



## Developmental Disabilities Council 2008 Position on Community Living

### Position Statement

All Americans should have the opportunity to live where they choose to live, how they choose to live, with whom they choose to live with dignity and mutual respect. Along with that opportunity comes the responsibility of being a good citizen and community member. Communities must allow for multi-dimensional mobility and universal access, privacy, safety and security.

People with disabilities have for too long experienced segregation from home, family, and community. They have been relegated to institutional care and robbed of their rights and responsibilities. They have been incarcerated, incinerated, herded, and forgotten. People with disabilities will no longer accept this minor status in America. Human Rights, Constitutional Rights, and other legal rights must not be abridged because of disability.

“We are part of community and community belongs to everyone in it. No longer will we beg or apologize or gratefully grovel. We know the value of our sons and daughters. We know their strengths, their gifts, their contributions. And we know who we are. Our voices will be heard. We are clear in our resolve. The sky is blue!” Cory Moore, Parent

Community Living in Delaware must include:

- “Nothing About Us Without Us.” People with disabilities should have a major role in the direction and control of programs and services designed for their benefit. This central role must be played by people with disabilities themselves, and should not be confused with the roles of family members, professional advocates, and others often play when “consumer” input is sought. (From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves)
- Freedom of choice in all aspects of a person’s life as any and all other Americans enjoy.
- A Quality of life equivalent to those without disabilities, which includes having access to the same opportunities as those without disabilities; education, employment, transportation, health care, housing, citizen privileges (e.g., voting, signing contracts, owning a home), social and recreational activities, spiritual activities, and all other opportunities afforded to the general public.
- Self determination in personal decision making and service delivery. This includes the ability for the person with a disability to maintain control of funds to pay for needed services. This keeps decision making empowering the person, not someone else.



- Long term care at home including Respite Care.
- The opportunity to age in place.
- The availability of trained, qualified support personnel to support people with the option to pay family members for support.
- Inclusion in all aspects of community life as the person chooses.
- Mutual respect between friends, family, neighbors, support staff, civic representatives, and other community members who we interact with every day.
- A recognition and plan for change throughout the life span. The lives of all people, including those with disabilities, change; we all have different support needs at different times in our lives.

#### Discussion

The Delaware Developmental Disabilities Council believes that people with disabilities must be able to live in their own communities as contributing members of society.

As noted in “A Path Forward: Building a Community Based Plan for Delaware” (E.O. #50, 2007), “Community inclusion builds a stronger, more diverse community and is more cost effective than housing and caring for all individuals with disabilities in an institutionalized setting.” “With the appropriate supports and services, individuals with disabilities can successfully work, participate in recreational activities, and contribute to their communities. They are also more likely to be educated alongside peers, retain employment, and be more satisfied with their environment.”

And from the preceding document, “A Call to Action: Building a Community-Based Plan for Delaware,” “The Americans with Disabilities Act of 1990, and the United States Supreme Court decision in *Olmstead v. L.C.* interpreting it, has had a far reaching impact on lives of persons with disabilities (also referred to as consumers) across this country, and especially those who are institutionalized or at risk of being institutionalized.

Respecting the rights of all citizens and upholding the dignity of persons with disabilities to live, work, and recreate in the community setting of their choice, our federal government and the Supreme Court have concluded that it is the basic human right not to be warehoused in an



institution, but to be able to live in a community with all of the support services necessary to make such community living successful.” (2003)

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 begins “Congress finds that disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society...” (Subtitle A, General Provisions). In fulfilling our mandates under this Act, we offer the following recommendations for action in Delaware.

#### Recommendations

- 1) Develop a flexible method of spending to allow for funds to flow directly to the person receiving services and allow the person the autonomy to decide how to spend their money.
- 2) Fulfill the Money Follows the Person (CMS) grant and institute the outcomes of the demonstration for all people with disabilities receiving Medicaid services and benefits.
- 3) An implicit conclusion from the *Olmstead v. L.C.* decision is that the state is required to provide adequate support for home care as a realistic alternative to institutional care. This requires the state to adequately fund home care, waiver programs and other support in the community. One preferable option to fund this requirement is to close the State institution for people with developmental disabilities and reallocate funds from that institution to the full continuum of community services.
- 4) The Department of Health & Social Services must create a system that permits payment to family members for their services to their family member with a disability. All disabilities should be included.

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