About the Autism CARES Act

The Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act (H.R. 113-157) expanded and coordinated the federal government's response to the increasing numbers of individuals diagnosed with Autism Spectrum Disorders (ASD), including:

- Research being conducted within and administered by the National Institutes of Health (NIH)
- Surveillance and awareness activities at the Centers for Disease Control and Prevention (CDC)
- Workforce development, research into evidence-based interventions, and efforts to establish more effective systems of care at the Health Resources and Services Administration (HRSA)
 - Including LEND programs
- The Interagency Autism Coordinating Committee (IACC)
- Reports to Congress on activities and outcomes related to critical issue areas, such as the transition from youth to adulthood.

Due to a sunset provision, the law will expire in September 30, 2019 if it is not first reauthorized. Bills to reauthorize the Act have been introduced (HR. 1058, S. 427).

About LEND

The national network of Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs works to improve the health of infants, children, and adolescents who have, or are at risk for developing, ASD and other neurodevelopmental and related disabilities. This is accomplished through graduate-level interdisciplinary training, as well as family-centered services and care. Autism CARES supports 52 LEND programs in 44 U.S. states, with an additional six states and three territories reached through program partnerships.

LENDs operate within a university system, allowing access to hospitals, expert faculty, facilities, and other resources necessary to provide exceptional training and services. Each year, thousands of LEND trainees:

- Receive top notch didactic (i.e. classroom) education;
- Participate in robust clinical and community experiences;
- Engage in research and systems change initiatives;
- Address emerging health and disability issues; and
- Practice foundational leadership skills.



Programs also serve as resources in their respective states by:

- Increasing access to and quality of direct clinical care;
- Providing technical assistance to public health agencies and other entities, including school systems;
- Offering continuing education to enhance the skills of practicing healthcare professionals; and
- Educating policymakers about issues relevant to the ASD/DD population.



Reauthorization

If Congress does not take action to reauthorize funding, available funds for LEND and other initiatives funded under the Autism CARES Act will expire in September 2019. This would eliminate:

- Interdisciplinary diagnostic services to confirm or rule out ASD/DD for 105,000 children per year.
- Short-, medium-, and long-term training in ASD/DD for more than 32,000 graduate students, practicing healthcare providers, family members, and self-advocates per year.
- Nearly 4,300 continuing education and community training events on ASD/DD topics per year.
- Important ASD/DD research being conducted by nearly 1,900 faculty members and trainees per year.

This document was prepared by the Association of University Centers on Disabilities. For more information, visit <u>www.aucd.org</u>, or contact Policy Director Rylin Rodgers at <u>rrodgers@aucd.org</u>.



- 1. Invite your federal legislators to join the Congressional Autism Caucus.
- 2. Encourage (by calling, writing, scheduling a meeting, etc.) your congressional delegation to support the reauthorization of the Autism CARES Act. Be sure to thank your members for their support!









