

Final Report to the AUCD Board of Directors

Fellowship Year 2011

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I have had the privilege of serving as the Disability Policy Leadership Fellow from January 9, 2011 until December 15, 2011. During this time, I have been able to serve in two main capacities, discussed below. Additionally, I have contributed to the role of policy fellow with the implementation of a few recommendations that I've had during my tenure, also discussed below.

ADD Grant - Self-Advocacy Summits

A series of Self Advocacy Summits, funded by the Administration on Developmental Disabilities, was held during the Spring. I was able to participate in the planning committee meetings as well as engage in internal AUCD preparations. I had three main responsibilities: 1) populate resources on the website (www.alliesinselfadvocacy.org); 2) create a Summit Guide for participants to aid them in what to expect at the summit; and 3) complete a webinar prior to each of the five regional meetings which reviewed the purpose of the Summits as well as portions of the Summit Guide. On items two and three, I was able to work with Liz Weintraub, Self-Advocacy Specialist at AUCD. I enjoyed working with Liz – I learned much about accessibility of written and spoken materials to accommodate people with intellectual disabilities. Additionally, I co-facilitated State Teams meetings during the Summits, took photographs, posted them on AUCD's Flickr page, and assisted with overall coordination. This experience allowed me to meet a number of network partners across the states, including those

from UCEDDs, DD Councils, P&As and self advocacy organizations such as SABE and ASAN. Meeting leaders in self-advocacy, veterans and up-and-coming leaders, was particularly satisfying to me.

Legislative Affairs – Combating Autism Reauthorization Act

Because the Summits lasted until the end of May, the majority of my first five months as a Fellow was spent engaged in that project. Once the Summits were over, I was able to turn my full attention to legislative activities, the first of which was the reauthorization of the Combating Autism Act (CAA). I was able to assist in setting up appointments with key members of Congress in conjunction with April - Autism Awareness month. Kim Musheno and I met with congressional staff of key committees to discuss the importance of the CAA, in particular the impact the LEND programs have had nationwide as a result of the expansion authorized by the law. As the summer went on, we began to focus almost exclusively on reauthorization of CAA. We identified key Congressional members with whom to schedule meetings (e.g., Senate Health, Education, Labor and Pensions Committee and House Energy and Commerce Subcommittee on Health). The precarious situation that we found ourselves in with the CAA, hitting roadblocks along the way, made our work challenging but it also provided me with valuable learning experiences about how the legislative process really works.

I also used my Fellowship time as an opportunity to develop relationships with staff of members on those committees from Illinois that I plan to maintain and use in my work back in my home Center. Senator Mark Kirk (R-IL) serves on the Senate HELP Committee making his sponsorship of CAA critical. Through working with his staff, we

were able to secure his support. Additionally, staff from Rep. Jan Schakowsky's office (D-IL-9th) became an ally and assisted us in securing her support. We were able to advocate for John Shimkus' (R-IL-19th) to agree not to oppose the bill. I am pleased to have forged these relationships.

Medicaid

Another policy area that I have been involved in is long term services and support, including protection of Medicaid-funded service from cuts during ongoing budget negotiations. I represented AUCD as a member of the Consortium for Citizens with Disabilities' (CDD) Ad Hoc Medicaid Task Force and the Long Term Services Task Force. Since June, I have been team leader for the group focusing on setting up meetings with Member of the House Energy and Commerce Subcommittee on Health – which has jurisdiction over Medicaid programs – for the Task Force. I also participated in the Friday Morning Collaborative, a coalition of aging and disability advocates working on mutual long term care issues.

Miscellaneous Products and Activities

Other activities that I have been involved in include:

- coordinated AUCD's Legislative Affairs Committee's [response](#) to CMS' proposed rules on HCBS Waiver Programs;
- developed action alerts and sample letters for grassroots advocacy; maintained AUCD's online [Action Center](#)
- maintained the [Health Reform Hub](#) providing resources on the implementation and grant funding related to the Affordable Care Act;

- contributed to AUCD's weekly newsletter, [Legislative News In Brief](#);
- created the AUCD Fellowship in Disability Policy Leadership [webpage](#) to assist AUCD with recruitment efforts as well as to maintain information on former Fellows as a matter of historical record;
- wrote an article for AUCD's Early Career Professionals [blog](#);
- initiated and coordinated a panel at the 2011 Annual Conference, titled "Celebrating Ten Years of Leadership in Disability Policy" featuring former AUCD Fellows in Disability Policy Leadership who will reflect on their experience and discuss how it continues to impact their work on systems change, research, advocacy and service;
- attended Hill briefings, congressional hearings and markups on the Hill; and
- participated in the monthly Legislative Affairs Committee calls where I reported on activities related to long term services and supports and other activities in which I was involved;
- revised a New Fellow Guide for future Fellows;
- created a self-assessment and Leadership plan template for incoming Fellows;
- co-instructed a LEND didactic during which I provided anecdotal information based on my experiences with CARA as a case study to a lesson on the policy cycle.

Future Plans

I am looking forward to returning to the Illinois UCEDD/LEND as Senior Research Specialist in Developmental Disabilities. I hope to maintain the relationships with staff in

Senators Durbin and Kirk's offices as well as Rep. Schakowsky. Additionally, I have already submitted paperwork to apply for membership on Rep. Danny K. Davis' Disability Task Force, as I live and work in his district. I have inquired as to whether or not Sen. Kirk has a similar advisory committee and hope to continue to work with his office.

I also am looking forward to using my Federal advocacy experiences as a teaching tool back at the UCEDD and LEND. I have been asked to rejoin the IL LEND faculty as a policy mentor and am excited about passing on information I've learned this year to LEND trainees in IL.

Depending on policies at the University, I hope to initiate some type of Legislative subcommittee of the Consumer Advisory Council in order to increase state level advocacy for disability issues. At minimum, I will continue to share information about my advocacy experiences with LEND trainees.

Recommendations

I've been providing recommendations all along this journey in lieu of waiting until the end of my time here to do so. This has enabled me to work with Kim and Ellen on implementing these ideas and not relying on the next fellow to do it. One recommendation that I made was to begin the recruitment process for the Fellow earlier in the year in an effort to increase the number of applicants. This year, the application deadline was a month earlier than last year. Another goal of mine was to clarify the Fellowship application information so that applicants have a clear vision of what the Fellowship entails. To do this, I created the Fellowship page on AUCD's website. It

provides detailed information about the Fellowship, as well as bios on former Fellows including the type of activities they engaged in during the Fellowship as well as where they are now. The incoming Fellow has already commented that this site was helpful to her during the application process. It also allowed an opportunity for me to connect with the former fellows and create a sense of community. I enjoyed our panel at the conference that celebrates 10 years of this program and hope that this type of collaboration continues.

Another way I feel that the Fellowship experience can be enhanced is through the use of a self-assessment and leadership plan. A self-assessment tool has been developed to enable future Fellows to rate their familiarity and interest in a variety of topics in order to determine opportunities for development. Based on the self-assessment, the Fellow will develop a Leadership Plan to act as a guide for the Fellowship period. This will enable the Fellow the opportunity for self-reflection both in the beginning and at the end of their experience.

Through my experience here, I have gained a better appreciation for the AUCD network and look forward to continuing as a member for years to come. I am thankful to Kim and Ellen for their guidance during this year as well as AUCD's Board of Directors, AUCD staff as well as the Institute on Disability and Human Development at the University of Illinois at Chicago for the opportunity to engage in this Fellowship experience. AUCD members are incredibly fortunate to have two such capable individuals advocating on their behalf.