

December 6, 2010

Centers for Medicare and Medicaid Services
Attention: Mary Sowers and Ms. Poisal
7500 Security Blvd
Baltimore, MD 21244

Dear Ms. Sowers and Ms. Poisal:

The National Association of Councils on Developmental Disabilities (NACDD), the National Disability Rights Network (NDRN), and the Association of University Centers on Disabilities (AUCD) are national organizations focused on serving people with developmental disabilities.

We are concerned about the potential use of Medicaid waiver funding that may support segregated rather than integrated housing for people with disabilities. We therefore submit the attached joint comments to CMS' Advance Notice of Proposed Rulemaking, of June 22, 2010, FR Doc E9-14559, CMS-2296-ANPRM.

If you have any questions or require further information, please do not hesitate to contact any of us.

Respectfully submitted,



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MEANINGFUL INCLUSION: WHAT DISTINGUISHES HOME AND COMMUNITY BASED SERVICES FROM INSTITUTIONAL LIVING

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.

We, the National Association of Councils on Developmental Disabilities (NACDD), the Association of University Centers on Disabilities (AUCD), and the National Disability Rights Network (NDRN), 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 Advance Notice of Rulemaking --*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.

Therefore, it is imperative to ensure that the Developmental Disabilities Home and Community Based Waiver funding source continues to be dedicated to furthering these values and goals. It is in this spirit that we submit these comments. In doing so, we highlight the beliefs and values we are collectively guided by with regard to community-based living, review legal standards, and highlight the characteristics that should be required in living arrangements that are supported with public funding via Medicaid Home and Community Based Waiver services for individuals with developmental disabilities.

In summary, while individuals with developmental disabilities have the right to choose where they live, it is the position of NACDD, AUCD, and NDRN 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

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BELIEFS AND VALUES

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 .."¹ 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."²

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-
 - (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

¹ P.L. 106-402, section 101 (b)

² P.L. 106-402, section 101 (a)

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(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.”³

- 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.”⁴
- 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.”⁵
- 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
 - (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;

³ P.L. 106-402, section 102 (15)

⁴ P.L. 106-402, section 102 (17)

⁵ P.L. 106-402, section 102 (27)

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- (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.”⁶

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.*⁷ 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).⁸

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.”⁹ Through its *Olmstead* decision, the United States Supreme Court applied the ADA to state operated publicly-funded institutions and explained that, “segregation 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.

⁶ P.L. 106-402, section 102 (16)

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

⁸ *Id.*, 527 U.S. at 597.

⁹ 42 U.S.C. § 12132.

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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.¹⁰

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.”¹¹

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.

It is imperative that these gains not be reversed. We urge CMS to adopt strong requirements that prevent the use of Developmental Disabilities Home and Community Based Waiver funds for living arrangements that are not consistent with the values and goals in the DD Act as well as with the ADA, the *Olmstead* decision and the Rehabilitation Act, and to protect the continued use of these funds for true integrated community living.

¹⁰ *DAI v. Paterson*, 2009 U.S. Dist. LEXIS 80975 at 114-115

¹¹ P.L. 93-112, section 2 (a)

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RESEARCH DEMONSTRATES THE BENEFIT OF COMMUNITY LIVING

In addition to these legal and social goals, adherence to these standards of community living furthers the public interest by promoting the wellbeing of those served.¹²

A study of the results of the 1994 closing of North Princeton Developmental Center in New Jersey, published by the American Association on Mental Retardation in 2005, compared people who moved from institutional settings to people with similar service and support needs who remained in institutions.¹³ The study produced “convincing evidence” that the multi-cognitive scores of people who remained in institutional settings significantly decreased from 1994-2001. The study also concluded that those who moved to community settings demonstrated significant increases in self-care skills over time. The authors concluded, “If we had focused solely on movers ... we would have missed one of the most salient findings of this evaluation, namely, the significant loss by stayers in their multi-cognitive competencies, particularly in the areas of social skills...”¹⁴

Similarly, a survey of guardians of people who moved from institutional settings to the community in Wisconsin led researchers to conclude that the vast majority of guardians felt that the transition to the community led to equal or enhanced satisfaction with their loved one’s living arrangements and overall happiness.¹⁵

Finally, a review of the literature concluded:

“The studies reviewed here demonstrate strongly and consistently that people who move from institutions to community settings have experiences that help them to improve their adaptive behavior skills. The studies suggest that community

¹² It should be noted that institutional living is not solely bound by CMS’ or other definitions of institutions and that features of institutions are also found in places currently referred to as community settings. More specifically, people living in congregate settings of seven or more residents are more likely to report loneliness, less frequent satisfaction with their home, lower levels of community participation, etc. See Lakin, K.C., Doljanac, R., Byun, S., Stancliffe, R., Taub, S., Chiri, G., (2008) Choice-making among Medicaid Home and Community-Based Services recipients and ICF/MR residents in six states. *American Journal on Mental Retardation*, 113(5), 325-341.

¹³ “Longitudinal Changes in Adaptive Behavior of Movers and Stayers;” Lerman, P., Apgar, D., Jordan, T. *Mental Retardation Journal*, American Association on Mental Retardation. February 2005, pp. 25-42. The study compared adaptive behaviors of individuals who lived in the North Princeton Developmental Center. The study assessed 150 movers and 150 stayers and looked at longitudinal changes. Movers and stayers were matched according to age, gender, cognition, social-emotional functioning, self-care, mobility, and challenging behaviors.

¹⁴ Id.

¹⁵ *Northern Wisconsin Center (NWC) Relocation Survey – March 27, 2006, prepared by APS Healthcare, Inc. for The Wisconsin Department of Health and Family Services (DHFS), Division of Disability and Elder Services (DDES).* See also Larson, S. A., & Lakin, K. C. (eds.). (1989). Deinstitutionalization of persons with mental retardation: Behavioral outcomes. *Journal of the Association for Persons with Severe Handicaps*, 14(4), 324-332. Updated in Kim, S., Larson, S., and Lakin, K.C. (2001) Behavioral outcomes of deinstitutionalization of people with intellectual disabilities. A review of U.S. studies conducted between 1980 and 1999, *Journal of Intellectual and Developmental Disabilities*, 26(1), 35-50.

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experiences increasingly provide people with environments and interventions that reduce challenging behavior.”¹⁶

The potential for an enhanced quality of life and skill improvements for people who move to community settings, and the risk that those remaining unnecessarily in institutions may experience a loss of skills provides further impetus to support people with developmental disabilities in appropriate community settings.

EMERGING OPTIONS FOR LIVING ARRANGEMENTS

Over time, numerous options for a continuum of living arrangements for individuals with developmental disabilities have and will continue to emerge across the United States. These options have been developed in response to a variety of issues, concerns, and desires, including but not limited to the following:

- The historic lack of services in the community to appropriately support individuals with developmental disabilities to live self-directed, participatory lives in the community;
- The desire of families for safety and continuity of care;
- The desire of individuals with developmental disabilities to socialize and/or live with others;
- The desire of individuals with developmental disabilities to be seen as equal participants in all that society has to offer; and
- The tightening economy that makes congregate service provision more appealing for service providers.

Now is, therefore, the opportune time to provide a framework for determining options that will and will not support Medicaid Home and Community Based Waiver standards for community living.

Below is an outline of some emerging living arrangement options and whether each option is consistent and/or inconsistent with the beliefs and values that are intrinsic to the DD Act, the legal requirements of the ADA and the *Olmstead* decision, and the CMS articulated standards of community living.

It is essential to understand that if a setting has even one aspect that is inconsistent with the values of the DD Act and CMS standards for community living, the setting is not integrated and should not be supported as such.

Options for Living Independently:

Contrary to popular belief, individuals with developmental disabilities are able to live in their own homes. Supports are offered in various forms and make living independently possible.

¹⁶ Larson & Lakin, *Id.*

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Emerging Independent Living options include the following:

- A variety of approaches are being used to support individuals with developmental disabilities with all levels of needs to live independently in the community.
 - One option is for the person providing the care and supervision to live next door or in the proximity of the individual with developmental disabilities.
 - Another option is paying a neighbor to provide emergency support to an individual with developmental disabilities as needed.
- Individuals with developmental disabilities live in apartments among other members of the community. They receive individualized assistance and have access to multiple activities that support their growing independence and active involvement in community activities. In this approach a community is prepared for the integration of individuals with developmental disabilities. Specifically, the community and the specific settings to be frequented by the individuals with developmental disabilities are educated about these individuals to provide a foundation for acceptance and support.
- Public/private partnerships are being developed to increase the supply of affordable and accessible housing available for individuals with developmental disabilities and to prepare and facilitate availability of rental and/or home ownership for individuals with developmental disabilities. Services are purchased separately as needed to provide the necessary support.

How Options for Living Independently Are Consistent with DD Act Beliefs and Values:

- Individuals with developmental disabilities have the opportunity to live independently, with choices and controls over their daily life activities.
- Individuals with developmental disabilities are living where they have regular contact with individuals without disabilities and the opportunity to develop friendships and relationships with a wide range of individuals and families of their choice.
- Individuals with developmental disabilities are living where they can take advantage of opportunities for participating in community activities. Such opportunities can be facilitated by the proximity of generic and natural supports, such as individuals with developmental disabilities living on the public bus route or with access to public transportation for individuals with disabilities, or living in proximity or with access to employment opportunities, places of worship, socialization, recreation, shopping, volunteering and civic engagement.
- Services and supports are individualized based on the particular needs of the individual with developmental disabilities and promote self-determination, independence, productivity, integration and inclusion.
- Individuals with developmental disabilities have a choice of all the providers and staff available in the community.
- Other individuals in the community have regular contact with the individuals with developmental disabilities who can observe and report potential abuse.

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Individualized Shared Living Options:

While many individuals with developmental disabilities live with their own families, there are also approaches where individuals with developmental disabilities live with roommates or in the private home of an individual or family who provides the individual with developmental disabilities with support, guidance and supervision.

Emerging Individualized Shared Living Options:

- There are approaches that emphasize the long term sharing of lives and forming caring households and close personal relationships between an individual with developmental disabilities and supportive persons.
- There are also approaches where the person providing care and supervision lives with the individual with developmental disabilities (with or without additional roommates with developmental disabilities). Each person in the apartment/home has his or her own lease, making the apartment the home of the individual with developmental disabilities, instead of the individual with developmental disabilities living in the caretaker's home as is the case with foster homes.

How Individualized Shared Living Options Are Consistent with DD Act Beliefs and Values:

- Individuals with developmental disabilities have the opportunity to live independently with choices and controls over their daily life activities.
- Individuals with developmental disabilities are living where they can have regular contact with individuals without disabilities, and thus have the opportunity to develop friendships and relationships with a wide range of individuals and families of their choice.
- Individuals with developmental disabilities are living where they can take advantage of opportunities for participating in community activities.
- Services and supports are individualized based on the particular needs of the individual with developmental disabilities and promote self-determination, independence, productivity, integration and inclusion.
- The personal care provider is the non-relative family with whom the individual with developmental disabilities lives. Individuals with developmental disabilities have a choice of all other providers and staff available in the community.
- Other individuals in the community have regular contact with individuals with developmental disabilities and can observe and report potential abuse.

Intentional Communities/Co-Operative Communities:

These communities contain homes, apartments and possibly other housing options that are clustered and designed for the purpose of meeting the unique needs of different populations or are unified by a common purpose and a fostering of mutual neighborhood support.

Whether these communities provide living opportunities that are integrated and otherwise consistent with DD Act beliefs and values and other legal requirements depends on how each

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situation is structured. In any case, a community should never be considered integrated based on only a token number of non-disabled people residing among a high percentage of individuals with disabilities.

Emerging Intentional/Co-Operative Communities:

- Clustering of housing and services to address more than one target population, such as individuals with developmental disabilities and individuals who are aging, or individuals with developmental disabilities and college students. Common areas for sharing social activities and dining can be offered.
- Intentional Communities/Co-operatives focus on developing mutual neighborhood support and communities where members share their lives, and encourage interactions between its members. Some of these communities specifically seek to provide homes and a community for people with and without disabilities. Avenues for developing natural supports through relationships and support for one another are provided.

How Intentional/Co-Operative Communities Can Be Consistent with DD Act Beliefs and Values:

- Individuals with developmental disabilities have regular social connections with other individuals.
- There is an opportunity for bringing together and sharing community supports and services for individuals with developmental disabilities.
- Individuals with developmental disability are living where they can have regular contact with individuals without disabilities, and thus have the opportunity to develop friendships and relationships with a wider range of individuals and families of their choice.
- Individuals with developmental disabilities are living where they can take advantage of opportunities for participating in the community activities made available to the population of individuals without disabilities.

How Intentional/Co-Operative Communities Are Inconsistent with DD Act Beliefs and Values:

- The choices and controls that individuals with developmental disabilities have over their daily life activities may still be limited by the requirements/rules imposed by the community organizing entity and to opportunities provided by the community organizing entity, depending on the population of individuals without developmental disabilities (i.e., aging individuals).

Clustered Housing Options:

Clustered Housing Communities are where residences, whether homes, apartments, group homes and/or other types of licensed residences (such as Assisted Living Facilities) are clustered/grouped together in some form to provide for a community. These Cluster Housing options are designed to meet the needs of individuals with developmental disabilities in congregate settings. These communities are intended to provide safety, opportunities for socializing with other individuals with developmental disabilities, and sense of belonging to a community.

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The main concern is that in these settings, there is little or no integration with people without disabilities. Even in those clustered housing communities that are open to others, it is generally the case that only a very small percentage of the residents are individuals without developmental disabilities.

Emerging Clustered Housing Options Include the Following:

- Small clustered housing arrangements where a small number of group homes are grouped together sharing common areas for social activities and dining.
- Large cluster housing arrangements offering campus style living where there are multiple housing units (all one type or mixed) and a wide range of services offered on the grounds.
- A clustering of apartments/homes for individuals with disabilities with no common services on site. Any supervision or personal care services are provided by organizations outside the cluster housing settings.
- A clustering of “condominium” units within one building, in which each individual owns his/her bedroom “unit” and has shared ownership of common areas for social activities and dining.

How Clustered Housing Options Are Inconsistent with DD Act Beliefs and Values:

- Individuals with developmental disabilities are segregated from individuals without disabilities. Regular contact with individuals without developmental disabilities, and therefore, opportunities to develop friendships and relationships with a wide range of individuals and families of their choice, is limited to trips off-campus.
- Opportunities to participate in everyday integrated community activities are not naturally available. The addition of congregate services in the cluster housing setting, such as meals, sheltered workshops, and on-site employment, further reduce opportunities for contact with integrated community activities.
- The choices and controls that individuals with developmental disabilities have over their daily life activities and, therefore, their opportunity to live as independently as possible, are limited by the requirements/rules imposed by the provider and to opportunities offered by the provider.
- Although there may be some choice of providers and staff available in the community, providers will have invested in housing and on-site services in the cluster housing community, which may limit availability of community providers and staff. Such an investment in the housing and on-site services may necessitate individuals moving out of the cluster housing community if they wish to change providers.
- It would be inconsistent with DD Act Beliefs and Values for a community to be considered integrated based on only a token number of non-disabled people residing among a large majority of individuals with disabilities.

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DEFINING WHAT IS AND IS NOT HOME AND COMMUNITY BASED LIVING ARRANGEMENTS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

In defining community for individuals with developmental disabilities, it is important to exercise caution since each individual possesses their own sense of what community means to them based on familial and cultural values. However, based on the beliefs and values established in the DD Act, as well as requirements of the ADA, the *Olmstead* decision and the Rehabilitation Act, that recognize the basic civil right of all people to make choices about their living arrangements, relationships, and daily activities, it is possible to outline characteristics that are fundamental for any community.

While defining community for individuals with developmental disabilities may be challenging, individuals with developmental disabilities and their families know when they "achieve" a satisfactory life in the community. Sometimes it is easier to say what community isn't than what it is, but for each individual, there is an ideal that allows that individual to feel that they are a community member living a life of self-direction and participation. Although there may be barriers to taking advantage of or enjoying all of these fundamental characteristics, it becomes clear that the more community characteristics in which an individual can participate, the more the living arrangement is home and community based. In turn, the less community participation, the more likely the living arrangement is aligned with a congregate setting with the characteristics of institutional living.

It is our position that for living arrangements to be consistent with the beliefs and values of the DD Act, as well as with the requirements of the ADA, the *Olmstead* decision and the Rehabilitation Act, they must comply with each and every one of the following fundamental characteristics that allow people with developmental disabilities, like all members of the community, to:

1. Make choices about their daily lives

What it is: Individuals with developmental disabilities must have access to options and make choices, such as where they live, work, or spend their day based on personal likes and dislikes. Decisions such as location of an individual's home, housemates, work activity, daily schedules, and personal choices such as clothing, friends, television programs, etc. must be specific to the person. Individuals with developmental disabilities must be supported to recognize that they can exercise their full rights and responsibilities as community citizens, volunteering time, assisting others, voting, etc.

What it isn't: The community would not be a system in which the state or provider agencies inform people where they will live, work or spend their day. People should not be offered housing arrangements that are only for people with disabilities, where all neighbors have disabilities and houses are clustered by provider or institution affiliation for the convenience of the provider or staff. People with disabilities, just like those without disabilities, should not expect to be told such things as with whom they will live, what they will eat, wear, watch on TV and when they will get up or go to bed.

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2. Live in integrated settings where not all residents and neighbors have disabilities

What it is: While disability is a natural part of life and many members of our society experience or will experience a disability, we do not expect all of our neighbors and household members to have a disability. While there will be variances in what becomes a normal expectation, people with disabilities should not have expectations of ratios higher than other members of their community.

What it isn't: People are only offered homes or living arrangements in settings where all or almost all of the residents have disabilities. These settings are often established for the convenience of the provider or funding system rather than the individual resident. Other choices may be diminished as well for the ease of management of the residence and staff.

3. Identify services and supports that are individualized to meet their needs

What it is: People receive support to help identify, design and access the resources and services they need to have a quality life and participate in the community. Individualized services and supports promote self-determination, independence, participation, and inclusion in all aspects of community life. Naturally occurring services and systems are considered first before a specialized service is created and purchased. There is a conscious effort to adapt existing services so that people can participate alongside people who do not have disabilities. Individuals' wishes, needs, and desires are genuinely taken into consideration. Individuals are supported to make informed choices.

What it isn't: People are placed in existing programs and projects. Their personal plans to help them access these programs are developed with little or no input from the individual. People are seldom offered options that all citizens enjoy with individualized adaptations that allow them to participate.

4. Fully participate in the community

What it is: People participate in activities and events of their choice, based on their likes and interests alongside people who do not have disabilities. Staff discreetly supports people only as needed and requested. People with disabilities take advantage of naturally occurring supports. They use transportation systems that are available and used by all citizens. People expect to "go out" to access the services and supports they need.

What it isn't: People "visit" the community in groups organized for people with disabilities. They participate in community activities that are determined by others to be fun or appropriate without meaningful input from individuals with disabilities.

Everything is "special" to meet their needs. Transportation is provided by "the system" and only offered to those with disabilities. In some cases, all of the services and necessities are chosen by others with little or no input from the individual and brought into the residence so that people are never required to leave their home.

5. Develop relationships with people with and without disabilities and with whom they have a wide range of interests

What it is: People develop interdependent friendships and relationships with people who do not have disabilities as well as those who have disabilities. They have friends and caring relationships other than support staff and family members. People feel loved and appreciated for who they are.

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What it isn't: People should not have to seek permission or stay within "rules" to talk with or call a friend. When people with developmental disabilities live in segregated settings they generally have no opportunity to develop relationships with people who do not have disabilities or who are not paid staff.

6. Make choices about providers and staff

What it is: People with developmental disabilities have the right to choose and hire their provider agency and staff. They have input into the hiring and managing of their staff. They receive assistance in dealing with staff problems and training on managing staff. Staff members understand that they work for the individuals and that the home belongs to the individual. Staff members allow personal space and privacy and respect the desires of the individual.

What it isn't: Staff members are assigned to people based on availability and scheduling. If there is a disagreement or complaint from the individual regarding the staff person, the individual must accept responsibility and change or an agency may refuse to provide further support. Staff feels that they are in charge of the people they serve, and they determine activities, make decisions and decide how support will be provided.

7. Feel that they are reasonably safe

What it is: People feel safe and are able to enjoy being out and about in their community without fear and with reasonable expectations that they will not be abused or mistreated while in the community. If they experience an uncomfortable situation or some type of abuse, they know how and to whom to report to and they feel confident that their concerns will be considered valid and will be addressed. People are empowered through education, training and support to safely navigate their community, to recognize, understand and prevent abuse and to engage in healthy reciprocal relationships.

What it isn't: People rely on paid staff or family members to observe abuse or neglect and report incidents because their input is not valid. People with disabilities have not been taught to say "stop" or "no" when strangers, family or trusted staff treat them inappropriately.

CONCLUSION

Congress and the United States Supreme Court have established a clear legal mandate that CMS and states must design and deliver federally funded services in a manner that does not unduly isolate or segregate individuals with developmental disabilities. Extensive empirical reports and scientific research further support this direction and provide ample evidence of the benefits of community living in settings that provide opportunities for self-direction and participation in all aspects of community life.


New approaches of living arrangements are emerging across the nation to support individuals with developmental disabilities for which Home and Community Based Waiver funds are being sought. While some of these living arrangements offer innovative options for supporting the inclusion and integration of individuals with developmental disabilities into our communities,

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there are models of living arrangements that challenge the fundamental values and goals set forth in the DD Act, as well as requirements of the Americans with Disabilities Act, the U.S. Supreme Court *Olmstead* decision, and the core standards for community living articulated for the Home and Community Based Waiver.

Advocates have worked for over 40 years to shift the bias of federal and state funding from institutional settings to the community. It is imperative that these gains not be reversed. NACDD, AUCD and NDRN urge CMS to adopt strong requirements that prevent the use of Developmental Disabilities Home and Community Based Waiver funds for living arrangements that are not consistent with these values and goals and to protect the continued use of these funds for true community living.

Respectfully submitted,



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