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Autism Spectrum Disorders
Diagnosis, Prevalence, and Services for Children and Families

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Abstract

Recent prevalence rates for autism spectrum disorders (ASDs) are now estimated at about 1 in 110 children in the U.S. Increases in public awareness and research funding in response to the growing numbers of children and adults with this disorder have led to numerous important scientific advances over the last several years. Nevertheless, because ASD remains a diagnosis that is defined completely on the basis of behavior, diagnostic assessment is both complex and expensive. Appropriate interventions and services are also multi-faceted and costly, and because of the pervasive nature of the disorder, are often required in some form across the lifespan. In the absence of standard societal mechanisms to pay for appropriate assessment and treatment, families must personally shoulder many of the costs associated with securing appropriate services for their children. This *Social Policy Report* summarizes selected recent studies on diagnosis, prevalence, and intervention, and discusses strategies for designing social policies to help improve the outcomes and independence of children and adults with ASDs.

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From the Editors

Autism Spectrum Disorder (ASD) has come into the awareness of western society in a big way. In the United States, popular movies such as *Rainman*, as well as feature articles in national news magazines such as *Time* and *Newsweek*, appearances of characters in television programs such as *Boston Legal* and *Parenthood*, and major public awareness campaigns operated by federal agencies such as the Centers for Disease Control and Prevention, have heightened awareness that a condition called "autism" exists and that it is serious for individuals and families as well as for societies. The seriousness of this disorder has been intensified by the rapid increase in prevalence, the costs to families and service agencies for providing treatment, and the costs to society for not providing treatment. In addition, ASD has been subject to a variety of claims about its cause(s) and cures. Once thought to be the product of "refrigerator moms," there is common agreement today that ASD is a neurodevelopmental disorder that has a genetic basis (perhaps in interaction with the environment). Claims for effective treatments have included hyperbolic chambers, wrapping in cold wet sheets, selective diets and nutrition, psychopharmacology, and developmental and behavioral interventions. Fortunately, there is a tremendous amount of very solid scientific research now addressing questions about etiology, epidemiology, diagnosis, and treatment.

In this issue of the *Social Policy Report (SPR)*, Lord and Bishop summarize this very active scientific literature that focuses on early identification and diagnosis, prevalence, and treatment. After reviewing the current economic context of ASD, they provide an introduction to terminology describing the disorder, which includes the evolution of the diagnostic classification of *autism* to the current conceptualization of *Autism Spectrum Disorders*. Lord and Bishop also highlight the importance of accurate screening and diagnosis and the policy issues that affect families' access to appropriate and affordable diagnostic and treatment planning services.

In their second section, the accelerating prevalence of ASD is examined. Is there an epidemic of ASD in the world today? Lord and Bishop describe the current epidemiological research, suggest reasons for the increased prevalence, and describe the current and future policy implication for the changing demographics of ASD.

In the concluding section, Lord and Bishop examine the concept of "evidence-based" practice as it applied to developmental and behavioral interventions for children with ASD and their families. They highlight issues related to intensity and nature of different intervention programs, the cost of delivery of these programs, and potential sources of support for those programs. They use a recently published treatment efficacy article to highlight important issues in translating even the best science into policy implications.

This *SPR* issue concludes with commentaries from three leading scientists in the field of diagnosis and treatment of ASD. We hope that this article and commentaries provide important basic information about ASD and policy implications from the most current research on diagnosis, prevalence, and treatment.

—Samuel L. Odom (Issue editor)
Donna Bryant, Kelly Maxwell,
Anne Hainsworth

Autism Spectrum Disorders
Diagnosis, Prevalence, and Services for Children and Families

Thirty years ago autism was considered to be a rare childhood disorder most often associated with severe intellectual disabilities, lack of social awareness and the absence of meaningful expressive language (Lotter, 1966). Today, the spectrum of autistic disorders (or Autism Spectrum Disorder, ASD) is now recognized as a set of common developmental disorders, with an estimated prevalence of about 1 in every 110 children in the U.S. (ADDM; Autism and Developmental Disabilities Monitoring Network Surveillance Year 2006 Principal Investigators, 2009). Many of the symptoms first described by Leo Kanner in his seminal article about autism in 1943 (Kanner, 1943), and delineated in research in the late 1960's and 70's (Rutter, 1978; Schopler, 1978; Wing, Yeates, Brierley, & Gould, 1976), still apply to the way the term ASD is used now. Although the concept of ASD has become more familiar, important questions remain about the most accurate and efficient procedures for diagnosis, the increase in prevalence, and the best treatments. Answers to these questions directly affect social policy decisions about clinical practice and education for children and adults with ASD and their families.

This report provides a brief introduction to ASD and more in-depth discussion and analysis of research in three key content areas relevant for public policy: 1) diagnosis, 2) studies of prevalence of ASD, and 3) treatment and education. Rather than providing a comprehensive review within each of these areas, we report recent research that highlights current, critical issues and propose policy implications.

ASD: The Current Economic Context

ASDs generate enormous financial and personal costs to families and society. Recent reports from both the United States (Ganz, 2007) and the United Kingdom (Knapp, Romeo, & Beecham, 2009) have estimated costs to families of more than $3-5 million dollars beyond the ordinary lifetime costs of raising a child. Societal cost estimates for the United States are almost $90 billion a year (www.autism-society.org). Compared to other children with specialized healthcare needs, children with ASD are underserved, with more delayed or foregone healthcare, less family-centered care, and more difficulties with referrals (Kogan et al., 2008). Additionally, families of children with ASD have more financial problems, provide significant amounts of healthcare coordination (more than 10 hours a week) for their own children, and are more likely to stop or reduce work than families of other groups of children with special needs (Honberg, Kogan, Allen, Strickland, & Newacheck, 2009; Kogan, et al., 2008).

Current costs of ASD primarily reflect caregiving provisions in adulthood and lost income in individuals with ASD and their families. The reality is that, in the absence of adequate standard societal mechanisms (e.g., state health or educational programs) that provide straightforward coverage of services for individuals with ASD, these costs are paid in other ways, such as when a parent stops working or goes into debt. An encouraging finding is that relatively minor changes in independence and adaptive skills can save significant amounts of money (Kogan, et al., 2008). The costs are less for individuals with ASD who have less severe cognitive impairments (Järbrink, McCrone, Fombonne, Zandén, & Knapp, 2007; Knapp, et al., 2009). The challenges, therefore, are to create social policies to help improve the outcomes, quality of life, and independence of children and adults with ASD, while also mitigating the potentially enormous financial and personal costs of having a child with ASD.

The Autism Spectrum (ASD)

A diagnosis of ASD is based on descriptions and observations of behavior. Although there is much evidence that autism is a neurodevelopmental disorder with a very strong genetic component, there is not yet a valid bio-

marker or biological test (Abrahams & Geschwind, 2008). The greatest risk factor for ASD is being male; autism occurs about 4 times more often in boys than girls. Intellectual disability frequently co-occurs with ASD, although the percentage of co-occurrences has reduced from 75% to 50% over recent decades (Centers for Disease Control and Prevention, 2000). Recently, several studies, though not completely consistent, have suggested that advanced age of parents (both fathers and mothers) is also associated with increased ASD risk (Grether, Anderson, Croen, Smith, & Windham, 2009).

In the fourth edition of the *Diagnostic and Statistical Manual* (DSM-IV) published by the American Psychiatric Association (1994), Autistic Disorder is defined by onset prior to 3 years and the presence of deficits or unusual behaviors within three domains: reciprocal social interaction, communication, and restricted, repetitive interests and behaviors. Social impairments are characterized by lack of social-emotional reciprocity, failure to seek to share enjoyment, poor use of nonverbal communication, and difficulty in peer relations. Communication disorders include failure to acquire speech without compensating through alternative communication methods, use of stereotyped speech or delayed echolalia, and/or difficulties having conversation. Limitations in imitative and/or imaginative play also often occur and are related to social and communicative abilities. Restricted and repetitive behaviors include unusual preoccupations and circumscribed interests, repetitive hand and finger movements, whole body mannerisms, compulsive behaviors and rituals, and "preoccupations with parts of objects," a phrase which is generally interpreted to include repetitive use of objects and unusual sensory seeking behaviors.

While almost all children with ASD have most of the social deficits and many have examples of most of the communication deficits, this is not always true for repetitive and restictive behaviors and interests (RRBs), which are much more variable across children. This variability has led some researchers to question the degree to which RRBs are necessarily an inherent part of the diagnosis of ASD. Yet, analyses of large samples of children with ASD suggest that the vast majority of individuals exhibit several examples of various RRBs at least until adolescence (Bishop, Richler, & Lord, 2006). Longitudinal studies have suggested that the stability of an ASD diagnosis is increased when RRBs are part of the definition, especially if they are carefully assessed with standardized caregiver interviews and observations (Lord et al., 2006). This debate has policy implications in terms of diagnostic criteria, diagnostic methods, and prevalence estimates. For example, whether or not to require evidence of RRBs could have a significant impact on the number of individuals diagnosed with ASD.

The "Spectrum"

In both DSM-IV (American Psychiatric Association, 1994) and the International Classification of Disease-10 (ICD-10, World Health Organization, 1993), the two most widely used diagnostic systems, Pervasive Developmental Disorders is the diagnostic umbrella classification for "autism-like" disorders, which includes Autistic Disorder, Asperger Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified. These subtypes were originally differentiated by age and type of onset, severity and comprehensiveness of symptoms, and association (or lack thereof) with language delay and intellectual disability.

Consistent with the concept of a spectrum of disorders, there are likely many different genetic patterns that contribute to autism or "autisms." Fragile X syndrome, Tuberous Sclerosis and Rett Syndrome have now been identified as genetic disorders that have specific developmental and behavioral profiles. These syndromes, however, account for only small proportions of children with ASD (e.g., less than 2 percent combined), and not all individuals with these disorders meet criteria for an additional diagnosis of ASD. Basic research into neurobiology is likely to make contributions in the future. To date, it has not yet substantially contributed to better understanding about prognosis or services for most individuals with ASD, except for pharmacological treatments for broadly defined irritability and disruptive behaviors (RUPP; Research Units on Pediatric Psychopharmacology Autism Network, 2002).

One could ask why, if there is no biological homogeneity, if medical treatments predominantly address secondary features, and if there is such diversity in behaviors, we should continue to have a general concept of ASD. Despite ongoing attempts to "unpack" autism into separable components (Happé & Ronald, 2008), significant and early-arising difficulties in basic aspects of social-communication and restricted, repetitive behaviors or interests are the commonalities that strongly define this group. Analyses of large datasets of behavioral descriptors of children with ASD, children with other disorders, and typically developing children repeatedly find that a single "autism" factor that includes both social-communication and fixated/repetitive behaviors accounts for most of the variance (Constantino & Todd, 2003; Gotham,

Risi, Pickles, & Lord, 2007). Diagnostic differences for ASD compared to other neurodevelopmental and psychiatric disorders are apparent in differential response to treatments, patterns of development from the early years into adulthood, risks for recurrence in siblings, and associations with particular behavioral phenotypes in parents and siblings (Levy, Mandell, & Schultz, 2009; Lord & Spence, 2006). Clearly, whereas there is striking behavioral heterogeneity among individuals with ASD, research continues to reinforce the concept that, as a group, individuals with ASD are characterized by a particular set of symptoms that differentiate them from other diagnostic groups.

Changing Diagnostic Criteria

For the revised fifth edition of the DSM, there are proposals for changes in the diagnosis of neurodevelopmental disorders, including ASD (see www.dsm5.org). The revised criteria include only two symptom domains (social-communication and fixated, repetitive interests), eliminate subtypes of ASD, and describe individual differences in terms of dimensions of severity in the two domains, relative to developmental levels and chronological age. Thus, an individual with an ASD diagnosis would be described in terms of severity of social-communication symptoms and severity of fixated or restricted behaviors or interests. This diagnosis could be associated with other known genetic or medical conditions (e.g., ASD and Rett syndrome or ASD and Fragile X), language disorders, or other psychiatric conditions (e.g., ASD with ADHD, ASD with intellectual disability).

Developmental referents for defining symptoms are key features of the DSM revision. Some symptoms, such as unusual social use of gaze, less subtle socially-directed facial expressions, and more limited or awkward gestures are characteristic of most individuals with ASD across ages and skill levels (Gotham, et al., 2007). However, the expression of other symptoms is quite different across development (Richler, Huerta, Bishop, & Lord, 2010). An articulate, talkative 10 year old with ASD cannot be evaluated using the same list of symptom examples as a two year old with no spontaneous expressive language or an adult with a repertoire of functional stereotyped phrases. Separating descriptions of symptoms by chronological age and developmental level is an important step toward understanding more about the specificity of autism-related deficits. In addition, in the proposed DSM-V criteria, individuals with ASD would be expected, by history and observation, to have evidence of each of the subdomains specified in social-communication (marked deficits in nonverbal communication, lack of social reciprocity, peer relationships) and two of three areas of fixated interests/repetitive behaviors (stereotyped motor or verbal behaviors, including sensory responses; routines and rituals; restricted, fixated interests). This is a higher threshold than exists now in DSM-IV. Providing specific examples appropriate for children and adults at different ages and ability levels should lead to greater sensitivity and better specificity (less overlap with other diagnoses) than more general statements.

Policy Issues Related to Diagnostic Assessment of ASD

Because the prognosis and treatment of individuals with ASD are strongly linked to cognitive and language levels, assessments must include standard developmental measures in addition to autism-specific measures. Referrals within a medical system (from a primary care pediatrician to a developmental pediatrician to a clinical geneticist or a pediatric neurologist) are often easier to accomplish than to mental health professionals (e.g., psychologists, psychiatrists). Often there is a reliance on school systems and early intervention programs to provide the assessment not provided within the medical setting. In some cases, these assessments through school systems or early intervention programs are impressive, but, particularly as states are pressed for funds, there is enormous variability in the diagnostic and assessment process.

Several groups, including a National Research Council committee (NRC; National Research Council, 2001), the American Academy of Pediatrics (Johnson & Myers, 2007), the American Academy of Child and Adolescent Psychiatry (Volkmar, Cook Jr, Pomeroy, Realmuto, & Tanguay, 1999), and the American Academy of Neurology (Filipek et al., 2000) have recommended specific practices that should be followed in an initial evaluation for a child or adult suspected of having ASD. Unlike other chronic diseases such as diabetes or cystic fibrosis identified or beginning in childhood, these protocols of nationally-recommended practices are not used in most clinical settings nor is there funding for these protocols to be carried out. In fact, even with respect to general developmental screening (let alone diagnostic practices for ASD), procedures have been found to vary widely among practitioners, with studies reporting that between one half and three quarters of physicians do not regularly use formal developmental screening tools for children younger than three years (Sand et al., 2005;

Sices, Feudtner, Mclaughlin, Drotar, & Williams, 2003). In addition to lack of time and staffing to carry out such screening, insufficient reimbursement was cited as a major barrier by physicians in these studies. Compared to initial screening, diagnostic practices for ASD are subject to even more variability across clinicians and settings. This is in contrast to a research context, where most major projects have had very similar diagnostic protocols in order to allow merging and comparisons of samples (Szatmari et al., 2007). Such protocols require several hours and rely on experienced examiners, and are therefore used infrequently in clinics because of lack of reimbursement and lack of trained personnel.

Thus, one route to diagnosis might be through a primary care pediatrician, who after several brief visits during which the parent expresses concerns, refers a child at 18 months to a developmental pediatrician. The developmental pediatrician sees the child at 24 months after 6 months on a waiting list, suspects ASD, and refers the child directly to a private practice that specializes in Applied Behavior Analysis (ABA) treatment. The family starts treatment quickly, but they are never told that the child likely has a significant cognitive impairment and severe language delays in addition to autism. The family receives (and pays for) excellent in-home behavioral teaching but does not realize the scope of the child's problems until, at age 4, they attempt to enroll him in a regular preschool and are rejected because he has very limited understanding of language and is not toilet-trained.

In an alternative scenario, an astute pediatrician might suspect ASD in a 15 month old child, but when she raises the possibility, the family is taken aback and do not return for a scheduled follow-up visit. At age 2, the child is asked to leave his second child care program because of behavior problems, and the parents take the child to a new pediatrician who refers the child to a psychologist who has difficulty testing her and raises the possibility of intellectual disability. At this point, the family hears about a local physician whose specialty is alternative treatments. ASD now seems like a more positive diagnosis than intellectual disability and they schedule an evaluation. After months of expensive tests, treatments, and supplements, the child, though bright, is 3 years old and has made minimal progress.

Each step in this series of assessments often involves months on waiting lists and confusion in interacting with insurance companies about what is and is not funded (Filipek, et al., 2000; Harrington, Rosen, Garnecho, & Patrick, 2006). In the end, the child or the family may still not see anyone who is particularly skilled in assessing or working with children with autism, and also may not receive any standardized assessment of ASD symptoms or their child's areas of strength or deficits (see Filipek et al., 2000).

One consistently recommended practice (NRC, 2001) involves multidisciplinary evaluations. In a multidisciplinary assessment for ASD, the goal is not to have numerous different disciplines diagnose the child with ASD. Rather it is to have the team members from different disciplines first examine difficulties that might affect and/or result in ASD symptoms (e.g., medical conditions, cognitive function, motor skills, language delays, or behavior problems), and then consider the severity of ASD symptoms in the domains of social-communication and fixated interests/repetitive behaviors. The team also looks at the intersection of the child's strengths and weaknesses and how they fit with a diagnosis, using this information to devise an appropriate treatment plan with the family (see also Filipek, et al., 2000). A multidisciplinary evaluation of this type takes time, teamwork and expertise.

Unfortunately, these recommended practices are not typically funded, or funded adequately, by insurance or other public sources. For example, the New York State Board of Health guidelines specify that a multidisciplinary evaluation, as just described, be conducted for young children suspected of having ASD, and the evaluation should occur in five developmental areas. Yet the funding that is provided does not even cover the standard fee for a typical initial visit with a developmental pediatrician or clinical psychologist (New York State Department of Health Early Intervention Program, 1999). This is an example of a policy (i.e., a multi-disciplinary assessment) that has good intentions but that may actually cause harm because restricted funding prevents professionals from carrying out a sufficient evaluation.

In terms of public policy, it is important to recognize that as ASD has become a more heterogeneous category, one-size-fits-all approaches to diagnosis and assessment are not appropriate (Gotham, Bishop, & Lord, in Press). Nevertheless, a standard protocol, with decision trees about different "branches" for individual children and families would at least raise the minimum threshold for acceptable services. Families should be encouraged to find a knowledgeable, experienced professional within a team to provide continuity over several years and who can assist the child and family in interactions with the early intervention, educational, and social services systems. Because so few services are reimbursed

by health insurance, the responsibility often falls on families and on school districts to make decisions about the intensity and types of treatments and educational services to be delivered. It is imperative, therefore, that the diagnostic assessment provides sufficient opportunities for the family to participate in and learn from the assessment in order to move to an individualized treatment plan. Furthermore, in addition to being in the best interest of the child and family, periodic re-evaluations of each individual's needs and family concerns are also likely to be cost-effective in the long run, as they allow for the opportunity to discontinue services that are no longer needed.

How should this affect health and educational policies? It seems critical to separate screenings for eligibility for services from an appropriate family-centered diagnostic evaluation that leads to decisions about possible interventions for a child with ASD and his/her family (Filipek, et al., 2000; Myers & Johnson, 2007). Some of this evaluation can be done in the schools, but it is not clear that schools are the most appropriate base for family-centered approaches to complex developmental disorders. Health insurance must be accessible for appropriate diagnostic evaluations that go beyond a brief visit with a physician. Parity for mental health services needs to recognize that psychological and language testing and measurement of adaptive skills are the equivalent of lab tests or other procedures in medicine that provide critical information about treatment decisions.

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Serious consideration must be given to ways to make sure that diagnostic evaluations are useful to families and contribute to decision-making about interventions. A major part of the concept of evidence-based medicine (Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000) is for patients to be active participants in their own treatment plans, which is of particular importance in the case of ASD. Here, the need for evidence about what works for whom and when is very clear. Provisions within insurance for time spent gathering information from other sources (for example, time requesting and scoring teacher reports or getting an update from a speech-language pathologist) should promote family action in a way that is ultimately financially justifiable. The fact that there are costs associated with NOT doing this (e.g., lost income and taxes, increased need for support services) may increase the likelihood of proactive funding. These issues arise again in the subsequent sections on policy and intervention.

Prevalence

The most recent results from the Centers for Disease Control and Prevention (CDC) suggest that, in the United States, the prevalence of ASD is 1/70 boys and 1/315 girls, yielding an overall rate of 1/110 (ADDM, 2009). This is nearly identical to the overall prevalence from a recent British study (Baird et al., 2006). Although the total prevalence of most studies has been relatively consistent, prevalence rates for different subtypes of ASD have varied considerably across research reports. In most studies, the number of children with Asperger syndrome, Rett's syndrome, and particularly PDD-NOS (i.e., nonautistic ASD diagnoses) has outnumbered children with Autistic Disorder almost 2 to 1 (Fombonne, 2009; Rosenberg, Daniels, Law, Law, & Kaufmann, 2009). At least for distinctions among Autistic Disorder, Asperger Syndrome, and PDD-NOS, most epidemiological and clinical studies have suggested that when the child's or adult's language level and intelligence quotient (IQ) are controlled, site and clinician-based variability may be greater than symptom variation (ADDM, 2009; Rosenberg, et al., 2009; Woodbury-Smith, Klin, & Volkmar, 2005). This diagnostic imprecision is a rationale for consolidating the current DSM-IV subgroups of autistic disorder, PDD-NOS, and Asperger Syndrome under the umbrella of a single concept of ASD. The search for more meaningful subtypes may be more productively continued through neurobiological studies or studies of treatment responses.

The variability within rates of subtypes of ASD has significant policy implications. Particularly as the effects of decreased revenue are felt in state and local

budgets, some school systems and social services require diagnoses of autistic disorder (as opposed to PDD-NOS or Asperger Syndrome) for services or funding. Although cutting costs in the short-term, this policy decision is unwarranted given the lack of reliability in these distinctions and the lack of evidence that the treatment needs of children or adults with non-autism ASD diagnoses are any less than those of individuals with a diagnosis of autistic disorder. Treatment needs do differ across individuals with ASD, but more because of the degree that the individuals are affected by the disorder and affected or not affected by other disorders (including intellectual disabilities, communication-language disorders, ADHD, and disruptive behaviors) than by the subtype into which they happen to be categorized.

Policy implications of the prevalence rates must start with the effect of the sheer numbers of children estimated to have ASD. These numbers equal the numbers for schizophrenia and exceed the numbers for most major specific developmental disabilities (Lord & Spence, 2006). For educational purposes, they mean that most elementary schools with a population of 500 children will have 4 or 5 children with ASD. A school district with 10,000 children and adolescents would be expected to serve just short of 100 children with ASD. This is a very large number, given the services required. Because of the heterogeneity of the population, it is also a difficult number for which to plan. For example, the five children in one elementary school could range in age from 5 to 12, in language level from nonverbal to verbally fluent, in IQ from profound intellectual disability to superior intelligence, and in challenging behavior from none to highly disruptive. Even if the school created an "autism" resource class, a single program would not be appropriate for the majority of the children because of the range in their ages and developmental levels.

A prevalence rate of 1/110 children necessitates programs that go beyond neighborhood schools, sometimes requiring a travelling facilitator who consults with teachers in several schools or transporting children with needs for special resources to a non-local school. This complexity again requires that families be informed and empowered to speak for the needs of their children and that service providers be aware of the heterogeneous needs of children and youth with ASD.

Estimates from state records and school systems are important in terms of indicating the number of children and adults who seek and, hopefully, receive services through public agencies. These numbers have shown very marked increases in the last 20 years. As reviewed by Newschaffer and colleagues (Newschaffer, Falb, & Gurney, 2005), a few studies of individual states reported concomitant decreases in other educational categories, such as mental retardation, but those decreases were not found in a national special education database. It would also be very unlikely if decreases in the number of children given educational classifications of mental retardation accounted for increases in the numbers of children with autism classifications, because the largest source of increase in ASD is children who do **not** have intellectual disabilities (Honda, Shimizu, & Rutter, 2005). A comparison to other categories of disabilities revealed that some educational categories, such as "other health impairment," which typically includes children with attention deficit-hyperactivity disorder (ADHD), also increased, but that the rise in prevalence of ASD was not due to a general rise in special education classifications (Newschaffer, et al., 2005).

It is also clear from the various surveillance and multi-stage studies that a considerable number of children with ASD do not have autism classifications in schools (ADDM, 2009; Charman et al., 2009). There are many possible reasons for this situation, including children who are incorrectly classified or not identified at all, children who have multiple diagnoses but can have only one educational classification (e.g., intellectual disability) and children whose parents are concerned about the possibility that the child will be stigmatized by an ASD classification. Thus, even though the increase in numbers of children with ASD in special education is striking, the actual prevalence rates provided by educational and state administrative databases still fall short of the expected numbers from surveillance and epidemiological studies, suggesting that there are more children with ASD to be found (Fombonne, 2009).

A variety of methods have been used to "count" individuals with ASD. Data sources have included national health registers, administrative databases, and multi-stage studies in which there is broad recruitment and then more detailed evaluation, with a direct assessment of the person with ASD in about half the studies (Fombonne, 2009). In the CDC studies in the United States (ADDM, 2007; 2009), estimates were based on record reviews of health and, in most cases, education records from 11 states that are participating in a surveillance study of 8 year olds. The surveillance consists of identifying children with autistic disorder or other ASD diagnoses, children receiving education within ASD programs,

and children with other neurodevelopmental disorders that overlap with ASD (e.g., intellectual disabilities, speech-language disorders). These children's medical and school records are abstracted to look for specific terms associated with ASD diagnoses. The procedure created by the CDC is as rigorous as a record review can be. For most children, 2–7 evaluations were abstracted from different examiners. Still, it is important to remember that even though these data are extracted from medical and school records, the extraction is either of behavioral diagnoses or behavioral descriptors. Several other studies have found that simply changing diagnostic criteria resulted in 2- to 4-fold variation in the number of children who met criteria for autistic disorder in the same dataset (Charman, et al., 2009; Kielinen, Linna, & Moilanen, 2000).

When information from standard diagnostic instruments is taken literally and applied to DSM-IV criteria, far more children receive diagnoses of ASD than would be justified clinically (Risi et al., 2006). In fact, whereas autism was once considered such a rare and devastating diagnosis that it was rarely over-diagnosed, today with the attraction of more intense services and the appeal of less-stigmatizing diagnoses such as Asperger Syndrome and PDD-NOS, now tertiary autism centers discover children with ASD diagnoses who do not seem to have or have ever had ASD (Kogan et al., 2009). As discussed earlier, the core of ASD lies in the intersection of multiple deficits in basic aspects of social-communication and the presence of restricted and repetitive behaviors (American Psychiatric Association, 1994; Siegel, Vukicevic, Elliott, & Kraemer, 1989; World Health Organization, 1993). The quality of this intersection is difficult to quantify with any specificity without interactive information (e.g. observation or interviewing) that allows the clinician to rule out a case either due to counter-examples or through follow-up questions. Research comparing diagnoses made purely on the basis of either families' reports or by examiners' direct assessments has shown that a combination of methods is consistently more similar to experienced clinicians' best estimate diagnoses and, probably more importantly, results in more stable diagnoses over time (Lord, et al., 2006; Risi, et al., 2006). Therefore, diagnostic classifications extracted from records have to be interpreted with caution.

The creation of the ongoing surveillance program by the CDC (Rice et al., 2007) represents a major step in providing data to inform public policies about ASD. Cross-sectional studies, even those using the same administrative database, cannot control for changes in referral or assessment patterns. By comparing prevalence estimates using the same methods in the same regions over time, we gain particular insights into whether or not there are changes in the incidence of ASD. This is particularly important when dealing with the highly-publicized question of whether there is an "epidemic" of autism. This question can only be answered if we can determine if increases in prevalence are due to rising numbers of affected children versus better (or different) identification of children who already had symptoms of ASD but did not have diagnoses.

Though the direction and magnitude varied, the 2009 ADDM reported that overall increases in ASD prevalence were observed within all major groupings, such as by gender, racial/ethnic group and cognitive functioning. Yet, as shown in Table 1, there was marked variability across sites in the composition of the different samples of children identified with ASD. Prevalence differed across racial/ethnic groups such that Black and Hispanic children were less likely to be identified as having ASD in 2006 (ADDM, 2009) and 2002 (Mandell et al., 2009). There was a substantial increase in Hispanic children identified with ASD in Arizona in the most recent report, but not in other states (ADDM, 2009). Non-Hispanic Black children with IQs over 70 were less likely than White children to have previous diagnoses of ASD in their records (Mandell, et al., 2009). For Hispanic and Asian-American children, disparity in documented diagnosis was concentrated among children with intellectual disability. Black and Hispanic children received diagnoses later than White children, as found in earlier studies (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007; Mandell, Listerud, Levy, & Pinto-Martin, 2002). Maternal education also affected the proportion of children with existing diagnoses, with more educated mothers more likely to have children with previously documented ASD diagnoses (Mandell, et al., 2009). Gender ratios varied from 3.2 to 7.6 males to 1 female in different states. Increases in prevalence occurred for males in 9/10 sites and for females in 4/10 sites. Reported IQs ranged from 29% of children with ASD falling under 70 in Colorado to 51% in South Carolina. Increases in prevalence from 2002 to 2006 occurred in all IQ groupings but were greatest in children with IQs in the borderline range (71 – 85).

This variability is notable for public policy for two reasons. First, there are striking disparities across races and ethnic groups in existing diagnoses and, to a lesser degree, in diagnostic characterizations based on ex-

traction from reports. Mandell and his co-authors have repeatedly emphasized that later and fewer diagnoses of ASD in children of ethnic minorities and children with less-educated parents are likely to have significant effects on health outcomes and access to services (Mandell, et al., 2009). They propose that the source of the disparity lies in the interaction between parents and professionals and in many other factors (including clinician and family beliefs, knowledge and behavior), again highlighting the importance of considering family characteristics when designing policies to improve screening and diagnosis. If there is neither insurance nor public funding for an adequate diagnostic assessment that conveys to families the strengths and deficits of their children, then families may be less likely to advocate for their children. A vicious cycle occurs because physicians may also be less likely to refer families for diagnoses, particularly earlier diagnoses, if they are uncertain what families will "get" from a diagnosis other than bad news (Oosterling et al., 2009; Swinkels et al., 2006). The disparities further reinforce the need to view assessment not as a means to an end (i.e., diagnosis), but as a process through which families learn more about the strengths and needs of their children.

The second policy concern is the significant variability across states and sites, which could potentially affect decisions about how to allocate funding. The ADDM is the only research group that has reported in such detail across various sites (see Table 1, only ethnic/racial group differences reported in this table). Though the total prevalence rates yielded from the overall sample are in line with reports from other epidemiological studies across the world, one cannot help but be struck by how different the children identified in the different locations were—in gender, in IQ, in race/ethnicity, in proportion of children in ASD services, in proportion of children with existing diagnoses. Differences in race/ethnicity in part reflect differences in populations, but it is unlikely that there are twice as many boys with ASD compared to girls in Florida than there are in Alabama. It seems similarly unlikely that there are twice as many children with ASD without cognitive impairments in Colorado as there are in South Carolina. Some of these differences must lie in who is being referred for evaluations (since health and

Table 1. Estimated prevalence of autism spectrum disorders among children aged 8 years by race/ethnicity—-Autism and Developmental Disabilities Monitoring Network, 11 Sites, United Stated, 2006

Site	Race/Ethnicity								Prev Ratio		
	White, non-Hispanic		Black, non-Hispanc		Hispanic		API**		White-to-Black	White-to-Hispanic	Black-to-Hispanic
	Prev	95%¶ CI	Prev	95% CI	Prev	95% CI	Prev	95% CI			
Sites with access to health records											
Alabama	5.8	(5.0–6.9)	6.8	(5.3–8.7)	0.6	(0.1–4.4)	2.7	(0.4–19.1)	0.9	9.4††	10.9§§
Florida	3.4	(2.3–5.2)	1.6	(0.9–3.0)	5.2	(4.1–6.5)	—¶¶	—	2.1††	0.7	0.3
Missouri	13.7	(12.1–15.5)	5.1	(3.6–7.1)	2.6	(0.6–10.3)	7.8	(3.5–17.3)	2.7§§	5.3††	2.0
Pennsylvania	10.1	(7.7–13.3)	7.5	(5.9–9.5)	7.7	(5.1–11.7)	1.0	(0.2–7.4)	1.4	1.3	1.0
Wisconsin	8.5	(7.4–9.8)	3.6	(2.4–5.4)	1.7	(0.8–3.5)	5.8	(2.8–12.2)	2.4§§	5.1§§	2.1
Sites with access to education and health records											
Arizona	14.8	(13.1–16.6)	12.9	(9.0–18.6)	8.3	(7.0–9.7)	16.2	(10.4–25.1)	1.1	1.8§§	1.6††
Colorado	6.7	(4.6–9.8)	12.5	(7.1–21.9)	4.5	(2.3–9.1)	7.3	(2.4–22.6)	0.5	1.5	2.8††
Georgia	12.0	(10.5–13.8)	9.5	(8.2–10.9)	4.8	(3.4–6.9)	7.8	(5.1–11.9)	1.3††	2.5§§	2.0§§
Maryland	9.3	(8.0–10.8)	7.9	(5.9–10.6)	6.3	(3.0–13.2)	9.6	(5.5–17.0)	1.2	1.5	1.2
North Carolina	12.2	(10.4–14.3)	7.5	(5.6–10.0)	6.1	(3.7–10.0)	4.8	(1.5–14.8)	1.6§§	2.0§§	1.2
South Carolina	7.1	(5.7–8.7)	7.3	(5.7–9.3)	4.8	(2.0–11.4)	3.6	(0.5–25.2)	1.0	1.5	1.5

Note: *Per 1,000 children aged 8 years. **Asian/Pacific Islander. ††Prevalence ratio significantly different within site ($p<0.05$). §§Prevalence ratio significantly different within site ($p<0.01$). ¶¶No children identified in this group. From *Autism and Developmental Disabilities Monitoring Network*, 11 Sites, United States, 2006. http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm#tab2

educational records were the source of the CDC data) and/or in how professionals described the behavior of children of different intellectual levels, genders and races/ethnicities. Federal standards and support for state programs to find and serve children are crucial.

Variability, at least in terms of IQ and ASD symptoms, has not been as significant a factor when comparing across research-recruited samples. Numerous studies have combined samples from different research labs where distributions were very similar. However, research in ASD has tended to use overwhelmingly White, middle to upper middle class samples, and has often excluded children with multiple disabilities and/or severe to profound intellectual disabilities. There is more variability in research reports of ASD in children under 3, where diagnostic criteria are more uncertain and diagnostic assessment batteries are less consistent (Ventola et al., 2006). Particularly for this age group, there is clearly a value in establishing guidelines across disciplines for selecting assessment and information gathering methods to be used in the context of ASD diagnostic evaluations.

This comes back to the need for researchers to work to improve practice, and the need for policies that support the integration of healthcare and education research. As noted previously, families need more effective, less expensive ways to learn about their children's impairments and relative strengths, as well as the best methods for services and treatments. Equitable access for families from different, underserved demographic groups is central to this endeavor. We need to better understand why such great disparities exist across races/ethnic groups, social classes and regions, in the numbers and ages of children identified with ASD (Mandell, et al., 2007; Mandell & Palmer, 2005; Shattuck et al., 2009) and how the inequities can be mitigated.

Where Needs Meet Prevalence: Policy Issues in Interventions for Children with ASD

In a time of rising healthcare costs and calls for faster, cheaper and better service delivery, the challenge presented by the numbers of children and adults with ASD who need services is daunting. Ten years ago, a committee examining the effectiveness of early education for the National Research Council (NRC, 2001) estimated that fewer than 1 in 10 children with autism received appropriate early intervention. While access to early intervention and insurance has improved in some states, in others, it has deteriorated. As with the identification of children noted previously, the disparities across states, employers, and insurance companies are marked (Wegner & Macias, 2009). It is still the case that assessment and treatment services, including educational programs for ASD, are not adequately funded. For individuals with ASD beyond school age, services are even more limited. Funding for assessment and treatment of individuals with ASD is limited through most health insurance packages. Employers may literally agree to an "autism rider" or "autism waiver" when they negotiate health insurance packages for their employees. Could we imagine employers negotiating a "heart disease rider" or a "diabetes waiver"?

Yet, resources are limited. Researchers and professionals have responsibility for delineating appropriate treatments that are likely to produce measurable improvements in the lives of persons with ASD and their families. If one scans the Internet or listens to the popular media, a number of treatments claim dramatic effects on core symptoms of ASD. Many parents become focused on diets and treatments that promise extraordinary outcomes, because they sound so much more straightforward and more "scientific" than multi-disciplinary step by step teaching and learning (Levy & Hyman, 2008). Yet, even among well-known comprehensive treatments, few have been evaluated in randomized efficacy studies, and when efficacy studies are conducted, the program developer's research group conducts the study (Odom, Boyd, Hall, & Hume, 2010). Thus, there is an urgent need to identify which treatments are most likely to be reliably effective so that we can focus on how to make them accessible to families through public funding and insurance.

The nature of evidence-based practice (Sackett, Richardson, Rosenberg, & Haynes, 1997 or the Cochrane Collaboration, www.cochrane.org; see Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996) and how best to use and convey standards for adequate evidence (Buysse, Sparkman, & Wesley, 2003; McCall, 2009) are ongoing discussions in many disciplines (e.g., medicine, psychology, and education) and for all populations—not just ASD. In this section we focus on practices and programs for young children because much of the intervention research has been conducted with this age group. .It is important to acknowledge that intervention services are important for older children, youth, and adults with ASD as well and much needed areas of research.

In recent reviews, researchers have proposed that there are three types of intervention practices for individuals with ASD: focused intervention practices, comprehensive treatments, and psychopharmacological studies (which will not be addressed here) (National Autism

Table 2. Examples of evidence-based comprehensive treatment models and focused intervention practices for children with ASD

Comprehensive Treatment Models (Odom et al., 2010)	Focused Intervention Practices National Autism Center (2009)
• Early Start Denver Model (ESDM) • Pivotal Response Treatment • Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) • UCLA Young Autism Project (Now the Lovaas Institute)	• Behavioral Package • Modeling • Naturalistic Teaching Strategies • Peer Training Package • Schedules • Self Management • Story-based intervention Package

Center, 2009; Odom, et al., 2010). Focused interventions are specific practices intended to change a targeted behavior in a relatively brief time (e.g., period of months). Examples, drawn from a review by the National Autism Center (2009), appear in Table 2. There are many studies, primarily using single case research design methodology (Horner et al., 2005), that have shown the efficacy of specific intervention techniques with children and adults with ASD (National Autism Center, 2009; Odom, et al., 2003). For example, functional behavior assessment is a focused intervention practice involving collecting data to describe antecedents and contingencies of behavior and offers a well-established way to link many other focused interventions to targeted behaviors (e.g., Cipani & Schock, 2007).

Comprehensive treatments are a set of practices designed to have a broad impact on core features of ASD. These treatments are characterized by their intensity, involving substantial amounts of time and service (e.g., 25 hours a week for a year or two) (see Handleman & Harris, 2008; Odom, et al., 2010). Comprehensive treatment programs usually incorporate a set of specific focused intervention techniques organized within a conceptual framework. Examples of focused interventions practices and comprehensive treatment programs are listed in Table 2. The most well-established comprehensive treatment models, such as the UCLA Young Autism Project (now the Lovaas Institute), are based on an applied behavior analysis model (see Odom, et al., 2010; Reichow & Wolery, 2009), although more studies of other approaches are gradually accumulating.

For a behavioral treatment or intervention to meet standard criteria to be considered evidence-based, it must arise from a theory about behavior change, be protocol-driven, and have supporting evidence published in peer-reviewed scientific literature available to support it (Lonigan, Elbert, & Johnson, 1998; Odom et al., 2003). Different reviews have different standards, some with such high standards that there is often little evidence to be interpreted (Cochrane Collaboration, www.cochrane.org; New York State Department of Health Early Intervention Program, 1999). However, in ASD in the last 10 years, more sophisticated research has been taking place (National Autism Center, 2009; Rogers & Vismara, 2008). There is more recognition that some interpretation of the quality of the outcome, the positive and adverse implications of intervention practices and "gray areas" add to the usefulness of the review (Odom, et al., 2010; Savoie, Helmer, Green, & Kazanjian, 2003).

The heterogeneity of ASD and the need for treatments to be family-centered (Bailey, Buysse, Edmondson, & Smith, 1992) offer challenges to identifying, in any systematic way, which comprehensive treatments are most appropriate for a particular child and family. Even between birth and age three, the range of skills and needs of young children with ASD are variable. For example, within this group there could be a 14 month old who is beginning to cruise, shows little facial expression or attention to others, does not babble, and has an intense interest in strings. In the same age group could be a 35 month old who continually surprises his family by reading upside down, reciting entire Disney videos, and identifying local shops by the kinds of doors (i.e., sliding, revolving, push/ pull) that enclose them.

For the 35 month old, the most pressing issue may be to determine the kinds of supports he needs to attend a regular preschool class, whereas for the 14 month old the most pressing issues may how to support the parents to engage their child in daily activities that lead to communication and social interaction.

Such complexities are not unique to ASD. Several authors have written about the tensions and challenges in applying evidence-based treatments to "real life" situations (e.g., Kazdin, 2008; McCall, 2009; Sackett, et al., 1997; Sackett, et al., 1996). What *is* perhaps more unique to ASD is the intensity required for a comprehensive treatment of ASD (i.e., several hours of treatment per day). Even focused interventions generally require several months of either daily direct teaching or weekly caregiver support (Odom, et al., 2010).

How can services for ASD be evidence-based *and* individualized *and* accessible to a critical mass of families? One response has come in the form of state-funded programs for Applied Behavior Analysis (or ABA); a number of states (e.g., Texas, Pennsylvania, Arizona, Florida, South Carolina, and Louisiana) have adopted rules indicating that ABA is the only well-established treatment for young children with ASD. With the impetus of a widely publicized paper in a major journal (Lovaas, 1987), an easily available and well-written curriculum (Maurice, 1996), and advocacy groups composed of parents and professionals, ABA offered the promise of theoretically-based, carefully researched principles that could be applied to almost any kind of learning. One of the cardinal requirements of ABA involves collecting data on the progress of the individual and then changing the treatment plan if progress is not occurring. Although the potential for individualization is always there, ABA is sometimes implemented with less emphasis on individualized treatment strategies (Howlin, Magiati, & Charman, 2009) and more focus on specific aspects of ABA that are easily apparent and feasible to carry out, such as discrete trials or different reinforcement schedules. Furthermore, ABA objectives do not typically include goals for family members or behavior plans for the ABA therapists to monitor with respect to their effects on the family.

Policy Issues in Evaluating Treatment Research

In evaluating interventions for ASD, one of the first questions we must ask is what are the goals of an intervention? This question seems obvious, but is not. When parents first hear about their child's diagnosis, their initial thoughts often are about helping their child recover from the disorder. In the case of ASD, a few recent studies have suggested that a small proportion of children identified early with mild symptoms of autism no longer have the disorder several years later (Helt et al., 2008; Kelley, Naigles, & Fein, 2010; Turner & Stone, 2007). However, the preponderance of research has suggested that, for almost all individuals, ASD is a lifelong disorder that may become milder as children grow older, but does not usually resolve completely (Farley et al., 2009; Howlin, Goode, Hutton, & Rutter, 2004; Lord, et al., 2006). Therefore, unlike many medical conditions where the goal is to cure the disease or achieve complete remission of symptoms, goals in ASD intervention must be tailored to developmental expectations for each child within his or her family.

So what should the goals be for treatments evaluated as efficacious? For most systematic reviews, the nature of the treatment goals is not taken into account at all. A goal of treatment might be something momentous, such as recovery, something significant but less momentous such as an increase in IQ of 10 points, something behaviorally significant such as fewer tantrums, or something more specific such as learning three words. In considering any of these goals, each of which might ultimately be "achieved" and judged as meeting scientific standards in terms of changes in slope and absolute level or effect sizes or odds ratios, the real value depends on how long it takes to be reached, how much money and labor went into its accomplishment, and how much the newly obtained skill then contributes to the individual and family's well-being and acquisition of other skills.

Whatever the goal is, it must be quantified, ideally with a measure that has some reliability across time and across raters (Lonigan, et al., 1998; Odom, et al., 2003). Documentation of maintenance and generalization of changes has become a more standard requirement of some journals, but it is still not required in most reviews (Lord, 2002; Odom, et al., 2003). Calls have also been made by various research organizations and individuals (Lord et al., 2005; National Institute of Mental Health, 2005; National Research Council, 2001; Odom, et al., 2003) for concomitant measures of the social validity (i.e., the social importance of the treatment outcome). That is, does the change that is measured have any observable effect on behavior that changes the child or family's independence, well-being, or participation in the community? Research that addresses these questions is still rare (Rogers & Vismara, 2008).

Another set of considerations concern the secondary and possible negative effects of a particular treatment. Negative effects also include financial burdens that result when families must pay for services out of pocket or when a caregiver must stop working so that he/she can coordinate or deliver services. Spending less time with other children may also be a secondary effect of some intervention approaches. These factors are rarely taken into account in evaluating different treatments (National Research Council, 2001).

In the following section, we describe a study recently published in *Pediatrics* that represents one of the first randomized controlled trials of a comprehensive developmental-behavioral treatment of very young children with ASD. Because of its breadth and strong design,

the study offers an ideal example of high quality efficacy research in ASD, and the difficulty in directly translating findings from a single research study into policy decisions (see also McCall, 2009).

Early Start Denver Model: An Example of a Multi-Method Early Comprehensive Treatment

Dawson, Rogers, and colleagues (2009) reported on the efficacy of the Early Start Denver Model (ESDM) for children with ASD under 30 months of age in a study. The researchers followed methodologically rigorous procedures, which included a careful and detailed description of the participants, randomize assignment to treatment and control conditions, assessment by naïve, independent but experienced clinicians, procedures documented in a treatment manual, and fidelity measures documenting the implementation of the treatment.

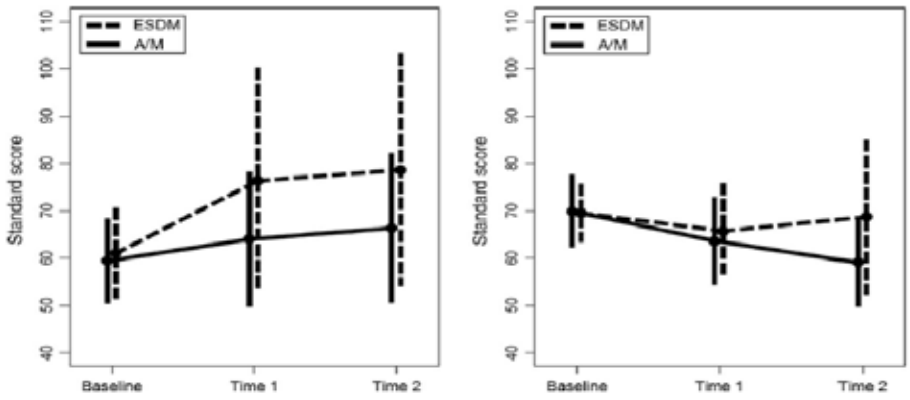
ESDM is a developmentally-grounded treatment model that addresses multiple domains. There is an emphasis on interpersonal exchange and shared affect, and a focus on verbal and nonverbal communication. Teaching strategies, while generally taking place in more natural contexts, were consistent with the principles of ABA. Children in the treatment group received 15 hours a week of in-home intervention by B.A. level therapists, supervised by graduate-level, experienced therapists and a team of specialists. Parents were asked to use the ESDM strategies (e.g., reinforce child attempts, use positive affect) during their everyday interactions (e.g., bathtime, meals) for at least 5 hours a week (mean reported hours were 16.3 per week). Families also reported another 5 hours a week on average participating in other therapies. Children in the community treatment-as-usual comparison group received an average of 9 hours a week of individual therapy and 9 hours a week of group intervention (ADDM, 2009).

The goal of the treatment was to improve the cognitive abilities of the participants. Was this treatment effective? Absolutely. As shown in Figure 2, children in the treatment condition showed increases in IQ of 17 points compared to changes of 7 points on average in the community treatment group (with an effect size of more than 1 standard deviation or SD). Children in the community treatment group showed about 10 point decreases in their adaptive scores over the two-year period; children in the ESDM group maintained the same level without the significant decrease. More children in the ESDM group moved from clinical diagnoses of autistic disorder to PDD-NOS than children in the community treatment group, suggesting a reduction in severity of ASD.

By any formal review, ESDM was a more effective treatment than the community interventions. In terms of policy decisions, there is much to be learned and even more to be followed up from the ESDM study. First, children in ESDM received many more treatment hours than did the comparison group (36 vs. 18 per week), with the parents of the ESDM group contributing 15 hours per week of treatment themselves, far beyond the 5 hours a week that was expected as part of the treatment. It seems likely that the ESDM parents, randomly assigned to treatment, were empowered by the program and took advantage of what they learned, which is a real strength of the treatment, but means that the comparison group received fewer total hours of intervention.

The fact that none of the families in ESDM left the study could be a reflection of the effectiveness of the treatment approach in engaging the commitment of the families. However, different attrition rates may also have

Figure 1. Mean scores on the MSEL and the VABS composite for children in the ESDM and A/M groups 1 and 2 years after entering study.



From "Randomized, controlled trial of an intervention for toddlers with autism: The Early Start Denver Model," by G. Dawson, S. Rogers, J. Munson, M. Smith, J. Winter, J. Greenson, … J. Varley, 2009, *Pediatrics, 125*(1), pp. e17-e23. doi: 10.1542/peds. 2009-0958.

created a select group of families and children. The sample was distributed across White, Latino, Asian-American and multi-racial children. All of the children lived within 30 minutes of the University of Washington. No data are provided about parental education levels, one- or two-parent families or other caregivers, working/non-working status, presence of siblings or parental occupations; all of which may be discussed in more detail in future papers. This does not mean that the treatment cannot be effective with other groups, but policy makers need to seriously consider the factors that made this treatment work and how those factors could be replicated in other community contexts. How could ESDM be put into place for a family with a working, single parent or a family with several other young children and little space for in-home treatment? These various moderators of treatment effectiveness *must* be empirically investigated in order to better inform policy decisions about intervention programs (Kazdin, 2008; McCall, 2009).

In terms of the effects, how large are they? Are they worth two years and many thousands of dollars effort on the part of the therapists, supervisors, consultants, and parents? An important caveat raised by Fombonne (2010) is that the standard deviations of many of the scores, while similar between the groups, grew steadily larger for the ESDM group with treatment, suggesting that there were some children who were improving dramatically and others who were not. Typically one might expect the children in the intensive treatment to show more similar outcomes and children in the control group to be more variable. Who were the children and which were the families who benefited the most? The least? Previous studies have found significant differences in treatment effects for ABA with children with milder versus more severe ASD (Smith, Groen, & Wynn, 2000) and with higher scores on intelligence tests (Sheinkopf & Siegel, 1998). Again, research is needed to identify mediators and moderators of treatment gains in children with ASD (see Rogers & Vismara, 2008).

Recent theories of child and adolescent development (Sameroff, 2010) have proposed the notion of developmental cascades in psychopathology. While these concepts arose from studies of disorders quite different from autism, in ASD there has been great interest in the idea that at least some of the manifestations of autism in older children and adults are the product of interactions with the environment that are secondary to the core features of the disorder (Mundy, Sullivan, & Mastergeorge, 2009; Rogers, 2009). The idea is that children with ASD reduce their own opportunities to learn, because of lack of understanding and or attention (e.g., Kasari, Gulsrud, Wong, Kwon, & Locke, 2010). This diminution of experience is compounded by the fact that, because of behavioral difficulties and restricted interests, other people (e.g., caregivers, teachers, therapists) also do not offer children with ASD the wealth of cognitive, social and emotional input that is provided to typical children. For example, ABA therapy, where the child is predominantly working with one person presenting one task at a time, provides fewer exposures to ideas and interactions than being part of a typical preschool where the scope is broader and other children contribute to the contexts of learning. On the other hand, the one-on-one individualization is one of the reasons ABA is effective. The hope, therefore, is that with a combination of traditional early interventions that emphasize engagement (Dawson, Meltzoff, Osterling, Rinaldi, & Brown, 1998; Kasari, et al., 2010; Prizant & Wetherby, 1998), together with more graduated exposure to the kinds of social contexts in which a child is likely to learn, a cascade of secondary effects of deficits in joint attention and social orientation can be prevented (Dawson et al., 2004; Mundy, et al., 2009).

Summary

There is much work ahead to determine how best to meet the growing needs of children and adults with ASD and their families. One point that is clear from the research to date is that this is a diverse group of children and adults whose needs are varied across the lifespan, both in terms of assessment and intervention. Given the current variability in rates across states and the disparities in diagnosis across ethnic groups and parental education levels, it seems most likely that if disparities decrease, numbers of children with ASD will rise even more (ADDM, 2009; Fombonne, 2009). Careful assessment is needed to determine the most appropriate services for different children, as well as within the same child at different points during the life course. While some children with ASD continue to need significant supports as they grow into adolescents and adults, other children require much more limited interventions after the pre-school years. Because the distinction between ASD and other disorders on any individual behavior, or even dimension of behavior, is arbitrary, multi-method approaches will be cost effective in more consistently identifying children and adults who exhibit the multiple and intersecting characteristics by which we define ASD. It is

imperative that insurance companies and policy makers understand that proper assessment of ASD involves more than simply arriving at a diagnosis; it provides a road map that is necessary to determine the most appropriate programming for each family.

A daunting question before us is how to provide individualized, evidence-based interventions to children and adults with such a wide range of needs. There are now many focused interventions and a few comprehensive treatments that are well supported by evidence, with information easily accessible through web-based programs (National Autism Center, 2009; National Professional Development Center on Autism Spectrum Disorders; www.fpg.unc.edu-autism; nectac.org/autism). The primary issues here are equitable funding and training. There remains complexity in which specific aspects of treatment make the most meaningful differences for children and for families, in considering how treatments can be extended to all children and adults with ASD, and in implementing treatments in communities.

It is also essential to stress the importance not only of providing appropriate assessment and treatment services to children and adults with ASD, but also to children and adults with other kinds of developmental disabilities. There is symptom overlap between ASD and other diagnoses. The assessment and intervention techniques that have been found to be effective for children with ASD may also be appropriate and beneficial for many children with intellectual disabilities and a range of other developmental disabilities. It would be erroneous to conclude that all children and adults with ASD are, by definition, in greater need of services than children with other disorders. Services should be based on need as determined through individualized assessment techniques—not on a categorization of autism instead of Asperger syndrome, or a label of ASD versus intellectual disability.

As a disorder (or set of disorders) that affects brain function, ASD awaits neurobiological approaches that will more directly ameliorate or prevent the core deficits that define them. In the meanwhile, with improved understanding of how many children and adults have ASD, how best to conduct assessments of strengths and difficulties that affect the well-being of children and adults with ASD and their families, and what is needed to measure changes in response to treatments, we will be better equipped to develop social policies that aid us in changing the many things that can be changed for families and their children with ASD.

Policy Recommendations

- Health insurance and public funding policies must support evidence-based practices for ASD and provide mechanisms to evaluate the effectiveness of treatments in addressing individual and family goals, and to coordinate health care with educational and other services.
- Federal policies and funding should promote equal access to services across states and across all individuals with ASD (i.e., from different racial/ethnic groups and family income levels).
- Criteria for evidence-based practices should require replications of new practices and treatments in community settings with results demonstrating generalization of effects and social validity.
- Research that meets standards for evidence-based practices in model programs and community settings in diverse populations and including families in different circumstances should be prioritized.

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Commentary

The Changing Face of Autism Requires Rethinking Policy Needs

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The face of autism is changing. Lord notes that autism used to be considered a rare childhood disorder associated with severe intellectual disabilities. In 2009, the Centers for Disease Control and Prevention released new data on the prevalence of autism spectrum disorders (ASD) in the US, showing that ASD now affects 1 in 110 children (CDC, 2009). When compared to similar data collected by the CDC four years earlier (CDC,2007), this represents a 57% increase in prevalence rates in a relatively short period. Over the past two decades, the prevalence of ASD has increased by over 600%. Clearly, autism is no longer a rare childhood disorder.

How can we explain a 57% increase in prevalence in four years? Although children were diagnosed at an earlier age in the 2009 study, the age of diagnosis only decreased by an average of five months, which is enough to account for the increase. The change was unlikely due to the inclusion of more children with milder ASD because the proportions of children with autism versus Pervasive Developmental Disorder (milder autism) in the two studies were not different. Although more children with higher cognitive functioning were included in the 2009 study, this varied substantially by sites and did not account for the majority of increase. As the authors of the 2009 study concluded, "Although improved ascertainment accounts for some of the increase, a true increase in the risk for ASD cannot be ruled out" (CDC, 2009, page 1).

The unexplained increase in prevalence of ASD has important policy implications. First, these findings underscore the need for more research on the potential role of environmental risk factors in ASD, including the role of prenatal, perinatal, and postnatal exposures and epigenetic influences (Landrigan, 2010). Given the very early stage of our knowledge in the area, we need to cast a broad net as it is certain that no single factor will explain the changes in prevalence. Second, our society needs to be prepared to address the needs of a large cohort of individuals with ASD moving through childhood into adulthood. Although we have made significant strides in developing effective intervention methods for children with ASD, programs to assist adolescents and adults with ASD to become productive members of society who have lives with dignity and purpose are lacking. The majority of adults with ASD do not live independently and are either under- or unemployed (Howlin, 2004). As Lord and Bishop noted, the financial cost of failing to develop appropriate services for adults with ASD will be significant.

The new CDC data also provide other insights into the changing face of autism, which have implications for policy needs. Close to 60% of children with ASD in this sample had IQs over 70. The needs of higher functioning individuals with ASD are varied and complex. Individuals with ASD suffer from co-morbid conditions, such as depression, anxiety, sleep problems, obesity, and gastrointestinal problems. These conditions require a comprehensive approach that often is not provided due to inadequate training and a lack of insurance coverage. This is unfortunate because research has shown that when co-morbidities are addressed, individuals with ASD have improved concentration, benefit more from educational programs, and exhibit fewer challenging behaviors (Coury, 2010). Efforts to address the need for clinical guidelines for diagnosis and assessment of ASD and its associated medical conditions are underway by the Autism Treatment Network, a collaboration of fourteen medical centers (Coury et al., 2009). However, there is much more work to be done, which will require increased resources in guideline development, professional training, and dissemination.

At the same time that we must address the needs of the current generation of individuals with ASD, it is crucial that policy focus on access to early interventions that can alter the developmental trajectory of persons with ASD, thereby reduc-

ing the costs of adult care and improving the quality of life. Synthetic reviews on the efficacy of early behavioral intervention conclude that these interventions can significantly impact cognitive functioning (Reichow & Wolery, 2009). We need to remove the barriers to access to such interventions by eliminating insurance discrimination, increasing our investment in professional training, and addressing health care disparities due to SES, ethnicity, and geography. Scalable and exportable interventions need to be developed. Tools for recognizing infants at risk for autism will be available over the next several years, and we must be prepared to offer parents feasible and effective interventions that are appropriate for toddlers. The cost savings of early intervention to society are likely to be substantial; as Lord points out, individuals with less severe cognitive impairments are less costly to care for (Jarbrink et al., 2007) and relatively minor changes in independence and adaptive skills can save significant amounts of money (Kogan et al., 2008). It is well within our ability as a society to improve the lives of individuals with ASD and their families. The benefits of policy changes that address these needs of persons with ASD would not only include significant cost savings and reduced stress and burden on families, but also result in improved well-being, productivity, and quality of life for the hundreds of thousands of persons with ASD who make up the new face of autism.

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Commentary

Diagnosis, Evidence-Based Practices and Autism

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Lord and Bishop carefully delineate recent studies of the diagnosis, prevalence and treatment of individuals with autism spectrum disorders (ASD), and thoughtfully describe the policy implications related to findings in these areas. They use recent improvements in diagnostic strategies as a springboard for a discussion of the healthcare environment in which diagnosis often occurs far too late or not at all. They point out that families often leave this process with many fewer resources than they need to make appropriate decisions regarding intervention. Lord and Bishop summarize recent prevalence estimates and describe the changing face of ASD. Children now are diagnosed at a younger age than they were previously. Intellectual disability occurs in a much smaller proportion of children meeting criteria for ASD, which results in a shift in which service systems are tasked with providing care. The authors describe startling increases —as well as geographic and ethnic disparities—in the identification of children with ASD and associated policy issues related to barriers to high-quality diagnostic practices. Finally, Lord and Bishop describe recent advances in intervention for young children with ASD, and the challenges to implementing evidence-based intervention for children with autism within current healthcare and education systems.

In summary, ASD now comprises a set of common, heterogeneous disorders previously thought to be relatively rare and homogeneous in presentation. The communities in which these children are diagnosed in ever-increasing numbers are unprepared to meet their complex and often expensive needs.

Addressing this burgeoning public health crisis of moving evidence-based practices quickly and efficiently into community settings will require a two-pronged approach. The first is to apply traditional health services research models to understanding the best ways to organize, finance and deliver care to individuals with autism. A growing body of observational studies describes the service utilization and associated expenditures of individuals with autism. To increase its policy relevance, these studies will have to move to more experimental designs, testing the effectiveness of competing models of intervention and intervention delivery. For example, the strategies states have taken, such as adopting Medicaid waivers or legislating insurance mandates, to pay for the varied and complex services Lord and Bishop describe, offer critical opportunities to test how different models for financing care affect the quality and quantity of service delivery.

The second approach to improving diagnosis and intervention in the community requires a dramatic rethinking of the usual approach to how the field develops related practices. Traditional strategies involve developing and testing new diagnostic tools and interventions in university-based research settings, after which it is expected that the resulting publication will result in widespread dissemination. A large body of research shows that this dissemination strategy is not effective, leading to what some have described as a 17-year gap between research findings and changes in community practice. Further delaying dissemination, these practices usually are developed with samples that may not represent the larger population of individuals with ASD, with more sophisticated clinical resources than are available in community settings, and measuring outcomes that may not have ecological validity to community practitioners. Community providers with limited resources therefore may have difficulty implementing these interventions or think that they do not apply to their settings. An alternative approach is to develop practices in partnership with the organizations that we hope ultimately will use them. Successful community-academic partnerships could facilitate successful adoption, implementation and maintenance of interventions that have already been developed, and result in the development of new interventions that meet the community's needs and capabilities, thereby increasing the likelihood of successful implementation.

Commentary

Autism and Social Policy:
Issues, Needs, and Directions for the Future

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In their review Lord and Bishop praise a number of important issues. This brief commentary will focus primarily on issues of diagnosis and of treatment and service delivery, and, finally, directions for the future as these relate to social policy. There has increasingly been a tendency to equate autism (more strictly defined) with the broader concept of the autism spectrum for several reasons, (e.g., genetic studies, increased public and media awareness of the condition, and recognition of the importance of intervention) (Rutter 2005; Towbin 2005; Volkmar, et al. 2009). Careful reviews of the available epidemiological literature (e.g., Fombonne, 2005) note the impact of increased public awareness, of diagnostic substitution, and a range of potential methodological issues in understanding what appear to be changes in prevalence. In DSM-IV (and ICD-10) there was concern about identification of autism (and Asperger's Syndrome) in more cognitively able children—itself a potential contribution to an apparent increase. The practical social policy implications of potential changes in diagnostic practice in DSM-V remain unclear. The focus on a spectrum would seem to imply a broadened diagnostic view but the actual approach proposed may, in some respects, be more stringent than the current one. Substantive, peer reviewed data on the practical implications of changes in diagnostic practice is needed for effective planning.

Treatment provision is a complex area (see Reichow et al., in press) given the difficulties in conducting treatment studies, the variability of availabile treatments, marked disparities in who is studied (based on age, diagnosis or level of functioning), the varied research traditions with the many professions involved, the growing emphasis on evidence-based treatment, and the wide, and perhaps widening, range of syndrome expression. Younger children and more strictly diagnosed cases have been most frequently studied, leading to gaps relative to older individuals and those with the broader autism spectrum. The widespread use of alternative treatments, comorbidities, difficulties in disseminating research findings and effective practices into schools, and the marked variation (from state to state or sometimes even from town to town) in available services present other challenges. Outcomes appears to be changing over time (Howlin 2005). Empirically based programs themselves evolve. Important issues of dose, timing, priority, and so forth remain to be addressed (Reichow, et al., In Press). The growing body of prospective studies likely will, over time, lead to improved diagnostic measures and the need for establishing parameters for effective treatments for infants and toddlers (Rogers 2009) which itself raises other challenges.

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