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Autism Spectrum Disorders: State Part C and Part B Initiatives to Serve a Growing Population

by Kelly Henderson, Ph.D.

INTRODUCTION

Autism is a neurodevelopmental disorder characterized by impairments in social relating, language and the presence of repetitive and stereotyped behaviors. Autism Spectrum Disorders (ASD) include a broader range of pervasive developmental disorders. Rapid growth in identification of children with Autism as defined by the Individuals with Disabilities Education Act (IDEA) and with ASD generally has been well-documented in special education data and research and in the popular press. State agencies responsible for special education and early intervention are responding to this growth. This document, completed as part of the cooperative agreement between Project Forum at the National Association of State Directors of Special Education (NASDSE) and the Office of Special Education Programs (OSEP), describes approaches states are using as part of their initiatives to identify and address the needs of children and youth with ASD.

METHODOLOGY

Information about state initiatives to address the needs of children and youth with ASD was requested through an online survey. Requests for information were made to all state education agencies (SEAs) responsible for implementing Part B of IDEA and all state agencies responsible for implementing Part C of IDEA (hereafter referred to as Part C lead agencies). Part C addresses early intervention services for infants and toddlers with disabilities and their families while Part B provides for a free appropriate public education for all children with disabilities between ages three and twenty-one. Survey respondents were asked if their state currently has a program or initiative that specifically addresses students with ASD and if they address Part B- and Part C-eligible children with ASD. A brief description of the initiative(s) was requested. Sixty-one survey responses were received from 43 states and non-state jurisdictions, (hereafter referred to as states) that represented 35 Part B and 27 Part C lead agencies. (The numbers do not add up to 61 because one state respondent represented both Part B and Part C.)

Based on responses to the online survey, agency personnel in five states were selected to interview for more detailed information on their ASD initiatives: *California, Massachusetts, Michigan, Missouri* and *Oklahoma*. Selection ensured representation by states that vary by lead Part C agency, emphasis on different types of initiatives such as professional development or model programs, or geographic region. For example, SEAs in *Michigan*,

Missouri and *Oklahoma* oversee implementation of both Parts C and B while *California* and *Massachusetts'* Part C lead agencies are the Department of Developmental Services and the Department of Health, respectively. Interview protocols were customized to the types of activities and efforts named in the survey responses and included questions about interagency participation, models of ASD identification and service provision and the specific nature of the technical assistance (TA) and professional development provided.

Using the customized protocols, Project Forum conducted nine interviews with 11 SEA and Part C lead agency staff from these five states December 2008 through February 2009. Survey data were examined quantitatively and interview data were coded for common approaches and themes.

FINDINGS

Prevalence of ASD Initiatives

Current initiatives were reported by at least one agency in 40 of the 43 responding states. Because the survey question asked if the state has a program or initiative that specifically addresses students with ASD without additional qualification, affirmative responses represent a wide variety of approaches and programs described by respondents. Of the 37 responses concerning Part C, 27 states reported an ASD initiative. Of the 35 responses about Part B agency efforts, 31 had an initiative. All five states interviewed reported having initiatives in both Parts C and B.

Professional Development

Provision of professional development opportunities was one of the most common approaches used by states to address the needs of children and youth with ASD. In describing their state initiatives, 26 survey respondents reported that professional development was part of their efforts. Specifically, training focuses on early identification, characteristics and behavioral approaches, and is delivered via intensive training institutes or symposia, shorter term trainings and state agency and state-supported TA or resource center conferences. Both direct training to practitioners and train-the-trainer delivery models are used.

Michigan's Statewide Autism Resources and Training (START) project utilizes several models of professional development specific to ASD. Year-long intensive trainings are offered regionally to K-12 and early intervention staff across the state. Local education agencies (LEAs) apply to send teams of teachers, administrators, parents and support staff. K-12 teams select a target student with ASD and attend two-day trainings every four to six weeks. The team focuses on the target student to implement effective practices using a team problem solving approach, and throughout the year they begin to expand their focus to classroom, building and district level systems change. Similar year-long training is in place for early intervention providers, who focus on a target classroom. The trainings follow a START-developed curriculum based on effective practices and participants commit to about 12 days of ASD-specific training a year. While START offers other avenues for training, including conferences and meetings, the year-long, team approach has proven the most powerful. A trainer/coach model is embedded in the intensive training so that members of the training team can become trainers of the content and coaches for implementation of practices.

Massachusetts supports a focus on autism as part of its statewide professional development grant program available to all LEAs and educational cooperatives. Funded through a state improvement grant, the program targets four priorities including one for “Inclusive Practices for Students with Autism Spectrum Disorders”. Awards are based upon total public school student enrollment and grantees may address topics from an SEA-generated list including accommodating sensory challenges, applied behavior analysis (ABA), positive behavior supports, social skills interventions, school and home partnerships and structured teaching. About a third of the state’s LEAs apply for support for the ASD priority. Grantees use a range of professional development delivery models such as inviting presentations from outside consultants, universities and private schools and collaborating with other LEAs or cooperatives to support certain coursework offerings. The activities may be offered to special educators alone or to special and general educators who jointly address inclusive practices. In 2007, LEAs who chose the ASD priority area for their professional development grants were invited to a statewide ASD-specific conference. In 2008, grantees were invited to a regional conference that included breakout sessions on ASD. In addition to the professional development grants, the Massachusetts SEA also offers content-specific summer institutes to general educators, some of which assist content-area teachers to better address the needs of students with disabilities in their classes. A separate set of special education summer institutes are also available and topics related to ASD are among the offerings.

Oklahoma’s Project PEAK (Programming and Evaluation for Kids with Autism), a training and support network for educating children with ASD and supported by the SEA, sponsors a two-week summer symposium for service providers and families. Educators participate in hands-on training sessions in classroom settings with children with ASD, while the families meet to network and learn more from each other and invited guests about resources. Trainees are predominately IDEA Part B teachers and providers, though 10 early intervention personnel have participated in each of the last several symposia. Trained practitioners who complete the symposia are placed on the *Oklahoma* Special Education Teacher Registry for Autism.

Missouri’s Project ACCESS provides support and technical assistance (TA) to LEAs serving students with autism. Project ACCESS trains and supports a cadre of statewide trainers and maintains training materials used by the state’s Regional Professional Development Centers (RPDCs). Credentialed autism trainers provide one-half to four-day-long seminars on topics ranging from “Introduction to Autism” to “Working with Young Children with Autism in Discrete Trial Formats.”

In addition to trainings, professional development opportunities include coursework offered by institutions of higher education (IHEs) and other providers. *Massachusetts* has witnessed growth in its universities’ offerings of autism-specific coursework. *California’s* professional associations provide well-regarded statewide training opportunities for speech language pathologists, school psychologists and other professionals on autism-specific topics including, assessment of ASD, sensory integration and behavioral interventions. *Missouri’s* Blue Ribbon panel found that ASD-specific training is relatively rare in teacher education curricula and professional development programs and recommended that additional curricula be added to teacher education programs that are specific to ASD and to the management of behavior problems encountered with ASD.

In some states, localities exercise more control over the specific types of ASD training they offer. *Michigan’s* Part C providers must submit evidence of competency-based training but generally seek out training based on their particular needs. The state does however offer

some opportunities through an early intervention training center on topics such as family-centered practices and “red flag” indicators. Similarly *California’s* SELPAs (Special Education Local Plan Areas) individually offer a menu of training opportunities from which practitioners select those that best meet their needs.

Michigan is one of six states that have been selected as a partner to the OSEP-supported National Professional Development Center on Autism Spectrum Disorders (PDA) at University of North Carolina’s Frank Porter Graham Center. The two-year partnerships assist states to better serve individuals with ASD by supporting efforts such as increasing the number of highly qualified personnel, implementing evidence-based practices and establishing a sustainable system of ongoing professional development and TA for the provision of high quality services.

Certificate or specialized training requirements

Several states are developing or supporting behavior analyst certification programs. Among the offerings are state credentials or graduate certificates in applied behavioral analysis (ABA) and in autism-specific interventions, and required coursework for the national Board Certified Behavior Analyst certification.

In *Massachusetts*, children with ASD and their families served under Part C may receive intensive behavioral interventions, a set of specialized services provided in addition to those regularly delivered through the early intervention program. The Department of Public Health currently contracts with 10 private providers who provide between five and 27 hours per week of intensive behavioral interventions to eligible toddlers and their families. Many of these contractors employ nationally certified behavior analysts or support their personnel in working towards the certification. Institutes of higher education and other training providers are finding great demand for ABA certification coursework and training.

Since 1990, *Oklahoma* has maintained a Special Education Teacher Registry for Autism. Registry training was created as a mechanism to provide approved training in federal disability category areas for which no state special education certification exists, including autism. Special education teachers who hold cross-categorical certification and teach students with autism must obtain registry status. Participants must complete 32 hours of training. Summer symposium participation is one option for completing the registry training.

Michigan offers an endorsement for teachers of students with autism. The Autism Collaborative Endorsement (ACE) program is an innovative online endorsement program that is offered through a four-university collaboration and requires the completion of 18 credit hours, including five specified courses and a practicum. Eligible individuals must hold basic teacher certification and a prior endorsement in special education. Following completion of coursework, ACE students must take the state teacher certification exam in the area of autism.

Missouri utilizes another approach to endorsing professionals trained in autism-specific skills. In addition to training Project ACCESS maintains a network of *Missouri* Autism Consultants (MACs) who provide TA and direct consultation to LEA and school staff. Project ACCESS selects MACs, trains them, monitors their effectiveness and ongoing education in autism and assigns them to LEAs requesting consultation. MACs have typically attended most Project ACCESS workshops and are invited to attend a refresher course once each year. While not a professional certification, MAC status has a well-regarded reputation in the

region. The Project also trains and maintains a record of In-District Autism Consultants (IDACs), who are certified teachers who consult with colleagues serving students with autism within their own LEA. Six days of autism specific training are a prerequisite to the two and one half day intensive IDAC training.

In addition, the *Missouri* Division of Special Education provides course reimbursement for educational professionals who participate in online ABA coursework toward National Board certification. Project ACCESS also makes available a list of in-state professionals who have specialized training in ABA and indicates those who have National Board credentials.

Technical assistance

Often linked to professional development efforts, provision of TA was a major approach used by states with ASD initiatives. Survey responses from 29 agencies referenced some level of TA activity. The most-commonly reported models of TA included resource centers, direct and indirect consultation services, and development and dissemination of best practice guidelines.

Resource Centers

Several states report having autism-specific resource centers or TA projects that provide consultation and report that their noncategorical resource centers provide TA on a broad range of special education issues including autism-specific ones.

An example of an autism-focused effort is *Oklahoma's* Project PEAK, a collaborative effort of the University of Oklahoma Health Sciences Center's Child Study Center and the SEA. In addition to coordinating the autism summer symposia, Project PEAK trains LEA teams on effective autism assessment and service provision practices. More than 70 teams have been trained and receive follow-up support each year. Project PEAK provides trainings for families and school personnel, including a two-day course for paraprofessionals and teaching assistants. Direct consultation and other TA is also provided to schools.

Other examples include *California's* new ASD Resource Project, supported by the Part C lead agency, which provides customers and families with a comprehensive collection of information on ASD. Initiated in 2007 with SEA funds, the *Oklahoma* Autism Network provides training, information and resources for persons with ASD, families, and professionals. Workshops for families and community organizations, links to effective practices literature and a resource center are among the Network's offerings.

Consultation

Missouri's Project ACCESS offers two tiers of autism consultation to schools. These services are available on a statewide basis. A network of trained *Missouri* Autism Consultants (MACs) provide on-site consultations to LEAs, while In-District Autism Consultants (IDACs) serve in a consulting capacity at the discretion of their LEAs and do not provide consultation outside their LEAs. The SEA has recently redoubled efforts to ensure that all MACs and IDACs are continuing to receive the most up-to-date information on effective practices for serving this challenging population.

Spun off from its year-long training efforts, *Michigan's* START Regional Collaborative Networks (RCNs) emphasize collaboration and coordination between school systems and

among community partners to support implementation of effective practices. Each RCN links with the START Project to identify and expand effective practices, create local training opportunities and establish local resource access. Most networks began with intensive training and are sustained through monthly or quarterly meetings, with an emphasis on building local capacity through training and coaching. Through START, SEA funds support RCNs in every county. Coaches are key to implementing with fidelity research-based practices for students with ASD. Coaches who have attended intensive year-long START trainings serve a proactive and preventive function within their buildings; coach leaders, culled from existing personnel, are responsible for maintaining a flow of information between the school and START and helping address more specific barriers to implementation.

Best Practices Guidance

The development and dissemination of best practices guidelines is an important tool for improving services to children and youth with ASD. In many cases, SEA and Part C lead agencies work with other noneducation agencies and offices in the state to craft and endorse the guidelines. Their development often utilizes national expertise, such as referencing National Academy of Science research reports. States also reported consulting with professionals from research centers interdisciplinary training programs supported by the U.S. Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau.

The *California* Department of Developmental Services (DDS), the Part C lead agency, created an ASD initiative in 1997 in response to the increasing numbers of persons diagnosed with ASD. As part of a larger governor's initiative that provided some direct funding, DDS has taken a leadership role in the development of a series of best practices documents on three topics: screening, diagnosis and assessment of ASD in 2002; inter-organizational collaboration in 2008; and effective interventions, final publication of which is anticipated in 2009. Recommendations from two high-profile groups have affirmed the need for the best practices guidelines on effective interventions for persons with ASD. The Superintendent's Autism Advisory Committee, which is education-focused, was charged with facilitating the development of consistent, evidence-based educational services for students with ASD. Its final report, which was submitted to the state legislature and the governor in November 2007, included recommendations for policy, TA and training, and establishing a statewide clearinghouse. The *California* Legislative Blue Ribbon Commission on Autism, established to identify the gaps in programs, services and funding for ASD, presented final recommendations to the state legislature and the governor in September 2007. The work of these two groups prompted the passage of eight ASD bills in the state legislature, some of which survived final executive approval.

Missouri stakeholders have sought the development of best practice guidelines for educational assessments and interventions to "help bring consistency in the therapies and methodologies used by local school districts." *Missouri's* legislature formed a Blue Ribbon Panel on Autism which heard testimony, developed findings and made recommendations to provide a better system for individuals and their families affected by ASD. The panel's December 2007 report made recommendations for a comprehensive, coordinated system of care, adult services, health care, developmental supports, education and training. Recommendations included refining the eligibility criteria and evaluation process for participation in early intervention, improving the transition between Part C and preschool and adding curricula to teacher education programs that are specific to ASD and the

management of behavior problems encountered with this population. Another outcome of the Panel's recommendations was the passage of state legislation establishing an ASD Commission. Tasked with developing a comprehensive statewide plan for an integrated system of training, treatment and services for individuals of all ages with ASD, the Commission began meeting in late 2008 and is to make preliminary recommendations by July 2009.

Early Identification Efforts

Attention to early identification of ASD was a component of initiatives reported by survey respondents from 19 agencies. Several states consider a medical diagnosis of autism an automatic eligibility for early intervention services. Some states have focused attention and training on establishing standardized screening protocols and procedures, while others have concentrated on assessment of the youngest children. While many states' efforts work to improve early identification of children ages 18 to 36 months, some Part B agencies are making efforts to better identify preschool children with high-functioning ASD. In many cases, initiatives to improve screening and early identification are joint efforts between Part C, Part B and other health, human services, developmental disability and mental health agencies. In some states, health care providers play a pivotal role in early identification of ASD and the medical community is often represented in state efforts to improve screening and diagnosis. Several states also reported use of Medicaid home- and community-based services for children with autism waivers to support intensive services to Part C-eligible children.

Missouri's Rapid Response, in part a response to the Blue Ribbon panel recommendations, works to improve early identification of children with developmental challenges, promote timely access to diagnostic and intervention services and identify family supports. A federal HRSA grant to the Thompson Center for Autism and Neurodevelopmental Disorders at the University of *Missouri* supported expansion of a pilot program to the entire state. Efforts to streamline and standardize Part C ASD eligibility are complicated by differing approaches used by medical and education personnel and by the more stringent requirements for 50% delay in this "narrow eligibility" state. The Blue Ribbon panel made several recommendations to address these perceived inconsistencies, such as allowing automatic eligibility for early intervention and special education to children who have received a medical diagnosis of ASD.

As of November 2008, *Oklahoma* screens all children entering Part C programs for ASD. The Modified Checklist for Autism in Toddlers (M-CHAT) is following by a more detailed screening if indicated. The decision to move to this approach of screening was a direct outcome of a state team attending a Centers for Disease Control Act Early regional summit. After learning of other states' early screening and identification, *Oklahoma's* interdisciplinary and interagency team revised its state autism plan, trained staff and implemented the screening approach.

California uses a statewide collaborative approach to improve screening, diagnosis and assessment of individuals with ASD. "Learning teams" of interested service providers for persons suspected of having an ASD are coordinated by regional centers throughout *California*. The 21 regional centers are private, nonprofit corporations under contract with DDS to provide services for persons with developmental disabilities and their families. The learning team members, who represent primary care providers, schools, mental health providers and academic medical centers, work together to implement selected best practice

recommendations from the screening, diagnosis and assessment guidelines. The teams have facilitated critical linkages between medical and early intervention and education professionals who are involved in screening for ASD in young children.

Another collaborative effort between the *California* SEA and the Part C lead agency was the 2004 publication of a widely-disseminated information brochure, "Reasons for Concern," that emphasizes the importance of early identification of developmental challenges. The plain language list of risk factors and behavioral and physical characteristics of concern for infants through five years of age is followed by an explanation of the next steps towards referral and assessment through the early intervention regional centers or the LEA.

The value of collaborating with medical professionals through the screening process is underscored by an effort in *Massachusetts* to develop and promote use of a Developmental Screening Tool Kit for primary care providers. Supported in part by the Maternal and Child Health Bureau and the state's developmental disability council, the tool kit provides pediatricians with a road map for selecting and using screening tools, referring to early intervention programs and billing for developmental screening services.

Michigan's ASD Planning Workgroup was initiated in 2005 to plan an integrated system of services and supports for children with ASD ages birth through six. Representatives from the Departments of Community Health, Education and Human Services, parents, advocacy groups and experts including pediatricians and the director of the START Project worked on five subcommittees to develop recommendations to assure screening for identification of children at the earliest opportunity, assure appropriate assessment and diagnosis and make available to parents a choice of evidence-based and effective treatments/interventions. The recommendations were presented in June 2007. An interdepartmental team that includes parents was charged with developing a more detailed action plan to implement the recommendations.

Direct Services

Agency support of direct intervention and educational services delivered to children with ASD was reported by 18 survey respondents in their descriptions of state initiatives. Creation of model sites and pilot programs and direct support of specialized personnel and services were most commonly reported.

Model and pilot programs

Oklahoma's Early Foundations: Autism Model and Outreach Project is a model program initiated in October 2007 to deliver intensive intervention to toddlers with ASD, ages 18 months through three years of age, including some who are receiving Part B services. Supported by the SEA, Early Foundations is a collaborative with the University of Oklahoma Health Sciences Center that provides an on-site program four days per week. Interventions include one-on-one instruction, socialization opportunities with typically developing peers, weekly home visits and monthly parent nights. Initial reception has been positive and the state is planning for replication and expansion.

An ASD pilot initiative in two *Michigan* counties is in the planning stage. Funded by the SEA and administered through intermediate school districts, the pilots will link clinical providers

with early intervention school personnel to create a Centralized Assessment Team, and promote evidence-based practices to address child, family and system outcomes.

Specialized personnel and services

California's 21 regional developmental disabilities service centers are brokers of direct assessment and intervention services for Part C-eligible children with ASD. Because developmental services are an entitlement to eligible infants and toddlers, there are no waiting lists for services. Regional centers receive referrals for screening and assessments from hospitals, pediatricians, preschool teachers, other professionals and directly from families. For older children, the SEA supports three regional diagnostic centers that provide direct assessment services upon request of a local district or SELPA. Services are provided by expert, transdisciplinary teams of diagnostic professionals who address the unique educational needs of most "difficult-to-serve" students with disabilities. Diagnostic evaluations are provided free of charge to the referring agency and are often requested in complex or unique cases. About half of the referrals received by the diagnostic centers were for ASD. The diagnostic centers also provide statewide training on topics including assessment of ASD.

Intensive behavioral interventions for young children with ASD are available through 10 programs in *Massachusetts*. The Part C lead agency specialty services program contracts with providers who deliver intensive behavioral interventions in natural environments to toddlers with diagnosed ASD. Family choice and programs including ABA and "floor time" approaches are emphasized. More than half of the children receive between five and 10 hours of individual intervention weekly, but as many as 27 hours have been offered. On average, toddlers are 25 months of age at entry to intensive services, though many receive other standard early intervention services earlier. Growth in enrollment for the intensive services has been phenomenal and has resulted in a re-examination and enforcement of more stringent eligibility criteria.

For older students with ASD, *Massachusetts'* Inclusive Concurrent Enrollment (ICE) grant supports partnerships between community colleges and LEAs to provide post-secondary training opportunities for competitive employment. Grants are awarded to partnerships of IHEs and LEAs to implement model inclusive education practices and programs for students ages 18-22 who have severe disabilities and have been unable to pass the state competency exam necessary for high school graduation. Some students with moderate and high functioning ASD have participated in the ICE program which emphasizes person-centered planning, linkages to adult agencies and organizations and academic, functional and social skills.

SUMMARY

Significant attention in the last several years has been focused on the rapid growth in identification of children with ASD and on approaches to best serve their often intensive needs. State agencies are using a variety of approaches to address the early intervention and special education needs of this challenging population. Among the most common approaches supported by Part C lead agencies and SEAs are professional development initiatives to improve training of inservice professionals who serve children with ASD and TA efforts through state resource centers, direct consultation and development and dissemination of best practice guidelines. The importance of early identification of children who may have ASD is emphasized in many states' initiatives. While much attention is placed

on screening and assessment of children age 18 months to three years, there are also efforts to improve the transition between early intervention program and preschool special education services. Collaborative, interagency and interdisciplinary efforts appear to be key to early and efficient identification of the youngest children with ASD. States are playing a greater role in supporting the provision of direct services to this population. Because services to high-need children and youth with ASD are often resource-intensive, state funds are used to subsidize and sustain pilot programs, model sites, specialized personnel and individualized services.

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NASDSE, 1800 Diagonal Road, Suite 320, Alexandria, VA 22314
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