

# National Disability Leadership Alliance

C/o Autistic Self Advocacy Network

PO Box 66122

NW Washington, DC 20035

November 23, 2011

Donald M. Berwick, Administrator  
Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
Attention: CMS-2296-P  
P.O. Box 8016  
Baltimore, MD 21244-805

Dear Administrator Berwick:

On behalf of the National Disability Leadership Alliance (NDLA) and a wide variety of allied organizations supporting the mission and goals of the disability rights movement, we write to urge you to issue a Final Rule clarifying that Home and Community Based Services must not be delivered on the grounds of an institution, in a housing complex designed expressly around an individual's diagnosis or disability, or in a setting that has the characteristics of an institution. The National Disability Leadership Alliance (NDLA) is a coalition of 14 leading national disability organizations led by individuals living with disabilities themselves and supported by grassroots constituencies living with disabilities in all states and the District of Columbia. The Alliance prides itself on serving as a leading voice for those with disabilities and actively supporting the expansion and quality of the Medicaid Home and Community Based Services (HCBS) program. It is in this spirit that we and our allies contact you to urge you to move swiftly to issue a Final Rule in line with CMS' stated policy positions and the clear intent of the Medicaid HCBS program.

In April of this year, CMS published a Notice of Proposed Rulemaking (CMS-2296-P) clarifying the types of settings for which Medicaid Home and Community Based Services (HCBS) waiver funding could be utilized. The proposed regulation would have clarified that a HCBS setting "must be integrated in the community; must not be located in a building that is also a publicly or privately operated facility that provides institutional treatment or custodial care; must not be located in a building on the grounds of, or immediately adjacent to, a public institution; or, must not be a housing complex designed expressly around an individual's diagnosis or disability, as determined by the Secretary...[and] must not have qualities of an institution, as determined by the Secretary. Such qualities may include regimented meal and sleep times, limitations on visitors, lack of privacy and other attributes that limit individual's ability to engage freely in the community<sup>1</sup>."

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<sup>1</sup> "Medicaid Program; Home and Community-Based Services (HCBS) Waiver, Notice of Proposed Rulemaking," 76 Federal Register 73 (April 15<sup>th</sup>, 2011), pps. 21311

We are writing to reiterate our support for CMS's proposed definition of Home and Community Based Services outlined in CMS-2296-P, and to urge you to issue a Final Rule consistent with the principles laid out in your April NPRM. The integrity of the HCBS program is essential to protecting the rights of hundreds of thousands of Americans with disabilities who receive HCBS. Twenty-one years after the Americans with Disabilities Act (ADA) and twelve years after the Supreme Court's *Olmstead v. L.C.* decision, it is imperative that CMS define what can and cannot be funded utilizing HCBS waiver dollars in specific and measurable terminology. Failure to do so would undercut efforts now being undertaken by both federal and state governments as well as advocates across the country to transition people with disabilities out of institutions and into the community in accordance with current law. Without a clear and sufficiently narrow definition of HCBS that delineates it from institutional settings, the effectiveness of de-institutionalization efforts could be seriously hindered, leaving the door open to subjective interpretations by policymakers and the likelihood of wide-ranging and inconsistent applications of the rules. As such, we urge you to move swiftly to issue a Final Rule consistent with your April NPRM, defining appropriate and inappropriate usage of HCBS waiver dollars.

### **Community Integration and Buildings on the Grounds of or Immediately Adjacent to Institutions**

Last year, CMS rejected a request to amend the State of Missouri's 1915(c) Home and Community Based Services waiver for persons with intellectual and developmental disabilities, on the grounds that Missouri was seeking to utilize HCBS funding to set up a segregated setting consisting of a cluster of group homes on the grounds of a large state-operated institution. To quote from your August 2<sup>nd</sup>, 2010 letter to the Director of the Missouri Department of Social Services, "42 CFR 441.300 permits states to offer HCBS that individuals need in order to avoid institutionalization. However, Missouri proposes to add capacity through this waiver amendment to serve individuals living on the grounds of an institution which provides inpatient institutional treatment, a setting which is segregated from and with restricted access to the larger community. Under the proposed amendment, Missouri would not provide services that permit individuals to avoid institutionalization, but would serve individuals in an institutional setting."

We believe that your interpretation of the incompatibility between this state's proposal and the function of the HCBS program was accurate and correct. As such, it is imperative that CMS issue a Final Rule that matches this earlier interpretation and upholds the idea that the purpose of the HCBS program is to fund alternatives to institutionalization, rather than providers which operate in the same fashion and location as an institutional setting. The proposed language in the aforementioned NPRM would provide necessary advance guidance to states to prevent the misuse of the HCBS program and ensure that CMS would not be forced into the position of having to make ad hoc judgments on the legitimacy of each state's proposed use of HCBS waiver funding.

### **Housing Complexes Designed Expressly Around Diagnosis or Disability**

Historically, the definition of an institution has been a setting which segregates individuals with disabilities from those without disabilities and which places upon individuals with disabilities rules and restrictions which are not applied to the non-disabled population. The section of the NPRM which proposed prohibiting the use of HCBS funds for "housing complex[es] designed

expressly around an individual's diagnosis or disability" represents a critical component of maintaining the quality of the HCBS program, and we urge CMS to retain it in its Final Rule.

Research has proven that individuals being served in congregate care settings experience less choice and autonomy in day to day life than those who are living in more integrated settings, even after controlling for severity of impairment<sup>2</sup>. The defining characteristic of community-based services has long been enhancing choice and control over ones' own life. In the April NPRM, CMS acknowledged this by expressing concern over settings that are, "segregated from the larger community, and do not allow individuals to choose whether or with whom they share a room, limit individuals' freedom of choice on daily living experiences such as meals, visitors, activities, and limit individuals' opportunities to pursue community activities<sup>3</sup>."

### **Characteristics of an Institution**

For the non-disabled population, the definition of home is not difficult to determine. No reasonable observer would claim that any non-incarcerated adult without a disability should be subject to arbitrary rules about when to eat and sleep or who they can allow to visit while living in their own home. These types of restrictions are the very definition of an institutional setting, in that they center power and decision-making authority with those providing services rather than with the individual being served. Yet, as efforts to ensure that states meet their requirements under the *Olmstead* decision have grown, many service-providers have attempted to claim that settings which did not meet these minimal requirements should be eligible to receive Medicaid HCBS funds.

According to the 2010 Keeping the Promise: Self-Advocates Defining the Meaning of Community Living report from the Autistic Self Advocacy Network, Self-Advocates Becoming Empowered and the National Youth Leadership Network, an effective definition of community must be multi-dimensional in nature, incorporating factors such as physical size and structure, rights and self-determination, qualities and attitudes of providers, access to community life, and the meeting of support and access needs. Including the NPRM's language in the Final Rule requiring that HCBS settings must not have the characteristics of an institution will help operationalize a multi-dimensional definition of community. We urge you to retain this language in the Final Rule and to consider expanding it to include other characteristics of institutional settings, such as the right of an individual receiving service-provision to choose with whom they live, what activities they engage in and who to hire and fire amongst their support staff.

We and the organizations listed below urge you to move swiftly to issue a Final Rule reflecting the priorities outlined in your April NPRM and this letter. Many of the organizations have submitted separate detailed comments concerning the NPRM and the most appropriate means to implement it; this letter is intended to complement rather than replace those comments. In addition, they and we would be glad to provide any assistance necessary to help clarify the

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<sup>2</sup> Lakin, K. C., Doljanac, R., Byun, S. Y., Stancliffe, R., Taub, S., & Chiri, G. (2008). Choice-making among medicaid hcbs and icf/mr recipients in six states. *American Journal on Mental Retardation*, 113(5), 325-342.

<sup>3</sup> "Medicaid Program; Home and Community-Based Services (HCBS) Waiver, Notice of Proposed Rulemaking," 76 Federal Register 73 (April 15<sup>th</sup>, 2011), pps. 21312

language of the NPRM or to address concerns raised by other stakeholders. Clarifying the specific characteristics of community-based living versus institutional settings will promote meaningful community inclusion and lead to better outcomes for those individuals receiving HCBS. These regulations will also assist states in meeting their obligations under *Olmstead v. L.C.* and the Americans with Disabilities Act. If you have any questions, please feel free to contact Ari Ne’eman, President of the Autistic Self Advocacy Network at [aneeman@autisticadvocacy.org](mailto:aneeman@autisticadvocacy.org).

Thank you for your time and we appreciate your commitment to the rights and equality of people with disabilities.

Sincerely,

**NDLA Steering Committee Organizations**

ADAPT

American Association of People with Disabilities

American Council of the Blind

Association of Programs for Rural Independent Living

Autistic Self Advocacy Network

Little People of America

National Association of the Deaf

National Coalition for Mental Health Recovery

National Council on Independent Living

National Federation of the Blind

Self Advocates Becoming Empowered

Not Dead Yet

United Spinal Association

**Other National Supporting Organizations**

The Arc of the United States

APSE

Association of University Centers on Disabilities (AUCD)

The Bazelon Center for Mental Health Law

Center for Self-Determination

Collaboration for the Promotion of Self-Determination (CPSD)

National Association of Councils on Developmental Disabilities (NACDD)

National Disability Rights Network (NDRN)

National Down Syndrome Society (NDSS)

National Organization of Nurses with Disabilities (NOND)

National Association of State Directors of Developmental Disability Services (NASDDDS)

National Center for Learning Disabilities (NCLD)

National Youth Leadership Network

TASH

**State and Local Supporting Organization:**

Access Living

Arc of Georgia  
Arc of Greater Cleveland  
Arc of Maryland  
ARISE of Syracuse, New York  
Boston Center for Independent Living  
Center for Disability Rights, New York  
Coalition to Protect the Integrity of Peer Support in New York State  
Concrete Change, Georgia  
Community Link, Denver, Colorado  
Community Consortium of Albany, New York  
Community Resource Alliance  
Center for Independence of the Disabled, Flushing, New York  
Center for Human Rights of Users and Survivors of Psychiatry  
Community Now! of Texas  
Disabilities Rights Center of New Hampshire  
Disability Law Center of Massachusetts  
Disability Rights Network of Pennsylvania  
Disability Rights New Jersey  
Disability Rights Florida  
Disability Rights Vermont  
Disability Rights Oregon  
Disability Rights North Carolina  
Disabled in Action of Philadelphia  
Disabled in Action of Greater Syracuse, New York  
Disabled in Action of Metropolitan New York  
Disability Options Network, Pennsylvania  
Disabled Rights Action Committee of Utah  
Enable of Syracuse, New York  
Georgia ADAPT  
Independent Living Center of the Hudson Valley  
Independent Living Center of Joplin, Missouri  
Independent Living of Middletown, New York  
IndependenceFirst, Milwaukee, Wisconsin  
Institute for Disability Rights, Austin, Texas  
Institute for Disability Access  
Rochester Regional Center for Independent Living  
Long Term Care Community Coalition  
Maryland Coalition for Inclusive Education  
Maryland Disability Law Center  
Maryland ADAPT  
Mental Health Empowerment Project, Albany, New York  
Missouri Association of Centers for Independent Living (MOCIL)  
Montana ADAPT  
National Action Network, Kansas Chapter  
New York Association on Independent Living  
New York Association of Psychiatric Rehabilitation Services

New York State ADAPT  
Options for Independence, Auburn, New York  
Personal Attendant Coalition of Texas (PACT)  
Philadelphia ADAPT  
Texas ADAPT  
The Whole Person, Kansas City, Missouri  
Statewide Independent Living Council of Georgia  
Staten Island Center for Independent Living  
St. Louis ADAPT  
Southwest Center for Independence, Durango, Colorado  
Southeast Kansas Independent Living (SKIL) Resource Center  
Southern Tier Independence Center, Binghamton, New York  
Southern Tier ADAPT  
Summit Independent Living Center of Missoula, Montana  
Silicon Valley Independent Living Center  
University Legal Services - Protection & Advocacy (DC)  
UTAH ADAPT  
Virginia Office for Protection and Advocacy  
Voice of the Heart, Glens Fall, New York  
Western New York Independent Living  
Westchester Disabled on the Move

CC: Kareem Dale, Special Assistant to the President for Disability Policy  
CC: Henry Claypool, Director of the Health and Human Services Office on Disability  
CC: Cindy Mann, Director, Center for Medicaid, CHIP, and Survey & Certification  
CC: Tom Perez, Assistant Attorney General, Civil Rights Division, Department of Justice  
CC: Sharon Lewis, Commissioner, Administration on Developmental Disabilities