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AMCHP Issue Brief

Environmental Scan: State Title V Program Response to Autism Spectrum Disorder and Other Developmental Disabilities

INTRODUCTION

The increasing incidence of children identified and diagnosed with Autism Spectrum Disorders (ASD) and other developmental disabilities (DD) poses a major challenge to Title V and other programs as they try to meet the diverse and sometimes complex needs of these children. However, those states that have initiated coordinated efforts to meet the needs of these children across systems have had the opportunity to form and/or strengthen relationships with new partners. In addition, these coordinated efforts will allow states to develop new policies, programs, and financing mechanisms addressing the health of children with ASD, which may also strengthen the system of care for all Children and Youth with Special Health Care Needs (CYSHCN).

This issue brief summarizes findings from the Association of Maternal & Child Health's (AMCHP) environmental scan of state Title V autism activities using information collected from three sources: 1) interviews with state MCHB-funded Combating Autism Awareness Initiative demonstration grantees; 2) summaries from the state action plans developed through Centers for Disease Control (CDC)/Association of University Centers on Disabilities (AUCD) -supported Learn the Signs Act Early Regional Summits; and 3) the Title V Information System. Information from this environmental scan is intended to capture key opportunities and challenges that states are currently facing as they work to strengthen systems of care for children and youth with ASD and DD. These findings will also supplement AMCHP's support of state efforts to improve systems and services for all CYSHCN. As part of the environmental scan, AMCHP collected opportunities and challenges around six key topics of concern in states: 1) Screening and Diagnosis; 2) Care Coordination/Medical Home; 3) Family Involvement; 4) Access to Services; 5) Health Care Financing and Coverage; and 6) Transition. Please note that the issues and findings here are meant to be preliminary and by no means represent a comprehensive scan of autism activities.

In reviewing these findings, it may appear that some of the opportunities and challenges contradict each other.

Depending on a state's system of care, the strengths of one state (e.g. financing mechanisms) may represent another state's toughest challenge. Such contrasts between states underscore the importance of ongoing communication between state Title V programs as well as the need for the continued collection and dissemination of best practices for serving children with ASD and DD.

SCREENING AND DIAGNOSIS

Research on children with ASD has demonstrated that in many cases, early screening and diagnosis particularly by the age of three can lead to improved developmental outcomes. Some Title V programs are taking a lead in providing and/or coordinating neurodevelopmental screening for children suspected of ASD, or are providing training to providers on screening. However, Title V programs are challenged in finding enough pediatric specialists with the training to provide appropriate screening and diagnostic services.

Opportunities: States recognize that the education and training of health care providers is one of their primary roles in addressing the identification and screening of children with ASD and DD. At this point, states have developed training programs for pediatricians, primary care physicians, and family physicians for the screening, diagnosis, and early intervention of infants and toddlers with ASD and other DD. Training strategies include providing autism screening and diagnosis information to medical students in residency programs, supporting Grand Round lectures, and creating online modules. In addition, some states have worked with local universities to create graduate level training programs for ASD. States have also tried to focus education and training initiatives on families, educators and health care providers at the local level. For example, in an effort to reduce wait time for diagnoses and to more effectively diagnose rural and underserved populations, several states have developed a team of professionals that are able to provide a rapid diagnosis to families in their communities. Other successful state efforts include creating online screening tools for parents, encouraging screenings in preschool settings, and developing written guidelines around best practices for screening, diagnosis, and assessment.

Challenges: Nearly all states note the lack of qualified professionals to diagnose and treat infants and children with

ASD and other DD. States report the need for more developmental pediatricians and other specialists who work with ASD because currently qualified providers are overwhelmed by wait lists and high demand. Additionally, many states struggle to engage physicians and motivate them to participate in trainings and utilize their resources. As a result, states have requested more efficient and effective training tools to build the capacity of physicians and educators to better diagnose and care for infants with ASD and other DD as well as effective practices to encourage primary care physicians and pediatricians to screen children. The lack of data on the numbers of children with autism in each state is challenge for state programs trying to plan and develop a system of care. States report inaccurate data around the rates of diagnosis due to poor surveillance and inconsistent data collection. In addition, differing eligibility criteria across state programs for children with ASD and other DD poses coordination challenges. States stressed the need for uniform screening and diagnosis criteria that can be used statewide.

CARE COORDINATION/MEDICAL HOME

The broad spectrum of behaviors and needs for children and youth with ASD and DD require access to and coordination of services between multiple systems and providers. Ideally, at the center of this coordination, is the medical home. Nearly all states have some type of initiative in place to promote the core outcome established by MCHB of ensuring that "children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home." Care coordination is an integral piece of comprehensive quality care provided within the medical home model for CYSHCN and focuses on the broad range of services that are needed by a child with a complex medical condition.

Opportunities: States feel that the development of current medical home initiatives and collaboratives will positively impact the care children and youth with ASD receive by implementing standards of care among physicians who care for children with ASD. Several states have incorporated ASD directly into their medical home initiatives. Other states have created interagency task forces to encourage collaboration, facilitate cross training among agencies, and coordinate programs and research around the care for children and families affected by ASD. One state developed a local program that promotes a "consultative" relationship between different entities that care for children with ASD, such as the primary care physician and the school. Many states have begun to use tools that measure the use and quality of medical homes, but these tools have yet to be standardized across systems. Additionally, some states have formed partnerships with a variety of programs and institutions within their states, including early childhood training centers, community based organizations, parent support groups, universities, public and private hospitals, and state departments of education. States have developed interagency committees or councils that bring together representatives from these various groups to address critical issues related to ASD and DD.

Challenges: Nearly all states commented on a lack of coordination and communication between systems and providers. States note that systems for CYSHCN are fragmented, reporting inconsistent levels of care and services provided to families and large "knowledge gaps" about ASD between professionals and families. States also shared the need for guidelines around care coordination to ensure delivery of high quality and consistent services. In order to provide more complete and coordinated care to all families, states note that educational, behavioral health, and medical programs must standardize the eligibility requirements and services. States also highlighted the need for improved collaboration between educational and medical approaches and the importance for improved interagency communication to minimize the duplication of services, training initiatives, and advocacy efforts. While many training programs are successful, states comment that hosting statewide interagency training initiatives to include health, education, and mental health professionals would increase interagency coordination while ensuring that all groups have the same basic understanding of ASD and available services. States are struggling to find appropriate tools to measure and monitor the effectiveness of care coordination and medical homes.

FAMILY INVOLVEMENT

Parents and families of children and youth with ASD and DD play many roles in caring for their child including advocate, coordinator, and educator. At the practice level, family-centered care is an approach to the planning, delivery and evaluation of health care that recognizes that vital roles that families play in ensuring the well-being of their child. At the program level, family involvement refers to a range of activities that involve families in the planning, development, and evaluation of programs and policies—which is particularly important in ensuring that programs meet the diverse needs of children with ASD and their families.

Opportunities: Most states commented that their strongest successes lay in the programs created by parents and families. For example, the development of parent support groups for ASD has created an effective network to deliver information to families and provide advice and support. In addition, parents groups have developed effective advocates to lead local and state policy and legislative initiatives affecting children with ASD. In order to further develop the potential of families as leaders and advisors, some states have begun to develop tools to train family support staff (referred to in some states as family navigators) to reach more families and expand their roles. At the community level, providers have supported families by funding parent education initiatives and making "survival" manuals and resource guides easily available for families online, in print, and in multiple languages.

Challenges: Families need support to meet the needs of children, youth, and adults with ASD and DD. States expressed a need for better family resources and training programs for parents with information provided in a more user and family-friendly format. States also noted that families still need assistance in sifting through the voluminous information available on autism, and, in particular, need assistance in understanding the role of evidence-based research/therapies versus other autism therapies. In addition, states cited the need to build resources to better assist families in understanding their rights to education, transportation, respite, and other services.

ACCESS TO SERVICES AND EVIDENCE-BASED PROGRAMS

Autism is a particularly challenging and complex disability because if affects each child uniquely. As a result, therapies to treat ASD have different outcomes depending on the child. The rising incidence of ASD has put a strain on existing services available to children with ASD as well as given rise to a variety of controversial approaches to treating autism—confusing families and stressing service providers particularly in underserved areas.

Opportunities: States want to improve the use of evidence-based programs by increasing the dissemination of best practices and the development of evidence-based best practice guidelines for physicians. To ensure that children and youth with ASD receive quality care based on effective methods, some states have created service guidelines for children with ASD based on evidence-based information. Other states host annual statewide conferences around supported evidence-based practices for children with ASD. Some states also utilize online searchable databases that help families find providers and service referrals. Additionally, parent support groups and networks serve as effective tools for helping families receive appropriate and needed services. States are also working to improve the ease and timeliness of receiving services.

Challenges: Overcoming disparities emerged as the biggest challenge for states in improving families' access to services. States reported geographic disparities in resources and provider shortages in rural areas as well as social, racial, and cultural disparities in the quality and type of care families receive. Families, according to states, often have uneven access to services with disparities between the needed services and the care actually received. Long waiting lists and delays in receiving services or seeing a physician, especially for diagnostic services, also represent large obstacles in families' access to care. States also have noted difficulties in establishing a initial point of contact with concerned families as well as families' confusion when trying to access evidence based interventions. States also note the lack of services and systems for adults with ASD, as well as a shortage of programs that support respite care for families and caregivers.

FINANCING OF CARE

Children and youth with ASD and DD require access to a range of health, education and related services. In many cases, insurance coverage is insufficient or capped. This lack of sufficient coverage from insurance and/or public programs such as CHIP and Medicaid, severely strains family budgets, adding additional stresses to families already coping with the challenges of caring for their child.

Opportunities: While no state has or even claims to have an ideal financing system of care for this population, some states have passed legislation requiring insurers to cover services for children and youth with ASD and DD, including behavioral therapies. In addition, states have also worked hard to get approval for Medicaid and insurance waivers that will make required services for ASD and DD more affordable for families.

Obstacles: Despite successes in Medicaid and insurance waivers, states report long wait lists for the waivers. In addition, states cited the need to raise reimbursement rates for providers who serve children with ASD. Additionally, states comment that ASD services are not adequately financed in relation to the demand for services, which exceeds Medicaid's capacity. While many families cannot afford all the care their child may need, even with insurance coverage, states report a large portion of families who do not even know about the existing and available funding for services.

TRANSITION

Among youth with ASD, transitioning in adulthood in terms of both health care and care planning/secondary education has added complexities. In addition, large numbers of children diagnosed with ASD are now entering adulthood further straining an already challenged transition system. The issue of transition repeatedly comes up as a major issue in addressing the needs of children with ASD; however, states acknowledge that much work needs to be done in this area particularly in expanding services to help youth with ASD find appropriate adult health care providers.

Opportunities Some states are recruiting and training youth and young adults with ASD to participate in youth task forces and advisory committees looking at transition issues for youth with special health care needs. As part of their participation, these youth will receive training around such issues as advocacy, medical home and transition issues. In addition, some states have developed specialized trainings around transition to adult services for families and youth with ASD including how to develop detailed action plans for families and their providers. Nearly all states grantees have asked for technical assistance in this area.

Obstacles: While states comment that transitions for children and youth with ASD and DD are particularly difficult, most programs and services do not focus on such transitions or lifespan supports. Transitions between schools and into adult

services are particularly challenging with states noting the importance of identifying obstacles to transitioning services.

CONCLUSION AND NEXT STEPS

The complexity of ASD as well as the uniqueness of autism in each child presents difficulties to state systems trying to address the needs of these children and their families. However, states also acknowledge that if they can meet the challenge of strengthening the system of care for these most complex children, they will almost certainly strengthen the system of care for all CYSHCN.

To further the work of Title V agencies addressing the needs of children with ASD, AMCHP will continue to collect and distribute information about the work state Title V agencies are doing to improve systems of care for children and youth with ASD and DD including 1) providing mentorship to states on key issues; 2) developing policy frameworks; 3) providing technical assistance calls on key issues; 4) sharing and highlighting state successes and promising practices, and 5) facilitating learning and dialogue between states.

Visit the SPHARC Website
For resources, promising practices, and state snapshots, visit the State Public Health Autism Resource Center (SPHARC) on AMCHP's website at www.amchp.org/SPHARC. SPHARC is a comprehensive web-based resource center intended to provide ongoing technical assistance for children, youth, and families with Autism Spectrum Disorders and other Developmental Disabilities. SPHARC is a tool designed to help facilitate ongoing peer to peer networks and timely exchanges of resources and information.

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