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Chairman Charles Grassley
Senate Finance Committee
219 Dirksen Senate Office Building
Washington, D.C. 20510-6200

Ranking Member Ron Wyden
Senate Finance Committee
219 Dirksen Senate Office Building
Washington, D.C. 20510-6200

Dear Chairman Grassley and Ranking Member Wyden,

VOR is a national 501(c)(3) organization that for over 35 years advocates for high quality care and the human rights of individuals with intellectual and developmental disabilities (I/DD). Our membership is primarily comprised of families of individuals with I/DD who access a range of supports, including Intermediate Care Facilities for Individuals with Intellectual Disability (ICF/IID) and Home and Community Based Services (HCBS). We wish to lodge our deep concerns with the Committee in regard to Money Follows the Person (MFP).

In 2005, Congress passed the Deficit Reduction Act, which included a CMS Rebalancing Demonstration Grant, Money Follows the Person (MFP). The aim of the program was to provide states with financial incentive grants to implement voluntary transitions from specialized facilities to home and community based services (HCBS) programs, reduce reliance on institutional care, expand and develop community based long term care opportunities, and enable people with disabilities to participate fully in their communities and improve their quality of life. The laudable goal of this program, which was to assist the elderly and those with the mental capacity and reasoning skills to move from facility to community, is now all too often being subverted to forcibly relocate the severely and profoundly intellectually and developmentally disabled from their own life-saving communities/facilities, exposing those who are ill-equipped for community settings to extraordinary risk of abuse, neglect, and even death. There is a lack of accountability regarding MFP, as states have been found obfuscating critical incidents and deaths that occur following the transfer of this vulnerable population to the “community”. MFP funds are reported as being routed to the state general operating budget, rather than “following” individuals who require support after their departures from licensed facilities.

Disability groups who have appointed themselves as advocates for all disabilities, including those with profound deficits, are imploring Congress to fund MFP, while openly anticipating the use of those funds to close facilities. While we believe in supporting those capable of living in a traditional setting, families and guardians know that not everyone is capable of or can benefit from living outside of a facility. These groups do not represent the severely disabled in a compassionate or reasonable manner, but instead, follow a misguided ideology that violates their civil rights and the very laws that protect them.

Olmstead vs L.C. (1999) is a decision rendered by the Supreme Court that supports the right of individuals to live in the community, IF they are able and desire to do so, and not at the expense of the option of facility-based care. On these points, in the holding of *Olmstead*, the majority opinion, Justice Ruth Bader Ginsberg states:

“...we conclude that, under Title II of the ADA, States are required to provide community based treatment for persons with mental disabilities when the State’s treatment professionals have determined that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.” (Olmstead v. L.C. 527 U.S. 581, 607)

“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 based settings...Nor is there any federal requirement that community based treatment be imposed on patients who do not desire it.” (Olmstead, 601-602)

MFP, while well-intentioned, has resulted in the incentivizing of forced relocation of the severely disabled, often placing them in isolating circumstances lacking the vital services that are offered by facilities designed to ensure safety

and provide the necessary ICF/ ICU level of care that meet strict federal regulations and oversight imposed upon ICFs/IID. The numerous reports of abuse, neglect, and deaths by news media and the failed reporting of major incidents in HCBS settings as found by the U.S. Health & Human Services Office of the Inspector General¹ (per Congressional request) may be attributed in large part to the ill-advised deinstitutionalization policies and programs implemented by the federal government which include offering financial incentive grants such as MFP to the states. The subsequent closing of facilities has forced the severely disabled to be abandoned in hospital ERs or jailed, when group homes or “community” decides to no longer serve them, because they cannot meet their needs. Meanwhile, the money is being used to achieve deinstitutionalization or moved into general state revenue or unrelated programs, and the soul who peacefully existed in a facility before MFP, is lost in an ill equipped, impersonal, often dangerous system of indifference. As stated by Justice Anthony Kennedy in his concurring opinion in *Olmstead*:

“It would be unreasonable, it would be a tragic event, then, were the Americans 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.” (Olmstead, 610)

“...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.” (Olmstead, 610)

There must be oversight in place, before MFP is funded again. Those who require and choose facility-based care should be allowed to exercise their civil right to do so. Congress should provide protection for the most vulnerable from the skewed ideology that is being forced upon the severely autistic or I/DD individuals who depend so desperately on supervised residential care. Any federally funded program created to enhance and improve the lives of the disabled and the elderly, should never be a blunt object to force the closure or destruction of beneficial and structured facilities to care for them. **We ask that Congress follow *Olmstead* and the ADA in the administration of the MFP program, while keeping our most innocent and vulnerable citizens safe.**

Requests to Senate Finance Committee re: Money Follows Person (MFP)

We respectfully request the Senate Finance Committee to halt actions to permanently reauthorize MFP to allow further review and consideration of the program by the Committee and to provide opportunity for testimony by interested parties, including families whose loved ones’ interests, health and welfare are directly impacted by this policy.

The Committee should require CMS to provide guidance to states on MFP clarifying that:

- MFP is in no way meant to preclude residential choice. It is not intended to preclude qualified individuals from the choice of nursing homes, memory centers, intermediate care facilities (ICFs) or other specialized facilities.
- MFP is a voluntary program and MFP may not be used for the wholesale transfer of residents from licensed facilities. MFP funds may not be used to finance the closure of licensed facilities.
- Halting admissions, closing and downsizing ICF programs are not proper actions to satisfy MFP goals to increase expenditures for HCBS services and decrease expenditures for institutional programs because these actions directly override the choice of the Medicaid beneficiary to their preferred form of health care. Such actions overturn the primary precondition of the MFP program - **that beneficiary’s participation is voluntary.**

Thank you for your consideration of our concerns.



Darrell Pickney
VOR President



Hugo Dwyer
Executive Director

¹Joint Report of U.S. Department of HHS Office of Inspector General, Administration for Community Living (ACL) and Office for Civil Rights: https://www.hhs.gov/sites/default/files/report_joint_report_hcbs.pdf