

### Autism CARES Act Legislation and Funding

Autism spectrum disorder (ASD) is a range of developmental disabilities (DDs) affecting an estimated 1 out of 59 children.<sup>1</sup> Individuals on the autism spectrum vary widely in their symptomatic presentation, sometimes exhibiting impairments in social communication and interaction and repetitive patterns of behavior, interests, and activities. Once diagnosed, individuals face numerous challenges accessing recommended health, education, and related support services.

In 2014, the U.S. Congress passed the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act.<sup>2</sup> Under the act, the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB) supports grant programs that advance professional training, research, and the development of comprehensive, coordinated State systems of care for ASD and other DDs. HRSA has provided autism-related funding for programs since 2008.

This document is one of four describing the activities and successes of the following types of grants:

- **State Implementation and Innovation in Care Integration grants programs (referred to as State systems grants), as highlighted in this document**
- Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) training programs
- Developmental-Behavioral Pediatrics (DBP) Training Program
- Autism Intervention Research Programs

For more information about these programs, please visit <https://mchb.hrsa.gov/maternal-child-health-initiatives/autism>.

### State Systems Grant Program Purpose and Goals

The HRSA State Systems grant program supports States in improving access to comprehensive, coordinated healthcare and related services for children and youth with ASD and other DDs. In 2013 and 2014, HRSA awarded one-time State Systems grants to nine entities that included universities, public agencies, and nonprofit organizations. When those grants ended in 2016, HRSA awarded four new State Systems grants under a new name: Innovation in Care Integration for Children and Youth with Autism Spectrum Disorders and Other Developmental Disabilities Program. Although the program goals remained largely the same, HRSA modified some of the requirements and objectives for the Innovation in Care Integration grants. These grants focused on implementing three key strategies to integrate care at a State system level for children and youth with ASD/DDs: shared resources, family navigators, and telehealth.

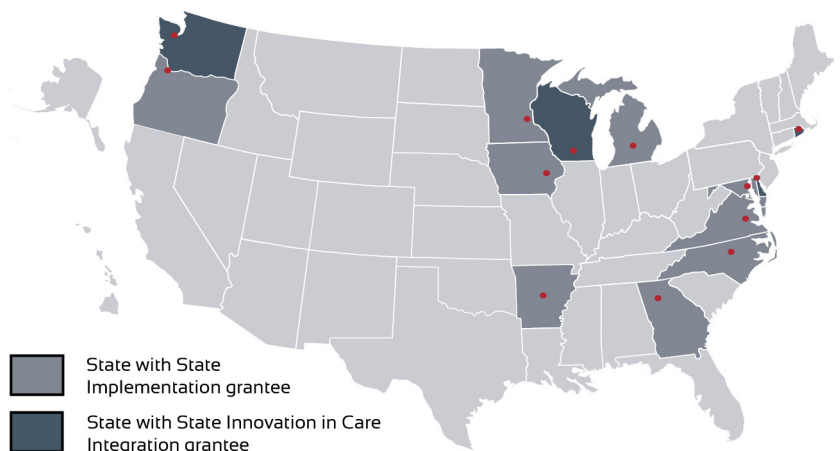
The primary goals of both types of grants follow:

- Promote early screening and referral for diagnostic evaluation and timely enrollment in early intervention services for children with ASD/DDs.

- Improve access to a coordinated, comprehensive State system of services for children and youth with ASD/DDs.
- Promote family-centered care and more shared decisionmaking among children/youth with ASD/DDs, their families, and providers.

Figure 1 shows the distribution of the 13 State Systems grantees across the United States.

**Figure 1. State Systems Grantee Locations**



### The Need for Improved Health and Related Systems of Care for People With ASD/DDs

ASD is characterized by a complex and heterogeneous array of symptoms that make the disorder difficult to diagnose and effectively manage once a diagnosis is confirmed. Accessing comprehensive diagnostic services is often the first of many challenges families encounter when they suspect their child has a developmental delay or related issue. Once a child has a confirmed diagnosis of ASD, additional challenges may include finding locally available and appropriate educational supports, behavioral interventions, and pharmacological treatments to effectively address the child's developmental and physical symptoms.

Ensuring coordination of services across all providers involved in the child's care represents another challenge families of children with ASD can face. According to a recent study using data from the 2009–2010 National Survey of Children with Special Health Care Needs, caregivers of children with ASD are more likely to report lack of care coordination compared with caregivers of children with DDs.<sup>3</sup> Results of the same study indicated a need for improved communications skills and stronger parent-professional partnerships, based on many parents' belief that their pediatrician or primary care provider fails to understand their concerns or provide information about their child's condition. The State Systems grants invested in a comprehensive set of initiatives to address these challenges and improve quality of healthcare and related services for children with ASD and their families.

### Key Contributions of the State Systems Grant Program

#### Improving access to early developmental screening, diagnostic evaluation, and intervention services

State grantees improved systems of care for children with ASD/DDs by ensuring families have access to early diagnostic screening, evaluation, and intervention services.



Virginia

State grantees addressed the need for improved access by training professionals to screen or evaluate children for ASD/DDs and make referrals to early intervention services

as needed. For example, Virginia implemented a tiered training model targeting providers who work with children at various critical points along the developmental trajectory. Each tier was designed to bolster capacity for screening and diagnosis within local communities that lacked a diagnostic clinic for ASD/DDs:

- Tier 1 training targeted childcare providers, early intervention professionals, and home visitors. The training focused on developmental milestones, the importance of early identification, and communicating with parents about developmental concerns. Early intervention professionals were also trained to administer and score the Modified Checklist for Autism in Toddlers, known as M-CHAT, a validated developmental screening tool for toddlers.
- Tier 2 training provided annual training on the Autism Diagnostic Observation Schedule, known as ADOS,<sup>4</sup> to local, multidisciplinary assessment teams including physicians, speech pathologists, school psychologists, and other community providers.
- Tier 3 training was an intensive 4-day seminar for pediatric specialists. In the years following the training, the number of children in two of the three demonstration sites who received an ASD screening by age 24 months increased steadily.



Michigan

Other State grantees improved access to early screening and diagnostic services by expanding existing programs. For example, Michigan leveraged ongoing efforts of a statewide physician quality-improvement program called *Screen for 3*. Prior to the State systems grant, the Michigan chapter of the American

Academy of Pediatrics offered *Screen for 3* free of cost to participating physicians and practices to promote

assessment of every child for DDs or special healthcare needs, using standardized, evidence-based developmental screening tools. Michigan expanded *Screen for 3* by incorporating enhanced information about ASD screening, plus information about referral sources and treatment options for Medicaid-enrolled children with ASD. Practices that participated in the expanded *Screen for 3* program in 2015 increased their developmental screening rates by 13 percentage points. Practices participating in 2016 increased their developmental screening rates by 19 percentage points. Results also showed a steady increase from 2013 to 2016 in the number and proportion of Medicaid-enrolled children aged 0–6 years who were diagnosed with ASD. The increase suggested broader use of M-CHAT-R, a parent-completed questionnaire that screens for developmental and behavioral problems in children aged 16–30 months needing further evaluation. This tool was not widely used in primary care practice prior to implementation of the expanded *Screen for 3* program.



**Arkansas**

Like Michigan, Arkansas boosted the efforts of an existing program to promote more timely access to ASD screening, diagnostic and early intervention services, and improved coordination with developmental-behavioral specialists. Before the

University of Arkansas's Medical Sciences (UAMS) Department of Pediatrics in Little Rock established the Community-based Autism Liaison and Treatment Project (CoBALT) in partnership with the Arkansas Department of Human Services Division of Developmental Disabilities, communities outside central Arkansas lacked locally available diagnostic services. Families had to wait for an available appointment and travel to the State's primary diagnostic center at UAMS. CoBALT aimed to address these problems by training professionals (including physicians, advanced nurse practitioners, speech pathologists, psychologists, and social workers) in underserved areas to provide developmental evaluations and referral for early intervention services. By providing families with local and timely access to assessment services, these teams also reduced wait times at UAMS,

which continued to provide comprehensive diagnostic services for particularly complex cases when children needed more extensive evaluation. The grantee provided 2-day refresher trainings to five regional CoBALT teams, thereby ensuring coordination between assessment teams and early intervention providers. Participating teams also received training in the use of Autism Detection in Early Childhood (ADEC), a standardized, validated tool for diagnosing autism, and an ADEC kit and packet of protocols for use in CoBALT clinics.

### Building more comprehensive and coordinated systems of care for people with ASD/DDs



**Georgia**

Several State systems grantees worked to increase referrals and ensure access to comprehensive coordinated services for people with ASD/DDs. Georgia addressed this problem through the use of parent partners. The grantee trained parents of children with ASD to work within

pediatric practices to help staff become familiar with locally available resources and referral procedures and to help connect families with needed evaluation or early intervention services. During the course of the grant, trained parent partners supported more than 100 families of newly diagnosed children.



**Oregon**

To promote access to more comprehensive coordinated services for ASD, State grantees also established integrated teams of educators, physicians, and social service providers. For example, Oregon established community-

based medical-educational teams with pediatricians, mental health providers, early intervention/early childhood special education providers, and parent partners to provide team-based evaluations of children at risk for ASD and referral for intervention services. Prior to establishment of these teams, education and medical professionals would conduct independent assessments of children for ASD/DDs. Results of an educational assessment

determined eligibility for school-based support services but did not determine eligibility for other services that require a medical diagnosis. A lack of communication and coordination between education and medical professionals contributes to parental confusion, delayed diagnosis, delayed entry into services, and fragmented care. The interdisciplinary teams established during the grant period addressed such problems and helped to connect families with appropriate services following diagnosis.

### Engaging families



**Maryland**

State systems grantees aimed to engage families in program planning, community outreach, and training for providers. Parent partners played a critical role in the Quality Improvement Learning Collaboratives

implemented under Maryland's grant. Project staff recruited parents of children with special healthcare needs to serve as parent partners in nine pediatric practices across Maryland that had agreed to participate in a learning collaborative. Parent partners supported clinicians and office staff in guiding families through the developmental screening process, referring them as needed to early intervention services and providing ongoing support to help them navigate the system of ASD services.

Parent partners were particularly helpful in ensuring that every child referred to early intervention services received appropriate follow-up. In some counties where the Office of Early Intervention made no more than three attempts to contact referred families, families faced the risk of "getting lost in the system." Parent partners worked to address these missed connections by following up with each family that received an early intervention referral to determine whether the family had been able to access the services. If no connection had been made, the parent partner would contact early intervention services directly on behalf of the family to ensure the family's access. Physicians overwhelmingly agreed the parent partners' ability to do the follow-up work for the practice was one

of the greatest strengths of the learning collaboratives. Five pediatric practices hired the parent partners directly to continue to provide services to families.



**Rhode Island**

Several grantees established or supported family navigator programs, which provide an innovative, evidence-informed strategy for improving access to coordinated, comprehensive services for children and youth with ASD/DDs. For

example, Rhode Island hired and trained family navigators to provide one-on-one support to families, facilitate support groups, and distribute campaign materials for *Learn the Signs. Act Early.*<sup>5</sup> at health fairs, with the goal of empowering families to make informed decisions and gain access to ASD services. Washington contracted with three family-led organizations to develop and conduct family navigator trainings. One of these organizations,

the Washington Autism Alliance and Advocacy, trained 127 family navigators and provided technical assistance to 379 organizations across the State to support families of children with ASD/DDs in choosing, understanding, and using health coverage, health providers, and ASD-related services.



**Washington**



**Michigan**

In addition to providing navigation support, grantees also aimed to empower families to partner with their child's healthcare provider in shared decisionmaking. Michigan provides one example. The grantee offered family empowerment training to 84 parents through a partnership with the Michigan Public Health

Institute. The Care Coordination: Empowering Families training offered participants practical tools on finding a medical home, communicating with providers and staff, and facilitating coordination among multiple providers.

### Reducing Disparities Among Underserved Populations



Delaware

Several research studies point to racial and income disparities in early identification and treatment of ASD.<sup>6,7,8,9</sup> State grantees implemented multiple strategies to reduce these disparities. For example, Delaware hired two

bilingual family navigators to increase access to services for Hispanic families throughout the State. These family navigators are increasing capacity by serving more children and families and ultimately increasing the number of at-risk children who enter early intervention services.



North Carolina

North Carolina partnered with the Assuring Better Child Health and Development (ABCD) program to provide pediatricians and primary care physicians across the State with ongoing webinar

training in developmental and ASD-specific screening. Funded by the Commonwealth Fund, the ABCD program enhances the ability of participating States to improve developmental services for young children from low-income families. Noting the success of these webinars, the grantee reported, "The latest available statistics show North Carolina to have one of the highest developmental screening rates in the country, with over 70 percent of ABCD pediatric practices using ASD-specific screening tools such as the M-CHAT."



Wisconsin

Wisconsin launched local projects called Engaged Community Quality Improvement Projects (ECQuIP) to improve access to ASD screening and related services in two medically underserved areas. The grantee launched the first ECQuIP in Milwaukee. Several partners, including the United Way of Milwaukee, the Children's Hospital

of Wisconsin Community Health program, Mental Health America of Milwaukee, and the Marquette University

autism clinic, helped to identify program sites in Milwaukee where community health workers would be trained to implement autism screening and family navigation services. Quality-improvement measures collected at baseline included the number of children in the ECQuIP community identified as at risk for ASD, referred for evaluation, diagnosed, and referred for services. Marquette University provided data collection support to track developmental monitoring and screening of children through the Milwaukee ECQuIP site. The grantee had started planning for a second site in rural Wisconsin at the time of the last progress report.



Iowa

Iowa established a partnership of Iowa's Child Health Specialty Clinics serving rural Iowans and the local area education agency to create the Regional Autism Clinic of Iowa. This clinic provides screening, evaluation, diagnosis, and intervention

recommendations for children that may have ASD/DDs. The regional centers conduct ADOS testing, record it, and transmit the recording to the grantee's medical director who can render a diagnosis. By using telehealth to expand local capacity for diagnostic evaluation, this pilot program has effectively provided families in one of the State's most rural areas with timely assessment services.

### Study Design and Methods

This document presents data from an evaluation of HRSA's Autism CARES grant programs. The evaluation covers activities across four HRSA grant programs (LEND, DBP, research, and State) between 2014 and 2017. The document draws from several data sources such as grantee reports, research network questionnaires and semistructured interviews with grantees, the Discretionary Grant Information System, and the National Information Reporting System for LEND and DBP programs.

# Building and Improving Systems of Care: Key Findings From an Evaluation of the Autism CARES State Systems Grant Program

## Endnotes

- <sup>1</sup> CDC (Centers for Disease Control and Prevention). (2018). Prevalence of autism spectrum disorder among children aged 8 years: Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014. *Morbidity and Mortality Weekly Report*. Retrieved from <https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm>
- <sup>2</sup> Public Health Service Act, § 3999BB(f), (42 U.S.C. 280i-1(f)) as amended by the Autism CARES Act of 2014 (P.L. 113-157).
- <sup>3</sup> Vohra, R., Madhavan, S., Sambamoorthi, U., & St. Peter, C. (2013). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Sage Journals* 18(7), 815-826.
- <sup>4</sup> ADOS is a semistructured assessment of communication, social interaction, and play; it is considered the “gold standard” in evaluating individuals suspected of having ASD/DDs.
- <sup>5</sup> *Learn the Signs. Act Early.* is an initiative launched in 2004 by the Centers for Disease Control and Prevention to raise awareness of developmental milestones, recommend developmental screening practices, and demonstrate the importance of early identification of DDs.
- <sup>6</sup> Durkin, M. S., Maenner, M. J., Meaney, F. J., Levy, S. E., DiGuseppi, C., Nicholas, J. S., ... Schieve, L. A. (2010). Socioeconomic inequality in the prevalence of autism spectrum disorder: Evidence from a U.S. cross-sectional study. *PLOS ONE* 5(7), e11551. Retrieved from <https://doi.org/10.1371/journal.pone.0011551>
- <sup>7</sup> Mazurek, M., Keefer, A., Shui, A., & Vasa, R. (2014). One-year course and predictors of abdominal pain in children with autism spectrum disorders: The role of anxiety and sensory over-responsivity. *Research in Autism Spectrum Disorders*, 8(11), 1508-1515.
- <sup>8</sup> Yingling, M. E., Hock, R. M., & Bell, B. A. (2017). Time-lag between diagnosis of autism spectrum disorder and onset of publicly-funded early intensive behavioral intervention: Do race-ethnicity and neighborhood matter? *Journal of Autism and Developmental Disorders*, 48(2), 561-571.
- <sup>9</sup> Zuckerman, K. E., Lindly, O. J., Reyes, N. M., Chavez, A. E., Macias, K., Smith, K. N., & Reynolds, A. (2017). Disparities in diagnosis and treatment of autism in Latino and non-Latino White families. *Pediatrics*, 139(5). Retrieved from e20163010; DOI: 10.1542/peds.2016-3010

## Grantees Included in the Evaluation

### State Innovation in Care Integration Grants

The Autism Project (Rhode Island)  
University of Delaware  
University of Wisconsin–Madison  
Washington State Department of Health

### State Implementation Grants

Arkansas Children’s Hospital Research Institute  
Georgia State University Research Foundation  
Michigan Department of Community Health  
Minnesota Department of Health  
Oregon Health and Science University  
The Parents’ Place of Maryland  
University of Iowa School of Medicine  
University of North Carolina at Chapel Hill  
Virginia Commonwealth University