized (Link & Phelan, 2001). Powerful members of these institutions create conditions that stereotype and discriminate against others based on physical, mental, or social characteristics. For instance, if early childhood professionals do not accommodate the sensory sensitivities of children with ASD, they are not only creating gaps between the classroom experience of children with disabilities and those without them but also signaling that the former group's needs are less relevant or important than the needs of the latter group.

Media representations of individuals with ASD can be another source of structural stigmatization. Some media accounts use "stigmatizing cues" in describing people with ASD, inappropriately emphasizing irrelevant social skill deficits or physical characteristics (Holton, Farrell, & Fudge, 2014). Media reports on the developmental origins of health and disease have tended to exaggerate the implications of animal research, minimize the extent to which multiple causal factors are implicated in a child health outcome, focus on maternal factors and downplaying paternal contributors, and ignore the role of social factors such as discrimination and poverty on the intrauterine stressors that have adverse effects on children (Richardson et al., 2014). By highlighting negative and stereotypical aspects of autism, and conveying inaccurate information about the scientific understanding of its origins, these stories contribute to a distorted perception of particular individuals and conditions (Corrigan & Miller, 2004).

Yet another form of structural stigmatization involves the perpetuation of professional discourses that have long been disproven by reputable research. For instance, although the notion that autism is caused by "refrigerator mothers" has been thoroughly discredited, it is still endorsed by individual health service providers (Grinker, 2007). With respect to mental health in general, long debunked theories and stigmatizing assumptions remain at the individual and institutional level, as noted by Mukolo and colleagues: "The institutional context for stigmatization goes far beyond attitudes of professionals in direct contact with consumers… but is reflected also in policies and practices of public institutions that result in the devaluation and discrimination of participants in the mental health sector" (Mukolo, Heflinger, & Wallston, 2010, p. 8).

Practitioners can support families by recognizing that family members may have internalized the stigmatizing narratives circulating in popular discourse about ASD and its causes. Even though a professional may not blame a "refrigerator mother" for causing her child's autism, the complex etiology of ASD makes it likely that parents and others may continue to speculate about the family's role in creating the condition. Even the emerging evidence of a genetic component to ASD can intensify the sense of responsibility attributed to a parent, in spite of the fact that this family "contribution" was not known or controllable by the parent.

Stigmatizing narratives about the role of the parent in "causing" a child's ASD are more available or salient to members of certain sociocultural communities. For instance, Grinker (2007; Grinker et al., 2015) has explored some common narratives or "folk" theories about autism that circulate among some Korean and Korean-American families, including the view that ASD can be attributed to poor parenting and inter-spousal conflict. To the extent that the parent of a child with ASD might internalize these stigmatizing attributions for ASD, she may also experience self-stigma, accepting the social rejection as legitimate or refraining from seeking treatment for her child. However, Grinker also notes that these stigmatizing views are increasingly less common among the younger generation of Koreans who have had more exposure to scientific discourses about the causes of the condition.

This fact prompts us to remember that cultural practices are in constant flux as members of a community constantly experience new conditions and access new sources of information.

It should also be noted that professional sources characterizing parent-professional relationships rarely mention the impact of stigmatization and related discriminatory treatment that is a daily reality for many families. In this section we have argued that by identifying the stigmatizing experiences that individuals with ASD and their parents may have encountered, early childhood providers can better understand parents' challenges and be more aware of their successes (Baquedano-López et al., 2013). By noticing and valuing family experiences, service providers and educators can open the door to the development of strong, positive relationships with parents of young children receiving ECSE services (Dunst, Trivette, & Hamby, 2007; Oono, Honey, & McConachie, 2013; Trivette & Dunst, 2000). We also wish to underscore the need to consider individuals from groups who are stigmatized for additional reasons other than the disability status of a family member. For instance, a woman who has a child with ASD and is Black may be treated differently at an interpersonal level and may encounter more barriers at a structural level than a White father of a child with ASD or than a parent who is not a member of a stigmatized racial group. To fully understand this dynamic process, it is helpful to understand the construct of intersectionality, which we introduce in the next section.

Understanding Intersectionality: Intersecting Categories of Stigma

> There is no such a thing as a single-issue struggle because we do not live single-issue lives (Lorde, 2007, p. 138).

The notion of intersectionality is a key analytic tool in sociology and gender studies that has been relatively underutilized in the fields of education and psychology (Crenshaw, 1989; Ferree, 2010). Intersectionality refers to the notion that individuals are located at the intersection of multiple social identities associated with race, social class, gender, sexuality, ethnicity, nation, disability, and age. These dimensions form mutually constructing features of social organization and potentially of oppression (Collins, 2000). The concept of intersectionality sheds light on the experiences of individuals with multiple stigmatized identities particularly by showing how these identities can't be understood as two or more separate realms of experience; rather, when experienced together they afford a qualitatively different experience that is greater than the sum of the parts. Through this construct, research has been able to describe how people from one identity group (e.g., a particular racial, gender, class, or disability status) have widely different experiences depending on their membership in other groups as well. As Moore argues, it is more effective to understand "the experiences of individuals who lie at the intersection of single dimensions of multiple categories" than to "compare respondents across race or gender categories" (2011, p. 4). These categories or identity statuses take meaning from each other as they intersect in the case of an individual.

The construct of intersectionality is particularly apt as a lens for understanding the experiences of families who have a child with a diagnosis of ASD. Parents who have a child with ASD and who are members of working class or non-dominant racial/ethnic groups are "triple outsiders" in the sense that they are positioned outside the ECSE culture, outside the group of families with typically developing children, as well as outside the dominant US White middle class (McHatton & Correa, 2005). A recent study by Fountain and Bearman (2011) illustrates clearly how intersectional stigma affects parents of children with ASD who are also members of non-dominant ethnic/racial groups. The authors found that subsequent to the passage of California anti-immigration policies limiting access to social services by undocumented immigrants, the number of ASD diagnoses waned among this population. In this case, discriminatory social policies limited access to services for individuals who were positioned at intersecting dimensions of ability status, class, immigration history, and country of origin.

Yet another instance of stigmatization and intersectionality can be seen when professionals respond differently to mothers who have a child with ASD than they do to fathers. It is common for the participation of fathers to be particularly noted and praised by early childhood special educators despite the fact that mothers are far more likely than fathers to manage their children's early educational experiences across ethnic/racial groups and class levels (Lareau, 2000). For instance, Domínguez-Pareto (2014, 2015) found that the activities of Spanish-speaking immigrant mothers who participated in special education advocacy trainings were perceived by program staff as "natural" and were not a source of praise, whereas participation by fathers was celebrated and held up as a sign of exemplary parenting. Thus, participatory fathers who were unusual among their own gender group were accorded institutional goodwill, whereas mothers who participated at the same level did not receive these accolades because they were not unusual among women, even though they too may have sacrificed a great deal or put a great deal of energy into their participation. As the concept of intersectionality would have us understand, however, gender-based expectations do not inevitably lead to the over-recognition of fathers. Within other groups, active involvement by fathers may be overlooked or misunderstood. For example, a study of Haitian immigrant families found that teachers consistently expected mothers to participate at the school even though it was fathers who most often attended teacher-parent meetings because of their higher level of spoken English (Doucet, 2011). Within this group, fathers' engagement was not recognized or appreciated, even though they were frequently the more active participants in school-based involvement activities.

In summary, we have argued in this chapter for a critical sociocultural approach that includes awareness of power and power inequalities within communities and between families and practitioners. We have also noted that the specialized norms, language, and meanings salient in the early childhood special education system constitute a socially constructed community of practice that parents need to grasp in order to act as effective cultural insiders. We have introduced the concept of structural stigmatization to capture the idea that discriminatory conditions can be instantiated not just at the level of individual beliefs and interactions but also at a societal level through policies, institutions, and programs. Lastly, we have shown that the process of stigmatization occurs not only through interpersonal interactions between family members or individuals with ASD and dominant outsiders but also how stigmatization is a function of multiple intersecting social categories, including gender, race/ethnicity, and social class.

We have also suggested that educators use these constructs to examine their personal heritage, membership in a professional community of practice, and institutionally rooted status vis-à-vis the families they are working with. By engaging in reflexive practice, ECSE practitioners can also identify the ways in which families caring for a child with ASD are themselves positioned at a nexus of cultural and class dimensions and are multiply impacted by positive forms of professional and informal support as well as intersectional processes of stigmatization and discrimination. In the final section of our chapter, we provide additional suggestions for how practitioners and policy makers can build on these nuanced understandings of culture, stigma, and intersectionality to strengthen programs and practices.

Implications for Service Providers

We begin by suggesting strategies for early childhood special educators, interventionists, and other service providers to use with families from non-dominant backgrounds to minimize stigma and promote true partnership between parents and practitioners. We then identify broader policy changes to improve the way the ECSE system functions for non-dominant families and their children.

Reflect on the possible consequences of one's own personal position. We encourage ECSE practitioners to reflect on their membership in various sociodemographic categories, including race, disability/ability status, country of origin, and gender, and examine how experiences in those groups shape their perceptions about family dynamics in general and ASD in particular (Ayers, 2010; Banks, 2013). Some questions to ask oneself include the following: *Do these personal experiences sensitize me to certain parent behaviors and not others? Do my personal experiences lead to evaluative or emotional responses that may be unwarranted? Or do they help me be more empathic?* By reflecting upon their own cultural beliefs and the sources of those beliefs, practitioners can avoid stigmatization and explicit or implicit discriminatory treatment of families.

Reflect on the possible consequences of one's professional training and experiences. By recognizing that the norms and practices of the early childhood special education system themselves constitute a complex cultural world (Kalyanpur & Harry, 1999), practitioners can be more conscious of how to support parents to become cultural "insiders" but also to be respectful of those who choose not to be. In addition, by considering parent-professional partnerships as a community of practice, practitioners can identify parents' strengths and knowledge that should be incorporated into practices involving that family. By reflecting on the study and experience that it took them to learn the language, attitude, assumptions, and values of the early childhood special education profession, practitioners may feel less evaluative of parents who do not appear to have internalized these same norms.

Engage in antibias teaching practices in ECSE classrooms. We encourage teachers to implement an antibias curriculum in their classrooms with children and their families. Antibias education is an approach that supports individual children and their families with the goal of affirming their sense of agency and acknowledging their social status (Derman-Sparks & Ramsey, 2011; Kuh, LeeKeenan, Given, & Beneke, 2016). Within an antibias approach, teachers are encouraged to reflect on their own practice, on the materials and books they use, and on the context where they teach in order to evaluate which cultural communities are privileged and which ones are silenced. They are also encouraged to identify "entry points" for teaching about individual differences, modeling reflective practices, and responding to children's questions and comments in an emergent setting during a typical day (Banks, 2013; Derman-Sparks & Ramsey, 2011). For example, a child may ask for a turn on the "wobble cushion" used by a classmate with a diagnosis with autism. The teacher can acknowledge the question and encourage a conversation with the class about various ways that help each of them to pay attention and learn during group time. Similarly, providers can listen to families' concerns and elicit their experiences about addressing bias. For example, if a parent is worried that her child may be teased for flapping his hands when he gets excited, the teacher can respond by explaining how she conducts discussions in the classroom regarding emotions and can ask the parent to describe personal experiences that have helped family members and friends become comfortable with the child's modes of self-expression.

Observe and identify family goals, strengths, and practices. Practitioners can identify beliefs and practices that may be salient within particular communities, as well as learning about the beliefs, routines, and experiences of the individual families in the community. Rather than assuming that members of a particular class, ethnic, or racial group share similar values, it may be helpful to learn about the individuals' narratives about parenting and about disability. Furthermore, practitioners can learn to recognize and work constructively with parents who express resistance or disagreement with certain therapeutic or educational goals. They can also recognize the forms of stigmatization that a family may be encountering from members of their own community and work with practitioners to identify strategies for alleviating stigma and promoting acceptance within their community.

Provide documentation and data about the child to the parents in a nonjudgmental way. The purpose of documentation is for the practitioner to learn, share, and gain insight into how a child learns. The effective use of documentation has been thoroughly illustrated in the writing of educators associated with the Reggio Emilia school system, who provide resources and training for teachers not only in how to undertake this documentation but also how to interpret and review it with colleagues and parents (Rinaldi, 1998). Practitioners working with parents of children with ASD can draw upon the Reggio Emilia model to assess how well the child responds to a specific intervention and also to identify the child's strengths and interests. For example, practitioners can document a first attempt of a child writing his name and praise the child for his effort in approximating certain letters. The teacher can continue documenting progress as the child develops his fine motor skills and begins to write his name using an appropriate hand grip. This documentation of the child's fine motor development can be shared with parents to collaboratively address developmental challenges (Gilman, 2007).

Encourage parents to provide observations and documentation to support collaborative lesson planning. Some parents may not see documentation as a part of their role or feel unsure how to go about doing it. Educators can offer the opportunity and can collaborate with parents on how to take notes or photographs, save artifacts, and otherwise share their observations of the child engaging in play at home. Parents can use these observations to make practical suggestions that would benefit the child in the classroom or for the adaptation of the child's IFSP or IEP goals. When parents' observations and opinions are valued, the power dynamic becomes more equal, and there is less opportunity for stereotyping and stigma (Link & Phelan, 2001). Parents and teachers can also use this extensive documentation to collaborate in developing activities based on the child's interests that can be implemented at home and at school and that promote the child's educational goals.

Open up space for parents to shape pedagogical and therapeutic practices. As we have seen, professional discourses and knowledge have shifted historically and thus must always be a target of reflection by practitioners who draw upon them. Furthermore, there are often multiple pathways to achieve a desired goal, and it is important to identify pathways that are viewed as legitimate by parents. Attending to parents' views in a truly equitable manner requires the practitioner to engage in the reflexive practices that we have discussed earlier in this chapter. However, if parents choose not to become engaged in the activities suggested by the practitioners, we believe it is crucial that they not be stigmatized or labeled as "noncompliant" or "uninvolved." Even if they receive genuine offers to participate, ample guidance and information, and attention to their goals and strengths, parents may choose to take other measures to promote their child's development, or their life circumstances might force them to prioritize issues of survival and sustenance that don't afford time or space for other forms of participation. Valuing different ways in which parents engage, and utilizing the practitioner's expertise and knowledge to support/promote the types of child engagement and learning that parents do with their child, even if it is outside the practices recommended by professionals, is a fundamental way to relate to parents in a more socially equitable way.

Identify sources of family "capital." Parents with ample community resources and supportive networks of friends and family are generally more able to effectively advocate for their child than those who are socially isolated (Benson, 2012; Trainor, 2010a, 2010b). However, as we have shown in this chapter, the experience of enacted stigma can undermine parents' sense of competence and discourage them from persisting with suggested interventions. Practitioners can help parents identify positive and constructive sources of support available to assist them in caring for their child as well as providing emotional support. By the same token, practitioners can also help parents identify stigmatizing experiences and minimize their negative impact. Participation in supportive social networks may also ameliorate feelings of social isolation and depression caused by stigmatizing experiences (Gray, 1993; Green et al., 2005). This may be particularly important when a parent is subjected to stigma from family or community members with greater social power.

Implications for Policy

Improve early childhood special education programs to include reflexive practice, knowledge about systemic inequalities, and a conceptual understanding of intersectionality and stigmatization. ECSE credential programs and professional development programs for early interventionists should utilize the practices highlighted above to help practitioners become aware of their own biases, learn to reflect on their beliefs about ASD and education, and examine how they may be different from those beliefs of the families whom they serve. Teacher education programs should also help students acquire historical information about systemic inequalities affecting early childhood special education. Coursework should feature open discussions of stigma and discrimination when examining the applicability of certain early interventions for children with ASD from non-dominant groups. Increasing the sociocultural diversity of pre- and in-service educators will also promote the goal of enhancing the quality of ECSE programs and the ECSE workforce.

Support interactions among families, early childhood special educators, and other community members. Prolonged and meaningful interactions can only occur when sufficient time and financial resources are available to allow busy individuals to come together and discuss their common interests, identify obstacles and opportunities, and build a sense of community and joint commitment to improving services. It is particularly essential to support parent-led organizations that reflect community values and promote the type of peer networking that has been shown to be effective in promoting family-school relations in the K-12 public school system. What is more, a seamless integration of developmentally appropriate educational and related services for children from birth through early elementary school has been shown to enhance long-term child outcomes (Peisner-Feinberg et al., 2001).

Support communication and collaboration among early childhood professionals and with families. We encourage early childhood service providers to engage in meaningful dialogue and communication with families. The individualized family service plan (IFSP), Part C of IDEA, was put in place to promote collaboration among the adults involved in the care of the child with disabilities (20 U.S.C. 1400 et seq.; 34 C.F.R. §§ 303 et seq.). In our experience working with young children with ASD and their families, this IFSP process often becomes a “training” session for parents to learn the “right way” to play and teach their children. We encourage early educators and families to build the child’s educational/intervention program together, utilizing the knowledge and expertise of everyone involved to develop a unique program that incorporates the strengths and abilities of the child, and the priorities, educational expectations, and resources of the family.

Engage in more frequent and comprehensive media training around the topic of ASD. Policy makers, researchers, and educators can serve as brokers to translate research findings and improve the media’s ability to provide public coverage of ASD that is less stigmatizing of parents and of individuals with ASD. For example, media outlets can build public awareness of the structural stigma that may impede access to appropriate ASD diagnosis and treatment. Additionally, members of the media can be encouraged to avoid the pitfalls of intersectional stigmatization, including the pervasive practice of stigmatizing mothers from non-dominant groups for the health outcomes of their children rather than undertaking a comprehensive analysis of the complex array of contributing social conditions.

Address systemic disparities in socioculturally diverse families' access to quality early interventions for ASD. Nationwide, 1 in 68 children is diagnosed with ASD (CDC, 2014). Research shows that ASD symptoms do not vary by race or ethnicity, but the diagnosis of ASD depends substantially on the income level of the family (Chaidez, Hansen, & Hertz-Picciotto, 2012). Children from Latino families, who tend to come from low-income households, are identified and diagnosed at a rate that is 50% below the national average (CDC, 2014). These disparities are only beginning to be addressed through comprehensive changes in state healthcare systems. For example, recent collaboration between researchers and government officials in California resulted in better coverage for early intervention through state-funded health insurance policies, leading to greatly improved access to high-quality interventions targeting underserved populations (SB 946, California Government Code, §§ 121022 et seq., 2011). In addition to initiatives like this one in California, states can also provide comprehensive support for families to successfully navigate the service system. For example, in order to ensure that families fully understand their role in gaining access to services their children need, states should provide increased funding for cultural/language brokers to help them navigate the system and advocate effectively to attain the appropriate services.

Attend to the unintended stigmatizing effects of public policies. As we have noted, sometimes policies inadvertently have a disproportionately negative effect on certain groups. To prevent this from occurring, policy makers and analysts can identify the likely effects of a new initiative on families located not just by comparing one broad sociodemographic category with another but rather by considering families' position at the intersection of multiple social dimensions. This more nuanced framework will permit reflection on how the available resources as well as barriers to opportunities within that group will shape policy impact.

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7

When Life Gets in the Way: The Complexities of Supporting Families Who Have a Child with Autism and Live in Poverty

Carol M. Trivette and Catherine P. Corr

Abstract

This chapter discusses the challenges that families of very young children with autism who are living in poverty face when trying to support the child as well as the complexities that practitioners face when working with these families. What is known about the challenges of autism for families and the challenges of poverty for families is examined. Evidenced-based family-centered practices that when used by practitioners enhance parents' confidence and competence are presented. In the last section, scenarios where family-centered practices are helpful when early interventionists are dealing with these complex situations are presented.

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The Glass Windows are Broken Out.[1]
Neighborhood Violence, Domestic Violence
Jail, Rehab, DCFS, Social Workers, Immigration
Unsafe housing, Public housing
Bed bugs. Critters. Cockroaches.
I'm in there a year and a half
and it has nothing to do with Early Intervention.

Parents of very young children with autism experience many challenges. Some of the challenges they face include, but are not limited to, the following: access to services (diagnostic, intervention), child level of disability (severity of autism, behavioral problems), parental mental and physical well-being (sleep deprivation, multiple time demands), and financial concerns (limited ability to work) (Abbeduto et al., 2004; Carter, Martinez-Pedraza, & Gray, 2009; Mandell, Novak, & Zubritsky, 2005). When these families are living in poverty, they often also experience financial instability, nutritional instability, limited

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[1] Data poems: A series of focus groups were conducted with early intervention providers about the successes and barriers they experience when supporting families of young children with disabilities who are also living in poverty. The data poems are comprised of direct quotes from the focus group participants.

M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_7

access to medical and psychological support, and dangerous neighborhoods (Churchill, Prochaska-Cue, Bosch, & Huddleston-Casas, 2006; Conger et al., 1990; Park, Turnbull, & Turnbull, 2002; Schorr, 1998). The challenges of living in poverty and of raising a child with autism can leave parents with little confidence in their abilities to support the child's growth and development on a daily basis (Hastings & Brown, 2002; Parish, Rose, & Andrews, 2010). Parents of young children with autism living in poverty are working very hard to meet the basic needs of their family (i.e., food, shelter, transportation, medical attention, etc.) and often do not have the time, energy, or expertise to devote to intensive therapy regimens (Arcia, Keyes, Gallagher, & Herrick, 1993; Strauss et al., 2012). Early interventionists can work diligently to build parents' capacities to successfully use evidence-based practices with their child and have a positive effect on the lives of families living in poverty (Guarlnick, 1998; Peterson, Mayer, Summers, & Luze, 2010; Strauss et al. 2012). In order to do so, early interventionists often find themselves needing to be respectful, flexible, and patient in their practice in order to be responsive to the complex needs of families living in poverty.

This flexibility and patience are not something that is regularly taught in preservice preparation programs or in-service professional development opportunities (Corr, Santos, & Fowler, 2015). This mismatch between how early interventionists are prepared to meet the needs of families and the actual needs of families can leave early interventionists feeling overwhelmed.

This chapter will examine what research reveals about the realities of poverty to show how this impacts parents' ability to support the growth and development of their young children with autism. It will review evidence-based practices that, when used by practitioners, build parent confidence and competence as well as practices that have been found to be effective in supporting the development of young children with autism. The final section will explore the specific challenges that practitioners and parents face and approaches that might be effective.

What Makes a Family?

Before continuing, the terms "parent" and "family" require defining. "Parent" will be used in this chapter to refer to the person who is involved in the child's everyday care and provides support for the child's development. This might be a biological parent, foster or adoptive parent, grandparent, or other relative. In this context, the gender of the individual providing the care and support is not relevant. The term "family" encompasses those persons that regularly join together to provide daily supports to this child regardless of legal or heredity links. Family is broadly defined in this chapter to represent the contemporary diversity of families.

What Is the Families' Role in Early Intervention?

Part C of the Individuals with Disabilities Education Act (IDEA) clearly states that intervention for children 0–3 years of age with disabilities should occur in the child's natural environment, such as the home, and that it should be done as part of children's activities and routines (IDEA 20 U.S.C. Section (a), 2004). This legislation also clearly states the importance of the family's active role in the delivery of the intervention in the home context (IDEA 20 U.S.C. Section (a), 2004). Therefore, when identifying evidence-based practices appropriate to be used with families of young children with autism, the search for practices must focus on practices that families can implement as part of the daily family activities or routines (see Chap. 13; Kashinath, Woods, & Goldstein, 2006; Stiebel, 1999; Woods & Brown, 2011). Beyond the practices that families use with their children, it is also important to identify practices that practitioners can use to build parents' confidence and competence in their parenting abilities (Dunst & Dempsey, 2007; Swafford, Wingate, Zagummy, & Richey, 2015; Trivette, Dunst, & Hamby, 2010).

Why Does Poverty Matter to Early Interventionist?

How Is Poverty Defined?

The federal poverty level (FPL) is a guideline used by the Department of Health and Human Services to gauge economic hardship in the United States. Within the FPL, delineations are made for families experiencing extreme poverty, poverty, or low income (see Federal Poverty Level delineations, Fig. 7.1). The guidelines vary by family size and the price of goods from the previous year. For example, in 2013, for a family of three, the FPL is $19,053, whereas for a family of five, the FPL is $27,570. The poverty guidelines are the same across the contiguous 48 states and the District of Columbia, but higher guidelines apply in Alaska and Hawaii (Cauthen & Fass, 2008). These guidelines are frequently used to determine eligibility for programs (e.g., Women, Infants, and Children [WIC], Early Head Start [EHS], and Head Start [HS]). It is important to note that the federal poverty level has not changed despite the fact that housing, child care, and health-care costs in the United States have far outpaced food-cost inflation (Parish et al., 2010).

According to the National Center for Children in Poverty (NCCP), there are over 4 million infants and toddlers experiencing poverty in urban areas in the United States, whereas 1 million infants and toddlers experience poverty in rural areas (Addy, Engelhardt, & Skinner, 2013). Poverty is not a homogenous experience for families; families and children living in rural and urban areas experience poverty differently (Amato & Zuo, 1992). For example, families experiencing poverty in rural areas are often geographically isolated from other poor families, whereas urban families experiencing poverty live in densely populated areas within cities (Burchinal, Vernon-Feagans, & Cox, 2008). As a result, families experiencing urban poverty often live in substandard housing, are exposed to higher crime rates and violence, and often lack access to adequate services (Amato & Zuo, 1992). Families living in poverty in rural areas have different struggles (Burchinal et al., 2008). These families often have no public transportation, limited employment opportunities, and limited services that are difficult to access (Marks, Dewees, Quellette, & Koralek, 1999). In fact, though eligible, families in rural areas are less likely to successfully access services such as food stamps (Braun, Lawerance, Dyk, & Vandergriff-Avery, 2002).

Who Is Experiencing Poverty?

In the United States, children under 18 years of age represent 23% of the entire population but are 34% of all people living in poverty. According to the National Center for Children in Poverty (NCCP, 2014), the percentage of young children in low-income families surpasses that of low-income adults. In particular, young children under age 6 years are vulnerable. There are 24 million children under the age of 6 living in the United States. Of those, 48% (11.4 million children) are living in low-income families, and 25% (6.0 million children) are liv-

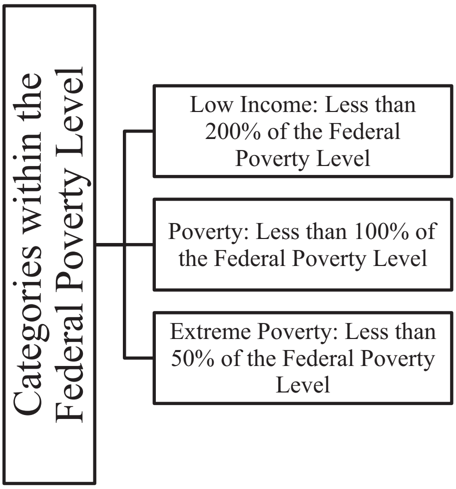

Fig. 7.1 Federal poverty level delineations

ing in poor families. The percentage of young children living in low-income families has been on the rise from 2006 to 2015 (Jiang, Ekono, & Skinner, 2015).

Certain groups of children and families have been targeted in order to create policies to provide family support and access to health and educational programming (Robbins, Stagman, & Smith, 2012). These groups include families who are experiencing the following risk factors: households without English speakers, large family size, low parental education levels, residential mobility, single parents, teen mothers, and non-employed parents. Table 7.1 provides definitions of these national and state risk factors. Children living in poverty disproportionally experience these risk factors, and these individual risk factors are frequently interconnected (i.e., low parental education and unemployment). The research evidence clearly demonstrates that as the number of risk factors grows, there is a greater negative impact on the overall health and development of young children (Center on the Developing Child, 2009).

Table 7.1 National and state prevalence of risk factors (Robbins et al., 2012)

Definitions of national and state risk factors	
Households without English speakers	Children in households where all members over age 14 years speak a non-English language and are not proficient in English
Large family	Children in families with four or more children.
Low parental education	Children whose parents both lack a high school degree
Residential mobility	Children in families who have changed residences one or more times in the last 12 months
Single parent	Children in families with one unmarried parent in the household
Teen mother	Children whose mothers were teenagers when the child was born
Non-employed parent(s)	Children whose parents had no employment in the previous year

Poverty and Race

According to the National Center for Children in Poverty (2014), the percentages of families living in poverty vary by race and ethnicity. For example, in the United States in 2012, White children comprised the largest share of all low-income children (37%), while Hispanic children make up the largest share of poor children (36%). However, Black, Native American, and Hispanic children are disproportionately low income and poor.

In many ways, poverty and disability are concomitant situations (Duncan, Brooks-Gunn, & Klebanov, 1994). In the United States, children with disabilities are significantly more likely to live in families that are considered to be poor (Parish, Seltzer, Greenberg, & Floyd, 2004). Disability and poverty have a bidirectional relationship, meaning disability can be both a cause and consequence of poverty (Emerson, 2007). Poverty, through exposure to environmental hazards, can lead to disability, whereas disability, by way of increased financial burdens, can lead to poverty (Emerson, 2007).

What Does It Mean to Experience Poverty?

Families and children experience poverty when they are unable to achieve a standard of living that allows them to participate fully in mainstream society (National Center for Children in Poverty, 2012). Often, poverty is related to economic hardship; families do not make enough money to cover their basic needs. However, other factors also impact families experiencing poverty such as subpar housing, lack of adequate health care, and the lack of substantive employment opportunities.

When compared to families of children without disabilities, families of children with disabilities face additional financial burdens, such as increased therapy costs, specialized child care, and adapting the home environment (Hastings & Brown, 2002; Newacheck & Kim, 2005; Parish & Cloud, 2006). Children with autism regularly require specialized therapy, medical attention, and nutritional considerations. Frequently, family members may reduce the number of hours they work or quit work altogether to stay at home and provide care for their children with disabilities (Emerson, 2007; Porterfield, 2002). This, in turn, reduces families' incomes and savings over time (Parish et al., 2004).

Research has also demonstrated the complexity of how poverty affects children and their families (Brooks-Gunn & Duncan, 1997; Shonkoff & Phillips, 2000). Minimal financial resources directly impact the quality and quantity of the nutrition and medical (general and specialized) and mental health services that young children and their families receive. The quantity and quality of available child care are restricted when there are few financial resources. The manifestations of economic instability often lead to high levels of stress, impacting parental health and well-being. Families living in poverty often experience family violence, child and spousal abuse, and higher divorce rates than families from higher-income groups (Conger et al. 2010; Duncan & Yeung, 1995). When the effect of poverty impacts parental health and emotional well-being, the quantity and quality of parent-child interaction are also compromised (Brooks-Gunn & Duncan, 1997).

Evidenced-Based Practices

Identifying appropriate evidence-based practices that are used with children with autism and their families is essential. The field has an ethical obligation to use practices that have been demonstrated to be effective in accomplishing the desired outcomes for children and for their families. When the goal is to enhance competence and confidence of families who live in poverty to support the learning of their children with autism, evidence-based practices must build the competence and confidence of parents to use effective strategies with their young children with autism.

Building Parent Capacity

When working with families, practitioners need to use strategies that enhance parents' understanding, use, and sense of proficiency in using effective practices with their children, with the goal being to enhance parents' capacity to support their child's development and learning. Practitioners' use of family-centered practices has been found to promote the confidence and competency of parents (Dunst & Dempsey, 2007; Trivette et al., 2010; Woods & Brown, 2011). These family-centered practices focus on the practitioners' interactions with families that build the families' capacities regardless of the specific child or family need that is being addressed. For example, these practices would be used when building the capacity of families to access needed community supports or using behavior management strategies with their child. It should be noted that these practices are intended to support ALL families, meaning both families living in poverty as well as those who are not.

Recently the Division for Early Childhood (DEC) of the Council for Exceptional Children (CEC) released the 2014 DEC Recommended Practices in Early Intervention/Early Childhood Special Education (Division for Early Childhood, 2014). Developed from research evidence that demonstrated better outcomes for children and families, these practices were written to provide guidance to practitioners and families in the following seven topics: assessment, environment, family, instruction, interaction, teaming and collaboration, and transition. The DEC Recommended Practices are not disability-specific; rather they provide guidance for working with all young children with disabilities (Division for Early Childhood, 2014).

The DEC Family Practices are particularly relevant to building the capacity of families in poverty by supporting the learning of their young children with autism (Division for Early Childhood, 2014). There are three themes that run through the family practices: "family-centered practices, family capacity-building practices, and family and professional collaboration"

Table 7.2 Division for Early Childhood recommended family practices strand

F1. Practitioners build trusting and respectful partnerships with the family through interactions that are sensitive and responsive to cultural, linguistic, and socioeconomic diversity
F2. Practitioners provide the family with up-to-date, comprehensive, and unbiased information in a way that the family can understand and use to make informed choices and decisions
F3. Practitioners are responsive to the family's concerns, priorities, and changing life circumstances
F4. Practitioners and the family work together to create outcomes or goals, develop individualized plans, and implement practices that address the family's priorities and concerns and the child's strengths and needs
F5. Practitioners support family functioning, promote family confidence and competence, and strengthen family-child relationships by acting in ways that recognize and build on family strengths and capacities
F6. Practitioners engage the family in opportunities that support and strengthen parenting knowledge and skills and parenting competence and confidence in ways that are flexible, individualized, and tailored to the family's preferences
F7. Practitioners work with the family to identify, access, and use formal and informal resources and supports to achieve family-identified outcomes or goals
F8. Practitioners provide the family of a young child who has or is at risk for developmental delay/disability, and who is a dual language learner, with information about the benefits of learning in multiple languages for the child's growth and development
F9. Practitioners help families know and understand their rights
F10. Practitioners inform families about leadership and advocacy skill-building opportunities and encourage those who are interested to participate

Division of Early Childhood (2014)

(Division for Early Childhood, 2014, p. 9). Table 7.2 contains all ten of the DEC Family Practices, which are written from the perspective of what a practitioner should do when working with families. The first eight practices contain many elements particularly important when working with families who are living in poverty. These elements include building a trusting and respectful relationship with the family, letting families make decisions and choices about what they and their children need, and building the capacity of the parent. The three examples below demonstrate how different combinations of strategies can be used to reach different outcomes.

In order to *build a trusting relationship with a family*, particularly with a family from a different cultural, language, and/or socioeconomic background, it is extremely important for the practitioners to listen carefully what a family member is trying to convey. It is very easy for a practitioner to respond using his/her frame of reference that might contain inaccurate assumptions about what the family is saying. One way to avoid this situation is to ask parents for examples about what they mean. "Can you give me an example of how that works in your family?" Sometimes it is necessary to ask more than one time for examples. Asking for clarification when one is not sure what was meant can improve understanding of what a parent is trying to convey. "Tell me a little more about what you mean." Practitioners can summarize what they think they heard and double check with the parent to be sure the interpretation is correct. Frequently, families who live in poverty have interacted with professionals who did not want to hear what they wanted or needed for their children. Using these strategies with families demonstrates to the family the practitioner's desire to really know and understand what parents want and need and builds a strong relationship between families and practitioners.

In order for *families to make informed decisions or choices*, it is important to provide information in a manner that the parent can understand. Frequently practitioners must offer the information in a variety of methods. Some strategies include the following: talking with the parent about the information, providing the information written in the home (native) language, providing a visual illustration of the information (i.e., video example of a particular interaction practices), and reviewing the material over several visits in order to answer any questions that arise. Practitioners should provide the information in various ways and then must give parents time to make a decision. It is also important to remember that often making a decision involves family members that are not easily accessible. It might take longer for a family to make a decision than what the practitioner would like; however, if the goal is to build the capacity of parents, then it is essential to let the family make the decision.

In order to enhance the *family's capacity* to help their child learn and develop, practitioners need to acknowledge what the family is already doing well. Frequently families, particularly families under a lot of stress, do not recognize what they are already doing well in any aspect of their lives. Too often professionals have spent a lot of time telling these parents what they do wrong or telling them what they should be doing (Ylven & Granlund, 2009).

Two easy ways to identify family strengths are by asking questions and observing the family. Asking questions is part of a respectful conversations about what the family or child is already doing in different situations (i.e., mealtime, bedtime) and clarifying what is heard ensures the accuracy of the assessment of strengths. Observations of parent-child interactions during play, daily routines, or family activities are also a very effective strategy to identify parent strengths. Observations allow the early interventionist to see what is working for the parent and to point out what was observed.

With all families, but particularly with families under stress, it is essential that home visitors point out what parents did well and explain why what they did is important (Powell, Batsche, Ferro, Fox, & Dunlap, 1997). Sometimes parents do not know that what they did or said is appropriate until it is pointed out to them. Therefore, it is very important to explicitly draw attention to parents their strengths. Parent capacity building means that parents feel competent in knowing what they are doing with their child and confident that they can accomplish what they try to do. Helping parents recognize that their efforts with their child are appropriate and ensuring that parents take ownership of what they accomplish are two essential components of building the capacity of families.

Parent-Mediated Interventions for Children with Autism

Research evidence demonstrates that parents of young children with autism can be primary interveners with their children (Wong et al., 2013). The research-based intervention strategies parents used are natural reinforcement, turn-taking and imitations, contingent responsiveness, following the child's lead, prompt fading, gestures/cues, and time delay (Kasari et al. 2010; Kashinath et al., 2006; Schertz & Odom, 2007). Parents demonstrated their ability to use of these strategies with fidelity in the home during daily routines and activities to enhance their children's communication, specifically joint attention (Schertz & Odom, 2007; Kasari et al. 2010) and communicative production (Kashinath et al., 2006; Reagon & Higbee, 2009; Stiebel, 1999). Studies have also shown that early interventionist used a variety of adult learning strategies (modeling, direct instruction, guided feedback, and coaching) to help parents learn the interventions that they can use with their children (Wong et al., 2013).

Though there are evidence-based practices that families use successfully with their young children with autism, the challenge is helping families use them in the context of their lives. The evidence suggests that helping parents learn these strategies requires meeting regularly so that parents can be supported as they master these new strategies (Schertz & Odom, 2007; Kasari et al. 2010). Yet, when families are living in poverty, it is often difficult for a practitioner and parent to arrange two consecutive weekly or bi-weekly home visits. The reality for these families is that their schedules are often dictated by many other situations such as working two part-time jobs or appointments with other professionals that must be kept in order to acquire basic resources for their children. When practitioners and parents are able to meet, there are many issues to discuss; so it is hard to focus on just one intervention strategy. Even when families learn to use the strategies, the implementation may be difficult if there is limited structure or time because of competing demands.

Supporting Families Within Their Realities

Working with families who have a young child with autism and also are living in poverty can be perplexing, because parents are often stressed and overwhelmed by the amalgamation of these two difficult life circumstances (Midouhas, Yogaratnam, Flouri, & Charman, 2013). To be successful, early intervention practitioners need to have a variety of strategies and a lot of professional support (Rush, Shelden, & Haft, 2003) in order to build the capacity of parents. The sections below provide a variety of strategies that can be used to build parents' capacity to support the learning of their children with autism.

Now What? Understanding My Role as a Practitioner

This section describes *what* practitioners can do to support families of young children with autism who are also living in poverty. It also describes *how* practitioners can use family- centered practices to support families of young children with autism living in poverty and how to use a variety of methods for gathering information.

What Can Practitioners Do?

The examination of evidenced-based family-centered practices provides important interactional strategies for working with families living in poverty with young children with autism. Table 7.3 list eight important strategies that practitioners can use. It is vital that the practitioner *identifies* with the family what their priority is and helps the family *connect* to the specific local community resources that can help them meet that priority. In the process of identifying the family priority, the practitioner builds *trust* with the family by seeking to *understand* and *respect* the family's circumstances, values, and beliefs. When supporting the family to accomplish their priority, the practitioner *affirms* the competence of the family to accomplish their priority and remains *flexible* when expectations have to change as a result of family circumstances. *Self-reflection* also is a critical strategy for the practitioner to use because family situations are complex and can be challenging. These strategies can be used at any time when working directly with a family or when trying to solve a problem if things are not going well. If used frequently, these strategies become habits and are particularly effective when helping families deal with multiple challenges simultaneously.

How Can Practitioners Do It?

As practitioners are using the interactional strategies listed in Table 7.3, there are a variety of methods to gather information to help a family develop their priority or to understand what might be interfering with accomplishing the priority. Using a variety of these strategies when working in a complex situation allows the practitioner to step back and look at what is happening. The four informational strategies found in Table 7.4 are eco-mapping, interviewing, observing, and using daily routines (Jung, 2007; McCormick, Stricklin, Nowak, & Rous, 2008; McWilliam, Casey, & Sims, 2009; Smidt, 2005; Woods & Lindeman, 2008). These strategies are defined in Table 7.4 with ideas about how to use each of the approaches. Though the strategies can be used at different stages of working with families, the table describes specific times when the

Table 7.3 Important actions practitioners use with families

What can I do to support families of children with autism who are living in poverty?	
Identify	Identify the family's priorities
Connect	Connect the family to community resources
Trust	Gain the family's trust
Understand	Seek to understand the family
Affirm	Affirm the family's competence
Respect	Respect the family's circumstances
Flexible	Be flexible in your practice
Reflective	Be self-reflective in your practice

Table 7.4 Ways to gather information from families

	What is it?	How to use?	When to use?
Eco-mapping (McCormick et al., 2008)	A snapshot in time of a family's formal and informal supports. It shows the links a family has to other social systems	• To gain information • To measure progress across time • To describe change in relationships between family members	• To build rapport • To provide a picture of family supports
Interviewing (Woods & Lindeman, 2008)	A strategy for getting and giving information, especially during initial contacts	• Identify the role of family on team • Provide information to support the child/family's progress	• Initial contact with families • Periodic updates with families
Identify routines (Jung, 2007; McWilliam et al., 2009)	The strategies on the IFSP must be meaningful to the family and caregivers. It should help them participate in and learn from the things they do every day	• Routines based • Outcome related • Understandable • Transdisciplinary • Implemented by family • Nonjudgmental • Evidence based	• When you want to ensure the strategies developed will address the outcomes of the IFSP in meaningful ways
Observation (Smidt, 2005)	An observation can lead to many understandings about children and families. What we observe can help us plan further	• What do I want to find out? • When and where should I observe? • How do I record what I observe? • How do I organize the information I collect?	• Connect with the child and family • Get to know each child and family • Respect and appreciate the child and family

approaches could be especially helpful to practitioners.

Scenarios

Three scenarios describe a variety of situations that are likely to occur at some point when working with families of young children with autism who are living in poverty. They are written from different perspectives to focus attention on how the speaker is thinking and feeling about the situation.

Scenario 1: Reflections from the Field: Parent Perspective

"Mary (the speech-language pathologist) comes to my apartment each week to do things with Tim. Tim needs help because he cries a lot, sometimes bangs his head, and sometimes bites me when he is really upset. He is too big to be doing that stuff, and I have a hard time finding people willing to babysit because of that stuff. We live in a small space, but all the neighborhood kids play in the park. Lots of the other kids on the block can just go outside and play together, but Tim sometimes runs away, and the other kids don't know how to play with him. He ends up staying with me all the time. I need to keep my eye on him all the time, but it's hard after a long night of work. One time I let him go play with the other kids, but he ran across the street chasing a fire truck and scared the living daylights out of me. After that, I said no more, he stays with me, all the time.

Mary told me a lot of that is because he is having hard time communicating his wants and needs. I feel like I don't have a lot of patience anymore. Typically, I get home from my work shift and I want to relax. Many days I just don't wait and let him do things on his own; I typically end up doing them so he doesn't have a tantrum.

To be honest sometimes, Mary comes and I just need to sleep; my shift ends 3 h before she comes and I can barely keep my eyes open. I know what she is doing is important, but she knows what she is doing; she is the professional. Sometimes I just need a break. Mary leaves me notes about things I can do with Tim, but to be honest, they just pile up on my kitchen counter. I have enough going on with work and the other kids. I don't have a whole lot of extra time to read the notes. And sometimes when I do read them, I have a hard time understanding what she means, and sometimes she uses words that look foreign to me."

What could happen next? Identify mom's priorities and focus on them (i.e., Tim behaving well enough to be able to be babysat by others).

- Identify respite care and other resources that mom may benefit from (free camps, etc.).
- Brainstorm with mom about how she can allow Tim more opportunities to be independent, perhaps on the weekend or when she knows she will have extra time.
- Ask if she would like to include other friends or family during therapy sessions if she can't physically be present.

Consider: Mom sounds physically and emotionally exhausted. The support she is getting from the practitioner is not meeting her needs. What might be an appropriate next step for the practitioner to take?

Scenario 2: Reflections from the Field: Practitioner Perspective

"I am feeling like I am getting nowhere. I have been doing home visits with Nia in her grandma's home for one whole year. Nia is almost three years old. She loves to be tickled, loves watching/popping bubbles, and likes to watch Dora the Explorer. Nia currently is using very few words to communicate her wants and needs, and we really need to get her talking or at least communicating. Grandma and mom are frustrated that she doesn't eat very much; she is very picky about textures/taste. I know that mom and grandma don't have a lot of money to be buying a wide variety of groceries; right now I am really concerned that Nia refuses to eat anything but pudding.

I believe Nia has made progress in her communication with me; she can sustain attention longer and is attempting to communicate her wants and needs more frequently. She is even willing to taste different foods and textures, but she still spits things out. Hey, at least she is willing to try them now! But I just don't know what is happening in the home when I leave. It's not that Nia's mom and grandma don't care about her. I believe they do; it's just that there is soooo many other things happening. I don't know where to begin.

For example, each week grandma welcomes me into her home. She looks forward to having me there and regularly tells me how important my visits are for Nia. It's sort of a unique situation because Nia's mom is actually in high school, and therefore she has to be at school all day. Every time I come grandma greets me at the door with a smile and offers me a quiet place to do my therapy with Nia. You see, Nia's grandmother runs an in-home day care. Therefore, there are typically four to five other children in the home when I come to work with Nia, and oftentimes I find myself in a quieter room opposite the room where the rest of the children and grandma are. This is helpful in some ways, fewer children to wrangle, and I can keep Nia on task; but it is not helpful in other ways; grandma never really sees what we are working on. I don't have any direct contact with Nia's mom because of scheduling conflicts, and I very rarely get to spend as much time as I would like with grandma.

Obviously, Nia's grandmother is very busy with her other day care responsibilities, and Nia's mother isn't physically present during the sessions. I don't want to overburden either of them but I just don't know what to do. Right now, I leave notes with grandma about what I did during the session, and oftentimes I take some time at the end of my session to demonstrate things to grandma. Also I regularly tell grandma to share this information with Nia's mom when she gets home from school, but that just doesn't seem to happen. I worry because no one is consistently practicing with Nia when I am not around. How can I support Nia and her family?"

What could happen next? Discuss with grandma the importance of her being physically present during the session, and acknowledge that she has many other responsibilities as well.

- With the grandma, find a time to include Nia in some of the activities with the other children (e.g., snack time) and demonstrate how the grandma can use the strategies with Nia in these activities.
- Call Nia's mom regularly to share progress. Ask if mom would like to have a short video of Nia communicating with the home visitor or another child. Despite her not being physically present during sessions, she still has some insight into how Nia is doing and about her overall goals.
- Arrange for therapy to take place during problematic times of the day (i.e., mealtimes). In this way, you can walk grandma through the steps she could try in a real situation.

Consider: Sometimes, even though the parents and practitioner are both trying their best to be participants in the child's intervention, often it is still difficult to use family-centered and natural learning practices. Think back to the strategies defined above (identify, connect, trust, understand, affirm, respect, flexible, reflect), what might the practitioner consider?

Scenario 3: Reflections from the Field: Parent and Practitioner Perspective

Parent Reba: "I am so frustrated with my almost 4-year-old daughter Carrie. Carrie is constantly in motion flitting from one thing to another. She is 'crazy', running back and forth, and will not stop when I ask her. I live in a two-room apartment, about 500 square feet; there is no room for Carrie to be running around like a crazy girl! She just can't be running from room to room and couch to chair. I want her to talk with me and listen when I talk to her! Carrie's home visitor comes all the time. She is really nice, but she is always asking me to tell her what I want for Carrie and what Carrie's goals should be; I just want her to be safe and stop bouncing off the walls."

Practitioner Allyssa: "I have been the early interventionist that works with Reba and Carrie for 12 months. I suspect that Carrie has autism. I have noticed a couple of warning signs but haven't mentioned anything to Reba yet. Carrie uses very little expressive language; she doesn't make eye contact, and she engages in some stereotypic behavior. They have rarely missed our weekly home visit during the year I have worked with them. But I don't feel like Reba really understands what is going on. I feel discouraged because Reba rarely has the energy to interact with Carrie; in fact, she rarely leaves the apartment and has not been able to make the necessary phone calls to schedule a diagnostic appointment for Carrie. I just don't know what else can I do."

What happened next? Both Reba and Allyssa are discouraged and concerned about the situation for different reasons. After some reflection with a colleague, Allyssa decides that she and Reba just need to talk honestly about this situation. So on the next home visit, Allyssa begins the conversation by asking Reba if she still feels that it is important to determine if her daughter has autism. Alyssa reminded Reba and complimented her about her previous decision to seek a better understanding of her daughter's behavior by getting a diagnosis. She asked Reba if she still felt that way. However, this time when they spoke, Reba appeared more depressed and despondent than usual. Allyssa tried to continue the conversation by saying "tell me about how you are feeling."

Reba told her "I am feeling annoyed, isn't this your job to help?" As Allyssa explained that she was supposed to support Reba's role as a parent, Reba became quiet. Eventually the home visit shifts to other issues. Allyssa leaves the home visit feeling awkward and Reba feeling agitated.

After multiple attempts over the next several months, Reba and Alyssa were able to identify that Reba's sister can help her access resources. It seems that Reba's sister helps with lots of things. Allyssa and Reba make a plan to ask Reba's sister if she can help make an appointment.

Consider: It took a long time to finally get someone to agree to make the appointment, which is a rather small but necessary step in the process of getting more resources. The process often felt very awkward to both Allyssa and Reba – like they were mad at each other. Allyssa realizes that it will still take time to get an appointment setup and to get through the diagnosis process. However, she reflects that she is building Reba's capacity to use appropriate resources, her sister, to meet Carrie's needs. Patience is important in this situation.

Summary

With the number of children diagnosed with autism and the number of young children and families living in poverty on the rise, today more than ever, early childhood practitioners need to be responsive to familial needs. While there is limited research focusing specifically on young children with autism living in poverty, many research studies have been focused independently on the young children with autism and young children experiencing poverty. In order to comprehensively meet the needs of twenty-first-century families, early childhood practitioners will need to not only be able to apply evidence-based practices, but they also will need to know how to adapt these practices to support families who are raising young children with autism in complex situations.

Nobody ever told me,[1]
practicum, seminar, courses, workshops, anecdotal stuff from professors.
They touched on multicultural and socioeconomics.
But you need to be prepared,
instead of just throwing people in.
Nobody ever told me,
so I had to think on my feet.
I had to be able to handle situations,
feel parents out for how you could approach them,
can you approach them?
do you need support?
can you do it on your own?
It's something to read it and
it's something totally different
to actually go in and try to do it.
Nobody ever told me.

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8

Parental Insightfulness into the Inner World of the Child with Autism: Its Significance for the Child and Implications for Parent-Mediated Interventions

David Oppenheim and Nina Koren-Karie

Abstract

Parental insightfulness– the capacity to see and feel things from the child's point of view– has been found to promote sensitive and emotionally regulating parental behavior as well as secure attachment and other positive socio-emotional outcomes in the child. Parental insightfulness is relevant for parent-mediated interventions because regardless of the specific focus of the interventions, parents are those who carry them out, and they need to do so in a flexible and appropriate way that takes the child perspective into consideration. In this chapter we first describe the concept of insightfulness and its measurement using the insightfulness assessment (IA). We then review studies of insightfulness of mothers and fathers of typically developing children. These studies demonstrate links between insightfulness and maternal sensitivity as well as secure attachment of the child to the parent and other child outcomes. We next review studies that show that insightfulness is equally important in the case of children with autism: Here too it is associated with sensitive maternal behavior and secure attachment, as well as predictive of more inclusive educational placement of the child. Excerpts from IA interviews of both insightful and non-insightful parents of children with autism are presented. We close with thoughts about the relevance of the "language of insightfulness" to parent-mediated interventions.

Parents' interactions with their children do not only involve their parenting behaviors but also engage the emotional meanings the child's behavior holds for the parent and particularly the thoughts, motives, and feelings the parent attributes to the child. In routine, everyday interactions as well as in emotionally charged and difficult moments, parents make sense of their children's external behavior in terms of the child's inner world and how the child's behavior draws on his or her inner experience. We refer to this emotional meaning-making process as *insightfulness*– the capacity to see and feel things from the child's point of view (Oppenheim & Koren-Karie, 2009). Insightfulness is thought to contribute to sensitive, emotionally regulating, and developmentally appropriate parenting.

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_8

While children on the autism spectrum show behaviors that for many parents can be difficult to understand, bewildering, meaningless, and perhaps anxiety-provoking, most parents nonetheless attempt to put such behaviors into context and understand their causes. When successful, such attempts lead to sensitive responses that facilitate the child's emotional and behavioral regulation.

In this chapter we argue that insightfulness is as relevant in the case of parenting children on the autism spectrum as it is in parenting typically developing children. It is therefore of potentially great importance for parent-mediated interventions. In fact, due to the challenges facing children with ASD, parental insightfulness may even be more important and critical in the case of these children. Research on parent-mediated interventions has shown their effectiveness for some parents but not others, and it may be that parental insightfulness (or lack thereof) may constitutes a moderator of treatment effectiveness (Siller, Hutman, & Sigman, 2013). Also, regardless of the specific treatment or intervention, its flexible and appropriate implementation in everyday circumstances outside of the treatment session can be greatly enhanced if it is based on an insightful stance of the parent. Finally, we argue that understanding the type of insightfulness and particularly lack of insightfulness characterizing the parent can help tailor the intervention so that it fits better the parent's cognitive-affective style when thinking about their child and interacting with him or her.

A hypothesis underlying work on parental insightfulness is that while autism can challenge and significantly strain the parent-child relationship, the relations between insightfulness, parenting, and the impact of these on the child are in essence similar in autism to these relations in the case of typically developing children. We therefore begin by introducing the insightfulness assessment (IA) and reviewing its validity in studies of typically developing children and their parents. We then move to studies of insightfulness in autism, and after reviewing the main group-level empirical findings, we provide interview excerpts from the IA that illustrate both remarkable insightfulness of some parents and the typical difficulties in insightfulness parents of children with autism can experience. We close by pointing to ways in which an insightfulness perspective can inform parent-mediated interventions.

The Insightful Assessment

Insightfulness involves three main features: *insight* regarding the motives for the child's behaviors, an *emotionally complex* view of the child, and *openness* to new and sometimes unexpected information regarding the child. *Insight* refers to the parent's capacity to think about the motives that underlie the child's behavior. Considering such motives is based on accepting the child as a separate person with plans, needs, and wishes of his or her own. The motives insightful parents suggest are framed positively and match the behavior they are intended to explain. Both understanding and acceptance are needed when considering such motives. The parent should be able to *understand* the motives underlying the child's behavior and accompany such understanding with *acceptance* of these motives. This stance provides the basis for appropriate and growth-promoting parental responses and is especially important in regard to challenging or unrewarding child behavior.

The second component of insightfulness is having an *emotionally complex view of the child*. Such complexity consists of a full and integrated portrayal of the child as a whole person with both positive and negative features. Positive features, which typically outweigh negative features, are described openly and are supported by convincing examples from everyday life. Frustrating, unflattering, and upsetting aspects of the child are discussed within an accepting framework and in the context of attempts to find reasonable and appropriate explanations for the child's negative behavior.

Finally, insightfulness involves openness to new information about the child and about the self as parent. Rather than imposing a preconceived notion of who their child is, insightful parents see not only the familiar and comfortable aspects of their children but are also open to see, without distortion, unexpected behaviors, and they may update their view of the child as they talk. Openness also involves a parent's attitude toward his or her own self: Insightful parents can reflect on their self and child observations without excessive criticism or defensiveness.

While the three positive features discussed above are associated with insightfulness, two negative features constitute barriers to insightfulness. The first involves shifts in the focus of the parents thinking from the child's experience to other matters due to anger or worry. For example, parents' preoccupations with the child's symptoms or future development can dominate the interview and lead to a shift in the focus of the interview from the child's thoughts and feelings *in the specific moment* to the parent's general worries about the child. There is no question that such worries are understandable, but if they dominate the parent's speech about the child and consistently lead to shifts in the parent's attention from the child's experience, they prevent the parent from considering, in a flexible and open manner, a wide range of possible motives or explanations for the child's behavior.

An additional barrier to insightfulness is lack of acceptance. This can be expressed in derogation of the child, detachment from or indifference to the child's internal experience, or rejection of certain child behaviors or even of the child as a whole. Such a stance is not insightful because the function of insightfulness is to provide a foundation for caregiving that promotes healthy emotional development in the child. Interestingly, such lack of acceptance can sometimes be observed even in conjunction with a moderate degree of insight into the child's motives and some understanding of what may lead the child to behave or feel in a certain way. For example, a parent may compellingly describe that her child does not cooperate in a competitive game because he is afraid to lose but then talk mockingly about his fear or angrily about his lack of cooperation. In this example the child does not benefit from the parent's understanding of the motives underlying the child's behavior. On the contrary, from the child's point of view, the combination of knowing that the parent understands the child's internal experience but, at the same time, rejects it can be particularly painful and confusing.

Assessment of Insightfulness

The IA is a video-replay procedure in which parents and children are first videotaped in three interactional contexts and then, after viewing short excerpts from the videos, are interviewed regarding their children's and their own thoughts and feelings. Three vignettes representing different aspects of the parent-child relationship (e.g., caregiving, play, and teaching) are selected. The vignettes are drawn from interactions that are age-appropriate. In infants it may involve a free play episode using various toys, in preschoolers it may involve co-constructing a play narrative using dolls and props, and in school-age children it may involve a competitive mother-child game. When the IA is used with children with autism, we use free play with toys, social play (play without toys), and play with a doll designed to elicit symbolic play. The IA is introduced to parents as an opportunity to better understand their children with a particular emphasis on what they believe their child is thinking or feeling. They are also asked whether the behaviors they saw on the video are typical of their child and about the way they felt when they were watching the video. These questions are presented following each of the three segments, and at the end of the interview, mothers are asked two general questions: the first about the child's characteristics more generally and the second about the mother's emotional reactions in response to the child. Throughout the IA, parents are asked to support their statements about the child with examples from the observations of the videotaped segments and from everyday life.

The IA was designed to reveal how parents apply their general representations of their children to a specific and concrete moment in the life of the child. The goal of this procedure is to simulate moments from everyday life in which parents try to make sense of their children's behavior and understand the motives and emotions that may underlie the behavior– in effect to answer the question "why is my child behaving this way?" Unlike "real-life" moments, however, in which these meaning-making processes are implicit and may operate outside of awareness, the IA interview requires parents to make these processes explicit. In this way the IA sheds light on parents' feelings, perceptions, and thoughts that are believed to underlie their caregiving behavior.

The interview transcripts are rated on ten scales (see Table 8.1) and, based on the profile of the scores on the ten scales, classified into one of four groups. The first of the four groups, positive insightfulness, indicates the capacity for insightfulness, while the remaining three (one-sided, disengaged, or mixed) indicate a lack of insightfulness (Koren-Karie & Oppenheim, 2001).

Table 8.1 Insightfulness assessment scales

IA scale	Low	High
Insight into child's motives	Mother[a] does not talk about possible motives for her child's behavior	Mother tries to understand the thoughts and feelings that may underlie her child's behavior; she moves freely between the videotaped observations and her knowledge about her child, draws parallels between the two, and tries to gain deeper understanding
Openness	Mother is not open to the information of the videotaped observations but rather speaks about her fixed and preset ideas about the child; the observation may be dismissed as not typical of the child	Mother is open to the information arising from the videotaped observations; she compares what she knows about her child with the video observations and modifies her perceptions if needed
Complexity in description of child	Mother describes the child in a unidimensional, one-sided way, emphasizing either only positive or only negative aspects of the child	Mother provides a believable description of the child in which the child is described as a "whole" with both positive and negative aspects
Maintenance of focus on child	The child is not the focus of discussion; rather, the focus is on the mother and her feelings and thoughts or other irrelevant issues	The child is the focus of discussion; if mother talks about herself, it will be when she is asked to do so or regarding her maternal role
Richness of description of child	Limited responses that lack substance or full responses with mostly irrelevant details	Mother responds to the interview questions in a full, comprehensive, and vivid way
Acceptance	Mother expresses dissatisfaction or disappointment in the child or talks about the child in a derogatory way	Mother accepts the full range of her child's behaviors and shows tolerance and understanding toward challenging aspects; she is open about difficulties in her child's behavior and conveys a deep acceptance of the child
Anger	Mother's speech does not include current anger even though she can talk about behaviors that caused her to feel angry in the past	Current anger toward the child is a central feature of mother's talk; the child is described as having many irritating traits, and many of his behaviors on the videotaped observation elicit anger in mother
Worry	Mother expresses belief in herself and her child's capacity to cope with challenges	Mother's worry regarding the child, her maternal behavior, or their relationship is a central, repetitive theme throughout the interview

(continued)

Table 8.1 (continued)

IA scale	Low	High
Separateness from child	Mother finds it difficult to talk about the child with a sense of clear boundaries; she may talk about the child's thoughts as if spoken out loud or refers to ideas regarding what the child *might* think or feel as facts	Mother sees the child as a separate person and accepts that the child may sometimes have needs and wishes that are different or even contradictory to hers
Coherence of thought– overall scale	Mother's speech does not convey a consistent and clear picture, and it is difficult to understand what she means; responses may contain digressions and contradictions, or mother may ignore the videotaped observations	Mother is focused on the videotaped segments, and in her answers she develops ideas in a consistent, connected, and relaxed way; her speech forms an integrated and clear picture linked both to the videotaped segments and the child as a whole

[a]Scales apply to fathers or other caregivers as well

Research has primarily focused on the four insightfulness *classifications* because these are thought to capture the overall capacity to show insightfulness or the specific form of difficulty in showing insightfulness. However, the IA scales can also be very useful, particularly for describing the parent's strengths and challenges. For example, a parent of a child on the autism spectrum may show good acceptance of the child and even a moderate capacity for insight, and these qualities can be captured on the acceptance and insight scales. At the same time, the parent can be flooded by anxiety, guilt, and worry when thoughts about the child's future enter their mind, and this may be captured by the concern scale. Additionally, this emotional response may lead the parent to lose the capacity to focus on the child and see things from the child's point of view. For example, the child may, in fact, be making progress in the intervention, but the parent's concern can overwhelm his or her capacity to focus on the child and see the progress that is made (captured by the focus and separateness scales). Thus, the profile of the parent on the IA scales can point to areas of strength in the parent but also to "blind spots" in which the parent has difficulties seeing the child as separate from the self. Such refined understanding can provide the basis for applying interventions in ways that are more nuanced and tailored to fit the parent. We return to this point at the end of this chapter.

The IA classifications. As mentioned above, the rating scales serve as a basis for the classification of the transcripts into one insightful and three non-insightful categories. Categories reflect more than a simple summation of scale scores. Rather, the coding manual provides guidelines regarding various constellations and combinations of scale scores that lead to each of the specific categories. The four categories are:

1. *Positively Insightful (PI):* The main characteristic of these parents is their ability to see various experiences through their child's eyes and to try to understand the motives underlying their child's behavior. They are flexible when viewing their child in the video segments, and they may gain new insights as they talk. Positively insightful parents convey acceptance of the child, and their speech is coherent. These parents talk openly about both positive and negative aspects of their child's personality and behavior as well as of their own caregiving. While all positively insightful parents share the above characteristics, they are also quite varied. Some talk about their child in a very warm and emotional manner, while others are more reserved and have a "matter of fact", focused style of speech. Other parents in this group have a didactic style and focus on their child's cog-

nitive competencies and achievements, and still others are most noted by their self-reflection. Thus we do not look for surface similarity when we group these parents into one category but try to identify the underlying features that reflect these parents' capacity to "see– and feel– things from the child's point of view."

2. *One-sided (Os):* One-sided parents have a preset conception of the child that they impose on the videotaped segments, and this conception does not appear open to change in response to inconsistent information. These parents often find it difficult to maintain the focus of their speech on the child and switch to discussing their own feelings or to other, irrelevant issues. Some one-sided parents overemphasize the child's positive qualities without being able to support their statements with episodes from everyday life or from the video segments. Others may describe the child as "all negative" and talk only about his/her difficulties, symptoms, and faults. Still others may show a good understanding of the child's underlying motives, but that understanding is coupled with a rejection of the motives. In other words, such parents show understanding without empathy.
3. *Disengaged (De):* Disengaged parents are characterized by their lack of emotional involvement during the interview. Their answers are short and limited, and they do not use the observation as an opportunity to reflect upon their child's and their own behavior. Attempts to understand what is on their child's mind seem novel to them, and they do not find them pleasurable or valuable. When asked what their child might be feeling in the video segment they viewed, they provide answers like "I don't know." As a result, the interviewer does not get a sense of who the child is. Disengaged parents talk very little about their children's emotions and focus more on their children's behavior.
4. *Mixed (Mx):* This category involves parents who do not show one style of narration as defined in the above categories. Rather, such parents may respond to one video segment in one style, and to another segment with a different style, and the reader cannot judge which of the styles is dominant. For example, a parent may sound overwhelmed, unfocused, or hostile in the responses to the three video segments but insightful, complex, and open in the response to the two general questions.

In sum, the assessment of parental insightfulness asks:

- Does the parent try to understand the reasons for the child's behavior, positive or challenging– the thoughts, feelings, and motives that may underlie the behavior?
- Can the parent empathize with the child's feelings and point of view, even when this includes feelings or experiences that are difficult for the parent to accept?
- Can the parent keep the focus on the child's experience, or do the parent's emotions, such as anxiety, anger, or disappointment, color the parent's view of the child?
- Can the parent contextualize the child's behavior and think about the specific and immediate events and reasons that may have led to the child's behavior?
- Does the parent coherently and logically link specific behaviors to the child's general traits and characteristics?

Empirical Support for the Insightfulness Assessment

Insightfulness Assessment and Attachment

The conceptual foundations of the IA are strongly rooted in attachment theory (Ainsworth, 1989; Bowlby, 1982; Cassidy & Shaver, 2008) which argues that the development of secure attachment hinges on the child experiencing sensitive and responsiveness care which is based on "seeing things from the child's point of view" (Ainsworth, Blehar, Waters, & Wall, 1978). Based on this theorizing, the goal of the initial studies using the

IA was to establish its links with children's attachment to their parents. Importantly, when possible, these studies attempted to not only match the IA with infant attachment patterns at the global level (i.e., insightful/non-insightful with secure/insecure) but also to match each of the four IA classifications (positive insightfulness, one-sided, disengaged, mixed) with each of the four infant attachment classifications, respectively (secure, ambivalent, avoidant, disorganized; Ainsworth et al., 1978; Main & Solomon, 1990). These specific concordances were important because attachment theory and research describe the specific adaptations (i.e., types of secure and particularly insecure attachment) children make to specific types of sensitive and particularly insensitive parental care (Weinfield, Sroufe, Egeland, & Carlson, 1999). Specifically, avoidance is thought to be an adaptation to the parent's rejection of the child's bids for closeness and protection particularly when distressed, resistance is seen as an adaptation to the parent's inconsistent availability, and disorganization is thought to arise in response to frightened, frightening, or otherwise affectively grossly misattuned and non-matched parental behavior.

Two studies of mothers and their typically developing infants largely supported the expected concordances (Koren-Karie, Oppenheim, Dolev, Sher, & Etzion-Carasso, 2002; Oppenheim, Koren-Karie, & Sagi, 2001). In both studies mothers classified as *PI* had secure children, mothers classified as *Os* had insecure/ambivalent children, and mothers classified as *mixed* had children classified as insecure/disorganized. Unexpectedly, no associations were found between the *De* classification and children's attachment, perhaps because the samples (like all those based on studies conducted in Israel; van IJzendoorn & Sagi, 1999) included very few children classified as avoidant.

Because the effects of insightfulness on attachment are thought to be mediated by sensitive and emotionally regulating caregiving behavior, studies using the IA investigated the associations between the IA and maternal sensitivity. In the Koren-Karie et al. (2002) study of typically developing infants mentioned above, mothers classified as insightful were more sensitive in their interactions with their infants in both home and laboratory observations than those not classified as non-insightful. Importantly, although the *De* classification was not associated with insecure attachment, as mentioned above, it was associated with relatively low ratings of sensitivity, thus providing support for its validity. Two additional studies linked insightfulness to other aspects of maternal behavior that are closely related to maternal sensitivity. Fridman (2005) studied the "mind-minded" comments (Meins, Fernyhough, Wainwright, Gupta, & Tuckey, 2002) of the mothers from the Koren-Karie et al. (2002) study. Such comments of mothers toward their infants reflect the mothers' orientation to their children as mental agents and individuals that have thoughts and intentions that guide their behavior. As expected, Fridman (2005) found that insightful mothers used fewer inappropriate mind-minded comments than non-insightful mothers, although no differences were found regarding appropriate mind-minded comments.

A study of foster mothers examined mothers' sensitivity in the context of guiding emotional dialogues with their children as a function of their insightfulness (Koren-Karie & Oppenheim, 2010; Yuval-Adler, 2010). The mothers, each of whom fostered several children, were observed with both the most and the least challenging child in their care while co-constructing a conversation about emotional themes. Insightful mothers guided the conversation more sensitively than non-insightful mothers, and this was true of their interactions with both the least challenging and the most challenging child.

Being rooted in attachment theory, the IA received its fundamental support from the associations with children's attachment, but it is thought to facilitate additional aspects of children's development, such as their theory of mind. Oppenheim, Koren-Karie, Etzion-Carasso, and Sagi-Schwartz (2005) assessed maternal insightfulness when children drawn from a low-risk sample were 1year of age and assessed children's theory of mind– their capacity to understand that the behavior of others is governed by internal thoughts, feelings, and beliefs– when children were 4years old. The authors hypothesized that maternal insightfulness, which involves the mother's attribution of mind to the child, would promote children's theory of mind, which involves the child's attribution of mind to others. The findings supported this hypothesis: Mothers who were insightful when children were 1year of age had children who showed at the age of 4years higher theory of mind scores than children of mothers who were non-insightful when they were infants (Oppenheim et al., 2005).

Another way in which insightfulness can promote children's development, particularly with respect to children with psychopathology, is by supporting the gains children make in treatment. Oppenheim, Goldsmith, and Koren-Karie (2004) examined preschoolers with emotional and behavioral problems who were in a day treatment program, and their mothers received parent therapy. Only 9% of the mothers were classified as positively insightful prior to treatment, but 50% were so classified following treatment. Lacking a control group, these findings cannot rule out that factors other than the intervention led to the gains in mothers' insightfulness, but interestingly the findings also showed that the gains mothers made in treatment were associated with improvements in children's behavior problems: Children of mothers who shifted from non-insightfulness to insightfulness showed a reduction in their behavior problems, whereas children of mothers who did not make the shift did not show such a reduction. Although it is not possible to determine whether changes in the mothers elicited changes in the children or vice versa, the findings nonetheless point to the potential importance of maternal insightfulness in supporting therapeutic gains in young children. This, of course, is highly relevant for parent-mediated interventions and will be discussed further later.

The studies reviewed above were based on a dyadic, mother-child focus, but it is widely understood that a fuller understanding of children's socioemotional development requires taking a broader, triadic perspective. Accordingly, Marcu, Oppenheim, and Koren-Karie (2015) studied the effects of *both* parents' insightfulness on triadic family interactions, by observing 79 families with 18-month-old toddlers in the Lausanne Trilogue Play (LTP; Fivaz-Depeursinge, Frascarolo, & Corboz-Warnery, 1996) procedure. The LTP classifies families as showing cooperative (optimal), conflictual (less optimal), or disordered (least optimal) alliances. The goal of the study was to link parental insightfulness to the type of alliance the families show, with the idea that parental insightfulness would promote more optimal family alliances. Because this study adopted a systems approach, the insightfulness of *both* parents was considered.

The first notable finding was that fathers were as likely as mothers to show insightfulness. Secondly, Marcu et al. (2015) found that when both parents were insightful, the triads were likely to have a cooperative alliance; when only one parent was insightful, the triad was likely to have a conflictual alliance; and when neither parent was insightful, the family was likely to be classified as having a disordered alliance. Although it is hard to infer causal pathways from correlational data, these findings seem to suggest that the insightfulness of both parents is needed to establish a cooperative family alliance; that when only one parent is insightful, the discrepancy in insightfulness appears to disrupt cooperation and lead to conflict; and that when neither parent is insightful, there is either exclusion of one of the partners or chaotic interactions resulting in a disordered alliance. The findings are significant because they show that insightfulness, which heretofore has been applied only in dyadic studies and only with mothers, is equally relevant in triadic studies (that include fathers). Moreover, as suggested by studies of co-parenting (McHale, Kuersten, Lauretti, & Rasmussen, 2000), it is only by taking the insightfulness of *both* parents into consideration that the associations with the family alliance emerged.

Finally, Gray, Forbes, Briggs-Gowan, and Carter (2015) demonstrated how maternal insightfulness can buffer children against the deleterious effects of violence exposure, reasoning that maternal insightfulness can help contain and regulate the distress evoked by exposure to violence and prevent the development of post-traumatic symptoms. Gray et al. (2015) found that violence-exposed children whose mothers were non-insightful experienced higher internalizing and externalizing behavior problems than similarly exposed children who had insightful mothers. The latter group's level of behavior problems was not different than those of a comparison group of non-exposed children.

In sum, research on insightfulness with typically developing children has demonstrated that it is associated with sensitive maternal behavior and with secure child-mother attachment, with sensitive guidance of emotional dialogues, with more cooperative family interactions, and with various additional positive child outcomes. Preliminary evidence has also pointed out to its potential role in promoting positive gains in children who receive intervention. We turn now to ask whether similar positive outcomes can be documented with regard to children on the autism spectrum.

Insightfulness and Autism

When the intersection between insightfulness and autism is concerned, two questions arise: First, given the difficulties of children with ASD in communication, their challenges in understanding the mind of the other, and the atypical behaviors they exhibit, is parental insightfulness even possible? Can parents of children with autism think about their children's inner worlds? Specifically, do they take their children's motives, thoughts, feelings, and desires into consideration when they try to figure out their behavior as do parents of typically developing children? Or do the barriers children's difficulties present interfere with insightfulness or block it altogether?

The second question that comes up is the importance of insightfulness for the child's development in the case of autism. Even if parents are capable of insightfulness, does it make a difference for children with autism? Is insightfulness associated with more sensitive parental behavior and more favorable child outcomes in a way that parallels findings with typically developing children? Or, alternatively, do differences in the severity of children's diagnosis or the level of functional impairment overwhelm the picture so that individual differences in insightfulness are of no meaningful consequence? Our studies, as well as those of others, have generally shown (a) that insightfulness is possible and not rare even when children with autism are concerned and (b) that it is associated with favorable maternal behavior and child outcomes in a way that parallels the findings from typically developing children. We review these studies next.

Oppenheim, Koren - Karie, Dolev, and Yirmiya (2009) studied 45 preschoolers with ASD and their mothers. Maternal insightfulness was assessed using the IA, maternal sensitivity was assessed from observations of mother-child interactions, and child attachment was assessed using the Strange Situation procedure. The findings showed that 42% of the mothers were classified as insightful, a percentage lower than the rates of insightfulness in parents of typically developing children but not much different than the rates of insightfulness of mothers of preschoolers with intellectual disability (38%; Feniger-Shaal, Koren-Karie, & Oppenheim 2011). Importantly, Oppenheim et al. (2009) found no associations between insightfulness and either the severity of the child's diagnosis on the autism spectrum or the child's IQ, suggesting that insightfulness (or lack thereof) is more a reflection of the parent's capacity to see the world from the child's point of view and is not simply a reflection of the child's IQ or symptomatology. This means that insightfulness is possible even when the child's diagnosis is relatively severe and cognitive capacity relatively low. Similar rates of insightfulness of mothers of children with ASD were found by Hutman, Siller, and Sigman (2009; 34% insightful) and Kuhn (2007; 54% insightful). Taken together these findings suggest that the answer to the first question– is insightfulness possible in the case of mothers of children with autism– is affirmative.

The second question involved the implications of maternal insightfulness for mother-child interaction and for children's attachment. Specifically, the hypothesis was that insightfulness would facilitate sensitive maternal behavior. Supporting this hypothesis the findings showed that mothers who were insightful were observed to be more sensitive in a measure derived from three observations of mother-child play: Free play (in which mothers and children were given the choice of a wide selection of toys to play "in a way that would be fun for the child"), structured play (in which mothers were asked to engage their children with specific toys provided by the examiner), and social play (in which mothers played with their children without any toys). In addition, the findings showed that insightful mothers were more likely to have securely attached children than non-insightful mothers. The findings also showed that maternal sensitivity mediated the link between maternal insightfulness and child security (Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2012; note that in this study the insightfulness measure also included a measure of the mother's reaction to the child's diagnosis, the discussion of which is beyond the scope of this chapter). Similar results, at least with regard to the insightfulness– sensitivity link, have been reported by Hutman et al. (2009), who found that mothers of children with ASD classified as insightful were more synchronous in their interactions with their children than mothers classified non-insightful. Thus, with regard to the second question– whether insightfulness has the same implications for the parent-child relationship and child attachment in the case of autism as it does in the case of typically developing children– the answer also seems to be yes, although clearly more studies are needed. It can be tentatively concluded that children with autism seem to benefit from maternal insightfulness in ways that are similar to the benefits insightfulness confers on typically developing children.

One limitation of these findings is that insightfulness and its postulated outcomes were assessed concurrently, so in an additional study, Dolev, Oppenheim, Koren-Karie, and Yirmiya (2014) examined the longitudinal associations between early insightfulness and later level of inclusion of the children in their educational settings. Mothers' insightfulness was assessed when children were preschoolers, and their educational placement was ascertained when they were 8 and 12 years of age. The findings showed that even after taking into consideration children's IQ, an obvious predictor of level of inclusion, and their interactive competency– how well they were able to interact with an unfamiliar adult– mothers' insightfulness and the security of children's attachment each increased the likelihood of children's placement in more inclusive educational settings (e.g., integrated in a mainstream classroom).

Finally, a study with direct bearing for parent-mediated intervention was conducted by Siller et al. (2013). In this randomized controlled trial, mothers were assigned either to Focused Playtime Intervention designed to increase maternal synchrony and shared attention between the mother and the child or a parent advocacy training intervention. Mothers' insightfulness was assessed before the intervention. The results showed that the intervention was effective in enhancing maternal responsive behavior but only for mothers who were insightful prior to treatment. In other words, maternal insightfulness moderated the effectiveness of the intervention. These results raise the possibility that other parent-mediated interventions that yielded no or weak results are in fact effective– but only for some mothers (e.g., those that are insightful).

We turn next to presentation of examples of how insightfulness is manifest in interview transcripts drawn from the IA of parents of children with autism. Examples of barriers to insightfulness will also be presented. We present this detailed information because becoming familiar with how insightfulness is manifested may be important for parent-mediated interventions, including those that do not target insightfulness. It is likely that many parent-mediated interventions could benefit from insightfulness in the parent because it is likely to facilitate more accurate, appropriate, warm, and flexible application of intervention principles and behaviors. Conversely, parental barriers to insightfulness can lead to rigid, inappropriate, or emotionally mismatched application of the intervention. This is what Siller et al.'s (2013) findings reviewed above suggest: The intervention was effective but only for mothers who were insightful.

Examples of Insightfulness Classifications in Mothers of Children with ASD

Positive Insightfulness

We begin with an example of a positively insightful mother of a 5-year-old child with ASD from the Siller et al. (2013) study mentioned above. The mother viewed a short video in which she and her child were engaged in free play. Her response demonstrates her complex view of her child, her acceptance of the child's challenging behavior, and her open and fresh thinking about the motives underlying the child's behavior.

The first question the mother was asked after watching the video was "What do you think is going through his head? What is he thinking? What is he feeling?" The mother responded as follows:

> Um, it, he was, he seemed to me actually, um, overwhelmed with the number of little buses and things that he had. I had noticed that when he has too many toys he just doesn't seem to be able to handle them all. This is what he does, which he did in the tape, he pushes them all together and he sort of squints like this and sort of drags them to himself. And that's how I know it's too many and I take some away because it's just, it's too many things for him. And then he just lost interest, it just wasn't interesting for him anymore, because the other toys were clearly more interesting, the toy pizza.

Several characteristics of insightfulness are noticeable in this vignette. It is clear from the mother's description that the child did not cooperate: He piled the toys next to him, and he also showed unusual behavior (squinting). Mother's insightfulness is evident in her search for the motives for the child's lack of cooperation and unusual behavior. She contextualized the child's behavior by suggesting that his lack of cooperation, which could have been seen as non-compliance or negativity, is due to being overwhelmed with the large number of toys, an experience he cannot tolerate. Of critical importance is mother's acceptance: She both understands the reasons for the child's challenging behavior and shows no anger, disappointment, or blame toward the child. The mother shows openness by integrating her observation of the child's behavior with her general knowledge about her child and familiarity with how he reacts in various situations and specifically when he is exposed to many objects. By doing so the mother demonstrates a complex, insightful, and open thought process that is at the service of understanding her child better and promoting his development.

A second example for insightfulness is taken from a transcript of a father of a 7-year-old child. The father observed a segment in which he and the child were asked to construct a puzzle following a fun episode in which the child was playing with a balloon. The father was asked what was going on in the child's head and he answered:

> This was real war. War in which he wants to play with the balloon and I fight him to move on to the puzzle. He's having fun with the balloon; it is every child's dream to sit and play with a balloon, and I am asking him to move on to something that is not only not fun but demands cognitive effort. It seems that he is thinking "what I want now is a balloon" and that is why it is difficult for him to start working on the puzzle. That is why he resists… you see, a balloon is no problem, anyone can fly it, but a puzzle is difficult, and maybe he will not be able to put it together by himself, so what I see here is that he is struggling with himself. It is as if he is telling himself: "Can I leave the previous game that was fun and move to something more difficult?" It began with "Absolutely not, I will stick to the balloon!" After that he moved on to "I am willing to listen, I am sitting on the fence…" You could see it in how he was holding the balloon in his hand but his eyes were already on the puzzle, and the third stage is "I take it!" And not only did he take it but he jumped directly to the difficult puzzle. As if saying "OK, I will not only do the task, I will choose the most difficult one." So that is what I saw– three stages of thought processes.

The father opens his discussion by a full and open acknowledgment of the conflictual situation: "This was real war." The father was asked to transition the child from the balloon playing to building a puzzle with the child, but the child refused. It is precisely at this point, which can easily trigger a negative view of the child as obstinate, non-compliant, and negativistic that this father's insight is so striking. Rather than blaming his child, he empathically understands that the child wished to continue and play with the balloon rather than struggle with the puzzle. The father is not only fully accepting but can openly and compellingly follow the stages of the child's thought process– from complete resistance, through "sitting on the fence," to compliance and even more so enthusiasm about the challenging task. While completely accepting and being open to the child's resistance and the difficulty it reflects, perhaps related to the child's autism diagnosis, the father ends by emphasizing the child's strength and coping.

One-Sided

In the next segment, the one-sided classification of a mother of an 8-year-old is illustrated. Mother's speech is flooded; she shifts the focus of her speech from the child to herself and has a pervasive, all-encompassing negative view of her child. This negative view, evident in the entire text, becomes already apparent at the beginning of the interview. After viewing the first segment the mother chooses the following adjectives to describe her child: No curiosity, no imagination, no motivation, passive, lacking joie de vivre, heavy, not interested, not competitive, obsessive, does not like change, gets angry quickly, gives up quickly, and pleasant. While it may be the case that the child is challenging and that many of the listed adjectives are descriptive of him, we have seen in the responses of many mothers of children with autism that even very difficult children have positive qualities. In fact, later in the text, in the context of longer responses and not when asked directly, this mother describes the child's love for music and helping behaviors– certainly positive qualities that she could have listed alongside the negative qualities. However, it seems that her one-sided negative "filter" leaves no room for positive features.

In response to a segment in which she and the child were drawing, she describes the child as noncooperative and impatient. She is then asked if this is typical of everyday life:

> Of course, very, he can sit and be stuck with himself. The only thing that may happen is that he will listen to music by himself, but you will not see him entering the room and taking a game for fun and pleasure. This is one of my problems: If I bring people to be with him and play with him so that he will not be stuck doing nothing, because he has no problem passing time doing nothing, he has no problem with this, it is totally my problem, that it is difficult for me to see him doing nothing. Sometimes I do something at home and I am just back from work, and I have to rest a bit, admittedly he will not bother me, but it always bothers and irritates you that he does nothing, it's like you say *urrgh*, another hour has gone by, another half hour, and he is doing nothing doing nothing, it's like I have to entertain him constantly, because otherwise he will not entertain himself… and then I need to find something so that he will move a bit and that is when I am just back from work and tired and want to rest.

Several features of the one-sided classification are evident in this example. The first is this mother's lack of complexity when speaking about her child. She stresses and emphasizes a single, negative characteristic: that her child is "stuck doing nothing." This point is repeated many times, with no attempts to balance this negative picture with positive characteristics. Importantly, the mother herself mentions a positive characteristic– namely, that her child enjoys music. However, rather than using this positive feature to expand her view of the child, she dismisses it as irrelevant, cannot accept that listening to music may be fun for her child, and by doing so maintains her one-sided view of her child.

An additional feature of the one-sided classification is evident in the mother's shifting the focus of discussion to herself. After a short description of the child and how he fails to initiate play (at least according to this mother's expectations of what constitutes play), she moves to talk about herself: That it is her problem and that it is difficult for her to see the child self-absorbed. At first glance such a statement may seem reflective. However, the question the mother was asked was to provide examples from everyday life for the child being "stuck with himself" and not to describe *her* feelings and reactions. It seems that the mother's worries and preoccupations about her child color and dominate her view of him and interfere with her capacity to keep the focus on her child's experience, separate from her worries. Of course, it is understandable and even expected that parents of children with autism will express a certain amount of concern and worry. The point we are stressing here, however, is that in this case the worry appears to overwhelm the mother so that even when she is asked about the child and begins to answer appropriately, she quickly shifts the discussion to her own concerns. During interactions with the child, such shifts in the mother's focus are likely to be experienced by the child as empathic failures in which the child and his feelings, thoughts, or actions are not seen.

A final feature of one-sidedness is evident in this mother's lack of openness and lack of acceptance of the child. Later in the interview she says:

> He has no competitive drive, almost nothing… he simply has nothing, nothing excites him, nothing shows that he wants something… a few days ago my daughter played with him and won and he was furious, screamed and yelled, and when the nanny said let's play he said "only if you do not win". So he *does* want to win and does not want to lose but he lacks restraint. You know, he can be so upset that he can scream and yell and cry without restraint. Even little childish things that you would not expect, but we no longer know what to expect, and that is part of the problem.

The mother's first statement about the child stresses that he has no competitive drive and "nothing excites him." However, this statement is immediately contradicted by a description of the child being very upset when losing and wanting desperately to win. This mother's negative and narrow view of her child limits her capacity to see that under certain circumstances he may, in fact, show competitiveness and does care about the outcomes of his play with others. Openly considering such possibilities could have led to a more nuanced, complex, and contextualized view of the child, but it seems that, for whatever reason, it is important for this mother to maintain a narrow and rigid view of the child as having no competitive drive. This mother's lack of acceptance is also evident in her insistence on a negative view of her child and failing to consider alternative and more benign reasons for the child's behavior. Finally, the mother's lack of openness, shifts of focus, contradictions, and lack of acceptance all lead to lack of coherence in her speech.

Disengaged

We turn finally to examples of the disengaged classification. Here the mother and her 8-year-old child were asked to draw together, and the mother was asked what she thought her child was thinking or feeling. To this she responded:

Mother: "What do you mean?"
Interviewer: "Whatever you think went through his head, what he felt, what he thought?"
Mother: "I kinda thought that he is happy"
I: "Where in the video did you see that?"
M: "In what you showed me…. I don't understand the questions, I am sorry, I am not sure where you are heading."
I: "Did you see any characteristic of your child in this segment"?
M: "Uhm, I don't think so… do you mean what I can learn about his personality? But he simply acts as usual… I am not sure where you are heading… maybe you can see that he has imagination"
I: "Where in the segment did you see that he has imagination?"
M: "That he wants to draw something complex."
I: "Do you have an example from everyday life for him having imagination"?
M: "He sometimes makes connections between odd things"

The disengaged classification is evident primarily in this mother's lack of insight, interest, and involvement. The mother is asked about the thoughts and feelings underlying her child's behavior but seems to be unable to make use of this question to think what might underlie the child's overt behavior. It seems that this way of thinking is foreign to her, and consequently we do not get a picture of the child's characteristics and thoughts but rather of the mother's difficulties in being an "active observer" of her child. The lack of involvement is evident in this mother's short and limited sentences and lack of engagement in a "dialogue" between herself and the video.

When asked to describe her child more generally, the mother uses only positive adjectives:

"Generous, curious, good-hearted, creative." Here, as well as throughout the text, we see another feature of the disengaged category: Lack of complexity, as evident in the mother's exclusive use of positive adjectives, leading to a narrow view of the child that does not leave room for less favorable, worrisome, and challenging behaviors.

The mother is subsequently asked to support each adjective with an example from everyday life. She provides adequate support for the adjective "creative": "He takes all kinds of objects and does something with them…. He can take a garbage bag and call it a kite, or connect a stick with a string and he has a kite, or build a tent with ropes and cloth."

With regard to the other adjectives, the mother has difficulties to provide episodic support, however.

I: "You said curious… do you have an example from everyday life"?

M: "He is interested in things, he asks questions."

I: "And an example for good-hearted"?

M: "He gives things."

Although this mother was able to provide good and vivid support for the "creative" adjective, her answers regarding the remaining adjectives were no more than dictionary definitions without personalized episodic support. Such support is needed to provide a complex and individualized picture of the child.

In the last question of the interview, the mother is asked "are there things that make you happy or concern you with regard to your child." The mother answers:

M: "Yes, when his responses are like others, it makes me happy, and when it is different, it concerns me."

For the first time in the interview we get a hint, albeit small, that the mother has concerns about her child when he behaves "differently." However, this point is mentioned only very briefly, with no elaboration, reflection, or contextualization, and is quickly followed by a return to stressing positive dimensions. The mother says: "He is very compliant, add this to the list, when he gets an explanation he does what you ask." It is as if even a very brief mentioning of anything less than positive about her child, possibly reflecting the child's difficulties, is too threatening and needs to be quickly minimized and balanced with positive and "normal" behavior.

In summary, when asked what was going on in her child's head, this mother does not try to think about her child's inner world with its depth, complexity, and challenges. This is reflected in a text that, although positive, does not portray a full, multidimensional, vivid, and genuine picture of the child and stays at the level of overt behavior.

Implications of Insightfulness for Parent-Mediated Interventions

Before discussing the implications of an insightfulness approach to parent-mediated interventions, a general comment is in place. As mentioned above, our premise is that the "language of insightfulness" is relevant to many if not all intervention approaches that are mediated by parents. This may include interventions that focus on insightfulness or related constructs that involve increasing the parents' awareness and understanding of the inner world of the child but also interventions that do not have such a goal. In all cases of parent-mediated interventions, the parent carries out the intervention and has to apply it flexibly and appropriately outside of the intervention session for the intervention to be effective. Therefore insightfulness may not only be helpful for such application but in fact be necessary. By this we do not mean that interventions should incorporate the insightfulness assessment as such and in the way it is used in research. Rather, what may be helpful for clinicians is familiarity with the general principles of insightfulness and the dimensions and categories we described, what we call the "language of insightfulness."

The first point regarding application of insightfulness involves the distinction between the two levels of analysis of insightfulness interviews: the higher level of the four insightfulness categories (PI, Os, De, Mx) and the lower level of the ten insightfulness scales (see Table 8.1). In most research applications, the main focus has been on the insightfulness categories, with the scales primarily aiding coders as a stepping stone to the categories. However, in the clinical arena, things may be different: Focusing on the scales and the dimensions they represent may be very helpful, sometimes even more than the overall categories. For example, a parent can be classified before intervention as one-sided due to being overwhelmed with concerns (which will be captured by high scores on the concern scale and probably also on shift of focus) as well as holding a negative view of the child (which will be captured by the lack of acceptance and possibly hostility scales). Following the intervention such a parent may remain with high concern regarding the child but may show a much less negative and a much more positive view of the child. This parent's overall classification may still be one-sided, although the gains made may be of great importance for both parent and child. In addition, the improvement in some of the scales may represent a step along the way to a more fundamental shift at the classification level from lack of insightfulness to insightfulness at a later point. For example, perhaps additional treatment is needed to make more progress or therapeutic gains. Such gains may initially be fragile and vulnerable to fluctuations and may need more time to become consolidated. These possibilities remain intriguing clinical and research questions.

An additional advantage of focusing on the IA scales is that they can assist in creating an individual profile for each parent. Each of the IA classifications can be expressed in various constellations of the IA scales. For example, a parent can be classified as insightful primarily due to showing high acceptance and richness and moderate insight or due to high scores on the openness scales and moderate acceptance. Or a parent can be classified as one-sided primarily due to being flooded by concerns about the child and focusing on the self or due to anger and lack of acceptance of the child. In both of these cases, the parents are equally insightful (in the first example) or non-insightful (in the second example), but the specific expressions of the respective classifications are somewhat different. Identifying the specific profile of each parent may be of great importance clinically because it can help tailor the intervention to the parent's profile. The profile helps identify the specific domains of difficulty and focus the intervention on these domains. For example, if the most salient dimension of a non-insightful parent is being overwhelmed by concern, the first priority may be to try and lower such concern. Additionally, using the profile the clinician can identify the parent's strengths (e.g., open thought process) as well as the difficulties (e.g., lack of acceptance) and make use of such strengths in order to overcome some of the difficulties.

We highlighted the importance of the IA scales and the dimensions they represent for clinical work, but the final point we raise goes back to the IA classifications. Here we argue that identifying the parent's overall strategy or way of thinking about the child's inner world– equivalent to the IA classifications– can be useful clinically. The four IA classifications– positive insightfulness, one-sided, disengaged, and mixed– represent four different approaches of the parent to the task of figuring out the motives underlying the child's behavior. The PI classification represents an open, flexible, and positive stance; the Os classification represents an overwhelmed, incoherent, and one-sided stance; the De classification represents a distant, minimizing, and "surface" stance; and the Mx classification represents a mixture of contradictory stances. Understanding these general characteristics can be useful for the clinician in planning how to deliver various interventions. For example, if the parent is insightful, the clinician can use a wide range of techniques based on the child's needs because they can rely on the parent's insightfulness and flexibility both in order to understand and learn the intervention and to apply it correctly. Working with non-insightful parents, by contrast, may require adapting the intervention not only to the child but also to the parent's stance. For example, when working with a one-sided parent, the clinician has to keep in mind the parent's tendency to become overwhelmed with emotions, self-focused, and highlight only negative or positive aspects of the child, whereas when working with a disengaged parent, the clinician may need to keep in mind the parent's tendency to distant the self from painful emotions, reject discussions that may elicit such emotions, and insist that the discussion remain at the level of behavior.

Finally, an understanding of the parent at the level of the overall stance related to the inner world– i.e., the parent's IA classification– can also help clinicians understand and deal with their own emotional reactions to the parent. Depending on the clinician's own characteristics, he or she may have distinct responses, both positive and negative, to the range of parental insightfulness stances. Working with insightful parents is likely to elicit in most therapists and interventionists empathy and feelings of effectiveness and competence, whereas working with non-insightful parents can elicit more difficult feelings such as being overwhelmed, discouraged, frustrated, or detached (among others). Awareness and acknowledgment of such emotional reactions within the clinician can contribute to an empathic understanding of the parent and are likely to enhance the parent's and child's benefit from the intervention.

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Part III

Principles of Family-Centered Practice

9

Facilitating Toddlers' Social Communication from Within the Parent-Child Relationship: Application of Family-Centered Early Intervention and Mediated Learning Principles

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Abstract

Two complementary theoretical orientations, family-centered early intervention and mediated learning, provide guidance for parent-mediated intervention for toddlers on the autism spectrum. Early intervention for infants and toddlers with disabilities and their families has evolved toward a set of practices that are family-centered, relationship-based, situated in natural environments, and embedded in natural experiences. Mediated learning emphasizes competency-oriented principles that promote "learning to learn" through focusing, organizing and planning, giving meaning, encouraging, and expanding. This chapter describes the integration of early intervention principles within a mediated learning framework to cultivate developmentally important social communication competencies for toddlers with autism. The aim of this approach is to embed relationship-based learning in naturally occurring interactions and to build on prior learning and personal interests as a means of promoting learner self-efficacy, motivation, and active engagement in the social learning process. This integrated framework provides a structure to guide both parent and toddler learning by actively facilitating parents' conceptual understanding and confidence for supporting toddler social engagement.

For toddlers, the parent-child relationship is a prime venue for learning, and when social communication challenges of autism are added to the picture, this relationship takes on special importance. Parent-mediated intervention, to the extent it supports a central role for families and promotes active involvement in the learning process, has the potential to harness the parent-child relationship toward critical intervention priorities while safeguarding the parent's primary role as nurturing caregiver. Two theoretical orientations, family-centered early intervention and mediated learning, contribute guiding frameworks that support a strong parent role in promoting toddler learning. This chapter describes how these complementary schemas can be applied synergistically to build family capacity for supporting social communication learning for toddlers on the autism spectrum.

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_9

As described below, the components of an integrated early intervention/mediated learning framework are aimed at helping parents guide interaction to support their toddlers' full integration into family life, developing both parents' and toddlers' sense of competence in their mutual engagement, and providing a strong social foundation to support broad-based learning across domains and settings. This orientation emphasizes toddlers' current and potential competencies over perceptions of deficit or disorder. A competency-based emphasis is important in parent-mediated intervention in which parents' belief in their children's potential is necessary to sustain their active involvement. In short, this framework promotes a view of toddlers and parents who bring competencies to and are actively engaged in a mutually interactive learning process.

Early Intervention Principles of Practice

The early intervention (EI) field has united around a theory of practice in which families and homes are a primary intervention venue for infants and toddlers with disabilities, intervention is provided collaboratively with families and is oriented toward relationships, and child learning is embedded in natural experiences (Odom & Wolery, 2003). Directly supporting caregivers to facilitate their children's development has been found to impact families' sense of empowerment and to predict positive child outcomes, and infants and toddlers whose parents received focused help to support child learning showed greater progress than those who received direct intervention from professionals (e.g., Dunst, Bruder, Trivette, & Hamby, 2006; Thompson & Lobb, 1997).

Policy and Recommended Practices for Toddlers and Families

Essential aspects of family-centered services and supports were promulgated into law in Part C of IDEA ("Individuals with Disabilities Education Improvement Act, 20 U.S.C. § 1400," 2004), key features of which set EI apart from educational provisions for older children. These features include a dual focus on the child and family, an orientation toward helping families support their infants' and toddlers' growth, and full integration of intervention in natural environments. The theoretical and policy provisions of family-embedded early intervention, along with scientific research and experiential knowledge and values gathered from stakeholder groups, gave rise to an evolving set of recommended practices to guide intervention for young children with disabilities and their families (Division for Early Childhood, 2014).

The National Association for the Education of Young Children (NAEYC) has also delineated recommended practices for young children (Copple & Bredekamp, 2009), and for toddlers specifically (Copple, Bredekamp, Koralek, & Charner, 2013), that are important if toddlers' status as young children and family members, rather their diagnosis, is to be viewed as their primary defining characteristic. The NAEYC guidelines for developmentally appropriate practice emphasize the importance of nurturing adult-child relationships, cross-domain learning, reciprocal family-professional relationships, active involvement in the process of learning, providing scaffolding to challenge children just beyond their mastery level, play as a learning vehicle, and confidence- and motivation-enhancing experiences.

Part C policies and early childhood special education- and NAEYC-recommended practices have been distilled into a set of four broad principles of early intervention (Schertz, Baker, Hurwitz, & Benner, 2011). The principles call for practices that (1) strengthen parent-child relationships and enhance the family's capacity to promote the child's development, (2) are provided in natural environments and integrated throughout typical everyday experiences, (3) promote an active child role in learning by enhancing child motivation and self-initiated learning across environments, and (4) use systematic and functional practices that challenge children just beyond their mastery level, recognizing individual differences. In a review of the extant toddler autism intervention research, 27 studies were evaluated for their interventions' congruence with these principles (Schertz et al., 2011). The most pronounced gaps in reported intervention practices with respect to EI principles were in the areas of natural and inclusive environments and family-centered and family supportive practices. Overall, the reported interventions appeared to align more closely with autism – than with EI-related recommendations, as indicated by more references to National Research Council (NRC) recommendations (Lord & McGee, 2001) than to Part C or EI recommended practices, perhaps accounting for their incomplete adherence to EI principles.

The need for increased attention to EI principles in early intervention designs for toddlers on the autism spectrum is beginning to gain recognition. A group of early intervention researchers recently called for interventions to incorporate some of the practices embodied in EI principles, including intervention methods that are naturalistic and developmentally appropriate, that involve families, that combine developmental with behavioral approaches, and that are integrated within natural settings (Schreibman et al., 2015). These researchers also acknowledged the need for more finely tuned study based on meaningful measures of functional change, active ingredients of interventions, more tailored intervention designs, and interventions' transportability to community-wide applications.

Intervention Considerations in Relation to EI Principles

One unresolved issue with respect to EI principles is that of intervention intensity or dosage, which may need a fresh look as it relates to intervention for toddlers on the autism spectrum and their families. The oft-cited recommendation of at least 25 h per week of intervention for young children with autism (National Research Council, 2001), often interpreted as time spent in face-to-face, professionally delivered intervention, was not based on research with children under age 3 because toddler screening and diagnostic procedures were not yet in general use at the time. Future research is needed to determine whether, or the extent to which, highly intensive professionally delivered intervention for toddlers on the autism spectrum has an independent effect on meaningful and important long-term outcomes. Another question for investigation concerns the compatibility of intensive professionally implemented interventions with recommendations for developmentally appropriate and family-centered practices. Parent-implemented interventions are now being more widely reported for toddlers on the autism spectrum; however, dosage, fidelity, quality, and child responsiveness are difficult to capture and measure in these models (Lieberman-Betz, 2015). Therefore, further research is also needed on intervention design conditions, meaningful outcome measures, and compatibility with key EI principles for parent-implemented intervention approaches.

Other broader variables may influence intervention outcomes. Some potential influences, which are also not yet well studied in relation to toddlers on the autism spectrum, are relevant to consider when designing interventions that incorporate EI principles. These include the degree to which the intervention (a) systematically focuses on developmentally sensitive core autism-related difficulties, (b) is relationship-based and integrated within natural interactions and routines, (c) promotes learner self-efficacy, and (d) accounts for influences known to affect early learning processes, such as motivation and child initiative. A discussion of each follows.

Well-targeted early intervention focus The dual challenges of social communication and repetitive and restrictive behaviors (American Psychiatric Association, 2013) take different forms for toddlers than they do for older children and adults on the autism spectrum. Evident at the preverbal level before verbal language emerges, toddlers on the autism spectrum experience social communication difficulties in the form of absent or diminished joint attention and other nonverbal forms of social communication and reciprocal interaction (Adamson, Deckner, & Bakeman, 2010). Such preverbal indicators have been found in replicated research to be foundational for verbal communication and related social and cognitive competencies (Bottema-Beutel, 2016; Charman, 2003; Freeman, Gulsrud, & Kasari, 2015; Gillespie-Lynch et al., 2012; Mundy & Newell, 2007; Poon, Watson, Baranek, & Poe, 2012; Tomasello, Carpenter, Call, Behne, & Moll, 2005). Thus, intervention focusing directly on the core challenge of social communication at the toddler's current level of functioning (i.e., usually at the preverbal level) is essential for laying a foundation from which other learning can be leveraged.

Unusual signs of repetitive behavior, the second core characteristic in autism, begin to appear in the second year for toddlers with autism when groups with and without later diagnoses are compared (Morgan, Wetherby, & Barber, 2008); however, there is considerable overlap between the groups in their manifestation of repetitive behaviors, which are a feature of typical as well as atypical early development (Barber, Wetherby, & Chambers, 2012). Perhaps as a consequence, intervention research in this area has been more limited than social communication-focused research. Although strategies to address repetitive and restrictive behavior (RRB) have been tested for (mostly) older preschoolers, their effects are as yet not well known, as specific RRB-focused intervention targets and associated primary outcome measures have not been widely reported (Harrop, 2014).

Integration in the natural environment The second consideration for designing interventions compatible with EI principles is the extent to which learning opportunities are integrated within natural everyday experiences. This variable may serve as a proxy for intervention intensity – but in a more developmentally appropriate manner than adult-directed didactic formats would allow. Social communication learning for very young children occurs primarily through interactions embedded in the parent-child relationship. The quality and focus of these relationships play a critical role in early learning with the potential to enhance learning in other developmental domains (Li & Julian, 2012). A challenge for interventionists is to provide caregivers with effective guidance to fully comprehend learning goals and processes, enabling them to flexibly "think on the fly" as they provide targeted learning opportunities seamlessly throughout daily interactions, activities, and caregiving routines. The effectiveness of relationship-based learning depends in part on the skillfulness with which parents support their children's preverbal social engagement through scaffolding, responsiveness, and positive emotional reactivity (Legerstee, Markova, & Fisher, 2007; Siller, Hutman, & Sigman, 2013; Vaughan et al., 2003). Relationship-based learning is bidirectional and transactional with both partners contributing to forward momentum in the learning process. In one example of this phenomenon, the child's contribution to relationship-based learning is illustrated in a parent-implemented intervention for toddlers on the autism spectrum in which, as toddlers' negative expressions decreased, parents' positive scaffolding increased (Gulsrud, Jahromi, & Kasari, 2010).

Researchers of early development have characterized parent-infant interaction as the primary medium through which meaning develops (Beeghly & Tronick, 2011). Compared to other forms of learning, social communication may be less amenable to traditional training approaches that require the child to follow directions – an instrumental form of interaction – than to opportunities for socially meaningful engagement in which a child interacts with a partner on a more equal basis. Unlike scripted or other instrumental forms of communication, authentic social engagement requires an awareness of and appreciation for a communication partner's perspective and the ability to share attention with the partner in relation to their common interests (Tomasello, 2007). It should be noted that children with autism tend to be relatively proficient with instrumental forms of communication such as following directions or requesting; it is the explicitly social forms, such as "commenting" or response to others' comments through gaze shifts in reference to an object, that present particular challenges for them (Mundy, Sigman, Ungerer, & Sherman, 1986). These more strictly social forms of communication are context dependent and may require more internal motivation and awareness of others' perspectives than do regulatory skills such as following directions, labeling objects, imitating actions, or regulating problem behaviors. Similarly, because of its contextual variability, social communication may be less amenable to intervention strategies that are bound by time or place or that are designed to elicit specific predetermined behaviors.

As early social communication is embedded within supportive relationships, it becomes naturally integrated within the routines and activities of everyday life. Further, to the extent that natural venues are used as learning opportunities, learning becomes more easily integrated into the child's repertoire than if it were conducted as separate training sessions divorced from everyday experiences. Integrating early learning within toddlers' natural experiences also avoids the need for separate "generalization training" to transfer formally taught skills to natural settings, as would be needed if intervention was conducted in separate settings by professionals who were not otherwise a part of toddlers' daily lives.

Promotion of parent self-efficacy A third influence, self-efficacy, or the perception of oneself as competent, is theorized to interact bidirectionally with environmental influences to produce change, in part because, without a belief that one's actions would produce an effect, there would be little incentive to act (Bandura, 1997). Thus, in self-efficacy theory, individuals have agency and are not viewed as mere reactors to environmental influences. A complex transactional relationship has been found between parent self-efficacy and a range of variables, including parent responsiveness in parent-child interaction, child and family characteristics, family functioning, the parent-child relationship, parental sense of well-being, and child social-emotional and developmental outcomes (Guimond, Wilcox, & Lamorey, 2008). Secondary benefits are also suggested in findings that parenting self-efficacy moderates the relation between autism severity and measures of parent mental health for parents of children on the autism spectrum (Hastings & Brown, 2002). Further, building competence in primary caregivers may have a compounding effect. As parents gain knowledge and skills to promote social communication and apply it in daily interactions, they see positive results from their efforts, which in turn circles around to strengthen their self-efficacy and bolster motivation to continue building on their own accruing success and that of their children.

Parents' direct involvement in intervention appears to play a role in their understanding of their own competence to support their children's development. In a study comparing a partnership approach with a clinician-directed approach for teaching parents of toddlers with ASD to implement intervention, parents in the partnership condition showed increased confidence compared to those in the clinician-directed condition (Brookman-Frazee & Koegel, 2004).

Active engagement in the learning process A fourth variable with potential for enhancing intervention effects for toddlers with social communication challenges concerns broad-based conceptions of learning that consider individual or transactional contributions to the learning process. A number of theories with relevance for promoting social engagement for toddlers with autism take into account internal or situational influences on early social learning. Examples of these theory-based influences include the dynamic relationship between current and prior learning (Smith & Thelen, 2003; Vygotsky, 1978), context-based participation (Lave & Wenger, 1991), ecological systems (Bronfenbrenner, 1992), self-efficacy (Bandura, 1997), culture (Rogoff, 2007), neural dynamics (Shonkoff, 2010), the social environment (Vygotsky, 1934/1986), and integration of environmental and biological influences (Sameroff, 2010). A commonality among these learning theories is that each attributes agency to the individual learner, who is seen as an active contributor to the learning process. Addressing the question of whether toddlers are active learners, as had been found for older children, Chen and Siegler (2000) studied toddlers' cognitive processes and found that, like older children, toddlers approached problem-solving experiences by expanding on their earlier learning and transferring it to new contexts and challenges, thereby actively integrating earlier learning to address new problems. One framework that incorporates precepts of learner competence, socially and culturally based learning, contextualized learning, and learner self-efficacy is mediated learning, which we describe next in relation to social communication learning for toddlers on the autism spectrum and their caregivers.

Mediating Learning: Fostering Active Involvement in the Learning Process

Toddlers on the autism spectrum, like their older counterparts, may show advanced learning in areas of targeted individual interest, learning that is guided primarily by internal motivation rather than adult direction, and in which children appear to generate their own learning by pursuing their individual specialized interests. A challenge for interventionists and parents is to help toddlers acquire a similar internalized drive to learn in areas that are relatively difficult for them, such as social communication, for which they may be less motivated to advance their own learning. One approach to encouraging motivation for self-directed or generative learning in social communication for toddlers with autism is to garner children's active engagement in social interaction, a central goal of mediated learning. The following section describes how mediated learning principles might be applied to promoting social communication learning for toddlers with autism-related concerns.

Sociocultural learning theory As interpreted in the Vygotskian social learning tradition, early learning is internalized through interactions with competent adults in everyday participation-based activities that are sensitive to children's current knowledge or skill levels (i.e., occur within the zone of proximal development) in familial culturally based contexts (Cole, 1985). Rogoff advanced the idea of guided participation as an ingredient in early developmental learning that generates a process of enhanced understanding (Rogoff, 1990; Rogoff, Mosier, Mistry, & Goncu, 1993). In this theory, awareness is created through socially guided mutual engagement that builds on prior knowledge and interests to create a new level of understanding. Guided participation-based learning contrasts with a more directive process of "importing an external process to the internal plane" (Rogoff et al., 1993, p. 229), that is, by incorporating learner contributions to the learning process rather than attempting to implant ready-made predetermined learning protocols into the child's repertoire. In other words, the child does not simply internalize pre-formed training regimens but is an active participant in the process of learning, sharing the learning agenda. In this view, the learning process is not separated from the learning outcome. Rogoff's et al., (1993) research showed that middle-class US parents assumed a more didactic role in interaction with their toddlers than did those from an indigenous culture in which children had more responsibility for learning, although both used guided participation to different degrees.

Mediated learning foundations Operationalizing Vygotsky's (1934/1986) social learning theory, Feuerstein (1980) described mediated learning as a theory of cognitive modifiability focused on broadening set patterns of thinking, countering resistance to change, and increasing awareness of others' perspectives. Although initially implemented with adolescents identified with cognitive disabilities (many of whom may have had ASD diagnoses if evaluated today), Feuerstein's theory would seem to carry particular relevance to designing intervention for those on the autism spectrum because of its focus on broadening thinking patterns and awareness of others' perspectives – both particular challenge in autism.

Klein (1996) extended Feuerstein's model to parents' mediation of infant cognitive learning, describing it as systematic promotion of flexible thinking through socially and culturally contextualized processes. In this way, mediated learning aims to extend the benefits of learning opportunities. As an active view of learning that is less didactic than some models, this approach is framed around promoting the child's ability to focus on what is important to learn, to self-regulate behavior, and to recognize their success (Klein, 2003). Mediated learning is socially based; that is, it does not occur as isolated training-oriented tasks divorced from the social environment but is integrated into everyday interactions. Because it focuses on building capacity to learn rather than on short-term skill attainment alone, benefits may be most evident in the long term. Three-year follow-up studies found sustained and even increased gains from the mediational intervention for sensitizing caregivers (MISC) intervention that was implemented in Israel and applied cross-culturally in Europe, the United States, Ethiopia, Sri Lanka, and Indonesia. Widely adaptable, the approach has been studied with families who experienced a wide variety of challenging child and family conditions, including Down syndrome, very low birth weight, communication difficulties, neglect, and extreme poverty (Klein, 2003; Klein & Aloni, 1993). Essential features of MISC include targeted support to caregivers in the home setting, flexibility in cultural interpretations, encouragement and acceptance to support parents' awareness of their own competence, regular and systematic review of parent-child interaction videos in relation to mediation criteria, a focus on everyday interactions, responsiveness to child initiations, and promotion of parents' positive perceptions of child potential.

The mediated learning approach closely aligns with the EI principles described above. Both are relationship-based and focus on enhancing the family's capacity to promote child development in natural environments through typical everyday interactions. A focus on an active child role in learning is emphasized in both sets of principles, including promotion of context-independent self-initiation. Finally, both call for the use of individualized systematic practices that are sensitive to the child's current competency level.

Mediating Toddler Learning

A characteristic common to the mediated learning principles is that they all focus on the process of "learning to learn" by building on emerging foundational abilities to enable personal investment in the learning process. The goal of learning to learn extends beyond acquiring specific skills to promoting flexible forms of learning that leverage the child's own interests and resources, that are not task specific, and that are adaptable across contexts. Rather than training in parent/interventionist-determined task-related strategies, the focus is on promoting children's and parents' internalization of learning processes. As defined in the mediated learning principles, these are processes from which learners can initiate flexible and transferrable strategies across a wide range of tasks and activities. These process-oriented competencies, which support active engagement in learning, include focusing on social engagement in the face of competing interests, self-regulation, self-efficacy, understanding the meaning of learning opportunities, and applying learned skills in new social situations.

These targeted mediated learning competencies are broad-based to set the stage for meaningful learning across contexts. The process begins with natural everyday interactions and activities and embeds learning within them as opposed to being adapted from predetermined adult-directed activities that are contrived to make them appear "naturalistic." The active participation and self-determination that this level of learning entails are important because social communication requires motivation and initiative to accommodate wide variations in time, place, and interactive partners.

A mediated learning orientation is incorporated in the Joint Attention-Mediated Learning (JAML) approach, which is designed to foster social communication at a preverbal level for toddlers with autism through guided parent-child interaction (Schertz, Odom, Baggett, & Sideris, 2018). Toddlers on the autism spectrum may have other areas of difficulty in addition to social communication; however, the approach is designed to focus most directly on social communication because of its primacy as a core area of difficulty in autism and because of its aforementioned role in supporting early learning in other areas. JAML's mediated learning principles are adapted from Klein's (2003) criteria. The five principles – focusing, organizing and planning, giving meaning, encouraging self-reliance, and expanding – are interpreted for each phase of intervention and introduced to parents in turn. These principles are operationalized in both parent-child and interventionist-parent interaction. They are identified in parentheses below as examples of their use are illustrated.

Mediation of social learning for toddlers with autism includes both more structured components related to the intervention content and less structured components that allow for flexibility in parents' use of mediated learning principles to translate the content into everyday activities. The intervention content focuses on the social, as opposed to instrumental, functions of preverbal communication and targets engagement at increasingly challenging levels. A developmental framework for building toward increasingly challenging levels of social communication at the preverbal level might take the form described in the following.

In their mediating role, parents apply these five principles to support their toddlers' ability to orient toward relevant learning targets, establish a sense of order and self-control in the learning process, achieve new insights, develop awareness of their own capability, and generalize learning to more complex problems and across contexts. At a first level of engagement, toddlers are encouraged to look freely and often to the parent's face in simple, pleasant interactions that occur with minimal competition from other objects or agendas. The parent avoids instrumental requests such as, "Look at me," seeking instead ways to encourage looks to the parent's face that arise from the child's own volition with purely social motives. To do this, the parent provides playful, engaging, and natural opportunities to look at each other, using the mediated learning principles as a framework. For example, before she begins a play session, a mother considers how she will help her child's looks to her face become the most important part of the play (*focusing*) and may decide to begin by positioning herself upright on the couch with the child facing her on her knees (*organizing and planning*) to play a game of "horsey-ride." As the parent bounces the child on her lap, the sole agenda is to watch each other's expressions of delight (*giving meaning*). Each time the child looks to the parent's face, the parent smiles broadly and nods (*encouraging*). As the child begins to look more fully and reliably at the parent's face, the parent intentionally introduces some variability into the game to ensure the child can continue to look at her face as circumstances change, at first perhaps adding a song to the play then later using that same song to promote face-looking during bath time (*expanding*).

At a second level – when attention to the parent's face is well established – the child is helped to engage in reciprocal repetitive play that requires tacit acknowledgment of the partner's shared interest, such as waiting for the parent to take a turn. The parent begins to help the child build competency to engage in back-and-forth interactions. The parent avoids deviating from this agenda with activities that are more easily accomplished alone (e.g., completing puzzles), activities that have unrelated goals like naming shapes or colors, or directives such as "take a turn" that are more likely to promote passive direction-following than active social engagement. Parents encourage reciprocal interaction by taking advantage of naturally occurring repetitive activities that the child enjoys. For example, a father may consider how he can enter into his daughter's solitary activities in a way that gives opportunity for reciprocity to become the most important part of the play (*focusing*). He may decide to take advantage of the child's repetitive finger tapping by first waiting for the child to begin (*organizing and planning*). When she begins tapping her fingers on the table, he leans in close and uses his own hand to emphatically "bang-bang" on the table, then pauses in a silly, exaggerated way that invites the child to tap again (*giving meaning*). When she does, the father laughs and answers with another "bang-bang-big pause" (*encouraging*) and continues this back-and-forth tapping for as long as his daughter holds interest. When she is responding readily and consistently and waits with anticipation for her father to take his turn, he intentionally introduces variability into the play by changing the tapping rhythm and later playing a rhythm game with spoons and forks after dinner (*expanding*). This reciprocal engagement helps to set the stage for joint attention, a triadic form of engagement that includes an external focus, and is a predictor of verbal communication (Carpenter, Nagell, & Tomasello, 1998; Mundy, Sigman, & Kasari, 1990).

This third level of preverbal social engagement, joint attention, often begins naturally in somewhat more complex reciprocal interactions between the toddler and parent that include shared attention to a toy or other object of common interest. In joint attention the child initiates or responds to bids for attention in relation to the object. Initiating bids have a purely social function of "commenting," which take the form of social sharing (e.g., showing) rather than being governed by underlying instrumental motives of requesting. Similarly, responses to partners' bids are also motivated by social rather than instrumental interest. In other words, the sole purpose of sharing interest in relation to the object or event is to communicate about it out of shared social interest rather than to address one's own preferences or to respond to another's direction. In one study, when parents approached their toddlers with social, as opposed to instrumental initiations, toddlers were likely to respond socially rather than instrumentally, indicating the importance of a socially focused intervention approach (Schertz et al. 2018).

To promote the child's ability to show joint attention, the parent invites the child to share interest in an object by choosing activities that include a surprising or novel element to elicit nonverbal commenting through exchanges of looks between the object and the partner while avoiding directives. For example, a mother may begin by considering how she can best facilitate making shared interest in an object the most important part of the play (*focusing*). She decides to use a favorite stuffed elephant and thinks about what games would naturally entice her son to look between the elephant and her face (*organizing and planning*). She decides to use the elephant to play a kissing game. First, she looks intentionally at her son and waits for him to look back. Then she shows him the animal by holding it out between them, looking at it with wide eyes and saying excitedly, "Oh, Elephant wants to give me a big kiss!" Then she waits expectantly for him to look at the elephant while playfully moving it or touching his hand to it to draw his look to the toy. She then draws his look back to her face by moving the elephant up to her mouth while making an anticipatory kissing sound (*giving meaning*). The parent and child continue to take turns kissing the elephant, with the parent patiently allowing time for gaze shifts between the toy and her face and acknowledging her child's success with loving smiles (*encouraging*). At bedtime she modifies the game by asking him to show her all the stuffed animals in his bed as they kiss them goodnight (*expanding*).

These preverbal social communication targets can be operationalized for parents in verbal, written, and video forms to help them conceptualize their meaning and their importance to the child's social and communicative development, how they look when a child is engaging in them, and strategies other parents have used to promote them with other toddlers who are on the autism spectrum. Similarly, other parents' use of mediated learning principles to engage their toddlers at each level can be interpreted and exemplified in verbal, written, and video forms.

Mediating Parent Learning

Mediated learning principles are applied in both parent-child and interventionist-parent interaction. The examples above have illustrated how parents can apply the mediated learning principles to support their children's development of foundational social communication competencies. In like manner, interventionists apply the principles as they consider how their support for parent learning will be provided. In their supportive role, interventionists guide parents' active facilitation of their children's learning by orienting parents toward salient aspects of parent-child interaction that support the phase of intervention (*focusing*), by strategically highlighting relevant features of parent-child interaction (*organizing and planning*), by helping parents discriminate between aspects of parent-child interaction that are and are not effective and relevant to the current intervention emphasis (*giving meaning*), by facilitating parents' recognition of their impact on the child's social communication development (*encouraging*), and by engaging parents to add breadth and depth to interaction opportunities (*expanding*).

A number of general strategies can be considered to bolster parents' leadership role in the intervention. An active parent role is important to assure robust integration of social communication within incidental learning opportunities that occur throughout the day. Parents' competence (based on conceptual clarity and initiative) and confidence (appreciation of their ability to support their children's development) are both important components of an active parent role in a mediated learning approach.

Promoting parents' conceptual clarity The interventionist begins the process of bolstering parents' active leadership by actively and systematically supporting their understanding of the central tenants of the intervention content (*focusing*). A first step to supporting parents' competence in mediating their toddlers' social communicative learning is to provide conceptual clarity on the foundational importance of the intervention goals, both as relates to the goals' relevance to core difficulties in autism and to their theoretical and evidentiary importance for future development. This conceptual base is needed for the overall intervention framework and for each of its developmentally sequenced components, including how each provides a foundation for succeeding levels of preverbal social communication, for more advanced verbal forms of social communication, and for related learning domains.

A second element associated with promoting conceptual clarity relates to how the specific targeted social communication outcomes are defined. These definitions or descriptions answer questions such as: How does reciprocal interaction look in toddler-parent interaction when a strong social element is or is not incorporated? What are indicators that a child is engaging in reciprocal interaction in ways that take the partner's separate role into account, such as by waiting for the partner's turn in back-and-forth interaction? How can we distinguish between social and instrumental functions when sharing attention around objects? Concepts generated from these questions can be demonstrated through multiple media. In our research, parents have been most responsive to video examples of other toddlers with autism demonstrating the relevant targeted outcomes.

A third element of conceptual clarity concerns parents' understanding of mediated learning principles. For some it may be a conceptual leap to understand parent-child interaction as more relational than didactic when it comes to helping children learn. The goal in a mediated learning approach is to guide the child toward taking an active role in her own learning and to engage socially through shared interaction rather than responding passively by following instructions. As described above, the mediated learning process orients the child toward active learning in order to add depth and ownership to the social learning process. Written, verbal, and video examples of other parents applying mediated learning principles are used to promote conceptual clarity about the mediated learning process, similar to the process used to help parents understand the targeted outcomes.

As parents conceptualize the current intervention focus with respect to the mediated learning principles, they are also guided to identify everyday activities and interactions to which they will translate the intervention content. This component focuses on how daily activities and caregiving routines can be adapted to promote current social communication outcomes. Parents are helped to take on a leadership role for this component since they are considered the experts with respect to their children's interests and aversions, family priorities and preferences, family routines, and cultural and language orientations.

The interventionist acts as a "guide on the side" to help parents assess the connection between the relevant intervention content and daily activities, that is, how the adapted activity or caregiving routine captures the essence of the currently targeted social communication competency. It is the intervention strategies rather than the intervention content that are the more context-dependent, and when parents assume leadership in translating intervention content into everyday parent-child interaction, accommodation to language and cultural preferences becomes a natural process because professionals are not dictating intervention activities and strategies. The overarching focus on preverbal social communication is assumed to be universally desirable, however interventionists should expect cultural variations in the form it takes for families who will have varying views of how parents and children should interact with one another.

Promoting parent confidence to support their children's learning In addition to supporting parents' competence, understanding, and faithful translation of intervention content into daily interactions, parents' confidence in their ability to promote their toddlers' social development and their belief in their children's potential to learn also play a role in their effectiveness. Interventionists can draw from a variety of strategies to support parents' understanding of their own and their children's competence and potential. For example, in the JAML approach, after parents are presented with the rationale and framework for the intervention content and mediated learning principles, translating this content into intervention activities becomes more open-ended and under direct parent control. To emphasize parents' expertise in devising intervention activities for integration into daily interactions, the interventionist avoids prescribing specific activities and instead presents ideas successfully used by other parents as "jumping-off points" from which the parent may invent her own activities (*organizing and planning*). These "ideas other parents have used" may be presented in multiple formats to illustrate parent-developed variations that are true to the current intervention content and mediated learning principle(s) while representing a range of cultural and familial values or preferences. Drawing from other parents' examples is one way to highlight parents' expertise to creatively integrate their own activity ideas into the intervention framework.

Other intervention strategies support parents' understanding of and appreciation for their own competence in guiding their children's learning. One approach central to the mediated learning framework is guided reflection on parent-child interaction during each intervention session. While filming weekly videos, the interventionist acknowledges the parent as a competent leader by remaining silent for the duration of the recorded interaction. No instruction or commenting is given, and the interventionist refrains from interacting with the child. The interventionist's back seat role during parent-child interaction is an intentional strategy to honor the parent-child relationship and the parent's primary role with the child (a detailed discussion of video feedback strategies is provided in Chap. 14).

The video is viewed immediately after being recorded, and the parent is encouraged to watch the interaction from a new vantage point – that of an expert observer. To promote parent self-efficacy, an equal partnership is encouraged. Through guided reflection on the video, the interventionist mediates the parent's more advanced learning of intervention content and processes in ways that enable the parent to internalize and incorporate them in parent-child interactions (*giving meaning*), and the parent uses this knowledge to mediate the child's ability to drive his own social learning. Parents are encouraged to take the lead in the video reflection process, while the interventionist initially functions as a questioner and listener. The interventionist encourages the parent to talk about what was happening in the interaction, to consider why they think initiations and responses occurred as they did, and to become aware of how the interaction felt to them. Questions are designed to draw out the parent's understanding of how the child interacted with them with respect to the current targeted outcome and mediated learning principle(s) and what parent actions seemed to facilitate the child's strongest engagement. Later, the interventionist may point out additional examples of positive instances in which the child's proactive engagement seemed to relate to a parent action (*encouraging*). To support self-efficacy, the interventionist refrains from highlighting negative examples, knowing that the parent will likely recognize and comment on them if they occur. If the parent describes a negative example, the interventionist may ask the parent to imagine alternative ideas for supporting the child's social engagement (*expanding*). It may be difficult initially for a parent to understand the difference between directing and facilitating their child's learning. This kind of reflective video review process is meant to enhance parents' understanding of how their actions can help their toddlers "learn to learn." When successful, the intervention is transformed from a parent-directed to a parent-mediated endeavor.

Summary

This chapter used a two-pronged focus to address intervention design considerations for toddlers who are identified with early concerns related to autism. The first concerns principles of early intervention that apply to all toddlers, including those with disabilities. These principles focus on integrating services and supports in the context of family systems and natural environments, promoting active child and family engagement in the learning process, and approaching intervention systematically. A second set of principles, complementary to the first, addresses the process of mediating child and parent learning. Mediated learning principles focus on promoting active learner attention to the *process* of learning to foster a capacity for "learning to learn." These principles involve the learner in focusing on specific learning targets, organizing and planning to facilitate active engagement, making meaning from learning opportunities, developing self-reliance and belief in one's competency, and integrating learning across contexts and time in everyday activities.

Acknowledgments We would like to acknowledge the support and assistance of our research colleagues Samuel L. Odom, Kathleen M. Baggett, Penny Githens, Stacia Mitchell, and Martha Lee. The conceptual framework for this chapter evolved in part through research on the Joint Attention Mediated Learning project with funding support from the Institute for Education Sciences, US Department of Education, #R324A120291.

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10

Strength-Based Approaches to Working with Families of Children with ASD

Amanda Mossman Steiner and Grace W. Gengoux

Abstract

The goal of this chapter is to provide an overview of strength-based approaches to working with young children with ASD, emphasizing the application of positive, strength-based techniques as a core part of parent education programs. We begin by providing a historical context for the increasingly popular focus on strength-based assessment and intervention in broader psychology and education fields and also provide a brief rationale for this trend by reviewing some of the many benefits of focusing on strengths. In addition, we discuss reasons that strength-based approaches may be especially powerful for families of children with ASD, given elevated levels of stress and depression in this parent population. The remainder of the chapter is focused on exploration of specific ways in which child and parent strengths can be incorporated into early intervention efforts. We specifically review strength-based assessment models, interventions which deliberately incorporate child strengths, the use of strength-based statements by clinicians as a means of promoting positive parental adaptation, as well as optimism training and mindfulness practices for parents.

While interventions aimed at changing child and parent behavior by default often emphasize areas of weakness, it is also possible to deliver effective interventions while incorporating greater emphasis on child and parent strengths. Termed a “strength-based” approach, this technique may be particularly powerful for families of very young children with ASD, as they are still in the process of understanding the implications of the diagnosis and forming a narrative for coping with a new family reality. This chapter is intended as a resource for professionals working with young children with autism and their families. The aim is to inspire interested individuals to incorporate strength-based practices, through a wide range of practical strategies which can be used alone or in combination. Although much more research is needed in this area, preliminary evidence suggests that a strength-based focus may have considerable collateral advantages in terms of supporting greater engagement in intervention, parental self-efficacy, and improved family quality of life.

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_10

Rationale for a Strength-Based Approach

Interest in the application of positive psychology (Seligman & Csikszentmihalyi, 2000) in domains ranging from psychotherapy with adults to school assessment (Chafouleas & Bray, 2004) is rapidly growing, and this positive, strength-based approach has clear utility in working with children with disabilities and their families (Cosden, Koegel, Koegel, Greenwell, & Klein, 2006). Emphasizing areas of strength may be particularly relevant to working with parents of children with ASD and may facilitate parental optimism and positive parental adaptation to raising a child with a disability. In particular, individuals who are optimistic are more likely to persevere in challenging situations (Peterson, 2000) and also demonstrate an increased ability to engage in problem-solving behaviors (Scheier & Carver, 1992). Additionally, parental optimism in the preschool years has been shown to predict less severe behavior problems at age 6 (Durand, 2001), even when the children initially presented with more severe issues (Durand, Hieneman, Clarke, & Zona, 2009). If clinicians, in the context of everyday interactions with families of very young children, can aim to facilitate greater parental optimism by employing strength-based approaches, child and family outcomes may be significantly improved.

Enhancing Optimism

Parental optimism has been shown to buffer parenting stress and depression across multiple studies (e.g., Baker, Blacher, & Olsson, 2005; Greenberg, 2004). In a recent systematic review, Peer and Hillman (2014) found that parental optimism, along with coping style and social support, was the primary factor predicting successful parental adaptation to raising a child with a developmental disability. Using structural equation modeling, Ekas, Lickenbrock, and Whitman (2010) reported that among families of children with ASD, increased family support was associated with increased optimism, which predicted more positive maternal outcomes. Moreover, parents who conceptualize their child's behavior in a more optimistic fashion are more likely to participate in and complete intervention (Durand, 2001). In addition to optimism, parental mindfulness, which is defined as an increased awareness of emotions and ability to reframe emotions in an adaptive manner (Bishop et al., 2004), has also been associated with lower levels of maternal stress for parents of children with ASD, even in the presence of significant child behavior problems (Conner & White, 2014).

In fact, professionals may actually overestimate the negative impact of a child with ASD on a family and underestimate parental coping skills (Knussen & Sloper, 1992; Urey & Viar, 1990). Additionally, parents report wanting professionals to be more optimistic in discussions of their children (Nissenbaum, Tollefson, & Reese, 2002). Therefore, while involving parents in early intervention programs, clinicians may also be able to promote optimism and positive parental adaptation to raising a child with ASD.

Combating Parental Stress and Depression

Strength-based approaches have particular promise in the field of ASD given high rates of clinically significant parenting stress, depression, and family discord reported by many families of children with ASD. We review these important issues in detail in the following section to highlight areas that professionals may need to carefully consider when working with families of children with ASD. In addition, we discuss how numerous families find positive meaning in the challenge of raising a child with ASD, as this resilience may hold clues for improving positive adaptation for all families.

Parenting stress. While this chapter is a message of hope and a roadmap to resilience for professionals and parents of children with ASD, it is important to consider that parenting itself is often considered to be a stressful experience (Abidin, 1992; Deater-Deckard, 2004). While parenting stress in general is considered somewhat normative, parents of children with ASD usually report significantly more parenting stress than parents of typically developing children (Eisenhower, Baker, & Blacher, 2005; Hayes & Watson, 2013; Tomanik, Harris, & Hawkins, 2004). In fact, across decades of research (Schopler & Mesibov, 1984), ASD continues to rank as one of the most stressful childhood conditions for parents to manage, consistently above and beyond the reported stress of parenting a child with other developmental disabilities (DDs) or medical conditions (Blacher & McIntyre, 2006; Estes et al., 2013). Whether compared to Down syndrome, Fragile X syndrome, cystic fibrosis, or developmental delay, in the vast majority of studies, parents of children with ASD have significantly higher reported stress levels (Abbeduto et al., 2004; Bitsika & Sharpley, 2004; Donenberg & Baker, 1993; Sharpley, Bitsika, & Efremidis, 1997; Smith et al., 2010).

There are several aspects of parenting a child with ASD that may be specific to the disorder and have been hypothesized to contribute to elevated levels of stress. First, parents of children with ASD often undergo a lengthy and highly stressful process in obtaining an accurate diagnosis for their child, a process which may be absent for parents of children with other developmental disabilities, such as Down syndrome (Moh & Magiati, 2012; Wiggins, Baio, & Rice, 2006). Recent research suggests that parents may even exhibit signs of post-traumatic stress following their child's diagnosis of ASD (Casey et al., 2012). Additionally, ASD is of unknown etiology, with wide variability in prognosis and limited ability to predict outcomes at an early age, and this uncertainty can also contribute to greater levels of stress (Dale, Jahoda, & Knott, 2006). Moreover, because children with ASD do not differ in physical appearance from typically developing children, parents of children with ASD often find trips into the community very stressful, as others will not readily recognize their child's disability as the source for any behavioral issues (Gray, 2002a).

Although the aforementioned factors may be specific to ASD and contribute to increased levels of stress among parents of children with ASD, the most commonly reported areas of stress for parents of children with ASD are not necessarily unique to the disorder. Koegel et al. (1992) found consistent and clinically significant stress profiles for mothers of children with ASD that were similar across geographic area, maternal age, and child functioning level, which related to the child's level of dependency, behavioral management challenges, limits on family opportunity, and need for life-span care. The most common factor identified by parents of children with ASD as stressful across studies is child challenging behavior, which parents report as more intense and frequent than that of children with other developmental delays (Dumas, Wolf, Fisman, & Culligan, 1991). Similarly, most studies suggest a positive relationship between overall ASD symptom severity and parental stress, particularly social and communication challenges, along with restricted and repetitive behaviors, which limit the ability of the family to engage in community activities (Benson, 2006; Davis & Carter, 2008). Several studies have investigated the relationship between the child's age and/or IQ level and the associated parenting stress (McStay, Dissanayake, Scheeren, Koot, & Begeer, 2014; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Tehee, Honan, & Hevey, 2009). While results are mixed, there is evidence suggesting that parents of recently diagnosed children may experience increased levels of stress, compared to parents of older children (Gray, 2002b; Schieve et al., 2011). In addition, mothers and fathers appear to have differing stress profiles (Davis & Carter, 2008). Thus, while there is no clear consensus on what aspects of parenting a child with ASD are the greatest contributors to parental stress, the presence of extreme levels of parental stress is a very consistent finding. While the majority of parenting stress research has been conducted with preschool- and school-aged children with ASD, there is evidence that parents of infants and toddlers with ASD or at risk for ASD also experience considerable stress (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Davis &

Carter, 2008; Estes et al., 2013). High levels of parenting stress are therefore a critical consideration when implementing intervention programs for families of young children with ASD.

Depression. The literature is also replete with studies documenting high levels of depression in parents of children with ASD (Bristol, Gallagher, & Holt, 1993; Yirmiya & Shaked, 2005). Similar to stress, parents of children with ASD have higher reported rates of depression than parents of children with other DDs, with mothers reporting greater levels of depression than fathers (Olsson & Hwang, 2001). While higher rates of depression are strongly related to the high levels of stress experienced by parents of children with autism, it is also important to note that several studies have identified parents of children with ASD to be at higher risk based on genetic liability (Bolton et al., 1994). Ingersoll, Meyer, and Becker (2011) found that symptoms of a broader autism phenotype (BAP) predicted depression scores in mothers of children with ASD, above and beyond child autism severity and parenting stress. Thus, it is important to consider that this group of parents may be particularly vulnerable to stress and depression, given the demands associated with raising a child with ASD along with their own potential genetic liability.

Parents of infants at risk. Genetic liability also extends to the realm of siblings. Specifically, parents of children with ASD may experience concern and stress regarding their infant children who are at elevated genetic risk for ASD (Chap. 3). While there is emerging research suggesting the utility of early intervention programs delivered via a parent education format for children who are "at risk," but not yet diagnosed with ASD (Green et al., 2015; Kasari et al., 2014; Koegel, Singh, Koegel, Hollingsworth, & Bradshaw, 2013; Rogers et al., 2014; Steiner, Gengoux, Klin, & Chawarska, 2013), relatively little is understood about this parenting experience. The literature would suggest that these parents are already highly stressed regarding their older child who is diagnosed with ASD and are now likely facing additional stressors with their infant, who may be evidencing some developmental delays as well. Several studies have indicated that parents of infants at risk for ASD often express early stress and concern regarding their child's development (Ozonoff et al., 2009) and that parents seem stressed even in the absence of specific developmental concerns (McMahon, Malesa, Yoder, & Stone, 2007). Although there is limited research in this area, one might hypothesize that this subpopulation of parents of children with ASD may be at an even greater risk, given added stressors related to raising an infant at risk in addition to having an older child with a diagnosis of ASD.

Need for interventions to reduce family stress. Parenting stress is associated with a plethora of negative outcomes for families. First, it is well documented that high levels of parental stress can be detrimental for the parent-child relationship (e.g., Abidin, 1992). In addition, high levels of stress are often related to greater marital discord, with some studies reporting significantly higher rates of divorce among families of children with ASD (Hartley et al., 2010; Hartley, Barker, Baker, Seltzer, & Greenberg, 2012). Chronic stress also leads to poor health outcomes for parents of children with disabilities, particularly mothers (Miodrag & Hodapp, 2010). Moreover, several studies have documented that higher levels of parental stress often lead to poorer outcomes for children in early intervention programs (Osborne, McHugh, Saunders, & Reed, 2008; Robbins, Dunlap, & Plienis, 1991; Strauss et al., 2012). For these reasons, any measures which can prevent the development or lessen the severity of stress and depressive symptoms in parents are likely to yield significant benefit for the whole family, especially when initiated early in the child's life.

While studies continue to report on the high stress levels associated with parenting children with ASD, there is little research to identify the best way to ameliorate this problem. Many popular and otherwise effective models for early intervention have little impact on reducing parenting stress. Though many early intervention programs designed to address child behavior also measure parental stress, most do not document significant changes in stress levels post-intervention (Birnbrauer & Leach, 1993; Remington et al., 2007), although the results are mixed, and some show promise after a year or more of intervention (Eikeseth, Klintwall, Hayward, & Gale, 2015). In a meta-analysis, Singer, Ethridge, and Aldana (2007) found significant improvements in parental stress for parents of children with developmental disabilities (but not ASD specifically) following intervention which either targeted child behavior or parental distress directly. More research specific to infants and young toddlers is certainly needed to establish best practice parameters for involving parents in very early intervention efforts. In fact, some studies suggest that early intervention programs which include a parent education component can lead to increases in stress in some cases (Benson & Turnbull, 1986; Diggle, McConachie, & Randle, 2003; Gallagher, Beckman, & Cross, 1983; Strauss et al., 2012).

Lack of change on measures of stress could also be related to a ceiling effect in the measurement of parental stress. Furthermore, it could simply be the fact that while early intervention programs often lead to increases in IQ, adaptive skills, and quality of social and communication behavior, along with reductions in challenging behaviors and repetitive behaviors for children with ASD, other variables (e.g., need for lifelong care, daily hassles) may continue to drive parental stress. In addition, while child behavior may change significantly during intervention, learned parental behavior and coping styles may not be as readily affected without specific attention to such issues. Thus, intervening with parents of very young children provides an opportunity to support families early on and to promote more productive coping strategies prior to the establishment of potentially maladaptive patterns.

Positive adaptation. Despite clinically significant levels of stress felt by many parents, some families also have positive adaptations to having a child with a disability (Cridland, Jones, Magee, & Caputi, 2014; Phelps, McCammon, Wuensch, & Golden, 2009). Specifically, some parents are able to create positive meaning from their child's disability and indicate experiencing greater appreciation for life in general, becoming closer as a family, and building spiritual strength (Bayat, 2007). As Green (2007) describes the sentiment of parents of children with disabilities, "we're tired, not sad." Scorgie and Sobsey (2000) discuss a transformative process, whereby parents ascribe meaning to the challenges presented by raising a child with a disability and report feeling blessed to have the experience. Understanding the factors which predict a parent's ability to engage in positive adaptations and how clinicians can promote these resilience processes is critical for early intervention work.

Specific Strength-Based Approaches

The remainder of this chapter is focused on reviewing strength-based approaches to assessment and intervention which apply positive techniques to enhance family adaptation to having a child with ASD.

Strength-based assessment. Utilizing a strength-based approach begins with the assessment process. First, by necessity, the clinician must complete an assessment to identify areas of child, family, and school/community strength which can be capitalized on during intervention. Epstein and Sharma (1998) define strength-based assessment as:

> the measurement of those emotional and behavioral skills, competencies, and characteristics that create a sense of personal accomplishment; contribute to satisfying relationships with family members, peers, and adults; enhance one's ability to deal with adversity and stress; and promote one's personal, social, and academic development. (p. 3)

Additionally, and perhaps even more critically, by conducting a strength-based assessment, the clinician can begin to share with the family a vision of their child through a more positive lens.

By identifying and sharing areas of strength, and emphasizing competence and quality of life issues, rather than simply symptom reduction, the clinician can begin to increase hope for the child's family (as well as themselves), with collateral benefits for the working alliance (Cosden et al., 2006; Cosden, Panteleakos, Gutierrez, Barazani, & Gottheil, 2004; Epstein, Dakan, Oswald, & Yoe, 2001).

When applying a strength-based approach to intervention, the clinician can elect to focus on several different types of strengths including child- or parent-related strengths, as well as emphasizing existing strengths and building and/or reframing potential strengths (see Table 10.1). We briefly review examples of each perspective below.

Child-Related Strengths

There are a number of helpful techniques for incorporating existing child strengths into intervention in order to enhance child engagement in learning. These strategies are routinely used in Naturalistic Developmental Behavioral Interventions (NDBI; Schreibman et al., 2015). For instance, in Pivotal Response Treatment (PRT; Koegel & Koegel, 2006), the clinician may use a child's interests or abilities to enhance motivation for learning a variety of skills. Examples of these strategies are provided below.

Other approaches, such as priming, involve pre-teaching a skill which will later be utilized as a child strength.

Table 10.1 Strength-based intervention approaches for children with ASD and their families

Approach	Sample references	Description of approach
Child-related strengths		
Capitalizing on existing strengths		
Child-choice	Koegel, Dyer, and Bell (1987)	Following the child's lead and using child-preferred activities for intervention
Use of restricted and repetitive behaviors	Baker, Koegel, and Koegel (1998); Campbell and Tincani (2011); Kryzak, Bauer, Jones, and Sturmey (2013); Vismara and Lyons (2007)	Utilizing restricted interests and repetitive behaviors to improve behaviors such as joint attention, direction-following, or social skills
Maintenance tasks	Dunlap (1984)	Interspersing maintenance (mastered skills) with acquisition tasks (new skills)
Building/reframing strengths		
Priming	Koegel, Koegel, Frea, and Green-Hopkins (2003)	Pre-teaching skills to improve child performance and competence
Parent education emphasizing child strengths	Steiner (2011)	Highlighting the child's areas of strength and positively reframing areas of need in everyday interactions with parents
Parent-related strengths		
Capitalizing on existing strengths		
Parent-professional partnerships	Brookman-Frazee and Koegel (2004)	Forming collaborative partnerships to empower parents, utilizing existing parental skills and parental expertise regarding their child to guide intervention sessions
Building/reframing strengths		
Optimism training	Durand et al. (2013); Kessler (2003)	Positive behavior support training for parents, along with cognitive-behavioral strategies to enhance optimism
Mindfulness training	Ferraioli and Harris (2013); Singh et al. (2014)	Improving parent mindfulness and awareness regarding parenting using cognitive-behavioral strategies

Child Choice

A clinician can incorporate a child's interests into intervention by following the child's lead and using **child choice** of activities during intervention sessions.

Example:

The clinician arranges a few toys on the floor and table before the intervention session. The child enters the room and immediately begins to play with the ring stacker. The clinician creates a silly game with the rings and prompts the child to request the rings.

Use of Restricted Interests and Repetitive Behaviors

A child's **restricted interests and repetitive behaviors** can be utilized as a strength in intervention programs. These are typically areas in which children with ASD have strong competencies (e.g., numbers and letters, types of trains or dinosaurs) and can be used to increase a child's motivation for a given activity, enhance a variety of other skills, and provide an opportunity for a child to excel.

Example:

Janet really loves street signs. Janet's mother wants her to learn colors and basic shapes. Janet's mother uses this **restricted interest** in street signs to teach colors and shapes. Using toy signs, Janet's mother prompts her to name the color and shape of each sign, allowing her to play with the sign when she answers correctly. On walks around the neighborhood, her mother motivates Janet to practice pedaling her new tricycle by having her pedal toward her favorite signs.

Interspersing Maintenance and Acquisition Tasks

A clinician can capitalize on the child's strengths by incorporating **maintenance** (already learned) tasks along with **acquisition** tasks (new learning).

Example:

Max can easily use single words to request items, but he is just learning to use word combinations. Max and the clinician are playing with toy cars and a toy garage. Using **maintenance and acquisition**, the clinician has Max request the cars using one word ("car," a **maintenance** task) but every sixth or seventh time puts the car in the garage and prompts Max to say "car out" (an **acquisition** task).

Priming

By **priming,** a parent or clinician can preview an activity or skill with a child in a low-demand, high reinforcement context in order to strengthen the child's competence and interest in performing that skill.

Example:

Kevin is often restless and distracted during the "Mommy-And-Me" class he usually attends with his mother on Monday mornings. On Sunday evening, his mother recites a few of the nursery rhymes and sings a few of the songs that the group usually practices Monday morning. When Kevin hears the familiar tune and words the next day, he listens attentively and even imitates a few hand movements when he sees the teacher make them.

Parent education emphasizing child strengths. Strength-based strategies can also be embedded into everyday interactions between parents and clinicians with the goal of bolstering parental optimism and facilitating positive parental adaptation. Specifically, in a study of parent education sessions with children aged 3 and under, Steiner (2011) found that when clinicians modeled a positive approach to the child's behaviors, emphasizing the child's strengths in the context of providing in vivo feedback to parents, parents evidenced more positive affect, made more positive statements about their children, and engaged in more playful interactions with more instances of physical affection than when clinicians utilized a more deficit-based approach. In fact, the difference in clinician behavior was extremely subtle, while the parental response to the clinician was quite significant. Consider the following examples:

Parent Ed: Emphasizing Strengths

Example: Child Attention

Deficit-Based

Clinician: "He does not seem to attend to one toy for very long. One way we can get his attention is…" (provides strategy)

Parent: "I have noticed that as well. He also doesn't play with toys the correct way. He mostly throws and bangs things."

Strength-Based

Clinician: "It seems like he is interested in several different toys. One way we can get his attention is…" (provides strategy)

Parent: "Yes, he can get really excited about things. The other day at the zoo, he was so interested to see all the different animals…"

In this way, clinicians can model greater optimism during parent training sessions and demonstrate positive conceptualizations of child behavior while discussing new approaches for engaging and teaching the child.

Parent Ed: Emphasizing Strengths

Example: Eye Contact

Deficit-Based

Clinician: "She does not make eye contact very often when she requests items. One way we can increase eye contact is…" (provides strategy)

Parent: "She usually looks at the object she wants, and not me. It is like I am not even there."

Strength-Based

Clinician: "It is nice to see that she makes eye contact when you tickle her. One way we can increase eye contact is…" (provides strategy)

Parent: "Yes, she loves tickles. That is our special thing together, since she was a baby. I love to hear her laugh."

Parent-Related Strengths

A strength-based perspective can also be incorporated into parent education by focusing on the strengths each individual parent brings to the intervention process or by helping the parent use positive cognitive strategies to better cope with the challenges of raising a child with ASD.

Parent-professional partnerships. This approach involves acknowledging significant parent expertise and treating parents as equal partners in the intervention process. The development of parent-professional partnerships can empower parents and increase engagement in the intervention process, thereby improving outcomes. Specifically, in a study of parent education sessions with toddlers with ASD, parents were observed to exhibit lower stress and higher confidence, and children demonstrated more positive affect as well as improved responding and engagement when clinicians employed a partnership approach compared to more directive clinician strategies (Brookman-Frazee & Koegel, 2004).

Parent Ed: Parent-Professional Partnerships

Clinician-Directed vs. Partnership

Clinician-Directed

Clinician: “It looks like he is interested in the ball. You could get him to roll you the ball, and then have him say ‘ball’ to get it back.”

Parent: “Okay.” (rolls ball with child but does not prompt child to request as suggested)

Partnership

Clinician: “It looks like he is interested in the ball. I wonder how we can use that to help him request?”

Parent: “He loves this sneezing game we do with the ball.” (Puts ball on top of her head and says “ah-choo” while knocking the ball down. Places the ball on her head again and prompts the child to request, using the word “ah-choo.”)

An alternative cognitive strategy involves helping parents reappraise the experience of parenting a child with ASD. Optimism- and mindfulness-based approaches aim to directly teach different patterns of coping to parents of children with ASD.

Optimism training. Several researchers have focused specifically on “optimism training” for parents of children with ASD. This approach involves the clinician and parent reviewing the child’s behavior as well as parent’s reaction to the child’s behavior. Clinicians then “teach” optimism, by helping parents become aware of potentially negative or pessimistic thoughts regarding their child’s current and future behavior, as well as their view regarding their own ability to manage that behavior and their view of themselves as a parent.

A clinician practicing **optimism training** might teach parents to challenge negative beliefs and incorporate positive thinking. For instance, the clinician might coach the parent to use optimistic self-talk, such as “this tantrum is really terrible, but I am dealing with it and staying calm. I am a good parent, and what I am doing is useful.”

In a pilot study, Kessler (2003) examined the use of “optimism training” as a component of parent education for parents of children with developmental disabilities. Specifically, during individual cognitive-behavioral therapy sessions in which parents and clinicians reviewed the child’s behavior as well as the parents’ reactions to behavior, clinicians “taught” parents to view child behavior in a more optimistic light. Preliminary data suggest that parents who completed optimism training were less likely to drop out of intervention and reported less pessimistic views of their child’s behavior. Subsequently, a randomized clinical trial of optimism training was completed by Durand, Hieneman, Clarke, Wang, and Rinaldi (2013) for 54 parents of children with developmental disabilities (ages 3–6), whose children engaged in severe disruptive behavior. Parents were randomly assigned to receive either 8 weeks of individualized positive behavior support or positive behavior support plus optimism training, termed positive family intervention (PFI). Both groups demonstrated decreases in parental pessimism and child disruptive behavior. Additionally, those who received the optimism component reported more confidence in implementing behavioral strategies at home and noted more improvements in their child’s positive behaviors.

Mindfulness training. Mindfulness training as a component of parent education also demonstrates additional promise for reducing parental stress (Ferraioli & Harris, 2013). Mindfulness training utilizes a cognitive-behavioral approach, whereby parents are coached to become more aware (i.e., mindful) of their thoughts and responses to their children with ASD, as well as how to accept or distance themselves from negative thoughts, along with additional relaxation techniques (See Chap. 18).

A clinician practicing **mindfulness training** might instruct parents to record their reactions to their child. Clinicians may teach mindful practices, such as focusing on being present in the moment, enhancing awareness of thoughts and sounds, as well as practicing meditation. The clinician might also encourage parents to engage in multiple pleasant activities during the week, including several with their child.

Although mindfulness training takes a somewhat different approach than optimism training, the two strategies share significant overlap in that they both emphasize parental awareness of thoughts regarding their child, along with the use of cognitive-behavioral strategies to mediate these thoughts. Preliminary studies suggest that mindful parenting approaches, while related to lower levels of parental distress, do not necessarily mediate the relationship between parental distress and child behavior (Beer, Ward, & Moar, 2013). Additional research is needed to further understand the relationship between these variables, as well as potential similarities and differences in the effects of mindfulness and optimism training.

Also utilizing an 8-week program, Singh et al. (2014) in a pilot study of parents of adolescents with ASD found that a mindfulness-based positive behavior support (MBPBS) resulted in improvements in child behavior and reductions in parental stress. Similarly, Singh et al. (2006, 2007) found that a 12-week mindfulness training was particularly helpful for parents who had difficulty completing parent training, with improvements in child behavior and parental satisfaction with parent-child interactions. Interestingly, parents reported improvements in child behavior despite the fact that specific behavior management strategies were not taught. Furthermore, Ferraioli and Harris (2013), in a randomized study, found significant reductions in parental stress and improvements in parental health following an 8-week mindfulness training program for parents of children with ASD compared to a skills-based intervention. However, further research is needed to understand the effectiveness of both optimism and mindfulness trainings for parents with very young and newly diagnosed children with ASD, as parenting stressors and coping strategies can vary by the child's age.

Conclusion

Strength-based intervention for children with ASD and their families is a growing area of interest and research. Given the significant stressors often faced by families of children with ASD, such approaches may be particularly helpful for this population. Several studies have identified optimism and mindfulness as significant factors in parental coping, parental stress, and parental participation in intervention for children with ASD. Understanding how to utilize techniques which draw upon child and parental strengths is a key element in the delivery of effective and high-quality intervention services.

While there are a number of studies which suggest approaches which incorporate existing child strengths into intervention, relatively few studies explore strength-based techniques that are focused on parents. In particular, one area clearly in need of additional research is the identification of parenting strengths and the individualization of parent education approaches according to specific parent profiles. For instance, as part of an intake assessment process, it could be helpful to identify both specific areas of parental skill and positive personal characteristics that may be incorporated into intervention efforts. Furthermore, additional research is needed to develop strength-based intervention programs which specifically address the needs of parents of very young and newly diagnosed children with ASD. Strength-based interventions applied when children are very young may have the unique potential to prevent some of the negative consequences of chronic parenting stress.

Too often intervention programs emphasize individualizing the program to the child's needs (but not specifically to the family's) and on ameliorating areas of weakness with little consideration of areas of strength or goals of achieving competence and well-being. Taking a strength-based approach to working with children who have significant areas of deficit is a challenging shift in perspective, but emerging research suggests that its effects may be quite significant for the child, family, and clinician.

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11

Parents as Developing Adults and Developing Adult Learners

Dana R. McDermott

Abstract

Theories of adult learning and development are reviewed in detail, in order to demonstrate the complexity of the parent and professional roles in caring for children with autism and the many potential opportunities for better outcomes when this information informs practice. A focus on process not just outcome, e.g., on reflection, continuous learning and improvement, experiential learning, and on ongoing parent development, offers an alternative to current problem-focused approaches to working with parents and all who care for children with autism. Examples are provided to elucidate theories whenever possible. Assumptions underlying adult learning are delineated as are implications for practice. Social-cultural context considerations and the perspective of parenting education theory, research, and practice are integrated throughout. Stages of adult learning are presented as are the many rich theories of how parents think (cognitive domain) and feel (affective domain) and how that affects their behavior. Heath's (2001, 2014) caring decision-making process which synthesizes adult learning, developmental theories, and best practices is described in detail as are the ego processes of parents. Links to additional practical resources are provided including the professional association, the National Parenting Education Network (npen.org).

In this chapter, adult learning theories, models, research, and best practices are reviewed to inform the helping professional's interactions with parents. Taking a mindful approach (Langer, 1998, 2014), i.e., looking at something familiar like interventions with parents, in a novel way, the focus here will be on parents as developing adults and developing adult learners. Kegan (1994), Shanook (1990), and Siegel and Hartzell (2003) have found that it is crucial for successful child development to focus on the developing parent. Belsky (1984), Heath (2006), and Hrdy (1999) have long noted that parents are often seen as an empty box through which one transmits information or training so they can help children. What is going on in their minds has not seemed to matter much, especially to behaviorists. The humanistic, cognitive, and constructivist approaches to adult learning theory provide a

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_11

different focus and require that professionals address the "meaning" of educator expectations for parent action, on parents and those sharing a caring role with their children. Culture and other social contextual variables also must be addressed to understand the meaning of interventions with parents and why they are not always as effective as hoped for (Gonzalez-Mena, 2008; Lynch & Hanson, 2004). As a new psychologist, I learned quickly that the language of empowerment and asking parents of children with autism for their suggestions on an intervention plan could be seen by some culturally diverse parents new to this country as a sign of my incompetence as a professional.

Marienau and Segal (2006) in describing interactions of helping professionals with parents noted that at times "… parents may come to be seen narrowly as representing problem A, B, or C. In contrast, a learning orientation (rather than a problem orientation) to working with the parent would focus on the potential for growth of both parent and child" (p.768). They ask: "What if professionals were to keep at the center of their interactions these two questions:

- What opportunities for learning do these challenges present?
- How can this individual be supported further in developing her or his skills and habits for continual learning or growth (p.768)?"

As a psychology graduate student in the 1970s, I worked in a behavioral clinic for children with autism at Loyola University. I worried about the children's parents, and I often saw a lack of self-efficacy and even confusion and fear in their eyes. It reflected Mezirow's (1978) description of a disorienting dilemma that comes about when a significant personal life event can precipitate a crisis in our lives. In addition to behaviorism, I was also learning about humanism (Rogers, 1973), cognitive development (Piaget, 1972), and the growth and development of parents (Erikson, 1963; McBride, 1973). No two theories (behaviorism and humanism) could be more different, but in the long run it helped me to understand how to work effectively with parents of children with autism by providing both information and emotional support. Simultaneously, others were focusing on developing adult learners (Frieri, 1973; Knowles, 1980; Rogers, 1983). This was reinforced by the family support movement (Bronfenbrenner, 1979; Dunst & Trivette, 2006; Dunst, Trivette, & Deal, 1988; Kagan, Powell, Weissbourd, & Zigler, 1987), which has had a tremendous impact on how professionals working with parents see themselves, not as the experts imparting information but as co-learners.

Many parenting educators had also been looking for alternatives to the "expert" approach to working with parents, which often does not take into consideration parent needs (Heath, 2014; Maslow, 1969), goals for children (Dix & Branca, 2003), values (Demick, 2002; Heath, 2000), beliefs (Sigel & McGillicuddy-DeLisi, 2002), feelings (Gottman & DeClaire, 1997), learning styles (Bowman, 1996), adaptation styles (Hinde, 1989), and sociocultural contexts (Bornstein, Putnick, & Lansford, 2011; Lareau, 2011). Myers-Wall (1998) has described moving from the role of expert with parents to facilitator and collaborator. Duncan and Goddard (2011) have added the critical inquirer, interventionist, and eclectic roles of parenting educators. Heath (2006) emphasized that:

> …focusing on the parents' lead role provides professionals with a different paradigm from which to work. The paradigm is no longer telling parents what they should do. Rather, it is asking of professionals, 'How can I help parents to become more confident about the decisions they are making and to feel more competent in their ability to carry them out?'(p. 762)

Greenspan, Wieder, and Simons (1998, p. 384) also emphasized the parent's lead role on the team. How do adult learning theories and theories of parents as developing adult learners and developing persons provide an answer to these concerns for the parent?

Adult Learning Theories and Models

The most oft utilized adult learning theories pertinent to parenting and parenting education with support draw from behaviorism, humanism, cognitive development, social cognitive development, constructivism, and social constructivism. Merriam and Bierema (2014) describe learning as both a process and an outcome (p. 25). When adult and parenting educators focus on outcome or acquired knowledge, skills, or competencies measured in observable behavior, and not also on the associated complex thinking or feelings of the learner, behavioral principles are often applied. Evidence-based practice with a focus on interventions with a quantifiable and observable changed behavioral outcome often stems from a behavioral approach. Unfortunately, sometimes the interventions become so narrow as to not adequately meet the needs of parents and children in complex situations such as is the case with children on the autism spectrum. Greenspan et al. (1998, p. 381) emphasized the need to fit programs to a child's profile rather than a child to a set program. Parents also have a unique set of characteristics that do not respond equally to set programs. Often fidelity to a program supersedes variations to address diverse individual, cultural, or social contexts. Often it is hard for specific parent populations to find appropriate evidence-based programs that meet their intellectual and emotional needs (Darling, Cassidy, & Powell, 2014, p. 168) as well as their family needs.

Taylor, Marienau, and Fiddler (2000) have described adult educator's different approaches to supporting learning: Educators take a behaviorist approach to learning when they focus on arranging the external environment and inputs to effect changes in behavior. A more cognitive developmental approach (Piaget, 1972; Belenky, Clinchy, Goldberger & Tarule, 1986/1997) focuses on internal mental processes and working to develop a person's thinking capacity. Thomas, Cooke, and Scott's (2005) Reflective Dialogue Parent Education Design is an example of this approach. They have parents view a video of a parent-child interaction and then reflect on what they might do and why when in a similar situation.

Social learning theory (Bandura, 1989, 1997) focuses on the interactions of thinking parents, their behavior and the environment or social context. It combines behavioral and cognitive approaches to learning and involves activities such as modeling and mentoring seen in programs like "Parents as Teachers" where parent educators help to discuss why they are responding to the child as they are and discuss how that meshes with a parent's thinking about adopting that behavior, taking into account their resources, beliefs, culture, etc. Bandura also believed that an individual's beliefs about their ability to affect change in the environment was a key ingredient for focus. For many parents of children on the autistic spectrum, helping them avoid cynicism about their ability to change complex institutions and systems' approaches to supporting their children and families is a task we often face. Bandura believed that how parents think about child rearing is combined with the child characteristics and the environment to affect a child's ultimate growth and development. If you have parents who believed in an authoritative parenting style involving discussion with children and explanations for their parenting choices and they have a nonverbal child with autism, how do you help these parents give up that plan and adapt to their child's needs and capacities?

The constructivist approach would put the focus on individuals to construct knowledge and gain meaning from their experiences, even that of dealing with the "loss of their dream" (Bowman, 1994a, b) of how they would communicate with their child. Growth for the parent often only comes when they adjust their image with reality (Galinsky, 1987). The social constructivist approach (e.g., Vygotsky, 1978) focuses also on the context in which this developmental process takes place. The focus on parents as developing adult learners in this chapter is thus less on outcome and more on the best process to facilitate the growth and development of both parents and children. To do that one needs to understand what and how the parent is thinking and feeling as well as what they are doing. The National Parenting Education Network (1996) defines parenting education as "… a process that involves the expansion of insights, understanding and attitudes, and the acquisition of knowledge and skills about the development of both parents and of their children and the relationship between them" (http://npen.org/about-npen/). To conclude, adult learning theories focusing on process may be more helpful in addressing professional–parent relationships than behavior-focused models alone.

The humanistic approach (Rogers, 1983) focuses on the development of the whole person and on relationships. As to actual parenting and/or working with parents, one would use empathy to understand another's needs and feelings; one then would reflect back what the other is feeling in order to help that person in turn grow in awareness and self-understanding. This was central to Greenspan's work with children and families (Greenspan & Weider, 2006, pp. 125–129). Jones (2012) has developed an evidence-based humanistic, solutions-focused parenting program for parents of youth offenders that tries to do this. He has worked with parents identifying their feelings and support needs. He found lower rates of repeat offenses in families where he tuned into the feelings and needs of parents. Rogers' (1983) humanistic learning theory focuses on student-centered learning including not just the outcome of external input on the child but on student's feelings as well as thinking.

Merriam and Bierema (2014, pp. 29–31) have suggested that Knowles' (1980, 1984) model of adult learning used by many today was very much influenced by Rogers' (1969, 1983) writing about lifelong learning, internally motivated learning, and the value of experience and of meaning-making in adult learning. The related concept of constructivism noted above focusing on making sense or constructing meaning from one's experience is also relevant in relationship-building and development (Driscoll, 2005). Constructivists also believe that learning is affected not only by the context in which an idea is taught but also by a learner's beliefs and attitudes. Candy (1991) has noted that constructivism has influenced many aspects of adult learning including the proven value of reflection, self-directed learning, and experiential learning. Today's educational philosophy and practice of "Process Education" to support self-directed learning and growth "integrates many of the tenets of constructivism with personal development, performance measures, and assessment in order to produce learner growth, promote critical thinking, and nurture continuous improvement" (Burke, Lawrence, El Sayed, & Apple, 2009, p. 37).

Adult educators have often noted that early philosophers focused on educating adults, not children, and many of their techniques (e.g., narrative and dialogue to be discussed below) are still advocated today. Knowles' (1980, 1984) assumptions about adult learners were influenced by philosophers but especially by Lindeman (1926, 1961), a social philosopher who asserted that the learner's experiences were the greatest resource to draw upon in adult education. Lindeman was an adult educator, a social scientist, a social worker, and a strong supporter of small group work and community development. This chapter draws from Knowles' model and assumptions about adult learners as well as from some theories and research on parent learning (e.g., Auerbach, 1968; Campbell & Palm, 2018). It also incorporates theories/research on parental thinking.

Assumptions About Adult Learners

Knowles and Associates (1984) put forth six assumptions about how adults learn best. Assumptions can be paradigmatic having to do with the big picture of how we see the world, prescriptive referring to what we think ought to be happening or causal focusing on how the world works and conditions under which it can be changed (Brookfield, 2012). Merriam and Caffarella (1999) and Merriam, Caffarella, and Baumgarten (2007) list these assumptions and describe other assumptions that have been found to help support adult learning.

1. *As a person matures, his or her self-concept moves from that of a dependent personality toward that of a self-directing person*

This may be especially true for topics about which adults feel very passionate, such as their own child's development and well-being. Brookfield (1995) postulated that self-directedness may be more valued in individualistic societies and interdependence more valued in collectivist societies. He was likely also informed by parenting educators' experiences with Hmong families in Minnesota. He cites research findings indicating that, e.g., “for the Hmong tribes people from the Mountains of Laos who are used to working cooperatively and to looking to their teachers for direction and guidance, ways of working that emphasize self-directedness and that place the locus of control with the individual student will be experienced, initially at least, as dissonant and anxiety producing (Podeschi, 1990)” (p. 378). Many of the parents with whom professionals work are often in transition between their culture of origin and a new culture. Thus, the issue of self-directedness needs to also be explored with community members who might provide insights. Brockett and Hiemstra (2012) though have found examples of self-directed learning across diverse social groups and societies.

A related concept, “self-authorship” is the “sense of being in charge of oneself, of being able to set one’s own standards, establish one’s own values, and make choices based on [these] self-constructed systems” (Taylor et al., 2000, p. 40). See Hurtig and Dyrness (2011) also on their work with parents from diverse cultures and self-authorship.

2. *Adults have rich experiences that serve as a great resource for learning*

See Brookfield (1987), Frieri (1973), and Kolb (1999) for further support of this assumption. Boud, Keogh, and Walker (1985) have found that adult learners wanted their own experiences acknowledged and wanted to connect their new learning to their existing or previous experiences. Robertson (1996) encourages us to focus on the experience of both the parent and the helping professional:

> the learner’s experience arises from a context that includes, among other important elements, a teacher or learning facilitator who is operating on the basis of her or his lived experience or subjective reality. Thus, the teaching-learning encounter involves critical interactions among subjective realities of the participants. The learner’s lived experience emerges within this complex, dynamic system. (p.47)

Dewey (1944) adds that “No experience having a meaning is possible without some element of thought” (p.145). Thus, reflection is also central to this assumption. Mezirow (1991) sees reflection as a process of critical thinking where people examine the content and process of their efforts to interpret their experience. Unfortunately, the typical methods of involving parents in interventions rarely include approaches such as reflective inquiry (Sarason, 1995). Greenspan et al. (1998, p. 359) have advocated helping parents self-observe.

Campbell and Palm (2004, 2018) have provided best practices for adult educators and parenting educators in terms of reflection. They draw upon Dewey (1933) and his focus on the attitudes central to good reflective practice which also apply to parents as teachers. He focused on open-mindedness, which for parenting educators would involve “listening to parents, researchers, and peers to gain a more complete understanding about the complexity of parenting and parent education practice” (Campbell & Palm, 2004, p. 211). Second, a professional or parent needs to be responsible to improve their work, the family and the larger society by working to understand the impact of what they are doing over the long-term. Finally, one needs to be wholehearted in terms of passion for what they are doing and a willingness to take risks and follow their ethical values in spite of challenges from others. The Minnesota Council on Family Relations has provided parenting and family educators with a very user-friendly ethical guide for our thinking and practice (2009). See also http://mn.ncfr.org/wp-content/uploads/sites/3/2014/02/ethical_thinking_and_practice.pdf.

Campbell and Palm (2018) have found that the complexity of working with adults, posed by Schon in 1987, is even more evident today. Schon (1987) emphasized the need for reflective practice to help educators grapple with the complexity of problems facing those they served. He noted that in addition to relying on and respecting traditional research there is a certain art and intuitive nature to an adult educator’s work that is harder to measure. Campbell and Palm (2004, 2018) have found that on the novice to master continuum of parenting educator competence, it takes a good deal of experience to be able to adapt to the individual needs of parents who exist in increasingly diverse, complex, and fragile systems. Often behavioral programs do not allow for that flexibility. This is unfortunate, as Kumpfer and Alvarado (1998) found that 50–80% of program quality was attributable to the person delivering the program. Ballard and Taylor (2012) have found that in terms of program effectiveness, how it is delivered is at least as important as what is delivered. Heath's plan-do-reflect model for parents (Heath, 2014) provides a good way to bring in the unique situations of parents, their goals, needs, feelings, options, characteristics, etc., and the creative adaptability of parenting educators to the parent and the model. Thomas, Cooke, and Scott's (2005) Reflective Parent Education Design is also exemplary in this regard. Rather than telling parents what to do, parent's viewing of vignettes of other parents interacting with children provides them an opportunity to reflect on what they might do and why. This also provides an opportunity for the professional to discuss possible implications of such choices. The design of programs such as these in light of adult learning principles may help compensate for the lack of experience of some parenting educators.

In addition to reflection on parenting practices, reflection on one's prior experiences is very important to address. Greenspan provided examples of professionals helping parents reflect on how their nonproductive interactions with their children with autism or other special needs (Greenspan et al., 1998) might be related to how they themselves were parented. McDermott (2008) highlighted Siegel's contention (2005) that if parents have not reflected on how their own childhood experience affects their parenting, they may be dismissive toward their own child. Parents whose unresolved issues and strong emotions from their own childhood intrudes into their own parenting may be so preoccupied with those issues and emotions that their children may have attachment problems. These unresolved issues interact with and are further complicated by their reaction to having a child with special needs. He believes that "By offering the opportunity to deepen self-understanding, to make sense of one's life, our hope is that parents could make the choice to enhance the security of attachment of their children while at the same time creating coherence and vitality in their own lives" (Siegel, 2005). Marineau and Segal (2006, p. 779) remind us that when parents tell their stories it is very helpful:

> adult education recognizes the power of narrative (i.e. telling of one's story) in helping people make meaning of their experiences as parents, identify new areas for learning and set the stage for further development (Rossiter, 1999). Each parent's story 'is situated in time and place, in society and family, in national religious and ethnic traditions-all of which form the basis of a shared sociocultural meaning system'. (Rossiter, p. 80)

Hurtig and Dyrness (2011) employed critical ethnographic participative action research and found that writing workshops for parents from marginalized communities helped them and schools see the "legitimacy of their experiences and perspectives" (p.540). By sharing their stories about their children's education and their role in it with each other and then via magazines distributed in schools and communities, they saw themselves as active, empowered, creative thinkers, and actors.

Reinke and Solheim (2015) and Fleischmann (2005) have found that online personal blogs for parents of children with autism were a very meaningful way to share and reflect on their life experiences. The sharing helped them learn from others within a context of emotional and informational support and helped them in their own choice making. In my experience with single parents of nonverbal children with severe autism, however, I have found that some seem to find it very difficult to listen to advice on blogs, because they have often tried everything that is suggested and have formed beliefs after painful and frustrating experiences with their children, institutions, and helping professionals that no one can understand their situation or make better decisions than they can.

3. *If an adult is expected to learn something, the instructors must discern that person's readiness to learn*

This is connected to the assumption about life experiences above. Belenky, Clinchy, Goldberger, and Tarule's (1986/1997) research with women's different ways of knowing described below will further explain different degrees of parent openness to new learning. Merriam and Caffarella (1999) and Merriam and Bierema (2014) add that readiness to learn is closely linked to the person's developmental tasks and social roles. Roles often change with age. Difficulties may occur when parents are taking on their roles off-time – too early or late – or are taking on too many roles simultaneously.

4. *Adults learn more effectively through experiential techniques of education such as discussion and immediate problem-solving than from directives or lecturing*

Florin and Dokecki (1983) and Auerbach (1968) describe how this is done. Adults often wish to be able to apply new learning or skills to their own immediate circumstances. Adults may prefer to have these discussions within small, culturally homogeneous groups rather than in large groups (DeBord & Reguero de Atiles, 1999). Kypros (1989) found that:

> The inductive reasoning used in this method of learning allows the learner to begin with his own particular life problem and situation and move outward seeking data and resources in order to assimilate the new experience or to accommodate conceptual structures so that the new experience fits in. (p. 208)

Heath's parent program described later (2014) perfectly demonstrates this process.

5. *Adults are more motivated to turn their learning into action if it is internalized and comes from within rather than from external sources*

See Brookfield (1986); Maslow (1969); Merriam and Caffarella (1999); Merriam et al. (2007); and Merriam and Bierema (2014) for examples. As noted in McDermott (2008, p. 90) "the goal of education and support in parenting and caring is self-generation for parents, teachers, and all who care for children: the ability to locate the resources within themselves and in relationships that would allow for continuous growth (Belsky, 1984; Flaherty, 1999; Rogers, 1973)." Snell and Rosen's research with parents of special needs children (1997) supports assumptions four and five:

> …the parents saw themselves as doing the 'normal stuff' of parenting but with a heightened sense of purpose and intentionality. The events of their stories were both similar and different, but each story contained the elements of a mastery process that was on-going and informed by prior experience. Each family found unique solutions to their own problems and challenges but the larger theme was one of a learning process where parent's experiences, perceptions, behaviors, and beliefs interacted to provide the context for healthy adaptation. (p. 428)

A related construct is self-determination. Grolnick (2003) explains that:

> self-determination theory begins with the idea that humans are born with innate propensities to be active and agentic with regard to their surroundings. Individuals are born with the energy to pursue challenges and master the environment. Self-determination theory … assumes that humans engage their surroundings in an attempt to elaborate and expand themselves and thus to grow and develop. (p.53)

6. *Adults need to know the reason for learning something*

This is related to the motivation to learn assumption above. Merriam and Bierema (2014) also explain that the need to know is often simultaneous with significant life changes or role changes like caring for a child recently diagnosed with autism.

7. *Adults learn best when a listening-dialogue-critical thinking-action process is involved*

Brookfield (1987, 2012), First and Way (1995), Frieri (1973), and Mezirow (1990) describe this process. Brookfield (2012) has defined critical thinking as "the ability to assess your assumptions, beliefs, and actions" (p. 222). McDermott (2008) cited Brookfield's expanded and rich description of critical thinkers: They engage actively with life, are creative, appreciate diversity, and see many possibilities in life. Critical thinkers continually question assumptions and discard inappropriate assumptions. They consider context. Critical thinking happens in positive or negative situations, and it may sometimes cause inner discomfort and confusion. It is emotional as well as rational. It involves both imagining and exploring options, as well as reflection leading to new understanding of self and others (pp. 7–9).

Pertaining to dialogue, McDermott (2008, pp.131–132) calls attention to the work of Janet Gonzalez-Mena (1997) who notes that in dialoging, rather than trying to convince someone of their own viewpoint, people try to understand the other perspective. The idea is not to win but to find the best solution for all people involved. Here are some of the differences she describes between an argument and a dialogue:

- The object of an argument is to win; the object of a dialogue is to gather information.
- The arguer tells; the dialoguer asks.
- The arguer tries to persuade; the dialoguer tries to learn.
- The arguer tries to convince; the dialoguer tries to discover.
- The arguer sees two opposing views and considers hers the valid or best one; the dialoguer is willing to understand multiple viewpoints. (pp. 3–4)

Dialoging is one aspect of what Gonzalez-Mena (2008) describes as an ideal multiethnic view, which also involves transformative education and culturally competent care for children. By transformative education, she means that "when we acknowledge that our experiences with one another are important, when we stretch to understand different points of view, we become transformed by each other's life experiences to a different level of knowledge and sensitive multiethnic care. That's good for children" (p. 25). Her definition of cultural competence is also helpful: "Caregivers and parents understand how program and family values may differ and work together toward blending differing value systems" (p. 26).

8. *Adults' learning is enhanced when they have opportunities to interact with peers during the learning process*

See Brookfield (1986) and Auerbach (1968) for further descriptions. Auerbach (1968) notes:

> parent group discussion …encourages parents to respond freely to one another, questioning, challenging, agreeing, adding, commenting, disagreeing, as they test their own ideas and convictions and gradually take a position for themselves" (p. 27). She adds that "the group discussion approach at no times puts pressure on an individual member to move into a discussion faster than he is prepared to (p. 28).

9. *Adults often like to plan their own learning experiences*

Belenky et al., (1986/1997), Brookfield (1987), and Kolb (1984) provide further explanation here. This applies to many teachers as well. For people from cultures in which planning one's own learning is not valued or relevant, this expectation may initially be stressful. One thing they assumed from their own experience was that others would tell them what they needed to learn and how they would do that. While they might eventually appreciate being able to do so they will need some scaffolding in this regard.

10. *Adults need to filter information through the affective domains of beliefs, feelings, and values*

We know from Krathwohl (2002) that the cognitive domains of learning involving remembering, understanding, applying, analyzing, evaluating, and creating information do not produce behavioral change unless learners filter this information through the affective domains of their beliefs, feelings, and value systems (see also Kypros, 1989). The affective domain includes (1) attending to stimuli (awareness, willingness to hear, selective attention), (2) responding to stimuli (in terms of either compliance, willingness to respond, or a real satisfaction in responding, often referred to as motivation), (3) valuing or being committed to a phenomenon (ranging from acceptance to real commitment and all that entails), (4) organizing a value system (contrasting different values, resolving conflicting values, and creating one's own unique value system), and (5) being characterized by a specific value system (internalizing a pervasive, consistent, and predictable value system unique to the adult learner (Krathwohl, Bloom, & Masia, 1973). If the levels of the affective domain are not engaged, people will not go beyond the first level of learning, which is merely receiving basic information. My own experience with some parents of children and young adults with severe autism was that over time, to remain confident in their own choices and behaviors on behalf of their child, they find it hard to hear others or trust them to have better solutions. I have also found that some parents are so emotionally drained from the labor-intensive work of just managing a child on the autistic spectrum that they put their remaining energy into a behavioral program and run out of energy to add other multilevel interventions that could benefit their child and family. Professionals need to help them navigate the affective domain in this regard. We also need to help parents get the respite care they need so much.

Many parents and teachers are just given information, and so they remain at the receiving stage. They do not think about and discuss how the agency or school's directives mesh with their own ideas and goals and what they believe children need. They end up consciously or unconsciously resisting what is asked of them (McDermott, 2008). Robertson (1996) would add that we also need to gain an understanding about the way social relations and culture have shaped one's beliefs and feelings.

Auerbach's Assumptions About Parents as Learners Within Groups

For parenting educators, Auerbach's (1968) assumptions about parents as learners (within groups) provide support of adult learning assumptions noted earlier as well as additional proven assumptions:

1. Parents can learn….
2. Parents want to learn, particularly about those issues and relationships which affect the growth and development of their children….
3. Parents learn best…when they are interested in learning….
4. Learning is most significant when the subject matter is closely related to the parents' own immediate experiences with their children and with one another in relation to their children. …
5. Parents can learn best when they are free to create their own response to a situation….
6. Parent group education is as much an emotional experience as it is an intellectual one. …
7. Parents can learn from one another….
8. Parent group education provides the basis for a remaking of experience….
9. Each parent learns in his own way. … (pp. 23–28).

McDermott (2003) has prepared workshop materials based on the assumptions above and other theories and research to help professionals plan for parent involvement with parents as adult learners. See https://us.sagepub.com/en-us/nam/developing-caring-relationships-among-parents-children-schools-and-communities/book228935#preview.

Recent Perspectives on Parental Learning and Thinking

What else do we now know about parental learning and thinking? Adult educators and psychologists have theorized the following (as detailed more extensively in McDermott, 2008, 54–67 and 138–156):

Kolb (1999) defined learning as "the process whereby knowledge is created through the transformation of experience" (p. 41). He describes four stages of the learning cycle: In concrete experience, one learns from relating to people and being sensitive to their feelings. In the reflective observation stage, one learns from watching and listening (carefully observing before making judgments, seeing issues from many perspectives, and looking for the meaning of things). In abstract conceptualization, one learns by thinking (logically analyzing ideas and systematically planning and acting on one's intellectual understanding of a situation). Finally, in active experimentation, one learns by doing (getting things done, taking risks, and influencing others through action).

The ideal way of working with parents is not a lecture but a plan-do-reflect process in which caregivers identify concrete experiences in their lives about which they are concerned, reflect on them, become informed about what educators know about the developmental characteristics of those involved, and then actively experiment with strategies inspired by their learning, reflection, and sharing.

Holden and Hawk (2003) have posed a theory of meta-parenting (a class of evaluative parental thought concerning the child-rearing domain that typically occurs before or after parent-child interactions" p. 191). They suggest that parents need opportunities to anticipate, assess, reflect, and solve problems as they adjust and modify their behavior to fit changing situations and changing relationships. Recent research finds evidence for this construct (Hawk & Holden, 2009).

Conditions that facilitate meta-parenting, according to Holden and Hawk (2003), include parents' willingness to be involved with their child and a sense of self-efficacy, that is, a sense that they can control outcomes and make things happen. Besides a willingness to be involved and a sense of self-efficacy, parents need certain "necessary conditions" (Holden & Hawk, 2003, pp. 197–198), such as time and energy for anticipating, assessing, problem-solving, and reflecting. Even with time and energy, we know from the research of Belenky and her colleagues that a parent's "way of knowing" figures into their readiness to do this. Please note that some of this theory as pertains to child capacity may not be pertinent to certain children on the autism spectrum.

Belenky, Clinchy, Goldberger, and Tarule (1986/1997) and Belenky, Bond, and Weinstock (1997) research with women and parents resulted in a description of five "ways of knowing" that have implications for how one works with parents. First, at the stage of "silenced knowing," a parent sees herself as mindless and voiceless, and sometimes, when asked to do something she may not be able to do, she may use "words as weapons." She may have been in relationships with people who called her stupid and never really gave her credit for having good ideas. In terms of others, this parent may be distant and guarded, believing she cannot really learn from dialogue of any kind. She may fear that any talking or sharing she does will lead only to more betrayal. She may tend to use raw power (just as she may have experienced) to influence her child and may see no point in listening or explaining.

Other parents may be described as "received knowers." They receive information from authorities and store it as is without adding their own thoughts or opinions. They receive information from friends if it is similar to their own. They see their children as needing to listen to others and to take in information without questioning it. They expect their child to obey them and do what they do. They may also think the child will learn through rewards and punishments and by imitating adult behavior. They may be seen as cooperative by school and agency staff.

Belenky and her colleagues (1986/1997, 1997) found that parents who were "subjective knowers" had discovered their inner voice and believed truth comes from within more than from outside authorities. The subjective knower would value individuality and be able to tolerate friends having beliefs different from hers. She can also see that her children have their own inner voice, and she is likely to let her children think for themselves. Even though this may be good for her children, it may cause trouble in the school, which may see this parent as noncooperative or even hostile. Because these parents tend to trust their own concrete experience, instincts, feelings, and insights when it comes to rearing their children, they may not attend lectures. Sometimes these parents are seen as neglectful. While neither extreme – trusting all authority without question or trusting only the self – is ideal, for some parents, one or the other may be a step along the way to relating more effectively to self and to others in the future.

Next, the authors describe parents who are "procedural knowers." They are interested in examining thoughts and feelings of both the self and others and searching for systematic ways to do so. They do not mind being in a group in which others do the same. They will help their children use such procedures as gathering information and posing and evaluating alternatives to arrive at answers to their questions. Simply to gather information in an objective, logical way is called separate knowing. Others will seek understanding, not just proof. This is connected knowing and involves trying to understand the feelings, perspectives, and experiences of others, which requires drawing people out to better grasp their thoughts and beliefs and encouraging their confidence in their own abilities and strengths.

Finally, as a constructive knower, the parent not only gathers information but synthesizes it. Parents at this level would not want to get information from just their own concrete experience, intuition, feelings, and insights or from just the school but to combine ideas from all perspectives, come up with a joint solution that could be better ideas, and then share that solution with school staff and others. Belenky and her colleagues (1986/1997) worked with mothers in rural Vermont in small groups providing the support needed to enhance their cognitive development and effectiveness as parents. Their interventions were successful, but they found success to be moderated by whether or not the boyfriends/partners of these women supported this growth work. Hence, there is the need to focus on the context in which learning takes place.

Sameroff and Feil (1985) in building on Piaget's model of cognitive development found levels of parental thinking as well. At the symbiotic level, parents rarely would differentiate between themselves and their child as separate, so it was hard to see the child as developing separate from what they did for the child. At the categorical level, the parent saw the child's behavior as separate from the parent but often placed children into categories such as good or bad, based on their behavior. Parents could think of only one cause for behavior: either internal dispositions of the child or the environment, but not a combination. In the compensating stage, parents saw children as separate from categories or labels. They could make exceptions and see that some behavior might be related to a child's age or capacities. Certain attributes might compensate for others. At the perspectivistic level, parents were able to think hypothetically and see the child's behavior in context. So perhaps a child can sit quietly at home in their room but not in a crowded classroom with fluorescent lights.

Newberger (1980) and Newberger and Cook (1983) described the related construct of parental awareness based on parents' experiences, needs, feelings, and cognitive abilities. For many, parental awareness progresses from self-centered, egoistic views, to conventionally oriented views reflecting cultural norms, to understanding that individuals are unique and different. The process culminates in an analytic, systems-oriented view of the parent and child in interdependent self-systems. Newberger and Cook (1983) found that levels of awareness were significantly and positively related to age and experience as a parent but not to gender, race, or social class. Sandy (1982) found significant increases in parental awareness in parents who received a parenting education intervention that included child development information and time for discussion.

Kegan (1994) also described parental cognition as thinking that is inseparable from feeling or social relations. According to Kegan, we construct our sense of self in the relationship between our own point of view and others'. His first order of consciousness is childhood. In his second order of consciousness, people focus their knowing or thinking on their own needs, and in the third order of consciousness, on a moral ethical code that comes from our group, family, culture, race, religion, or society. In the fourth order of consciousness, one respects differences in people's thinking and realizes values are based more on situations and the way each person construes or views situations.

To conclude, theorists studying and working with parents have expanded Piaget's focus on cognitive development over the lifespan. In fact, Mackeracher (2004) has asserted that the highest stage of thinking for Piaget (formal operations) cannot resolve the "uncertainties, doubts, and ambiguities" in adult life today as there are "complex systems of roles and relationships requiring systems thinking" (pp. 120–121). Christian (2006) and Greenspan and Weider (2006, pp. 163–176) have described a systems approach to working with parents. In addition, current research in neuroscience merits our serious attention. Ellison, e.g. (2005), highlights the positive impact of becoming a mother on a woman's thinking capacity.

A Caring Paradigm for Synthesizing Adult Learning and Development Best Practices

It is hoped that helping professionals would manifest constructive knowing and the higher levels of thinking from the theorists above whenever possible. In looking at the theories and research described above, one wonders how to think about best practices going forward. It is suggested that Heath's (1983, 2001, 2014) caring paradigm for working with parents combines the best of research in adult learning and psychology. It has been described by Holden and Hawk (2003) as exemplary and has been proven to enhance higher-order thinking skills in parents (Kypros, 1989). Heath's approach to parent learning and development allows for all Kolb's learning styles while also reflecting Holden and Hawk's construct (2003) of meta-parenting. In addition her theory of parental ego processes (See https://us.sagepub.com/sites/default/files/upm-inaries/24029_3___Understanding_the_Elements_of_Parenting_and_Caring.pdf) speaks to the complexity described above. McDermott (2014) describes her successful parenting programs for children and adults which help develop 17 cognitive skills.

Any group of parents and teachers, with the right preparation, motivation, and support, can use a "planful," caring decision-making process that is culturally sensitive and allows all involved to bring their own thinking, feelings, needs, goals, beliefs, and experiences into the process (McDermott, 2006). Such a process provides a way for parents and teachers to develop and change their behavior if needed because it considers both their cognitive and their affective capacities (Krathwohl et al., 1973).

By walking through the components of this planful process of decision-making in more detail, one will see how this model supports adult learning principles and cognitive and affective development of children and all the adults in their lives. Please note that when referring to Bloom's taxonomy (1956) this review will use Krathwohl's (2002) revision of Bloom. Details of the caring process are expanded in McDermott (2008) and in Heath (2000, 2001, 2014) and are described below.

1. *Describe the situation about which you are concerned*. This activity is based on helping parents develop observation skills important in behavioral programs also. It is comparable to Krathwohl's (2002) first cognitive domain of remembering, which has to do with describing, recalling, listing, recognizing, and data collecting. The cognitive and affective domains (Krathwohl, 2002; Krathwohl et al., 1973) are used here because it often remains a pertinent part of adult and parenting educator training.

We encourage parents to become aware of the situation using nonjudgmental awareness techniques. Parents list a sequence of events objectively. They reflect objectively on questions such as, what happened first? Then what happened? What time of the day does this happen? Does it always happen this way or just when he is tired? The goal is to get parents, teachers (and future teachers) to think about a situation in a new way.

As they start to process this information they move into the second cognitive domain of understanding. Here they gain insight into some of the correlates of the child's behavior. At the next level of applying, parents and teachers use their descriptive information in creative ways, such as changing the environment. They are open to looking for a range of possible causes and using these possibilities to begin crafting solutions.

2. *Brainstorm choices*. Here, we ask parents, teachers, or students using this process to think of all the possible ways to deal with the problem.

We make lists of every single thing we could do, whether it is good, bad, or in between. Each member of the group is asked to come up with ten different ways to deal with the situation of concern. This is a very important step because it demonstrates that there is more than one way to deal with a situation. Often people get into serious problems when they think they have only one option. Several of the most successful problem-solving programs (Heath, 2000, 2001, 2014; Shure, 1988, 2004) involve the formulation of alternative solutions, which taps into the same creativity present in mindful learning. Next we consult guides for deciding which option to choose.

3. *Identify goals.* Our goals are crucial when choosing options. The selection of goals has to do with long-range thinking. Heath (2000, 2014) provides a list of attributes parents would want a child to have by age 18. The list of positive attributes engages the affective domain (Krathwohl et al., 1973), deepening parent involvement in the process. Parents and teachers can keep their list of long-term goals for the child and refer to it each week as they gather information and decide on options.

Then parents are asked to think specifically about their goal for the particular situation in light of their list. This request strengthens the engagement of the parent's affective domain because it requires a commitment to one or more of the goals. With a specific goal or goals in mind, parents revisit their brainstorming list and omit the options inconsistent with their values and goals (which corresponds to the sixth level of cognition, which was synthesize for Bloom and is creating for Krathwohl). If the parents' goal for their child in a particular situation is to be kind to the teacher and classmates, for example, certain brainstormed options like hit the teacher or classmate who hurts them can be rejected.

4. *Consider needs* (Heath, 2000, 2014, pp. 25–28). Looking at the needs of everyone involved in a situation – child, parent, teacher, trainer, other children, other family, and sometimes the community, country, and beyond – is very important and very therapeutic for all involved. These needs are identified via the third level of cognition, applying, in which we use knowledge gained and then take action based on that knowledge. Information about all persons' needs enters into a planful and caring process of decision-making. Parents deal with the issues of conflicting values within their own list of goals and conflicting values between themselves, their family, school, and society.
5. *Think about feelings.* Heath (2000, 2014) provides a way to guide parents and practitioners to think about feelings. Looking at feelings involves Bloom's and Krathwohl's first four levels of cognition and Krathwohl et al.'s (1973) third level of the affective domain valuing or being committed to a phenomenon. From a cognitive perspective, parents and teachers are listing feelings, gaining insights, and considering a wider range of feelings than is typically discussed. They start to see how the feelings of everyone involved relate to their values and goals. If they want their son to be a a young adult capable of independent living someday, they may begin to question whether how they respond to his interactions with other children is helping him toward that goal. This process is related to important recent work on emotional intelligence and emotionally intelligent parenting (Gottman, 1998; Elias, Tobias, & Friedlander, 1999). Auerbach (1968, p. 26) adds this insight:

> Parent group education therefore encourages the expression of feelings, not for their own sake in a vacuum, but in relation to the substance of parent-child relationships and family living. The leaders are always alert to the need for maintaining some kind of balance between fact and feeling, between the outer reality and the emotional responses of parents to their real-life situations.

Heath's systematic approach to addressing feelings accomplishes this goal.

6. *Recognize individual characteristics.* Heath (2000, 2014) provides information about an important dimension often omitted from

problem-solving models for parents. This area, involves Krathwohl's fourth level, analyze and Krathwohl et al.'s third level commitment. Parents and teachers identify and describe developmental differences and other individual characteristics in people and extrapolate those characteristics to the situation of concern. Is the child's resistance related to temperament or how their brain functions? Is a parent's resistance to a lecture related to the parent's preferred learning style, which is not auditory but kinesthetic or visual? Is the child's gender a factor in parent and teacher expectations?

Information on these developmental factors and other individual characteristics leads to understanding. Note how this process involves Belenky and colleagues' ways of knowing (1986/1997) and takes parents beyond just receiving lectures to bringing in their own experience, instincts, and feelings and then using them to analyze different options and different points of view. From there, they can engage in connected knowing or trying to understand the perspectives of everyone in the situation and then construct options that are based on all the information they have gathered from their own thinking and the thinking of others.

The next step is for parents to take action, which corresponds to Krathwohl's fifth level of evaluation. They compare options, justify which one is best and most consistent with their goals and values, implement it, and appraise the results. They can decide if it works for that situation or whether they need to do something different. Our hope is that parents will internalize this caring model of making decisions. It would benefit children and helping professionals greatly to know where parents stand and what values guide their decision-making.

Some reflections on additional components of the model: As pertains to the influence of energy level, as well as a parent's physical condition, Snell and Rosen's (1997, p. 439) conclusions to their research with parents of children with special needs are informative:

> When working with families who are struggling with how to cope with a child who has special needs it seems important for the practitioner to be viewed as a resource rather than an intruder who saps precious energy from an already burdened system….family therapists who work with these families may need to examine their own beliefs and values as a first step towards establishing a healthy therapeutic relationship. (p. 439)

As pertains to looking at parental conditions including one's financial situation in this model, Brody, Flor, and Gibson (1999) as cited in Luster and Okagaki (2005) found a relationship between African American mothers' perceptions of adequate family finances and their parental efficacy and developmental goals for their children. When finances were adequate, mothers had more parental self-efficacy and held higher expectations for their children. They talked more about goals. This research supports the view that family-serving professionals must find the other actors/resources to improve the conditions in which parents do their parenting "work" before placing generic, one-size-fits-all involvement expectations on parents.

In looking at characteristics, Snell and Rosen (1997) add that: "In establishing a therapeutic relationship, the therapist needs to understand and accept the family's unique style of adapting and enhance this style while exploring this goodness of fit" (pp. 438–439).

In looking at family traditions, McDermott (2008, chapter 5) poses a list of questions to ask before engaging parents of diverse backgrounds in learning activities. In thinking about families in terms of culture, one might ask: Are the parents willing to change beliefs on the basis of new information they might receive? Can the parents only go to their family for all or certain advice? Can they go to experts, books, and other sources outside the family for all, any or certain advice? Is there a shared understanding of events or issues between parents, parents and children, other family members who have decision-making power over children, teachers, counselors, and other parents? Do the parents see themselves as capable of meeting their children's needs? Do the parents see themselves more as observers or as actors in their children's life? Do the parents have an opportunity to observe other parents or professionals interacting with their children or does their culture or situation prevent them from doing so?

Thinking about why there might be disagreements or misunderstandings between parents and teachers is time well spent. Some parents believe that if children are safe and fed, they will develop naturally, without much parental intervention (an approach some teachers may view as neglect). This naturalistic view is found more often in parents of lower socioeconomic status (Lareau, 2011). Lareau also found that middle-class and upper-class families of many cultural backgrounds believe their role is "conscious cultivation" to help their children achieve as much as possible.

McDermott (2008, pp. 152–153; 2014) has used Heath's model with students and parents in several culturally diverse schools in the Chicago area. Parents appreciated the opportunity to bring in their own goals and beliefs into the process. Parents from many diverse backgrounds had only experienced formal lectures in schools and upon reflection, preferred the small group work with Heath's model to lectures. Contrary to expectations, McDermott found that Mexican American mothers in a poor neighborhood were more willing to do the group work of this 8-week-long program than middle-class parents wanting her to provide quick answers.

Conclusions

Mayeroff (1971) has described caring as having someone's development in mind. Adult educators Taylor et al. (2000) research project summarizes some of what has been presented here. They asked teachers and trainers to describe their own caring or developmental intentions for their students. In analyzing the results, they described development as marked by a movement along five dimensions which are listed here as well as an example of one of the several characteristics or indicators listed under each domain and crossing the domains. They saw development as movement: (1) toward knowing as a dialogic process (including perceiving and constructing one's reality by observing and participating), (2) toward a dialogical relationship to oneself (exploring and making meaning of one's life stories within contexts), (3) toward being a continuous learner (reflecting on one's own and others' experiences as a guide for future behavior), (4) toward self-agency and self-authorship (constructing a value system that informs one's behavior), (5) and toward connection with others (engaging the affective dimension when confronting differences and contributing one's voice to a collective endeavor) (pp. 32–33).

Adult learning principles challenge helping professionals who are often asked to use particular curricula that are not always geared to support parent development. Clinicians have known for years that one needs to help the parent to help the child and ensure more long-lasting results. It is hoped that by knowing more about best practices for adult learners and parenting educators (See also McDermott, Heath, & Palm, 2006) one can work to more carefully select interventions or do the preparation/support work to make traditional interventions more effective.

It is clear that no one format can work for all parents. All modes of intervention be they individual (seen often in home visitors, coaching, therapy) the valued small group mode (seen in workshops, seminars or support groups) or the mass mode (via lectures, print and social media including podcasts, webinars, mobile apps, etc.) should be considered in light of relevance for select parents. Darling et al. (2014, pp. 281–284) reviewed these formats as well as primary, secondary, and tertiary prevention modes. Ideally, one begins to teach children all that is involved in parenting and caring for another human being in school. McDermott (2014) has described several evidence-based programs that do this around the world. Heath's caring paradigm for parents that was described above has been used successfully with students from pre-K-grade 12 for decades

(Heath, 1995). Thus before even having a child with special needs, new parents would be prepared to face this challenge with confidence and competence.

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Part IV

Engaging Parents as Partners: Approaches and Strategies

12

Coaching Parents of Young Children with Autism

Laurie A. Vismara and Sally J. Rogers

Abstract

Parents face many questions, uncertainties, and fears at the time children are diagnosed with autism. At the heart of this process is the relationship with early interventionists who work early on and intimately with families to help children with autism learn, connect, and engage. This chapter describes a series of early intervention strategies to promote a coaching (versus expert-driven) relationship between interventionists and families. The approach, procedures, and examples come from our own line of research and work coaching families with the Early Start Denver Model (Rogers, Dawson, & Vismara, 2012) as we talk about how to define and address child learning goals inside everyday routine-based activities and how to increase parents' motivation when it comes to making the change necessary to address goals. The outcome is a stronger working alliance to guide, support, and ultimately empower parents toward active learning and child-family engagement.

Introduction

As methods for infant/toddler autism identification evolve and improve, and ever-younger children are being referred to early intervention, a dilemma is arising for interventionists. We know that infant-toddler development is profoundly influenced by characteristics of parent-child interaction. Young typically developing children spend their waking hours (approximately 70 h per week!) interacting with the people and objects in their everyday lives, and developmentalists assume that this level of engagement is needed in order to foster typical social communicative development. Thus, the oft-cited recommendation that young children with autism need at least 25 h per week of active social engagement in organized, developmentally appropriate activities that are interesting and meaningful to them (National Research Council, 2001) reflects a "dosage" far less than that occurring in the lives of typically developing young children in adequate learning environments.

However, too often early intervention for autism is equated with 1:1 structured interactions

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_12

with a trained adult delivering clinician-generated treatment plans and procedures for many hours daily, thus replacing parent/caregiver-child interaction times with scheduled child-therapist interaction and replacing opportunities for engagement in everyday activities with adult- structured and adult-designed learning activities. Furthermore, scheduling 15–25 h of clinician-delivered treatment in between a young child's sleep and care schedules by necessity replaces parent-child interaction times in everyday activities.

There are two potentially damaging messages to parents embedded in the intensive therapist delivery approach. The first is that time with (often paraprofessional) therapists is more important for child learning than time with parents and family. The second is that "adult-directed therapy" involving highly specified and preplanned lessons is the only way their child can learn and is thus more important than learning opportunities within ongoing family activities. Such messages implicitly assume the lack of parental competence to provide for child needs and undercut parents' confidence in their parenting and their ability to help their child thrive. When these messages are delivered at the start of a young child's life, they can set in motion a lifelong assumption that the child with autism's treatment needs will always be best served outside the family, creating a dependence on others that may last a very long time.

There is another way. At the point of a young child's diagnosis, most parents will ask the diagnostician, "What can we do to help our child?" Instead of responding with a recommendation that parents should enroll their child in 25 or more hours a week of behavioral therapy, we can focus on the parents' goals and the learning needs and styles of the child and think with the family about the many ways that the family as well as others in the child's life can be brought together to meet these needs. Including the parent and family interactions as one of the critical "interventions" for the young child reflects parent expectations that they will provide their child's care.

Instead of replacing parents with therapists as young children's primary teachers, this chapter will describe early intervention strategies for autism that embrace parents as central players; that work from a family-centered, rather than child-centered perspective; and that develop strong working alliances that support active family engagement in defining and addressing child learning goals inside parent-child activities and interactions in everyday routine-based activities.

In the first part of the chapter, we will describe some procedures that we have found to help families engage with the early intervention provider, clinician, or interventionist in a particular type of relationship – a coaching relationship (Hanft, Rush, & Shelden, 2004). The coaching relationship begins at the first point of contact with the family in the goal setting process and contributes to a strong alliance with the interventionist so that all can work together to create a set of treatment objectives that address children's learning needs across environments. Principles for coaching, examples of the process unfolding with families, and a format for using coaching in sessions with parents and children will be shared from the coaching principles, approach, and philosophy of the parent-implemented Early Start Denver Model (P-ESDM; Rogers et al., 2012).

In the second part of the chapter, we will describe procedures for supporting families to embed treatment objectives into everyday activities at home. One process involves helping families identify the settings and range of learning opportunities that already exist in the daily routines, rituals, and moments that parents and young children spend together. A second process that supports families recognizes the unique challenges and strengths of their own family in raising their child with autism and supporting their individual child's learning.

Finally, we will end by describing a particular method for working with family motivation to make the changes needed to address their goals for their child in everyday routines. The procedures and approaches we describe come from our work over the past 10 years in supporting parents to use techniques from the ESDM (Rogers & Dawson, 2010) at home, supported by a foundation of clinical experience and empirical data, from our own work and from others.

Defining a Family-Centered Approach

Early intervention models for autism were originally developed for children between 3 and 5 years of age, and several different intervention approaches have demonstrated efficacy in improving preschoolers' social-communicative and cognitive development. However, preschool-aged children have very different needs and capabilities than those younger than 3. Infants and toddlers need to sleep and eat frequently, need considerable physical and emotional care, and require a great deal of adult attention and interaction. The long-term dependency that human infants and toddlers have on adults is believed to be an important mechanism for developing the advanced communication and cognitive abilities that we have as a species. Infant-toddler developmental progress is dependent on the language and actions used by parents and the meanings that are associated with the socially charged routines, rituals, and activities that make up each and every day. And families expect to have ongoing interaction with infants and toddlers, even more so than with their preschoolers and older children, who can do much more for themselves. Helping parents to interact and communicate based on engagement and learning strategies developed for infants and toddlers therefore becomes important to promoting the long-term development of social-communicative skills and brain functioning affected by early autism (Dawson et al., 2012). The quality of parent–child interaction is a crucial component of long-term change (Anderson, Rosalind, Lord, & Welch, 2009; Lord, Luyster, Guthrie, & Pickles, 2012). For all these reasons, parents are key members of a young child's treatment team. However, parents have a unique perspective, investment, and responsibility about their child's care. Their unique role requires that their participation in their child's learning be defined by them and that their relationship with interventionists whom they have asked to help needs to evolve to fit their goals for seeking help. Thus, the intervention focus for the youngest children with autism expands from the child alone to the child in interaction with parents and other family members – a family-centered approach that recognizes the centrality of family life and learning for young children with autism. And this intervention focus also requires a shift away from directly eliciting specific skills in the child and instead supporting parents to use strategies that will promote specific child learning goals inside everyday activities.

However, parents are not students. They are consumers of intervention services. They have choices about clinicians, and they have choices about what they will do and not do with their child in everyday life. They approach an interventionist asking for specific help, and the type of response they receive, both in the moment and over time, will determine how successful, and how long-lasting, the shared work will be.

What kind of relationship will be most helpful in supporting the parents to determine and achieve their goals for their child? Hanft et al. (2004) have made an excellent argument for the utility of a coaching relationship between clinician and parent working together in early intervention. A coach is someone an adult seeks out from whom to learn something very specific. The adult (or parent in this case) articulates what he or she wants to learn (i.e., personal goals) and locates a coach to help him or her achieve the stated goals (i.e., a coaching plan). As the coaching continues, the adult gauges whether or not the relationship is helping to reach his or her goals (i.e., evaluation). If things feel successful and positive, the coaching continues, and if not, the adult may end the relationship and either go elsewhere for support or give up on the goal. Thus, in an adult learning framework, the adult seeks the coach's skill in achieving personal goals, and the evaluation of the success of the relationship in moving toward goals determines the outcomes of the relationship.

Coaching shares certain characteristics with other approaches to helping adults, like counseling, mentoring, teaching, or supervising. All may include a one-to-one relationship with helping the adult access specialized expertise. The distinction though between coaching and these other types of relationships rests on the degree of responsibility between the adult and coach participating in the learning experience. Coaching aims to support the learner when, where, and how the support is needed. This is different from an expert-driven model where the information transfers from a master to a student. Coaching is an interactive process and builds on the learner's ideas, experiences, skills, and knowledge to integrate new information and skills with current ones. In early intervention, the provider's role as the "coach" is redefined from being an expert to being a resource to the parents in the development or refinement of their ability to use new and existing skills and information in ways that will meet their personal goals. The coaching relationship supports parents and other caregivers to (1) identify how to strengthen and enhance a child's learning within existing, real-life situations and to (2) ensure that child learning happens as anticipated. The coaching plans for the intervention (i.e., what learning opportunities will occur, when and how they will happen, and who will be involved) evolve from a discussion with parents about the opportunities and demands of their daily life, their goals, and their current knowledge and skills integrated with the coach's observation and assessment of the current situation and child and family needs. The coach explores with the parents how and when to use specific strategies and information to help their child participate and learn within meaningful family activities. It is a mutual conversation in which the coach and parents share and receive information, ideas, and feedback rather than one telling the other what to do.

Coaching Principles

In this adult learning relationship between parents and coach, each partner has resources to share and skills to gain from interacting with the other. The coach has information to share about child growth and development and specific intervention strategies to enhance this process. The parents and other caregivers have intimate knowledge of a child's abilities, challenges, and typical performance in any situation. They understand the child's and family's daily routines, lifestyle, environments, family culture, and ideas for teachable moments and desirable goals they would like to accomplish for their child, themselves, and as a family. This exchange of ideas, experiences, methods, and resources between the coach and parents ensures that coaching does not become telling someone what to do and how to do it but rather remains a dialogue of joint learning and insight about new or expanded skills that can be used inside existing interactions to promote growth. One of the coach's tasks is to keep the conversation between the coach and parents well-balanced.

Listening to the parents, the coach comes to understand their story and their perspective and expectations with the context of their daily life. The coach uses this information to find common ground between the parents' beliefs and what they want to make happen and the resources that will help to meet their goals. The coach must also know when and how to share new information and ideas in a way that supports the parents in achieving mutually agreed-upon outcomes. Part of doing so involves the coach's skills in quickly understanding both (1) what information, ideas, and skills may be useful to this set of parents and also (2) how these can be integrated into the parents' current knowledge, skills, values, and priorities.

Clearly, then, the coach's role is not didactically telling or showing the parents what they should or should not be doing. An effective coach supports the parents to examine their ideas and experiences so as to promote self-discovery while sharing his or her own knowledge and skills as needed. The coach and parent sessions focus on exploring, sharing, and testing of ideas supported by the coach's skills in listening, asking the right questions, observing ongoing interactions, and supplementing this with their own knowledge base in order to build parents' capacity to identify and implement strategies and/or solutions to help the child in learning goals that they have prioritized.

Also important to the coaching relationship is the parents' emotional experience with the coach. The coach demonstrates a caring, compassionate attitude through encouragement, patience, and creation of a safe environment for the parents to learn, to ask for help without feeling inept or ignorant, and to accept and learn from unsuccessful attempts that naturally occur in the learning process. The coach empathizes with challenges, experiences them himself or herself, and assists parents to reflect mistakes or failures in order to consider other options. It is a balanced, reciprocal relationship guided by a mutual understanding of values and with clear roles to encourage and support ideas for learning.

Supporting Parents in the Goal Setting Process

The first contact In ESDM work, the diagnostic process is carefully separated from intervention work. Different teams, different spaces, different tools, and different questions define these activities. The intervention process begins with the first contact of the clinician or interventionist who will serve as a coach to the family. In the situation in which the diagnostician is also the interventionist, it is important to separate these activities in time and in type. The diagnostic process ends with a diagnostic discussion with parents and recommendations for the next steps. A dialogue about beginning intervention begins at a different time, in a different appointment, and in a different style.

The intervention/coaching relationship begins at the point at which parents ask, and the interventionist agrees, to "help them provide intervention for their child." The wording is important here. A coaching interventionist does not agree to do the intervention but rather to help the parents provide the intervention. This wording, both the nature of the relationships and the nature of the early intervention approach, is delivered in the message that parents are capable and motivated to help their child, and the role of the coach as a parent helper rather than a child therapist is defined.

A helpful follow-up question leads directly to parent goals for child progress: "And what is it that you most want to teach your child? or "What would you most like to see your child accomplish in the next three months?" (The ESDM works in 12-week periods to write and achieve objectives; our examples in this chapter come from our work inside P-ESDM with families). Focusing on a reasonable period of time for progress, rather than the immediate "this week or today," recognizes that learning and change take time, and we will be working toward a point in the short term, but not immediate future. While more data are needed before short-term learning objectives can be developed, asking parents their goals at the very beginning of the relationship emphasizes who is steering the ship – the parents as consumers – and it prioritizes their goals, not the interventionist's goals. The parents are already in the driver's seat. Taking down parent goals verbatim without offering changes, suggestions, or modifications delivers this message strongly.

What about parents who are unsure of what skills or goals to teach to their child? Coaches still want to refrain from telling parents what to do and instead opt for other strategies that will encourage parents' reflection and to select goals. For example, the coach may ask the parent to describe a typical day with the child and in particular those behaviors, activities, or events that are more challenging to manage. Identifying child challenges helps lead the conversation to goals. Another option is for the coach to watch the parent carrying out a usual routine with the child, such as reading a book together or attempting to occupy the child with a toy to make a phone call. Once the routine ends, the coach can ask questions to help the parent identify the child skills that contributed to positive, enjoyable interactions and what other behaviors could extend or increase those moments. If involving the child is difficult or not possible to do, the coach and parent may act out scenarios to generate potential goals. Visualization, demonstrations, and role-play then create alternative techniques to parents maintaining their role as the leaders in the goal selection process.

The assessment phase The next procedural step generally requires some type of assessment of child and family needs, strengths, and routines to specify reasonable short-term objectives, as well as to determine what supports the family needs to support their child. Maintaining parent involvement and engagement in the intervention process can be helped or hurt by how this assessment is managed. In our ESDM work, the treatment assessment is temporally, physically, and procedurally quite separate from any diagnostic assessment. The treatment assessment involves the parents, interventionist, and child together in the child's home or in a clinic room setup as family-friendly as possible, on the floor, interacting across a series of typical toddler play and care tasks (e.g., snack time, changing diapers, dressing). The interventionist and parents are in ongoing dialogue about the child, what he or she likes, what he or she does with similar things at home, and what outcomes are important to achieve.

During the assessment, an ESDM coach orchestrates the various activities that get carried out for the assessment, though it is usually the parent who is primarily interacting with the child. This is because infants and toddlers typically prefer interacting with parents over strangers and because the parents know what the child is likely to do with the materials or activities. The interventionist uses the ESDM Curriculum Checklist, an itemized list of typical infancy through preschool-age skills (e.g., child responds to adult's instruction without the use of gestures; see Rogers & Dawson, 2010 for more information), to gather data on the child's developmental abilities and needs while suggesting and setting up various activities, observing the child and parents' interaction in the different activities, adding various probes, suggesting variations to the parents, and orchestrating the hour in order to complete the checklist. Based on the parents' preference for learning, the interventionist may suggest play ideas, model actions, hand over materials, and/or ask questions to effectively support the parents. The coach may certainly also initiate activities with the child but as a secondary person, not the main interactor. As the child finishes with one activity, child, parent, and interventionist transition to another type of activity that occurs in everyday life for them and often a change in location (e.g., floor to table, inside to outside, bathroom to kitchen). Activities, play, and dialogue continue until the interventionist has gathered all the data needed or until child needs dictate that the session ends. The assessment session provides a great deal of information about child skills and behavior in various settings from parent descriptions, from direct observation, and from conversation. Interactions with the child also reveal much about the strengths and needs that the parents experience in everyday life with their child. The interventionist needs to understand the daily routines of the family and child, how they go, and where the parent intervention priorities fall in terms of teachable moments and activities and problem moments and activities. The next appointment is scheduled with the parent to use the information collected from the first session that will define the short-term objectives and the family's learning plan for the shared work of parents, interventionist, and child. Parents are asked about any additional goals they would like the intervention to focus on over the coming 12-week period, which the interventionist writes down, and they know that the next session will begin with a review and final agreements about the intervention plan for the next 12 weeks.

We have described a treatment assessment that is highly interactive and quite family-centered. When the assessment process is handled in this way, the parents and the interventionist are from the beginning working as partners to share information, learn from each other, and work with the child. The assessment requires active participation and engagement from both, and the interventionist and parents are in both a teaching and learner roles. In this way the assessment delivers the message of parental competence and knowledge and the need for therapist-parent partnership and coordination, necessary to accomplish intervention tasks.

Beginning treatment In ESDM work, this next contact bridges from treatment-based assessment to intervention. The first treatment session begins with reviewing and agreeing on treatment objectives for the next 12 weeks. The interventionist shares with the parent a first draft of objectives based on the parents' statements of their goals for their child as well as on ideas the interventionist has based on the child assessments. The objectives are written in parent-friendly language and typical ESDM structure, describing the everyday setting and activities within which certain skills will be practiced, the parent or environmental antecedent, the desired child behavior, and the criterion and generalization aspects for mastery. Parental agreement is sought for each objective. If the objective is not endorsed by the parents (e.g., toilet training, using a fork, self-dressing), the objective is removed from the list. Other objectives that may not seem important to parents in terms of daily life (e.g., symbolic play) are explained by the interventionist as foundations for critical, later emerging skills to help the parents understand their importance. Parental wishes for different materials, instructions, etc. are incorporated into the treatment plan, and once parent and interventionist agree on the treatment plan, the therapist creates a finalized list and writes a set of teaching steps for each objective that will take the child from current skill level to the skill specified in the objective and datasheet that captures the objectives and steps to be used in treatment sessions These are provided to the family at the next visit and are used and discussed in each session, so that parents see and experience the systematic approach to child learning used in ESDM.

Here is an example of a parent-friendly objective and steps to increase the child's play skills, engagement, and ability to play back-and-forth with the parent no matter who initiates the play idea. Notice that a few toy ideas are suggested (from previous parent input) but not specified in this example. This is deliberate ESDM planning so that the parent and child are not restricted to a set list of activities but instead can use any type of toy or play-based material to work toward this goal and maximize the child's ability to develop this skill.

*When my child and I are playing with toys, he and I will take at least four back-and-forth turns to put in, take out, or do an action with the toy he or I choose for three or more different play activities (*e.g.*, cars and racetrack, train puzzle, animal farm) each day for 1 week.*

Step 1: Watches and stays with the activity when I hand him pieces or materials to take his turns for 2–3 activities each day.

Step 2: Watches and stays in the activity when I hand him pieces, and take at least one turn to copy his play actions for 2–3 activities each day.

Step 3: Watches and stays in the activity when I hand him pieces, and we take 3–4 back-and-forth turns to copy his play actions for three or more activities each day.

Step 4: Watches and stays in the activity when we take at least three back-and-forth turns to do my play actions for three or more activities each day.

Step 5: Watches and stays in the activity when we take at least four back-and-forth turns to do each other's play actions for three or more activities each day.

The presence of already specified treatment objectives does not override the parents' or interventionist's ability to generate a new objective at any time during treatment sessions. New challenges or changes emerge that may require the alteration, elimination, or addition of other short-term objectives. As this occurs, the list of objectives is updated, so that the written treatment plan always defines what is actually being taught. In this section, we have described a way of handling the dialogue between parents and interventionist at the very start of treatment, one in which parents are highly engaged throughout the contacts and play a major role in the treatment assessment and setting of treatment goals. The parents maintain their authority as experts in their child's needs and skills, in their family's strengths and needs, and in their decision-making role. The interventionist joins them and learns a great deal about the family's routines, priorities, and views, as well as the way that they play with, help, teach, care for, and communicate with their child. The interaction style and the process of developing the treatment plan represent two aspects of ESDM work with parents: "shared control" and partnerships with parents.

Coaching Parents in the Implementation of Child Goals

As parents put new learning into practice, the interventionist or coach provides feedback and observations, remaining focused on the parents' goals, perspectives, and actions. Through the back-and-forth engagement, the coach comes to understand the parents' preferred learning styles for processing information, problem-solving, and ongoing ability to put new knowledge into practice. The coach monitors parents' understanding carefully, noting when additional information may be required to extend progress, how consistent new information is with what is already known, and what resources or examples may be drawn to further their understanding of a topic. The coach and parents then review together the outcomes from practiced actions compared to previous experiences. The coach offers and encourages the parents' ideas of what steps to take that will help to build on current skills and promote ongoing learning and practice day by day. There evolves a respectful partnership and a supportive learning environment shaped by the parents, not imposed by the coach.

The coach has several methods to understand what parents know or understand about a particular topic, strategy, or goal before sharing new information and suggesting actions to try. Using observations, active listening, prompting, and questioning, the coach guides the parents through a process of self-discovery about what they already know, are doing, have tried, and think about in relation to a specific need or situation. This process is based on the researched practices of Hanft et al. (2004) following a process of planning, observation, coaching, reflection, and evaluation. The coach and parents move through each step not in a linear process but back and forth, in and out, as many times as necessary as needs and goals are determined, refined, and put into practice. The steps do not change the expectation for an equal, reciprocal relationship between the coach and parents but aim to strengthen the trust and respect already established and the learning that comes from the practice, reflection, and continued interaction of the coaching process.

Planning Sometimes in coaching, the plan of what content to address with the parents may not be planned or selected ahead of the session but instead may come from the observations or conversations that occur from the parents' and coach's time together. For example, a parent may express to the coach more confidence and ability in using a teaching strategy following her practice since the last session. She may now let the coach know she now feels ready in the session to try the strategy in another context so as to expand the child's behavior. The coach has to be ready to follow the parent in this direction and to respond with the coaching tools now to facilitate this next step in the learning process. In another unexpected moment, the coach hears the parent's uncertainty in his description of how to follow the child's play interests and imitate the child's actions so as to keep her engaged longer in the activity. The coach has to put aside any of his or her goals for what the session might have addressed and instead focus on what the parent is expressing now as a pertinent need. In each example, the parent and coach may not have known what new information would come inside the session or how exactly the child would respond until tried. The parent's response becomes a priority for the coach to now support in the existing session. Whether planned or spontaneous, both ways in which needs arise contribute information to understanding parents' learning goals and the first step to developing an intervention plan for change. In turn this plan for change creates the agenda or focus of the session. It specifies the area in need of support and the goal(s) to follow for more appropriate, productive, and meaningful change. It also creates a clear outline for the subsequent coaching steps to reference as the rest of the intervention plan is developed. This check-in helps to ensure original goals are preserved and at an appropriate learning pace based on the parent-child response to the intervention. Example questions are suggested below to guide the conversation between the coach and parents in the discovery of learning goals to set the sessions.

Observation Once a plan is set for the session, a period of observation follows. The coach can observe the parents in action with the goal(s), or the parents can observe the coach modeling some type of action, technique, or activity with the child and related to the goal. There is also the option for self-observation in which the parents consciously observe themselves during an activity or situation. The parents think about personal behaviors that could promote their effectiveness with the goal, another caretaker's ability to meet the goal, or the child's learning as a result of the implemented goal. For example, a parent may want the coach to observe how he followed the child's lead while drawing with markers to support his goal of increasing the child's communicative gestures and vocalizations. The coach observed the father creating opportunities to practice this goal through the use of choices to the child inside the preferred activity. The father asked the child which color marker she wanted and which picture on the paper to color. The father responded with the preferred item or action each time the child pointed or vocalized her choice. The father also created moments for the child to ask for help by giving her the marker to open or close the cap and pointing to other markers to use or pictures to color. From the observation, the coach acknowledges the father's intervention skills to facilitate communicative opportunities from the child. The observation also allows the coach to make other suggestions of how to extend the activity if and when the child loses interest in coloring the pages. The coach helps the father think of other materials and actions that could be added to the activity, such as placing stickers on the paper, cutting out colored pictures, and drawing child-preferred pictures of animals.

In another example, the parent may ask for the coach's assistance to meet her goal of reading books to her child. During the coach's observation of the parent and child reading books, the child sat in the parent's lap and did not listen to the story. The child did not look at the pictures pointed out by the parent and preferred to quickly turn the pages to the end of the book. The coach demonstrated different seated or standing options for the child, such as a chair, beanbag, or leaning against a table, so that the child's attention from the very start of the book could be more primed to the parent's language and actions. The parent observed the coach positioning her body to the child's eye level and holding the book close to her face as she named the object or action that held the child's interest. The coach also added sounds or gestures related to the actions on each page that the child found funny. As a result, the child looked briefly from the pages to the coach's face. The child still wanted to turn the pages of the book ahead of the coach but he paused before doing so to check out the modeled action.

Through observation, the coach and parents can demonstrate knowledge and understanding of a skill and share particular challenges or difficulties blocking further progress. In the examples above, the coach observed the different learning opportunities the father created to elicit communication from his child, as well as the setbacks the mother experienced in reading a book with her child. Observation allows the coach and parent to reevaluate their progress toward reaching the goal(s) set forth at the start of the session and to revisit that plan or agenda with additional supports or resources when necessary. In the father's case, the coach's observation generated several activity ideas to help the father expand his teaching skills with more playful learning opportunities he can build inside the activity to promote the child's use of communication. The selection of activities, learning opportunities, and communicative behaviors both short and long term become a part of the session's plan for how to meet this goal. A similar process happens from the coach's observation of the mother's book routine with her child. The coach demonstrates additional techniques to refine the mother's goal of sharing books with her son. The coach supports the child's body and positions herself in front of the child to make it easier for the child to see her. Next the coach names the object or action of each picture the child looks at and adds playful sounds or gestures to entice the child to look at her. These modeled techniques and intended outcomes become a part of the session plan in development with the mother.

Coaching With each conversation (whether coach or parent-led), the information gathered feeds into the coaching plan. It tells the coach and parents what is working to meet the goal versus what needs to be changed, problem-solved, or anticipated to reach the desired outcome. It helps the coach and parents plan what new strategies can support the goal and how they will be used to ultimately increase the child's participation in family, community, or early childhood activities. In the P-ESDM, the style of coaching involves a method of communication to guide this conversation (at any point in the session) and to continue building the parents' capacity to self-assess, self-correct, and expand skills to other situations.

Effective communication starts with parents feeling that they have been heard. When the parents believe that the coach is listening and understanding the message that they are trying to express, the parents are encouraged to share more information. Good listening means the coach is attentive with his or her whole body and with sincere interest in what the parents say. This includes direct eye contact, positive facial expressions, an open body posture, and appropriate proximity to the parents. The coach focuses on the present moment and listens to the words, meaning, and feelings expressed by the parents so as to acknowledge what they are trying to communicate. The coach does not pass judgment or take sides on the issue or topic.

As the coach passes the lead to the parents in these dialogues, the coach needs to be comfortable with the silences that may occur as the parents reflect and organize their thoughts. Quiet waiting is respectful of the parents' thought processes, and it emphasizes how important the parents' input is to the work going on.

When it is the coach's turn in the dialogue, the coach's goal is to build on the parents' themes. One important technique for encouraging parents' learning and self-discovery is asking open-ended questions to acquire additional information (e.g., "Tell me what you have tried so far?" "What are your child's likes and interests at this moment?") or to clarify (e.g., "What do you mean by noncompliant when you use that word to describe your son?" "Tell me more about everyone being concerned at your child's school?"). A second important technique involves restating the content and feelings he or she has heard from the parents to confirm the information or clarify any miscommunication (e.g., "What I heard as your immediate priority for your child is to establish some boundaries or limits as to how often he plays with the i-Pad or watches television. Is that correct?" "So it becomes very stressful and worrisome to take your child outside of the house when you're not sure how he will behave.").

Another skill required of the coach is knowing how to provide just the right amount of feedback to the parents. Too much information can overwhelm a parent if not able or ready to process and understand what is being shared, whereas not enough information can leave the parent feeling unsatisfied or frustrated. In our P-ESDM approach, reciprocal evaluative feedback between coach and parents occurs after each parent-child activity, while the event is still fresh in the minds of the coach and the parents. It is descriptive: What the child's specific response was to the parent's specific behavior. This emphasizes the key relationship between parents' acts and child learning. The information shared in this way is clear, concise, and specific to this parent and this child. The coach works hard to avoid using evaluative (e.g., "Good job," "that was nice," "I like…") and directive or absolute words (e.g., "should," "must," "all the time," "always") with the parents. Reviewing and evaluating the session at the end in a dialogue between coach and parents help the parents solidify the learning content of the day, and it helps the coach understand the effectiveness of her use of the coaching tools.

Reflection In reflection, the coach and parents engage in a back-and-forth discussion to help the parents analyze their practices and behavior in relation to the goal. The intent of the reflective discussion is for the parents to discover what they may already know or be doing, to identify what they may need to know or do, and to make any necessary or desired changes. The process unfolds through the coach's use of questions, acknowledgments, and observations to explore what the parents have tried and think about those past efforts compared to the current situation or need. The coach actively listens and supports the parents in comparing their actions and observations to the characteristics of the effective intervention practices, research findings, or core values and beliefs. Throughout this process, the parents discover existing and new strategies and potential ideas to build on current strengths and address identified questions, priorities, and interests.

A main component to reflection is the question-asking process. The coach must ask good questions, at appropriate times, and in helpful ways (Kinlaw, 1999). Questions should encourage active thinking and elaboration from the parents rather than brief, "yes," "no" responses. They should be open-ended, not closed. According to Hanft et al. (2004), questions may be objective, comparative, or interpretive. Objective questions start with "what," "where," "who," or "how" to provide a framework to the parents for self-evaluation. Comparative questions help the parents compare current knowledge, experience, or practice to past actions, as well as to the desired outcome(s). Interpretive questions help the coach understand the parents' impression of a specific situation so as to make a decision about what to do next in the session. Overall, reflection and the types of questions used by the coach assist in exploring how the parents think and feel about a given situation.

Example

The following coaching example illustrates the coach's use of reflective questions and active listening as part of a coaching conversation with the mother of a 2-year-old son with ASD. The mother initiated the session's topic with the goal of how to minimize her son's repetitive hand and arm motions when excited by an activity. The coach began by inviting the mother to explain more about the current situation.

Coach: Tell me more about your son's behavior. When is it likely to occur? How you respond when your son does this? What have you found to work or not work?

Mother: He's most likely to do it when he really enjoys something, like playing with trains and cars. He will move the vehicle back and forth and then stop to shake his arms and hands. I tell him no or to stop and try to hold his hands to block him from doing the motion but it only makes him upset. I really haven't found any strategy to work except for not playing with trains and cars. But then he will find something else he likes and the motion can happen again. Plus, I feel bad not letting him play with something he enjoys so much, especially if we can use his interests to help him learn.

Coach: What ideas do you have about how he could still have fun but without the repetitive movements, or less of it?

Mother: It's important to me that he has fun but somehow to control his motions so he can attend and stay engaged with me. I notice that when he's focused on something, like putting together the tracks or running the train over the tracks, he's less likely to move his hands and arms.

Coach: So that may be something to explore. What other ways could you involve his hands and arms in the activity?

Mother: What if I gave him the bag to hold and we took turns taking out the tracks and putting them together? I could add blocks to the game for him to build a tunnel a bridge over the tracks as we run the trains under and over them. We could then knock them over with the trains and rebuild them to keep the game going. We could also add animal or people to ride on top of the trains so that he has to use his both hands to move them together.

Coach: Sounds like you have a lot of ideas to keep the game fun and his hands busy with purposeful actions.

Mother: Yes, I do. I'm excited to try this.

Coach: How about we set up these materials now for the two of you to get started in today's session?

Mother: Great!

In this example, the coach used reflection to help the mother develop a plan for reducing her son's repetitive movements during play. The coach began by asking the mother to reflect on how she currently handled her son's repetitive movements and the success of the practice and actions compared to today. Then the coach asked open-ended questions to encourage the mother's problem-solving. The information shared was useful as the coach helped the mother explore options for increasing functional play actions that would naturally interfere with the repetitive motions and yet skill maintain the child's motivation and interest to participate. The coach sought to have the mother identify possible strategies to ensure her outcome for her son could be achieved in a meaningful way to his needs and likes. The reflection helped the mother identify ideas about what to do.

Once the coach has supported the parent in exploring his or her knowledge, skills, and experience related to the topic of the coaching conversation, the coach may facilitate additional reflection and discussion by providing feedback on the observation or practice. Feedback can be used to provide new insights to the parent regarding use of the targeted skill or practice. Feedback should follow the parent's reflection so that the coach first understands the parent's thoughts, ideas, and needs before providing recommendations. It should be clear and shared concretely with only the necessary information so that the parent knows exactly what the coach means. Feedback should also be shared in a timely manner as soon after the observation as possible or using as few words as possible if said during the observation to avoid disruption to the parent and child. Lastly, feedback should not criticize, blame, or be negative. It should promote confidence, trust, respect, and open communication. In the previous example, the story ended with the mother getting ready to play trains with her son in order to practice a new strategy. She had thought of actions she could encourage her son, Aiden, to do in lieu of moving his arms and hands back-and-forth. The coach observed the mother and child in practice with this approach and provides feedback once the activity ended.

Coach: I noticed that when you saw Aiden starting to move his hands in an excited manner, you gave him an item to hold or a play idea to do. You didn't touch his hands or arm or tell him to stop. Rather, you provided ways in which he could engage with you, doing actions he liked and as a result, there were more opportunities to increase his play skills and understanding and use of language. Is there anything else you wanted to do or can think of now to continue working on this goal?

Mother: Sometimes I felt like I rushed him to help him physically do the play action or to tell him what to do because I wanted to stop the first sign of the movement. I could have waited at least a moment or two to see whether he would carry out the action by himself or what other ideas he might add to the activity.

Coach: That sounds like a good idea to build his independence both with physical movement of using his fingers, hands, and body to complete play actions and in his ability to be creative with the play and express his ideas to you. How will you try this?

Mother: I'm not sure. Do you have ideas?

Coach: The goal is to give him enough support without taking over for him. Last week we spent some time talking about and practicing least-to-most prompting.

Mother: Oh, that's right. I remember that. Now let me think. Least to most means I would gradually provide more assistance if and when he can't stop his hands from shaking. So when I see him starting to shake his hands, I could offer him an object and ask him a question like, "Does this train go next?" or a choice, "Should we build a tunnel or bridge?" to refocus his attention and get him to do something more appropriate with his hands.

(continued)

Coach: Yes, those ways of using least-to most prompting assures that you can redirect him back to the activity as well as encourage his spontaneity of ideas, language, and play skills. What if he doesn't take the object?

Mother: I don't know what I should do next.

Coach: We want to add as much support as he needs to help him control his hands without just blocking his hands. Maybe you could bring the pieces closer to his hands or put them right in his hand so that it's easier for him to pick them up and then carry out the action. You could also cover up the train, since we know the sight of it goes with his hand shaking. Then when he stops you could uncover it and try again. What do you think?

Mother: I could do those. They sound easy, and I think they will work fine.

Coach: Shall we stay with this and try these ideas in another activity?

Mother: I would like that.

Coach: What else is something he likes to shake his hands with that are not trains or cars so that you have more practice with other types of play?

Mother: I can't think of anything right now.

Coach: I remember you sharing he also shakes his hands when he plays with water.

Mother: Yeah, he does.

Coach: I have some toys we could play with where he can scoop, pour, and spray water if you don't mind him or yourself getting a little wet. You could engage his hands to do these actions and prevent his hand shaking the same way, as well as help him communicate the different actions and toys he wants or doesn't want. What do you think?

Mother: I don't mind water play, but let's do it in the kitchen sink.

The coach provided feedback based on her observations of the mother's practices. She encouraged the mother's reflection on what occurred during the play with trains and shared additional strategies and later play ideas to extend the mother's practice. Her feedback gave the mother a reason to reflect on how to increase her son's independence and further direction to continue working toward this important priority. The session will continue to alternate between practice, observation, and reflection with the final coaching component of evaluation added to review the effectiveness of the coaching process, not to evaluate the parent.

Evaluation Evaluation occurs after each coaching activity and at the end of the session to accomplish two goals. One is to assist the parents to make changes and progress toward the objectives and desired outcomes as they practice the intervention techniques. We have talked about the coach's use of active listening and conversational strategies in the coaching section to elicit parents' evaluation of their child's and their own behavior and how to move forward in meeting personal goals. The second reason for evaluation is to check in with the parents about the usefulness and relevance of the coaching relationship and sessions conducted thus far. The coach may ask the parents how the sessions compare to meeting their goals, what other resources can be provided to aid their learning, and what changes they would recommend the coach make to improve the coaching relationship. The coach should also self-evaluate his or her coaching skills to make sure the approach, techniques, and communication are the best fit to serve the parents and child. This question may be posed to the parents, for their thoughts (e.g., "How do you like to learn something new?" "What other ways could I explain this technique to make it more relatable to your child?"), or stated as an observation of changes the coach would like to make in his or her own behavior (e.g., "The next time your child and I draw together, I will include other materials than markers, such as stickers and paints, and see whether this increases her participation and time in the activity.").

Evaluation also helps to summarize the actions practiced in the session and to confirm the parents' understanding before going home to practice the techniques further. In P-ESDM coaching sessions, a plan is finalized of how the parents will continue their practice of the information discussed. Details are specified by the parents, such as the behaviors, conditions, circumstances, and/or people involved in the practice and whether additional resources or needs will have to be considered in order to achieve desired outcomes. The plan is finalized of the steps, actions, people, and outcomes the parents will work toward in between sessions, and the plan is readdressed at the next point of contact to check in on progress and to continue developing as current goals are met and new needs are identified.

The coaching process ends when the parents have determined that the outcomes on the initial coaching plan and any additional goals that came out of the coaching experience have been achieved. The parents have developed the competence and confidence to move forward in present and future situations without the immediate need of the coach. Before the coaching relationship ends though, the coach and parents develop a final joint plan that outlines how the parents will continue to evolve their knowledge and skills. The plan should also consider the point at which the parents may resume the coaching relationship with the current coach or another individual in a coaching role, depending on the circumstance, type of support, and expertise needed by the parent.

Working with Parents' Motivation for Change

Embedding child learning opportunities into everyday experiences in a purposeful fashion requires one to change typical patterns of one's own behavior. Entering a process of learning from another involves a process of personal behavior change. This is not how we have typically viewed parent-implemented interventions. In fact, the field has not been very specific about what processes are actually involved, other than relationship-based processes. We have found it extraordinarily helpful to cast ESDM and other parent-implemented interventions as interventions in which parent behavior is being changed in explicit ways as a vehicle for changing child behavior in explicit ways. The value of this viewpoint is that it provides a number of empirically based tools and procedures, as well as a very important set of concepts, to incorporate into the early intervention work, namely, adult learning, cognitive behavioral techniques, methods for increasing and decreasing behaviors in the adult's repertoire, and a very helpful body of evidence that comes from other types of interventions in the psychological literature – particularly substance abuse, weight loss, depression, anxiety, organization and time management, and personal growth literatures – that target changing the behavior of adults.

Personal growth manuals (e.g., Duhigg, 2012; Grant & Greene, 2001; Prochaska, Norcross, & DiClemente, 1994) provide helpful visuals, data collection systems, and adult self-management strategies for acquiring new, adaptive habits and curtailing unhelpful habits. We have these manuals on our bookshelves, use them ourselves, and gather ideas and tools that may help one or another family member as they add some repertoires to their own skills in order to add learning opportunities to their child experience. We find them invaluable in our work with parents and also in our work with supervisors, trainees, and colleagues.

A second literature that has been invaluable in our work in the past few years comes from the work on supporting adult motivation for change that has come from colleagues in the field of substance abuse treatment, and this is the work on motivational interviewing (MI; Miller & Rollnick, 2002). While both of us are still very much learners in this field, we have found two sets of tools from this field extremely helpful in our work with families of young children with autism in several ways. First, we have found that the careful work done in this field on indirect verbal and nonverbal expressions of motivation in clients has helped us to listen and to "hear" parents' motivational messages more clearly and to describe and restate motivational messages we perceive in dialogues with parents, bringing more attention to parent motivation in interactions with families.

Second, the MI dialogues and the stages of change concepts that adults undergo to change their behavior (i.e., pre-contemplation, contemplation, preparation, action, maintenance, and repair; Prochaska et al., 1994) have given us very helpful tools for supporting families to increase motivation for change and slowly become more active in the change process. This has been particularly helpful when working with families in which various adults are at different points in the motivation and change process. In the past, it has frequently been our experience that, when working with a couple for whom one member is quite motivated to provide new ways of working with their child at home, and the other parent is still working on the question of whether there is a problem with the child's development or not, the interventionists tend to align with the parent who is motivated to move ahead, and the parent who is not yet at that point tends to be left out of the process, a situation that causes additional stress on the couple relationship and hurts rather than helps the family process. Using MI techniques, there is a respectful, active dialogue that can support each partner, a dialogue based on individual differences and individual insights combined with a shared love for the child and commitment to the family. By addressing each partner in terms of understanding and respecting their points of view, acknowledging the authority of both vis-a-vis their child, asking each for goals, and sharing information with both the intervention help them recognize their common ground and shared commitment and goals for their child's best outcome. Parents are less likely to withdraw from the intervention process when their points of view and interactive skills with their child are acknowledged and respected and their contributions valued. Child change over time also lessens the differences between the two, particularly when child change is consistently attributed to both parents' efforts and interactions.

A third very helpful contribution of MI work to our ESDM interventionists' skills has been the idea of the inevitability of relapse, the idea that behavior change follows predictable cycles and that relapse, far from signaling failure, instead is an expected part of the process and does not represent an ending but rather the period before a renewal of energy and motivation for change. The dialogues for recognizing and addressing relapse without casting it as failure are extremely helpful for both the interventionist and the parents. Raising a child with autism takes decades or a lifetime. It is neither a marathon nor a sprint but rather a journey to an unknown continent, and the cycles involved in living a life – identifying challenges, setting goals, working to achieve them, making good progress, running out of steam, or getting ambushed by a different set of problems, taking a rest, picking up, and starting again – require a set of tools and a body of knowledge, and early interventionists are the first helpers in a family's life to help them acquire the tools and learn to manage themselves through the cycles.

Supporting Fathers' Engagement in the Intervention Process

A key component of practice of early intervention involves understanding how to work effectively with the adults, particularly the parents, who are involved in the lives of children in need of the services (Rush & Shelden, 2011). Fathers of children with autism are underrepresented in terms of understanding how to support their involvement in the early intervention process (Rivard, Terroux, Parent-Boursier, & Mercier, 2014). Fathers have unique interaction styles that can contribute to the development of their child and have cascading effects to the well-being of their family. If and when fathers are not involved in early intervention, coaches or interventionists may be missing important opportunities to maximize the social-communicative gains that come from parent-child interactions and exchanges. Overlooking fathers in intervention also may have unintended consequences for families, including increased levels of parental stress and decreased family cohesion as the result of one parent taking on the dual roles of caregiver and intervention provider (Rivard et al. 2014; Tehee, Honan, & Hevey, 2009). Therefore, increased father participation in early intervention may not only maximize the child's development but also ease the overall workload and stress for mothers or other primary caregivers. Furthermore enhancing the role of fathers in early intervention marks an important direction in realizing optimal "family-centered" services with all family members are involved in the process for children with autism (Shannon, Tamis-LeMonda, London, & Cabrera, 2002).

The ESDM approach to working with families centers on the rationale that intervention must be amenable to both parents and caregivers; otherwise it is not effective. This process starts at the beginning of the coaching relationship when the coach meets both parents and takes the time to understand each of their perspectives, needs, and priorities. To the best of everyone's ability, sessions are scheduled with both parents present; otherwise effort is made from the coach to follow up via phone calls, video conferencing, etc. so that each parent is involved from the onset of intervention. It is equally important for both parents to have specific goals identified in the intervention plan. Just like mothers, fathers have their own ideas for what they want to gain from the coaching with their child and family. Ensuring fathers are involved in the goal-setting process gives them incentive to participate and follow the plan.

It is also important for the coach to follow both parents' style of interaction with the child. Fathers and mothers have different approaches to communicating and playing with their child. Fathers may use a higher level of vocabulary and complex language models with more directive statements than mothers, and they tend to engage their child in more acts of symbolic play compared to mothers who engage in fewer play schemas (see Flippin & Crais, 2011 for a review). Coaching activities take into account how parents learn new information and the gender differences that may influence their own motivation to participate. Fathers have shared with us that embedding intervention within active or physical activities has made them feel more successful in helping their child learn. This may involve simple games done in the home or outdoors, such as playing chase, going to the playground, or swimming in the pool, or more elaborate activities such as participating in little league or other recreational teams. Finding out not only the child's interests but the fathers' as well and the activity settings that can support these interests can increase the likelihood that those opportunities are used for child learning and development. The coach can ask the father about his interests, the types of activities in which he participates with the child in a given day or week, and other less frequent activities that are important to do again. Some questions we have used with fathers (or with any parent) to elicit this information are:

- How do you spend time as a family?
- What do you enjoy doing with your child?
- What activities are less enjoyable and why?
- What activities do you wish you did more often with your child?
- What interactions and skills would you like your child to develop?

This approach speaks to family-centered practice in which the coach uses and promotes what the parents are already doing or would like to do as a natural part of their family and community life. It provides a framework within which the coach can build from parents' strengths and support their capacity to identify and use already available environments for engagement and learning. Even when families have limited activity settings and/or share minimal information, most participate in some type of eating, bathing, and dressing routines with their child. These activities may be a starting point to jointly identify child and adult interests for both parents and support participation and learning during family life activities. Remember that without interest, opportunity, and parent responsiveness, coaching cannot help promote child growth and development. Although the term parent still dominantly refers to mothers in autism early intervention research and clinical practice, our hope is that continued efforts to develop "father-friendly" methods will change this way of thinking.

Summary

In this chapter, we have descried many of the practices and techniques that have come from our work with families on embedding therapeutic practices into everyday activities and to increase children's learning opportunities and learning rates. We have described a particular way of interacting with parents using a coaching framework and adult learning perspective. We have described parent-coach interactions that are grounded in parent goals for their child's learning; consist of balanced, reflective, and evaluative interactions; focus on parent-child everyday activities; and address motivation of each partner.

We have evolved these practices from the existing literature in parent coaching (particularly writings by and dialogues with Hanft, Dathan Rush, and M'Lissa Shelden – thank you) and worked out in the therapeutic experiences we have had with families from many different cultures and walks of life in the Sacramento area. We have worked with single-parent families, families from many different ethnic backgrounds, families for whom English is a second (or third) language, and parents who themselves suffer from developmental disabilities. While many of the physical materials that we needed were individualized for each family, based on their preferred learning modalities, the materials they had at home, and their favorite activities to carry out with their children, we have used and built on the same interpersonal framework across all the families and have found it very flexible in its ability to create satisfying dialogues as well as measurable change in parent ways of interacting and child responses, as demonstrated in our various papers. Just as in our work with children, we have found that integrating concepts from developmental psychology relationship-based work and the science of learning, including adult learning, results in a very individualized interpersonal environment that fosters growth in child, parents, and coach as well.

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13

Embedding Intervention Strategies within Everyday Family Routines

Shubha Kashinath and Betty Yu

Abstract

Legislative mandates and professional consensus support the use of daily routines and activities as contexts for embedding social communicative interventions for young children with autism. This chapter outlines research-based and systematic procedures for therapists to collaborate with families to address social communication goals for children with autism in naturally occurring and preferred routines and activities. We will describe information-gathering strategies that are family-centered and culturally responsive. We will also share tools for collaborative planning to assist families in identifying and prioritizing goals. Evidence-based consultative strategies will be shared which facilitate parents' implementation of naturalistic intervention strategies with their young children with autism.

With an increased number of children being diagnosed with autism spectrum disorder (ASD) at an earlier age, there is a need for developmentally appropriate, evidence-based interventions for young children with autism that address core social communication challenges, support the parent-child relationship, and are consistent with Part C guidelines of the Individuals with Disabilities Education Act (IDEA, 2004). Best practices and legislation in early intervention for young children with autism mandate the use of a family-centered, collaborative approach with families and caregivers with the aim of building caregiver competence and capacity to foster their children's development within everyday activities and routines (American Speech-Language-Hearing Association [ASHA], 2008; Espe-Sherwindt, 2008; Girolametto et al., 2006; National Research Council [NRC], 2001; National Early Childhood Technical Assistance Center [NECTAC], 2008; Salisbury & Cushing, 2013; Woods, Wilcox, Friedman & Murch, 2011). The American Speech-Language-Hearing Association (2008) guidelines also identified helping children with ASD actively participate in natural routines as a priority in the treatment of autism across the lifespan. This chapter outlines an approach to working with caregivers/family members within daily routines and activities as contexts for achieving social communication goals for young children with autism.

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_13

As described by Woods & Lindeman (2008), "the ecological context of everyday routines, activities, and settings serves as an anchor for the transactional interplay between caregivers and the child where learning occurs" (p. 274). That is, children's outcomes cannot be predicted solely by the status of the child or by the environment in which the child is embedded. Rather, development is dependent on the ongoing transactions over time between the child and the environment, which includes caregivers, in such a way that is mutually shaping. Similarly, Bronfenbrenner (1989) referred to human development as "the progressive, mutual accommodation *throughout the life course* between an active, growing human being and the changing properties of the immediate settings in which the developing person lives…" (p. 188). In considering the translation of an ecological philosophy to practice for young children with autism, there are three important areas of focus that providers must consider: (a) how to understand and integrate families' values, wishes, and preferred ways of supporting their children's development in the context of daily routines and activities, (b) how to implement evidence-based intervention strategies that target core social communication and developmental outcomes within family-preferred routines and activities, and (c) how to collaborate with caregivers to build capacity to foster specific developmental outcomes for each child. The purpose of this chapter is to address these dimensions by outlining research-based, systematic procedures for interventionists to collaborate with families in order to address social communication goals for children with ASD in naturally occurring and preferred routines.

Understanding and Supporting Development in Family Routines

What are family routines and why are they important contexts for intervention? *Natural environments* is a term used in IDEA legislation to refer to the landscape of everyday routines, activities, and settings that are typical or natural for a family. They often occur in families' homes, child care settings, the homes of friends and extended family members, or other community settings such as the park or church (Woods, 2008). Routines are crucial to human development because they are the building blocks of psychologically salient and socioculturally meaningful environments that become developmental pathways for children (Weisner, 2002, 2005). Much of children's early learning experiences occur in the context of routines. According to Spagnola and Fiese (2007), "Naturally occurring family routines and meaningful rituals provide both a predictable structure that guides behavior and an emotional climate that supports early development" (p.284), including in the domains of social communication (Blum-Kulka & Snow, 2002; Heath, 2012; Schieffelin & Ochs, 1986) and cognition (Rogoff, 1990). Routines are also a key means of enculturation because it provides standing patterns of engagement within which children can participate in local practices, much of which is imbued with sociohistorical meaning (Rogoff, Moore, Najafi, Dexter, & Correa-Chávez, 2007).

Not only are routines optimal contexts for early learning, but they are also the most impactful and realistic contexts for family-implemented interventions. Bernheimer and Weisner (2007) argued that "no intervention, no matter how well designed or implemented, will have an impact if it cannot find a slot in the daily routine" of the family or individual who is expected to carry it out (p. 199). For interventions to be effective, they must match the values, beliefs, and practices of the families they are meant to benefit, or they will be neither sustainable nor effectual. They are not prescribed by the interventionist and given to caregivers as homework; rather, successful routine interventions in the family context are activities that are developed through a close collaboration between caregivers and practitioners and that find a meaningful fit within the constraints and opportunities of families' daily lives.

In this chapter, we will use the term *routines* to refer to both recurrent family activities and rituals. Both refer to specific, repeated practices that involve family members, but they differ in terms of communication, commitment, and continuity

(Spagnola & Fiese, 2007). Family routines are characterized by communication that is more transactional in nature, momentary, repeated frequently, and hold no special ceremonial meaning. Routines like setting the table, washing dishes, and preparing food, for example, are the activities that give family mealtimes a predictable shape. Rituals are more specialized activities, involving "communication with symbolic meaning...often transcend[ing] the here and now and can include repetitive practices across generations" (Spagnola & Fiese, 2007, p. 285). Rituals can occur in routine activities. For example, mealtimes can include saying grace, telling stories, and celebrating special occasions. By using an inclusive definition for routines, we emphasize the potential of routines as a context for children to gain a wide range of knowledge for meaningful participation both in day-to-day local activities and more expansive cultural practices.

Family routines such as mealtimes, dressing, visit to family's place of worship, or a visit to a neighborhood park provide excellent opportunities to embed critical social communication goals for young children with autism because they promote a joint focus of attention within a logical and predictable sequence, offer opportunities for turn taking, and allow for practice through repetition. Facilitating meaningful participation of children in the context of family rituals promotes overall family functioning and decreases the isolation families of children with special needs may feel. Routines are functional and contextualized and therefore support meaningful learning and generalization of knowledge (Woods & Wetherby, 2003; Woods, Wetherby, Kashinath, & Holland, 2012). Most young children spend a majority of their waking hours engaged in play and caregiving routines that allow for the embedding of teaching opportunities for the child and supportive instructional strategies for the parent.

Children are not only socialized into routines but can also greatly impact how family routines unfold. For instance, bedtime routines are a context in which children are socialized into the sleep-wake rhythms of a family's life, but at the same time, the rhythms of the home are impacted greatly by the children's own temperament, preferences, sleep/wake cycles, etc. Even in the same family, a bedtime routine that works for one child may not work for another. Similarly, a routine that works in one family may not work for another, even if their children seem to have similar needs. The establishment of routines requires taking in account the dynamic nature of the whole family as an ecological system.

Gathering Information about Family Routines

Embedding intervention strategies within family routines starts with learning about the family's routines, values, wishes, and preferences, as well as communicating with them about the intervention process. Learning about a family's daily routines and activities requires a variety of supportive communication strategies that embrace family participation and that set the stage for a meaningful partnership during intervention. The process is a reciprocal one that involves not only getting but also sharing information with families (Woods & Lindeman, 2008). That is, as interventionists begin the process of working with families to address their child's needs, it is important that they provide caregivers with information about the features of a routine that might make it an appealing context for social communication intervention. Most routines have a clear beginning and end (e.g., a snack routine might begin with a request for food/drink and end with that food/drink being consumed) and tend to be outcome-oriented (e.g., getting a snack, putting on a dry diaper, playing with a toy or getting dressed). Most daily routines are also predictable in that families and caregivers tend to follow a repeated and familiar set of steps in order to execute them. This predictability offers caregivers a supportive framework within which meaningful child outcomes can be addressed, and it matches the learning style of children with autism who benefit from predictable and contextualized learning experiences.

Despite the similarities in the features described above, daily routines are highly individualized to each child and family based on their interests, beliefs, cultural practices, and other characteristics (Bernheimer & Weismer, 2007). It is, therefore, of utmost importance to develop an understanding of the unique nature of the routines within each family. These efforts can be accomplished through a variety of ways, through more formalized means such as conducting interviews, or through more incidental means like spending time with and observing the family (Woods & Lindeman, 2008). A variety of strategies for gathering information from families has been validated in early intervention (Bernheirmer & Weismer, 2007; Boavida, Aguiar & McWilliam, 2014; Dunst, Hawks, Shields & Bennis, 2001; Woods & Lindeman, 2008). A few examples of such strategies are described below.

Family Story

Each family is unique, and family members are constantly and proactively responding to the circumstances in which they live to build suitable contexts and to organize meaningful activities for their children. Bernheimer and Weisner (2007) argued that encouraging family members to "describe a typical day" can be a very effective way of providing interventionists with rich detail on the unique circumstances of families' lives. For most people, describing their day may come much more naturally than articulating what specific routines they engage in throughout the day. Interventionists can utilize an open-ended, semi-structured interview to learn about how families structure their days and to hear about the activities that are repeated, with variations, from day to day. These family stories can also reveal a great deal about the accommodations and modifications that family members make in their daily routines in order to meet their children's special needs.

Conversations and Informal Interviews

Family members are often overwhelmed with information as they learn to navigate the complexities of the early intervention and school system. Consequently, they may be less likely to offer detailed information when presented with a list of questions that may be perceived as intrusive or intimidating. Instead, asking open-ended questions in plain language may begin to open up communication pathways between the caregiver and interventionist. Woods and Lindeman (2008) provide a list of conversation starters that can help open a dialogue between the interventionist and caregiver. Questions can be focused on learning about a family's day, learning more about specific times of the day (such as while getting ready for bed, going shopping, or visiting a doctor's office), as well as learning about their child's preferences and dislikes. Interventionists can ask caregivers about routines that are preferred by the child and comfortable for the family and take them into consideration as contexts for addressing specific goals. The key is to adopt a nonintrusive communication style that focuses on empathetic enquiry rather than focused information gathering (McWilliam & Scott, 2001).

Questionnaires and Checklists

As conversations progress, interventionists can gather information about specific issues through the use of questionnaires and checklists that are either self-developed or commercially available. One advantage of this approach is that it may elicit important information that has not come up naturally in a more open-ended conversation, such as the date of a child's last hearing test. Written questionnaires and checklists may also offer time for parents/family members to reflect on specific topics/questions and also offer an opportunity for multiple caregivers (such as parents, grandparents, or childcare providers) to contribute their responses even if they are not available to talk face-to-face. There are many resources that are available to interventionists to gather information in family-friendly formats. Through the activities of a federally funded outreach project, Woods and colleagues have created a number of web-based forms and checklists that can be used to gather information from families about their child's day, routines, and preferences

(Family Guided Routines Based Intervention, n.d.).

While many web-based resources exist, it is important to tailor the use of questionnaires and checklists for different families. It is always a good idea to skip over questions that are not directly relevant or that can be obtained from a review of existing reports to lessen demands on family members. It may also be important to explain why certain questions are being asked so that family members do not have to guess at their purpose, which can result in misunderstanding or even undue stress. For example, one mother reported feeling guilty after being asked if she used medications during pregnancy. The question caused her to wonder if her use of over-the-counter cold medication while pregnant might have caused her child's delays. These potential pitfalls notwithstanding questionnaires and checklist can add valuable information and contribute to a comprehensive picture of a child and his/her family.

Community Mapping

As initially described by Dunst, Hawks, Shields, and Bennis (2001), community mapping is a strategy that allows caregivers and families to identify resources and locations within their neighborhood that offer opportunities to address their child's goals and outcomes. Interventionists and parents work together to identify the kinds of learning opportunities that might be beneficial to their children, gather information about the community resources for those learning opportunities, and work with community partners as needed to involve the children in those activities. These can be both structured and unstructured activities. For example, going to a playgroup once a week requires planning, but picking flowers or feeding ducks in the park can occur spontaneously. Community mapping can be especially useful as families begin to think of ways to expand opportunities for learning and practice for their young child in ways that are accessible and that can be integrated into their existing routines.

Environmental Scans

As interventionists, we are often trained to be keen observers of children's communication and developmental milestones. In routine-based intervention, it is also important to be observant of a child's environment. For example, interventionists should be attentive to and observant of the recurrent activities within a family's preferred routines that can be used to help a child to achieve his/her learning goals. They may observe that a family has a number of friends who visit often, which offers many opportunities for a child to practice waving hello and goodbye. Interventionists can consider what potential adaptations or modifications could be made to a routine without altering the essential nature of the routine. Relating to the previous example, interventionists can suggest that the family pause briefly at the door when they greet visitors so as to allow the child to wave hello – a simple modification that offers many opportunities for a child to practice communication during the course of the family's naturally occurring routines and activities. Interventionists can also take note of which materials are familiar versus novel to a child. Familiar routines and materials provide a scaffold for the child to acquire new skills. In contrast, novel materials and routines can expand current skills to new contexts. These observations may be useful in furthering conversations with caregivers regarding where, when, and how they might embed intervention strategies to move toward their desired outcomes for their children.

Interventionists who are aware of and skilled with the use of a range of informational exchange strategies, such as those listed above, are well prepared to help families identify the best matches between intervention strategies and their preferred routines. They are also more likely to be attuned to caregiver concerns and priorities as they work with families to develop plans for intervention. This begins to set the stage for implementation of embedded intervention.

Implementing Evidence-Based Intervention Strategies in Routines

The use of jointly identified, familiar, and naturally occurring routines as contexts for intervention increases the likelihood that intervention is individualized for each child and family (Wilcox & Woods, 2011). Interventionists play a critical role in helping families and caregivers identify the multiple teachable moments that exist in simple daily interactions such as washing hands or answering the door to greet a visitor. Daily routines and activities offer the contextual support that a child needs to learn a skill in a meaningful manner with the caregiver mediating the environment and interactions (Hancock & Kaiser, 2006; Woods & Brown, 2011). As caregivers begin to understand the connections between daily learning opportunities, their involvement in the routines, and how young children learn to communicate within them, it can empower them to expand opportunities for learning and practice across different routines in their everyday environment. In supporting caregivers along this path, interventionists must facilitate the accomplishment of several things, including (a) finding a contextual match, (b) planning the logistics, (c) creating sufficient opportunities for learning, and (d) embedding evidence-based social communication strategies. Each of these will be discussed in more detail below.

Finding a Contextual Match

A critical feature of embedded interventions is the contextual match between the goals for the child, the strategies used by the caregiver(s), and the degree to which there are naturally occurring opportunities for learning within family-preferred routines. The essence of a family-centered, embedded intervention approach is not to create "templates" – that is, plans for familiar routines that are professionally created and offered to parents as homework. Rather, it is the responsibility of the interventionist to work *with* caregivers to identify routines that offer adequate opportunities for the child with ASD to work on specific developmental outcomes that *fit* into the family's existing routines without interfering with the enjoyment or completion of those routines. Interventionists can begin by observing the caregiver-child interaction within parent-preferred routines and activities that are motivating, engaging, and purposeful for the parent and child. Interventionists can observe the child's engagement, communication, and opportunities for embedding target outcomes for the child. Observing caregiver-child interactions also gives interventionists a glimpse of the types of naturalistic communication strategies that the caregiver may already be using so that future interventions can build on the caregiver's competence and expand their use of strategies that they are not yet using. For example, a parent may naturally name food items during snack and offer the child the preferred snacks. The interventionist could build on the caregiver's skills by encouraging them to wait before offering the child their snack so that the child has an opportunity to initiate communication. The contextual match between child goals, parent use of evidence-based strategies, and the routines may not occur as easily if interventionists had not observed the unfolding of that routine.

Planning Logistics

It is important to plan the logistics of routine-based intervention with the caregiver. As experts on their child and family, caregivers are keenly aware of factors that may support or interfere with consistent implementation of a planned routine/activity. For example, an interventionist may consider mealtime activities to be a perfect opportunity for a caregiver to arrange the environment with small portions or preferred food items out of reach for a child with ASD to practice using words to request. However, if the caregiver has to attend to multiple children or adults, their attention may be divided, and they may not find this an ideal time to work on their child's skills. A better and more focused interaction opportunity may occur when the caregiver and child are engaged in a book-reading activity before naptime or bedtime, where the distractors of siblings and other members of the family are minimized and the caregiver is able to offer undivided attention to facilitating communication goals of his/her child. To support buy-in and consistent implementation, interventionists and caregivers need to develop the intervention plan collaboratively, paying close attention to all the members of the family who will be involved in the routine, when and how often the routine/activity will occur, what materials will be used, and what the caregiver's role in the routine will be.

Creating Sufficient Learning Opportunities

When parents and caregivers use targeted teaching strategies with their child with ASD across a variety of daily routines and activities throughout their day, as opposed to specific scripted interventions or lessons, it is logical for the child's opportunities for practice to increase (Woods & Brown, 2011). Based on adult learning theories (Knowles, Holton & Swanson, 2005), engaging caregivers in conversations about the "why" of routine-based intervention and the need for consistent and intentional implementation across routines and activities can further increase generalization. Interventionists need to support caregiver learning and active participation by providing opportunities for discussion around what is working well and why. In particular, interventionists and parents can explore the degree to which there is a match between the suggested intervention strategy, the nature and demands of the routine, and the child's interests. In places where mismatches are identified, interventionists can engage with parents in reciprocal problem-solving to address those challenges.

Embedding Evidence-Based Social Communication Strategies

There is a body of research to support the use of naturalistic intervention strategies in daily routines. The following is a sample of evidence-based, naturalistic communication strategies that can be used to promote communication in young children (Hancock and Kaiser, 2006; Hwang & Hughes, 2000; c et al., 2011):

(a) Strategies to increase communication opportunities such as environmental arrangement, increasing structure, predictability, and turn-taking in routines.
(b) Strategies to promote child initiations such as following the child's lead and offering choices.
(c) Strategies to respond and maintain children's communication attempts such as contingent imitation, reinforcers, and expanding on child utterances.

Regardless of which intervention strategies are adopted, they should meet families' needs and fit into the flow of their routines. For example, an interventionist may be able to highlight the use of contingent imitation as a communication strategy to increase turn-taking and reciprocity when the caregiver discusses the challenge of long car rides as part of the family's daily routines. When interventionists find strategies that match a family's priorities, the likelihood of its implementation between sessions can greatly increase.

The true spirit of natural environment legislation and embedded intervention occurs when interventionists support caregivers in their intentional use of specific teaching strategies to address social communication outcomes for young children with ASD. By directing careful attention to collaborative planning with caregivers to find a contextual match, to plan, to create opportunities for learning, and to embed evidence-based social communication strategies, interventionists are able to facilitate more successful routine-embedded interventions. The goal is to embed intervention strategies in preferred routines in order to promote active engagement and learning without interfering with the natural flow of families' preferred activities. It is also to support caregivers to gain the knowledge and skills to ensure consistent implementation of intervention across their day.

Collaborating with Caregivers to Build Capacity in Routines

Once intervention goals have been prioritized, preferred routines identified, and the appropriate caregiver/parent teaching strategies discussed, the interventionist then needs to use effective consultation and coaching strategies to help caregivers to implement the intervention in a supportive and respectful manner. To do this, early interventionists focus on the triadic interaction between the child, parent/caregiver, and the interventionists to support caregivers in becoming confident in and validating their capacity to address their child's communication (ASHA, 2008; Dunst & Trivette, 2009; Salisbury & Cushing, 2013; Woods et al., 2011).

Because family routines often take place within intimate social spaces and activities, interventions that affect family routines must be built on trusting family-centered relationships that are respectful of the family's priorities and values. Collaborating with families to provide routine-based intervention is a process-oriented endeavor that consciously strives to equalize the balance of decision-making power in ways that supports families to be the primary agents of change for their children. This is contrasted with the mindset that family routines are merely a context for implementing professionally driven intervention activities. Providing family-centered services requires a high degree of interactional competence, cultural responsiveness, and self-awareness that takes dedicated effort to develop.

Many professionals working with children with ASD enter their fields with a significant amount of content knowledge but have had limited preparation in the art and science of help-giving. According to Dunst, Boyd, Trivette, and Hamby (2002), family-centered care rests on two aspects of help-giving – *relational help-giving practices* and *participatory help-giving practices*. Relational help-giving involves forming positive bonds with families, being warm and empathetic, listening actively to family needs, and involving families in services. Although relational help-giving is an important element of family-centered practice, it does not represent the full scope. It is possible to deliver services with great warmth and compassion that are nevertheless practitioner-driven. What is needed in addition to relational support is *participatory help-giving*. These are more action-oriented supports that make the space for families to be in control – that is, to take a central role in planning, carrying out assessments, and interventions; to define progress; and to monitor outcomes.

There is a difference, however, between participatory help-giving and simply expecting parents to take the lead in the absence of appropriate supports. Gwyn and Elwyn (1999) found that in medical encounters, without a match in expectations or shared knowledge/competencies in key areas of collaboration, physician's expectations that patients make their own decisions actually resulted in the patients feeling abandoned rather than empowered. An important step in addressing this gap is being sensitive to and respectful of the extent to which families want to take the lead in their children's intervention or even whether they want to modify their routine interactions with their children (McWilliam, 2015).

The past 10 years have seen a growing role of coaching as a component of early intervention as opposed to "parent education" or "parent training" which are terms that convey a more unidirectional flow of information from the interventionist (perceived as the expert) to the caregiver/family (Chap. 12; Winton, Sloop & Rodriguez, 1999). Turnbull, Blue-Banning, and Park (1999) argued that such traditional parent training approaches ran the risk of infusing an unnatural didactic flavor to parent-child interactions in the home due to an overemphasis on the types of strategies/interventions that parents learned to implement with their child. An alternative to parent training is *family capacity building*, wherein family capacities are bolstered by access to information, recognition of existing strengths and resources, and the development of additional competencies through active practice with ongoing coaching in accordance with adult learning principles (Woods & Brown, 2011).

Coaching is meant to help caregivers develop new skills and gain access to new information/resources as consistent with behavioral models, sociocultural and eco-cultural theories, and situated learning approaches (Woods et al., 2011; Bronfenbrenner, 1989). The purpose of coaching is to help caregivers feel increasingly self-efficacious. Interventionists acting in the coaching role helps caregivers discover and build on the skills and knowledge that they already have and things they can already do. Coaches also assist caregivers to develop additional capacities to achieve caregivers' own desired outcomes (Rush & Sheldon, 2011). At the very basic level, family-guided coaching practices in early intervention mean that caregiver interests, priorities, and child needs lead/dictate learning opportunities and conversations. Caregivers and family members are integral decision-makers and collaborators in who, how, where, and when the intervention is implemented (Brown & Woods, 2015; Kashinath, Woods & Goldstein, 2006; Wetherby & Woods, 2006; Woods, Kashinath, & Goldstein, 2004).

Supporting the caregiver and child in early intervention is neither simple nor direct, rather it involves scaffolding adult learning for the caregiver that is focused on supporting their child's developmental outcomes (Woods, Wilcox, Friedman, & Murch, 2011). Kemp and Turnbull (2014) provide a synthesis of second-generation research on interventions that utilize coaching practices with parents in early interventions. The growing body of professional development and evidence-based resources for interventionists include some distinct strategies but also share some similarities. Consensus across these approaches is that (a) caregivers benefit from scaffolding to assist them in learning new information to support their child's skills; (b) for mastery to occur, teaching and learning has to occur in multiple contexts; and (c) self-reflection and goal setting can help adult learners apply their knowledge and skills to new situations.

To facilitate the caregiver's knowledge and skills in working with their child with autism, interventionists can use a variety of coaching strategies to provide information, promote practice, and give respectful and meaningful feedback. These strategies include information sharing, observation, joint interaction, direct teaching/demonstration, guided practice, and problem-solving/reflection (Friedman, Woods, & Salisbury, 2012). Beyond these specific teaching strategies, the ultimate goal is to enhance caregivers' autonomy and ownership of their role in the intervention process.

Summary

This chapter introduced the reader to the central components of working with caregivers of children with autism within daily routines. Implementing a family-centered routine-based approach with children with autism implies that intervention is embedded in multiple, diverse routines that are identified in collaboration with caregivers/family members. Successful routine-based interventions must also ensure sufficient practice opportunities as well as generalization of intervention outcomes. Embedding intervention in daily routines requires interventionists to attend to the complex interplay between family, child, and ecological factors. The goal is to create interventions that fit into a family's life and address specific child outcomes while also building on caregiver confidence and competence. Translation of this intervention approach is impacted by the degree to which interventionists are successful in partnering with caregivers, implementing social communication interventions with high fidelity, and addressing relevant social communication outcomes for young children.

First-generation research on embedded intervention in routines has established positive effects for parents and children. However, we need to better understand the impact of specific components of routine-based intervention on caregiver and child outcomes. Research is needed to establish functional relationships between specific coaching approaches, strategies to facilitate parent involvement, implementation across diverse routines, and their impact. As we learn more, we can begin to identify the exact composition of active ingredients that constitute successful intervention in the routine context. This will allow us to develop resources for interventionists to support their implementation of this evidence-based practice with fidelity to individualize intervention in order to yield the most successful outcomes for every child and family.

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14

Using Video Feedback Strategies in Parent-Mediated Early Autism Intervention

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Abstract

Video feedback (VF) is a widely used method of facilitating behavioral change across adult skill training and mental health interventions. We review the theory and procedural background of VF methods to promote change in parent-child dyadic communication as part of parent-mediated early intervention for autism. Overview of studies incorporating VF in autism treatment shows positive effects in all but one on the targeted parent behavior outcomes, supporting the efficacy of the method in comparison to non-VF methods. We include in-depth case studies of three VF-mediated interventions: a preschool intervention for children with autism (PACT), a prodromal intervention (iBASIS), and a cross-cultural adaptation in South Asian (PASS). Each works just with parents within a developmental model to impact on child dyadic interaction, aiming for more generalized long-term child social development and symptom severity outcomes. The studies show that VF appears to be effective in altering parent interactive behavior in desired ways across child developmental age and family socioeconomic background and culture. They also show that targeted parental change leads to positive child social interaction change, and, in PACT, to reduction of child symptom severity sustained into middle childhood, 6 years after therapy ends.

Introduction

Video feedback (VF) methods use video recording review to help participants learn about their own and other's behavior, with a view to developing insight, behavioral change, or skill enhancement. Because the technique works with the grain of what we know about effective adult learning processes, VF is used widely in education, skill development, supervision, and mental health treatment. In the context of child development, it can be a powerful medium for reflection and understanding of habitual parent-child interactions as well as a potential catalyst for change (Adamson, Bakeman, Deckner, & Nelson, 2012; Aldred, Green, Emsley, & McConachie, 2011; Fraser, 2014; Steele et al., 2014). Improved technology has made video more portable and therefore a feasible and useful tool in a range of interventions.

In this chapter we make a distinction between VF defined in this way and the use of video *demonstration* in a coaching or education context. This latter use, as will become clear, is rather different and does not have the same intervention

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_14

intent or mechanism as the "therapeutic" VF that we will be discussing. This distinction is important in the context of a discussion of VF for autism intervention, since the tradition in this field has generally been a more explicit parent coaching or psychoeducation model, conducted in parallel with direct therapist intervention with the child (Oono, Honey, & McConachie, 2013). Our use of VF with parents in autism therapy is by contrast within an intervention for the child mediated wholly through the parent. As well as tending to use less direct therapist contact time, such "parent-mediated" intervention could in theory have a number of benefits; above all, if successful, it could result in the child's 24/7 exposure to altered interactions with the parent and thus changed experience of early social communication in development. Furthermore, these changes may then become embedded into longer-term "sleeper effects" on social and communication outcomes later in development. There are also naturally additional potential benefits on parental engagement, morale, and confidence as well as broader benefits for family life.

However to achieve success in parent-mediated intervention of this kind, it is necessary to be able to generate a substantial, focused, and reproducible impact on targeted parental behaviors. The intervention techniques to do this need to be transformational for the parent – in that sense they are a true "intervention," rather than psychoeducation or coaching. What this does *not* suggest however is that the parents involved in some sense "need" intervention because they have problems or because their parenting is "sub-optimal." The reverse is the case. There is no evidence of systematically altered parenting quality overall in autism, still less that "poor parenting" causes autism in some way. Instead the transformation needed in parenting behavior is more by way of lifting ordinary parent interaction with their child to a heightened level sufficient to provide a corrective developmental input, almost for parents to become "co-therapists" within their ordinary parenting duties. Some have doubted that a parenting transformation of this kind, at a level sufficient to impact developmental autism, is actually achievable and that direct therapist input will inevitably be needed in order for treatment to be effective. Work with parents, reviewed in this chapter (e.g., Aldred, Green, & Adams, 2004; Green et al., 2010; Pickles et al., 2016; Rahman et al., 2016), shows in fact that desired changes in parent interactive behaviors are achieved with parents of differing social class, education, and culture through use of VF and that this change can feed through – as developmental theory might suggest – into relevant long-term developmental gains in children (Pickles et al., 2016). Other work using similar video-aided methods in both autism (Kasari et al., 2014; Poslawsky et al., 2015) and non-autism (Juffer, Bakermans-Kranenburg, & van IJzendoorn, 2008) reports positive effect in the same or related parental interaction behaviors. Overall this gives replicated support for the efficacy of VF methods in this context.

Mechanism and Active Ingredients of Video Feedback Interventions

VF presents participants an opportunity to observe their own and others' behavior in a reflective context; they see the evidence directly for themselves rather than just receiving feedback based on others' perceptions and can process and reflect on this rather than needing to respond in the moment (Vik & Rohde, 2014). In addition, methods of VF therapy combine this self-observation with collaborative work with the therapist, who can in various ways support, structure, and inform the parent's observations of the material. We will see below the ways in which this collaborative work varies within different therapies, ranging for instance from use of whole video sequences to pre-selection of short video clips for viewing, and different therapist inputs ranging from more or less directive or structured programs to nondirective work.

Potential therapeutic processes at play within VF methods can be understood from a number of different theoretical perspectives (Fraser, 2014; Smith, 2011). Simply the ability to observe oneself and others can sharpen sensitivity and insight and provide an objective view of interaction

(Juffer et al., 2008). Video interactive work here allows parents to be involved in a process of self-regulated learning in which awareness of their own behavior accelerates the rate and process of behavior change in a self-directed fashion (Dowrick, 1991). Such behavioral change is enhanced by the focused attention and emotional arousal involved in viewing oneself rather than some neutral exemplar or model and also enhanced by the relationship with the therapist (Benzies et al., 2013; Buggey & Ogle, 2012). In this VF is a paradigm technique to encourage adult self-directed learning and sense of effectiveness.

VF can additionally be used in developing parents' reflective function and mentalization ability to sustain awareness of the child's state of mind and intentionality (Beebe, 2010; Dorwick, 2012; Jones, 2006; Lena, 2013; Zelenko & Benham, 2000). Improved capabilities of this kind in the parent are associated with increased empathy and attuned responsiveness to a child in all contexts, and empirical studies link this capacity to the development of resilience and reduction of risk of later emotional and behavioral difficulties (Fonagy, Steele, Steele, Higgitt, & Target, 1994; Fonagy & Target, 1997; Slade, Grienenberger, Bernbach, Levy, & Locker, 2005; Wolff & van IJzendoorn, 1997).

Finally, VF allows parents to focus on the infant or child's behavior and communication in a reflective way removed from the pressures of immediate "online" interaction. Particularly in the context of the subtle atypical communication in childhood disability as seen in autism, VF provides key opportunities for the parent to understand the nature of their child's communication when it may not be totally overt. These features will be discussed further below in the context of VF therapy in autism.

Therapist orientation. Different balances are struck in VF models between the self-directed aspects of parent learning during video observation and the degree of therapist structuring. Some styles encourage an active therapist input with a high frequency of praise statements to the parent as a reinforcement that enhances parents' confidence and self-efficacy (Juffer et al., 2008), on the basis that increased confidence will facilitate positive behavioral change (Bandura, 2001). This kind of active reinforcement also reduces the risk that, for some parents, an open-ended watching of themselves interacting might on the contrary reinforce negative self-perceptions, self-criticism, and reduced effectiveness. On the other hand, overstructuring can reduce parental autonomy and self-directedness and the benefits that go along with that. In some models (see PACT below), it is an important feature that the way the therapist works in relation to the parent watching the video is designed to mirror and model the way that the therapy encourages the parent to respond to the infant and child in their interaction (the parent feeling themselves attended to in the same way as the therapy wants the child to feel attended to by the parent). This process mirroring becomes an important implicit ingredient in how this kind of therapeutic model works.

It is an empirical question as to which overall therapist style may be most effective in what situation, but there will always also be relevant individual differences to take into account. In practice it is likely that the best results are going to be from a sensitive accommodation by the therapist to the individual needs of a particular parent. In addition the level of therapist support or scaffolding is also likely to vary within a particular individual therapy as it progresses through phases. Thus, while particular therapeutic approaches will emphasize the balance more or less differently, therapist training needs to enhance therapist flexibility to respond to individual parent needs. A related empirical consideration is which aspects of VF method best enhance parental self-efficacy, self-motivation, and therapeutic alliance, since all of these factors are likely to mediate better outcomes for the therapy (Hodgetts & Wright, 2007). Investigations of this kind have not yet been undertaken but could be useful in the future in order to refine aspects of what is already a powerful method and to enhance the quality of therapist training. As will be discussed below in relation to PACT, therapist flexibility in adapting to parental learning and information processing styles will probably be central to outstanding outcomes, as is commonly the case with psychological interventions generally (Green, 2015).

Evidence for Video Feedback in Non-autism Contexts

In infancy and the preschool years, VF has been incorporated into parent-infant and early parent-child interaction therapy across other areas of mental health (Rusconi-Serpa, Sancho Rossignol, & McDonough, 2009). Much of the early work of this kind was done in the context of *within-parent* risk rather than *within-child* risk that is in terms of problems with parental mental health such as depression, risk of early relationship failure, or high psychosocial stress affecting early parenting, rather than problems related to "within-child" risk such as autism (Green, 2015; Stein et al., 2006; Fonagy & Bateman, 2007). This different focus is important to emphasize when describing below how such techniques have been adapted in the work in autism, since a simple generalization may suggest that, because they have been used here in the context of parental difficulty, their use in autism implies parental difficulties in that condition too. As emphasized above the reverse is the case, and VF use in autism therapy contexts has a different theoretical basis.

A meta-analysis of 51 randomized trials of this kind (Bakermans-Kranenburg, van IJzendoorn, & Juffer, 2003) found that brief (<6 sessions), developmentally-based, tailored, and individualized interventions, often using video-aided techniques, were most effective in optimizing attachment-related parental behaviors such as sensitive responding (overall effect size of $d = 0.45$), whereas general parental support or longer-term therapy aimed at altering maternal mental state showed less effectiveness ($d = 0.27$). There was an attenuated response on child outcomes ($d = 0.22–0.05$). It will be noted how brief the interventions are in this model: it is a feature that parental behavioral change in these contexts can often be achieved fairly rapidly, and the suggestion from the meta-analysis is that the outcomes are better with briefer rather than longer interventions (Doria, Kennedy, Strathie, & Strathie, 2013). However a big question is whether such change is sustained over time (no real longitudinal post-treatment studies have been achieved in this context yet). The best evaluated program of this kind is the Video Interaction for Positive Parenting (VIPP; Juffer et al., 2008). The targeted skills in the various studies in the meta-analysis range from facilitating mutual interaction, relationship building, sensitive responding (Steele et al., 2014; van IJzendoorn et al., 2007), attention focus, skill acquisition, reducing the child's disruptive behaviors, or facilitating child communication skills. VF also varies in the target skills taught to parents; some interventions aim to identify the function of a behavior, prevent disruptive behavior, and use positive reinforcement and techniques to promote compliance. Similar programs have been tested in the context of infants at developmental risk (e.g., highly reactive infants – Klein Velderman, Bakermans-Kranenburg, Juffer, & van IJzendoorn, 2006; Green, 2015). Our own adaptation of VIPP for infants with autism is described below as we turn to VF interventions in autism.

Video Feedback Interventions in Autism

In the context of autism, VF has mainly been used to promote communication within a developmental model based on an understanding of the evolution of naturalistic patterns of interaction within both autism and typical infant communication development. This use of VF aims at enhancing naturalistic parent-child interactions in ways that are known from developmental science to improve child outcomes. This is the sense in which such interventions are described as "naturalistic" or "developmental." The hypothesis is that optimizing developmental interactions will produce a sustained, integrated, and meaningful improvement of the child's developmental trajectory. VF is an excellent method to this end since it helps the parents sensitize themselves to child behavior and opportunities for enhancing child development (Gibson, 2014) within a naturalistically occurring daily context. For example, parent synchronous dyadic interactions that match and extend child language and play have been shown to have positive outcomes on shared attention (Adamson et al., 2012; Kasari et al., 2014). Individual differences in parental sensitivity and synchronicity influence short- and longer-term development of language (Siller & Sigman, 2002, 2008) and child communication initiations (Pickles et al., 2014).

Autism can potentially present a challenge to dyadic interaction, influencing adult responses (Blacher, Baker, & Kaladjian, 2013). Evidence suggests reduced early child social orientations, shorter duration of maintained social engagement and later social disengagement, and reduced communication initiations (Muratori, Apicella, Muratori, & Maestro, 2011; Saint-Georges et al., 2011). Parental interactive behaviors in turn can show a relatively more directive style of communication, including increased verbal, nonverbal, and physical demands and prompts (Wan et al., 2013), behaviors which tend to be focused primarily on stimulating activity or to make a bid for child responsiveness (Saint-Georges et al., 2011). Reflective processes used in VF interventions can be used to address the balance of parent and child contribution in communication initiation and enhance opportunities for intersubjectivity, child intentionality, and communication initiation (Aldred et al., 2004; Doussard-Roosevelt, Joe, Bazhenova, & Porges, 2003; Hudry et al., 2013).

The therapeutic VF methods described in this chapter focus on social-pragmatic models of early child communication intervention (e.g., Sameroff, 2009; Tomasello, 2003) which observe and build on dynamic and reciprocal processes within an affective relationship context between parent and child, achieving a higher threshold of sensitivity and synchronicity in parent responses (*responsive* contributions or *follow-in comments*, e.g., Mahoney & Perales, 2003; McDuffie & Yoder, 2010). Such dyadic interventions are modeled on the precursor skills for communication development in typically developing infants, with additional components targeting the social communication autism impairments. The model supports child communication by enhancing parental attention cues (Walton & Ingersoll, 2015), developmentally appropriate contingent comments, and optimizing child motivated initiation and communication functions, to create the platform for reciprocal social engagement and from which communication and future language growth occurs (Siller, Hutman, & Sigman, 2013).

Two different, albeit conceptually related, VF interventions based on such theory have been tested in the context of autism in trials, using analogous blinded dyadic interaction outcome measures. Intervention within the British Autism Study of Infant Siblings (iBASIS-VIPP) used a therapeutic model adapted from VIPP, and intervened with infants aged 9–14 months at high risk of developing autism by virtue of being a sibling of a child with autism. The aim of this 5-month intervention is to work with the developmental processes in the early pre-symptom phase of autism to modify prodromal trajectories and overall diagnostic outcome. The preschool autism communication trial (PACT) also used a VF model, in a 12-month therapy and was adapted for preschool children who already had an autism diagnosis. The PACT model was then adapted for implementation with children in the preschool and early school years in South Asia, in the parent-mediated intervention for autism spectrum disorders in South Asia (PASS) study. All these therapies were wholly parent-mediated with no direct work with the child; target parental behavioral change in both interventions however was convergent. Outcomes from both methods have been similar (Green et al., 2010; Green, Rahman et al., 2015). There is a large treatment effect on the analogous proximal targeted parental behaviors (parental nondirectiveness in iBASIS-VIPP; parental synchronous response in PACT and PASS), with lower but still substantive effect in relevant child dyadic interaction (infant attentiveness in iBASIS-VIPP; child communication initiation in PACT and PASS). Mediation analysis showed that the PACT therapy worked via the theoretically expected pathway: treatment effect on targeted parental synchrony strongly mediated the effect on child initiation; increase in child dyadic communication in turn mediated changing autism symptom behaviors on ADOS. These outcomes are detailed more fully below. The VIPP technique has also been subjected to separate adaptation for preschool autism (VIPP-AUTI) and tested in a trial that showed effects on parent behaviors but not child outcomes (Poslawsky et al., 2015). In the 2013 UK NICE guidance social communication interventions, including those using video-aided training of parents and teachers, are the only interventions recommended for consideration for treatment of core symptoms in children with autism (Kendall et al., 2013). VF methods are also incorporated, but less centrally, in other autism interventions such as the focused playtime intervention (Kasari et al., 2014), where targeted effects on parental behaviors were found, and Hanen More than Words (Carter et al., 2011), where a non-significant trend only was found, but in the expected direction.

Video Feedback Methods for Autism in Practice

Methods of Video Recording and Playback

Most intervention programs involving VF work to a manualized protocol, with scripts guiding the therapist on the implementation and feedback (Fukkink, 2008; Wels, 2004). The selection of video clips varies across interventions, for example, in PACT selecting a sequence demonstrating a child's signal, the corresponding response of a parent, and the reaction of the child. Furthermore, therapist feedback techniques vary, from therapists highlighting pre-selected video clips during review to direct parent attention to predetermined skills (iBASIS-VIPP) to the therapist jointly viewing the whole uninterrupted video recording with the parent and then reviewing parent selected clips by rewinding the video to selected moments (PASS and PACT). VF methods vary in their rationale, from eliciting the parent's perspective (PACT), where the therapist explores the parent's interpretation based on their representations and reliving the interaction, to directing the parent to predetermined therapy goals.

Parent-Mediated Interventions in Preschool Autism: The PACT Approach (Preschool Autism Communication Therapy)

PACT is a developmentally orientated parent-mediated VF intervention, starting from early skills that precede the development of social communication and progress to meaningful communication and language. PACT addresses the abnormal communication developmental pathways seen in autism (i.e., speech imitation without functional use or meaningful understanding, echolalia, scripts). Language development is targeted using language mapping and modeling and communication skill targeted by facilitating child communication initiation and a range of pragmatic function (Green et al., 2010). PACT is founded on a collaborative evaluation of videoed parent-child play interaction; the parent brings to the discussion their unique prior knowledge of their child, and the therapist simultaneously complements this with theoretical and analytical skill. Parents observe imperceptible moments of communication on video to build on sensitive timely responding and to extend child communication initiation and language. This includes identifying opportunities to share the child's focus, responding with synchronous responses and reducing demands (Aldred et al., 2010). The intervention emphasizes the development of child spontaneous communication initiation, functional communication, and language comprehension along a more typical developmental course. Therapy goals are individually determined primarily by the child's developmental skills and pace of child and parent progress.

Parents bring their expectations, assumptions, and experience of their child to bear in the therapy session, thus enhancing their independent learning anchored to meaningful and authentic situations observed in the video. The parent and therapist engage in a "conversation" exploring possible explanations for child signals and responses by rewinding and reviewing short 1–2 min video clips. In this context, the therapist fosters a collaborative role, drawing on parent interpretation, thoughts, and beliefs while guiding parent understanding and new insights through video replay. In this way, parents validate their role and reappraise or reframe their understanding of communication priorities, expectations, and goals.

At the beginning of each session, a video is made of the parent and child in free play. A range of developmentally appropriate toys, chosen in advance by the therapist, is placed in a clear plastic box in the center of the room. Toys are varied across sessions to maintain child motivation and toy novelty and to encourage interaction appropriate to the stage of the intervention. Parents are asked to play with and talk to their child as they have been doing at home. The therapist makes a 10-min video recording of the play to use immediately as the basis of the feedback discussion for that session.

Initially parent and therapist watch the video together; this gives parents the opportunity to observe the whole interaction for themselves before discussing with the therapist. During this viewing the therapist makes notes and identifies short video clips to play back and review. These clips demonstrate accomplishment of previous therapy goals, highlight successful episodes of interaction to help the parent reflect on positive ways of interacting with their child, or introduce new strategies appropriate to the stage of the intervention. In early sessions, parents identify enjoyable moments and activities that worked well and where shared engagement is achieved. In later sessions, the therapist guides review of video clips related to the PACT stage-specific goals and strategies *(today let's look particularly for moments when you think he was attending and understanding what you were saying).*

Cascading probes, starting with broad observations and narrowing to focused questions, are employed by the therapist to elicit parent observation and interpretation, within the PACT stage-specific strategies. This method of VF supports parent reflection, interpretation, and problem-based learning while validating and reinforcing parent skills. The therapist asks, for example, "What was his action here?" "What do you think he means by that action?" "How did you respond?" "What did he learn from that?" "Why do you think this skill is important?"

Since the video is reviewed and discussed immediately after the recording, the real-time analysis builds on the parent's memory of their experience in play, representation, and contextual knowledge. The level of therapist structure is adapted according to parental style and progress. Therapy sessions build from initial structured guidance to a point of independent parent VF reflection and interpretation.

The VF technique supports parents' in verbalizing, in their own words, their video observations and interpretation. In addition therapists use analogies to elicit insight (e.g., learning a foreign language) or draw cartoons to visualize concepts of interaction and communication. In this way parents relate firsthand to their child's experiences, intentions, and thoughts. At the end of the feedback discussion, which lasts approximately 30 min, the discussion is summarized in a written program, including the parent's own vocabulary, comments, and observations. The parent, in negotiation with the therapist, chooses two to three goals or strategies for 30 min daily home practice. Progress and targets are coded and recorded by the therapist in the manualized therapy notes at the end of each stage of the PACT program.

The PACT manual provides measurable criteria for moving to the next stage of the PACT program. Not all children will progress through the six stages; progress is determined by the child's developmental level and, within that, the parent's accomplishment of key skills. The core PACT intervention comprises of 18 sessions within a 12-month time frame; in clinical practice further maintenance and follow-up sessions may be necessary as determined by the therapist. The PACT intervention comprises six stages, each covering a specific topic for VF.

Firstly shared attention is enhanced through observation of the child's focus of attention and nonverbal and verbal signals on the video. VF is used to help parents identify opportunities for shared object exploration and actions. The therapist uses sensitive probes during VF, e.g., "What is he looking at?" "What is he interested in?" "How could you keep his interest in the same toy?" Parents identify opportunities to build a crescendo of sustained mutual engagement, compared with the more typical a cycle of interruptions and reengagement.

In the second stage, VF is used to guide the parent to observe and identify their own synchronous responses to the child and the positive effect of these on the child's communication. Synchronous responses include following, acknowledging, and commenting on the child's existing focus of attention and matching the child's pace/timing. In this way the parent is encouraged to reduce asynchronous communication which involves demanding, directive, or mistimed responses. The therapist enquires into the parent's intentions observed on the video, "What were you thinking here?" "What were you wanting him to do?" "What could you say here to follow his actions and ideas?" In this way VF highlights convergent and divergent parent and child intentions.

The third stage supports child language processing and understanding with VF clips illustrating opportunities for the parent to model and map contingent words and phrases matched to the child's focus and communication skill. Therapists may use cartoon drawings with speech bubbles in addition to VF to extend parent's use of vocabulary input, asking, "What could you say here?" "What other words could you use?" Here analysis of the video also involves interpreting the child intentions, so parents can say what the child means, e.g., if a child gives a toy the therapist asks, "What did he want here?" "What words could you say that describe his wishes?"

The fourth stage establishes routines to consolidate child verbal understanding and to create opportunities for anticipation of repetitive rhymes and routine familiar actions and phrases. This helps to extend the frequency of child communication initiations in preparation for stage five. VF supports parents in identifying opportunities for verbal repetition and routines and in the subtle use of pause to create openings for the child to initiate.

Stage five has greater structure, where therapists support parents to purposely use pause, fun teasing, or gentle sabotage within predetermined activities to increase child communication functions. Here VF is used to help the parent to observe, record, and identify opportunities to extend the range of child pragmatic communication acts, including the child requesting an object or action, negating, directing, asking for help, acknowledging, and commenting. Communication opportunities are created in play for the child by, for example, pausing before releasing bubbles, or having a toy, or parts of a toy, missing, and the play interaction around this is videoed. The therapist reviews the video clips with the parent and encourages them to identify just the right window or moment to pause for longer or present a sabotage to elicit child response in fun interaction.

The final stage expands language and conversations, where VF is used to identify opportunities for parents to provide simple, verbal, complementary expansions and descriptions of the child's play actions and respond to child language, thus elaborating on the child's vocabulary and grammar. In addition VF clips identify examples of simple verbal sequences of to- and- fro reciprocal comments between parent and child to build conversational reciprocity. Parents identify ways to maintain and expand on sequenced topics and build conversation reciprocity.

Empirical testing. The PACT intervention was tested in a multisite randomized controlled trial conducted in 2006–2009 in the UK (Green et al., 2010) and a 6-year posttreatment follow-up (Pickles et al., 2016). One hundred fifty-two children with core autism (aged 2–4 years and 11 months) were randomly assigned to PACT intervention or treatment as usual at three specialist centers. Families came from a range of demographic backgrounds: of the caregivers undertaking the intervention, 60% were white and 40% other ethnicity; 66% consisted of one parent who held undergraduate or higher qualifications, and 33% below graduate level. All therapy intervention sessions were videotaped, and fidelity to the VF method was tested by double coding 5% of session videotapes, randomized to balance therapist and treatment stage, against 15 prespecified fidelity criteria. Therapist adherence to the intervention model was high, with fidelity shown for a median of 13.4 criteria (IQR 12.5–14.0) per session. Family adherence to the therapy was also high, with median 16 of 18 possible sessions attended (IQR 13–17) and good parent-reported adherence to home practice. Therapist rated implementation of home goals in subsequent sessions reflected the level of home practice. Parents reported enjoyment and feasibility of home practice sessions, progressing from play sessions to embedding strategies into daily routines, e.g., snack, bath, and bedtime.

Parent feedback was positive, demonstrating the value they gained from VF, illustrated by the following quotations:

> It was a revelation to me…I thought I was the only person who knew my child…and I didn't. When I watched the video he had his back to me…. He wasn't playing with me at all…. Now I know him best…but I didn't at the start of PACT.

> Before I was trying too hard, trying to get him to notice me, play with toys,…now I know just the right moment to join him, when he's with me, when he's ready to play…. I know when I'm pressing the right buttons…. It's easier now

> I couldn't tell how he was feeling, he didn't communicate with me…. I was at a loss…now I know, now he doesn't stop telling me

Intention to treat (ITT) analysis of the VF intervention in PACT showed that it succeeded in achieving the targeted parental interaction behavior change, with a large increase in parental interactive synchrony (effect size (ES) 1.22, 95% CI 0.85, 1.59). There was no evidence in the data of moderation of treatment effects by parental social class, education, or ethnicity. Further, in line with developmental theory and the intent of the intervention, this improvement in parental synchrony mediated an improvement in child communication initiation within the parent-child dyad (ES 0.41, CI 0.08, 0.74). This is a particularly striking finding in the absence of any direct therapy with the child, since the improvement in the child must therefore have been due to the behavioral change in the parent. Mediation analysis further supports this, showing that parent synchrony change strongly mediated (70%) the change in child communication initiation and also that in turn the improvement in child initiation mediated the change seen in autism symptoms. Regarding symptom change, analysis combining treatment effects on both social affect (SA) and repetitive and restricted (RRB) symptom domains using the ADOS comparative severity scale (CSS) (Pickles et al., 2016) showed that PACT did produce a reduction in autism symptom severity at treatment endpoint (log odds ES 0.64, 95% CI 0.07, 1.20). Then, results from the 6-year follow-up study, using intention-to-treat (ITT) analysis from the original randomization, suggested a continuing effect on autism symptom severity at follow-up (log odds ES 0.70, 95% CI −0.05, 1.47), which gave a significant moderate averaged overall treatment effect on symptoms over the total period (ES 0.55, 95% CI 0.14, 0.91, $p = 0.009$; Fig. 14.1 top panel). There is a similar pattern seen for child dyadic communication initiation, with a group difference at follow-up being more modest than endpoint but the mean Cohen's d effect size over the whole trial being 0.33 (CI 0.1, 0.6, $p = 0.004$) and clearly significant (Fig. 14.1 middle panels). Rating of parent synchrony showed a reduction of effect at follow-up from the significant change during the trial, but when the overall time path is considered (Fig. 14.1, bottom panels), the effects of intervention overall still remain strongly significant (ES 0.61; CI 0.375, 0.863, $p < 0.001$). Non-blind parent-rated autism symptoms, including repetitive behaviors, also showed comparable improvement at follow-up (Social Communication Questionnaire, ES 0.40, 95% CI 0.05, 0.77; Repetitive Behaviour Questionnaire, ES 0.87, 95% CI 0.47, 1.35).

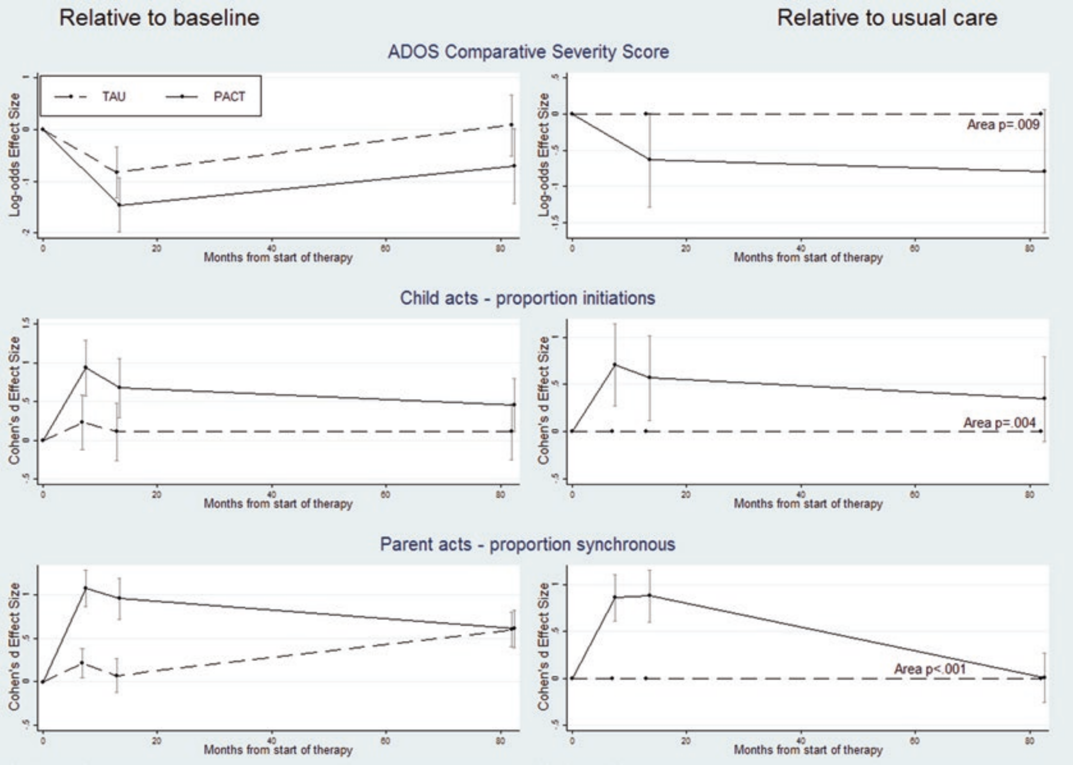

Fig. 14.1 Course of outcomes in the PACT trial from baseline to follow-up. Group time paths relative to baseline (left) and PACT relative to treatment as usual (right). Bars represent time-specific estimates with 95% CIs from repeated measures models and *p* values for area test of no-difference between group profiles. ADOS CSS, Autism Diagnostic Observation Schedule Comparative Severity Score; AUC, area-under-curve estimation; PACT, preschool autism communication trial. Re-preprinted from Pickles et al. (2016)

Use in the Infancy Prodrome: Intervention in the British Autism Study of Infant Siblings (iBASIS-VIPP)

The iBASIS-VIPP intervention is another example of a parent-mediated intervention for autism that uses VF methods to help parents optimize their interaction with their infant (Green, Charman et al., 2015; Wan et al., 2012). The intervention has been developed for parents of young infants (9–14 months) at risk of autism and is an adaptation of the successful Video Interaction for Positive Parenting program (Juffer et al., 2008). The pilot randomized control trial of the iBASIS-VIPP intervention for at-risk infant siblings of children with autism also demonstrated a similar pattern of results, with increased parent nondirectiveness, improved child adaptive social behavior, and faster attention disengagement (Green, Charman et al., 2015).

iBASIS-VIPP is theoretically based on the “interactive specialization” model of social development, based on the theory that the social brain in infants develops through active interaction with the environment. The model suggests that while typically developing infants are biased to orient toward and learn from social stimuli, children with autism, due to atypicalities in the underlying mechanisms, do not show the same biases. In consequence their interactions with the social environment, including caregivers, become atypical, and this further disrupts the development of the social brain, contributing to the profile of symptoms diagnostic of autism in early childhood. Intervention in iBASIS-VIPP aims to identify any “interactional perturbations” in early infancy and work with the parent to alter these, aiming for more sensitive and responsive interactions, which theoretically might result in better developmental trajectories for the child.

In the first instance the intervention seeks to provide the infant with an enriched core interactive social experience by increasing maternal sensitivity and responsiveness through close observation of the infant. At the same time any emerging atypicalities in interaction associated with prodromal autism are monitored and addressed. Video is used to allow the parent to look back on interaction with the infant in a variety of contexts, to reflect initially on the infant's thoughts, emotions, and behaviors and, as the intervention proceeds, to consider her responses to the infant's intentional acts and the effect of these on the infant.

The intervention comprises six core sessions, each covering a specific topic, followed by up to five booster sessions. Since iBASIS-VIPP is designed for use with an at-risk population rather than children already diagnosed with autism, the core sessions of the intervention focus on achieving a high level of parent responsivity in ways that have been shown to be beneficial for typically developing children as well as those with autism. The number of booster sessions offered is negotiated between the therapist and parent and depends on the progress the parent has made and whether any atypicalities in development have been observed in the at-risk infant. These additional sessions allow the therapist and parent to revisit and consolidate skills already learned and heighten parent's levels of observation, interpretation, and responsivity where emerging atypicalities have been noted.

The method of VF in iBASIS-VIPP differs on a number of levels from PACT but has the common aim of allowing the parent to observe infant behavior and communication and reflect on the parent's role in the dyadic interaction. In iBASIS-VIPP each of the six core sessions begins with the therapist making a video of parent-child interaction to be used as the basis of feedback in the following session. The context of each video is specified to be appropriate to the aims and content of the session in which it is to be used; contexts include, for example, parent and child in toy play, at mealtimes, singing nursery rhymes/playing sound games and looking at a book together. The process of making videos in advance of sessions gives the therapist the opportunity to carefully view the interaction in her own time and prepare feedback before the session, thus ensuring the feedback is focused and emphasizes the key messages of the session. Preparation involves making a “script” to guide the feedback, which identifies specific episodes to highlight and discuss with the parent.

In each subsequent session, the video clips are reviewed together. The therapist leads the feedback based on the prepared script, stopping the video at pre-selected points that highlight particular messages, and encourages parents to make their own observations and participate in discussion. Feedback begins with a positive comment about what is observed in the first 10–15 s of the video; the therapist then aims to make a comment or observation at least every 30 s while focusing on session goals and finishes with a positive comment. The video is paused when comments are made to allow the parent time to contribute, and highlighted episodes are replayed to reinforce positive interaction.

The iBASIS-VIPP intervention builds up gradually and sensitively to reach a point where parents reflect on their own role in the interaction and uses specific VIPP therapist techniques to bring this about. In the first session, “infant watching,” the focus of feedback is solely on observation of the infant, with no discussion of the parent's behaviors or responses. This gives the parent time to get used to watching the videos while ensuring the first session is non-threatening and allows the parent and therapist to begin developing a therapeutic relationship. The therapist uses a technique known as “speaking for the baby” to encourage the parent to think about the play and interaction from the infant's point of view; this involves the therapist describing the infant's thoughts, emotions, and behaviors through interpreting physical gestures and emotional expressions. The therapist may make comments, for example, on the infant's enjoyment or actions, e.g., “Look how curious he is about that toy”; the pace at which he is playing, “he's taking his time exploring the box"; or her mood, "she's really pleased with herself." The parent is encouraged to discuss and respond to the therapist's comments.

In the second session, which covers the infant's attachment and exploratory behavior, the focus remains on observing the child, but the parent is now explicitly encouraged to also "speak for the baby" through the use of therapist probes "What do you think he might be feeling there?", "What do you suppose he is thinking right now?". The "speaking for the baby" technique continues to be used by the therapist, and encouraged in the parent, throughout the intervention from then on.

In the third session, the feedback focuses on how the parent and child respond to each other in play, and the therapist begins to include comments on the parent's responses to the child, by highlighting episodes in the video where "sensitivity chains" are apparent. A sensitivity chain is an interactive sequence that demonstrates a child signal, followed by a sensitive response from the parent, followed by a reaction from the child; these provide an opportunity for the therapist to highlight positive episodes of maternal responsiveness and reciprocity. All feedback scripts from now on in the intervention include at least two sensitivity chains. At this stage the therapist also begins to use occasional "corrective messages." With these the therapist sensitively points out an episode where the parent may have responded differently "I wonder if he'd have preferred to carry on playing with the bricks then"; "here you could perhaps have waited to see if she wanted more." As always, parents are encouraged to discuss these observations with the therapist. "Corrective messages" allow the therapist to gently introduce discussion on aspects of the interaction that might be an area for improvement for the parent. Feedback for the fourth session, which continues the focus on responsiveness and reciprocity but this time in an everyday mealtime context, follows a similar pattern.

A final VIPP VF technique "baby talk" is introduced in session 5, which focuses on understanding and responding to the infant's affect and emotions. "Baby talk" is subtly different from "speaking for the baby" in that rather than simply commenting on the infant's thoughts and intentions, the therapist or parent provides a narrative to the video as if they were the infant and the infant could talk themselves "this is beginning to frustrate me"; "oh, I love it when mum tickles me, I'm so happy." The therapist models this first for a few minutes then gets the parent to take over. Although some parents initially feel a bit inhibited using this technique, it is a really powerful way of putting themselves into the child's shoes and understanding the emotions the infant is trying to convey.

The sixth and final core session focuses on further enhancing reciprocity and infant vocalizations, making use of all therapists' VF techniques so far introduced. Booster sessions, focusing on parental responses to any emerging atypicalities, continue the use of these techniques; the manual includes a list of atypical behaviors seen in prodromal autism and associated strategies for the parent to try. In keeping with the rationale of the iBASIS-VIPP intervention, these strategies are of a developmental and naturalistic orientation. New parent-child interaction videos appropriate to the theme of the booster session may be made for video feedback; in addition videos previously made may be reviewed again and compared and contrasted with new videos. All the VF techniques described above serve to help the parent observe her infant closely and reflect on their dyadic interaction.

Empirical testing. The iBASIS-VIPP intervention has been tested in a pilot RCT of intervention between 9 and 14 months ($N=54$; Green, Charman et al., 2015). Acceptability and adherence to the intervention was good, with parents finding it quite possible to fit the home visits for therapy into the everyday routines, despite the fact that the families by definition already also had a child with preschool autism. Many parents described how on the contrary the interaction gave them the chance to have quality time with their babies and avoided them for a time being distracted by other tasks. Although the numbers in this initial study are relatively small, there was a signal of the effect of intervention.

Firstly the video feedback method was successful in producing the desired change in parental interactive behavior. The target interaction variable assessed objectively within the interaction observation was to increase parental nondirective communications, a variable somewhat similar to synchrony although not identical with it, which had been associated with autism risk status in the first year. The treatment improved parental nondirectiveness substantially, showing an effect size of 0.81 (95% CI 0.28, 1.52). Secondly, although the results showed wide confidence intervals and each individual point estimate of effect could have been by chance, there was an evidence of an overall pattern across measures suggesting positive infant response to intervention, with suggestion of increased attentiveness to parent (ES 0.29, 95% CI −0.26, 0.86), a reduction in autism pre-symptoms as measured by the autism observation schedule for infants (AOSI) undertaken in interaction with a researcher (ES 0.50, CI −0.15, 1.08), and improved attentional flexibility on laboratory testing (ES 0.48, CI −0.01, 1.02). Parent-rated adaptive function showed strong overall improvement on treatment (VABS adaptive Behavior composite chi2 (2) 15.39, p = 0.0005). More striking, follow-up when children were aged 27 and 39 months suggested maintenance of these gains over time, with results supporting the theoretical embedding of such interaction change into longer-term development (Green et al., 2017).

Use of VF Across Cultures Using Remote Training and Supervision: Parent-Mediated Intervention for Autism Spectrum Disorders in South Asia (PASS)

The PACT intervention (see above) has been adapted for use in South Asia using a “task shifting” paradigm. The specialist therapists who delivered the intervention in the UK studies were replaced with nonspecialist community health workers, who had received higher education but had no experience in child development, child mental health, or autism. This adaptation process posed a number of major and interesting challenges for the robustness of the VF method. Firstly, VF was to be used for the first time in this context in a culture which was less used to video technologies. Secondly, there was a challenge as to whether nonspecialist community workers could make use of what is a quite sophisticated intervention style to produce change in the parents and children similar to that achieved in the UK PACT trial. The systematic adaptation took place over a year, with an intensive mixture of local consultation, focus groups, expert advisory groups, and field trials. The process is described in detail elsewhere (Divan et al., 2015). A key aim was to culturally adapt the intervention to be compatible with local beliefs and parenting practices, working within family schedules and procedures and for the VF method to be feasible for delivery by nonspecialist workers. Analysis of focus groups, intervention development workshops, and qualitative interviews, during this formative phase, suggested that the adapted PACT and VF methods of intervention were feasible, acceptable to parents, and appropriate for delivery with children up to 9 years, particularly with the more severely affected children identified in the South Asian context (Minhas et al., 2015).

For the implementation of the therapy in the field, a cascade model of training and supervision was set up. Local child development professionals were trained to be local specialists in PACT by UK consultant therapists. These local specialists implemented PASS with practice cases and achieved acceptable video rated fidelity before then training and supervising the implementation with nonspecialist health workers. The health workers underwent a 10-day training including classroom instruction, role-play, and observations, followed by practice-based learning with supervised VF on non-trial cases. A predetermined level of fidelity was achieved before health workers were passed as competent to take on trial cases. The PASS trial process involved the use of Internet-based telecommunication for cascading consultant supervision. The local specialists were responsible for direct regular supervision of the health workers. Trial therapy sessions were video-recorded and reviewed by the local specialist and the health worker together, using a reflective VF style similar to that used with the parents, in one-on-one and group supervision. The local specialists also sent selected videos of the health worker's cases, at different stages of the intervention, for review by the UK consultant therapists, and had a supervision session themselves conducted through telecommunication. This use of international telecommunication proved feasible in achieving acceptable supervision and skill enhancement in health workers.

The PASS remote training and supervision model was tested through rigorous measurement of health worker treatment fidelity to monitor acceptable adherence to prespecified criteria during the trial. Using the same rating scale as the PACT trial, 10% of sessions were randomly selected and fidelity rated from session videos and translated transcriptions, with 20% of these double coded for reliability. The PACT fidelity measure rates key aspects of PACT implementation, including the therapist style, i.e., whether the overall session was delivered with warmth, empathy, and active listening and with demonstration of authenticity by validating the parent experience. Application of the VF therapy methodology is rated on the quality of the therapist's selection and review of appropriate video clips, their use of cascading probes to facilitate parent observation and understanding, their negotiation of parent goals, and their setting of the home program. Therapists are also rated for maintaining a focus on communication and managing other concerns appropriately. Videos of parent-child play and therapist feedback were randomly selected and sent to the UK consultant therapists for fidelity rating. Health workers were required to pass 80% of items relating to therapist style, application of the VF methodology, and setting of goals and home programs. Additionally they were required to pass all items related to the application of the theoretical concepts and strategies of the particular stage of the manual. Health workers who did not achieve fidelity on all items were given feedback via the cascading supervision model on problematic items. Against the background of the use of this novel technique in South Asia, it was notable that the nonspecialist therapists achieved very high therapist fidelity, with median 15/16 fidelity items passed per session (IQR 14–16) and 89% sessions meeting key fidelity criteria.

Parent feedback from the trial reflected enjoyment and high ratings of the VF intervention, as illustrated below:

> It helps me because sometimes you are so involved in what you're saying and what you are doing that you don't notice what the child is doing or feeling because he really can't tell you…. Only his body movements, gestures, the way he turns his head is actually enough to tell you; but we are so used to (instructing). So when I saw it I actually realized the importance of being in sync with what he wants or doesn't want.

Another parent described how the VF method helped them understand the strategies parents were being asked to adopt.

> Seeing myself in video made a difference. When you observe yourself you realize what you are doing and how pushy you are towards your child. (Divan et al., 2015)

The PASS intervention was tested in a pilot randomized control trial of 65 children (32 randomized to treatment and 33 to treatment as usual) in India and Pakistan (Green, Rahman et al., 2015). Families in the PASS treatment arm of the trial attended fortnightly 2–3 h sessions for 6 months in the home and specialist clinics. Families came from a range of demographic backgrounds; of caregivers undertaking the intervention, 28% consisted of one parent who held undergraduate or higher qualifications and 69% below graduate level.

The intervention showed high participant adherence with 26/32 (81%) overall completing the 12-session intervention. No adverse events were reported in either group. Baseline levels of parental synchrony and child initiations were lower than in the UK study, reflecting the increased severity of autism in the sample. At endpoint, there was a treatment effect in favor of PASS in parental synchrony (adjusted mean difference AMD 0.25; 95% CI 0.14, 0.36; effect size ES 1.6) and child communication initiation with parent (AMD 0.15; 95% CI 0.04, 0.26; ES 0.99).

These findings are striking when compared to the UK PACT study above; they show that translated and task-shifted VF technique in South Asia was able to achieve at least as good an effect size on parental synchrony and child communication initiations as in the UK setting.

Training. The above three models of VF intervention require training for therapists. Currently each training package involves attending an initial face-to-face course, delivered by experienced therapists, followed by regular supervision sessions and independent fidelity checking, through rating of therapy videos.

Strengths and Potential Limitations of Video Feedback

The advantages of VF technique include the simultaneous observation and analysis of parent and child intervention and communication sequences, efficiently maximizing adapted communication interactions in a meaningful and affective social context. Such micro-moments are frequently lost, missed, unnoticed, unless captured on video and recognized with the support of a trained therapist. Experiencing an expert reflecting to a parent "that was a wonderful moment, I like the way you did that" validates the parent's role. This parental validation engages a different level of interaction in which the focus shifts from interaction based on standard advice and preconceived ideas to individualized interaction and responding.

Parent-mediated VF intervention does require a level of time commitment, placing a demand on both professionals and parents. Professionals often seek a quicker, efficient method of intervention by instructing parents using direct coaching methods with parents "on looking" and receiving take-home advice. However, parents, who are the primary consistent interactive partners, spend a great deal of one-to-one time in social interaction with young children in the first years of life, and this method of VF builds on these existing parent-child interactions, embedding sensitively adapted communication in authentic and natural interaction contexts. VF can capture and maximize moments of spontaneous reciprocal communication to develop child potential in ways that are often basically simple, that do not require vast amounts of time, and that can be easily embedded in existing daily life. The results of the above trials demonstrate the feasibility of a modest intensity of therapy successfully delivered by parents with therapist supervision and support.

Arguably not all parents benefit from VF, depending on their readiness to engage in intervention following their child's diagnosis and their own emotional needs and different levels of ability to reflect and adapt responses. The current VF trials, described in this chapter, confirm parents of diverse socioeconomic backgrounds and differing levels of support and emotional well-being were able to respond to and effectively enhance their communication skill with VF intervention. Furthermore, the method of VF intervention was found equally effective across different cultures, countries, and resources, including families of low economic conditions in India and Pakistan (Divan et al., 2015). VF was demonstrated to be an effective method for changing "online" parent and child communicative responses. VF builds on the parent's existing representations based on their past experience, making new skills easily transferred to typical daily interactions. The therapist simultaneously takes the parent's perspective, enhancing parent validation (Macran, Ross, Gillian, Hardy, & Shapiro, 1999) while motivating parents to take a new perspective with greater understanding of child intentions (Welsh & Dickson, 2005). These mutual negotiations, resulting in enhanced parent insights, foster a heightened sensitivity and balance of responding while maintaining a joint partnership with parents.

A further advantage of VF is the focus on relatively simple, natural transactions, making the interaction less effortful and contrived for parents. Parents learn to respond to spontaneous child communication signals and cues instead of applying conventions, for example, prompting talk (saying "what is it?") or directing child attention (saying "look" or calling the child's name, touching, or withholding an object). Instead, VF techniques focus on child active participation and communication initiation instead of adult prompting. Such skills, once practiced, may be easily embedded in daily life routines.

Professionals may question whether parents can be trained to deliver "therapy style" interaction in such a complex neurodevelopmental condition or whether VF increases parental guilt and added emotional overlay. Current research found VF methods generally acceptable, accessible, and supportive to parents of all backgrounds (Divan et al., 2015) feasible in different environments, clinic or home, and for different parent styles. VF intervention builds on parents existing emotional investment, and parents reported positive experiences of VF intervention, enhancing their sense of connection and knowing their child better, often helping parents to take a new perspective, supporting their adjustment and adaptive skill. Undoubtedly, parents need different levels of expert support to extend self-awareness and reflection, e.g., the flexibility of facilitating parent reflection in PACT (Green et al., 2010). Some parents need initial direction and guidance, while others utilize video playback as a catalyst for awareness, self-regulation, and change in their responses. Parents who themselves have experience of social communication issues may share a unique insight which can strengthen adjustment to their child. Importantly, parents may direct their anxieties into a sense of self-validation and self-worth, through affirmative VF.

Possible concerns of VF techniques relate to the level of therapist skill required and managing parent's expectations. Although some parents had initial expectations in the above trials to be coached, or for the therapist to demonstrate strategies with the child, the consistently high level of parental adherence with the VF intervention demonstrates parent engagement, motivation, and self-efficacy. Although these issues required careful individual management and flexible adaptation to different parent styles, the VF therapy structure proved effective in changing parent interaction to a more "therapist-like" style, which in turn enhanced child communication skill.

Although VF intervention is structured into clear therapy-manualized protocols within realistic time constraints, training and fidelity checking is needed to ensure consistency and fidelity to the manualized protocols.

Future Developments in Practice and Research

The above trials support the efficacy of VF therapy intervention in adapting parental interaction and communication responses to the child who has autism with substantial mediating effect. Future research needs to analyze the process of change, for example, the therapist-parent interaction for the purposes of both fidelity and process analysis. Further process research may analyze the components of therapeutic skills and therapists' flexibility in accommodating individual differences in parent processing and style. Equally, process analysis could help elucidate aspects that facilitate parent self-efficacy, motivation, and empowerment. Furthermore, research needs to explore additional parental support by expanding the range of targeted contexts including additional parental behavior in the home and communication development mediated with other adults in the education setting.

Conclusions

Video feedback is a widely used method of facilitating behavioral change across adult skill training and mental health interventions. We have reviewed in this chapter efforts to apply VF technology to promote change in parent dyadic communication with infants in the prodrome of autism and with children with diagnosed autism. This has been done in the context of intervention in naturalistic parent-child interactions based on developmental theory, from both neurotypical and atypical developmental science, as to how this interaction change could then modify downstream child autism trajectories. The overarching idea is that if normative developmental interactions in the home can be strategically modified in a sustained way, then predictable positive effects on autism trajectory should ensue, which should continue after the end of treatment. In this context VF proved highly successful in predictably modifying parental interactive behaviors in a targeted way; and as evidence for mediation processes that predict improvements in child communication both within the treatment context and in a more generalized fashion. Three therapeutic VF protocols and trials have been described, comparing and contrasting adaptation across different age ranges and social and cultural contexts. VF has shown itself applicable to both the infancy prodrome and preschool autism and also within implementation in a low to medium income setting in South Asia – this latter use is impressive for the effectiveness of remote training and supervision in allowing nonspecialist therapists to achieve fidelity in the method.

Further research is required to elucidate the relative effectiveness of the therapeutic processes and factors in addition to expanding the natural contexts in which such intervention is applicable. However the evidence to date suggests that intervention for autism using VF is efficient and strikingly effective in its targeted aims. The field should benefit from more work in refining these techniques and better understanding the effective ingredients for creating and maintaining generalized and useful change in autism development.

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15

Using Technological Innovations to Support Parents of Young Children with Autism

Susan L. Hepburn and Elizabeth M. Griffith

Abstract

In this chapter, we will explore the current research on the use of technology in parent education and support and will reflect on our clinical experiences implementing a family-focused telehealth program. We will begin broadly, providing a brief synopsis of what has been studied in various clinical populations, highlighting what we believe can be applied to families of young children with ASD. We will then emphasize the translational aspects of telehealth practice, drawing from our group's experiences launching a videoconferencing version of a family-focused, evidence-based intervention. After outlining the implementation steps of telehealth program development, we will conclude with specific modifications to therapist/educator communication when interacting with families through a videoconferencing platform.

Technological Innovations for Parent Education and Support for Families of Young Children with Autism Spectrum Disorder

Obstacles to Family-Centered Care

Family-centered, evidence-based intervention can be difficult for parents of young children with ASD to access for many reasons. First, there's geography: for families who live in rural communities, these services may be too far away to access on a regular basis. Then, there's time: even families from urban and suburban communities report that travel time is a significant obstacle to consistent participation in family-focused interventions (DeVany, Alverson, D'Iorio, & Simmons, 2008; Kaiser, 2011). Furthermore, given the economic stresses of raising a child with special needs, many parents find themselves working more, leaving little time for in-person contact with clinicians (Parrette et al., 2012). Some families adapt to these new challenges by compartmentalizing roles, whereby one parent

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This research was supported by grants from the Department of Health and Human Services/Human Resources and Services Administration (HRSA)/Maternal and Child Health Bureau and the University Centers for Excellence in Developmental Disabilities (UCEDD), Association of University Centers on Disabilities, JFK Partners, University of Colorado Denver, and Children's Hospital of Colorado.

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_15

works extra hours and one participates actively in the child's treatment and education. Even this strategy has its drawbacks, as the parent who is primarily in the "work" role likely misses out on important learning opportunities focused on how to interact and intervene within the flow of everyday life. These missed opportunities for the parent can result in missed learning opportunities for the child, increasing tension within the parents' relationship, and a decrease in perceived self-efficacy for the working parent (Jones et al., 2014). Thus, space and time pose real barriers to our ability as practitioners to educate, support, and collaborate with parents of young children with ASD.

The Potential of Technology to Overcome Access Barriers

Technology may offer some feasible, cost-effective, and promising solutions to barriers to delivering parent education and support to families of young children with ASD. See Boisvert and Hall (2014) for a review. In fact, there's a growing evidence base on this topic in the general early childhood literature, as well as in special populations, such as traumatic brain injury (Wade, Oberjohn, Conaway, Osinska, & Bangert, 2011), fetal alcohol syndrome (Hanlon-Dearman, Edwards, Schwab, Cox, & Longstaffe, 2014), attention deficit disorder (Xie et al., 2013), developmental coordination disorder (Miyahara, Butson, Cutfield, & Clarkson, 2009), and autism spectrum disorders (Wainer & Ingersoll, 2014; Vismara, et al., 2016). Findings across studies are fairly consistent, suggesting that feasibility (i.e., user-friendliness, cost/time burden, reliability, user satisfaction) is strong across many different technological applications, used for many different purposes (Baharav and Reiser, 2010; Burke et al., 2008, Gettings, 2015; Hall and Bierman, 2015; Jones et al., 2014; Wainer and Ingersoll, 2011).

Anytime we discuss the role of technology as either an enhancement to an intervention or as the primary delivery method for an intervention, it is important that we specify what we mean by the term "technology." See Table 15.1 for a summary of the technological applications, features, and uses (appropriate and inappropriate).

Lessons Learned About Technology and Parent Education

In a thoughtful review of studies of early childhood parent education delivered or enhanced by technology, Hall and Bierman (2015) suggest that the field has produced several evidence-based approaches to effective parenting; the current challenge is not to conceptualize interventions but rather to figure out how to implement the interventions in real-world settings. This emphasis on uptake in communities or "diffusion" is also viewed as the next step in the field of parent education by other leaders in intervention research (e.g., Brooks-Gunn, Berlin, & Fuligni, 2000; Jones et al., 2013). Technological approaches to parent education, such as online courses or videoconferencing sessions with parent coaches, have the potential to facilitate the diffusion of evidence-based parenting programs; however, researchers and practitioners are reporting some important considerations in supporting parents through technological applications, as described below. In the next section, we summarize the common themes from the existing literature on this topic that we believe are most relevant to the use of telehealth in parent education for families of young children with ASD.

Begin with an evidence-based parent education program It is important to remember that technology merely provides a medium for delivery of content but does not replace the content. Effective use of technology in parent education will begin with a parent education curriculum or intervention that has been systematically developed, evaluated, refined, and evaluated again, sometimes several times before a technologically rich delivery method is even contemplated. Examples of evidence-based parent training approaches that have been studied in various formats in the general parent-child literature (e.g., live and in-person or through videoconferencing)

Table 15.1 Considering the fit between technological tools and clinical use

		Clinical use	
Tools	Description/features	Appropriate	Inappropriate
Listserves and forums	Web-based information service provided through email or website to individuals who have signed up to learn more and share with others about a particular topic Self-paced Asynchronous	Sharing tips, experiences, and resources Familiarity-building (i.e., broadens one's exposure to the topic, allows for exploration of ideas and viewpoints) Support-building (i.e., reminds learner that others understand and also grapple with the topic)	Individualized advice or intervention Crisis support Private/sensitive information-sharing
Online educational modules	Web-based, multimedia, and explicitly structured instructional tools that deliver chunks of content in a predetermined sequence for a clearly defined user group "Asynchronous": instructor builds the modules but doesn't interact with learner Learner can repeat content until learned	Motivated adult learners Foundation-building (i.e., good method for teaching concepts, facts, and general knowledge in preparation for later skill-building) Illustrating different perspectives on complex phenomena	Skill-building and procedural learning (i.e., doesn't work as well for teaching how to perform complex actions, behaviors – or any skill where feedback or coaching is critical for mastery, such as interacting with a child)
Webinars	Web-based lectures – usually covering a topic or theme and not part of a larger curricula like online modules – often presented as a PowerPoint slide show accompanied by a speaker's voice Delivered live and often archived for later reference Often includes opportunity to ask questions and make comments (during live version)	Interested adult learners – topic and speaker(s) need to be compelling to maintain interest, as learner is mostly passive Presenting an overview of a topic/area of study Describing a project or sharing results of a study Engaging a panel in moderated discussion	Adult learners who need to be more active and self-directed Skill-building
Video-conferencing	"Real-time" video chat between a clinician and parent(s) via cameras mounted on computers in separate locations; all participants see and hear all other participants through multiple windows on the computer screen Can be conducted in several formats, such as (a) 1:1 context (1 clinician to 1 parent), or (b) in a small group context (1 clinician to 5 parents – All on screen simultaneously from 5 different places), or (c) in a 1: Large group context (1 clinician in office to 25 parents all sitting in a classroom together, viewing clinician via LCD projected image) Participants are actively engaged in discussions, activities, and sharing experiences Can record and archive sessions	Adult learners of various levels of familiarity and experience with shared topic who are interested in learning from a specialist and from other learners Foundation-building Skill-building – Introducing a new skill or honing application of learned skills Facilitating social support among learners with similar goals Engaging learners in self-reflection by sharing progress since last session Promoting critical thinking and problem-solving through discussion of real-life challenges in applying skills	Adult learners who prefer to learn through passive or independent means Adult learners who are not available when clinicians are available (e.g., adults who work nights) – Requires consistent attendance to be useful

include the Triple P Positive Parenting Program (Sanders, 2012; Telehealth version: Reese, Slone, Soares, & Sprang, 2012) and the Incredible Years Program (Webster-Stratton & Reid, 2010).

Several autism-specific parent education programs designed for telehealth delivery are also based on evidence-based approaches. Vismara, Young, and Rogers, (2012), Vismara, McCormick, Young, Nadhan, and Monlux (2013), Vismara et al. (2016) used videoconferencing to deliver parent education based on the Early Start Denver Model (ESDM; Rogers & Dawson, 2010; P-ESDM; Rogers et al., 2012). Ingersoll, Wainer, and colleagues (2013, 2016) developed a caregiver training program as an adaptation to Reciprocal Imitation Training (RIT; Ingersoll & Schreibman, 2006). Lindgren, Wacker, and colleagues (Lindgren et al., 2016; Suess et al., 2014; Wacker et al., 2013) developed a series of studies examining the use of telehealth to teach parents how to implement functional communication training (FCT; Carr & Durand, 1985). Boutain (2014) reported on a parent education program focused on empirically supported principles of applied behavior analysis.

Adapt responsibly When adapting an intervention for delivery through a novel medium (such as videoconferencing), it is important to differentiate the critical elements, or the core/fundamental aspects of the intervention that are associated with evidence-based outcomes, from the delivery features, or elements that are not essential for therapeutic benefit. This allows for flexible adaptation to the evidence-based practice, which is often required when translating intervention research into practice (Kendall, Chu, Gifford, Hayes, & Nauta, 1999). Sometimes it's an empirical question as to which intervention features are critical and which are optional. For example, in our study of the impact of cognitive behavior therapy (CBT) for anxiety in youth with autism spectrum disorder delivered via videoconferencing (Hepburn, Blakeley-Smith, Wolff, & Reaven, 2015), we worked to preserve the critical elements of CBT within the in-person *Facing Your Fears* program (i.e., psychoeducation, cognitive restructuring, exposure practices; see Reaven, Blakeley-Smith, Culhane-Shelburne, & Hepburn, 2012) in the telehealth version, knowing that the method of interacting with the clinicians would be different (i.e., via videoconferencing). In order to understand the potential efficacy of using technology to deliver the CBT program, it was important to conduct fidelity assessments to examine the presence of the critical elements across treatment and to obtain parent and youth ratings of the quality of the therapeutic alliance. The information obtained by these process measures provided a context for interpreting the observed outcomes. Results of this study suggested that fidelity to critical elements of CBT was very strong for sessions that focused on psychoeducation, but only moderately strong for sessions that focused on practicing facing fears (i.e., exposure), which is similar to what's reported in the live version of the program (Blakeley-Smith et al., 2016). The quality of therapeutic alliance was high and comparable to what is reported in live sessions. There was a significant reduction in youth anxiety symptom severity in the telehealth program; however it was not as robust as has been observed in live sessions. The fidelity and alliance data helped us to identify which aspect of the telehealth program was lacking, relative to its live counterpart. Thus, the next step for this program is to revisit the exposure protocols and try to bring this component of the telehealth program closer to the empirically supported live version.

Embed some interactions Asynchronous technology use (e.g., an online portal for self-instruction) has been found to be less effective than a blended approach, where technology use either involves or is accompanied by some kind of interaction (e.g., email, videoconferencing). This has been found in studies of parent training for youth with traumatic brain injury (Antonini et al., 2014; Wade et al., 2011), fetal alcohol syndrome (Kable, Coles, Strickland, & Taddeo, 2012), and child behavioral disorders (Sanders, 2012). The evidence suggests that interpersonal interaction – even through a device, such as a telephone or computer – adds value to asynchronous web-based learning approaches in promoting adherence and thus increasing the potential for positive change (Hall & Bierman, 2015 Ingersoll et al., 2016)

Maximize motivation Adherence to an intervention requires persistence, and maintaining motivation is an important part of promoting change. Jones et al. (2013) suggest that self-determination theory (Deci & Ryan, 2002) has relevance for technology-assisted parent training interventions. Briefly, self-determination theory posits that lasting behavior change happens when people are motivated by one or more of three basic human needs, to be competent, autonomous, and connected to others. Jones et al. (2013) suggest that technological delivery of parent training interventions will promote lasting behavioral change if these three human needs are addressed. Social networking tools, asynchronous web-based content, videoconferencing, and coaching-at-a-distance programs could each address aspects of self-determination. Combining them may even maximize motivation, as has been suggested by the developers of InfantNet, a multimedia, multi-platform parent education and coaching program with elements and services that range from asynchronous self-study content on the Internet to text message reminders to personalized coaching via telephone (Baggett et al., 2010). Such diverse approaches offered simultaneously help to engage adults with different learning styles.

Monitor intervention dosages Engaging parents so that they want to attend parent education sessions is absolutely critical for intervention success. Given that many technologically assisted interventions depend upon the adult initiating the learning activity, motivation (as described above) will impact the intensity – or dosage – of the intervention that is delivered to a particular parent. Few studies have examined this factor, and more work is needed in this area to understand the impact of intervention intensity on outcome. For example, Antonini et al. (2014) studied the impact the *iInteract* program, a technology-enhanced intervention for parents of youth with traumatic brain injury and reported that the number of sessions completed by the parents was correlated with intervention impact.

Employ technology to individualize interventions Several parent education interventions incorporate technology as a tool for individualizing interventions within a clinic or school-based program. For example, asking parents to film interactions with their children at home and then reflecting on those films in treatment sessions has been used in many parent-child interventions (Jones et al., 2013; Webster-Stratton & Reid, 2010). In the parent education literature in autism, videotape review procedures are included in many parent training programs, including the Early Start Denver Model (Vismara et al., 2013; P-ESDM; Rogers et al., 2012), Hanen-More than Words (Sussman, 1999), and the RUPP behavioral parent training program (Bearss et al., 2013). This practice may help to ground the concepts being discussed in vivid, real-life examples that have meaning for the parents. The use of videotaped examples also helps to promote problem-solving and generalization of parenting practices (Kaminski et al., 2008).

Consider access issues Although access to the Internet is improving, there are still significant obstacles to broadband connectivity for a substantial segment of the population in the United States of America. According to the Pew Research Foundation's 2013 report, 30% of people who earn less than $20,000 per year are not online at all, and another 30% rely on schools or libraries for Internet access. Mobile phones are now more affordable, and more common and intervention researchers are focusing on smartphone applications, particularly when trying to reach younger parents (Baggett et al., 2010; Hall & Bierman, 2015).

Fit matters: technology is not everyone's favorite source of parenting information Technology may not be embraced by everyone, and parents need choices regarding how information about parenting is delivered to them. Hall and Bierman (2015) summarize this literature and conclude that families with higher incomes tend to value technology-assisted interventions more than families with lower incomes (see Larose et al., 2008; Lerner et al., 2012).

Don't forget to think about the supports outside of the parent Parenting interventions are strengthened by providing consistent information and support to multiple caregivers in a child's life (McMahon & Forehand, 2003). Technology can be used to share live sessions with another caregiver (e.g, by filming sessions or maintaining archived videoconferenced sessions). It can also be used to provide asynchronous access to information through web-based self-study modules (Jang et al., 2012; Wainer & Ingersoll, 2014).

Case Study: Launching a Telehealth Service Using Videoconferencing

Implementing a telehealth program involves significant planning. In this section, we offer an overview of the implementation steps that were involved in launching a family-focused telehealth project in Colorado. Clearly, different steps may be necessary across communities, interventions, and technologies, but hopefully this will provide an illustration for the steps involved in launching a telehealth version of a clinic-based, empirically supported intervention for families of youth with ASD.

Overview

TeleCopes (Hepburn et al., 2015) is the videoconferencing version of *Facing Your Fears* (FYF; Reaven, Blakeley-Smith, Nichols, & Hepburn, 2011), a multifamily, cognitive-behavioral intervention focused on reducing anxiety symptoms in youth with ASD. FYF integrates evidence-based practices in anxiety intervention with children with educational practices for engaging youth with ASD, and the empirical support for its efficacy is growing. For example, in a randomized controlled trial that included 50 youth with ASD and significant anxiety, 78% improved significantly after FYF, as determined by clinical evaluators who were blind to the youth's treatment group assignment (FYF or treatment-as-usual) (Reaven et al., 2012). Treatment gains persisted for youth who completed FYF at 12- and 24-month follow-up visits (Hepburn, Blakeley-Smith, & Reaven, 2016). As a clinic-based intervention, the reach of FYF has been limited to those families who live within driving distance of a specialized medical center. Thus, developing a feasible, technologically simple, telehealth intervention that would allow for multifamily group interaction, parent psychoeducation and coaching, and active engagement by the youth with ASD across geographic distance became a goal for the FYF team.

The initial development phase of the project took 4 months. As with the live version, *TeleCopes* was designed to be delivered to four parent-child dyads simultaneously, thus allowing for family-to-family interaction as well as clinician-to-family interaction. The *TeleCopes* intervention includes ten 1.5 h sessions, with homework assigned and reviewed during each session. Each session follows a parallel structure to the live version, including consistent schedule elements (e.g., catch-up (review of week, previous homework), new topic, activity, homework, reward, parents-only time). Visual supports are used to support concepts. Video-modeling activities are used to help parents and youth establish a common vocabulary and to generalize concepts. (For more information on the feasibility and preliminary outcomes associated with the TeleCopes project, see Hepburn et al., 2015.)

Implementation Steps

As you might imagine, there were lots of moving pieces to this project. In fact, in our experience, the project management skills involved in telehealth delivery were more challenging than the technical skills required. Finding support staff who can coordinate communication, disseminate program materials, handle scheduling, and guide families through any program setup will be very helpful if you intend to work with multiple families in this modality. With that in mind, here are the implementation steps suggested by our experiences launching a videoconferencing intervention in rural Colorado.

Step 1: Research ethical issues and practice parameters Ethical guidelines for telehealth services are provided by the American Telemedicine Association (2015), as well as by specific disciplines (APA, ASHA). Carefully consider issues of privacy/confidentiality and other potential risks for participating families and communicate clearly with these families about the risks involved. Include statements about your intended use of technology and the limits of technology in your "permission to treat" or disclosure forms.

Step 2: Determine which technology you want to pursue Table 15.1 (presented previously) describes the features and potential uses of different platforms to consider, depending on the focus and goals of your specific parent education/support program.

Step 3: Explore options for videoconferencing from clinics to homes that are financially feasible and sustainable for your practice In some states, clinic-to-home videoconferencing is not billable (i.e., not approved for reimbursement by insurance, waivers or Medicaid). Clinic-to-clinic videoconferencing is more likely to be "billable"; however, this can also vary and requires confirmation. Thus, depending upon the laws in your state of licensure and practice, you may need to (a) collaborate with a primary care practice, mental health center, public health department, or school and ask them to host a parent group, while you lead from a distance or (b) consider if the parent education program you are delivering via videoconferencing fits billing code definitions for an educational (as opposed to therapy) service and if that service can be delivered via clinic-to-home videoconferencing.

Step 4. Explore applications/videoconferencing programs and consider project priorities In particular, consider the following parameters: (a) complexity/sophistication of program options (i.e., do you want to share video clips or just have a video chat? do you want a program that can archive a digital video of your sessions? Do you plan to run groups or individual sessions?), (b) ease of installation and use for families, (c) availability of technical support for the therapist team, (d) cost (for your practice and per family), (e) system requirements (particularly memory and bandwidth), and (f) overall stability and reliability of the program. Talk to other professionals who have experience with different programs. Sign up for free trial periods in order to fully explore possible programs.

Step 5: Prepare therapists to communicate through videoconferencing Not all experienced therapists will be comfortable communicating with parents through videoconferencing. In our experience, some therapists needed ongoing technical assistance by an eLearning specialist, even if just delivering a webinar and not necessarily engaging in two-way interactions. Practice interacting with the technology can be critical for promoting therapist comfort with the telehealth platform. Consider convening some staff meetings via videoconferencing in order to facilitate more practice opportunities. See Table 15.2 for a partial list of communication modifications our team found to be helpful in promoting therapeutic alliance via videoconferencing.

Step 6: Whenever possible, include videoconferencing as a choice, not a sole option Consider parent's experience and communication preference in determining intervention modality – videoconferencing is not for everyone. Provide opportunities for parents who do not use this technology often to practice in some 1:1 interactions.

Step 7: Learn about how the parents you serve currently use technology In our rural outreach videoconferencing project, we conducted a brief intake interview with participating parents specifically concerning how they used their computer (i.e., what programs they used, whether they had ever used videoconferencing before), what kind of equipment they were using (hardware and Internet connection), and how confident they felt using their computer for different purposes.

Table 15.2 Suggested modifications for interactions via videoconferencing

Challenges	Modifications for interaction
Slight delay in transmission of audio (i.e., timing of when a person speaks and when others can hear what is said has a 1–5 s delay)	Slow down the pace of verbal interactions and wait for others to finish talking before speaking Remind all participants to allow for wait time and introduce a visual cue ("wait" gesture) if cross talking occurs
Audio quality may vary across participants	Speak slowly, deliberately, and clearly. Sometimes you'll need to speak more loudly than you would do in person; however, try to do this without seeming to shout or adding a sense of urgency to the communication. The use of headsets and microphones is very helpful here Remind families of how to change the volume settings on their end, so that if you need to speak more loudly for one family, others can dampen the sound as needed If sound issues persist within a session, consider supplementing the videoconference with a phone call to the family impacted by sound problems. This way, they remain visually present in the group and can still hear the content. Reflect content back to participant fairly frequently to make sure you have heard correctly
Visual image of therapist can seem "too close for comfort"	Sit back about 18 inches from the camera and monitor. Position yourself prior to initiating the call so that your head/shoulders and possibly top half of body are in view. Avoid close-ups to face
Nonverbal reflective listening behaviors (such as making eye contact, nodding, empathic vocalizations, and gestures) can feel "out of sync" within the interaction	Practice looking into the camera instead of on the computer screen. This is counterintuitive, because if the therapist is looking at the parent/youth on the screen, it appears that she isn't paying attention to the person or to what is being said. Placing the camera as close as possible to the image on the screen helps, as does consciously practicing looking at the camera Prolong and even exaggerate gestures so that the timing isn't as disjointed
Awkward turn-taking in group discussions (i.e., in multiple family group discussions, it can be difficult to know whose turn it is to talk)	Institute a clear routine for turn-taking and explicitly identify who is to be speaking at a given time Remind all participants to use a gesture to indicate they'd like the floor (raising hands works well)
Distracting environment (i.e., sounds or images behind the therapist that could distract participants)	Take time to set up the room where telehealth interactions occur. Cover windows and other distracting visuals with a dark-colored curtain, so that the participant sees the therapist only. Post "do not disturb" signs on room and in hallway

Step 8: Create technical support materials for families and therapists In our experience, we needed two sets of materials: (a) beginner's tool kit: (i.e., initial orientation session and a visual step-by-step guide to installation and troubleshooting sound or connectivity issues) and (b) experienced users quick summary (i.e., one-page bullet-pointed list of essential info). Provide contact information for a reliable and knowledgeable person who can help families troubleshoot any problems with installing software or maintaining connectivity in sessions.

Step 9: Develop a schedule of a block of sessions, enroll an appropriate number of families, and provide clear information about program logistics Identify an appropriate number of participating families for each session by considering your goals for the intervention and the optimal number of participants for achieving those goals. Working with two families at once poses fewer facilitation challenges for the interventionist than a group of four families; however, the inclusion of more families adds depth to the examples that will be discussed and may promote better parent-to-parent supports (Kaiser, 2011). In addition, provide the participating families with clear information about expectations for attendance, participation, and other logistics. Describe how you will help a family get caught up if they missed a session (i.e., a phone call? A handout? A brief video chat?). Although technology can reduce difficulties with transportation in order to attend sessions, moving the intervention into the home setting may introduce other factors that impede attendance. For example, we found it helpful to talk with participating parents about a plan for keeping their children safely engaged in another activity while they are participating in the telehealth intervention.

Step 10: Convene first a videoconference Keep it brief and socially focused. Discuss the goals of the group, ground rules (including confidentiality), session routines, and procedures. Describe how you will send out materials to the group and establish a way that group members can reach you. Remind everyone of technical information and see if anyone needs assistance. Remind everyone that if their video feed isn't working, they can call into a speaker phone in your office.

Step 11: Conduct a block of sessions, checking in with participating families for feedback on their experiences with the intervention along the way As you implement your telehealth intervention, build in routines for obtaining feedback from participating families. This can be done by asking everyone how it's going during the intervention sessions or by a follow-up email or confidential survey. Revisit your goals with each family, and – just like any other form of psychosocial intervention – be ready to adjust your therapeutic strategies and foci based upon the responses of the participants.

Concluding Comments

Parent education programs are an important part of intervention for young children with ASD. Barriers to accessing evidence-based approaches are a practical problem that technological innovations have the potential to address effectively. In this chapter, we presented a synthesis of the existing literature on technological approaches to delivering parent education, noting that the findings of autism-specific intervention studies are very similar to those conducted with families of children with other developmental, physical, or mental health challenges. This is a rapidly changing research landscape, and the programs cited herein are offered as examples, and our review is, by no means, exhaustive. Different technological applications offer different features and may be more appropriate for some uses than for others. Technological innovations in parent education and support are likely to be more effective when they are based on evidence-based practices that have been adapted in a manner that replicates the critical elements of the intervention but is flexible enough in form to fit the novel delivery medium. Approaches that include interaction appear to be more effective than approaches that are purely self-instructional and self-paced. Motivating parents to participate consistently in order to experience a meaningful amount of the target intervention is an important consideration when designing technological interventions for busy adults facing significant stressors. Technology can be used to individualize interventions and improve generalization, as with the integration of videotape reviews in many parent-training programs. It may also provide innovative ways to extend parent education and supports beyond the child's primary caregiver through asynchronous access to training materials. There are also limitations to the use of technology in parent education and support. Access is still limited for many people in poverty, and not all adults view technology favorably as a parenting tool.

From a practical, implementation perspective, integrating technology into practice involves a significant amount of planning; however, careful consideration of the steps and resources required will facilitate the process. Aspects of parent education that are taken for granted – such as the ability to communicate effectively with the parent, (listening actively, nonverbal communicative cues, coaching in the moment, and providing specific suggestions in a dignified tone) – may require careful consideration when interacting through technology. As with other clinical skills, integrating technology into parent education and support will require practice, openness to feedback, and objective, ongoing program evaluation. More studies with rigorous designs are needed to evaluate the impact of technological innovations and investigations into uses of relatively affordable technologies, such as mobile telephone applications, and are also needed to move the field forward.

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16

Engaging Fathers in the Care of Young Children with Autism

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Abstract

In recent years, there have been numerous parent training studies of children with autism that provide strong empirical support for these parent-mediated approaches. However, to date, most report findings from mothers, and fathers continue to be underrepresented. This is unfortunate in that fathers have been prominent figures throughout history. Furthermore, there is clinical and preliminary empirical evidence that informed and empowered fathers can significantly contribute to child development and the overall quality of life for all family members. Thus, the purpose of this chapter is to discuss current literature about the unique role that fathers play in raising a child with autism, identify common paternal reactions to an autism diagnosis, describe how male learning styles may affect parent training approaches, discuss clinical implications related to father involvement, and identify areas for future research.

Background Related to Roles of Fathers

Throughout history, fathers have remained a prominent figure in the family even as their roles in society have changed and evolved. Pleck (1982) presents a historical account of the father's role beginning in colonial times through the 1970s where the feminist influence is described. This evolution from strong patriarch and breadwinner to co-parent is striking and appears to have been influenced by factors such as the following: (a) society's current view of parental roles that includes a shift in expectations of fathers, (b) increased maternal employment, (c) evidence of the father's influence on child development, and (d) demographic profiles of modern families (McBride & Lutz, 2004).

Even with the notable societal shift to co-parenting, most parent-child intervention studies only report findings from mothers, and fathers continue to be underrepresented in the literature (Flippin & Crais, 2011). For this reason, the author and colleagues made a deliberate departure from more traditional parent training to focus exclusively on fathers. The ultimate aim was to help fathers interact in ways they felt were constructive with their children and empower them to train other family members to use strategies for promoting socialization and language development. Through years of this type of

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_16

in-home participation, we have observed fathers interact with their children with autism and noted that informed and empowered fathers can significantly contribute to child development and the overall quality of life for all family members. Thus, the purpose of this chapter is to discuss current literature about the unique role that fathers play in raising a child with autism, identify common paternal reactions to an autism diagnosis, describe how male learning styles may affect parent training approaches, discuss clinical implications related to father involvement, and identify areas for future research.

What We Know about Fathers

Lamb (1976) was the first to document the positive influence of fathers in child development. His seminal work was produced in the mid-1970s at a time when most social scientists doubted that fathers significantly influenced the development of their children, especially their daughters. His early and subsequent work has primarily focused on three areas: father engagement, accessibility, and responsibility (Lamb & Tamis-Lemonda, 2004).

Theoretical Models

In addition to Lamb's organization of his research in the stated areas, Doherty, Kouneski, and Erickson (1998) have created a theoretical framework to assist in the development of a systematic knowledge base to guide our understanding of the paternal role in child development. This model indicates that a number of mother, child, father, and contextual factors may influence father involvement. For example, a father's sense of capability, self-efficacy, and psychological well-being may greatly influence his desire to participate and succeed in his paternal role (Doherty et al., 1998). In addition, "role salience" (if the father is fully engaged in his role) may indicate how likely a father is to assume the role given contextual factors over time (Stryker, 1991). Finally, the father's involvement in child rearing often depends on the mother's attitudes and expectations about his role. In some cases, the mother acts as a "gatekeeper" and determines what aspects of child raising the father is permitted to do. In our work, we have noted that mothers often assume caretaking duties that become integral to their identities and have difficulty relinquishing even the most stressful aspects of their roles to fathers. As mentioned, child characteristics such as gender also play a part in determining father involvement. For example, Flouri and Buchanan (2003) found that fathers spent more time with their sons than daughters. This suggests possible gender identification which, in turn, could affect paternal expectations of the child and the father-son relationship.

Clinical Insights

Father involvement may also depend on whether the father perceives that he can make a positive difference in the child's behavior or overall quality of life. This was clearly illustrated by one father who was initially very reticent to participate in our in- home training program. In fact, the day that we arrived to enroll the family, he was outside gardening with no intention to meet with us. His wife joined us in the living room and was happy to complete the necessary paperwork. After we explained to the mother that the focus of our training was directly on fathers, she accompanied us to the front yard where the father was grooming his hedges. At our approach, he stopped his work and admitted that he felt reluctant to be involved with his child who had severe ASD. "I can work in my yard and accomplish great things. Our yard is the pride of the neighborhood. I can spend the same amount of time, or even more, with my son, and nothing changes. It makes no difference." Grateful for the father's candidness, we were able to convince him to participate in our program. Even though his son's progress was slow, the son responded positively, and the father found that he could successfully execute the play-based intervention and actually "had fun" doing it. This had unexpected generalization effects: not only did the father become more involved with his child at home, but he also eventually replaced his wife as the family's school liaison and primary vocal advocate. This is a clear example of how empowering fathers can enhance their self-efficacy and produce positive outcomes for the family.

Effects of Paternal Stress

It is well-known that raising a child with ASD can be very stressful (Hall & Graff, 2011; Little, 2013). In their study of parents of children with ASD, Hastings et al. (2005) found that fathers' stress was positively correlated with maternal anxiety and depression and that maternal and paternal depression significantly predicted partner stress. These findings were similar to those of Kayfitz, Gragg, and Orr (2010) who noted that fathers', but not mothers', positive experiences were negatively related to their partners' reports of parenting stress. Although these results are preliminary, they show that focusing on mothers at the exclusion of fathers only "paints half of the picture" because the marital relationship influences the family as a whole. Thus, if parental stress is not examined, there is no opportunity to intervene appropriately when needed.

Indeed, evidence demonstrates that fathers and mothers differ in their psychological experiences (e.g., stress, reactions, and expression of stress and anxiety) related to their child with ASD. In order to define the experiences and reactions of fathers to an ASD diagnosis, Hastings and colleagues (2005) have focused on fathers and report that fathers employ different coping strategies for stress than mothers when raising a child with ASD. They and others also report that rates of depression, anxiety, and overall distress for fathers differ from those of mothers (Davis & Carter, 2008). Our clinical experiences have confirmed these findings and revealed that while mothers may overtly express stress, fathers also experience it but often remain silent. For example, we found that both mothers and fathers scored over the 90th percentile on the Parenting Stress Index even though the fathers did not appear to be or stressed or verbalize this emotion (Bendixen, Elder, Donaldson, Kairella, Valcante, & Ferdig, 2011). We also observed that mothers were more likely to admit that they were depressed, whereas fathers reacted to depression in other ways, such as working more outside the home. This has implications for healthcare providers who may have to "dig deeper" to identify stress and depression in fathers. They may also find that interventions for addressing depression and lowering stress may need to be tailored with fathers in mind.

Father Reactions to an ASD Diagnosis

In addition to what has already been mentioned, we have noted that fathers may react and adapt differently to an ASD diagnosis than mothers. While gender differences in reaction and adaptation to an ASD diagnosis are not well-documented in the literature, there are important clinical implications, as noted in the following vignette:

Case Vignette

Johnny was born after a normal pregnancy, labor, and delivery to John and Melissa. The parents had tried for years to conceive and both were in their mid-thirties. They had been thrilled to learn not only of the pregnancy but that they were having a boy. John, like many expectant fathers, set about making future plans for college, baseball, soccer, and father-son campouts. What fun they would have together! When Johnny was about 15 months old, Melissa noted that he did not act quite like the other children at the playground: he was nonverbal, avoided direct eye contact, used her hand like a tool to reach things he wanted, and had great difficulty with changes in routine. John, on the other hand, who was a brilliant engineer, was not concerned and even reminded Melissa that he did not speak until he was 4 years old. Several months passed and Melissa's concern mounted. John traveled frequently with his work, and Melissa often found herself alone trying to socially engage her son and manage his tantrums.

As illustrated by this case vignette (where the names are fictitious but the story is not), one of the first challenges for parents of children with ASD is acquiring and accepting an ASD diagnosis. Often mothers are the first to suspect that there is abnormal development before an official diagnosis is made and that fathers are more reticent to accept an ASD diagnosis. This may be because, in many cases like our vignette, mothers are typically more involved in the day-to-day caregiving and thus may be more sensitive in discerning communication and socialization delays as well as behavioral problems. Second, we have observed that fathers may initially dismiss maternal concerns and, as in the case vignette, explain that they were also "slow to talk" and socially shy and awkward when they were young. Finally, Ingersoll and Hamrick (2011) explain that some fathers of children with ASD may express the broader autism phenotype (BAP), making it difficult for them to recognize the core features of ASD in their children, particularly the deficits in social and communication skills.

However, once the diagnosis is made, both parents may experience a period of mourning over the loss of their "perfect child" or the one they had imagined. For the father in our vignette, he had to accept the fact that his son might not go to college or achieve other high academic goals. Learning to accept this reality was complicated by the fact that, unlike some other developmental and neurological childhood disorders, children with ASD are frequently physically normal and even exceptionally attractive. His mother later explained, "God knew what he was doing when he created our son. He understood how challenging it would be so He made him really cute."

In addition to the initial denial and subsequent mourning, fathers often go through other phases similar to those described by Kubler-Ross (1969): denial, anger, bargaining, depression, and acceptance. Keeping these phases and related reactions in mind, it is particularly important for healthcare providers to understand that many paternal reactions are actually a normal and expected part of the grieving process. A common example is anger that may even be targeted at those trying to help the family. Rather than reacting to the anger, well-informed providers can be instrumental in helping fathers as well as mothers navigate through the grieving process to access the situation and recalibrate to what Ross and Kessler (2007) refer to as a "new normal." In our experience, we have also noted that fathers may have more difficulty moving past the denial phase than mothers.

Because fathers can play a significant role in their child's development, it is important to help them through the grieving process in a way they feel is beneficial. For example, clinicians can encourage fathers to assume and maintain key roles rather than conclude that "mothers do it better." In our experience, fathers require concrete direction about techniques they can use with their child, as well as evidence that the techniques will make a difference. Once again, much of what we know about father involvement comes from anecdotal reports and observations such as ours. This is because most parent training studies with empirical data usually involve only mothers and the word "parent" is misleading. Thus, we have limited scientific evidence about fathers and the potential impact they can have. However, preliminary evidence suggests that fathers may be able to positively influence their children's development, and father contributions to child development may even go beyond those made by mothers (Pleck & Masciadrelli, 2004).

Applying Male Learning Principles

In addition to limited reports regarding father-focused parent training, there is evidence from clinical practice and the literature that fathers and mothers may not learn in the same manner or benefit equally from certain popular parent training modalities. In fact, research confirms that gender plays a role in how individuals obtain knowledge. In a self-report investigative study conducted at a Midwestern University in the United States, researchers used a questionnaire with six domains, realistic, investigative, artistic, social, enterprising, and conventional, each with four variables—performance accomplishments, vicarious learning, social persuasion, and physiological arousal to determine the influence of gender on learning. Men reported greater learning experiences in the traditionally masculine *realistic* and *investigative* domains, while women's learning experiences were reported as predominantly *social*, a traditionally female domain. Similarly, in a Canadian study that assessed groups of students from grades 5, 8, and 11, Hunter, Gambell, and Randhawa (2005) revealed that in all male or predominantly male groups, language use was significantly less than in groups made up of all or predominantly females. They concluded that the education system is primarily focused on oral and aural learning skills favoring female learners. This finding suggests that parent training approaches that are highly dependent on verbal instruction may be more effective if they include written materials and examples to which fathers can relate. In a more geographically diverse study, Honigsfeld and Dunn (2003) looked at high school students from five countries including Bermuda, Brunei, Hungary, Sweden, and New Zealand to determine differences in gender learning styles in varied nations. They found that males showed significantly more kinesthetic and peer-oriented learning styles than females, while females tended to be more auditory learners, self-motivated, persistent, and responsible than male learners. This implies that fathers may benefit from participation with other fathers and interventions that focus on interaction/action as opposed to communication/relatedness.

In addition, females may use more words and have better listening skills, but along with higher scores in math and science, males obtain route knowledge from landmarks more rapidly and demonstrate greater spatial cognition than females (Cutmore, Hine, Maberly, Langford, & Hawgood, 2000; Driscoll, Hamilton, Yeo, Brooks, & Sutherland, 2005). According to the research conducted by Driscoll et al. (2005), the latter may be in part due to circulating testosterone levels. Whatever the reason behind the different learning styles, recognizing and addressing these gender differences is imperative and has implications for future research about how best to help fathers intervene to enhance communication and socialization in their children with ASD.

Fathers as Effective Interveners

Understanding the influence of male learning principles and recognizing the important roles that fathers can have in child development lead to further examination of strategies that can be considered to increase father involvement. Play-based interventions may be particularly appealing to fathers and serve as a means of empowering them to intervene in ways that promote child socialization and language development. In fact, Flippin and Crasis (2011) note in their critical review that fathers may be uniquely suited to enhance play skills. Lamb (1981) also note that there is ample evidence that fathers tend to specialize in play whereas mothers focus on caretaking and nurturance. They further assert that boisterous, stimulating, and emotionally arousing play is more a characteristic of father-child play and is especially "salient" for the children (Lamb, Frodi, Hwang, & Frodi, 1983).

Acquiring strategies that promote language development is also particularly important for fathers who typically spend less time with their children than mothers and thus may be less familiar with their children's language competencies. This may result in fathers using more directives, wh-questions, and imperatives that can challenge young children (Lamb & Tamis-Lemonda, 2004). We found in our work that children with ASD often have difficulty processing wh-questions and can become very frustrated by directives and imperatives that they may not fully understand or be given adequate time to respond to.

We considered these findings related to fathers, play, and language development when we developed and tested our in-home father intervention for promoting socialization and language development in young children with ASD (Elder et al., 2010). The intervention targeted four skills: following the child's lead (rather than directing the child), imitating the child with much animation, commenting on the child's actions, and waiting expectantly for child responses. We video-recorded all play sessions with fathers and evaluated the father's acquisition of the target skills twice a week for 12 weeks. We found that playbacks of video recordings and video-recorded examples of other fathers applying the target skills were particularly well-received by fathers. In addition to video playbacks, graphs were used to illustrate progress in the fathers' learned behaviors and child outcomes. This concrete visual evidence was of particular interest to the fathers in this study—a finding that concurs with information found in the studies cited above. Indeed, the use of visual support such as graphs and video demonstrations may be more helpful than verbal explanations when working with fathers.

Results from 18 dyads showed significant increases in frequencies of fathers' imitation with animation, expectant waiting, and commenting on the child. Child social initiating rates during play increased significantly as well as child non-speech vocalizations. Mothers, who received their training from the fathers rather than our team, showed significant increases in frequencies of imitation with animation, expectant waiting, and following the child's lead. Child behaviors had similar results for father and mother sessions. Results from this as well as an earlier NIH-funded father-focused study (Elder, Valcante, Yarandi, White, & Elder, 2005) demonstrated that fathers could help their children with ASD improve in the areas of language and social skills through naturally occurring play interactions (Elder et al., 2010).

In addition to these quantitative findings, we also made other important observations. For example, one child with ASD responded to his father's imitations and roughhouse play by making eye contact and saying "Daddy" to the father for the first time. This experience led to the father stating that he felt the intervention was effective and that he would engage in the target skills on a regular basis with his child. In other clinical experiences, we have observed that when fathers feel that what they do is effective, they are more likely to co-parent, which can lessen the maternal workload and stress and increase family cohesion. Further, Allen and Daly (2007) reported that higher levels of father involvement in general were associated with a variety of positive outcomes for children with autism, including improved cognitive development and physical health.

We gained additional insight about fathers by adding a qualitative arm to our in-home study (Donaldson, Elder, Self, & Christie, 2011). Through this work, we were able to more fully describe fathers' perceptions of their parental roles, relationships with their children with ASD, and participation in the in-home training program. In-depth semi-structured interviews with ten fathers were conducted at home, video-recorded, transcribed, and reviewed for common themes and significant statements. We identified several common themes that inform the current discussion related to empowering fathers. These themes included the importance of accepting the diagnosis, sharing time with the child, having a close relationship, and concerns and hope for the future. We also noted that communication between fathers and their children appeared to be the key to what fathers considered to be a more meaningful relationship even if the child was predominantly nonverbal. These fathers reported other ways of effective communicating including more time spent playing or just being with the child either at home or during outside activities.

Instilling Hope through Empowerment

We also found that trained and empowered fathers expressed a more positive outlook and hope for the future. The importance of hope is well-documented in the literature, and there are indications that parental optimism may have effects that extend beyond the psychological well-being of the parent (Ekas, Lickenhrock, & Whitman, 2010). For example, Durand (2001) studied how parental optimism/pessimism impacts the development of later challenging behaviors in young children with cognitive and/or developmental disabilities. This longitudinal study measured a number of parental variables that were thought to predict the development of severe behavior problems. They determined that the best predictor was a measure of parental optimism; that is, parents who had less confidence in their ability to influence their children's behavior by age 3 were more likely to have children with difficult behaviors later in life.

This finding leads to several other considerations that warrant further investigation. First, there is the possibility that parents with more confidence may have better natural skills at interacting with children with ASD. Second, parents with more confidence may simply try harder to engage with their child and are likely to reach out to receive the appropriate professional training for their child. Third, there is the likely notion that it may be a combination of these.

Recommendations

Findings from the literature related to fathers and male learning, father intervention research, and anecdotal accounts from clinical practice suggest several recommendations for clinical practice and highlight areas needing future research to enhance our understanding of fathers and the importance of their parental roles (Table 16.1).

Table 16.1 Recommendations for clinical practice and future research

Recommendations	
1	Actively involve fathers from the beginning and recognize that fathers' reactions related to diagnosis and treatment may differ from those of mothers
2	Understand that fathers may not express their stress as overtly as mothers and yet, they, like mothers, are likely to need assistance in recognizing and managing it
3	Involve both fathers and mothers in parent training programs
4	Tailor parent training interventions to incorporate male learning principles that are less verbally dependent, use more visual examples, and provide concrete feedback, particularly related to successful implementation
5	Encourage fathers to employ play and roughhousing when appropriate to facilitate social interactions
6	Recognize the importance of instilling hope that may serve to make the father role more “‘salient” and empowering

Conclusion

As discussed, recent societal shifts toward more active father involvement and co-parenting indicate an urgent need to further understand the father's role in child development and how to enhance healthy father-child interactions. This is particularly true for fathers of children with ASD who are rarely included in reported parent training studies, and yet preliminary studies indicate that these fathers may be very effective interveners. Clearly, more research is needed since educated fathers are well-positioned to assume critical roles for improving the quality of life for their children with ASD and subsequently their entire families.

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The Incredible Years® Group-Based Parenting Program for Young Children with Autism Spectrum Disorder

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Abstract

A new *Incredible Years*® (*IY*) Parent Program for preschool children with autism spectrum disorder (ASD) and language delays (ages 2–5) was recently developed and piloted. It is designed to either complement the 18–20-week *IY* Preschool Basic Program for parent groups where children have a mix of behavioral and developmental challenges or to be used independently in a combination of 14–18-week group-based course plus individual home coaching for parents with children with ASD. This chapter includes a summary of the rationale for IY parent program content that promotes social communication and language development, positive relationships and social skills, emotion- and self-regulation, and positive behavior management. The *IY* collaborative approaches for training and supporting parents are also presented. These approaches include mediating vignettes of children with ASD to trigger parent self-reflection; problem-solving and experiential practices with child-directed play and imitation; communicating with children with and without language skills; practicing parenting skills such as persistence, social and emotion coaching, gesturing, modeling, and prompting; incorporating social sensory routines; engaging in pretend play and using puppets to enhance joint play, social communication, and empathy; and learning the ABCs for managing behavior, including the concepts of antecedent accommodations and environmental modification to promote appropriate behavior, teaching replacement behaviors, and reinforcing target behaviors by providing praise, incentives, and sensory activities as rewarding consequences. Parents learn to identify behaviors that can be ignored and how to use differential attention

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Carolyn Webster-Stratton has disclosed a potential conflict of interest due to the fact she provides training and instructional materials for these treatment programs and therefore stands to gain financially from a positive review. This interest has been disclosed to the University of Washington and has been managed consistent with federal and university policy.

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_17

and get into their child's attention spotlight. The importance of parent goal setting, self-monitoring, home activities, stress management, self-care, and building parent support networks is emphasized.

Introduction

Children with autism spectrum disorder (ASD) have exceptionally diverse service needs. Compared to typically developing children and those with other developmental disabilities, children with ASD can have higher rates of disruptive behaviors (Hartley, Sikora, & McCoy, 2008), atypical sleep patterns (Limoges, Mottron, Bolduc, Berthiaume, & Godbout, 2005), gastrointestinal problems (Nikolov et al., 2009), anxiety and other psychiatric comorbidities (Simonoff et al., 2008), unique reactions to sensory stimuli (Baranek, David, Poe, Stone, & Watson, 2006), and self-regulatory difficulties from an early age (Gomez & Baird, 2005). As many as 50% of children with ASD exhibit behavioral problems, including tantrums, noncompliance, aggression, and self-injury (Mazurek, Kanne, & Wodka, 2013). These challenging behaviors interfere with children's ability to benefit from parents' socialization efforts. Moreover, parent uncertainty on how to manage these challenging behavior problems adds to their high levels of stress (Estes et al., 2013; Koegel, 1992; Schieve, Blumberg, Rice, Visser, & Boyle, 2007), which in turn contribute to other troubling outcomes such as poor family quality of life (Lee et al., 2009), depression (Phetrasuwan & Shandor Miles, 2009), family isolation, and lack of support (Osborne, McHugh, Saunders, & Reed, 2008).

Intervention programs for young children with ASD are increasingly available (Boyd, Odom, Humphreys, & Sam, 2010; Wong et al., 2013). Clinician-implemented intervention studies have resulted in significant positive effects with regard to children's developmental level and adaptive functioning (Dawson, Rogers, & Munson, 2010; Landa, Holman, O'Neill, & Stuart, 2011; Landa & Kalb, 2012). Interventions that target joint attention, social play, parental responsiveness, imitation skills, and parent-mediated social communication therapy have been shown to develop communication abilities in children with ASD (Kasari, Paparella, Freeman, & Jahromi, 2008; Pickles et al., 2016; Poon, Watson, Baranek, & Poe, 2012; Siller & Sigman, 2008). Parent involvement has been recognized as a potentially effective method to deliver treatment to children with ASD and to improve sustainability of results (Matson, Mahan, & Matson, 2009). For example, an evaluation of a community−/home-based parent-implemented early intervention reported significant gains in child social communication and receptive language skills, compared to a clinic sample (Wetherby et al., 2014). Randomized controlled trials of a parent-implemented early intervention reported an improvement in parent-child communication (Green, Charman, & McConachie, 2010; Rogers et al., 2012), which was sustained in long-term follow-up (Pickles et al., 2016). Overall, interventions which target parent-child interactions within their natural environments have produced encouraging improvements in children's social communication skills and other core ASD symptoms (See Chaps. 12 and 13; Stahmer & Pellecchia, 2015; Wetherby et al., 2014). However, some studies with parent-implemented early interventions have reported less effective child outcomes compared with those implemented by clinicians (Oono, Honey, & McConachie, 2013; Rogers, Estes, et al., 2012; Stahmer & Pellecchia, 2015).

There are several possible reasons for differences in child outcomes in parent- versus clinician-implemented early interventions in existing research. These include the primary intervention approach focusing on the clinician-child curriculum more than the parent-child implementation or being a brief, didactic parent education approach rather than a therapeutic, collaborative, comprehensive approach (Stahmer & Pellecchia, 2015). Furthermore, parent interventions aimed at very young children with ASD have not necessarily focused on teaching parents specific evidence-based active strategies for managing their children's self-regulation problems. In general, early intervention research has failed to attend to parent stress, depression, and lack of support or to report on the inclusion of fathers or other caregivers in the intervention (Dababnah & Parish, 2016a). Such approaches are needed for stressed parents of children with ASD to adhere to complex and time-intensive intervention methods (Stahmer & Pellecchia, 2015). In fact, parent outcomes, such as stress, depression, and parenting competence, are rarely measured in ASD early intervention research (Dababnah, 2016; Dababnah & Parish, 2016a, 2016b; Karst & Van Hecke, 2012; Stahmer & Pellecchia, 2015). A recent Cochrane Collaboration review reported inconclusive results with regard to reduction of parent stress in early ASD interventions (Oono et al., 2013). Clearly, there is an urgent need to develop and test more cost-effective interventions that address child behavior and parent well-being in families raising young children with ASD.

Evidence-based parenting programs designed to reduce challenging behavior in children with conduct problems and ADHD, as well as to improve parent stress, have been developed over several decades. In particular, group-based parent programs have been shown to improve parent psychosocial well-being, reduce stress, and build parent confidence and support networks, as well as improve children's social competence and reduce conduct problems. For example, a meta-analysis of group-based parent training programs reported significant improvements in parent depression and confidence, which were maintained at a 6-month follow-up (Barlow, Smailagic, Huband, Roloff, & Bennett, 2012). Evidence-based parent training programs also hold promise to improve the outcomes of children with ASD and their families (Brookman-Frazee, Stahmer, Baker-Ericzen, & Tsai, 2006). In one recent study (Bearss et al., 2016), a 24-week randomized trial compared parent training with parent education. Results indicated parent training was superior to parent education in reducing disruptive behavior in children with ASD, although the clinical significance of the improvement was unclear.

In this chapter, we will discuss how *The Incredible Years*® *(IY) Preschool Basic Parent Program (IY-BASIC),* an evidence-based parent training program, originally developed to prevent and treat children with conduct problems, hyperactivity, anxiety, and other social issues (Webster-Stratton & Reid, 2010; Webster-Stratton, Reid, & Hammond, 2004), was tailored and revised for parents of children with ASD and language delays. In the following sections, we outline basic content components of a newly-revised and adapted version of *IY-ASD* specifically targeting young children with ASD and the group-based collaborative process and principles of delivering the program. Content and research related to the *IY-BASIC* and *IY-ASD* programs are briefly summarized.

The Incredible Years® (*IY-BASIC*) Program

The Incredible Years (IY-BASIC) Toddler and Preschool Programs targets children ages 2–5 years and their families (Webster-Stratton, 2011). Depending on whether the program is using the prevention or treatment protocols, parents meet with trained leaders in groups for weekly 2-h sessions over a 14–20-week period. *IY-BASIC* is based on attachment theories (Ainsworth, 1974; Bowlby, 1988), social learning theory (Patterson, 1995), social cognitive theory (Bandura, 1986), and developmental stage theories (Piaget, 1962). With a foundation of building parent-child attachment through child-directed play, parents learn strategies to model appropriate social communication interactions; coach their children's persistence, social, emotional, and academic skills; manage parent stress; stay calm while managing children's misbehavior; and broaden their support networks. Additionally, through the use of role plays, video vignettes, coaching methods, group support, and collaborative group discussion sessions, parents gain skills to challenge their negative cognitions, increase problem-solving abilities, and enhance positive communication with their partners and children. Three decades of evidence by the developer and others (Webster-Stratton, 2012a) utilizing randomized controlled trials of *IY* Parent Programs have pointed to improved levels of parent stress, depression, and coping skills, as well as decreased negative child outcomes such as aggressive behavior in a broad array of ethnically and socioeconomically diverse populations (Jones, Daley, Hutchings, Bywater, & Eames, 2007; Linares, Montalto, Min, & Oza, 2006; Reid, Webster-Stratton, & Beauchaine, 2001). A recent meta-analysis of 50 studies indicated positive parent and child outcomes for both the treatment and prevention protocols (Menting, Orobio de Castro, & Matthys, 2013). Cost-effectiveness analyses have also been performed with positive results (Edwards, O'Ceilleachair, Bywater, Hughes, & Hutchings, 2007; O'Neill, McGilloway, Donnelly, Bywater, & Kelly, 2013).

Several studies have been conducted to pilot *IY-BASIC* with parents of children with ASD and other developmental disorders (Garcia & Turk, 2007; McIntyre, 2008; Roberts & Pickering, 2010). These results indicated a reduction in child behavior problems and improved parent mental health. In a recent pilot trial of *IY-BASIC* with parents of preschoolers with ASD, participant acceptability and confidence was high, and parent stress was significantly reduced after completion of the program (Dababnah & Parish, 2016c). Furthermore, parents reported that the *IY-BASIC* program helped them address the needs of their families as a whole (including the child with ASD, other children without ASD, parents, and extended family members) and that the naturalistic, child-directed play-based nature of *IY-BASIC* allowed some of the participants a temporary respite from other highly structured ASD therapies. The program was flexible enough to allow group leaders to individualize content to participants' specific family and child needs, particularly addressing child emotion regulation, anxiety challenges, and sensory-seeking behaviors. Nonetheless, some aspects of the *IY-BASIC* program, such as program videos, time-out strategies for child noncompliance, and parent self-care, were insufficient for some participants in the pilot trial. The parents in this research overwhelmingly requested a longer program in order to practice skills gained in the program, particularly related to parent stress and family burden. In total, these preliminary studies suggest the *IY-BASIC* program has promising implications for future use with parents of young children with ASD.

IY Autism Spectrum and Language Delays Program for Parents with Preschool Children (IY-ASD)

In order to address the specific needs of parents raising children with ASD, a new *IY* program was adapted, *IY* for Preschool Children on the Autism Spectrum or with Language Delays *(IY-ASD).* It was designed to complement the *IY-BASIC* for groups where children (2–5 years) have a mix of behavior and developmental problems. Alternatively, *IY-ASD* can be used independently in a 14–18, 2-h weekly course for a group of 8–10 parents with children who have ASD. In order to deliver *IY-ASD,* group leaders must first be trained in *IY-BASIC* and have experience with this program. They then participate in 23 additional days of training and practice with *IY-ASD*. It is recommended that group leaders have graduate degrees in psychology, social work, or education. Effective *IY-ASD* group leaders must also possess a broad understanding of ASD, including its symptoms and intervention approaches, as well as experience working with children with ASD and their families. Finally, it is critical that group leaders have knowledge of local resources in order to connect families to community supports.

One pilot study evaluating *IY-ASD* was recently published (Hutchings, Pearson-Blunt, Pasteur, Healy, & Williams, 2016), and while the sample size was small ($N = 9$), parent report, observational assessments, and semi-structured interviews indicated positive results. High satisfaction scores by participants supported the findings of Dababnah and Parish (2016c) with the original *IY-BASIC* program. In the revised program, parents found the video vignettes of children with ASD particularly helpful, in contrast to the earlier study with the *IY-BASIC* program, where vignettes were rated lower. Parents also reported that the group discussion and support were very useful and provided an opportunity to share problems and solutions with parents in similar situations. Results also showed significant pre-post reductions in behavior and peer problems and an increase in pro-social behavior.

IY-ASD is currently being evaluated in two sites. Preliminary pre-post analyses have found child-related parenting stress; and child irritability, agitation, lethargy, and social withdrawal significantly decreased at posttest (Dababnah & Olsen, in preparation). Acceptability was high among graduates of the program, particularly regarding the program's play-based approach, the specific skills in improving parent and child emotion regulation, and the opportunities for social support and peer learning. Participants' most common recommendation was to extend the program's duration.

Differences and Similarities with *the Incredible Years* Preschool Basic Parent Program

The *IY-ASD* program follows the *IY-BASIC* approach by focusing on developing positive parent-child relationships, building responsive parenting skills, and promoting appropriate child behavior. In addition, *IY-ASD* similarly focuses on reducing parent stress and barriers to participation by offering support to families such as childcare, meals, and transportation. Support can include assisting parents to access the Family Medical Leave Act (FMLA) in order to maintain employment while participating in the program. *IY-ASD* differs from *IY-BASIC* in that its content has been modified to address ASD-specific areas of emphasis (Table 17.1 compares *IY-BASIC* with the *IY-ASD* program). Based on research and direct parent feedback, video vignettes depicting parents working with their children with ASD are now available. The content has an increased focus on imitation of child behavior and use of sensory routines as a means of establishing joint attention; methods for promoting pretend play to build language, empathy, and social skills; and development of self-regulation. Due to the communication difficulties of children with ASD, parents also learn to assess and coach their child's language and social communication. Use of visual supports is demonstrated by group leaders and encouraged for all children on the spectrum.

IY-ASD emphasizes a functional approach to behavior change, and parents learn the "ABCs" of behavior change. More attention is given to the antecedents of behavior change than in the *IY-BASIC* program. Methods are introduced for identifying reasons for, or the function of, behaviors, such as obtaining preferences or escaping nonpreferences, by recognizing the antecedents (A) that set up a behavior (B) and the consequences (C) that maintain it. Then, antecedent accommodations and reinforcing consequences to promote appropriate and/or replacement behaviors are discussed, in addition to strategies to decrease inappropriate behavior.

Another key difference between *IY-ASD* and *IY-BASIC* is that *IY-ASD* does not present the use of time-out as a primary discipline strategy. Children with ASD often avoid social interaction. Time-out can inadvertently reinforce problem behaviors by rewarding those behaviors with escape from the nonpreferred social interaction. Rather, *IY-ASD* focuses on ignoring inappropriate behavior and redirecting and reengaging when the child is calm. This approach promotes attentive parenting, as parents learn to monitor child behavior during an "ignore" period and immediately reengage once the child has calmed. It also supports development of the child's emotion regulation by refraining from interrupting the child's regulatory process and by reinforcing the state of being calm.

Lastly, due to the isolation felt by many parents raising a child with ASD, increased emphasis on support and network building is critical. Parents of children with ASD often report being unable to take their children into community settings due to their behavior. *IY-ASD* promotes relationships with other families experiencing similar circumstances and networking to build understanding of ASD within the community and to increase advocacy for resources. Children with ASD also often require time-consuming and

Table 17.1 How IY-ASD differs from basic IY parenting program

IY-BASIC preschool program (3–5 years)	IY Autism spectrum and language delays program (2–5 years)
Topics 1. Strengthening children's social skills, emotional regulation, and school readiness 2. Using praise and incentives to encourage cooperative behavior 3. Positive discipline: Rules, routines, and effective limit setting 4. Handling misbehavior (ignoring, time-out, consequences, and problem-solving)	*Topics* 1. Increased focus on coaching language development, imitation and sensory routines, social communication, use of pretend play to promote empathy and social skills, and promoting self-regulation skills 2. Enhanced focus on self-care and building support group 3. Older (4–5 years old) verbal children with conduct problems: Families can continue with program 4 of basic *IY* program to discuss time-out and problem-solving (not included in *IY-ASD* program)
Basic *IY* vignettes	New *IY-ASD* vignettes depict children with ASD. Additional vignettes from basic *IY* may be added if parents in the group need more help with behavior management and problem-solving
Program dosage (18–20 sessions)	(14–18 plus sessions) increased dosage often needed to adequately cover the material since there are more practices and discussions to tailor the strategies to each unique child
Group size: 10–12 parents	Smaller group size: 6–8 parents plus partners or other family members
Group leader: Knowledgeable in child Development	Group leader: Knowledgeable and experienced in ASD practice, local ASD-specific supports, and functional approaches to behavior change
Key group teaching/learning methods (behavioral practice, principle building, values exercises, tailoring to meet cultural and developmental issues, home activities)	1. Increased teaching about ASD and ways to use visual support including picture schedules, choice cards, command, and feeling cards 2. Tailoring group practices according to children's communication stage; imitation as a means to gain attention, learning alternative incentives to motivate children with ASD (e.g., sensory activities) 3. More explicit teaching about prompting, use of nonverbal signals, and the functions of behavior and ABCs of behavior change 4. More practice with use of pretend play and puppet use as well as self-regulation strategies
Alliance-building techniques (collaborative learning, buddy calls, weekly leader support calls, praise to parents, incentives for parents)	All standard alliance-building techniques apply to this population but increased efforts to help build families support systems and reduce their stress by working on self-care and promoting weekly buddy calls and peer dates with other parents. Regular emails, texts, and calls from group leaders are essential
Food, transportation, daycare	No adaptations needed but essential to offer these for this population in order to reduce barriers to participation
Core model does not offer home visits	Providing home visits to coach parent-child interactions using coach home visit manuals and additional DVD vignettes as needed; use these to make up missed sessions or show additional vignettes or do coached practice with the children
Core model does not address collaboration with educators and other professionals for coordination of care	Coordinate with educators and therapists for developing behavior plans with agreed upon goals for child's target behaviors. Consult with medical providers to understand effects of medical issues on child behavior and parent stress
Core model suggests use of IY advance, child, and teacher programs for children with diagnoses or very high risk families	Consider additional IY programs: Advance program to teach anger and depression management and problem-solving steps Child social, emotional and problem solving skills program ("dinosaur school") offered alongside parent program Offer follow-up training in the *Helping Preschool Children with Autism: Teachers and Parents as Partners* to help parents learn how to promote positive peer interactions and social communication with 2–3 children

costly neurodevelopmental and medical interventions. Parents need support to advocate for and provide these therapies to their children. Group leaders must be knowledgeable about community resources and assist families in accessing them both during and after the program. Efforts to coordinate care among educators, therapists, and medical providers are also essential.

The Incredible Years Program Content

This section briefly summarizes each of the eight parts of *IY-ASD*, with some examples from the video vignettes and the rationale for the content with this population. In addition, the foundational principles of the program are discussed, such as the importance of the collaborative process and building family support networks to reduce family stress.

Part I: Child-directed narrated play promotes positive relationships All *Incredible Years*® Parent Programs have at their foundation child-directed play. This is important because young children's key language, social, and emotional learning come from watching, imitating, and interacting with parents. However, children with ASD are often more interested in interacting with nonsocial objects than with people. Therefore, parents learn how to increase their children's attentional focus with them by following their interests, getting into their attentional spotlight, and making their play interactions more rewarding. By linking the child's favorite activity to social interactions with parents, the child will be more motivated to interact with them (Ingersoll & Gergans, 2007; Rogers & Vismara, 2008; Sussman, 2012). Thus, the parent can facilitate joint play and create more opportunities for their child to learn from them.

Children with ASD often exhibit atypical or unconventional play behaviors (e.g., repetitive or nonfunctional play). Their sensory needs may influence the way they play, and they may chew or smell toys, rub them against their face, or repetitively line them up in rows to make a pattern and become upset if someone tries to move them. For this reason, parents must develop several strategies to engage their children in interactive play. Parents learn to follow their child's lead and utilize his or her interests during play and to describe and comment on the child's actions. Key concepts in Part I of *IY-ASD* include engaging in child-directed play, narrating and imitating play, waiting for the child to indicate choice, considering positioning for face-to-face interaction, encouraging verbal and nonverbal communication, and modeling and prompting play behaviors and language. The concepts are individualized using parents' observations of their own child's play and language skills, preferred activities, and what seems to motivate their children. Parents share their children's favorite toys and foods, any hyper- or hyposensitivities (e.g., sights, sounds, touch, and smells), and what kinds of physical or sensory routines they enjoy (e.g., running, jumping, hide-and-seek games, spinning, songs). This group-sharing process helps parents see similarities and differences in their children's sensory preferences, and parents begin to develop a support group around their children's shared experiences.

Part II: Pre-academic coaching promotes language development and school readiness After parents have learned how to get into their child's "attention spotlight" by being child-directed and using descriptive commenting, imitation, and modeling, in Part II they learn another type of descriptive commenting called *pre-academic coaching*. This coaching method is used for children who have begun communicating with gestures, sounds, and some back-and-forth exchanges. In essence, parents learn to turn up the volume of their communication and attention by describing pre-academic concepts such as colors, shapes, names of objects, sounds, numbers, and positions during play. For children with no language, parents incorporate pictures of objects, shapes, colors, sounds, and actions to communicate the concepts. The use of visual supports is encouraged for all children to support both expressive and receptive language development. Additionally, visual supports can promote child engagement, making choices, and understanding of routines or expectations. Group leaders can provide parents with tailor-made books with targeted pictures illustrating such things as a child's favorite toys or activities (e.g., train, blocks, bubbles), actions (e.g., sit, play, read, tickle), common routines (e.g., wash hands, eat dinner), clothing (e.g., hat, coat, shoes), or food items (e.g., apple, cereal).

Children with ASD often get frustrated when their pattern or routine is disrupted, or they are trying something new. They may also become frustrated about their inability to communicate or be understood by others. They may give up easily and revert to solitary play or repetitive actions that are more comfortable. In Part II, parents learn a second type of coaching called *persistence coaching* that is used to help scaffold a child's ability to stay focused and persist with a difficult learning activity, even when frustrated or anxious. Parents name the child's internal state when she/he is being patient, trying again, staying calm, concentrating, persisting with a challenging task, or trying to engage in joint play. Parents explore how to support their children to persevere with tasks such as brushing their teeth, getting dressed, doing a puzzle, looking at a book, or initiating an interaction. Pairing pre-academic and persistence coaching, along with engaging in a child's favorite activities, is intended to expand children's communication abilities and improve school readiness.

Part III: Social coaching promotes friendship skills The ability to share, ask, help others, wait, initiate interactions, and take turns is fundamental to social development and social communication. Yet, these social behaviors are more difficult for children with ASD. The ability for these children to cooperate in give-and-take exchanges is difficult because they are far more interested in exploring their own nonsocial object and often do not have the language to ask for a turn. They may even be unaware of another child's desire for a turn or need for help, because they are less tuned into subtle communication of others' eyes, face, gestures, and tone of voice. The risk is that these children will continue to play alone, rather than draw others into their activities. This means that they will miss important learning opportunities provided from parents or peers in joint play. In Part III, parents learn to use *social coaching*, modeling social skills and prompting social communication in their play interactions. Parents learn how to help these children shift their attention from objects to other people by spotlighting others' needs and activities. Social coaching builds on the content in Parts I and II. Given the common challenges, children with ASD have with regard to social communication; this part of the program is one of the most complex. The major learning goals of this part of the program are:

- Using play and books, gesturing, prompting, and modeling to promote turn-taking skills.
- Introducing parents to the "ABCs" (antecedent, behavior, consequence) and function of a behavior. An example of teaching this concept is provided in Box 17.1.
- Increasing children's enjoyment of social interactions through shared sensory activities (e.g., dancing, bouncing on a trampoline, swinging).
- Prompting and enhancing face-to-face joint attention.

Parents learn how to use social coaching during play interactions with their child to encourage critical social skills. They learn that the same principles used during child-directed play can also be regularly used with daily family life routines, such as getting dressed for school and toilet training.

Box 17.1: Teaching Parents the ABCs of Social Behavior Change

The group leader shows parents a vignette of a father engaging his son's attention by playing with a red balloon, one of the boy's favorite games. This shared activity appears to be light-hearted play, but serious learning about social interaction is taking place as the child learns to ask for a turn, share, listen, and communicate with his father. First, the father holds the balloon next to

(continued)

Box 17.1: (continued)

his face to capture his son's attention and gain eye contact. Then he waits for his son to use his words to ask for what he wants. Holding up the prized balloon, which he knows his son will want, is the antecedent (A) that precedes the behavior the father wants to encourage. Once he gets his son's attention, he models and prompts the verbal requesting behavior he wants his son to learn by saying, "You can say, I want the balloon please." When the father gets the desired behavior (B) from his son, his verbal request, the father rewards his use of verbal or nonverbal language by giving him the balloon and praising his verbal request, which is the consequence (C). These are the ABCs of how parents turn a play interaction into a social communication learning opportunity. The function of the behavior is also discussed, which in this case is the child's desire to obtain a preferred object. After the video vignette has been paused several times for group discussion, the group leader sets up practice experiences with parent dyads, where one parent acts as their child, while the other is the parent using the ABC learning steps. Several more vignettes are shown to illustrate these interaction sequences, and then parents are given home activities that include completion of an ABC chart regarding their efforts to create a social learning opportunity during their play times.

Since children on the spectrum often enjoy sensory physical activities such as throwing and catching a balloon, dancing to music, bouncing on a trampoline, being chased, and swinging, parents learn how to use these motor play experiences to increase their children's internal motivation to play with them and create social coaching opportunities. As seen in the balloon example above, in order to prompt and enhance face-to-face joint attention, parents learn how to get into their child's attention spotlight (showing balloon) and motivate them to shift their gaze from objects to people and back again. By watching the video vignettes, parents learn the value of exaggerated facial expressions, getting down close to their child's face, making eye contact, prompting or modeling the desired behavior, and waiting for a response before giving the child what he wants and rewarding this behavior.

Part IV: Emotion coaching promotes emotional literacy In Part IV of the program, parents learn the importance of drawing attention to their child's feelings by using *emotion coaching*. This is helpful for all young children but especially for children on the autism spectrum. While children with ASD experience the full range of feelings, they often find it hard to share their emotions with others through language, facial expressions, or gestures. Parents start this coaching by naming their children's emotions at the time their child is experiencing them, which helps the child link the feeling word with an internal emotional state. The goal is for children to develop a feeling vocabulary, recognize their own feelings, and share them with others. The ultimate aim is for children to be able to recognize and respond sensitively to others' feelings. Moreover, supporting a child's emotional language eventually contributes to the development of emotional self-regulation, empathy, and secure attachment.

IY-ASD demonstrates several ways for parents to begin to build their child's feeling literacy. One method is through the use of pictures of feelings faces (e.g., mad, happy, excited, calm, frustrated), which children use to indicate their emotions. Parents learn the importance of describing and naming the feelings of book characters to help their children learn feeling words. Reading face to face also gives parents the opportunity to make eye contact and to model facial expressions and gestures or sound effects to represent the emotions they are naming. Parents learn to use social coaching in combination with emotion coaching, for example, taking turns when reading to point out a picture and using a partial prompt by pausing to let the child fill in the answer. Finally, physical games (e.g., water play, spinning) can be used to motivate a child's feeling vocabulary. Coaching children's unpleasant emotions is tricky because giving excessive attention to negative emotions can make the child more angry, frustrated, fearful, or sad. Therefore, parents are encouraged to give more attention to naming the "positive opposite" behaviors such as feeling calm, patient, brave, or happy. Parent's naming of uncomfortable feelings is paired with persistence coaching such as a positive coping statement. For example, saying, "*You are frustrated getting those shoes on, but you keep trying. You can do it*." When emotion coaching is done skillfully, this can strengthen a parent's relationship with their child and help the child feel understood. In total, these emotion coaching methods can be incorporated into parents' efforts to engage in positive, child-directed activities with their children.

Part V: Pretend play promotes empathy and social skills For young children with ASD, the world of pretend play does not always emerge naturally. In this part of the program, parents learn how to encourage their children's imaginary play skills. Studies have shown that when a child with ASD develops pretend play, his language abilities and social skills also increase (Rogers, Dawson, & Vismara, 2012). Pretend play with parents helps the parent and child engage in a shared experience, opens the door for powerful learning opportunities, and helps the child learn what others are feeling and thinking.

Group leaders help the parents discuss how to use pretend play to encourage empathy, emotion language, and social behaviors such as helping, sharing, waiting, and trading. The use of puppets, dolls, or other figures is another effective way parents can encourage children's imaginary play. In one video vignette, a boy has become so attached to his turtle puppet that the boy wants to take the puppet spinning with him. The father effectively builds his son's empathy and language skills by stopping the spinning game periodically to talk together about how the turtle is feeling while they are spinning. Because the boy is highly motivated to spin, stopping the spinning forces the child to verbally communicate and interact with both the turtle and his father. In another vignette, the mother uses a baby dinosaur puppet to express feelings of shyness and fear of coming out of his shell. The mother prompts her daughter with the words to help the puppet feel safe to come out and play. The mother models a gentle, friendly behavior, which leads the little girl to use more positive behavior that is reinforced by the mother. If a child does not have the language skills to respond verbally to the puppet, it is still good for the puppet to model the words involved in the social interaction. Parents can also structure interactions that involve nonverbal responses from their child (such as "Would you like to shake the puppet's hand?"). Echolalic responses also receive attention, rephrasing, and praise, as parents learn to reinforce successive approximations of desired behavior.

Part VI: Promoting children's self-regulation skills One of the major developmental tasks for all preschool children is to learn to manage their anger and develop emotional self-regulation skills. In Parts IV and V, parents have learned how emotion coaching, puppets, and pretend play can be especially helpful to gain their children's attention and build their emotion vocabulary. Once children are able to recognize and express their own feelings verbally, or with pictures and signs, then they can begin to understand feelings in others and express their own.

As emotional literacy and empathy slowly develop, parents can begin to teach children some self-calming strategies. Because children are visual thinkers, it continues to be effective to use pictures, books, puppets, and coaching methods discussed earlier in the program. In Part VI, parents learn scenarios designed to help children use visual tools such as a "calm down thermometer" and practice self-calming strategies such as positive imagery, self-talk words, and deep breathing. For example, parents view a video vignette where a father is helping his child learn about breathing by practicing taking big breaths while visualizing smelling a flower and blowing out a candle. This imaginary visualization, also shown on a picture cue card, helps children to stay calm and remember how to take deep breaths. Because this father has previously spent a lot of time teaching his son emotion vocabulary, he is ready to support his son to learn what the boy can do when he experiences feelings of anger, sadness, frustration, and anxiety. When the boy looks at another picture, he repeats the breathing strategy, and the father helps him understand how it helps him feel calm.

Part VII: Using praise and rewards to motivate children Children on the autism spectrum may seem unaware or less interested in their parent's pleasure, approval, or praise in response to what they say and do, signals that normally motivate most children. In this part of the program, parents learn they cannot be subtle or vague with praise; rather praise must be put in the spotlight by being more attractive, exciting, and clear for positive behaviors. Parents discuss methods to enhance praise with a warm tone or enthusiasm, smiles, eye contact, as well as gestures or specific language. For example, one of the vignettes shows a boy who has been rather aggressive with his cat. His parents give him attention and labeled praise whenever he is gentle with his cat in order to teach him what it means to be gentle. They help him understand the connection between his being gentle and the cat's happiness and willingness to stay with him. Their use of effective praise helps this boy develop empathy for his cat and understanding that his gentle behavior results in more positive consequences for himself.

Parents also learn how to add to the impact of praise by pairing it with tangible rewards such as their child's favorite stickers, bubbles, or special food items. Other powerful motivators are sensory physical activities such as spinning, running, jumping, chasing, riding on a parent's legs, or being tickled. These activities can be used as a reward for practicing a social communication skill or for using some self-regulation calming strategies.

Finally, the group leader helps parents learn how to praise and reward themselves and other family members for their parenting efforts. The leader starts group sessions by asking parents to share their successes and to think about how effectively they handled a particularly difficult situation. Parents learn how to formulate positive statements about themselves and to compliment each other. The group leader helps parents set up tangible rewards for their efforts, such as dinner out with a spouse or friend, a hot bath, or a good book, and encourages them to reward themselves for achieving their weekly goals. Prizes are given out at this session for parents completing their home assignments, which include self-care items such as bubble bath, chocolate, lotion, and gift certificates. This promotes a sense of parenting competence, helps parents reframe their experiences by focusing on positive aspects of their interactions and effort, and encourages the development of positive self-talk.

Part VIII: Effective limit setting and behavior management By this stage in the program (group session 11 or 12), parents have been encouraging and motivating their child's interest in pleasing and being with them through their use of child-directed play and engaging rewards. Parents have been learning and practicing the ABCs of behavior change and applying it to the goals they have set for their children. But just like any other child, at times a child with ASD will be defiant and refuse to comply with a parent's requests or prompts. Parents learn that children are not deliberately misbehaving but actually are biologically programmed to explore and test the limits as part of their development. This exploration stage is thought to help children develop a sense of independence and eventually self-control, both of which are goals for most parents. Moreover, for children with ASD and limited language, their resistance may stem from the fact they do not actually understand the parent's verbal instructions because the request is too complex or unclear.

In the final part of the program, parents learn ways to:

- Give positive, clear, simple, and necessary limits or instructions verbally and nonverbally.
- Transition their children to new activities using visual-auditory tools (such as buzzers,

music, sand timers, and songs), command cards, and positive reminders.
- Utilize proactive discipline approaches such as distractions, redirections, self-regulation prompts, and ignoring selected misbehaviors.
- Understand the principle of "differential attention."

Most parents need to give children extra time to understand what is happening and what they can do or say. Slowing down the pace is a key behavior management principle. Discussions of the function of behavior show how behavior is a means to an end. It is critical to identify whether a behavior is motivated by attention-seeking, a desire to obtain a favorite object or activity, an escape from something nonpreferred, or a sensory stimulation, in order to promote appropriate behaviors that meet the child's needs.

The Incredible Years Program Principles

The Incredible Years (*IY)* series are guided by a set of principles that allow parent programs to be flexible enough to permit adaptations for given family and cultural situations, parent skill levels, and children's developmental and communication abilities. The following section summarizes each principle and how the group leader uses each principle to support parents.

Principle 1: The Collaborative Model

The core value driving the *IY* program is that work with families should be experiential, self-reflective, and collaborative. In the collaborative model, the group leader does not set him/herself up as an "expert" dispensing advice about how caregivers should parent more effectively. With the root meaning of "to labor together," collaboration implies a reciprocal relationship based on utilizing equally the group leader's expertise and the parents' knowledge, strengths, and perspectives of their own children's communication and relationship difficulties (Webster-Stratton, 2012b). For instance, during *IY* sessions the group leader invites parents to share their experiences, thoughts, and feelings and engage in problem-solving. The collaborative group leader style is demonstrated by open communication patterns within the group and an attitude of acceptance toward all the families. By building a relationship based not on authority, but on group rapport, the group leader creates a climate of trust. The goal of this approach is to make the group a safe place for parents to reveal their problems and worries, to risk trying new approaches, and to gain support. The collaborative group leader is a careful listener and uses open-ended questions when exploring issues. In the leader's manual, there is a list of suggested open-ended questions for each vignette shown. Some example group leader questions include *What is effective about this parent's approach with his child? What are the benefits for his child? What is this child learning? What would you do differently? Can you use this approach with your child? Let's try it.* During the discussion, the group leader encourages all parents to respond and records their key ideas on a flip chart and even at times, gives a parent credit for a "principle" when sharing an important idea or concept. The group leader's empathy is conveyed by the extent to which she/he actively reaches out to parents, elicits their ideas, listens reflectively, affirms positive steps taken, and attempts to understand parents' challenges.

The collaborative process can be effective for parents raising children with ASD for several reasons. This approach gives back respect and self-control to the parents who, because of their children's difficulties, can be in a vulnerable time of low self-confidence and intense feelings of guilt and self-blame. A collaborative approach is more likely than didactic approaches to increase parents' confidence and self-efficacy, as well as their engagement and motivation for change (Webster-Stratton, 2012b). The group leader works with each parent to adapt concepts and skills learned in the group session to their particular situation. This flexibility increases the likelihood that the skills learned during the group will generalize into home practices in a way that fits with each parent's skill level, values, and the specific needs of their children. For more details on the collaborative group leader process, see the book *Collaborating with Parents to Reduce Children's Behavior Problems* (Webster-Stratton, 2012b), which is the text group leaders receive during the training.

Principle 2: Start with Parents Assessing Their Child's Stage of Communication, Setting Goals, and Self-Monitoring Progress

In the first group session, parents share descriptions of their children's strengths and difficulties and identify their long-term goals. These goals are written on flip charts and posted on the wall and can be changed over subsequent weeks if parents recognize their goal is unrealistic or another goal is more important. Also in the first two sessions, parents actively self-assess what they believe is their children's present communication stage by completing two *Child Communication Checklists,* focused on child-parent and child-peer communication skills, respectively. For example, parents are asked to identify their children's communication abilities (e.g., using pictures rather than words) and behavioral challenges (e.g., lack of response to directions). It is important to help parents think about how, why, and when their children communicate (e.g., child is requesting something, is protesting, is using sounds or words to calm down or express feelings). Children may communicate primarily to get what they want or may function at a more advanced level to ask and answer questions, socialize, and engage in pretend play. Once parents complete the checklists, group leaders help them set realistic goals for their children and family. For example, if a child ignores the parent whenever the parent offers a choice, then the goal will be for the parent to identify ways to get into their child's attention "spotlight," so the child can attend to the request. On the other hand, if a child responds to a parent choice with eye contact or gestures, then the parent's goal may be to use pictures or other signs to encourage further communication. Parents' understanding of their child's present stage of communication and social abilities is important. Through this process, group leaders can assist parents to set realistic goals and provide the kind of coaching that suits their child best.

Over subsequent group meetings, the group leaders continue to reevaluate the communication checklists and set new goals with parents. This process helps group leaders to individualize each week's program content and select the most appropriate video vignettes for particular parents, as well as to set up tailored practices that address the specific communication and play-related challenges faced by each parent. As the program continues, the group leaders help parents develop plans that target specific parenting strategies toward a particular child's behavior and communication goals.

Principle 3: Build Parents' Confidence and Self-Efficacy

Given the connection between knowledge, efficacy, and behavior, increasing parent confidence and self-efficacy is a major principle of the *IY* program (Bandura, 1977, 1982, 1989). The collaborative partnership between the parents with each other and with *IY* group leaders empowers parents to celebrate success and support their knowledge and skill acquisition. *IY* group leaders utilize an array of strategies that focus on parent strengths and emphasize the positive. For instance, embedded in the collaborative process is the strategy of group leaders asking probing questions that promote parents' self-reflection and problem-solving and giving them time to discover the rationale for a specific strategy. Parents feel empowered by this process and the opportunity to learn from each other and share ideas. Additionally, group leaders recognize and praise parents' achievements from completed home activities. These achievements are shared and celebrated in the group, and sometimes parents are asked to demonstrate a particular strategy that worked well for them. Further, group leaders reward parents for reaching personal weekly goals and completion of home practice exercises with prizes (e.g., special stickers, balloons, bubbles), all the while building self-efficacy and modeling a host of strategies the parents are being trained to use with their children.

Principle 4: Address Parents' Cognitions, Emotions, and Behaviors

IY targets the link between thoughts, emotions, and behaviors (Bandura, 1989). For instance, parents who have worked for months with a challenging child on the autism spectrum with limited success may have developed very negative views of the child. Frequent thoughts, such as "He's doing that just to irritate me," "Nothing I try is working," and "He is never going to change," make it likely that the parent will have negative feelings and antagonistic interactions with their child. These feelings can also influence parents' interactions with others, such as the child's teacher, who parents may believe is not qualified to work with their child. Parenting stress, limited access to resources, and lack of support may lead to parental depression and low motivation to implement effective new strategies offered during the parent groups. Likewise, negative perceptions of their own ability to manage their frustrations (e.g., "I'm going to explode!") produce unproductive internal dialogues that will undermine nearly any intervention unless these are systematically addressed.

The *IY* Parent Program directly addresses these self-defeating thoughts and the emotions and behaviors they engender. Group leaders work with parents to reflect on their internal dialogue bringing negative thought patterns to light and encourage parents to develop positive coping mechanisms. This can include group activities designed to challenge and rewrite specific negative thoughts, to use positive imagery about successful implementation of new practices, and to practice simple coping messages and calm down breathing throughout the day. For example, one session activity includes breaking the group up into parent buddy pairs to work on a record sheet that lists negative gripes and asks parents to rewrite them with positive statements or coping thoughts. Another activity asks them in pairs to share calm down strategies they can use in problem situations. After this buddy sharing, the group leader asks the group to share these ideas with everyone and records them on the flip chart. This flip chart list can be added to in subsequent sessions as new self-talk scripts or strategies are discovered. *IY* weekly group meetings provide opportunities to practice these self-talk strategies through role plays. For example, a parent may be practicing how to ignore a child who is tantruming, and another parent will act as the "angel on her shoulder" giving her the positive thoughts to use while she is ignoring this defiant behavior. After this practice the group leader solicits positive feedback from other parents as well as giving encouragement herself. Furthermore, the safe, supportive group atmosphere where other parents are facing similar difficulties, thoughts, and feelings normalizes their experience and provides the parent with opportunities to express emotional challenges with others while learning new strategies for coping.

Principle 5: Video Modeling, Mediation of Vignettes, and Self-Reflection

Observation and modeling can support the learning of new skills (Bandura, 1986). This theory suggests individuals can improve parenting skills by watching video examples of other parent-child interactions that promote their children's social communication and interactions and decrease inappropriate behaviors. *IY-ASD* video vignettes depict four different children on the autism spectrum. All are the same age but have very different developmental abilities. One boy has limited language, uses echolalia frequently, flaps his hands, and often responds with a blank stare or ignores the parent's choices offered. Another girl has quite a bit of language but at school does not initiate interactions with peers, plays alone, and can be oppositional at home. Another boy has no language and is shown in a classroom throwing tantrums. The fourth boy has one- to two-word language skills. All vignettes show mothers or fathers interacting with their children during play or snack time. The majority of vignettes depict one-on-one play, with a few additional vignettes incorporating siblings in the interactions. The parents are shown using a variety of strategies to gain their children's attention and promote their children's social communication and emotion regulation. The vignettes are intended to trigger group discussion, self-reflective learning, and practices to reenact vignettes using some of the suggested strategies.

Before the group leader shows a vignette, she/he begins by helping the parents understand what they are about to see and what they should look for when they watch the vignette. For example, the group leader might say, "*In the next vignette, see if you can determine why this parent is effective and what her child is learning.*" While the group leader is showing the vignette, she/he pauses the video at various points to give parents a chance to discuss and react to what they have observed. Sometimes vignettes are paused two to three times to encourage parents to reflect on or even practice what they would do next. The group leader asks open-ended questions such as, "Why do you think singing gets your child's attention and promotes language development?" Suggested questions and discussion topics are included in the group leader's manual. If parents are unclear about the specific strategy, or have missed a critical feature of the vignette, the vignette can be shown again. The goal is not only to have parents grasp the intended concept but also to ensure parents become actively involved in reflecting on the interactions, problem-solving, and sharing ideas. The group leader promotes integration and relevance of the concepts or behavioral principles by asking how the concepts illustrated in the vignettes do or do not apply to their own interactions with their child at home. For example, "Do you think could use a puppet at home with your child to enhance your interactions? What kind of puppet would you use? Would this be difficult? How will your child react?" After several of these vignettes are shown and discussed, then a puppet practice is set up.

It is important to emphasize video vignettes are used collaboratively, as a catalyst to stimulate group discussion and problem-solving, not as a device that renders parents as passive observers. Parents' reactions to the vignettes and the ways in which they process and interpret what they see on the vignettes are more important than what is actually shown on them. The vignettes are designed to illustrate specific concepts, and it is up to the group leader to ask questions that permit parents to self-reflect and discover the key behavior management or communication principle and how this can be used with their child. For example, a group leader may explore a principle arising from a vignette such as prompting a child's verbal response and then ask the parents, "How do you see yourself prompting some of the social skills you have identified on your goals list at home with this idea?"

Principle 6: Experiential Practice Learning Methods

IY parent training places a major emphasis on experiential learning such as role-playing scenarios, rehearsal and practice of newly acquired behaviors and cognitions, rather than simply didactic instruction. A group leader might believe from the discussion of the vignette that parents understand the behavior management principle or content. However, until the parent is seen "in action," it will not be clear whether she/he can put the ideas into real-life behaviors. There can be a discrepancy between how participants understand a strategy and how they actually behave. It can be very difficult for parents to think of the right words to use with children and manage angry thoughts and stressful or depressed feelings when children misbehave or fail to respond. Role play or experiential learning is effective because it helps parents anticipate situations more clearly, dramatizing possible sequences of behaviors, feelings, and thoughts. It helps them to rehearse behaviors, practice staying calm, use positive self-talk, and get feedback from the group about their skills.

It is recommended that group leaders set up three to four brief role plays in each session. During weekly sessions, parents are first given the opportunity to discuss several vignettes of a new parenting skill, such as social coaching. Their ideas and social coaching scripts have been recorded on a flip chart. Then, the group leader sets up a large group practice by inviting a parent to demonstrate implementation of the new skill learned (such as coaching of emotions or social skills, prompting, and using picture cards) with another parent who plays the role of "child." Or, one of the group leaders using a large child-size puppet can act the part of child with no language and/or with echolalia. Afterward, the group debriefs and gives positive feedback to the parent for the particular skills she/he was demonstrating, such as imitation, prompting, gesturing, or picture cards. The parent "in role" as child also gives feedback from the child's perspective of her experience and finally the group leader summarized the key learning that came out of the practice. Sometimes replays occur, trying out different ideas from the group. Putting parents in the role of the child can be very helpful not only to learn parenting skills but also to help parents experience the perspective of their child and to show what their child does.

Once the large group role play or practice has been demonstrated and debriefed, has role-played or practiced, the parent group is divided into triads, so everyone can practice the particular skills being covered in the session. During these practices one person is parent, one is child, and the third is observer who watches the interaction and offers suggestions and support as needed. At the end, the observer parent gives positive feedback for the skills she/he observed. Then the triad members change positions. It is important that all parents have opportunities to practice. At the end of these small practices, the triads report the key ideas learned from this experience back to the larger group. The *IY* manual recommends some planned role plays, but group leaders are encouraged to do spontaneous practices. For example, a parent might say, "My child doesn't let me touch his line of cars in play or let me change anything." This is the strategic moment for the group leader to do a spontaneous role play and ask that parent to demonstrate her child's behavior. The group leader then chooses another parent who seems to have an understanding of how to enter into play even when she feels rejected by her child by showing how she/he would respond to this rejection. The group leader can prompt the parent in role to keep back some cars and set up the ABC sequence, so the boy has to ask for each car and engage in joint play. While parents are often nervous about role plays and may resist at first, our weekly evaluations indicate that over time, parents find the role plays one of the most useful learning methods and frequently request to act out certain situations. Parents report role plays help them prepare realistically for what occurs at home. Here are a few group leader tips to setting up successful role play practices:

- Do large group practices before small group practices. This allows participants to observe exactly what you expect them to practice in small groups.
- Remember you are the "director" of the role play and get to choose actors, set the stage, and determine the script or roles or props needed.
- Scaffold large and small group practices and remember you can always pause action to give feedback and replay if needed.
- Be sure you have covered the content to be practiced first and have developed a script before practice begins.
- Start with simple role-play first (with well-behaving child) to practice and learn parenting skill, and then add complexity by changing the difficulty of the child's response.
- Tailor the parenting skill to be learned according to child's developmental and communication level. Ask parents to role-play what their children would do and practice possible responses.
- Make practices fun and relevant to their personal situation.

Principle 7: Buddy Buzzes and Brainstorms

In order to keep all parents actively involved in self-reflective experiential learning, build relationships among parents, differentiate activities, and manage time during the group sessions, group leaders frequently do buddy "buzzes" and brainstorming exercises. Buzzes are when parents are paired up with a buddy to work on a specific exercise such as writing praise statements for their targeted "positive opposite" behavior (i.e., replacement behavior for negative behavior), sharing calming strategies or self-care efforts, or rewriting negative thoughts into positive coping thoughts. These exercises contribute to the shared experience of raising a child with ASD and allow for further individualization of the program to specific child and parent needs. The benefit of doing a paired buzz instead of a group brainstorm is that every parent is immediately engaged in a task and involved in coming up with solutions. While large group brainstorms can be beneficial as well, they can be less effective than buzzes as perhaps only half the group contributes ideas, and the other half is disengaged, quiet, or distracted. After these buzzes (3–5 min), each buddy can report to the group on their buddy ideas, and these are recorded on the flip chart by the group leader. Buzz handouts are also included in the group leader manual for use in these exercises.

Principle 8: Weekly Home Activity Practice Assignments and Self-Monitoring Checklists

Parents practice the strategies they are learning first in the group with other parents and subsequently at home with their children. They are asked to record their experiences with these activities on *record sheets* that can be found in the *IY* manual. For example, in the first part of the program, parents identify play behaviors they want to increase, such as imitation, use of choice activity boards, being child-directed, and descriptive commenting. They record a brief script of their practice on the record sheet and how their child responded. Parents return these records at the subsequent group session for the group leader to review and help parents fine tune their approaches with further role plays as needed. The record sheets can also assist group leaders to assess parents' understanding of program content and their success at applying these ideas with their children at home. For parents who are having difficulty using these approaches, it can be helpful to set up some additional parent play sessions with their children where they receive individual coaching from the group leader. In addition to home practice assignments, parents are also given *The Incredible Years* book or *Incredible Toddler* book (Webster-Stratton, 2011) and asked to read or listen to a chapter each week to prepare for the subsequent session.

Although standard home assignments are suggested, each week parents complete the self-monitoring checklists, which allow them to commit to what aspect of the home activities or goals they will try to achieve. Each week the group leader reviews these goals and gives parents personal written feedback, as well as placing surprise stickers, candies, cartoons, or cards in their personal folders to applaud a particular achievement. These personal folders become a private communication between the group leader and the parent. The individual attention to the home assignments encourages parents to self-monitor their own progress.

Principle 9: Reviewing Weekly Evaluations and Making Calls

At the end of every group session, parents complete brief weekly evaluation forms. This provides the group leader with immediate feedback about how each parent is responding to the group leader's style, group discussions, the content, and video vignettes presented in the session and the role play practices. The evaluations bring to light a dissatisfied parent, a parent that does not see the relevance of a particular strategy for their child, or a parent who wants more group discussions or vignettes or practices. The group leader calls or meets with parents individually to resolve issues and ensure the program is addressing their goals. At the end of the program, the entire program is evaluated. This information is helpful for identifying parents who may need further help.

Principle 10: Building Parents' Support Team

Parenting is stressful at times for most parents, but research indicates that parenting a child with ASD is associated with significantly elevated depression and anxiety symptoms and disorders (see Introduction). Parents of children on the spectrum experience a sense of being stigmatized and socially isolated from others. Parents often do not feel they can share the burden of the many decisions they make each day and fear if they are honest with their friends about their child's strange behaviors; they will be met with misunderstanding, indifference, or outright rejection. Struggling to get support services, relentless worry about the future, and financial strain all can be overwhelming. The group leader's role, then, is to facilitate the parent group so that it serves as a powerful source of support: an empowering environment.

The collaborative learning process allows parents to problem solve together, to express their appreciation for one another, and to learn to cheer each other's successes in tackling difficult problems. The group leaders encourage parents to curb negative thoughts, use positive imagery, take deep breaths, get enough sleep, and develop support systems to stay calm. For example, in Part VI, when children are learning the calm down breathing techniques, the parents also learn how these techniques can be applied to themselves. In Part VII, on the topic of praise and incentives, leaders explore self-reinforcement and self-care with the group, another important strategy for reducing stress. One of their home activity assignments is to do something pleasurable for themselves (e.g., coffee with a friend, date night out, massage, exercise class, etc.) which they share the following week. It is important to help parents understand the importance of self-care in terms of refueling the energy required to care for their children. Weekly calls from group leader also help parents feel supported as they try out new parenting strategies. Group leaders help parents become support systems for each other. Each parent is paired with a "buddy" from the group, to allow parents to support one another outside of the weekly group sessions, process challenges and successes, and share ideas and experiences generalizing *IY* skills at home. Throughout the program parents are given weekly assignments to call or contact their buddy to talk about the new skill they are trying out. Parents can make these weekly contacts in a variety of ways: texting, email, web groups, phone calls, or meeting in person. Initially parents may be hesitant about making these calls but become more confident as they receive support from other parents. Buddies are changed at least once during the program so that parents can benefit from other parents' insights. These assignments further expand the parents' support networks, as they usually express a desire to continue calling their previous buddies.

In addition to building the support system within the group, the group leader also helps them build support within the extended family. Parents often report conflicts with partners, grandparents, and teachers over how to handle the child's problems, resulting in stressed relationships. Every parent is encouraged to have a spouse, partner, or family member such as a grandparent participate in the program with them to provide mutual support. During the program, parents complete a *support network handout* where parents fill in five "helping hands" with the people they think will support them (e.g., friends, family, teachers, counselors, health care providers, childcare providers, neighbors).

Principle 11: Combining Individual Home Coaching with Group Program

Generalization of the strategies parents learn is also an important consideration. To that end, some individual coached practice between the parent and child is recommended for all parents. The amount of individual coaching parents need will vary depending on their confidence in using the parenting techniques and level of the child's behavioral difficulties. Even if parents seem to demonstrate understanding of the parenting strategies in group discussions and role plays, seeing them interacting with their own children is the best way to find out how well they are integrating the skills. These coaching sessions can be delivered in a clinic setting but ideally will be provided in home- and community-based or naturalistic settings such as the grocery store, playground, or preschool. It is ideal for coaching to occur four times, after group sessions on language coaching, social and emotion coaching, pretend play and self-regulation, and handling misbehavior. The format for these coaching sessions includes (1) review of parent's goals, (2) discussion of one to two video vignettes relevant for goals, (3) coached practice between parent and child, (4) debriefing practice, and (5) setting new goals. Ideally the person doing the home coaching is the group leader; if this is not feasible, it is important that the home coach has connected with the group leader to discuss what has been covered in the group at that time and builds on recommended home activity assignments.

Principle 12: Provide Follow-up Sessions and Promote Parent-Teacher Partnerships

Because social-communication deficits are core features of ASD, it is recommended that after parents complete *IY-ASD,* focused on one-on-one interactions, they are offered another program called *Coaching Children with Autism: Teachers and Parents as Partners.* This four- to six-session program that preferably is offered to both parents and teachers together focuses on classrooms where teachers are coaching two to three children with ASD to facilitate peer interactions and social communication with sequenced picture cue cards. Doing this curriculum with teachers builds the parent-teacher partnership and makes it easier for the parent to occasionally participate in the classroom if they have the time. It means that parents and teachers can work on behavior plans together and promotes cross-setting consistency in language and methods used. For example, if the "calm down thermometer" works well at home, the teacher can also use it in the classroom.

Supplemental content from the *IY-BASIC* program *Managing Misbehavior* may also be necessary for some older children with significantly challenging behaviors. Parents may require further practice understanding the function of behavior, antecedent and environmental accommodations, and consequence modification. *IY-BASIC* content regarding the use of time-out can be adapted for this population by helping the parent understand the value of allowing the child space and time to calm down while emphasizing the potential for time-out strategies to inadvertently reinforce behaviors of a child who prefers to be alone and escape social interactions.

Principle 13: Help Advocate for Families

Due to the limited knowledge regarding the causes of ASD and lack of a cure, parents find themselves researching for information and seeking a variety of interventions. Children with ASD and their families frequently participate in multiple approaches with several different providers. For example, parents often seek behavioral, neurodevelopmental (i.e., speech and occupational therapies), school-based, and biomedical interventions. Effective group leaders will collaborate with other providers and coach parents in ways to advocate for their children's needs. Several options can be incorporated into the program in order to promote collaboration and advocacy. For example, leaders can communicate directly with therapists and educators to share the approaches parents are learning, consult about the child's behavior, or arrange team meetings. Additionally, supplemental content can be added from the *IY* Advanced Parent Program that focuses on advocacy, family and teacher problem-solving, and working as a team to support the child.

Future Directions and Summary

Over half of young children with ASD exhibit behavioral problems including oppositional behaviors and aggression (Bearss et al., 2016). However, evidence-based parenting training interventions known to reduce disruptive behavior problems have rarely been evaluated with parents raising young children with ASD. One example of an evidence-based parent training programs is *The Incredible Years* (*IY-BASIC)* which has been evaluated in over 50 randomized control group studies in an effort to prevent and reduce conduct problems (Menting et al., 2013). In a pilot study in which *IY-BASIC* was evaluated with parents of children with ASD, results indicated a positive response to the program, along with several recommendations, such as inclusion of children with ASD on the video vignettes (Dababnah & Parish, 2016c). A revised *Incredible Years* program, *IY-ASD* program, was developed by Webster-Stratton for parents of children 2–5 years with ASD. *IY-ASD* offers promise for improving parent confidence and support; reducing stress and depression; promoting children's social, emotional, and language development; and reducing misbehavior. Preliminary evaluations of *IY-ASD* have found positive reductions in parenting stress and child behavior problems, as well as high participant acceptability (Hutchings et al., 2016).

Future research is needed using randomized controlled group trials to examine the effectiveness of the *IY-ASD* Parent Program for parents and children. The outcomes of these studies should include parents' feelings of competence and level of support, parent stress and depression, as well as child behavior improvements. A recent study suggested that an individual home-based parent intervention was more effective than a group-based parent intervention program in terms of child outcomes of social communication and receptive language (Wetherby et al., 2014). We argue for the added benefits that a group-based approach can provide in terms of building family support systems and reducing parent stress and depression, which may in the long run lead to more sustainability of outcomes. However, by offering parents individual coaching alongside a group approach, we believe it is possible to enhance the outcomes for both children and their families and still reduce the cost of intense clinician-implemented interventions. This is an important direction for future research.

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18

Self-Help for Parents of Children with Autism: Mindfulness and Compassion

Samuel Fernandez-Carriba and Jessica Bradshaw

Abstract

Whereas the role of the parent as natural therapist for their child with autism has been studied at length, much less attention has been given to understand and support the emotional needs of those we bestow with such a great responsibility. In this chapter, we refer to interventions that provide support for the mental health and overall well-being of these parents as self-help programs. First, we highlight the scarcity of studies addressing self-help in the parent-training literature. Next, we discuss practical and ethical reasons why more attention should be given to this topic. We then provide a detailed account of self-help programs that have been empirically studied, with attention to specific techniques that have shown promising results, such as mindfulness meditation or training in full awareness. Mindfulness and compassion meditation, defined by the cultivation of full awareness of others and self with the desire to alleviate all suffering, will be presented as a potentially successful coping strategy to reduce distress in parents of children with autism as well as a social skill training to reduce isolation and increase social competence. We will conclude with the brief report of a pilot program at the Marcus Autism Center in which we aimed to teach parents mindfulness and compassion meditation which, in turn, may benefit their children with autism.

Why Is Self-Help Missing from Parent Training?

The explosion of empirical studies in the world of autism in the last three decades involving parents or primary caregivers as active agents in their children's intervention seems more than justified, given the parents intimate knowledge of their child's abilities, their context, and the intervention goals (Vismara & Rogers, 2010). In addition, parent-delivered treatments have the benefits of increased intensity and integration of treatment in everyday contexts, as well as a lower cost. By bringing the intervention to the home environment, parents take advantage of everyday naturally occurring opportunities, which are much more frequent than those created in a specialized center. Learning is also more likely to be generalized and maintained in this natural context, which is still currently one of the greatest challenges of therapies addressing autism symptoms (Barton & Harn, 2012). Finally, the

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_18

family will not have to rely as heavily on costly professionals.

In their review of parent-training programs, Bearss, Burrell, Stewart, and Scahill (2015) propose a helpful taxonomy of parent-training interventions. They argue that precise categorization of the different interventions is more than an academic issue; it also affects clinic administrators, funding agencies, insurance companies, and policy-makers. In essence, they differentiate between parent-mediated (or parent-implemented) interventions and parent-support interventions. Parent-mediated interventions are technique-focused programs where the parent is the agent of change and the child is the direct beneficiary of treatment. In contrast, parent-support interventions are primarily knowledge focused, aiming to support the parents' need for information, although the child may benefit indirectly. Within the category of parent-support interventions, Bearss et al. include two types of interventions: care coordination services and psychoeducational programs.

Care Coordination Services

The Agency for Healthcare Research and Quality (AHRQ) defines care coordination as "the deliberate organization of patient care activities between two or more participants involved in a patient's care to facilitate the appropriate delivery of health care services" (AHRQ, 2014). Although the benefits of care coordination programs for the families and the children are widely accepted, empirical evidence supporting their effectiveness is rare, the challenge being the wide diversity of services and populations served, as the authors note (Bearss et al., 2015). There is therefore a need for rigorous evaluation of this kind of program as a helpful support system for families with children with autism.

One model of a care coordination program has been published by Parellada et al. (2013). The program, Comprehensive Medical Care for Autism Spectrum Disorders (AMI-TEA), developed in Spain, provides families with a care coordinator who facilitates care by organizing medical appointments, accompanying the family to appointments, and communicating with relevant practitioners regarding the individual's needs. There is no explicit mention of emotional support to parents in this program, although escort/accompaniment is one of the key elements, and the case manager also gathers information on the family's previous experience with medical services, including their level of stress and satisfaction. The AMI-TEA program is not too different from the care coordination program at the Marcus Autism Center in Atlanta, Georgia, under the direction of Cheryl Rhodes (Rhodes, Stiles, & Hall, 2017), which offers the following services:

- A point person to assist families in navigating services in the Marcus Autism Center and in their local community
- Linkage to local service providers for therapies and services
- Connection to family supports like parent groups, respite services, emergency services, funding, and advocacy groups
- Emotional support
- Information and connection with transportation and local hotel and hospitality options in coordination with scheduled appointments at the center

Psychoeducational Programs

There is more research available on psychoeducational programs for parents of children with autism than on care coordination. There is no question about the benefits for the children of providing parents with quality up-to-date information on ASD that helps them both have realistic expectations and empowers them to make decisions leading to the best possible outcomes (Brookman-Frazee, Stahmer, Baker-Ericzén, & Tsai, 2006). As several advertised treatments for autism are not grounded in evidence-based practice and do not have adequate empirical support for their safety and efficacy, parents themselves carry the burden of ensuring that time and resources are allocated to treatments with the most guarantees.

Psychoeducation is generally provided informally in clinical practice or through self-guided resources offered also in clinics or by care coordination services, for example, Volkmar and Weisner's (2009) book *A Practical Guide to Autism: What Every Parent, Family Member, and Teacher Needs to Know* or the web-based Autism Speaks 100 Day Kit (http://www.autismspeaks.org/family-services/tool-kits/100-day-kit). Benefits of formally structured psychoeducational programs for the parents are also well known, not only in increasing parental knowledge and encouraging advocacy skills but also in reducing stress and feelings of isolation (Tonge et al., 2006). An interesting question is whether it is the informational aspect of this training, the social support provided by the group format, or an interaction of both that produces improvements in parent well-being (Daley, Singhal, Weisner, Barua, & Brezis, 2013; Farmer & Reupert, 2013). Regardless of the mechanism, it seems that broad psychoeducational programs that teach parents about autism and behavioral management strategies in a didactic format, under the category of parent-support interventions, have consistently resulted in reductions in parent distress.

Parent Mental Health and Well-Being in the Context of Parent-Mediated Interventions

Several studies suggest the high levels of parenting stress may interfere with the efficacy of parent-mediated interventions for young children with ASD (Osborne, McHugh, Saunders, & Reed, 2008; Stadnick, Stahmer, & Brookman-Frazee, 2015). At the same time, other authors report that a certain level of parenting stress actually improved parent implementation of intervention strategies during everyday interactions (Alquraini & Mahoney, 2015). It has also been documented that mothers who are less depressed and angry are more likely to actively engage with their children with autism in healthier and more consistent ways (Gray, 2002; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008; Vail & Xenakis, 2007). For this reason, the term "parenting distress" (instead of "stress") may be more appropriate to describe the general lack of well-being reported by some of these parents. In any case, these findings warrant further research into what mechanisms are in play in parent-mediated interventions. Chapter 8, "Parental insightfulness into the inner world of the child with autism: Its significance for the child and implications for parent-mediated interventions", introduces parent insightfulness, the capacity to see and feel things from the child's point of view, as a crucial capacity for interventions.

Although the severity of a child's autism symptoms and behaviors has consistently been found to be one of the strongest predictors of parental distress (Davis & Carter, 2008; Hastings et al., 2005; Ingersoll & Hambrick, 2011; Lyons, Leon, Roecker Phelps, & Dunleavy, 2010), it does not necessarily follow that parent-mediated interventions addressing the child's symptoms will have a positive effect on the parents' well-being: research does not always indicate there is a linear positive relationship between the two. Variables like lack of social support and ineffective coping styles, such as avoidance, contribute significantly to parent distress (Mancil, Boyd, & Bedesem, 2009; Tehee, Honan, & Hevey, 2009). Furthermore, some studies exploring parent distress following parent-mediated interventions for children with autism indicate no improvements when the children's symptoms improve (Drew et al., 2002; Kasari, Gulsrud, Paparella, Hellemann, & Berry, 2015), while others demonstrate mixed findings (e.g., Bradshaw et al., 2017). This is in contrast with the consistent reductions in parent distress shown by the psychoeducational programs mentioned above (Tonge et al., 2006). However, psychoeducational programs are not designed to support parent mental health and overall quality of life.

Self-Help for Parents of Children with ASD

In the current chapter, we would like to argue that the taxonomy of parent-training interventions proposed by Bearss et al. (2015) should be amended by adding a group of interventions that primarily target parents and aim to improve parental mental health and well-being (i.e., self-help interventions). These interventions are similar to other interventions in the broader category of parent support in that they also focus on the parent while the child is an indirect beneficiary. However, these interventions differ from care coordination services and psychoeducational programs in that the focus goes beyond meeting the parents' informational needs. Not only do we think it is necessary to consider the parents' mental health and well-being in any intervention for their children with autism, we will offer preliminary evidence that such a program is feasible and promising for the parents and for the children. We also encourage researchers to verify and quantify the impact of such programs on the children to understand better the role of stress in parents' participation in the children's intervention.

There is a vast literature describing the challenges of being a parent of a child with autism. These parents are more likely to divorce than parents of typically developing children (Hartley et al., 2010). They also have greatly increased loss of income: the lifetime cost of care and loss of revenue for a family with one child with ASD has been estimated to be between $1.4 and $2.4 M, depending on the level of the child's disability (Buescher, Cidav, Knapp, & Mandell, 2014). Additional data show diminished maternal health-related quality of life (Allik, Larsson, & Smedje, 2006), increased problems in physical health and bodily pain (Khanna et al., 2011), and increased depression, anxiety, and emotional distress (Estes et al., 2013; Hayes & Watson, 2013; Jeans, Santos, Laxman, McBride, & Dyer, 2013; Schieve, Blumberg, Rice, Visser, & Boyle, 2007; Weitlauf, Vehorn, Taylor, & Warren, 2014).

On the other hand, epidemiological data (Mandell et al., 2012) looking at 28,428 Medicaid-enrolled families showed that each $1000 increase in spending on respite care during the preceding 60 days resulted in an 8% decrease in the odds of hospitalization for the children with autism. Surprisingly, the use of therapeutic services was not associated with reduced risk of hospitalization. In conclusion, the best investment for a family to avoid hospitalization of their child with autism seems to be just respite for the parents. Although an improvement in the children's symptoms may not automatically improve parental well-being, Mandell et al.'s study strongly suggests the reverse: improvement in parental well-being may help the child.

Although there is an abundance of studies describing parents' psychological distress, relatively few studies address it directly. This is a shocking finding, given the ethical and practical considerations supporting this line of research: the consensus is that enhancing the parents' quality of life does not only reduce the family burdens but may increase their ability to contribute to their children's progress in treatment and education. A recent review by Da Paz and Wallander (2017) lists only 13 studies that targeted improvements in mental health for parents of children with autism. Five of them were pre-post quasi-experimental designs, with no control groups, and eight were randomized controlled trials (RCTs).

Da Paz and Wallander (2017) conclude in their review that interventions using Stress Management and Relaxation Techniques, Expressive Writing, Mindfulness-Based Stress Reduction, and Acceptance and Commitment Therapy are promising interventions at improving the mental health for parents of children with ASD. Among the eight RCT studies summarized in this article, six suggest a reasonable likelihood of efficacy, based on medium to large size effects post-intervention. Feinberg et al. (2014) used Problem-Solving Education (PSE), a manualized cognitive behavioral therapy (CBT) program that helped participants identify feelings associated with a problem to be able to focus on the solution and generate a plan to achieve the solution. Expressive Writing (EW), also known as written emotional disclosure, was employed by Campbell (2003), whose participants were encouraged to divulge personally traumatic events in a non-threatening environment. Kowalkowski (2013) tested a protocol combining mindfulness and Acceptance and Commitment Therapy, with parents being taught acceptance, rather than avoidance of undesirable feelings, and awareness of their own stream of thoughts without judgmental reaction. Finally, three additional studies used mindfulness with different variations, including Mindfulness-Based Stress Reduction (MBSR) (Benn, Akiva, Arel, and Roeser (2012), Dykens, Fisher, Taylor, Lambert, and Miodrag (2014), and Ferraioli and Harris (2013).

Smaller effects were found in one of the two remaining RCT studies, conducted by LaPlante (2013), who used the Three Good Things (TGT) technique, a protocol derived from positive psychology that charges participants to find three good things that happened during their day and helps individuals reappraise their unpleasant experiences, focus on more positive aspects of their lives, and achieve overall well-being. Finally, the only negative effects were reported by Whitney and Smith (2015), due to the short-term distress that EW produces. The lack of a follow-up assessment in this study potentially prevented a positive finding, unlike Campbell (2003), who did observe improvement at that time point following EW.

For the quasi-experimental designs in Paz and Wallander's review (2017), the studies using biofeedback training and family systems therapy did not produce significant results in parent mental health outcomes. Family systems therapy (FST) is conceptualized to include all members of the family while taking into consideration subgroups of interactions such as parent-child, sibling-child, and marital relationships (Morgan, 1988). Peck (1998) used FST, stress management techniques, ASD education, parent self-advocacy, and social support and reported nonsignificant findings on parenting stress. Bitsika and Sharpley's results (2000), using biofeedback training and relaxation techniques, were also nonsignificant for anxiety, depression, and parenting self-efficacy. The studies using ACT (Blackledge & Hayes, 2006) and relaxation training (Gika et al., 2012) reportedly produced significant improvements in psychological well-being and life satisfaction and decreases in negative consequences, such as depression and parental stress.

Studies that resulted in positive effects in parenting stress, general health (including anxiety, insomnia, and depression), and parental distress and anxiety also showed maintenance of gains 2 to 3 months after completion of the study (Da Paz & Wallander, 2017). Only one study (Dykens et al., 2014), using MBSR, assessed treatment effects past 2–3 months and showed continued, medium effects sizes after 6 months. Overall, the biggest effects were shown in the studies using MBSR, suggesting that mindfulness may be a promising treatment for parents caring for a child with autism.

Mindfulness meditation refers to a group of self-regulation practices, derived from Buddhism but secular, "that focus on training attention and awareness in order to bring mental processes under greater voluntary control and thereby foster general mental well-being and development and/or specific capacities such as calmness, clarity, and concentration" (Walsh & Shapiro, 2006, p. 228). Although there are different protocols for meditation practice, for example, MBSR, mindful awareness is an essential component in all. Mindfulness refers to the ability to pay attention and retain specific information, whether the object of attention is specific (e.g., breathing) or open (i.e., mental experience from moment to moment). Mindfulness meditation can be an effective coping strategy with the potential to help individuals under distress, including parents of children with autism. A large number of published research articles consistently show mental as well as physical health benefits of mindfulness meditation for short- or long-term practitioners (see Grossman, Niemann, Schmidt, & Walach, 2004, and Davis & Hayes, 2011, for comprehensive reviews).

Among all these findings, it is noteworthy, although expected, that one of the largest effects at outcome is observed in parenting stress, as measured by the total score of the Parenting Stress Index or PSI (Dykens et al., 2014; Feinberg et al., 2014; Ferraioli & Harris, 2013; Kowalkowski, 2013). Effects are also found in the parent-child interaction subscale of the PSI (Benn et al., 2012), parenting self-efficacy as measured by the Parenting Sense of Competence Scale or PSOC (LaPlante, 2013), family climate (Campbell, 2003), and self-compassion (Benn et al., 2012). In other words, parent well-being includes a myriad of outcomes that are directly related to parenting, like parent-child interactions and parenting self-efficacy. None of these studies however assessed direct benefits for the participants' children with autism.

Also missing in Paz and Wallander's review, with the exception of Peck (1998), is a component in the training that would help parents reduce their social isolation. Other than the fact that most of these programs were developed in a group format, and therefore it was assumed that this may have contributed to the positive outcomes, there is no formal training on social skills or direct assessment of benefits in social competence. As we saw earlier, this is an element that most psychoeducational programs capitalize upon and something that should also be included in self-help programs as well. A training that targets social skills in parents will not only help reduce feelings of isolation but will also empower them to be better advocates for their children in increasingly difficult healthcare and education systems.

More Than Self-Help for Parents: Social Competence

Enhancing the quality of life and engagement of parents in the care of children with autism should be a major priority in interventions. And yet, professionals in the field of autism often communicate with these families as if they existed in a sociocultural vacuum, ignoring their sociocultural background and individual context. We live nowadays in an increasingly diverse society, and healthcare and education systems face the unique challenge to recognize these differences in background and context if they want to operate effectively. In the USA, for example, for the first time in history, almost half (49.5%) of American children under the age of 5 are of a nonwhite racial or ethnic minority group according to estimates for July 1, 2015 by the US Census Bureau (US Census Bureau, 2016), despite a predominantly Anglo-Saxon ancestry and tradition.

Cultural and socioeconomic differences are the focus of attention in numerous medical and health scientific journals due to great disparities in health outcomes in a large number of medical conditions, including autism (CDC, 2012, 2014). Such disparities in healthcare have led the US *Department of Health and Human Services* to underline the importance of cultural competence in providers, stating that "cultural competency is one the main ingredients in closing the disparities gap in health care" and "health care services that are respectful of and responsive to the health beliefs, practices and cultural and linguistic needs of diverse patients can help bring about positive health outcomes" (US Department of Health and Human Services, 2001).

The focus has been naturally to train providers in being socially and culturally sensitive. Care coordination services, as we mentioned above, respond to the need to help the families navigate in a healthcare system that has become highly academic and bureaucratic. There is a need for families to communicate with providers, as much as for providers to communicate with the families, and doing this not by adding another burden to the family's heavy load of responsibilities but by releasing them from the distress that may come from communicating and interacting with professionals they do not always understand. This is a major issue when raising a child with autism. We believe that it would not only be beneficial, but also possible, to teach parents basic social skills, e.g., assertion with healthcare professionals, while targeting stress reduction.

Sue and Sue's model (2002) describes cultural competence in professionals as involving (1) awareness of oneself own assumptions, values and beliefs, (2) knowledge of the worldviews of culturally diverse others, and (3) skills in the use of therapeutic modalities and interventions appropriate for culturally different clients. Awareness and knowledge/skills have then remained the two pivotal concepts when creating professional guidelines to help healthcare providers to work with culturally diverse groups, including those published by the American Psychological Association (APA, 2003). We could bring very similar principles to our population in need: awareness and knowledge/skills.

In more detail, awareness refers to being able to identify oneself and the others in context while acknowledging the differences and encouraging discussion about those differences. Knowledge and skills in culturally competent providers stem from this awareness but also from specific professional training and culturally sensitive resources, beyond the scope of parents' possible repertoire of skills. For both providers and parents, it is necessary not to generalize cultural patterns to all members of a particular group and to acknowledge the vastness and richness of human diversity and the uniqueness of each person and their context. For that reason, we advocate for the term "social competence," instead of cultural competence: it encompasses attention to differences among cultures as well as within cultures and brings the focus on the relation of two individuals and not simply on the differences of one of them compared to the "norm." Our argument is also in consonance with the relatively new trend in healthcare to speak about relation-centered services, which emphasizes client-provider interaction, rather than simply patient-centered services (Nundy & Oswald, 2014).

Awareness and knowledge/skills are then necessary qualities for a parent to become more socially competent: awareness of our own views and the views of others, knowledge about those views, and skills to build the bridge between to "translate" our views to others and those of others for us. In other words, socially competent people should possess high self-awareness and awareness of others as well as sophisticated social skills. As we will describe below, there is a method to train both attention and social skills while reducing distress in parents of children with autism.

Compassion Training: A Potential Intervention for Families of Children with ASD

While there is abundant data on the distress associated with parenting a child with autism, there are also some studies indicating actual benefits for parents, such as increased spirituality (Ekas, Whitman, & Shivers, 2009) or increased compassion and acceptance of differences (Pakenham, Sofronoff, & Samios, 2004). Not enough research has been conducted on the personal characteristics and coping strategies of those resilient parents who successfully deal with autism. Neff and Faso (2014) suggest that self-compassion may be such a helpful coping strategy. According to these authors, self-compassion involves being kind to oneself in times of difficulty, recognizing the shared nature of human suffering, and being mindfully aware of negative thoughts and emotions. They reported that self-compassion was associated with well-being in 51 parents of a child with ASD, over and above the effects of child symptom severity: it was positively associated with life satisfaction, hope, and goal reengagement and negatively associated with depression and parental stress.

Compassion, on the other hand, can be defined as the motivation to remove others' and one's suffering, and it includes self-compassion as an essential feature. It is both a social skill and a coping strategy. Compassion from others, or social support, protects us from disease and even death (e.g., Broadhead et al., 1983). Remarkably, psychophysiological evidence suggests that social support is most beneficial, in turn, for those best able to take advantage of it: individuals high in compassion (Cosley, McCoy, Saslow, & Epel, 2010). In other words "If you want others to be happy, practice compassion. If you want to be happy, practice compassion" (the Dalai Lama, 2012, p. 48). The four mechanisms proposed by His Holiness the Dalai Lama (2012) when discussing the benefits of compassion for self are diversion (worrying less about ourselves), comparison (the fact that there are always worse problems than ours), problem-solving (engaging creatively in possible positive outcomes), and connectedness (feeling closer to others).

While compassion is considered to unfold naturally in some mindfulness meditative practices, there are also analytical meditation techniques that specifically promote compassion toward self and others. In this sense, compassion is more than a personal characteristic; it can be developed and expanded. CBCT® (Cognitively Based Compassion Training), developed and empirically validated at Emory University (Pace et al., 2009), and Compassion Cultivation Training (CCT), developed and empirically validated at Stanford University (Jazaieri et al., 2014), are two of the most frequently utilized manualized forms of compassion meditation training. Also available are Compassion-Focused Therapy (Gilbert, 2009) and, specifically for self-compassion, the Mindful Self-Compassion Training (Neff & Germer, 2013).

CBCT is a protocol for mindfulness and compassion meditation practice developed by Emory University's Department of Religion Professor Geshe Lobsang Tenzin Negi, PhD., who is also director of the Emory-Tibet Partnership and director and founder of Drepung Loseling Monastery, Inc., a center under the patronage of His Holiness the Dalai Lama. CBCT is a secular and analytical practice based on the Tibetan Buddhist tradition of *lojong*, which means "mind training" or "thought transformation." CBCT follows a strict protocol developed in August 2012 at Emory University and revised in September 2014 (Negi, 2012; Ozawa de Silva, Dodson-Lavelle, Raison, & Negi, 2012). It consists in its current format of six modules, two on mindfulness and four on compassion, taught in eight 2-hour-long or ten 90-minute-long weekly sessions with a certified teacher, with each session including instruction, discussion, and a 30- to 40-min-long meditation session.

The sessions include a series of sequential steps aimed to help practitioners progressively cultivate other-centered thoughts and behaviors while overcoming maladaptive, self-focused thoughts and behaviors. These are (1) developing attention and stability of mind through focused attention training, (2) cultivating insight into the nature of mental experience, (3) cultivating self-compassion, (4) developing equanimity and impartiality, (5) developing appreciation and affection for others, and (6) realizing engaged empathy and compassion. Topic overviews and their corresponding guided meditation recordings are available online for participants at http://www.tibet.emory.edu/cbct/CourseMaterials.html. CBCT-certified instructors follow a rigorous training that is to date only provided by Emory University. The contents of each of the six modules are summarized in Table 18.1.

Recent research on the impact of 6–8 weeks of CBCT practice on undergraduate students without prior experience in meditation shows reduced immune inflammatory and emotional distress responses to psychosocial stressors (Pace et al., 2009), as well as enhancement of empathic accuracy when assigning emotions to other people's faces with changes in the neurobiology supporting it (Mascaro, Rilling, Tenzin Negi, & Raison, 2013). In addition, CBCT has shown benefits with at-risk adolescents in foster care (Reddy et al., 2013), breast cancer survivors (Dodds et al., 2015), and medical students (Mascaro et al., 2016).

Little is known about the brain mechanisms of compassion, and CBCT in particular, when operating in response to real-life challenges. Some interesting insight comes from Desbordes et al.'s study (2012), when she compared the effects of a mindfulness-only training and CBCT (mindfulness and compassion) in a RCT using fMRI and self-reported measures of depression. When presenting participants with images of emotionally positive, neutral, and negative stimuli, they found decreased activity in the amygdala (a part of the brain that is typically used to assess the intensity of a person's emotional response) for all participants, with one important exception. When looking at the negative stimuli, amygdala activation increased in the participants that took CBCT. The CBCT mindfulness-compassion group also showed a significant decrease in self-reported depression, compared to mindfulness-only participants. These findings suggest that although amygdala activation may be part of an empathic and compassionate response, other factors

Table 18.1 Themes and contents of each of the six modules of CBCT

Module 1: Developing attention and stability of mind. Participants are provided with an introduction to the concept of meditation, as well as basic breathing exercises to help them understand how to cultivate refined attention and mental stability
Module 2: Cultivating insight into the nature of mental experience. Building on basic meditation and refined attention strategies provided in module 1, participants are provided with guidance to use their meditative mind to gain insight into their own thoughts, feelings, emotions, and reactions
Module 3: Cultivating self-compassion. The focus is on observing the innate desire for happiness and Well-being, as well as freedom from unhappiness and dissatisfaction. Participants use meditation to focus on shedding toxic mental and emotional states that promote unhappiness
Module 4: Developing equanimity and impartiality. Participants are encouraged to examine the labels they assign to people in their lives (e.g., friends, adversaries, strangers, etc.) and to consider the superficiality of these labels. Meditations focus on connecting more deeply to others through understanding of the shared desire for happiness
Module 5: Developing appreciation and affection for others. Session focuses on recognizing the interdependence of all things and people. Participants are encouraged to consider the many ways in which they are dependent on others, so as to develop appreciation and gratitude for the people in their lives. Meditations seek to achieve this aim through 1) reflecting on the kindness of others, as well as the drawbacks of a self-centered attitude, 2) using gratitude to cultivate affection and endearment for others, promoting, in turn, a deep sense of empathy
Module 6: Realizing engaged empathy and compassion. The focus of this module is on using the gratitude and empathy cultivated in previous sessions to help participants cultivate compassion for themselves and others. Meditations focus on moving from wishing happiness for others to actively committing to assistance in the pursuit of happiness and freedom from suffering. Participants are also provided with strategies and tools to continue their compassion meditation training beyond the CBCT program

contribute to the person's judgment of their general state of well-being: participants trained in CBCT may feel more, but they feel better. There is more to the complex subjective experience of an emotion than the brain assessment of the valence and intensity of the stimulus that provokes it. This is particularly relevant for people who deal with pervasive lifetime conditions, like autism, which could be considered challenges a priori, but do not necessarily lead to depression or distress for all.

Training in compassion and mindfulness meditation, and in CBCT in particular, has the potential to improve overall well-being and social competence and reduce distress in adults involved in the care of children with autism. Training in CBCT would affect directly the quality of social interactions (e.g., by increasing empathy) but also indirectly by reducing overall stress. More specifically, the mindfulness component of this training should be associated with a greater control of mental processes in the participants and therefore improve behavioral regulation and flexibility. In addition, the compassion component should enhance empathy and compassion, skills that will allow parents to take advantage of social support and navigate more skillfully the health-care system. As a consequence, there should be a positive effect on parent stress level, on social competence (parent-child and parent-professional interactions), and, ultimately, on the children's intervention outcomes.

CBCT for Parents of Children with Autism: A Pilot Experience at the Marcus Autism Center

We recently pilot-tested CBCT as an intervention for parents of children with autism at the Marcus Autism Center, in Atlanta, Georgia, with data recently presented at several international conferences (Fernandez-Carriba et al., 2015, 2016). Our attempt was both to offer a community-based service to this population and to collect empirical data on the feasibility of implementing this intervention eventually as a full-scale scientific efficacy study. We also hypothesized that engaging regularly in mindfulness and compassion-based meditation would reduce parenting distress, increase parent's sense of competence, and improve parent ratings of child behavior.

The study had a quasi-experimental design, without a control group. The sample included 14 parents of children with ASD and 1 mother of a child with fetal alcohol syndrome (FAS) (age in years M ± SD = 44.7 ± 5.9; 12 females). Among the 15 participants, 11 completed the training, i.e., missed 3 classes or less out of 10 weekly sessions. Only six parents completed pre- and post-measures. There were also follow-up measures sent 2 months after the training, which three participants completed. One of the four parents who did not complete the program reported months later to have incorporated meditation as a habitual practice as a result of the class, and two more remained in touch with the researchers and attended an informational meeting on the results of the study.

Overall, results from this pilot research demonstrated the feasibility and social acceptability of this intervention. Although the intervention was delivered in a group format, emphasis was placed on the very personal learning and practice. Satisfaction was very high for all participants for whom there was data. In a scale from 1 to 7, 7 being the maximum satisfaction, ten participants responded 7 and one responded 6. All of them also said that "they would recommend it to a friend"; in fact four of them added that they had already done so.

Quantitative Results

Before and after the intervention period, parents completed a battery of self-report questionnaires. These measures included the following:

- Stress and acceptance: Parenting Stress Index or PSI/SF, Perceived Stress Scale or PSS, and Acceptance and Action Questionnaire or AAQ
- Empathy and compassion: Interpersonal Reactivity Index or IRI
- Behavioral flexibility: Mindful Attention Awareness Scale or MAAS and Behavior Rating Inventory of Executive Function or BRIEF-A
- Parent-child relationship: Parenting Sense of Competence Scale or PSOC
- Perceived severity of the child's symptoms: Aberrant Behavior Checklist or ABC-Irritability Scale

As Table 18.2 shows, there were significant changes in seven of the eight measures in the six participants who returned the questionnaires. These participants were also the ones who had the highest values in attendance and homework. First, the indices of distress (four scales out of five in the PSI, including the PSI total scale, and the PSS) showed significant lower values for these parents after the training. Second, acceptance, mindfulness, and parenting sense of competence increased significantly (AAQ scores went down and MAAS and PSOC scores went up). Third, executive functioning skills, including the ability to shift attention and focus on something new, significantly improved after intervention. Finally, and probably one of the most interesting findings, was that parent-reported disruptive behavior of the children with autism decreases from Time 1 to Time 2, as measured by the Irritability Scale of the ABC, significantly decreased. Only one parent reported changes in their child's community or school intervention during the course of the study, suggesting that child gains may have been directly related to the CBCT training. Unfortunately, little can be said at this time about maintenance of benefits. Only three parents completed the measures 2 months after the training concluded, suggesting that at least some of these benefits were maintained.

Qualitative Results

Qualitative analysis of a small number of testimonials shared by the participants upon completion of the training indicated a number of common themes. Specifically, a general experience of self-growth and feeling of compassion emerged toward self (despite nonsignificant changes in the IRI scale). An increased sense of control, enhancement of coping skills, facilitation of interpersonal abilities, and broadening of perspective were also identified. For instance, one participant stated, "CBCT is allowing me to take care of my son in a much healthier way." Another one extended her experience to an interaction with a provider, "My frustration with that provider dissolved when I started to think of her as another confused human

Table 18.2 Pre-post changes in measures of distress, acceptance, empathy and compassion, behavior flexibility, parent-child relationship, and child's perceived symptomatology in CBCT participants at the Marcus Center

Measure, estimate (95% CI)	Time 1 (M±SD)	Time 2 (M±SD)	P-value
Parent distress			
PSI – defensive responding	23.2 (5.4)	15.6 (5.03)	**0.003**
PSI – parent distress	35 (7.18)	24.6 (7.7)	**0.009**
PSI – parent/child dysfunction	31.6 (10.31)	27.6 (8.56)	**0.065**
PSI – difficult child	43 (4.42)	35 (9.03)	**0.029**
PSI – total	109.6 (19.03)	87.2 (19.78)	**0.003**
PSS	20.83 (2.79)	10.33 (2.94)	**0.005**
Acceptance			
AAQ[a]	23.6 (6.1)	14.2 (1.92)	**0.019**
Empathy and compassion			
IRI – perspective taking	20.67 (2.94)	23.17 (3.25)	0.166
IRI – fantasy	17.5 (4.89)	14.17 (9.43)	0.441
IRI – empathic concern	20.5 (4.59)	24.5 (1.64)	**0.041**
IRI – personal distress	13.17 (3.37)	11.5 (6.57)	0.541
Behavior flexibility			
BRIEF – behavioral regulation[a]	55 (4.73)	45.33 (5.68)	**0.006**
BRIEF – metacognition[a]	56 (5.33)	48.5 (5.05)	**0.003**
BRIEF – global composite score[a]	83.17 (5.60)	64.33 (6.53)	**<0.001**
MAAS	42.2 (4.92)	67 (10.39)	**0.004**
Parent-child relationship			
PSOC	68 (6.36)	79.8 (3.42)	**0.008**
Perceived child's symptomatology			
ABC-I	8.6 (5.18)	5.4 (4.51)	**0.009**

Note: PSI refers to Parenting Stress Index (Abidin, 1995), PSS to Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983), AAQ to Acceptance and Action Questionnaire (MacDonald, Hastings, & Fitzsimons, 2010), IRI to Interpersonal Reactivity Index (Davis, 1980), MAAS to Mindful Attention Awareness Scale (Brown & Ryan, 2003), BRIEF-A to Behavior Rating Inventory of Executive Function (Roth, Isquith, & Gioia, 2000), PSOC to Parenting Sense of Competence Scale (Gibaud-Wallston & Wandersman, 1978), and ABC-I to Aberrant Behavior Checklist-Irritability Scale (Aman, Singh, Stewerat, & Field, 1985)

P-values in bold are at the 0.05 significance level

[a] Interpretation is inversed for results of the AAQ and the BRIEF scales. Higher scores indicate lower acceptance and lower behavioral flexibility, respectively

being; she didn't have the information I needed but I remained open enough to see that she could be helpful in other ways, and she was."

Other themes participants reported included feeling validated, recognizing the universality of their difficulties, being more able to accept their feelings, and having hope in their capacity to face challenges. Finally, the experience of normalization of personal struggles was also revealed through this analysis. "The CBCT program shows we are human, we can be balanced," shared one of the participants. And another one added, "Two weeks into CBCT I was told that something about me had changed; I was not so argumentative, something had opened up."

As reported in Marchant (2016), one of our participants eloquently described her experience in the CBCT training, not only the success of her participation in the program but also her new understanding and acceptance of her life experience with her children's autism:

> <<CBCT is now being taught in a range of communities at risk of stress, including breast cancer survivors, veterans with PTSD, native Americans – and autism carers. For Fhena, the course, led by Marcus Center psychologist Samuel Fernandez-Carriba, was a revelation. "The fog started clearing," she says. During the course, Fhena says she realized that autism had come to define her children in her eyes. "All you see is a burden. It was robbing me of so much I could give to them." Instead of being overwhelmed by her own stress and misery, she started to view the world from her kids' perspective and to see them as people in their own right. "In the class, I released a feeling of entitlement," she says. "The feeling that I was supposed to have a life without these challenges." She had always tried to be a good person. "I thought, this isn't what I put into the pot, why am I getting this out?
>
> Then I realized. These special beings were given to me because of what I put into the pot."

And with that single thought, much of the stress in Fhena's life disintegrated. Instead of feeling bitter and resentful, "I'm enjoying being with them." And her children have responded beautifully. "Every day there is a new blossoming," she says. "Ahav is drawing cruiseships in 3D detail. Analiel is writing 25 songs a day." And the best moment of all is when Ahav said "Mommy, I'm so proud of you. Because I know that you love me even more now.">>

Taken together, these promising results indicate that CBCT is a feasible training for parents of children with ASD, with potential benefits on their stress, on their parenting sense of competence, and on their perceived children's severity. A randomized controlled trial should test its efficacy under controlled conditions.

Conclusions

Despite the active role parents have been given in the last few decades in the interventions designed for their children with autism, there is very limited research on the mechanisms that make their participation most helpful for themselves and the children. There is also a large corpus of data on their distress and lack of quality of life, while much less attention has been paid to how to address these challenges, other than treating directly the symptoms of their children. Although parent distress can negatively impact children's outcome, it does not follow that improvements in children's severity are associated with improvements in the parents' well-being, suggesting that there is more to a person's distress than their challenging circumstances, e.g., their coping strategies with those circumstances and level of social isolation. The question about how exactly a self-help program for the parents may benefit their children warrants further investigation. We propose mindfulness and compassion meditation, and CBCT in particular, as a feasible, potentially helpful training in stress reduction and social competence for parents of children with autism. Its focus on self-regulation and social regulation, two well-known difficulties in the life of families living with autism, makes it especially fitting. Empowering the parents this way, we believe, will benefit their children.

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Part V

Comprehensive Parent-Implemented Models for Young Children with Autism

19

Supporting Parents to Promote Emotion Regulation Abilities in Young Children with Autism Spectrum Disorders: A SCERTS Model Perspective

Amy C. Laurent, Barry M. Prizant,
and Kathleen S. Gorman

Abstract

Emotional regulation is a key developmental capacity concerned with the regulation of physiological arousal, emotion, and attention. Effective emotional regulation is associated with social success, academic readiness, and pro-social behaviors. Young children with autism spectrum disorder (ASD) have documented emotional regulatory challenges. These difficulties include challenges in managing emotions, focusing attention, inhibiting reactions, delaying gratification, and seeking comfort in conventional ways. Some of these difficulties are associated with neurological differences and cognitive learning style differences, which are associated with an ASD diagnosis. Other challenges may be associated with ASD-related social learning differences, which impact the nature and effectiveness of parent/child interactions that are geared toward expanding a young child's emotional regulatory abilities. An emotional regulation approach to intervention represents a relatively new focus in intervention for young children diagnosed with ASD and holds the promise of supporting active engagement in everyday activities resulting in more emotionally satisfying social interactions between children and their caregivers. A brief framework for assessment of young children's emotional regulatory abilities and selection of developmentally appropriate emotional regulatory objectives utilizing the SCERTS® Model is presented. Parent coaching, embedding teaching opportunities within natural routines, and modeling are discussed as developmentally appropriate intervention techniques for young children at presymbolic and symbolic levels of communication.

Overview of Emotional Regulation

There is much debate regarding the precise definition of emotional regulation. Throughout the literature the term emotional regulation is used conceptually to refer to a vast array of developmental abilities and behaviors which serve to

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_19

help an individual shift physiological arousal level, modulate emotional state, and modify attentional focus, all in an effort to meet social expectations, maintain engagement, and accomplish objectives (Cole, Martin, & Dennis, 2004; Eisenberg & Spinrad, 2004; Kopp, 1982). Emotional regulation is also regarded as an underlying process that provides a foundation for attention and social engagement, which in turn supports the development of communication and social relationships (Prizant & Meyer, 1993).

In order to understand emotional regulation as a developmental capacity, it is first essential to establish the nature of emotion. Emotions are multidimensional internal states experienced by an individual in response to an event or interaction which is either actual, remembered, or imagined (Fox, 1994). A given emotion may vary along multiple continua. These include polarity (e.g., positive to negative) and intensity (e.g., mild to extreme). Emotions are biologically driven processes that are linked to rapid appraisal of situations, and their regulation can contribute to and/or undermine the development of new abilities in young children (Eisenberg & Spinrad, 2004; Eisenberg & Sulik, 2012; Spinrad et al., 2006) . It is widely regarded that heightened emotional states which correlate to heightened physiological arousal states may compromise a young child's ability to function adaptively, maintain engagement, and sustain interactions. Therefore, emotion-focused self-regulation seeks to moderate emotional experience in order to promote adaptive responses in the environment (Fox, 1994). Emotional regulation is accomplished by modulating all aspects of emotional states through the use of a variety of strategies in order to cope with arousing and/or stressful events (Eisenberg & Sulik, 2012; Grolnick, Bridges, & Connell, 1996; Spinrad, Eisenberg, & Gaertner, 2007).

Emotional regulation has been defined as having five distinct, yet interrelated, dimensions: (1) cognitive appraisal of the situation, interaction, or event, (2) resultant physiological experience (e.g., arousal changes), (3) emotional expression (e.g., affective display and action), (4) socialization of the emotional response within context, and (5) shifting of emotion or mood states (Degangi, 2000; Sherrer, 1994). In other words, in order to respond to an event or interaction adaptively, a child first registers the stressor, then experiences a resultant shift in arousal and emotion, and finally produces an observable behavioral reaction appropriate for the context. These dimensions are useful when conceptualizing the development of emotional regulation in young children, as well as when identifying emotional regulatory difficulties. When emotional regulation is successful and effective, children are able to use strategies to shift emotion or arousal states to meet the demands of social and physical environments. This match between internal state and environment is often referred to as a well-regulated state, a state in which an individual is available for learning and engaging. In contrast, when a child does not adaptively shift emotion and arousal level, resulting in an arousal level that is either too high or too low to engage adaptively, that individual experiences emotional dysregulation (Eisenberg et al., 2003; Rothbart & Bates, 1998). It should be noted that emotional regulation is not a dichotomous process yielding either a complete match between internal state and environmental demands or a complete mismatch. Effectiveness of emotional regulation may be regarded along a continuum ranging from well-regulated states to mild, moderate, and even extreme states of dysregulation. This continuum of regulatory states is associated with emotions of all valences. For example, mild dysregulation associated with happiness may present as giddiness, while mild dysregulation associated with fear may present as nervousness. In contrast, extreme dysregulation for these emotions may present as ecstasy and panic, respectively.

Emotional regulation is regarded as a developmental construct; as such, a child's skills and capacities increase with age and maturation. This developmental expansion of a child's emotional regulatory abilities facilitates the child's transition from complete dependence on caregivers for regulatory assistance, to competent and independent functioning in the face of dysregulating circumstances (Grolnick, Kurowski, McMenamy, Rivkin, & Bridges, 1998; National Research

Council, 2000). It's the process whereby young children gain control over their emotional state rather than allowing their emotions to have control over them. The principle function of emotional regulation is attainment and maintenance of emotional and arousal states that support engagement and learning. As a child develops so does his/her repertoire and sophistication of emotional regulatory abilities. This expanding repertoire of strategies supports flexible and adaptive responses to situations in the environment as well as internalized and external expectations (Zimmerman, 2000). Effective and efficient age-appropriate emotional regulatory abilities have been critically linked to positive social-emotional development in early childhood and to pro-social engagement, social competence, and desirable academic outcomes in later childhood (Eisenberg, Spinrad, & Eggum, 2010; Kopp, 1982; McClelland & Cameron, 2012; Spinrad et al., 2006; Trentacosta & Shaw, 2009; Tronick, 2002). Deficits in age-appropriate emotional regulation abilities (e.g., difficulties resulting in heightened physiological reactivity, unmodulated emotion, and poor impulse control) are associated with reactive aggression and externalizing behaviors throughout childhood (White, Jarrett, & Ollendick, 2012).

Development of Emotional Regulation

As previously discussed, emotional regulation is a developmental capacity and a dynamic skill set that evolves as part of this development. A young child's emotional regulatory abilities change with maturation, in response to modeling by others, and as the result of direct teaching by caregivers. It is generally conceived that emotional regulatory abilities develop rapidly in early childhood and continue to mature into adulthood (Eisenberg et al., 2010; Eisenberg & Sulik, 2012). Infants are born with a biobehavioral drive for homeostasis and maintenance of a well-regulated state (Fox, 1994). However, infants have very few strategies available to them to help regulate their arousal level, emotional state, and attention. In general, infants are born with the reflexive abilities to avert their gaze, to engage in a non-nutritive suck, and to shut down in response to arousing interactions events or situations. The utility of these strategies is limited in terms of supporting engagement; therefore, infants require assistance with regulation (Fox, 1994). In an effort to support infants' regulation, caregivers typically respond to signals of dysregulation (e.g., crying and vocalizing) by employing a range of respondent mutual regulatory strategies to either facilitate engagement or to comfort (Tronick, 2002). These strategies provide infants with opportunities to experience new emotional regulatory means in supportive interactive relationships. Repeated interactions with caregivers scaffolding regulatory development, paired with increasing developmental abilities (e.g., motor skills, communicative abilities, and social-cognitive awareness), support a young child's ability to learn, integrate, and utilize new, more sophisticated, and socially conventional emotional self-regulatory strategies in his or her behavioral profile.

The interplay of supportive mutual regulatory interactions, child development, and acquisition of new self-regulatory strategies continues throughout childhood, eventually leading to a child's ability to initiate intentional requests for emotional regulatory assistance and to continued refinement of socially appropriate emotional self-regulatory abilities based on feedback given by caregivers. Children typically exhibit the ability to utilize their expanding emotional regulation abilities for the function of intentional behavioral control starting at 9–12 months of age (e.g., using comfort object to self-soothe), to guide interactive responses with internalized behavioral expectations by 24 months (e.g., labeling and sharing emotional state using conventional means), and to meet situational demands with considerable flexibility and expanded effortful control by 36 months (e.g., waiting and delaying gratification) (Eisenberg et al., 2010; Kopp, 1982; Sanders & Mazzucchelli, 2013). However, children do demonstrate variability in their abilities to utilize their expanding emotional regulatory strategy repertoire efficiently and effectively to maintain a well-regulated state. Several factors contribute to this variability in employing effective regulatory strategies. These include biological factors (e.g., factors related to sleep and health states), psychological factors (e.g., factors related to cognition, emotional memory, and reactivity bias), and social factors (e.g., factors related to social complexity and interactive demands) (Prizant & Laurent, 2012b).

Emotional Regulatory Strategies

The emotional regulatory strategies that a young child acquires through the interactive cycle described above vary widely and serve a variety of functions (e.g., soothe, distract, self-comfort, delay gratification, and problem solve) (Grolnick et al., 1996). The nature of emotional regulatory strategies that comprise a young child's repertoire and that caregivers can use effectively to support young children is largely dependent upon the child's motoric, communicative, cognitive, and social-emotional developmental capacities. For example, young infants are capable of using and benefitting from sensory-motor/behavior strategies for emotional regulation and comfort seeking. However, when an older toddler makes the transition to being a symbolic communicator, he/she is also able to employ and respond to language-based strategies to express emotions, focus attention, manage needs, and gain assistance (Prizant, Wetherby, Rubin, Laurent, & Rydell, 2006b). In typically developing young children, language-based self-regulatory abilities emerge between 18–24 months of age and lay the foundation for metacognitive strategies (Grolnick et al., 1996; Zimmerman, 2000). Metacognitive self-regulation strategies develop during the preschool and early elementary school years when children actively begin to consider the effectiveness of self-regulatory strategies previously used and planfully assess their utility in current contexts and situations based on feedback given by their social partners (Spinrad et al., 2007; Zimmerman, 2000). It should be noted that a typically developing child's repertoire of emotional self-regulatory strategies expands to include all three types of strategies – behavioral, language/symbolic, and metacognitive – throughout the course of childhood and adolescence. The specific strategies used by a young child is thought to depend upon context, regulatory process, and degree of arousal (Prizant et al., 2006b).

Emotional Regulation Challenges in ASD

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impairment in social communication and the presence of restricted repetitive and stereotyped patterns of behavior, interests, and activities (American Psychiatric Association, 2013). In addition to these diagnostically significant observable behaviors, it is widely accepted that individuals with ASD display characteristics that are consistent with challenges in emotional regulation (Mazefsky et al., 2013). Difficulties managing emotions, focusing attention, inhibiting reactions, delaying gratification, tolerating transitions, and seeking comfort in conventional ways have been found in this population (American Psychiatric Association, 2013; Baron, Groden, Groden, & Lipsitt, 2006; DeGangi, 2000; National Research Council, 2001). Several studies document the existence of deficits in age-appropriate self-regulation abilities in the ASD population when compared to same aged typically developing controls or other developmentally disabled populations. For example, Konstantaras and Stewart (2006) found evidence of impaired affect regulation and reduced numbers of effective self-regulation strategies in the behavioral profile of children with ASD when compared to those of typically developing controls. Likewise, Glaser and Shaw (2013) reported evidence of greater emotional regulatory challenges in children diagnosed with ASD as opposed to those diagnosed with 22q13 deletion syndrome. And, Samyn and colleagues noted reduced effortful control in children diagnosed with ASD when compared to typically developing children during mildly frustrating tasks (Samyn, Roeyers, & Bijttebier, 2011). Given the perceived prevalence of emotional regulatory challenges in this population, there is mounting interest in understanding the development of emotional regulation difficulties for individuals with ASD and in designing interventions to minimize the far-reaching implications of such deficits.

Factors Influencing the Development of Emotional Regulation in ASD

Several authors have offered theoretical perspectives on the regulatory challenges faced by children with ASD (Laurent & Rubin, 2004; Loveland, 2005; Prizant, Wetherby, Rubin, Laurent, & Rydell, 2006a). In fact, it has been suggested that developmental patterns observed in ASD are characterized by impairments in emotional regulation and that early emotional regulation difficulties may function as red flags for an ASD diagnosis (Gomez & Baird, 2005; Mazefsky et al., 2013; Whitman, 2004). Still others have suggested that the degree of emotional self-regulatory impairment displayed by a child with ASD may account for at least a portion of the heterogeneity seen in long-term outcomes and adaptive functioning exhibited by children on the spectrum, with the most dysregulated children demonstrating the poorest outcomes (Jahromi, Bryce, & Swanson, 2013). Challenges in emotional regulation are thought to be influenced by several factors and ASD-related characteristics. These include, but are not necessarily limited to, neurological differences, learning style differences, social impairments, and communicative impairments.

Several differences in neurological structure and function which are thought to be related to the development of emotional regulation have been detailed in the ASD literature. In particular, the orbitofrontal-amygdala circuit which is employed in social cognition and is considered to be essential for the regulation of attention and behavior and the prefrontal cortex which is involved in conscious emotional expression have been implicated in contributing to regulatory challenges in the behavioral profiles of individuals with ASD (Bachevalier & Loveland, 2006; Ben Shalom et al., 2006). Additionally, learning style differences associated with ASD have also been highlighted as factors contributing to emotional regulation challenges in ASD. For example, preference for non-transient information observed in ASD correlates with decreased attention to and awareness of others' feelings, beliefs, and intentions and to decreased comprehension of abstract language such as emotional vocabulary (Prizant et al., 2006b). These difficulties are associated with challenges identifying and expressing emotion, two core dimensions of emotional regulation (Fitzgerald & Bellgrove, 2006). In addition, the bias of attention to objects rather than people is associated with deficits delayed in imitation which is a critical skill supporting the expansion and refinement of emotional regulatory strategies within the context of interactions with caregivers (Kopp, 1982). This particular challenge has been implicated in the persistence of early developing behavioral strategies for emotional regulation such as the use of repetitive behaviors in the face of stressful conditions which are frequently exhibited by young children diagnosed with ASD and is also related to social impairments seen in the behavioral profiles of children with ASD (Leekam, Prior, & Uljarevic, 2011; Loveland, 2005).

Deficits in joint attention are associated with difficulties responding consistently to the sound of caregivers' voices, following gaze, referentially looking, social referencing, and understanding the communicative perspective of another person. For young children diagnosed with ASD, these are diagnostically significant social challenges that relate to limited responses to and initiation of reciprocal social interactions. Such interactions are necessary for increasing the sophistication of the development of emotional regulation abilities (American Psychiatric Association, 2013; Jahromi, Meek, & Ober-Reynolds, 2012). Typically developing children who engage more frequently in joint attention with caregivers demonstrate more sophisticated regulatory strategies, as well as a greater ability to modify emotional reactions and regulatory strategies in response to feedback of others (Bachevalier

& Loveland, 2006; Konstantareas & Stewart, 2006; Raver, 1996). Implications of these findings extend to ASD, and emerging research suggests that children with ASD who demonstrate less joint attention exhibit greater emotional self-regulatory challenges (Gulsrud, Jahromi, & Kasari, 2010). In addition to the influence of social impairments, deficits in receptive and expressive language exhibited by young children with ASD are also thought to influence emotional regulation skill development. Receptive language deficits may relate to compromised abilities to benefit from caregivers modeling emotional labels and using language to preview potentially stressful events, such as transitions. While, expressive communication delays make bids for assistance and distress signals less readable to caregivers. As a result mutual regulatory assistance tends to be less efficient and effective, compromising the acquisition of new self-regulatory strategies (Fitzgerald & Bellgrove, 2006).

Finally, young children diagnosed with ASD also demonstrate additional behaviors and characteristics that are associated with emotional regulatory challenges. These include difficult temperament (e.g., less positive affect, greater irritability, challenges with inhibitory control, difficulty soothing, unfocused attention, and hypersensitivity to environmental stimuli), sensory processing differences (e.g., heightened or dampened responses to sensory information), and motoric challenges (e.g., difficulty motor planning and gross/fine motor developmental delays) (American Psychiatric Association, 2013; Clifford, Hudry, Elsabbagh, Charman, & Johnson, 2013; Jahromi et al., 2012; Konstantareas & Stewart, 2006; Loveland, 2005). Individually, as well as collectively, these characteristics may result in intense emotional reactions, relative high states of distress, and difficulties enacting efficient and effective regulatory strategies. This behavioral presentation in early childhood contributes to frequent episodes of dysregulation for children diagnosed with ASD and is associated with increased risk for the development of anxiety and maladaptive behaviors (Gulsrud et al., 2010; Loveland, 2005; Mazefsky et al., 2013).

Social Environmental Influences Contributing to the Development of Emotional Regulation for Children with ASD

Parents and other caregivers also play a critical role in the development of emotional regulation. Indeed, the mutual interdependent relationship between the young child and the social context is the foundation of emotional regulation development (Hubley & Trevarthen, 1979; Kopp, 1982; Sameroff & Fiese, 1990; Tronick, 2002). Emotional regulation is a transactional process and develops rapidly within environments that are supportive of social-cognitive and social-emotional learning (Sanders & Mazzucchelli, 2013; Zimmerman, 2000). For example, the quantity and quality of regulatory behaviors utilized by typically developing children is shaped by parental emotional expressivity in interactions and their use of emotional regulatory strategies in the home environment (Eisenberg et al., 2001, 2003).

Within the family context, several factors have potential to impact aspects of regulatory interactions between parents and young children diagnosed with ASD. Early in childhood, caregivers help infants and very young children regulate their emotional and physiological state by reading their emotional and behavioral signals, imputing communicative intent, and providing direct sensory-motor/behavioral support aimed at modulating arousal levels and reinforcing children's adaptive emotional regulatory behaviors (Cole, Ledonne, & Tan, 2013; Sanders & Mazzucchelli, 2013). The quality and effectiveness of these responsive mutual regulatory interactions is considered to be significant to a child's developing ability to regulate his or her own physiological state and emotions through the acquisition of new and more sophisticated regulatory skills (Kochanska, Murray, & Harlan, 2000; Tronick, 2002). If caregivers are successfully supportive and responsive, young children shift from states of dysregulation into better regulated and engaged behavioral patterns and attempt new self-regulatory behaviors (Eisenberg et al., 2010). Conversely, if caregivers have difficulty reading a young child's signals accurately due to social communication delays and in turn have difficulty providing relevant and effective sensory-motor mutual regulatory strategies, a young child will not learn and integrate new behavioral emotional regulatory skills, often resulting in greater risk for experiencing dysregulation (National Research Council, 2000; Prizant et al., 2006a).

Likewise, social communicative deficits demonstrated by young children with ASD may further impact the quality of supportive regulatory interactions undertaken by parents. Parents shape the development of language-based strategies by socializing arousal into emotional states (Saarni, 1998). They do so initially by responding to a child's emotional expressions, labeling the emotional states, assisting with regulation, and later discussing the emotions in the context of experiences to give rich emotional meaning to events (Zimmerman, 2000). Indeed, children of parents who discuss emotions frequently demonstrate more sophisticated understanding of emotion and accurate emotional expression. When this type of interaction is not facilitated, children are less likely to spontaneously communicate their emotional state in interactions with others and use other language-based strategies for self-regulation (Begeer, Koot, Rieffe, Meerum Terwogt, & Stegge, 2008). Research suggests that parents of young children diagnosed with ASD use language infrequently for regulatory functions such as emotional expression and previewing stressful events during play (Gulsrud et al., 2010). This profile translates to reduced exposure to more sophisticated language-based regulatory strategies for young children diagnosed with ASD.

The transactional relationship between children and caregivers that strongly influences the development of a child's regulatory abilities is bidirectional. Evidence suggests that child factors beyond social communication such as emotional state, regulatory attempts, and age all affect how parents scaffold regulation for their children (Cole et al., 2013; Grolnick et al., 1998; Sameroff & Fiese, 1990). Cole et al. (2004) examined the relationship between typical children's negative emotional expression and parental response and found that mothers experienced negative emotional reactions and subsequently decreased their scaffolding of regulatory behaviors for their children. These results are potentially significant to consider in relation to young children with ASD who exhibit difficult temperaments, as they highlight another potentially disruptive factor impacting upon the interactive/relational context critical to the development of a child's self-regulation abilities.

Parental factors have also been implicated in altering the nature of interactions related to the development of emotional regulation. Parenting a child with ASD is highly correlated with high levels of stress (Domingue, Cutler, & McTarnaghan, 2000). Research suggests that high levels of parental stress interfere with responsive parenting which is associated with supporting, scaffolding, and modeling emotional regulatory strategies (Kochanska et al., 2000). Likewise, heightened levels of stress are also related to the type of mutual regulatory strategies enacted by caregivers to support a child's emotional regulation. Specifically, parents experiencing stress tend to rely on early developing behavioral/sensory-motor strategies such as holding a child rather than employing more sophisticated language-based and cognitive regulatory strategies regardless of their child's age and developmental abilities (Gulsrud et al., 2010). The combination of these phenomena suggest that parents of children with ASD may have difficulty providing tailored and effective regulatory supports which expand their child's emotional regulatory repertoire (Gulsrud et al., 2010).

Several other contextual factors are related to the development of emotional regulation for all young children, including those with ASD. These include family economic and socio-cultural factors. Cultural variations in caregiving practices also influence parent/child mutual regulatory interactions and, in turn, the development of emotional self-regulation in children. Cultural preferences, beliefs, and practices determine which of the child's signals are responded to, what strategies are modeled, and which characteristics of behaviors are viewed as problematic in the context of regulation (National Research Council, 2001). In this way culture provides a significant context for children as they learn to understand and interpret emotional experience, determine the appropriateness of regulatory strategies, and organize their behaviors (Eisenberg et al., 2003; Li-Grining, 2012).

Additional environmental factors are known to influence the development of self-regulatory competence. For example, socioeconomic adversity, low levels of parental education, and lack of social resources are considered to be risk factors correlated with regulatory disorders (Li-Grining, 2012; Supplee, Skuban, Trentacosta, Shaw, & Stoltz, 2011). In contrast, a positive educational environment is considered to be a protective factor. For example, active engagement in classroom activities is associated with increasing emotional regulatory abilities (Williford, Vick Whittaker, Vitiello, & Downer, 2013)

An Emotional Regulatory Approach to Intervention for Young Children with ASD

An emotional regulatory approach (ERA) represents a relatively new focus in intervention for young children diagnosed with ASD and holds the promise of bolstering a child's active engagement and sustained, mutually fulfilling interaction (Prizant & Laurent, 2012a). The overarching goals of an emotional regulation approach are to support emotional well-being of the young child diagnosed with ASD and to and maximize the child's active engagement and learning within the context of trusting relationships. Secondary goals include the reduction of problem behavior and the increase in developmental capacities (Prizant & Laurent, 2012b). These broad, programmatic goals often align with parental priorities for intervention for their young children. Parents of young children diagnosed with ASD often identify therapeutic and educational goals for their children consistent with increasing attention to tasks, engaging in extending play, sharing positive experiences in interactions, and reducing challenging behaviors. These intervention priorities in turn align with long-term desires for their children's development, which relate to effective emotional regulation abilities and include social success, academic success, and pro-social behaviors (Prizant et al., 2006b).

An ERA is based on family-centered intervention practices (Chapters "Facilitating toddlers' social communication from within the parent-child relationship: application of family-centered early intervention and mediated learning principles, Strength-based approaches to working with families of children with ASD, and Parents as developing adults and developing adult learners"). Family-centered intervention has long been recognized as an effective and appropriate intervention model for young children diagnosed with developmental disabilities (IDEA, 2004). Recent studies have demonstrated the effectiveness of this type of approach for young children diagnosed with ASD, as well (Dunn, Cox, Foster, Mische-Laweson, & Tanquaray, 2012; Wetherby et al., 2014). Central to this philosophy is the involvement of family members in all aspects of programming from assessment to selection of objectives and the implementation of intervention strategies in the home environment. Additional hallmarks of family-centered practices also include partnering with the family to identify the strengths of a family, recognizing family members as experts with respect to their child's abilities and challenges, and supporting the family's efforts to scaffold the child's abilities (McWilliam, 2010). A family-centered ERA also recognizes and honors family members for the critical role that they play in the development of their young child's emotional regulation abilities within the context of daily activities and interactions.

One family-centered intervention model that provides a useful framework for implementing an ERA is the SCERTS® Model. In the subsequent sections of this chapter, portions of the SCERTS® Model will be used to illustrate key aspects of an ERA for young children on the spectrum. Parent coaching, embedding teaching opportunities within natural routines, and modeling will be discussed.

The SCERTS® Model

The SCERTS® Model is a comprehensive intervention model for young children and older individuals with ASD and their families. It is designed to identify and address significant social communication and emotional regulation difficulties experienced by individuals with ASD while building upon strengths through parent/professional collaboration (Prizant, Wetherby, Rubin, & Laurent, 2003). In both assessment and intervention efforts, the SCERTS® Model uses an ERA that recognizes a child's developmental capacities and encourages the caregivers to understand their child's emotional regulatory profile and challenges within the context of that child's larger developmental profile, social experiences, and environments. This profile then forms the basis for deriving developmentally appropriate interventions. The SCERTS® Model (Prizant et al., 2006a) provides a framework that supports this line of inquiry and resulting intervention practices. The SCERTS® curriculum builds upon the natural developmental processes associated with emotional self-regulation while embracing the transactional influence of mutual regulation.

Assessment Assessment of emotional regulation for young children diagnosed with ASD requires careful consideration of a child's full developmental profile. High priority is placed on accurately capturing the child's social communicative abilities since these skills are closely related to emotional self-regulatory abilities and are transactionally linked to developmental processes supporting the expansion of emotional regulation abilities. Identifying and understanding a young child's profile of cognitive learning style, communication, and social abilities helps to contextualize the regulation challenges identified in assessment and inform developmentally appropriate intervention planning. Likewise, given that the development of emotional regulation is a transactional process, concurrent assessment of transactional supports (e.g., the social context and parent abilities) is critical for understanding functional regulatory challenges within natural contexts. The SCERTS® Assessment Process (SAP) is designed to gather such information (Prizant et al., 2006b).

There are several priorities when undertaking assessment of a young child's emotional regulatory abilities. These include (1) building a profile of strengths related to the child's current emotional regulatory abilities, (2) gathering information related to the emotional regulatory challenges experienced by the child, (3) and ascertaining information related to caregivers' strengths and challenges supporting emotional regulation. These priorities are designed to reflect the relational qualities of a child's emotional regulatory profile. Specifically, information is gathered, organized, and interpreted with respect to mutual regulatory abilities, those that occur in the context of a supportive relationship and facilitate emotional regulatory development, and also with respect to separate but complementary self-regulatory abiltiies, those emotional regulatory skills which a young child independently displays.

The SCERTS® Assessment Process uses caregiver questionnaires (i.e., SAP-Report Form) and interviews, as well as observations of a young child within typical social and physical environments to gather information related to these priorities (Prizant et al., 2006b). Emotional regulation-focused questions are structured in such a way that the parent or other caregiver is able to reflect and generate answers based on that family's experiences interacting with their child. Follow-up questions eliciting further information are also used. Questions may include:

- What activities are the most fun or engaging for your child?
- What activities are distressing or boring for your child?
- Is your child able to maintain focus in activities? Does he or she use strategies to do so?
- How do you help your child maintain his/her focus during play or caregiving activities?
- How do you know when your child is happy or distressed? How readable are your child's emotions?

- Do you need to assist your child in recovery from extreme emotional upset, or does he/she recover by him/herself?
- What type of supports do you offer your child when he or she is upset?
- Does your child engage in challenging or problematic behaviors?
- How do you react or what strategies do you use if your child exhibits problem behaviors? (Prizant et al., 2006b)

Once this information is gathered, it may be used to start to build an emotional regulation profile for the young child with ASD. It may also be used to help identify useful times to observe the child within natural environments and daily routines in order to gain information and insights related to the young child's functional emotional regulation abilities. Naturalistic observation is crucial to truly understanding the emotional regulatory abilities of a child in relation to everyday experiences within the SCERTS® Model (Prizant et al., 2006b).

Assessment observations are conducted within the home and/or familiar community environments in order to gather data about the child's use of self-regulatory and mutual regulatory abilities. Professionals structure their observations of a child's emotional mutual regulatory abilities (i.e., those emotional regulatory skills that reflect an interactive component between the child and parent), in order to determine how the child (1) expresses emotions, (2) responds to regulatory assistance when offered by partners, (3) requests partners' assistance with regulation, and (4) uses assistance provided by partners to recover from extreme dysregulation (Prizant et al., 2006b). Observations of emotional self-regulation are structured to gather information about how the child is independently able to (1) demonstrate active engagement in activities and interactions, (2) use sensory-motor strategies to regulate emotional state and arousal level, (3) use language-based strategies to help regulate emotional state and arousal level, (4) use strategies to regulate emotional state and arousal level in new and changing situations, and (5) use strategies to recover from extreme dysregulation without assistance (Prizant et al., 2006b). Concurrent with assessing the child's emotional regulatory strengths and challenges, professionals gather additional information related to the supports families have put in place and utilize to scaffold their young child's emotional regulatory abilities. Information such as how family members are providing supportive interactions, how they are reading and responding to their young child's shifts in arousal and emotional state, and how they respond to challenging behavior is noted.

Collectively, all of this information is combined to create an overall profile of the child's regulatory abilities and challenges, as well as a profile of the supportive features of the child's physical and social environments. As previously discussed, this emotional regulation profile is assembled while considering other aspects of the young child's development. It is particularly useful to consider the child's language and cognitive learning style, specifically, whether the child has developed symbolic communication or utilizes presymbolic means to communicate. Interpretation of skills and behaviors can vary greatly based on this question. For example, is this a presymbolic child who constantly struggles with transitions and drops to the ground because language-based picture supports are beyond his comprehension? Or, is this a young boy who demonstrates fairly good abilities to understand language-based communication but struggles to use it for the purpose of emotional self-regulation? Considering data collected related to the child's abilities in this way helps to identify developmentally appropriate next steps for supporting the development of emotional regulation abilities.

In keeping with family-centered practice, assessment results are discussed and corroborated by family members. Adjustments to the child's emotional regulatory profile may be made if the parents feel there are inaccuracies or omissions prior to the selection of objectives and program planning.

Goal Selection and Intervention Priorities Priorities in a child's intervention plan are determined by identifying specific relevant objectives in self- and mutual regulation that are identified in the SCERTS ER curriculum

(Prizant et al., 2006b). Guidelines for selection of specific objectives within the SCERTS® Model are based on three key criteria when selecting emotional regulation objectives: (1) Is the objective a family priority?; (2) Is the objective developmentally appropriate?; and (3) Is the objective functional (i.e., will it make a meaningful difference in the child's life)? Will there be opportunities throughout the child's day to learn and apply the new ability targeted in the objective?

With respect to family priorities and functionality, family members are asked to reflect on what they consider to be critical skills for their child to attain. Would their child benefit from learning new behavioral strategies to cope with transitions, or would it be appropriate for this child to start to use basic emotion words to convey his feelings to his/her partners (e.g., sad, mad, happy)? Teams reflect and ask which objectives would likely bring more meaningful change and growth to the child and his/her family. During goal selection parents and professionals also discuss the transactional nature of the acquisition of emotional regulatory abilities. Consideration is given to whether goals should include mutual emotional regulation abilities as a means to bolster emotional self-regulatory strategies.

A child's team also discusses the developmental appropriateness of potential emotional regulatory objectives. The child's chronological age, regulatory profile, and symbolic communication abilities are considered when selecting either behavioral/sensory-motor means (e.g., movement activities, oral sensory support, tactile, or proprioceptive supports such as fidgets or deep pressure input) or conventional language (e.g., symbolic) means as new emotional regulatory strategy targets. For presymbolic children, only behavioral/sensory-motor strategies are considered. For developmentally more advanced children who are symbolic communicators, selecting objectives targeting the acquisition of either language-based or behavioral strategies may be included as part of the child's educational plan.

Below are sample emotional regulation goals and objectives, which may be appropriate for inclusion in the education plans of young children diagnosed with ASD. These represent both mutual regulatory strategies and self-regulatory strategies (see Tables 19.1 and 19.2).

Table 19.1 Goals and objectives for a child who is a presymbolic communicator, not yet using language[a]

Goal area	Sample objectives
Child responds to emotional regulatory assistance offered by partners	Calms when partners offer sensory-based comfort Engages when partners provide alerting or organizing sensory supports
Child independently uses behavioral strategies to regulate emotional state and arousal level	Uses behavioral strategies to increase and decrease arousal level during social activities Uses behavioral strategies that have been modeled by partners

[a]Excerpted and adapted from the SAP-Observation Forms. (Prizant et al., 2006b)

Once objectives are selected, the child's team selects interpersonal and activity-based supports that will be used by family members and caregivers in an effort to help the child attain the selected emotional regulatory objectives. These supports are consistent with responsive caregiving and are designed to help, engage, comfort, and distract as appropriate. Table 19.3 displays sample interpersonal and learning supports related to an ERA.

Intervention Within an ERA, intervention planning and execution is also guided by family-centered practice. As part of the assessment process, family members share detailed information about their child and their child's natural routines, while professionals consider this information within the ERA framework. Collectively, the parent/professional team uses this knowledge to develop a comprehensive educational plan to address the child's emotional regulation objectives.

SCERTS® is an activity-based model. As such, the team works to identify naturally occurring routines that present salient learning opportunities and considers how to embed the selected learning supports across the child's day in order to help the child accomplish the identified

Table 19.2 Goals and objectives for the child who is a symbolic communicator, using language to communicate[a]

Goal area	Sample objectives
Child responds to emotional regulatory assistance offered by partners	Calms when partners offer sensory-based comfort Engages when partners provide alerting or organizing sensory supports Changes behavioral strategies for emotional regulation based on feedback from partners
Child initiates requests for assistance in regulating arousal and emotional state	Seeks assistance when experiencing frustration Shares negative emotions to seek comfort from partners Uses symbolic communication to express a range of emotional states
Child uses behavioral strategies to regulate emotional state and arousal level	Uses behavioral strategies to increase and decrease arousal level during social activities Uses behavioral strategies that have been modeled by partners Uses behavioral strategies to actively engage in extended activities and interactions
Child uses language-based strategies to regulate emotional state and arousal level	Uses language strategies to increase or decrease arousal during solitary activities Uses language strategies that have been modeled by partners Uses language strategies to actively engage in extended activities and interactions

[a] Excerpted and adapted from the SAP-Observation Forms. (Prizant et al., 2006b)

Table 19.3 Sample interpersonal and learning supports[a]

Interpersonal supports	Learning and activity supports
Recognize signs of dysregulation and offer support Allow child to take breaks Secure child's attention before communicating Provide guidance for expressing emotions Model nonverbal means for communicating	Provide predictable sequence to activity Introduce augmentative communication for emotional expression Use visual supports for transitions Modify sensory properties of the environment

[a] Excerpted and adapted from the SAP-Observation Forms. (Prizant et al., 2006b)

emotional regulatory objectives. For very young children diagnosed with ASD, many of these activities will occur within the context of the home environment. Targeting skills in the home environment is important because it not only provides a natural context for learning but also presents repeated opportunities to use the targeted skills. Both of these qualities of intervention have been identified as critical in effective educational programming for young children diagnosed with ASD (National Research Council, 2001).

Once routines and activities are identified, the parent/professional team discusses the instructional and interactive techniques (i.e., transactional supports) that will be used by the family to facilitate the child's growth and development. The team also considers how the professionals will work to support parents and caregivers with implementation of these techniques. One family-centered technique that aligns with implementation of an ERA is parent coaching (Chapter "Coaching parents of young children with autism"). Parent coaching can be described as an interactive, collaborative process between professionals and parents in which parents are guided to implement intervention techniques, strategies, and supports that meet the needs of their children and of their family given their resources (Foster, Dunn, & Mische-Laweson, 2012; Graham, Rodger, & Ziviani, 2009). Within the context of this reciprocal relationship, focus is maintained on the family's perspective, addressing identified challenges and delivering intervention in authentic settings and activities (Dunn, 2011; Dunn et al., 2012).

Professionals provide guidance and information about different teaching strategies that support the development of emotional regulation such as modeling, direct teaching, and scaffolding. Modeling techniques involve the parent demonstrating the targeted emotional regulation skill for the child within the context of the ongoing activity. In essence this technique involves the parent showing or guiding the child to use more effective, conventional, and socially desirable regulatory strategies in context. For example, if a young child with ASD becomes very excited and begins jumping and flapping his/her hands, the parent may model clapping. Direct teaching strategies are those in which the parent not only shows the child an alternative regulatory strategy but for symbolic children also talking to him/her about this strategy and discussing its use. For a young child learning emotion vocabulary words and related regulatory strategies, parents may use picture cards during activities with emotion vocabulary and regulatory strategies depicted on them. For example, if a child appears sad when leaving a favorite store, the child is shown a picture of "sad"; the emotion is labeled for them; and choices for strategies to cope with the emotion are shown and modeled. Finally, scaffolding refers to parents previewing emotional regulation strategies are that slightly more advanced than the child's current developmental abilities (Vygotsky, 1962). This is done with the intent of exposing the child to these strategies and preparing them for future use. For example, parents may label the child's emotional state even if the child is not yet a symbolic communicator.

Once an ERA plan is created and agreed upon (i.e., activities are identified, ER objectives and supports are embedded, and teaching techniques are determined), roles within the coaching model shift. Typically, parents and caregivers implement the plan while professionals observe. At times, families may require or request greater support with implementation. When this occurs, professionals may step into a more active role in engaging with the child and modeling intervention techniques for parents. Following the observation, the parent/professional team meets to reflect on the child's participation and the effectiveness of emotional regulation strategies. If appropriate, professionals may share additional knowledge related to emotional regulation and/or intervention techniques in relation to the child or family's self-identified needs (Foster et al., 2012). Parents continue to implement the ER intervention plan in the home environment between scheduled coaching sessions.

A child's progress in achieving ER objectives is monitored through information shared at coaching meetings as well as through data collection related to the child's functional and independent use of emotional regulation strategies in natural contexts. This type of data collection is thought to reflect authentic progress (Prizant et al., 2006b). Recent research has demonstrated that parent coaching is an effective strategy to facilitate the participation and engagement of children with ASD in their daily routines and activities (Dunn et al., 2012; Wetherby et al., 2014).

Example of Addressing Emotional Regulatory Objectives within a Natural Activity Model Below is an example of a plan generated by a parent/professional team for Grayson, a verbal 2 1/2-year-old boy, who relies almost entirely on behavioral strategies for emotional regulation. He frequently sucks his fingers, jumps while flapping his hands, and/or clutches comfort objects when his arousal level starts to climb. He is not yet using words to assist with emotional regulation. He frequently becomes overly excited during transitions and gross motor activities, which impacts his ability to participate (see Table 19.4).

Addressing Challenging Behaviors Within an ERA

In addition to creating a proactive ERA plan that is aimed at expanding a young child's emotional regulation repertoire, it is important to consider the creation of a reactive plan to help families and children cope with challenging behaviors and known risk factors contributing to extreme dysregulation. During the assessment phase, families are asked to identify challenging behaviors, high-risk situations for dysregulation, as well as risk and protective factors in relation to their child's emotional regulation abilities. Risk factors are those that make the child more vulnerable to experiencing emotional dysregulation and displaying behaviors that may be perceived by others as problematic. Protective factors are those that make it less likely that dysregulation will occur. Risk and protective factors may include (1) psychological/emotional factors such as lack of control and emotional memory, (2) biological/physiological issue (health, sensory processing differences, arousal bias), and (3) social factors (social communication challenges, social and sensory complexity of the environment).

Table 19.4 Emotional regulatory objectives embedded in natural activities for Grayson

Objective (what)	Activities (where)	Partners (who)	Strategies/supports (how)	
Grayson will use words and picture symbols to prepare himself for and manage emotions during transitions	Transition from home to car Transition from car to playground Transition from book reading to bed	Mom Dad Grandma	Direct teaching	First/then board with icons depicting activities, show board and model use Visual support depicting emotions and corresponding regulatory strategies
Grayson will use words to express positive emotion and seek interactions with others	Playground Chase games	Mom Babysitter	Modeling	"This is fun" "Chase me" "Yay" Get down on Grayson's level and secure his attention before communicating

Challenging behaviors can vary widely; and they may be associated with dysregulated states ranging from mild to extreme dysregulation, periods of time when a young child's emotional and arousal state make the child unavailable for learning or interacting or create harmful or unsafe conditions (Prizant et al., 2003; Tronick, 2002). As a first step of creating this portion of the child's ER intervention plan, it is critical that parent/professional teams achieve consensus in identifying a behavior as problematic (Prizant & Laurent, 2012a). In general, it is commonly agreed that behaviors involving danger to self or others are challenging and require a plan for proactive and reactionary intervention; however, there are many other behaviors that may or may not be viewed as problematic depending on the perspective of the team members including cultural values and norms across different environments. Factors impacting how behaviors are perceived include degree of conventionality, social acceptability, disruptiveness to environment or learning, and destructiveness. Thus, teams should weigh factors such as child's age, frequency of behavior, and family/cultural values when determining if a behavior is challenging (Prizant & Laurent, 2012a).

Once a behavior has been identified as problematic or challenging, it is important for the parent/professional team to consider this behavior within the context of the other information gained through the assessment. Discussion is guided by the following questions.

- What is the behavior? What does it look like? Are there signals/signs prior to the child engaging in the problem behavior?
- Are there contributing risk factors? (see Table 19.5, columns 1 and 2)
- When does it occur? Are there predictable triggers associated with location, people, and activity?
- What are the young child's arousal and/or emotional states?
- What is the function of the behavior? (see Table 19.6)

The answers to these questions are then considered in the context of the child's evolving ERA plan; and strategies to prevent and recover from extreme dysregulation are generated cooperatively and added to the plan. This portion of the plan is also enacted by parents between coaching sessions and discussed and modified as needed (Table 19.6).

Example of Plan to Address Challenging Behavior Lizzy is a 24-month-old child diagnosed with ASD who is not yet using language to communicate and frequently becomes distressed during bath time. When this occurs, she will bang her head on the side of the bathtub. Family members have offered that they feel that several factors contribute to this behavior.

Table 19.5 Risk factors

Risk factors	Examples	Strategy to reduce risk and support prevention
Physiological factors	Fatigue Hunger Illness	Address need (hunger, sleep, medical issue)
Social understanding	Difficulty predicting the actions of others Challenges understanding social norms	Create and implement social routines Video modeling of expected behavior
Sensory processing differences	Hyper-reactivity to environmental stimulation Hypo-reactivity to environmental stimulation	Modify environment to accommodate sensory differences (e.g., reduce visual clutter for hyper-reactive bias, increase movement in activities for hypo-reactive bias) Provide supports for coping with environment (e.g., noise reduction headphones for child who is hypersensitive to noise)
Receptive communication	Receptive language delays Difficulty understanding picture symbols	Use objects to support understandings Simplify speech Use consistent cues to mark transitions
Expressive communication	Expressive language delays Difficulty using nonverbal gestures that have shared meaning Challenges with conventional emotional expression	Support communication development (gestural and symbolic) Introduce augmentative communication
Negative emotional memory	Recurrent experiences of intense negative emotions associated with a particular person, activity, or place	Pair preferred activities/objects/people with challenging circumstances to create positive associations Avoid triggering situations when possible Teach coping strategies
Executive functioning	Challenges with flexible thinking Organizational difficulties	Implement object-based or picture-based schedule routines Create consistent places to store preferred objects Create video models to depict possibilities for situations with more than one possible outcome
Task demands exceeding abilities	Overwhelmed by task Developmentally inappropriate activity	Modify activity to reflect child's developmental abilities Lessen duration of task Assist the child with the task
Task demands not challenging	Bored Developmentally inappropriate activity	Modify activity to reflect child's developmental abilities Incorporate special interests into activities

Adapted from Prizant & Laurent (2012a)

These include miscommunication related to expectations, Lizzy's memories of previous stressful experiences in the tub, and the sensory properties of the activity. Table 19.7 outlines a sample plan to address challenging behavior for Lizzy within an ERA.

Family Support as Part of an ERA

A final component of a family-centered ERA support plan outlined in the SCERTS® Model is family support. As stated earlier, families of young children diagnosed with ASD are recognized as experiencing heightened levels of stress (Domingue et al., 2000). And, heightened levels of stress are correlated with decreased effectiveness scaffolding emotional regulatory abilities, as well as the increased use of less sophisticated strategies by caregivers (Kochanska et al., 2000). Therefore, it stands to reason that support to families that is designed to reduce stress and bolster capacity is a priority within a family-centered ERA. Types of support

Table 19.6 Functions of problem behaviors

The following list is not exhaustive but is designed to provide examples of common problem behaviors in relation to their possible functions

Problem behaviors	Possible function (communicative and sensory/regulatory)	Intervention/replacement strategies tailored to function
Hitting	Protest Share negative emotion Seek interaction	Push away Head shake High five
	Seek proprioceptive information	Joint compression Jumping
Screaming	Protest Share positive emotion	Teach request break Clapping
	Auditory blocking	Decrease noise Noise-canceling headphones
Bolting	Protest	Teach to request break Teach “all done”
	Escape overwhelming environment	Teach to request break Use quiet spot
Head banging	Protest	Teach all done Teach request break
	Seek vestibular input Seek proprioceptive input	Swinging and jumping Joint compressions
Flapping hands	Share positive motion	Clapping hands High five
	Seek visual input Seek vestibular input	Tap fingers Kaleidoscope Rocking chair
Perseverant speech	Express uncertainty Convey emotions	Model emotional expression Provide information
	Auditory blocking	Reduce stimulation in the environment
Incessant questioning	Express uncertainty Convey emotion	Model emotion expression Provide schedule
	Express and convey emotion	Provide schedule Model emotional expression

Modified from Prizant & Laurent (2012a)

Table 19.7 Sample plan to address challenging behavior

Behavior	Risk factors	Possible functions	Preventative measures	Reactive replacement strategies
Head banging	Social understanding Emotional memory Sensory properties	Emotional expression Seeking proprioceptive and vestibular input	Create new routines Use objects to mark transitions in bath Give time to process Use rough cloth to increase deep pressure	Head squeezes Turn into social game of row, row your boat Use short simple language to label emotional state

include emotional support (e.g., support group involvement, one-to-one support meetings, social gatherings) and educational support (e.g., provision of resources, interactive guidance, parent workshops, etc.). Caregiver engagement in these types of support activities is an important way to assist family members in their efforts to consistently implement interventions designed to foster their young children’s regulation. Research suggests that families who feel supported have children who demonstrate fewer problem behaviors and demonstrate more positive developmental outcomes in early intervention settings (Durand, 2013).

Table 19.8 Sample family support plan

Educational support	Emotional support
Invitation to attend parent education series hosted by early intervention staff Access to lending library at early intervention office stocked with parent friendly resources Coaching sessions	Invitation to attend local parent support group Provision of contact information for "more experienced" family willing to serve as "mentor" to help navigate the system Referral to local counselor Coaching sessions

Example of a Family Support Plan John is a 30-month-old boy diagnosed with ASD who struggles with emotional regulation. He is an only child, and his parents struggle to understand whether his challenges are due to his young age or are related to his diagnosis of ASD. At times, John's screaming and dropping to the ground in public causes his parents to pick him up and remove him from the situation. His parents often express that they feel overwhelmed and isolated (see Table 19.8 for a sample family support plan for John).

Conclusion

In this chapter, we have outlined the development of emotional regulation, challenges to this process that have been documented in young children with ASD, and critical components of an ERA that are consistent with SCERTS® Model programming to help address these challenges. Each of the ERA components is considered essential to family-centered practice and in supporting the development of crucial emotional regulation abilities for young children diagnosed with ASD. By addressing such challenges in a developmentally grounded and individualized manner, children with ASD and their families will be provided with a solid foundation that will result in greater availability for learning and interacting and more positive and trusting relationships.

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Family Implemented TEACCH for Toddlers

Kara Hume and Lauren Turner-Brown

Abstract

Family Implemented TEACCH for Toddlers (FITT) is a collaborative parent education and support model designed to help families better understand and engage their toddler with autism spectrum disorder (ASD). Based on and adapted from the TEACCH Autism Program, FITT uses structured teaching and naturalistic strategies to facilitate toddler's receptive and expressive communication, social communication, and play skills, as well as parent groups and parent coaching to enhance parent well- being. The blended structured teaching and naturalistic strategies used in FITT support both the development of new routines designed to enhance attention, understanding, and engagement such as table- and floor-based play sessions and generalization of skills to routines that occur across the day and home environment. Across the 6-month manualized intervention, parents identify intervention priorities, conduct informal assessments to identify toddler strengths and emerging skills, and then jointly plan the implementation of FITT strategies to target identified skills across domains and routines, while the FITT interventionist serves as a consultant and coach supporting and guiding parents. Outcomes from a randomized controlled trial of the FITT intervention included improved functioning for the toddlers with ASD, as well as reduced parent stress and improved parent well-being, indicating that FITT is a promising approach for young children with ASD and their families.

Introduction

Family Implemented TEACCH for Toddlers (FITT) is a collaborative parent education and support model designed to help families better understand and engage their toddler with autism spectrum disorder (ASD). Based on and adapted from the TEACCH Autism Program, FITT uses structured teaching and naturalistic strategies to facilitate toddlers' receptive and expressive communication, social communication, and play skills, as well as parent groups and parent

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This work is funded by grant R40 MC 22648 through the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Research Program and funding from Frank Porter Graham Child Development Institute.

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_20

coaching to enhance parent well- being. The TEACCH Autism Program is a comprehensive treatment model serving individuals with autism spectrum disorder (ASD) across the lifespan. Established in North Carolina in 1972, TEACCH provides clinical and diagnostic services for individuals on the spectrum and their families, as well as training and consulting for professionals around the world. TEACCH has a long-standing history of including parents as "co-therapists" in the treatment of their children (Schopler, Mesibov, & Baker, 1982; Schopler & Reichler, 1971; Short, 1984). In fact, Schopler and Reichler (1971) conducted one of the earliest studies that demonstrated the positive role parents could play in the education and care of their children with ASD. In addition, TEACCH was an early developer of both assessment methods which identify emerging skills (e.g., Psychoeducational Profile) and intervention strategies (termed structured teaching) which capitalize on visual-perceptual strengths by providing physical and visual supports to enhance understanding and engagement (Mesibov, Shea, & Schopler, 2005). These tenets—family partnership, individualized intervention based on assessment and emerging skills, and a strengths-based approach—are common elements of high-quality early intervention programs that have been core principles of TEACCH since its inception over four decades ago.

When TEACCH began in the 1970s, most children with what is now called ASD received their diagnosis between the ages of 5 and 10 years (Treffert, 1970); thus structured teaching strategies and other clinical services at TEACCH were developed for elementary-aged children through adults. However, as a result of earlier identification, structured teaching strategies have been adapted and blended with other proven strategies for very young children with ASD to best meet the needs of toddlers on the autism spectrum and their parents. TEACCH services for toddlers have become more formalized and studied more rigorously in the past decades. Initially termed the "Home TEACCHing Program" (HTP; Ozonoff & Cathcart, 1998; Welterlin, Turner-Brown, Harris, Mesibov, & Demoloino, 2012), parents of young children with ASD were provided with 10–16 weekly in-home sessions focusing on implementation of structured teaching strategies. Weekly visit topics included elements of structure, communication, play, transitions, advocacy, and community functioning. Sessions were led by TEACCH interventionists, with parents primarily observing during initial sessions and taking a more active role in the final sessions. Across the sessions, parents learned how to implement strategies successfully resulting in increased use of antecedent strategies and effective prompting (Welterlin et al., 2012). In addition, children in the HTP group improved significantly more than those in the control group on subtests of imitation, fine motor, gross motor, and nonverbal conceptual skills (Ozonoff & Cathcart, 1998).

Modifications have been made to the HTP to enhance parent participation and parent coaching, as well as increase the intervention duration to strengthen the focus on communication and social engagement. Now termed "Family Implemented TEACCH for Toddlers" (FITT; Hume, Turner-Brown, & Boyd, 2013), FITT is a parent-mediated approach that blends structured teaching strategies (an emerging approach per the National Standards Project and includes evidence-based practices per the National Professional Development Center on ASD) (NSP, 2015; NPDC, Wong et al., 2015) with proven naturalistic and behavioral strategies to improve the skills of toddlers on the autism spectrum and improve well-being for their parents. FITT provides a manualized 6-month curriculum to support parents in better understanding their toddler, how ASD may be impacting their toddlers' understanding and relatedness, and to facilitate communication, social interaction, adaptive behavior, and play.

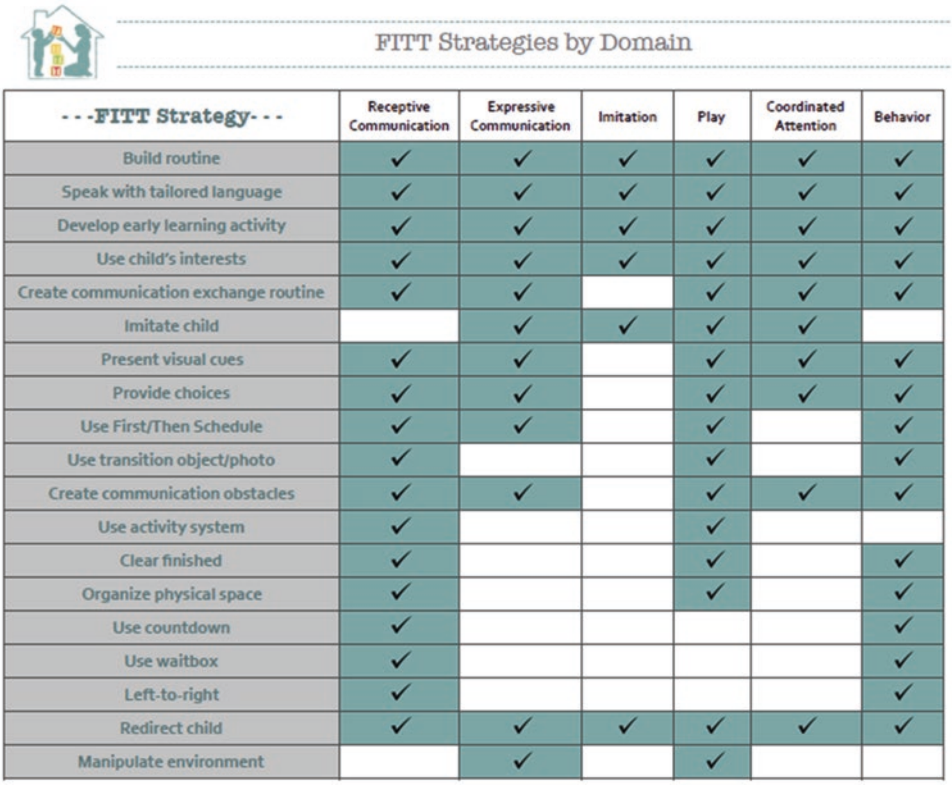
FITT strategies are implemented in several ways including through structured activities designed to explicitly teach skills, through typical play and interaction between toddler and parent, as well as during family-selected routines that occur across the day. Session topics include engagement through routines, expressive communication, receptive communication, imitation, toy and social play, joint attention, behavior, and the basics of structured teaching. Each weekly session, lasting 90 minutes, includes collaboration between the FITT interventionist and parent to identify goals related to session topics and to develop a plan for targeting goals. Parent group sessions provide opportunities for more in-depth psycho-education for parents and informal parent support (Boyd, 2002). Outcomes for the FITT model include improved functioning of the toddlers with ASD, as well as reduced parent stress and improved parent well-being (Turner-Brown et al., 2015). The following core values and principles of the TEACCH Autism Program are emphasized in FITT:

- Helping families to better understand autism and how autism may influence how their toddler thinks, learns, understands, communicates, and interacts with others
- Recognizing the expertise of families and respecting their roles as partners in working with and understanding their toddlers
- Conducting ongoing informal assessment with families to better understand their toddler's strengths, interests, and emerging skills
- Highlighting the strengths of individuals with autism and teaching families how those strengths can be used to facilitate interactions with their toddlers on the spectrum
- Using structured teaching principles, adapted to be developmentally appropriate for toddlers, as a vehicle in which a number of skill areas can be taught, including initiating and responding to joint attention, expressive communication, and play skills

Each aspect of the intervention model will be detailed in the sections below, including the basics of structured teaching and other naturalistic strategies, session structure, how to target various developmental domains with FITT strategies, and how families embed these strategies across daily routines. The next steps for the FITT intervention will also be discussed.

FITT Strategies

FITT draws from several theoretical contexts, including behavioral and developmental theory (Schreibman et al., 2015). For example, FITT recognizes the individual strengths, interests, and emerging skills of toddlers and develops individualized activities based on frequent informal assessment information (*developmental theory*, Schreibman et al., 2015). In addition, FITT recognizes that efficient teaching technology is beneficial, as is the role of reinforcement in increasing skill demonstration, and both systematic prompting and embedded reinforcement play key roles in the FITT (*behavioral theory*, NPDC, Wong et al., 2015). In addition, structured teaching strategies are primarily antecedent-based practices which emphasize increasing engagement and adaptive behaviors through enhancing understanding (*behavioral theory*, NPDC, Wong et al., 2015). FITT aligns with a new classification of intervention approaches, termed "Naturalistic, Developmental, Behavioral Interventions" or NDBIs (Schreibman et al., 2015), which include interventions implemented in natural settings, that involve shared control between child and therapist/parent, utilize natural contingencies, and use a variety of behavioral strategies to teach developmentally appropriate and prerequisite skills. This planful blending of approaches is recommended to ensure procedures adequately address the needs of toddlers and comport with the values of families. Such blended approaches have recently been termed "state of the art" (Stahmer, Schreibman, & Cunningham, 2011). Key FITT strategies used are described/bolded below and highlighted in Fig. 20.1. It is important to note that a number of FITT strategies can be linked to several theoretical contexts (e.g., providing choices is both an antecedent-based behavioral strategy and a naturalistic strategy) and the strategies below are only a sampling of the structured teaching and naturalistic FITT strategies used.



FITT Strategies by Domain

- - -FITT Strategy- - -	Receptive Communication	Expressive Communication	Imitation	Play	Coordinated Attention	Behavior
Build routine	✓	✓	✓	✓	✓	✓
Speak with tailored language	✓	✓	✓	✓	✓	✓
Develop early learning activity	✓	✓	✓	✓	✓	✓
Use child's interests	✓	✓	✓	✓	✓	✓
Create communication exchange routine	✓	✓		✓	✓	✓
Imitate child		✓	✓	✓	✓	
Present visual cues	✓	✓		✓	✓	✓
Provide choices	✓	✓		✓	✓	✓
Use First/Then Schedule	✓	✓		✓		✓
Use transition object/photo	✓			✓		✓
Create communication obstacles	✓	✓		✓	✓	✓
Use activity system	✓			✓		
Clear finished	✓			✓		✓
Organize physical space	✓			✓		✓
Use countdown	✓					✓
Use waitbox	✓					✓
Left-to-right	✓					✓
Redirect child	✓	✓	✓	✓	✓	✓
Manipulate environment		✓		✓		

Fig. 20.1 FITT strategies with associated domains

Structured Teaching Strategies

Structured teaching strategies are used to support two primary goals for toddlers with ASD and their families: (1) to support engagement and (2) to make the environment meaningful and understandable. "Engagement" is defined as being actively and productively involved in an activity, and FITT focuses on engagement with people, toys/objects, and people and toys/objects together (Hume & Odom, 2007). There are four components of structured teaching used as part of FITT to support the above goals, and these are first introduced to families during an initial group session and then reinforced across all in-home sessions.

Physical organization The use of an organized intervention setting when working with young children with disabilities, including those with ASD, is a widely recommended and long-studied practice (Bailey & Wolrey, 1984; Norquist & Twardosz, 1990; Sandall, Hemmeter, Smith, & McLean, 2005). An environment that provides functional cues about the activities that will occur in each space as well as the behavioral expectations for those activities is more likely to promote and sustain engagement in young children (Norquist & Twardoz, 1990). Using **physical or visual boundaries** to better define space and expectations is a key FITT strategy, and families are taught how furniture arrangement, covering or removing unused toys/household items, and/or adding visual cues such as a rug or blanket can provide cues to young children about what activity will be occurring and what behavioral expectation is required in each activity.

The parent and interventionist will use physical organization to establish two areas for different types of play with toddlers—an area for **table-based play** (e.g., puzzles, ring stackers, shape sorters, paints, or markers) and an area for **floor-based play** (e.g., balls, trucks, cars, bubbles). The table-based play area is often used during FITT sessions as a location to introduce new play activities or teach new skills. A designated location for teaching new skills helps in creating positive routines around learning, which can help toddlers accept new activities and materials (Hume, Plavnick, & Odom, 2012). An additional step in physically organizing spaces in the home includes **minimizing distractions**, as young children with ASD can be highly distractible and have difficulty in processing environmental stimuli (Siegel, 1999). This can better allow the toddler to increase attention to the desired person or activity rather than attending to less relevant stimuli in the environment. The parent and interventionist may put away or limit extra toys during play activities, turn off screens, cover items, or use a divider to reduce competition for the toddler's attention during play sessions.

Schedules Visual schedules are a type of visual support that allows young children with autism to "see" their upcoming events or activities through the use of objects, photographs, icons/line drawings, written words, or any combination of the listed formats (Mesibov, Shea, & Schopler, 2005). Visual schedules can be used for several purposes but have historically been used to provide support for transitions between locations and activity periods, essentially serving as a between-activity support (i.e., move from location to location in the home or community) (Dooley, Wilczenski, & Torem, 2001). Visual schedules can attract and hold a child's attention (Rao & Gagie, 2006) and provide a concrete form of representation which is developmentally appropriate for young children who are not yet able to process more abstract concepts (Ginsburg & Opper, 1988).

There are several considerations required when using schedules with toddlers with ASD. First, toddlers are concrete learners and are not likely able to understand a schedule that uses abstract representations such as line drawings, words, or even some photographs. Likely, the most appropriate schedule form for toddlers is the use of objects—either functional objects that will be used in the scheduled activity, such as a sippy cup to use at mealtime, or representational objects that represent where the toddler is going, such as a set of toy keys that represents transitioning to the car. Next, toddlers are not ready to process long sequences of schedule information; instead they best understand one piece of information at a time. This information is communicated through a **transition object**—a concrete way to show the toddler where she/he is going next. Each activity or location is represented by a specific object. For example, if a toddler has difficulty transitioning to the changing table during diaper changes, parents may select a diaper as a transition object. When it is time to transition for a diaper change, the parent will give the diaper to the toddler and say "Time for diaper change" and help the toddler get to the correct location. In time, with the consistent use of transition objects and corresponding language, toddlers will learn what the transition object means, and transition difficulties will decrease as understanding improves.

For some toddlers, a very short sequence of two objects, called a **first/then schedule**, may be used to help them understand when a favorite activity is going to return. For example, if a toddler has difficulty transitioning away from a favorite toy to come to the table for snack, two objects may be presented. First, the transition object used for snack is presented, and next to it is a piece of the toy (e.g., a train) indicating that first the toddler will have snack and then she/he can return to the toy. Transition objects do not need to be used for all transitions across the day. During FITT sessions, the interventionist and parent select objects for the table- and floor-based play routines, as well as any other activities or locations that are consistently difficult for the toddler to transition to or from. These objects are then used during FITT sessions and across the week when parent and toddler are transitioning to the selected activities.

Activity systems An activity system is a visually based organizational system that provides individuals with visual information about what to do. Often called work systems or activity schedules, activity systems are an evidence-based practice (per NPDC, visual supports category, Hume, 2013) and deemed an established intervention (per NSP, schedules category). Several recent studies have examined the use of activity systems with young children and have found positive results in increasing engagement (Bennett, Reichow, & Wolrey, 2011; Hume & Odom, 2007; Mavropoulou, Papadopoulou, & Kakana 2011). An activity system helps toddlers better understand what to do once they arrive at a designated space or location, such as the table-based play space or the bathroom. The activity system shows the toddler what activities will be completed, how long the activities will take, how she/he will know that the activities are finished, and what will happen next. The activity system is first introduced in FITT during the table-based play routine by placing the structured activities that the parent and toddler will do together on the toddler's left and a finished basket on the toddler's right (a **left-to-right activity system**). The **finished basket** is a designated location where toddlers put their activities when they are finished with them. Parents and interventionists teach the system to the toddler by emphasizing that activities are taken from the toddler's left, completed together at the table, and then put in the finished basket on the right. This allows toddlers to see how many activities will be completed and what the activities are. Also, they can see that activities are finished when they are in the finished basket. Toddlers also learn that a transition object after the structured activities will direct them to the "what's next" activity, typically playing on the floor or moving to a caregiver-selected routine like snack or outside play.

After toddlers become familiar with the activity system at the table, the system is introduced during other routines in the home. For example, if the dressing routine is challenging for a toddler, the FITT interventionist and parent may develop an activity system for dressing to help clarify what the toddler is supposed to do, how long it will last, how she/he knows she/he is finished, and what activity is coming next. Specifically, laying the clothes out in a left-to-right fashion allows the toddler to see how many steps are required, and as each piece of clothing is put on, she/he can see that progress is being made. A transition object such as a favorite book at the end of the line of clothes helps the toddler know what preferred activity is coming next. While the toddler cannot yet dress himself/herself, the left-to-right system allows him/her to better understand the sequence of steps required during the dressing routine.

Visually structured activities and cues Providing additional visual information to young children with ASD can increase engagement, understanding, and participation (Carnahan, Musti-Rao, & Bailey, 2009; Mavropoulou et al., 2011). In FITT, the interventionist and parent work together to create or adapt a set of **early learning activities** to teach toddlers new skills and routines. These are highly visual activities that teach the toddler how to engage with play materials (e.g., blocks, farm animals) and how to participate in play routines (e.g., use activity system, understand finished). The initial activities introduced during the table-based play routine typically have a very clear beginning and end, include a sensory component like preferred sounds or textures, are highly motiving, and build on the toddler's strengths. These may also include **visual instructions** such as a series of photos or objects that may be used to teach a multistep play activity. For example, when teaching a toddler with ASD a play routine with a baby doll, interventionists or parents may take a series of photos of play actions to do with a doll (e.g., put baby in tub, wash baby, dry baby) or lay out a series of objects that will be used in each step. Single photos may also be used to provide support for toddlers as they are learning functional and symbolic play routines (e.g., a farm animal completes an action, such as the pig jumps, the horse sleeps). Activities may be **visually organized** which can include stabilizing them on a tray, providing containers for extra parts and pieces, and reducing the number of parts and pieces.

Additional visual cues, or reminders of what the toddler should be doing before, during, or at the conclusion of an activity, have proven effective with young children with ASD and are part of the structured teaching strategies used in FITT (e.g., Ulke-Kurkcuoglu & Kircaali-Iftar, 2010; Dettmer, Simpson, Myles, & Ganz, 2000). These include the use of **visual countdowns** which allow a toddler to "see" how much time remains in an activity, **visuals for choice making** which allow toddlers to see a field of choices during activities, and **visuals for expectations** which help toddlers better understand rules and limits (e.g., stop signs at back door). During FITT sessions, parents identify routines and skills they would like to target and then together with the FITT interventionist may develop a visually structured activity or cue to help facilitate learning. For example, a parent indicated that their toddler was having difficulty during bath time and refused to sit in the bathtub. During the coaching conversation, the parent hypothesized that perhaps the toddler didn't know where to sit in the bathtub and decided to affix a visual cue to the bathtub floor, a laminated circle with a picture of Minnie Mouse, to help the toddler know where to sit. In addition, the parent decided to use the same circle when playing games on the floor, so the toddler would become familiar with the visual cue and be more likely to generalize its use when in the bathtub. This visual cue assisted in increasing bath time success.

Naturalistic Strategies

Naturalistic strategies are based on the science of applied behavioral analysis and are typically implemented within the context of natural routines such as playing, bath time, and mealtime (NPDC, Wong et al., 2015; Schreibman et al., 2015). Naturalistic strategies emphasize **modifying the environment** to elicit specific skills. For example, a parent targeting initiation of expressive communication may put a preferred activity in a container that the toddler can access but cannot open independently to encourage the toddler to initiate a communicative act (e.g., passing container to parent, vocalizing, shifting eye gaze between container and parent). This strategy, termed a **communication obstacle** in FITT, would be used in combination with **responsivity**, a naturalistic strategy ensuring that parents and FITT interventionists recognize the communicative attempt and respond, thus teaching the toddler that communication is powerful. Additional naturalistic strategies used in the FITT intervention include:

Build routines FITT emphasizes building routines across the day using structured teaching strategies such as the table/floor play routines, use of left-to-right activity systems, finished box, visual cues, and transition objects. In addition, parents develop engaging play routines, often with a gross motor or sensory component like swinging, tickling, chasing, or singing to begin increasing toddler engagement. Parents are also supported in using FITT strategies in ongoing routines across the day in the home or community settings. For example, a parent was having difficulty transitioning a toddler to the car when she was busy playing indoors. The parent decided to try using his shoes as a transition object to help her better understand when it was time to go and began bringing her shoes to her at departure times. After practicing this shoe/transition pairing several times, the toddler began to expect that she would have to leave her toys when the shoes were presented, thus reducing the transition latency and difficulty.

Tailored language Adult language can impact the language learning of young children. To support both the receptive and expressive language of young children with ASD, FITT supports parents in using "tailored language" or language that is simplified in type and amount to match the receptive and expressive skills of the toddler. Limiting extraneous language to help the toddler focus on the key words while adding simple clear narration by labeling objects and actions ("bounce ball," "fall down") can support language development. Sometimes called the "one-up" rule (e.g., Rogers & Dawson, 2010), parents are encouraged to use one more word/utterance than their toddler typically does when modeling, expanding, responding to, or commenting on a toddler's communication or actions. For example, if the toddler usually communicates in one word utterances such as "cup," parents may respond with two words, like "want cup" or "red cup."

Imitate child An important naturalistic strategy and a key feature of NDBIs is adult imitation of the toddler's language, play, and movements (Schreibman et al., 2015). Several FITT sessions focus on imitation and support parents in better understanding why imitation is difficult for toddlers with ASD and why it is a pivotal skill in development. Parents learn how to observe the imitation skills of their toddler and how to imitate their toddlers in an effort to increase their toddler's attention to adult actions which may lead to possible imitation or continuation of imitative routines (e.g., parent pauses in the middle of singing "Wheels on the Bus," and toddler attempts to continue the song by making gesture for the wheels). FITT includes in-home sessions on object and social imitation, and parents are supported in embedding imitation across daily routines. For example, during a floor-based play activity, a parent ensures that there are two of several toys (e.g., cars, blocks, spoons/pans to use as a drum), and when the toddler starts banging on the pot with the spoon, so does the parent. Once the parent has the toddler's attention, the parent changes the activity slightly by banging quietly and loudly in an effort to encourage the toddler to watch and then imitate the parent.

Use child's interests A number of FITT strategies are designed to increase toddler motivation to engage with a variety of toys and people, including the use of structured teaching strategies and building early learning activities and play routines around the toddler's interests. Through informal assessment and observation, parents note the toddler's interests, strengths, and emerging skills and build on those when targeting new skills and routines. For example, a parent was concerned about a toddler's resistance to taking a bath which often resulted in large tantrums. Using the toddler's interest in Clifford, the parent and interventionist created an early learning activity which allowed the toddler to give Clifford a bath several times to increase comfort and familiarity with the bath time routine.

The structured teaching and naturalistic strategies used in FITT support both the development of new routines designed to enhance attention, understanding, and engagement and generalization of skills to routines that already occur across the day and home environment. The strategies are introduced systematically to parents across the intervention sessions which are described in more detail in the following section.

FITT Intervention

Intervention Structure

A total of 24 weekly sessions are provided across a 6-month intervention time period: 4 clinic-based parent group sessions (3 families per group) plus 20 in-home intervention sessions. Families initially attend a 4-h "Parent Basics" group workshop that provides an overview of autism and of the structured teaching philosophy/strategies. Parents and interventionists then create and/or adapt a set of structured teaching materials that includes a range of developmentally appropriate early learning activities. Each of the 20 home sessions has a specific topic (see Table 20.1), although the activities conducted during each session vary based upon the individual needs and interests of the child and/or family, as well as the developmental level of the child. An excerpt from a manualized session can be found in Fig. 20.2.

The FITT interventionist is a trained practitioner or clinician (e.g., LCSW, SLP, educator) who has significant experience with autism, structured teaching, and toddlers. Training by FITT developers or current FITT interventionists on the use of FITT strategies and the FITT manual is required as is ongoing coaching to ensure high-quality implementation.

Table 20.1 FITT session topics

1. *Parent basics of structured teaching* (group sessions are italicized)
2. Using structured teaching in the home
3 and 4. Engagement and learning: establishing functional routines
5 and 6. Communication basics: receptive language/transitions
7. *Communication routines*
8 and 9. Communication basics: requesting/exchange
10. Communication basics: Next steps
11 and 12. Communication basics: imitation
13 and 14. Play skills: appropriate toy play
15. *Let's play: make it and take it*
16 and 17. Social communication: reciprocal play
18, 19, and 20. Social communication: responding to and initiating coordinated attention
21. *Preventing challenging behavior*
22 and 23. Understanding behavior
24. Next steps

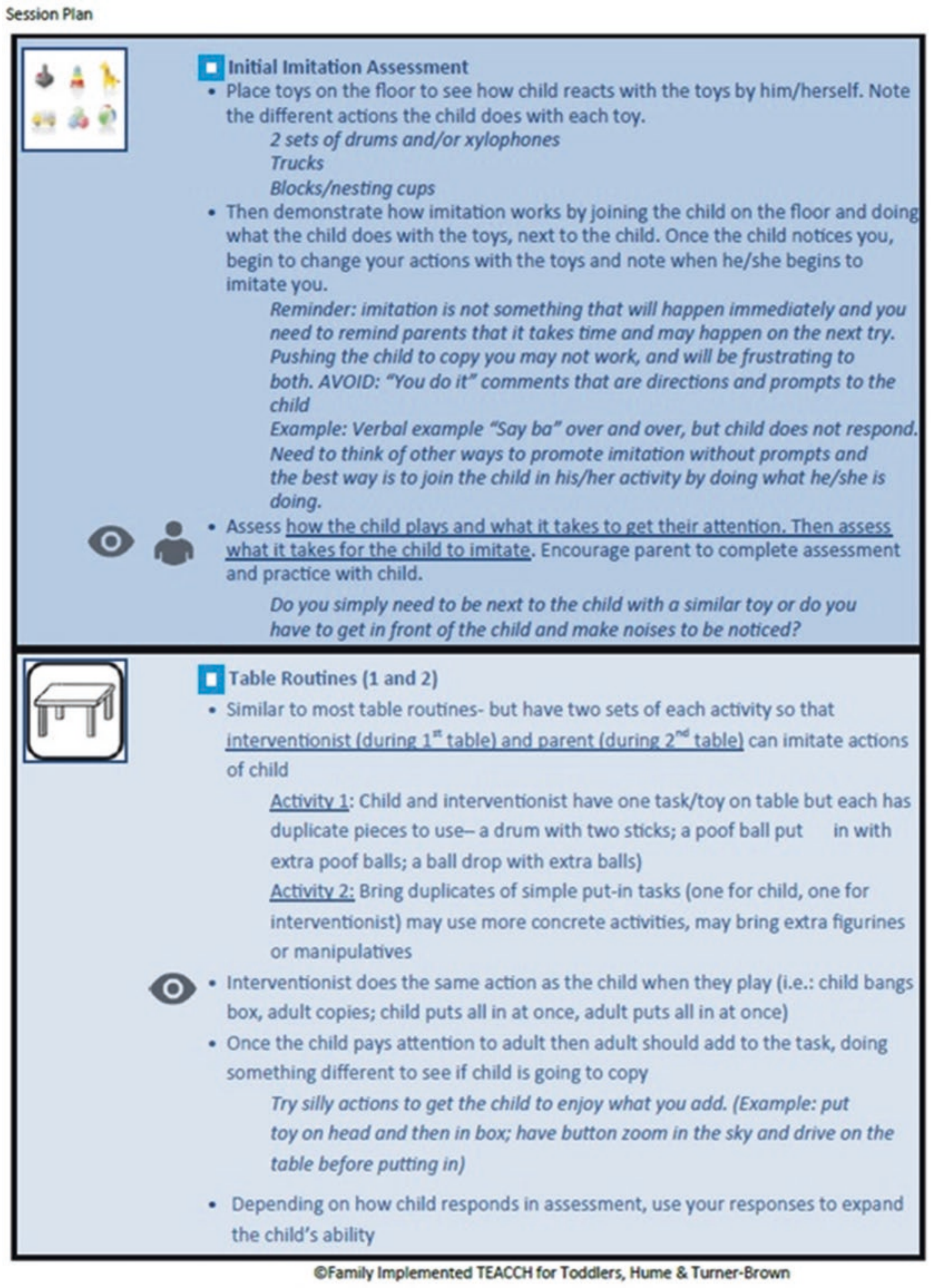
Session Structure

Home sessions are 90 min, and time is allocated to five types of activities during each session, including table- and floor-based play routines, family-selected routines, and parent coaching (see Table 20.2). Table-, floor-, and routines-based activities are interspersed throughout the session (e.g., parent and toddler may engage in two, 10-minute play sessions on the floor). Interventionists serve primarily as a coach to families, modeling strategies and providing support for families as they gain a greater understanding of the learning style of their child and of the FITT strategies.

Across the first four sessions, parents complete several informal assessment forms to provide additional information that will help shape future sessions. These are revisited across the 6-month intervention and include:

(a) A parent priority checklist where parents identify their most pressing concerns related to their toddler's development and current functioning. Parents choose from a field of ten areas including language, eating, sleeping, and social interaction, and families can add any additional concerns.
(b) An "All About Me" inventory which allows the parent to identify the toddler's current likes/dislikes, areas of strength, and current skills across domains, as well as how the parent currently interacts with the toddler.
(c) A routines' checklist where parents describe how the toddler currently participates in family routines such as meals, various types of play, bedtime, bath time, and community outings, as well as any goals the caregiver has about how the toddler might participate in family routines in the future. This checklist is revisited every session as the parent and interventionist add ideas on how to embed structured teaching and naturalistic strategies in priority routines to increase engagement and enhance understanding.

The in-home sessions typically begin with a review of the week, a preview of the upcoming topic, and the link between the topic, autism, and their toddler. Parent coaching strategies are central to the FITT intervention and embedded across the session. Details about the strategies and their use in FITT are provided in the section below. There is often an informal assessment period during the session where parent and interventionist observe the toddler while focusing on a specific skill or domain, such as imitation, toy use, or expressive communication (see Fig. 20.3 for an example). Parent coaching focuses on supporting parents in identifying the toddler's emerging skills in each area and targeting those skills for intervention across the session. During each activity, the FITT interventionist highlights concepts related to the topic, and the parent and interventionist jointly plan how to target the identified skill area within each activity. For example, after completing an informal assessment related to object imitation and noting that the toddler was beginning to watch the parent when the parent imitated him/her, the parent and interventionist may select table- and floor-based play activities that facilitate watching and possible imitation, such as two identical early learning activities at the table or two sets of cars to go down the racetrack on the floor. In addition, the parent and interventionist weave in opportunities to practice skills addressed in previous sessions, such as communication exchange or favorite play routines. Sessions end with the parent and interventionist creating a



Session Plan

☐ **Initial Imitation Assessment**

- Place toys on the floor to see how child reacts with the toys by him/herself. Note the different actions the child does with each toy.

  2 sets of drums and/or xylophones
  Trucks
  Blocks/nesting cups

- Then demonstrate how imitation works by joining the child on the floor and doing what the child does with the toys, next to the child. Once the child notices you, begin to change your actions with the toys and note when he/she begins to imitate you.

  Reminder: imitation is not something that will happen immediately and you need to remind parents that it takes time and may happen on the next try. Pushing the child to copy you may not work, and will be frustrating to both. AVOID: "You do it" comments that are directions and prompts to the child

  Example: Verbal example "Say ba" over and over, but child does not respond. Need to think of other ways to promote imitation without prompts and the best way is to join the child in his/her activity by doing what he/she is doing.

- Assess how the child plays and what it takes to get their attention. Then assess what it takes for the child to imitate. Encourage parent to complete assessment and practice with child.

  Do you simply need to be next to the child with a similar toy or do you have to get in front of the child and make noises to be noticed?

☐ **Table Routines (1 and 2)**

- Similar to most table routines- but have two sets of each activity so that interventionist (during 1st table) and parent (during 2nd table) can imitate actions of child

  Activity 1: Child and interventionist have one task/toy on table but each has duplicate pieces to use– a drum with two sticks; a poof ball put in with extra poof balls; a ball drop with extra balls)

  Activity 2: Bring duplicates of simple put-in tasks (one for child, one for interventionist) may use more concrete activities, may bring extra figurines or manipulatives

- Interventionist does the same action as the child when they play (i.e.: child bangs box, adult copies; child puts all in at once, adult puts all in at once)
- Once the child pays attention to adult then adult should add to the task, doing something different to see if child is going to copy

  Try silly actions to get the child to enjoy what you add. (Example: put toy on head and then in box; have button zoom in the sky and drive on the table before putting in)

- Depending on how child responds in assessment, use your responses to expand the child's ability

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Fig. 20.2 FITT manual excerpt from session 11 on imitation

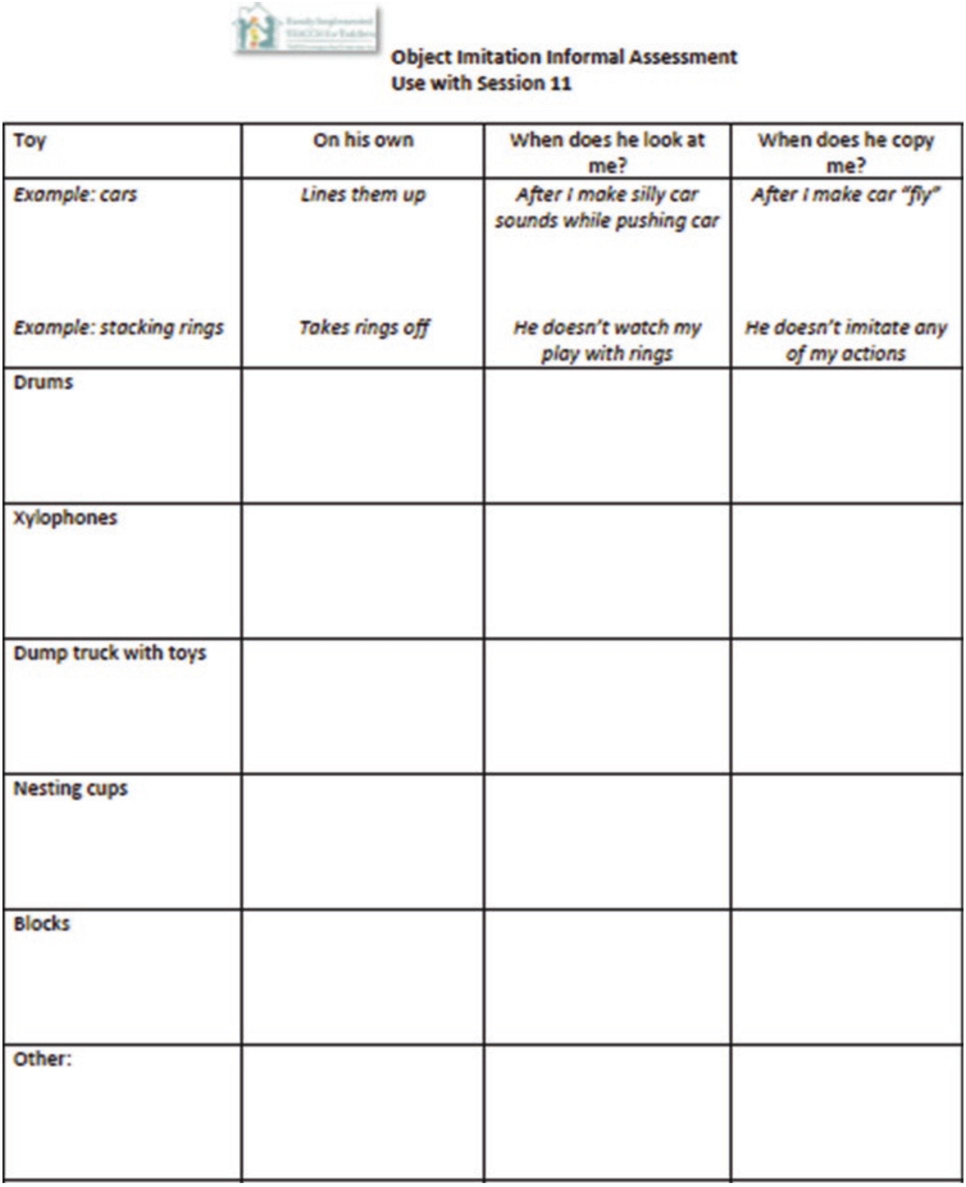
Table 20.2 Session activities

20 minutes: Didactic session with parent discussing manual topics and strategies
20 minutes: Interventionist and parent engage child during table-based activities
20 minutes: Interventionist and parent engage child during floor-based activities
20 minutes: Interventionist and parent engage child during routines-based activities (e.g., snack, bath, diaper change, outside play)
10 minutes: Wrap-up, plan in-between session activities, and preview of future topics

plan to practice the skills across the week, and this plan along with a parent-friendly handout with photo examples is hung in a central location to serve as a reminder across the week.

Parent Coaching

FITT recognizes the expertise of parents and supports parents in better understanding how autism may be impacting their toddler. Reducing parent



Object Imitation Informal Assessment
Use with Session 11

Toy	On his own	When does he look at me?	When does he copy me?
Example: cars	*Lines them up*	*After I make silly car sounds while pushing car*	*After I make car "fly"*
Example: stacking rings	*Takes rings off*	*He doesn't watch my play with rings*	*He doesn't imitate any of my actions*
Drums			
Xylophones			
Dump truck with toys			
Nesting cups			
Blocks			
Other:			

Fig. 20.3 Example informal assessment form from object imitation session

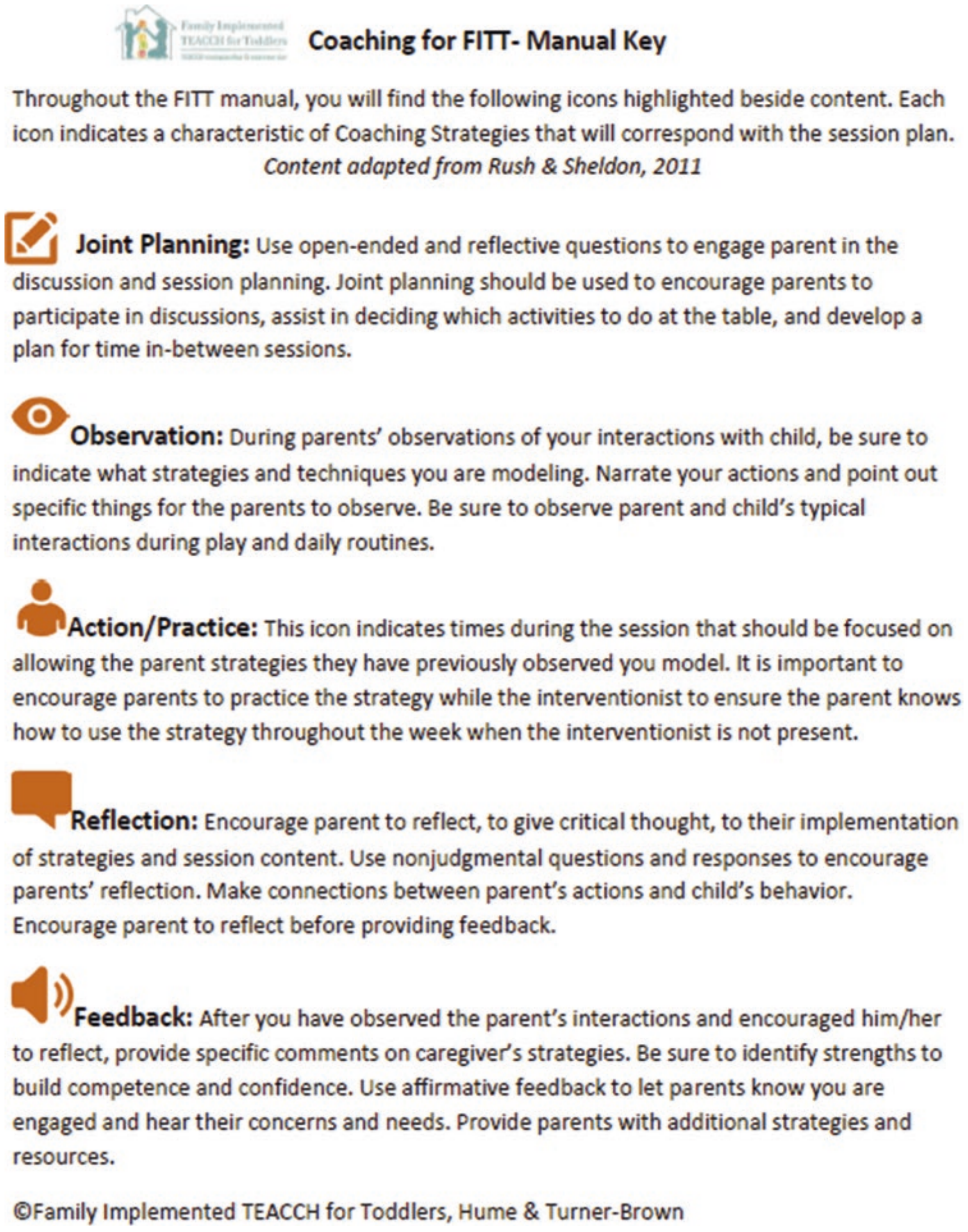
stress and improving parent well-being is a key desired outcome for enrolled families, and building capacity, competence, and confidence in parents through coaching is one way FITT focuses on these parent outcomes (Rush & Sheldon, 2011). FITT uses the coaching model developed by Rush and Sheldon in their book *The Early Childhood Coaching Handbook* (2011). This includes the use of observation, action and practice, joint planning, reflection, and feedback which are used across the session (see Fig. 20.4; Rush & Sheldon, 2011). Their coaching strategies draw from the work of Hanft and Pilkington (2000), who encouraged early childhood practitioners to reconsider their role and "to move to a different position alongside a parent as a coach rather than lead player." During FITT sessions, parents are involved in the planning process, sessions focus on parent concerns, parents have opportunities to practice strategies with interventionist support, and parents are encouraged to reflect on their experiences during the session. FITT interventionists focus on developing the parent's ability to engage with their toddler with less focus on the interventionist and toddler's relationship. FITT does incorporate two elements of consultation into sessions along with the coaching strategies, including providing new information and strategies to families and planning session topics in advances (part of the manualized approach, though each session is individualized and addresses parent concerns). FITT interventionists do provide information on FITT strategies as the enrolled families are, due to their very young children, new to autism and autism-related intervention and do not often have a base of skills or strategies that can be expanded upon.

Targeting Developmental Domains with FITT Strategies across Routines

FITT interventionists partner with parents at each session to develop new routines designed to address parent priorities across developmental domains (e.g., receptive communication, play, behavior) and embed FITT strategies into existing family routines. This partnering ensures that the FITT goals of increasing both engagement and understanding are addressed across the toddler's day. Following are some examples of how FITT strategies have been implemented to target several developmental domains across family-selected routines. Note that FITT strategies should be individualized based on the informal assessment conducted by the parent and FITT interventionist. FITT strategies are in bold print for easier identification.

Receptive Communication

Layton's family was concerned that toothbrushing was such a stressful activity for everyone in the family. His mom or dad had to carry him to the bathroom, place him on the counter, and hold onto him so he didn't run away while brushing. Layton cried during most of the routine and often his parents felt like crying as well. With support from the FITT interventionist, Layton's family selected several FITT strategies to help Layton better understand the expectations related to toothbrushing, such as how long it would last, what would happen next, and what the procedures were. First his parents **identified his interest** in Elmo and created an **early learning activity** which allowed Layton to brush Elmo's teeth and better learn the toothbrushing procedures. They also created five pictures of toothbrushes and laid them next to Elmo. As Layton brushed Elmo, his parent put each of the pictures in a **finished box** to indicate the passage of time and let Layton know when brushing was complete (when the brushes were all in the finished box). This was introduced at the **table-based play** area, and then this **visual countdown** system was transferred to the bathroom. They began using a **first/then** with his toothbrush and a photo of his iPad, so Layton would know that toothbrushing was coming (rather than his parents simply picking him up) and what activity would come next (watching brief YouTube clips on the iPad). Across 2 weeks the parents implemented these strategies daily and saw great improvement in Layton's resistance to toothbrushing: he



Coaching for FITT- Manual Key

Throughout the FITT manual, you will find the following icons highlighted beside content. Each icon indicates a characteristic of Coaching Strategies that will correspond with the session plan.
Content adapted from Rush & Sheldon, 2011

Joint Planning: Use open-ended and reflective questions to engage parent in the discussion and session planning. Joint planning should be used to encourage parents to participate in discussions, assist in deciding which activities to do at the table, and develop a plan for time in-between sessions.

Observation: During parents' observations of your interactions with child, be sure to indicate what strategies and techniques you are modeling. Narrate your actions and point out specific things for the parents to observe. Be sure to observe parent and child's typical interactions during play and daily routines.

Action/Practice: This icon indicates times during the session that should be focused on allowing the parent strategies they have previously observed you model. It is important to encourage parents to practice the strategy while the interventionist to ensure the parent knows how to use the strategy throughout the week when the interventionist is not present.

Reflection: Encourage parent to reflect, to give critical thought, to their implementation of strategies and session content. Use nonjudgmental questions and responses to encourage parents' reflection. Make connections between parent's actions and child's behavior. Encourage parent to reflect before providing feedback.

Feedback: After you have observed the parent's interactions and encouraged him/her to reflect, provide specific comments on caregiver's strategies. Be sure to identify strengths to build competence and confidence. Use affirmative feedback to let parents know you are engaged and hear their concerns and needs. Provide parents with additional strategies and resources.

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Fig. 20.4 Example of FITT coaching icons that are embedded across manual to remind interventionists of coaching strategies to be used during each aspect of every session

learned to transition to the bathroom independently, tolerate the routine without physical restraint, and remain calm during the routine which reduced stress across the household. This change in his participation on the toothbrushing routine had a positive impact on his parents' stress level daily.

Auggie's mom was frustrated that he would only take 1–2 bites of food at snack time before fussing to get out of the high chair to play and then be hungry again only a short time later. She wanted him to eat a bit more so that he wasn't snacking every 30 min as this made it difficult for her to get things done at home or go on errands in between snack sessions. Mom and the FITT interventionist decided to set up **a left-to-right activity system** to use at snack time, so Auggie could see how many bites he was going to eat before he could get down and play. Mom placed four empty spoons on the left of his high chair tray, the yogurt container in the middle, and then an empty Tupperware container to serve as a **finished** container on Auggie's right. She selected the first spoon, scooped up some yogurt, fed Auggie, and then placed it in the finished box. She followed suit with the additional spoons, and when the spoons were all in the finished box, she handed him a **transition object** (a bubble wand) to indicate that he was finished with snack and able to get down and play with bubbles during a **floor-based play** activity. Auggie soon learned this concrete system which visually answered his questions, and mom was able to add additional bites and snack items by laying them out on the table in front of his high chair.

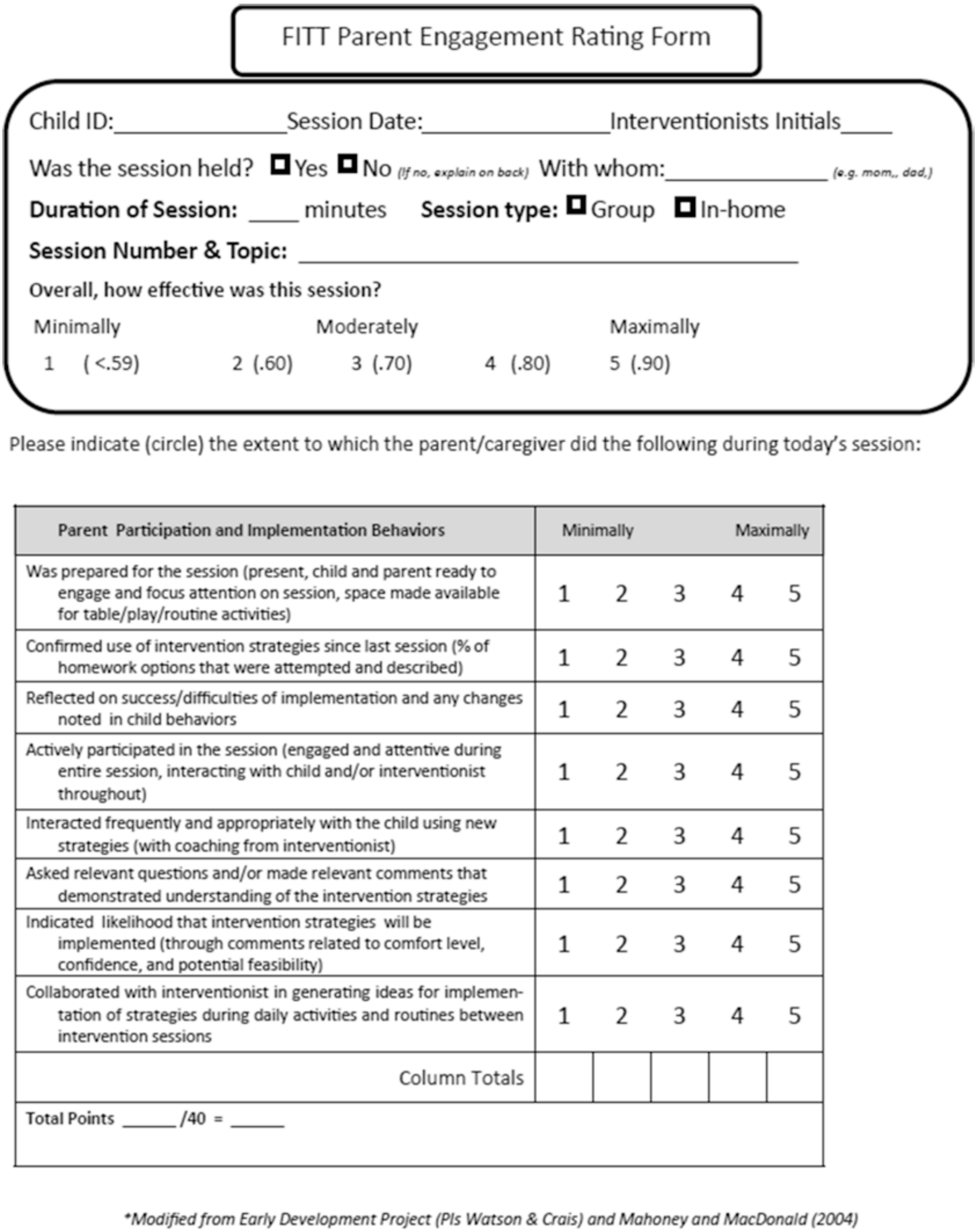
Expressive Communication

Emma's parents were concerned that she rarely communicated with them. She preferred to do or get things on her own even if it meant climbing up shelves to reach snacks, attempting to operate the family DVD player on her own, and creatively retrieving toys out of reach by stacking things up. Her parents observed that when she did communicate with them, she often took their hands and pulled them to a location or handed them an object (e.g., empty cup indicating wanting a drink). Her parents and the FITT interventionist decided to implement both **communication obstacles** and **communication exchange** using objects to increase her initiation of communication. They began by developing several **early learning activities** to help teach Emma the communication exchange process. For example, they removed several pieces from a favorite puzzle and placed them a clear container with a tight lid that would serve as the object Emma would hand to her parent to request a puzzle piece. They introduced these at the **table-based play area**. Next they took the DVDs out of her favorite DVD cases, leaving the cases accessible and the DVDs placed on a high shelf. When Emma wanted a DVD and opened the case, the DVD would not be available, thus necessitating that Emma ask for the DVD by bringing the DVD case to a parent. The DVD case served as the object for use in the communication exchange routine. Once Emma was successful in using communication exchange with several objects, her parents created a few more obstacles and objects to exchange (e.g., favorite snacks were placed in containers she could not open) to provide multiple opportunities to practice across daily routines.

Mario's dad was pleased that his son was starting to use more phrases to communicate, but he noticed that his son rarely looked at him or shifted his gaze while playing and never seemed to point to things during their play together. His FITT interventionist described joint attention during a session, and dad was concerned that his son was not initiating joint attention bids. He and the FITT interventionist decided to use Mario's **interest** in Yo Gabba Gabba and create an **early learning activity** to play with during the **floor-based play** routines to support the initiation of joint attention which included pointing and shifting eye gaze. They created a scavenger hunt using Mario's stuffed Yo Gabba Gabba characters. They were hidden in the living room in sight but out of reach. As Mario and dad hunted for the five characters, dad modeled pointing up high and down low ("Is Brobee up on the TV?"). When Mario found a character, dad waited to retrieve it until Mario looked at him or pointed and provided prompts and modeling if needed. Dad used the scavenger hunt routine with different characters and during different play routines to provide multiple opportunities to initiate pointing and gaze shifting.

Next Steps for FITT

The efficacy of FITT on caregiver and toddler outcomes was examined in a recently completed randomized controlled trial. Participants included 50 children with ASD under age 3 and their caregivers who were randomly assigned to



FITT Parent Engagement Rating Form

Child ID:______________Session Date:_______________Interventionists Initials_____

Was the session held? ☐Yes ☐No *(If no, explain on back)* With whom:______________ *(e.g. mom,, dad,)*

Duration of Session: ____ minutes **Session type:** ☐Group ☐In-home

Session Number & Topic: ____

Overall, how effective was this session?

Minimally		Moderately		Maximally
1 (<.59)	2 (.60)	3 (.70)	4 (.80)	5 (.90)

Please indicate (circle) the extent to which the parent/caregiver did the following during today's session:

Parent Participation and Implementation Behaviors	Minimally				Maximally
Was prepared for the session (present, child and parent ready to engage and focus attention on session, space made available for table/play/routine activities)	1	2	3	4	5
Confirmed use of intervention strategies since last session (% of homework options that were attempted and described)	1	2	3	4	5
Reflected on success/difficulties of implementation and any changes noted in child behaviors	1	2	3	4	5
Actively participated in the session (engaged and attentive during entire session, interacting with child and/or interventionist throughout)	1	2	3	4	5
Interacted frequently and appropriately with the child using new strategies (with coaching from interventionist)	1	2	3	4	5
Asked relevant questions and/or made relevant comments that demonstrated understanding of the intervention strategies	1	2	3	4	5
Indicated likelihood that intervention strategies will be implemented (through comments related to comfort level, confidence, and potential feasibility)	1	2	3	4	5
Collaborated with interventionist in generating ideas for implementation of strategies during daily activities and routines between intervention sessions	1	2	3	4	5
Column Totals					
Total Points _____ /40 = _____					

**Modified from Early Development Project (PIs Watson & Crais) and Mahoney and MacDonald (2004)*

Fig. 20.5 FITT parent engagement/adherence form

participate in 6 months of FITT or 6 months of community services as usual. Results revealed significant treatment effects on parent stress and well-being, with families in the FITT group showing decreased stress and improved well-being over time (Turner-Brown, Hume, Boyd, & Kainz, 2016). There were also significant treatment effects on social communication skills, as measured by the Parent Interview for Autism—Clinical Version, with no treatment effects found for global child measures (i.e., Mullen).

A unique feature of the FITT study described above was the rate of families from rural areas (50% from counties identified as rural by the North Carolina Rural Center and have an average population density of 250 per square mile or less). Families in rural communities with young children with autism are more likely to have difficulty in accessing high-quality early intervention services and are less likely to reap the benefits of early intervention (Mandell et al., 2010). Study findings indicated that rural families were able to successfully implement FITT strategies during and between sessions as rated by the parent adherence rating form (see Fig. 20.5; 0.86 out of 1; Hume, Turner-Brown, Boyd, & Arnold, 2014) and were highly satisfied with the FITT intervention (4.75 out of 5; Hume et al., 2014). These findings were similar to the non-rural sample; thus, our preliminary results suggest FITT is feasible and acceptable for families in rural and non-rural communities alike.

We have evidence of a highly promising intervention that has been successfully implemented in the homes of toddlers with ASD from diverse communities. The positive impact on caregivers is aligned with recommendations for parent-implanted approaches that a focus on family well-being is an important intervention emphasis area (Stahmer & Pellechia, 2015). While there may always be a need for more intensity for robust treatment effects on child skills, supporting family well-being should be an important focus in early ASD intervention.

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Caregiver-Mediated Intervention and the Achievements for Little Learners Model

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Abstract

ASD risk can be identified in infants and toddlers. Therefore, effective interventions tailored to the developmental characteristics of this young population are needed. Caregiver-mediated approaches provide a cost-effective venue for high-dosage immersion of children in enriched and scaffolded engagement experiences. This chapter examines caregiver-mediated approaches designed for infants and toddlers with ASD or ASD risk. A review of the literature is provided on features of interventions showing promising or limited treatment effects. The Achievements for Little Learners caregiver coaching and child intervention program, designed by the authors, is described. This intervention was designed to address gaps in existing intervention approaches by combining adult-learning principles and naturalistic developmental behavioral interventions (NDBI), as well as translating principles from embodied cognition and situated learning theories to create a potent learning environment for caregivers and their children. The design of the Achievements for Little Learner program also was intended to support caregivers' adaptation to the ASD diagnosis or ASD concerns and their emotional resolution and to assist in the emotional resolution process. Preliminary data showing promise of the intervention for improving caregiver fidelity of implementation of intervention strategies and child outcomes is provided.

The signs of autism spectrum disorder (ASD) are detectable as early as age 14 months (Landa, Gross, Stuart, & Faherty, 2013; Landa, Holman, & Garrett-Mayer, 2007) and often include communication delay, disruption in social responsivity and reciprocity, infrequent and low diversity of social initiations, atypical or delayed play behavior, and repetitive and stereotyped patterns of behavior and interests (Landa et al., 2007; Landa et al., 2013; Watt, Wetherby, Barber, & Morgan, 2008). While early ASD indicators align with the DSM-5 (American Psychiatric Association, 2013) diagnostic criteria for this neurodevelopmental disorder, they often are subtler than symptoms observed in the preschool years (Hess & Landa, 2012; Landa et al., 2007; Landa et al., 2013; Ozonoff et al., 2010) (see video tutorial about the early signs of ASD

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_21

involving one-year-olds, half of whom were later diagnosed with an ASD (Landa, 2013), https://www.youtube.com/watch?v=YtvP5A5OHpU; see below for an explanation about possible worsening of ASD symptoms during the second and third years of life). These subtle ASD risk indicators may be easily overlooked or dismissed (Caronna, Augustyn, & Zuckerman, 2007). Early intervention services should commence as soon as ASD risk is identified.

Because child outcomes may be improved through very early intervention (e.g., Butter, Mulick, & Metz, 2006), by capitalizing on neuroplasticity, a national campaign to detect ASD risk early in life has been launched by federal (Daniel, Prue, Taylor, Thomas, & Scales, 2009), professional (e.g., Johnson & Myers, 2007), and advocacy organizations. Skills and knowledge gained through very early intervention are likely to prepare children to absorb more information from interactions with people and objects as they grow older (Ramey & Ramey, 1998), thereby inviting more frequent and high-quality engagement and learning opportunities. Thus, numerous investigators have prioritized developing and evaluating interventions to improve outcomes of young children showing early signs of ASD and/or who are at heightened familial risk for ASD. Hereafter, both will be referenced by the term “ASD risk.”

Early intervention should focus on both the child and caregiver. Intervention approaches should accelerate the child’s acquisition of adaptive skills and establish a foundation for lifelong learning. In addition, caregivers should be empowered to utilize potent, empirically supported child-engagement strategies that positively enhance development. Specifically, when caregivers are more responsive to their child’s interests, developmental level, and communication focus, gains in children’s language, social, and emotional abilities are greater than when their interactions with their child are more directive (e.g., Drew et al., 2002; Kasari, Gulsrud, Wong, Kwon, & Locke, 2010; Mahoney & Perales, 2003; Schertz & Odom, 2007). Indeed, Siller and Sigman (2002, 2008) found that the synchronistic engagement style of parents of children with ASD predicted children’s joint attention skills 1 year later, which, in turn, predicted adolescent language outcomes. Furthermore, both verbal and nonverbal parent behaviors contributed to this predictive relationship. A particularly strong predictor of children’s initiation of joint attention was caregiver synchronization of their communication and attention to the object of their child’s attention. Such child-responsive engagement strategies are fundamental to many parent-mediated early interventions for children with ASD and their caregivers (Mahoney & MacDonald, 2007). Indeed, findings from a randomized controlled trial indicate that improvement in communication by preschoolers with ASD during engagement with parents is mediated by increases in frequency of parent synchronistic responses to their children’s communication bids (Green, Charman, McConachie, Aldred, et al., 2010). Caregivers’ use of child-responsive engagement strategies fosters a positive engagement dynamic with their child that, hopefully, will endure. For reasons stated above, the purpose of this chapter is to describe existing interventions, and a new intervention, that coach caregivers to be an active part of their child’s early intervention.

Family Response to the Diagnosis and Early Intervention

Given the emergent nature of the ASD clinical syndrome, many parents of children with ASD initially envision a neurotypical course for their child’s development. Often, parents having early concerns about their child are reassured by well-meaning friends, family, and medical professionals. Receiving an ASD diagnosis for one’s toddler is often met with disbelief, grief, and a high level of stress (Davis & Carter, 2008). What follows is a period of adaptation to the diagnosis (Baker-Ericzn, Brookman-Frazee, & Stahmer, 2005), possible lifestyle changes, resource seeking, determining intervention types and intensities, configuring financial plans, and much more. Some families may decline intervention opportunities (Rogers et al., 2014). Others seek as many resources and interventions as possible.

Still others may feel caught in limbo, wanting to begin early intervention but not knowing where to start. Since family emotional resolution with the diagnosis likely will influence many aspects of their response to their child's intervention process, we strategically designed a coaching and early intervention approach (Achievements for Little Learners; ALL) that provides redundant exposure to intervention principles, emotional supports, and a collaborative interventionist-caregiver paradigm. The ALL intervention is discussed later in this chapter.

Empowering Caregivers to Promote their Child's Development

The practice of empowering caregivers to implement child-responsive engagement strategies in early intervention (EI) is aligned with a family-centered intervention practice (e.g., family choice, culturally responsive practice), endorsed by the Individuals with Disabilities Education Act (IDEA, Part C, 2004, 34 CFR §303.18), Division for Early Childhood of the Council of Exceptional Children (Sandall, Hemmeter, Smith, & McLean, 2005), and National Association for the Education of Young Children (Copple & Bredekamp, 2009). Within a family-centered approach, caregiver-mediated models are emphasized to achieve family-centered aims, including empowering caregivers to maximize their child's developmental outcomes (IDEA, 2004, section 1436), strengthening the caregiver-child bond (Odom & Wolery, 2003), creating an ecoculture that promotes child well-being (Gallimore & Goldenberg, 1993), and even reducing parental depression (Solomon, Van Egeren, Mahoney, Huber, & Zimmerman, 2014).

These aims may be accomplished by providing intervention in natural environments (e.g., naturally occurring routines with individualized adaptations), offering children active learning experiences (e.g., motivating, developmentally appropriate activities), and utilizing functional and systematic practices (e.g., targeting clearly defined behaviors/skills using strategies that support ASD learning needs within well-structured contexts; Schertz, Baker, Hurwitz, & Benner, 2011). The consensus among leading ASD intervention researchers is that intervention strategies should integrate principles from the developmental (e.g., child-responsive engagement strategies) and behavioral sciences; such approaches are now identified as naturalistic developmental behavioral intervention (NDBI) approaches (Schreibman et al., 2015) (see Table 21.2 below, for examples of NDBI strategies).

The EI literature involving children with ASD has varied in the ages of child participants, the intervention's targeted goals, and the degree to which family-centered practices have been the primary focus of investigation. Most studies have included children between two- and six-years of age. Some have focused primarily on children's social functioning (e.g., Kasari et al., 2010), others on cognition and language (e.g., Dawson et al., 2010), and still others on comprehensive developmental targets (e.g., Landa, Holman, O'Neill, & Stuart, 2011; Wetherby et al., 2014).

Below, we review the EI literature, focusing on studies that enrolled primarily toddlers with, or at risk for, ASD and that incorporated caregiver-mediated methods with or without direct clinician-implemented child-focused intervention. Most of these studies utilized child-responsive intervention strategies. Such strategies aim to motivate child engagement by following the child's attentional lead and interests, arranging the environment to elicit communication, offering children choices, balancing adult-child turns, commenting on children's actions, and so forth (Lang et al., 2009). Ideally, caregiver-mediated interventions should address parents' priorities for their children and empower caregivers (DEC; Sandall et al., 2005) to strategically engineer the consistent learning experiences required to optimize outcomes for children with ASD. To accomplish this, and to approximate the recommended intervention intensity for children with ASD (National Research Council, 2001), Rule and colleagues (Rule, Losardo, Dinnebeil, Kaiser, & Rowland, 1998) have endorsed the adaptation of EI strategies for caregiver implementation (with coaching by professionals) to heighten the learning value of children's everyday activities; this does not preclude direct intervention provided to the child by professionals.

Early Intervention Studies Involving Children with ASD or ASD Risk

This review is not intended to comprehensively analyze the treatment approaches, study designs, or child/parent outcomes from the ASD EI literature. Rather, we seek to identify intervention elements that may positively impact development in young children with ASD. Consistencies across approaches and gaps in existing approaches will be defined.

Early Intervention Studies Showing Promise of Treatment Effect

In general, the literature on caregiver-mediated interventions for toddlers with ASD indicates that with consistent, sufficiently intensive, and high fidelity coaching, caregivers often show increased fidelity in the strategies on which they have been trained, and, in some cases, children show gains in targeted behavioral/developmental outcomes (e.g., Baranek et al., 2015; Kasari et al., 2010; Rogers et al., 2014).

The most comprehensive and extensive intervention-related child gains are associated with higher dosage, defined as the number of hours per week or months over which the intervention was provided. This is of interest given the basic premise that, by training caregivers to implement intervention strategies with their children in daily life, the dosage of intervention would be high and the effects on children's development should be considerable. Of the studies reviewed here, a randomized controlled trial (RCT) examining the effects of the Early Start Denver Model (ESDM) provided the most intensive intervention for toddlers (18–30 months) with ASD (Dawson et al., 2010) published thus far. Children in the ESDM condition received 15 hours per week of direct 1:1 clinician-child intervention within the child's home, as well as 5 hours per week of parent-mediated ESDM intervention. Children in the business as usual (BAU) condition received standard community intervention. At the end of 2 years, the ESDM group exhibited significantly greater gains in developmental quotient (mean = 100, standard deviation = 15) compared to the BAU group by 17.6 versus 7.0 points, respectively. The greatest impact was on receptive and expressive language outcomes. Little information is available about the caregiver coaching model used to prepare caregivers to implement the ESDM intervention at home.

In a comparative efficacy trial, Landa et al. (2011) randomized two-year-olds to one of two therapeutic nursery classroom-based conditions differing only in the implementation of an interpersonal synchrony curriculum within one of the classrooms. Children in both conditions attended the intervention 10 hours per week for 6 months. Parents in both groups participated in parent education classes, guided classroom observations, and in-home coaching on NDBI strategies. Moderate to large effect sizes indicated that the interpersonal synchrony curriculum differentially promoted social, language, and nonverbal cognitive improvements. The gains achieved in this 6-month intervention were comparable to gains made by children with ASD of a similar age and impairment level in a more intensive 2-year home-based intervention (Dawson et al., 2010).

In the two studies described above, trained therapists provided much of the intervention. Other RCTs have examined the effectiveness of parent training in the implementation of child-responsive engagement strategies, with minimal intervention provided by trained interventionists. For example, Wetherby et al. (2014) trained one group of parents, in individual parent-child dyads, to implement child-responsive strategies in home and clinic settings three times per week for 6 months and then twice per week for 3 months. A four-step coaching model was used where a trained interventionist modeled the strategy, provided guidance and feedback as parents implemented the strategy, promoted caregiver reflection, and then backed the coaching out to promote caregiver independence. In the comparison group, four to five families of children with ASD, communication delay, or typical development met as a group once per month without children to discuss a child-responsive engagement strategy and three times per month in a playgroup format to talk with a therapist and practice implementing the strategies without coaching. Children whose parents received intensive training and coaching exhibited significantly greater social and receptive language gains than children in the comparison group. In another study, Baranek et al. (2015) recruited parents of slightly younger children (13–17 months) with identified ASD symptoms from a community screening study and randomly assigned them to a direct training condition or a comparison condition in which children received only the community-provided services sought by their parents. Only the former group of parents received training (using mini scripted conversations to define the child-responsive engagement strategy) and coaching (interventionist modeling use of the strategy with the child and coaching the parent to do so) to implement an adaptation of the Responsive Teaching curriculum (Mahoney & MacDonald, 2007). Again, children of trained parents showed greater gains in social, communication, and sensory domains than children of untrained parents, paralleling the findings of Green et al.'s RCT (2015; reviewed below) and Brian, Smith, Zwaigenbaum, Roberts, and Bryson's (2016)) descriptive study of parent-mediated intervention.

In addition, two single-subject intervention studies (*n*'s = 3) examined the effects of training parents to implement child-responsive engagement strategies along with principles of applied behavior analysis (Pivotal Response Training [PRT], an NDBI) with their infants (4–9 month-olds: Koegel, Singh, Koegel, Hollingsworth, & Bradshaw, 2013; 12-month-olds: Steiner, Gengoux, Klin, & Chawarska, 2013). At enrollment, infants exhibited communication delays (Steiner et al., 2013) or social and behavioral difficulties (Koegel et al., 2013). These research teams limited the variety of strategies that parents were trained to implement, focusing on selecting motivating infant engagement activities. Koegel et al. (2013) used a classical conditioning approach to promote children's association of preferred activities with parents. During breaks, interventionists provided feedback to parents about their implementation of the intervention approach. Steiner and colleagues modeled then provided coaching with constructive feedback as parents implemented the PRT strategies. In both studies, parents reached fidelity in implementing the intervention strategies, and children demonstrated gains in social (Koegel et al., 2013; Steiner et al., 2013) and communication (Steiner et al., 2013) domains.

Additionally, Rogers et al. (2014) examined intervention effects in seven infants exhibiting signs of ASD (ages 6–15 months). In 12 weekly 1-hour sessions, parents in the Infant Start group were trained to implement child-responsive engagement strategies. Compared to an archival dataset of younger siblings of children with ASD who also received an ASD diagnosis, children in the Infant Start group achieved higher levels of nonverbal cognitive and language functioning at 36 months. The Infant Start group also exhibited lower rates of ASD diagnosis at 36 months than a symptomatic group of four infants who qualified for the intervention study at 9 months but whose parents declined to participate.

Green et al. (2013) also focused on late infancy (8- to 10-month-olds), conducting a case series study of infants, selected simply because they had an older sibling with ASD, not based on exhibiting signs of delay or ASD risk symptomatology. Following 12 training sessions given over 5 months, there was no clear benefit for infants in the intervention group. In a subsequent larger study, similar infants and parents were randomized to a parent training or no-intervention group (Green et al., 2015). Trained parents received up to 12 training sessions aimed at increasing their implementation of child-responsive engagement strategies. Overall, infant attentiveness to parent improved; however, individual outcomes varied considerably, from a negative treatment effect (worsening) to a very large positive effect (clinically significant improvement). Some treatment effects were more consistent, including decreased parental directiveness, reduced ASD risk behaviors, improved infant ability to disengage attention, and improved infant adaptive functioning (Green et al., 2015). Unexpectedly, infants in the intervention group exhibited slower language development than those in the no-intervention group.

Early Intervention Studies Showing Limited Evidence of Treatment Effect

In contrast to the positive treatment effects and trends reported above, some parent-mediated intervention studies focused on toddlers with ASD, or infants at risk for ASD (due to having an older sibling with ASD or exhibiting delays) have demonstrated no, or minimal, treatment effects on young children with ASD. Such studies tended to rely on indirect parent education (e.g., Carter et al., 2011), have large (2–3 weeks) intervals between parent training sessions (e.g., Drew et al., 2002), or deliver low doses (12 sessions in 12 weeks) of parent training (Rogers et al., 2012).

Carter et al. (2011) conducted an RCT, examining Hanen's More Than Words program. Treatment group parents received eight group training sessions (without children) and three home-based coaching sessions, designed to facilitate parents' use of trained child-responsive engagement strategies. No treatment effects were identified in toddlers (mean age 20.25 months) at risk for ASD. Of the studies reviewed here, Carter's group (2011) provided the least direct training of parents.

Drew et al. (2002) also failed to detect differential treatment effects for children (mean age 23 months) with ASD in an RCT comparing a parent-mediated to BAU community-based intervention. The parent-mediated group received 3-hour training sessions with a speech-language pathologist in their homes, conducted once every 6 weeks over the course of 12 months (about 8 sessions or 24 hours). Treatment targeted social and communication development within joint action routines and daily child routines, similar to the activities in Wetherby et al.' intervention (2014). Marginal gains were found in words produced and language comprehension for children in the parent training group. In a follow-up 1 year later, there was no evidence that parent-mediated intervention provided added value (Oosterling et al., 2010).

Similar to Drew et al. (2002), Rogers et al. (2012) evaluated the effect of coaching on parent implementation of child-responsive engagement strategies and child developmental gains. In their RCT, parents of 14- to 24-month-olds at risk for ASD were assigned to parent-delivered ESDM (P-ESDM) or a community BAU intervention group (Rogers et al., 2012). The P-ESDM group received 12 1-hour parent-coaching sessions, about half the dosage provided in Drew and colleagues' study (2002). Both groups exhibited gains in parent use of child-responsive engagement strategies and child development; no between-group differences were detected (Rogers et al., 2012).

Summary of Early Intervention Impact

While parents indicate satisfaction with training in child-responsive engagement strategies (Carter et al., 2011; Green et al., 2013; Rogers et al., 2014), evidence about the impact of parent-mediated intervention on children's development is mixed. While numerous factors could complicate the identification of treatment effects (e.g., receipt of more intervention by control groups), Rogers et al. (2012) concluded that parent-mediated interventions do not yield child gains comparable to those of interventionist-delivered treatment intervention (particularly intensive interventions) (e.g., Dawson et al., 2010; Landa et al., 2011; also see Stahmer et al., 2015).

Yet, a variety of intervention options are needed to meet the unique needs of families having a child with ASD. Innovative approaches must be explored to foster parents' implementation of child-responsive or NDBI strategies. Schertz and Odom (2007) highlight this point in their single-subject design study in which parents achieved varying levels of fidelity (8%, 70%, and 85%) in implementing child-responsive engagement strategies targeting social development with their toddlers who had "strong early markers (p 1564)" for autism. Variables contributing to the potential success of parent training include focusing on a limited set of strategies (e.g., Ingersoll & Gergans, 2006; Koegel et al., 2013), providing at least part of the training in structured contexts with minimal distractions ensuring high dosages of parent training and practice (e.g., Ingersoll & Gergans, 2006; Wallace & Rogers, 2010), and supporting the transfer of strategies to the home (Wetherby et al., 2014). Yet, even if these conditions are met, demands of family and job may restrict parents' implementation of intervention strategies (Drew et al., 2002), so direct child intervention is likely an important intervention element. Since few intervention studies focus on one-year-olds with ASD risk, no consensus has yet been reached on how best to intervene at this age; yet intervention delivered at age 1 year may yield better outcomes than when initiated later for toddlers with early signs of ASD (Rogers et al., 2012).

Achievements for Little Learners Intervention for One-Year-Olds

Achievements for Little Learners (ALL; Landa & Sharpless), an intervention for one-year-olds at risk for, or diagnosed with, ASD and their caregivers, was designed to address gaps in existing intervention models, with an eye toward affordability, adoptability, generalizability, and sustainability. The model provides a unique blend of center- and home-based learning experiences targeting children's communication and social development and caregivers' adoption of NDBI strategies (see Table 21.2 for examples). To achieve caregiver success in implementation, the strategies are systematically taught with strategic coaching to support generalization of implementation across engagement routines. To account for the steep learning curve in store for caregivers, multiple supports are provided to gently guide caregivers' reinterpretation, and response to, their child's behavior. After all, caregivers are not just learning a new skill; they are learning how to navigate a dynamic interaction process with their child.

Design of ALL

In designing ALL, the putative active ingredients of our interpersonal synchrony curriculum (Landa et al., 2011) were adapted for use with younger children. The intensity of caregiver coaching and training was increased, and the focus narrowed to address the developmental needs of 12- to 24-month-olds (eliminating more advanced social and communication curricular goals). Adult learning models (Rush & Sheldon, 2011) designed to increase caregiver fidelity in implementing intervention strategies were employed in three settings:

1. At dyad and group levels within a nursery classroom where activities align with naturally occurring home routines such as mealtime, play time, hand washing, interactive book reading, and song-gesture routines
2. In an interactive group-based caregiver training while children received intervention provided by paraprofessionals in the nursery classroom
3. In the home to promote generalization (see Table 21.1)

Adult Learning Components

Within the center and home, coaches emphasize one or two intervention strategies each session. The coach models the strategy as needed, coaches the caregiver in implementing the strategy (guided practice), provides feedback, and encourages caregivers to reflect on their experiences implementing the strategy. Caregivers have many opportunities to practice, and caregivers' implementation is video recorded and discussed periodically. Within the classroom, caregivers are coached in 1:1 interactions with their child and in various group activities that include peer-to-peer and child-adult engagement.

Table 21.1 Overview of the Achievements for Little Learners intervention

Context	Children	Caregivers
Nursery classroom (center-based)	Group intervention twice per week: Structured schedule Ecologically valid learning contexts Individualized child targets Interventionists provide: Direct treatment, 90 mins/wk. Coaching of caregiver-child interactions, 90 mins/wk	In the classroom with their child 2x/wk. for first month, then 1x/wk. Interventionists provide structured caregiver training curriculum with modeling, coaching, and feedback on NDBI strategy use
Caregiver training class (center-based)	While caregivers are in the caregiver training class, the children are in the nursery classroom, as stated above Child curriculum delivered by trained paraprofessionals	Caregiver-only group 1x/wk. while child attends classroom Training curriculum parallels nursery classroom curriculum Reflect on intervention strategies and child progress Network with other caregivers
Home visit	1x/wk. for 90 mins Targeted skills aligned with those in nursery program and caregiver training class Coaching and feedback provided during home routines	Coaching and feedback on caregivers' carryover of the NDBI strategies at home
Total dosage	4.5 hrs/wk. for 6 months + home-based engagement with trained caregiver	4.5 hrs/wk. of training, coaching, and feedback for 6 months

Caregiver and Child Intervention Targets

The caregiver curriculum focuses on implementing NDBI strategies (which are inclusive of caregiver-responsive engagement strategies (Schreibman et al., 2015)) and understanding of their child's behavior and play, communication, and social/emotional indicators to facilitate caregivers' establishing developmentally appropriate expectations for their child (see Table 21.2). Caregivers are coached to promote child initiation and sustained engagement in ecologically valid developmentally appropriate activities that bridge home- and center-based experiences. These features of ALL promote rapid success for caregivers and children, engendering caregiver buy-in and increasing the likelihood of sustained strategy implementation once the intervention ends (Kasari et al., 2010).

The ALL caregiver coaching model is comprised of direct and indirect strategies. In the nursery classroom and during home visits, the session's child-engagement strategy is defined and its rationale explained. Next, the interventionist models the implementation of the strategy with the child. The caregiver then receives guidance, as needed, while practicing the strategy during interaction with their child. After a brief reflection period in which the caregiver comments on their experience and reaction to implementing the strategy, the interventionist provides specific supportive and constructive feedback to the caregiver. Sessions end with preparing a concrete action plan for how, when, and where the caregiver will implement the strategy in the coming week. During the caregiver training classes, the interventionist explains the child-engagement strategy of focus for the week with the support of exemplary videos. The participating group of caregivers engages in discussion about how the strategy might be implemented for their child and about perceived barriers to successful implementation. The session ends with planning their at-home practice. During the next week, caregivers practice implementation at home. During the next class, caregivers report back on their experiences and troubleshoot with other caregivers and the interventionist. Caregivers also hear other caregivers' successes and challenges and offer encouragement and share ideas and resources.

In addition to coaching caregivers' strategy implementation, ALL strategically supports positive caregiver-child relationships. This is important because children with ASD or ASD risk exhibit impairment in social engagement; care-

Table 21.2 Summary of caregiver and child targets in the ALL intervention

Caregiver-focused targets (strategy implementation, relationship gains)	Child-focused targets (developmental gains)
NDBI strategies: Contingently responding to child interests and communication focus and following child focus of attention or interests (including imitating and commenting on child actions and vocalizations) Arranging environment to enhance communication and play Establishing predictable joint action routines, then systematically varying those routines Balancing turns (and pausing to give time for child response/initiation) Creating communicative temptations Providing contingent natural consequences	Social and communicative initiations and responses, category and concept formation: Receptive language Expressive language Joint attention Imitation Play Social engagement Self-regulation Peer-to-peer engagement Sustained engagement in ecologically valid, developmentally appropriate activities and routines
Improving caregiver-child relationship Understanding child's development, preferences, and behavior Identification of enjoyable child-engagement activities Confidence in ability to accelerate child learning and support positive child behaviors	

givers often perceive them as having a difficult temperamental style; and high levels of parenting stress have been linked to low social responsivity in children (Kasari & Sigman, 1997). At the start of ALL intervention, parents often report high stress levels related to their child, consistent with Kasari and Sigman (1997). To foster positive caregiver-child relationships, ALL supports caregivers' (a) understanding of their children's development, preferences, and behavior; (b) identification of enjoyable child-engagement activities; and (c) confidence in their ability to accelerate their child's learning and support positive child behavior. To adapt their current engagement strategies and accommodate evidence-based child-responsive engagement strategies, caregivers must exert effort and patience and develop confidence in the interventionist (Kazdin, 2000). To support caregivers through this process, ALL provides multiple opportunities for caregiver success during practice implementing the intervention strategies across multiple activities and settings.

Children's targets include social engagement, communication, expressive and receptive language, joint attention, imitation, and play skills. To advance development in these domains, an emphasis is placed on enhancing category and concept formation, spoken and gestural communication, social engagement, and self-regulation. Ultimately, the goal is to help children make sense of the world around them and become active participants in their daily activities.

Conceptual Foundation of ALL

ALL was designed to provide a multimodal learning environment for caregivers and children, wherein concepts could be taught and re-taught with a continuum of support (from the controlled, systematically organized center-based setting to the less-structured home setting) each week. A group learning model provides frequent opportunities for caregivers to support and encourage each other and practice strategy implementation (e.g., as caregivers and children rotate through their turn in group activities) and for children to engage with peers.

The ALL intervention is anchored in the developmental and cognitive sciences. ALL takes a constructivist approach, wherein the environmental arrangement, instructional strategies, and child-engagement activities converge to help children construct meaning from their experiences. Said another way, ALL is designed to help caregivers help children to make sense of the world around them. Within this constructivist approach, two major themes permeate the learning milieu that caregivers are trained to create for their children. The first theme is *embodied cognition* (Gibson, 1977), interpreted as active learning, wherein learning is promoted through children's physical interactions with the world around them. The second major theme, tightly linked to embodied cognition, is *situated cognition*. In ALL, children's learning opportunities are situated (e.g., Chiel & Beer, 1997) in meaningful and ecologically valid action routines. Caregivers learn to simplify and enrich naturally occurring events to make them motivating and meaningful for their child. They also learn how to create developmentally appropriate, predictable, playful action sequences (routines) out of opportunities afforded by available objects or interpersonal exchanges within their homes. Caregivers are coached to create and expand these routines, which provide scaffolding for children to learn from their own self-generated action contingencies as they engage with objects and people. For example, when a child drops a block into a bucket, s/he sees and hears the immediate effect of the block bouncing against the sides and bottom of the container, signaling that the block is, indeed, in the container. Likewise, during a table washing activity in the ALL nursery classroom, each child is given a damp cloth to use as the adults slowly and rhythmically sing “This is the way we wash the table” and model the motorically simple horizontal action of “washing” the table with their cloths. As children explore the cloth, usually moving it back and forth even before grasping the idea of “washing” the table with it, they notice the parallel ‘washing’ movements of the children and adults around them. This gives way to imitation, turn-taking, anticipation, communication, and the development of a “table cleanup” routine, as staff and caregivers expand the activity sequence and layer in language and interpersonal communication. Caregivers adapt and repeat the routine at home, empowered by their child’s cooperation and the steady gains they see in their child’s language and social development. As caregivers present similar events across contexts, children’s memory of those events is enhanced, facilitating learning and generalization (Barr, Rovee-Collier, & Learmonth, 2011).

Activity-based Approach

Embodied cognition and situated learning theories are evident in the activity-based approach of ALL. Action routines provide children with guided and scaffolded opportunities to learn about objects, object relations, people-object relations, and the uses of objects with multiple affordances. Objects are selected and arranged to encourage object exploration and facilitate imitation, interpersonal synchrony, language development, and the development of action sequences. These action sequences map onto event sequences, which develop over time into cognitive constructs known as event representations. As children form event representations, their performance of activities associated with the events becomes more automatic. Increasing automaticity permits children to integrate ever-more complex and diverse elements, such as pairing eye contact with vocalization, pairing gesture with spoken language, and ultimately achieving symbol-infused coordinated joint engagement (Adamson, Bakeman, & Deckner, 2004). Because the objects used in ALL afford multiple actions, including simple motor acts requiring only early developmental play skills, children often are motivated to explore them. This is important because at the start of intervention, many children do not engage with objects or primarily engage with them in repetitive, often nonfunctional, ways.

Promoting Children’s Play and Language

As part of their training, caregivers’ critical thinking about available toys and objects is supported. They learn to see the value of simple, readily available objects (e.g., shoe boxes as a container, drum, bed, bathtub, table, or stackable building block). They learn to appreciate that children’s object use provides a window into their minds; when caregivers look through this window, they gain a new understanding of how to interact with their child in ways that promote sustained engagement and turn-taking. Caregivers learn to honor their children’s preferences and join in their play as a partner. As the child experiences motivating play activities with their caregiver, rather than redirection, engagement duration increases. This provides caregivers with more opportunity to expand and model new play, language, and social behaviors.

Most toddlers entering the ALL intervention present with no to minimal spoken language. While other concerns also exist, parents almost always identify the development of expressive communication as a main priority. Thus, a major emphasis is placed on teaching caregivers about language and communication development. ALL interventionists help caregivers understand that their children are already producing interpretable (if not intentional) communication signals, such as crying, smiling, and directional gaze. Caregivers learn how to help their child discover the power of communication as they use the intervention strategies to target new communicative forms, such as gestures, vocalizations, words, and/or handing a picture or object to another person. Caregivers are guided to discover that children learn words for things that are meaningful and relevant to them and that they can enhance this learning by adjusting their timing (labeling objects their child is holding and looking at) and language complexity (being within the zone of proximal development for the child's language level). Also, caregivers are coached to select certain nouns (e.g., "ball, car, Elmo"), verbs (e.g., "go, push, eat"), and prepositions (e.g., "in") to promote children's thoughts and communication about their actions and ideas and to be prepared to combine words (e.g., "ball go," "car go," "Elmo go in car," "Elmo eat," "ball go in"). Caregivers are strongly encouraged to create repeated opportunities throughout the day during which their child has the opportunity to hear and use targeted vocabulary words because, compared to typical development, word learning in children with language delay requires more frequent exposures to words (Gray, 2003). Caregivers learn, often for the first time, to value and support their toddler's understanding and production of functional vocabulary, de-emphasizing rote memorization of letters and numbers.

To further empower caregivers' success in scaffolding their child's language, caregivers learn how to create joint action routines to entice engagement. The ALL interventionists demonstrate and coach caregivers in experiencing the power of pausing at critical times within those routines (to elicit targeted vocabulary or gestures), using event casts (talking about what their child or they are doing), reinforcing communicative attempts using natural reinforcers (giving their child a block when the child attempts to say "block"), and creating various communicative temptations for their child. In all classroom routines, a core set of words and communicative forms are used to ensure that children receive high-dosage input (i.e., hear the words often) and have frequent related expressive communication opportunities. For example, children choose the group's song-gesture game by selecting one of two pictures or objects that represent the song. The song options repeat targeted words many times, and the singing pauses at strategic times to elicit child productions of targeted words, word approximations, or gestures or their use of a low-tech augmentative communication system.

Promoting Children's Social Development

Children's goals are targeted through caregivers' establishment, and systematic variation, of developmentally appropriate and motivating joint action routines. Four major types of joint action routines are emphasized: caregiving-related events (e.g., dressing, cleaning up, washing hands), spontaneously occurring engagement opportunities, interactive book sharing, and song-gesture routines. These routines are established within the classroom where distractions can be controlled. Caregivers gain confidence as they rapidly succeed in establishing and expanding routines along with other caregivers. In addition, caregivers are coached to adapt and generalize routines to priority contexts and activities at home. Caregivers learn the components of routines: (1) introducing the routine with a starter phrase/song, (2) using gestures and words to help their child know which target behavior is expected, (3) pausing to give the child an opportunity to produce that behavior (or an approximation), (4) reinforcing their child's attempt by acknowledging the child's behavior and providing a natural consequence (e.g., offering a relevant object, tickle, and/or continuation of the routine), and (5) signaling the end of the routine.

Structure of the Therapeutic Nursery Classroom with Direct Caregiver Coaching

Many young children with ASD do not have opportunities to engage with peers. Their caregivers may avoid such situations because of their child's delays and behavioral difficulties, and group-based early intervention programs may not be readily available. The classroom's daily routine revolves around child learning activities that parallel naturally occurring activities, promoting adoptability, feasibility, and sustainability of caregivers' intervention strategy implementation at home and in the community. Some of the activities are specifically incorporated to address caregiver-reported challenges (e.g., dressing, feeding, playing, transitioning). Thus, for example, the classroom schedule incorporates dressing (coats and shoes taken off upon entry and put on at departure) and meal routines. Some classroom activities foreshadow preschool learning contexts, such as snack, interactive book sharing, and play. Engaging in these activities with their child, caregivers learn strategies to actively support their child's language, social, and regulatory abilities that are pivotal to later success in preschool. Across the classroom activity schedule, there is redundancy of intervention strategy implementation (promoting caregivers' generalization of strategy implementation) and targeted child development skills to promote caregivers' attainment of implementation fidelity and hence empowerment and perception of feasibility of the intervention.

Weekly In-home Coaching Visits

Weekly interventionist home visits focus on caregivers' generalization of the intervention strategies to the home in play and daily routines. During this time, caregivers demonstrate their implementation of the strategies, receive coaching and feedback, and reflect on the intervention strategies. In addition, spouses and other family members are able to participate in the coaching process by attending these home sessions. The home sessions also enable the interventionist to support caregivers' inclusion of siblings in activities while still maintaining fidelity in the implementation of the intervention strategies. Caregivers report high levels of satisfaction and reduced stress when they find ways to productively engage multiple children simultaneously.

Caregiver-only Group Sessions

The caregiver-only group component enables caregivers to focus entirely on the specific child-engagement strategies being targeted in the intervention while their children attend the nursery classroom where paraprofessionals conduct the same intervention and activity routines used when caregivers are in the classroom. This provides consistency for children and an added benefit of promoting generalization of skills to engagement with other adults. During the caregiver-only group sessions, one or two strategies from the nursery class are discussed, including an explanation about why the strategy is used, our expectations for each child, and how to improve child engagement. Explicit planning activities provide time for caregivers to specifically define how home-based activities can be adapted to effectively promote child engagement and learning. For example, caregivers plan how to arrange their child's clothing at home during dressing routines to promote behavior regulation, initiation, communication, and social engagement. Caregivers plan what they will say and exactly what child skills they will target within dressing activities, for example.

The ALL caregiver-only group curriculum, designed by the authors, utilizes interactive PowerPoint presentations to convey developmental and intervention concepts, provide video illustrations of strategy implementation and effective troubleshooting, launch role-playing and other adult learning activities, and promote reflection on strategy implementation. Each session begins with a review of the previous week's strategy. Caregivers describe their implementation of the strategy at home, share pictures and, when possible, videos of their implementation of the strategy, and reflect on successes and perceived challenges to implementing the strategy. Caregivers provide encouragement and alignment with each other during this segment of the session. Next, the new topic (or elaboration of the strategy presented the prior week) is introduced.

Caregivers who participated in ALL inform us that they made an intentional effort to practice the strategies so that they might participate meaningfully in the weekly opening review activities. They reported looking forward to hearing other caregivers' experiences and to benefitting from the support and input of other caregivers as well as to demonstrating their own successes. Some reported that this group became their support group.

Caregiver Perspective at Intervention Onset

When a new group of caregivers begins ALL, they are shown videos (consented) of caregiver-child dyads engaged in the classroom routines described above. Often, the caregivers are emphatic that their child would not be able to attain the skills displayed by the children in the videos. At the end of the 6-month intervention, we share videos of these caregivers with their own children at the start and end of the intervention. They usually comment that they could not remember their child having such an early developmental level at the start of the intervention. They express their feelings of pride at seeing what they and their child have accomplished. One parent shared that she had bought many books on early intervention, but she could never figure out how to apply the information. Some of the books sat unread on her bedside table; she said she felt she needed to keep reading, but she just couldn't bring herself to do it. She further explained that the ALL format enabled her to make positive changes in her interactions with her child and in her family's daily routine. She attributed the substantial child gains to those changes. Another parent echoed this mother's comments, saying that she too bought numerous books, but there were always other demands on her time, such as housework or job-related tasks. She said that carving out the time every week to focus on learning how to help her child paved the way for her success. The success that she experienced in the classroom, seeing other caregivers experiencing similar challenges to hers and progressing through learning the strategies along with other caregivers changed her perspective on her child, herself, and the future. These experiences also helped her clearly see how to apply the strategies and adapt home routines to support her child's development.

Preliminary Data Indicating Promise of ALL

A preliminary study was conducted to evaluate whether (1) toddlers with ASD or ASD risk receiving ALL show greater gains in cognitive, language, and play development from pre- to post-intervention assessments compared to toddlers whose caregiver attended the caregiver-only group education component only; and (2) caregivers receiving the full ALL training in strategies for enhancing their children's engagement and communication development utilize those strategies more effectively than caregivers in the comparison group. Caregiver-child dyads were randomized into one of two 6-month intervention conditions: ALL as described above ($n = 7$) or the caregiver-only group (CO) ($n = 6$) condition which met once per week at our center. The study was registered with the National Institutes of Health's Clinical Trials Registry and was approved by the Johns Hopkins Medical Institutional Review Board; all families gave written informed consent for their child's participation.

Participants were 13 toddlers between ages 11 and 21 months and their caregiver(s). Eligibility criteria included meeting the Autism Diagnostic

Observation Schedule-Generic (ADOS; Lord, Rutter, DiLavore, & Risi, 1999) algorithm criteria for ASD or autism as well as having a clinical judgment of ASD ($n = 10$) or being at “high risk for ASD” ($n = 3$). Most of the caregivers who participated in the program were parents. However, one full-time nanny participated, and for three families, a mother/father or a parent/grandparent alternated attendance.

Outcome measures Children were assessed at baseline (pre-intervention) and at post-intervention by a clinician blinded to group membership, study protocol, and whether the assessment was being conducted pre- or post-intervention. Language, social, and play skills were assessed using standardized (i.e., Mullen Scales of Early Learning (Mullen, 1995), ADOS) and nonstandardized but structured (e.g., caregiver-child play sample) measures.

Caregiver fidelity of intervention strategies was coded from the 10-minute caregiver-child play sample. Dependent variables were aligned with the instructional strategies taught to both groups.

Data analysis T-tests and chi-square tests assessed group comparability at baseline. The Mann-Whitney U test was used to compare groups’ change scores on each variable. Effect sizes were calculated using Cohen’s d (Cohen, 1988); pretest pooled standard deviation was used. Pearson’s correlation (r) coefficient was calculated to examine the relation between change in caregiver use of the NDBI strategies and amount of child change on all four variables.

Results T-tests and chi-square tests revealed no between-group differences on any of the dependent variables at the pre-intervention assessment (p’s ≥ 0.24) except for ADOS Reciprocal Social Interaction algorithm score, on which the CO group’s scores were significantly lower ($p = 0.04$), indicating less severe social impairment.

Effect sizes were moderate to large for change in Mullen Receptive ($d = 0.90$) and Expressive Language ($d = 0.51$) standard (T) scores and caregivers’ use of the intervention strategies ($d = 1.13$) (see Table 21.3) from pre- to post-intervention, with the ALL group gains being greater than those of the CO group. Two caregivers in the CO group, but none in the ALL group, exhibited decreased use of the intervention

Table 21.3 Pre- and posttest mean scores and change scores for ALL and CO groups

	ALL $N = 7$			CO $N = 6$				
Dependent variable	Mean (sd) Pre	Mean (sd) Post	Change mean (sd)	Mean (sd) Pre	Mean (sd) Post	Change mean (sd)	Effect size	Mann-Whitney p
VR T[a] score	34.43 (16.84)	45.71 (16.32)	11.29 (12.53)	39.33 (18.39)	49.00 (17.36)	5.8 (9.04)	0.49	0.37
RL T score	25.14 (10.84)	39.71 (21.31)	14.57 (15.08)	30.00 (14.3)	33.00 (16.17)	3.00 (9.70)	0.90	0.20
EL T score	27.00 (12.12)	40.00 (23.27)	13.00 (16.03)	29.67 (9.52)	36.00 (13.18)	6.33 (7.97)	0.51	0.67
Functional play acts[a]	3.71 (2.93)	8.00 (3.74)	4.29 (1.6)	8.40 (9.48)	9.80 (6.10)	1.40 (6.54)	0.67	0.46
Caregiver strategy use[a]	20.86 (3.34)	27.71 (5.35)	6.86 (4.74)	21.00 (1.73)	23.00 (4.64)	2.00 (3.54)	1.13	0.09

[a] n = 5 in the CO group

VR Visual Reception scale of the Mullen Scales of Early Learning (Mullen), *RL* Receptive Language scale of the Mullen, *EL* Expressive Language scale of the Mullen, *T* Mullen standard score with a mean of 50 and standard deviation of 10 strategies at post- compared to pre-intervention assessments. The mean gain on each variable each group is shown in Table 21.3.

Contrary to our expectations, caregiver improvement in fidelity of implementation was not correlated with any child gain for any of the dependent variables (r between −0.08 and 0.19; *p*'s ≥ 0.55) within this short-term intervention.

Discussion of results The data presented above offer promise that toddlers with ASD or ASD risk receiving ALL may accomplish greater developmental gains than those whose caregivers receive education only, even when training in both groups focuses on the same intervention strategies. This inference is based on moderate to large effect sizes. Likewise, large effect sizes provide preliminary support for the hypothesis that caregivers receiving the full ALL training in implementing strategies designed to enhance child engagement and communication development would exhibit those strategies during interactions with their children more successfully than caregivers receiving the CO program.

Although this study is preliminary and has a small sample size, the information gained has relevance for other investigators who are planning very early intervention studies involving toddlers with, or at risk for, ASD. The efficacy of ALL requires additional research. Future research on the ALL program should examine the effects of density of the intervention. In our study, caregivers and toddlers received three intervention sessions per week, similar to that provided in Kasari et al.'s (2010) parent-mediated intervention study of two-year-olds. Kasari et al. (2010) reported that improvement in parent-child engagement in the intervention group was greater than in the waitlist control group. In contrast, an intervention with less density in parent training sessions (once every 6 weeks (Drew et al., 2002) or once a week for 12 months (Rogers et al., 2012)) did not result in greater language or social gains than routine care.

Another important ALL feature is provision of group-based caregiver training and child instruction. Group instruction is cost-effective and provides for scalability of the intervention. It affords caregivers the opportunity to form a community of support. Caregivers in the ALL group are able to share experiences about parenting/caring for a child with ASD and ideas about how to successfully implement the strategies at home. They also have the opportunity to encourage each other in the classroom with their children, celebrate breakthroughs, and practice strategies for helping their child successfully engage with age peers. Their children had opportunities twice per week for age-peer interaction and to generalize skills to engagement activities with adults who were not family members. The developmental gains that most children achieve, along with their growing ability to approach and engage with other children's caregivers, are viewed by parents as major benefits. Parents often comment that the ALL experience prepares their children to, for the first time, be comfortable with child care providers so that they may run errands and have time away with their spouse.

A similar curriculum for caregivers was implemented in the caregiver education sessions for the ALL and CO groups, but only caregivers in the ALL group received direct coaching in implementation of these at the clinic and home. Given the large effect size for change in caregivers' use of NDBI strategies, our data preliminarily indicate that caregiver education alone is insufficient to substantially alter caregiver-engagement behavior with their toddlers with ASD, a finding supported by Carter et al. (2011). Our findings substantiate those of Kaiser, Hancock, and Nietfeld (2000), who showed that parent training improves parents' frequency of use of language-enhancing strategies during interactions with preschoolers with ASD. Caregivers in the ALL group learned to implement NDBI strategies in multiple interaction contexts within the nursery classroom and at home, thus promoting generalization of the use of these strategies. Finally, the opportunity for toddlers in the ALL group to have interventionist-mediated treatment may have contributed to the cross-domain, high-level, and generalized gains.

We found that only caregivers in the CO condition had a decrease in the use of NDBI strategies from pre- to post-intervention assessment. Without having specific coaching and guidance around the use of the strategies in authentic interactions with their child, caregivers of toddlers with ASD may be at risk for becoming less synchronized with their child over time. This may be especially true if children are not responding in expected ways to the caregivers' use of such strategies. Caregivers are likely to benefit from professionals' guidance in understanding their child's development and how to create a physical and interpersonal environment to maximize child's learning and engagement. We also found that only toddlers in the CO condition exhibited a decrease in functional play acts despite having less severe baseline ASD symptoms than the ALL group. Worsening in toddlers with ASD has been documented by Landa et al. (2007; Landa et al., 2013). The degree to which worsening is preventable is unknown. However, the possibility that very early intervention may thwart such an untoward event gives rise to the notion of "preventative intervention." This does not connote prevention of autism per se but rather prevention of declining or plateaued trajectories, secondary impairments, severity, and certain maladaptive behaviors. Further research is needed to determine the nature, density, and dosage of intervention required to achieve preventative effects.

Effective early interventions for infants and toddlers with ASD or ASD risk likely will require a high density of caregiver training involving a blend of explicit instruction and coaching, specific strategies to promote generalization, a therapist-mediated intervention component, and the right level of intensity. More research is needed to specify intervention ingredients that maximize generalized change in social, communication, and play development in toddlers with ASD. Findings from such research are needed to guide Part C providers and parents in their quest to improve outcomes and ensure the highest possible quality of life for children with ASD.

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Part VI

Supporting Families of Children with Autism Around the Globe

Parent-Implemented Interventions Around the Globe

22

Kristen Gillespie-Lynch and Rachel Brezis

Abstract

Parent-mediated interventions for children with autism are spreading around the globe, heralded as the most practical response to a dearth in professionally trained interventionists. Yet the evidence base for these interventions remains unclear. In this chapter we survey published English-language evaluations of parent-mediated interventions from different continents, supplemented by an online survey of 29 interventionists from 11 countries, and an in-depth case study of the parent-led Action for Autism organization in New Delhi, India. Together, these data reveal that parent-mediated interventions are being used in many low-resource countries, yet inequities in access to these programs remain a challenge, due to financial, geographic, and cultural barriers. For those families that do access parent-mediated training, challenges to implementation include family and caregiver characteristics, as well as different cultural values (such as parenting practices, the willingness to question authority, and degree of understanding among extended family members). Interventions vary along a continuum of indigenously based and imported interventions, drawing from a range of Western interventions. While efforts to adapt and evaluate these interventions in low-income settings are applauded, methodological flaws (such as quasi-experimental designs and poorly validated outcome measures) as well as limitations in the evidence base of imported interventions in their countries of origin limit our ability to properly assess and compare the effectiveness of different interventions. Future research should focus on continued standardized evaluation of interventions, hand in hand with the careful adaptation and dissemination of parent-mediated interventions around the globe.

Current evidence suggests that autism affects people around the globe at similar rates (Elsabbagh et al., 2012), yet services to support people with autism and their families are far from equally distributed around the globe and across families with different backgrounds (Durkin et al., 2010; Grinker, Yeargin-Allsopp, & Boyle, 2011). Access to evidence-based autism interventions in low- and middle-income countries, and for lower-income and/or minority families within high-income countries, remains limited (Hahler & Elsabbagh, 2015; Hastings, Robertson, &

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_22

Yasamy, 2012). These global inequalities in access to autism care are sustained by financial and geographical barriers, such as lack of governmental support and a paucity of trained professionals, as well as cultural differences, such as stigma toward autism, insufficient autism awareness, and differences in child care practices that may render interventions that have been established as effective for certain groups ineffective when exported to new populations.

A central strategy recommended by the World Health Organization (2013) to begin to address global inequalities in access to evidence-based autism care is task-sharing, or training "nonspecialists" – often parents – to provide autism care and to raise community awareness. In regions with insufficient infrastructure to support people with autism, family members often bear the full responsibility for educating individuals with autism (e.g., McCabe, 2007) and have often led the way in developing infrastructure (Grinker, 2008; Khan et al., 2012). They often desire training to help them more effectively support and advocate for the people with autism whom they care for. Parent-mediated interventions have the potential to begin to address global disparities in access to evidence-based care by empowering the people who are already caring for individuals with autism in low-resource areas. A key, often unexplored, benefit of parent-mediated interventions is their potential to improve the lived experiences of autistic people and their families by positively impacting family functioning and empowering parents to raise awareness, decrease stigma, and advocate for resources.

Parental involvement in interventions for their children has long been recognized as essential for promoting sustainable improvements in children with and without autism (Brofenbrenner, 1974; Schopler & Reichler, 1971). Parent-mediated interventions have the potential to encourage generalization by creating consistent opportunities for children to practice skills in diverse contexts (Boyd, Odom, Humphreys, & Sam, 2010). Moreover, longitudinal studies have shown that positive family processes (e.g., maternal praise) predict greater improvements in autism symptoms and maladaptive behaviors in adults above and beyond their individual and demographic characteristics (Woodman, Smith, Greenberg, & Mailick, 2015).

The effort to spread parent-mediated autism interventions on a global scale is part of the Global Mental Health (GMH) initiative (Patel, 2012), which aims to address disparities in mental health services between low-, middle-, and high-income countries, as well as between high- and low-resource populations within wealthy nations (e.g., indigenous peoples, immigrants, urban poor) by identifying, developing, and adapting evidence-based practices from high-income regions and scaling them up in low-and middle-income regions.

Are Parent-Mediated Interventions Effective for Diverse Populations?

Despite strong theoretical and practical reasons for focusing on parent-mediated interventions as a viable strategy to decrease global inequalities in access to autism care, available evidence that parent-mediated interventions for young children with autism are effective remains conflicted. A recent review of randomized controlled trials (RCTs, wherein families are randomly assigned to an intervention or a comparison condition) of parent-mediated early interventions for autism revealed strong evidence that the interventions improved proximal intervention targets or behaviors that were taught during the interventions (such as parent-child engagement and responsive parenting behaviors) but limited evidence that the interventions improved distal targets that were not directly taught (such as observational measures of child initiations and child language, child adaptive behaviors, and parental stress; Oono, Honey, & McConachie, 2013). This suggests that benefits of parent-mediated intervention may be diluted as they pass from the specialist to the parent and then to the child (Roberts & Dissanayake, 2013). The lack of a consistent impact of parent-mediated interventions on parental stress may arise because the psychological benefits associated with honing one's parenting skills may be counteracted by increased stress surrounding the added responsibility of merging one's role as parent and interventionist (O'Toole, 1989).

These findings raise questions about the process of exporting parent-mediated interventions from high-resource to low-resource countries by suggesting that the evidence base for many parent-mediated interventions for autism remains fairly weak even in their countries of origin. What constitutes an evidence-based intervention for autism in many communities is further complicated by the relative lack of social validity research evaluating the degree to which the goals and procedures of interventions are culturally appropriate for the populations they are intended to serve (Callahan, Henson, & Cowan, 2008; Hahler & Elsabbagh, 2015). Evidence for the effectiveness of autism interventions is typically established in high-income countries with families living in large urban centers who tend to be more affluent than the general population of the countries they inhabit (Kasari et al., 2014). Families facing socioeconomic hardships may struggle to find the time and resources to implement interventions with sufficient intensity (Hastings et al., 2012). Some parents who are overburdened with other responsibilities may seek relief from their children rather than greater involvement as the primary interventionist (O'Toole, 1989).

Cultural factors, including religious orientations, viewpoints about development, and caregiving practices, also influence the types of interventions families desire (Mandell & Novak, 2005). For example, communities may differ in the perceived importance of treating certain symptoms. While Indian families are more likely to view social differences as early signs of autism, families in the USA and Taiwan are more likely to identify linguistic challenges as red flags (Daley, 2004; Lee, 2017 this volume). Furthermore, certain characteristics of autism may become disabling only in cultures that stigmatize autism (Grinker et al., 2011; Hahler & Elsabbagh, 2015) and may be viewed as strengths that do not require treatment in other cultural contexts (Prince, 2010).

Cultural values and associated caregiving practices vary as a function of available resources. For example, collectivism (or valuing harmonious relationships with close others over personal goals) is more common in low-resource regions where people often live in tightly knit groups while individualism (or valuing independence and personal success over interpersonal relationships) is more common in high-resource regions where fleeting relationships are more common (Greenfield, 2009). Desired developmental outcomes influence preferred parenting practices. For example, parents in Asian and African nations often promote interdependence by teaching children to be obedient to adults rather than playing with them while parents in Western nations often nurture autonomy through play and other child-led activities (Parmar, Harkness, & Super, 2004; Weisner, 2000). While the child-centered play-based strategies that many parent-mediated interventions teach are compatible with parenting practices in Westernized countries, they may be less compatible with parenting practices in low-resource regions where children are often expected to learn by participation and modeling others rather than through dyadic verbal interactions with parents who tailor their interactions to child perspectives (Goncu & Gaskins, 2012; Ochs, Solomon, & Sterponi, 2005). Applied Behavior Analysis (ABA) may be better aligned with more hierarchical parent-child relationships than more child-centered play-based approaches, such as Developmental, Individual-Difference, Relationship-Based (DIR) Floortime or TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children). Developmental interventions that focus on teaching children by integrating them into ongoing family routines (e.g., chores), such as Wetherby and colleagues' Early Social Interaction Project (2014), might also be more appealing than more play-based developmental approaches in regions where play between parents and children is not a priority.

It is important to note that many modern developmental approaches to parent-mediated intervention, such as the Early Start Denver

Model (ESDM) and the Joint Attention, Symbolic Play, Engagement, and Regulation (JASPER) intervention, combine play-based developmental and naturalistic behavioral techniques (Schreibman et al., 2015). Therefore, some components of these models may be more culturally appropriate than others in regions where play between parents and children is not emphasized. Given that extended caregiving by grandparents, aunts, uncles, and siblings is common in low-resource countries (Ochs et al., 2005), involvement of varied family members in interventions may increase the social validity of interventions (See Chap. 23). However, most parent-mediated interventions focus on training mothers and assume that techniques will generalize to other family members (Flippin & Crais, 2011). All of these cultural differences may strongly affect the effectiveness of parent-mediated interventions in low-resource regions.

Strengths and Challenges of Cultural Adaptation: The Parent-Mediated Intervention for Autism Spectrum Disorder in South Asia (PASS)

As will be discussed throughout this chapter, autism interventions currently in use in low-resource countries vary along a continuum from “branded” interventions exported with minimal alterations from more developed countries (e.g., Pajareya & Nopmaneejumruslers, 2011), through cultural adaptation or modifying imported interventions to suit local needs (e.g., Divan et al., 2015), to “culturally derived” interventions that have been developed indigenously by melding local customs with often eclectic evidence-based elements from other communities (e.g., Brezis et al., 2015; Samadi, McConkey, & Kelly, 2013). This continuum arises from a tension between the desire to avoid “reinventing the wheel” by importing services that are evidence-based elsewhere and the need to develop services that are consistent with the goals and practices of people in the community.

Cultural adaptation is the systematic modification of an evidence-based treatment to align it with the cultural-linguistic practices of the community it is being adapted to serve (Bernal, Jiménez-Chafey, & Domenech Rodríguez, 2009). This approach is exemplified in the domain of autism treatment by the Parent-Mediated Intervention for Autism Spectrum Disorder in South Asia (PASS) study (Divan et al., 2015; See Chap. 24) which was co-led by Vikram Patel, one of the major proponents of the GMH initiative (Patel, 2012). The PASS project provides an impressive example of local adaptation in India and Pakistan of an evidence-based parent-mediated intervention developed in the UK (Preschool Autism Communication Trial, or PACT), based on the Medical Research Council guidelines for the development and adaptation of complex interventions (Craig et al., 2008). The adaptation process employed multiple steps to ensure proper adaptation and scaling-up of the intervention to nonspecialist workers who then trained parents, including:

(a) In-depth interviews and focus groups with parents of children with autism and special educators to identify needs and feasibility
(b) An expert-led adaptation of the manual which included translation into local languages, inclusion of culturally appropriate sayings, and simplified explanations of the theoretical basis of the intervention for nonspecialists
(c) Further adaptation by 40 local- and national-level experts in autism, including parents of people with autism
(d) Pilot interventions conducted by three regional specialists who received 1 week of PACT training in the UK followed by Skype feedback on their intervention administrations in Asia.

These regional specialists trained nonspecialists (using a lengthened training that included key principles of child development) who then piloted administering the intervention themselves. Parents who participated in the 17 pilot administrations of the intervention provided their perspectives during interviews. Although attempts were made to train more than one family member, differences in learning styles complicated matters. Thus, the intervention was focused on one parent, typically the mother. These methods were chosen to ensure fidelity vis-a-vis the original intervention, while at the same time ensuring maximum uptake by the local communities.

While applauding the highly systematic method with which PACT was adapted to new cultural contexts, it is important to note that the original study that established PACT's evidence base with 2–5-year-olds with autism in the UK exhibited the aforementioned challenges with generalizability of treatment effects that are apparent in many parent-mediated interventions (Oono et al., 2013). Namely, participants in the original PACT study in the UK exhibited larger improvements in parent-child interactions (proximal behaviors) than a control group who received "treatment as usual" (or the autism services they received prior to signing up to participate in the study; Green et al., 2010).

Participation in PACT was associated with small improvements in children's parent-reported language comprehension and adaptive behavior and no significant reductions (as evinced by confidence intervals including 0) in the primary outcome variable, social communicative symptoms associated with autism (assessed with the Autism Diagnostic Observation Schedule; Lord, DiLavore, & Gotham, 2012), relative to the control group. A progressive weakening of the effects of intervention as it passed from clinician to parent to child was noted wherein proximal targets (such as parent-child interactions) were more affected by the intervention than distal targets (such as child behaviors during standardized assessments). This apparent dilution of intervention effects contrasts with one of the primary purported benefits of parent-mediated interventions by suggesting that some parent-mediated interventions may be limited in generalizability.

More recently, a video-feedback, parent-mediated intervention conducted by the researchers who developed PACT was found to be associated with improvements in infants' attentiveness to their parents, attention disengagement, autism risk behaviors, and adaptive functioning (Green et al., 2015). The authors contrasted these effects of the intervention on both proximal and distal behaviors to the less generalized effects observed with PACT and hypothesized that impacts of parent-mediated interventions on distal targets may be greater in infancy due to neural plasticity. Notably, PACT participants were compared to other children receiving "treatment as usual" in the UK while participants in the video-feedback intervention were compared to other infants in the UK who received little to no intervention (as interventions are not widely available for at-risk infants). Therefore, the effects of interventions may be amplified in regions, such as low-resource countries, wherein "treatment as usual" is sparse.

A recent randomized controlled trial evaluation of PASS in India and Pakistan revealed strikingly similar findings to those obtained in the original PACT study in the UK (Rahman et al., 2016). Families of 2–9-year-olds with ASD were randomly assigned to PASS ($n = 32$) or treatment as usual ($n = 33$). Families assigned to PASS received bi-weekly hour-long trainings delivered in their native language for 6 months. Parents were asked to spend 30 min a day using strategies taught in PASS to help their child progress toward individualized treatment goals. Children whose families received the PASS intervention exhibited improvements in parent-child synchrony and child initiations, as they had in the PACT study in the UK. The effect size of improvements in these domains was larger than it had been in the UK. However, no intervention-related improvements in parent-reported child adaptive behaviors and verbal or nonverbal communication were observed. These findings suggest that the original effects of interventions may indeed be amplified in low-resource countries but that similar patterns of strengths and weaknesses may reemerge when interventions are adapted for new cultural contexts.

Parent-Mediated Interventions in Low-Resource Countries

A recent comprehensive review of RCTs of parent-mediated interventions for young children with autism around the world conducted by Oono et al. (2013) contained data from 17 studies, but only 2 of these were conducted in non-English-speaking countries (China and Thailand). This paucity of studies evaluating parent-mediated interventions in non-Western contexts is consistent with a slightly earlier review paper commissioned by the WHO (Hastings et al., 2012) that revealed only four controlled intervention studies for pervasive developmental disorders in low- and middle-income countries, only one of which involved parents.

In the following sections, we will provide an overview of parent-mediated interventions utilized in low-resource countries, by continent. We conducted a comprehensive review of extant research (as of December, 2016) published in English about parent-mediated interventions in low-resource countries using the keywords parent-mediated, intervention, and autism. We excluded articles from our overview if they focused on regions where research about parent-mediated autism interventions is relatively common according to recent review articles (e.g., the USA, Canada, Europe, and Australia; McConachie & Fletcher-Watson, 2015; Oono et al., 2013) unless they explicitly described a focus on economically disadvantaged families within these "high-resource" regions. Given that the extant literature about parent-mediated interventions in low-resource countries is very limited (Hastings et al., 2012), we supplement published findings about each region with embedded examples of ongoing research in each region derived from an online survey that we distributed to international autism interventionists, as well as a case study about a parent-mediated intervention in India which the second author of this chapter observed during 7 months of living in New Delhi as coordinator of a collaborative evaluation study.

The online survey consisted of 13 open-ended questions (e.g., "Please provide a few specific examples of ways that your intervention is adapted to the local culture"). It was distributed via emails that contained a SurveyMonkey link to the authors' colleagues and through the mailing lists of the Cultural Diversity Committee and the Early Intervention Special Interest Group of the International Society for Autism Research as well as a local mailing list for autism interventionists in Israel. It was geared toward professionals who work in or with parent-mediated autism interventions. A total of 29 responses were obtained from 11 countries between June and August of 2015: Nigeria (N =1), India (N =2), Malaysia (N =1), Nepal (N =1), Argentina (N = 4), Brazil (N =1), Norway (N =1), Israel (N =5), Lebanon (N =2), United Arab Emirates (N =1), and the USA (N =10). All relevant survey responses are summarized below.

Asia

In Asia, stigma toward autism is high, and misconceptions, such as that autism is caused by behaviors in past lives or poor parenting, are common (Kang-Yi, Grinker, & Mandell, 2013; Ha, Whittaker, Whittaker, & Rodger, 2014; Lee, 2017 this volume). Despite laws mandating public education for all children in many countries in Asia, schools often reject children with autism because they lack the resources to care for them or feel that they will disrupt the learning of other children (McCabe, 2007; Sun, Allison, Auyeung, Baron-Cohen, & Brayne, 2013). Autism is often viewed as a "family problem." Services are costly and rare (particularly in rural areas). Despite limited governmental support for autism in many parts of Asia (except perhaps Singapore; Neik, Lee, Low, Chia, & Chua, 2014), a number of published studies have described parent-mediated interventions for autism in Asia. These include evaluations of a range of interventions, from ABA (commonly supported at the institutional level) to developmental techniques such as DIR and JASPER, which are often privately led.

In response to a lack of infrastructure to treat autism in China, public and private autism organizations often focus on intensive parent training to prepare parents to be the only service providers for their child (Feng et al., 2013). An early study describing attempts to train parents to use ABA documented high attrition (Guo, 2006). The authors reported challenges teaching parents key behavioral concepts, such as token economies, which suggests that they themselves were not sufficiently trained in ABA to effectively train parents. Child outcomes were not examined.

In a more systematic assessment, Wang (2008) randomly assigned 27 families of children with autism in China to a parent training intervention or a control group. Parents in the intervention group received 20 h of training in naturalistic ABA. Training consisted of group trainings (without children) and individualized instruction in the home with the parent and child. Coding of videotaped interactions between the parent and child suggested that parents in the intervention group were more warm and accepting toward their child at posttest than parents in the control group. However, the same researcher conducted the training and assessments and children's behaviors were not assessed.

Although evidence that ABA is commonly taught to parents in East Asia is consistent with our expectation that ABA or other less play-based interventions might be more attractive to families in cultures with more authoritarian parenting styles, a study conducted in Hong Kong utilized a combined play-based, developmental, behavioral approach (Wong & Kwan, 2010). Researchers developed a brief parent-mediated intervention employing speech-pathology techniques adapted from Canada. The intervention focused on teaching parents strategies to promote communication immediately after diagnosis (approximately 26 months). Seventeen families were randomly assigned to the intervention or a wait-list control. The intervention consisted of 30-min sessions with the parent and child 5 days per week for 2 weeks. Parents were asked to use techniques for 5–10 min every hour and to log their use of techniques. Toddlers in the intervention group exhibited improvements in social-communicative symptoms as assessed by the ADOS relative to the control group. Parents reported increased child communication as well as decreases in parental stress. Given that parent-mediated interventions often fail to decrease parental stress (Oono et al., 2013), this study suggests that low-intensity interventions at a time when stress is likely to be very high and services are limited (i.e., immediately after diagnosis) may be highly beneficial.

A quasi-experimental study (wherein participants are *not* randomly assigned to different treatments) conducted in Taiwan focused on a more exclusively play-based intervention. An occupational therapist provided a 10-week training (approximately 10 h a week) in DIR Floortime (which focuses on helping parents engage their children in cycles of meaningful communication and play) to the mothers of 11 children with autism who were between 45 and 69 months of age (Liao et al., 2014). Children exhibited improvements in engagement and communication during videotaped interactions with their mothers (assessed by blind raters using the Functional Emotional Assessment Scale; FEAS, Greenspan, DeGangi, & Wieder, 2001). Parents reported improvements in child adaptive skills and parent-child interaction. Mothers reported that they did not know how to play with their child prior to the intervention and were more confident playing after the intervention. The authors indicated that parents may struggle initially to play with their children as parenting relationships in East Asia focus on control of the child in contrast to the more child-directed parenting style that is favored in the West.

The first systematic assessment of DIR Floortime in Asia was conducted in Thailand (Pajareya & Nopmaneejumruslers, 2011). The authors stated that hospitals and special education units in Thailand provide 20–40 h of ABA. However, most families are not able to access these services as there is a national shortage of trained personnel. Consequently, some institutes provide parent training in an eclectic blend of techniques. Thirty-two children with autism (24–72 months old) were randomly assigned to a DIR Floortime parent-mediated intervention or to a wait-list control. Parents received a group training, a DVD, manual and individualized training wherein the investigator modeled how to use DIR Floortime techniques with their child which the parents then practiced. Thai families preferred to observe first and practice later rather than receiving feedback on unmodeled skills. Parents were given weekly logs to track the amount of time they used DIR Floortime with their children (approximately 15 h a week). Children in the experimental group improved in their engagement with their caregiver (assessed by blind raters using the FEAS) and in autism symptoms (assessed with the Childhood Autism Rating Scale; CARS, Schopler, Reichler, & Renner, 1986). Some families found the intervention difficult to implement due to other obligations. As in China, the authors noted that the majority of parents did not know how to play with their children at the beginning of the intervention as a focus on child discipline is the norm in Thai culture.

Further evidence that the child-centered approach to play that is a focus of many imported autism interventions may be challenging for families in Asia emerged from our survey. One of the respondents to our survey conducted a pilot study administering a non-adapted version of the JASPER intervention to parents of 3–6-year-olds from middle- to upper-class families in Malaysia. JASPER has been shown to support joint attention development among young children with autism in varied low-resource communities in the USA (Kasari et al., 2014). The aim of our respondent's work was to examine how JASPER could be adapted to the Malaysian cultural context in the future. She indicated that there are very few evidence-based treatments for autism in Malaysia. While family members are resourceful in seeking these out, they often lack the information needed to reject a proliferation of non-evidence-based treatments. Parents also faced time constraints and some difficulty playing as suggested. Some parents reported that the free-play setting where the intervention was implemented "didn't feel natural to them." Extended family members could either be a tremendous source of support or an obstacle depending on whether they understood autism. Mothers were the only ones to implement the intervention. Echoing Oono et al. (2013), she indicated that the intervention was "effective in changing the parents' behaviour within the study settings, but less so outside of study settings." She pointed out that it was only an 8-week intervention and might have been more effective with more prolonged support and if parents were provided with more information about autism and the ideas behind the intervention.

Similar to China and Thailand, in Japan, parent training in ABA techniques is provided to ameliorate a lack of autism services (Kamio, Haraguchi, Miyake, & Hiraiwa, 2015). Our literature review revealed one parent training study published in English from Japan. It provided very limited information about the instruction parents received. Japanese mother-child pairs were randomly assigned to either a training that focused on helping mothers imitate their child or to respond contingently to child bids (Sanefuji & Ohgami, 2013). Eight pairs were randomly assigned to each training. The children were an average age of 53 months. Mothers were instructed to engage their child for 5 min a day by imitating or contingently responding. Children who were assigned to the imitation group looked longer at their mothers during posttest than children in the contingent responsiveness group. The article did not state whether the rater was blind to assignment.

The pattern emerging from the literature suggests that parent training provided by institutions in many Asian countries often focuses on ABA. However, conceptions of autism in South Korea may make relationship-based training more broadly appealing there than it is in many countries in Asia. In South Korea, children who would be diagnosed with autism in the USA are often diagnosed with reactive attachment disorder (RAD) which places the blame for children's social atypicalities on cold parenting (Kang-Yi et al., 2013). The South Korean interpretation of RAD mirrors the outdated Western concept of the "refrigerator mother" as RAD is believed to emerge when mothers are not sufficiently attached to and responsive to their children. A review article published in English from South Korea (Kang-Yi et al., 2013) referred to four intervention studies, all of which focused on improving the parent-child relationship (these studies were published in Korean): one used an attachment promotion intervention, one examined music therapy paired with attachment promotion, one used a quasi-experimental design to compare a combination of massage therapy and attachment promotion to just attachment promotion, and one examined a maternal social responsivity training.

These studies highlight how community conceptions about what causes autism, e.g., the belief that it is caused by maternal behaviors and common parenting practices, e.g., authoritarian rather than playful, non-hierarchical parenting, influence the types of treatments that are commonly adopted and developed. Therefore, a first step toward adapting evidence-based interventions to new regions is identification of community viewpoints about autism and parenting more generally. In regions with high levels of misconceptions about autism, interventions should include group trainings to raise autism knowledge and encourage families to work together to address community misconceptions in the community. A unique parent-led intervention in India demonstrates the importance of educating parents to bring about systems change.

Case Study: The Parent-Child Training Program at Action for Autism, India

The Parent-Child Training Program (PCTP) at Action for Autism (AFA) is an example of a parent-led intervention developed from the ground up in a low-resource setting. AFA, now the National Center for Autism in India, was founded by Merry Barua, an advocate and mother of an individual with autism, in 1991. When her son was first diagnosed, no specialized services for autism existed, and Barua trained herself. The PCTP, a 3-month training program in New Delhi for parents of children with autism, was founded in 2001 to address the dearth of services in India. The program is currently run by a trainer who is herself a mother of an adult with autism and incorporates Western interventions (such as TEACCH, ABA, and DIR Floortime) with cultural adaptations. The training includes group and one-on-one activities with the children (led by the parents) and group discussions for the parents (provided 5 h a day, 5 days a week). About a third of participants live in Delhi and the rest come to Delhi with their child for the 3-month training. Over 500 families have attended the program, coming from various Indian states and neighboring countries, including Nepal, Bangladesh, and Oman. The overwhelming majority of participants are mothers, though some fathers have attended as primary caregivers in the past. Financial aid is available.

In contrast to many interventions in high-income countries which are first developed in research settings, implemented by trained clinicians, and then transferred to parents, the PCTP, from its inception, focused on training and empowering parents. Beyond the short-term goal of increasing parental acceptance and empowering parents to care for their child in a more professional way, the PCTP aims to empower parents to become agents of societal change – teaching others in their communities about autism and training other parents. Indeed, several graduates of the PCTP have become parent-trainers themselves, and some have opened their own parent training programs, such as in Nepal.

Dr. Amatya, one of the respondents to our survey, participated in AFA's PCTP with her son and now serves as the chairperson of Autism Care Nepal Society. She and her staff have adapted the PCTP techniques to Nepalese practices and now work with low-to-middle-income Nepalese families from diverse ethnic groups. She reported that the vast majority of parents indicate improvements in their child and greater acceptance of their child after training. However, families face difficulties implementing techniques back home due to lack of time or financial constraints and difficulty explaining the training to extended family members. Extended family members often do not understand behavioral principles and give a child what he wants when he cries in order to avoid embarrassment. Extended family members can also be very supportive by taking on roles in the household to give mothers (the primary interventionists) time to conduct interventions. The respondent emphasized that the PCTP model would be beneficial in a range of low-resource countries as it empowers parents to be their child's teacher and advocate.

Recognizing the need for societal change, AFA itself has now grown to encompass a special education school, an occupational center for adults, an advocacy arm, and an active training program for parents and professionals. Yet at its core, AFA remains a mother-led organization, with some of the key positions (such as the school director, director of finance and operations, and director of the PCTP itself) staffed by mothers of individuals with autism. Rather than being viewed as semiprofessional partners in decision-making, parents are *leading* the conversation, drawing from their simultaneous experiences as both parents *and* professionals to guide decisions large and small.

The PCTP recently underwent a systematic evaluation, co-developed by professionals at AFA and researchers from the USA. The quasi-experimental evaluation focused on changes in the parents, rather than the children, over the 3-month period of intervention for 40 mother-child pairs (Brezis et al., 2015) and at 8 and 15 months following the intervention (talk presented by Daley et al., 2014 at IMFAR). Participation in the PCTP was associated with increases in parent-reported empowerment, acceptance, understanding of autism, ability to teach, and decreased parental stress, using a range of standardized and locally developed questionnaires and observational methods, which have maintained at follow-up.

The shift from 3-month training in the protective setting of the PCTP to parents' home settings is often fraught with tensions, as mothers need to not only readjust their own routines but also deal with other family members who may not ascribe to the same parenting styles taught in the PCTP. Yet, one of the reasons the PCTP may be successful in maintaining treatment gains over time is its emphasis on providing a training setting that is more ecologically valid. Thus, for instance, rather than training dyads in isolated rooms, during daily training sessions, 3 to 4 dyads sit side by side in a small multipurpose room. While this may seem like a disorganized cacophony to a Western observer, such a setting may actually provide a better model for the lived realities of these families, who may not be able to set aside a separate physical space to play with their child. Another example includes teaching the parents to create their own training items rather than relying on expensive imported games.

More importantly, however, the concerted focus on parental empowerment is likely to affect parental (and possibly child) gains in the long term. In a setting like India, parents, especially mothers, often enter the program with a strong sense of deference to authority, though in many cases, doctors, teachers, and other service providers know very little about autism (Daley, Singhal, & Krishnamurthy, 2013). Thus, in order to change mothers' parenting styles and encourage them to question the advice given to them by often misguided authority figures (Daley et al., 2013), the PCTP must create a fundamental shift in parents' view of themselves and of society (Brezis et al., 2015). One of the ways this is effected is by having parents take turns leading daily group activities from the very first weeks of the intervention. By so doing, parents are exposed to many different children and begin practicing leadership roles that will serve them well in disseminating the knowledge and skills they have learned back in their hometowns. Daily group discussions between the mothers and the training leader, herself a mother of an individual with autism, also provide mothers with a strong support group and a unique role model to aspire to.

AFA's parent-led organization serves as an example of how parents can become agents of family-level and societal change. Yet, despite its unique strengths, the evidence base for PCTP remains relatively weak due to a reliance on quasi-experimental evaluations and a focus on parental reports. Given that parent buy-in is an essential component of treatment effectiveness over time (Karst & Van Hecke, 2012; Wainer, Hepburn, & Griffith, 2016) and parent-child interactions mediated changes in child symptoms in the PACT study in the UK (Pickles et al., 2015), it would be interesting to evaluate whether the parental empowerment taught at AFA indeed mediates potential changes in child or family outcomes. We nonetheless acknowledge that it is often very difficult, and at times unethical, to implement randomized controlled trials in low-resource community settings as families may not fully understand the consequences of participating in a randomized trial and may assume that interventions are effective just because they are being researched (Daley et al., 2013).

Indeed, a number of other parent training studies have been published in India which also utilize quasi-experimental designs. Nair et al. (2014) evaluated a low-intensity parent training program in Kerala, India, with 52 children who were younger than 6 years. Specialists helped mothers assemble low-cost kits based on the developmental level of their children and gave them training in how to address the social-communicative and behavioral symptoms of autism. Initial trainings were less than an hour long. Parents were asked to practice skills at home and to place their children in school for social stimulation. Follow-up sessions were conducted once a week to once a month based on the availability of the parent. Pretest-posttest assessments revealed improvements in child symptoms (assessed with the CARS), social skills (assessed with the Vineland Social Maturity Scale; VSMS; Doll, 1935), and language (assessed with the Receptive-Expressive Emergent Language Scale; REELS; Bzoch & League, 1971). In direct contrast to the focus of the PCTP, parent outcomes were not assessed. Assessments were conducted by the same therapist at pretest and posttest. There was no mention of controlling for therapist knowledge about which time point it was.

Juneja et al. (2012) also used a quasi-experimental design (also without parent outcome measures) to evaluate a parent-mediated naturalistic behavioral intervention program for 16 children (mean age 39 months) with autism in New Delhi. An individualized program with an emphasis on socializing in the community was developed to support the child in developing verbal and nonverbal communication skills and decreasing unwanted behaviors (which were not specifically defined but included “temper tantrums”). Initial trainings occurred every 2 weeks for 2–3 months followed by monthly trainings. Other family members, such as siblings and grandparents, were encouraged to be part of the intervention. Parents were asked to spend 45–90 min a day working with their children. Reductions in autism symptoms (CARS) and improvements in developmental quotients (Early Developmental Profile; Mundkur, Agarwal, & Puri, 1999), language (REELS), and adaptive functioning (VSMS) were observed. Who provided assessments and whether they were blind to time point were not stated.

In another quasi-experimental study conducted in India, researchers examined medical charts collected over a 3-year period from young children with autism (mean age 3.7 years) who had participated in a parent-mediated intervention that had been in use at their autism clinic for 11 years (Krishnan et al., 2016). Parents attended group training with their children for 12 weeks (4 h a day; 5 days a week). The training consisted of facts about autism and opportunities to practice behavioral techniques and interactive skills. With the support of their trainers, the parents themselves conducted assessments with their children before and after the intervention. Developmental age, assessed with the PEP-R (Schopler, Reichler, Bashford, Lansing, & Marcus, 1990), improved over the course of the intervention. However, it is unclear if improvements in developmental age were due to the intervention or maturation.

An experimental study conducted in Vellore, India, began to address a key gap in the field of parent-mediated interventions. Louis and Kumar (2015) developed a father-mediated therapy designed to involve fathers in nurturing their children. Fathers of 30 children with autism (3–5 years old) were randomly assigned to receive a 3-month intervention or not. The intervention consisted of group sessions (the amount of intervention was not specified) at the clinic where fathers observed and practiced techniques to reinforce attachment and reciprocity including massages, rough and tumble play, and techniques to support their children's daily living skills. The intervention group, but not the control group, exhibited significant improvements in language (Griffiths Mental Developmental Scales, 1970), play (Play-Based Observation Scale), self-help and socialization (VSMS), and attachment to parents and repetitive behaviors (Rendel Shorts Questionnaire). The authors did not indicate if the researchers who conducted assessments were blind to which group participants were assigned to.

A survey respondent from Mumbai, India, uses an adapted version of Project ImPACT with diverse families of nonverbal young children with autism who often have co-occurring intellectual disabilities. Project ImPACT (developed by Ingersoll & Dvorcsak, 2010) uses naturalistic behavioral and developmental approaches to support child communication and foster relationships. A quasi-experimental study conducted with a diverse community sample of young children with ASD in the USA revealed that participation in Project ImPACT was associated with communication gains (Stadnick, Stahmer, & Brookman-Frazee, 2015). Project ImPACT has been adapted to cultural practices in Mumbai by encouraging *all* family members to attend trainings (including extended family members and nannies), including a psychoeducational component, and modifying materials to align with local languages, activities, and time pressures. The intervention is currently evaluated through parental questionnaires about child progress. Our respondent stated that parents face challenges implementing interventions due to lack of time (as mothers are often the primary caretakers with many responsibilities), lack of support from extended family members (although family members can also be key sources of strength), mental health issues such as untreated depression, and lack of prolonged services, as interventions tend to be brief. Fathers typically provide financial support for intervention but are not directly involved.

Fathers' lack of involvement in caregiving in certain regions can even become an aspect of cultural adaptations of interventions. In a recent pilot study conducted in Bangladesh, a native clinician and interventionists from the USA worked together to adapt training materials that had initially been developed in Taiwan and the USA to the cultural context in Bangladesh (where mothers are typically the primary caregivers). Adaptations included replacing all pictures of fathers and children with pictures of mothers and children (to align training materials with caregiving practices in the region), focusing on common routines in Bangladesh, removing images of expensive toys that families couldn't afford, simplifying language, and using the term "problem behaviors" in lieu of ASD, which is stigmatized in Bangladesh (Lee, In press). These training materials were then delivered to ten families during a 1-day long group training and two follow-up trainings with individual families to help them use pivotal response training to address parent-identified "problem behaviors" (e.g., hitting or wandering). In response to an open-ended interview after the second follow-up session, parents reported that the training was helpful. Although most parents reported that they learned concepts better during the individualized sessions, they enjoyed connecting with families who faced similar concerns during the group session.

While there is an emerging body of literature on parent-mediated interventions from Asia, evidence that they effectively change child or parent behaviors remains weak. Small controlled studies from East Asia have demonstrated benefits of both a combined developmental behavioral (Hong Kong) and a fully play-based (Thailand) intervention on distal targets. Therefore, the paucity of "treatment as usual" in low-resource regions may enhance researchers' ability to detect intervention effects in these regions. However, participants in play-based studies in East and Southeast Asia, who tended to be affluent relative to the broader population (and possibly more Westernized), expressed some challenges playing with their children as directed by the intervention. A number of less controlled studies conducted with more diverse families in South Asia reveal evidence that indigenously developed interventions may impact distal targets such as child behaviors and parent cognitions. However, with the notable exception of the PASS studies, evaluations tended to focus on either parent or child characteristics, to use unvalidated measures, and to not control for bias.

Attempts to provide more controlled interventions to diverse populations are complicated by funding challenges. Indeed, Gauri Divan, the lead author of the PASS intervention described above, was one of the respondents to our survey. She indicated that a key challenge with providing culturally adapted interventions is obtaining funding to reach broader populations. Given that many creative approaches to parent-mediated interventions for autism have emerged across Asia, a significant next step would be discussions between groups (similar to ongoing discussions between early interventionists in Europe; McConachie & Fletcher-Watson, 2015) to share effective techniques and develop a set of common outcome measures to evaluate the impacts of interventions on the child, parent, family, and community.

Middle East

In the Middle East, families are often turned away from services and may travel out of their home countries to obtain appropriate autism services (Dababnah & Bulson, 2015). Out of the 75 articles about autism from Arab countries published between 1992 and 2012, only 3 focused on interventions, none of which were parent-mediated (Hussein & Taha, 2013). Families tend to rely on social support due to the lack of knowledgeable professionals. In Saudi Arabia, parents often seek out indigenous interventions, such as visiting religious healers, and non-evidence-based treatments, such as hyperbaric oxygen, as they believe that the “evil eye” (and vaccines) causes autism (Alqahtani, 2012); services are mainly only available in the private sector, and all three governmental autism centers typically employ TEACCH methodology. Researchers affiliated with two governmental autism centers in Saudi Arabia recently published a paper describing a training that they had developed to help parents understand autism and care for their children with autism (El–Magd, El-Nagger, Al Zamil, & Kashkar, 2016). A brief survey administered to 79 parents before and after the training suggested improvements in family cohesion. However, the paper was published in a journal that is not peer-reviewed, and details needed to evaluate the study were obscured by an apparent lack of proofreading. Pilot training of the Early Start Denver Model has also occurred in Saudi Arabia through Autism Speaks’ Global Autism Public Health (GAPH) initiative. In Egypt, the government plays some role in service provision, but people typically do not use services due to lack of knowledge, mistrust, and high cost (Hussein & Taha, 2013). In rural areas of Egypt where services are scarce, almost all people with autism are kept home with their family. Access to autism services may be particularly limited in the West Bank due to instability and stigma (Dababnah & Bulson, 2015).

Although autism is also stigmatized in Iran, Iranian culture may be more tolerant of behaviors seen as atypical in the West (Samadi, Samadi, & McConkey, 2015). Parent training in Iran tends to focus on enhancing family functioning. A recent study combined family-focused therapy, which focuses on empowering families, with techniques from DIR Floortime (Aali, Amin Yazdi, Abdekhodaei, Ghanaei Chaman Abad, & Moharreri, 2015). The authors emphasized the importance of empowering families to make the family unit as a whole healthy and responsive to the child. Using a quasi-experimental design, they evaluated the effects of 1 of 3 interventions on 12 children with autism (mean age 5.1 years) who were enrolled at the Ibn-e-Sina psychiatric hospital. Children were assigned to DIR Floortime (focused on the child’s development), family-focused therapy based on the Floortime model (wherein the family as a unit was taught to pass through the stages of the DIR Floortime model), or a control group who received treatment as usual (from autism centers). Family-focused therapy was associated with improvements in the developmental functioning of the family.

Although the study had a number of limitations (e.g., small sample size, insufficient detail about the intervention, use of author-designed measures, and the lack of blind raters), family functioning is an important variable to examine in future parent-mediated interventions (Wainer et al., 2016).

Another parent intervention developed in Iran illustrates an indigenous parent training technique (Samadi et al., 2013). Guided by prior research and a survey administered to parents of children with autism in Iran, the authors developed a parent training about autism and coping strategies. The intervention was based on an ecological model of development. It consisted of seven group sessions (approximately 10 h total) with supplementary DVDs and written materials for families to use to educate themselves and others. Thirteen fathers and 14 mothers of children with autism (3–17 years of age) were assigned to an experimental group or a wait-list control. Participation was associated with improvements in self-reported health, stress, and family functioning. Participants went on to form a non-governmental organization (NGO), the first of its kind in Iran. The authors asserted that opportunities to meet other parents through groups are essential for self-advocacy and that the use of a male facilitator attracted fathers as participants. These findings mirror those from the PCTP in India and suggest that parent-mediated interventions should include a group component focused on understanding autism in order to encourage empowerment.

Stigma toward autism is high in Lebanon and services are sparse (Obeid et al., 2015). One survey respondent from Beirut provided ABA interventions to 3–4-year-olds from lower-income families. She believed that ABA was a technique that parents could pick up easily but reported that cultural issues and a lack of an understanding of interventions made it challenging for parents to implement interventions. The other respondent from Beirut did intervention research with 3–7-year-olds on the spectrum at a university. She indicated that there is no public or insurance funding for ABA or other services (so even high-income families cannot always afford services), a lack of properly trained professionals, and a proliferation of pseudo-professionals who claim to provide ABA with limited training. “It is not uncommon for families to ‘hide’ their children’s autism diagnosis from extended family members, mainly because of stigma.” She indicated that education, social networks, and research skills are essential for obtaining appropriate services in a country with such limited supports. Both respondents indicated that mothers were far more involved than fathers in interventions.

A survey respondent from an ABA school in Abu Dhabi worked with 10–14-year-olds on the spectrum. The respondent indicated that a key challenge with implementing interventions is that many parents hire a nanny rather than caring for the children themselves. Due to religious beliefs, important themes surrounding adolescence, such as sexuality, are not addressed.

Israel seems to be an outlier among Middle Eastern countries, with extensive government-supported services for individuals with autism across the life span (Brezis, 2015). Many evidence-based treatments have been imported and adapted to Israel, including ABA, DIR Floortime, and TEACCH. In fact, the first study to systematically examine the degree to which interactions with parents contribute to observed benefits of a technology-based intervention was recently conducted in Israel (Gev, Rosenan, & Golan, 2016). This randomized controlled trial study revealed that greater parental involvement in *the Transporters* technology-based intervention was associated with enhanced generalization of emotion recognition skills. This finding suggests that hybrid interventions that teach parents to use inexpensive technological interventions with their children could promote generalization in low-resource regions. However, access to technology is also limited in low-resource regions.

Not only is innovative autism research being conducted in Israel, the Israeli government also provides specialized schooling from ages 3 to 21 which is augmented by subsidized treatments, including physical, occupational, speech therapy, and art therapies. Though the law provides for all Israeli citizens, inequities in the distribution of services reflect global trends, in terms of SES, geography, and ethnicity (e.g., more services are provided to the Jewish majority than the Arab minority). Among the Jewish majority, access to services also varies with degree of religiosity. Ultra-Orthodox Jews choose to reject many aspects of modernity and are hence exposed to less knowledge of autism. While they are otherwise highly educated and live primarily in urban centers, stigma against autism is still very high among ultra-Orthodox Jews, and providing services in this community remains a challenge (Brezis, 2015). Indeed, one survey respondent from Jerusalem, Israel, who provides DIR Floortime to 2–9-year-olds from varied backgrounds, including religious and nonreligious Jews and Arabs, stated that religion and family structure were barriers to interventions for some families and that mothers were the primary interventionists. These challenges underscore the need to address varied cultural groups even within countries with a high amount of services.

Africa

Little remains known about autism in Africa. Available evidence suggests that autism is infrequently diagnosed and/or diagnosed late (e.g., in adolescence) due to very limited awareness, heightened stigma, lack of infrastructure, lack of culturally appropriate diagnostic tools, and factors that limit engagement with a consistent caregiver who could notice atypicalities, such as the AIDS epidemic (Bakare & Munir, 2011; Tekola et al., 2016). Cultural differences in perceptions of child development may reduce help seeking. For example, low levels of communicative behaviors in infancy may not be viewed as red flags among the Zulu people who tend to not view infants as intentional communicators (Grinker et al., 2012). Likely due to lack of care (the few interventions that are available are often prohibitively expensive), autism in Africa is often associated with a lack of expressive language (Bakare & Munir, 2011).

Low levels of knowledge and stigmatizing misconceptions, such as that autism is caused by evil spirits, have been documented among healthcare and education professionals in Nigeria and Kenya and parents of children with autism in Ethiopia, Tanzania, and Kenya (Ambikile & Outwater, 2012; Bakare et al., 2009; Gona et al., 2015; Tilahun et al., 2016). Attempts to improve autism understanding and supports in Africa are ongoing; an autism research center recently opened in South Africa (headed by de Vries), and autism trainings are underway with community health workers in Ethiopia (headed by Hoekstra) and mothers in Nigeria (headed by Bakare).

One of our survey respondents worked with 4–10-year-olds with autism at a hospital in Nigeria. Families seeking care were low- to middle-income Black African families with strong cultural and religious beliefs. The respondent indicated that families faced disjointed services, limited personnel, financial barriers, unclear paths to treatment, and a lack of structured parent training. Mothers were described as carrying the burden of care while fathers often focused on providing material support. The respondent indicated that so far they focus on providing a support group for parents of children with autism which they hope to evaluate in the future.

More recently, a paper describing a pilot quasi-experimental intervention for mothers of children with autism in Nigeria was published (Bello-Mojeed, Ani, Lagunju, & Omigbodun, 2016). Twenty mothers of children with autism (3–17 years of age) participated in five weekly sessions of a manualized group intervention designed to teach them how to identify the function of behaviors and develop individualized treatment plans. A third of the children in the study were not enrolled in school; the authors stated that a lack of educators who have received training in behavior management causes many children with autism to be excluded from school in sub-Saharan Africa. Mothers' responses to questionnaires that the researchers had developed or adapted revealed reductions over the course of the training in children's aggression and self-injury as well as improvements in the mothers' understanding of how to control child behavior. Most of the mothers (80%) indicated that the program was helpful.

Rather than focusing on decreasing aggressive behaviors as Bello-Mojeed had done in Nigeria, Harrison (a clinical psychologist from the USA) and colleagues (2016) developed a training to help caregivers understand autism and use naturalistic behavioral strategies to support child communication and adaptive skills. Families of children with autism or general developmental delays who were visiting free diagnostic clinics were invited to participate in the training. The families had often come great distances to visit the clinic and needed to return home. Therefore, the training was delivered to each family over the course of a single day. In order to incorporate parent feedback into intervention design, Harrison developed the training in two phases and delivered it with the help of translators. During Phase 1, she piloted a brief autism knowledge training and conducted needs assessments to develop targeted modules for the second phase. Twelve caregivers participated in Phase 1 (primarily parents but also uncles/aunts and an adult sibling). They completed a structured intake interview to assess their concerns about their child's development as well as the Malawi Developmental Assessment Tool, a well-validated measure designed to assess adaptive behavior among people in rural Africa (Gladstone et al., 2010). Areas of common need identified during Phase 1 were used to develop Phase 2, which focused on teaching basic behavioral strategies, such as reinforcement techniques, to promote self-help (e.g., independent toileting) and communicative skills (e.g., eye contact). Parents indicated that children needed self-help skills in order to attend school. Principles were broken down into simple steps, and parents were provided with lectures, modeling of key skills, opportunities to practice the skills and receive feedback, and handouts to take home. Twenty-nine caregivers (six of whom had also participated in Phase 1) participated in Phase 2. They individually received an hour-long training about autism followed by from one to seven of nine possible behavioral modules (specific modules were selected for each family based on their reported needs). Due to the number of modules covered, opportunities to practice skills were limited. All but one of the participating families (97%) indicated that the training was beneficial. A number of parents wished that the intervention could have been longer. The authors stated that handouts are particularly useful training tools in places like Nigeria where access to technology is limited.

Although autism resources and research remain very limited in Africa (Abubakar, Bakare, Wilmshurst, & Newton, 2016), peer-reviewed papers about parent-mediated interventions have recently begun to emerge from Africa. These pilot studies suggest that parents may be particularly responsive to interventions that allow flexibility in terms of who attends them and what topics are covered. Given that there are many pressing issues competing for resources in Africa, it may be beneficial for parents of children with varied disorders (such as those who participated in Harrison and colleagues' study) to receive training together, so they can develop collaborative advocacy strategies. Mothers of children with autism have spearheaded the development of autism supports in Africa (Feinstein, 2010), so it is fitting that the first papers describing interventions for autism in Africa have focused on empowering parents.

Latin America

Autism services and awareness remain limited throughout much of Latin America (Feinstein, 2010). Ironically, though parents of people with autism have played a leading role in addressing the paucity of services by opening autism schools and organizations throughout countries in Latin America, given the predominantly psychoanalytic approach to psychology in Latin America, the view that parents require treatment in order to effectively parent their children remains dominant throughout much of this region. A review article about autism research published in Brazil between 2002 and 2009 revealed that a relatively large proportion, 25 out of 93 articles, focused on interventions (Teixeira et al., 2010). This contrasts with a research focus in high-income countries on basic mechanisms (Pellicano, Dinsmore, & Charman, 2014) and suggests that intervention is of high interest among researchers in Latin American communities.

Our literature search revealed only one article published in English describing a pilot parent-mediated intervention for autism in a Latin American country. Nunes, Araújo, Walter, Soares, and Mendonça (2016) conducted a pilot study with two mothers of children with autism (both under 3 years of age) in Brazil. The mothers received training in naturalistic teaching strategies designed to promote communicative development derived from the Hanen More Than Words Program (Carter et al., 2011) and the Family-Guided Routines-Based Intervention Model (FGRBI, 2014). In an initial session at each of the participants' homes, the mothers and interventionists worked together to identify daily routines in each of three categories (pre-academics, caregiving, and play) wherein the mothers would practice intervention strategies. The mothers then received training in a classroom setting for 3 months (3 h a week every few weeks), followed by another training in their homes, and then 5 more weeks of classroom-based training. They were videotaped interacting with their children before and after training and were also asked to bring videotapes of themselves interacting with their children to each training session in order to reflect upon them during training. The researchers coded how responsive the mothers and children were during the videos and concluded that participation in the training was associated with increased responsiveness during caregiving and pre-academic routines but not during play routines. They stated that Brazilian children are expected to play with other children rather than their parents, so parents may have found it unnatural to play with their children during the intervention.

One survey respondent did research with mainly low-income youth with autism through a university in Sao Paulo, Brazil. She reported that few clinicians were trained in evidence-based models and most used whichever treatment they found most relevant. Four survey participants were from Buenos Aires, Argentina, including Dr. Alexia Rattazzi, a child psychiatrist and leading figure in the Cultural Diversity Committee of INSAR. Two of these participants worked at PANAACEA, an NGO providing many services for individuals with autism and their families, including an adapted version of the Transforming Everyday Moments (TEM) Intervention to young children on the spectrum from varied socioeconomic backgrounds (Houghton et al., 2015 IMFAR poster presentation). TEM was developed by Houghton to help diverse parents use everyday moments to improve their child's communication. Adaptations included condensing a 6-week intervention into 2 days, using local video materials and translating materials. They reported that a lack of resources is a key obstacle to intervention in Argentina but that low-income families really appreciate and take advantage of the training. Mothers attended trainings more than fathers. The intervention was assessed by coding parent-child interaction before and after the training and parent feedback. One respondent indicated that TEM provides children with opportunities to explore their interests as well as opportunities for parents to share their experiences, form associations, and gain empowerment. They reported that the impact of TEM in Argentina is very positive and parents are very grateful for it. Another interventionist in Argentina worked at a hospital providing a combination of ABA and TEM. She reported that participants were not good at time management but had strong social support networks. She indicated that fathers were reluctant to implement the intervention and that it was difficult to adapt the intervention to local routines. She said that she found professional intervention with parent generalization most effective. The last Argentinian respondent worked at a university hospital. She stated that poor families of children with autism came to the hospital from Bolivia, Paraguay, and Peru. They lacked services in their home countries and most were single-mother households. She stated "we need the help of the government to change the present situation."

Parent-Mediated Interventions with Low-Resource Families in High-Resource Countries

The majority of research evaluating parent-mediated interventions for autism has been conducted in the USA, Canada, Europe, and Australia (McConachie & Fletcher-Watson, 2015; Oono et al., 2013). This research is discussed in detail in other chapters of this book and is not the focus of this chapter. However, low-resource regions are common within these areas. Many countries within Europe (e.g., the Balkans, Russia, Romania, and the Czech Republic) have high stigma toward autism and very scarce resources, and others (like France) focus on non-evidence-based practices like psychoanalysis (Feinstein, 2010). No survey respondents or papers about parent-mediated interventions were available from these countries. However, a paper presented at the Brazilian Conference on Special Education by Preece and colleagues (2016) describes ongoing efforts to develop trainings for parents of children with autism in low-resource regions in Europe (Croatia, Cyprus, and the former Yugoslav Republic) as part of the Equity and Social Inclusion Through Positive Parenting project.

The ten survey responses from the USA highlight themes that bridge across high- and low-resource countries. Six respondents provided ABA training to parents of young children of varied backgrounds in New York ($N = 3$), New Jersey ($N = 2$), and Seattle ($N = 1$). They indicated that it was challenging to train ethnically diverse parents with limited resources due to language barriers, limited time and infrastructure, and social isolation. Mirroring reports from Asia, a participant noted that “multicultural families have extended family support and include them in the therapy.” Respondents agreed that mothers are typically the interventionists as fathers often work and may be resistant to intervention. Training was highly variable. One respondent reported “I know providers who received only about 6 h of ABA training and were sent to the field to work with a child with severe autism.”

A respondent from Michigan evaluated the Project ImPACT intervention with primarily rural young children from a variety of socioeconomic backgrounds. She indicated that it is difficult to reach rural families to provide services but that rural families benefit from strong family support networks. While mothers are the primary interventionists, when fathers participate, they behave much like mothers. They are currently evaluating whether the program can be conducted online.

A respondent from Indiana provided the Joint Attention Mediated Language Learning intervention to diverse families with toddlers on the spectrum. The intervention, developed by Schertz and Odom (2007), utilizes home-based training to promote joint attention. She noted that “This intervention asks parents to be the interventionists and the leaders in their children’s learning. Many enter with such feelings of guilt, depression and inadequacy that they have very low levels of self-efficacy and struggle to believe they can personally impact their child’s outcomes.” She also pointed out that “children of parents with better cognitive ability and social skills have better outcomes. I’ve felt for a long time that we don’t adequately measure these attributes in parents, and they are more important than, and often not adequately reflected by, SES or educational attainment.” Parents were asked to select a “lead” parent to participate in the trainings. Mothers were more likely to take on this role due to scheduling. “However, when fathers are the lead participant, I’ve found them to be equally effective.”

Another respondent works with Spanish-speaking mothers of 1–8-year-old children with autism in Chicago through Parents Taking Action, a parent-education intervention for Latino families (who tend to receive subpar autism services) that was developed through community-based research (Magaña, Lopez, & Machalicek, 2015). The intervention is provided in Spanish and uses culturally appropriate sayings, flexibly scheduled home visits, and the Promotora de Salud model, which is a low-cost and effective method to promote health in communities that are distant from and/or distrustful of medical care. Intervention is delivered by a promotora, or a trained peer who speaks the same language, is from the same community, and is a mother of a child with a disability. The intervention consists of two 8-week modules delivered during 2 h-long home visits each week. The modules address autism knowledge and evidence-based practices. Fourteen of 22 mothers completed both modules. Those who dropped out cited time constraints. Quasi-experimental improvements were observed in parent-reported autism knowledge, understanding of their child and rights, intervention self-efficacy, and child language, but not in autism symptoms or maternal depression. The respondent reported that financial and linguistic barriers impede families' access to care. While mostly mothers attended trainings, fathers attended when possible. She indicated that they are applying for funding to use the intervention in Colombia.

Discussion: Overarching themes

A clear theme emerging from this chapter is that disparity in autism care is a global phenomenon, as are concerted efforts by families to overcome disparity and obtain needed care. Indeed, many of the autism organizations that are directly addressing disparities in autism care internationally, such as AFA in India, were started by parents of people on the spectrum (Feinstein, 2010; Grinker, 2008). Building on strong familial interest in caring for their loved ones, parent-mediated interventions for autism are a logical strategy endorsed by the WHO (2013) to address a severe lack of trained interventionists in many low-resource regions. Although the English-language literature on parent-mediated interventions which we reviewed is sparse in many low-resource regions (such as the Middle East, Latin America, and Africa), this chapter revealed that parent-mediated interventions are emerging increasingly often in low-resource countries. While low-intensity parent trainings about autism (like Samadi's work in Iran) are likely to be beneficial in all regions of the world, the degree to which longer-term parent-mediated interventions will be effective in regions like Africa where poverty and disease compete for scarce resources remains an important question for future research.

Factors that may impact a family's ability to provide parent-mediated interventions include cultural values (e.g., parenting practices, beliefs about autism, and religious orientations), infrastructure (distance from and cost of services, governmental support), family characteristics (financial resources, available time, and social support), caregiver characteristics (diversity of caregivers, caregivers' understanding of autism, and social-emotional characteristics including possible mental health concerns), and child characteristics (severity of symptoms and comorbid conditions). Parents from Asian (e.g., China, Thailand, and Malaysia) and South American (e.g., Brazil) cultures, where parenting practices tend to be more discipline- than play-oriented, experienced challenges playing with their children during play-based interventions such as DIR Floortime and JASPER. While parents and children often reacted positively to these interventions, cross-cultural research is needed to determine which cultural values align with openness to learning play-based interventions and to develop alternative teaching strategies for families for whom play-based interventions are not culturally appropriate. Religious beliefs may also influence how flexible families are in adopting new parenting strategies. Part of the challenge of implementing parent-mediated interventions in varied cultural settings is navigating diverse beliefs and values and providing the best available care without disrupting the existing social structure.

Collectivism, more common in low-resource regions, is associated with submission to authority (Kemmelmeier et al., 2003; Lee, 2017 this volume). As described in the case study of the PCTP in India, parents often come in to the intervention fearing to question authoritative figures, including medical professionals, who may be misguided with regard to best practices in autism treatment. Programs that empower parents to question authority and encourage critical, innovative thought may improve their ability to self-advocate and decrease stigma. Indeed, a growing number of studies in high-income settings have shown that parent buy-in and empowerment are critical components in the long-term effectiveness of parent-mediated trainings, though they remain understudied and overlooked (Karst & Van Hecke, 2012; Wainer et al., 2016).

Parental empowerment may be particularly important in low-income settings, where parents face many cultural and financial barriers in implementing interventions. For instance, in cultures where extended families are common, training of one individual, often the mother, could lead to conflicts if other family members do not understand autism or the intervention. These conflicts may be exacerbated in rapidly developing countries, or among immigrants, where the generational gap in literacy and education, and hence access to knowledge of autism, can be wide. In order to encourage families to work together to provide a consistent learning environment for the child, it would be beneficial to diversify trainings provided during parent-mediated interventions to include both one-on-one meetings with the lead interventionist in the family and group trainings about autism and intervention techniques with multiple family members from diverse families. Such group meetings may empower families to increase autism awareness in their communities and may also yield benefits in terms of family functioning.

Given that responsive fathering is associated with better social, linguistic, and cognitive development (Flippin & Crais, 2011), it may be particularly important to involve fathers in parent-mediated interventions. Training techniques that are effective for mothers often fail to generalize to fathers, who may prefer more hands-on and peer-guided learning. Strategies to involve fathers will need to be creative as respondents indicated that fathers are often not involved in interventions because they are busy securing funds for the family and father involvement in caregiving is not an accepted practice in some regions. Indeed, limited time was a consistent challenge faced by caregivers around the globe. Thus, low-intensity family-mediated interventions that focus on pivotal behaviors in the context of ongoing family routines and invite cooperation from extended family members are likely to be most useful.

Conclusions

Sustainable solutions to disparities in care should be rooted in local customs while incorporating evidence-based practices from the broader research literature. However, the degree to which interventions that are imported (even with adaptations) from high-resource to low-resource communities are warranted and evidence-based remains unclear (see Kirmayer & Pedersen, 2014, for a broader discussion of the cultural validity of the exportation of any mental health treatment beyond the culture in which it was developed). High-quality evaluations of parent-mediated interventions in high- and low-resource areas are needed that include measures of social validity, the intensity and fidelity of training that parents receive and give to their children, and well-validated outcome measures that assess not only the parents' perspectives but also objective measures of children's behaviors, parental empowerment, and family functioning. Such evaluations are difficult to conduct even in high-resource regions. Indeed, the paucity of literature about parent-mediated interventions from many regions of the world is likely partially due to disparities in access to diagnostic and training materials and research-based measures of change which are often not available in the local language, are very expensive, and may require training from mentors who are often situated in high-resource regions to use appropriately. Although the WHO (2013) has developed open access autism resources to promote autism screening, more open access diagnostic and training resources are needed to promote intervention research in low-resource countries.

Few studies that evaluated imported interventions conducted systematic cultural adaptations while promising indigenously developed techniques have so far only been assessed with quasi-experimental designs that rely extensively on parent-report measures. Reliance on quasi-experimental designs may be particularly problematic in low-resource regions where people may believe that interventions are effective simply because they are being researched (Daley et al., 2013) and consequently may report improvements simply because they were part of a study. Discussions between researchers who are developing and evaluating cultural adaptations of interventions from high-resource areas and researchers who have developed indigenous interventions are needed so that each approach can learn from the strengths of the other. These discussions may further help us discern the active ingredients which lie at the core of parent-mediated interventions for children with autism and how these principles refract through different cultures around the globe.

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23

Home-Based, Parent-Implemented Intervention for Underserved Families in Taiwan

Li-Ching Lee, Aubyn C. Stahmer, Chin-Chin Wu, Peng-Chou Tsai, and Chung-Hsin Chiang

Abstract

The prognosis and outcomes of autism spectrum disorder (ASD) are highly influenced by social and family contexts, cultural history, public policies, available programs, environment, and opportunities. Families who live in under-resourced environments face more than their share of stress and obstacles. Social determinants that prevent families affected by ASD from accessing needed interventions may have a detrimental impact on child and family outcomes. Addressing these issues is particularly critical for vulnerable families who are SES disadvantaged. In this chapter, we describe general understanding and cultural interpretation of ASD in disadvantaged families in Taiwan. We also summarize ASD-related services in the Taiwanese health-care and education systems available to families of children with ASD, as well as common barriers to ASD diagnosis and ASD services. Furthermore, we discuss the challenges and opportunities for adapting individualized parent-implemented intervention for the underserved and SES-disadvantaged families who are affected by ASD. Lastly, we suggest feasible strategies for successful adaptation and adoption of parent-implemented intervention for these families.

Understanding of ASD in Disadvantaged Families in Taiwan

Although health-care providers and child development researchers in Taiwan have gradually become more aware of autism spectrum disorder

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_23

(ASD) and are catching up with updated research findings and knowledge about ASD, many families continue to have a limited understanding about the signs of ASD and potential interventions. While public awareness of ASD has been increasing recently, disparity of ASD awareness between high-SES (social economic status) and SES-disadvantaged families remains (Lai, Tseng, Hou, & Guo, 2012; Lung, Chiang, Lin, & Shu, 2016). The percentage of low-income households in Taiwan is 1.68% as of 2016 (definition of low-income varies by district; the threshold ranged from US$300 to 450 per person/month) (Ministry of Health and Welfare Republic of China (Taiwan), 2016). We recognize that great variation exists across SES groups in experience of health-care access. In this chapter, we focus our discussion on families living in Taiwan who have lower SES and access to fewer resources.

Cultural differences in understanding and interpreting child behavior may relate to challenges recognizing early signs of ASD. Often families misunderstand the disorder due to cultural influence and societal desirability (Wong, Yang, Steward, Chiang, & Wu, 2017). For example, a study conducted in Japan reported that Japanese caregivers may interpret a lack of interest in other children as modesty or shyness rather than a problem behavior (Inada, Koyama, Inokuchi, Kuroda & Kamio, 2011). Such observation is also common in Taiwan. Although lack of shared affect or enjoyment is considered a hallmark sign of autism in Western developed countries, in Taiwanese society, this is often seen as emotional suppression. Another ASD early sign, not responding to name, can be attributed by a caregiver as a child being appropriately focused on an activity – a positive trait that is thought of as being appropriate in Taiwan. Unusual preoccupations or circumscribed interests with numbers, blocks, books, or other academic-related objects are considered signs of great potential for high academic achievement rather than a developmental concern.

Another challenge in recognizing ASD is limited experience with typical development. Taiwan bears one of the lowest birth rates in the world, with a fertility rate of 1.18 per woman of childbearing age in 2015 (Department of Human Resources Development, 2016) and an estimated 2015 annual crude birth rate of 18.47 births per 1000 persons, ranked as the 216th of 224 countries (Central Intelligence Agency, 2016). With such a low birth rate, it is not surprising that most families only have one child. Thus, a child has fewer opportunities to interact with other children, and parents have less experience comparing their child's behaviors to other same-age children or siblings. Even if caregivers notice something is not quite right about their child, denial of ASD symptoms is not uncommon for parents in Taiwan as they wish to "save face" for the family. Denial of the diagnosis and refusal of follow-up services or treatments are often seen in Taiwanese families when ASD is suspected (Wong et al., 2017).

ASD-Related Services in Taiwan

In the health-care system. The National Health Insurance (NHI) Program was launched in 1995 to provide all civilian residents with mandatory comprehensive medical care coverage with modest cost sharing. As a result, an estimated 99% of all resident citizens are covered by NHI (Wu, Majeed, & Kuo, 2010). However, early detection and early intervention processes for children were not well established until 1997 when the Child Welfare Bureau of the Ministry of the Interior announced the Children with Developmental Disabilities Early Intervention Service Act. The act requires an integration of resources from social welfare, health-care, education, and police agencies to provide early detection and screening, referral, comprehensive evaluation, treatment and services, follow-up, and support to families of children with a developmental delay. Since then, early detection and early intervention methods have become well known by health-care providers. Currently, more than 100 health-care settings are eligible to provide evaluations for children with developmental concerns (Health Promotion Administration, 2016). The assessments and evaluations are covered by the NHI. With the coverage, developmental evaluations have become more affordable for many families, especially those of lower SES.

In the education system. Children with ASD were not eligible to receive special education services until 1997 (C.-F. Chang 2014a). As of March 2016, a special education classification of ASD makes up 6.2% (900/14423) of children who receive special education services in preschools, 13.9% (5569/40086) in elementary schools (grades 1–6), 12.3% (3230/26273) in middle schools (grades 7–9), and 11.2% (2252/20185) in high schools (grades 10–12) (Special Education Transmit Net, 2016). However, the special education programs often do not have enough resource to provide adequate individualized program for children with ASD (Chu et al., 2017); rather, the classrooms consist of students with a variety of disabilities – this is particularly the case in the regions that have fewer education resources.

In Taiwan, ASD-related treatments are mainly clinic- or center-based; that is, a treatment team delivers the intervention at a hospital or private practice. The treatment can be 1:1 or in group. The team members who deliver the intervention may include a rehabilitation physician, child psychiatrist, or pediatrician as a lead person, with occupational therapists, physical therapists, clinical psychologists, language pathologists, or social workers as part of the multidisciplinary team. Parent or family member involvement often is not a focus of such treatment/intervention. Although parent-delivered intervention has been known for quite some time in the field of child psychiatry and psychology in Taiwan, it has not yet been widely implemented as a part of early intervention service. One of the reasons is that professionals and parents both feel that health-related treatments should be delivered by professional care providers and that parents should not serve, or may not be qualified to serve, as a therapist and that treatments should be a responsibility of health-care professionals (T.-T. Chen, 2009).

Quality ASD-related education and health services are typically only available in the metropolitan areas of Taiwan. Given the limited resources in nonmetropolitan and rural areas, children in these regions are diagnosed at an older ages than children residing in metropolitan areas (Chen, Liu, Su, Huang, & Lin, 2008). Common barriers that delay ASD screening and detection include the following: First, with the increase of nuclear families (54.3% in 2010), multiple-generation families are no longer the mainstream (National Statistics Republic Of China (Taiwan), 2010). However, the society traditionally practices vertical collectivism where a hierarchical structure of power is in place such that senior family members' (often grandparents) ideas and opinions play a key role in decisions on all aspects of all family members' lives, even if members do not live in the same household. Senior family members of the older generation consider a delay of development in young children as a sign that the child will later accomplish greatness (an old saying: a great rooster crows late) and, therefore, often advise parents not to rush to have the child evaluated by health-care professionals (Chao, Chang, Chin, Li, & Chen, 2017). Second, typically, developmental evaluations are carried out in a pediatric or psychiatric clinic, and an ASD diagnosis is made by a psychiatrist. Having a family member being diagnosed with ASD (or any mental disorders) continues to be considered punishment for what family ancestors have done wrong (H.-H. Chang, 2014b; Chung and Wong, 2004; Fung, Tsang, Corrigan, Lam, & Cheng, 2007). Such fatalism is not uncommon in the society, particularly in older generations, and in families in lower SES populations or living in nonmetropolitan areas. To reduce this resistance to seeing a psychiatric health-care provider, clinics that provide services for developmental concerns have been renamed as "physical and psychological medicine clinics" in Taiwan. Third, stigma remains a major issue for having an ASD diagnosis. Parental concern over having the label of such diagnosis can trigger bullying, and they are therefore reluctant to have their child evaluated. Fourth, the most common first concern parents of children with ASD have is delay in verbal communication. Often, an ear, nose, and throat clinic is the first clinic visit a family makes to have their child evaluated. Because no organic injuries or damage is found, families often either wait and see or do not think there is a problem and feel the child is just too shy to talk. Conventionally, as long as the child does not have an obvious physical disability, lack of social interaction/communication may not be a major concern a parent has. Fifth, families may be concerned that life insurance companies may refuse to insure the family if the child has the pre-existing condition (i.e., ASD diagnosis).

Some of the common barriers to ASD-related services underserved families are facing in Taiwan are similar to those found in low-resource families throughout the world, whereas some are more specific to the families in Taiwan. The following are the most common barriers: (1) Families may not have enough knowledge about child development (Chao et al., 2017), or may not be aware of existing services because most information is available online. Many low-SES families either cannot afford or are not familiar with the Internet and computer usage. This is particularly the case for residents outside of major cities (Ministry of Education Republic of China (Taiwan), 2015). Even if they know ASD services exist, they may lack information and understanding on how to access them or they may not recognize the importance of needed services. (2) Families may consider the diagnosis to be fate and feel that there is nothing they can do about it. (3) Low-resource families often lack transportation or child care and have few resources to pay for these related expenses. (4) Although the NHI provides mandatory comprehensive medical care coverage, the number of visits allowed and reimbursement for behavioral intervention are limited. Even though such costs may not be substantial, they can be significant for families who are struggling to make ends meet. (5) There is a shortage of trained professionals delivering ASD-related services outside of major cities. Because communication and language delay is the major concern for most families who have a child with ASD, language therapy is the most requested treatment by the families. Due to the high demand and limited number of speech and language pathologists available, wait times for treatment are prolonged, with a majority of children receiving language therapy after age 3 (Wang and Lin, 2008). (6) In multiple-generation households, grandparents may have more influence on decision-making about whether or what types of treatment a child with a developmental concern should receive. In many cases, grandparents care greatly about losing family “face” by having a child in the family labeled with ASD. (7) Taking time off from work to take care of their child’s health-care need can have significant impact on their family income; this is particularly true for families with limited resources or with lower SES. (8) Over the past two decades, there has been a steady and significant increase of children born to new immigrants in Taiwan. Specifically, in 2015, 10.6% of children in 1st to 9th grades were born to immigrant families (Ministry of Education Republic of China (Taiwan), 2016). The vast majority of these are international marriages between a Taiwanese man and his wife from nearby Asian countries. Because these families also tend to be SES disadvantaged and the mother is the primary caregiver of their children, speaking a foreign language becomes a major barrier to a child being evaluated and treated for possible developmental concerns. Additionally, the immigrant mothers often live socially isolated lives and are not able to have much social connection outside of the husband’s family. Such isolation and language barriers not only delay early diagnosis but also make parent-mediated intervention more challenging.

Challenges and Opportunities for Adapting Individualized Parent-Implemented Intervention

Parent-implemented interventions could be a very feasible way for increasing access to treatment for children with ASD in rural and low-resource areas. However, the popular perception is that treatments for ASD and other medical conditions should be provided by specialized and highly trained clinicians rather than family members. Furthermore, it can be highly stressful and anxiety provoking for parents to receive the training to be a “therapist” for their own child, and therefore many refuse to be trained as they think they should not and are not eligible nor can learn to be a therapist for their child (T.-T. Chen, 2009; Yen and Chang, 2014). It is worth noting that there are parents who reported they feel “empowered” to be able to serve as a therapist for their child (Tsai et al., 2015). Some of the aforementioned barriers to services also are true when it comes to training parents in implementing evidence-based intervention at home. For example, lower literacy levels can make it challenging for parents to read and understand treatment materials. Many of these families also bear excess stress from other demands in life, for example, financial demands to meet basic living needs of the family (Yen and Chang, 2014). Other challenges include different views among family members on how to raise and discipline the child, predeterminism belief (fatalism), significant physical health issues and mental health concerns of the primary caregivers, and immigrant mothers' language barrier and their isolated social network. A combination of these barriers makes the implementation of parent-mediated evidence-based intervention a great challenge.

This has resulted in children of SES-disadvantaged families having limited access to appropriate interventions. Addressing the aforementioned barriers requires the delivery of evidence-based intervention adapted for contextual acceptability (Dingfelder and Mandell, 2011) in family-friendly settings, without losing their model fidelity and effectiveness. Parent-implemented interventions for ASD that were developed and evaluated in Western countries need to be adapted in several aspects in order to enhance acceptability and feasibility in Taiwan (Drmic, Aljunied, & Reaven, 2017).

Family members need to be involved as a unit, including extended family rather than just parents. This is particularly critical for a multiple-generation family homes where grandparents, siblings, and other relatives live in the same household and therefore should be involved as a part of the treatment team. If there are barriers to involving all these family members in the parent training sessions, providers need to at least have their "approval" to allow caregivers receiving such training to implement the strategies at home. The procedures put in place need to work for the whole family. For example, if a parent is working on waiting until a child is calm before responding, but the grandparents believe this is damaging to the child and do respond, the behavior is not likely to change, and there may be conflict within the family.

Working with parent groups. Parent groups not only provide support to families but also allow parents to share their experiences with other parent members of the group (Rodrigo, Almeida, Spiel, & Koops, 2012). Such support systems empower parents to learn and therefore can serve as a platform for the parent training to happen. Knowing that SES-disadvantaged families may not actively participate in social groups of this kind, such groups should consider including a broader scope (e.g., child development rather than specific focus on ASD) to reduce the resistance due to the stigma of ASD and to increase the acceptance level of other family members (specifically the grandparents). Needless to say, ASD-focused activities and trainings surely should be included. A well-trained parent member of the group can later serve as a consultant or trainer for other parent members. One of the main advantages of this approach is that the trained parent members can share the obstacles and experiences their family is facing and can provide a more culturally relevant and sensitive training for the new parents.

Families living in disadvantaged SES status in Taiwan are likely minorities, new immigrants, or residents outside of major cities. These families often are more comfortable in speaking dialects or other languages (e.g., new immigrant mothers) rather than Mandarin Chinese. Therefore, it is crucial that the support groups or intervention training have the capacity to be implemented in dialects and native languages of immigrant mothers in order to make the training accessible to the families who are in great need.

Expanding the workforce Taiwan is forecasted to become an aged society in 2018 and super-aged society by 2026 (Department of Human Resources Development, 2016). This means that those 65 years and older will account for 14.5% of the population by 2018 and 20.5% by 2026. However, between 2010 and 2015, men and women left their full-time workforce at age 63.3 and 60.6, respectively

(Ministry of Labor Republic of China (Taiwan), 2015). With the increased life expectancy, this presents as an opportunity for retirees to spend their golden years making a difference by volunteering. Retired health-care professionals or educators who have worked in the fields related to child development or working with children with developmental disabilities could be a great resource to provide behavioral intervention after appropriate training. If such training is set up systematically and ongoing, these retirees can either implement the intervention at the child's home or train the families/caregivers in groups at low or no cost. If this increasing number of retirees receives appropriate training, this may increase the likelihood that families residing in rural areas could be reached. Health-care professionals and teachers are often highly respected in the society; having them working with the families would make such training more accepting and convincing to the family.

Conclusion

The prognosis and outcomes of ASD are highly influenced by social and family contexts, poverty, cultural history, public policies, available programs, environment, and opportunities. Implementation of a parent-mediated evidence-based intervention presents a great potential in addressing major obstacles to intervention access for affected children and their families who are underserved in Taiwan (Tsai et al., 2015), although such intervention is still in the developing and adapting stages for many low-resource settings in the world (Blake et al., 2017) and in some communities in Taiwan.

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Supporting Intervention Providers and Families in South Asia

24

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Abstract

South Asia is one of the most densely populated geographical regions in the world with a young and fast-growing population. The region is characterized by widespread poverty, poor health and social-care infrastructure, and high rates of illiteracy. In recent decades, parts of the region have shown rapid economic development, leading to urbanization and rising social inequality. It is estimated that the region has about 10 million children with autism spectrum disorder (ASD), and the majority have little or no access to any type of service. This chapter reviews existing practices of care for children with ASD in low-income settings in the region and describes some recent advances in supporting intervention providers and families caring for these children.

Introduction

The term South Asia is used to represent the southern region of the Asian continent, which comprises the sub-Himalayan countries and adjoining countries to the west and east. Commonly, the countries included in South Asia are Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka. The terms 'Indian subcontinent' and 'South Asia' are sometimes used interchangeably. South Asia is home to well over one fifth of the world's population, making it the most densely populated geographical region in the world (CIA, 2013). About half the population is under the age of 18, and three fourths live in rural areas. The countries of the region have similar sociodemographic and health profiles (The World Bank, 2015). Literacy rates range between 55% and 60%, with lower rates among women. The major religious traditions are Hinduism, Islam, Buddhism, Sikhism, and Christianity. Faith plays an important role in people's lives, especially in rural areas, and traditional healing practices are widespread (Sarkar, 2014). Large parts of South Asia have a topology that makes travel and thus access to health and educational facilities difficult and time-consuming. Nearly 500 million people live on less than $1.25 per day, and over 30% of all children are malnourished (UNICEF, 2014). Infant and maternal mortality rates are still

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_24

unacceptably high. Economic growth in the last decades has fueled migration from rural to urban areas, eroding traditional support systems and adding to the burden of poor health (Trivedi, Sareen, & Dhyani, 2008).

The challenges that the region's healthcare systems face in providing care to its citizens are substantial. High levels of both infectious diseases and noncommunicable diseases lead to a double burden on already weak health systems. Public spending on health in all South Asian countries remains low. For example, in Pakistan in recent years, healthcare spending has amounted to just over 1% of the GDP. When public and private expenditure and external aid are combined, the total health expenditure amounts to about 4% of the GDP. The vast majority of the funds are spent in the area of physical health, and very little is allocated to mental healthcare. With such deficiencies in the public healthcare system, people are dependent on private and traditional healthcare providers who currently treat over 60% of individuals with healthcare needs (Sarkar, 2014), especially for conditions that are not thought to have a physical basis. Thus, people often consult traditional and religious healers for children with developmental disorders. These traditional healers include the *pirs* and *gadinashins* (meaning "the person who sits on the master's or teacher's seat" and commonly applied to people who have inherited the craft of healing from previous generations), imams, pandits, ayurvedic and herbal practitioners, and others involved in magic and sorcery (Karim, Saeed, Rana, Mubbashar, & Jenkins, 2004). It is clear that the sociocultural, demographic, economic, and health systems context is quite different from the West, where most interventions for such conditions are researched and developed (Minhas et al., 2015).

Caring for Children with Autism in South Asia

With an estimated prevalence of ASD of 1.4% in the region (Elsabbagh et al., 2012) and about 680 million children under the age of 18, there are probably about 10 million children with the condition in the region. Except for a few urban centers, there are no services of any type, and very few mental health specialists, for these children. Thus, the 'treatment gap' for ASD in the region is nearly 100%.

Minhas et al., (2015) reviewed qualitative studies from India and conducted original research in Pakistan to understand existing care practices for children with ASD in the South Asia. In India, a narrative review of qualitative studies was conducted in April 2014. The literature search was conducted using PubMed. Keywords for the search included India, autism, ASD, qualitative, impact, help seeking, coping, family support, and interventions. The review covered studies from years 2003 to 2013. Studies were included if parental and community beliefs and practices related to ASD were the focus of at least one aspect of analysis. The review of literature identified five relevant studies which included a total of 145 In-depth Interviews (IDIs) with families and stakeholders and 9 focus group discussions. In Pakistan, the qualitative study was conducted with 15 parents of children with ASD. Parents were recruited purposively using a maximum variation sample to capture the diversity of sociodemographic characteristics. The IDIs explored beliefs and care practices for the children inside and outside the home.

The studies showed that in both countries it was mostly the mother and her family, who bore the main burden of care for these children. In rural areas, families generally lived in extended families (three generations, or one or both parents with married sons, their wives, and children living together). In the absence of any external support, spouses, siblings, grandparents, and extended family members provided the main respite support for mothers (Daley, 2004; Desai, Divan, Wertz, & Patel, 2012; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Krishnamurthy, 2008; Vaidya & Ignou, 2009). Often, families moved closer together so that the extended family could provide this support (Divan et al., 2012). Even in urban areas, state-provided respite or remedial care was very limited. Some very small private facilities offered day-care services, but the costs were high and could not be afforded by most. Even affluent families had little access to specialist help and instead relied on hired domestic servants to assist with child care.

Most parents, especially in the rural areas, had very limited information about the condition. Only the few educated had information about the causes and management for ASD, and most rural parents ascribed the child's condition to the "will of God" and "a test by God." It was common to explain the condition as God's will, and the belief in supernatural explanations for the condition was widespread. While most held negative beliefs (e.g., the condition was a result of the 'evil eye' or punishment for a past misdeed), some believed that care of such a child was divine duty, which would be rewarded in the afterlife (Minhas et al., 2015). The studies surmised that parents had no strategies to play, interact, or manage problem behaviors in these children. Occasionally, physical restraint such as tying with ropes or chains and locking in a room was used for behavioral problems.

The review and other previous studies from the region (Mirza et al., 2009) found that there was a delay in recognizing the problem: typically, parents sought help outside the home when the secondary behavioral and social problems associated with ASD became visible and disrupted family life. Such problems also caused the most stress to the parents. Parents reported that challenging behaviors were socially embarrassing and contributed to stigma toward these children and their families from neighbors and other community members. These included behaviors such as hitting others, screaming, crying, shouting, and throwing and breaking things or behaviors that were self-destructive, such as hitting and biting oneself. In cases where medical or psychological advice was available (especially in the urban areas), 'doctor shopping' was common. The main reason for this was the expectation for a 'cure' of the condition (Minhas et al., 2015).

The studies reviewed also found that there was a lack of understanding about the condition among frontline health professionals such as general practitioners and pediatricians, further delaying diagnosis and appropriate management. Parents consulted a range of professionals, including psychiatrists, psychologists, pediatricians, neurologists (Daley, 2004; Divan et al., 2012; Vaidya & Ignou, 2009), therapists (Divan et al., 2012; Krishnamurthy, 2008), and special educators (Divan et al., 2012). All the reviewed studies described the financial pressures on families due to the distances they had to travel to reach a facility, the cost of staying in a city, and the expensive diagnostic tests and interventions that were prescribed. In many cases, drugs or tranquilizers were the only intervention offered. Apart from biomedical consultations, families also consulted religious practitioners where rituals such as prayers and ceremonies to remove 'evil' spirits were attempted. Traditional Indian systems of medicine – Ayurveda – were also consulted by families in India (Desai et al., 2012; Divan et al., 2012).

Carers also reported that they had to deal with stigma associated with the condition in their communities (Minhas et al., 2015). Some community members were unsympathetic and intolerant, using derogatory terms such as *pagal* (mad) or *Jhalla* (idiot) for such children. Others were more sympathetic and understood that the children had special needs and should be treated with kindness. However, the stigma associated with the condition was a cause for concern for most parents. Many worried about mistreatment at the hands of the community, and this led to a very restricted life for the child (Rahman et al., 2008), resulting in parents not sending their child out into the community to play or for social celebrations (Divan et al., 2012). The child's disruptive behavior and a lack of understanding of the disorder in the community were the main reasons for social isolation and embarrassment for the parents (Divan et al., 2012; Krishnamurthy, 2008; Minhas et al., 2015). Parents of children at the milder end of ASD reported efforts to get their children into mainstream education but were concerned that even teachers had very limited understanding of the condition and could not understand the needs of their children. Most of the parents interviewed in the Pakistan study did not send their child to any educational establishment for fear that it would do them harm (Minhas et al., 2015).

All the studies reviewed (Desai et al., 2012; Divan et al., 2012; Krishnamurthy, 2008; Vaidya & Ignou, 2009) highlighted the emotional burden experienced by the parents while raising the child with ASD. Parents also reported personal health problems from the stress of bringing up a child with ASD, including aches, pains, and disturbed sleep (Divan et al., 2012). One study (Krishnamurthy, 2008) found that fathers had great difficulty talking about their feelings due to cultural expectations of how they should behave. Studies also reported the mothers' isolation and disrupted spousal and family relationships (Desai et al., 2012; Divan et al., 2012; Krishnamurthy, 2008; Vaidya & Ignou, 2009). Being a carer affected the parents' professional careers. Mothers, as the prime carers, often sacrificed their professional life to take care of their child's needs, while fathers worked long hours to take over the financial responsibilities of the family (Divan et al., 2012).

Stress in Carers and Approaches to Address It

Studies that have quantitatively measured carer distress using questionnaires in mothers of young children with developmental delays and disorders including autism and intellectual disability in South Asia have found high rates of distress (Mirza, Tareen, Davidson, & Rahman, 2009; Rahman, Patel, Maselko, & Kirkwood, 2008). First-line interventions for ASD are generally parent-mediated, requiring considerable parental effort for effective delivery (Kendall et al., 2013). Mothers who are psychologically distressed may require extra support. It would therefore be important to be aware of parental stress while planning delivery of such interventions. Maternal distress and depression, and its impact on child care and development, is increasingly being recognized as a public health challenge (Rahman, Patel, et al., 2008; Wachs, Black, & Engle, 2009), and strategies have been developed to integrate intervention in child care programs. Involving other family members to support the mother, particularly fathers and mothers-in-law, is an important component of such strategies (Atif, Lovell, & Rahman, 2015; Zafar et al., 2014). This is important for two reasons – first, to enlist support for the mother and, second, to achieve buy-in for the intervention from the whole family.

Zafar et al. (2014) developed and integrated a cognitive behavioral therapy-based maternal psychosocial well-being intervention (the five pillars approach) into a child nutrition and development program in Pakistan. Following formative research with community health workers (CHWs; *n* = 40) and families (*n* = 37), CHWs were trained in the five pillars approach. A qualitative feasibility study in one area with 13 CHWs demonstrated that CHWs were able to apply these skills effectively to their work, and the approach was found to be useful by CHWs, mothers, and their families. The success of the approach can be attributed to (1) mothers being the central focus of the intervention, (2) using local CHWs whom the mothers trust, (3) simplified training and regular supervision, and (4) an approach that facilitates, not adds, to the CHWs' work. Box 1 describes the approach that can be integrated into routine community-based visits by community health workers to support mothers and other carers.

Box 1 Case Study: Five Pillars (5-PA) Approach to Maternal Psychosocial Well-Being

5-PA is derived from the Thinking Healthy Program (THP), a cognitive-behavior therapy-based psychosocial intervention for mothers with depression and their infants. THP was a targeted intervention for women suffering from perinatal depression and their infants and was delivered by community health workers (CHW) in rural Rawalpindi, Pakistan. In a randomized controlled trial to evaluate the approach, there were impressive improvements in maternal depression and functioning compared with controls (Rahman, Malik, Sikander, Roberts, & Creed, 2008), and THP was adopted by the World Health

(continued)

Box 1 (continued)
Organization as a first-line low-intensity treatment for perinatal depression (see http://www.who.int/mental_health/maternal-child/thinking_healthy/en/).

5-PA is an adaptation of the THP to integrate it into a child care and development program (Zafar et al., 2014) and targets not only depressed women but all mothers of child-bearing age.

The key feature of the approach is that it is integrated into, and facilitates the delivery of, a CHW-delivered intervention for early child development. Thus, whenever the CHW delivers a session for health education around child development, she uses the 5P approach to strengthen support for the mother. In practice, the approach works as follows:

Pillar 1. Family support. An initial home visit emphasizes family participation, and the training manual gives specific instructions on how this can be facilitated. Family members are encouraged to be active partners for the whole duration of the program. Strategies to engage key decision-makers, such as mothers-in-law and fathers, are emphasized.

Pillar 2. Empathic listening. Each session begins in an open-ended fashion, with the CHW allowing the woman to talk freely. She uses active listening skills to convey empathy and makes a list of problems the woman faced in performing the desired activities the CHW might have suggested in her previous visit.

Pillar 3. Guided discovery using illustrations. Each new key message related to health or development is conveyed using this approach. Using carefully researched illustrations, the CHW discusses both undesired and desired behaviors. She is trained not to impose her views but to allow the mother and family to consider each illustrated viewpoint and come to their own conclusions. The idea is that the basis of any behavior change begins at the cognitive level.

Pillar 4. Behavioral activation. Once the message is received and accepted, the activities related to it have to be made manageable so that a sense of mastery is achieved. The training manual has suggestions for how each health- or development-related task can be broken down and monitored with the help of family members.

Pillar 5. Problem-solving. The CHW spends time discussing the problems the woman faced in carrying out the tasks suggested in the previous session (see Pillar 2). She discusses possible solutions, which she can generate through discussion with the family or through her supervision.

Task-Shifting Strategies to Support Intervention Providers

In the absence of specialist services, "task-shifting" has been recommended as a key implementation strategy for mental health in low- and middle-income countries (Kakuma et al., 2011). A task normally performed by a specialist is transferred to a health professional with a different or lower level of education and training or to a person specifically trained to perform a limited task only, without having a formal health education. The approach has been successfully tested for a number of mental health conditions in South Asia, including depression (Patel et al., 2010), schizophrenia (Chatterjee et al., 2003, 2014) and perinatal depression (Rahman, Malik, et al., 2008). In this model, specialists play the roles of building capacity, quality assurance, and offering a referral pathway when needed. While a number of studies have demonstrated the feasibility and effectiveness of using nonspecialist workers to deliver child and adult mental health interventions (Van Ginneken et al., 2011), these approaches have only recently been applied to the field of autism.

Divan et al. (2015) reported the adaptation of an evidence-based specialist speech and language therapist-delivered intervention for autism for delivery by nonspecialists in two South Asian settings (India and Pakistan). The nonspecialists in this study were defined as graduates without any specific child development training but possessing a range of nonacademic "soft" skills, including good communication skills, especially with younger children. The selection of the intervention for adaptation was informed by (a) the method of its delivery (the intervention would require to be parent-mediated, as parents are the only available and affordable human resource in these settings) and (b) the quality of prior evidence (parent-mediated interventions targeting social communication are the only ones recommended by the UK National Institute for Health and Care Excellence for the early treatment of core symptomatology in ASD) (Kendall et al., 2013). These are psychosocial interventions that act to make specific and theoretically based alterations in a child's dyadic communication environment in order to improve the child's social communication, attention, and language. In the South Asian study, the intervention selected for task-shifting was the UK Preschool Autism Communication Therapy (PACT; Chapter 14). PACT combines both parent mediation and a social communication focus (Green et al., 2010). The original UK PACT follows a developmental approach to supporting communication, addressing social, prelinguistic, pragmatic, and linguistic impairments that are present in ASD. It has six stages supporting parents to adapt their communication outputs to their child's abilities. It was delivered during the original UK study through twice monthly sessions by specialist speech and language therapists using video feedback, enabling the parents to identify windows of opportunity to facilitate joint attention and stimulate child intentionality. The twice monthly sessions were continued by six monthly sessions to complete a 12-month delivery. Details of this intervention can be obtained at www.bbmh.manchester.ac.uk/pact/about/Interventionmanual.pdf.

The evidence to support the effectiveness of PACT in UK settings was obtained from a randomized controlled trial (Green et al., 2010) and a mediation study that explored the mechanism of its treatment effect (Pickles et al., 2015). The intervention had a rapid and substantial impact after 6 months of treatment on parental communication style with their child with ASD, with a large intervention effect size (ES = 1.37) compared to treatment as usual in UK National Health Service settings. This change in parental communicative synchrony was found to mediate over 70% of the improvement observed in the child's communication initiations with the parent (ES 0.5 after 6 months) and 73% of the modest gains in child Autism Diagnostic Observation Schedule (ADOS) symptom score at 13 months (ES 0.24).

The adapted intervention was called PASS (Parent-Mediated Intervention for Autism Spectrum Disorder in South Asia), and a tailored 10-day training program to train nonspecialist graduates in its delivery to parents was developed (Divan et al., 2015). Training included learning concepts of child development, an introduction to disabilities, counseling approaches, opportunities for observing typically developing children and children with ASD, exercises to support the scaffolding of trainee's observation skills, and the details of the PASS stages. Progression to practice cases was dependent on trainees passing a basic competency assessment focusing on knowledge gained. The first two sessions of the practice cases were co-delivered with a supervisor, with the nonspecialist leading the second session. Four weeks after the commencement of training, when each trainee had led at least one practice session under supervision, they underwent another objective competency test focusing on both knowledge and skills and was an essential prerequisite for independent delivery by the nonspecialist. Subsequently, provisions were made for 'top-up' training as transition to later stages of the intervention took place. An important component of the initial engagement with the family was added to the original intervention: this was designed to be delivered by the specialist supervisor as a one-off session with the aim of clarifying the goals of PASS as well as explaining the intervention framework to the parents. The adaptation contained clear guidelines explicitly detailing potential concerns (e.g., behavioral problems) that needed to be referred to supervisors, to safeguard nonspecialists from being consulted on issues beyond the scope of their training.

Rahman and colleagues conducted a parallel group single-blind randomized trial comparing the adapted 12-session nonspecialist delivered PASS intervention with treatment as usual delivered by nonspecialist health workers in two South Asian settings – Goa, India, and Rawalpindi, Pakistan (Rahman et al., 2016). They randomly allocated 65 children aged 2–9 years to either PASS plus treatment as usual (TAU) or treatment as usual (TAU) arms, controlling for treatment center, age, and functional impairment. Primary endpoint was change in the quality of parent-child interaction on Dyadic Communication Measure for Autism (DCMA) at 8 months from the baseline. Secondary endpoints were change in language, social communication, and functional adaption in children. Data was analyzed using the intention to treat (ITT) approach. Twenty-six out of 32 parent-child dyads allocated to the intervention arm completed the intervention (81%). The treatment effect was positive in the favor of PASS in parent synchrony (adjusted mean difference AMD 0·25; 95% CI 0·14, 0·36) and child communication initiation with parent (AMD 0·15; 95% CI 0·04, 0·26) but reduced time in mutual shared attention (AMD −0·16; 95% CI −0·26, −0·05) as measured on the primary outcome. Successful replication of treatment effects (except one negative effect not found in the UK) in a low-income setting, using nonspecialist delivery agents, demonstrated the feasibility and acceptability of task-shifting approach to support parents and caregivers of children with autism spectrum disorders in seeking evidence-based therapy in low-resource settings.

Peer Support for Families

Addressing parental needs has been identified as important to service organization for ASD in other regions of the world (Karst & Van Hecke, 2012). It has been recommended that policy-makers need to provide comprehensive, continuous, and coordinated care to strengthen the patient-family dyad and promote the full development and societal inclusion of children with ASD (Gomes, Lima, Bueno, Araújo, & Souza, 2015). Ignoring parent and family factors may have an influence on both the immediate and long-term effects of any intervention. Informal and formal support networks, including through the Internet, have been advocated for families with a child with ASD (Twoy, Connolly, & Novak, 2007). In most poorer and rural areas of South Asia, the absence of such facilities and dedicated health professionals is a barrier to implementation of such strategies. Clearly, other approaches to supporting parents in mediating care to their children are warranted.

Hamdani and colleagues (2014) conducted qualitative studies in rural Pakistan to explore if task-shifting could be taken to its most proximal level, i.e., families living with a child with developmental disorder, thus creating a new system for intervention delivery. The key finding was that volunteer family members of affected individuals could be organized to form an active, empowered group within the community that, (a) using a task-shifting approach, could be trained by specialists to provide evidence-based interventions to their own children, and to cascade it down to other families in their villages; (b) supports each other, with the more experienced and motivated "champion volunteers" providing peer supervision to new family members who join the group; and (c) works to reduce the stigma associated with the condition and improve opportunities for participation in community life.

Based on these findings, a small demonstration project was successfully conducted in a rural locality in Rawalpindi, Pakistan (Hamdani, Minhas, Iqbal, & Rahman, 2015). In a rural population of about 30,000, a self-sustaining Family Network (FaN), consisting of 10 trained "champion" family volunteers working under supervision of a specialist at the local NGO, providing intervention to 70 families of children with developmental disorders was successfully established. Each champion was responsible for training and providing ongoing support to 5–7 families from his or her village, and the families supported each other in the management of their children. The network members campaigned for better facilities for the children in local schools and primary healthcare centers and pushed to improve participation in community life.

Using Technology to Support Task-Shifting to Families

The implementation of such networks at scale would require identification of families with children with a developmental disorder and potential "champions" who could undertake training in intervention delivery. A house-to-house survey or screening program would not be sustainable at scale. Taking advantage of mobile phone access available to 85% of Pakistan's population, a technological solution to this problem was developed in the form of an *interactive voice response (IVR) system*. This consisted of telephone equipment, a software application, a database, and supporting infrastructure. The automated telephone system interacts with callers, gathers information, and routes calls to a database that can be accessed by a human at any time. A leaflet with key signs of a developmental disorder, a motivational message, and a free phone number was distributed to every household in one rural area (pop 50,000) through local community health workers, who visit every household at least once a month. When the free phone number was called, the IVR application provided prerecorded voice responses to the Ten Questions Screen (TQS; for developmental disability) (Durkin, Hasan, & Hasan, 1995). After each prerecorded question had been read out, the caller was given the choice to select options by pressing a digit. When all ten questions had been answered, the application used an algorithm to determine the results of the screening and fed it back to the caller. Callers who screened positive for developmental disorders were asked to leave their address and contact number and whether they were willing to be trained in the intervention to help other families. The application was also able to map out the address of the callers through Global Positioning System (GPS), allowing for the organization of families into networks within villages and neighborhoods.

Training "Champions" to Deliver Evidence-Based Intervention: Avatar-Assisted Cascade Training (ACT) for Developmental Disorders

The World Health Organization's (WHO) Mental Health Gap Action Programme (mhGAP) intervention guide (mhGAP-IG) (World Health Organization, 2010) developed by following a rigorous process overseen by the WHO (Dua et al., 2011) was used, as the *scientific* basis of the "champion-delivered" intervention.

While the mhGAP-IG provides guidelines for *what* to do, they do not specify *how* to do. This is particularly challenging when training lay workers such as family members, both as delivery agents and recipients of the intervention. Some would have limited or no literacy, and none would have any experience in mental healthcare. To overcome this challenge, a standardized, intuitive tablet-based training tool was developed. The mhGAP-IG diagnostic and management guidelines were incorporated into a "real-life" narratives of the lives of three children with developmental disorders and their family members, their local "champions," a "specialist," and other supporting characters. The guidelines were broken down into training scenarios, which were converted into narrative scripts by a panel of experts. An artist converted the characters into "Avatars" (graphic image representing each character) which were used to voice the narrative scripts. The tablet application was operated by a simple two-button operation (forward and back). The narratives were interactive, allowing family members to discuss each scenario in the context of their own lives, develop individualized management plans for their child based on his or her strengths and difficulties, practice parent-management skills through roleplay, discuss ways of increasing participation in communal life, and share problem-solving strategies. The training scenarios were organized into modules covering every aspect of the guidelines (psychoeducation; parent skills training including care for development; physical health including nutrition advice; parental stress; community participation; stigma and rights). Everyday language in the local dialect was used. The training scenarios can easily be updated, modified, or added to without disturbing the overall architecture of the software. This technology-assisted system of training to support task-shifting has been named as the Avatar-Assisted Cascade Training or ACT (Hamdani et al., 2015).

A master trainer, using the ACT system, trained the "champions," and they, in turn, used the same devices to cascade the training down to 5–7 families allocated to each champion. The training took 8 days to complete, but the "champions" continued to have a monthly support group session with the master trainer. Similarly, after a "champion" had trained all the families under her care, she continued to have a monthly group session with the families at one of their homes.

A pre-post-evaluation of the program ($n = 68$) indicated that there was significant improvement in disability and socioemotional difficulties in the child, reduction in stigmatizing experiences, and greater family empowerment to seek services and community resources for the child (Hamdani et al., 2015).

Conclusions

The densely populated and socioeconomically deprived region of South Asia presents unique challenges to provision of care for the millions of children with ASD. In the absence of widely available services or trained professionals, the burden of care for such children is entirely with the mother and her extended family. This contributes to the high levels of stress in the primary caregiver. However, task-shifting strategies have the potential to deliver evidence-based parent-mediated interventions in such settings through nonspecialist providers. Close-knit communities and motivation of families to support each other provide further opportunities to deliver support and evidence-based interventions for these children through motivated family members. Even in areas of low literacy and deprivation, the receptivity toward the use of technology to assist such family support and capacity-building networks was notable. The adaptation of evidence-based specialist-delivered best practice in a simplified technology-supported format that can be used effectively by nonspecialists or even trained family volunteers, holds promise for the future.

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Part VII

Scaling-Up Evidence-Based Practices: Parent-Implemented Interventions in the Community

25

Supporting Parent Use of Evidence-Based Practices for Infants and Toddlers with Autism Spectrum Disorder

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Abstract

As reliable diagnosis of autism spectrum disorder (ASD) becomes possible for children at younger and younger ages, the need increases for early intervention systems and providers to be well acquainted with effective implementation of evidence-based practices (EBPs). Implementing EBPs in natural settings, such as homes and communities, requires that knowledge and use of EBPs is accessible to parents and caregivers. This chapter describes a model, the ASD Toddler Initiative model, which through funding from Autism Speaks supports early intervention programs and providers in building and sustaining quality programs for coaching of parents on the selection, implementation, and monitoring of EBPs with their infants and toddlers. Grounded in implementation science, facilitators and challenges to implementing the ASD Toddler Initiative model are described at the system (i.e., state, agency) and personal (i.e., family, practitioner) levels. An integration of these implementation drivers with the model processes and professional development supports prepares early intervention systems and practitioners to meet the developing needs of families and their young children with ASD.

Introduction

When do the first signs of autism appear? Recent research on eye tracking suggests that differences between children who will develop autism spectrum disorder (ASD) and those who will not may be seen as early as the first 6 months of life (Jones & Klin, 2013). Researchers have proposed that a reliable diagnosis may occur as early as 18 months (Ozonoff et al., 2015). With the possibility of detecting ASD at an earlier age than any time in the past, care providers have emphasized the importance of screening and diagnosis at early age (Johnson, Myers, & the Council on Children with Disabilities, 2007). In turn, earlier identification of infants and toddlers with autism creates a greater need for the provision of early intervention services for young children with ASD. A basic rationale for treating ASD at an early age is that children may achieve greater gains and indeed, different life courses, as compared to children who receive services at a later age (Koegel, Koegel, Ashbraugh, & Bradshaw, 2014).

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_25

Early Intervention Services

The Individuals with Disabilities Education Act (IDEA) require services for children with disabilities, including those with ASD, to be delivered in naturally occurring settings. For young children in early intervention programs, the naturally occurring setting is their families' homes and/or community. Early intervention service providers work with family members, primarily parents. Family members are supported in their implementation of specific evidence-based, focused intervention practices to foster their infants'/toddlers' acquisition of basic social, communication, and adaptive behavior. The purpose of this chapter is to describe a process of professional development for early intervention providers that would lead to parents' adoption and use of evidence-based practices (EBPs) with their children with ASD in home- and community-based settings.

Infants and Toddlers with ASD

A normative course for early social and communicative development is that infants initially show attention to their care providers by observing them, often focusing on their faces. Undifferentiated smiles during the first 3 months change into social smiles (i.e., smiles directed toward people often in response to adults' overtures). As infants mature through that first year, they begin to use nonverbal (prelinguistic) forms of communication, participate as a responder and then an initiator of parent-infant games, and begin to imitate actions of others. In the second year, toddlers begin to engage in pretend play, which becomes more sophisticated as the year progresses, and share joint attention to objects and activities with adults. Also, children begin to use words to communicate with others, with vocabulary increasing dramatically as children approach their third year (18–24 months). In parallel with social and communication skills, motor skills advance from sitting to crawling to walking. With locomotion enabling physical independence from adult, toddlers increase their desire to be independent in the engagement with the world, and parents often talk about the "terrible twos," in which children express "I can do it" and tantrum when their efforts are limited by adults or unsuccessful (Centers for Disease Control and Prevention, 2015).

A different pattern of development exists for infants and toddlers with ASD. As noted previously, their social gaze to adults may drop off after the first 3 months of life. They may not attend to their name when called and may have delayed or not develop imitation skills. They may be delayed in engaging in joint attention with caregivers to objects or actions. For some infants and toddlers with ASD, motor milestones may be delayed. In addition, infants and toddlers with ASD often engage in more repetitive and restrictive behavior than typically developing children. Also, they may have a difficult time establishing a diurnal sleep schedule, and many parents report digestive disturbances of their young children with ASD (Chawarska, Macari, Volkmar, Kim, & Shic, 2014).

For the majority of infants and toddlers with ASD, these delays in development appear early and are progressive. However, for a minority of children who eventually develop ASD, normal development of early social and communication skills occurs well into the second year. At that point, their development becomes delayed, and they may even lose skills (Ozonoff et al., 2011). For example, parents report some children beginning to acquire and use words up to a point, and then communication becomes impaired.

This pattern of early development and description of children's characteristics has implications for early intervention programs. As for older children with ASD, the areas of concern and need for developmental intervention are focused on social and communication skills and repetitive/restrictive behavior. But also, parents may express needs for information about ASD and its life course, children's sleep patterns, and other health issues.

Early Intervention Programs for Infants and Toddlers with ASD

The first intervention programs for children with ASD, such as Lovaas' applied behavior analysis program (Lovaas, Koegel, Simons, & Long, 1973) and TEACCH (Schopler & Reichler, 1971), focused on preschool- and school-aged children and tended to occur in clinical settings. Until recently, this age trend continued (National Research Council, 2001; Odom, Rogers, McDougle, Hume, & McGee, 2007). In part spurred on by an initiative funded by Autism Speaks, different groups of researchers began developing and evaluating programs for infants and toddlers with ASD and their families. Several of these programs now have published research documenting their efficacy (Siller et al., 2014). Most prominent among these programs is the Early Start Denver model, for which the developers have demonstrated (Dawson et al., 2010) and partially replicated (Rogers et al., 2012) important outcomes for infants and toddlers with ASD and their families (Estes et al., 2014). Also, a variety of other interventions have focused on joint engagement or attention (Kasari, Gulsrud, Paprella, Helleman, & Berry, 2015; Schertz, Odom, Baggett, & Sideris, 2013) and communication skills (Siller, Hutman, & Sigman, 2013). Researchers have begun describing these programs as Developmental Behavior Naturalistic Interventions (Schreibman et al., 2015) in that they utilize behavior and developmental techniques in "naturalistic" contexts (e.g., play activities that build on the children's interests). Also, they all involve parents, primarily mothers, in some capacity, which represents a family-focused feature of the programs.

The intervention programs just described are known as comprehensive treatment models (Odom, Boyd, Hall, & Hume, 2014). Comprehensive treatment models (CTMs) are defined by having a conceptual and/or theoretical framework, documentation (e.g., procedural manuals operationalize their practices), intensity, focus on the core features of ASD (social communication, repetitive/restrictive behavior), longevity (they occur over a period of time), and often replication. CTMs are designed to be delivered as an organized package of practices. In most of the literature on CTMs, developers use standardized developmental measures (e.g., the Mullen Developmental Scale) to assess effects.

A second type of intervention that also appears in the literature is called focused intervention practices. These are individual intervention practices that address more directly individual goals of children, rather than broad developmental outcomes. Practitioners implement these practices over a shorter period of time, and the outcomes reflect progress on individual goals. For example, naturalistic intervention is a focused intervention practice that an early interventionist might select to promote a toddler using words to request a desired toy or adult action. Focused intervention practices are the "building blocks" of comprehensive treatment programs, in that developers organize these practices in a specific way around, as noted, a conceptual framework. This distinction (between CTMs and focused intervention practices) is important because to successfully use a CTM, the early intervention program has to adopt the entire model and implement it with a high degree of fidelity. Alternatively, early interventionists may build their own program by systematically identifying the goals for infant and toddlers with ASD and their families and selecting the focused intervention practices that are most likely to be effective in meeting those goals. When practitioners follow this approach and chose practices that have scientific evidence of effectiveness (i.e., evidence-based practices), they are following what is called a "technical eclectic" model of intervention (Odom, Hume, Boyd, & Stabel, 2012).

Evidence-Based Practice (EBPs)

The concept and history of EBPs is based in the evidence-based medicine movement that began in the 1960s (Pring & Thomas, 2004). However, for the last decade, researchers and program developers have turned their attention to the identification of EBPs for children with ASD and their families. The National Professional Development Center on Autism Spectrum Disorders (NPDC) conducted an initial review of the focused intervention literature published between 1997 and 2007 and, following a systematic screening and evaluation process, identified 24 focused intervention practices that met their criteria for EBP (Odom, Collet-Klingenberg, Rogers, & Hatton, 2010). Recently, NPDC investigators updated the review, expanding the years of coverage to 21 years (1990 to the beginning of 2012), engaging a national set of reviewers in the evaluations of the literature, and using a more rigorous review process (Wong et al., 2014). This review yielded 27 practices that met EBP criteria. However, the authors noted that most of the literature focused on older (than 3 years) children with ASD (Wong et al., 2015). To identify the focused intervention practices that had evidence for infants and toddlers with ASD and their families, Cox, Kucharczyk, Shaw, and Odom (2013) reviewed the original set of studies from the Wong et al. 2014 review and identified nine practices that had studies in which infants/toddlers with ASD were participants. These practices became the basis of the model that will be described in a subsequent section.

Implementation Is the Next Step

Identification of EBPs for infants and toddlers with ASD is the first step toward grounding practices on a solid research foundation, but only having the knowledge that a practice is potentially effective is not enough to lead to practitioners' or family members' everyday use of the practice with young children with ASD. In the broad human-service field as well as in education, implementation science (IS) has emerged as a feature that supports the adoption and use of evidence-based practice (Cook & Odom, 2013; Fixsen, Naoom, Blase, Friedman, & Wallace, 2005). IS is based on the assumption that simply sharing information with professionals and providing training in single, didactic workshops are insufficient to lead to adoption. Rather, IS takes a systems approach in which innovation is supported by the administrative level of systems. Individuals with expertise provide the necessary training needed to introduce the innovations, such as a form of early intervention that is based on evidence-based practices. Importantly, they provide ongoing coaching to support practitioners in using the innovations in their work. Although quite a number of IS models have been developed, they tend to follow a progressive process (Meyers, Durlak, & Wandersman, 2012) in which a) practitioners become very familiar with the model (i.e., exploration) before making the decision to adopt, b) a planned process for training (i.e., installation) and sharing materials is provided, c) a planned process for supporting (e.g., coaching, time to meet, etc.) the adoption of the new program is established (initial implementation), and d) adoption continues after initial support is reduced until the flow of information from practitioners to administration and back occurs (full implementation) (Fixsen, Blase, Metz, & Van Dyke, 2013). As models for family-centered early intervention move from development and efficacy studies to actual implementation in the field by practitioners, following the principles that are beginning to emerge from the field of IS is likely to lead to successful scaling-up and sustainability.

Features of the ASD Toddler Initiative Model

The ASD Toddler Initiative model (Autism Toddler Initiative, 2013) was funded by Autism Speaks and developed following the principles of IS described in the previous section. It was derived from a modification of the professional development model developed and tested by the NPDC (Cox et al., 2013; Odom, Cox, & Brock, 2013). As per the NPDC model, the ASD Toddler Initiative begins with engagement with state-level systems of Part C and B leaders and others identified as key to system-level planning. State-level buy-in is essential to securing a commitment to change needed to support and sustain program-level activities. Then, program-level activities include assessing program quality, planning through identification of priority toddler and family outcomes and selection of appropriate EBP, implementing EBPs by families and practitioners supported through coaching and training, and evaluating child outcomes and family and practitioner use of EBPs. These program-level features of the model will be discussed in this section.

Assessing Program Quality

The Autism Program Environment Rating Scale (APERS) originally was developed by the NPDC for use in school programs. The infant/toddler version (APERS-IT) was specifically developed to capture quality indicators of mostly home-based early intervention programs. It covers seven domains (i.e., positive relationship, physical environment, activity and daily routines, intervention strategies, behavior, assessment and IFSP development, and teaming). The APERS-IT provides total and domain scores as well as a program profile. The results of the APERS-IT are provided to the program by way of a debrief and a report, which includes a graphic representation of areas of program strength and of areas that could be improved.

The APERS-IT findings provide the foundation upon which EBPs can be successfully implemented to improve child and family outcomes through training, technical assistance, and coaching. Typically a plan is developed to strengthen the program using the results of the APERS-IT. Results from the APERS-IT are used at baseline in a formative way to create a program profile of strengths and areas for improvement for each program. Together the team identifies a plan of action to enhance the quality of the program. Further, the APERS-IT completed at the beginning of the process can yield useful information to assist with the selection of EBPs that address priority outcomes for individual children. Figure 25.1 shows the conceptualization of how program quality, use of evidence-based practices, and family participation contribute to the achievement of child and family outcomes.

Identifying and Scaling Priority Toddler Outcomes

In order to address the specific needs of the infant/toddler, the family and EI provider identify three priority needs/outcomes found on the IFSP. In order to proceed to scaling, each outcome is refined and restated, if necessary, in clearly observable and measurable terms. Collecting, recording, and analyzing data on the toddler's use of the skill or behavior described in the priority outcome determine the toddler's present level of performance. The data are used to establish a criterion for achievement of the target outcome statement. The outcomes are then scaled following a process called Psychometrically Equivalence Tested Goal Attainment Scaling (PET-GAS) (Ruble, McGrew, & Toland, 2012). A five-point scale is developed to quantify progress across the current level of performance, the desired outcome, and three benchmark steps (2 before outcome; 1 after outcome) for each selected outcome.

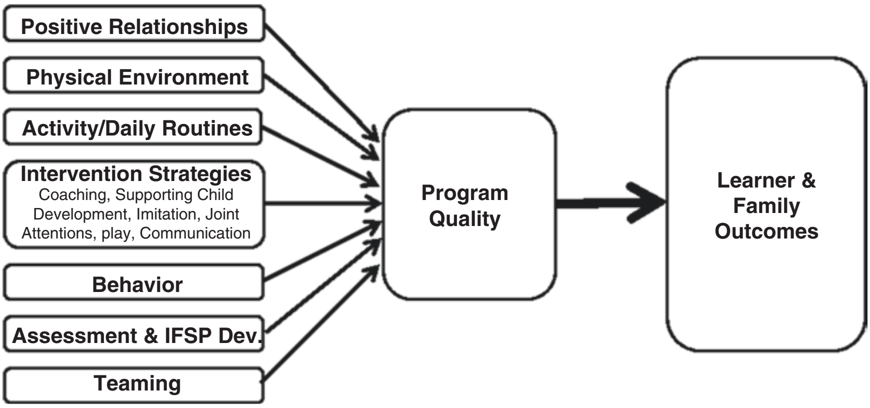

Fig. 25.1 APERS-IT program quality domains

The PET-GAS process is particularly useful to assist the family and interventionist as they monitor progress toward achieving the desired and stated outcome. Typically with infants and toddlers, a 6-month time frame is set for achievement of the outcome, although the time frame may vary depending on the unique needs of the toddler and the family. Aidens case study (Fig. 25.4) in the next section provides an example of outcome scaling.

Identifying and Selecting Evidence-Based Practice to Address Toddler and Family Outcomes

As discussed earlier, Wong et al. (2014) reported 27 EBPs that met criteria as evidence-based practices for children with ASD. Of these EBPs, nine included infants and toddlers as subjects and therefore were found to be effective with this population. These are described in Table 25.1 Evidence-based practices for infants and toddlers with ASD.

While these 9 practices should be considered first when linking EBPs with child outcomes, the other 18 identified EBPs specific to older children with ASD may also be considered in developing and implementing an early intervention plan with the family. The EI provider should be especially mindful that the use of these interventions be developmental appropriate for the young child (i.e., the child must be able to comprehend the meaning of a visual support) and should seek out resources specific to the implementation of each EBP with young children. For example, Hume, Wong, Plavnick, and Schultz (2014) are one resource for implementation of visual supports for young children. A list of the 27 identified EBPs and learning modules can be accessed through the Autism Focused Intervention Resources & Modules (AFIRM) website (AFIRM Team, 2015; http://afirm.fpg.unc.edu). Knowledge of these EBPs is critical for effectively linking toddler and family priorities with appropriate interventions. In the EBP selection process, the infant or toddler's family and EI providers consider the following: clues found in the outcome statement, toddler and family characteristics, practitioner characteristics, and the availability of other resources. Information obtained by considering these four parameters will provide a link between the desired priority outcome and the EBPs to include in the intervention to meet that outcome (Fig. 25.2).

Clues found in the outcome statement It is important for EI teams to discuss and agree upon the outcome of the targeted intervention. By answering "what is the outcome targeting?," the EI team, which includes the family, can begin to narrow the choices of EBPs to be considered. For example, the outcome "During family dinners, Joey will sit at the dining room table either eating preferred food or quietly playing with a preferred toy for at least 10 min for 2/3 dinners" provides cues to use reinforcers ("preferred").

Family and child characteristics Child and family characteristics should be considered when choosing the best EBP to include in an intervention. There are four areas to consider when identifying EBP for individual students, including (1) temperament, (2) interest and motivators, (3) history of what has and has not worked for the child, and (4) history of what has and has not worked for the family. It is important to assess family characteristics such as cultural values, comfort level of the parents in delivering intervention, and knowledge and availability of the family members.

Knowledge and interest of practitioners/team members Practitioners are encouraged to look at their own strengths and interests in the selection of EBPs. Practitioners identify what they are comfortable with and what training/coaching they will need. For example, technology-minded professionals may be interested in exploring the use of video modeling. While practitioners are encouraged to build on the strengths and interests of families, not every EBP will work for every learner. Further, the NPDC and ASD Toddler Initiative encourage

Table 25.1 Evidence-based practices for infants and toddlers with ASD

EBP	Description	Example
Antecedent-based interventions	Proactively arranging the environment, events, or materials to support reduction of interfering behavior	Alternating preferred and non-preferred activities during bedtime routine (e.g., bubbles, bath, read favorite book, lights out)
Functional behavior assessment	Systematic collection of information about a challenging behavior in order to analyze why the child is using the behavior in order to make a plan to reduce or replace the behavior	One step of FBA - parent and childcare provider keeping data on what happens before and after child bites herself
Modeling	Demonstrating the behavior or skill for child	Showing each step of hand washing routine before asking child to complete routine independently
Naturalistic interventions	Strategies such as antecedent-based interventions, prompting, and reinforcement applied in the child's and family's setting/activities/routines	When child motions hands to show mom he wants to be picked up mom prompts child to say "up." When child says "up," mom cheerfully raises child saying "up!"
Parent-implemented interventions	Parents deliver the intervention to increase the child's use of a skill/behavior or reduce a behavior	Early intervention shows family how to use reinforcement, family members implement with support from interventionist until they are able to deliver on their own
Pivotal response training	Use of motivation, responding to multiple cues, self-management, and self-initiatives in settings that build on learner interests	Child's interest in trains is used to practice specific communication and social skills
Prompting	Use by an adult of gesture, verbal, or physical prompts to assist child in learning a skill	While putting together a puzzle, dad points to the correct location for each piece 3 s after cuing son to start puzzle. If his son doesn't put the piece in within 3 s, dad holds his son's hand to help him place the piece
Reinforcement	Use of a child's preferred activity, object, or event to increase the child's desire to use a skill/behavior	During play with her daughter, mom blows bubbles immediately after her daughter says "more bubbles please"
Video modeling	Video recording and showing learner a model, of learner, other child, or adult, performing the behavior or skill	Dad videotapes on his smartphone an older sibling performing three simple playground activities safely. He shows his younger son the video when they arrive at the playground. He replays video if son uses equipment inappropriately

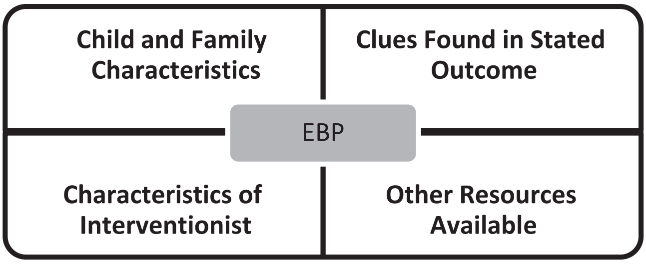

Fig. 25.2 Information used for EBP selection

practitioners to develop their skills in foundational EBPs. These are EBPs which are often integrated into implementation of other EBPs (e.g., prompting, reinforcement).

Availability of other resources Supplemental resources such as equipment, technical support (e.g., mom's cousin has app development expertise), people resources for training and coaching,

Child & Family Characteristics - 2 year old, nonverbal child with recent difficulty completing tasks, following directions, transitioning - Needs physical prompts - Loves videos/TV - Follows model well when reinforcing - Mom motivated to try new intervention and has collected data successfully on her phone	***Clues from Outcome*** - Motivation important to consider – use reinforcement - Tasks/toys need to be clearly defined and analyzed so that Aiden is clear when they end/when he's successful - Use video modeling to show task from start to finish
Characteristics of Interventionist - Good relationship with mom and Aiden - Has used video modeling successful in past - Per APERS-IT has strong family-centered philosophy	***Other Resources*** - Mom proficient with technology, has smartphone

Fig. 25.3 Four parameters to select EBP – Aiden

the degree of flexibility with schedules, and parent schedule and availability are all examples of resources that may influence the selection of evidence-based practices.

Figure 25.3 illustrates the type of information that EI teams gather and analyze in their selection of appropriate EBPs. The characteristics of child, family, and interventions, clues in outcome, and other resources listed are connected with Aiden's case study that is provided in the next section.

Evaluation and data-based decision-making The use of data to make intervention decisions is critical to the success of the implementation process. Data are used to establish a baseline, to understand a behavior, and to measure progress toward an outcome. Data also should be collected and analyzed on the EI provider and parent's fidelity of implementation of given EBPs. Implementation fidelity data are important to monitor to support coaching feedback and to make informed changes to implementation as needed. Without quality data, making adjustments becomes haphazard and ill-defined. Because of the necessity of data for effective implementation, a critical support feature of the ASD Toddler Initiative model is the support it provides in collecting data through (1) sample data sheets for many of the evidence-based practices, (2) means by which to easily graph data to facilitate interpretation, and (3) customized data collection measures that teams and parents can use to check on fidelity of implementation. Equally important is the professional development that is provided through training and coaching support, which is described in the next section (Fig. 25.4).

Making It Happen: Professional Development Process

The ASD Toddler Initiative model incorporates systematic and focused coaching and training processes to support EI provider and parent use of the APERS-IT profile, scaling of outcomes, and selection and implementation of EBPs described above.

Aiden, a 2 year old boy with ASD. Aiden is not verbal and often requires physical prompts (hand over hand) as support for completing tasks. Aiden enjoys watching TV, looking at videos on his mother's tablet, and jumping on the indoor trampoline.

Services: Aiden and his family have received EI home-based services for the past 6 months. The early interventionist visits the family weekly for 1-2 hours and has been focusing on task completion, following directions, and transition between activities and places.

Priority Outcome: Recently Aiden began refusing to complete tasks previously learned such as cleaning up after dinner, taking a bath, and picking up toys. Initially his mom and EI provider thought his refusals were typical 2-year-old behavior; however, the refusals persisted and have changed over the past month. Now Aiden becomes anxious over participating and completing tasks at home. He has difficulty finishing activities such as book reading, puzzles, meals, and "seems to get stuck" on tasks that had been mastered previously.

Aiden's mom and the early interventionist have tried a number of highly structured and systematic interventions to support Aiden in completing tasks (e.g., supports, prompting, and reinforcement). While these interventions have been helpful, Aiden continues to have difficulty staying engaged through to the completion of the task. Completing tasks is a priority for this mother.

After collecting data on how many steps of a known task Aiden was currently performing (0-50% depending on length of tasks; completion dropped after 3 steps) Aiden's mom and EI providers developed a measurable, observable outcome:

When doing a preferred tasks (must have a clear ending, such as putting on clothes, completing fish puzzle) Aiden will complete 100% of the steps of the toy or task (up to 6 steps) at least 2x a day for a week.

Scaling the Outcome: The EI providers and mom scaled the outcome.

Current Performance	Given 3 or less steps – completed 60-80% of steps 4 or more steps – completed 0-50% of steps
1st Benchmark	When doing a preferred task (must have a clear ending, such as putting on clothes, completing fish puzzle) Aiden will complete 100% of the toy or task (up to 2 steps) at least 2x a day for a week.
2nd Benchmark	When doing a preferred task (must have a clear ending, such as putting on clothes, completing fish puzzle) Aiden will complete 100% of the steps of the toy or task (up to 4 steps) at least 2x a day for a week.
6 Month Objective	**When doing a preferred task (must have a clear ending, such as putting on clothes, completing fish puzzle) Aiden will complete 100% of the steps of the toy or task (up to 6 steps) at least 2x a day for a week.**
More than Expected	When doing a non-preferred task (must have a clear ending) Aiden will complete 100% of the steps of the toy or task (up to 4 steps) at least 2x a day for a week.

Selecting EBP(s): Aiden's mom and EI providers choose EBPs based on the clues in outcome, resources available, and characteristics specific to Aiden, mom, and EI provider described in Figure X. Since Aiden is interested in watching TV and videos on the tablet and has demonstrated some copying and imitation behavior, the interventionist discussed the possibility of intervening by using video modeling to help Aiden achieve his outcome related to completing tasks. Also, since the priority is for Aiden to complete the task they decide to use a prompting strategy that would involve backward chaining. Mom would complete all the steps of the toy or task except last 2 steps (and then last 4, 6, or 8 as Aiden progresses) and use prompting until Aiden has completed the task or toy. Together, the EI provider and Aiden's mom identified toys and tasks that Aiden enjoys and used these as reinforcers when Aiden completes the remaining steps. The early interventionist worked with mom on creating videos of the provider completing preferred toys and tasks. Mom was not comfortable being recorded and no peers or siblings were available. The video was shown to Aiden using his mom's smartphone.

Fig. 25.4 Aidens case study

Training

Training provides EI providers and families with new information about ASD Toddler Initiative features and processes, EBPs, and resources available to support implementation. The primary training opportunity for EI providers is a 3-day training institute usually conducted prior to the APERS-IT. An additional day of training occurs prior to the 3-day institute to provide state autism coaches information on the coaching model and processes used throughout the implementation of the model, as well as their role throughout the 3-day institute. Content delivered during the 3-day institute includes as follows: ASD Characteristics and Current Research, Importance of Program Quality, Developing and Scaling Outcomes, and focus on three EBPs. These three EBPs include at least two foundational EBPs (e.g., prompting, reinforcement) and one other EBP chosen by the state contacts or committee supporting the implementation of the model in the state. Additional training is available throughout the implementation of the model as teams select EBPs to ensure that EI providers are able to assist parents in their own implementation to fidelity.

Coaching

Coaching in early intervention settings refers to the learning support provided by state autism coaches to early intervention providers as well as the learning support provided to parents by early intervention providers (Snyder et al., 2012). The NPDC coaching model and the adapted coaching model for early intervention settings are detailed in Kucharczyk et al. (2012). The coaching manual describes the steps involved in implementation of interventions with families and the coaching processes used at each step. The previously described program features (e.g., APERS-IT, outcome scaling, EBP selection and implementation) are integrated into the work of the early intervention provider as they support the family in their implementation of EBPs through coaching.

Program quality and coaching The APERS-IT provides the early intervention provider and team information on their use of coaching in their work with family members implementing EBPs. Early intervention providers use their APERS-IT profile to identify strengths and areas to develop in how they use coaching to inform family members, support family members in their implementation, use EBPs in interventions, and assess child progress through collection and analysis of data.

Selecting EBP, implementing EBP, and assessing progress EI providers are trained to use a cyclical process of pre-observation, action/observation, and post-observation, as illustrated in Fig. 25.4, to support parent implementation of EBPs. The ongoing coaching cycle provides the early intervention provider and team key contacts during which they systematically plan and negotiate support with the family. During planning and negotiation, the EI provider or team of providers and family prioritize needs and scale outcomes and select EBPs in the manner previously described. The coach's role during this part of the cycle is to provide the family with open-ended, reflective questions, which help the family to identify priorities, consider what successful outcomes would look like, and recognize their capacity and strengths relative to evidence-based practices. The early intervention provider shifts from the role of expert to one of facilitator by ensuring the decisions and know-how emerges from the family.

In the second part of the coaching cycle, the early intervention provider uses observation, mentoring, and feedback to ensure that parents are implementing EBPs to fidelity. As example, an early intervention provider working with a mother on using reinforcement and prompting simplified the fidelity checklist for each found on the ASD Toddler Initiative website (http://asdtoddler.fpg.unc.edu). Mom used the simple checklist as she observed the EI provider's use of reinforcement and prompting with her son. The provider coached the mom by asking questions (e.g., on fidelity, child reactions) about her observations. Then the provider watched mom as she implemented EBPs. She followed up by coaching mom through an evaluation of her own implementation with open-ended questions such as "what did you expect to happen?," "how might it have gone if you would have done the reinforcement differently?," and "what would need to be in place for you to be able to prompting and reinforcement the same way when I'm not here?."

This support of the parent's self-evaluation moves the early intervention provider into the third part of the coaching cycle – post-

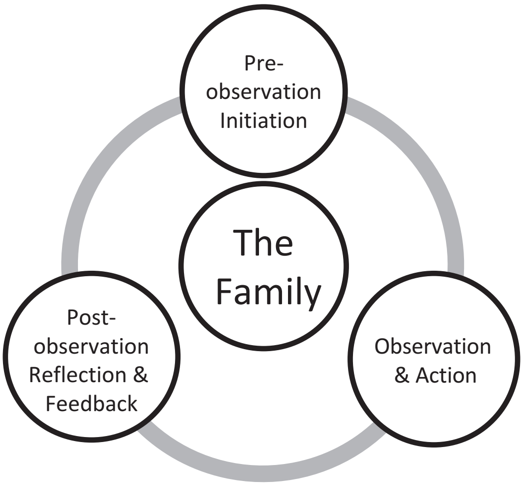

Fig. 25.5 The coaching cycle

observation. In this stage, the EI provider coaches the family in their self-reflection to provide them with the questions needed to assess future implementation of EBPs. An important component of this phase of coaching is the analysis of data gathered on the toddler's progress toward the outcome, as well as parent implementation of the selected EBPs. This third phase is often the beginning of the next pre-observation (i.e., the first phase of the next coaching cycle). Here the early intervention providers and family discuss and negotiate a plan for the next observation/action. Figure 25.4 depicts the coaching cycle emphasizing how the family is central for the process. Throughout the three phases, early intervention providers use the learning resources developed on the ASD Toddler Initiative website, described in the next section, in their work with families (Fig. 25.5).

Making It Happen: Learning Resources for Families and Practitioners

The ASD Toddler Initiative focused on developing a process and resources to assist early intervention providers in their use of evidence-based practices for infants and toddlers with ASD and their families. To support early intervention providers, the ASD Toddler Initiative Project created self-paced learning modules for the identified practices described previously (Cox, Kucharczyk, Shaw, & Odom, 2013). The modules are available for free on the ASD Toddler Initiative website: http://asdtoddler.fpg.unc.edu.

Framework

The toddler modules consist of five key components: (1) overview, (2) planning, (3) implementing, (4) monitoring progress, and (5) application resources (see Fig. 25.5). Designed to support adult learning, each module includes engaging practice scenarios that demonstrate application of the practice in both home- and center-based settings with multimedia content presentation including pictures and video clips.

Family members and early intervention providers will increase their knowledge and ability to apply the practice by accessing each of the five module components (see Fig. 25.5). The overview section provides background information about the evidence-based practice including a description of the practice, reasons for using the practice, settings to implement the practice, and the evidence base for the practice with infants and toddlers. The second component details how to plan for the practice providing steps an early intervention provider can follow to easily plan for the practice with infants and toddlers. The next component, implementing, details how to use the practice and involve family members with video examples. The monitoring progress component provides case examples of how to collect data and determine if progress is being made. Finally, application resources including a parent and practitioner guide, implementation checklists, data sheets, and coaching resources are available for free to print and use with infants and toddlers and their family members (Fig. 25.6).

How to Use Modules

The modules provide a free, self-paced, e-learning tool for early intervention providers and family members to increase their knowledge

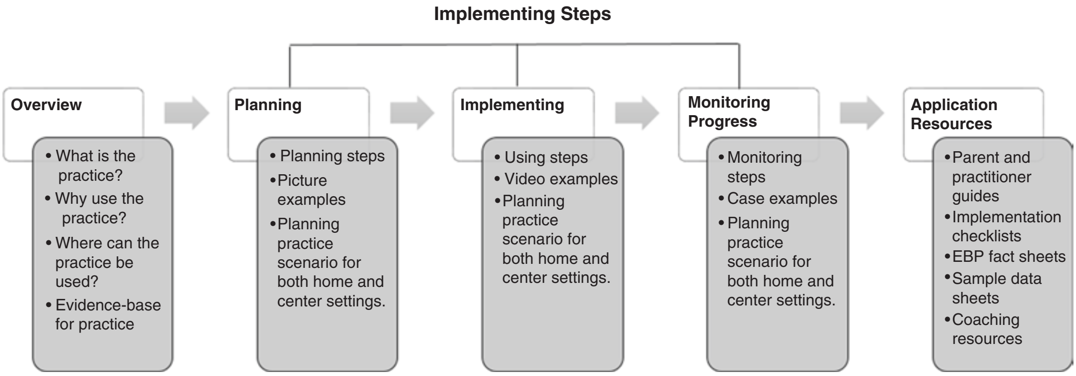

Fig. 25.6 Key components of toddler modules

of evidence-based practices for infants and toddlers. Early intervention providers share application resources such as the parent and practitioner guides or the home-based practice scenarios with family members for examples and real-world application ideas. Early intervention providers use the data sheets to monitor progress and the implementation checklists to make sure the practice is implemented with fidelity. The application resources provide families and early interventionists tools needed to address target skills and behaviors with fidelity. Figure 25.6 provides examples of how ASD Toddler Initiative tools might be used by early intervention providers with families (Fig. 25.7).

Qualitative Evaluation of Drivers for Successful Implementation

As described, the ASD Toddler Initiative model is an adaptation of the National Professional Development Center on ASD's model for supporting states and school programs (Franzone et al., 2012) in the development of high-quality programs and effective implementation of evidence-based practices for children with youth with ASD. To date, the adapted model for early intervention has been piloted and implemented across three states and ten early intervention teams or programs. Based on this work, facilitators and challenges to the effective implementation of the ASD Toddler Initiative model have been noted systematically. Understanding structures and systems which support or facilitate implementation and those that pose barriers or challenges assists model developers, states, and early intervention programs in addressing the key components to successful implementation and sustained change. Fixsen et al. (2013) labeled these key components *implementation drivers* and included competency, organization, and leadership as the integrated infrastructure features common to programs with successful implementation. The following section describes these drivers of implementation analyzed across two of the states implementing ASD Toddler Initiative at three levels: state, agency/program, and practitioner. The section concludes with supports and challenges experienced by families of toddlers and infants in their implementation of EBPs.

State-Level Implementation

Two states, one in the northeast and one in the southeast of the USA, participated in the in-depth piloting of the model processes and resources. Each state's experience of implementation of the model was analyzed in order to systematically consider and make revisions to model resources and processes. State-level implementation drivers of competency, leadership, and organization are described next.

Competency Competency drivers are mechanisms (e.g., coaching, training) through which the state

Parker's Family – Parent and Practitioner Guide & Tips for Implementing:

Linda recently began working with Parker and his family. Parker's mom, Julie, struggles with getting Parker ready in the morning. Parker screams and kicks his legs when his mom tries to dress him. He also refuses to open his mouth to have his teeth brushed. Julie talked with Linda about these concerns and has asked for help. After reviewing the evidence-based practices and thinking about the needs of the family, Linda decides reinforcement could be used to address these issues. Linda brings a copy of the Reinforcement Parent and Practitioner Guide to the next session to review with the family. She reviews with Julie what reinforcement is and the steps for implementing the practice. Linda and Julie work together to identify potential reinforcers for Parker. They develop a plan for Julie to try the next few days to see if she has more success. Linda reminds Julie to use the Tips for Implementing Reinforcement Checklist to make sure she follows each step.

Daniel's Family – Practice Scenarios:

Daniel is working on the target skill of requesting. His early intervention provider, Maria, wants to try video modeling with Daniel, because he enjoys watching shows and has an interest in iPads. After Maria explains video modeling to Daniel's parents, they are excited to try using it with him. Before Daniel's next session, Maria asks Daniel's parents to review the Video Modeling Practice Scenario for the home-based setting. By reviewing the Practice Scenario in advance, the family is primed to see Maria demonstrate the practice and can have questions prepared to ask Maria.

Marcus' Family – Parent and Practitioner Guide & Implementation Checklist:

Susan wants Marcus's family to begin using prompting. She discusses with the parents the key components of prompting and gives them the Prompting Parent and Practitioner Guide to review before Marcus's next session. At the next session, Susan models prompting and explains how the family can use prompting within their daily routines. After reviewing the guide, Marcus's mom has several questions for Susan. Susan and the parents discuss these issues together and develop a plan for the family to begin using. They use the Implementation Checklist for Least to Most Prompting as they develop their plan for implementation. At the next session, Marcus's parents check off the Implementation Checklist as they watch Susan model. Susan, in turn, uses the implementation checklist to help Marcus's family identify their successful use of the EBP as well as challenges to work through.

Fig. 25.7 Examples of the use of ASD Toddler Initiative Resources

system develops the abilities of professionals and parents to implement evidence-based practices and the processes of the ASD Toddler Initiative model. In the states that piloted the implementation of the ASD Toddler Initiative model, competency drivers were facilitated by a culture of learning. Both states had a system of professional development, which was accessed for the introduction of the model. Technical assistance providers, such as lead early intervention providers and agency-level administrators, were identified and employed to support the implementation of the model as coaches. Having previously articulated the roles and responsibilities supported the fast uptake of model by the state. Additionally, one state had a specific focus on identifying and addressing gaps in their provision of services to children with ASD (e.g., early identification, linking between physicians and early intervention) which further supported model buy-in across the state. Capacity for sustainability of implementation was facilitated by a common vision to develop competency across these lead ASD professionals.

Organization States employed organization drivers to create and maintain an environment supportive of implementation of the model. One organization driver greatly facilitating implementation was a webbed system of interconnectedness between early intervention programs across the state and various state and city agencies responsible for supporting children with ASD and their families (e.g., diagnostic centers, family support groups). Interconnectedness between agencies allowed for knowledge of effective implementation practices to be shared across agencies. Additionally, interconnectedness supported identification of barriers at the state level which otherwise might have remained unsolved if the root of the issue was not clear (e.g., state mandated service forms which dis-incentivized teaming and coaching of parents). States using the ASD Toddler Initiative model facilitated implementation when there was clarity around how agencies and individuals could be creative in their use of the state organization to effectively support parent implementation of EBP. One state, once alerted to the disincentive for teaming set up by the funding system, clarified the system so that interventions could be paid for teaming in addition to the time spent at the 6-month IFSP meeting, as long as the parent was present during the teaming meeting. This change doubled the amount of teaming opportunities interventionists had previously.

Leadership The leadership driver enables technical and adaptive strategies (Fixsen et al., 2013) needed in an environment of change such as effective problem-solving systems, provision of guidance and support, and organization. One state leadership system supportive of the change process of the ASD Toddler Initiative model provided avenues for identification of challenges as they arose throughout implementation, a mechanism for problem-solving, a commitment to address these challenges, and finally mechanisms to broadly communicate how challenges were addressed. Implementation of the ASD Toddler model was greatly facilitated in states that clearly communicated a commitment to effective ASD identification, use of evidence-based practices, and support for capacity building in agencies, professionals, and families and, importantly, aligned such communication with expectations and documentation systems.

Agency-Level Implementation

Agency-level facilitators and challenges to implementation were analyzed across the early intervention programs and groups of providers implementing the ASD Toddler Initiative model and were often influenced by state-level drivers previously raised. Other facilitators and challenges were solely attributed to the culture and practices of individual agencies or groups of interventionists. The agency level is far more varied across states and within states. One state has an agency model that hires groups of early interventionists who are deployed to directly work with families. The other state has a state agency and regional offices, which identify and hire individually contracted interventionists to work with families. Some states have a blend of these two structures. Descriptions of the various forms of early intervention across states can be found in the IDEA Infant and Toddler Coordinators Association report (2014). *Agency* here refers to the system that identifies and connects families with early intervention providers. As with the state level, the agency-level experiences of implementation are organized based on implementation drivers.

Competency Agencies facilitate competency building in interventionists and families when they communicate and enact a culture of learning. Such a culture requires clear communication of expectations, support for knowledge development, and systems for dissemination of knowledge across stakeholders. For example, one agency, through various learning activities, highlighted a commitment to parent implementation of EBP with provider coaching. One activity was a monthly journal article review during which each team of interventionists chose a journal article related to an evidence-based practice for review. Each month one team member was responsible for facilitating a critique of the article and discussion of application of its findings in their work. This same agency made a change in their focus for supervision. Supervision became less about ensuring compliance with agency and state regulations and more about providing and modeling coaching for interventionists. Ensuring compliance remained an important component of meetings and periodic check-ins, while more time was afforded to supervisors observing home visits, either in person or on video, and providing coaching support to interventionists as they in turn coached families.

Agencies that struggled with sustaining competence were those that identified and relied on a talented individual to hold knowledge on an area of expertise without mechanisms for that individual to support others in developing their own applied expertise. Such agencies also found it difficult to communicate with the families their commitment to releasing interventionists from the primary expert role and sharing that role with families as they implemented EBPs. A facilitator to this shift in practice was evidenced in one agency that recognized a need to communicate a change in expectation by including in their welcome letter to new parents a statement about parent participation in implementation of EBPs. The letter included a clear, family-friendly rationale for the importance of parent implementation of EBP and reassurance that interventionists were well prepared to coach families through this process. Finally, agencies facilitate parent implementation of EBP when professional development time is protected for focus on parent implementation of EBPs. These agencies have clear guidelines about the topics and processes that align well with this focus and protect their interventionists' time and resources.

Organization Agency-level organizational structures and systems provide commitment to support parent implementation of EBP when there is alignment between that expressed value and direct avenues for enacting that value. Time for teaming across interventions was a critical driver to support implementation of the ASD Toddler Initiative model. As discussed earlier, the ability for teams, including parents, to meet and identify priorities, scale goals, select EBPs, make a plan for implementing EBPs, and measure progress is critical to the effectiveness of the process. Teaming can be challenging in systems, which do not have the organizational structures and funding capacities to allow for time for people to come together. Some agencies implementing the ASD Toddler model had to creatively develop such systems. Examples included overlapping visits thus allowing for team members to connect with families together, use of technology (such as Skype, Google Hangout) to connect between visits online, and brief weekly conference calls to check in on how each interventionist was supporting the family in their implementation and troubleshooting.

Leadership Implementation of the ASD Toddler Initiative model was facilitated when agency leaders clearly communicated their expectations to interventionists and parents. Beyond communication, agency leaders were supportive of change when they identified interventionists who were not onboard with the shift in role from interventionist to parent as primary implementer and considered their concerns. These concerns were often related to a family with specific challenges and needs, a comfort with a long developed and reinforced way of working with families, or a lack of understanding of the value of the parent as primary provider. Not considering these concerns, especially from particularly vocal members of the team, undermined the implementation of the model. Addressing concerns led to an identification of barriers (e.g., not enough time to team, lack of understanding, fear of coaching parents with their own challenges) which when addressed led to more effective implementation.

Interventionist and Family-Level Implementation

Facilitators and challenges to implementation at the level of interventionists and families interact and often are triggers for the drivers discussed at the level of the state and agency. For example, interventionists holding to the role of expert and direct clinician will need guidance and support from their agency and state on how to shift toward a coaching role with family. This interaction exposes gaps in the system in need of attention by interventionists, agencies, states, researchers, policy-makers, and so on.

Interventionist For some interventionists, parent implementation of EBPs requires a shift in their work that can be disorienting. One shift requires leaving their bag of tools (e.g., toys, intervention materials) in favor of using the resources available in the home in the coaching to the family. Another shift is moving from the role of "expert" to one of "facilitator" through their coaching. A number of interventionists brought up that they were taught in their studies and professional learning how to work with young children, not adults. A valid point that speaks to the needs of states and agencies to develop and support professional development discussed earlier with a focus on this gap in knowledge. Further, both of these shifts require an orientation of openness to professional development. Interventionists ready to learn as team members can greatly facilitate the effective implementation of EBP by families through coaching which inherently requires a provider to come with open questions rather than answers (Kucharczyk et al., 2012).

Family Family-specific facilitators and challenges are important for interventionists and agencies to consider and be prepared to address as they arise so that families are able to build up progress and momentum. Siller et al. (2014) outlined many of the challenges faced by families involved in the implementation of parent-mediated interventions undergoing research. These include individual needs for information and support, questions around diagnosis and development, and contextual challenges related to time, resources, and complex family systems. Specific to the implementation of EBP through the ASD Toddler Initiative, some families expressed feeling burdened by the pressure and fear of not having an expert to rely on. In these situations, interventionists supported families by providing them all the resources they need as they need them while maintaining their role as coach. Early interventionists provided support by relying on modeling and incrementally through negotiation and coaching relinquishing implementation to the parent. Helping parents identify their own interests and strengths can support families worried about their own capacity to implement EBP. One family, who showed expertise and comfort with technology, was encouraged to use their iPad to implement EBP and to augment their twin sons' communication. Some families expressed concern with their capacity to collect data on their child's progress. In order to support families in data collection, interventionists must be well versed in understanding why data is critical to evaluating progress and in exploring with families data collection processes which can be easily integrated into their already occurring routines and family tasks (e.g., keeping a tally on a smartphone, sending videos to interventionist, moving rubber bands from one hand to another to count occurrences of a behavior).

Supports for and challenges to parent implementation of EBPs lie at each of the levels of the system including the State, early intervention agencies, individual interventionists, and families. This section explored the implementation experiences across these systems in the application of the ASD Toddler Initiative across two states. These states provide interesting case studies in that they differ on many factors such as size, geographic location, population characteristics, structure of the early intervention system, and so on. These differences provide opportunities to explore the variety of implementation facilitators and challenges and to highlight those that arise in both settings regardless of these differences. The congruence and convergence of experiences across levels provide professionals, administrators, agencies, and state policy-makers with a framework for supporting effective implementation of EBPs by parents of young children with ASD.

Conclusion

An early intervention workgroup (2008), convened by an OSEP early childhood technical assistance center, outlined a list of key principles and practices for early intervention providers. These include supporting infants, toddlers, and their families in their own context based on their own priorities with interventions that are evidence-based. With the capacity to diagnose autism spectrum disorder at younger ages, it is imperative that early intervention systems and providers have the tools and know-how to support parents in the implementation of evidence-based practices identified for infants and toddlers with ASD. This chapter described the ASD Toddler Initiative model, a model for provision of professional development to early intervention programs and providers in support of their effective coaching of parents. Training and coaching of both families and providers are integrated into the ASD Toddler Initiative core features of program quality, identification and scaling of priority outcomes, and selection of EBPs for implementation by parents. With a grounding in implementation science, the ASD Toddler Initiative model provides the content, processes, and resources to support intervention providers, agencies, and state programs as they meet the growing needs of families with young children with autism spectrum disorder.

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Designing for Dissemination: The Utility of the Deployment-Focused Model of Intervention Development and Testing for Parent-Mediated Intervention

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Abstract

There are many identified barriers to the dissemination and implementation of evidence-based care for individuals with autism spectrum disorder (ASD). Modifications to the way in which interventions are developed, studied, and implemented are necessary to facilitate fit between interventions and the community settings in which they will ultimately be delivered. Throughout this chapter, we will describe how the deployment-focused model of intervention development can be used in the development and evaluation of parent-mediated interventions for children with ASD to increase the likelihood of dissemination and implementation to ultimate practice settings. We will use our own experience with the development and evaluation of Project ImPACT (Improving Parents as Communication Teachers), a parent-mediated social communication intervention for young children with ASD, to illustrate a number of key points in the model. We will also address how other key concepts from the field of dissemination and implementation can be applied to the intervention development process, with the goal of facilitating treatment uptake and implementation.

Autism spectrum disorder (ASD) is a lifelong developmental disorder characterized by chronic and pervasive deficits in social communication abilities and the presence of restricted and repetitive behaviors that are apparent early in development (American Psychiatric Association, 2013). Recent epidemiological reports estimate that the prevalence of an ASD diagnosis is 1 in 68 (Baio, 2014). Although the prevalence of the disorder has increased, there has not been a parallel growth in the dissemination and implementation of effective interventions, contributing to high levels of unmet needs for individuals with ASD and their families (Kogan et al., 2008; Sperry, Whaley, Shaw, & Brame, 1999; Stahmer & Gist, 2001; Symon, 2005). An expansion in the availability of, and access to, appropriate and effective intervention is essential.

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_26

One approach to increasing access to intervention has centered on systematic attempts to train parents in evidence-based intervention techniques. The importance of the close involvement of parents in education and intervention for children with ASD has been widely acknowledged (e.g., Wilczynski et al., 2009; National Research Council, 2001), and the evidence base for the efficacy and effectiveness of ASD parent training, or parent-mediated intervention, either as a stand-alone intervention or as a component of a more comprehensive intervention program, is growing (e.g., Oono, Honey, & McConachie, 2013). Indeed, the last decade has seen the development and evaluation of a number of promising parent-mediated interventions for toddlers and young children with ASD (e.g., Siller et al., 2014), many of which are described in this book.

There is evidence to suggest that parents and community providers value parent-mediated intervention approaches. For example, in an Indiana survey of families' use of ASD interventions, parents rated parent training as the intervention which contributed most to their child's growth (Hume, Bellini, & Pratt, 2005), and parents of children receiving early intervention services rated parent training as their number one family service priority (Mahoney & Filer, 1996). Similarly, early intervention providers reported the inclusion of parent training as a desirable change to the existing service delivery systems (Campbell & Halbert, 2002), while other community providers have indicated that parent-mediated interventions have the potential to be well-integrated into existing services and systems if they include adequate training and fit with the values of the providers and organizations (Stahmer & Aarons, 2009).

Despite positive views of parent-mediated intervention held by parents and providers, formal parent-mediated intervention programs are highly underutilized in community settings. For example, in the same Indiana survey, parent training ranked 15 out of 19 possible interventions in terms of rate of use, and only 21% of families with a child with autism ages 2–8 years reported ever having received it (Hume et al., 2005). The underutilization of parent-mediated intervention for younger children is even more striking; in a North Carolina survey, only 8% of parents of children with ASD aged 4 and under reported receiving parent training (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Underutilization of parent-mediated intervention may also be influenced by socioeconomic status (SES). For example, in a recent mixed methods study, parents from lower SES backgrounds were more likely to identify parent training as an unmet service need than families from higher SES backgrounds (Pickard & Ingersoll, 2015).

There is also evidence to suggest that community-based ASD intervention providers typically do not utilize evidence-based parent-mediated intervention packages, and those who do may only implement pieces of the program and/or fail to implement the intervention in the intended way (e.g., Stahmer, 2007; Stahmer, Collings, & Palinkas, 2005). For example, although early intervention providers who worked with children with ASD indicated a high rate of family involvement in services, only 25% reported offering formal parent training (Stahmer, 2007).

Research has identified several family-, provider-, and organizational-level barriers that may impede the successful dissemination and implementation of evidence-based interventions, including parent-mediated interventions for ASD. First, many parent-mediated interventions were developed by placing traditional therapist-delivered interventions into a parent-mediated delivery model (e.g., parents use the same strategies, within the same kinds of interactions, targeting the same goals as a therapist would). However, this approach fails to fully consider the unique context of families of young children with ASD. As such, a misalignment between the values, needs, and daily lives of the family and traditional parent-mediated intervention approaches may contribute to a lack of implementation of such programs within community settings. Additionally, practical barriers to program access can prevent parents' participation in such programs. For example, the structure and extensive time commitments of some parent-mediated intervention models can make it hard for parents with limited flexibility to participate (e.g., Patterson & Smith, 2011).

Providers' attitudes regarding the role of parents in their child's intervention services may also hinder the dissemination and implementation of such programs (Mahoney et al., 1999). Although many providers indicate positive views about parent-mediated interventions for ASD, there have been a number of criticisms of parent-mediated intervention in general, including the burden it imposes on parents (Rosenberg & Robinson, 1988), implicit blaming of parents (Turnbull & Turnbull, 1990), and role conflict for parents (Hanson & Hanline, 1990; Vincent & Beckett, 1993). Historically, there was concern that parent-mediated approaches did not allow for parents as equal and active partners, but rather tended to be professionally driven and based on the idea that parental behavior contributed to child challenges (implying that parental deficiencies cause developmental challenges), and therefore were incompatible with a family-centered approach to care (Mahoney et al., 1999). Such attitudes may negatively affect providers' willingness to use parent-mediated intervention with families (Mahoney et al., 1999). Additionally, providers' experience (or lack thereof) in training parents may also serve as a barrier (Mahoney et al., 1999; McCollum, 1999). For example, pre-service training is focused on preparing providers to work directly with children; yet knowledge of intervention strategies and knowledge of adult learning principles and effective teaching strategies for conveying information about the intervention strategies to parents are necessary foundations for parent-mediated intervention models (Hester, Kaiser, Alpert, & Whiteman, 1996; Mahoney et al., 1999). Additionally, it has been suggested that a lack of proactive facilitation strategies, such as accessible trainer and parent manuals and data monitoring and collection strategies, can make the successful dissemination and implementation of ASD parent-mediated interventions difficult (Carroll et al., 2007; Fagan, Hanson, Hawkins, & Arthur, 2008).

Another major barrier can be the lack of fit between the structure of the parent-mediated intervention program and the structure of existing service delivery models (Hoagwood, Bums, Kiser, Ringeisen, & Schoenwald, 2001). For example, the majority of evidence-based parent-mediated interventions involve a parent and child meeting individually with a therapist once or twice per week over several months, with some programs lasting longer than 12 months (Beaudoin, Sebire, & Gouture, 2014). This type of service delivery may be consistent with home-based early intervention models; however, most intervention programs for children with ASD over the age of three are provided in classroom settings (Bitterman, Daley, Misra, Carlson, & Markowtiz, 2008), where the provision of weekly individual parent training sessions may not be a feasible or sustainable option. Further, in-service provider training models for evidence-based practices, including parent-mediated interventions, are often time intensive and expensive and thus incompatible with the organizational training structures of many community programs (Fairburn & Cooper, 2011).

One approach to surmounting these barriers is to alter current community practices, across various dimensions, to better support the structure of existing parent-mediated interventions (Hoagwood et al., 2001). At the upper most policy level, national and statewide practice guidelines can provide organizations and practitioners with information about best practices and evidence-based interventions. A number of national technical review panels and working groups have identified parent training in evidence-based intervention strategies as best practice in autism intervention (National Research Council, 2001; Maglione, Gans, Das, Timbie, & Kasari, 2012; Wilczynski et al., 2009; Wong et al., 2015; Zwaigenbaum et al., 2015). Despite the intuitive appeal of the use of such strategies, evidence suggests that even with explicit guidelines and protocols, clinicians may struggle to apply new recommendations to practice, and therefore these guidelines have only moderate effects on altering clinician behaviors (Cabana et al., 1999; Waddell, 2001). Intervention developers can also serve to encourage the modification of current community practices by supporting the active dissemination of their parent-mediated intervention programs. This includes pushing out an intervention out to the community by holding seminars and workshops (academic detailing), using opinion leaders, and working with service settings via implementation auditing and feedback (Waddell, 2001). Reviews of the literature suggest that the use of active dissemination strategies alone, much like the use of practice guidelines, has weak to moderate effects on clinician behavior change (Davis & Taylor-Vaisey, 1997). Making explicit changes to existing service delivery models has been identified as another way to overcome barriers associated with implementation of evidence-based interventions (Mancini et al., 2009) and may support better short-term intervention implementation and longer-term program sustainability (Elliott & Mihalic, 2004). However, altering the structure of an organization is rarely sufficient for sustainable implementation and is often a lengthy and resource-intensive process, and the extent to which such changes are possible varies significantly across organizations and practice settings (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005).

Thus, simply altering community practices is not sufficient to ensure successful dissemination and implementation of parent-mediated ASD interventions. Modifications to the way in which parent-mediated interventions are developed, studied, and implemented may also be necessary to facilitate fit between interventions and the community settings in which they will ultimately be delivered (Hoagwood et al., 2001). The traditional model of intervention development advocates a sequential process starting with small-scale efficacy studies to refine techniques, manualization of the intervention, full-scale efficacy studies using randomized clinical trials, and finally effectiveness studies in community settings (e.g., Smith et al., 2007). While this research strategy has resulted in efficacious interventions for other disorders (e.g., *Multisystemic Treatment for Antisocial Behavior in Children and Adolescents*, Henggeler et al., 2009), this process has contributed to a lag of up to 20 years between the development of evidence-based interventions and their integration into routine practice (Walker, 2004), at which point the interventions may no longer look like or achieve the same outcomes as those studied in university-based research settings (Schoenwald & Hoagwood, 2001). As Weisz and colleagues suggest, "differences between efficacy trial (or lab) conditions and clinic conditions may be too substantial to be bridged as simply the final stage at the end of a long series of efficacy experiments" (Weisz, Chu, & Polo, 2004, pg. 304).

Given the limitations associated with the traditional sequential or stage model of intervention development and evaluation, several modified approaches have been proposed, all of which involve some degree of collaboration between the intervention developers and key stakeholders to whom the intervention program is ultimately targeted (e.g., Dingfelder & Mandell, 2011). One such model, the deployment-focused model (DFM) of intervention development and testing, articulates six steps that intervention developers can follow to create practice-ready interventions, each of which involves an awareness of and collaboration with key stakeholders (Weisz et al., 2004). These steps include (1) development, refinement, pilot testing, and manualization of the intervention; (2) initial efficacy trials with clinically referred populations; (3) single-case design pilot tests to explore the extent to which a program can be modified to increase contextual fit, without compromising the core principles and mechanisms of change of the intervention; (4) partial effectiveness studies in the context of "representative clinical care;" (5) clinical trials in real-world settings; and (6) studies examining the relationship between the intervention and the practice context in which it is utilized (Weisz et al., 2004).

Given that the DFM is focused on producing effective practice-ready interventions, it appears ideally suited, with some modifications, for application to the development of parent-mediated interventions for children with ASD. Throughout the rest of this chapter, we will describe how this model can be used in the development and evaluation of parent-mediated interventions for children with ASD to increase the likelihood of dissemination and implementation to ultimate practice settings. Although, like Weisz et al., we will describe this model in terms of steps, unlike the traditional stage model (Smith et al., 2007), the steps should not be considered to be unidirectional. Rather, important work in different steps of the model can (and should) be occurring concurrently. We will use our own experience with the development and evaluation of Project ImPACT, a parent-mediated social communication intervention for young children with ASD, to illustrate a number of key points in the model. We will also address how other key concepts from the field of dissemination and implementation can be applied to the intervention development process, with the goal of facilitating treatment uptake and implementation.

Step 1. Development, Refinement, Pilot Testing, and Manualization of the Treatment Protocol Drawing from Theory and Evidence on the Nature and Treatment of the Target Condition with Input from Providers, Parents, and Administrator

Treatments that are developed using the traditional approach often do not account for provider-level barriers that are typically encountered in practice settings (Weisz, Jensen, & McLeod, 2005). Thus, the DFM emphasizes using input from experienced providers, alongside theory and research, to guide development of the treatment components and plan clinically sensitive ways of presenting those components in a manual (Weisz et al., 2005). We expanded this step to include input from parents and administrators, as well as providers, because barriers to implementation of parent-mediated interventions can occur at the family, provider, and organizational level, and each stakeholder group offers important and often unique information in this regard.

Parent-mediated interventions are, by definition, multilevel; they involve the transfer of an intervention from the provider to the parent and the parent to the child. Thus, it was necessary to develop a treatment protocol at the level of the child (intervention) and the level of the parent (coaching model). In addition, although provider training protocols are not typically developed until the implementation stage (Fixsen et al., 2005), we felt that it was vitally important to develop and pilot a provider training model early in the treatment development process, given that insufficient provider preparation is a major barrier to the use of evidence-based ASD interventions, including parent-mediated intervention (Stahmer et al., 2005).

Treatments that are compatible with stakeholder values, experiences, and needs, easy to use, and include all necessary materials and clear procedural guidelines are more easily adopted (Boardman, Arguelles, Vaughn, Hughes, & Klingner, 2005; Dingfelder & Mandell, 2011; Rogers, 2003). In addition, quality technical supports are key to effective implementation of evidence-based practices (Fixsen et al., 2005). Thus, we worked closely with each stakeholder group to ensure that the relevant components of the program were compatible and simple to use and that program contained all needed materials and user-friendly technical supports.

Naturalistic interventions are generally more acceptable to parents than structured interventions because they are more compatible with typical parent-child interaction styles and can be easily incorporated into ongoing family routines (Vismara & Rogers, 2010); thus, we began by identifying common elements of existing evidence-based naturalistic interventions (e.g., Kaiser, Yoder, & Keetz, 1992, Mahoney, 2004a, 2004b). Parent input helped us ensure that the final set of techniques was compatible and simple to use and that their sequence of instruction enabled parents to meet fidelity of implementation by the end of the program. In addition, parent input helped us choose simple and jargon-free language to describe the techniques and user-friendly materials to support parent learning (e.g., parent manual, video examples).

Provider input allowed us to better align our coaching model with a family-centered approach to care. It also helped to more fully develop the intervention's theoretical framework to ensure that it was compatible with various intervention philosophies (Stewart, Stirman, & Chambless, 2012). For example, naturalistic intervention techniques are used in both developmental and ABA intervention models (Ingersoll, 2010). Thus, we chose to incorporate elements of both of these intervention philosophies into the theoretical framework guiding Project ImPACT, so that providers from different theoretical orientations could "see" the intervention philosophy that they subscribed to reflect in the program. This was done in a thoughtful, systematic way, with a goal toward enhancing the intervention's effectiveness as well as its acceptability to stakeholders with a range of theoretical backgrounds (Stewart et al., 2012).

Provider input also helped us identify providers' informational needs and technical supports that could assist providers in their delivery of the coaching model. This input resulted in the development of a provider manual with detailed instruction in adult learning principles, a written description of the structure and content of each session, PowerPoint presentations with notes, video examples and guide, homework sheets, checklists, simple fidelity measures, and troubleshooting tips.

Input from administrators was particularly helpful for ensuring that the structure of the program (e.g., frequency, length, location) was compatible with the structures of a range of service delivery models and that the program could be implemented successfully. While providers are often aware of system-level barriers, administrators frequently have a better perspective on whether the structural constraints of the delivery system are mutable or not and are typically the ultimate decision-makers when it comes to program adoption (Rohrbach, Ringwalt, Ennett, & Vincus, 2005). Thus, we worked with both community providers and administrators to identify a program structure that was most compatible with the range of community programs serving young children with ASD. We found that two structures were required (group and individual) to fit the range of service settings. We also discovered that these two structures would not be sufficient for all community intervention programs. Thus, we had to consider those elements that were fundamental to the program and those that were not, as a way to guide community organizations in making additional modifications in a theoretically driven way (Fixsen et al., 2005). Similarly, we used input from providers and administrators to develop a provider training model that fit with existing organizational training structures and allowed for the ability of community organizations to build capacity over time (Stahmer, Brookman-Frazee, Lee, Searcy, & Reed, 2011).

The final piece of this step is to pilot test the intervention. At the time we were developing the original parent training model, we (Ingersoll and Dvorcsak, 2010) were working in a practice setting. Thus, we were able to pilot test the final individual parent training model within the clinic in which we worked using an informal process, first by implementing it ourselves with several families and then by training other clinicians to implement it with their clients.

We used a more formal process to obtain feedback on the development of the group parent training model. We partnered with teachers and administrators of several early childhood special education (ECSE) classrooms for children with ASD. These classrooms served as model demonstration sites as part of a State-funded quality improvement initiative and were similar in terms of their classroom make-up (composition of students, class size, number of teaching staff), curriculum (e.g., ABA-based STARS curriculum), and service delivery model (e.g., hours of student attendance, teacher compensation). The teachers and administrators at these sites provided invaluable guidance and feedback on the Project ImPACT model and served as sites for the initial pilot evaluation (Ingersoll & Dvortcsak, 2006).

Results from the pilot study indicated that parents increased their knowledge of the intervention techniques. Furthermore, both parents and teachers indicated positive views of the intervention. Importantly, although parents reported that they felt as though their children's social communication skills improved as a result of the program, they felt less strongly that they understood what skills their child was working on and why and how to address goals during every day activities. Thus, we were able to return to our protocol and make adjustments to add in additional parent psychoeducation related to social communication skills and why they are important. We also included additional suggestions and activities related to using the intervention strategies within every day routines. Teachers felt that the program was effective and manageable (in terms of time commitment and incorporating with current services), although they expressed a desire for additional parent coaching opportunities as they felt as though it had the biggest effect of parent behavior. Thus, three additional parent coaching sessions were added to the Project ImPACT protocol for a total of six hands-on coaching sessions in the group format.

Step 2 (Modified DFM). Feasibility Testing in New Settings that Differ from the Settings in Which the Program Was Developed

Unless the goal is to work exclusively within a single community or setting, it is important to examine the feasibility of the intervention within new community settings with individuals who were not involved in the program's early development and, thus, not personally invested its success. This step can identify additional barriers associated with different service delivery systems, settings, providers, and families. Our initial pilot of the group training model was conducted in model demonstration classrooms that were selected due to the teachers' high level of training and motivation. Thus, we wanted to make sure that our model was feasible for use in additional classrooms, which have different structures, by teachers who were more diverse with respect to training and motivation. We also felt that it was important to pilot our provider training protocol, since we had been the parent trainers for the initial pilot (Ingersoll & Dvorcsak, 2006).

To do this, we conducted a feasibility trial of the group parent training format with three new school districts using the fully developed Project ImPACT provider and parent materials (Ingersoll & Wainer, 2013a). We approached administrators at five diverse school districts, of which three agreed to participate. These administrators identified 13 educators across the districts who served young children with ASD to participate. These educators then recruited families of children on their caseload; a total of 28 families agreed to participate in data collection, although 2 discontinued before the program began due to scheduling conflicts.

There were several key differences in the structures of the programs in the feasibility study relative to those in the initial pilot study. First, while the majority of the children had an ASD eligibility, 25% of the children were being served under another disability category (early childhood developmental delay, speech-language impairment, other health impaired), and most classrooms were mixed-disability as opposed to ASD only. Second, there was substantially greater variation in the service delivery models used (classroom-based, toddler group, home-visiting model), with a wide range of hours of instruction, ranging from 1 to 28 h per week. Finally, the participating educators used a variety of curricula and had substantially less expertise in ABA.

We examined parent participation and the acceptability of the program to parents and providers as our primary outcome measures. As secondary measures, we examined changes in parent fidelity of implementation of the intervention and parenting stress and child social communication skills. Results indicated that 89% of families completed the program and that both parents and teachers found the group format of Project ImPACT to be acceptable, useable, and effective. Additionally, parents who improved in their use of the intervention strategies reported decreases in parenting stress, and their children demonstrated gains in social communication skills via observational coding of a parent-child interaction and parent/teacher reports.

Our pilot data suggested that the final program, including the intervention, parent coaching model, and provider training model were feasible for use in a variety of community settings. Since the initial pilot testing occurred in the community as opposed to the lab, we were able to identify technical supports and anticipate structural adaptations to support community implementation, if the program was found to be efficacious in subsequent testing.

Step 3 (Modified DFM). Series of Small Controlled Studies Designed to Systematically Test the Efficacy of the Individual Components of the Model (Intervention, Parent Training Protocol, Provider Training Protocol) in a Controlled Setting

Once an intervention has been conceptualized, manualized, and pilot tested, the next step is to establish its efficacy. At this point, Weisz et al. (2005) recommend a group-design efficacy trial conducted in a controlled setting, in order to understand how the intervention works under controlled conditions prior to investing in a large-scale effectiveness trial. However, there were several considerations that made us question whether a group-design efficacy trial was the most appropriate next step given the broader context of ASD parent-mediated intervention. First, a handful of recent efficacy trials of parent-mediated interventions for young children with ASD have failed to find robust treatment effects on expected outcomes (Carter et al., 2011; Oosterling et al., 2010). As these models were tested in their entirety, it is unclear whether the limited treatment effect was due to use of a sub-optimal intervention with the child, an insufficient training protocol with the parent, or a limitation in the effectiveness of parent-mediated intervention for this age group more generally. In addition, in efficacy trials that have found a robust treatment effect, it has been assumed that improvements in child outcomes are *a result of* improvements in their parents' ability to implement the treatment. However, this relationship has rarely been directly tested. While parent fidelity is a likely candidate, it is also possible that changes in other important parent behaviors, such as parent self-efficacy, may be important factors in promoting child change. Further, as most social communication interventions for young children with ASD contain multiple techniques, it is often unclear which techniques most influence child behavior (e.g., use of prompting or use of responsive parenting behaviors). Thus, a better understanding of the active ingredients of promising parent-mediated interventions is needed. Finally, as previously noted, a significant barrier to the use of parent-mediated intervention in community settings is the lack of sufficient provider preparation and support. As such, the development and testing of provider training models, alongside the parent-child intervention, may be critical yet are often overlooked in traditional intervention studies. When considered together, these issues highlight the need to examine the intervention at its three levels individually (child, parent, and provider), prior to conducting a fully powered efficacy study.

Thus, this phase of Project ImPACT development and testing emphasized the development of a preliminary understanding of the efficacy of all aspects of the intervention model. We did this by systematically testing the efficacy of the individual program components (direct child intervention, parent training protocol, provider training protocol) using single-case experimental designs and quasi-experimental designs. This phase also allowed us to generate empirically guided hypotheses regarding active ingredients/mechanisms of effect for each component, empirically examine potential modifications to the original protocol that may enhance its efficacy or transportability, and develop the tools necessary for a large-scale evaluation in community settings (e.g., intervention fidelity measures for parents, providers, and trainers). While this phase could have been implemented in community settings, we chose to do much of this work in a lab setting, in order to exact the degree of control needed to determine an intervention's efficacy.

The first component of the intervention we examined during this phase was the efficacy of the intervention strategies used with the child. Given that the individual intervention techniques were selected, in part, based on their existing evidence base, we expected that they would be effective for increasing social communication skills. However, because we combined them in a novel way, we wanted to ensure that the techniques continued to maintain their efficacy when used as a single "package." Concurrently, we wanted to better understand the relative contributions of the different intervention techniques in the package so that we were not making the intervention more complex than necessary. For example, our intervention package included several techniques designed to target language skills. These strategies included language modeling/expansions and prompting/reinforcement within child-directed activities. Both sets of strategies have been shown to increase language skills in children with language delays including ASD, but the relative or additive effects of these strategies on child language skills were not clear. We used trained therapists instead of parents to implement the interventions in order to isolate the effect of the intervention techniques on child social communication skills from other potentially active parent behaviors and to ensure a high degree of treatment fidelity.

To examine whether the intervention package was effective for increasing child social communication skills, we used a single-case experimental design with nine children with ASD between the ages of 2 and 6 (Ingersoll, Wainer, Berger, & Walton, 2017). Each child received 1 h of intervention twice a week for 8 weeks. For five of the children, language and play skills were targeted separately in 30-min blocks, and for four of the children, both language and play skills were targeted together for the full hour. This manipulation allowed us to examine whether the way in which skills are targeted (together or separately) affects child learning. All children made clinically significant improvements in their use of expressive language targets, and eight of the nine children made improvements in their social engagement. Gains in play skills were less robust, however, and were only evident among the children for whom play skills were targeted separately from language. This finding suggests that the intervention package is generally effective for increasing language and social engagement. The intervention, however, is less effective for increasing play skills, and additional intervention, focusing exclusively on play skills, may be important.

To examine the relative contributions of the different sets of intervention techniques designed to teach language, we used a single-case, ABACAD design with five children with ASD between the ages of 2 and 6 (Ingersoll, Walton, Bonter, & Jelinek, 2012). The children received 3 weeks of each of the following conditions presented in different orders: (a) language modeling and expansions, (b) language prompting and reinforcement, and (c) a combination of the two. Although all three intervention conditions showed a benefit compared to baseline, the children demonstrated substantially greater use of their language targets in the two conditions (b and c) that included prompting and reinforcement, and, across children, the combined condition did not substantially outperform the prompting- and reinforcement-only condition. This finding provided strong support for the inclusion of prompting and reinforcement strategies in the intervention package and suggested that they are likely active ingredients. The next question then became, are language modeling and expansions necessary to include in the intervention package? Given our empirical findings, perhaps not. At the same time, two of the children responded slightly better to the combined condition, suggesting the benefit of an integrated approach for some children. In addition, we only examined the effect of the techniques on one set of language skills (expressive language targets); thus it is possible that language modeling and expansions may benefit other aspects of language use, such as syntactic complexity or receptive language. And finally, in our formative work with community providers, there was strong support for the inclusion of these strategies. Thus, their inclusion in the treatment package may positively influence community uptake (Weisz et al., 2005).

The second component of the intervention examined was the parent training model, in this case the individual parent training format. This format involves a coach, parent, and child meeting for 1 h twice a week for 12 weeks for a total of 24 sessions. We were interested in the efficacy of this format for increasing parents' ability to use the intervention techniques with their child. However, in our ongoing work with community providers, many of them expressed interest in conducting parent training once a week for 12 weeks (12 sessions total) to better fit their service setting. Thus, we were also interested in whether reducing the number of parent coaching sessions from twice to once a week would negatively impact parent learning. Finally, and arguably most important, we wanted to examine the extent to which parents' use of the intervention techniques was related to changes in their child skills.

We conducted a single-case, multiple-baseline design across eight 2- to 6-year-old children with ASD and their mothers (Ingersoll & Wainer, 2013b). In order to examine whether the protocol could be successfully modified to once a week, we assigned five families to the original twice a week parent training protocol and three families to a modified once a week protocol. Our primary outcomes included parent fidelity of implementation and child use of expressive language targets. We found a strong effect of treatment on the parents' intervention fidelity; all parents demonstrated a substantial improvement in intervention fidelity as the intervention techniques were introduced. Most parents were able to achieve our fidelity criterion by the end of the 12 weeks of training and maintained these skills at a 1-month follow-up. Interestingly, parent learning was very similar for the parents who received training twice a week versus once a week. Thus, we found evidence that this adaptation to the parent training model did not negatively affect parent learning and may increase the fit of the program for some practice settings. We also found improvements in the children's use of expressive language targets concurrent with parent improvements in fidelity, and multilevel modeling revealed a significant association between parents' fidelity ratings and their child's language use within the session, providing relatively convincing evidence that parents' use of the intervention techniques was driving improvements in child language. Interestingly, multilevel modeling also revealed that following the child's lead and of prompting and reinforcement, each independently predicted child spontaneous language. Thus, both responsive parent behaviors and direct prompting may uniquely contribute to the development of spontaneous language. This finding expanded upon our earlier work described above and is consistent with the proposition that combined developmental and naturalistic behavioral intervention approaches may be particularly beneficial for increasing social communication in young children with ASD (Schreibman et al., 2015).

The final component of the program that we are currently examining is the provider training protocol. In the feasibility trial, we trained community providers to implement the parent training model through an initial 2-day workshop followed by onsite technical assistance during 4 of the 6 coaching days. While this training approach was found to be acceptable in the initial pilot test and feasibility trial, we realized that it would not be feasible if the programs were located further from our research site. In other words, the technical assistance model was feasible for the providers, but not for us! Thus, we made alterations to the provider training protocol to enhance our ability to deliver the training to programs which were located in geographically distant locations. The new protocol involved a combination of distance learning, two 1-day in-person workshops, and follow-up remote consultation.

Given the extent of the changes described above, an evaluation of the newer protocol was warranted. We conducted a quasi-experimental study to examine the integration of self-directed distance learning (website with written text, video examples, interactive exercises) with two 1-day interactive workshops (an initial one about the intervention strategies and a follow-up about parent coaching strategies; extensive video review and role play) and then six remote consultation sessions with feedback and supervision (three for the intervention strategies, three for parent coaching) to train community-based intervention providers in Project ImPACT techniques and parent coaching. We were primarily interested in examining changes in providers' perceptions of the different phases of the training and changes in self-efficacy, confidence, proficiency, and fidelity. Our findings suggest that providers liked the training model, particularly the opportunities for remote consultation which afforded feedback and supervision in a way that was easily integrated into their existing, and often hectic, schedules. Initial data indicated that providers' self-efficacy, confidence, and proficiency in using the intervention strategies with a child, as well as their fidelity of implementation of the intervention, increased as a function of the training protocol. We are currently examining data from the portion of the training protocol related to parent coaching strategies. Objective measures, along with quantitative and qualitative provider feedback, suggest that this protocol offers training in a way that is feasible, acceptable, and sufficient for mastery of the Project ImPACT strategies in community settings (Wainer, Pickard, Ingersoll, 2017).

Taken together, these studies have allowed us to examine the initial efficacy of important components of the intervention package. By no means is this set of studies exhaustive, as one can easily imagine a number of additional aspects of our program that could be evaluated in this manner (e.g., effect of intervention on additional child, parent, and provider behaviors, effect of the group parent training model on parent fidelity, alternative modifications to the parent or provider training protocol). However, at a minimum, these studies have given us enough confidence that our model is likely to be effective to warrant a large-scale evaluation. In addition, by examining the components of the model individually in a controlled setting, we have been able to generate some strong hypotheses regarding their active ingredients and mechanisms of effect (e.g., prompting and reinforcement; parent responsiveness). This is particularly important since the model was fully developed in the community, and although we were using strategies drawn from the literature, we were not clear as to *how* these strategies were working to produce changes in child behavior, particularly when combined into a single intervention package. Finally, these studies have allowed us to "fine-tune" some aspects of the intervention components to enhance their effectiveness (e.g., targeting play independently from language) and transportability (e.g., once a week parent training vs. twice week).

Step 4 (Modified DFM): Fully Powered Hybrid Effectiveness-Implementation Trials in Settings in Which the Program Is Intended to Be Used (Program Should Be Compared to Usual Care)

Once there is evidence for the ability of an intervention to be feasibly implemented in a range of community settings (Step 2) and the preliminary efficacy for its individual components in controlled settings (Step 3), we believe that Step 4 should include effectiveness-implementation trials, in our case likely a Type 2 Hybrid trial (Curran, Bauer, Mittman, Pyne, & Stetler, 2012). Type 2 Hybrid trials are most appropriate when there is evidence supporting clinical effectiveness, along with information about barriers and facilitators to implementation. Such a research approach allows for concurrent a priori focus on examining clinical effectiveness and implementation and supports more rapid translation to practice settings (Curran et al., 2012). In order to examine both clinical effectiveness and implementation in a meaningful way, this phase should focus on the delivery of intervention to treatment-seeking families. This means including families with children across the range functioning (e.g., different levels of autism severity, different cognitive levels) and those children with comorbidities. Similarly, parents with mental health or developmental concerns of their own and non-English-speaking families should be included in these kinds of research studies. Additionally, community-based providers who have been trained using a community-viable preparation protocol should provide the intervention. Implementation strategies should be monitored, and data reflecting provider fidelity, adaptations, and barriers should be collected. Finally, the intervention should be delivered within a range of practice settings such that a better understanding of organizational-level characteristics (e.g., organizational climate) can be understood and appropriate implementation tools can be utilized as indicated to support intervention uptake, use, and sustainability.

In our own work, this would mean a hybrid trial of Project ImPACT including the provider training protocol and parent-mediated intervention across community-based settings. In conducting this research, we will simultaneously collect two levels of data: one level of clinical outcomes data (e.g., parent/child/family outcomes) and one level of implementation strategies data (e.g., provider support). Given that formative evaluation is often a part of Type 2 Hybrid studies (Brown, Cohen, Chinman, Kessler, & Young, 2008), collecting and analyzing both levels of data within larger trial will allow for local adaptations, along the way, in order to support maximal uptake of the intervention in the community settings. Although a relatively unexplored research strategy within the ASD intervention field, this approach has been utilized by researchers in other areas, such as those applying a chronic illness care model to the outpatient treatment of schizophrenia (Brown et al., 2008).

Potential Challenges

Although we strongly believe that such an approach to intervention development is likely to encourage the transportability of evidence-based ASD interventions to community settings, it is not without its challenges. For this model to be successful, intervention developers need to work closely with stakeholders during the development phase, a process which can be both time- and cost-intensive. The traditional stage model of intervention development and testing is the prevailing model in ASD intervention research (Smith et al., 2007). Thus, it can be difficult to get the funding necessary to support the development of the intervention. Luckily, there are some funding mechanisms that can support this process, most notably the Institute for Education Sciences Goal 2 mechanism and the National Institutes of Health's R34 mechanism.

A second challenge comes with balancing the slower nature of good science with the immediate needs of the community. Our approach advocates that the key elements of the program needed to support community adoption and implementation be developed before a formal, large-scale efficacy trial is undertaken (although smaller n studies will have been conducted on important components of the intervention along the way). Thus, the program's use in the community will begin prior to the establishment of efficacy and may result in pressure to disseminate the intervention into additional community settings. Indeed, we have experienced this dilemma with our own work. When we began developing Project ImPACT, despite several decades of small n studies demonstrating the efficacy of parent-mediated intervention for children with ASD and national guidelines recommending its use, there were no commercially available parent training curricula for families of young children with ASD that had undergone rigorous efficacy trials. Thus, in response to a significant need in the community and lacking better options, we made the somewhat controversial decision to publish and disseminate our curriculum during early stages of testing the intervention. However, once an intervention has been disseminated, there may be less pressure for intervention researchers to establish efficacy. Furthermore, once community providers have adopted a program, it may be difficult to get them to unadopt if a subsequent efficacy trial fails to show support for the intervention. Nonetheless, it is imperative that we conduct this work, as the unexpected findings of several recent studies of parent-mediated interventions highlight (Carter et al., 2011; Oosterling et al., 2010). To this end, a better understanding of how programs are implemented by community providers (as advocated in our model) will be helpful in understanding how or why a program does not perform as expected.

Finally, although we are optimistic that an approach like the one we have proposed will lead to the development of ASD interventions that are more readily transportable, the degree to which such a model would speed the diffusion of effective treatments remains unclear. Stahmer et al. (2011) examined stakeholder perceptions of elements that may help speed up the transport of evidence-based ASD intervention from research to practice settings. Quality materials, flexible formats, fit with a variety of theoretical approaches, and evidence of use of the program in similar settings were identified as some of the critical factors which support rapid movement of interventions into community settings. Importantly, our approach to examining Project ImPACT allowed us to consider and address such issues and to develop an intervention model including these aspects. Indeed, when presented with several different parent-mediated intervention models, the stakeholders in that study selected to pursue the use of Project ImPACT in their community, perhaps in part because our approach to development and testing made it relatively ready for a speedy transition into practice settings.

A final challenge to this approach is that it operates from the assumption that programs are unchangeable. By working with community providers to develop programs that are compatible with existing service delivery models, we may be accepting a suboptimal method of intervention. For example, there is evidence that intensity does matter (Reichow & Wolrey, 2009). We are challenged by the potentially difficult task of developing interventions that are effective when implemented in current service delivery systems, yet it may be that current service delivery systems are suboptimal. Thus, as a field we need to find a balance between what is feasible (and thus currently transportable) and what is optimal for promoting change in critical outcome domains. This will likely require different approaches, with the proposed approach supporting exploration of the former. However, the growing field of dissemination and implementation science may provide us with a road map to navigate these complexities as we work to develop, test, and use effective ASD interventions.

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A Community Collaborative Approach to Scaling-Up Evidence-Based Practices: Moving Parent-Implemented Interventions from Research to Practice

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Abstract

Moving efficacious interventions for ASD from research to practice requires careful attention to the context in which the practices will be used. The EPIS (Exploration, Preparation, Implementation, and Sustainment) model from implementation science describes the inner (individual agencies and providers) and outer (sociopolitical climate, funding, etc.) context influences on the use of evidence-based practices in community mental health settings. Attention to the influences on implementation at all phases and levels can facilitate the ultimate success of the practice in the community. The following chapter describes the work of the BRIDGE Collaborative, a group of parents, providers, researchers, and funding agency representatives, in moving and scaling up a parent-implemented intervention for young children with or at risk for autism. The BRIDGE Collaborative addressed barriers at all levels of implementation through the use of targeted strategies aimed to support community uptake and use. The goal of this discussion is to provide a framework for how to effectively move evidence-based practices (EBP) from research to community-based delivery where children and families can benefit.

Over the last two decades, research has identified a growing number of efficacious interventions for autism spectrum disorder (ASD; National Autism Center, 2009, 2015). There is growing consensus around the common elements of what works (Schreibman et al., 2015), the ages at which various approaches are appropriate, and the symptoms of ASD that are best addressed through psychosocial intervention (Wong et al., 2014).

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_27

Despite this wealth of knowledge, however, there remains a concerning gap between research and practice: best-practice interventions are not reaching the community where the majority of children and families can benefit from quality care. Surveys of existing community practices for ASD demonstrate the absence of high-quality evidence-based practice use in community settings (Hess, Morrier, Heflin, & Ivey, 2008; Stahmer, Collings, & Palinkas, 2005). Although this gap is a generalizable problem across health and mental health interventions and practices, the pervasive nature of ASD and the complexity of the ASD service system require unique attention for translation to community settings.

Specifically, parent-implemented interventions for ASD are one class of approaches that have been consistently supported in the literature (Wong et al., 2014). The challenges of moving parent-implemented approaches into community settings exist at several levels. First, service providers must not only become proficient in relatively complex, evidence-based interventions themselves, but they must also understand the intervention well enough to coach parents to effectively use the strategies. A majority of parent-implemented interventions are naturalistic developmental behavioral intervention (NDBI; Schreibman et al., 2015), which are less structured than traditional ASD interventions. Providers of varying levels of education and experience are being asked to use a high level of clinical judgment to individualize strategies to specific children as well as tailor coaching to parents. Additionally, due to the nature of working with families whose child was recently identified as having a developmental concern, these providers are often asked to help parents cope with the emotional challenges of a new diagnosis. Providers may not have had training in adult learning strategies, coaching practices, or methods to support families experiencing stress and grief. In addition to the challenges at the provider level, there are also complexities to address in the wider system of early intervention. Leadership at agencies providing early intervention may not value the parent-implemented model and so may not support clinicians implementing such models (e.g., focus of intervention not directly on the child, frequency and length of appointments needed). Funding agencies may not be willing to pay for providers with the increased level of expertise that is optimal for parent-implemented models. These realities of utilizing parent-implemented interventions for ASD in community settings require additional consideration when aiming to move practices from research to the community.

To address these complex concerns, we must develop and employ clear and specific tools to help service systems, organizations/agencies, and providers from multiple disciplines effectively support families. These tools can be informed by implementation science research. This area of study specifically examines methods for successfully moving new practices into community settings in ways that are both feasible and effective. In this chapter, we apply one prominent implementation framework to support the implementation of evidence-based practices (EBPs) for ASD. We then discuss a successful (and ongoing) community implementation of a specific parent-implemented EBP that was informed by implementation science and incorporates several strategies to combat the challenges of using these models in applied settings.

Introduction to Implementation Science: The EPIS Model

Implementation science refers to “the scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and thereby improve the quality and effectiveness of health services and care” (Eccles & Mittman, 2006, p. 1). A growing body of research demonstrates that a unidirectional model of developing and testing innovative practices in research settings and then subsequently rolling the practice into the community is ineffective and inefficient. Particularly in the mental health services field, this method rarely results in successful use of the practice, and the positive effects of intervention for clients seen in research labs are not replicated in community practice (Glasgow, Lichtenstein, & Marcus, 2003; Lenfant, 2003). Research in the field of ASD shares this problem. Implementation researchers have responded to this challenge by developing multistage and multilevel models and frameworks that specify the complex context for implementation of EBPs and factors that potentially support or hinder the implementation of innovative practices in each stage. The EPIS (Exploration, Preparation, Implementation, and Sustainment) model is one such model that is highly relevant to ASD services as it focuses on the implementation of EBP in publicly funded services targeted to children and families (Aarons, Hurlburt, & Horwitz, 2011). Close consideration of the unique influences at play in the child and family services sector is necessary to optimally inform our approach to scaling up and implementing EBPs for children with ASD and their families. The model posits four phases of implementation (Exploration, Preparation, Implementation, and Sustainment) and highlights the contextual factors that are likely to be most influential at each phase. Additionally, it separates the outer context of implementation (e.g., funding, sociopolitical influences, advocacy, interorganizational networks) from the inner context of implementation (e.g., individual providers and agencies) and addresses the separate factors that must be considered at each level. The following brief description highlights factors in each phase and context that may be particularly relevant in implementing a parent-implemented EBP for ASD in community early intervention agencies.

The *Exploration phase* involves the search for appropriate, innovative practices to address issues or problems facing an organization or population (Grol, Bosch, Hulscher, Eccles, & Wensing, 2007). There may be awareness from within an organization that current practice is lacking in some way (inner context) or it may be knowledge that arises in response to outside social or political forces placing new or altered demands on the organization (outer context). For example, client advocacy has been identified as a major impetus for organizations to make systems change (Hoagwood, 2003). Advocacy is most likely to be influential when it comes from consumer-based organizations. For example, the Autism Society of America, Autism Speaks, and the Autism Science Foundation all recommend parents to obtain training on how to implement intervention with their children, and these recommendations may be a driving force in a community agency searching for a parent-implemented intervention to use with their clients. This is an example of the wider, outer context for services influencing the actions of an individual organization. Agencies may also be catalyzed to explore new practices by requests from individual clients, such as parents requesting coaching or support to manage their child's behavioral challenges. In this case, the inner context of the actual client served is the driving force for change. The organization's willingness and readiness to change, as well as their ability to use new knowledge gained, will determine how they undertake explorations for innovative practices to meet unmet needs.

Once potential options have been explored, the *Preparation phase* involves deciding to adopt a particular practice. The influence of interorganizational networks (formal or informal ties across agencies) is one of the outer context factors that must be considered at this stage. For example, increased, specific referrals from the local Part C administrator may motivate an agency to adopt a particular practice. Agencies must also examine other outer context factors such as funding possibilities, likelihood that they will receive referrals, and policies related to the use of the strategy. This stage also involves determining the capacity building needed within the organization to use a selected practice. Factors such as the size of the organization, the resources available to support adoption, and the existing knowledge and expertise in the organization (which determines if/how much training is necessary) are all important considerations. Organizations must consider the type of training needed for staff that will implement the intervention as well as those that will supervise and support implementation. Training standards may be determined by some interventions (e.g., Hanen programs, Pepper & Weitzman, 2004, can only be implemented by licensed speech -language pathologists), or the organization itself may determine specific qualifications (e.g., necessary years of experience in the field or within the organization). The cost of training and ongoing support needed to deliver the intervention correctly and sustain the practice following initial training should also be considered during preparation. Additionally, leadership plays a crucial role in championing a practice, and strong endorsement from leadership during the preparation phase increases the likelihood of subsequent adoption in an organization (Aarons, 2006; Forgatch, Patterson, & DeGarmo, 2005; Price, Friedland, Choi, & Caplan, 1998). Leaders can support preparation by providing specific incentives to participate in training and providing forums for information dissemination about the new practice, for example.

The *Implementation phase* involves the delivery of the newly adopted practice to children and families in the community by individual providers. Outer context factors most relevant at this stage include the funding available to pay for the practice (plus the certainty and longevity surrounding that funding) and the availability of contracts from large public systems for a particular service. For example, is the service one that can be covered through private insurance or local Part C programs for children with ASD? Within the inner context of the individual organization, interventions that best fit the structure and ideology of an organization are more likely to be used. For example, an early intervention agency that believes the parent-child relationship is a driving force of development may be more likely to successfully use and sustain a parent-implemented intervention than an agency that subscribes to a model that the child will most benefit from a high intensity of interaction with an expert interventionist. The attitudes of individual members of an organization and their adaptability and facility with changing their current practices (as well as the extent to which the intervention is actually a change from their current practice) likely also play a crucial role. For example, some interventions may be implemented more successfully by providers who are open to learning new strategies (Addis & Krasnow, 2000) or by therapists whose theoretical background and training closely matches the new intervention strategies (Lee, Stahmer, Reed, Searcy, & Brookman-Frazee, 2011).

The *Sustainment phase* involves continued use of a practice; this is often the greatest challenge with a novel innovation and yet has only recently begun to receive adequate attention (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004). In a systematic review of sustainment studies, Stirman et al. (2012) identified the following categories of influences on sustainment: outer and inner context, the innovation itself (e.g., fit, adaptability, and effectiveness), processes (e.g., fidelity monitoring, evaluation), and the capacity to sustain (e.g., funding, resources, workforce characteristics). These factors need to be considered fully as related to sustainment during the Exploration and Preparation phases of selecting and planning for EBP use in order to ensure ongoing effective use of the strategies in the community.

A thorough understanding of the inner and outer context influences at each phase of implementation allows for a targeted, proactive approach to potential barriers. This approach is taken in the hopes of maximizing the successful deployment of an intervention in the community. *Implementation strategies* are the practical tools or approaches designed to address factors across phases. These approaches may be discrete single actions, such as educational community meetings about an intervention to create demand, or they may be multifaceted approaches, which combine two or more discrete actions (Powell et al., 2012, Powell et al., 2015). The following section describes the implementation strategies used by a community-academic partnership (called the BRIDGE Collaborative) to improve community intervention for young children with or at risk for ASD. Table 27.1 gives an overview of the selected strategies, as identified by Powell et al. (2015), which have been or will be utilized at each phase. Specifically, successes and difficulties in using implementation strategies during the Exploration, Preparation, and Implementation phases of moving an EBP into the community will be described, as well as strategies that were utilized across

Table 27.1 Implementation strategies utilized by the BRIDGE Collaborative

Stage	Exploration or population	Preparation	Implementation	Sustainment (Planned)
Strategies (Powell et al., 2015)	*Outer context*: Conduct local need assessment	*Outer context*: Tailor strategies to overcome barriers and honor preferences Promote adaptability	*Outer context*: Stage implementation scale-up Identify early adopters	*Outer context*: Fund and contract for the clinical innovation Use mass media Centralize technical assistance
	Inner context: Conduct local consensus discussions	*Inner context*: Develop effective educational materials, including dynamic training	*Inner context*: Use a train-the-trainer model Make training dynamic Develop tools for quality monitoring	*Inner context*: Provide ongoing consultation (including fidelity checks) Facilitate relay of clinical data to providers
	Outer context: community-partnered participatory research (build a coalition, develop academic partnerships)			

multiple phases. Planned implementation strategies to support Sustainment will also be presented. The goal of this discussion is to provide a framework for how to effectively move EBP from research to community-based delivery where children and families can benefit.

The BRIDGE Collaborative and CPPR

The Southern California BRIDGE Collaborative (as described in Brookman-Frazee, Stahmer, Lewis, Feder, & Reed, 2012) is a community-academic partnership developed with the goal of improving intervention for young children with or at risk for ASD and their families. The Collaborative consists of clinicians, funding agency representatives, parents, and researchers all with expertise in ASD and/or the intervention service system. Early in the development of the Collaborative (which began meeting in 2007), members jointly decided to target the implementation of evidence-based, parent-implemented practices in community settings as a primary purpose. Over the last 8 years, members have worked together to utilize implementation strategies and address barriers in the outer and inner contexts in order to build community capacity to serve toddlers with ASD and their families. Indeed, the involvement of a community-academic partnership in and of itself is an implementation strategy that has been shown to improve the use of EBPs in multiple settings (Drahota et al., 2016; Powell et al., 2015; Powell et al., 2012; Spoth, Clair, Greenberg, Redmond, & Shin, 2007). The BRIDGE Collaborative is founded in a community-partnered participatory research (CPPR) approach, which is one type of community-based participatory research (CBPR; Israel, Eng, Schulz, & Parker, 2005). CPPR explicitly focuses on the use of EBPs in community mental health services (Jones & Wells, 2007). The use of CPPR is an overarching implementation strategy that attends to influential factors at all phases of implementation. In the project described here, CPPR has allowed for close and continual attention to potential barriers to the implementation process and the use of multifaceted implementation interventions.

Exploration: Identification of Need and Local Consensus Discussions

The same community need that led to the formation of the BRIDGE Collaborative was the impetus for the initial Exploration phase around supporting toddlers with ASD. In 2006, more and more children were being identified as having autism or symptoms that indicated risk of autism at younger and younger ages (i.e., under 24 months). However, available interventions in the community were highly structured and had been developed and studied primarily in children over 3 years of age. Community providers and early intervention funders had concerns about providing appropriate services for this growing group of families. A community provider and a funding representative approached a local researcher for support in the development of a strategic plan to build community capacity in this area. This led to the development of the BRIDGE Collaborative and the beginning of the exploration of how to best support families of toddlers with social communication concerns. A full discussion of the process of Collaborative formation and outcomes is available in Brookman-Frazee et al., 2012 (Table 27.2).

The primary implementation strategies utilized in the Exploration phase were to *conduct a local need assessment* and *conduct local consensus discussions* (Powell et al., 2015). Once formed, the BRIDGE Collaborative spent an initial period in which they continued the process of identifying local needs as a group and developing plans for how those needs may be addressed. Activities involved researchers conducting literature reviews to examine the state of the evidence for various interventions and tools, community providers sharing information regarding interventions they currently used with children in their care or in which they had training or expertise, and funders sharing information regarding eligibility and other funding requirements that needed to be considered. These activities primarily focused on the outer context of intervention, or the general, cross-agency considerations that needed to be taken into account for the service system as a whole. A broad range of community needs were identified through this process, including opportunities for peer-to-peer family support, mechanisms to follow families over time and address children's changing needs across development, avenues for training service providers in a variety of evidence-supported strategies that could be individualized to the family, and appropriate interventions that met all stakeholder needs. One of the largest challenges in conducting the need assessment within the BRIDGE Collaborative was narrowing the space of all possible needs to address related to toddlers at risk or with autism and their families and focusing on the avenues that were actionable. Ultimately, the group decided to work within the infrastructure of the existing service system (i.e., attending to outer context) to select a parent-implemented intervention that would be suitable for use by a wide variety of multidisciplinary service providers, would address comprehensive developmental needs for toddlers, and was supported by research. With this purpose in mind, the Collaborative jointly applied for NIH funding to gather community input on potential interventions and run a small feasibility test on the ultimately selected intervention.

Table 27.2 Implementation strategies utilized by the BRIDGE Collaborative during Exploration

	Implementation strategy (Powell et al., 2015)	BRIDGE application
Outer context	**Conduct local need assessment** *Collect and analyze data related to the need for the innovation*	Initial activities of the BRIDGE Collaborative included identifying existing community resources, exploring available research literature, and holding ongoing discussions among stakeholders (parents, funding agency representatives, providers, researchers) about areas of shared concern
Inner context	**Conduct local consensus discussion** *Hold local discussions to determine appropriate clinical innovation to address identified problems*	Community conferences and parent/provider focus groups were held to inform the selection of an intervention to address the identified need of appropriate intervention for toddlers with/at risk for ASD

In initial discussions and through the needs exploration, the Collaborative identified three possible interventions that potentially fit the values of all stakeholders. The group hosted a series of local conferences in which they invited the developers of each of the three interventions to present to the community. After each conference, BRIDGE Collaborative members with expertise in leading focus groups convened groups of parents of children with ASD or service providers to gather their feedback on the intervention presented. These focus groups represent local consensus discussions at the inner context level, as data were gathered on individual provider, agency, and parent opinions on proposed innovations. A full discussion of the values of various stakeholders can be found in Stahmer, Brookman-Frazee, Lee, Searcy, and Reed 2011. Questions regarding each intervention included areas of strengths and concern, how the intervention compared to an "ideal" approach for toddlers and families (as defined through discussions in an introductory focus group), how the intervention differed from existing services, and whether it was feasible to implement as part of current service models (asked to providers). The same parents and providers attended the focus groups after each conference in order to facilitate comprehensive comparison between the three options. The BRIDGE Collaborative also met after each conference to hold similar discussions and met with each intervention developer to gather additional information about potential collaboration, training, and adaptation. In addition to the focus groups, paper and pencil surveys were distributed to all attendees at each conference; surveys asked questions about the format of the intervention, the content of the intervention (e.g., play-based, uses natural environment, clear goals, family involvement, etc), community fit, and other areas of value.

As discussed in Stahmer et al. (2011), there was high concordance across stakeholder groups (parents, providers, BRIDGE Collaborative experts). The following values were shared across all groups of stakeholders: the use of a parent-implemented intervention, involvement of a parent-to-parent support or group element, good fit with a variety of disciplines and philosophies, a comprehensive intervention that would be engaging and play-based with a focus on the parent-child relationship, individualized to the family, using quality materials, a flexible format, would be fundable by existing sources, delivered by experienced providers, and supported by research. As can be expected, individual groups spent more time discussing elements that were most relevant to them; for example, the parent group had a long discussion regarding the importance of involving all caregivers for a child in intervention, while the therapist discussed training methods and procedures extensively.

The actual selection process for the intervention occurred once all three conferences had taken place and data from surveys and focus groups had been summarized and analyzed. Because the three interventions that were chosen for conferences were carefully selected from the start, there was not a clear favorite across all stakeholders when all the data were examined. This left the BRIDGE Collaborative with the important task of selecting the "best fit" intervention by prioritizing and ranking various values of the parent, provider, and expert groups. This process occurred across two half-day meetings with BRIDGE members. The first meeting was spent examining the qualitative (focus groups and audience survey free responses) and quantitative (audience survey Likert responses) feedback from the conferences. Information from each intervention was compared across all the values identified by the stakeholder groups (e.g., to what degree/in what way does each intervention focus on the parent-child relationship? How does each intervention train providers, and what types of providers are eligible to be trained?). The group collectively developed a summary grid of the top priorities and how each intervention addressed (or failed to address) those areas. This grid was then provided to an outside facilitator, who was not part of the BRIDGE Collaborative (or indeed, involved in early intervention at all) but who had specific expertise in supporting group decision-making processes. She led the second half-day meeting with the goal of ultimately deciding on the intervention for community implementation. Primary activities led by the facilitator involved each individual casting "votes" for their most important intervention values and then comparing interventions across the top-ranked factors. The facilitator also led discussions about how choosing each intervention would affect the dynamics in the group and the plan for moving forward once an intervention was chosen. Ultimately, the values of parent-focus, research-base, professional materials, easily accessible training, broadly appealing and appropriate for a variety of disciplines, and flexible implementation were primary for the group. Through extensive discussion and support of the facilitator, one intervention was chosen that had the strongest match across this pattern of values. By ultimately leading to a decision, the process with the impartial, outside facilitator was the culmination of the local consensus discussions around choosing an innovation to meet the needs of the community after carefully considering multiple options.

Preparation: Intervention Adaptation and Training Development

The primary work of the BRIDGE Collaborative in the Preparation phase has been to tailor the selected intervention to toddlers, to individualize the materials for varied family needs, and to develop and refine effective training tools to support providers learning the intervention. Although the intervention shares many characteristics with others in the field that providers may already be using (Schreibman et al., 2015), part of the innovation is a consistent terminology and frame of reference for the intervention strategies and structure to use with parents and other providers. In order to motivate agencies to adopt the practice and best support all providers in learning the intervention, the BRIDGE Collaborative has utilized an iterative process of intervention adaptation and training development that continually builds on previous experiences to shape and improve the intervention, materials, and training model (Table 27.3).

During the Exploration phase, several areas of needed adaptation were identified that applied regardless of the specific intervention selected. This tailoring of the intervention strategies (implementation tool: *tailor strategies*) was necessary in order to fully address the outer context needs in the community of an intervention specific for toddlers and their parents. Accordingly, the BRIDGE Collaborative, in conjunction with the model developers, spent considerable time in the Preparation phase adding content and adjusting the language of the selected intervention. Adjustments included a focus on "communication" rather than "language" in the stated goals of the intervention, as well as on back-and-forth social play rather than play with objects. The Collaborative felt that these adjustments such as these to the developmental appropriateness of the intervention goals would facilitate organization, parent, and provider buy-in to use the strategies. BRIDGE members also shifted the framing of the intervention to focus on daily routines and activities and how the intervention strategies

Table 27.3 Implementation strategies utilized by the BRIDGE Collaborative during Preparation

	Implementation strategy (Powell et al., 2015)	BRIDGE application
Outer context	**Tailor strategies** *Adjust strategies to address barriers and leverage facilitates identified in earlier phases*	The intervention content was adjusted to be toddler-appropriate and individualized for families; information was added to training on working collaboratively with parents, dyadic engagement, sensory integration, regulation, and reflective practice. Intensity and length of the program were adjusted to address needs of funding agencies (Part C and insurance)
Inner context	**Develop educational materials** *Create and format manuals, tool kits, and other supporting materials in ways that make it easy for clinicians to learn to deliver the innovation*	The training format used a train-the-trainer model, delivers content in small chunks, and allows time for hands-on practice with feedback; the presentations and modules for providers can be delivered flexibly (in person, in person/online hybrid)

could be used within the context of day-to-day life with a toddler. Finding time to use the strategies was a barrier identified by parents during focus groups that influenced their willingness to participate in intervention programs. Additional adjustments included fully integrating the developmental and behavioral strategies that are part of the blended intervention and altering some of the language and names of strategies to better reflect the broad range of intervention values reflected in the local consensus discussions (e.g., change "playful obstruction" to "back-and-forth play" to emphasize the joint nature of play over the intrusiveness of the adult).

In addition to adjustment to the intervention content, considerable tailoring went in to the form and structure of the materials that are shared with the family as part of the intervention. Feedback from both parents and providers during the Exploration phase indicated that large amounts of reading and written homework were a barrier to parents fully participating in the intervention (Stahmer et al., 2011) and additionally more flexibility was needed for parents with literacy difficulties or non-English-speaking families. To address these barriers, the BRIDGE Collaborative considerably shortened the parent manual from the original program and produced a Spanish translation. Members also developed single-page handouts for each stage of the intervention that simplified the techniques even further and used graphics and pictorial representations of strategies when possible to support families who were not able or did not wish to fully read the text. To support parents who were having difficulty with individual parts of a strategy, a bank of example cards were developed for each small piece of the intervention (over 50 cards). Each card gives simple examples of parent and child behavior related to the strategy to illustrate the concept. These cards can be given to parents who may struggle with an individual piece and need focused additional support. Providing multiple tools and materials to share information with parents allowed clinicians to individualize their use of the intervention based on the specific family needs, a value that was shared across stakeholders in early discussions.

Further cross-intervention areas of need were identified related to provider training during the Exploration phase. These areas were not specific to any one organization, agency, or provider discipline but rather were the product of the current service system. Parent-implemented interventions require that an early intervention provider work closely with the child's parent, despite the fact that they may not have any training in adult learning strategies or effective coaching methods. Accordingly, the BRIDGE Collaborative worked closely with the developer of a parent engagement intervention to incorporate additional information into training on working with parents (Haine-Schlagel et al. under review; Haine-Schlagel and Martinez, 2015a, 2015b). This information gives providers practical tools and strategies for how to best collaborate with parents around individualizing the intervention for their family. Additionally, there were a few other topics on which information was added to the training to tailor the intervention. These areas included parent-child interactions, subtle communication behavior in toddlers with social communication challenges, sensory integration, behavioral regulation, and reflective processes. All these additive pieces of the training represent efforts to tailor strategies a priori to overcome the potential barrier of necessary background information and foundational skills for providers to implement the intervention effectively.

The development of effective educational materials for providers has been a major focus of the BRIDGE Collaborative and a primary inner context implementation strategy utilized in the Preparation phase. The initial phase of training in the intervention was part of the pilot and feasibility study of the selected intervention for community providers. A description of the pilot study is available in Stahmer et al. (2017). Though several Collaborative members had expertise in the selected blended intervention model, the group elected to invite the model developer to deliver the initial training to the therapists. A member of the model developers' team came to San Diego and delivered an intensive 2-day workshop to therapists (and interested Collaborative members) on how to implement the intervention.

Anonymous evaluations from therapists participating indicated that they felt the training prepared them to use the intervention with families and that lecture and videos were the most helpful modalities of training (Stahmer, unpublished data). In addition to the content provided by the model developers, BRIDGE members delivered a half-day training on the added topics discussed above.

Despite positive feedback following the training, however, none of the therapists participating in the pilot study met fidelity for implementation of the intervention immediately following the 2-day workshop. This is consistent with teacher education research demonstrating that an in-service training is not sufficient to support teacher learning of a new teaching technique (Odom, 2009). All therapists required additional coaching and feedback to implement the intervention more fully, which was primarily provided electronically after members of the research team reviewed videos and made comments using an online video review software (Behavior Connect ™).

Though additional coaching allowed most therapists to meet fidelity on the majority of components, some strategies continued to be difficult for therapists to use. Careful examination of the data revealed that though there were some common areas of strength across all therapists, the strategies that therapists had trouble using correctly varied systematically with their theoretical orientation. That is, therapists who self-reported their training as primarily "behavioral" had different areas of weakness than therapists who reported their training as predominantly "developmental." For example, behavioral therapists, on average, met fidelity on adjusting the level of prompting in accordance with the child's responding to best promote spontaneous use of skills, but developmentally trained therapists did not. On the other hand, developmental therapists were better able to provide developmentally appropriate expansions on children's subtle communication and play behaviors, which was an area of difficulty for behaviorally trained therapists. Strategies such as letting the child choose the activity, staying face to face with the child during interaction, imitating child behavior, and modeling language around the child's focus of attention to give meaning to their actions were used appropriately by all therapists (Lee et al., 2011). This information on therapists' performance based on their background was incorporated into future training materials: current trainings begin with a broad overview of both developmental science and behavioral principles, and therapists' backgrounds are assessed (informally, and through a demographics questionnaire) before coaching begins. This information allows the coach to focus initial coaching on areas of the intervention that are likely to be more difficult for the therapist and provide feedback accordingly. This individualized approach to training is another example of tailoring the implementation effort based on information from earlier data collection.

Overall, the initial training in the pilot study and subsequent data collection on therapist implementation were crucial in informing the BRIDGE Collaborative's work to *develop effective educational materials*, including dynamic training (Powell et al., 2015). This implementation strategy holds that by varying the information delivery methods and catering to different learning styles, training can be improved, higher learning is promoted, and clinicians are therefore more likely to use a practice once they have received training. The BRIDGE Collaborative used an iterative process of training development in order to continually improve the quality of the model. Observations of therapists' differential implementation of various strategies as well their direct feedback on their experience (gathered in surveys and focus groups) were all used to inform the design of the training approach for the next round of training (conducted through subsequent research funding). For example, based on therapists' feedback in focus groups that the initial 2-day training was an overwhelming amount of information without sufficient opportunity to practice the material covered, the current training model alternates didactic information sessions with hands-on practice with feedback sessions, such that therapists learn a small chunk of the intervention each week and then have the opportunity to practice implementing that same piece the following week. In a parallel process to how the intervention teaches parents, trainees have an opportunity to see the trainer interact with a child to implement the strategies covered the previous week, and then they try them themselves while receiving feedback from the trainer. This spreading out of the training information is also consistent with the recommendation to divide materials into small time intervals to improve comprehension and retention. It is also an example of dynamic and interactive training that is considered best practice in the field (Powell et al., 2015).

This alternating didactic and coaching model stands in contrast to the traditional intensive, brief model of training that is currently the norm for intervention training (LaVigna, Christian, & Willis, 2005). The increased time commitment required by this more comprehensive model of training has been challenging for some agencies that wish to train therapists. Agency leaders are concerned both with the cost and scheduling headaches of supporting therapists to attend such a drawn-out and intensive training. In response to these concerns, the BRIDGE Collaborative developed web-based versions of the didactic portions of the training, such that agencies could cut the in-person time required by the training in half. In the web-based model, therapists watch one or several brief (6–25-min) segments of content on the intervention online each week, on their own. These segments contain the same information, video examples, and activities as the in-person didactic sessions and also contain comprehension questions to check for understanding and opportunities for free response. The total time for all of the segments is roughly 6–8 h, which is less than the 12 h of meeting in the face-to-face model. In-person meetings when using the online modules occur every other week (rather than every week, per the face-to-face model). These meetings are coaching sessions (with volunteer families) covering the techniques that the therapists have just learned in the online didactic sessions, just the same as the face-to-face model of training. In addition to coaching at these sessions, the trainer provides a brief check-in for questions or concerns on the didactic content covered in the web sessions and may briefly conduct any activities that are not suitable for online presentation (e.g., having partners use nonverbal cues to play with a balloon as a tool for understanding the nonverbal social communication of toddlers). Offering the didactic portion of the training online allows agencies flexibility in how much time the training takes and how much in-person meeting between the trainer and therapists is required. This flexibility has been crucial in moving the intervention into a broader range of agencies. Of the 10 agencies that have participated in the most recent round of training, 40% have opted to utilize the web-based training, per their organizational structure and needs. This flexibility is one example of an inner context implementation strategy of catering to different work contexts in order to deliver the training in as many agencies as possible.

Implementation: Intervention Delivery in the Community

The Implementation phase of using the intervention has occurred in several waves, and information from the early iterations of using the intervention in the community has been used to inform later rounds. This approach stems from the implementation strategy of *staging implementation scale-up*, that is, moving gradually and semi-systematically from a small-scale tightly controlled rollout of the intervention in the community to a larger, more dispersed effort with decreasing levels of researcher involvement (Chamberlain, Price, Reid, & Landsverk, 2008). Figure 27.1 illustrates the successive waves of providers who were trained in the intervention utilizing this approach. This strategy was primarily accomplished through beginning with a small (ten providers) pilot study in which all therapists were directly trained by the model developer and BRIDGE Collaborative members and received ongoing researcher support while initially implementing the program with a family. Therapists at four of the five agencies who participated in this pilot continued using the inter-

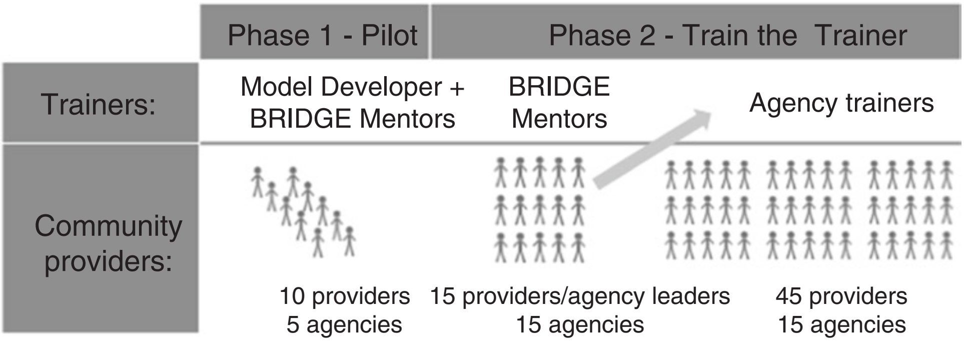

Fig. 27.1 Phases and number of providers trained in the intervention, illustrating the "scale-up" approach

vention after the research pilot was complete, which allowed for some minimal level of penetration and awareness of the intervention in the community. Starting small in this way allowed for close attention to the outer context factors that would likely influence cross-organization use of the intervention. We gathered extensive information on pilot providers' experience and their use of the program when designing later trainings and materials for the intervention and allowed us to work with funding agencies to determine the best model of reimbursement. Learning from early adopters (*identify early adopters)* in this way has been another implementation strategy. For example, the four agencies with trained therapists had differing flexibility in terms of session structure and location; some were home-based, while others were center-based; some offered the intervention as a stand-alone 12-week program, while others offered it as part of ongoing services with a family up to the age of 3; some provided the intervention in twice weekly, 90-minute sessions, while others provided twice weekly hour sessions, based on their appointment slots. These variations allowed researchers to gather rich feedback on the use of the intervention in various contexts and structures when there was an opportunity to conduct further training (i.e., additional grant funding secured). The presence of such variability even in a tiny sample of possible agencies that might implement the intervention corroborated the necessity of a flexible intervention that could be implemented under various constraints. Without this flexibility, it likely would have been impossible for 80% of the agencies from the pilot to continue using the practice. Additionally, the potential to implement the intervention flexibly was crucial in recruiting new agencies to participate in the second phase of scale-up, which is a train-the-trainer model of training delivery that is currently ongoing. This second phase has two graduated elements: (1) it is a train-the-trainer model, such that the BRIDGE Collaborative is providing training to a small group of agency leaders who will then return to their agencies and train individual therapists (at least three each), and (2) the training is occurring in a multiple-baseline format, such that small groups of agency leaders were trained in a series of cohorts, allowing for some refinement and tightening of the training procedure between groups (though minimal, to ensure consistency in how the groups were treated for research purposes) (Table 27.4).

The *train-the-trainer* model is a valuable tool for capacity building and scale-up, and a significant body of research demonstrates the effectiveness of the model in supporting the implementation of new practices (e.g., Suhrheinrich, 2015). It is also an implementation strategy that addresses a major problem that plagues many health service sectors: staff turnover. Though the current train-the-trainer model occurred in the context of a research study and costs to agencies were already limited (training was provided to agency trainers at no cost, but agencies had to support providers in attending training and coaching sessions), there are important benefits of this approach. Train-the-trainer models of support are much more cost-effective for agencies because they

Table 27.4 Implementation strategies utilized by the BRIDGE Collaborative during Implementation

	Implementation strategy	BRIDGE application
Outer context	**Stage implementation scale-up** *Phase implementation efforts by starting with small pilots and moving up to system-wide rollout*	Implementation began with training a small number of providers across agencies with close ties with the BRIDGE Collaborative; a second phase of training was a train-the-trainer approach designed to expand the number of organizations capable of using the intervention and the number of individual providers who were trained. This allowed examination of the process of referrals from Part C, funding issues through Part C and insurance, and issues of cross-agency training and communication
	Identify early adopters *Learn from experiences of early adopters at a local site*	Feedback on the intervention was gathered from therapists who participated in the pilot study in order to inform future implementation efforts
Inner context	**Use train-the-trainer strategies** *Train designated clinicians to train others*	Clinicians at 15 agencies received training from BRIDGE mentors to be "agency trainers" in the intervention; once trained, each agency trainer led the program with at least three therapists at their own agency
	Make training dynamic *Vary the information delivery methods, shape the training to be interactive*	Training involved didactic sessions with interactive activities alternating with sessions of hands-on practice with feedback as clinicians practiced the strategies with volunteer families
	Develop and implement tools for quality monitoring *Develop, test, and introduce into quality-monitoring systems that are specific to the innovation*	Fidelity of implementation tools were introduced and used throughout training for both use of the strategies and of the parent-coaching model; providers were encouraged to use the fidelity tools to support their own learning and implementation

allow for the development of in-house support to continue the use of the intervention, rather than continually paying costly external experts to train new waves of staff. In this case, train-the-trainer is also a valuable scale-up strategy because it naturally moves the intervention to a growing number of providers in the community and includes a mechanism for continued expansion. Additionally, having online modules of training content (as discussed in *Preparation*) supports agency capacity to train new staff with a decreased time commitment from the agency trainer.

Fidelity is another key issue in the implementation phase, and the intervention training involves multiple fidelity monitoring tools to support providers that have been developed by the BRIDGE Collaborative. We consider this an example of the strategy *develop tools for quality monitoring,* which is intended to support intervention use (Powell et al., 2015). Therapists who receive training in the intervention are introduced to two fidelity tools in the didactic training sessions: a strategy checklist and a parent-coaching fidelity tool. Both these forms are introduced once all of the strategies of the intervention have been covered (i.e., near the end of the didactic sessions). The strategy checklist tool measures how the therapists use the components in the model and so is a measure of adherence to intervention content (Carroll et al., 2007). It requires a simple minus/check/plus rating system on each of the primary components of the intervention (20 items). A "minus" means the component is missing completely, a "check" means the component is present but used with room for improvement, and a "plus" means the component is implemented fully and competently. A "plus" score on 80% of components is necessary to be considered "meeting fidelity," although this is a threshold we plan to explore experimentally in current training studies. The tool is designed for use both as a self-assessment (the therapist completes ratings on each component of her own implementation after interacting directly with a child) and an observer assessment (an observer rates the therapist's implementation of the intervention after watching at least 10 min of implementation). It can also be a way to spark discussion between an implementer and the observer through comparison of their scores of the same interaction. The initial intervention training includes an opportunity to practice using the tool (i.e., watching a video and rating the therapist's implementation in the video) and discuss ratings with the group. Additionally, once the tool has been introduced, therapists practice using it during the coaching training sessions as both a self- and observer assessment. Repeated use with the tool is provided as part of training with the goal that it will become a valuable support for therapists as they continue to use the intervention themselves and possibly as they support others at their agency in using the intervention as well.

In addition to the fidelity tool regarding therapists' implementation of the actual strategies of the intervention, a second tool for quality monitoring is also introduced in training. A fidelity rating tool for the parent-coaching structure of the sessions requires the therapist (or an observer) to rate themselves on a 1–3 scale on whether their interaction with the family matched the design of the program. This is a measure of adherence to the parent-coaching format of the intervention. Similar to the implementation fidelity, a 1 indicates the therapist does not implement the item appropriately, and a 3 indicates that she does so fully and competently. Example items include "The therapist provides a brief explanation of the session" and "The therapist provides a demonstration of the technique(s) with the child while explaining the impact of child's behavior." Similar to the implementation fidelity tool, a therapist must receive a 3 rating on at least 80% of the items to be considered meeting fidelity on the structure of the session. This tool is introduced to therapists during training, and they are encouraged to rate themselves using this form once they begin using the program with families. When the clinical trainers provide feedback to therapists learning the intervention, this form is also utilized. This may be during the training period, or after the training period has ended if a therapist seeks additional feedback from the trainer. Providing therapists with simple and straightforward tools to assess their use of the intervention itself and whether their sessions contain all the prescribed components of a high-quality parent-coaching session supports their use of the intervention as learned in the training.

Planning for Sustainment

The train-the-trainer research study is currently ongoing, with the third group of agency trainers currently completing their 3 months of ongoing practice with BRIDGE mentor support. Additionally, agency leaders in the two previous groups are at various stages of providing training to their therapists. It is therefore premature to discuss the benefits and barriers to various sustainment strategies for this intervention; we are still in the Implementation phase. However, there are several issues surrounding sustainment that are worth examining, as well as some implementation strategies that have been put into place in the hopes of supporting continued use of the intervention, once the research team is fully withdrawn (Table 27.5).

Sustained delivery of the intervention has been a major focus of the BRIDGE Collaborative decision-making process since the Preparation phase. One implementation strategy for sustainment relates to supporting providers receiving public funding for delivering the intervention (*fund and contract for the clinical innovation)*. The availability of funding is an outer context issue that has cross-agency implications. In Southern California, Part C is administered by regional centers and agencies vendor directly with the regional center to fund services. Several agencies who expressed interest in using the intervention were not contracted with the regional center for the specific type or structure of service that the intervention required. To support putting these contracts in place, the BRIDGE

Table 27.5 Implementation strategies utilized by the BRIDGE Collaborative during Sustainment

	Implementation strategy	BRIDGE application
Outer context	**Fund and contract for the clinical innovation** *Use contracting process from payers of service to motivate organizations to deliver the intervention*	Developed and shared a contract application template for the local Part C funder Developed and shared referral and report documents appropriate for local Part C funder
	Use mass media *Use mass media to reach large numbers of people to spread the word*	Created a publicly accessible website with information about the intervention, a promotional video for parents, and example materials
	Centralize technical assistance *Develop and use a centralized system to deliver assistance on implementation issues*	Created "Ask the Experts" and "Troubleshooting" online forums for clinicians using the intervention to seek input, get questions answered, and receive support
Inner context	**Provide ongoing consultation** *Provide ongoing consultation with experts to support implementation*	Following the training, all providers are invited to monthly reflective practice meetings to discuss use of the intervention at their agencies. Ongoing fidelity monitoring is available from BRIDGE mentors and agency trainers
	Facilitate relay of clinical data to providers *Provide data about key measures of process/outcomes of the innovation*	As a next step in our understanding of the effectiveness of the implementation process, child and family outcomes in community programs using the intervention will be examined

Collaborative developed templates of vendor applications that agencies can use to apply to the regional center to receive referrals and funding for the service. At least 66% of the agencies that received training in the most recent rounds have made use of this template and are now (or will soon be) vendored with the regional center to provide the intervention due to the BRIDGE Collaborative's support. BRIDGE members also created additional template documents, such as the necessary ongoing referral and child reports that the regional center requires at the end of intervention, to further facilitate the use of regional center referrals and funding. As laws shift and private insurers becomes a larger payer of services for children under 3, the BRIDGE Collaborative will likely continue to play a role in advocating for and facilitating the process of agencies receiving funding for the intervention from those sources as well.

A central inner context issue around sustainment has been the ongoing use of the intervention when faced with individual provider and leadership changes at an agency. Concerns around the need to train new staff in the context of high staff turnover at many community agencies initially drove the requirement for local capacity for train new personnel in the intervention. This requirement alone ruled out some interventions that otherwise met all stakeholder requirements. However, even with the capability to develop local experts in the intervention in each agency, retaining a workforce at any individual agency that is adequately trained and comfortable with the intervention remains a challenge. For example, of the ten providers who were initially trained in the pilot study of the selected intervention in 2011, only 60% of these therapists have remained with the same agency 3 years later (Stahmer, unpublished data).

Consistency in leadership at individual agencies has also been challenge to sustainment. Different leaders are likely to value and reward different aspects of provider behavior and allocate organizational resources differently (Schein, 2004). Their individual style may support or hinder the implementation of EBP as a whole or of a specific practice. For example, at one agency with several trained providers in the intervention, a change in leadership meant a shift in the population offered services by that agency. The new population did not match the way in which the EBP had been previously presented to that organization, and thus the new leadership planned to discontinue the practice. Without the ongoing relationships from the BRIDGE Collaborative, it is unlikely the intervention would have been sustained, despite enthusiastic support and desire to implement from individual clinical providers at that agency. A mid-level provider at that agency who is a member of the BRIDGE Collaborative has facilitated ongoing conversations between the new leadership and the research team to promote the idea that the EBP is appropriate for the new population focus. This is one example of how the BRIDGE Collaborative has continued to be important in the Sustainment phase of scaling up an EBP to the community.

Two additional implementation strategies are being utilized with the goal of furthering sustainment, and both involve the intervention website. The website was initially created with funds from research grants, but the goal is for it to be self-sustaining (through fee-for-service training) in the future, such that it can continue to exist beyond the period of research funding. The website contains a description of the intervention, example materials, and a video of parent testimonials on their experience with the program. This content is the initial stages of an implementation strategy to *use mass media* to promote awareness of and demand for the intervention from individual consumers. Naturally there is extensive room for growth in this strategy in terms of marketing and outreach, but a web presence is an important place to start when consumers are so quick to search the Internet for resources (or legitimize resources they've heard about). In the future, the didactic portions of the intervention training will be available on a fee-for-service basis on the web, with systems in place for intervention experts to provide distance coaching in conjunction with the online training for new therapists. The second implementation strategy that is being utilized via the website is the *centralization of technical assistance* for individual providers (Powell et al., 2015). Providers who have been trained in the intervention can access frequently asked questions and troubleshooting areas of the website, as well as participate in a discussion board or seek input form an "ask-the-expert" feature, which is managed by members of the BRIDGE Collaborative on a rotating basis. These features are available with the goal of creating a community of learners around the intervention to provide social support and an incentive for ongoing use.

Finally, in order for community agencies to continue to sustain the use of an EBP, it is important to facilitate the relay of clinical information to community providers, including linking the use of the practice to improved child and family outcomes (Aarons, Ehrhart, Farahnak, & Sklar, 2014). This is also important for ongoing support by funders. In order to address this, we are in the process of examining child and family outcomes in agencies trained using the train-the-train model described above. We are conducting a preliminary randomized trial that uses a hybrid effectiveness-implementation model, which includes dual testing of clinical and implementation interventions/strategies (see Curran, Bauer, Mittman, Pyne, & Stetler, 2012). Children and families receiving early intervention from providers who participated in the training project will be compared with children and families receiving usual care from providers who did not receive the training. We expect that children will have improved social communication outcomes, and caregivers will have increased satisfaction with services, feelings of competence and use of the intervention strategies. Assuming good implementation and effectiveness, the BRIDGE Collaborative will seek funding for a larger trial of both implementation and child outcomes.

Summary

Tools informed by implementation science can help to close the research to practice gap in services for children with ASD and their families. The BRIDGE Collaborative is a community-academic partnership focused on improving community intervention for toddlers with or at risk for ASD that has utilized a variety of implementation strategies in order to scale up an EBP available in the community. During the Exploration phase, close attention was paid to the needs and values of the community in order to identify an intervention that best met all stakeholder requirements. In the Preparation phase, the intervention was adapted to fully address those identified needs and values, and high-quality educational materials were developed. The Implementation phase involved a slow scale-up in terms of the number of providers trained, with an ongoing feedback loop such that previous efforts always informed later iterations of training and intervention use. Sustainment efforts for the intervention will focus on supporting agencies in receiving funding for the service and providing accessible forums for individual providers to discuss their use of the intervention. Overall, close consideration of the potential barriers to community use at both the inner and outer contexts of implementation use can facilitate scale-up of EBPs and improve access of children and families to high-quality service.

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Implementing Services for Children with ASD and Their Families Within State Early Intervention Programs: A View from Two States – Opportunities, Challenges, and Future Directions

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Abstract

The US Centers for Disease Control and Prevention estimates about 1 in 59 children in the USA has an autism spectrum disorder (ASD). A compelling parallel can be drawn between states' implementation of the national Part C Early Intervention Program, established in 1986 under the Individuals with Disabilities Education Act (IDEA), and the increased prevalence of very young children affected by ASD. States participating in this national program for infants and toddlers and their families have been on the front line of service delivery to the growing population of very young children with ASD and their families. This chapter provides a broad overview of the Part C Early Intervention Program, state practices and challenges related to Part C implementation with import to young children with ASD and their families, and the experiences of two states, New York and Massachusetts, in addressing the needs of these toddlers and families.

Introduction

Scientific understanding of identification, diagnosis, and early intervention with toddlers with ASD has rapidly evolved in the past five decades. According to the Centers for Disease Control, epidemiologic studies conducted in the late 1960s and 1970s estimated 1 in 2500 children in the population had autism, with prevalence estimates from the 2000s indicating 1–2% of children with autism (Centers for Disease Control and Prevention, 2014). Based on 2014 data from the Autism and Developmental Disabilities Monitoring Network, CDC now estimates that about 1 in 59 children in the USA has an ASD (Baio et al., 2018). In addition, research has demonstrated ASD can be detected as early as 18 months and reliably diagnosed by experienced professionals by the age of 2 (Centers for Disease

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https://doi.org/10.1007/978-3-319-90994-3_28

Control, 2016). The positive impact of early intervention services on young children's development is well-established, and science-based evidence in this area is rapidly expanding (Boyd et al., 2010; Lord & Bishop, 2010; Warren et al., 2011; Weitlauf, McPheeters, Peters, et al., 2014).

A compelling parallel can be drawn between states' implementation of the national Part C Early Intervention Program, established in 1986 under the Individuals with Disabilities Education Act (IDEA), and the increased prevalence of very young children affected by ASD. Arguably, states participating in the national program have been on the front line of service delivery to the growing population of young children under the age of 3 with ASD and their families (Noyes-Grosser et al., 2013).

The delivery of family-centered services is a central tenet of the IDEA Part C Early Intervention Program founded in the federal act, a primary purpose of which is to implement statewide, comprehensive, coordinated, multidisciplinary interagency service delivery systems to provide early intervention services for infants and toddlers with disabilities *and their families*. (Individuals with Disabilities Education Act, Purpose and Findings, §§631, 2004, 2016a). A substantial body of literature exists on family-centered services and parent involvement in early intervention programs (Dempsey & Keen, 2008). The Early Intervention Family Alliance has aptly articulated guiding principles of family-centered early intervention services (Early Intervention Family Alliance (2016) Guiding Principles, http:// http://eifamilyalliance.org):

- Families are essential partners in implementing family-centered practices in all levels of early intervention.
- Families are respected experts on the services their child should receive.
- Families have equal access to training and technical assistance to foster meaningful involvement.
- Family diversity and voices of the underrepresented are essential to quality services and implementation of policies and practices.
- Family-centered services that are community based and culturally competent ensure the highest quality programs.

This chapter provides a broad overview of the IDEA Part C Early Intervention Program (Part C) for infants and toddlers with disabilities and their families, state practices and challenges related to Part C implementation with particular import to young children with ASD and their families, and experiences of two states, New York (NY) and Massachusetts (MA), in addressing the needs of these toddlers and families.

Overview of Part C

The Part C program under IDEA is a national program for families and their infants and toddlers from birth to 3 years of age with disabilities and their families, including young children with ASD. In contrast to Part B of IDEA, which requires states[1] to provide a free, appropriate public education (FAPE) for children and youth aged 3–21 years with disabilities, participation in Part C is discretionary to states. All states currently participate in the program.

Required components of Part C for states are a state definition of developmental delay, which specifies the level of developmental delay and diagnosed conditions used for eligibility purposes; availability of early intervention services; evaluation, assessment, and nondiscriminatory procedures; Individualized Family Service Plans (IFSPs); comprehensive child find system; public awareness program; central directory of early intervention services, resources, and research and demonstration programs; comprehensive system of personnel development; personnel standards; a lead agency responsible for oversight of the program; a policy for contracting or otherwise arrange for services; reimbursement procedures; data collection system; state interagency coordinating council; and policies and procedures to ensure services are delivered to the maximum

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[1] For purposes of this article, the term "state" encompasses the 50 states and 6 US territories.

extent appropriate in natural environments (Individuals with Disabilities Education Act, §§635, State Requirements, 2004) (Individuals with Disabilities Education Act of 2004, 2016b).

States participating in the national program receive an annual appropriation through a formula grant for Part C implementation, driven by the proportion of children under 3 years of age residing in the state. These federal grants obligate participating states to adhere to a rigorous and comprehensive set of statutory and regulatory requirements applicable to all state Part C programs, including an entitlement to early intervention services included in children and families' Individualized Family Service Plans (IFSPs). While states are allowed to use their Part C formula grants to fund early intervention services (Individuals with Disabilities Education Act of 2004, §§638) (Individuals with Disabilities Education Act of 2004, 2016a), singularly the federal appropriations have been insufficient to meet the full need experienced by states in delivering services to eligible infants and toddlers and their families (IDEA Infant Toddler Coordinators Association, 2014). Importantly, in establishing and reauthorizing Part C, congress was clear in its intent that services were to be financed through a broad array of existing federal and state programs, most notably the Medicaid program under Title XIX of the Social Security Act (Individuals with Disabilities Education Act of 2004, §§635(a)(10), 2004) (Individuals with Disabilities Education Act of 2004, 2016b).

All states and territories currently participate in the Part C program. Collectively, in the 2014 program year, states delivered early intervention services to 350,581 or 3% of infants and toddlers in the USA and outlying territories based on the annual point in time count of children with an IFSP and in the Part C EIP on either October 1 or December 1 of that year (US Department of Education, Office of Special Education Programs, IDEA Data Products 2014–2015, 2016). Across 40 states optionally reporting the count of infants and toddlers receiving early intervention services at some point during the 2014–2015 reporting period (referred to as a "cumulative count" of children and families participating in state early intervention programs), 434,806 children and their families received early intervention services in this time frame. In our respective states, 4% of children under the age of 3 in NY and 8.89% in MA (which includes infants and toddlers at risk for disability in the state's eligibility criteria) participated in Part C, with 54,560[2] children in NY and 36,092 in MA receiving early intervention services at some point during the reporting period (US Department of Education, Office of Special Education Programs, IDEA Data Products 2014–15, 2016).

Both NY and MA have experienced significant growth in the number of children with ASD and their families enrolled in our respective Part C programs. In the 2014–2015 program year (July 1 through June 30), 7986 toddlers in NY's Part C program had a reported diagnosis of ASD, compared with 639 children reported with an autism diagnosis in 1999–2000 (the first year in ICD-9 diagnostic codes associated with children's eligibility for were collected). MA anticipates that 2066 children with ASD will participate in the MA Part C program 2016 state fiscal year.

The reauthorization of IDEA in 2004 added new requirements on states intended to shift the focus from compliance with federal law and regulations governing early intervention and special education systems to results-driven accountability. The state is required to develop state performance plans and report annually on federally established compliance and performance indicators (Individuals with Disabilities Education Act of 2004, §§616) (Individuals with Disabilities Education Act of 2004, 2016c). For Part C, performance indicators include metrics related to delivery of services in natural environments (defined as settings where typically developing peers are found, including home and community settings), percent of children under 3 years of age receiving Part C services, percent of children under 1 year of age receiving Part C services, child outcomes, and family outcomes. Notably, states are required to

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[2] For NY, the child counts reported to the US Department of Education exclude toddlers aged three and older who have been found eligible for Part B preschool special education services and, at parent option, can remain in the early intervention program for a period of time determined by their month of birth.

collect and report on the following child and family indicators: percent of infants and toddlers who demonstrate improved positive social-emotional skills, including social relationships; acquisition and use of knowledge and skills, including early language and communication; and use appropriate behaviors to meet their needs (Indicators 3a, b, and c) and percent of families who report early intervention services helped them know their rights, effectively communicate their child's needs, and help their child develop and learn (Indicators 4a, b, and c). Table 28.1 presents all compliance and performance indicators for Part C programs reported annually by states (US Department of Education, Office of Special Education Programs, 2014a, 2014b).

In 2014, the state performance plan/annual performance report requirements were augmented to include a new State Systemic Improvement Plan (SSIP) designed to focus state efforts on a State Identified Measurable Result (SIMR), either a child outcome, family outcome, or suite of outcomes, selected in conjunction with stakeholders (US Department of Education, Office of Special Education Programs, 2014b). In further alignment with the enhanced focused on accountability for results being achieved for children and families in state early intervention service delivery systems, the US Department of Education, Office of Special Education Programs, recently included child outcomes data for the first time in determining the extent to which states met federal requirements for the Part C EIP (US Department of Education, Office of Special Education Programs, 2014a).

Table 28.1 State performance plan and annual performance report indicators

1	Percent of infants and toddlers with IFSPs who receive the early intervention services on their IFSPs in a timely manner
2	Percent of infants and toddlers with IFSPs who primarily receive early intervention services in the home or programs for typically developing children
3	Percent of infants and toddlers with IFSPs who demonstrate improved A. Positive social-emotional skills (including social relationships) B. Acquisition and use of knowledge and skills (including early language/communication) C. Use of appropriate behaviors to meet their needs
4	Percent of families participating in Part C who report that early intervention services have helped the family A. Know their rights B. Effectively communicate their children's needs C. Help their children develop and learn
5	Percent of infants and toddlers birth to 1 with IFSPs compared to (A) other states with similar eligibility definitions and (B) national data
6	Percent of infants and toddlers birth to 3 with IFSPs compared to (A) other states with similar eligibility definitions and (B) national data
7	Percentage of eligible infants and toddlers with IFSP's for whom an evaluation and assessment and an initial IFSP meeting were conducted within Part C's 45-day timeline
8	Percent of all children exiting Part C who received timely transition planning to support the child's transition to preschool and other appropriate community services by their third birthday including A. IFSPs with transition steps and services B. Notification to LEA, if child potentially eligible for Part B C. Transition conference, if child potentially eligible for Part B
9	Percent of hearing requests that went to resolution sessions that were resolved through resolution session settlement agreements (applicable if Part B due process procedures are adopted by the lead agency under 34 CFR §303.420(a))
10	Percent of mediations held that resulted in mediation agreements
11	State Identified Measurable Result (from among indicators 3 and 4 or related to 3 and 4) and State Systemic Improvement Plan

Adapted from the US Department of Education, Office of Special Education Programs (2014b). FFY 2013–2018 Part C SPP/APR Part C SPP/APR Indicator/Measurement Table – Page 1 (OMB NO: 1820-0578/Expiration Date: 5/31/2017)

From Policy to Practice: Variations in State Implementation of the Part C EIP

The IDEA Infant Toddler Coordinators Association (ITCA) is a membership association for state Part C coordinators and staff organized as a not-for-profit corporation. The core work of ITCA is to promote mutual assistance, cooperation, and exchange of information and ideas in the administration of Part C and to provide support to state and territory Part C coordinators (IDEA Infant Toddler Coordinators Association, Association Information, 2016). MA and NY are long-standing members of ITCA, which in the ITCA fiscal year 2015 included 51 states. An important function of ITCA is to work strategically with the membership on identifying, assessing, and reporting on a wide range of policy and operational issues impacting state participation in Part C.

Annually, ITCA works with member states on issues related to eligibility criteria included in state definitions of developmental delay, a required Part C component. ITCA also conducts an annual state challenges survey (known as *Tipping Points*) of member states to assess current status of states' implementation of federal Part C requirements, including state challenges and responses (IDEA Infant Toddler Coordinators Association, Board Approved Surveys, 2015). On a biennial basis, a finance survey is conducted to examine the revenue sources used by states to support their early intervention systems (IDEA Infant Toddler Coordinators Association, Board Approved Surveys, 2014). Combined results from the Tipping Points and finance surveys provide comprehensive information available on state management and implementation of Part C requirements.

Among ITCA's initiatives with and on behalf of member states, these three areas of focus – eligibility, state challenges and responses, and finance – are especially informative in understanding the milieu in which infants and toddlers with ASD and their families are receiving Part C services and in which specific service delivery models to treat ASD are being delivered. Highlights of key findings from each of these three areas of focus follows.

Eligibility Issues

Under Part C, states must include infants and toddlers with disabilities (defined as inclusive of developmental delay) in state definitions of developmental delay and may include children at risk for disability in state-established eligibility criteria (Individuals with Disabilities Education Act of 2004, §§ 635) (Individuals with Disabilities Education Act of 2004, 2016b). State eligibility criteria establish the degree of delay required for eligibility in one or more areas of development (cognition, communication, physical, social, emotional, and adaptive) and specify the diagnosed physical and mental conditions with a high probability of resulting in developmental delays. ITCA works with member states to review and categorize states' definition of developmental delay as "broad" (15 states), "moderate" (18 states, including MA and NY), and "narrow" (19 states) (IDEA Infant Toddler Coordinators Association, Child Count Data Charts, 2013).[3] Only five states, including MA, include children at risk for developmental delay in their eligibility criteria. Children with ASD are frequently referred to and found eligible for state early intervention programs based on developmental delays rather than on a particular diagnosed condition.

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[3] Broad eligibility is defined as including state eligibility definitions which include children at risk or with any delay or atypical development: a delay of one standard deviation in one developmental domain, 20% delay in two or more domains, 22% delay in two or more domains, or 25% delay in one or more domains. Moderate eligibility is defined as state eligibility definitions which include children with a 25% delay in two or more domains, 30% delay in one or more domains, 1.3 standard deviations in two domains, 1.5 standard deviations in any domain, or 33% delay in one domain. Narrow eligibility is defined as state definitions of eligibility which include children with a 33% delay in two or more domains, 40% delay in one domain, 50% delay in one domain, 1.5 standard deviations in two or more domains, 1.75 standard deviations in one domain, 2 standard deviations in one domain, or 2 standard deviations in two or more domains.

ITCA has also developed an innovative "birth cohort" approach to collecting and analyzing data on child and family participation in state Part C EIPs (Noyes-Grosser & MacCleod, 2013). Using the common demographic characteristic of year of birth, ITCA queries states on the extent to which children born in a given calendar year participate in major benchmarks of program participation (referral, evaluation/eligibility determination, IFSP/early intervention services, and transition/exit). Data available from 30 states demonstrate that of children born in 2010, the most recent cohort for which data are available, across all states on average 10% of children were found eligible for the Part C EIP at some point between birth and age 3 (Barger et al., 2015). The birth cohort approach provides a clearer picture of the scope and reach of state Part C EIPs by examining the extent to which young children access early intervention services at any point in time while age-eligible for the program.

More recently, ITCA has collaborated with member states and federal partners, including the Centers for Disease Control and Prevention, National Center for Birth Defects and Developmental Disabilities, and the US Department of Education, Office of Special Education Programs, on a project to collect and analyze information on the diagnosed physical and mental conditions with a high probability of developmental delay used by states to establish eligibility for Part C. At least 20 states include autism spectrum disorder as diagnosed conditions with a high probability of resulting in developmental delay (Barger et al., 2015).

State Challenges and Responses and Financing of Early Intervention Services

Lead Agency and Organizational Structure

States are required under IDEA to identify a state lead agency responsible for the administration of their early intervention programs. Of 49 states responding to the Tipping Points survey in 2015, 21 (43%) reported the state health agency (including NY and MA), 12 (24%) reported the education agency (24%), and 16 (33%) reported others (e.g., developmental disabilities agencies, early childhood offices, human services) as responsible for administration of their early intervention programs. State-level organization of Part C varies across states which have been described and analyzed using data from Tipping Points in four broad categories:

- Private programs (57% of respondents, $n = 28$): programs/agencies in a direct relationship with states are responsible for all eligible children from referral through transition in an assigned regional or local catchment area, with services provided by program/agency employees or contractors.
- Regional public/private (18% of respondents, $n = 9$): regionally based programs responsible for initial intake (referral, service coordination, and initial IFSP development), with services provided by practitioners or agencies and reimbursed as contractors/vendors through a state fiscal administrator.
- State operated (14% of respondents, $n = 7$): state personnel from one ($n = 5$) or multiple lead agencies ($n = 2$), based in state-defined local areas, are responsible for all activities from referral through service delivery.
- Others (10%, $n = 5$): alternative structures uniquely identified by respondent states.

Funding and Sources for Early Intervention Services

States are responsible for maintaining systems of payments for financing of early intervention services, which may include use of public and private insurance and a system of parent fees that meet federal requirements (parents cannot be charged for functions related to child find, evaluation and assessment, service coordination services) (Individuals with Disabilities Education Act of 2004, §§636, Individualized Family Service Plan) (Individuals with Disabilities Education Act of 2004, 2016d). Results of the finance survey, based on 47 state member respondents, revealed reimbursement for early intervention services approaching $3.7 billion in the

2013–2014 federal fiscal year, across all identifiable sources of funding. Only 15 of the 47 states participating in the survey were able to account for all revenues for each fund source reported, suggesting that reimbursements were unreported with the exception of federal Part C formula fund grants (IDEA Infant Toddler Coordinators Association, 2014).

States participating in the finance survey reported a range from 2 to 15 different funding sources supporting early intervention services, with an average of seven fund sources. Across all funding sources for early intervention services reported by respondents, state funds (including state general funds) accounted for 55% of all reimbursements to providers for early intervention services delivered to infants and toddlers and their families participating in state Part C programs. Federal funding, largely Medicaid, accounted for 31%, local governments accounted for 15%, and private insurance accounted for only 3% of provider reimbursement for early intervention services delivered to children and families through state Part C programs. Twenty-one percent of finance survey respondents indicated that their states have statutory requirements related to use of private insurance for reimbursement of early intervention services (IDEA Infant Toddler Coordinators Association, 2014).

Forty-four states responding to the finance survey reported some form of family cost participation in use in the Part C EIPs. Eleven states reported use of private insurance (i.e., parents are required to use insurance coverage for early intervention services), three states reported use only of a parent fee schedule, and fourteen states implement both parent fee schedules and require parents to use private insurance coverage for early intervention services (IDEA Infant Toddler Coordinators Association, 2014).

In a recent program year, NY reimbursements to providers totaled $137 million in state and local funds for early intervention services delivered to children with an ASD diagnosis and their families. Total reimbursements for services to children with ASD and their families were over $200 million, with Medicaid reimbursement of more than $67 million. MA reimbursed providers $7 million in state funds for services to children with an ASD diagnosis, with a total of $22.8 million across all fund sources combined (Medicaid and commercial insurance) for ASD specialty services only (applied behavior analysis (ABA), ABA-informed), not inclusive of other early intervention services provided to toddlers and their families.

As noted above, Medicaid is a critical source of funding for early intervention services delivered through state Part C programs. With respect to children with ASD, important new guidance was recently issued by the US Department of Health and Human Services, Center for Medicare and Medicaid Services (CMS). On July 7, 2014, CMS published an Informational Bulletin indicating that federal approval for autism-related services for children, such as ABA, may be available under traditional Medicaid state plan authority (Centers for Medicare and Medicaid Services, Center for Medicaid and CHIP Services, 2014a). CMS indicated that federal requirements for early and periodic screening diagnosis and treatment (EPSDT) entitle Medicaid-eligible children under 21 years of age to all medically necessary services that can be approved under a traditional Medicaid State Plan, which would now include autism-related services. Subsequent information provided by CMS in September 2014 indicated that states do not have to provide ABA therapy per se but must provide services that produce similar outcomes. CMS encouraged states to develop state plan amendments and offered assistance in this process (Centers for Medicare and Medicaid Services, Center for Medicaid and CHIP Services, 2014b).

Planned and Delivered Hours of Service

The Tipping Points Survey asks states to respond to two questions related to the intensity of services delivered to children and families in their Part C programs. First, states are asked to report the number of planned hours of direct services (excluding service coordination and evaluation and assessment services) per child per month. Of 49 states participating in the 2015 survey, 24 responded to this question. The number of planned services across these states ranged from

1 to 12 h per month, with a median of 5 h per month. Second, states were asked to report the average number of direct service (excluding service coordination and evaluation and assessment services) per child per month. Across the 25 state respondents, delivered service hours per child per month ranged from less than an hour (54 min) to 12 h, with a median of 4.3 h per month (IDEA Infant Toddler Coordinators Association, 2015).

The Tipping Points survey does not ask states to provide data on planned and delivered services based on the type of developmental delay or diagnoses affecting children. In both NY and MA, children with ASD receive a more intensive level of services than toddlers with other disabilities or developmental delays and their families. In NY, on average, the median hours of service per month delivered to toddlers with ASD is 37 and ranges from 11 (tenth percentile) to 78 h (ninetieth percentile) per month. In MA, the median hours per month of service for toddlers with ASD is 40 h, with a range from 24 to 100 h per month.

Length of Child and Family Program Participation

Tipping Points also asks states to report the average length of time children participate in the state Part C program. Thirty-six states responded to this question. Among these states, the average length of time children and families participate in Part C programs ranged from 9 to 36 months, with a median of 15 months.

The *Tipping Points* survey does not ask states to provide these data based on the type of developmental delay or diagnoses affecting children. In NY, children with ASD experience a similar length of stay as other children with developmental delays and disabilities, with an average length of Part C program participation of 16 months. In MA, the average length of program participation for children with ASD and their families is 14 months.

State Identified Measurable Results (SIMR) for State Systemic Improvement Plans (SSIP)

Because State Systemic Improvement Plans will be a driving force in state Part C EIPs through 2020, the Tipping Points survey was expanded to request information from member states on the State-Identified Measurable Result included in those plans. Twenty-three (50%) of 49 states responding to this question identified child outcome indicator 3a, "social-emotional development, including positive social relationships," as the SIMR selected by the state in collaboration with stakeholders (State Interagency Coordinating Councils, parents, providers, state and local officials, etc.) (IDEA Infant Toddler Coordinators Association, 2015). MA is included among these states. Eleven states (24%) selected child outcome indicator 3b, "acquisition and use of knowledge and skills (including early language/communication)," and two states selected child outcome indicator 3c, "use of appropriate behavior to meet their needs," as the SIMR.

Three states selected family outcome indicator 4c, "help their child develop and learn," as the SIMR. NY is among states selecting family outcomes as the focus of the SIMR, collaborating with stakeholders to set a state standard on NY's modified version of the National Center for Special Education Accountability Monitoring "Impact on Family" scale which encompasses all three indicators for family outcomes (New York State Department of Health, Bureau of Early Intervention, 2015).

The New York Experience

New York has one of the nation's largest early intervention programs, delivering services to about 65,000 infants and toddlers with disabilities and their families with an Individualized Family Service Plan (IFSP) annually. The NYS Department of Health (NYSDOH) is the lead agency for NY's Early Intervention Program (NYEIP). The NYEIP local programs are administered by 57 counties and New York City, largely by public health agencies. Providers of early intervention services are approved by and have agreements with the NYSDOH to deliver services to eligible children and their families and include both agencies and independent practitioners. Statewide, close to 15,000 professionals participate in the NYEIP.

Like many states across the nation, in the initial years of statewide implementation of Part C, the NYSEIP experienced increasing referrals of children with ASD and their families. As noted above, participation of children with ASD and their families has grown dramatically during the past two decades, from 639 children reported as having an autism diagnosis in the 1999–2000 PY (1% of all children participating in the NYSEIP) to 7986 in the 2014–2015 program year.

Both nationally and within NY, wide variation existed in the types and amounts of early intervention services provided to young children with developmental disabilities during the first several years of the Part C EIP implementation in the 1990s (Noyes-Grosser et al., 2005). A key challenge experienced by NY and other states across the nation was the need for information and support for program administrators, parents, and early intervention service providers in making decisions about high-quality and cost-effective evaluation, assessment, and early intervention services for children and families referred for Part C EIP services. This need was particularly pressing for children with autism and their families, given emerging evidence from research indicating that early and intensive treatment could significantly improve children's developmental outcomes.

Evidence-based Autism Clinical Practice Guideline

In 1996, a multiyear effort was initiated by the NYSDOH to develop a series of evidence-based clinical practice guidelines focused on the identification, assessment, and intervention for young children with developmental problems likely to require early intervention services. The overall goal of this effort was to improve the quality and consistency of care for young children with developmental disabilities by providing families, service providers, and public officials with recommendations about best practices based on scientific evidence and expert clinical opinion.

To ensure that the guidelines would have maximum credibility and impact, the NYSDOH followed an established and well-accepted science-based methodology for guideline development used by the US Department of Health and Human Services Agency for Healthcare Policy and Research (later renamed the Agency for Healthcare Research and Quality (AHRQ)). The AHRQ clinical practice guideline methodology is considered to be the standard for developing evidence-based medical and healthcare clinical practice guidelines and has been described in numerous publications (Eddy and Hasselblad, 1995; Holland, 1995; Schriger, 1995; Shekelle et al., 2001; Wolf, 1991, 1995). The NYSDOH was the first to adapt the AHRQ methodology for use in development of clinical practice guidelines addressing assessment and intervention practices for children with disabilities (Noyes-Grosser et al., 2005).

Six Early Intervention Program clinical practice guidelines on assessment and interventions for young children (0–3 years of age) were completed by the NYSEIP. The first guideline, and arguably the guideline which has had the most impact, was *the New York State Early Intervention Program Clinical Practice Guideline: Assessment and Intervention with Young Children (0–3) with autism and pervasive developmental disorders (NY Autism Guideline)*. The guideline is posted on the NYSDOH website, http://www.health.ny.gov/community/infants_children/early_intervention/disorders/autism.

A defining feature of the AHRQ methodology is the use of a multidisciplinary consensus panel, including clinicians, researchers, and consumers, to review all available scientific evidence on the guideline topic and develop consensus recommendations based on the evidence. To develop the NY Autism Guideline, the NYSEIP engaged an expert project team and a panel comprised of consumers, researchers, clinical experts, and physicians (four parents of children with autism, two developmental pediatricians, four psychologists, two speech-language pathologists, a special educator, occupational therapist, social worker, and psychiatrist) to review 20 years of research and reach consensus on recommended practices for identifying, assessing, and treating autism in children from birth to 3 years.

The panel reached consensus on a total of 256 practice recommendations for delivering services to young children with autism/pervasive developmental disorders and their families, 122 of which addressed assessment (early identification and screening, diagnostic, developmental, and medical assessments) and 134 of which addressed intervention methods (general approach, behavioral and education approaches, other experiential approaches, and medical treatments). These recommendations include a combination of evidence-based (i.e., supported by scientific evidence from more studies published in peer-reviewed journals) and panel consensus opinion recommendations (i.e., opinion based on standards of practice in the field for which either a systematic literature search was conducted and no studies were found or no systematic literature search was completed). Each of these recommendations was rated by the panel for strength of evidence supporting the recommendation. Table 28.2 provides a broad overview of these recommendations and the distribution of evidence-based and consensus opinion recommendations.

The NY Autism Guideline underwent an extensive national peer review by 62 experts and parents, including clinicians, researchers, and early intervention program administrators. Reviewers were asked to comment on the final draft guidelines, rate them on usefulness and understandability, and identify any research that may have been missed by the panel that would lend support or provide evidence to modify or refute guideline recommendations. Comments received through the peer review process were reviewed by the panel at a final panel meeting. Final decisions regarding the recommendations were made by the panels on the basis of the strength of evidence provided by the reviewer and with the consensus of the full panel.

The NY Autism Guideline is intended to guide families, service providers, and local public officials with scientific evidence and expert clinical opinion on effective practices for early identification of children with ASD; conducting evaluations and assessments that establish a diagnosis of ASD or rule out this diagnosis, as well as information about children's developmental strengths and needs; and determining effective intervention strategies and reaching agreement on the frequency, intensity, and duration of early intervention services that will result in positive outcomes for children with ASD and their families.

The role of the parent and the family in early intervention services for children with ASD was an important area of focus of the 1999 NY Autism Guideline. Recommendations for family involvement include the early intervention process which includes the following:

Role of the Family in Assessment and Intervention Processes

> It is important that parents be involved as active participants in all aspects of the child's ongoing assessment and intervention process to the extent of their interests, resources, and abilities.
> Parental involvement is important to ensure that the family's desired outcomes for the intervention, as well as the family's values and priorities, are considered when developing the intervention plan.
> It is recommended that professionals share with parents the scientific evidence about effectiveness of intervention methods being proposed or used, as well as the advantages and disadvantages of the proposed methods.
> It is important for professionals working with the child to understand and respect the family's values, priorities, and parenting philosophies. New York State Department of Health, 1999, pg. 127).

Considering the Cultural Context of the Family

> A child's life is embedded within a cultural context. It is essential to consider and respect the family's culture when providing interventions for children with autism.
> If English is not the primary language of the family, it is important for professionals to look for ways to communicate effectively with the family and the child, including use of healthcare professionals, early intervention professionals, or translators who speak the family's language. (New York State Department of Health, 1999, pg. 127).

In addition, the guideline includes specific recommendations on parent involvement and training as an important component of early intervention service delivery to toddlers with ASD. These are:

Table 28.2 NYS Autism Guideline recommendations overview

Early identification and assessment	Number of evidence-based recommendations	Number of consensus opinion recommendations
Early identification	1	–
Establishing a diagnosis	3	3
Developmental assessment	–	9
Health evaluation	–	6
Consideration for professionals	–	9
Principles	–	7
Clinical clues	1	3
Screening	3	1
Autism assessment instruments	6	10
Developmental assessment	–	25
Assessing communication	–	3
Assessing social interaction	–	5
Child and family environment	–	2
General health evaluation	–	9
Associated conditions	–	8
Use of MRIs to diagnose autism	–	2
Use of SPECT to diagnose autism	–	–
Immune status	–	–
Food allergies	–	1
Yeast overgrowth	–	1
Intervention methods		
Linking assessment to intervention	3	11
General considerations	2	9
Role of the family	–	6
Common elements of effective interventions	9	–
Intensive behavioral and educational programs	1	1
Principles of behavioral techniques	13	1
Reducing maladaptive behaviors	8	3
Improving communications	9	5
Improving social interactions	3	3
Parent training	1	1
DIR model	–	5
Sensory integration	–	5
Auditory integration	1	–
Facilitated communication	–	1
Music therapy	1	–
Touch therapy	1	–
Diet and medication		
General approach	3	4
Psychoactive medications	5	6
Hormone therapies	–	1
Immunologic therapies	–	3
Anti-yeast	–	2
Vitamin therapies	1	2
Diet therapies	–	2

> It is important to include parents as active participants in the intervention team to the extent of their interests, resources, and abilities. Parent involvement is important to ensure that behavioral and educational outcomes, goals, and strategies most important to the family are incorporated in the intervention.
>
> It is recommended that parents be trained in behavioral techniques and encouraged to provide additional hours of instruction to the child.
>
> Parent training is important to help the family incorporate these techniques into the daily routines of the child and family and to ensure consistency in the intervention approach.
>
> It is recommended that training of parents in behavioral methods for interacting with their child be extensive and ongoing and include regular consultation with a qualified professional. (NYS Department of Health, 1999, pg. 140).
>
> It is recommended that parent training be included as an important component of comprehensive intervention programs for children with autism. Parent training programs may be useful because they help support the family in caring for the child; involve the parents in choosing intervention outcomes, goals, and strategies that are important to the family; help the family incorporate the intervention strategies into the daily routines of the child and family; help to ensure consistency in the intervention approach; improve the interaction between the parents and their child; and increase parent satisfaction and reducing parent stress (NYS Department of Health, 1999, pg. 150).

The guideline also included questions, based on recommendations on interventions that may be helpful to parents, caregivers, or other individuals when interviewing potential intervention providers to work with the child and family (New York State Department of Health, 1999, pg. 131). These questions are presented in Table 28.3.

More than 100,000 copies of the NY Autism Guideline are in circulation, and requests for the guideline have been received from around the world. Since its issuance, the guideline has been used as an educational tool and decision-making resource for families, primary referral sources, public officials, and providers on evidence-based practices for delivering early intervention services to young children with ASD. The NYSEIP implemented an intensive, initial statewide training effort on the guideline in 1999 and currently offers ongoing regional training sessions for program constituents.

To be effective and useful to clinicians, families, and public officials, clinical practice guidelines need to reflect current scientific evidence. The NYSDOH received a grant from the FAR Fund to update the NY Autism Guideline, work completed in 2017. A 20-member expert panel,

Table 28.3 NYS Autism Guideline: Questions to ask providers

Questions to ask providers The following are questions that may be helpful to parents, caregivers, or other individuals when interviewing potential intervention providers. These questions were developed from the guideline recommendations on interventions
1. What kinds of intervention, therapy, and services do you provide? Please describe a typical day or session
2. Do you have a particular philosophy on working with children with autism/PDD?
3. How many hours per week do these services require, and how much of this is one-on-one time with the child?
4. Please describe a typical day or session.
5. What experience do the teachers and/or therapists have in working with children with autism?
6. What experience does the person who supervises the program have? How closely does the program supervisor work with the therapists, teachers, and parents?
7. What kinds of ongoing training do your full- and part-time staffs participate in?
8. Are parents involved with planning as part of the intervention team?
9. Do you provide a parent training program?
10. How much and what kinds of involvement are expected of parents and family members?
11. Are parents welcome to participate in or observe therapy and/or group sessions?
12. What techniques do you use to manage difficult behaviors?
13. Do you ever use physical aversives or any physically intrusive procedures? If yes, please describe them.
14. Please describe your program for communication and language development. Do you use a picture communication system, sign language, other kinds of communication systems, or all of these?
15. Are there opportunities for integration with typical and/or higher functioning children?
16. How do you evaluate the child's progress, and how often?
17. How do you keep parents informed of the child's progress?

including several members of the original panel, was convened to use the AHRQ evidence-based methodology (Shekelle et al., 2001, Holland, 1995) to complete the guideline update. Research experts were commissioned to review new scientific evidence published in peer-reviewed journals since 2000 and prepare reports and presentations for the panel. Topic areas addressed by these expert reviewers were ASD screening and diagnosis, medical management (health evaluations and medical treatments), and early intervention approaches for young children with ASD and their families (New York State Department of Health, 2017b). The expert reports and presentations were used by the consensus panel in their deliberations to update the NY Autism Guideline (New York State Department of Health, 2017b).

As part of their initial work, panelists were asked to complete an extensive survey of all of the original recommendations in the 1999 guideline, to identify those recommendations which in the panelist's opinion were relevant and continued to be supported by the evidence; where new evidence had emerged such that the recommendation needed to be revised; and where new evidence was available to refute the recommendation. Three subsequent meetings and several webinars discussed the most recent scientific evidence with the expert reviewers and collaborated to update the original and develop new recommendations. Consistent with AHRQ methodology (Holland, 1995), a final draft of the guideline was reviewed by 21 peer reviewers, including parents of children with ASD, nominated by panel members. The final *Clinical Practice Guideline on Assessment and Intervention for Young Children with ASD, 2017 Update*, incorporating revisions based on the peer review process, consists of three documents: the *Report of the Research Evidence,* which details the expert literature reviews used by the panel (New York State Department of Health, 2017b); the *Report of the Recommendations*, which describes the work of the panel and includes all recommendations (New York State Department of Health, 2017a); and the *Quick Reference Guide for Parents and Professionals (New York State Department of Health, 2017c)*. All three documents are available on the NYSDOH website *(www.health.ny.gov/community/infants_children/early_intervention/memoranda.htm)*.

The important role of parents in all aspects the early intervention process for young children with ASD is reflected in panel recommendations included throughout the 2017 update. In addition, the 2017 update includes the following new recommendations on parent-mediated approaches to intervention and on family well-being and support:

Parent-Mediated Approaches

> It is recommended that parent-mediated interventions be offered to parents as part of a comprehensive plan of early intervention services for parents and young children with ASD.
> If a child spends significant amounts of time with other caregivers beside the parents (e.g., grandparents, nannies, daycare staff), these caregivers should be provided the opportunity to learn strategies for promoting learning objectives during familiar daily routines.
> It is recommended that parent-mediated interventions be implemented with sufficient duration and intensity to effectively increase children's learning opportunities during a broad range of familiar daily life routines.
> It is recommended that comprehensive parent-mediated interventions be implemented in the child's natural environment whenever possible. This includes the families' home, the child's daycare, and various community locations.
> It is recommended that the intensity, duration, and context of comprehensive parent-mediated interventions be adapted in ways that reflect the child's schedule, the parents' time constraints, and the families' physical and social home environment. (New York State Department of Health, 2017a, pages 71–72).

Family Support

> It is important to recognize that parents with children with ASD often experience high levels of stress.
> It is recommended that when professionals are interacting with families that they be aware of and be sensitive to family and caregiver well-being and increased stress levels of caregivers of young children with ASD.

> Families may benefit from referrals to other resources in their community and information and support that may be of assistance.
> It is important to recognize that many families can benefit from peer to peer support and should be provided information about parent support groups in their area.
> It is recommended that families who are experiencing stress in raising their children with ASD be referred to mental health support services. (New York State Department of Health, 2017a, 2017b, pages 71–72).

In addition to the NY Autism Guideline, the NYSDOH has completed two other major projects to improve early intervention services for young children with ASD and their families. In 2010, the NYSDOH was the recipient of a state implementation grant to improve services for children and youth with ASD and other developmental disabilities and their families from the Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services. A major area of focus for this grant was to implement training programs and resources for pediatricians to adhere to American Academy of Pediatrics (AAP) guidelines for the identification, evaluation, and management of children with ASD, including universal screening of toddlers at 18 and 24 months for possible autism (Johnson et al., 2007). The NYSDOH collaborated with the NYS Chapter of the AAP to develop a Best Practice Protocol for Universal Screening of Young Children for ASDs by Pediatric Primary Care Providers, available on the NYSDOH website at: *http://www.health.ny.gov/community/infants_children/early_intervention/autism/docs/best_practice_protocol.pdf*. A companion physician's desk reference on early identification, diagnosis, and referral for early intervention services was published and distributed to 4500 members of AAP across NY State.

More recently, the NYSDOH Bureau of Early Intervention completed a large study to evaluate the impact of participation in Part C services on toddlers with ASD and their families, funded by the US Department of Health and Human Services, Health Resources and Services Administration, Maternal Child Health Research Program.

In the first phase of this study, concept mapping methodology (Kane & Trochim, 2007) was used with stakeholders representing diverse perspectives to identify the ASD-specific child and family outcomes expected to be achieved through EIP participation. A detailed description of the concept mapping study is reported in Noyes-Grosser et al. (2013).

During the brainstorming phase, 724 child and family ASD outcome items were generated by study participants and reduced by the research team to a set of 105 items (54 child-related and 51 family-related outcomes) representing the breadth and depth of the initial brainstormed content for use in sorting and rating activities. The study found moderately strong agreement between parent and professional ratings of the importance of child and family outcomes to be achieved through early intervention program participation. Moderate agreement was also found between parent and professionals on ratings of the likelihood that EIP services will impact child and family outcomes (Noyes-Grosser et al., 2013).

Among the family outcome items, those with the highest ratings on importance and likelihood by parents and professionals were:

- Learn ways to help their child develop basic social interaction skills.
- Be supported and educated in understanding their child's diagnosis.
- Know and understand their rights with respect to early intervention services.
- Learn ways to promote positive behavior.
- Carry over techniques used by therapists and teachers and use these with their children (Noyes-Grosser et al., 2013, page 346, Table 28.3).

Among the child outcomes, those with the highest ratings on importance and likelihood by parents and professionals were:

- Learn how to communicate needs and wants using spoken language, sign language, or assistive device.
- Be able to seek assistance when distressed.
- Learn appropriate skills and behaviors to participate in social, educational, and recreational activities with other children.
- Develop trusting relationships with caregivers.
- Be able to handle every day transitions (Noyes-Grosser et al., 2013, page 3345, Table 28.2).

In a subsequent phase of this study, the child and family outcomes generated by stakeholders in concept mapping were integrated into existing NY Impact on Child (NYICS) and Impact on Family (NYIFS) scales included in the annual family survey conducted by the NYSEIP for program evaluation and federal reporting purposes (Elbaum et al., 2014). These scales measure the extent to which early intervention services are helpful to families in achieving child outcomes (NYICS) and family outcomes (NYIFS) expected from program participation (Noyes-Grosser and Elbaum, 2011). The NYIFS scale is a modified version of the national Impact on Family Scale developed by the National Center for Special Education Accountability Monitoring (Fisher et al., 2012), currently in use by 23 states for collection and reporting of family outcome data required by the US Department of Education, Office of Special Education Programs (Early Childhood Outcomes Center, 2015).

Families participating in the study were asked to complete a family survey with these modified NYSICS and NYSIFS, among other child and family outcome measures, as they exited the NYSEIP and the study. A total of 167 families in the ASD group and 95 families in the comparison group completed and returned the family survey.

Analyses completed on the results found no meaningful differences in how families in both groups responded to these scales, suggesting that a common set of items can be used for families receiving early intervention services, including children with ASD, for program evaluation purposes (Elbaum et al., 2014). Based on these results, the NYSEIP has revised the annual family survey completed by families of children exiting the program to include a subset of the ASD-specific items generated through this study in the NYICS and NYIFS scales. Both scales hold promise for state-level efforts to evaluate outcomes of early intervention services on children and families participating in state early intervention programs, including children with ASD and their families (Noyes-Grosser et al., in press).[4]

The Massachusetts Experience

By the late 1990s, the Massachusetts Department of Public Health (MA DPH), Part C lead agency, was concerned about meeting the needs of the increasing numbers of very young children identified with ASD. The MA DPH contracts with local Early Intervention Programs (MA EIPs) who are responsible for delivering evaluations, service coordination services, and therapeutic and support services when selected by families residing within the MA EIPs' designated catchment areas.

Existing MA EIPs did not have appropriately trained staff to deliver the clinical approaches most effective for this population. Resources to train staff with traditional early intervention disciplines (for example, special instruction, speech language pathology, occupational therapy, etc.) to meet this need in a reasonable time frame were insufficient, and changing the rate system for MA EIPs to accommodate intensive behavioral intervention would have been a time-consuming process. A request for response was issued to solicit providers able to offer intensive intervention to children with a diagnosis on the autism spectrum and work in conjunction with MA EIPs to address the needs of the family related to enhancing the child's development. Applicants responded to a competitive process that required demonstration of:

- Expertise in addressing the needs of very young children with ASD
- Ability to asses a child's functional skills across domains impacted by ASD
- Use of an evidence-based developmental approach designed to address the core components of ASD, with a focus on promot-

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[4] The NY State Family Survey, including the NYS Impact on Child and Impact on Family Scales, are available from the NYS Department of Health, Bureau of Early Intervention Program, upon request beipub@health.ny.gov, Room 208 Corning Tower Building, Albany, NY 12237-0660.

ing communication, social interaction, and play skills
- Ability to provide planned, systematic instruction based on the ongoing assessment of the child's strengths and needs
- Use of a functional behavioral assessment and support plan to decrease challenging behavior and increase appropriate behavior when indicated
- Commitment to work in collaboration with MA EIPs to address parent needs for technical assistance around promoting skill development, meeting behavioral challenges, and generalization of skills into the child's natural routines through individual and group networking opportunities
- Staffing patterns reflective of current credentialing and licensing requirements for performing child assessments, developing treatment plans, and training and supervision of direct care staff in the intervention approach used by the program
- Administrative capacity to meet MA DPH specifications regarding billing requirements and clinical record keeping and comply with MA EIP operational standards, health and safety standards, procedural safeguards and due process procedures, and other program requirements

The MA DPH contracted directly with the initial group of Specialty Service Providers (SSPs) selected through the competitive proposal process in 1998 and provided operational procedures to establish consistency in service provision across the state, a claims submission system, monitoring to assure fiscal and clinical accountability, and administrative support. SSPs have increased in number and approach since that time. Currently, 16 provider agencies use a range of intervention approaches to address the core characteristics of ASD (including applied behavioral analysis, Early Start Denver Model (Rogers & Dawson 2009a, 2009b) and Interventions Based on the Developmental, Individual Difference, Relationship (DIR or "Floortime") Model (Greenspan & Weider, 1997).

Services are selected in collaboration with families, using an Individualized Family Service Plan (IFSP). Services and staff reflect the cultural, linguistic, and ethnic composition of the state and of the families served. Programs must demonstrate a commitment to respond to the diversity of families in their communities. MA EIPs and Specialty Services Providers focus on the family unit, recognizing the crucial influence of the family on development. Children and families receive individualized services in accordance with the outcomes identified in the IFSP.

Intervention is designed to include the child, staff member(s), and parent or designated caregiver. Parents are strongly encouraged to participate in intensive services. Determinations of the number of hours per week of service are individualized, based on particular child and family circumstances. Factors such as the child's age, prevalence of the core characteristics of autism, behavioral characteristics, rate of progress, schedule of ancillary services, and family availability are taken into consideration. The service plan can be adjusted at any time as child and family needs change and are documented through the IFSP review process.

The growth in the SSP system has exceeded all expectations for a variety of reasons. There is near universal health insurance coverage for children in Massachusetts, which provides fiscal support for diagnostic services. There are a number of medical schools in Massachusetts that train developmental pediatricians and neurologists and several specialized diagnostic centers that focus on ASD and are committed to providing appointments for young children as quickly as possible. An active Massachusetts Act Early team has promoted the growing national focus on early screening and identification of developmental disabilities promulgated by the US Department of Health and Human Services, Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, 2016). The average age of diagnosis of ASD for children in the Part C EIP in MA is under 26 months of age, and the number of young children identified with ASD from birth to age 3 cohort continues to increase, with 1 in 78 children in the 2010 MA birth cohort diagnosed with ASD by the time they reached 36 months of age (Manning & Kernan, 2015).

Dramatic growth typically equates with dramatic cost increases for the MA DPH Part C program. Autism-related services consumed ever increasing percentages of the MA DPH Part C budget annually. It was anticipated that legislation mandating insurance coverage for medically necessary services for individuals with ASD enacted in 2010 (Massachusetts GL 2010, H4935, An Act Relative to Insurance Coverage for Autism) would somewhat mitigate the fiscal demand on the MA DPH Part C program. However, the impact of this law, known as the ARICA Law, was minimal as most families whose health plans offered this benefit were reluctant to take on the burden of meeting private insurers co-payments and deductibles when they already had access to appropriate services for their young children with ASD through the MA Part C program.

Historically, the federal Centers for Medicare and Medicaid Services (CMS) deemed ABA and certain other autism-related services to be facilitative and therefore not coverable under traditional Medicaid state plan authority as a standard benefit. In 2011, the MassHealth, the State Medicaid, and the Child Health Insurance Program received approval under an existing 1115 demonstration waiver to provide ABA services through the MA DPH's intensive early intervention program, delivered by MA EIPs and SSPs to any eligible child under age 3. While navigating the waiver process, MassHealth and CMS were challenging; ultimately it was apparent that CMS was interested in working with MA to explore ways to support for behavioral interventions for young children with ASD.

The CMS application required specification of proposed treatment approaches for young children with ASD. Both ABA-based and DIR/Floortime-based treatment was proposed; however, only ABA-based treatment and the Early Start Denver Model (Rogers & Dawson, 2009a, 2009b) were approved as part of the delivery system by CMS. The MA EIP has continued to support the provision of DIR/Floortime (Greenspan & Weider, 1997)-based treatment as it is recommended by some diagnosticians and sought by families.

Implementation of the CMS waiver required systemic changes, most significantly in the methodology of contracting with SSPs. Prior to the waiver, all appropriate claims by SSP providers were processed and satisfied by the MA DPH. MA EIPs had no responsibility for assuring the appropriateness of claims, and SSPs were accustomed to the practice management system DPH had developed. When the CMS waiver was approved, SSPs were required to establish contracts with community MA EIPs, as only certified MA EIPs could submit claims to MassHealth. Implementation required significant guidance and training to the MA EIPs and SSPs communities to orchestrate a change not only in billing rules but in the relationships between MA EIPs and SSPs.

MA DPH prepared for the changes more than a year in advance of the implementation date, working with SSPs, MA EIPs, and MA DPH Part C practice management system developers to make the transition as smooth as possible. New billing procedures assured that there would be no interruption in MA EIP or SSP services, or in the panel of SSPs available to children with ASDs and their families, when the waiver was initiated in July 2012. Qualitative and quantitative analyses conducted by an independent evaluation entity determined that the transition was seamless from the family perspective but challenging for all MA EIP and SSP system administrators and billing staff. Despite this, service access, provision and utilization did not seem to be impacted, and transition activities were thought to be invisible to children, families, and direct service providers. The contracting shift has facilitated more communication between MA EIP and SSPs, promoted effective service coordination, and provided a more comprehensive approach for children and families.

The MA Part C program has had a long standing positive relationship with the private insurance community in the state. Private insurers were kept informed about the progress of the CMS waiver and expressed interest in replicating a similar model within their systems. A number of the major private insurance providers opted to roll out intensive behavioral services for children with ASD through their existing contracts with MA EIPs with the proviso that families would not be responsible for co-payments or deductibles.

This resulted in a significant shift in costs for intensive behavioral services from the MA DPH Part C program to private insurers. Private health plans typically applied the policies developed to implement the ARICA legislation to the MA DPH Part C program ASD benefit. Submission of a physician or licensed psychologist's diagnosis, an initial assessment of the child, and a detailed treatment plan developed by a board certified behavior analyst (BCBA) were typically required as part of the prior approval process. SSPs had to meet the private insurer's specifications for ABA-based service providers. DPH initiated a gradual rollout of this transition to coverage by private health plans to give MA EIPs the opportunity to accommodate the significant changes in practice management systems and prior authorization processes necessitated by this change.

From the initiation of autism specific service in the late 1990s, MA DPH reimbursed via a unit rate of service for a specific dollar amount. The initial rates were tied to a similar service type that had been implemented previously by MassHealth. For many years forward, these rates were exclusively paid by the MA DPH with either (or both) state appropriated funding or IDEA funds through the state Part C formula grant.

As efforts progressed seeking additional payment sources to support ASD services, including those for infants and toddlers, MA DPH staff and stakeholders worked in concert to identify and maximize to the extent possible these resources. As noted above, the MA DPH had been particularly successful in working cooperatively with public and private insurers to fund Part C services, and these sustainability efforts were pursued based upon that historic success. MA DPH staff were acutely aware that to be successful in working with insurance partners, autism services had to be defined within a unit of service context.

Coverage for treatment and diagnosis of ASD achieved through passage of ARICA in 2010 moved the question of broad-based coverage to the forefront of stakeholder's advocacy. This legislation was consistent with many efforts in many states led by Autism Speaks (Autism Speaks, 2016). While this legislation affected only certain types of healthcare policies, private insurers, the state insurance plan covering employees and retirees, hospital service plans, and HMOs are all required to comply with the autism coverage mandate. Although many employers have "self-funded" plans regulated under a federal law and were not subject to ARICA, a majority of "self-funded" plans in MA have covered autism treatments.

This action, while predating ongoing consideration of broad payment coverage by the federal Center for Medicaid and Child Health Insurance Programs, did lay critical groundwork for acceptance by public health coverage as well. MA DPH staff approached the state Medicaid program post passage of ARICA seeking a possible opening to cover infants and toddlers. These actions, coupled with MassHealth's desire to be assistive, took the form of a possible waiver from the Center for Medicaid and Medicare Services (CMS). This relationship focused on utilization of a federal 1915 Demonstration Waiver which was ultimately approved and implemented in MA state fiscal year 2013. The result of fiscal effort has led to a robust system of autism services within a shared public and private payment model.

Conclusions and Future Directions

The national Part C Early Intervention Program under the Individuals with Disabilities Education Act offers very young children with ASD and their families the opportunity to participate in statewide, comprehensive, multidisciplinary service delivery systems strongly grounded in principles of family-centered care. While the financing of early intervention services varies across states, including the extent to which family cost participation in early intervention services is required, *all* families of infants and toddlers from birth to 3 years must be provided, at no cost, with the opportunity to have their child identified (child find); receive case management (service coordination services); engage in a multidisciplinary evaluation to determine eligibility and assess the child's developmental needs and strengths and an optional family-directed assessment of the family's resources, priorities, and concerns; and participate in the development of an Individualized Family Service Plan (IFSP) and implementation of that plan with parent consent. State Part C programs are remarkable among early childhood delivery systems in their comprehensive approach and the entitlement to needed services for infants and toddlers who meet state eligibility criteria.

During the past two decades, the estimated prevalence of ASD among toddlers has changed dramatically, from a relatively rare condition to a disorder impacting 1 in 59 children (Baio et al., 2018). Children with ASD and their families are increasingly engaged in Part C EIPs, creating tremendous opportunities to improve their developmental outcomes and their families' abilities to help their children and the quality of life for their family. State administrators of Part C have been at the center of the changing landscape of services for young children with ASD and their families – uniquely challenged by the increasing demands on the service delivery system and uniquely positioned to offer help and support.

In considering how to work within state Part C programs to provide services to toddlers with ASD and their families, it is important for stakeholders to understand these programs by design and definition are very diverse. As discussed earlier in this chapter, data collected by the IDEA Infant Toddler Coordinators Association with member states demonstrate that states have different approaches to conceptualizing, financing, and delivering services to children with ASD and their families, within the framework IDEA Part C requirements.

Our colleagues in the IDEA Infant Toddler Coordinators Association identified some of these challenges and opportunities, and we close this chapter with our collective thoughts and compelling questions that remain to be addressed as we strive to deliver high-quality early intervention services for toddlers with ASD and their families.

Financing

States have had varied success in accessing third-party payers for reimbursement for early intervention services. Both NY and MA have been successful at accessing Medicaid reimbursement for early interventions, and MA has been the most successful state in the nation in accessing private insurance for early intervention services generally and now for specialty ASD services to children and families in the early intervention program. Increasingly, providers of early intervention services may need to meet potentially higher licensing and certification requirements for delivery of services to children with ASD and their families established by insurers or in state laws on insurance coverage for individuals impacted by ASD.

Service Delivery Approaches

In our experience, it is important to consider how the types of specialized and intensive services needed by children with ASD and their families can be coordinated and integrated within the Part C framework for early intervention services for all infants and toddlers with disabilities and developmental delays and their families. Some states, including MA, have developed specialty providers for toddlers with ASDs, and others, such as NY, have integrated ASD services across their provider systems. Regardless of the approach, states can expect an increase in growth of children with ASDs when specialized programs and services are developed to address the specific needs of these children and their families.

States are experiencing a high demand for highly qualified and experienced personnel with knowledge and expertise in delivering services to toddlers with ASD consistent with evidence-based practices, including service delivery in natural environments with typically developing peers. Personnel needs experienced by Part C programs include the need for teams of providers with training and certification in applied behavior analysis and other intensive behavioral intervention approaches to coordinate interventions and family supports. Strategies for supervision and monitoring to ensure high-quality service delivery are critical in states that rely on independent practitioners and contractors to deliver early intervention services.

Increasingly, state Part C programs will be competing with other service delivery systems for personnel with expertise in ASD services, as has been the experience in MA. A challenge for many states is balancing the fiscal demands associated with funding early intervention services and those needed to implement Part C federal requirements, including comprehensive systems of personnel development. Limited resources often mean a shift of funding from preservice and in-service training to support for direct services. Partnerships with other personnel development systems, especially institutes of higher education and resources such as training programs funded by the US Department of Health and Human Services, Maternal and Child Health Bureau (University Centers for Excellence in Disabilities, Leadership in Neurodevelopmental Disabilities, Developmental Behavioral Pediatrics, etc.), can be important resources for state Part C programs (US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (http://mchb.hrsa.gov/training/index.html)).

Measuring/Reporting Results

At the national level, the US Department of Educations Office of Special Education Programs is moving from compliance to results-driven accountability. For more than a decade, states have been required to collect and report child and family outcome data for children and families in Part C, including those with ASD. Because of these new requirements and state efforts to implement them, the use of state data systems for program evaluation purposes holds new promise. States will increasingly have the ability to analyze information on the ASD diagnosis/identify trends (e.g., age of child, diagnosis, by whom) and child and family outcomes. In this context, it is important to recognize that standardized developmental assessment tools may be inadequate to measure child and family outcomes being achieved through participation in state early intervention systems. There is a high need for child and family outcome measurement strategies that are appropriate to use pre- and post-intervention to provide helpful outcome information for children and families with ASD. NY's Impact on Child and Impact on Family Scales are potential promising approaches for measuring outcomes and engaging families in the program evaluation process (Noyes-Grosser et al., in press).

We view ongoing research specific to the very young child with ASD and their families as essential, particularly with respect to promising new approaches, such as parent-mediated intervention models and comprehensive programs such as the Early Start Denver Model (Rogers & Dawson 2009a, 2009b). Efforts to identify family characteristics that predict parent support of intervention approaches and link to treatment efficacy are essential. Some parent-mediated approaches (e.g., Hanen Centre "More Than Words"; http://www.hanen.org/Programs/For-Parents/More-Than-Words.aspx) that are routinely delivered by early intervention providers may be viewed as methods or approaches to service delivery that are available and may be appropriate for any child and family receiving early intervention services, and not necessarily as methods or approaches specific to toddlers with ASD and their families.

Given the insistence of public and private insurance payers that treatment approaches for children with ASD are based on scientific evidence, it is important that professionals committed to parent- implemented intervention continue to research and document positive outcomes from these approaches. As the field continues to evolve, strategies to informing policymakers, health plan decision-makers, early intervention providers, families, and public officials about scientific evidence validating intervention and treatment efforts will be important to ensure access to high-quality, effective intervention methods for children with ASD and their families. Evidence-based guidelines on recommended practices for assessment and intervention with young children with ASD and their families offer an approach to integrating scientific evidence with recommended practices for informing all stakeholders.

The following are specific considerations for states when deliberating expansion of services to young children with ASD and their families:

- *Financing*: Is there state legislation mandating autism-related coverage? Does the state Medicaid program have a mechanism for funding these services (e.g., incorporated in the state Medicaid plan or regulations or waiver program)? How does it impact the state's Part C program? Does such coverage mandate maximum benefits in dollar or hours of service amounts? Should the state's Part C program reflect similar limitations?
- *Eligibility*: Methods for establishing eligibility for ASD-specific services delivered through the state's Part C program have significant implications. Massachusetts elected to use a diagnosis of ASD conferred by a physician or licensed psychologist that reflected autism legislation and MassHealth eligibility criteria to confer eligibility for ASD-related intervention, which casts a rather wide net of eligible children. The MA DPH provides guidance indicating that a differential diagnosis by a licensed practitioner working within his/her scope of practice who is qualified and experienced in providing ASD evaluation services is preferred. Other states require substantiation of the diagnosis through administration of a recognized ASD diagnostic instrument. This narrows the eligibility net for ASD services as some diagnostic instruments are not sensitive in identifying very young children on the spectrum.
- *Work force*: Is there a cadre of appropriately trained personnel in the state's Part C program or is there a need to collaborate with other service delivery systems for a provider network? Can the staffing requirements of the state Medicaid program and private insurance providers be met within the state's Part C program? What credentialing and licensing requirement exist in the state? Do qualified personnel as defined in the state's Part C program meet ABA-based credentialing requirements? What additions to academic preparation, professional experience, or continuing education expectations need to be made to ensure availability of personnel to deliver the types of services and intervention methods needed by young children with ASD and their families?
- Practice management systems: What changes or enhancements may be necessary to Part C EIP billing and reimbursement systems to comply with public and private third-party payer requirements for claims submission and transmittal (e.g., diagnostic codes, procedure codes, policyholder information, compliance with federal Health Information Portability and Accountability Act (HIPAA) requirements, etc.)?
- Infrastructure: Is there sufficient capacity in the state's Part C EIP to design and oversee an expanded service system, either internally or through external contracting? Private and public health insurers expect Part C participation in the monitoring of medical necessity determinations for ABA-based treatment, ensure timeliness of service delivery, document improvement and sustainability of functional abilities of enrolled children, and measure the effectiveness of treatment type and staff training.

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M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3