Training Professionals in Service Delivery:
Key Findings From an Evaluation of the Autism CARES Developmental-Behavioral Pediatrics Training Program

HRSA Maternal & Child Health

Autism CARES Act Legislation and Funding

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

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

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

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

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

DBP Program Purpose and Goals

As a subspecialty of pediatrics, developmental-behavioral pediatrics—or DBP—provides evaluation, counseling, and treatment for a wide range of developmental and behavioral concerns and conditions, including attention and learning disorders, ASD, and other DDs.

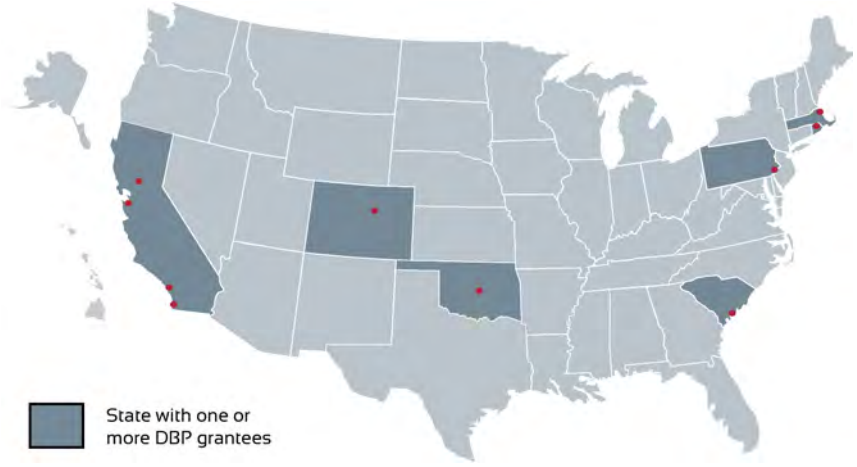
DBP grantees also conduct ongoing outreach and education for a range of populations including undergraduates and families. During the evaluation period, the 10 DBP programs supported by HRSA were located in 7 States, as shown in figure 1.

The goal of the DBP Training Program is to enhance the behavioral, psychosocial, and developmental aspects of pediatric care in the following ways:

Support and prepare long-term fellows in DBP for leadership roles as clinicians, teachers, and investigators who can advance the field of DBP.

Provide pediatric practitioners, residents, and medical students with essential biopsychosocial knowledge and expertise to implement evidence-based developmental screening and interventions for ASD/DDs.

Figure 1. DBP Program Locations



The Need for Professionals Trained in ASD/DD Diagnosis and Service Delivery

As the number of individuals identified with ASD/DD increases, there is a need for well-trained clinicians who can diagnose developmental and related conditions and provide children and their families with evidence-based support services. Despite this need, there is a shortage of DBP specialists who can provide these services,[3] with research suggesting an aging workforce and provider burnout as contributing factors in the shortage.[4] Having too few specialists results in long wait times for families needing diagnostic evaluations—ranging from 3½ months to a year—as well as to obtain other supportive services.[5] This situation can be particularly problematic for underserved groups such as low-income populations who are more likely than other groups to have unmet specialty and therapy care needs[6] and individuals in remote areas or States without any developmental-behavioral pediatricians at all.[7,8] HRSA's DBP programs address these critical gaps by increasing the number of trained clinicians available to diagnose and provide services to children with ASD/DD and their families.

DBP program activities can be categorized into four main areas: training professionals, increasing awareness, expanding the evidence base, and building systems of care. This document presents some examples of the varied activities undertaken by DBP programs across the country in support of the ASD/DD community.

Key Contributions of DBP Program

Training Professionals in ASD/DD Diagnostic Methods and Evidence-Based Services

Increasing the Number of Trainees

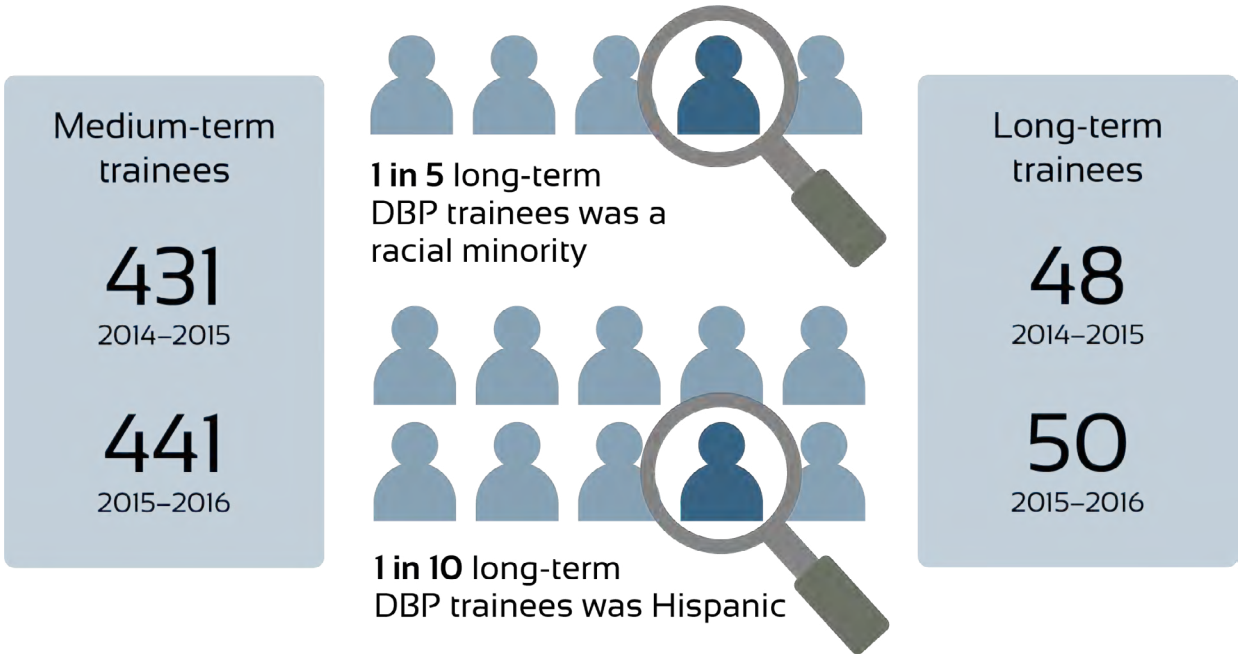
One of the most important results of Autism CARES funding is that it enabled many grantees to support one to two additional DBP fellows, which substantially increased the number of well-trained professionals in this small subfield. According to 2017 data from the American Board of Pediatrics, only 16 physicians trained in DBP took the General Pediatrics Certifying Examination for the first time in 2016.[9] Between 2014 and 2016, DBP programs trained an average of 49 long-term fellows and 436 medium-term trainees each year (see figure 2). 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. Programs also developed unique training opportunities, such as mini-fellowships, to provide in-depth training to practitioners without the commitment of the 3-year fellowship program.

HRSA's DBP programs also worked to recruit a diverse cadre of trainees. Between 2014 and 2016, 1 in 5 DBP fellows was a racial minority, and approximately 1 in 10 was Hispanic (see figure 2). Enrolling trainees from a range of racial, ethnic, and cultural backgrounds extends grantees' reach into underserved areas and creates opportunities for professionals to communicate more effectively with families from a wide range of circumstances.

Reaching more trainees through mini-fellowships

The Medical University of South Carolina's 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 DBP almost exclusively, serving as the main developmental-behavioral pediatrician in his part of the State. Similarly, Rhode Island Hospital introduced a certificate DBP program, which provided 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.

Figure 2. Number of DBP Medium- and Long-Term Trainees by Year



Source 1: From 2014 to 2015, DBP programs enrolled 431 medium-term trainees and 48 long-term trainees during this period. From 2015 to 2016, DBP programs enrolled 441 medium-term and 50 long-term trainees. This figure was generated using Discretionary Grant Information System (DGIS) data on the number of DBP medium- and long-term trainees enrolled each year from 2014 to 2015 and 2015 to 2016.

Source 2: From 2014 to 2015, 18.8 percent of long-term DBP trainees were identified as racial minorities; 8.3 percent of DBP long-term trainees were Hispanic. From 2015 to 2016, 22.0 percent of long-term DBP trainees were identified as racial minorities; 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.

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

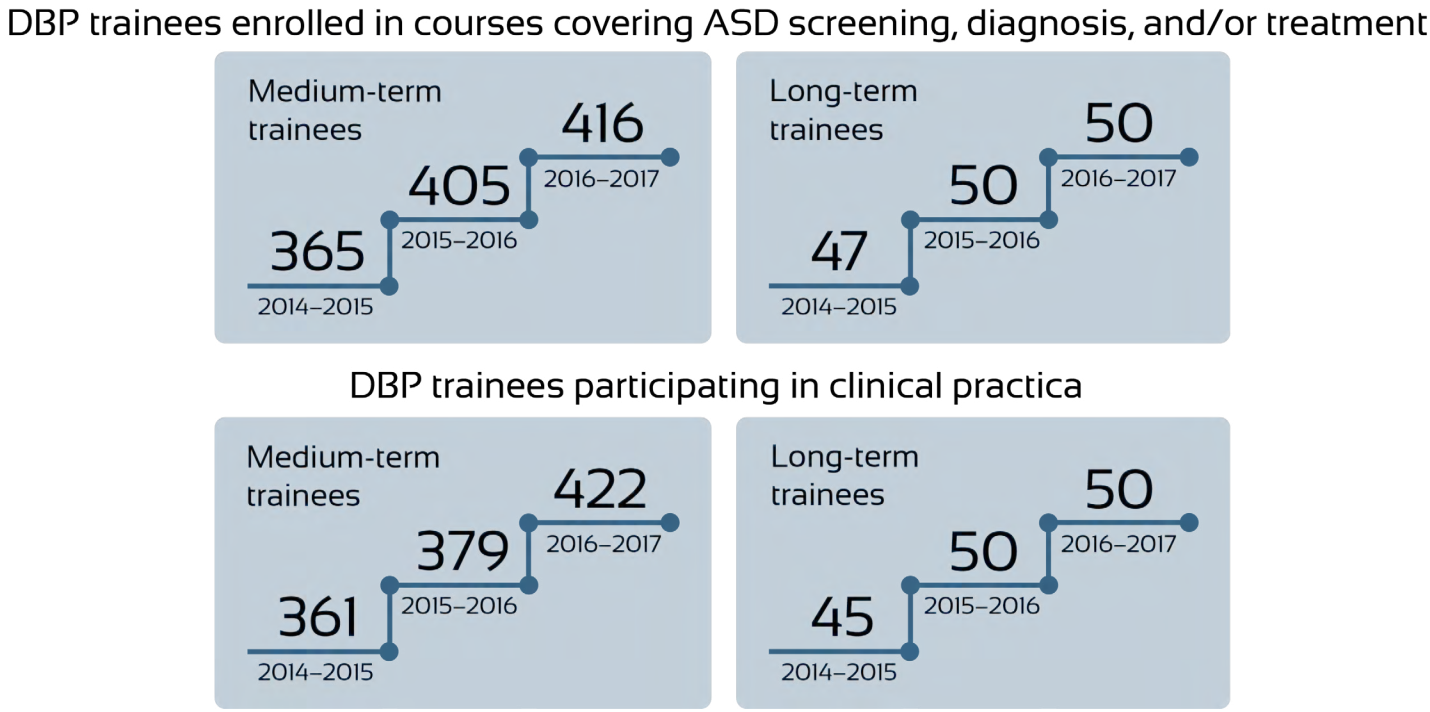
Enhancing Clinical and Didactic Instruction

During the evaluation period, DBP programs enrolled an average of 49 long-term and 395 medium-term trainees each year in didactic courses covering ASD screening, diagnosis, and treatment (see figure 3). An average of 48 long-term and 387 medium-term trainees enrolled in clinical practice annually, providing interdisciplinary, diagnostic services to confirm or rule out ASD/DD to nearly 35,000 children alongside their faculty members in DBP program clinics.

Didactic training in DBP programs is interdisciplinary, with courses covering ASD screening and assessment tools, interventions, cultural and linguistic competency, life-course issues, and family-centered care. DBP fellows became expert diagnosticians, completing certifications to administer tools such as the Autism Diagnostic Observation Schedule and receiving training in many other relevant screening and assessment tools for developmental and behavioral conditions.

DBP programs prioritized increasing the linguistic and cultural competency of their trainees to better serve diverse populations through lectures and workshops and interactive discussions with individuals affected by ASD/DDs and their families. Programs often incorporated a life-course perspective to training on ASD/DDs, examining experiences across the lifespan rather than focusing solely on early development. For example, the University of California, San Diego, developed its curriculum around life-course theory, emphasizing the importance of early childhood and the influences of family and society on long-term health and development.

Figure 3. Number of Long-Term and Medium-Term DBP Trainees Enrolled in Courses Covering ASD Screening, Diagnosis, and/or Treatment by Year, and Number of Trainees Participating in Clinical Practica by Year



Source: This figure was generated using the National Information Reporting System (NIRS) data describing the number of 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, and 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.

Clinical practica enable trainees to practice or observe the diagnostic and intervention skills they learn in the classroom. Autism CARES funding supported enhanced clinical opportunities, enabling trainees to gain hands-on experience under faculty guidance in program-based clinics. Clinical training also took place in hospital outpatient clinics, university-based resource and treatment centers, community clinics, schools, shelters, homes, and virtual clinics using telehealth technology. Examples follow:

- **Developed clinics targeting new populations.** Stanford University introduced a middle childhood program that focused on children older than 7. This project enabled fellows to work with older children, a group with potentially different treatment needs such as medication management, to help developmental-behavioral pediatricians improve skills with this age group.
- **Used telehealth to reach underserved areas.** The University of California, Davis, established a telehealth consultation program with a federally qualified health center serving rural, Native-American, and low-resourced patients. The clinic, which reached several indigenous tribes in northern California, provided unique training and advocacy opportunities for fellows while expanding healthcare services to underserved groups.

Developing Leaders in the Field of ASD/DD Care

Beyond training expert diagnosticians, DBP programs prepared trainees to become leaders in the field. DBP Training Program graduates 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. Grantees fostered leadership among their fellows through training in teaching skills, disability policy, effective communications with policymakers, and experiential learning through capstone or leadership projects. The following examples demonstrate some of these activities:

Developed teaching skills. As future leaders in the field, DBP fellows are likely to take positions where they will be required to educate others on developmental issues. HRSA's DBP programs typically emphasized the development of teaching skills to prepare fellows for this critical role. For example, as part of the Boston Children's Hospital program, fellows participated in a "teaching to teach" seminar, presenting to pediatric residents, peers, and other learners and receiving feedback to improve their teaching skills. Similarly, at Rhode Island Hospital, fellows taught residents and medical students on DBP rotations. They developed seminars, mentored residents, and guided students and residents in general pediatric approaches to screening, assessing, and managing children with developmental-behavioral concerns.

- **Trained in policy issues related to ASD/DDs.** In addition to exploring the individual- and family-level challenges their patients face, DBP trainees learned about broader policy-level issues affecting medical care. DBP programs typically provided education related to policy and legislation affecting individuals with ASD/DDs, with many requiring trainees to complete projects that explored policy topics of interest. For example, trainees at Children's Hospital Los Angeles completed policy-related projects that drew on their training in legislation, needs assessment, program planning, research, and community education. Fellows completed 360-degree analyses of topical areas or themes relevant to DBP that included a literature review and a policy brief. One of these leadership projects was *Preserving Access to Applied Behavioral Analysis Services for Children With ASD in California*.

Trained providers to deliver transition services

Healthcare providers need training to feel confident working with young adults with ASD as they age into adulthood. To address this need, many DBP grantees incorporated learning opportunities about the transition to adulthood into their didactic and clinical training programs. The University of Colorado program set up a formal transition clinic offering 2-hour appointments. During the first hour, fellows focused on the transition of medical care, considering the relevant health issues faced by the patient, including an assessment of whether the individual could manage some of his or her own care. The appointment included communication with the individual's current primary care provider and the identification of adult medical care providers. For the second half of the appointment, patients met with either a social worker or a family navigator about the nonmedical aspects of transition to adulthood, such as supported decisionmaking (or in some cases guardianship), housing services, and vocational training programs. The DBP Program at Children's Hospital of Philadelphia provided a continuing medical education course to professionals on the transition to adulthood at a regional conference; the trainees also presented and delivered posters at the annual meetings of the American Public Health Association and Society for Adolescent Health and Medicine.

Increasing Awareness of Developmental Milestones and ASD/DD Interventions and Resources

To increase awareness of developmental milestones and ASD services among professionals in their States, DBP programs reached out to students, local healthcare providers, school and community leaders, and families. Table 1 shows some examples of these efforts.

Table 1. Examples of Activities to Increase Awareness

Activity	Example
Engaged medical students and students in other disciplines on ASD/DD topics	Most DBP programs had pediatric medical residents complete a rotation in ASD/DDs and often provided lectures and case presentations to medical students. • Children's Hospital of Los Angeles provided short-term training for nursing trainees, psychology postdoctoral trainees, and physical therapy/occupational therapy trainees. • Boston Children's Hospital provided several psychology postdoctoral fellows direct training in the evaluation and care of children with ASD.
Offered ASD/DD workshops for providers	Programs held workshops for practitioners and providers on various topics related to ASD/DDs. • University of Colorado Denver and University of California, Davis, programs held workshops for ASD/DD 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/DDs aged 12–24 months.
Led office grand rounds to educate primary care physicians on ASD/DDs	Grand rounds provided another mechanism to help community practitioners with challenging cases and provide practical instruction using real-life cases. • The University of Oklahoma held 1-day office rounds for primary care physicians that focused on ASD/DD screening, diagnosis, and treatment. These rounds showcased developmental surveillance and screening of ASD/DDs using a practice enhancement model. • The Medical University of South Carolina held annual office rounds for pediatricians and other pediatric providers using telemedicine to reach rural practitioners and offering in-person training as appropriate.
Facilitated family forums on ASD	Programs held family forums, giving presentations on various topics related to ASD. • Boston Children's Hospital held an in-person family forum. Families attended the meetings, and the presentations were recorded and posted on the web. The DBP director noted, "You may have 50 people who come to the lecture because they've got kids with autism, but you have 1,000 people who watch it on the web."

DBP programs also conducted outreach to underserved populations, such as individuals in hard-to-reach areas, those with low incomes, or those with limited health literacy. For example, the Medical University of South Carolina partnered with the Area Health Education Consortium Program, which provided outreach to professionals in rural and underserved regions of the State. This outreach included updates to recent research and recommendations related to screening, diagnosis, and intervention for ASD. The sessions were archived on the internet for later viewing by professionals unable to attend in person.

Building the Evidence Base for ASD/DD Care and Services

DBP programs provided fellows with training on research methods and mentorship from experienced researchers. The goal was to prepare fellows to be thought leaders and sophisticated consumers of research who could also contribute to the ASD/DD evidence base on strategies for improving screening, diagnosis, and systems of care. DBP programs varied in their approach to research methods, with some offering a full course in research methods and others having fellows complete coursework in research methods through another department (such as the school of public health) at the same or a nearby institution.

In addition to formal training in research methods, trainees were also exposed to research methods in practice. Most DBP programs provided opportunities for active participation in a research project under the guidance of a faculty member or through collaboration with trainees or researchers at other institutions. Fellows often presented findings in posters at seminars or conferences and were encouraged to publish their work in formal or informal publications.

Examples of research collaborations follow:

- **Engaged in community projects.** At the University of California, San Diego, a fellow developed a project to study the use of a tool to assist reading development among deaf and hard-of-hearing children.
- **Contributed to qualitative research.** At the University of Oklahoma, fellows have contributed to services research, including a qualitative study of structure and rituals in families who have children with ASD.
- **Tested cutting-edge interventions.** At Stanford, shared decisionmaking (SDM) is a major topic faculty and fellows implement and study in the community. SDM is communication between care providers and families that facilitates family-centered practice and cultural humility. Families participate in the decisionmaking process, receiving support from their care providers in this nontraditional role. Findings have shown SDM is more common for children with a medical home and is less common for children with severe functional impairment and with ASD after controlling for other factors.

Building and Improving Systems of Care for Individuals With ASD/DDs

Improving systems of care for children with ASD/DDs starts with ensuring families have access to early screening, diagnostic evaluation, and intervention services. Common barriers to early identification include noncompliance with American Academy of Pediatrics screening recommendations among primary care physicians and pediatricians, long waiting lists for comprehensive diagnostic evaluation, and

Raised awareness among hospital personnel

Boston Children's Hospital LEND and DBP programs worked together on an ASD-friendly hospital initiative, training support staff throughout the hospital 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.

lack of information about next steps for children with a confirmed diagnosis.

DBP grantees worked to improve access to screening and referral among underserved populations in the following ways:

- **Provided services at federally qualified health centers.** The University of California, San Diego, operated a clinic in a federally qualified health center on the border of Mexico. Having recently celebrated a 3-year anniversary at that location, the grantee used the center to conduct training and provide DBP services.
- **Worked with underserved beneficiaries.** The Children's Hospital of Philadelphia noted that three of their large practices are in urban, underserved communities in Philadelphia, where more than three-quarters of the clients receive Medicaid. This grantee also worked with a federally qualified health center serving the Asian community, providing assistance and training in autism screening and educating the community.

As demonstrated in the broad range of activities highlighted in this document, DBP programs have trained the next generation of leaders in ASD/DDs, increased awareness of ASD and developmental milestones, contributed to the evidence base on DDs, and expanded systems of care.

Study Design and Methods

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

Endnotes

[1] CDC (Centers for Disease Control and Prevention). (2018). Prevalence of autism spectrum disorder among children aged 8 years: Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014. *Morbidity and Mortality Weekly Report*. Retrieved from https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm

[2] Public Health Service Act, § 399BB(f), (42 U.S.C. 280i-1(f)) as amended by the Autism CARES Act of 2014 (P.L. 113–157).

[3] Committee on Pediatric Workforce. (2013). American Academy of Pediatrics pediatrician workforce policy statement. *Pediatrics, 132*, 390–397. Retrieved from http://pediatrics.aappublications.org/content/132/2/390

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[6] Yingling, M. E., Hock, R. M., & Bell, B. A. (2017). Time-lag between diagnosis of autism spectrum disorder and onset of publicly-funded early intensive behavioral intervention: Do race-ethnicity and neighborhood matter? *Journal of Autism and Developmental Disorders, 48*(2), 561–571.

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[9] American Board of Pediatrics. (2017). *Pediatric physicians workforce data book, 2016–2017*. Chapel Hill, NC: American Board of Pediatrics. Retrieved from https://www.abp.org/sites/abp/files/pdf/pediatricphysiciansworkforcebook2016-2017.pdf

Grantees Included in the Evaluation

Boston Children's Hospital

Children's Hospital of Los Angeles

Medical University of South Carolina

Rhode Island Hospital

Stanford University

The Children's Hospital of Philadelphia

University of California, Davis

University of California, San Diego

University of Colorado Denver

University of Oklahoma