

# Efforts To Improve Autism Spectrum Disorder Service Delivery Under the Autism CARES Act

## Research, Training, and State Systems Grants for FY 2014–2017

### Final Report

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# Executive Summary

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## **What is ASD and what is the Autism CARES Act?**

Autism spectrum disorder (ASD) is a range of developmental disabilities (DDs) affecting an estimated 1 out of 59 children (CDC [Centers for Disease Control and Prevention], 2018). Characterized by impairments in social communication and interaction and repetitive patterns of behavior, interests, and activities, ASD is diagnosed by observation of behaviors (Masi, DeMayo, Glozier, & Guastella, 2017). Although multiple psychiatric and medical comorbidities are commonly reported among individuals with ASD, individuals on the spectrum vary widely in their symptomatic presentation and levels of impairment. Once diagnosed, individuals face additional challenges accessing the array of health, education, and related support services recommended for them.

In 2014, the U.S. Congress passed the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act, thereby reauthorizing Federal investments in research, surveillance, and education activities related to ASD and other DDs (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)). Under the act, the Health Resources and Services Administration’s (HRSA) Maternal and Child Health Bureau (MCHB) receives funding to support grant programs that advance professional training, research, and the development of comprehensive, coordinated State systems of care for ASD and other DDs. HRSA’s Autism CARES grantees aim to accomplish one overarching goal: enable all infants, children, and adolescents who have or are at risk of developing ASD/DDs to reach their full potential by developing a system of services that includes screening children as early as possible for ASD/DDs, conducting early interdisciplinary evaluations to confirm or rule out ASD/DDs, and providing early evidence-based interventions when a diagnosis is confirmed. MCHB specified the following objectives for grant programs funded under the act:

- ▶ Increase awareness of ASD/DDs.
- ▶ Reduce barriers to developmental screening and diagnosis.
- ▶ Support research to advance evidence-based interventions for ASD/DDs.
- ▶ Promote the development of evidence-based guidelines for interventions.
- ▶ Train professionals to use valid and reliable developmental screening and diagnostic tools and to provide evidence-based interventions for ASD/DDs.

These grantees are also encouraged to consider issues related to youth with ASD as they transition to adulthood.

## **Which Autism CARES grantees are included in the evaluation?**

The funding supports four separate but complementary program areas. Through MCHB, HRSA has been supporting these programs with autism-related funding since 2008, following enactment of the initial legislation. The evaluation, covering the approximate period between 2014 and 2017,<sup>1</sup> included the following grantees:

- ▶ Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) training programs: 43 grants awarded in 2011; 52 grants awarded in 2016

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<sup>1</sup> See appendix A for more information on data sources and funding periods included in the evaluation.

- ▶ Developmental-Behavioral Pediatrics (DBP) training programs: 10 grants awarded in 2013
- ▶ Autism Intervention Research Programs including—
  - Research Networks: The Autism Intervention Research Network on Physical Health (AIR-P), awarded in 2014; the Autism Intervention Research Network on Behavioral Health (AIR-B), awarded in 2014; the Developmental-Behavioral Pediatrics Research Network (DBPNet), awarded in 2013 and again in 2016; Health Care Transitions Research Network (HCT-RN), awarded in 2014; and Healthy Weight Research Network (HW-RN), awarded in 2013 and again in 2016
  - Independent research studies: 10 R40 Field-Initiated Innovative Research Studies (Autism-FIRST) grants awarded between 2012 and 2013; 12 R40 Secondary Data Analysis Research (SDAR) grants awarded between 2012 and 2014
- ▶ State Implementation and Innovation in Care Integration grants: nine State Implementation grants awarded between 2013 and 2014; four State Innovation in Care Integration grants awarded in 2016
- ▶ National Resource Centers: The Autism CARES Act National Interdisciplinary Training Resource Center and the State Public Health Coordinating Center for Autism both awarded cooperative agreements in 2012 and again in 2017.

### ***How have Autism CARES grantees increased awareness of ASD/DDs and disseminated related information?***

While more communities and providers are aware of ASD after decades of outreach, and developmental screening rates have improved in some areas, the proportion of children who receive routine developmental screening remains low (Van Cleave et al., 2012). Grantees adjusted their awareness-building content and strategies, finding new ways to educate providers and the general public, and developing content to address remaining gaps in knowledge. Specifically, many focused on addressing the persistent disparities in early ASD/DD identification among underserved populations by customizing outreach and developing culturally appropriate materials for diverse groups.

During the evaluation period, grantees conducted several activities with the ultimate goal of reducing delayed identification of ASD/DDs. They offered thousands of continuing education courses, thereby reaching hundreds of thousands of healthcare professionals and other providers, and conducted conferences, workshops, office rounds and grand rounds, online courses, and webinars. Grantees also developed products for professional audiences including newsletters, videos, referral guides, and toolkits.

Grantees reached out to communities and families to increase knowledge about ASD/DDs, frequently partnering with community organizations and advocacy groups to enhance their efforts. Materials for the campaign *Learn the Signs. Act Early.* were used extensively for many of these efforts. Grantees also educated policymakers about ASD/DDs, leveraged web-based tools to increase awareness, and facilitated accommodations for individuals with ASD/DDs in public spaces and at public events. For supporting details related to increasing awareness, see chapter 4.

### ***How have Autism CARES grantees contributed to the training of professionals who provide services for children and youth with ASD/DDs?***

The LEND and DBP grantees increased the national workforce capacity to provide screening, diagnostic evaluation, and evidence-based intervention services for children with ASD/DDs through their medium- and long-term training programs for providers. During the evaluation period, the LEND and DBP programs enrolled more than 1,367 long-term fellows and 3,886 medium-term trainees annually. They also provided training on cultural and linguistic competency, life-course issues, and family-centered care and expanded their overall reach through distance learning approaches. During the 2014–2017 evaluation period, an annual average of nearly 1,300 long-term trainees and more than 2,000 medium-term trainees enrolled in clinical practica. An average of 113,623 children received interdisciplinary, diagnostics services to confirm or rule out ASD/DD services from LEND and DBP faculty and trainees each year, marking an 11-percent increase in the number of children receiving such services between 2014–2015 and 2016–2017. Training programs emphasized community service and leadership skills, with many graduates poised to occupy leadership positions in teaching, research, policy, and direct service across the country. For supporting details related to training professionals, see chapter 5.

### ***How have Autism CARES grantees contributed to ASD/DD research?***

The Autism CARES grantees, particularly the research networks and the Autism-FIRST and Autism-SDAR programs, advanced ASD/DD-related research in several ways. They conducted research on the efficacy of ASD interventions, developed medical and behavioral treatment guidelines, created assessment measures and toolkits for caregivers and providers, and developed guidelines for standards 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, better understand the transition to adulthood, and assess overweight and obesity. These grantees also advanced the evidence for ASD/DD interventions, conducting 26 intervention studies that resulted in 70 peer-reviewed publications. Many of the intervention research activities involved families and underserved populations.

Principal investigators who have received Autism CARES research program funds have mentored hundreds of students, primarily at the graduate and doctoral level. Both LEND and DBP programs have provided training on research methods to prepare trainees as leaders in the field as sophisticated consumers or as those generating their own research. By the end of 2017, research program grantees had prepared 299 peer-reviewed manuscripts related to ASD intervention research, developing measures, tools, and guidelines and improving care practices. Research grantees also delivered 327 scientific conference presentations related to interventions for ASD. During the evaluation period, Autism CARES research program grantees produced 13 sets of guidelines covering topics such as treatment of anxiety and behavioral problems, weight management and nutrition education, healthcare transition, and behavioral interventions for social engagement. During the evaluation period, research program grantees developed or validated and disseminated a total of 19 tools for healthcare and educational professionals. They also created products for families and caregivers to help them manage common challenges and train them on interventions. Together, their efforts expanded national understanding of ASD/DDs and increased the knowledge base on successful interventions. For supporting details related to ASD/DD research, see chapter 6.

### ***What efforts did Autism CARES grantees undertake to reduce barriers to care for children and youth with ASD/DDs and improve systems of care for this population?***

The LEND, DBP, and State systems grantees worked to improve the quality of care for children with ASD/DDs and their families by implementing broad systemic changes. To address gaps in service, grantees worked to improve access to early developmental screening, diagnostic, and early intervention services by expanding local capacity, reducing wait times for comprehensive diagnostic services by training providers to conduct developmental screening, and leveraging existing initiatives and resources to expand their reach. The grantees also worked to build more comprehensive, coordinated systems of care through improved referral and care coordination and by addressing gaps identified through community needs assessments.

Grantees ensured families were involved in planning, implementing, and evaluating their initiatives. They also promoted shared decisionmaking and created family navigator programs to leverage family members as valuable assets on the care team. Throughout their efforts, grantees focused on reducing disparities for underserved populations. For example, they created and expanded clinics in underserved regions and used telehealth technology to expand their reach. Collectively, these efforts improved systems that provide care and support for people with ASD/DDs and their families. For supporting details related to building and improving systems of care, see chapter 7.

### ***What efforts did Autism CARES grantees undertake to identify needs and develop services and supports for young adults with ASD/DDs transitioning to adulthood, and how have they helped families and communities with issues related to transition?***

As ASD prevalence has increased, so too has the number of adults with ASD/DDs. Grantees' activities during the evaluation period increasingly addressed the transition to adulthood, a new and critical focus outlined in the 2014 Autism CARES Act. Although much work in this area focuses on young children and early diagnosis, ASD/DDs are lifelong disabilities that affect needs throughout the lifespan, and grantees worked to support families during the critical time of transition.

Grantees undertook a wide array of activities to promote awareness and disseminate information about local transition resources to professionals and community members. Training program grantees incorporated transition-related content in their didactic training and ensured trainees had opportunities to support transition-aged youth during clinical training. Research program grantees conducted 14 studies to further the knowledge and understanding of the transition to adulthood among individuals with ASD/DDs and to direct the national research agenda to this issue.

Grantees also improved the systems of care to support youth as they transition to adulthood by conducting needs assessments with youth, families, and providers. They delivered clinical services at transition clinics and provided employment and postsecondary education support services. Grantees also improved the clinical systems within their institutions and at the State level to better support young adults with ASD/DDs. For supporting details related to the transition to adulthood, see chapter 8.

### ***How did the National Resource Centers support Autism CARES grantees?***

To promote collaboration among grantees and thereby increase their potential impact, HRSA funds the Autism CARES Act National Interdisciplinary Training Resource Center and the State Public Health Coordinating Center for Autism. These resource centers support a collaborative national network to help

ASD-related grantees carry out their objectives by providing training and technical assistance, supporting the annual Autism CARES conferences, offering resources and training materials to support grantees in areas of need, and managing data and reporting systems to help track and measure grantee successes. For supporting details related to the national resource centers, see chapter 9.

***How have grant programs progressed and what are the grantees' remaining challenges and opportunities?***

HRSA initiated Autism CARES-related funding opportunities more than a decade ago, amid growing national concern about ASD. Over the years, HRSA has increased the number of grantees and programs it funded and expanded key activities and areas of focus. Despite grantees' progress and accomplishments, contextual challenges remain, including generating and disseminating new research, reducing disparities and building a diverse workforce, developing sustainable coordinated systems of care, meeting the needs of youth with ASD/DDs as they transition to adulthood, and conducting State-level tracking. For supporting details related to overall grantee progress, challenges, and opportunities, see chapter 10.

# Chapter 1. Introduction

In 2014, the U.S. Congress passed the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act, thereby reauthorizing Federal investments in research, surveillance, and education activities related to autism spectrum disorder (ASD) and other developmental disabilities (DDs) (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)). Under the act, the Health Resources and Services Administration’s (HRSA) Maternal and Child Health Bureau (MCHB) receives funding to advance professional training, research, and the development of comprehensive, coordinated State systems of care for ASD/DDs. The funding supports four separate but complementary program areas:

1. Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) training programs
2. Developmental-Behavioral Pediatrics (DBP) Training Program
3. Autism Intervention Research Programs, including five research networks and two research grant portfolios
4. State Implementation and Innovation in Care Integration grants programs (referred to as State systems grants)

HRSA has been supporting these programs with autism-related funding since 2008, following enactment of the initial legislation. Two previous studies described the activities and accomplishments of these grant programs during the years 2008–2011 and 2011–2014, respectively. This report provides an update on grant-funded activities since the last study was completed in 2014 and summarizes grantees’ progress in improving ASD/DD services through training, research, and systems change initiatives.



HRSA implements the Autism CARES Act through MCHB, which leads the Nation in ensuring all women, infants, children, adolescents, and their families, including fathers and children with special healthcare needs, have access to high-quality healthcare. Each year, MCHB measures the effectiveness of more than 900 grants designed to promote and support the development of family-centered, culturally and linguistically competent, community-based systems of care. These programs often target specific population groups, such as low-income families, racial and ethnic minority families, children with special healthcare needs, and rural families. MCHB also builds service capacity by training health professionals, developing standards of care, and increasing the capabilities of State and local government MCHB programs.

## A. Overview of ASD and the Changing Healthcare Landscape

ASD represents a range of DDs affecting an estimated 1 out of 59 children (CDC [Centers for Disease Control and Prevention], 2018). Characterized by impairments in social communication and interaction and repetitive patterns of behavior, interests, and activities, ASD is diagnosed through observation of behaviors (Masi, DeMayo, Glozier, & Guastella, 2017). Although multiple psychiatric and medical comorbidities are commonly reported among individuals with ASD, individuals on the spectrum vary widely in their symptomatic presentation and levels of impairment. This heterogeneity, coupled with the lack of any generally accepted diagnostic biomarkers to date (Howson, Kruger, Melnyk, James, &

Hahn, 2017), make confirming or ruling out ASD particularly challenging. Once diagnosed, individuals face additional challenges accessing the array of health, education, and related support services recommended for them.

As coverage for ASD-related services continues to increase, research and treatment guidelines also change, and providers are faced with the challenge of staying informed. The national understanding of autism is continually evolving. While research on genetic risk and the underlying causes of ASD remain important, there is increased focus on “effective tools and strategies to maximize quality of life, and minimize disability, while also ensuring that individuals on the autism spectrum are accepted, included, and integrated in all aspects of community life” throughout their lifespan (Interagency Autism Coordinating Committee, 2017, p. vi).

Federal and State efforts to promote early identification and intervention have been in place for more than a decade; however, the need for support services for individuals with ASD/DDs as they age into adulthood has gained momentum more recently. With the rising number of children diagnosed with ASD comes an increase in the number of adults who need supportive services outside child-focused delivery systems. Providers, communities, and States must actively care for youth with ASD/DDs as they age into adulthood, preparing for the wave of young adults who will need services.

These ongoing and new challenges underscore the need for continued attention to research, professional training, and systems change. Within this policy and legislative context, researchers are working to understand which interventions and treatments are most effective, professionals are striving to keep up with evolving guidelines, and communities and States are building responsive systems to best support people with ASD/DDs from childhood to adulthood.

## **B. HRSA’s Implementation of the Autism CARES Act of 2014**

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HRSA’s Autism CARES investments have one overarching goal: enable all infants, children, and adolescents who have or are at risk of developing ASD/DDs to reach their full potential by developing a system of services that includes developmental screening of children as early as possible for ASD/DDs, conducting early interdisciplinary evaluations to confirm or rule out ASD/DDs, and providing early evidence-based interventions when a diagnosis is confirmed. HRSA investments also aim to ensure that all individuals with ASD/DDs have access to comprehensive, coordinated, community-based services that are family centered and culturally competent.

In accordance with Autism CARES legislation, HRSA specified the following objectives for grant programs funded under the act:

- ▶ Increase awareness of ASD/DDs.
- ▶ Reduce barriers to developmental screening and diagnosis.
- ▶ Support research to advance evidence-based interventions for ASD/DDs.
- ▶ Promote the development of evidence-based guidelines for interventions.
- ▶ Train professionals to use valid and reliable developmental screening and diagnostic tools and to provide evidence-based interventions for individuals with ASD/DDs.

## C. Report Overview

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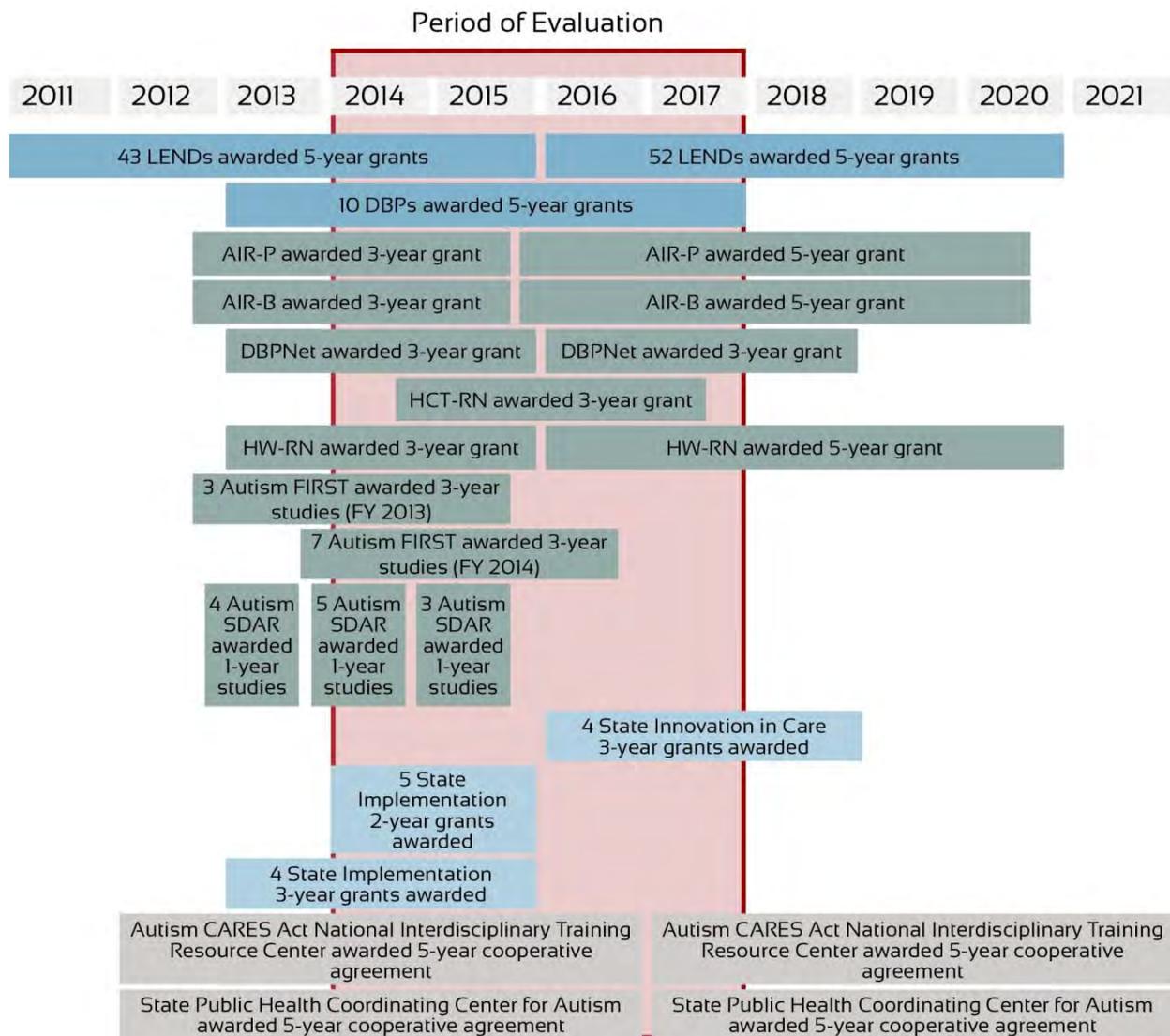
The following chapters describe grant-funded activities and associated progress toward improving training, research, and State grant programs aimed at improving healthcare and related services for ASD/DDs:

- ▶ Chapter 2 presents an overview of the grant programs included in the evaluation and describes each program’s objectives.
- ▶ Chapter 3 presents the research questions addressed by this study and the data sources used to address the questions and discusses the logic model in appendix C that shows the relationships among program inputs, outputs, and anticipated outcomes.
- ▶ Chapter 4 describes efforts by the grantees to raise awareness of developmental milestones and signs of developmental delays by providing practicing professionals with continuing education on developmental screening tools and referral practices, promoting understanding of ASD at the local and regional levels, and promoting awareness of ASD resources; the chapter also highlights research manuscripts and presentations.
- ▶ Chapter 5 reviews the LEND, DBP, and State grant programs’ workforce development activities aimed at building the supply of leaders and practitioners with expertise in ASD screening, diagnostic evaluation, and intervention. This chapter also includes data on the number of professionals trained in the use of evidence-based developmental screening tools and the conduct of interdisciplinary, diagnostic evaluations for children suspected of having ASD/DDs.
- ▶ Chapter 6 reviews HRSA-funded research studies that advance the evidence base on interventions for ASD/DDs and provide parents and clinicians with effective tools and guidelines for treating the physical and behavioral symptoms of ASD/DDs.
- ▶ Chapter 7 discusses systems of care, including reducing barriers to early developmental screening, diagnosis, and intervention and efforts to build more comprehensive, coordinated systems of care; engage families; and reduce disparities in ASD services for underserved populations.
- ▶ Chapter 8 describes grantee efforts to address transition-related challenges for youth with ASD and their families as the youth approach adulthood.
- ▶ Chapter 9 describes the role of the two resource centers HRSA funded to coordinate efforts of the training, research, and State grant programs and to provide those programs with technical assistance.
- ▶ Chapter 10 concludes with a summary of the grantees’ most notable successes. The final chapter also describes remaining challenges grantees face and presents grantee perspectives on the positive effects of the Autism CARES funding.

## Chapter 2. Overview of Grant Programs

Through its support of programs that include research, training, health-service delivery, and infrastructure-building activities, HRSA is building the Nation’s capacity to provide comprehensive, coordinated services for the growing population of individuals diagnosed with ASD/DDs. The evaluation period began where the previous evaluation ended. For the purposes of this report, we refer to the evaluation period as 2014–2017, although additional information about the reporting periods and program-level data reviewed for this evaluation appears in appendix A. Figure 2.1 shows the timeframe of the evaluation period in relation to the various grant periods, listing only the grant periods included in this evaluation. The grantees were awarded funding on an ongoing basis beginning as early as 2008 for some programs.

**Figure 2.1. Grant Periods in Relation to Evaluation Timeline**



Source: HRSA funding opportunity announcements

Table 2.1 illustrates the financial resources HRSA invested in each program from fiscal year (FY) 2014 to FY 2017 to provide context for the approximate scope of each program in relation to the others. As illustrated in figure 2.1, the annual number of grantees fluctuated. The grantees described below collaborated within and across grant programs and with external partners to extend their reach and leverage resources. For example, many grantees collaborated with organizations supported by the Title V Maternal and Child Health Service Block Grants, which fund partnerships between Federal and State maternal and child health services to improve access to high-quality healthcare for mothers and children.

**Table 2.1. Approximate Average Funding Amounts by Program, FY 2014–FY 2017**

Program	FY 2014	FY 2015	FY 2016	FY 2017	Approximate Average Annual Funding Amount
LEND Training Programs	\$28,608,816	\$28,703,650	\$31,948,877	\$32,597,509	\$30,464,713.00
DBP Training Programs	\$1,901,443	\$1,833,323	\$1,948,555	\$1,873,853	\$1,889,293.50
Research Networks	\$4,588,729	\$5,774,702	\$5,824,895	\$5,524,950	\$5,428,319.00
Autism-FIRST and Autism-SDAR	\$10,808,443	\$9,664,767	\$8,339,463	\$5,423,288	\$8,558,990.25
Autism CARES Act National Interdisciplinary Training Resource Center	\$809,182	\$816,201	\$777,141	\$771,000	\$793,381.00
State Public Health Coordinating Center for Autism	\$272,103	\$275,000	\$275,000	\$180,000	\$250,525.75

Source: Acquired from Autism CARES grantee Notice of Award information

## A. Training Programs

The LEND and DBP programs provide training to enhance the clinical expertise and leadership skills of a variety of healthcare and other professionals dedicated to caring for children with neurodevelopmental and other related disabilities, including ASD. Autism CARES funding for the LEND and DBP programs supports the training of short-, medium- and long-term trainees. Short-term trainees complete up to 40 hours of training in a single academic year. Medium-term trainees complete between 40 and 299 hours of training during a single academic year. Long-term trainees complete more than 300 hours of training. This study covers 43 LEND grantees funded in 2011, 52 LEND grantees awarded in 2016, and 10 DBP grantees funded in 2013. Appendix B provides a complete list of the universities and hospitals affiliated with each training program.

### 1. LEND Training Program

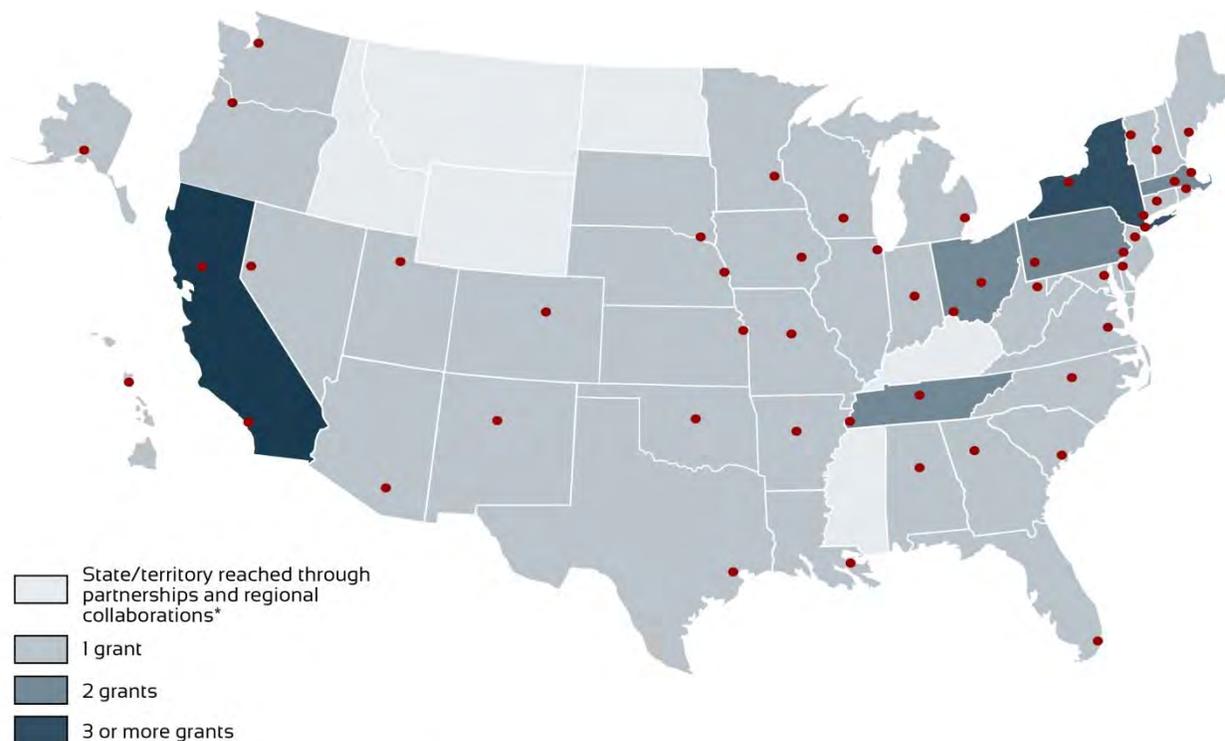
LEND grantees provide interdisciplinary training to prepare future leaders to improve the health of children who have or are at risk of developing neurodevelopmental disabilities such as ASD/DDs or similar conditions. Trainees represent disciplines that include psychology, speech-language pathology, occupational therapy, education/special education, pediatrics, psychiatry, and social work. The 52 LEND

programs included in the evaluation were located in 44 States leveraging partnerships and regional collaboratives to reach all 50 States plus Puerto Rico, the U.S. Virgin Islands, the Republic of Marshall Islands, the Federated States of Micronesia, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands (see figure 2.2).

LEND programs aim to improve healthcare delivery systems for children with ASD/DDs by—

- ▶ Providing interdisciplinary training that emphasizes leadership and clinical skills
- ▶ Engaging faculty from multiple disciplines to mentor trainees
- ▶ Increasing access to diagnostic evaluations and evidence-based interventions conducted by LEND faculty and trainees
- ▶ Collaborating with other LEND grantees
- ▶ Increasing the number of LEND trainees from underrepresented groups to improve the cultural competency of services provided
- ▶ Increasing the role of families and self-advocates as trainees and faculty in LEND programs to bring diverse perspectives to training programs and promote family-centered care

**Figure 2.2. LEND Program and Partnership Locations**



\*Partnerships include Puerto Rico, U.S. Virgin Islands, Marshall Islands, Guam, American Samoa, Federated States of Micronesia, Commonwealth of the Northern Mariana Islands

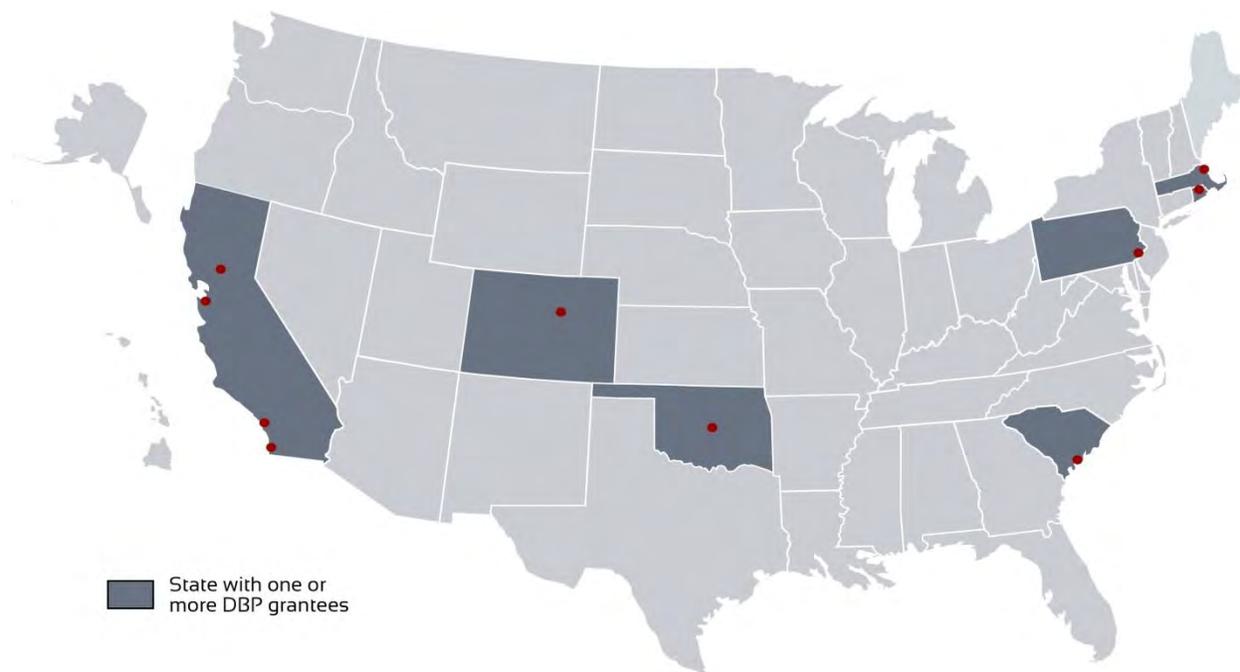
## 2. DBP Training Program

Developmental-behavioral pediatricians are pediatric specialists that provide diagnostic and treatment services to children with ASD/DDs. The overall goal of the DBP Training Program is to enhance the behavioral, psychosocial, and developmental aspects of pediatric care by—

- ▶ Supporting and preparing long-term fellows in DBP for leadership roles as clinicians, teachers, and investigators who can advance the field of DBP
- ▶ Providing pediatric practitioners, residents, and medical students with essential biopsychosocial knowledge and expertise to implement evidence-based developmental screening and interventions for ASD/DDs.

The 10 DBP training programs included in the evaluation were located in seven States (see figure 2.3).

**Figure 2.3. DBP Training Program Locations**



## B. Research Programs

The 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).



- ▶ Providing a collaborative laboratory for developing and testing evidence-based interventions and accelerating the adoption of effective interventions to improve care and reduce disparities
- ▶ Supporting development and mentorship of emerging or new investigators
- ▶ Developing and disseminating guidelines for interventions
- ▶ Accelerating the adoption of effective interventions in practice settings and communities, especially underserved communities
- ▶ Leveraging network capacity to compete for grant opportunities from other Federal and private sources

#### **b. The Autism Intervention Research Network on Behavioral Health**

The goal of the Autism Intervention Research Network on Behavioral Health (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. AIR-B consists of an NCC (University of California, Los Angeles, or UCLA) and three network CREs across the United States. AIR-B's activities focus on advancing knowledge related to the following:

- ▶ Using evidence-based strategies to support low-resourced parents in the gap between ASD diagnosis and service initiation
- ▶ Transitioning from one school to another (preschool to kindergarten, elementary to middle, and middle to high school)
- ▶ Using technology to assist in school transitions and to understand the social networks and social support of participants
- ▶ Collaborating with community partners from health agencies and schools that primarily serve low-resourced families and children

#### **c. The Developmental-Behavioral Pediatrics Research Network**

Founded in 2010, the mission of the Developmental-Behavioral Pediatrics Research Network (DBPNet) is to conduct collaborative, interdisciplinary research in developmental-behavioral pediatrics that advances clinical practice, supports research training, and optimizes the health and functional status of children with developmental and behavioral concerns and disorders, including children with ASD/DDs. DBPNet consists of an NCC (the Children's Hospital of Philadelphia) and 14 network CREs across the United States. DBPNet focuses on five core activities:

- ▶ Promoting and coordinating research activities in developmental, behavioral, and psychosocial aspects of pediatric care
- ▶ Improving clinical services, health, and related outcomes for children and adolescents with ASD/DDs
- ▶ Supporting multidisciplinary research that focuses on translation of research to practice
- ▶ Training a new generation of DBP researchers
- ▶ Fostering the implementation of multisite studies

#### **d. Healthcare Transitions Research Network**

The Healthcare Transitions Research Network (HCT-RN), established in 2014, focuses on the health, family, and social needs of adolescents and young adults on the autism spectrum. The network was established as a partnership that included the Center for Healthier Children, Families, and Communities at the University of California, Los Angeles, and the A.J. Drexel Autism Institute at Drexel University. HCT-RN focuses on the following activities:

- ▶ Improving life course outcomes for youth and young adults on the autism spectrum
- ▶ Enhancing the ability of the families of these individuals to cope effectively
- ▶ Increasing the capacity of communities to create adequate opportunities for successful lifelong living, learning, and working for these individuals and their families

#### **e. Healthy Weight Research Network**

The Healthy Weight Research Network (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. HW-RN consists of an NCC (University of Massachusetts Medical School, Shriver Center for Excellence in Developmental Disabilities) and 14 network CREs that contribute to research in obesity and/or health of children with ASD/DDs. HW-RN focuses on the following:

- ▶ Advancing the understanding of obesity risk factors in children with ASD/DDs
- ▶ Promoting the development of evidence-based solutions to achieve healthy weight in this population
- ▶ Disseminating research findings to broad and diverse audiences

## **2. Research Grant Programs**

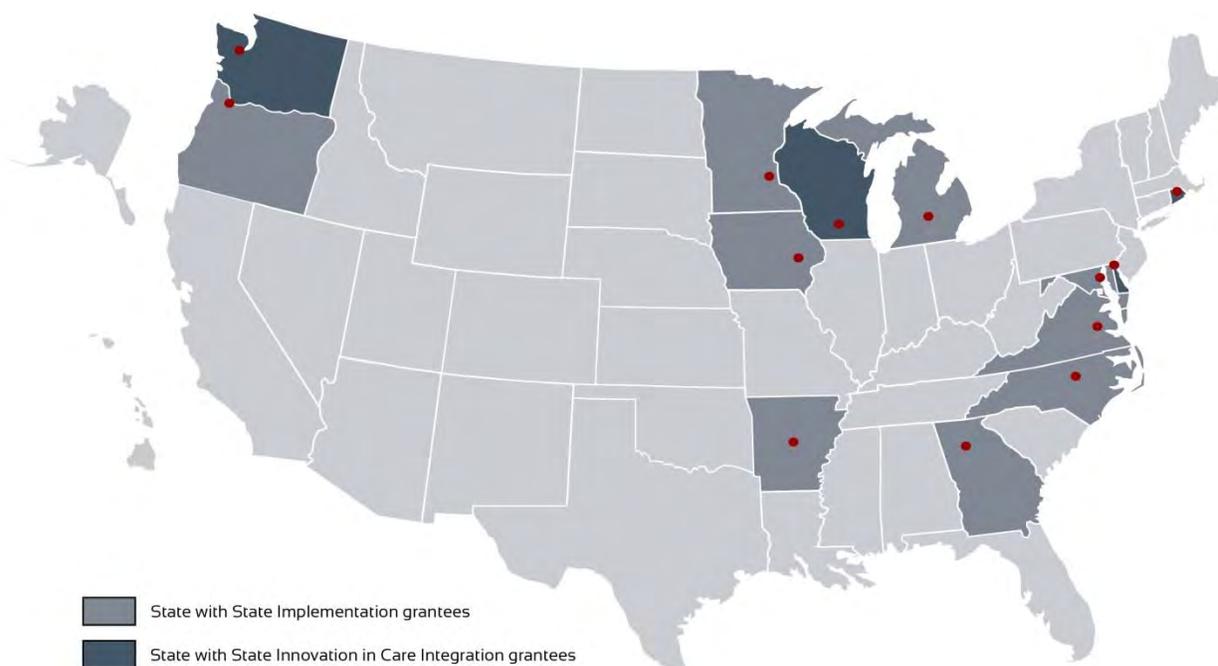
The Autism Field-Initiated Innovative Research Studies (Autism-FIRST) and Autism Secondary Data Analysis Research (Autism-SDAR) programs fund individual studies that collect primary (Autism-FIRST) and secondary (Autism-SDAR) data to advance the current ASD/DD knowledge base. The Autism-FIRST grants support 3-year studies on evidence-based practices for ASD/DD intervention. The Autism-SDAR grants support 1-year studies using analysis of secondary data that inform ASD/DD interventions through the evaluation of existing data sources. This study includes 10 Autism-FIRST grants and 12 Autism-SDAR grants. These grantees focus on the following:

- ▶ Addressing improvements in public health systems and infrastructure
- ▶ Reducing health disparities
- ▶ Increasing quality of care
- ▶ Promoting the health of ASD/DD populations

## C. State Implementation Grants and Innovation in Care Integration Grants

State Implementation and Innovation in Care Integration grants provide support for States to carry out plans for improving the system of services for children with ASD/DDs. HRSA awarded one-time State Implementation grants to public or nonprofit agencies through a competitive application process in 2013 and 2014. In 2016, HRSA released a new funding opportunity announcement for Innovation in Care Integration grants to replace the State Implementation grants that included updated program requirements and more specific objectives with quantified targets. This study includes nine State Implementation grants awarded between 2013 and 2014 and four State Innovation in Care grants awarded in 2016, all listed in appendix B (see figure 2.5).

**Figure 2.5. State Implementation Grant and State Innovation in Care Integration Grant Locations**



### 1. State Implementation Grants

The State Implementation grants awarded in 2013 and 2014 focused on six core activities:

- ▶ Increasing the number of children and youth with ASD/DDs who are identified by age 24 months, receive their first evaluation by 36 months, and are enrolled in intervention services by 48 months. Activities focus on reducing barriers to developmental screening, referral, and diagnosis
- ▶ Increasing access to culturally competent family-centered medical homes that coordinate care with pediatric subspecialties
- ▶ Improving the organization and capacity of community-based service systems within States for easy use by families
- ▶ Increasing public and provider awareness of the signs and symptoms of ASD/DDs

- ▶ Increasing the number of families satisfied with their role as partners with providers in shared decisionmaking
- ▶ Increasing family and youth involvement in ASD/DD program planning, implementation, and evaluation activities

## 2. State Innovation in Care Integration Grants

The State Innovation in Care Integration grants awarded in 2016 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. Each State identified different ways to implement these strategies and participated in a community of learners to share best practices and lessons learned. To achieve their overarching goals, these grantees focused on five specific activities:

- ▶ Increasing the proportion of children identified as at risk for ASD/DD diagnosis and referred for diagnosis and ASD/DD services
- ▶ Increasing the percentage of children with ASD/DDs within the State enrolled in services before 37 months of age
- ▶ Increasing the percentage of children with ASD/DDs residing in medically underserved communities within the State enrolled in services before 37 months of age
- ▶ Increasing the proportion of children and youth with ASD/DDs and their families who have increased knowledge, skill, ability, and self-efficacy in family-centered care
- ▶ Increasing the number of referrals of children at risk for ASD/DDs within the State to early intervention programs and/or specialists for comprehensive evaluation

## 3. State Planning Grants

In 2014, HRSA also awarded four 2-year Planning grants, which supported States in developing strategic plans to improve the system of services for children and youth with ASD/DDs. The grants were limited to States that had not received an Implementation grant; they helped fund a statewide needs assessment and efforts to assemble collaborative networks that contributed to strategic plan development. Planning grantees invested their limited funding in developing networks and plans. Though their efforts helped position them to implement activities aimed at systems change, the grants did not support implementation activities. As a result, the Planning grants are not covered in this evaluation.

## D. National Resource Centers

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HRSA funded two national resource centers focused on fostering collaboration among grantees.

### 1. Autism CARES Act National Interdisciplinary Training Resource Center

In 2012, HRSA awarded a cooperative agreement to the Association of University Centers on Disabilities (AUCD) to support the Autism CARES Act National Interdisciplinary Training Resource Center. Under this 5-year agreement, AUCD supports the LEND and DBP grantees by providing technical assistance, disseminating information and resources, and providing program coordination to promote collaboration across the grant programs.

## **2. State Public Health Coordinating Center for Autism**

In 2012, HRSA also funded a 5-year cooperative agreement with the Association of Maternal and Child Health Programs (AMCHP) to operate a State Public Health Coordinating Center for Autism. This center supports State systems grantees in their efforts to improve care for children and youth with ASD/DDs through activities including ongoing technical assistance, maintenance of a comprehensive web-based resource center, peer-to-peer learning events, and dissemination of best practices. To promote cross-State learning, the State Public Health Coordinating Center for Autism facilitates the exchange of resources and information through an ongoing peer-to-peer network.

## Chapter 3. Study Design and Methods

The purpose of this study was to describe the activities of HRSA’s Training, Research, and State grant programs, report their outputs and activities, and assess their progress in meeting the objectives established by HRSA in response to the authorizing Autism CARES legislation. As outlined in chapters 1 and 2, those objectives include training professionals to provide developmental screening, diagnostic evaluation, and evidence-based interventions for ASD/DDs; increasing awareness of ASD/DDs; disseminating information; advancing research; reducing barriers to developmental screening and diagnosis through improvements in systems of care; and identifying needs and developing services for youth transitioning to adulthood.

The program logic model (see appendix C) illustrates the intended trajectory from inputs to activities and outputs, and from outputs to anticipated short- and long-term outcomes. This model provided the basis for the research questions addressed in this descriptive study and helped identify the data points needed to address those questions. The following sections present the research questions, describe the data sources used to produce the study findings, and discuss the procedures used for analyzing and synthesizing data from multiple sources.

### A. Research Questions

Table 3.1 presents the overarching research questions that address each Autism CARES objective. The data to address these questions came from existing sources and primary data collection efforts. The complete list of research questions and data sources appears in appendix D.

**Table 3.1. Crosswalk of Autism CARES Objectives and Overarching Research Questions**

Broad Objective	Overarching Research Question
Train professionals to provide developmental screening, diagnostic evaluation, or intervention services for ASD/DDs	How have Autism CARES grantees contributed to the training of professionals who can provide services for children and youth with ASD/DDs?
Increase awareness and disseminate information about ASD/DDs	How have Autism CARES grantees increased awareness of ASD/DDs and/or disseminated related information?
Contribute to research/develop evidence-based and/or consensus-based guidelines and developmental screening tools	How have Autism CARES grantees contributed to ASD/DD research?
Reduce barriers to developmental screening and diagnosis through improvements in systems of care	What efforts did Autism CARES grantees undertake to reduce barriers to care for children and youth with ASD/DDs? What efforts did they undertake to improve systems of care for this population?
Identify transition needs and develop supportive services for youth transitioning to adulthood	What efforts did Autism CARES grantees undertake to identify needs and develop services and supports for young adults with ASD/DDs transitioning to adulthood? How have they helped families and communities with transition issues?

## B. Data Sources

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This report presents descriptive findings based on multiple data sources (using both existing information and new data collection instruments). A full list of data sources collected for each grant program appears in appendix D. The data sources include the following:



**Grantee reports:** HRSA requires grantees to submit interim and final reports that describe grant-funded activities and progress toward project goals. Each grant year, grantees submit documents (i.e., noncompeting continuation applications or progress reports) to update HRSA on project activities and accomplishments for the reporting period. At the end of the grant, grantees submit final reports summarizing grantee objectives and accomplishments, barriers encountered, and responses to summary questions regarding the grantee's overall experiences over the entire project period. The study team reviewed and abstracted data from grantee reports submitted between 2014 and the end of 2017.



**Research networks questionnaire:** Insight developed a data collection instrument for Research program grantees to gather information about research grantee activities to develop guidelines, develop and validate tools, mentor new investigators, disseminate research products, and improve ASD service delivery. The Office of Management and Budget (OMB) approved the use of this questionnaire.



**Semistructured interviews:** To supplement the information grantees submit in their reports, Insight conducted in-depth interviews with current project directors. During the interviews, staff gathered additional details about program-level activities and accomplishments related to the grantees' Autism CARES objectives. Interviews provided a rich context for understanding the data reported by grantees. The study team developed customized interview protocols for each program and conducted 60-minute interviews with representatives of each grant. For grants that operate a joint LEND and DBP program, interviews lasted 90 minutes. After receiving approval from OMB, researchers conducted the interviews between October and December 2017. All interviews were recorded and transcribed.



**Discretionary Grant Information System (DGIS):** DGIS is a program- and performance-measurement system developed by HRSA's MCHB to assess the effectiveness of its programs and to support project officers in monitoring the progress made under its grants. MCHB has developed 37 national performance measures and many program-specific performance measures across various maternal and child public health areas. The performance measures for a given program are assigned by MCHB based on their applicability to that program.



**National Information Reporting System (NIRS):** NIRS is a web-based data reporting system developed and managed by AUCD. LEND and DBP grantees use this system to report data on their training programs, projects, activities, and products to comply with Federal reporting requirements. Insight worked with MCHB and AUCD to develop a NIRS module to measure the outputs and outcomes related to the LEND and DBP grantees' Autism CARES objectives.



**Environmental scan:** Insight reviewed available literature and existing background data on ASD to provide context for the environment in which the Autism CARES programs operate. The background data review included information on developmental screening rates, mean age of referral for early intervention services, and mean age of diagnosis. The study team explored data from sources that include the National Survey of Children’s Health, the Autism Developmental Disabilities Monitoring Network, and the Individuals with Disabilities Education Act (part C programs), plus relevant data from keyword searches of journal databases and relevant Federal reports such as the *Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder*.

## C. Analysis

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Insight analyzed the data across programs and by research objective. For qualitative data, researchers reviewed appropriate reports and interview transcripts for all grantees and abstracted relevant information on their activities, accomplishments, and outcomes related to each research question. Insight developed a detailed coding scheme for each study objective and grant program and coded the narrative summary data using NVivo 11 qualitative data analysis software. The coding scheme uses nodes to code specific themes that align with the research question topics, such as training, building awareness, and research. Each node included more granular codes, such as training healthcare professionals, training early childhood professionals, and training families.

Following coding of the data, the team reviewed and synthesized the data for each node. Insight also tabulated and summarized the quantitative NIRS and DGIS data provided by MCHB. The results of that synthesis provided the narrative material for this report.

## D. Considerations

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This study has several contextual factors to consider:

- ▶ MCHB started revising the DGIS performance measures during the course of this study, midway through the evaluation period. When data collection for this study ended, the new measures had not yet been implemented. As a result, these performance measure data were only available through 2016.
- ▶ The grant programs included in this study had different periods of performance and different award dates. Some grantees had well-established programs and had successfully recompleted for funding multiple times, enabling them to build on existing work and make accelerated progress toward program goals. Other grantees were first-time awardees, just finishing the first year of their grants when data collection ended. As a result, findings regarding grantee progress and reported outcomes vary widely. For grants that had been awarded as late as 2016, the findings are limited to startup efforts. Conversely, for grantees with continued funding, or those whose period of performance ended prior to data collection, final results are reported.

- ▶ The semistructured interviews provided an opportunity to ask follow-up questions about the grantees' last progress reports and enabled grantees to expand on what they considered their most significant contributions. Interviewers used standard interview guides to facilitate discussions with project directors. The study team intentionally chose a semistructured format for those guides to account for variation across grantees. Interviewers did not attempt to collect a standard set of data points from all grantees, and time limitations did not allow for in-depth discussions on all subjects. As a result, the findings do not necessarily represent the entire scope of grantee efforts and accomplishments from the study period.
- ▶ Grantees regularly leverage other funding to augment work they conduct under Autism CARES. In practice, this means it is difficult to disentangle parts of a project or initiative funded by Autism CARES grant money and parts supported through other funding streams. For example, Autism CARES may fund part but not all of an employee's salary or part but not all of a teaching or outreach clinic.

## Chapter 4. Increasing Awareness of Developmental Milestones and ASD/DD Interventions and Resources

### Principal Grantee Activities To Increase Awareness of Developmental Milestones and ASD/DD Interventions and Resources

The evaluation aimed to assess grantees' activities to increase awareness of ASD and disseminate information to a range of target audiences. LEND, DBP, and State systems grantees primarily focused on these efforts. However, while more communities and providers are aware of ASD after decades of outreach, and developmental screening rates have improved in some areas, the proportion of children who receive routine developmental screening remains low (Van Cleave et al., 2012). Multiple factors such as lack of awareness of developmental screening recommendations, lack of parent and caregiver knowledge of developmental milestones, and disparities in developmental screening among underserved populations lead to low developmental screening rates. Long waiting lists for experienced specialists can also delay developmental screening and diagnosis.

**Grantees promoted awareness of ASD among professionals.** Grantees offered thousands of continuing education courses that enabled hundreds of thousands of practicing professionals to learn about the latest evidence-based practices for identifying and caring for children with ASD. They conducted conferences, workshops, office rounds and grand rounds, online courses, and webinars on topics such as monitoring and assessing development; providing treatment and intervention; and supporting families and improving quality of care. Grantees also developed products for professional audiences including newsletters, videos, referral guides, and toolkits.

**Grantees promoted awareness of ASD among community members.** Grantees increased awareness of developmental milestones in coordination with CDC's *Learn the Signs. Act Early.* campaign by competitively selecting Act Early ambassadors to engage community members and by participating in Act Early regional summits. Grantees also educated policymakers about ASD/DDs, promoted web-based tools to increase awareness, and facilitated accommodations for individuals with ASD/DDs in public spaces and at public events.

**Grantees focused their outreach efforts on reaching underserved groups.** To address disparities in diagnosis and access to care, grantees (1) visited rural locations to provide services, provided remote access to training, and disseminated information; (2) reached immigrant and refugee communities through television, websites, radio, video, and social media outlets; (3) built upon *Learn the Signs. Act Early.* efforts by translating materials for non-English speakers; and (4) collaborated with local partners to disseminate information to underserved communities.

Section A of this chapter describes the need for ASD/DD-related awareness-building; sections B and C highlight key activities to promote awareness among professionals and communities, respectively. Unless otherwise noted, the numbers and figures cited throughout this chapter come from evaluation-specific interview data and materials reviewed as part of the evaluation, including grantee reports and websites.

## **A. The Need for Building Awareness of ASD**

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The American Academy of Pediatrics (AAP) recommends performing general developmental screening at every infant and child wellness visit at 9, 18, and 24 months, with an autism-specific screening for all children at 18 and 24 months (Hagan, Shaw, & Duncan, 2008). However, while more communities and providers are aware of ASD after decades of outreach, and developmental screening rates have improved in some areas, the proportion of children who receive routine developmental screening remains low (Van Cleave et al., 2012). One study found that an estimated 25 percent of family physicians do not screen for developmental delays using recommended tools (Fenikilé, Ellerback, Filippi, & Daley, 2015). Another study indicated that when parents of children with ASD first express concerns about their child's development, they are more likely than parents of children with other DDs to receive a reassuring or passive response from their provider rather than the indicated developmental screening (Zuckerman, Lindly, & Sinche, 2015). Multiple factors contribute to low developmental screening rates, including lack of awareness of the AAP recommendations among providers and parents, lack of parent and caregiver knowledge of developmental milestones, an insufficient supply of professionals trained to screen for ASD/DDs, disparities in developmental screening and awareness among underserved populations, and uncertainty about appropriate referral procedures and available services among providers and caregivers.

## **B. Promoting Awareness of ASD Among Professionals**

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To promote awareness among professionals, grantees offered continuing education opportunities and conducted other outreach activities. This section describes those efforts.

### **1. Facilitating Professional Continuing Education Related to ASD/DDs**

Healthcare providers play a pivotal role in early identification of children with ASD/DDs. When providers fail to assess children at the recommended ages using a formal developmental screening tool, or adopt a “wait and see” approach in response to parental concerns, they contribute to diagnostic delays. LEND and DBP programs offered more than 7,800 continuing education courses between 2014 and 2016 to enable practicing professionals to learn about the latest evidence-based practices for identifying and caring for children with ASD. These events included seminars/grand rounds presentations, webinars, and conference presentations and workshops, where grantees reached more than 417,000 participants (figure 4.1). In addition to providing information, some of these events provided continuing education credit to help professionals maintain licensures.

**Figure 4.1. Total Number of LEND and DBP Continuing Education Events and Participants Between 2014 and 2016**



Source: From 2014 to 2015, the LEND programs held 3,385 continuing education sessions reaching 161,764 participants, and the DBP programs held 528 continuing education sessions reaching 41,525 participants. From 2015 to 2016 the LEND programs held 3,418 continuing education sessions reaching 183,818 participants, and the DBP programs held 526 continuing education sessions reaching 30,733 participants. This figure was generated using DGIS data for LEND and DBP from 2014 to 2015 and 2015 to 2016.

Didactic sessions designed for LEND and DBP trainees, with seminar instruction on relevant ASD-related topics, were also offered as continuing education for Title V staff and other professionals.<sup>2</sup> These events targeted pediatricians, genetic counselors, speech/language pathologists, primary care physicians, social workers, nurses, occupational therapists, psychologists, parents/families, and educators. Continuing education activities spanned a variety of topics such as the following:

- ▶ **Monitoring and assessing development.** Grantees provided continuing education on topics such as developmental monitoring, developmental assessment of children who are deaf or hard of hearing, newborn hearing screening and intervention, developmental screening and interdisciplinary team assessments of students with ASD/DDs, and recognizing developmental delays in early childhood
- ▶ **Providing treatment and intervention.** Grantees provided continuing education on topics such as augmentative and alternative communication/assistive technology, psychiatric medication use among individuals with DDs, and supporting children with behavioral challenges in the preschool setting
- ▶ **Supporting families and improving quality of care.** Grantees provided cultural competency and family functioning; disability advocacy; family-focused behavioral pediatrics; transition services and postsecondary education for students with ASD/DDs

Nearly every LEND and DBP program provided continuing education to practicing professionals. Table 4.1 highlights a sample of these continuing education activities.

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<sup>2</sup> Title V Maternal and Child Health Service Block Grant funds partnerships between Federal and State maternal and child health services to improve access to high-quality healthcare for mothers and children who need assistance.

**Table 4.1. Examples of LEND and DBP Continuing Education Activities, 2014–2017**

Activity	Examples
Conferences	<ul style="list-style-type: none"> <li>• University of Alabama LEND held an annual conference for school personnel, medical professionals, families, and self-advocates. The Alabama Autism Conference hosted nationally recognized speakers to discuss evidence-based ASD information and practices.</li> <li>• University of Miami LEND held a 1-day conference several times per year for speech/language pathologists, psychologists, social workers, and educators. The Innovation and Connection Conference brought together community members and professionals to address ASD/DD-related issues. The conference included an interdisciplinary panel that addressed different issues as they related to the conference topic. The last conference held during the evaluation period focused on strategies for managing behaviors in the office and the classroom and how to use visual supports.</li> </ul>
Workshops	<ul style="list-style-type: none"> <li>• The University of California, Davis, DBP program held workshops for ASD intervention practitioners on the Early Start Denver Model. These events provided intensive hands-on training on a comprehensive behavioral intervention approach for children with ASD aged 12–24 months.</li> <li>• University of Arizona LEND held a half-day workshop multiple times per year for child psychiatrists, social workers, and pediatricians to feel more comfortable diagnosing ASD.</li> </ul>
Office Rounds and Grand Rounds	<ul style="list-style-type: none"> <li>• University of Oklahoma DBP held 1-day office rounds for primary care physicians that focused on ASD screening, diagnosis, and treatment. These rounds showcased developmental surveillance and screening of ASD using a practice enhancement model.</li> <li>• Medical University of South Carolina LEND and DBP held annual office rounds for pediatricians and other pediatric providers using telehealth to reach rural practitioners and offering in-person training as appropriate.</li> <li>• Dartmouth Medical School LEND held monthly office rounds for pediatricians, nurse practitioners, and primary care providers. Psychiatry and developmental pediatrics departments met with community pediatricians to discuss specific ASD cases they found challenging.</li> </ul>
Online Courses or Webinars	<ul style="list-style-type: none"> <li>• North Carolina State systems grantee presented approximately 60 professional development trainings and webinars on early identification of ASD, developmental screening, ASD-specific screening, diagnosis, and cultural/linguistic competence for more than 4,500 families and professionals including pediatricians, family physicians, child development service agency diagnostic teams, early childhood professionals, and managed care organizations.</li> <li>• University of New Mexico LEND held monthly webinars in collaboration with Envision New Mexico for physicians and pediatricians to learn about various ASD-related topics. Examples of webinar topics included “Early Warning Signs of ASD” and “Motor Delays: Early Identification and Evaluation.”</li> </ul>

In addition to conducting group conferences and workshops, grantees provided similar trainings for community professionals in one-on-one settings. For example, a Vanderbilt University LEND psychologist visited pediatric offices nationwide and trained pediatricians to use STAT-MD, a screening tool for ASD designed for medical providers serving young children. This training covered performing interactive screening, conducting developmentally sensitive caregiver interviews, generating diagnostic impressions and communicating them to caregivers, and identifying billing procedures. Similarly, the Michigan State Systems grantee partnered with the Michigan chapter of the AAP to educate primary care and pediatric practices statewide about ASD/DDs in children and teach the skills to conduct developmental screening and make appropriate referrals.

## 2. Developing Products To Support Professionals' Awareness of ASD/DDs

Grantees developed and disseminated a variety of materials about early identification of ASD, local resources available to families, and upcoming events to raise awareness of ASD and related topics.

**Newsletters.** Grantees developed newsletters targeting professionals and the community at large. For example, the University of Colorado DBP program distributed a quarterly newsletter to all primary care practitioners in the State. Topics included how to identify ASD and steps that can be taken in the primary care office before an individual with ASD is seen for a diagnostic evaluation.

**Videos.** The LEND program at the University of Alaska developed a video for primary care providers to guide them on the best ways to communicate with patients with DDs. The video is available for free on the internet. The content is based on peer-reviewed literature and stakeholder input from families, medical professionals, and self-advocates.

**Referral guides and toolkits.** The University of Colorado LEND program formed an interdisciplinary "autism workgroup" at their hospital and developed a referral guide to help practitioners direct individuals with ASD to the appropriate providers. This was an important effort as individuals with ASD often see practitioners of several disciplines for their care. The University of Massachusetts LEND and the Eunice Kennedy Shriver Center developed a web-based information and referral tool called the Index Program. This tool allows individuals to log onto the website (<https://www.disabilityinfo.org>) to download information about autism and various other developmental disabilities and search for physicians, specialists, and programs for specific populations.

## C. Promoting Awareness of ASD Among Community Members

Autism CARES grantees disseminated ASD-related information to communities. Grantees often partnered with community organizations and advocacy groups to improve awareness of developmental milestones, ASD interventions, and resources. One 2017 study showed these general kinds of efforts improved awareness and knowledge about ASD and attitudes toward children and young people with

### Raising Awareness Among Hospital Personnel

Boston Children's Hospital LEND and DBP programs worked together on an ASD-friendly hospital initiative in which they trained support staff throughout the hospital both in person and online. Employees from across the hospital were involved in the initiative, including personnel in food preparation, parking, and reception, as well as phlebotomists, EEG technicians, and nurses to help them understand how to best work with individuals with ASD and provide a more comfortable healthcare experience.

ASD (Dillenburger, Jordan, McKerr, Lloyd, & Schubotz, 2017). This section describes ways grantees contributed to increased ASD awareness among community members.

### 1. Disseminating “Learn the Signs. Act Early.” Materials To Increase Awareness of Developmental Milestones

In 2004, CDC launched the *Learn the Signs. Act Early.* (LTSAE) program to raise awareness of developmental milestones, recommend developmental screening practices, and demonstrate the importance of early identification of DDs. Research suggests LTSAE materials are useful to these communities; for example, a 2009 research study indicated a substantial increase in the number of healthcare professionals who believed they had the resources to educate parents about monitoring their child’s cognitive, social, and physical development after LTSAE materials became available (Daniel, Prue, Taylor, Thomas, & Scales, 2009). Most grantees incorporated these materials into their trainings and/or disseminated them in some capacity. Examples follow:

- ▶ **Selecting Act Early ambassadors.** Many grantees promoted LTSAE by recruiting team members to serve as Act Early ambassadors. The ambassadors were selected for this position through a competitive application and review process. Once appointed, they engaged community service providers and professionals from programs such as Head Start; Early Head Start; the Supplemental Nutrition Assistance Program for Women, Infants, and Children home visiting; and childcare in disseminating LTSAE messages and strategies. Grantees also advanced this public health campaign by customizing the LTSAE materials with information on local resources and disseminating the materials to pediatric practices, early childhood education centers, service providers, and families.
- ▶ **Participating in Act Early summits.** The Act Early Regional Summits convened teams of early intervention leaders, including parents, State public health agencies, medical providers, educators, and personnel from academic institutions across regions. The summits are designed to strengthen the capacity of States to respond to the increasing demand for coordinated systems to address the needs of children with ASD/DDs. Several grantees contributed to their regional annual Act Early Summits, drawing on close partnerships with local Act Early chapters. For example, the DBP programs at Children’s Hospital of Los Angeles and the University of California, Davis, collaborated with the Department of Education and autism stability services in the hospital’s family resource centers in a statewide initiative called the California Autism Professional Training and Information Network (CAPTAIN). The goal of this collaborative was to improve dissemination of evidence-based practices to schools and the broader community. Findings showed that CAPTAIN facilitated a higher competency level in use of evidence-based practices through its educational summit using LTSAE materials and improved adherence to fidelity measures within the CAPTAIN cohort.

- ▶ **Finding new ways to disseminate Act Early materials.** The Iowa State grantee engaged regional autism assistance program teams of advanced registered nurse practitioners, registered nurses, and family navigators in marketing efforts to distribute autism-related materials in English and Spanish. Materials and resources designed to increase awareness of early identification, early intervention, and local referral sources were mailed to each regional center. These materials (e.g., ASD fact sheets, differential diagnosis factsheet, medical home brochure, list of local resources) were then distributed to healthcare and community service providers. Over the course of the project, the 15 Regional Centers distributed more than 20,000 ASD brochures and materials to families and providers across the State.

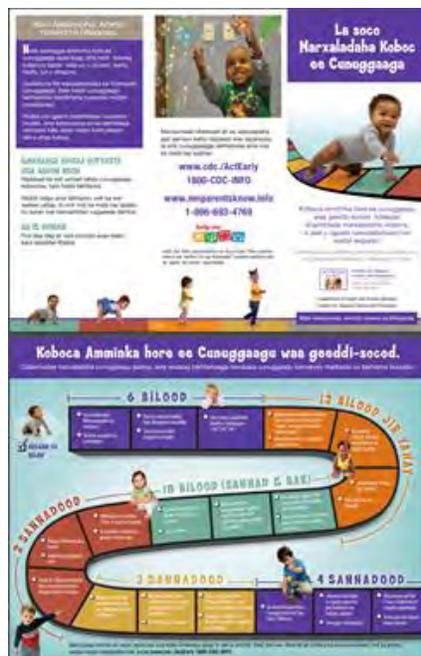
## 2. Conducting Outreach to Underserved Populations

Disparities in diagnosis and access to care persist for minority populations. For example, African Americans are diagnosed with ASD an average of 2 years later than other children, with low rates of physician developmental screening thought to be the cause (Johnson & Van Hecke, 2015). Other barriers include inadequate access to providers with foreign language skills and cultural competency for specific communities. To address these needs, grantees conducted a range of activities to reach underserved populations. Several examples follow:

- ▶ **Reaching rural communities.** Autism CARES grantees visited rural locations and used remote access for training and information dissemination to increase awareness among rural providers. The DBP program at the Medical University of South Carolina partnered with the Area Health Education Consortium Program, which provides outreach to professionals in rural and underserved regions of the State. This outreach included updates to recent research and recommendations surrounding developmental screening, diagnosis, and intervention for ASD. The sessions were archived on the internet for later viewing by professionals unable to attend in person.
- ▶ **Reaching immigrant and refugee communities.** Grantee efforts to build awareness among underserved populations often focused on immigrant and refugee communities, most commonly through electronic media including television, websites, radio, video, and social media outlets. Rhode Island's State Systems grantee used several media outlets, including Latino Public Radio of Rhode Island, a local southern Rhode Island talk radio channel, a cable television show hosted by the president of the Rhode Island chapter of the NAACP (National Association for the Advancement of Colored People), and the local evening news to increase awareness and disseminate information to rural, Hispanic, and African-American communities throughout the State. The LEND program at the University of Utah created and aired a radio novella, which they found to be an effective way to reach the Hispanic community. This "mini-novela" featured a series of skits played out like a soap opera scene, where a child is diagnosed with ASD, the resources the parent found, and how the parent got through the experience. The series was about early identification, interventions, and the emotional impact of the diagnosis on the family.

- ▶ **Customizing LTSAE materials for underserved communities.** To build on their LTSAE outreach activities described in the section above, grantees translated LTSAE materials for non-English speakers and provided relevant information about local resources for these populations. For example, the University of Iowa LEND program distributed LTSAE packages in English and Spanish to healthcare and community services providers. The materials included an ASD fact sheet, a fact sheet on differential diagnosis, and a medical home brochure with a list of resources for Iowa families. Over the course of this effort, the grantee distributed 20,310 ASD brochures and materials to families and providers across the State and sent materials on ASD best practices to 4,400 providers and educators. This grantee also created an Act Early web page that included a map of each county in Iowa with links to local resources and support services and free materials for healthcare providers (e.g., Autism Case Training: a developmental-behavioral pediatrics curriculum) and for families and childcare providers. The North Carolina State grantee produced 2,500 North Carolina-specific “*Learn the Signs. Act Early.*” booklets and brochures, 1,000 of which were printed in Spanish. These were distributed to each region of the State, reaching vulnerable populations such as Hispanic attendees at a local church-based health fair, families at birthing hospitals referred by providers through Family Support/Goodwill Industries, and patients at federally qualified health centers and health departments across the State.
- ▶ **Collaborating with other partners to disseminate information to underserved communities.** The Minnesota LEND and Minnesota Department of Health State grantees collaborated on community outreach projects and disseminated LTSAE materials to underserved communities. See figure 4.2.

**Figure 4.2. Developmental Milestones Brochure in Somali From University of Minnesota LEND Program**



The Minnesota Act Early Delegate Network recruited and trained Hmong, Somali, and Latino delegates to conduct outreach on the importance of developmental monitoring, developmental screening, and acting early if there were any parental concerns about a child’s cognitive development. They held a community kickoff meeting where two University of Minnesota LEND fellows became inspired to help

promote early developmental screening in their respective Oromo and Somali communities. One fellow noted the absence of an Oromo Act Early delegate and decided to step into this role. Oromo is one of the largest East African communities in the region. The other fellow worked to create an Oromo and Somali video for YouTube and social media promoting the importance of early developmental screening and intervention (see figure 4.3). This project also incorporated a significant media outreach component. The goal was to connect with culturally and linguistically diverse families in a variety of ways because the grantee identified this as an effective way to deliver messages to immigrant populations. The liaisons and delegates developed a media outreach campaign in which they developed Minnesota Act Early radio public service announcements (PSAs) promoting early developmental screening, early intervention, and connection with a primary care doctor or the State’s early intervention referral system in Minnesota. The PSAs were developed in English, Spanish, and Hmong.

**Figure 4.3. Outreach Video for East African Communities From University of Minnesota LEND Program**



Source: Photo retrieved from University of Minnesota LEND Program’s website at <http://www.youtube.com/watch?v=yGPPpNojudY>

### 3. Other Activities To Increase Awareness

This section describes grantee activities to raise ASD/DD awareness by educating policymakers, conducting web-based activities, and facilitating accommodations in public spaces and at public events.

#### a. Educating Policymakers About ASD/DDs

An important aspect of awareness building is ensuring policymakers and legislators are familiar with community resources and materials for individuals with ASD and their families. Examples follow:

- ▶ **Meeting with legislators.** Grantees across the country met with local and national legislators to discuss issues related to ASD/DDs. For example, the University of Iowa LEND program developed a unit in their curriculum for trainees to learn about the legislative process and policymaking. Activities involved navigating the State legislative website, identifying legislators, tracking legislation, and meeting with State legislators to educate them about the LEND program and policies important to families they serve. Similarly, trainees from the University of Iowa who attended the National Disability Policy Seminar in Washington, DC, an annual training held each spring in cooperation with AUCD, met with Federal policymakers to discuss LEND and policies important to the families they serve. Describing similar kinds of activities at the University of Iowa LEND, a representative noted, “It certainly increases awareness about autism and the developmental disabilities with our policymakers.”

- ▶ **Creating educational materials for policymakers.** Several grantees produced policy briefs and fact sheets with background on ASD-specific issues. For example, two trainees from the University of Vermont LEND turned two fact sheets into policy briefs, one on inclusion and one on restraint and seclusion. Grantees shared these materials with State and Federal legislators to provide background information on the issues.

### b. Using the Internet To Increase Awareness

Many grantees used social media platforms such as Facebook, Twitter, and Pinterest to call attention to information on ASD-related topics such as local ASD-related events, information on new research findings on ASD, and local resources. Examples follow:

- ▶ **Online forums.** The Boston Children’s Hospital DBP held an in-person family forum, giving presentations on various topics related to ASD. Families attended the meetings, and the presentations were recorded and posted on the web. A DBP director noted, “You may have 50 people who come to the lecture because we’ve got kids with autism, but you have 1,000 people who watch it on the web.” Similarly, the University of Colorado Denver DBP program noted attendance at its webinars is regularly between 200 and 300 people.
- ▶ **Social media campaigns.** The University of Iowa State systems grantee contracted with the Iowa chapter of the AAP to launch a social media campaign using Facebook, Twitter, and Pinterest to raise awareness of developmental milestones, AAP best practices related to ASD/DDs, and other evidence-based ASD/DD resources. Target audiences were providers and families. The LEND program at Vanderbilt University created a social networking site for families from Africa who have a child with ASD or related disability. The intention was to raise awareness of ASD and change the way ASD is perceived within their communities. Many groups the grantees worked with experienced significant social stigma related to mental health and disabilities; there were also few cultural comparisons to convey concerns related to DDs. Most did not have a word for autism, making it a difficult concept to address.
- ▶ **Online referrals to support services.** A robust web presence enables grantees to connect families with local resources and expand their outreach with limited financial resources. A representative from the Medical University of South Carolina LEND was able to connect family and community members directly through the LEND’s website with links to local services and programs.

#### Grantee Participation in Autism Awareness Month Events

An analysis of Google Trend data suggested that National Autism Awareness Month activities in April and televised reports on ASD are an effective method of piquing public interest in the topic they will subsequently search more about on the internet (DeVilbiss & Lee, 2014). Several Autism CARES grantees held Autism Awareness walks with thousands of participants and contributed to events surrounding the Light It Up Blue campaign, when local business owners partner to light their buildings in blue light during Autism Awareness Month.

- ▶ **Email lists.** Grantees used email lists regularly to reach large numbers of people who had shown interest in ASD-related topics. For example, the LEND program at Westchester Institute for Human Development communicated with a broad audience using an email marketing service. The email list was generated over several years of connections made at ASD-related events and decades of former LEND trainees and their contacts, many of whom are in leadership positions within their communities. The LEND program used the list to inform different audiences or obtain input on materials or other program projects.

### **c. Facilitating Accommodation in Public Spaces and at Public Events**

Many grantees partnered with local organizations to help create an ASD-friendly environment in public spaces and at public events. Some examples follow:

- ▶ **Accommodations at sporting events.** Some programs used local sports as a venue to raise awareness of ASD while also accommodating those with ASD at public events. For example, the LEND program at the University of Alabama contributed to an ASD-friendly minor league baseball game. Throughout the game, the jumbotron featured slides and information about ASD, and the radio station broadcasting the game interviewed two LEND trainees about ASD. The University of New England LEND program sponsored a sensory room at a local baseball game where children with ASD could attend and participate in activities that helped reduce their anxiety level. One trainee shared a story about a child who came into the sensory room multiple times throughout the game but continued to go back to his family at the game. At the end of the game, the child's mother thanked the LEND representative explaining this was the first time her child was able to stay to the end of the game, crediting the sensory room as the reason it was possible.
- ▶ **Accommodations in hospitals.** The DBP program at Boston Children's Hospital created a website called "My Hospital Story" that displayed picture stories of common scenarios for coming for an appointment that parents can download before visiting the hospital. This helped families know what to expect, prepare for a hospital visit, and promote a positive experience.
- ▶ **Partnerships with restaurants.** The clinics associated with the University of Alabama LEND are located in close proximity to restaurants families would frequent before or after attending the clinic. The LEND director shared, "It occurred to us that these local restaurants are getting a lot more exposure to people with developmental disabilities than many other places." For that reason, the LEND program partnered with the restaurants to educate their employees on ASD/DDs. This association developed into a close partnership between the LEND program and the restaurants, leading to the LEND program providing families attending their clinics with coupons for the restaurants that are the most "ASD-friendly."

## Chapter 5. Training Professionals in ASD/DD Service Delivery

### Principal Grantee Activities to Train Professionals in ASD/DD Service Delivery

The evaluation aimed to assess grantees' activities to train professionals, deliver clinical and didactic training related to ASD/DDs, and expand trainee leadership capacity; it also assessed the characteristics of trainees. LEND and DBP grantees primarily engaged in these activities.

**Grantees increased the number of professionals trained to provide ASD/DD services.** Collectively, the LEND and DBP programs trained an average of more than 3,886 medium-term and 1,367 long-term trainees each year according to data from 2014–2015 and 2015–2016. Medium-term trainees completed between 40 and 299 hours of training during a single academic year. Long-term trainees completed more than 300 hours of training. The programs worked to increase the number of trainees from underrepresented groups by leveraging non-HRSA funds to increase diversity, participating in formal technical assistance opportunities such as MCHB's Diversity and Health Equity Peer Learning Collaborative and utilizing local and national networks to establish a pipeline to their programs. Grantees also generated interest in ASD by engaging future professionals such as students studying medicine or other disciplines and even those in college and high school.

**Grantees enhanced clinical and didactic instruction related to ASD/DDs.** Combined, DBP and LEND programs enrolled an average of 1,363 long-term and 2,615 medium-term trainees each year in didactic courses covering ASD screening and assessment tools. They also provided training on cultural and linguistic competency, life-course issues, and family-centered care and expanded their overall reach through distance learning approaches. During the 2014–2017 evaluation period, an annual average of nearly 1,300 long-term trainees and more than 2,000 medium-term trainees enrolled in clinical practica. An average of 113,623 children received interdisciplinary, diagnostic services to confirm or rule out ASD/DD from LEND and DBP faculty and trainees each year, marking an 11-percent increase in the number of children receiving services between 2014-2015 and 2016-2017. Clinical experiences varied across programs, but often trainees worked as part of an interdisciplinary team overseen by faculty to evaluate children suspected of having ASD/DDs, identify an appropriate course of treatment, and help families take the first steps in implementing that course. Clinical training took place in a wide range of settings including hospital outpatient clinics, university-based resource and treatment centers, community clinics, schools, shelters, homes, and telehealth virtual clinics.

**Grantees developed a cadre of strong leaders in the field of ASD/DD care.** Most training programs required long-term trainees to complete a leadership project to fill a community need. These capstone projects led to the creation of community resources or contributed to systems improvements at the local or regional levels. Trainees honed their teaching skills and developed a deep understanding of disability policy. LEND and DBP programs have trained the next generation of leaders. After completing their training, trainees moved on to serve in leadership roles at State and local health levels.

This chapter is organized as follows: section A provides an overview of the chapter findings, while section B explains the importance of training. Findings appear in sections C, D, E, and F. Section C also describes ways grantees increased the number of professionals trained to work with individuals with ASD/DDs, and sections D and E describe how grantees enhanced their didactic and clinical instruction,

respectively. Section F outlines ways grantees enhanced leadership training. Unless otherwise noted, the numbers and figures cited throughout this chapter come from evaluation-specific grantee interview data and materials reviewed as part of the evaluation, including grantee reports and websites.

## A. The Need To Train Professionals in ASD/DD Service Delivery

As the number of individuals with ASD/DD increases, there is a fundamental need for well-trained clinicians who can screen children and for specialists who can diagnose, rule out, and treat this set of disabilities. However, several reports have identified a lack of trained providers to meet the current demand. A 2013 policy statement by the AAP identified a shortage of pediatric medical subspecialists (Committee on Pediatric Workforce, 2013). Some States do not have any developmental pediatricians at all (Gordon-Lipkin, Foster, & Peacock, 2016), and there is evidence that provider shortages will persist if changes are not made in the field. One study found that the DBP workforce is aging with many planning for retirement or part-time work. Given this limited provider pipeline and increased demands for complex clinical care, the study found that “viability of the DBP subspecialty requires strategies to maintain and expand the workforce, improve efficiency, and prevent provider burnout” (Bridgemohan et al., 2018). Relatedly, a 2012 survey by the Children’s Hospital Association identified shortages in all the pediatric subspecialties that diagnose and treat ASD, including developmental-behavioral pediatricians, pediatric neurologists, and child and adolescent psychiatrists. This shortage of specialized staff results in extended wait times to obtain diagnostic evaluation appointments, ranging from 3½ months to a year.

Once children are diagnosed, families often experience long delays receiving evidence-based, appropriate treatment and care. A recent study found the average wait time from diagnosis to the start of early intensive behavioral intervention is nearly 3 years (Yingling, Hock, & Bell, 2017). Underserved groups such as low-income populations are more likely than other groups to have unmet specialty and therapy care needs (Chiri & Warfield, 2012).

### LEND Grantee Perspectives on the Need for Improvements in Training for Providers

“I think some of the most significant problems are the lack of early identification of a neurodevelopmental disability. Children are entering school at the age of 5 never having received a diagnosis. They have significant and diagnosable disability that has not yet been diagnosed and therefore not treated.”

—University of New England LEND Director

“The other side of that is that once they get diagnosed, there aren’t enough people that are trained to do applied behavioral analysis, or parent-child interaction therapy, or floor time, or any of those kinds of treatments.”

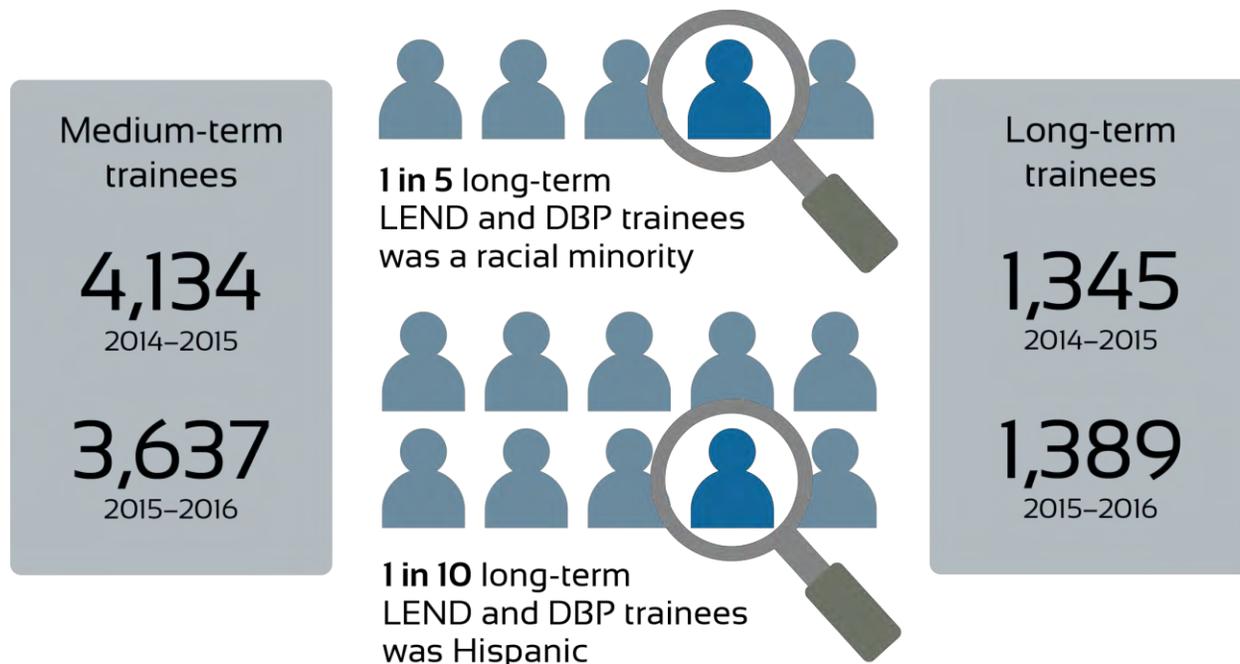
—University of Alabama LEND Director

## B. Increasing the Number of Professionals Trained To Provide ASD/DD Services

To accomplish the goal of increasing the number of professionals in the pipeline, the LEND and DBP programs provide interdisciplinary didactic and clinical training as well as leadership development to graduate students and professionals from multiple disciplines who have a role in identifying, evaluating, or caring for children with ASD/DDs. Collectively, the LEND and DBP programs trained an annual average

of more than 3,886 medium-term and 1,367 long-term trainees on diagnostic evaluation and evidence-based interventions for ASD/DDs according to 2014–2015 and 2015–2016 DGIS data (figure 5.1). Activities related to short-term trainees who received 40 hours or less of training are discussed in chapter 4, which focuses on awareness building.

**Figure 5.1. Number of LEND and DBP Medium- and Long-Term Trainees by Year**



Source: From 2014 to 2015, LEND programs enrolled 3,703 medium-term trainees and 1,297 long-term trainees; DBP programs enrolled 431 medium-term trainees and 48 long-term during this period. From 2015 to 2016, LEND programs enrolled 3,196 medium-term trainees and 1,339 long-term trainees; DBP programs enrolled 441 medium-term and 50 long-term. This figure was generated using DGIS data on the number of LEND and DBP medium- and long-term trainees enrolled each year from 2014 to 2015 and 2015 to 2016.

Note: Data for each year represent the aggregate number of trainees from 52 LEND programs and 10 DBP programs. DGIS data were not available for 2016–2017.

### 1. Increasing the Number of Trainees From Underrepresented Groups

Between 2014 and 2016, on average, at least 1 in 5 long-term LEND and DBP trainees was a racial minority, and approximately 1 in 10 long-term trainees was Hispanic.<sup>3</sup> While this picture reflects the population in many sites, several grantees expressed concern about limited diversity in the applicant pool, and they were working to increase the diversity of trainees and faculty. Enrolling trainees and fellows from a range of racial, ethnic, and cultural groups extends grantees’ reach into underserved areas and creates opportunities for professionals to communicate more effectively with families from a wide range of backgrounds.

<sup>3</sup> From 2014 to 2015, 22.8 percent of long-term LEND trainees and 18.8 percent of long-term DBP trainees were identified as racial minorities; 9.3 percent of LEND long-term trainees and 8.3 percent of DBP long-term trainees were Hispanic. From 2015 to 2016, 21.6 percent of long-term LEND trainees and 22.0 percent of long-term DBP trainees were identified as racial minorities; 8.9 percent of LEND long-term trainees and 12.0 percent of DBP long-term trainees were Hispanic. These figures on the race and ethnicity of long-term trainees were generated from DGIS data from 2014 to 2015 and 2015 to 2016.

Grantees described the following successful strategies for recruiting racially and ethnically diverse trainees and faculty:

- ▶ **Leveraging non-HRSA funds to increase diversity.** Some programs successfully obtained outside funding to build a more diverse cohort of faculty and trainees. For example, Stanford’s DBP program used non-HRSA funds to increase fellow salaries and offer an additional housing bonus to help cover the high cost of living.
- ▶ **Participating in MCHB’s Diversity and Health Equity Peer Learning Collaborative.** Several LEND programs, including those at Indiana University, Dartmouth Medical School, University of Wisconsin, and University of Missouri, participated in formal technical assistance opportunities such as HRSA’s Diversity and Health Equity Peer Learning Collaborative<sup>4</sup> and established diversity committees to develop and implement diversity plans. Additional funding from the collaborative enabled them to expand their committees, identify best-practice resources, and make connections with other universities to improve the diversity of faculty and trainees and create a more welcoming environment.
- ▶ **Using local and national networks.** Many LENDs and DBPs tap local or national networks to help establish a pipeline to recruit undergraduate, medical school, and resident-level students into their programs. For example, the University of North Carolina LEND developed a partnership with a historically Black university and successfully recruited and enrolled long-term trainees from this program.

Several programs reported that Autism CARES funding helped increase the likelihood of recruiting top long-term training candidates, including candidates from diverse backgrounds. Although stipends are set by individual grantees and not HRSA, some felt that increased funding would allow for increased stipends and would make the fellowship programs and opportunities more desirable.

## 2. Generating Interest in ASD and Engaging Future Professionals

Programs educated students on ASD/DDs early in their academic and medical careers to generate interest among future professionals. Grantees used the following approaches:

### Reaching More Trainees Through Mini-Fellowships

The Medical University of South Carolina’s DBP program provided education and training to rural healthcare providers through mini-fellowships, where general pediatricians attend DBP training for 1 year. One mini-fellow from a remote rural community now works in developmental-behavioral pediatrics almost exclusively, serving as the main developmental-behavioral pediatrician in his part of the State. Similarly, the University of Rhode Island DBP introduced a certificate DBP program, which provided DBP training support, either part-time over a year or full-time for 3 months, to pediatricians and nurse practitioners. The flexibility of this program enabled clinicians to participate in ways most convenient to their schedules and to use new skills in direct service to the community.

<sup>4</sup> The collaborative took place January–June 2017 to facilitate sharing and use of information among grantees and to highlight successes, challenges, and solutions to more effectively address diversity and health equity within training programs. Each participating team identified a project through the learning collaborative, designed to result in a policy or practice change through the use of a quality improvement cycle.

- ▶ **Engaging medical students and students in other disciplines.** DBP programs routinely train medical students and advanced students in other disciplines. Most LEND and DBP programs had medical residents complete a rotation in ASD/DDs and often provided lectures and case presentations to medical students. The Children’s Hospital of Los Angeles DBP provided short-term training for nursing trainees, psychology postdoctoral trainees, and physical therapy/occupational therapy trainees. Similarly, the Children’s Hospital of Boston DBP provided several psychology postdoctoral fellows direct training in the evaluation and care of children with autism.
- ▶ **Engaging college and high school students.** Several LEND and DBP programs offered programs to high school students, aiming to increase their exposure to new academic fields (e.g., child development, biomedical science, public health) and introduce them to related career paths. For example, the Stanford University DBP participated in a collaborative to improve disability education on campus. The University of Alabama LEND also developed high school and undergraduate programs to engage students and future leaders in learning about interdisciplinary service through observation and shadowing programs.

### C. Enhancing Didactic Instruction About ASD/DDs

The LEND and DBP programs used Autism CARES funding to enhance the already robust didactic components of their training program, including instruction on evidence-based developmental screening and assessment tools and cultural and linguistic competency. Combined, DBP and LEND programs enrolled an annual average of 1,363 long-term and 2,615 medium-term in didactic courses covering ASD screening, diagnosis, and treatment, according to NIRS data from 2014 to 2015, 2015 to 2016, and 2016 to 2017 (see figure 5.2).

**Figure 5.2. Number of Long-Term and Medium-Term LEND and DBP Trainees Enrolled in Courses Covering ASD Screening, Diagnosis, and/or Treatment by Year**



Source: From 2014 to 2015, LEND programs enrolled 2,061 medium-term trainees and 1,238 long-term trainees in courses covering ASD; DBP programs enrolled 365 medium-term trainees and 47 long-term trainees. From 2015 to 2016, LEND programs enrolled 2,048 medium-term trainees and 1,328 long-term trainees in courses covering ASD; DBP programs enrolled 405 medium-term trainees and 50 long-term trainees. From 2016 to 2017, LEND programs enrolled 2,461 medium-term trainees and 1,377 long-term trainees in courses covering ASD; DBP programs enrolled 416 medium-term trainees and 50 long-term trainees. This figure was generated using NIRS data describing the number of LEND and DBP medium-term trainees and long-term trainees enrolled in coursework on ASD/DD from 2014 to 2015, 2015 to 2016, and 2016 to 2017.

#### 1. Providing Training on Evidence-Based Developmental Screening and Assessment Tools

Autism CARES funding helped support didactic training on evidence-based developmental screening and assessment tools. The LEND and DBP training courses provided information on the latest evidence-based

tools for developmental screening and assessment, including those listed in table 5.1. For example, short- and medium-term trainees often observed the administration of the Autism Diagnostic Observation Schedule (ADOS) and familiarized themselves with its components, while some long-term LEND trainees received intensive training in ADOS administration. DBP fellows learned to administer and score the ADOS models I and II with faculty training and supervision, to eventually become certified administrators.

**Table 5.1. Examples of Developmental Screening, Diagnostic, and Assessment Tools Covered in Some LEND and DBP Didactic Instruction**

Developmental Screening, Diagnostic, or Assessment Tool	Description
Ages and Stages Questionnaires (known as ASQ-3)	A general developmental screening tool assessing children aged 1 month to 5½ years
Parents' Evaluation of Developmental Status (known as PEDS)	A developmental screening tool used to identify children aged 0–9 years for further evaluation
Modified Checklist for Autism in Toddlers (known as MCHAT-R)	A parent-completed questionnaire designed to screen for developmental and behavioral problems in children aged 16–30 months needing further evaluation
Social Communication Questionnaire (known as SCQ)	A developmental screening tool focusing on social and behavioral impairment in older children
Screening Tool for Autism in Toddlers and Young Children (known as STAT)	A developmental screening method that can be used by community service providers (such as early education staff, special educators, nurse practitioners) and pediatricians
Brief Observation of Social Communication Change (known as BOSCC)	A cutting-edge assessment tool designed to measure subtle, individual changes in symptoms over time
Autism Diagnostic Observation Schedule (known as ADOS)	A semistructured assessment of communication, social interaction, and play; considered the “gold standard” in evaluating individuals suspected of having ASD/DDs
Childhood Autism Rating Scale (known as CARS)	A rating scale designed to identify symptom severity in children over 2 years
Bayley Scale	A tool for assessing the development of infants and toddlers between 1 and 42 months
Wechsler Individual Achievement Test-III	An intelligence test appropriate for children and adolescents of all ages

## 2. Providing Training on Cultural and Linguistic Competency, Life-Course Issues, and Family-Centered Care

Autism CARES funding supported LEND and DBP programs’ continued focus on cultural competency and family-centered care in their training programs. Several areas of focus are summarized below:

- ▶ **Training professionals on cultural competency, diversity, and health equity.** LEND and DBP programs prioritized increasing the linguistic and cultural competency of their trainees to better serve diverse populations. Programs offered a variety of different training approaches, including lectures on diversity and cultural competence, workshops, and interactive discussions with family members or individuals affected by ASD/DDs. Several LEND programs’ online training platforms, such as Moodle, facilitated remote instruction on cultural competency, diversity, and health equity. Other programs addressed health equity through coursework on social determinants of health and maternal and child health policy.

▶ **Providing education on the transition to adulthood and life course framework.**

Several LEND and DBP training programs modified their curriculum or started new programs to incorporate a life course perspective to training on ASD/DDs, examining experiences across the lifespan. For example, the DBP at the University of California, San Diego, framed the curriculum with life course theory, emphasizing the importance of early childhood and the influences of family and society on long-term health and development. Several training programs (the University of Colorado DBP, the Westchester Institute for

Human Development LEND, and the University of Cincinnati LEND) play the Life Course Game (by CityMatCH) during their coursework, where players receive birth certificates that identify socially and biologically based factors. Throughout the game, players face different life hardships and adjustments to their overall health trajectories. Following the game, trainees debrief, discuss, and conduct exercises on incorporating awareness of adverse life circumstances into everyday work. Other LEND and DBP programs highlighted the life course model and brought forth issues such as the integration of services, postsecondary education, individual challenge, employment, sexuality, long-term care, and other issues related to the transition to adulthood (see chapter 8, which focuses on the transition to adulthood).

- ▶ **Focusing on family-centered care and self-advocacy.** Grantees incorporated family-centered care and self-advocacy in their programs in various ways. Many training programs integrated principles of family-centered care in their didactic curriculum by recruiting trainees with disabilities and family members of children, adolescents, and adults with ASD/DDs. The Michigan LEND presented a video produced by the co-located University Center for Excellence in Developmental Disabilities focusing on a young man with ASD who calls himself “the Self-Determinator.” Representatives invited him to deliver a guest lecture to the trainees and engage in group discussion. At Georgia State University LEND, as part of a course on systems of care, trainees identified best practices for early intervention, the transition from pediatric to adult healthcare, and natural supports for children with special healthcare needs (CSHCN) and their families. They then interviewed family members, self-advocates, and service providers to gather information on their experiences and perspectives with these systems and subsequently developed a resource for families on how to navigate the healthcare system.

Grantee Perspective on Prioritizing Families

“To orient trainees to the priorities of families and how ... they may diverge from those of professional partners, trainees play “Family Feud,” [a] HI LEND training product which forces the trainees to identify the top community- based service needs of the families of children and youth with special health care needs ... trainees are often out of sync with the priorities of families. This activity grounds them in learning and understanding the needs of families and the subculture of families of children and youth with special health care needs.”

—Hawaii LEND Director

### 3. Expanding Reach Through Distance Learning

From 2014 to 2017, LEND and DBP grantees expanded the reach of their training programs by integrating technology in their didactic training. Many training programs reported using distance technologies to expand their reach to medium- and long-term trainees. For example, prerecorded training modules and a variety of videoconferencing and distance learning technologies enabled LEND trainees from Tulsa to participate in the University of Oklahoma LEND, trainees from Puerto Rico to

participate in the Westchester Institute for Human Development LEND, and trainees in the U.S. Virgin Islands to participate in the University of Vermont LEND. Trainees accessed learning materials remotely and participated in didactic learning and discussions through videoconferencing while conducting clinical training under local supervision.

## D. Ensuring Access to Clinical Training Opportunities

Clinical practica enable trainees to practice or observe the diagnostic and intervention skills taught in the classroom. During the 2014–2017 evaluation period, an annual average of more than 1,300 long-term trainees and more than 2,000 medium-term trainees enrolled in clinical practica, according to NIRS data from 2014 to 2015, 2015 to 2016, and 2016 to 2017 (see figure 5.3). An average of 113,623 children received interdisciplinary, diagnostic services to confirm or rule out ASD/DD services from LEND and DBP faculty and trainees each year, marking an 11-percent increase in the number of children receiving services between 2014–2015 and 2016–2017.<sup>5</sup> Clinical experiences varied across programs, but trainees often worked as part of an interdisciplinary team overseen by faculty to evaluate children suspected of having ASD/DDs, identify an appropriate course of treatment, and help families take the first steps in implementing that course. Clinical training took place in a wide range of settings including hospital outpatient clinics, university-based resource and treatment centers, community clinics, schools, shelters, homes, and telehealth virtual clinics. This section describes how grantees used the Autism CARES funding to expand clinical opportunities for trainees via local clinics, community- and home-based care settings, and telehealth.

**Figure 5.3. Number of Trainees Participating in Clinical Practica by Year**



Source: From 2014 to 2015 LEND programs engaged 1,835 medium-term trainees and 1,292 long-term trainees in clinical practica, while DBP programs engaged 361 medium-term trainees and 45 long-term trainees. From 2015 to 2016, LEND programs engaged 1,909 medium-term trainees and 1,309 long-term trainees in clinical practica, while DBP programs engaged 379 medium-term trainees and 50 long-term trainees. From 2016 to 2017, LEND programs engaged 1,946 medium-term trainees and 1,378 long-term trainees in clinical practica; DBP programs engaged 422 medium-term trainees and 50 long-term trainees during that time. This figure was generated using NIRS data describing the number of LEND and DBP medium-term trainees and long-term trainees participating in clinical practica from 2014 to 2015, 2015 to 2016, and 2016 to 2017.

<sup>5</sup> Interdisciplinary, diagnostic services to confirm or rule out ASD/DDD were provided by LEND and DBP programs. Such services were provided in 2014 to 2015 by LEND programs to 94,439 infants and children, and DBP programs to 14,263 infants and children. From 2015 to 2016, such services were provided by LEND programs to 102,306 infants and children, and by DBP programs to 9,730 infants and children. From 2016 to 2017, such services were provided by LEND programs to 109,215 infants and children, and DBP programs to 10,915 infants and children. These data were generated using NIRS data from 2014 to 2015, 2015 to 2016, and 2016 to 2017.

## 1. Gaining Hands-On Experience in the Clinical Setting

Autism CARES funding helped support enhanced clinical opportunities, enabling trainees to gain hands-on experience under faculty guidance. For example, trainees gained clinical experience in the following clinics:

- ▶ **Middle childhood program.** Stanford University’s DBP program introduced a middle childhood program that focused on children older than 7. This project provided an opportunity for fellows to work with older children, a group that developmental-behavioral pediatricians may have less experience with and that is more likely to have different treatment needs such as medication management.
- ▶ **Young adults clinic.** The University of Illinois LEND established a new partnership with the Rush Autism, Assessment, Research, Treatment and Services Center, which expanded opportunities for trainees to engage in clinical work with transition-aged young adults and young children with autism/DDs.
- ▶ **New multispecialty outpatient facility.** The Stanford University DBP gained access to a new, multispecialty outpatient facility in 2016 with new capabilities including conference space and rooms with one-way mirrors and video cameras to enable more observation of trainees without trainers being in the room.
- ▶ **Family autism resource center.** The LEND program at the University of California, Los Angeles, created the first family autism resource center focused on developmental screening and educational access for underrepresented groups.
- ▶ **Interdisciplinary clinic.** The West Virginia University LEND developed the interdisciplinary “Next Steps” clinic. Run by LEND trainees, fellows provided support to families after a diagnosis including helping them find services, helping with issues at school, and connecting with community supports.

### Grantee Perspective on the Growth in Clinical Opportunities

“Our institute started a community-based early intervention program for young children with autism ... and it served, primarily, kids who didn’t have any insurance .... It’s called the Autism Clinic for Toddlers, A.C.T. ... The person who started the clinic was a former LEND trainee, and she worked very closely with us with our autism funding. I think the LEND has a huge part in initiating this Autism Clinic for Toddlers, which has subsequently tripled in size.”

—University of Nebraska LEND Program

## 2. Providing Services in Community and Home-Based Settings

Many clinical opportunities stemmed from partnerships grantees developed with community sites. LEND and DBP programs incorporated community experiences in their clinical curriculum by working with local clinics, schools, shelters, foster care agencies, and family courts. This section highlights some of these activities:

- ▶ **Local clinics.** The Autism CARES grants enhanced trainees' opportunities to work or observe in clinics in their community. For example, the LEND trainees at Boston Children's Hospital gained exposure to a wide array of populations including Haitian, Somali, Ethiopian, Chinese, Eritrean, African American, Latino, and Vietnamese through partnerships with community-based organizations. Similarly, fellows at the University of California, San Diego, DBP conducted diagnostic evaluations and provided ongoing pediatric care in diverse settings, including a major HMO (Kaiser Permanente) and a Naval Medical Center.
- ▶ **School environments.** Several programs coordinated activities in schools or Early Head Start Programs to facilitate trainee involvement in family reviews. Other school-based activities included providing technical assistance on assessments for nonnative English speakers (Children's Hospital of Philadelphia DBP), consulting on behavior at a school for homeless children (University of California, Davis, LEND), and conducting developmental screening and coordinating activities with schools and families related to developmental screening (University of Hawaii LEND).
- ▶ **Family or home visits.** Almost all LEND and DBP programs pair trainees with families in the community and give them an opportunity to spend time with parents and children outside the clinic setting. For example, University of Arizona LEND trainees visited Hopi and Navajo reservations to learn about services and support available to infants, young children, adolescents, and adults with disabilities and the culture and life on the reservation. As part of a 3-day trip in 2017, LEND trainees and faculty attended meetings with key stakeholders, visited with a Hopi family, and sat in on a Hopi tribal council meeting. This helped the program identify needs and provided trainees with a better foundation for providing culturally competent care.
- ▶ **Virtual clinics.** Some LENDs and DBPs used virtual clinics to increase trainees' exposure to underserved populations and communities and to improve access to services in these areas. In Kansas, for example, where families live an average of 150 miles away from the LEND's medical center, LEND trainees participated in telehealth outreach clinics to rural and underserved populations across the State. University of Minnesota LEND trainees used telehealth to join faculty conducting assessments, diagnostic work, and intervention planning. The University of California, Davis, DBP established a telehealth consultation program with a federally qualified health center serving rural, Native-American, and low-resourced patients. The clinic provided training and advocacy opportunity for fellows and healthcare services to several northern California indigenous tribes and other low-resourced families in rural settings. The fellows gained experience in clinical referral decisions, differential diagnosis and local referral/supportive resources, and communication with referring physicians and families.

## E. Building a Cadre of Strong Leaders

Building a cadre of strong leaders is a central goal of the LEND and DBP training programs. Most programs required long-term trainees to complete a leadership project, some focused on community service and others on policy, and all required applying knowledge and skills to an existing problem or need at the local or regional level. Their projects varied across programs, but all were designed to fill a community need (e.g., underserved population, health disparity, knowledge or service gap). After identifying the area of need, trainees developed an evidence-based methodology for addressing the need; defined outcomes and indicators of success; and developed a product summarizing need, methodology, and impact. Trainees worked with a State Title V agency or community-based organization, sometimes responding to a direct solicitation for help. Other capstone projects involved developing policy briefs to provide an in-depth analysis of a relevant topic area. In many LEND and some DBP programs, trainees selected an initiative or policy issue, researched it in depth, interacted with advocates or policymakers about the impact of the initiative on achieving MCHB core objectives, and/or developed a policy brief on the issue. Some leadership projects led to the creation of community resources or contributed to system improvements at the local or regional level.

Many programs also reported increasing representation among people with disabilities and their families. Nearly all LEND programs include family members as trainees and an increasing number include self-advocates. Family members and self-advocates play a crucial role in strengthening the workforce by using their unique perspectives, drawn from their own experiences with disabilities, to enhance the training of others while developing their own leadership skills. For example, the University of Illinois LEND has included self-advocates as long-term trainees since 2010 and has two self-advocate faculty. Their efforts are further guided by a consumer advocacy council that provides feedback on program planning, program activities, materials development, and recruitment. In 2016–2017, one self-advocate trainee was organizing a community-building summit among autistic people of color in Chicago to enable autistic self-advocates and leaders from underrepresented groups in the Chicago area to come together and discuss current social and political issues affecting this community in the inner city.

### Grantee Perspective: One LEND Fellow's Mission To Ensure Insurance Coverage for People With ASD

“We had a fellow that, many years ago, spent her LEND year really thinking about how insurance companies should pay or cover the needs and services that children—or people with autism need. She went on and actually created a piece of legislation and got legislators here in the State to sign on. The bill got signed into law. It’s actually the strongest law in the country as far as guaranteeing insurance coverage for people with autism. She [later] came back to Shriver Center and developed an autism insurance resource center. She helps individual families as well as insurance companies and providers to implement that law.”

—University of Massachusetts LEND,  
Program Director

Trainees developed their leadership skills in the following ways:

- ▶ **Developing teaching skills.** DBP programs train fellows as clinicians and educators. For example, as part of the Boston Children’s Hospital DBP program, trainees participated in a “teaching to teach” seminar, presenting to pediatric residents, peers, and other learners and received feedback to improve their teaching skills. The State’s Department of Child Safety asked the University of Arizona LEND to help train its staff on home assessments with children who have ASD/DDs. Trainees worked with a local clinic and the department to develop web-based training modules, providing workers with better background information on developmental conditions so they are better able to conduct initial assessments.
- ▶ **Creating learning aids.** University of Pittsburgh LEND trainees created a social story about a young adult with autism who was driving a vehicle and stopped by the police. It explains to young adults with ASD what to expect if they are stopped by a police officer, what kinds of information the police may want, and what to do and not do in such a situation. This story was used to help individuals with autism understand the importance of how they respond when interacting with police officers.
- ▶ **Increasing understanding of disability policy.** Several LEND programs focused their leadership training on increasing knowledge of policy issues. For example, the University of Nebraska LEND’s leadership seminar included topics on disability history, policy, special education law, and assessing the evidence base. LEND and DBP fellows also attended leadership training events hosted by AUCD (such as the Disability Policy Seminar) or attended policy-related trainings offered by collaborating partners.
- ▶ **Learning to communicate effectively with policymakers.** Trainees in the Louisiana State University LEND program met with representatives of public interest advocacy organizations (e.g., the Developmental Disabilities Council, Autism Speaks, Louisiana Partnership for Children and Families) to learn about each organization’s mission and current initiatives. Through seminars on public policy, trainees learned strategies to communicate more effectively with policymakers. They made appointments to meet with their local representatives of both the State House and Senate to educate lawmakers on topics such as healthcare, insurance, education, disabilities, autism, and behavioral health.
- ▶ **Meeting with elected officials.** At the University of Massachusetts LEND, one fellow talked with her representative about the importance of family bathrooms. Although family bathrooms are neither covered by the Americans with Disabilities Act nor in most building codes, they represent an issue of great import for families of children with ASD/DDs and others.

Grantee Perspective: Career Trajectories of Trainees Are Evidence of Lasting Effect of Training Programs

“[Our LEND program has] produced three LEND directors, four UCEDD directors, and many professors, deans, and academics along with a large cadre of clinical professionals, policy and Title V leaders both on local and regional levels but also across the country and on the national scene. [LEND] has been a crucial training vehicle and continues to address the needs of the country as we face new challenges across the MCH professional fields, seen most recently in the increase in children diagnosed with ASD and the service challenges those changes bring to systems of care and support.”

—Boston Children’s Hospital LEND Director

Through these and other activities, LEND and DBP programs have trained the next generation of leaders in ASD/DDs. Trainees from LEND and DBP programs have become directors of LEND and the University Center for Excellence in Developmental Disabilities (UCEDD) programs and have filled leadership positions at State and local health departments, State departments of human services, State departments of education, Title V agencies, schools, universities, and children's hospitals. Individual graduates have developed school and adult programs at autism centers; written and fostered the passage of State legislation supporting services for children with ASD; started an autism resource center; initiated or led programs on intensive behavioral or early interventions for young children with ASD; and focused their work on communities in need, such as those living in rural areas. Graduates also hold Federal leadership positions.

## Chapter 6. Building the Evidence Base for ASD/DD Care and Services

### Principal Grantee Activities To Build the Evidence Base for ASD/DD Care and Services

The evaluation aimed to assess grantees' research pursuits and products. It assessed how grantees contributed to evidence-based guidelines, tools, and interventions; how grantees mentored new investigators; and how grantees promoted the uptake of new research to transfer findings into practice. The five research networks (AIR-P, AIR-B, DBPNet, HCT-RN, and HW-RN) and the two research grant portfolios (Autism-FIRST and Autism-SDAR) primarily focused on these efforts.

**Grantees conducted research on a breadth of topics related to ASD/DD screening, diagnosis, 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, understand the transition to adulthood, assess overweight and obesity, and address disparities in access to care and early intervention. 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.

**Grantees trained and developed students as ASD/DD researchers by including them on research projects and studies and inviting them to be coauthors on 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. 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. Both LEND and DBP programs prepared trainees to become leaders in the field by providing education on how to review and use research to inform practice and how to generate their own research.

**Grantees published papers in peer-reviewed journals and delivered presentations at national and international conferences to disseminate their research findings.** By the end of 2017, research program grantees had prepared 299 manuscripts related to ASD intervention research, developing measures, tools, and guidelines, and improving care practices. Research grantees delivered 327 scientific conference presentations related to interventions for ASD.

**Grantees developed medical and behavioral treatment guidelines and piloted and validated toolkits to improve the quality and standards of care, diagnostic criteria, and treatment.** During the evaluation period, Autism CARES research program grantees produced 13 sets of guidelines covering various topics such as treatment of anxiety and behavioral problems, weight management and nutrition education, healthcare transition, and behavioral interventions for social engagement. During the evaluation period, research program grantees developed or validated and disseminated a total of 19 tools. Twelve were designed for healthcare and educational professionals. They also created seven products for families and caregivers to help them manage common challenges and train them on interventions.

Section A of this chapter covers the need for research on ASD/DDs. Section B addresses grantee activities to conduct research on ASD/DD, including efforts to translate research into practice. Section C describes how grantees are mentoring new investigators. Sections D, E, and G outline grantees activities to develop manuscripts and presentations, medical and behavioral treatment guidelines, and assessment measures and tools respectively. Section G presents the grantees activities to collaborate with other researchers and stakeholders. Unless otherwise noted, the numbers and figures cited throughout this chapter come from evaluation-specific grantee questionnaires and interview data and materials reviewed as part of the evaluation, including grantee reports and websites.

## **A. The Need for Research on ASD/DDs**

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Scientific evidence about the effectiveness of autism interventions has increased in recent years in part because of research funds made available through Autism CARES (Park, Harwood, Yu, Kavanaugh, & Lu, 2016). Still, there are areas where evidence is lacking (Kasari & Lawton, 2010; Camarata, 2014). For example, in a review of evidence-based practices for children, youth, and young adults with ASD, Wong and others found few evidence-based interventions addressing motor skills, cognitive performance, vocational skills, and mental health (Wong et al., 2015). 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 (Kasari & Lawton, 2010; Dawson & Burner, 2011). Although the Autism CARES grantees have made significant efforts toward conducting intervention research with minority and underserved populations, there are still socioeconomic, racial, and ethnic disparities in the identification and treatment of children with ASD (Coury, 2015; Mazurek et al., 2014; Daniels & Mandell, 2014; Mandell et al., 2009). Routine standardized developmental screening has the potential to reduce disparities in age at diagnosis and possibly reduce racial and ethnic disparities in access to services (Coury, 2015; Herlihy et al., 2014; Daniels & Mandell, 2014; Mandell et al., 2009).

## **B. Conducting Research on ASD and Translating Research Into Practice**

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This section provides an overview of studies by research network grantees and describes the topic areas covered by grantee research including innovations in intervention research.

Autism CARES grantees conduct research on a breadth of topics related to ASD/DD screening, diagnosis, intervention, and systems of care. From September 1, 2014, to August 31, 2017, research program grantees conducted 84 studies. Figure 6.1 provides a summary of some of the more prevalent topics studied by the Autism CARES research programs.

**Figure 6.1. Number of Research Studies by Topic, 2014–2017**



Note: Topics of interest were determined by MCHB prior to the evaluation. Some studies covered multiple topics.

Source: Evaluation-specific grantee questionnaires and interviews

The following sections describe selected Autism CARES research program activities to advance the knowledge base in physical health, behavioral health, clinical practice research, transition to adulthood, and overweight and obesity. Also highlighted is research on interventions and secondary data analyses studies. A full list of research program grantees' studies, the year each was initiated, and study descriptions appear in appendix E. Appendix G includes summaries of Autism-FIRST and Autism-SDAR research studies.

### 1. Improving Physical Health

Most AIR-P studies focused on interventions related to improving the physical health of children and adolescents with ASD/DDs. Research topics included sleep, gastrointestinal issues, dental care, toilet training, and weight management. AIR-P also supported several secondary data analysis studies that use the Autism Treatment Network (ATN) registry data (Murray, Fedele, Shui, & Coury, 2016). For example, the data collected through the ATN registry was used to study the effectiveness of early intensive behavioral intervention services for children with ASD, communication deficits, repetitive behaviors, sleep disorders, development of daily living skills, behavioral comorbidities and medication treatment,

race/ethnicity disparities, and underserved populations. HW-RN addresses physical health; however, the focus is exclusively on overweight and obesity (see section 5 below for additional details).

## 2. Improving Behavioral Health

Most AIR-B studies focused on interventions to improve mental and behavioral health for children with ASD/DDs, with a special focus on underserved populations. The majority of AIR-B studies are related to social skills/engagement/communication in school settings. AIR-B completed six studies that employed methods such as focus groups and interviews, observational study, and pilot studies assessing several interventions. One intervention, Remaking Recess, was effective in increasing social engagement of children with autism (aged 5–11) and typically developing peers. At the end of 2017, AIR-B had two randomized controlled trials in progress. One of these studies, Building Better Bridges, conducted focus groups and interviews with parents of children with ASD across different sites (University of California, Los Angeles; University of California, Davis; University of Pennsylvania; and University of Rochester) 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.

## 3. Standardizing Clinical Practice

Several studies aimed to better understand variation in clinical practice with the goal of standardizing care for people with ASD/DDs. For example, the majority of DBPNet studies focused on variations in clinical practice; two studies were related to social skills/engagement/communication at home, and two studies were related to standardizing care practices. DBPNet also conducted one study related to cultural and linguistic competency and one study related to disparities in access to care and early intervention. Two ongoing 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 relationships<sup>6</sup> and stress experience.<sup>7</sup> DBPNet also developed consensus research priorities for the field of developmental-behavioral pediatrics and described the clinical practices of physicians in the DBPNet according to their methods for diagnosing ASD, identifying comorbidities and adherence to established guidelines (Blum et al., 2012; Hansen, Blum, Gaham, Shultz, & DBPNet Steering Committee, 2016). Another study is assessing the ability of a family navigator to improve access to ASD diagnostic and treatment services and outcomes. Several DBPNet studies use electronic health record data to increase knowledge and understanding of DBP practice and examine treatment outcomes among children with ASD/DDs.

### Research on Transition to Adulthood

Autism CARES grantees have been active in attempting to expand the knowledge base on transition to adulthood for adolescents with ASD. Notably, the three National Autism Indicator Reports have drawn national attention to the issue of transition to adulthood and are a valuable resource for researchers, policymakers, and the public. The reports addressed developmental disability services and outcomes in adulthood, vocational rehabilitation, and transition into young adulthood. The rapid-cycle improvement tests conducted by HCT-RN have enhanced the process of implementing the *Health Care Transition Curriculum for Primary Care Residents*. See the reports at <http://www.drexel.edu/autismoutcomes/publications-and-reports/nat-autism-indicators-report/> and chapter 8 for more information about studies by HCT-RN.

<sup>6</sup> This measure was validated with children aged 5–12.

<sup>7</sup> This measure was validated with children aged 12–17.

#### 4. Understanding the Transition to Adulthood

The transition to adulthood is a challenging time for all children with ASD. When HCT-RN was initially funded, there was a dearth of information and intervention resources for transitioning adolescents, their families, and their healthcare providers. All 12 HCT-RN studies, one AIR-P study, and one Autism-SDAR study have examined issues related to the transition to adulthood.

The 12 HCT-RN network studies addressed transition topics involving the critical lack of research on life course issues for individuals, families, health systems, and policy. The AIR-P study, *First Impressions: Strategies To Enhance Initial Adult Care Visits for Transitioning Youth with ASDs*, tested an intervention that prepared youth, their families, and the medical professionals providing their care for transition. The Autism-SDAR study, *Medical Care Utilization and Costs Among Transition-Age Young Adult Medicare Beneficiaries With Autism Spectrum Disorder*, examined healthcare use and costs associated with medical care among transition-age young adults with ASD. More information about these transition efforts appears in chapter 8.

#### 5. Assessing Overweight and Obesity Among Those With ASD/DDs

The HW-RN studies focused on obesity, physical activity, and diet/nutrition for children and adolescents with ASD/DDs. HW-RN has implemented 17 research studies on topics including obesity and weight management, physical activity, and nutrition. Some HW-RN studies also relate to clinical practice variation and standardizing care practices. Examples of findings from HW-RN studies related to overweight and obesity follow:

- ▶ **Promoting physical activity.** One 12-week pilot study, *Promotion of Physical Activity in Adolescents With Intellectual and Developmental Disabilities*, was successful in using technology to deliver a physical activity program. Participants attended 30-minute group physical activity sessions three times per week. The sessions were delivered in their homes by video conferencing on a tablet computer. Group-based physical activity delivered remotely may be a feasible approach for the promotion of physical activity in adolescents with intellectual disabilities.
- ▶ **Understanding differences in food selectivity.** The study, *Influence of Race/Ethnicity and Sex on Food Selectivity Among Children With Intellectual Disabilities*, examined food selectivity in a diverse community-based convenience sample of children with intellectual disabilities between the ages of 3 and 8. This sample of children exhibited differences in food selectivity by sex, but not by race or ethnicity. Boys showed greater levels of food refusal, and boys who also had ASD had narrower food repertoires. Cultural differences in parent feeding practices by race/ethnicity or in response to child sex should be explored as potential explanations for these findings.

## New Research Shows Disparities in Prevalence of Overweight and Obesity Between ASD and Non-ASD Populations

Two HW-RN studies were the first to show evidence of disparities between ASD and non-ASD populations in prevalence of overweight and obesity and are among the most frequently cited HW-RN SDAS. HW-RN also provided the first nationally representative estimates of obesity in children and adults with ASD/DDs, along with obesity-related risk factors for this population.

- The study titled *Intellectual Disability Is Associated With Increased Risk for Obesity in a Nationally Representative Sample of U.S. Children* found that the prevalence of obesity among youth with intellectual disabilities was almost double that of the general population. Prospective studies are needed in this population to examine the impact of consistent family mealtimes and infrequent physical activity.
- The study titled *The Effect of Age on the Prevalence of Obesity Among U.S. Youth With Autism Spectrum Disorder* found that the patterns of prevalence observed with increasing age among children with and without ASD were unexpected. A better understanding of the etiological and maintenance factors for obesity in youth with ASD is needed to develop interventions tailored to the specific needs of these children.

During the evaluation period, AIR-P also studied weight gain among children with ASD. Specifically, the AIR-P intervention research study examined weight gain induced by antipsychotic medication, which affects a large proportion of children with ASD. The study found that metformin was effective in reducing body mass index scores of study participants.

## 6. Advancing the Evidence for ASD/DD Interventions

The Autism-FIRST program exclusively focuses on developing and testing evidenced-based interventions to support improvements in children and adolescents with ASD/DDs and their families. Intervention research is also a focus of the research networks. Grantees paid particular attention to including families and underserved populations in the research process.

From 2014 to 2017, Autism-FIRST grantees completed 10 intervention studies, and research network grantees conducted 16 intervention studies. Of the 10 Autism-FIRST studies included in this evaluation, the majority examined disparities in access to care and early intervention, or social skills, engagement, and communication at home or at school. Other topics these grantees investigated included anxiety and depression, interdisciplinary care, and cultural and linguistic competency. Some studies tested parent- or teacher-mediated interventions or increased the capacity of families and schools to help improve developmental outcomes for children with ASD/DDs. Other studies assessed the effectiveness of medical or behavioral interventions and practices intended to improve outcomes for

### Effective Teacher-Mediated Interventions by Autism-FIRST Grantees

- One study found that a toilet training intervention, using a moisture pager and an iPhone, could improve toilet training behavior when implemented in community classroom settings.
- Another study found a significant change in social and communication behaviors among children exposed to a teacher-mediated intervention.

children with ASD and support their families. For example, 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. Between 2014 and 2017, the research programs conducted 26 intervention studies resulting in 70 publications that shared the results.

### a. Research Involving Families

There is a need for research that addresses family-specific challenges and incorporates the family perspective. Of the 62 research network studies, 18 intervention studies included children with ASD/DDs and/or families as consultants and/or study participants. Collectively, these studies included more than 104 children or families of children with ASD/DDs.

Some studies focused on parent-/caregiver-mediated interventions; although many parent-/caregiver-mediated interventions have been effective, recruitment and retention were identified as barriers to implementation. Researchers indicated a family-centered research approach where parents/caregivers are consulted during study design through analysis could improve the effectiveness and fidelity of these interventions.

#### Grantee Perspective on Involving Underserved Groups in Research

“There are very few studies that are randomized controlled trials ... situated in low-resource schools. The reason we choose schools [is] because all kids go to school. If you look at the ASD intervention research literature, it's almost all high [socioeconomic status] White and privileged and high functioning. Our studies are ... showing really good results with these other, more diverse populations.”

—AIR-B Principal Investigator

Several grantees have developed interventions to provide additional resources for parents of young children and toddlers with ASD/DDs, such as the following:

- ▶ **Developing parent- and caregiver-mediated interventions.** Five Autism-FIRST grantees developed interventions mediated by parents or caregivers. Preliminary outcomes show one intervention, *Comprehensive Communication Intervention for Minimally Verbal Children With Autism*, was rated favorably by parents, and implementation fidelity of both child-intervention and parent-training components of the intervention was consistently high throughout the study.
- ▶ **Studying family navigators.** DBPNet has been studying whether the use of family navigators will improve ASD services for young, newly diagnosed children; decrease parental stress; and improve family functioning. Families have been involved in the design and implementation of the study.
- ▶ **Assessing parental stress.** HCT-RN analyzed data collected by AIR-B to explore the impact of family obligations and parental stress on use of intervention services for young children with ASD. The study identified the need for additional support or alternative service delivery models for mothers of children with ASD who have multiple children in the home, low levels of education, and/or high levels of stress.

## **b. Research Involving Underserved Populations**

Recruiting underserved children into research studies can be challenging, leading to their underrepresentation in ASD research. Investigators report difficulties with initial engagement of populations that already have difficulty accessing care. Many studies have potentially burdensome participation requirements and call for rigid adherence to study protocols, which can lead to high attrition. It is particularly difficult to ensure consistent participation of rural, non-English-speaking, or low-literacy participants when a study requires participation of parents and caregivers who may have inflexible work schedules and/or language barriers. Research with non-English-speaking populations may involve additional costs because of the need for translators and interpreters. For example, study teams must include bilingual research assistants and/or translators to recruit study participants and relay important intervention information.

Research program grantees have made efforts to address the underrepresentation of minority and underserved populations in ASD intervention research studies. For example, AIR-B implements intervention studies specifically designed for use in low-resourced public schools to enhance their reach to participants from underserved populations. AIR-B and other CARES investigators form relationships with community partners that work with underserved populations. Other research networks and R40 grantees have implemented telehealth initiatives to alleviate the burden of traveling to and from research clinics and increase scheduling flexibility for underserved families. Many research program grantees increased cultural competency in their interventions by offering study materials in multiple languages, adding bilingual researchers to the study teams, and recruiting from clinics and hospitals that primarily serve underserved populations.

According to HRSA, a study is considered to target or focus on underserved populations if more than 30 percent of participants self-identify as Hispanic, African-American, low-income, or rural populations. Across all research programs, 62 percent of studies completed or in progress between September 1, 2014, and August 31, 2017, included underserved populations as study participants. Across research networks, 26 percent of studies focused on the needs of underserved populations. One network, AIR-B, specifically targeted underserved populations in all four of its studies.

Several Autism-SDAR studies focused on combating health disparities among underserved populations with ASD/DDs. Examples follow:

▶ **Assessing disparities in service utilization.**

The study titled *Racial and Ethnic Disparities in Diagnostic and Health Services of Children With Developmental Disabilities* assessed whether there are significant differences in pathways to diagnosis, early service utilization, and care among racial and ethnic minority children with ASD/DDs. The study found differences in quality of healthcare between non-Latino Asian and White children with special healthcare needs. While there were no differences in service utilization between White and Latino children whose conditions were not severe, Latino children with severe conditions received significantly fewer services than their White peers. Finally, compared to White parents, Latino parents had four times higher odds of receiving a nonproactive response from a provider, indicating a difference in the pathway to diagnosis for White and Latino children.

Improving Access to Care for Underresourced Children With ASD

One AIR-B study, Mind the Gap, ongoing as of December 2017, aimed to address the critical need to increase access to care for underresourced children with ASD and their families by conducting several focus groups and interviews with parents of low-income, minority children with ASD across different sites to better understand challenges, barriers, and needs in the community.

- ▶ **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.

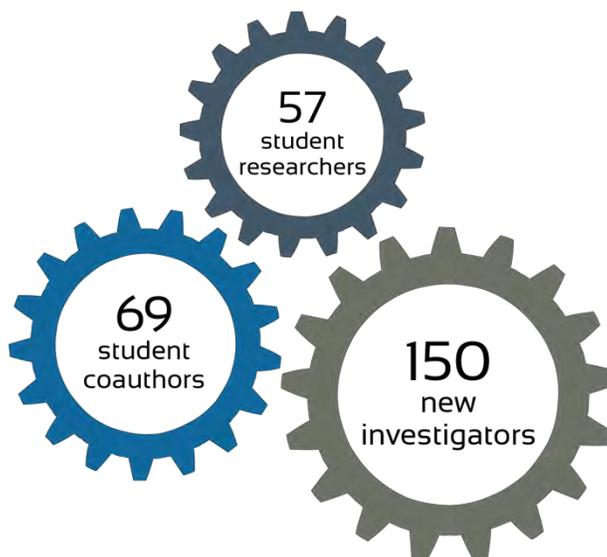
## C. Mentoring New Investigators

Autism CARES grantees train and develop students as ASD/DD researchers by including them on research projects and studies and inviting them to contribute to and coauthor peer-reviewed publications and scientific conference presentations. The LEND and DBP training programs also mentor trainees to be informed consumers and producers of research.

### 1. Engaging Students in Research Program Efforts

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 (see figure 6.2). For example, one multisite study on communication for minimally verbal children with autism provided training to 12 students at 3 different universities. These students (a mix of undergraduate, master's-level, and doctoral students) were given the opportunity to provide language strategies training for children with ASD/DDs to children and parents with ASD/DDs. They also received training in data collection and data entry techniques. In an Autism-FIRST study of a self-directed, therapist-assisted telehealth parent training intervention for children with ASD, all the parent coaches were graduate students in clinical psychology. This grantee also provided cultural competency training to the participating students. Another Autism-FIRST study of health disparities in ASD diagnosis, service utilization, and school engagement mentored several graduate-level, postdoctoral, and undergraduate students. The principal investigator explained how leveraging graduate students and volunteer staff facilitated reach. The grantee added how student involvement also ensured that a new generation of professionals will be well versed in ASD/DD interventions.

**Figure 6.2. Number of New Investigators, Student Authors, and Student Researchers Involved in the Autism CARES Research Program, September 1, 2014–August 31, 2017**



Source: Evaluation-specific grantee questionnaires and interviews.

## **2. Educating LEND and DBP Trainees About Research**

Both LEND and DBP programs prepared trainees to become leaders in the field by providing education on how to review and use research to inform practice, and how to generate their own findings. Programs varied in their approach to didactic research training, but most offered formal research methods coursework in some capacity. In addition to formal training in research methods, trainees were also exposed to research methods in practice. Most LEND and DBP programs required trainees to participate in a research project, often with the guidance of a faculty member or in collaboration with other trainees or researchers at other institutions. Trainees often presented findings in posters at seminars or conferences, further building their leadership skills. In some programs, trainees worked on evaluating a community project or quality improvement initiative in lieu of or in addition to a traditional research project. For example, the University of Hawaii LEND paired trainees with a Title V organization in need of answers to a research question, a needs assessment, or program evaluation, and trainees worked with the program administrator to devise an approach. Some community projects were also driven by the initiative of trainees, as in the case of a fellow at the University of California, San Diego, DBP program who developed a project to study the use of a tool to assist reading development among deaf and hard-of-hearing children.

## **D. Developing Manuscripts and Presentations**

One measure of the grantees' efforts to communicate new research developments and findings to healthcare professionals is the number of research papers published in peer-reviewed journals. This section describes grantees' efforts related to producing research manuscripts and presentations.

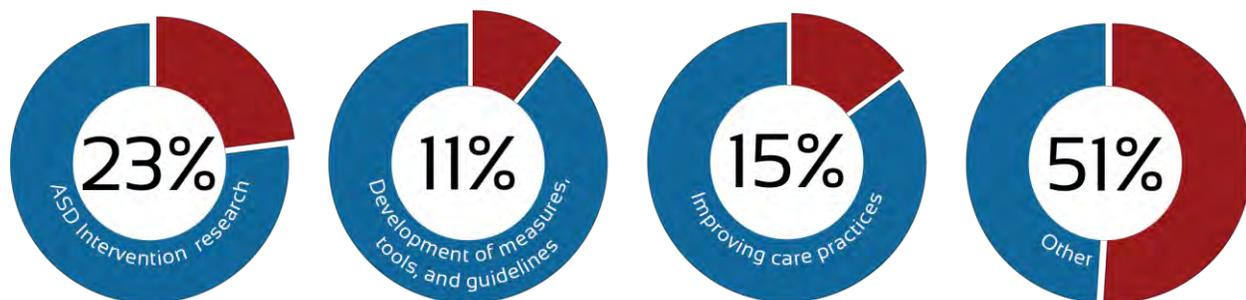
### **1. Writing Manuscripts and Other Publications**

All research grantees have published or are in some stage of publishing key outcomes and findings of their Autism CARES-funded research. By the end of 2017, they had prepared 299 manuscripts. Of these,

204 articles had been published, 28 had been accepted and were in press, 24 had been submitted for publication, and 43 were in preparation. Appendix G provides a complete list of the published manuscripts from the grantees over the 3-year evaluation period.

Of the manuscripts prepared by research program grantees, 23 percent were related to ASD interventions, 11 percent focused on the development of new tools and guidelines, 15 percent were related to improving care practices, and 51 percent were related to other topics. The majority of Autism-FIRST grantees' manuscripts (66 percent) were related to ASD interventions and practices intended to improve outcomes for children with ASD/DDs and support their families. The majority of Autism-SDAR grantees' manuscripts (72 percent) were related to disparities in access to care, quality of care, and healthcare utilization. Figure 6.3 shows the percentage of research manuscripts by topic.

**Figure 6.3. Research Program Manuscripts by Topic**



Source: Interviews and associated data collection activities

Autism CARES grantees produced notable publications on the following topics:

- ▶ **Low-resourced public schools.** AIR-B published manuscripts focusing on interventions based in low-resourced public schools and interventions targeted at underserved populations.
- ▶ **Diabetes medication.** AIR-P published one highly cited article on the use of a diabetes medication to treat weight gain induced by the use of antipsychotic medication in children with ASD (AAP, 2011).
- ▶ **Diagnostic measures.** DBPNet published several manuscripts detailing the validation of several diagnostic measures used by pediatricians.
- ▶ **Obesity estimates.** HW-RN produced the first nationally representative publication of obesity estimates for individuals with DDs, which is highly cited in the field (Segal et al., 2016).
- ▶ **Shared decisionmaking.** In a study of parental perception of shared decisionmaking among parents of children with ASD and severe functional impairment (i.e., children with Down Syndrome, children with cerebral palsy), the Stanford DBP found there was more shared decisionmaking occurring with children with a medical home, and less shared decisionmaking with children with severe functional impairment and with children with ASD (Hubner, Feldman, & Huffman, 2016).

- ▶ **Adverse childhood experiences.** Though adverse childhood experiences (ACEs) have been correlated with adult health disparities, studies by University of Illinois LEND and a self-advocate Autism-SDAR grantee were among the first to examine correlations between ACEs and DDs. The seminal publication from the LEND study revealed that individuals with DDs experience more ACEs and that those with past ACEs were more likely to have delayed diagnoses (Kerker et al., 2015).

Of note, three of HCT-RN's publications were coauthored by self-advocates or family members of people with ASD who were engaged in network studies.

## 2. Delivering Conference Presentations

In addition to publishing results of the research, grantees presented their study methodologies and results at scientific conferences. For this evaluation, scientific conferences were defined as those that include an abstract peer-review process and were sponsored by university, national, or international organizations. Some grantees also presented at AUCD's Annual Meeting and at HRSA-sponsored Autism CARES grantee meetings designed for sharing study results across grantee programs. In total, the research grantees delivered 327 scientific conference presentations related to interventions for ASD. Examples of presentations grantees delivered follow:

- ▶ **International Meeting for Autism Research.** HCT-RN presented findings from the 2016 National Autism Indicators Report on the role and effectiveness of vocational rehabilitation services in helping individuals with autism gain paid employment, contrasting those outcomes to those of individuals with intellectual disability and other mental illness at the 2016 International Meeting for Autism Research (now called the International Society for Autism Research).
- ▶ **American Public Health Association Annual Meeting.** HW-RN presented on the incidence of obesity in early elementary school children with ASD at the American Public Health Association's 2016 conference.
- ▶ **AUCD Annual Meeting.** The University of Missouri LEND program presented at the 2015 AUCD conference about their project, *LEND ECHO Autism: An Innovative Model That Expands Knowledge To Increase Specialty Care for Children and Youth with Autism*, sharing their innovative work with the ECHO Autism collaborative described earlier.
- ▶ **Early Hearing Detection and Intervention Annual Meeting.** At the annual Early Hearing Detection and Intervention Conference, fellows from the Boston Children's Hospital LEND program presented a poster titled, *Audiologists' Role in Directly Referring to Early Intervention*. This poster was awarded the Blue Ribbon and received significant accolades from colleagues who attended the conference.

## E. Developing Medical and Behavioral Treatment Guidelines

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Autism CARES grantees produce clinical guidelines to improve the quality and standards of medical care, diagnostic criteria, and treatment for families and children with ASD. This section describes clinical guidelines developed by Autism CARES grantees and their efforts to disseminate those guidelines to providers and families.

From September 1, 2014, to August 31, 2017, Autism CARES research program grantees produced 13 sets of guidelines. The guidelines covered various topics relevant to the ASD/DD population, including

treatment of anxiety and behavioral problems (AIR-P), weight management and nutrition education (HW-RN), healthcare transition guidance for medical professionals (HCT-RN), and behavioral interventions for social engagement and communication (Autism-FIRST). The following provides a summary of the guidelines produced by AIR-P, HW-RN, HCT-RN, and Autism-FIRST grantees. Appendix H provides a full description of each guideline and resulting publications.

- ▶ **Anxiety management.** AIR-P developed two empirically based guidelines for the management of anxiety (Vasa et al., 2016) and treatment of irritability and problem behaviors (McGuire et al., 2016). Both sets of guidelines were published in the 2016 *Pediatrics* Supplement, *Improving Health Care for Children and Youth With Autism and Other Neurodevelopmental Disorders*.
- ▶ **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 2017.
- ▶ **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 work group. The five guidelines contribute to the network's overall mission to promote best practices in healthcare transitions through national professional organizations for physicians.
- ▶ **Intervention.** Although Autism-FIRST program grantees are not expected to develop guidelines, 3 of the 10 grantees funded in FY 2013 and FY 2014 developed intervention-related materials that can be disseminated more broadly 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 about minimally verbal children. A 2014 Autism-FIRST grantee developed a set of guidelines for conducting parent coaching over the internet.

## F. Developing Assessment Measures and Toolkits

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This section summarizes the efforts of research grantees to develop, pilot, and validate toolkits to support both clinicians and parents in diagnosing and treating the medical and behavioral issues that commonly occur in children with ASD. This section also addresses grantees' efforts to validate tools or measures that can be used to assess the outcomes of ASD interventions over time. The grantees develop measures and tools for use by two main audiences: (1) healthcare and education professionals who work with and treat individuals with ASD/DDs, including school teachers; and (2) family members and caregivers of individuals with ASD/DDs.

### 1. Developing and Validating Measures and Toolkits for Providers and Professionals

The research grantees developed and/or validated and disseminated a total of 12 tools and measures for healthcare and education professionals, including school teachers.<sup>8</sup> Examples of some tools and measures for providers and professionals follow:

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<sup>8</sup> The measures and toolkits that AIR-B developed were unique in that they were specifically designed for use in underserved communities and low-resourced schools.

- ▶ **EEG Guide for Providers.** Developed by AIR-P, this guide gives providers information about the EEG procedure, how a child’s ASD diagnosis might impact his or her experience of having an EEG, and how to help children with ASD successfully prepare for and complete an EEG.
- ▶ **Schedules, Tools, and Activities for Transitions in the Daily Routine Manual.** Created by AIR-B, this toolkit is for use by teachers in special education classrooms. It is designed to improve behavior and transitions among students with ASD. The intervention uses behavioral strategies found in functional routines to address classroom management and environmental structures in special education classrooms.
- ▶ **“Let’s Go” Toolkit.** Developed by HW-RN and Maine Medical Center, this toolkit is 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 is designed to raise awareness of the needs of children with intellectual disabilities and support the expectation that, given more support, children with intellectual disabilities can lead healthy, active lives.

A full list of measures and toolkits for providers and professionals appears in appendix I.

## 2. Creating Toolkits for Families and Caregivers

The research grantees developed and/or validated and disseminated seven tools for caregivers. Most of the tools and measures developed for parents and families are designed to support them in effectively managing common challenges, such as sleep problems and the transition to puberty. Other products were designed to train parents and families on specific interventions, such as the following examples:

- ▶ **Puberty and Adolescence.** AIR-P developed a 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.
- ▶ **Toddlers and Families Together Manual: Addressing Early Core Features of Autism.** Developed by a 2013 Autism-FIRST grantee from University of North Carolina, Chapel Hill, this parent-friendly intervention manual for the *Together* intervention has been found to reduce stress in parents of children with ASD and improve caregiver-child interactions. Engagement, joint engagement, play, and joint attention behaviors were significantly improved in toddlers receiving the intervention. The manual is publically available in both English and Spanish.
- ▶ **Improving 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.

A full list of toolkits for families and caregivers appears in appendix I.

## G. Collaborating With Grantees and Other Stakeholders

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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. Examples follow:

- ▶ **Collaboration among research networks.** 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.
- ▶ **Collaboration with community partners.** AIR-B collaborated closely with two community partners, Healthy African American Families<sup>9</sup> and Fiesta Educativa,<sup>10</sup> to recruit study participants. 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 has been in regular communication with the council and private insurers to ensure key stakeholders have the information they need to translate study findings into practice.
- ▶ **Collaboration among research programs and other Autism CARES grantees.** The LEND programs at the University of Illinois and Children’s Hospital of Philadelphia collaborated on a Autism-SDAR study, *Family Adversity and Health Disparities for Young Children With Autism*. This study aimed to examine whether racial and ethnic disparities in timing and receipt of diagnosis and treatment for children with ASD vary based on adverse family experiences. Researchers found that cumulative ACEs did not vary by race/ethnicity and that the reporting of ACEs was associated with delayed diagnosis of ASD and entry into therapy. The findings indicate children with ASD experience higher cumulative ACEs and higher prevalence of exposure to specific ACEs, including neighborhood violence, parental divorce, parental mental illness, and parental substance abuse (Berg, Shiu, Acharya, & Msall, in press).

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<sup>9</sup> 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/>.

<sup>10</sup> 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://www.fiestaeducativa.org/>.

## Chapter 7. Building and Improving Systems of Care for Individuals With ASD/DDs

### Principal Grantee Activities To Build and Improve Systems of Care for Individuals With ASD/DDs

The evaluation aimed to assess grantees' activities to reduce barriers to screening and diagnosis of ASD/DDs, improve systems of care, and identify the needs of underserved populations. LEND, DBP, and State systems grantees primarily focused on these efforts. Addressing the common barriers to care for children with ASD/DDs and their families is important, particularly in areas where there are too few providers to meet demand and where treatment systems are not coordinated.

**Grantees improved access to early developmental screening, diagnostic evaluation, and intervention services by expanding local capacity, reducing bottlenecks, and leveraging existing initiatives and resources.** Grantees built local capacity by implementing quality-improvement projects in underserved communities and building community-based assessment teams. They also made developmental screening tools available to families and those working with children and provided associated training. To reduce wait times and expedite delivery of comprehensive diagnostic services, grantees reduced bottlenecks by training providers to conduct developmental screening. Grantees commonly expanded existing initiatives and programs in their efforts to achieve sustainable improvements with respect to early screening, referral, and diagnostic evaluation services.

**Grantees improved coordination of ASD/DD services across agencies and systems of care.** By working to bridge the divide between education and healthcare systems, grantees addressed challenges associated with education and medical professionals conducting independent assessments of children. Grantees also improved referral and care coordination by dismantling silos, facilitating referrals, and improving awareness of local resources among families and providers by mapping community resources and ASD/DD services.

**Grantees engaged families and underserved populations.** To ensure their efforts were informed by the needs of families, grantees engaged families in planning, implementation, evaluation, pilot, and quality-improvement initiatives. Each State systems grantee established a multidisciplinary advisory group to oversee implementation of its strategic plan. Parents, caregivers, and representatives from family organizations represented an essential component of these advisory groups. Grantees also established family navigator programs to promote partnerships between professionals and families. In an effort to reduce disparities in ASD services for underserved populations, grantees established clinics in underserved regions and used telehealth to extend their influence. They also worked to reduce disparities among populations such as Native Americans, refugees, those living in rural areas, and non-English speakers.

Section A of this chapter outlines the need for efforts to improve systems of care for individuals with ASD/DDs. Section B outlines efforts to improve access to early developmental screening, diagnostic evaluation, and intervention services. Section C outlines grantee efforts to build more comprehensive, coordinated systems of care. Section D describes grantee efforts to engage families, and section E

describes efforts to reduce disparities in ASD services for underserved populations. Unless otherwise noted, the numbers and figures cited throughout this chapter come from evaluation interview data and materials reviewed as part of the evaluation, including grantee reports and websites.

## **A. The Need for Improving Systems of Care for Individuals With ASD/DDs**

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Increased awareness and increased insurance coverage have led to greater demand for autism services in an already overburdened system. This situation is exacerbated in areas where demand permanently exceeds supply or where multiple distinct streams of treatment work in parallel (Austin et al., 2016). For example, children may enter the system through a referral from a pediatrician's office or through a school referral. These referral systems may not always communicate with one another. The medical home is one way to address the fragmented system of care. The concept of the medical home was first introduced by the AAP in 1967. Originally, the term was used to describe a single source of patient information, but over time it came to include the idea of partnership approaches with families (Robert Graham Center, 2007). A study by Farmer and others (2014) noted that of the 371 parent-child dyads in a survey, almost two-thirds had unmet needs. The study showed children with ASD who have a medical home are more likely to have access to the services they need. However, fewer than one in five children in the survey had a medical home (Farmer et al., 2014).

The preceding chapters have described how the Autism CARES grant programs are addressing common barriers to care for children with ASD/DDs and their families. The efforts of each program are essential to improving the health and well-being of individuals with ASD/DDs. Sustaining such improvements, however, requires system-level changes. Professional training, research, and educational campaigns need to be embedded within systems where services are comprehensive, coordinated, community based, family centered, and culturally competent.

## **B. Improving Access to Early Developmental Screening, Diagnostic Evaluation, and Intervention Services**

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Improving systems of care for children with ASD/DDs starts with ensuring families have access to early developmental screening, diagnostic evaluation, and intervention services. Common barriers to early identification include noncompliance with AAP developmental screening recommendations among primary care physicians and pediatricians, long wait lists for comprehensive diagnostic evaluation, and delays in access to treatment for children with a confirmed diagnosis (Fenikilé et al., 2015; Gordon-Lipkin et al., 2015; Yingling et al., 2017). Grantees implemented three primary strategies to address each of these barriers: building local capacity for developmental screening, referral, and diagnosis through partnerships with community-based providers; reducing the bottlenecks that contribute to long wait lists for diagnostic services; and leveraging existing initiatives to promote more widespread ASD screening and referral.

### **1. Expanding Local Capacity**

A key strategy for improving access to ASD services involves building local capacity through education and engagement of families, early childhood professionals, educators, clinicians, and community-based organizations. Such efforts are particularly important in underserved communities where access to developmental screening and preventive care services is limited. Making developmental screening tools

and associated training available to families and those who work with children is one way grantees started to build local capacity for early identification, such as in the following examples:

- ▶ **Using a web portal to facilitate developmental screening.** In partnership with Act Early Texas!, the University of Texas LEND developed and launched a web portal that provides online, automated MCHAT and ASQ-3 developmental screens for parent and childcare provider use. All users are required to register as a parent or professional and provide an email address before completing one or both instruments. Parents receive the results via email. If results indicate cause for concern, the email message includes information on where to go for further evaluation and services. The results are also faxed to an early childhood intervention specialist or local school district and to the family’s primary care physician, as identified during registration. Early childhood professionals who provide Act Early Texas! screenings must first complete an online training for certification as a developmental screening consultant.
- ▶ **Providing free training on early identification.** Rhode Island’s State systems grantee offered a no-cost training, *Creating the Connections*, for professionals, paraprofessionals, volunteers, and families to build local capacity for early identification. The primary goal of *Creating the Connections* is to help families access developmental screening, evaluation, and intervention services for ASD/DDs by making training available to “frontline” staff who work with families in underserved communities. Within the first 8 months of the grant, more than 120 professionals participated in *Creating the Connections*, including staff from early childhood centers, early intervention specialists and caseworkers for foster care programs, and in-home support services.
- ▶ **Building a tiered training model for developmental screening and referral.** Virginia’s State systems grantee engaged three demonstration sites in different areas of the State to build local capacity for developmental screening, referral, and diagnostic evaluation. Virginia implemented a tiered model for developmental screening and referral. Tier 1 involved training childcare providers about developmental milestones, the importance of identifying developmental delays early, and where to refer children who do not meet developmental milestones. Early intervention professionals and home visitors were trained to administer M-CHAT. Tier 2 training provided annual ADOS training to local, multidisciplinary assessment teams including physicians, speech pathologists, school psychologists, and other community providers. Tier 3 training was an intensive 4-day seminar that covered not only ADOS and the Autism Diagnostic Interview-Revised (known as ADI-R) but also other topics such as team functioning, consensus scoring, and writing reports. 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 (see figure 7.1).

**Figure 7.1. Changes in the Number of Norfolk Children Who Received an ASD Screening at Demonstration Sites by 24 Months Following the Implementation of Virginia’s Local Capacity-Building Initiative**



Note: One icon represents five children.  
 Source: Data provided by the Virginia State systems grantee.

**a. Implementing Quality Improvement Projects in Underserved Communities**

Several grantees implemented quality-improvement projects in underserved communities. For example, Maryland’s State systems grantee expanded local capacity for early identification by engaging local providers in quality-improvement projects. The grantee recruited nine pediatric practices serving low-income and minority populations to participate in a quality-improvement learning collaborative (QILC). Practices that participated in this 11-month QILC learned how to use quality-improvement methods to incorporate recommended developmental screening procedures in their clinical workflow and refer children for further evaluation and early intervention as needed. Specific components included quarterly didactic webinars; monthly quality-improvement calls conducted by project staff to review data, discuss challenges, and provide ongoing support; monthly practice team meetings; onsite office visits; and technical assistance for practices that showed the least improvement in developmental screening. The didactic webinars covered an array of topics such as the importance of early intervention, choosing an evidence-based developmental screening tool, integrating developmental screening into workflow practices and referral practices when screening results indicate a need for further evaluation. Each practice had a designated parent partner to support the providers in administering the developmental screening tools, discussing results with parents, and making referrals. To offer incentive to participate in the QILC, the grantee offered (1) a \$2,500 scholarship to help defray the costs associated with the work of the QILC; (2) maintenance of certification credit; (3) continuing medical education (CME) credit; and (4) the services of a paid parent partner who was hired, trained, and paid by the project. Data collected from the participating practices at baseline and at the end of the 11-month collaborative indicated a 30-percent increase in developmental screening rates over time.

Increased Developmental Screening Rates in Maryland

Practices that participated in Maryland’s Quality Improvement Learning Collaborative had a 30-percent increase in developmental screening rates over the 11-month period.

Wisconsin's State systems grantee launched local projects called Engaged Community Quality Improvement Projects (ECQuIP) to improve families' timely 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 being 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 developmental 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.

### ***b. Building Community-Based Assessment Teams***

One State systems grantee focused on building underserved communities' capacity to provide timely, interdisciplinary, team-based diagnostic evaluations for ASD/DDs. In Oregon, prior to the grant, families living in the eastern or southern parts of the State had to travel long distances to access a medically based diagnostic clinic. Although children in these communities could qualify for special education services based on an educational assessment, a medical diagnosis was required to be determined eligible for other services. To address these problems, the grantee identified communities with interest, capacity, and readiness to build medical-educational autism identification teams. Each team included a local healthcare provider, a mental health professional, educational staff (e.g., autism specialist, speech pathologist, school psychologist, special educator) and a parent partner (parent of a child with ASD).

The grantee assembled eight autism identification teams in rural or otherwise underserved communities. Teams received training in the use of ADOS-2 and participated in bimonthly webinars focusing on ADOS and STAT scoring reliability checks, coding and billing for developmental screening or evaluation services, differential diagnosis, team process issues, and cultural competency. The grantee conducted site visits to each autism identification team's community and hosted annual trainings in Portland to reinforce what the teams were learning in the webinars.

By the end of the grant, autism identification teams had provided comprehensive, team-based evaluations for 119 children, with more than 80 percent of those children receiving an evaluation within the recommended educational timeline (45 or 60 days, depending on whether the child was already in early intervention/early childhood special education services). This compares to the 5–6-month wait families in Oregon experience once referred for evaluation by a medical center-based team. The average age of diagnosis for children evaluated by the autism identification teams was 3.8 years.

## **2. Reducing Bottlenecks**

Grantees also worked to reduce or eliminate common bottlenecks that contribute to delayed identification of ASD/DDs. As awareness about the importance of early identification has increased, so has the number of referrals for diagnostic services. State systems and LEND and DBP grantees tested and implemented various strategies to streamline the assessment process for families with concerns about their children's development.

### a. Training Providers To Conduct Secondary Developmental Screening

Many State systems and LEND grantees worked to reduce wait times for comprehensive diagnostic services by training providers in the use of secondary developmental screening tools such as STAT. STAT was designed for use by a wide range of community professionals to identify children between 24 and 36 months of age who may be on the autism spectrum. STAT requires less time and training to administer than a more comprehensive diagnostic tool such as ADOS, but it can effectively rule out children whose symptoms and behaviors indicate a developmental challenge other than ASD, thereby reducing the number of children requiring a more comprehensive evaluation by an autism specialist.

For example, Iowa's State systems grantee offered STAT-MD training to advanced registered nurse practitioners working in child health specialty clinics (CHSCs). The grantee oversees 14 CHSCs around the State that serve children with special healthcare needs and their families. By training all advanced registered nurse practitioners from the 14 CHSCs to administer STAT-MD, the grantee effectively reduced the number of "false positive" referrals, thereby freeing up diagnostic appointments for children requiring more comprehensive evaluation. Concurrently, the grantee implemented a pilot program with three multidisciplinary ASD clinics, whereby the clinics reserved a limited number of priority appointments per month for families referred from one of the CHSCs.

### b. Empowering Primary Care Practices To Expedite Service Delivery

Although grantees invested a substantial amount of effort into building and improving systems of care, they bolstered their own efforts by empowering primary care providers to address medical and care coordination issues for individuals with ASD/DDs. Examples follow:

#### ▶ Helping primary care providers augment their

**direct services.** The DBP program at Rhode Island Hospital created a new program called a Certificate in DBP for Pediatric Primary Care Providers. This program supported pediatricians and nurse practitioners seeking to develop targeted skills in DBP to augment their primary care practice. Trainees focus on one or two topics during the training, facilitating a faster and more flexible completion than a traditional fellowship. They deepen their understanding of DBP issues and return to their practices quickly, better prepared to treat individuals with ASD/DDs.

#### LEND, DBP, and Research Grantees' Efforts To Improve Systems of Care

- LEND and DBP programs increased the number of professionals trained to provide ASD/DD services and emphasized recruiting those from underrepresented groups (see chapter 5).
- LEND and DBP programs provided interdisciplinary, diagnostic services to more than 100,000 individuals each year through clinical training programs (see chapter 5).
- LEND and DBP programs operated local clinics, facilitated family and home visits, and collaborated with schools to provide services to individuals with ASD (see chapter 5).
- Research program grantees systematically involved families, self-advocates, and underserved populations in their studies (see chapter 6).
- Research program grantees studied clinical practice variation and disseminated clinical guidelines and toolkits to improve the quality and standards of care (see chapter 6).

- ▶ **Developing initiatives to strengthen the medical home.** Stanford’s DBP program established a primary care initiative to promote recognition and management of developmental issues inside the patient-centered medical home. DBP faculty identified and partnered with primary care practices in their region (including several federally qualified health centers and a network of private practices) to expand access to resources. For example, at one practice, a DBP faculty member helped the primary care practice establish a hotline for immediate consultations, supported training for care coordinators, enhanced feedback systems, and developed quality improvement plans tailored to individual practice strengths, areas for improvement, needs, and interests.

### 3. Leveraging Existing Initiatives and Resources

Autism CARES grantees commonly expanded upon existing initiatives and programs in their efforts to achieve sustainable improvements in early developmental screening, referral, and diagnostic evaluation services. Examples follow:

- ▶ **Utilizing an AAP effort to promote quality improvement.** Michigan’s State systems grantee leveraged ongoing efforts of a statewide physician quality-improvement program that promotes pediatric practices’ use of standardized, evidence-based developmental screening tools to assess every child for DDs or special healthcare needs. The Michigan Chapter of the American Academy of Pediatrics offered the quality improvement program, *Screen for 3*, free of cost to participating physicians and practices. Participants earned 20 CME credits and received the ASQ-3, ASQ–Social Emotional (ASQ-SE) toolkits, and a *Screen for 3* practice resource manual. Michigan’s State systems grantee expanded upon *Screen for 3* by incorporating enhanced information about ASD screening and information about referral sources and expanded treatment options for Medicaid-enrolled children with ASD. The expanded *Screen for 3* program included a Plan-Do-Study-Act (known as PDSA) component, in which practices reviewed their own medical records to document the rate of developmental screening with recommended tools (ASQ-3, ASQ-SE2, MCHAT), referral to appropriate diagnostic/treatment services, and coding/billing of the screen. The grantee implemented the screen for three quality-improvement training program in two regions of the State during the initial 18 months of the grant, and then in two additional regions during the final 18 months. Practices that participated in the program demonstrated substantial increases in their developmental screening rates. For all well-child visits with children 9–33 months, Group 1 (practices trained in 2015) developmental screening rates increased from 39 percent at baseline to 52 percent at follow-up; Group 2 (practices trained in 2016) increased from 42 percent to 61 percent.
- ▶ **Implementing an AAP CME course to train primary care providers.** Washington’s State systems grantee (Washington State Department of Health) partnered with the Washington chapter of AAP prior to receiving the Autism CARES award to develop and implement the Great MINDS (Medical homes INclude Developmental Screening) training curricula for primary care providers. Great MINDS delivers CME-accredited provider trainings on the use of validated tools for universal developmental screening under the Autism CARES grant. The grantee expanded the original Great MINDS curriculum to include autism screening using validated tools such as MCHAT. The expanded training is codelivered by a physician and a parent of a child with developmental disabilities. Great MINDS trainings address developmental screening and referral for diagnosis and evaluation and referral for community-based services.

- ▶ **Leveraging State programs to promote early developmental screening and diagnosis.** North Carolina’s State systems grantee leveraged the capacity of two statewide programs to promote early ASD screening and diagnostic evaluation. North Carolina’s Early Intervention Infant-Toddler Program operates 17 child development service agencies (CDSAs) throughout the State. These agencies offer evaluation, treatment, service coordination, and consultation services to families of children birth to 36 months of age. The grantee conducted 2-day ADOS-2 trainings with interdisciplinary teams of three to five individuals from each CDSA and offered a follow-up webinar to discuss clinicians’ concerns, successes, suggestions, and next steps with respect to application of ADOS-2. The grantee also partnered with the Assuring Better Child Health and Development (ABCD) program to provide pediatricians and primary care physicians across the State with ongoing training via webinar in developmental and ASD-specific screening. The ABCD program is funded by the Commonwealth Fund to enhance participating States’ ability to improve developmental services for low-income young children. 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.”

## **C. Building More Comprehensive, Coordinated Systems of Care**

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A primary goal of the State systems grantees is to improve coordination of ASD services across agencies and systems of care. Families who have a child with ASD/DDs can encounter multiple points of entry into services, but too often the paths that follow those different entry points never converge. Families commonly report frustration and confusion as they try to navigate these disparate systems to secure the services they need for their children. Grantees aimed to address these problems in several ways. This section highlights some of their efforts.

### **1. Bridging the Divide Between Education and Healthcare Systems**

Multiple grantees noted problems that can result when education and medical professionals conduct independent assessments of children for ASD/DDs. Whereas many States require an educational assessment to qualify for school-based support services, that assessment does not take the place of a medical diagnosis. The problem is further complicated when education and medical professions reach different conclusions. Oregon’s State systems grantee effectively addressed this problem through its autism identification teams, described earlier. In addition to helping families access local services, these interdisciplinary teams worked together to determine educational eligibility for autism services and provide a medical diagnosis for children up to age 5. In particularly complex cases when team members could not reach consensus on the diagnosis, the family had the option of getting a second opinion at Oregon Health & Science University’s Child Development and Rehabilitation Center. Children referred there for further evaluation were placed at the top of the waiting list.

### **2. Improving Referral and Care Coordination**

Recommendations regarding early developmental screening are based on evidence that early intervention services can lead to improved cognitive and behavioral outcomes among children with ASD (Pierce, Courchesne, & Bacon, 2016). To ensure families have access to more integrated care that includes appropriate follow-up services for children suspected of having ASD/DDs, State systems grantees worked to dismantle silos, facilitate referrals, and improve awareness of local resources among families and providers.

Minnesota's State systems grantee expanded on an existing statewide program funded by a Title V block grant to improve early identification, referral, and care coordination for children aged 3 or younger. The *Follow Along Program* supports periodic monitoring and assessment of infants and toddlers at risk for health and developmental problems. Under the existing program, participating families receive the ASQ-3 and Ages and Stages Questionnaire–Social Emotional (ASQ:SE) screening tools and information about typical child development by mail every 4–6 months until their child reaches 36 months. Completed questionnaires are scored by a nurse or other trained program staff and results are shared with the parents.

Under the State systems grant, Minnesota's State grantee used the *Follow Along Program* model to ensure that children identified as being at risk for ASD/DDs received appropriate diagnostic evaluation and/or intervention services as early as possible. The grantee partnered with three local public health agencies that mailed developmental screeners to families in the respective communities they served. During the 25-month implementation phase of the project, families completed and returned more than 10,000 ASQ-3 and close to 5,000 ASQ-SE questionnaires at the appropriate intervals. Program staff scored the completed questionnaires, discussed all concerning results with parents, and provided referrals for diagnostic evaluation and intervention services. Follow-up efforts with the family continued 2 weeks, 45 days, and 3 months after referral to ensure children were evaluated and connected with services.

Washington's State systems grantee also expanded on an existing program, *Community Asset Mapping* (CAM), to build local, integrated systems of care wherein families could access timely and appropriate developmental screening diagnostic evaluation services. Initially developed in 2009 by the Washington Autism Advisory Council, CAM brings together all agencies and professionals in a community that have a role in identifying or working with children with developmental delays, such as pediatricians, educators, public health, early intervention, and concerned parents to form a CAM team. That team works together to identify the community's assets and needs with respect to developmental screening, evaluation, and intervention services and sets goals to address identified needs, such as filling service gaps or establishing referral procedures.

Washington's State systems grant engaged eight communities in CAM to improve access to timely developmental screening, diagnostic evaluation, and intervention services for families. Of the eight CAM teams, four used a process called School Medical Autism Review Team (SMART) to provide comprehensive ASD assessments. In the SMART approach, a child's family and school-based team share their knowledge of the child with the child's pediatric primary care providers to facilitate a virtual, comprehensive assessment of a child. Using a shared document, the SMART tool, families collect records of evaluations from their school, early intervention agency, local providers, and the pediatrician. Those records, combined with input from the family and school team, help to inform an interdisciplinary evaluation and diagnosis of autism. Across the 4 CAM communities using SMART, 81 referrals were received, 71 children were evaluated, and 16 children were diagnosed with ASD using the SMART process. This pilot evaluation and results will be used to design and conduct an ongoing evaluation of the SMART process.

Georgia's State systems grantee conducted resource mapping with a goal of increasing access to autism services and supports. More than 100 agencies/organizations completed detailed surveys regarding the populations served and areas of specialization/range of services. The results of the resource mapping were added to the Parent-to-Parent Provider Database, which includes more than 150 searchable

categories and the *Roadmap to Success*, a webpage designed to assist parents with navigating services and supports across the lifespan (see figure 7.2).

**Figure 7.2. Parent to Parent of Georgia, Roadmap to Success Website**



Note: Graphic retrieved from <http://www.roadmap.p2pga.org/>

## D. Engaging Families and Self-Advocates

Each Autism CARES grant program addresses family engagement in some capacity; for example, by recruiting family members to participate in program planning, training for clinicians, community outreach, and research. This section describes efforts to involve and support families of children with ASD to help ensure programs, policies, and services are family centered.

### 1. Engaging Families in Planning, Implementation, and Evaluation

Each State systems grantee established a multidisciplinary advisory group to oversee implementation of its strategic plan for developing more comprehensive, coordinated systems of care for children and youth with ASD/DDs. Parents, caregivers, and representatives from family organizations, such as Family to Family Health Information Centers (F2F HICs), represent an essential component of these advisory groups. F2F HICs are family-staffed organizations funded by

### Additional LEND Program Engagement of Families and Self-Advocates

LEND programs actively engaged families and self-advocates in their activities by—

- Disseminating information to families about developmental milestones and topics related to ASD (see chapter 4)
- Creating an ASD-friendly environment in public spaces and at public events (see chapter 4)
- Recruiting family members and individuals with ASD/DDs as trainees (see chapter 5)
- Providing clinical training opportunities that emphasize family-centered care (see chapter 5)
- Developing resources and providing clinical and other support services for families and self-advocates related to the transition to adulthood (see chapter 8)
- Inviting families and self-advocates to share their experiences and needs related to transition-related services with trainees (see chapter 8)

MCHB that assist families of children with special healthcare needs and the professionals who serve them. The participation of these organizations helps to ensure that efforts to improve statewide systems of care reflect the needs and values of families served by those systems. Identifying and recruiting parents of children with ASD/DDs who have the time and resources to participate in such activities, however, can be challenging.

Two of the State systems grant recipients, The Autism Project of Rhode Island and The Parents' Place of Maryland, were well positioned to meet this challenge. Both are nonprofit organizations established by, or in collaboration with, parents of CSHCN to provide resources, support, and training to other parents of children with ASD/DDs. The Parents Place of Maryland serves as the State's F2F HIC and is staffed primarily by parents of CSHCN. The Autism Project of Rhode Island represents a collaboration of parents, professionals, and community members who provide training and programming for children and adults with ASD and their families. Given their mission to educate, support, and empower families who have CSHCN, both organizations have strong connections with parents in the communities they serve. These connections facilitate engagement of those parents in needs assessments, program planning, and other grant activities.

Grantees also actively recruited parents and family members in the community to participate in their advisory groups or serve in other leadership roles. Making it easy for families to serve was essential to successful engagement, so many grantees compensated family members for their time. For example, Michigan's State systems grantee offered parents who participated in the Project Advisory Council stipends and reimbursement for travel and child care.

Additional efforts to engage parents and families in leadership roles include the following:

- ▶ **Equipping parents to become advocates.** The Michigan Public Health Institute, one of the grantee's key partners, conducted an annual *Parent Leadership in State Government* workshop for 25 parents. This workshop is designed to equip parents to become advocates for services for children with special health needs, including ASD/DDs.
- ▶ **Engaging parents in strategic planning.** Iowa's grantee engaged 15 families that served on the grantee's Strategic Planning Committee. These families played an instrumental role in the development of Iowa's 5-year strategic plan to improve services and supports for individuals with ASD and their families.<sup>11</sup>
- ▶ **Leveraging family-led organizations.** The Washington State grantee's family engagement coordinator leads a statewide coalition of family-led organizations known as the Washington State Leadership Initiative (WSLI) Network, which aims to increase opportunities for trained family leaders to participate and partner in strategic and program planning for systems improvement. During the first year of the grant, the WSLI Network established formal partnerships with three family-led organizations: the Northwest Autism Center, Washington Autism Alliance, and Advocacy and Open Doors for Multicultural Families. These three organizations share information about upcoming family leadership trainings they offer or are aware of, and they help WSLI promote family leadership, advisory, and advocacy opportunities for trained family leaders.

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<sup>11</sup> The complete strategic plan is available for download at <https://www.chsciowa.org/sites/chsciowa.org/files/resource/files/iowa-strategic-plan-2016.pdf>

## 2. Engaging Families in Pilot Programs and Quality-Improvement Initiatives

Grantees recruited family members to participate in quality-improvement initiatives and pilot projects designed to improve developmental screening and referral practices, coordination of care, and effective navigation of services. Examples follow:

- ▶ **Recruiting families of children with ASD to participate in interdisciplinary teams.** Oregon’s State systems grantee recruited families of children with ASD/DDs to participate on autism identification teams and medical home quality improvement teams. As described earlier, the grantee assembled interdisciplinary autism identification teams were in eight underserved communities to improve timely ASD screening, referral and diagnostic evaluation for children suspected of having ASD/DDs, and reduce family confusion regarding an autism diagnosis versus educational eligibility for autism services. Each team included a healthcare professional, mental health provider, education staff (e.g., autism specialist, speech pathologist, school psychologist, special educator) and a parent partner who had a child with ASD. The Medical Home Quality Improvement project was designed to enhance the care of children with ASD/DDs in the primary care office. The grantee’s family involvement coordinator oriented and provided ongoing mentoring to all parent partners to ensure they knew how they could most effectively support their team. Parent partners participated in diagnostic evaluations and monthly conference calls with the primary care practices participating in the project and reviewed all project materials geared to families. The principal investigator credited parent partners with helping educators and health professionals recognize the important contributions parents can make as members of the team. He explained, “We had a school administrator say, ‘I wish I had a parent on all of our school-based teams.’ There was some resistance when we started out requiring parents to be on these teams but overwhelming acceptance once they got the experience of what parents can bring and contribute to the teams.”
- ▶ **Integrating parent partners into quality-improvement initiatives.** Maryland’s State systems grantee integrated parent partners into its QILCs (described above). Parent partners were on site in the pediatric practices to assist families through the developmental screening process, provide follow-up to referrals for early intervention services, and give ongoing support to families of children with ASD/DDs served by the pediatric practice. Veteran parents of children with special healthcare needs were recruited from across Maryland, and the project staff selected parents who most closely matched the location of the practice and brought the needed skills for the project. The parent partners participated in an intensive 3-day training followed by weekly conference calls with their project mentor/supervisor and additional self-directed training. Working within those practices, parent partners ensured that every child referred to early intervention services received appropriate follow-up. In some counties, the Office of Early Intervention would make three attempts to contact referred families. As one member of the grant team explained, “These are moms and dads who've got little kids who are trying to put food on the table and work. If you've got to continuously make calls, or try to get people to call you back, that’s a huge barrier. That’s a huge challenge for families.” Parent partners worked to address these missed connections by following up with each family whose child was referred to early intervention to find out if the family had been able to access the services, and they would contact early intervention services directly on behalf of families that had not managed to make the connection. Physicians overwhelmingly agreed the parent partners’ ability to do the follow-up work for the practice was one of the greatest strength of the learning collaboratives. One participating physician shared:

“It’s dramatically improved the follow-up stats on families getting connected to Infants and Toddlers [the State’s Early Intervention System]. Just having somebody holding the tether who can call them, doesn’t seem hurried, doesn’t seem annoyed when they’re not there. Just to be a resource.”

At the end of the Phase I QILC, practices were given the option of hiring their parent partner directly as a staff member. Two practices opted to do so. At the end of Phase II, five pediatric practices hired the parent partners directly to continue to provide services to the families they care for.

- ▶ **Hiring parents to work in clinical settings.** Several State grantees hired parents of children with ASD to train or otherwise support providers working in developmental clinics or medical homes. Virginia’s State systems grantee engaged family members as leaders, advisors, and peer navigators in each of the three demonstration sites where the grantee launched a model intervention to increase early developmental screening, identification, and diagnosis of children and youth with ASD/DDs. Georgia’s State grantee hired 5 parent partners who collectively supported more than 100 newly diagnosed families during the grant period. Arkansas’s State systems grantee engaged parents and families in trainings delivered to providers working in family-centered medical homes specializing in autism-specific screening and assessment. The presence of parents of children with ASD/DDs on these teams helped ensure that providers understood how to engage families and deliver family-centered care.

### **3. Establishing Family Navigator Programs To Promote Partnerships Between Professionals and Families**

To promote stronger family-provider partnerships, State systems grantees implemented strategies to improve communication and promote shared decisionmaking between parents and providers. Family navigator programs provide an innovative, evidence-informed strategy for improving access to a coordinated, comprehensive system of services for children and youth with ASD/DDs. State systems grants commonly engaged family navigators in helping families access comprehensive ASD services.

Washington’s State systems grantee contracted with three family-led organizations that develop and conduct family navigator trainings. One of the three organizations, Northwest Autism Center, conducted a training for 24 Head Start program staff in Eastern Washington. The Washington Autism Alliance and Advocacy (WAAA) trained 127 family navigators in rural and urban areas of Western Washington and provided technical assistance to 379 organizations across the State on helping families with children with ASD/DDs in choosing, understanding, and using health coverage and health providers and services. WAAA also provided one-on-one family navigation and insurance navigation assistance to families in understanding their child’s diagnosis, health and education needs; how to use and understand their child’s health coverage; and how to partner with healthcare providers in shared decisionmaking.

During the first year of its grant, Delaware’s State grantee initiated development of a robust family navigator program to support families from the point of early concern through diagnosis and provision of services. Parent partners hired to work with primary care practices as part of Maryland grantee’s pilot followed up with parents and early intervention services to ensure families were connected with the services they needed. Similarly, Georgia’s State systems grant hired five parent partners to work in developmental clinics across the State. These parent partners supported more than 100 families with newly diagnosed children over the course of the grant.

The Michigan State systems grantee offered family empowerment training to 84 parents through a partnership with the Michigan Public Health Institute. The *Care Coordination: Empowering Families* training offers practical tools on finding a medical home, communicating with providers and staff, and facilitating coordination among multiple providers.

#### 4. Additional LEND Program Engagement of Families and Self-Advocates

As outlined in earlier chapters, a central tenet of the LEND programs is to actively engage families and self-advocates in their activities. For example, as outlined in chapter 4, LEND programs disseminated information to families about developmental milestones and topics related to ASD. They also worked to create ASD-friendly environments in public spaces and at public events. As outlined in chapter 5, LEND programs recruited individuals with ASD/DDs and their families into training programs. These programs also provided clinical training opportunities that emphasized family-centered care. As described in chapter 8, LEND programs developed resources and provided clinical and other support services for families and self-advocates related to the transition to adulthood. They invited families and self-advocates to share their experiences and needs related to transition-related services with trainees.

#### 5. Reducing Disparities in ASD Services for Underserved Populations

Several research studies point to racial and income disparities in early identification and treatment of ASD (Yingling et al., 2017; Zuckerman et al., 2017; Mazurek et al., 2014; Durkin et al., 2010). For example, analysis of data from the Survey of Pathways to Diagnosis and Services showed that Latino children with ASD who had severe limitations received fewer autism-related services than White children with similarly severe conditions (Magaña, Parish, & Son, 2016). Other studies have found that African-American and Hispanic children tend to be diagnosed later than their White counterparts (Zuckerman et al., 2013). Once the children are in treatment, racial disparities persist. Data from two waves of the National Survey of Children with Special Healthcare Needs (2005–2006 and 2009–2010) showed that Black and Latino parents were significantly less likely than White parents to report that their provider spent adequate time with their child and was sensitive to the family’s values. This finding was unchanged between the two surveys (Magaña, Parish, & Son, 2015).

Urban/rural disparities exist as well. For example, a recent study showed that although children with ASD in rural areas are no less likely to initiate therapy (physical, occupational, or speech) than children in urban areas, they have approximately one-third as many visits as those in urban areas. The study also showed that children living in the most rural areas were diagnosed, on average, 18 months later than those children who lived in large metropolitan areas (Paul, 2017).

Grantee efforts to improve access to developmental screening and referral among underserved populations took various forms. Two of the most common approaches during this evaluation period

#### Grantee Perspective: Building Relationships Takes Time

“Work in diverse communities just takes longer and takes more resource(s) and you spend a lot of time. It’s really not about having interpreters. It’s really not about translation. It’s about development [of] trust and relationships that have trust and that just takes a long time. Policymakers I think and funders aren’t always interested in that, but it’s a big barrier.”

—University of Minnesota LEND Project Director

were locating clinics in areas with large underserved populations or using telehealth to reach out to rural areas.

## 6. Establishing Clinics in Underserved Regions

Several grantees established clinics in underserved regions. Examples follow:

- ▶ **Providing services at federally qualified health centers.** The DBP grantee at the University of California, San Diego, operated a clinic in a federally qualified health center on the border of Mexico; the grantee recently celebrated a 3-year anniversary at that location. The grantee used the center to conduct training and provide DBP services.
- ▶ **Working with Medicaid beneficiaries.** The Children’s Hospital of Philadelphia DBP noted that three of their large practices are in urban, underserved communities in Philadelphia, where more than three-quarters of the clients receive Medicaid.
- ▶ **Serving rural, Hispanic, and Native-American populations.** The University of Arizona LEND has worked actively to recruit partner clinics in the rural parts of the State that serve Hispanic and Native-American populations. Similarly, the University of New Mexico LEND sends representatives to travel to rural parts of the State to conduct outreach clinics to see children who may not be able to travel.

## 7. Utilizing Telehealth To Extend Reach

In areas where the population is not large enough for a clinic, many grantees have been using telehealth to extend their reach. The most common platform for this is Project ECHO. Project ECHO is a telehealth program that began in New Mexico. Primary care doctors and various specialists from a wide geographical area participate in multipoint HIPAA-compliant video conferences to discuss cases and mentor primary care providers who care for children from underserved geographic regions and populations. The University of Missouri LEND holds a 90-minute ECHO autism clinic twice monthly. Although the majority of participants practice in Missouri, others from Arizona, Michigan, New Mexico, and as far away as Uruguay have participated. The Children’s Hospital of Philadelphia DBP noted that Project ECHO reaches rural practitioners as well as urban low-income practices. The Medical University of South Carolina DBP participates in a similar program, the Virtual Tele-Consult Clinic, which is part of a statewide Telehealth Alliance that focuses on underserved and rural communities.

## 8. Other Innovative Approaches To Reach Underserved Populations

Table 7.1 illustrates additional approaches grantees have taken to reduce disparities in ASD services for underserved populations.

**Table 7.1. Grantee Efforts To Reduce Disparities in ASD Services for Underserved Populations**

Approach To Reduce Disparities	Description
Coordinate existing resources	University of Miami LEND committed resources to support expansion of capacity in two communities of focus (Overtown and East Little Havana) that are culturally diverse, economically challenged, and underserved by health and education professionals. They collaborate with local community partners in these neighborhoods to coordinate existing resources and provide technical assistance and leadership when requested. Work in these communities will serve as a pilot test for efforts that can be translated to other communities in the region.
Deliver annual developmental screening events	University of Illinois LEND goes to underserved neighborhoods and communities to conduct annual developmental screening events. Events are scheduled in places where children will already be; if parents have concerns about their children, they can have them screened. Trainees then connect families to resources. Some diagnostic appointments are available, and those children are fast-tracked into diagnostic clinics.
Screen and provide services to Native American populations	University of Kansas LEND takes trainees to Native American reservations to serve four tribes in northeast Kansas. A Native American faculty member has been active in conducting needs assessments on the reservations. University of Nevada LEND conducts developmental screening clinics at Native-American reservations, including the Pyramid Lake Paiute Tribe’s reservation, 35 miles northeast of Reno.
Provide monthly services to remote areas	University of New England LEND works with the Child Development service in Presque Isle in northern Maine, a rural, difficult-to-access part of the State, to provide monthly physical therapy where it was not previously available.
Serve refugee groups	University of Rochester LEND focuses on developmental screening and identification of developmental challenges in refugee groups, recognizing that language and cultural differences change how people perceive whether there is a developmental challenge in the children: “Those kids often have posttraumatic stress and similar experiences,” the project director explained. That factor, in combination with language barriers and cultural differences in perception of disability, can make it difficult for the families or the care providers to recognize there are developmental challenges. The Vermont LEND utilizes foreign language support service providers and “cultural brokers” to promote engagement with local refugee communities. Since autism is not a term that translates directly into the languages of the local refugee populations, these individuals help facilitate communications with these groups.
Hold developmental screening events in rural areas	University of Oregon LEND holds an annual 3-day developmental screening event in the Tillamook community in a rural, impoverished area of the State. Providers screen children aged 1–5 at the event to identify those at risk of DDs, including autism, to link them to services.
Provide technical assistance	University of Washington LEND provides program evaluation and technical assistance for the Yakima Valley Farmworkers Clinic Rural Health Network Development grant. The grant addresses universal developmental screening in rural settings, outreach clinic assessment for early intervention eligibility, and care coordination of rural children with special healthcare needs.

Approach To Reduce Disparities	Description
Leverage partnerships with faith-based organizations	North Carolina State systems grantee focuses on early identification of ASD in two severely underserved regions in the southeastern sector of the State with high minority representation. Project staff and partners conducted an ASD screening event in July 2015 and two large faith-based presentations in 2016 that involved families, church communities, and community partners interested in improving developmental screening, early identification, assessment, diagnosis, and intervention for children with ASD and their families. As of the end of 2017, these efforts are ongoing.
Utilize bilingual family navigators	Delaware's State systems grantee works with two bilingual family navigators to increase access to services for Hispanic families throughout the State. These additional family navigators are helping Autism Delaware reach the goal of increasing capacity by serving more children and families, and ultimately increasing the number of at-risk children who enter early intervention services.
Create regional centers to serve rural areas	Iowa's State systems grantee 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 developmental 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 effectively provided multiple families with services in one of the State's most rural areas.
Provide services to groups with co-occurring health conditions	A deaf trainee from the University of Rochester LEND has become the preferred developmental pediatrician for the large deaf community in Rochester. This trainee, who is fluent in American Sign Language, worked to understand the issues related to identifying autism in a child who is deaf.

## Chapter 8. Improving Services for Youth With ASD as They Transition to Adulthood

### Principal Grantee Activities To Improve Services for Youth With ASD as They Transition to Adulthood

The evaluation aimed to assess grantees' efforts to identify needs and develop services for youth with ASD as they become adults. LEND, DBP, research networks Autism-FIRST and Autism-SDAR, and State systems grantees worked to incorporate transition-related issues in their efforts. As the number of children diagnosed with ASD continues to rise, an increasing number of youth with ASD are aging into adulthood (Christensen, 2016). The Autism CARES Act of 2014 placed new and increased focus on young adults and transitioning youth.

**Grantees increased awareness and provided training about transition issues.** They undertook a wide array of activities to promote awareness and disseminate information about local transition resources to professionals and community members. Grantees convened professional conferences or sent faculty and trainees to such conferences focused on transition. To reach community members, grantees hosted workshops about transition-related issues for youth, parents, and teachers that addressed topics such as self-advocacy; relationships, dating, and sexuality; postsecondary education and college preparation; and employment. They also developed and disseminated materials related to transition such as planning tools, transition toolkits, and local resource guides. Training program grantees also incorporated transition-related content in their didactic training by including panels and guest lectures by parents and young adult self-advocates in their curriculum. They also ensured trainees had opportunities to support transition-aged youth during clinical training.

**Grantees improved the evidence base around the needs of transition-aged youth.** Research program grantees conducted 14 studies to further the knowledge and understanding of the transition to adulthood among individuals with ASD/DDs and to help focus the national research agenda on this issue. Studies addressed issues such as psychiatric and medical conditions, barriers to service, stakeholder perspectives, and care utilization and costs.

**Grantees improved the systems of care to support youth as they transition to adulthood.** To ensure the needs of young adults were met and to better understand the challenges providers faced, grantees conducted needs assessments in their communities. They improved the systems of care supporting young adults with ASD/DDs by establishing transition clinics. Grantees focused their transition efforts on providing health-, employment-, and education-related transition supports. Grantees also worked to improve the clinical systems both within their institutions and at the State level to support young adults with ASD/DDs and their families.

Section A of this chapter discusses the need for a focus on the transition to adulthood, and section B discusses grantees' activities to build awareness about transition issues. Section C highlights activities to train providers to deliver transition services. Section D discusses activities to build the evidence base around issues related to transition, and section E outlines activities to improve systems of care for youth as they transition to adulthood. Unless otherwise noted, the numbers and figures cited throughout this

chapter come from evaluation interview data and materials reviewed as part of the evaluation, including grantee reports and websites.

## A. The Need for Focus on the Transition to Adulthood

As the number of children diagnosed with ASD continues to rise, an increasing number of youth with ASD are aging into adulthood (Christensen, 2016). An estimated 50,000 youth with ASD turn 18 each year, and there are currently approximately 450,000 youth with ASD aged 16–24 in the United States (HHS [U.S. Department of Health and Human Services], 2017). As these individuals age, they need support with postsecondary education and vocational training, employment, primary healthcare and treatment for co-occurring conditions, housing and independent living, and coordinated wraparound services (HHS, 2017). However, young adults with ASD are more likely to report unmet service needs compared to young adults with other disabilities, and youth with ASD who represent racial/ethnic minorities on average have three times more unmet needs relative to their White and non-Hispanic counterparts (Taylor & Henninger, 2015). As a result of the Autism CARES Act of 2014, which placed new and increased focus on young adults and transitioning youth, MCHB grantees are focused on identifying needs and developing services and supports for this population.

## B. Building Awareness About Transition Issues

MCHB grantees have undertaken a wide array of activities to promote awareness about issues associated with the transition to adulthood and to disseminate information about local transition resources. This section describes efforts of the LEND and DBP programs to build awareness among professionals and members of their communities.

### 1. Building Awareness Among Professionals

Many physicians feel ill equipped to meet the healthcare needs of youth and adults with ASD. Individuals with ASD and their caregivers believe that aging is an important aspect of ASD and that it requires a customized approach to care provision (Mukaetova-Ladinska & Stuart-Hamilton, 2016). A common approach to building awareness among professionals has been to convene or train faculty and trainees on transition. For example, LEND trainees at the University of Kansas helped facilitate and present at their annual Autism Across the Lifespan conference. The DBP at Children’s Hospital of Philadelphia provided a CME course to professionals on the transition to adulthood at a regional conference; their trainees also presented and delivered posters at the annual meetings of the American Public Health Association and Society for Adolescent Health and Medicine.

Faculty at the University of Massachusetts LEND gathered anecdotal information that few nutritionists feel prepared or knowledgeable to work with young adults with ASD on topics of healthy eating, food choices, and physical activity. To increase nutritionists’ exposure to young adults

#### University of Wisconsin LEND Trainee Fieldwork on Increasing Awareness of Transition

After completing an extensive literature review and needs assessment with clinicians, family members, and public health professionals, one trainee developed a curriculum to raise awareness, knowledge, and skills of adult healthcare providers in serving youth and young adults with DDs. Her approach, which emphasized the dissemination of existing materials, was presented in national forums such as the AUCD Annual Meeting and will be adapted by the Wisconsin Youth Health Transition Hub for statewide use.

with ASD, the University of Massachusetts LEND collaborated with Charlestown High School. The university nutrition students learned best practices for weight management to help these high school-aged youth with ASD/DDs.

## **2. Building Awareness Among Members of the Community**

A common approach to promoting awareness of transition-related issues in the community was to host workshops for youth, parents, community members, and teachers. These workshops covered myriad topics such as self-advocacy; relationships, dating, and sexuality; postsecondary education and college preparation; guardianship, conservatorship, and living arrangements; employment; nutrition and healthy lifestyle; and health insurance.

Several LEND grantees promoted awareness of the transition to postsecondary education. For example, two trainees from the Virginia Commonwealth University LEND organized the first meeting of an area consortium on Autism College Student Transition. Because these two trainees are parents of children with ASD, their focus was to ensure the parent voice is included in transition planning. The Children's Hospital of Los Angeles LEND worked across its campus to identify supports and bring services together to address the social needs of students with ASD. They developed a social program that included neurodiversity dinners and game nights to reduce social isolation. They also addressed faculty requests for training on how to best support neurodiverse students.

Some LEND programs held transition fairs in their communities connecting local community service providers and vendors with youth and families. For example, LEND trainees from the Oregon Health & Science University helped implement the annual fair, the Institute on Development and Disability's Passport to a Healthy Future. Under the mentorship of LEND faculty, the trainees coordinated the logistics, speakers, and evaluations for the event, which was free and open to the public. Eighty families and providers attended the event in 2016, with a keynote address by Oregon State Senator Sara Gelser (D-Corvallis). The LEND trainees planned the event to be accessible to all audiences, with additional emphasis on recruiting families who speak English as a second language. See also the bilingual invitations to a transition fair in figure 8.1.

**Figure 8.1. English and Spanish Invitations to the Oregon Health & Science University LEND's 2017 Transition Fair**



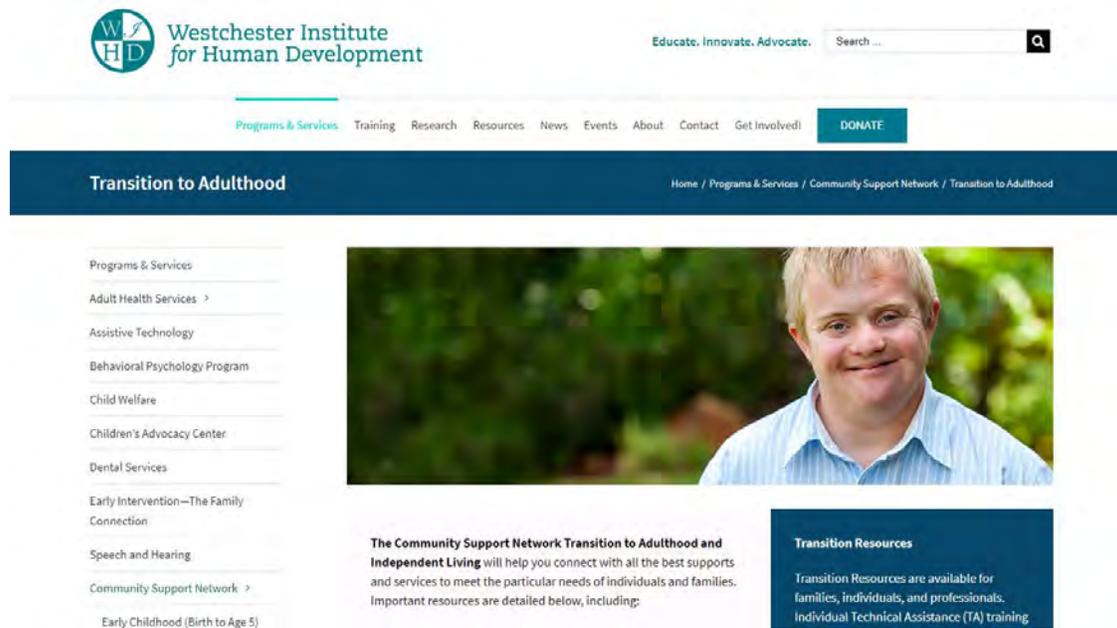
Source: Retrieved from <http://www.factoregon.org/wp-content/uploads/2017/04/transition-fair.jpg>

Finally, many grantees developed and disseminated materials related to transition issues, such as the following:

- ▶ Planning tools and transition toolkits
- ▶ Brochures and textbooks
- ▶ Local resource guides
- ▶ Websites for youth, parents, providers, and policymakers
- ▶ Video content and webinars

See figure 8.2 for Westchester Institute for Human Development LEND's example of sharing resources on the transition to adulthood.

**Figure 8.2. The Westchester Institute for Human Development LEND Website: Sharing Resources on the Transition to Adulthood**



Source: Westchester Institute for Human Development website

## C. Training Providers To Deliver Transition Services

Healthcare providers need training to feel confident supporting young adults with ASD as they age into adulthood. However, more than three-quarters of adult healthcare provider respondents in one study rated their knowledge and skills in providing care to patients with ASD as poor or fair. Only 13 percent of providers agreed or strongly agreed they had adequate tools, referral resources, or practice models to accommodate patients with ASD (Zerbo, Massolo, Qian, & Croen, 2015). To address this need, many LEND and DBP grantees incorporated learning opportunities about the transition to adulthood into their didactic and clinical training programs. This section highlights some of the ways programs incorporated transition issues into didactic and clinical training.

### 1. Incorporating Transition-Related Content in Didactic Training

DBP and LEND grantees included transition in their curricula to varying degrees. Some training programs historically incorporated content on transition in their didactic training as part of an approach that focuses on development across the lifespan; others described a more recent attention to the topic. As the Virginia Commonwealth University LEND described, “In the 2017–2018 training year, we are increasing our focus on transition, especially transition from youth to adult. It [has] always been part of our curriculum, but we now are increasing it in one of our seminars to make sure our trainees are exposed to information of the needs of individuals and families in transition, both healthcare and education transitions.” Grantees based the transition components of their curricula on several existing resources such as MCHB’s *Got Transition* materials, State developmental disability councils, and AUCD’s transition guides.

Several training program grantees included panels and guest lectures by parents and young adult self-advocates in their curriculum. As the Children’s Hospital of Los Angeles DBP explained, “It’s one thing to have parents talk about their kids going through the transition process, it’s another one to have actual young adults come in and talk about that.” For example, the University of Vermont LEND delivered a session on transition that was co-led by LEND faculty and young adults from their partner organization Green Mountain Self-Advocates. The University of Delaware LEND’s didactic sessions included a self-advocate panel of three young adults with DDs who described their experiences, goals, and challenges as they age into adulthood. That LEND also facilitated a parent panel of four parents of adolescents.

Outside of formal classroom learning, many trainees also attend transition workshops, summits, seminars, and webinars. In 2017, the Autism CARES Act National Interdisciplinary Training Resource Center continued to support the online broadcast of the Baylor College of Medicine 18th annual Chronic Illness and Disability Conference: Transition from Pediatric to Adult-based Care, attended by trainees from several LENDs. Trainees also attended statewide transition conferences, UCEDD workshops on transition, and *Transitioning Together* workshops.

## **2. Increasing Opportunities To Support Transition-Aged Youth Through Clinical Training**

LEND and DBP programs trainees had opportunities to observe and support transition-aged youth at clinical rotations and transition clinics. The LEND at the University of Texas, for example, leveraged a partnership with the Vocational Advancement and Skills Training Academy, which provided postsecondary transition programs and comprehensive support services for individuals with disabilities. Trainees were required to rotate at the Academy at least once, where they observed students obtaining vocational certificates, attending precollege bridge courses, and participating in internships and employment assistance to prepare for their futures. In Indiana, a LEND trainee gained hands-on experience working with a diverse group of adolescents and their families at their partner clinic, the Center for Youth & Adults with Conditions of Childhood. The University of Kansas LEND worked with family medicine residents to implement a 1-week rotation at the LEND clinic to focus on early recognition of ASD and introduce transition issues.

Some trainees completed leadership and community projects related to transition. Some trainees at the University of Arizona LEND, for example, completed an intensive leadership project on adolescent transition. In collaboration with a local clinic, these LEND fellows developed policies and facilitated the healthcare transition for adolescents. The fellows presented their lessons learned so the full LEND cohort could learn from their experience.

### **Topics in Grantees' Didactic Transition Training**

- Financial independence
- Guardianship
- Healthcare transition, ongoing service needs, and advance directives
- Independent community living and housing arrangements
- Insurance, Medicaid, Social Security, and other benefits
- Local transition resources
- Mental health and addiction
- Person-centered planning and supported decisionmaking
- Postsecondary education
- Recreation, social skills interventions, relationships, and sexuality
- Vocational rehabilitation and employment

## D. Building the Evidence Base on the Needs of Transition-Aged Youth

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As the population of individuals with ASD ages, the need for research on the transition to adulthood grows more important. The Autism CARES research program grantees conducted 14 studies to further the knowledge and understanding of the transition to adulthood among individuals with ASD/DDs.<sup>12</sup>

HCT-RN conducted the majority of studies pertaining to transition, and some were designed to identify research gaps and set a research agenda. A full list of HCT-RN studies appears in appendix E; some examples follow:

- ▶ **Psychiatric and Medical Conditions in Transition-Aged Individuals With ASD.** This study described the frequency of medical and psychiatric conditions in a large population of diverse, insured transition-aged individuals with ASD. It underscored the need for physicians to approach ASD as a chronic health condition that requires regular follow-up and routine developmental screening and treatment for medical as well as psychiatric issues.
- ▶ **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.
- ▶ **Stakeholder Perspectives on Research and Practice in Autism and Transition.** This study identified gaps in current research and practice and current research infrastructure needs. Key-informant interviews were conducted with researchers, professionals/clinicians, young adults with ASD, and parents of young adults with ASD, highlighting the need for interagency, multidisciplinary collaboration on research related to transition.
- ▶ **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. Participants also provided their ratings in multiple phases because the list of topics presented was refined over the course of each round of data collection. The top-rated research topics set the official HCT-RN research agenda.

In addition to the studies conducted by the HCT-RN outlined above, Autism-SDAR, AIR-P, AIR-B, and LEND programs also conducted research related to the transition to adulthood such as the following:

- ▶ **Medical Care Utilization and Costs Among Transition-Age Young Adult Medicare Beneficiaries With Autism Spectrum Disorder.** In addition to addressing healthcare costs and usage, this 2015 Autism-SDAR study also analyzed racial and ethnic differences in utilization and potential disparities between young adults with ASD and young adults with other intellectual disabilities.
- ▶ **First Impressions: Strategies To Enhance Initial Adult Care Visits for Transitioning Youth With ASD.** This 2016 AIR-P tested an intervention designed to prepare youth and their families for the transition to adult care and to increase the capacity of primary care physicians and office staff to welcome referred youth with ASD.

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<sup>12</sup> Because the Autism Transitions Research Project was established in fall 2017, it was not included in the scope of this evaluation. It was created to support the implementation and completion of programmatic research studies that examine factors associated with healthy life transitions among adolescents and young adults with ASD who are transitioning to adulthood.

- ▶ **Building Better Bridges.** AIR-B conducted a multisite study on transitions in the school system that aimed to identify barriers to successful transitions between educational systems for children with ASD.
- ▶ **Transitioning Together Effectiveness Study.** LEND trainees at the University of Wisconsin had the opportunity to assess the effectiveness of the *Transitioning Together Program*, which aims to develop strategies and resources for parents and teens that support the teen’s transition to adulthood. The program involves group sessions for parents and social group sessions for adolescents geared to foster peer interaction.

## E. Improving Systems of Care for Youth as They Transition to Adulthood

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Exiting the supportive environment of high school is associated with a decline in utilization of supportive services. Young adults with ASD are more likely than those with other disabilities to receive no formal services after leaving high school (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). One study found that less than a quarter of youth with ASD received healthcare transition services and youth with ASD received fewer transition services when compared to their peers with other special healthcare needs (Cheak-Zamora, 2013).

One particular concern to MCHB and its grantees is the medical transition from pediatric care to adult care, which according to the AAP, can enhance lifelong functioning and well-being for all youth (AAP, 2011). As youth with ASD transition out of the pediatric healthcare system, both the percentage of youth receiving services and the total number of healthcare visits they receive per year declines (Nathenson & Zablotsky, 2017). Caregiver respondents in one study believed that finding adult providers was one of the greatest barriers faced by youth with special healthcare needs (Kuhlthau, 2016).

### 1. Conducting Needs Assessments With Youth, Families, and Providers

To ensure the needs of young adults with ASD and their families were being met and to better understand the challenges providers faced, a few grantees conducted needs assessments in their communities. For example, through collaboration with the State Title V organization, the University of Oklahoma DBP program surveyed families of children with a disability who are 12 or older about transition. They also surveyed providers to assess whether their practices had programs or procedures in place related to transition and learn which providers were comfortable providing transition plans. A trainee from the Dartmouth LEND surveyed pediatric practices in the neighboring State of Maine to learn (1) what proportion of providers/practices provide primary care to children with special healthcare needs, (2) what proportion utilize a care coordinator/nurse navigator on either a full- or part-time basis, (3) whether the provider/practice has a formal transition protocol in place for transitioning patients with special needs to adult care, and (4) what kinds of supports would be most useful to providers in developing transition protocols. The Maryland State systems grantee conducted a QILC around transition (see chapter 7 for more information on this quality-improvement initiative).

A few grantees also conducted interviews, focus groups, or surveys with young adults with ASD and their families to assess challenges associated with the transition process. At the University of Pittsburgh LEND, trainees worked with partner organization Autism Connection of Pennsylvania to create a survey to identify what young adults with autism need for their medical transition. Through these needs assessments, grantees learned directly from young adults and their families about the challenges they face with all aspects of transition, particularly the medical transition away from pediatric healthcare to

adult healthcare systems. The University of Miami LEND identified several additional service gaps outside the medical arena, including a lack of high-quality community-based service providers, and lack of high-quality group homes that specialize in residents with autism. Based on their experience, many adult community service providers were underprepared to deal with young adults with ASD and their families.

## 2. Providing Clinical Services at Transition Clinics

Some grantees improved the systems of care supporting young adults with ASD by establishing transition clinics or otherwise enhancing the clinical transition-related services they provided. Examples follow:

- ▶ **Utilizing a monthly clinic to create “roadmaps” to transition.** Created by a former fellow from the University of Colorado DBP, this clinic establishes a plan for transition-related activities for the individual, parents, and primary care providers. It is attended by DBP faculty, a third-year fellow, the self-advocate, and the social worker or family navigator. The clinic approach involves an initial 2-hour appointment that covers medical and nonmedical issues and annual follow-up appointments throughout the entire transition process.
- ▶ **Partnering with a local high school to provide transition services.** The University of Hawaii LEND ran a transition clinic through a partnership with Oahu High School, working with young adults with disabilities aged 14–16. They identified stepwise mapping processes for managing transition through working with teachers and families and leveraging the students’ existing individualized education programs.
- ▶ **Establishing interdisciplinary teams to facilitate the healthcare transition.** The University of Iowa LEND offers a transition service that helps teens and their families move from pediatric healthcare to the adult service system by providing tools to teach self-advocacy and independence. Members of the team include a social worker, nurse, physician, employment specialists, and other experts (e.g., physical therapists, occupational therapists, nutritionists). The interdisciplinary team discusses issues ranging from guardianship and living arrangements to nutrition and healthy lifestyle to activities of daily living.

## 3. Providing Employment Support Services

Some grantees focused their transition efforts on providing employment-related transition supports to young adults. For example, the DBP at the Children’s Hospital of Philadelphia runs the Career Path program; job coaches in this initiative train individuals for future employment at the hospital. The University of New Mexico LEND partnered with the New Mexico Developmental Disability Council to establish the New Mexico School to Work Transition Alliance, focusing on developing and improving postsecondary education for competitive and integrated employment outcomes of young adults with significant support needs for transition from school to work. This LEND also developed an employment awareness training workshop for youth in transition, their families, and school personnel; the purpose of the training

### LEND Participation in the TennesseeWorks Collaborative

The Vanderbilt University LEND trainees were involved in the TennesseeWorks Collaborative, a large-scale systems change project bringing together more than 40 State agencies focused on equipping young people with intellectual disabilities and DDs with the skills, supports, aspirations, and relationships needed to thrive in the workplace.

was to increase their expectations, knowledge of, and access to competitive employment resources and information for young adults with intellectual disabilities and DDs. During the evaluation period, the University of New Mexico LEND provided employment-related transition training to more than 330 participants including youth, families, and personnel from the Department of Vocational Rehabilitation, Bureau of Indian Affairs, schools, and disability services organizations.

#### 4. Providing Postsecondary Education Support Services

As young adults with ASD age out of high school, many are interested in obtaining postsecondary education and may need education-related transition supports. The University of Delaware LEND provided educational coaching to students to establish a student-centered plan and offered supports to individuals as they engaged in campus life, developed career goals, learned organization skills to fully participate in academics, and gained understanding of how to effectively communicate with colleagues and supervisors. This LEND described how this opportunity gives trainees a chance to “hear directly from those ... students about what it’s like for them to be a college student, to enable them to start to picture ... younger children that they’re working with and instill an idea that college could be an option for anybody if that is a place where they would like to continue after high school.”

Two parent trainees from the Virginia Commonwealth University LEND who had high-school-aged sons with ASD organized a regional consortium on college student transition. To promote parent involvement in conversations with offices on college disability, these trainees successfully orchestrated the event to address a critical gap between the services students in the Richmond area receive in their high schools and those they receive after graduation.

#### 5. Initiating System-Wide Change

Some grantees worked to improve the clinical systems within their institutions and at the State level to support young adults with ASD and their families. Examples follow:

- ▶ **Embedding a transition checklist in electronic health records.** The DBP at the University of Colorado Denver embedded a transition checklist in its electronic medical records for individuals aged 14 through early 20s; the checklist was completed by DBP faculty and fellows.
- ▶ **Creating a medical home focused on transition.** The Rutgers University LEND collaborated with New Jersey’s statewide parent advocacy network and worked on a collaborative grant with the Children’s Specialized Hospital to develop an autism medical home that focuses on the transition to adult healthcare.

#### Rhode Island Parent Information Network Peer Navigator

The DBP program at Rhode Island Hospital obtained an AUCD Autism CARES Act National Interdisciplinary Training Resource Center grant in 2015–2016 that funded a Rhode Island Parent Information Network Peer Navigator. This navigator was the parent of a 17-year-old with special needs who focused on educating families with older children with DDs about issues related to transition to adult life, including healthcare, work, educational advancement, and independence. This navigator has continued to support families in her clinical work and has remained active teaching DBP fellows and LEND long-term trainees about the value of family mentorship and peer navigation.

- ▶ **Developing statewide special interest groups or advisory committees.** The Vanderbilt University LEND collaborated with the State of Tennessee to develop a special interest group for adolescents or young adults with intellectual disabilities and DDs. The Youth Advisory Council, which was directed by a LEND faculty member and supported by trainees, advised the State on services for people with ASD. University of Nebraska LEND faculty served on the State Respite Advisory Committee, a workgroup of parents, community agency staff, academicians, and healthcare providers. The committee worked to address needs for respite care and support during transition and throughout the life course.

## Chapter 9. Supporting Collaboration and Coordination Through the National Resource Centers

### Principal Activities To Support Collaboration and Coordination Through the National Resource Centers

The evaluation aimed to assess how the national resource centers facilitated collaboration among grantees. The Autism CARES Act National Interdisciplinary Training Resource Center, housed at AUCD, worked to foster collaboration among LEND and DBP grantees. The State Public Health Coordinating Center for Autism, housed at AMCHP, supported collaboration among State systems grantees. Autism CARES grantees worked to address systemic service delivery challenges too great and complex for any single organization to solve alone, and the national resource centers helped address this issue.

**National resource centers extended the reach of grantee activities.** During the evaluation period, the resource centers facilitated collaboration across 62 training grantees working to address the shortage of trained professionals who provide services to children and youth with ASD/DDs in 44 States. They also supported 13 State Implementation grantees working to improve access to coordinated services for this population in their respective States.

**National resource centers engaged grantees in collaborative technical assistance.** Throughout the evaluation period, resource centers provided grantee-driven technical assistance. Center staff solicited input from grantees to ensure products and services met their needs through one-on-one phone calls, surveys and written feedback, and site visits. The resource centers leveraged grantee knowledge and expertise to strengthen the network through activities such as peer-to-peer exchange programs, technical assistance and mentorship site visits, and learning communities. Since November 2014, the Autism CARES Act National Interdisciplinary Training Resource Center leveraged AUCD funding to support 16 special grants for LEND and DBP programs. Projects awarded in September 2017 addressed three priority areas: (1) demonstrating program impact through data collection and analysis, (2) using technology to provide statewide technical assistance and short-term training, and (3) increasing trainee and faculty diversity.

**National resource centers supported the annual Autism CARES grantee meeting.** Each year the resource centers, led by the Autism CARES Act National Interdisciplinary Training Resource Center, plan and support the annual meeting for grantees, providing valuable opportunities for collaboration.

**National resource centers provided informational and training resources to grantees.** Resource centers disseminated information by delivering webinars and training modules, distributing web-based materials, and managing data-reporting systems for grantees to track progress and achievements using a core set of performance measures.

Section A of this chapter describes the need for supporting collaboration and coordination among grantees. Sections B and C describe the national resource centers' efforts to provide technical assistance and informational and training resources, respectively. Unless otherwise noted, the numbers and figures

cited throughout this chapter come from evaluation interview data and materials reviewed as part of the evaluation, including grantee reports and websites.

## A. The Need for Supporting Collaboration and Coordination Among Grantees

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As reported by the U.S. Government Accountability Office (GAO), collaborative activities aim to “produce more public value than could be produced when ... organizations act alone” (GAO, 2012). This statement applies to Autism CARES grantees as they work to address systemic service delivery challenges too great and too complex for any single organization to solve alone. Despite the importance of working together, grantees face several barriers to effective collaboration, including geographical distance from other grantees and competing demands for their limited staff. To overcome these hurdles and increase the value of Autism CARES investments, MCHB funding supports two national resource centers that provide technical assistance and promote collaboration. The Autism CARES Act National Interdisciplinary Training Resource Center primarily supports the LEND and DBP training grantees, while the State Public Health Coordinating Center for Autism supports State grantees. During this evaluation period, the resource centers facilitated collaboration across—

- ▶ Sixty-two training grantees (52 LEND programs and 10 DBP programs) across 44 different States, working to address the shortage of trained professionals who can provide developmental screening, diagnostic services, and treatment for children and youth with ASD/DDs
- ▶ Thirteen State Implementation grantees working to improve access to comprehensive, coordinated services, including healthcare, education, and social services for children and youth with ASD/DDs in their respective States

## B. Engaging Grantees in Collaborative Technical Assistance

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Throughout the evaluation period, resource centers provided grantee-driven technical assistance. Center staff solicited input from grantees to ensure products and services met their needs, and they leveraged grantee knowledge and expertise to strengthen center activities.

### 1. Soliciting Grantee Input

In addition to encouraging and tracking ad hoc communications with center staff, both resource centers described formal, organized efforts to solicit information about grantees’ specific needs and concerns. Common methods of soliciting grantee input included the following:

- ▶ **One-on-one phone calls.** The State Public Health Coordinating Center for Autism conducted one-on-one telephone interviews with grant directors to build rapport and gauge technical assistance needs. Joined by an MCHB project officer to formally kick off the grant cycle, staff from the State Public Health Coordinating Center for Autism spoke with grantees at the start of each grant period to discuss their grant plans and anticipated technical assistance needs.

- ▶ **Surveys and written feedback.** Each year, the State Public Health Coordinating Center for Autism sends an annual evaluation questionnaire to its listserv with questions about each respondent's top priorities and anticipated needs in the coming year, along with each respondent's anticipated challenges. The Autism CARES Act National Interdisciplinary Training Resource Center developed a new needs assessment form to collect data from grantees about critical issues they face, collaborators they work with to address community needs, and areas where they have had success or required technical assistance.
- ▶ **Site visits and other select in-depth activities.** The Autism CARES Act National Interdisciplinary Training Resource Center provides organizational support to MCHB on its annual site visits to selected training programs. Resource center staff help with intensive preparation for the visits, conducting activities such as reviewing grantee applications and progress reports and identifying relevant resources grantees might need. Center staff also provide onsite support during the visits, attending approximately five LEND or DBP visits annually with an MCHB project officer, where they take notes and contribute to the site visit reports. The Center also helps to secure a peer consultant for the visit—generally a project director from another currently funded LEND or DBP program, selected because of the ability to provide technical assistance in an area relevant to the site being visited.

Many grantees commented positively on the responsiveness of resource center staff to their technical assistance needs, their openness to feedback and requests, their professionalism, and their ability to bring grantees together.

## 2. Leveraging Grantee Knowledge and Expertise To Strengthen the Network

Through their regular communication with grantees, the resource centers build a strong understanding of grantee areas of expertise, providing the basis for peer mentoring and collaboration. The resource centers and their parent organizations engaged many grantees in network leadership and mentoring activities. For example, training grantees said representatives from their program had served key roles within the Autism CARES Act National Interdisciplinary Training Resource Center or AUCD, including serving on the planning committee for the annual Autism CARES grantee meeting, serving as a board member for AUCD, and supporting other special committees. Several grantees also discussed their participation in one of seven AUCD-supported regional consortia (e.g., Southeast Consortium, PacWest Regional Consortium), which bring together LEND programs, UCEDDs, and DBP programs to share ideas and address needs within specific regions. While some of these initiatives apply to AUCD more broadly, the Autism CARES Act National Interdisciplinary Training Resource Center leverages the relationships formed and resources developed through these activities to inform its technical assistance.

The resource centers also facilitated peer mentoring, matching grantees for informal and formal hands-on technical assistance and support. Informal efforts included pairing new grantees with mentors from more established programs. More formal collaborative technical assistance projects, supported logistically and financially by the resource centers, include the following:

- ▶ **The State Public Health Coordinating Center for Autism peer-to-peer exchange program.** This program provides a mechanism for States to learn from one another about building systems of care for children and youth with autism. Through these in-person events, State grantees share lessons learned and best practices and develop plans of action for moving ahead. For example, in June 2015, a peer-to-peer exchange meeting brought together seven State teams (from Connecticut, Iowa, Massachusetts, Maine, Minnesota, New Hampshire, and Virginia) for 2 days to brainstorm and problem-solve about educating parents from culturally and linguistically diverse backgrounds on healthy developmental milestones in young children and reducing barriers to early identification of ASD/DDs.
- ▶ **State Public Health Coordinating Center for Autism technical assistance and mentorship site visits.** Each year, the center funds State grantees seeking mentorship from another grantee engaged in innovative practices. The program aims to support States in replicating or adapting an effective practice to improve systems of care for children and youth with ASD/DD, along with their families. For example, the Iowa and Massachusetts State grantees partnered for a one-on-one exchange of information. The Iowa team visited Massachusetts to learn about that grantee’s family navigator program and *Considering Culture* curriculum. Massachusetts, in turn, visited Iowa to learn about best practices its team had identified for using telehealth to deliver applied behavioral analysis services.
- ▶ **Learning community.** To better support the most recent cohort of State grantees (Delaware, Rhode Island, Washington, and Wisconsin) whose 2016 awards placed a special emphasis on shared resources, telehealth, and family navigation, the State Public Health Coordinating Center for Autism established a learning community to enhance coordination and technical assistance among its members. The community kicked off with an in-person meeting in fall 2017, with representatives from all four States and other partners. Ongoing support included monthly technical assistance calls and a collaborative SharePoint site where participants could communicate and share resources. In 2017, grantees collaborated extensively on the topic of family navigation, coming together through a peer exchange on this topic area and developing a common evaluation instrument to measure family empowerment.

Grantee Feedback on Peer-to-Peer Exchange

“The peer-to-peer meeting in Boston [about working with culturally diverse families] was ... eye-opening to us ... I just thought it was really ... innovative ... it was just the idea that these problems can be solved ... We came away from that meeting feeling really ... good, not only about what we were doing and trying to do, but what everybody [within the State network] was doing.”

—Virginia State Systems  
Grant Director

- ▶ **Workgroup support.** The Autism CARES Act National Interdisciplinary Training Resource Center coordinates and supports several workgroups focused on established or emerging issues in the field. These groups address critical knowledge and resource needs. In addition to promoting networking and collaboration among grantees, they are designed to generate guidelines and responsive curricular materials. For example, several LEND leaders established a work group in 2014 to promote the full and intentional inclusion of people with disabilities (PWD) in training programs. With support from the resource center, this group successfully created, disseminated, and analyzed the results of an survey on the extent to which PWDs are engaged in LEND; published a white paper on inclusion and support strategies (focusing on topics such as recruitment, funding flexibility, and accommodations); held two interactive workshops; and presented posters summarizing the survey results and activities at annual conferences. This work group continues to serve as a source of technical assistance for programs as they strive to promote self-advocacy-related activities.
- ▶ **The Autism CARES Act National Interdisciplinary Training Resource Center’s Focused Assistance to Support Training (FAST) projects.** Since November 2014, the Autism CARES Act National Interdisciplinary Training Resource Center has used some of its funding for 16 special projects for LEND and DBP programs. Grantees submit proposals for their projects and can receive funding small amount of reimbursement if selected. Selected grantees demonstrate an ability to address identified challenges in priority technical assistance areas of the network in ways that could be replicated by other programs or that could benefit the broader network. The cohort of FAST projects starting in September 2017, for example, focused on priorities identified through program needs assessments: demonstrating program impact through data collection and analysis, increasing trainee and faculty diversity, and using technology to provide statewide technical assistance and short-term training. During the funding period, resource center staff provided individualized assistance to the selected programs and facilitated multiple peer-to-peer learning opportunities to disseminate project results. As the LEND project director from Ohio State University described, “It’s almost a requirement that you apply [for FAST projects with] other LEND programs. That’s been a culture change ... I appreciate that they’ve been able to move that needle and make us look at the greater good as opposed to your own program all the time. [FAST grants encourage us to ask] how do we tell the world what an amazing thing this training is and how it’s helping individuals and families and society as a whole?” See table 9.1 for a description of FAST projects awarded in 2017.

**Table 9.1. FAST Projects Begun in September 2017**

<b>Grantee</b>	<b>Project Description</b>	<b>Priority Area</b>
Boston Children’s Hospital DBP	Working to improve fellow and resident training by developing a web-based evaluation system that promotes formative and bidirectional feedback for fellows in clinical training and their faculty in didactic training	Demonstrating Program Impact Through Data Collection and Analysis
Stanford University DBP	Expanding program evaluation processes by gathering and analyzing medium- and long-term outcome data for pediatrics residents trained in their 4-week DBP rotation	Demonstrating Program Impact through Data Collection and Analysis

Grantee	Project Description	Priority Area
Waisman Center of the University of Wisconsin-Madison, partnering with the University of Pittsburgh and Ohio State University LEND Programs	Examining the impact of LEND training outcomes and on the knowledge, attitudes, and skills of LEND trainees and comparison peers 2 years after completion of LEND training through a revised set of follow-up survey questions	Demonstrating Program Impact Through Data Collection and Analysis
University of Cincinnati and Ohio State University LEND Programs	Facilitating statewide training in Ohio on the opioid epidemic and its impact on children via web-based training technology	Using Technology To Provide Statewide Technical Assistance and Short-Term Training
University of New Mexico LEND Program	Partnering with the PacWest LEND Consortium to increase diversity in regional programs, using a train-the-trainer model to increase mentorship capacity of racially and ethnically diverse faculty who will then support the leadership and success of racially and ethnically diverse trainees	Increasing Trainee and Faculty Diversity

### C. Supporting the Annual Autism CARES Grantee Meetings

The two resource centers, led by the National Interdisciplinary Training Resource Center, collaborate in planning the annual Autism CARES grantee meetings. These meetings provide opportunities for participants to explore emerging issues and learn about the work of other grant programs through networking. Grantees attend plenary, concurrent, and virtual poster sessions as well as group discussions on a range of topics such as reducing disparities, expanding the reach of the *Learn the Signs. Act Early.* campaign, and enhancing self-advocacy. The annual meetings alternate between an in-person and virtual format. In addition to bringing in outside experts, the resource centers enlist grantees to present their work and share their expertise.

Grantees greatly valued these opportunities to collaborate and learn from one another. For example, 180 participants attended the 2015 grantee meeting, and 100 percent of those who completed the evaluation survey reported being “very satisfied” or “satisfied” with the meeting. Following the meeting, the Autism CARES Act National Interdisciplinary Training Resource Center created a new annotated grantee-generated resource compendium (*Identifying Autism in Young Children*) that was widely disseminated.

Relatedly, the broader AUCD and AMCHP conferences also bring grantees together to discuss issues related to CSHCN. As the University of Connecticut LEND director noted, the in-person meetings “have been wonderful ... if they weren’t [there] we would really miss them. That’s where we do all our collaborations.”

### D. Providing Informational and Training Resources

In addition to supporting direct technical assistance and collaboration, the resource centers disseminate ASD/DD-related information and materials through several web-based platforms. Common methods of sharing information included resource center listservs and websites. Grantees reported receiving regular emails from the resource centers including newsletters, funding opportunity announcements,

information about newly available resources, and policy information. Additional examples of resource center materials are described below.

### **1. Delivering Webinars and Training Modules**

Throughout the evaluation period, the resource centers facilitated and recorded webinar presentations for grantee use. Topics included leadership development, data systems integration and performance measurement, resources for trainees, developmental screening, various aspects of ASD/DD, and other areas of grantee need. Several grantees commented on the high quality of these webinars and training modules, including the orientation webinars that provided grantees and trainees with a better understanding of what resources are available through the resource centers and the role of various organizations in the grant process.

### **2. Disseminating Web-Based Materials**

The resource center websites serve as a repository for all materials, including the webinars, training modules, and products from collaborative technical assistance projects identified above. Other resources include a training toolbox to share innovative training strategies and a “State spotlight” page highlighting State Public Health Coordinating Center for Autism activities of each State, along with a packet of developmental and ASD/DD screening resources. To better support busy grantees who have reported struggling to quickly find the materials they need, the resource centers have made several improvements to their websites, including improving their site search functions.

### **3. Managing Data Reporting Systems**

The ability to track progress and achievements using a common set of measures is critical to the success of collaborative endeavors. To that end, AUCD continued to maintain the NIRS platform, which LEND and DBP grantees use to report their performance data to MCHB. NIRS includes an Autism CARES-specific module where LEND and DBP grantees report on ASD-specific information (e.g., the number of children served in their program’s clinics, the number of trainees enrolled in ASD/DD-specific curricula). AUCD continued to support MCHB’s evaluation of grantees by providing technical assistance related to data collection and management. AUCD hosts in-person sessions and webinars for grantee data managers to ensure submission of high-quality data.

## Chapter 10. Autism CARES Grantees' Progress, Remaining Challenges, and Opportunities

While HRSA's Autism CARES funding supported more than 100 grantees between 2014 and 2017, related efforts to improve the health and well-being of individuals with ASD/DDs began in 2008. Autism CARES grantees have been working alongside other local, State, and national partners hoping to improve the quality of life for individuals with ASD/DDs. Section A of this chapter provides context for grantees' accomplishments, highlighting progress and changes in the field since HRSA's Autism CARES funding began. Section B presents several remaining challenges as HRSA looks to the future.

### A. HRSA's Progress, 2008 to 2018

Autism CARES-related funding opportunities were initiated more than a decade ago, amid growing national concern about ASD. In 2010, national estimates of ASD prevalence indicated 1 in 110 U.S. children had been identified with ASD (Office of Autism Research Coordination, National Institutes of Health [NIH], 2011). The Nation's focus on ASD has grown stronger during that time. ASD prevalence has increased to 1 in 59 children, prompting corresponding demand for ASD-related services and research. HRSA and its grantees have worked to fill this need in several ways, including increasing the number of grantees and programs funded (see table 10.1) and expanding their key activities and areas of focus (see table 10.2) from the initial funding period to the current evaluation. During this time, some grantees built new programs from the ground up, while others expanded the reach of existing programs that predated the Autism CARES-related funding.

**Table 10.1. Number of Initial Programs Funded Compared to Number Included in This Evaluation**

Program Type	Number of Programs Funded in FY 2008 and FY 2009 <sup>a</sup>	Number of Programs Included in This Evaluation <sup>b</sup>
Training Programs	39 LEND grants and 6 DBP grants	52 LEND grants and 10 DBP grants
Research Programs	2 research networks (AIR-P and AIR-B), 5 autism intervention Research Program grantees, and 2 secondary data analysis studies	5 Research Networks (AIR-P, AIR-B, DBPNet, HCT-RN, and HW-RN) and 22 Autism-FIRST and Autism-SDAR studies
State Implementation Grant Programs	9 State Implementation grants	5 State Implementation grants and 4 State Innovation in Care Integration grants

<sup>a</sup> Source: Office of Autism Research Coordination, NIH, 2011

<sup>b</sup> Source: evaluation results

**Table 10.2. Selected Grantee Accomplishments and Areas of Focus, Initial Programs Compared to Those Included in This Evaluation Period**

Program Type	Number of Select Activities or Areas of Focus for Programs Funded in FY 2008 and FY 2009 <sup>a</sup>	Number of Select Activities or Areas of Focus for Programs Included in This Evaluation Period <sup>b</sup>
Training Programs	In FY 2009, LEND and DBP programs trained 1,377 medium-term trainees and 510 long-term trainees.  In FY 2010, LEND and DBP trainees conducted 781 continuing education events reaching 92,252 participants.	Between 2014 and 2017, the LEND and DBP programs enrolled more than 3,886 medium-term trainees and 1,367 long-term trainees each year.  Between 2014 and 2016, LEND and DBP grantees offered more than 7,800 continuing education courses reaching more than 417,000 participants.
Research Programs	In the first 2 years of MCHB funding, the Research Programs implemented 11 studies on interventions. They had not yet published any tools or guidelines.	From September 1, 2014, to August 31, 2017, the Research Programs conducted 84 studies, prepared 299 manuscripts for publication, delivered 327 scientific conference presentations, and produced 13 guidelines and 19 tools.
State Grant Programs	State Implementation grantees focused on improving access to developmental screening and diagnosis services and enhancing frontline services through the development of medical homes for children with ASD/DDs.	In 2016, HRSA's funding of the State Innovation in Care Integration grants replaced the State Implementation grants. The focus evolved to emphasize strategies to integrate care and work toward more specific objectives and quantified targets.

<sup>a</sup> Source: Office of Autism Research Coordination, NIH, 2011

<sup>b</sup> Source: evaluation results

## B. Remaining Challenges and Opportunities

Despite HRSA's progress and accomplishments described here and the efforts of other national and local efforts, the constantly changing landscape of ASD/DD means providers, children, and families face new and ongoing barriers to care. These contextual challenges include the following:

- ▶ **Generating and disseminating new research on ASD/DDs to ensure services for individuals with ASD/DDs are based on evidence.** Caregivers and service providers struggle to monitor constantly emerging research, covering topics such as ASD's complex symptoms, comorbidities, and effective treatments and interventions. Grantees must continue to think creatively both in designing research studies and disseminating the findings to ensure the evidence is reaching those involved in making care decisions at the individual and systemic levels.
- ▶ **Reducing disparities and building a diverse workforce of ASD/DD providers to ensure access to care for all individuals with ASD/DDs.** The shortage of qualified providers who can screen for, diagnose, and treat ASD/DDs persists and is a major barrier to timely care for these individuals and their families. Although grantees have focused on ensuring all individuals with ASD/DDs have access to appropriate care, including vulnerable groups such as racial and ethnic minorities or those living in remote areas, truly reducing disparities remains a challenge. As for many other professional fields, a dearth of diverse applicants for Autism CARES training programs persists. An emphasis on hiring a diverse workforce and reducing disparities should remain a focus for grantees.

- ▶ **Developing sustainable coordinated systems of care for individuals with ASD amid the ever-changing healthcare landscape.** State and national policies related to ASD care have evolved dramatically in recent years, and individuals with ASD/DDs and those who support them are faced with the challenge of navigating these dynamic systems. The changes to healthcare systems and insurance policies make coordination of care and sustainability of programs difficult. HRSA should continue to focus on improving systems of care to ensure individuals with ASD have access to the coordinated care they need, despite the local and national changes occurring around them.
- ▶ **Meeting the needs of youth with ASD/DDs as they transition to adulthood.** Historically, ASD/DD-related work has focused on young children and the importance of early developmental screening, diagnosis, and intervention. These topics remain important, but there is an increased need to support youth with ASD/DDs who are transitioning to adulthood. The number of youth with ASD/DDs who become adults grows each year, and these individuals are aging into systems not fully prepared to meet the increased demand. Some grantees have not yet begun to turn attention to the issues affecting young adults with ASD, and HRSA should continue to emphasize the need for research, training, and services related to the transition to adulthood.
- ▶ **Conducting State-level inventory and capacity assessment.** The State systems grantees of the 2016 cohort were tasked with specific, quantifiable targets, such as increasing the proportion of children within the State identified as at-risk for ASD diagnosis and referred for diagnosis and ASD/DD services by 25 percent over baseline. Several grantees found that baseline data were not available and struggled to find ways to measure progress. Requiring applicants to conduct a needs assessment related to data systems prior to applying for a grant may help to address these challenges in the future.

## Abbreviations and Acronyms

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AAP	American Academy of Pediatrics
ABCD	Assuring Better Child Health and Development
ACE	adverse childhood experience
ADI-R	Autism Diagnostic Interview-Revised
ADOS	Autism Diagnostic Observation Schedule
AIR-B	Autism Intervention Research Network on Behavioral Health
AIR-P	Autism Intervention Research Network on Physical Health
AIT	autism identification team
AMCHP	Association of Maternal and Child Health Programs
ASD	autism spectrum disorder
ASQ	Ages and Stages Questionnaire
ASQ-SE	Ages and Stages Questionnaire–Social Emotional
ATN	Autism Treatment Network
AUCD	Association of University Centers on Disabilities
Autism CARES Act	Autism Collaboration, Accountability, Research, Education, and Support Act
Autism-FIRST	Field-Initiated Research Studies
Autism-SDAR	Secondary Data Analysis Research
CAM	Community Asset Mapping
CAPTAIN	California Autism Professional Training and Information Network
CDC	Centers for Disease Control and Prevention
CDSA	child development service agency
CE	continuing education
CHSC	child health specialty clinic
CME	continuing medical education

CRE	collaborating research entity
CSHCN	children with special healthcare needs
DBP	developmental-behavioral pediatrics
DBPNet	Developmental-Behavioral Pediatrics Research Network
DD	developmental disability
DGIS	Discretionary Grant Information System
ECHO	Extension for Community Healthcare Outcomes Autism
ECQUIP	Engaged Community Quality Improvement Projects
F2F HIC	Family-to-Family Health Information Center
FAST	Focused Assistance to Support Training
FY	fiscal year
HCT-RN	Health Care Transitions Research Network
HHS	U.S. Department of Health and Human Services
HRSA	Health Resources and Services Administration
HW-RN	Healthy Weight Research Network
LEND	Leadership Education in Neurodevelopmental and Other Related Disabilities
L TSAE	<i>Learn the Signs. Act Early.</i>
MCHAT	Modified Checklist for Autism in Toddlers
MCHAT-R	Modified Checklist for Autism in Toddlers (Revised)
MCHB	Maternal and Child Health Bureau
MINDS	Medical homes INclude Developmental Screening
NCC	Network Coordinating Center
NIRS	National Information Reporting System
OMB	Office of Management and Budget
PEDS	Parents' Evaluation of Development Status

PSA	public service announcement
QILC	quality-improvement learning collaborative
SMART	School Medical Autism Review Team
STAT	Screening Tool for Autism in Toddlers and Young Children
UCEDD	University Center for Excellence in Developmental Disabilities
WAAA	Washington Autism Alliance and Advocacy
WSLI	Washington State Leadership Initiative

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## Appendix A. Data Sources Included in Evaluation

This evaluation began where the prior study of Autism CARES activities left off, covering activities from 2014 to 2017. Grantees were at different stages in their grant cycles during this period, and the evaluation does not neatly align with Federal fiscal years or grantee funding and reporting periods. This appendix, along with figure 2.1 in the body of the report, shows the data and activities included in the evaluation. To supplement the information in table A.1, Insight sought clarifying details from grantee websites and other resources as needed.

**Table A.1. Data Sources by Program**

Data Source	Year
<b>LEND Program</b> (43 grantees, 2011–2016; 52 grantees, 2016–2021)	
DGIS	2014–2015; 2015–2016
Progress Report/Noncompeting Continuation Application	2015; 2017
NIRS	2014–2015; 2015–2016; 2016–2017
Application (2016–2021 grantees only)	2016
Final Reports (2011–2016 grantees only)	2016
Grantee Interviews	2017
<b>DBP Program</b> (10 grantees, 2013–2018)	
Progress Report/Noncompeting Continuation Application	2015; 2016; 2017
NIRS	2014–2015; 2015–2016; 2016–2017
DGIS	2014–2015; 2015–2016
Grantee Interviews	2017
<b>Research Programs</b>	
<b>AIR-P and AIR-B</b> (2012–2015; 2015–2020)	
Application	2015
Semiannual Performance Report	2015; 2016; 2017
Noncompeting Continuation Application	2016; 2017
Research Networks Questionnaire	2017
Grantee Interviews	2017
<b>DBPNet</b> (2013–2016; 2016–2019)	
Semiannual Report	2015; 2016
Performance Report	2015; 2016
Final Report	2017
Noncompeting Continuation Application	2016
Research Networks Questionnaire	2017
Grantee Interview	2017

<b>Data Source</b>	<b>Year</b>
<b>HCT-RN (2014–2017)</b>	
Application	2014
Performance Report	2017
Semiannual Report	2015; 2016
Noncompeting Continuation Application	2015; 2016; 2017
Research Networks Questionnaire	2017
Grantee Interview	2017
<b>HW-RN (2013–2016; 2016–2021 )</b>	
New Competing Continuation Application	2016
Performance Report	2015; 2017
Semiannual Report	2014; 2016; 2017
Research Networks Questionnaire	2017
Grantee Interview	2017
<b>Autism-FIRST (3 grantees, 2013; 7 grantees, 2014)</b>	
Application	2013; 2014
Midproject Progress Report	2014; 2015; 2016
Final Report	2013; 2014; 2015; 2016
Research Summary (completed by Insight and confirmed by grantee via email)	All completed by December 2017
Grantee Interview (and research summary clarification where necessary)	2017
<b>Autism-SDAR (4 grantees, 2013; 5 grantees, 2014; 3 grantees, 2015)</b>	
Application	2012; 2013; 2014; 2015
Midproject Progress Report	2014; 2015; 2016
Final Report	2013; 2014; 2015; 2016; 2017
Research Summary (completed by Insight and confirmed by grantee via email)	All completed by January 2018
<b>State Implementation and Innovation in Care Integration Grantees (4 grantees, 2013–2016; 5 grantees, 2014–2016; 4 grantees, 2016–2019)</b>	
Progress Report and Noncompeting Continuation Application	2014; 2015; 2017
Final Report	2017
Application	2016
Grantee Interview	2017
<b>Autism CARES Act National Interdisciplinary Training Resource Center (2011–2016 cooperative agreement; 2016–2021 cooperative agreement )</b>	
Progress Report/Continuation Application	2015; 2016
Application	2017
Grantee Interview	2017
<b>State Public Health Coordinating Center for Autism (2012–2017 cooperative agreement; 2017–2022 cooperative agreement)</b>	
Progress Report/Continuation Application	2015; 2016
Application	2017
Grantee Interview	2017

## Appendix B. Autism CARES Grantees

**Table B.1.LEND Grantees**

Number	Full Grantee Name	Alternative Name, if Applicable	Location
<b>Relevant Funding Periods For Evaluation: July 2011–June 2016 and July 2016–June 2021 (prior awardees)</b>			
<b>1.</b>	Albert Einstein College of Medicine	–	Bronx, NY
<b>2.</b>	Children’s Hospital (Institute for Community Inclusion)	Boston Children’s Hospital	Boston, MA
<b>3.</b>	Children’s Hospital of Los Angeles	–	Los Angeles, CA
<b>4.</b>	Dartmouth Medical School	Dartmouth	Lebanon, NH
<b>5.</b>	Indiana University School of Medicine	Indiana University	Indianapolis, IN
<b>6.</b>	The Children’s Hospital of Philadelphia	–	Philadelphia, PA
<b>7.</b>	University of Alabama at Birmingham	University of Alabama	Birmingham, AL
<b>8.</b>	University of Kansas Medical Center Research Institute	University of Kansas	Kansas City, KS
<b>9.</b>	University of Nebraska (Munroe-Meyer Institute for Genetics & Rehabilitation)	University of Nebraska	Omaha, NE
<b>10.</b>	University of North Carolina at Chapel Hill (Center for Development and Learning)	University of North Carolina	Carrboro, NC
<b>11.</b>	University of Rochester (Strong Center for Developmental Disabilities)	University of Rochester	Rochester, NY
<b>12.</b>	University of Tennessee Boling Center for Developmental Disabilities	University of Tennessee	Memphis, TN
<b>13.</b>	University of Utah	–	Salt Lake City, UT
<b>14.</b>	University of Vermont (VT Interdisciplinary Leadership Education for Health Professionals)	University of Vermont	Burlington, VT
<b>15.</b>	University of Washington (Center on Human Development and Disability)	University of Washington	Seattle, WA
<b>16.</b>	Vanderbilt University	–	Nashville, TN
<b>17.</b>	West Virginia University	–	Morgantown, WV
<b>18.</b>	University of Arkansas for Medical Sciences	University of Arkansas	Little Rock, AR
<b>19.</b>	University of Colorado Denver (JFK Partners)	University of Colorado	Aurora, CO
<b>20.</b>	University of Illinois at Chicago	University of Illinois	Chicago, IL
<b>21.</b>	Kennedy Krieger Institute	–	Baltimore, MD
<b>22.</b>	Westchester Institute for Human Development		Valhalla, NY
<b>23.</b>	Ohio State University (Nisonger Center UCEDD)	Ohio State University	Columbus, OH
<b>24.</b>	Oregon Health & Science University (Oregon Institute on Disability and Development)	Oregon Health & Science University	Portland, OR
<b>25.</b>	University of Cincinnati	–	Cincinnati, OH
<b>26.</b>	University of Hawaii at Manoa	University of Hawaii	Honolulu, HI
<b>27.</b>	University of Iowa	–	Iowa City, IA
<b>28.</b>	University of Massachusetts Medical School	University of Massachusetts	Worcester, MA

Number	Full Grantee Name	Alternative Name, if Applicable	Location
29.	University of Miami (Mailman Center for Child Development)	University of Miami	Miami, FL
30.	University of Missouri, Columbia (TIPS for Kids)	University of Missouri	Columbia, MO
31.	University of New Mexico Health Sciences Center (Center for Development and Disability Pediatrics)	University of New Mexico	Albuquerque, NM
32.	University of Oklahoma Health Sciences Center	University of Oklahoma	Oklahoma City, OK
33.	University of Pittsburgh	–	Pittsburgh, PA
34.	University of South Dakota	–	Vermillion, SD
35.	University of Wisconsin-Madison (Waisman Center)	University of Wisconsin	Madison, WI
36.	Virginia Commonwealth University	–	Richmond, VA
37.	Regents of the University of Minnesota	University of Minnesota	Minneapolis, MN
38.	Georgia State University (Center for Leadership in Disability)	Georgia State University	Atlanta, GA
39.	University of Alaska Anchorage (Center for Human Development)	University of Alaska	Anchorage, AK
40.	University of Arizona	–	Tucson, AZ
41.	University of Nevada, Reno (Nevada Center for Excellence in Disabilities)	University of Nevada	Reno, NV
42.	University of Texas Health Science Center at Houston	University of Texas	Houston, TX
43.	Medical University of South Carolina	–	Charleston, SC
<b>Relevant Funding Periods For Evaluation: July 2016–June 2021 (new awardees)</b>			
44.	University of California, Davis	–	Davis, CA
45.	University of California, Los Angeles	–	Los Angeles, CA
46.	University of Connecticut Health Center	University of Connecticut	Farmington, CT
47.	University of Delaware	–	Newark, DE
48.	Louisiana State University Health Sciences Center Project	Louisiana State University	New Orleans, LA
49.	University of New England	University of New England	Biddeford, ME
50.	Rutgers, the State University of New Jersey	Rutgers University	Piscataway, NJ
51.	Rhode Island Hospital	Rhode Island Hospital	Providence, RI
52.	Wayne State University	–	Detroit, MI

**Table B.2. DBP Grantees**

Number	DBP Grantee	Alternative Name, if Applicable	Location
<b>Relevant Funding Periods For Evaluation: July 2013–June 2018</b>			
1.	Boston Children’s Hospital	–	Boston, MA
2.	The Children’s Hospital of Philadelphia	–	Philadelphia, PA
3.	Stanford University	–	Palo Alto, CA
4.	Rhode Island Hospital	–	Providence, RI
5.	University of Oklahoma	–	Oklahoma City, OK

Number	DBP Grantee	Alternative Name, if Applicable	Location
6.	Children’s Hospital of Los Angeles	–	Los Angeles, CA
7.	Medical University of South Carolina	–	Charleston, SC
8.	University of California, Davis	–	Davis, CA
9.	University of California, San Diego	–	San Diego, CA
10.	University of Colorado Denver	University of Colorado	Aurora, CO

**Table B.3. Autism Intervention Research Grantees**

Number	Research Grantee	Alternative Name, if Applicable	Location
<b>AIR-P</b>			
<b>Relevant Funding Periods for Evaluation: 2014–2017</b>			
1.	Massachusetts General Hospital for Children	AIR-P	Boston, MA
<b>Collaborating Research Entities</b>			
a.	Thompson Center for Autism and Neurodevelopmental Disorders at University of Missouri	AIR-P	Columbia, MO
b.	University of Rochester Medical Center (Golisano Children’s Hospital)	AIR-P	Rochester, NY
c.	Cincinnati Children’s Hospital Medical Center (The Kelly O’Leary Center for Autism Spectrum Disorders at Cincinnati Children’s)	AIR-P	Cincinnati, OH
d.	University of Pittsburgh Medical Center (Center for Autism and Developmental Disorders at UPMC)	AIR-P	Pittsburgh, PA
e.	Vanderbilt University Medical Center	AIR-P	Nashville, TN
f.	Autism Treatment Network of Toronto	AIR-P	Toronto, ON, Canada
g.	The Lurie Center for Autism at Massachusetts General Hospital	AIR-P	Lexington, MA
h.	Nationwide Children’s Hospital Child Development Center	AIR-P	Columbus, OH
i.	Boone Fetter Clinic at Children’s Hospital Los Angeles	AIR-P	Los Angeles, CA
j.	The Children’s Hospital of Philadelphia	AIR-P	Philadelphia, PA
k.	University of Alberta and Glenrose Rehabilitation Hospital	AIR-P	Edmonton, AB
l.	The Center for Autism & Neurodevelopmental Disorders at University of California Irvine	AIR-P	Santa Ana, CA
<b>AIR-B</b>			
<b>Relevant Funding Periods for Evaluation: 2014–2017</b>			
1.	University of California, Los Angeles (UCLA), Center for Autism Research and Treatment (CART)	AIR-B	Los Angeles, CA
<b>Collaborating Research Entities</b>			
a.	University of Rochester Medical Center	AIR-B	Rochester, NY
b.	University of Pennsylvania, Center for Mental Health Policy and Services Research	AIR-B	Philadelphia, PA

Number	Research Grantee	Alternative Name, if Applicable	Location
<b>c.</b>	University of California, Davis – MIND Institute	AIR-B	Sacramento, CA
<b>DBPNet</b>			
<b>Relevant Funding Periods for Evaluation: 2013–2016; 2016–2019</b>			
<b>1.</b>	The Children’s Hospital of Philadelphia	DBPNet	Philadelphia, PA
<b>Collaborating Research Entities</b>			
<b>a.</b>	Boston Medical Center	DBPNet	Boston, MA
<b>b.</b>	Children’s Hospital–Boston	DBPNet	Boston, MA
<b>c.</b>	Cincinnati Children’s Hospital Medical Center	DBPNet	Cincinnati, OH
<b>d.</b>	Children’s Hospital at Montefiore/Albert Einstein College of Medicine	DBPNet	Bronx, NY
<b>e.</b>	University of California-Davis MIND Institute	DBPNet	Davis, CA
<b>f.</b>	Hasbro Children’s Hospital	DBPNet	Providence, RI
<b>g.</b>	Stanford University/Lucile Packard Children’s Hospital	DBPNet	Palo Alto, CA
<b>h.</b>	Rainbow Babies and Children’s Hospital	DBPNet	Cleveland, OH
<b>i.</b>	University of Arkansas for Medical/Arkansas Children’s Hospital	DBPNet	Little Rock, AR
<b>j.</b>	University of Oklahoma Health Sciences Center	DBPNet	Oklahoma City, OK
<b>k.</b>	Yale-New Haven Children’s Hospital	DBPNet	New Haven, CT
<b>l.</b>	Children’s Hospital Colorado	DBPNet	Aurora, CO
<b>m.</b>	Children’s Hospital Los Angeles	DBPNet	Los Angeles, CA
<b>HCT-RN</b>			
<b>Relevant Funding Periods for Evaluation: 2014–2017</b>			
<b>1.</b>	University of California, Los Angeles, Center for Healthier Children, Families, and Communities	HCT-RN	Los Angeles, CA
<b>Collaborating Research Entities</b>			
<b>a.</b>	A.J. Drexel Autism Institute at Drexel University	HCT-RN	Philadelphia, PA
<b>HW-RN</b>			
<b>Relevant Funding Periods for Evaluation: 2013–2016; 2016–2019</b>			
<b>1.</b>	University of Massachusetts Medical School	HW-RN	Worcester, MA
<b>Collaborating Research Entities</b>			
<b>a.</b>	University of California, San Diego	HW-RN	San Diego, CA
<b>b.</b>	Boston University School of Medicine	HW-RN	Boston, MA
<b>c.</b>	Energy Balance Laboratory and Center for Physical Activity and Weight Management, University of Kansas Medical Center (KUMC), Kansas City, KS, and University of Kansas, Lawrence, KS	HW-RN	Kansas City, KS, and Lawrence, KS
<b>d.</b>	Department of Internal Medicine, Cardiovascular Research Institute, at the University of Kansas Medical Center	HW-RN	Kansas City, KS
<b>e.</b>	Childhood and Adolescent Weight Management Clinic, Nemours/A.I. duPont Hospital for Children and Jefferson Medical College	HW-RN	Wilmington, DE

<b>Number</b>	<b>Research Grantee</b>	<b>Alternative Name, if Applicable</b>	<b>Location</b>
<b>f.</b>	Developmental and Behavioral Pediatrics at the Golisano Children’s Hospital at the University of Rochester Medical Center	HW-RN	Rochester, NY
<b>g.</b>	Department of Biobehavioral Health Sciences, University of Pennsylvania School of Nursing	HW-RN	Philadelphia, PA
<b>h.</b>	Kinesiology and Nutrition in the College of Applied Health Sciences at the University of Illinois at Chicago	HW-RN	Chicago, IL
<b>i.</b>	Lakeshore Foundation/University of Alabama-Birmingham Research Collaborative	HW-RN	Birmingham, AL
<b>j.</b>	Research Center for Health Care Decision-Making, Inc.	HW-RN	Wyndmoor, PA
<b>k.</b>	Division of Epidemiology and Community Health, School of Public Health, University of Minnesota	HW-RN	Minneapolis, MN
<b>l.</b>	Department of Psychiatry and Behavioral Sciences, Duke Center for Autism and Brain Development	HW-RN	Durham, NC
<b>m.</b>	Department of Exercise and Health Sciences at the University of Massachusetts-Boston (UMB)	HW-RN	Boston, MA

**R40 Autism-FIRST Grantees, 2014–2017**

<b>1.</b>	Michigan State University	Comparative Efficacy of a Self-Directed and Therapist-Assisted Telehealth Parent Training Intervention for Children With ASD	East Lansing, MI
<b>2.</b>	Vanderbilt University	Does Mindfulness Training Enhance Early Evidence-Based Parent-Coaching Interventions?	Nashville, TN
<b>3.</b>	Vanderbilt University	Comprehensive Communication Intervention for Minimally Verbal Children With Autism	Nashville, TN
<b>4.</b>	University of Rochester Medical Center	Investigation of Teacher-Mediated Toilet Training Using a Manualized Moisture Alarm Intervention	Rochester, NY
<b>5.</b>	University of Colorado, Denver	Parent-Mediated Interventions in Autism: The Search for Meaningful Outcomes	Aurora, CO
<b>6.</b>	University of California, Davis	A Controlled Trial of Sertraline in Young Children With ASD	Davis, CA
<b>7.</b>	University of Colorado, Denver	Screening and Linkage to Services for Autism (SaLSA)	Aurora, CO

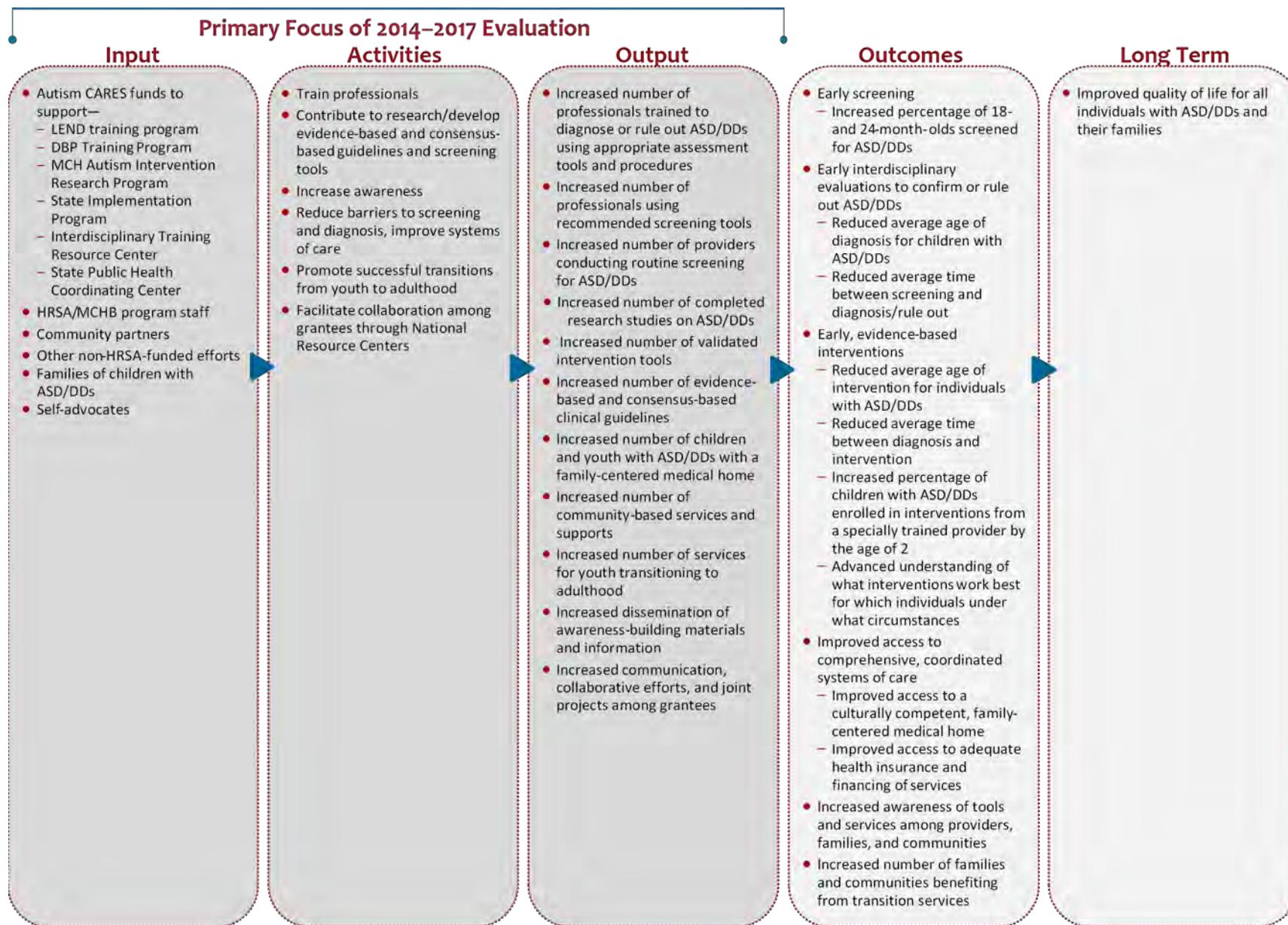
<b>Number</b>	<b>Research Grantee</b>	<b>Alternative Name, if Applicable</b>	<b>Location</b>
<b>R40 Autism-FIRST Grantees, 2013–2016</b>			
<b>8.</b>	University of Massachusetts, Boston	Addressing Health Disparities in Autism Diagnosis, Service Utilization, and School Engagement Among Young Children Living in the Circle of Promise	Dorchester, MA
<b>9.</b>	Hugo W. Moser Research Institute at Kennedy Krieger, Inc.	Improving Part C Services and Outcomes for Underserved Children With ASD	Baltimore, MD
<b>10.</b>	University of North Carolina at Chapel Hill	Toddlers and Families Together: Addressing Early Core Features of Autism	Chapel Hill, NC
<b>R40 Autism-SDAR Grantees, 2015–2016</b>			
<b>1.</b>	Florida State University	Medical Care Utilization and Costs Among Transition-Age Young Adult Medicare Beneficiaries With Autism Spectrum Disorder	Tallahassee, FL
<b>2.</b>	Northern Illinois University	Racial and Ethnic Disparities in Autism Diagnosis and Educational Therapy Utilization: Quantifying the Contribution of Modifiable Mediators	DeKalb, IL
<b>3.</b>	Temple University	Family Adversity and Health Disparities for Young Children With Autism	Philadelphia, PA
<b>R40 Autism-SDAR Grantees, 2014–2015</b>			
<b>4.</b>	University of North Carolina at Chapel Hill	Tough Choices: Autism, Private Health Insurance, and Family Out-of-Pocket	Chapel Hill, NC
<b>5.</b>	University of North Carolina at Chapel Hill	Patterns and Variations in Emergency Department Visits for U.S. Children With Autism: A Rural-Urban Comparison	Chapel Hill, NC
<b>6.</b>	Institute for Disability Policy, Brandeis University	Racial and Ethnic Disparities in Diagnostic and Health Services of Children With Developmental Disabilities	Waltham, MA
<b>7.</b>	University of California, San Francisco	Peer-Victimization of Adolescents With ASD: Filling the Knowledge Gaps To Create Anti-Bullying Interventions	San Francisco, CA
<b>8.</b>	Texas Tech University	Making a More Effective and Efficient Social Communication Questionnaire (SCQ)	Lubbock, TX

Number	Research Grantee	Alternative Name, if Applicable	Location
<b>R40 Autism-SDAR Grantees, 2013–2014</b>			
9.	American University and University of Maryland College Park	A Longitudinal Analysis of Maternal Depression and its Associations With Child Obesity and Health Care Use	Washington, DC
10.	Brandeis University	Trends in Racial and Ethnic Health Care Disparities for Children With Autism/DD	Waltham, MA
11.	University of Washington	Dental Homes for Medicaid-Enrolled Children With Autism Spectrum Disorders in the Iowa I-Smile Program	Seattle, WA
12.	Thomas Jefferson University	Access to Therapy for Children With Autism: A Population-Based Analysis	Philadelphia, PA

**Table B.4. State Systems Grantees**

Number	Grantee	Alternative Name, if Applicable	Location
<b>2016 Cohort of State Innovation in Care Integration Grants</b>			
1.	Washington State Department of Health	Washington	WA
2.	University of Delaware	Delaware	DE
3.	The Autism Project	Rhode Island	RI
4.	University of Wisconsin - Madison	Wisconsin	WI
<b>2014 Cohort of State Implementation Grants</b>			
5.	Georgia State University Research Foundation	Georgia	GA
6.	Arkansas Children's Hospital Research Institute	Arkansas	AR
7.	University of Iowa School of Medicine	Iowa	IA
8.	Michigan Department of Community Health	Michigan	MI
9.	Minnesota Department of Health	Minnesota	MN
<b>2013 Cohort of State Implementation Grants</b>			
10.	The Parents' Place of Maryland	Maryland	MD
11.	University of North Carolina at Chapel Hill	North Carolina	NC
12.	Virginia Commonwealth University	Virginia	VA
13.	Oregon Health and Science University	Oregon	OR

## Appendix C. Logic Model



## Appendix D. Evaluation Research Questions by Data Source

Research Question	Data Source					
	Continuation Applications and Progress Reports	Grantee Surveys and Questionnaires	Semistructured Interviews	DGIS	NIRS	Existing Background Data
<b>Train professionals</b>						
<i>How have Autism CARES grantees contributed to the training of professionals who can provide services for children and youth with ASD/DDs?</i>						
a. Who receives ASD/DD training from Autism CARES grantees? What are trainees' key characteristics, and how have grantees contributed to a diverse and interdisciplinary field of professionals?	●		●	●	●	
b. How have LEND and DBP grantees enhanced the didactic and clinical training opportunities related to ASD/DDs?	●		●	●	●	
c. How have LEND and DBP grantees prepared trainees for ASD/DD leadership positions?	●		●	●	●	
d. How have Autism CARES grantees collaborated with one another and with other stakeholders to provide ASD/DD training?	●		●	●	●	
e. What training strategies have Autism CARES grantees found to be successful, and what factors have facilitated their success?	●		●			
f. What major barriers prevent the training of professionals who can provide services for children and youth with ASD/DDs? What challenges have Autism CARES grantees faced in overcoming these barriers?	●		●			●
g. How have Autism CARES grantees evaluated their own efforts to train professionals, and what were their evaluation results?	●		●	●		
<b>Increase awareness and disseminate information</b>						
<i>How have Autism CARES grantees increased awareness of ASD/DDs and/or disseminated related information?</i>						
a. Who are the target audiences for Autism CARES grantees' ASD/DD awareness and dissemination efforts? What main messages do Autism CARES grantees convey to these audiences?	●	●	●	●	●	
b. How are Autism CARES grantees targeting their awareness and dissemination efforts to appropriate audiences?	●	●	●			
c. What are Autism CARES grantees' primary modes of ASD/DD awareness outreach and dissemination (e.g., conferences, webinars, campaigns)?	●	●	●	●	●	
d. What products, actions, or initiatives have resulted from Autism CARES grantees' efforts to increase awareness of ASD/DDs and/or disseminate related information?	●	●	●	●	●	
e. How have Autism CARES grantees collaborated with one another and with other stakeholders to increase awareness of ASD/DDs and/or disseminate related information?	●	●	●	●	●	
f. What awareness and dissemination strategies have Autism CARES grantees found to be successful, and what factors have facilitated their success?	●		●			

Research Question	Data Source					
	Continuation Applications and Progress Reports	Grantee Surveys and Questionnaires	Semistructured Interviews	DGIS	NIRS	Existing Background Data
g. What major awareness and/or dissemination gaps remain? What challenges have Autism CARES grantees faced in bridging these gaps?	●		●			●
h. How have Autism CARES grantees evaluated their own efforts to increase awareness of ASD/DDs and/or disseminate related information, and what were their evaluation results?	●	●	●	●		
<b>Contribute to research, develop evidence-based guidelines and screening tools</b>						
<i>How have Autism CARES grantees contributed to ASD/DD research?</i>						
a. What ASD/DD-related research topics are Autism CARES grantees pursuing, and what are the products of this research?	●	●	●			
b. How have Research Program grantees contributed to evidence-based or consensus-based ASD/DD guidelines, tools, and interventions?	●	●	●			
c. How have Autism CARES grantees mentored and developed new investigators in the ASD/DD field?	●	●	●			
d. How have Autism CARES grantees collaborated with one another and with other stakeholders on ASD/DD research?	●	●	●			
e. What major research gaps remain, and what challenges have Autism CARES grantees faced in addressing these research gaps?	●	●	●			●
f. What strategies have Autism CARES grantees found to be successful in promoting the uptake of new research or the transfer of new findings into practice, and what factors have facilitated their success?	●	●	●			
g. What barriers prevent the uptake of new research or the transfer of new findings into practice, and what challenges have Autism CARES grantees faced in addressing these barriers?	●	●	●			●
h. How have Autism CARES grantees evaluated their own efforts to contribute to ASD/DD research, and what were their evaluation results?	●	●	●			
<b>Reduce barriers to screening and diagnosis, improve systems of care</b>						
<i>What efforts did Autism CARES grantees undertake to reduce barriers to care for children and youth with ASD/DDs? What efforts did they undertake to improve systems of care for this population?</i>						
a. How have Autism CARES grantees' activities addressed needs of underserved populations with ASD/DDs?	●	●	●	●	●	
b. How have Autism CARES grantees collaborated with one another and with other stakeholders to reduce barriers to care and/or improve systems of care for children and youth with ASD/DDs?	●	●	●	●	●	
c. What strategies have Autism CARES grantees found to be successful in reducing barriers to screening and diagnosis and improving systems of care, and what factors have facilitated their success?	●	●	●			

Research Question	Data Source					
	Continuation Applications and Progress Reports	Grantee Surveys and Questionnaires	Semistructured Interviews	DGIS	NIRS	Existing Background Data
d. What major barriers to care do children and youth with ASD/DDs face? What challenges have Autism CARES grantees faced in addressing these barriers?	●	●	●			●
e. How have Autism CARES grantees evaluated their own efforts to reduce barriers to screening and diagnosis and improve systems of care, and what were their evaluation results?	●	●	●	●		
<b>Identify needs and develop services for youth transitioning to adulthood</b>						
<i>What efforts did Autism CARES grantees undertake to identify needs and develop services and supports for young adults with ASD/DDs transitioning to adulthood? How have they helped families and communities with transition issues?</i>						
a. How have Autism CARES grantees incorporated the issue of transition into their efforts to train professionals, increase awareness and disseminate information, contribute to research and develop evidence-based or consensus-based guidelines and screening tools, support transitions, and facilitate collaboration?	●	●	●			
b. What strategies have Autism CARES grantees found to be successful in improving services and supports for young adults transitioning to adulthood, and what factors have facilitated their success?	●	●	●			
c. What major challenges remain to improving services and supports for young adults transitioning to adulthood? What challenges have Autism CARES grantees faced in addressing these issues?	●	●	●			●
d. How have Autism CARES grantees evaluated their own efforts to support the transition to adulthood for young adults with ASD/DDs and their families, and what were their evaluation results?	●	●	●			
<b>National Resource Centers: facilitate collaboration</b>						
<i>How have National Resource Centers supported Autism CARES grantees (e.g., providing technical assistance, facilitating collaboration, convening Autism CARES grantees, collecting and managing data, producing and disseminating resources, providing a central resource center)?</i>						
a. What strategies have Resource Centers found to be successful in serving grantees, and what factors have facilitated their success?	●		●			
b. What major challenges do Resource Centers face in serving grantees? What challenges do Autism CARES grantees face in using Resource Centers' services? How have Resource Centers and Autism CARES grantees worked to overcome these challenges?	●		●			
c. How have Resource Centers evaluated their own efforts to support Autism CARES grantees, and what were their evaluation results?	●		●			

<sup>1</sup>The word "care" encompasses the full continuum of care for individuals with ASD/DDs (screening, diagnosis, intervention, treatment, transition, etc.).

## Appendix E. Research Program Studies

**Table E.1. Autism Intervention Research Network on Physical Health Studies**

Year Initiated	Study Title	Brief Description
2012	Treatment of Overweight Induced by Antipsychotic Medication in Young People With ASD	This double-blind, placebo-controlled randomized trial aimed to determine whether metformin can decrease weight gain among children with ASD on atypical antipsychotic medication.
2014	Bone Accrual Rates in Boys With Autism Spectrum Disorder	This study aimed to reexamine boys with ASD and controls from an earlier AIR-P research study, evaluate changes in BMD over time, and examine volumetric BMD, microarchitecture, and strength estimates.
2014	Communication Deficits and the Motor System in ASD: Dissecting Patterns of Association and Dissociation Between Them	This study aimed to understand the relationship between motor, language, and social measures in individuals on the autism spectrum by exploring the ATN database.
2014	Effectiveness of Early Intensive Behavioral Intervention Services for Children With Autism Spectrum Disorders	This study aimed to identify variation in the receipt of early intensive behavioral intervention (EIBI) services for children with ASD in relation to the severity of the condition and other characteristics and to calculate quality-adjusted life year gains for children with ASD from EIBI services.
2014	Expanding Capacity of Primary Care To Care for Children With Autism Spectrum Disorder	This study aimed to incorporate an evidence-supported toolkit and clinical pathway for identifying and managing associated physical problems for primary care clinicians by developing a system to support primary care clinicians in caring for children with ASD.
2014	Improving Hospitalizations for Children With ASD: Testing the Cost and Clinical Efficacy of Integrated Behavioral Intervention	This study aimed to implement and test a specific brief applied behavior analysis model for assessing and responding to severe challenging behavior during acute medical and behavioral hospitalization for children with ASD. The study also intended to evaluate the impact of this program by conducting a randomized trial across both medical and psychiatric hospital settings to improve outcomes at the child (e.g., medical/behavioral needs), family (e.g., improved satisfaction with care), provider (e.g., improved morale and sense of efficacy in providing care), and system (e.g., diminished stays, dramatic reduction in costs and noncompensated care) levels.
2014	Relationship Between Subtypes of Restricted and Repetitive Behaviors and Sleep Disturbance in ASD	This study aimed to explore the relationship between insistence on sameness behaviors and repetitive sensory motor behaviors associated with sleep disturbance in individuals with ASD by examining factors related to immune markers and whole blood serotonin. The study also intended to determine how stress response, gastrointestinal disorders, immunity, and the serotonin system interact in ASD.

Year Initiated	Study Title	Brief Description
2015	Characterizing Underserved Populations Participating in the ATN: Evaluating Disparity Through Demographic Influences	This secondary data analysis of populations participating in the Autism Treatment Network aimed to (1) understand the disparity of services found in ASD populations, including those with low socioeconomic status, (2) expand the ability to generalize the results, and (3) share the findings with clinicians, social workers, and the public, leading to earlier diagnosis and treatment of ASD by examining demographic factors that affect the age of diagnosis.
2015	Exploration of the Development and Trajectory of Daily Living Skills in Children and Adolescents With Autism Spectrum Disorder	This study aimed to (1) explore the effects of demographic variables (e.g., age, gender, race, family size) and individual variables (i.e., IQ, ASD symptomatology, internalizing/externalizing symptoms, and language abilities) on the development of daily living skills as measured by the Vineland Adaptive Behavior Scales, 2nd edition, (2) determine if there are subtypes of daily living skills in children and adolescents with ASD, and (3) explore the trajectory of daily living skills development over time using longitudinal data.
2015	Exploration of the Relationship Between Race/Ethnicity and Behavioral Co-Morbidities and Medication Treatment in Children With Autism Spectrum Disorder	This secondary data analysis aimed to understand whether disparities in diagnosis and treatment of behavioral comorbidities in children with ASD exist. It explored the relationship among (1) race/ethnicity, (2) behavioral comorbidities (attention deficit hyperactivity disorder, anxiety, depression, aggression, and disrupted sleep), and (3) the use of medications for those comorbidities in a population of children with ASD.
2015	Extension for Community Healthcare Outcomes (ECHO) Autism	This study aimed to increase provider knowledge, improve clinical practice, and enhance self-efficacy in the care of children with ASD by assessing the impact of a collaborative telehealth intervention using ECHO technology with primary care providers.
2015	Improving Participation in Dental Care and Oral Health Outcomes for Underserved Children With ASD	This study aimed to improve home dental hygiene, oral health, and compliance with dental procedures in underserved populations with ASD by comparing the efficacy of the AIR-P Dental Toolkit with a combined regimen involving the toolkit and a parent-mediated behavioral intervention.
2015	Physical Exercise To Reduce Anxiety in Underserved Children With ASD	This study aimed to provide critical insight into the feasibility and efficacy of a physical exercise intervention to reduce anxiety in children from underserved families. The study also sought to aid in the development of an evidence-based physical exercise intervention toolkit for the treatment of anxiety and other behaviors and improvement of physical health in children with ASD from underserved populations.
2016	Clonidine and Trazodone for Sleep Disturbance in Children With ASD	This study aimed to evaluate the feasibility of conducting a large multisite trial of Clonidine and Trazodone for sleep disturbance to address the general lack of systematic data available to guide practitioners. The study tested the efficacy of Clonidine following a brief sleep hygiene intervention.
2016	Development of a Resiliency Program for Parents of Children With Autism Spectrum Disorder	This study aimed to implement a national parental resiliency program by refining the resiliency treatment program consisting of eight virtual 1-hour group sessions.

Year Initiated	Study Title	Brief Description
2016	First Impressions: Strategies To Enhance Initial Adult Care Visits for Transitioning Youth With ASD	This study aimed to test an intervention designed to prepare youth and their families for the transition to adult care and increase the capacity of physicians and office staff in primary care adult clinics to welcome referred youth with ASD. The study also intended to establish a single point of contact in the adult primary care office by working with community health center pediatric and adult primary care clinics.
2016	A Novel Walking Route Pilot Program Aimed at Promoting Physical Activity in Children With Autism	This study aimed to increase physical activity levels among children with ASD by creating a walking route protocol for the children, determining the feasibility of using walking routes as a new physical activity opportunity, and determining the preliminary efficacy of walking routes for children with ASD who are obese.
2016	Study of Oxytocin in ASD To Improve Reciprocal Social Behaviors	This study aimed to investigate the effects of intranasal oxytocin, a bone anabolic hormone, on bone mineral density (BMD) and structure in children with ASD by conducting BMD assessments.
2016	Two-Phase Study of Probiotics for Quality of Life Through Gastrointestinal (GI) and Emotional Stability in Youth With ASD and Anxiety: Single-Site Pilot Trial Followed by 3-Site RCT	This study aimed to improve quality of life for children with ASD and their parents by exploring the microbiome-mental/physical function connection for ASD, GI dysfunction, and anxiety to potentially improve GI and emotional function.

**Table E.2. Autism Intervention Research Network on Behavioral Health Studies**

<b>Year Initiated</b>	<b>Study Title</b>	<b>Goal of Study</b>
2011	Remaking Recess	Remaking Recess is an intervention that focuses on increasing social engagement between children with ASD (aged 5–11) and their typical peers during the less structured times of the school day. Trained interventionists worked with school staff (particularly the one-on-one aides) to employ strategies aimed to increase the quantity and quality of peer engagement.
2011	Tools for Teachers	The STAT (schedules, tools, and activities for transitions in the daily routine) intervention was designed to improve behavior and transitions among students with ASD in special education classrooms by using behavioral strategies found in functional routines to address classroom management and environmental structures in these classrooms.
2015	Building Better Bridges	This study aimed to identify the barriers to successful transitions between educational systems for children with ASD by conducting focus groups and interviews with parents of children with ASD across different sites (UCLA, UC Davis, U Penn, and U Rochester). The findings informed an intervention to improve transition outcomes for children with ASD and their families.
2015	Mind the Gap	This study aimed to address the critical need to increase access to care for underresourced children with ASD and their families by conducting focus groups and interviews with parents of low-income minority children with ASD across different sites (UCLA, UC Davis, U Penn, and U Rochester) to better understand challenges, barriers, and needs in the community.

**Table E.3. Developmental-Behavioral Pediatrics Research Network Studies**

<b>Year Initiated</b>	<b>Study Title</b>	<b>Brief Description</b>
2011	Developmental-Behavioral Pediatrics Practice Variation in the Diagnosis and Treatment of ADHD and Autism	This study aimed to identify similarities and differences in the assessment and treatment of attention deficit hyperactivity disorder and ASD across sites.
2011	What Is the Scope of Practice for DBPs at Academic Medical Centers	This study aimed to identify the reasons children are referred to developmental and behavioral pediatricians (DBPs).
2012	Extracting Electronic Health Record (EHR) Data on Use of Psychotropic Medications in DBPNet: Costs, Feasibility, and Practice Variation	This study aimed to determine the feasibility of using electronic health record data for research on the clinical practices and variation in clinical practices across sites by extracting data on children’s diagnoses and prescribed psychotropic medications at three DBPNet sites.
2013	Maternal Immune Status and Autism Severity	This study investigated whether mothers of children with ASD have specific antibodies in their blood that predict the severity of ASD in their children. The study was conducted to determine if findings at one DBPNet site could be replicated at two other sites.
2014	Preliminary Validation of PROMIS Self-Report Measures of Peer Relationships and Psychological Stress in Youth With ASD	This study investigated the validity of two measures developed as part of NIH PROMIS when completed by youth aged 12–17 with ASD reading at a third grade level and by their parents.
2014	Preliminary Validation of Selected Pediatric PROMIS Measures in Children With ASD	This study aimed to examine the validity of three National Institutes of Health’s Patient-Reported Outcomes Measurement Information System (known as PROMIS) measures (stress experiences, family involvement, and peer relationship) in children with ASD.
2015	Project EARLY	This study aimed to determine if a family navigator could improve access to ASD diagnostic and treatment services (including early intervention services) and improve outcomes for children who screen positive for ASD at pediatric primary care centers serving low-income communities.
2017	Enhancing Care of Children With Complex Autism	This study aimed to assess the effect of an educational intervention on shared decisionmaking in the care of children with complex ASD.
2018 planned	Autism Diagnostic Observation Schedule (ADOS) Study	This study aimed to identify when the ADOS is needed or not needed to enhance clinical decisionmaking regarding an ASD diagnosis.
2018 planned	A Retrospective Description of the Effectiveness and Adverse Effects of Stimulants and Alpha-2 Agonists Used by Developmental-Behavioral Pediatricians for the Treatment of ADHD in Preschool Aged Children	The primary objectives of this study were (1) to determine the percentage of preschool-aged children with ADHD who responded positively to stimulants and alpha-2 agonists (A2A) based on a review of data in the electronic health record, and (2) to determine if there was a difference in the positive response rate to these two classes of medication. The secondary objectives were to describe the type and frequency of adverse effects to stimulants and A2A when prescribed for the treatment of preschool-aged children for ADHD.

**Table E.4. Health Care Transitions Research Network Studies**

<b>Year Initiated</b>	<b>Study Title</b>	<b>Goal of Study</b>
2014	Autism Diagnostic Odyssey	This study consisted of qualitative interviews with families of children with ASD to describe the odyssey-like process of obtaining an autism diagnosis for their child. It highlighted the need for more consistent and continuous support for individuals with ASD and their families and resources that better represent the diversity of experiences and symptoms associated with ASD.
2014	Family Characteristics and Receipt of Autism	This secondary data analysis of AIR-B data explored the impact of family obligations and parental stress on utilization of intervention services for young children with ASD. It suggested the need for additional supports or alternative service delivery models for mothers of children with ASD, especially those with multiple children in the home, low levels of education, and/or high levels of stress.
2014	The Medical Home and Transition for Youth With Autism	This secondary data analysis of the National Survey of Children with Special Health Care Needs dataset described the association between receiving healthcare transition services and having a medical home for youth with autism. It identified implications and suggestions for increasing the percentage of youth with ASD who receive effective healthcare transition services.
2015	A Health Care Transition Curriculum for Primary Care Residents: Identifying Goals and Objectives	Medical professionals with expertise in healthcare transition were recruited to participate in a survey to assist in the development of a healthcare transition curriculum for primary care physicians using a modified Delphi process to determine curricular goals and objectives, feasibility of developing activities for objectives, and appropriateness of objectives for specified learners.
2015	Stakeholder Perspectives on Research and Practice in Autism and Transition	This study aimed to identify gaps in current research and practice and current research infrastructure needs. Key-informant interviews were conducted with researchers, professionals/clinicians, young adults with ASD, and parents of young adults with ASD.
2015	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 dynamics that lead to poor young adult outcomes. The goal was to help pediatricians understand family concerns and develop anticipatory guidance strategies.
2015	Network Measures of Collaborative Support for Young Adults with Autism	This pilot study aimed to determine the feasibility of using a newly developed longitudinal, dynamic social network survey to measure changes in autism knowledge and social connectivity across time and throughout the transition period.
2015	Social Ecological Correlates in Adult Autism Outcome Studies: A Scoping Review	This scoping literature review characterized the use of social ecological factors in adult ASD outcome studies. It identified understudied areas of research and provided recommendations for future research.

<b>Year Initiated</b>	<b>Study Title</b>	<b>Goal of Study</b>
2015	Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies	This qualitative review gathered the perspectives of youth and young adults with ASD, parents, services providers, and other stakeholders to identify barriers and facilitators to optimal transition outcomes to inform future research, policy, and practice.
2016	A National Research Agenda for the Transition of Youth With Autism	A Delphi survey distributed to HCT-RN Advisory Board members asked them to rate lists of research topics according to perceived importance. The survey asked participants to provide their ratings in multiple phases because the list of topics presented was refined over the course of each round of ratings. The top-rated research topics set the official HCT-RN research agenda.
2016	Psychiatric and Medical Conditions in Transition-Aged Individuals With ASD	This study described the frequency of medical and psychiatric conditions in a large population of diverse, insured, transition-aged individuals with ASD. It underscored the need for physicians to approach ASD as a chronic health condition that requires regular follow-up and routine screening and treatment for medical and psychiatric issues.
2017	Collaborative Improvement Network for Transition in Residency Training	Medicine-pediatrics residency training programs will be recruited for a collaborative improvement network to conduct rapid-cycle improvement tests to refine and enhance the process of implementing the Health Care Transition Curriculum for Primary Care Residents.

**Table E.5. Healthy Weight Research Network Studies**

<b>Year Initiated</b>	<b>Study Title</b>	<b>Goal of Study</b>
2013	Influence of Race/Ethnicity and Sex on Food Selectivity Among Children With Intellectual Disabilities (ID)	Selective eating is linked to poor nutrient intake and may put children at increased risk of adult chronic disease. Research has suggested children with developmental disabilities (DDs) are more food-selective than typically developing children, but race/ethnicity and sex differences have not been explored. Therefore, this study examined food selectivity in a diverse community-based convenience sample of children with IDs aged 3–8.
2014	Family-Based Weight Loss Treatment for ASD (FBT-ASD)	This project implemented a weight-loss treatment that combines parenting skills and weight-loss strategies tailored for parents of overweight and obese children aged 5–13 with a diagnosis of ASD.
2014	Intellectual Disability Is Associated With Increased Risk for Obesity in a Nationally Representative Sample of US Children	This study sought to determine the prevalence of obesity in children aged 10–17 with IDs compared with children without an ID in the U.S. population. The study also compared family meal frequency, physical activity, and sedentary behavior of those with and without IDs.
2014	Promotion of Physical Activity in Adolescents With Intellectual and Developmental Disabilities	This 12-week pilot study explored the use of technology to deliver a physical activity program to 30 adolescents with intellectual and developmental disabilities (IDDs) using video conferencing via tablet computer.
2015	An Adaptive Research Design To Optimize Weight Management Intervention in Young Children	This study aimed to determine the impact of a pilot adaptive weight management intervention on health outcomes for families of 4- to 8-year-olds with ASD and overweight, and to evaluate the acceptability and feasibility of the intervention.
2015	Becoming Obese: The Incidence of Obesity in Early Elementary Grade School Children With Autism Spectrum Disorder (working title)	This study sought to compare incidence of obesity between children with and without ASD in second grade and third grade using data from the Early Childhood Longitudinal Study, Kindergarten cohort.
2015	Contextual Correlates of Regular Physical Activity (PA) in Children With and Without Intellectual Disability (ID)	Researchers conducted an exploratory secondary data analysis using data from the National Center for Health Statistics of the physical activity of youth with and without IDs.
2015	Diet Quality, Parental Perceptions and Weight Gain Among Adolescents With Intellectual and Developmental Disabilities	This study aimed to identify important predictors of diet quality among adolescents with IDDs enrolled in an ongoing treatment trial. Funding from HW-RN allowed the team to leverage a larger NIH-funded study to obtain data on key variables hypothesized to play important roles in influencing diet quality and weight loss for adolescents with IDDs.
2015	The Effect of Age on the Prevalence of Obesity Among U.S. Youth With Autism Spectrum Disorder	This study sought to assess the association between age and the prevalence of obesity among children with and without ASD in the 2011–2012 National Survey of Children’s Health.

<b>Year Initiated</b>	<b>Study Title</b>	<b>Goal of Study</b>
2015	Management of Overweight and Obesity in Children With Autism Spectrum Disorders by Developmental and Behavioral Pediatricians	This project aimed to understand how developmental pediatricians viewed obesity in the population of children with ASD/DDs. Using electronic medical records available from three DBP practices in DBPNet, the study examined the prevalence of obesity in children with ASD/DDs and the extent to which this problem is identified by DBPs. The study examined factors associated with providers' identification of obesity.
2015	Using Dance To Promote Fitness and Well-Being in Adolescent Girls With Intellectual Disabilities	This pilot study tested the feasibility of a 10-week dance intervention for 16–20 adolescent girls with intellectual disabilities (IDs). The intervention included group dance classes at a YMCA and an at-home practice component. The study evaluated changes in cardiorespiratory fitness and participants' physical self-perception.
2016	HW-RN Research Agenda Survey	A survey was developed to obtain input on the HW-RN research agenda. The survey was disseminated to HW-RN members, associate members, newsletter subscribers, and through community networks.
2017	Does Food Addiction Mediate the Relationship Between BMI and Autism Spectrum Disorder?	This study sought to identify possible psychological mechanisms underpinning overeating and its links to increased body mass index in children with ASD.
2017	Exploring Physical Activity Among Preschoolers With Developmental Delay and Autism	This study aimed to (1) develop a reliable observational instrument to measure the physical activity of preschoolers with developmental delay, (2) describe the physical activity behaviors of preschoolers with developmental delays in the preschool setting, and (3) identify associations between the physical activity behaviors of preschoolers with DD and features of the social and physical environment within the preschool setting.
2017	Facilitating Management of Overweight and Obesity in Children With Autism in Primary Care	This project sought to provide an in-depth understanding of the potential barriers and facilitators to the successful implementation of guideline-recommended care or interventions for children with ASD.
2017	How Concerned Are Parents About Obesity in Their Children With ASD? (working title)	This study aimed to use newly released data from the 2016 National Survey of Children's Health to update obesity prevalence estimates and explore how parental concern may differ between parents of children with and without ASD.
2017	Trajectory of Body Mass Index in Children With Autism Spectrum Disorders: A Follow-Up to a Feeding Intervention	This project followed up with participants from a randomized controlled (wait-list) trial on parent training for feeding, in which 42 parents of children with ASD aged 2–7 learned behavioral strategies to increase their children's acceptance of new foods, improve their children's behavior during meals, and teach self-help skills related to meals.

**Table E.6. Field-Initiated Innovative Research Program Studies**

<b>Year Initiated</b>	<b>Study Title</b>	<b>Brief Description</b>
2013	Addressing Health Disparities in Autism Diagnosis, Service Utilization, and School Engagement Among Young Children Living in the Circle of Promise	The goal of this intervention was to increase ASD diagnosis and reduce disparities in diagnosis and service-use outcomes by providing universal access to the diagnostic process to all early-intervention-enrolled children in Boston’s Circle of Promise.
2013	Improving Part C Services and Outcomes for Underserved Children With ASD	This study aimed to increase Part C practitioners’ implementation of early intensive behavioral intervention practices. Providers were trained with a professional development program to improve caregiver-child engagement outcomes and improve child social and communication outcomes.
2013	Toddlers and Families Together: Addressing Early Core Features of Autism	The goal of the study was to test the efficacy of a group-based intervention, Toddlers and Families Together, for families of young children with or suspected of having ASD. The intervention targeted behavior regulation, joint attention, and play to improve maternal health and child developmental outcomes.
2014	Comparative Efficacy of a Self-Directed and Therapist-Assisted Telehealth Parent Training Intervention for Children With ASD	This study aimed to examine the effect of ImPACT Online—a novel, telehealth parent-mediated intervention for children with ASD—on parent and child outcomes to identify moderators and mediators of treatment response and to identify predictors of parent adherence to the program.
2014	Comprehensive Communication Intervention for Minimally Verbal Children With Autism	This study built on the existing Joint Attention, Structured Play, Engagement and Regulation and Enhanced Milieu Teaching (JASP-EMT) intervention to test the effectiveness of a comprehensive communication intervention (i.e., JASP-EMT-Plus, or JEP), which includes a direct teaching component to improve spoken language and social communication, and to reduce the proportion of children with ASD who are minimally verbal at age 5.
2014	A Controlled Trial of Sertraline in Young Children with ASD	This study aimed to assess the effects of sertraline treatment in children with ASD aged 24–72 months.
2014	Does Mindfulness Training Enhance Early Evidence-Based Parent-Coaching Interventions?	This study aimed to develop a novel treatment paradigm that could significantly increase the efficacy of parent training programs and positively affect children, caregivers, and families in both the short term and long term.
2014	Investigation of Teacher-Mediated Toilet Training Using a Manualized Moisture Alarm Intervention	The purpose of this study was to develop a teacher-mediated model of toileting instruction for children with ASD in school settings that incorporates an innovative, manualized moisture pager intervention and compare its efficacy with a standard behavioral treatment.
2014	Parent-Mediated Interventions in Autism: The Search for Meaningful Outcomes	This study aimed to partner with families to redefine “success” in parent-mediated interventions with very young children with ASD. The goal of the study was for parents and families to influence clinical practice and intervention outcomes research.

Year Initiated	Study Title	Brief Description
2014	Screening and Linkage to Services for Autism (SaLSA)	The overall goal of Screening and Linkage to Services for Autism was to test the effectiveness and feasibility of patient navigation to facilitate developmental screening follow-up and referral, diagnostic evaluation, and linkage to services in young minority and disadvantaged populations.

**Table E.7. Secondary Data Analysis Research Program Studies**

<b>Year Initiated</b>	<b>Study Title</b>	<b>Brief Description</b>
2013	Access to Therapy for Children With Autism: A Population-Based Analysis	The purpose of this study was to examine access to therapy services among children with ASD before and after the implementation of the Combating Autism Act of 2006.
2013	Dental Homes for Medicaid-Enrolled Children With ASD in the Iowa I-Smile Program	This study compared dental home and preventive dental care utilization rates for Medicaid-enrolled children by ASD status, examined the factors associated with having a dental medical home, and assessed the outcomes of having a medical home—specifically, the use of an emergency department for nontraumatic dental problems and the use of the operating room for dental treatment under anesthesia.
2013	A Longitudinal Analysis of Maternal Depression and Its Associations With Child Obesity and Health Care Use	This was one of the first U.S. studies to longitudinally examine the associations between maternal depression, child obesity, the moderating effect of children’s healthcare use, and the mediating effect of parenting behaviors using a nationally representative sample.
2013	Trends in Racial and Ethnic Health Care Disparities for Children With Autism/DD	This study examined whether racial and ethnic disparities in healthcare quality, access, and utilization for children with ASD/DDs have diminished over time. The study examined longitudinal population trends and correlates of disparities between Black, Latino, and White children with ASD/DDs.
2014	Making a More Effective and Efficient SCQ	The purpose of the study was to develop a more effective and efficient social communication questionnaire (SCQ) as a developmental screening instrument for early identification of ASD. The revised version of the SCQ addresses measurement bias according to age, gender, and ethnic group, as appropriate.
2014	Patterns and Variations in Emergency Department Visits for U.S. Children With Autism: A Rural-Urban Comparison	The purpose of this study was to determine whether disparities in emergency department utilization exist between children with ASD in rural versus urban settings.
2014	Peer-Victimization of Adolescents With ASD: Filling the Knowledge Gaps to Create Anti-Bullying Interventions	This study aimed to examine peer victimization in adolescents with ASD who spend most of the day in a regular education setting. The study examined relationships between peer victimization and both academic outcomes and ASD symptoms.
2014	Racial and Ethnic Disparities in Diagnostic and Health Services of Children With Developmental Disabilities	This study assessed whether there were significant differences in pathways to diagnosis, early service utilization, and care among racial and ethnic minority children with ASD/DDs. Informed by Goldberg and Huxley’s pathway to care model, this study examined several stages of help-seeking, including parental perceptions of problems, use of primary care services, recognition within primary care, and referral to or use of specialty care services among children with ASD/DDs.
2014	Tough Choices: Autism, Private Health Insurance and Family Out-of-Pocket	The purpose of this study was to develop firmer evidence about the relationships between private health insurance plans and family needs. The researchers hypothesized that families value low-deductible plans and that low-deductible plans expose families to unanticipated expenditures.

Year Initiated	Study Title	Brief Description
2015	Family Adversity and Health Disparities for Young Children With Autism	This study aimed to examine whether racial and ethnic disparities in timing and receipt of diagnosis and treatment for children with ASD vary based upon adverse family experiences.
2015	Medical Care Utilization and Costs Among Transition-Age Young Adult Medicare Beneficiaries With Autism Spectrum Disorder	This study examined healthcare use and costs associated with medical care among transition-aged young adults with ASD who were moving from pediatric to adult care providers. The study also analyzed racial and ethnic differences in utilization and potential disparities between young adults with ASD and young adults with other IDs.
2015	Racial and Ethnic Disparities in Autism Diagnosis and Educational Therapy Utilization: Quantifying the Contribution of Modifiable Mediators	The purpose of the study was to advance understanding of the composition of racial and ethnic disparities in ASD diagnosis and treatment among children using the framework and methods put forth in the Institute of Medicine's 2003 report <i>Unequal Treatment</i> . The study aimed to determine the extent to which geography contributes to racial and ethnic disparities in ASD diagnosis and treatment.

## Appendix F. Summaries of Autism-FIRST and Autism-SDAR Research Studies

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### Autism-FIRST

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#### 1. A Controlled Trial of Sertraline in Young Children With ASD, University of California, Davis

<b>Brief Description of Study</b>	<p><b>Purpose:</b> The study aimed to assess the effects of sertraline treatment in children with ASD from 24 to 72 months old.</p> <p><b>Methods:</b> A randomized double-blind, placebo-controlled trial of sertraline lasting 6 months with primary outcome measures including the Mullen Scale of Early Learning (MSEL) average composite score</p> <p><b>Outcomes:</b> The primary outcome measures will be the changes, from baseline to 6 months, in both the expressive language raw scores and the combined age equivalent scores as measured by the MSEL. Since the study was ongoing and treatment assignments remain double blinded, there were no data on outcomes to report at the time of the evaluation.</p>
<b>Problem or Issue Addressed</b>	<p>Preliminary retrospective data of sertraline treatment and an interim analysis of the first 30 children with ASD who participated in an initial controlled trial of sertraline in fragile X syndrome (FXS) demonstrated remarkable benefit from sertraline versus placebo in language, behavior, and overall development. It is critical to show the benefit of early sertraline treatment that can work synergistically with behavioral interventions to stem the tide of the growing prevalence of ASD in children. This work provides much-needed rigorous evidence of a scientifically validated treatment in young children with ASD and will provide biomarker evidence of who may respond best. There is a great need to develop treatment programs early on in ASD because it is the time to rectify the synaptic abnormalities that are taking place within a developmental window, which will affect the rest of life.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>• Evaluate the benefit of sertraline for treatment of social deficits and language delays in young children with ASD (24–72 months old) in a double-blind, placebo-controlled trial.</li> <li>• Explore biomarkers associated with response to early treatment with sertraline in children with ASD.</li> </ul>

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<b>Study Methodology</b>	<p>This study was a randomized double-blind, placebo-controlled trial of sertraline lasting 6 months with the MSEL expressive language raw scores and the combined age equivalent scores used as the primary outcome measure. Secondary measures included the Preschool Language Scale–5th Edition; Vineland Adaptive Behavior Scales–2nd Edition; Aberrant Behavior Checklist–Community; Preschool Anxiety Scale–Revised; Social Responsiveness Scale–2; Sensory Processing Measure–Preschool; Clinical Global Impression Scale–Improvement; and Visual Analogue Scale with specific target behaviors: anxiety and obsessive-compulsive behaviors; language and communication; and aggression and hyperarousal/hyperactivity. The study also assessed biomarkers associated with ASD and response to sertraline, including brain-derived neurotropic factor (BDNF) levels, allelic variants of BDNF, Serotonin Transporter gene (SCL6A4), and the serotonin-synthesizing tryptophan hydroxylase 2 (TPH2) gene, in addition to cytokine and chemokine profiles both pre- and posttreatment. Researchers aimed to study 20 patients per year for a total of 60 patients in 3 years. Because of recruitment and retention challenges, after 3 years, a no-cost extension period was entered to complete enrollment targets.</p>
<b>Extant Data Sources</b>	<p>This study collected primary data and did not use external data sources.</p>
<b>Specific Populations Targeted</b>	<p>The study targeted children with ASD who were 24–72 months old at enrollment. Participants were required to be receiving behavioral interventions that may have included speech and language therapy and occupational therapy in the community/school for their ASD. Exclusion criteria included current or past selective serotonin reuptake inhibitor (known as SSRI) treatment, other serious comorbid medical disorders affecting brain function and behavior, and uncontrolled seizure disorder. All participants were on a stable medication and therapy regimen for 2 months prior to the start of the study.</p>
<b>Underserved Populations</b>	<p>Efforts were made to enroll underserved populations in the study by giving priority to ethnic and racial minorities. Of the 50 families enrolled to date, 66 percent identified as Caucasian/White, 10 percent as African American/Black, 26 percent as Asian (6 percent Chinese, 14 percent Indian, and 6 percent mixed descent), 8 percent Native American, and 6 percent Pacific Islander. (The sum of these percentages exceeds 100 percent because 12 percent of families identified as mixed race.) Hispanic/Latino families represent 20 percent of the study population to date, with less than half (44 percent) of families identifying as non-Hispanic/Latino White. Besides English, other languages spoken by families at home included Spanish, Chinese, Vietnamese, Telugu, Hindi, Italian, Portuguese, and Tagalog. Of the 50 subjects enrolled to date, 20 percent were female. Response rate for yearly household income was only 32 out of 50 families because some families declined to state this information. Out of the 32 families who reported yearly household income, the average household income was \$75,000–\$100,000, with 25 percent of families reporting \$50,000 or less.</p>
<b>Geographic Areas</b>	<p>Study participants were recruited from Central California. Specifically, participants were recruited from the MIND Institute in Sacramento; Kaiser; Autism programs in the San Francisco Bay Area; and University of California, San Francisco.</p>
<b>Study Limitations Addressed or Considered</b>	<p>The study encountered recruitment challenges because of the refusal of many families to give medications to their young children with ASD. Only a small proportion of parents approached would allow medication use to treat ASD in their children between 2 and 6 years. The study also encountered challenges enrolling an equal number of males and females because of the greater prevalence of ASD among males.</p>

<b>Impact or Outcomes</b>	<ul style="list-style-type: none"> <li>● Sertraline for treatment of social deficits and language delays: Because the study was ongoing at the time of this evaluation, there were no outcome data available. The primary outcome measure will be the changes, from baseline to 6 months, in both the expressive language raw scores and the combined age equivalent scores as measured by the MSEL.</li> <li>● Biomarkers associated with response to early treatment with sertraline: Because the study was ongoing at the time of this evaluation, there were no outcome data on biomarker analysis to report.</li> </ul>
<b>Dissemination Plans</b>	<p>Because the study is still ongoing, there are no manuscripts yet in progress with the actual data. Once the study is finished and unblinded data analyses are completed, a manuscript will be prepared and submitted for publication in a relevant medical journal. The researchers have cited this grant in manuscripts that discuss the use of low-dose sertraline in FXS and in ASD. Once data from this study are analyzed, the researchers will prepare a press release and disseminate study findings at national and international meetings including the International Society for Autism Research, the Society for the Study of Behavioural Phenotypes, American Academy of Pediatrics, etc.</p>
<b>Publications Generated</b>	<p><b>Peer-reviewed articles</b></p> <p>Greiss Hess, L., Fitzpatrick, S. E., Nguyen, D. V., Chen, Y., Gaul, K. N., Schneider, A., ... Hagerman, R. J. (2016). A randomized, double-blind, placebo-controlled trial of low-dose sertraline in young children with fragile X syndrome. <i>Journal of Developmental Behavioral Pediatrics, 37</i>(8), 619–628.</p> <p>Hanson, A. C., &amp; Hagerman, R. J. (2014). Serotonin dysregulation in fragile X syndrome: Implications for treatment. <i>Intractable &amp; Rare Diseases Research, 3</i>(4), 110–117.</p> <p>Hagerman, R. J., Berry-Kravis, E., Hazlett, H. C., Bailey, D. B., Moine, H., Kooy, F., ... Hagerman, P. J. (2017). Fragile X syndrome. <i>Nature Reviews: Disease Primers, 3</i>(17065), 1–19.</p> <p>Ligsay, A., &amp; Hagerman, R. J. (2016). Review of targeted treatments in fragile X syndrome. <i>Intractable &amp; Rare Diseases Research, 5</i>(3), 158–167.</p> <p>Yoo, K. H., Burris, J. L., Gaul, K. N., Hagerman, R. J., &amp; Rivera, S. M. (2017). Low-dose sertraline improves receptive language in children with fragile X syndrome when eye tracking methodology is used to measure treatment outcome. <i>Journal of Psychology &amp; Clinical Psychiatry, 7</i>(6), 00465.</p>

## 2. Screening and Linkage to Services for Autism, University of Colorado, Denver

<b>Brief Description of Study</b>	<p><b>Purpose:</b> The overall goal of Screening and Linkage to Services for Autism (SaLSA) is to test the effectiveness and feasibility of patient navigation to facilitate developmental screening follow-up and referral, diagnostic evaluation, and linkage to services in young minority and disadvantaged populations.</p> <p><b>Methods:</b> The effectiveness of the patient navigation intervention was tested through a randomized controlled trial implemented in an urban safety net system. To increase patient navigation’s potential for widespread application and public health impact, this study also used the RE-AIM framework, a set of criteria for translating research into action, to examine the patient navigation intervention’s reach and implementation in a disadvantaged population and its potential for adoption and maintenance in public safety net systems.</p> <p><b>Outcomes:</b> This study was ongoing at the end of the evaluation period. Study findings will be shared through conference presentations and peer-reviewed journals.</p>
<b>Problem or Issue Addressed</b>	<p>Despite its relatively high rate of occurrence, ASD is underdiagnosed and undertreated in young children, particularly in minority and disadvantaged populations. Although screening for ASD in the primary care setting is recommended as best practice, inadequate attention has been paid to addressing important obstacles to early recognition and treatment of ASD, including barriers to referral after positive screening, completion of diagnostic evaluations, and receipt of treatment. This study hypothesizes that a patient navigation intervention could improve early identification and treatment of young children with ASD.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>• Test the effectiveness of a patient navigator intervention on ASD screening follow-up and referral, diagnostic evaluation, and linkage to services in a minority (primarily Hispanic), disadvantaged population.</li> <li>• Examine the reach, implementation, and potential for adoption and long-term maintenance of autism patient navigation in a minority, disadvantaged population.</li> </ul>
<b>Study Methodology</b>	<p>SaLSA used the RE-AIM framework, a set of criteria for translating research into action, to guide planning and evaluation of autism patient navigation to increase its potential for widespread application and public health impact. The study population represents children aged 16–30 months (estimated 74 percent Hispanic, 90 percent Medicaid eligible) who are seen for well visits in community health centers (CHCs) within Denver Health, a large, urban community healthcare system. In a mixed-methods design, a randomized controlled trial of children with positive M-CHAT-R screens is testing the effectiveness of patient navigation for improving rates and timing, and reducing age of referral, diagnostic evaluation/eligibility determination and initiation and sustained engagement in early intervention services (effectiveness, maintenance). Descriptive and qualitative methods are examining reach in the target population, implementation consistency, and potential for widespread adoption and maintenance. Data collection includes linked electronic records of the CHC system and early intervention provider, patient navigator records, standardized interviews with intervention families, and key informant interviews with clinical and service providers and families.</p>
<b>Extant Data Sources</b>	<p>The study uses administrative data from the Denver Community Health Services Department of Denver Health and links the data to administrative data of Rocky Mountain Human Services. The linked dataset will be used to assess the effectiveness of the patient navigation intervention. Primary data collection includes patient navigator records and structured interviews with clinical service providers and families.</p>

<b>Specific Populations Targeted</b>	All children aged 16–30 months who are seen for a well visit in a Denver Health CHC who have a positive M-CHAT-R screening test recorded in their electronic health record are being randomized to the intervention or control group. Children aged 18–27 months were the primary population recruited as this time period aligns with well-child visits at Denver Health.
<b>Underserved Populations</b>	Of children seen at Denver Health for well visits, 90 percent are Medicaid eligible and 74 percent of their families identify as Hispanic. In preliminary results at the time of the evaluation, 94 percent of randomized children were enrolled in Medicaid, 60 percent identified as Hispanic, 20 percent identified as Black or African American, and 24 percent of families spoke Spanish as their primary language. To ensure the project’s cultural competence, a community-based network of Spanish-speaking families with CSHCN collaborated on planning and evaluation.
<b>Geographic Areas</b>	Study participants were primarily recruited from Denver Community Health Services, a large, urban community health center system, with 9 primary care clinics and 17 school-based health centers in the city of Denver.
<b>Study Limitations Addressed or Considered</b>	<p>Although the CHCs recruiting patients into the study had planned to implement the screening tool in their routine workflow before the start of the trial, they experienced substantial delays and difficulty. Therefore, the study team spent much effort providing additional support to the recruitment centers in their efforts to implement the M-CHAT-R screener. This delayed the timeline for the study; however, the additional support provided by the study team was beneficial in enhancing the capacity of the recruitment centers to screen underserved children in the Denver region for ASD.</p> <p>Other challenges to implementing the M-CHAT-R screener follow:</p> <ul style="list-style-type: none"> <li>● Patients frequently miss their 18- and 24-month well child visits</li> <li>● Incomplete M-CHAT-R implementation and documentation on the part of the staff at the recruitment facility</li> <li>● Replacement of the electronic health records system 1 year into the trial</li> <li>● Staff turnover at recruitment sites</li> <li>● Additional requirements for children in foster care</li> </ul>

<p><b>Impact or Outcomes</b></p>	<p><b>Research outcomes</b></p> <ul style="list-style-type: none"> <li>● <b>Effectiveness of autism patient navigation, SaLSA.</b> Randomization and enrollment of trial participants was ongoing at the time of this evaluation, so there were no outcome data on the intervention’s effect on occurrence and timing of ASD diagnosis, referral, and linkage to care.</li> <li>● Reach, implementation, and potential for adoption and long-term maintenance of autism patient navigation for young, underserved, Hispanic children. In preliminary results, children whose parents consent to patient navigation are representative of all children randomized to this group with regard to M-CHAT score, age, gender, ethnicity, race, and insurance status, indicating successful reach. The patient navigator has successfully implemented a wide range of activities to support families who identified scheduling, information, and transportation as their most important needs. Navigator assistance included contacting the early intervention provider on behalf of the family; making reminder calls to the family; educating parents about autism, M-CHAT, testing, and early intervention; providing bus tokens or taxi cab fare; and communicating with cab companies for non-English-speaking families. Structured interviews with the navigator, clinic and early intervention providers, and families are currently being conducted to examine the feasibility and acceptability of the intervention and perceived reasons for success or failure.</li> </ul> <p><b>Other study outcomes and impacts</b></p> <ul style="list-style-type: none"> <li>● <b>M-CHAT-R screening test was less sensitive and more specific than expected.</b> Use of the M-CHAT-R screening tool in this study population found screen positive rates lower than those reported in a similar Hispanic population (Windham et al., 2014<sup>a</sup>) but consistent with the rates found in English-speaking populations, reported by M-CHAT-R authors (Robins, Fein, &amp; Barton, 2009). Therefore, a 9-percent screen positive rate accurately reflects rates in a young, underserved, Hispanic population (versus 21 percent as reported by Windham et al., 2014). The rate of M-CHAT-R/F positive results after an initial positive screen is higher than anticipated (33 percent versus 20 percent in previous studies). This suggests that while the initial screening test is less sensitive than anticipated, it is more specific with fewer false positives.</li> <li>● <b>Lessons learned from implementing M-CHAT-R screening tool in CHCs.</b> The study team learned that implementing the M-CHAT-R screening tool in CHCs required more clinical staff support and training than initially anticipated. The support that was ultimately successfully included 19 training sessions for clinic staff and providers, individualized feedback to providers, education about the referral process and dual diagnoses in ASD, outreach to families for scheduling well visits, and chart audits with feedback to clinics about their screening rates.</li> <li>● <b>Revisions to the M-CHAT-R for use at CHCs.</b> The format of the M-CHAT-R screener was revised to reduce errors that could lead to false-negative results and to clarify the identification of scores prior to data entry into the electronic health records. These revisions were reviewed and approved by Denver Health’s internal committee on form development. The study team created and implemented a scoring template overlay to assist clinic staff in more accurately scoring the results of the screening tool.</li> </ul>
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<p><b>Dissemination Plans</b></p>	<p><b>Manuscripts planned</b></p> <ul style="list-style-type: none"> <li>● Feasibility and acceptability of autism patient navigation in an urban, safety net system</li> <li>● Effect of patient navigation on referral for evaluation for ASD, receipt of evaluation, and initiation of early intervention services in young children who screen positive for ASD</li> <li>● Challenges in implementing the M-CHAT for ASD screening in an urban, safety-net system</li> </ul> <p><b>Other dissemination plans</b></p> <ul style="list-style-type: none"> <li>● Oral presentation by K. Hightshoe (Project Coordinator) and Silvia Gutiérrez-Raghunath (Patient Navigator) on Autism Patient Navigation for Low Income Families with Young Children at the Rocky Mountain Early Childhood Conference 2018 (Denver, CO, March 2018), a conference designed to meet the professional development needs of early childhood practitioners</li> <li>● Webinar through AUCD Early Intervention Special Interest Group webinar series, to be coordinated by Dr. C. Rosenberg (coinvestigator) of JFK Partners</li> </ul>
<p><b>Publications Generated</b></p>	<p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Rosenberg, S. A., Robinson, C. A., Dickinson, L. M., Hambidge, S. J., Dooling-Litfin, J. K., Hightshoe, K. D., ... DiGuseppi, C. G. (2015, July). <i>Screening and linkage to services for autism (SaLSA)</i>. Poster presented at Autism CARES Meeting: Implementing Evidence-Based Practices in Real World Settings, Bethesda, MD.</p>

<sup>a</sup> Windham, G. C, Smith, K. S., Rosen, N., Anderson, M. C., Grether, J. K., Coolman, R. B., & Harris, S. (2014). Autism and developmental screening in a public, primary care setting primarily serving Hispanics: Challenges and results. *Journal of Autism and Developmental Disorders*, 44(7), 1621–1632.

### 3. Parent-Mediated Interventions in Autism: The Search for Meaningful Outcomes, University of Colorado, Denver

<p><b>Brief Description of Study</b></p>	<p><b>Purpose:</b> The study was designed to partner with families to redefine “success” in parent-mediated interventions with very young children with ASD with the aim of influencing clinical practice and intervention outcomes research.</p> <p><b>Methods:</b> This study was guided by the principles of community-based participatory research (CBPR) and strategies of community engagement. All aspects of the study were overseen by the Research Team and a Community Advisory Council (CAC; six families with a child with ASD who had participated in an early intervention). To address the four aims of this project, multiple methods were used. First, parents of very young children with ASD who had already participated in parent-mediated interventions were retrospectively interviewed and qualitative methods used to determine themes/outcomes that were meaningful and functional to them. Then the research team and the CAC collaborated to select a battery of outcome measures that matched these themes for the prospective phase of the study. Finally, the measures were implemented in a prospective mixed-methods phase to determine the impact of an ongoing real-world parent-mediated intervention based on the strategies of the Early Start Denver Model (ESDM) with 40 parent-child dyads (40 parents + 40 children). The impact of this intervention is being measured on family, parent, parent-child, and child outcomes in a robust within-subjects manner across four time points (two preintervention and two postintervention).</p> <p><b>Outcomes:</b> Through the collaboration of the research team and the CAC, six themes were identified from the retrospective qualitative phase of the study that reflect families’ experience with a parent-mediated intervention (Aim 1). A battery of outcome measures was selected from the existing literature through an extensive collaborative process between the research team and the CAC (Aim 2). The measures operationalized the six themes and used a family-focused strengths-based language. The CAC helped ensure the outcome measures were also feasible to complete. At the end of the evaluation period, recruitment for the prospective mixed-methods phase of the study was ongoing (Aims 3 and 4). At that time, researchers had recruited 35 dyads into the study. The researchers planned to continue recruitment through early 2018, at which point they anticipated the 4 time points would be completed on 40 dyads (40 children + 40 parents). Results are expected in fall 2018.</p>
<p><b>Problem or Issue Addressed</b></p>	<p>The lack of understanding of the impact on parents and families of parent-mediated intervention with very young children with ASD creates a barrier to adequate support of child and family well-being. This study sought to advance knowledge of parent-mediated interventions for young children with ASD, providing a common language and consistent set of measures for research in the important area of family well-being, while supporting more extensive engagement of families and the need to consider the child within the family context in clinical practice paradigms.</p>

<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>● Explore themes in family narratives related to their experiences of parent-mediated early interventions, including a Spanish-speaking group in addition to the original English-speaking group; specifically, to understand meaningful, family-focused outcomes of early intervention.</li> <li>● Use the themes identified in Aim 1 and feedback from the CAC to guide selection of meaningful parent and family outcome measures.</li> <li>● Assess the effect of a “real-world” parent-mediated intervention using the strategies of ESDM on the retrospectively derived, CAC-approved, child, parent, and family outcome measures.</li> <li>● Explore the interactions among parent, family, and child outcomes.</li> </ul>
<b>Study Methodology</b>	<p>This project was designed to partner with families of young children with ASD as key stakeholders and to answer the research questions within a real-world clinical setting. Researchers have relied on principles of CBPR and strategies of community engagement to advance knowledge and development of parent-mediated interventions for children with ASD. The collaborations among the members of the three project teams (i.e., a research team to direct the study, a clinical team to implement the study, and a community advisory council to oversee all aspects of the study) have determined the course of the study.</p> <p><b>Aim 1:</b> Families who previously participated in a parent-mediated intervention (either the ESDM or Hanen More than Words program) were recruited for telephone interviews and focus groups to discuss their experiences. This was a retrospective qualitative study. Responses were coded to ascertain content themes. Collaboration between the research team and the CAC guided the development of the interview content and the final determination of themes that arose. Families whose primary language is Spanish participated in the same process under the supervision of a native-Spanish-speaking researcher.</p> <p><b>Aim 2:</b> Outcome measures were chosen from the research literature that matched themes determined in Aim 1. Collaboration between the research team and the CAC determined the final battery of measures that have reliability and validity as indicated in the research literature and use of strengths-based family centered language, and reduce participant burden by being able to be completed more quickly and occur in mixed modalities.</p> <p><b>Aims 3 and 4:</b> Using a one-group, multiple pre- and posttest study design, 40 parent-child dyads (40 parents + 40 children) completed the assessment measures during at 4 time points: (1) baseline, when a child is entered onto the waitlist, 3 months prior to the intervention; (2) pretest, at the start of the intervention, (3) posttest, at the end of the intervention; and (4) follow-up, after 3 months of no contact with the intervention. During the intervention, parent-child dyads participated in 12 weekly intervention sessions of 1 hour each with their regular provider. Parents were coached to use the strategies of ESDM to address child skills and behaviors.</p>
<b>Extant Data Sources</b>	<p>This study collected primary data.</p>
<b>Specific Populations Targeted</b>	<p>Study participants were families with a child between 12 and 60 months who had a diagnosis of ASD and requested enrollment in an ongoing parent mediated intervention (“Parent Coaching in the Strategies of ESDM”) at Children’s Hospital Colorado. Families were enrolled in the study soon after they asked to be placed on the wait list for the clinical intervention.</p>

<p><b>Underserved Populations</b></p>	<p>Over the course of the study, the CAC has included a total of nine parents: seven mothers and two fathers; seven Caucasian, three Hispanic, two self-identified as a racial minority; five for whom English was not their first language.</p> <p><b>Participants in Aim 1:</b> Of the 16 participant parents, the majority were White and female; however, 50 percent of their children were served by Medicaid. Of note, researchers added a replication of Aim 1 with a primarily Spanish-speaking population (current <math>n = 9</math>), which is being led by a native-Spanish-speaking researcher and is in process.</p> <p><b>Participants in Aims 3 and 4:</b> Of the current 35 child participants, 54 percent are Caucasian, 3 percent Asian, 11 percent biracial, 9 percent Black/African American, and 23 percent identified as Hispanic/Latino. This race/ethnicity breakdown fairly closely matches that of the Metro area from which the hospital draws. Of the 35 parent participants, 43 percent reported household incomes below \$50,000, and 37 percent indicated they had not completed college. Issues of cultural and linguistic competency are addressed at least monthly in the weekly research team and clinical team meetings.</p>
<p><b>Geographic Areas</b></p>	<p>Study participants were recruited from the Children’s Hospital Colorado or JFK Partners (Colorado’s LEND/UCEDD), which are both in Aurora, Colorado, and primarily serve the broader Denver Metro/“Front-Range” area.</p>
<p><b>Study Limitations Addressed or Considered</b></p>	<ul style="list-style-type: none"> <li>● Commitment to the principles of CBPR and community engagement has necessitated additional time to ensure the research team truly partnered with the CAC. While serving this commitment altered the study’s timeline (e.g., more time and effort needed to determine the measurement battery as specified in Aim 2), it also enriched the outcomes by providing a better understanding of the needs of the participant population and meaningful outcomes.</li> <li>● Using a “real-world” clinical team and patient population introduced variables outside the research team’s control but enriched both the research and the clinical outcomes. For example, the timeline was negatively affected by turnover in the hospital’s scheduling staff, leading to delays in the research team’s recruitment of participants because of an inability to effectively predict the timing of the start of intervention for each parent-child dyad. However, the research outcomes will be more generalizable to other clinical groups and the clinical intervention itself has been strengthened.</li> <li>● While all the above increases the likelihood the study’s results will be generalizable and meaningful to other populations, there remain some limits to the generalizability of study outcomes. For example, the results may not be generalizable to non-English- speaking families, rural groups, and families and providers with less education.</li> </ul>

<p><b>Impact or Outcomes</b></p>	<p><b>Research outcomes</b></p> <ul style="list-style-type: none"> <li>● <b>Themes in family narratives related to experience with parent-mediated early interventions.</b> Work on Aim 1 illuminated six key themes, outcomes, and supports that families who participated in a parent-mediated intervention with their young child with ASD feel are meaningful and functional.</li> <li>● <b>Selection of meaningful parent and family outcome measures.</b> Aim 2 operationalized the themes determined in Aim 1 into a battery of measures to examine meaningful outcomes to address Aims 3 and 4 that are research reliable and valid and have acceptable burden and strengths-based content.</li> <li>● Work on Aims 3 and 4 was in progress as of the end of the evaluation period (December 2017).</li> </ul> <p><b>Other study outcomes</b></p> <ul style="list-style-type: none"> <li>● During the study, the researchers made alterations to the clinical intervention based on feedback from the CAC.</li> <li>● Materials developed for this intervention may be useful outside the current study.</li> <li>● The clinical team conducted national trainings on the parent-mediated interventions in autism.</li> </ul>
<p><b>Dissemination Plans</b></p>	<p><b>Manuscripts in progress</b></p> <p>Kaiser, K., Crain, H., Folan, A., Hepburn, S., Moody, E., &amp; Griffith, E. M. (in review). <i>Parent perspectives on meaningful outcomes of early intervention for children with autism spectrum disorder.</i></p> <p>Additional products planned include manuscripts around the Spanish-speaking group in Aim 1b, the process of the collaboration between the research team and the CAC, the outcomes from the final phase of the study addressing Aims 3 and 4, and the changes suggested by this work to the clinical service. The CAC has requested local presentations and articles in parent-accessible publications.</p>

<b>Publications Generated</b>	<p><b>Peer-reviewed articles</b></p> <p>Wainer, A. L., Hepburn, S., &amp; Griffith, E. M. (2016). Remembering parents in parent-mediated early intervention: An approach to examining impact on parents and families. <i>Autism</i>, 21(1), 5–17. doi:10.1177/1362361315622411</p> <p><b>Other publications</b></p> <p>Hepburn, S., &amp; Griffith, E. M. (in press). Using technological innovations to support parents of young children with autism. In M. Siller and L. Morgan (Eds.), <i>Handbook of parent-implemented interventions for very young children with autism</i>.</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Kaiser, K., Folan, A., Hepburn, S., &amp; Griffith, E. M. (2015, July). <i>Partnering with families to determine meaningful outcomes of parent mediated interventions for young children with autism spectrum disorder</i>. Presented in Poster Symposia at the 2015 Autism CARES Grantee Meeting: Implementing Evidence-Based Practices in Real-World Settings, hosted by MCHB, Washington, DC.</p> <p>Griffith, E. M., &amp; Hepburn, S. (2015, November). Invited session: <i>Extending the research of evidence-based practices in autism intervention</i>. Presented at the ASHA (American Speech and Hearing Association) Conference.</p> <p>Griffith, E. M., Kaiser, K., Folan, A., Crain, H., &amp; Hepburn, S. (2017, July). <i>Collaborating with community partners: Impacts on the course of research</i>. Presented in Poster Symposia at the 2017 Autism CARES Grantee Meeting: Pathways to Progress, hosted by Maternal and Child Health Bureau, Washington, DC.</p> <p><b>Other Products</b></p> <p><i>Parent Guidance for ESDM Sessions</i>, handouts for use in the clinical service (being revised)</p> <p><i>Guide to Content for a 12-Session Parent Coaching series “Strategies of ESDM”</i> (being revised)</p>
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#### 4. Addressing Health Disparities in Autism Diagnosis, Service Utilization, and School Engagement Among Young Children Living in the Circle of Promise, University of Massachusetts, Boston

<p><b>Brief Description of Study</b></p>	<p><b>Purpose:</b> The goal of this intervention was to increase ASD diagnosis and reduce disparities in diagnosis and service use outcomes by providing universal access to the diagnostic process to all early intervention-enrolled children in Boston’s Circle of Promise (CoP).</p> <p><b>Methods:</b> Routine, early, multistage screening and assessment were implemented in CoP-serving early intervention agencies. Three phases of the study included provider training in a standardized, multistage screening process; assessment of service utilization of children diagnosed in phase one; and a parent-focused intervention to empower and equip parents to care for and advocate for their children with an ASD diagnosis.</p> <p><b>Outcomes:</b> Results provide evidence that in the context of an early intervention-based, multistage screening protocol for ASD, rates of ASD detection among early intervention-participating children were increased (from 2.6 percent to 12.9 percent of the served populations). Evidence of reduced disparities was apparent with children diagnosed through the program being significantly more likely to be English learners, to be parent-identified as racial minorities, or to qualify for public insurance (as a proxy for income level). The mean age at diagnosis (27 months) represented a significant reduction from mean diagnostic age in past samples. Findings support the importance of universal screening even in the absence of parent concern; 36 percent of diagnosed cases had parents who were not concerned in the first stage of screening and therefore may have been missed in the absence of universal screening (i.e., relying instead on surveillance and screening based on parental concern). Additional findings outline areas for further systemic improvement at multiple points along the pipeline from screening to diagnosis to receipt of postdiagnostic intervention services.</p>
<p><b>Problem or Issue Addressed</b></p>	<p>Early diagnosis and intervention are crucial to ensuring optimal long-term outcomes for children diagnosed with ASD, yet there are substantial disparities in rates and age of diagnosis. Children from racial and ethnic minority backgrounds are less likely to be diagnosed (Mandell et al., 2009) and are diagnosed on average 1–2 years later than White children (Mandell et al., 2002; Shattuck et al., 2009). These delays in diagnosis limit access to autism-specific early treatments (Liptak et al., 2009). The disparity is larger for poor children and English language learners (Durkin et al., 2010; Kogan et al., 2009).</p> <p>Health disparities in ASD diagnosis have grave implications for children in the CoP, 98 percent of whom are children of color. In this study, routine, early, multistage screening and assessment were implemented in CoP-serving early intervention agencies. The goal of this intervention was to increase ASD diagnosis and reduce disparities in diagnosis and service use outcomes by providing universal access to the diagnostic process to all early intervention-enrolled children.</p>
<p><b>Goals</b></p>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>● Improve early detection of ASD for children in early intervention living in the CoP, a geographic zone in Boston targeted for resource mobilization efforts because of high rates of poverty and social risk factors.</li> <li>● Enhance family engagement during the transition to preschool for the families of these children.</li> <li>● Identify early ASD-specific disparities in service utilization and determine whether such disparities shrink in the context of an improved screening and assessment process.</li> </ul>

<b>Study Methodology</b>	<p>This study was conducted in three phases:</p> <p>In Phase 1, early intervention providers were trained to implement a standardized, multistage screening process and researchers evaluated screen-positive referred children to diagnose ASD; the multistage screening protocol was embedded in the early intervention services the children received prior to the study.</p> <p>In Phase 2, children diagnosed with ASD through this assessment protocol were followed to assess their service utilization over the remaining course of their early intervention enrollment and during the first 6 months following their transition into public school or alternative preschool services at age 3.</p> <p>In Phase 3, the study developed and tested a parent-focused intervention (2–3 sessions) aimed at empowering and equipping parents to successfully advocate for their children in the public school context as they navigate the special education system.</p>
<b>Extant Data Sources</b>	<p>This study collected primary data and did not use external data sources.</p>
<b>Specific Populations Targeted</b>	<p>The intervention targeted early intervention providers, children (aged 14–33 months) who participate in CoP-servicing early intervention agencies, and their parents or guardians.</p>
<b>Underserved Populations</b>	<p>The study intervention aimed to reduce health disparities in rates and age at diagnosis for children (aged 14–33 months) who are poor, English language learners, and/or identify as ethnic/racial minorities.</p>
<b>Geographic Areas</b>	<p>The CoP is a geographic zone in Boston targeted for resource mobilization efforts because of high rates of poverty and social risk factors.</p>
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>● In response to learning about high turnover among early intervention providers, the researchers developed a video training for the screening process, so new early intervention providers can access training more easily.</li> <li>● In response to observing the variability across early intervention providers in their preparedness to have difficult conversations with families about ASD-related concerns, the authors developed and conducted multiple training sessions with early intervention providers on “Holding Difficult Conversations With Families.” These trainings were aimed at developing early intervention specialists’ skills and comfort in discussing developmental concerns with families, drawing on motivational interviewing and stages of change principles.</li> </ul>

<p><b>Impact or Outcomes</b></p>	<ul style="list-style-type: none"> <li>● <b>Improve early detection of ASD for those participating in early intervention residing in the CoP.</b> The study's first goal was to improve early detection of ASD for children participating in early intervention, particularly those residing in the CoP and more generally those at risk for health disparities that relate to racial minority status, English-language-learner status, or household poverty status. Results provide evidence that an early intervention-based, multistage screening protocol for ASD results in improved rates of detection of ASD. The sample of children diagnosed with ASD through this protocol show significantly greater representation of racial minorities, English language learners, and children from low-income households, providing evidence that the program reduces previously documented health disparities. The mean age at diagnosis (27 months) also reflects a significant reduction from mean diagnostic age in past samples.</li> <li>● <b>Improve family engagement during transition from early intervention to preschool.</b> A second goal of the study was to improve family engagement during the transition from early intervention to preschool-based ASD services. In-depth, quarterly interviews were conducted with participating families to gather information about levels of engagement, satisfaction, and related constructs with regard to families' involvement in both early intervention-based services and school-based services for ASD. These findings were used to develop a two-session, motivational interviewing-based, parent-focused intervention to support families making the transition from early intervention to school-based special education services. Analyses are underway to examine whether families in the experimental versus control arms of the resulting randomized controlled trial showed greater engagement, empowerment, communication with school staff, or satisfaction with school-based services.</li> <li>● <b>Identify early ASD-specific disparities in utilization of ASD services.</b> The third study aim was to identify early ASD-specific disparities in utilization of ASD services in the context of the early intervention-based, multistage screening and assessment process. Preliminary analyses suggest that while overall disparities may be reduced relative to other diagnostic contexts, English-language-learner children and children whose parents were born outside of the United States report particular difficulty receiving postdiagnostic services; on average, these children received 6.7 hours/weekly of intervention relative to 12 hours/weekly of ASD-related services for children of U.S.-born, English-proficient parents. Other disparities persist in relation to lag time between screening and assessment stages. Future research will examine early intervention provider and contextual factors that may account for these persisting differences.</li> </ul>
<p><b>Dissemination Plans</b></p>	<p><b>Manuscripts in progress</b></p> <p>Carter, A. S., Vera, J. D., Oosting, D., &amp; Sheldrick, R. C. (in progress). <i>Challenging behaviors in toddlers in early intervention: Measurement equivalence and increased risk.</i></p> <p>Eisenhower, A. S., Martinez, F., Fettig, A., Frenette, E., Ozit, A., &amp; Carter, A. S. (in progress). <i>Preliminary evidence for a community-based, early intervention autism screening model.</i></p> <p>Fettig, A., Eisenhower, A. S., Levinson, S., Carter, A. S., Sheldrick, R. C., Benneyan, J., &amp; Mackie, T. (in progress). Perspectives on improving early screening and reducing disparities in the early detection of autism spectrum disorders: A multidisciplinary approach.</p> <p>Kiss, I. G., Esmaili, N., Sheldrick, R. C., Carter, A. S., &amp; Benneyan, J. (in progress). <i>Diagnostic stability of autism spectrum disorder from a Markov state-transition perspective.</i></p> <p>Sheldrick, R. C., Frenette, E., Vera Jones, J. D., Mackie, T., Carter, A. S., Hoch, N., ... Fettig, A. (in progress). <i>Screening pathways to autism spectrum disorder diagnoses within an early intervention context.</i></p>

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**Publications  
Generated****Peer-reviewed articles**

- Fettig, A., Barton, E. E., Carter, A. S., & Eisenhower, A. S. (2016). Effects of e-coaching on function based intervention. *Infants and Young Children, 29*(2), 130–147.
- Fettig, A., Schultz, T. R., & Sreckovic, M. A. (2015). Effects of coaching on the implementation of functional assessment-based parent intervention in reducing challenging behaviors. *Journal of Positive Behavior Interventions, 17*(3), 170–180.
- Sheldrick, R. C., Benneyan, J., Kiss, I., Briggs-Gowan, M., Copeland, W., & Carter, A. S. (2015). Thresholds and accuracy in screening tools for early detection of psychopathology. *Journal of Child Psychology and Psychiatry, 56*(9), 936–948.

**Peer-reviewed scholarly conference presentations**

- Carter, A. S. (2015, July). *Addressing health disparities in autism spectrum disorder identification and service receipt: Changing systems of care*. Invited Grand Rounds presentation, Columbia University Medical School, New York, NY.
- Carter, A. S. (2015, October). *Addressing health disparities in autism spectrum disorder identification and service receipt: Changing systems of care*. Invited Grand Rounds presentation, Cornell Medical School, New York, NY.
- Carter, A. S. (2015, November). *Addressing health disparities in autism spectrum disorder identification and service receipt: Changing systems of care*. Invited Grand Rounds presentation, University of Connecticut Health Sciences Center, University of Connecticut Medical School, Farmington, CT.
- Carter, A. S. (2015a, December). *Classification of autism spectrum disorders in infants and toddlers*. Invited presentation at the World Association of Infant Mental Health, Israeli affiliate, Akko, Israel.
- Carter, A. S. (2015b, December). *Screening for autism spectrum disorders (ASD) and broader infant-toddler mental health needs*. Invited presentation at the Soroka Medical Center, Beersheba, Israel.
- Carter, A. S. (2015c, December). *Screening for autism spectrum disorders (ASD) and broader infant-toddler mental health needs*. Invited presentation at the University of Haifa Department of Psychology and Occupational Therapy, Haifa, Israel.
- Carter, A., Eisenhower, A., Martinez-Pedraza, F., & Fettig, A. (2015, July). *Addressing health disparities in early diagnosis and service receipt: Implementing two-stage screening in early intervention*. Poster presented at the ASD CARES Convention for HRSA Grantees, Bethesda, MD.
- Carter, A., Eisenhower, A., Fettig, A., Martinez-Pedraza, F., & Sheldrick, R. (2016, February). *Addressing ASD health disparities in early diagnosis and service receipt: Implementing two-stage screening in early intervention*. Poster presented at the Conference on Research Innovations in Early Intervention, San Diego, CA.
- Carter, A. S. (2016, April). *Addressing health disparities in autism spectrum disorder identification*. Invited Grand Rounds presentation, Department of Psychiatry, College of Medicine, University of Illinois, Chicago, IL.
- Eisenhower, A. (2016, August). *From screening to schooling: Maximizing the benefits for children with ASD*. Invited presentation upon receipt of the Sara Sparrow Early Career Award at the 123rd Annual Convention of the American Psychological Association, Denver, CO.
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**Publications  
Generated  
(continued)**

**Peer-reviewed scholarly conference presentations (continued)**

- Eisenhower, A. (2016, November). *From screening to schooling: Maximizing the benefits for children with ASD, a tribute to Bruce Baker*. Invited presentation at the UCLA Psychology Department Celebration in Honor of Dr. Bruce Baker, University of California Los Angeles, CA.
- Feldman, M., Buitrago, L., Eisenhower, A., Sheldrick, R. C., & Carter, A. (2017, May). *Examining disparities in duration of screening-to-diagnosis time in a multistage, early intervention--based screening protocol for ASD*. Presented at the International Meeting for Autism Research (IMFAR), San Francisco, CA.
- Fettig, A., & Barton, E. (2015, March). *Function-based intervention with e-coaching in reducing challenging behaviors during home visits*. Session presented at International Conference on Positive Behavior Support, Boston, MA.
- Fettig, A., Carter, A. E., Eisenhower, A. E., & Martinez-Pedraza, F. (2015, December). *Supporting toddler's social emotional development and reducing challenging behaviors: Tools for early intervention providers*. Poster presented at ZERO TO THREE National Training Institute, Seattle, Washington.
- Fettig, A., Fox, L., & Barton, E. (2016, March). *Achieving implementation fidelity: Coaching early education professionals and parents to use PBIS*. Session presented at Association for Positive Behavior Support Conference, San Francisco, CA.
- Frenette, E., Vera, J. D., Sheldrick, R. C., Mackie, T., Tan, C., Fettig, A., Eisenhower, A., & Carter, A. S. (2017, May). *Screening pathways to autism spectrum disorder diagnoses within an early intervention context*. Poster presented at the International Meeting for Autism Research (IMFAR), San Francisco, CA.
- Giserman Kiss, I. & Carter, A. S. (2015, May). *Developing ASD screening criteria for the Brief Infant Toddler Social Emotional Assessment (BITSEA)*. Poster presented at the 14th Annual International Meeting for Autism Research, Salt Lake City, UT.
- Giserman Kiss, I., Martinez-Pedraza, F., & Carter, A. S. (2016, May). *Using the BITSEA to screen for ASD in young diverse populations*. Presented at the 15th Annual International Meeting for Autism Research, Baltimore, MD.
- Giserman Kiss, I., Martínez-Pedraza, F., Feldman, M., Eisenhower, A., & Carter, A. (2015, December). *Use of training video to aid in implementation of autism screening in early intervention*. Poster Presentation at the Zero to Three National Training Institute, Seattle, Washington.
- Martinez, F. P., & Eisenhower, A. (2014, December). *The power of mentor-mentee relationships to propel meaningful research: Efforts to reduce health disparities in early screening for autism*. Annual University Research Celebration, UMass Boston.
- Martínez-Pedraza, F., & Carter, A. (2015, December). *Implementing a multi-stage autism screening model in early intervention settings serving culturally and linguistically diverse children*. Presented at the Zero to Three National Training Institute, Seattle, Washington.
- Martinez Pedraza, F., Maye, M. P., & Carter, A. S. (2015, May). *Moderating effects of spoken language in the home on the relations between age at referral and ASD symptoms and expressive language for young children at risk for ASD screened in early intervention*. Poster presented at the 14th Annual International Meeting for Autism Research, Salt Lake City, UT.
- McCullough, A., Fettig, A., Eisenhower, A., Carter, A., Santos, K., & Frenette, E. (2017, May). *Multi-faceted ASD screening partnership: Supporting family-centered practices*. Panel session presented at the Massachusetts Early Intervention Conference.
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<b>Publications generated (continued)</b>	<p><b>Peer-reviewed scholarly conference presentations (continued)</b></p> <p>Murphy, J., Corkum, K., Carter, A., Eisenhower, A., &amp; Fettig, A. (2016, May). <i>Engaging in difficult conversations with parents about suspected autism: Lessons learned from an EI agency-university early detection initiative</i>. Panel session presented at the Massachusetts Early Intervention Conference, Marlborough, MA.</p> <p>Oosting, D., Eisenhower, A., Frenette, E., Sheldrick, R. C., &amp; Carter, A. S. (2017, April). <i>Sociodemographic indicators of health disparities: Parent and provider concerns about toddlers enrolled in early intervention</i>. Poster presented at the Society for Research in Child Development Biennial Conference, Austin, TX.</p> <p>Vera, J. D., Oosting, D., &amp; Carter, A. S. (2016, May). <i>Challenging behaviors in toddlers in early intervention: Does an autism spectrum disorder diagnosis predict increased risk?</i> Poster presented at the International Conference on Infancy Studies, New Orleans, LA.</p>
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**5. Improving Part C Services and Outcomes for Underserved Children With ASD, Hugo W. Moser Research Institute at Kennedy Krieger, Inc.**

<p><b>Brief Description of Study</b></p>	<p><b>Purpose:</b> This study aimed to increase Part C practitioners’ implementation of evidence-based early intervention practices. Specifically, providers were trained with a manualized professional development program to improve caregiver-child engagement outcomes and improve child social and communication outcomes.</p> <p><b>Methods:</b> For a randomized controlled trial (RCT), 60 Part C practitioners were assigned to an evidence-based practice training condition or a control group that did not receive any training. Measures of professional development training, caregivers, and children were taken pre- and postintervention. To assess generalizability, the researchers assessed practitioners’ implementation with a different child with ASD and the caregiver.</p> <p><b>Outcomes:</b> The manualized professional development program could be implemented in authentic community settings by providers with a high degree of fidelity and resulted in a statistically significant change in measures of social and communication behaviors among children of providers in the intervention condition. Data analysis for the parent implementation of evidence-based strategies was ongoing during the end of the evaluation period; however, preliminary results suggest trained caregivers demonstrate greater change in use of strategies (expressive language elicitations, motor imitation, and use of objects) during book sharing than untrained caregivers.</p>
<p><b>Problem or Issue Addressed</b></p>	<p>There is a growing gap between research and practice in early intervention services (early intervention or Part C) for toddlers with or at risk for ASD and their caregivers. As the research base of effective early interventions for this population grows, there is a pressing need for research focused on the translation of these interventions for community-based implementation. Intervention components must be adapted to reflect the needs and values of community provider systems and the culturally diverse populations served. The effects of increased implementation of evidence-based early intervention practices on children and their caregivers must be evaluated to meaningfully improve the training and service provision standards of the Part C system.</p>
<p><b>Goals</b></p>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>● Improve Part C practitioners’ implementation of evidence-based practices through participation in a manualized professional development program established through prior (National Institutes of Health, the Health Resources and Services Administration R40) and current Institute of Education Sciences funding.</li> <li>● Improve caregiver-child engagement outcomes through training Part C practitioners to coach caregivers in the use of evidence-based early intervention strategies during caregiver-child interactions.</li> <li>● Improve child social and communication outcomes through training Part C practitioners to implement evidence-based early intervention strategies, caregiver coaching, and a child social and communication development curriculum.</li> </ul>

<b>Study Methodology</b>	For an RCT, 60 Part C practitioners were randomized to either a 6-month evidence-based practice training condition designed to increase implementation of evidence-based early interventions (i.e., instructional strategies, caregiver coaching, and a developmental child curriculum) or to a business-as-usual condition. Baseline, pre- and postprofessional development training measures of practitioners (fidelity, self-efficacy, attitudes toward evidence-based practice, perception of intervention acceptability), caregivers (engagement, self-efficacy, fidelity), and children (language, social) were collected. A generalization probe was also conducted to assess practitioners' implementation with a different child with ASD and the caregiver. Data were collected through a combination of standardized and experimental measures.
<b>Extant Data Sources</b>	This study collected primary data and did not use external data sources. Materials and procedures were guided by feedback from a diversity advisory committee.
<b>Specific Populations Targeted</b>	The study targeted providers, children, and caregivers from minority populations; however, the sample targeted was representative of the geographic region: 60 percent White, 26 percent Black, 18 percent Hispanic or Latino, and 8 percent Asian. Of the recruited population, 60 percent were minority and 40 percent were of low socioeconomic status.
<b>Underserved Populations</b>	The study sample was drawn from multiple diverse Maryland county Part C programs that reflect the large proportion of minority and underresourced (underserved) families in the study region.
<b>Geographic Areas</b>	The study was conducted in Baltimore County, Maryland.
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>• Although the research team established productive, collaborative relationships with community providers serving families of young children with developmental disabilities from underserved and economically disadvantaged communities, many providers and families were lost to attrition, which influenced the study sample size.</li> <li>• To address the lack of field measures that can assess social and communication treatment outcomes in a community setting, the team developed and tested the Social-Communication Assessment in Book Sharing (SABS) measure. While the study documented SABS scores that were psychometrically reliable and valid in young children with developmental disabilities, the SABS tool requires further psychometric evaluation in a broader sample of children.</li> </ul>
<b>Impact or Outcomes</b>	<p><b>Research outcomes</b></p> <ul style="list-style-type: none"> <li>• <b>Improvement in Part C practitioners' implementation of evidence-based practices.</b> Providers in the intervention group of the study demonstrated significantly greater change in their use of evidence-based instructional practices compared to providers in the control group (<math>F_{(1,46)} = 614.45, p &lt; .001</math>, with a large effect size (Hedges' <math>g = 7.06</math>) favoring the intervention condition. This suggests a causal effect between the professional development intervention and providers' use of evidence-based instructional practices. Providers trained through the intervention were able to learn and implement the evidence-based instructional practices with high fidelity in their authentic, community-based settings.</li> <li>• <b>Improvement in caregiver-child engagement outcomes.</b> Data analysis for the parent implementation of evidence-based strategies was ongoing during the end of the evaluation period; however, preliminary results suggest that trained caregivers demonstrate greater change in use of strategies (expressive language elicitation, motor imitation, and use of objects) during book sharing than untrained caregivers.</li> </ul>

<p><b>Impact or Outcomes (continued)</b></p>	<p><b>Research outcomes (continued)</b></p> <ul style="list-style-type: none"> <li>● <b>Improvement in child social and communication outcomes.</b> Children of providers who received the evidence-based intervention (<math>n = 18</math>) demonstrated significantly greater change in social and communication behaviors from baseline to posttest compared to children of providers who did not receive the intervention (<math>n = 16</math>), <math>F_{(1,32)} = 9.33</math>, <math>p &lt; .01</math>, with a large effect size (Hedges' <math>g = 1.02</math>) favoring the intervention group.</li> </ul> <p><b>Other study impacts</b></p> <ul style="list-style-type: none"> <li>● <b>Intervention tools for parents.</b> In developing the study intervention, the research team created parent training materials to provide families with evidence-based strategies to use with their children during book sharing. Training materials included a storybook with three-dimensional materials to use at home with their children.</li> <li>● <b>Intervention tools for teachers.</b> Teachers received tools during a 2-day teacher training. The training was approved by the Maryland State Department of Education for 15 Core of Knowledge clock hours in the area of child development, curriculum development, and special needs. The full 2-day teacher training included PowerPoint presentations, video examples, interactive group activities, and handouts. Teachers attending the training each received five book-share bundles for use in the classroom and handouts titled “what we are reading now” to be completed by teachers each week and sent home to families to support teacher-parent communication and encourage at-home activities that correspond to the book discussed in class. During the book-share intervention, teachers were observed by coaches, who completed feedback and debriefing forms during and immediately after each classroom observation. Completed feedback forms were emailed to the teacher to give clear and constructive feedback on how to implement the treatment in their classrooms.</li> <li>● <b>New measures developed</b> <ul style="list-style-type: none"> <li>● <b>SABS</b>, an innovative, experimental, 30-item measure, was developed to assess change in 6 social communication behaviors in young children. The measure is embedded in a children’s book-sharing interaction. Data from this study supported the SABS’ reliability, construct validity, sensitivity to change in response to intervention, ecological validity, and appropriateness for use with young children with developmental disabilities.</li> <li>● <b>A provider implementation fidelity form and coding manual</b> were developed to measure the presence and quality of providers’ use of evidence-based instructional strategies during videotaped book-share interactions.</li> </ul> </li> </ul>
<p><b>Dissemination Plans</b></p>	<p><b>Manuscripts in progress</b></p> <p>Feuerstein, J., Baker, E., &amp; Landa, R. Preliminary reliability and validity evidence for the SABS, an innovative experimental measure of child change. <i>Journal of Speech, Language, and Hearing Research</i>.</p> <p>Landa, R., Feuerstein, J., &amp; Baker, E. Coaching processes in implementation science? <i>Implementation Science</i>.</p> <p>Landa, R., Feuerstein, J., &amp; Baker, E. Primary outcomes on provider implementation fidelity and child social and communication behaviors following exposure to the EA-CP PD intervention. <i>Journal of Early Intervention</i>.</p>

<b>Publications Generated</b>	<p><b>Peer-reviewed articles</b></p> <p>Landa, R. (in press). Efficacy of early interventions for infants and young children with, and at risk for, autism spectrum disorders. <i>International Review of Psychiatry</i>.</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Feuerstein, J., Greenslade, K., Baker, E., &amp; Landa, R. (2017, November). <i>Measuring young children's social-communication in a book share context: Preliminary reliability and validity evidence</i>. Presented at the American Speech-Language-Hearing Association Annual Convention, Los Angeles, CA.</p> <p>Feuerstein, J., &amp; Landa, R. (2018, March). <i>Measuring early intervention outcomes: A novel book sharing approach</i>. Presented at Conference for Research Innovations in Early Intervention, San Diego, CA.</p> <p>Goldstein, H., Kaiser, A., Landa, R., Hemmeter, M. L., &amp; Kretzer, J. (2016, February). <i>Incorporating tiered interventions into preschool classrooms: A discussion of evaluation issues</i>. Presented at the Conference for Research Innovations in Early Intervention, San Diego, CA.</p> <p>Green, S., Feuerstein, J., &amp; Landa, R. (2016, October). <i>Exploring the relationship between child care providers' use of instructional strategies and children's social, communication, and joint attention behavior</i>. Student poster presentation at the University of Pennsylvania Penn Honors Diversity Symposium, Philadelphia, PA.</p> <p>Green, S., Feuerstein, J., &amp; Landa, R. (2016, November). <i>Exploring the relationship between child care providers' use of instructional strategies and children's social, communication, and joint attention behavior</i>. Student poster presentation at the Annual Biomedical Research Conference for Minority Students, Tampa, FL.</p> <p>Landa, R. (2015, July). <i>Innovations in intervention</i>. Presented at the Autism CARES Grantee Meeting: Implementing Evidence-Based Practices in Real World Settings, Bethesda, MD.</p> <p>Landa, R. (2015, March). <i>Grand rounds: Early diagnosis and intervention for autism</i>. Seminar presented at the Ninth Annual Allen D. Schwartz, M.D. Lectureship: Autism, Baltimore, MD.</p> <p>Landa, R. (2015, March). <i>Outcomes of early intervention and future directions for autism</i>. Seminar presented at the Ninth Annual Allen D. Schwartz, M.D. Lectureship: Autism, Baltimore, MD.</p> <p>Landa, R. (2015, September). <i>Translation of the Early Achievements intervention for implementation in public pre-k classrooms with children with ASD</i>. Webinar presented for the Association of University Centers on Disabilities Resource Center: Early Intervention/Early Childhood Special Interest Group Webinar Series, Silver Spring, MD.</p> <p>Landa, R. (2016, March). <i>Parent stress and coping</i>. Presented at the Association of Maternal and Child Health Programs (AMCHP) Annual Conference, Kansas City, MO.</p> <p>Landa, R., &amp; Feuerstein, J. (2018, March). Professional development for childcare providers serving young children with developmental delays: An RCT. <i>Conference for Research Innovations in Early Intervention</i>, San Diego, CA.</p> <p>Landa, R., &amp; Olswang, L., (2017, November). <i>Insights into designing collaborative research</i>. Presented at the American Speech-Language-Hearing Association Annual Convention, Los Angeles, CA.</p>
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<b>Publications Generated (continued)</b>	<b>Peer-reviewed scholarly conference presentations</b> <p>Mahajan, R., Singh, V., Schrembs, A., Neely, J., Pinkett-Davis, M., &amp; Landa, R. (2016, May). <i>Five factor structure of parenting stress index: Short form in evaluating stress in parents of children with ASD</i>. Presented at the International Meeting for Autism Research, Baltimore, MD.</p> <p>Saulnier, C., Klaiman, C., Landa, R., &amp; Carter, A. (March, 2015). <i>Challenges associated with parental consent to early intervention for infants at high risk for autism spectrum disorder</i>. Presented at the Society for Research in Child Development, Philadelphia, PA.</p>
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## 6. Comparative Efficacy of a Self-Directed and Therapist-Assisted Telehealth Parent Training Intervention for Children With ASD, Michigan State University

<p><b>Brief Description of Study</b></p>	<p><b>Purpose:</b> The aim of this study was to examine the effect of ImPACT Online, a novel, telehealth parent-mediated intervention for children with ASD, on parent and child outcomes to identify moderators and mediators of treatment response and to identify predictors of parent adherence to the program.</p> <p><b>Methods:</b> Ninety families of young children with ASD were assessed at pretreatment (T1), randomized to the self-directed ImPACT Online, a therapist-assisted or web-based information control condition, and received treatment for 4 months. Outcome assessments occurred at posttreatment (T2) and a 3-month follow-up (T3).</p> <p><b>Outcomes:</b> Data collection was ongoing at the end of the evaluation period (December 2017), so outcome data were not available. At that point in the study, the intervention retention rate was 95 percent; one participant withdrew after a group assignment and one participant was lost to follow-up.</p>
<p><b>Problem or Issue Addressed</b></p>	<p>Parent-mediated intervention is one cost-effective and ecologically valid approach to increasing access to intervention for families of young children with ASD. Additional benefits include increases in parenting self-efficacy and decreases in parenting stress. However, there continue to be barriers involved with the dissemination of training to parents. Telehealth interventions have the potential to replace or at least augment traditional service models to increase access to evidence-based services, particularly in rural and medically underserved areas. Although there has been growing interest in extending telehealth interventions to parent-mediated intervention for children with ASD, empirical evaluations of such programs are limited, and little is known regarding the relative benefits of self-directed and therapist-assisted telehealth interventions for ASD. A better understanding of the relative benefits of these two delivery formats on parent and child outcomes—and the families for whom each format is most and least effective—is crucial for the development of effective and efficient telehealth parent-mediated interventions.</p>
<p><b>Goals</b></p>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>● Examine the comparative efficacy of self-directed and therapist-assisted ImPACT Online on <i>parent outcomes</i> (i.e., parent fidelity and parent self-efficacy) at posttreatment and the 3-month follow-up.</li> <li>● Examine the comparative efficacy of self-directed and therapist-assisted ImPACT Online on <i>child outcomes</i> (i.e., child verbal language) at the 3-month follow-up.</li> <li>● Examine whether <i>pretreatment parenting stress</i> moderates the effects of ImPACT Online on parent fidelity and parent self-efficacy at posttreatment.</li> <li>● Examine whether <i>gains in parent fidelity and parent self-efficacy</i> at posttreatment mediate the effects of ImPACT Online on child verbal language at the 3-month follow-up.</li> <li>● Identify program-level (i.e., therapist assistance), individual-level (i.e., computer/internet fluency, parent expectancies, and treatment acceptability) and sociodemographic variables as predictors of adherence to ImPACT Online.</li> </ul>

<b>Study Methodology</b>	The study compared participant outcomes of three interventions: (1) the self-directed ImPACT Online, (2) the therapist-assisted ImPACT Online, and (3) the web-based information control condition. Through a randomized controlled trial design, parent fidelity and parent self-efficacy were compared for all three study conditions at posttreatment and 3-month follow-up. Assessments used to evaluate intervention outcomes included ImPACT Online Fidelity Scale, Parent Sense of Competence Scale, Mullen Scales of Early Learning, MacArthur-Bates Child Development Inventory, Parent-Child Interaction, Parenting Stress Inventory, ImPACT Online electronic tracking system, Intervention log, Computer-Email-Web Fluency Scale, Parent Expectancies for Therapy Scale, Treatment Evaluation Inventory, and the Family Demographic Form.
<b>Extant Data Sources</b>	This study collected primary data and did not use external data sources.
<b>Specific Populations Targeted</b>	The study recruited children with ASD and their primary caregivers in the State of Michigan. The final sample is not complete as recruitment is ongoing. However, the demographic information for the sample so far follows: 82 percent of the children were male, reflecting the higher rate of ASD in males, and 84 percent of caregivers were female. The race/ethnicity of participants is as follows: 71 percent White, not Hispanic or Latino; 5 percent Black/African American; 8 percent Asian, 8 percent Hispanic or Latino; and 8 percent more than one race. These demographics are similar to the demographics of the State of Michigan, with the exception of a lower percentage of Black/African-American participants and a higher percentage of participants whose race was reported as “more than one race.”
<b>Underserved Populations</b>	The study overrecruited families who reside in rural or medically underserved areas. The sample thus far includes 37 percent of individuals residing in a rural area and 38 percent of individuals residing in a medically underserved area. As a number of household fell into both categories, 53 percent of the overall sample thus far resides in a rural or medically underserved area. This is lower than the recruitment target and the authors are focusing on additional targeted recruitment in these areas.
<b>Geographic Areas</b>	Participant recruitment occurred in the State of Michigan, with special focus on rural and medically underserved populations.
<b>Study Limitations Addressed or Considered</b>	In 2012, the State of Michigan passed insurance legislation that requires private insurance companies and Medicaid to cover the cost of applied behavioral analysis (ABA) services for children with ASD up to age 8. During the course of this study, there has been a gradual increase in the availability of community-based ABA services in Michigan. This has been helpful for Michigan families because more families are receiving needed ASD support in their communities; however, this has negatively affected recruitment success. The authors are continuing recruitment and data collection to achieve the target goal.

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**Impact or Outcomes****Other study outcomes and impact**

Data collection was incomplete at the end of the evaluation period (December 2017). However, a subset of data from the study was used to examine the potential reach of the self-directed version of ImPACT Online. The researchers compared the demographics of families who enrolled in an open trial of the self-directed version of ImPACT Online with families who enrolled in one of two controlled trials of the same program. The researchers also examined program engagement for the open versus controlled trials and the relationship between program engagement and parents' intervention knowledge:

- **Reach of the self-directed version of ImPACT Online open trial.** Twenty-six percent of parents given information about the program at their child's diagnostic feedback session registered with the program. Additional research that can examine differences in referral methods and the optimal times to refer parents to such programs would be helpful.
  - **Representativeness of the open trial study population.** The parents who enrolled in the open and controlled trials were similar in gender (85 percent female in the open trial compared to 88 percent in the controlled trial), marital status (80 percent married in the open trial compared to 70 percent in the controlled trial), education (58 percent college degree or higher in the open trial compared to 54 percent in the controlled trial), and employment status (58 percent employed outside the home in the open trial compared to 65 percent in the closed trial). The child participants were similar with regard to gender (83 percent; 76 percent male) and race/ethnicity (62 percent; 76 percent White). However, the mean chronological age of the child participants in the open trial group was significantly older ( $M = 59.99$  months) than the controlled trial group (43.02 months),  $t = 5.22$ ,  $P < .001$ . These data suggest that for the most part participants who enrolled in the controlled trials were very similar to families who enrolled in the open trial and provide some confidence that the data being generated from the ongoing efficacy study may well generalize to community users.
  - **Engagement in the self-directed ImPACT Online open trial.** Parents in the open trial engaged with the program at a significantly lower rate than the controlled trial,  $F(3, 81) = 21.14$ ,  $P < .001$ . There was an early dropoff in lesson completion among participants in the open trial. This finding suggests a possible need to introduce intervention content earlier or use additional strategies during the first few lessons to boost engagement in real-world contexts.
  - **Relationship between program engagement and parent learning.** Program engagement was significantly associated with gains in parent intervention knowledge across both groups,  $\beta = .46$ ,  $t = 2.79$ ,  $P = .008$ , suggesting program engagement is an important factor in learning.
  - **Parents' evaluation of the self-directed version of ImPACT Online.** Program evaluation data for the open-trial participants suggested high levels of treatment acceptability and website usability and low levels of perceived barriers. Parents identified several benefits of the program, including the accessibility of the program, ease of learning the intervention, the acceptability of the intervention strategies, and improvement in their child's social communication skills. The most consistently reported barriers were related to competing stressors at home and difficulty finding time to complete the program. Parents also indicated a need for therapist support, simplification of some of the training components, and a desire for greater online community support.
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<p><b>Dissemination Plans</b></p>	<p><b>Manuscripts planned</b></p> <p>Four manuscripts are planned for submission to peer-reviewed journals.</p> <p><b>Other dissemination activities</b></p> <ul style="list-style-type: none"> <li>• The research team is in consistent contact with key stakeholders on the Governor’s Autism Council, which works with public and private insurance agencies covering autism intervention services in the State of Michigan. Study findings will be disseminated through this council to Michigan Department of Health and Human Services and private insurers to inform the use and coverage of telehealth delivery of parent-mediated intervention.</li> <li>• Radio interview on the use of telehealth for providing parent-mediated intervention for ASD, Michigan Public Radio</li> <li>• MSU press release</li> </ul>
<p><b>Publications Generated</b></p>	<p>The analysis for the study research questions was ongoing at the end of the evaluation period (December 2017); however, a subset of data from the project was used to examine the potential reach of the self-directed version of IMPACT Online. Findings from this subset of data have been disseminated.</p> <p><b>Peer-reviewed articles</b></p> <p>Ingersoll, B., Shannon, K., Berger, N., Pickard, K., &amp; Holtz, B. (2017). Examining the potential reach and utilization of a self-directed telehealth parent-mediated intervention for children with ASD in community settings. <i>Journal of Medical Internet Research, 19</i>(7), e248.</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Ingersoll, B. (2017, November). <i>Potential of a self-directed telehealth parent-mediated intervention for children with ASD in community settings</i>. Presented in K. Bearss (Chair), Approaches to access to parent mediated interventions for families of children with autism spectrum disorder. Symposium at the annual meeting of the Association for Behavioral and Cognitive Therapies, San Diego, CA.</p> <p>Ingersoll, B., Shannon, K., Berger, N., &amp; Holtz, B. (2017, May). <i>Examining the dissemination potential of a self-directed telehealth parent-mediated intervention for children with ASD in community settings</i>. Poster presented at the annual meeting of the International Meeting for Autism Research, San Francisco, CA.</p> <p>Ingersoll, B., Shannon, K., Berger, N. &amp; Holtz, B. (2017, July). <i>Examining the potential reach and utilization of a self-directed telehealth parent-mediated intervention for children with ASD in community settings</i>. Poster presented at Autism CARES Meeting, Bethesda, MD.</p> <p>Shannon, K., Holtz, B. E., &amp; Ingersoll, B. (2016, May). <i>Examining the potential reach and engagement with a self-directed telehealth parent-mediated intervention for children with ASD in community settings</i>. Poster presented at the annual meeting of the International Meeting for Autism Research, Baltimore, MD.</p> <p>Shannon, K., Berger, N. I., Pickard, K., Bonter, N., &amp; Ingersoll, B. (2015, July). <i>Comparison of a self-directed and therapist-assisted telehealth parent training intervention for children with ASD</i>. Poster presented at Autism CARES Meeting, Bethesda, MD.</p>

## 7. Toddlers and Families Together: Addressing Early Core Features of Autism, University of North Carolina, Chapel Hill

<b>Brief Description of Study</b>	<p><b>Purpose:</b> The goal of the study was to test the efficacy of a group-based intervention, Toddlers and Families Together (Together), for families of young children with or suspected of having ASD. The intervention targets behavior regulation, joint attention, and play to improve maternal health and child developmental outcomes.</p> <p><b>Methods:</b> The Together intervention was provided to 10 groups of 4 toddlers and their families by embedding the intervention within everyday routines and activities for toddlers within 8 weekly 3-hour group sessions. A series of quantitative and qualitative measures assessed the efficacy of the intervention in changing family and child outcomes. ANCOVA models were used to evaluate each outcome being regressed on a treatment indicator, the pretest score, and potential moderators.</p> <p><b>Outcomes:</b> Caregivers participating in the Together intervention showed lower levels of stress, used more descriptive language, and followed the child’s lead more often during caregiver-child interactions than caregivers who did not participate in the intervention. Toddlers receiving intervention showed higher levels of engagement, including joint engagement, and higher frequencies of play and joint attention behaviors compared to toddlers in the control group. Findings suggest the Together model of intervention can positively affect caregiver and child outcomes.</p>
<b>Problem or Issue Addressed</b>	<p>Given the prevalence of 1 in 68 children along with the increase in early diagnoses of ASD and that those caregivers of children with ASD report greater stress than parents of children with other disabilities, it is extremely important to establish practical and evidence-based programs for toddlers with or at risk for ASD and their families. This study tests an intervention for addressing early core features of ASD and improving maternal health and child development outcomes.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>● Examine the effects of Together on caregiver outcomes of stress, coping, support, and interaction style.</li> <li>● Examine the effects of Together on children’s engagement, behavior regulation, joint attention, and play.</li> <li>● Examine caregiver and child characteristics affecting optimal treatment outcomes.</li> </ul>
<b>Study Methodology</b>	<p>Toddlers between the ages of 16 and 36 months with or at risk for ASD (as identified with a positive screen for ASD on the ASQ: SE or M-CHAT) and their families were randomized in a 2:1 ratio to the Together intervention group (<math>n = 39</math>) or a services-as-usual control group (<math>n = 22</math>). The Together intervention content of behavior regulation, joint attention, and play was provided to 16 groups of 4 toddlers and their families (<math>n = 39</math>). These intervention targets were embedded within a context of everyday routines and activities for toddlers within eight weekly 3-hour group sessions that also included a family education segment to learn, practice, and discuss the topic strategy with one facilitator while other intervention staff members engaged the toddlers in various learning activities. A series of quantitative and qualitative measures assessed the efficacy of the intervention in changing family and child outcomes. Specifically, the study assessed the intervention through the use of standardized caregiver report measures, semistructured interviews, caregiver diaries, caregiver implementation ratings, video-recorded caregiver-child interactions, semistructured assessments of play and joint attention, and standardized child measures of autism and early development. ANCOVA models were used to evaluate each outcome being regressed on a treatment indicator, the pretest score, and potential moderators.</p>

<b>Extant Data Sources</b>	This study collected primary data and did not use external data sources.
<b>Specific Populations Targeted</b>	Toddlers between the ages of 16 and 36 months with or at risk for ASD (as identified with a positive screen for ASD on the M-CHAT) and their families
<b>Underserved Populations</b>	This study provided an intervention in diverse settings to establish the feasibility of recruiting a diverse sample of young children with autism. Families were recruited primarily from Early Head Start to ensure a diverse population and to include those who have historically been underrepresented.
<b>Geographic Areas</b>	The sample is nationally representative and was collected from two diverse areas of the country (North Carolina and Southern California).
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>To address a small sample size because of recruitment challenges, the study used family testimonials collected to encourage families to commit to an 8-week intervention, brought the intervention (not just recruitment activities) into communities (e.g., local agencies) to increase access to targeted underserved populations, and offered intervention coaching in addition to materials to control group participants after their participation in the study was concluded to discourage attrition.</li> <li>Because this is a study with two sites, the research team used detailed manuals, frequent meetings, and study implementation fidelity checks to maintain consistency between the two sites.</li> </ul>
<b>Impact or Outcomes</b>	<ul style="list-style-type: none"> <li><b>Caregiver outcomes of stress, coping, support, and interaction style.</b> Primary caregivers participating in the intervention were found to have significantly lower levels of parental stress than those who did not receive the intervention. Although there were no significant effects for caregiver outcomes of coping and support, caregiver participants reported feeling more supported throughout the intervention, which facilitated better coping than before the start of intervention. Finally, significant effects were found in the primary caregiver's interactions with the child after participating in the intervention as compared to those in the control group. Caregivers in the intervention group showed higher levels of joint engagement and descriptive language and following the child's lead than the caregivers who did not participate in the intervention.</li> <li><b>Children's engagement, behavior regulation, joint attention, and play.</b> During play interactions with family members, children participating in the intervention showed significantly higher percentages of time in a joint engaged state and less time in an unengaged state compared to children who did not participate in the intervention. Although there were no significant differences in behavior regulation outcomes between the two groups, many caregivers participating in the intervention reported the successful management of difficult child behaviors at home. The frequency of joint attention behaviors and play behaviors during the assessments were significantly higher for children participating in the intervention than for the children in the control group.</li> </ul>

<b>Impact or Outcomes (continued)</b>	<ul style="list-style-type: none"> <li> <b>Caregiver and child characteristics affecting optimal treatment outcomes.</b> Significant interaction effects were found for children’s cognitive scores, with the children showing higher cognitive scores demonstrating higher levels of joint engagement and having caregivers that used more descriptive language during caregiver-child interactions. A similar pattern was found for children’s level of autism severity with the children showing fewer symptoms of ASD having higher levels of joint engagement and having caregivers that used more descriptive language during caregiver-child interactions. </li> </ul>
<b>Dissemination Plans</b>	<p><b>Manuscripts in progress</b></p> <p>Gallagher, K. C., &amp; Wong, C. (in preparation). <i>Raising young children with or at risk for an autism spectrum disorder: Caregiver stress, coping, and support.</i></p> <p>Obitko, J., Wong, C., &amp; Gallagher, K.C. (in preparation). <i>Interactions between young children with autism spectrum disorder and their caregivers.</i></p> <p>Page, J., Gallagher, K. C., &amp; Wong, C. (in preparation). <i>Families of toddlers with or at risk for ASD: Parental perceptions of navigating early intervention.</i></p> <p>Wong, C., Gallagher, K. C., Page, J. P., Arbiv, S., Zheng, S., Nieto, L., &amp; Obitko, J. (in preparation). <i>A group-based social-communication intervention for toddlers with or at risk for an autism spectrum disorder and their families: A randomized controlled trial.</i></p> <p>Wong, C., &amp; Gallagher, K. C. (in preparation). <i>Toddlers and Families Together: Fathers of young children with or at risk for an autism spectrum disorder.</i></p> <p>Wong, C., &amp; Gallagher, K. C. (in preparation). <i>Toddlers and Families Together: Promoting joint engagement for young children with or at risk for autism spectrum disorder in a single case design experiment.</i></p> <p><b>Other dissemination</b></p> <p>Wong, C., &amp; Gallagher, K. C. <i>Toddlers and Families Together: Manual.</i> Chapel Hill: The University of North Carolina, Frank Porter Graham Child Development Institute, Toddlers and Families Together Research Team.</p> <p>Wong, C., &amp; Gallagher, K. C. <i>Toddlers and Families Together: Manual, Spanish.</i> Chapel Hill: The University of North Carolina, Frank Porter Graham Child Development Institute, Toddlers and Families Together Research Team.</p> <p>Wong, C., &amp; Gallagher, K. C. (2018). <i>A randomized controlled trial of a group-based intervention for families and their toddlers with or at risk for autism spectrum disorder: Research issues.</i> To be presented at the Conference on Research Innovations in Early Intervention, San Diego, CA.</p>

<b>Publications Generated</b>	<p><b>Peer-reviewed articles</b></p> <p>Gallagher, K. C., Wong, C., &amp; Williams, S. (in progress). <i>Implementing Toddlers &amp; Families Together: Supporting communication, play, and collaborative learning</i>.</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Wong, C., Gallagher, K. C., &amp; Page, J. (2014). <i>Toddlers and Families Together: Addressing early core features of autism</i>. Presented at the Frank Porter Graham Child Development Institute Fall Brown Bag Series, Chapel Hill, NC.</p> <p>Wong, C., Gallagher, K. C., &amp; Arbiv, S. (2014). <i>Toddlers and Families Together: Addressing early core features of autism</i>. Presented at the INTERACT Project Review Meeting at the Child and Adolescent Services Research Center, San Diego, CA.</p> <p>Wong, C., Gallagher, K. C., Page, J., Wong, K., Arellano, G., &amp; Arbiv, S. (2015). <i>Toddlers and Families Together: Caregiver implementation and perceptions of strategies to facilitate joint engagement</i>. Presented at the International Meeting for Autism Research (IMFAR), Salt Lake City, UT.</p> <p>Wong, C., &amp; Gallagher, K.C. (2015). <i>Toddlers and Families Together: Promoting joint engagement for young children with or at risk for autism spectrum disorder</i>. Presented at the 2015 Autism CARES Meeting, Bethesda, MD.</p> <p>Gallagher, K. C., Wong, C., &amp; Page, J. (2015). <i>Family perceptions of an intervention to support toddlers' social communication and play</i>. Presented at the Annual DEC Conference on Young Children with Special Needs and Their Families, Atlanta, GA.</p> <p>Wong, C., Gallagher, K. C., Wong, K., Nieto, L., Arbiv, S., &amp; Page, J. (2016). <i>Toddlers and Families Together: Promoting joint engagement for young children with or at risk for autism spectrum disorder</i>. Presented at the Annual Gatlinburg Conference on Research &amp; Theory in Intellectual &amp; Developmental Disabilities, San Diego, CA.</p> <p>Wong, C., &amp; Gallagher, K. C. (2016). <i>Toddlers and Families Together: Addressing early core features of autism spectrum disorder</i>. Presented in the symposium, Measuring and Teaching Play: Current Issues in Research and Practice, at the Conference on Research Innovations in Early Intervention (CRIEI), San Diego, CA.</p> <p>Arbiv, S., Wong, C., &amp; Gallagher, K. C. (2016). <i>The effect of parental stress on symbolic play development</i>. Presented at the Conference on Research Innovations in Early Intervention (CRIEI), San Diego, CA.</p> <p>Page, J., Wong, C., &amp; Gallagher, K. C. (2016). <i>Families of toddlers with or at risk for ASD: Parental perceptions of navigating early intervention</i>. Presented at the Conference on Research Innovations in Early Intervention (CRIEI), San Diego, CA.</p> <p>Gallagher, K. C., Wong, C., &amp; Williams, S.<sup>a</sup> (2017). <i>Implementing Toddlers &amp; Families Together: Supporting communication, play, and collaborative learning</i>. Presented at the Annual DEC Conference on Young Children with Special Needs and Their Families, Portland, OR.</p> <p>Obitko, J., Wong, C., &amp; Gallagher, K. C. (2017). <i>Interactions between young children with autism spectrum disorder and their caregivers</i>. Presented at the International Meeting for Autism Research (IMFAR), San Francisco, CA.</p>
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<sup>a</sup> Parent of a child with ASD was a copresenter

## 8. Investigation of Teacher-Mediated Toilet Training Using a Manualized Moisture Alarm Intervention, University of Rochester Medical Center

<p><b>Brief Description of Study</b></p>	<p><b>Purpose:</b> The purpose of this study was to develop a teacher-mediated model of toileting instruction for children with ASD in school settings that incorporates an innovative manualized moisture pager intervention (i.e., the MP intervention) and compare its efficacy to a standard behavioral treatment (SBT).</p> <p><b>Methods:</b> A randomized clinical trial compared the teacher-mediated, manualized toilet training intervention that employs a wireless moisture pager with a teacher-mediated behavioral intervention that represents the SBT at three sites. Sixty-one children with ASD aged 3–10 were recruited from 30 community classrooms and randomly assigned to 1 of 2 treatment conditions. After 60 days of treatment, the rate of accidents and toilet use, independence of skilled toileting behavior, and teacher satisfaction were assessed.</p> <p><b>Outcomes:</b> The study protocol and data collection were completed by the end of the evaluation period, but data analysis was still ongoing. Preliminary findings suggest the MP intervention can be implemented with a high degree of fidelity in community classroom settings, with no adverse events related to the MP intervention. The technology was successful in this pilot, and useful information was obtained to further improve the technology and use of the intervention in school settings.</p>
<p><b>Problem or Issue Addressed</b></p>	<p>Urinary incontinence is a significant threat to the quality of life for people with ASD and other disabilities, jeopardizing their autonomy, community inclusion, comfort, hygiene, and peer acceptance. Despite repeated and prolonged efforts of caregivers, some individuals are not trained to use the toilet by their school-age years or beyond. For these individuals, next-step training methods often require expert consultation and methods that are time consuming, disruptive and difficult to implement in everyday settings (e.g., home, school). A training method that requires minimal expert consultation can be implemented with a high degree of caregiver fidelity and increases the rate of toileting skill acquisition over standard methods is greatly needed.</p>
<p><b>Goals</b></p>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>• Prepare the teacher-mediated moisture pager (MP) intervention for large-scale testing in classroom settings by modifying the current parent manual for classroom use and evaluating the feasibility of the study protocol.</li> <li>• Compare the efficacy of the MP intervention and standard behavioral treatment (SBT) by conducting an RCT.</li> </ul>
<p><b>Study Methodology</b></p>	<p>A teacher-mediated, manualized toilet training intervention that employs a wireless moisture pager using an iOS-based app was developed for a randomized clinical trial at three sites (i.e., Rochester, Vanderbilt, Nashville). The teacher-mediated moisture pager (MP) was compared with a teacher-mediated behavioral intervention that represents the current standard of care (SBT). Sixty-one children with ASD, aged 3–10 were recruited from 30 community classrooms and randomly assigned to 1 of the 2 treatment conditions. Both conditions occurred over 60 days and received initial comprehensive staff training and three follow-up sessions. Study feasibility was assessed, along with the following outcome measures: rate of accidents and toilet use, independence of skilled toileting behavior at the end of the 3-month intervention phase, and teacher satisfaction.</p>
<p><b>Extant Data Sources</b></p>	<p>There were no extant data sources used in this study.</p>

<b>Specific Populations Targeted</b>	Children with ASD aged 3–10 enrolled in a community classroom setting (e.g., special education, general education classrooms) who never, rarely, or occasionally use the toilet but still have accidents and are far from independent with toileting behavior.
<b>Underserved Populations</b>	The study recruited from diverse regional, ethnic, and racial populations and promoted cultural competency among all researchers and study staff.
<b>Geographic Areas</b>	The study was conducted in 30 community classrooms in Rochester, New York; Columbus, Ohio; and Nashville, Tennessee.
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>• Recruitment was a challenge because some community sites were reticent to adopt the study intervention in place of their standard toileting interventions. Once schools were on board and teachers were trained, recruitment was less challenging.</li> <li>• The study recruited fewer females than the previous intervention. The reason for this is unclear but will be examined further during data analysis.</li> <li>• Although the technology was useful, some limitations were identified related to the convenience of use and the ability to easily attach and disconnect the device. Improvements in these areas will be sought in the next study.</li> </ul>
<b>Impact or Outcomes</b>	<ul style="list-style-type: none"> <li>• <b>Moisture pager intervention can be implemented in community classroom settings.</b> The study protocol and data collection were completed by the end of the evaluation period, but data analysis was still ongoing. Preliminary findings suggest the MP intervention can be implemented with a high degree of fidelity in community classroom settings, with no adverse events related to the MP intervention. The technology was successful in this pilot, and useful information was obtained to further improve the technology and use of the intervention in school settings.</li> <li>• <b>Efficacy of the MP intervention.</b> At the time of the evaluation, analysis of data examining the effectiveness of the MP intervention over the SBT was still ongoing. However, these results will be published in the peer-reviewed literature once available.</li> </ul>
<b>Dissemination Plans</b>	<p><b>Manuscripts in progress</b></p> <p>Mruzek, D. W., McAleavey, S., Aponte, C., Smith, T. Loring, W. A., Butter, E., Wilkins, J. &amp; Zanibbi, K. (submitted, 2015). A pilot randomized controlled trial of an iOS-based app for toilet training students with autism spectrum disorder in the school setting. <i>Autism</i>.</p>

<b>Publications Generated</b>	<p><b>Peer-reviewed articles</b></p> <p>Levato, L., Aponte, C., Wilkins, J., Travis, R., Aiello, R., Zanibbi, K., ... Mruzek, D. W. Use of urine alarms in toilet training children with intellectual and developmental disabilities: A review. <i>Research in Developmental Disabilities, 53</i>, 232–241.</p> <p>Mruzek, D. W., McAleavey, S., Loring, W. A., Butter, E., Smith, T., McDonnell, E., ... Zanibbi, K. A pilot investigation of an iOS-based app for toilet training children with autism spectrum disorder. <i>Autism, 1362361317741741</i>. doi:10.1177/1362361317741741</p> <p>Mruzek, D. W., Handen, B. L., Aponte, C. A., Smith, T., &amp; Foxx, R. M. (in press). Parent training for toileting. In Johnson, C. R. &amp; Butter, E. (Eds.), <i>Parent training in autism spectrum disorder: Evidence-based approaches</i>. Washington, DC: American Psychological Association.</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Mruzek, D. W. (2016a, March). <i>Invited Workshop: Behavioral Treatment of Enuresis: How to Be a Great Toilet Training Consultant in Home and Community Settings</i>. Presented at the Pennsylvania Applied Behavior Analysis Association (PennABA) Annual Conference, Hershey, PA.</p> <p>Mruzek, D. W. (2016b, March). <i>Using behavioral principles to toilet train individuals with developmental disabilities</i>. Presented at the Association for Professional Behavior Analysts Annual Convention, Washington, DC.</p> <p>Mruzek, D. W. (2016, May). <i>Teaching daily living skills with learners with ASD: What's new and what's next</i>. Invited presentation at the International Meeting for Autism Research Preconference, Towson, MD.</p> <p>Mruzek, D. W., (2016, October). <i>Adventures in Toilet Training: Insights Ripped from a Behavior Analyst's Notebook</i>. Invited presentation at the New York State Association for Behavior Analysis Conference, Albany, NY.</p>
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## 9. Does Mindfulness Training Enhance Early Evidence-Based Parent-Coaching Interventions? Vanderbilt University Medical Center

<b>Brief Description of Study</b>	<p><b>Purpose:</b> The aim of the study was to develop a novel treatment paradigm that may significantly increase the efficacy of parent training programs and positively impact children, caregivers, and families in both the short and long term.</p> <p><b>Methods:</b> The study compares the effectiveness of two parent-coaching intervention programs. The first is a conventional, empirically supported program called the Parent-implemented Early Start Denver Model (P-ESDM). The second is a variation of the P-ESDM intervention enhanced with a Mindfulness-Based Stress Reduction program for caregivers (P-ESDM + MBSR).</p> <p><b>Outcomes:</b> Although this study was ongoing at the time of this evaluation, preliminary results suggest that parents who received MBSR report lower levels of dysfunctional interactions with their children at the end of P-ESDM treatment as measured by the Parenting Stress Inventory.</p>
<b>Problem or Issue Addressed</b>	<p>Caregivers of children with ASD report higher levels of depression and distress than caregivers of typically developing children and children with other developmental disabilities. These levels of depression and distress among caregivers can have significant negative effects on parental mental and physical health and on the potential effectiveness of early intervention strategies. Given the importance of early intervention to improve child functioning and the fact that parents often play significant roles in facilitating treatment, it is critical to design and implement early intervention programs that directly address and treat parental distress.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>• Compare the effectiveness of P-ESDM versus P-ESDM + MBSR in enhancing caregiver health.</li> <li>• Examine the effectiveness of P-ESDM versus P-ESDM + MBSR in enhancing child and family related outcomes.</li> </ul>
<b>Study Methodology</b>	<p>Researchers recruited 63 child participants and their caregivers who self-reported mild-to-moderate mean levels of depression, anxiety, and parenting stress. Children were between 18 and 36 months of age and had recent diagnoses of ASD. All children received 12 sessions of intervention (P-ESDM). Half of caregivers were randomized to also receive six individual sessions of a stress reduction program (MBSR). Follow-up assessments occurred at 1, 3, and 6 months after P-ESDM conclusion.</p>
<b>Extant Data Sources</b>	<p>This study collected primary data and did not use extant data sources.</p>
<b>Specific Populations Targeted</b>	<p>This study targeted children aged 18–36 months with a recent diagnosis of ASD and their primary caregivers.</p>
<b>Underserved Populations</b>	<p>The majority of the recruited sample at the conclusion of the funding period were White (50), but several non-White families participated (6 Hispanic or Latino, 2 Black or African American, 5 Asian). Eighteen of 63 recruited participants had an annual household income less than \$50,000, with 4 reporting incomes less than \$20,000. Ten of 63 had educational levels ending in high school and 5 were single parents. Parents in both ESDM and ESDM + MBSR groups reported mild-to-moderate mean levels of depression, anxiety, and parenting stress at intake.</p>

<b>Geographic Areas</b>	The majority of participants live within a reasonable geographical distance (< 60 miles) to the Vanderbilt Kennedy Center’s Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) in Nashville, Tennessee. Two families drove from out of State (Alabama, Kentucky) to participate.
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>● Scheduling time for treatment was a major challenge to study participation. Some families took an additional 6 weeks to move through the treatment protocol because of scheduling issues. Seven families withdrew midtreatment because of difficulty balancing study requirements with their own work or intervention schedules, and an additional six families were lost to follow-up. Researchers will address this by developing home-based interventions in the future.</li> <li>● Even with reminder phone calls, emails, and preaddressed envelopes, some families did not consistently return data packets.</li> <li>● This study did not have the resources to offer the intervention in languages other than English, which restricted the ability to recruit a more ethnically and culturally diverse sample.</li> <li>● The study did not actively track or collect qualitative data regarding caregiver feedback about study experiences and impact. However, attempts have been made to retroactively capture handwritten data and pursue a postparticipation survey to families via email.</li> </ul>
<b>Impact or Outcomes</b>	<p><b>Research outcomes:</b> The analysis of the effectiveness of the two parent-coaching intervention programs was ongoing at the end of this evaluation. However, some preliminary findings are presented.</p> <ul style="list-style-type: none"> <li>● <b>Effectiveness in enhancing caregiver health.</b> Preliminary outcomes suggest there are no between-group differences on most aspects of parental mental health and functioning; however, depression scores decreased across the entire sample.</li> <li>● <b>Effectiveness in enhancing child and family-related outcomes.</b> Preliminary results have found strong and consistent differences on a subscale of the Parent Stress Inventory called Parent Child Dysfunctional Interaction, which generally assesses how caregivers perceive their attempts to play and be with their children as disrupted or atypical. Parents who received MBSR consistently reported significantly lower levels of dysfunctional interactions at Time 3. Although limited to <i>t</i>-tests and ANCOVA at the time of the evaluation, the researchers plan to use multilevel modeling to examine whether discontinuous slopes (different rates of treatment versus posttreatment change) exist, and to account for any missing data.</li> </ul>
<b>Dissemination Plans</b>	<p><b>Manuscripts planned</b></p> <ul style="list-style-type: none"> <li>● Primary outcomes related to main hypotheses</li> <li>● Feasibility of recruitment, retention, and execution of this model as compared to other hybrid models of care offered in partnership with the early intervention system</li> <li>● Modified manual for use with caregivers within research or private practice</li> </ul>

<b>Publications Generated</b>	<p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Garrett, L., Dorris, K., Weitlauf, A., Stainbrook, J. A., Juárez, A. P., &amp; Warren, Z. E. (May, 2017). <i>Comparing the impact of caregiver training provided in clinical and natural environments</i>. Presented at the meeting of the Association for Behavior Analysis International, Denver, CO.</p> <p>Weitlauf, A. S., Broderick, N., Stainbrook, A., Herrington, C., Nicholson, G., Juárez, P., &amp; Warren, Z. E. (May, 2017). <i>Using mindfulness-based stress reduction to reduce caregiver distress as part of behavioral intervention for young children with ASD</i>. Presented at the International Meeting for Autism Research, San Francisco, California.</p> <p><b>Invited presentations</b></p> <p>Weitlauf, A. (October, 2016). <i>Strategies for reducing stress and increasing engagement for families of children with autism spectrum disorder</i>. Presented at the VUMC Department of Pediatrics Research Conference, Nashville, TN.</p> <p>Weitlauf, A. (May, 2017). <i>Strategies for reducing stress and increasing engagement for families of children with autism spectrum disorder</i>. Presented at the VUMC Bill Wilkerson Center Research Conference, Nashville, TN.</p> <p><b>Other dissemination activities</b></p> <p>Parent Stress and MBSR for Special Education Master’s Students. Invited course-level presentations. (May, June, 2017). Vanderbilt University, Nashville, TN.</p> <p>Wellness Conference on MBSR for Pediatric Residents. (April, 2017). Vanderbilt University, Nashville, TN.</p> <p>Four-week MBSR courses for Gilda’s Club Members.<sup>a</sup> (May, June, 2017).Vanderbilt University, Nashville, TN.</p> <p>Brief Online Training series designed by key personnel (set of eight lessons, geared toward teachers) covering a curriculum similar to the MBSR sessions.</p> <p>Two key personnel are working with a middle school in Metro Nashville Public Schools to lead a mindfulness group for teachers.</p> <p>As a result of their participation in this study, three of the four MBSR therapists who worked on the study have pursued advanced mindfulness coursework to enhance their ability to train others on mindfulness. The course is called “An Introduction to Mindfulness for Educators.”</p>
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<sup>a</sup> Gilda’s Club Members are individuals who are cancer patients, cancer survivors, and/or family members of cancer patients/survivors.

## 10. Comprehensive Communication Intervention for Minimally Verbal Children With Autism, Vanderbilt University

<b>Brief Description of Study</b>	<p><b>Purpose:</b> This study built on the existing Joint Attention, Structured Play, Engagement and Regulation and Enhanced Milieu Teaching (JASP-EMT) intervention to test the effectiveness of a comprehensive communication intervention (i.e., JASP-EMT-Plus, or JEP), which includes a direct teaching component to improve spoken language and social communication and to reduce the portion of children with autism who are minimally verbal at age 5.</p> <p><b>Methods:</b> Ninety-seven children aged 36 to 54 months were randomly assigned to an intervention (i.e., JEP) or a control condition, which received usual care. In the intervention condition, children received a comprehensive assessment linking their extant communication skills to the skills taught in the intervention, thus adapting the protocol for each child within the framework of the treatment model. The intervention included 42 sessions over a 3-month period, and assessments were conducted at 4 time points: preintervention, postintervention, 2 months postintervention, and 4 months postintervention.</p> <p><b>Outcomes:</b> Though the study was completed by the end of the evaluation period (December 2017), data analysis was still ongoing. Results were not available for publication with this report.</p>
<b>Problem or Issue Addressed</b>	<p>Nearly one-third of children with autism remain minimally verbal after years of intervention. Children with autism who are minimally verbal (fewer than 20 words used communicatively) are an extremely heterogeneous population. Although there are specific factors that increase risk for remaining nonverbal (early emergent responsive joint attention, lack of verbal imitation, reduced object interest), any child with autism who is not yet using spoken language by age 4 should be considered at high risk for remaining minimally verbal. This randomized controlled trial will test the effectiveness of a comprehensive communication intervention (i.e., JASP-EMT-Plus, or JEP) to improve spoken language and social communication and to reduce the portion of children with autism who are minimally verbal at age 5.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>● Examine the effects of JEP on social communication. Specifically, do children with ASD who receive JEP produce significantly more social communication than the control condition at each postintervention assessment?</li> <li>● Examine the effects of JEP parent training on parent social communication strategies. Specifically, do parents in the JEP intervention use more social communicative support strategies at each postintervention assessment, and does use of these strategies predict long-term child social communication outcomes?</li> <li>● Examine moderators of JEP intervention outcomes. Specifically, do receptive language, imitation, and/or joint attention behaviors predict response to treatment and/or persistently minimally verbal status?</li> </ul>

<b>Study Methodology</b>	<p>The intervention includes four components:</p> <ul style="list-style-type: none"> <li>● Direct teaching for foundational language skills</li> <li>● Systematic introduction of a speech-generating device paired with spoken language</li> <li>● A naturalistic communication intervention: Joint Attention, Structured Play, Engagement and Regulation and Enhanced Milieu Teaching (JASP-EMT)</li> <li>● Parent training to support and generalize newly learned communication skills.</li> </ul> <p>Ninety-seven children aged 36 to 54 months were randomly assigned to an intervention (i.e., JEP) or a control condition, which received usual care. In the intervention condition, children received a comprehensive assessment linking their extant communication skills to the skills taught in the intervention, thus adapting the protocol for each child within the framework of the treatment model. The intervention included 42 sessions over a 3-month period, and assessments were conducted at 4 time points: preintervention, postintervention, 2 months postintervention and 4 months postintervention</p>
<b>Extant Data Sources</b>	<p>No extant data sources were used. This study collected primary data.</p>
<b>Specific Populations Targeted</b>	<p>Children aged 36 to 54 months with a diagnosis of ASD on the ADOS-2 were the target population for the study. Participants could have no other diagnosis of disability, had to have normal hearing and vision, speak English at home, use fewer than 20 social communicative utterances in a 20-minute language sample, and demonstrate cognitive functioning of at least 12 months on the Mullen Scales Early Learning. The study required that parents provide informed consent to the training portion of the intervention and to their child’s participation.</p>
<b>Underserved Populations</b>	<p>By the second year of the study, 31 percent of children recruited were from high-need and/or diverse backgrounds. The study also developed collaborative relationships with six community organizations or local agencies that serve high-needs and/or diverse families and provided them with intervention strategies and materials to share with the populations they serve.</p>
<b>Geographic Areas</b>	<p>Participants were recruited from Nashville, Tennessee, and surrounding rural areas. Study participation involved in-person meetings in the city of Nashville; therefore the ability to travel to Nashville, Tennessee, was part of the study inclusion criteria.</p>
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>● Recruitment and attrition represented a barrier with this population. Many in this age group were newly diagnosed and were beginning other kinds of therapies, along with starting school. Despite being only a 3-hour intervention, the time commitment was still a barrier to recruitment and reaching low-income and diverse populations.</li> <li>● To provide an incentive to participate, families were given an iPad to use as a communication device and encourage communication with their children. However, the research team learned the iPad created additional challenges for parents participating in the intervention and concluded they would not likely use iPads as an incentive in future studies. The study team felt iPads may be useful as an intervention tool.</li> </ul>

<p><b>Impact or Outcomes</b></p>	<p><b>Research outcomes:</b> Results of the study were ongoing at the end of the study period (December 2017); however, preliminary outcomes were available.</p> <p><b>Preliminary study outcomes and other study impacts</b></p> <ul style="list-style-type: none"> <li>● <b>Intervention training was well received by parents.</b> Parents who received training in the JEP intervention rated the intervention strategies highly. On average, parents who received the intervention rated it as a 4.95 (of 5) on effectiveness, 4.76 on their own competence posttraining as a language teacher for their child, and 4.74 as a worthwhile use of their time.</li> <li>● <b>Communication skills of the study population.</b> The population of children in the study who had fewer than 20 words at the age of 3 was highly variable, with a range of 49 to 103 on the Mullen Early Learning Composite, 50 to 130 on the PLS Total Language Standard Score, and 5 to 10 on the ADOS Severity Score.</li> <li>● <b>Service utilization of the study population.</b> Parents reported their children were receiving a range of outside services, including behaviorally based services, speech services, and occupational therapy services. The amount of outside services ranged between 1 hour per week and 36 hours per week.</li> <li>● <b>Intervention fidelity.</b> Fidelity of implementation for child intervention and parent training was consistently high throughout the study.</li> <li>● <b>Fidelity of intervention measures.</b> Measures were administered with high fidelity and data were transcribed and coded with high levels of reliability.</li> </ul>
<p><b>Dissemination Plans</b></p>	<p><b>Manuscripts in progress</b></p> <p>Fuller, E. A., Kaiser, A. P., &amp; Hampton, L. H. (in progress). <i>Understanding mediators and moderators of an adaptive communication intervention for young children with autism spectrum disorders.</i></p> <p>Fuller, E. A., Kaiser, A. P., &amp; Hampton, L. H. (in progress). <i>Understanding language sampling for children with autism using G-theory.</i></p> <p>Kaiser, A. P., Hampton, A. K., &amp; Fuller, E. A. (in progress). <i>Comprehensive communication intervention for minimally verbal children with autism.</i></p> <p><b>Other dissemination activities</b></p> <p>Emerging researchers from three universities (Vanderbilt University, Lipscomb University, and Belmont University) were trained in the complexities of a large randomized control trial; specifically, eight undergraduate and graduate student interns, four graduate students in special education.</p> <p>As part of the study, 73 families were trained in a responsive language intervention. All handouts used in the three parent training workshops are posted on the website <a href="http://vkc.mc.vanderbilt.edu/kidtalk/kidtalk-hrsa/">http://vkc.mc.vanderbilt.edu/kidtalk/kidtalk-hrsa/</a>.</p>

<p><b>Publications Generated</b></p>	<p><b>Peer-reviewed articles</b></p> <p>Hampton, L. H., &amp; Kaiser, A. P. (2016). Early intervention effects on spoken language outcomes for children with autism: A systematic review and meta-analysis. Special Issue. <i>Journal of Intellectual Disability Research</i> 60(5), 444–463. doi: 10.1111/jir.12283</p> <p>Kaiser, A. P., Hampton, L. H., &amp; Roberts, M. Y. (2016). Parents as partners in effective communication intervention. Invited chapter. In R. A. Sevcik and M. Ronski (Eds.), <i>Communication interventions for children with severe disabilities</i>. Baltimore, MD: Paul H. Brookes Publishers.</p> <p>Kaiser, A. P., &amp; Hampton, L. H. (in press). Enhanced milieu teaching. Invited chapter. In R. J. McCauley and M. E. Fey (Eds.), <i>Treatment of language disorders in children</i>, 2nd ed. Baltimore, MD: Paul H. Brookes Publishers.</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Hampton, L. H., Thompson, S., &amp; Jordan, S. (2015, August). <i>Teach-Model-Coach-Review: Training parents and teachers to implement language intervention</i>. Presented at the annual Vanderbilt School Speech-Language Pathologist Conference, Nashville, TN.</p> <p>Kaiser, A. P., Hampton, L. H., &amp; Fuller, E. A. (2016a, March). <i>Enhanced milieu teaching</i>. Presented at the Alpha School, Cape Town, South Africa.</p> <p>Kaiser, A. P., Hampton, L. H., &amp; Fuller, E. A. (2016b, March). <i>Enhanced milieu teaching</i>. Presented at the University of Cape Town, Cape Town, South Africa.</p> <p>Thompson, S. S., Jordan, S., Quinn, E., &amp; Kaiser, A. P. (2015, May). <i>Building best practices: The Teach-Model-Coach-Review model of parent training</i>. Presented at the Building Best Practices Conference for early interventionists, Murfreesboro, TN.</p>
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## Autism-SDAR

### 1. Peer-Victimization of Adolescents With ASD: Filling the Knowledge Gaps To Create Anti-Bullying Interventions, University of California, San Francisco

<b>Brief Description of Study</b>	<p><b>Purpose:</b> The study aimed to examine peer victimization in adolescents with ASD who spend most of their day in a regular education setting. Specifically, the study examined relationships between peer victimization and both academic outcomes and ASD symptoms.</p> <p><b>Method:</b> Data from parent surveys completed through the Interactive Autism Network (IAN) were analyzed for relationships between academic outcomes and ASD symptoms.</p> <p><b>Outcomes:</b> The strongest, most consistent associations were between verbal or relational victimization and academic outcomes. Physical victimization had the weakest association with academic outcomes, though further study is needed. Poor hygiene and frequent meltdowns were associated with higher likelihood of experiencing peer victimization. These findings suggest social skills interventions could be targeted to reduce peer victimization for adolescents with ASD.</p>
<b>Problem or Issue Addressed</b>	<p>No previous studies have tested associations between peer victimization and poor academic outcomes among students with ASD in an inclusive setting, nor has any study examined the relationships between specific ASD behavioral characteristics (i.e., ASD symptoms) and peer victimization. This study explored what types of bullying were most likely to affect academic performance for adolescents with ASD and why adolescents with ASD experienced increased rates of bullying.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>• Examine peer victimization in adolescents with ASD and its associations with academic outcomes.</li> <li>• Examine peer victimization in adolescents with ASD and its associations with ASD symptoms.</li> </ul>
<b>Study Methodology</b>	<p>The IAN survey data—in particular, the 20-minute Bullying and School Experiences of Children with ASD Survey—were analyzed for this study. The study variables were operationalized as follows:</p> <ul style="list-style-type: none"> <li>• To measure peer victimization, parents were asked in what ways their child was bullied during the past month by selecting from a list of possible types of peer victimization (e.g., verbal, physical, relational, provoking).</li> <li>• To measure school-based well-being and academic performance, parents were asked about students’ enjoyment of school, feelings of belonging, feelings of safety, academic performance, academic problems, and social problems.</li> <li>• To measure ASD symptoms that may be linked to being bullied, parents were asked to indicate whether their child had any unusual behaviors or issues children with ASD can have. Parents were asked to select all that apply from a list of 17 possible responses (plus an option that their child had none of the 17 responses). Seven items were not correlated with any of the four types of bullying in preliminary analyses; therefore, only 10 of the 17 behaviors or issues were analyzed in this study.</li> </ul>

<b>Study Methodology (continued)</b>	A series of multiple regressions (i.e., outcomes of enjoys, belongs, and safe at school and academic performance) and logistic regressions (i.e., outcomes of academic and social problems) were performed to examine the associations between peer victimization and academic outcomes. Four logistic regressions were performed to examine the associations between bullying and ASD symptoms. For each logistic regression, 1 of the four types of bullying was the outcome measure, and all 10 of the symptoms were entered at the same time. Gender and age were added to each model as control variables.
<b>Extant Data Sources</b>	Data came from a survey completed by parents recruited from a national registry of families, the IAN. A total of 1,221 parents completed the web-based, 63-item, 20-minute Bullying and School Experiences of Children with ASD Survey. Of these parents, 432 met the criteria for and were included in the analysis of academic outcomes and 279 were included in the study of ASD symptoms.
<b>Specific Populations Targeted</b>	Children with a diagnosis of ASD from a medical professional, aged 10–18 (grades 7–11), who spent at least half of the school day in a mainstream setting (as reported by their parent).
<b>Underserved Populations</b>	The study samples for each analysis did not appear to reach a large number of people from underserved populations. For both analyses, the sample participants were approximately 13 years of age, predominantly male (82–85 percent), White (91–93 percent), non-Hispanic (93–95 percent), and attended public school (90–94 percent).
<b>Geographic Areas</b>	The IAN is a national network.
<b>Study Limitations Addressed or Considered</b>	<p>Most of the limitations of the studies stem from reliance on existing data.</p> <ul style="list-style-type: none"> <li>• Because the study design is cross-sectional, the direction of the associations cannot be determined (i.e., it cannot be determined if victimization leads to school adjustment or if school adjustment leads to victimization). There are also issues of shared-method variance because one person completed all measures.</li> <li>• The fact that all the academic outcome measures were single-item measures raises concerns about measurement error of these constructs. However, these initial findings can be followed up with future studies that test whether reductions in these behaviors lead to reductions in peer victimization experiences.</li> </ul>
<b>Impact or Outcomes</b>	<ul style="list-style-type: none"> <li>• <b>Peer victimization and academic outcomes.</b> The strongest and most consistent associations with the academic outcome measures were verbal victimization and relational forms of victimization, including being ignored. Findings were not as consistent for those forms of peer victimization that are especially unique to ASD (e.g., peers using knowledge of what bothers them to provoke them to be aggressive), but these forms of peer victimization had some of the strongest associations with negative academic outcomes, such as disobedience at school, poor school work, and social problems at school. Physical victimization had the least consistent and weakest associations with academic outcomes. Overall, the strongest effects of peer victimization were seen for disobedience at school and for social problems. Alternatively, some of the findings for similar academic constructs were inconsistent with one another. Further study is needed.</li> <li>• <b>Peer victimization and ASD symptoms.</b> This study indicates several individual characteristics, including poor hygiene and frequent meltdowns, appear to be associated with a higher likelihood of experiencing peer victimization. This finding is important because it suggests potential treatment options that could be specifically targeted in social skills interventions for adolescents with ASD to reduce peer victimization of these adolescents.</li> </ul>

<b>Dissemination Plans</b>	<p><b>Publications in progress:</b></p> <p>Bishop, S., Taylor, J., &amp; Adams, R. (in progress). <i>Individual-level characteristics as predictors of peer victimization in adolescents with ASD</i>. In preparation.</p>
<b>Publications Generated</b>	<p><b>Publications</b></p> <p>Adams, R., Taylor, J., Duncan, A., &amp; Bishop, S. (2016). Peer victimization and educational outcomes in mainstreamed adolescents with autism spectrum disorder (ASD). <i>Journal of Autism and Developmental Disorders</i>, 46(11), 3557–3566. doi:10.1007/s10803-016-2893-3</p> <p><b>Conference presentations</b></p> <p>Adams, R., Bishop, S. L., Fredstrom, B. K., Gotham, K., &amp; Lord, C. (2015, March). <i>Loneliness and friendships predicting depressive symptoms in adolescents with ASD</i>. Symposium paper presented at the Society for Research on Child Development, Philadelphia, PA.</p> <p>Bishop, S. L., Adams, R., Gotham, K., &amp; Lord, C. (2015, May). <i>Longitudinal associations between social experiences and depression for youth with autism spectrum disorders</i>. Symposium paper presented at the International Meeting for Autism Research, Salt Lake City, UT.</p> <p>Bishop, S. L., &amp; Adams, R. (2017, March). <i>Individual behavioral characteristics associated with negative peer experiences in adolescents with ASD</i>. Presented at the Gatlinburg Conference, San Antonio, TX.</p>

## 2. A Longitudinal Analysis of Maternal Depression and its Associations With Child Obesity and Healthcare Use, American University and University of Maryland College Park

<b>Brief Description of Study</b>	<p><b>Purpose:</b> Depression affects 13 to 24 percent of mothers with young children and has implications for children’s cognitive, social-emotional, and behavioral development. Limited research has demonstrated maternal depression negatively affects the health and food security of young children, but the effects on children’s eating habits and obesity have received even less attention. This is one of the first studies in the United States to longitudinally examine the associations between maternal depression, child obesity, the moderating effect of children’s healthcare use, and the mediating effect of parenting behaviors using a nationally representative sample.</p> <p><b>Methods:</b> Ordinary least squares (OLS) regression models, linear probability models (LPM), and child fixed effects (FE) models were estimated using five waves of data from the Early Childhood Longitudinal Study-Birth Cohort (ECLS-B) to explore hypothesized associations between all variables.</p> <p><b>Outcomes:</b> The study found an association between maternal depression and mother’s report of children’s consumption of unhealthy foods. Maternal depression was associated with a higher likelihood of child body mass index (BMI) only in families where both parents lack a college degree. Higher maternal depression at 9 months postpartum was associated with a small decrease in the odds her infant was obese or overweight. Receipt of more well-child visits strengthens this relationship. The presence and duration of maternal depressive symptoms during early childhood were associated with poorer parenting behaviors related to children’s eating and physical activity patterns.</p>
<b>Problem or Issue Addressed</b>	<p>In the United States, 17 percent of children aged 2 to 19 are considered obese and 31 percent are considered overweight. Research has demonstrated maternal depression, which affects 13 to 24 percent of mothers, may negatively affect the general health and food security of children. No prior research has conducted longitudinal analysis of how maternal depression may contribute to child obesity. The study also examines how children’s eating habits and parenting behaviors mediate this relationship and how well-visits moderate this relationship.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>● Estimate the associations between maternal depression and children’s weight outcomes.</li> <li>● Examine the extent to which the associations between maternal depression and children’s weight outcomes are mediated by children’s eating habits.</li> <li>● Examine the extent to which the associations between maternal depression and children’s weight outcomes are moderated by children’s healthcare use.</li> </ul>
<b>Study Methodology</b>	<p>This project used longitudinal analyses to limit the potential biases resulting from unmeasured differences between children, which could have an influence on their likelihood of experiencing both the effect of a mother’s depression and obesity. Researchers used OLS regression models, LPM, including a range of family and child covariates, and within-child FE models that exploit within-individual changes in predictors and outcomes over time, thereby using each child as his or her own counterfactual. The study used cross-sectional OLS and logit analyses to explore the moderating effects of well-child visits.</p>
<b>Extant Data Sources</b>	<p>Early Childhood Longitudinal Study-Birth Cohort (ECLS-B)</p>

<b>Specific Populations Targeted</b>	The baseline sample of approximately 10,700 children was designed to be nationally representative of children born in the United States in 2001 with an over-sample of Asian and American-Indian children, twins, and low- and very-low-birthweight children.
<b>Underserved Populations</b>	N/A
<b>Geographic Areas</b>	No specific geographic area was sampled. The sample is nationally representative.
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>• The relationships between maternal depressive symptoms, child obesity, and parenting behaviors identified cannot be interpreted as causal or directional; results represent cross-sectional associations, and it is important to consider that associations may be driven by time-invariant characteristics.</li> <li>• Several measures were self- or mother-reported. Self-reported measures of depressive symptoms were used as a proxy for depression, as opposed to a clinical diagnosis of maternal depression, which would be the most objective measure. Measures of children’s food consumption were based on mother’s reporting and may not be as valid as possible.</li> <li>• Attrition and nonresponse were a challenge with pooled data across waves of data collection.</li> <li>• The study chose to use weight and height standards recommended by the Centers for Disease Control and Prevention, which differ from the World Health Organization (WHO) standards. The WHO standards are based on a broader sample of children.</li> </ul>

<p><b>Impact or Outcomes</b></p>	<ul style="list-style-type: none"> <li>● <b>Maternal depression, children’s eating habits and weight outcomes:</b> In the nationally representative sample, results indicate mothers’ depressive symptoms are associated with less healthy food consumption among young children; however, the study found little evidence that maternal depressive symptoms are associated with children’s weight outcomes across the general population. In a subsample of families where neither parent has a college degree, the duration of a child’s exposure to maternal depressive symptoms was associated with a small increase in the likelihood of being obese. Future research should examine the mechanisms underlying these differences, such as meal routines, physical activity, or stress-induced metabolic changes, in families with less educational attainment.</li> <li>● <b>Maternal depression, well-child visits, and children’s weight outcomes:</b> Maternal depressive symptoms, measured at 9 months, are associated with a slightly lower likelihood of obesity and overweight among infants. There is some evidence well-child visits are associated with lower odds of overweight among children of mothers with higher depression scores. Although the causal directions and mechanisms remain unclear, findings suggest well-child visits may provide an opportunity to educate parents about healthy eating habits, potentially benefitting the weight outcomes of children at risk for overweight.</li> <li>● <b>Maternal depression, parenting behaviors, and access to healthcare services:</b> Compared with mothers without depressive symptoms, the children of mothers with moderate or severe depressive symptoms are less likely to eat at regular times, go to sleep before 9 p.m., and have rules regarding the foods they eat. They are more likely to go to bed with a bottle, and they watch more television than children of mothers with mild or no depressive symptoms. The use of a doctor’s office or clinic for routine healthcare does not mitigate most of the above associations; however, it does reduce the association between maternal depressive symptoms and going to bed with a bottle. Future research should investigate whether parenting practices are a mechanism through which maternal depressive symptoms affect children’s growth and weight outcomes, and whether interventions in primary healthcare settings may mitigate these associations.</li> </ul>
<p><b>Dissemination Plans</b></p>	<p>The results of the study were disseminated through three peer-reviewed journal publications and two conference presentations.</p>
<p><b>Publications Generated</b></p>	<p><b>Peer-reviewed articles</b></p> <p>Morrissey, T. W., &amp; Dagher, R. K. (2014). A longitudinal analysis of maternal depressive symptoms and children’s food consumption and weight outcomes. <i>Public Health Nutrition</i>, 15, 1–10.</p> <p>Dagher, R. K., &amp; Morrissey, T. W. (2015). Postpartum depressive symptoms and child weight outcomes: Do well-child visits make a difference? <i>Journal of Women’s Health Issues &amp; Care</i>, 4(2), 1–11.</p> <p>Morrissey, T. W. (2014). Maternal depressive symptom and weight-related parenting behaviors. <i>Maternal and Child Health Journal</i>, 18(6), 1328–1335.</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Morrissey, T. W., &amp; Dagher, R. K. (2012, October). <i>A longitudinal analysis of maternal depressive symptoms and children’s food consumption and weight outcomes</i>. Presented at the American Public Health Association 140th Annual Meeting, San Francisco, CA.</p> <p>Morrissey, T. W., &amp; Dagher, R.K. (2013, April). <i>A longitudinal analysis of maternal depressive symptoms and children’s food consumption and weight outcomes</i>. Presented at the Society for Research in Child Development Biennial Meeting, Seattle, WA.</p>

### 3. Medical Care Utilization and Costs Among Transition-Aged Young Adult Medicare Beneficiaries With Autism Spectrum Disorder, Florida State University

<b>Brief Description of Study</b>	<p><b>Purpose:</b> This study examined healthcare use and costs associated with medical care among transition-aged young adults with ASD who are moving from pediatric to adult care providers. The study also analyzed racial and ethnic differences in utilization and potential disparities between young adults with ASD and young adults with other intellectual disabilities (IDs).</p> <p><b>Methods:</b> The Centers for Medicare &amp; Medicaid Services (CMS) Limited Data Set (LDS) for 2008–2010 was used for this secondary data analysis study. First, the researchers conducted a descriptive analysis of utilization and costs associated with medical care encounters among transition-aged young adults with ASD by examining racial and ethnic groups within that population. Next, <i>t</i>-tests and other multivariable approaches examined differences between individuals with ASD and individuals with other IDs, controlling for characteristics that invariably affect health outcomes.</p> <p><b>Outcomes:</b> Preliminary analyses suggest differences exist in the likelihood of experiencing a potentially preventable hospitalization (PPH). The ID-only group was more likely than the ASD-only group to have a PPH.</p>
<b>Problem or Issue Addressed</b>	<p>Disparities have been noted for some racial and ethnic minorities in the type and amount of ASD services received. No studies on service utilization or healthcare costs have been done to understand healthcare young adults with ASD over the age of 20 receive, and no studies have examined utilization and costs among different racial or ethnic groups. Identifying transition-aged adult healthcare use and costs for persons with ASD is of critical importance for families of persons with ASD who need to plan for care. It is also important from a systems perspective to ensure providers and systems are prepared to address the needs of the transition-aged young adults. A greater understanding of the service use and costs associated with that use will fill a void in the literature and will contribute to policy and practice aimed at improving transition care for this group, especially for underrepresented minorities.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>● Summarize utilization and costs of services (hospital-based services, ambulatory services, therapy services) among young adults with ASD aged 18–25 in Medicare fee-for-service 100 percent or 5 percent national sample of beneficiaries’ claims (years 2008–2010).</li> <li>● Examine differences in utilization and costs among racial and ethnic subgroups.</li> <li>● Compare utilization and costs between young adults with ASD with an age-, sex- and comorbidity-matched sample of persons with ID.</li> </ul>
<b>Study Methodology</b>	<p>The CMS Medicare LDS for 2008–2010 was used for this secondary data analysis study. Researchers identified all individuals with at least one diagnosis of ASD and/or one ID diagnosis on claim records. All Medicare claims associated the identified individuals were extracted for 2008–2010. Researchers conducted a descriptive analysis of utilization and costs associated with medical care encounters among transition-aged young adults with ASD by examining racial and ethnic groups within that population. Next, <i>t</i>-tests and other multivariable approaches examined differences between individuals with ASD and individuals with other IDs, controlling for characteristics that invariably affect health outcomes.</p>

<b>Extant Data Sources</b>	The study used the CMS Medicare LDS for 2008–2010. Most ASD studies of utilization and cost look at Medicaid and private health system data because they examine a pediatric population. However, this study looked at young adults with ASD aged 21–25, 65 percent of whom receive disability insurance through their parent’s Old Age Survivor Benefits or through their own work history.
<b>Specific Populations Targeted</b>	The study targeted transition-aged youth with ASD and a comparison population of youth with ID. All study youths aged 18 or older were observed for 1 to 3 years.
<b>Underserved Populations</b>	This study examined racial and ethnic disparities in healthcare utilization and costs, and differences between young adults with ASD and young adults with other IDs. Comparisons were made between youths identified as White versus all minority youths, defined as youths identified as Black, Hispanic, or Native American.
<b>Geographic Areas</b>	No specific geographic area was sampled. The sample is nationally representative.
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>• One limitation of this analysis is the lack of Medicaid claims data available to examine utilization by young adults who have received a disability determination and therefore are also eligible for Medicare. For persons with dual eligibility (i.e., persons eligible for both Medicaid and Medicare), Medicare is the primary payer and therefore provides a more complete picture of utilization and costs for covered services common to both plans than Medicaid alone.</li> <li>• The study was unable to measure prescription drug utilization because those records are not available with the CMS LDS.</li> <li>• The use of one instance of an ASD claim versus two or more instances may have diluted the apparent impact of ASD utilization and costs per person if false positive cases were included. Unpublished analysis suggests using two or more criteria for claim instances to define a case reduces the analytic population by half but probably identifies ASD cases with more specificity.</li> <li>• It is likely that the reason for Medicare eligibility is related to a disability determination because of ASD or ID. Without access to SSA disability eligibility files, it is not possible to know with certainty the reason for an individual’s disability determination.</li> </ul>

<p><b>Impact or Outcomes</b></p>	<ul style="list-style-type: none"> <li>● <b>Differences in inpatient hospital-based service utilization and cost.</b> A high proportion of the ASD and ID population aged 18–25 in the Medicare FFS data use inpatient hospital services. Overall, 28.4 percent of the study population had 1 or more hospital discharges in 2010. This percentage compares with only 6.0 percent in the general population aged 18–44. Mean expenditures per person with 1 or more discharges were ~\$19,000 for the study population and are also high relative to the national per person average for the 18–44 age group (\$12,282).</li> <li>● <b>Differences in emergency department (ED) service utilization and cost.</b> An even higher proportion of the study population accessed ED services (48.9 percent) as compared with national estimates for the general population of about 10.8 percent for the 18–44 age population. Mean reimbursement in the general population was \$1,467 versus \$1,038 in this study’s population. It is unclear whether this difference reflects lower reimbursement rates for Medicare or some other factor possibility associated with the reasons ASD families access EDs. Although not all inpatient and ED events are avoidable or preventable, the high utilization rates suggest a deficit in regular outpatient care.</li> <li>● <b>Differences in office-based primary care.</b> Preferences for ED use instead of outpatient physicians may be supported by the fact that 53 percent of the general U.S. population has some office-based physician utilization, whereas only 5–7 percent of the study population accessed a primary care physician in 2010 and only 6–9 percent accessed a specialty care physician.</li> <li>● <b>Differences in therapy service utilization.</b> Therapy service utilization, although lower than expected for the study population (3 to 6 percent), is somewhat exceeded by physical therapy and occupational therapy service utilization in the general population aged 18–44 (2.3 percent).</li> <li>● <b>Racial and ethnic disparities in utilization and costs.</b> No racial or ethnic disparities were identified in the utilization and costs measures used for this study.</li> </ul>
<p><b>Dissemination Plans</b></p>	<p><b>Manuscripts in progress</b></p> <p>Benevides T., Carretta H., &amp; Graves K. (under review). Case identification and characterization of autistic young adults in 2010 Medicare fee-for-service claims. <i>Autism in Adulthood</i>.</p> <p>Benevides, T., Carretta, H., &amp; Graves, K. (under review). <i>Emergency department utilization in transition-age young adult Medicare beneficiaries with autism spectrum disorder</i>.</p> <p>Carretta, H., Benevides, T., &amp; Graves, K. (submitted). <i>Overall hospitalization rates, preventable hospitalizations and hospitalizations associated with injury and associated costs among transition-age young adult Medicare beneficiaries with autism spectrum disorder</i>.</p>

<p><b>Publications Generated</b></p>	<p><b>Peer-reviewed abstracts</b></p> <p>Benevides, T. W., Carretta, H., &amp; Graves, K. (2017). Health care utilization and costs among transition-age young adult Medicare beneficiaries with autism spectrum disorder. <i>AJOT: The American Journal of Occupational Therapy</i>, 71. doi:10.5014/ajot.2017.71S1-PO1183</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Benevides, T., Carretta, H. J., &amp; Graves, K. (2017). <i>Characteristics and health conditions of publicly-insured autistic young adults</i>. Poster presented at the 2017 International Meeting for Autism Research, San Francisco, CA.</p> <p>Benevides, T., Carretta, H. J., &amp; Graves, K. (2017). <i>Healthcare utilization and costs among transition-age young adult Medicare beneficiaries with autism spectrum disorder</i>. Paper presented at the 2017 AOTA Annual Conference &amp; Centennial Celebration, Philadelphia, PA.</p> <p>Benevides, T., Carretta, H. J., &amp; Graves, K. (2017). <i>Preventable hospitalizations as a measure of health care quality for transition-age young adult Medicare beneficiaries with autism spectrum disorder</i>. Presented at the 2017 Annual Occupational Therapy Research Summit, Fort Worth, TX.</p> <p>Benevides, T., Carretta, H., &amp; Graves, K. (2016). <i>Medical care utilization and costs among transition-age young adult Medicare beneficiaries with autism spectrum disorder</i>. Poster presented at the 2016 International Meeting for Autism Research, Baltimore, MD.</p> <p>Carretta, H. J., Benevides, T., &amp; Graves, K. (2017). <i>Racial and ethnic differences in the utilization of emergency departments for transition age young adults with ASD only and ASD with ID</i>. Poster presented at the 2017 International Meeting for Autism Research, San Francisco, CA.</p> <p>Carretta, H. J., Graves, K., &amp; Benevides, T. (2015). <i>Prevalence and utilization of medical care services in persons with autism spectrum disorder using Medicare claims</i>. Poster presented at the American Public Health Association, Chicago, IL.</p> <p>Carretta, H. J., Graves, K., &amp; Benevides, T. (2015). <i>Use of Medicare claims as a source for research prevalence and utilization of medical care services in persons with autism spectrum disorder over and under age 65</i>. Poster presented at the 2015 International Meeting for Autism Research, Salt Lake City, UT.</p> <p>Carretta, H., Graves, K., &amp; Benevides, T. (2016, June). <i>Preventable hospitalizations as a measure of health care quality for transition-age young adult Medicare beneficiaries with autism spectrum disorder</i>. Poster presented at the Academy Health disability interest group, Boston, MA.</p> <p>Carretta, H., Graves, K., &amp; Benevides, T. (2016, June). <i>Preventable hospitalizations as a measure of health care quality for transition-age young adult Medicare beneficiaries with autism spectrum disorder</i>. Poster presented at the Academy Health annual research meeting, Boston, MA.</p> <p>Graves, K., Carretta, H., &amp; Benevides, T. (2017). <i>Autism spectrum disorder: Mortality and healthcare implications from the national mortality files</i>. Poster presented at the 2017 International Meeting for Autism Research, San Francisco, CA.</p> <p>Graves, K., Carretta, H., &amp; Benevides, T. (2016, November). <i>Preventable hospitalizations as a measure of health care quality for transition-age young adult Medicare beneficiaries with autism spectrum disorder</i>. Poster presented at the American Public Health Association meeting November 2016, Denver, CO.</p>
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#### 4. Racial and Ethnic Disparities in Autism Diagnosis and Educational Therapy Utilization: Quantifying the Contribution of Modifiable Mediators, Northwestern University

<b>Brief Description of Study</b>	<p><b>Purpose:</b> The purpose of the study was to advance understanding of the composition of racial and ethnic disparities in autism diagnosis and treatment among children using the framework and methods put forth in the Institute of Medicine’s (IOM) 2003 report <i>Unequal Treatment</i>. The study aimed to determine the extent to which geography (e.g., urban versus rural land use) contributes to racial and ethnic disparities in autism diagnosis and treatment. This study rigorously measured both racial and ethnic disparities and geographic barriers for children with ASD.</p> <p><b>Methods:</b> The Centers for Medicare &amp; Medicaid Services (CMS) Medicaid Analytic Extract for 2012 was used for this secondary data analysis study. Researchers analyzed service use for 9,347 unique Medicaid-enrolled children in Illinois with an ASD diagnosis in fiscal year (FY) 2012. Researchers defined nine types of service use and created measures for service use, the number of services used, and the mean expenditures for services during the FY. They also created independent variables related to patient need (i.e., gender, age, and co-occurring intellectual disability) and the operational functioning of the healthcare system, and several geographic variables reflecting the functioning of the healthcare system.</p> <p><b>Outcomes:</b> Researchers found significant racial and ethnic disparities in autism services overall among Medicaid-enrolled children with ASD. The most significant finding is that racial and ethnic disparities differ depending on the location of service (i.e., school- or community-based service). Specifically, African-American and Hispanic Medicaid-enrolled youth with ASD are more likely to received school-based services than White children and are less likely to receive non-school-based services than White children. This racial disparity persists by urban versus rural land use type for school-based services. It only persists for Black children (not Hispanic children) by urban versus rural land use type for non-school-based services.</p>
<b>Problem or Issue Addressed</b>	<p>There has been no systematic study of racial and ethnic disparities in autism diagnosis and treatment that attempts to decompose racial and ethnic differences according to the Institute of Medicine’s definition and explain the contribution of geographic variation (e.g., urban versus rural land use). This project fills the gap in the understanding of racial and ethnic disparities in the field of autism services. A more complete understanding of the composition of disparities is important because strategies to reduce true racial and ethnic disparities may require a fundamentally different approach than strategies needed to reduce geographic differences.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>● Describe racial and ethnic disparities in the prevalence of autism service use (developmental assessment, diagnostic services, educational therapies, and case management) among Medicaid-enrolled children with ASD.</li> <li>● Describe racial and ethnic disparities in expenditures for autism treatment among Medicaid-enrolled children with ASD.</li> <li>● Identify the independent contribution of geography (e.g., urban versus rural land use) to racial and ethnic disparities in the prevalence of autism diagnosis and expenditures for treatment among Medicaid-enrolled children with ASD.</li> </ul>

<b>Study Methodology</b>	<p>The CMS Medicaid Analytic Extract for 2012 was used for this secondary data analysis study. Researchers analyzed service use for 9,347 unique Medicaid-enrolled children in Illinois with an ASD diagnosis in FY2012. Researchers defined nine types of service use and created measures for service use, the number of services used, and the mean expenditures for services during the FY.</p> <p>Dependent variables for the study included dichotomous measures of service use and continuous Medicaid expenditures. Services included diagnostic, educational therapies, and case management. Diagnostic services included one-on-one services related to diagnosis or assessment. The primary independent variable in the analysis was a combined race and ethnicity eight-level categorical variable that defines the following groups: White non-Hispanic (NH), Black NH, Hispanic (includes Mexican, Puerto Rican, Cuban, and other South American), American Indian or Alaska Native, Asian, Native Hawaiian or Pacific Islander, multiracial, or missing. Researchers tested hypotheses about the impact of mediators on racial differences between White NH, Black NH, and Hispanic children. Spatial analysis using Geographic Information System methods was used to create several mediators of disparity.</p>
<b>Extant Data Sources</b>	Medicaid Analytic Extract (Medicaid claims data) for Illinois from 2012 (obtained from CMS)
<b>Specific Populations Targeted</b>	Children with ASD insured through the State of Illinois Medicaid program in calendar year 2012
<b>Underserved Populations</b>	All study participants were enrolled in Medicaid, a program that provides health insurance support to low-income or underserved populations.
<b>Geographic Areas</b>	The sample was drawn from the State of Illinois.
<b>Study Limitations Addressed or Considered</b>	The study encountered a significant challenge related to the use of the dataset that was originally planned for the study. Researchers had to purchase alternative data to complete the project and disseminate the study findings.
<b>Impact or Outcomes</b>	<ul style="list-style-type: none"> <li>• There were significant racial and ethnic disparities in autism services overall among Medicaid-enrolled children with ASD. The most significant finding is that racial and ethnic disparities differ depending on the location of service (i.e., school- or community-based service).</li> <li>• There were significant disparities in expenditures for autism treatment among Medicaid-enrolled children with ASD.</li> <li>• African-American and Hispanic Medicaid-enrolled youth with ASD are more likely to received school-based services than White children and are less likely to receive non-school-based services than White children. This racial disparity persists by urban versus rural land use type for school-based services. It only persists for African-American children (not Hispanic children) by urban versus rural land use type for non-school-based services.</li> </ul>
<b>Dissemination Plans</b>	<p><b>Manuscripts in progress</b></p> <p>Bilaver, L., Weiner, D., &amp; Mandell, D. (in progress). <i>Explaining racial and ethnic disparities in autism service use among Medicaid-enrolled children: A decomposition analysis.</i></p> <p>Bilaver, L., &amp; Mandell, D. (in progress). <i>Racial and ethnic variation in 2012 Medicaid expenditures for autism-related service use.</i> Policy brief to be presented at Northwestern University.</p>

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<b>Publications Generated</b>	<b>Peer-reviewed scholarly conference presentations</b> Bilaver, L. (2016). <i>Racial and ethnic differences in the use of Medicaid-funded services for children with autism spectrum disorder</i> . Presented at the Academy Health 2016 Annual Research Meeting, Boston, MA.
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## 5. Trends in Racial and Ethnic Healthcare Disparities for Children With Autism/Developmental Disabilities, Brandeis University

<b>Brief Description of Study</b>	<p><b>Purpose:</b> The study examined whether racial and ethnic disparities in healthcare quality, access, and utilization for children with autism and other developmental disabilities (DDs) have diminished over time. Specifically, the study examined longitudinal population trends and correlates of disparities between Black, Latino, and White children with autism and other DDs.</p> <p><b>Methods:</b> A secondary analysis of data from the 2005–2006 and 2009–2010 waves of the National Survey of Children with Special Healthcare Needs (NS-CSHN) examined Black, White, and Latino children with autism and other DDs living in the United States. Descriptive bivariate analyses and multivariate logistic regression analyses were conducted in Stata 12.0.</p> <p><b>Outcomes:</b> Disparities in the quality of healthcare providers’ interactions with Black and Latino parents of children with autism and other DDs have not diminished from 2005 to 2010. Disparities between White and Latino children in healthcare access have persisted over the same time period. These findings suggest healthcare providers may benefit from training in cultural competency and integration of patient- and family-centered models of care.</p>
<b>Problem or Issue Addressed</b>	<p>In 2002, the Institutes of Medicine published a report that found racial and ethnic minorities, in contrast to Whites, receive less healthcare and obtain poorer quality health services, even when adjusting for age, income, insurance, and severity of condition. Since then, this study is the first longitudinal investigation of changes in racial and ethnic disparities in the quality, access, and utilization of healthcare among children with autism and other DDs.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>• Determine whether health disparities exist between White children and Latino or Black children on healthcare access, service utilization, and quality care.</li> <li>• Determine whether health disparities varied across years 2005–2006 and 2009–2010.</li> </ul>
<b>Study Methodology</b>	<p>Researchers used the Wald statistic to test bivariate associations between each covariate and healthcare quality outcomes. Covariates included family income, parental education, family structure, child’s severity of condition, and child’s lack of health insurance. An interaction term (year x race/ethnicity) was modeled to identify statistical difference across years and racial/ethnic groups. The independent measures included parent-reported race and ethnicity of the child and the year of the survey. The dependent measures included <b>access to care</b> (i.e., whether the child had been uninsured in the past year, type of insurance, public or private insurance, whether the insurance meets the child’s needs, and whether the child has a personal doctor or nurse), <b>health service utilization</b> (i.e., problems getting referrals for specialty care, unmet needs for care, number of visits, and receipt of preventative care), and <b>indicators of quality of care</b> (i.e., parental satisfaction with care, receipt of culturally competent care, receipt of professional care coordination, and whether provider spent enough time on child’s care). Child and family characteristics were included as multivariate model covariates (i.e., income, parental education, insurance coverage, child’s sex, and child’s age).</p>
<b>Extant Data Sources</b>	<p>The study used the NS-CSHN, a cross-sectional, random digit-dialed, computer-assisted telephone survey administered by the National Center for Health Statistics. The study examined data from 2005 to 2006 and from 2009 to 2010.</p>
<b>Specific Populations Targeted</b>	<p>Black, White, and Latino children (i.e., toddlers, preschool children, school-aged children, and adolescents) with autism and other developmental disabilities living in the United States in 2005–2006 and 2009–2010</p>

<b>Underserved Populations</b>	In the 2005–2006 sample, 13.4 percent of participants identified as Black, and 12.9 percent of participants identified as Latino. In the 2009–2010 sample, 10.6 percent of participants identified as Black, and 13.3 percent of participants identified as Latino.
<b>Geographic Areas</b>	No specific geographic area was sampled. The NS-CSHN is a national sample.
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>• Both quality of healthcare provider interactions and children’s diagnosis of autism or other DDs are self-reported by parents in the NS-CSHCN database.</li> <li>• Small sample sizes prevented analysis of disparities in healthcare access, service utilization, and quality among children from racial and ethnic groups that were not Black, Latino, or White—namely, Asian and American Indian.</li> <li>• There is significant State variability in health policy characteristics, particularly Medicaid, but the sample size of Latino and Black children was too small to examine State policy correlates of the disparities.</li> </ul>
<b>Impact or Outcomes</b>	<ul style="list-style-type: none"> <li>• <b>Ethnic disparities in quality of healthcare.</b> Disparities in the quality of healthcare provider interaction with Black and Latino parents have not diminished over time.</li> <li>• <b>ASD disparities in access to healthcare.</b> Healthcare access of Latino children with autism and other developmental disabilities has not improved over time.</li> <li>• <b>Ethnic disparities in access to healthcare.</b> Disparities between White and Latino children in healthcare access have persisted over time.</li> </ul>
<b>Dissemination Plans</b>	<p><b>Manuscripts submitted</b></p> <p>Parish, S. L., Magaña, S., &amp; Son, E. (under review). <i>The persistence of health care access disparities among Latino and white children with autism and other developmental disabilities.</i></p>
<b>Publications Generated</b>	<p><b>Peer-reviewed articles</b></p> <p>Magaña, S., Parish, S. L., &amp; Son, E. (2015). Have racial and ethnic disparities in the quality of health care relationships changed for children with developmental disabilities and ASD? <i>American Journal on Intellectual &amp; Developmental Disabilities, 120</i>(6), 504–513. doi:10.1352/1944-7558-120.6.504</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Magaña, S., Parish, S. L., &amp; Son, E. (2015, April). <i>Trends in racial disparities in quality of care for children with autism and other developmental disabilities.</i> Paper presentation at the 48th Annual Gatinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, New Orleans, LA.</p> <p>Parish, S. L., Magaña, S., &amp; Son, E. (2015, January). <i>Trends in racial disparities in quality of care for children with autism and other developmental disabilities.</i> Paper presentation at the Society for Social Work and Research, New Orleans, LA.</p> <p>Son, E., Parish, S. L., &amp; Magaña, S. (2014, June). <i>Trends in health care disparities among Latino children with autism and other developmental disabilities.</i> Poster presentation at the American Association on Intellectual and Developmental Disabilities (AAIDD) annual meeting, Orlando, FL.</p> <p><b>Policy briefs</b></p> <p>Magaña, S., Parish, S. L., Son, E., &amp; Igdalsky, L. (2014, November). <i>Racial disparities in the quality of health care provider interactions for children with autism and other developmental disabilities.</i> Lurie Institute on Disability Policy, Brandeis University, Waltham, MA.</p>

## 6. Racial and Ethnic Disparities in Diagnostic and Health Services of Children With Developmental Disabilities, Institute for Disability Policy, Brandeis University

<b>Brief Description of Study</b>	<p><b>Purpose:</b> This study assessed whether there are significant differences in pathways to diagnosis, early service utilization, and care among racial and ethnic minority children with autism/DD. Informed by Goldberg and Huxley’s pathways to care model, this study examined several stages of help-seeking, including parental perceptions of problems, use of primary care services, recognition within primary care, and referral to or use of specialty care services, among children with autism/DD.</p> <p><b>Methods:</b> Data were analyzed from two national surveys: the 2009/10 National Survey of Children with Special Health Care Needs and the Survey of Pathways to Diagnosis and Services for 2011. The study population consists of school-aged children (aged 6–17) with autism/DD (<math>N = 3,518</math>). Descriptive and bivariate analyses and multivariate modeling described the extent and correlates of racial and ethnic disparities in pathways to care.</p> <p><b>Outcomes:</b> This study found differences in quality of healthcare between non-Latino Asian and White children with special healthcare needs. Although there were no differences in service utilization between White and Latino children whose conditions were not severe, Latino children with severe conditions received significantly fewer services than their White peers. Finally, compared with White parents, Latino parents had four times higher odds of receiving a negative response from a provider (OR = 4.07, 95%CI: 1.37-12.08, <math>p &lt; 0.01</math>), indicating a difference in the pathway to diagnosis for White and Latino children.</p>
<b>Problem or Issue Addressed</b>	<p>Racial and ethnic healthcare disparities are persistent in the United States and represent a major U.S. public health problem. Prior to this study, little was known about racial and ethnic healthcare disparities for children with autism and other DDs.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>• Examine whether non-Latino Asian children with special healthcare needs have worse healthcare quality than non-Latino White children with special healthcare needs, independent of socioeconomic status, demographic characteristics, and severity of children’s impairments.</li> <li>• Examine whether ethnic disparities exist in ASD specialty services and condition severity between Latino and non-Latino White children with ASD and what role clinical need plays in relation to service utilization and ethnicity.</li> <li>• Examine ethnic disparities in medical provider responsiveness to parents of children with autism and other DDs when parents raised initial concerns about their child’s development. This aim attempts to understand drivers of disparities in age at diagnosis among Latino children with ASD and their White peers.</li> </ul>
<b>Study Methodology</b>	<p>To achieve all three research aims, both descriptive bivariate analyses and multivariate modeling were performed using Stata 12.0. All quantitative analyses were conducted using appropriate weighting and variance adjustment procedures to account for the complex sample design of the datasets (i.e., 2009/10 National Survey of Children with Special Health Care Needs and the 2011 Survey of Pathways to Diagnosis and Services).</p>

<b>Extant Data Sources</b>	This study examined data from the 2009/10 National Survey of Children with Special Health Care Needs and the 2011 Survey of Pathways to Diagnosis and Services. The 2009/10 National Survey of Children with Special Health Care Needs was sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration and conducted by the Centers for Disease Control and Prevention’s National Center for Health Statistics. The National Survey is a cross-sectional, population-based, random digit-dial telephone survey, which used samples between 751 and 878 children with special healthcare needs from each State and the District of Columbia. The 2011 Survey of Pathways to Diagnosis and Services is a supplement to the 2009/10 National Survey of Children with Special Health Care Needs.
<b>Specific Populations Targeted</b>	The 2009/10 National Survey of Children with Special Health Care Needs provides data on infants, toddlers, preschool children, school-aged children, adolescents, and their parents/mothers/fathers. The first study aim focused on Asian and White children with special healthcare needs. The second and third study aims focused on White and Latino children with autism and other DDs.
<b>Underserved Populations</b>	Asian children with special healthcare needs, and Latino children with autism and other DDs
<b>Geographic Areas</b>	No specific geographic area was sampled. The sample is nationally representative.
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>● In the study of quality of healthcare for Asian children with special healthcare needs, the sample included children in 9 States where the population of Asian children met the minimum 5-percent threshold for making the data public without breaching confidentiality. Therefore, the results are not necessarily generalizable to all 50 States but do reflect responses of parents in the 9 sample States.</li> <li>● The data used for this study are based on self-report of parents or guardians, and there could be cultural differences in the way parents perceive quality of care. Furthermore, there was no clinical corroboration of the children’s condition or quality of care.</li> <li>● In the study of ethnic disparities in ASD specialty services and condition severity, when the data were collected, all interviews were conducted in English, excluding a significant subset of the Latino population living in the United States. Therefore, these findings likely have a conservative bias—the outcomes for the entire population of Latino children would likely be worse because non-English speakers would have lower rates of insurance and other access-related barriers to care.</li> <li>● Because Latino children are consistently underdiagnosed with ASD, Latino children who were diagnosed much later or who were never diagnosed are not represented in the sample.</li> <li>● The data on diagnosis and condition severity are drawn from parental reports and are subject to both social desirability bias and recall bias. However, there is no evidence indicating this bias would differ among parents of different ethnicities.</li> </ul>

<b>Impact or Outcomes</b>	<ul style="list-style-type: none"> <li>● <b>Ethnic disparities in healthcare quality.</b> The results of the bivariate analyses indicated there are differences in quality of healthcare between non-Latino Asian and White children with special healthcare needs. After controlling for a range of demographic factors, Asian children with special healthcare needs were significantly less likely to have a healthcare provider who offered the information they needed, helped parents feel like a partner in their child’s care, and was sensitive to family values and customs.</li> <li>● <b>Ethnic disparities in service utilization.</b> There were no differences in overall service utilization between White and Latino children whose conditions were not severe. However, Latino children with severe conditions received significantly fewer services than White children whose conditions were severe.</li> <li>● <b>Ethnic disparities in medical provider responsiveness.</b> Compared with White parents, Latino parents had four times higher odds of receiving a negative or nonproactive response from a provider (OR = 4.07, 95%CI: 1.37-12.08, <math>p &lt; 0.01</math>) after they initially reported perceiving problems with the child. There was no statistically significant relationship between Latino ethnicity and receiving any proactive provider response.</li> </ul>
<b>Dissemination Plans</b>	<p><b>Manuscripts in progress</b></p> <p>Parish, S. L., Magaña, S., Son, E., Martinez-Pedraza, F., &amp; Moring, N. F. S. (in progress). <i>Ethnic disparities in health care providers’ responsiveness to low-income parents’ concerns about their children with autism.</i></p>
<b>Publications Generated</b>	<p><b>Peer-reviewed articles</b></p> <p>Magaña, S., Parish, S. L., &amp; Son, E. (2016). Functional severity and Latino ethnicity in specialty services for children with autism spectrum disorder. <i>Journal of Intellectual Disability Research, 60</i>, 424–434. doi:10.1111/jir.12293</p> <p>Son, E., Igdalsky, L., &amp; Parish, S. L. (2017). Disparities in health care quality among Asian children with special health care needs. <i>Health &amp; Social Work, 42</i>, 95–102. doi:10.1093/hsw/hlx004</p> <p><b>Policy briefs</b></p> <p>Magaña, S., Parish, S. L., Son, E., &amp; Igdalsky, L. (2015, November). <i>Severity and Latino ethnicity in specialty services for children with autism spectrum disorder.</i> Waltham, MA: Lurie Institute for Disability Policy, Brandeis University.</p> <p>Magaña, S., Parish, S. L., Son, E., &amp; Igdalsky, L. (2014, November). <i>Racial disparities in the quality of health care provider interactions for children with autism and other developmental disabilities.</i> Waltham, MA: Lurie Institute for Disability Policy, Brandeis University. Retrieved from <a href="http://lurie.brandeis.edu/pdfs/disparity%20trends%20policy%20brief%20final.pdf">http://lurie.brandeis.edu/pdfs/disparity%20trends%20policy%20brief%20final.pdf</a></p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Parish, S. L., Magaña, S., &amp; Son, E. (2015, June). <i>The persistence of health care access disparities among Latino and White children with autism and other developmental disabilities.</i> Paper presented at the American Association on Intellectual and Developmental Disabilities, Louisville, KY.</p> <p>Son, E., Igdalsky, L., &amp; Parish, S. L. (2016, January). <i>Disparities in health care quality among Asian children with special health care needs.</i> Paper presented at the Annual meeting of the Society for Social Work Research, Washington, D.C.</p> <p>Parish, S. L., Magaña, S., Son, E., &amp; Igdalsky, L. (2017, January). <i>Ethnic disparities in health care providers’ response to parent concerns.</i> Paper presented at the Society for Social Work and Research, New Orleans, LA.</p> <p><b>Invited presentation</b></p> <p>Parish, S. L. (2015, April). <i>Racial and ethnic health care disparities for children with developmental disabilities.</i> Invited presentation at the University of Massachusetts, Lowell, MA.</p>

## 7. Tough Choices: Autism, Private Health Insurance and Family Out-of-Pocket Spending, University of North Carolina, Chapel Hill

<b>Brief Description of Study</b>	<p><b>Purpose:</b> Families who have children with autism continue to be more likely to report inadequate insurance and difficulties with access to care compared with families who have children with other special healthcare needs. The purpose of this study is to develop firmer evidence about the relationships between private health insurance plans and family needs. The researchers hypothesized that families value low-deductible plans and that low-deductible plans expose families to unanticipated expenditures.</p> <p><b>Methods:</b> Medical Expenditure Panel Survey (MEPS) data from 2002 to 2011 (<math>N = 346</math>) examined children with autism who also met the criteria for special needs. MEPS data were linked with the National Health Interview Survey (NHIS) data to determine family ratings of insurance plan adequacy, and State health insurance plan information was used to characterize plans as generous, moderate, or restrictive. Descriptive statistics provided child and family characteristics of children with autism and characteristics of insurance plans offered within and across States. For each child-plan pair from the MEPS and collected plans (<math>346 \times 100</math>), the researchers calculated the amount the plan would pay versus the amount the family would pay out of pocket. The child-plan level data were used to estimate ordinary least squares (OLS) regressions of log-transformed total medical expenditures paid by the family out of pocket.</p> <p><b>Outcomes:</b> This study found the mean annual total expenditures for all medical services for children with autism and special healthcare needs were \$6,316. Out-of-pocket costs were 13 percent of total costs. This study identified specific relationships between health insurance plan features and family out-of-pocket expenditures. State benchmarking and variation in coverage have an impact on children with autism. For example, 40 States mandate coverage of autism, but only 25 cover autism in their exchange policies. The study makes recommendations for policy changes that could simplify insurance plan decisions for families and describes future research and data needs to address these critical issues.</p>
<b>Problem or Issue Addressed</b>	<p>Previous studies have found insurance choices of families are influenced by out-of-pocket expenditures without regard to the breadth and depth of services covered. There is a gap in understanding how insurance plan features are associated with plan-paid versus family out-of-pocket spending.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>● Determine the private health insurance plan features and child service use experiences associated with family ratings of insurance plan adequacy.</li> <li>● Develop objective measures of plan quality for selected health insurance plans offered through State health insurance exchanges by generating family expenditures for premiums, copayments, and uncovered services.</li> <li>● Develop subjective measures of plan quality for selected insurance plans by simulating family ratings based on the model from aim 1 and the expenditures from aim 2 to highlight family choice strategies needing improvement.</li> </ul>

<b>Study Methodology</b>	<p>First, the MEPS data from 2002 to 2011 (<math>N = 346</math>) were restricted to include only children with autism who also met the study criteria for special needs. Next, State health insurance plan information was collected to characterize benchmark plans as generous, moderate, or restrictive, based on a study of the State rules regarding health insurance plan features. Plans with the largest plan-paid amount were considered most generous, and plans with the lowest plan-paid amount were considered least generous. MEPS data were then linked with the NHIS data to determine family ratings of insurance plan adequacy.</p> <p>The study focused on examining variables related to annual out-of-pocket expenditures, private health insurance plan features (i.e., deductible, outpatient visit copayment, outpatient stay coinsurance, inpatient visit copayment, and inpatient stay coinsurance), and volume of services (i.e., deductible, outpatient visit copayment, outpatient stay coinsurance, inpatient visit copayment, and inpatient stay coinsurance) used by children with autism.</p> <p>Descriptive statistics characterized the sample of children with autism by child and family characteristics, and by the benchmark plan features and plan offerings within and across States. For each child-plan pair from the MEPS and collected plans (<math>346 \times 100</math>), the researchers calculated the amount the plan would pay and the amount the family would pay out of pocket. The child-plan level data were used to estimate OLS regressions of log-transformed total medical expenditures paid by the family out of pocket.</p>
<b>Extant Data Sources</b>	<p>Extant data sources included the MEPS data from 2002 to 2012 and the NHIS data from 2002 to 2012. Also, State benchmark plans and related rules as of January 2015 were collected from Centers for Medicare &amp; Medicaid Services, National Center for State Legislators, Autism Speaks, and <i>U.S. News &amp; World Report</i>.</p>
<b>Specific Populations Targeted</b>	<p>Preschool children, school-aged children, adolescents, and their parents/mothers/fathers</p>
<b>Underserved Populations</b>	<p>The MEPS provides data from a complex national probability sample, with clustering of respondents within households and oversampling of low-income and minority households. This research contributes to the goal of eliminating health disparities and barriers to healthcare access for maternal and child health (MCH) populations, including ethnic, racial, cultural, linguistic, gender, developmental, geographic (rural, urban, frontier), immigrant, underserved, and/or economic considerations.</p>
<b>Geographic Areas</b>	<p>No specific geographic area was sampled. The MEPS provides nationally representative data on the civilian noninstitutionalized population, including family and individual-level data.</p>
<b>Study Limitations Addressed or Considered</b>	<p>The major limitation of the study is that the MEPS data may not capture all family spending for autism. If families consider autism-related services outside the realms of medical care, such as education services, social support services, or disability-centered community activities, these services may or may not be considered autism-related medical services in the dataset.</p>

<p><b>Impact or Outcomes</b></p>	<ul style="list-style-type: none"> <li>● <b>Medical expenditures for children with ASD and special healthcare needs.</b> Mean annual total expenditures for all medical services for children with autism and special healthcare needs were \$6,316. Out-of-pocket costs were 13 percent of total costs.</li> <li>● <b>Child service use experiences and family ratings of insurance plan adequacy.</b> State benchmarking and rule-making have led to significant variation in coverage for mental health services across the United States. This variation makes it important and difficult to educate families about health insurance coverage terms, how plans work, and how to choose plans.</li> <li>● <b>Family expenditures for premiums, copayments, and uncovered services.</b> The association of plan features and estimated family out-of-pocket expenditures suggests some plan features have minimal or no independent impact on family expenditures.</li> <li>● <b>Family choice strategies needing improvement.</b> Policy changes could be made to simplify the choices families make. For example, standards could be set to limit plan variation to low, medium and high levels of deductibles, copayment structures, and allowable loss limits that are the same levels across plans. The standards would limit the number of plans offered and make comparisons simpler. Future studies should explore how to provide simplified information to families to highlight plan features that drive expenditures.</li> </ul>
<p><b>Dissemination Plans</b></p>	<p>This grantee has received a newly funded project leveraging investments across multiple Federal agencies to provide timely evidence on State insurance benchmarking strategies that support improved access to and quality healthcare for people with disabilities.</p> <p><b>Manuscripts in progress</b></p> <p>Thomas, K. C., Kahn N., McDermott, K., Annis, I., &amp; Williams, C. S. (in progress). <i>Tough choices: Children with autism and other mental health needs, private health insurance and family out-of-pocket spending.</i></p>
<p><b>Publications Generated</b></p>	<p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Thomas, K. C., McDermott, K., Kahn, N., Williams, C., deJong, N., Williams, C. S., &amp; Morrissey, J. P. (2015, November). <i>Health insurance for children with autism and other mental health needs: Benchmark plans, mandates and lingering uncertainty.</i> Presented at the 143rd Annual Meeting of the American Public Health Association, Chicago, IL.</p>

## 8. Access to Therapy for Children With Autism: A Population-Based Analysis, Thomas Jefferson University, Philadelphia

<b>Brief Description of Study</b>	<p><b>Purpose:</b> The purpose of this study was to examine access to therapy services among children with ASD before and after the period of the Combating Autism Act of 2006 (CAA).</p> <p><b>Methods:</b> Data from the National Survey for Children with Special Health Care Needs (NS-CSHCN) from two cross-sectional time periods (2005–2006 and 2009–2010) were used to determine the impact of the CAA on access to therapy services among children with ASD. The study also examined factors associated with unmet therapy need, including well-child visits, predisposing child characteristics, enabling characteristics, and child need characteristics.</p> <p><b>Outcomes:</b> Reported need for therapy services for those with ASD did not differ between the 2 time points; approximately 75 percent of children with ASD in the sample were reported to need therapy services in 2005 and 2010. However, among all children, including those with ASD, unmet therapy need was greater in 2009 than in 2005. Broad access differences affecting all study groups suggest other factors affected therapy access beyond the specific CAA policy.</p>
<b>Problem or Issue Addressed</b>	<p>Although children with ASD often are referred to therapies such as occupational therapy, physical therapy, and speech therapy, obtaining access to needed services can be difficult for the population. This study examined differences in access to therapy in the United States at two separate cross-sectional time points.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>• Examine access to therapy services among children with ASD.</li> <li>• Identify differences in access during a period when the CAA had aimed to increase awareness and funds for autism research and practice.</li> </ul>
<b>Study Methodology</b>	<p>This study analyzed the NS-CSHCN. It specifically used the 2005–2006 and 2009–2010 NC-CSHCN data to compare access to therapy among children with ASD before and after passage of the CAA and to compare children with ASD with other children with special healthcare needs (CSHCN) across both time points. Perceived need for therapy was measured by the response to the question, “During the past 12 months, was there any time when [child] needed physical, occupational, or speech therapy?” Follow-up questions examined barriers to therapy. Bivariate methods (Rao-Scott design-based F statistics) examined demographic characteristics, therapy need, unmet therapy need, and access problems by diagnostic group while accounting for complex survey design. Multivariate logistic regressions examined associations of child and family factors with unmet need, and predisposing, family-enabling factors (child insurance status, FPL), and child need characteristics such as receipt of a well-child checkup.</p>
<b>Extant Data Sources</b>	<p>Data for this study came from the 2005–2006 and 2009–2010 NC-CSHCN. The survey interviewed caregivers of children under the age of 18 with special healthcare needs, and the analysis used responses from a total of 40,723 respondents in 2005–2006 and 40,242 respondents 2009–2010.</p>
<b>Specific Populations Targeted</b>	<p>Caregivers of children with ASD and children with other special healthcare needs who took part in the 2005–2006 or 2009–2010 NC-CSHCN studies</p>

<b>Underserved Populations</b>	The sample was a population-based sample that used methods to ensure representation of demographic characteristics in the U.S. population at the time of sampling. This means the sample of children from Hispanic backgrounds and minority race backgrounds was consistent with national trends.
<b>Geographic Areas</b>	The NS-CSHCN is a national study. The sample included more urban participants than nonurban participants.
<b>Study Limitations Addressed or Considered</b>	Because the study examines two cross-sectional surveys rather than one longitudinal survey, differences in sampling may account for some of the differences found by comparing the two time periods. The 2009–2010 wave included a sample collected via cell phone, whereas the 2005–2006 did not. Data gathered for the NS-CSHCN are based on caregiver-reported diagnosis, i.e. parents may have reported their child had ASD when their child did not have ASD and vice versa. Factors such as the geographic availability of therapy providers who accept insurance and the impact of changing macroeconomic circumstances were not assessed.
<b>Impact or Outcomes</b>	<ul style="list-style-type: none"> <li>● <b>Access to therapy services among children with ASD.</b> Factors associated with unmet therapy needs included forgoing well-child visits, having private insurance rather than public insurance, and reporting greater functional difficulty. The therapy access problems most frequently identified by respondents included “cost too much,” “lack of school resources,” “health plan problem,” and “not available in the area/no transportation.”</li> <li>● <b>Influence of CAA on access to ASD therapy.</b> The study was unable to determine whether the CAA influenced access to therapy for children with ASD. All children with special healthcare needs, including those with ASD, in 2009 demonstrated greater rates of unmet therapy need than in 2005. This finding suggests other factors affected access.</li> </ul>
<b>Dissemination Plans</b>	The results of the study were disseminated through three peer-reviewed journal publications and eight conference presentations. Presentations were made to a variety of health and practitioner groups, including physicians, public health practitioners, occupational therapists, autism researchers, and statisticians. Publications aimed to target maternal and child health practitioners, physicians, and developmental/medical specialists who refer children with autism to therapy services.

<p><b>Publications Generated</b></p>	<p><b>Peer-reviewed articles</b></p> <p>Benevides, T. W., Carretta, H. J., &amp; Lane, S. J. (2016). Unmet need for therapy among children with ASD: Results from the 2005–2006 and 2009–2010 National Survey of Children with Special Health Care Needs. <i>Maternal and Child Health Journal</i> 20(4), 878–888.</p> <p>Benevides, T. W., Carretta, H. J., &amp; Mandell, D. S. (2016). Differences in perceived need for medical, therapeutic, and family support services among children with ASD. <i>Pediatrics</i>, 137(2), S176–S185.</p> <p>Benevides, T. W., Carretta, H. J., Ivey, C. K., &amp; Shelly J. L. (in press). Therapy access among children with autism spectrum disorder, cerebral palsy, and attention-deficit hyperactivity disorder: a population-based study. <i>Developmental Medicine and Child Neurology</i>.</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Benevides, T. W., Carretta, H., &amp; Lane, S. J. (2014, May). <i>Access to therapy services for children with autism</i>. Poster presented at the International Meeting for Autism Research, Atlanta, GA.</p> <p>Benevides, T. W., Carretta, H., &amp; Lane, S. J. (2014, May). <i>Access to therapy services for children with autism</i>. Oral presentation at the 3rd Annual Occupational Therapy Scholars Summit, Philadelphia, PA.</p> <p>Benevides, T. W., Carretta, H., &amp; Lane, S. J. (2014, July). <i>Access to therapy services for children with autism</i>. Virtual presentation at the Combating Autism Act Initiative Virtual Poster Presentation.</p> <p>Benevides, T. W., Lane, S. L., &amp; Ivey, C. (2015, April). <i>Access to therapy services for children with ASD: A population-based analysis</i>. Oral presentation at the 2015 American Occupational Therapy Association Annual Conference, Nashville, TN.</p> <p>Benevides, T. W., Carretta, H. J., &amp; Mandell, D. (2015, July). <i>Differences in perceived need for medical, therapeutic, and family support services among children with ASD</i>. Poster presented at the 2015 AUCD Autism CARES Meeting, Bethesda, MD.</p> <p>Carretta, H., Benevides, T. W., &amp; Lane, S. J. (2015, August). <i>Unmet need for therapy service among children with ASD: Findings from the 2005-06 and 2009-10 NS-CSHCN using imputed and non-imputed files</i>. Poster presented at the 2015 National Conference on Health Statistics, Bethesda, MD.</p> <p>Benevides, T. W. (2016, April). <i>Differences in perceived need for medical, therapeutic, and family support services among caregivers of children with autism</i>. Oral session presented at the American Occupational Therapy Association Conference, Chicago, IL.</p> <p>Benevides, T. W., Carretta, H., &amp; Mandell, D. (2016, June). <i>Differences in perceived need for medical, therapeutic, and family support services among caregivers of children with autism spectrum disorder</i>. Poster session presented at the Academy Health Conference, Boston, MA.</p>
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## 9. Family Adversity and Health Disparities for Young Children With Autism, Temple University

<p><b>Brief Description of Study</b></p>	<p><b>Purpose:</b> This study aimed to examine whether racial and ethnic disparities in timing and receipt of diagnosis and treatment for children with ASD vary based upon adverse family experiences.</p> <p><b>Methods:</b> A secondary analysis of data from the 2011–2012 wave of the National Survey of Children’s Health examined children aged 2–17 with ASD in the United States. Descriptive and bivariate analyses with Rao-Scott Chi-Square test were conducted to describe and compare frequency and type of adverse child experiences (ACEs) among families of children with ASD by racial/ethnic status. Logistic and log logistic parametric survival models were used to explain the individual and cumulative effects of ACEs on timing of diagnoses and timing and receipt of evidence-based therapy by racial/ethnic status. Finally, statistical models were expanded to include family and community factors that might moderate the relationship between ACEs and timing and receipt of ASD diagnosis and therapy.</p> <p><b>Outcomes:</b> Cumulative ACEs did not vary by race/ethnicity. Report of ACEs was associated with delayed diagnosis of ASD and entry into therapy. Most children with ASD (92.6 percent) who received therapy and received services did not differ by racial/ethnic group or type and accumulative levels of ACEs. Parental coping moderated the relationship between number of ACEs and age of ASD diagnosis. The findings indicate children with ASD experience higher cumulative ACEs and higher prevalence of exposure to specific ACEs, including neighborhood violence, parental divorce, parental mental illness, and parental substance abuse.</p>
<p><b>Problem or Issue Addressed</b></p>	<p>Although evidence suggests adverse experiences accrue disproportionately for both ethnic minority families and families with CSHCN, there is clear need for more information about the complex relationship between adverse family experiences and healthcare access specific to racially diverse families of children with ASD. Families of children with ASD are not routinely screened for ACEs, and as a result, the information required to effectively meet the healthcare needs of underrepresented children with ASD who experience adversity was not available prior to this study. Knowledge generated from this research could build the case for widespread adoption of routine screening for adverse family experiences in clinical practice and allocation of resources to support families of children with ASD who experience multiple adversities.</p>
<p><b>Goals</b></p>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>• Describe and compare frequency and type of adverse family experiences among families of children with ASD (aged 2–17) by racial status using a population-based survey of U.S. households.</li> <li>• Examine the individual and cumulative effects of adverse family experiences on timing of diagnoses and receipt of evidence-based ASD treatments (therapy services to meet developmental needs, such as early intervention, occupational therapy, or behavioral therapy; individual family service plan or individual education plan) by racial/ethnic status among a population-based sample of U.S. families of children with ASD aged 2–17.</li> <li>• Examine to what extent family and community protective factors, including family social support/engagement and neighborhood social capital, moderate the relationship between adverse family experiences and timing of diagnoses/receipt of evidence-based treatments among racial/ethnic minority and White families of children with ASD aged 2–17.</li> </ul>

<b>Study Methodology</b>	<p>To ensure the generalizability of results, statistical procedures were applied to all the analyses that accommodate the survey sampling and weighting schemes. Domain analysis was used to analyze the subsample representing national population of families of children with ASD. All analyses were stratified by age group (2–11 years old versus 12–17 years old) to verify the estimates among children in different developmental stages. Descriptive statistics were carried out to estimate the prevalence rates of different types of adverse family experiences within each racial and ethnic group. Bivariate analysis was used with Roa-Scott Chi-Square test to compare the prevalence rates across racial and ethnic groups. Log-logistic parametric survival models and logistic models were used to test the associations between the adverse family experiences and the outcomes.</p> <p>To estimate the individual effects of adverse family experiences on the outcomes, different types of adverse family experiences were entered into the model separately. To evaluate their cumulative effects, the composite scores that total nine adverse family experiences were entered into the model. Covariates and confounding variables were entered into the model. To assess potential health disparities among racial and ethnic minority, the statistical modeling was stratified by race and ethnicity so that the estimated relationships between adverse family experiences and the outcomes could be compared across racial and ethnic groups with the Hausman test. Log-logistic parametric survival models and logistic models were used to examine the protective effects of family and community protective factors. All statistical procedures were conducted in Stata 13 and R.</p>
<b>Extant Data Sources</b>	<p>The study used the National Survey of Children’s Health from 2011/2012. The survey was administered by the National Center for Health Statistics at the Centers for Disease Control and Prevention under the direction and sponsorship of MCHB.</p>
<b>Specific Populations Targeted</b>	<p>Families of children with ASD aged 2–17 living in the United States between 2011 and 2012</p>
<b>Underserved Populations</b>	<p>In the sample, 9.1 percent (<math>n = 147</math>) of participants identified as Hispanic; 7.6 percent (<math>n = 123</math>) of participants identified as Black, non-Hispanic; and 11.5 percent (<math>n = 186</math>) of participants identified as other, non-Hispanic.</p>
<b>Geographic Areas</b>	<p>No specific geographic area was sampled. The sample is nationally representative.</p>
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>● This study draws from cross-sectional data, which precludes establishing causality.</li> <li>● The dataset did not provide information on timing of ACEs, which makes it impossible to determine whether ACEs occurred before or after the ASD diagnosis and therapy.</li> <li>● Because the NSCH relies on parent report, specific ACEs may be underreported.</li> </ul>

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**Impact or Outcomes**

- **Cumulative ACEs did not vary by race/ethnicity.** Multiracial/other racial/ethnic group children were associated with higher rates of specific ACEs, including parental divorce and racial discrimination. More than half (58.9 percent) of children with ASD were exposed to 1 or more ACE, with approximately 20 percent experiencing 3 or more ACEs. Additional analysis with redefined dummy groups revealed prevalence of four or more ACEs was significantly higher among children with ASD. For children with ASD, the adjusted relative risk ratio of 1–3 and 4 or more ACEs was 1.53 and 1.99, respectively.
  - **Report of ACEs was associated with delayed diagnosis of ASD and entry into therapy.** Mean age of initial ASD diagnosis was 4.3 years for children who reported no ACEs versus 5.24 and 5.66 years for children who experienced 1–2 ACEs and 3 or more ACEs, respectively. Mean age of entry into therapy for children who experienced no ACEs was 3.53 years compared with 4.59 years and 4.70 years for children who experienced 1–2 ACEs and 3 or more ACEs, respectively. The adjusted effects of 1–2 ACEs and 3 or more ACEs resulted in prolonged time to receipt of diagnoses, with time ratios of 1.17 and 1.23, respectively. Compared with children without ACEs, report of 1–2 ACEs and 3 or more ACEs was associated with a 22-percent and 27-percent increase in the median age of entry into therapy services, respectively. However, time to therapy did not differ between children who experienced one or two ACEs versus three or more ACEs. Similarly, time to diagnosis did not differ between children with one or two ACEs and three or more ACEs. Multiracial children were associated with a significant decrease in median age of ASD diagnosis (22-percent decline) after adjusting for ACEs. Child race/ethnicity, however, did NOT moderate the relationship between ACEs and timing of entry into therapy. Most children with ASD (92.6 percent) who received therapy and receipt of services did not differ by racial/ethnic group or type and accumulative levels of ACEs.
  - **Parental coping moderated the relationship between number of ACEs and age of ASD diagnosis.** Parental coping had significant nonlinear relationships with timing of ASD diagnoses and moderated the relationship between number of ACEs and timing of ASD diagnoses. Family (except parental coping) and community protective factors did not moderate the association between ACEs and timing of ASD diagnoses, although some community variables were independently associated with timing of ASD diagnoses. Results were consistent across racial/ethnic groups. Family and community protective factors did not moderate the relationship between the number of ACEs and timing of entry into therapy. Results were consistent across racial/ethnic groups. Although a select number of family and community factors appeared to moderate the relationship between number of ACEs and receipt of treatment among children with ASD, the models did not yield consistent and sufficiently stable results that were clearly interpretable. The sample of nontreated ASD children may not have been sufficiently large to facilitate effective analyses.
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<p><b>Dissemination Plans</b></p>	<p><b>Manuscripts submitted</b></p> <p>Berg, K. L., Shiu, C. S., Feinstein, R. T., Medrano, J. A., &amp; Acharya, K. (under review). Neighborhood disadvantage and exposure to adversity among children with developmental disabilities. <i>Research in Developmental Disabilities</i>.</p> <p>Berg, K. L., Shiu, C. S., Feinstein, R. T., Msall, M. E., &amp; Acharya, K. (under review). Adverse child experiences (ACEs) and unmet health care needs among children with autism spectrum disorder. <i>Journal of Pediatrics</i>.</p> <p>Berg, K. L., Shiu, C. S., Acharya, K., &amp; Msall, M. E. (accepted with revision). Children with developmental disabilities experience disparities in family adversity. <i>Journal of Developmental and Behavioral Pediatrics</i>.</p> <p>Berg, K. L., Acharya, K., Shiu, C. S., &amp; Msall, M. E. (under review). Delayed diagnosis and treatment among children with autism who experience adversity. <i>Pediatrics</i>.</p> <p><b>Manuscripts in progress</b></p> <p>Berg, K. L., Shiu, C. S., Acharya, K., &amp; Msall, M. E. (in progress). Age of diagnosis among children with ASD: the role of ecological adversity and parental coping. <i>Journal of the Society for Social Work and Research</i>.</p> <p>Acharya, K., Berg, K. L., Shiu, C. S., Pfeiffer, E., &amp; Msall, M. E. (in progress). Health disparities in children with autism. <i>Annals of Pediatrics</i>.</p> <p>Berg, K. L., Acharya, K., Shiu, C. S., Pfeiffer, E., &amp; Msall, M. E. (in progress). The role of ACEs in health care utilization: Revising the Andersen model of health care utilization. <i>Social Science &amp; Medicine</i>.</p> <p><b>Other dissemination</b></p> <ul style="list-style-type: none"> <li>● <i>Podcast: Developmental Medicine &amp; Child Neurology</i>. Retrieved from <a href="http://www.onlinelibrary.wiley.com/journal/10.1111/(ISSN)1469-8749">http://www.onlinelibrary.wiley.com/journal/10.1111/(ISSN)1469-8749</a>.</li> <li>● Msall, M. E., &amp; Berg, K. L. (2016, May). <i>Disparities in adversity among children with autism spectrum disorder: A population based study</i> [Video podcast]. Retrieved from <a href="https://www.youtube.com/watch?v=K78-2A3ojwE&amp;t=2s">https://www.youtube.com/watch?v=K78-2A3ojwE&amp;t=2s</a></li> <li>● Temple University. (2016, June 10). <i>Do youth with autism experience more adversity?</i> [Press release]. Retrieved from <a href="https://cph.temple.edu/news/do-youth-autism-experience-more-adversity">https://cph.temple.edu/news/do-youth-autism-experience-more-adversity</a></li> <li>● Temple University College of Public Health. (2017, August 31). <i>New research links late autism diagnosis to adverse childhood experiences</i> [Press release]. Retrieved from <a href="https://www.cph.temple.edu/news/new-research-links-late-autism-diagnosis-adverse-childhood-experiences">https://www.cph.temple.edu/news/new-research-links-late-autism-diagnosis-adverse-childhood-experiences</a></li> <li>● Accessible research briefs: Accessible research briefs based on the publication findings have been developed in lay language. These briefs, along with a companion YouTube video, will be posted on the IDHD public website. These briefs have been disseminated to the members of the Illinois LEND program’s Advisory Council.</li> <li>● Training for developmental and behavioral pediatric clinicians and fellows: A brief workshop on ACEs and its role in health and healthcare utilization among families of children with ASD is being developed for Children’s Hospital of Philadelphia, University of Chicago, and University of Illinois-Chicago.</li> </ul>
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<p><b>Publications Generated</b></p>	<p><b>Peer-reviewed articles</b></p> <p>Berg, K. L., Acharya, K., Shiu, C. S., &amp; Msall, M. E. (2017). Delayed diagnosis and treatment among children with autism who experience adversity. <i>Journal of Autism and Developmental Disorders</i>, 48(1), 4554. doi:10.1007/s10803-017-3294-y</p> <p>Berg, K. L., Shiu, C. S., Acharya, K., Stolbach, B., &amp; Msall, M. E. (2016). Disparities in adversity among children with autism spectrum disorder: A population-based study. <i>Developmental Medicine &amp; Child Neurology</i>, 58(11), 1124–1131. doi:10.1111/dmcn.13161</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Berg, K. L. (2016, May). <i>Adverse family experiences are associated with age of diagnosis among children with autism spectrum disorder</i>. Poster presented at the Children’s Hospital of Philadelphia Leadership Education in Neurodevelopmental &amp; Related Disabilities (LEND) Annual Research Symposium &amp; Poster Day, Philadelphia, PA.</p> <p>Berg, K. L., Shiu C. S., Acharya K., &amp; Msall, M. E. (2016, June). <i>Disparities in family adversity among children with disabilities: A population-based U.S. study</i>. Poster presented at the International Conference on Cerebral Palsy and other Childhood-onset Disabilities, Stockholm, Sweden.</p> <p>Berg, K. L., Shiu C. S., Pfeiffer, E., &amp; Acharya K. (2017, April). <i>Adverse family experiences are associated with age of diagnosis among children with ASD</i>. Presentation at the AOTA Annual Conference &amp; Centennial Celebration, Philadelphia, PA.</p> <p>Berg, K. L., Shiu C. S., Acharya K., &amp; Msall, M. E. (2016, September). <i>Children with autism spectrum disorders experience disparities in exposure to family and neighborhood adversity</i>. Presentation at the Annual American Association of Cerebral Palsy and Developmental Medicine Conference, Hollywood, FL.</p>
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## 10. Making a More Effective and Efficient Social Communication Questionnaire, Texas Tech University

<b>Brief Description of Study</b>	<p><b>Purpose:</b> This study aimed to develop a more effective and efficient social communication questionnaire (SCQ) as a screening instrument for early identification of ASD. The revised version of the SCQ addresses measurement bias according to age, gender, and ethnic group, as appropriate.</p> <p><b>Methods:</b> The psychometric properties of the SCQ were reexamined using Item Response theory with data from the National Database of Autism Research (NDAR). Also, a hierarchy of items was prescribed using Mokken scaling techniques.</p> <p><b>Outcomes:</b> A 7-item version of the SCQ was identified, which has better sensitivity (0.79) and specificity (0.75) than the 40-item version of the SCQ. Confirmatory factor analysis provided evidence of sufficient construct validity for the seven-item version of the SCQ (CFI = 0.97, TLI = 0.95, RMSEA = 0.06).</p>
<b>Problem or Issue Addressed</b>	<p>The SCQ is one of the most widely used and studied screening instruments in identifying individuals at risk for ASD. However, it uses classical test theory, which is an outdated statistical technique. A more effective and more efficient SCQ was possible by utilizing new techniques that address these technical limitations.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>• Examine the psychometric properties of the SCQ using Item Response Theory, thereby improving the effectiveness of the SCQ as a reliable and valid screener for ASD.</li> <li>• Prescribe a hierarchy of items using Mokken scaling techniques, thereby improving the efficiency of the SCQ.</li> </ul>
<b>Study Methodology</b>	<p>A two-parameter logistic model for SCQ item-level responses was examined. All analyses were completed with Lifetime or Current Form responses of the SCQ, which has corresponding cutoff scores to determine whether individuals are at risk for ASD. Current form responses were analyzed for individuals younger than age 4. Classic test theory techniques were used to assess the internal consistency of scores and to test a higher-order confirmatory factor analysis (CFA). CFA results provided evidence of the multidimensionality of SCQ and the unidimensionality of sets of items at the subscale level. Differential item functioning (DIF) was examined according to age, ethnicity, and sex before creating IRT/Mokken-scaled scores to replace the existing simple summed score procedure. DIF analyses examined possible item bias that may threaten the validity of the measurement.</p> <p>To develop a more efficient set of SCQ items, Mokken scaling techniques were employed to determine if there was a hierarchy of items to abbreviate the SCQ. Loevinger’s scalability coefficient was calculated as an estimation of scalability according to each dimension or subscale. Dimensions/subscales of the SCQ that had weak scalability were examined in more depth at the item level via the evaluation of Guttman errors for each pair of items. The sensitivity and specificity of the new IRT/Mokken-scaled abbreviated SCQ scores was compared with the summed score sensitivity and specificity via the Receiver Operator Characteristic (ROC) curve analyses with ASD diagnosis as the state variable to assess external validity.</p>
<b>Extant Data Sources</b>	<p>NDAR</p>
<b>Specific Populations Targeted</b>	<p>This study uses a national database, so no underserved populations were directly targeted; however, the analysis will explore measurement bias according to age, gender, and ethnic group.</p>

<b>Underserved Populations</b>	Infants, toddlers, preschool children, school-aged children, adolescents, and young adults (20–24)
<b>Geographic Areas</b>	No specific geographic area was sampled. The sample is nationally representative.
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>• Because of lack of age neutrality in SCQ responses, it may be necessary to develop different versions of the SCQ for different age groups.</li> <li>• Because of the change in diagnoses from DSM-IV to DSM-5, there may be individuals in the NDAR sample who were diagnosed with an ASD under DSM-IV but do not fit the criteria for ASD under the DSM-5.</li> <li>• The NDAR sample for the sensitivity analysis is much smaller than the sample used for the overall analysis because, in some instances, instead of conducting both SCQ and Autism Diagnostic Observation Schedule (known as ADOS) tests, only one was administered.</li> </ul>
<b>Impact or Outcomes</b>	<ul style="list-style-type: none"> <li>• <b>Favorable psychometric properties of the revised SCQ.</b> A 7-item version of the SCQ was identified, which has better sensitivity (0.79) and specificity (0.75) than the 40-item version of the SCQ. Also, confirmatory factor analysis provided evidence of sufficient construct validity for the seven-item version of the SCQ (CFI = 0.97, TLI = 0.95, RMSEA = 0.06).</li> <li>• <b>Seven items in the more efficient SCQ.</b> The seven items in the new SCQ follow: asking socially inappropriate questions/statements; using other’s hand like a tool; exhibiting odd, preoccupying interests; exhibiting unusual, intense special interests; exhibiting odd ways or movements; looking directly at you in communicating; and playing imaginative games.</li> <li>• <b>Impact of the new, seven-item SCQ.</b> The resulting, more effective and efficient SCQ is more valid and reliable and has a lower false positive rate. This shorter version of the SCQ could reduce barriers to screening for ASD and possibly increase screening access for currently underserved populations.</li> </ul>
<b>Dissemination Plans</b>	<p><b>Manuscripts in progress</b></p> <p>Barnard-Brak, L., Richman, D. M., Jamison, R., &amp; Almekdash, H. (in progress). Examination of gender differences in leaky pipeline for diagnosis of autism spectrum disorder. <i>Research in Autism Spectrum Disorders</i>.</p>
<b>Publications Generated</b>	<p><b>Peer-reviewed articles</b></p> <p>Barnard-Brak, L., Brewer, A., Chesnut, S., Richman, D., &amp; Schaeffer, A. M. (2016). The sensitivity and specificity of the social communication questionnaire for autism spectrum with respect to age. <i>Autism Research, 9</i>(8), 838–845.</p> <p>Barnard-Brak, L., Richman, D. M., Chesnut, S. R., &amp; Little, T. D. (2016). Social communication questionnaire scoring procedures for autism spectrum disorder and the prevalence of potential social communication disorder in ASD. <i>School Psychology Quarterly, 31</i>(4), 522.</p> <p>Chesnut, S. R., Wei, T., Barnard-Brak, L., &amp; Richman, D. M. (in press). A meta-analysis of the social communication questionnaire: Screening for autism spectrum disorder. <i>Autism, 21</i>(8), 920–928. doi:10.1177/1362361316660065</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Barnard-Brak, L., Richman, D., &amp; Chesnut, S. R. (2015, May). <i>Mokken scaling procedures for ASD diagnosis</i>. Invited presentation at the University of New South Wales Special and Inclusive Education Research Group, Sydney, Australia.</p> <p>Barnard-Brak, L., Richman, D., &amp; Chesnut, S. R. (2015, July). <i>Revising social communication questionnaire scoring procedures for autism spectrum disorder and potential social communication disorder</i>. Presented at AUCD CARES, Bethesda, MD.</p>

## 11. Patterns and Variations in Emergency Department Visits for U.S. Children With Autism: A Rural-Urban Comparison, University of North Carolina Chapel Hill

<b>Brief Description of Study</b>	<p><b>Purpose:</b> The purpose of this study was to determine whether disparities in emergency department (ED) utilization exist between children with autism in rural versus urban settings.</p> <p><b>Methods:</b> This secondary data analysis study used the Nationwide Emergency Department Sample (NEDS) to examine ED visits among children with an ASD diagnosis aged 3–17 in 2009 and 2010. Multivariate regression analyses were conducted to determine the potential effect of rural residence on the likelihood of ED utilizations after controlling for demographic and clinical characteristics.</p> <p><b>Outcomes:</b> Rural children with ASD, especially those with multiple chronic conditions, have less access to primary care, leading to greater likelihood of using an ED when compared with urban children with ASD. Health interventions and health policies should carefully consider the health services utilization challenges for rural children with ASD. Making essential mental health services available and providing adequate access to primary care could lead to reductions in ED admissions and inpatient hospitalizations for children with ASD, especially in rural areas.</p>
<b>Problem or Issue Addressed</b>	<p>An emerging area of interest in health services research is the effect of Federal, State, and local policy changes and healthcare coverage changes on health services utilization, particularly changes among children with autism and rural-urban differences within that population. Prior to this study, it was determined children with autism were more likely to visit an ED for psychiatric problems compared with children who do not have autism. This study was the first to use the largest national dataset of ED data (i.e., the 2009 and 2010 NEDS data) to study rural and urban differences in the utilization of autism-related ED services among children in the United States.</p>
<b>Goals</b>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>• Examine rural-urban differences in the likelihood of ED visits, child characteristics associated with visits, and clinical measures of ED visits for U.S. children with autism, based on child’s residence in rural or urban areas.</li> <li>• Describe rural and urban differences regarding specific reasons for using the ED, costs of using the ED, and geographic differences associated with these ED visits for U.S. children with autism.</li> </ul>
<b>Study Methodology</b>	<p>The rural-urban differences in ED visits for children with autism were investigated by both patient residence and hospital location. Multilevel regression models were used to correct for the nonindependence of individual-level observations nested within hospital EDs and to determine whether disparities in ED utilization exist between children with autism in rural versus urban settings.</p>
<b>Extant Data Sources</b>	<p>The 2009 and 2010 Nationwide Emergency Department Sample (NEDS); a database maintained by the Agency for Healthcare Research and Quality as a part of the Healthcare Cost and Utilization Project</p>
<b>Specific Populations Targeted</b>	<p>Children aged 3–17 years</p>

<b>Underserved Populations</b>	This study responds to the need for MCH services and systems of care efforts to eliminate health disparities and barriers to healthcare access for MCH populations, including ethnic, racial, cultural, linguistic, gender, developmental, geographic (rural, urban, frontier), immigrant, underserved, and/or economic considerations.
<b>Geographic Areas</b>	The sample is nationally representative, with a specific focus on rural populations.
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>● The NEDS database contains event-level record, and individual patients who visit the ED multiple times in one year may be counted in the NEDS database multiple times.</li> <li>● This analysis may not capture the pediatric patient population with ASD, because the child has not yet been diagnosed or has been diagnosed in the past but no longer displays relevant symptoms, or because the symptoms are simply not relevant to the purpose of the ED visit.</li> <li>● Since these data cannot be compared with similar children from the same regions who did not make ED visits, the study may be identifying characteristics that appear to increase ED use but instead are underlying features of ASD or other medical conditions. For example, male gender is highly correlated with the diagnosis of ASD, and this study found females were significantly less likely to use the ED than males.</li> </ul>
<b>Impact or Outcomes</b>	<ul style="list-style-type: none"> <li>● <b>Rural-urban residence and child characteristics associated with ED visits.</b> Several significant differences were identified among children with autism in rural versus urban areas: (1) children with autism in rural areas were poorer than their urban counterparts, (2) children with autism in rural areas were significantly more likely to visit the ED for externalizing behaviors compared with their urban counterparts with ASD, (3) children with autism in rural areas were significantly more likely to be hospitalized after an ED event compared with their urban counterparts.</li> <li>● <b>Geographic and cost differences in children with ASD in rural versus urban residences.</b> Geographic differences and cost differences were also identified between rural and urban children with ASD. The average cost per ED visit for children with ASD was higher than the average ED cost for children without ASD. Majority of children in rural areas were from the South and Midwest regions. The differences in ED charges between rural children with and without ASD were significantly larger than the differences in ED charges between urban children with and without ASD.</li> </ul>
<b>Dissemination Plans</b>	<p><b>Manuscripts in progress</b></p> <p>Zhang, W., Baranek G., Boyd, B., et al. (in progress, 2017). Emergency department visits and the financial burden for U.S. children with autism. To be submitted to <i>BMC Health Services Research</i>.</p> <p>Zhang, W., Baranek G., &amp; Boyd, B. (under review, 2017). Factors associated with emergency department visits for epilepsy among children with autism spectrum disorder. Submitted to <i>Journal of Autism and Developmental Disorders</i>.</p> <p><b>Other dissemination</b></p> <p>The allied health sciences department at the University of North Carolina at Chapel Hill shared a summary of key study findings through a research newsletter distributed via hard copy, website, and group listservs. The key findings of this project were also presented at a research display site located in the UNC School of Medicine lobby.</p>

<b>Publications Generated</b>	<p><b>Peer-reviewed articles</b></p> <p>Zhang, W., Mason, A. E., Boyd, B., Sikich, L., &amp; Baranek, G. (2016). A rural-urban comparison in emergency department visits for U.S. children with autism spectrum disorder. <i>Journal of Autism and Developmental Disorders</i>, 47(3), 590–598. doi:10.1007/s10803-016-2982-3</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Zhang, W., Mason, A., Boyd, B., &amp; Sikich, L. (2015, June). <i>Rural-urban disparities in emergency department visits for U.S. children with autism</i>. Presented at the 2015 Academy Health Annual Research Meeting, Disparities Interest Group, Minneapolis, MN.</p> <p>Zhang, W., Williams, K., Baranek, G., Boyd, B., &amp; Mason, A. (2015, July). <i>Factors related to hospital admissions after emergency department visits among U.S children with autism spectrum disorder</i>. Presented at the 2015 Autism CARES Meeting, Bethesda, MD.</p>
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## 12. Dental Homes for Medicaid-Enrolled Children With ASD in the Iowa I-Smile Program, University of Washington

<p><b>Brief Description of Study</b></p>	<p><b>Purpose:</b> Medicaid-enrolled children with ASD encounter significant barriers to dental care. Iowa’s I-Smile Program was implemented in 2006 to improve dental use for all Medicaid-enrolled children. This study compared dental home and preventive dental care utilization rates for Medicaid-enrolled children by ASD status, examined factors associated with having a dental medical home, and assessed outcomes of having a medical home, specifically use of an emergency department (ED) for nontraumatic dental problems and use of the operating room (OR) for dental treatment under anesthesia.</p> <p><b>Methods:</b> A retrospective analysis of data from the Iowa Medicaid program (2001–2011) examined data from three cohorts of children aged 3–17 years (<math>N = 30,059</math>). The researchers identified each child’s ASD status and assessed whether the child had a dental home or used preventive dental care. Log-linear regression models were used to generate rate ratios. Analyses were conducted in 2015.</p> <p><b>Outcomes:</b> Among newly Medicaid-enrolled children in Iowa’s I-Smile Program, the study resulted in the following conclusions: (1) those with ASD were not less likely than those without ASD to have dental homes but were significantly less likely to use preventive dental care, (2) medical care use and having a family member also enrolled in Medicaid were significantly associated with having a dental home, and (3) there was no difference by dental home status in the odds of utilizing the ED for nontraumatic dental problems or the odds of utilizing the OR for dental treatment under anesthesia.</p>
<p><b>Problem or Issue Addressed</b></p>	<p>No studies to date have evaluated whether a comprehensive dental home model, such as the I-Smile program, can improve access to dental care for Medicaid-enrolled children with ASD, a growing population at high risk for disparities in access to dental care and poor oral health.</p>
<p><b>Goals</b></p>	<p>The study aimed to—</p> <ul style="list-style-type: none"> <li>• Determine if there are dental home disparities for newly Medicaid-enrolled children with ASD in the I-Smile program—specifically, whether children with ASD are less likely to have a dental home than children without ASD.</li> <li>• Identify child-level, family-level, and geographic factors associated with having a dental home for Medicaid-enrolled children with ASD—specifically, whether race/ethnicity, chronic condition severity, preventive medical care use, and family enrollment in Medicaid are associated with having a dental home for children with ASD.</li> <li>• Assess outcomes associated with dental homes for Medicaid-enrolled children with ASD—specifically, whether they are less likely to use the ED for nontraumatic dental problems and less likely to use the OR for dental treatment under general anesthesia than children with ASD who do not have a dental home.</li> </ul>
<p><b>Study Methodology</b></p>	<p>A retrospective analysis of data from the Iowa Medicaid program examined data from three cohorts: (1) new Medicaid enrollees in any cohort from 2002 to 2011, (2) Medicaid-enrolled children with ASD who were enrolled in any cohort from 2007 to 2011, and (3) Medicaid-enrolled children with ASD who were enrolled in any cohort from 2007 to 2009 and who were also enrolled in Medicaid for the subsequent 3 years. Dental home was defined as 2 or more dental visits within 1 year. Log-binomial regression models were used to generate crude rates and rate ratios with 95 percent confidence intervals. A hierarchical log binomial regression analysis was used to assess child-level factors, family-level factors, and geographical factors associated with having a dental home for children with ASD. All analyses were conducted in 2015.</p>

<b>Extant Data Sources</b>	Iowa Medicaid data, 2001–2012
<b>Specific Populations Targeted</b>	Medicaid-enrolled children with ASD living in Iowa
<b>Underserved Populations</b>	Medicaid-enrolled children with ASD
<b>Geographic Areas</b>	Iowa
<b>Study Limitations Addressed or Considered</b>	<ul style="list-style-type: none"> <li>• Regardless of ASD status, claims data show only 8 percent of children had a dental home (defined as 2 or more dental visits within 1 year). This definition of dental home does not assume care was easily accessible, family-centered, continuous, comprehensive, coordinated, compassionate, or culturally competent—factors typically attributed to having a medical or dental home.</li> <li>• Though the prevalence of ASD in the study sample is reflective of ASD estimates in the general population, the study acknowledges using claims data to identify ASD through diagnostic codes assumes accuracy by the healthcare provider and is subject to misclassification bias.</li> <li>• Although regular dental visits have an important role in dental caries prevention, diet and dental maintenance behaviors are also key contributors. These behaviors may be difficult to reinforce in children with ASD.</li> <li>• Because the study only uses secondary data available in Medicaid data files, behavioral and social factors could not be tested as potential determinants of dental homes. Future studies should consider primary data collection with parents and caregivers of Medicaid-enrolled children with ASD.</li> <li>• Potential confounding factors, such as parental oral health status, may be associated with a child’s dental home status and dental outcomes. These factors could not be analyzed with secondary data analyses, but future studies should conduct primary data collection to assess these potentially confounding factors.</li> <li>• Parent-reported outcomes associated with dental homes have not been empirically assessed, warranting additional research.</li> </ul>
<b>Impact or Outcomes</b>	<ul style="list-style-type: none"> <li>• <b>Preventative dental care of Medicaid-enrolled children with and without ASD.</b> Among the newly Medicaid-enrolled children in the I-Smile program, children with ASD were significantly less likely to receive preventative dental care than children without ASD.</li> <li>• <b>Factors associated with having a dental home.</b> The study identified the following two factors significantly associated with Medicaid-enrolled children with ASD having a dental home: (1) medical care use, and (2) having a family member who was also enrolled in Medicaid.</li> <li>• <b>Odds of using emergency medical care.</b> Among Medicaid-enrolled children with ASD, there was no significant difference by dental home status in the odds of using the ED for nontraumatic dental problems, or the odds of using the OR for dental treatment under general anesthesia.</li> </ul>

<b>Dissemination Plans</b>	<p><b>Manuscripts in progress</b></p> <p>Chi, D. L., Momany, E. T., Mancl, L. A., Lindgren, S. D., Zinner, S. H., &amp; Steinman, K. J. (in progress). Determinants and outcomes associated with dental homes for Medicaid-enrolled children with autism spectrum disorders. To be submitted to the <i>American Journal of Public Health</i>.</p> <p>Chi, D. L., Momany, E. T., Mancl, L. A., Lindgren, S. D., Zinner, S. H., &amp; Steinman, K. J. (in progress). Distance to dentist as a barrier to dental care use for Medicaid-enrolled children with autism spectrum disorders. To be submitted to <i>Demography</i>.</p>
<b>Publications Generated</b>	<p><b>Peer-reviewed articles</b></p> <p>Chi, D. L., Momany, E. T., Mancl, L. A., Lindgren, S. D., Zinner, S. H., &amp; Steinman, K. J. (2015). Dental homes for children with autism: A longitudinal analysis of Iowa Medicaid's I-Smile program. <i>American Journal of Preventive Medicine</i>, 50(5), 609–615.</p> <p>Nakao, S., Scott, J. M., Masterson E. E., &amp; Chi, D. L. (2015). Non-traumatic dental condition-related emergency department visits and associated costs for children and adults with autism spectrum disorders. <i>Journal of Autism and Developmental Disorders</i>, 45(5), 1396–407.</p> <p><b>Peer-reviewed scholarly conference presentations</b></p> <p>Chi, D. L., Momany, E., Mancl, L., Lindgren, S., Zinner, S., &amp; Steinman, K. (2015, November). <i>Dental homes and preventive dental care use for Medicaid-enrolled children with autism spectrum disorders: Iowa's I-Smile program</i>. Presented at the American Public Health Association Meeting, Chicago, IL.</p> <p>Nakao, S., &amp; Chi, D. L. (2013, October). <i>Non-traumatic dental condition-related emergency department visits and associated costs for children and adults with autism spectrum disorders</i>. Poster presented at the University of Washington School of Dentistry Research Day, Seattle, WA.</p>

## Appendix G. Research Program Grantee Publications

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### AIR-B

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- Almirall, D., DiStefano, C., Chang, Y. C., Shire, S., Kaiser, A., Lu, X., ... Kasari, C. (2016). Longitudinal effects of adaptive interventions with a speech-generating device in minimally verbal children with ASD. *Journal of Clinical Child & Adolescent Psychology, 45*(4), 442–56.
- Anderson, A., Locke, J., Kretzmann, M., & Kasari, C. (2015). Social network analysis of children with autism spectrum disorder: Predictors of fragmentation and connectivity in elementary school classrooms. *Autism, 20*(6), 700–709. doi:10.1177/1362361315603568
- Azad, G. F., Kim, M., Marcus, S., Sheridan, S., & Mandell, D. S. (2016). Parent-teacher communication about children with autism spectrum disorder: An examination of collaborative problem-solving. *Psychology in the Schools, 53*(10), 1071–1084. doi:10.1002/pits.21976
- Azad, G., Locke, J., Kasari, C., & Mandell, D. (2016). Race, disability, and grade: Social relationships in children with autism spectrum disorders in elementary school. *Autism, 21*(1), 92–99. doi:10.1177/1362361315627792
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## Appendix H. Guidelines Produced by Research Programs and Resulting Publications

**Table H.1. Description of Guidelines Produced by Research Programs and Resulting Publications**

Guideline Name	Brief Description	Resulting Publication(s)
<b>AIR-P</b>		
Guideline on treatment of anxiety	The combined AIR-P/ATN network developed systematic ways to assess and treat coexisting conditions such as ASD and anxiety. This guideline provides methods for managing coexisting conditions for which management was previously highly variable or sporadic. This guidance is intended for parent and professional communities.	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. <i>Pediatrics</i> , 137(2), S115–S123.
Guideline on treatment of irritability and problem behaviors	The combined AIR-P/ATN network developed systematic ways to assess and treat irritability and problem behaviors when they coexist with ASD. This guideline provides methods for managing coexisting conditions for which management was previously highly variable or sporadic. This guidance is intended for parent and professional communities.	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. <i>Pediatrics</i> , 137(2), S136–S148.
<b>HW-RN</b>		
Obesity management recommendations for primary care providers of children with ASD	The HW-RN Dissemination Core developed the first set of recommendations on obesity management in children with ASD. The recommendations are based on feedback from an expert panel of primary care providers for children with ASD.	This publication was under development at the end of the evaluation period (December 2017).
Position of the Academy of Nutrition and Dietetics: Nutrition services for individuals with intellectual and developmental disabilities and special health care needs	Nutrition services should be provided throughout life in an interdisciplinary, family-centered, community-based, and culturally competent manner. Public policy for individuals with intellectual development disabilities and children and youth with special healthcare needs has evolved, resulting in a transition from institutional facilities and programs to community and independent living. The position of the Academy of Nutrition and Dietetics is that nutrition services provided by registered dietitian nutritionists and nutrition and dietetics technicians, registered, who work under registered dietitian nutritionist supervision, are essential components of comprehensive care for all adults with intellectual and developmental disabilities and children and youth with special healthcare needs.	Ptomey, L.T., & Wittenbrook, W. (2015). Position of the Academy of Nutrition and Dietetics: Nutrition services for individuals with intellectual and developmental disabilities and special health care needs. <i>Journal of the Academy of Nutrition and Dietetics</i> , 115(4), 593–608. doi:10.1016/j.jand.2015.02.002

<b>Guideline Name</b>	<b>Brief Description</b>	<b>Resulting Publication(s)</b>
Positive Health Practices Curriculum for Adults With Developmental Disabilities	This manual is available in paper and web-based formats to promote healthy eating and physical activity for adults with disabilities living in the community. It was sponsored by the Pennsylvania Office of Developmental Programs, Department of Public Welfare, 2015.	The manual is available from the authors: Segal, M., Metoxen, B., Morrow, J., & Cooper, J.
A new framework and practice center for adapting, translating, and scaling evidence-based health/wellness programs for people with disabilities	The National Center on Health, Physical Activity and Disability (NCHPAD) developed the Knowledge Adaptation, Translation and Scale Up (N-KATS) framework to systematically build and advance the evidence base of health/wellness programs, practices, and services applicable to people with disabilities. The N-KATS framework supports the role of rehabilitation professionals as knowledge brokers, facilitators, and users in a collaborative, dynamic structure that will grow and be sustained over time through the NCHPAD.	Rimmer, J. H., Vanderbom, K. A., & Graham, I. D. (2016). A new framework and practice center for adapting, translating, and scaling evidence-based health/wellness programs for people with disabilities. <i>Journal of Neurologic Physical Therapy, 40</i> (2), 107–114.
<b>HCT-RN</b>		
Health care transition for people with ASD/DD: Learning objectives and curriculum content for medical residents	Learning objectives for medical residents were developed through a consensus-building process by the Health Care Transitions Research Consortium, the Transition Committee of the Medicine-Pediatrics Program Directors Association, and the Society for General Internal Medicine's Task Force on Adults with Chronic Conditions Originating in Childhood.	This publication was under development at the end of the evaluation period (December 2017).
Health Care Transition Curriculum for Primary Care Residents: Identifying Goals and Objectives	Guidelines for healthcare transition curriculum for primary care residents were developed via modified Delphi survey and will be published in Pediatrics in April 2018.	Kuo, A. A., Ciccarelli, M., Sharma, N., & Lotstein, D. S. (in press). Health care transition curriculum for primary care residents: Identifying goals and objectives. <i>Pediatrics, 140</i> (Suppl. 2).
Care of Adults with Chronic Childhood Conditions: A Practical Guide	Guidelines for providing care to adults with a chronic disorder originating in childhood were developed and published in a textbook for medical providers.	Pilapil, M., DeLaet, D. E., Kuo, A. A., Peacock, C., & Sharma, N. (Eds.). (2016). <i>Care of adults with chronic childhood conditions: A practical guide (1st ed.)</i> . Switzerland: Springer International Publishing. doi:10.1007/978-3-319-43827-6
Health care transition: Best practices for adolescents with ASD/DD	This position statement on best practices for transition care for adolescents with ASD/DD was developed for the Society for Adolescent Health and Medicine.	This publication was under development at the end of the evaluation period (December 2017).
A textbook for internal medicine education programs	This textbook will offer guidelines for providing care to adults with a chronic disorder originating in childhood. The guidelines were under development at the end of the evaluation period.	This publication was under development at the end of the evaluation period (December 2017).

Guideline Name	Brief Description	Resulting Publication(s)
<b>Autism-FIRST</b>		
Guidelines for use of book-share bundles to improve language development for minimally verbal children	Guidelines for developing book-share bundles were developed during an Autism-FIRST intervention for minimally verbal children. The bundles were part of a teacher training package that included PowerPoint presentations, example videos, group activities, and handouts for the 2-day teacher training. Teachers can receive continuing education credits for the workshop in Maryland.	At the end of the evaluation period (December 2017), this publication was under development by an Autism-FIRST grantee, R40MCH 26193, from Kennedy Krieger Institute in Maryland.
Guidelines for delivering parent coaching over the internet	Guidelines for conducting parent coaching over the internet were developed for use during the ImPACT online telehealth parent training intervention and may be used for other online coaching interventions. The guidelines were developed by Autism-FIRST R40MCH 27704, a 2014 grantee from Michigan State University.	The second edition of the manual, which incorporates findings from the Autism-FIRST study, was under development at the end of the evaluation period (December 2017). Ingersoll, B., & Dvortcsak, A. (2010). <i>Teaching social-communication: A practitioner's guide to parent training for children with autism</i> . New York: Guilford Press.

## Appendix I. Tools and Measures Developed for Providers and Professionals

**Table I.1. Tools and Measures Developed for Providers and Professionals Between September 1, 2014, and December 15, 2017**

Grantee	Toolkit	Description
AIR-B	AIR-B Social Dynamics of Intervention (SoDI) Tool Used in Building Better Bridges Study	This tool explores the networks and individuals supporting students with ASD in the SoDI study as they make their school transitions. The goal of the intervention is to form stronger social network connections over time, ensuring necessary supports for students to make positive transitions.
AIR-B	Remaking Recess Booklet	This booklet provides school personnel with naturalistic strategies they can use in their daily routines and interactions with students with autism and their peers. It is designed to improve the social inclusion of elementary school- aged children with ASD through facilitated interactions with their peers.
AIR-B	Schedules, Tools, and Activities for Transitions in the Daily Routine (STAT) Manual	This manual is designed for teachers in special education classrooms to improve behavior and transitions among students with ASD. This intervention uses behavioral strategies found in functional routines to address classroom management and environmental structures in special education classrooms.
AIR-P	EEG Guide for Providers	This guide provides information about the electroencephalogram (EEG) procedure, the impact of a child's ASD diagnosis on his or her experience with an EEG, and advice on helping children with ASD successfully prepare for and complete an EEG. (Developed during previous evaluation period, which ended August 31, 2014; finalized and made available to the public in March 2015)
Autism-FIRST	Making a More Effective and Efficient SCQ (R40MC 27476)	A modified version of the social communication questionnaire (SCQ) is used as a screening instrument for early identification of ASD. The revised version addresses measurement bias according to age, gender, and ethnic group. The researchers found the modified version of the SCQ had better sensitivity and specificity than the original version, and confirmatory factor analysis provided evidence of sufficient construct validity for the modified version.
HCT-RN	Medical Summary for Young Adults With Intellectual Disabilities or Developmental Disabilities (Essential Clinical Information)	This summary of the key medical record elements contains the essential information needed for communication between pediatric and adult clinicians for the specific patient, including pertinent disease-specific information. The summary is to be completed by the pediatric or other sending clinician, shared with the youth and family, and sent to the receiving adult clinician.

Grantee	Toolkit	Description
HCT-RN	Network Measures of Collaborative Support for Young Adults With Autism	This pilot study aims to determine the feasibility of using a newly developed longitudinal, dynamic social network survey (SoDI) to capture changes in intervention, autism knowledge, and social connectivity across time and throughout the transition period.
HCT-RN	Self-Care Assessment for Young Adults With Intellectual Disabilities or Developmental Disabilities	This assessment tool, filled out by the youth with ID, is used by the adult care team to assess any remaining gaps in self-care knowledge and skills or additional issues to be addressed to ensure optimal management of the medical condition(s). (HCT-RN modified this toolkit to a fourth-grade literacy level to make it more accessible to individuals with ASD and DDs. This toolkit can be completed either by a parent/caregiver or by individuals with ASD and DDs.)
HCT-RN	Transition Readiness Assessment for Youth With Intellectual Disabilities or Developmental Disabilities (Pediatric)	This assessment tool, filled out by the youth with ID, is used by the pediatric care team or other clinicians caring for the youth to begin the conversation about the individual's needed skills to manage his or her health and healthcare. This tool indicates the elements specifically related to the clinical condition that should be assessed and documented by the transferring pediatric practice. (HCT-RN modified this toolkit to a fourth-grade literacy level to make it more accessible to individuals with ASD and DDs. This toolkit can be completed either by a parent/caregiver or by individuals with ASD and DDs.)
HW-RN	"Let's Go" Toolkit by Maine Medical Center and HW-RN	Designed for professionals who work with children with IDD, the toolkit includes strategies, tools, and resources that address the healthy eating and physical activity needs of children with IDD. Its aim is to raise awareness of the needs of children with IDD and support the expectation that, given more support, children with IDD can lead healthy, active lives.
HW-RN	Assessing Community Satisfaction With Community Based Participatory Research	This survey assesses satisfaction of HW-RN Advisory Board members and conference participants with the level of their engagement in projects about children and families with disabilities. (In development as of December 15, 2017)
HW-RN	Measure of Adaptive Behaviors Surrounding Eating	This tool for clinicians and researchers will assess adolescents' ability to engage in behaviors such as assisting with meal preparation, self-feeding, etc. The questions were developed as a result of a lack of appropriate measures to test one of HW-RN's secondary aims. (In development as of December 15, 2017)

## Appendix J. Tools and Measures for Families and Caregivers

**Table J.1. Tools and Measures for Families and Caregivers Developed by Research Networks Between September 1, 2014, and December 15, 2017**

Grantee	Toolkit Name	Description
AIR-P	EEG Guide for Parents	This guide provides parents with information about the electroencephalogram (EEG) procedure, the impact of a child's ASD diagnosis on his or her experience with an EEG, and advice on helping children with ASD successfully prepare for and complete an EEG. (Developed during previous evaluation period, which ended August 31, 2014; finalized and made available to the public in March 2015)
AIR-P	Melatonin and Sleep Problems: A Guide for Parents	This guide was designed to provide parents with information about melatonin and help them decide if it is right for their child.
AIR-P	Puberty and Adolescence	This parents' guide on puberty can be directly applied to preteens with ASD. It aims to increase families' understanding of puberty and ability to adapt to these changes with confidence.
Autism-FIRST	Improving Part C Services and Outcomes for Underserved Children With ASD	These training protocols and materials are designed 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.
Autism-FIRST	Toddlers and Families Together Manual: Addressing Early Core Features of Autism	This parent-friendly intervention manual for the "Together" intervention was found to reduce stress in parents of children with ASD and improve caregiver-child interactions. Engagement, joint engagement, play, and joint attention behaviors were significantly improved in toddlers receiving the intervention. The manual is publicly available in both English and Spanish.
HW-RN	Strategies To Optimize Healthy Eating on a Low Budget	This tool is being developed to provide guidance on buying and preparing healthy food for people on a low food budget. Because many people with disabilities have modest incomes, the guide will help navigate this difficult subject. (In development as of December 15, 2017)
HW-RN	Video Sports Illustrated for Children With Disabilities	This interactive tool shows CSHCN playing sports, including baseball, soccer, swimming, track and field, basketball, and Wii-sports. While watching the video, children have the opportunity to describe their level of enthusiasm for each sport. Because the presentation is mostly visual rather than verbal, it is appropriate for CSHCN who have communication difficulties. (In development as of December 15, 2017)