

States Grapple with Autism’s Rising Tide

By Carol Kreck

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Autism Spectrum Disorders are the fastest-growing developmental disability in the United States. In March 2013, the Centers for Disease Control [estimated](#) the prevalence of diagnosed ASD in 2011-12 to be one in 50 based on parent reports for children ages 6 to 17. Six years earlier, the CDC estimated the rate was one in 86.¹

In recognizing the increasing needs of children affected by ASD, as well as the associated financial implications for local governments, some states are re-assessing their current systems of support and looking for better and more efficient ways to serve individuals with ASD and their families.

As states have struggled to respond to the phenomenon, they have formed task forces, created pilot programs and launched resource and support services. Among some of the highlights of state activity:

- A handful of states require professional training for teachers and classroom aides to help with their oversight of students with autism. **Minnesota** established a new special education licensure category for teachers of students with ASD, for example, while **Virginia** requires aides working with autistic students to demonstrate competency in student behavioral management.
- **Maine**’s Department of Education and the University of Maine are collaborating on an institute serving as the state’s primary resource for leadership, training and technical assistance for educators and others working with ASD students and their families. The institute also supports K-12 schools.
- **Missouri** established a scholarship tax credit for children with ASD while **Ohio** requires parents of such students to be notified about the state’s autism scholarship program.

State leaders continue to grapple with numerous issues related to increased reports of autism, from best practices in the classroom to students who wander away from campus. While some of these areas delve into federal or local policy spheres, this report is intended to aid state leaders by providing examples of state activity, national context and recent research findings.

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Early Diagnosis and Quality Intervention

Though most children are diagnosed between the ages of 3 and 5, the American Academy of Pediatrics [recommends](#) well-baby screening at 18- and 24-month intervals for earlier intervention.²

Now there is evidence that diagnosis may be possible even earlier than the AAP suggests. According to a November 2013 [article](#) in the journal *Nature*, researchers at Emory University used eye-tracking technology to discover that infants later diagnosed with autism began looking less at people's eyes when they were 2- to 6-months old.³ Those researchers — Warren R. Jones and Ami Klin — said they hope eye tracking and other measures of social development will be used as routinely in checkups as height and weight charts are now.

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For preschool children up to the age of 3, intervention is usually paid for by a combination of state and federal funds. However, the federal Individuals with Disabilities Act mandates children be evaluated for services by public schools after age 3. It is important that the transition be smooth. In December 2013, a [complaint](#) against Chicago Public Schools was filed with the Illinois State Board of Education by Health and Disability Advocates alleging the district failed to evaluate thousands of children with disabilities and move them into special education preschool programs.⁴

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), released in May 2013, raised some concern about schools' role in treatment. This new edition of the DSM, considered the definitive source by health care providers for the diagnosis of mental and behavioral disorders, narrowed the criteria for ASD diagnosis. Parents and providers of school-based care were assured no child with the diagnosis would lose it and, further, that autistic children in school would get treatment no matter what their diagnosis is called.

Some [sounded](#) the alarm for children younger than 3 and suggested DSM-5 criteria may be too stringent for toddlers who would benefit from early intervention.⁵ With the Emory-based research results pointing toward the need for even earlier diagnoses, some asked what that meant for the DSM. On the weekend of the DSM-5's release, the advocacy group Autism Speaks posted [a statement](#) on its website noting the DSM-5 committee "has stressed that the new DSM-5 criteria represent a 'living document,' in which changes can and likely will be made as new studies are conducted."⁶

Although earlier diagnosis is now possible, most children are preschoolers at diagnosis. In a [study](#) released in 2013, researchers found that children who get high-quality intervention — a comprehensive treatment model as opposed to shorter, focused interventions — benefit regardless of which particular treatment model is used. That includes Learning Experiences and Alternative Program for Preschoolers

and Parents (LEAP), Treatment and Education of Autistic and Related Communication Handicapped Children (TEACHH) or other comprehensive treatment models. This could influence cost of care to the district.

“For instance, by design, LEAP classrooms are operated as half-day programs, and if children are able to receive similar outcomes to full-day programs in half-day, then the cost-benefits may factor into school administrators’ decisions to select a particular CTM (comprehensive treatment model),” wrote the authors.⁷

5 Policy Questions for State Policymakers to Consider

1. Does your state have a plan or standards for the early diagnosis of Autism Spectrum Disorders and subsequent interventions?
2. Does your state require insurers to cover treatment for children with ASD?
3. Will your state provide options for a child to attend an education program specifically targeted to this disability – and if so, how will costs be handled?
4. What competencies do school staff with primary oversight of students with autism need to demonstrate (aides, teachers and leaders)?
5. What standards are in place for determining when ASD students can and should be included in mainstream classrooms so that they have access to the common curriculum?

Cost of Educating Students with Autism

In 2011, an in-depth study by the *Los Angeles Times* uncovered racial disparities in public spending on autism. For autistic children aged 3 to 6, the California Department of Developmental Services spent an average of \$11,723 per white child in 2010, \$11,063 for Asians, \$7,634 for Latinos and \$6,593 for blacks, the newspaper found. The gaps were blamed, at least in part, on parent assertiveness and ability to participate in therapy:

“The divide is starker when it comes to the most coveted service – a behavioral aide from a private company to accompany a child throughout each school day, at a cost that often reaches \$60,000 a year. ... In the state’s largest school district, Los Angeles Unified, white elementary school students on the city’s affluent Westside have such aides at more than 10 times the rate of Latinos on the Eastside.”⁸

*A study published in April 2007 in *Pediatrics and Adolescent Medicine* estimates that the lifetime cost of caring for an autistic person is about \$3.2 million.*

In Kansas, a 2009 [report](#) of the Kansas Autism Task Force to the legislature referred to the growing body of evidence that pointed to the effectiveness of early, intense intervention. It said such intervention for at least three years during the crucial developmental stage of ages 1 to 7 could cost more than \$150,000.⁹

While the Kansas legislature declined to expand the program that existed, “one of the recommendations was to consider the state insurance mandate,” said task force member Linda Heitzman-Powell in an email to the author. “The State did mandate a ‘pilot’ for the State Employees Health Plan. The pilot was ‘successful’ and the state insurance plans voted to make it a part of the general policy versus a pilot/mandate. No other mandate has been enacted.”

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Insurance Coverage as a Cost-Containment Strategy

According to an August 2012 article by the National Conference of State Legislatures, at least 31 states have laws that specifically require insurers to provide coverage for the treatment of autism. Arizona, for example, requires benefits up to \$50,000 per year for a child younger than 9 and up to \$25,000 per year for children ages 9-15.

An Autism Speaks [report](#) on the cost of mandating coverage ranged from 9 cents per member, per month (PMPM) to 30 cents PMPM the first year, or 15 cents on average. The second-year average was 31 cents PMPM.

Professional Training

Several states require professional training of teachers and classroom aides or assistants, known by educators as paraprofessionals.

Alabama, for example, has established regional autism centers that are required to provide staff with expertise in autism and related disabilities. In addition, [state law](#) calls for the centers to provide assistance to families, training for professionals and programs to increase public awareness about ASD.

Minnesota revised its [special education teacher licensure](#) system to prepare teachers in a [hybrid-specific and cross-categorical system](#). The state established two new licensure fields: Academic and Behavioral Strategist and Autism Spectrum Disorders.

Virginia now requires each school board to ensure that aides assigned to work with a teacher who has primary oversight of students with autism spectrum disorder demonstrate competency in student behavioral management within 60 days of assignment. That bill also requires the Board of Education to provide standards to measure competency.

In addition, a new center in **Florida** is expected to have nationwide reach.

In September 2012, the U.S. Department of Education [announced](#) a \$25 million award to the University of Florida — or \$5 million a year for five years to establish a center to support the development of effective special education teachers nationwide. A release from the University of Florida states the grant is the largest investment ever in improving education for students with disabilities.

Maine Autism Institute for Education and Research

Maine's Department of Education has partnered with the University of Maine's College of Education and Human Development to create the Maine Autism Institute for Education and Research, known as MAIER.

MAIER, which opened Jan. 1, is intended to serve as a statewide autism resource and research institute. It will be the state's primary resource for leadership, training and technical assistance for professional educators and others, as well as a support to Maine's K-12 schools, which enroll about 2,600 students with ASD.

MAIER will also help families navigate services from birth to adulthood, according to an [announcement](#) made by the Maine Department of Education.

The Power of Technology

A critical element for professionals working with children with ASD is an understanding of the power of technology – a tool that appears to particularly resonate with autistic students.

Some children may focus better on a computer — backed up by teachers via phone and email — than in colorful classrooms with other students. However, leaders at the Center on Online Learning and Students with Disabilities wrote in an open [letter](#) that their concerns include inconsistent policies from state to state, a void in preparation to provide online teaching to students with disabilities and a lack of data on the extent to which students with disabilities take online courses.¹¹

Several journal articles attest to the efficacy of touchscreens, especially for nonverbal autism spectrum students; some specifically refer to iPads.

In an [article](#) in *Personal and Ubiquitous Computing*, the authors developed a set of activities for multi-touch pads and concluded, "Our observations suggest these activities increased pro-social behaviors such as collaboration and coordination, augmented appreciation for social activities and provided children with novel forms of expression."¹²

State policymakers can request data around the type and reach of technology options being provided to autistic students, and have the authority to require that online learning and other options are available.

Inclusion versus Separate Classrooms, Separate Schools

Some autistic students are served in separate classrooms and others in special separate schools. Depending on severity, however, most parents opt for inclusion in mainstream classrooms, sometimes with a classroom aide.

In the book, "The Exceptional Child: Inclusion in Early Childhood Education" speech pathologist Diane Twachtman-Cullen cites the following as the worst practices in inclusion:

- Insisting on inclusion at all costs

- Settling for a mere presence in the classroom, giving priority to the inclusive model over a child's individual needs
- Providing little or no staff training
- Keeping the paraprofessional out of the loop
- Teaching rote information for standardized tests instead of needed skills
- Watering down the curriculum
- Failing to teach children about the nature of disabilities and how to interact with peers who have a disability.¹³

Reducing Wandering Away From Schools

An October 2012 [article](#) in *Pediatrics* found that nearly half of children on the spectrum wander or bolt, the first published findings in the United States to provide an estimate of wandering prevalence.

Of that group, more than half go missing (i.e., missing long enough to cause concern). Almost 30 percent of incidents occur from classrooms or schools. While most children did it for fun or to return to a place they enjoyed, 34 percent were trying to escape an anxious situation. Those anxious would-be escapees were more likely to have a diagnosis of Asperger syndrome, at the low end of the spectrum.

Escapist behavior begins at age 4, often leading to close calls with traffic injury and drowning. Half their parents reported receiving no guidance from anyone on preventing their child from wandering away from home or school.¹⁴

Disappearances from school often occur during [in-school transitions](#). It is estimated that as much as 25 percent of a school day involves transition activities, such as moving from classroom to classroom, coming in from recess or leaving the cafeteria.¹⁵

A Missing Child Sparks 'Avonte's Law'

On Oct. 4, 2013, Avonte Oquendo went missing in the New York borough of Queens . He was last seen leaving his Riverview School in Long Island City near the East River waterfront. His remains were found along the East River in January.

It didn't take long for New York Sen. Charles Schumer to [propose](#) legislation called "Avonte's Law," which would create and fund a program to provide voluntary tracking devices for families with autistic children.

On Jan. 27, 2014, Schumer said the program would put the Department of Justice in charge of providing grants to local law enforcement and other organizations, modeled off a program already in place to track seniors with Alzheimer's.

High School Transitions

Under the federal IDEA, schools are required to have a transition plan in place for all students by the age of 16, although states can mandate an earlier age. Lisa Goring, vice president of Family Services for Autism Speaks, said the transition may need to start earlier than 16, given the challenges that some with autism face in terms of communication, social interactions and repetitive behaviors.

“In many cases, the transition process should start at age 14 or as the student enters high school. This would provide more time to develop the skills necessary to gain and maintain employment and independent living skills when the student leaves the educational system.”¹⁶

A 2008 Easter Seals [study](#) found that 79 percent of young adults with ASD continue to live with their parents.¹⁷ A more recent Easter Seals [study](#) found that one third of grown siblings provide financial support for a brother or sister with a disability, and 81 percent are the primary caregiver.¹⁸

If state education systems can improve the instructional services provided to all children and youth who fall on the autism spectrum, a greater number of this 79 percent may be able to be more self-supporting and to contribute in additional ways to the world around them.

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Endnotes

¹ Stephen J. Blumberg et al., *Changes in Prevalence of Parent-Reported Autism Spectrum Disorder in School-Aged U.S. Children: 2007 to 2011-2012*, (Hyattsville, MD: National Health Statistics Reports, March 20, 2013), <http://www.cdc.gov/nchs/data/nhsr/nhsr065.pdf>.

² American Academy of Pediatrics, *Prevalence of Autism Spectrum Disorders*, March 29, 2012, <http://www.aap.org/en-us/about-the-aap/aap-press-room/Pages/Prevalence-of-Autism-Spectrum-Disorders.aspx>.

³ W. Jones, K. Carr, and A. Klin, “Attention to Eyes Is Present but in Decline in 2–6-Month-Old Infants Later Diagnosed with Autism,” *Nature*, Nov. 6, 2013, <http://www.nature.com/nature/journal/vaop/ncurrent/abs/nature12715.html>.

⁴ Health and Disability Advocates complaint filed against Chicago Public Schools, Dec. 31, 2013, http://www.hdadvocates.org/files/HDAFiles/Progs%20and%20Svcs%20for%20Children%20Materials/REDACTED_2013_CPS_StateComplaint.pdf.

⁵ Marianne L. Barton et al., “Sensitivity and Specificity of Proposed DSM-5 for Autism Spectrum Disorder in Toddlers,” *Journal of Autism and Developmental Disorders*, Vol. 43, 2013, 1184-1195, <http://www.ncbi.nlm.nih.gov/pubmed/22449643>.

⁶ Autism Speaks, *DSM-5 Will Be Released This Weekend*, May, 2013, <http://www.autismspeaks.org/news/news-item/dsm-5-will-be-released-weekend>.

⁷ BA Boyd et al. “Comparative Efficacy of LEAP, TEACCH and Non-Model-Specific Special Education Programs for Preschoolers with Autism Spectrum Disorders,” *Journal of Autism and Developmental Disorders*, February 2014, <http://www.ncbi.nlm.nih.gov/pubmed/23812661>.

⁸ Alan Zarembo, “Warrior Parents Fare Best in Securing Autism Services,” *Los Angeles Times*, Dec. 13, 2011, <http://www.latimes.com/news/local/autism/la-me-autism-day-two-html,0,3900437.htmlstory#axzz2t9ZvFRUZ>.

⁹ Kansas Autism Task Force, *Report of the Kansas Autism Task Force to the 2009 Kansas Legislature*, December 2008, <http://www.skyways.org/ksleg/KLRD/2008CommRepts/autism-cr.pdf>.

¹⁰ Michael L. Ganz, “The Lifetime Distribution of the Incremental Societal Costs of Autism,” *Pediatrics and Adolescent Medicine*, Vol. 161, April, 2007, 343-349, <http://www.ncbi.nlm.nih.gov/pubmed/17404130>.

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- ¹¹ Don Deshler et al., *Concerning Participation: An Open Letter*, (Lawrence: Center on Online Learning and Students with Disabilities, Oct. 3, 2012), <http://centeronlinelearning.org/openletter/>.
- ¹² Juan Pablo Hourcade, Natasha E. Bullock-Rest and Thomas E. Hansen, "Multitouch Tablet Applications and Activities to Enhance the Social Skills of Children with Autism Spectrum Disorders," *Personal and Ubiquitous Computing*, Feb. 20, 2012, <http://homepage.divms.uiowa.edu/~hourcade/asd-puc-publicversion.pdf>.
- ¹³ Eileen K. Allen and Glynnis Edwards Cowdery, *The Exceptional Child: Inclusion in Early Childhood Education*. (Belmont: Wadsworth Cengage Learning, 2012, 2009).
- ¹⁴ Connie Anderson et al., "Occurrence and Family Impact of Elopement in Children with Autism Spectrum Disorders," *Pediatrics*, 2012, <http://pediatrics.aappublications.org/content/early/2012/10/02/peds.2012-0762.full.pdf+html>.
- ¹⁵ Kara Hume, *Transition Time: Helping Individuals on the Autism Spectrum Move Successfully from One Activity to Another*, *The Reporter* 13(2), 6-10, <http://www.iidc.indiana.edu/?pageId=399>.
- ¹⁶ Lisa Goring, Vice President, Family Services, Autism Speaks, in an email to the author, Jan. 4, 2014.
- ¹⁷ *Easter Seals' Living with Autism Study*, Dec. 16, 2008, http://es.easterseals.com/site/DocServer/Study_FINAL_Harris_12.4.08_Compressed.pdf?docID=83143.
- ¹⁸ *Mass Mutual & Easter Seals: Sibling Disability Study*, November 2012, http://es.easterseals.com/site/DocServer/Mass_Mutual_-_Easter_Seals_Sibling_Study_Report.pdf?docID=156638.

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