

The Disability and Aging Collaborative

June 30, 2023

Centers for Medicare & Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244–1850

Submitted via regulations.gov

RE: Medicaid Program; Ensuring Access to Medicaid Services CMS-2442-P

The undersigned members of the Disability and Aging Collaborative and allied organizations appreciate the opportunity to comment on the Ensuring Access to Medicaid Services Notice of Proposed Rulemaking (NPRM). As organizations committed to increasing access to high-quality Medicaid home and community-based services (HCBS) and strengthening the direct care workforce, we support the goals of this rulemaking and the critical steps the Centers for Medicare and Medicaid Services (CMS) is taking to improve HCBS and to support the people who provide these services to older adults and people with disabilities.

The Disability and Aging Collaborative (DAC) is a coalition of approximately 40 national organizations that work together to advance long-term services and supports (LTSS) policy at the federal level. Formed in 2009, DAC was one of the first coordinated efforts to bring together disability, aging, and labor organizations. We are committed to ensuring that older adults and people with disabilities can access the support and services they need to live in the community, including health care. Recently, we have coalesced around [goals for using administrative action to increase access to high-quality Medicaid home and community-based services \(HCBS\) and strengthening the direct care workforce](#). We are pleased to see many of these principles reflected in the Access NPRM.

We share CMS's goals of improving access to care, care quality, and health and quality-of-life outcomes; promoting health equity; and ensuring safeguards for enrollees in fee-for-service (FFS) HCBS programs. We also support strengthening standards across Managed Care and FFS delivery systems. Our comments focus on the NPRM provisions related to HCBS and are organized around principles that are important to achieving these shared goals.

1. Expand Access to High Quality HCBS & Advance Health Equity

We support the aim of the NPRM to ensure state Medicaid programs comply with the equal access requirements with respect to HCBS. Previous rulemaking on the equal access requirement did not include the vast majority of HCBS. We know inequities in access to HCBS exist by race, age, disability, sexual orientation and gender identity, income and wealth, geography, and other factors. But we need more information to address them. The proposals in this rule are long-overdue steps to better identify disparities in HCBS access and close gaps, while improving quality.

It is well known that HCBS are underfunded. While CMS cannot fix the funding issue through rulemaking, we do want to ensure that these administrative actions do in fact expand access. As discussed below, we believe that strengthening the workforce is necessary to expand HCBS access and improve quality. CMS is rightly focused in this rulemaking on ensuring adequate compensation for direct

care workers. We also want to ensure CMS remains vigilant in monitoring the impact of these proposals on HCBS access. Both CMS and states should monitor overall access and provider availability, and pay particular attention to whether access (including quality, community integration, and culturally and linguistically appropriate services) is increasing or decreasing for underserved populations.

We support the proposals to measure access to HCBS. Given the wide variation across states in how HCBS programs are structured, who is eligible, and how services are delivered, it is critical to improve data collection to establish baselines and set federal standards for measuring access. For this reason, we recommend CMS require states to gather and report data across all HCBS authorities and delivery systems. This includes collection of data on state plan HCBS under Section 1905(a). Not only is this state plan benefit data important to understand the current HCBS landscape, including it now will also better prepare for the future when HCBS become a mandatory Medicaid state plan benefit. Requiring data reporting across all HCBS authorities also minimizes opportunities for states to avoid these reporting requirements by changing HCBS program structure.

To enable measuring disparities and progress in access for marginalized populations, we recommend CMS require demographic data collection for these measures as is required for the proposed quality measures. We recognize that states are starting at various places and some will take longer than others to stand up these data collection systems, but it is easier to build these demographic elements into the systems now than add them later.

We support the proposal to require states to report on their HCBS waiver waiting lists. This information would bring transparency to the waiver eligibility and enrollment processes for current and prospective applicants and help CMS ensure that states comply with the terms of their waiver by filling all approved slots. We recommend CMS clarify what information states that do not maintain waiting lists for any or some of their waivers are required to report. We also encourage CMS to consider additional measures to better assess unmet need, especially among populations that face barriers to navigating the HCBS programs, applying, and getting on a waiting list.

With respect to measuring timely access and percent of hours authorized that are actually delivered, we recommend CMS incorporate qualitative measures to provide more transparency about what is happening. For example, reporting the hours and percentages alone does not enable understanding of whether fewer hours were provided than authorized due to workforce shortage or because, for example, the enrollee made other arrangements and told their aide that they did not need services that day.

We support the proposal to strengthen assurances that person centered care service plans (PCSPs) are reviewed and revised as necessary at least every 12 months or at the enrollee's request. PCSPs are a central component of delivering high-quality HCBS. We urge CMS to consider ways to improve not only compliance with requirements for timely PCSP review and revision, but also the PCSP process itself to center cultural competency and ensure the enrollee's goals and preferences are met. We also recommend that these requirements apply to state plan personal care, home-health, and case-management services, as these are important supports for many people with disabilities and older adults. Doing so advances consistency and coordination across HCBS, and promotes equity by ensuring quality, person-centered services regardless of which HCBS program a person is enrolled in.

2. Strengthen the Direct Care Workforce

We strongly support the aim of the NPRM to ensure payment adequacy for the direct care workforce. As CMS recognizes, inadequate compensation of direct care workers results in workforce shortages and instability that limit access to high quality HCBS for older adults and people with disabilities. To rectify this long-standing issue that was exacerbated by the COVID-19 pandemic, workers must be paid a living wage. We also hope CMS will take action in the future to ensure access to job training and measure job quality improvement.

We believe that transparent and effective rate setting is a necessary prerequisite to ensuring competitive compensation for direct care workers. The process for improving provider payment rate transparency CMS has outlined in this NPRM moves us in the right direction. In § 447.203(b)(6), CMS proposes requiring states to establish an interested party advisory group to advise the Medicaid agency on HCBS provider payment rates. We support this proposal to create an advisory group that is required to include direct care workers, HCBS beneficiaries and their authorized representatives. However, to ensure the state's engagement with the advisory group is meaningful, CMS should strengthen the rule's requirements around how the state considers the group's recommendations. Specifically, we recommend requiring states to consult the advisory group before making any rate changes, as well as encouraging states to adopt the advisory group's recommendations and engage the group to work through differences in an attempt to reach consensus. Finally, we recommend strengthening the requirements for states to consider and analyze the advisory group's input by requiring a state that is not adopting the advisory group's recommendation to report their decision back to the advisory group and explain to CMS why they are not adopting the recommendation.

At § 441.302(k)(3)(i), CMS is proposing to require that at least 80 percent of all Medicaid payments for homemaker services, home health aide services, and personal care services be spent on direct care worker compensation. We support the concept of setting a federal standard for ensuring that provider reimbursement payments include and pass through competitive compensation for direct care workers. However, the proposed provisions should be clarified and CMS should take additional steps to ensure that the pass-through mechanism, the percentage, and the scope of applicability will actually achieve the goal of increasing direct care worker compensation.

We recommend, as soon as possible after the rule is finalized, that states gather and report data on payment rates to establish transparency about how much is being spent not only on wages and other compensation, but also training, other service delivery costs, and administrative costs across HCBS. This assessment and reporting (proposed § 441.311(e)) should be broader than the homemaker, home health aide, and personal care services and apply across state plan and waiver authorities, as well as fee-for-service and managed care. These reports should also be broken down by HCBS program, self-directed vs. agency providers, and by delivery system. Further, the underlying rate model for each service should be transparent, accessible, and include, at minimum, separate components for wage, employee related expenses, program related expenses, and general and administrative expenses.

With this information, states should work with the interested party advisory committee to assess the necessary compensation to attract and retain an adequate workforce, as part of the rate setting process discussed above. Again, this work should be broad but prioritize direct care workers such as direct support professionals, personal care attendants, and home health aides. This information will help CMS refine the mechanisms to ensure competitive wages are passed through to workers. It may be that the

mechanism itself or the percentage pass through should vary by service, provider type, and/or provider size. To support the work of the interested party advisory committee and ensure implementation of the pass-through mechanism within the proposed four years, we recommend a shorter timeline for implementing the reporting requirements as this information is critical to rate setting and determining payment adequacy.

3. Promote Transparency & Accountability

Ensuring transparency and accountability in Medicaid HCBS is paramount to delivering high-quality care, addressing disparities, and fostering stakeholder trust. The data gathering and reporting requirements, newly proposed grievance and incident management systems, enrollee input mechanisms, and oversight provisions in this NPRM will enable policymakers to identify areas for improvement and target resources to address care inequities older adults and individuals with disabilities experience. We encourage CMS to use this rulemaking to create a strong, comprehensive, forward-looking foundation for accountability that helps bring about the robust and equitable HCBS system we envision.

We support the data collection and reporting requirements outlined in this proposal to enable a more accurate and comprehensive understanding of the quality of Medicaid HCBS. Differing reporting requirements and quality measurement expectations across HCBS authorities prevent comparisons within and across states and mask disparities in service quality. We commend CMS for the mandatory Medicaid and CHIP core quality measure set. We ask that CMS affirmatively and clearly state that the Medicaid core measures apply to all Medicaid HCBS recipients, as they are Medicaid enrolled individuals. We support the introduction of standardized definitions and reporting processes, coupled with effective oversight mechanisms, to ensure accurate, reliable, and comparable data. To advance meaningful quality measurement, we prioritize “importance of measure” and “usability and use” criteria for measure selection, and suggest an additional evaluative category of “advancing equity.” We also strongly support, as outlined in the HCBS Quality Measure proposal, disaggregating this data by delivery system, population type, and demographic characteristics to identify disparities in HCBS quality.

We also support requiring grievance and incident management systems to promote transparency and accountability and safeguard the health and wellbeing of people receiving HCBS. A grievance system is a fundamental consumer protection that HCBS enrollees across delivery systems should have equal access to. As these proposals establish pathways at the beneficiary and systems levels for reporting, tracking, and addressing issues with person-centered planning and provider noncompliance, they will also advance efforts to ensure states’ ongoing compliance with the HCBS Settings Rule. We support making state grievance systems accessible and ensuring they include protections from provider retaliation. We also recommend continuity across grievance systems in fee-for-service and managed care to ensure consistent and equitable processes for addressing enrollee concerns. For example, we support the proposal to include an expedited resolution process in FFS and recommend that be added to managed care as well.

Additionally, we strongly support requiring states to have Medicaid Advisory Committees (MACs) and Beneficiary Advisory Groups (BAGs), as a key component of overseeing and improving states’ HCBS programs. These entities will uplift the perspectives and experiences of older adults, people with disabilities, direct care workers, and consumer advocates to inform HCBS policymaking. We recommend increasing the minimum percentage of MAC members who are also BAG members with Medicaid lived experience from 25% to 50% to rectify inherent power imbalances that suppress enrollee voices. We

further recommend requiring the BAG and MAC to include people who use HCBS, as HCBS is a unique Medicaid benefit that the majority of Medicaid enrollees do not have access to. CMS should also consider how to ensure states include tribal representation in their MAC and BAG and aim to make the BAG reflect the diversity of Medicaid enrollees in their state. We strongly support the provisions to facilitate accessibility accommodations and language access and support technical assistance and administrative needs. To enable more meaningful contributions, we recommend that the rule require states to compensate individuals with lived experience for their expertise, time and work.

To ensure proper implementation of this Rule, and improve HCBS Settings Rule enforcement, we recommend establishing a national HCBS Ombuds program. Ombuds are a successful component of many Medicare and Medicaid programs, especially during implementation. A dedicated and well-resourced HCBS Ombuds program would provide essential education, representation, and advocacy support to older adults and people with disabilities living in the community, to match what is currently available to residents of long-term care facilities. An ombuds would complement the grievance system by helping individuals navigate the HCBS system and avoid issues, as well as triage issues that arise and seek the appropriate remedy. CMS, states, and other policymakers could analyze the HCBS Ombuds complaints and investigations to identify implementation challenges and address issues more promptly.

4. Support Implementation

We appreciate that implementing the proposals in this NPRM will require a lot of resources, including funding and time. We support the majority of the implementation time frames proposed, and urge CMS not to delay any of the compliance dates. However, as discussed in the workforce section, we do recommend that CMS expedite the data gathering and rate setting processes to allow that information to shape the finalization of federal standards for ensuring competitive compensation for direct care workers. We also recommend CMS require a faster timeline for the quality measure phase in, which is critical to understanding disparities and improving access.

States will need significant technical and financial support to implement these requirements. We recommend CMS use approaches it has used with Medicaid continuous eligibility unwinding and the HCBS Settings Rule and ask states to submit implementation plans soon after the rule is finalized. These plans should be made public on state and CMS's website, and regularly reviewed and updated in consultation with the MAC and BAG. In addition to robust technical support, we recommend CMS make all states aware of any opportunities for federal funding to support implementation, including enhanced federal matching funds for IT systems.

We also recommend CMS leverage the Administration for Community Living and other HHS divisions to support implementation. For example, the Developmental Disabilities Councils, RAISE Family Caregiving Advisory Council, and SAMHSA administered state mental health councils can serve as models and resources for MACs and BAGs.

Conclusion

Thank you for the opportunity to comment on this NPRM. We celebrate the goals of this rule to strengthen HCBS access and quality for older adults and people with disabilities and ensure adequate compensation for direct care workers. Members of the disability, aging, and labor communities remain committed to working with CMS and states to implement a strong Medicaid Access Rule and achieve our shared goals.

Please reach out to the DAC co-chairs with any questions: Natalie Kean (nkean@justiceinaging.org), Nicole Jorwic (nicole@caringacross.org), and Howard Bedlin (Howard.Bedlin@ncoa.org).

Sincerely,

Aging Life Care Association
Allies for Independence
American Association of People with Disabilities
American Association on Health and Disability
American Geriatrics Society
Association of California Caregiver Resource Centers
Autism Society of America
Autistic Self Advocacy Network
California Foundation for Independent Living Centers (CFILC)
Caring Across Generations
Center for Medicare Advocacy
Community Catalyst
Disability Policy Consortium
Diverse Elders Coalition
Families USA
Hand in Hand: The Domestic Employers Network
Justice in Aging
Lakeshore Foundation
Lutheran Services in Iowa
Medicare Rights Center
National Academy of Elder Law Attorneys
National Asian Pacific Center on Aging (NAPCA)
National Association of Councils on Developmental Disabilities
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Consumer Voice for Quality Long-Term Care
National Council on Aging
National Domestic Workers Alliance
National Health Law Program
National Hispanic Council on Aging
New Disabled South
Placer Independent Resource Services
Service Employees International Union
Special Needs Alliance
The Balm In Gilead, Inc.
The Gerontological Society of America
United Spinal Association
Well Spouse Association