

## **2005 AUCD DISABILITY POLICY FELLOWSHIP REPORT**

**Joe Caldwell**

My fellowship ran approximately a year, from February 2005 through early January 2006. Timing of events and my particular interests led me to focus in five areas: 1) Medicaid and the Budget Process; 2) Long-Term Services and Supports Legislation; 3) White House Conference on Aging/Older Americans Act; 4) End-of-Life and Life-Sustaining Decisions; and 5) Council on Community Advocacy (COCA) and Consumer Advisory Committees.

### **Medicaid and the Budget Process**

I started the fellowship with very little understanding of the federal budget process. For better or worse, 2005 turned out to be a fascinating year to follow the ups and downs of the entire process. My fellowship began just prior to the release of the President's FY2006 Budget and within the first week I literally found myself rushing from the Department of Health and Human Services to the Department of Education gathering and analyzing information about the budget. As anticipated, the budget contained significant cuts in Medicaid, which set the stage for a year-long grassroots battle.

The President's Budget called for \$60 billion in Medicaid cuts over 10 years. As the Senate and House began to put forth their budget recommendations it became apparent that reconciliation would likely occur for the first time since 1997. I had the opportunity to attend the House mark up of the budget resolution. The House passed a budget resolution identifying \$20 billion in Medicaid cuts over 5 years. In what seemed like a major victory at the time Senators Smith (R-OR) and Bingaman (D-NM) passed an

amendment stripping all Medicaid cuts in the Senate and calling for an independent, bi-partisan commission to study Medicaid through the Institutes of Medicine. However, in the final conference agreement \$10 billion in cuts were targeted with reconciliation instructions to committees. Also, the Administration initiated a more biased Medicaid commission through the Department of Health and Human Services, which AUCD decided to take a stance against.

I became an active member of the Health and Long-Term Services and Supports Task Forces of the Consortium of Citizens with Disabilities (CCD), in addition to representing AUCD in the broad-based Medicaid coalition of Families USA. Together we leveraged opposition to Medicaid cuts that would harm beneficiaries, particularly individuals with disabilities and other low-income populations. AUCD Legislative Affairs Director, Kim Musheno and I prepared countless updates, press releases, and action alerts during the year that resulted in hundreds of grassroots contacts to members of Congress to oppose harmful cuts. We sent numerous letters on behalf of AUCD to members of Congress, met with key Congressional staff, monitored briefings and hearings on the Hill, and submitted testimony to the Medicaid Commission. In addition, I assisted the Council on Community Advocacy (COCA) to engage in the battle, sending a letter about Medicaid cuts from the perspective of individuals with disabilities and families to all members of the Senate Finance and House Ways and Means Committees. I was also able to connect some of my own research with advocacy efforts, which was very empowering to me. Data on out-of-pocket costs of families with relatives with developmental disabilities, drawn from my dissertation, was included in a CCD letter sent to Congress opposing increased Medicaid cost-sharing.

Budget reconciliation was slightly pushed back due to the devastation of Hurricane Katrina. Many of us hoped to indefinitely postpone cuts in Medicaid and other low-income programs. We strongly supported new legislation to provide healthcare and emergency Medicaid relief to victims of Katrina. Unfortunately, the moment was short-lived: Congress failed to act on a bill by Senators Grassley (R-IA) and Baucus (D-MT) to provide broad healthcare relief to victims and the region. I actually was able to observe the Senate floor proceedings in person as the bill was blocked by Republican leadership in September.

In late October, the House and Senate again took up reconciliation and passed their respective versions of their budget reconciliation packages. We were pleased with the Senate's version, which identified \$10 billion in cuts that would not directly harm beneficiaries, found much of the savings through Medicare and prescription drug pricing, and even included positive reforms –such as the Money Follows the Person demonstrations and the Family Opportunity Act. However, the House version contained very harmful cuts, primarily through increased cost-sharing and decreased entitlements to benefits, particularly EPSDT for children with disabilities. We pushed hard for the conference agreement to adopt the Senate provisions. Unfortunately the budget reconciliation conference report adopted many of the harmful House provisions.

In one last push, we galvanized grassroots to oppose the conference report. This culminated in an extremely close vote in both the House and Senate. The conference report narrowly passed the Senate, with Vice President Cheney casting the tie-breaking vote. The report also narrowly passed the House, but will require another House vote in the next session of Congress due to a political move by Democrats prior to the Senate

vote. This presents one last opportunity for grassroots organizing to defeat the conference report.

Regardless of the final outcome, however, there is some comfort in the battle that was waged. Congressional staff commented on the outpouring of grassroots opposition that made proposed cuts extremely difficult for the majority party. In some small part, it has been rewarding to be part of this. I personally learned a great deal about grassroots organizing, targeting key members of Congress, and the importance of coalitions. Furthermore, I never thought I would find the budget process so fascinating; one of the key lessons instilled in me this past year, particularly through Donna Meltzer and Kim Musheno, is that you cannot afford not to pay close attention to the budget: it drives everything else.

### **Long-Term Services and Supports Legislation**

Overlapping somewhat with the budget battle, we worked to re-introduce and support many long-standing AUCD legislative priorities concerning long-term services and supports: Money Follows the Person Act, MiCASSA, the Family Opportunity Act, and the Lifespan Respite Care Act. I developed action alerts and helped monitor developments on all these pieces of legislation for *In Brief*. I developed a summary of the Family Opportunity Act and gathered stories from families to support the bill –stories of families having to institutionalize, relinquish custody, become impoverished, or file for bankruptcy in order to obtain needed Medicaid coverage for their children. We supported efforts to move the bill as part of the Department of Defense Authorization. Ultimately, the Family Opportunity Act and Money Follows the Person demonstrations were attached to the budget reconciliation conference report.

The other piece of legislation where there was some movement during the year was the Lifespan Respite Care Act. A briefing on the Lifespan Respite Care Act was organized in June on the Hill to educate Congressional staff. I went on Hill visits organized by the National Respite Coalition to urge support of the bill in the Senate and we began to strategize about how to move the bill early in the next session of Congress.

A couple new pieces of new legislation were introduced that AUCD played an active role in supporting. Senator Grassley (R-IA) introduced the Improving Long-Term Care Services Act, S.1602. We strongly supported Title II of the bill, which would allow states to expand home and community-based services outside of the waiver process. This would be an important incremental step towards MiCASSA and removal of the institutional bias in Medicaid. I helped educate the AUCD network about the bill, met with Congressional staff, and prepared action alerts to support the bill. We were hopeful it would be included in reconciliation. However, ultimately a harmful House initiated version was included that would do virtually the opposite of what we hoped for –make it easier for states to impose caps and limits on services. If reconciliation is passed, this will require a new strategy to correct this issue in the next session of Congress.

Perhaps the single most exciting experience for me during my fellowship was the opportunity to provide input into a new bill called the Community Living Assistance Services and Supports Act (CLASS) Act, S.1968, introduced by Senators Kennedy (D-MA) and DeWine (R-OH). We worked closely with Congressional staff and a coalition of diverse groups, from aging and disability organizations to unions, to provide input into this legislation. I also met with staff of Representative Shimkus (R-IL), a co-sponsor of MiCASSA, to educate them about the CLASS Act and urge consideration of co-

sponsoring a companion version of the bill in the House. The CLASS Act takes a broad approach to long-term care needs, particularly within the context of the aging baby boom generation. It develops a national long-term care insurance program, modeled on social insurance programs developed in other countries. The CLASS Act provides consumer-directed, cash benefits and allows hiring of family caregivers, which overlapped a great deal with my dissertation research and interests in aging. As I return to Illinois, I hope to continue to support the movement of this bill through education within the disability community and contact with Congressional members in Illinois.

### **White House Conference on Aging/Older Americans Act**

The area where I was most able to combine my research background with policy concerned the White House Conference on Aging and upcoming reauthorization of the Older American Act. I worked with the AUCD Aging Workgroup to submit a resolution on aging family caregivers and adults with developmental disabilities to the Policy Committee. We brought the resolution to the White House Conference on Aging Mini-Conferences on Caregiving and Aging and Disability in May. The main White House Conference on Aging took place in December and many of our recommendations concerning long-term services and supports were included in the final top 50 resolutions voted on by delegates. Furthermore, Tamar Heller attended the conference as one of the more than 1,300 delegates and successfully advocated for inclusion of adults with lifelong disabilities in the implementation strategy for the resolution on supporting informal caregivers. Together, this was a major victory.

Recommendations from the White House Conference on Aging have historically led to policy developments. In addition to developments surrounding the White House

Conference on Aging, Kim Musheno and I worked with individuals from the National Disability Rights Network, the Arc/UCP, and AUCD Aging Workgroup to draft legislative language for inclusion of caregivers of adults with developmental disabilities in the National Family Caregiver Support Program during reauthorization of the Older American Act. Reauthorization could occur as early as next year when the final report from the White House Conference on Aging is released.

### **End-of-Life and Life-Sustaining Decisions**

The media frenzy over the Terri Schiavo case occurred early during my policy fellowship. I attended the House and Senate hearings on the Hill concerning the case. As media and congressional attention quickly faded, many advocates within the disability community were concerned about lack of attention to the disability rights perspective. This perspective was not recognized by Congress and not well covered by the mainstream media. In the aftermath of the Schiavo case, the Arc and Not Dead Yet organized a strategy meeting in the Washington DC area. The meeting was facilitated by Bobby Silverstein and brought together many leaders in the area from the disability community. I attended of AUCD and participated in the development of a consensus statement of common principles of life sustaining care and rights of individuals with disabilities.

The statement was placed on the website of the Center on Human Policy, Law, and Disability Studies at Syracuse University <http://thechp.syr.edu/endorse/>. To date, it has been endorsed by such national organizations as ADAPT, Not Dead Yet, American Association of People with Disabilities, The Arc of the United States, National Council on Independent Living, National Spinal Cord Injury Association, TASH, SABE, and

United Spinal Association. It has also been endorsed individually by such leaders in the field as David Coulter, Steven Eidelman, Leigh Ann Kingsbury, Ruth Luckasson, and Rud Turnbull. AUCD decided not to endorse the statement as an organization. However, several individuals within the network have endorsed it as well as my home center, the Illinois Institute on Disability and Human Development. The AUCD board elected to develop a workgroup on end-of-life issues to further consider the statement as well as other initiatives in the area of end of life.

In addition to working on the statement of common principles, I also had the opportunity to attend the Supreme Court Case on the Oregon assisted suicide law that took place in September. This was a fascinating experience. It was one of the first cases of Chief Justice John Roberts and there was a great deal of media interest, which again paid little attention to the disability rights perspective and presence at the hearing. Finally, in December AAMR and the RRTC on Aging with Developmental Disabilities co-sponsored a conference on Aging and End of Life Issues. I worked with Maggie Nygren and Kim Musheno to develop a panel on federal initiatives in aging and disability. The panel included Pat Morrissey from the Administration on Developmental Disabilities and Rick Greene from the Administration on Aging. I also joined another panel at the conference and presented my dissertation research on consumer-directed family supports.

### **COCA and Consumer Advisory Committees**

A considerable portion of my fellowship focused on enhancing participation of individuals with disabilities and families within AUCD and university centers. I provided support from the AUCD Central Office to the Council on Community

Advocacy (COCA). This involved working closely with the COCA Co-Chairs to build off vision and momentum created by the COCA Workgroup. Gordon Richins, Sharon Hauss, and I presented at the AUCD Directors' retreat, met with ADD Commissioner Pat Morrissey, initiated regular conference calls, introduced a new COCA listserve, and revised the COCA webpage. All of these things greatly improved communication, both within and outside of COCA. COCA worked with the AUCD Board and changed the name of the council, primarily to eliminate the use of the word "consumer" and better reflect the new mission statement. COCA was successful in recruiting a couple new centers to appoint representatives with disabilities or family members. However, this remains an ongoing priority. COCA became more active in supporting grant initiatives; they wrote letters of support for a grant on international practices and a participatory action research grant. The grant on participatory action research was awarded to the Oregon Institute on Disability and Development and COCA is now playing a leading role in this project. To better manage involvement in new initiatives, COCA organized a steering committee. Under the leadership of Susan Yuan, exciting collaboration has also begun between COCA and the Multi-Cultural Council.

Finally, I developed a technical assistance project through ADD aimed at enhancing meaningful participation of individuals with disabilities and families on consumer advisory committees of university centers. There were four primary objectives of the project: 1) Identify supports that enhance the meaningful participation of individuals with disabilities and effectiveness of consumer advisory committees; 2) Develop case studies on innovative or best practices; 3) Provide recommendations concerning assessment of consumer advisory committees; and 4) Provide

recommendations to consider during the reauthorization of the DD Act. A participatory action research approach was taken that involved collaboration of COCA in all phases of the project. A series of telephone focus groups were conducted with directors from university centers and individuals with disabilities and family members on advisory committees. An electronic survey was distributed. COCA representatives and I jointly visited two consumer advisory committees: University of Kentucky and University of Wyoming. The project was a lot of fun and everyone who participated seemed to gain new knowledge about consumer advisory committees. I am hopeful the rest of the AUCD network will also see the findings as exciting, interesting, and helpful.

### **Reflections on the Fellowship Experience**

The past year was honestly one of the best years I have had. In addition to the fellowship I also somehow managed to finish my Ph.D., get married to the AUCD virtual trainee, and become a step-father. The fellowship experience was more than I ever hoped for and will shape things to come. I have always situated myself within the intersection of advocacy and research. Sometimes pulled in different directions, this past year I have balanced both and contemplated the interconnections. I have gained a stockpile of new research ideas and hands-on policy knowledge that coursework could not hope to match. Furthermore, I have gained a deeper appreciation of vast knowledge the expertise within the AUCD network. As I return to the University of Illinois at Chicago, I know I will always be welcomed to reach within the network out and tap that expertise at any time.