



June 20, 2023

Dear Chairman Casey, Ranking Member Braun, Chairman Sanders, and Ranking Member Cassidy,

We write in response to the panel being held on June 20th to mark the anniversary of the landmark Supreme Court Decision in *Olmstead v L.C.* The *Olmstead* decision was a huge victory for the civil rights of individuals with disabilities and its anniversary deserves notice and celebration. The decision led to a major expansion in of Medicaid home and community-based services (HCBS) delivery models; an outcome we applaud.

It also led to CMS's development of the HCBS settings final rule ("the rule"). The rule aims to ensure that Medicaid services are delivered to individuals with disabilities in the most integrated settings.

The rule applies broadly to all populations receiving HCBS. This lack of specialization has created challenges for aging services providers, particularly those that provide adult day and assisted living services to a high proportion of participants with a dementia diagnosis.

The components of the rule that focus on receiving supports for community integration and employment are well suited for certain populations – such as those with intellectual or developmental disabilities. People with dementia are working (and struggling) to **retain** skills in contrast to those who may be skill building and working to stabilize their community participation and optimize independence.

Adult day and assisted living providers in some states report that they are being told they must offer clients, including those with advanced dementia, opportunities for employment and volunteering in the community. Older adults with dementia are typically beyond their working years. Many have already completed extensive careers. These requirements run in opposition to person centered planning for this population.

Additionally, the rule requires providers to offer trips into the community to participate in activities where individuals without disabilities are present. For adult day services providers, this requirement is absurd. Individuals have typically ridden a bus from their homes, occasionally for upwards of hours, to attend activities and programming at the adult day center. Attendance at the day center quite literally is their field trip into the community, in addition to serving as respite so their family caregivers can work or take care of other needs. Without day programs, these consumers would likely be isolated within their homes. Many cannot be alone during the day. Adult day programs for people with dementia make it possible for family members to continue their caregiving, rather than seek residential placement for their loved one.

Please don't mistake our critique of the rule for aging services providers as an overt dissatisfaction or affront to the intent of the rule or a lack of understanding of the significance of the *Olmstead* ruling. All individuals who are eligible for Medicaid funded long-term services and supports should have access to the most integrated and person-centered programming possible to support and optimize their independence. But we must not conflate independence for individuals able to learn new skills with

independence for those desperately holding on to their long-held skills. Person-centered planning should take into account that many organizations have released best practices for providing services to people with dementia that include sticking to routines, lessening excess stimuli, and ensuring individuals are surrounded by familiar faces.

Proposing field trips and volunteer activities for these recipients could cause disastrous and debilitating anxiety if pursued for the individual with dementia or even an older adult with multiple chronic physical conditions for whom the additional mobility requirements of a field trip present an additional burden.

Long-term services and supports for older people have many similarities with services for working-aged people with disabilities, but there are critically important differences in their lives, goals, and functional needs.

LeadingAge applauds the strides Medicaid programs have made in promoting access to and quality of long-term services and supports in home and community-based settings. But we urge policymakers to closely examine the assumption that all HCBS users regardless of age share the same need and desire to find employment or a volunteer job and venture out for excursions in the community. Independence and quality of life evolves through the life span. We applaud your attention to this important anniversary and look forward to partnering with you and the Administration on creating a more equitable long term care system.

Sincerely,

A handwritten signature in black ink that reads "Katie Smith Sloan". The signature is written in a cursive, flowing style.

Katie Smith Sloan
President and CEO
LeadingAge