

# AUCD Hill Visit Talking Points

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## *AUCD 2015 Conference*

Thank you for participating in the 2015 hill visits in conjunction with the AUCD Annual Meeting. The purpose of your visit is to make sure that your Senators and Representatives hear directly from you about the work that you do and why it is important to people with disabilities in your state as well as nationwide. In the current fiscal environment in which there is a continued focus on cutting federal government supported programs, it is important that your Senators and Representatives know about our network and understand why it's a good investment.

Be sure to talk about the families you serve, the interdisciplinary training that you provide (or receive), the research you conduct, the community services you provide, and any other innovative or interesting projects that are impacting the lives of people with disabilities and their families in your state and nationwide. Also, please add that you are part of a national network of state-based centers – UCEDDs, funded by the Administration on Intellectual and Developmental Disabilities, and LENDs, funded by the Maternal and Child Health Bureau, and/or IDDRCs funded through the NICHD within the National Institutes of Health. Please feel free to use any of the following talking points.

### Sample Talking Points:

- We are part of a national network of 67 University Centers for Excellence in Developmental Disabilities in each state and territory that provide research, interdisciplinary training, and exemplary evidence-based services to support people with disabilities and their families.
- On average, over the past 5 years, the national network of UCEDDs provided direct services to more than 70,000 people with disabilities annually; trained 2,000 professionals working in the disability field annually, and conducted nearly 3,000 research projects each year.
- UCEDDs exist to provide a unique, expert, state and community resource to facilitate independence and full participation for people of all ages living with developmental disabilities. They address issues that are not funded by other agencies or organizations and fill gaps in the system of services for people with disabilities.
- We are part of a national network of 43 Leadership Education in Neurodevelopmental Disabilities programs in 39 states that are training the next generation of clinicians to respond to the needs of children with developmental disabilities and their families. This includes children with autism, Down syndrome, spina bifida, epilepsy, fragile X, and a wide range of genetic and metabolic disorders.
- LEND programs are funded through HRSA's Maternal and Child Health Bureau but the appropriations funding line item has been tied to the Autism CARES Act (PL 113-157) since 2006. The law encourages an increase in the number of interdisciplinary training sites that can diagnose, rule out, and treat individuals with ASD.
- LEND programs are reducing wait times for diagnostic evaluation and entry into intervention services. In 2012 alone, LEND programs provided interdisciplinary diagnostic evaluations for close to 56,000 infants and children.
- LEND trainees go on to serve in hospitals, clinics, schools, and other community programs as nurses, pediatricians, special education teachers, audiologists, geneticists, nutritionists, occupational and physical therapists, psychologists, speech-language pathologists, social workers, and more.



- Every year, more than one million children under the age of 5 who have disabilities or developmental delays go undiagnosed and enter school without the skills to be successful. We know that children who get the supports they need at the start of their lives have greater opportunities for independence as adults. Our network trains future clinicians to identify children with delays and provide crucial early interventions.
- With a small amount of federal funding, our programs respond to the needs of our states and communities through research, service projects, and training. For example, in my center we started *[insert a program your center is proud of]* to respond to the need for *[insert problem your program seeks to solve]* in our state.
- As a *[pediatrician]* I want to provide the best care to my patients. However, my training does not give me a lot of background on disabilities or chronic health conditions so I rely on LEND training programs to provide me with information on specialty care that helps me serve my patients and keep them healthy.
- As *[a parent of a child with a disability]*, I rely on the community services and trained professionals that the UCEDD/LEND network provides.
- We need a balanced approach to handling our national debt that does not harm people with disabilities, for whom government services and supports are vital to their ability to remain healthy, employed, educated and independent in their communities.
- Many disability services programs have been grossly under-funded for years, with appropriations not coming close to addressing the current unmet needs. We are extremely concerned about how the continued cuts to the federal budget will impact these vital *programs [give specific stories about impact of cuts you have seen or expect to see]*.

For your reference, here are the most recent funding numbers for UCEDDs, LENDs.

<i>In millions</i>	FY 2015	President's FY2016	House Subcommittee	Senate Subcommittee	<b>AUCD's FY 2016 Request</b>
UCEDD	37.7	39.0	37.7	35.7	<b>39.0</b>
LEND	28.0	28.0	30.0	28.0	<b>30.0</b>