4-20-2009

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HEALTH CARE REFORM ACT NEEDS YOUR STORIES

April 20, 2009 by cpehrson

The Association of University Centers on Disabilities (AUCD) is working with other disability organizations to ensure that long-term services and supports are included in health care reform. One important bill they are advocating for is the Community Choice Act (CCA) that would offer choice and independence for people with disabilities. This legislation, sponsored by Senator Tom Harkins (D-IA), will bring people with disabilities into the mainstream of society and provide equal opportunity for employment and full involvement in community activities. It allows people with disabilities who need an institutional level of care the choice of receiving their services and supports in their own communities, rather than in an institution.

“The legislation sends a message to the rest of Congress and to America: We want real homes, not nursing homes;” said Harkin, one of the authors of the Americans with Disabilities Act (ADA). “Our current system effectively forces people into institutions and requires them to impoverish themselves in order to become eligible for the assistance they need. It is wrong – and this legislation changes it.

Senator Harkin’s office has asked for assistance. They need personal stories that can help make the case of why long-term services and the Community Choice Act should be included in health care reform. They especially would like stories from the developmental disabilities community. In writing your story, you may want to consider the following questions:

- Are you caring for a family member or family members who need long-term services?
- Are you an aging caregiver concerned about future services?
- Do you have out-of-pocket expenses for long-term services that are difficult for your family?
- Has providing care impacted your employment?
- Are you on a waiting list for Medicaid home and community-based long-term services?
- How long have you been waiting? How long is the waiting list?
- Have you ever had to move or become improvised to get the long-term services you need?
- Have you only had a choice of nursing home or institutional placement?

There is no set format for the stories, but short, one-page stories are most effective with lots of details included. Be sure to include your name and what state you live in. Your story should make the case of why long-term services and the CCA should be part of health care reform.

Health care reform is moving very quickly, so the stories are needed as soon as possible. You can send them to Joe Caldwell at jcaldwell@aucd.org, or mail them to: Joe Caldwell, Association of University Centers on Disabilities, 1010 Wayne Avenue, Suite 920, Silver Spring, MD 20910.