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September 26, 2022

Representative Cathy McMorris Rodgers
House Energy & Commerce Committee
1035 Longworth House Office Building
Washington, DC 20515

Dear Representative McMorris Rodgers,

On behalf of Advancing States, I am writing you in response to the Request for Information (RFI) regarding disability policies in the 21st century. Advancing States is a nonpartisan association of state government agencies that represents the nation's 56 state and territorial agencies on aging and disabilities. We work to support visionary state leadership, the advancement of state systems innovation, and the development of national policies that support home and community-based services for older adults and persons with disabilities. Our members administer a wide range of services and supports for older adults and people with disabilities, including overseeing a wide range of Medicaid-funded home and community-based services (HCBS). Together with our members, we work to design, improve, and sustain state systems delivering long-term services and supports (LTSS) for people who are older or have a disability and for their caregivers.

We appreciate that you and your staff are seeking information on ways to improve the lives of individuals with disabilities in the community. Due to our organization's focus on LTSS administered by state agencies, we will largely limit our comments to opportunities to improve Medicaid HCBS and reduce the institutional bias inherent in the program. We believe that Congress has a number of tools that can be used to reduce the institutional biases in Medicaid, including modifications to eligibility, payment, and services. We offer several recommendations, based upon our ongoing conversations with state long-term services and supports (LTSS) leaders and our cataloging of efforts to promote community integration that are occurring around the country.

Before providing specific recommendations, we believe it is important to articulate broader principles that can be used to drive the overall restructuring of Medicaid LTSS to promote individualized supports that enable individuals to live, work, and participate in activities based on their own needs, preferences, and choices. As such, we believe that the ideal Medicaid LTSS structure should include the following components:

- Eliminating the institutional bias through parity in financial eligibility between HCBS and institutional services, removing the requirement that institutional services are the Medicaid entitlement, and eliminating the limitation that forces states to secure a waiver to provide HCBS;

- Establishing eligibility criteria and service designs that promote early intervention and diversion strategies that enable states to tailor benefits packages that appropriately respond to different levels of assessed participant need;
- Creating and supporting meaningful choices in residences that suit individual preferences and support needs, ranging from Nursing Homes, Assisted Living Facilities, Group Homes, Shared/Supported Living, and private homes, apartments, and similar residences;
- Comprehensive approaches to workforce recruitment, retention, and development that leverage expertise and resources from sources beyond Medicaid, such as the Department of Labor;
- Establishing strong options counseling supports that provide clear information about and assistance with accessing available services, supports, residences, and other programs for individuals currently enrolled in Medicaid as well as those who are at risk of entering Medicaid-funded LTSS in the near future;
- Incorporating person-centered planning practices that empower and inform beneficiaries to better control their lives and create service and support plans that reflect the needs and preferences of each individual;
- Enhanced financing to promote HCBS as the preferred method for LTSS delivery;
- Strong protections that establish safeguards against abuse, neglect, and exploitation; and,
- Performing ongoing oversight and monitoring to reduce the risk of fraud, waste, and abuse in the system.

Implementing this structure will likely require wholesale changes to the Medicaid statute and must be done on an incremental basis that recognizes the significant amount of work necessary to restructure the program while also providing adequate funding for such changes.

Provide Comprehensive Options Counseling for Individuals and Families.

Any efforts to increase rebalancing between institutional and HCBS must be accompanied by strong options counseling resources. Individuals' lives are greatly impacted by the decisions regarding the services they receive, the providers that they use, and their location of care. Sufficient supports are essential to assist people understand the implications of their choices and to facilitate meaningful selections from the wide array of services potentially available to them. CMS and ACL have supported state development of aging and disability resource centers (ADRCs) and No Wrong Door (NWD) systems; however, the lack of consistent, reliable funding for this critical function of LTSS access systems has led to various stages of development across the country.

Options counseling is part of a continuum that extends beyond traditional case management or information and referral services and is often needed prior to the formal determination of eligibility. In many cases, proper options counseling that demonstrates the variety of choices available to individuals,

coupled with the benefits and considerations of each, may result in an individual refraining from enrolling in Medicaid, or may delay enrollment by using private funds more efficiently. Because of this, funding for options counseling is better provided through ADRCs and NWDs and funding should be available specifically for these systems irrespective of whether individuals are eligible or applying for Medicaid.

Remove the institutional bias inherent in Medicaid entitlement structure. Currently, Medicaid policy establishes nursing homes as an entitlement whereas HCBS is optional. When state budget constraints necessitate difficult financial decisions, it is much more difficult to enact restrictions on institutional services compared to HCBS. We recommend that Congress provide parity that allows states to implement the same restrictions on HCBS and institutional services. Additionally, if Congress does seek to reduce and eliminate waiting lists, we recommend that it be done on an incremental basis to allow for appropriate structural improvements to accommodate the additional enrollees – such as strengthening the workforce to provide access to services for the new enrollees – as well as providing enhanced match to financially support the additional costs associated with waitlist elimination.

Allow states to establish presumptive eligibility for home and community-based services. Currently, presumptive eligibility is allowed for pregnant women, children, and other eligible adults under sections 1920, 1920A, 1920B, and 1920C of the Social Security Act. We recommend establishing an additional option that provides presumptive eligibility for older adults and persons with disabilities who are likely to qualify for HCBS. Importantly, such presumptive eligibility must include presumptive financial eligibility (which deems Medicaid entitlement during the PE period) as well as presumptive eligibility for the level of care and/or needs-based criteria associated with the HCBS option. This policy would allow for rapid delivery of HCBS and reduce institutional entry, particularly in the case of hospital discharge following an acute event.

Specify that HCBS can be delivered on an interim basis pending the completion of a comprehensive person-centered plan. Current policy requires HCBS participants to complete their planning process and have a plan in place prior to the provision of services based on the statutory requirement that services must be provided “pursuant to a written plan of care” in section 1915(c)(1) as well as the plan of care requirements contained in 1915(i)(1)(G) and 1915(k)(1)(A)(i). While we agree that person-centered planning is a crucial component of individualized HCBS, the time required to complete an eligibility determination, assessment, and plan of care development can lead to substantial delays in HCBS delivery. We recommend providing the option to deliver HCBS based on an interim plan of care that draws from a preselected menu of services pending the completion of a comprehensive person-centered plan. This option, coupled with the presumptive eligibility recommendation, would significantly expedite the delivery of HCBS and allow more individuals to remain at home.

Promote Early Intervention Before Institutionalization. We believe that there is value in pursuing expanded nursing home diversion initiatives for individuals who are not yet eligible for Medicaid but who are likely to require Medicaid-funded LTSS in the future, including those who are considering entering an institution on private pay. These diversions can be implemented through Medicaid at-risk programs and/or Medicare diversions. At-risk programs allow states to identify individuals who have conditions or illnesses that do not yet qualify for LTSS but that are likely to require services in the future.

Many individuals who enter Medicaid-funded LTSS are already in an institutional setting during their first contact with the state agency prior to an eligibility determination. Attempts to implement pre-eligibility diversions and coordination with Medicare hospital discharges and post-acute benefits could begin to address this problem but would likely require modifications to eligibility criteria. Such eligibility flexibilities could include the establishment of an “at-risk” group for LTSS, as well as an option to capture individuals with a chronic condition in Medicare-funded hospital or nursing facility services.

We also recommend expanding the availability of short-term HCBS in the Medicare program. Currently Medicare Advantage plans have options to provide “Special Supplemental Benefits for the Chronically Ill Enrollees” (SSBCI) that, in many cases, are supports that mirror Medicaid HCBS services. SSBCI, however, are limited to individuals enrolled in MA plans who meet the plan’s criteria for services and are also based upon the plan rebate amounts, which significantly limits the scope of services that can be provided. While we recognize that the development of a comprehensive Medicare HCBS benefit is unlikely, we encourage Congress to evaluate options for including short-term services in the program. This could be done via demonstration projects or other models that ensure cost-effectiveness, such as including a similar time limit on Medicare HCBS that exists in Medicaid post-acute benefits, as well as including a cost-neutrality requirement for these demonstrations.

Lastly, the Older Americans Act (OAA) includes services and supports that are targeted and less comprehensive than Medicaid HCBS. We recommend increased allocation’s for OAA Title III services, coupled with research through the OAA’s Research, Demonstration, and Evaluation Center for the Aging Network that focuses on evaluating whether the funding increases result in lower LTSS expenses for participants.

Establish flexibilities with level of care (LOC) requirements in Medicaid. Providing states with the option to create differentiated benefits based upon the assessed level of need could also allow states to implement changes that reduce the institutional bias. Currently, states have the opportunity to create a separate LOC for HCBS and for institutional care via 1115 demonstrations as well as the statutory option available in section 1915(i) of the Social Security Act. Further expanding this option and allowing the creation of differentiated benefit packages based upon the assessed level of need would allow states to develop a system of care that promotes individualized, person-centered models of care. By allocating more comprehensive services to those with the greatest needs, while simultaneously implementing targeted but limited benefits to individuals with a lower assessed level of care, state Medicaid programs could provide a type of “preventive” LTSS benefit that focuses on retaining individuals in the community.

We note, however, that these proposals may create some challenges as many individuals living in institutional settings do not have a home-based setting available. Lowering the LOC for HCBS and/or increasing the institutional LOC and forcing these individuals to enter HCBS could create unintended consequences where affordable housing is unavailable. Such changes should be accompanied by a “grandfather” clause for those currently in institutional settings as well as a concerted effort to improve affordable housing availability. Additionally, implementing a system such as this would require diversion and early intervention strategies that enable individuals to access supports prior to institutionalization as

well as policies that preserve an eligible person's rights to enter a nursing facility or similar institution if they so choose.

Ease the Redetermination Process for Individuals with Conditions Unlikely to Change. We encourage Congress to make improvements to LOC determination process for participants. Currently, CMS requires that a LOC determination be performed at least annually. This process is labor intensive and creates burdens on states, participants, and providers. LOC determinations can also lead to process-based disenrollments for individuals who would otherwise remain in the programs. We recommend that Congress explicitly provide states with the flexibility to identify participants with conditions that are unlikely to improve and allow for longer durations between LOC evaluations for these individuals. We recognize that Congress, states, and CMS must ensure the integrity of the functional eligibility requirements for LTSS. However, there are instances where it is extremely unlikely that a condition will either change or improve. Performing annual recertifications of these conditions is overly burdensome on participants and is also an unnecessary use of programmatic resources. Congress could potentially direct CMS to establish guidance, such as a minimum threshold and/or a listing of conditions for participants, to articulate instances where states can elect to perform much more infrequent LOC determinations than current policy allows.

We also encourage Congress to consider similar flexibility for LTSS recipients with predictable income sources such, as Social Security Disability benefits, and allow 24-month recertification periods for financial eligibility renewals in these instances.

Expand Housing Options Targeted to Individuals Eligible for HCBS. Many individuals may not have a community residence where they can live, particularly those who have lived in an institution and whose home or apartment may have been sold or otherwise relinquished during their institutional stay. In fact, reports from administrators of the Money Follows the Person programs around the country indicate that lack of affordable, accessible housing is one of the most significant barriers to community transition of institutionalized individuals. We recommend that Congress allow states to fund room and board expenses in HCBS programs, subject to the same cost-neutrality requirements that currently exist in 1915(c) and 1115 waivers, as well as provide funding to the Department of Housing and Urban Development to develop accessible housing units that are specifically reserved for individuals receiving HCBS. We further recommend that Congress allow states to count room/board expenses as part of the medically needy spend-down calculation similar to how the NF daily rate includes R&B when individuals calculate institutional costs for their spend-downs.

Include HCBS as an Allowable Class of Provider Taxes. Current law allows states to tax certain classes of providers, subject to a number of restrictions, in order to generate revenue for Medicaid financing. Provider groups that can be taxed include hospitals and institutions but do not include HCBS. Frequently, this revenue is used to increase Medicaid provider rates which can increase access to care and improve quality. Current law and policy create a financial disadvantage for HCBS within the context of Medicaid financing and the law should be altered to create parity between institutional and community-based providers.

Allow States to Implement Risk-Based Asset Verification. Documentation related to the mandatory five-year look-back period for asset transfer penalties is extremely burdensome on staff and applicants. We recognize the need to prevent wealthy individuals from inappropriately shielding assets; however, a significant portion of LTSS applicants do not have any current or history of holding assets beyond the LTSS thresholds, particularly when spousal impoverishment criteria are considered. We recommend that Congress either evaluate options for waiving the five-year look back period and/or allow states to implement a risk-based approach to asset verification that allows eligibility staff to only focus on applicants most likely to currently, or previously, hold disqualifying assets.

Provide Flexibility Regarding Home Equity Limits. The availability of housing is a crucial component of maintaining community-based services and supports for LTSS participants. While we recognize that it is important to retain limitations on assets to ensure that benefits are targeted to those who most need them, establishing firm caps on home equity limits can have unintended consequences. Many older adults purchased their homes before the drastic price increases of the past several decades and, therefore, may have significant home equity despite never having large incomes or assets of other kinds. Forcing these individuals to sell their homes could remove the only available, affordable, community-based residence for these individuals and result in them entering an institution. We recommend that states be given the option to define home equity exclusion amounts, including the ability to set different exclusions in various regions within their borders, based upon the regional cost of living and home values.

Create Options for States to Waive Estate Recovery. Estate recovery requirements can impact the self-sufficiency of surviving family members and perpetuate generational poverty issues. This can lead to further dependence on various low-income services and supports, resulting in greater governmental expenses that outweigh the value of recovered assets. We support the MACPAC recommendation to make estate recovery a state option rather than a requirement. We also suggest that Congress allow states to establish reasonable thresholds that estates must exceed prior to the state pursuing asset recovery, as well as the option to establish types of assets excluded from recovery – such as houses that will be occupied by surviving relatives.

Provide Additional Support and Structure to Address Asset Shielding. A 2014 GAO report identified four main methods that individuals use to reduce countable resources and qualify for Medicaid. While some of these approaches may be legitimate and support the overall goals of the Medicaid program, others may promote inequities that favor those with the resources to hire financial planners and/or lawyers that specialize in benefits access and Medicaid planning. Each of the four methods has specific considerations that Congress should consider when evaluating eligibility:

- Spending countable resources on goods and services that are not countable towards financial eligibility, such as prepaid funeral arrangements: Congress has long recognized the importance of allowing individuals to finance necessary expenses without impacting Medicaid eligibility.
- Converting countable resources into noncountable resources that generate an income stream for the applicant, such as an annuity or promissory note: While this type of arrangement does potentially

provide value by enabling individuals to finance some of their own expenses, we recognize that the approaches have been exploited to shield inappropriate amounts of assets. In this instance, we recommend that Congress and states ensure the income stream is treated as countable income for purposes of eligibility.

- Giving away countable assets as a gift to another individual: As discussed earlier, we agree that inappropriate asset transfers should be disqualifying for Medicaid LTSS eligibility; however, the amount of administrative overhead required to identify transfers during the look back period for all applicants often negates the savings generated when such transfers are found. We recommend that Congress allow states to establish risk-based criteria to prioritize look-back verification for certain applicants most likely to have asset transfers.
- For married applicants, increasing the amount of assets a spouse remaining in the community can retain, such as through the purchase of an annuity: It is important to balance protections that prevent impoverishing a community spouse with the need to prevent inappropriate asset shielding strategies. We believe that spousal impoverishment protections should remain and that, in cases such as the annuity example, income and assets be counted towards Medicaid eligibility standards once reasonable thresholds are exceeded.

Modernize SSI to Prevent Impoverishment. Current asset limits for SSI eligibility have not been increased in over 30 years and provide substantially less purchasing power than was allowed when the SSI program was created. Further, the limit of \$2,000 for an individual compared to \$3,000 for a married couple creates disincentives for marriage. We support Congress updating SSI asset limits to reflect inflation since the program's inception and implementing an automatic inflationary update, as well as establishing limits for a married couple that are twice the single person rate. States should continue to have the options provided by current statute to either have SSI convey automatic eligibility for Medicaid; to establish more restrictive methodologies under Section 1902(f) of the Act; or to perform their own determinations based on the SSI standards.

Expand ABLE Accounts to Promote HCBS. ABLE accounts provide individuals with disabilities an opportunity to establish savings accounts that can be spent on goods, services, and other expenses related to the person's disability. Many of the allowable uses of these accounts are particularly valuable and useful for individuals in community-based settings, such as education, housing, transportation, employment training and supports, assistive technology, and basic living expenses. In some cases, using ABLE accounts to purchase these supports may offset Medicaid expenses that would otherwise be used to provide the same services. Current law requires that an individual's disability occur before age 26 to qualify for an ABLE account, which limits the availability of the program and prevents many LTSS participants from benefitting. We recommend that Congress expand ABLE account eligibility specifically to include individuals enrolled in HCBS programs regardless of the onset of their disability. By maintaining targeted uses of the funds and limiting eligibility to HCBS participants, we believe that the integrity of ABLE accounts will be retained while simultaneously promoting autonomy and community integration as well as reducing Medicaid HCBS expenditures.

Increase the Age Limit for D4A Special Needs Trusts. Current law requires that individuals be under age 65 and have a disability when these trusts are established. With the advances in technology leading to longer lifespans, the increases in full Social Security Retirement Age, and other changes to work and life cultures since the enactment of these trusts, allowing individuals to establish trusts after the age of 65 would increase access to needed HCBS for participants. If the state payback provision remains, there could be minimal fiscal impact to state and Federal governments.

Address Limitation in Low-income Subsidy Calculations. Currently, an issue in the statute omits clients who receive 1915k Community First Choice services from getting automatic exemption from Medicare Part D copays, which drives clients with high prescription drug costs into Medicaid waivers. Creating equitable treatment across the different HCBS options provides individuals with more choices and flexibility to secure HCBS.

Provide Additional Tools to Improve Medicaid Buy-in Programs. Medicaid Buy-in programs are extremely valuable eligibility categories that allow individuals with disabilities to work without losing necessary health insurance coverage. Unfortunately, the buy-ins are largely underutilized due to a variety of issues, including lack of knowledge regarding their availability; programmatic limitations; and complex eligibility issues. We recommend several improvements to enhance their applicability, including:

- Enable states to maintain the integrity and purpose of the programs by creating the option to define “work” for the purposes of eligibility;
- Providing the statutory option to exclude retirement accounts and other savings accrued during buy-in enrollment when determining eligibility for other Medicaid categories, including (at state option) portability across state lines;
- Providing states with the flexibility to define their own maximum age limit for eligibility under 1902(a)(10)(A)(ii)(XV);
- Providing additional guidance and support regarding ways to determine whether an individual has a qualifying disability without regards to their ability to work; and
- Establishing grant programs to increase outreach and enrollment in the options and to promote alignment between the buy-in and other employment programs, such as the Department of Labor, Vocational Rehabilitation, the Ticket to Work Program, and Medicaid supported employment.

Address Workforce Challenges. Currently, recruitment and retention of LTSS workers is the most significant challenge that state agencies are experiencing. Expanding the available pool of workers is a complex issue that will require multifaceted approaches ranging from increased Federal funding to enhance worker wages and benefits; improvements to licensure and certification that promote job ladders and career advancement for the workers; expanded awareness of the jobs and the value the work; and, expanding workforce initiatives to train and place individuals in these positions.

Expand Supports for Family Caregivers. Several changes can improve the infrastructure and support for family caregivers, including:

- Align 1905(a) policy with 1915 policy. Currently, states may reimburse family caregivers for extraordinary care delivered to their family members under programs authorized by sections 1915(c), (i), (j), and (k) of the Social Security Act; however, this is not allowed under section 1905(a)(24) personal care services. Standard Medicaid policy requires that participants exhaust state plan benefits [i.e. 1905(a)] prior to accessing other services. This creates confusion and misalignment when family members can be paid under 1915 options but not under the 1905 benefits that are available first.
- Allow states to provide supports to caregivers for pre-Medicaid eligible individuals. Current law requires services to be delivered directly to an eligible and enrolled individual. However, caregiver supports delivered to family members that are caring for an individual who is not yet, but likely to become, Medicaid eligible can ameliorate burnout and delay enrollment into Medicaid. We recommend that Congress provide states with options to identify individuals who are not yet eligible but who are likely to become eligible for Medicaid without supports from a caregiver and tailor supports to assist those caregivers.
- Expand the National Family Caregiver Support Program under the OAA and the Lifespan Respite program to further support caregivers of individuals who are not yet Medicaid eligible.
- Establish research projects to evaluate the effectiveness and outcomes of respite programs and identify ways to improve the targeting and delivery of respite care.
- Create and fund standalone caregiver training programs to provide family members with skills, education, and other supports regardless of whether their loved one is a Medicaid-eligible individual.

Provide States with Flexibility to Reimburse for Broader Assistive Technology. Current law prevents states from financing certain types of technology that has “general utility” in addition to specific benefit for LTSS purposes. For example, some tablets, phones, and smartwatches have functionality to identify falls and automatically call for help – which can be particularly valuable for individuals with Alzheimer’s and related dementias as well as other individuals who may not be able to proactively use a lifeline alert or similar product that requires specific action to call for help. However, because such products can be used for functions beyond the health care purpose, states may not finance them through the Medicaid program. This technicality severely limits the ability of states to finance and tailor the best available interventions for participants, particularly given the rapid advancements in many types of technology. Similarly, the availability of internet is crucial to a wide range of interventions for individuals – including access to telehealth, reminders, and cueing. We recommend that Congress explicitly allow states to reimburse internet and other technology that increases access to supports and services regardless of whether there are other potential uses.

Rescind the Requirement for States to Implement Electronic Visit Verification. The 21st Century Cures Act mandated that states implement electronic visit verification (EVV) for Medicaid-funded personal care

services and home health care services. States that do not implement these programs are subject to a financial penalty for noncompliant services. We recognize that the provision was intended to address fraud, waste, and abuse; however, the expense of implementation and ongoing operation has been substantial. Furthermore, EVV has led to provider and participant concerns about privacy, challenges with the processes, and exacerbation of ongoing workforce shortages. Although the EVV provision was originally projected to reduce costs due to a reduction in spending on personal care and home healthcare services, state feedback indicates that the cost of developing and implementing the systems has already greatly exceeded the projected savings. Due to all of the challenges discussed above, we believe that there would be positive policy outcomes as well as savings associated with repealing the EVV mandate and allowing it to be a state option rather than requirement.

Expand Availability of Long-term Care Insurance. While there are complex economic and social reasons that limit the availability of LTCI, every incremental improvement could have value for expanded access to private insurance for these supports and services. We support the expansion of available tax-incentivized options to finance both the purchase of LTCI as well as purchasing the services themselves, which could include the creation of specific tax-favored accounts for LTSS and/or expanding the allowable use of existing options such as HSAs or retirement accounts to include these types of purchases. We also encourage Congress to identify ways to support state initiatives and innovations that promote the development of broader LTCI programs, such as the Washington State Cares Fund or the Long Term Care Partnership Programs across the country.

We appreciate the opportunity to comment on this important topic. We recognize that there are a substantial number of technical and significant changes included in our recommendations. Any wholesale changes to the Medicaid benefits will be an extremely intensive and long-term effort. We request that you continue to engage frequently with state agencies on this issue in recognition of the critical role states play in the administration of Medicaid LTSS. If you have any questions regarding this letter, please feel free to contact Damon Terzaghi at dterzaghi@advancingstates.org.

Sincerely,



Martha Roherty
Executive Director
ADvancing States