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Re: Docket No. OLP 164

To: Mr. Robert Hinchman, Senior Counsel, Office of Legal Policy, U.S. Department of Justice

CC: Members of Congress

August 14, 2017

Department of Justice Request for Public Comment: Enforcing the Regulatory Reform Agenda; Department of Justice Task Force on Regulatory Reform Under E.O. 13777

Introduction

VOR is a national non profit organization that advocates for high quality care and the human rights of individuals with intellectual and developmental disabilities (I/DD). Our members are primarily family members and guardians of individuals with I/DD who access state Medicaid long-term services and supports. Many of our members are on the severe and profound end of the disability continuum, some functioning at the level of a small child or infant. Their intellectual disabilities are often accompanied by complex physical and medical conditions and behavioral concerns. The disabilities of these individuals are such that many require and choose 24-hour supervision and nursing care and community integration found in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID) and similar facilities.

Regulatory Burden - DOJ's Integration Mandate

DOJ Statement on Enforcement of the Integration Mandate of Title II of the ADA and *Olmstead*, June 22, 2011

DOJ Statement on Application of the Integration Mandate of Title II of the ADA and *Olmstead* to State and Local Governments' Employment Service Systems for Individuals with Disabilities, October 31, 2016

The DOJ interpretation, enforcement, and application of the ADA and *Olmstead* wrongly impose an "Integration Mandate" that denies individual choice and need. The adverse affects of this policy is manifold:

1. Health and safety are placed at risk when DOJ's "integration mandate" forces individuals against choice and need out of ICF/IID homes into small group homes without appropriate services, supports, and supervision. This policy acts counter to *Olmstead*.¹
2. For some individuals, community integration is placed at risk in a four person group home with only a 1:4 staffing ratio. Small settings do not have sufficient staffing and transportation resources to accompany severely and profoundly intellectually disabled individuals on outings.² These individuals require 1:1 supervision in the community, and for some, nursing support.
3. Facility-based supported employment and day programming are placed at risk leaving individuals with disabilities who cannot perform competitive work without opportunities for skill development.
4. ICF/IID, sheltered workshop, and day programs employ experts in the care and treatment of I/DD. The development of this expertise and access to it is lost as congregate settings are closed.
5. The per person cost of care increases dramatically as congregate care is shut down as sharing of resources is limited in small HCBS waiver settings. Nursing, therapy, adaptive equipment, direct care, and transportation are

¹ "As already observed, the ADA is not reasonably read to impel States to phase out institutions placing patients in need of close care at risk." *Olmstead* v. LC 527 US 581, 604.

² "Isolation in a home can just as 'severely diminish the everyday life activities' of people with disabilities. *Olmstead*, 527 US at 601. **Isolation in a home may often be worse than confinement to an institution** on every other measure of 'life-activities' that *Olmstead* recognized. *Steimel v. Wernert* and *Beckham v. Indiana Family and Social Services Administration et al.*, Nos. 15-2377 and 15-2389, slip op at 2, (7th Cir. May 10, 2016)

shared in an ICF/IID. These services are separately contracted on an individual basis in waiver settings. Forcing complex needs people into community settings against choice has adversely affected Home and Community-Based Services Wait Lists (HCBS). See Exhibit A.

6. Access to appropriate medical care can be difficult to obtain in scattered small settings as few medical practitioners have experience in treating individuals with severe and profound I/DD.
7. Forcing individuals with I/DD into competitive employment against choice puts individuals with I/DD in risky circumstances as many private businesses are not set up to address maladaptive behaviors, personal care, special feeding needs, and medication administration. Employees of private businesses are placed in difficult situations if they are not trained to handle violent and other maladaptive behaviors, health issues such as seizures, and personal care needs.
8. Costly lawsuits brought by DOJ and Protection & Advocacy agencies (P&A) against state governments have cost millions in taxpayer dollars and resources at the federal and state level to litigate and defend against. Families fighting these lawsuits must fundraise to hire legal representation to ensure their loved ones interests are protected. The cost and worry these lawsuit inflict on law abiding Americans who already face a difficult road in life protecting their intellectually disabled loved ones is inhumane.

DOJ's notion of an "integration mandate" emanates from: **28 C.F.R. § 35.130(d) A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.** A mandate conflicts with the requirement that integrated placements are "*appropriate to the needs of qualified individuals with disabilities.*"

The disability population is complex and diverse encompassing mental, intellectual, physical, medical and behavioral conditions. The *Olmstead* Court recognized this diversity, and therefore, cautioned and warned of the need for a range of settings, including institutional settings, throughout its majority and concurring opinions. Justice Ginsburg stated,

"We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle and benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." *Olmstead* 601-602

Therefore, the notion of an "integration mandate" defies *Olmstead*. It also defies DOJ regulation:

- 28 CFR 35.130(e)(1) Nothing in this part shall be construed to require an individual with a disability to accept an accommodation, aid, service, opportunity, or benefit provided under the ADA or this part which such individual chooses not to accept.
- 28 C.F.R § 35.130 public entities are required to ensure that their actions are based on facts applicable to individuals and not on presumptions as to what a class of individuals with disabilities can or cannot do.

DOJ regulation defines an "*integrated setting appropriate to the needs of an individual*" to be:

28 C.F.R. Pt. 35, App. A (2010) (addressing § 35.130)

i.e., in a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible, and that persons with disabilities must be provided the option of declining to accept a particular accommodation

DOJ's June 22, 2011 guidance states that integrated residential settings are "scattered-site housing with supportive services" and that congregate settings are "segregated."

DOJ's October 31, 2016 guidance states that integrated work settings allow individuals "to work in a typical job in the community like individuals without disabilities" and that sheltered workshops are "segregated."

DOJ fails to understand that just as beauty is in the eye of the beholder, integration is as well.

- A profoundly intellectually disabled young man in a wheelchair who has no concept of hazards cannot maneuver his wheelchair independently in the community, but can on his own in a large ICF/IID with long, wide hallways, no stairs to fall down, lots of areas to visit, and plenty of caregivers, visiting family members, and volunteers to keep a watchful eye on him. In a small community setting, this young man would find himself bumping into walls and furniture with his wheelchair.
- A severely autistic man prone to violent behaviors and elopement may be a danger to himself and others in a small setting. But, he may find more freedom and independence in a large facility with more staff on hand to support his behaviors, more places to visit and activities to engage in, and in many cases, large grounds on which to take recreate where he cannot harm others.
- A severely intellectually disabled woman with quadriplegia and a ventilator likely will not have sufficient staff to take her on outings if she lives in a four person group home with the typical 1:4 staffing ratio. She requires 1:1 supervision in the community and possibly nursing support.
- A severely autistic young lady with maladaptive behaviors may find a full work-day of supported employment daily in a sheltered workshop. This young lady may be too costly to employ in a community business and her behaviors too hazardous to herself and others which may severely limit the number of hours she is employable in the private sector.

Therefore, for some, a large ICF/IID provides more independence, freedom and community integration than a small community group home, and a sheltered workshop provides more hours of employment and integration than a competitive job. **Integration is in the eye of the beholder.**

It is for these reasons the *Olmstead* Court held,

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* at 597 (Emphasis added.)

Informed Choice

DOJ's guidance asserts a concept of "informed choice" and suggests that individuals and families have historically not acted in an informed way when they have chosen institutional placements. But, the ADA and *Olmstead* do not qualify the term "choice" by defining an informed or ill-informed choice. Doing so, would negate choice.

Throughout *Olmstead's* majority and concurring opinions, the justices state the need for a range of facilities, recognize the right of an individual to oppose an accommodation, and establish a three-pronged test for community placement that incorporates individual need and choice. In doing so, the *Olmstead* Court emphasizes the rights of the individual with disabilities and the importance of health and safety. *Olmstead* states,

For other individuals, no placement outside the institution may ever be appropriate. *Olmstead* 605

"Some individuals, whether mentally retarded or mentally ill, are not prepared at particular times—perhaps in the short run, perhaps in the long run—for the risks and exposure of the less protective environment of community settings"; for these persons, "institutional settings are needed and must remain available." *Olmstead* 605

"Each disabled person is entitled to treatment in the most integrated setting possible for that person—recognizing that, on a case-by-case basis, that setting may be in an institution." *Olmstead* 605

"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." Justice Kennedy, Concurring Opinion, *Olmstead* 610

DOJ Actions

DOJ brings what it terms “*Olmstead* actions” against states to enforce its “integration mandate.” These actions are ostensibly aimed at expanding HCBS services, but have the effect of reducing the ICF/IID and sheltered workshop choice. To the extent that the DOJ is successful in intimidating states to force closures of ICFs/IID and sheltered workshops, these actions also have the effect of fundamentally altering a states’ service system, overriding the executive and legislative decisions of elected officials and the placement decisions of private citizens. Justice Ginsburg stated,

Accordingly, we further hold that the Court of Appeals’ remand instruction was unduly restrictive. In evaluating a State’s fundamental-alteration defense, the District Court must consider, in view of the resources available to the State, not only the cost of providing community-based care to the litigants, **but also the range of services the State provides others with mental disabilities, and the State’s obligation to mete out those services equitably.** *Olmstead* 597 (Emphasis added.)

States are in a better position to know the needs of their fragile constituents, and therefore, federalism calls for decisions concerning the balance of service systems to be deferred to states to ensure the effective, compassionate, and efficient use of resources.

DOJ enforcement in relation to the make-up of state developmental disabilities (DD) service systems ignores the reality that these systems are overwhelmingly balanced in favor of community services. Exhibit A shows that ICF/IID care makes up just a fraction of DD service system capacity. Most states do not notify families of the ICF/IID choice in defiance of federal Medicaid law for fear of a DOJ or P&A action. As noted, the loss of a vital choice on the continuum of care has contributed to large HCBS wait lists that have grown dramatically for the reasons stated in Exhibit A.

Historically, individuals and their families accessing services at targeted facilities are overwhelmingly opposed to a DOJ action. Such actions impose an intense burden on families both in terms of emotional hardship, worry, and financial stress. Important accommodations which make life manageable for individuals with I/DD and their caregivers are callously put at risk with DOJ actions. Families must fundraise and expend significant resources to defend against DOJ actions as publicly funded legal assistance through the P&A program is not available from highly conflicted advocates who only advocate for people who can handle and benefit from community services. District Court Judge Leon Holmes best described the position of families in his Dismissal Order of a DOJ action,

“Most lawsuits are brought by persons who believe their rights have been violated. Not this one...All or nearly all of those residents have parents or guardians who have the power to assert the legal rights of their children or wards. Those parents and guardians, so far as the record shows, oppose the claims of the United States. Thus, the United States [Department of Justice] is in the odd position of asserting that certain persons’ rights have been and are being violated while those persons – through their parents and guardians disagree.” *US. v. Arkansas*, 4:09-CV-0033, Dismissal Order, June 8, 2011

Ignoring the careful and loving decision-making of families has come with tragic consequences. Justice Kennedy warned against just this in his concurring opinion in *Olmstead*,

“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.” Justice Kennedy, Concurring Opinion, *Olmstead* 610

The DOJ settlement agreement in Georgia was paused due to the high number of deaths resulting from DOJ’s integration mandate. Recent tragedies in Virginia connected to a DOJ settlement agreement have also caused alarm. See Exhibit B for a discussion on abuse, neglect & death resulting from deinstitutionalization.

The threat of DOJ interference in a state can have serious ramifications for individuals with I/DD. P&A and DOJ activity in Illinois led to deinstitutionalization efforts, but the state was unable to fund and provide appropriate community supports. A recent Chicago Tribune investigation revealed that widespread abuse was occurring in Illinois’ community system while the state’s P&A was either unaware or did not address issues. See Exhibit B. It

took newspaper reporters to bring the rampant mistreatment to light. Illinois' P&A failed the fragile clients of Illinois' community system. DOJ's Statements of Interest filed in Illinois P&A actions helped to drive deinstitutionalization there before an adequate community service system was put in place.

Protection & Advocacy

VOR wishes to correct DOJ's citation of the Protection & Advocacy statute in its June 22, 2011 guidance. The statute states, "the State shall have in effect a system to protect and advocate the rights of individuals with **developmental** disabilities." 42 USC 15043 DOJ leaves out the qualifier "developmental" in its guidance.

Conclusion

VOR requests DOJ to honor individuals in their application of the ADA and *Olmstead*. Congress and the *Olmstead* Court did not mean for disability law to be feared by individuals with disabilities, as DOJ's interpretation yields. Enabling community services for those who can handle and benefit from them should not come at the expense of more vulnerable individuals with I/DD who need and choose congregate care.

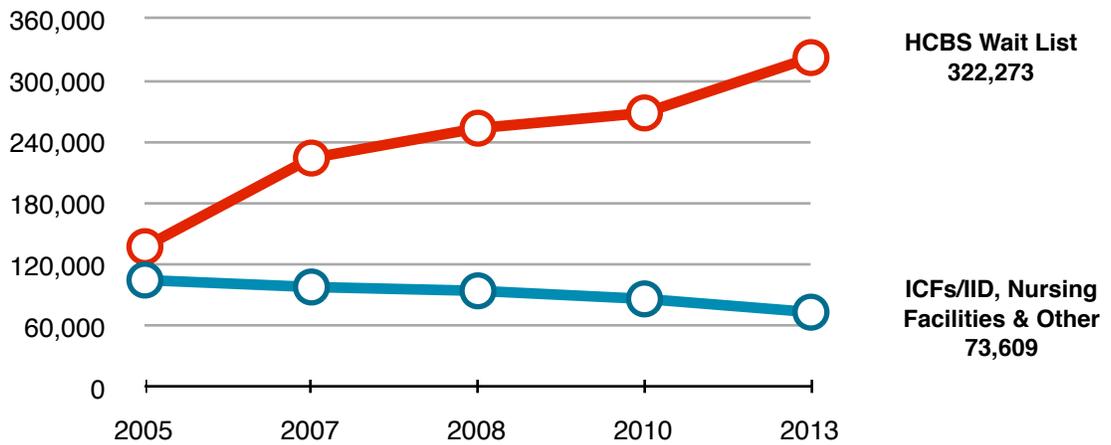


Adverse Effect of Deinstitutionalization Policy on Home & Community Based Services Wait List

HHS' Administration on Community Living (ACL) and the Department of Justice (DOJ) have pursued a policy of "deinstitutionalization," driving individuals with severe and profound I/DD and complex medical and behavioral needs from large Medicaid-certified residential facilities, such as Intermediate Care Facilities for Individuals with Intellectual and Developmental Disabilities (ICFs/IID), into small group homes.

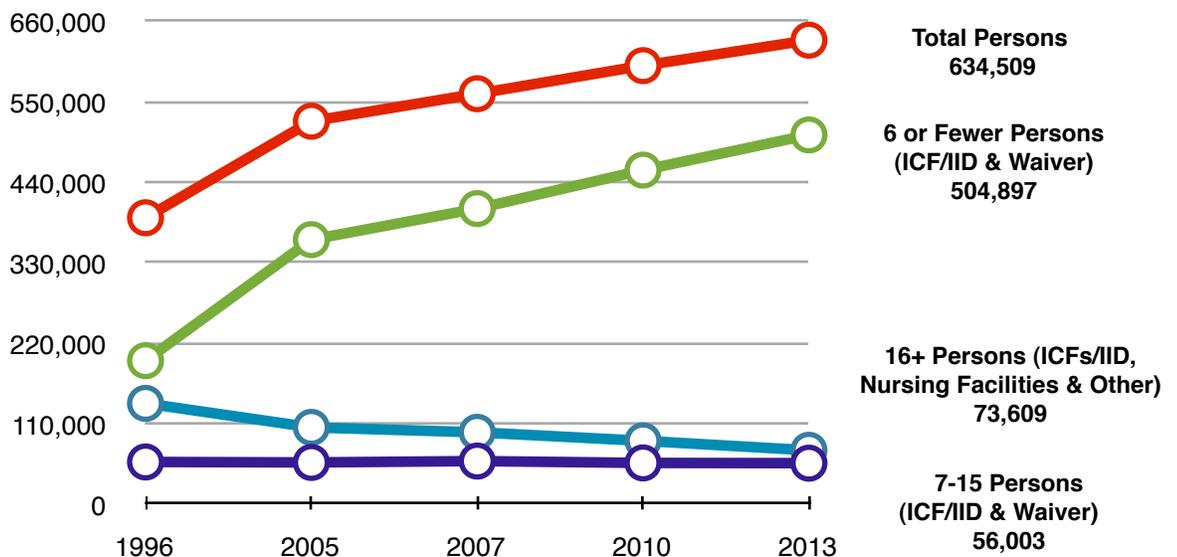
Instead of decreasing wait lists, this policy has contributed to nearly doubling their total size nationwide, stranding over 320,000 people because (1) too many resources are spent transferring happily-placed ICF/IID residents to community settings, rather than addressing the unmet needs of those on wait lists; (2) proper care for residents with complex needs who are transferred from ICF/IID homes is more costly in small community settings, crowding out those on wait lists from services.

Total Persons in ICFs/IID, Nursing Facilities & Other Homes of 16+ Beds vs. Total Persons on Home & Community Based Services (HCBS) State Wait Lists



Sources: United Cerebral Palsy Case for Inclusion and Coleman Institute and Dept. of Psychiatry, University of Colorado

of Persons Served in Supervised Residential Setting by Setting Size



Source: Coleman Institute and Dept. of Psychiatry University of Colorado



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Tragic Consequences Driven by Litigation and Threats of Litigation

*“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...**”*

- Justice Anthony Kennedy, concurring opinion on *Olmstead v L.C.* 527 U.S. 581, (1999) (**emphasis added**)

As foreseen by Justice Kennedy, the policy of litigation against Medicaid-licensed residential facilities has been tragic for the fragile individuals with severe and profound intellectual and physical disabilities and complex medical needs at which it has been targeted. Individuals in states that have been forced to close ICF/IID homes or divert individuals from them because of litigation have paid a horrible price, as can be seen in the following examples:

California: Up to 88% greater risk of mortality in community settings (peer reviewed studies, 1996-2005).¹

Georgia: In 2016, The Augusta Chronicle reported that of 503 residents moved as a result of a DOJ settlement agreement, 79 died, a mortality rate far higher than the rate in ICFs/IID.² Thousands of hospitalizations and hundreds of reports of abuse, elopements, and interactions with law enforcement have been reported in Georgia’s Annual Quality Management Reports for 2013 and 2014.³

Illinois: In 2016, The Chicago Tribune’s three-part series, “Suffering in Secret,” reported widespread abuse, neglect, and deaths in Illinois’ Home and Community Based Services settings.⁴

Most alarmingly, the forced transfer away from appropriate settings and supports took place even though the HHS-funded Protection and Advocacy attorneys and the Department of Justice knew community-based supports were wholly inadequate.

Samuel Bagenstos, former **DOJ Civil Rights Division** Principal Deputy Assistant Attorney General stated:

“It should not be surprising that the coalition of deinstitutionalization advocates and fiscal conservatives largely achieved their goal of closing and downsizing institutions and that deinstitutionalization advocates were less successful in achieving their goal of developing community services.”⁵

Vicki Smith, Executive Director of **Disability Rights North Carolina** and Board Member of the National Disability Rights Network (NDRN), a national association of Protection & Advocacy agencies, stated:

“So, let’s just be clear that people with intellectual and developmental disabilities living in community are not safe. And, that’s what we found with the project that Curt (Curt Decker, Executive Director, NDRN) referenced earlier to go out and look at and use the same kind of monitoring strategies and techniques that we use at our DD centers (i.e. ICFs/IID), and we still have some in North Carolina. And so, they’re not safe and it’s much harder to monitor these folks and the facilities (in the community), and many of the facilities are owned and operated by our traditional allies, the Autism Society, the ARC, and then other provider organizations.”⁶

¹ Widespread Abuse, Neglect, and Death in Small Settings Serving People with Intellectual Disabilities
<http://www.vor.net/get-help/more-resources/item/abuse-and-neglect-document>

² <http://chronicle.augusta.com/news-metro-health/2016-10-18/girls-death-among-500-one-year-community-care>

³ <http://dbhdd.georgia.gov/documents/georgia-quality-management-system>

⁴ <http://www.chicagotribune.com/news/watchdog/grouphomes>

⁵ The Past and Future of Deinstitutionalization Litigation, 34 Cardozo L. Rev. 1, 21 2012. http://repository.law.umich.edu/cgi/viewcontent.cgi?article=1156&context=law_econ_current

⁶ Panel Discussion, “The Disability Rights Movement: Immediate Challenges,” Staff In-Service, Advocacy Center of Louisiana, August 4, 2015, 47:06 min. mark. https://www.youtube.com/watch?v=daGi_mstQy0