



## SOUTHERN LEGISLATIVE CONFERENCE

OF

## THE COUNCIL OF STATE GOVERNMENTS

# AUTISM AND SCHOOLS

A REGIONAL RESOURCE FROM THE SLC

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## CHAPTER 1: INTRODUCTION

### What is autism?

Autism Spectrum Disorders (ASD), including autism and Asperger syndrome and the less common Rett syndrome and childhood disintegrative disorder, are complex pervasive developmental disabilities that result in potentially significant impairment in social interaction and communication, restricted or repetitive movement or the exhibition of unusual behaviors or interests. Individuals with ASD may present a wide range of abilities and skills, including those who are profoundly disabled and those who are exceptionally gifted. Furthermore, many individuals with ASD may have attention, learning and processing patterns that are unusual, or unpredictable responses to intense sensory input. Alongside a diagnosis of ASD, individuals may be identified as having another disorder, including mental retardation, obsessive-compulsive disorder or depression, the presence of which complicates both the diagnostic and treatment approaches. While a diagnosis may not be made until later, most disorders on the spectrum can be identified by age 3, and often as early as 18 months.

A wide range of behavioral peculiarities and deficiencies are included within the autism spectrum. For example, individuals with autism may not respond to their name or make eye contact when being addressed and may appear to be deaf. Children with autism may not want to cuddle or be held. They typically demonstrate little anxiety about strangers or being separated from parents or caregivers and seldom engage in social play. Furthermore, children with ASD may not engage in conversations and may have difficulty expressing needs and desires. Behaviorally, these children often have limited interests and react negatively to even small changes in routines. They also may engage in repetitive movements, such as rocking back and forth or flapping their arms. They may be overly sensitive to stimuli such as noise, light, touch or smell, and may exhibit reduced awareness of pain.

Children who miss significant early developmental milestones or exhibit specific early behaviors often are assessed for ASD. All children with a disorder on the spectrum will have deficits in social interactions, verbal and non-verbal communication, and demonstrate repetitive behaviors or interests. Linguistic milestones that may be delayed or missed entirely in children with autism may include not babbling, pointing, or making meaningful gestures by age 1, not using words by 16 months, or not combining two words by 2 years. Children with ASD also may not respond to their name or lose language or social skills and have poor eye contact and minimal facial expression. They may also have an inability or lack of interest in playing with toys, excessive or obsessive lining up of toys or other objects, or overly strong attachment to a particular toy or object. These children may not play pretend games, point out objects to show interest in or look at an object indicated by someone else. Socially, children with ASD may not develop attachments to caregivers, demonstrate empathy, or seek interactions. Children with ASD may develop peculiar linguistic patterns, including flat intonation or sing-song speech, as well as facial and body language that does not match what they are saying, although others may be essentially mute for their entire lives. Older children with ASD may have great difficulty regulating their emotions, including crying or angry outbursts, often out of proportion to the triggering event.<sup>1</sup>

### Why the sudden rise in autism?

The causes of autism still are undetermined, and assigning responsibility for the rapid rise in the incidence of ASD is not entirely possible. Autism seems to have a strong genetic component, although the mechanism for inheritance—pre-disposition, mutation, or multigene interaction, among others—remains unexplained. Environmental factors for both the mother and the newborn child, maternal and neo-natal health factors, and other causes all have been discussed as potential triggers or contributors to autism, but conclusive evidence remains elusive.

Equally, there is no clear answer as to why there has been such a steep rise in the identification of children with autism, although part of the increase can be attributed to better detection and diagnosis. Changes in the definition of autism (as outlined in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders, or DSM-IV, the manual published by the American Psychiatric Association that covers mental health disorders for both children and adults most recently published in 1994) somewhat expanded the definition of autism for diagnostic purposes, leading to children who previously would have been labeled as mentally or emotionally limited or retarded being diagnosed with a disorder on the spectrum. Public awareness of the disorder and the availability of federal funds to serve children with ASD could have some relationship with increasing the prevalence rate\* and also may have contributed to an increase in the identification of children (and adults) with ASD who previously were overlooked.

Recent research has been inconclusive as to whether changes in diagnosis can account for the sudden rise in incidence, although it generally is believed that better ascertainment has resulted in much of the recent growth.<sup>2</sup> However, research reported in January 2009 found that changes in criteria accounted for only a 2.2-fold increase in incidence (well below the actual rate experienced). Earlier diagnosis also was

not viewed as significant, largely because while more children were being identified at earlier ages, there was not any correlative drop in the identified population at later ages, which would be expected if the age of identification had simply shifted. Thus, there remains an unknown factor to fully explain the recent growth in the affected population.<sup>3</sup> Furthermore, the increased incidence mirrors that in other developed countries (for years the U.S. rate was typically reported as much lower), pointing to a realignment rather than an epidemic.

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### Why does this matter?

Determining the cause of the rise in the number of autism cases is of significance for policymakers because it has implications for future policy directions. If the increase principally is the result of better and more aggressive diagnoses, then the recent and sharp rise in the autistic population should be expected to level off at a new higher, but stable, rate. If, however, the rise represents an increase in the actual number of new cases of autism, the rise in identification simply is measuring a growing epidemic of ASD and projections for the size of the population in the years ahead are much more uncertain. This scenario raises the specter of long-term increases in the number of children identified consuming ever-increasing amounts of resources.

\*Prevalence is the percentage of the population segment in consideration that is affected.

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## Federal Law and Autism

Congress crafted the programs and services covered under the Individuals with Disabilities Education Act (IDEA) in a manner that reflected the multidisciplinary nature of disabilities in children. First proposed as the Education for All Handicapped Children Act in 1975, the Act was renamed IDEA in 1990 and expanded in scope in 1997. While most federal programs are specific to a single agency or department, IDEA has at its core an interagency mandate to coordinate services and financing. Children served by IDEA are covered from birth or first diagnosis to age 21 by different sections of the legislation, with the lead coordination agencies changing as the child moves into preschool and school settings. Children from birth to age 2 are served under IDEA part C, which may be coordinated by a state department with responsibility for disabilities and rehabilitation, health or education. Section 619 of the Act, which addresses programs for preschool children, and Part B, which addresses the needs of school age children, typically are administered by a state office of special education within the state department of education. These lead agencies are expected to work with other departments and agencies—such as those responsible for health, disabilities, rehabilitation and others—to ensure that children receive comprehensive care.

Although federal law has required coordination for two decades, varying forms of program delivery, imperatives to screen, diagnose, identify, treat, and manage disability cases, as well as manifold programs intended to serve individuals and programs with the purpose of serving the entire family, have made this coordination difficult. Furthermore, as the number of eligible children has increased, the available resources for providing services has been stretched thin, further limiting opportunities for interagency coordination. While coordination at the state level is a potentially straightforward effort involving a handful of stakeholders relatively familiar and comfortable with federal and state requirements, local agencies and service providers, who generally are focused on service delivery and care, often do not have the capacity to navigate the multiple funding sources and requirements of the involved federal and state programs. For example, children and families eligible under Section C of IDEA may be qualified to receive services from not just the department of education at the state and federal level, but also Medicaid Title XIX, Medicaid Title V (Children with Special Health Needs), State Children's Health Insurance Program (SCHIP), Temporary Assistance to Needy Families (TANF) or private insurance. For a local service agency or office working with children with disabilities—whether across the full spectrum of disabilities or focused on a single challenge—making the most of these possible resources is an enormous challenge.

## CHAPTER 2: POPULATION AND PRACTICES

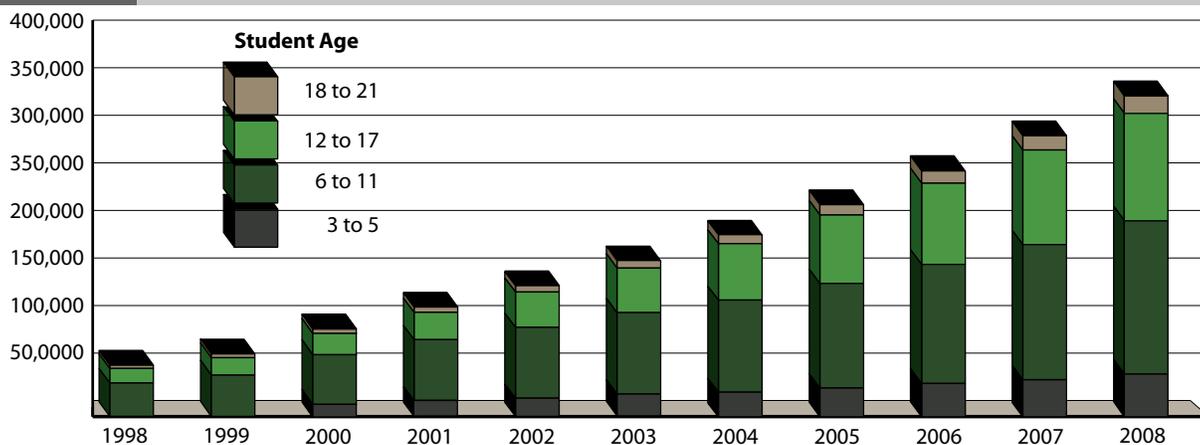
### What is the prevalence of autism among school children?

For decades, researchers and public health officials believed that between four and five in every 10,000 children were affected by autism. These figures were based on relatively old models and were inconsistent with both studies from other industrialized countries and with the number of students with autism reported to the federal government. Following a series of reports from the late 1990s and early 2000s that pointed to a marked discrepancy between the presumed and actual prevalence of the disorder, the Autism and Developmental Disabilities Monitoring Network of the U.S. Centers for Disease Control and Prevention (CDC) conducted a multi-state survey to arrive at a more accurate picture of the prevalence of the disability. A report developed using this data, released in 2007, showed that about 1 in 150 children have ASD. Using this estimate, the CDC projected approximately 560,000 individuals under the age of 21 in the United States may have a disorder on the spectrum. A follow-up report released by the CDC in October 2009 indicated that the incidence rate based on survey sites was closer to 1 in 100 for 8-year-olds (the age by which most autism cases will be diagnosed). This refinement of the previous report may not indicate a sudden surge in the population, however, but improvements in detection. Even prior to the new research, it has long been known that autism affects four times as many boys as girls, but has only limited or no correlation (depending on the study) with socio-economic status or ethnicity.

According to the U.S. Department of Education, the size of the school age population<sup>†</sup> with autism has grown markedly over the past decade, from 53,644 children identified under the Individuals with Disabilities Education Act in 1998, to 337,572 in 2008, an increase of nearly 529 percent, even as the total student population only increased by 6 percent and the resident population increased by even less. This figure still is considerably lower than the number of students with specific learning disabilities<sup>‡</sup>, but the trend for students in that category actually has declined over the past 10 years by roughly 8 percent. The prevalence of autism in the school age population has risen from .08 percent in 1998 to .45 percent in 2008, a more than fivefold increase. While this may seem a thin sliver of the total student population, the rapid growth and the strains it has placed on teachers, schools and specialists are acute. This steep rise in prevalence is of even greater concern when viewed against the background of an only slight rise in the prevalence of all disabilities among school age children, from 7.26 percent in 1998 to 8.31 percent in 2008. Further, because not all students with a diagnosis of autism will receive services under the autism classification (if, for instance, they have other learning or developmental disabilities as well), the actual number of children with ASD being served through IDEA programs actually is greater than the population listed.

Overall, the most explosive growth of students with ASD occurred in the older cohort of students, those age 12 to 17. In 1998, the student population nationally with autism was approximately 15,326, a figure that rose to 112,913 by 2008, an increase of 636 percent. For children age 6 to 11, the in-

**Figure 1 Student population with autism by age group 1998 to 2008**



Source: U.S. Department of Education, Office of Special Education Programs; Data Accountability Center, Individuals with Disabilities Education Act data. Note: IDEA reports did not require child counts for disability categories prior to 2000.

<sup>†</sup> For the purpose of a discussion of students with disabilities, the school age population is considered to be from the age of 3 to 21 years old. Prior to 2000, IDEA counted but did not report the number of children served by disability category. Therefore, the inclusion of children with ASD and other disabilities in the 2000 count does not disproportionately increase the population figures over time.

<sup>‡</sup> The largest categorical learning disability covered by IDEA, specific learning disabilities, are disorders that interfere with one or more of the basic processes involved in understanding or using language, including listening, speaking, thinking and cognitive processing, literacy and numeracy. Included in this category would be children with brain injuries and minimal brain function, as well as dyslexia, attention deficit disorder, dysgraphia, dyspraxia, or an auditory processing disorder, among many others.

crease is still an astonishing 361 percent—from 34,938 in 1998, to 161,121 in 2008—the age group that represents the largest portion of the affected population. The oldest cohort eligible for services under IDEA, those 18 to 21 years of age, grew 450 percent between 1998 and 2008, although the absolute size of that population remains relatively small (18,604 in 2008). Figure 1 illustrates the growth in the student population with autism diagnosis overall, as well as the age distribution for these individuals, between 1998 and 2008.

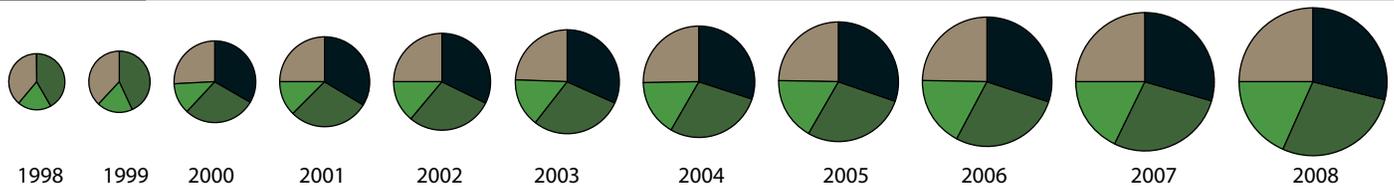
When viewed as a percentage of the disabled population, children with autism represented less than 1 percent of all children eligible for services under IDEA in 1998. By 2008, this figure had risen to 5.1 percent. In the cohort of children ages 3 to 5, the percentage of children with autism rose from 2.2 percent in 2000 (the first year for which data is available), to 6.3 percent in 2008. Among children age 6 to 11, the percent with autism served under IDEA rose from 1.28 percent in 1998, to 6 percent in 2008. Finally, among students age 12 to 17, the percent of children served increased from .62 percent to 3.95 percent over the same period. The increasing proportion of children with autism served under IDEA has significant implications for state and school policy, as it signals a need to adjust resources and assets to serve this population, shifts that require new personnel, technology, and training, among other things. Figure 2 illustrates the growth of autism as a percentage of all students receiving services through IDEA by age, demonstrating the swift growth of this disability group as a proportion of the total special needs population.

The prevalence rate for autism in the South as reported through IDEA data was .35 percent in 2008, significantly below the national prevalence rate of .45 percent. Table 1 provides the number and percentage of children with autism served by IDEA in the region. The South is below the rest of the country in students with autism in both the age

3 to 5 cohort (.24 percent compared to .36 percent) and the age 6 to 17 group (.37 percent compared to .44 percent). Autism also is a smaller component of all students with disabilities. In this, however, the discrepancy is most notable with children age 3 to 5, with 4.85 percent of children in this age range in the region identified as students with ASD, compared to 6.34 percent nationally. For age 6 to 21, this figure is much closer to the national average (4.29 percent in the South compared to 4.97 percent nationally). The discrepancy between national and regional rates of incidence is not necessarily an indicator of a lower rate in the South. Differences in screening and detection among and within states can account for much of the variation (both in terms of overidentification and underidentification). The tendency of the region to report fewer children with ASD across all age ranges, and particularly in the early years, could indicate a need for improved screening, diagnosis and awareness.

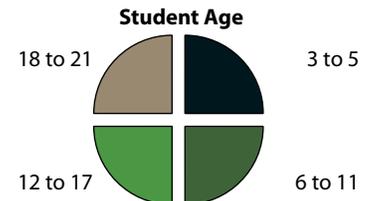
The relatively small size of the student population with ASD still requires attention to be paid to the disorder. The significance of even small numbers of children with autism diagnoses is in the complexity of meeting their educational, social, and communication needs, particularly as compared to a child with a more specific learning disorder. Few children in the latter category will spend much time with specialists outside the classroom, and the specificity of the learning need helps to fine-tune treatment. The degree to which a child with autism or a disorder on the spectrum presents with a unique pattern of deficiencies and peculiarities is an indicator of the complexity of the treatment regime and, concomitantly, the costs of serving that student. Children with autism may move through a range of treatment approaches as they advance in skills and their needs change, requiring varying expertise from support staff, teachers and paraprofessionals resulting in unpredictable cost and budgetary implications.

**Figure 2 Children with autism as a percent of all students served through IDEA 1998 to 2008**



Circles are scaled to the relative size of the population of all ages with autism as a percentage of all children served under IDEA.

Year	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008
<b>Autism as a percent of All Children Served by IDEA</b>	0.9	1.1	1.5	1.8	2.1	2.5	2.8	3.3	3.9	4.5	5.1



Source: U.S. Department of Education, Office of Special Education Programs; Data Accountability Center, Individuals with Disabilities Education Act data.

Table 1

## Number of children served under IDEA and the number and percentage of children served with autism in the Southern states Fall 2008

State	Age 3 to 5					Age 6 to 21				
	Resident Population	All Disabilities	Autism	% Autism	Autism Prevalence	Resident Population	All Disabilities	Autism	% Autism	Autism Prevalence
Alabama	182,959	7,079	285	4.03%	0.16%	1,009,825	75,782	2,958	3.90%	0.29%
Arkansas	117,095	12,288	209	1.70%	0.18%	613,150	52,431	2,073	3.95%	0.34%
Florida	665,301	33,796	2,175	6.44%	0.33%	3,549,150	351,179	12,532	3.57%	0.35%
Georgia	436,899	16,185	800	4.94%	0.18%	2,184,806	163,522	8,747	5.35%	0.40%
Kentucky	167,436	19,755	379	1.92%	0.23%	882,694	87,977	2,764	3.14%	0.31%
Louisiana	185,157	9,860	371	3.76%	0.20%	1,003,276	76,162	2,480	3.26%	0.25%
Mississippi	127,116	8,968	140	1.56%	0.11%	683,565	55,439	1,332	2.40%	0.19%
Missouri	231,892	15,245	355	2.33%	0.15%	1,263,350	117,701	5,589	4.75%	0.44%
North Carolina	378,853	18,682	1,164	6.23%	0.31%	1,976,612	169,046	8,582	5.08%	0.43%
Oklahoma	153,196	7,431	127	1.71%	0.08%	793,383	86,505	2,170	2.51%	0.27%
South Carolina	175,688	10,763	442	4.11%	0.25%	962,619	91,133	2,612	2.87%	0.27%
Tennessee	243,313	12,325	581	4.71%	0.24%	1,291,459	106,100	4,014	3.78%	0.31%
Texas	1,192,869	38,169	3,367	8.82%	0.28%	5,685,627	414,142	22,589	5.45%	0.40%
Virginia	306,692	17,124	879	5.13%	0.29%	1,640,571	149,565	7,913	5.29%	0.48%
West Virginia	63,228	5,899	61	1.03%	0.10%	352,387	41,079	1,035	2.52%	0.29%
SLC	4,627,694	233,569	11,335	4.85%	0.24%	23,892,474	2,037,763	87,390	4.29%	0.37%
United States	12,470,003	708,481	44,934	6.34%	0.36%	66,885,751	5,884,739	292,638	4.97%	0.44%

Source: U.S. Department of Education, Office of Special Education Programs; Data Accountability Center, Individuals with Disabilities Education Act data.

### The cost of autism

Children with an ASD diagnosis are eligible for special educational services for 18 years beginning at age 3, and often are served earlier than this through other state-supported programs. Federal law stipulates that children with disabilities are entitled to a free and appropriate public education in the least restrictive environment possible. The costs of these services can vary widely from state to state, and within states, depending on the kinds of services and supports available and required, among a host of other factors. Autism, however, is one of the most costly of all disabilities to treat regardless of location. A 2003 report by the Special Education Expenditure Project (SEEP) of the American Institutes for Research, a behavioral and social science research organization, found that in public schools the average per pupil expenditure for regular and special education instructional and related services for students with autism was \$18,790 per year, an amount surpassed only by the total costs for students with visual impairment or blindness and students with multiple disabilities. By way of comparison, annual per pupil expenditures for a typical student in general education were \$6,556. Thus, students with autism in a public setting have a cost factor of 2.9 times the cost of a typical regular education student. The special education services component\*\* of total expenditures for students with autism was larger

in absolute terms than for any other categorical disability, including students with multiple disabilities and visual impairments, with these services costing, on average, \$11,543 annually per pupil with ASD. This amounts to roughly 90 percent of the instructional and related services for children with autism.<sup>4</sup> Children with multiple disabilities have an only slightly higher percentage of their total costs from special education services (91 percent) but require, on average, slightly less in actual dollar amounts (\$11,397) in special education services per pupil.

The significance of these numbers becomes more apparent when considering the population size of various disability categories. While the largest single disability category among school age (3 to 17) children receiving services through IDEA is specific learning disabilities (2,536,780 children in 2008, or 38 percent of the total), the per pupil cost for serving this population is relatively low (\$10,558 in total yearly expenditures in the SEEP study, and \$6,489 in instructional and related services). Of the high-cost disability categories (those over \$8,000 annually per pupil for special services in the SEEP study), only mental retardation surpasses autism in terms of the number of identified students. However, as the number of ASD diagnoses rises, it is likely that some students who previously would have been

\*\* Special education services include special education classes, resource specialists, related services and other special education services. Regular education expenditures reported in the SEEP study varied in absolute amounts among categorical disabilities.

**Table 2 Special Education Population 2008 and Costs 1999-2000**

Disability	2008			Per pupil expenditures (1999-2000)	
	Total (ages 3-21)	Percent of all students with disabilities	Prevalence of disability (total/resident population)	Total	Instructional (regular and special education)
<b>Autism</b>	337,572	5.12%	0.43%	18,790	12,773
<b>Deaf-blindness</b>	1,942	0.03%	0.00%	-- <sup>a</sup>	-- <sup>a</sup>
<b>Developmental delay</b>	353,882	5.37%	0.45%	-- <sup>b</sup>	-- <sup>b</sup>
<b>Emotional disturbance</b>	421,359	6.39%	0.53%	14,147	9,200
<b>Hearing impairments</b>	79,098	1.20%	0.10%	15,992	10,803
<b>Mental retardation</b>	488,111	7.40%	0.62%	15,040	9,246
<b>Multiple disabilities</b>	131,776	2.00%	0.17%	20,095	12,587
<b>Orthopedic impairments</b>	70,012	1.06%	0.09%	14,993	9,314
<b>Other health impairments</b>	666,192	10.10%	0.84%	13,229	8,427
<b>Specific learning disabilities</b>	2,536,780	38.48%	3.20%	10,558	6,489
<b>Speech or language impairments</b>	1,451,462	22.01%	1.83%	10,958	6,681
<b>Traumatic brain injury</b>	25,824	0.39%	0.03%	16,542	11,146
<b>Visual impairments</b>	29,210	0.44%	0.04%	18,811	13,161
<b>All disabilities</b>	6,593,220	100.00%	8.31%		

Source: U.S. Department of Education, Office of Special Education Programs; Data Accountability Center, Individuals with Disabilities Education Act data; Jay G. Chambers, Jamie Shkolnik and María Pérez, Total Expenditures for Students with Disabilities, 1999-2000: Spending Variation by Disability, Special Education Expenditure Project, American Institutes for Research, Washington, D.C., June 2003. Notes: <sup>a</sup> Costs for students with deaf-blindness are not included due to small sample size; <sup>b</sup> costs for developmental delay were not included in the SEEP report.

diagnosed with mental retardation will be identified as autistic, shifting the proportion of students from a high-cost category into the highest. Because of the high costs for services for ASD treatment, the growth of the population with ASD will lead to faster growth in special education services than would be expected by a proportionate increase in the overall special needs population. Table 2 provides an overview of the relative sizes of the special education student populations in 2008 and both the total and instructional services expenditures per pupil for the 1999-2000 school year, the date examined in the SEEP report.

Autism is a disorder that requires management over a lifetime, adding further to the costs associated with it. As with treatment, the nature of autism demands a wide range of interventions, supports and responses throughout the life of the individual. The cost of services and lost productivity from an individual case of autism or a related disorder is impossible to gauge. However, recent research has begun to provide some insight into the costs that accrue over a lifetime. Research released in 2006 from the Harvard School of Public Health estimated the direct and indirect costs over the entire affected population at \$35 billion each year, or an average of \$3 million per individual.<sup>5</sup> Direct medical costs were high for the initial years following diagnosis, averaging \$35,000 annually, but decline markedly as an individual ages. Average non-medical costs (including childcare and home modifications) grow as medical costs decline, how-

ever, ranging between \$10,000 and \$16,000, as do indirect costs (such as lost productivity and economic activity), which can be as much as \$52,000 annually for middle-aged individuals with ASD. These indirect factors constitute nearly 60 percent of autism-related costs, with direct medical care responsible, on average, for less than 10 percent of the total, and behavioral therapy accounting for the majority of this cost.

### Programs and approaches

There is no cure for autism. Individuals and their families must manage their symptoms through a host of therapies and techniques throughout their lives. Some symptoms related to the disorder can be treated with medication, but there is no pharmacological response to the disorder as a whole. Further, there is no single treatment strategy for autism and individuals respond to different treatments, a situation which can lead to frustration for parents and children alike. For some children, these therapies can result in full reintegration into the educational and social life of their schools and broader communities, eventually with little or no additional supports. Schools and school districts may focus on one approach which best fits their population, resources, and staff, or may attempt to provide a range of choices for parents. Moreover, as children grow, treatments that were successful in addressing behavioral, developmental or educational needs may cease to be effective or require adaptation, necessitating a new approach be instituted to

meet the child's needs or adjusting the treatment to meet new conditions. Because the home component of autism therapy is a significant factor in its success, the match between therapy and parenting style also is crucial.

For mild instances of ASD, interventions may be easily grafted onto everyday routines at home and school. For others, however, autism therapy can require a significant investment of time spent in intensive work each week. Among the more widely used approaches is applied behavioral analysis (ABA), which builds on the work of B.F. Skinner from the 1930s. This approach involves a highly structured behavioral reinforcement program.<sup>5</sup> This approach, which is widely used in the United States, often requires several hours a day of intensive therapy with trainers as well as reinforcement at home and other environments. Because of this, ABA is very costly for schools to implement, and few school districts have the personnel and resources to fully implement such programs. Nonetheless, ABA and related therapies often are at the core of primary strategies for serving children with autism.

In recent years, considerable work and research has been invested in Early Intensive Behavioral Intervention (EIBI). This approach applies the principles and methods of ABA, addressing a comprehensive range of skills (including social, individual, motor, intellectual, and creative) in children typically younger than 4 years old. Therapy is provided for 25 hours to 40 hours a week for up to three years, an intensive period during which children with autism are given opportunities to learn and reinforce typical skills for children of their age. Recent research has shown that for children enrolled in EIBI therapies, nearly half are able to graduate from the program to regular classrooms without further interventions. Nearly two-fifths of participants make improvements but continue to require support, with only one-tenth making minimal gains.

Children with ASD often require services year round to avoid regression during school breaks and holidays. Under federal law, children who are likely to suffer setbacks or complications due to extended absences from services (such as summer and winter breaks) are entitled to full-year services. Not all children with autism require such intervention, although demand for the programs is increasing, particularly in the early grades. Furthermore, by the time a child with autism reaches 16 years old, schools must provide transition services to help the student adapt to life outside of school. This can include basic life skills and job training as well as assistance with transitioning to post-secondary education. This also is the point at which many children with autism begin a relationship with state agencies and offices that are responsible for the care and protection of the disabled. In the same manner in which a child's education is guided by

<sup>5</sup> Typically, ABA involves a focus on a stimulus requiring a response from the child, a response (or lack thereof) that is a behavioral outcome, and a consequence that is based on the behavior, such as positive reinforcement for the desired response or no reinforcement for an undesirable response.

an Individualized Education Program (IEP), the student's transition to independent life is guided by a transition plan which outlines goals and identifies the appropriate steps. The transition plan is in effect from age 16 until the goals in the plan are met or the child turns 21, when the authority of IDEA ends.

In recent years, evaluation of therapies and treatments has garnered some long-overdue attention. Several recent projects have attempted to offer service providers, parents, and educators with a guide to what has been demonstrated as effective in treating children with ASD. Among these are the National Autism Center's National Standards Project, which identified 11 treatments as "established" (those that have sufficient research-based evidence demonstrating that they produce beneficial outcomes), 22 "emerging" treatments (those that have some research-based evidence demonstrating effectiveness, but not enough for high confidence), and five "unestablished" treatments (those for which there is little to no sound evidence of effectiveness). The 11 effective treatments in this study mirror somewhat the findings of the previous work, but the 22 therapies identified as emerging represent the expansion of the research base for this field.<sup>6</sup> Additionally, the National Professional Development Center (NPDC) on Autism Spectrum Disorders at the University of North Carolina has established criteria for evidence-based treatments of ASD. Their criteria, which focuses largely on the rigor of the research, has identified 24 evidence-based practices for children and youth with ASD. Additionally, because the NPDC is intended as a resource for parents and practitioners, the Center provides overviews of these practices.<sup>7</sup> Teachers and school systems can use and adapt these resources to help teachers learn the basics of serving children with autism, as well as to familiarize staff and families about the specific strategies available to help serve these children.

Having programs with a substantial research base help to guide treatment strategies and fine-tune therapy. It can also provide a conceptual basis for weighing the relative costs and merits of various strategies. Even as outcome research has advanced, information on the cost-benefits for ASD-related therapies is extremely limited. Indications from existing literature point to considerable returns on what are initially very large investments. Given the long-term direct and indirect costs, as well as lost productivity which runs into the millions over the lifespan of an individual with ASD, early investments, even at costs of \$50,000 or more a year, could realize enormous savings. As noted, results from studies of children diagnosed with ASD who were provided with early intensive behavioral interventions for three years found some positive results for nearly 90 percent of children, and an ability to essentially integrate fully for nearly half of all treated children. For those children who can be moved into

regular classrooms with little or no accommodations, the savings to both families and school systems are considerable. While those children who still require services realize smaller savings, the total costs for services for this group, and the lifespan costs of the disorder, could be reduced. By contrast, children who do not receive treatment in this manner will be eligible for special educational services until they are 22 years old at a cost that exceeds \$30,000 annually, depending on the jurisdiction.

A 2007 study in Texas comparing the costs of 18 years of special education services to three years of EIBI found a savings to the state of \$208,000 per child.<sup>8</sup> Given an ASD population in the state in excess of 10,000, early intervention translated to an estimated \$2.1 billion in savings to the state. These savings do not factor in the additional costs that families bear during the school years, nor does it calculate the costs of autism over the lifespan. A study of costs in Pennsylvania found that the state could save between \$187,000 and \$203,000 per child enrolled in three years of early intensive intervention compared to a child enrolled in special education. This study estimated individual lifetime savings of \$656,000 to \$1.1 million to the state by providing early intervention. Using a similar methodology, a Virginia study estimated per student savings for EIBI at \$137,000, although lifetime savings were not determined.<sup>9</sup>

### Early surveillance and identification

A key component in successful interventions regardless of the therapy used is early intervention. Treating children with ASD early can dramatically improve outcomes. In order to do this, however, adequate services for early diagnosis, surveillance and awareness must be in place. Autism can be diagnosed in some cases by age 2 or earlier and often is apparent by a child's third birthday. Because of this, the burden of early identification is on parents, healthcare and childcare providers. Parents who notice abnormal developmental patterns in their child may not be aware of the early signs of autism, however, and physicians and healthcare personnel are not necessarily consistent in their diagnostic and screening practices. This results in a number of children with ASD diagnosed upon entering school, a delay of two to three years in which valuable time for treatment is lost as are opportunities to integrate into routine life without accommodation. This problem is particularly acute among low-income families, especially those without access to healthcare. Children who are enrolled in Medicaid or State Children's Health Insurance Programs are, however, diagnosed at the rate of their middle- and upper-income peers.<sup>10</sup>

To remedy this delay in identification, states and private groups are moving to improve awareness of autism among parents and improve screening and diagnosis practices among healthcare professionals. There are several well-established screening tools that can be used to assess the need for a referral to a specialist and possible diagnosis; some as simple as parental reporting and observations of typical

behaviors among children younger than 2. These screenings, while effective, may not identify all children with ASD, particularly high-functioning autism or Asperger syndrome, but serve as highly effective tools for aiding early detection. Screening tools for Asperger syndrome and highly-functioning autism recently have been developed and may not be as widely recognized among pediatricians and other healthcare professionals. Furthermore, because of the difficulty in diagnosing Asperger syndrome in young children, many will be misdiagnosed with obsessive-compulsive disorder, anxiety or depression before arriving at an Asperger diagnosis, often too late for effective treatment.

The Child Neurology Society and American Academy of Neurology, along with several other professional organizations, outlined a two-stage screening process for autism in 1999. The first stage, to be conducted by healthcare providers at every well-child visit, involves a series of checks for typical behavior at specific age benchmarks which are indications for immediate evaluations. The second stage is a combination of formal diagnostic procedures and specific evaluations to determine the developmental delay and thus recommend treatment. The American Academy of Pediatrics recommended in 2007 that every child be screened for autism twice by the time they reach age 2 and provided a clinical report to help doctors recognize the signs of ASD.

This effort is necessary, in part, because, while early screening is vital to improved outcomes for children with ASD, research indicates that few doctors conduct routine screenings for the disorder. While rates of screening vary widely by geography, a 2007 report indicated that only 28 percent of children were regularly screened, and earlier research found that while 82 percent of surveyed pediatricians screened for developmental delays, only 8 percent screened for autism, with the most common reason given for not screening is a lack of familiarity with the tools.<sup>11</sup> Furthermore, while autism typically can be diagnosed by age 3, evidence from 13 study locations around the United States indicates that the average age of diagnosis is nearly 6 years old, denoting that many children are well into their first year of school before a diagnosis is made.<sup>12</sup> An encouraging trend in recent years is that the age of identification appears to be declining, with a 2009 report from the National Early Childhood Assistance Center indicating that nearly 88 percent of surveyed program coordinators make an early diagnosis before age 3.<sup>13</sup>

The state of California developed comprehensive best practices guidelines on autism in 2008, which sets out expectations, tools and resources for early screening, diagnosis and treatment. Other states, including Missouri, have used this framework in their efforts to establish screening policies for autism. Possibly most importantly, the California document specifies the resources for referral of children and their families. Many states have indicated that this final guidance, helping families with children diagnosed with autism connect with therapeutic and educational resources, often is

absent, leading to considerable frustration on the part of caregivers seeking to navigate the numerous agencies and departments responsible for delivering services and care to children with developmental disabilities.

Because many children will spend substantial time in day-care centers, state public health officials have recognized the need to work with these institutions on awareness of the early signs of autism. This work is especially challenging because many childcare facilities are not formally in the network with the state public health system and, thus, difficult to reach. Nonetheless, as research on autism has advanced, providing this sector with clear, direct information about developmental disabilities and autism has become easier.<sup>††</sup>

## CHAPTER 3: SCHOOLS AND AUTISM

### How are schools serving autistic children?

Children diagnosed with ASD typically are eligible for special education services under IDEA, which mandates interventions and educational therapies for children with disabilities. The Act stipulates that all children with disabilities must receive a free, appropriate public education that prepares them for further education, employment, and independent living. Educational services for children with autism can vary as widely as the disability, in particular because of the wide variation in students' needs. Students served under IDEA must have an IEP that outlines how the student learns, how progress can be measured, and how the student's education can be enhanced. Each IEP is a very specific document created through the collaborative work of teachers, special service providers, parents, administrators and, when appropriate, the child.

An IEP is intended to help guide the child through the educational system, attempting to ensure appropriate interventions and services in order to facilitate growth into an independent adult, when possible. An IEP can include specific approaches or be more descriptive of a child's learning needs. Because classroom teachers are not required to have any training in autism specifically, and due to the wide range of therapies used, it is not uncommon for lead teachers to have a very limited capacity to apply autism-specific approaches. Depending upon the school, special education and exceptional student services staff may have familiarity with only a limited range of therapies for ASD. As a result, children for whom specific approaches are either recommended or requested may find their educational team unable to fully deliver these services.

This situation is exacerbated by an information gap that exists between individuals with autism and autism therapies. Parents of children with autism often are, by necessity, pursuing options and information for their child from

a wide network of sources and partners. This can contribute valuable input for the treatment matrix for their child as they identify approaches that are suitable for their parenting style, and available resources and meet the needs and challenges of their child. Not every therapy is equally well researched, however, nor are they all equally well-suited for school settings, and parents can at times demand therapies that are inappropriate or ineffective. Those who approach schools seeking specific therapies with which the school has limited or no experience, or in which they have no confidence, is a source of conflict and frustration on the part of both parties. The lack of research-based decision-making about approaches to autism within school systems and at the state level adds to the application of a very wide (and possibly unsupportable) array of techniques, heightening the potential for conflict and disputes and decreasing the opportunities to ensure adequate staff development.<sup>14</sup>

The vast majority of children with autism will be served in a school setting of some kind. Children with high-functioning autism or Asperger syndrome may spend much of their time in a general classroom with limited accommodations and time with specialists; students with more severe autism and greater social, communication, or behavioral problems may be in special education settings for much or all of their school day.

For decades, autism was a disorder of such limited prevalence that many schools may not have had a student enrolled with a diagnosis for many years, if at all, consequently limiting the demand for special services and staff for autism. As the prevalence of ASD has increased, however, there has been a parallel rise in demand in both services for these children and for special placements to serve them. In response, a number of special schools have emerged that serve children with autism or which are oriented toward providing interventions that target some of the specific behaviors and deficits of these students. For the most part these are private institutions, including the New England Center for Children in Massachusetts, a pioneer in the field that has served children with autism in residential and day-school settings for three decades. Recently, a handful of public schools have been established to provide autism-specific interventions, typically as charter institutions organized within a school district or a state.

The Florida Autism Center of Excellence is a public charter school in Tampa serving students ages 3 to 22 with moderate to severe autism. The school, founded in 2006 through a \$700,000 grant from the Legislature, is open to families from the six-county metropolitan Tampa area. Outside the Southern region, the New York Center for Autism (NYCA), a program of the New York City Public Schools, provides training and operates as an exchange for strategies to serve students with ASD. The NYCA Charter School is intended

<sup>††</sup> An additional, if unexpected, aid in connecting state public health systems and daycare programs has been the recent H1N1 flu, which resulted in new and aggressive steps by state and local public health workers to reach out to childcare providers.

as a model program for the public school system, providing access to high quality, scientifically-based educational programming for students with ASD, their families and public school educators. The NYCA Charter School has the dual purpose of providing educational services as well as training for professionals to learn some of the specialized interventions in use at the school. The school is intended as a site for clinical training opportunities for master's degree candidates in special education as part of an effort to increase the supply of qualified personnel to serve the special needs population in the public school system.

### Preservice training and professional development

Three decades ago, teachers rarely would have a student with an autism diagnosis in their classroom and, even as recently as the late 1990s, classroom interventions for ASD were unfamiliar to most teachers. Each child with autism represents a unique combination of behavioral, social and communication deficits and peculiarities that demand the implementation of various approaches and techniques in a comprehensive, well-planned manner. Because of this, there is a need for teachers to enter the profession with an understanding of autism and the various treatment approaches and for all teachers to be kept up-to-date on research-based interventions for ASD. Furthermore, because the majority of chil-

dren with autism will spend at least part, if not all, of their school day in a regular classroom, training is necessary for teachers in general education programs across all grades as well as for those in exceptional student services. This is especially pressing given the pervasive and chronic shortage of qualified special education personnel in almost every school district in the country.<sup>88</sup>

In the South, school districts often scramble to fill vacancies for special education teachers, a situation that can lead to children with special needs being taught by staff without appropriate qualifications or training or by long-term substitutes. Furthermore, as the number of students eligible for special services under IDEA increases, the supply of new teachers to serve this population has not kept pace. Table 3 provides a snapshot of the number of teachers employed to provide special education and related services in the region and the number of students they serve. These figures include all staff assigned to special education, and illustrate both the great variation within the region and the varying pressures on staff.

Because statistically almost every teacher will work with a child with an autism diagnosis during their career, teachers and paraprofessionals need a foundation of autism-specific

**Table 3 Special Education Personnel and Student:Teacher Ratios 2006**

State	Ages 3-5					Ages 6-21				
	Total Employed	Highly Qualified	Not Highly Qualified	Population Served	Student:Staff Ratio	Total Employed	Highly Qualified	Not Highly Qualified	Population Served	Student:Staff Ratio
Alabama	289	265	24	8,026	27.77	5,600	4,910	690	80,987	14.46
Arkansas	554	431	123	11,689	21.10	3,803	3,489	314	56,444	14.84
Florida	1,392	9	1,383	33,644	24.17	17,155	7,879	9,276	364,645	21.26
Georgia	734	572	162	20,410	27.81	15,376	13,609	1,767	176,400	11.47
Kentucky	399	390	9	21,007	52.65	6,569	6,216	353	88,347	13.45
Louisiana	661	532	129	10,503	15.89	6,350	4,209	2,141	78,919	12.43
Mississippi	--	--	--	8,430	--	1,124	853	271	59,160	52.63
Missouri	822	798	23	15,415	18.75	9,155	8,949	206	125,991	13.76
North Carolina	872	830	42	20,433	23.43	10,264	9,860	403	172,018	16.76
Oklahoma	--	--	--	7,625	--	7,948	5,967	1,981	88,235	11.10
South Carolina	550	521	29	13,864	25.21	6,112	5,665	447	93,489	15.30
Tennessee	709	397	312	11,967	16.88	6,070	5,322	748	108,296	17.84
Texas	3,163	3,089	74	39,351	12.44	22,628	21,686	942	454,951	20.11
Virginia	739	734	5	16,968	22.96	13,322	11,175	2,146	153,826	11.55
West Virginia	273	223	50	6,013	22.03	2,818	2,506	312	43,041	15.27
SLC	11,157	8,791	2,365	245,345	21.99	134,294	112,295	21,997	2,144,749	15.97
United States	34,179	30,045	4,134	706,635	20.67	399,222	354,298	44,924	5,986,644	15.00

Source: U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS) "Personnel (in Full-Time Equivalency of Assignment) Employed To Provide Special Education and Related Services for Children with Disabilities," 2006. Data updated as of July 15, 2008. Ages 3-5 staff data not reported for Mississippi or Oklahoma.

<sup>88</sup> According to the most recent *Educator Supply and Demand in the United States* report from the American Association for Employment in Education, special education accounts for nine of the 13 categories of teachers that are in considerable shortage, including five that moved into that category in 2007, indicating an expansion of the deficit for schools seeking qualified staff.

training and support. There also is a need for schools to have trained specialists who are familiar with the field of developmental disorders and can navigate the many approaches to treating these children in order to create and implement appropriate, effective IEPs. Neither of these goals currently is being achieved, however, as teachers are entering service inadequately prepared to serve children with ASD, and schools are being challenged to find staff who are sufficiently well-versed in autism therapies. The problem is exacerbated by a shortage of capacity at institutions of higher education responsible for training new educators.

Remediating this shortfall requires new investments in the infrastructure for preparing teachers to serve children with ASD. According to the U.S. Bureau of Labor Statistics, the United States will see a 17 percent growth in the number of special education teachers across all levels (and a 20 percent growth in preschool, kindergarten and elementary level) in the next decade.<sup>15</sup> This substantial increase highlights a need for expanded preparation programs across all special needs areas. Preparing teachers and paraprofessionals to serve the swiftly expanding ASD student population potentially poses a tremendous challenge due to the infrastructure limitations of the current system, the scope of the need, and the complex nature of the services required. Schools of education within institutions of higher education, which prepare the vast majority of new teachers, have a distinct shortage in the number of faculty specializing in special education in general and autism in particular. Recent research indicated that approximately one-third of all higher education faculty searches with a specialization in special education failed to identify a candidate, resulting in lost positions and a greatly diminished capacity to train new educators.<sup>16</sup> In turn, this void in qualified higher education faculty contributes to a shortage of special education teachers available to fill an ever-expanding number of positions. The final result of this shortage is a number of special education children being taught by teachers who are either not specifically qualified, are insufficiently prepared, or by substitutes with no background in special education.

While there is a shortage of qualified staff to serve children on the spectrum, it is possibly more acute in rural areas. This is an item of particular concern in the South, which has a greater proportion of its population (and thus a larger population of affected children and youth) in rural areas than the nation as a whole. Pennsylvania and Vermont both have dedicated rural autism programs, but the South has none. Statewide regional service delivery models, as are found in Florida, Missouri and North Carolina, help to extend services to rural residents through this regional approach, although they do not specifically focus on the rural component of service and treatment delivery challenges.

According to the National Center to Improve Recruitment and Retention of Qualified Personnel for Children with Disabilities (a federally-funded technical assistance and dis-

semination project staffed by the National Association of State Directors of Special Education), there are 77 doctoral programs in special education and 300 that provide a bachelor's degree in the region. Of these, federal funding assistance is available through the U.S. Department of Education's Office of Special Education Programs at 15 doctoral programs and 70 undergraduate/graduate programs in the region. Many of these programs operate at less than capacity due to limited student enrollment. The challenge is to encourage high achieving students to enter the field of special education. States such as Arkansas and North Carolina (among others) offer loan forgiveness for college students who pursue degrees in education in identified shortage areas (including special education) and go on to serve in these areas. Unfortunately, several of these programs have had to be curtailed due to strained state finances, eliminating a valuable pipeline for special education staff at a time when they are considerably in demand. Furthermore, students with federal Perkins Loans (low-cost loans for low-income students) typically are eligible for loan forgiveness if they teach in an identified critical shortage area for a specified period.

In order to prepare more staff and train more in-service teachers, there is a need to increase the number of graduate students entering special education at the doctoral level and remaining in academia to train future special education teachers. Furthermore, because so many in-service teachers have deficits in their skill with respect to autism, creating a network to provide basic information on autism and related disorders and their treatment to teachers is critical. Several models for achieving this are in place, including the National Professional Development Center on Autism Spectrum Disorders (NPDC) and the Ohio Center for Autism and Low Incidence (OCALI), both of which are developing online training modules for a wide range of audiences, particularly teachers and paraprofessionals, on characteristics, diagnosis, interventions and supports, transitioning and employment for individuals with autism. These networks both aim to promote evidence-based practices for serving individuals with autism. The NCPD model also includes state-specific trainers who are responsible for leading exercises and modeling practices within their states in order to greatly expand the number of qualified professionals working on ASD issues.

Federal funding has been available through the Special Education-State Personnel Development Grants Program since fiscal year 2000 to help state education agencies fund personnel preparation and professional development to improve the lives of children with disabilities. Congress appropriated \$362 million for this effort between fiscal 2000 and fiscal 2008. While these funds are not restricted to addressing autism, they represent an opportunity for states to leverage federal dollars to extend existing training activities or develop new professional development programs.

Specific actions in several states regarding professional development have included making autism and autism awareness a requirement of teacher training and enhancing educator networks to increase access to information on ASD. For example, in the 2008 legislative session, the Oklahoma Legislature passed Senate Bill 2017, which requires autism training and awareness for general education teachers and education support professionals of children in early childhood programs through grade three to complete training in autism at least once a year. Texas has designated and provided funding for the regional education service center to lead statewide training for autism in public schools, including the development of a recommended practices manual and training resources that are consistent, easy to access and available when needed.

Looking outside the Southern region, a report commissioned by the Connecticut General Assembly in 2009 recommended integrating methods of teaching children with autism and other developmental disabilities with programs for teacher preparation; requirements and competencies for candidates seeking initial and provisional educator certificates; in-service training; and training and competencies for paraprofessionals, related services professionals, early childhood certificate holders, administrators and parents. The recommendations established clear mandates for inclusion of ASD curricula at every level of the teacher supply system, including alternative teacher certification on characteristics of ASD, evidence-based instruction and classroom management, assessment and professional responsibilities, among other topics. Educators seeking an advanced certificate or focusing in special education have greater expectations. Paraprofessionals and related service providers also have specific expectations in the Connecticut recommendations.<sup>17</sup>

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### Services in private settings

Federal law requires schools to reimburse families for the costs of private services if the public schools are unable to provide services to meet a student's needs. Typically, parents partner with schools to provide services in the least restrictive environment that will ensure the best outcome for the child and the least disruption to the education of their peers. Public schools in many areas have developed expertise in addressing the needs of children with ASD, and many more are working to put this capacity in place. Should a school be unable to provide the services a child requires, parents may request (or school officials suggest) that the child be served in a private setting. In such instances, the costs of services, be they discrete therapy sessions or tuition for residential treatment, are borne by the district, including transportation to and from the service provider, if necessary. These may be private providers, including specialists, clinics, and independent schools, or other public school systems with appropriate programs and available space. In general, for parents to be reimbursed for the cost of private services, they must prove that the placement and services

offered by the public school were inappropriate and that the private services were appropriate.

The costs of services in a private setting generally are considerably greater than those in public settings. According to the SEEP report noted earlier, special education students served in non-public settings cost 3.9 times more than that of a regular education student does. While this figure includes the full range of special needs children, including hospital and institutional settings, it provides a gauge for the costs of non-public institutional placements for children with autism. Many, if not most, of the students at the handful of private autism specialty facilities attend at public expense. Yearly tuition at these institutions can be as much as \$50,000 and, while not all children are referred to such residential facilities, many families advocate and receive public support for the private education of their child with ASD in settings that exceed the costs of services at local schools.

The U.S. Supreme Court recently ruled in *Forest Grove S.D. v. T.A.* that parents may choose a private school setting for their child and apply for reimbursement from the child's local school system without first allowing the public school an opportunity to meet his or her needs. This decision lifted the requirement for a public placement prior to seeking private services and raised concerns among school districts that parents would rush to move their children into costly private programs without allowing schools to serve them, incurring great and unpredictable fiscal burdens without demonstrations of the capacity of the school system. The Court's decision, however, only allowed parents to seek reimbursement, and left in place the process for doing so. Thus, parents choosing to place their child with a disability in a private setting bear the burden of proof that the public setting was inappropriate and that the private placement will yield superior results.

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## CHAPTER 4: STATE PROGRAMS

### State responses

Publicly supported services for the diagnosis, treatment and management of ASD typically are available through a number of agencies or offices, most notably state departments of health and their offices of behavioral health and state departments of education. Families also may be eligible for a number of medical-related services through Medicaid, such as waivers for treatment of developmental disabilities in states where they are made available, most often through state departments of health. Federal law requires some services to be available to families and individuals, including early intervention services from birth to age 2 (IDEA Part C), targeted for children with or at-risk of developmental disabilities in the early years, and school-based special education (IDEA Part B) for children in public school settings. In addition to these federally supported programs, states also provide vocational training and support for individuals with developmental disabilities and may include screenings

for developmental disabilities in state-sponsored pre-K programs.

While federal mandates have established a general range of services that are mandated for children with special needs, states may not always provide comprehensive services for individuals with ASD. Parents often resort to privately provided therapies, supports and interventions to meet the needs of their child. For many families, the costs of these services can constitute significant barriers to providing care for their child. This is particularly true for children who are most severely affected and in need of intensive early intervention. Furthermore, for families living in or near poverty, access to private services may be financially unfeasible. While early intervention has demonstrated success in mitigating many of the barriers ASD imposes on a child's intellectual and social development, the inability to access services at an early age leads to more complicated, costly and less effective therapies later on. The burden for this costlier treatment is then borne by public school systems.

Under Part C of IDEA, states are required to coordinate early intervention services for children with disabilities. States are to assist families with access to services and information about their child's disability and ensure that they understand their rights. Under federal law, children and their family are to have a service coordinator (essentially, a caseworker) who is responsible for coordinating services across agency lines and serves as the single point of contact for families to receive the services and assistance they require. States are free to establish models that best suit their needs in creating service coordination.

The service coordination requirement of IDEA is for all children with disabilities, including ASD. The complex nature of the disability, the need for close observation for what are at times subtle early indicators and the imperative for early intervention, complicates the work of state coordinators who may not even be drawn into the process at a stage when a child is eligible for services. Moreover, there exists wide variation in the quality and sophistication of the support provided through service coordination programs, both among and within states. As a result, families may have to navigate the complicated thicket of bureaucracies associated with the autism care and potential treatment options with limited information and assistance. Resolving these deficiencies where they exist is partly just a matter of improved training and expanded personnel. But in many states, the system of autism care simply lacks coordination overall.

The service coordination requirement in federal law does not mandate any coordination of resources and information at the state level, which means that caseworkers often may be working without full access to the most recent research and evidence in support of (or contraindicating) therapies and treatments. The absence of centrally managed networks also imposes barriers to information on identification and

diagnosis, effective treatments, qualified service providers and programs and available resources. Even with service coordinators in place, the distributed nature of this system places a tremendous burden on families to manage and coordinate care for their child and provides little guarantee that the information that is used in decision-making is consistent with best practices and current research. Furthermore, the absence of coordination in autism services inevitably leads to inconsistent public policy, particularly on supported interventions and therapies and in the application of resources. To resolve this concern, a handful of states have turned to formalized autism networks that focus on care and services for individuals and families across the state, serving as a conduit for information and research to inform care decisions in the field as well as gather information on conditions across the state to help mold public policy. Such systems can further help bridge the divide between research and practice. For individuals with autism, this system also minimizes the discrepancy that can exist in the services that are available and the level of care provided, based solely on geographic location.

There are examples of coordination at the state level, notably Florida and North Carolina, that offer publicly supported, autism-specific clinics to help with the identification and delivery of services. These institutions do not duplicate services provided by schools or public agencies, but serve as an initial (and central) point of contact for autism service delivery. Both North Carolina (through Division TEACCH, a division of the Department of Psychiatry in the School of Medicine at The University of North Carolina) and Florida (through the Center for Autism and Related Disabilities) extend the resources of the state's university system into communities throughout the state, broadening the range of the service delivery system and closing the gap between program implementation and research.

### **Paying for services**

When Congress last reauthorized IDEA in 2004, autism was included in the list of disorders for which public early intervention and special education services must be provided. Due to a host of reasons, these federally mandated services only meet about 3 percent of the needs of children with autism.<sup>18</sup> Expanding the number of children included in services is a priority for a number of autism advocacy and family groups, and has been championed in several states.

Since private services can be such an important component of ASD treatment, some states have moved to require healthcare insurers to include ASD treatment in their coverage. State and federal mental health parity laws, which mandate equal levels of coverage for mental illness and medical complaints, do not specifically include autism and other pervasive developmental disorders, but because they are described in the DSM IV, they generally are included. Parity laws, however, do not explicitly provide for access to the specific kinds of therapies most recommended for chil-

dren with autism, typically only stipulating that coverage be equal for mental health and medical services. Thus, plans may provide only for the costs of medical treatment related to autism, a small component of the range of costs for the treatment of ASD. Furthermore, because parity laws only address the levels of coverage, insurance companies are not obligated to provide any coverage at all, since the law only promulgates that those treatments that are included in coverage are not subject to limitations or restrictions different from medical treatment.

In order to resolve this inadequacy, states have turned to two strategies to expand the range of coverage for families with children with autism and related disorders. The first is to use the waiver process in Medicaid to make services available to families regardless of their income. The second approach is to require private insurers to provide coverage for approved ASD therapies.

Following the passage of the Tax Equity and Financial Responsibility Act of 1982, states can apply for Medicaid waivers to allow individuals with disabilities and family incomes above the eligibility threshold access to the low-income health insurance program. Many states have applied for waivers in order to support autism-related services provided in either home or community settings through this program. (School-based interventions generally are not part of a Medicaid waiver.) Not all children with ASD may be eligible to receive services in this manner, as the child must meet the criteria for placement in a nursing home or intermediate care facility for at least part of the day. Each state negotiates waivers with the federal government, so some states, including Georgia and Florida, make any child with an ASD diagnosis automatically eligible for services through Medicaid. Not every state program has room for new enrollees, however, and waiting lists for waiver programs can be very extensive. Because early treatment is so important for improving outcomes for individuals with ASD, time spent on a waiting list for assistance with critical services can result in significantly diminished functional capacities later in life. In the Southern region, Arkansas, Florida, Georgia, Mississippi, South Carolina and West Virginia have some form of Medicaid waiver.

Given the structural limitations and budgetary impacts of expanding Medicaid programs to serve the entire child population with autism, in recent years states have turned to private insurance coverage for autism therapies. Because insurance coverage is regulated at the state level, state laws and regulations can stipulate the inclusion of coverage for a wide range of services, therapies and treatments for policies issued within their jurisdiction. In most states, autism is not a covered disorder by itself, but is included under other mental disorders. This tends to leave very significant discrepancies between the kinds of therapies that demonstrate the greatest effectiveness and the kinds of therapies that are covered by insurance, generally restricted to medical pro-

cedures associated with the disorder. This occurs, in part, because while ASD is included as medical disorder by dint of inclusion in the DSM-IV, they are developmental disorders and do not have standard medical therapies and interventions.

The number of states with autism mandates varies depending on the definition of the mandate. Autism Speaks, the largest autism advocacy group in the United States, indicates eight states with mandatory coverage for autism-related services, while a report from the Connecticut Office of Legislative Research points to five additional states that include autism within some non-treatment requirements of insurance, most typically through actions to prohibit the denial of coverage due to an autism diagnosis. These actions have met with concerns over expenses and the impact these mandates will have on insurance premiums in states where this treatment is required. Because ASD has such high costs for services, the expansion of coverage for a disorder that affects perhaps as many as 1 percent of children entails a substantial increase in liabilities. Insurers also note that most therapies for autism are not medical in nature insofar as they are not delivered by medical professionals and, thereby are outside of their area of service. In this regard, they note that the kinds of therapies sought for children with autism are more habilitative than medical. This brings them more in alignment with long-term care, or educational in nature and, therefore, outside the realm of healthcare. Furthermore, insurers have suggested that the appropriate solution to any deficiencies in service and care is to bolster the existing system of public supports and not to shift responsibility to private insurance.

In the past few years, four states in the Southern region have passed autism mandates for private insurers. While the purpose of this legislation is to require private insurers to provide for autism-specific treatment as part of their coverage, the of each state's legislation—including the group size for mandated coverage, limits on treatment and services, age limits for beginning or completing treatment, and covered therapies—vary across states.

### States in the South with mandates for private insurance coverage for autism-related services.

**Florida** Senate Bill 2654, signed into law in May 2008, requires insurance companies to cover up to \$36,000 a year for ABA and other therapies for children under age 18, with a lifetime limit for treatments of \$200,000. The legislation went into effect on all policies issued or renewed after April 1, 2009, but does not apply to individual policies or those offered by employers with fewer than 50 employees.

**Louisiana** House Bill 958, signed into law in July 2008, requires group health insurance plans to include diagnosis and treatment of ASD within their coverage for individuals under age 17, with an annual benefit limit of \$36,000 per

year (adjusted for inflation) and a lifetime limit of \$144,000. The law stipulates a specific range of care which must be covered and does not allow for limitations on the number of visits to a service provider. Employers with 50 or fewer employees are exempt.

**South Carolina** Senate Bill 20, which became law in June 2007, requires health insurers to provide coverage for the treatment of ASD as prescribed by a doctor in accordance with a treatment plan. Health insurers cannot deny, terminate or otherwise restrict coverage on an individual solely because of an ASD diagnosis. To be eligible for benefits and coverage, an individual must be diagnosed with an ASD at age 8 or younger. The law does not apply to individual policies or employers with fewer than 50 employees.

**Texas** House Bill 1919, signed into law in June 2007, requires health insurance coverage for autism-related services prescribed by a primary care physician, including evaluation and assessment, along with a number of treatments and interventions. Treatment must be delivered by an appropriately licensed, certified or registered healthcare practitioner. Cost limitations must be set at the same levels as for other coverage. The law originally provided a mandate for children older than 2 years old and younger than 6 years old (although services for a child with ASD could continue past age 6). In June 2009, the governor signed House Bill 451 into law, extending the age for coverage to individuals younger than age 10.

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### States with activity, but no laws, on private insurance mandates

**Arkansas** saw the Senate approve Senate Bill 913 in the 2009 legislative session, which would have mandated private health insurance companies to provide coverage for the diagnosis and treatment of ASD, but the measure did not pass the House.

**Georgia** reviewed House Bill 426 in the 2009 legislative session, which would have provided coverage for the diagnosis and treatment of ASD, with services for ABA capped at \$36,000 per year (a figure that would adjust with inflation) and a maximum lifetime benefit of \$200,000. Treatments would have to be prescribed by a physician or psychologist. The measure was referred to a committee for further study but was not acted upon.

**Kentucky** considered Senate Bill 74 and its companion legislation, House Bill 190, during the 2009 legislative session. The bills, which did not win passage in either chamber, would have required private insurers to cover the diagnosis and treatment of ASD. A licensed physician or psychologist must prescribe the treatment as medically necessary (as defined by the legislation), with specific therapies (including ABA) outlined in the bill. Kentucky does have a law requir-

ing health benefit plans to provide coverage for autism, subject to a monthly limit of \$500.

**Mississippi** debated House Bill 720 in the 2009 legislative session. This legislation would have required private health insurance coverage for the diagnosis and treatment of ASD for individuals under age 21. Benefits would have been limited to an inflation-adjusted maximum of \$50,000 annually, but placed no limit on the number of visits annually.

**Missouri** considered Senate Bill 167 during the 2009 legislative session, which would have required coverage for diagnosis and treatment of autism for individuals under age 18, although coverage for ABA extended only to age 15 and was subject to a maximum benefit of \$55,000 annually. A bill in the House (House Bill 357) would have provided coverage up to age 21, with a maximum benefit for ABA services of \$72,000 annually for individuals under age 11, and \$36,000 for individuals between ages 11 and 21. While neither bill passed both chambers, the Senate legislation was passed in its originating chamber and was reviewed in the House. The final action on the House bill was an affirmative recommendation by the Rules Committee.

In light of these legislative actions, House Speaker Ron Richard created an Interim Committee on Autism Spectrum Disorders which is to review and make recommendations on insurance and autism. Such legislation has the support of Governor Jay Nixon.

**Tennessee** debated House Bill 2105 during the 2009 legislative session, which would have required health insurers to provide for diagnosis and treatment for ASD up to age 16, with an annual maximum benefit of \$50,000 for children up to age 9, and \$25,000 between ages 9 and 16. Current law in the state requires insurers that provide coverage for neurological disorders (the category into which autism is typically classified) to include autism treatment, but limits this requirement to age 12 and does not require insurers to provide coverage at all.

**Virginia** reviewed House Bill 1588 and its companion legislation, Senate Bill 1260, during the 2009 legislative session, which would have required health insurers to provide for diagnosis and treatment of ASD up to age 21, with an annual inflation-adjusted maximum benefit of \$36,000. The legislation did not pass either chamber, but the state did commission a comprehensive autism report following the session.

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### Autism commissions, networks and the continuum of care

Individuals with autism require services throughout their lives, services that can change over time as new therapies develop and an individual's needs shift. In light of this, many interventions for autism take a lifespan approach, considering the long-term success of the person and how these

approaches may need to be adapted as the individual ages. Furthermore, because services span such a range of ages, from early childhood (detection and therapy) and adolescence (federally mandated school services) and into adulthood (workforce training and independent living skills), planning for transitions between stages is critical. Unfortunately, the providers of the varying services are not always well-coordinated and families often are faced with the need to reinvent their network at every new stage.

In recent years, several states have created autism commissions to help develop and coordinate policy for individuals with autism. States may have various uses for autism commissions, but in general they will review existing autism services, policies, population figures and trends in order to make recommendations for changes to the current system. In some instances, states have established commissions for the purpose of creating comprehensive and coordinated systems out of an existing patchwork of agencies and departments with piecemeal responsibilities and identifying areas with limited support.

In the Southern region, Alabama, Arkansas, Florida, Kentucky, Louisiana, Mississippi, Missouri and Texas have established task forces or commissions charged with reviewing and making recommendations on autism services. A handful of states have had commissions or study groups of limited duration that have since either concluded their work or been incorporated into other activities.

### States in the South with autism task forces or commissions

The **Alabama** Autism Task Force, formed in 2007, was charged with studying the diagnosis and treatment of individuals with autism and reporting to the legislature. Among the results was Alabama's Interagency Autism Coordinating Council, which was created by HJR 3 in 2008, with the purpose of developing a long-term plan for a coordinated and comprehensive statewide approach to autism.

In 2007, **Arkansas** House Bill 2739 created a legislative task force on autism, with requirements to meet annually to review both the treatment of autism and related disorders and the state services and support of individuals with autism, and then offer recommendations for improvements. The task force issued its final report to the General Assembly in 2008. In the 2009 legislative session, Arkansas lawmakers reestablished the task force with the same mission but without a sunset, requiring instead an annual report to the General Assembly.

The **Florida** Task Force on Autism Spectrum Disorders was established in March 2008 by executive order to make recommendations on the public policy agenda for research, screening, education, and treatment of autism and to present a unified and coordinated agenda for addressing ASD in the

state. The Task Force submitted recommendations to the governor in March 2009, and was subsequently extended by the governor to serve until January 2011. Included in the task force's recommendations were: increased awareness campaigns on technologies, resources, and detection, including targeted outreach for individuals with autism and their families; additional research on prevalence, causes and links to autism; expansion of the *Take Me Home* program for first responders (a database for people who may need assistance in case of an emergency, including those who are unable to verbally communicate); and exploration of cost-saving opportunities related to medical reimbursements.

The **Kentucky** Commission on Autism Spectrum Disorders was created by House Bill 296 in 2005 and met for a year, delivering a state plan with recommendations to the governor, Legislative Research Commission, and state Council on Developmental Disabilities (COD) in 2006, and was disbanded the following year. To monitor progress on the implementation of the state plan, a subcommittee was appointed by the COD which must make a report to the governor and Legislative Research Commission annually until 2015.

**Louisiana** passed a resolution during the 2008 session to have the House and Senate Committees on Health and Welfare meet and function as a joint study committee on autism to develop a comprehensive and practical model for adequately addressing the needs of children and adults with ASD. The study, planned for release before the 2009 legislative session, was not completed.

The Caring for **Mississippi** Individuals with Autism Task Force was established by the Legislature in 2007 to study the growth of autism and how to identify, treat and serve individuals with ASD and improve the delivery and coordination of services provided by the state. The Task Force made its final report to the governor and Legislature in December 2007. The report found that care and services for individuals with autism was inadequate in the state and recommended, among other things, increased training for teachers and the creation of courses at the state's technical colleges on the disorder to help develop a workforce with skills to assist these individuals. A proposal to renew the Task Force did not pass in the 2009 legislative session.

The **Missouri** Blue Ribbon Panel on Autism was commissioned in 2007 to determine the "state of autism" in Missouri, assess services, teaching, training and research and make recommendations to the General Assembly. The Panel took testimony across the state in order to identify issues associated with children, youth and adults with autism. The Panel then made several recommendations, including review of the services and resources with a focus on coherence and coordination, suggestions for training standards for professionals and paraprofessionals, changes

to insurance coverage, and the establishment of a statewide body to oversee and implement an autism policy.

The Missouri General Assembly took up these recommendations in the 2008 legislative session, creating the Missouri Office of Autism Spectrum Disorders within the state Department of Mental Health to develop programs for individuals with autism (Senate Bill 1127). The Office also has the responsibility for implementation of the recommendations by the Blue Ribbon Panel. The General Assembly further established the Missouri Commission on Autism Spectrum Disorders in the 2008 session (Senate Bill 768), an independent commission with the mission of reviewing and making recommendations on autism services and programs in the state. In the 2009 session, the General Assembly passed Senate Bill 157 and House Bill 525, which codified the five regional autism projects currently serving persons with autism and their families as autism centers. These centers may offer a range of services, including assessment, advocacy, communication and language therapy, crisis intervention, life skills, and respite care.

In 2001, the **Oklahoma** Department of Human Services convened an Autism Working Group to develop a state plan. The Working Group met with a variety of stakeholders, completing its work in 2002 with a statewide plan for autism but later disbanded. Among the first actions resulting from the plan was the creation of the Oklahoma Autism Network, which has the task of helping to guide the implementation of the plan across the many collaborating agencies, coordinating resources in the state, and reporting on progress toward the plan's goals. The Network has grown since its inception from a virtual network linking professionals with resources and information to an entity that extends numerous supports and services, including training and technical assistance.

The **Texas** Council on Autism and Pervasive Developmental Disorders was created in 1987 to make recommendations to the Legislature and state agencies on meeting the needs of individuals with autism and their families and to coordinate the available resources for addressing ASD. The Council develops a state plan every two years outlining the needs of individuals with autism (and other pervasive developmental disorders) and how these needs can be met. The plan additionally provides a status review of previous recommendations and outlines any further action that is needed.

While **Virginia** does not have an active commission or task force, the General Assembly commissioned the Joint Legislative Audit and Review Commission to conduct a study of the services available to Virginians with ASD. The report concluded that programs are not sufficiently coordinated and are inadequate to meet the needs of the population, and provided some recommendations for enhancing identification and treatment in the state. The state Department of Mental Health, Mental Retardation

and Substance Abuse Services noted in its response to the report that it had been provided with funding by the General Assembly for two autism specialists. This staff will work on establishing a plan for coordination among state agencies serving individuals with ASD, identifying areas where service is lacking and improve communication, and expanding training for individuals working with autism.

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### Statewide networks for autism

Many states have established formal autism networks to provide diagnostic, clinical, and therapeutic support to individuals with autism and their families. Two prominent models in the Southern region are found in North Carolina and Florida, which have similar, university-based centers that provide assistance and support that is not found in school or other settings. Florida's statewide program, the Center for Autism and Related Disabilities, came out of a legislatively mandated census of individuals with autism conducted in 1983 and a similarly mandated 1985 study conducted by the Florida Mental Health Institute which recommended the formation of an autism task force. This task force was formed two years later and recommended, in 1988, the establishment of regional resource and training centers on autism. In 1990, the Florida Autism Program established a demonstration project, expanding to include seven regional centers based at state universities, that provides child and adult services over a county-based service area. Center services build upon the capacities of state and local resources and are not intended to duplicate or replicate existing services. Funding for the Center is provided by the Legislature through the state Department of Education. Services are provided free of charge.

Established in the early 1970s, North Carolina's Division TEACCH, Treatment and Education of Autistic and Communication Handicapped Children, a division of the Department of Psychiatry in the School of Medicine at The University of North Carolina, is a statewide program for treatment and education of individuals of all ages with autism and their families. Division TEACCH has nine regional outpatient clinics located throughout the state and a residential facility for adults. In addition to providing outpatient services through their nine clinics, TEACCH also provides early intervention programs for young children with autism and their families and provides training and consultation to students and professionals throughout the state. Services provided by TEACCH are at no cost to families.

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### Moving toward a national network for autism

State responses to ASD vary considerably. Early childhood and educational programs do not provide smooth transitions within school settings and often are not aligned with adult services. Equally, service providers, teachers, therapists, counselors and primary care professionals may not be connected with one another, resulting in a lack of sharing of valuable information. This tends to be the case both for individuals as it is for a system as a whole, with each compo-

ment operating with insufficient information about the scope of resources and research available, as well as the full picture of each individual case.

Autism's demand on specialists across a spectrum of skill areas makes coordination difficult. Given the inevitable strains at the state and local level to serve an increasingly large population, there is a need for a national network to tie together the many elements of diagnosis, surveillance, treatment, and research. Several organizations are working to fill this gap, such as the National Autism Center, located outside of Boston, Massachusetts, which recently completed a multiyear project to establish standards for effective and research-based educational and behavioral interventions for children with ASD. The National Professional Development Center on Autism Spectrum Disorders, located at the University of North Carolina, is developing a series of training modules available on the Internet for use by professionals and parents and is a key partner in collecting and disseminating information about effective treatments. The National Association of State Directors of Special Education has joined with several partner organizations to create communities of practice around a number of special education issues, of which autism is one. These communities link practitioners, parents, and individuals with autism together into virtual networks, sharing best practices, research, policy and outcomes.

A challenge in the autism field, and one which poses hurdles to ensuring consistency in treatment and policy across jurisdictions, is the presence of many well-established organizations pursuing separate but, at times, overlapping objectives. There is not just one but several national centers for autism to which policymakers, practitioners and parents can turn for information. This embarrassment of riches in the field ensures that research and treatments are reviewed from a variety of perspectives, helping to advance thinking on the disorder, but it also can lead to confusion and disagreement on what the best approach may be for any given individual. As interest and resources are directed into autism support, pressure is building to resolve this issue, and states are key players in determining the shape of any national autism council, since state resources, assets and infrastructure will serve as the foundation for this effort.

## CHAPTER 4: CONCLUSION AND RECOMMENDATIONS

For reasons that are not entirely known, the number of children in schools with a diagnosis on the autism spectrum has grown explosively during the past decade. As a result, schools are facing demands on services for this population far in excess of what is likely to be available. Furthermore, with the increased population has come increased attention to treatments for the disorder, resulting in a better understanding of effective strategies for serving children with

ASD. Even with the recent growth, there are indicators that too many children are left undiagnosed or are not identified as early as possible, particularly in the South.

Additionally, while research into appropriate treatment options for children with autism now provides some indications of appropriate interventions, there remain gaps in the capacity of local systems to deliver these and for schools and parents to pay for services that are most likely to provide results. There also exists room for improvement in the coordination of services and the accessibility of information on treatment and supports that are available to individuals with autism and their families. In light of all of this, states have taken a variety of steps to close the gaps and coordinate care across the delivery system and throughout an individual's life. Among the most promising are:

- » Establishing a statewide autism commission to review public policy;
- » Formalizing connections to interstate autism networks through a coordinated state autism manager;
- » Networking schools and professionals within a state to support the dissemination of research-based practices, with particular attention to reaching rural and urban school systems that may be at greater disadvantages in accessing information and expertise;
- » Including autism awareness, knowledge and skills in teacher preservice training and non-traditional entry programs, as well as supplementing teacher professional development with autism-specific curricula;
- » Developing awareness programs for healthcare providers to improve screening and diagnostic practice;
- » Coordinating services/establishing a central office to help families and care providers locate and share resources;
- » Promoting awareness and early identification by working with primary care physicians on screening and diagnosis;
- » Identifying and addressing service gaps by taking a lifespan approach to autism management; and
- » Connecting resources and providers vertically (early childhood, schools, workforce development) and horizontally (state departments of education, public health, family services and welfare, as well as healthcare providers, schools, and autism service centers).

Each of these strategies has proven effective in Southern states, and many states have applied a number of them simultaneously. By creating a statewide strategy for autism and coordinating resources for families, individuals, service providers and healthcare professionals, states have demonstrated improved outcomes and benefits for those with ASD and their families. As the population with a diagnosis on the spectrum grows, and grows older, the need to ensure robust services for them will continue to expand and change. Meeting this challenge early and planning for the future is critical to the goal of delivering the best quality of life for these

individuals, as well as minimizing to the extent possible the costs to the state of providing services.

The current fiscal crisis that continues to grip states severely curtails the range of options available. Large-scale programs of treatment would, under current conditions, seem improbable for states to undertake. Wise investments in early detection and treatment, including awareness programs and screening support for healthcare professionals, have proven to produce net savings for states, reducing the lifetime costs of treatment for children identified early, while improving the likelihood of a more productive life for the individual. Professional development and teacher training equally provide considerable benefits for more modest

investment, particularly in partnership with the national organizations working to promote research-based interventions for ASD. Finally, planning and coordination activities at the state level can help to more efficiently distribute autism-related information and services and provide states with a resource for developing a comprehensive approach to the disorder. Even these modest activities will have fiscal costs, costs that must be weighed in light of the total budget. Given the size of the affected population and the scope of autism schools currently are facing, increasing outlays for services and treatment are inevitable. By making prudent early investments in services and infrastructure, however, states may be able to realize savings on the total cost of the disorder to the state and its citizens in years to come.

## **APPENDIX: Other Autism Treatments**

There are a number of therapies related to ABA, including Pivotal Response Therapy and Verbal Therapy. Relationship Development Intervention (RDI) is a similar behavioral modification program focused on social interactions and self-awareness. Among therapies, RDI is one of the few that is intended to be implemented by parents, who are trained and guided by specialists. Floortime, a therapy that often is seen as an alternative or supplement to behavioral approaches, has the child take the lead in treatment. Parents and therapists meet the child at the level of their behavior, engaging in activities with them that the child enjoys, and let the child take the lead, with the parent eventually moving the child toward more complex interactions.

Another treatment placing the child very firmly in the center is Social Communication/Emotional Regulation/Transactional Support (SCERTS), which builds on the approaches of several models, including ABA, but is focused first and foremost on helping children apply what they learn in therapy to real world situations. The SCERTS approach uses children as models for appropriate social and language skills as much as possible, which makes it ideal for use in school settings. Finally, the Division TEACCH model uses “structured teaching” to capitalize on the relative strength and processing style of children with autism to accommodate for the difficulties these children have with other forms of information processing. Tailored to each child, TEACCH uses a very structured approach with visual cues helping to organize the social and physical environment to guide the child through their day.

In addition to these strategies, there exist a large number of other practices for serving individuals with ASD are in place, including those addressing specific behaviors or aspects of the disorder and those which attempt to address perceived sources. Not all of these approaches are equally well-supported by research, which can lead to problems in adaptation and implementation. Furthermore, some approaches may be completely ineffective, counterproductive or harmful. It is perhaps not surprising that as the incidence of ASD has grown, the number of treatments has seen a similar expansion. Of the numerous tactics used today, few have a significant research base and track record for gauging their effectiveness.

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This report follows upon a discussion of autism and schools that was conducted by the Southern Legislative Conference (SLC) Education Committee under the leadership of Senator Jimmy Jeffress, Arkansas, during the 63<sup>rd</sup> SLC Annual Meeting in Winston-Salem, North Carolina, August 16, 2009.

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## Autism in the South

According to recent research from the Centers for Disease Control and Prevention, about one in 100 children is affected by an autism spectrum disorder (ASD). The disorder has an overall growth rate of 1,148 percent in the past decade in some parts of the country, presenting overwhelming challenges to schools, healthcare, and social services agencies charged with providing care and support to individuals with autism and their families.

Because it is a spectrum disorder, it does not present itself the same way in all children, with some cases being mild and others more severe. This makes it difficult to accurately assess the actual situation in schools and, in turn, means local agencies must adjust programs and services to meet the changing needs of the population. Because of the nature of autism, the needs of children served by a school can change over time as the population changes.