

## Chapter 5

# EARLY INTERVENTION PROGRAMS AND POLICIES FOR CHILDREN WITH AUTISTIC SPECTRUM DISORDERS

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Autistic Spectrum Disorder (ASD) is characterized by impairments in social interaction and communication along with restricted, repetitive, and stereotyped patterns of behavior. Social deficits manifest in avoidance of eye contact, failure to develop peer relationships, resistance of affection, high levels of isolated play, and limited play skills. The preference for being alone may persist as the child grows older. Approximately 30 percent of children with autism do not develop language. Children who do acquire speech often develop noncommunicative speech patterns, use language sparingly, and the language they do develop is often quite rote in nature. Speaking children with autism often exhibit a specific speech anomaly called *echolalia*, the repetition of words or phrases spoken by others. Disturbances of behavior may include a demand for sameness in the environment, ritualistic preoccupations (e.g., memorizing bus schedules; closing doors), or self-stimulatory behavior (e.g., hand flapping; spinning objects). Finally, these children may exhibit anomalies in their sensory responding including over- or under-response to sound, pain, touch, or light. While the severity of these symptoms varies across children and changes with development, they affect almost every aspect of social and psychological development. Children with autism face many of the same challenges at home, in school, and in the community as other children with mental health problems.

Most children with autism (as many as 75%) have impaired cognitive development such that their level of functioning falls into the mentally

retarded range. While higher-functioning individuals with autism can have average to above average abilities in several domains, they typically experience difficulty in some academic areas. A child with autism may be able to recite the dialogue from a movie, complete with voices and expression, yet rarely vary his voice when speaking with others. She may have no interest in playing with other children, instead choosing to engage in repetitive behaviors or playing with toys in unusual ways. As he gets older, he may seek attention from others but only to talk about his own interests. A young child with autism may show the remarkable ability to identify letters and numbers and “read” words but have delayed language abilities. An older child with autism may be able to perform well on standardized academic tests and yet have difficulty making it through school without special accommodations, and will often have difficulty holding a job.

These symptoms are pervasive and often severe, which can cause significant challenges to families. Families of children with autism exhibit higher levels of stress than parents of children with other disabilities (Holroyd & McArthur, 1976). Many parents report feeling their child is not emotionally attached to them. In some cases, children may have some social attachment to their parents, which often manifests as extreme clinging to parents in new situations, or the affection may be odd, such as hugging parents backwards or enjoying physical contact only in the context of rough-and-tumble play. Difficulties with communication often cause frustration. This frustration, along with sensory sensitivities, can lead to issues such as severe tantrum behavior, nutrition issues (from limited food preferences), and dental problems (from refusal to brush teeth). Some children have difficulty with crowded places and therefore cannot go to the grocery store or a restaurant. This can severely limit family mobility. Parents struggle with their child’s inability to engage with peers or play appropriately. Children with autism often need constant supervision, have difficulty sleeping, and because they do not use their parents as a secure base, may run off easily. As we will see, families also struggle with obtaining an appropriate diagnosis as well as adequate treatment for their children, often paying out-of-pocket for many essential services. Autism is a disorder that affects the entire family for a lifetime.

Autism is now more commonly seen as a spectrum of disorders (Lord & Bailey, 2002). This includes Autistic Disorder, children with more “classic” symptoms of autism; Asperger’s Disorder, children with average to above average cognitive abilities and less severe communication problems; and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), children who have many of the symptoms associated with Autistic Disorder but do not meet the full diagnostic criteria (American Psychiatric Association, 2000). The prevalence of ASD is approximately

60 per 10,000 (Fombonne, 2003), which makes them more common than previously thought but lower in incidence than other child mental health problems. It appears that better identification, broader categorization, and the growth of available services have contributed to the increased number of children being identified with ASD and requiring specific educational interventions.

The specific causes for autism are not clear. Data from family and twin studies suggest that there is a genetic component in autism. Studies have found a variety of genetic abnormalities associated with autism; the genetic underpinnings are complex and related to a variety of factors. A number of studies are currently being conducted to determine the genes that appear to be most commonly affected in children with autism. Across a number of brain imaging and postmortem studies, a range of structural and functional abnormalities in the brain have been identified in children and adults with autism (for review, see Akshoomoff, Pierce, & Courchesne, 2002). More recent findings suggest that brain growth abnormalities occur early in postnatal development, before the behavioral symptoms become apparent, and may vary with the functional outcome of the child (Akshoomoff et al., 2004; Courchesne, Carper, & Akshoomoff, 2003).

The authors of a report about a group of 12 children with pervasive developmental disorders raised the possibility that there was a link between the gastrointestinal problems observed in the children, the development of autism, and the measles, mumps, and rubella (MMR) vaccine. Although this suggestion has led to a great deal of concern about the safety of the MMR vaccine (Horton, 2004), epidemiological studies have not supported the relationship between prevalence of autism and the MMR vaccine (Institute of Medicine, 2001; Madsen et al., 2002; Taylor et al., 2002). Ten of the authors of the original study that suggested this possibility published a retraction of that interpretation of their data (Murch et al., 2004). Others have raised concerns that perhaps it is the mercury-based preservative in the vaccines, thimerosal, that is linked to the development of ASD. A review of 10 epidemiologic studies and 2 pharmacokinetic studies of ethylmercury concludes that there is not sufficient evidence to demonstrate a link between thimerosal-containing vaccines and ASD (Parker, Schwartz, Todd, & Pickering, 2004). The pharmacokinetics of ethylmercury also appear to make such an association less likely.

## EARLY IDENTIFICATION AND DIAGNOSIS

Recent progress has been made in the early identification of children with autism, and most children are now identified in the early preschool ages (Charman & Baird, 2002). Primary healthcare providers and other

professionals who interact with very young children have more information available to them about the early features of autism, and screening tools have become more readily available.

Not all parents may be aware that their child is showing delays in their development or exhibiting unusual behaviors. However, parental concerns have been shown to be an important early indicator for children later diagnosed with autism. Screening questionnaires were never intended to be a diagnostic “gold standard,” particularly for low-base-rate disorders. When the parent or the primary care provider raises concerns about a young child, the child should then be referred for a comprehensive evaluation. While parents may be concerned about labeling, and primary care providers may be concerned about incorrect diagnosis or alarming the parent unnecessarily, the referral should be viewed as a standard follow-up practice to a failed screening and the potential for early intervention, if deemed necessary. A general medical examination and a hearing test should be part of the initial screening process.

Diagnostic accuracy has been a critical area of investigation for autism researchers for a number of years due to the increasing number of studies aimed at uncovering the underlying biological causes and concern about increased prevalence rates. Diagnostic precision is perhaps less of a concern among community professionals responsible for identifying children with ASD who may benefit from early intervention programs. However, children under the age of four who appear to have an ASD should be considered to have a “provisional diagnosis” for a number of reasons (Lord & Risi, 1998; National Research Council, 2001). In very young children, it may be difficult to differentiate the symptoms of autism from language delay or global developmental delays. A proportion of children identified with “possible autism” before age three may not meet criteria for DSM-IV Autistic Disorder at later follow-up but are highly likely to meet criteria for PDD-NOS, a less severe form of autism. Alternatively, children under age four may not show significant evidence of repetitive and stereotyped behaviors and restricted patterns of interest as required to meet the DSM-IV criteria. The use of a standardized observation of social and communicative behavior and play, such as the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 2001), is critical for determining how the young child’s behavior fits within the developmental context and may warrant a diagnosis. The ADOS may be more sensitive and stable over time than the use of a standardized parent report measure (such as the Autism Diagnostic Interview-Revised [ADI-R]; Lord, Rutter, & Le Couteur, 1994) alone. As the child gets older and receives intervention, repeated assessment, including the use of a tool such as the ADI-R, is necessary for diagnostic clarification and to assist in treatment planning.

The ADI-R and the ADOS are complementary diagnostic instruments originally created for research that are now available for clinical purposes. It is not known how useful they will be in community settings or schools, where the mix of developmental problems is wide compared to specialty clinics or research studies targeted towards children with ASD. Research indicates that experienced clinical judgment using information from a variety of sources is more reliable for determination of diagnosis in very young children than the use of standard assessment instruments alone.

Given the increasing population of children with autism in the community, earlier diagnosis for this population, and the cost of intensive services provided by many agencies, the effectiveness of assessment is increasingly important. Several reports have concluded that the proper assessment should consist of a formal multidisciplinary evaluation of social behavior, language and nonverbal communication, adaptive behavior, motor skills, atypical behaviors, and cognitive status by a team of professionals experienced with autistic spectrum disorders (Charman & Baird, 2002; National Research Council, 2001). This will typically include an experienced clinical psychologist or school psychologist, a speech/language pathologist, and an occupational therapist. Many children with ASD experience difficulties with fine motor coordination, low muscle tone, behavior control and aggression, and/or the presence of a seizure disorder, warranting a consultation with an experienced pediatric neurologist or child psychiatrist. While experts agree that experienced professionals are needed for proper assessment, a formal definition of "experience" is lacking.

Two "best practices" guidelines from California present a list of instruments for diagnostic assessment, developmental assessment, adaptive assessment, communication assessment, standardized tests of intelligence and nonverbal intelligence, and behavior assessment (California Department of Developmental Services, 2002; California Departments of Education and Developmental Services, 1997). Limited specific information is provided about reliability, validity, and training requirements for each instrument. Limited information about the utility of these instruments in educational settings is available. This type of "best practices" guide therefore has limited practical value for professionals responsible for assessment in the schools or for clinicians who are asked to provide assessment information and recommendations for the child that will be utilized by the school.

### **SERVICE SYSTEMS FOR CHILDREN WITH ASD**

During the past 25 years, the United States has developed systems for providing early intervention services for children with developmental disabilities, including autism. In 1990, when Congress updated Public Law

94–142 and changed the title to the “Individuals with Disabilities Education Act” (IDEA; P.L. 101–476), the term “autism” and its definition was added to the previous list of disability terms and definitions. Many schools and early intervention programs did not have services specific to the disorder before that time. A number of amendments followed (IDEA’97; P.L. 105–117), which include provisions for full, individualized, and appropriate evaluations and educational services to be provided by the local schools.

Under IDEA, Congress made funds available to help states and territories provide additional services for children with special needs, including school-age children as well as infants, toddlers, and preschoolers. A majority of states have chosen to provide one set of services for children ages birth to three and a different set of services (usually provided by the school district) from three to five years of age. States are following federal breakdowns of services in doing this, as the government has provided different guidelines for children in each of these age categories. For children under age three, services (educational and otherwise) can be provided by the education system, the mental health system, the Department of Health and Human Services, and/or the developmental disabilities agency. Infants and toddlers with autism or at-risk for an autistic spectrum disorder are served under the category “other health impaired.” Services for children ages three to five follow the same regulations as those for school-age children with autism and are primarily provided by the school district, which provides educational services. Other agencies may be responsible for behavioral intervention, parent support, and so on. Service intensity, type and amount of family support, service quality, and the agency responsible for service coordination vary greatly state by state and even city by city. Only a few states provide comprehensive services in a single system from birth through five (e.g., Oregon).

Some states (e.g., Delaware, North Carolina, Florida) have service agencies that provide services to children with autism specifically. However, the majority of states serve children with autism using the same service providers as children with other disabilities. Other states, such as California, provide differential services for children with autism (e.g., different intervention techniques, increased intensity), but use the same service pathways as are used for other children with disabilities. All states are required to provide an Individual Family Service Plan (IFSP) for each child under the age of three, which outlines goals and services needed to reach those goals, including family-centered services. At age three, the school district provides an Individual Education Plan (IEP) that focuses solely on the needs of the child who qualifies under Special Education law. IDEA also requires that states use treatments that have an evidence base and that a fair and appropriate public education (FAPE) is provided.

The diagnosis of autism typically occurs between 24 and 36 months of age, at which time the early intervention system develops an IFSP for the family. As a part of this process, service providers develop a relationship with the family and set up an initial intervention program based on the needs of the child and the policies of the area in which the child lives. Unfortunately for children with autism, very soon after early intervention begins (when the child reaches 36 months of age), many families must transition to a new system with different eligibility criteria, service provision, and standards for family participation. Additionally, the services provided are not typically coordinated across agencies such that families may not receive the same level or type of services once their child turns three. The lack of coordination and planning between these systems can lead to conflict, confusion, and litigation for families of children with autism and the school system (Schreibman & Anderson, 2001).

In general, federal guidelines for the administration of early intervention programs provide individual states with a large amount of decision-making authority in order to make programming appropriate for families in their own area. This has led to many different methods of administering services for children with or at risk for developmental disabilities. The federal regulations do not offer any specific guidelines for administering programs for specific disabilities such as autistic spectrum disorders. Systematic studies of the effect of service systems are imperative for the development of appropriate programming and service delivery for this population. Additionally, a cursory examination of state policies did not lead to an understanding of the actual services children and families receive. States appear to have very similar services on the surface; however, further investigation indicates that services may differ for children in the same city, and even in the same school district.

Numerous litigation cases over the appropriate identification of and the development of educational services for children with ASD have occurred over the past decade (Yell, Katsiyannis, Drasgow, & Herbst, 2003). Many more disputes are resolved through mediation or due process hearings. While these processes ensure that school districts and early intervention agencies comply with regulations, they are often associated with high costs and controversy. Disputes and procedural violations are often associated with a failure to evaluate all areas of the student's need, having evaluations conducted by school personnel with no knowledge of autism or appropriate evaluation procedures to assess students with autism, developing inadequate IEPs or IFSPs, not adequately involving parents in the IEP or IFSP process or informing parents of their procedural rights, and not having qualified personnel needed to work with students with autism.

### PROVISION OF DIAGNOSTIC SERVICES

Who is responsible for providing a comprehensive multidisciplinary evaluation? Although nationwide data are not readily available, medical professionals through their healthcare plan probably most commonly evaluate children diagnosed with autism when they are young and then they are reevaluated by state services agencies and/or their local school districts. These agencies also follow the children to assess continued need for and effectiveness of services. The National Research Council's Committee on Educational Interventions for Children with Autism (NRCA) recommended that if the school system cannot carry out a formal multidisciplinary assessment, the local education authority should fund the assessment through external sources (National Research Council, 2001). However, the provision of such services may not necessarily be the responsibility of the local school district, depending on the child's age, location, and the extent of the evaluation. For children over the age of three, the California Department of Developmental Services stated, "The educational system is not responsible for providing concomitant medical or other diagnostic evaluation services that may be necessary for a comprehensive interdisciplinary evaluation. Thus, while it is necessary to refer families of children with ASD and other developmental disabilities to the school district for special education services, referral to a comprehensive diagnostic team is usually necessary for a full diagnostic evaluation" (California Department of Developmental Services, 2002).

Colorado has interpreted IDEA'97 such that trained school personnel can be involved in making the *educational diagnosis* rather than requiring a differential *medical diagnosis* to determine eligibility for special education services (Noland & Gabriels, 2004). They acknowledge that it is important for school personnel to know when to refer an identified child to a physician. It is thus clear that differences across states with regard to the IDEA definition of the autism category make it difficult to use prevalence estimates based on students enrolled in the autism category, which may be limited to their interpretations of the educational diagnosis rather than the more specific medical diagnosis required for epidemiological studies (Noland & Gabriels, 2004).

Experts agree that school districts should have professionals with expertise in the area of autism conduct comprehensive and individualized evaluations of referred students. This again raises the question of how to define "expertise." If a school district's personnel do not have the necessary expertise, the school district must either train their personnel or hire outside consultants to conduct the evaluations (Yell et al., 2003). This is an issue that is not easily resolved.

Using funds provided to the state through Part B of IDEA'97, a multi-disciplinary evaluation team was developed in two rural school districts in Colorado (Noland & Gabriels, 2004). Implementation of the project involved training, purchase of instruments associated with best practices for screening and assessing ASD, and supervision from an outside consultant with extensive experience in the assessment and treatment of children with ASD. This model is appealing because it utilizes evidence-based practices, includes provision for both assessment and intervention services, uses a team approach, and provides necessary training for school personnel rather than relying on a more expensive outside consultant approach. Further research is needed to determine how well this program can be maintained without additional funding, and the degree to which this program improves identification and service delivery compared to standard practice. Before such a program is implemented in other school districts, consideration needs to be given to whether any modifications may have an impact on reliability and validity and cost effectiveness.

## TREATMENT

Although we continue to have a poor understanding of the etiology of autism and early development of the disorder, recent research in the field of autism has heavily emphasized the importance of early intervention (i.e., treatment before the age of four years). This emphasis may be attributed in part to results of treatment studies suggesting substantial gains may be achieved when treatment is provided at a very early age (National Research Council, 2001). Treating children with autism at an early age is the best hope we currently have for "preventing" the most severe cases of the disorder. Gains made by children with autism in early intervention programs may result in a cost savings of nearly one million dollars by the time a person with autism reaches 55 years of age (Columbia Pacific Consulting, 1999).

Although children with ASD may face significant limitations (i.e., mental retardation, severe autistic symptoms), and the initial causes of the disorder are believed to be biological, it is important to remember that the environment has a significant influence on the outcome of the child, including the development of the brain. Although early intervention is critical for optimizing outcome, intervention should not end after age five. It is also important to note that if a child is not diagnosed until a later point in development or did not receive early intervention services, behavioral and educational intervention services can still have a major impact on promoting development and the best possible outcome.

Currently, no treatment method completely ameliorates the symptoms of ASD and no specific treatment has emerged as the established standard

of care for all children with ASD. Several methods have been demonstrated to be efficacious with some children in research settings. The most well-researched programs are based on the principles of applied behavior analysis. Treatments based on behavioral principles represent a wide range of early intervention strategies for children with autism. These range from highly structured programs that are conducted in a one-on-one treatment setting to behaviorally based inclusion programs that include typically developing children as models.

The first types of treatment programs researchers developed and examined were highly structured, very intensive, one-on-one programs, which were shown to be highly effective for as many as half of children enrolled (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993). However these intensive programs were very expensive and children often had difficulty generalizing the information they learned into group and community settings. To remedy this issue, researchers began using less structured, more naturalistic, behavioral programming in both individual and school settings (e.g., Schreibman & Koegel, 1996). Children had greater generalization of skills, and these programs were more easily adapted for use in parent education and training programs (Schreibman, Kaneko, & Koegel, 1991). Again, approximately half of the children have good outcomes in these types of programs. Studies of inclusion models (educating children with autism alongside typically developing peers) using naturalistic behavioral techniques also report positive results for children with autism. As with studies of in-home programs, inclusion programs lead to as many as 50 percent of children being mainstreamed into regular education programs (McGee, Morrier, & Daly, 2000). Other behavioral techniques are also reporting promising results. Some techniques involve comprehensive educational programs, while others focus on one area of difficulty, such as communication or problem behaviors.

A few techniques that are not behavioral in nature are beginning to demonstrate effectiveness as well. Some of these are functional techniques that use structured environments, visual cueing, and other strategies to assist children with autism in navigating their environments. Case studies and studies of components of these techniques are supportive of treatment efficacy (e.g., Panerai, Farrante, & Zingale, 2002). Developmental models have also shown some promising results and, again, indicate that about half of the children do very well (Greenspan & Weider, 1997). In addition, many model programs for early intervention have shown success using the techniques described above or a combination of techniques (for a complete description of several model programs see Handleman & Harris, 2001).

Some researchers believe that combining treatments in a systematic way may be most appropriate (e.g., Rogers, 1996; Siegel, 1996), as the

exclusive use of one treatment method may ignore important aspects of social, emotional, communicative, or preacademic development. Early studies indicate that combining methods is a promising avenue to pursue (e.g., Stahmer & Ingersoll, 2004); however, some researchers feel it may actually be detrimental to learning, confuse the children, and reduce the fidelity with which any one treatment is administered (e.g., McGee, Morrier, & Daly, 1999). Community programs typically report using more than one method; therefore, continued research on the efficacy of treatment combinations is imperative.

The medications most commonly used in the treatment of individuals with ASD are directed toward improving the associated symptoms of the disorder, such as hyperactivity, aggression, irritability, and agitation, to increase the likelihood that the child will benefit from behavioral and educational programs. While improvement in core symptoms is unlikely to result from medication use, some aspects of social behavior may improve as a result of the reduction in associated symptoms.

Recent, well-controlled studies have focused on the atypical antipsychotic medications, most notably risperidone. In the largest controlled drug treatment study in autistic disorder to date, the RUPP Autism Network completed a randomized controlled trial of risperidone in 101 children with autistic disorder (McCracken et al., 2002). Treatment for eight weeks was effective in reducing tantrums, aggression, or self-injurious behavior in children with autistic disorder. Side effects included weight gain, increased appetite, fatigue, drowsiness, dizziness, and drooling. In an open-label, naturalistic study of 53 preschoolers with ASD, low-dose risperidone was associated with reducing behavior problems and affect dysregulation (Masi, Cosenza, Mucci, & Brovedani, 2003). Few controlled studies of selective serotonin reuptake inhibitors have been completed (McDougle & Posey, 2003). Studies of fluvoxamine (Luvox) suggest that it may be less efficacious and less tolerated in children and adolescents with ASD than adults (McDougle et al., 1996). Studies of fluoxetine (Prozac) indicate favorable results, although possible side effects include hyperactivity, agitation, decreased appetite, and aggression (Cook, Rowlett, Jaselskis, & Leventhal, 1992). The use of psychostimulants (e.g., Ritalin) has generally resulted in mixed results (McDougle & Posey, 2002). While motor hyperactivity and poor attention may improve in some children with autism, adverse side effects of aggression and irritability have been noted. There is some interest in the use of clonidine and guanfacine, particularly for those children and adolescents with ASD who are nonresponders to psychostimulants. All medications should be prescribed by an experienced specialist with regular monitoring.

There has also been a proliferation of treatments that do not have an evidence base. Perhaps due to the limited understanding of the disorder, the heterogeneity of the children, or the splinter skills often seen in this population, hope for a miracle treatment among parents and some professionals has been extremely high. Promoters of specific treatments often report dramatic results in a few children but do not have scientific data to support their claims. Often extensive media coverage and the enthusiasm of families looking for a cure provide an avenue for dissemination of unproven methods. While some of these methods may be effective for some children, there is currently no evidence to support them. Therefore, clinicians and families are advised to proceed with caution when examining methods that promise a cure for all children on the autism spectrum.

### **EXAMINING EVIDENCE-BASED PRACTICES FOR AUTISM**

Thus far, direct comparison of specific behavioral treatment methods has not been conducted. Therefore, no one program can claim to be more effective than another, nor are we able to predict efficacy of individual treatment methods for specific children (Feinberg & Vacca, 2000; Lord et al., in press). Researchers are beginning to compare methods directly; however, this has proved difficult due to differences in assessment procedures and populations served. Additionally, parents are hesitant to allow their child to be randomly assigned to a specific treatment method at such a critical stage in development. Therefore, choosing a specific treatment for use with a particular child can be difficult for families and community providers.

Recently, there have been several movements to deal with the proliferation of multiple treatment methods for children with autism. The first involves the development of best practice guidelines, which either list common practices used with children with autism, or include a critical assessment of available practices. Some best practice guidelines list the majority of treatments available for children with autism, without regard for whether or not research has shown these treatments to be effective (California Departments of Education and Developmental Services, 1997). Others consider the limited experimental evidence for treatment efficacy when defining best practice (New York State Department of Health Early Intervention Program, 1999). However, these guidelines still offer no recommendations for specific strategies to be used or how to choose a strategy for a specific case.

Secondly, in order to address the multiple treatments that appear to be effective, as well as the possibility that a combination of treatments

may be necessary, researchers have delineated some elements common to various treatments. Several researchers have reviewed programs and techniques with both published descriptions and intake and outcome data (Dawson & Osterling, 1997; Hurth, Shaw, Izeman, Whaley, & Rogers, 1999; National Research Council, 2001). Iovannone, Dunlap, Huber, & Kincaid (2003) examined those reviews and expanded them to include not only early intervention, but also recommendations for school-age children as well. Table 5.1 depicts common elements found across reviews of effective practices. These critical elements are common across many of the techniques listed in best practice guidelines and may be more important to child outcome than the use of individual programs or philosophies.

The heterogeneity and developmental nature of the disorder make it unlikely that one specific treatment will be best for all children, or will work for any one child throughout his or her educational career. Because there is always a subset of children who do not respond favorably to each of the studied treatment methods, many researchers recognize the need for the individualization of treatment based on specific characteristics of the individual child and family (Anderson & Romanczyk, 1999). The goal, then, is not to find the perfect treatment, but to identify the important variables that influence the effectiveness of specific interventions for each child. Research that furthers our understanding of how to match clients with efficacious treatments will enable consumers to make better choices between procedures, decrease the outcome variability that characterizes early intervention research at present, and provide for the most efficient allocation of resources during the critical early intervention time-period. This type of research is in its infancy but is imperative if we are to determine a priori which treatment method will be most effective for a specific child.

This line of research may lead to guidelines similar to those available for other mental health disorders, such as childhood depression, in which practice guidelines have been developed for both adults and children with the disorder (American Academy of Child and Adolescent Psychiatry, 1998; Karasu, Gelenberg, Merriam, & Wang, 2002). Treatment recommendations vary based on many individual case factors, such as the severity of the disorder, age/developmental level of the individual, family involvement, motivation for treatment, and comorbid features. These factors are considered when choosing the first route of treatment as well as in treatment adjustment and maintenance. Like autism, this disorder is being recognized at younger and younger ages, and the development of new treatments and assessment methods for this age is essential. As is the case with all childhood disorders, numerous child and environmental factors that must be examined in order to obtain appropriate guidelines that

**Table 5.1**  
**Comparison of Commonality Studies. (Adapted from Iovannone et al., 2003.)**

<i>Component</i>	<i>Powers (1992)</i>	<i>Dawson and Osterling (1997)</i>	<i>Hurth et al. (1999)</i>	<i>National Research Council (1999)</i>	<i>Iovannone et al. (2003)</i>
Supportive/structured learning environment	X	X	X		X
Family involvement	X	X	X	X	X
Early intervention	X		X	X	
Specialized curricula focusing on communication and social interaction	X	X	X	X	X
Integration with typical peers	X				
Predictability and routine		X			
Functional approach to problem behaviors		X		X	X
Planned transitions between preschool and kindergarten/first grade		X			
Individualization of supports and services			X	X	X
Systematic, carefully planned instruction			X	X	X
Intensity of engagement			X	X	
Developmentally appropriate practices				X	

have a research base but are also flexible enough to manage complex cases complicate assessment and treatment.

In summary, while positive results have been reported for many treatment methods, there are no autism treatments that currently meet criteria for well-established or probably efficacious, empirically-supported treatment (Lonigan, Elbert, & Johnson, 1998). Additionally, due to the heterogeneity of the disorder and the changing needs of children with autism as they

develop, it is unlikely that one specific treatment will emerge as the treatment of choice for all children. Currently, researchers and clinicians must use their judgment and training to choose the most suitable methodology for a specific child. Critical elements have been defined that can assist in the development of treatment programs. Eventually, a prescriptive method of choosing treatment based on child and family characteristics may be developed.

### **TRANSLATION OF EVIDENCE-BASED PRACTICE TO COMMUNITY SETTINGS**

Research in other areas of child psychotherapy indicates the importance of examining outcomes of children when translating research-based treatments into systems settings. There is a large body of work that shows that psychotherapeutic treatments delivered in highly controlled studies can produce improved clinical and functional outcomes for children. In contrast, research comparing children receiving treatment in a community setting with those receiving no treatment found that there were no differences between treatment and no-treatment groups in terms of outcomes (Weisz, Weiss, Han, Granger, & Morton, 1995). This highlights the need to examine the use of efficacious programs for children within a system setting.

The outcome data for the treatment methods designed for children with autism comes from highly controlled research programs. Research examining the effectiveness of any of these techniques in the context of service systems, such as early intervention programs, community clinics, and schools is lacking (National Research Council, 2001). There are many potential differences between the research intervention programs and community settings. Schools that attempt to replicate research models often do not have the funding to replicate all aspects of the research program. For example, it is likely that very few early intervention programs in community service systems are currently providing the same intensity of services as the research programs, which often schedule 20 to 40 hours per week of programming (e.g., Handleman & Harris, 2001). In addition, research programs have rigorous fidelity of implementation standards to ensure appropriate application of the treatment. These standards have not been translated to community settings due to limited training, limited time for measurement, and complexity of fidelity measures. Quality control in community programs (both public and private) is extremely variable and staff turnover is high. These factors may greatly alter the effectiveness of research-based treatment strategies and may result in poorer outcomes for children with autism.

Legislators and researchers are currently emphasizing the delivery of research-based practices in many areas of child mental health, including disruptive disorders, attention deficit disorders, childhood depression, and autism services (National Research Council, 2001). Therefore it is critically important to examine the attitudes and experiences of treatment providers in community-based settings as we attempt to move these practices into service settings. A recent paper asked early intervention providers about specific treatment use in autism programs (Stahmer, Collings, & Palinkas, 2005). Although many treatment providers were supportive of the use of evidence-based techniques, most did not have a good understanding of the research. While most of the providers reported using at least one evidence-based technique, these same providers were just as likely to report techniques with no published research reports. Additionally, all of the providers stated that they modified existing methods to fit the needs of their specific program and therefore were not using the methods as they were researched.

These findings provide insight into recommendations for successful translation of research-based practices into intervention programs for children with autism and highlight the need for effectiveness trials. Pragmatic issues regarding the use of the techniques in classroom and group settings must be addressed. Validity concerns when techniques are combined or modified should also be examined.

### **FUTURE DIRECTIONS**

Although the autistic spectrum disorders are relatively less common than other child mental health problems, they have become more commonly identified in recent years, particularly with the establishment of autism as a category for special education and early intervention services under IDEA. These disorders are complex in their presentation and service needs, causing confusion and concern among parents wanting the best for their children and service providers who must determine need and allocate resources for services.

Some of the major service issues for children with autism and their families that need to be addressed include the inconsistency of services in various areas of the country, individualization of services, and eligibility for services. Families in different states, and even districts in the same county, may receive very different services in terms of type, intensity, and quality. Additionally, the transition from the earliest intervention (birth to three) to the preschool programming needs to be examined. This transition comes at a period when children with autism are first receiving a diagnosis, and this sometimes difficult transition may affect treatment efficacy.

Additionally, very few of the research programs described have taken family variables into consideration, even though it is clear that family variables play a role in the type of services a child receives. Family structure, culture, resources, and support may be very important to the intensity and types of services children are receiving (Dunlap, 1999). Research in the area of special needs indicates that parents with more limited skills and/or resources are less likely to receive intensive services for their children. The most intensive services are received by children whose parents have time and resources to negotiate effectively for those services (Mahoney & Filer, 1996). Families with increased financial resources also often supplement services with privately funded therapies, thereby increasing the intensity of programming. Families with higher educational levels and/or access to information regarding the possibility of legal action may take an agency to fair hearing in order to obtain appropriate programming for their child. Many agencies that now use research-based treatments do so because they have been ordered to do so by the courts. Consequently, an abundance of active families in an area may lead to an increased use of research-based programs in community early intervention and school-based programs. A lack of such families, or an increase in families with high stress and low resources, may lead to a shortage of evidence-based services for these children.

As in other areas of mental health, few efficacy studies have included sufficient numbers of ethnic minority children to permit generalization across cultures. Efficacy studies in autism have rarely examined efficacy for ethnic minority groups separately, and most do not even provide information about the race/ethnicity of the subjects. This lack of research is a concern given the widespread recognition that culture has a powerful impact on service utilization, treatment attendance, parenting, and other service-related factors (e.g., McCabe, Clark, & Barnett, 1999). Available data suggest that children from ethnic minority backgrounds are more likely to be diagnosed and receive treatment at a later age than white children, for reasons that do not appear to be due to race alone (Croen, Grether, & Selvin, 2002). Parental immigrant status, language barriers, access to quality health care, level of parental education, and social support are among the factors that have been hypothesized to lead to suboptimal identification, diagnostic accuracy, and access to early intervention services for these children.

Early intervention research looking at the system of services provided to young children clearly indicates that early intervention is highly effective for children who are at-risk for, or have a developmental disability. Guralnick (1993) suggests that it is time for a second generation of early intervention research that looks more specifically at child characteristics, family

characteristics, and program features that can better enhance outcomes. One way to assess programming is by looking at the specific needs of a particular population of children, such as children with ASD. Because of the pervasive nature of this disorder, and the severe difficulties these children have with learning from their environment, it appears that a higher-intensity treatment with relative specificity to the needs of the child and family at each stage of the disorder is necessary. No research to date has looked at how our system of early intervention provision affects this disorder, or how specific family and child characteristics may affect the system.

State agencies across the country are working to determine the best way to provide services to children and families dealing with this very difficult and pervasive diagnosis. However, empirical data regarding accuracy of diagnostic and functional assessment for children being served by public agencies are lacking. Improvement in diagnostic and assessment practices through public schools was identified by the NRCA as one of the highest priorities in developing and disseminating services for children with ASD (National Research Council, 2001).

There is a large gap between the diagnostic and treatment methods used for controlled research studies and the practices employed in community and school settings for children with ASD. This is an area that we are currently investigating in our research studies. The first step is to determine what standard practices are currently employed in community and school settings and the rationale behind these practices. When conducting services research, it is essential to determine the constraints of the system, issues related to service provider experience and background, and willingness for change. Models of assessment and treatment derived from research studies may need to be modified before they can be implemented within individual community settings. However, these modifications need to be limited so as to not compromise the effectiveness, reliability, and validity demonstrated in controlled studies. We hope to find effective ways to bring more evidence-based practices into community and school settings to improve the delivery of services for children with ASD.

## REFERENCES

- Akshoomoff, N., Lord, C., Lincoln, A.J., Courchesne, R.Y., Carper, R.A., Townsend, J., & Courchesne, E. (2004). Outcome classification of pre-schoolers with autism spectrum disorders using MRI brain measures. *Journal of the American Academy of Child and Adolescent Psychiatry*, 43, 349–357.
- Akshoomoff, N., Pierce, K., & Courchesne, E. (2002). The neurobiological basis of autism from a developmental perspective. *Development and Psychopathology*, 14, 613–634.

- American Academy of Child and Adolescent Psychiatry. (1998). Practice parameters for the assessment and treatment of children and adolescents with depressive disorders. AACAP. *Journal of the American Academy of Child and Adolescent Psychiatry*, 37(10 Suppl.), 63S-83S.
- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4th rev. ed.). Washington, DC: American Psychiatric Association.
- Anderson, S. R., & Romanczyk, R. G. (1999). Early intervention for young children with autism: Continuum-based behavioral models. *Journal of the Association for Persons with Severe Handicaps*, 24(3), 162-173.
- California Department of Developmental Services. (2002). *Autistic spectrum disorders: Best practice guidelines for screening, diagnosis, and assessment*. Sacramento: Author.
- California Departments of Education and Developmental Services. (1997). *Best practices for designing and delivering effective programs for individuals with autistic spectrum disorders*. Sacramento: Author.
- Charman, T., & Baird, G. (2002). Practitioner review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children. *Journal of Child Psychology & Psychiatry*, 43(3), 289-305.
- Columbia Pacific Consulting. (1999). *Preliminary report: Cost-benefit analysis of Lovaas treatment for autism and autism spectrum disorders (ASD)*. Vancouver, BC: Harper Grey Easton Barristor and Soliciters.
- Cook, E., Rowlett, R., Jaselskis, C., & Leventhal, B. (1992). Fluoxetine treatment of patients with autism and mental retardation. *Journal of the American Academy of Child and Adolescent Psychiatry*, 31, 739-745.
- Courchesne, E., Carper, R., & Akshoomoff, N. (2003). Evidence of brain overgrowth in the first year of life in autism. *Journal of the American Medical Association*, 290, 337-344.
- Croen, L. A., Grether, J. K., & Selvin, S. (2002). Descriptive epidemiology of autism in a California population: Who is at risk? *Journal of Autism and Developmental Disorders*, 32(3), 217-224.
- Dawson, G., & Osterling, J. (1997). Early intervention in autism: Effectiveness and common elements of current approaches. In M. J. Gurnick (Ed.), *The effectiveness of early intervention: Second generation research* (pp. 307-326). Baltimore, MD: Paul H. Brooks.
- Dunlap, G. (1999). Consensus, engagement and family involvement for young children with autism. *Journal of the Association for Persons with Severe Handicaps*, 24, 222-226.
- Feinberg, E., & Vacca, J. (2000). The drama and trauma of creating policies on autism: Critical issues to consider in the new millennium. *Focus on Autism and Other Developmental Disabilities*, 15(3), 130-137.
- Fombonne, E. (2003). The prevalence of autism. *Journal of the American Medical Association*, 289(1), 87-89.
- Greenspan, S. I., & Weider, S. (1997). Developmental patterns and outcomes in infants and children with disorders in relating and communicating: A chart

- review of 200 cases of children with autistic spectrum diagnosis. *The Journal of Developmental and Learning Disorders*, 1, 87–141.
- Guralnick, M.J. (1993). Second generation research on the effectiveness of early intervention. *Early Education and Development*, 4, 366–378.
- Handleman, J.S., & Harris, S.L. (2001). *Preschool education programs for children with autism* (2nd ed.). Austin, TX: PRO-ED, Inc.
- Holroyd, J., & McArthur, D. (1976). Mental retardation and stress on the parents: A contrast between Down's syndrome and childhood autism. *American Journal of Mental Deficiency*, 80(4), 431–436.
- Horton, R. (2004). The lessons of MMR. *Lancet*, 363, 747–749.
- Hurth, J., Shaw, E., Izeman, S.G., Whaley, K., & Rogers, S.J. (1999). Areas of agreement about effective practices among programs serving young children with autism spectrum disorders. *Infants and Young Children*, 12, 17–26.
- Institute of Medicine. (2001). *Immunization safety review: Measles-mumps-rubella vaccine and autism*. Washington, DC: National Academy Press.
- Iovannone, R., Dunlap, G., Huber, H., & Kincaid, D. (2003). Effective educational practices for students with autism spectrum disorders. *Focus on Autism & Other Developmental Disabilities*, 18, 150–165.
- Karasu, T.B., Gelenberg, A., Merriam, A., & Wang, P. (2002). American Psychiatric Association practice guidelines for the treatment of psychiatric disorders: Compendium 2002. In *American Psychiatric Association practice guidelines for the treatment of psychiatric disorders: Compendium 2002* (2nd ed., pp. 463–545). Washington, DC: American Psychiatric Press.
- Lonigan, C.J., Elbert, J.C., & Johnson, S.B. (1998). Empirically supported psychosocial interventions for children: An overview. *Journal of Child Clinical Psychology. Special Issue: Empirically Supported Psychosocial Interventions for Children*, 27(2), 138–145.
- Lord, C., & Bailey, A. (2002). Autism spectrum disorders. In M. Rutter & E. Taylor (Eds.), *Child and adolescent psychiatry: Modern approaches* (4th ed., pp. 636–663). Oxford: Blackwell Publications.
- Lord, C., & Risi, S. (1998). Frameworks and methods in diagnosing autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 4, 90–96.
- Lord, C., Rutter, M., DiLavore, P.C., & Risi, S. (2001). *Autism diagnostic observation schedule*. Los Angeles: Western Psychological Services.
- Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24(5), 659–685.
- Lord, C., Wagner, A., Rogers, S., Szatmari, P., Aman, M.G., & Charman, T. (in press). Challenges in evaluating psychosocial interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders*.
- Lovaas, O.I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55(1), 3–9.

- Madsen, K., Hviid, A., Vestergaard, M., Schendel, D., Wohlfahrt, J., Thorsen, P., Olsen, J., & Melbye, M. (2002). A population-based study of measles, mumps, and rubella vaccination and autism. *New England Journal of Medicine*, *347*, 1477–1482.
- Mahoney, G., & Filer, J. (1996). How responsive is early intervention to the priorities and needs of families? *Topics in Early Childhood Special Education*, *16*(4), 437–457.
- Masi, G., Cosenza, A., Mucci, M., & Brovedani, P. (2003). A 3-year naturalistic study of 53 preschool children with pervasive developmental disorders treated with risperidone. *Journal of Clinical Psychiatry*, *64*, 1039–1047.
- McCabe, K.M., Clark, R., & Barnett, D. (1999). Family protective factors among urban African American youths. *Journal of Clinical Child Psychology*, *28*(2), 137–150.
- McCracken, J.T., McGough, J., Shah, B., Cronin, P., Hong, D., Aman, M.G., Arnold, E., Lindsay, R., Nash, P., Hollway, J., McDougle, C.J., Posey, D., Swiezy, N., Kohn, A., Scahill, L., Martin, A., Koenig, K., Volkmar, F., Carroll, D., Lancor, A., Tierney, E., Ghuman, J., Gonzalez, N.M., Grados, M., Vitiello, B., Ritz, L., Davies, M., Robinson, J., McMahon, D. J., & the Research Units on Pediatric Psychopharmacology Autism Network. (2002). Risperidone in children with autism and serious behavioral problems. *New England Journal of Medicine*, *347*, 314–321.
- McDougle, C.J., Naylor, S.T., Cohen, D.J., Volkmar, F.R., Heninger, G.R., & Price, L.H. (1996). A double-blind, placebo-controlled study of fluvoxamine in adults with autistic disorder [see comments]. *Archives of General Psychiatry*, *53*(11), 1001–1008.
- McDougle, C.J., & Posey, D. (2002). Genetics of childhood disorders: XLIV. Autism, part 3: Psychopharmacology of autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, *41*, 1380–1383.
- McDougle, C.J., & Posey, D.J. (2003). Autistic and other pervasive developmental disorders. In A. Martin, L. Scahill, D.S. Charney, & J.F. Leckman (Eds.), *Pediatric psychopharmacology* (pp. 563–579). New York: Oxford University Press.
- McEachin, J.J., Smith, T., & Lovaas, O.I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal of Mental Retardation*, *97*(4), 359–372; discussion, 373–391.
- McGee, G.G., Morrier, M., & Daly, T. (1999). An incidental teaching approach to early intervention for toddlers with autism. *Journal of the Association for Persons with Severe Handicaps*, *24*, 133–146.
- McGee, G.G., Morrier, M., & Daly, T. (2000). The Walden preschool. In J.S. Handleman & S.L. Harris (Eds.), *Preschool education programs for children with autism* (2nd ed.). Austin, TX: PRO-ED, Inc.
- Murch, S.H., Anthony, A., Casson, D.H., Malik, M., Berelowitz, M., Dhillon, A.P., Thomson, M.A., Valentine, A., Davies, S.E., & Walker-Smith, J.A. (2004). Retraction of an interpretation. *Lancet*, *363*, 750.

- National Research Council. (2001). *Educating children with autism. Committee on Educational Interventions for Children with Autism. Division of Behavioral and Social Sciences and Education*. Washington, DC: National Academy Press.
- New York State Department of Health Early Intervention Program. (1999). *Clinical practice guidelines: Report of recommendations, autism/pervasive developmental disorders*. New York: Author.
- Noland, R. M., & Gabriels, R. L. (2004). Screening and identifying children with autism spectrum disorders in the public school system: The development of a model process. *Journal of Autism and Developmental Disorders, 34*, 265–277.
- Panerai, S., Farranto, L., & Zingale, M. (2002). Benefits of the Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) programme as compared with a non-specific approach. *Journal of Intellectual Disability Research, 46*(4), 318–327.
- Parker, S. K., Schwartz, B., Todd, J., & Pickering, L. K. (2004). Thimerosal-containing vaccines and autistic spectrum disorder: A critical review of published original data. *Pediatrics, 114*, 793–804.
- Rogers, S. J. (1996). Brief report: Early intervention in autism. *Journal of Autism and Developmental Disorders, 26*(2), 243–246.
- Schreibman, L., & Anderson, A. (2001). Focus on integration: The future of the behavioral treatment of autism. *Behavior Therapy, 32*(4), 619–632.
- Schreibman, L., Kaneko, W. M., & Koegel, R. L. (1991). Positive affect of parents of autistic children: A comparison across two teaching techniques. *Behavior Therapy, 22*, 479–490.
- Schreibman, L., & Koegel, R. L. (1996). Fostering self-management: Parent-delivered pivotal response training for children with autistic disorder. In E. D. Hibbs & P. S. Jensen (Eds.), *Psychosocial treatments for child and adolescent disorders: Empirically based strategies for clinical practice*. Washington DC: American Psychological Association.
- Siegel, B. (1996). *The world of the autistic child*. New York: Oxford University Press.
- Stahmer, A. C., Collings, N. M., & Palinkas, L. A. (2005). Early intervention practices for children with autism: Descriptions from community providers. *Focus on Autism and Other Developmental Disabilities, 20*, 66–79.
- Stahmer, A. C., & Ingersoll, B. (2004). Inclusive programming for toddlers with autistic spectrum disorders: Outcomes from the Children's Toddler School. *Journal of Positive Behavioral Interventions, 6*(67–82).
- Taylor, B., Miller, E., Lingam, R., Andrews, N., Simmons, A., & Stowe, J. (2002). Measles, mumps, and rubella vaccination and bowel problems or developmental regression in children with autism: Population study. *British Medical Journal, 324*, 393–396.

- Weisz, J.R., Weiss, B., Han, S.S., Granger, D.A., & Morton, T. (1995). Effects of psychotherapy with children and adolescents revisited: A meta-analysis of treatment outcome studies. *Psychological Bulletin*, *117*, 450–468.
- Yell, M.L., Katsiyannis, A., Drasgow, E., & Herbst, M. (2003). Developing legally correct and educationally appropriate programs for students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *18*, 182–191.

