VOR
Speaking out for people with intellectual & developmental disabilities

Toll free
877-399-4867

www.vor.net

Executive Director
Julie M. Huso
836 S. Arlington Heights Rd, #351
Elk Grove Village, IL 60007
605-370-4652 Voice
605-271-0445 Fax
Jhuso@vor.net

Dir. of Govt. Relations & Advocacy
Tamie Hopp
PO Box 1208
Rapid City, SD 57709
605-399-1624 Voice
605-399-1631 Fax
Thopp@vor.net

Washington, D.C.
Larry Innis
529 Bay Dale Court
Arnold, MD 21012-2312
410-757-1867 Voice/Fax
LarryInnis@aol.com

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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-2249-P2, Department of Health and Human Services, Centers for Medicare & Medicaid Services, Medicaid Program: State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Setting Requirements for Community First Choice, 77 FR 26362 (May 3, 2012)

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 smaller housing 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 detailed comments in response to proposed rule CMS-2249-P2 (May 2, 2012) will be limited to the proposed amendments to "Medicaid regulations to provide home and community-based setting requirements of the Affordable Care Act for the Community First Choice State plan option." In response to proposed rules "Option to Disregard Comparability" and related sections, we resubmit our June 2009 comment with regard to concerns associated with combining disability-types based on needs in a single waiver. The present proposal (77 FR 26367) continues to provide states the option to disregard comparability without, it seems, adequate federal safeguards to ensure a state's convenience will not outweigh beneficiary safety. (*See*, **Attachment A**, "VOR Comments: Same Waiver for Different Disability-Types," August 17, 2009 in response to CMS-2296-ANPRM).

Our detailed comment follows.

A. Defining and Describing Medicaid Home and Community-Based Services (HCBS)

1. Federal law and individual choice

VOR is heartened to find this language in the preamble, which recognizes an individual's right to choose ICF/MR care:

> "We note that this proposal in no way preempts broad Medicaid requirements, such as an individual's right to obtain services from any willing and qualified provider of a service.
>
> "We further note that States are not prohibited from funding institutional care under Medicaid. The exclusion of these settings from HCBS waivers and from the State plan HCBS benefit does not limit the availability of institutional and facility-based care for those individuals who require long-term services and supports, and who freely choose to receive services in those settings." (77 FR 26380)

This language is consistent which the U.S. Supreme Court's *Olmstead* decision which held choice a necessary prerequisite and cautioned against forced deinstitutionalization:

> "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"; and Developmental Disabilities Assistance and Bill of Rights Act (DD Act), 42 U.S.C. 15001(c)(3)(2000) (individuals with developmental disabilities and their families be the "primary decisionmakers" with regard to services, supports and policies, including residential choice)).

For reasons discussed below, amendments are needed to ensure adherence to the choice principles espoused in the preamble of the proposed rule and required by federal law. Olmstead supported a range of options. The Court expressly recognized "institutional care" as one legitimate option. The proposed rule must take care not to further limit choice by reducing funding for innovative programs which CMS – not the Supreme Court or even Medicaid law – deem "institutional."

2. Principles of "community" still biased, risking support for quality residential programs that, in fact, "promote independence and integration"

In the spirit of choice, and in furtherance of federal law, VOR strongly urges CMS to reconsider its position with regard to the provision of home and community-based services on ICFs/MR campuses and planned residential communities for people with developmental disabilities.

We do not agree that proposals by states to provide HCBS on ICFs/MR campuses or planned residential communities "clearly exceed reasonable standards for HCBS," (77 FR 26378) especially when the provision of such services meets needs, is sought by individuals and their families, and would ensure good outcomes for those served.

VOR and our members are especially troubled by the "authority with strings attached" given to Secretary of the U.S. Department of Health and Human Services (HHS). Specifically, the proposed rule provides the Secretary ultimate discretion, however requires her to begin with a "rebuttable presumption" that a setting is not a home and community-based setting and requires that she "engage in heightened scrutiny for any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or disability-specific housing complex." (77 FR 26401)

This presumption, coupled with the requirement of heightened scrutiny for certain proposals, makes it very difficult for the Secretary to find in favor of innovative partnerships that provide immediate and consistent access to necessary health care, dental care and therapies, recreation opportunities, peer relationships, and legitimate "integration" (versus isolation), including HCBS homes located on vast

ICF/MR campuses and planned residential communities.[1] The proposed rule cites this very concern and claims to have made the effort to define **"**quality principles essential in determining whether a setting is community-based," while also avoiding the risk of excluding from federal financing programs that may not be deemed "community-enough" in principle, but "promote independence and integration." (77 FR 26378). Yet, singling out HCBS homes in close proximity to an ICF/MR and planned residential communities as presumably "non-community" and subject to heightened scrutiny runs afoul of the proposed rule's own cautionary statement and makes overcoming this presumption nearly impossible for individual and family advocates who support and choose such options. Volunteer advocates simply cannot match the access HHS' DD Act programs have to the HHS Secretary, who is not an elected official. This is paramount concern given the DD Act programs opposition to the ICF/MR and planned residential community options, without regard to individual and family support.[2]

VOR has 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 Home and Community-Based Services (HCBS) waiver funding as assisted living facilities. There is legitimate concern among families whose loved ones benefit from these settings, due to a proposed 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).

While the present proposal seems to embrace certain principles of community, such as individual choice and person-centered planning, there remains a bias that characterizes any sort of program-wide structure and safety measures as too "institutional," without any regard to the input of individuals, their families and their legal guardians. Given that "institution" for the purpose of Medicaid funding is already narrowly defined in the Social Security Act's Title 19 (Medicaid), is it proper for CMS to be proposing an expansion of current Medicaid law and redefining what is "institutional"?

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[1] Due to aggressive deinstitutionalization over the past several decades, people who have been displaced from ICFs/MR often suffer from isolation and a lack of access to quality health care supports. The ability of these "community-based" individuals to access ICF/MR supports and amenities – aided by proximity – may be the difference between a successful community placement and tragedy in the form of isolation or worse.

[2] 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. Lobbying by the federal DD Act programs reportedly influenced CMS' decision to reject the State's proposal. In contrast, Florida family advocates successfully prevailed upon the Florida legislature (elected officials) to allow planned residential communities for people with developmental disabilities, overturning a 1,000 foot rule which had prohibited the provision of HCBS services within close proximity of each other (F.S. 419.001 (2010)).

VOR urges CMS to delete from the final rule any language restricting the Secretary's discretion with regard to "locations that have qualities of an institutional setting." 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" (see Attachment C), we appreciate the program differences between facility programs and HCBS settings, and recognize that different funding streams are appropriate. However, we believe strongly that ***proximity*** to a facility, services, peers with disability, and amenities, at best *enhances* community qualities and should *not* disqualify such settings from HCBS funding. To cut off HCBS funding based on arbitrary criteria threatens the viability of current and future homes that provide high quality, inclusive care.

3. Person-Centered Planning and the role of families and guardians

The proposed rule strongly promotes person-centered planning," stating:

> "Underpinning all aspects of successful HCBS is the importance of a complete and inclusive person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences. The person-centered approach is a process, directed by the individual with long-term support needs, and may also include a representative whom the individual has freely chosen." 77 FR 26371

The involvement of an individual's "representative," where necessary is further clarified as follows:

> "When an individual is not capable of giving consent, or requires assistance in making decisions regarding his or her care, the individual may be assisted or represented by another person. Section 1915(i)(2) of the Act defines the term 'individual's representative' by listing certain examples, but also provides that '* * * any other individual who is authorized to represent the individual' may be included. We believe that 'authorized' refers to State rules concerning guardians, legal representatives, power of attorney, or persons of other status recognized under State law or under the policies of the State Medicaid program."

Although this is an improvement over past proposals, concerns remain.

Federal law recognizes that individuals and their families are the "primary decisionmakers" regarding services, supports and policies (DD Act, 42 U.S.C. 15001(c)(3)(2000); see also, Heller v. Doe (1993); and Olmstead v. L.C. (1999)). The proposed rule seems consistent with federal law and expressly recognizes that some individuals will not be capable, due to profound cognitive limitations of giving consent and will require assistance in making decisions regard their care and support. 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 seems to recognize this and, by implication, disavows the prevalent though misguided and dangerous notion that all individuals with intellectual disabilities, no matter the severity, must "self determine" care, medical, and other decisions.

VOR, however, is concerned by the phrase "state rules," which could be interpreted as guidance other than a state's guardianship laws. **VOR strongly urges that the proposed rule be amended to replace "state rules" with "state guardianship law" to guard against any state-level initiatives (e.g., executive orders) to erode guardianship authority.**

4. Modifications to “community” criteria must include safety and welfare

In addition to several criteria which the proposed rule attributes to the “qualities” of “community” (77 FR 26378), the proposed rule seeks additional comment on whether two criteria which are not presently included in the proposed regulation should be added.

Specifically, input is sought on “whether for provider-owned or controlled residential setting, any modification of the conditions must be supported by specific assessed needs and documented in the person centered service plan,” to discourage providers from unnecessarily abridging individual “independence or freedom” for provider convenience, while also recognizing that “individuals with cognitive disabilities and other impairments may require modification of the aforementioned conditions [criteria for community] for their safety and welfare.” The proposed rule indicates that the addition of this provision is being contemplated to “establish that service planning is the process in which these decisions are made, rather than ad hoc on a daily basis.” (77 FR 26379)

VOR strongly supports the inclusion of these criteria. “While the proposed text establishes the requirement that any modification to the conditions are supported by a specific assessed need and documented in the person-centered service plan” (77 FR 26379) we support the inclusion of language to explicitly set forth the requirement that need-based safety measures must be express in an individual’s care plan and not be viewed as overly restrictive. This is a refreshing step away from a “dignity of risk” mindset, where safety measures in the community (often ad hoc and inconsistent) are viewed as restrictive rather than helpful and humane. With more and more people with profound developmental disabilities being displaced from facility settings in favor of smaller, unlicensed supports, a care plan that considers honestly and individual’s functional, cognitive, health and quality of life needs is critical for individual well-being.

B. Conclusion

We appreciate the opportunity to submit these comments and for your thoughtful consideration.

Sincerely

Ann Knighton
VOR Co-President
706-993-6329

Sybil Finken
VOR Co-President, finkensrc@aol.com

Sam Golden, Chair, VOR Government Affairs Committee
770-288-3459 phone
sgolden@uchicago.edu

Tamie Hopp, Director, VOR Government Relations and Advocacy
605-399-1624 direct
605-399-1631 fax
thopp@vor.net

ATTACHMENT A

Option to Disregard Comparability:
Same Waiver for Different Disability-Types
Submitted by VOR, August 17, 2009, in response to CMS-2296-ANPRM

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

The Olmstead Decision and Individual Choice

Citing Medicaid law, CMS-2249-P2 correctly states:

> "We note that this proposal in no way preempts broad Medicaid requirements, such as an individual's right to obtain services from any willing and qualified provider of a service.
>
> "We further note that States are not prohibited from funding institutional care under Medicaid. The exclusion of these settings from HCBS waivers and from the State plan HCBS benefit does not limit the availability of institutional and facility-based care for those individuals who require long-term services and supports, and who freely choose to receive services in those settings." (77 FR 26380)

This language is also consistent which the U.S. Supreme Court's *Olmstead* decision. *Olmstead v. L.C.*, 119 S. Ct. 2176 (1999). 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*, *Olmstead* at 2181, *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 and choice, has been relied upon and cited in subsequent federal cases: *See*, *U.S v. Virginia* (May 9, 2012) granting intervention (""Petitioners have a significant, protectable interest in receiving appropriate care of their choice and protecting their rights under the ADA," citing *Olmstead* ("Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it"); *Ligas v. Maram* (Illinois, July 7, 2009) ("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"); *U.S. v. Arkansas* (June 2011) ("There is no requirement that community based treatment be imposed on persons who do not desire it," citing Olmstead at 2188 and 28 C.F.R. § 35.130(e)(1)); and *Arc of Virginia v. Kaine* (December 17, 2009) (". . . a key principle in the Olmstead decision: personal choice).

The Supreme Court and subsequent federal rulings recognize 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. Choice matters.

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

ICFs/MR as inclusive communities and isolated 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).
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> “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.