

Every Voice Is Important

The Vanderbilt LEND, like other national LENDs and UCEDDs, prepares future health care and related professionals to be leaders in improving systems of care and services for persons with developmental disabilities and their families. Leadership preparation includes providing experiences in educational advocacy with state and national legislators. Two LEND Trainees describe recent advocacy experiences.

Family Trainee Perspective

BY LYNISE PARISIEN

s a parent of a child with a disability, I have been vaguely aware of how disability policies impact my family. With my daughter only 8 years old, my focus has been on her current and short-term needs rather than seeing the larger, long-term picture.

As the 2010-11 LEND Family Trainee, I attended the 2011 Disability Policy Seminar in Washington, DC, sponsored by several national disability organizations. As I sat there alongside the other 600 advocates, parents, and individuals with disabilities, reality started to sink in. I 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.

Our federal and state governments are focused on reducing spending, which means that funding for important programs to help individuals with disabilities and their families are at risk of funding reductions or even elimination. This includes helping individuals with disabilities find affordable housing, health care, training skills for jobs, and finding jobs.

The first two days were information sessions about the federal budget and what we might address with our U.S. Representatives and Senators. The third day was "on the Hill." Personally, I have never been interested in politics



Lynise Parisien and daughters Rachel (age 11) and Brooke (age 8)

or even wanting to meet with politicians—but I must say it was an interesting experience.

A long time ago when I realized that what I was doing for my daughter was considered advocacy, 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 legislators understand how programs impact individuals with disabilities and their families and what the ramifications would be if funds were cut.

I went with a small group to see three Tennessee legislators. They were in session and unable to meet with us directly, so we met with aides. The first aide was interested in what we had to say and was up to speed on our organization. It was an easy conversation to share some personal stories and how cuts would impact families. The second was unfamiliar with why we were there and was distant. It wasn't until we were able to make it real by telling personal stories that we created some traction in showing the importance of funding these programs. The final session was with a legislator who continues to support programs for individuals with disabilities. The aide spoke with us for about 30 minutes and then the legislator joined us, spending about 10 minutes listening to our stories and suggesting ways to address our initiatives.

My takeaway: one person can make a difference. Politics will be politics, but if we learn to have meaningful conversations with our representatives, our message will go much further. It was a whirlwind of information, but overall it was a wonderful experience. 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.

Social Work Trainee Perspective

BY NICOLE WEST

attended Middle Tennessee Disabilities Day on the Hill in March. I arrived at Legislative Plaza early and visited the disability tables. Individuals with disabilities were there ready to meet with their representatives. At The Arc Tennessee table, we gathered materials to give to legislators with whom we were meeting and we discussed proposed legislation, such as limits on restraint and isolation in school settings.

In our first meeting with a State Representative, I discussed how I came to know about the disability world and what makes me want to continue in the field. We shared information about the bills in which we were interested and gave information about disabilities and their impact on families.

Our State Senator was in a Committee Meeting, so we left materials with his staff. I wish we had been able to present the material and provide a fresh perspective and different thinking.



NiCole West

Observing a Committee Meeting, I was able to see some of Tennessee's legislators in action. Their differing viewpoints showed me how important it is for all of Tennessee to be represented, because what might work for big cities, like Nashville, does not necessarily work for rural towns, like mine.

This was a wonderful experience. I left feeling I could make a difference and that there was not really anything to keep me from going to Legislative Plaza and learning about what my legislators are doing. I became aware that it is possible to go and speak directly to my representatives, and that I do have a voice in the State of Tennessee. I also learned that because I have a voice, I need to speak up for those who are not able to do so for themselves. This is the only way that every voice will be heard—because every voice is important.

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