



VIA ELECTRONIC DELIVERY

April 26, 2021

U.S. Senator Maggie Hassan
324 Hart Senate Office Bldg.
Washington, DC 20510

U.S. Senator Sherrod Brown
503 Hart Senate Office Bldg.
Washington, DC 20510

U.S. Senator Bob Casey
Chairman, Senate Special Committee on Aging
393 Russell Senate Office Bldg.
Washington, DC 20510

U.S. Representative Debbie Dingell
16 Cannon House Office Bldg.
Washington, DC 20515

Re: Comments on Discussion Draft of the Home and Community Based Access Act (HAA)

Dear Senators Hassan, Brown, and Casey and Representative Dingell,

On behalf of Parent Project Muscular Dystrophy (PPMD), I am writing to comment on the discussion draft of the Home and Community Based-Services Access Act (HAA). PPMD appreciates your leadership and efforts to solicit feedback from community members on the Medicaid home and community-based services (HCBS) system. Access to long-term care services and supports are critical for people living with Duchenne muscular dystrophy and their families. As the leading advocacy organization for Duchenne community, we are committed to ensuring their perspectives are central to this process.

Duchenne muscular dystrophy is a genetic disorder that affects approximately 1 out of 5,000 live male births worldwide, characterized by the progressive loss of muscle. Clearly this is a devastating condition that currently leads to a rising need for services addressed in the draft legislation. PPMD fights to end Duchenne by accelerating research, raising our voices to impact policy, demanding optimal care for every single family, and striving to ensure access to approved therapies. It is with this context in mind that we provide the following comments.

COMMENTS ON DISCUSSION DRAFT

PPMD appreciates your support to develop **an HCBS infrastructure to support the people who use the services, their families, and the workers who provide services**. The current HCBS patchwork of state waivers sometimes fails to provide adequate support and funding to those in need in the Duchenne community. PPMD has identified the following key issues with the current HCBS system. We encourage you to consider these comments as you develop an HCBS system that serves all who need long-term services and adequately supports the HCBS workforce.

Pediatric and Adult 1915(c) and Pediatric TEFRA Waiver

There are stark differences between each state's programs and prioritizations. Some states differentiate

prioritization between people with physical, mental health and/or intellectual disabilities and may only serve one of those groups. For example, there are waivers available specifically for children with autism. Many states also differentiate eligibility based on both the type of disability and the type of care needed (e.g., intermediate care facility, nursing facility, hospital). There is little consistency between various state programs, even if those programs serve similar patient populations, resulting in variations in how individual and/or family income and assets are assessed for eligibility, the potential fees for pediatric waivers, and states' definitions of developmental differences. An example of a state with a very restrictive targeted waiver, the Florida Model Waiver, is only for children and adults up to the age of 20 who are medically fragile, technology dependent, *and* diagnosed with a degenerative spinocerebellar disease. Each state sets priorities and assigns targeted groups for their 1915(c) HCBS Waiver and Tax Equity and Fiscal Responsibility Act (TEFRA) programs resulting in a patchwork of policies that can be extremely difficult to navigate and have restrictive eligibility that is targeted based on various disabilities.

Other Pediatric Waiver programs may completely waive family income and assets, only consider a child's financials, and have a fee scale based on a family income range with all family income and assets considered. This lack of consistency makes it very difficult for families to navigate the rules and for national organizations like PPMD to help advise families.

Disparities in Services

Services and supports vary by state and program and there is little uniformity among similar programs, leading some eligible individuals to be better served depending on geography. Some programs may only offer modest supports such as case management, respite care, and family training. Others, such as TEFRA plans, may provide only Medicaid health insurance, but may still be of value for families whose income and assets exceed requirements and whose children have expensive and complex medical needs. Additionally, simply helping people avoid being placed in care facilities is inadequate and fails to consider the whole person. Individuals capable of remaining active in their community may need additional supports and services including accessible home modifications, transportation and other measures. A determination of a standard for supports and services is needed to allow those eligible for HCBS to remain at home and in the community, not just receive care in the community.

Program Information and Waiting Lists

Finding adequate information on eligibility and which plans are best suited for an individual's personal circumstances can be difficult because state websites vary in how information is presented and vary in the ease of determining criteria and eligibility. Individuals and families may face difficulties because of poorly designed websites that are difficult to navigate or websites with inadequate information regarding coverage and eligibility. Some states may have no individuals waiting for services while other states may have as many as several thousand on waiting lists that may be years in length, resulting in eligible individuals not receiving the supports and services needed.

Overall Income and Asset Limits

Income and asset limits, particularly for Aged, Blind, and Disabled Medicaid, are exceptionally low. Aged, Blind, and Disabled Medicaid's income limit is \$794 to \$1,073 per month for a single applicant or \$1,191 to \$1,452 per month for a married couple. In states that cover in-home care through HCBS Waiver, nursing home Medicaid, and assisted living services, a single individual, 65 years or older, must have

income less than \$2,382 per month to qualify. To be eligible for nursing home Medicaid, HCBS Waiver, and most Aged, Blind and Disabled Medicaid, an individual is permitted up to \$2,000 in countable assets but certain exclusions apply. For Pediatric Waivers, similar financial rules may apply to the child's financials. Overall, eligibility seems to be more focused on a poverty income level rather than based on needs. Those with greater assets are required to "spend down" (i.e. make allowed purchases, undertake home improvements, or pay for private healthcare) until their countable assets fall below the maximum allowed.

Direct Care Worker Reimbursement

Direct Care Worker wages are often among the lowest in the US, with the annual average wage being approximately \$24,000. Employers experiencing high turnover due to low salaries also face greater training costs and more difficulty in attracting motivated and skilled staff. In addition to low wages, Direct Care Workers are typically offered modest benefits, including a lack of or poor health insurance and little or no retirement benefits. These poor wages and modest benefits contribute to employee dissatisfaction, low productivity, reduced employee retention, and high turnover. Low employee retention and high turnover place the burden in covering unfilled shifts on those still employed and puts a burden on patients already being underserved.

Paid Caregiver Programs

Where a patient lives matters and can impact the family unit's overall quality of life. In Duchenne and other rare progressive conditions, the care required increases over time. When allowed hours for caregiving fail to match an individual's requirements or needs, it is often families who fill the void but and at the detriment of regular employment. The ability to pay a member of the family can be life changing for the family as many members are forced to leave their jobs in order to take care of their loved one. Some states offer the ability for a family member to serve as a paid care attendant using a consumer or self-direction option, which often proves to be a tremendous help for families who take care of a child or adult with a progressive pediatric condition. There is a need for examining those states that have programs of this nature and the rules against hiring certain members and examine the impact on outcomes, not just for the person affected by the condition, but for the entire family unit.

In closing, PPMD thanks you for your commitment to understanding the issues of the current HCBS system and for investing time and resources to gather meaningful input from patient communities. Should you have any questions regarding our comments, please don't hesitate to reach out to me at Ryan@parentprojectmd.org.

Respectfully,



Ryan Fischer
Chief Advocacy Officer
Parent Project Muscular Dystrophy