

Clinical Forum

Early Identification of and Intervention for Infants and Toddlers Who Are at Risk for Autism Spectrum Disorder

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There is now mounting evidence demonstrating the effectiveness of intensive early intervention using a range of behavioral and naturalistic approaches with a substantial proportion of young children with autism spectrum disorder (ASD; Dawson & Osterling, 1997). For these children, research indicates that intervention provided before age 3 has a much greater impact than intervention provided after age 5; this is consistent with early intervention research with other populations (Harris & Handleman, 2000). The first purpose of this article is to review the social communication characteristics of very

young children with ASD, which have important implications for early identification. The second purpose is to review evidence-based intervention practices for children with ASD and to develop a set of guiding principles for providing intervention for infants and toddlers who are at risk for ASD. A pressing need exists to develop early intervention programs that are appropriate and effective for very young children with ASD and that are consistent with the Individuals with Disabilities Education Act Amendments of 1997, Part C, which address the provision of services within natural environments.

ABSTRACT: Providing intensive early intervention is critical to maximizing outcomes for children with autism spectrum disorder (ASD), and evidence suggests that the earlier intervention can begin, the better the outcome. The first purpose of this article is to review the earliest indicators of ASD in very young children—social and communication impairments—which have important implications for early identification. The second purpose is to review evidence-based intervention practices for children with ASD and to develop a set of guiding principles for providing intervention for infants and toddlers who are at risk for ASD. Issues that are delineated include providing intervention in natural environments, supporting families in early intervention, and embedding intervention in daily routines.

KEY WORDS: early identification, early intervention, young children, autism, communication disorders

SOCIAL COMMUNICATION CHARACTERISTICS OF CHILDREN WITH ASD

ASD is currently understood to involve a triad of symptoms: (a) impairments of social interaction; (b) impairments of verbal and nonverbal communication; and (c) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities (American Psychiatric Association [APA], 1994). Communicative competence may be the primary factor determining the extent to which individuals with ASD can develop relationships with others and participate in daily activities and routines at school, at home, and in the community. The level of communicative competence achieved by persons with ASD is closely related to the development of social behavior (Garfin & Lord, 1986) and measures of outcome (Lotter, 1978; McEachin, Smith, & Lovaas, 1993). The presence of fluent

speech before the age of 5 continues to be a good prognostic indicator of IQ, language measures, adaptive skills, and academic achievement in adolescence (Lord & Paul, 1997). The severity of the communicative impairment may be one of the greatest sources of stress for families (Bristol, 1984). Moreover, improvements in receptive and expressive communication have been found to prevent problem behaviors and maintain reductions of these behaviors (National Research Council [NRC], 2001). The emphasis of successful communicative interactions is one of the most critical components of education programs for children with ASD found in current literature from both behavioral and developmental perspectives (Dawson & Osterling, 1997; Prizant & Wetherby, 1998).

Enhancing social and communication skills for children with ASD entails not only increasing vocal and verbal repertoires, but also increasing social communication so that children will initiate interactions with their existing lexicons. For children who do not talk, it is important to develop nonverbal means to initiate interactions. Research during the past decade has identified two core social and communication skills that children with ASD have particular difficulty acquiring (Wetherby, Prizant, & Schuler, 2000): joint attention and symbol use.

Joint Attention

Children with ASD have difficulty acquiring joint attention skills (Wetherby et al., 2000). Deficits in joint attention reflect difficulty coordinating attention between people and objects and are evidenced by problems in (a) orienting and attending to a social partner, (b) shifting gaze between people and objects, (c) sharing affect or emotional states with another person, (d) following the gaze and point of another person, and (e) being able to draw another person's attention to objects or events for the purpose of sharing experiences.

Joint attention has been found to be a significant predictor of language outcome. Mundy, Sigman, and Kasari (1990) found that measures of gestural joint attention (e.g., showing or pointing to direct attention) at initial testing were a significant predictor of language development 1 year later for preschool children with ASD; none of the other nonverbal measures, initial language scores, mental age, chronological age, nor IQ were significant predictors. These findings were further substantiated in a larger follow-up study examining the communicative behaviors and language skills of more than 50 children with ASD between the ages of 10 and 13 (Sigman & Ruskin, 1999). Limitations in joint attention were closely linked with deficits in play, emotional responsiveness, and peer interactions. Accumulated data suggest that the failure to acquire gestural joint attention may be both a critical milestone that impairs language development and an important target for early communication intervention.

Symbol Use

Deficits in symbol use reflect difficulty learning conventional or shared meanings for symbols and are

evident by problems in (a) using conventional gestures, (b) understanding and using conventional meanings for words, and (c) using objects functionally and in symbolic play. Deficits in symbol use have been documented across modalities. Children with ASD do not compensate for lack of verbal skills with gestures, but instead use gestures that are limited in both quantity and quality. Primitive motoric gestures (i.e., contact gesture of leading, pulling, or manipulating another's hand) are predominately used to communicate. The use of many conventional gestures (i.e., showing, waving, pointing) and symbolic gestures (i.e., head nodding and miming actions) are often lacking (Stone & Caro-Martinez, 1990; Stone, Ousley, Yoder, Hogan, & Hepburn, 1997; Wetherby, Prizant, & Hutchinson, 1998; Wetherby, Yonclas, & Bryan, 1989). In lieu of conventional means of communicating, children with ASD may develop idiosyncratic, unconventional, or inappropriate behaviors to communicate, such as self-injurious behavior, aggression, or tantrums.

There is much variability in the capacity to use vocal communication in this population, which likely contributes to the wide range of speech skills. Some children with ASD have been found to use a limited consonant inventory and less complex syllabic structure; others show adequate complexity of vocalizations (Stone & Caro-Martinez, 1990; Wetherby et al., 1998; Wetherby & Prutting, 1984). In a recent study of vocal behavior of preverbal children, Sheinkopf, Mundy, Oller, and Steffens (2000) found that, compared to children with developmental delays, children with ASD used a comparable proportion of well-formed syllables containing consonants but a significantly greater proportion of syllables with atypical phonation, such as squeals, growls, and yells. The vocal atypicalities were independent of joint attention deficits in this small sample but were negatively correlated with mental age, suggesting that the joint attention and vocal deficits arise from different pathological processes.

The vast majority of children with ASD who do learn to talk go through a period of using echolalia, the imitation of speech of others, which may be immediate or delayed (Prizant, Schuler, Wetherby, & Rydell, 1997). An echolalic utterance is usually equivalent to a single word or a label for a situation or event, and appears to reflect limitations in symbolic capacity. Many children learn to use echolalia purposefully in communicative interactions, and eventually are able to break down the echolalic chunks into smaller meaningful units as part of the process of transitioning to a rule-governed, generative language system (Prizant & Rydell, 1993).

Further evidence of a deficit in the symbolic capacity in ASD is the limited ability to develop symbolic or pretend play. Although play is a social-cognitive skill, it is noteworthy that a lack of varied, spontaneous make-believe play is one of the four possible features of the impairment in communication in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*; (APA, 1994). Children with ASD show significant deficits in symbolic or make-believe play (i.e., using pretend actions with objects) and limited abilities in functional play (i.e., using objects functionally) (Dawson & Adams, 1984;

Sigman & Ungerer, 1984; Wetherby et al., 1998; Wetherby & Prutting, 1984; Wing, Gould, Yeates, & Brierly, 1977). Symbolic and functional play skills have been found to be significantly correlated with receptive and expressive language (Mundy, Sigman, Ungerer, & Sherman, 1987; Sigman & Ruskin, 1999). In contrast to deficits in functional object use and symbolic play, children with ASD perform at similar or higher levels on constructive play (e.g., using objects in combination to create a product, such as stacking blocks, nesting cups, or putting puzzles together) as compared to typically developing children or children with language delays at the same language stage (Wetherby et al., 1998; Wetherby & Prutting, 1984).

Exploring developmental profiles of strengths and weaknesses in communication and symbolic abilities has contributed to a better understanding of the nature of these problems in ASD. Studies by Stone et al. (1997) and Wetherby et al. (1998) examined the developmental profiles of 2- to 4-year-old children with ASD as compared to children with delayed language who were at the same language stage. Using similar strategies for gathering communication samples, both sets of researchers reported a comparable profile for children with ASD characterized by a distinct constellation of strengths and weaknesses in parameters of communication. More specifically, the children with ASD showed comparable or higher use of communication to request and protest, but significantly less use of gaze shifts, shared positive affect, conventional gestures, coordinated gestures with vocalizations and eye gaze, and communication for joint attention. The children with ASD performed at comparable levels of constructive play but significantly poorer levels of language comprehension and symbolic play. Correlational findings from the Wetherby et al. study showed that children who displayed a greater capacity to coordinate attention and affect were more likely to communicate for more social reasons, to use a larger repertoire of conventional gestures, and to use a higher rate of communicating.

These findings have important implications for earlier identification of children with ASD because the deficits identified are in skills that typically develop during the first 12 to 18 months of life. These findings suggest that there is a constellation of communicative and symbolic behaviors that may be important early indicators of ASD, including gaze shifts, shared positive affect, joint attention, conventional and distal gestures, rate of communicating, language comprehension, and symbolic play (Wetherby et al., 1998). These core skills offer a framework for individualizing child goals and documenting meaningful outcomes for children with ASD.

EARLIEST INDICATORS OF ASD IN INFANTS AND TODDLERS

In spite of the severity of the behavioral characteristics of most children with ASD, the average age for diagnosis in the United States is not until 3 to 4 years (Filipek et al., 1999). Most children identified as having ASD are reported

by their caregivers to demonstrate symptoms within the first 2 years of life, based on retrospective accounts (Short & Schopler, 1988). Furthermore, most families initially express concern to their pediatrician by the time their child is 18 months (Howlin & Moore, 1997; Siegel, Pliner, Eschler, & Elliot, 1988). Factors precluding early detection include the variability of behavior in young children, lack of appropriate referrals by primary care providers to whom parents expressed concern, and/or the family's lack of knowledge of services or access to services. It is not uncommon for professionals to disagree as to whether there is cause for concern when a child demonstrates delays in the development of social and communication skills. Earlier referral is more likely to occur when biological risk factors (e.g., very low birthweight, perinatal complications) are present, or when communication and language delays coexist with significant physical, sensory, or cognitive disabilities. Families may experience significant stress and confusion related to difficulties in identifying, acknowledging, and understanding their child's problem (Prizant & Wetherby, 1993). In fact, parents of children with ASD have identified inconsistent diagnosis as a major stressor in the preschool years (Bristol, 1984).

The diagnostic features of ASD should be evident in very young children because they involve abilities that typically develop in the first few years of life. Although most children with ASD are not diagnosed until at least 3 years of age, current research indicates that a diagnosis can be made reliably at 24 months of age by experienced clinicians, and that this diagnosis is very likely to persist until 36 months of age. Research has demonstrated that a clinical diagnosis of ASD at 24 months of age was associated with the same diagnosis at 36 months of age or older in at least 80% of the children studied (Lord, 1995; Stone et al., 1999). Clinical diagnosis at 24 months was more accurate than the standard diagnostic instruments, which were designed for older children (Lord, 1995). These studies indicate that there is some movement along the autism spectrum from 24 to 36 months of age, with most of that movement from atypical autism (pervasive developmental disorder—not otherwise specified, PDD-NOS) to autistic disorder. Furthermore, the first two diagnostic features using the *DSM-IV* (impairments in social interaction and impairments in communication) were found to be evident by 24 months, but the third diagnostic feature (restricted and repetitive activities and interests) usually was not evident until closer to 36 months of age. This latter finding may explain the movement along the autism spectrum.

These research findings on diagnostic features indicate that social and communication impairments are the earliest indicators of ASD. There is now a growing body of research on children under 24 months of age who are later diagnosed with ASD that further suggests patterns of early indicators of ASD. One research approach has been a longitudinal, prospective study conducted by Baron-Cohen and colleagues using the Checklist for Autism in Toddlers (CHAT; Baird et al., 2000; Baron-Cohen, Allen, & Gillberg, 1992; Baron-Cohen et al., 1996). The CHAT consists of 9 items reported by parents and 5 items observed by a health professional at the 18-month developmental checkup.

Baron-Cohen and colleagues screened more than 16,000 children using the CHAT and identified 19 children at 18 months who were later diagnosed with ASD based on failure of the following three key items: (a) protodeclarative pointing, (b) pretend play, and (c) gaze monitoring. However, at follow-up at age 7 years, 94 cases of ASD were identified. These findings indicate that the CHAT has a specificity of 98%, but a sensitivity of 38% (Baird et al., 2000). In other words, the CHAT did not report many false positives, but it had a substantial number of false negatives. That is, it missed many children at 18 months who were later diagnosed with ASD. Although the validity of the CHAT is disappointing, it indicates the need for further research on children with ASD at 18 months and provides important clues to early indicators of ASD, based on the children the researchers were able to identify early.

Another research approach reported by Osterling and Dawson (1994, 1999) was a retrospective study based on home videotapes of first-year birthday parties. Osterling and Dawson (1994) found that children with ASD displayed significantly fewer social and communicative behaviors at this young age as compared to typically developing controls. Lack of the following four behaviors correctly classified 10 of the 11 children with ASD: (a) pointing, (b) showing objects, (c) looking at the face of another, and (d) orienting to name. These results suggest that impairments in these early social and communicative behaviors should contribute to earlier detection of ASD.

THE ROLE OF SOCIAL COMMUNICATION IN IMPROVING EARLY DIAGNOSIS

Many factors may limit families of children with ASD from receiving a diagnosis, including training of pediatricians and other professionals on the early signs of ASD and lack of coverage based on a family's health plan. A multidisciplinary consensus panel endorsed by the American Academy of Neurology and Child Neurology Society and representing nine professional organizations (Filipek et al., 1999) reviewed the existing research on the screening and diagnosis of ASD and made interdisciplinary recommendations on practice parameters. The panel pointed out that fewer than 30% of primary care providers conduct regular standardized screening tests for ASD.

The panel recommended that routine developmental screenings should be performed by primary care providers at each well-child visit with standardized screening tools that use parent report. The panel suggested that failure to meet any of the following milestones is an absolute indication for immediate further evaluation:

- no babbling by 12 months;
- no gesturing (pointing, waving bye-bye) by 12 months;
- no single words by 16 months;
- no 2-word spontaneous (not just echolalic) phrases by 24 months; and
- any loss of any language or social skills at any age.

However, it is important to point out that these early indicators are not specifically designed to distinguish ASD, but are also common early indicators of other developmental delays in young children. The panel recommended that the diagnosis of ASD be made through interdisciplinary collaboration and collaboration including speech-language pathologists. Although some states limit the professionals who can make a diagnosis of autism or ASD, the panel recommended that speech-language pathologists be included in interdisciplinary collaboration and consultation processes that are indicated in the diagnosis and assessment of children with ASD.

The literature reviewed suggests that there is a constellation of social and communication parameters that are important early indicators of ASD, particularly deficits in joint attention and symbolic communication (Stone et al., 1997; Wetherby et al., 2000). The lack of language and limitations in communication development may be among the first symptoms that are evident to parents and professionals, underscoring the significant role of speech-language pathologists in the early identification of ASD. The early indicators for further evaluation or "red flags" identified by the consensus panel focus on the use of sounds, gestures, words, and word combinations; however, delays in these areas may be evident in children with developmental delays without ASD and in some "late bloomers" who catch up without intervention. Further research is needed to identify more precise "red flags" in social communication skills that distinguish children with ASD from other populations.

Given the limitations of current research, it may not be possible to differentiate ASD from other developmental delays in children under 24 months of age. Additionally, it may not be possible to confirm or rule out a diagnosis of ASD until closer to 3 years of age. Therefore, identifying social communication delay and red flags for ASD may be more meaningful than specific diagnosis for infants and toddlers. This focus helps families gain appropriate diagnostic referrals to experienced professionals, which in turn facilitates access to appropriate early intervention.

INTERVENTION RESEARCH: WHAT WE KNOW

At the request of the U.S. Department of Education's Office of Special Education Programs, the NRC formed the Committee on Educational Interventions for Children with Autism. This committee was charged to (a) integrate the scientific, theoretical, and policy literature and (b) create a framework for evaluating the scientific evidence concerning the effectiveness of educational interventions for young children with ASD (NRC, 2001). To achieve a systematic and rigorous assessment of research studies, the committee established guidelines for evaluating the quality of the scientific evidence based on the following criteria: (a) internal validity or control for nonspecific factors, such as maturation, expectancy, and experimenter bias; (b) external validity or selection biases; and (c) generalization of changes to natural settings. The committee gathered

information from a wide range of sources to assess the strengths and limitations of different sources of information with an eye toward convergence. The committee's report provides valuable guidelines for evidence-based practice derived from a systematic study of current research findings.

The committee was asked to review research on children from birth through 8 years of age; however, there is virtually no research yet with infants and toddlers because the usual age of diagnosis is at least 3 years or older. In this section, the findings and recommendations of the NRC will be summarized, with a focus on communication intervention. The following section will consider how to apply what is known about preschoolers and older children with ASD to infants and toddlers who are at risk for ASD.

Providing intensive early intervention is critical to maximizing outcomes for a child with ASD because evidence suggests that the earlier intervention can begin, the better the outcome may be. Although there is consensus on the importance of enhancing social and communication abilities for children with ASD, intervention approaches vary greatly and even appear diametrically opposed in regard to specific approaches advocated. In order to examine the critical elements of treatment programs that impact on the social and communication skills of children with ASD, it is useful to characterize the active ingredients of treatment approaches along a continuum from traditional discrete trial to more contemporary behavioral approaches that use naturalistic language teaching techniques to developmentally oriented approaches (Anderson & Romanczyk, 1999; Prizant & Rubin, 1999; Prizant & Wetherby, 1998).

Treatment Programs

The earliest research efforts at teaching speech and language to children with ASD used massed discrete trial methods to teach verbal behavior. Lovaas (1977, 1981) provided the most detailed account of the procedures for language training using discrete trial approaches. Outcomes of discrete trial approaches have included improvements in IQ and in communication domains of broader measures, such as the Vineland Adaptive Behavior Scales (McEachin et al., 1993). A major limitation of a discrete trial approach on language acquisition is the lack of spontaneity and generalization. Lovaas (1977) stated that "the training regime...its use of 'unnatural' reinforcers, and the like, may have been responsible for producing the very situation-specific, restricted verbal output which we observed in many of our children" (p. 170). In a review of research on discrete trial approaches, Koegel (1995) noted, "Not only did language fail to be exhibited or generalize to other environments, but most behaviors taught in this highly controlled environment also failed to generalize" (p. 23).

There is now a large body of empirical support for more contemporary behavioral approaches using naturalistic teaching methods that demonstrate efficacy for teaching not only speech and language, but also communication. Some examples of naturalistic behavioral approaches include the natural language paradigm (Koegel, O'Dell, & Koegel, 1987), incidental teaching (Hart, 1985; McGee, Krantz, &

McClannahan, 1985; McGee, Morrier, & Daly, 1999), time delay and milieu intervention (Charlop, Schreibman, & Thibodeau, 1985; Charlop & Trasowech, 1991; Hwang & Hughes, 2000b; Kaiser, 1993; Kaiser, Yoder, & Keetz, 1992), and pivotal response training (Koegel, 1995; Koegel, Camarata, Koegel, Ben-Tall, & Smith, 1998). These approaches use systematic teaching trials that have the following common active ingredients: (a) initiated by the child and focused on the child's interest, (b) interspersed and embedded in the natural environment, and (c) use of natural reinforcers that follow what the child is trying to communicate. There are only a few studies, all using single-subject design, that have compared traditional discrete trial approaches with naturalistic behavioral approaches. These studies have reported that naturalistic approaches are more effective than discrete approaches at leading to generalization of language gains to natural contexts (Koegel et al., 1998; Koegel, Koegel, & Surratt, 1992; McGee et al., 1985).

Communication Intervention

There are numerous intervention approaches based on a developmental framework that are described in the literature (e.g., Greenspan & Wieder, 1997; Klinger & Dawson, 1992; Prizant & Wetherby, 1998; Wetherby et al., 2000). A common feature of developmental approaches is that they are child directed; that is, the environment is arranged to provide opportunities for communication, the child initiates the interaction or teaching episode, and the teacher follows the child's lead by being responsive to the child's intentions and imitating or expanding on the child's behavior. Although the empirical support for developmental approaches is more limited than that for behavioral approaches, there are research studies that provide preliminary support for using developmental strategies (Hwang & Hughes, 2000a; Lewy & Dawson, 1992; Rogers & DiLalla, 1991; Rogers & Lewis, 1989). There are also many case studies; the largest case review is Greenspan and Wieder (1997). Furthermore, developmental approaches share many common active ingredients with contemporary naturalistic behavioral approaches and are compatible along most dimensions (Prizant & Wetherby, 1998).

General speech language approach. Gains in speech and language outcomes for children with ASD have been documented using a variety of behavioral and developmental intervention approaches. The most impressive language outcomes have been reported by McGee and colleagues (1999) using natural reinforcers of vocalization, speech shaping, and incidental teaching. They reported that 36% of the toddlers studied used verbalizations at program entry, with a mean age of 2;5 (years;months), and 82% were verbalizing meaningful words 1 year later. Most other programs have reported on children entering at 3 years of age or later, and therefore, the impressive treatment outcomes may be related to the young age at entry of treatment.

Functional communication training. Research that has documented changes in the communication skills of children with ASD falls into three major categories: functional communication training to replace problem

behavior, increases in the initiation of verbal and nonverbal communication, and increases in the core social and communication skills. There is strong empirical support for the efficacy of functional communication training to replace problem behaviors (NRC, 2001). It is necessary first to conduct a functional assessment of the particular behavior to determine its function (e.g., desire for tangible or sensory item; attention; or to escape a situation or demand). Teaching communication skills that serve efficiently and effectively as functional equivalents to problem behaviors has been documented to be the most effective technology for reductions in behavior problems (Horner et al., 1990). Naturalistic behavioral language intervention leading to improved communicative skills has been associated with reductions in disruptive behavior (Koegel et al., 1992) and provides further evidence supporting the relationship between communication and behavior.

Increasing initiation. There is a growing body of research on increasing the initiation of communication in children with ASD. This has been described as a pivotal behavior in that if a child initiates communication more often, then this will trigger more responses from others, which will enhance and expedite the improvement of other communication and language skills (Koegel, 1995). Two important findings have been reported. First, children who show more spontaneous self-initiations at the beginning of treatment show more favorable language treatment outcomes (Koegel, Koegel, Shoshan, & McNeerney, 1999). Second, self-initiations can be taught to children with ASD who have been associated with favorable treatment outcomes and show few or no spontaneous communications (Charlop et al., 1985; Charlop & Trasowech, 1991).

Social communication training. In spite of the large number of studies documenting the core social and communication deficits associated with ASD (i.e., joint attention and symbolic capacity), there are only a few studies that have documented intervention effects on these core skills. Most of the comprehensive programs do not present data targeting improvement in these skills, with the exception of the programs described by Rogers and Lewis (1989), who documented improvements in symbolic play. The few other studies that have documented improvement in these core social and communication skills have demonstrated increases in eye gaze to regulate interaction, shared positive affect, use of conventional gestures, and joint attention.

Lewy and Dawson (1992) compared the within-session effects of a child-directed teaching strategy in which the adult imitated the child's behavior with an adult-directed teaching strategy in a group comparison study. They demonstrated that the imitation strategy improved eye gaze, turn-taking, object use, and joint attention in children with ASD, whereas the adult-directed strategy did not lead to these communicative gains. More recent studies have used single-subject design and provided systematic evidence of naturalistic language teaching techniques improving joint attention skills in children with ASD (Buffington, Krantz, McClannahan, & Poulson, 1998; Hwang & Hughes, 2000b; Pierce & Schriebman, 1995). Thus, the NRC (2001) concluded that at this point in time, a naturalistic behavioral or developmental method appears to be the most

effective to address the core social and communication skills of children with ASD.

Summary and Discussion of Intervention Research Findings

Four major research findings emerge from current empirically supported intervention strategies for children with ASD and should form the basis for clinical decision making.

- There is empirical support demonstrating the effectiveness of a range of approaches for enhancing the communication skills of children with ASD along a continuum from behavioral to developmental (Dawson & Osterling, 1997; Prizant & Wetherby, 1998; Rogers, 1998). Furthermore, there are no group design studies directly comparing the effectiveness of different approaches using randomly assigned, matched control samples that are methodologically sound (Dawson & Osterling, 1997; Sheinkopf & Siegel, 1998). However, available single-subject design studies have found that naturalistic behavioral approaches are more effective at leading to generalization of language gains to natural environments than are traditional discrete trial approaches (Koegel et al., 1998; Koegel et al., 1992; McGee et al., 1985).
- Intervention research is not yet available to predict which specific intervention approaches or strategies work best with which children with ASD. No one approach is equally effective for all children, and not all children in outcome studies have benefited to the same degree (see Dawson & Osterling, 1997; Rogers, 1998). In order to determine whether an individual child is benefiting from a particular educational program, measurement of that child's progress using methods of single-subject research design are recommended.
- There is a need to go beyond traditional outcome measures to include "ecologically compelling child characteristics" (Shonkoff, Hauser-Cram, Krauss, & Upshur, 1988, p. 90). The most common reported outcome measures in comprehensive interventions for children with ASD are changes in IQ scores and postintervention placement (NRC, 2001). These measures may not be ecologically valid, because they do not measure changes within natural environments, do not address the core deficits in ASD, and are particularly problematic for infants and toddlers. Service providers need to gather meaningful measures of a child's abilities in order to guide intervention decisions and to determine whether intervention effects are being achieved. The NRC recently recognized the need for more meaningful outcome measures in research on children with ASD and recommended that measures should include (a) gains in the *initiation* of spontaneous communication in functional activities and (b) *generalization* of gains across activities, interactants, and environments. The NRC concluded that current research indicates that learning in natural

environments is likely to be the most effective intervention approach to address gains in initiation and generalization for children with ASD. The importance of documenting progress for the core communication skills becomes even more evident with younger children, because these skills allow for development of the early underpinnings of later social competence so that children are able to participate more successfully in developmentally appropriate activities with caregivers and peers in a variety of contexts (Wetherby et al., 2000).

- There is now mounting evidence indicating that age at intervention is predictive of outcome for children with ASD. Children who participate in intensive intervention beginning by 3 years of age have a significantly better outcome than those beginning after 5 years of age do (Fenske, Zalenski, Krantz, & McClannahan, 1985; Harris & Handleman, 2000). The findings of McGee et al. (1999) suggest that intervention beginning before 3 years of age has an even greater impact. These intervention findings indicate the pressing need to identify and provide intervention for children with ASD as early as possible.

INTERVENTION FOR INFANTS AND TODDLERS AT RISK FOR ASD: WHAT WE CAN DO

Because most children with ASD are not identified until close to 3 years of age, there is little research on intervention with infants and toddlers who are at risk for ASD. Evidence-based practice with preschoolers with ASD as delineated in the report of the NRC (2001) offers the best available guidelines for providing services for younger children until intervention research with infants and toddlers is available. The following discussion addresses the special challenges faced in supporting families of very young children with ASD and providing intervention in natural environments.

Early Interactions With Families

Parents are very often the first people to recognize a concern with their child's development and seek information and services in the area of communication and language delay. Unfortunately, very early identification may come at a cost to families. This cost can include disbelief, fear, anger, grief, and confusion. Manifestations of these emotions for individual family members will vary and may range from refusal of services, continued quest for a different diagnosis, participation in experimental or alternative procedures, to a consuming search for information and zealous application of multiple interventions (Domingue, Cutler, & McTarnaghan, 2000). One parent may be relieved with the diagnosis and ready for early intervention; another may want to wait a little longer to see if improvement occurs with maturation. Service providers

may find appointments cancelled or services discontinued altogether as the family processes the information or chooses to disbelieve it (Nissenbaum, Tollefson, & Reese, 2002). Other families may want or demand "more" of every type of service (McWilliam, 1996).

The word "autism" is hard for both families to hear and providers to say. As previously stated, early identification of infants and toddlers is not easy or definitive, particularly under 2 years of age, and few personnel are prepared for or experienced in early identification and family conferencing. Literature that focuses on the parents' and professionals' perceptions of the process of reporting a diagnosis of ASD is limited, but does describe the experience as emotionally charged for both parents and professionals (Nissenbaum et al., 2002).

Professionals report concerns about their competence, the quality of the evaluation, their lack of training, and the young age of the child as reasons for not clearly stating a diagnosis (Nissenbaum et al., 2002). However, providers may inadvertently deprive the child of more intensive, specialized services that are important for optimal gains when they do not share their concerns about the red flags with families. This well-meaning attempt to prevent the pain and fear of the "autism" label or to eliminate a negative emotional response may prolong the families' search for an answer and result in additional stress, financial burden, and professional mistrust (Kostantareas, 1990). Early interactions with the family must establish a relationship of mutual respect and a willingness to listen and learn, to ask and answer questions, to problem-solve individualized solutions, and to seek additional resources as appropriate. No one family member or professional can be expected to have all of the answers or the energy to meet the child's needs (Guralnick, 2000).

Although family members are effective partners in the identification and intervention process, they also have other responsibilities and roles that may include parenting other children, employment, education, and health needs of their own or other family members (Turnbull & Ruef, 1996). Nonetheless, families should never be left out. All of the 10 preschool comprehensive programs for children with ASD with evidence-based outcomes reviewed by the NRC (2001) acknowledged the importance of having parents play a central role in their children's intervention. The key to family-centered practices is individualization for each family based on the family's priorities, concerns, and interests (Allen & Petr, 1996; Sandall, McLean, & Smith, 2001). Family members, as well as the children, benefit from involvement. Service providers must recognize that time spent by parents working with their child can enhance their confidence and competence to interact with their child, increase the child's independence in family activities, and improve the quality of the family's life (Gallagher, 1990; Turnbull & Ruef, 1996).

Providing Intervention in Natural Environments

For families seeking services through the public sector, the Individuals with Disabilities Education Act Amendments

of 1997 (PL 105-17) Part C, Sections 632, 635, and 636 strengthened the language addressing the provision of early intervention services within natural environments. Natural environments are defined to “include the home and community settings in which children without disabilities participate,” (PL 105-17) and would not include settings designed for treatments or therapy such as clinics, hospitals, or segregated special education programs. The Amendments clearly require services to be provided in the natural environment and “in a setting other than a natural environment only when early intervention cannot be achieved satisfactorily for the infant or toddler in a natural environment,” (PL 105-17, June, 1997). A justification must be written on the child’s individualized family service plan (IFSP) if services are provided outside of the natural environment. These statements send a clear message to state agencies, families, and providers about where the services will be located and necessitate significant adjustments in current service delivery models (Walsh, Rous, & Lutzer, 2000) as services for children with ASD have traditionally been delivered in segregated settings (Strain, McGee, & Kohler, 2001).

Although the intensity of intervention necessary to provide optimal outcomes is as yet undetermined for infants and toddlers who are at risk for ASD, it has been shown that more time spent in active, positive engagement results in better outcomes for preschoolers (NRC, 2001). Intensity is an essential consideration for families and service providers as they initiate the implementation of interventions within natural environments. Based on the limited research available, it should not be presumed that the current early intervention practice of 1–2 hours per week of special instruction or related services will be adequate for infants and toddlers with ASD (McGee et al., 1999). When applying the requirements of the natural environment legislation to infants and toddlers with ASD and their families, it is imperative that providers look to all potential natural environments and caregivers and not just the home and parents.

The natural environment for most children under age 3 does not include formal school settings or organized social groups such as sports or clubs as it does with older children. In order for the younger child to be successful, opportunities for social interaction and play may need to be planned and supported (Goldstein & Kaczmarek, 1992). Child care, nursery school, “Mother’s morning out” activities, and organized recreation classes are examples of natural environments that can be used to support the child’s learning with peers. Children with ASD who participate in settings and activities with other children should not be expected to learn just by being there. Inclusive opportunities must have adequate support for the child to learn from engagement with the materials, activities, and other children in the environment (Strain et al., 2001).

The reality in many programs serving 0- to 3-year-old children is that services often fall short of the ideal. Nationally, early care and education programs are focusing on the development and implementation of standards to support high-quality programs (Kagan & Neuman, 2000). However, there is a long way to go before universal access

is achieved for children without disabilities, and data suggest that for children with identified disabilities, access is even more limited (Guralnick, 2001). For young children with ASD, even a good-quality early care and education program is not likely to be good enough.

A review of research on evidence-based practices for preschool children identified the need for a curriculum with a focus on social interaction, play, and communication; specialized services including speech-language and occupational therapy; family involvement; consistent and ongoing communication between team members; a capacity to address the child’s behavioral challenges; and specialized and ongoing training and support to staff in the program about interventions specific to children with ASD (NRC, 2001). This does not mean, however, that the program needs to be specialized for children with ASD only. Most instructional methods with evidence to support their effectiveness with young children with ASD have been transported from studies with various types of developmental disabilities (Strain et al., 2001; Wolery, 2000).

The philosophy of intervention in natural environments encompasses more than just the location of services and includes the utilization of naturalistic interventions. Interventions in the natural environment are approaches that maximize teaching and learning throughout the day using routines, materials, and people that are common to the family and child (Dunst, Hamby, Trivette, Raab, & Bruder, 2000; Woods Cripe & Venn, 1997). They include the caregiver(s) with the child undertaking the activities, events, and chores of daily life as defined by the family’s values and choices. The basic tenets of intervention in natural environments include (a) children learn functional and meaningful skills; (b) learning occurs within daily caregiving, play, and social interactions; and (c) caregivers mediate the teaching and learning process for the child as it occurs. This philosophy is compatible with many of the contemporary behavioral and developmental approaches used for children with ASD (Dunlap & Fox, 1999; McGee et al., 1999), but is difficult to reconcile with traditional discrete trial interventions (Lovaas, 1981). The embedding of intervention within typical daily routines and community activities focuses on the generalization of skills for the child while reducing the stress of specialized training activities that are irrelevant to the child’s problem behaviors for families (Dunlap & Fox, 1999).

Supporting Families in Early Intervention

Embedded intervention for young children with ASD requires service providers to look beyond the specific skills or disabilities of the child and look to the interaction of the child within the family system—who they are, where and how they live, what they value and believe, and what they want for themselves and each other (Bristol, 1984; Bronfenbrenner, 1979). Family-centered principles—respecting family members’ perceptions, priorities, and preferences; planning for active participation of family members in assessment and intervention; building consensus; and sharing decision making—have been advocated and required for early intervention within the law and recommended practice.

A discrepancy exists between recommended practice and common practice (Sandall et al., 2001).

Parents are included in many programs primarily in the role of parent-delivered child interventions and predefined services, such as parent training classes and classroom observation with the focus on the child (NRC, 2001). Individualization of services and supports based on the priorities and interests of the family are more recently emerging as essential for families dealing with behavioral challenges and emotional stress (Dunlap & Fox, 1999). For families of children with ASD, depending on the age of identification and the degree of behavioral concerns for the child, their competence and confidence in their ability to guide the team and make informed decisions may have been affected. Both formal and informal supports may be required to provide families with information and guidance, as well as assistance in gaining access to services, respite, or financial resources (Turnbull & Ruef, 1996).

Families report lack of involvement in assessment, intervention planning, and identification of evaluation strategies (Odom & McLean, 1996). The IFSP may not include family outcomes or active family participation in child outcomes, may not be based on family-identified priorities or concerns, and may not reflect family activities or natural environments (Bruder & Staff, 1998). Intervention plans often fail to incorporate daily routines, caregiving activities of the child, and the family's diverse interests and preferences (McWilliam, 1996). Although recommended practices call for the integration of treatment into the child's total daily routine, interventions frequently consist of isolated, skill-oriented activities (McWilliam, 1996; Rogers, 1998). The problem is further complicated by the lack of empirical data on approaches that go beyond global effectiveness of programs and identifies more specifically the factors that contribute to intervention effectiveness (Carta & Greenwood, 1987). "Second generation" data that address the identification of specific program features associated with positive outcomes for children and families have been identified as essential (Guralnick, 1997; Wetherby et al., 2000; Wolery, 2000). This research is particularly critical for the development of appropriate programs for young children with ASD.

Embedding Intervention in Daily Routines

Reviews of empirically supported interventions for social interaction and communication for preschool children have identified intervention strategies that may be particularly useful in embedded interventions with younger children, including (a) *environmental arrangement*, which refers to arranging or modifying the environment to prompt or cue a child to initiate social interaction; (b) *natural reinforcers*, which refers to providing access to objects or events that the child desires or removing undesired objects or events; (c) *time delay*, which refers to providing a stimulus and waiting briefly before giving a verbal prompt for a child to respond; and (d) *contingent imitation*, which refers to imitating a child's actions within the child's field of vision immediately following the child's actions (Hwang & Hughes, 2000a; Koegel, 1995; McGee et al., 1999). Family

members in parent-implemented interventions and within daily routines and play have successfully implemented these strategies.

Goals and objectives should be identified with an emphasis on increasing spontaneous *initiation* of communication and *generalization* across activities, interactants, and contexts. Using a developmental approach, initial targets for social interaction and relationships, communication and language, and play and engagement would be chosen based on the child's profile and the family's priorities. Developmental curriculum-based assessments, autism-specific assessments, and discipline-specific measures offer sequences of goals and objectives that address the core deficits of infants and toddlers with ASD (Schwartz, Boulware, McBride, & Sandall, 2001). Examples may include accepting and giving positive touch, accepting another's proximity and staying within the proximity of another person, smiling and looking, increasing the rate of turn-taking with actions and objects as well as communicative signals, participating in group actions, and using conventional gestures in play (e.g., giving and showing). Targets such as these can be embedded into functional and meaningful daily routines and activities multiple times throughout the day and can be integrated with other communication and play targets rather than taught in isolation. Having parents implement strategies to enhance communication, play, and social interaction skills with their child increases opportunities for practice in meaningful and functional situations for the child.

The documentation supporting the use of daily routines and activities as a preferred natural learning environment for young children with disabilities includes many studies conducted with preschool children with ASD (NRC, 2001) and with adults with ASD (Lucyshyn, Kayser, Irvin, & Blumberg, 2002). The development of routines as an organizational structure to enhance participation by individuals with ASD is a long-standing intervention strategy (Horner, Albin, Sprague, & Todd, 2000; Marcus, Schopler, & Lord, 2000; Wetherby & Prizant, 1999) and is particularly useful with young children who spend large amounts of time engaged in daily living and play routines with caregivers. Daily living routines are the functional and meaningful contexts that families and children engage in throughout each day and include tasks such as washing hands and face, combing hair, brushing teeth, dressing, undressing, preparing for or participating in meals and snacks, and getting ready for or up from naps and bedtime. Many routines result in positive outcomes for the child, such as a drink, music, chocolate chip cookie, or story and snuggle time with Dad and are motivating and reinforcing to the child, thereby increasing the likelihood that engagement and participation will occur. Daily caregiving and play routines that are identified by family members as primary contexts for embedded intervention with young children because of their repetition, frequency, systematic implementation, functionality, cultural appropriateness, and brevity.

The routine sequence and its frequent repetition provide familiarity, predictability, and security for the child, thereby developing a framework for the child to anticipate and produce an appropriate response (Snyder-McLean,

Solomonson, McLean, & Sack, 1984). Although important for all children, predictability has been identified as critical for children with ASD for both learning new skills and decreasing challenging behaviors (Dalrymple, 1995; NRC, 2001). With the routine framework to support the child, new information or experiences can be added to increase the child's ability and lead to increased independence. Routines further exemplify the philosophy of natural environments through the use of common everyday materials of child and family rather than specialized therapy materials (Dunst et al., 2000). Engaging in routines as intervention in the child's and family's everyday environments using their toys, household objects, and familiar materials enhances generalization. Generalization is further enhanced with the portability of routines. Intervention embedded in caregiving routines at home, such as snacks and hand washing, can occur at Grandma's house, at child care, or in stores and restaurants during Saturday shopping trips (Woods Cripe & Venn, 1997).

Routines also support interaction between the child and the caregiver by providing clear roles and responsibilities that can be learned to increase engagement, communication, and social interaction—the core deficits associated with ASD (Bruner, 1975). Examples abound in the literature for preschool program scripts and activities (Goldstein & Kaczmarek, 1992; McGee et al., 1999; Strain et al., 2001). For younger children and caregiver-implemented interventions, the procedures are embedded into the preferred routines identified by the family. For example, getting a drink can become a framework for embedding meaningful targets, such as requesting help with vocalizations, gestures, or words; making choices between milk or juice; showing an empty cup to request more; smiling and looking toward the communication partner as a social exchange; and placing the empty cup on the kitchen counter to indicate satisfaction. The roles provide systematic patterns of interactions for reciprocity and turn-taking, further enhancing the quality of the intervention. The adult responds to the child's signal that initiates the routine and may imitate the child's request or model a more sophisticated communication target and signal the child to respond. The child, familiar with how a drink is obtained in his home and motivated by thirst, requests again. The adult's turn provides a choice for the child on available drink options and another opportunity for the child to communicate in the interaction. This routine provides materials that can be used to support the child's responses or to increase the child's role and engagement. The cup can be identified as the "symbol" for a drink. It can be used to gain the child's attention initially and then to shift attention to the interaction as the caregiver holds the cup by her face. As the child responds, his gaze is directed to the adult's face. The adult may also use exaggerated facial expressions or comments to share enjoyment with the child's response. The child is following the adult's actions that are integral to the routine—not establishing eye contact to the mand, "look at me" (McGee et al., 1999). The sequence of the routine and familiarity with the materials provide a scaffold of support to the family implementing the intervention. The family can predict when the next opportunity for communication or

social interaction will occur in the routine and be prepared to support the child's response positively. These everyday experiences also make intervention more meaningful and consistent with the family's priorities.

Families participate in the intervention process when they identify their daily or typical routines, activities, and environments; their concerns and priorities for their child; and their interests and their expectations for the child's participation. Conversations are started with families with the intent to accommodate the preferences of the family and the child by identifying those routines and activities that are most interesting, reinforcing, and familiar to the child and family. For children with ASD, families also identify routines, activities, and settings that are problematic for their child. The active participation of caregivers in assessment sets the stage for the use of naturally occurring interactions in intervention, eliminating the need for arbitrary reinforcers when the activity or routine is positive and functional.

From the list of activities, routines, and play times identified, the caregiver and early interventionist begin to evaluate those that are most likely to be successful for intervention considering such factors as child interest, caregiver comfort, time available, materials of interest, ease of completion, and the types of targets that would logically be taught to the child within the sequence. The interventionist observes the caregiver and child as they participate and looks for the defining components and sequence of the routine, the child's participation and responsiveness, the caregiver's current use of teaching strategies, and reciprocity in the dyadic interaction. This observation provides a common base for planning intervention. The interventionist is knowledgeable about the sequence and materials used and will be able to make specific recommendations rather than general suggestions.

FUTURE NEEDS

Providing early intervention to infants and toddlers who are at risk for ASD and their families offers new challenges and promising opportunities for improving children's outcomes. The challenges for professionals range from how to identify young children early and accurately, to how to ensure that identified children receive intervention with sufficient intensity to maximize outcomes, to how to develop systems that ensure that services are coordinated with effective communication between professionals and the family (Whitiker, 2002). Although the range of intensity of intervention for infants and toddlers is yet undetermined, the recognition of the family's unique role in the care and education of very young children must be considered. There is little evidence to support that once- or twice-weekly specialized therapy (e.g., speech-language pathology, occupational therapy) will have an impact on child outcomes without interaction by caregivers in the child's natural environment. However, there is also little evidence that speech-language pathologists are increasing their use of parent-implemented interventions, such as providing

informational and emotional supports to families (McWilliam & Scott, 2001).

Working with family members in parent-implemented interventions will necessitate the “rethinking” of prevalent service delivery models and include an increased emphasis on service provision in the child’s and family’s natural environment (Dunst, 2002). Although logically appealing to most speech-language pathologists, the reality of designing and implementing embedded intervention within the child’s routines and activities where they occur is not a common practice. It is not likely to be an easy shift for service providers to make without changes in program policies (e.g. reimbursement for parent training and travel) and practices (e.g., consultation with caregivers instead of direct “hands-on” therapy). Personnel may need additional training on techniques for scaffolding with adults to make parent-implemented interventions maximally effective (Guralnick, 2001). Further, there is much to learn about working collaboratively with families from poverty, diverse cultures, or linguistic differences (Bernheimer & Keogh, 1995; Harry, 2002).

Agencies supporting service delivery, including Part C early intervention programs, will need to expand service options and opportunities for children and families. The determination of the intensity of services must not be based on the ability of the family to either access or afford them for the child. Early identification should be emphasized, with intervention available for all children according to their needs and the families’ preferences. Although costly, early identification and intervention efforts are likely to result in savings in service delivery later; more importantly, they are likely to result in increased potential for the child’s success.

Future research should strive to document meaningful changes for children that reflect the core social communication deficits associated with ASD, such as the capacity for joint attention and symbol use. Intervention research is needed to document the relationship between specific treatment procedures and specific outcomes (Wolery, 2000). Such research findings will help families and educators to determine what goals are important and then to implement specific intervention strategies designed to best meet the goals targeted. Interventions within the natural environment will need further delineation of “match” between strategies used by professionals and those that are comfortable and meaningful to family members implementing them. The idea of “contextual match” offers exciting opportunities to increase parent participation through the individualization of programs (Lucyshyn et al., 2002). Measurement of embedded intervention will need systematic and agreed-on definitions for studies to move practice forward, and data collection in a variety of environments with multiple caregivers will require new techniques and methods for reporting efficacy results. As new methods evolve, collaboration among researchers can enhance the quantity and quality of evidence to share and move practice forward.

The list of future needs is broad. It extends from increased public awareness on ASD and young children to improved personnel training across the wide range of medical, educational, and social service personnel that are

important to the child and family. It includes the need for the development of proactive approaches for identification and intervention with young children and their families on functional and meaningful outcomes, for coordination of services, and for careful and thorough evaluation of the services provided. Researchers and practitioners need to maintain focus on early identification and intervention. Young children who are identified with ASD and their families deserve to have the existing knowledge implemented effectively and efficiently and to have new knowledge pursued to assist in early identification and intervention.

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