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A.W.A.R.E. the assessment of autism spectrum disorders: a resource manual for parents with young children (ages 0-3 years)

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Pepperdine University

Graduate School of Education and Psychology

A.W.A.R.E.
THE ASSESSMENT OF AUTISM SPECTRUM DISORDER: A RESOURCE MANUAL FOR PARENTS WITH YOUNG CHILDREN (AGES 0-3 YEARS)

A clinical dissertation submitted in partial satisfaction
of the requirements for the degree of
Doctor of Psychology

by
Tiffany Lin
February, 2011
Carolyn Keatinge, Ph.D. – Dissertation Chairperson

This clinical dissertation, written by

Tiffany Lin

under the guidance of a Faculty Committee and approved by its members, has been submitted to and accepted by the Graduate Faculty in partial fulfillment of the requirements for the degree of

DOCTOR OF PSYCHOLOGY

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TABLE OF CONTENTS

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ABSTRACT

Autism spectrum disorder is the most common pervasive developmental disorder affecting young children. It results in significant impairments in the acquisition of language, social, and adaptive behaviors. In recent years, participation in intensive early intervention has resulted in significant improvements in communication skills and a more positive prognosis. While the symptoms of autism spectrum disorder, such as impaired social reciprocal interactions, can be identified in the first months of a child’s life, parents often encounter difficulty in obtaining appropriate diagnostic assessments. Delays in the assessment process result in a later involvement in critical early intervention and a poorer outcome. To date there is a lack of information educating parents on the need for and the nature of the assessment process. This dissertation sought to develop a resource manual to help parents understand and recognize early warning signs of autism spectrum disorder, increase their awareness about the assessment process, and the importance and impact of early identification and early intervention. A review of the research and literature were conducted and graphs, tables, and checklists were developed to create a parent-friendly resource manual. A survey was emailed to 25 experts in the field of autism and their feedback was incorporated into the manual. The goal of the manual was to empower parents to become effective advocates for their child and to follow through on having their child assessed in order to access early intervention. A potential plan for future evaluation, revision, and dissemination of the resource manual was also discussed.

Chapter I: Introduction

Autism (autism spectrum disorder) is a developmental disorder that impacts 1 in 110 children in the United States (Centers for Disease Control and Prevention, 2009). It is characterized by the presence of pervasive social deficits, communication problems, and repetitive behaviors which first present in early childhood and follow a steady course through adulthood. In recent years, there has been a developing public awareness of autism and while to date there is no cure, research has found that early intervention can profoundly impact a child's quality of life and future. Specifically, the earlier a child can be identified and treated, the better the long-term outcome (Branson, Vigil, & Bingham, 2008). In fact, children who start early intervention programs at an earlier age make greater developmental gains including being placed in less restrictive educational settings than later-starting children (Corsello, 2005). Consequently, undiagnosed autism can result in the non-acquisition of speech and basic social skills and the inability to live independently in adulthood.

Currently, there is no known medical assessment that can diagnose autism spectrum disorders definitely. Instead, multiple screenings over a period of time are necessary to determine if there is a risk for an autism diagnosis. If the screening measures indicate a possible risk, then obtaining a comprehensive diagnostic assessment is crucial. The determination of an autism spectrum disorder is not a brief process but entails multidisciplinary evaluations involving a child psychologist, speech-language pathologist, and developmental pediatrician. It is critical for parents to apprehend and advocate for a comprehensive diagnostic assessment that include domains such as speech, intelligence, social skills, sensory processing, academic achievement, and gross and fine motor skills.

These assessments are not only helpful in diagnosing autism, but are also essential for determining what type of intervention is appropriate for the child.

While the prognostic advantages of early screening and intervention are apparent, there is often a delay in accessing services. Parents play a pivotal role in determining their child’s access to appropriate assessment and critical early intervention services. Obtaining an appropriate and timely evaluation is crucial for accessing services. Thus, one of the key determining factors of the child’s involvement in early intervention is the parents’ level of knowledge and access to appropriate resources. For many parents this can be an extremely daunting task as they often have to educate themselves in order to advocate for their child’s rights.

Although there is a wealth of information emphasizing the need for early intervention and its impact, there is a widespread lack of resources for educating parents on the importance of early screening and the critical need for continuous screening throughout their child’s early years. It is not uncommon for parents to feel overwhelmed with the volume of information available through the Internet and consequently have difficulty determining what is relevant and applicable, ultimately delaying a diagnosis. Delays in obtaining an accurate diagnosis contribute to parental distress and often result in lost opportunities for valuable early intervention. Educating parents about autism and the assessment process serves to empower parents to seek and access resources. As their child’s best and most influential advocates, parents make a significant difference in the child’s access to and participation in early intensive intervention services.

Additionally, certain socio-cultural influences impact the likelihood of a child being diagnosed with autism spectrum disorder (Mandell et al., 2009). Notably, children from socially disadvantaged groups, such as those from families with low income, tend to be diagnosed later compared to children from more socially advantaged groups (Shattuck & Grosse, 2007). This results in missed opportunities for early identification, referral, and intervention which can lead to an increased level of dependence and disability in the child. These findings further emphasize the importance of parent education in order to access services in a timely manner. Only by having parents confidently pursue their questions and concerns, form collaborative relationships with health care professionals, and follow up with routine visits, can parents ensure the very best possible outcome for their child.

The purpose of this study, by developing a parent resource manual, is to enhance parents' awareness of the significance of autism assessments, the need for multiple screenings, and the importance of a comprehensive diagnostic evaluation. The focus of the manual is to educate parents about the need and value of autism assessments in order to empower them to become active participants in obtaining necessary services for their child. The manual is unique in that it will provide parents with information that is current, reliable, and comprehensive but accessible to parents by utilizing tables, charts, and bullet points. Thus, it is hoped that the manual will empower parents to become advocates for their child in the early identification of autism and in obtaining access to early intervention programs in a timely manner.

Chapter II: Autism: An Overview

Historical Evolution of Autism and Autism Spectrum Disorders

According to Kanner (1965), the term autism was first introduced by Bleurer in 1911 to describe autistic (dereistic) thinking which was seen as a fundamental characteristic of schizophrenia. Autistic thinking was described as a withdrawal from the external world. Kanner believed that children diagnosed with autism lived in their own world, but he differentiated them from those individuals diagnosed with schizophrenia. He proposed that autism, unlike schizophrenia, was not a regression but a failure of development (Volkmar & Klin, 2005). In a 1943 article, "Autistic Disturbances of Affective Contact," Kanner portrayed children as exhibiting "an extreme autistic aloneness" and an "obsessive desire for the maintenance of sameness" in their play and daily routines (as cited in Corbett, Harris, Taylor, & Trimble, 1977, p. 215).

In 1979, Wing and Gould found that children with deficits in reciprocal social interaction also had deficits in communication and imagination which led to repetitive pattern of activities. They described these children as having a "triad of social impairments" (Wing & Gould, 1979, p. 14). Since then, autism has been characterized by multiple social deficits in interpersonal relationships, communication, imagination, and behavioral rigidity (Allen & Mendelson, 2000). These social impairments are not observed in normally developing infants and could not be accounted for by mental retardation (Kanner, 1965).

In recent years, the definition of autism has broadened to that of a spectrum disorder that ranges from a very mild to severe complex and heterogeneous clinical presentation (American Psychiatric Association, 2000, 2010). Autism spectrum disorders

(ASDs) describe a set of neurodevelopmental disorders that consist of lifelong conditions with core features characterized by deficits in social interaction and communication, and stereotyped and ritualistic behaviors (Leonard et al., in press; Matson & LoVullo, 2009; Matson & Sipes, 2010). The symptoms of the early onset form of autism generally develop prior to 3 years of age (Oostering et al., 2010) with most parents reporting concerns of abnormal behavior in the child's first year (Chawarska & Volkmar, 2005; Lord, Shulman, & DiLavore, 2004; Matson & Sipes, 2010). This is differentiated from regressive autism also known as late-onset or acquired autism (Hansen et al., 2008). Individuals who develop this late-onset form of autism generally follow a typical developmental pattern up to 18 to 30 months of age followed by noticeable worsening in language and socialization skills (Matson, Wilkins, & Gonzalez, 2008; Ozonoff, Williams, & Landa, 2005).

Epidemiology

Although autism was once considered rare, it is currently believed to be the most widespread of the childhood disorders in the United States (Matson et al., 2008; Matson & Nebel-Schwalm, 2007) and is consistently more prevalent in boys than girls with an average male:female ratio of 4.3:1 (Fombonne, 2005). In the past decades, numerous studies have suggested a significant increase in the prevalence of individuals diagnosed with autism spectrum disorder (Kogan et al., 2008; Kogan et al., 2009). In the 1960s to 1980s, studies showed prevalence rates from 2 to 5 in 10,000 (Fombonne, 2003; Kogan et al., 2009). However, after reviewing 36 surveys of children with autistic disorder with a total of 7,514 subjects, Fombonne (2005) described median prevalence rates that have significantly increased to 12.7 in 10,000 since 1993. Studies in the early 2000s reported a

10-fold increase with prevalence rates from 30 to 60 in 10,000 with recent prevalence rates from 50 to 90 in 10,000 (Kogan et al., 2009). In December 2009, the Centers for Disease Control and Prevention (CDC, 2009) estimated that 1 in 110 children were affected with autism spectrum disorder in the United States. These elevated rates of autism spectrum disorders have been attributed to several factors including an increased public awareness (Kogan et al., 2009), a younger age of diagnosis (Fombonne, 2003, 2005), improved screening and identification from health care professionals (Kogan et al., 2009), and increased referrals to autism specialists, clinics, and agencies (Heidgerken, Geffken, Modi, & Frakey, 2005). Thus while the number of reported cases of autism spectrum disorder has surged in recent years, the question still remains as to whether this rise in prevalence reflects an actual increase in the occurrence of the disorder, increase public awareness, evolving definitions of diagnosis, or a combination of these factors.

Etiology

In the years since Kanner first described autism, research findings have supported his initial insights that autism may be innate (Folstein & Piven, 2001). Although the specific cause of autism remains unknown, several studies have highlighted the importance of genetics in explaining the disorder (Baker, 2008; Gupta & State, 2007; Mazefsky, Goin-Kochel, Riley, & Maes, 2008). Crane and Winsler (2008) reported a significant increase of withdrawal, social discomfort, and apprehension in first-degree relatives of children with autism. Furthermore, the concordance rate for autism is 60-90% greater for monozygotic twins compared to approximately 10% for dizygotic twins (Folstein & Piven, 2001; Muhle, Trentacoste, & Rapin, 2004) suggesting that the observed familial aggregation of autism may in part be influenced by genetic factors.

Additionally, various studies have concluded that autism is not caused by only one gene, but rather caused by the interaction of multiple genetic regions and environmental exposure (Gupta & State, 2007; Leonard et al., in press). Though there is strong evidence for genetic causes, the concordance for genetic causes in monozygotic twins implies that at least 40% of autism cases are possibly influenced by an environmental cause that might include prenatal exposures to thalidomide, valproic acid, or rubella (Hertz-Picciotto et al., 2006). Despite the evidence of a strong genetic component, currently there is no medical test that can detect autism spectrum disorder (Doyle & Iland, 2004; Pinto-Martin, Dinkle, Earls, Fliedner, & Landes, 2005; Pinto-Martin & Levy, 2004).

In addition to genetic studies, research has focused on identifying underlying biological or physiological differences between children with autism and non-affected peers. Notably, there are morphological differences such as head circumference and brain weight (Crane & Winsler, 2008). Macrocephaly (i.e., excessive largeness of the head) was one of the phenotypic features of autism that was first described by Kanner (Newschaffer, Fallin, & Lee, 2002). In fact, Courchesne, Carper, and Akshoomoff (2003) identified an acceleration of head size growth between 2 and 14 months of age as a potential early indicator for autism. Moreover, autopsy and neuroimaging studies have generally supported the idea that the brains of young children later to be diagnosed with autism were indeed larger and heavier when compared to typically developing peers (Gupta & State, 2007; Palmen et al., 2005). In addition, imaging studies have indicated enlargement or other anomalies in particular areas of the brain such as the cerebellum and the subcortical forebrain regions of the limbic system. However, the relationship of these structural abnormalities and the clinical presentation of autism still remain elusive (Newschaffer et al., 2002).

Current technical advancements in neuroimaging have prompted studies in cortical gray and white matter. Research has suggested increased white matter in individuals with autism spectrum disorders is the result of enlarged brain volume (Hazlett, Poe, Gerig, Smith, & Piven, 2006; Herbert et al., 2003; Palmen et al., 2005). Happe and Frith (2006) proposed that a cause for the enlarged brain volume is due to the breakdown of the brain's normal pruning process that should occur several times during child development. Pruning helps to optimize neural functioning and eliminates faulty connections. Therefore, a lack of pruning might lead to an increased brain size with neural abnormalities that can result in weak central coherence such as information processing abnormalities, theory-of-mind deficits, and executive dysfunction (Hallahan & Murphy, 2005; Herbert, 2005). The pruning theory indicates that a favorable environment, such as early intervention, could enhance and optimize brain development (Aly, Taj, & Ibrahim, 2010). Consequently, there have been rising demands to recognize children with developmental delays at earlier ages because it is believed that maximum success can be attained if intervention services are initiated as early as possible.

Recent neurobiological research has focused on the function of the mirror-neuron system. Mirror neurons were first observed in the prefrontal motor cortex of monkeys. Researchers noted that specific neurons fired when the monkeys carried out an action, such as grasping; tearing; holding; mouthing, or while observing another monkey performing those actions (Iacoboni & Mazziotta, 2007; Tager-Flusberg, 2007). Since the discovery of the role of mirror neurons, researchers have suggested that the weak information processing between social and cognition for children with autism spectrum disorders is a result of mirror neuron dysfunction that leads to impairments in motor, language, and social skills (Iacoboni & Mazziotta, 2007; Oberman & Ramachandran, 2007; Tager-Flusberg, 2007).

A very controversial theory regarding the etiology of autism relates to the probable role of childhood vaccinations and the development of autism. In 1998, Wakefield et al. reported 8 of 12 children who displayed signs of developmental regression had had a measles-mumps-rubella (MMR) vaccination preceding the onset of decline (Newschaffer et al., 2002). Specifically, parents expressed concern about the presence of thimerosal, a known fetal neurotoxin, as the cause of autism (Baker, 2008; Newschaffer et al., 2002). At high doses, thimerosal can cause neurologic injury while at low doses can cause developmental delays and neurologic dysfunction. However, numerous epidemiological studies have reported no proof of the involvement of the MMR vaccinations in autism (Stigler, Sweeten, Posey, & McDougle, 2009). Notably, 10 of the 13 authors of the 1998 article later retracted their account of the relationship between MMR vaccinations and the development of autism (Parker, Schwartz, Todd, & Pickering, 2004). Furthermore, comprehensive safety reviews conducted by the Centers for Disease Control and Prevention, American Academy of Pediatrics, Medical Research Council, and the Institute of Medicine have all refuted the claim that MMR vaccinations are a risk factor for any neurodevelopmental disorder, including autism, due to inadequate evidence (Blackwell & Niederhauser, 2003; Ibrahim, Voigt, Katusic, Weaver, & Barbaresi, 2009; Newschaffer et al., 2002).

While researchers have cited many genetic/biological predispositions for autism, they have also considered several psychological factors. In the 1950s and 1960s, it was commonly assumed that the etiology of autism was rooted in “parents who were emotionally unresponsive to their children” (Klin, 2006, p. 4). In fact, early psychological studies suggested that autism was caused by parents (i.e., *refrigerator mother*) who were characterized as well-educated, serious-minded, perfectionistic, emotionally distant, and appeared to lack interest in social interactions (Corbett et al., 1977; Kanner, 1965). However, current research has contradicted these early findings of the *refrigerator mother* hypothesis due to compelling evidence that the etiology is mostly genetic and neurological in nature (Iacoboni & Mazziotta, 2007; Oberman & Ramachandran, 2007).

Current psychological theories that are empirically based include Baron-Cohen’s Theory of Mind, which describes the cognitive ability to attribute mental states including beliefs, intents, and desires to self and to others (Baron-Cohen, Leslie, & Frith, 1985; Jarrod, Butler, Cottington, & Flora, 2000). Typical developing children at the age of 2 are able to talk about their own feelings and feelings of others and able to establish a link between people’s behaviors and their intensions, desires, and beliefs by 3 to 5 years of age (Montes & Halterman, 2007). Notably, a core cognitive trait for children with autism is their struggle to understand the minds of others and therefore, this is a common explanation for the social interaction difficulties observed (Baron-Cohen, 2001; Bauminger & Kasari, 2000; Hallahan & Murphy, 2005).

The etiology for autism has rapidly evolved over the years. There is currently no empirical support for theories that implicate unloving mothers or childhood vaccinations as the cause of autism. Rather, scientific evidence points to a multi-factorial model including genetic predispositions and various environmental factors as the cause for autism.

Diagnostic Classification

In 1943, Kanner first described autism as a developmental disorder in a classic article of case studies of 11 children. As a result of continued observations and research, the diagnostic criteria have since evolved, and autism was officially included in the *DSM-III* in 1980 as a class of disorder called Pervasive Developmental Disorder (PDD) (Volkmar & Klin, 2005). The term *pervasive developmental disorder* was intended to suggest that individuals in this category experienced impairment in multiple areas of functioning (Shtayermman, 2007). Most importantly, the *DSM-III* officially recognized autism and discarded the previous belief of a relationship between autism and childhood schizophrenia. The three major domains of disturbances included qualitative impairments in reciprocal social interactions, verbal and nonverbal communication, and restricted repertoire of activities and interests. However, the *DSM-III*'s definition of autism was limiting in that it focused on autism as displayed in younger children (Chawarska & Volkmar, 2005). In the *DSM-III-R*, major changes were established to the concept of autism in that the previous requirement of an early onset was dropped and the 16 proposed criteria were grouped into three broad domains consisting of social interaction, communication, and restricted and repetitive interests (Volkmar & Klin, 2005).

The diagnostic labels and criteria for autism and similar disorders have evolved several times since *autism* was first introduced in Kanner's 1943 paper. The *International Classification of Diseases* or *ICD-10* (World Health Organization, 2006) adopted the term childhood autism and the *DSM-IV-TR* (American Psychiatric Association, 2000) continued to use the category of pervasive developmental disorder to include diagnostic categories of autistic disorder, Asperger's disorder, and pervasive developmental disorder – not otherwise specified (PDD-NOS). Despite changes in the diagnostic label, the clinical presentation consistently describes specific behaviors such as deficits in social reciprocity, delayed language, restricted imagination or play, failure to share objects or interests, and repetitive motor movements with onset in one of these areas prior to 3 years of age which is consistent with Kanner's 1943 portrayal of autism as an early-onset disorder (Corsello, 2005).

In recent years, autism spectrum disorder (ASD) is the descriptor preferred by the majority of parents, health care professionals, and professional organizations (Filipek et al., 2000; Hallahan & Murphy, 2005; Matson et al., 2008). This trend is reflected in the upcoming *DSM-V* expected to be released in May 2013 (American Psychiatric Association, 2010). In a draft released February 10, 2010, the American Psychiatric Association's *DSM-V* has planned to represent autism as a single diagnostic category named "autism spectrum disorder" that will include autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS) (American Psychiatric Association, 2010). Additionally, the three domains of social interaction, communication, and restricted repetitive interests in *DSM-IV-TR* will merge into two domains of social/communication deficits and fixated interests and repetitive patterns of behavior with an onset in early childhood.

Clinical Presentation

In order to fully understand autism, it is imperative to recognize the nature of the disorder's clinical presentation. It is characterized by an onset in early childhood and defined by pervasive deficits in social communications and interactions and the presence of restrictive, repetitive patterns of behavior, interests, and activities. These areas will now be reviewed.

Social Communication and Interactions

Impaired social communication is characterized by persistent and pervasive deficits in reciprocal social interactions, including early language skill deficits that may consist of marked difficulties in nonverbal and verbal communication, absent or delayed speech, atypical language, and language regression (Watson, Baranek, & DiLavore, 2003). In addition, a lack of social reciprocity is often reflected in early social skill deficits, joint attention, and social orienting abilities (Gargus & Yatchmink, 2005). Further, an inability to develop play skills and maintain appropriate peer relationships is also evident.

Early language deficits. Typically developing newborns generally display a variety of communicative behaviors by the end of their first year. At 6 to 12 months of age, they start to show signs of social babble (e.g., verbal turn taking) and nonverbal actions including simple gestures (e.g., pointing) to express intent (Werner, Dawson, Osterling, & Dinno, 2000). However, analyses of retrospective home videos and parental reports have revealed that children later diagnosed with autism spectrum disorders lack many of these typical communicative behaviors (Watson et al., 2003). Specifically, children later diagnosed with autism predominately display primitive motor gestures (e.g., pulling a parent’s arm) to communicate and demonstrate a significant lack of using conventional gestures (e.g., waving bye-bye, pointing, showing) (Johnson, 2008; Tager-Flusberg, Paul, & Lord, 2005). Parental concerns about early communication problems can often be predictive of a diagnosis of an autism spectrum disorder later on (American Academy of Pediatrics, 2001; Sivberg, 2003). In fact, delayed speech development is a common reason for referral of further assessments of children later diagnosed with autism spectrum disorder (Watson et al., 2007).

Besides early language concerns, children who have autism may express atypical language such as echolalia, the repetition of someone else's words or phrases, and nonfunctional communication (Tager-Flusberg et al., 2005). For example, children with autism may show extraordinary verbal memory such as reciting ABCs and nursery rhymes at much younger ages (Dawson et al., 2004). They may also exhibit nonfunctional communication with their obsession to label things (e.g., numbers, letters, shapes, colors) but are not able to share their interests upon request (Woods & Wetherby, 2003). Unfortunately, at times such complex speech expressions can disguise true deficits in functional communication and delay early evaluation.

Recent studies show that about 25% to 30% of children later diagnosed with autism appear to develop social and language skills normally followed by symptoms of regression (Johnson, 2008; Spence, Sharifi, & Wiznitzer, 2004; Werner & Dawson, 2005). Parents may report that children made significantly less eye contact and slowly stopped gesturing and talking. Particularly, such regression typically occurs between 18 and 21 months of age (Johnson, 2008).

Lack of social reciprocity. Social development was the first feature Kanner (1943) reported as being unusual when he initially described a child with autism. Early social skill deficits such as gaze, joint attention, play, peer relationships, and affective development continue to be the hallmark manifestation of autism spectrum disorders

(Carter, Davis, Klin, &Volkmar, 2005; Dawson et al., 2004). Specifically, children with autism appear to display a lack of “social relatedness” marked by their desire to be alone and their minimal attempts to connect with others for affection or attention (Johnson, 2008; Spence et al., 2004).

Facial expressions and eye contact are the two most frequent methods of communication between the newborn and his or her primary caregiver (Blanc, Adrien, Roux, & Barthelemy, 2005). This results in the sharing of affective states, which provides crucial information regarding interests, safety threats, and attentional and emotional states of others (Chawarska, Klin, & Volkmar, 2003). Typically developing newborns spend a significant amount of time engaging in eye contact with their caregivers while children with autism fail to establish this pattern of mutual gaze (Matson et al., 2008). In fact, many parents can recall noticing abnormalities in their children (e.g., lack of eye contact) by the time they were 2 years of age (Inglese, 2009). Notably, gaze deviations appear to be specific to autism as it has not been observed among children with other developmental delays (Carter et al., 2005).

A deficit in joint attention is a distinct characteristic of children who have autism (Johnson, 2008; Spence et al., 2004). Joint attention is defined as a preverbal social communicative skill that involves sharing with another individual the experience of a third object or event (Delinicolas & Young, 2007; Woods & Wetherby, 2003). For typically developing children, joint attention develops in the 8 to 12 month age period (Carter et al., 2005; Johnson, 2008). For instance, typically developing infants will smile and point at an interesting toy and alternate between looking at the toy and their caregiver. In contrast, even when joint attention is observed in children with autism, its quality is poor with minimal coordination of gaze, vocalizations, and gestures (Carter et al., 2005). Notably, research indicates that language development can be predicted by joint attention abilities and consequently, limitations in joint attention are closely linked to deficits in emotional responsiveness, play skills, and peer interactions (Dawson et al., 2004; Woods & Wetherby, 2003).

The lack of joint attention is one of the primary characteristics in individuals with autism and therefore is a significant part of current autism screening and diagnostic measures (Johnson, 2008). On joint attention measures, Dawson et al. (2004) found the lack of joint attention was likely to correctly recognize 63% of children without autism spectrum disorders and 83% with autism spectrum disorders. Moreover, Robins and Dumont-Mathieu (2006) showed that joint attention items (e.g., following another person's gaze, pointing to share) on the Checklist for Autism in Toddlers (CHAT) strongly predicted toddlers at 18 months of age who were later diagnosed with autism at 30 months of age.

Social orienting is another area of social development that children with autism struggle with and is defined as the capability to orient to verbal stimuli, specifically, turning to respond to one's name (Johnson, 2008). Werner et al. (2000) discovered infants approximately 10 months of age who were later diagnosed with autism were significantly not as likely to turn their heads to orient towards the verbal stimuli when compared to typically developing infants. Consequently, it has been suggested that social and communicative developments may be negatively impacted by a failure to orient to social stimuli (Mundy & Neal, 2001).

Play skills and peer relationships. Play skills usually develop in a predictable manner within the first 2 years of life in typically developing children (Carter et al., 2005; Johnson, 2008). After children can grasp and hold on to objects, sensory-motor play (i.e., mouthing and manipulating items such as blocks) emerges at about 4 months of age. Infants may begin to throw items or pound items on the table at 8 to 10 months of age. As toddlers become aware of the intended use of items, functional play begins to develop at 12 to 14 months of age. Pretend play (e.g., using a small plastic bottle to feed a hungry doll) usually emerges around 16 to 18 months of age. Eventually, pretend play increases in complexity and imagination as children engage in multiple successive pretend scenarios (e.g., washing hands, sitting down at the table, eating a sandwich, drinking juice, and wiping one's mouth). In time, symbolic play occurs and involves imagined scenarios, pretend roles, and substitution and manipulation of objects (Woods & Wetherby, 2003).

In contrast, the play of children with autism is generally characterized by a lack of social engagement, repetitive and stereotyped object manipulation, and nonfunctional use of objects (Carter et al., 2005). Children with autism often display minimal interest in toys and instead prefer common items such as rocks, sticks, paper, and string (Johnson, 2008). When they do express interest in typical toys (e.g., cars), they often play with them in a non-functional manner (e.g., lining up the cars, spinning the wheels). In school settings, Anderson, Moore, Godfrey, and Fletcher-Flinn (2004) noted that children with autism usually sought out the climbing structures in the playground and while they were in close proximity to other peers, they engaged largely in solitary play. Children with autism also made fewer initiations with peers, did not offer greetings, displayed poor eye contact, displayed lack of response to the approach of others, did not notice or offer comfort to a peer who was injured, and were more likely to approach adults than children (Ingram, Mayes, Troxell, & Calhoun, 2007; Johnson, 2008). In general, when compared to typically developing children, children with autism often engaged in self-stimulatory behaviors rather than social interaction with peers (Carter et al., 2005).

Restrictive, Repetitive Patterns of Behavior, Interests, and Activities

According to the Diagnostic and Statistical Manual of Mental Disorders, the presence of restricted, repetitive, and stereotyped patterns of behaviors, activities, and interests is a defining diagnostic characteristic of autism spectrum disorder (American Psychiatric Association, 2000). It is depicted by restrictive and recurring patterns that include stereotyped motor or verbal behaviors, ritualized routines, and fixated interests that interfere with daily functioning.

Research indicates that stereotypic behaviors, routines, and rituals are not only present in individuals with autism but also present in individuals with mental retardation and those with obsessive compulsive disorder (Chowdhury, Benson, & Hillier, 2010; Cunningham & Schreibman, 2008; Gabriels, Cuccaro, Hill, Ivers, & Goldson, 2005; MacDonald et al., 2007). However, young children with autism spectrum disorder between 18 and 24 months of age exhibited more frequent repetitive motor behaviors when compared to same aged peers with mental retardation (Lewis & Kim, 2009; Richler, Bishop, Kleinke, & Lord, 2007). Further, McDougle, Kem, and Posey (2002) reported that individuals with obsessive compulsive disorder displayed more behaviors of checking, cleaning, and counting whereas behaviors of touching, ordering, tapping, and self-injurious behaviors were observed in individuals with autism. Therefore, the stereotypic behaviors, routines, and rituals demonstrated in individuals with autism were more severe and occurred more frequently when compared with individuals with mental retardation and those with obsessive compulsive disorder (Cunningham & Schreibman, 2008).

Stereotyped motor or verbal behaviors. Stereotypic behaviors are defined as repetitive motor gestures (e.g., rocking, hand flapping, twirling) or vocalizations (i.e., non-contextual phrases, repetitive noises) that appear to serve no adaptive function and have been shown to negatively affect social interactions and interfere with learning new skills (Delinicolas & Young, 2007; MacDonald et al., 2007). Specifically, Liss et al. (2001) found in individuals with autism spectrum disorder, an association between IQ less than 70 and deficits in adaptive behaviors such as social communication and the presence of restricted and repetitive interests.

Ritualized routines. Some children with autism may demonstrate an inflexible adherence (i.e., sameness) to specific, nonfunctional rituals (e.g., lining objects) or routines (e.g., taking a specific route to school) and may protest violently when things change unexpectedly (Cunningham & Schreibman, 2008). The objection to the change may escalate into a tantrum that subsequently results in behaviors of aggression or self-injury (Blackwell & Niederhauser, 2003). In fact, Baghdadli, Picot, Pascal, Pry, and Aussilloux (2003) found the occurrence of self-injurious behaviors to be highly associated with lower adaptive skills.

Research suggests that ritualistic intensity in individuals with autism might possibly be influenced by level of intellectual functioning. Behaviors such as hand and finger gestures, repetitive use of objects, and self-injury were more likely to be observed in individuals with autism with lower IQ scores whereas insistence on sameness, limited interests, and unusual attachment to objects were commonly associated with higher IQ scores (Chowdhury et al., 2010; Militerni, Bravaccio, Falco, Fico, & Palermo, 2002; Turner, Stone, Pozdol, & Coonrod, 2006).

Fixated interests. Many children with autism are preoccupied with unusual interests (e.g., dinosaurs) and often will verbalize extensive facts regardless of others' level of interest (Filipek et al., 2000). Typically developing children often form attachments to objects (e.g., blanket, stuffed animal), however children with autism have been noted to prefer unusual solid items (e.g., pencil, string, book, specific toy figurines) (Johnson, 2008). Furthermore, children with autism display extreme attachments to their items and frequently demonstrate rigid and inflexible behaviors such as insistence with holding the item all day or having a tantrum when the item is misplaced (Cunningham & Schreibman, 2008).

Co-Morbid Conditions

In addition to the core clinical symptoms several co-morbid conditions have been found in individuals with autism spectrum disorders. Specifically, a high-rate of co-morbidity for epilepsy has been established with a reported prevalence ranging from 11% to 39% (Myers, Johnson, & the Council on Children with Disabilities, 2007). Also 46% to 85% of individuals with autism spectrum disorders present with gastrointestinal problems including chronic constipation and diarrhea (Horvath & Perman, 2002). Furthermore, up to 65% of children with autism spectrum disorders have co-morbid sleep disturbances (Oyane & Bjorvatn, 2005). In contrast, conditions such as congenital rubella, PKU, neurofibromatosis, cerebral palsy, and Down syndrome have been found to have no particular association with autism (Fombonne, 2005).

Of the children with autism in Fombonne’s epidemiological study, 70.4% had intellectual impairment, and 29.3% of these children fell into the mild-to-moderate range while 38.5% were in the severe to profound range (Fombonne, 2005). The definition of autism spectrum disorder includes a broad range of children with a heterogeneous clinical presentation many of whom have less-developed social and language skills, which are frequently associated with lower mental ages (Silverman & Brosco, 2007; Wing, 1997). However, recent studies support the notion that it is often complicated to differentiate autism spectrum disorders and mental retardation (Gray & Tonge, 2005; Matson & LoVullo, 2009). In the past, many children with autism were inappropriately assessed using verbally based measures of cognitive functioning which tended to underestimate their cognitive abilities (Inglese, 2009). Only recently has there been an emphasis on developing assessments to differentiate autism spectrum disorders and mental retardation (de Bildt et al., 2004).

Standards of Care for Developmental Screening

While studies of autism spectrum disorder provide support for a genetic origin for the disorder, currently there is no medical assessment that can unquestionably diagnose autism (Doyle & Iland, 2004; Pinto-Martin et. al., 2005; Pinto-Martin & Levy, 2004). At this time, screening measures and clinical observation by early childhood professionals and primary care physicians are the primary means of detection of children with autism (Gray & Tonge, 2005; Klinger & Renner, 2000; Matson et al., 2008). Screening is the use of standardized measures to identify and provide an initial indication of the possible risk for a disorder and identifies children who are in need of a more comprehensive diagnostic evaluation (Coonrod & Stone, 2004; Robins, 2008; Williams & Brayne, 2006).

Since 2000, the American Psychiatric Association, American Academy of Neurology, and American Academy of Pediatrics, have officially recommended that the standards of care is for all young children to be screened for developmental delays, particularly for autism spectrum disorders (American Academy of Pediatrics, 2001). Specifically, the American Academy of Pediatrics (2006) proposes all children be administered standardized developmental screening measures at the 9, 18, and 24 month visits. This is significant because by 9 months of age, critical features of emerging language skills such as nonverbal and social communication (e.g., gestures, vocalizations) can be assessed (Dawson et al., 2004) and by 18 months of age, language development and communication deficits are often evident (Johnson, 2008). Additionally, approximately one third of children with autism will show developmental regression between 18 and 30 months, which emphasizes the importance of multiple screenings before 3 years of age (Pinto-Martin et al., 2008). Most importantly, it is highly recommended that every single child be formally screened for autism spectrum disorder at the 18 month and 24 month visits, even if parents do not express any concerns (American Academy of Pediatrics, 2006; Inglese, 2009; Johnson, Myers, & the Council on Children with Disabilities, 2007; Zwaigenbaum et. al., 2009).

Developmental surveillance is a continuous, longitudinal, cumulative, and flexible course of action that allows parents and health care professionals to monitor concerns together and detect children who may be at risk for a developmental disorder (Aly et al., 2010; Baird et al., 2001; Charman, 2003; Gargus & Yatchmink, 2005). In accordance with the American Academy of Pediatrics (2006), developmental surveillance must include: obtaining a developmental history, addressing parental concerns, and the use of standardized assessment measures. Thus emphasizing the need to merge the observations of parents with the health care professional's developmental knowledge and the use of particular assessments. Notably, Branson et al. (2008) reported only 30% of children were detected to have a developmental delay when merely clinical judgment and informal checklists were utilized compared to 70-80% detection rate with the use of ongoing screening and diagnostic measures. This approach of ongoing monitoring of the child's development suggests that a single screening will not accurately identify deficits, but rather regular and repeated screening is more likely to identify problems (American Academy of Pediatrics, 2006; Eaves, Wingert, & Ho, 2006; Klinger & Renner, 2000).

Screening Measures for the Detection of Autism

In recent years, the quality of autism screening measures to identify those at risk has improved dramatically (Filipek et al., 2000; Inglese, 2009). Current research studies have clearly supported the efficacy of the use of screening measures and diagnostic assessments to reliably detect autism spectrum disorders in children as young as 18 months of age (Mawle & Griffiths, 2006; Pinto-Martin et. al., 2005). These assessments vary from all-purpose developmental screening measures that address several developmental areas (e.g., language abilities, fine motor skills, adaptive skills) to measures that target specific domains of development. Screening measures are often completed by parents, scored by non-physician staff, and then interpreted by health care professionals. Developmental screening measures do not give enough information for a diagnosis, however they are used to identify the areas where a child's development may vary from same-age individuals (American Academy of Pediatrics, 2006; Gray & Tonge, 2005).

Three stages of clinical investigation are necessary to detect those at risk for autism spectrum disorder. The first level referred to as level 1 screening is given to all children and is used to identify children at risk for any kind of abnormal development (Eaves et al., 2006; Filipek et al., 2000; Robins, 2008). The second level (level 2 screening) involves further exploration to differentiate autism from other developmental disorders in already identified children (Eaves et al., 2006; Filipek et al., 2000; Johnson et al., 2007). Health care professionals utilize level 2 screening measures to determine the necessity of a referral to the third level, a diagnostic evaluation which consists of a comprehensive multidisciplinary battery of assessments (Filipek et al.,2000; Inglese, 2009).

Level 1 Screening

Level 1 screening measures are primarily designed to be administered to all children to detect those at risk of autism spectrum disorders from the general population (Coonrod & Stone, 2004; Johnson et al., 2007; Ozonoff, Goodlin-Jones, & Solomon, 2005; Stone, Coonrod, Turner, & Pozdol, 2004; Williams & Brayne, 2006). Level 1 screening is critical because unless children are identified as being at risk, it is not likely that they will see other health care professionals (Lubetsky, McGonigle, & Handen, 2008; Nadel & Poss, 2007; Robins, 2008). Pediatric practices often give level 1 screening measures to children during their routine visits. These measures are brief and often in the format of a parent-report questionnaire. Notably, level 1 screening measures are not specifically designed to identify autism. Instead, these measures aid in the identification of a broader array of developmental deficits, such as language, cognitive, and motor delays. The most commonly used level 1 screenings consist of the Checklist for Autism in Toddlers (CHAT), Modified Checklist for Autism in Toddlers (M-CHAT), and Pervasive Developmental Disorders Screening Test-II (PDDST-II). The CHAT (Baird et al., 2000) is a screening measure given to parents of 18 to 24 month old children that includes both parent responses and a brief observation of the child. The M-CHAT (Robins, Fein, Barton, & Green, 2001) includes CHAT items, but was lengthened to a 23-item yes/no questionnaire to be used with 16 to 48 month old children. The PDDST-II (Siegel, 2004) is a 10 minute parent-report questionnaire that determines whether children 18 months or older is at risk for autism spectrum disorder.

Level 2 Screening

Level 2 screening measures differentiate children at risk for autism from those at risk for other developmental disorders (Johnson et al., 2007; Ozonoff et al., 2005; Williams & Brayne, 2006). Generally, level 2 screenings require a comprehensive analysis of developmental problems and therefore involve additional training time for health care professionals to learn how to administer, score, and interpret the measures. These particular screening measures are most often used in evaluation centers or early intervention programs that offer services to children with a range of developmental disorders. The Gilliam Autism Rating Scale – 2nd Edition (GARS-2) and the Social Communication Questionnaire (SCQ) are commonly utilized level 2 screening measures. The GARS-2 (Gilliam, 2006) is a revision of the Gilliam Autism Rating Scale and consists of 42 items describing characteristics of behaviors that are clustered into three subscales of social interaction, stereotyped behaviors, and communication. The SCQ

(Rutter, Bailey, & Lord, 2003) is based on the Autism Diagnostic Interview-Revised (ADI-R), which is a written questionnaire for parents with 40 items that correspond to a diagnosis of autism from the *DSM-IV-TR.*

Diagnostic Assessments

If the child fail level 2 screening measures, a formal diagnostic evaluation is warranted from a multidisciplinary team, which often includes a developmental pediatrician, child psychologist, speech-language pathologist, and an occupational therapist (Blackwell & Niederhauser, 2003; Ozonoff et al., 2005; Spence et al., 2004). A complete evaluation focused on the developmental progress in numerous domains (e.g., social interaction, cognition, social skills, adaptive functioning, and language) is necessary for differential diagnosis and identification of appropriate interventions for the child (Ozonoff et al., 2005; Zwaigenbaum et. al., 2009). Standardized diagnostic measures including the Autism Diagnostic Observation Schedule (ADOS) have been found to be extremely helpful with assisting clinicians in decision-making (Eaves & Ho, 2004).

The Role of the Parent

The presence of a possible disability in a child provides new challenges for parents and it is not uncommon for parents to face many stressors throughout the process of obtaining a diagnosis for their child. One of the greatest stressors is not knowing or understanding what to expect. Many parents become overwhelmed with the wealth of information available on the Internet and struggle with identifying what is pertinent. For instance, parents often do not realize that a question of autism spectrum disorder gets answered through a course of many assessments over a period of time. They often do not understand the importance of having a comprehensive evaluation done by a team of service providers that includes a psychologist, occupational therapist, speech pathologist, psychiatrist, social worker, and a physical therapist (Greenspan et al., 2008). This lack of understanding of the assessment process often results in parents being financially and emotionally unprepared for the array of professionals and the numerous assessments involved often at several locations (Eagle, 2009; Kanne, Randolph, & Farmer, 2008). This can cause negative emotions including frustration and hopelessness and ultimately contribute to a delay in diagnosis (Harrington, Patrick, Edwards, & Brand, 2006).

Research suggests that parents' satisfaction with the overall diagnostic process is associated to the length of time between the first concerns and final diagnosis (Renty & Roeyers, 2006). Earlier research indicates that 25% of parents did not follow the advice of having a follow-up evaluation for their child after an initial developmental screening (Cadman et al., 1987; Volkmar et al., 1994). Current research by Dietz, Swinkels, van Daalen, van Engeland, and Buitelaar (2007) suggests that 31% of parents did not comply after level 1 screening and 32% of parents did not comply after level 2 screening.

Reasons for noncompliance after level 1 screening included: parents not worried about the positive screening result, parents found a follow-up screening to be an inconvenience, the child was already being seen by a specialist for medical reasons, or parents felt their child was too young to be participating in screening procedures (Dietz et al., 2007). Parents report as reasons for noncompliance after a level 2 screening including wanting to wait for further development in their child, personal and practical reasons, and not being educated about the advantages and disadvantages of all possible courses of action so that, they as advocates for their child, can make informed decisions (Dietz et al., 2007). Thus, in order for parents to be willing to follow professional advice regarding successive assessments, they need to understand the importance of following through on recommendations.

Early Identification and Early Intervention

Individuals with Disabilities Education Act (IDEA)

In the late 1950s, Congress embarked upon legislating educational services for children with physical disabilities and those with mental retardation (Crane & Winsler, 2008). However, it was not until 1975 that the Education for All Handicapped Children Act (EHA) was approved which sanctioned support to expand educational services and Head Start programs for children with disabilities (Crane & Winsler, 2008). The EHA was renamed the Individuals with Disabilities Education Act (IDEA) in 1990 with the introduction of early intervention services for young children and their families (Katsiyannis, Zhang, & Conroy, 2003). Most importantly, IDEA also identified autism spectrum disorders as a developmental disability and stressed the impact of intervention for children with autism spectrum disorders. Notably, for each child diagnosed with a developmental deficit including autism spectrum disorder, IDEA mandates an Individualized Family Service Plan (IFSP) (Pinto-Martin & Levy, 2004).

According to IDEA, children starting at the age of 3 are qualified to receive special education and related services through the public education system (Filipek et al., 2000; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Wiggins, Baio, & Rice, 2006). Therefore, it is critical for children to be identified and diagnosed early so that they have access to the entitled *free, appropriate education* that the school system must plan and provide for (Klinger & Renner, 2000; Rhoades, Scarpa, & Salley, 2007; Wiggins et al., 2006). However, despite this legislation, many parents feel overwhelmed, confused, and struggle to manage the impact of autism (Filipek et al., 2000; Rhoades et al., 2007). As a result, many children fail to receive services because they are not identified at an early age and therefore not referred to appropriate agencies.

Early Identification

The concern over the increased prevalence of autism combined with greater professional and public awareness has resulted in a need for earlier detection of children with autism spectrum disorders. Research studies have consistently established that an autism spectrum diagnosis at 2 years of age is reliable and stable (Corsello, 2005; Eaves & Ho, 2004; Kleinman et al., 2008; Matson et al., 2008; Moore & Goodson, 2003; Turner et al., 2006; Wiggins et al., 2006). Eaves and Ho (2004) assessed 49 children diagnosed with autism or PDD-NOS at 2 years of age and retested them at 4 ½ years old with results indicating that 88% still had a diagnosis of autism or PDD-NOS, with the autism diagnosis as the more stable of the two. Charman et al. (2005) studied 26 children who were diagnosed with autism spectrum disorder at age 2 and were reassessed at age 3 and age 7. The results indicated that with the exception of one child, all the children remained on the spectrum. Consistent with previous studies, Moore and Goodson (2003) diagnosed 16 children between 29 and 40 months of age with an autism spectrum disorder and when re-evaluated 24 months later, all of these children continued to be on the autism spectrum.

Early Intervention and the Importance of Early Entry

It is recognized that environmental influences and intervention have a significant impact during the initial few years of life (Crane & Winsler, 2008; Shattuck et al., 2009). The importance of providing an early autism diagnosis is supported by studies of neural development which suggests that very young children have increased brain plasticity and therefore, have greater opportunities to overcome neurodevelopmental deficits if interventions begin early (Branson et al., 2008; Coonrod & Stone, 2004). Therefore, early intervention programs are effective because they place children in developmentally enriching settings with a focus on building skills and offering parent training and support. Empirical evidence indicates that early intensive intervention optimizes long-term prognosis by enabling children to achieve important milestones (Granpeesheh, Dixon, Tarbox, Kaplan, & Wilke, 2009; Matson et al., 2008; Robins, Fein, Barton, & Green, 2001). Research continues to support the advantageous outcome of developmental and behavioral intervention for children with autism spectrum disorders, particularly when it is initiated in a timely manner (Filipek et al., 2000; Scambler, Rogers, & Wehner, 2001; Shattuck et al., 2009).

Generally, beneficial intervention treatments include substantial treatment hours per week that consist of structure and consistency, social skill training, development of functional language, and direct instruction (Sutera, et al., 2007; Zachor, Ben-Itzchak, Rabinovich, & Lahat, in press). Studies state that marked gains in socialization, communication, and cognition are examples of successful early intervention outcomes (Johnson, 2008; Matson et al., 2008; Sallows & Graupner, 2005). Kasari (2002) examined 10 different autism spectrum disorder intervention studies and discovered 47% of participants showed considerable improvements in social interactions, cognition, and behavior for all of the interventions. Additionally for children with autism, gains in functioning associated with early treatment have been estimated to result in substantial financial savings for the families (Mandell, Novak, & Zubritsky, 2005). Consequently, early access to such services is crucial.

Current research suggests that intervention initiated prior to age 3 has a better prognosis than that after age 5 (Corsello, 2005; Harris & Handleman, 2000; Johnson, 2008). Glascoe (2000) found that children with two years of intervention prior to kindergarten were more likely to graduate high school, have a steady job, and live independently as adults. Additionally, Corsello (2005) found that individuals who receive early intervention prior to 48 months of age have better success than individuals who start intervention after 48 months of age. In fact, significant increases in IQ were found in children with autism who started early intervention prior to 4 years of age (Branson et al., 2008; Harris & Handleman, 2000). Charman and Baron-Cohen (2006) found that children who obtain services at an early age are more likely to be in less restrictive educational placements and develop verbal communication. Therefore, the research consistently suggests that early identification and early intervention are significant and necessary factors for successful prognosis in the management and treatment of children with autism (Branson et al., 2008; Klinger & Renner, 2000; Shattuck & Grosse, 2007).

Importance of "Red Flags"

Research studies indicate that symptoms of autism are often seen prior to 12 months of age and that parents are frequently accurate regarding their child's development (Chawarska, Klin, Paul, & Volkmar, 2007; Scrambler et al., 2001; Zwaigenbaum et al., 2009). Most children with autism spectrum disorders show early signs (i.e., *red flags*) of delay in motor, language, and cognitive skills during infancy, which parents need to be aware of and alert for (Gargus & Yatchmink, 2005; Johnson, 2008). Using these *red flags*, a study by Landa (2007) found that by 14 months of age approximately 50% of affected children could be diagnosed reliably. Current studies have demonstrated the importance of early recognition of potential autism symptoms as the first step to obtaining screening, diagnostic assessments, and then receiving intervention treatments (Crane & Winsler, 2008; Gray & Tonge, 2005; Lubetsky et al., 2008).

Early Indicators of Autistic Development

Presently, various methods including retrospective studies and prospective research are being utilized with the purpose of identifying early signs of autism spectrum disorder to aim for timely diagnosis and initiation of intervention services. Retrospective studies, including parental accounts of early symptoms and analysis of home videos, focus on early behavioral signs in children who have already received an autism spectrum disorder diagnosis (Zwaigenbaum et al., 2007). In fact, based on retrospective parent reports, 50% of parents identified signs of autism in their children by 2 years of age and 93% reported features of autism by 3 years of age (Matson et al., 2008). Additionally, Wing and Gould (1979) noted that parents identified unusual social relating (e.g., lack of eye contact) and labile temperament. Similarly, Baird et al. (2001) found that parents' account of their child's poor imitation of movements, lack of smiling, and a failure to attract attention were strong predicators of a later autism diagnosis.

Another retrospective method used to identify early indicators of atypical development is an examination of home videos of the child taken prior to an autism spectrum disorder diagnosis. In a study of videos of infants less than 1 year of age, Adrien et al. (1993) observed five abnormal behaviors consisting of lack of facial expressions, hypotonia, lack of smiling, no eye contact, and poor social attention. Osterling and Dawson (1994) in their study of first birthday party videos noted that children with autism were less likely to orient to their names, not as likely to show an object, and displayed poor eye contact when compared to typical peers. Similarly to previous studies, Werner et al. (2000) found significant differences, particularly in ability to orient to name, that can be detected at 8 to10 months of age between children with autism and typical developing peers. Furthermore, Matson et al. (2008) noted delayed response to name, visual staring and fixation on objects, and excessive mouthing of objects were potentially behavioral indicators for a later autism diagnosis.

Prospective studies offer numerous advantages including the ability to study early development and behaviors longitudinally across different ages which can further the understanding of the impact of early delays in one domain (e.g., join attention) on the subsequent development of another domain (e.g., language) (Ozonoff et al., 2010; Zwaigenbaum et al., 2005). There is growing interest in studying infant siblings of children with autism spectrum disorder. Landa and Garrett-Mayer (2006) reported developmental behaviors beginning at 6 months of age that start to differentiate infant siblings later diagnosed with autism spectrum disorder. In fact, Ozonoff et al. (2010)

stated that loss of social communicative behaviors were particularly dramatic between 6 and 18 months of age. Zwaigenbaum et al. (2005) found that by 12 months of age specific behavioral markers including atypical eye contact, orienting to name, visual tracking, and lack of social smiling can be distinguished by 12 months of age from siblings who are later diagnosed with autism. Furthermore, findings from Mitchell et al. (2006)'s infant sibling study showed delays in onset of intentional communication (e.g., shaking and nodding head, pointing, showing) by 12 months of age.

A multidisciplinary panel representing nine professional organizations and endorsed by the American Academy of Neurology and the Child Neurology Society reviewed research on autism screening and diagnosis of autism spectrum disorders and made interdisciplinary recommendations on practice parameters (Filipek et al., 2000). The panel recommended that absolute signs for immediate additional evaluation include absence of babbling at 12 months, lack of gesturing at 12 months, no single words at 16 months, no spontaneous phrases of at least two words at 24 months, and any loss of social skills or language at any age (Baird et al., 2001; Lubetsky et al., 2008; Spence et al., 2004; Wetherby et al., 2004).

Parents are frequently the first to suspect developmental problems in their child and their concerns are often accurate and valid (Coonrod & Stone, 2004). However, even though nearly all parents recognize something is wrong with their child by 18 months of age, most parents do not immediately share their concerns with health care professionals (Harrington et al., 2006). Although parents report deficits in response to clinician's specific questions, they rarely spontaneously report concerns about their child's development (Coonrod & Stone, 2004). Sivberg (2003) noted there was a five year delay between parents' initial suspicions until the completion of the diagnostic process. Fombonne, Simmons, Ford, Meltzer, and Goodman (2003) found that although parental concerns were expressed when the child was between 15 and 22 months, there was a delay of approximately six months before the child was seen by a specialist.

Therefore, an increased awareness of early signs of autism and parents' role as an advocate can help assist access to screening measures in a timely manner, entry to appropriate interventions at an earlier age, and consequently have significantly improved long-term prognosis.

Barriers to Implementing Screening

Several barriers exist that may impede the implementation of early screening including the lack of developmental pediatric training for health care professionals. While, the majority of students starting medical schools have strong science academic backgrounds they usually have minimal training in psychology, child development, and education (Pinto-Martin, et al., 2005). Woodgate, Ateah, and Secco (2008) found that physicians often are not able to accurately identify features of autism and are not knowledgeable concerning empirically supported autism spectrum disorder treatments. Furthermore, fourth year medical students were found to perform poorly on survey questions regarding prognosis and treatment of autism, causation, and IQ profiles (Rhoades et al., 2007; Shah, 2001).

According to Filipek et al. (2000), in any primary care practice there will be approximately 25% of children who will have developmental issues. While screening might initiate the assessment process earlier, thereby achieving earlier diagnosis, fewer than 10% of pediatricians were found to be using autism spectrum disorder specific screening measures due to reasons including lack of training and experience with autism spectrum assessments (Dosreis, Weiner, Johnson, & Newschaffer, 2006; Robins, 2008; Williams & Brayne, 2006). In fact, fewer than 30% of primary care providers routinely administer even one developmental screening test because of barriers that include time constraints, lack of training, and limited insurance reimbursement (Inglese, 2009; Pinto-Martin et al., 2005; Sand et al., 2005).

Parents often express frustration because of physicians' tendency to minimize or dismiss their concerns (Bryson, Zwaigenbaum, & Roberts, 2004; Goin-Kochel, Mackintosh, & Myers, 2006; Inglese, 2009). However, these health care professionals may delay providing the parents with a diagnosis secondary to concern regarding intense emotional reaction from parents after they are informed of the diagnosis (Pinto-Martin et. al., 2005; Rhoades et al., 2007; Zwaigenbaum et al., 2009) and the fear of incorrectly diagnosing or labeling the child (Filipek et al., 2000; Rhoades et al., 2007). Nonetheless, many studies have shown that parents desire to be informed and a postponement in discussion consequently creates greater distress (Zwaigenbaum et al., 2009). In fact, Whitaker (2002) demonstrated that parental dissatisfaction tends to be greater with increasing age at diagnosis. Notably, Goin-Kochel et al. (2006) found that parents reported greater satisfaction with the diagnostic process when their children received diagnoses at earlier ages and visited fewer clinicians. Specifically, the more health care professionals that families saw to achieve a diagnosis, the more negatively parents viewed the experience because more clinicians indicates more hassle, more money, and more of a wait before receiving a formal diagnosis (Pinto-Martin et al., 2005).

Common Barriers that Parents Encounter

Research suggests that families of children with developmental disabilities are often faced with multiple stressors and barriers (e.g., obtaining referrals, finding providers with appropriate training, delay in diagnosis) in obtaining an early diagnosis (Krauss, Gulley, Sciegaj, Wells, & Taylor, 2003). Despite knowing that early intervention can reduce symptoms and improve a child’s capability to obtain new skills, the National Institute of Mental Health estimates that “only 50% of children are diagnosed before kindergarten” (NIMH, 2007, p. 4). Notably, the time lag between the parents’ initial concern and formal evaluation leads to a later initiation of intervention and the loss of precious time (Inglese, 2009; Filipek et al., 2000; Rhoades et al., 2007).

Primary care pediatricians play a major role in the process of identifying children at risk for autism spectrum disorders because they have more frequent contact with children under the age of 3 years than other medical or educational professionals (Heidgerken et al., 2005; Pinto-Martin et al., 2008; Rhoades et al., 2007). However, few physicians were found to have the background, time, or training to offer parents tips and strategies to successfully obtain services for their child (Pinto-Martin et. al., 2005). Indeed, Krauss et al. (2003) found that a third of the parents of children with autism reported problems when initially accessing specialty care for their children. Additionally, parents often receive information from multiple sources including health care professionals and personal supports involving family and friends. At times, the provided information is confusing and parents experience stress and difficulty determining which information is reliable. In fact, Rhoades et al. (2007) found that 33% of physicians spontaneously offered non-empirically based autism therapy treatments to parents. Thus parents may not be provided with accurate information about autism spectrum disorder and empirically supported treatment options at the time of diagnosis (Krauss et al., 2003; Rhoades et al., 2007).

Rationale for the Resource Manual

It is generally recognized that the relationship between parents and health care professionals can either hinder or enhance outcomes depending on the nature of the relationship (Dunst & Dempsey, 2007). Thus it is crucial for parents with children with autism spectrum disorders to develop a collaborative relationship with their health care professionals. Parents provide a great deal of knowledge regarding their child's behavioral, social, and cognitive functioning in various settings including school and home environments. In fact, parents have been found to be accurate reporters of their child's general development and often are the first to suspect developmental delays (Coonrod & Stone, 2004). Therefore, during the assessment process, health care professionals need the assistance of parents to help create a thorough conceptualization of the child (Eagle, 2009). Forming a positive and collaborative relationship with health care professionals can also promote empowerment within parents and consequently, parents become self-sufficient in eliciting additional resources (Brookman-Frazee & Koegel, 2004). Thus, parents are an invaluable resource and play an essential role in obtaining assessment and services for their children.

While all parents at some time act as information seekers, spokespersons, and advocates for their children, these roles become even more critical for parents of children with developmental disabilities. Harrington et al. (2006) found that 75% of parents expressed little or no confidence in their physician's ability to recognize autism. This highlights and illustrates the need for parents to take on the role as advocates to ensure proper care for their child. Most importantly, this stresses the need for reliable resources in order to educate parents.

The purpose of this resource manual is to educate parents about autism spectrum disorder assessments and empower them to have a significant role in the screening process. Parents need to recognize that they have an important role as advocates for their child and need to feel confident in their own abilities and take control of the situation. In fact, parent empowerment has been identified as both a goal and an important outcome for long-term prognosis (Nachshen & Minnes, 2005; Siklos & Kerns, 2006). Brookman-Frazee and Koegel (2004) suggest that an *empowered parent* is one who demonstrates confidence interacting with service providers, managing daily routines successfully, efficiency with obtaining services, and eludes poise in teaching his or her child. The characteristics of empowerment have been shown to be correlated with enhanced perceptions of control, confidence, and competence (Dunst & Dempsey, 2007). Chakrabarti, Haubus, Dugmore, Orgill, and Devine (2005) state that empowered parents are knowledgeable about the nature and source of their child’s difficulties and consequently they take control of the situation by advocating for appropriate services for their child. Ultimately, empowered parents provide a wealth of knowledge, resources, and expertise, which are particularly advantageous in obtaining assessment and services for their children.

This resource manual provides a general overview of the screening process and explains the importance of multiple screenings at various developmental stages. Specifically, research has shown that timely assessment is crucial to the child’s growth and development (Lubetsky et al., 2008; Rutter, 2006). Therefore, by understanding autism, the importance of screening measures, and using the information provided in the resource manual, parents will become stronger advocates for their child. Consequently, parents will feel confident and actively seek out appropriate resources and services necessary for their child to succeed. Ultimately, by being an informed and active participant in the screening process, parents will make certain that their child’s needs are being met.

Chapter III: Research Methodology

Purpose of the Resource Manual and Target Audience

The diagnosis of autism is based on the identification of a cluster of behavioral and clinical symptoms through the use of screening and diagnostic measures. Due to the complexity of autism spectrum disorders, there is often a delay in obtaining this diagnosis which contributes to missed intervention opportunities. Participation for children with autism in specialized early intervention programs at younger ages is critical for optimizing the long-term outcomes in areas such as language functioning, cognitive/developmental abilities, and socials skills. Therefore, it is essential for parents to recognize the early warning signs of autism, comprehend the importance of screening measures, and be aware of the effectiveness of early intervention. Thus, there was a need to develop an easily understandable and comprehensive resource manual that provided parents with information about the nature and course of autism, the outcome of early intervention, the purpose of screening measures, and the critical importance of subsequent screenings. Information in the manual was written succinctly and presented in an easy-to-read format that utilized bullet points, tables, figures, and charts.

Plan for Development of the Resource Manual

The resource manual was developed using two major strategies for identifying relevant information: (a) the existing research literature was reviewed and (b) a survey was conducted of experts in the field of autism spectrum disorders.

Use of existing literature. A review of existing literature about autism spectrum disorders was conducted utilizing numerous sources of information including articles from peer-reviewed journals, books, and book chapters. A systematic search through information databases such as PsychInfo, PsychArticles, EBSCOhost, ScienceDirect, Scopus, SpringerLink, and Sage Journals Online was completed. An Internet search was also utilized using Google and Google Scholar with search terms including *autism spectrum disorder, autism assessments, autism screening, autism and early intervention,* and *parents' knowledge of autism assessments.*

The resource manual included information on the historical evolution of autism, etiology, epidemiology, clinical presentation, early signs of autism spectrum disorder, overview of the assessment process, role of early identification and intervention, barriers that parents face, and strategies for success. To ensure that the resource manual was useful for diverse populations, an additional review of articles that specifically addressed multicultural issues in the diagnosis of autism was conducted. This review helped determine the optimal format for the resource manual to address the needs of underserved populations.

The American Academy of Pediatrics' (2006) recommendations for the detection of developmental disorders were also reviewed to ensure that the information presented in the resource manual reflected the most up-to-date information for detecting autism spectrum disorders. Details about current clinical assessment measures (i.e., purpose, description, target population, administration time, assessment type) and their limitations (i.e., who administers it) were obtained. These assessment measures were organized into level 1 screening, level 2 screening, or comprehensive diagnostic measures and a summary of the most commonly used assessments that parents encountered at the physician's office was compiled.

Due to recent advances in and current changes of conceptualization of autism, the literature review was restricted to the year 2000 onwards. The resource manual reflected the proposed revisions of the upcoming *DSM-V,* which stated that autism spectrum disorder included autistic disorder (autism), Asperger’s disorder, childhood disintegrative disorder, and pervasive developmental disorder, not otherwise specified (PDD-NOS). Because the resource manual was targeted for parents with young children, the search criteria were limited to children with autism spectrum disorder and not adolescents, young adults, or adults. Therefore, the resource manual did not include Asperger’s disorder as it is usually identified later in life and was beyond the purpose and scope of this study. Childhood disintegrative disorders were also not included because they are characterized by unique presentations and are not identified through screening but rather extensive medical evaluations.

Consultation with experts on autism spectrum disorders.

Overview of the process. After approval from the Graduate and Professional Schools Institutional Review Board, a pool of 20-25 professionals with expertise in the field of autism spectrum disorders were contacted by email and invited to participate in the study. The email was composed of the following: (a) information about the investigator and her faculty advisor; (b) the purpose of the request, the time commitment required, and a succinct explanation of what participants were asked to do; (c) instructions for completing the study; (d) the presentation of the clinical scenario that served as the stimulus for the study; and (e) the two questions which required responses, i.e., what advice they would offer parents in response to the clinical scenario and secondly whether they grant permission to have their name associated with their contribution (see Appendix A). The first email invitation was sent on 08/20/2010 and received five responses. To those who had yet to respond, a second email invitation reminder was sent out on 09/02/2010 and received an additional three responses. The last email invitation reminder was sent out on 09/16/2010 and received two more responses for a total of 10 responses.

All participants were forwarded a copy of the resource manual after its completion to review. The opportunity to review the final document allowed the participants to offer comments about the manual in general, their own contribution, and the information about their title and affiliation. It also allowed the professionals who elect not to have their names associated with their contribution verify that their wish for anonymity was respected.

Analysis of experts' responses. An initial review of all the experts' responses indicated that there were common themes and overlapping concepts. The experts' responses were found to generally address four major areas: basic information regarding autism, early intervention, assessment, and parents' role in the process. A framework to systematically organize each experts' responses into four sections was developed with specific inclusion and exclusion criteria for each section. The first section titled, "Autism: An overview," targeted advice that related to general information about ASD. For inclusion in this section, the expert's response had to include advice about (a) resources that provided general information on autism spectrum disorders (b) organizations that provided overview materials on early intervention or (c) the steps parents could take to become informed about what to do. Advice about early intervention, the assessment process, and the role of the parents were excluded from this section.

The second section titled, “Why it is important to be informed,” addressed the importance and impact of early intervention. For inclusion in this section, the expert’s response had to include advice regarding information about (a) how to enroll in early intervention services (b) starting services as soon as possible and remaining hopeful or (c) contacting Regional Centers, school districts or early intervention services agency for assistance. Advice about the overview of ASD, the assessment process, and the role of the parents were not included in the second section.

The third section titled, “Assessment,” focused on advice relevant to the assessment process. For inclusion in this section, the expert’s response had to include advice about (a) the importance of having a multidisciplinary team of professionals conducting assessments (b) using gold-standard assessments including Autism Diagnostic Interview-Revised (ADI-R) and Autism Diagnostic Observation Schedule (ADOS) (c) ruling out medical conditions or (d) information on agencies providing the assessment services. Advice about the overview of ASD, early intervention, and the role of the parents were not included in the third section.

The fourth section titled, “Role of parents,” emphasized parents’ role as advocates for their child and provided parents with strategies and supports that parents. For inclusion in this section, the expert’s response had to include advice about (a) joining a parent support group (b) seeking parent training (c) joining a parent-toddler group such as music class (d) organizational strategies such as keeping detailed records and files or (e) encouraging parents to be advocates for their child. Advice about the overview of ASD, early intervention, and the assessment process were not included in the fourth section. All of the experts' individual responses were reviewed by the experimenter and assigned to these sections based on the above criteria.

In an attempt to validate the information collected, several strategies (i.e., triangulation, member checking, peer debriefing) were implemented. In triangulation, autism experts from different professional backgrounds (i.e., psychology professionals, advocates, legal experts) were invited to participate in the study. This allowed for checking the consistency of information across different sources using the same method (i.e., email invitation to participate in the study by providing advice they would offer parents in response to a clinical scenario). The results indicated that the experts from different professional backgrounds generally provided similar advice (e.g., obtain a multidisciplinary assessment, join a parent support group, start early intervention as soon as possible).

After categorizing the experts' responses into the four sections, all participants were forwarded a copy of the resource manual for review. In member checking, this gave participating experts' an opportunity to review the accuracy and credibility of their own responses. In addition, the experts were also asked to review the entire manual and to provide comments about the accuracy of the content. Of the 10 experts who contributed to the study, 8 of them responded. The feedbacks consisted of positive comments (e.g., "It looks great! What a wonderful project" "The manual is very thorough and well-done") and reflected the accuracy of their responses (e.g., "Yes, it is correct" "My information looks correct").

In peer debriefing, the faculty advisor served as the reviewer by providing an external review of the research process. Extended discussions between the author and the faculty advisor were focused on findings, accuracy of responses, and conclusions. The faculty advisor also provided guidance on the next steps for the project.

Format, Structure, and Content

The resource manual was written as a series of chapters covering the nature of autism, early signs of autism spectrum disorder, standards of care for developmental screening, an overview of the assessment process, role of the parents, early identification, and strategies and tips for obtaining appropriate assessments and interventions for one’s child. In order to increase the usability of the resource manual for parents, it was aimed to be written at an early high-school reading level. To ensure that the intended audience was not presented with an overwhelming amount of information, the content of this resource manual did not exceed 25 pages. Tables, graphs, and other visual strategies for organizing information were used in an effort to increase the comprehension and accessibility of the information. Included among these visual aids were flow charts and checklists that delineated the important sequential steps that the American Academy of Pediatrics (2006) recommends for parents to follow from the point at which they express concern about their child’s development.

The experts’ advice was a significant contribution to this resource manual as these were professionals in the field who interact daily with parents of children seeking information about assessment and intervention. The feedback provided by the professionals helped determine the content for the manual by validating the information gathered from the literature review and prioritizing the information presented to parents. For example, based on the experts’ feedback, an entire section was dedicated to the importance of early intervention and identification.

One of the major goals for the manual was to provide parents with a means to access information and resources. Developmental checklists, examples of commonly used screening and assessment measures, autism organizations, publications, and state specific resources (i.e., Regional Centers and Medical Centers in California) were identified during the literature search. Additional information was gathered from autism national organizations such as Autism Speaks and pediatric healthcare organizations such as American Academy of Pediatrics. This information was then collated and organized into a series of parent-friendly appendices. This included the list of commonly used screening and assessment measures (Appendix C in resource manual) based on testing measures strongly recommended by the American Academy of Neurology, American Psychiatric Association, and American Academy of Pediatrics. A list of frequently asked questions that parents might encounter throughout the assessment process (Appendix G in resource manual) was gathered from a review of clinical intake interviews and parent interview surveys (e.g., Vineland Adaptive Behavior Scales). Specific referral sources were provided to assist parents in connecting with Regional Centers, service providers, and other sources of support to obtain services for their child in a timely manner.

Summary

Being faced with the reality of possibly having a child with autism poses a significant source of distress for parents. The distress is compounded for parents who are often overwhelmed with the volume of information available through the Internet, difficulty deciding what information is relevant and applicable, and parents' lack of knowledge regarding the importance of subsequent autism screening. This manual aimed to educate and empower parents to take the necessary steps (e.g., voice their concerns, request and complete screening measures) to access appropriate services (e.g., seek for a comprehensive diagnostic assessment, early intervention services). Specifically, the parents' ability to identify early signs (i.e., *red flags*) helps their child receive proper health care attention (e.g., screening measures) in a timely manner which allows their child to benefit from early intervention services. Thus parents can become effective advocates for their child in dealing with health care professionals and not lose valuable time in delaying early identification and intervention.

The future goal is to have the resource manual translated into various common spoken languages such as Spanish, Mandarin, and Korean. Although publication and dissemination of the resource manual is beyond the scope of this dissertation project, the manual is eventually intended to be distributed to pediatric health care offices or evaluation clinics, as these are the places where parents often seek information regarding their child's developmental delay.

Chapter IV: A.W.A.R.E.

The Assessment of Autism Spectrum Disorder

A Resource Manual for Parents with Young Children (ages 0-3 years)

A resource manual was developed with the intention of providing critical information to parents with an effort to educate them about the nature and course of autism, the outcome of early intervention, the purpose of screening measures, and the importance of subsequent screenings. By providing parents with a comprehensive, concise, and easy to use resource manual, it is hoped that parents will feel empowered to take the next necessary steps to access appropriate services in a timely manner. The resource manual, in its entirety, can be found in Appendix B.

Chapter V: Discussion

Summary of the Project

Identifying children with autism and initiating intensive early intervention during the preschool years results in improved lifelong outcomes including cognitive gains, increased verbal and nonverbal communication, and peer interaction (Wiggins et al., 2006). This resource manual was developed as a tool to provide information as well as to provide hope to parents with children who may have an autism spectrum disorder (ASD). To date there is no known medical test to diagnose autism spectrum disorder. Instead, a diagnosis is based on health care providers' observations of the child's communication, behavior, and development followed by the administration of screening measures and a comprehensive diagnostic evaluation. There is often a delay in the early identification and diagnosis of developmental delays resulting in a loss of critical early intervention time for the child (Matson et al., 2008; Shattuck et al., 2009). Research indicates that one of the key factors that determine a child's involvement in early intervention is the parents' level of knowledge and access to appropriate resources (Eagle, 2009). Thus, parents play a pivotal role in obtaining services for their child with ASD. However, for many parents this can be a daunting role, as they often lack the necessary information to educate themselves in order to advocate for their child's rights.

This resource manual was written specifically for parents who have a child under the age of 3 years. The goal was to provide basic information on autism spectrum disorders, the role of screening and assessments, and how to advocate for appropriate assessments and intervention services. Having the knowledge needed to take the necessary steps can help the parent feel a sense of control and thus expedite crucial assessments and interventions. The manual also includes advice from experts in the field of autism thus providing parents with the tools and information that they need to maximize the outcome for their child with autism. Current research suggests that early identification and early intervention are crucial factors for effectively managing and treating children with autism spectrum disorder (Branson et al., 2008; Shattuck & Grosse, 2007). Therefore, educating parents is an important step towards empowering them to cope with this lifelong challenge.

Strengths of the Current Manual

One of the major strengths of this manual is that it will serve as a succinct, preventive care tool for parents of children under the age of 3 years. The manual integrates information from a range of sources (i.e., research literature, books, Internet resources, experts' advice and suggestions) and compiles this information into one source for parents. To date this information was widely dispersed and often not accessible to parents. The manual includes research related to autism spectrum disorder, prevalence, etiology, diagnostic criteria, the importance of recognizing early warning signs, the overall assessment process, and strategies and tips from experts in the field. The goal was to provide parents with the knowledge necessary to understand autism spectrum disorders and to encourage their involvement in early identification and intervention. As part of this emphasis on parent education and preventive care, the manual also included crucial up-to-date research information obtained from the research literature. This included demonstrating the importance of having all children screened specifically for autism spectrum disorder at their 18- and 24-month child preventive care visits even if there are no concerns raised.

The second major strength of the manual is its parent-friendly format. The manual was intended to simplify the assessment process for parents who might otherwise feel overwhelmed by what can appear to be a convoluted and complex process. The focus of the resource manual was to present the information in a clear, simple, and jargon-free manner. Because much of the material related to autism spectrum disorder can be challenging to read, understand, and be potentially overwhelming for parents, efforts were made to use tables, checklists, graphs, and bullet points as a mean to present the information in a parent-friendly fashion. Thus, parents can easily understand the steps involved in obtaining services and feel empowered to take the initial steps in doing so. Additionally, this resource manual is versatile in that it is not necessary to read the resource manual in its entirety. Instead, each section of the resource manual can stand alone and provide a basic level of knowledge to the reader about the area in question thus allowing parents to read the relevant section. A detailed table of contents is presented as a tool for parents to quickly find specific information.

Another strength of the resource manual is that it provides strategies and clear steps for parents to follow and identifies pathways and means to obtain information and support. The experts contacted provided highly relevant applied information that served as the foundation for the content of the resource manual. This information was organized in a manner that encourages the parent’s active engagement. The appendices include checklists, questions that will be asked, and in depth state specific resources. Furthermore, the manual was written in an empathic tone that acknowledges the considerable stressors faced by a parent with a young child with early warning signs for autism spectrum disorder. The combination of this empathic tone and the concise information provided was aimed at instilling hope and motivating parents to become successful advocates for their child.

Limitations of the Current Manual

There are several limitations associated with the current resource manual. The manual was aimed at parents with children under the age of 3 years, thus limiting its applicability to parents with older children who may have concerns about autism spectrum disorder. The decision to target parents of younger children was based on the fact that while an experienced clinician can reliably diagnose autism spectrum disorder as young as 18 months of age, parents often face significant delays between 6 months and 5 years in obtaining services and recommendations (Fombonne et al., 2003; Sivberg, 2003). Parents of older children may still find certain parts of the resource manual useful including the information on autism spectrum disorders, experts' advice, and the appendices related to helpful resources and individual state resources.

The initial intention was for the manual to be written at an early high-school reading level. However, the nature of the content of the resource manual was difficult to simplify to this level. By utilizing Microsoft Word's readability statistics (i.e., Flesch-Kincaid grade level), it was determined that the majority of this resource manual was written at an 11.1 grade reading level. Further simplifying the language or including additional checklists, graphics, and tables may enhance the resource manual's readability and make it easier to comprehend and more accessible to a wider audience. The very nature of this resource as a written manual may pose as a limitation in terms of the ease with which it can be accessed by families with lower income and or educational levels. For many such families, identifying, obtaining, and reading a manual may not be the way that they typically gather information or seek answers to questions. Written resources such as this may be demanding for parents with reading skills below eleventh-grade level. Furthermore, parents whose first language is not English may struggle with the content and would be best served by information presented in their primary language. The aim in the future is for versions of this resource manual to be translated for non-English speaking populations thus targeting families of children that are often underserviced. The goal is also to provide this manual to a range of community and outreach free clinics many of whom provide services to often marginalized families.

Although it is shorter than most existing resources related to autism spectrum disorder, the manual can still be overwhelming for parents since it consists of 17 pages of content and 14 pages of appendices. While the addition and extensive use of graphics makes the resource manual parent-friendly, it does contribute to the overall length of the manual. Another way of potentially making the resource manual more engaging would be to include a vignette continued over the course of the resource manual about a parent whose child is displaying early warning signs for autism spectrum disorder. The vignette could describe the experiences the parent has gone through, any concerns and questions, the process of educating himself/herself about the disorder, and the steps he/she took to obtain the necessary support and services. Such a vignette might provide a more personally relevant and engaging means of presenting information that otherwise may be somewhat difficult to read.

Research studies indicate that email survey response rates are usually between 19% to 43% (Yun & Trumbo, 2000). The current version of the manual was based on a survey of advice from 6 psychology professionals, 2 attorneys, and 2 advocates that responded from a pool of 25 experts. While this is a relatively high number of respondents from an e-mail survey (i.e., 40% response rate), future revisions may also consider adding additional advice from a variety of experts in the field. Other experts to consider contacting and obtaining advice from are more advocates, more attorneys, social workers, and Regional Center caseworkers. Community or parent support organizations could also be surveyed and the information obtained can be included.

As a written resource, the current resource manual is limited to research data that were available at the time that the resource manual was developed. Given the increased awareness and attention that autism spectrum disorder is currently receiving, some of the material in the resource manual may become outdated relatively quickly. One way in which the resource manual attempts to address this problem is by providing parents with information on how they can continue to educate themselves and stay up-to-date with respect to the latest developments in this field (i.e., Appendix E: Helpful Resources, Appendix F: State Specific Resources). If parents are able to take advantage of community resources such as the Regional Center and seek information through the Internet Websites provided, this will help them keep up-to-date with the most current information. However, this will be a limitation for individuals who do not have computers, have access to the Internet, or have the computer skills to obtain information in this manner. By making the manual available to community-based resources it is hoped that even those without Internet access will be able to obtain the information.

Although this resource manual was developed with the purpose of helping parents with young children under the age of 3 years, it is not yet known whether this resource manual will be a useful tool for these parents. The usefulness of this resource manual is only assumed, based on the literature and the scarcity of available information for parents. To assess its usefulness and comprehensiveness for parents, a formal evaluation of this resource manual would need to be undertaken. A possible future plan for evaluating this resource manual is outlined in the following section titled, “Plan for an Evaluation of the Current Manual.”

Plan for an Evaluation of the Current Manual

After some of the preliminary improvements are made to the resource manual, both informal and formal assessment of its adequacy, ease of use, and benefits could be assessed in an effort to improve the resource manual. The evaluation process can begin with a distribution of the revised resource manual to several experts in the field of autism, with a request for them to review and critique the resource manual. It is important to note that these experts will not be the same experts in the resource manual who already provided an informal feedback to the resource manual. Informed consent procedures would be implemented whenever human subjects are involved, as well as institutional board review approval, where indicated. Additional modifications will be made based on the feedback obtained from the field-testing. In the initial phase of evaluating the resource manual, professionals who coordinate and implement services in California for children with autism will be contacted. They will be asked to read the resource manual and provide feedback on its content and format. Efforts will be made to include professionals who are Regional Center caseworkers, psychologists and psychiatrists who assess children, advocates, legal experts, and coordinators of early intervention programs for children on the autism spectrum disorder spectrum. In order to improve the ease with which professionals can provide this feedback and increase the cohesiveness of the feedback, an evaluation form will be submitted along with a copy of the resource manual. Professionals will be asked to rate the manual on content, readability, organization, and visual presentation. The evaluation form will also pose questions about the accuracy and relevance of the material presented. Additionally, they will have an opportunity to respond to open-ended questions regarding how the resource manual could be revised to increase its value as a resource.

Once the feedback from professionals have been incorporated into the resource manual and relevant revisions have been made, there will be a phase of field-testing with actual parents who have young children under the age of 3 years. Parents will be asked to read the resource manual and provide feedback using a standard questionnaire. The questionnaire would ask parents to rate the various aspects of the resource manual including readability, how useful they found the information, and overall presentation of the material. Additionally, parents will have the opportunity to respond to open-ended questions specifically regarding what they found most useful and least useful in the resource manual. The feedback collected from the parents during the field-testing would also be incorporated into another revision of the resource manual.

Plan for Dissemination

Dissemination of the resource manual is premature at this time, as it is still in draft form and has not yet been evaluated. Such distribution would occur only after the resource manual has been modified based on expert review and field-testing. If the resource manual is found to be a useful resource for families, it will be distributed to families on a larger scale. Once it has been adequately developed and assessed for effectiveness, there are a number of options for dissemination of this resource manual.

Specifically, health care providers who provide direct services to young children and their families can be contacted, including pediatricians, Regional Centers, and autism clinics. These service providers, national autism organizations and support groups can be provided with a brief overview of the resource manual. Those who are interested in utilizing the resource manual as a resource for parents will be sent a copy as well as a questionnaire to assess the resource manual's usefulness. Their feedback would be valuable for any further revisions of the resource manual.

The vast amount of online resources that provide information related to autism spectrum disorder would be another option for dissemination of the resource manual. The manual can be provided to websites with a downloadable PDF version of the resource manual in an effort to increase parents' access to important information. This form of dissemination can also provide an opportunity for further feedback and evaluation of the resource manual.

Conclusion

In the process of writing this resource manual, a surprising finding has been the scarcity of information regarding the importance and role of screening and the overall assessment process for autism spectrum disorder. Given that research identifies early detection and early intervention as key components of the prognosis for autism spectrum disorder (Branson et al., 2008; Granpeesheh et al., 2009; Matson et al., 2008), there is a significant shortage in the number of resources available to parents. Future research may involve interviewing parents who have gone through the entire assessment process asking for suggestions or advices they would offer other parents. This information could help motivate and instill hope for other parents. It is crucial for future studies to continue to analyze what causes parents to not follow through with subsequent screenings or prevents them from obtaining a comprehensive diagnostic evaluation. Finding the answers to these types of questions will be an invaluable guide to the development of resources and services that are specially targeted to meet the needs of parents.

Based on the limited amount of resources on the role of screening and the assessment process, this resource manual represents an initial effort to provide parents with a tool for helping them recognize the need and importance of assessment, while working collaboratively with a qualified health care professional. This resource manual aims to empower and help parents familiarize themselves and become aware of the assessment process so that they would feel well informed and educated when making decisions in a timely manner for their child.

REFERENCES

Adrien, J. L., Lenoir, P., Martineau, J., Perrot, A., Hameury, L., Larmande, C., & Sauvage, D. (1993). Blind ratings of early symptoms of autism based upon family home movies. *Journal of the American Academy of Child & Adolescent Psychiatry, 32*(3), 617-626. doi:10.1097/00004583-199305000-00019

Allen, D. A., & Mendelson, L. (2000). Parent, child, and professional: Meeting the needs of young autistic children and their families in a multidisciplinary therapeutic nursery model. *Psychoanalytic Inquiry, 20*, 704-731. doi:10.1080/07351692009348917

Aly, Z., Taj, F., & Ibrahim, S. (2010). Missed opportunities in surveillance and screening systems to detect developmental delay: A developing country perspective. *Brain & Development, 32*(2), 90-97. doi:10.1016/j.braindev.2009.06.004

American Academy of Pediatrics. (2001). Developmental surveillance and screening of infants and young children. *Pediatrics, 108*, 192-195.

American Academy of Pediatrics. (2006). Identifying infants and young children with developmental disorders in the medical home: An algorithm for developmental surveillance and screening. *Pediatrics, 118*, 405-420. doi:10.1542/peds.2006-1231

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders, 4th edition, text revision (DSM-IV-TR).* Washington, DC: Author.

American Psychiatric Association (2010). *DSM-5 development.* Retrieved from http://www.dsm5.org/Pages/Default.aspx

Anderson, A., Moore, D. W., Godfrey, R., & Fletcher-Flinn, C. M. (2004). Social skills assessment of children with autism in free-play situations. *Autism, 8*(4), 369-385. doi: 10.1177/1362361304045216

Baghdadli, A., Picot, M. C., Pascal, C., Pry, R., & Aussilloux, C. (2003). Relationship between age of recognition of first disturbances and severity in young children with autism. *European Child & Adolescent Psychiatry, 12*(3), 122-127. doi: 10.1007/s00787-003-0314-6

Baird, G., Charman, T., Baron-Cohen, S., Cox, A., Swettenham, J., Wheelwright, S., & Drew, A. (2000). A screening instrument for autism at 18 months of age: A 6-year follow-up study. *Journal of the American Academy of Child & Adolescent Psychiatry, 39*(6), 694-702. doi:10.1097/00004583-200006000-00007

Baird, G., Charman, T., Cox, A., Baron-Cohen, S., Swettenham, J., Wheelwright, S., & Drew, A. (2001). Screening and surveillance for autism and pervasive developmental disorders. *Archives of Disease in Childhood, 84*, 468-475. doi:10.1136/adc.84.6.468

Baker, J. P. (2008). Mercury, vaccines, and autism. *American Journal of Public Health, 98*(2), 244-253. doi: 10.2105/AJPH.2007.113159

Baron-Cohen, S. (2001). Theory of mind in normal development and autism. *Prisme, 34,* 174-183.

Baron-Cohen, S., Leslie, A. M., & Frith, U. (1985). Does the autistic child have a "theory of mind?" *Cognition, 21,* 37-46.

Bauminger, N., & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child Development, 71*(2), 447-456. doi: 10.1111/1467-8624.00156

Blackwell, J., & Niederhauser, C. (2003). Diagnose and manage autistic children. *The Nurse Practitioner, 28*(6), 36-43.

Blanc, R., Adrien, J. L., Roux, S., & Barthelemy, C. (2005). Dysregulation of pretend play and communication development in children with autism. *Autism, 9*(3), 229-245. doi: 10.1177/1362361305053253

Branson, D., Vigil, D. C., & Bingham, A. (2008). Community childcare providers' role in the early detection of autism spectrum disorders. *Early Childhood Education Journal, 35*, 523-530. doi: 10.1007/s10643-008-0243-6

Brookman-Frazee, L., & Koegel, R. L. (2004). Using parent/clinician partnerships in parent education programs for children with autism. *Journal of Positive Behavior Interventions, 6*, 195-213. doi: 10.1177/10983007040060040201

Bryson, S. E., Zwaigenbaum, L., & Roberts, W. (2004). The early detection of autism in clinical practice. *Pediatrics & Child Health, 9*(4), 219-221.

Cadman, D., Chambers, L. W., Walter, S. D., Ferguson, R., Johnston, N., & McNamee, J. (1987). Evaluation of public health preschool child developmental screening: The process and outcomes of a community program. *American Journal of Public Health, 77*, 45-51.

Carter, A. S., Davis, N. O., Klin, A., & Volkmar, F. R. (2005). Social development in autism. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 312-334). Hoboken, NJ: John Wiley & Sons, Inc.

Centers for Disease Control and Prevention. (2009). *National center on birth defects and developmental disabilities.* Retrieved from http://www.cdc.gov/ncbddd/features/counting-autism.html

Chakrabarti, S., Haubus, C., Dugmore, S., Orgill, G., & Devine, F. (2005). A model of early detection and diagnosis of autism spectrum disorder in young children. *Infants and Young Children, 18*(3), 200-211. doi:10.1097/00001163-200507000-00004

Charman, T. (2003). Screening and surveillance for autism spectrum disorder in research and practice. *Early Child Development and Care, 173*(4), 363-374. doi:10.1080/0300443032000079050

Charman, T., & Baron-Cohen, S. (2006). Understanding drawings and beliefs: A further test of the metarepresentation theory of autism: A research note. *Journal of Child Psychology and Psychiatry, 33*(6), 1105-1112. doi:10.1111/j.1469-7610.1992.tb00929.x

Charman, T., Taylor, E., Drew, A., Cockerill, H., Brown, J., & Baird, G. (2005). Outcome at 7 years of children diagnosed with autism at age 2: Predictive validity of assessments conducted at 2 and 3 years of age and pattern of symptom change over time. *Journal of Child Psychology and Psychiatry, 46*(5), 500-513. doi:10.1111/j.1469-7610.2004.00377.x

Chawarska, K., Klin, A., Paul, R., & Volkmar, F. (2007). Autism spectrum disorder in the second year: Stability and change in syndrome expression. *Journal of Child Psychology and Psychiatry, 48*(2), 128-138. doi:10.1111/j.1469-7610.2006.01685.x

Chawarska, K., Klin, A., & Volkmar, F. (2003). Automatic attention cueing through eye movement in 2-year-old children with autism. *Child Development, 74*(4), 1108-1122. doi:10.1111/1467-8624.00595

Chawarska, K., & Volkmar, F. R. (2005). Autism in infancy and early childhood. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 223-246). Hoboken, NJ: John Wiley & Sons, Inc.

Chowdhury, M., Benson, B. A., & Hillier, A. (2010). Changes in restricted repetitive behaviors with age: A study of high-functioning adults with autism spectrum disorders. *Research in Autism Spectrum Disorders, 4,* 210-216. doi:10.1016/j.rasd.2009.09.006

Coonrod, E. E., & Stone, W. L. (2004). Early concerns of parents of children with autistic and nonautistic disorders. *Infants and Young Children, 17*(3), 258-268. doi:10.1097/00001163-200407000-00007

Corbett, J., Harris, R., Taylor, E., & Trimble, M. (1977). Progressive disintegrative psychosis of childhood. *Journal of Child Psychology and Psychiatry, 18,* 211-219. doi:10.1111/j.1469-7610.1977.tb00433.x

Corsello, C. M. (2005). Early intervention in autism. *Infants and Young Children, 18*(2), 74-85. doi:10.1097/00001163-200504000-00002

Courchesne, E., Carper, R., & Akshoomoff, N. (2003). Evidence of brain overgrowth in the first year of life in autism. *Journal of the American Medical Association, 290*(3), 337-344. doi:10.1001/jama.290.3.337

Crane, J. L., & Winsler, A. (2008). Early autism detection: Implications for pediatric practice and public policy. *Journal of Disability Policy Studies, 18,* 245-253. doi:10.1177/1044207307311527

Cunningham, A. B., & Schreibman, L. (2008). Stereotypy in autism: The importance of function. *Research in Autism Spectrum Disorders, 2*, 469-479. doi:10.1016/j.rasd.2007.09.006

Dawson, G., Toth, K., Abbott, R., Osterling, J., Munson, J., Estes, A., & Liaw, J. (2004). Early social attention impairments in autism: Social orienting, joint attention, and attention to distress. *Developmental Psychology, 40*(2), 271-283. doi:10.1037/0012-1649.40.2.271

de Bildt, A., Sytema, S., Ketelaars, C., Kraijer, D., Mulder, E., Volkmar, F., & Minderaa, R. (2004). Interrelationship between Autism Diagnostic Observation Schedule-Generic (ADOS-G), Autism Diagnostic Interview-Revised (ADI-R), and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) classification in children and adolescents with mental retardation. *Journal of Autism and Developmental Disorders, 34*(2), 129-137. doi:10.1023/B:JADD.0000022604.22374.5f

Delinicolas, E. K., & Young, R. L. (2007). Joint attention, language, social relating, and stereotypical behaviours in children with autistic disorder. *Autism, 11*(5), 425-436. doi:10.1177/1362361307079595

Dietz, C., Swinkels, S. H., van Daalen, E., van Engeland, H., & Buitelaar, J. K. (2007). Parental compliance after screening social development in toddlers. *Archives of Pediatrics & Adolescent Medicine*, *161,* 363-368. doi:10.1001/archpedi.161.4.363

Dosreis, S., Weiner, C. L., Johnson, L., & Newschaffer, C. J. (2006). Autism spectrum disorder screening and management practices among general pediatric providers. *Developmental and Behavioral Pediatrics, 27*(2), S88-S94. doi:10.1097/00004703-200604002-00006

Doyle, B. T., & Iland, E. D. (2004). *Autism spectrum disorders from A to Z: Assessment, diagnosis…& more!* Arlington, Texas: Future Horizons, Inc.

Dunst, C. J., & Dempsey, I. (2007). Family-professional partnerships and parenting competence, confidence, and enjoyment. *International Journal of Disability, Development and Education, 54*(3), 305-318. doi:10.1080/10349120701488772

Eagle, J. W. (2009). The role of family and situational problems in understanding and reducing impairment. In S. Goldstein & J. Naglieri (Eds.), *Assessing impairment: From theory to practice* (pp. 15-30). New York, NY: Springer Science + Business Media.

Eaves, L. C., & Ho, H. H. (2004). The very early identification of autism: Outcome to age 4 ½ - 5. *Journal of Autism and Developmental Disorders, 34*(4), 367-378. doi:10.1023/B:JADD.0000037414.33270.a8

Eaves, L. C., Wingert, H., & Ho, H. H. (2006). Screening for autism: Agreement with diagnosis. *Autism, 10*(3), 229-242. doi:10.1177/1362361306063288

Filipek, P. A., Accardo, P. J., Ashwal, S., Baranek, G. T., Cook, G., Dawon, G., … Volkmar, F. R. (2000). Practice parameter: Screening and diagnosis of autism. *Neurology, 55*, 468-479.

Folstein, S. E., & Piven, J. (2001). Etiology of autism: Genetic influences. *Pediatrics, 1,* 767-773.

Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders, 33*(4), 365-382. doi:10.1023/A:1025054610557

Fombonne, E. (2005). Epidemiological studies of pervasive developmental disorders. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 42-69). Hoboken, NJ: John Wiley & Sons, Inc.

Fombonne, E., Simmons, H., Ford, T., Meltzer, H., & Goodman, R. (2003). Prevalence of pervasive developmental disorders in the British nationwide survey of child mental health. *International Review of Psychiatry, 15,* 158-165. doi:10.1080/0954026021000046119

Gabriels, R. L., Cuccaro, M. L., Hill, D. E., Ivers, B. J., & Goldson, E. (2005). Repetitive behaviors in autism: Relationships with associated clinical features. *Research in Developmental Disabilities, 26,* 169-181. doi:10.1016/j.ridd.2004.05.003

Gargus, R. A., & Yatchmink, Y. (2005). Early identification and assessment of young children with autism. *Medicine and Health, 88*(5), 17-20.

Gilliam, J. (2006). *GARS-2: Gilliam Autism Rating Scale-Second Edition.* Austin, TX: PRO-ED.

Glascoe, F. P. (2000). Early detection of developmental and behavioral problems. *Pediatrics in Review, 21*(8), 272-280. doi:10.1542/pir.21-8-272

Goin-Kochel, R.P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism, 10,* 439-451. doi:10.1177/1362361306066601

Granpeesheh, D., Dixon, D. R., Tarbox, J., Kaplan, A. M., & Wilke, A. E. (2009). The effects of age and treatment intensity on behavioral intervention outcomes for children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 3,* 1014-1022. doi:10.1016/j.rasd.2009.06.007

Gray, K. M., & Tonge, B. J. (2005). Screening for autism in infants and preschool children with developmental delay. *Australian and New Zealand Journal of Psychiatry, 39*(5), 378-386. doi:10.1111/j.1440-1614.2005.01585.x

Greenspan, S. I., Brazelton, B., Cordero, J., Solomon, R., Bauman, M. L., Robinson, R., … Breinbauer, C. (2008). Guidelines for early identification, screening, and clinical management of children with autism spectrum disorders. *Pediatrics, 121*(4), 828-830. doi:10.1542/peds.2007-3833

Gupta, A. R., & State, M. W. (2007). Recent advances in the genetics of autism. *Biological Psychiatry, 61,* 429-437. doi:10.1016/j.biopsych.2006.06.020

Hallahan, B. P., & Murphy, K. C. (2005). Autistic spectrum disorders. *Irish Journal of Psychological Medicine, 22*(4), 137-142.

Hansen, R., Ozonoff, S., Krakowiak, P., Angkustsiri, Jones, C., Deprey, D., … Hertz-Picciotto, I. (2008). Regression in autism: Prevalence and associated factors in the CHARGE study. *Ambulatory Pediatrics, 8,* 25-3 doi:10.1016/j.ambp.2007.08.006

Happe, F., & Frith, U. (2006). The weak coherence account: Detail-focused cognitive style in autism spectrum disorders. *Journal of Autism and Developmental Disorders, 36,* 5-25. doi:10.1007/s10803-005-0039-0

Harrington, J. W., Patrick, P. A., Edwards, K. S., & Brand, D. A. (2006). Parental beliefs about autism: Implications for the treating physician. *Autism, 10,* 452-462. doi:10.1177/1362361306066609

Harris, S. L., & Handleman, J. S. (2000). Age and IQ at intake as predictors of placement for young children with autism: A four- to six- year follow-up. *Journal of Autism and Developmental Disorders, 30*(2), 137-142. doi:10.1023/A:1005459606120

Hazlett, H., Poe, M., Gerig, G., Smith, R., & Piven, J. (2006). Cortical gray and white brain tissue volume in adolescents and adults with autism. *Biological Psychiatry, 59*, 1-6. doi:10.1016/j.biopsych.2005.06.015

Heidgerken, A. D., Geffken, G., Modi, A., & Frakey, L. (2005). A survey of autism knowledge in a health care setting. *Journal of Autism and Developmental Disorders*, *35*(3), 323-330. doi:10.1007/s10803-005-3298-x

Herbert, M. R. (2005). Large brains in autism: The challenge of pervasive abnormality. *The Neuroscientist*, *11*(5), 417-440. doi:10.1177/0091270005278866

Herbert, M. R., Ziegler, A., Deutsch, C. K., O'Brien, L. M., Lange, N., Bakardjiev, A., … Caviness, V. (2003). Dissociations of cerebral cortex, subcortical and cerebral white matter volumes in autistic boys. *Brain*, *126*, 1182-1192. doi:10.1093/brain/awg110

Hertz-Picciotto, I., Croen, L. A., Hansen, R., Jones, C. R., van de Water, J., & Pessah, I. N. (2006). The CHARGE study: An epidemiologic investigation of genetic and environmental factors contributing to autism. *Environmental Health Perspectives, 114*(7), 1119-1125. doi:10.1289/ehp.8483

Horvath, K., & Perman, J. A. (2002). Autism and gastrointestinal symptoms. *Current Gastroenterology Reports, 4*(3), 251-258. doi:10.1007/s11894-002-0071-6

Iacoboni, M., & Mazziotta, J. C. (2007). Mirror neuron system: Basic findings and clinical applications. *Annals of Neurology, 62*(3), 213-218. doi:10.1002/ana.21198

Ibrahim, S. H., Voigt, R. G., Katusic, S. K., Weaver, A. L., & Barbaresi, J. (2009). Incidence of gastrointestinal symptoms in children with autism: A population-based study. *Pediatrics, 124*, 680-686. doi:10.1542/peds.2008-2933

Inglese, M. D. (2009). Caring for children with autism spectrum disorder, part II: Screening, diagnosis, and management. *Journal of Pediatric Nursing, 24*(1), 49-59. doi:10.1016/j.pedn.2008.06.005

Ingram, D. H., Mayes, S. D., Troxell, L. B., & Calhoun, S. L. (2007). Assessing children with autism, mental retardation, and typical development using the Playground Observation Checklist. *Autism, 11*(4), 311-319. doi:10.1177/1362361307078129

Jarrold, C., Butler, D. W., Cottington, E. M., & Flora, J. (2000). Linking theory of mind and central coherence bias in autism and in the general population. *Developmental Psychology, 36*, 126-138. doi:10.1037//0012-1649.36.1.126

Johnson, C. P. (2008). Recognition of autism before age 2 years. *Pediatrics in Review, 29*, 86-96. doi:10.1542/pir.29-3-86

Johnson, C. P., Myers, S. M., & the Council on Children with Disabilities (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics, 120*(5), 1183-1215. doi:10.1542/peds.2007-2361

Kanne, S. M., Randolph, J. K., & Farmer, J. E. (2008). Diagnostic and assessment findings: A bridge to academic planning for children with autism spectrum disorders. *Neuropsychology Review,* 18, 367-384. doi:10.1007/s11065-008-9072-z

Kanner, L. (1965). Infantile autism and the schizophrenias. *Behavioral Science, 10*(4), 412-420. doi:10.1002/bs.3830100404

Kasari, C. (2002). Assessing change in early intervention programs for children with autism. *Journal of Autism and Developmental Disorders, 32*(5), 447-461. doi:10.1023/A:1020546006971

Katsiyannis, A., Zhang, D., & Conroy, M. A. (2003). Availability of special education teachers: Trends and issues. *Remedial and Special Education, 24*(4), 246-253. doi:10.1177/07419325030240040701

Kleinman, J. M., Robins, D. L., Ventola, P. E., Pandey, J., Boorstein, H. C., Esser, E. L., … Fein, D. (2008). The Modified Checklist for Autism in Toddlers: A follow-up study investigating the early detection of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38,* 827-839. doi:10.1007/s10803-007-0450-9

Klin, A. (2006). Autism and Asperger syndrome: An overview. *Brazilian Journal of Psychiatry, 28,* 3-11. doi:10.1590/S1516-44462006000500002

Klinger, L. G., & Renner, P. (2000). Performance-based measures in autism: Implications for diagnosis, early detection, and identification of cognitive profiles. *Journal of Clinical Child Psychology, 29*(4), 479-492. doi:10.1207/S15374424JCCP2904_3

Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., … van Dyck, P. C. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics, 124*(4), 1-9. doi:10.1542/peds.2009-1522

Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P.C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005 2006. *Pediatrics, 122*(6), 1149-1158. doi:10.1542/peds.2008-1057

Krauss, M. W., Gulley, S., Sciegaj, M., Wells, N., & Taylor, S. J. (2003). Access to specialty medical care for children with mental retardation, autism, and other special health care needs. *Mental Retardation, 41*(5), 329-339. doi:10.1352/0047-6765(2003)41<329:ATSMCF>2.0.CO;2

Landa, R. (2007). Early communication development and intervention for children with autism. *Mental Retardation and Developmental Disabilities Research Reviews, 13,* 16-25. doi:10.1002/mrdd.20134

Landa, R., & Garrett-Mayer, E. (2006). Development in infants with autism spectrum disorder: A perspective study. *Journal of Child Psychology and Psychiatry, 47*(6), 629-638. doi: 10.1111/j.1469-7610.2006.01531.x

Leonard, H., Dixon, G., Whitehouse, A., Bourke, J., Aiberti, K., Nassar, N., … Glasson, E. (in press). Unpacking the complex nature of the autism epidemic. *Research in Autism Spectrum Disorders.* doi:10.1016/j.rasd.2010.01.003

Lewis, M., & Kim, S. (2009). The pathophysiology of restricted repetitive behavior. *Journal of Neurodevelopmental Disorders, 1*, 114-132. doi:10.1007/s11689-009-9019-6

Liss, M., Fein, D., Allen, D., Dunn, M., Feinstein, C., Morris, R., … Rapin, I. (2001). Executive functioning in high-functioning children with autism. *Journal of Child Psychology and Psychiatry, 42*(2), 261-270. doi:10.1111/1469-7610.00717

Lord, C., Shulman, C., & DiLavore, P. (2004). Regression and word loss in autistic spectrum disorders. *Journal of Child Psychology and Psychiatry, 45*(5), 936-955. doi:10.1111/j.1469-7610.2004.t01-1-00287.x

Lubetsky, M. J., McGonigle, J. J., & Handen, B. L. (2008). Recognition of autism spectrum disorder. *Speaker's Journal, 8*(4), 13-23.

MacDonald, R., Green, G., Mansfield, R., Geckeler, A., Gardenier, N., Anderston, J., … Sanchez, J. (2007). Stereotypy in young children with autism and typically developing children. *Research in Developmental Disabilities, 28*, 266-277. doi:10.1016/j.ridd.2006.01.004

Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of American Academy of Child Adolescent Psychiatry, 41*(12), 1447-1453. doi:10.1097/00004583-200212000-00016

Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics, 116,* 1480-1486. doi:10.1542/peds.2005-0185

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., … Kirby, R. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. ,*American Journal of Public Health, 99*(3), 493-498. doi:10.2105/AJPH.2007.131243

Matson, J. L., Wilkins, J., & Gonzalez, M. (2008). Early identification and diagnosis in autism spectrum disorders in young children and infants: How early is too early? *Research in Autism Spectrum Disorders, 2*(1), 75-84. doi: 10.1016/j.rasd.2007.03.002

Matson, J. L., & LoVullo, S. V. (2009). Trends and topics in autism spectrum disorders research. *Research in Autism Spectrum Disorders, 3*, 252-257. doi:10.1016/j.rasd.2008.06.005

Matson, J. L., & Nebel-Schwalm, M. (2007). Assessing challenging behaviors in children with autism spectrum disorders: A review. *Research in Developmental Disabilities*, *28*(6), 567-579. doi:10.1016/j.ridd.2006.08.001

Matson, J. L., & Sipes, M. (2010). Methods of early diagnosis and tracking for autism and pervasive developmental disorder not otherwise specified (PDD-NOS). *Journal of Developmental and Physical Disabilities, 3*, 105-125. doi: 10.1007/s10882-009-9184-2

Matson, J. L., Wilkins, J., & Gonzalez, M. (2008). Early identification and diagnosis in autism spectrum disorders in young children and infants: How early is too early? *Research in Autism Spectrum Disorders 2,* 75-84.

Mawle, E., & Griffiths, P. (2006). Screening for autism in pre-school children in primary care: Systematic review of English language tools. *International Journal of Nursing Studies, 43,* 623-636. doi:10.1016/j.ijnurstu.2005.11.011

Mazefsky, C. A., Goin-Kochel, R. P., Riley, B. P., & Maes, H. H. (2008). Genetic and environmental influences on symptom domains in twins and siblings with autism. *Research in Autism Spectrum Disorders, 2,* 320-331. doi:10.1016/j.rasd.2007.08.002

McDougle, C. J., Kem, D. L., & Posey, D. J. (2002). Case series: Use of Ziprasidone for maladaptive symptoms in youths with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, *41*(8), 921-927. doi:10.1097/00004583-200208000-00010

Militerni, R., Bravaccio, C., Falco, C., Fico, C., & Palermo, M. T. (2002). Repetitive behaviors in autistic disorder. *European Child & Adolescent Psychiatry, 11*(5), 210-218. doi:10.1016/S0167-8760(98)90516-5

Mitchell, S., Brian, J., Zwaigenbaum, L., Roberts, W., Szatmari, P., Smith, I., & Bryson, S. (2006). Early language and communication development of infants later diagnosed with autism spectrum disorder. *Developmental and Behavioral Pediatrics, 27*(2), S69-S78. doi:10.1097/00004703-200604002-00004

Montes, G., & Halterman, J. S. (2007). Psychological functioning and coping among mothers of children with autism: A population-based study. *Pediatrics, 119*(5), e1040-e1046. doi:10.1542/peds.2006-2819

Moore, V., & Goodson, S. (2003). How well does early diagnosis of autism stand the test of time? *Autism, 7*(1), 47-63. doi: 10.1177/1362361303007001005

Muhle, R., Trentacoste, S. V., & Rapin, I. (2004). The genetics of autism. *Pediatrics, 113*(5), e472-e486. doi:10.1542/peds.113.5.e472

Mundy, P., & Neal, A. R. (2001). Neural plasticity, joint attention, and a transactional social-orienting model of autism. *International Review of Research in Mental Retardation, 23*, 139-168. doi:10.1016/S0074-7750(00)80009-9

Myers, S. M., Johnson, C. P., & the Council on Children with Disabilities (2007). Management of children with autism spectrum disorders. *American Academy of Pediatrics, 120*(5), 1162-1182. doi:10.1542/peds.2007-2362

Nachshen, J. S., & Minnes, P. (2005). Empowerment in parents of school-aged children with and without developmental disabilities. *Journal of Intellectual Disability Research, 49*, 889-904. doi:10.1111/j.1365-2788.2005.00721.x

Nadel, S., & Poss, J. E. (2007). Early detection of autism spectrum disorders: Screening between 12 and 24 months of age. *Journal of the American Academy of Nurse Practitioners, 19*(8), 408-417. doi:10.1111/j.1745-7599.2007.00244.x

National Institute of Mental Health. (2007). *Autism spectrum disorders (pervasive developmental disorders).* Retrieved from http://www.nimh.nih.gov/health/publications/autism/complete-index.shtml

Newschaffer, C. J., Fallin, D., & Lee, N. L. (2002). Heritable and nonheritable risk factors for autism spectrum disorders. *Epidemiologic Reviews, 24*, 137-153. doi:10.1093/epirev/mxf010

Oberman, L. M., & Ramachandran, V. S. (2007). The simulating social mind: The role of the mirror neuron system and simulation in the social and communicative deficits of autism spectrum disorders. *Psychological Bulletin, 133*(2), 310-327. doi:10.1037/0033-2909.133.2.310

Oosterling, I. J., Wensing, M., Swinkels, S. H., van der Gaag, R. J., Visser, J. C., Woudenberg, T., … Buitelaar, J. K. (2010). Advancing early detection of autism spectrum disorder by applying an integrated two-stage screening approach. *Journal of Child Psychology and Psychiatry, 51*(3), 250-258. doi:10.1111/j.1469-7610.2009.02150.x

Osterling, J., & Dawson, G. (1994). Early recognition of children with autism: A study of first birthday home videotapes. *Journal of Autism and Developmental Disorders, 24*(3), 247-257. doi:10.1007/BF02172225

Oyane, N., & Bjorvatn, B. (2005). Sleep disturbances in adolescents and young adults with autism and Asperger syndrome. *Autism, 9*, 83-94. doi:10.1177/1362361305049031

Ozonoff, S., Goodlin-Jones, B. L., & Solomon, M. (2005). Evidence-based assessment of autism spectrum disorders in children and adolescents. *Journal of Clinical Child and Adolescent Psychology, 34*(3), 523-540. doi:10.1207/s15374424jccp3403_8

Ozonoff, S., Iosif, A., Baguio, F., Cook, I., Hill, M., Hutman, T., … Young, G. (2010). A prospective study of the emergence of early behavioral signs of autism. *Journal of the American Academy of Child and Adolescent Psychiatry, 29*(3), 256-266. doi:10.1097/00004583-201003000-00009

Ozonoff, S., Williams, B. J., & Landa, R. (2005). Parental report of the early development of children with regressive autism: The “delays-plus-regression” phenotype. *Autism: The International Journal of Research and Practice, 9*, 495-520. doi:10.1177/1362361305057880

Palmen, S. J., Hulshoff, H.E., Kemner, C., Schnack, H.G., Durston, S., Lahuis, B. E., … van Engeland. (2005). Increased gray-matter volume in medication-naïve high-functioning children with autism spectrum disorder. *Psychological Medicine, 35*(4), 561-570. doi:10.1017/S0033291704003496

Parker, S. K., Schwartz, B., Todd, J., & Pickering, L. K. (2004). Thimerosal-containing vaccines and autistic spectrum disorder: A critical review of published original data. *Pediatrics, 114*, 793-804. doi:10.1542/peds.2004-0434

Pinto-Martin, J. A., Dunkle, M., Earls, M., Fliedner, D., & Landes, C. (2005). Developmental stages of developmental screening: Steps to implementation of a successful program. *Journal of Public Health, 95*(11), 1928-1932. doi:10.2105/AJPH.2004.052167

Pinto-Martin, J., & Levy, S. E. (2004). Early diagnosis of autism spectrum disorders. *Current Treatment Options in Neurology, 6,* 391-400. doi:10.1007/s11940-996-0030-x

Pinto-Martin, J. A., Young, L. M., Mandell, D. S., Poghosyan, L., Giarelli, E., & Levy, S. E. (2008). Screening strategies for autism spectrum disorders in pediatric primary care. *Journal of Developmental & Behavioral Pediatrics, 29,* 345-350. doi:10.1097/DBP.0b013e31818914cf

Renty, J. O., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder. *Autism, 10*(5), 511-524. doi:10.1177/1362361306066604

Rhoades, R. A., Scarpa, A., & Salley, B. (2007). The importance of physician knowledge of autism spectrum disorder: Results of a parent survey. *BMC Pediatrics, 7*(37), 1-10. doi:10.1186/1471-2431-7-37

Richler, J., Bishop, S. L., Kleinke, J. R., & Lord, C. (2007). Restricted and repetitive behaviors in young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 37*, 73-85. doi:10.1007/s10803-006-0332-6

Robins (2008). Screening for autism spectrum disorders in primary care settings. *Autism, 12*(5), 537-556. doi:10.1177/1362361308094502

Robins, D. L., & Dumont-Mathieu, T. M. (2006). Early screening for autism spectrum disorders: Update on the Modified Checklist for Autism in Toddlers and other measures. *Developmental and Behavioral Pediatrics, 27*(2), S111-S119.

Robins, D. L., Fein, D., Barton, M. L., & Green, J. A. (2001). The Modified Checklist for Autism in Toddlers: An initial study investigating the early detection of autism and pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 31*(2), 131-144.

Rutter, M. (2006). Autism: Its recognition, early diagnosis, and service implications. *Developmental and Behavioral Pediatrics, 27*(2), S54-S58.

Rutter, M., Bailey, A., & Lord, C. (2003). *Social Communication Questionnaire (SCQ).* Los Angeles, CA: Western Psychological Services.

Sallows, G. O., & Graupner, T. D. (2005). Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Association on Mental Retardation, 110*(6), 417-438. doi:10.1352/0895-8017(2005)110[417:IBTFCW]2.0.CO;2

Sand, N., Silverstein, M., Glascoe, F. P., Gupta, V. B., Tonniges, T. P., & 0’Connor, K. G. (2005). Pediatricians’ reported practices regarding developmental screening: Do guidelines work? Do they help? *Pediatrics, 116*, 174-179. doi:10.1542/peds.2004-1809

Scambler, D., Rogers, S. J., & Wehner, E. A. (2001). Can the Checklist for Autism in Toddlers differentiate young children with autism from those with developmental delays? *Journal of the American Academy of Child & Adolescent Psychiatry, 40*(12), 1457-1463.

Shah, K. (2001). What do medical students know about autism? *Autism, 5*(2), 127-133. doi: 10.1177/1362361301005002003

Shattuck, P. T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D. S., Wiggins, L., … Cuniff, C. (2009). Timing of identification among children with an autism spectrum disorder: Findings from a population-based surveillance study. *Journal of American Academy of Child and Adolescent Psychiatry, 48*(5), 474-483.

Shattuck, P. T., & Grosse, S. D. (2007). Issues related to the diagnosis and treatment of autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 13,* 129-135. doi:10.1002/mrdd.20143

Shtayermman, O. (2007). Peer victimization in adolescents and young adults diagnosed with Asperger's syndrome: A link to depressive symptomatology, anxiety symptomatology, and suicidal ideation. *Issues in Comprehensive Pediatric Nursing, 30*(3), 87-107. doi:10.1080/01460860701525089

Siegel, B. (2004). *Pervasive Developmental Disorder Screening Test-II (PDDST-II).* San Antonio, TX: Harcourt.

Siklos, S., & Kerns, K. A. (2006). Assessing need for social support in parents of children with autism and down syndrome. *Journal of Autism and Developmental Disorders, 36,* 921-933. doi:10.1007/s10803-006-0129-7

Silverman, C., & Brosco, J. P. (2007). Understanding autism: Parents and pediatricians in historical perspective. *Archives of Pediatrics and Adolescent Medicine, 161*, 392-398. doi:10.1001/archpedi.161.4.392

Sivberg, B. (2003). Parents' detection of early signs in their children having an autistic spectrum disorder. *Journal of Pediatric Nursing, 18*(6), 433-439. doi:10.1016/S0882-5963(03)00139-8

Spence, S. J., Sharifi, P., & Wiznitzer, M. (2004). Autism spectrum disorder: Screening, diagnosis, and medical evaluation. *Seminars in Pediatric Neurology, 11*, 186-195. doi:10.1016/j.spen.2004.07.002

Stigler, K. A., Sweeten, T. L., Posey, D. J., & McDougle, C. J. (2009). Autism and immune factors: A comprehensive review. *Research in Autism Spectrum Disorders, 3,* 840-860. doi:10.1016/j.rasd.2009.01.007

Stone, W. L., Coonrod, E. E., Turner, L. M., & Pozdol, S. L. (2004). Psychometric properties of the STAT for early autism screening. *Journal of Autism and Developmental Disorders, 34*(6), 691-701. doi:10.1007/s10803-004-5289-8

Sutera, S., Pandey, J., Esser, E. L., Rosenthal, M. A., Wilson, L. B., Barton, M., … Fein, D. (2007). Predictors of optimal outcome in toddlers diagnosed with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 37*, 98-107. doi:10.1007/s10803-006-0340-6

Tager-Flusberg, H. (2007). Evaluating the theory-of-mind hypothesis of autism. *Current Directions in Psychological Science, 16*(6), 311-315. doi:10.1111/j.1467-8721.2007.00527.x

Tager-Flusberg, H., Paul, R., & Lord, C. (2005). Language and communication in autism. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 335-364). Hoboken, NJ: John Wiley & Sons, Inc.

Turner, L. M., Stone, W. L., Pozdol, S. L., & Coonrod, E. E. (2006). Follow-up of children with autism spectrum disorders from age 2 to age 9. *Autism, 10*(3), 243-265. doi:10.1177/1362361306063296

Volkmar, F. R., & Klin, A. (2005). Issues in the classification of autism and related conditions. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 5-41). Hoboken, NJ: John Wiley & Sons, Inc.

Volkmar, F. R., Klin, A., Siegel, B., Szatmari, P., Lord, C., Campbell, M., … Kline, W. (1994). Field trial for autistic disorder in DSM-IV. *American Journal of Psychiatry, 151*, 1361-1367.

Watson, L. R., Baranek, G. T., Crais, E. R., Reznick, J. S., Dykstra, J., & Perryman, T. (2007). The first year inventory: Retrospective parent responses to a questionnaire designed to identify one-year-olds at risk for autism. *Journal of Autism and Developmental Disabilities, 37*, 49-61.

Watson, L. R., Baranek, G. T., & DiLavore, P. C. (2003). Toddlers with autism: Developmental perspectives. *Infants and Young Children, 16*(3), 201-214.

Werner, E. W., & Dawson, G. (2005). Validation of the phenomenon of autistic regression using home videotapes. *Archives of General Psychiatry, 62*, 889-895. doi:10.1001/archpsyc.62.8.889

Werner, E., Dawson, G., Osterling, J., & Dinno, N. (2000). Brief report: Recognition of autism spectrum disorder before one year of age: A retrospective study based on home videotapes. *Journal of Autism and Developmental Disabilities, 30*(2), 157-162.

Wetherby, A. M., Woods, J., Allen, L., Cleary, J., Dickinson, H., & Lord, C. (2004). Early indicators of autism spectrum disorders in the second year of life. *Journal of Autism and Developmental Disorders, 34*(5), 473-493. doi:10.1007/s10803-004-2544-y

Whitaker (2002). Supporting families of preschool children with autism. *Autism, 6*(4), 411-426. doi:10.1177/1362361302006004007

Wiggins, L. D., Baio, J., & Rice, C. (2006). Examination of the time between first evaluation and first autism spectrum diagnosis in a population-based sample. *Journal of Developmental and Behavioral Pediatrics, 27,* S79-S87. doi:10.1097/00004703-200604002-00005

Williams, J., & Brayne, C. (2006). Screening for autism spectrum disorders: What is the evidence? *Autism, 10*, 11-35. doi: 10.1177/1362361306057876

Wing, L. (1997). The history of ideas on autism. *Autism, 1*, 13-23. doi:10.1177/1362361397011004

Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders, 9,* 11-29. doi:10.1007/BF01531288

Woodgate, R., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research, 18*(8), 1075-1083. doi:10.1177/1049732308320112

Woods, J. J., & Wetherby, A. M. (2003). Early identification of and intervention for infants and toddlers who are at risk for autism spectrum disorder. *Language, Speech, and Hearing Services in Schools, 34*, 180-193. doi:10.1044/0161-1461(2003/015)

World Health Organization. (2006). *Mental and behavioural disorders.* Retrieved from http://apps.who.int/classifications/apps/icd/icd10online/

Yun, G. & Trumbo, C. (2000). Comparative response to a survey executed by post, E-mail, & web form. *Journal of Computer-Mediated Communication, 6*(1), 3-15.

Zachor, D. A., Ben-Itzchak, E., Rabinovich, A., & Lahat, E. (in press). Change in autism core symptoms with intervention. *Research in Autism Spectrum Disorders.* doi:10.1016/j.rasd.2006.12.001

Zwaigenbaum, L., Bryson, S., Lord, C. Rogers, S., Carter, A., Carver, L., … Yirmiya, N. (2009). Clinical assessment and management of toddlers with suspected autism spectrum disorder: Insights from studies of high-risk infants. *Pediatrics, 123*(5), 1383-1391. doi:10.1542/peds.2008-1606

Zwaigenbaum, L., Bryson, S., Rogers, T., Roberts, W., Brian, J., & Szatmari, P. (2005). Behavioral manifestations of autism in the first year of life. *International Journal of Developmental Neuroscience, 23,* 143-152. doi:10.1016/j.ijdevneu.2004.05.001

Zwaigenbaum, L., Thurm, A., Stone, W., Baranek, G., Bryson, S. Iverson, J., … Sigman, M. (2007). Studying the emergence of autism spectrum disorders in high-risk infants: Methodological and practical issues. *Journal of Autism and Developmental Disorders, 37*, 466-480. doi:10.1007/s10803-006-0179-x

APPENDIX A

Email Invitation to Experts of Autism Spectrum Disorder

Dear __________:

My name is Tiffany Lin and I am a doctoral student in clinical psychology at Pepperdine University, Graduate School of Education and Psychology. I am conducting a study for my dissertation entitled, “A Parents' Guide to the Assessment of Autism Spectrum Disorders” under the direction of Carolyn Keatinge, Ph.D., my dissertation chairperson.

The purpose of this study is to develop a parent resource manual to educate parents about the significance of autism assessments, the need for multiple screenings, and the importance of a multidisciplinary evaluation. Early assessment and involvement in intensive intervention are critical in ensuring a child’s positive outcome, yet there is often a delay in accessing these services. Parents play a pivotal role in determining their child’s access to appropriate evaluations and critical early intervention services. One of the key factors in a child’s involvement in early intervention is the parents’ level of knowledge and access to appropriate resources. This can be an extremely daunting task for many parents, as they often have to educate themselves in order to advocate for their child’s rights.

The resource manual will provide parents with a history of autism, associated features of autism, early developmental warning signs, purpose of assessments, state the current standards of care for developmental screening, role of early identification and intervention, and provide additional resource recommendations. Most importantly, the resource manual will include helpful strategies and tips to help parents navigate and access services in a timely manner.

As part of the development of the resource manual, we are interested in the advice of experts in the field of autism, and as one of those experts, we invite you to share your insights. Your participation in this study is strictly voluntary. However, your input would be greatly appreciated and would be a substantial contribution to the resource manual.

Below is a brief scenario of a parent who is informed that his/her child may be exhibiting delayed development (in blue font). We would appreciate what you might suggest to the parent. We do not anticipate this exercise will require more than 5-10 minutes of your time.

We would also like to include your name as a contributor to the resource manual. Granting permission to publish your identity is strictly voluntary. Your identity will not be revealed in any publication that may result from this study unless you grant permission. Furthermore, you will receive a copy of the final draft of the resource manual to verify the accuracy of the document in general, the specific advice that you offered, and the information we include about you. For those of you who prefer not to be associated with your contribution, it will allow you an opportunity to verify that your wish for anonymity has been respected.

To provide your response to both the scenario and the request to include your name as a contributor, please REPLY to this email.

Thank you for your time, consideration, and any assistance you can provide. If you have any additional questions concerning this resource manual please feel free to contact us.

Tiffany Lin, M.S., Doctoral Candidate	Carolyn Keatinge, Ph.D., Dissertation Chair
Pepperdine University	Pepperdine University
Graduate School of Education and Psychology	Graduate School of Education and Psychology

A parent has had regular routine appointments monitoring his/her child’s health and development from birth to 12 months of age. During these appointments, the child’s pediatrician administered general developmental screening measures. At the 12-month visit, concerns were raised by both the parent and the pediatrician about the child’s delayed development and the possible presence of autism. The parent wonders what to do next.

1. **If you could offer 5 suggestions to this parent about his/her next steps, what would you recommend?**

2. May we have permission to publish your name as a contributor to the resource manual?   ___ Yes   ___ No

Please **REPLY** to this email to offer your responses to the two questions.

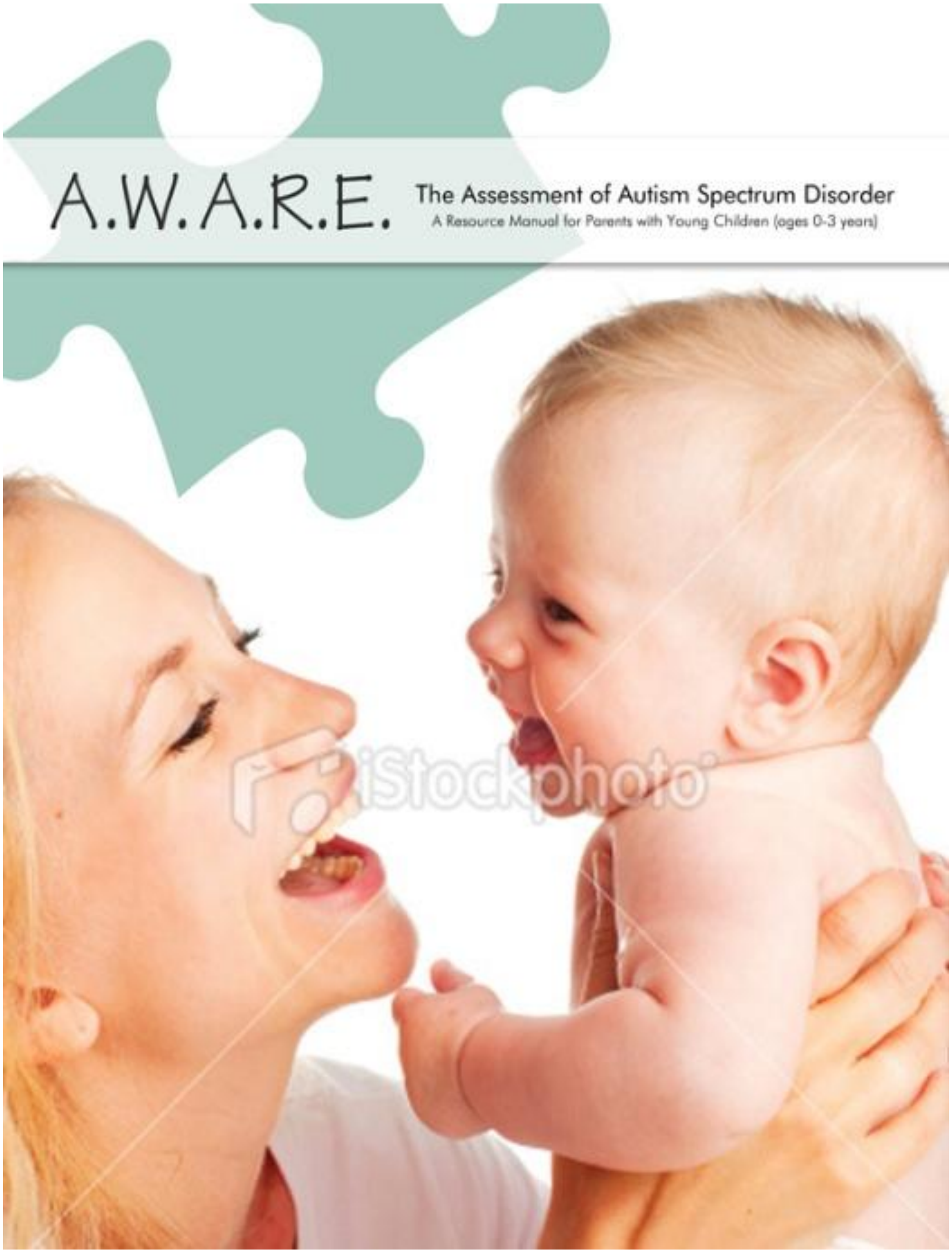
Your time is most appreciated.

APPENDIX B

A.W.A.R.E.

The Assessment of Autism Spectrum Disorder

A Resource Manual for Parents with Young Children (ages 0-3 years)



A.W.A.R.E. The Assessment of Autism Spectrum Disorder

A Resource Manual for Parents with Young Children (ages 0-3 years)

TABLE OF CONTENTS

Introduction page

Autism: An overview

Why it is important to be informed

Assessment

Role of parents

Appendix

INTRODUCTION

For whom is this resource manual written?

This resource manual is intended for parents with young children between 0 to 3 years of age. At this time, there are no medical tests that can diagnose autism. However, there are early developmental warning signs that can be detected through careful observations. As a parent, you are likely to be the first to notice these early warning signs. By educating yourself, you can become an active participant and an effective advocate for your child in seeking crucial assessments and appropriate services. In an effort to make this resource manual parent-friendly, the references are not dispersed within the content of the manual. Instead, you can find a list of references on page 18.

What is the purpose of this resource manual?

The purpose of this resource manual is to enhance parents' awareness of the significant role of assessment in the early detection of autism spectrum disorders. This manual will help you understand the general definition of autism, the role of early identification and intervention, the purpose of developmental and autism screenings, and the nature and types of assessments available. Overall, the goal is to make you **A.W.A.R.E.** so that you can advocate for your child by obtaining critical services in a timely manner. Using this acronym, the following information will be reviewed:

Autism: Defining characteristics and diagnostic criteria for autism spectrum disorders.

Why it is important to be informed about early identification and intervention.

Assessment: An overview of the assessment process.

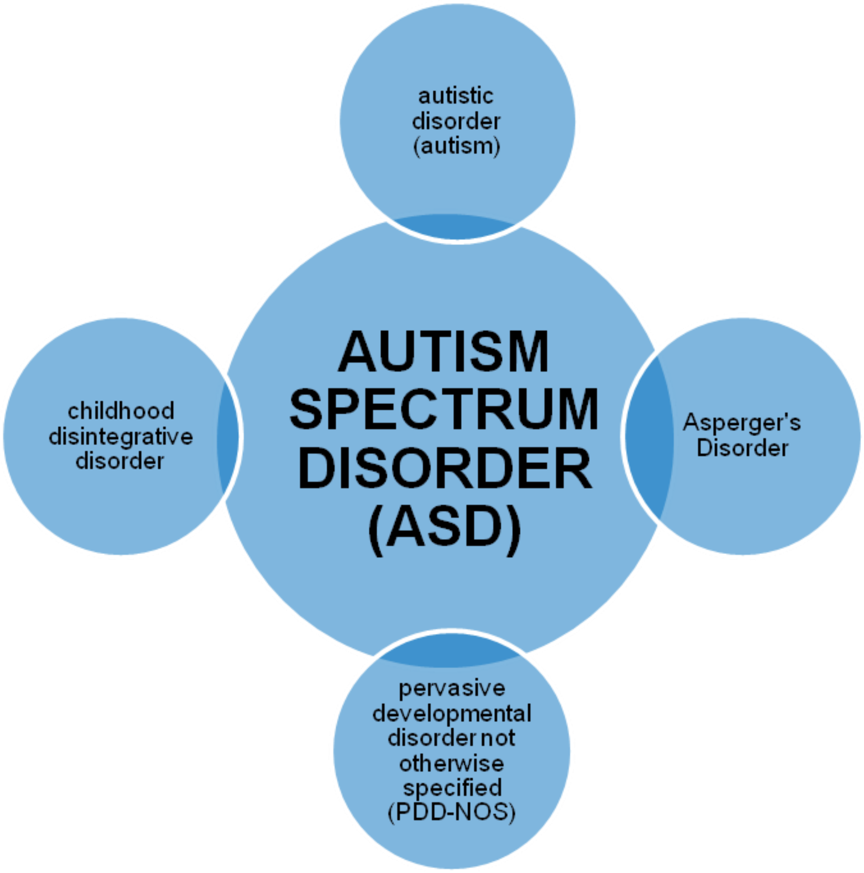
Role of parents: Parents as active participants and strategies for success.

Experts' advice: Advice, tips, and suggestions from experts in the field of autism.

AUTISM: AN OVERVIEW

What is autism and how common is it?

Autism is characterized by delays and impairments in the development of social interactions, language, and behavior. It occurs in early childhood and follows a steady course through adulthood. It was first identified in 1943 by Leo Kanner who used the term “autism” to describe children with severe social, communication, and behavioral problems. The American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders is the primary diagnostic reference utilized by mental health professionals in the United States. The upcoming 5th edition will use the term “autism spectrum disorder” (ASD) to group together autistic disorder and several related disorders into a single diagnostic category.



Autism is considered to be the fastest growing developmental disability in the United States. It occurs in all races, ethnic groups, and socioeconomic levels and is four times more often in boys than girls. Approximately 1 in 110 children are identified as having an autism spectrum disorder. Currently two forms have been identified: early and late onset. The symptoms of the early onset form of autism generally develop prior to 3 years of age with most parents reporting concerns of abnormal behavior in the child's first year. In the late onset form of autism parents report that their child seemed to develop normally up to 18 to 30 months of age followed by major regression in language and socialization skills.

Interventions for autism have evolved dramatically since it was first described by Kanner. Autism is now recognized as a developmental disorder and current interventions focus on teaching effective communication skills, improving developmental skills, managing behavioral difficulties, and developing play and social skills.

What causes autism?

The exact cause of autism is still unknown. Recent studies suggest that genetics play a major role. Twin and family studies have strongly suggested that some people have a genetic predisposition to autism. For instance, identical twins are much more likely than fraternal twins or siblings to both have autism. Generally, research studies conclude that autism is likely caused by a combination of genetic and environmental risk factors including prenatal exposures to thalidomide, valproic acid, or rubella. One of the largest controversies in autism is focused on whether a link exists between autism and certain childhood vaccines, particularly the measles-mumps-rubella (MMR) vaccine. No reliable study to date has shown evidence to support this theory.

Common characteristics of children with autism

Autism is a spectrum disorder and it affects each child differently. Children with autism spectrum disorder have deficits or difficulties in the core areas of social interactions, verbal and non-verbal communication, repetitive behaviors, and unusual or limited activities and interests. An overview of some of the common characteristics seen in children with autism spectrum disorder is presented in the following diagram.

Current diagnostic criteria for ASD:

ASD is a spectrum disorder meaning that no two children will have exactly the same symptoms or necessarily look alike. In addition to experiencing different combinations of symptoms, the severity of symptoms among children will vary. Studies have shown that parents are often the first to recognize symptoms, most often before their child's first birthday. As a parent, you know your child best. If you think there is a problem with the way your child speaks, learns, or acts, be sure to share your concerns with your child's pediatrician immediately. Research shows that when parents have concerns about their child's development, they are usually right and a diagnosis of autism made at age 2 can be accurate and stable.

Deficits in social communications

- Lack of eye contact or use of gestures
- Does not smile in response to others
- Does not enjoy or engage in social games such as peek-a-boo

Repetitive patterns of behavior, interests, and activities

- Unusual sensory behaviors
- Difficulty with changes in routine
- Plays with toys in unusual ways (e.g., lining up, spinning)

Symptoms must be present in early childhood

See Appendix A for the complete diagnostic criteria for autism.

WHY IT IS IMPORTANT TO BE INFORMED

The role of early identification and intervention

As autism is a developmental disorder, it is extremely important to minimize the delays in your child's development. If a child experiences a developmental delay, this can possibly become more severe over time. While there is no cure for autism spectrum disorders, research shows that intensive educational and behavioral interventions reduce the impact of autism on a child's life when started as soon as possible (i.e., two years of age and earlier). The earlier a diagnosis is made the earlier an intervention can take place.

Why is early intervention important?

The first few years of a child's life are critical to development and growth. Research shows that the brain grows quickly between the ages of zero and three and the best chance of overcoming neurodevelopmental deficits is with early intervention. Early interventions include targeted treatments to minimize developmental delays and maximize your child's chances of reaching typical developmental milestones. Basic and brand new skills that infants typically develop during the first three years of life include:

- Cognitive (thinking, learning, problem solving)
- Communication (talking, listening, understanding)
- Physical (reaching, rolling, crawling, walking)
- Social/emotional (playing, feeling secure and happy)
- Self-help (eating, dressing, toileting)

The earlier a child receives early intervention services the better his or her outcome and future. Thus, intervening therapeutically before age three allows a child to learn new communication skills at a time when he or she is most ready to grasp these skills. Children in early intervention programs show significant cognitive, language, and social gains, and are more likely to be placed in less restrictive educational placements, including mainstream classrooms. Thus, early intervention is crucial for children's language acquisition and provides you and your child with the skills to cope with autism.

What are developmental milestones?

Child development describes the various stages a child experiences as he or she develops. Developmental milestones are a set of skills or age-specific tasks that most children can do at a certain age range such as walking and talking. While most children reach milestones at a similar age, there is some variability. As a parent it is important to be aware of what normal development is and to remain alert for developmental delays and early signs or red flags of ASD. During your child’s first year, monitoring his or her social-emotional development (e.g., eye contact, gestures, smiling) is especially important for spotting early warning signs.

Early signs (“red flags”)

A multidisciplinary panel representing nine professional organizations, including the American Academy of Pediatrics, strongly recommends immediate additional evaluation for ANY of the following “’red flags.”

- No babbling at 12 months
- No gesturing at 12 months
- No single words at 16 months
- No spontaneous phrases of at least 2 words by 24 months
- Any loss of language or social skills at any age

If your child shows ANY “red flags,” do not wait for your next child preventive care visit.

A child who displays one or more “red flags,” does not necessarily have autism. Some children may have many warning signs, whereas other children may only have a few. However, it does mean that your child’s developmental differences need to be assessed with a formal evaluation as soon as possible. Similarly, if your child is delayed or has difficulty with many age specific skills or meeting developmental milestones (See Appendix B) you should consult your pediatrician immediately.

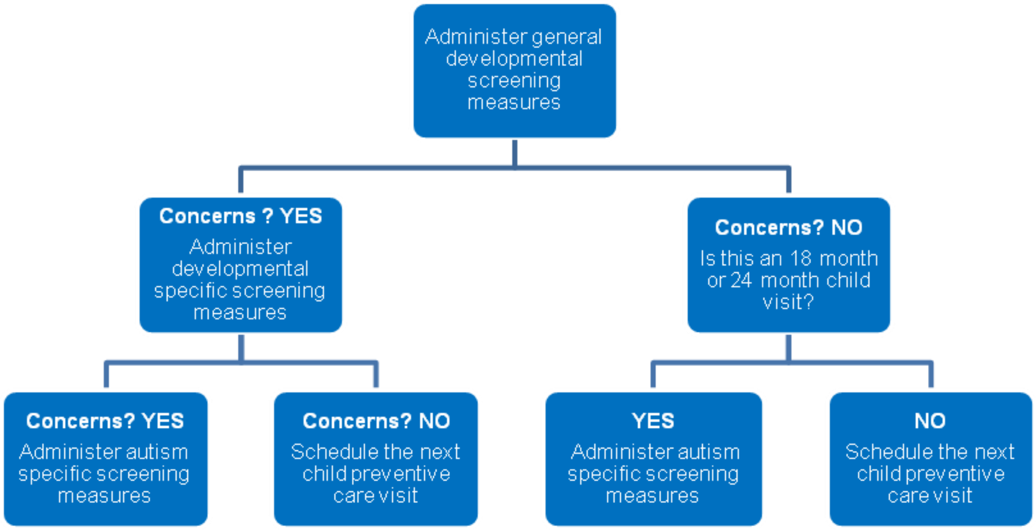
Remember: You are the most important observer of your child’s development!

The purpose of screening

If you are concerned that your child demonstrates signs of autism, talk with your child's pediatrician about your concerns. There is no medical test (e.g., blood tests, genetic tests, or brain imaging) that can diagnose autism. An autism spectrum disorder diagnosis is based on direct observation, child and clinician interaction, and parent questionnaires. Typically these assessments look for difficulties in areas that include social interaction, communication, and unusual interests or behaviors. If there are concerns, your pediatrician can complete a screening tool designed for autism and/or refer you to a professional for a comprehensive diagnostic evaluation.

What is screening? Screening is a means of assessing children for developmental delays and identifying those who need a more in-depth evaluation. Typically it involves administering standardized measures along with a series of decisions that are made during routine child preventive care visits at 9, 18, or 24 months or at an extra visit for autism-related or other developmental/behavioral concerns.

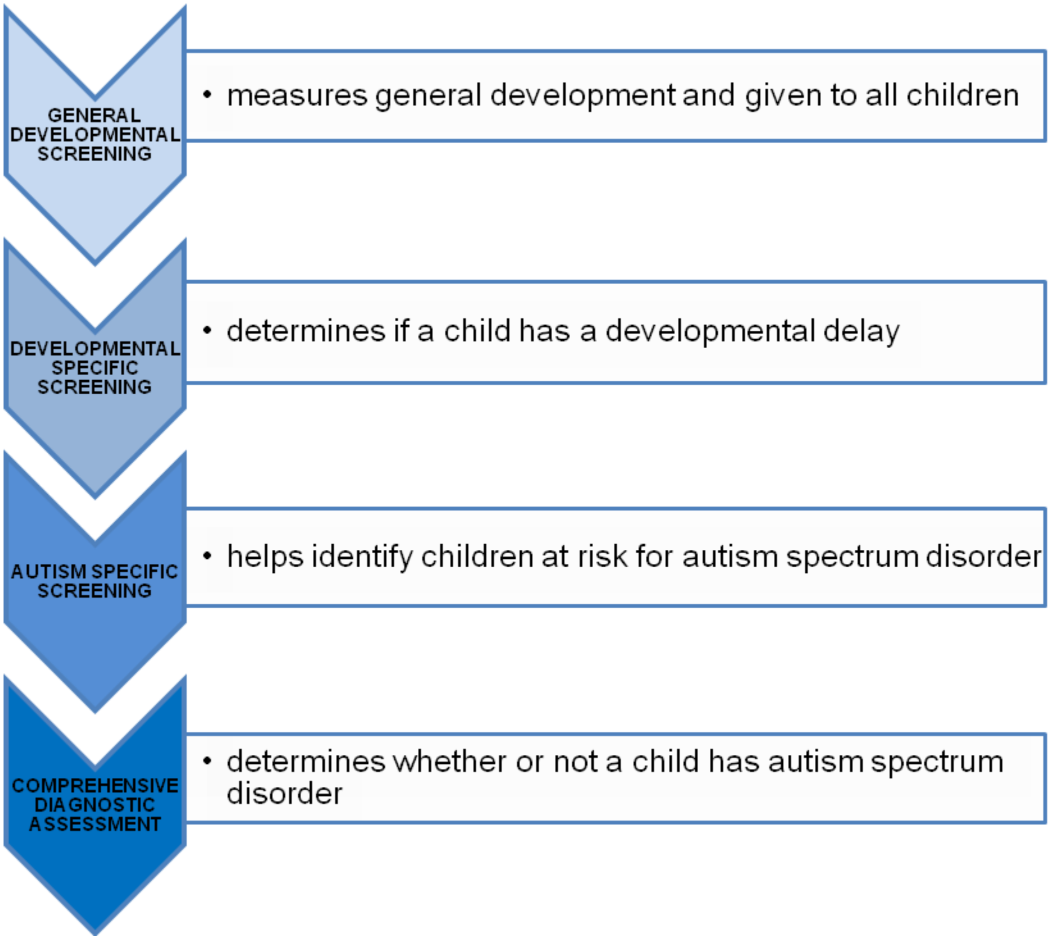
TYPICAL DEVELOPMENTAL and ASD SCREENING



Overview of the assessment process

For most children and their families, the assessment process begins with developmental screenings that will determine if your child is learning basic skills or if there is a delay in development. Additional information on family background, child's personality, eating habits, sleep schedule, interaction with other children, and development will also be gathered at this time. Screenings specific to ASD will be administered if your child is determined to be at risk for developmental delays. A screening will not provide a diagnosis but it will determine if a referral for a comprehensive diagnostic assessment is needed.

At what ages can screening measures be administered? Each screening measure is designed for a specific age group. Some measures can be used on children as young as 18 months of age. Different assessment measures are selected depending on the age of your child and his or her verbal or communication ability. For example, if your child does not speak or uses only a few words, he/she should be evaluated using a nonverbal assessment. Most importantly, the American Academy of Pediatrics recommends that ALL children be screened specifically for autism spectrum disorder at their 18- and 24-month preventive visits.



What should I know about screening measures?

- Screening measures are not intended to indicate (i.e., diagnose) whether or not a child has autism. Instead, if the results of the screening measures indicate signs of autism, the child needs a comprehensive diagnostic evaluation.

- The screening measures will focus on developmental and behavioral milestones. A list of commonly asked questions is provided in Appendix G.

- Most measures involve a parent interview, a questionnaire, a professional interacting with the child, and clinical observations of the child (see Appendix C).

- The measures are typically quick to complete (5-20 minutes) and cost less than a comprehensive diagnostic evaluation.

Who can I contact to obtain a screening?

- Your child's pediatrician may be able to complete a screening or provide a referral.

- Each state has one agency that is in charge of the early intervention system for infants and toddlers (ages birth through 2 years) with special needs. See NICHCY State Specific Resources (www.nichcy.org/Pages/StateSpecificInfo.aspx) or call 1-800-695-0285 for more details.

- The Department of Developmental Services (www.dds.ca.gov/EarlyStart/Home.cfm) or call 1-800-515-2229 can also provide additional resources for parents.

Who can administer screening measures? Health care professionals conducting autism specific screening assessments must be trained, qualified and/or licensed and should have an understanding of child development and autism. These professionals may include a physician, psychologist, speech pathologist, behavioral therapist, etc.

What is the purpose of comprehensive diagnostic evaluation?

- ***What is a comprehensive diagnostic evaluation?*** The purpose of a comprehensive diagnostic evaluation is to determine whether or not a child has autism, to help identify the child's strengths and challenges, and to target areas for intervention.

- ***Who can perform comprehensive diagnostic evaluations?*** Health care professionals who diagnose autism spectrum disorders must either be a licensed psychologist (Ph.D., Psy.D.) or a physician (M.D. or O.D.). Other professionals with expertise in autism may assist in the diagnostic process (e.g., speech pathologist, occupational therapist).

The comprehensive diagnostic assessment team may include:

- **Clinical psychologist**: who will measure a child's level of cognitive functioning, conduct autism-specific diagnostic testing, and perform assessments for other co-occurring conditions (e.g., ADHD).

- **Speech pathologist**: who will evaluate a child's language and social communication skills using a variety of methods (i.e., clinical observations, parent reports, speech and language assessments).

- **Occupational therapist**: who will evaluate fine and gross motor skills, assess for sensory processing areas of concern, and ask parents about their child's self-help skills (e.g., dressing, eating, toileting).

- **Child psychiatrist**: who will gather family history of medical and developmental disorders and conduct medical assessments (e.g., EEG, genetic testing).

- **Parents**: who will provide valuable information including developmental history regarding language and social behavior in the home and social environments.

- **Social worker/case manager**: who will provide referrals, make suggestions about future appropriate steps for the child, and be available to the parents for support.

At what ages can a comprehensive diagnostic evaluation be completed? An experienced clinician can reliably diagnose autism spectrum disorder as young as 18 months of age. It is extremely important for young children to be screened for autism because early intervention services depend on early detection and having a formal diagnosis.

Whom can I contact to obtain a comprehensive diagnostic evaluation?

- The same professionals and organizations identified for screening (listed above on page 10).

What should I know about comprehensive diagnostic evaluations?

- It requires a multidisciplinary team of professionals that may include a psychologist, psychiatrist, speech pathologist, and occupational therapist and is more detailed, costly and time consuming than screening measures.

- It is intended to indicate whether or not a child has autism and will focus on communication, social skills, and overall behavior.

- It is standardized and designed specifically to assess for autism spectrum disorder. Two common measures used to diagnose autism are the Autism Diagnostic Observation Schedule (ADOS) and Autism Diagnostic Interview-Revised (ADI-R). (See Appendix D).

- A comprehensive diagnostic evaluation may also include several medical tests:

    - Hearing: An audiogram can indicate whether a child has a hearing impairment by measuring responses such as head turning, blinking, or staring when a sound is present.

    - EEG: An EEG (electroencephalogram) measures brain waves that can show seizure disorders, brain abnormalities, and tumors.

    - MRI: An MRI (magnetic resonance imaging) can create an image of the brain and areas of functioning in extremely fine detail.

    - CAT scan: CAT (computer assisted axial tomography) scans are helpful in diagnosing structural problems with the brain.

    - Genetic test: Blood tests can determine abnormalities in the genes which could cause a developmental disability.

ROLE OF PARENTS

The role of parents in the detection of autism spectrum disorders is crucial. You are the expert on your child's development and your concerns are often justifiable. Having a child with a possible disability creates challenges and stressors.

Barriers that parents face

Parents often face significant barriers as they try to obtain essential referrals and services for their child. Parents also often experience increased levels of stress and confusion. However, it is important to remember that your child needs your help in obtaining services in a timely manner.

Early detection of autism is up to you

As a parent, you are in the best position to spot the earliest warning signs of autism. Your child's pediatrician may not have the opportunity to observe the critical behaviors during routine check-ups. That does not mean those behaviors do not exist. You know your child better than anyone. Do not disregard the importance of your own observations and experiences. The key is to educate yourself so that you know what is normal, what is not, and what to ask for.

- **Monitor your child's development.** Keeping track of when your child meets or does not meet developmental milestones (See Appendix B for developmental checklists) is an effective way to identify early warning signs.

- **Do not wait!** It is important to recognize that every child develops at a different pace. However, if your child is not meeting many of the milestones for his or her age, share your concerns with your child's pediatrician immediately. Take action if you are concerned.

- **Do not accept a "wait and see" approach.** Many parents are told by health care professionals "Don't worry" or "Wait and see." However, waiting is the worst thing you can do for your child. You risk losing valuable intervention time for your child at a time when your child has the best chance for improvement.

- **Be persistent!** Ideally, your child's pediatrician will take your concerns seriously and perform thorough evaluations. However, health care professionals can sometimes miss red flags or underestimate problems. Listen to your instincts if you feel there is something wrong. Schedule a follow-up appointment with the doctor, seek a second opinion, or ask for a referral to a specialist. Trust your instincts.

- **Be assertive!** If you do not let people know what your child's needs are, they may never know! You may need to keep asking questions until you get answers that you understand. Often times if you do not say anything, it is easy for health care professionals to assume that everything is okay.

Things that you can do

Follow through with appointments
Become an expert on your child
Seek support
Be patient and optimistic
Work together with health care professionals
Do not wait to seek treatment
(See Appendix F for State Specific Resources)

Write down everything
Be organized
Be an active participant
Express concerns
Be prepared for appointments
Educate yourself about autism
(See Appendix E for Helpful Resources)

What to do if you are worried

- **Schedule an appointment.** If you have observed "red flags" for autism, you should schedule an appointment with your child's pediatrician immediately. Generally, it is a good idea to have your child routinely screened even if he or she is meeting all the developmental milestones.

- **Take advantage of early intervention treatment.** The diagnostic process for autism can sometimes take awhile. However, you do not have to wait for an official diagnosis before you can seek services for your child (See Appendix F for state specific resources). As soon as you suspect your child has developmental delays, ask your child's pediatrician to refer you to early intervention services.

- **Do not be afraid to ask for help.** This whole process and experience can be overwhelming. Frequently, adults view the need to ask for help as a sign of weakness. Do not be afraid to ask. The worst that can happen is for someone to say "no." However, by asking, you give people the opportunity to assist you.

- **Follow through and do not give up.** It is essential to understand the importance of screening measures over a course of time (i.e., 9, 18, 24 months child preventive care visits). Your child should always be screened with at least a general developmental screening measure even if you do not express concerns. If you do have concerns or if prior screening indicated concerns, be persistent and follow through with subsequent appointments. This persistence will help prevent a crucial delay in diagnosis and intervention.

Be your child's best advocate

Advocating for your child is an extremely important role. When you believe that your child's needs are being met, express your gratitude to the team member(s) providing the service. However, when you believe that your child's needs are not being met, it is crucial to be assertive. Your child is counting on you to be **A.W. A.R.E.** You are your child's best advocate.

EXPERTS’ ADVICE

Experts in the field of autism were emailed and asked to offer advice and suggestions to parents who have young children under 3 years of age. Listed below are the recommendations that these experts provide to the parents of a child who has been diagnosed with ASD.

Autism: An overview

- Get educated! Ask health care professionals for a list of books and Websites.
- Download 100-Day Kit from Autism Speaks. This is a valuable resource.
- Effective early intervention can be found in the National Standards Report.
  www.nationalautismcenter.org
- Be familiar with Individuals with Disabilities Education Act, Part C (IDEA, Part C). In California: www.dds.ca.gov/EarlyStart/Home.cfm

Why it is important to be informed

- It is not too early to start intensive intervention if your child has red flags for autism.
- Contact your local early intervention service agency and consult with service providers on how to promote your child’s development.
- In California, Regional Centers are responsible for early intervention services for a child prior to age 3. Contact Regional Center to see if your child is eligible for services.
- Put your child on the waitlist for an in-home program as soon as possible.
- Enroll your child in your school district’s developmental preschool program.
- Consider participating in an early intervention research study for young children with autism spectrum disorder and developmental disorders. This can sometimes be the best way to obtain high quality services in your area.
- Do not panic. Do not give up hope. If your child is diagnosed, early intervention works!

Assessment

- Have an evaluation done by an autism spectrum disorder diagnostic expert.
- Rule out medical conditions with genetics consultation and medical tests.
- Request a thorough medical examination examining sleeping, neurological, gastrointestinal functioning, and feeding.
- Include evaluations from speech therapist, occupational therapist, developmental pediatrician, and psychologist.
- It needs to include developmental testing, behavioral observation, parent questionnaires, the Autism Diagnostic Interview-Revised (ADI-R), and Autism Diagnostic Observation Schedule (ADOS).
- In California, contact the Regional Center for your area and request an intake and evaluation for the Early Start Program or the State Prevention Program.
- Be sure that the involved professionals use the results from your child’s evaluation to determine appropriate interventions.

Role of parents

- Join a parent support group because other parents can be a great source of support.
- Request an Individualized Family Service Plan (IFSP) from the Regional Center.
- Seek parent education/training in order to communicate and engage more effectively with your child. For example, use activities in the “More Than Words” book to provide opportunities to communicate and have positive interactions with your child.
- Seek opportunities for building communication skills and encouraging social interactions with activities such as toddler-parent music groups or gym classes.
- Start a notebook with your child’s photo on the front cover. Keep detailed records and files. Divide the notebook in sections for evaluations, reports, and other documentations.
- Enroll in the Hanen Program for Parents of Children with Autism Spectrum Disorder.
- Listen to your instincts. You know your child the best. You have the right to disagree and fight for more or fight for different services. You are your child’s most effective advocate.

Experts’ advice

Thank you to the following autism experts for their participation and invaluable suggestions:

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REFERENCES

American Academy of Pediatrics (2001). Developmental surveillance and screening of infants and young children. *Pediatrics, 108,* 192-195.

American Academy of Pediatrics (2006). Identifying infants and young children with developmental disorders in the medical home: An algorithm for developmental surveillance and screening. *Pediatrics, 118,* 405-420. doi: 10.1542/peds.2006-1231

American Psychiatric Association (2010). *DSM-5 development.* Retrieved from http://www.dsm5.org/Pages/Default.aspx

Baird, G., Charman, T., Cox, A., Baron-Cohen, S., Swettenham, J., Wheelwright, S., & Drew, A. (2001). Screening and surveillance for autism and pervasive developmental disorders. *Archives of Disease in Childhood, 84,* 468-475. doi:10.1136/adc.84.6.468

Brookman-Frazee, L., & Koegel, R. L. (2004). Using parent/clinician partnerships in parent education programs for children with autism. *Journal of Positive Behavior Interventions, 6*, 195-213. doi: 10.1177/10983007040060040201

Carter, A. S., Davis, N. O., Klin, A., & Volkmar, F. R. (2005). Social development in autism. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 312-334). Hoboken, NJ: John Wiley & Sons, Inc.

Centers for Disease Control and Prevention. (2009). *National center on birth defects and developmental disabilities.* Retrieved from http://www.cdc.gov/ncbddd/features/counting-autism.html

Charman, T. (2003). Screening and surveillance for autism spectrum disorder in research and practice. *Early Child Development and Care, 173*(4), 363-374. doi:10.1080/0300443032000079050

Chawarska, K., & Volkmar, F. R. (2005). Autism in infancy and early childhood. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (pp. 223-246). Hoboken, NJ: John Wiley & Sons, Inc.

Greenspan, S. I., Brazelton, B., Cordero, J., Solomon, R., Bauman, M. L., Robinson, R., … Breinbauer, C. (2008). Guidelines for early identification, screening, and clinical management of children with autism spectrum disorders. *Pediatrics, 121*(4), 828-830. doi:10.1542/peds.2007-3833

Inglese, M. D. (2009). Caring for children with autism spectrum disorder, part II: Screening, diagnosis, and management. *Journal of Pediatric Nursing, 24*(1), 49-59. doi:10.1016/j.pedn.2008.06.005

Johnson, C. P., Myers, S. M., & the Council on Children with Disabilities (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics, 120*(5), 1183-1215. doi:10.1542/peds.2007-2361

Matson, J. L., Wilkins, J., & Gonzalez, M. (2008). Early identification and diagnosis in autism spectrum disorders in young children and infants: How early is too early? *Research in Autism Spectrum Disorders, 2*(1), 75-84. doi: 10.1016/j.rasd.2007.03.002

Myers, S. M., Johnson, C. P., & the Council on Children with Disabilities (2007). Management of children with autism spectrum disorders. *American Academy of Pediatrics, 120*(5), 1162-1182. doi:10.1542/peds.2007-2362

Shattuck, P. T., & Grosse, S. D. (2007). Issues related to the diagnosis and treatment of autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 129-135. doi:10.1002/mrdd.20143

Williams, J., & Brayne, C. (2006). Screening for autism spectrum disorders: What is the evidence? *Autism, 10*, 11-35. doi: 10.1177/1362361306057876

APPENDIX A

DIAGNOSTIC CRITERIA

Autism Spectrum Disorder 299.00

Must meet criteria 1, 2, 3:

1. Clinically significant, persistent deficits in social communication and interactions, as manifested by all of the following:
    a. Marked deficits in nonverbal and verbal communication used for social interaction
    b. Lack of social reciprocity
    c. Failure to develop and maintain peer relationships appropriate to developmental level

2. Restricted, repetitive patterns of behavior, interests, and activities, as manifested by at least TWO of the following:
    a. Stereotyped motor or verbal behaviors, or unusual sensory behaviors
    b. Excessive adherence to routines and ritualized patterns of behavior
    c. Restricted, fixated interests

3. Symptoms must be present in early childhood (but may not become fully manifested until social demands exceed limited capacities)

Information has been adapted from American Psychiatric Association DSM-5 Development and can be found at http://www.dsm5.org

APPENDIX B

DEVELOPMENTAL CHECKLIST AT THE END OF 3 MONTHS

Social		
• Begins to recognize family members	Y	N
• Turns head toward direction of sound	Y	N
• Cries in response to parent leaving room	Y	N
• Follows moving object with eyes	Y	N
• Watches faces intently	Y	N
• Smiles at the sound of parents' voices	Y	N
• Imitates some physical movements and facial expressions	Y	N
Language		
• Begins to babble	Y	N
• Begins to imitate some sounds	Y	N
Fine Motor and Gross Motor		
• Raises head and chest when lying on stomach	Y	N
• Supports upper body with arms while lying on stomach	Y	N
• Stretch legs out and kick when lying on stomach or back	Y	N
• Opens and shuts hands	Y	N
• Grasps and shakes hand toys	Y	N
• Starts using hands and eyes in coordination	Y	N

Information has been adapted from Centers for Disease Control and Prevention and can be found at http://www.cdc.gov

DEVELOPMENTAL CHECKLIST AT THE END OF 7 MONTHS

Social		
• Imitates actions	Y	N
• Recognizes familiar people, objects, and voices	Y	N
• Smiles responsively	Y	N
• Shows pleasure during social games	Y	N
• Shows displeasure when game ends	Y	N
• Turns toward sounds and voices	Y	N
• Enjoys playing peek-a-boo	Y	N
• Interested in mirror images	Y	N
Language		
• Imitates sounds such as “baba” “dada”	Y	N
• Babbles chains of consonants (ba-ba-ba-ba)	Y	N
• Responds to own name	Y	N
Fine Motor and Gross Motor		
• Rolls over both ways (stomach to back, back to stomach)	Y	N
• Reaches for object with one hand	Y	N
• Transfers object from hand to hand	Y	N
• Supports whole weight on legs	Y	N
Cognitive		
• Finds partially hidden object	Y	N
• Explores objects with hands and mouth	Y	N

Information has been adapted from Centers for Disease Control and Prevention and can be found at http://www.cdc.gov

DEVELOPMENTAL CHECKLIST AT THE END OF 12 MONTHS

Social		
• Shy or anxious with unfamiliar people	Y	N
• Cries when mother or father leaves	Y	N
• Turns head when name is called and establishing eye contact	Y	N
• Points to desired object	Y	N
• Plays patty-cake and peek-a-boo	Y	N
• Shows specific preferences for certain people and toys	Y	N
Language		
• Uses simple gestures (e.g., shaking head “no”)	Y	N
• Understands “no” and simple verbal requests	Y	N
• Says “mama” and “dada”	Y	N
• Uses exclamations such as “oh-oh!”	Y	N
• Tries to imitate words	Y	N
Fine Motor and Gross Motor		
• Sits without assistance	Y	N
• Crawls on hands and knees	Y	N
• Pulls self up to stand	Y	N
• Walks holding onto furniture	Y	N
• Feeds self finger food (e.g., raisins)	Y	N
• May walk two or three steps without support	Y	N
• Puts blocks in and takes them out of a container	Y	N
Cognitive		
• Finds hidden object easily	Y	N
• Explores objects in many ways (shaking, throwing, dropping)	Y	N
• Begins to use objects correctly (drinking from cup, brushing hair)	Y	N
• Looks at correct picture when the image is named	Y	N

Information has been adapted from Centers for Disease Control and Prevention and can be found at http://www.cdc.gov

DEVELOPMENTAL CHECKLIST AT THE END OF 24 MONTHS

Social		
• Pulls adult to show a need or desire	Y	N
• Gives or shows object on request	Y	N
• Imitates behavior of others	Y	N
• Begins to show defiant behavior	Y	N
• Seeks attention	Y	N
Language		
• Follows simple directions	Y	N
• Speaks in two-to-four word sentences (e.g., “want juice”)	Y	N
• Combines words and gestures to make needs known	Y	N
• Responds to instructions (e.g., “give mommy a kiss”)	Y	N
• Have a vocabulary of several hundred words	Y	N
• Hums or tries to sing simple songs	Y	N
Fine Motor and Gross Motor		
• Walks without assistance	Y	N
• Begins to run	Y	N
• Walks up and down stairs holding onto support	Y	N
• Scribbles with crayon	Y	N
• Build tower of four blocks or more	Y	N
• Feed self with a spoon	Y	N
Cognitive		
• Points to objects in pictures or books	Y	N
• Recognizes names of familiar people, objects, and body parts	Y	N
• Does simple puzzles	Y	N
• Begins to sort objects by shapes and colors	Y	N
• Begins make-believe play	Y	N

Information has been adapted from Centers for Disease Control and Prevention and can be found at http://www.cdc.gov

APPENDIX C

GENERAL DEVELOPMENTAL SCREENING MEASURES

Ages and Stages Questionnaire, 2nd Edition (ASQ-2) *4 months to 60 months* administration time: 10-20 min	• screens for early developmental delay and social emotional difficulties • parent questionnaire (30 items)*
BRIGANCE Screens (Infant & Toddler Screen, Early Preschool Screen-II, Preschool Screen-II) *Birth to 5 years* administration time: 15-20 min	• screens for giftedness or disability and the need for special placement • English, Spanish, Laotian, Vietnamese, Cambodian, and Taglog versions available
Child Development Inventory (CDI) *18 months to 6 years* administration time: 30-50 min	• measures social, self-help, gross and fine motor, expressive language, language comprehension, academic skills • parent questionnaire (300 items) • English and Spanish versions available
Parent's Evaluation of Developmental Status (PEDS) *Birth to 8 years* administration time: 2-10 min	• screens for developmental problems • parent interview (10 items) • English, Spanish, Vietnamese, Arabic, Swahili, Indonesian, Chinese, Taiwanese, French, Somali, Portuguese, Malaysian, Thai, and Laotian versions available

DEVELOPMENTAL DELAY SPECIFIC SCREENING MEASURES

Autism Screening Questionnaire (ASQ) *4 years to 6 years* *$\geq$ 6 years* administration time: 15 min	• assess for reciprocal and social interaction, language, and communication, and repetitive and stereotyped behaviors • parent questionnaire (40 items) • English and Spanish versions available
Checklist for Autism in Toddlers (CHAT) *18 months to 24 months* administration time: 15 min	• measures social interest, social plan, joint attention, pretend (functional) play • parent questionnaire (9 items), clinician observations (5 items)*
Modified Checklist for Autism in Toddlers (M-CHAT) *16 months to 48 months* administration time: 5-10 min	• assess social/communication behaviors • parent questionnaire (23 items) • English, Spanish, Turkish, Chinese, and Japanese versions available
Pervasive Developmental Disorders Screening Test-II (PDDST-II) Stage 1 Primary Care Screener *12 months to 18 months* administration time: 10-15 min	• screens for autism in early childhood • parent questionnaire (22 items)*

***** English version available

AUTISM SPECIFIC SCREENING MEASURES

Autism Behavior Checklist (ABC) *≥18 months* administration time: 10-20 min	• assess five areas: sensory behaviors, social relating, repetitive behaviors, language and communication skills, and social and adaptive skills • behavioral checklist completed by parent, teacher, or clinician (57 items)*
Childhood Autism Rating Scale (CARS) *≥2 years* administration time: variable	• measures domains such as resistance to environmental change and verbal and nonverbal communication • behavioral checklist completed by trained interviewer (15 items)*
Gilliam Asperger's Disorder Scale (GADS) *3 years to 22 years* administration time: 10 min	• assess for social interaction, restricted patterns of behavior, cognitive patterns, and pragmatic skills • questionnaire completed by parent, teacher, or clinician (32 items)*
Gilliam Autism Rating Scale – 2nd Edition (GARS-2) *3 years to 22 years* administration time: 10 min	• assess for stereotyped behaviors, communication, and social interaction • questionnaire completed by parent or teacher (42 items)*
Pervasive Developmental Disorders Screening Test-II (PDDST-II), Stage 2 Developmental Clinic Screener *18 months to 48 months* administration time: 10-15 min	• screens for autism in early childhood • parent questionnaire (14 items)*
Pervasive Developmental Disorders Screening Test-II (PDDST-II), Stage 3 Autism Clinic Severity Screener *18 months to 48 months* administration time: 10-15 min	• screens for autism in early childhood • parent questionnaire (12 items)*
Screening Tool for Autism in Two-Year Olds (STAT) *24 months to 36 months* administration time: 20 min	• assess play skills, communication skills, and imitation skills • trained clinician interacts with child in a play context (8 items)*
Social Communication Questionnaire (SCQ) *≥ 4 years* administration time: 5-10 min	• measures social interaction, language and communication, and repetitive stereotyped patterns of behaviors • parent questionnaire (40 items) • English and Spanish versions available

* English version available

Information in this section has been adapted from American Academy of Pediatrics and can be found at http://www.aap.org

APPENDIX D

COMPREHENSIVE DIAGNOSTIC ASSESSMENT MEASURES

COGNITION & ACADEMIC ACHIEVEMENT

Bayley-III Scales of Infant and Toddler Development, 3rd Edition *1 month to 42 months* administration time: 30-60 min	• assess cognitive, motor, language, social-emotional, and adaptive behavior • trained clinician interacts with child
Leiter International Performance Scale – Revised (Leiter-R) *2 years through 20 years* administration time: 25-40 min	• a nonverbal measure of intelligence with game-like tasks assessing reasoning, visualization, memory, and attention • trained clinician interacts with child
Mullen Scales of Early Learning *Birth to 5 years 8 months* administration time: 15-35 min	• measures gross & fine motor, visual reception, expressive & receptive language • trained clinician interacts with child
Psychoeducational Profile Revised (PEP-R) *3 years to 5 years* administration time: 45-90 min	• provides information on developmental functioning in imitation, perception, gross and fine motor, eye-hand integration, cognitive performance, and cognitive verbal areas • trained clinician interacts with child
Stanford-Binet Intelligence Scales, 5th Edition *2 years to 85+ years* administration time: varies	• assess factors of cognitive ability including visual-spatial processing, knowledge, and working memory • trained clinician interacts with child
Wechsler Preschool and Primary Scale of Intelligence, 3rd Edition (WPPSI-III) *2 years 6 months to 7 years 3 months* administration time: 30-45 min	• intelligence test used to measure skills and abilities • trained clinician interacts with child

LANGUAGE

Clinical Evaluation of Language Fundamentals-Preschool: 2nd Edition (CELF Preschool-2) *3 years to 6 years* administration time: 30-45 min	• assess domains including expressive vocabulary, following directions, and recalling sentences • speech pathologist interacts with child
Peabody Picture Vocabulary Test, 4th Edition (PPVT-IV) *2 years 6 months to 90+ years* administration time: 10-15 min	• receptive vocabulary test • speech pathologist interacts with child
Preschool Language Scale, 4th Edition (PLS-4) *Birth to 6 years and 11 months* administration time: 20-45 min	• access receptive and expressive language • speech pathologist interacts with child

ADAPTIVE SKILLS

Vineland Adaptive Behavior Scales, 2nd Edition (Vineland-II) *Birth to 90 years* administration time: 20-60 min	• assess communication, daily living skills, socialization, motor skills, and maladaptive behavior • English and Spanish versions available

FINE MOTOR/GROSS MOTOR

Beery-Buktenica Developmental Test of Visual-Motor Integration, 6th Edition (Beery VMI) *2 years to 100 years* administration time: varies	• assess visual-motor skills • occupational therapist interacts with child
Peabody Developmental Motor Scales, 2nd Edition (PDMS-2) *Birth to 5 years* administration time: 45-60 min	• assess motor skills in the following areas: reflexes, stationary, locomotion, object manipulation, grasping, and visual-motor integration • occupational therapist interacts with child
Sensory Profile *3 years to 10 years* administration time: varies	• assess how a child process sensory information in everyday situation • parent questionnaire (125 items)

DIAGNOSTIC MEASURES

Autism Diagnostic Interview, Revised (ADI-R) *Broad age range* administration time: 120 min	• assess behavior in three main areas: qualities of reciprocal social interaction; communication and language; and restricted and repetitive, stereotyped interests and behaviors • parent interview with trained clinician (93 items)
Autism Diagnostic Observation Schedule (ADOS) *≥18 months* administration time: 30-45 min	• assess social play and communication • semi-structured activities and direct observation from trained clinician

Information in this section has been adapted from American Academy of Pediatrics and can be found at http://www.aap.org

APPENDIX E

HELPFUL RESOURCES

ORGANIZATIONS

American Academy of Pediatrics (AAP)
(847) 434-4000
www.aap.org

Autism Research Institute (ARI)
(619) 563-6840
www.autismwebsite.com/ari/index.htm

Autism Society of America (ASA)
(301) 657-0881
www.autism-society.org

Autism Speaks
(212) 332-3580
www.autismspeaks.org

Center for Disease Control and Prevention
www.cdc.gov

Cure Autism Now (CAN)
(888) 828-8476
www.canfoundation.org

First Signs, Inc.
(978) 346-4380
www.firstsigns.org

Organization for Autism Research (OAR)
(703) 351-5031
www.researchautism.org

Wrightslaw
(804) 776-7605
www.wrightslaw.com

Zero to Three
(202) 638-1144
www.zerotothree.org

RECOMMENDED PUBLICATIONS

The Autism Asperger's Digest Magazine
www.autismdigest.com

The Autism File
www.autismfile.com

The Autism Perspective
www.theautismperspective.org

Autism Spectrum Quarterly
www.asquarterly.com

The Special Ed Advocate
www.wrightslaw.com/subscribe.htm

Spectrum Magazine
www.spectrumpublications.com

Autism Spectrum News
www.mhnews-autism.org

Exceptional Parent
www.eparent.com

APPENDIX F

STATE SPECIFIC RESOURCES

CALIFORNIA REGIONAL CENTERS

Regional Center	areas serve
Alta California Regional Center (916) 978-6400 http://www.altaregional.org/	Alpine, Colusa, El Dorado, Nevada, Placer, Sacramento, Sierra, Sutter, Yolo, and Yuba counties
Central Valley Regional Center (559) 276-4300 http://www.cvrc.org	Fresno, Kings, Madera, Mariposa, Merced, and Tulare counties
Eastern Los Angeles Regional Center (626) 299-4700 http://www.elarc.org	Eastern Los Angeles county including the communities of Alhambra and Whittier
Far Northern Regional Center (530) 222-4791 http://www.farnorthernrc.org	Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama, and Trinity counties
Frank D. Lanterman Regional Center (213) 383-1300 http://www.laternman.org	Central Los Angeles county including Burbank, Glendale, and Pasadena
Golden Gate Regional Center (415) 546-9222 http://www.ggrc.org	Marin, San Francisco, and San Mateo counties
Harbor Regional Center (310) 540-1711 http://www.harborrc.com	Southern Los Angeles county including Bellflower, Harbor, Long Beach, and Torrance
Inland Regional Center (909) 890-3000 http://www.inlandrc.org	Riverside and San Bernardino counties
Kern Regional Center (661) 327-8531 http://www.kernrc.org	Inyo, Kern, and Mono counties
North Bay Regional Center (707) 256-1100 http://www.nbrc.net	Napa, Solano, and Sonoma counties
North Los Angeles County Regional Center (818) 778-1900 http://www.nlacrc.org	Northern Los Angeles county including San Fernando and Antelope Valleys

Redwood Coast Regional Center (707) 445-0893 http://www.redwoodcoastrc.org	Del Norte, Humboldt, Mendocino, and Lake counties
Regional Center of the East Bay (510) 383-1200 http://www.rceb.org	Alameda and Contra Costa counties
Regional Center of Orange County (714) 796-5100 http://www.rcocdd.com	Orange county
San Andreas Regional Center (408) 374-9960 http://www.sarc.org	Monterey, San Benito, Santa Clara, and Santa Cruz counties
San Diego Regional Center (858) 576-2996 http://www.sdrc.org	Imperial and San Diego counties
San Gabriel/Pomona Regional Center (909) 620-7722 http://www.sgprc.org	Eastern Los Angeles county including El Monte, Monrovia, Pomona, and Glendora
South Central Los Angeles Regional Center (213) 744-7000 http://www.sclarc.org	Southern Los Angeles county including the communities of Compton and Gardena
Tri-Counties Regional Center (805) 962-7881 http://www.tri-counties.org	San Luis Obispo, Santa Barbara, and Ventura counties
Valley Mountain Regional Center (209) 473-0951 http://www.vmrc.net	Amador, Calaveras, San Joaquin, Stanislaus, and Tuolumne counties
Westside Regional Center (310) 258-4000 http://www.westsiderc.org	Western Los Angeles county including the communities of Culver City, Inglewood, and Santa Monica

Information in this section has been adapted from the State of California Department of Developmental Services and can be found at http://www.dds.ca.gov

MEDICAL CENTERS IN CALIFORNIA WITH SPECIALIZATIONS IN ASD

Northern California

Children's Hospital Oakland
Child Development Center
(510) 428-3351
http://www.childrenshospitaloakland.org

Kaiser Permanente San Jose Medical Center
Autism Spectrum Disorders Center
(408) 360-2350
http://www.permanente.net/homepage/kaiser/pages/d11809-top.html

Stanford University
Autism and Developmental Disorders Clinic
(650) 723-7704
http://wwwcap.stanford.edu/services/outpatient/autism_main.html

University of California, Davis
M.I.N.D. Institute
(888) 883-0961
http://mindinstitute.ucdmc.ucdavis.edu/

University of California, San Francisco
Benioff Children's Hospital – Autism & Neurology Clinic
(415) 476-7500
http://www.ucsfbenioffchildrens.org/clinics/autism_and_neurology_clinic/

Southern California

Rady Children's Hospital, San Diego
Autism Discovery Institute
(858) 966-7453
http://www.rchsd.org/

University of California, Irvine
For OC Kids
(888) 9-OC-KIDS
http://www.forockids.com

University of California, Los Angeles
Autism Evaluation Clinic
(310) 794-4008
http://www.semel.ucla.edu/autism/clinic

University of California, Santa Barbara
Koegel Autism Center
(805) 893-2049
http://www.education.ucsb.edu/autism/

APPENDIX G

FREQUENTLY ASKED QUESTIONS

Parents are often asked the following questions during the assessment process.

- Does your child initiate and sustain eye contact?
- Does your child try to share his/her interest by showing or pointing to an item?
- Does your child imitate others without being asked to?
- Does your child appear to be bothered by certain sounds, lights, or textures?
- Does your child use gestures (e.g., waves bye-bye, nods/shakes head)?
- Does your child follow your eye gaze to see what you are looking at?
- Does your child toe-walk, hand-flap, or show other unusual motor movements?
- Does your child engage in the same behaviors over and over again?
- Does your child smile back at you when you smile at him/her?
- Does your child show interest in other peers?
- At what age did your child say his/her first words?

Information in this section adapted from Centers for Disease Control and Prevention and can be found at http://www.cdc.gov