

AMCHP Issue Brief

Environmental Scan: How State Title V Programs Are Responding to Autism Spectrum Disorder and Other Developmental Disabilities

INTRODUCTION

The rising numbers of individuals identified and diagnosed with autism spectrum disorder and other developmental disabilities (ASD/DD) poses a major challenge to state Title V programs. Autism spectrum disorder is characterized by deficits in social interaction, verbal and nonverbal communication, and repetitive behaviors or interests. These deficits present themselves differently in each child, with symptoms ranging from mild to severe, which constitutes the *spectrum* of ASD/DD.¹ The Centers for Disease Control and Prevention (CDC) now estimate that one out of every 110 children has an autism spectrum disorder. In response to this challenge, state Title V programs have developed new policies, programs and financing mechanisms to meet the diverse and often complex needs of children and youth with ASD/DD. In recent years, state Title V programs have led coordinated efforts to improve the system of care for the growing number of children and youth with ASD/DD, and in doing so, have also improved the system of care for all children and youth with special health care needs (CYSHCN). CYSHCN includes those

who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.²

METHODS

In an effort to document the level of activity among states in the area of ASD/DD, the Association of Maternal & Child Health Programs (AMCHP) conducted an environmental scan of state Title V program ASD/DD activities. This environmental scan provides insights into approaches that state Title V programs are taking to address the growing incidence of ASD/DD and catalogues ASD/DD activities that fit within the framework of the Maternal and Child Health Bureau (MCHB) critical indicators for CYSHCN (see text box below). Information was obtained through a text search for “autism” using information from the 2010 Maternal and Child Health Block Grant State Narratives contained in the Title V Information System (TVIS) online database. It does not represent an exhaustive list of every state ASD/DD activity.

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.

FINDINGS

Based on the findings of the environmental scan, state Title V programs are reporting a wide range of involvement in ASD/DD activities along the six MCHB critical indicators. Easy-to-use services and family-professional partnerships were mentioned most frequently (35 states and 20 states, respectively), and transition to adulthood was mentioned least frequently (9 states). Table 1 highlights the U.S. states and jurisdictions with known ASD/DD activities organized by the six MCHB critical indicators for CYSHCN. The findings of the environmental scan are further explored in the discussion section (pages four through seven).

OVERALL FINDINGS

The environmental scan of TVIS revealed that 45 of the 59 U.S. states and jurisdictions (40 states and five jurisdictions) mention some level of involvement with ASD/DD activities ranging from basic participation on state workgroups, to more involved activities such as developing autism-screening programs (Alaska), developing autism registries (Delaware), and using parent consultants to train families on behavioral therapies (Iowa). This level of activity reflects an increase of nearly 30 percent since a previous AMCHP review of the 2008 Maternal and Child Health Block Grant State Narratives.

Of the 45 U.S. states and jurisdictions that reported involvement in ASD/DD activities, 35 states (78 percent) reported easy-to-use services as a specific area of focus. This may be explained by the fact that this indicator can be broadly defined; many policies, programs and financing mechanisms can be considered to improve the ease of use of services within a state. Some examples reported by state Title V programs include: implementing quality-

improvement methodology through all programs and services for CYSHCN; assisting with the design, development, implementation and evaluation of systems of care for children and youth with ASD/DD; and convening ASD/DD workgroups as a platform to address issues surrounding ASD/DD and to develop recommendations.

The second most reported critical indicator was family-professional partnerships, with 20 of the 45 U.S. states and jurisdictions (45 percent) reporting involvement. State Title V programs recognize the importance of including families in program development and decision making, and have historically worked closely with family organizations such as Family-to-Family Health Information Centers and Family Voices. Examples of family-professional partnerships reported by state Title V programs include: funding family mentors to provide support to families of children and youth with ASD/DD at the state and local levels; employing family leaders to serve as a liaison between state Title V staff and families; and inviting parents of children and youth with ASD/DD to serve on state advisory councils and in family-professional partnerships.

Insurance and financing was the third most reported indicator, with 18 of the 45 U.S. states and jurisdictions (40 percent) reporting involvement. Insurance and financing is a well documented, critical need for families of ASD/DD and all CYSHCN, and with the passing of the Affordable Care Act of 2010, financing of care has come to the national forefront. This may provide insight as to why many states have designated insurance and financing as focus areas. Examples of insurance and financing reported by state Title V programs include: implementing state ASD/DD waivers; working with joint commissions to

Table 1.

Indicator	U.S. States and Jurisdictions with Known Autism Activities by MCHB Critical Indicator
Medical Home	AK, CT, IA, IL, MA, MN, MO, NM, NY, OH, OR, PR, UT, WA, WI [15]
Insurance and Financing	AK, AR, HI, IA, KY, MA, ME, MO, NE, NJ, OK, PA, RI, TX, UT, VT, WA, WI [18]
Early and Continuous Screening	AK, IA, MA, MN, MP, NH, ND, NV, OH, OK, OR, PA, PR, RI, WA, WV, WY [17]
Easy-to-Use Services	AK, AR, AS, AZ, DE, GU, HI, IA, ID, IL, IN, KS, MA, MD, MI, MN, MO, MP, NC, ND, NH, NJ, NV, NY, OR, PR, RI, TX, UT, VA, VI, VT, WA, WI, WY [35]
Family-Professional Partnerships	AK, DE, IA, IN, KS, ME, MN, MO, NC, NH, NM, OK, OR, RI, TX, UT, VT, WA, WI, WY [20]
Transition to Adulthood	AZ, IA, LA, MO, MN, NC, OR, RI, WA [9]

DISCUSSION AND STATE ACTIVITIES

The following pages further explore the environmental scan findings. Each section represents a MCHB critical indicator and is organized by the frequency in which it was mentioned as a focus area within state Title V programs. The *State Activities* section highlights important activities and initiatives that state Title V programs are undertaking to address the rising incidence of children and youth with ASD/DD. The *Opportunities* section highlights areas for growth in ASD/DD and documents technical assistance needs as gathered from the environmental scan of TVIS.

EASY-TO-USE SERVICES

Easy-to-use services were mentioned by 35 states in all 10 HRSA regions. An organized, accessible and family-centered service-delivery system is essential for children and youth with ASD/DD and their families. The level of services needed for children and youth with ASD/DD varies by the severity of the disorder, as well as other co-morbidities. It is critical that all children and youth with ASD/DD receive services, regardless of where their disorder falls on the autism spectrum.

State Activities

- Nineteen states and jurisdictions reported serving on state ASD/DD committees and/or task forces (AK, GU, HI, IA, IL, IN, KS, MO, NH, ND, NV, NY, OK, PR, UT, VT, WA, WI, WY).
- Fourteen states and jurisdictions reported efforts to educate parents, professionals and the public about ASD/DD and its impact, through disseminating resources, participating in fairs and sponsoring family members to take part in trainings (AK, AZ, GU, IA, IL, MN, MO, MP, NV, OR, RI, TX, UT, WA).
- Five states reported that they are providing ASD/DD resources and training materials to youth, families and professionals (AZ, MO, RI, UT, WA).
- Three states reported hosting multidisciplinary clinics, including ASD/DD diagnostic clinics (AK, MN, ND).
- Two states and jurisdictions are developing integrated service-delivery systems that enhance the capacity of individual communities to respond to the needs of CYSHCN, including ASD/DD (MO, MP).
- One state reported engaging providers, including the education system, around the challenge of building an ASD/DD registry (DE).

Opportunities

State Title V programs noted the need to develop a more integrated service-delivery system that enhances the capacity of individual communities to respond to the needs of children and youth with ASD/DD. Electronic state ASD/DD registries are helpful in organizing state services, but provider data is often limited, and ASD/DD registries do not continuously track children and families to determine if, and which, services were offered to registered children. Another reported need was the promotion of a greater variety in program options and resources for preschool students with ASD/DD.

FAMILY-PROFESSIONAL PARTNERSHIPS

Family-professional partnerships were referenced by 20 states in eight HRSA regions. Family involvement plays an important role in state Title V programs. Family members volunteer, advise and/or are employed by state Title V programs, bringing unique insight and experience and are prepared to advocate on behalf of maternal and child health. Families, professionals and community members must partner to help children and youth with ASD/DD reach current and future goals. Family-professional partnerships are a means of including families in decision making along with professionals at all levels of their child's care. In working toward a comprehensive and coordinated, family-centered system of care for children and youth with ASD/DD, it is crucial that state Title V programs continue to partner with families.

State Activities

- Sixteen states reported that parents and/or family members of CYSHCN serve as navigators, consultants and advocates, are active participants on committees, advisory councils and practice groups on ASD/DD, and are tasked with helping families navigate the state system of care (AK, DE, IA, IN, ME, MN, NH, OK, OR, RI, TX, UT, VT, WA, WI, WY).
- Nine states reported involving families through family-professional partnerships (CT, KS, MA, NC, OH, OR, RI, UT, WA).
- Four states reported providing financial compensation to engage families in ASD/DD work (KS, MO, UT, WA).
- Two states employ family liaisons statewide to serve as resources for families at the local level (NM, OK).
- One state has developed navigation tools for persons with ASD/DD and their families (NM).

Opportunities

As a general area of need, state Title V programs reported that family-professional partnerships should be further promoted at the community level. State Title V programs also reported that additional outreach to families of older children with ASD/DD is needed (e.g. once the child enters school). In addition to these, training opportunities, forums and support groups for parents of children and youth with ASD/DD are needed to link families to services.

INSURANCE AND FINANCING

Insurance and financing was mentioned by 18 states in all 10 HRSA regions, and is an integral part of the service-delivery system for CYSHCN. The complex medical, educational and related needs of children, youth and adults with ASD/DD require adequate private and/or public health insurance to cover the cost of services. However, private and/or public health insurance, such as the Children's Health Insurance Program (CHIP) and Medicaid, is often limited. State programs may also 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 ASD/DD leaders to push for state-level insurance mandates.

State Activities

- Five states are working to implement a Medicaid waiver that covers children and youth with ASD/DD (AK, AR, NE, RI, UT).
- One state has developed written materials for families and professionals on financing services for children and youth with ASD/DD to assist with service delivery (MO).
- One state reported participating in governance groups related to the implementation of the Global Medicaid Waiver resulting in the expansions of Early and Periodic Screening, Diagnosis and Treatment (EPSDT) standards to include oral health, and ASD/DD screening (RI).
- One state is working with joint commissions to pass private insurance mandated coverage for the identification and treatment of children with ASD/DD, including coverage for Applied Behavior Analysis therapy (RI).
- One state has a mandate for disability insurance policies and self-insured health plans to cover certain services for anyone with an ASD/DD, including coverage for intensive, in-home treatment (WI).

Opportunities

State Title V programs reported the need to identify cost-effective telehealth technologies. States that have not yet developed an ASD/DD waiver reported a need for additional technical assistance in this area. Enhanced medical reimbursement for state health providers was also noted as an area of need within states.

EARLY AND CONTINUOUS SCREENING

Early and continuous screening was referenced by 17 states in nine HRSA regions. Early diagnosis and intervention has been shown to improve outcomes for children and youth with ASD/DD³ as well as decrease the cost of lifelong care by as much as two-thirds.⁴ ASD/DD is present at birth, with an onset of symptoms occurring before 26 months. Accurate diagnosis is possible at 18-24 months or earlier. Parents often voice concerns around 18 months, but diagnosis is typically not made until the child is three years or older. Because of the diverse and complex needs of children and youth with ASD/DD, no 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 have initiated comprehensive efforts to meet the needs of these children and youth as well as their families.

State Activities

- Four states are using statewide screening clinics to increase overall screening rates (AK, ND, WV, WY).
- Two states convened statewide, universal developmental screening forums to develop plans and recommendations (NH, WA).
- One state is promoting culturally and linguistically-competent approaches to developmental screening for children of families whose primary language is not English and, when indicated, timely evaluation for ASD/DD in families' native language (MA).
- One state employed community consultants to provide ASD/DD screening trainings to primary care providers in local communities (OR).
- One state provides technical assistance on standardized measures of development regarding ASD/DD-specific screening (RI).
- One state increased reimbursements to encourage providers to perform complete EPSDT services and to support the extra time it takes to perform each screening (PA).

Opportunities

State Title V programs noted that even with adequate screening and referral, some children may not receive a diagnosis for quite some time. This is often due to a lack of providers that can follow up with children who have received positive screens for ASD/DD. State Title V programs also noted the need for increased ASD/DD-specific screening in preschools, as screening may be limited to broad developmental screening.

MEDICAL HOME

Medical home, which was mentioned by 15 states in seven HRSA regions, involves patients, physicians and families, and is a model for delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective to every child and adolescent.⁵ All children and youth, especially those with complex health conditions such as ASD/DD, deserve care within a medical home. Currently, less than half of children with ASD/DD receive this level of care.⁶

State Activities

- Thirteen states reported a focus on medical home for children and youth with ASD/DD (AK, CT, IL, MA, MN, MO, NM, NY, OH, OR, UT, WA, WI).
- Four states reported conducting quality improvement learning collaboratives and/or implementing quality improvement methodology (IA, IL, MN, UT); two of those states' quality improvement efforts were specific to medical home (IL, UT); Utah also reported training dental practices to become dental homes.
- Three states reported providing medical home training to health services providers and/or education workshops for Leadership Education in Neurodevelopmental & Related Disabilities (LEND) grantees (IL, NM, OR).
- One state reported community asset mapping (a mechanism for communities to identify partners and capacity) as one method being used to scan for state and local needs (WA).
- One state is convening a Medical Home Practice Group in conjunction with a Community of Practice on ASD/DD (WI).

Opportunities

Several state Title V programs reported efforts on increased early identification (such as CT), while others reported a focus on improved transition services for older individuals with ASD/DD (such as AK). One obstacle is that linkages between

primary and specialty care providers vary considerably within states. Another area of focus reported by state Title V programs is how to establish medical homes in rural areas that have a shortage of providers (AK, NM, UT). Additional technical assistance is needed in these areas.

TRANSITION TO ADULTHOOD

Transition to adulthood was mentioned by nine states in seven HRSA regions. Youth transition to adulthood is an ongoing process. For children and youth with ASD/DD this process also carries tremendous challenges, in which social and communication difficulties can impede the process of change. Among youth with ASD/DD, transition to adult health care, care planning and secondary education all carry added complexities. While transition may occur at different times for different youth, early planning and discussion between children and youth with ASD/DD, their families and providers may help ensure better options, opportunities and outcomes. One of the many challenges of transition is moving from an entitlement/mandated system of care, to a system based on eligibility or qualification. Mandated education programs are no longer available, and instead the individual and their family must navigate the uncertainties of the adult system of care, such as employment, legal and financial issues, and adult health care.

State Activities

- Three states reported utilizing transition toolkits for youth with special health care needs, including ASD/DD (MN, NC, RI). Transition toolkits are disseminated to parents and professionals to drive best practices in the diagnosis and treatment of CYSHCN within a family-centered framework.
- One state is taking part in a transition project that provides employment opportunities for youth with ASD/DD, and educates hospital staff and physicians about youth with ASD/DD (AZ).
- One state has youth represented on both a Family-to-Family Health Information Center council and the state ASD/DD council (IA).
- One state is partnering with existing state youth leadership programs to support the inclusion of youth with ASD/DD in leadership-development opportunities (MO).
- One state is funding an adolescent health transition project, one aspect of which is increasing access to health care for youth transitioning to adulthood (WA).

Opportunities

An ongoing challenge reported by states is a lack of adult health care providers who are trained in ASD/DD within the medical community. Some providers do not feel comfortable with their level of training in serving children and youth with ASD/DD, and may be reluctant to treat these patients. In addition, physicians often experience a lack of time and adequate reimbursement for their services, and may not discuss continuity of care with families or screen for secondary disabilities.⁷ Identifying and implementing effective approaches to training and mentoring adult health care providers in screening, referral and management of youth with ASD/DD is an area of need. Transition between service systems was also identified as an area in need of improvement.

CONCLUSION

The complexity of ASD/DD presents difficulties to state systems trying to address the needs of these children and their families. However, state Title V programs acknowledge that if they can meet the challenge of strengthening the system of care for these most complex children and youth, they will also strengthen the system of care for all CYSHCN.

To further the work of Title V programs addressing the needs of children with ASD/DD, AMCHP, through its State Public Health Autism Resource Center (SPHARC) will continue to collect and distribute information about state Title V program work that improves systems of care for children and youth with ASD/DD through activities that include: 1) providing technical assistance calls on key issues, 2) providing mentorship to states on key issues, 3) sharing and highlighting state successes and promising practices, and 4) facilitating learning and dialogue between states.

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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 www.amchp.org/spharc. SPHARC is a comprehensive resource center for state Title V programs and others interested in improving systems for children and youth with ASD/DD and their families. SPHARC facilitates ongoing peer networks and timely exchanges of resources and information.

For additional information about the AMCHP State Public Health Autism Resource Center (SPHARC), please contact Melody Cherny, Program Associate, Children and Youth with Special Health Care Needs at mcherny@amchp.org.



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¹ National Institutes of Mental Health (NIMH) definition of autism spectrum disorders.

² Health Resources and Services Administration, Maternal and Child Health Bureau definition of CYSHCN.

³ Autism Speaks: Early Intervention, <http://www.autismspeaks.org/family-services/tool-kits/100-day-kit/early-intervention>

⁴ The Autism Program of Illinois (TAP), *Early Autism Detection, Screening and Referral*.

⁵ American Academy of Pediatrics (AAP) definition of medical home, <http://www.aap.org/healthtopics/medicalhome.cfm>

⁶ National Survey of Children with Special Health Care Needs Data Resource Center, 2005/06 data.

⁷ AMCHP's SPHARC Technical Assistance Call on *Transition*, March 2010.

