April 23, 2021

U.S. Representative Debbie Dingell
116 Cannon House Office Building
Washington, DC 20515

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

U.S. Senator Bob Casey
393 Russell Senate Office Building
Washington, DC 20510

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

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

On behalf of the American Network of Community Options and Resources (ANCOR), thank you for the opportunity to provide feedback on the Home and Community Based Services Access Act (HCBS Access Act). The HCBS Access Act highlights an essential Medicaid program that has survived decades of under-investment and is now rendered more fragile by the COVID-19 pandemic. We are grateful for the hard work that went into the discussion draft and excited to work with you on this groundbreaking legislation.

ANCOR is a national, nonprofit trade association representing more than 1,600 private community providers of services to people with intellectual / developmental disabilities (I/DD). Combined, we support over one million individuals with disabilities, and work to shape policy, share solutions and strengthen community. Our members assist people with disabilities to live full and independent lives by providing staff support with instrumental activities of daily living. The HCBS program lays at the heart of our efforts, as our members rely almost exclusively on Medicaid funding.

The success of this legislation depends on extensive investment in DSPs and other direct care workers. To create true access to HCBS for all Americans who need supports, the direct care workforce must be stable, well trained, compensated fairly, and commensurate with consumer demand. ANCOR conducted extensive conversations with our members to obtain their insights on the topics for which you sought feedback in your March 16 release announcing the HCBS Access Act, as well as some additional topics. We have organized that feedback by topic below, touching upon broad themes and specific recommendations that arose within those topics. Please reach out to me at smeek@ancor.org if you have any questions.

Sincerely,

Sarah Meek
Senior Director of Legislative Affairs

Workforce development and support

Create a standard occupational classification for DSPs – Congress should direct the Bureau of Labor Statistics to create a federal designation specific to DSPs to recognize the profession and gather data that can inform policy making and funding decisions.

Establish a commission on workforce development - A DSP workforce commission should develop and champion DSP career ladders, oversee grant development and opportunities for DSPs, worker groups, consumers and providers, and link to regional workforce development boards. The commission could partner with the highest levels of federal government to ensure the HCBS workforce is a key component of federal initiatives (such as Raise the Wage) and others

Incentivize career ladders and lattices for DSPs - Employers and other bodies should be incentivized to offer DSPs career development programs, scholarship opportunities, subsidize career development training, and partner with local colleges. Programs should be funded and developed to provide opportunities for DSPs to grow in their current profession aside from climbing the direct care ladder.

Formalize communications between DOL and HHS – Since Medicaid providers also fall under the jurisdiction of DOL, we strongly encourage Congress to incentivize and/or encourage formal processes and communications channels between DOL and HHS. This would ensure that providers can comply with new labor regulations that result in increased costs and interdepartmental outreach on apprenticeships and other programs.

Rate setting

Include HCBS in the equal access provision – Congress should include HCBS under the equal access rule, which would require Medicaid reimbursement rates be set to ensure equal access to services.

Develop inclusive rate setting bodies - So that adequate rates are set at the state level to attract and maintain a vibrant and diverse array of providers to ensure that access and choice are available to individuals and their families as they seek services, state rate setting bodies should be created that include consumers, DSPs, providers, state officials, and other stakeholders.

Access and quality should be measures of rate adequacy - Often a lack of access to HCBS is an indicator of an inadequate rate. The Colorado Alliance (state provider association) has looked at measuring access by understanding how long it takes individuals to find providers for the services they are seeking. For services without adequate rates, individuals wait months to find a willing provider or never find one. In addition, access should be measured by individuals having alternatives among providers for a given service. True access also means more than one provider available for a particular service.

DSP turnover as a measure of rate adequacy - The 2019 National Core Indicators (NCI) Staff Stability noted the average DSP turnover rate was 42.8% for the 26 surveyed states, with 32.7% of DSPs separating from provider employment in the first six months. DSP turnover is a strong indicator that rates are too low to recruit and retain DSPs in a given service category, creating barriers to access in those services as well as potential quality concerns.

Tie rates to DSP wages – Wages are a significant factor contributing to both staff retention and as stated above, turnover. In 2019, nearly 40% of DSP average wages were only between 21-40% above a given state minimum wage. Furthermore, the DSP workforce should not be, nor was intended to be, a minimum wage level profession. Congress should consider automatically setting starting DSP wages to a fixed percentage above the living wage calculation for that particular geographic region.

Rates should include realistic overhead – Many states do not offer adequate rates to cover provider overhead and assume that providers can cover any shortfalls with charitable donations. We posit that most nonprofit providers are lean and 'underspend' on overhead, which include mission critical expenses such as insurances, capital expenses, property maintenance, utilities, and accounting compliance.

Rates should include the cost of training – The spirit of federal HCBS rules is that state laws, regulations, and policies must be person-centered. Person-centered services require person-centered culture, which is a near constant state of evolution. To ensure frontline staff have the best, and most appropriate training and professional development, the cost of training, including non-billable staff time to attend training, should be funded and not wrapped into administrative overhead funding.

Federal oversight on rate setting methodologies – The federal government must clearly define minimum parameters of what should be included in a state's rate setting methodology for different services, which will assure participation by providers. Rate setting methodology should be built on calculations of Direct Support Professionals wages above a living wage level, provider's administrative and capital expenses, retained earnings, and other expense variables in order to achieve an adequate rate for services. Provider led Alternative Payment Models should be considered and encouraged.

HCBS infrastructure

Shift to a truly person-centered model of support - Currently, most HCBS programs operate under a fee-for-service model that provides neither the financial support nor flexibility to provide personalized services and supports, and by the nature of its billing codes encourages a service approach more relevant to medical settings than to community settings. One example our members frequently mention is being required to track, report and bill for 15-minute increments, which requires Direct Support Professionals (DSPs) to spend a significant amount of time on paperwork rather than supporting individuals. We encourage Congress to discuss how operating models under this proposal could be more person-centered with the Centers for Medicare and Medicaid Services (CMS).

Clear waitlists in a phased approach - Even prior to the pandemic, many providers reported turning away new clients due to a lack of DSPs. Effectively ending -- or dramatically reducing waitlists to a reasonable timeframe to access HCBS services -- requires not only direct funding associated with an individual enrolled in a waiver service, but also ensuring service providers have sufficient staff. In order to end waitlists and ensure that providers have capacity to adequately and appropriately support people, Congress should direct states to clear their waitlists in stages. For example:

- Phase 1: Initial investment in the DSP workforce for people currently receiving services and emergency funding for family caregivers
- Begin Phase 2 when DSP turnover is reduced by a certain percentage
- Phase 2: Bring people with most need/urgency off the waiting list. Many states triage their waiting lists with something like urgent, emergent, and everyone else. Phase 2 could be clearing the "urgent" waiting list.
- Phase 3: Clearing the emergent waiting list
- Phase 4: Clearing the "everyone else" waiting list

Ensure equity in access – Congress should include strategies for addressing long-standing inequities in access to HCBS, including but not limited to:

- Requiring states to develop equity plans for their HCBS programs
- Providing technical assistance
- Providing funding for outreach to Black people, indigenous people and people of color, as well as the providers that support them.

Advisory Panel – We believe ANCOR should be added as a member on the Advisory Panel to adequately represent the provider perspective. There must be a balance of people supported, families, DSPs, providers, and other stakeholders represented on the panel. We encourage Congress to allow for public comment on the composition of the Advisory Panel and feedback outside of the Advisory Panel process.

Clarity on state-federal partnership – With the 100% FMAP, this legislation reflects a significant reframing of traditional state-federal partnership. To ensure successful implementation, we encourage Congress to consider the following questions:

- Would each state continue to set their own rates? How else would the role of the state change?
- Under a 100% FMAP, how could the role of the state change when a different Administration is in office?
- By what mechanism would Congress require states to participate in the 100% FMAP and ensure the full Federal payment was allocated fully to services?
- What happens to the current Medicaid local match funding by states?

Interaction with the HCBS settings rule – We encourage Congress to specifically address if and how this change will interact with the settings rule.

Minimum services and standards

Review of state waivers – Given the state-to-state variations in current HCBS waivers, Congress should order a review of state waivers to ensure that supports currently offered are not removed as HCBS transitions from optional to mandatory. Congress should also review state administration strategies of dispersing Medicaid funds to better address variations in managed LTSS.

Change in minimum benefits – Guardrails should be in place to ensure that HHS must go through an extensive stakeholder process with opportunity for public comment when redefining or changing the definition of HCBS and the minimum services and supports provided.

Level of care assessment – Congress should set national standards/parameters for states to meet, including validity and reliability. The standard setting process should be transparent and provide an opportunity for public comment on the level of care assessment.

Aging in place – Life expectancy for people with I/DD is on the rise as a result of important medical advances that have been made. There needs to be a federal focus on financing the changing support needs throughout a person's life. The number of people with I/DD and Alzheimer's has grown exponentially in recent years. Payment models need to reflect those demographic changes and not just broad categories. Services such as temporary skilled nursing, nursing care, medical equipment, home modifications, technology, and rehabilitative services (OT, PT, Speech) should be accessible and at an adequate level to facilitate an individual's desire to age in place.

Dental care - Poor Oral Health can be directly correlated to serious health conditions and significant pain. Dental care for adults is not required to be covered by Medicaid, as it is an optional service ; we encourage you to read the National Council on Disabilities' report on this issue for additional context.

Emergency preparedness - Services, supplies and equipment to support people with disabilities before, during and after public health emergencies and disasters so that they can continue to receive or begin receiving HCBS in the community. These services including personal preparedness assistance, evacuation, transportation and sheltering supports, personal assistance services and transition services to support transition from a temporary institutional placement back to permanent community living, supplies and

equipment including assistive devices, medications and home modifications to address immediate disaster-related losses to meet the accessibility, health-maintenance, communication, and other immediate needs of disaster-impacted people with disabilities. Community officials and emergency responders also need resources available to support people with I/DD during disasters.

Family caregivers – Family caregivers could be employed by a provider agency, fiscal intermediary, or directly by the person supported. Family caregivers should also be able to support more than one family member.

Housing assistance – While housing is included in institutional settings by their very nature, housing support is not formally woven into the HCBS program. This has created a significant, and largely unmet, demand for affordable, accessible housing and has become a barrier to community living. We encourage Congress to embrace creative approaches including but not limited to:

- Funding modifications to make the existing housing supply more accessible (including smart technology)
- Investigating how to leverage use of accessory dwelling units to increase the housing supply
- Allowing the use of Medicaid dollars to assist with rent payments
- Supplementing the low-income tax credit to encourage and/or require greater emphasis on affordable housing in development

Non-medical transportation – Transportation to facilitate integration remains a major obstacle for people with disabilities, whether it be public transportation, paratransit or private transportation. We urge Congress to incorporate flexible transportation solutions that extend beyond paratransit or non-emergency medical transportation. We recommend solutions that accommodate transportation challenges for all Medicaid recipients, including rural areas.

Preventative and behavioral supports – Preventative and habilitative mental health and behavioral health services for people with I/DD are not currently covered adequately. Congress should ensure that coverage of mental health and behavioral health services for people with I/DD is not solely dependent upon a crisis that requires emergent and acute care. Furthermore, primary diagnosis of a serious mental illness or developmental disability should not have the effect of limiting access to either behavioral supports nor long-term services and supports. The care model should integrate public health, biopsychosocial, person-centered, trauma-informed and wellness-based models. Services should be available face-to-face and virtually.

Shared liability models – We encourage Congress to allow for policies at the state level that ensure shared liability models as states and providers fully implement the HCBS Settings Rule.

Technology infrastructure, adoption, and training – The legislation should fund:

- Quality reporting infrastructure to feed into states' data tracking systems
- Purchasing technology that modernizes provider and employee practices
- Purchasing technology along with the on-going implementation costs, such as broadband access, hardware and software upgrades, data security and storage, that improves direct services
- Training people leveraging services, their families, DSPs and others on the use of the aforementioned technology

Transitions from group homes to more integrated settings – The HCBS system should motivate and incentivize moving to the least paid supports necessary. Transitioning from a group home to independent living or shared living often has upfront costs that are not covered by Medicaid. We encourage Congress to cover those upfront costs similarly to how transition costs are covered in the Money Follows the Person program.

General

Clear definitions – Because state interpretations of legislative intent and statutory language may result in disparities from state to state, we encourage Congress to provide clear definitions for the following terms:

- Congregate – There is no clear definition for a congregate setting in either statute or the CFR. Similar to the HCBS Settings Rule, we recommend defining congregate by the characteristics of that type of setting rather than the number of people supported in that setting.
- Integrated – Most integrated should not only be assessed by the size, scope and location of the setting but also by the opportunities available to readily participate and connect with others in the community.
- Housing supports – Medicaid has a longstanding prohibition on covering any costs of "room and board" outside of an institution. Without directly addressing this bias, it will be difficult to serve many individuals in the community. If the legislation does not intend to change the prohibition, what would the housing supports look like?
- Wraparound - Legislation should define how and which supports funded by other payors (federal, state, local, etc.) can be layered upon and braided with Medicaid HCBS.
- Case management - Case management should be conflict-free, separate from funder and provider.
- Nursing services - Nursing services should include healthcare coordination, direct nursing services, medication/treatment support (not just by licensed staff). These services must be provided using a whole person care model.

Strike presumption language – It does not seem that the presumption language (page 13) is necessary to achieve the goal of the legislation. If that language is determined not to be necessary, we support striking it from the legislative text to mitigate some potential anxiety from individuals electing to live in ICFs.