

Background for this letter:

John Sherman, the oldest of my three children, turned 54 on December 8, 2022. John continues on a slow, positive developmental arc. Nonverbal, today my son pours love to me from his beautiful eyes, silently communicating that he knows me, a message that in his childhood years I despaired that I might never receive. One of my companions in my early journey with John, a college friend, said to me, "well, we will pray that he knows you." Although he has never called my name, there is no doubt now: John "knows" me.

I do not think of my son as an "institutionalized" person. He lives where his complex behavioral and safety needs are best met. When I think of his licensed facility, I see the faces of people - especially his housemates, but also the talented superintendent, the direct care and training staff, the dietary, medical, and dental staff. I see the safe spacious grounds. I like to arrive early for our visits, before he leaves the morning program, and take up a watch outside his cottage. From a great distance, I see my son, walking without assistance, maneuvering the parade of passing residents, staff, volunteers, food carts, golf carts and bicycles, walking with purpose toward his home. No harm will come to him on his protected walk. He sees and recognizes me and begins vigorous marionette-type-windmill arm motions, increasing his gait. I revel in his excitement. He approaches and I hold out my arms knowing that he will avoid an embrace. He bends his forehead for me to kiss. He is smiling in greeting. I am grateful.

Wednesday, June 28, 2023

To: Hon Bob Casey, Hon Mike Braun, Members of Senate Special Committee on Aging and Committee Staff

Re: Senate Special Committee on Aging - Panel Discussion on SCOTUS Decision in *Olmstead v. L.C.* Tuesday, June 20, 2023 | 5:00 PM ET

Dear Chairman Casey, Ranking Member Braun, Members of the Committee and Staff:

It is distressing that the Senate Special Committee on Aging sponsored a one-sided panel discussion last week on the use of the U.S. Supreme Court decision in *Olmstead v. L. C.* to promote policies of undermining and eliminating the option of facility-based care for individuals like my son who are unable to care for themselves.

Many voices should contribute to a public forum that addresses complex human services policies for individuals living with the life-long, incurable

conditions of cognitive and other developmental disabilities. That was not the case last week.

The panel, convened by the Special Committee, was moderated by the Executive Director of National Disability Rights Network (NDRN), a national organization representing state protection and advocacy systems (P&As), programs which oppose and work to eliminate the option of congregate care. The four panelists included two high functioning self-advocates, one a rising junior in college, at Harvard, as I understood, and the other a married man with a family, a former resident of Forest Haven. I celebrate the successes of these individuals; however, neither of these persons, who presumably were invited to represent people with disabilities, remotely represent my son and his peers, individuals who live with severe and profound intellectual deficits, who function as young toddlers, who are nonverbal, who have no concept of danger and who all their lives will *require* “eyes-on 24/7 care.” The other two panelists were the Acting Administrator of Administration for Community Living (ACL), who once led the “*Olmstead* Enforcement” work at the civil rights division at Department of Justice (DOJ) and the P&A Executive Director from Georgia. These two panelists have made careers of working to eliminate licensed facility-based care. Both from Georgia, they did not report the horrific outcomes following the DOJ *Olmstead* lawsuit settlement which required closure of Georgia’s institutions:

The Augusta Chronicle, Saturday, March 21, 2015

The Augusta Chronicle requested the investigative reports of all 2013 deaths of developmentally disabled people living in community-based care homes. The reports were prepared by the state’s Department of Behavioral Health and Developmental Disabilities.

.....

The Chronicle used other Open Records Act requests to discover that nearly 1,000 patients had died in community care in the past two years and that a majority of the unexpected deaths are among patients with developmental disabilities.” (Emphasis added.)

Repeatedly, members of the Special Committee panel and moderator used the occasion to cast a negative light on institutional care. Of great concern, the Special Committee chair’s remarks took the same line: “No one should be forced to live in a facility or institution of any kind...”

An impartial hearing would have included individuals and their families or legal representatives who have benefited from the option of congregate care programs. Such individuals might have provided the following clear passages from *Olmstead*:

We emphasize that nothing in the Americans with Disabilities Act (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.* 119 S. Ct. 2185, 2187 (1999).

...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 into settings with too little assistance and supervision. Justice Anthony Kennedy writing in *Olmstead*.

At the committee event on June 20, the moderator, the panelists, and the chairman promoted one needed long-term care program, Home and Community-based Services (HCBS), over another needed long-term care program, licensed, specialized residential treatment centers for citizens with lifelong developmental disabilities.

The panel discussion provided a forum to individuals who oppose congregate care settings. The audience and virtual viewers are left with inaccurate and misleading messages of the care provided in 24-hour facility-based programs. These messages are meant to undermine the availability of essential care for our country's citizens who urgently need a different kind and level of support than those represented on the panel. Our family and others have worked for over 40 years to support and preserve the option of licensed facility-based care for persons unable to care for themselves. It is impossible for us to counter the negative images, words, and perceptions of "institutional care" put forward at a partisan Senate committee meeting if the individuals and families who actually benefit from Medicaid certified care in Intermediate Care Facilities (ICFs) are not at the policy-making table. Why would the committee exclude the innocent voices of our loved ones and their representatives if the committee truly seeks "inclusion?"

There is a pressing need for public officials to understand the relentless, unending, devastating effects of life-long developmental disabilities, both on the individual and the individual's family. There is a pressing need for safe residential treatment programs when families cannot provide the never-ending care for their loved ones with disabilities. In many states without licensed specialized long-term care programs, area jails, hospitals and foster care have become the dangerous default residential programs for persons unable to care for themselves.

I respectfully request an opportunity to appear - and for others similarly situated to appear - before the Senate Special Committee on Aging. If invited, I could provide the committee with a list of at least a dozen or more individuals and families with different kinds of needs and experiences than those you have already heard from (e.g., a NE father, a WI mother, an OH mother, a TX sister, a KY mother, a KS grandmother, a LA father, a MD brother, a MI mother, a MO sister, a PA mother). These individuals should also have a voice in Senate proceedings which affect their loved ones with disabilities; we would welcome the opportunity to be at the table. Our family members with disabilities cannot

come to Washington to “self-advocate;” they rely on their families and legal representatives to bring their stories and realities to Congress.

If the committee is certain of its preferred program (Home and Community Based Services), surely it cannot object to hearing from an opposing perspective. If you are not open to another hearing, then help us understand in what forum the needs of individuals, like my son, John, should be discussed. *Who cares for the most vulnerable among us?*

Our country needs a range of programs to address the needs of its citizens with disabilities. Senate committee proceedings are an opportunity to thoughtfully investigate and evaluate such policies.

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