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Screening for Autism Spectrum Disorders: Pediatric Practices Eight Years After Publication of Practice Guidelines

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SCREENING FOR AUTISM SPECTRUM DISORDERS:
PEDIATRIC PRACTICES EIGHT YEARS AFTER
PUBLICATION OF PRACTICE GUIDELINES

A Dissertation

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Indiana University of Pennsylvania

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The School of Graduate Studies and Research

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Screening for Autism Spectrum Disorders:
Pediatric Practices Eight Years after
Publication of Practice Guidelines

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This project describes current general developmental and autism screening practices of pediatricians in the United States following the latest practice guidelines published by the American Academy of Pediatrics (AAP) in November 2007. It compares results to data collected in previous surveys on this topic, which suggest that pediatricians are not following the AAP guidelines despite repeated recommendations to do so over the past 8 years.

A 110-question web-based survey was made available to 3863 potential participants via an invitation letter sent out by email. Questions about developmental screening practices, knowledge of reimbursement for screening, training, and knowledge of the latest AAP practice guidelines on developmental screening were asked.

Results from the analysis of distribution frequencies indicated that a majority of respondents are not familiar with current AAP guidelines on general developmental and autism-specific screening. Furthermore, only 42% reported routinely screening for autism. In terms of barriers, it was found that 28% of those who do not routinely screen specifically for autism reported that they rely primarily on clinical observations instead of using a standardized screening tool as recommended. Twenty-seven percent identified lack of familiarity with autism screeners as the reason. Sixty-six percent of the respondents in this survey admitted never having billed for reimbursement for brief developmental screening using CPT code 96110, and over 85% have never used CPT code 96111 to obtain reimbursement for extended developmental screening. Ninety-five percent of the respondents believe that there is currently an “Average” (35%) or “Above Average” (60%) need for professional postdoctoral training related to developmental delays and autism spectrum disorders.

The data from this survey indicate that pediatricians continue to fall short in meeting the AAP recommended practice guidelines on developmental and autism-specific screening and that comprehensive professional training is needed to address this problem.

ACKNOWLEDGEMENTS

This project is first and foremost dedicated to my son Gabriel, who has taught me much about autism, parenting, and overcoming adversity. It was his remarkable courage and hard work over many years that inspired me to return to school for a doctoral degree in clinical psychology. At age 11, Gabe remarked to me, “Mom, I think I know a cure for autism—you just have to figure out who you are.” I assured him that we all work on that one.

Second only in its place on the page is my gratitude to husband, William Zeiger, and my three sons, Benjamin, Gabriel, and Nathaniel, all of whom sacrificed many hours of time with me and contributed much in the way of love and support so that I could continue my studies and embark on a new career path at this stage of my life.

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I wish also to thank the many parents of children with autism who have shared their stories and their lives with me, and sparked in me a desire to use my education to get involved with this cause as a social activist and advocate for every child on the spectrum.

And finally, this dissertation project is lovingly dedicated to my son Jeremy Reid McDougall (1979-1992).

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CHAPTER ONE

AUTISM: AN OVERVIEW

> There are plants and animals that live so far down under the sea, beyond sunlight, that they create their own light through an internal chemical synthesis. A parent of a child with autism once said to me, “Nobody knows the way we live. Sometimes it feels as though we are inhabiting the same planet but in another dimension—perhaps somewhere just this side of normal.” (Gerlach, 1999, p. 123)

Gabe’s Story

Imagine living in a world where nothing makes sense to you. A world inhabited by people who seem to communicate with each other but whose language and behavior leave you confused, scared. Imagine trying to navigate through the strangeness alone, not able to ask for what you want or need, not able to stop the bombardment of painful or frightening sights, sounds, and touch. This is a world that often seems hostile and dangerous. It’s a frightening world, where you are viewed as an oddity, something to be avoided, something to be “fixed.” The other inhabitants do and say things you don’t understand. The only time you feel safe is when you are left alone to rock or spin or stare into space. This is a world that increasingly more children, including my son, are born into. This is the world of autism.

My introduction to this world came in 1997, when my then three-year-old son Gabe was diagnosed with autism. We had concerns about his development, particularly his lack of language, before he was 18 months old. Although we expressed these concerns to our child’s pediatrician, he told us not to worry, that many boys, especially those with older siblings, were “late talkers.” We took our child home from that visit with *assurances that he was a perfectly healthy baby. By the time of his two-year-old checkup, our concern had deepened. Not only was Gabe not learning new words, but he had “lost” the few words he had spoken in earlier months. He had developed an odd stare, looking not* at *us but* through *us. He no longer smiled, responded to his name, or showed interest in toys or other people. Wandering about the house or yard aimlessly, he would make strange repetitive sounds and wave his hands around in odd patterns. He began to have violent tantrums, without provocation, and he wouldn’t allow us to comfort him. We knew something was terribly wrong; but despite these developmental red flags, our pediatrician was reluctant to give a diagnosis. When he finally agreed, upon our insistence, to give us a referral to Children’s Hospital in Pittsburgh, we were put on a long waiting list for an appointment. It would be another year before we would get the diagnosis of autism, and a year after that before we would find the type of intensive behavioral intervention that would eventually help Gabe to no longer fit the typical diagnostic profile for autism, to become “indistinguishable” from his neurotypical peer in many ways.*

Over the years, I have heard our story repeated many times by other parents. It seems that our experience of trying to get our child diagnosed is a common one: Parents express concerns about their child’s development, only to be assured by the pediatrician that “nothing appears to be wrong” and told to “give it more time.” Autism is a serious diagnosis, and it is understandable that a physician would want to take care not to make a diagnosis of this magnitude capriciously. However, it is well documented that early intensive intervention is critically important in maximizing the child’s social, cognitive, and communication outcomes. For this reason, it is crucial that children suspected of having autism receive treatment as soon as possible. In order to be eligible for many early intervention services and to receive the appropriate types of treatment, the child needs a diagnosis. And, in order to get that diagnosis and get it in a timely way,

pediatricians, who are usually the first healthcare practitioners the child sees, must become more familiar with the early signs of autism and add routine autism screening to their overall developmental surveillance of every child.

Introduction

Autism is a pervasive developmental disorder characterized by a constellation of deficits in communication and social interaction, as well as by unusual behaviors such as repetitive or stereotyped body movements and a restricted range of interests (APA, 2000; Baird, Slonims, & Cass, 2003). Although the etiology of autism remains largely a mystery and may well consist of many genetic and environmental interactive factors, it is well accepted that autism is a neurologically-based disorder that manifests in social, communication, and behavioral deficits before the age of three (Baird, et al., 2003; Beauchesne & Kelley, 2004; Kabot, Masi, & Segal, 2003; Lord & Risi, 1998; Sigman et al., 2006). The number of children being diagnosed with autism spectrum disorders (ASD) is rising. Results from a project conducted by the Autism and Developmental Disabilities Monitoring (ADDM) Network of the Center for Disease Control (CDC) "showed the average ASD prevalence among states participating in the project was approximately 1 in 150 children" (Center for Disease Control, 2008), making autism more prevalent than childhood cancer or Down syndrome (Bryson, Rogers, & Fombonne, 2003; Filipek et al., 1999).

There is no known prevention or cure for autism, but early intervention is linked to better treatment outcomes (Bryson et al., 2003; Dumont-Mathieu & Fein, 2005; Goin & Myers, 2004; Lovaas, 1987; National Research Council, 2001), thus making routine autism screening at the earliest possible age a critical first step in the process of assessment and diagnosis (Filipek et al., 2000; Stone et al., 1999; Prater & Zylstra, 2002). Within the last eight years, several comprehensive sets of professional guidelines have been published, calling for routine screening and early diagnosis of autism spectrum disorders.

The first set of guidelines, formulated by the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society, recommended that pediatricians, who are in a position to screen their patients at early ages, implement these recommendations as standard practice parameters (Filipek et al., 1999). In May of 2001, the American Academy of Pediatrics' (AAP) Committee on Children with Disabilities published a set of recommendations based on the practice guidelines that had been developed by Filipek et al. in 1999 (Dumont-Mathieu & Fein, 2005; American Academy of Pediatrics, Committee on Children with Disabilities et al., 2001). A more recent set of guidelines on developmental screening, intended to replace the original one, was published as a clinical report by the AAP in November 2007 (Johnson & Myers, 2007).

The new guidelines build on the previous ones, and include updated and expanded information on the "definition, history, epidemiology, diagnostic criteria, early signs, neuropathologic aspects, and etiologic possibilities in autism spectrum disorders. In addition, this report provides an algorithm to help the pediatrician develop a strategy for early identification of children with autism spectrum disorders" (Johnson & Myers, 2007, p. 1183). Specific steps towards identifying a child with an ASD include conducting general developmental surveillance, interacting with a child during the exam, and administering an autism-specific screening instrument at the 18- and 24-month well child visits or whenever concerns of autism are raised.

Developmental surveillance includes asking parents questions about their child's development, monitoring developmental milestones, and being alert for the "red flags" of autism: a 1-year-old child who does not gesture (e.g., pointing, waving "bye-bye") or babble; a 16-month-old child who does not communicate using single words; a 2-year-old child who does not use spontaneous phrase speech; and, a child of any age who shows regression in communication or social skills. The publication of these practice guidelines indicates that pediatricians' own governing body recognizes the need for its members to take more of a leadership role in the identification of children with ASD and is urging primary care practitioners to implement the guidelines into their clinical practice.

Eight years after the publication of the first set of guidelines, there is evidence that the majority of primary care pediatricians do in fact screen their patients for a broad range of developmental problems. However, there exists a problem with the type of screening that is carried out in terms of specificity for autism spectrum disorders. In one recent national study of pediatric screening practices (Sand et al., 2005), a majority of pediatricians (71%) admitted relying on clinical judgment only to identify possible developmental problems, a practice that results in a detection rate of fewer than 30%. Of the 23% who did use a formal screening instrument, 14% used the Denver II, a general developmental screening measure that is time-consuming and whose accuracy in detecting autism spectrum disorders is questionable (Glascoe et al., 1992; Prater & Zylestra, 2002; Sices, Feudtner, McLaughlin, Drotar, & Williams, 2003). The latest studies indicate that 70% to 80% of children with developmental disorders remain unidentified by the time they enter school (Rydz, 2005; Sand et al., 2005).

It seems clear that further education for primary care pediatricians regarding the availability and use of validated screening tools and ways to incorporate routine screening into their current practice is needed. A number of organizations have undertaken this effort. Project First S.T.E.P., developed by the Autism Research and Training Center (ARTC) in California (Koegel, 2005); *Learn the Signs/Act Early,* an educational campaign sponsored by the Centers for Disease Control and Prevention (CDC); and First Signs, Inc., a national nonprofit organization, offer training in autism screening and referral practices to a range of healthcare practitioners, educators, and intervention specialists. In addition, they maintain comprehensive websites that disseminate information to help raise autism awareness of parents, professionals, and the general public (Dumont-Mathieu & Fein, 2005; www.firstsigns.org). In addition, a training program aimed specifically at primary care pediatricians is currently being piloted by the clinical research team at the Center for Promotion of Child Development through Primary Care in Maryland. This program, known as the Child Health and Development Interactive System (CHADIS), is described as a “unique, web-based diagnostic, management, and tracking tool” which analyzes responses from parent questionnaires and guides the pediatrician in making diagnostic and referral decisions during routine well-child visits (www.childhealthcare.org).

There is evidence that these types of training efforts are effective. Project First S.T.E.P. reported a 23% increase between 2003 and 2004 in the number of autism referrals received from pediatricians and an overall 10% decrease in age of children referred for developmental problems in their first year of outreach training (Koegel, 2005). First Signs, Inc., has conducted training on how to improve screening and referral practices for over 7,000 pediatric healthcare providers and child educators throughout the United States and in Guatemala since 2003. Statewide training campaigns have taken place in Alabama, Delaware, Minnesota, New Jersey, Ohio, Pennsylvania, Texas, and Wisconsin (Wiseman, 2008). Preliminary data, analyzed by researchers at the University of Pennsylvania, showed a significant increase between 2002-2003 in the number of children with autism being identified at earlier ages, particularly in the 0-2 age group (First Signs, Inc., 2004). The CHADIS program is currently being used in 15 pediatric practices in the states of Maryland and Mississippi, and is in the process of being launched in an additional 15 practices.

One possibility for the improvements reported by organizations providing training is that pediatricians are doing a better job at screening for autism and making appropriate referrals as a result of their training. Another explanation is that there may be greater parental awareness because of the increased education, outreach, and media coverage of autism. A third, more likely, alternative is a combination of these factors. The main recommendation that came from the First Signs, Inc., Minnesota analysis was that a two-year efficacy study should be conducted to help determine how and to what extent autism screening and referral training has changed the participants' actual practices (First Signs, Inc., 2004).

Statement of the Problem

The current literature clearly points to the need for primary care pediatricians to follow the recommended practice guidelines that call for ongoing developmental surveillance of all their patients, which includes the use of validated screening tools designed to detect autism spectrum disorders at specified times during a child's early years of development. The current practice guidelines outline very specific procedures for both general developmental and autism-specific screening. It seems unreasonable to expect pediatricians to suddenly change the way they practice without providing them with the kind of training necessary to work within the practice parameters set forth by the new guidelines.

Efforts such as the CHADIS program and educational campaigns headed by Learn the Signs/Act Early, Project First S.T.E.P., and First Signs, Inc., are currently underway to provide pediatric providers with professional training to assist them in incorporating routine autism screening into everyday practice. Determining the type of education needed, the best methods of instruction, attitudes of physicians towards training, and the efficacy of such training will be an important part of the overall evaluation of pediatric developmental screening practices.

There is widespread agreement in the medical and mental health fields that early diagnosis and early, intensive intervention is critically important in helping children with autism spectrum disorders reach their full potential. Teaching primary care pediatricians how to implement routine autism screening using validated screening instruments as part of their ongoing developmental surveillance practice is an important first step in the process of early identification and diagnosis of autism.

Relevant Research on Autism Spectrum Disorders

Definition of Autism

Autism is called a spectrum disorder because the defining characteristics fall along a continuum of behavior. The *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition, text revision (DSM-IV-TR) outlines deficits across three domains of functioning that are found in individuals with autism: (1) social interaction, (2) communication, and (3) interests that are restricted in range and/or behaviors that are repetitive or stereotyped. In order to meet diagnostic criteria for Autistic Disorder, impairment in all three areas must be present. Deficits in social interactions, pragmatic language skills, or imaginary play must be present within the first three years of life, and the impairments cannot be better explained by other types of developmental disorders (APA, 2000; Ozonoff, Goodlin-Jones, & Solomon, 2005). The following description of the characteristics of autism is based on DSM criteria for Autistic Disorder as it is the most commonly diagnosed type of autism. A discussion of differential diagnosis between Autistic Disorder and other autism spectrum disorders will follow the discussion of Autistic Disorder.

There is no single entity called “autism” and no single defining behavioral deficit that all individuals with autism share (Lord & Risi, 1998; Sigman et al., 2006). Rather, each individual will present with a unique blend of the behavioral characteristics outlined in the DSM-IV-TR criteria. In addition, there are variations in how and when the pattern of deficits may emerge (deBildt et al., 2004), and it is important to recognize that although children with autism are often described as “lacking” a certain ability, it is more often the case that there is a deficit or impairment in that ability and not a complete “lack of” it. For example, a child may demonstrate emerging pretend play skills, but these skills may be impoverished compared to typically developing children of the same age. A child may make some eye contact, but it may not be of the amount or quality expected from a child of that age, or it may not be used in coordination with gestures and vocalizations during communication or social interactions (Filipek et al., 1999; Sigman et al., 2006).

Developmental Characteristics of Autism

By definition, children with autism manifest deviation from typical childhood development within the first three years of life (APA, 1994; Sigman et al, 2006). Some parents report developmental and behavioral differences in their children from birth (Coonrod & Stone, 2004; Goin & Meyers, 2004). Other children are described as following a fairly typical developmental trajectory during the first year of life, with concerns arising in the second year as language fails to develop or the child loses language skills previously attained. Infants who later receive a diagnosis of autism are often retrospectively described by their parents as having had unusual responses to typical social and nurturing overtures. In the first year of life some infants sometimes seem to resist touch. They may arch their bodies away from a parent or caregiver when held or not anticipate being picked up. Other early markers may include lack of social smiling and eye contact, hypotonia (low muscle tone), and not responding when their names are called. These differences generally intensify during the second year when, in addition, language delays are noted (Goin & Meyers, 2004; Prater & Zylstra, 2002).

Deficits in communication extend beyond a delay in spoken language in children on the autism spectrum. Receptive language is usually delayed as well, with children sometimes appearing to be deaf, as they often do not respond to others’ attempts to communicate with them. Lack of gesturing, particularly protodeclarative pointing (i.e., pointing to something of interest to “comment” on it or bring it to the attention of another), to replace spoken language is also noted. When the child is verbal, the utterances often have a perseverative quality, with certain sounds, words, or phrases repeated over and over in what is considered to be a self-stimulatory behavior (Ozonoff et al., 2005). Some children with autism repeat “scripts” from commercials, television programs, videos/DVD’s, or conversations they have overheard, a behavior called “delayed echolalia.” Immediate echolalia is heard when the child immediately repeats a word or phrase in response to something said by another person. For example, if a parent asks the child, “Do you want juice?” the child may respond, “You want juice?” instead of answering the question (APA, 2000).

With verbal children, communication is usually limited to expressing wants and needs, and does not often occur for the purpose of social interaction. Children with autism tend to use language in a very concrete and sometimes idiosyncratic way, and they struggle with the more social aspects of communication, including nonverbal cues. They may have difficulty understanding commonly used idioms, such as “It’s time to hit the road,” and may incorrectly interpret the phrase as meaning they should physically strike the road. It is also not uncommon for a child with autism to describe objects in unusual ways. Instead of using the term “windshield wipers,” a child with autism may say, “the sticks that swish the water off.” Lack of reciprocal conversation skills or the ability to engage in “chit chat” is also common (APA, 2000; Kabot et al., 2003).

Children with autism are often described as lacking empathy or the ability to take another’s perspective, both of which are considered to be key features of a developmental milestone called “theory of mind” (Baron-Cohen, 1993; Sigman et al., 2006; Sobel, Capps & Gopnik, 2005), in which typically developing children learn that others may have thoughts, beliefs, motivations, and feelings contrary to their own. Theory-of-mind deficits in children with autism lead to a lack of understanding of humor, deceit, and conditions that are contrary to fact, which helps to explain their tendency to be very literal in their use and understanding of language. It also helps to explain the difficulty interpreting complex social situations and the limited imaginary or symbolic play behavior (Garfield, Peterson, & Perry, 2001; Silliman et al., 2003; Sobel, Capps, & Gopnik, 2005). Often described as being “in their own world,” children with autism seem to “look through” others instead of making appropriate eye contact. Related social difficulties include a preference for or tendency to play in isolation, ignoring or being unaware of social advances made by peers, and difficulty recognizing subtle, nonverbal social cues (Prater & Zylestra, 2002; Sigman et al., 2006).

In addition to a seeming lack of interest in others, there is generally marked impairment in the range of facial expression and the directing of these expressions toward another person. Inability to engage in joint attention (i.e., a three-point communication in which a child shifts his or her gaze between an item of interest and another person) is also common (APA, 2000; Johnson & Myers, 2007). Showing items of interest to another person or bringing them to that person are also behaviors that typically developing children engage in but children with autism often do not.

Children with autism tend to engage in solitary activities. Their play skills are generally restricted to manipulation of mechanical toys, with a noticeable lack of pretend, symbolic, or socially imitative play. Some children on the spectrum exhibit unusual interests in the parts of objects (e.g., spinning the wheels on a small car) or in playing with toys in atypical ways: rubbing a toy on a body part or arranging toys, blocks, or other objects in lines or intricate patterns. Other children develop obsessive interests in unusual objects such as fans, radios, windshield wipers, maps, or clocks (APA, 2000). Nonpurposeful play also occurs, with children repetitively dropping, dumping, or throwing toys or other objects.

Along with impairments in communication, social interaction, and pretend play, children with autism often demonstrate atypical responses to sensory stimuli. Some children with autism find hair-cuts and shampoos painful. Others scream and cover their ears at common loud noises, such as vacuum cleaners, lawnmowers, and hair dryers. Tactile defensiveness may lead some children to refuse to wear shoes, to resist playing in sand or with play dough, to avoid certain food textures, and to pull away from hugs or other forms of touching. Disturbances in the vestibular and proprioceptive systems may cause children with autism to rock, spin in circles, jump repetitively, flap their hands, toe-walk, or engage in other peculiar and self-stimulatory body movements (APA, 2000). The world that most of us find quite comfortable in terms of sensation and perception is filled with discomfort and even pain for people with the sensory dysregulation that often accompanies autism.

Cognitive deficits, although not part of the diagnostic criteria, are common in children with autism, with an estimated 50% to 70% scoring lower than 70 on standardized intelligence tests (Sigman, Spence, & Wang, 2006). However, since most standardized intelligence tests do not include norms for autistic populations, the results of these tests must be interpreted cautiously (D'Angiulli & Siegal, 2003; Dawson, 1998; Guidubaldi, Perry, & Walker, 1989; Jenkinson, 1997). Of particular concern is the question of whether commonly used intelligence measures are even capturing the same underlying cognitive processes when used on children with various types of cognitive or language deficits (Dethrone, 2003; Swisher & Plante, 1993; Swisher, Plante, & Lowell, 1994).

In this same vein, several recent studies show support for the idea of uneven cognitive development in children with autism. Charman et al. (2005) found that standardized cognitive testing administered to children with autism at age 2 was not predictive of cognitive functioning when they reached age 7 and that children's diagnostic categories changed over time as well. Sigman & Ruskin (1999) found that despite evident stability of diagnosis over time, a number of children with autism achieved “remarkable intellectual growth” and no longer fell into the mentally retarded range. Finally, intelligence test scores often change when the children are tested with nonverbal measures or when only the nonverbal subtests are used as the determinant of cognitive functioning (Atlas,1997; DeMauro, 1997; DeThorne, L. S., 2003; Marco, 1998; Mayes & Calhoun, 2003; Stinnett, 1998).

Interpretation of Behaviors

Although behavioral characteristics are outlined in discrete categories in the DSM-IV-TR, there is much overlap between groups of symptoms (APA, 2000), and particular behaviors may be interpreted in different ways. For instance, poor eye contact may be considered a deficit related to communication or to social interaction. As well, communication difficulties have consequences in the social and behavioral realms. The function or cause of a particular behavior may not always be clear and may change over time, across settings, or through the course of development (Cooper, Heron, & Heward, 2007). Is the child banging his head as a sensory activity, because he is frustrated that he can not communicate, or because he has learned that this behavior will allow him to escape a task or demand? Does the child avoid hugs because she does not understand the social implication of hugging as a way to demonstrate affection, or is it because she is tactilely defensive and such contact is physically uncomfortable?

There is sometimes a tendency to assume that because children with autism have difficulty with expressing emotion or engaging in social interaction, they must not have a desire to share their emotions or to be social. There is a tendency to equate *having difficulty identifying and expressing emotions* with *being incapable of feeling* different emotions. Likewise, there is a difference between *wanting to play alone*, for instance, and *not knowing how to socially interact* with others. An example of how we might misinterpret a behavior or assume that a feeling doesn't exist because it can't be expressed is offered in the following story about Gabe:

When Gabe was four years old, he was essentially nonverbal. Not only did he not have friends, he did not show interest in other people, including his siblings or us, his parents. Because he could not effectively communicate, we had to guess at what we thought he wanted. One day, using a permanent black marker, he drew a crude circle with eyes, nose and a lop-sided smiling mouth on the back of a cloth office chair. It would be another year before he would painstakingly learn to first receptively, then expressively, identify simple emotions from pictures of people showing various facial expressions. It would be several years before he would be able to form an appropriate response to the question, "How do you *feel?" A couple of years ago, at age 11, Gabe pointed to the faded but still visible face on the chair and asked, "Mom, do you remember when I drew that smiley face on the chair?" I replied, "Yes, I do. That was a long time ago." He responded, "Do you know why I did it?" "No," I replied, "Why?" He answered, "Because I was lonely and wanted a friend."*

There was no observable evidence at age four that Gabe felt loneliness or that he wanted friendship. He certainly lacked the language to express it, and his behavior, which was consistent with the diagnosis of autism, as defined in the DSM-IV-TR, led us to other assumptions: He didn't *want* to play with others and he didn't *feel* things the same way we did. Seven years later, when he was able to articulate this earlier feeling of loneliness and his desire to have a friend, I realized that we had made assumptions about his inner experiences based on our own understanding of how people show or express their feelings and desires. Of course, memory is unreliable, and it is certainly possible that his commentary reflected his *current interpretation* of that time and not necessarily a true description of his emotional state at age four. Still, it is a reminder that we cannot always assume that the underlying motivation of a behavior in a child with autism is the same as our own.

Differential Diagnosis of Autism Spectrum Disorders

Although the behavioral and developmental deficits of autism are quite clearly described in the literature, there is no definitive medical test for autism. No single underlying etiology has been found — rather, the observed developmental delays and unusual behaviors are thought to be the result of dysfunction in many organic processes (Kabot et al., 2003; Sigman et al., 2006). Because we lack knowledge of distinct biological markers that would help to explain the pathophysiology of autism, we must rely on reports of atypical development and observation of unusual behavioral presentations to make a diagnosis (Baird et al., 2003; Lord & Risi, 1998; American Academy of Pediatrics, Committee on Children with Disabilities et al., 2001).

A number of concerns arise when a diagnosis of autism is considered. Although parents are often excellent sources of information about their children's development (Coonrod & Stone, 2004), many times their concerns are dismissed or downplayed by medical professionals (Filipek et al., 2000; Zeiger, 2005). When parents *are* listened to, even the most vigilant of them are sometimes mistaken in their recollections of a child's early development. In addition, the small sample of behavior observed during a single medical exam may not be sufficient to raise concerns about autism (Robins, Fein, Barton, & Green, 2001). Does the child lack joint attention skills or is she just distracted by the unfamiliar environment? Is the child demonstrating deficits in social interaction or is he just shy? Further complicating the diagnostic picture is the fact that not all children with autism share the same autistic features, either in degree or number (deBildt et al., 2004; Bryson et al., 2003; Sigman et al., 2006).

A large number of children with autistic-like features either do not meet DSM-IV-TR criteria in one or more areas or manifest the characteristics at a sub-threshold level, leading to the ubiquitous and relatively nonspecific diagnosis of Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). In addition to Autistic Disorder, there are other disorders that fall within the autism spectrum that are similar to, but considered distinct from, Autistic Disorder. These include Rett Syndrome, Childhood Disintegrative Disorder, and Asperger's Disorder (APA, 2000).

Rett Syndrome is a relatively rare condition found almost exclusively in females and is typically associated with head growth deceleration, severe or profound mental retardation, psychomotor difficulty, social deficits, and severe language impairment. Childhood Disintegrative Disorder, marked by "regression in multiple areas of functioning following a period of at least 2 years of apparently normal development," is found to occur at a much lower rate than Autistic Disorder. Asperger's Disorder is similar to Autistic Disorder, with the main distinctions being 1) no significant delay in onset of language (although communication may still be impaired), 2) no significant delays in adaptive functioning, 3) average or above average cognitive profiles, and 4) a more "eccentric and one-sided approach to" social interactions, in contrast to the seeming indifference to social situations manifested by those with Autistic Disorder (APA, 2000).

Differential diagnosis between these disorders sometimes proves difficult as many of the behavioral symptoms overlap and because even children diagnosed with a specific type of pervasive developmental disorder (PDD) will often present with markedly dissimilar behavioral profiles, including differences in the number, type, and level of impairment in associated diagnostic characteristics (Freeman, Cronin, & Candela, 2002). For the purposes of this study, the term "autism" or "autism spectrum" will be used to refer to the broad category of disorders falling under the heading of pervasive developmental disorders, while the term "Autistic Disorder" will be reserved for those children who meet the DSM-IV-TR criteria for this particular diagnosis within the PDD category.

Etiology and Incidence of Autism

Although autism has probably always existed, it was first clinically defined by Leo Kanner in 1943. At that time, Kanner used 11 case histories of children to describe a constellation of characteristics, including deficits in social interactions, communication, and thinking (Leekam, Libby, Wing, Gould, & Taylor, 2002). He called this syndrome “autism.” Kanner suspected that autism developed from a specific organic defect. This theory was trumped, however, by the classification of autism as a subtype of schizophrenia in the DSM-I and DSM-II (Filipek et al., 1999) and the prevailing psychoanalytic view of the time that autism resulted from pathogenic parenting (Prater & Zylstra, 2002).

Just a few decades ago, it was still commonly believed that autism was caused by “refrigerator mothers”, a term coined by German philosopher, Bruno Bettleheim, to explain his belief that children developed autism as a protective response against the supposed hatred and rejection felt towards them by their mothers. His now discounted views about the cause of autism and his recommendation for mothers and children to undergo psychoanalysis to correct the painful effects of this “rejection” did great harm to untold numbers of children with autism and their parents (Baker, 2008; Olney, 2000). Although we understand today that autism is a neurologically based disorder and not psychogenically induced, there is much about it that continues to baffle us. We are just beginning to understand the ways in which the brains of young children with autism are still plastic and how early and intensive behavioral intervention can bring about sometimes amazing and lasting improvements in all domains of social, communication, and adaptive functioning (Bryson et al., 2003; Glascoe, 2005); Goin & Meyers, 2004; Lovaas, 1987).

Despite the evident difficulties associated with making a differential diagnosis of autism, it is clear that the number of children in the United States being diagnosed somewhere on the autism spectrum is rising. What it is not as clear is whether the increase in numbers represents a true increase in prevalence, more refined screening and diagnostic instruments, relaxed diagnostic criteria, or a combination of these factors (Baird et al., 2003; Eagle, 2004; Gernsbacher et al., 2005; Newschaffer, Falb, & Gurney, 2005; American Academy of Pediatrics, Committee on Children with Disabilities, 2001). Once believed to be a rare condition, autism is now considered a common childhood disorder (Filipek et al., 1999). Autism occurs more often in males, diagnosed at an approximate 4 to 1 ratio. The exact number of children being diagnosed with autism is not known. Currently, estimates place the incidence of autism spectrum disorders at 1 in 150 (Centers for Disease Control, 2007). These figures translate into well over 100,000 children under the age of 15 in the United States alone who have an autistic spectrum disorder (Filipek et al., 1999).

Benefits of Early Intervention

Autism is understood as a spectrum disorder. As such, the symptom profile of one diagnosed child may vary significantly from the profile of another child. Just as there is disagreement over the true incidence of autism, there are debates among professionals and parents about possible outcomes. There exist documented cases of children who seem to have overcome many of the challenges associated with autism. Sometimes these children are referred to as “indistinguishable” from their peers. Other times, they are called “recovered.” Few people use the word “cure.” The research on long-term outcomes to date suggests that the disabilities related to autism are often severe and life-long (Lord & Risi, 1998; Sigman et al., 2006), although this trend may change as the generation of children currently receiving intensive early intervention services approaches adulthood.

Advances in our understanding of how early intervention can bring about significant improvements in overall functioning has led to a push for early diagnosis

(Bryson et al., 2003; Rydz, 2005; Stone et al., 1999). Evidence abounds demonstrating that intensive treatment over a period of years during the preschool years is most effective in increasing language, improving social and play skills, and eliminating or reducing stereotyped or ritualistic behaviors in children with autism.

A number of studies, including the seminal experiment conducted by Lovaas (1987), demonstrate the significant improvements made by children who receive early, intensive treatment. In the Lovaas study, 47% of the children (n = 19) who received 2 years of intensive (average of 40 hours per week) behavior analytic treatment increased their IQ scores to an average or above-average range and successfully completed first grade in a typical classroom. In the control group (n = 40), where treatment consisted of 10 hours or less per week, only 1 child achieved this level of functioning. Other studies offer further evidence that children benefit from early intensive behavioral treatment by significantly improving communication, social and play skills, cognitive functioning, academic success, and adaptive functioning (Bryson et al., 2003; Eikeseth, Smith, Jahr, & Eldvik, 2006; Eldevik, Eikeseth, Jahr, & Smith, 2006; Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; McEachin, Smith, & Lovaas, 1993; Smith, Eikeseth, Klevstrand, & Lovaas, 1997).

Although treatment at any age is likely to produce gains, the most significant achievements are made with younger children (Bailey, Skinner, & Warren, 2005; Charman & Baird, 2002; Coonrod et al., 2004; Lord & McGee, 2001; Sigman et al., 2004). A number of studies show a negative relationship between age and successful outcome of treatment, indicating that intervention produces fewer gains as children age (Goin & Meyers, 2004; Robins et al., 2001). For this reason, it is imperative that affected children receive a diagnosis as early as possible.

Professional opinions regarding the best type of intervention for autism vary, despite overwhelming support for behaviorally-based interventions (Eldevik et al., 2006;

Erikson, Swiezy, Stigler, McDougle, & Posey; Harchik, 2006; Howard et al, 2005; Lovaas, 1987; McClannahan, MacDuff & Krantz, 2002). Several attempts have been made to evaluate treatment outcomes and to disseminate the results in a comprehensive publication. The New York State Department of Health, Early Intervention Division, produced such a document in 1999. In this publication, clinical practice guidelines for treating young children with autism were outlined (New York State Department of Health, Early Intervention Division, 1999). Shortly after, a publication of the best identified autism interventions was made available by the National Research Council's Committee on Educational Interventions for Children with Autism (National Research Council, 2001).

Both of these reports were weighted heavily in favor of behavioral treatments. Currently, the National Standards Report, compiled by a team of field reviewers led by Dr. Susan Wilczynski, Executive Director of the National Autism Center (NAC) and Vice-President of Autism Services, provides a comprehensive review of outcome studies on educational and behavioral interventions covering a 50-year time span from 1957 to 2007 (National Autism Center). Despite lingering theoretical differences, however, most experts do agree that whatever the intervention chosen, outcomes are improved by starting therapy early (Bryson et al., 2003; Rydz, 2005; Stone et al.,1999).

Although children with autism are beginning to be identified and diagnosed at younger ages (First Signs, Inc., 2004; Koegel, 2005), there remains an unacceptable lag—often years--between the time parents first become concerned and the time the child finally receives a diagnosis. Most parents begin to express concern about their child's development before their child reaches the age of two; however, physicians are often reluctant to make a diagnosis of autism that early, sometimes resulting in a delay of diagnosis for several years

(Baird et al., 2003; Coonrod et al., 2004; Goin & Meyers, 2004; Robins et al., 2001; Zeiger, 2005). Many children are not diagnosed until they are well beyond preschool age, thus losing out on important years of early intervention (Bryson et al., 2003).

The interim period between the onset of parental concerns and eventual diagnosis is often fraught with frustration and distress as parents visit one professional after another, seeking confirmation of their concerns and worrying about lost time (Bryson et al., 2003; Robins et al., 2001; Zeiger, 2005). The high incidence of autism means that most practicing primary care pediatricians will have several, if not many, children with an ASD in their caseload. Identifying autism early leads to early diagnosis and early intervention. It is imperative that we take a more systematic approach to screening all children for autism. The AAP has recognized this need, but its members appear slow to embrace the recommendations.

Researchers have repeatedly demonstrated that early and intensive intervention leads to significant improvements in all areas of impairment. The importance of early detection is clear: Children with autism need to be diagnosed early and accurately in order to be referred to the intensive intervention services needed to maximize their developmental outcomes.

CHAPTER TWO

ROUTINE AUTISM SCREENING

In the last decade, a growing consensus of parents and professionals has called for routine autism screening of every child at various intervals from birth through school age. Adding this specific screening to the ongoing developmental surveillance already being done would increase the likelihood of detecting autism earlier, thus enabling parents to seek appropriate intervention services when their children are most likely to receive full benefit from them (Bryson et al., 2003; Chakrabarti, Haubus, Dugmore, Orgill, & Devine, 2005; Dumont-Mathieu & Fein, 2005; Lord, et al., 1998). Current research suggests that screening tools specifically developed for detecting autism be routinely administered at the developmental checkpoints of 18 and 24 months and that more general developmental screening should continue to take place with patients younger than 18 months (Dumont-Mathieu & Fein, 2005).

Questions have been raised about whether pediatricians are the best group to conduct autism screening. Other models, including school-based and community-based programs have been implemented with varying levels of success (McKay, Shannon, Vater, & Dworkin, 2006; Noland & Gabriels, 2004). Certainly, educators, early intervention specialists, and mental health providers, including psychologists, need to become familiar with the early signs of autism and know how to make appropriate referrals. However, many children to not have contact with these specialists before they reach school age. To ensure that all children are screened at the recommended intervals, it makes sense that routine autism screening be carried out by pediatricians, who often follow their patients from birth and who already conduct more general developmental screening with their young patients at regular intervals.

Relevant Research on Autism Screening

Professional Guidelines for Routine Autism Screening

Professional guidelines calling for routine screening and early diagnosis were published by the American Academy of Neurology and the Child Neurology Society in 1999 (Filipek et al., 1999). The American Academy of Pediatrics followed with their own guidelines in 2001 (American Academy of Pediatrics, Committee on Children with Disabilities, 2001). A second set of practice guidelines was published by the AAP in October of 2007 (Johnson & Myers, 2007). In the original guidelines, a multidisciplinary panel proposed two levels of developmental evaluation. Level 1 called for "Routine Developmental Surveillance and Screening Specifically for Autism" (Filipek et al., 2000). This level of screening was aimed at pediatricians and other primary health care physicians. It recommended specific evaluation of age-appropriate developmental skills at every well-child checkup from infancy through school-age. In addition, developmental concerns raised by parents called for an immediate investigation into these concerns. The panel urged pediatricians to listen carefully to parents, as parents have been found to be generally reliable informants about their children's development (Filipek et al., 2000; Glascoe, 1999; American Academy of Pediatrics, Committee on Children with Disabilities, 2001). If a pediatrician identified developmental deficits in the core areas of language, social interaction, and unusual behavior, the child should be immediately referred for further evaluation.

The most recent AAP practice guidelines, released in November, 2007, added the specific recommendation to screen for autism using a standardized screening tool at the 18- and 24- month well visit, regardless of risk, and even if there are no developmental concerns voiced by parents; a very detailed surveillance and screening algorithm for autism spectrum disorders (ASDs); and an updated summary of appropriate standardized screening instruments and their psychometric properties available for Level 1 and Level 2 screening (Johnson & Myers, 2007).

Evaluation at Level 2 calls for differential diagnosis of autism from other developmental disorders. As this level, evaluation is more in-depth and calls for additional expertise, it is usually carried out by a developmental specialist rather than a primary care physician (Filipek et al., 2000). For the purpose of this study, then, the discussion of routine screening for autism by pediatricians will refer to Level 1 recommendations.

For the past 8 years, professional protocol regarding the pediatrician's role in routine screening, diagnosis, and management of children with autism spectrum disorders has been available (Filipek et al., 1999; Johnson & Myers, 2007; American Academy of Pediatrics, Committee on Children with Disabilities, 2001). A current review of the literature (Dosreis, Weiner, Johnson, & Newschaffer, 2006; Sand et al., 2005; Sices et al., 2003) and a recent internet survey of parents' experiences with their children's autism diagnosis process (Zeiger, 2005) raises the question of whether and to what extent the recommended screening procedures are being implemented by pediatricians in the United States. A related concern is to identify the barriers that currently prevent pediatricians from incorporating routine autism screening into their practice and to identify the type of training that would bring them more in line with current practice parameters.

Current Pediatric Screening Practices

A study of over 1200 children with autism, conducted in the United Kingdom (Howlin & Moore, 1997), found that almost all the parents had concerns about their child's development by the time the child was 18 months old and sought medical evaluation by the time the child was two years old, but that the average age at diagnosis was 6 years. In the Howlin & Moore study, 90% of the children were eventually referred to other medical professionals. However, almost 20% of these parents reported that they had to press for the referral and 25% of those who did get a referral were still told that concern was unwarranted. Of the remaining 10% who did not get referrals, more than 50% were advised to return at a later date if they continued to have concerns, and the remaining parents were reassured that over time, their child would outgrow current concerns. The conclusion reached by the authors of this study was that physicians should take parents' concerns about their child seriously and make appropriate referrals immediately when questions about the child's development arose.

In a 2005 internet survey of parents of children with autism in the United States (Zeiger, 2005), 91 of the 106 respondents stated that someone other than the child's pediatrician was the first to raise concerns about the child's development, the majority being the child's parents or a close relative. 92% of these parents expressed their concerns with the pediatrician before the child's third birthday. Eighty-six percent of the parents were told either that nothing appeared to be wrong with the child or were advised to wait a period of time before seeking further evaluation. Furthermore, there was no significant difference in the pediatricians' responses to parents of children who were diagnosed *before* the recommendation for routine screening was made in 2000 and those children who were diagnosed *after* this time. Findings such as these suggest that pediatricians are not yet changing their practices in terms of screening for autism, despite the fact that their own governing body has called for them to do so. Current research identifies a number of potential barriers that may impede progress in this area.

Barriers to Routine Autism Screening

In a 2005 national survey of pediatricians, Sand et al. identified nine barriers to conducting standardized developmental screening. The most widely endorsed reasons for pediatricians not using standardized screening measures included time limitations, lack of auxiliary medical staff, inadequate reimbursement, and language barriers. A later study looking more specifically at autism screening practices among pediatricians found that only 8% of primary care pediatricians routinely screen for autism using a standardized screening instrument (Dosreis et al., 2006). Furthermore, 62% of the respondents claimed to be unfamiliar with autism screening tools. Early identification is dependent upon routine developmental screening using standardized screening instruments. Professional training that offers practical solutions the identified barriers to routine screening seems the most direct route to systematically removing these barriers that currently impede the diagnosis process for many children.

Routine screening for autism would change the way pediatric medicine is currently practiced. Typically, pediatricians receive little if any formal training in screening, assessment, and diagnosis of autistic spectrum disorders (Goin & Meyers, 2004; Skellern, McDowell, & Schluter, 2005). Most physicians are not familiar with the array of valid screening instruments available (see Recommended Standardized Screening Instruments for Autism below), nor are they aware that Level 1 autism screening can be conducted in only minutes during a routine office visit (Beauchesne & Kelley, 2004; Dumont-Mathieu & Fein, 2005). Furthermore, many practitioners are not aware that they can receive reimbursement for developmental screening. Current Procedural Terminology (CPT) code 96110 is available for brief screening reimbursement, and CPT code 96111 can be used to bill for extended developmental screening that includes a direct testing component (Johnson & Myers, 2007).

Lack of time has also been identified as a leading barrier to conducting routine standardized screening. In the Sand et al. (2005) study, 83% of pediatricians identified time as a major barrier to standardized general developmental screening. Dosreis et al. (2006) found that lack of time was cited as a barrier to general developmental screening for 73% of the respondents and a barrier to specific autism screening for 32% of the respondents.

Pressure from health management organizations and insurance companies create an environment in which primary care pediatricians are called upon to accomplish many healthcare tasks, including the physical exam, listening to parent concerns, asking questions about development, answering parent questions, and providing counseling or referrals in an office visit that lasts on average 17-18 minutes (Olsen et al., 2004). It is not surprising that pediatric providers are reluctant to add one more task to an already rushed visit. Still, pediatricians see most of their patients a number of times before they reach school age. Because they have frequent contact with their patients from birth on, pediatricians are in the unique position of being able to observe the developmental trajectories of each child and to identify developmental concerns (Halfon et al., 2004). It is no longer acceptable for pediatricians to rely on clinical observation alone to identify children with developmental problems. We need to find a way to encourage this group of physicians to respond to the practice guidelines calling for routine autism screening. The many children at risk for autism cannot afford to wait.

Recommended Standardized Screening Instruments for Autism

Although the current screening and diagnostic tools for autism are not 100% accurate, a number of standardized instruments have proven to meet acceptable practice standards for sensitivity and specificity in detecting autistic spectrum disorders in young children (Constantino et al., 2003; Filipek et al., 2000; Glascoe, 2005; Goin & Meyers, 2004; Kabot et al., 2003; South et al. 2002; Stone et al., 2004). Sensitivity refers to the ability of a measure to accurately identify children who have the disorder they are being screened for. Specificity refers to the instrument's ability to correctly identify children who do not meet criteria for the disorder. A summary of the most widely-used validated instruments suitable for Level 1 screening will follow. This summary is not meant to be an exhaustive list of all available measures; rather, it is an overview of the instruments that are currently considered to be appropriate tools to be used for Level 1 autism screening in a pediatric primary care setting.

According the to the practice parameters recommended by the multi-disciplinary panel, any child who is not pointing and babbling by 12 months of age, uttering single words by 16 months of age, or speaking in two-word phrases by 24 months should undergo further developmental assessment using one of the following standardized autism screening instruments (Filipek et al., 2000; Johnson & Myers, 2007).

The Ages & Stages Questionnaires (ASQ) is a series of 19 parent-completed questionnaires that can be given at various ages, from four months to five years. Each questionnaire consists of 30 items that elicit information about the child's development across five major developmental domains (Bricker & Squires, 1999). Each form takes approximately 15 minutes to complete and contains illustrations to help guide parents in making their responses. Sensitivity is rated at 72% and specificity at 86% (First Signs, Inc., 2004).

The Childhood Asperger Syndrome Test (CAST) is a parent questionnaire consisting of 39 questions covering behaviors related to communication, social interactions, restricted range of interest, unusual body movements, and adaptive functioning. The CAST takes about 10 minutes to complete. Sensitivity is reported at 88-100%, and specificity is reported at 97-98% (Johnson & Myers, 2007; Center for Disease Control and Prevention, 2008).

The Checklist for Autism in Toddlers-23 (CHAT-23) is a screening tool that combines parent answers with practitioner observations. The first part is "a self-administered parent questionnaire addressing rough and tumble play, social interest, motor development, social play, pretend play, protoimperative pointing (pointing to ask for something), protodeclarative pointing (pointing the index finger to indicate interest in an object), functional play, and showing. The second section consists of five items recorded after observation by general practitioners or health visitors: eye contact, ability to follow a point (gaze monitoring), pretend (pretend play), produce a point (protodeclarative pointing), and make a tower of blocks" (www.medscape.com). It takes 10 minutes to complete and has a sensitivity rating of 84-93% for part A and 74% for Part B. Specificity rating is reported at 77-85% (Johnson & Myers, 2007).

The CHAT, Denver Modifications, is similar to the original CHAT but has only 9 parent questions instead of 23. This version takes only 5 minutes to administer. Reported sensitivity is 85%, while specificity is reported at near 100% (Johnson & Myers, 2007).

The Communication and Symbolic Behavior Scales Developmental Profile (CSBC DP Infant-Toddler Checklist) is a 24-item checklist that parents can complete in about five minutes. Designed for use with children between six and 24 months of age, this measure screens for pre-linguistic communication behavior, such as using gestures, making sounds, showing appropriate emotion, and exhibiting proper eye gaze (Wetherby & Prizant, 2002). This tool has a sensitivity rating of 84% and a specificity rating of 72% (First Signs, Inc., 2004).

The Modified-CHAT (M-CHAT) is used as an initial autism screening tool for children as young as 18 months of age. Designed to be used in the primary care setting, the M-CHAT consists of a "yes/no" format parent questionnaire of 23 items that are designed to probe for developmental deficits consistent with DSM-IV-TR criteria for autistic spectrum disorders, such as impairments in communication, joint attention, pretend play, and social interaction (Bryson et al., 2003; Dumont-Mathieu & Fein, 2005; Filipek et al., 1999). Six of the 23 items are labeled as "critical items," meaning that they relate to behaviors most likely to indicate an autistic spectrum disorder. Sensitivity and specificity are high, 90% and 99% respectively (Glascoe, 2005). Any child who fails two of the six critical items or any three items from the 23-item checklist should be considered at high risk for an autistic spectrum disorder (Dumont-Mathieu & Fein, 2005) and should be immediately referred for further, more extensive evaluation by a developmental specialist (Filipek et al., 1999). Chinese, Japanese, Spanish, and Turkish translations of the M-CHAT are currently being evaluated, taking into consideration how differences in both language and cultural practices may affect accuracy (Dumont-Mathieu & Fein, 2005). The M-CHAT takes less than 5 minutes to administer.

The Parents' Evaluation of Developmental Status (PEDS) is a broad screening instrument to be used for children ages zero to nine years. This 10-item questionnaire elicits parents' concerns about their child's development and provides practitioners with guidance in making referral, education, or further screening decisions. The PEDS takes less than five minutes and is available in English, Spanish, and Vietnamese. It rates a sensitivity of 74% to 79% and a specificity ranging from 70% to 80% (Glascoe, 2005).

The Pervasive Developmental Disorders Screening Test-II, Primary Screener (PDDST-II PCS) is a parent questionnaire consisting of 22 questions related to symptoms of a pervasive developmental disorder that parents might observe in their children. It takes approximately 10-15 minutes to complete, and it has a reported sensitivity of 92% and specificity of 91% (Johnson & Myers, 2007).

Using one of these screening instruments along with other sources of information about the child's development, and administering the screen at periodic follow-up appointments will increase the likelihood that children with autism are identified as early as possible (Robins et al., 2001). Nearly 25% of all children being seen by physicians have some sort of developmental issues, but some studies show that fewer than 30% of pediatric providers routinely administer standardized screening tests to their patients (Filipek et al., 1999; Sand et al., 2005), and less than 50% of children's developmental problems are detected before school age (Glascoe, 2000). The need for education of pediatricians in this area is clear. Identifying barriers to training as well as types of training that pediatricians would be most likely to participate in are also key steps in this process. Furthermore, evaluation of the training that is currently being conducted is needed in order to support the ongoing efforts to improve autism screening and diagnosis in young children.

Purpose of the Study

The purpose of this study is five-fold: 1) to describe the current autism screening practices of pediatricians in the United States; 2) to determine the extent of pediatricians' familiarity with published AAP practice guidelines regarding autism screening; 3) to identify remaining barriers preventing pediatricians from carrying out the developmental screening procedures recommended by the AAP; 4) to describe pediatricians' attitudes and beliefs about the need for autism screening training; and 5) to find out what types of training pediatricians are most likely to participate in.

Expectations

Recent studies and informal discussions with pediatricians and parents of children with autism suggest that more research needs to be done in this area. Currently, children are routinely screened for a host of other potential health problems, such as hearing or sight deficits, child abuse, and nutritional status (Sices et al., 2003). If a problem were suspected in any of these areas, it is hard to imagine a pediatrician dismissing the parents' concerns or recommending that they wait before pursuing further evaluation. Yet, this is exactly what often happens when developmental concerns related to autism are raised.

A current review of the relevant literature and widespread anecdotal evidence suggest that pediatricians are not yet heeding the call to make screening for autism part of their routine practice, despite several publications of professional practice guidelines over the past 8 years. These findings led to the five expectations driving the current project. First, it was expected that only a minority of pediatricians are following the AAP practice guidelines by routinely screening for autism at the 18- and 24-month visits, using standardized screening instruments. Second, it was expected that the majority of pediatricians continue to rely on clinical observations instead of conducting routine screening using standardized screening tools. Third, it was expected that pediatricians remain unfamiliar with the types of valid standardized autism screening tools that are currently available. Fourth, it was expected that most pediatricians are not aware of the CPT codes for developmental screening that can be used to obtain reimbursement for screening time. Fifth, it was expected that the majority of primary care pediatricians will report that the training they received in medical school and residency was inadequate to prepare them to follow the AAP practice guidelines regarding routine screening, referral, and follow-up care for children with autism spectrum disorders.

The latest published data describing how pediatricians are responding to the call to lead the medical profession in early surveillance and screening for autism were collected in 2004 (Dosreis et al., 2006) and provide a current picture of the autism screening practices of pediatricians. However, these data were obtained from pediatricians in the states of Maryland and Delaware only. Previous national surveys of pediatricians described general developmental screening practices and did not focus specifically on autism screening (Sand et al. 2005; Sices et al. 2003).

This study was designed to build on the work done in previous studies by surveying a national sample of primary care pediatricians about their current autism screening practices. It is believed that the results of this study will increase our understanding of the current autism screening practices among pediatricians in the United States, help us to understand the barriers preventing routine autism screening from taking place, and identify training needs to bring pediatric practitioners in line with the current practice guidelines. This information can be added to the growing number of other strategies aimed at improving our ability to identify and diagnose children with autism.

CHAPTER THREE

PROCEDURES

Method

Study Sample

Four thousand pediatricians who were members of the American Academy of Pediatrics (AAP) United States chapters at the time of sampling were randomly selected to participate in this study. Canadian, Puerto Rican, and military base chapters were excluded for the purposes of this project. The number of pediatricians selected from each chapter was calculated by dividing the number of current members in each chapter by the number of total current members in the AAP (59,338) and multiplying that number by the total desired sample size (4,000).

Random number lists calculated by the sequence generator on the website random.org were used to select the specified random number of participants from each chapter. Participants' email addresses were then selected according to their correspondence to a number on the random number list. If a randomly selected pediatrician did not have an email address, then the next available number on the random number list was used to select a replacement.

The final sample consisted of 3,863 pediatricians. One-hundred thirty-seven of the 4,000 email addresses selected were found to be invalid in one way or another and were discarded. The first invitation to participate was emailed to the 3,863 pediatricians on January 28, 2008. A follow-up invitation was emailed to those who had not yet responded on February 14, 2008.

Measures

All participants received an invitation via email to participate in a web-based survey asking about their current general developmental and specific autism screening practices (see Appendix A). Some of the questions used in this survey were based on questions from previous surveys on this topic (e.g., Dosreis et al., 2006; Sand et al., 2005; Sices et al., 2003). Other questions reflected the need for new information, including pediatricians' beliefs and attitudes toward professional training in autism screening, their knowledge of CPT billing codes for developmental screening reimbursement, and their familiarity with recently updated AAP practice guidelines on general developmental and autism screening published in November 2007 (Johnson & Myers, 2007). As part of its theoretical framework, the survey design incorporated recommendations outlined in Dillman's *Mail and Telephone Surveys: The Total Design Method* (Dillman, 2000) and included 41 questions covering a range of topics related to general developmental and specific autism screening practices. It took an estimated 20 minutes to complete (see Appendix B).

Survey questions were developed with the assistance of Drs. Raymond Sturner and Barbara Howard, co-directors of the Clinical Research Team for CHADIS at The Center for Promotion of Child Development through Primary Care, Baltimore, MD. Ray Sturner, M.D., is a developmental-behavioral pediatrician and an Associate Professor of Pediatrics and former Director of the Developmental and Behavioral Pediatrics Fellowship Training Program at The Johns Hopkins University School of Medicine. Barbara Howard, M.D., is a developmental-behavioral pediatrician trained by Dr. Brazelton at Harvard, an Assistant Professor of Pediatrics at Johns Hopkins and former Co-Director of the fellowship program. A version of the survey is currently in use by the CHADIS project directed by Dr. Sturner and Dr. Howard.

Feedback about survey design and content was obtained from the research team working with Dr. Sturner and Dr. Howard; from Dr. Paul Lipkin, Chair of the AAP Council for Children with Disabilities Committee, Director of the Center for Development and Learning at Kennedy Krieger Institute, and Assistant Professor of Pediatrics at

Johns Hopkins University School of Medicine; from Dr. Laura Sices, Division of Behavioral Pediatrics and Psychology, Department of Pediatrics at Case Western Reserve University, and first author of *How Do Primary Care Physicians Indentify Young Children with Developmental Delays? A National Survey* (2003); Dr. Frances Glascoe, Professor of Pediatrics at Vanderbilt University, and an author of *Pediatricians' Reported Practices Regarding Developmental Screening: Do Guidelines Work? Do They Help?* (2005); Nancy Wiseman, President and Founder of *First Signs, Inc.;* and Dr. Howard Eckstein, F.A.A.P., at Galion Community Hospital Health Services in Ohio.

Data Collection

The survey was originally created as a Word document and later transcribed into a web-based format by technicians at Student Voice (www.studentvoice.org), a multi-service agency contracted by Indiana University of Pennsylvania's (IUP) Applied Research Lab. Participants clicked on a link in the invitation letter that took them directly to a secure website where they could then take the survey. Participants were advised in the invitation letter that participation was voluntary, that responses were anonymous and confidential, and that they could stop responding at any time before hitting the "Submit" link at the end of the survey. A follow-up letter was sent by email approximately 2 weeks later to pediatricians who had not yet responded (see Appendix C). Data collection took place via a secure website provided and maintained by Student Voice. In keeping with the anonymity and confidentiality practices assured to participants in the proposal for this project and approved by the IUP Institutional Review Board (IRB) for the Protection of Human Subjects, identifying information was removed from data responses, and the author had no access to this information at any time.

Data Analysis

Frequency distributions related to stated expectations and other behaviors of interest were reported to gain a clear understanding of pediatricians' current general developmental and autism-specific screening practices. When appropriate, Chi-square tests were conducted to look for significant differences between groups of respondents on key variables (see Table 1 below). In some cases, these data were compared to data collected in previous surveys in order to demonstrate whether or not changes in developmental and autism-specific screening practices have taken place following the publication of recent practice guidelines.

CHAPTER FOUR

DATA AND ANALYSIS

Results

Survey Response

A total of 338 response sets were received for a response rate of 9%. This response rate is considerably lower than traditional mail-based surveys targeting this population. However, it is not unusual for a web-based survey. In 2004 a large (n = 5,387), cross-sectional, group-comparison study titled “Mail versus Internet surveys: Determinants of method of response preferences among health professionals” was conducted to evaluate factors related to response rate in Internet surveys of healthcare professionals. The overall response rate in this study for all groups of healthcare providers was 9.3%, with physicians comprising the group of lowest responders at 7.8% (Lusk, Delclos, Burau, Drawhorn, & Aday, 2007). In light of these findings, the 9% response rate to the present study is not disheartening.

In the present study, 65 incomplete response sets were removed from the sample, leaving a total of 273 completed surveys for analysis. The goal of this study was to describe the general developmental and autism screening practices of primary care pediatricians in the United States. However, a number of subspecialists were inadvertently selected for the sample. Many of these contacted the author via email to disqualify themselves. Completed survey responses from 16 respondents were removed as they identified themselves on a series of routing questions as physicians who practiced primarily in a subspecialty and did not spend the majority of their time practicing in primary care pediatrics. This left a total of 257 survey response sets that were suitable for analysis.

Characteristics of Respondents

Responses were received from all states with the exceptions of Alaska, Georgia, Hawaii, Idaho, Massachusetts, Mississippi, North Dakota, Rhode Island, South Dakota, and Wyoming (see Appendix D). The highest return rates came from Maryland and Colorado (17%), with other states ranging from 1% to 16%.

For the purpose of exploring possible differences between groups of respondents in terms of autism screening practices, Tables 1, 2, 3, and 4 below divide the sample into 2 broad demographic categories: 1) Male and Female, and 2) Respondents who graduated from medical school *before* the first set of practice guidelines regarding autism screening were published in 2000 and those who graduated *afterwards*. Previous studies found gender to be a factor in developmental screening practices (Dosreis et al., 2006; Sices et al., 2003), so this variable was analyzed using Chi-square statistics in bi-variate tests for association between gender and a number of developmental screening behaviors. A second grouping was chosen to determine whether physicians graduating before the initial practice guidelines were published in 2000 differ from those graduating after 2000. Differences found between these groups of participants in terms of demographics and in terms of autism screening and referral practices are reported below.

Differences in Respondent Sample by Gender

Table 1 describes broad demographic characteristics of the sample. Of the 257 completed surveys, females comprised slightly more than half of the respondent sample. Sixty-four percent of the female sample fell between the ages of 26 to 45 years, whereas only 37% of the male sample fell in this age bracket (row I).

Table 1.

Descriptive Characteristics of Sample by Gender and Year of Graduation from Medical School (before or after 1st practice guidelines published in 2000)

	Percent and number of respondents endorsing:			
	Male n = 96	Female n = 130	Graduated before 2000 n = 155	Graduated after 2000 n = 42
Demographic characteristics of interest	*% (n)*	*% (n)*	*% (n)*	*% (n)*
I. Age:				
26-35	17 (16)	31 (40)	6 (9)	95 (40)
36-45	20 (19)	33 (42)	32 (50)	5 (2)
46-55	26 (25)	26 (34)	36 (55)	0 (0)
56-65	27 (26)	10 (13)	22 (34)	0 (0)
> 65	9 (9)	0 (0)	5 (7)	0 (0)
II. Race/Ethnicity:				
White	88 (84)	82 (106)	86 (133)	91 (38)
Hispanic	5 (5)	5 (7)	5 (8)	0 (0)
Black	1 (1)	5 (7)	3 (50)	7 (3)
Asian or Pacific Islander	5 (5)	6 (8)	5 (7)	2 (1)
Not noted/known	0 (0)	2 (2)	1 (2)	0 (0)
III. Board Certified:	90 (86)	87 (113)	99 (154)	48 (20)

An inverse relationship with age and gender was found in the over-46-year-old age bracket which comprised 36% of female respondents and 62% of males. These data indicate a reversing trend toward a female-dominated field of primary care pediatric medicine.

Other differences were found in demographic variables by gender. Female primary care pediatricians were more likely to report working in a community out-patient clinic, whereas males were more likely to work in private practice (row IV). Male respondents reported servicing a larger percent of patients who rely on Medicaid than did their female counterparts (row V), but there were no reported differences in the percent of their patients who have no insurance (row VI). There were no significant differences by gender (X^2 test) found in terms of racial/ethnic identity or board certification (rows II & III).

Differences in Respondent Sample by Year of Graduation

As would be expected, the group of respondents graduating from medical school after 2000 is a younger cohort, with 95% falling in the 26-35 year-old age range (row I, Table 1 above). Those graduating before 2000 had age ranges rather evenly distributed between the ages of 36-77 years. Although more than twice as many respondents from the group who graduated before 2000 were likely to be board certified (row III), this result is not surprising given the fact that many of those graduating after the year 2000 are still completing internship training and are not yet eligible to sit for their state board exam.

Table 1. (continued)

Descriptive Characteristics of Sample by Gender and Year of Graduation from Medical School (before or after 1st practice guidelines published in 2000)

	Percent and number of respondents endorsing:			
	Male n = 96	Female n = 130	Graduated before 2000 n = 155	Graduated after 2000 n = 42
Demographic characteristics of interest	*% (n)*	*% (n)*	*% (n)*	*% (n)*
IV. Type of practice (more than one choice possible):				
Private practice	69 (66)	53 (69)	71 (110)	31 (13)
HMO	9 (9)	6 (8)	8 (12)	2 (1)
Hospital-based/affiliated out-pt. clinic	13 (12)	16 (21)	8 (13)	36 (15)
Community-based out-pt. clinic	6 (6)	16 (21)	10 (15)	19 (8)
Other:	(6)	14 (18)	9 (14)	14 (6)

V. Patients with Medicaid:				
0 -- 25 %	66 (51)	44 (39)	62 (77)	33 (8)
26 – 50 %	17 (13)	23 (20)	20 (25)	13 (3)
51 – 75 %	9 (7)	11 (10)	6 (8)	17 (4)
> 75 %	8 (6)	23 (20)	12 (15)	38 (9)
VI. Patients with no insurance:				
0 – 25 %	96 (71)	99 (82)	98 (117)	93 (14)
26 – 50 %	4 (3)	0 (0)	2 (2)	7 (1)
51 –100 %	0 (0)	1 (1)	0 (0)	0 (0)

Graduates before the year 2000 varied from more recent graduates in the types of practices they reported working in as well (row IV). Those graduating before 2000 were more than twice as likely to work in private practice as compared to those who graduated after 2000. They were also more likely to work for a Health Maintenance Organization (HMO) and less likely to work for community-based or hospital-based out-patient clinics compared to more recent graduates. A further difference between the two groups was reported in the socioeconomic (SES) status of their patients. Respondents who graduated after 2000 were more than twice as likely to report servicing a caseload with over half of their patients dependent upon Medicaid compared to those who have been practicing longer (row V), although there was no difference in the percent of their patient caseload who have no insurance. Ethnic and racial make-up of the sample (row

II) did not differ significantly by gender or year of graduation from medical school (X^2 test).

Adherence to Current AAP Guidelines on Developmental Screening

The first expectation of this study was that despite several sets of practice guidelines being published over the past 8 years, only a minority of primary care pediatricians would report routinely screening for autism at the 18- and 24-month visits as recommended by the AAP. Previous studies found that physicians are more likely to conduct general developmental screening than they are to conduct autism-specific screening (Dosreis, 2006). That result was found by the present study as well (X^2 test). Overall, nearly 70% percent of the pediatricians in this sample reported using a standardized screening tool to carry out routine general developmental screening, while only 42% in the whole sample reported using standardized tools to routinely screen for autism. However, as shown in Table 3 below, significant differences were found between groups of respondents by gender (significant values appear in bolded print).

Table 2.

Adherence to AAP Guidelines on Developmental Screening by Gender and by Year of Graduation from Medical School (before or after 1st practice guidelines published in 2000)

	Percent and number of respondents endorsing:			
	Male n = 96	Female n = 130	Graduated before 2000 n = 155	Graduated after 2000 n = 42
Adherence to AAP guidelines on developmental screening	*% (n)*	*% (n)*	*% (n)*	*% (n)*
I. Pediatricians who routinely use a general developmental screening tool	60 (58)	**75 (98)**[a]	65 (100)	76 (32)[b]
II. Pediatricians who routinely use an autism-specific screening tool	52 (50)	**37 (48)**[c]	41 (63)	45 (19)[d]

III. Pediatricians familiar with AAP guidelines on general developmental screening at the 9-, 18-, 30- or 24-month visits	32 (31)	39 (51)[e]	37 (57)	41 (17)[f]
IV. Pediatricians familiar with AAP guidelines on autism-specific screening at the 18- and 24-month visits	29 (28)	31 (40)[g]	29 (45)	36 (15)[h]

[a] X^2 (1) = 5.79, p < .02 [b] X^2 (1) = 2.04, p < .15
[c] X^2 (1) = 5.17, p < .03 [d] X^2 (1) = 0.29, p < .60
[e] X^2 (1) = 1.15, p < .28 [f] X^2 (1) = 0.19, p < .66
[g] X^2 (1) = 0.07, p < .80 [h] X^2 (1) = 0.70, p < .40

Although female pediatricians were more likely than males to report the routine use of standardized tools during general developmental screening (*row I*), they were significantly *less* likely to report using standardized tools for autism-specific screening (row II). No differences were found between the graduating groups in terms of their general developmental or autism-specific screening; however, the majority of respondents in both groups reported that they do not conduct routine autism screening. Related questions that asked respondents about their familiarity with the current AAP practice guidelines on developmental screening revealed that the majority of respondents in both groups were unfamiliar with current recommendations for both general developmental and autism-specific screening (rows III & IV).

Barriers to General Developmental and Autism Screening

The second expecation of this study was that most pediatricians continue to rely on clinical observations to detect autism instead of routinely administering standardized screening instruments at the intervals as recommended in the current AAP practice guidelines. In a question aimed at those who said they do not routinely conduct general developmental screening using a standardized tool, the number one reason cited by the entire sample was “I rely primarily on clinical observations” (18%). This same reason was endorsed as the main barrier to routine autism-specific screening by 28% of the sample. Table 3 below shows the significant differences in reported barriers found between groups by gender and by year of graduation from medical school on 2 items. Female physicians reported being nearly 3 times more likely than their male counterparts to refer a child with developmental red flags to a specialist instead of conducting standardized ASD screening (row III). Physicians graduating before 2000 are significantly more likely to report lack of adequate reimbursement as a barrier to autism screening than are more recent graduates (row V).

Table 3.

Reported Barriers to ASD Screening by Gender and by Year of Graduation from Medical School (before or after 1st Practice guidelines published in 2000)

	Percent and number of respondents endorsing:			
	Male n = 96	Female n = 130	Graduated before 2000 n = 155	Graduated after 2000 n = 42
Reported barriers to ASD screening	*% (n)*	*% (n)*	*% (n)*	*% (n)*
I. I rely primarily on clinical observations	24 (23)	30 (39)[a]	32 (49)	21 (9)[b]
II. I am not familiar enough with ASD screening tools	21 (20)	29 (37)[c]	23 (36)	31 (13)[d]
III. I refer to a specialist	**7 (7)**	**20 (26)[e]**	16 (24)	12 (5)[f]
IV. There is not enough time to screen	13 (12)	11 (14)[g]	14 (21)	10 (4)[h]
V. I do not receive adequate reimbursement for using these screening tools	6 (6)	6 (8)[i]	**8 (13)**	**0 (0)[j]**
VI. These screening tools are too costly	1 (1)	4 (5)[k]	4 (6)	0 (0)[l]
VII. ASD screening tools are not effective	1 (1)	1 (1)[m]	1 (1)	2 (1)[n]
Other reasons:	15 (14)	19 (25)	21 (32)	10 (4)

[a] X^2 (1) = 1.01, p < .31 [b] X^2 (1) = 1.7, p < .20
[c] X^2 (1) = 1.7, p < .19 [d] X^2 (1) = 1.06, p < .30
[e] X^2 (1) = 7.15, p < .01 [f] X^2 (1) = 0.34, p < .56
[g] X^2 (1) = 0.16, p < .69 [h] X^2 (1) = 0.48, p < .49
[l] X^2 (1) = 0.001,p < .98 **[j] X^2 (1) = 3.77, p < .05**
[k] X^2 (1) = 1.68, p < .20 [l] X^2 (1) = 1.68, p < .20
[m] X^2 (1) = 0.05, p < .83 [n] X^2 (1) = 0.99, p < .32

No other statistically significant differences between groups were found regarding reported barriers to conducting routine autism screening. Other reasons listed as barriers to routine autism screening using standardized tools included pediatricians using an instrument of their own design, using a general developmental screener to detect autism, being in the process of implementing routine screening, being part of a practice that does not routinely screen for autism, relying on parent concern/history, language barriers, and a lack of resources if screen is positive.

In addition to the specific barriers described above, it is important to consider other factors that may interfere with pediatricians following practice guidelines regarding general developmental and autism-specific screening. Pediatricians provide myriad preventive services to their patients and, as noted previously, well-child visits allow only minutes to cover a range of preventive health topics and to accomplish any number of vital healthcare tasks. Choosing which topics to cover may well depend on a physician’s belief in how important each topic is, both in and of itself and in relation to other topics that they consider important. In order to find out how pediatricians rate the importance of developmental screening compared to other preventive healthcare services, participants were asked to prioritize a number of common preventive health topics to developmental screening (see Table 4 below). Results from the present study are shown compared to previous survey results from Sices et al. (2003).

The results to questions about prioritizing developmental screening indicate that, in general, pediatricians do consider developmental screening an important preventive healthcare topic. It was found that the majority of respondents rated developmental screening as having the same priority as counseling for car seats/transportation safety (row I), immunizations (row II), behavior (row IV), and diet/nutrition (row V). Safe storage of weapons and household chemicals was the only topic rated as a lower priority (row III).

Table 4.

Pediatricians' Responses to Questions Assessing the Importance of Developmental Screening as Compared to Other Preventive Health Services They Routinely Provide

	Percent of respondents endorsing:					
	Compared to developmental screening how are the following services rated in terms of importance?					
	Zeiger 2008 (n = 257)	Sices et al 2003 (n = 537)	Zeiger 2008 (n = 257)	Sices et al 2003 (n = 537)	Zeiger 2008 (n = 257)	Sices et al 2003 (n = 537)
Domain of service	Lower Priority (%)		Same Priority (%)		Higher Priority (%)	
I. Car seats and transportation safety	26	20	52	47	22	33
II. Counseling for immunizations	11	8	53	47	34	45
III. Safe storage of chemicals/weapons	42	24	38	51	20	25
IV. Behavioral counseling	16	28	56	54	27	18
V. Diet/nutrition counseling	10	13	55	59	35	28

However, 20 to 35% of the respondents from the present study gave a *higher* priority to all other topics compared to developmental screening. This means that if time is limited and a physician has to choose which topic to cover, developmental screening may be abandoned in favor of a topic considered more important.

Familiarity with Standardized Autism Screening Tools

The third expectation predicted that pediatricians remain unfamiliar with valid standardized screening instruments that are currently available. In fact, only 27% of those respondents who do not routinely screen for autism admitted to lacking familiarity with available screening tools. This figure represents clear improvement over the 62% who were unfamiliar with autism screeners in the 2006 Dosreis et al. study. While this trend indicates definite improvement in this area, it also highlights the more troubling question of why more pediatricians are not routinely screening for autism using standardized instruments if familiarity with screeners is not a major barrier.

Familiarity with Current Procedural Terminology (CPT) Billing Codes for Developmental Screening

The fourth expectation predicted that despite lack of reimbursement being cited as a major barrier in previous studies, pediatricians, as a group, are not aware of the CPT codes that can be used to obtain reimbursement for developmental screening. In Sices et al. (2003), lack of adequate reimbursement was cited as a reason preventing 89% of pediatricians from conducting developmental screening. Sand et al. (2005) found that this reason was endorsed by 46% of their sample. In the present study (Table 5 below), it was found that a solid majority of respondents have never billed for developmental screening using CPT code 96110 for brief screening (row1) or CPT code 96111 for extended developmental screening (row 2).

Table 5.

Pediatricians' Estimation of Number of Times They Use CPT Billing Codes for Developmental Screening

	Percent and number of respondents endorsing:		
Type of CPT Code	Never Used *% (n)*	1-100 Times *% (n)*	> 100 Times *% (n)*
Please estimate how many times you have used CPT billing codes 96110 and 96111 during the past year.			
I. CPT code 96110 (brief developmental screening)	66 (151)	23 (52)	11 (25)
II. CPT code 96111 (extended developmental screening)	85 (194)	14 (32)	1 (2)

For those physicians who do submit billing under these CPT codes (Table 6 below), between 64% (row I) and 77% (row II) reported being reimbursed fewer than 50 times. Furthermore, 84% percent of the respondents were unsure if, in the state in which they practice, Medicaid would reimburse them for developmental screening submitted for billing using CPT billing codes 96110 and 96111.

Table 6.

Pediatricians' Estimation of Number of Times Developmental Screening is Reimbursed Using CPT Billing Codes

	Percent and number of respondents endorsing:		
Type of CPT Code	≤ 25 Times *% (n)*	≈ 50 Times *% (n)*	≥ 75 Times *% (n)*
Please estimate how many times you have been reimbursed for using CPT billing codes 96110 and 96111 during the past year.			

I. CPT code 96110 (brief developmental screening)	64 (54)	16 (13)	20 (17)
II. CPT code 96111 (extended developmental screening)	77 (49)	11 (7)	13 (8)

Training for General Developmental and Autism Screening

The fifth and last expectation of this study was that the majority of primary care pediatricians would report that the training they received during their medical training was inadequate to prepare them to follow the AAP practice guidelines regarding routine screening, referral, and follow-up care for children with autism spectrum disorders. Currently practicing pediatricians reported obtaining specific instruction, training, and/or experience in screening for autism from a variety of sources, including medical school (24%), residency (46%), professional postdoctoral training (50%), professional journals or newsletters (69%) personal experience (44%), and lay press or media (12%). Only 3% of this sample reported obtaining this type of experience/knowledge through a specialized pediatric fellowship program.

When asked to rate their medical education and training in terms of how well it prepared them to conduct developmental screening for autism, nearly half of the participants reported that their preparation was either below average or nonexistent (Table 7 below). Furthermore, 95% percent of the respondents believe that there is currently a need for professional postdoctoral training related to developmental delays and autism spectrum disorders.

Table 7.

Pediatricians' Ratings of the Extent to Which Their Medical Training Adequately Prepared Them to Conduct ASD Screening and Their Belief Regarding the Importance of Post-graduate Training Related to ASD and DD

Rating of medical training and need for further training	*Percent and number of respondents endorsing:* Below Average *% (n)*	Average *% (n)*	Above Average *% (n)*
Please rate the level of preparation you received during medical training for ASD screening and your belief regarding need for post-graduate training related to ASD and DD for primary care practitioners.			
How well prepared to conduct ASD screening	44 (100)	41 (92)	15 (34)
Need for professional training related to ASD and DD	4 (10)	35 (80)	60 (136)

These data are interesting, given the high levels of confidence from respondents in their ability to recognize the signs of autism and the need for further referral in their young patients, to understand how to treat autism, to know where to refer patients with autism in their communities, and to answer parents' questions about developmental problems (Table 8 below).

Table 8.

Pediatricians' Reported Levels of Confidence or Expertise in Recognizing and Responding to Children with ASD or Developmental Delays

Domain of Knowledge	*Percent and number of respondents endorsing:* Below Average Confidence/ Expertise *% (n)*	Average Confidence/ Expertise *% (n)*	Above Average Confidence/ Expertise *% (n)*
Please estimate your level of confidence or expertise in the following areas related to ASD and developmental delays.			
I. Recognizing ASD by observing an 18-month-old during well visit	8 (18)	42 (94)	50 (114)
II. Recognizing mild DD in an 18-month-old during well visit	9 (21)	39 (88)	52 (117)

III. Answering questions about behavior and development in an 18-month-old	1 (3)	24 (54)	75 (169)
IV. Current research-based understanding of the etiology of ASD	21 (48)	51 (116)	27 (62)
V. Diagnostic criteria for ASD	11 (25)	50 (114)	39 (87)
VI. Warning signs indicating further diagnostic evaluation for ASD	4 (9)	34 (77)	62 (140)
VII. Empirically supported interventions for ASD	25 (57)	47 (107)	27 (62)
VIII. Where to refer children with ASD in your community	9 (20)	36 (82)	55 (124)

From the data in Tables 7 and 8, it appears that there is a discrepancy between pediatricians' belief that further training for developmental screening is needed and their sense of their own competency and expertise. On one hand, they reported feeling that they have been underprepared and believe that more training is needed. On the other hand, they reported being experts in a variety of topics related to general developmental and autism-specific screening.

When asked about the format and/or location of the CME training they would be interested in, participants were mixed in their preferences. The following tables outline responses to a question about what types of continuing medical education (CME) opportunities related to general developmental and autism-specific screening practices pediatricians would most likely participate in:

Table 9.

Pediatricians' Ratings of the Likelihood They Would Attend Continuing Medical Education (CME) Courses in the Following Formats/Locations

	Percent and number of respondents endorsing:		
Format/location of CME	Not Likely	Possibly	Very Likely

	% (n)	*% (n)*	*% (n)*
Please indicate the likelihood of your participating in the following types of CME training related to general developmental & ASD screening—Check all that apply.			
I. Attend 1-day CME in neighborhood	8 (18)	47 (106)	45 (100)
II. Attend 1-day CME requiring overnight ravel	46 (104)	47 (105)	7 (15)
III. Participate in CME monthly webcast discussions	44 (99)	44 (98)	12 (27)

In an open question on this topic, participants listed a number of other preferred venues for CME related to general developmental and autism-specific screening, including materials available in a web-based/internet/email (*not* webcast or podcast) format, listening to audio CD, watching a DVD, attending an AAP or other large pediatric conference, reviewing written materials in professional journals, receiving written materials through the US mail, participating in grand rounds/observerships /preceptorships, or taking Pediatric Review and Education Program (PREP) courses.

CHAPTER FIVE

DISCUSSION

Summary, Conclusions, and Recommendations

Are Pediatricians Following Current AAP Guidelines on Developmental Screening?

The overarching concern of this study was to answer the question of whether most primary care pediatricians are following the AAP practice guidelines for routine autism screening. The short answer to this question is “no.” A closer analysis of the data from this national survey does reveal some reasons to be optimistic, however. In a study of pediatricians’ autism screening practices published in 2006, it was found that only 8% of the respondents were routinely screening for autism using a standardized screening instrument (Dosreis et al., 2006). In the present study, it was found that 42% of the respondents reported routinely conducting autism screening using a standardized screening instrument.

A related area of improvement is found in pediatricians’ reported familiarity with autism screeners. Dosreis et al. found that approximately two-thirds of their sample cited unfamiliarity with autism screening tools as a barrier to routine autism screening, whereas the current study found that only 27% of the respondents reported lack of familiarity with autism screeners as a barrier to screening. Finally, only 11% of pediatricians from the current study seemed to consider time a major barrier to autism screening compared to 32% who endorsed this factor as a barrier in the Dosreis et al. study. Although the differences may be partly explained by the fact that the Dosreis et al. study sampled only pediatricians from Maryland and Delaware, whereas the present study drew from a random national sample, it also leaves room to speculate that pediatricians, as a group, are improving their autism screening practices.

Despite what appear to be improvements in the numbers of pediatricians conducting routine autism screening and their growing familiarity with available screening tools, there remain many areas where physicians are falling short of bringing their pediatric practice more in line with AAP guidelines on developmental screening. A full 66% of the sample from the current study reported having read practice guidelines on developmental or autism screening in the past year, and 56% report having taken CME courses on this topic. However, only 28% seemed to be familiar with the new AAP practice guidelines' recommendation to conduct routine autism screening at the 18- and 24-month visits. Although many pediatricians listed the 18- and 24-month visits *in addition to other visits* as routine screening opportunities, the fact that they weren't familiar with this particular guideline leaves open the possibility that they are not familiar with other practice parameters in the AAP report. And, in fact, this seems to be the case. Less than one-third of the respondents were aware of the AAP recommendation to conduct general developmental screening at ages 9, 18, and 30 or 24 months.

These results are troubling in many regards. If a large majority of pediatricians are not familiar with recommended practice guidelines, it stands to reason that they are not incorporating these recommendations into practice. Previous surveys have documented the seeming reluctance of this group of practitioners to respond to their governing body's call for action regarding autism screening. Although there appears to be improvement since the last data were collected in 2004, the interim period has not been one of rapid advancement. Considering the monumental problem that the increasing number of children with ASD presents, pediatricians have been quite slow in taking their place as leaders on the issue of routine autism screening.

Specific Areas of Concern

One area of pediatric practice that seems particularly resistant to change is the number of pediatricians who continue to rely primarily on clinical observations to identify developmental problems in children instead of using a standardized screening instrument. In the current study, "I rely primarily on clinical observations" was endorsed as the leading barrier to administering a standardized autism or general developmental screening tool. This response reveals something about physicians' perception of their own competency when it comes to developmental screening.

Specifically, a majority of the respondents reported above average confidence levels in their ability to recognize autism or developmental delay during a well visit and to recognize the developmental red flags that would indicate a need for further evaluation for autism (Table 7). Data from reported barriers to screening, however, indicate that less than half of the pediatricians in this sample reported routinely screening for autism (Table 3), and only 28% were familiar with the recommendations made in the current AAP practice guidelines regarding autism-specific screening (Table 2). What we are left with is an equation that does not add up. By their own admission, the main reason pediatricians do not follow AAP practice guidelines for autism screening is because they rely primarily on clinical judgment. However, despite their lack of adherence to the guidelines and their stated desire for more training, most claim confidence and expertise in these areas.

A major source of medical mistakes is believed to stem from errors in clinical judgment (Berner & Graber, 2008). According to recent publications, medical errors continue to receive much attention, both from within the medical field itself and from increased public scrutiny (Mamede, Schmidt, & Rikers, 2006). In particular, current research examines the underlying mechanisms of thought processes related to clinical judgment. In a comprehensive literature review on this subject titled “Overconfidence as a cause of diagnostic error in medicine,” Berner & Graber present a strong case for the link between overconfidence and error, stating that “physicians in general underappreciate the likelihood that their diagnoses are wrong and that this tendency to overconfidence is related to both intrinsic and systemically reinforced factors” (2008, Abstract).

Cognitive processes that can lead to error in judgments are widely studied by cognitive theorists. Kahneman describes a “two-system view” of cognitive processes (first proposed by Stanovich and West in 2000), that differentiates between the characteristics related to intuition and reasoning. Intuitive thought processes are described as “fast, automatic, effortless, associative, implicit (not available for introspection, and are also . . . governed by habit and therefore difficult to control or modify” (Kahneman, 2003, p. 698). Berner & Graber posit that “the great majority of medical diagnoses are made using automatic, efficient cognitive processes” (2008, Abstract). Mamede et al. specifically examine “medical heuristics,” those “mental shortcuts . . . that are invoked, largely unconsciously, by clinicians to expedite clinical decision making” (2006, p. 140). Heuristics can be helpful and effective tools to aid in decision-making processes, but they can lead to bias as well.

A particular type of bias that is associated with medical error is overconfidence, which according to Mamede et al., may lead a doctor to “replace a systematic and careful gathering of evidence by opinion” (2008, p. 140). It is beyond the scope of this study to conclusively state that the data from this survey demonstrate overconfidence as the primary reason that pediatricians fail to comply with current AAP practice guidelines on autism screening. However, a majority of the respondents’ responses endorse both confidence and noncompliance when it comes to following recommendations related to routine autism screening. It is not an unreasonable hypothesis that these two behaviors are related, and it is a hypothesis worth further study.

The second most common barrier reported was the lack of familiarity with standardized autism screening tools. In order for pediatricians to follow the AAP practice guidelines regarding autism screening, two things must occur. First, they must accept the fact that clinical observation is not enough. If pediatricians continue to rely primarily on clinical observation instead of administering standardized autism screeners, they will continue to miss many opportunities to identify a large proportion of young children at risk for autism. Second, pediatricians must make themselves familiar with the available autism screening tools and find a way to incorporate routine autism screening into their everyday practice. Both of these barriers can be addressed through professional training, such as that offered by the CHADIS project, First Signs, Inc. workshops, Learn the Signs/Act Early project, and Project First S.T.E.P.

Interestingly, there is little overlap between these two groups of barriers. Only 28% of respondents indicated that both reliance on clinical observations *and* unfamiliarity with screening tools were barriers to implementing routine autism screening. This finding seems to suggest that these are two distinct areas that need to be targeted in professional training efforts. In other words, it will not be enough to simply make physicians more familiar with autism screeners. It will also be necessary to change their attitudes about improving how they identify autism and other developmental problems. To this end, it may require changes in how students are educated during their medical training, not only making them more familiar with available screeners but also teaching them that use of these tools will significantly increase the numbers of children identified with developmental problems. If primary care pediatricians believe that they can identify autism without the help of standardized autism screening instruments, then making them more familiar with these tools will not solve the problem.

This belief may well be the most difficult barrier to overcome, as it taps directly into physicians' beliefs about their own competence. Despite high levels of confidence in their own abilities to detect autism, more than half of primary care pediatricians do not routinely screen for autism and are therefore failing to provide a crucial preventive care measure that could help to identify more at-risk children at earlier ages. When those who are affected by this practice are children at risk for severe, life-long developmental disabilities, it seems unconscionable that a failure of this magnitude continues to occur without penalty. The American Academy of Pediatrics, the American Academy of Neurology, and the Child Neurology Society have all published specific guidelines calling for pediatricians to conduct routine autism screening using standardized screening instruments. This group of doctors has had 8 years to make changes in the way they practice pediatric medicine in order to incorporate recommended guidelines regarding routine autism screening. Why is it still not being done by a majority of the practicing primary care pediatricians in the United States?

It appears that a major effort must be directed towards changing pediatricians' perceptions of their own abilities. The data in this survey do not suggest that primary care pediatricians do not know enough about autism screening and referral. Rather, they point toward a need for pediatricians to change their *belief* that clinical expertise alone will suffice when it comes to developmental screening. They need to be convinced, during their initial medical training or through professional continuing education, that the only way to identify the most children with autism and other developmental disorders at the earliest ages is to routinely administer standardized screening instruments as recommended by the AAP practice guidelines.

An alternative solution would be to embrace a more collaborative model among healthcare providers, one in which pediatricians share the responsibility of routine developmental screening (Coker, Casalino, Alexander, & Lantos, 2006; Palfrey, Singer, Walker, & Butler, 1987). There has been much resistance in other areas of medicine when it comes to physicians agreeing to share or relinquish specialized practices to other healthcare providers. The intense fight against allowing clinical psychologists to gain prescribing privileges is one recent example (Daly, 2007). In the case of conducting routine general developmental and autism-specific screening, perhaps it is time for pediatricians to relinquish this practice to other types of pediatric healthcare or education providers. Pediatricians could continue to conduct ongoing developmental surveillance but have psychologists, physician assistants, nurses, nurse practitioners, or early intervention educators administer the standardized screening instruments and make appropriate referrals.

A community-based effort in Hartford, CT, led to implementation of a model called *ChildServ,* which was developed as a collaborative effort of multidisciplinary child health and education providers with the purpose of identifying children with developmental problems who were not being detected in primary pediatric settings (McKay et al., 2006). Other models propose a school-based screening process (Noland & Gabriels, 2004).

A related area of collaboration that is worthy of further investigation is related to pediatricians' referral practices. The current survey shows that pediatricians overwhelmingly refer suspected cases of autism to other types of physicians instead of to developmental psychologists. Only 7% reported making a referral to a developmental psychologist their first choice, while over 80% reported a preference for referring to a developmental pediatrician. Professional training helping pediatricians take a more collaborative, systems approach to autism screening and referral would help to make pediatricians feel more supported in their role as first-line developmental screening agents and would potentially increase the numbers of children identified at earlier ages.

If pediatricians continue to ignore the practice guidelines on developmental screening, they may lose the freedom of deciding for themselves, how to implement autism screening into their practice. There are many precedents for mandated services by health-care providers. Most states have a number of mandated healthcare services/screenings, many of them for children with special needs (Catalyst Center for Children & Youth, 2006). Massachusetts recently implemented a mandatory mental health screening protocol following lengthy class-action litigation, which resulted from nearly 15,000 children with severe mental health problems not receiving adequate care and service coordination (Hanlon, 2008). New Jersey enacted mandated universal hearing screenings for all newborns in 2002 (New Jersey Department of Health & Senior Services, 2008).

One familiar mandate, the Child Abuse Prevention and Treatment Act (CAPTA), was enacted in 1974 and remains in place in all 50 states (Smith, 2008). Those who are mandated reporters (e.g., teachers, daycare workers, and healthcare professionals) face stiff penalties, including substantial fines and jail time, for failure to comply with CAPTA. Although this example is not meant to suggest that we begin imposing fines or other penalties on pediatricians who do not screen for autism, there must be a mechanism for accountability, such as making proof of compliance with AAP screening guidelines necessary for continued licensure. If the AAP is not able to elicit cooperation with published practice guidelines regarding autism screening, perhaps state or federal regulation should be considered.

Mandated screening for autism would ensure that all children are screened for autism at specified ages, but the cost to tax payers would be steep. Blue Cross/Blue Shield of Tennessee reports that the costs for mandated health services in that state exceed 8 million dollars per year (Cecil, 2004). If pediatricians could be persuaded to conform to AAP recommendations, the costs related to mandated screening might be avoided. And, of course, the long-term costs averted by early identification, diagnosis, and intervention are incalculable.

General Limitations of Present Study

As with any large research undertaking, this project has a number of limitations that must be acknowledged. First, despite the adequate final sample, the overall return rate was considerably lower than other survey studies with this population of participants. Studies of pediatricians' developmental screening practices by Sices et al. (2003), Sand et al. (2005), and Dosreis et al. (2005) reported response rates of 42% to

55%, which are considerably higher than those of the present study. There are several possible reasons for this discrepancy. One reason may be related to the fact that the present survey was conducted by a graduate student as a dissertation project, whereas other studies on this same topic were conducted by physicians who are already widely recognized and published experts in this field.

Another reason for the lower response rate may be that the previous studies were sent out to participants via a more traditional method, with a paper-based survey mailed through the US postal service, whereas this survey was web-based, and participants were solicited through an email invitation letter. Although web-based services, procedures, and practices are becoming more familiar in this age of rapidly expanding technology, it is possible that people are still not as familiar or comfortable with this mode of survey administration as they are with the traditional “pen and ink” variety. As noted in Chapter Four, Web-based or Internet surveys tend to have overall low response rates, with physicians in particular being a group notorious for low responding.

A related possibility may be that the same technology that makes it relatively easy to send out thousands of surveys is the same technology that allows potential participants to hit a delete button and make the invitation to participate disappear into cyberspace. Whereas a paper-based survey with a return address of a known colleague may sit on someone’s desk as a visual reminder, it is very easy to delete an email message coming from an unknown source without even opening the email message. Furthermore, many professionals have sophisticated mail filtering systems on their computers to prevent unwanted solicitations from filling up their inboxes.

Another limitation of the present study related to response rate is the fact that although the 3863 potential participants were drawn from a random national sample that was weighted according to each state’s membership in the AAP, no surveys were returned from the following 10 states: Alaska, Georgia, Hawaii, Idaho, Massachusetts, Mississippi, North Dakota, Rhode Island, South Dakota, and Wyoming. For some of the smaller states in terms of population, such as Wyoming or North Dakota, it is easy to dismiss the lack of response as related to the small number of pediatricians who practice in those states, particularly as oversampling procedures were not used. For instance, Wyoming had only 5 surveys mailed out and North Dakota only six.

What is harder to explain is why a state with a larger population of pediatricians—thus a larger number of surveys sent out—would end up with a return rate of zero. One hundred and forty-three pediatricians in Massachusetts, for example, received the request to participate, but none of the randomly selected participants from that state returned the survey. A similar result occurred with Georgia, with 131 surveys mailed out and none returned. It is not known whether these occurrences represent some kind of preexisting difference between these states and those with a high return rate or whether it is just a quirky result that has no discernable meaning.

Another possible weakness of this study is that of the 10 states that had a zero return rate, 4 of them are in the same geographical area across the Midwest and Central Mountain regions. Again, it is possible that this pattern reflects meaningful differences in attitudes and practice among pediatricians in these states, based on training, local practices, or state resources. However, without data for comparison, it is impossible to investigate the potential significance of these differences given the limitations of the present study.

In general, responses were obtained from all geographical regions of the continental United States, so it is believed that the results can be analyzed as representing pediatricians practicing in the United States despite the fact that some individual states had a zero response rate while some of their neighbors responded at a rate as high as 17%, and certain regions had relatively more states with a zero response rate. An investigation into possible state-by-state differences might yield interesting data, but for the purpose of this study, the results were presented as a whole national sample.

A further limitation of this project is one that any survey faces. Because the method of data collection relied on the accuracy of pediatricians' self-report rather than observation of actual practice, the data may not be as accurate as data collected using more reliable, direct observation methods.

A final limitation of this study is related to potential preexisting differences in the sample. Although the sample was drawn using accepted random sampling procedures, the title of the survey clearly stated the purpose of the study, which may have influenced who chose to respond and who chose not to. Pediatricians with a strong interest in general developmental issues or autism specifically may have been more likely to respond than those without that interest. It is also possible those who chose to respond represent a subset of pediatricians who are more knowledgeable than the larger population in terms of developmental screening.

Although the data do not seem to lead to any obvious differences in this sample, the fact that only 338 pediatricians out of nearly 4,000 chose to participate may indicate that these 338 participants are different in some significant way from the nonrespondents, which may limit the generalizability of the results from this data set. In addition, it is quite possible that this factor is related to the improvements in autism screening found in this study compared to other studies conducted recently. The data gathered from this survey should be cautiously interpreted as they may reflect an optimistic bias in terms of actual changes in screening practices.

Implications for Future Research

As with most projects, the limited scope of this one prevented many other important questions on this topic from being addressed. One major area of concern identified by this and previous studies is that of the barriers preventing primary care pediatricians from conducting routine developmental and autism-specific screening, using standardized screening tools, as recommended by published AAP practice guidelines. While some previously reported barriers (e.g., not enough time, inadequate reimbursement) seem to be decreasing over time, this current project highlighted a particularly persistent barrier: pediatricians' belief that they can identify developmental disorders, including autism, by relying on clinical judgment rather than by administering a standardized screener. More research in the area of barriers, particularly this one, needs to be done if we are to improve pediatric developmental screening practices. Changing beliefs and attitudes, especially those tied to physician competence, may prove much more challenging than making pediatricians more familiar with available developmental screening tools for instance.

Other research that may help to address the problem of routine screening for autism needs to focus on whether pediatricians are the best group to provide this screening or whether screening can and should be conducted by psychologists, physician assistants, nurses, nurse practitioners, or early intervention specialists. Studies that look more closely at how pediatricians are educated and trained on developmental and autism screening in medical school, residency, and fellowships are also needed. The majority of respondents in this study felt that there is a "High Need" for post-graduate training related to developmental delay and autism. Forty-four percent reported that the training on developmental screening specific to ASD they received in a residency and/or fellowship placement was either below average or nonexistent. It seems more logical and efficient to train physicians during their years of medical education, rather than attempting to retrain them when they are already in practice.

In addition, more research is needed to identify the types and modes of professional training that currently practicing pediatricians would be most likely to participate in. Clearly, the publication of AAP practice guidelines has not been sufficient in changing developmental screening practices to any appreciable degree. Nationwide, comprehensive programs are needed to address the identified barriers that currently exist, preventing pediatricians from following the practice guidelines.

The recent media coverage, spawned at least in part by the many families who have children affected by this disorder, has made autism a household word. Still, autism continues to baffle medical researchers. Scientists, parents, healthcare providers, clinicians, educators, and public policy-makers are all involved in the quest to better understand autism, to recognize the early signs of the disorder, to educate and manage problems behaviors of affected children, and hopefully, one day, to find a means of prevention. We do not currently have the knowledge or the means to prevent autism, but we do have the ability to catch most at-risk children at an early age and provide intensive services that will impact their development in a positive way.

The key to early detection of autism is for pediatricians to conduct routine screening of all children at specified well child visits, using standardized screening instruments. The specific procedures are outlined in the AAP practice guidelines, and validated screening tools are available. We know that the tools and the procedures are effective when implemented according to practice parameters. Currently, far too many children and their families wait unnecessarily long periods of time for diagnosis and implementation of early intervention services. It is a loss in terms of time, money, and human potential that we cannot afford to continue to ignore.

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APPENDICES

Appendix A Cover Letter to Sample Pediatricians

Dear Dr. ____________,

Your clinical expertise and 15 minutes of your time are needed to help us understand current developmental screening practices of primary care pediatricians in the United States. The goal of this study is to obtain a current description of pediatricians' developmental screening and referral practices and to identify further training needs. Results from this survey will add to the growing body of research aimed at improving our ability to identify, diagnose, and treat children with autism and other developmental disorders.

This project is supported by First Signs, Inc. (www.firstsigns.org), a leading national nonprofit organization dedicated to improving early identification and intervention of children with developmental delays and disorders, and The Center for Promotion of Child Development though Primary Care, (www.childhealthcare.org), developers of The Child Health and Development Interactive System (CHADIS), a web-based decision support tool that facilitates comprehensive pediatric care. This project has been approved by the Indiana University of Pennsylvania Institutional Review Board for the Protection of Human Subjects (Phone: 724/357-7730).

I am asking for your support in helping me make this project successful. I believe that pediatricians have a vital role in the early detection of autism and related disorders. As a parent of a child with autism and as a professional, I'm committed to efforts that will improve early identification and diagnosis of children with suspected developmental problems.

Your participation in this survey is voluntary. If you choose to participate, please click on the link below, and you will be directed to a secure website to take the survey. You may decide to not participate at any point while responding to survey questions up to the point where you actually click on the submit link. Once the data are submitted online, there is no mechanism for withdrawing it from the database. All responses are completely anonymous and confidential. All data will be sent to a secure database and will at no time be connected to individual participants.

Should you have any questions about this project, please contact me via telephone or email.

Thank you in advance for your support. I am excited to be working on a project that may help children with autism spectrum disorders be identified at earlier ages and referred for the intervention that is so critical to enhancing their developmental and educational outcomes.

Sincerely,

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Appendix B Developmental Delay Screening and Referral Practices:
Survey of General Pediatricians

DEVELOPMENTAL DELAY SCREENING AND REFERRAL PRACTICES: SURVEY OF GENERAL PEDIATRICIANS

Dear Physician, your responses to this survey will help to provide much needed information about the current developmental screening practices of primary care pediatric providers in the United States. Thank you in advance for your participation.

<u>This survey is intended for providers who practice general pediatrics.</u>

A. I am a pediatric sub-specialist.

[ ] Yes (please specify specialty area)______________________

(please estimate percent of time providing primary care)

[ ] < 10%
[ ] 10-25%
[ ] 25-50%
[ ] 50-75%
[ ] >75%

[ ] No

B. I am predominantly a primary care provider.

[ ] Yes
[ ] No

**note: either or both responses should take respondents to the rest of the survey

1. **<u>Primary care pediatric providers provide a broad array of preventive care services to their patients. When you are seeing a child 1 to 3 years of age for a well-child visit, how do you prioritize the following topics compared to developmental screening? Please check (√) the box that best represents your view:</u>**

	Much Lower	**Lower**	**Same**	**Higher**	**Much Higher**

Compared to developmental screening:	**Priority**	**Priority**	**Priority**	**Priority**	**Priority**
Car seats and transportation safety	[ ]	[ ]	[ ]	[ ]	[ ]
Counseling for immunizations	[ ]	[ ]	[ ]	[ ]	[ ]
Safe storage of household chemicals or weapons	[ ]	[ ]	[ ]	[ ]	[ ]
Behavioral counseling	[ ]	[ ]	[ ]	[ ]	[ ]
Counseling on diet and nutrition	[ ]	[ ]	[ ]	[ ]	[ ]

2. **On average, how many children (36 months of age or less) do you see in a month for a well child evaluation?**

[ ] 0   [ ] 1-10   [ ] 11-20   [ ] 21-30   [ ] 31-40   [ ] >40

3. **On average, how many children (36 months of age or less) do you see in a month during well child evaluations, who present with delays in language and/or social skills?**

[ ] 0   [ ] 1-5   [ ] 6-10   [ ] 11-15   [ ] 16-20   [ ] >20

<u>Please answer the following questions about GENERAL DEVELOPMENTAL SCREENING:</u>

4. **Do you routinely use a GENERAL DEVELOPMENTAL SCREENING TOOL for <u>well child exams</u>?**

[ ] No (*GO TO question 4 d*)
[ ] Yes (*GO TO question 4a*)

4a. Which of the following instruments do you use? Check (√) all that apply:

[ ] Denver or Denver II (DDST-II)

[ ] Revised Denver Prescreening Development Questionnaire (R-DPDQ)
[ ] Ages and Stages Questionnaire (ASQ)
[ ] Child Development Inventories (CDI)
[ ] Parents Evaluation Developmental Status (PEDS)
[ ] BRIGANCE® Screens
[ ] Early Language Milestone Scale (ELM)
[ ] Bayley Infant Neurodevelopmental Screener (BINS)
[ ] Another standard tool (please specify)___________________________________
[ ] My own instrument (describe briefly) ____________________

(*GO TO question 4b*)

4b. On average, how old are your patients when you begin using a general developmental screening tool?

[ ] 3 mos
[ ] 6 mos
[ ] 9 mos
[ ] 12 mos
[ ] 15 mos
[ ] 18 mos
[ ] 24 mos
[ ] Other:_______________________

(*GO TO question 4c*)

4c. How often do you conduct the general developmental screening?

[ ] Every well visit
[ ] Once a year
[ ] Only if parent expresses concern
[ ] Other (please specify ages of child at visits) __________________

(*GO TO question 5*)

4d. Why do you not routinely administer general developmental screening tools? Check (√) all that apply:

[ ] These screening tools are not effective
[ ] I am not familiar enough with general developmental screening tools
[ ] These screening tools are too costly
[ ] There is not enough time to screen
[ ] I do not receive adequate reimbursement for using screening tools
[ ] I rely primarily on clinical observations
[ ] Other (please explain briefly)_______________________________

(*GO TO question 5*)

Please answer the following questions about SCREENING AND REFERRAL FOR AUTISM SPECTRUM DISORDERS:

5. Do you routinely use any SCREENING AND/OR EVALUATION TOOLS SPECIFICALLY FOR AUTISM SPECTRUM DISORDER (ASD)?

[ ] No (*GO TO question 5c*)
[ ] Yes (*GO TO question 5a*)

5a. Which of the following tools do you routinely use? Check (√) all that apply:

[ ] Checklist for Autism in Toddlers (CHAT)
[ ] Modified checklist for Autism in Toddlers (M-CHAT)
[ ] Pervasive Developmental Disorder Screening Test (PDDST-II Stage One)
[ ] Childhood Autism Rating Scale Standardized (CARS)
[ ] Social Communication Questionnaire (SCQ), formerly the Autism Screening Questionnaire (ASQ)
[ ] Autism Behaviors Checklist (ABC)
[ ] Gilliam Autism Rating Scale (GARS)
[ ] American Academy of Neurology Practice Parameter—Indicators for Immediate Evaluation
[ ] An abbreviated version of a standard tool (please name)_________
[ ] My own instrument (describe briefly)__________________________
[ ] Other (please specify) _____________________________________

(*GO TO question 5b*)

5b. When do you typically conduct ASD screening? Check (√) all that apply:

[ ] If child fails general developmental screen
[ ] Every well child visit
[ ] Once a year
[ ] Parent expresses concerns or suspicions
[ ] You suspect ASD based on history/exam
[ ] Other (please specify when) ________________________________

(*GO TO question 6*)

5c. Why do you not routinely administer ASD screening tools? Check (√) all that apply:

[ ] ASD screening tools are not effective
[ ] I am not familiar enough with ASD screening tools
[ ] These screening tools are too costly
[ ] There is not enough time to screen for ASD
[ ] I do not receive adequate reimbursement for using these screening tools
[ ] I refer to a specialist
[ ] I rely primarily on clinical observations
[ ] Other (please explain briefly)___________________ ___________

(*GO TO question 6*)

6. **Please indicate the level of concern you would have for a child at each age listed who exhibits or is reported to exhibit the following behaviors. Check (√) one box for each age:**

**Note to web developer: Please make sure that only one response per ROW is available for A through E

A. No babbling

	No Concern	**Mild Concern**	**Not Sure**	**Moderate Concern**	**Strong Concern**
3 months	[ ]	[ ]	[ ]	[ ]	[ ]
6 months	[ ]	[ ]	[ ]	[ ]	[ ]
12 months	[ ]	[ ]	[ ]	[ ]	[ ]
18 months	[ ]	[ ]	[ ]	[ ]	[ ]
24 months	[ ]	[ ]	[ ]	[ ]	[ ]
36 months	[ ]	[ ]	[ ]	[ ]	[ ]

B. Lack of gesturing (e.g., pointing, waving bye-bye)

	No Concern	**Mild Concern**	**Not Sure**	**Moderate Concern**	**Strong Concern**
3 months	[ ]	[ ]	[ ]	[ ]	[ ]
6 months	[ ]	[ ]	[ ]	[ ]	[ ]
12 months	[ ]	[ ]	[ ]	[ ]	[ ]
18 months	[ ]	[ ]	[ ]	[ ]	[ ]
24 months	[ ]	[ ]	[ ]	[ ]	[ ]
36 months	[ ]	[ ]	[ ]	[ ]	[ ]

C. No single words

	No	**Mild**	**Not**	**Moderate**	**Strong**

	Concern	Concern	Sure	Concern	Concern
3 months	[ ]	[ ]	[ ]	[ ]	[ ]
6 months	[ ]	[ ]	[ ]	[ ]	[ ]
12 months	[ ]	[ ]	[ ]	[ ]	[ ]
18 months	[ ]	[ ]	[ ]	[ ]	[ ]
24 months	[ ]	[ ]	[ ]	[ ]	[ ]
36 months	[ ]	[ ]	[ ]	[ ]	[ ]

D. No 2-word spontaneous phrases

	No Concern	Mild Concern	Not Sure	Moderate Concern	Strong Concern
3 months	[ ]	[ ]	[ ]	[ ]	[ ]
6 months	[ ]	[ ]	[ ]	[ ]	[ ]
12 months	[ ]	[ ]	[ ]	[ ]	[ ]
18 months	[ ]	[ ]	[ ]	[ ]	[ ]
24 months	[ ]	[ ]	[ ]	[ ]	[ ]
36 months	[ ]	[ ]	[ ]	[ ]	[ ]

E. Loss of any language or social skills

	No Concern	Mild Concern	Not Sure	Moderate Concern	Strong Concern
3 months	[ ]	[ ]	[ ]	[ ]	[ ]
6 months	[ ]	[ ]	[ ]	[ ]	[ ]
12 months	[ ]	[ ]	[ ]	[ ]	[ ]
18 months	[ ]	[ ]	[ ]	[ ]	[ ]
24 months	[ ]	[ ]	[ ]	[ ]	[ ]
36 months	[ ]	[ ]	[ ]	[ ]	[ ]

7. **Approximately how many children in your current practice caseload have an Autism Spectrum Disorder (ASD), either diagnosed by yourself or another clinician? ______________**

8. **For how many of these children, were you the first to suspect ASD?_________**

9. **When you first suspect ASD, regardless of how you've become suspicious, what is usually your first course of action (assuming that**

there is no question about the child's hearing)? Check (√) ONE box in each column (corresponding to patient's age).

	For Patients Aged:		
	< 24 months	**2-3 years**	**4-5 years**
Administer an ASD screening tool	☐	☐	☐
Monitor symptoms and follow up	☐	☐	☐
Refer to a clinical specialist	☐	☐	☐
Refer to early intervention program or special education	☐	☐	☐
Other (please specify)____ _____	☐	☐	☐

**note to web developer: please make sure that only one response per COLUMN is available to respondents

10. **Whether a first or later action, to what kind of clinical specialist (s) do you refer a child you think may be exhibiting signs of ASD? Please number in rank order (1-5):**

☐ Psychiatrist
☐ Psychologist
☐ Neurologist
☐ Developmental Pediatrician
☐ Other (please specify)_________
____

11. **Which of the following factors influence where you refer a child with suspected developmental problems? (Check all that apply).**

☐ child's health care coverage (e.g., Medicaid, HMO, Private insurance)
☐ available local resources that specialize in developmental evaluations
☐ physician relationship with particular providers
☐ parent request for referral to a specific provider
☐ parent concern about privacy
☐ other; please specify___________________________________

12. **Please indicate which of the following you believe to be part of the current AAP guidelines for general developmental screening. (Check all that apply):**

☐ Developmental surveillance with formal screening only for suspect cases
☐ Developmental surveillance and eliciting questions about developmental milestones from parents
☐ Administer standardized developmental screen before every well child visit

[ ] Administer standardized developmental screen at ages 6, 12, 24, & 36 months
[ ] Administer standardized developmental screen at ages 9, 18, 30 or 24 months.

13. According your understanding of the current AAP guidelines on developmental screening, at which ages should you administer a standardized screen for autism? (Check all that apply):

[ ] 12 months
[ ] 18 months
[ ] 24 months
[ ] 36 months
[ ] 48 months

14. Please estimate how many times you or your office have used the CPT billing code 96110 for developmental screening in the past year:

[ ] Never
[ ] 1-10 times
[ ] 10-50 times
[ ] 50-100 times
[ ] Over 100 times

15. If you have used the CPT billing code 96110 for developmental screening, what percent of the time was it reimbursed? Does Medicaid reimburse for this 96110 code in your state?_______

[ ] Yes
[ ] No
[ ] Not sure

16. Please estimate how many times you or your office have used the CPT billing code 96111 for hands-on developmental assessment in the past year:

[ ] Never
[ ] 1-10 times
[ ] 10-50 times
[ ] 50-100 times
[ ] Over 100 times

17. If you have used the CPT billing code 96111 for developmental assessment, what percent of the time was it reimbursed? ____

18. Does Medicaid reimburse for this 96111 code in your state?

[ ] Yes
[ ] No

[ ] Not sure

<u>Please answer the following questions about your training and knowledge regarding Autism Spectrum Disorders:</u>

19. Indicate your level of confidence in your ability to perform the following (1 = no confidence, 2 = limited confidence, 3 = average confidence, 4 = above average confidence, 5 = high level of confidence)

	1	2	3	4	5
A. recognize the features of autism by observing an 18-month-old during a well child visit?	[ ]	[ ]	[ ]	[ ]	[ ]
B. recognize the features of mild developmental delay by observing an 18-month-old during a well child visit?	[ ]	[ ]	[ ]	[ ]	[ ]
C. answer typical questions about behavior and development voiced by parents of 18 month olds?	[ ]	[ ]	[ ]	[ ]	[ ]

20. Please rate your current level of expertise with the following (1 = no expertise, 2 = limited expertise, 3 = average expertise, 4 = above average expertise, 5 = advanced expertise):

	1	2	3	4	5
Current research-based understanding of the etiology of ASD	[ ]	[ ]	[ ]	[ ]	[ ]
Diagnostic criteria for ASD	[ ]	[ ]	[ ]	[ ]	[ ]
Warning signs indicating the need for further diagnostic evaluation for ASD	[ ]	[ ]	[ ]	[ ]	[ ]
Empirically supported interventions for ASD	[ ]	[ ]	[ ]	[ ]	[ ]

Where to refer children with

ASD in your community	[ ]	[ ]	[ ]	[ ]	[ ]

21. Through which of the following have you received specific instruction/training/experience on screening for Autism Spectrum Disorders? (check all that apply)

22.

[ ] Medical school
[ ] Residency
    [ ] lecture
    [ ] case discussion
    [ ] ward rotation
    [ ] continuity clinic
    [ ] developmental/behavioral rotation
[ ] Fellowship
[ ] Post-graduate CME
[ ] Reading professional journals/newsletters
[ ] Personal experience
    [ ] Family member
    [ ] Friend or acquaintance
    [ ] Other (please specify)
[ ] Lay press/media
[ ] None of the above

23. Please indicate to what extent you feel your residency and/or fellowship training prepared you to conduct developmental screening specific to ASD?

[ ] Not at all
[ ] Below average
[ ] Average
[ ] Above average
[ ] Exceptionally well

24. Please rate your belief of the current need for post-graduate training related to Developmental Delay and/or ASD for practicing pediatric providers.

[ ] No need
[ ] Low need
[ ] Moderate need
[ ] High need
[ ] Not sure

Please answer the following questions about yourself and your practice:

25. What is your age: ____________________(years)

26. What is your sex: [ ] Male [ ] Female

27. Which of the following best describes your race/ethnicity:

[ ] White, not of Hispanic Origin
[ ] Black, not of Hispanic Origin
[ ] Asian or Pacific Islander
[ ] Not Noted/Unknown
[ ] Hispanic
[ ] Native American
[ ] Other (please specify) ___________________

28. What year did you graduate from (fill in all that apply):
medical school: __ __ __ __
residency: __ __ __ __
fellowship: __ __ __ __

29. Are you board certified?
[ ] Yes [ ] No [ ] Not applicable

30. What is the Zip Code for the area where your office/practice is located:_____________________________

31. Which of the following best describes your current practice type:
[ ] HMO
[ ] Community Outpatient Clinic
[ ] Private Practice [ ] Hospital-based Clinic
[ ] Other (Please specify)________________________

32. What is the number of FTE pediatricians in your practice?

____

33. What is the number of PNPs in your practice? ____________________

34. What is the number of Physician Assistants in your practice?

____

35. Please estimate the number of active patients in your current practice:

___ ___ ___ ___

36. Please estimate the percent of patients with:

Medicaid __ __%　　No insurance __ __%

37. In the past year, have you (check all that apply):

☐ **Read guidelines on developmental or autism screening?**
☐ **Read CME materials re: developmental screening?**
☐ **Read CME materials re: autism screening?**
☐ **None of these**

38. Please indicate how likely you are to do the following in your practice:

	Never	**Rarely**	**Occasionally**	**Usually**	**Always**
Provide caregivers handouts in cases where developmental delay is suspected?	☐	☐	☐	☐	☐
Provide handouts to caregivers in cases where autism is suspected?	☐	☐	☐	☐	☐
Read about the topic of DD or ASD during or within a few days after a visit where that is a concern?	☐	☐	☐	☐	☐
Provide to caregivers written contact information with addresses and phone numbers regarding resources for children with developmental problems?	☐	☐	☐	☐	☐

Provide caregivers with maps that give directions to referral resources?	[ ]	[ ]	[ ]	[ ]	[ ]
Recommend books/articles for families to read re: developmental or mental health issues?	[ ]	[ ]	[ ]	[ ]	[ ]
Send clinical records about your patients with delays or ASD to early intervention?	[ ]	[ ]	[ ]	[ ]	[ ]
Send clinical records about your patients with delays or ASD to specialist consultants?	[ ]	[ ]	[ ]	[ ]	[ ]
Receive written information about your patients with delays or ASD from their early intervention or specialist professionals?	[ ]	[ ]	[ ]	[ ]	[ ]

39. What is the likelihood that you would attend the following types of Continuing Medical Education regarding developmental and autism screening? (1 = Not very likely, 2 = Possibly, 3 = Somewhat likely, 4 = Very Likely, 5 = Not sure):

	1	**2**	**3**	**4**	**5**
A. One-day seminar in my neighborhood	[ ]	[ ]	[ ]	[ ]	[ ]
B. One-day seminar in a city requiring overnight travel	[ ]	[ ]	[ ]	[ ]	[ ]

C. One-hour monthly Webcast discussions	[ ]	[ ]	[ ]	[ ]	[ ]

40. Please add any Continuing medical Education training types that were not mentioned above, and your likelihood of attending them:

____
____
____

41. Please use this space to ask questions or add any comments that you feel are relevant to this topic, but were not covered by the content of this survey:

____
____
____

……

Thank you! We really appreciate the time you took to complete this survey. The information you have provided will be used for analysis of overall patterns of developmental screening by pediatricians in the United States and will help to inform the development of educational programs on screening, referral and diagnosis of autism spectrum disorders.

Click on the Finish button to submit your survey responses.

Appendix C Follow-up Cover Letter to Sample Pediatricians

Dear Physician,

Two weeks ago, you received an invitation to participate in a developmental screening and referral survey. Please take a moment to read the survey invitation letter below and consider contributing 15 minutes towards this important project. I do appreciate the tremendous time demands placed on primary care physicians, and I thank you in advance for your help.

The goal of this study is to obtain a current description of pediatricians' developmental screening and referral practices, and to identify further training needs. Results from this survey will add to the growing body of research aimed at improving our ability to identify, diagnose, and treat children with autism and other developmental disorders.

This project is supported by The Center for Promotion of Child Development though Primary Care, (www.childhealthcare.org), developers of The Child Health and Development Interactive System (CHADIS), a web-based decision support tool that facilitates comprehensive pediatric care, and by First Signs, Inc. (www.firstsigns.org), a leading national nonprofit organization dedicated to improving early identification and intervention of children with developmental delays and disorders. This study has been approved by the Indiana University of Pennsylvania Institutional Review Board for the Protection of Human Subjects (Phone: 724-357-7730).

I am asking for your support in helping me make this project successful. I believe that pediatricians have a vital role in the early detection of autism and related disorders. As a parent of a child with autism and as a professional in the field of clinical psychology, I'm committed to efforts that will improve early identification and diagnosis of children with suspected developmental problems.

Your participation in this survey is voluntary. If you choose to participate, please follow the directions at the end of this paragraph, and you will be directed to a secure website to take the survey. You may decide to not participate at any point while responding to survey questions up to the point where you actually click on the submit link. Once the data are submitted online, there is no mechanism for withdrawing it from the database. All responses are completely anonymous and confidential. All data will be sent to a secure database and will at no time be connected to individual participants.

Should you have any questions about this project, please contact me or my faculty sponsor via telephone or email.

Thank you in advance for your support. I am excited to be working on a project that may help children with autism spectrum disorders be identified at earlier ages and referred for the intervention that is so critical to enhancing their developmental and educational outcomes.

Sincerely,

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