ANCOR

September 26, 2022

The Honorable Cathy McMorris Rodgers
Republican Leader
Energy and Commerce Committee
U.S. House of Representatives
2322 Rayburn House Office Building
Washington, D.C. 20515

Dear Republican Leader McMorris Rodgers:

On behalf of the American Network of Community Options and Resources (ANCOR), we appreciate the opportunity to respond to this memo, *Disability Policies in the 21st Century: Building Opportunities for Work and Inclusion*. We appreciate your long-standing commitment to removing barriers and expanding the rights of people with disabilities. We write primarily to respond to the first prompt that asks how to reduce or eliminate institutional bias and to express support for additional policies such as the transformation to competitive integrated employment.

Founded more than 50 years ago, ANCOR is a national, nonprofit association representing nearly 2,000 private community providers of long-term supports and services to people with intellectual and developmental disabilities (I/DD), as well as 56 state provider associations. Combined, our members support more than one million individuals I/DD across their lifespan, and are funded almost exclusively by Medicaid. Our mission is to advance the ability of our members to support people with I/DD to fully participate in their communities.

1.1 Regarding Medicaid's Institutional Bias

A. *How can Congress reduce or eliminate the institutional bias in Medicaid?*

Reform Must Address Immediate Needs Including the Direct Support Workforce Crisis

We appreciate this committee's commitment to ensuring more individuals have access to Medicaid Home and Community-Based Services (HCBS). Ending the institutional bias is an important reform that will enable more eligible individuals, including those with I/DD, to receive home- and community-based supports. However, the current state of the Medicaid HCBS program necessitates action from Congress now to bolster the system and address the direct support workforce crisis that jeopardizes individuals' access to supports and services.

There is and has been for many decades a workforce crisis in HCBS settings due to stagnant reimbursement rates and the inability of providers to offer wages that enable them to compete with industries offering entry-level positions, such as fast-food restaurants or retail and convenience stores. This crisis is one of the greatest barriers to accessing community-based supports and services. The effects of underinvestment in the direct support workforce can be seen in turnover rates of approximately 44% nationally.[1] With the onset of COVID-19, new pressures and hazards of providing essential, close-contact services have further exacerbated and accelerated the workforce crisis with full-time vacancy rates rising to 12.3% in 2020 – a roughly 45% increase from 2019.

At approximately $13 per hour, the median wage for direct support professionals nationally is simply insufficient to slow the exodus of direct support professionals from the field and the closure of programs which threatens access to long term supports and services. Because these rates are set by Medicaid, they are outside of the normal market system. While many in the private sector pivoted by offering increased wages and hazard pay, community providers—who rely almost exclusively on Medicaid funding and are thus beholden to paying wages that state Medicaid reimbursement rates will permit—lack the resources to fund these kinds of unanticipated programmatic costs. With inflation rates reaching all-time highs,[2] these already low wages continue to lose value and direct support professionals struggle to meet basic living expenses while working overtime.

Without sufficient staffing, community providers have been forced to close programs and reject referrals. By 2021, 77% of community providers were turning away new referrals, 58% of providers were discontinuing programs and services (a nearly 71% increase in just over a year), 84% of community providers were delaying the launch of new programs or services, and 81% of community providers reported struggling to achieve quality standards due to lack of staffing.[3] Survey results further indicated that nearly 3 in 10 (29%) respondents reported spending more than $500,000 annually in costs related to high turnover and vacancy rates, while more than 1 in 6 respondents (18%) reported spending more than $1 million annually.

Any responsive measure to expand access to HCBS services as a means of reducing institutional bias must recognize and address the workforce crisis as a crucial component of reform. Without sufficient staffing, programs and services are forced to close, leaving people with disabilities without choice or options of community-based settings for support even after receiving funding. Simply expanding benefits without creating the sustainability of the workforce and infrastructure may unintentionally increase reliance on institutions and institutional bias.

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[1] National Core Indicators, 2022, National Core Indicators Intellectual and Developmental Disabilities 2020 Staff Stability Survey Report

[2] In July 2022, inflation reached 8.5%, its highest rate since 1982.

[3] ANCOR, 2021, The State of America’s Direct Support Workforce

Congress Should Enact Legislation to Reinforce Adequate Payment Rates

The Social Security Act currently requires that payment rates are “consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers” (i.e. access provision). However, the Centers for Medicare and Medicaid Services’ (CMS) current distinction between state plan services and services provided via HCBS waivers prevents their inclusion in access monitoring review plans and adequate rate methodology review. The resulting direct support workforce crisis is perpetuated by inadequate payments rates and rate methodologies that have often not been adjusted for decades at a time to reflect inflation and increased costs of service provision.

In addition to extending the increased Federal Medical Assistance Percentage (FMAP), as addressed below, legislation addressing the following issues would support and preserve access to the current HCBS infrastructure:

- Amending the equal access provision to expressly include HCBS waivers and managed care; and
- Requiring HCBS payment rates are reviewed at least every three years and include an automatic annual inflation adjustment.

Congress Should Direct the Office of Management and Budget to Create a Standard Occupational Classification for Direct Support Professionals

The current standard occupational classification (SOC) system directly impacts state and federal agencies’ HCBS policy decisions, including the determination of payment rates. To demonstrate compliance with the access provision, most states use SOCs to determine direct support professional (DSP) wages. DSPs are the workforce supporting individuals with I/DD with activities of daily living, self-direction, and goals to increase community integration and inclusion. Unlike other industries where employers can raise employee wages and offset costs, community providers are bound by Medicaid payment rates—meaning DSPs are uniquely impacted by the SOC or lack thereof.

Since there is no DSP SOC, states blend a variety of current and retired SOCs in an attempt to account for the wide array of DSP activities.[4] For example, states may cherry pick from current classifications blending an array of codes such as Personal Care Aides, Home Health Aides, and even Recreation Workers. This has led to further inconsistency in DSP wage trends. A unique SOC for DSPs will aid in the retention of DSPs by providing a foundation for rate-setting and stabilizing wages.

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[4] Health Management Associates, Prepared for ANCOR, 2022, Review of States’ Approaches to Establishing Wage Assumptions for Direct Support Professionals When Setting I/DD Provider Rates.

The lack of a specific SOC for DSPs also impairs data collection. There is currently no mechanism to comprehensively collect employment and wage data specifically for DSPs. Without comprehensive data, the totality of the workforce crisis cannot be properly assessed. By designating the DSP as its own SOC, the U.S. Bureau of Labor Statistics will be able to more accurately capture employment and wage data specific to the profession, which will in turn assist federal and state policymakers to inform and impact future policy.

A new SOC for DSPs will also assist in the professionalization of the DSP workforce, thereby increasing retention of DSPs. The current classification system falls short of adequately capturing the complexity of the role DSPs play in the lives of the people they support. The closest current proxy classification for DSPs is Home Health Aides and Personal Care Aides. However, this merged classification does not encompass the full and unique spectrum of work performed by DSPs. For example, it does not capture the role DSPs fulfill in supporting community integration, person-centered goal setting, vocational or career planning, or in empowering and advocating for the individuals supported.

Creating a SOC for DSPs is a no cost solution that will support adequate payment rate methodology and transparent data collect as a necessary step in beginning to address the workforce crisis.

Extend and Make Permanent Current Programs that Reduce Institutional Bias

Congress Should Extend the Increased FMAP for HCBS

States are currently receiving a temporary 10% FMAP bump for HCBS, and the National Association of State Directors of Developmental Disabilities Services (NASDDDS) reports that at least 44 states are using the increased FMAP to address the workforce crisis.[5] This funding has been particularly crucial in response to the challenges the pandemic created for the HCBS service system. Extending this funding when it runs out would allow states to continue their work to eliminate institutional bias.

Congress Should Permanently Reauthorize the Money Follows the Person Program

The Money Follows the Person (MFP) demonstration program assists people with disabilities with funding, not covered by Medicaid, to move out of institutional or facility-based care and into the community. Without funding to offset the new expenses of living in the community (e.g. moving expenses, security deposits, and home modifications), people with disabilities can face insurmountable barriers to transition out of an institutional setting. The original MFP pilot expired in 2016 and has continued to be funded by a series of short-term renewals with the most recent three-year renewal available through September 2023. Short-term renewals do not give states the stability they need to implement the program, leaving many individuals waiting

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[5] NASDDDS, 2021, State Workforce Initiatives, ARPA Spending Plan Topical Analysis.

to transition into the community until a more permanent solution is reached. Permanent reauthorization would provide states with much-needed continuity and individuals with the means necessary to transition away from institutional settings.

Transition Home and Community-Based Services to Mandatory Benefits

To fully eliminate the institutional bias in the Medicaid program, Congress must make a basic package of HCBS mandatory benefits accessible to all eligible beneficiaries who choose them.

This committee rightly notes that while "HCBS care remains an optional service for states" individuals with disabilities and their families will be forced to endure waiting lists for services. The current status quo requiring the coverage of institutional services but maintaining HCBS as optional leaves HCBS disproportionately vulnerable to cuts while protecting funding for institutions. Such a disparity is especially glaring given that HCBS have been shown to be more cost-effective, lead to better outcomes, and the preference of most service recipients.

Individuals' needs vary and some may choose institutional settings—which cover a variety of services from state-run residential facilities to intermediate care facilities. Making HCBS a mandatory benefit will not alter current access to institutional services; rather it will ensure that people with disabilities who are currently eligible for Medicaid have a choice to receive HCBS if they want those services and are not forced to wait years for services or remain trapped in a single state for fear of facing a new state's waiting list.

ANCOR supports making a basic set of HCBS mandatory benefits, however we note that such a transition will need time, flexibility, and funding due to the fragility of the current infrastructure. States that currently offer HCBS are already unable to fully meet the needs of those eligible and authorized for services due to the workforce crisis. Expanding service offerings without first stabilizing the current system may have the unintended impact of overwhelming the already scarce provider network.

We offer the following considerations while transitioning HCBS to mandatory benefits:

- Increased funding through grants and/or an increased federal match will be necessary to support initial system development and ongoing costs and ensure that wages for direct support professionals can be raised to competitive rates within local markets;
- A baseline set of services will need to be covered by all states to ensure that people with disabilities, older adults, and their families can move from state to state;
- Program and implementation requirements must take into account that states remain in very different places in their provision of HCBS services for different populations, including people with I/DD, physical disabilities, and mental health disabilities; and

- States will need time, flexibility, and oversight to come into compliance. This could be achieved through the development of statewide implementation plans and substantial technical assistance from CMS.

B. What tools can Congress give to the Federal Government and states to help them enact policies to reduce or eliminate the institutional bias in Medicaid in the most cost-effective way? In your answer, please also address whether phasing in specific HCBS services as mandatory benefits over time or phasing in eligibility for services by specific populations over time would be cost-effective solutions.

While creating a mandatory set of HCBS benefits is necessary to fully eliminate the institutional bias, there are a number of actions Congress can take immediately to reduce the bias and ensure that states maintain a robust community service system as an alternative to institutionalization. Directing the collection and analysis of available data would provide Congress with an adequate picture of the current landscape to provide more targeted reform.

Congress Should Direct CMS to Analyze National Data Trends

There is currently a lack of basic data at the state and federal levels which makes tracking the workforce and addressing workforce issues difficult in the provision of current services and development of new services. Given the variations in HCBS programs, it is critical for CMS to have a fundamental understanding of the services available to ensure transition to a mandatory set of benefits does not disrupt or displace the services currently offered. Congress should direct CMS to implement certain data and reporting requirements, including but not limited to, a national review and published analysis of:

- State waivers and current utilization of HCBS programs;
- State waiting lists, including eligibility and priority standards; and
- State reimbursement rate methodology and frequency of review for HCBS services.

Congress Should Direct States to Collect and Track Workforce Metrics

The direct support workforce crisis has resulted in program closures and reduced service offerings, making it difficult to assess whether current HCBS programs are meeting the needs of the people authorized for services. Making HCBS a mandatory benefit is meaningless if there is no workforce to offer the services and no means of measuring the availability of a service. It is vitally important that minimum standards are developed for measuring access to HCBS to adequately assess the availability of community services.

Workforce metrics should include, at minimum:

- Workforce Volume (availability):

    - Total number of direct support professionals disaggregated by each designated service;
    - This data should be stratified by agency employer vs. independent provider, and by age, race/ethnicity, gender, disability, and languages spoken (including a comparison of workforce language competency compared to indicated language preferences of person supported).
- Workforce Stability (retention/turnover):
    - The average annual turnover rates (percentage of direct support professionals who left their positions for any reason over a twelve-month period) and turnover rates for new workers (e.g., with less than 6 months of tenure);
    - Vacancy rates (for agencies, measured as number of empty positions divided by the total number of empty positions plus total filled positions), as well as number of self-directed beneficiaries unable to fill positions; and
    - Service continuity, as measured by (a) frequency and length of services interruptions, and (b) calculating the average number of direct support professionals who serve each beneficiary in a calendar year
- Compensation (wages and benefits):
    - Average hourly wage and average annual earnings across service type;
    - Ratio of average hourly wage and average annual income for direct support professionals =compared to similar positions in institutional settings; and
    - The proportion of HCBS reimbursement that is designated for direct support wages and benefits, with an accounting of the amount designated for wages and benefits.

Congress Should Direct CMS to Develop Metrics to Evaluate Access to HCBS

Measuring access to long-term services and HCBS is different from measuring access to other clinical services and states are significantly "behind the curve" when it comes to measuring access due to a dearth of metrics.[6] The most frequently used access criteria such as time and distance standards are generally inappropriate to services provided in a fixed home, community, or institutional location. Additionally, HCBS services have a wider range of amount, duration, and scope variations (for example, home attendant services that may be prescribed for 7 hours per week, or 17 hours, or 27 hours, etc.) and a wide range of unique conditions that may complicate providing services (such as travel time to an individual's home or very particular skills needed for at-home care for a specific individual). Given these factors, access to HCBS required for individuals' health, inclusion is less reliable.

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[6] University of California, 2018, Managed Long-Term Services and Supports: Assessing Provider Network Adequacy.

To establish a baseline understanding of access, Congress should direct CMS to develop and provide guidance which requires states to measure and assess access to HCBS, at minimum, across the following metrics:

- If needed services are being prior authorized. In long term supports and HCBS, it is all too common to evaluate need based on system capacity rather than actual individual need. In this process, individuals are routinely pressured into accepting far fewer services and support than they need, which can lead to serious consequences.
- If provider capacity is sufficient. This should be considered beyond the availability of provider agencies in existence to the availability of providers to offer comprehensive services with a sufficient workforce.
- What proportion of authorized hours is *actually* being filled. One of the most pervasive problems in HCBS is that many individuals only receive a fraction of the services they need even though they *have* an approved authorization for the services (for example, they may receive only 20 of their 40 hours authorized), especially due to provider and workforce shortage.

Congress Should Require States to Allow Retainer Payments During Short-Term Institutional Stays

Many individuals enter an acute care facility or other institution for short-term stays but stay for much longer without a community placement to transition to because their state does not allow for retainer payments. Retainer payments permit temporary payments to HCBS providers while the beneficiary is unable to receive services, allowing them to keep their placement, equivalent to "bed-hold payments" for institutional services.[7] Retainer payments do not duplicate other payments and may not exceed the amount for services which would have been provided but for the temporary stay. However, unlike institutions, states can choose whether or not to provide retainer payments and for which services. With the COVID-19 pandemic, 40 states received approval for retainer payments through emergency waivers which are set to expire with the expiration of the public health emergency declaration.[8] Requiring continued retainer payments limited to short-term institutional stays would be a cost-saving measure, as it would prevent costly long-term institutional stays.

Congress Should Require States to Cover HCBS Services Retroactively and Make Presumptive Eligibility a Medicaid Standard

Retroactive coverage is a crucial financial protection for low-income, uninsured, and underinsured adults with I/DD who need long-term care services and supports. This protection in federal law requires the Medicaid program to pay retroactively for institutional services received

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[7] MACPAC, 2021, Use of Medicaid Retainer Payments during the COVID-19 Pandemic.

[8] Kaiser Family Foundation, 2020, State Medicaid Programs Respond to Meet COVID-19 Challenges.

up to three months before the date an individual applied for Medicaid.[9] While federal policy allows Medicaid coverage for care provided in an institution based upon immediate need, current federal law prohibits Medicaid programs from covering HCBS before the approval date of an HCBS service plan.[10] This disparity contributes to the institutional bias: a person can be admitted to an institution immediately but cannot get help at home immediately.

Circumstances surrounding the need for HCBS for many people with I/DD, such as a health emergency, the demand for long-term care services following an illness, or other unexpected high-cost health needs, results in an inability to plan for needed services. Many adults with I/DD also rely on aging family caregivers to provide natural supports in their home, creating a dependency on the availability of their assistance. Additionally, the application process for HCBS can be lengthy, requiring multiple clinical evaluations and extensive financial documentation at a time of emergency and/or limited support. Consequently, because Medicaid policy does not allow for retroactive coverage of HCBS, many individuals are forced to go without needed services or accept costly and unwanted placement in a nursing facility. This policy imbalance removes the ability of people with disabilities to choose where to live, and funnels people into the more expensive setting option. It is important to note that retroactive coverage is only paid if the person was determined to be eligible for Medicaid; in other words, Medicaid will not cover costs for an individual who was not eligible for Medicaid at the time they received care or services, therefore ensuring financial protection for states and the federal government.

The following legislative language could be added at the end of Section 1902(a)(34) of the Social Security Act (42 U.S.C § 1396(A)(34)) to address this disparity:

- *If care or services are provided through a plan of care or any similar document, including but not limited to services provided under the authority of any provision of 42 U.S.C. §§ 1315 or 1396n, medical assistance must be available pursuant to this subsection without regard to whether the plan of care or similar document was developed or approved before or after the care or services were provided.*[11]

Under presumptive eligibility, evaluators can use a simplified process involving basic financial information and screening tools to determine if a low-income individual is eligible for Medicaid services before making a formal determination. In the HCBS context, states can implement presumptive eligibility to allow people with I/DD to access HCBS as their need arises, providing recipients with the option to receive services in the setting of their choice. This issue uniquely impacts adults with I/DD who often must additionally prove their diagnosis occurred during the

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[9] 1 Section 1902(a)(34) of the Social Security Act, codified at 42 U.S.C. § 1396a(a)(34), requires states to "provide that in the case of any individual who has been determined to be eligible for medical assistance under the plan, such assistance will be made available to him for care and services included under the plan and furnished in or after the third month before the month in which he made an application (or application was made on his behalf in the case of a deceased individual) for such assistance if such individual was (or upon application would have been) eligible for such assistance at the time such care and services were furnished[.]".

[10] CMS, Application for a § 1915(c) Home and Community-Based Waiver; Instructions, Technical Guide and Review Criteria, at 52, 73 (Appendix B), 190 (Appendix D-1).

[11] Justice in Aging, 2019, Medicaid Retroactive Coverage.

developmental period (i.e. before age 18), requiring decades old record reviews from childhood services which may never have occurred or no longer exist.

However, only six states have implemented HCBS presumptive eligibility. Two additional states have used waiver authority during the public health emergency to implement presumptive eligibility for people needing HCBS**.** Allowing retroactive coverage of HCBS would remove the most significant barriers to state adoption of presumptive eligibility for HCBS. The legislative language above could be accompanied by instructions to CMS to provide guidance to states regarding the application of presumptive eligibility to HCBS in light of changes to retroactive coverage. These two policies combined would allow older adults and people with disabilities in need of services greater opportunity to exercise choice and would reduce more expensive placements in institutional facilities.

C. *Should waitlists be eliminated for certain classes of beneficiaries immediately (such as military or veteran families with disabled children) while other waitlist reforms are implemented over a longer period of time?*

There is currently insufficient data available to measure or determine need or priority across populations, services, and states.

Waitlists are currently implemented and measured with considerable variability across state systems. For example, one state may calculate its waitlist by the number of people eligible for a service while another may only count people with no other source of support. Further, some states prioritize their waitlists by risk of institutionalization while others maintain a first-come, first-served basis. Moreover, two states may maintain the same budget for services with one offering a comprehensive service array with a waitlist and another with a much smaller service offering without a waitlist.

There is currently no baseline set of standards all waiting lists are required to meet. Nor is there a publicly available database of all waiting lists and priority systems across the United States. This impedes any ability to compare waitlists across states or populations or suggest eliminating waitlists for certain classes in an informed and equitable way.

We recommend Congress require states to make the following information on waiting lists publicly available and updated at least quarterly:

- The number of people waiting on each list;
- The criteria for eligibility and prioritization; and
- Any other criteria the state uses to determine placement and movement within the list.

It would also be helpful to require Assistant Secretary for Planning and Evaluation (ASPE) or other subagencies at HHS to study the different standards that states use for waiting lists and propose best practices.

Additionally, while state waiting lists generally refer to waiting lists comprised of people who are eligible for HCBS but are not authorized for funding due to limitations of the state's Medicaid budget, these are not the only waitlists faced by people with disabilities eligible for HCBS. Even after being removed from a state waiting list, people with disabilities may not find a provider available to offer them services for years at a time due to the workforce crisis. We recommend any waitlists resulting from the workforce crisis be publicly maintained in addition to waitlists for funding.

D. *Please provide any relevant data regarding the characteristics of waitlist populations, the costs of those individuals, and any other data relevant to waitlist reform.*

As noted in this committee's report, certain populations are more susceptible to being left lingering on state waiting lists. On average, people with I/DD experience longer wait times than other populations and constitute a disproportionate number of those currently on waiting lists. In fact, in 2017, people with I/DD comprised 67% of total waiver waiting list enrollment.[12] More must be done to ensure people with I/DD are not categorically excluded from accessing services relative to other populations.

As discussed above, there is currently little available data on waitlist populations, and we recommend engaging CMS in a review and report of waitlist methodologies and priorities to expand on the below reports:

- MACPAC, August 2020, State Management of Home- and Community-Based Services Waiting Lists
- Kaiser Family Foundation, April 2019, Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists

Competitive Integrated Employment and Meaningful Day

We deeply appreciate Republic Leader McMorris Rodgers' commitment to transitioning to competitive integrative employment through her sponsorship of the Transformation to Competitive Integrated Employment Act (TCIEA). We support the gradual phase out section 14(c) certificates coupled with supports to enable states to transition to competitive integrated employment. The TCIEA's discerning approach to strengthen the employment opportunities while also providing the necessary support to transition current certificate holders to business models to competitive integrated employment offers workers with disabilities choice and continuity of employment supports.

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[12] Kaiser Family Foundation, 2019, Key Questions About Medicaid Home and Community-Based Services Waiver Waiting Lists.

We also appreciate the TCIEA's inclusion of a technical assistance center which supports employers to make the transition while offering the services workers with disabilities may need to make the position successful. Many community providers are interested in making the transition to competitive integrated employment, but without the guidance and necessary funding to transition they risk disrupting support for workers with I/DD, leaving those individuals simultaneously without an employer and provider.

Similarly, many community providers seek opportunities to transition from congregate day programs to meaningful day and life supports. Rich and hands-on technical assistance for providers is critical to successful transitions which improve community integration and inclusion. The lack of technical assistance was a serious problem pre-COVID and has only become more exacerbated with the catastrophic workforce crisis.

Conclusion

We again wish to express our sincere gratitude for this opportunity to provide information and your dedication to removing barriers and expanding the rights of people with disabilities. Please reach out to our Director of Policy, Regulatory, and Legal Analysis, Lydia Dawson, at ldawson@ancor.org if we can provide further clarification or information to the above.

Sincerely,

Shannon McCracken

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VP of Government Relations