# Autism Intervention Every Day!

## Embedding Activities in Daily Routines for Young Children and Their Families

by

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and

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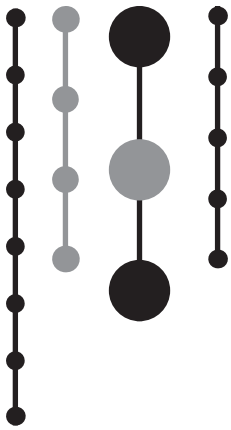

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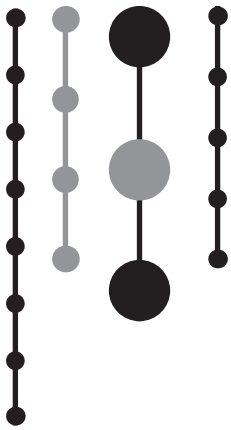

# About the Authors

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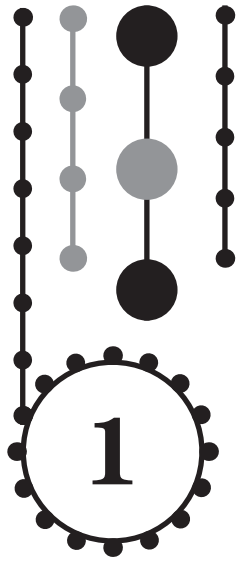

# 1 Autism and Early Intervention

Early intervention (EI) providers bring unique expertise and experience to the children and families with whom they work. Knowledge about and experience in working with young children who are on the autism spectrum vary. Some providers feel quite comfortable working with children on the autism spectrum, whereas others do not believe they have the needed skills. Those who believe they do not have the needed skills may pass up referrals for children diagnosed with autism and instead prefer to work with children with challenges for which they have expertise: perhaps children with feeding challenges, medical issues, physical challenges, or sensory impairments. However, in some instances, an EI provider may work with a child who initially does not show "red flags" for being on the autism spectrum, and, as time elapses, the provider may find him- or herself challenged to provide strategies to achieve outcomes. For example, a physical therapist may have successfully helped a family facilitate skills such as sitting, crawling, and walking, but when coaching the family to help the child with higher level skills that require following directions and imitation, the provider and parents may find themselves struggling to facilitate the child's motor development. Thus, it is important that all providers have an understanding of autism and related disorders and recommended practices regarding autism in EI.

According to Daniels and Mandell (2014), in their reviews of 42 studies from 1990 to 2012, the mean age of diagnosis for autism spectrum disorder (ASD) ranged from 38 to 120 months. They cited a trend toward earlier diagnosis and discussed a variety of reasons why children are not diagnosed earlier. In the authors' (Crawford's and Weber's) experiences working in EI, how parents proceed after providers discuss the red flags of autism varies. Some families want to get or rule out a diagnosis for their child as soon as they suspect autism or soon after an EI provider discusses concerns regarding an ASD. Other parents are hesitant, as they think they are receiving the needed services for their children regardless of a diagnosis or they do not want their children to receive a label at such a young age. Though it is the parents' choice regarding how to proceed once they are aware of the concerns, all EI providers must have an understanding of ASD and young children in order to provide support and resources.

In the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (*DSM-5;* American Psychiatric Association [APA], 2013), diagnostic criteria for ASD include "persistent deficits in social communication and social interaction" and "restricted, repetitive patterns of behavior, interests, or activities," with symptoms presenting in "the early developmental period" (p. 50). These deficits cause "clinically

significant impairment in social, occupational, or other important areas of current functioning" (APA, p. 50) that are not explained solely by an intellectual disability or global developmental delay. The *DSM-5* cites examples of behaviors that are applicable to infants and toddlers, including abnormalities in eye contact, lining up toys, flipping objects, echolalia, extreme distress at small changes, difficulties with transitions, preoccupation with unusual objects, and hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment.

Many studies have looked at red flags in order to identify infants and toddlers who have ASD. For example, Wetherby, Watt, Morgan, and Shumway (2007) found that by 18–24 months, there are five social communication core deficits in children with autism: "gaze shift, gaze point/follow, rate of communicating, acts for joint attention, and inventory of gestures" (p. 973). Trillingsgaard, Sørensen, Němec, and Jørgensen (2005) found red flags for ASD if a child does not exhibit the following indicators by 24 months "during a professional semi-structured play interaction": "smiles in response to a smile; responds to his/her name; follows pointing; looks to 'read' faces for information when cheated; initiates requesting non-verbal behavior; joins functional play with miniature toys with an adult; initiates requesting verbal and non-verbal behaviours" (p. 71).

Autism Speaks, an advocacy organization whose web site contains a great deal of information for parents and professionals, presented a list of red flags, including the following (2015b):

No big smiles or other warm, joyful expressions by six months or thereafter

No back-and-forth sharing of sounds, smiles, or other facial expressions by nine months

No babbling by 12 months

No back-and-forth gestures such as pointing, showing, reaching, or waving by 12 months

No words by 16 months

No meaningful two-word phrases (not including imitating or repeating) by 24 months

Any loss of speech, babbling, or social skills at any age

The Centers for Disease Control and Prevention (CDC; 2014) delineates other red flags, advising that people with autism might exhibit the following behaviors at an early age:

Not respond to their name by 12 months of age

Not point at objects to show interest (point at an airplane flying over) by 14 months

Not play "pretend" games (pretend to "feed" a doll) by 18 months

Avoid eye contact and want to be alone

Have trouble understanding other people's feelings or talking about their own feelings

Have delayed speech and language skills

Repeat words or phrases over and over (echolalia)

Give unrelated answers to questions

Get upset by minor changes

Have obsessive interests

Flap their hands, rock their body, or spin in circles

Have unusual reactions to the way things sound, smell, taste, look, or feel

In 2007, Johnson and Myers published a comprehensive article in *Pediatrics* to educate physicians about autism, providing "background information, including definition, history, epidemiology, diagnostic criteria, early signs, neuropathologic aspects, and

etiologic possibilities in autism spectrum disorder," an "algorithm to help the pediatrician develop a strategy for early identification of children with autism spectrum disorder," and a clinical report that addressed management of children with ASD (p. 1183). Since its publication, routine screening has become common at well-child visits and often results in a referral for further evaluation and/or referral for EI. The type of evaluation a child receives often varies depending upon where a child lives and resources in the area. Two widely used screening tools are the Modified Checklist for Autism in Toddlers–Revised (M-CHAT-R; Robins, Fein, Barton, & Green, 2001) and the Brief Infant-Toddler Social and Emotional Assessment (BITSEA; Briggs-Gowan, Carter, Irwin, Wachtel, & Cicchetti, 2004). The M-CHAT-R, designed for toddlers between 16 and 30 months, is a set of 20 yes/no questions asked of the child's parent and administered by a physician or other professional. The M-CHAT-R's follow-up questionnaire (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is administered when the child fails any item. The BITSEA, designed for children ages 12 months to 35 months and 30 days, reveals both social-emotional problems and competencies. For children who need further assessment, the administration of the Autism Diagnostic Interview–Revised (ADI-R; Rutter, Le Couteur, & Lord, 2003) and the Autism Diagnostic Observation Scale, Second Edition (ADOS-2; Lord et al., 2012) has been considered the "gold standard" for diagnosing ASD (Falkmer, Anderson, Falkmer, & Horlin, 2013). The ADI-R is a semistructured caregiver interview consisting of 93 questions and is appropriate for use with children who exhibit cognitive skills of at least approximately 18 months and the ADOS-2 is a semistructured assessment administered to individuals 12 months and older.

Some children who exhibit red flags will receive an autism diagnosis, but others will not. In the authors' experiences, many children exhibit some of the characteristics of ASD but not enough to fit the diagnostic criteria during the infant to toddler years. Some young children receive a diagnosis of a global developmental delay and then later receive an autism diagnosis—sometimes by the same diagnostician and sometimes by another. Guthrie, Swineford, Nottke, and Wetherby (2013) discussed reasons a diagnosis may change over time, including the experience of the clinician, whether a standardized test is utilized, changes in severity of symptoms over time, and whether the evaluation occurred in multiple settings, such as in the home and in a clinic. Another consideration regarding diagnoses is that, to date, there is little research regarding the very early signs and symptoms of other disorders that manifest in atypical behavior. For example, bipolar disorder and obsessive compulsive disorder are not typically diagnosed until a child is older, yet many times parents report atypical behaviors occurring when their children were infants and toddlers (Faedda, Baldessarini, Glovinsky, & Austin, 2004; Mian, Godoy, Briggs-Gowan, & Carter, 2011).

The causes of autism continue to be investigated by many researchers who are focusing on genetic and environmental risk factors. Epidemiologic studies have provided important information that warrants further investigation. For example, advanced age of the parents has been found to be a risk factor for ASD, and further study is needed to determine if this is due to a specific genetic mutation and/or because some individuals who marry later in life have mild traits of being on the autism spectrum (Sucksmith, Roth, & Hoekstra, 2011).

Discovering different phenotypes for ASD is another focus for researchers. Variability exists in the severity of deficits in language, cognition, social skills, and repetitive behaviors. Researchers are also examining regression of skills in autism. Kern, Geier, and Geier (2014) found in their literature review that the reported percentage of children with autism who exhibited regression during the second year ranged widely from 15% to 62%. Though research is needed to discover more about autism, the heterogeneity of the diagnosis is conveyed by the popular saying, "When you've met one person with autism, you've met one person with autism."

This individuality in ASD is a very important tenet for all early interventionists. In the authors' experience, many times a specific tool or strategy known to be effective with some children with autism is used without looking at the individual child's strengths and needs. An example of this was seen when a child started at a new preschool program. On the first day, the teacher used sign language and a picture schedule, both of which were unfamiliar to him, rather than asking his mother what makes transitions easier. Her answer would have been to tell him what is coming next by using language such as "first bathroom, then more bike" and giving him a day or two to understand the routine rather than introducing him to a system he did not understand or need.

Not only does an EI provider need to be well versed in understanding autism spectrum and related disorders, he or she also needs to know how to implement services according to recommended practices. When one researches the topic of teaching strategies and autism, one finds two types of intervention. The first type is comprehensive treatment models such as the Early Start Denver Model (ESDM; Rogers & Dawson, 2010), Learning Experiences and Alternative Program for Preschoolers and their Parents (LEAP) (Hoyson, Jamieson, & Strain, 1984), and Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) Program (Mesibov, Shea, & Schopler, 2005), which are "conceptually organized packages of practices and components designed to address a broad array of skills and abilities" (Odom, Boyd, Hall, & Hume, 2010, p. 425). The other type is focused intervention practices, which are "designed to produce specific behavioral or developmental outcomes" (Odom, Collet-Klingenberg, Rogers, & Hatton, 2010, p. 276). Examples include techniques such as video modeling, prompting, reinforcement, and visual supports.

Recommended practice dictates that intervention be evidence based, and both the American Academy of Pediatrics (Myers & Johnson, 2007) and the National Research Council Committee on Educational Interventions for Children with Autism (2001) have published research regarding which methods from both categories are considered evidence based. These publications are quite useful for professionals and for families; however, as Strain, Schwartz, and Barton (2011) pointed out, the publications do not ensure that children with ASD

> Have access to systematic and effective instruction. Systematic and effective instruction does not just mean that educators have toolboxes full of the strategies that have been identified as being evidence based by a national panel. It requires that educators know how to identify the instructional needs of their students, develop instructional plans to address those needs, and then match the needs of their students with the instructional strategies that they have at their disposal. (p. 324)

Some treatment models and intervention practices are considered behavior based, whereas others are considered developmental. Some bridge a gap that has historically been controversial and combine both approaches. As stated by Leach (2012), "There is much to be learned from the work of leading researchers and practitioners from both the behavioral and developmental perspectives, and the strengths from both perspectives can contribute to quality interventions for young children with ASD" (p. 70). As Leach points out—and as is confirmed in the experience of this book's authors (Crawford and Weber), who have had extensive training in both behavioral and developmental approaches—many strategies are used in both approaches, though the terminology may be different.

Some of the treatment models and interventions in the literature have been deemed evidenced based with older children; however, some have had little or no research regarding use with infants and/or toddlers. If one compares cognitive and communication processes, learning characteristics, and daily routines, significant differences exist between infants and toddlers and preschoolers (Zwaigenbaum et al., 2009). Thus, EI providers must synthesize their knowledge about development, autism research, and

recommended practices. One of the recommended practices in EI is coaching. According to Rogers and Vismara (2014),

> The birth-to-3 world of public intervention services is currently working from a client-centered, adult-learning framework rather than an expertise driven framework, reflecting the family-centered values explicit in IDEA. As articulated by Rush and Shelden (2011), whose work is well known and quite popular in the birth-to-3 world, coaching has replaced parent training as the preferred framework for parent-professional interactions, vis-à-vis supporting young children with disabilities. (p. 759)

Rogers and Vismara go on to ask,

> How do we integrate parent-centric values of coaching and individualization for varying adult learning styles with the emphasis on empirically based practices, consistency, and adult behavior change that lie at the heart of the ASD parent intervention approaches? This is an active point of dialogue and practice revision in many early ASD intervention groups, and we look forward to the syntheses that will begin to emerge in the literature in the next few years. (p. 760)

The authors (Crawford and Weber) have found coaching strategies to be very effective with many families. The caregiver's needs, family needs and resources, and caregiver interactions within intervention approaches influence efficacy of EI (Strauss et al., 2012). Legislation and policy have underlined the need for collaborative relationships with caregivers (Individuals with Disabilities Education Improvement Act [IDEA] of 2004, PL 108–446). It is now a widely accepted practice in EI to build the provider's understanding of adult learning so that he or she can help the caregiver learn how to help the child through his or her input within daily routines. Coaching entails using adult learning strategies to promote the caregiver's ability to reflect upon his or her actions for effective change and to create a plan for further development by joint planning with the provider, observation of the child, planning actions he or she will practice, reflecting on the successes or lack of success, and feedback between the caregiver and the provider (Rush & Shelden, 2011). The coaching service delivery model focuses on strengthening caregiver–child exchanges. This caregiver-focused model requires the provider to know evidence-based interventions that help support child development and to be skilled in using the coaching process in collaboration with the important caregivers (Woods, Wilcox, Friedman, & Murch, 2011).

There are two components of coaching: It is family centered and it uses family identified contexts. Family-centered practice entails asking for and respecting caregivers' views, ensuring equal participation by the caregivers in the decision-making process, and recognizing caregivers' rights to make decisions (Dunst, Trivette, & Hamby, 2007). Family-identified contexts include using community and daily routines to facilitate growth and development (e.g., a provider may help a family embed following directions into bath time or gross motor development into an outing to the park). *Natural environments* is the term used in IDEA 2004 Part C to refer to settings that are typical for all infants and toddlers. Children learn through participating in their everyday activities, which provides children with multiple opportunities for intervention throughout each day (Woods, 2008).

In working with children with ASD, the authors have found that many everyday occurrences are affected by the child's skills and preferences (e.g., resisting wearing warmer pajamas when the season changes, being a selective eater, reacting to noise at a birthday party, having difficulties with transitions). Coaching caregivers within these routines provides the learning and support needed to facilitate changes within everyday experiences. One of the authors worked with a family who had several EI providers in the home in addition to providers from the behavioral health system who worked on discrete skills while the child sat at the table. When the author asked the parents about the challenges they had, they cited experiences with challenging behaviors during frequently

occurring routines such as getting out of the tub at bath time, going on shopping trips, and wearing new shoes. The parents reported that no one was helping them with these challenges, so the therapist scheduled her sessions during bath time, shopping, and at times new shoes would be worn. The therapist and parents collaborated to find solutions that worked for the family. The parents were grateful and appreciative of the support, which made their lives easier and fostered a positive relationship with their child.

Coaching within daily routines is an efficient process for quickly solving problems and enables caregivers to learn strategies to help their children develop new skills in natural learning contexts. EI providers often need to make families aware that EI services can and should occur within family routines. In the authors' experiences, some families embrace this easily, whereas with others, it is a process. The families may have experience with other models of services, such as going to an outpatient clinic, or they may have had EI providers who do not have experience using coaching and a family-centered model. It is helpful when the philosophy of EI is explained and reiterated to families from the first point of contact, through the individualized family service plan (IFSP) process, and during sessions, via asking questions about the child's everyday experiences.

It can be challenging to integrate family routines into therapy time due to schedule constraints. The authors have found that developing a plan with the caregivers for the next session has helped facilitate coaching within routines. For example, the authors have asked caregivers if they can plan for the child to brush his or her teeth, get dressed, have breakfast, sweep the floors, or go grocery shopping with the caregivers during an upcoming session. Families' belief systems can also affect routines-based intervention. One of the authors worked with a mother who thought that therapy should be doing tasks like puzzles and working on drills such as imitation and pointing to request crackers. She thought that other activities were "a waste of time," as her son was not learning enough. She was very reluctant to implement strategies and skills into daily routines, but after persistent encouragement, the mother agreed to dress her son after the therapist arrived. The therapist immediately noticed that the mother was in a hurry to get the child dressed, the child was not attending to the process, and there was no interaction between mother and child. The therapist suggested that the mother turn the child toward her, which then resulted in intermittent attention to the mother's face. The mother was then coached to take the time to label clothing and body parts and to embed simple directions such as "give me your arm" and "hands up." The therapist suggested that the mother use the sign for "all done" when finished dressing the child, which the child previously had used only when songs ended with his music therapist. The mother later remarked, "I cannot believe what a difference those small changes made. It's as if he is 'there,' not somewhere else in his own little world." She also told the therapist that during an upcoming vacation she planned to "do that dressing thing. Like turn him toward me and make sure he is 'there.' We can do that when we take a walk, or get ice cream or with anything."

Many parents embrace the coaching model and are very successful at integrating strategies to facilitate their child's development throughout a variety of daily routines. Some parents seek resources to obtain a certain number of hours a week, often based on the National Research Council's (2001) report that recommended at least 25 hours per week of "active engagement in intensive instructional programming" (p. 219). This recommendation has been a topic for many researchers, administrators, developmental pediatricians, and other professionals in the field, as interpretation of what constitutes "active engagement" varies widely and the type of intervention that is appropriate for infants and toddlers is quite different from the intervention needed for older children. According to Leach (2012), many professionals and caregivers erroneously interpret the recommended 25 hours per week to mean one-to-one instruction. Many people do not realize that active engagement can occur with parents and other caregivers during embedded learning opportunities at home and in the community and are unaware of the

role that EI providers can play in coaching families to successfully engage their children in everyday learning opportunities. As Strain et al. (2012) suggested,

> The challenge to the research community, however, is to not attempt to answer the question of intensity for toddlers with ASD and their families with a prescription of hours but rather, with a process for judging support needs and whether those needs are addressed. (p. 326)