July 3, 2023

Chiquita Brooks-LaSure, Administrator
Centers for Medicare & Medicaid Services, Department of Health and Human Services
Attention: CMS–2442–P, P.O. Box 8016, Baltimore, MD 21244–1850.
Submitted via regulations.gov.

RE: Medicaid Program; Ensuring Access to Medicaid Services

Dear Administrator Brooks-LaSure,

United States of Care (USofCare) is pleased to submit comments in support of the proposed rule by the Centers for Medicare & Medicaid Services (CMS) entitled "Medicaid Program; Ensuring Access to Medicaid Services."

USofCare is a nonpartisan nonprofit working to ensure everyone has access to quality, affordable health care regardless of health status, social need, or income. We drive change at the state and federal level in partnership with everyday people, business leaders, health care innovators, fellow advocates, and policymakers. Together, we advocate for new solutions to tackle our shared health care challenges — solutions that people of every demographic tell us will bring them peace of mind and make a positive impact on their lives. Through our work in states, we are able to identify unique perspectives from people on the ground to amplify on both the state and federal levels. Where possible, we uplift the voices of real people engaging with the health care system at the patient level whose perspectives have shaped our advocacy work.

Previously, USofCare submitted comments in response to a September 2022 proposed rule to streamline Medicaid and Children's Health Insurance Program (CHIP) enrollment and eligibility requirements. We were pleased that CMS incorporated that stakeholder feedback into the rule we seek to comment on today, which will improve health outcomes and expand access to care within Medicaid programs. **Overall, USofCare strongly supports this rule and advocates for its swift adoption.**

As we articulate how the rule will positively impact people's access to health care, we focus our comments on the following topics:

1. Access & Network Adequacy
2. Rate Transparency
3. Home- & Community-Based Services (HCBS)
4. Beneficiary Voice & Engagement

Access & Network Adequacy

Access Standards

USofCare's extensive listening work across the country reinforces that people's experience navigating the healthcare system and accessing the care they need is not without its challenges. We appreciate CMS's efforts to improve access for Medicaid enrollees in both this proposed rule and the companion proposed rule entitled "Medicaid and Children's Health Insurance Program Managed Care Access, Finance, and Quality." **We urge CMS to add access standards for states with a fully fee-for-service (FFS) delivery system, or for services that are covered outside of managed care in particular states, that mirror the important requirements being proposed in the managed care rule.** Adding wait time standards,

secret survey shopper requirements, and related publication requirements for certain services will provide Medicaid enrollees with accessible services, regardless of whether their states elect to deliver services via a FFS or managed care delivery system. **CMS should hold states accountable for assuring access to the same degree that CMS proposes to hold managed care organizations responsible for access.**

> *"A lot of people are intimidated by the [healthcare] system; you have to make the system more approachable to them. And explain to them how it's for their benefit."*
> *~ Black man, Texas*

We also understand these requirements are costly for states to administer. To that end, **CMS could phase in these requirements and we recommend that CMS begin by applying timeliness standards to primary care in states with little or no managed care.** In states that employ a combination of managed care and FFS to deliver services, CMS could start by developing and enforcing standards for select services, such as mental health and substance use services, dental services, and private duty nursing.

Rate Transparency

USofCare applauds CMS for taking steps to ensure Medicaid enrollees have adequate access to providers by instituting new rules related to Medicaid provider rate transparency. The proposed rule will ensure there are safeguards in place for Medicaid enrollees' access to care and will create consistent processes and safeguards nationwide. We know from our listening work that people value a system that is transparent and understandable. By having new and needed information about provider rates across state Medicaid programs, people will have more information about their access to care beyond the Medicaid program itself.

We strongly support the proposed requirements specified in § 447.203(b)(1) requiring all states to post all FFS rates on a publicly-available website by January 1, 2026. CMS should clarify the proposed rule to specify that detailed information showing the FFS rates *by Current Procedural Terminology (CPT) code* is required. We believe that rate transparency, including any variation based on population, provider type, and geographical location will be useful to Medicaid stakeholders and researchers interested in identifying how provider payment rates impact access to care over time. **Moreover, we support the proposal to prioritize rate transparency for primary care, OB/GYN, and outpatient behavioral health services, and encourage CMS to consider including rate transparency for services beyond the proposed list of services in the future.** CMS should clarify the proposed rule to specify that detailed information showing the FFS rates *by CPT code* is required.

Like CMS, we understand that states are already facing capacity constraints, and want to reiterate the need for CMS to provide states with regular updates and detailed information to ensure the rule is implemented as intended. It is critical that CMS prioritize working with states to ensure the data and information states will be required to put out about provider rates is clear, understandable, and usable.

Interested Parties' Advisory Group

We also welcome the proposed requirements to create an interested parties' advisory group, bringing lived perspectives into these important conversations. We urge CMS to require that at least 25% of the seats in the group are reserved for Medicaid beneficiaries and their legally authorized representatives and at least another 25% for direct care

workers and their representatives. **We also urge CMS to require that states publish public responses to the advisory group's direct care worker payment rates recommendations, explaining the evidence used to make their final rate recommendations, whether they accepted the recommendations of the advisory group, and if the rates differ from the recommendations, explaining their reasoning.** This will ensure critical voices are both heard and responded to. Creating opportunities for enrollees and direct care workers to influence these matters allows for a health care system that is more responsive and reflective of the experiences of the people who depend on it.

State Plan Amendments

We support the proposal to revamp current requirements in effect for state plan amendments (SPAs) that propose to reduce rate or restructure payments and strongly urge CMS to consider changes to the final rule to ensure the new proposed structure doesn't permit states to alter rates in ways that harm beneficiary access.

Home- & Community-Based Services

HCBS Network Adequacy

Despite significant evidence to support the provision of services in Home- and Community-Based Settings (HCBS) instead of in historically harmful psychiatric institutions, Medicaid coverage of HCBS remains optional for all states. The overall percentage of long-term services and supports (LTSS) delivered in an HCBS setting exceeded 50% for the first time in FY2013 and has continued to increase. We appreciate the outreach CMS has done to stakeholders in previous years that will inform future changes to HCBS for beneficiaries. **As the percentage of Medicaid beneficiaries receiving HCBS increases, it is important that CMS implement these changes with minimal disruption to care.** We are pleased to see CMS continue to prioritize access to "person-centered care," which benefits older adults, people with disabilities, and the general Medicaid population. USofCare has long championed the personalized nature of health care in improving health outcomes and promoting health equity.

Establishing Grievance & Incident Management Systems

Disturbing reports and data illuminate a deadly, systemic neglect for basic health and safety protocols in HCBS settings across the country. **USofCare applauds CMS's proposal to establish a critical incidents grievance system for HCBS beneficiaries.** We suggest a requirement that providers *simultaneously* report critical incidents to both the state and the designated Protection & Advocacy program, which is consistent with incident reporting requirements in psychiatric institutions. Implementing these systems as suggested allows for states to respond to incidents in an urgent manner that mitigates further harm.

Supporting Caregivers

> *"There are so many programs that are out there for respite. But again, for us as parents, it's very hard to go and just give your son or your daughter to these people, you need to trust them so much . . . The programs are good, they are there, but the people are not ready . . . the amount they're getting paid per hour is not enough."*
> *~ Hispanic woman, Virginia*

USofCare supports CMS's efforts to ensure that home care workers are paid adequately amid a dire, growing shortage of direct care workers. By requiring that 80% of payments in HCBS settings go directly towards the compensation, salary, and benefits of

home care workers, states will better ensure that home care workers are appropriately compensated for the critical services they provide. The workforce experiences high turnover rates, and in 2021, the median wage for direct care workers was $14.27 per hour. BIPOC women and immigrants disproportionately make up the care workforce. The low pay, scant benefits, and lack of respect that these workers receive stem from a long history of racism, sexism, and xenophobia. We further implore CMS to extend these payment adequacy provisions to state plan personal care and home health services. Properly and transparently investing in the direct care workforce not only provides the workers with the respect and dignity they deserve, but also leads to an improved quality of care for enrollees.

> *"One sleepless night, I'm on Google and there's this caregiver burnout thing . . . there's all these articles that popped up. On one hand, I thought 'It's not just me' because you second-guess yourself honestly. Your brain is functioning for two people all the time, and that is exhausting. It can be very isolating and very lonely because it's not like everyone around you is doing this."*
> *~ Caregiver Interviewed by USofCare*

USofCare encourages additional investments into "informal" caregivers. Informal caregivers are often family members or friends who care for their loved ones, increasingly in part due to the shortage of direct care workers. While about two-thirds of states permit the payment of legally-authorized relatives to provide HCBS services under Medicaid waivers, family caregivers require further support. Informal caregivers provide an estimated $600 billion in unpaid care to their relatives, which can result in them shouldering financial, physical, and mental burnout from their responsibilities. We recommend that CMS follow in the footsteps of states like Colorado, who have implemented Medicaid programs to train family members as certified nursing assistants and pay them to become caregivers, yielding comparable levels of care to that of direct care workers. Furthermore, CMS should maintain the Appendix K Waiver so that families can be paid for caregiving work, which proved to effectively combat the workforce shortage during the COVID-19 pandemic. Supporting informal caregivers alleviates the shortage of direct care workers and leads to personalized continuity of care for recipients.

HCBS Data Reporting

It is increasingly difficult for stakeholders to obtain HCBS quality, access, and outcomes data in different states. Under the proposed rule, states must publish data related to waiting list eligibility, time elapsed between being approved for and receiving services, and what percentage of home care services were provided in the last 12 months in an accessible, frequent manner. **This will provide sorely-needed transparency to a system that people often spend years waiting on for critical care.** The rule will also ensure that states report on select measures included in the HCBS Quality Set. While states would have to make a significant investment into how they report data, this would allow for consistent, standardized data across the states, which is not currently the case. People need to be provided with understandable information as they make complex decisions related to their care, which we know will provide them peace of mind.

Beneficiary Voice & Engagement

USofCare supports opportunities to incorporate beneficiary participation into the Medicaid policy process. If enacted, the rule would replace the current Medical Care Advisory Committee (MCAC) with a Medicaid Advisory Committee (MAC) and a Beneficiary Advisory Group (BAG). By establishing these committees, the federal government will follow states like Colorado and Virginia, whose State Medical Assistance and Services Advisory Council and Member Advisory Committee, respectively, ensure that feedback and perspectives of people enrolled in the

program are meaningfully incorporated into Medicaid policy. **The lived experiences of people receiving coverage via Medicaid must be appropriately included in the Medicaid policy process for a more equitable system of care.**

Conclusion

United States of Care applauds CMS's efforts to improve access to Medicaid through the proposed rule. If finalized, this rule will build towards our mission of ensuring that everyone can access high-quality, affordable, personalizable, and understandable health care. Please reach out to Lisa Hunter at LHunter@usofcare.org with any questions.

Sincerely,

Natalie Davis
Co-Founder and CEO
United States of Care