

FOCUS *on How SREB States are Addressing the Education Needs of Children with Autism*

SREB

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Autism Spectrum Disorders (ASD) are a set of complex disorders that have no single diagnosis, manifest themselves in various ways, and are unique to each individual. Although symptoms can range from mild to severe, children with ASD (also known as Pervasive Developmental Disorders) generally have marked difficulty with social interaction and communication, and they display repetitive behaviors. ASD can be diagnosed in children as young as 2 years old. Autism is the most severe disorder within the spectrum.

As of yet, there is no consensus on what causes ASD. A study published in 2009 in the *Journal of the American Academy of Pediatrics* found that more than 1 percent of children ages 3 to 17 in the United States had been reported by their parents as diagnosed with some form of ASD, an even higher rate of incidence than previously had been estimated.

The medical community continues to debate whether the increasing incidence of ASD in recent years is simply due to greater understanding of these disorders, or whether ASD are actually becoming more prevalent among children. Whatever the cause of the rising rates, they represent a unique policy challenge as SREB states and others attempt to address the educational needs of children with ASD. While increasing awareness is spurring coordinated responses by state policy-makers, it has also highlighted the fact that **many states are struggling to provide comprehensive and coordinated services to individuals with ASD.**

Understanding IDEA

Education for children with ASD is mandated under the federal Individuals with Disabilities Education Act (IDEA), requiring states and school districts to provide a “free and appropriate public education” to all children with disabilities, including those diagnosed with ASD. Education for children with ASD extends beyond academics to address behavioral issues and the improvement of communication abilities and social skills.

Part C of IDEA requires states to provide early intervention services for children with disabilities from birth through age 2. This is particularly important as “early and ongoing educational intervention” has been identified by the American Psychological Association as “the major treatment for autism.” Early intervention services are managed through an Individualized Family Service Plan, which guides the provision of services to a child with disabilities and that child’s family, and which establishes educational goals for the child.

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Under Part B of IDEA, individuals ages 3 through 21 who have been diagnosed with ASD are entitled to state-provided education services as well as necessary related services including transportation, therapy, counseling and medical services. Public school districts are required to develop an appropriate Individual Education Program (IEP) for each student. To develop an IEP, the local school district must evaluate the child to determine the extent of his or her disability. The IEP then may range from placement in a traditional classroom, combined with supplementary special education services, to placement in a residential medical treatment program, depending on the severity of symptoms.

The 2004 reauthorization of IDEA allows states, with federal approval, to continue early intervention services for children with disabilities from 3 years of age until they begin kindergarten. (Normally, children with disabilities must immediately begin special education at age 3.) This is designed to help states ease the transition from early intervention services to special education services, particularly by allowing children to continue receiving in-home care services that might not be available through special education.

Though states are required under IDEA to provide services to disabled children, specific eligibility criteria for these services are left to individual states to determine. Furthermore, the eligibility criteria for early intervention services and special education services are generally not the same, with more numerous and more specific eligibility requirements for special education.

At a minimum, the differences in eligibility requirements may cause difficulty and confusion for families attempting to transition their child from early intervention to special education services. More troubling, some children who have been diagnosed with ASD subsequently have been ruled ineligible for special education services. With the importance placed on both successful transitions from early intervention to special education as well as the importance of continual treatment for children with ASD, a loss of or even a gap in services may have a very serious impact on a child's progress.

Providing an appropriate education for students with ASD may require highly individualized services, instruction and treatment, which in turn may require considerable effort and financial resources. **The degree to which school districts have the capacity to provide appropriate services varies widely, and school districts may struggle to meet federal requirements.** It is not uncommon for the parents of autistic children and local school districts to dispute what constitutes an appropriate education. However, as pointed out by the Autism Society, federal law does not require school districts to provide an ideal education or that which parents may consider the best, but rather “an appropriate educational program, one that meets the needs of the individual student.”

A particular point of contention is that IDEA requires school systems to place students with disabilities in “regular” classroom settings as often as possible, known in IDEA as the “least restrictive environment” and generally referred to as “inclusion.” Because ASD affect individuals in different ways and with vastly differing degrees of severity, decisions on inclusion are made on a case-by-case basis, but the issue of inclusion is nevertheless highly sensitive and a subject of great debate in the education community.

Steps some SREB states are taking

Creating autism task forces

For many states, the first step toward ensuring a comprehensive, statewide network of services for individuals with ASD is to convene a task force or committee to review the services provided and the degree to which services are coordinated between responsible agencies. From there, state policy-makers can identify needed changes in law and policy to improve services and treatment. SREB states that have established such task forces include Alabama, Arkansas, Delaware, Florida, Kentucky, Louisiana, Maryland, Mississippi, Oklahoma, Tennessee, Texas and Virginia; most of those were established to provide a one-time review of state laws and policies. In 2009, Maryland convened its second such task force in a dozen years; the Maryland Commission on Autism will develop a statewide plan by 2011 for an integrated system of services for individuals with ASD.

In some states, task forces have focused on a specific area of autism policy. Delaware's Autism Adults Service Needs Task Force (2006-2007) examined services available to adults with ASD, while the Tennessee Task Force for Postsecondary Education for Students With Intellectual Disabilities is concerned with helping students with ASD and other disabilities succeed in college.

Texas and Kentucky have taken a different approach in convening long-term councils to address issues. The Texas Council on Autism and Pervasive Developmental Disorders maintains an ongoing review, issuing recommendations every two years. However, in its most recent state plan (covering 2010-2014), the council noted that despite this review and the increasing prevalence of ASD, "no state agency is charged with coordinating ASD services, collecting uniform data, or assessing the needs of the tens of thousands of people with ASD in Texas." The Kentucky Commission on Autism Spectrum Disorders (2005-2006) developed the plan for an integrated statewide system of training, treatments and services for individuals of all ages with ASD. While the commission disbanded after making its recommendations, the Kentucky Council on Developmental Disabilities is responsible for monitoring implementation of the statewide plan and proposing necessary modifications.

Improving interagency coordination

While educating children with ASD is ultimately the responsibility of local school districts, these educational services are inextricably linked to health and behavioral development services. As a result, statewide responsibility for the services that children with ASD require to thrive and develop is typically the domain of more than one agency. In order to provide a comprehensive set of uninterrupted services for these children, interagency coordination is crucial.

Alabama is currently addressing the coordination of services to individuals with ASD. Established in 2008, the Alabama Interagency Autism Coordinating Council is establishing a comprehensive statewide system of coordinated services for individuals with ASD through regional autism centers. However, as of late 2010, the council is still at the strategic planning and guideline development stages.

Based on the recommendations of a joint legislative commission that met in 2008 and 2009, Virginia has begun coordinating services for individuals with ASD between the Department of Education, the Office of Developmental Services at the Virginia Department of Behavioral Health and Developmental Services, and nonprofit organizations such as the Commonwealth Autism Service. Additionally, the Department of Education's statewide Autism Priority Project provides training and technical assistance for educators who teach students with ASD.

To better coordinate services for individuals with developmental disabilities including ASD, Tennessee in 2010 approved legislation to split the state Department of Mental Health and Disabilities into two separate agencies — the Department of Mental Health, and the Department of Intellectual and Developmental Disabilities. With the creation of the latter agency, a statewide entity now has the direct responsibility to coordinate, set standards for, plan for, monitor and promote the development and provision of services and supports to meet the needs of persons with intellectual and developmental disabilities, including ASD.

Strengthening regional and statewide service delivery

Some SREB states have established networks that help to coordinate services statewide through a regional structure. In Oklahoma, the Autism Working Group (2001-2002) developed a comprehensive statewide plan for research, service delivery and support for all individuals with ASD, and it established the Oklahoma Autism Network, which began operations in 2003. The network is responsible for implementing the Oklahoma Plan for Individuals with Autism and Their Families. The network provides referrals for services statewide; oversees the Autism Pilot Program (which provides in-home services to a broader range of children with ASD); offers training and technical assistance to parents, caregivers and professionals; and builds collaboration with various agencies and professionals.

More specific to education, Delaware has for more than 30 years operated the Delaware Autism Program, a statewide special education program for children with ASD that is housed in six school districts across the state. The program provides students ages 3 and up with an extended school year; a curriculum that addresses the communication, teaching and behavioral needs of children with ASD; and residential and vocational services.

The Georgia Department of Education's Georgia Network for Educational and Therapeutic Support (GNETS) maintains a system of regional programs that support local school districts' services for students with disabilities, including students with ASD. The programs provide inclusion services to students with disabilities so they may remain enrolled in regular classes at local schools while receiving GNETS services, instead of being placed in residential programs or other, more restrictive educational environments.

The Alabama State Department of Education established Autism Alabama as an online resource center for parents of students with ASD and teachers working with children with ASD. Similarly, in Maryland, the State Department of Education established AutismConnect, an Internet portal to provide a resource for parents, educators and other professionals for information on ASD and available services within the state.

The state of Florida has established a regional network of Centers for Autism and Related Disorders (CARD). The seven regional CARD centers are located at universities across the state and provide training for families and professionals, technical assistance for schools and school districts, and consultations for parents and care providers, as well as service and resource referrals. However, CARD centers do not directly provide services to children with ASD, operating in more of a support and referral capacity.

The TEACCH (Treatment and Education of Autistic and Communication related handicapped CHildren) program in North Carolina, based at the University of North Carolina's School of Medicine, also runs a network of regional centers that help provide training and information for individuals with ASD, their families and teachers, caregivers and other professionals. Additionally, these centers directly provide early intervention services to children with ASD and their families. The West Virginia Autism Training Center at Marshall University and the Kentucky Autism Training Center at the University of Louisville provide services across their respective states for individuals with ASD and their families, and they provide information and training for professionals working with individuals with ASD.

Helping educators work with students with ASD

Another approach that states have taken is attempting to bolster the abilities of education professionals to work with and educate children with ASD. The Department of Public Instruction in North Carolina has established an Autism Spectrum Disorders Program as a resource to assist school districts in providing appropriate services to students with ASD. To develop educational capacity for students with ASD on a systematic, statewide basis, the program provides training for groups of instructional professionals in local schools, as well as creating "local experts" to directly support those groups.

As a result of legislation approved in Florida in 2010, continuing education and in-service training for instructional professionals will incorporate training regarding students with ASD and other developmental disabilities. This training will include early identification of and early intervention for these students, as well as curricular and instructional methods for educating students with developmental disabilities. Additionally, minimum training standards for child care workers were expanded under the legislation to include training on identifying and working with children with developmental disabilities.

Setting up financial assistance programs

Several SREB states have instituted financial assistance programs, which provide state funds that students with disabilities may apply toward their education. Florida, Georgia and Oklahoma have established programs that provide financial assistance that parents of children with disabilities may use to send their children either to a different public school or to a private school. Louisiana will initiate a similar pilot program in the 2011-2012 school year. While these programs have proven fairly popular once established, their growth has been hindered by the economic downturn of recent years. Furthermore, very little research currently exists on how well these programs actually improve the education of students with disabilities.

Questions for policy-makers

Not only is education for children with ASD a complex issue, but it involves other policy considerations that encompass health care, statewide service delivery and interagency coordination. While understanding of ASD and the most effective treatments for it is still evolving, you and other policy-makers can ask the six key questions below to guide you as you consider whether your state is providing adequately for the educational needs of children with ASD:

- Given the importance of early diagnosis and intervention for children with ASD, does your state have sufficient capacity to provide diagnostic and intervention services?
- How well do your state's policies aid children in transitioning from early intervention to special education?
- Do your state's special education eligibility requirements hinder children with ASD in obtaining special education services?
- Is there a comprehensive statewide plan for assisting individuals with ASD?
- How well are services for individuals with ASD coordinated across state agencies and delivered on a statewide basis?
- Do training and continuing education requirements for educational professionals in your state assist them in identifying and working with children with ASD?

References

2010-2014 Texas State Plan for Individuals with Autism Spectrum Disorders. Texas Council on Autism and Pervasive Developmental Disorders, 2010.

Educating Children with Autism. National Research Council, Committee on Educational Interventions for Children with Autism, National Academy Press, 2001.

Kogan, Michael D., et al. "Prevalence of Parent-Reported Diagnosis of Autism Spectrum Disorder Among Children in the US, 2007." *Journal of the American Academy of Pediatrics*, published online October 5, 2009.

Winerman, Lea. "Effective Education for Autism." *Monitor on Psychology*, December 2004.

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