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**Attn: File Code, CMS—2404—NC; RIN 0938-ZB33; Centers for Medicare and Medicaid Services, Medicaid Program; Request for Information (RFI): Federal government Interventions To Ensure the Provision of Timely and Quality Home and Community Based Services**

*Response from to a CMS Request for Information to inform the agency's future decision-making with regard to: accelerating access to Home and Community Based Services (HCBS); ensuring the quality of HCBS including beneficiary health and safety; safeguards to ensure safety and reduce fraud, waste and abuse in the HCBS program; and strengthening the HCBS home care workforce.*

[VOR](http://www.vor.net)<sup>1</sup> is a national non-profit advocacy organization representing individuals with intellectual and developmental disabilities (I/DD) and their families. We support a continuum of quality care options to meet the diverse needs of people with I/DD. This includes residential options in the family home, the individual's own home, licensed group homes, disability farms, intentional communities, and Medicaid-licensed facility-based care/congregate care facilities (*i.e.*, ICF's/IID). We also support the full array of employment options – competitive employment, sheltered workshops and facility-based day programs.

VOR's members represent individuals over a broad spectrum of need, including those with severe and profound Intellectual Disabilities and complex medical and/or behavioral challenges. We are the only national organization that represents the interests of individuals who choose and require facility-based residential supports. Federal law, including Medicaid, the Americans with Disabilities Act and the 1999 U.S. Supreme Court *Olmstead* decision require the provision of a range of service options responsive to all levels of need.

We support a developmental disability service system driven by the choices of individuals with I/DD with the aid, when necessary, of their parents and guardian. A person centered planning process guided by these primary decision-makers ensures the formation of individualized plans of service which identify and address the unique needs and desires of the vulnerable persons served through the selection of appropriate supports from a full continuum of care. Such a system honors *Olmstead*, which makes individual choice paramount and emphasizes the need for a wide range of services.

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<sup>1</sup> [www.vor.net](http://www.vor.net)

Before answering the questions put forth in the CMS Request for Information, VOR has concerns about CMS policies, including the 2014 HCBS Settings rule. Changes to the rule should be considered to remove barriers to a cost-effective system of care for people at all levels of disability:

**1. HCBS policies as now written are being used to enforce an incorrect and harmful misunderstanding of the Americans with Disabilities Act as interpreted by the 1999 Supreme Court [Olmstead](#)<sup>2</sup> decision:**

Many, if not most, federal agencies and federally-funded advocacy groups serving people with I/DD, incorrectly interpret Olmstead and the ADA to require deinstitutionalization and HCBS settings, regardless of individual need and choice. The 2014 HCBS rule encourages this interpretation by disqualifying certain settings from receiving HCBS funding unless they have undergone “heightened scrutiny”, a process that ultimately leaves the determination of whether a setting is “community enough” up to CMS, rather than the individual with I/DD, and when necessary, their parents and guardian.

The bias against any kind of congregate residential setting where more than 3 or 4 people with disabilities are served together is clear from the restrictions placed on even the contemplation of future planned communities and congregate settings. The same holds true for facility-based occupational settings and the increasing restrictions placed on them. Such settings offer features to ensure the safety and health of residents while providing a community in which individuals with I/DD can reach their full potential and maximize their independence. This bias is particularly destructive as it directly attacks the right of individuals with I/DD to freedom of assembly, a fundamental American right.

The ADA and Olmstead assure opportunities for people with I/DD, but they do not dictate one-size-fits-all solutions. Individual choice among the widest possible range of quality living and occupational options is what is necessary to realize the goals of the ADA and Olmstead. VOR supports the full reading of Olmstead, making individual choice of services paramount and ensuring a full range of living and work options in order to meet the spectrum of needs of this very diverse population.

See also from VOR, [The Olmstead Decision Has Been Misinterpreted](#)<sup>3</sup> and [Celebrating The 17<sup>th</sup> Anniversary of the Olmstead Decision: Opportunities and Choices](#)<sup>4</sup>

**2. The HCBS rule makes presumptions about the abilities of people with IDD to live independently, work, and participate in the community that do not apply to many individuals with I/DD, especially those with the most complex, severe, or profound disabilities. These can lead to inappropriate services and residential options being imposed on individuals and their families that are unwanted and ignore individual needs for special accommodations to ensure the health and safety of the person with I/DD.**

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<sup>2</sup> <https://supreme.justia.com/cases/federal/us/527/581/case.html>

<sup>3</sup> <http://vor.net/images/stories/2016-2017/TheOlmsteadDecisionHasBeenMisinterpretedUpdated.pdf>

<sup>4</sup> [http://vor.net/images/stories/2016-2017/The\\_17th\\_Anniversary\\_of\\_Olmstead.pdf](http://vor.net/images/stories/2016-2017/The_17th_Anniversary_of_Olmstead.pdf)

In the Request for Information, CMS cites the ADA, as saying that “the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals”. CMS needs to clarify that this goal is not a requirement imposed on individuals with disabilities. In fact there are numerous protections in the ADA, Olmstead, and Medicaid law that assure appropriate services based on individual need and preference. The integration mandate from the ADA regulations states that “a public entity must administer services, programs, and activities in the most integrated, least restrictive setting appropriate to the needs of qualified individuals with disabilities.” [28 C.F.R. § 35.130(d)] [emphasis added]

Making presumptions about an individual’s abilities and setting unrealistic goals which do not recognize their disabilities is dangerous, dehumanizing policy. If we as a society are to honor the full reading of Olmstead, we must first be willing to honor the individual with I/DD by recognizing and accepting who they are – abilities, disabilities and all. Doing so is the first step in providing a quality disability service system that protects health and safety.

**3. CMS should lift its prohibition on using HCBS funding to pay for services that are available in Medicaid-licensed facilities, such as Intermediate Care Facilities (ICF’s/IID), or in proximity to these facilities. These facilities have many resources that are often desperately needed by people living in community settings: specialized medical, behavioral, and dental services, recreation, social activities, and respite care, to name a few. To arbitrarily cut off HCBS funding to individuals living in community settings who wish to avail themselves of these resources, squanders resources that could give valuable support to individuals living in the community.**

We believe strongly that **proximity** to a facility with its services, peers with disabilities, and amenities, at best enhances community qualities and should not disqualify individuals living in HCBS settings from voluntarily utilizing the resources available in ICF’s/IID. Often, the nature of the services provided by the ICF/IID are specifically tailored to the needs of individuals with I/DD, and the individuals performing those services are more familiar with the needs and sensibilities of this unique population.

Therefore, CMS regulations that prohibit the provision of HCBS residential and work settings on or adjacent to ICF/IID campuses are harmful in terms of limiting opportunities and marginalizing vulnerable people. Segregating people with lower levels of disability from people with higher levels of disability has the effect of stigmatizing and marginalizing the individuals who choose and rely upon ICF’s/IID care. CMS disparages ICF/IID settings by labeling them “isolating” or “segregating” from the larger community. The residents and their families view their homes as communities designed to address their needs and provide them with a combination of opportunities and services not available anywhere else. CMS should embrace ICF’s/IID as an important part of a continuum of care.

**4. CMS needs to assess the true cost of implementing the 2014 HCBS rule. Complying with the rule is proving costly for the states, resulting in states cutting services and displacing vulnerable individuals from their homes. The closing of congregate settings to comply with the new rule and so-called *Olmstead* enforcement activities have further harmed disability service systems in states by increasing waits lists and forcing people into inappropriate settings they did not choose, settings that are often unprepared to ensure their health and safety. The whole system of care is being undermined in the name of inclusion, integration and *Olmstead* enforcement, contrary to the plain language and intent of *Olmstead* as a vehicle for choice.**

The expectation of savings from moving individuals from congregate care (ICF's/IID) to smaller licensed group homes, or from small group homes to unlicensed community settings, is unlikely to be realized unless there is also a reduction in the quality or quantity of services needed by individuals with I/DD. These expectations are often based on faulty cost comparisons, which fail to account for the full array of public benefits accessed by individuals

receiving HCBS care. Unsustainable costs have resulted in even longer waiting lists and tragic outcomes. [See VOR's "[Widespread Abuse, Neglect and Death](#)"<sup>5</sup> in Small Settings Serving People with Intellectual Disabilities", 2016 ]

Often, the increase in HCBS comes at the expense of ICF/IID residents who lose their homes due to federally funded litigation. Happily situated ICF residents pressured or forced to leave ICFs through litigation receive HCBS placements ahead of individuals who have been wait-listed for years. The policy of shutting down successful residential placements is even more absurd when you consider many of the wait-listed individuals may in fact prefer and can benefit from HCBS settings. These individuals are forced to wait longer now that former ICF/IID residents move to the front of the line.

[The Case for Inclusion](#)<sup>6</sup>, annual reports produced by UCP on how well state Medicaid programs serve people with I/DD, shows that with the increase in the use of Home and Community Based Services over the last decade, waiting lists for residential and other services have increased from 74,000 in 2005 to 350,000 in 2016, an increase of nearly 400%. At the very least, it can be said that increased use of HCBS has not resulted in fewer people waiting for services.

**5. CMS policies as well as federally-funded advocacy organizations portray congregate settings as isolating and segregating, a "last resort" on the continuum of care and services. Whether these settings are technically "institutions" as defined by Medicaid law, the individuals and families who rely on this level and type of care do not view them as "institutions" in the disparaging way the term is usually used.**

Facilities such as ICF's/IID, and other licensed and regulated group settings, and innovative intentional communities for people with I/DD provide lifesaving care in an environment that enhances the individual's access to family, friends, and the greater community, just as small, unlicensed supported living situations can isolate and segregate individuals in settings that jeopardize the individual's safety, health, and peace of mind. (For example, please see the 2012 report from Disability Rights Washington and Columbia Legal Services, "[Too Little, Too Late: A Call to End Tolerance of Abuse and Neglect](#)"<sup>7</sup>, an investigation of abuse and neglect in the Medicaid-funded Supported Living Program. Also, the 7th Circuit Court of Appeals found that, "Isolation in a home can just as 'severely diminish the everyday life activities' of people with disabilities. (*Olmstead*, 527 U.S. at 601) "In fact, although family relations might be enhanced at home if people are around, isolation in a home may often be worse than confinement to an institution on every other measure of 'life activities' that *Olmstead* recognized." (Steimel and Maertz, et al., v. Wernert)

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<sup>5</sup> [http://vor.net/images/stories/2016-2017/AbuseandNeglect\\_2016.pdf](http://vor.net/images/stories/2016-2017/AbuseandNeglect_2016.pdf)

<sup>6</sup> <http://cfi.ucp.org/about/>

<sup>7</sup> [http://www.disabilityrightswa.org/sites/default/files/uploads/Too%20Little%20Too%20Late\\_Redacted.pdf](http://www.disabilityrightswa.org/sites/default/files/uploads/Too%20Little%20Too%20Late_Redacted.pdf)

See also VOR's "[Giving a Voice to Families and Guardians](#)<sup>8</sup> - A Survey of Families and Guardians of Individuals with Intellectual and Developmental Disabilities In Various Residential Settings", April 2015.

As Sister Rosemary Connelly, the director of [Misericordia](#)<sup>9</sup>, so wisely puts it: "Big can be bad. Small can be bad. Both can be good." Misericordia is a "community of care" in Chicago that serves over 600 people with mild to profound I/DD through a spectrum of residential options and services.

### **VOR Responses to Questions Posed by the CMS Request for Information**

#### **What are the additional reforms that CMS can take to accelerate the progress of access to HCBS and achieve an appropriate balance of HCBS and institutional services in the Medicaid long-term services and supports (LTSS) system to meet the needs and preferences of beneficiaries?**

The cost of care for individuals must necessarily vary and be responsive to varying needs. The right balance of HCBS vs. ICF or other congregate care will vary by state and should be driven by the individuals accessing services. Currently, CMS and states are pushing all parties to non-congregate HCBS settings regardless of need and choice. This can only result in people being placed in inappropriate settings.

Too often the quest for "rebalancing" the service system – to shift "institutional" and other congregate care funding to non-congregate HCBS supports – neglects true person-centered options that avoid inappropriate and potentially dangerous settings and are in accordance with the needs and preferences of the individual.

Better oversight of HCBS services is also needed. Oftentimes, homes are staffed at inappropriate levels with little to no supervision of staff. Additionally, individuals requiring 24 hour nursing are being placed in HCBS settings where a nurse is not available at all or for insufficient hours. Delegating nursing responsibilities to non-professional staff members cannot replace the years of training and knowledge of a licensed nurse. This has also led to cases of abuse, where non-licensed staff members have overmedicated patients to keep them sedated and easier to manage. The penalties for nurses mistreating patients can result in loss of license and career. The penalties for staff members overmedicating patients may not even result in dismissal. See, "[In Treating Disabled, Potent Drugs and Few Rules](#)"<sup>10</sup>

Sadly, there are numerous reports of abuse, neglect and death that have occurred when individuals are placed in inappropriate settings in deference to a one size fits all mindset. The tragic deaths in Georgia are but one example. See, "[Girls Death among 500 in One Year In Community Care](#)".<sup>11</sup>

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<sup>8</sup> [http://vor.net/images/stories/pdf/VOR\\_Survey\\_Giving\\_a\\_Voice\\_to\\_Families\\_and\\_Guardians\\_April\\_2015.pdf](http://vor.net/images/stories/pdf/VOR_Survey_Giving_a_Voice_to_Families_and_Guardians_April_2015.pdf)

<sup>9</sup> [www.misericordia.com](http://www.misericordia.com)

<sup>10</sup> <http://www.nytimes.com/2011/12/23/nyregion/potent-pills-few-rules-in-states-treatment-of-the-disabled.html>

<sup>11</sup> <http://chronicle.augusta.com/news-metro-health/2016-10-18/girls-death-among-500-one-year-community-care>

We would also like to draw your attention to the recent series in the Chicago Tribune on abuse and neglect in the Illinois HCBS service system entitled [“Suffering in Secret”](#)<sup>12</sup>, as well as the full 2011-2012 [“Abused and Used”](#) series on the abuse and neglect of the intellectually disabled in New York State from the New York Times.<sup>13</sup>

Until there is an accelerated effort to provide better oversight for HCBS and to improve the quality of services overall, it would be irresponsible to accelerate access to HCBS where individuals are placed at risk of significant harm.

### **What actions can CMS take, independently or in partnership with states and stakeholders, to ensure quality of HCBS including beneficiary health and safety?**

The first step is to honor *Olmstead* choice by allowing for individuals with I/DD, and when necessary, their parents and guardians to drive decisions about residential and employment care. Just as individuals without disabilities are in the best position to choose where and how they want to live, so are people with disabilities. Honoring *Olmstead* choice will ensure that individuals can choose the residential and occupational setting most appropriate for their individual needs and desires, whether that is in an HCBS setting or a congregate care setting, thus furthering health and safety.

The second step, naturally, is to preserve and rebuild the congregate care system nationally as part of the continuum of services offered by HHS and CMS. As people with I/DD age, even those who can thrive in an HCBS waiver setting today may need the higher level of care that an ICF can offer when medical complications increase and their current residence is unable to provide the necessary services. The need for such care for aging individuals with I/DD currently served in HCBS settings was addressed in a June 27, 2016 article in the Chicago Tribune, [“Misericordia Opens Home to Care For Elderly with Disabilities”](#)<sup>14</sup> concerning Misericordia’s addition of four new homes to provide for sixty aging Down syndrome residents whose needs had increased. *“Advocates and service providers say it’s one of a variety of care options that will be needed with increasing urgency as people with disabilities live longer than ever before. In 1983, the average life expectancy for a person with Down syndrome was 25. Today, it’s 65 to 70, fueled largely by the mastery of a surgical procedure that corrects a heart defect present in 1 out of 2 people with Down syndrome”, said Sara Weir, president of the National Down Syndrome Society, a nonprofit organization based in New York. “It’s a new frontier,” Weir said. “We just don’t have enough resources in this area.”*

As a result of the shortage of appropriate accommodations for the aging I/DD population, many individuals are displaced from their HCBS settings and moved into nursing homes, hospitals, hospices, or other inappropriate facilities that lack the resources and trained staff required to deal with their increasingly complex needs. In many states there are too few remaining ICF/IID homes to meet the needs of this population. Staff in nursing homes and other default settings are rarely trained in the field of developmental disabilities and the programs and activities are not centered around the needs of people with intellectual disabilities. Many nursing homes are ill-prepared to handle the range of unique

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<sup>12</sup> <http://www.chicagotribune.com/news/watchdog/grouphomes/ct-group-home-investigations-cila-met-20161117-htmlstory.html>

<sup>13</sup> <http://www.nytimes.com/interactive/nyregion/abused-and-used-series-page.html>

<sup>14</sup> <http://www.chicagotribune.com/news/ct-disabled-memory-loss-home-met-20160621-story.html>

conditions and behaviors exhibited by individuals with I/DD. As a result, these individuals miss out on the opportunity to live in a community that suits their needs and is designed to offer them a fuller life. CMS has not yet addressed this issue adequately, and would do well to follow the example set by Misericordia.

Reinforcing the role of ICF's/IID in the structure of our system will benefit everyone, not only the individuals who require that level of care. The presence of a person who is inappropriately placed into an HCBS waiver facility destabilizes the environment. They may require more time and energy from the staff, depriving other residents of time and services they need. Their behaviors may be disruptive, and the fact that their needs are not being met may actually elevate these behaviors. The other members of the home may begin to exhibit behaviors as well, in order to receive the attention they require. In addition, the presence of inappropriate clients in waiver settings increases the workload and stress levels of the already overworked and admittedly underpaid staff, causing greater turnover. The provider agency is resultantly stressed, trying to full time staff or getting people to cover in a "difficult" home. In short, no one benefits from placing individuals who would benefit from ICF/IDD care into a group home environment. The One-Size-Fits-All treatment of individuals with I/DD hurts everyone.

We have seen evidence that providers understand that they are incapable of meeting the needs of some members of the I/DD community. In Illinois, when the state decided to close the Jacksonville Developmental Center, an auction was held for providers to choose which residents they wanted to take in: *"In April 2012, as Illinois moved to close several state institutions and relocate adults with disabilities into the community, representatives from group home businesses gathered inside the Jacksonville Developmental Center for a hastily organized auction. Adults with mild disabilities were the most coveted. A state official read aloud medical histories of residents with intellectual and developmental disabilities, prompting group home officials to raise their hands for desired picks. Group home operators knew that then-Gov. Pat Quinn wanted to empty Jacksonville quickly — before any serious union or community opposition could be mounted — but some were taken aback by what they saw as a dehumanizing approach. "We were appalled by the auction," said Art Dykstra, executive director of Trinity Services, the state's largest group home provider. (See, "[A Troubled Transition](#)" The Chicago Tribune, Dec. 30, 2016)*<sup>15</sup>

A similar story occurred in Connecticut, when the state offered private providers the opportunity to take over some of the group homes that had been run by the CT Department of Developmental Services. Many of the homes were unsuitable to the providers, as the needs of the residents were too high, the costs prohibitive. The providers would have lost money given the current wages. *"It becomes difficult to bid on something you know doesn't cover your costs," said Barry Simon, president and CEO of Hartford-based Oak Hill, the largest nonprofit social services provider in Connecticut. (The Connecticut Mirror, December 7, 2016)*<sup>16</sup>

The third step that CMS can take to improve the system of care is to work within HHS to promote the reform of DD Act Programs such as DD Councils, Protection and Advocacy

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<sup>15</sup> <http://www.chicagotribune.com/news/watchdog/grouphomes/ct-group-home-investigations-cila-met-20161229-htmlstory.html>

<sup>16</sup> <http://ctmirror.org/2016/12/07/dds-group-home-privatization-effort-slows-down-for-now>

Agencies and University Centers on Disabilities, which use federal tax dollars to attack and undermine facility-based care. These agencies are overwhelmingly stacked with individuals who support a one size fits all solution to disability care. The token individuals placed on DD Councils who support Olmstead choice and the full continuum of care oftentimes find themselves marginalized, even bullied by others with opposing views. This imbalance leads to undue pressure placed on state disability service systems forcing system change before HCBS supports are in place and moving highly vulnerable individuals into inappropriate settings.

**What program integrity safeguards should states have in place to ensure beneficiary safety and reduce fraud, waste, and abuse in HCBS?**

Stronger regulations must also be placed on providers to report instances of abuse, neglect and major unusual incidences (MUI's). Currently, the level of incident reporting in HCBS facilities falls far short of the standards required of ICF's/IID. Furthermore, data on abuse, neglect and deaths in provider homes should be available to the public including information on the circumstances of the instances, barring the names of the individuals involved as dictated by HIPPA regulations.

Similarly, the level of inspection of HCBS facilities is insufficient to ensure the health and safety of residents, again falling short of the levels required of ICF's/IID. While acknowledging that there are differences in the requirements of these different types of facilities, we believe that the gap is too wide, and that it has become far too common for incidents of abuse to go unnoticed or unreported, sometimes for years, in HCBS settings. We recommend that a Medicaid inspection system, similar to that which is used for ICF/IID homes, should take place in HCBS settings.

People involved in the person centered planning process should have clear and accurate information about the full array of residential and occupational services and settings that must be made available to the individual and information on "medically necessary" services that are funded by Medicaid. This includes information on both HCBS settings and congregate care settings, such as ICF's/IID, as well as employment options including competitive integrated employment, supported employment, sheltered workshops and facility-based day programs.

The best advocate for a person who is unable to advocate for himself or herself is a parent, guardian, or family member who knows the individual well and cares about them. This is reinforced by the DD Act policy that states,

*"...individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families"* – (The Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 USC 15001(c)(3)(2000)



Protecting the rights of individuals and their families in determining needed services and where the individual is to live assures accountability of the system of care to the individuals it serves.

**What are specific steps CMS could take to strengthen the HCBS home care workforce, including establishing requirements, standards or procedures to ensure rates paid to home care providers are sufficient to attract enough providers to meet service needs of beneficiaries and that wages supported by those rates are sufficient to attract enough qualified home care workers?**

HCBS workers take on a great deal of responsibility - the health and safety of very vulnerable individuals - with low pay and often no on-site supervision or form of back up should their colleagues not report to work or not perform their duties appropriately.

The burden placed on home care workers is increased when they are placed in understaffed homes void of skilled nursing care when such care is needed. Additionally, the nature of their work is physically and emotionally draining and can be dangerous when one considers behavioral challenges of some residents and injuries which may occur when transferring individuals with poor mobility and when attending to the personal care of the residents.

Low wages and high staff turnover among direct care professionals limits the ability of providers to recruit and train new staff and reduces the intimate familiarity between staff and the residents with I/DD they serve who have unusual needs, symptoms, and limited ability to communicate. As continuity of care declines, so does the health and safety of the residents.

Ensuring appropriate supports for the staff in terms of sufficient back-up, supervision and nursing will help ease their burden and have the added benefit of increasing the health and safety of residents. Please bear in mind the stress that workers live with, and the fact that a caring and conscientious staff member will suffer throughout their life if a person should suffer under their care due only to the fact that the worker had not been trained sufficiently or if an incident were to occur because the facility was understaffed. Workers need back up and support and should have protections for health and safety and individual rights.

Additionally, efforts should be made to bring direct care professionals together for mutual support, especially those who work in small community homes where they lack the support and supervision that is available in larger licensed settings.

A sustainable workforce should include requirements for training and a path for people to advance. Long-term caregiving is a skill. Caregivers should be encouraged to view this vocation as a career, not just a job. Experience, job-related training, education, and certification in specific treatment modalities are important qualities that providers should cultivate and reward. Without such support, the high levels of turnover and staff discontent will continue to plague the HCBS system.

## **Conclusions**

In conclusion, a successful developmental disabilities service system must be driven by *Olmstead* choice. *Olmstead* recognized that to support people with lifelong intellectual and developmental disabilities, we must take into account a widely diverse population who need

a full range of options to address their needs. Doing so will enable individuals with I/DD to engage in the larger community in a manner which protects health and safety and their rights.

CMS is charged with attending to the needs of every individual, regardless of their degree of ability or disability. We do not see evidence that depriving one segment of the population to serve another (robbing Peter to pay Paul) is a reasonable or ethical policy position for CMS and other federal agencies serving people with I/DD, nor do we see evidence that following such policies results in serving more individuals or improving care overall. System biases that marginalize or target segments of the I/DD population result in depriving vulnerable people of the services and settings they need for their survival.