Management

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Abstract Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder that requires ongoing coordinated care and management across caregivers and professionals. A variety of interventions are used in the management of ASD, and it is important to evaluate the effectiveness and implementation of interventions and programs. First, this chapter discusses ASD core challenges for young children such as social engagement, play skills, and social communication, to set the stage for intervention and management strategies. Then, family navigation approaches are described given their relevance for coordinated care in management strategies. The chapter concludes with a case example of an interdisciplinary management approach.

Introduction

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder that requires ongoing coordinated care and management across caregivers and professionals to improve outcomes and improve overall functioning and quality of life (Hyman et al., 2020). Core symptoms of ASD include difficulties with social communication and the presence of restricted interests and repetitive behaviors (American Psychiatric Association, 2013). People with ASD commonly have co-occurring medical or behavioral health disorders which underscore the need for interdisciplinary care coordination to ensure comprehensive care and seamless integration of treatment across providers and disciplines (Shahidullah, Azad, Mezher, McClain, & McIntyre, 2018). These comorbid conditions may range from seizures to sleep disorders to anxiety (e.g., Hyman et al., 2020) and significantly impact the family and caregivers (Blacher & McIntyre, 2006).

The purpose of this chapter is to discuss the evidence supporting a variety of interventions in the management of ASD. Interdisciplinary coordinated care will be discussed within the context of these management approaches. Coordinated care

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involves teaming with a range of providers in the evaluation, treatment, and management of core symptoms and related conditions. Coordinated care also includes consultation and planning with the family in order to best understand and support the goals and priorities of the family and child (Shahidullah, McClain, Azad, Mezher, & McIntyre, in press). ASD core challenges will be discussed first to set the stage for intervention and management strategies. Then, family navigation approaches will be described given their relevance for coordinated care in management strategies. We conclude with a case example of an interdisciplinary management approach.

Core Challenges

Over the first two to three years of life, children demonstrate rapid growth in their social engagement with people and objects during daily interactions (Tomasello et al., 2005). Children can practice communicating their ideas and needs and practice actions with objects through routine interactions with their caregivers. These moments allow caregivers the opportunity to scaffold their children's bids into increasingly more clear and sophisticated communication and play skills (Adamson et al., 2012). Seminal early childhood research has demonstrated the link between access to these early learning opportunities and children's growing language and cognitive skills (e.g., Risley & Hart, 2006). However, many young children with autism spectrum disorder (ASD) may miss out on a number of these early learning opportunities due to differences in early social engagement (e.g., Adamson, Bakeman, Deckner, & Romski, 2009) leading to a cascading impact on development in other core early childhood skill domains including play and social communication.

Social Engagement

While typically developing young children will master the ability to sustain long periods of coordination between people and shared activities, known as joint engagement (Adamson, Bakeman, & Deckner, 2004) by about 18 months, this can be an ongoing challenge for young children with ASD. Research has demonstrated that children with ASD spend significantly more time focused exclusively and intensely on objects or not engaged with either objects or people (unengaged) than typically developing children and children with other developmental disorders (e.g., Adamson et al., 2009). When children are exclusively object engaged or unengaged, they are not noticing the input of adults who provide a critical mapping of spoken language and gestures to the materials in the environment. Further, children may also miss out on the actions that the adult may demonstrate with the materials, key opportunities to learn to develop the skills to appropriately use these items. Joint engagement creates a critical foundation for early learning contributing to children's cognitive and communicative development (Adamson, Bakeman, Suma, & Robbins, 2019).

Play Skills

When children are not noticing an adult's actions on objects, children lose information on how to functionally use these objects. A child's actions on objects can be categorized as functional or symbolic play acts (Sigman & Ungerer, 1984). Functional play emerges first between approximately 12 and 24 months followed by symbolic play (Sigman and Ungerer, 1981). The development of play skills is associated with gains in social, cognitive, and communicative skills (e.g., Pierucci, Barber, Gilpin, Crisler, & Klinger, 2015; Toth, Munson, Meltzoff, & Dawson, 2006). Yet, for young children with ASD, the emergence of this hierarchy of skills may take more time (Jarrold, Boucher, & Smith, 1996; Rutherford, Young, Hepburn, & Rogers, 2007). In particular, additional support may be required to advance symbolic level play skills (e.g., Kasari & Chang, 2014). Further, the diversity or number of different ways that children can flexibly play with an object may be more limited whereby play is often rote and repetitive than the play of their typically developing peers (Jarrold et al., 1996). This insistence to use an object, in the same way, each time, or intense interest in a play topic, character, physical feature of a toy, or specific action may range in intensity where some children show little repetition and others may experience significant distress if change occurs. This can pose a substantial barrier to dynamic social play with peers who may not want to engage in the same topic or action as often as the child with ASD. These social demands are significant and require children to flexibly play with the objects appropriately in the context of reciprocal, dynamic interactions. Peer play interactions require negotiation and navigation of the social context with other children, such that intervention is often required in order for children with ASD to participate in common early childhood and preschool activities such as free play and outside playtime.

Social Communication

The symbolism and abstraction required for higher level social play is also required for children's use of words as communication symbols. As such, it is logical that the development of joint engagement and play skills are intertwined with the development of children's nonverbal and spoken communication skills (e.g., Adamson & Bakeman, 2006; Tomasello, Carpenter, & Liszkowski, 2007). Children's spontaneous nonverbal communication both to request (e.g., pointing to ask for an item that is out of reach) and for the purpose of social sharing (joint attention, for example, holding up a toy to show it to another person) are key skills that are often missing for young children with ASD. Initiations of joint attention (IJA), in particular, (e.g., pointing to share an airplane in the sky with another person) are unique challenges that are used to differentially diagnose ASD from other developmental disorders. Developing children's IJA skills can bolster children's expressive language skills (e.g., Kasari et al., 2008; Mundy, Sigman, & Kasari, 1990).

It is estimated that approximately 30–50% of children with ASD will not have word combinations and may have few or no spontaneous, functional words to request or comment by school entry (e.g., Tager-Flusberg & Kasari, 2013). Reducing social communication challenges in early childhood is one of the best predictors of later developmental outcomes (Anderson, Liang, & Lord, 2014). Therefore, core challenges that present during early childhood including joint engagement, play skills, and initiations of joint attention are key targets for care management.

Management Approaches

Given the complexity of ASD and the range of symptoms associated with core features and co-occurring conditions, a number of approaches have been used in the management and care of people with ASD. The lion share of the research on interventions for people with ASD focuses on early behavioral intervention given some of the seminal studies demonstrating that early, intensive interventions may significantly improve intellectual and adaptive functioning and special education outcomes (e.g., Lovass, 1987). Beyond strict behavioral approaches, interventions have been developed that are based on naturalistic and developmental approaches that are intended to address core symptoms.

Applied Behavior Analysis (ABA)

The overwhelming majority of evidence-based intervention models in ASD are based on the principles of ABA (National Autism Center, 2015; Rogers & Vismara, 2008). ABA approaches involve using behavioral theory to systematically teach skills and/or reduce challenging behavior by modifying the environment and manipulating the antecedents and consequences surrounding a target behavior. Discrete trial training is one of the most well-known and well-researched forms of intervention based on ABA (Bogin, 2008; National Autism Center, 2015). In discrete trial training, specific skills are taught systematically through structured, one-on-one teaching sessions. In each adult directed teaching trial, the task is clearly presented to the learner and a programmed consequence is provided after each learner's response (e.g., verbal praise following a correct response) to increase the occurrence of desired behavior or decrease the occurrence of undesired behavior (Bogin, Sullivan, Rogers, & Stabel, 2010). Discrete trial training and other forms of ABA approaches have been demonstrated to be effective in producing gains in adaptive and intellectual functioning in comparison to eclectic treatment approaches (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005). Although there are numerous studies demonstrating the efficacy of ABA-based approaches in preschool and early elementary school (e.g., Cohen, Amerine-Dickens, & Smith, 2006; Eikeseth, Smith, Jahr, & Eldevik, 2002; Howard et al., 2005; Remington et al., 2007), there remain challenges with using strict ABA

approaches to symptom management. For example, some studies use small sample sizes and nonexperimental research designs (for a review see Reichow, Hume, Barton, & Boyd, 2018), which make the evidence less compelling. Although discrete trial training programs are effective in teaching discrete skills, the skills may not generalize to other settings, teachers, or materials. Further, children may become overly reliant on adult prompts, and therefore, reduce their spontaneous interactions or initiations with adults and peers (Schreibman et al., 2015). Most notably, ABA approaches may not comprehensively address core symptoms in young children with ASD. For these reasons, there have been a number of recent advances in naturalistic developmental approaches in an effort to address some of these limitations.

Naturalistic developmental behavioral interventions (NDBIs). **NDBIs** were developed in part, to address some of the concerns with strict ABA and discrete trial training approaches. NDBIs, although behaviorally based, focus on a range of naturalistic approaches to teach early developmental and prerequisite skills such as joint attention, play skills, and initiating requests (Schreibman et al., 2015). Some specific NDBIs include Pivotal Response Training (PRT; Koegel & Koegel, 2006), Early Start Denver Model (ESDM; Dawson et al., 2010), and Joint Attention Symbolic Play Engagement and Regulation (JASPER; Kasari, Freeman, & Paparella, 2006). JASPER, in particular, has quite a few randomized controlled trials that support its efficacy in enhancing early social communication skills in children with ASD (Kasari et al., 2006, 2008, 2010, 2014). JASPER is a targeted social communication intervention that has been shown to improve joint attention, language, play skills, and engagement in toddlers, preschoolers, and minimally verbal children with ASD (Kasari et al., 2014).

Care Management in the Community: Intervention Effectiveness Trials

A number of behavioral interventions have been developed in university research settings to address the core challenges children with ASD can experience in social engagement, play, and communication (Smith & Iadarola, 2015). Although significant advances in intervention development and testing have been accomplished, leading to gains for children and their families who are able to reach university clinics in large urban centers, fewer interventions have been tested when delivered by community clinicians to diverse samples of children in the community who demonstrate great heterogeneity in their profiles of strengths and needs.

Understanding where to start: Setting service targets. Although children with ASD are unified as a group by challenges in social engagement, play, and communication skills, there is significant variability in the rate of acquisition of these skills and thus, individualization of care is necessary. Tools have been developed for use by community practitioners and educators to identify individualized targets matched

to our understanding of the developmental emergence of these skills in early childhood. For example, the Short Play and Communication Evaluation (SPACE: Shire, Shih, Chang, & Kasari, 2018) is a tool that was developed and tested with preschool teachers. The brief, play-based assessment is designed to help the practitioner identify which play and social communication skills the child has mastered and then to identify a developmentally appropriate target for intervention. The tool has been validated with gold standard tools to assess play and social communication which are used in research settings, demonstrating that the intervention targets identified through the brief SPACE administered by teachers are not significantly different than those identified by researchers using the longer, more complex protocols (Shire et al., 2018). Such freely available tools are examples of resources available to community clinicians to help identify the unique needs of a child experiencing some delays in the core developmental domains and to set personalized and developmentally appropriate targets for service. Communication between parents, community clinicians, and early childhood educators is critical to identify the most relevant developmental targets for psychoeducational management approaches.

Transitioning efficacious interventions into the community. Interventions that have an established base demonstrating the efficacy of the intervention under highly controlled conditions with research staff delivering the intervention, must also be tested when transported and potentially adapted to fit the community care context. Considerations in the community for adoption of an intervention service include those related to the implementation of the intervention (e.g., training for clinicians to reach and maintain implementation fidelity, clinical supervision, etc.), as well as the sustainability of the intervention within the local service context, a challenge which is not presented in short term clinical research (Proctor, Powell, & McMillen, 2013). Therefore, a partnership between the community service team and the research team is needed to bring together an understanding of the facilitators and barriers to service adoption and implementation and then select the implementation strategies to best support success. This partnership model is demonstrated in Community Partnered Participatory Research (CPPR: Jones & Wells, 2007). While *community-based* research takes place in community settings, CPPR emphasizes joint leadership and shared decision-making power amongst the team of community and research members (Jones & Wells, 2007). CPPR sets the context to understand how interventions may be adapted to best fit the needs of the community.

Testing effectiveness in the community. Several empirically supported efficacious interventions that target the development of social engagement, communication and/or play skills have been tested when delivered by community clinicians or educators under real-world conditions. NDBIs utilize natural contingencies and behavioral strategies in natural settings to teach developmentally appropriate targets have the greatest number of examples of programs that have been tested in randomized controlled trial designs. To best understand how the intervention is being delivered by those who will use it in the community and whether or not children are making significant gains, it is important to examine both the effectiveness (e.g., outcomes for children and caregivers) and implementation (e.g., fidelity) of the program. Effectiveness trials have included various community stakeholders who learn the intervention

strategies and deliver the program with the child including caregivers, educators, and community clinicians. These trials differ from when research staff deliver the intervention in the context of a natural setting such as a school or a family's home. Comprehensive reviews of efficacy and effectiveness trials are available (e.g., Green & Garg, 2018; Smith & Iadarola, 2015), as well as interventions targeting core early childhood skills (e.g., joint attention interventions: Murza, Schwartz, Hahs-Vaughn, & Nye, 2016).

As highlighted by Green and Garg (2018), caregiver mediated interventions, in particular, have demonstrated consistent effects to increase children's time jointly engaged and children's dyadic social interaction. Interventions focused on creating this foundation in order to advance children's social communication skills have been demonstrated by models including the Preschool Autism Communication Trial (PACT: Green et al., 2010), a developmental intervention developed in the United Kingdom and JASPER (Kasari, Gulsrud, Paparella, Hellemann, & Berry, 2015), an NDBI developed in the United States. Both the PACT and JASPER caregiver mediated interventions have been adapted and then tested in community settings. The PACT intervention has been adapted for delivery by community providers working in India and Pakistan (Rahman et al., 2016). Further, JASPER has been tested when delivered in families' home focusing on families who are underserved and underresourced in five centers across the United States (Kasari et al., 2014) leading to increases in children's initiations of joint attention, as well as their play skills. The JASPER intervention has also been mediated by paraprofessional and head teachers in preschool and toddler classroom settings, similarly leading to gains in children's joint engagement, initiations of joint attention, and language (Chang et al., 2016; Shire et al., 2017).

Service Navigation and Care Coordination for Families

Families report finding timely access to high quality care is a significant topic of concern and stress (Brookman-Frazee, Baker-Ericzen, Stadnick, & Taylor, 2012). With multiple intervention models at various stages of development, efficacy, and effectiveness, existing within a fragmented service systems and often no single point of entry within a community, significant supports are required to help families understand which services may be available in one's community, let alone match the possible options to best fit the unique needs of the children and their families. Family Navigation (FN, also referred to as Patient Navigation in the medical literature) has emerged as a strategy to support timely access to both diagnostic and intervention services by integrating the disconnected parts of the system for the benefit of the user (Broder-Fingert et al., 2019). FN is a case management framework that has been applied to support an individual or family's ability to quickly and efficiently find their way to assessment and service which has been studied in medical interventions (e.g., cancer treatment), as well as mental health and substance abuse. However, the application of

FN to families' navigation of the autism assessment and intervention service system has emerged more recently.

The navigator is an individual who is trained to provide information that is communicated in an accessible form to the family. Through qualitative studies including navigators and families who have accessed FN services, several core features of FN have been reported. Specific to FN services for mental health and addiction services, successful navigation services were defined first by the navigator's abilities including the ability to understand the needs of the child and their family, to build strong rapport without judgment, be reliable, demonstrate strong communication skills, demonstrate expertise and knowledge, as well as flexibility, and provide family centered support (Markoulakis, Chan, & Levitt, 2019). Second, the actions of the family also contributed to successful navigation, including involvement in the creation and implementation of the navigation plan and engaging in open communication (Markoulakis et al., 2019). Findings from this study also emphasize how the bidirectional relationship between the navigator and the family access the service is key to perceptions of a successful fit for the match of navigator to family. The combination of responsive services that connect with the child, knowledgeable and supportive service providers, as well as both the child and family, demonstrating a willingness to engage with the recommendations and services provided by the navigator and clinicians led to the highest perceptions of successful FN. In addition to these characteristics, recent examination of care components of FN specific to serving children with ASD and their families emphasize additional considerations. For example, considering the need for care over time, ongoing navigator training and supervision including fidelity monitoring is recommended through regular check-ins to continue to support challenging cases (Broder-Fingert et al., 2019).

FN has been piloted to target a reduction in disparities in the time to diagnosis for families of 40 young children referred for ASD diagnostic evaluation (Feinberg et al., 2016). The study focused on families who are traditionally underserved (e.g., from racial/ethnic minority groups, born outside the United States, speak a language other than English) and under-resourced (e.g., with income less than 200% of the federal poverty level). Three targeted in-person visits and three phone contacts were provided to families randomized to FN. Significantly more families who received FN completed the diagnostic assessment (19 of 20) than those who received community access as usual (11 of 19). This is one of the first examples of FN case management as a strategy to support families of young children with ASD. FN is also highly applicable to support families' access to timely and appropriate intervention services with a trial exploring the application to service access underway (Broder-Fingert et al., 2018).

Care Coordination

Given the breadth and scope of management approaches to support people with ASD in early childhood and across the lifespan, care coordination is critical. A number of professionals may be working with a child with ASD and their family. For example,

special educators, psychologists, speech and language pathologists, and a variety of medical specialists may be involved in the child's care. Progress on IEP goals and objectives, data on speech and language targets, and sleep, diet, and behavioral data can all be shared across the team for more seamless planning.

Case Example

Barry is 30-month old who received an autism specific screening tool during a routine well-child visit with his primary care physician. Barry's mother reported concerns with sleep, intense tantrums, and speech. Barry used about 10 words to communicate and had few functional play skills. Barry's primary care physician referred Barry to receive a comprehensive developmental evaluation to assess for autism spectrum disorder. Barry also was assigned to a Family Navigator (FN) who met with Barry's caregivers at home and in the primary care physician's office. The FN helped Barry's caregivers the early intervention referral process while Barry was on a waiting list for a comprehensive developmental evaluation. Barry was determined to be eligible for early intervention services under federal special education law (Individuals with Disabilities Education Improvement Act, 2004). Barry received specialized instruction delivered for an early childhood special educator in a community preschool. The early childhood educators at the preschool received training and implementation guidance of the JASPER intervention and the multidisciplinary team, comprised of Barry's caregivers, a special educator, paraeducator, speech-language pathologist, and occupational therapist conducted an assessment of Barry's social, communication, and play skills to develop intervention targets. Progress on Barry's individualized education plan was shared with the medical team conducting the comprehensive developmental evaluation. Medical management and follow-up was provided to Barry by a developmental pediatrician and nurse practitioner on an annual basis. During the medical management visits, Barry's caregivers shared the progress on Barry's educational and behavioral goals that were being tracked by Barry's early childhood special education team. Barry's team noted that on days in which Barry had significant sleep disruptions, his maladaptive behavior intensified. Barry's caregivers, in conjunction with the school team, were able to chart these co-occurrences and share with Barry's developmental pediatrician. Although no medical treatment was initially recommended to address the sleep and disruptive behavior issues, the developmental pediatrician recommended that the educational team consult with a pediatric school psychologist who was well versed in behavioral approaches to improving sleep problems and behavior problems. Barry's caregivers continued to work with the FN who assisted with care coordination and psychoeducation to Barry's family.

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