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VIA ELECTRONIC TRANSMISSION

June 30, 2023

The Honorable Chiquita Brooks-LaSure
Administrator, Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244

RE: RIN 0938–AU68; CMS-2442-P
Medicaid Program; Ensuring Access to Medicaid Services

Dear Administrator Brooks-LaSure:

The National Women’s Law Center appreciates the opportunity to comment on the proposed rule “Ensuring Access to Medicaid Services.”¹ Since 1972, we have striven to protect and advance the progress of women and their families in core aspects of their lives, including health, income security, employment, education, and reproductive rights, with an emphasis on the needs of people experiencing poverty and those who face multiple and intersecting forms of discrimination. To that end, we have long worked to ensure that all people, including women of color, disabled women, low-income women, and LGBTQI+ people, have meaningful access to health care, including through Medicaid and other insurance affordability programs.

Medicaid programs offer critical services for its enrollees, who are disproportionately women of color, disabled women, and women overall.² Many enrollees, however, face barriers to accessing needed care. Enrollees also have limited pathways to influence the development and administration of policies that impact their lives. We therefore generally support the Department’s efforts to improve access, quality, and accountability in Medicaid services, and we provide suggestions to further strengthen the rule.

¹ 88 Fed. Reg. 27960 (proposed May 3, 2023) (to be codified at 42 C.F.R. pts. 431, 438, 441, and 447) [hereinafter “Proposed Rule”].

² Ivette Gomez et al., *Medicaid Coverage for Women* (Feb. 17, 2022), www.kff.org/womens-health-policy/issue-brief/medicaid-coverage-for-women.

I. Advisory Committees

Medicaid advisory committees have the potential to improve engagement with beneficiaries and other stakeholders, provide channels for feedback, and enhance agency accountability. In practice, however, the design, implementation, and ultimately effectiveness of these advisory boards has been inconsistent across states, due in part to vague and inadequate federal guidelines. We therefore support the Department's efforts to adopt more robust requirements related to advisory committees, and we recommend that the Department further strengthen these requirements in the final rule.

(a) Membership

We support the proposal to restructure the Medical Care Advisory Committees into Medicaid Advisory Committees (MAC) and Beneficiary Advisory Groups (BAG). In particular, we support providing a dedicated space for beneficiaries through the BAG, which would amplify the priorities of those most directly impacted by program policies and facilitate their participation in the advisory process.

We support reserving a minimum proportion of seats on the MAC for BAG members, but we encourage the Department to require that BAG members make up at least 51% of the MAC, rather than the proposed 25%. Several states have had success with majority-beneficiary advisory committees, in the context of both MCACs and other health programs.³ When beneficiaries make up the majority of the advisory committee, they have more meaningful control over the topics and direction of the feedback provided—which is especially critical since beneficiaries are less likely than other stakeholders to have existing pathways for providing input on Medicaid policies.

We also support the requirement that the MAC include consumer advocacy groups or other community-based organizations that represent the interests of, or provide direct services to, Medicaid beneficiaries. We recommend that the Department require states to include representation from Protection and Advocacy agencies as one component of this category. The Department can also encourage states to draw from a spectrum of advocacy and community-based organizations for participation in the MAC, including reproductive health, rights, and justice organizations, racial justice organizations, disability rights advocates, and LGBTQI+ organizations.

Conversely, we do not support the Department's requirement that states guarantee representation for managed care plans or state health associations representing these plans. While states may choose to include managed care plans in the MAC, mandating that they do so is unwarranted. Unlike beneficiaries, managed care plans have numerous existing avenues to share their perspectives and influence Medicaid policy, making their participation on the MAC less necessary than that of other stakeholders. While managed care plans can often offer important contributions, in some cases their presence on advisory committees may make it more difficult for beneficiaries to fully participate, due to the potential power differentials as well as the sometimes-conflicting interests of managed care plans and beneficiaries. We therefore believe

³ For example, the implementation council of the Massachusetts Financial Alignment Initiative has successfully implemented a majority-beneficiary model.

that the Department should not mandate that managed care plans be represented on the MAC across states.

The preamble offers a range of optional factors for states to consider during MAC and BAG membership selection. We recommend that the Department supplement this list with an additional factor: representation of Medicaid populations facing the greatest health disparities. Persistent health disparities help identify the enrollees for whom Medicaid policies have traditionally fallen short and who may require the most urgent policy interventions. For example, women of color, LGBTQI+ women, and disabled women enrolled in Medicaid need specific policy changes to address the significant health disparities they face, but their unique priorities may continue to be undervalued if they are not adequately represented on advisory committees. Accordingly, the Department should encourage states to consider data on health disparities among enrollees when selecting members for the MAC and BAG. The Department can offer examples of health disparities states may wish to prioritize, such as mortality or life expectancy, while encouraging Medicaid agencies to select the measures that are most severe or pertinent in their states.

Further, the Department proposes that the Beneficiary Advisory Group be made up of family members and caregivers in addition to beneficiaries. While family members and caregivers offer valuable perspectives, we believe that the BAG should be a space dedicated primarily to beneficiaries. Without a limit on the participation of family members and caregivers, some states may be inclined to draw heavily on representation from non-beneficiaries, particularly in lieu of representation from beneficiaries who may need supports and accommodations to take part. Accordingly, we recommend that the Department clarify that beneficiaries themselves must make up the significant majority of the BAG membership.

Finally, we support requiring states to provide meaningful accommodations that would allow Medicaid beneficiaries, including beneficiaries with disabilities and beneficiaries whose primary language is not English, to participate in the BAG.

(b) Committee Procedures and Functions

We appreciate the guidelines outlined in the proposed rule related to the advisory committees' procedures and functions. In particular, we support the Department's proposal to expand the scope of the advisory committees to encompass policy development and administration of the Medicaid programs, including services related to social determinants of health and health-related social needs. Especially as states expand the non-medical services provided under Medicaid, realigning the scope of the advisory committees will allow these services to better reflect the social needs of beneficiaries and become more accountable to stakeholders.

In other respects, we believe that more specific federal requirements are needed to make the advisory committees effective and equitable, especially in states where Medicaid agencies have historically declined to meaningfully engage with those committees. The Department can strengthen its guidelines by offering more specific guardrails and parameters, while still giving states flexibility to build on the minimum requirements and adapt them to local needs.

First, we recommend that the final rule set more robust guidelines for how agencies must engage with the advisory committee and its feedback. While many states have meaningfully relied on the recommendations of the advisory committees, some agencies have failed to integrate the

input into the policy-making process, rendering the committees largely ineffective. Improved guidelines can make it more likely that feedback is given its due weight in decision-making, that the input is conveyed to appropriate policy makers and to the public, and that the committees can serve as a source of accountability. We believe that requiring the agency to produce a publicly available report reflecting the feedback provided is an important initial step, but on its own, this requirement may be insufficient to ensure that the feedback is relied upon in decision-making. We recommend that the Department also adopt other measures, like requiring the agency to document the ways it has used the feedback or its reasons for not implementing certain pieces of input. Taken together, these measures can help strengthen accountability in this process.

Second, we are concerned that leaving the topics addressed by committees entirely up to state agencies' discretion will mean that some advisory committees will not address the full range of priorities their members bring. The Department should specify that both the overall topics for discussion as well as agendas for specific meetings must be set by committee members themselves, provided that the majority of those committee members are beneficiaries as recommended above. Allowing the committee to determine the topics covered by a majority vote would empower beneficiaries and other representatives to set the direction of the committee's work and select topics that are responsive to local needs. The Department can facilitate the topic-selection process by providing committees with guidelines for issues that can be addressed, which committees can then adapt according to their own priorities.

The Department should also provide clearer requirements for when states must offer compensation and other financial arrangements for BAG members. For many beneficiaries, compensation is a prerequisite to participating in the BAG. Beneficiaries may need funding to cover childcare and other caregiving responsibilities, take time off work, secure a reliable internet connection, or travel to the meeting site. Funding should therefore include compensation for participants' time preparing for and attending the meeting, a stipend for caregiving costs and/or onsite caregiving options, and funding for internet or travel, if needed.

Finally, the Department should set a range for the length of committee appointees' terms. This will ensure that terms are short enough to allow for a continuous rotation of diverse perspectives on the BAG and MAC, but that turnover is not so fast that the committee is unable to build on its work over time. We suggest a range of two to four years for appointments, which is consistent with many states' current practice.

(c) Other practices to improve engagement and accountability

With stronger guidelines, advisory committees can become effective tools for engagement and accountability. At the same time, advisory committees have inherent limitations, and so they must be just one method as part of a broader strategy to expand bidirectional feedback and stakeholder empowerment. We urge the Department to explore other measures that states should take to supplement advisory committees, including focus groups, compensated surveys, and point-of-contact data collection. These additional methods can offer measurable benchmarks to assess Medicaid policies, create more frequent opportunities for beneficiaries to provide input, and inform the work of the advisory committees.

II. Home- and Community-Based Services

We appreciate the Department's commitment to improving access to home- and community-based services (HCBS). HCBS allow disabled and aging people to live in their homes and integrate into community settings with dignity and agency, promoting better health outcomes, wellbeing, and quality of life.⁴

HCBS are especially critical for women, who make up the majority of HCBS recipients.⁵ Women also make up most of those who are currently in institutional settings and who might benefit from expanded access to HCBS. For example, disabled and aging women represent nearly seven in ten nursing home residents.⁶ Women also bear the majority of unpaid caregiving duties, which are often needed to fill in gaps when HCBS are unavailable. This labor is frequently devalued and under-supported, and as a result, women who provide unpaid care may see long-lasting impacts on their mental health, as well as their opportunities to participate in the workforce.⁷ And as discussed further below, women of color make up the majority of the direct care workforce, where they not only face the job quality and wage deficiencies impacting direct workers as a whole, but also experience these problems more severely than their white or male colleagues due to racial and gender inequities within the field.⁸

(a) Person-Centered Care and Annual Reassessments

Person-centered care standards help ensure that beneficiaries can determine their own care goals and select services that reflect their priorities and preferences. Allowing people to make choices about the services they receive is core to HCBS' purpose of promoting the dignity and autonomy of disabled and aging people. We therefore support the Department's clarification regarding these person-centered care standards, including its proposal that states conduct annual reassessments for 90% of HCBS users and update their person-centered plans accordingly.

(b) Grievance Procedures

We support the proposed grievance procedures, as they will provide a much-needed pathway for fee-for-service Medicaid enrollees to raise concerns with HCBS service delivery. We believe, however, that the 90-day timeframe for resolving grievances is too long, especially when beneficiaries raise serious and time-sensitive violations of their rights. We appreciate the expedited option for issues posing a substantial risk to the health, safety, and welfare of the

⁴ See, e.g., Agency for Healthcare Research and Quality, *Assessing the Health and Welfare of the HCBS Population* (2012), <https://www.ahrq.gov/patient-safety/settings/long-term-care/resource/hcbs/findings/find5.html>.

⁵ *Id.*

⁶ Centers for Medicare & Medicaid Services, *Nursing Home Data Compendium 2015 Edition* 181 (2015), https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/nursinghomedatacompendium_508-2015.pdf.

⁷ National Partnership for Women & Families, *Women Carried the Burden of Unpaid Caregiving in 2020* 1 (May 2021), <https://www.nationalpartnership.org/our-work/resources/economic-justice/women-carried-the-burden-of-unpaid-caregiving-in-2020.pdf>; Richard W. Johnson et al., *Lifetime Employment-Related Costs to Women of Providing Family Care* (2023), https://www.dol.gov/sites/dolgov/files/WB/Mothers-Families-Work/Lifetime-caregiving-costs_508.pdf.

⁸ Stephen McCall & Kezia Scales, *Direct Care Worker Disparities: Key Trends and Challenges* (Feb. 2022), <https://www.phinational.org/resource/direct-care-worker-disparities-key-trends-and-challenges>.

beneficiary, but we are concerned that violations that are not considered to meet this definition may still require more urgent action than the 90-day period provides. Accordingly, we recommend that the Department reduce the grievance resolution timeframe to 45 days.

(c) Incident Management System

We support the proposed incident management system, including the adoption of a uniform definition of “critical incidents.” In order to ensure that critical incidents are identified even when not reported by providers, we recommend that the Department clarify that a critical incident may reported by anyone, including by enrollees and other interested parties. We also recommend that providers report critical incidents to the state’s Protection and Advocacy program at the same time that they report them to the state, as this will help ensure that states respond appropriately and with sufficient urgency.

(d) HCBS Workforce

Direct care workers make access to HCBS possible for many disabled and aging Medicaid beneficiaries, allowing millions to live their lives with greater dignity. Systemic racism and devaluation of care work, however, has plagued this workforce, leading to poor job quality, minimal benefits, and suppressed wages. The vast majority of HCBS direct care workers—nearly 85%—are women; more than one-quarter (27%) are Black, 23% are Latine, and 31% are immigrants.⁹ Their demanding jobs often pay poverty-level wages: Nationally, the median wage for direct care workers was just \$14.09 per hour in 2021.¹⁰ As a result, 43% of the direct care workforce lives in low-income households, and a similar share (41%) is enrolled in public health coverage programs like Medicaid, while 16% have no health insurance at all.¹¹ Low wages and minimal benefits also lead to high turnover and an ongoing shortage of workers in the field, which in turn undermines the quality and availability of services.¹² Yet as our population ages, the number of people in need of long-term care will only grow; indeed, the Bureau of Labor Statistics projects that 924,000 home health and personal care aide jobs will be added to our economy over the next decade—more than any other occupation.¹³

Improved wages and working conditions are thus critically needed, both to value the work of direct care workers and to ensure more meaningful access to HCBS for people using those services. While substantially increased funding will ultimately be necessary to ensure that all Medicaid beneficiaries who need HCBS can access them—and that all workers providing this

⁹ PHI, *Direct Care Workers in the United States* 6 (Sept. 6, 2022), <https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-3/>. We refer in these comments to PHI’s data on “home care workers” because this population most closely aligns with the Department’s definition of “direct care workers” providing Medicaid HCBS.

¹⁰ *Id.* at 9.

¹¹ *Id.* at 2.

¹² MACPAC, *State Efforts to Address Medicaid Home- and Community-Based Services Workforce Shortages* 4 (Mar. 2022), <https://www.macpac.gov/wp-content/uploads/2022/03/MACPAC-brief-on-HCBS-workforce.pdf>; PHI, *Caring for the Future: The Power and Potential of America’s Direct Care Workforce* 75 (Jan. 2021), <https://www.phinational.org/caringforthefuture>.

¹³ U.S. Bureau of Labor Statistics, *Employment Projections: Occupations with the Most Job Growth* (Sep. 8, 2022), <https://www.bls.gov/emp/tables/occupations-most-job-growth.htm>.

essential care have high-quality, well-paying jobs—the proposed rule can help make significant progress towards these goals.

We support setting a percentage of Medicaid payments for homemaker services, home health aide services, and personal care services that must be spent on compensation to direct care workers, rather than on administrative or overhead costs. Such a policy will help ensure that the bulk of the funding spent on HCBS goes towards improving wages for those who directly provide these services. However, we recognize that many providers currently fall substantially short of the 80% threshold and some may face difficulty maintaining their full scope of services without sufficient time to adjust their expenses. We suggest the Department phase in this requirement over time, beginning with a lower threshold and graduating to 80%. A phased-in approach would allow the Department to gather more comprehensive data about the outcomes of this requirement, which it can then use to assess whether the policy is in fact contributing to higher wages, examine its impact on the availability of services, and determine if a more tailored approach may be needed for specific types of providers or service areas.

We support requiring states to publish average hourly rates for direct care workers. This proposal will allow policymakers, workers, and the general public to assess how sufficient wages are in their state, see how their state compares to others, and move towards improving pay for direct care workers. To provide further transparency, we recommend requiring states to publish hourly rates by gender, race, and other demographic information, as well as by type of service provided. As noted, existing data indicates race and gender pay disparities among direct care workers. More systematic data would provide a fuller picture of these disparities and offer an important tool towards correcting them.¹⁴ We also support requiring assurances that payment rates are “adequate to ensure a sufficient direct care workforce to meet the needs of beneficiaries,” but recommend that the Department provide benchmarks and/or other specific guidance to clarify how states should measure whether the workforce is sufficient for these purposes.

We appreciate, too, that the proposed rule requires states to create Interested Party Advisory Groups to consult on provider payment rates and direct compensation for direct care workers. A specialized advisory group can help ensure that states determine payment rates in consultation with direct care workers and other stakeholders. We recommend, however, that the Department establish clearer guidelines in the final rule to ensure stakeholders are fully represented and empowered to participate, as well as to ensure that the feedback from this group is used meaningfully in policy making. To that end, we recommend that the Department require states to reserve at least 25% of seats in the IPAG for Medicaid beneficiaries and 25% for direct care workers. To ensure diverse representation and avoid conflicts of interest, the Department should also require that states publicly recruit IPAG members; that members serve for set terms and only be removed for cause, so they can provide recommendations without fear of reprisal; and that state employees not be permitted to serve on the IPAG. In addition, the Department should

¹⁴ See generally, e.g., National Women’s Law Center, *Salary Range Transparency Reduces Gender Wage Gaps* (Jan. 2023), <https://nwlc.org/wp-content/uploads/2022/09/Salary-Transparency-FS-1.13.23.pdf>; National Women’s Law Center, *Promoting Pay Transparency to Fight the Gender Wage Gap: Creative International Models* (Mar. 2020), <https://nwlc.org/wp-content/uploads/2018/06/International-Pay-Transparency-Models-v2.pdf>; Morten Bennedsen et al., *Research: Gender Pay Gaps Shrink When Companies Are Required to Disclose Them*, HARV. BUS. REV. (Jan. 23, 2019), <https://hbr.org/2019/01/research-gender-pay-gaps-shrink-when-companies-are-required-to-disclose-them>.

make clear that the IPAG is to play a lead role in the rate-setting process by, for example, requiring states to consult the IPAG before making rate changes; granting deference to the IPAG's recommendations; and taking steps (defined by CMS) to reach consensus in the event of disagreement with the IPAG regarding appropriate rates. Should the state elect not to adopt recommendations of the IPAG, it should be required to provide written justification for its alternate choice to the IPAG as well as to CMS. Finally, we recommend that the Department adopt further guidelines for IPAGs that are comparable to those it applies to the Medicaid Advisory Committees and Beneficiary Advisory Groups.

(e) HCBS Quality Measures

We support the proposal to mandate quality measures, which have long been needed to improve quality and equity in HCBS. We appreciate the emphasis of the selected quality measures on choice, autonomy, and community integration. We also strongly support the stratification of data by factors such as race, ethnicity, tribal status, sex, age, rural/urban status, disability, and language. The limited data that is available indicates concerning inequities in access to and quality of services, health outcomes, and self-determination, including across race and gender.¹⁵ More systematic data is necessary to assess the scope of these inequities and develop policies to address them. Additionally, beyond the factors listed in the proposed rule, we recommend requiring stratification of data by sexual orientation, gender identity, and sex characteristics (including intersex traits), and we encourage the Department to offer guidelines to ensure this data is collected and reported on in a manner that protects beneficiaries' privacy.

However, we are concerned about the lengthy seven-year phase-in period for the stratification of data. Stratified data collection sets a foundation for long-overdue policies to redress disparities—policies that will likely be pushed back the longer demographic data collection is postponed. We recommend that the Department shorten this phase-in period to a maximum of four years. We also suggest that HCBS measures be updated and reported annually rather than biannually, particularly as this will provide the Department with the data it needs to adjust its new quality measures over time.

(f) Waiting List Reporting Requirements

We support requiring states to report on waiting lists for section 1915(c) waiver programs, including on the number of people on the waiting list, the average time they spend there, whether they are screened for eligibility, and how states manage waiting lists. In 2021, an estimated 656,000 people were on waiting lists for HCBS, sometimes waiting years for necessary services.¹⁶ While this is a strong indicator of significant unmet needs, it is difficult to fully assess the exact scope of the gap, in part because over half of those on HCBS waiting lists are living in

¹⁵ E.g., Tetyana P. Shippee et al., *Racial/Ethnic Disparities in Self-Rated Health and Sense of Control for Older Adults Receiving Publicly Funded Home- and Community-Based Services*, 32 JOURNAL OF AGING AND HEALTH 1376 (Jun. 14, 2020), [www.doi.org/10.1177/0898264320929560](https://doi.org/10.1177/0898264320929560); Chaneé D. Fabius, *Racial Disparities in Medicaid Home and Community-Based Service Utilization and Expenditures Among Persons with Multiple Sclerosis*, 18 BMC HEALTH SERVICES RESEARCH 773 (2018), <https://doi.org/10.1186/s12913-018-3584-x>.

¹⁶ Alice Burns et al., *A Look at Waiting Lists for Home and Community-Based Services for 2016 to 2021* (Nov. 28, 2022), <https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-home-and-community-based-services-from-2016-to-2021>.

states that do not screen people for eligibility.¹⁷ Additionally, some waitlist policies governing how people can join and advance on the waitlist give rise to racial and other inequities.¹⁸ More detailed data will allow for a better assessment of both overall unmet needs and disparities within the waiting lists. Accordingly, we support the Department's proposed data collection and strongly urge that the data be stratified by race, gender, disability, language, and other factors.

III. Fee-for-Service Payment Rates

We support requiring states to publish fee-for-service (FFS) payment rates. Doing so will improve transparency and accountability, and it will help stakeholders assess the degree to which payment rates are sufficient to ensure quality and supply of providers. Available data suggests that FFS payment rates are significantly lower than those offered by other payers, which often results in lower levels of provider participation and consequently impacts Medicaid beneficiaries' ability to access care.¹⁹ The Department's proposal would allow for the more complete data that is needed to reform FFS payment rates.

We generally support the Department's proposal to change requirements related to state plan amendments that would reduce rates or restructure payments. However, we recommend that all proposed rate analyses be subject to enhanced analysis and procedures, not only those that fail to meet the specified criteria. Particularly as FFS payment rates are already so low, we are concerned that rate reductions may harm beneficiary access even when states meet the three prongs that the Department outlines. If the Department does adopt the two-tier structure for enhanced analysis, we recommend that it make the criteria more robust. It should lower the 4% reduction threshold, as a 4% reduction to a rate that is already too low can have a material impact on beneficiaries' access to services. It should also change the requirement that affected services be paid at 80% of the Medicare rates or higher by increasing the 80% threshold to 100% over time. Finally, it should implement robust mechanisms for states to gather public feedback, including by providing a specific role for the MAC and BAG in collecting complaints, assessing access concerns, and making recommendations.

IV. Conclusion

We appreciate the opportunity to comment on this proposed rule. We request that the supporting documentation we have made available through direct links in our citations be considered part of the formal administrative record for purposes of the Administrative Procedure Act. For further information, please contact Ma'ayan Anafi, Senior Counsel for Health Equity and Justice at the National Women's Law Center, at manafi@nwl.org.

¹⁷ *Id.*

¹⁸ Amber Christ & Natalie Kean, *An Equity Framework for Evaluating and Improving Medicaid Home and Community-Based Services* 4 (Jun. 2023), <https://justiceinaging.org/wp-content/uploads/2023/06/An-Equity-Framework-for-Evaluating-and-Improving-Medicaid-HCBS.pdf>.

¹⁹ Cindy Mann & Adam Striar, *How Differences in Medicaid, Medicare, and Commercial Health Insurance Payment Rates Impact Access, Health Equity, and Cost* (Aug. 17, 2022), <https://www.commonwealthfund.org/blog/2022/how-differences-medicare-medicare-and-commercial-health-insurance-payment-rates-impact>.