



## ROLES FOR STATE TITLE V PROGRAMS

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

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#### 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 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 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.



## INTRODUCTION

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. This is particularly true with regard to children and youth with ASD/DD from minority or immigrant populations, who are less likely to be identified early, if at all, and who often have a more difficult time accessing appropriate and sufficient services. 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 take in building, improving, and sustaining their system of care for children and youth with ASD/DD and their families. While 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). In reviewing the framework, please keep in mind that it will be revised as changes to the delivery system occur, especially in light of the Affordable Care Act of 2010 and as new knowledge about serving children and youth with ASD/DD emerges. AMCHP encourages states to consider the roles and examples presented in this framework to help determine the most appropriate activities for their state.

## ABOUT AMCHP

The Association of Maternal & Child Health Programs is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth and families, including those with special health care needs.

AMCHP supports state maternal and child health (MCH) programs and provides national leadership on issues affecting women and children. We work with partners at the national, state and local levels to expand medical homes, provide and promote family-centered, community-based, coordinated care for children with special health care needs and facilitate the development of community-based systems of services for children and their families.

[amchp.org](http://amchp.org)

The AMCHP State Public Health Autism Resource Center (SPHARC) is a comprehensive resource center for state Title V programs and others interested in improving systems of care for children, youth and families with autism spectrum disorders and other developmental disabilities.

[amchp.spharc.org](http://amchp.spharc.org)

## BACKGROUND

Autism is a complex developmental disability that typically appears during the first three years of life and affects a person's ability to communicate and interact with others. It is defined by a certain set of behaviors that affects individuals differently and to varying degrees, and is often grouped with similar disorders, all of which may be referred to collectively as autism spectrum disorders (ASD), which are life-long conditions.<sup>2</sup> Researchers have observed an increase in the proportion of children diagnosed with ASD in the past decade. It is not clear how much of the observed increase is due to improved diagnostic procedures and detection or to a true rise in the number of cases.<sup>3</sup> A recent estimate from the Centers for Disease Control and Prevention (CDC) says that one out of every 110 children has an ASD.<sup>4</sup> Autism is four times more likely to affect boys than girls. There is no cure for ASD/DD; however, research shows that children with ASD/DD are greatly helped if they receive appropriate early intervention services, including educational therapies, behavioral intervention and some medications.<sup>5</sup>

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

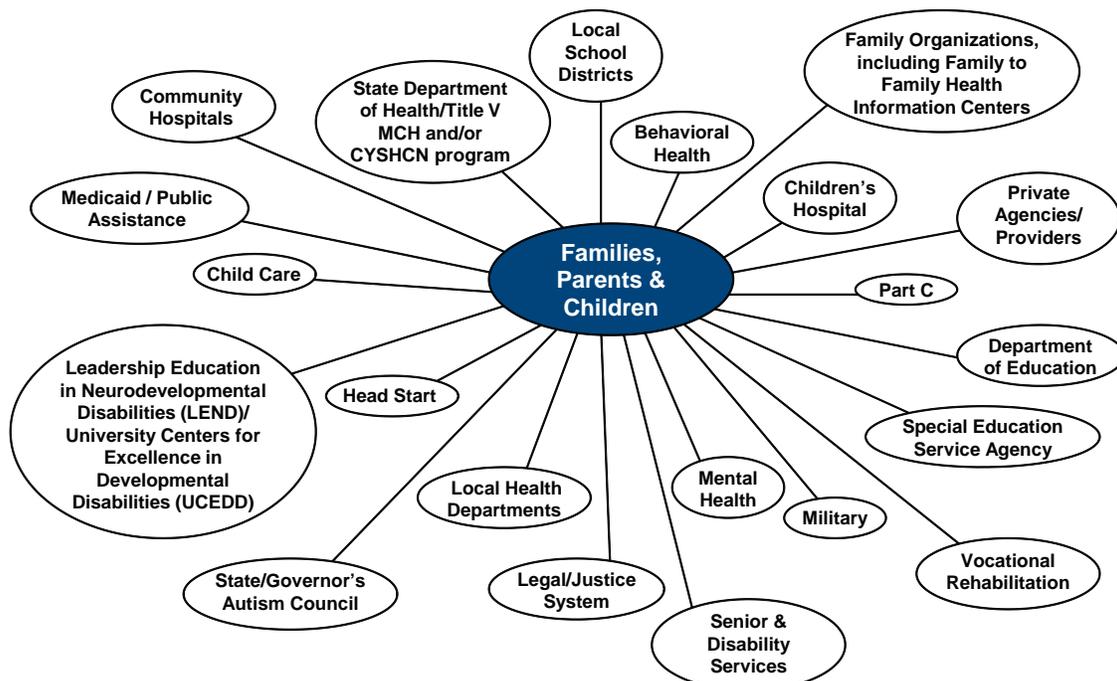
In addition to the challenges states face in dealing with the rising numbers of children identified with ASD/DD, autism manifests differently in each child, which can complicate early identification and diagnosis. The services and treatments needed for each child may vary considerably depending on the severity of the condition, as well as other co-morbidities.

**Variability of ASD/DD:** The variability related to ASD/DD in terms of both the age of the child and their functional level impacts roles and responsibilities for Title V and other state programs. A young adult with autism and a high IQ but significant social impairments has very different needs than a three-year-old with autism who also has a significant intellectual disability/cognitive impairment. Children and youth with ASD/DD and their families may require a broad array of developmental and behavioral services based on age and functional level. Services targeted to persons with ASD/DD can include: screening, diagnostic assessment, functional assessment, information and referrals, early intervention (autism), behavioral support, applied behavior analysis, in-home care, skill training/acquisition, parent training and education, respite care, case management, service coordination, supportive housing, supportive employment, self-directed services, and other specialized services (see visual below).<sup>6</sup>

**Cultural, Linguistic and Socio-Economic Considerations:** Several studies have examined racial disparities in the diagnosis of ASD/DD. These studies suggest that white children are more likely to receive an autism diagnosis and more likely to receive it at an earlier age than children in other racial groups. One study found that, "white children received the diagnosis 1.4 years earlier than African-American children."<sup>7</sup> Another study suggested that "many factors besides patient's actual signs and symptoms are influencing diagnosis" and went on to specify that "ethnicity, race, evaluator types, region, and urbanicity all significantly influence initial diagnosis."<sup>8</sup>

Further studies show that the presence of an intellectual disability can inhibit the diagnosis of autism and thus disqualify

## Network of State and Local Programs that Children and Youth with ASD/DD and Their Families May Need to Access



a child for any services that are designated only for children with ASD/DD. Intellectual disability is present in 50 to 60 percent of children with more severe autism and, in cases where both disabilities exist, the primary diagnosis can have a major effect on the types of services and supports that children will be able to access.<sup>9</sup> At the same time, families can encounter challenges in accessing services when a child presents with a diagnosis of autism without intellectual disabilities. In addition, the limited availability of trained developmental screening and service providers who speak languages other than English can impact screening and access to services for non-English speaking families and families from other cultures.



**Uncertainty in Causes/Treatment:** Families may face considerable stress due to both uncertainties about the causes of ASD/DD, as well as uncertainty about the efficacy of treatments. Wait times for initial diagnoses vary considerably depending on the availability of developmental screening and the extent of its use by primary care providers. At the same time, the increasing incidence of ASD/DD has given rise to a variety of approaches to treating autism, some controversial, confusing both families and providers. Even when there is clarity on the diagnosis and a needed treatment plan, the services may not be adequately funded through a family's health plan or by public funding mechanisms.

**Screening:** For state Title V programs that provide developmental screening as part of their services, the rise in numbers of children needing to be screened will continue to place a burden on already scarce resources. State Title V directors and staff note that the uniqueness of ASD/DD in each child presents difficulties for local providers in identifying and diagnosing ASD/DD. State Title V directors and autism grantees

consistently remark that additional training for providers in identifying ASD/DD is necessary to provide children and their families the services and supports they need in a timely manner.

**Service System Overlaps:** The needs of children and youth with ASD/DD often straddle the medical and behavioral health systems (service systems that are not always coordinated). In addition, the behavioral issues associated with ASD/DD often mean that their needs also extend into the education system. Navigating these three systems poses additional challenges for families already dealing with a fragmented system of health care where specialty services are not coordinated with primary care or other community-based services, and coverage for services is not comprehensive. Dealing with the education system adds an additional layer of coordination, complication and potential stress for families.

**Data Gaps:** At the state level, planning for services is hindered by a lack of surveillance data on numbers of children and youth with ASD/DD. Many states do not have adequate data on the numbers of children and youth in the state with ASD/DD, especially specific information about age, location and level of functioning. While the CDC has funded surveillance programs in 14 sites (including one located at the CDC) through the Autism Developmental Disabilities Monitoring Network (ADDM) in order to determine the number of people with ASD/DD in the United States, it does not yet have a nationwide reach.<sup>10</sup>

**Financing:** Children and youth with ASD/DD require access to a range of health, education and related services. However, coverage for these services from private insurance and/or public programs such as CHIP and Medicaid is often limited, with long lists for waiver programs, if they are available. For state programs serving children and youth with ASD/DD, the ability to fund diagnostic and treatment services through Early Periodic Screening, Diagnosis and Treatment (EPSDT)<sup>11</sup> or other mechanisms may be hindered by state rules and regulations that limit the type of provider who can deliver a particular service. State programs also may face confusion on how to develop a process to determine whether a treatment is evidence-based and, if so, whether it should be covered in public plans. For private insurance, coverage for ASD/DD-related services can be even more limiting, leading some state autism leaders to push for state-level insurance mandates.

## Background on State Title V CYSHCN Programs

Within each state, Title V Maternal and Child Health (MCH) and Children and Youth with Special Health Care Needs (CYSHCN) programs are charged with providing “family-centered, community-based, coordinated care.” Authorized by Title V of the *Social Security Act*, the Title V Maternal and Child Health Services Block Grant supports the capacity of MCH programs to provide services in every state and territory. Consisting of state MCH and CYSHCN programs, Title V supports efforts within both the public and private sectors to shape and monitor health-related services for women, children and youth. Although several state programs may provide services for CYSHCN, state Title V programs often have the greatest expertise in reaching the CYSHCN populations, the strongest connection to networks of pediatric specialists, and the best data on the service needs of CYSHCN and their families. They are also most likely to have meaningful relationships with family organizations comprised of parents of CYSHCN, such as Family Voices affiliates, Family to Family Health Information Centers and Parent to Parent programs, among others.

The specific structure of state Title V CYSHCN programs varies considerably across states. Some state Title V programs have moved away from delivering direct services to focus on other core public health functions such as assessment and surveillance. While in other states, Title V programs continue to provide direct services to CYSHCN. However, despite structural differences, all state Title V programs share a common goal of improving the system of care for the entire population of CYSHCN, which is defined by the American Academy of Pediatrics as “those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition who also require health and related services of a type or amount beyond that required by children generally.” Approximately 10.2 million, or 14 percent, of U.S. children younger than 18 meet this definition (excluding the at-risk population). In addition, many state Title V programs administer other key programs that serve CYSHCN such as the Early Intervention (Part C) program.

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

Every state has a unique structure for its system of care for CYSHCN, including children and youth with ASD/DD, based on a variety of factors such as historical commitment to children with disabilities, the availability of specialty care throughout the state, relationships with key constituencies, and financial and demographic issues. There is no one state health care system that is able to meet all the complex needs of CYSHCN equally well.

For children and youth with ASD/DD and their families, additional variations include the availability of developmental specialists and the existence of autism waivers or insurance mandates. In addition, nearly all states are facing serious budget cuts that threaten existing systems of care for CYSHCN. At the same time, the implementation of the *Affordable Care Act of 2010*, which, while including key provisions to address the needs of CYSHCN and children and youth with ASD/DD in particular, may also place additional strain on state budgets.

A review of the 2011 state Title V Maternal and Child Health Services Block Grant (Title V MCH Block Grant) applications showed that 45 U.S. states and jurisdictions mention some type of involvement with autism activities ranging from participation on state workgroups to specific program activities such as developing autism-screening programs (Alaska); developing autism registries (Delaware); and using parent consultants to train families on behavioral therapies (Iowa). This activity reflects an increase of nearly 30 percent since a review of the Title V MCH Block Grant applications in 2008.<sup>12</sup>

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. Systems that are strengthened to meet the needs of the ASD/DD population also are of benefit for all CYSHCN.

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 developed by MCHB to measure the quality of a system of care for CYSHCN (see text box).<sup>13</sup>

### MCHB Six Critical Indicators of Quality for a System of Care for CYSHCN

1. **Medical Home** – All children with special health care needs will receive coordinated ongoing comprehensive care within a medical home.
2. **Insurance and Financing** – All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need
3. **Early and Continuous Screening** – All children will be screened early and continuously for special health care needs
4. **Easy to Use Services** – Services for children with special health care needs and their families will be organized in ways that families can use them easily
5. **Family-Professional Partnerships** – Families of children with special health care needs will partner in decision making at all levels and will be satisfied with the services they receive
6. **Transition to Adulthood** – All youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work and independence

### State Title V as Leader and Partner

Issues such as state politics, resources and health care systems all affect how a state Title V program will approach its role in building the system of care for children and youth with ASD/DD. Nevertheless, as the roles and state examples that follow this section will demonstrate, state Title V programs across the country are addressing ASD/DD-related issues in a variety of innovative ways that speak to the broad possibilities and key contributions of Title V programs.

It is important for the state Title V CYSHCN agency to engage in partnership with projects and efforts within the state that provide services and supports for those with ASD/DD and their families, and to provide assistance in areas for which Title V traditionally has more experiences, such as care coordination and accessing resources. In this way, collaboration can strengthen (not duplicate) systems. State Title V programs can play a role by leading or serving on autism task forces, developing standards, helping identify and setting standards for medical homes, and by providing care coordination. Even where there is a clearly defined lead agency for ASD/DD that is not the state Title V program, Title V programs still have an

important role to play in building the system of care for children and youth with ASD/DD within the context of building an overall system of care for all CYSHCN.

### The Combating Autism Act

One crucial support to state Title V and the larger public health community's ability to address ASD/DD-related issues has been the enactment of the *Combating Autism Act of 2006*. HRSA implementation of this law, the Combating Autism Act Initiative (CAAI) — a \$42 million effort — addresses some of the most urgent issues affecting people with ASD/DD and their families. A national evaluation has been conducted to report to Congress on progress related to ASD/DD. Among the goals of the HRSA effort are to enable all infants, children and adolescents who have, or are at risk for developing, ASD/DD to reach their full potential by:

- Developing a system of services that includes screening children early for possible ASD/DD
- Conducting early, interdisciplinary evaluations to confirm or rule out ASD/DD
- Providing evidence-based, early interventions when a diagnosis is confirmed

As part of this implementation, the State Public Health Coordinating Center for Autism (SPHCCA) was funded by a cooperative agreement to the Association of Maternal & Child Health Programs. SPHCCA, better known as the State Public Health Autism Resource Center (SPHARC) (see Appendix D), is a comprehensive resource center intended to provide ongoing technical assistance for states as they build and sustain a system of care for children and youth with ASD/DD. In addition to this funding, state or nonprofit agencies in 13 states, including nine Title V programs, have received *State Implementation Grants for Improving Services for Children and Youth with Autism Spectrum Disorder and Other Developmental Disabilities* to improve access to health care and related services for children and youth with ASD/DD. Grantee activities have focused on implementing existing state plans to improve services for these young people.

The Combating Autism Act also supports the Interagency Autism Coordinating Committee (IACC). The IACC is charged with coordinating ASD/DD research and other efforts within the Department of Health and Human Services (HHS) (see Appendix D). Other federal efforts related to ASD/DD include the CDC *Learn the Signs. Act Early.* (LTSAE) Campaign. Launched in 2004 by the National Center on Birth Defects and Developmental Disabilities (NCBDDD), the goal of LTSAE is to educate parents, health care professionals and child care providers about developmental milestones, and the importance of early identification and intervention for children with signs of ASD/DD. The Combating Autism Act was reauthorized for three years in September 2011.

## STATE TITLE V AND PARTNER CAPACITY BUILDING

### How State Title V Programs and Their Partners Can Assess Their Role in Building and Sustaining Systems of Care for Children and Youth with ASD/DD and Their Families

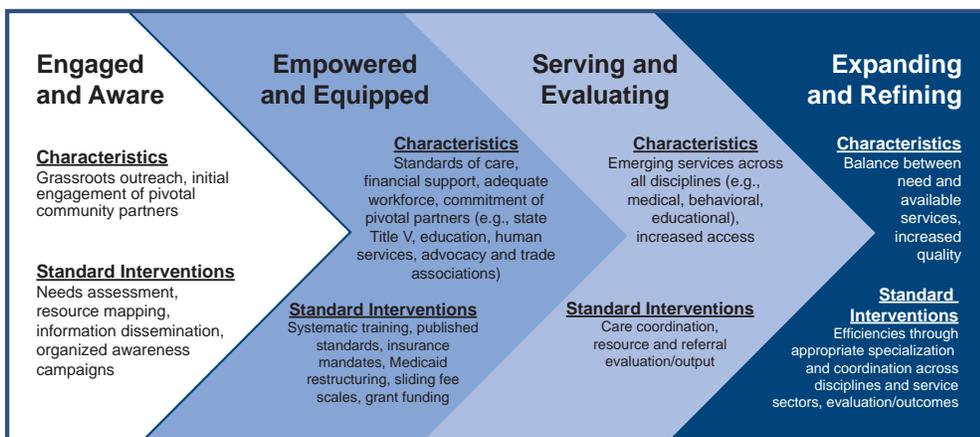
As states build and sustain systems of care for children and youth with ASD/DD and their families that address the CYSHCN critical indicators, they may want to consider evaluating their roles by looking at both leadership and capacity. There are existing tools to support such efforts. The Title V index, developed by state Title V CYSHCN leaders participating in a team collaborative, addresses broad capacity by leadership areas, while the autism continuum of involvement looks at capacity by level of involvement. Because systems change for children and youth with ASD/DD often affects several critical indicators for CYSHCN, these frameworks may be useful to states.<sup>13</sup>

The Title V index<sup>1</sup> 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: outreach/awareness, and family participation, which highlights the importance of family leadership and involvement. The addition of these essential components of partnerships (which overlap with the core CYSHCN performance measure) make a total of eight leadership areas.

Leadership Areas
Overall Leadership in the System of Care
Building Partnerships Across Public and Private Sectors
Family Participation
Quality Improvement
Use of Available Resources
Coordination of Service Delivery
Data Infrastructure
Outreach and Awareness

To address the level of involvement in these areas, it is helpful to look at activities and capacity using the Continuum of Involvement, developed by State Autism Implementation Grantees, that defines four levels of involvement: 1) engaged and aware, 2) empowered and equipped, 3) serving and evaluating, and 4) expanding and refining. These levels of involvement are applicable to any type of program or partner at the state and/or local level, seeking to improve the system of care for children and youth with ASD/DD and their families. Attaining the highest levels of mastery and sustainability in all areas, however, is not a realistic goal. Rather, states must evaluate their current and potential strengths, resources in each area and then focus their efforts accordingly.

### Continuum of Involvement<sup>14</sup>



### Guide to 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. In nine states (Alaska, Hawaii, Maine, New York, Rhode Island, Utah, Vermont, Washington and Wisconsin), the Title V program or Division of Health serves as the lead for autism activities, while in four states (Illinois, Missouri, New Jersey and New Mexico), 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 10 of the 13 grantee states, although primarily from the initial nine funded states, reflecting the importance of state Title V programs as leaders and partners. (For a complete list of grantees, please see Appendix E.)

Because the following examples can fit into numerous frameworks, examples are presented alphabetically in each leadership area, and are categorized by CYSHCN core outcome and continuum of involvement by the state Title V program. Many of the examples focus on the CYSHCN critical indicator of screening—reflecting the current priority to identify children at-risk for ASD/DD at the earliest possible age. Also, the level of involvement on the continuum reflects Title V, not state involvement. Finally, because systems development for children and youth with ASD/DD is a relatively new process, no examples are characterized as expanding and refining.

## Leadership Areas with State Examples

### OVERALL LEADERSHIP IN THE SYSTEM OF CARE

The increasing incidence and visibility of ASD/DD has led to a number of statewide efforts to improve services for children and youth with ASD/DD offering a range of opportunities for Title V leadership and involvement, through Governor's Councils, Act Early Summit Teams, and others. Title V involvement in state- and community-level autism system planning is essential to ensure that the systems of care developed for children and youth with ASD/DD build on, support and improve existing systems of care for all CYSHCN. If a state Title V program has not been initially included in state- or community-level planning teams, their existing partnerships with families, providers, Leadership Education in Neurodevelopmental & Related Disabilities (LEND) programs, and other state programs can help provide an entry and opportunity to participate and determine where their program resources and expertise can have the greatest impact.

### State Examples

#### **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 the 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. Ongoing efforts are currently coordinated, in part, through the Division of Public Health through a State Autism Implementation Grant. Sustainability is being explored as a joint effort of the State of Alaska Title V CYSHCN program and the Governor's Council on Disabilities and Special Education Autism Alliance. (Screening/Empowered and Equipped)

#### **Missouri: Enhancing the State System of Care**

The Missouri Title V program is a participating partner in the Missouri Commission on Autism Spectrum Disorders, which provides leadership and promotes strategic planning regarding the development and coordination of services for individuals and families affected by ASD/DD. The commission was a strong advocate for improving the adequacy of health insurance for individuals with ASD/DD, supporting legislation that passed in May 2010, which greatly improved coverage for Missourians ages birth to 18 years. In May 2011, the commission approved the Show-Me State Plan for ASD/DD. This plan addresses the development and expansion of ASD/DD services across the life span, with a specific focus in health care, education, individual/family supports and workforce development. (Organization of Services, Engaged and Aware)

#### **New Jersey: Providing Comprehensive Leadership to Multiple State Public-Private Initiatives**

The New Jersey Title V program has responded to its state having the third highest rate of autism in the country through a variety of initiatives that are all coordinated through, or in collaboration with, the Title V program, including a Governor's Council and a Community of Care Consortium for CYSHCN. The Governor's Council for Medical Research and Treatment of Autism, created by state statute in 1999, is housed within the New Jersey Department of Health and Senior Services (DHSS), which also houses the New Jersey Title V program. The Council awards grants and contracts with funding from a one dollar surcharge on motor vehicle violations and fines. Among the initiatives of the Council is an \$8.55 million Clinical Enhancement Center grant program that funds six regional Autism Clinical Enhancement Programs throughout the state. (Organization of Services/Empowered and Equipped)

#### **New York: Interagency Task Force**

In May 2008, an Interagency Autism Task Force was established to improve the state system of services for children and youth with ASD/DD and their families. The task force was charged with reviewing the state service delivery system and recommending actions for improvement. The New

York State Department of Health, as the lead agency for the New York State Early Intervention Program and Title V agency, was an active member of this task force. The task force issued a comprehensive report of its findings in January 2010, including 27 recommendations for change and improvement to guide state efforts to meet the needs of individuals with ASD/DD and their families.<sup>15</sup> The report identifies five areas of need; the first is the need for early identification of children with ASD/DD, which became the primary goal for the state Autism Implementation Grant. A second is a need for coordination of services. A new interagency ASD/DD website was developed and is currently maintained with information about ASD/DD resources available across agencies.<sup>16</sup> (Screening/Title V: Empowered and Equipped)



### **Rhode Island: Overall Leadership in the System of Care**

The Rhode Island Department of Health, the designated Title V Agency for the state of Rhode Island, shares membership on the Joint Legislative Commission to Study the Education of Children with Autism in the state of Rhode Island. The commission was appointed to conduct a comprehensive study of the education of children and youth with ASD/DD, particularly the diagnosis and assessment, the prevalence of numbers in the state, the effect and role of families, the appropriate goals for education, effective interventions/educational programs and public policy. The commission has been instrumental in introducing recent legislation to mandate services for children and youth with an ASD/DD with private insurances. The joint commission has a formalized state plan including specific responsibilities for Part C, Part B, Higher Education, Rhode Island Department of Health and the Rhode Island General Assembly. (Insurance Coverage/ Empowered and Equipped)

### **Utah: Title V Leadership in Partnership with University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD)**

The leadership of the Utah Title V CYSHCN programs in disability issues led to an expanded state role in ASD/DD activities in 2006. Since taking on this expanded ASD/DD role, Utah developed the Utah Autism Initiative (UAI), consisting of members representing all major state agencies that serve people with ASD/DD, including non-governmental groups such as parent advocates. The committee chair is the Medical Director of Children with Special Health Care Needs. The desired outcome is to identify service gaps and prioritize initiatives, which will be considered for further state funding support. In coordination, the Utah UCEDD convened a landmark meeting to bring various groups together to develop a consensus-based set of findings and recommendations; a state plan focused on ASD/DD. This is a dynamic document that is updated and revised as major partners continue to meet every four months. As funding becomes available for ASD/DD-related initiatives, partners may use the data and recommendations to serve as an evidence-based foundation for ASD/DD training, research or services. (Families Roles/ Title V: Empowered and Equipped)

### **Washington: Autism Task Force**

In 2005, the Washington Legislature created an Autism Task Force (ATF) to research coordination and delivery of ASD/DD services. The Washington State Department of Health Title V Children with Special Health Care Needs Program (DOH CSHCN) provided staffing. The ATF presented 31 recommendations for improvement to the governor in 2007. The recommendation to develop an Autism Guidebook for Washington State was completed in July, 2008. During this same timeframe, the *Combating Autism Act of 2006* passed, authorizing federal funding to fight ASD/DD through research, surveillance, awareness and early identification. The DOH Title V CSHCN program and the University of Washington Leadership Education in Neurodevelopmental and Related Disorders Program (LEND) each received a federal ASD/DD grant. To guide the efforts of these grants, the Combating Autism Advisory Council was formed and continues to operate. Grant activities build upon 11 of the 31 ATF recommendations that fall under the DOH-CSHCN scope of work, the national *Combating Autism Act*, and the six national Children with Special Health Care Needs Performance Measures. These activities began the process for carrying out the state strategic plan to explore and improve needed changes and connect ASD/DD-related information, services and research to the public. (Screening/Engaged and Aware)

## BUILDING PARTNERSHIPS ACROSS PUBLIC AND PRIVATE SECTORS

State Title V programs have long recognized the benefits of collaborative efforts among state and local agencies and community-based programs and between the public and private sectors for maximizing resources, increasing efficiency and expanding services to those in need. As state Title V programs look to expand these partnerships to the ASD/DD community, they may want to consider that the greater ASD/DD community consists of a variety of organizations sometimes advocating for vastly different strategies and approaches to meeting the needs of children and youth with ASD/DD. Unlike other public health issues, ASD/DD presents challenges because there is no known cause or cure and no universally accepted treatment. When assessing strategic partnerships, some natural partners may emerge. For example, if the state has already created *Learn the Signs. Act Early.* teams, they can look to their state University Centers of Excellence in Developmental Disabilities Education, Research and Services (UCEDD) and Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs for leadership in training and education, and other issues. Among other state programs, Medicaid, CHIP, and both the Part C of the Individuals with Disabilities Education Act (Early Intervention) and Part B (Special Education) are essential partners.

Indeed, effective collaboration on ASD/DD issues may require stronger and more coordinated relationships with the education community. While some Part C programs are located in health departments, others are located with the Part B program in the state education department. Working with the education community, which also faces service and budget pressures in addressing the rising incidence of ASD/DD, may be challenging but it is essential to improving the system of care. For example, the related services that schools must provide to students with disabilities, including ASD/DD, at no cost to their families, if needed in order for the student to benefit from their education, are critical to the development of students with ASD/DD. In addition, MCH programs can improve the services offered by schools to students with ASD/DD by sharing information on best practices such as positive behavior supports and partnering with families.

For the private sector, states can contact pediatricians and family practice providers who may often be the first point of inquiry for families through working with individual practices, as well as state chapters of the American Academy of Pediatrics and American Academy of Family Physicians. Medical home initiatives that help practices partner more effectively with parents, that address practice quality improvement, and inform families about state and community-based resources for children with ASD/DD and their families, lead to more effective and efficient care and better outcomes.

State Title V programs working on building systems of care for children and youth with ASD/DD through State Autism Implementation Grants have reported strengthened relationships with programs and agencies serving children with ASD/DD, and partnerships that will be sustained once the grant period ends. Again, through service improvement efforts for ASD/DD, these examples offer an opportunity for a new discussion to strengthen partnerships with key programs serving CYSHCN.

### State Examples

#### **Alaska: *Tearing Down the Silos to Make Systems Work***

The Alaska State Autism Implementation Grant, housed within the Division of Public Health, (the state Title V program), worked collaboratively with federal, state and local partners to examine, adopt or infuse best practices into infrastructure development. Having the grant as a foundation, partners came together as part of an Autism Steering Committee and agreed to work toward reducing the silo effect (the independent building of program and/or projects by local agencies). For example, efforts to promote consistent developmental screening were relatively isolated by region and scope of practice (by individual agencies, private providers, Tribal Health Organizations or state divisions). As a result, no statewide consistent message existed regarding policy, practice or even the choice of screening tools for universal early and consistent developmental screening. During the State Autism Implementation Grant campaign, the Ages & Stages Questionnaires (ASQ-3) and Modified Checklist for Autism in Toddlers (M-CHAT) tools used by the Infant Learning Program (ILP) were used to successfully train the Yukon-Kuskokwim Health Corporation Rural Cap and Head Start providers. By supporting the evidence-based tool selection of the ILP and providing these materials to both a different health care delivery system as well as a complimentary discipline, the cross-pollination led to not only cooperative practice, but a reduction in costs for tool selection and efficiency across systems. (Screening/ Empowered and Equipped)

#### **Missouri: *Rapid Response Community Collaboratives***

In Missouri, the State Autism Implementation Grant expanded a model program in central Missouri called the Rapid Response Initiative. This program has brought together local representatives from state and community agencies (including Title V) to form a professional network that promotes comprehensive and coordinated services for those with ASD/DD in the region. Through the State Autism Implementation Grant, similar community collaboratives have been established in two metropolitan areas (St. Louis City and Kansas City) and in a rural region (southeast Missouri). These Rapid Response groups share common goals: enhancing screening for early identification; improving access to timely and accurate diagnosis and effective interventions, and providing family members with education and supports. Activities

differ in each region, but include the development of awareness materials and outreach to primary care health professionals and early childhood educators. The grant facilitated a statewide meeting in July 2011 that participants plan to continue on an annual basis. (Organization of Services, Engaged and Aware)



### **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, practical steps to incorporate universal screening into their practices, 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 important and relevant local, state and national ASD/DD resources, and to support pediatricians' efforts to screen and make appropriate referrals in their communities. NYSDOH is actively collaborating with the three University Centers for Excellence in Developmental Disabilities (UCEDD) in New York that are engaged in this effort. (Screening/Engaged and Aware)

### **Rhode Island: *Leadership in Transition***

The Rhode Island Transition Council (established by state law in 1994) is a public entity charged with developing and overseeing a cooperative agreement among state departments for transition planning for youth with ASD/DD. The Transition Council includes key state agencies (including the state Title V program), local transition centers, higher education and advocacy organizations. (Transition/Engaged and Aware)

### **Washington: *Community Asset Mapping***

In Washington state, the Title V CYSHCN program staff convenes the Combating Autism Advisory Council, to advise on State Autism Implementation Grant activities. The council has many partners, including state agencies, private sector, nonprofit organizations and the military. The council has 40 to 50 regular attendees and nearly 70 on the mailing list. Full partnership was established with the University of Washington LEND program for leadership of the council and helps to move the group forward in a structured manner at each meeting. Communication is open with listservs and e-letter updates on a regular basis. A strong partnership was established with the Part C program in the state and with education — at all levels — university, schools, regional Educational Service Districts down to Part C Early Support for Infant and Toddlers. As the subcommittee work of the council has spread out into counties with the Community Asset Mapping project (a mechanism for communities to identify partners and capacity), the coalitions built in those communities often closely mirror the composition of the state-level Advisory Council. (Medical home, Organization of Services/Empowered and Equipped)

### **Wisconsin: *Communities of Practice***

As a result of the State Autism Implementation Grant, the Wisconsin state Title V CYSHCN program (Division of Public Health) strengthened its connection to programs and agencies serving children with ASD/DD. The Wisconsin CYSHCN program brought together diverse partners using the Community of Practice (CoP) model, a strategy supported by the Office of Special Education. The CoP on ASD/DD, led by its 27 member Steering Team (representing families, education, early intervention, long term care financing, Title V Regional Centers, academic partners (University of Wisconsin-LEND, UCEDD), community providers and others), connects over 400 individuals to work on issues of common concern. Members of the Steering Team have created a plan to sustain this work after the end of the grant period in order to continue building systems of care for children and youth with ASD/DD. (Organization of Services/Empowered and Equipped)

## FAMILY PARTICIPATION

Parents and families of children and youth with ASD/DD assume many roles in caring for their children, including early identifier, 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 the vital roles that families play in ensuring the well-being of their children. At the program level, family participation refers to a range of activities that involve families in the planning, development, and evaluation of programs and policies — a strategy which assures programs meet the diverse needs of children with ASD/DD and their families.

With the development of a CYSHCN performance measure focusing on family participation in 2003, state Title V MCH programs have a tremendous incentive to involve families in a comprehensive manner. As many states note, their strongest successes lie in the programs created by parents and families. Over the years, state Title V programs have gained expertise in fostering family leadership and gathering family input to develop and strengthen programs. State Title V programs can lead or assist in the development of parent support groups for ASD/DD to create effective networks to deliver information to families and provide advice. They can also help nurture the potential of families as leaders and advisors, through training of family support staff (referred to in some states as family navigators) to reach more families and expand their roles. At the community level, state Title V programs can assist providers in designing and funding parent education initiatives and making “survival manuals” and resource guides easily accessible for families online, in print and in multiple languages. Families with children with ASD/DD may need specialized assistance, such as assistance in understanding the role of evidence-based research/therapies versus other ASD/DD therapies.

### Illinois: Families Engaging Providers

The Autism Project (TAP) of the Hope Institute for Children and Families in Illinois, which serves as the State Autism Implementation Grantee, developed the Family Advisory program that equips families to work as advocates for quality improvement through interactions with their health care providers. Family Advisors participate in training, receive resources and consultation regarding communicating physicians, creating a care plan, early detection, evidence-based treatment and a variety of electives (i.e. nutrition, sleep disorders, etc.). Family Advisors have served as an effective conduit of information to their physicians. The Title V program was instrumental in providing parents with transition information on how to engage both their doctor and their child through medical transitions at various times in the child’s life. Title V also provided resources and training materials about medical home to empower parents to discuss medical home concepts with their child’s health care provider. (Families Roles, Medical Home/Empowered and Equipped)

### Missouri: Families as Mentors

The Missouri Rapid Response Project (MORR) is utilizing parent peer mentors through the MCH Family-to-Family Health Information Center (Missouri Family-to-Family). The Missouri Title V agency is a main partner on the Family-to-Family initiative and is connected through the Title V Family Partnership program. Title V staff (as well as MORR project staff) also play an important role in the Family-to-Family Stakeholders that meets quarterly to guide the projects of the Family-to-Family initiative. Seventy percent of the members of this stakeholders group are parents.

Overall, the MORR project has included extensive involvement from family partners, including a Family Consultant who is funded by the project. In addition, the three Family Mentors (parents of children with ASD/DD) work with the Missouri Autism Centers (MAC) Family Resource Specialists to provide services to families in need of care coordination and emotional support by linking families to the statewide parent peer mentor network (mentioned above). A representative from Family Voices in Missouri also serves on the project leadership team. Parent partners provided invaluable insight into the development of a family-centered care survey. In addition to input from the Family Consultant, the project also solicited feedback on the survey from the former representative of Family Voices in Missouri. The survey was piloted with several families in the community and their feedback was integrated into the final version of the survey. (Families Roles/Engaged and Aware)



### New Jersey: Developing Leadership in Collaboration with Title V Programs

The Statewide Parent Advocacy Network (SPAN) of New Jersey is a comprehensive resource center for families of children with the full range of disabilities and special health care needs. SPAN houses both the HRSA-funded State Implementation Grant for Integrated Community Based Systems of Care for CYSHCN and their Families (D70 grant) and the HRSA-funded State Autism

Implementation Grant for ASD/DD Family Voices-New Jersey, the New Jersey Family to Family Health Information Center, New Jersey Statewide Parent to Parent, the New Jersey Parent Training and Information Center, and a chapter of the Federation of Families for Children's Mental Health. By combining three federal and state grants and coordinating with the state Title V CYSHCN program, SPAN can recruit, train and supervise a Family Resource Specialist, the parent of a child with disabilities, in each of the 21 county-based Title V Special Child Health Services Case Management Units, as well as in each of the six ASD/DD Clinical Enhancement Programs. SPAN multilingual Family Resource Specialists represent the full diversity of the New Jersey parent population, and many are parents of children and youth with ASD/DD.

In addition, SPAN recruits, trains and supports parents of children with special health care needs, including ASD/DD, to serve as parent partners and resources to pediatric and family practices as part of the state medical home initiative. It has collaborated with Autism-New Jersey to develop and translate a resource guide for families on how to get services paid for under the New Jersey new state law requiring insurers to pay for therapies for children with ASD/DD. SPAN also facilitates a Statewide Youth Advisory Council to provide input into policies that impact CYSHCN, including the State Autism Implementation Grant. (Transition, Families Roles/Serving and Evaluating)



### **New Mexico: Families as Leaders**

Through the State Autism Implementation Grant, the University of New Mexico Center for Development and Disabilities (CDD)/Autism Programs convened an Advisory Board to assist in all aspects of the state plan, including a representative from the state Title V program. An early recommendation of this group

was to assist parents in the state to become leaders in broad disability advocacy efforts. After research, the CDD/Autism Programs selected the Partners in Policymaking curriculum and has begun a partners group in New Mexico. At least 29 participants have been selected for this initial cohort group and represent self advocates, parents of children with ASD/DD and others. The group was chosen through a competitive process and several of the statewide partners have been involved in the planning and initial implementation. This intensive, eight-month program began in May 2011 and will continue until December 2011. (Families Roles/Engaged and Aware)

### **Rhode Island: Family Participation**

The Rhode Island system of care for CYSHCN, including those with ASD/DD, is based on a 15-year partnership with parents/family members. Parents/family members of CYSHCN and peers with disabilities are recruited, employed, trained and strategically placed throughout the special health care needs service delivery system through the Rhode Island Department of Health Pediatric Practice Enhancement Project and Peer-Assisted Health Initiative to ensure the provision of a family-centered, community-based, coordinated system of care for children and youth with ASD/DD and their families. Through a contract with the Rhode Island Department of Health, the Autism Project of Rhode Island partners with families to provide a Training & Support Center for parent mentorship, support groups, informational/training workshops, in-home training, electronic newsletters, playgroups and a resource library. (Families Roles/Serving and Evaluating)

## **QUALITY IMPROVEMENT**

Developing guidelines and standards requires collaborative efforts among state programs, families, communities, clinicians and others at the state and local level. State Title V programs can play a key role in developing guidelines for services and training. In many states, programs are challenged in determining whether a service or treatment targeted to children and youth with ASD/DD is truly evidence-based and how to determine which children would qualify for the service. Additionally, family-centered evaluation and recognizing promising or best practices is critical because of the vast quantity of research and practice information available related to ASD/DD interventions. State Title V programs, who are often looked to as experts in MCH, could lend credibility to such determinations by developing and/or reviewing guidelines for screening, best practices, EPSDT screening protocols and Medicaid waivers that include children and youth with ASD/DD. Specifically, they can play a role in working with state Medicaid and CHIP programs to change eligibility and covered services. Additionally, they may share information with private insurers about evidence-based practices covered by state programs.



Guidelines Initiative has reconvened to develop the Missouri Reference and Users Guide for the Treatment of ASD. The Missouri Department of Elementary and Secondary Education has joined this effort as a sponsor to help build consensus on ASD/DD intervention strategies across health and educational systems. (Screening/Engaged and Aware)

### **New York: Leader in Development of Clinical Practice Guidelines**

In 1999, the New York State Early Intervention Program (NYSEIP), which is housed in the same division as the Title V program, developed and issued the nation's first clinical practice guideline on the assessment and intervention for young children with autism/pervasive developmental disorders. Since its issuance, the guideline has been used as an educational tool and decision-making resource for families, primary referral sources, public officials, and providers on evidence-based practices for delivering early intervention services to young children with ASD/DD. The Autism/Pervasive Developmental Disorders Clinical Practice Guidelines are in the process of being updated. In addition, under a recently enacted law, the Department of Health was tasked with developing a Best Practices Protocol for the Early Screening of Young Children for ASD/DD by Pediatric Primary Care providers. The NYDSOH is collaborating with the American Academy of Pediatrics (AAP) District II in New York State to develop and disseminate the best practices protocol. The best practices protocol includes standards and the following: 1) guidelines recommended by the AAP, and 2) routine use of ASD/DD screening tools at regular times during important stages in child development. (Screening/ Empowered and Equipped)

### **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.

In addition, the Rhode Island Department of Health Title V program developed two tools to educate families, teachers, administrators, and treatment providers through the convening of local and national experts about the diagnosis of ASD/DD. *The Identification & Evaluation of Autism Spectrum Disorder*

### **Illinois: Developing a Practice-Based Screening Protocol**

The Autism Program of Illinois (TAP) — the State Autism Implementation Grantee — provides practice-based training to support early detection. The training is provided to all practice staff. The broad practice-based approach creates a team that is able to address barriers to developmental screening (from scheduling, to billing, to choice of standardized tools). Through partnership with Title V, TAP was able to provide the early detection training to a small number of practices currently conducting medical homes through Title V sponsorship. This collaboration provided new ASD/DD tools and approaches for these practices as the Illinois Title V program is not currently assigned to address primary diagnoses of ASD/DD. (Screening/ Engaged and Aware)

### **Missouri: Developing Best Practice Guidelines**

The state of Missouri, under direction of the Missouri Autism Guidelines Initiative (MAGI) project, recently developed a set of best practice guidelines for ASD/DD screening, diagnosis and assessment. The MAGI project consisted of more than 40 health, educational and behavioral professionals and families from across the state and was a collaborative effort funded by the Missouri Division of Developmental Disabilities and a private foundation (Thompson Foundation for Autism). The resulting document, *Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment*, is tailored specifically for Missouri health care clinicians, educators, service providers and families. The Guidelines are intended to help with informed decision making regarding identification, diagnosis and assessment for intervention planning. Copies of the best practice guidelines, as well as three smaller overview booklets, have been disseminated across the state to families, educators, health care providers and service providers, including the Missouri Title V agency, in an effort to promote best practices related to ASD/DD screening, diagnosis and assessment. The Missouri Autism



*Guidelines* developed diagnostic standards, including the necessary components of a diagnostic evaluation and standardized tools to use. *The Assessment of Function and Intervention Planning* tool provided a means to identify individual levels of functioning across several domains in order to plan for appropriate intervention for individuals with an ASD/DD in the home and school. (Screening/Empowered and Equipped)

### **Washington: New Standard of Autism Screening Recommended**

With the support of their State Autism Implementation Grant, the Washington State Combating Autism Advisory Council adopted and endorsed the STAT (Screening Tool for Autism in Toddlers) as a robust second level screener. STAT is an evidence-based interactive measure used to screen for ASD/DD in children between 24 and 36 months old. It consists of 12 activities in the areas of play, imitation, and communication that can be administered in 20 minutes by community service providers. The interactive screener is administered by someone trained in its use and familiar with ASD/DD in young children. Forty-three providers from across the state including psychologists and school psychologists, pediatricians, speech-language pathologists, preschool teachers, and early intervention specialists trained and are becoming certified in its use. Several of those trained are going on to become state trainers in the screener. At least two members of the grants Community Asset Mapping Project in rural communities took the training to help increase local autism evaluation services. In addition, the council developed recommendations that all Birth to Three programs (Part C programs) be trained in the use of the screener for use in eligibility determination, intervention planning and communication of findings to primary care and specialty health care providers who would

be doing further assessment. Leadership Education in Neurodevelopmental & Related Disabilities (LEND) partners are gearing up to use the STAT in training of Developmental Behavioral Pediatric subspecialists and perhaps other LEND trainees. (Screening/Empowered and Equipped)

### **Wisconsin: Guidelines for Medicaid Waivers and Evidence Based Practices**

The Wisconsin LEND program and the Community of Practice (CoP) ASD/DD Medical Home Practice Group, led by the state Title V program and the University Centers for Excellence in Developmental Disabilities (UCEDD), are working with a group of professionals to establish clear diagnostic guidelines related to the Children's Long Term Support Waiver. In addition, the CYSHCN Connections Initiative has partnered with the National Professional Development Center and local physician champions to offer trainings in all five public health regions on evidence-based practices (EBP). Expert training on the importance of EBP to parents, physicians, educators, and community members aims to promote the use of EBP and clarify questions parents should ask when seeking treatment for their children. (Financing of Care/Empowered and Equipped)

## **USE OF AVAILABLE RESOURCES**

Linking and leveraging resources in a fragmented health care system is a challenging but necessary task to ensure access to needed services. Eligibility requirements among programs differ and programs may have difficulty accessing client or patient data from other programs. State Title V programs' collaborative efforts with other programs gives them significant experience in leveraging alternative funding mechanisms and linking other funding and resources to make the best use of limited resources. In particular, financing of care is one of the most challenging but important aspects to meeting the needs of children and youth with ASD/DD as families seek access, financing and coordination services in the medical, behavioral health and education systems. State Title V programs' knowledge of financing systems and their strong links to state Medicaid and CHIP programs, and providers, can help strengthen resources and financing systems for this population. Specifically, Title V programs can provide leadership and guidance as states develop and implement waivers and insurance mandates for the ASD/DD population.

State Title V programs' expertise in leveraging resources and linking programs has been applied to ASD/DD systems of care through linking tribal networks, ensuring that Medicaid waivers are designed to maximize resources, linking funds for developmental screening, and ensuring that families with children and youth with ASD/DD understand financing options and resources and participate in the decision making.

## State Examples

### **Alaska: Linking Tribal Networks to Improve Screening**

Alaska is nearly 98 percent inaccessible by roads, making travel expensive, difficult and often traumatic for children with neurodevelopmental concerns. Efforts to create new initiatives in early screening and detection are difficult due to highly individualized organizational structures and processes within each tribal entity serving these communities – 16 regional tribal health consortiums and 17 local health programs. In 2010, the Alaska Title V program expanded regional pediatric neurodevelopmental and ASD/DD screening clinic services from two to 10 Alaskan communities.

The main goals of expansion are to reduce the average two-year disparity in early identification in rural Alaska versus urban Alaskan children; reduce the cost and trauma of travel for families with a child with neurodevelopmental issues living in rural Alaska; and to offer training, assistance and resources to local tribal health organizations. In addition to the *Learn the Signs. Act Early.* campaign content, outreach efforts include discussions regarding the value of consistent and universal screenings for all children through the EPSDT programs.

The coordination and planning involved in the expansion of these clinic services included extensive outreach to community, family and tribal health leaders. Families were included in all active planning and frequently consulted throughout program development. Parent navigators provided support for outreach and awareness efforts. New and promising partnerships would likely not have been possible without the personalized outreach offered through the clinical outreach opportunities. As a result, Alaska has increased numbers of appropriate referrals for diagnostic work-up from rural Alaska, while significantly reducing unnecessary travel for patients with neurodevelopmental concerns. (Screening, Organization of Services/Serving and Evaluating)

### **Missouri: Helping Families Access Resources and Financial Assistance**

In Missouri, members of the Rapid Response Learning Collaboratives (including Title V staff) are sharing valuable information about resources and financial assistance programs available in their region for children and families affected by ASD/DD. In Central Missouri, for example, Title V and Early Intervention staff members have been cross-trained about each other's services, thereby increasing the service providers' understanding of the others' services. In addition, Rapid Response members in St. Louis have shared information about where to find translation and interpreter services for non-English speaking families, making it easier to serve a more diverse population.

As a member of the Missouri Commission on Autism Spectrum Disorders, the Chief of the Bureau of Special Health Care Needs (and Title V Director) has advocated for the

Missouri health insurance legislation that passed recently and that greatly improves access to services for children and youth with ASD/DD. The commission also provides updates on the work of the Department of Mental Health in establishing and operating the Missouri autism waiver. Title V also assisted in the development of a statewide guide to financial resources for those with ASD/DD to promote improved access to services. (Organization of Services/Engaged and Aware)

### **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. The New Mexico ASD/DD insurance mandate was the result of strong partnerships among advocacy organizations, state agencies, including Title V, the Center for Developmental Disability (CDD) and the legislature. However, the majority of New Mexicans who have private health insurance are covered through large company or government sponsored self-insured plans, where the Employee Retirement Income Security Act, preempts most state insurance regulations, including benefit mandates. Current work by the CDD and advocates is focusing on a few of the large self-funded plans to convince them to voluntarily implement the ASD/DD insurance mandate or to include benefits that specifically focus on covering intensive services for young children with ASD/DD.



At the same time, in order to also ensure coverage for children who are on Medicaid (for which 50 percent of New Mexican children qualify), the CDD and this same group of advocates, including Title V, worked with the state Medicaid program to develop a service definition that would include intensive behavioral services for young children with ASD/DD who are five and under. Implemented in 2011, these services include development and execution of an intervention plan that includes Applied Behavioral Analysis. Currently, only a limited number of providers have been approved to provide services through this service definition. (Financing of Care/Engaged and Aware)

## **Utah: Creative Leveraging of Resources**

In Utah, the Title V CYSHCN Program administers and funds a number of multi-specialty diagnostic clinics throughout the state. As funds for direct services have diminished, the Title V program continues to be involved in other ways to provide services for the ASD/DD population. The medical director for the Title V CYSHCN program was an active member on the Autism Waiver Committee. This committee was mandated by the legislature to consider and propose an Autism Waiver for Utah. This proposal was presented to the Utah Legislature in October of 2010 and will be under consideration in the 2011 legislative session. (Financing of Care/Empowered and Equipped)

## **Washington: Combining Resources for Developmental Screening**

Within the MCH program at the Washington Department of Health (DOH), developmental screening is part of the work plans for three federal grants, Project LAUNCH (Linking Actions for Unmet Needs in Children's Health), Autism and the Title V MCH Block Grant. Additional blended funds from the Early Support for Infants and Toddlers American Recovery Act helped to move forward on a system design that provides universal developmental screening and linkages to appropriate services for all young children in Washington state. With a broad base of private, nonprofit and state agencies stakeholders, the Developmental Screening Partnership Committee Project has completed a thorough review of a state strategic framework; development of a DOH identified state performance measure on developmental screening; and an outcome map and a theory of change model that blends the state efforts of the Department of Early Learning Plan, the Birth to Three plan. Stakeholders received additional support with a two-year Help Me Grow grant for technical assistance from the W.K. Kellogg Foundation. Work continues with formation of several work groups on different parts of the system, which include data needs, resources and care coordination, screening, and reaching all populations and policy. (Financing of Care/Empowered and Equipped)

## **Wisconsin: Informing Families about Financing Options**

Wisconsin has seen changes in insurance coverage, including an autism insurance mandate, in the last two years. The Title V Connections compiled state fact sheets and made them available to parents at statewide conferences and through website posting. In partnership with a LEND trainee, a survey was used to gauge the understanding of parents about the legislative changes. Parents, providers and community members now have access to a webcast about how insurance interacts with the Children's Long Term Support (CLTS) Waiver. In response to Wisconsin's 2011 renewal of the Medicaid Waiver for CLTS, the Community of Practice Parents and Policy Practice Group met with the manager of the CLTS in October 2010 for a presentation along with questions and answers on the renewal process. In addition, the group has contacted other states and experts to find out best practices and possible recommendations to the CLTS Waiver program. (Financing of Care/Empowered and Equipped)

## **COORDINATION OF SERVICE DELIVERY**

Care coordination, access to a medical home, and family-centered and culturally competent services are considered key elements of coordinated services for children and youth with ASD/DD. Facilitating the development of family-centered, community-based coordinated care for children and youth with CYSHCN, including ASD/DD, is a key responsibility of state Title V programs. This coordination may include the intersection of the education system, as well as physical and behavioral health care systems.

State Title V leaders are working to develop approaches to providing these comprehensive services that acknowledge that individuals with ASD/DD and their families are part of a much larger framework of ongoing services, including medical, educational and social services, in addition to others such as child and residential care. This collaboration looks different for each family, however, its primary goal remains the same: to promote the healthy development and well-being of each child and family.<sup>17</sup> For example, families of children needing screening for ASD/DD or already diagnosed may face confusion in figuring out where to access services and how to ensure care is coordinated. State Title V programs, through family leadership, can help families in navigating the service maze, developing medical homes, and ensuring earlier screening and access to services.

## State Examples

### Illinois: Linking with Title V to Identify Medical Homes

The Autism Project (TAP) of Illinois relies on the Illinois Title V CYSHCN Program for assistance and expertise in identifying and developing medical homes to serve children and youth with ASD/DD. Illinois is providing intensive monthly consultation toward the development of four medical homes, where the consultants provide expertise in ASD/DD. Grant staff execute agreements with chosen practices, conduct data evaluations of both the practice staff and family consumers, provide training on medical home concepts, and support and implement quality improvement teams. Title V provides regional care coordinators to serve on the quality improvement teams, thus strengthening the relationship between Title V, medical and social providers, schools and families. (Medical Home/Serving and Evaluating)

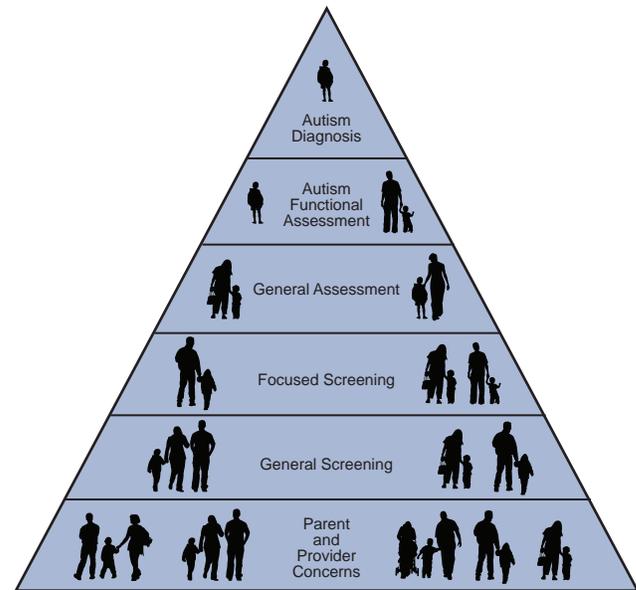
### Missouri: Family Resource Service Expansion

In a previous partnership with the Missouri Title V program, the State Autism Implementation Grantee developed and evaluated a model of care coordination through the medical home. This Family Resource Service model was then piloted in a tertiary care setting to enhance care coordination through the ASD/DD Health Home, which provides specialty care to individuals with ASD/DD and consultation to the primary medical home. The pilot was successful, so it was expanded to two other state-supported Missouri Autism Centers through the State Autism Implementation Grant. This program helps families navigate the health and educational systems of care for younger children with ASD/DD and promotes transition from adolescence into adulthood for older youth. At each of the three Missouri Autism Centers, the Family Resource Service includes the Family Mentoring program, employing a family member to provide information and emotional support. (Families Roles, Organization of Services/Serving and Evaluating)

### 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 above)<sup>18</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. (Screening/Empowered and Equipped)

## Tiers to Diagnosis and Referral of Other Disorders



### Health System

### Wisconsin: Helping Families Navigate the Service Maze

A new publication has been developed in collaboration with the Community of Practice (CoP) ASD/DD, the UCEDD, the Wisconsin Title V CYSHCN program and a number of other partners that addresses the family's need for quality information on how to navigate the system of care of Wisconsin for CYSHCN. *The Finding Your Way: A Navigation Guide for Wisconsin Families Who Have Children and Youth with Special Health Care Needs and Disabilities* incorporates input from parents and a large number of stakeholders to guarantee relevant and accurate information. In addition to the guide, utilizing contracts with the existing five Regional Centers for CYSHCN, Connections Regional Center Liaisons are responsible for supporting and facilitating a Regional Core Team, conducting resource mapping and co-sponsoring trainings and helping gather information for this guide. Through the Regional Core Teams efforts, the number of resources concerning ASD/DD listed in the statewide database has more than doubled and regional specific ASD/DD resource sheets have been developed. (Families Roles, Organization of Services/Empowered and Equipped)



## DATA INFRASTRUCTURE

The lack of detailed state-by-state surveillance data on children and youth with ASD/DD is a source of frustration to state leaders and a roadblock to states who choose to approach the increased demand for services in a more systematic way. State Title V programs in each jurisdiction are required to collect data on the health status of mothers and children, the services available and any relevant gaps in the system of care. The collection, management and dissemination of such data in collaboration with state vital records sections, local health departments and others is essential to developing an effective and accountable system.

Incomplete data on the numbers, functional level and location of children and youth with ASD/DD in states continue to frustrate state efforts to develop comprehensive needs assessments of this population. As a solution, states are trying to build a data infrastructure through collecting information via birth defects surveillance systems, sharing Autism Developmental Disabilities Monitoring (ADDM) data with families and providers, and gathering data through Title V information systems. State Title V programs, particularly in those states with ADDM sites, could use their expertise in linking and evaluating data to coordinate and share ADDM data and make recommendations to CDC for future surveillance efforts.

## State Examples

### **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.

The MORR project also collected data on Missouri families registered with the Interactive Autism Network (IAN). Families in Missouri and across the nation were invited to participate in an Access to Care survey through IAN. The results revealed similarities in access to services between Missouri and non-Missouri families. Among the findings, Missouri families reported having an unmet need for their child in the areas of behavioral therapy, occupational/physical therapy, communication aids and devices, speech therapy, and mental health services. In addition, parents reported significant difficulties with access to family support services, and a high percentage described unmet needs for genetic counseling, family mental health services and respite care. The full

results of this survey will be shared with the Missouri ASD/DD Commission, of which Missouri's Title V agency is a part. (Screening, Organization of Services/Engaged and Aware)

### **New Jersey: Implementing an Autism Registry**

In 2007, a law establishing the New Jersey Autism Registry was enacted. Since then, over 4,000 children have registered. The goals of the Autism Registry are threefold: 1) to connect families in need of health care services to coordinated care through county-based case management units, and 2) to improve the current knowledge and understanding of ASD/DD by conducting thorough and complete epidemiologic research of ASD/DD; and 3) to use the analysis of this information to plan for more targeted services for children with ASD/DD in New Jersey. Once a child is registered, families are linked to the New Jersey Special Child Health Services program. The Special Child Health Services Case Management Unit from the county in which the child resides contacts the family to inform them of services that are available in their community. A Case Management Unit is available in each of New Jersey's 21 counties and are staffed by nurses and social workers that advocate and assist families. They assist with referrals, linkages and obtaining necessary resources at no cost to the families. (Screening, Empowered and Equipped)



### **Rhode Island: Using Title V Data Information Systems to Improve Services for Children and Youth with ASD/DD**

The Rhode Island Pediatric Practice Enhancement Project's (PPEP) data and evaluation system, housed in the Title V program, provides activity- and systems-level outcomes for services provided to CYSHCN, including those with ASD/DD in pediatric primary and specialty care practices in Rhode Island. The analyses are used to assist in the development of a statewide information system capable of measuring and

monitoring care delivery to CYSHCN. The evaluation utilizes the expertise of the Rhode Island Department of Health Data & Evaluation Unit to determine the effectiveness of using the PPEP model to assure continuous quality improvement in an integrated community system of CYSHCN and their families.

In addition, the Rhode Island Birth Defects program identifies newborns with birth defects, ensures that these children receive appropriate preventative, specialty and other health care services, and monitors trends. The system describes the occurrence of birth defects in children up to age five, detects trends of morbidity and mortality, and helps make sure children with birth defects receive services and treatment on a timely basis. Information on children diagnosed with ASD/DD is also captured through this system, which identified cases through multiple sources, including hospital and specialty clinic data. (Screening, Organization of Services/Serving and Evaluating)

#### **Washington: First Steps in Surveillance**

Washington state, through the leadership of the Title V program, has taken a first step in surveillance by ensuring that ASD/DD is one of the specific disorders listed as a Notifiable Condition for the state Birth Defect Surveillance System. However, the vast majority of data for the surveillance system comes from hospitals at the time of an infant's birth when an ASD/DD diagnosis is not yet known, and, at this time in the state, there is no centralized reporting of autism other than what is collected by school districts for students in special education, leaving ongoing gaps in the surveillance system for ASD/DD. (Screening/ Engaged and Aware)

#### **Wisconsin: Sharing Data to Address Issues**

Wisconsin also has an Autism Developmental Disabilities Monitoring Network grant. The Wisconsin Surveillance of Autism and Other Developmental Disabilities System (WISADDS) is a multiple-source investigation to determine and monitor the number of eight-year-old children in the population with an ASD/DD and/or cerebral palsy. One way that WISADDS disseminates information is through exhibiting at the statewide annual ASD/DD conference alongside Connections and the Regional Centers for CYSHCN (funded by the state Title V program). WISADDS has been involved in the Community of Practice through serving on the Steering Team and as a leader in the Early Identification Practice Group. (Screening/ Engaged and Aware)

## **OUTREACH AND AWARENESS**

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

Education and training of health care providers is a key role for states in improving the early identification and screening of children with ASD/DD. 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/DD. Training strategies include providing ASD/DD screening and diagnosis information to medical students in residency programs, supporting CDC Grand Rounds, and creating online modules. In addition, some states have worked with local universities to create graduate-level training programs for ASD/DD. States have also tried to target education and training initiatives to families, early childhood and school-age 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 who 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.

States report the need for more developmental pediatricians and other specialists who work with ASD/DD because the current number of qualified providers is overwhelmed by wait lists and high demand. Additionally, many states struggle to engage physicians and motivate them to participate in the trainings and use ASD/DD 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/DD plus effective practices encouraging primary care physicians and pediatricians to screen children early. The lack of data on the numbers of children with ASD/DD in each state is a 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/DD poses coordination challenges. States have stressed the need for uniform screening and diagnostic criteria that can be used statewide.

Because early detection of ASD/DD can lead to improved developmental outcomes, the importance of outreach and awareness to families and professionals is essential. State Title V programs have used their considerable expertise in running public health campaigns, developing culturally competent messages and materials, and providing outreach to hard-to-reach populations through traditional public awareness campaigns, as well as new online resources and virtual training.



## State Examples

### **Illinois: Disseminating Resources**

The Autism Program (TAP) of Illinois has disseminated resources to primary care practices and dentists, including a Medical Accessibility Kit, the American Academy of Pediatrics (AAP) Autism Tool Kit, and a Dental Desensitization Kit, through funding from its State Autism Implementation Grant. The Medical Accessibility Kit is provided to the trained practices as a tool to work with families, using social guides, picture dictionaries and visual schedules to help families prepare their child for a visit to the office or emergency room. It is also available online for families to access on their own. The Illinois Title V medical home team also received copies of the kits to provide to practices that are being engaged in medical home projects. The Dental Desensitization Kit includes an entertaining DVD designed to acclimate children to dental procedures, a DVD for dental providers, and a manual. Each TAP Center has copies for loan through TAP Family Community Resource Rooms so families can also prepare themselves before a dental appointment. (Medical Home/Engaged and Aware)

### **Missouri: Online Training in ASD/DD Screening, Intervention & Transition**

Missouri made online access to information and training a priority. In addition, to ensuring that best practice guidelines for ASD/DD screening, diagnosis and assessment are available to download for free from the Missouri Department of Mental Health, several training modules are also available at no cost for families, service providers and health care providers. Currently, the University of Missouri Extension Office is hosting two online modules entitled Understanding Autism and Autism Screening and Referral. These modules have also been converted into DVDs, which are sent at no cost to trainers who do not have access to high-speed internet (a concern in much of rural Missouri). Within the next several months, the Missouri Rapid Response (MORR)

Project will add two additional modules – one on ASD/DD interventions and another on family-professional partnerships.

Missouri also recently completed a module entitled Autism Spectrum Disorders: Transition to Adulthood. Intended for youth, families and service providers, the module provides an overview of the major areas of transition to be considered as youth with ASD/DD moves to adulthood. The module was developed by the Missouri ASD/DD Youth Coalition, a group established by the State Autism Implementation Grant that includes representation from the state Title V agency. In addition to the training module, the ASD/DD Youth Coalition has developed a transition website ([asdtransition.missouri.edu/index.html](http://asdtransition.missouri.edu/index.html)) and is updating the transition section of Missouri's Navigating Autism Services: A Community Guide.

In an effort to ensure quick and effective dissemination of information, the MORR project has developed a dissemination map that depicts the ideal flow of information about developmental disabilities to families, health care providers, service providers and others across the state. A spreadsheet of contact information for the major players has been developed and now contains over 2000 entries. This spreadsheet will be used to quickly disseminate new information about ASD/DD to large audiences across the state. (Organization of Services/Engaged and Aware)

### **New Jersey: Addressing Identification Delays in Minority Children**

In New Jersey, the Governor's Council for Medical Treatment and Research on Autism awarded research grants to increase early identification of ASD/DD among children in underserved communities. One of these grantees, Children's Specialized Hospital, reached out to New Jersey's SPAN for assistance in developing and implementing effective outreach strategies, particularly for immigrant and non-English speaking populations. (Screening/Engaged and Aware)

### **Rhode Island: Training and Awareness for Professionals**

Under contract with the Rhode Island Department of Health, the Autism Project of Rhode Island provides outreach to the community. A newly developed Summer Institute (held in 2009) educated and trained professionals, including school personnel, direct service providers, law enforcement and medical personnel on evidence-based practices. The Autism Project in collaboration with Johnson & Wales University in Providence, Rhode Island has developed six graduate-level courses for teachers and other educational personnel who are interested in developing specialized knowledge and skills in evidence-based practices for students with ASD/DD. The courses combine classroom time with field-based guided experience and include concrete and adaptive materials. The courses began in the summer of 2011.

During 2009, Rhode Island held a statewide conference that focused on critical issues to prepare youth for transition. Results from a Rhode Island survey of both parents and school personnel regarding understanding of the transition process and resources revealed a significant gap in knowledge with more than 77 percent reporting that they were not or were only somewhat knowledgeable of the individual survey items. Most striking was that 83 percent did not understand the eligibility guidelines for adult services. Currently, Rhode Island is planning the 2011 Summer Institute for school personnel that will focus on developing transition targets for middle school and high school students. (Transition/Serving and Evaluating)

**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 for 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. (Medical Home/Serving and Evaluating)

## WHAT DOES THIS MEAN FOR MY STATE?

As the above examples demonstrate, 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 critical indicators 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. 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 1) change practice to identify children earlier using best practice guidelines for screening and services; 2) make public and private resources work to meet the needs of families through waivers, insurance mandates and best practice guidelines, and 3) develop a more comprehensive picture of the number, location, and service needs of children and youth with ASD/DD in their state.

For those state programs that are completing new or expanded roles in building systems of care for children and youth with ASD/DD, the suggested categories and concrete examples can serve as an initial point of discussion. Both the leaders of these state initiatives and the resources they have produced can help states in assessing their capacity at the agency and state-level (please see Appendix C for a set of discussion/assessment questions). 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.





## APPENDIX A

OUTCOME	State, Program Title & Level of Involvement <i>(based on Continuum of Involvement on page 8)</i>
<p><b>1</b> <b>Medical Home</b></p>	<p><b>Engaged and Aware</b></p> <ul style="list-style-type: none"> <li>• Illinois: Disseminating Resources (p. 22)</li> </ul> <p><b>Empowered and Equipped</b></p> <ul style="list-style-type: none"> <li>• Washington: Community Asset Mapping (p. 12)</li> </ul> <p><b>Serving and Evaluating</b></p> <ul style="list-style-type: none"> <li>• Illinois: Linking with Title V to Identify Medical Homes (p. 19)</li> <li>• Wisconsin: Increasing Awareness Virtually (p. 23)</li> </ul>
<p><b>2</b> <b>Insurance Coverage</b></p>	<p><b>Engaged and Aware</b></p> <ul style="list-style-type: none"> <li>• New Mexico: Influencing Payment Systems (p. 17)</li> </ul> <p><b>Empowered and Equipped</b></p> <ul style="list-style-type: none"> <li>• Rhode Island: Overall Leadership in the System of Care (p. 10)</li> <li>• Utah: Creative Leveraging of Resources (p. 18)</li> <li>• Wisconsin: Guidelines for Medicaid Waivers and Evidence-based Practices (p. 16)</li> <li>• Wisconsin: Informing Families about Financing Options (p. 18)</li> <li>• Washington: Combining Resources for Developmental Screening (p. 18)</li> </ul>
<p><b>3</b> <b>Screening</b></p>	<p><b>Engaged and Aware</b></p> <ul style="list-style-type: none"> <li>• New York: Linking Pediatricians to Screening/Referral (p. 12)</li> <li>• Washington: First Steps in Surveillance (p. 21)</li> <li>• Missouri: Using Data to Find Families and Determine Service Needs (p. 20)</li> <li>• Wisconsin: Sharing Data to Address Issues (p. 21)</li> <li>• New Jersey: Addressing Identification Delays in Minority Children (p. 22)</li> </ul> <p><b>Empowered and Equipped</b></p> <ul style="list-style-type: none"> <li>• New York: Interagency Task Force (p. 9)</li> <li>• Alaska: Combining Forces for Improved Screening (p. 9)</li> <li>• Alaska: Tearing Down the Silos to Make Systems Work (p. 11)</li> <li>• Illinois: Developing a Practice-Based Screening Protocol (p. 15)</li> <li>• New York: Leader in Development of Clinical Practice Guidelines (p. 15)</li> <li>• Washington: New Standard of Autism Screening Recommended (p. 16)</li> <li>• Rhode Island: Developing Screening Guidelines for EPSDT (p. 15)</li> <li>• Washington: Partnering with Leadership Education in Neurodevelopmental &amp; Related Disabilities (LEND) for Earlier Screening (p. 19)</li> <li>• New Jersey: Implementing an Autism Registry (p. 20)</li> </ul> <p><b>Serving and Evaluating</b></p> <ul style="list-style-type: none"> <li>• Missouri: Developing Best Practice Guidelines (p. 15)</li> <li>• Alaska: Linking Tribal Networks to Improve Screening (p. 17)</li> <li>• Rhode Island: Using Title V Data Information Systems to Improve Services for Children and Youth with ASD/DD (p. 20)</li> </ul>
<p><b>4</b> <b>Organization of Services</b></p>	<p><b>Engaged and Aware</b></p> <ul style="list-style-type: none"> <li>• Washington: Autism Task Force (p. 10)</li> <li>• Missouri: Enhancing the State System of Care (p. 9)</li> <li>• Missouri: Rapid Response Community Collaboratives (p. 13)</li> <li>• Missouri: Helping Families Access Resources and Financial Assistance (p. 17)</li> <li>• Missouri: Family Resource Service Expansion (p. 19)</li> <li>• Missouri: Online Training in ASD/DD Screening, Intervention &amp; Transition (p. 22)</li> </ul> <p><b>Empowered and Equipped</b></p> <ul style="list-style-type: none"> <li>• New Jersey: Providing Comprehensive Leadership to Multiple State Public-Private Initiatives (p. 9)</li> <li>• Wisconsin: Communities of Practice (p. 12)</li> </ul>
<p><b>5</b> <b>Families Roles</b></p>	<p><b>Engaged and Aware</b></p> <ul style="list-style-type: none"> <li>• Missouri: Families as Mentors (p. 13)</li> <li>• New Mexico: Families as Leaders (p. 14)</li> </ul> <p><b>Empowered and Equipped</b></p> <ul style="list-style-type: none"> <li>• Utah: Title V Leadership in Partnership with University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) (p. 10)</li> <li>• Illinois: Families Engaging Providers (p. 13)</li> <li>• Wisconsin: Helping Families Navigate the Service Maze (p. 19)</li> </ul> <p><b>Serving and Evaluating</b></p> <ul style="list-style-type: none"> <li>• New Jersey: Developing Leadership in Collaboration with Title V programs (p. 13)</li> <li>• Rhode Island: Family Participation (p. 14)</li> </ul>
<p><b>6</b> <b>Transition to Adulthood</b></p>	<p><b>Engaged and Aware</b></p> <ul style="list-style-type: none"> <li>• Rhode Island: Leadership in Transition (p. 12)</li> </ul> <p><b>Serving and Evaluating</b></p> <ul style="list-style-type: none"> <li>• Rhode Island: Training and Awareness for Professionals (p. 22)</li> </ul>

**APPENDIX B**

**State Title V Roles in Building Systems of Care for Children and Youth with ASD/DD Index with Change Concepts and Change Ideas**

This document contains an index of state Title V roles in building systems of care for children and youth with ASD/DD and then, on the following pages, shows each of the six areas and a list of Change Concepts and related Change Ideas that might be helpful in moving Title V roles in building systems of care for children and youth with ASD/DD along the Index. The Change Concepts have been chosen from the more complete list contained in the Improvement Guide and provide a broad description of key theories that have led to improvement in a number of settings. This table was adapted from the Title V Index developed by state Title V CYSHCN Directors participating in a learning collaborative led by the National Initiative for Children's Healthcare Quality (NICHQ).<sup>20</sup>

PLANNING	PRELIMINARY ACTION STEPS	IMPLEMENTATION	MASTERY	SUSTAINABILITY
<p><b>1. Overall leadership</b> A mission and vision for building systems of care for children and youth with autism spectrum disorder and other developmental disabilities (ASD/DD) has been established.</p>	<p>The mission and vision for building systems of care for children and youth with ASD/DD have been shared and communicated across the Title V program</p>	<p>The will and trust for realizing the mission and vision for building systems of care for children and youth with ASD/DD have been established within the Title V program and key stakeholders and partners.</p>	<p>The mission and vision for building systems of care for children and youth with ASD/DD is embedded within the Title V program. A number of goals associated with the mission and vision have been achieved and long term plans for sustaining these achievements are being developed.</p>	<p>Goals associated with the mission and vision for building systems of care for children and youth with ASD/DD are met consistently. Lessons learned are shared and acted on across the Title V program in an environment of mutual trust. Plans for the long-term sustainability of the goals are being executed.</p>
<p><b>2. Partnerships across public and private sectors</b> The Title V program's mission and vision to build systems of care for children and youth with ASD/DD include areas that are specific to partnerships across public and private sectors/constituency.</p>	<p>Key public and private sector constituencies have been identified and initial relationships have been established.</p>	<p>A number of programs have begun to partner effectively with key public and private sector constituencies.</p>	<p>A number of targets in the Title V program's mission and vision for building systems of care for children and youth with ASD/DD have been met in partnership with key public and private sector constituencies.</p>	<p>Partnerships with key public and private sector constituencies have been sustained and have led to the realization of relevant targets in the Title V program's mission and vision for building systems of care for children and youth with ASD/DD.</p>
<p><b>3. Quality Improvement</b> The Title V program's mission and vision for building systems of care for children and youth with ASD/DD includes areas that are specific to quality improvement.</p>	<p>The quality improvement mission and vision have been shared and communicated across key stakeholders and partners.</p>	<p>A number of quality improvement projects, in partnership with key stakeholders, partners and families are underway.</p>	<p>A number of quality improvement projects, in partnership with key stakeholders, partners and families have achieved positive results.</p>	<p>Quality improvement is embedded in all programs and process. Sustained results have been achieved. Lessons learned are consistently shared across key stakeholders, partners and families.</p>
<p><b>4. Use of available resources</b> The Title V program understands the need to maximize the use of available resources.</p>	<p>The Title V program is cognizant of available resources, including financial, personnel skill sets and knowledge systems.</p>	<p>Are actively engaged in maximizing productivity in some system of care areas by directly or indirectly leveraging available resources.</p>	<p>Has achieved some success in achieving targets by directly or indirectly leveraging available resources effectively.</p>	<p>Available resources are consistently levered so as to maximize the likelihood that the targets associated with the overall mission and vision for building systems of care for children and youth with ASD/DD are achieved.</p>
<p><b>5. Coordination of service delivery</b> The Title V program's mission and vision for building systems of care for children and youth with ASD/DD includes areas that are specific to service coordination.</p>	<p>Have identified where there are gaps in the provision and coordination of services.</p>	<p>Plans are in place to reduce gaps in the provision and coordination of services.</p>	<p>Some success has been achieved in reducing gaps in the provision and coordination of services.</p>	<p>Rapid improvements in service and coordination are consistently realized in partnership with key stakeholders and families to remove these.</p>
<p><b>6. Data Infrastructure</b> The Title V program's mission and vision for building systems of care for children and youth with ASD/DD includes areas that are specific to data infrastructure.</p>	<p>The need to establish effective data systems has been communicated across key stakeholders and partners.</p>	<p>A number of data systems have been established.</p>	<p>A number of data systems exist and are routinely used to share system of care performance information across key partners and stakeholders.</p>	<p>Information of the whole system of care is shared routinely across key partners and stakeholders in a manner that informs the knowledge and actions required to meet the targets of the overall mission and vision for building systems of care for children and youth with ASD/DD.</p>

## APPENDIX C

### Key Questions for Building a Comprehensive System of Care for Children and Youth with ASD/DD

For those state programs that are completing new or expanded roles in building systems of care for children and youth with ASD/DD, the suggested categories and concrete examples should serve as an initial point of discussion.

The questions below, based on the Title V Index (see Appendix B) are meant as a suggested starting place for states as they assess present and desired capacity and roles in building systems of care for children and youth with ASD/DD.

#### Key Questions for Title V Programs

1. What is my state's current level of involvement in meeting the needs of and building systems of care for children and youth with ASD/DD based on the eight leadership areas and/or the six CYSHCN critical indicators?
2. What is the current level of involvement of the state Title V MCH and/or CYSHCN program in my state in meeting the needs of and building systems of care for children and youth with ASD/DD (state self-assessment)?
3. What are the most pressing needs in my state for families with children and youth with ASD/DD (Title V needs assessment)?
4. What is the goal level for the overall systems of care in my state for children and youth with ASD/DD?
5. What is the goal level for the state Title V program role and contribution to building systems of care for children and youth with ASD/DD?
6. Based on the strengths of my state, the strengths and capacity of the state Title V program and the needs of my states, what short- and long-term action steps should my program pursue?
7. Who are the key partners and what are the key factors that can help improve the state system of care?
8. As a state Title V program, which partnerships should the program develop and/or strengthen to ensure success?
9. As a partner with Title V, where should my program focus its activities?
10. Are there examples from other states that my program and partners should study and review?
11. How will we define successful outcomes in the short- and long-term?

## APPENDIX D

## Key Resources and Websites

- **The State Public Health Autism Resource Center (SPHARC)** is a comprehensive resource center for state Title V programs and others interested in improving systems for children, youth and families with autism spectrum disorders and other developmental disabilities (ASD/DD). The SPHARC website provides informational call recordings and materials, state spotlights/best practices in building systems of care for children and youth with ASD/DD, an expert's corner of key issues facing states, regularly updated resources for families and health care/service providers, and timely announcements for state Title V programs on ASD/DD ([amchp.org/spharc](http://amchp.org/spharc)).
- **The Interagency Autism Coordinating Center (IACC)** is a federal advisory committee that coordinates all efforts within the Department of Health and Human Services (HHS) concerning autism spectrum disorder. The IACC website provides information on meetings and events, IACC subcommittees, requests for public comment, news, publications and more ([iacc.hhs.gov](http://iacc.hhs.gov)).
- **The CDC *Learn the Signs. Act Early. State Plans*** can be found on the AUCD website at [aucd.org/template/event\\_mgt.cfm?type=&topic=105&parent=547&parenttitle=Materials from Past Events](http://aucd.org/template/event_mgt.cfm?type=&topic=105&parent=547&parenttitle=Materials%20from%20Past%20Events). Search by Act Early Regional Summits, and click on "State Materials" to access each state's plan.
- **The Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities (ITAC)** of the Association of University Centers on Disabilities (AUCD) provides technical assistance to interdisciplinary training programs to better train professionals to utilize valid and reliable screening tools to diagnose or rule out and provide evidence-based interventions for children with ASD/DD. The ITAC website provides news, resources, events, funding opportunities and more ([aucd.org/itac](http://aucd.org/itac)).
- **The Autism Society**, the nation's leading grassroots autism organization, exists to improve the lives of all affected by autism. The Autism Society website provides information on autism, living with autism, research, news, ways to get involved and more ([autism-society.org](http://autism-society.org)).
- **Autism Speaks** is the nation's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism, increasing awareness of autism spectrum disorders, and advocating for the needs of individuals with autism and their families. The Autism Speaks website provides information on autism, science, family services, advocacy, ways to give, news, events and more ([autismspeaks.org](http://autismspeaks.org)).



*Participant Ethan Algarate-Carter works on an arts and crafts project during the New Mexico State University and Mariposa Autism Service Center's Autism Summer Camp. (NMSU photo by Harrison Brooks)*

## APPENDIX E

### State Autism Implementation Grantees

**Alaska** – Alaska Department of Health and Social Services, Division of Public Health

**Hawaii** – Hawaii Pediatric Association Research and Education Foundation

**Illinois** – The Autism Program of Illinois (TAP), Hope Institute for Children and Families

**Maine** – Maine Department of Health and Human Services, Maine Center for Disease Control, Division of Family Health, Children with Special Health Needs

**Missouri** – University of Missouri Thompson Center for Autism and Neurodevelopmental Disorders

**New Jersey** – Statewide Parent Advocacy Network (SPAN) of New Jersey

**New Mexico** – University of New Mexico’s Center for Development & Disability

**New York** – New York State Department of Health, Bureau of Early Intervention

**Rhode Island** – Rhode Island Department of Health and the Autism Project of Rhode Island

**Utah** – Utah Department of Health, Title V Children with Special Health Care Needs Program

**Vermont** – Vermont Department of Health

**Washington** – Washington State Department of Health, Title V Children with Special Health Care Needs Program

**Wisconsin** – Wisconsin Department of Health Services, Division of Public Health, Title V Children and Youth with Special Health Care Needs Program



## END NOTES

- <sup>1</sup> National Initiative for Children's Healthcare Quality (NICHQ), Title V Index, <http://www.nichq.org/CYSHN/index.html>
- <sup>2</sup> Caring for Washington Individuals with Autism Task Force. Report to Governor and Legislature. Priority Recommendations and Implementation Plans, December 2007.
- <sup>3</sup> Caring for Washington Individuals with Autism Task Force, Report to Governor and Legislature, Priority Recommendations and Implementation Plans, December 2007.
- <sup>4</sup> Centers for Disease Control and Prevention (CDC), Autism Information Center, Department of Health and Human Services, February 2009.
- <sup>5</sup> Caring for Washington Individuals with Autism Task Force, Report to Governor and Legislature, Priority Recommendations and Implementation Plans, December 2007.
- <sup>6</sup> Final Report on State Services: Autism Spectrum Disorders (ASDs) Services Project, April 1, 2011) Abt Associates.)
- <sup>7</sup> Mandell, D.S., Listerud, J., Levy, S.E. & Pinto-Martin, J.A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry* 41:12 1447-1453.
- <sup>8</sup> Rosenberg, R.E., Daniels, A.M., Kiely Law, J., Law, P.A. & Kaufmann, W.E. (2009). Trends in Autism Spectrum Disorder diagnoses: 1994-2007. *Journal of Autism and Developmental Disorders*, 39: 1099-1111.
- <sup>9</sup> Mandell, D.S., Wiggins, L.D., Arnstein Carpenter, L., Daniels, J., DiGuseppi, C., Durkin, M.S., Giarelli, E., Morrier, M.J., Nicholas, J.S., Pinto-Martin, J.A., Shattuck, P.T., Thomas, K.C., Yeargin-Allsopp, M. & Kirby, R.S. (2009). Racial/ethnic disparities in the identification of children with Autism Spectrum Disorders. *American Journal of Public Health*, 99(3): 493-498.
- <sup>10</sup> The Centers for Disease Control and Prevention (CDC), Autism Spectrum Disorders, <http://www.cdc.gov/ncbddd/autism/addm.html>
- <sup>11</sup> The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program is the child health component of Medicaid. It's required in every state and is designed to improve the health of low-income children, by financing appropriate and necessary pediatric services. Additional information can be found at <http://mchb.hrsa.gov/epsdt/>
- <sup>12</sup> AMCHP Fact Sheet – 2011 Environmental Scan: State Title V Program Response To Autism Spectrum Disorder And Other Developmental Disabilities, September 2011. UNPUBLISHED DRAFT
- <sup>13</sup> Maternal and Child Health Bureau, Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs, [www.mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm](http://www.mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm).
- <sup>14</sup> Winson, Georgia, The Autism Program of Illinois (TAP).
- <sup>15</sup> [www.omr.state.ny.us/autism/images/hp\\_autism\\_interagencyreport.pdf](http://www.omr.state.ny.us/autism/images/hp_autism_interagencyreport.pdf)
- <sup>16</sup> [www.nyacts.com](http://www.nyacts.com)
- <sup>17</sup> Missouri Autism Guidelines
- <sup>18</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)
- <sup>19</sup> <http://www.autismguidelines.dmh.mo.gov>
- <sup>20</sup> National Initiative for Children's Health care Quality (NICHQ), Title V Index, <http://www.nichq.org/CYSHN/index.html>





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### Visit the SPHARC Website

For resources, promising practices, state snapshots and technical assistance call recordings, visit the AMCHP State Public Health Autism Resource Center (SPHARC) website at [amchp.org/spharc](http://amchp.org/spharc). SPHARC is a comprehensive resource center for state Title V programs and others interested in improving systems for children, youth and families with autism spectrum disorders. SPHARC provides facilitates ongoing peer to peer networks and timely exchanges of resources and information.

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).



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