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July 22, 2018

Representative Jan Schakowsky, Member 115th Congress, Illinois District 9
Representative Greg Harper Member 115th Congress, Mississippi District 3
Representative Jim Langevin Member 115th Congress, Rhode Island District 2

Cc:

Lance Robertson, Administrator, Administration for Community Living
Mary Lazare, Principal Deputy Administrator, Administration for Community Living

Dear Representatives Schakowsky, Harper, and Langevin

We are writing in response to your July 13th letter to Administrator Lance Robertson of the Administration for Community Living (ACL) regarding comments made by Principal Deputy Administrator Mary Lazare at the recent ASA Conference. As there is no actual record of Ms. Lazare's comments, we can only conclude that some of her statements deviated from the past positions expressed by the ACL, which have held that everyone does better in the community. Since the conference, accusation have flown around the internet, accusing the ACL of trying to re-institutionalize everyone and reverse the course of the last 30 years. We are concerned by the level of anger and hyperbole to which this issue has been raised.

Our concerns are legitimate, as our organization has been mischaracterized in many of these online diatribes. VOR is a national non-profit organization, founded in 1983 by families of individuals with intellectual disabilities (IDD). Many of our members have loved ones with severe/profound intellectual disabilities or behavioral problems. Many are non-verbal, non-ambulatory, have PICA or self-injurious behaviors, are subject to frequent seizures, or are medically fragile. Some families have loved ones with far less extreme disabilities, but feel that their needs are not being properly addressed by our health care system. VOR advocates for a full continuum of care, respecting the rights of all to the level of care that is most appropriate to their needs. We support the goal of community integration for those who desire inclusion, but we also support the need for high quality care, comfort and stability offered by Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) for those who have higher levels of need. We advocate for choice, and for supporting a full range of options to meet the diverse needs and goals of this population. Unlike other advocacy groups, VOR does not rely on government grants for funding. We are self-supported by membership dues and donations.

In response to the uproar about Ms. Lazare's purported comments and your letter to the ACL, we are concerned that the 1999 Olmstead Decision continues to be misrepresented by advocates and by members of Congress. Olmstead is a well-balanced decision, supporting the ideal of providing access to the most integrated setting, but admitting that for some, the most integrated setting may be an "institution" (ICF/IID). The justices recognized the need to support ICFs/IID as part of a full continuum of services. The balance of Olmstead has been overlooked or ignored by many who quote only the passages about supporting what has become a mandate for integration-for-all.

Please read the accompanying document for further reference about the full meaning of Olmstead.¹

For years, our families have been told that their loved ones can receive the same level of support in HCBS waiver settings. We disagree. ICFs/IID are a vital component of our safety net. They are well regulated and must meet rigorous standards to qualify for certification from CMS. The current CMS State Operations Manual for ICFs/IID, Appendix J, contains 247 pages of requirements and protocols for treatment.ⁱⁱ There is no equivalent for HCBS waiver settings. While the level of service provided by ICFs/IID are not appropriate to most persons with IDD, they are vital to those with high levels of need.

In January, 2018 the HHS Office of the Inspector General, the ACL, and the HHS Office of Civil Rights issued a joint report addressing the under-reporting of critical incidents (abuse and neglect) of individuals with intellectual disabilities in HCBS waiver settings.ⁱⁱⁱ This followed a November 21, 2016 series “Suffering in Secret” by the Chicago Tribune^{iv} and a 2011-2012 series “Abused and Used” in the NY Times.^v Just two days ago, the Auditor General of the State of Illinois issued a report on the performance of DHS oversight on the state’s CILA (group home) program, which found systemic failures in Illinois’ licensing and oversight of taxpayer-funded group homes for adults with disabilities.^{vi} Even more distressing are the facts in the case of Georgia earlier this decade. A determination by the U. S. Department of Justice led the state to closing many of its ICFs/IID, without ensuring that the HCBS system was prepared to handle the medically fragile IDD population. The consequences were tragic. Over the years that ensued, many people died. A March, 2015 article in the Augusta Chronicle reported that 500 individuals died in group homes in the previous year.^{vii}

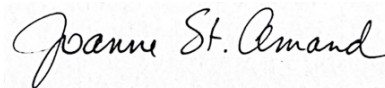
Our purpose in this letter is not to point fingers or to say that one form of care is better than another. It is to say that the system as a whole needs to be re-evaluated, that we need to do better with the resources we have and build up every asset and resource we have. We need to stop diverting time, energy, and funds on ideologies and on committees and organizations that serve only a portion of our IDD population and devote our resources to direct care of individuals, sufficient wages for Direct Support Professionals, monitoring our system for abuse, neglect, and misuse of funds, moving people from the waiting list to appropriate services, and strengthening all of our existing forms of residential care, services, and employment opportunities.

The time has come to drop the dogmas that divide us and learn to support each other, to work to address the needs of all of our members and their families. Our waiting lists are too long. Too many of our people are underserved. Too many of our people are not receiving the right level of services and supports. Too much money is being wasted, spent on oversight agencies that fail to provide oversight or being diverted to lobbying groups that support their own self-interest instead of the interests of those they are tasked to serve.

Thank you,



Hugo Dwyer – Executive Director, VOR



Joanne St. Amand – President, VOR

ⁱ Also available on-line at https://www.vor.net/images/stories/2017-2018/2018_Conference_Materials/5.-Olmstead-Protections.pdf

ⁱⁱ https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/som107ap_j_intermcare.pdf

ⁱⁱⁱ <https://oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf>

^{iv} <http://www.chicagotribune.com/news/watchdog/grouphomes/>

^v <http://archive.nytimes.com/www.nytimes.com/interactive/nyregion/abused-and-used-series-page.html>

^{vi} https://www.auditor.illinois.gov/Audit-Reports/Performance-Special-Multi/Performance-Audits/2018_Releases/18-CILA-Perf-Full.pdf

^{vii} <http://www.augustachronicle.com/news/health/2015-03-21/girls-death-among-500-one-year-community-care>

Olmstead: Protecting the Rights of All Individuals with Intellectual and Developmental Disabilities

Olmstead v. L. C., 527 U.S. 581 (1999)

Some advocacy groups who hold the view that all individuals with intellectual disabilities (ID) should live in the community have told legislators that there is a mandate in the Supreme Court's *Olmstead* decision to move individuals with ID out of their homes in Intermediate Care Facilities (ICF's) and into community based settings. **This is not true. There is no such *Olmstead* mandate.** Rather, *Olmstead* requires that those who are moved to the community from institutional care meet criteria for appropriateness and choose that placement. There is no *Olmstead* mandate to deny access and place at risk those who need and choose institutional care. Some advocacy groups misrepresent or refuse to acknowledge the actual holding of *Olmstead*, which supports institutions for those who need that level of care and guarantees choice for individuals and guardians.

The Supreme Court recognized the need for States to maintain a range of facilities for the diverse needs of persons with developmental disabilities:

*"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."*¹

*"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."*²

The majority opinion revealed the need for standards in determining the appropriate level of care:

*"Consistent with these provisions, the State generally may rely on the reasonable assessments of its own professionals in determining whether an individual 'meets the essential eligibility requirements' for habilitation in a community-based program. Absent such qualification, it would be inappropriate to remove a patient from the more restrictive setting."*³

The Court set conditions before the State is required to move individuals to the community:

*"[U]nder Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities [1] when 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."*⁴

A plurality of Justices concurred:

*"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. . . Some individuals . . . may need institutional care from time to time 'to stabilize acute psychiatric symptoms' . . . For other individuals, no placement outside the institution may ever be appropriate."*⁵

In his concurring opinion, Justice Anthony Kennedy warned about the possibility of tragic consequences for ICF residents if the ADA is misinterpreted:

*"It would be unreasonable, it would be a tragic event, then, were the American with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision."*⁶

"In light of these concerns, if the principle of liability announced by the Court is not applied with caution and circumspection, States may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition."^{7,8}

¹ *Olmstead v. L. C.*, 527 U.S. 581, at 597

² *ibid*, at 601-602

³ *ibid*, at 602

⁴ *ibid*, at 607

⁵ *ibid*, at 604-605

⁶ *ibid* at 610

⁷ *ibid* at 610

⁸ *(emphasis added on all quotes)*