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April 26, 2021

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

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

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

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

Congresswoman Debbie Dingell
Cannon House Office Building,
Washington, D.C. 20515-2212

Via Email: HCBSComments@aging.senate.gov

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

Thank you for this opportunity to respond to the request for public comment on the draft language in the proposed HCBS Access Act of 2021. The issues raised in this proposed bill are important to providers of services to people with disabilities and the individuals they serve.

ACCSES is a Washington, D.C.-based policy and advocacy organization that provides a voice for disability service providers on issues that significantly affect the lives of individuals with disabilities they serve. The more than 1,200 disability service providers that make up the ACCSES network serve over three million individuals with disabilities, many of whom have significant intellectual and developmental disabilities. The providers' efforts for decades have expanded opportunities for individuals with disabilities to live, work, and thrive where and with whom they want – just like people without disabilities. These efforts are made in accordance with person-centered planning and strive to meet the individual needs and desires of the people providers serve. In keeping with that philosophy, ACCSES supports a full array of options for individuals rather than artificial limitations on choice. This is the only way to give real meaning to the choice component found in the U.S. Supreme Court's landmark *Olmstead* decision.

“Community” is a word that has been turned into a political football, but if we look at the basic dictionary definition, it is clear that “community” means not just a physical, geographically defined space, but also the social and emotional common ground that individuals with shared interests enjoy. The next draft of this proposed legislation should adopt a broad definition of

community in order to honor the rights of individuals with significant disabilities to receive services in the settings of their choice.

Rather than providing detailed comments on this first draft, we want to make an overall observation on the bill's purpose as set forth in Section 2, which includes a goal "to fulfill the purposes of Americans with Disabilities Act to ensure people with disabilities and older adults live in the most integrated setting." This language is chilling in that it ignores entirely the rights recognized in *Olmstead* for individuals to have a choice in where they receive services. Let us be very clear: no one wants to see people segregated – but that word has been misused for years to denigrate and spread misinformation about a range of choices where individuals are not "segregated" but rather are living robust lives in the settings of their choice.

The phrase "people with disabilities" is too-often used in a monolithic sense as if one group of individuals speaks for all. Nothing could be further from the truth, and this is to the detriment of individual choice. No one person or organization represents the vast population of individuals that would fall under the "people with disabilities" banner. At ACCSES, we recognize the need for a full array of options to maximize opportunities that best fit the lifestyles individuals choose. No one tells an individual 55-plus that they cannot live in an adult community nor are there restrictions on adults of any age in the choices of where to live or work or spend their time. Individuals with significant disabilities may need more federally funded support, but that should not require sacrificing their right to choose for themselves what works best for them. Just as adults without disabilities do not want their options defined by Congress, neither do individuals with disabilities. The focus of Congress should be on expanding and properly funding the choices that individuals make. Many individuals choose independent living, living with family, living in adult family homes, living in supported group homes, and some individuals with significant medical complexities often choose to live in intermediate care facilities. Each of these choices is a legitimate option and should be retained. The same holds true for choices people make in respect to their employment or to their day habilitation services. It is past time for Congress to recognize and respect the rights of individuals with disabilities to have a broad array of options.

During COVID, we have seen a great deal of loneliness and isolation. Many disability service providers have kept individuals connected and engaged who, like many people around the world, have been unable to live their normal lives. And just like a lot of us, the overwhelming refrain from many individuals with disabilities has been a strong desire to get back to work, to see their friends, to return to being a part of their communities – whether their community fits within the narrow definition used in the HCBS Access Act or not. We ask that the final draft of the bill recognize the civil rights of individuals to receive services in the setting of their choice.

One of our deepest concerns with this bill is the inadvertent denigration it includes of individuals with disabilities. There is nothing innately superior about people without disabilities. The idea that a "congregate setting" is inherently bad is offensive. Churches are congregate settings. Schools and workplaces are congregate settings. Places where people routinely gather are congregate settings. It is only in respect to individuals with disabilities that the right to gather is being placed at risk. The freedom to associate is recognized by U.S. courts as a fundamental freedom, and that right must be honored in this legislation. Language in Section 2 to "silos" and

“congregate settings,” may not be intended to be offensive, but taking a torch to individual choices does not improve lives. Expanding opportunities and giving individuals more options and funding for broader supports will make a difference. ACCSES therefore asks that the final draft of this bill focus on expanding choice and on showing individuals with disabilities the respect they deserve.

Among the many things we have learned working with disability service providers is the volume of opportunities they create and support for individuals. Many of the individuals served need a lifetime of support, both in their living arrangements and their employment. These efforts deserve to be lauded because they have made a huge difference in many lives. Disability service providers should be your strongest partners in drafting legislation that will truly be meaningful. We would gladly work with you to arrange a virtual meeting with providers from across the country who can help you with the final draft of this bill. The broad goal of this proposed legislation to eliminate the waiver waiting lists is going to require all hands to reach the outcomes that best serve individual needs. We encourage you to take advantage of this invitation and hear from the providers who have the first-hand knowledge and experience that can help you achieve success. Please contact Kate McSweeney at (202) 349-4279 or via email at kmcsweeney@accses.org.

Thank you for this opportunity to comment.

Sincerely yours,



Terry R. Farmer
President & Chief Executive Officer



Kate McSweeney
Vice President of Government Affairs & General Counsel