



togetherforchoice.org

April 6, 2021

By Email

The Senate Special Committee on Aging
G41 Dirksen Senate Office Building
Washington, D.C. 20510
HCBScomments@aging.senate.gov

Re: Comments on HCBS Access Act Draft

Sens. Hassan, Brown, and Casey and Rep. Dingell:

Thank you for the opportunity to comment on your discussion draft of the Home and Community-Based Services Access Act (the “HAA”). Unfortunately, the HAA, as currently drafted, would take disabilities policy in the wrong direction by eliminating residential and vocational options and reducing choice for individuals with intellectual disabilities.

A. Background on Together for Choice

Together for Choice (“TFC”) is a nationwide disabilities advocacy organization representing individuals with significant intellectual disabilities, their families, and the providers that serve them. TFC’s mission is to expand residential and vocational options for individuals with significant intellectual disabilities and ensure that the individual’s and their family’s choice of where to live and how to spend their day is respected. We believe that the government should support and adequately fund all high quality settings and then leave it to the individual and their family to choose the setting that best meets their needs and preferences.

I am the chair of TFC, and I have a daughter, Sarah, who is 39 and has a significant intellectual disability. My wife, Sarah and I have chosen for Sarah to live in a private intermediate care facility

Different voices, different choices.

for individuals with an intellectual or developmental disability (ICF/IID) located in a campus setting on the north side of Chicago. We looked very closely at all residential options in the

Chicago area, including home and community-based settings, before choosing Sarah's home. Sarah and we determined that Sarah would be much more isolated in a home and community-based setting, a small group home or apartment in a suburban neighborhood. In Sarah's campus setting, she has numerous activities on and off the campus where she interacts with peers and with non-disabled men and women. Our experience has taught us that the initials "HCBS" or "ICF" are meaningless. What matters are the quality and type of services and the community environment offered by the setting. Sarah is one of over 70,000 men and women nationwide who have chosen an ICF as their home.

B. Together for Choice's Position on the HAA

As an advocate for choice, TFC supports ending waiting lists for HCBS settings. TFC believes that everyone in need of services should have services available to them, without waiting years. That should be true whether the individual prefers HCBS or an ICF/IID.

Unfortunately, the HAA eliminates waiting lists for HCBS while simultaneously ensuring the end of ICF/IIDs. Currently, under Section 1915(c) of the Social Security Act, a state that chooses to offer HCBS must also offer ICF/IID services. Every state has opted to offer HCBS and, therefore, all also offer ICF/IID services. (A small number of states have elected not to have ICF/IIDs in state and they meet their ICF/IID obligation by contracting with other states to serve their citizens who prefer ICF/IID services.) The HAA proposes to phase out Section 1915(c), which would end the requirement that states offering HCBS must also offer ICF/IID services.

While in theory, states could still elect to offer ICF/IID services, the funding provisions in the HAA make it highly unlikely that a state would do so. Currently, Medicaid covers both HCBS and ICF/IID services. Pre-pandemic, the federal share of the cost of HCBS for individuals with intellectual disabilities and ICF/IID services in a state was the same, an average of 56%. (This percentage has changed temporarily during the pandemic.) The HAA would dramatically change existing funding, such that the federal government would cover 100% of the cost of HCBS but only, on average, 56% percent of the cost of ICF/IID services. Under such a financing structure, states would have a strong incentive to cease offering ICF/IID services, and the HAA would remove the requirement that states do so. 70,000 men and women currently living in ICFs across the country, including my daughter, would be forced to leave their chosen homes.

The HAA seems to be built on the assumption that men and women are living in ICFs against their will. This is a myth. In Illinois, there is ongoing litigation, *Ligas v. Eagleson*, over residential options. In that case, every adult living in a private ICF/IID in Illinois was given the option of

leaving their ICF/IID for HCBS. The vast majority of men and women chose to stay in their chosen ICF/IID home. Ligas Data Report, as of 12-31-16, ICFs/DD Resident Outreach, found at www.dhs.state.il.us/page.aspx?item=93459 (3,443 ICF residents contacted, 242 (7%) elected to move).

TFC fully supports a more rational and updated Medicaid system for men and women with significant intellectual disabilities. Ending waiting lists for HCBS does not require closing ICF/IIDs. Both HCBS and ICF/IIDs should be made mandatory services under Section 1905 of the Social Security Act. States should be required to provide HCBS and ICF/IID services, whichever is chosen by the individual, with reasonable promptness - no waiting lists for either service. Minimum standards and sufficient levels of funding should be established for both services. It is also critical that direct care staff in HCBS and ICF/IID be paid an appropriate wage and provided appropriate training. The care of individuals with intellectual disabilities is a difficult and demanding job in both settings. It is not and should not be a minimum wage job.

Another failing of the HAA is that it proposes to improve the quality of direct care only in HCBS. The workforce crisis is the same in ICF/IID as it is in HCBS. Both face the same issues of attracting and retaining high quality direct care staff. The men and women in both settings need and deserve high quality care. The shortage of quality direct care staff and high turnover is causing serious harm to the men and women in both settings and depriving them of the services they need and desire. It is unfair and discriminatory to address the workforce crisis in HCBS and ignore it in ICF/IID.

C. The Solution

The HAA can easily be revised to address the issues raised in this comment. TFC requests that the HAA be changed so that:

1. Both HCBS and ICF/IID services are mandatory services under the Social Security Act and that waiting lists for either setting are prohibited;
2. The workforce crisis in both settings be addressed in the same way to ensure sufficient high quality direct care staff in HCBS and ICF/IID; and
3. Equal and sufficient federal funding be provided to the states for both types of settings so that individuals have a real choice of the setting that best meets their needs and preferences.

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With these three simple changes, TFC would wholeheartedly support the HAA and would work with you for its passage.

Thank you for your consideration of the above.

Scott M. Mendel

Chairperson, Together for Choice