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April 5, 2017

The Honorable Thomas E. Price, M.D.  
Secretary of Health & Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

The Honorable Seema Verma, MPH  
Administrator, Centers for Medicare & Medicaid Services  
Department of Health & Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

Dear Secretary Price and Administrator Verma:

VOR is a national advocacy organization working to protect high quality care and the human rights of all individuals with intellectual and developmental disabilities (I/DD). Our membership is made up of family members and guardians of individuals with I/DD who access multiple forms of disability services under Medicaid such as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID), Home & Community Based Services (HCBS) group homes and intentional communities, sheltered workshops and facility-based day programs. Through the provision of a wide-range of services, we as a society hold true to the principles of the Americans with Disabilities Act (ADA) and the U.S. Supreme Court *Olmstead* decision which make the needs and choices of individuals paramount in the design of public accommodations for people with disabilities.

In your letter to the Nation's Governors, you affirm the federal government's commitment to Medicaid as a safety net that provides life-saving services to our nation's most vulnerable people. You recognize the "diversity and complexity" of the Medicaid population and the federal government's duty to "ensure quality, accessibility and choices for Americans who rely upon the program." VOR shares these sentiments and we urge you to remember the people we serve as you craft policy, namely individuals with intellectual disabilities, many of whom have severe and profound intellectual and physical handicaps accompanied by complex medical and/or behavioral conditions.

A significant number of the individuals we serve choose and require the life-sustaining care only possible in large congregate care settings such as ICF/IID homes. The ability to efficiently share expert staff such as licensed nurses, therapists and direct care professionals and to provide a central location for medical specialists and dentists to hold clinics, allow individuals in these settings to receive the care they need in the most effective way to the taxpayer. Breaking up these settings is akin to tearing apart the Intensive Care Units of hospitals and spreading out

fragile patients inefficiently across a community. It just wouldn't be done if high quality, compassionate care at the most reasonable cost is the goal.

Opponents of ICFs/IID homes, unable to argue against these obvious merits, attack ICF/IID homes by stigmatizing them as “segregating.” Residents of these facilities often require 1:1 or 2:1 assistance in the community to push wheelchairs, assist with transfers, attend to personal care, administer medication and tube-feedings, and manage behavioral concerns. A large ICF/IID setting has the training and resources, both manpower and transportation, to ensure regular community outings for this level of need. It's humanly impossible for the one or two staff members in a four-bed group home to manage the community integration of four residents with complex conditions while also covering in-home care needs. That's why for some individuals, an ICF/IID home offers the greatest opportunity for integration into the community.

The U.S. Supreme Court understood these concerns and foresaw the possibility of a campaign to force all individuals into community settings regardless of individual need and choice. The Court was compelled, therefore, to strongly re-affirm the importance of institutional 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, 601-02 (1999)

Your letter to Governors addresses new CMS regulations connected to HCBS settings. We are pleased to learn that you will allow states increased involvement and more time to implement this policy to protect health and safety and to limit the disruption to the communities of friends and caregivers that individuals with I/DD already enjoy at home and work.

There is a great deal of controversy surrounding these regulations and the degree to which they limit the rights of individuals with I/DD to make their own choices about where to live, work and with whom to associate, especially if the choice is a disability-specific HCBS intentional community or work setting. No other group of American citizens faces such restrictions on their personal autonomy. We hope you take the comments and concerns of constituents into account as you ensure CMS rules respect disability law and individual rights.

While ICF/IID homes are not regulated by the new CMS rules for HCBS settings, they are affected by them. These new regulations marginalize fragile ICF/IID residents by labeling their homes as “isolating,” and prohibiting HCBS residential and work settings to be operated on or adjacent to ICF/IID campuses. **The hypocrisy inherent in such policy should be evident to all – we are going to label ICF/IID homes as isolating while we isolate them.**

And who does such policy isolate and marginalize? It marginalizes individuals with severe and profound intellectual disabilities, severe maladaptive behaviors, autism, quadriplegia,

epilepsy, non-verbal, tube-fed, many with tracheotomies and dependent upon ventilators, to name only a few conditions common among residents of ICF/IID homes. Many require life-long monitoring from orthopedic surgeons, physical medicine doctors and physical and occupational therapists to limit the deformities and discomfort their conditions bring.

We urge you to keep the needs and rights of individuals choosing large congregate care settings such as ICF/IID homes, HCBS intentional communities, sheltered workshops and facility-based day programs, in your mind and heart as you continue Medicaid's commitment to the most vulnerable citizens of our society. Please remember the people for whom Medicaid was first intended. Their voice may be small in terms of decibels and votes, but the fortitude and goodness with which they lead their lives is boundless. We can all learn a great deal from them and we have a duty to protect them.

Sincerely,

A handwritten signature in blue ink that reads "Caroline A. Lahrmann". The signature is written in a cursive style and is contained within a light blue rectangular box.

Caroline A. Lahrmann, VOR President

CC: Nation's Governors