Training Professionals in Service Delivery:

Key Findings From an Evaluation of the Autism CARES Leadership Education in Neurodevelopmental and Other Related Disabilities 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:

- Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) training programs, as highlighted in this document
- Developmental-Behavioral Pediatrics (DBP) Training Program
- 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.

LEND Program Purpose and Goals

The LEND Training Program provides 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 such as psychology, speech-language pathology, occupational therapy, education/special education, pediatrics, psychiatry, and social work and include families and self-advocates. This

document includes data from the 52 LEND programs examined for the 2014– 2017 Autism CARES Act evaluation.[3] These programs were located in 44 States that made use of partnerships and regional collaboratives to reach all 50 States plus Puerto Rico, the U.S. Virgin Islands, the Republic of the Marshall Islands, the Federated States of Micronesia, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands (see figure 1).

LEND programs aim to improve healthcare delivery systems for children with ASD/DDs in the following ways:

Provide interdisciplinary training that emphasizes leadership and clinical skills.

Engage faculty from multiple disciplines to mentor trainees

Figure 1. LEND Program Locations

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

- Increase access to diagnostic evaluations and evidence-based interventions conducted by LEND faculty and trainees.
- Collaborate with other LEND grantees.
- Increase the number of LEND trainees from underrepresented groups to improve the cultural competency of services provided.
- Increase 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.

The Need to Train Professionals in ASD/DD Service Delivery

As the number of individuals identified with ASD/DD increases, there is a need for well-trained clinicians and specialists who can screen children for, diagnose, rule out, and treat this set of disabilities. However, several reports have identified a shortage of trained providers to meet the current demand. Some States do not have any developmental pediatricians at all.[4] 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. 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."[5]

Once children are diagnosed, families often experience long delays in 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.[6] Underserved groups such as low-income populations are more likely than others to have unmet specialty and therapy care needs.[7] The LEND programs address these critical needs by increasing the number of professionals in leadership positions who understand how to screen for, diagnose, and treat ASD/DDs.

Key Contributions of the LEND Program

Training Professionals in ASD/DD Service Delivery

Increasing the Number of Trainees

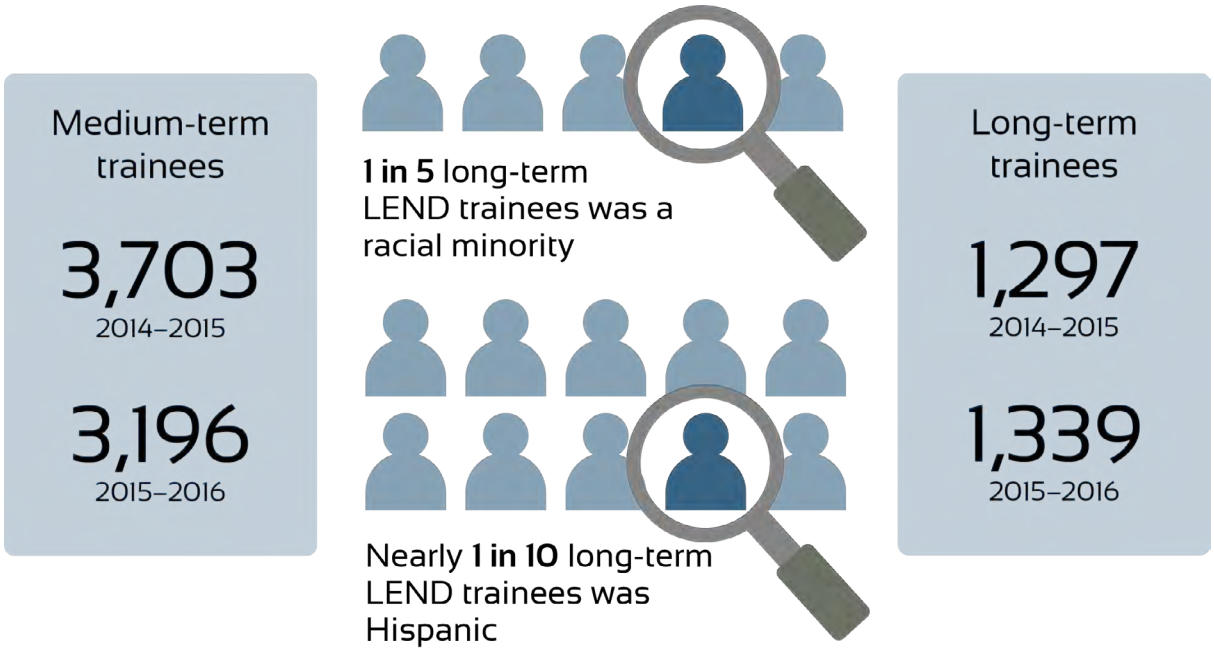
To increase the number of professionals qualified to identify, evaluate, or care for children with ASD/DDs, LEND grantees provided graduate students and professionals from multiple disciplines including family and self-advocate trainees with interdisciplinary didactic and clinical training and leadership development. The LEND program trained an average of more than 3,400 medium-term and 1,300 long-term trainees each year between 2014 and 2016 on diagnostic evaluation and evidence-based interventions for ASD/DDs (figure 2). Medium-term trainees completed between 40 and 299 hours of LEND training during a single academic year. Long-term trainees completed more than 300 hours of LEND training.

LEND grantees worked to increase the number of trainees from underrepresented groups by leveraging non-HRSA funding, participating in HRSA's Diversity and Health Equity Peer Learning Collaborative, and using local and national networks to establish a pipeline to their programs. Grantees also generated interest in ASD by engaging future professionals, including undergraduate and high school students, by increasing their exposure to related academic fields and career paths (e.g., child development, biomedical science, public health).

Enhancing Clinical and Didactic Instruction

Over the evaluation period, the LEND grant program enrolled an average of 1,314 long-term and 2,190 medium-term trainees each year. The trainees engaged in didactic courses covering ASD screening and assessment tools, cultural and linguistic competency, life-course issues, and family-centered care. During the same period, an annual average of 1,326 long-term trainees and more than 1,897 medium-term trainees enrolled in clinical practica (figure 3). LEND faculty and trainees provided interdisciplinary, diagnostic services to confirm or rule out ASD/DDto a steadily increasing number of children each year of the evaluation, from 94,439 in 2014–2015 to 109,215 in 2016–2017,

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



Source 1: From 2014 to 2015, LEND programs enrolled 3,703 medium-term trainees and 1,297 long-term trainees. From 2015 to 2016, LEND programs enrolled 3,196 medium-term trainees and 1,339 long-term trainees. This figure was generated using Discretionary Grant Information System (DGIS) data on the number of LEND medium- and long-term trainees enrolled each year from 2014 to 2015 and 2015 to 2016.

Source 2: From 2014 to 2015, 22.8 percent of long-term LEND trainees were identified as racial minorities; 9.3 percent of LEND long-term trainees were Hispanic. From 2015 to 2016, 21.6 percent of long-term LEND trainees were identified as racial minorities; 8.9 percent of LEND 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 52 LEND programs. DGIS data were not available for 2016–2017.

marking a 7-percent increase in the number of children receiving such services during this time.

Autism CARES funding helped LEND programs enhance the already robust didactic components of their training curricula, including instruction on evidence-based developmental screening and assessment tools and cultural and linguistic competency. Many 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. Programs emphasized cultural and linguistic competency, life-course issues, family-centered care, and self-advocacy in their instruction. For example, at Georgia State University, 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 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. At the University of Delaware, didactic sessions included a self-advocate panel of three young adults with DDs who described their experiences, goals, and challenges as they were aging into adulthood.

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 such as hospital outpatient

clinics, university-based resource and treatment centers, community clinics, schools, shelters, homes, and telehealth virtual clinics, with grantees regularly developing partnerships and collaborations that provided new clinical training opportunities. For example, the University of Illinois 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.

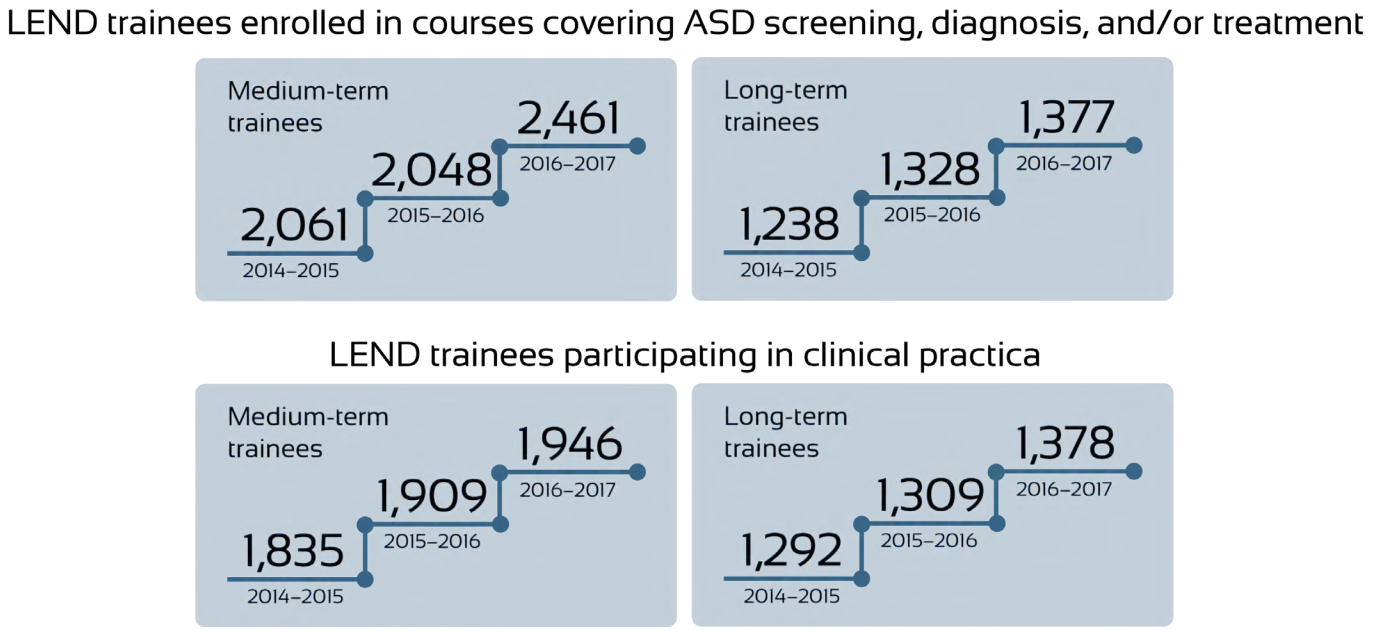
Increasing Representation Among People With Disabilities and Their Families

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.

Developing Leaders in the Field of ASD/DD Care

Most LEND programs required long-term trainees to complete a leadership project; many aimed 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. For example, one trainee at the

Figure 3. Number of Long-Term and Medium-Term LEND 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 National Information Reporting System (NIRS) data describing the number of LEND medium-term trainees and long-term trainees enrolled in coursework on ASD/DDs 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.

University of Pittsburgh LEND created a social story that 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. After completing their training, trainees moved on to serve in critical leadership roles across the Nation. For example, the Boston Children's Hospital director noted the program had produced three LEND directors; four directors of University Centers for Excellence in Developmental Disabilities (known as UCEDDs); many professors, deans, and academics; and a large cadre of clinical professionals and policy and Title V leaders.

Training Providers to Deliver Services for Youth Transitioning to Adulthood

Healthcare providers need training to feel confident supporting young adults with ASD as they age into adulthood. To address this need, many LEND grantees incorporated learning opportunities about the transition to adulthood into their didactic and clinical training programs.

Incorporating Research Into the LEND Program Curriculum

The LEND program provided training on research methods to prepare trainees as leaders in the field either as sophisticated research consumers or as those generating their own research. Some LEND programs incorporated research training into seminars and courses, while others had trainees obtain these skills through their own discipline-specific training. In addition to formal training in research methods, trainees were also exposed to research methods in practice. In some programs, trainees evaluated a community project or conducted quality improvement initiatives in lieu of or in addition to a traditional research project. For example, the University of Wisconsin program 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 a teen's transition to adulthood. The program involves group sessions for parents and social group sessions for adolescents geared to foster peer interaction.

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

While more communities and providers are aware of ASD after decades of outreach, and screening rates have improved in some areas, the proportion of children who receive routine screening remains small.[8] Multiple factors such as lack of awareness of screening recommendations, lack of parent and caregiver knowledge of developmental milestones, and disparities in screening among underserved populations lead to low screening rates. LEND grantees promoted awareness of ASD among professionals and community members and focused outreach efforts on underserved groups to help fill this gap.

Topics in grantees' didactic transition training

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

LEND programs offered 6,803 continuing education courses between 2014 and 2016, reaching more than 345,582 participants.[9] This enabled practicing professionals to learn about the latest evidence-based practices for identifying and caring for children with ASD. Grantees provided continuing education on topics related to monitoring and assessing development, providing treatment and intervention, and supporting families and improving quality of care. In addition to providing information, some of these events provided continuing education credit to help professionals maintain licensures.

LEND grantees also increased awareness of developmental milestones in coordination with the Centers for Disease Control and Prevention's *Learn the Signs. Act Early.* campaign by recruiting 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.

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) built on *Learn the Signs. Act Early.* efforts by translating materials for non-English speakers; (3) collaborated with local partners to disseminate information to underserved communities; and (4) reached immigrant and refugee communities through television, websites, radio, video, and social media outlets. For example, the program at the University of Utah created and aired a radio novella, which they found to be effective in reaching the Hispanic community. This "mini-novella" featured a series of skits played out like a soap opera scene, where a child is diagnosed with ASD. The series was about early identification, interventions, and the emotional impact of the diagnosis on the family.

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

A key strategy for improving access to ASD services involves reducing or eliminating 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. LEND grantees tested and implemented various strategies to streamline the assessment process for families with concerns about their children's development. At the University of Kansas Medical Center Research Institute, 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. Relatedly, the University of Texas developed and launched a web portal that provides online, automated development screens for parent and childcare provider use. The screening tools are the Modified Checklist for Autism in Toddlers, known as M-CHAT, and the Ages and Stages Questionnaires, known as ASQ-3. If results indicated cause for concern, the email message included information on where to go for further evaluation and services. The results were also faxed to an early childhood intervention specialist or local school district and to the family's primary care physician, as identified during registration.

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] Forty-three grantees received 5-year grants from 2011 to 2016, and 52 received grants for the period from 2016 to 2021 (including 43 prior and 9 new grantees).

[4] Gordon-Lipkin, E., Foster, J., & Peacock, G. (2016). Whittling down the wait time: Exploring models to minimize the delay from initial concern to diagnosis and treatment of autism spectrum disorder. *Pediatric Clinics of North America, 63*(5), 851–859.

[5] Bridgemohan, C ., Bauer, N. S., Nielsen, B. A., DeBattista, A., Ruch-Ross, H. S., Paul, L. B., & Roizen, N. (2018). A workforce survey on developmental-behavioral pediatrics. *Pediatrics 141*. Retrieved from http://iranarze.ir/wp-content/uploads/2018/03/E6094-IranArze.pdf

[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.

[7] Chiri, G., & Warfield, M. E. (2012). Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Maternal and Child Health Journal, 16*(5), 1081–1091. Retrieved from https://doi.org/10.1007/s10995-011-0833-6

[8] Van Cleave, J. V., Kuhlthau, K. A., Bloom, S., Newacheck, P. W., Nozzolillo, A. A., Homer, C. J., & Perrin, J. M. (2012). Interventions to improve screening and follow-up in primary care: A systematic review of the evidence. *Academic Pediatrics, 12*(4), 269–282.

[9] In 2014–2015, 3,385 LEND continuing education sessions reached 161,764 participants. In 2015–2016, 3,418 continuing education sessions reached 183, 818 participants. No data were available for 2016–2017. The data source was DGIS.

Grantees Included in the Evaluation

Albert Einstein College of Medicine
Children's Hospital (Institute for Community Inclusion)
Children's Hospital of Los Angeles
Dartmouth Medical School
Georgia State University (Center for Leadership in Disability)
Indiana University School of Medicine
Kennedy Krieger Institute
Louisiana State University Health Sciences Center Project
Medical University of South Carolina
Ohio State University (Nisonger Center UCEDD)
Oregon Health & Science University (Oregon Institute on Disability and Development)
Regents of the University of Minnesota
Rhode Island Hospital
Rutgers, the State University of New Jersey
The Children's Hospital of Philadelphia
University of Alabama at Birmingham
University of Alaska Anchorage (Center for Human Development)
University of Arizona
University of Arkansas for Medical Sciences
University of California, Davis
University of California, Los Angeles
University of Cincinnati
University of Colorado Denver (JFK Partners)
University of Connecticut Health Center
University of Delaware
University of Hawaii at Manoa
University of Illinois at Chicago
University of Iowa
University of Kansas Medical Center Research Institute
University of Massachusetts Medical School
University of Miami (Mailman Center for Child Development)
University of Missouri, Columbia (TIPS for Kids)
University of Nebraska (Munroe-Meyer Institute for Genetics & Rehabilitation)
University of Nevada, Reno (Nevada Center for Excellence in Disabilities)
University of New England
University of New Mexico Health Sciences Center (Center for Development and Disability Pediatrics)
University of North Carolina at Chapel Hill (Center for Development and Learning)
University of Oklahoma Health Sciences Center
University of Pittsburgh
University of Rochester (Strong Center for Developmental Disabilities)
University of South Dakota
University of Tennessee Boling Center for Developmental Disabilities
University of Texas Health Science Center at Houston
University of Utah
University of Vermont (Vermont Interdisciplinary Leadership Education for Health Professionals)
University of Washington (Center on Human Development and Disability)
University of Wisconsin–Madison (Waisman Center)
Vanderbilt University
Virginia Commonwealth University
Wayne State University
Westchester Institute for Human Development
West Virginia University