

Building the Evidence Base:

Key Findings From an Evaluation of the Autism CARES Research Program

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.¹ 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.² 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:

- **Autism Intervention Research Programs, including five research networks and two research grant portfolios: (1) Field-Initiated Innovative Research Studies, known as Autism-FIRST grants; and (2) Secondary Data Analysis Research, known as Autism-SDAR grants—as highlighted in this document**
- Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) training programs
- Developmental-Behavioral Pediatrics (DBP) Training Program
- State Implementation and Innovation in Care Integration grants programs (referred to as State systems grants)

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

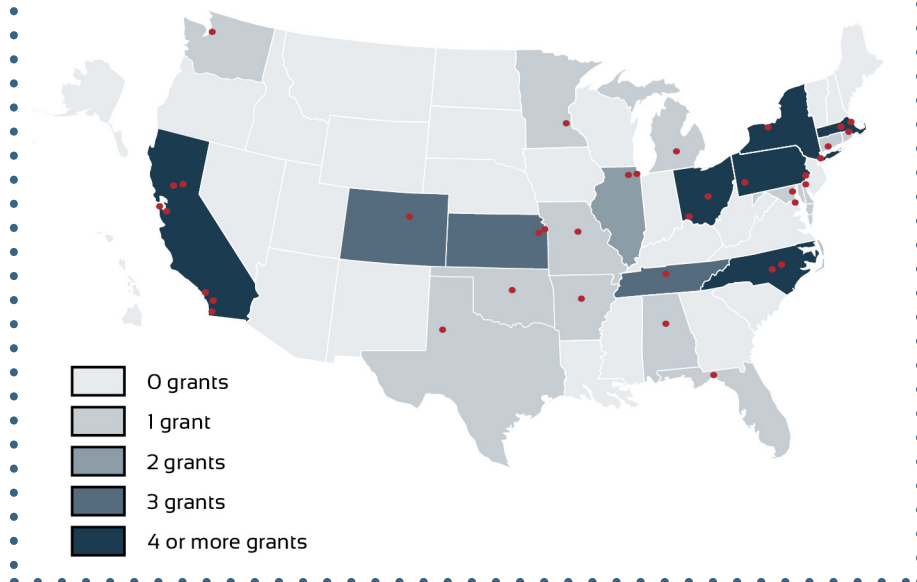
Autism CARES Research Program Purpose and Goals

HRSA autism research programs have four primary objectives:

- Support research studies that advance the current knowledge base pertaining to ASD/DDs and lead to improvements in interventions that address the physical and behavioral health needs of children and adolescents with ASD/DDs.
- Promote the development of evidence-based guidelines for intervention.
- Validate tools for ASD/DD screening or intervention (e.g., an assessment tool that can be used by primary care and other providers).
- Disseminate information to health professionals and the public, especially families affected by ASD/DDs.

The evaluation of 2014–2017 Autism CARES Research Program grantees includes five autism intervention research networks and two research grant portfolios. The research institutions and hospitals affiliated with the research programs span 22 States and the District of Columbia (see figure 1).

Figure 1. Research Program Locations



The Need for Research on ASD/DDs

Scientific evidence about the effectiveness of autism interventions has increased in recent years in part because of research funds made available through Autism CARES.³ Still, there are areas where evidence is lacking.^{4,5} For example, a review of evidence-based practices for children, youth, and young adults with ASD revealed few evidence-based interventions addressing motor skills, cognitive performance, vocational skills, and mental health.⁶ Much remains to be learned about the fidelity of interventions in real-world settings, timing and dose of interventions, and long-term or maintenance effects of interventions.^{7,8} Although the Autism CARES grantees have made significant efforts toward conducting intervention research with minority and underserved populations, socioeconomic, racial, and ethnic disparities persist in the identification and treatment of children with ASD.^{9,10,11,12} Routine standardized screening has the potential to reduce disparities in age at diagnosis and possibly reduce racial and ethnic disparities in access to services.^{13,14,15,16} Research program grantees worked to address these issues by building the evidence base for ASD/DD care and services.

Key Contributions of the Autism CARES Research Program

Conducting studies on a breadth of topics related to ASD/DD screening, diagnosis, intervention, and systems of care

From September 1, 2014, to August 31, 2017, the research program grantees conducted 84 studies to improve physical and behavioral health, standardize clinical practice, promote understanding of the transition to adulthood, assess overweight and obesity, and address disparities in access to care and early intervention. Figure 2 provides a summary of some of the more prevalent topics the Autism CARES research programs studied.

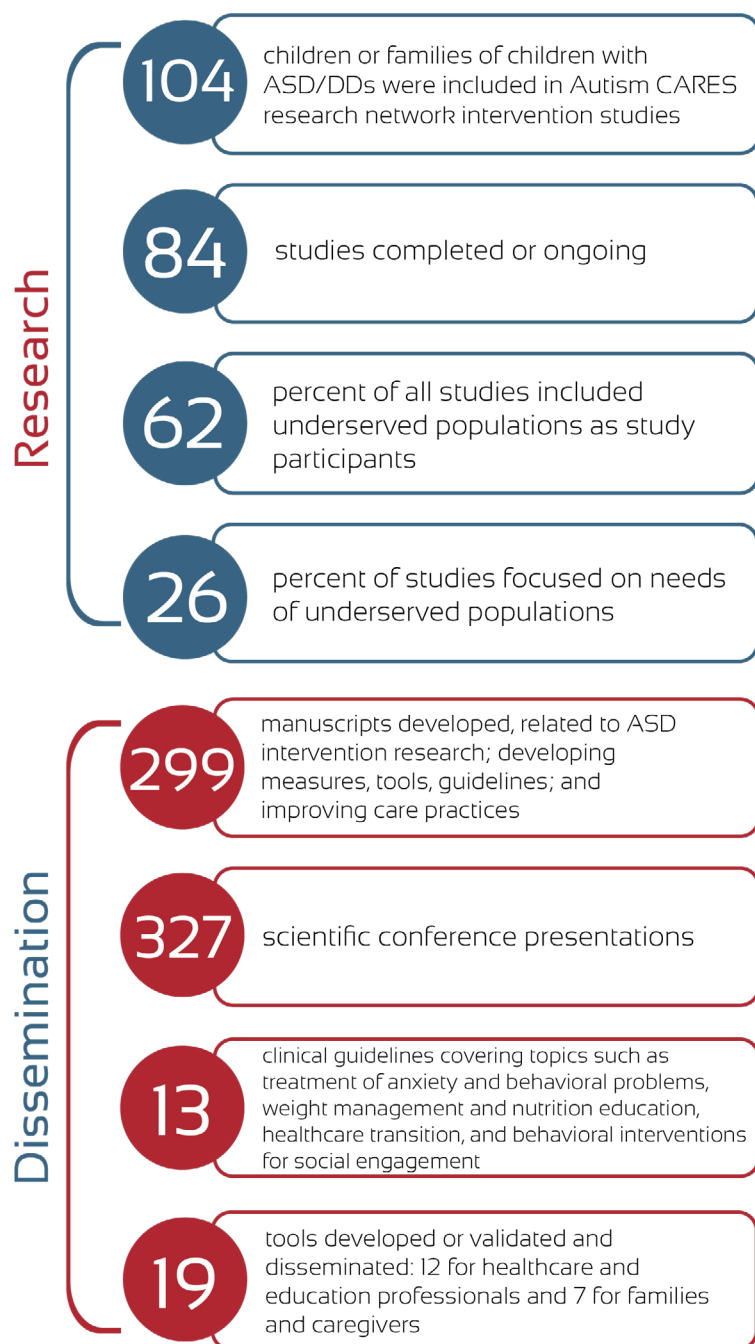
Figure 2. Number of Research Studies by Topic, 2014–2017



Note: Topics of interest were determined by HRSA prior to the evaluation. Some studies covered multiple topics.
Source: Evaluation-specific grantee questionnaires and interviews

Building the Evidence Base: Key Findings From an Evaluation of the Autism CARES Research Program

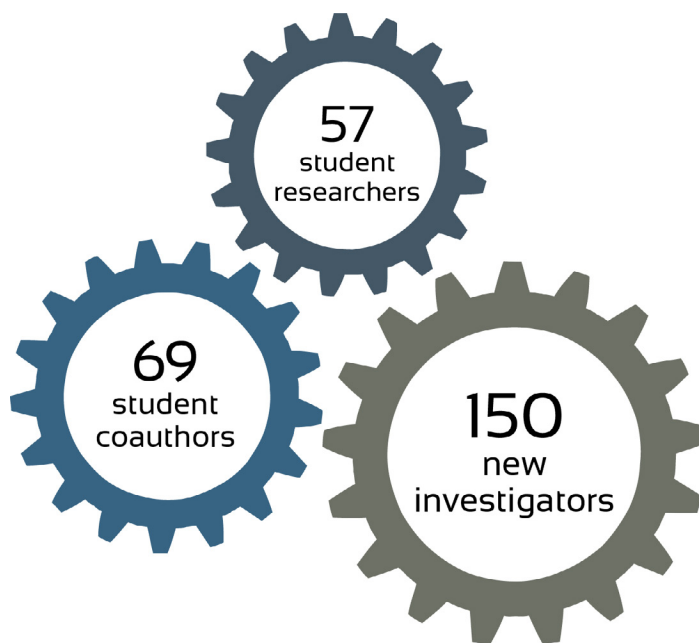
These grantees also advanced the evidence for ASD/DD interventions, conducting 26 intervention studies that resulted in 70 peer-reviewed publications to disseminate the results. Many of the intervention research activities involved families and underserved populations. The following summarizes research and dissemination outcomes of all research program grantees during the evaluation period 2014–2017:



Mentoring New Investigators

Grantees trained and developed students as ASD/DD researchers by including them on research projects and studies and inviting them to contribute to and be coauthors of publications and presentations. Principal investigators who receive Autism CARES research program funds have mentored hundreds of students, primarily at the graduate and doctoral level, in important roles on Autism CARES grants. Between September 1, 2014, and August 31, 2017, the Autism CARES research program involved 150 new investigators, 69 student coauthors, and 57 student researchers in their activities. See figure 3.

Figure 3. Number of New Investigators, Student Authors, and Student Researchers Involved in the Autism CARES Research Program, September 1, 2014–August 31, 2017



Building the Evidence Base: Key Findings From an Evaluation of the Autism CARES Research Program

Collaborating With Grantees and Other Stakeholders

The Autism CARES initiative sets up an infrastructure that facilitates opportunities for research collaboration among research program grantees, external stakeholders, and other Autism CARES grantees. Noteworthy examples of collaboration with external stakeholders follow:

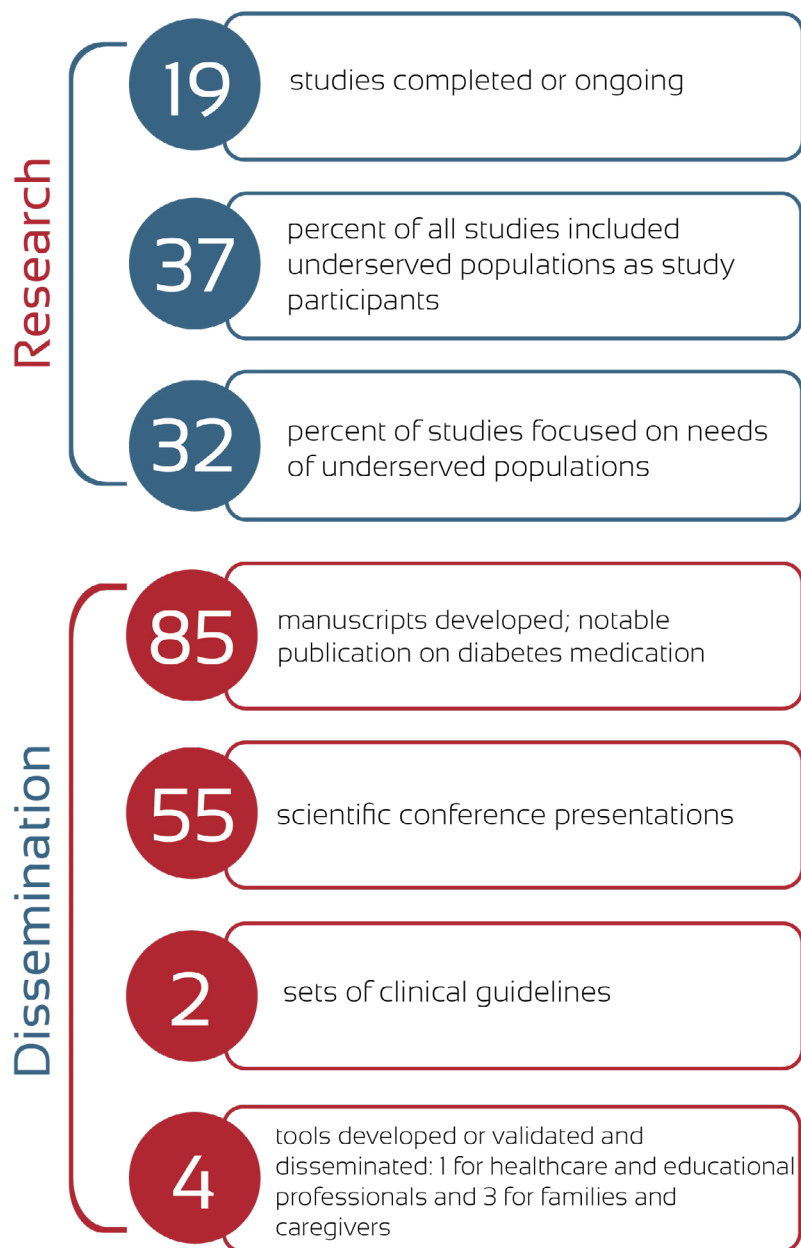
- **Collaboration with community partners.** The Autism Intervention Research Network on Behavioral Health—or AIR-B—collaborated closely with two community partners, Healthy African American Families¹⁷ and Fiesta Educativa,¹⁸ to recruit study participants at one of AIR-B's sites. Because AIR-B studies specifically target underserved and traditionally hard-to-reach populations, forming partnerships with community stakeholders actively engaged with the targeted population made recruitment and retention less challenging.
- **Collaboration with State government.** One Autism-FIRST study team collaborated with the Michigan Governor's Autism Council, which works with public and private insurance agencies covering autism intervention services. The study, *Comparative Efficacy of a Self-Directed and Therapist-Assisted Telehealth Parent Training Intervention for Children With ASD*, aimed to (1) examine the effect of a telehealth-based parent-mediated intervention for children with ASD on parent and child outcomes, (2) identify moderators and mediators of treatment response, and (3) identify predictors of parent adherence to the program. The grantee was in regular communication with the council and private insurers to ensure key stakeholders had the information they needed to translate study findings into practice. See figure 4 for examples of how collaborations can occur.

Figure 4. Autism CARES Research Program Collaborators



Key Contributions of the Autism Intervention Research Network on Physical Health—AIR-P

Established in 2008, the goal of AIR-P is to improve physical and medical health interventions for children and adolescents with ASD/DDs through research and the development of guidelines used in assessment and treatment of ASD/DDs. There are 14 network sites across North America. Below is a summary of the research and dissemination outcomes for AIR-P during the evaluation period:

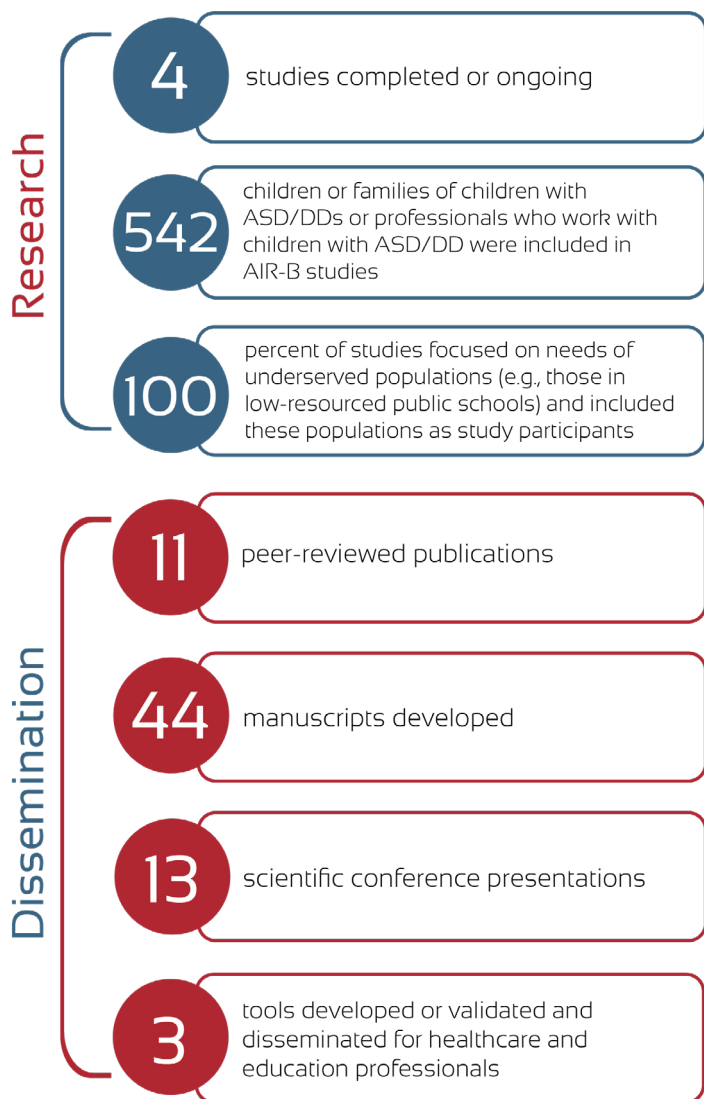


Highlights

- **Using telehealth technology to disseminate information.** AIR-P investigated how a collaborative telehealth intervention using Extension for Community Healthcare Outcomes Autism (ECHO) technology may increase provider knowledge, improve the clinical practice, and enhance the self-efficacy of providers in their care of children with ASD/DDs. As of October 2017, AIR-P had enrolled more than 150 primary care providers in the Project ECHO Autism telementoring project.
- **Developing anxiety management guidelines.** AIR-P developed two empirically based clinical guidelines for the management of anxiety¹⁹ and treatment of irritability and problem behaviors.²⁰ Both sets of guidelines were published in the 2016 *Pediatrics* Supplement, *Improving Health Care for Children and Youth With Autism and Other Neurodevelopmental Disorders*. AIR-P also produced three other publications related to guidelines.
- **Producing an EEG (electroencephalogram) guide for providers.** Developed by AIR-P, this publication gives providers information about the EEG procedure, how an ASD diagnosis might affect a child's experience of having an EEG, and how to help a child with ASD successfully prepare for and complete an EEG.
- **Creating a puberty and adolescence guide for parents.** AIR-P developed the *Puberty and Adolescence* toolkit that provides parents with guidance on the subject of puberty that can be directly applied to preteens with ASD. The toolkit aims to increase families' understanding of puberty and their ability to adapt to the changes with confidence.

Key Contributions of the Autism Intervention Research Network on Behavioral Health—AIR-B

The goal of AIR-B is to advance behavioral, mental, social, and cognitive interventions for individuals with ASD/DDs by testing behavioral and social treatments and developing tools and materials to aid intervention efforts. Established in 2008, AIR-B aims to decrease the discrepancies in behavioral health for low-resourced and underserved children with ASD and their families. The following summarizes research and dissemination outcomes for AIR-B during the evaluation period:



Highlights

- **Improving social engagement.** *Remaking Recess* is an intervention aimed to help children with ASD engage with peers at school. An AIR-B study of this intervention found it was effective in increasing social engagement of children with autism (aged 5–11) and typically developing peers.
- **Facilitating the transition to the school system.** *Building Better Bridges* is a multisite study on transitions in the school system that aimed to identify barriers to successful transitions between educational systems for children with ASD. The findings informed an intervention to improve transition outcomes for children with ASD and their families.
- **Providing support for the time between diagnosis and treatment.** *Mind the Gap* aims to address the need to increase access to care for underresourced children with ASD and their families. This study informed an ongoing evidence-based intervention that will support low-resourced parents during the time between ASD diagnosis and service initiation.
- **Managing daily routines.** The *Schedules, Tools, and Activities for Transitions in the Daily Routine* manual was developed for use by teachers in special education classrooms. It is designed to improve behavior and transitions of students with ASD. The intervention uses behavioral strategies found in functional routines to address classroom management and environmental structures in special education classrooms.

The Developmental-Behavioral Pediatrics Research Network—DBPNet

Founded in 2010, the mission of DBPNet is to conduct collaborative, interdisciplinary research in DBP that advances clinical practice, supports research training, and enhances the health and functional status of children with developmental and behavioral concerns and disorders, including children with ASD/DDs. DBPNet leverages the Society for Developmental Behavioral Pediatrics' national reach of more than 700 practitioners who care for children and families with developmental and behavioral problems. The following summarizes research and dissemination outcomes for DBPNet during the evaluation period:

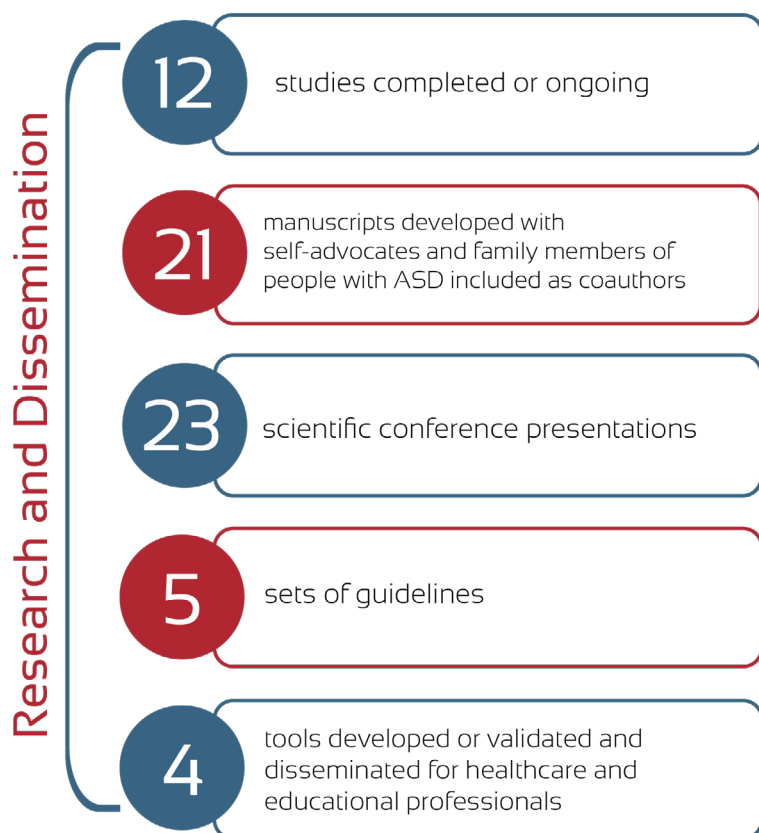


Highlights

- **Measuring peer relationships and stress experience.** Two ongoing, multisite DBPNet studies seek to validate the National Institutes of Health Patient-Reported Outcome Measurement Information System (known as PROMIS) measures with children with ASD to improve the assessment of changes in peer relationships²¹ and stress experience.²²
- **Using family navigators.** DBPNet studied whether the use of family navigators improves ASD services for young, newly diagnosed children; decreases parental stress; and improves family functioning. Families of children with ASD were involved in the design of the *Project EARLY* study; low-income families participating in the study received assistance in accessing diagnostic and treatment services.
- **Assessing obesity prevalence through collaboration among research networks.** The Healthy Weight Research Network (HW-RN) and DBPNet collaborated on the study, *Management of Overweight and Obesity in Children With Autism Spectrum Disorders by Developmental and Behavioral Pediatricians*. Using electronic medical records data available from three practices in DBPNet, the study, which was ongoing as of December 2017, examines the prevalence of obesity in children with ASD/DDs and will determine the extent to which this problem is identified by developmental-behavioral pediatricians.

The Healthcare Transitions Research Network—HCT-RN

HCT-RN, established in 2014, was the first research network to focus exclusively on the health, family, and social needs of adolescents and young adults on the autism spectrum. The following summarizes research and dissemination outcomes for HCT-RN during the evaluation period:



Highlights

- **Developing guidelines for transition to adulthood.** HCT-RN developed five clinical guidelines for transitioning youth, parents/caregivers, and providers to facilitate the transition from pediatric to adult healthcare. These transition care guidelines were developed in collaboration with key stakeholders through a consensus-building process that occurred during the HCT-RN Design Meeting's Quality Improvement and Practice workgroup. The five guidelines contribute to the network's overall mission to promote best practices in healthcare transitions through national professional organizations for physicians.
- **Assessing Barriers to Receipt of Services for Young Adults With Autism.** This qualitative study examined the experiences of families of young adults with ASD to better understand the dynamics that lead to poor outcomes for young adults. The goal was to help pediatricians understand family concerns and develop anticipatory guidance strategies.
- **A National Research Agenda for the Transition of Youth With Autism.** This survey distributed to HCT-RN Advisory Board members asked them to rate research topics according to perceived importance. The top-rated research topics set the official HCT-RN research agenda.

The Healthy Weight Research Network—HW-RN

HW-RN was established in 2013 to improve the Nation's understanding of factors contributing to the increased risk of overweight and obesity among children with ASD/DDs. The network conducts research and disseminates findings to improve prevention efforts, healthcare delivery services, and the health and well-being of children and adolescents with ASD/DDs. The following summarizes research and dissemination outcomes for HW-RN during the evaluation period:

Highlights

- **Developed weight management curricula.** HW-RN developed four guidelines that address the need for a curriculum for creating standards of care for weight management for children with ASD. Of the four guidelines developed, two were published by the end of the evaluation period.
- **Created the *Let's Go* toolkit.** Developed by HW-RN and Maine Medical Center, this toolkit was designed for professionals who work with children with intellectual disabilities. The toolkit includes strategies, tools, and resources that address the healthy eating and physical activity needs of children with intellectual disabilities and was designed to raise awareness of the needs of children with intellectual disabilities and support the expectation that, given appropriate support, children with intellectual disabilities can lead healthy, active lives.

Research

17

studies completed or ongoing

94

percent of all studies included underserved populations as study participants

6

percent of studies focused on needs of underserved populations

64

manuscripts developed; notable publications on obesity prevalence among ASD/DD population

58

scientific conference presentations

4

sets of guidelines

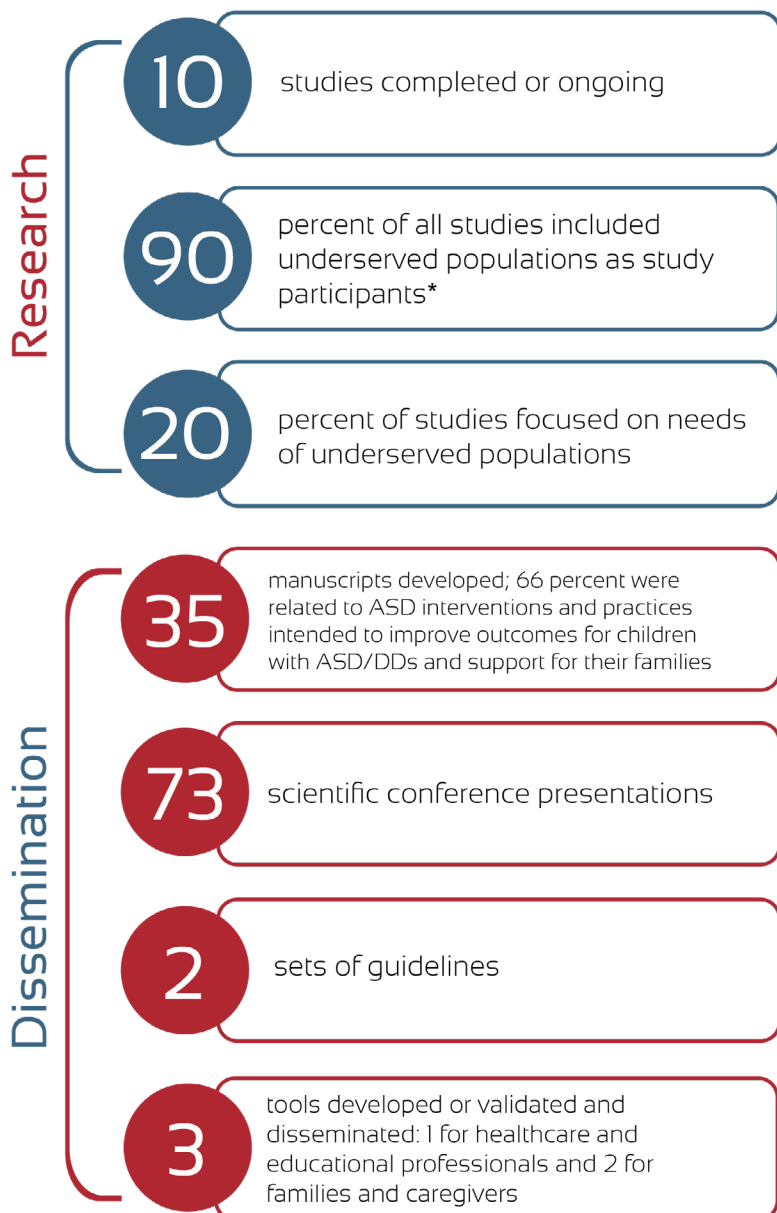
5

tools developed or validated and disseminated: 3 for healthcare and educational professionals and 2 for families and caregivers

Dissemination

Key Contributions of the R40 Autism Field-Initiated Innovative Research Studies—Autism-FIRST

The R40²³ Autism-FIRST program funds individual intervention studies that evaluate the effects of interventions and collect primary data to advance the current ASD/DD knowledge base. The Autism FIRST grants support 3-year studies on interventions that could result in evidence-based practices for ASD/DD. The following summarizes research and dissemination outcomes for Autism-FIRST during the evaluation period:



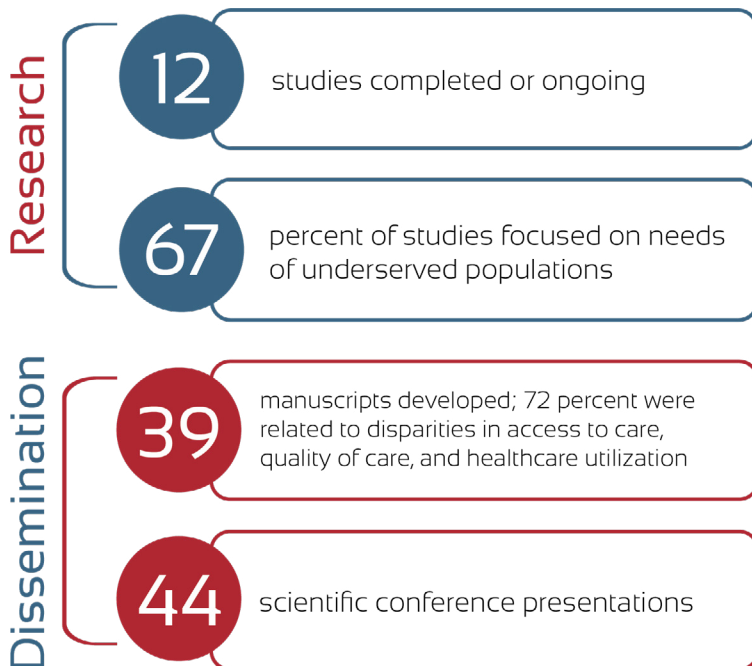
* The one study that did not include underserved populations was excluded because at the time of the evaluation, results were not yet available.

Highlights

- **Developing guidelines.** Although Autism-FIRST program grantees are not required to develop guidelines, 3 of the 10 grants developed intervention-related materials for broad dissemination to train others in evidence-based interventions for children with ASD/DDs. One 2013 Autism-FIRST grantee developed intervention guidelines for a 2-day teacher training workshop on minimally verbal children. A 2014 Autism-FIRST grantee developed a set of guidelines for conducting parent coaching over the internet.
- **Producing the *Toddlers and Families Together Manual: Addressing Early Core Features of Autism*.** Developed by a 2013 Autism-FIRST grantee from the University of North Carolina, Chapel Hill, this parent-friendly manual for the *Together* intervention has been found to reduce stress in parents of children with ASD and improve caregiver-child interactions. Behaviors including engagement, play, and joint attention were significantly improved in toddlers receiving the intervention. The manual is publically available in English and Spanish.
- **Developing protocols to improve Part C Services and Outcomes for underserved children with ASD.** These training protocols and materials were designed by an Autism-FIRST grantee to provide evidence-based strategies for parents and families to use with children in the home. The intervention was designed to improve caregiver-child engagement outcomes and improve child social and communication outcomes by training providers with a manualized professional development program and encouraging at-home activities that correspond to the intervention.

Key Contributions of the R40 Autism Secondary Data Analysis Research Program—Autism-SDAR

The R40 Autism-SDAR program funds individual studies that analyze publicly available datasets to advance the current ASD/DD knowledge base. These 1-year studies can inform ASD/DD interventions and highlight new areas of research. The following summarizes research and dissemination outcomes for Autism-SDAR during the evaluation period:



Highlights

- **Assessing disparities in service utilization.** The study titled *Racial and Ethnic Disparities in Diagnostic and Health Services of Children With Developmental Disabilities* found differences in quality of healthcare between non-Latino Asian and White children with special healthcare needs. The study also found that Latino children with severe conditions received significantly fewer services than their White peers, and Latino parents were four times more likely to receive a nonproactive response from a provider, indicating a difference in the pathway to diagnosis for White and Latino children.
- **Understanding disparities in emergency department utilization.** The study titled *Medical Care Utilization and Costs Among Transition-Age Young Adult Medicare Beneficiaries With Autism Spectrum Disorder* found a much greater proportion of transition-aged young adults (18–25) with ASD accessed emergency department services compared with the general population.

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 the Evidence Base: Key Findings From an Evaluation of the Autism CARES Research Program

Endnotes

- ¹ 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>
- ² Public Health Service Act, § 399BB(f), (42 U.S.C. 280i-1(f)) as amended by the Autism CARES Act of 2014 (P.L. 113-157).
- ³ Park, H. Y., Harwood, R. L., Yu, S. M., Kavanagh, L., & Lu, M. C. (2016). Autism and other developmental disabilities research programs of the Maternal and Child Health Bureau. *Pediatrics*, 137(2), S61–S66.
- ⁴ Kasari, C., & Lawton, K. (2010). New directions in behavioral treatment of autism spectrum disorders. *Current Opinion in Neurology*, 23(2), 137.
- ⁵ Camarata, S. (2014). Early identification and early intervention in autism spectrum disorders: Accurate and effective? *International Journal of Speech-Language, 16*(1), 1–10.
- ⁶ Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, S., ... & Schultz, T. R. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of Autism and Developmental Disorders*, 45(7), 1951–1966.
- ⁷ Kasari, C., & Lawton, K. (2010). New directions in behavioral treatment of autism spectrum disorders. *Current Opinion in Neurology*, 23(2), 137.
- ⁸ Dawson, G., & Burner, K. (2011). Behavioral interventions in children and adolescents with autism spectrum disorder: A review of recent findings. *Curr Opin Pediatr*, 23(6), 616–620.
- ⁹ Coury, D. L. (2015). Babies, bathwater, and screening for autism spectrum disorder: Comments on the USPSTF recommendations for autism spectrum disorder screening. *Journal of Developmental & Behavioral Pediatrics*, 36(9), 661–663.
- ¹⁰ Mazurek, M. O., Handen, B. L., Wodka, E. L., Nowinski, L., Butter, E., & Engelhardt, C. R. (2014). Age at first autism spectrum disorder diagnosis: The role of birth cohort, demographic factors, and clinical features. *Journal of Developmental & Behavioral Pediatrics*, 35(9), 561–569.
- ¹¹ Daniels, A. M., & Mandell, D. S. (2014). Explaining differences in age at autism spectrum disorder diagnosis: A critical review. *Autism*, 18(5), 583–597.
- ¹² Mandell, D. S., Wiggins, L. D., Daniels, J., DiGuseppi, C., Durkin, M. S., Giarelli, E., ... Kirby, R. (2009) Racial/ethnic disparities in the identification of children with ASD. *AJPH*, 99(3), 493–498.
- ¹³ Coury, D. L. (2015). Babies, bathwater, and screening for autism spectrum disorder: Comments on the USPSTF recommendations for autism spectrum disorder screening. *Journal of Developmental & Behavioral Pediatrics*, 36(9), 661–663.
- ¹⁴ Herlihy, L. E., Brooks, B., Dumont-Mathieu, T., Barton, M. L., Fein, D., Chen, C. M., & Robins, D. L. (2014). Standardized screening facilitates timely diagnosis of autism spectrum disorders in a diverse sample of low-risk toddlers. *Journal of Developmental and Behavioral Pediatrics*, 35(2), 85.
- ¹⁵ Daniels, A. M., & Mandell, D. S. (2014). Explaining differences in age at autism spectrum disorder diagnosis: A critical review. *Autism*, 18(5), 583–597.
- ¹⁶ Mandell, D. S., Wiggins, L. D., Daniels, J., DiGuseppi, C., Durkin, M. S., Giarelli, E., ... Kirby, R. (2009) Racial/ethnic disparities in the identification of children with ASD. *AJPH*, 99(3), 493–498.
- ¹⁷ Healthy African American Families is a nonprofit organization that works to improve the health outcomes of the African-American, Latino, Korean, and other minority communities in Los Angeles County by enhancing the quality of care and advancing social progress through education, training, and collaborative partnering with community stakeholders, academia, researchers, and government. See <https://haafphasetwo.squarespace.com/>.
- ¹⁸ Fiesta Educativa is a nonprofit organization that works to provide information and training to Latino families on how to obtain services for all persons with disabilities. See <http://fiestaeducativa.org/>.
- ¹⁹ Vasa, R. A., Mazurek, M. O., Mahajan, R., Bennett, A. E., Bernal, M. P., Nozzolillo, A. A., ... Coury, D. L. (2016). Assessment and treatment of anxiety in youth with autism spectrum disorders. *Pediatrics*, 137(2), S115–S123.
- ²⁰ McGuire, K., Fung, L. K., Hagopian, L., Vasa, R. A., Mahajan, R., Bernal, P., ... Hardan, A. Y. (2016). Irritability and problem behavior in autism spectrum disorder: A practice pathway for pediatric primary care. *Pediatrics*, 137(2), S136–S148.
- ²¹ This measure was validated with children aged 5–12.
- ²² This measure was validated with children aged 12–17.
- ²³ As of June 2018, HRSA has changed the grant activity code from R40 to R41.

Grantees Included in the Evaluation

Research Networks (Network Coordinating Center)

AIR-P

Massachusetts General Hospital for Children

AIR-B

University of California, Los Angeles (UCLA), Center for Autism Research and Treatment (CART)

DBPNet

The Children's Hospital of Philadelphia

HCT-RN

University of California, Los Angeles, Center for Healthier Children, Families, and Communities

HW-RN

University of Massachusetts Medical School

R40 Autism-FIRST Grantees

Hugo W. Moser Research Institute at Kennedy Krieger, Inc.
Michigan State University
University of Colorado, Denver (two grants)

R40 Autism-FIRST Grantees (continued)

University of Massachusetts, Boston
University of North Carolina at Chapel Hill
University of Rochester Medical Center
Vanderbilt University (two grants)

R40 Autism-SDAR Grantees

American University and University of Maryland College Park
Brandeis University
Florida State University
Institute for Disability Policy, Brandeis University
Northern Illinois University
Temple University
Texas Tech University
Thomas Jefferson University
University of California, San Francisco
University of North Carolina at Chapel Hill (two grants)
University of Washington