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September 26, 2022

The Honorable Cathy McMorris Rodgers
Ranking Member
Energy and Commerce Committee
U.S. House of Representatives
2322 Rayburn House Office Building
Washington, DC 20515

Re: Request for Information on Disability Policies in the 21st Century: Building Opportunities for Work and Inclusion

Dear Ranking Member McMorris Rodgers:

On behalf of the Medicaid and CHIP Payment and Access Commission (MACPAC), I am pleased to offer these comments in response to your request for information (RFI) on policies that affect individuals with disabilities. As you know, MACPAC is a nonpartisan legislative branch agency that provides policy and data analysis and makes recommendations to Congress, the Secretary of the U.S. Department of Health and Human Services, and the states on a wide array of issues affecting Medicaid and the State Children's Health Insurance Program (CHIP). MACPAC appreciates this opportunity to share insights from our work over the last several years.

The RFI seeks stakeholder input on a wide array of Medicaid and other long-term care issues, with a focus on three areas: (1) access to long-term services and supports (LTSS), (2) accommodations in the community, and (3) barriers to integrated employment. Our comments focus on access to LTSS, an area where we have developed a body of work, in three areas: home- and community-based services (HCBS) waiver waiting lists, barriers states face to increasing access to HCBS, and estate recovery. Our comments draw on the following MACPAC analyses:

- An issue brief and compendium on HCBS waiver waiting lists that details select information on waiver capacity and waiting list management practices (MACPAC 2020a, 2020b);
- A contractor report that identifies barriers that states face in trying to increase the share of beneficiaries receiving HCBS compared to institutional care, as well as opportunities to address these barriers (Bernaceti et al. 2021);
- A roundtable of experts that MACPAC convened on the HCBS delivery system and potential opportunities and considerations for designing a core HCBS benefit of services (Albaroudi and Vardaman 2022); and
- A chapter in our March 2021 report to Congress on the burden of Medicaid estate recovery on beneficiaries and states (MACPAC 2021a).

In the coming year, the Commission will continue its work in the LTSS space with a focus on access to HCBS and financial eligibility.



HCBS Waiver Waiting Lists

The RFI asks about waiting lists as a barrier to accessing HCBS and considers whether they should be eliminated for certain populations. In 2020, MACPAC analyzed Section 1915(c) and Section 1115 waiver documents for all 50 states and the District of Columbia. As part of that work, we compiled selected information on HCBS waiver capacity and waiting list management in a *Compendium of Medicaid Home- and Community-Based Services Waiver Waiting List Administration*, conducted stakeholder interviews, and described the results in an issue brief (MACPAC 2020a, 2020b). We heard from stakeholders that waiting lists are indicative of unmet need for HCBS waiver services, however, they are an imperfect measure (MACPAC 2020b).

While waiting lists vary in their size, the length of a waiting list is not a precise measure of unmet need for HCBS waiver services. In particular, eligibility screening for waiver services happens at different times in different states, making it difficult to compare waiting lists across states (MACPAC 2020b). Seven states do not screen for eligibility before placing people on waiting lists; individuals on waiting lists in these states account for 59 percent of the national total waiting list population. Most states with waiting lists also allow individuals to be on more than one waiting list at a time (O'Malley Watts et al. 2022). While some individuals on waiting lists in states that do not screen for waiver eligibility first may not qualify for waiver services, a few interviewees said that the likelihood that individuals with intellectual and developmental disabilities (ID/DD) would be eligible for waiver services was high. (MACPAC 2020b).

A state's waiting list management approach can influence the length of its waiting list. For example, a first-come, first-served approach—the most commonly used—can encourage individuals to seek enrollment in anticipation of future needs. This would be particularly true in states that do not screen for eligibility prior to waiting list placement. For example, in some states, families add their children at a young age to waiting lists for services offered to individuals with ID/DD, assuming that by the time they reach the top of the waiting list, they will have developed the need for services (MACPAC 2020b).

Waiting list times vary among states and within some states by waiver. One study found that among all populations, in 2020, the average wait time for waiver services was 44 months, but there was substantial variation among populations, with a range of 1 month for individuals with HIV/AIDS to 60 months for individuals with ID/DD (O'Malley Watts et al. 2022). Among states that we interviewed, estimates of wait times ranged from less than 1 year to 14 years. Wait times also differed within states among their various waivers, often by differences of more than five years (MACPAC 2020b).

State funding was cited as the most important factor in many states for increasing waiver capacity, with the number of waiver slots dependent on the state funding that the Medicaid or other operating agency receives. In some states, explicit support from the governor or the state legislature has led to funding increases that helped reduce waiting lists (MACPAC 2020b).

Stakeholders noted that beneficiaries may get their HCBS needs met through state plan services or support from family caregivers while they wait for an HCBS waiver slot to become available. It is difficult to judge how many people on waiting lists are actually going without any HCBS because states do not track how individuals meet their care needs while waiting for waiver services. Some states periodically reassess the needs of individuals on waiting lists, and sometimes find individuals who are eligible for state plan services that would meet their needs in lieu of waiver services (MACPAC 2020b). All but two states that responded (out of 42 states) to a recent survey reported that individuals on waiting lists receive Medicaid state plan HCBS (O'Malley Watts et al. 2022).

Many individuals with HCBS needs have informal supports, such as family caregivers, who provide care. When asked how individuals manage their needs while waiting for services, interviewees most frequently cited support



provided by family caregivers. Many caregivers are unpaid, although some may be paid when services are provided through waivers that allow for self-direction of services. One state said that they use state-only funding to provide a caregiver respite benefit (MACPAC 2020b). Given the key role of family caregivers for many people in need of HCBS, the loss of a caregiver can change a person's level of need for waiver services to urgent.

At the time of our interviews, many states were experiencing or anticipating a growing need for waiver services; and some anticipated increasing difficulty meeting HCBS needs in the future. Both states and advocacy organizations expressed concern over the effect that an aging population would have on state capacity. At the same time, some states were experiencing increasing demand for HCBS waiver services for children. Several stakeholders also noted that even if waiting lists were eliminated or reduced, there may not be adequate HCBS workforce capacity to meet the increased demands (MACPAC 2020b).

Increasing lifespan and service intensity also affect states' ability to meet the needs of individuals with ID/DD. Several interviewees noted that people with ID/DD receive waiver services for many years and thus waiver slots do not open up as frequently as they do for older adults. As more individuals with ID/DD live longer and maintain community placements, this may result in longer wait times for waivers serving individuals with ID/DD (MACPAC 2020b). There are more waiting lists for individuals with ID/DD, and often more people on those waiting lists, than those for older adults or individuals with physical disabilities (O'Malley Watts et al. 2022). Two states also noted that people are entering state HCBS systems with greater needs than those leaving the system (MACPAC 2020b).

MACPAC has not conducted any follow up work on HCBS waiting lists beyond our compendium and issue brief published in 2020 but there are other available sources of information on waiting lists. For example, the Kaiser Family Foundation (KFF) publishes an annual survey of states, and in their most recent report for fiscal year (FY) 2020 found that 39 states have a waiting list for at least one HCBS waiver, with over 665,000 people on waiting lists. People with ID/DD comprised 70 percent of the total waiver waiting list population; however, there is state variation based on the approach toward waiting list management. In the seven states that do not screen for eligibility first, individuals with ID/DD comprise 86 percent of the waiting list population, while in the 32 states that do screen first, they comprise 47 percent of the population. In these 32 states, a greater share of the waiting list population (52 percent) is older adults and people with physical disabilities (O'Malley Watts et al. 2022).

Long-Term Services and Supports

The RFI also asks how Congress can reduce or eliminate Medicaid's institutional bias. Shifting the balance of Medicaid spending from institutional services to HCBS has been a federal and state policy goal for several decades. At the national level, this goal has been achieved. Medicaid spending on HCBS has exceeded spending on institutional care since FY 2013 (Murray et al. 2021). The federal government has supported state efforts to increase access to HCBS through several initiatives, including the Balancing Incentive Program and the Money Follows the Person (MFP) demonstration.

In 2020, MACPAC contracted with RTI International to better understand the factors that affect states' efforts to increase access to HCBS. RTI conducted stakeholder interviews and developed case studies of five states (Louisiana, Mississippi, New Jersey, North Dakota, and West Virginia). MACPAC published the contractor report *Examining the potential for additional rebalancing of long-term services and supports: Final report* on its website in 2021 (Bernacot et al. 2021). Some of the barriers and issues that states were facing at the time of our interviews have been exacerbated by the COVID-19 pandemic, which other groups such as KFF have reported on (O'Malley Watts et al. 2022).



During interviews with states, one key barrier to increasing HCBS that was identified was limited state support, particularly a lack of executive and legislative champions. In one state, beneficiary advocates noted that they had never heard state officials openly discuss rebalancing as a state priority. Although state officials had noted recent efforts to increase access to HCBS, the beneficiary advocates in that state attributed all of those efforts to Olmstead settlements rather than specific state policy priorities (Bernacot et al. 2021).¹

States also have a limited number of staff available with expertise to administer complex HCBS programs. It can be difficult for states to operate HCBS programs that are primarily based on staff knowledge and community connections. Increasing access to HCBS requires a consistent pool of state staff that have knowledge and expertise in the various parts of the LTSS system, including payment and service delivery. Several stakeholders cited the MFP program as particularly helpful in providing the resources necessary for states to establish staff with relevant knowledge and expertise (Bernacot et al. 2021).

Persistent and growing LTSS workforce shortages are another primary barrier to increasing HCBS. All interviewees discussed workforce shortages across all long-term care settings and among different provider types, but emphasized unique challenges in recruiting and retaining direct care workers (e.g., home health aides, personal care aides, certified nursing assistants). Employed by HCBS provider agencies or, increasingly, through independent arrangements with beneficiaries and their families, direct care workers drive the delivery of HCBS, providing beneficiaries assistance with activities of daily living such as eating, bathing, and getting dressed (Bernacot et al. 2021). For more information on Medicaid HCBS workforce issues, please see our issue brief [State Efforts to Address Medicaid Home- and Community-Based Services Workforce Shortages](#).

In some states, stakeholder relationships can influence state efforts to increase HCBS. The influence of nursing facility industry advocates was cited by most of the national-level stakeholders interviewed as a challenge to efforts to increase access to HCBS across the country (Bernacot et al. 2021). Nursing facility provider taxes often finance a large portion of a state's LTSS budget, which is also often a significant percentage of the state's overall budget (KFF 2017). In addition, in rural areas, nursing facilities can be the largest employers, and efforts to increase access to HCBS may cause concern about job loss. As an example of how this dynamic can play out, interviewees in one case study state shared that the legislature passed a series of laws that essentially guaranteed continued rate increases for nursing facilities without requiring the same rate enhancements for HCBS providers. In two of the five states examined in this study, state-level stakeholders perceived nursing facility industry advocates as being strongly resistant to increasing access to HCBS (Bernacot et al. 2021).

An additional barrier is a lack of affordable and accessible housing, particularly for residents of institutional care facilities attempting to transition back to the community and for some individuals at risk of nursing facility placement. This issue is exacerbated further in rural settings. Furthermore, affordable housing that is available to LTSS beneficiaries often lacks one or more of the necessary characteristics that would make the housing option accessible for them (e.g., access ramp, wheelchair or walker friendly entrances and halls, etc.).²

Finally, there is limited public awareness and understanding of HCBS options. The medical community and many families' beliefs about where care should be provided for older adults can impede efforts to increase access to HCBS. The hospital-to-nursing home pathway is difficult to overcome, and the referral process to the nursing home is much easier than the multi-step process involved for HCBS referral and access. Moreover, nursing homes can accept a hospital patient immediately and then work on eligibility. Conversely, a beneficiary cannot start accessing community services until after the state has worked through the entire eligibility process, eligibility has been determined, and a plan of care has been developed (Bernacot et al. 2021).

In December 2021, MACPAC convened a roundtable of federal and state officials as well as national experts to consider the design of the Medicaid HCBS benefit with an eye toward streamlining access to and simplifying the



administration of HCBS. We presented the results of the roundtable discussion at our March 2022 public meeting (Albaroudi and Vardaman 2022). One of the key takeaways was that a core benefit, or any other approach to redesign the HCBS benefit, should promote person-centeredness and equitable access to services in order to support meaningful community living. Also, any redesign of the HCBS delivery system needs to weigh the tradeoffs between standardization and uniformity with state flexibilities, a longstanding Medicaid principle. A redesign also needs to consider the diverse needs of the people who use LTSS. Implementation considerations in rethinking the HCBS benefit include state and federal capacity to operationalize a novel approach to HCBS delivery systems. Finally, given existing disparities in HCBS by race, ethnicity, and geography, roundtable participants emphasized the need to promote equitable access to care that is also culturally competent.

Roundtable participants reiterated how HCBS workforce capacity is an essential consideration in any discussion of increasing access to services. A 2021 survey of HCBS agencies found that 77 percent have turned away new referrals, 58 percent have discontinued certain programs or services, and 84 percent have delayed programs due to staffing shortages (ANCOR 2021). Due to the current shortage of HCBS workers, there likely would not be enough providers to meet an increased demand for HCBS services that could arise from increasing access to HCBS. MACPAC has observed that states are using new federal dollars provided in the American Rescue Plan Act (ARPA, P.L. 117-2) to address workforce shortages, and plans to monitor efforts that could inform future work.

Estate Recovery

MACPAC published a chapter in its March 2021 report to Congress on estate recovery (MACPAC 2021a). During the course of this work, we reviewed the literature and federal guidance on estate recovery program operations; analyzed the results of a survey on assets held by Medicaid decedents age 65 and older; analyzed Medicaid state plans to understand the extent to which states pursue recovery beyond minimum federal requirements; compiled aggregate data on estate recovery collections; surveyed a sample of states regarding the number and size of estates recovered, hardship waivers granted, and probed as to whether these states would continue to pursue estate recovery if this requirement were made optional, as it was prior to 1993; and interviewed stakeholders and reviewed the literature for insights into whether estate recovery has affected access to LTSS.

States are required to seek recovery from the estates of certain deceased beneficiaries for payments for LTSS and related services. Since 1993, estate recovery has been mandatory for individuals expected to be permanently institutionalized; those age 55 or older when they received Medicaid LTSS and related services; and those with long-term care insurance policies, under certain circumstances. The chapter included three recommendations:

- Congress should amend Section 1917(b)(1) of Title XIX of the Social Security Act to make Medicaid estate recovery optional for the populations and services for which it is required under current law.
- Congress should amend Section 1917 of Title XIX of the Social Security Act to allow states providing long-term services and supports under managed care arrangements to pursue estate recovery based on the cost of care when the cost of services used by a beneficiary was less than the capitation payment made to a managed care plan.
- Congress should amend Section 1917 of Title XIX of the Social Security Act to direct the Secretary of the U.S. Department of Health and Human Services to set minimum standards for hardship waivers under the Medicaid estate recovery program. States should not be allowed to pursue recovery for: (1) any asset that is the sole income-producing asset of survivors; (2) homes of modest value; or (3) any estate valued under a certain threshold. The Secretary should continue to allow states to use additional hardship waiver standards.



The RFI seeks feedback on our first recommendation, as well as other financial eligibility policies that apply to individuals who use Medicaid LTSS. MACPAC appreciates the Committee's interest in our recommendation and reaffirms that taking up this recommendation could help to address equity concerns about how this practice perpetuates generational poverty and wealth inequality. MACPAC has not conducted further work on estate recovery since 2021, but others have conducted potentially applicable work (e.g., Cornelio et al. 2021, Colello and Morton 2019, Colello 2017, Johnson 2016). We highlight the following information from the chapter as highly relevant to the questions posed in the RFI.

Making estate recovery optional

States should have the option to eliminate estate recovery. This would allow states that determine the return on investment is low to cease recovery, while permitting states that find estate recovery useful to continue the practice. Were Congress to take this step, we expect that some states would opt out (MACPAC 2021a).

MACPAC spoke with a number of stakeholders who supported making estate recovery optional, noting that the current policy primarily does not affect beneficiaries with sizable resources in their estates after their death and instead affects beneficiaries with modest means. Individuals with greater awareness of estate recovery and resources may protect their assets from estate recovery while preserving Medicaid eligibility, allowing resources to be passed on to their heirs. Stakeholders noted that individuals with little income and few assets besides a home, however, are less likely to be aware of estate recovery or have the resources to obtain an attorney. In addition, unless someone is able to protect assets, Medicaid eligibility rules require they impoverish themselves, except for assets that are not counted toward eligibility. As a result, the estates that actually get pursued are usually modest in size. For heirs of these modest estates, estate recovery may remove a source of income or a residence which, if retained, would protect the heirs from poverty or housing insecurity. Given that estate recovery likely only occurs for those without the resources and awareness to avoid it through estate planning, making it optional will help address equity concerns we heard in our interviews (MACPAC 2021a).

Effects of estate recovery on seeking Medicaid coverage

A criticism of estate recovery policies is that they reduce access to Medicaid-covered LTSS. In our stakeholder interviews, beneficiary advocates, elder law attorneys, and state officials all commented that some people choose to forego or delay Medicaid LTSS for fear of estate recovery and losing their home. As one interviewee noted, delays in LTSS can lead to poor health outcomes (MACPAC 2021a).

Although stakeholders could not quantify how many individuals are deterred from seeking Medicaid LTSS due to estate recovery, prior research noted it as a barrier to enrollment in Medicare Savings Programs (MSPs), which provide assistance with Medicare cost sharing (Nemore 2007, Sanchez 2007). As such, the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA, P.L. 110-275) barred estate recovery collections for premiums, deductibles, and coinsurance made on behalf of individuals participating in MSPs. In addition, estate recovery as a deterrent to Medicaid enrollment was also raised as a concern for the new adult group when the Commission previously explored this issue (MACPAC 2015, Schilling 2015, Brown 2014). A number of states subsequently eliminated estate recovery from populations that they are not required to pursue (MACPAC 2015).

Although fear of estate recovery may deter some individuals from seeking Medicaid LTSS, awareness and understanding of estate recovery policies by the general public and by Medicaid beneficiaries is low. Individuals may first learn about estate recovery during the Medicaid application process, as information is included in the rights and responsibilities section of the application. Two stakeholders, however, noted that this can get lost in the fine print of long applications, and questioned how many people read or understand that information. Additionally, interviewees noted that individuals who have urgent needs for services may not have the time or ability to consider estate recovery policies. Finally, one stakeholder pointed out that even though a Medicaid beneficiary



may be aware of estate recovery, if they do not pass that information along to the beneficiaries of their estate, it can come as a surprise to those individuals after the enrollee's death (MACPAC 2021a).

Assets held by older adults

The RFI also seeks feedback on policies related to the assets of beneficiaries who use Medicaid LTSS, such as home equity limits and asset limits. While MACPAC's prior work does not explicitly address the questions raised in the RFI, we analyzed data related to household wealth as part of our estate recovery work.

Data related to household wealth suggest that recoverable assets are quite limited for individuals who receive Medicaid-covered LTSS. The published literature on the assets held by older adults typically focuses on all individuals over a certain age or those with limitations in activities of daily living (JCHS 2018, Johnson 2016). To gain insight into the population of individuals likely to be subject to estate recovery, we contracted with researchers at the LeadingAge LTSS Center @UMass Boston, to review the Health and Retirement Study (HRS), a nationally representative longitudinal survey of adults age 50 and older. They identified Medicaid beneficiaries in the dataset who participated in the HRS and died during the 2012, 2014, and 2016 survey periods. The team then calculated the net value of total wealth based on reported assets, subtracting out the debts individuals held.

In general, this study found that, with some exceptions, the assets of older adults enrolled in Medicaid are quite modest, with a substantial proportion of individuals having little to no wealth. Therefore, the assets that Medicaid programs can recover after a beneficiary's death are limited, particularly for individuals who do not own their homes. More specifically, we found that three-quarters of beneficiaries had net wealth below \$48,500. At age 65 and older, the average net wealth among Medicaid decedents was \$44,393 and average home equity held by the total sample was \$27,364 (MACPAC 2021a).

Additional research on homeownership might also be useful. A 2018 report from the Joint Center for Housing Studies of Harvard University provides some context and data on homeownership and net worth of homeowners. The report found that in 2016, 65 million households were headed by individuals age 50 and older, and 76.2 percent of these households owned their homes. When stratified by race and ethnicity, however, the study found that 81 percent of white households age 50 and older owned their home compared to 57 percent of Black households, 60 percent of Hispanic households, and 71 percent of Asian American and other households headed by individuals age 50 and older (JCHS 2018). The report also found that in 2016, 41 percent of homeowners age 65 and older still had mortgages on their homes (JCHS 2018).

Additional Resources

MACPAC has conducted additional work that may be of interest to the Committee. In 2020, MACPAC contracted with Health Management Associates to develop a resource with comprehensive information about people with ID/DD and the Medicaid program policies and services that support their needs (Barth et al. 2020). (A plain language version of this report that is designed to be accessible to a wide audience, including people with ID/DD, is also available on our website (Blachowiak et al. 2021). That report briefly touches on employment services. Employment and day services are a growing component of HCBS for people with ID/DD, yet individuals are often unable to pursue their employment goals, participating in day services instead. In 2017, states spent over \$9.12 billion on these services. Over 641,600 people with ID/DD participated in employment and day services in 2017. However, only about 20 percent of people with ID/DD receive integrated employment services, despite CMS policy to encourage integrated employment (Barth et al. 2020, CMS 2019). Research indicates that ID/DD HCBS resources have not shifted away from facility-based work toward integrated employment, and participation in non-work day services continues to grow. In 2017, less than 12 percent of HCBS day and employment funding was



spent on integrated employment services, yet research has documented that many people with ID/DD want to participate in the general workforce. Among individuals who do not have a paid job in the community, nearly half indicate they would like a job. Within this group, 60 percent do not have this goal documented on their individual person-centered plan (Barth et al. 2020).

As part of MACPAC's issue brief on the HCBS workforce, we provided some brief information on family caregivers (MACPAC 2022). Beneficiaries receiving care from paid family members have similar satisfaction with their care and similar community living outcomes to those receiving paid care from others (Edwards 2014). The use of family caregivers allows many beneficiaries to select care that is culturally competent and in the language they speak. Additionally, family caregivers can often provide more flexible hours than other providers. Historically, however, federal policy has restricted Medicaid's ability to pay family caregivers. For example, state plan personal care options do not allow spouses or legal guardians to be paid for providing care, but states do have the option to pay this group using Section 1915(c) waivers.

Due to the HCBS workforce shortage and the COVID-19 pandemic, there has been growing interest in expanding which family members can be paid to provide care. In 2020, 17 states used Appendix K flexibilities permitted by the public health emergency to allow more payment for family caregivers in their Section 1915(c) waivers (Ujvari et al. 2020). Additional funding (an estimated \$12.7 billion) for HCBS was made available under ARPA. ARPA provides states with a temporary 10 percentage point increase to the federal medical assistance percentage for HCBS. States have until March 31, 2025 to use this funding (CMS 2022). Thirty states plan to use ARPA funds to support family caregivers, seven of which specifically plan to increase pay to family caregivers (NASHP 2021).

Other groups have more in-depth work on family caregiving, such as the Center for Health Care Strategies, KFF, and the National Academy for State Health Policy (NASHP) (Ralls 2022, Musumeci et al. 2021). The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act of 2017 (P.L. 115-119) created the RAISE Family Caregiving Advisory Council, which released a report to Congress in 2021 and is currently developing a national family caregiving strategy (RAISE Family Caregiving Advisory Council 2021). To support the council's work, NASHP created the RAISE Act Family Caregiver Resource and Dissemination Center to provide resources and convene experts on family caregiving issues. A recent post on their website, for example, notes that the median percentage of Section 1915(c) waiver funding allocated for respite care is 0.49 percent of total waiver costs (Hodges 2022).

Conclusion

We hope these findings from MACPAC's work examining access to HCBS, barriers states face in increasing access to HCBS, and estate recovery are helpful as the Committee considers future policy options. We appreciate the Committee's work in this area and commitment to increasing access to meaningful community living for Medicaid beneficiaries.

Sincerely,



Melanie Bella
Chair



Endnotes

¹ The Supreme Court ruled in *Olmstead v. L.C.*, 119 S. Ct. 2176 (1999) that the unjustified institutionalization of individuals with disabilities violated the American with Disabilities Act of 1990 (ADA, P.L. 101-336) (MACPAC 2019).

² For more general information on Medicaid housing policy, please see our issue brief [Medicaid's Role in Housing](#).

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