October 06, 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 Cathy McMorris Rodgers,

The undersigned members of the Disability and Aging Collaborative (DAC), and state partners, thank you for the opportunity to comment on your report, *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 and older adults. DAC is a coalition of approximately 40 national organizations that work together to advance long-term services and support (LTSS) policy at the federal level. Below are our responses to the requests for information in your report.

1.1 Regarding Medicaid's Institutional Bias

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

Addressing the Direct Care Workforce Crisis

As a critical consideration of reducing or eliminating the institutional bias in Medicaid, it is important to raise an issue that was not discussed in the summary of the challenges preventing access to Long-Term Services and Supports (LTSS). There is and has been for many decades a workforce crisis in Home and Community Based Service (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 supports and services. The effects of underinvestment in the direct care 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 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 care workers nationally is simply

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[1] 2020StaffStabilitySurveyReport_FINAL.pdf (nationalcoreindicators.org)

insufficient to slow the exodus of direct care workers from the field and the closure of programs which threatens access to LTSS. 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 care workers 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 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 close leaving people with disabilities without choice or options of community-based settings for support even after authorized to seek services. Simply expanding benefits without creating a sustainable workforce and infrastructure may unintentionally increase reliance on institutions and institutional bias.

Home and Community Based Services as 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 need them. Overwhelmingly, older adults and people with disabilities prefer to receive LTSS in their own homes and communities. Yet, too many low-income older adults and people with disabilities are forced into institutional settings to receive the care they need, particularly for women, communities of color, and individuals with Alzheimer's disease or other dementias. While nursing home use has steadily been declining among white older adults, for example, use has increased among Hispanic, Asian, and Black older adults in part due to the fact that communities of color have less access to home and community-based services.

As the discussion sections of the memo lay out, "HCBS care remains an optional service for

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

[3] the_state_of_americas_direct_support_workforce_crisis_2021.pdf (ancor.org)

states" resulting in waiting lists for services and people with disabilities and their families unable to move between states. This is despite the lower cost of many HCBS services when compared with the cost of institutional care. The current status quo requiring the coverage of institutional services, while HCBS are optional, leaves HCBS disproportionately vulnerable to cuts while protecting institutions, despite the fact that HCBS are more cost-effective, lead to better outcomes, and are the preference of most service recipients.

Furthermore, as long as states are allowed to impose limits to the provision of HCBS beyond assessments of need, while institutional services must be made available to all who need them, the two service types will never be on equal footing. States will continue to use this dial to manage their budgets by denying HCBS to people who need it, an option not available in regards to institutional care.

We recommend Congress implement a basic set of HCBS as mandatory benefits with the following considerations:

- 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 care workers can be raised to competitive rates within local markets;
- A baseline set of services, identified via engagement of beneficiaries and their advocates, will need to be covered by all states to ensure that people with disabilities of all ages, older adults, and their families can move from state to state;
- People with disabilities and older adults themselves, including those from underserved communities, should be involved at all levels of development of new services and the incorporation of them into Medicaid.
- 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 intellectual and developmental disabilities, 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 and oversight from the Centers for Medicare and Medicaid Services (CMS) and the Administration for Community Living (ACL).

Creating these mandatory benefits will not change current access to institutional services or eligibility for Medicaid. Rather, it will ensure that people with disabilities who are currently eligible for Medicaid have a choice to receive care in the community without being trapped in institutional settings and/or within a single state.

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 to reduce the bias and ensure that states can maintain a robust community service system as an alternative to institutionalization. These involve addressing the workforce crisis, reducing waiting lists, collecting demographic data to identify disparities in access and quality, and building out state systems to ensure community services are meeting the needs of service recipients:

We recommend that Congress continue the increased federal matching percentage (FMAP) for HCBS to allow for states to continue to rebuild infrastructure after the pandemic and ensure that workers are paid competitive market rates.

States are currently receiving a 10% FMAP bump for HCBS and as the National Association of State Directors of Developmental Disabilities Services (NASDDDS) reports, this funding is being used by at least 44 states to address the workforce crisis.[4] This funding has been particularly crucial in response to the challenges the pandemic created for the HCBS system. Extending this funding when it runs out would allow states to continue their work to eliminate institutional bias.

We recommend Congress implement certain data and reporting requirements to facilitate strengthening HCBS systems.

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. The direct care 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. Addressing the institutional bias is meaningless if there is no workforce to offer community services and no means of measuring the availability of a service.

To establish a baseline of workforce data, Congress should direct CMS to develop and require state reporting on, at minimum, the following metrics:

- Workforce Volume (availability):

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[4] NASDDDS, State Workforce Initiatives, ARPA Spending Plan Topical Analysis (Aug 2021).

    - Data elements that will help stakeholders to identify to what extent workforce shortages are disproportionately impacting access to specific services, including self-direction.
    - Data stratified by age, race/ethnicity, gender, disability, and primary language (including a comparison of workforce language competency compared to indicated language preferences of person supported). This will require Congress and CMS to address IT infrastructure investments.

- Workforce Stability (retention/turnover):
    - The average annual turnover rates (percentage of direct care workers 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 care workers 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 care workers compared to similar positions in institutional settings; and
    - The proportion of HCBS reimbursement rates that is included for the purpose of ensuring that direct care wages and benefits are sufficient.

Congress should direct CMS to work with stakeholders, including beneficiary advocacy organizations, to determine appropriate and attainable data elements to identify these disparities. These enhanced data collection requirements will necessitate increased federal investments. Given the variations in HCBS programs, it is also critical for CMS to have a fundamental understanding of the services currently available to strengthen the existing service infrastructure. To establish a baseline of service data, Congress should direct CMS to further build on the HCBS taxonomy and, at minimum, publish the following national trend analyses:

- A report on state waivers and current utilization of HCBS programs;
- A report on state waiting lists, including eligibility and priority; and
- A report on state reimbursement rate methodology and frequency of review for HCBS services.

We also recommend Congress direct CMS to develop metrics which evaluate access to HCBS.

Measuring access to LTSS 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[5]. 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 (1) 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 (2) 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 and community inclusion is less reliable.

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

- If needed services are being authorized. In LTSS 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 less services and support than they need, which can lead to serious consequences.
- If provider capacity is sufficient. This should include 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.

Additionally, technical assistance from CMS and funding is needed to support the establishment and implementation of a uniform set of demographic data, utilization, and access measures across HCBS and LTSS to enable states to deploy targeted strategies that better account for peoples' needs, including intersectional needs resulting from heightened vulnerabilities. For example, gathering information on people's geographic location will allow states to better understand access and utilization trends amongst rural older adults and people with disabilities, aiding in the identification of rebalancing challenges and, correspondingly, the development of tailored community-based services that reduce nursing home placements.

- Suggested demographic elements include information about a person's race, ethnicity, sexual orientation, gender identity, age, disability status, primary language, geography, and other demographic factors.
- Suggested utilization and access information comprise data on approvals, denials,

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[5] https://clpc.ucsf.edu/publications/managed-long-term-services-and-supports-assessing-provider- network-adequacy

terminations, grievances, and rebalancing.

- Analysis should stratify utilization and access information by demographic elements to identify disparities in HCBS access and care quality.
- Funding is needed to support CMS in establishing these measures and to support state-level implementation.

We recommend that Congress consider new legislation to begin to address the institutional bias and the workforce crisis moving forward.

There is currently a regulatory structure addressing access to institutional services offered through state plans, but no equivalent focus on access to HCBS currently exists. Developing standards and strategies for access to HCBS would decrease institutional bias and ensure equal access to community-based services. In addition to extending the increased FMAP, as addressed above, legislation addressing the following issues would support and preserve access to the current HCBS infrastructure:

- Developing equal access standards for HCBS and managed care; and
- Requiring states to review HCBS payment rates at least every three (3) years and to include an automatic annual inflation adjustment.

We urge Congress to pass H.R. 4779 / S. 1437, the Standard Occupational Classification for Direct Support Professionals Act.

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. 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.[6] 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.

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

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[6] Health Management Associates, *Review of States' Approaches to Establishing Wage Assumptions for Direct Support Professionals When Setting I/DD Provider Rates,* July 6, 2022.

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 will support adequate payment rate methodology and transparent data collection.

We recommend that Congress make the Money Follows the Person Program and the Spousal Impoverishment Protections for HCBS permanent to ensure that people with disabilities and older adults who do not want to live in institutions have that flexibility.

Money Follows the Person (MFP) 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 transitioning 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 (3) year renewal available through September 2023. These short-term renewals do not give states the stability they need to implement the program, leaving many waiting to transition into the community until a more permanent solution is reached.

- To strengthen the impact of MFP specifically, we recommend the following:
    - Make MFP permanent.
    - The program is currently only available in 33 states. To reduce institutional bias, we encourage expanding this program to every state.
    - In January 2022, CMS increased the reimbursement rate for “supplemental services” to eliminate barriers that inhibit transitions to the community. Supplemental services include, among other provisions, short-term housing and food assistance. Continued funding for supplemental services is critical to increasing the community transition rate and effectiveness of the Money Follows the Person program.
    - Congress should direct CMS to conduct an analysis using demographic elements that include race, ethnicity, sexual orientation, gender identity, age, disability status, geographic location, and languages spoken to understand program utilization rates amongst specific populations to ensure equitable access.

There also remains an institutional bias disparately impacting married individuals. Medicaid currently requires modified eligibility rules for spouses when one spouse needs and chooses institutional care. This allows the “community spouse” to maintain their income and assets while the “institutional spouse” meets impoverishment eligibility requirements. However, this requirement only extends to spouses choosing institutional care, leaving a spousal impoverishment requirement when choosing HCBS. In 2010, Congress expanded the spousal impoverishment protection to HCBS, but this is set to expire December 2023. Making MFP and spousal impoverishment protections permanent are critical steps to reducing institutional bias in current programs.

We recommend allowing individuals admitted to institutions for temporary stays to maintain their homes to facilitate their return to the community

Many individuals enter a nursing facility or other institution for short-term stays but often do not have a place to return to because they cannot pay to maintain their home while in the facility. Medicaid does allow an optional deduction from an institutional co-payment to pay for home maintenance for up to six months. However, most states have narrowly construed this provision and only permit the deduction for individuals who own their homes, therefore inequitably excluding renters. Furthermore, the deduction amount is usually so low that it is inadequate to help individuals maintain their homes. Establishing a federal minimum allowance based on the actual minimum cost of maintaining the home, including but not limited to mortgage or rent, property taxes, and required insurance, would allow individuals to keep their homes for short-term institutional stays. Allowing this would be a cost-saving measure, as it would prevent costly long-term institutional stays.

We recommend Congress cover HCBS services retroactively and make presumptive eligibility for HCBS a Medicaid standard to enable eligible individuals across states to immediately choose between HCBS and institutional care.

Retroactive coverage is a crucial financial protection for low-income, uninsured, and underinsured older adults who need LTSS. This protection in federal law requires the Medicaid program to pay retroactively for nursing home services received up to three months before the date an individual applied for Medicaid.[7] While federal policy allows Medicaid coverage for care provided in a nursing facility based upon immediate need, current federal law prohibits Medicaid programs from covering HCBS before the approval date of an HCBS service plan.[8] This disparity contributes to the institutional bias: a person can be admitted to a nursing home immediately but cannot get help at home immediately. Circumstances surrounding the need for

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[7] 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[.]”

[8] https://justiceinaging.org/wp-content/uploads/2021/09/Medicaids-Unfair-Choice.pdf

HCBS for many older adults and people with disabilities, such as a health emergency, the demand for LTSS following an illness, or other unexpected high-cost health needs, results in an inability to plan for needed services.[9] Additionally, the application process for HCBS can be lengthy, requiring multiple clinical evaluations and extensive financial documentation. 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 older adults and 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.*[10]

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 older adults and people with disabilities to access HCBS as their need arises, providing recipients with the option to receive services in the setting of their choice.[11] However, only six states have implemented HCBS presumptive eligibility. Two additional states used waiver authorities 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.

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[9] https://www.justiceinaging.org/wp-content/uploads/2019/09/Medicaid-Retroactive-Coverage-Issue-Brief.pdf

[10] Ibid.

[11] https://www.aarp.org/ppi/info-2021/ltss-choices-presumptive-eligibility-medicaid-home-community-based-services.html

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.*

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. Additionally, current data limitations inhibit an understanding of the populations that comprise waitlists. 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, including information on people's demographic characteristics, including age, disability, geographic location, race, ethnicity, sexual orientation, gender identity, and primary language;
- 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 the 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.

We recommend any waitlists resulting from the workforce crisis be publicly maintained in addition to waitlists for funding.

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.

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 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:

- https://www.macpac.gov/wp-content/uploads/2020/08/State-Management-of-Home-and-Community-Based-Services-Waiver-Waiting-Lists.pdf
- https://www.kff.org/medicaid/issue-brief/key-questions-about-medicaid-home-and-community-based-services-waiver-waiting-lists/

1.2 Medicaid is an essential program for those in need, and it should remain available only to those that need it. In regard to ensuring that Medicaid can remain available to just those that need it.

A. What should Congress consider as we examine the current, allowable home equity amounts permitted by the DRA to qualify for Medicaid? Should Congress consider capping home equity values at $500,000 (in 2005 dollars)? Should Congress consider resetting the $500,000 to $750,000 limit to 2022 dollars or some other level? Please provide any information on the impact of these changes or alternatives that will ensure Medicaid for those who need it.

As LTSS transitions towards HCBS, we believe the home should remain a non-countable resource, at a minimum to the exemptions provided in the Deficit Reduction Act of 2005 (DRA). Those values adjust for inflation every year under the law. The DRA was more restrictive than previous law, which exempted homes entirely. Under the DRA, states were given the flexibility to exempt homes of greater value given the difference in valuations throughout the country. For example, the median home price is $633,000 in Long Island, New York, a state that has the expanded home equity limit[12]. Lowering the maximum limit would force more home sales at the time of Medicaid application, leading to increased institutionalization.

B. *What steps should Congress consider to prevent wealthy individuals from shielding assets in order to qualify for Medicaid (including but not limited to the means highlighted in the 2014 GAO report, like exploiting annuities and promissory notes to shield gifts to family members)?*

It is critical to note that most Medicaid recipients are not shielding assets and that legislative efforts should be focused on encouraging, as opposed to restricting, access to Medicaid services[13]. Because Medicaid is virtually the only health care coverage that includes HCBS,

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[12] https://www.redfin.com/neighborhood/219261/NY/New-York/Long-Island/housing-market

[13] Are Wealthy Older Adults who use Medicaid Opportunistically Accessing the Program?: Journal of Aging & Social Policy: Vol 0, No 0 (tandfonline.com)

actions that make it more challenging to access benefits will likely have a disproportionate impact on marginalized groups, like adults with limited English proficiency, for whom additional administrative hurdles can result in decreased access.

The DRA developed new standards for Medicaid eligibility, including the protection of some resources through the use of Medicaid compliant annuities and promissory notes. Our LTSS system needs substantial financial reform that provides coverage in a meaningful way without bankrupting the middle class. Until Congress undertakes substantial LTSS financing reform, we urge you to take a do no harm approach. One equitable measure is to eliminate the asset test, which the state of California has recently done[14]. Eliminating the asset test would provide more straight-forward access to Medicaid LTSS and eliminate the need for Medicaid planning. Importantly, qualifying for Medicaid does not mean someone does not pay for services. For example, individuals who qualify under the "medically needy" pathway for nursing homes must typically spend all of their income minus a small personal needs allowance towards the cost of care. For Section 1915(c) and other HCBS waivers with income limits, Congress should examine allowing individuals over the 300% income limit to qualify with a cost-share.

Many people with disabilities rely on Medicaid services to be able to work and would not be able to work without Medicaid services. This is why there has been bipartisan support for programs such as the Medicaid Buy-in for Workers with Disabilities. This program is in dire need of reform. The Medicaid Buy-in should be offered in every state.

C. *What considerations should Congress consider when examining asset limits tied to SSI, like its lack of an inflation growth rate and marriage penalty?*

SSI provides an extremely modest cash benefit, a maximum of $841 a month in 2022, for low-income individuals with disabilities and older adults that meet the program's strict means-tested criteria. As of July 2022, nearly 7.6 million people relied on SSI to meet their basic needs: 4.3 million working-age individuals with disabilities; 1 million children with disabilities; and 2.3 million older adults. Additionally, nearly 40 percent of SSI recipients identify as a racial minority. In most states, individuals that qualify for SSI are categorically eligible for Medicaid.

Unfortunately, SSI's low, outdated resource limit of $2,000 for individuals/$3,000 for couples does not allow people to save for emergencies, such as a leaky roof, car repair, or other unexpected expenses. This makes it difficult for them to weather these crises. To make matters worse, the $2,000 asset limit does not adjust for inflation every year; in fact, the limit has remained the same since 1989 even though today's cost of living is nearly 2.5 times higher. Recently, Sens. Sherrod Brown and Rob Portman introduced *The SSI Savings Penalty Elimination Act*, which would raise the asset limit to $10,000 per individual/$20,000 per couple. The legislation also adjusts that number for inflation every year, a critical element in today's inflationary environment. This will allow SSI beneficiaries to use their own savings to address

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[14] https://cahealthadvocates.org/medi-cals-asset-test-to-be-eliminated-by-july-1-2022/

needed emergencies when they arise. We urge you to support measures to raise, if not fully eliminate, SSI's asset test.

Additionally, several marriage penalties exist within SSI for people with disabilities. They should be eliminated, including:

- 25% lowered asset limit for couples;
- 25% reduced benefit for couples;
- spousal deeming of assets and income when the spouse is not a SSI beneficiary
- The "holding out" rule, which can treat non-married couples as married for the purposes of SSI.

Moreover, the Disabled Adult Child benefit also contains marriage penalties. Under this benefit, if someone loses their status as a Disabled Adult Child beneficiary because they got married, they will also lose access to Medicare. The only exceptions are if the Disabled Adult Child beneficiary marries another Disabled Adult Child beneficiary, a person on Social Security Disability Insurance, a person entitled to "old age" SSA benefits (earliest age 62), or a person receiving another "secondary" benefit. For example, a Disabled Adult Child beneficiary marrying someone on SSI will cause them to lose their benefits. H.R.6405, *the Marriage Equality for Disabled Adults Ac*t, introduced by Rep. Panetta, would solve this issue, and we would encourage Republican Leader Rodgers to co-sponsor the legislation.

D. MACPAC recommends making estate recovery optional. The Committee is interested in feedback on this and other options to mitigate the burden of estate recovery for states and the families of beneficiaries. Please provide comments and data on the impact of this and similar proposals.

DAC strongly supports eliminating estate recovery and appreciates the Committee's focus on it in this RFI. Federal law requires state Medicaid programs to seek repayment of specific Medicaid benefits, including nursing home services and home and community-based services provided to beneficiaries ages 55 and older. Due to limited asset requirements associated with Medicaid, a beneficiary's family home is often their only remaining property. Upon the beneficiary's death, states must pursue *estate recovery* against the heirs of now deceased persons for the cost of their long-term care services. Estate recovery forces surviving family members to sell a family home where they would have otherwise resided or incur personal debt to pay off the Medicaid claims. Estate recovery also contributes to increased rates of homelessness for surviving family members.[15]

Because Medicaid-funded LTSS is the only realistic source of LTSS for most people, estate recovery programs do not encourage people to "plan ahead" and avoid using Medicaid—they simply punish the families of those who have or develop a health condition that requires LTSS. Estate recovery disproportionately harms economically oppressed families and communities of

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[15] https://justiceinaging.org/wp-content/uploads/2021/04/Medicaid-Estate-Claims.pdf

color, preventing these families from obtaining financial stability through home ownership. The burden also falls inequitably on families due to medical unpredictability. This unpredictability is exacerbated by inequities in our health care system that harm people with lower incomes, and people of color. Notably, no other public benefit program requires that correctly paid benefits be recouped from a deceased family member's estate.[16]

The primary rationale of estate recovery is to recuperate funds supporting state Medicaid programs. Despite this financial rationale, a 2021 MACPAC evaluation of estate recovery demonstrated that the policy is ineffective, recovering only 0.55 percent of total fee-for-service long-term care spending[17].

Medicaid estate recovery should be eliminated so that low-income families are better able to retain wealth and pass it on to future generations. H.R. 6698, *Stop Unfair Medicaid Recoveries Act*, would eliminate all Medicaid estate recovery claims, except in cases where benefits were incorrectly paid.[18] Eliminating estate recovery will eradicate the inequitable effect of this policy on low-income families and communities of color, affording them increased financial and housing stability.

At a minimum, as MACPAC suggests, federal law should be amended to make estate recovery claims voluntary for states.[19] For example, although West Virginia previously attempted to eliminate and reduce the negative impacts of estate recovery, the state was unsuccessful due to current federal law.[20] If a state believes that estate claims are counterproductive, the state should not be forced to assess them.[21]

For more information, please read this sheet: https://justiceinaging.org/wp-content/uploads/2021/04/Medicaid-Estate-Claims.pdf

E. *Are there means to shield certain assets, like ABLE Accounts and Qualified Income Trusts, that Congress should consider expanding or making more flexible so that more beneficiaries can utilize them?*

We thank the Republican leader tremendously for her leadership and advocacy in creating, and now expanding, ABLE Accounts. Given the restrictive nature of Medicaid and SSI, particularly for working people with disabilities, Congress should continue to examine ways to protect assets of people with disabilities to ensure their dignity and independence. This includes expanding

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[16] Ibid.

[17] https://www.macpac.gov/wp-content/uploads/2021/03/Chapter-3-Medicaid-Estate-Recovery-Improving-Policy-and-Promoting-Equity.pdf

[18] https://www.congress.gov/bill/117th-congress/house-bill/6698/text

[19] https://www.macpac.gov/wp-content/uploads/2021/03/Chapter-3-Medicaid-Estate-Recovery-Improving-Policy-and-Promoting-Equity.pdf

[20] West Virginia v. United States HHS, 132 F. Supp. 2d 437, 441 (S.D. W. Va. 2001); West Virginia v. Thompson, 475 F.3d 204, 214 (4th Cir. 2007).

[21] https://justiceinaging.org/wp-content/uploads/2021/04/Medicaid-Estate-Claims.pdf

ABLE Accounts. First, we must raise ABLE account eligibility to a minimum of an onset before age 46, as included in the ABLE Age Adjustment Act. After raising the age, we recommend examining means to further encourage savings for people with disabilities from low-income families, such as a matched savings program with federal funds.

1.3 In regard to ensuring that Medicaid beneficiaries can better utilize the existing eligibility pathways, so that people with disabilities are not held back by bureaucracy and red tape:

A. Should Congress reevaluate the asset eligibility requirements for SSI that allow for Medicaid eligibility? If Congress takes this approach, are there certain SSI-eligible populations, like those with I/DD, that should be exempted from SSI's eligibility thresholds?

SSI remains a vital benefit to maintain access to the community. However, its restrictive methodology, which needs to be revised, does not cover every person with a disability who requires access to HCBS. For example, a number of people with disabilities that work, but may not need SSI are limited by the current system. While "Medicaid buy-ins" exist they are underutilized and often inadequate. Mandating and funding pathways for working people with disabilities is critical. Moreover, buy-ins should be income-only cost-share pathways without regard to asset tests. Asset tests for working people with disabilities cause a massive disincentive for individuals with disabilities to reach their full potential and independence. At the same time, we don't believe one's "type" of disability makes one more worthy than others.

Another possible reform for people who developed a disability before the age of 22 is to allow Disabled Adult Child beneficiaries who meet the SSI financial criterion -- excluding the income from the benefit -- to qualify. Presently, Disabled Adult Child beneficiaries who qualified for SSI first can retain their Medicaid, but Disabled Adult Child beneficiaries who were not first eligible for SSI cannot.

B. Should Congress keep the SSI eligibility pathway for Medicaid beneficial to people with disabilities or are other, existing pathways better suited to supporting the needs of people with disabilities? Please provide further information on the value of SSI benefits for people with disabilities relative to those gained by using alternative eligibility pathways that may otherwise allow for people with disabilities to have higher levels of income and assets.

Categorical eligibility via SSI remains critical and all states should be mandated to provide SSI beneficiaries with coverage. Presently, states have the option to provide more restrictive methodology under Section 1902(f) of the Social Security Act otherwise known as 209(b) states. These states can provide more restrictive eligibility rules than SSI so long as they are not more restrictive than what was contained in the state's Medicaid plan as of January 1, 1972. At a minimum, SSI should be categorically eligible in all states and the 209(b) provision should be eliminated.

1.5 In order to build upon the existing infrastructure available to support family caregivers, including ensuring access to respite care and essential caregiving training:

Millions of family caregivers currently provide a substantial amount of unpaid care for the people with disabilities and older adults who rely on Medicaid services or who are on waiting lists for services. As a recent report from the Community Living Policy Center at Brandeis University put it:

> "The majority of individuals who need long-term services and supports (LTSS) in the US rely on unpaid assistance from family and friends. Among the approximately 11 million individuals with LTSS needs living in the community, 92% receive unpaid assistance and only 13% receive any form of paid assistance. Nationally, there are over 53 million family caregivers. The economic value of the unpaid care they provide is estimated to be over $470 billion annually."

Ensuring that these family caregivers have access to the support they need to continue caregiving is crucial, even more so given the worsening HCBS workforce crisis discussed above. Respite and training, and flexibilities to allow family caregivers to become paid caregivers are all crucial pieces of ensuring this workforce has the support they need.

We also believe that it is long past time for the United States to enact a comprehensive national paid leave program that ensures that family caregivers do not have to choose between their job and being there for their loved ones. This is not simply a problem for families, it is also a problem for the economy. Family caregivers find balancing their jobs and their caregiving responsibilities very hard– research shows that many stop saving, take on more debt, and are unable to pay bills because of their caregiving responsibilities. Others must take time off, reduce the number of hours they work, turn down promotions, or even leave the workforce entirely. As the country faces a labor shortage across sectors, ensuring that people have access to paid leave to provide care so that they can continue to work and employers do not need to onboard new staff has never been so important. Surveys of state programs report that paid leave has a positive or neutral effect on employers, including small businesses, and that the state programs have poised morale and reduced turnover. There also may be some savings to the health care system as a whole from paid leave–evidence from the paid leave program implemented in California suggests that nursing home utilization declined when paid leave programs were implemented. One small step towards providing additional protections for family caregivers is ensuring that all family caregivers have access to existing unpaid leave protections. While the Family and Medical Leave Act (FMLA) provides some protections for 59% of the United States workforce, there are huge gaps in that law. Because the definition of family is so narrow, siblings and grandparents or grandchildren who need to take time off to help care for a child or adult with a disability cannot. Similarly, the rules for taking leave for adult children are extremely complex and often exclude situations where parents of adult children with disabilities might need to take leave. Congress should look at this definition and ensure that it captures all family caregivers.

A. *Should Congress make respite care available to more populations within Medicaid? If so, which populations?*

Respite is not included in the definition of "medical assistance" in Medicaid. Thus, respite is only available in Medicaid via waivers or at times via managed care organizations "in lieu of" services. Thus, access to respite in Medicaid varies greatly by state and waiver. However, in the 1915(c) waivers, spending on respite is a tiny percentage of total waiver spending. Caps in different states vary from children to adults and from 7 days to 180 days. If an individual is eligible for HCBS services, regardless of specific disability (physical, intellectual, developmental, mental health), respite should be an available service for any caregivers of the individual—something that is not currently the case in many waivers while other states do not have any respite available. Given this variation, it is hard for us to recommend specific populations since state needs will vary. We would suggest that Congress instruct CMS to issue respite-specific guidance and provide technical assistance to states based on the work that ACL is currently doing via the Lifespan Respite Act to develop best practices. Respite is among the most frequently requested services by families supporting individuals with I/DD. The provision of respite services will help to prevent unnecessary institutionalization and improve health equity. We recommend that respite care be made available in all states for anyone who needs it. One potential approach to expand access to respite would be to amend the definition of "medical assistance" in 42 U.S.C. 1396d to include respite. Respite could be defined in a manner that indicates it is a service intended to directly benefit the enrollee and provide services for their medical condition. If respite were defined as "medical assistance," then the EPSDT benefit would cover respite when medically necessary for all enrollees under 21, and states could opt to cover such services for those over 21, eliminating the need to use waivers simply to access this benefit. States could still apply reasonable utilization management methods to this service to ensure that it is only used when it is medically necessary.

In addition, Congress could instruct CMS to expand the requirement for caregiver assessments in Medicaid 1915(i) Home and Community-Based Services (HCBS) State Plan Option programs to all Medicaid HCBS authorities, issue guidance on family caregiver assessments, and provide training and technical assistance to assist states with implementation.

A caregiver assessment asks questions of the family caregiver. It is a systematic process of gathering information about a caregiving situation to identify the specific needs, strengths, and resources of the family caregiver, as well as the caregiver's ability to contribute to meeting the needs of the care recipient. Caregiver assessments can be used to identify needed services and supports, such as respite, training, and other supports. Some states and health plans have implemented caregiver assessments. Regulations for 1915(i) require caregiver assessments. However, CMS has not issued any guidance on caregiver assessments or conducted oversight to ensure this is happening. Moreover, to streamline HCBS and improve consistency, requirements for caregiver assessments and guidance should apply not only to 1915(i) but across all HCBS authorities.

B. What discretionary programs for respite care are working? Which ones should be reviewed and reconsidered by Congress?

We strongly support the respite provisions in the Older Americans Act and the Lifespan Respite Act and would urge significant additional funding for these programs. Since 2009, Congress has appropriated approximately $2 to $4 million annually for this program. As of 2018, initial grants of up to $200,000 each have been awarded to eligible agencies in thirty-seven states and the District of Columbia. The original law authorized appropriations to gradually increase to $94,810,000 by the fiscal year 2011 (H.R. 3248/P.L. 109-716). Current appropriations fall severely short of what is necessary to address the needs in our country.

We would also recommend additional investment in research on respite for different populations, specifically via the National Institute on Disability Independent Living and Rehabilitation Research (NIDILRR) at the Administration on Community Living. This could focus on less well-known caregivers, including child or teen caregivers and caregivers from different racial, ethnic, and cultural backgrounds. National experts on respite have developed a research agenda on respite, which could form the basis for new investments in respite research.

It is also important to fund outreach efforts to family caregivers who are unaware of their options, to ensure that when respite services are available, caregivers are aware of them. The RAISE Family Caregivers Act Initial Report to Congress highlights in Recommendation 1.3.

C. What discretionary programs for caregiver training are working? Which programs should be reviewed and reconsidered by Congress?

The RAISE Family Caregivers Act Initial Report to Congress pointed out that most caregiving programs are “modest in size and funding” and very population specific. They specifically highlight ACL’s National Family Caregiver Support Program and Lifespan Respite Care Act Program, the Veterans Health Administration’s Caregiver Support Program, and HHS’ Administration for Children and Families’ (ACF’s) Kinship Navigator Program as programs that focus specifically on the needs of caregivers. This “fragmentary and disparate approach creates missed opportunities for more comprehensive support that comes at significant risk to the ability of family caregivers to support their family members over time.” We agree with this assessment and believe that a more comprehensive approach would be better.

The RAISE Family Caregiving Advisory Council, authorized by Congress, is an important mechanism that brings together agencies across the federal government, non-federal members, and input from other stakeholders to develop and implement a National Family Caregiving Strategy. The Council released its initial report to Congress on September 22, 2021, which included an inventory of federal programs that support family caregivers and 26 recommendations. The Council finalized the first National Family Caregiving Strategy on

September 30[22]. Congress should continue to authorize the RAISE Family Caregiving Advisory Council and provide annual appropriations to update the strategy and provide reports to Congress on implementation.

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Thank you again for the opportunity to comment on your report, *Disability Policies in the 21st Century: Building Opportunities for Work and Inclusion.* If you have any questions, please contact David Goldfarb, Director of Financial Security Policy, the Arc of the United States at goldfarb@thearc.org/(202) 534-3729.

Sincerely,

Disability and Aging Collaborative Members:
American Network of Community Options and Resources
American Association on Health and Disability
The Arc of the United States
Association of Maternal & Child Health Programs
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State Organization Supporters:
The Arc of South Florida
Miami-Dade County Office of the Mayor
Florida Health Justice Project

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[22] https://acl.gov/CaregiverStrategy