

Disability Leadership Fellowship

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Final Summary Report

"I'm feeling that this fellowship has been a resounding success... I've made some great friends with advocates in DC. I've met wonderful people who work hard to help others. These relationships will last with me throughout my career. I've learned how things work (and don't) and I've been able to be a part of some interesting and exciting initiatives... Who knows where this opportunity will take me? It has opened many doors and will be a positive benefit to me, my family and the Center for Persons with Disabilities. It is a 'win' situation for everyone." – November 9, 2001

Early in my fellowship I decided to maintain a journal of thoughts, ideas and experiences. I've called on it frequently to remind me of the tremendous opportunity this fellowship experience has provided. It will also serve as a "to do" list upon my return to my home program. I've maintained a list of things that we, as a center, should explore to expand our programs and influence in the intermountain region, the nation and beyond.

Below is a brief summary of the activities in which I have been involved. These activities have ranged in scope from several hours to hundreds of hours. Each has served to broaden my perspective of the network of which I'm a part and my potential role within that network.

My main reason for completing a fellowship this year was to work on assistive technology legislation. My concern was the continuance of state grant programs in an era of "sunset" statutory language. Upon my arrival I became a member of the Consortium for Citizens with Disabilities (CCD) Technology/ Telecommunications Task Force. Along with the Association of Tech Act Projects (ATAP), I worked with Congressional and executive branch staff to remove or waive the sunset language in federal legislation. We were able to convince the Chair of a House subcommittee to hold oversight hearings in 2002. Consequently, the sunset was granted for one year to allow for the hearings to take place in the spring of 2002. This one-year fix will require the same appropriations maneuvering next year unless new legislation is written and passed to continue or revamp the state programs. I prepared several documents describing the connection between the New Freedom Initiative and the activities of state grant programs as well as a point-by-point rebuttal to the US House position that the state grant programs should be allowed to sunset. At the specific request of the Assistant Secretary of the Office of Special Education and Rehabilitation Services, I developed a four page brief outlining the success of state AT programs in leveraging non-federal funds to support their activities. These were used extensively by advocacy organizations to describe the benefit of state AT programs. They've also been used by executive branch agencies to assist them in understanding the benefit and role of these programs. I've also drafted the first version of a new assistive technology bill. This is being used by advocacy organizations as a "starter" for discussions on a new assistive

technology bill.

Also during this year I've worked with the National Institute on Disability and Rehabilitation Research (NIDRR), advocacy groups, and grantees to clarify the statutory inconsistencies within Title III of the Assistive Technology Act of 1998. I've written a position statement and letter on behalf of all year one grantees.

My other interests include health care policy and education policy. In addition to serving on the CCD Technology/ Telecommunications Task Force, I served on the Health Task Force and Education Task Force. As a member of the Health Task Force I participated in Medicaid reform and Patient Bill of Rights discussions, rallies, and assisted in developing the written responses and comparisons from the disability community to Congress and the Bush Administration. I attended a constituent meeting in the LBJ room of the Capitol and a late June, Senator-studded rally on the Capitol steps. As part of the Education Task Force I worked on IDEA funding and discipline policy issues. I wrote letters on behalf of AUCD and several information briefs for the AUCD membership. I also compiled a list of reading initiatives undertaken by UCEDDs that would accomplish the goals of the Bush Administrations "Reading First Initiative." In addition, I was part of the team that developed the CCD response to the Progressive Policy Institute's "Rethinking Special Education" report. As a member of a small work group, I developed the first draft of CCD's Principles for the upcoming IDEA Reauthorization.

In mid August, AUCD was asked to participate in the Surgeon General's Initiative on Health Disparities and Mental Retardation. I was given the assignment to coordinate all programmatic and technical aspects for the four regional listening sites across the country. I served as the primary coordinator for the involvement of four UCEDDs located in Oregon, Alabama, Wisconsin, and Massachusetts. This opportunity propelled AUCD into a new level of visibility within the National Institutes of Health (NIH). NIH looks to the UCEDD network as a competent partner in addressing health disparity and mental retardation issues. The October 10th regional listening session was preparatory for the December 5 and 6 conference that included over 120 consumers and professionals from around the country, many of whom were affiliated with UCEDDs. The final report and action plan from this event constitutes the direction of research and policy activities in this area over the next decade.

Of tremendous use to me are the relationships that I was able to develop during my 10 months as a Disability Leadership Fellow. I made a specific point to visit with key disability staff from each office of the Utah delegation. Unfortunately, 3 of the 5 staffers changed during my time; I did meet with the new staff, but my time in DC was nearly gone when these changes occurred. I was able to develop working relationships with several key disability staffers on Capitol Hill. Staff from Senator Harkin and Representative Hoyer worked diligently on assistive technology legislation. We worked together to ensure that funding levels and appropriate report language reflected the desires of the disability community. I developed collegial relationships with staff in the Administration on Developmental Disabilities, NIDRR, the Office of Special Education Programs, and the Administration on Aging. I also developed relationships with staff from disability advocacy organizations located in Washington, DC. These collegial relationships will continue as I return to Utah and emphasize federal and national relationships in my home program.

This fellowship gave me the opportunity to develop relationships with senior level staff from UCEDDs throughout the country. My colleagues from other programs, the

AUCD central office and I have discussed a number of initiatives that might benefit from our experiences and mutual interests. I better understand the UCEDD network and the abilities of sister programs. I've concentrated on learning what other programs do to address expanding needs. I involved myself in various email and phone conversations to learn about ongoing activities in areas of interest such as criminal justice and quality improvement. In October I completed a one day visit to the UCEDD at Temple University in Philadelphia, PA to gain specific knowledge regarding quality improvement, assistive technology activities, and policy and legislative initiatives. Finally, I was able to work with fellows from other fellowship programs such as the Joseph P. Kennedy Jr. Foundation, National Council on Disability and the Presidential Merit Internship. Again, these relationships, if properly maintained, will serve me well in the years to come.

Ageing and disability policy is another area of high interest and one to which I had anticipated devoting more time. Early in the fellowship experience I learned about and attended meetings of the Disability and Aging Coalition loosely operated by the National Council on Aging (NCOA). I attended three meetings of this group; then the meetings ceased. Unfortunately, this group did not have leadership to maintain regularly scheduled meetings during this year. However, I was able to initiate a relationship with NIDRR staff and with a policy specialist from the Administration on Aging (AoA). I've attempted to maintain these relationships during my 10 month fellowship. The AoA policy person also served as the main contact person for the interdepartmental effort to describe ways in which the federal government can improve services to meet the community inclusion standards set forth in the *Olmstead* decision. I've had several conversations with the AoA staff in regards to this latter issue as it relates to ageing and disability policy.

In November, I was invited to attend the International Research Symposium on Ageing and Developmental Disability. During this two day meeting I met with researchers and program administrators from around the country who are involved in increasing community inclusion of people with developmental disabilities who are ageing. I participated in one of the three workgroups that described the current state of research and developed a draft research agenda for the next decade.

Planning the AUCD Annual Meeting and Conference was part of my disability leadership fellowship experience. I provided the staff function to the symposium planning workgroup. I also worked with central office staff to develop and implement the online presentation submission and online registration system. I assisted members of the conference planning committee to select presentations. Early in the planning process I assisted the conference committee chair in organizing and developing the theme and outline of the three day event. As AUCD staff I was part of the preliminary planning process for the 2002 annual meeting and conference.

As an AUCD staff member I had the opportunity to develop materials and assist in the dissemination of network information. My first task was to develop a guidebook for future fellows. Based on my experience I described the kinds of things a new fellow should know and be prepared to deal with upon beginning the fellowship experience. I also located and included several documents that, if read and understood, provide a solid knowledge base regarding disability policy, the evolution of the UCEDD network, and the legislative process. This information was compiled into the Disability Leadership Fellowship: A Guide for Successful Survival. I was also part of the staff team that developed the template for the electronic *AUCDigest* that is sent to network members on a monthly basis. I assisted the AUCD staff in the revision of the AUCD

website; its look, navigation system and text.

The Executive Director of AUCD included me in all of the discussions regarding the change of name from the American Association of University Affiliated Program for Persons with Developmental Disabilities (AAUAP) to the Association of University Centers on Disabilities (AUCD). I was able to view the process and participate in the decisions that led to the name change.

Several activities, while not taking a great deal of my time, enabled me to expand my perspective of the developmental disabilities network and how it can be used to meet the needs of expanding federal initiatives. For example, I accompanied AUCD representatives on their one day tour of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention in Atlanta, Georgia. I learned about this new center and how UCEDDs engage in the mission and activities of the NCBDDD. I also became aware of additional opportunities available to UCEDDs as the center defines its specific role in regards to people with developmental disabilities and their families. The United States International Council on Mental Retardation (USICMR) meets on a quarterly basis to discuss ways in which the network of developmental disabilities-related programs in the United States can benefit from and provide technical assistance to similar programs in other countries. In most instances, the discussion revolved around how US programs could benefit others. This opportunity put me in regular contact with executive directors of all the major national developmental disability/mental retardation organizations in the country. Being part of these small group discussions enabled me to learn about national approaches to complex policy and service issues in the US and abroad. Finally, I was given the opportunity to represent AUCD in a meeting with a delegation of 15 representatives from Russia. I presented information regarding UCEDDs and how they meet the expanding needs of individuals and families in the United States and its outlying areas. This was a tremendous experience in that I not only shared what I knew, but was able to glean from the discussion the types of individual and family services and supports available to the developmental disability community in Russia.

The ongoing debate regarding use of the term 'mental retardation' came to a preliminary conclusion during my fellowship term. The Consortium on Language, Image, and Public Education (CLIFE) issued its interim final report at the annual meeting of the American Association on Mental Retardation in June 2001. During my fellowship I participated in the meeting prior to and following the publication of the report. Again, I was included in discussions with national leaders in this field regarding a topic that will likely continue to surface for many years. I agreed to participate as a member of the small workgroup assigned to develop several concept papers called for in the interim final report. With staff from the Arc of the United States and the President's Committee on Mental Retardation, I drafted the introductions and rationales for the first two papers. Hopefully these will be used to further the work of the CLIFE.

In conclusion, this experience could never be equaled by book learning, in seminars nor in symposia. No amount of university coursework could teach me what I have learned and experienced in the past ten months. This summary ends as it began, with a quote from my fellowship journal.

"I attended a Quality Assurance Coalition meeting with executive directors of national

disability organizations. It is fun to be a part of these national discussions of policy that will probably influence the way things are done over the rest of my lifetime. This fellowship has helped me learn about the national perspective on disability. I appreciate the many relationships that I've been able to form and hope to foster and maintain them for many years to come." --June 22, 2001