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Prepared For: Senate Appropriations, Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (lhhs@appro.senate.gov)
Regarding: U.S. Department of Health and Human Services (HHS) Agencies: Administration on Community Living (ACL) / Administration on Intellectual and Developmental Disabilities (AIDD)
Request: Language Request, FY 2021 Appropriations Bill¹

Thank you for the opportunity to provide outside witness testimony for the record to the Senate Appropriations, Subcommittee on Labor, HHS, Education, and Related Agencies regarding the FY 2021 Budget for the Department of Health and Human Services (DHHS). This testimony does not include any funding request.

VOR submits this testimony as a **request for language in the FY 2021 Labor, HHS, Education and Related Agencies appropriations bill that:**

- **Expressly prohibits** the use of appropriations by a Protection and Advocacy (P&A) System to bring a lawsuit against a Medicaid licensed and certified intermediate care facility for individuals with intellectual disabilities (ICF/IID), unless the affected individuals and their legal guardians have been provided reasonable notice of the lawsuit.
- **Expressly prohibits** states from using Money Follows the Person (MFP) funds or the resulting Federal Matching Assistance Percentages (FMAP) to override beneficiary choice and be used by a state to finance and abet the closure of an ICF/IID home and the resulting transfer of its residents, or to incentivize private providers to close or reduce the number of beds in their ICF/IID facilities.

Introduction

VOR is a national nonprofit organization advocating for high quality care in a full continuum of residential options and human rights for all people with intellectual and developmental disabilities (I/DD).

It has been twenty years since the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) was last reauthorized. During that time, the Administration for Community Living (ACL) through its agency, the Administration on Intellectual and Developmental Disabilities (AIDD), and their state-based DD Act programs, especially Protection & Advocacy (P&A) Systems for Individuals with Developmental Disabilities, have engaged in activities designed to close intermediate care facilities for individuals with intellectual disabilities (ICFs/IID). This activity has occurred against the wishes of the vast majority of legal guardians of the residents, disregarding the plain language of the Americans with Disabilities Act (ADA) and the Supreme Court's *Olmstead* decision. Too often the consequences have been disastrous for the residents, resulting in abuse, neglect and even death. Since the last DD Act reauthorization expired 13 years ago, these programs have been able to continue to ignore the DD Act and the Supreme Court only through the appropriations process. To remedy this problem VOR makes the above referenced language requests for the Labor, HHS Appropriations Bill and Report.

¹ Submitted in March 26, 2020 email from Caroline Lahrman to Senator Blunt's staff, Dan Burgess and Caitlin Wilson.

The *Olmstead* Decision, Medicaid Law, and the DD Act Protect Choice Based on Need

HHS-funded P&A Systems cite the landmark U.S. Supreme Court decision, *Olmstead v L.C. (1999)*² as justification for their position to close HHS-funded ICF/IID homes. These federal agencies misrepresent and misapply the *Olmstead* decision's requirements. The Supreme Court is clear in its holding that the ADA requires individual choice before community placement can be imposed and recognizes the need for specialized care:

“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 v. L.C.* 527 U.S. 581, 601-602 (1999)]

“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)³

Likewise, Medicaid law and regulations require that ICF/IID residents be “[g]iven the choice of either institutional or home and community-based services.” [42 C.F.R. §441.302(d)(2); see also, 42 U.S.C. §1396n(c)(2)(C)]

The DD Act⁴, which authorizes funding for P&A Systems, supports residential choice and recognizes that individuals and their families are in the best position to make care decisions:

“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.” [DD Act, 42 U.S.C. 15001(c)(3)(2000)]

Protection & Advocacy Class Action Lawsuits

Protection & Advocacy (P&A) Systems are a DD Act program charged to protect and advocate the rights of individuals with developmental disabilities. [42 U.S.C. § 10543] Lawsuits have been a favorite tool of P&As. P&As have filed more than 15 class action lawsuits seeking closure (*not* relating to conditions of care) over the objections of residents and their families.

In 2014, for example, Disability Rights Ohio (DRO), the State's P&A, cited *Olmstead* when it threatened⁵ and later filed a class action against Ohio's ICF/IID program over the widespread objections of ICF/IID families. Families filed over 21,000 hardcopy petition signatures with the Ohio General Assembly objecting to DRO's threats and policy proposals, including closing and downsizing ICF/IID facilities. The threat of litigation alone led to the closing of two state-run ICFs/IID and hundreds of private ICF/IID beds. Despite state concessions, DRO still filed a class action on March 31, 2016 against the state without notifying families of individuals who DRO sought to include as class members. Eventually, ICF/IID families who learned of the suit intervened in the action. The Court ordered ICF/IID families' intervention and eventually dramatically narrowed the class to protect the interests of ICF/IID residents and those individuals who may want an ICF/IID placement in the future. In its Order on intervention, the

² The full Supreme Court Ruling in *Olmstead* is available for download at: <https://supreme.justia.com/cases/federal/us/527/581/>
<https://www.vor.net/legislative-voice/legislator-toolkit/dd-act-reauthorization/item/vor-olmstead-amicus-brief>

³ The DD Act is available for download at: https://acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf

⁵ July 1, 2014 DRO letter to state of Ohio: <https://www.vor.net/images/stories/pdf/DROLetterGovernorKasich.pdf>

Court noted that the rights of ICF/IID residents in the litigation “were not protected until the Guardians filed their Motion to Intervene.” (*Ball v. Kasich* 2:16-cv-282, Opinion and Order, July 25, 2017, Doc #261, pp 17-18.) The Court’s statement highlights the importance of VOR’s language request, to provide notice to families of P&A litigation so that they can act to protect the rights of their severely disabled loved ones.

Money Follows the Person

MFP was passed in 2005 as part of the Deficit Reduction Act, the primary goal being to rebalance state service systems toward home and community-based services (HCBS), rather than institutional care.⁶ For the I/DD population, this goal has been accomplished. Today, Home & Community Based Services (HCBS) represent approximately 54% of the total federal Medicaid I/DD budget; ICFs/IID represent only 17%.⁷ As the goal of the program has been realized, MFP has now become hijacked by ideological extremists as a means to close all institutional care for individuals with I/DD. In December 2019, the CEO of the ARC stated, “We applaud elected officials who understand the value of MFP, core to our mission to advance community living and **close all institutions.**”⁸ (Emphasis added.) P&As play a key role in this effort, creating the environment for litigation-wary states to close ICFs/IID. Then, MFP furthers states’ ability to implement the resulting closings. As such, a program that expressly honored choice⁹ consistent with *Olmstead*, has lost its way and is being misused to override the choice of I/DD beneficiaries to their life-sustaining ICF/IID homes. VOR families have experienced states’ misuse of MFP in two ways: (1) Using MFP and its enhanced FMAP to help finance whole closures of state-run ICFs/IID and the resulting transfers of residents; (2) Using MFP’s enhanced FMAP to incentivize private providers to close their ICFs/IID and transfer residents with MFP funds. Here are a few examples:

Ohio: MFP was used to help finance closings of two state-run ICFs/IID in 2015 affecting about 200 persons; families passionately opposed the closures in the state legislature. MFP’s enhanced FMAP was used to financially incentivize private providers to close ICFs/IID and transfer residents.

Pennsylvania: In 2017, MFP was used to help finance the closing of Hamburg, a state-run ICF/IID, affecting 74 residents. Closures of two more state centers were announced in 2019. Families of the centers have filed a federal lawsuit to halt these closures.

Virginia: Deaths increased by 70%¹⁰ when the state closed several of its Training Centers (state run ICFs/IID) in response to DOJ litigation. Four of five centers closed, affecting approximately 1,000 residents. Families opposed the closures by intervening in the litigation to protect their loved ones’ interests. MFP was used to help transfer displaced residents to community settings.

Illinois: Moved to close two state run ICFs/IID, Jacksonville and Murray, in 2012. The Chicago Tribune reported¹¹ that an “auction” was held to find new homes for residents of Jacksonville. “A state official read aloud medical histories of residents...prompting group home officials to raise their hands for desired picks.” Beneficiary choice was not considered when making the decision to close the centers. In fact, families of Murray filed a federal lawsuit to halt the closing of Murray and were successful in keeping Murray open. The Tribune reported that state officials promised an independent and safe life for residents in community settings, “but those promises obscured evidence found in the state’s own investigative files that revealed many group homes were underfunded, understaffed and dangerously unprepared for the new arrivals with complex needs.”

⁶ Public Law 109-171 § 6071(a)(1)

⁷ <https://stateofthestates.org/wp-content/uploads/documents/UnitedStates.pdf>

⁸ <https://thearc.org/huge-victory-for-community-living-for-people-with-disabilities-agreement-in-congress-to-commit-to-money-follows-the-person-program/>

⁹ Public Law 109-171 § 6071 (a)(2)

¹⁰ Robert Anthony, PhD. Study of Mortality Rates Connected to Virginia Training Centers Closures: <https://www.vor.net/get-help/more-resources/item/mortality-studies>

¹¹ <https://www.chicagotribune.com/investigations/ct-group-home-investigations-cila-met-20161229-htm1story.html>

Deinstitutionalization Efforts Persist Despite Widespread Abuse, Neglect, & Deaths

ACL/AIDD and their state-based programs persist in their ideological devotion to community placement despite reports:

- ✓ of an extraordinary death rate of nearly 16% in Georgia¹²
- ✓ deaths increased by 70% for individuals moved from ICFs/IID to the community in Virginia¹³
- ✓ 1,200 “unnatural and unknown” deaths in New York¹⁴
- ✓ a risk of mortality in community settings of up to 88% in California¹⁵
- ✓ more than 100 deaths in Connecticut¹⁶
- ✓ hundreds of deaths in the District of Columbia¹⁷
- ✓ a Chicago Tribune series on widespread abuse and neglect in Illinois’ community system¹⁸

plus many more reports of abuse, neglect and death across the majority of all states.¹⁹ Sadly, such results, when beneficiary choice and need are overridden, are not surprising.

Conclusion and Solution

Reauthorization of the DD Act is the appropriate place for a comprehensive review of HHS activities to determine if the programs they fund, such as P&A Systems, are operating within the letter and spirit of relevant law. As the DD Act programs continue to be funded through the appropriations process, VOR believes it is necessary and proper to require the programs to take actions to protect beneficiaries’ rights.

VOR’s requests build on previous actions by this Committee. In FY 2016, 2018, and 2019, the Omnibus Appropriations Act required that P&As provide affected individuals and their families with notice of any class action that a P&A would initiate on their behalf. We request that the Committee continue this requirement. The FY 2016 appropriations also included language that “strongly urged [HHS] to continue to factor the needs and desire of patients, their families, caregivers, and other stakeholders, as well as the need to provide proper settings for care, into its enforcement of the Developmental Disabilities Act.” Nearly identical language was also included in the FY 2017 Commerce, Justice Appropriations. VOR is unaware that HHS followed the laws and requests the Committee to require HHS to submit reports to Congress with respect to each of these areas so the Congress can start the process of determining whether and/or how HHS is meeting its obligations to respect the right of choice and make sure proper care is provided for those who leave ICFs/IID.

¹² Augusta Chronicle, August 26, 2019 <https://www.augustachronicle.com/news/20190826/report-deaths-lack-of-housing-plague-georgia-system-for-disabled-mentally-ill>

¹³ Robert Anthony, PhD. *Op Cit*.

¹⁴ New York Times series, Abused and Used, 2011-2012 <http://archive.nytimes.com/www.nytimes.com/interactive/nyregion/abused-and-used-series-page.html>

¹⁵ Mortality of Persons With Developmental Disabilities After Transfer Into Community Care: A 1996 Update, Robert Shavell and David Strauss <https://www.ncbi.nlm.nih.gov/pubmed/10207577>

¹⁶ Abuse, Neglect Cited As Factors In Deaths Of Dozens of Developmentally Disabled In State Care

<https://www.courant.com/news/connecticut/group-home-deaths/hc-dds-deaths-0303-20130302-story.html>

¹⁷ “Invisible Lives: Residents Languish; Profiteers Flourish,” March 15, 1999, https://www.washingtonpost.com/wp-srv/local/daily/march99/grouphome15_full.htm; and “Invisible Deaths,” December 5, 1999, <https://www.washingtonpost.com/wp-srv/local/invisible/deaths5.htm>

¹⁸ Chicago Tribune, “Suffering in Secret,” three-part series beginning November 2016 <https://www.chicagotribune.com/investigations/ct-group-home-investigations-cila-met-20161117-htmlstory.html>

¹⁹ VOR Abuse and Neglect Document <https://www.vor.net/get-help/more-resources>