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The Senate Special Committee on Aging  
G41 Dirksen Senate Office Building  
Washington, D.C. 20510  
Via email: [HCBScomments@aging.senate.gov](mailto:HCBScomments@aging.senate.gov)

April 8, 2021

**Re: NCSA comments on the HCBS Access Act proposal**

Dear Congresswoman Dingell, Senator Hassan, Senator Casey, and Senator Brown:

The National Council on Severe Autism, an advocacy organization representing the interests of individuals and families affected by severe forms of autism and related disorders, thanks you for this opportunity to comment on the proposed Medicaid Home and Community Based Services Access Act (HCBSAA). We appreciate your concern for the growing numbers of Americans suffering from disabilities, including the burgeoning population disabled by severe forms of autism, a number that has dramatically increased — more than 4,000% — over the past three decades.

The idea of ending waitlists for Medicaid disability services sounds like a dream — it is heartbreaking to see growing ranks of adults with intellectual and developmental disabilities (I/DD) “fall off the services cliff” after high school and into a system so woefully unprepared for them, with very limited and rationed options for programming, housing, or supports. This terrible situation is exponentially worse for young adults with severe autism who possess little to no capacity to care for themselves or earn a living, and whose complex needs often include aggression (e.g., pinching, biting, hitting, kicking), self-injury, elopement, property destruction, extreme rigidity, disruptive behaviors like screaming, throwing and stripping, and comorbid medical conditions such as psychiatric disturbances and epilepsy.

We agree wholeheartedly that dramatic updates to Medicaid are needed, and if the HCBSAA offered person-centered options along the full continuum of care, we would vigorously support it. But unfortunately the current draft is not aimed at that goal; though it may have been unintentional, the draft systematically discriminates against and marginalizes Americans with severe cognitive, functional and behavioral disabilities, and would have the catastrophic effect of shuttering programs designed to serve them, while prohibiting development of desperately needed new capacity. Let us explain:

**(1) The proposal is based on myths rather than facts**

First, we are concerned that the proposal is founded on a number of myths about disability and disability services.

First, the draft is based on a false assumption that the Medicaid system is riven with an “institutional bias” that keeps adults with disabilities locked away from the community at large. While this may have been true half a century ago, **this bias simply does not exist in America today**. For example, in our most populous state, California, about 99.8% of residents with autism live in the community, and not in institutions. There is simply no scary “institutionalization” ogre looming in our states, and no need for draconian measures that further narrow and eliminate scarce options for the severely disabled. The steady closure of intermediate care facilities (ICFs) and sheltered workshops — two of the exceedingly few options equipped to serve severely autistic individuals — has already had the devastating impact of depriving individuals of critical options, with the HCBS Settings Rules further restricting appropriate options in some states. The University of Minnesota National Residential Information Systems Project found that while the number of long-term support recipients living with family or in their own homes surged, those living in larger group settings declined dramatically, a decrease of 43% for those in an IDD facility, nursing home or psychiatric facility.

Second, the draft **is based on a fiction that any setting labeled as “institutional” must be somehow nefarious, while all settings in the “community” must somehow be benign**. But facts tell a different story. Disability-serving settings today have nothing in common with the infamous Willowbrook in New York, while at the same time stories abound of community settings rife with abuse, such as an HCBS group home in the Bronx where staff regularly answered the phone with “Hello, Bronx Zoo,” and where repeated physical, sexual and psychological abuse of the residents was belatedly revealed by a whistleblower. Even the victims’ many trips with unexplained injuries to neighborhood hospital emergency rooms elicited no inquiry or protective action by the doctors and nurses who treated them. To cite another of many examples, a young man in an HCBS setting suffered repeated abuse, was exposed to pornography, was afraid to take off his clothes to shower, was deprived of clean towels and even a bar of soap, and slept on a bare mattress in his dirty street clothes and shoes. While community care can be wonderful it can also be abysmal and deadly, as we saw with the rash of deaths (nearly 1,000) in community services in Georgia following closure of institutions. As Dr. David Mandell, Director of the Center for Mental Health Policy and Services Research at the University of Pennsylvania, observes, “Today, media exposés of abuses in community settings rival those of psychiatric hospitals a generation before.”

“Community services” in reality often mean no supervision, no licensing, no consulting medical or nursing personnel, no properly trained staff to handle medical/behavioral crises, high burnout and turnover, no therapeutic or nutritional supervision, and high reliance on 911 calls to address crises, often resulting in violence, trauma, incarceration and psychiatric hospitalization, all delivered by a tattered and fragmented system nearly impossible to navigate. It also can mean a prohibition on necessary safety features and amenities often need by our population, which may include swimming pools, swings, trampolines, sensory equipment, plexiglass over the windows, electrical and plumbing equipment that cannot be ripped out, safety furniture, safe rooms for staff, sound muffling walls and ceilings to prevent noise from bothering neighbors or preventing sensory overload in sensitive clients, line-of-sight building layouts, crash carts, specialized gurneys and bathing apparatus that make the care of clients easier and effective, and more. Further, the HCBS system offers few financial mechanisms to deal with the daily need for repairs and replacement of destroyed property.

Third, **the draft is explicitly premised on a false presumption that all, no matter how severely disabled, can be served “in the community”** — a presumption not based on fact,

and that, puzzlingly, appears to be un rebuttable. While it would be wonderful to believe that all those with severe disabilities can have their needs met in generic community settings, one can easily see this is untrue. Almost every day we hear of adults with severe autism being threatened with eviction due to dangerous or disruptive behaviors, or who are threatened by neighbors who consider them a nuisance, or who are unable to locate qualified caregivers or day programs, or who are raped, abused or neglected in isolated, unsupervised settings where, due to low cognitive and verbal skills, they cannot report their trauma. Even the government's own research exposes the falsehood of the presumption: recent investigations of group homes in New York, Chicago and Philadelphia found rampant abuse and neglect in small dispersed settings that, as Dr. Mandell report **“are often not up for the task of caring for individuals with more profound impairments.”** Dr. Lee Elizabeth Wachtel, director of the Neurobehavioral Unit at Kennedy Krieger Institute, has also testified: “Some autistic adults have severe behaviors that cannot be managed in community settings. They may not exhibit them all the time, but they need to be somewhere with experienced caregivers who can manage dangerous behaviors when they do occur, with access to professionals who can treat them, as well as structured programs to maximize community access as well as providing satisfying site-based programming. This population needs to be surrounded with well-trained, well-paid aides, because the health and happiness of these adults depends almost exclusively on that one variable.”

Indeed, the Supreme Court, in interpreting the Americans with Disabilities Act in the Olmstead decision, held that “nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings.” Justice Kennedy added that it would be “tragic” if the ADA were interpreted to force individuals “into settings with too little assistance and supervision.” The Supreme Court has recognized that the ADA requires a wide range of facilities to meet the diverse needs and preferences of individuals with disabilities.

Fourth, the HCBSAA asserts there exists “decades of research and practice show that everyone, including people with the most severe disabilities, can live in the community with the right services and supports.” In fact, there is no good data around this issue at all; there has been not a single study on outcomes and metrics for adults with severe autism across a variety of programs. As Dr. Mandell has stressed, “Right now, our decision-making regarding which types of placements to pay for and prioritize is based on values rather than data” (<https://journals.sagepub.com/doi/full/10.1177/1362361317722101>).

## **(2) The proposal relies on vague euphemistic terms that lack clear definition and set the stage for endless battles over terminology**

The express purpose of the HCBSAA is to limit access to institutions, nursing homes or other “congregate settings,” and is built on notions of promoting “community-based” programming. Unfortunately these all-important terms are nearly meaningless, and subject to individual whim and interpretation. What is meant by “congregate settings”? A group home with 2, 3, 4... 12 disabled people? An apartment community serving 2, 3, 4... 50... 100 disabled people? A day program serving 2, 3, 4... 20...50...100 disabled people? A farmstead serving 2, 3, 4... 50... 100 disabled people? A cluster of homes serving 2, 3, 4... 50... 100 disabled people? What is “institutional” or “congregate” is amorphous, undefined and susceptible to the ideologies and whims of advocates or bureaucrats. As a result, these terms could be interpreted broadly,

encompassing any group-oriented program with any disability-specific purpose, which would amount to a nightmarish, permanent “no vacancy” sign for adults with severe autism.

Similarly, what is meant by “community”? If there are farms in a community, would residing on a farm be considered “community-based”? If an individual requires disability-specific programming and amenities in his apartment cluster, is that considered “community”? Or is “community” solely defined by generic physical structures and situations preferred by people without disabilities? Unless these terms are clearly defined we can anticipate years, if not decades, of blistering battles over their meaning — and therefore over allowable options for the severely disabled.

### **(3) The HCBSAA "Advisory Committee" would place extraordinary veto power in the hands of a few advocates**

The proposed Advisory Committee is designed to be made of a majority of self-advocates and allies, with a minority (if any) representation from those who lack the capacity to advocate for themselves, and who must rely on parents/guardians/conservators to represent their interests, i.e., almost the entire severe autism population which we represent. A small, unelected and unaccountable committee would be handed broad discretion to determine what qualifies as HCB services across the country, trumping whatever needs and preferences of severely disabled individuals, an idea that is clearly untenable. While of course self-advocates have the right to self-determination, there is no reason they should be handed gatekeeping power over services and supports for all individuals with I/DD and across the broad spectrum of needs and abilities, in contravention of person-centered principles. It is frightening to contemplate such an undemocratic process at the helm of such a massive public benefit program that serves as the very lifeline for countless thousands with severe disabilities.

### **(4) The HCBSAA explicitly excludes supports needed by many with severe autism and buries person-centered principles under arbitrary strictures**

On its face, the bill is grounded on person-centered planning, but this worthy goal is undermined not only by the unforeseeable directives of the Advisory Committee but also by incorporation of the HCBS Settings Rule into statute. Ideally, any law authorizing expenditure of Medicaid dollars would focus on person-centered planning, without erecting unnecessary barriers to service access. The primary question should be, “What arrangement makes most sense for this individual, given his/her desires and needs?” and not “How can we satisfy arbitrary requirements that are irrelevant to the well-being and quality of life for this individual?”

Moreover, it is very concerning that **those with severe autism and I/DD seem to be excluded from the express purpose of the HCBSAA**, which is to help “individuals attain or retain capability for independence or self-care.” Since almost no individuals with severe autism have capacity for independence or self-care, their realities, their lives, are excluded from the goals of this bill.

Indeed, the HCBSAA would only support “supported employment and integrated day services.” What is meant by “integrated” day services? This bill could shutter desperately needed programs serving the severely disabled who are incapable for integrated day services owing to their severe cognitive, behavioral, medical and functional challenges. Similarly, we cannot understand why transportation resources would be limited “to facilitate community integration.” What if severely disabled individuals need transportation for other reasons? Our population

often cannot even attend medical appointments without access to adapted vehicles with harnesses staffed with specialized behavior and medical support personnel; eliminating options for transportation for other settings could be life-threatening for those with profound disabilities. Along the same lines, we cannot understand why the bill only supports “Home and community-based intensive behavioral health and crisis intervention services.” What about options for site-based, inpatient or specialized services for those with severe behaviors? We can think of no reason to exclude these vital services that are so necessary for the health and well-being of many adults with severe autism.

#### **(5) The de facto de-funding of ICFs punishes the most severely disabled**

While the vast majority of adults with severe autism currently reside in the community (mainly with parents) and only a small minority in ICFs, it is critical to retain an ICF option for those who require that level of wrap-around care, either temporarily or permanently. The HCBSAA would **for all practical purposes result in the de-funding of ICFs** by eliminating the requirement that states cover ICF services if they cover HCBS services for the I/DD population, and by providing that the FMAP for HCBS services would be 100%, a strong incentive for states to eliminate the ICF option. ICFs are a key component of the national safety net, offering intensive, professional therapeutic level of care to the medically fragile and the severely autistic found nowhere else and in the most economical way possible. Just as we would not eliminate the ICU from the hospital, we must not eliminate the ICF option from the array of disability programs. As we have seen repeatedly, HCBS providers often not only refuse services to clients who are too difficult or unprofitable to manage, they generally lack the training, facilities and structure to provide care to the most severely disabled.

While it eschews services needed by many with profound impairments, the bill also expands the pool of eligibility to those with mild impairments. Under the current law, HCBS is available to people who require an institutional level of care. In contrast, the HCBSAA broadens eligibility to anyone who needs assistance with 2 or more activities of daily living. We are concerned that prior to any relaxation of eligibility standards the HCBS system should first be able to meet the needs of the most severely disabled.

#### **(6) The HCBSAA overlooks the fact that adults with severe autism seldom have access to housing**

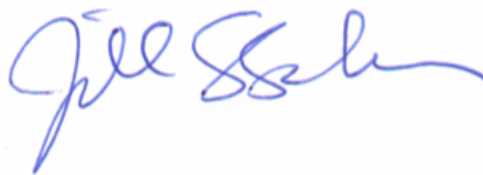
The bill makes a critical error of assuming that people disabled by severe autism will have places to live “in the community.” This assumption is tragically false. At this time there is almost no public support for providing brick and mortar housing for adults with severe autism. First, private residential providers for people with I/DD are typically allowed to cherry-pick the individuals they serve – and they rarely choose those with severe autism, due to the risks for injury and/or damage, and need for excess staffing and costs. Second, few adults with severe autism (whose income is typically limited to Supplemental Security Income (SSI) of about \$700-900 per month) have access to housing subsidies, such as HUD Section 8, that would allow them to reside in “their own home” in the community. Then, even if they have the good fortune to possess a housing voucher, they often cannot find appropriate housing, or face eviction, due to disruptive and destructive behaviors. Finally, the chilling effect caused by the Settings Rule has seriously threatened the financial viability of new projects intended to serve the severely disabled. Unlike standard housing serving the non-disabled, disability housing that

by law must be isolated and dispersed cannot take advantage of crucial economies of scale (both for construction and operation) available to every other segment of our society.

In sum, while we are overwhelmingly grateful for initiatives to eliminate Medicaid waitlists and improve caregiver quality and pay, we are concerned that in operation the HCBSAA could dramatically restrict options for those with severe disabilities, particularly the severe cognitive and behavioral disabilities seen in severe autism. Given the exceptional urgency to fix our broken Medicaid system, we hope that the sponsors will reconsider the current approach outlined in the HCBSAA to more fairly incorporate the needs of the full spectrum of Medicaid-eligible disabilities.

The National Council on Severe Autism would be honored to participate in a re-drafting of the proposed bill to ensure that the needs of this large and growing sector of the disability community are properly recognized. Many thanks for your courageous work on behalf of Americans with disabilities.

Very truly yours,

A handwritten signature in blue ink, appearing to read "Jill Escher". The signature is fluid and cursive, with a long horizontal stroke at the end.

Jill Escher  
President