

Association of University Centers on Disabilities:

Disability Policy and Leadership Fellow

Final Report

By Paul Galonsky

The AUCD Disability Policy Leadership Fellow Work Week

A week for me as the AUCD Disability Policy Leadership Fellow usually begins on Monday morning at 5:00 am in Wilmington, Delaware, where I begin my trek down to Silver Spring for the week. Although I live in Silver Spring during the week, I have the luxury due to proximity of going back to my home base in Wilmington on the weekends to be with my wife. Once in the office at 9:00am, I open up my emails from a host of organizations such as Congress Daily, the Department of Health and Human Services (HHS), the Administration on Developmental Disabilities, the Kaiser Family Foundation, the Consortium for Citizens with Disabilities (CCD), the Bazelon Center for Mental Health Law, Disability.gov, etc., to learn about the latest disability news and policy implications that could potentially affect people with developmental disabilities, their families, and the entire AUCD Network. This year, the Legislative Affairs Department has been particularly interested in, and focused on, new information that provides summaries and analyses of the health care reform law. All new and pertinent information is uploaded by me to AUCD's Health Reform Hub webpage daily.

During the week, there have been opportunities for me to schedule and meet with Congressional staff members to educate them about AUCD's legislative priorities. As such, I have been to hill meetings to meet with Democratic and Republican offices to discuss health care, restraints and seclusion in schools, crimes against people with disabilities, extending the Federal Medical Assistance Percentages for states (FMAP), and Rosa's Law.

During the week, I also have opportunities to go into Washington DC, where I represent AUCD's Legislative Affairs Department at disability advocacy meetings. Several of these meetings are hosted by CCD Task Forces pertaining to Long-Term Services and Supports, Employment, Health, Education, and International Disabilities Rights. During these meetings, I participate and take notes. I use the information gathered at these meetings to help write

AUCD's weekly legislative newsletter, In Brief. Some of the issues I have followed this year include employment, affirmative action for people with disabilities, health care reform (preexisting condition exclusions, lifetime and annual limits, rescissions, and

patient protections), Rosa's Law, and the Convention on the Rights of Persons with Disabilities.

I also have many opportunities throughout the week to go to conferences and disability briefings from organizations such as the Robert Wood Johnson Foundation, Mathematica Policy Research, Health Affairs, and the National Academy of Social Insurance. During these learning sessions, I have the opportunity to further expand my knowledge on health reform implementation, Medicare and Medicaid, and Social Security.

When I am in the office, I usually work on writing two to three weekly entries for the Legislative News InBrief. I also update AUCD's Action Center, posting informational action alerts that allow network members to take action on the issues quickly and easily. I am also busy throughout the week updating the AUCD Legislative Policy webpages, where I will upload current disability policy information onto the various webpages as needed.

In addition to my work in the Legislative Affairs Department, throughout the week, I am collaborating with the AUCD and National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC) Cooperative Agreement to provide technical assistance to sixteen state disability and health projects. I usually participate and take notes for monthly Module calls, support disability and health webinars, disseminate disability and health related resources, and plan for the Disability and Health Annual Meeting. In addition, I recently supported an "Act Early" Regional Summit Project, where I helped to facilitate the State of Illinois in developing a birth to five autism screening and intervention strategic plan.

In sum, a week in the life for me as the AUCD Disability Policy Leadership Fellow is always busy and has provided opportunities for me to learn from disability leaders in Washington, contribute to AUCD's legislative goals through updates on legislative priorities, and grow professionally and personally. I am convinced that I am a better professional and person as a result of this Fellowship opportunity.

#### What the AUCD Disability Policy Leadership Fellowship has meant to me

The AUCD Disability Policy Leadership Fellowship has been a wonderful and unique life experience, which has given me the opportunity to study, support, and contribute to AUCD's legislative priorities and the AUCD/CDC Cooperative Agreement. In addition, the fellowship has exposed me to the intricacies of the lawmaking process on the Federal level. Specifically, the opportunity has allowed me to observe how disability advocacy and education affects the legislative process and steps necessary to create change for people with disabilities nationwide. I have learned that advocating and educating Federal lawmakers on disability issues is a hopeful challenge and serious

task that takes knowledge, patience, and compromise. I have also learned that within the spirit of compromise, disability groups are not always in tandem with their priorities, which can stymie the important legislative steps necessary for change and progress. This type of discourse is what my policy professors warned me about while I was in graduate school. Nonetheless, having exposure to the action and seeing progress, however incremental, is much better than discussing it in a classroom, or not having the chance to see it at all. The good news is that incremental improvements did occur, and good disability legislation and progress did transpire while I was here at AUCD.

Perhaps most important, the Affordable Care Act passed, providing greater protections and opportunities for all Americans, but specifically for people with pre-existing conditions and disabilities who will now have greater access and opportunities to take better care of their health. Before the passage of the legislation, I was attending weekly meetings with Congressional Health Staffer Connie Gardner, learning and supporting the inclusion of the Community Living Assistance Services and Supports program (the CLASS Act) into the legislation. After the passage, I worked with CCD's Long Term Services and Supports Task Force to break down and dissect the provisions in the law that impact Home and Community-Based Services in Medicaid, the CLASS Act, and the new State Balancing Incentives Payment Program. In addition, I developed a summary of the law's prevention and wellness provisions for the AUCD Network, which provides detailed information on those provisions in the health reform law, with particular focus on those that impact AUCD network programs. I also helped to design AUCD's Health Reform Hub, which is an online gateway to provide technical assistance and information about the Affordable Care Act.

In addition to the passage of Health Care Reform, I advocated for and followed the passage of Rosa's Law (P.L. 111-256), which was signed into law on October 5, 2010. Rosa's Law will now replace the terms "mental retardation" and "mentally retarded" with "intellectual disability" and "individual with an intellectual disability" in specific federal laws. For me, the passage of Rosa's Law is special. When I worked for many years at the Mental Health Association in Delaware, it was common for people with mental illnesses to discuss how certain words used to describe people with mental illness are demeaning, discriminating, and stigmatizing. So, too, are certain words in federal legislation that describe people with intellectual disability. For me, this type of progress, which promotes better attitudes towards how our government identifies people with intellectual disabilities, is essential to future legislation and to further enhance and protect people with all types of disabilities in the United States.

In terms of progress and milestones, on July 22, 2010, I had the opportunity to see the celebrations in Washington for the 20th Anniversary of the American's with Disabilities Act of 1990, which reminded Americans all across the nation about the progress towards equity that people with disabilities have made over the past twenty years, and

that people with disabilities have basic civil rights that must always be acknowledged and protected.

Finally, and since the beginning of the year, I helped to rekindle progress towards introducing the Crime Victims with Disabilities Act (S. 3668) in Congress. The legislation provides grants for research to assist the Attorney General in collecting valid, reliable, national data relating to crimes against individuals with developmental disabilities for the National Crime Victims Survey conducted by the Department of Justice. Throughout the course of the year, I scheduled and conducted hill visits with the offices of Sen. Kaufman (D-DE), Sen. Cardin (D-MD), Rep. Castle (R-DE), and Rep. Bobby Scott (D-VA). In addition to hill visits, I coordinated several meetings with the National Disability Rights Network, National Council on Disability, National Center for Victims of Crime, and the National Organization for Victim Assistance to generate support for AUCD's efforts. Current efforts within the Network and the aforementioned disability advocacy groups continue for this issue.

#### Finally, thank you

Finally, although I have written about what I do in the course of week and what I believe the Fellowship has meant to me, I have not mentioned thank you to all the wonderful people in the Network who supported me throughout this endeavor. As such, I want to say thank you to the University of Delaware's Center for Disabilities Studies for advocating for me to be this year's Fellow; thank you to George Jesien for hiring me and giving me this wonderful opportunity to be a part of the AUCD Network and all the important work that generates as a result of his leadership; thank you to Kim Musheno for teaching me the disability policy ropes in Washington and for being a good friend at the same time; thank you to Ellen Jensby for working with me in the Legislative Affairs Department and always supporting me when I needed help; thank you to Adriane Griffen who was always an optimistic team player and energetically welcomed me into the AUCD/CDC Cooperative Agreement; thank you to Danielle Edson for taking time to listen to me when I was self-doubting; and thank you to Jennifer Bogin who allowed me to learn more about autism and always provided positive support and feedback for the work I did with her on the Act Early Summit. Finally, I want to extend a warm thank you to the AUCD Board of Directors for supporting the idea of an ongoing Disability Policy Leadership Fellowship at AUCD and the wonderful experiences that the Fellowship has brought to my life.

My professional experiences with all of the AUCD staff will always be with me and will remind me of the importance of teamwork, professionalism, and dedication. This is what the AUCD Disability Policy Leadership Fellowship has meant to me.