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Margaret O'Neill Building,  
2<sup>nd</sup> Floor  
410 Federal Street, Suite 2  
Dover, Delaware 19901

Office: (302) 739-3333  
Fax: (302) 739-2015  
[www.ddc.delaware.gov](http://www.ddc.delaware.gov)

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The Honorable Jack Markell  
Governor  
Tatnall Building  
Dover, Delaware 19901

Dear Governor,

In June 2009, The Centers for Medicare and Medicaid Services (CMS) issued an Advance Notice of Proposed Rulemaking (CMS-2296-ANPRM) soliciting comments on the most effective means of defining home and community. The noticed intention of CMS was to publish proposed amendments to the regulations for implementing the Medicaid Home and Community Based Services waivers under section 1915 (c) of the Social Security Act.

In January 2014, CMS has issued the Final Rule for the Medicaid Home and Community Based Services waivers (HCBS). The intent of the Final Rule is to ensure that individuals receiving long-term services and supports through home and community based service (HCBS) programs under the 1915(c), 1915(i), and 1915(k) Medicaid authorities have full access to benefits of community living and the opportunity to receive services in the most integrated setting appropriate, and to enhance the quality of the HCBS and provide protections to participants.

We, the Developmental Disabilities Council (DDC), applaud the efforts of CMS to more explicitly describe the expectations that individuals with developmental disabilities should be served in their homes and communities. We believe that the standards for community living articulated in the Final Rule that defines, describes, and aligns home and community-based setting requirements across three Medicaid authorities --*optimizing participant independence and community integration, promoting initiative and choice in daily living, and facilitating full access to community services*-- reflect the values and goals that many individuals with developmental disabilities, along with their families and advocates have struggled to achieve for over 40 years. Home and Community Based Waiver funding is the primary source of funding for individuals with developmental disabilities and families in achieving these goals.



While individuals with developmental disabilities have the right to choose where they live, it is the position of the DD Council that state and federal funds, including Developmental Disabilities Home and Community Based Waiver funds, should not support segregated living arrangements where all or nearly all of the residents are people with disabilities. Rather these funds should support living arrangements that “promote self-determination, independence, productivity, and integration and inclusion in all facets of community life” as set forth in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and consistent with requirements of the Americans with Disabilities Act and other legal requirements

In defining home and community characteristics, it is important to understand the values and beliefs that are fundamental to the standards for community living that CMS has stated. The DD Act provides an excellent context for understanding the basis for the community integration, choice, control and independence principles set forth in the CMS standards. The purpose of this act is "to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports and other forms of assistance that promote self-determination, independence, productivity and integration and inclusion in all facets of community life .."<sup>1</sup> The first finding of the DD Act is 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.”<sup>2</sup>

When read in its entirety, the intent of the DD Act is to recognize the competencies, capabilities and personal goals of individuals with developmental disabilities and to contribute to a system where individuals with developmental disabilities have the ability and opportunity to make personal decisions, exert control over their lives and participate in the same community activities that are available to individuals without disabilities. Inclusion and integration of individuals with developmental disabilities in the communities of our society, as well as individual choice and control of life decisions and daily living activities, are core intents of the DD Act and of the Medicaid Home and Community Based Waiver services.

The DD Act provides excellent definitions of these principles that can be used to guide your consideration. All definitions are used with respect to individuals with developmental disabilities.

- Inclusion: The term “inclusion” means “the acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enables individuals with developmental disabilities to-

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<sup>1</sup> P.L. 106-402, section 101 (b)

<sup>2</sup> P.L. 106-402, section 101 (a)



- A.** have friendships and relationships with individuals and families of their own choice;
  - B.** live in homes close to community resources, with regular contact with individuals without disabilities in their communities;
  - C.** enjoy full access to and active participation in the same community activities and types of enjoyment as individuals without disabilities; and
  - D.** take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.”<sup>3</sup>
- **Integration:** The term “integration” means “exercising the equal right of individuals with developmental disabilities to access and use the same community resources as are used by and available to other individuals.”<sup>4</sup>
- **Self-Determination Activities:** The term “self-determination activities” means “activities that result in individuals with developmental disabilities, with appropriate assistance, having-
  - A.** the ability and opportunity to communicate and make personal decisions;
  - B.** the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individuals receive;
  - C.** the authority to control resources to obtain needed services, supports, and other assistance;
  - D.** opportunities to participate in, and contribute to, their communities; and
  - E.** support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and play a role in the development of public policies that affect individuals with developmental disabilities.”<sup>5</sup>
- **Individualized Supports:** The term “individualized supports” means “supports that-
  - A.** enable an individual with a developmental disability to exercise self- determination, be independent, be productive, and be integrated and included in all facets of community life;
  - B.** are designed to-
    - i.** enable such individual to control such individual’s environment, permitting the most independent life possible;
    - ii.** prevent placement into a more restrictive living arrangement than is necessary; and

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<sup>3</sup> P.L. 106-402, section 102 (15)

<sup>4</sup> P.L. 106-402, section 102 (17)

<sup>5</sup> P.L. 106-402, section 102 (27)



- iii. enable such individual to live, learn, work, and enjoy life in the community; and
- C. include-
- i. early intervention services;
  - ii. respite care;
  - iii. personal assistance services;
  - iv. family support services;
  - v. supported employment services;
  - vi. support services for families headed by aging caregivers of individuals with developmental disabilities; and
  - vii. provision of rehabilitation technology and assistance technology, and assistive technology services.”<sup>6</sup>

While individuals with developmental disabilities have the right to choose where they live, public state and federal funds, including Developmental Disabilities Home and Community Based Waiver funds, should support living arrangements that “promote self-determination, independence, productivity, and integration and inclusion in all facets of community life” as set forth in the DD Act.

## THE LEGAL OBLIGATION TO PROVIDE SERVICES IN THE LEAST RESTRICTIVE SETTING

CMS standards require that programs should optimize participant independence and community integration, promote initiative and choice in daily living, and facilitate full access to community services. Accordingly, public funds should be used to support living arrangements that are consistent with these values and beliefs.

The guiding principle of the U.S. Supreme Court’s landmark 1999 decision in *Olmstead v. L.C.*<sup>7</sup> is the inherent right of an individual to be free from unnecessary segregation from the general public. The Court made the legal and social imperative for deinstitutionalization clear: unnecessary institutionalization is a form of discrimination under Title II of the Americans with Disabilities Act (ADA).<sup>8</sup>

The ADA expressly states that, “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”<sup>9</sup> Through its *Olmstead* decision, the United States Supreme Court applied the ADA to state operated publicly-funded institutions and explained that, “segregation

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<sup>6</sup> P.L. 106-402, section 102 (16)

<sup>7</sup> *Olmstead v. L.C.*, 527 U.S. 581, 119 S.Ct. 2176 (1999).

<sup>8</sup> *Id.*, 527 U.S. at 597

<sup>9</sup> 42 U.S.C. § 12132



perpetuates unwarranted assumptions that institutionalized people are incapable or unworthy of participating in community life.” The Justices also concluded that, “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.” The Court then reasoned that since people with disabilities should not have to give up the benefits of full participation in their communities in order to obtain needed medical services and supports, states should make reasonable accommodations under the ADA to ensure that Medicaid and other funds are used to provide the most integrated and inclusive settings appropriate for individuals with developmental disabilities.

In 2009, the U.S. District Court for the Eastern District of New York, also weighed in on the characteristics of a community based setting. In *Disability Advocates, Inc. v. Patterson*, the Judge was asked to determine whether adult care homes for individuals with mental illness in New York meet the definition of the “most integrated setting appropriate” as used in the Department of Justice (DOJ) regulations governing the ADA Title II 28 C.F.R. 35.130(d); 42 U.S.C. 12134; and the U.S. Supreme Court in *Olmstead*. The regulations define “most integrated setting appropriate” as “a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.” 28 C.F.R. Pt. 35, App. A at 452. New York argued that adult home residences for individuals with mental illness met this definition because they were: in the community; unlocked; and permitted residents the opportunity to interact with non- disabled people. The Judge rejected this argument, holding that the ADA does not require “an” opportunity for interaction with non-disabled people, but rather the maximum opportunity for such interactions. The Court considered the essential characteristics of institutions to be:

- the degree of control that people exercised over their own lives, for example: could they cook or plan their own meals, control their own budgets, decide when to eat and sleep, and host visitors in private at times of their choosing;
- the degree of individualization of the setting and services, for example, whether people could choose their own roommate and their own medical professionals; and
- whether residents had non-disabled friends, worked or volunteered with non-disabled people, and had opportunities for recreation with non-disabled people.<sup>10</sup>

The Rehabilitation Act mirrors the DD Act in its intent for inclusion and independence for individuals with disabilities. Specifically, the act states that “disability is a natural part of human experience and in no way diminishes the right of individuals to live independently; enjoy self- determination; make choices; contribute to society; pursue meaningful careers; and enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society.”<sup>11</sup>

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<sup>10</sup> DAI v. Paterson, 2009 U.S. Dist. LEXIS 80975 at 114-115

<sup>11</sup> P.L. 93-112, section 2 (a)



Consistent with all these precedents, CMS recently denied a request from the state of Missouri to amend its 1915(c) MR/DDR Comprehensive Home and Community-Based Services waiver for increased transition of individuals into residential units clustered on the grounds of a large state- operated institution. In the letter dated August 2, 2010, CMS stated that the proposed waiver amendment proposal is not consistent with both statute and regulations as Missouri would not be providing services that permit individuals to avoid institutionalization.

More recent Olmstead litigation concerning residential settings include:

- United States v. O’Toole et al., (2013) (DAI’s “adult homes” case)
- United States v. Virginia, (2012) (developmental centers)
- United States v. North Carolina, (2012)
  - All Three settlement agreements included requirements to developed scattered-site supportive housing.

Recent Olmstead litigation concerning non-residential settings include:

- United States v. Rhode Island (settled 2014):  
Consent decree requires phase-outs of sheltered workshops and increase in supported employment services.
- United States v. Virginia (2012): requires states to provide supported employment to people with ID/DD.
- Lane v. Kitzhaber (Oregon, pending):  
Department of Justice issued findings letter stating that segregated employment services violate the ADA.

In closing, the Developmental Disabilities Council, and in collaboration with our national association, the National Association of Councils on Developmental Disabilities (NACDD), thanks you, Governor Markell, for your sincere consideration of these remarks. We are hopeful that in development of this year’s state budget you will take advantage of our research and continue your commitment to support full inclusion of people with disabilities in our communities.

Should you need any further information or discussion on this topic, you are always welcome to contact our office at 302.739.3333 or [pat.maichle@state.de.us](mailto:pat.maichle@state.de.us). In addition, you can visit the national web site <http://www.HCBSadvocacy.org>.



Sincerely,  
*Diann Jones*

Diann Jones, Chair  
Delaware Developmental Disabilities Council

cc. The Honorable Rita Langraf, DHSS  
The State Council for Persons with Disabilities  
The Governor's Advisory Council for Exceptional Citizens  
Donna Meltzer, NACDD