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Chairman Bob Casey
Senate Special Committee on Aging
Dirksen Center Office Building, G 31
Washington, D.C. 20510-6050

Ranking Member Tim Scott
Senate Special Committee on Aging
Dirksen Center Office Building, G 31
Washington, D.C. 20510-6050

Senator Maggie Hassan
Hart Senate Office Building, Room 324
Washington, D.C. 20510-2908

Senator Sherrod Brown
Hart Senate Office Building, Room 503
Washington, D.C. 20510-3505

Representative Debbie Dingell
Cannon House Office Building, Room 116
Washington, D.C. 20515-2212

Dear Chairman Casey, Ranking Member Scott, Senator Hassan, Senator Brown, and Representative Dingell,

VOR – A Voice of Reason – is a non-profit, volunteer led organization that was founded in 1983 to advocate for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD). VOR strongly believes that individual choice among the widest possible range of options is the best way to meet the diverse needs of the I/DD population. VOR primarily represents individuals with the most severe degrees of I/DD and their families and guardians. Most, but not all, of the individuals reside in federally licensed facilities where they benefit from a full range of services to meet their considerable needs. Thus, we work to support a full range of quality residential options and services, including own home, family home, community-based service options and licensed facilities. VOR is reaching out today because draft legislation, which is similar to previously introduced legislation, limits funding for and living options for people with disabilities and does not accurately consider the health and safety needs of the less than five percent of the I/DD population with the most severe disabilities.

The I/DD population is not monolithic. Most individuals with I/DD can, with some assistance, enjoy the benefits of society and enrich it. At the other hand of the spectrum, the vast majority of our loved ones function at this lowest level of these disabilities. They are full grown individuals age-wise who typically function at an intellectual level ranging from four months to two or three years. Most also have significant complicating physical and/or psychiatric/behavioral issues. They need assistance in feeding, bathing, toileting and diapering, dressing, lifting and the administration of medications and therapies. They depend on staff to attend to seizures, fit orthotic equipment to prevent deformities, address maladaptive behaviors and monitor the environment to prevent them from harming themselves or others, or to protect them from those who would do them harm. Many require special diets or must have their food ground or pureed in order not to choke. In short, the people we represent need 24- hour-around-the-clock supervision for their survival.

VOR believes that the overarching principle for meeting the needs of the I/DD population must be what is best for each individual. For its lowest functioning members, safety and health, not civil rights, are

the most important objectives. Writing for the majority in the Supreme Court’s *Olmstead* decision, Justice Ruth Bader Ginsburg acknowledged that some people will always need the level of care provided by “institutions”. The Americans for Disabilities Act (ADA) and *Olmstead* support community living only for those who *choose* it. As Justice Ginsburg cautioned, “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.”¹

The legislation as currently written would effectively eliminate Intermediate Care Facilities for Individuals with Intellectual and Developmental Disabilities (ICFs/IID or ICFs for short) which are critically necessary for the proper care of the I/DD population. In providing 100 percent federal funding for Home and Community Based Service (HCBS) programs while maintaining the federal/state share for ICFs, the legislation incentivizes states to abandon their ICF programs, subsequently leaving people with the most severe degrees of I/DD with fewer of the services they need to survive.

In the *Olmstead* opinion, Justice Ginsburg directly addressed the above: “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 that, on a case-by-case basis, that setting may be an institution.’”²

While some contend that community care is less expensive than ICF care, it is only true when community care provides fewer services. Community care does not provide the level or continuum of care needed by most of the I/DD population at the lowest level of these disabilities. Fewer necessary services are not proper care, and in the short-term (much less the long-term) do not provide necessary, life-sustaining care at the same cost level as ICFs.

Samuel Bagenstos, General Counsel for the Office of Management and Budget, formerly the Principal Deputy Assistant Attorney General, Civil Rights Division, in the Obama administration and an attorney who has brought numerous suits to close ICFs, wrote in a 2012 law review article:

Although studies of deinstitutionalization have found that people who move from institutions to the community can achieve better outcomes at lower cost, it is reasonable to expect that the cost cap will shrink [or reverse] as people in the community receive more services. This may be especially true because a significant part of the cost gap reflects differences in the wages paid to workers in institutional and community settings.³

In a study of individuals with the most severe needs, Kevin Walsh reached the same conclusion: “Findings do not support the unqualified position that community settings are less expensive than are institutions and suggest that staffing issues play a major role in any cost differences that are identified.”⁴ Most of the studies that conclude that it is less costly to serve people in the community are not apples-to-apples comparisons. They suffer from several key defects. First, they compare the cost for the average person in the community, whose degree of disability is relatively mild and who needs limited assistance, with the costs of the people in ICFs, whose disabilities are much greater and require far more intensive services. Second, they look at the costs to the state disability budget only. This approach fails to take into account the fact that people in HCBS homes pay for the costs from multiple sources. For example, physicians’ costs are included in the cost of ICFs while they are paid separately from Medicaid when an

¹ *Olmstead v. L. C.*, 527 U.S. 581, at 601 – 602.

² *Olmstead v. L. C.*, at 605.

³ Bagenstos, Samuel, *The Past and Future of Deinstitutionalization Litigation*, 34 *Cardoza L. Rev.* no. (2012), 1, 44 <https://repository.law.umich.edu/articles/1084/>.

⁴ Kevin Walsh, et al, *Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research*, *Mental Retardation*, Vol. 41, No. 2: 103-122 (April 2003):

individual lives in an HCBS home. Residents of group homes also pay much more for their room and board from their SSI or SSDI. Further, as previously discussed, wages are usually much higher in ICFs. These are just a few of the reasons why these cost studies conclude – inaccurately – that it is less expensive to serve people in the community.

Not only is there no cost difference but, due in part to the oversight of ICFs, their environment is safer than HCBS homes. Medicaid requires ICFs to comply with nearly 400 standards of care while federal standards for HCBS homes are few and general. While abuse can occur in any setting, logic and experience indicate that it would occur less often in larger facilities because there are more “eyes” to watch out for abuse. These eyes encompass not only staff but also the visiting members of all the residents’ family members and various specialists involved in the care of residents.

In California, for example, between 1996 and 2005, three peer-reviewed studies found that the people who left an ICF experienced far greater mortality rates than those with similar disabilities who stayed behind, ranging from 44 percent to 88 percent higher. Dr. Robert Anthony found that, in 2017 in Virginia, the most at-risk ten percent of those receiving the most intense level of waiver supports in the community also experienced a mortality rate a little over four times the normal risk level. He documented an 88 percent higher mortality rate for individuals who moved from ICFs to the community relative to those who remained in the ICFs.

The cost of the legislation is another key consideration. While VOR lacks the expertise of CBO or CMS to estimate the cost, here are some of the certain costs and some of the key factors that would go into estimating the annual cost:

- **The cost of assuming the states’ share of Medicaid long-term services and supports (LTSS): approximately \$105 billion annually.** The federal cost of existing LTSS costs for both nursing home and DD services was \$129 billion in FY2018.⁵ The program is a joint federal-state cost-sharing one, with the state share varying from state-to-state. If the states’ share of the total cost averages 45 percent, then it would cost the federal government approximately an additional \$105 billion annually to cover the full cost of Medicaid.
- **The cost of HCBS services for the 820,000 individuals with I/DD on waiting lists: unknown but substantial.** As these people are not presently receiving such services, the bill would have the federal government pick up 100 percent of their costs.
- **The cost of the “woodwork” effect, i.e., services for a population not presently being counted: unknown but substantial.** Some of these people might be ones who have not put their names on waiting lists because of the length of the lists. Perhaps a larger category might be people who want to move from individual homes to group homes because they can get more comprehensive services there or because their parents are getting too old to care for them.
- **Another cost would come from the lower eligibility standard in the bill: unknown but substantial.** Under section 1915(c) of Medicaid law, HCBS services are available to people who meet the institutional level of care. In contrast, the bill creates eligibility for anyone who needs assistance with just two activities of daily living, a far lower standard of eligibility.

⁵ Murray, Caitlin, Alena Tourtellotte, Debra Lipson, and Andrea Wysocki. “Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018.” Chicago, IL: Mathematica, January 7, 2021, 5.

Most LTSS dollars for people with I/DD already go to fund HCBS services and supports (nearly \$36 billion in FY 2018) versus ICFs (roughly \$7 billion in FY 2018)⁶. Instead of identifying and addressing the needs of people with the full range of disabilities – from mild to the most severe imaginable – the legislation would substitute the judgment of the government for that of the individuals and their families and guardians and impose a one-size-fits-all HCBS system. Based on the experience of our members’ severely disabled loved ones in the community versus ICFs, the result would be fewer services and more lost lives.

The draft legislation reflects a preexisting governmental view that all individuals with I/DD are best off living in “the community” by not allocating representation for family or guardians of ICF residents on the key advisory panel. This establishes a void for the voice of ICF residents. For the most severely disabled, who is better positioned to determine the best setting – the government or a family member or guardian? VOR believes the policy that will lead to the best outcome is one that provides a wide range of options and then allows individuals and their families or guardians to choose the setting they believe would best meet the individual’s needs.

At the same time, VOR is well aware of the long waiting lists and inadequate services people with I/DD face in today’s community. We support increasing the quantity and quality of services. We just believe these worthy objectives should not be accomplished at the expense of maintaining life-preserving services for our loved ones.

VOR encourages the drafters to drop the provisions that would have the federal government define what is best for individuals with I/DD and to address head-on the unmet needs of the I/DD population. Specifically, VOR calls on the drafters to amend the bill in the following ways:

1. Remove the provisions that would eliminate the ICF option and include additional funds for people on the waiting lists. The new funds should be provided on an even-handed basis so the individuals can choose the residential setting they believe is best for them.
2. Provide for increased wages for direct care staff in all settings, making sure that there are commensurate additional funds for all providers to cover the additional costs.
3. Establish standards for improved oversight of HCBS homes. Replace existing inefficient and burdensome paperwork requirements with sufficient analytical and IT support to implement streamlined approaches to capturing data to be analyzed in determining systemic causes and solutions.

As family members and advocates for the I/DD population for nearly 40 years, VOR welcomes the opportunity to further discuss this draft legislation and the specific, intense, and medically necessary needs of these individuals. Please do not hesitate to contact us at any point with questions or to arrange a time to meet. We appreciate you taking the time to weigh our concerns and work to improve this legislation.

Sincerely,

Sam Friedman - President
Hugo Dwyer - Executive Director

⁶ Medicaid Long Term Services, 71.