August 12, 2009

The Honorable Thomas R. Carper United States Senate 513 Hart Building Washington, DC 20510

RE: Community Choice Act (S. 683)

Dear Senator Carper:

I write on behalf of the State Council for Persons with Disabilities (SCPD) to encourage you to endorse and become a co-sponsor of the Community Choice Act (S. 683). The proposed legislation amends title XIX (Medicaid) of the Social Security Act (SSA) to require state Medicaid plan coverage of community-based attendant services and supports for certain Medicaid-eligible individuals. In addition, it outlines requirements for: (1) an enhanced federal medical assistance percentage (FMAP) for ongoing activities of early coverage states that enhance and promote the use of community-based attendant services and supports; and (2) increased federal financial participation for certain expenditures incurred by the state for the provision of such services and supports. Finally, it directs the Secretary of Health and Human Services to: (1) award grants to eligible states which have established a Consumer Task Force to assist the state in its development of real choice systems change initiatives; and (2) conduct a demonstration project for the purpose of evaluating service coordination and cost-sharing approaches with respect to the provision of community-based services and supports to dually eligible individuals. By providing an enhanced match and grants for the transition to Real Choice before October 2011 when the benefit becomes permanent, the Community Choice Act offers states financial assistance to reform their long term service and support system to provide services in the most integrated setting.

People with disabilities overwhelming prefer alternatives to nursing homes and other institutions when they need long term services, which is contradictory to the nation's long term care system that has a heavy institutional bias. Nationally, Medicaid expenditures for institutional long-term care were 64.6% of total long-term-care expenditures, compared to 35.4% for HCBS in fiscal year 2007 and it is similar in Delaware. Every state that receives Medicaid must provide nursing home services, but community based services are optional. When support services are needed, persons with disabilities may not have real choices in the community. Whether a child is born with a disability, an adult has a traumatic injury or a person becomes disabled through the aging process, they want their services provided in their own homes, not nursing homes or other large institutions. A national long-term service policy should not favor any one setting over the other.

It should let the users choose where services should be delivered. It's time for Real Choice. The Community Choice Act establishes a national program of community-based attendant services and supports for people with disabilities, regardless of age or disability. This bill would allow the dollars to follow the person, and allow eligible individuals, or their representatives, to choose where they would receive services and supports. Any individual who is entitled to nursing home or other institutional services will now be able to choose where and how these services are provided. Instead of making a new entitlement, the Community Choice Act, makes the existing entitlement more flexible.

The demographics of our country are changing. More and more people with disabilities are living, and could be thriving! Our long-term service system must change. Created over forty years ago, it is funded mainly by Medicare and Medicaid dollars; medical dollars not originally meant to meet people's long-term care needs. People with disabilities should be empowered to have real choices.

The current system is needlessly expensive. Community based services have been shown to be less expensive on average than institutional services and is greatly preferred by individuals with disabilities.

SCPD understands that change can cause fear of the unknown. Some long time providers of services and families believe that real choice of where services and supports are provided may threaten their current situation. This is not true and the country cannot continue the system as it is today. It is expensive, fragmented, medically based instead of functionally based and does not meet the needs of people who require such services.

Thank you for your consideration.

Sincerely,

Daniese McMullin-Powell, Chairperson State Council for Persons with Disabilities

Cc: Developmental Disabilities Council
Governor's Advisory Council for Exceptional Citizens
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