

Testimony for the Record
Submitted to the
House Committee on Energy & Commerce
Subcommittee on Health
For the Hearing
“Reauthorizing Vital Health Programs for American Families”
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Chairwoman Eshoo, Ranking Member Burgess, and distinguished Members of the Subcommittee, thank you for inviting me to participate in today's hearing. It is a great honor to appear before you to share my experience as Director of the Institute on Community Integration (ICI) at the University of Minnesota, to discuss the work and impact of Autism Collaboration, Accountability, Research, Education, and Support (CARES) over the past five years, and the importance of Congress' reauthorization of HR 1058 CARES Act.

In my role at the University of Minnesota, I am the director of the Institute on Community Integration (ICI), a University Center of Excellence on Developmental Disabilities (DD). My research, training and outreach work has focused on community long-term services and supports for children, youth and adults with intellectual and developmental disabilities, including autism. Currently our Center has several CARES projects, including the Autism and Developmental Disabilities Monitoring Network, targeted efforts to integrate the CDC's "Learn the Signs Act Early" campaign tools across our state, and the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program. I am proud to share that I am a Maternal and Child Health LEND Trainee Alumni, having received training at the Riley Child Developmental Center in Indiana over 25 years ago. I am the current President of the Board of Directors for the Association of University Centers on Disabilities, a network that includes all 52 LEND centers, as well as the CARES-funded national resource center that provides technical assistance to LENDs, Developmental Behavioral Pediatrics (DBP) Training Programs and the CDC "Act Early" Ambassadors that have a presence in nearly every state and territory in the United States.

DATA AND NEEDS

Autism and related neurodevelopmental disabilities continue to pose significant challenges to communities across the United States. The prevalence of autism spectrum disorder (ASD) diagnoses has risen dramatically – over 600% -- in the past several decades. According to the CDC, autism affects about 1 in 59 children, and boys are four times more likely than girls to be identified with ASD. Beyond autism, about 1 in 6 children has a developmental disability.¹ This means that it is highly likely that everyone in this room knows someone that has a family member with autism or another developmental disability. While I am here in my professional role as a researcher and professor, I understand the importance of these issues as a family member, too. My brother-in-law, Nathan, is 45 years old and is autistic. He has lived with our family, in his own apartment in our home, for the past 25 years. He reminds me daily that children grow up and become working adults who want good lives in our communities. Nathan makes me aware that we have much to learn from autistic adults about the systems we

¹ <https://www.cdc.gov/ncbddd/autism/data.html>

create to support autistic people and that we need these systems of support across the lifespan.

The Autism CARES Act has helped to build a critical infrastructure to further advance our understanding of autism. The Autism CARES Act supports several important programs. It supports the Autism and Developmental Disabilities Monitoring (ADDM) Network, a group of programs funded by the CDC to estimate the number of children with ASD and other developmental disabilities living in different areas of the United States. The CDC also established regional centers of excellence for ASD and other developmental disabilities. They make up the Centers for Autism and Developmental Disabilities Research and Epidemiology Network (CADDRE) that are working in part to help identify factors that may put children at risk for ASD and other developmental disabilities.

Findings from the Minnesota-Autism and Developmental Disabilities Monitoring Network (MN-ADDM) helps us to understand more about the number of children with Autism Spectrum Disorder (ASD), the characteristics of these children, and the age at which they are first evaluated and diagnosed.

This is the first time Minnesota has been a part of the ADDM network, and we are building our geographic area. Through this work, we know that 1 in 42 8-year-old children were identified with ASD in 2014.² We now know that boys were 4.6 times more likely to be identified than girls and that there were no significant differences found in the percentage of white, black, and Hispanic children identified with ASD.

The findings in our report reflect a limited number of children concentrated in a large metropolitan area. Through the reauthorization of the Autism CARES Act, we are hopeful that we will be able to increase our scope geographically and include the lifespan of individuals with autism. This is particularly important because in addition to the race/ethnicity categories routinely studied by CDC, in Minnesota we were interested in understanding prevalence for our local Hmong, Somali and other immigrant populations. Expansion of the geographic area in which we gather data is the only way we will be able to know with certainty if differences exist among these groups in Minnesota.

The data that has emerged on disparate populations has resulted in partnerships with the CDC-funded “Learn the Signs Act Early” initiative to conduct outreach and education activities on early developmental screening and early identification directly in under-identified communities such as Latino, American Indian, Hmong, and Somali communities.³

ADDM’s critical findings across the nation are being used to promote early identification of ASD, plan for ASD services and training, guide future ASD research, and inform

² <https://www.cdc.gov/ncbddd/autism/addm-community-report/minnesota.html>

³ Ibid.

policies promoting improved outcomes in health care and education for individuals with ASD. Most importantly, we know that behind each of these numbers is a child and their family needing access to services and supports to live a full life in their communities.

WORKFORCE INVESTMENTS

The Autism CARES Act also funds workforce programs. The Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs have been funded for nearly 50 years to provide advanced training to students and fellows from a broad array of professional disciplines – including medicine, social work, public health, nursing, psychology, physical therapy and many others – in the identification, assessment, and treatment of children, youth and young adults with a wide range of developmental disabilities including ASD, intellectual disability, fragile X syndrome, cerebral palsy, spina bifida, Down syndrome, epilepsy and many other genetic and metabolic disorders. Importantly, individuals with autism and family members are part of these LEND training cohorts, building the skills and partnerships needed for successful systems of support for children, youth and adults with ASD. Nationally, and particularly in more rural communities, there are tremendous shortages of personnel trained to screen, diagnose and provide treatment to individuals with autism and related developmental disabilities. As a result, families often must wait months and travel long distances to get a comprehensive diagnosis for their child. LEND programs train the next generation of leaders who will move the field of autism and developmental disabilities forward by improving research, clinical services, and public policy.

In 2006, the Combating Autism Act (P.L. 109-416) amended the Public Health Service (PHS) Act to add an emphasis in the early identification, diagnosis, and treatment of children with ASD because of the rising prevalence rates across the U.S. This law was reauthorized in 2011 as P.L. 112-32 and again in 2014 as the Autism CARES Act (P.L. 113-157). The law recognized the benefits of the LEND network in addressing this significant public health issue by authorizing the expansion of the network. The law extended the reach of the LEND program by gradually adding LEND host and/or partnership sites in each of the thirteen states that did not then have such a presence.

There are currently 52 LEND programs located in 44 U.S. states, with an additional six states and three territories reached through program partnerships. According to the Congressionally-mandated report to Congress on Autism CARES (2018)⁴, the LEND programs have collectively made significant strides toward improved screening and diagnosis of autism among younger children while helping train a variety of healthcare professionals who treat a number of different developmental and intellectual disabilities.

Critical voices in this work are the people who have lived experiences including autistic adults and families. Ensuring the first-person perspective, the role of autistic trainees, partners, and faculty has provided an imperative lens for LEND programs to increase

⁴ https://iacc.hhs.gov/publications/report-to-congress/2018/report_to_congress_2018.pdf

the quality of care provided. Thanks to the expanded number of LEND grantees and trainees representing a broad range of roles within healthcare systems, the national LEND network provided interdisciplinary diagnostic evaluations for an average of 113,623 infants and children annually between 2014 and 2017.⁵ By continuing to meet the growing demand for these services, LENDs are reducing wait times for diagnostic evaluation and entry into intervention services. Moreover, because LENDs typically target underserved populations, their efforts are also helping to address disparities in early identification of ASD and other developmental disabilities. Additionally, the law authorized a technical assistance award for the interdisciplinary training network that helps to build connections across programs and provides a venue for collecting efficacy data, shared learning, curricula development, and identification/sharing of exemplary practices.

The Developmental-Behavioral Pediatrics (DBP) Training Program is training the next generation of leaders within the medical community and building capacity to evaluate, diagnose or rule out, develop and provide evidence-based interventions to individuals with ASD and other developmental disabilities through primary care practitioners. Right now, the average wait time for a family to see a Developmental-Behavioral Pediatrician is 14.5 weeks.⁶ CARES currently funds twelve DBP programs that provide extensive, multi-year training to doctors post-residency. Importantly, reauthorization includes new language directing the prioritization of awards to Developmental-Behavioral Pediatrics Training Programs located in rural areas or underserved areas. This is imperative as entire predominantly-rural states such as North Dakota and Wyoming do not have a Developmental-Behavioral Pediatrician.⁷

SYSTEMS

Through current legislation, the Interagency Autism Coordinating Committee (IACC) coordinates federal efforts and provides advice to the Secretary of Health and Human Services on issues related to ASD. Through its inclusion of both federal and public members, including people with lived experience of autism, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum. I am excited that changes in the CARES reauthorization expand the IACC membership to include representatives from the Department of Labor, Department of Justice, and Department of Housing and Urban Development, and reflect the role these agencies fulfill related to individuals with autism and their families. In addition, the restrictions that non-federal members of the IACC may only be reappointed for one additional four-year term instead of one or more terms as statute currently reads will allow for a broader representation of voices.

⁵ <https://mchb.hrsa.gov/sites/default/files/mchb/autism-cares-act-report.pdf>

⁶ <https://www.childrenshospitals.org/issues-and-advocacy/graduate-medical-education/factsheets/2012/pediatric-specialist-physician-shortages-affect-access-to-care>

⁷ <https://www.abp.org/content/us-distribution-abp-diplomates-state#overlay-context=content/general-information-all-certified-diplomates>

The coordination created by the IACC at the federal level translates to local levels. In addition, CARES provides State Implementation Grants (SIGs) for Improving Services for Children and Youth with Autism Spectrum Disorder. I have seen in Minnesota how these grants improve access to care through referrals, timely diagnosis and feedback, and entry into quality, coordinated care across systems for children with ASD and other developmental disabilities through family navigation and provider training.

Act Early Ambassadors are state-level experts who work to improve early identification practices. They serve as state liaisons to the "Learn the Signs Act Early" campaign and work as community champions with programs that serve young children and their parents, such as Head Start and Early Head Start, WIC, home visiting, and others, as well as with health care and childcare professionals, to improve early identification of developmental delay. In Minnesota this project has provided the opportunity to reach families in diverse communities with a focus on parent-to-parent networking that promotes early identification and connection to services directly in communities. With this approach, we know we have reached families with young children with early developmental delays we would not have reached through more traditional means.

A hallmark of the CARES programs has been an intentional and strategic partnership with Maternal and Child Health Title V programs in the states. The close working relationships between CARES programs and Title V results in more effective, coordinated and collaborative leadership on state and local coalitions. In Minnesota and across the country, we see how the alignment between research and systems helps to ensure that we are more effectively supporting people.

RESEARCH

The Autism CARES Act supports NIH-funded research, including studies of the developmental processes underlying autism biology, research on the molecular and neurological underpinnings of ASD and gene function, and research on potential environmental risk factors and biomarkers for ASD, including gene-environment interactions. The NIH Autism Centers for Excellence across the country conduct research on possible treatments and interventions, then report findings to the National Database for Autism Research, which increases the efficacy of and access to the research. This research is answering questions and addressing needs of individuals and families with the most effective treatments and interventions for both ASD and co-occurring conditions. It also directs policy by tracking the impact of policy changes on ASD health care spending, patterns of injury mortality, and prevalence differences across demographic groups.

SUPPORTING THE FUTURE

Importantly, Autism CARES mandates a progress report on activities related to autism and other developmental disabilities, which provides a chance for stakeholders and policymakers to reflect on both progress and needs. It is a consequence of this learning that reauthorization introduces new requirements for the report to include information on

home and community-based services and residential services - vital issues for adults with ASD and other developmental disabilities. This inclusion of the life course of autism reflects the growing need to expand our research, service, and collaboration to all ages of individuals with autism.

In addition, a new report authorized by the 2019 bill will focus on health and well-being of individuals on the autism spectrum; this includes an overview of programs and policies, proposals on establishing best practices, and proposals to improve health outcomes for individuals with autism.

The continued investment in building a workforce in every state and territory that is able to meet the needs of individuals with autism and their families has far-reaching implications. These include the potential to drive how thousands of health professionals are trained via LEND and DBP programs and also the many individuals and systems that are touched by the technical assistance and continuing education provided by these programs.

In closing, the reauthorization of the Autism CARES Act shows the commitment from each of you to provide a coordinated federal response to the needs of individuals diagnosed with ASD. This legislation has provided the opportunity to answer critical questions and address disparities in the area of autism through research, public health surveillance, and workforce development. Therefore, I urge Congress to renew its investment and enact a 5-year reauthorization before it expires on September 30, 2019.

Thank you for your time and for this opportunity to share my experiences as a former LEND trainee, director of CARES projects, an advocate in the field of autism and developmental disabilities and most importantly as a family member, to provide my perspectives on the importance of CARES and its potential for the future. If I can provide you with any additional information I am happy to do so and I look forward to further discussion on this important topic.