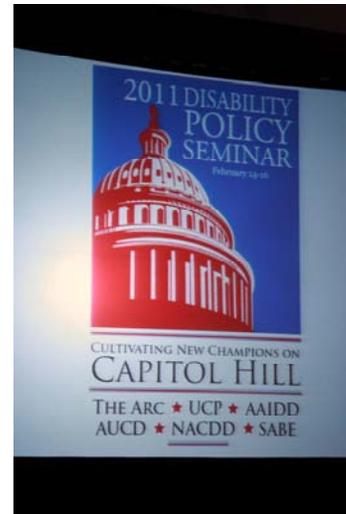


2011 Disability Policy Seminar: Reflections from AUCD Trainees



Introduction to the Disability Policy Seminar from AUCD's Virtual Trainee

I had the pleasure of attending the 2011 Disability Policy Seminar (DPS) with over 110 other trainees from across the AUCD network. The DPS took place over three days, February 14th through February 16th. The first two days, we had the opportunity to hear leading public policy experts, disability advocates, and Congressional staff discuss key policies important to the disability community, such as the Affordable Care Act, the Combating Autism Act, the President's Budget, the Developmental Disabilities Act, the Elementary and Secondary Education Act, Medicaid and Medicare, and Social Security. After learning about these issues and policies, we set out on Wednesday to meet with our Congressional delegation to advocate that persons with disabilities have equal opportunity to participate in our economy and society, as well as receive necessary services and supports. In order to capture and share the experiences of trainees at the DPS, trainees were asked to respond to the following three sentence/paragraph starters: "At the DPS, I...," "On the Hill, I...," and "One thing I will bring back to my LEND program is...." This publication will include trainees' responses to these sentence/paragraph starters and will provide you with an overview of what was learned and the impact the DPS had on trainees.

Suzanne Engel
2010-2011 Virtual Trainee

March 2011

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Trainees who attended the AUCD trainee reception at the 2011 DPS

At the Disability Policy Seminar, I...

...found out about the dire state of disability service funding at the federal and state levels and how important programs and services are for people with disabilities.

*Sinan Turnacioglu
Physician
DC LEND/IDDRC, Children's
National Medical Center
Consortium of Universities*

...was able to learn all about policies that affect individuals with DD that I would have not otherwise been exposed to in my academic program.

*Joliana Zelaya
Speech-Language Pathology
Ohio UCEDD/LEND,
Nisonger Center*

...was lucky enough to hear the most current and direct information regarding not only disability policy but also budget, social security, Medicaid/Medicare, and other vital issues just by virtue of being in Washington, D.C. surrounded by seasoned political advocates.

*Frank Wartinger
Audiology
Massachusetts
UCEDD/LEND/IDDRC,
Institute for Community Inclusion*



Illinois Trainees: Emily Tegenkamp, Jillian Schuh, Robyn Westfallen

...was very excited to see so many other trainees from programs all over the United States. The information we received was well written and the issues were well framed for discussion with policy makers. Upon returning to CT, I gave a short update on policy issues to the other LEND fellows and encouraged them to meet with their legislators when they are in their home districts. ***As a result of my attendance at the seminar, I do feel more capable of intelligently discussing these issues with others, and am determined to continue to follow the legislative updates so I am aware of the progress of these very important policies.***

*Christine A. Sullivan,
Special Education
Connecticut UCEDD/LEND, A.J. Pappanikou Center for Developmental Disabilities*

...was amazed at the amount of information that was provided to all that attended. It was also scary to learn about the potential cuts that Congress is proposing and how it will impact the disability community. ***The presentations were excellent, well thought out and planned, and presented so everyone could understand.***

*Theresa Revans-McMenimon
Family*

New York UCEDD/LEND, Westchester Institute for Human Development

...learned a multitude of ways policies affect individuals with developmental disabilities. I was surprised at the amount of self-advocate attendees and impressed with their contribution. I was most touched by a young student who wants to see teachers be required to learn about developmental disabilities to prevent children from having to change schools due to ignorance.

Janice Kilgallen

Social Work and Child Development (Psychology)

New York UCEDD/LEND, Westchester Institute for Human Development



Members of the Cincinnati, Ohio LEND

...was very encouraged with the number of groups (The ARC, UCP, AAIDD, AUCD, NACDD, SABE) that joined together to convene this Policy Seminar. It was exciting to see all this support for the disability community. ***The Seminar notebook contains comprehensive information for disability advocacy. I plan on keeping this notebook to help me in my future advocacy pursuits.***

*Jenny Wade
Family*

*Missouri UCEDD/LEND,
Institute for Human Development*

At the Disability Policy Seminar, I...

... gained the knowledge and courage to go advocate for a variety of important issues. ***The speakers were enthusiastic about their specific topic, and by making the information more understandable I was very encouraged by their messages.*** Previously I lacked knowledge of health care reform and appreciated gaining a better understanding of the details involved.

*Katie Hare
Physical Therapy
Iowa UCEDD/LEND,
Center for Disabilities
and Development*



Trainees from LEND programs located in the Northeast at a Disability Policy Seminar event

...had the ability to network with many professionals throughout the country about a shared passion. I also received a comprehensive review of the major issues in various areas affecting individuals with developmental disabilities. The topics included education, employment, legislative advocacy, Developmental Disabilities Act, housing, Social Security, autism, Medicare and Medicaid, healthcare and budget, and appropriations. It was an added bonus that President Obama introduced the budget the first day of the seminar. As the information was presented, we had real time updates from policy experts and members of the Administration.

*Stephanie A. Rosati-Pratico
Family
Children's Seashore House of the Children's Hospital of Philadelphia, LEND/IDDRC*



The Honorable Barbara Mikulski (D-MD), United States Senator (center) standing among Maryland constituents, including LEND trainee Ajita Robinson (standing immediately to the right of the Senator with a turquoise shirt and black skirt)

...had an exciting and informative experience. I felt energized after listening to all of the various endeavors that AUCD and the associated organizations were embarking upon on behalf of the disability community. I was thankful to have met several self advocates who were in attendance. I was additionally inspired by Betty Williams, SABE president, who presented Senator Barbara Mikulski with an award for her continued work with and on behalf of the disability community. Senator Mikulski accepted the award and offered words of inspiration and continued dedication to the fight for services and equality for those impacted by a disability. She also graciously agreed to a photo opportunity with her Maryland constituents in attendance, which I was pleased to be a part of. ***Overall, the experience was one of enlightenment and inspiration and I'm glad that I was a part of the event.***

*Ajita M Robinson
Counseling*

DC LEND/IDDRC, Children's National Medical Center Consortium of Universities

...gained valuable knowledge about disability policy and advocacy that I would not have obtained from other experiences or courses.

*Katlin Maher
Speech-Language Pathology
Ohio UCEDD/LEND, Nisonger Center*

At the Disability Policy Seminar, I...

...seven trainees from the Iowa LEND program attended...to learn about federal legislative initiatives related to individuals with disabilities...

Trainees from Iowa UCEDD/LEND, Center for Disabilities and Development (pictured at right)

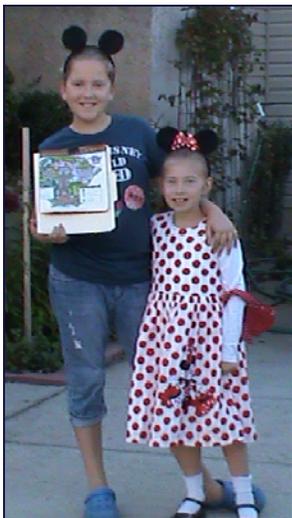


...met with other LEND trainees and learned about the different LEND programs that are out there.

*Sue Engle
Nutrition
New Hampshire LEND, Children's
Hospital at Dartmouth*

...learned a lot about the different Acts that not only impact the services that we provide but our training as professionals to help people that have disabilities with respect and cultural competency.

*Ana Vivian Escalante
Social Work
New York UCEDD/LEND,
Westchester Institute for Human Development*



Lynise's daughters
Rachel and Brooke

...realized that the policies that are being implemented now will be reaching maturation by the time my daughter graduates from high school and will potentially need these services. My blissful ignorance about needing to look ahead 10 years is more crucial than ever anticipated.

The Disability Policy Seminar was an eye-opening experience to the amount of support individuals with disabilities need, what is available currently to help those individuals and also what still needs to be addressed.... I was glad to learn more about the different programs so I can pass that information along to other parents so they can look into it for their family members...

*Lynise Parisien
Family
Tennessee UCEDD/LEND/IDDRC,
Vanderbilt Kennedy Center*

...we were energized and inspired by the individuals who were in attendance and spoke so passionately about disability rights from both personal and professional perspectives. We had the opportunity to meet disability advocates from across the country, and to hear from knowledgeable leaders about the state of federal disability policy and its impact on individuals and communities. We realized there are a lot of people invested in fighting for disability rights and individuals have their own stories. We learned about the numerous policies that are currently being threatened by proposed budget cuts and the misinformation about several disability right issues. For example, we learned how drastic changes to the Social Security system would affect individuals with developmental disabilities. It was surprising to some of us to learn that Social Security is not, in fact, a contributor to our national financial crisis, as it is often stated in the media. We were refreshed to hear the facts from experts and to meet so many wonderful people, especially individuals from other LEND programs. ***While the current budget situation may be dire, we left excited because there are still things we can do!***

Trainees from New York UCEDD/LEND, Strong Center for Developmental Disabilities



Trainees from the Strong Center for Developmental Disabilities in New York and a representative from
Congresswoman Ann Marie Buerkle's office

On the Hill, I....

...was able to meet with Congressman Stivers in person and learn how to advocate for policies in which I strongly believe.

*Katlin Maher
Speech-Language Pathology
Ohio UCEDD/LEND,
Nisonger Center*

...was able to advocate on issues that are vital to the developmental disability community and all of the progress that has been made so far.

*AnaVivian Escalante
Social Work
New York UCEDD/LEND,
Westchester Institute for Human
Development*



Trainees from Massachusetts on the Hill with Congressman William Keating (center)



Illinois Trainees and Faculty: Amie Lulinski-Norris, Tamar Heller, Arden Handler, Shauna McCarthy (Senator Kirk's Health Policy aide), Myrtis Sullivan, Ann Cutler, Leslie Stiles, Jillian Schuh

...was able to be part of the process as a citizen and to realize how accessible our government is to the people. I was grateful for all of the information presented at the workshops because I felt well prepared to go to Capitol Hill.

*Theresa Revans-McMenimon
Family
New York UCEDD/LEND,
Westchester Institute for Human Development*

...learned how exciting and rewarding policy advocacy can be. Before this experience, I was not involved in politics, and frankly, didn't even know that talking to our legislators was something that regular people did. Now, I am excited about policy advocacy and I know that I can have a real impact. I am excited for what the future holds for me with my new interest in politics!

*Megan Bell
Genetic Counseling
Utah Regional LEND*

On the Hill, I....

...went with a small group to see two Congressmen and one Senator...It was an easy conversation to bring up some personal stories and how any cuts would impact families...

I personally have never been a person interested in politics or even wanting to meet with politicians. But I must say it was an interesting experience. A long time ago *when I realized what I was doing for my daughter was considered advocating, it put a whole new perspective on standing up for her needs and rights*. I started to understand the importance of fighting for her needs and learning to assertively request those needs. It is no different sitting with legislators and their aides. It really comes down to helping the legislators understand how the programs impact individuals with disabilities and what the ramifications would be if the funding to those programs were cut.

*Lynise Parisien
Family
Tennessee UCEDD/LEND/IDDRC,
Vanderbilt Kennedy Center*



Trainees from the Cincinnati LEND program on the Hill

...attended Senator Harkin's Constituent Breakfast, and also met with Congressman Loebsack and his staff members to discuss issues related to individuals with disabilities... Two Iowa trainees had an opportunity to talk directly with the Appropriations staff members about how funding is used in LEND training programs to prepare future leaders in healthcare. The trainees and their training coordinator accompanied Bob Bacon, Iowa's UCEDD Director and co-chair of AUCD's Legislative Affairs Committee, and AUCD staff members George Jesien and Kim Musheno.

*Trainees from Iowa UCEDD/LEND,
Center for Disabilities and Development*

...got to talk to two of our State Senators
and some of their aides.

*Sue Engle
Nutrition
New Hampshire LEND
Children's Hospital at Dartmouth*



Amie Lulinski-Norris (AUCD Policy Fellow), Tia Nelis, self-advocate trainee, and Katie Arnold from Illinois visiting with staff of Rep. Danny Davis

On the Hill, I....

...met with legislative aides from two Massachusetts Representatives. We had open discussions of disability policy and promoted the most pertinent and pressing issues pertaining to people with disabilities. ***The experience demystified the political process for me and reassured me that there are good people doing good things for the good of us all on the Hill.***

*Frank Wartinger
Audiology
Massachusetts UCEDD/LEND/IDDRC,
Institute for Community Inclusion*



Trainees and Faculty from the Iowa UCEDD/LEND

...was able to express the importance of the representatives' continued support for individuals with developmental disabilities.

*Joliana Zelaya
Speech Language Pathology
Ohio UCEDD/LEND,
Nisonger Center*

...became empowered by the importance of meeting and sharing personal stories with legislators. Also with the budget proposal being made right then I was surprised at the extent of cuts which are being planned to happen and will effect many programs supporting those with disabilities. All of the legislators mentioned "the tough time we are in right now," which really made the impact of these cuts all the more real.

*Katie Hare
Physical Therapy*



Trainees and Faculty from New Mexico LEND:
Michelle Haswood (Fellow), Sandra Heimerl (Faculty), Terry Crowe (Faculty), Sen. Tom Udall,
Lancing Adams (Fellow), Jonathan Clark (Fellow)

On the Hill, I....

...met with Congressman Smith and his staff as well as Congressman Runyan's staff. Seeing that time is limited, I targeted two specific areas I felt passionate about and used personal stories to illustrate the effect these issues have on my family. ***It is always amazing to me the added impact of my children being with me.***

As a result of our Hill visit, I have begun to have ongoing conversations with Congressman Runyan about working together regarding an idea I had related to education.

In addition, we spoke to Congressman Runyan, who is newly elected, about the fact that any changes to Medicaid and Medicare will have an adverse affect on those with developmental disabilities. We wanted to make it clear to him that many people with developmental disabilities rely solely on the program and services. Individuals with developmental disabilities are often overlooked as a significant population utilizing these programs.

*Stephanie A. Rosati-Pratico
Family
Children's Seashore House of the
Children's Hospital of Philadelphia, LEND/IDDRC*



Stephanie Rosati-Pratico, Sara Rosati, Congressman Chris Smith, John Rosati, and Michael Pratico, Jr. in Congressman Smith's Washington, DC, office



LEND trainees who met with a representative from Senator Charles Schumer's office from 2 New York LEND programs—Westchester Institute of Human Development (WIHD) and Strong Center for Developmental Disabilities

...visited our local Congressional leaders and one New York State Senator. ***The staffers were eager to talk with us and we found that our effective preparation and teamwork allowed our voices to be heard.*** We were able to share the experiences we have had through our LEND training and advocate for the importance of supports and services for those with autism and other developmental disabilities. We learned the value of meeting with Congressional leaders or staffers to talk about policy because it allows them to understand how policies affect people. While there may be funding cuts to some programs, our voices were heard by policy-makers with the ability to make change. We learned that anyone can educate lawmakers, and we all have a right to talk to our representatives and inform policy.

*Trainees from New York UCEDD/LEND,
Strong Center for Developmental Disabilities*

One thing I will bring back to my LEND program is...



Several trainees and staff from the LEND program at Massachusetts' Shriver Center

...how easy it is for LEND trainees to at least contact their Congress people and state representatives to express support for disability policy services and programs.

*Sinan Turnacioglu
Physician
DC LEND/IDDRC, Children's
National Medical Center
Consortium of Universities*

... the experience of being empowered as a constituent and professional.

*AnaVivian Escalante
Social Work
New York UCEDD/LEND,
Westchester Institute for Human
Development*

...all the information I learned during this seminar so that I can share it with all the other disciplines that may lack this type of knowledge.

*Joliana Zelaya
Speech-Language Pathology
Ohio UCEDD/LEND,
Nisonger Center*

...how easy it can be to set up meetings with staff members for federal and state legislators alike to get your voice heard. At first I was very intimidated about going to the Hill, but after taking part I was shocked as to how influential it is. From now on I will not just talk about changes that need to be made, but take actions via talking to our legislators.

*Katie Hare
Physical Therapy
Iowa UCEDD/LEND,
Center for Disabilities and Development*

...is ***one person can make a difference***. I now truly believe that. It is important that everyone needs to know that politics will be politics but if we learn to have meaningful conversations with our politicians our message will go much further. It was a whirlwind of information but overall it was a wonderful experience. I got to meet several other LEND trainees at the conference. I look forward to learning more about these programs, keeping up with the budget cuts and continuing to advocate for my daughter and others with disabilities and their families.

*Lynise Parisien
Family*

Tennessee UCEDD/LEND/IDDRC, Vanderbilt Kennedy Center



AUCD's Director of Legislative Affairs, Kim Musheno, talking with VT LEND Director Steve Contompasis and the VT LEND trainees before the reception

...the knowledge and experiences of advocating for support and the understanding of the importance of advocating for policies. We felt ***the time and effort we put forth to contact and meet with our representatives was well worth it. Our Congressional leaders listened to what we had to say and we learned that they value the work we do in the community and the research we are conducting.*** We have a better understanding of our roles as advocates for our clients and our community. We now know that advocacy is everyone's responsibility and sending an e-mail or making a phone call does make a difference. We CAN have our voices heard and effect change on both local and national levels.

*Trainees from New York UCEDD/LEND,
Strong Center for Developmental Disabilities*

One thing I will bring back to my LEND program is...

New Hampshire LEND trainees



...an excitement about advocacy.

*Sue Engle
Nutrition
New Hampshire LEND
Children's Hospital at Dartmouth*

...the importance of gaining knowledge about policy and how easy it is to make a difference.

*Katlin Maher
Speech-Language Pathology
Ohio UCEDD/LEND, Nisonger Center*

...all of the information I learned.

*Theresa Revans-McMenimon
Family
New York UCEDD/LEND,
Westchester Institute for Human
Development*



Massachusetts trainees outside the White House

...a newfound feeling of importance for the policy advocacy side of working with individuals with disabilities. It is slow going, but important work that paves the way for greater improvement in the current systems of health care delivery and community supports.

*Frank Wartinger
Audiology
Massachusetts UCEDD/LEND/IDDRC,
Institute for Community Inclusion*

...to use their education and experience to advocate on behalf of those they serve. There is nothing lost by some real conversations about real situations. It is important for our legislators to hear how their decisions or potential decisions impact individuals and families. I would encourage all LEND fellows, past, present and future, to participate in these seminars. ***Although not always immediately apparent, it is imperative to take advantage of the opportunity to speak with representatives on the Hill on behalf of those who do not have the chance.***

*Stephanie A. Rosati-Pratico
Family
Children's Seashore House of the Children's Hospital
of Philadelphia LEND/IDDRC*



Trainees and staff from the Virginia UCEDD/LEND
Edgar Gamba is pictured on the far left

...there are many different ways to participate actively in policy making...In this long journey, we as parents of people with special needs have a lot to do and to show, providing real life evidence to inform the decision making process. Through our collaborative participation with organizations like LEND, The Arc, AUCD, AAIDD, NACDD, UCP, SABE and others, we can make good things happen.

We as parents should raise awareness in others that together we can make a difference for our loved ones. Educating ourselves and others is the key to making good things happen for the benefit of people with disabilities. Small change in policy directly impact the lives of people with disabilities. This effort must be mutual, we as members of a community that work for the well-being of people with disabilities and those who are government representatives, to make a policy more humane and dignified.

*Edward Gamba
Family
Virginia UCEDD/LEND, Partnership for People with Disabilities*

Links to Learn More

Disability Policy Seminar

www.disabilitypolicyseminar.org

Association of University Centers on Disabilities (AUCD)

www.aucd.org

AUCD Trainee Page

[http://www.aucd.org/template/
page.cfm?id=313](http://www.aucd.org/template/page.cfm?id=313)

AUCD Action Center

[http://www.aucd.org/template/
capwiz.cfm](http://www.aucd.org/template/capwiz.cfm)

If you are interested in learning more about the Disability Policy Seminar, visit www.disabilitypolicyseminar.org for more information and downloadable “Fact Sheets” of key policies. Visit the [AUCD website](http://www.aucd.org) for more [trainee information](#) or to access the archived webinar “[2011 Disability Policy Seminar Debrief](#)” that allowed trainees from across the network to share what they learned at the DPS and their experiences on the Hill. If you are interested in taking “action,” visit [AUCD’s Action Center](#).



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