



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

September 8, 2021

The Honorable Chuck Schumer
Majority Leader
U.S. Senate

The Honorable Mitch McConnell
Minority Leader
U.S. Senate

The Honorable Nancy Pelosi
Speaker
U.S. House of Representatives

The Honorable Kevin McCarthy
Minority Leader
U.S. House of Representatives

The Honorable Dick Durbin
U.S. Senate

The Honorable Adam Schiff
U.S. House of Representatives

Dear Leaders Schumer and McConnell, Speaker Pelosi, Leader McCarthy, Senator Durbin, and Representative Schiff:

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. The undersigned CCD Long-Term Services & Supports (LTSS) Taskforce members write to share our opposition to a proposal to increase federal medical assistance percentage (FMAP) for ICF/ID services.

A core tenet of the disability rights movement, enshrined in the Americans with Disabilities Act (ADA) and *L.C. v. Olmstead*, is that people with disabilities of all ages have a right to receive services and supports in the most integrated setting, regardless of the source of payment for services or the intensity of their service needs. Most people far prefer to age in their homes, and research has shown that individuals who receive needed services in their communities – including individuals with the most complex intellectual disabilities who require the most substantial supports -- experience improved quality of life.

However, due in large part to inadequate resources, the system itself is not serving everyone who both needs and wants home and community-based service (HCBS). More than 31 years after the passage of the ADA, over 800,000 people with disabilities are currently on waiting lists for HCBS. Many others are entering institutions against their wishes because they do not have qualified and trained direct care staff to support them in the home, though that is their preference. Yet others are forced to piece together inadequate networks of unpaid supports. This historic and ongoing underinvestment in HCBS leaves people with disabilities, including people with the most significant disabilities, aging adults, and their families waiting years -- even decades -- for needed community services.

Providing more resources for care in institutional settings like ICF/IDs will not address this need. The demand for and the history of these two categories of services is distinct. Because ICF/IDs are not a waiver service, wait lists for ICF/IDs do not exist like they do for HCBS. There is not the overwhelming demand for ICF/IDs that there is for HCBS. There has not been a discriminatory history of denying qualified individuals access to ICF/IDs that needs correction, as there has been in HCBS, nor has there been the same historic underinvestment. We therefore reject any paradigm that suggests that increased funding for home and community-based (HCBS) services should be coupled with additional funding for ICF/IDs.

We recognize that there have been misunderstandings regarding the Better Care Better Jobs Act (BCBJA). BCBJA, or any of the Biden Administration proposals to expand HCBS, does not reduce funding for institutional settings, which are funded as a separate service from HCBS. Every state currently covers ICF/ID services, and would need to continue to do so as long as they wanted to maintain their 1915(c) waivers. What the BCBJA *would* do is repair and build the missing infrastructure for the hundreds of thousands of people on waiting lists who want and need HCBS, or the thousands of others who receive services but cannot get adequate HCBS to meet all their needs. The BCBJA provides an opportunity to take a huge step toward correcting the historic underinvestment by state and federal government in HCBS since their creation forty years ago. We implore you to use this opportunity to take that necessary step, without diverting critical funds towards other, better resourced service streams.

We appreciate your consideration of these concerns. If you have any questions or concerns, please feel free to contact Jennifer Lav at lav@healthlaw.org.

Sincerely,

Allies for Independence

American Association on Health and Disability

American Therapeutic Recreation Association

Association of People Supporting Employment First (APSE)

Association of University Centers on Disabilities (AUCD)

Autistic Self Advocacy Network

Brain Injury Association of America

Center for Public Representation

CommunicationFIRST

Epilepsy Foundation

Family Voices

Justice in Aging

Lakeshore Foundation

National Association of Councils on Developmental Disabilities

National Council on Independent Living

National Disability Rights Network (NDRN)

National Down Syndrome Congress

National Health Law Program

TASH

World Institute on Disability