VOR
A Voice Of Reason
Speaking Out for People with
Intellectual & Developmental Disabilities

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Secretary Alex Azar
U.S. Department of HHS
200 Independence Ave., S.W.
Washington, D.C. 20201

Administrator Seema Verma
Centers for Medicare & Medicaid Services
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Director Jean Moody-Williams
Center for Clinical Standards and Quality
7500 Security Blvd.
Baltimore, Maryland 21244

Director Robert Redfield, MD
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, Georgia 30329

Re: VOR Response to June 23, 2020 ACLU/SEIU Petition

Dear Secretary Azar, Administrator Verma, Director Moody-Williams, and Director Redfield,

No sentient being, nor any parent, guardian or advocate with compassion and concern for the elderly or the disabled could possibly fault the stated desire of the ACLU and its partnership organizations to protect the health and safety of vulnerable individuals residing in congregate care throughout the United States. But, the means by which they proceed and the proposals they seek do not address these concerns, but in fact, place individuals at risk. As such, those of us who are parents, guardians, and advocates for loved ones with intellectual and developmental disabilities (I/DD); the medically fragile; behaviorally impaired; or those who have other needs requiring intensive levels of care must separate or bifurcate ourselves from the ACLU petition.

By putting forth their petition as an overarching indictment of the HHS delivery system in this time of the novel coronavirus pandemic, the ACLU has cast its net too wide, and falsely claimed to represent the interests of everyone receiving federally funded services who is classified as elderly or who has intellectual and developmental disabilities. In doing so, it apparently assumes that all such persons look and feel alike and need the same supports and level of care. We, who represent our family members and loved ones with I/DD, must disagree with that assumption that ignores the diversity and the very rights of this vulnerable population. We, therefore, must soundly reject the petitioner's claim to represent us.

We do so separate from their petition, particularly in consideration of the petitioner's contention that HHS must "reduce the census of congregate care,"[1] which, for the I/DD population, is represented by Intermediate Care Facilities for Individuals with Intellectual Disability (ICFs/IID) and Home and Community Based Service (HCBS) group homes. The ACLU and other advocacy groups who sing this refrain must know by now, that there is no statutory, judicial or regulatory mandate for such reduction. Additionally, the petitioner argues the reduction must begin now, at a time when quarantine and separation are so universally sought. Below, you will find the

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[1] ACLU and partner organizations' petition, p. 20.

arguments of those who truly represent individuals living in congregate care settings for individuals with I/DD. We show that the petitioners' push to reduce the census of congregate care facilities has in its genesis an ideological mission, not a needs-based assessment reflective of the current crisis.

Olmstead and Its Application to ACLU's Petition

The petitioners refer to the anniversary of the U.S. Supreme Court *Olmstead* decision and attempt to argue that census reduction is a principle mandated by it. The petitioners wrongly assert that HHS has a legal obligation to support independent living wherever and whenever possible. This position ignores the crucial qualifier "unjustified" in the *Olmstead* Court's holding that "unjustified isolation…is properly regarded as discrimination based on disability." And, it disregards the Court's subsequent finding in the opinion, "But we recognize, as well, the States' need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States' obligation to administer services with an even hand."[2]

To effectuate this understanding of the varying needs of the population of Americans with mental disabilities, as memorialized in the Americans with Disabilities Act, the holding[3] in *Olmstead* established a three-part test for when states are required to provide community-based placement: "when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive environment is not opposed by the affected individual, and the placement can be reasonably accommodated taking into account the resources available to the State and the needs of others with mental disabilities." Dicta in the decision affirm that *Olmstead* relates not to a class of people, but rather that its holding must be administered on a case-by-case basis.[4] Therefore, the Court's holding – the three-part test – allows for this individualized treatment that respects the diversity of the population of individuals with mental disabilities and their right to choose where and with whom to live.

The petitioners present two arguments for their attack on congregate care, each of which is not grounded in law, data, or fact. By misstating the Supreme Court decision above, the petitioners attempt to argue that the failure to meet the alleged mandated transfer from congregate care has somehow placed residents at risk, and the situation must be remedied immediately. First, we must consider that the individual who remains in a congregate care setting has had the right to relocate to the community for 21 years pursuant to *Olmstead*; and, one can further argue that if

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[2] "Unjustified isolation, we hold, is properly regarded as discrimination based on disability. But we recognize, as well, the States 'need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States 'obligation to administer services with an even hand." *Olmstead v. L.C.* 527 U.S. 581, 597

[3] "For the reasons stated, we conclude that, under Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities when (1) the State's treatment professionals determine that such placement is appropriate, (2) the affected persons do not oppose such treatment, and (3) the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities." *Olmstead*, 607

[4] "As already observed (by the majority), the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk… 'Each disabled person is entitled to treatment in the most integrated setting possible for that person – recognizing on a case-by-case basis, that setting may be an institution.'" *Olmstead*, 605 (quoting VOR's *Amici Curiae* brief)

the individual's needs and desires so warranted the transition, it could have been accomplished by now. The residents still residing in congregate care do so, in large part, because one or more of the three requirements set out in the holding of *Olmstead* has not been met. In other words, the individuals are likely receiving services in the setting which most appropriately meets their needs and desires. Any move to a less restrictive environment solely in response to the current health crisis would, therefore, be made without consideration for basic human and civil rights.
The petitioner's remaining argument, health and safety, does not justify a reduction in the congregate care census either. The petitioners lack data or any evidence to show that all individuals living in a congregate care ICF/IID or HCBS setting would be made safe by transferring them to unspecified[5] locations merely because such destinations are deemed by others to be less restrictive. There is no nexus between the move to a family home, private residence, or some other less monitored community location and the provision of more protection from the social spread of the novel coronavirus or any future contagion. This is especially so amongst a population of citizens who by the nature of their disabilities require intensive supports provided by trained caregivers, including nurses, therapists, and direct support professionals.

Rather, the petitioners attempt to seize on this present crisis to secure through threats of litigation what the petitioners have been unable to achieve through the legislative or judicial process for nearly 40 years, dating back to the 1980's – the end of congregate care.[6] These efforts have been beaten back as Members of Congress and the courts have realized what we all know to be true – each person with mental disabilities has unique needs, hopes, dreams, and desires that manifest themselves in different choices. In the most American of spirit, these differences must be honored to protect health, safety, and rights.[7] Having failed to secure their objectives through the Congress and the courts, the petitioners now ask HHS to override these judgements and rights administratively. VOR submits that HHS has no such authority.

Standing

In addition to asking the question as to why and how the petitioners can prove the need to reduce the population of congregate care settings for legal or health reasons, we must also ask how the ACLU has standing to petition on behalf of this class. The petitioners and their aligned parties have spent the last several decades trying to close congregate care, particularly ICFs/IID, which provide safe and appropriate services offered to those who reside therein. It seems relatively clear, not only empirically, but in case law, that the petitioners and friends have an open and

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[5] "Unspecified" is aptly put, as where would they go? The petition would not only close all ICFs/IID, it would close all congregate HCBS settings. Beyond those major residential options for the I/DD population, there is no existing infrastructure of care options other than family homes.
[6] See, e.g., S. 873, the Community and Family Living Amendments of 1985, sponsored by Senator John Chafee in the 99th Congress, H.R. 2020, the Medicaid Community Attendant Care Services Act of 1997, sponsored by Rep. Newt Gingrich in the 105th Congress, and S. 910, the Disability Integration Act of 2017, sponsored by Senator Chuck Schumer, and its House counterpart, H.R. 2472 of the same name, sponsored by Rep. James Sensenbrenner, in the 115th Congress. None of these efforts to end congregate care nor any others were ever reported from any committee in the U.S. House of Representatives or the Senate.
[7] "Some individuals, whether mentally retarded or mentally ill, are not prepared at particular times – perhaps in the short tun, perhaps in the long run – for the risks and exposure of the less protective environment of community settings; for these person, institutional settings are needed and must remain available." *Olmstead,* 605.

ongoing conflict with the best interest of the I/DD population who choose and need to live in settings deemed "congregate." In other words, the petitioners, who seek to represent the class, have a conflict with the class itself. Therefore, on this point of standing, we must again reject the inclusion of our wards in this petition.

Guardianship

Those of us who are parents, family members, and guardians of individuals with I/DD residing in congregate care settings wish to assert that as the parties who speak for our loved ones and wards who lack the capacity to represent their own interests, we are the only entities given legal and moral voice to petition on their behalf. We most forcefully reject the attempt by the petitioners to seize this moment of crisis to move their narrow philosophical and political agenda forward. Federal law recognizes that individuals and their families are the primary decisionmakers regarding care decisions for the very reason that each American is in the best position to understand their own needs and desires and make appropriate choices based on that intimate knowledge.

> "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."[8]

Timing

That petitioners should seize on this moment when the nation is engulfed in crisis and tragedy to bring their threats and demands is particularly troubling. While no one can fault earnest parties' efforts to improve perceived failures in delivery systems, doing so by calling for the end of a primary form of care is not reasonable or responsible. ACLU and its partners demand for the census of congregate care to be reduced by 50 percent. But, where would they go? News reports[9] show that community disability service providers nationwide are struggling to remain solvent[10] and some state systems are on the brink of collapse.[11] Higher costs for pandemic-related expenses, lost revenue due to mandated shut-downs, and challenges finding staff to provide direct care given the increased risks of the contagion have left providers in dire circumstances. Surely, reducing providers' capacity by 50 percent, and thus cutting what revenue remains by half, in the midst of a crisis, would be the final nail in the coffin for providers. As such, petitioners seek to reduce, or actually, wholly remove the congregate care census without offering a viable alternative. Their policy proposal, therefore, must be read for what it is –

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[8] Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. 15001(c)(3)(2000).

[9] Diament, Michelle, "Disability service providers struggling to stay afloat amid COVID-19," Disability Scoop, May 4, 2020.

[10] Griffith, Corrine, "$22 million in disability funding cut by Governor; push to get it back," KSN News, Capitol Bureau, June 29, 2020

[11] Serres, Chris, "Minnesota disability service providers on the brink of collapse from COVID-19," Star Tribune, June 25, 2020.

not grounded in health and safety, but a purely political and ideological effort to implement the petitioners' long desired goal to de-institutionalize all individuals. And given the crisis that is before us, we see this ideological goal is to be had at all costs, regardless of the needs, choices, health and welfare, and the rights of the individuals with I/DD and the elderly who will be set adrift.

Conclusion

Lodging threats, attesting to speak for over a million people regarding their most personal interests, twisting Supreme Court holdings, and putting forth specious proposals is no way to protect the health and safety and the rights of the most vulnerable Americans. Concerns regarding the coronavirus response can be addressed without advocating for the end to a vital form of care. Lives are precious. Rights are precious. The vulnerabilities of the elderly and persons with I/DD can be addressed without violating the needs, desires and rights of Americans to access congregate care.

Thank you for your consideration,

Steve Wallace, Chair, VOR Legislative Committee
Caroline Lahrmann
Peter Kinzler