

## ROLES FOR STATE TITLE V PROGRAMS

### *Building Systems of Care for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities*

#### State Examples

The following state examples reflect activities in states funded by *State Implementation Grants for Improving Services for Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities* (referred to in the document as State Autism Implementation Grants) through the Combating Autism Act.

##### **Alaska: Combining Forces for Improved Screening**

In Alaska, the Governor's Council on Disabilities and Special Education served as the initial leader and joined forces with the state of Alaska Title V program to recognize the rapidly emerging need to serve Alaskan children with autism. An Autism Ad Hoc Committee was formed in 2004, and by 2006, a state plan was developed to improve state systems of care for this population. With a focus on infrastructure development, the Ad Hoc Committee identified five target areas as essential for long-term improvement of systems of care for Alaskans with ASD/DD. These include universal screening; diagnostic clinic expansion; resource, referral and training; workforce development; and time-limited early intervention services. The plan has provided a platform for multiple agencies and stakeholders to deliberately and collaboratively address needs and gaps in the system of care for Alaskans with ASD/DD.

#### EXECUTIVE SUMMARY

The increasing numbers of children identified and diagnosed with autism spectrum disorders and other developmental disabilities (ASD/DD) poses a major challenge to state Title V maternal and child health (MCH) and children and youth with special health care needs (CYSHCN) programs as they try to meet the diverse and often complex needs of these children and their families. This incidence has led to a demand on states to increase their focus on developing and implementing systems to assure that all children and youth with ASD/DD receive early and timely identification, diagnosis and intervention services. Because of these varied needs, no one single agency can accomplish the systems changes needed to ensure that all children and youth with ASD/DD receive early and comprehensive screening, diagnosis and treatment. As a result, state Title V programs that have initiated comprehensive efforts to meet the needs of children and youth with ASD/DD and their families have used this opportunity to form and strengthen interagency and interorganizational partnerships. These coordinated efforts may allow states to develop new policies, programs and financing mechanisms that could strengthen the system of care for all CYSHCN.

The framework in this document is designed to help states determine appropriate roles and approaches to pursue in building, improving, and sustaining their system of care for children and youth with ASD/DD and their families. While the framework is primarily targeted to state Title V CYSHCN programs, the recommendations are applicable to other state agencies and groups (e.g. Medicaid, Children's Health Insurance Program (CHIP), Developmental Disabilities, Early Intervention, providers and families). The Association of Maternal & Child Health Programs (AMCHP) encourages states to use the roles and examples in this framework to help determine the most appropriate activities for their state.

#### Challenges in Meeting the Needs of Children and Youth with ASD/DD and Their Families

In addition to the challenges states face in dealing with rising numbers of children identified with ASD/DD, autism manifests differently in each child, which may complicate early identification and diagnosis. The services and treatments needed for each child may vary considerably depending on the severity of the condition, as well as other co-morbidities. States face challenges in addressing the variability of ASD/DD; as well as cultural, linguistic and socio-economic considerations; uncertainty in the causes and treatment of ASD/DD; training providers to screen for ASD/DD; service system overlaps; lack of comprehensive surveillance data; and adequate financing for services and therapies that these children and their families may need.



## Roles for State Title V Programs in Building Systems of Care for Children and Youth with ASD/DD

State Title V programs can play an essential role in providing the leadership for interagency/interorganizational partnerships that are needed to create systems change. This is especially important for ASD/DD where it can be challenging to build consensus among multiple advocacy groups and agencies, particularly between those who may feel it is important to develop a system of care for children and youth with ASD/DD separate from other CYSHCN programs. Among families and providers, many state Title V programs have the credibility, reputation, and authority to bring together diverse groups and agencies (e.g. Medicaid, CHIP, Developmental Disabilities, providers and community health centers) at the state and local level to ensure a focus on family-centered care, evidence-based practices and quality improvement. While certain state Title V CYSHCN programs may provide some type of direct services, including screening and diagnosis, clinic services, and/or care coordination for children and youth with ASD/DD, state Title V programs may want to consider involvement beyond direct services and examine their roles in the context of the six critical indicators (medical home, insurance and financing, early and continuous screening, easy-to-use services, family/professional partnerships, and transition) developed by the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) to measure the quality of a system of care for CYSHCN.

### State Examples

#### **New York: Linking Pediatricians to Screening/Referral**

The New York State Department of Health (NYSDOH) Bureau of Early Intervention, through the State Autism Implementation Grant, is working with the American Academy of Pediatrics (AAP) New York Chapter, which represents over 4,500 pediatricians, to improve and increase screening for ASD/DD and provide appropriate referrals to local early intervention programs. NYSDOH and the AAP chapter convened joint meetings in three regions of New York to educate physicians about the signs of ASD/DD and the important role of the physician in early intervention. Additionally, NYSDOH is developing an online portal for pediatricians and family physicians to serve as a clearinghouse of relevant local, state and national ASD/DD resources, and to support pediatricians' efforts to screen and make appropriate referrals in their communities.

#### **Rhode Island: Developing Screening Guidelines for EPSDT**

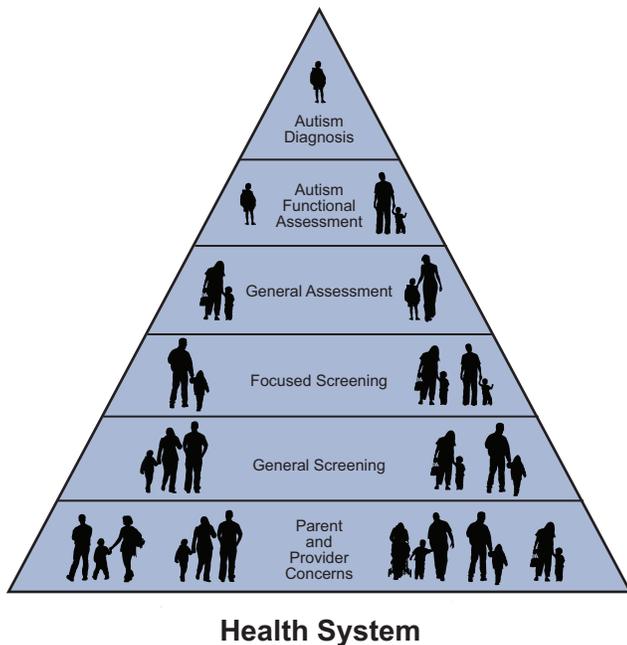
The Rhode Island Department of Health is legislatively mandated under the Rhode Island Autism Spectrum Disorder Evaluation and Treatment Act to provide guidance to the medical community concerning appropriate testing and screening models. The Rhode Island Medicaid Early Periodic Screening, Diagnosis and Treatment (EPSDT) schedule was recently revised to include developmental surveillance, developmental screening, ASD/DD screening, and all American Academy of Pediatrics (AAP)/Bright Futures recommended well-child visits. Rhode Island implements developmental and ASD/DD screening through a Successful Start Early Childhood Initiative – *Watch Me Grow*. *Watch Me Grow* provides technical assistance and implementation support to pediatric primary care practices on developmental and autism screening that is currently implemented in Pediatric Practice Enhancement Project practice sites, other pediatric medical practices, and child care sites throughout the state.

#### **New Mexico: Influencing Payment Systems**

The New Mexico State Autism Implementation Grant addressed payment systems for both the private and public sectors. In 2009, the New Mexico legislature passed an insurance mandate to ensure adequate coverage for children with ASD/DD for diagnostic and intervention services. The law mandates private health insurance plans in New Mexico cover the diagnosis and treatment of ASD/DD for children to age 19 or through the age of 22 if they are still attending high school. Benefits are capped at \$36,000 a year, with a lifetime cap of \$200,000. The law also states that insurers can not terminate or restrict coverage based on a diagnosis of ASD/DD.



## Tiers to Diagnosis and Referral of Other Disorders



### State Title V and Partner Capacity Building

As states begin to strategically evaluate their roles in building and sustaining a system of care for children and youth with ASD/DD and their families that addresses the core CYSHCN critical indicators, it may help to evaluate their roles by looking at both leadership and capacity. There are tools available to assist states in this assessment. The Title V index, developed by state Title V CYSHCN leaders participating in a learning collaborative, addresses broad capacity by *leadership areas*, while the ASD/DD Continuum of Involvement looks at capacity by *level of involvement*.<sup>1</sup> Because systems change for children and youth with ASD/DD often affects several CYSHCN critical indicators, these frameworks may be useful to states.

The Title V index addresses leadership in six areas of involvement: 1) overall leadership, 2) partnerships across public and private sectors (which includes families), 3) quality improvement, 4) use of available resources, 5) coordination of service delivery, and 6) data infrastructure. Two additional areas have been added to address specific ASD/DD issues: the initiatives in outreach/awareness and family participation, which highlights importance of family leadership and involvement.

The state examples included in this document primarily reflect activities in states funded by the HRSA *State Implementation Grants for Improving Services for Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities* through the Combating Autism Act. In nine states (Alaska, Hawaii, Maine, New York, Rhode Island, Utah, Vermont,

### Washington: Partnering with Leadership Education in Neurodevelopmental & Related Disabilities (LEND) for Earlier Screening

In Washington State, Title V, the state LEND program and the grant's Combating Autism Advisory Council combined to develop a Multidisciplinary Team Summit that brought together health professional teams from all over the state to look at strategies to increase early identification of children with ASD/DD. The year one summit yielded the concept for the Tiers to Autism Spectrum Disorders Pyramid tool (see health system example)<sup>2</sup> and led to the Community Asset Mapping project in eight counties. The tools are used to walk the communities through the process of identification of strengths/assets or gaps for local screenings, assessments, and referrals for services across health, education and mental health systems. These tools and visuals are an important part of people understanding how different systems cross and can work together to promote early screening and intervention at the community level and control the referrals to a limited number of autism specialists.

### Missouri: Using Data to Find Families and Determine Service Needs

Missouri participated in the CDC Autism and Developmental Disabilities Monitoring Network (ADDM). This research revealed that Missouri has one of the highest ASD/DD prevalence rates in the country, with more than one percent – one in every 83 children – identified with ASD/DD in the St. Louis area. These data led Missouri to focus its *Learn the Signs. Act Early.* project on reaching children and families residing in St. Louis City.

### Wisconsin: Increasing Awareness Virtually

Wisconsin has expanded its medical home webcasts to make them available to more audiences, especially those serving children and youth with ASD/DD. The webcasts have been an excellent way to archive topical presentations and make them available to all at no cost. Wisconsin has held one half-day webcast and has plans for a second webcast in the spring. The webcasts are geared toward primary care providers and include the following topics: care coordination in the medical home, general oral health, oral health with special health care needs or sensory issues, evidence-based practices, developmental screening in child care settings, waiver/diagnosis/insurance benefits, typical child development based on Early Learning Standards, detection of child abuse, social-emotional development and Children's Long Term Services.



Washington and Wisconsin), the state Title V programs serve as the lead for autism activities, while in four states (Illinois, Missouri, New Mexico and New Jersey) an organization outside of the state Title V program serves as the lead, with Title V as a key partner in their statewide efforts. The examples in this document are drawn from all 13 grantee states, reflecting the importance of state Title V programs as leaders and/or partners.

## What Does This Mean for My State?

State Title V programs are working with key partners in their state on a variety of critical activities in building systems of care for children and youth with ASD/DD spanning all CYSHCN core outcomes and a range of leadership competencies as leader, partner and facilitator. From education and training to developing guidelines and standards, state Title V programs are offering their essential expertise to address the needs of a complex and growing population of children and youth with ASD/DD. State Title V programs are engaging with a wide range of partners using a variety of approaches and mechanisms to address the specific needs of children and youth with ASD/DD in their state. At the family, provider and systems levels, state Title V programs are working with partners to change practice to identify children earlier using best practice guidelines for screening and services. They are working with partners to make public and private resources work to meet the needs of families through waivers, insurance mandates and best practice guidelines, and are trying to develop a more comprehensive picture of the number, location, and service needs of children and youth with ASD/DD in their state. The attention and resources now focused on ASD/DD offer state Title V programs an opportunity to participate in the development of a stronger system of care, ideally one that will benefit all CYSHCN and their families.

<sup>1</sup> National Initiative for Children's Healthcare Quality (NICHQ), Title V Index, <http://www.nichq.org/CYSHN/index.html>

<sup>2</sup> The Association of University Centers on Disabilities (AUCD), Act Early Region X Summit, Washington State, [http://www.aucd.org/template/event.cfm?event\\_id=2067](http://www.aucd.org/template/event.cfm?event_id=2067)

For additional information about the AMCHP State Public Health Autism Resource Center (SPHARC), please contact Treeby Brown, Senior Program Manager, CYSHCN at [tbrown@amchp.org](mailto:tbrown@amchp.org) or Melody Cherny, Program Associate, CYSHCN at [mcherny@amchp.org](mailto:mcherny@amchp.org).

The full report is available online at [amchp.org/programsandtopics/CYSHCN/resources/Documents/AutismPolicyProfile\\_10-20-11.pdf](http://amchp.org/programsandtopics/CYSHCN/resources/Documents/AutismPolicyProfile_10-20-11.pdf).



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