

AUCD Hill Visits Talking Points

AUCD 2013 Conference



Thank you for participating in 2013 hill visits! This is only the second year AUCD has asked members to visit the hill in conjunction with the AUCD Annual Meeting, and we are excited about the opportunity for our members continue existing relationships and build new relationships with Members of Congress and staff.

The purpose of your visit to the Hill 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 the people with disabilities and families that you serve. In the current fiscal environment, it is even more important that your Senators and Representatives get to know your Center and understand that the research, education, and services that your Center provides is a worthwhile investment to the state and the country.

Be sure to mention 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 –are responsive to needs in your states and communities. You can also mention the families you serve, the interdisciplinary training that you provide (or receive if you are a trainee), 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. Please feel free to use any of the following talking points.

Examples of 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 37 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 out of HRSA's Maternal and Child Health Bureau but the appropriations funding line item has been tied to the Combating Autism Act (P.L.112-32) since 2006. This law will sunset if it is not reauthorized by September 30, 2014.

- In FY 2010 alone, the LENDs screened more than 46,000 infants and children for autism and other developmental disabilities and provided diagnostic evaluation services for more than 35,000 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, and social workers.
- 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 deficit reduction 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.
- The savings needed to replace sequestration should come from both spending cuts and revenues, such as tax expenditures. Any relief from sequestration should be evenly split between defense and non-defense programs.
- 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, and Autism/Other DD programs.

<i>In millions</i>	FY 2012	FY 2013*	President's FY 2014 Request	FY 2014 AUCD Request
UCEDD	\$38,792,000	\$37,602,000	\$39,000,000	\$41,000,000
LEND	\$28,400,000	\$26,498,000	\$28,400,000	\$28,400,000
Autism and other DD	\$47,142,000	\$44,652,000	\$47,142,000	\$47,142,000

* FY 13 Numbers reflect rescissions resulting from sequestration