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June 1, 2011

Ms. Cindy Mann
Director, Center for Medicaid & State Operations
Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services
200 Independence Ave., SW, Room 445-G
Hubert H. Humphrey Building
Washington, D.C. 20201

Submitted electronically: http://www.regulations.gov

Attn: File Code, CMS-2296-P, Medicaid Program: Home and Community-Based Services (HCBS) Waivers, Federal Register, April 15, 2011.

Dear Ms. Mann,

VOR is a national advocacy organization representing individuals with intellectual and developmental disabilities (ID/DD) and their families. We very much appreciate this opportunity to comment on this proposed rule which will impact our family members for decades into the future.

VOR strongly supports a continuum of quality care options to meet the wide range of needs, from family home, own home, or other community-based alternatives to Medicaid-licensed facility-based care (e.g., ICFs/MR). VOR is the **only** national advocacy organization representing the interests of individuals who choose and require facility-based supports. The provision of a range of service options responsive to all levels of need is required by federal law, including Medicaid, the Americans with Disabilities Act (including its federal regulations) and the U.S. Supreme Court (*Olmstead*).

VOR's comments, which follow, relate to the three substantive sections of the proposed rule:

(I) Target Groups;
(II) HCBS settings (defining "community"); and
(III) Person-Centered Planning.

I. Target Groups

This section of the proposed rule is designed to "remove a barrier for States that wish to design a waiver that meets the needs of more than one target population" by enabling States to combine target groups ("Aged or disabled, or both; Mentally retarded or developmentally disabled, or both; and Mentally ill") into a single waiver.

Consistent with our comments in response to CMS-2296-ANPRM (submitted August 17, 2009), we remain concerned that there are not adequate assurances in place to avoid placing individuals with incompatible disabilities “under one roof.” The proposed rule does not expressly provide for beneficiary choice and, while acknowledging safety concerns, does little to address safety:

> The comments provided on this provision were largely positive, advising CMS to consider carefully quality elements and protections needed to ensure that all target groups are protected sufficiently in such a structure. Through this proposed rule, we include expectations that each individual within the waiver, regardless of target group, has equal access to the services necessary to meet their unique needs. (p. 21312)

In our opinion, “equal access” to necessary services does not adequately address safety. The proposed rule’s “State Assurances” section also does not address quality and safety concerns and requirements; it is largely technical. Likewise, the “Duration, extension, and amendment of a waiver” section is procedural. Rather than preventative measures, the proposed rule’s only reference to beneficiary protection relates to penalties, an “after the fact” reaction to predictable tragedies.

As we noted in our August 2009 comments, there is ample justification for concern. We shared examples of “co-mingling” tragedies in North Carolina, Florida, Washington, D.C., Wisconsin, Massachusetts, Maryland, and Ohio (*see,* Attachment A). More recent examples include the following:

> “A judge this week will consider whether a 59-year-old man accused of strangling an 85-year-old dementia patient [over spilled juice] at a group home on Milwaukee's northwest side is competent to stand trial. What will not be under consideration, however, is the wisdom of housing elderly, frail dementia patients with younger and potentially violent residents - a practice that in Wisconsin is not against the law.” (*Milwaukee Journal Sentinel*, February 13, 2011).
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> VOR members in Oregon report that placing individuals with developmental disabilities alongside people with mental illness in group homes is a dangerous and emerging trend in Oregon, where there are no long any ICFs/MR.
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> “Even when the [Florida Agency for Health Care Administration] found enough violations to close facilities, which frequently mix elderly and mentally ill residents, regulators rarely act under state law. . . When Darryl McGee moved into the Munne Center in 2007, he was supposed to get psychiatric care and medication . . . . Instead, caretakers gave him a bed in the home’s locked Alzheimer’s ward with people twice his age and never arranged for care, state reports show. During the next four months, the burly man with a criminal past became a 214-pound nightmare, beating the elderly residents at least four times before he brutally raped a 71-year-old woman in her bedroom. The 33-year-old man, diagnosed with bipolar disorder and schizophrenia, was like thousands who flooded into ALFs [Assisted Living Facilities] during the past decade — a younger generation that would now be housed with older people with dementia . . . For four months in 2007, McGee terrorized the home’s elderly residents during drunken rages, beating elderly men and women. . . State agents concluded the home was an ‘unsafe environment to live’ and eventually slapped it with a $19,000 fine — later reducing it to

> $2,000. Then in 2010, it happened again: AHCA found the home had placed another resident with severe mental illness in the Alzheimer's ward, leading to an assault on an elderly resident . . . McGee, who had been arrested 11 times before the rape on charges ranging from simple assault and vandalism to cocaine possession, was found incompetent to stand trial. The incidents at the Munne Center underscore a wider problem in Florida ALFs that care for people with mental illnesses: Homes are allowed to stay open despite histories of violence that jeopardize the safety of residents." (*Miami Herald*, May 8, 2011).

While we agree that there are situations in which a combined waiver can assist in keeping families together (*e.g.,* Planned Residential Communities; *see related comment herein at p. 6*), the rule must ***expressly require beneficiary choice***. For example, the proposed rule cites the example of elderly parents providing care to their family member with disabilities. A combined waiver that provides HCBS supports for both parent and child seems efficient, but could be cruel if imposed upon families long beyond what is reasonable. In 2004, Clare Ansberry of the *Wall Street Journal* wrote about these concerns, which have only increased as baby boomers have aged:

> Today, about 76% of the 4.3 million people with developmental disabilities live at home, a quarter of them cared for by a family member who is at least 60 years old. . . .
>
> That dedication enriched lives and created a symbiosis between parent and child that strengthened over time, but that time likewise makes untenable. Now in their 60s, 70s and 80s, some with weak hearts or limbs and others coming off bypass surgeries or chemotherapy, these aging parents are realizing that carrying a disabled adult child down steps is dangerous. Tending to breathing tubes throughout the night is exhausting. These parents' lifelong concern with their child's mortality is coupled with a growing awareness of their own . . .
>
> Yet for the most part, these 670,000 older parents -- those 60 years plus -- continue because they are afraid not to. Relinquishing care of a fragile child prone to violent seizures or terror of the unfamiliar is difficult even as it becomes physically harder to provide. ("Parents Devoted To a Disabled Child Confront Old Age," *Wall Street Journal*, January 7, 2004).

Any regulation that allows states to combine target populations in a single waiver must expressly require a right of beneficiary choice and include a process whereby CMS can reasonably ensure beneficiary safety before tragedies happen. Without these improvements, VOR remains concerned that fiscal efficiency and provider convenience will put some HCBS waiver beneficiaries at risk.

II. HCBS settings (defining "community")

a. Background

CMS proposes several qualities necessary for a setting to be truly "community":

> . . . HCBS settings: 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 ground 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. In addition, we proposed that the settings 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." (pp. 21312 – 21313).

b. Does the input of families matter?

CMS seems especially persuaded by comments in response to the ANPRM (2009) and additional comments received more recently outside the context of a formal comment opportunity. VOR is aware of one such communication from representatives[1] of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) programs ("Meaningful Inclusion," December 6, 2010).

VOR is left wondering, "***Where are the voices of individuals and their families***?"

Although the DD Act program communication acknowledges that "individuals with developmental disabilities have the right to choose where to live," (*Id*. p. 4) and indeed, the DD Act expressly requires that individuals with developmental disabilities and their families be the "primary decisionmakers" with regard to services, supports and policies, including residential choice (*see*, DD Act, 42 U.S.C. 15001(c)(3)(2000)), the balance of "Meaningful Inclusion" reveals plainly the DD Act program bias: These programs support choice as long as it is not an ICF/MR or other "institutional" program.

The bias of the DD Act programs is not a new revelation to VOR and its members. The apparent weight that their bias has had on CMS, however, is of grave concern. Families of fragile facility residents have long appreciated and been comforted by the CMS-enforced quality assurance and standards that ensure their family members receive compassionate and highly specialized supports.

This is not to say that ICF/MR and other "institutional" settings should benefit from HCBS funding. Although we feel strongly that licensed facilities have many of the same hallmarks of a true "community," we appreciate the program differences between facility programs and HCBS settings, and recognize that different funding streams are appropriate. However, we strongly disagree with the notion that ***proximity*** to a facility should have any bearing on HCBS waiver qualification.

For example, in Missouri ***families and legal guardians, on behalf of their family members,*** strongly supported the development of HCBS waiver homes on the vast campus of a state-operated ICF/MR. According to the Supreme Court, choice is paramount:

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[1] Michael J. Brogioli, Executive Director National Association of DD Councils; Curt Decker, Executive Director, National Disability Rights Network (P&A); and George S. Jesien, Ph.D., Executive Director, the Association of University Centers on Disabilities.

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. . . Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it. (*Olmstead* at 2187) (*see also*, Attachment B, "*The Olmstead Decision and Individual Choice"*).

Yet, in Missouri, it was the perspective the DD Act programs and others that apparently swayed CMS to reject the State's proposal. ***Families were ignored***.

Due to aggressive deinstitutionalization over the past several decades, the people now benefiting from licensed-facility based care (e.g., ICFs/MR) by vast majority have severe or profound intellectual disabilities, have multiple physical disabilities, and are medically fragile and/or experience dangerous behavioral challenges that pose a danger to themselves or others. These individuals rely significantly on their families and legal guardians to provide decision-making support. For most ICFs/MR residents, facility-based care is not imposed, but a choice that is required by Medicaid law, Olmstead, and the DD Act.

c. Characteristics of Community

VOR stands by its ANPRM comments (August 2009) (*see* Attachment B, Defining "Home and Community-Based Services").

As we stated then, VOR urges the consideration of a definition of "community" that is consistent with typical usage, rather than what that term has come to mean in the disability arena and reliant on irrelevant tangibles such as residence size, distancing requirements, location, and type.

Webster's defines Community to include, "a unified body of individuals" and "a body of persons or nations having a common history or common social, economic, and political interests."

In this typical sense, "community" relates to rights, happiness, convenience, comfort, safety and access. It is not a term that can be fully and adequately defined using solely tangible criteria. "Community" means a non-isolated environment where one is safe from harm and has consistent access to a social network of peers, friends, supports (informal and formal, such as healthcare, work programs, and transportation).

Around the country, facility campuses are used by their neighbors for summer camps, soccer practices, school gatherings, fairs, and more. Some facilities also extend their professional health care services and amenities (such as therapeutic swimming pools) to nonresidents who would not otherwise have access to these services. Some campuses also offer teaching opportunities to area college students (e.g., Northern Virginia Training Center, Tachachale Developmental Center (Florida), Hogan Regional Center/REACH program (Massachusetts), Hazelwood ICF/MR (Kentucky), and Central Wisconsin Center). One of the most compelling examples of a truly integrated campus is in Glenwood, Iowa:

> "'The Glenwood Community School District, serving school children from pre-school through high school, shares the same campus as Glenwood Resource Center [a state

> operated ICF/MR]. There is also a workforce development center, a domestic violence shelter, offices for the Department of Natural Resources Conservation and Forestry, a variety of University training and research programs, and much more on the Glenwood campus,' shares Finken. 'If that's not integrated, I don't know what is.'" [*Glenwood Opinion Tribune*, April 30, 2008].

Yet, if any of these states were to propose expanding upon already integrated campuses by building HCBS homes or providing for other non residential HCBS supports, the proposed regulation would require that CMS reject these proposals. Such arbitrary decisions are cruel in the face of significant needs as evidenced by long waiting lists. Even respite arrangements which are now HCBS funded could be at risk. One VOR advocate wrote:

> I know a man who takes care of his severely brain-damaged son at home - who has found that the only really reliable and appropriate overnight respite care for his son is at a nearby nursing home. I just talked to a parent who found a group home specifically designed for people like her son with Prader Willi syndrome. Her son has been unsuccessfully served in several apartment settings and he always ends up back in a psychiatric facility because the care is not appropriate for him. The proposed rule, as written, would not consider these arrangements integrated, so HCBS funds would be denied (VOR advocate from Michigan, May 9, 2011).

Likewise, typical notions of what constitutes "community living" does not always equate to optimal choice, control, and community integration. The following examples, and many more like them, are what worry parents and family members and suggest a lack of correspondence between the promise of community living and the reality:

> "[C]ommunity activities at the group home are 'spontaneous' and left to 'staff discretion' (what happened to client choice?). The result is that everything (quality of diet, exercise programs, clothing, holiday celebrations, health care and community participation) depends on the spirit, initiative and endurance of the house manager. In too many instances house managers receive little support and constant obstacles from their superiors. As a parent observer, it often seems to be an impossible job. When there are no planned community activities on a weekend, evening or holiday, residents sit, often isolated, alone in their rooms, sometimes for 2-3 days in a row. How is this more desirable than sitting in a group with staff at the facility?" ["Outcomes that matter: A parents' perspective," ("Mary Speaks" section) Mental Retardation, Volume 43, Number 3, pp. 214–220 (June 2005)].
>
> "Dennis was a beautiful sweet person, and needed to be supervised 24/7. He had lived in group homes his whole life. His provider received funding for 'independent living' and moved Dennis into this program. Dennis was killed 1 month later, while crossing a 7 lane intersection by himself." (Anonymous, August 2009).
>
> "A long-time participant in our Sunday School for Exceptional Adults stopped coming regularly when he was placed in a community residence. With the one caregiver on duty per shift, if one of the three residents doesn't want to, or is unable to come, to Sunday School, or any outing, all must stay home." (VOR advocate, August 2009).

VOR has also received extensive communication from families whose loved ones have benefited from planned residential communities, like L'Arch USA, Bishop Grady Villas (FL), and Noah's Ark (FL). Many of these programs receive HCBS waiver funding as assisted living facilities. There is very real concern among families whose loved ones benefit from these settings, due to a CMS definition of "community" which continues to adhere to tangible and arbitrary criteria. These planned residential communities are much like retirement communities where amenities such as bowling alleys, theatre, community centers, restaurants and shopping are readily available, along with necessary health care, support staff, vocational training and other services. As one parent stated,

> "The success of these creative initiatives and our own Bishop Grady Villas is that they were conceived as interactive arrangements with the broader community – through hospitality businesses, gift shops, coffee shops, amusement parks, craft studios, organic farming, baking industries, the arts, for example, as well as developing apprenticeships and employment opportunities with local businesses, even setting up housing for their more independent residents.
>
> "Our plea to you and the CMS is to support Waiver funding that is person-centered, choice-based, and consumer-driven where money follows the person, not some extremist agenda of forced integration." (Lila Klausman, President, Parents Planning Programs, Inc., comments to President Obama, May 11, 2011).

Simply, "community" is a concept, not a place. CMS efforts to define community using tangible criteria – which have no bearing on true integration and community - will have the effect of reducing or eliminating options and choice by displacing people from places that will lose HCBS waiver funding and also from keeping people from necessary services by discouraging innovative partnerships.

III. Person-Centered Planning

The proposed rule strongly promotes "person-centered planning," noting that a "complete and inclusive person-centered planning process" underpins "all aspects of a successful HCBS program."

To the extent that a person-centered process includes the legally-required input of families and court-appointed legal guardians, we agree. As noted above, individuals and their families are the "primary decisionmakers" regarding services, supports and policies (DD Act, 42 U.S.C. 15001(c)(3)(2000)).

The proposed rule with regard to "person-centered planning," however, ignores completely the value and right of family/guardian input.

Individuals who are eligible for HCBS services are also, by law, eligible for ICF/MR services. Many of these individuals, due to profound intellectual disabilities, benefit from the support of legal guardians and close relatives (often one and the same). In 1993, the Supreme Court upheld the common sense conclusion that residential placement decisions are enhanced by including family members who have intimate and unmatched knowledge of their family member's need and desires (Heller v. Doe (1993)).

Yet, the CMS in its proposed rule completely overlooks the important role of families and guardians. Indeed, in the background section for "Person-Centered Planning," "individual" is mentioned at least 25 times. **There are no references – not even one – to family or legal guardian.**

To deny or ignore the severity of cognitive disabilities for some individuals does these citizens a grave disservice. Individuals with profound intellectual disabilities have the cognitive ability of infants or small children. These individuals need the protection of legally-appointed guardianship arrangements, preferably by a family member or another individual who is familiar with an individual's unique needs. The proposed rule ignores the value of family/guardian decision-making, and in doing so, promotes the misguided, potentially dangerous, notion that all individuals with intellectual disabilities, no matter the severity, must "self determine" care, medical, and other decisions.

IV. Conclusion

We appreciate the opportunity to submit these comments. The proposed rule would benefit from amendments which indicate a right to beneficiary choice, the primary decision making authority for individuals, families, and where appointed, legal guardians, much stronger, preventative, safety requirements, and a definition of "community" that considers the "intangibles" that define "community" for all Americans.

Sincerely

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ATTACHMENT A

VOR Comments: Same Waiver for Different Disability-Types and Defining Community
Originally submitted on August 17, 2009 in response to File Code CMS-2296-ANPRM (June 22, 2009)

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Removing the Regulatory Barrier to Designing 1915(c) Waivers Based on Needs Rather than Diagnosis or Condition.

State funding and service flexibility must not come at the expense of the individuals being served. The proposal to allow single waivers to serve different disability types based on similar service needs raises several questions and related concerns, including:

1. **Will the regulation to allow single waivers for people with different disabilities expressly prohibit serving different disability types "under the same roof?"**

   VOR is concerned that the primary objectives of equal access to service, regardless of disability-type, and fiscal efficiency will lead to providers mixing populations with potentially disastrous consequences.

   The ANPRM is not clear on whether a regulation to allow for single waivers will include a prohibition against serving different disability-types in the same service setting. Failure to protect against comingling incompatible disability populations presents serious and foreseeable risks to beneficiaries being served. Fiscal constraints could well tempt a provider to mix populations and accept residents that are not well suited or the existing client mix or the homes' accessibility.

   This is already happening in some states. For example, Wisconsin allows residential providers to serve multiple populations. In one case, a provider is licensed for 19 people, male or female, for all populations: elderly, alcohol/drug dependent, developmentally disabled, and emotionally disabled/mentally ill. Problems mixing populations are well-documented:

   - In **North Carolina**, Ruth, an 84-year-old resident of a small, quiet elder care home was brutally stabbed by another resident, age 25, with severe mental illness. He was placed in an elder care home despite his well-documented history of violence.

   - In **Florida**, M.C., a 48-year-old woman with mental retardation, schizophrenia, and heart problems, was raped by another resident in her group home, a 16-year-old who had a history of sexual assaults but had always been declared incompetent to stand trial. Following the rape, M.C. was taken to the hospital after suffering "episodes of vomiting." Shortly after her release from the hospital, she died in her group home.

- In **Washington, D.C.,** Michael, a 52-year-old resident of a group home for the mentally ill died after being attacked by another resident with a fire extinguisher in a fight over cookies.

- In **Wisconsin**, a community-based "geared toward serving an elderly population" with a minimum age of 55 years old, admitted residents who "were not compatible with the facility clients served," including a suicidal 16 year old and a 19 year old who had a history of violence, according to state Quality Assurance Reports. In one case, a younger resident's behavior got "increasingly worse and is to the point where it is a great disturbance to the other residents," including an instance where she was "yelling, screaming, upsetting the other residents [because her bus was late] . . .Her temper escalated until she started throwing coffee and water at the other residents, screaming vulgarities at [staff] and residents, and threatening to hurt herself, the residents and [staff] and run away."

- In **Massachusetts**, Claudia, age 53, has mental retardation and is legally blind, non-verbal, and has had medical complications and behavioral issues. Citing financial savings, her group home was closed and she was transferred to another home with a swimming pool and three other residents, all of whom used wheelchairs, despite her mobility, blindness and behavioral concerns.

- In **Florida**, a healthy baby was born to a severely mentally disabled mother, who was referred to in documents as "J.D.S." and was tragically raped in an Orlando, Florida, group home where she lived.

- In **Florida**, the mother of G.C. complained that her boy, who could not communicate, ''appeared to be over-medicated when she took him home for Thanksgiving,'' and that she was concerned about a bite mark on his face. The Jackson Rape Treatment Center personnel ''diagnosed anal penetration,'' possibly by G.C.'s roommate.

The tragedies described occurred in small group homes. Some large ICFs/MR ("institutions") have accepted court-ordered individuals whose disabilities render them incompetent to stand trial or, because of their disability, cannot be held criminally responsible. Due to the bias against ICFs/MR, in some cases, new admissions are limited to these "forensic" placements. Predictably, when residents accused of violent offenses live with each other, and also with the very vulnerable traditional residents, tragedies can and ***do*** occur:

- In **Maryland**, a resident, whose placement at an ICF/MR was court-ordered and who was known to make racist comments lived in the same cottage with an individual who became enraged by the comments, and beat him severely.

- In **Ohio**, an ICF/MR resident (Edward, age 20) with a history severe aggressive behavior was placed as a roommate to an autistic individual (Joseph, age 50) who also had a history of violent outbursts. Edward killed Joseph by wrapping a belt around his neck and strangling him.

As these examples illustrate, foreseeable injuries, abuses and deaths are inevitable. Even more "benign" scenarios are predictable: An elderly resident with dementia is placed with a profoundly developmentally disabled roommate; an individual with physical disabilities is placed with someone with mild mental illness; an individual with severe autism is placed with someone with profound developmental disabilities who is unable to defend himself or recognize danger. The individual pairings in these scenarios may well have very similar ***functional*** needs, but what about their interests, their peers, their health care needs, their "community."

To achieve legitimate person-centered planning and to adhere to *Olmstead* directives, need and disability diagnosis are both fundamental factors to be considered. A focus on need alone could well lead to totally incompatible people being served at the same residence. If CMS removes regulatory barriers to combining target populations in one waiver, CMS must expressly prohibit using these waivers to serve different populations ***in the same location***.

2. **Will the new regulation protect against a scenario in which a state opts to use its single population waiver funding to serve the most people it can, at the expense of the most needy, most costly of the population?**

   Presumably, the purpose of removing targeting requirements to allow for one waiver for different disability-types is to enhance access to services and make the provision of services more equitable across disability lines.

   VOR fears that the blending of target audiences could have the opposite impact, and leave the "voiceless" minority without access to adequate services. Consider a waiver that includes aged beneficiaries and individuals with mental retardation. The institutionally-eligible elderly population far outnumbers ICF/MR-eligible individuals with mental retardation. The elderly are far better positioned to lobby for and receive necessary supports.

   A state looking to demonstrate that it has served more people with a targeted approach could well be tempted to serve the most at the expense of a few, while also serving incompatible populations in the same service setting, as discussed above.

3. **Will the new regulation protect against a triage approach, in which the most needy get served first at the expense of the less needy?**

   Even if a state does right by its most needy, the CMS objectives of fiscal efficiency and equitable access will be thwarted.

ATTACHMENT B

VOR Comments: The Olmstead Decision and Individual Choice (emphasis added).
Originally submitted on August 17, 2009 in response to File Code CMS-2296-ANPRM (June 22, 2009)

The ANPRM states that –

> "Many States have used the home and community-based services waiver as a component of their *Olmstead* compliance efforts and we are interested in receiving comments about how this change may affect these efforts. We are intending to propose this change in an effort to remove barriers to person-centered, needs-based service delivery methods." (ANPRM, p. 24953).

Although *Olmstead* is frequently cited as requiring deinstitutionalization, the Supreme Court actually called for the provision of person-centered supports based upon professionally assessed needs and individual choice, while also considering available state resources (*see*, 119 S. Ct. 2176, 2181 (1999), *holding*). With regard to whether "institutional" care is appropriate for anyone, the court was very, very clear:

> "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. . . Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it. (*Olmstead* at 2187).

Olmstead, and its requirement for individualized supports, was at issue in a recent Illinois case. *Ligas v. Maram* was originally filed by nine individuals who claimed that Illinois had not provided them with the community-based supports that they had requested and were eligible for. These few plaintiffs sought remedy for their individual claims, and sought to speak for a class of 6,000 developmentally disabled individuals. The Court recognized that a class of 6,000 could not have homogenous needs. Thus, the remedy sought by the nine plaintiffs – community integration – failed the *Olmstead* test which requires consideration of individual need and choice:

> A common theme among the [more than 2,500] objectors was the concern that many developmentally disabled individuals, who are within the class definition, would be adversely affected by provisions of the Proposed Consent Decree even though the individual neither met the *Olmstead* criteria nor desired placement in a community-based setting. [*Ligas*, Case No. 05 C 4331 (July 7, 2009)].

The Supreme Court, and more recently the *Ligas* court, recognized what we family advocates have always known: neither institutions nor community settings alone can meet **all** the needs of **all** people with developmental disabilities **all** of the time.

In any final rule, CMS is cautioned not to overstate – as so many advocates and even state officials have – what *Olmstead* actually requires. *Olmstead* stands for choice, not the elimination of choice through downsizing and closure of facility-based care.

ATTACHMENT C

VOR Comments: Defining "Home and Community-Based Services" (emphasis in original).
Originally submitted on August 17, 2009 in response to File Code CMS-2296-ANPRM (June 22, 2009)

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ICFs/MR as inclusive communities

ICFs/MR residents and their families overwhelmingly view their ICF/MR homes as a community in every sense of that word. They resent the frequent implications that ***all*** ICF/MR residents are isolated and do not receive person-centered care and that ***all*** residents of small homes automatically benefit from "inclusion." Consider these perspectives:

> "'The Glenwood Community School District, serving school children from pre-school through high school, shares the same campus as Glenwood Resource Center [a state operated ICF/MR]. There is also a workforce development center, a domestic violence shelter, offices for the Department of Natural Resources Conservation and Forestry, a variety of University training and research programs, and much more on the Glenwood campus,' shares Finken. 'If that's not integrated, I don't know what is.'" [*Glenwood Opinion Tribune*, April 30, 2008].
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> "Like Florida seniors and others who embrace planned communities, residents of Florida's residential campuses for people with profound mental retardation - Sunland (Marianna) and Tachachale (Gainesville) - have safe and comfortable accommodations, with ample opportunity to socialize with peers and neighbors. They receive compassionate life-sustaining support from specialists and direct care staffers, some of whom have worked with residents for decades . . . families embrace a "one size does not fit all" motto, pointing to choice and need as paramount. For some people with mental retardation, a small neighborhood setting, with minimal supports is the better option. For others, onsite specialized services such as dental, medical, therapy, work programs, religious services and recreation, are needed." [*St. Petersburg Times*, "Check with families first before evicting residents," February 5, 2007].
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> The Turtle Creek Youth Program at the South Dakota Developmental Center (SDDC) serves 40 behaviorally challenged, school-aged children who are between 10 and 21 years of age at the time of admission to the center. All youth attend school on the campus of SDDC in a building designed for classroom teaching. The Redfield Public School provides the educational program, including the employment of special education teachers. The curriculum is comprised of the core educational courses as well as several group curricula that are facilitated by Youth Counselors who are staff of the Turtle Creek Program. The group courses can be taken for elective high school credit. Once an individual completes the requirements for graduation, he or she participates in the graduation ceremony at the public school. (*The Voice*, Winter 2008).

> "By 2009, I am happy to report that the detractors of the original project, from all areas, have been proven wrong. The Underwood and Lee Clinic [located at the Hazelwood ICF/MR in Louisville, Kentucky] now serves over 820 patients [nonresidents] from 44 counties in the state. By the summer of 2010, we expect to be serving over 1000 patients. Despite the fact that some of our patients drive 4 to 5 hours each way to access care at our clinic, we have a 97.2% patient satisfaction rate . . . The Underwood and Lee Clinic's research program established, early on, that it was not performing redundant care. Frequently, the clinic would see patients who had been unable to access adequate care for over 10 years. Some patients arrived at the clinic with more than a dozen painful dental abscesses in their mouths – a testament to their long-standing inability to find care at any other medical or dental facility in the state. . . . The teaching program at the clinic has positively affected the entire community of dental providers in the state. Since inception, nearly 500 dental students and dental hygiene students have rotated through the clinic, learning how to care for our special patient population." [Matthew Holder, MD, MBA, CEO, Underwood and Lee Clinic, March 24, 2009 (letter)].
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> In Massachusetts, one-third (11,000) of all Department of Developmental Services clients use the six state developmental centers (ICFs/MR) for health and dental care, services which are not available in the community from private practice physicians. Closing these centers will put an undue hardship on the clients, their families, and the staff who care for them. (David Hart, President, MA Coalition of Families and Advocates, August 14, 2009).
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> Around the country, ICF/MR campuses are used by their neighbors for summer camps, soccer practices, school gatherings, fairs, and more. Some ICFs/MR also extend their professional health care services and amenities (such as therapeutic swimming pools) to nonresidents who would not otherwise have access to these services. Some campuses also offer teaching opportunities to area college students (*e.g.,* Northern Virginia Training Center, Tachachale Developmental Center (Florida), Hogan Regional Center/REACH program (Massachusetts), Hazelwood ICF/MR (Kentucky), Central Wisconsin Center and others.

Isolated Communities

Likewise, typical notions of what constitutes "community living" do not always equate to "optimal choice, control, and community integration." (ANPRM, p. 29455). The following examples, and many more like them, are what worry parents and family members and suggest a lack of correspondence between the promise of community living and the reality:

> "[C]ommunity activities at the group home are 'spontaneous' and left to 'staff discretion' (what happened to client choice?). The result is that everything (quality of diet, exercise programs, clothing, holiday celebrations, health care and community participation) depends on the spirit, initiative and endurance of the house manager. In too many instances house managers receive little support and constant obstacles from their superiors. As a parent observer, it often seems to be an impossible job. When

> there are no planned community activities on a weekend, evening or holiday, residents sit, often isolated, alone in their rooms, sometimes for 2-3 days in a row. How is this more desirable than sitting in a group with staff at the facility?" ["Outcomes that matter: A parents' perspective," ("Mary Speaks" section) *Mental Retardation,* Volume 43, Number 3, pp. 214–220 (June 2005)].
>
> "Dennis was a beautiful sweet person, and needed to be supervised 24/7. He had lived in group homes his whole life. His provider received funding for 'independent living' and moved Dennis into this program. Dennis was killed 1 month later, while crossing a 7 lane intersection by himself." (Anonymous, August 2009).
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> "A long-time participant in our Sunday School for Exceptional Adults stopped coming regularly when he was placed in a community residence. With the one caregiver on duty per shift, if one of the three residents doesn't want to, or is unable to come, to Sunday School, or any outing, all must stay home." (VOR advocate, August 2009).

Furthermore, a regrettable reality is the fact that many "neighbors" are not welcoming of these homes and their residents. NIMBY ("*Not In My Backyard*"*)* often prevails and is an isolating factor that cannot be ignored.