



December 2006

State Approaches to Serving Students with Autism Spectrum Disorders

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The number of children and youth identified with autism has grown exponentially over the past decade and a half. During 1992-93 (the first required reporting year for the category of autism) only 7,168 students with autism ages 6-21 were served under the Individuals with Disabilities Education Act (IDEA) (U.S. Department of Education, 1994).¹ This number grew to 193,637 students with autism ages 6-21 during the 2004-05 school year—more than 27 times the number first identified.² Although some of this growth in numbers can be attributed to the fact that it often takes several years for state data systems to adapt, this certainly does not fully account for such extreme growth in numbers. In response to this growth, states have begun to institute specialized infrastructures and/or programs to serve children and youth with autism and other autism spectrum disorders. The purpose of this document is to describe state approaches to serving this growing population. Project Forum conducted this analysis as part of its cooperative agreement with the U.S. Department of Education's Office of Special Education Programs (OSEP).

Terminology

IDEA regulations provide the following definition of autism:

(1)(i) Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

(ii) Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in paragraph (c)(4) of this section.

¹ Data from 1992-1993 did not include information on children ages 3-5.

² Data available at www.ideadata.org.

(iii) A child who manifests the characteristics of autism after age three could be identified as having autism if the criteria in paragraph (c)(1)(i) of this section are satisfied. [34 CFR §300.8 (c)]

In recent years, however, some states have adopted the term autism spectrum disorders (ASDs) to include a broader range of conditions. The National Institute of Mental Health (NIMH) provides the following definition of ASDs:

Autism spectrum disorders (ASDs), also known as Pervasive Developmental Disorders (PDDs), cause severe and pervasive impairment in thinking, feeling, language, and the ability to relate to others. These disorders are usually first diagnosed in early childhood and range from a severe form, called autistic disorder, through pervasive disorder not otherwise specified (PDD-NOS), to a much milder form, Asperger syndrome. They also include two rare disorders, Rett syndrome and childhood disintegrative disorder.³

For the purposes of this document, the more inclusive term—autism spectrum disorders—is used.

Data Collection

Project Forum developed a survey protocol with input from Delaware’s state director of special education. The survey was distributed in July of 2006 to all states and non-state jurisdictions. By September 2006, Project Forum had received responses from a total of 46 state education agencies (SEAs). Results were analyzed and findings are reported in the following section of this document.

Findings

State-level Staff

Thirty-four of the 46 responding SEAs reported having one or more state-level staff designated to handle issues relating to students with ASDs. All 34 provided information on full-time equivalency (FTE). Ten SEAs dedicate 1.0 FTE to issues relating to students with ASDs; 20 dedicate less than 1.0 FTE (ranging from .05 FTE to .7 FTE); and three SEAs dedicate more than 1.0 FTE (ranging from 4.0 FTE to 9.0 FTE). Thirty-three of the responding SEAs reported that funding for these positions comes either from IDEA funds—both discretionary and set-aside (27 SEAs); state funds (4 SEAs); or a combination of both IDEA and state funds (2 SEAs). Roles and responsibilities associated with these positions most commonly include:

- collaborating with state-or local-level autism agencies (33 SEAs);
- providing technical assistance to local education agencies (LEAs), schools, parents and/or students with ASDs (30 SEAs);
- responding to inquiries from parents or students with ASDs (32 SEAs);

³ More information on ASDs is available at NIMH’s website: <http://www.nimh.nih.gov/publicat/autism.cfm>.

- developing handbooks, guidelines or other publications on the topic of ASDs for use by special education teachers, parents and/or students with ASDs (28 SEAs);
- providing LEAs with information on federal laws, initiatives and research on ASDs (27 SEAs);
- developing state-wide policies and procedures (27 SEAs);
- identifying research-based practices related to ASDs (26 SEAs);
- coordinating/providing professional development (25 SEAs);
- overseeing state-level grants relating to ASDs (20 SEAs); and
- collaborating/coordinating with national initiatives concerned with ASDs (20 SEAs).

Less commonly, roles and responsibilities include:

- collecting outcome data relating to ASDs (12 SEAs);
- managing a website addressing ASD-related issues (10 SEAs);
- collaborating with institutions of higher education (3 SEAs);
- coordinating research efforts related to ASDs (1 SEA);
- supporting medical screening services (1 SEA); and
- working directly with teachers, students and families (1 SEA).

Part C Eligible Children

Children served under IDEA fall under either Part B (ages 3 to 22) or Part C (birth to age 3). Eight SEAs described programs and/or publications relating specifically to the identification and/or provision of services to Part C eligible children with ASDs. The Part C lead agencies in *New York*, *North Dakota* and *Connecticut* have published clinical practice guidelines to assist service providers in identifying young children with ASDs. The Part C lead agencies for *Tennessee*, *Minnesota* and *Delaware* work collaboratively with state-wide autism projects. Additional examples include:

- *South Carolina*—The Department of Disabilities and Special Needs, Autism Division contracts with local disabilities and special needs boards and other providers to bring an array of services to young children with ASDs.
- *Nebraska*—The ASD Network, which consists of five regional coordinators and one state-level coordinator, provides specific technical assistance to Individualized Family Service Plan (IFSP) teams related to identification of children with ASDs.
- *New York*—The SEA conducted a study of the availability and effectiveness of preschool programs for children with ASDs in order to inform policy and program development.

Students with Asperger Syndrome

Four SEAs described state-level programs specifically for serving students with Asperger Syndrome or high-functioning autism. *Kansas*, *Alabama* and *California* all offer professional

development opportunities for teachers and parents relating to this population. Also, Project PEAK—a partnership between the *Oklahoma* State Department of Education and the Oklahoma University Health Sciences Center Child Study Center—provides evaluation, diagnostic and related services to students with Asperger Syndrome and high-functioning autism. Several states mentioned that although there are no state-level programs in place to serve this population of students, specialized programs are in place at the LEA-level.

Professional Development Activities

Forty-two SEAs reported offering professional development activities related to ASDs. For example:

- annual summer institutes or autism symposia (3 SEAs);
- ASD-specific workshops, trainings and/or coursework including data-based instruction for students with autism, strategies for working with students with Asperger Syndrome, social and communication skills training, assessment of students with autism, transition for students with autism, integrated instructional methods including pivotal response training, discrete trial, developmental approaches and specific strategies (such as Treatment and Education of Autistic and related Communication-handicapped Children [TEACCH], Comprehensive Autism Programming System [CAPS], and Picture Exchange Communication System [PECS]) (20 SEAs); and
- related training activities on topics such as positive behavioral supports, applied behavior analysis and augmentative and alternative communication (13 SEAs).

Ten SEAs also described supporting and/or collaborating with state-wide autism programs such as the *Ohio* Center for Autism and Low Incidence, the *Illinois* Autism Training and Technical Assistance Project, *Connecticut's* Initiative on Autism, *Missouri's* Project ACCESS, *Michigan's* Statewide Autism Resource Center, *Florida's* Center for Autism and Related Disabilities, the Autism Society of *Maine* and *Washington's* Autism Outreach Project—all of which provide professional development and technical assistance to children, families, school districts and others. Additionally, eight SEAs described ASD-specific institution of higher education (IHE) programs for preparing teachers, related service personnel or paraprofessionals to better serve this population. Examples of these programs include the following:

- *New York* awarded three-year grants to 17 IHEs and each is now offering courses relating to ASDs at both the inservice and preservice level. The SEA funds an ASD-specific certificate program at one of the state's IHEs that is offered across the state via distance learning. State legislation also mandates that all special education teachers and administrators applying for a license after February 2007 complete coursework or training in the needs of students with autism.
- *Minnesota* developed paraprofessional competencies for ASDs and has proposed ASD teacher competencies in collaboration with IHEs and autism professionals. These are

being used as a guide for professional development and developing competence in IHEs and LEAs throughout the state.

Task Forces and Advisory Groups

Twenty-eight SEAs reported having some type of state-level task force or advisory group that focuses on issues relating to students with ASDs. Eighteen noted that the groups are exclusively devoted to ASD-related issues and three noted that they are more “generic” in nature. Five noted that these groups are governor appointed and/or mandated by state law and make recommendations to the governor and/or legislature in the areas of education, employment, health, family support and funding as they apply to individuals with ASDs. Examples of task forces and advisory groups include:

- *Rhode Island*—The state has an autism coalition that coordinates an annual autism awareness day and publishes a quarterly calendar of events. An autism task force was also convened in order to produce an autism handbook for families with newly diagnosed children.
- *Illinois*—A legislatively mandated task force conducted an initial review of the status of services for individuals with autism. The task force is now conducting a more in-depth review and generating recommendations on specific services and policies.

Measuring Outcomes

Sixteen SEAs described state measures for tracking outcomes for children and/or youth with ASDs. Of these, nine noted that they were able to disaggregate state assessment scores and three noted that they collected post-secondary outcomes data for this population. Five SEAs noted that although they do not consistently track outcomes for students with ASDs, they have the capacity to generate reports on an as-needed basis.

Other State-level Initiatives

Twenty-three SEAs reported having one or more state-level initiatives in place not already covered in this document. For example:

- *New Jersey*—The governor dedicated \$15 million in new spending to enhance programs for students with ASDs. With these funds, the SEA, in collaboration with the governor’s office, will offer a grant program to LEAs and regional special education service providers to improve the continuum of public school program options for this population. Funds can be used for professional development, family outreach, transition planning, community-based instruction and assistive technology.
- *New York*—Under the direction of the SEA, the New York Autism Network developed Autism Program Quality Indicators (APQI), a compilation of best practices in educating

students with autism, to serve as a means for guiding quality improvement activities for schools and programs serving children with ASDs. The APQI is used extensively throughout the state. The SEA also awarded grants to five schools with successful programs for students with ASDs in order to assist other schools in replicating their effective practices.

- *Louisiana*—The SEA is in the process of developing quality indicators and is implementing intensive training to improve inclusive practices for students with ASDs. This effort will include the establishment of demonstration sites.
- *Maine*—The Autism Society of Maine, funded through the SEA and the Department of Health and Human Services, provides information resources to educational professionals and families, publishes a newsletter, maintains a library and runs ASD support groups.

Four SEAs described efforts to improve interagency collaboration (e.g., between the state-level autism program and LEA-level programs or between the SEA and other state-level agencies serving individuals with ASDs). Three SEAs described autism-related research efforts such as prevalence studies. Several respondents described ASD-related initiatives in their states that operate independently of the SEA—including initiatives being spearheaded by the Department of Human Services, IHEs, parent training and information centers (PTICs) and/or state-wide autism outreach projects.

Due Process Hearings and Complaints

Twenty-nine SEAs provided information on the percentages of total due process hearings and/or complaints lodged by families of students with ASDs—figures which varied considerably. Of these, seven SEAs reported 5% or fewer (ranging from less than 1% to 5%), 15 reported between 6% and 12%, four reported between 13% and 20%, and three reported 30% or more (ranging from 30% to 75%).

Barriers

SEAs described a wide range of barriers to serving students with ASDs, most commonly the shortage of experienced teachers and paraprofessionals with ASD-expertise (22 SEAs), lack of consensus in the field about research-based interventions (7 SEAs), the challenge of serving students with ASDs in low-density and rural areas (7 SEAs), lack of state and federal resources for developing and sustaining an ASD-related infrastructure as well as the provision of professional development and technical assistance (5 SEAs) and lack of opportunities at IHEs for autism specialization (4 SEAs). Other barriers identified by no more than two SEAs included the following:

- state and federal definitions of autism that do not include the full range of ASDs;
- slow rate at which new programs are being developed that does not keep pace with population growth;

- challenge of meeting the needs—within a public school context—of students with dual diagnoses, mental health issues and/or severe aggression;
- insufficient support for secondary transition services;
- high cost of early intervention;
- lack of parental knowledge regarding available resources;
- difficulty coordinating with other state agencies due to conflicting priorities and eligibility criteria;
- physicians’ reluctance to diagnose young children causing children to miss receiving services early; and
- high rates of litigation.

Summary

All of the 46 responding SEAs reported one or more programs and/or activities in place relating specifically to ASDs. Most reported having one or more SEA-level staff designated to handle ASD-related issues, offering state-sponsored professional development activities and convening ASD-specific task forces and/or work groups. Many reported collecting one or more types of outcome data for this population as well as sponsoring other types of ASD-related initiatives. A few also reported having specific programs in place to serve Part C eligible children with ASDs and/or students with Asperger Syndrome. In spite of the numerous programs/activities in which SEAs are engaged, most reported one or more barriers to serving this growing population—most commonly, the lack of educational professionals with ASD expertise.

References

U.S. Department of Education. *Sixteenth annual report to Congress on the implementation of the Individuals with Disabilities Education Act*. Washington, D.C.: Author.

This report was supported by the U.S. Department of Education (Cooperative Agreement No. H326F050001). However, the opinions expressed herein do not necessarily reflect the position of the U.S. Department of Education and no official endorsement by the Department should be inferred.

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