



June 29, 2023

The Honorable Xavier Becerra
 Secretary of Health and Human Services
 U.S. Department of Health and Human Services
 200 Independence Avenue SW
 Washington, DC 20201

The Honorable Chiquita Brooks-LaSure
 Administrator Centers for Medicare and Medicaid Services
 U.S. Department of Health and Human Services
 200 Independence Avenue SW
 Washington, DC 20201

Re: Medicaid Program; Ensuring Access to Medicaid Services; Proposed Rule - CMS-2442-P

Dear Secretary Becerra and Administrator Brooks-LaSure,

Thank you for the opportunity to comment on, “Medicaid Program; Ensuring Access to Medicaid Services; Proposed Rule - CMS-2442-P,” hereinafter referred to as the proposed rule.

The undersigned organizations represent millions of patients and consumers facing serious, acute, and chronic health conditions across the country, including millions receiving healthcare coverage through the Medicaid program. Our organizations have a unique perspective on what patients need to prevent disease, cure illness, and manage chronic health conditions. Our breadth enables us to draw upon a wealth of knowledge and expertise that can be an invaluable resource in this discussion.

In March 2017, our organizations agreed upon three overarching principles¹ to guide any work to reform and improve the nation's healthcare system. These principles state that: (1) healthcare should be accessible, meaning that coverage should be easy to understand and not pose a barrier to care; (2) healthcare should be affordable, enabling patients to access the treatments they need to live healthy and productive lives; and (3) healthcare must be adequate, meaning healthcare coverage should cover treatments patients need, including all the services in the essential health benefit (EHB) package.

In April 2022, many of our organizations submitted recommendations to the Centers for Medicare and Medicaid Services (CMS) in response to the Request for Information: Access to Coverage and Care in Medicaid and CHIP.² We appreciate that CMS incorporated some of our feedback into the development of this proposed rule. Individuals with chronic illnesses depend on prompt access to high-quality care to maintain their optimal level of health, and in some cases, to stay alive. While Medicaid is incredibly beneficial to persons with chronic illness, access problems in both fee-for-service (FFS) and managed care have negative impacts on health status and outcomes. This proposed rule will improve access to Medicaid for individuals with chronic illness that are enrolled in FFS and improve the function of Medicaid programs by empowering the voice of enrollee stakeholders. We provide the following recommendations in our comments below to strengthen the proposed rule.

Medicaid Advisory Committee and Beneficiary Access Group

We support the important changes in the proposed rule to update the current Medical Care Advisory Committee (MCAC) structure in Medicaid. MCACs are stakeholder committees that every state must establish to provide feedback and recommendations to the state Medicaid agency. The proposed rule includes numerous provisions to address long-standing deficiencies with the MCAC process. These changes will make state Medicaid programs more responsive to the lived experiences of enrollees, including enrollees with chronic illness who often have unique health care needs that may not be identified or addressed without their participation.

The proposed rule would change the MCAC name to Medicaid Advisory Committee (MAC) and create a new Beneficiary Advisory Group (BAG), comprised entirely of individuals with lived experience in Medicaid (including beneficiaries, family members, or caregivers), that will provide direct feedback to the state Medicaid agency and participate in the MAC. We support this new dual committee structure proposal, including the incorporation of family members and caregivers. Individuals with chronic illnesses may be intimidated by participating in the MAC, and the BAG will allow a safer space for participation and providing input. Additionally, our organizations support the requirements that at least 25% of the MAC be BAG members. We appreciate CMS requiring the MAC include at least one stakeholder from each of several categories, including a beneficiary advocacy organization.

We support CMS' proposals for the BAG to meet ahead of MAC meetings and for an executive member of the state agency to meet directly with BAG members. This is critical to establish direct communication and accountability with the state agency. However, in terms of composition, we recommend that CMS require states to include a diverse range of enrollees on their BAGs, considering factors such as categorical eligibility for Medicaid; race and ethnicity; age; disability, illness, and functional status; rural versus urban; etc.

¹ Consensus Health Reform Principles. Available at: <https://www.lung.org/getmedia/0912cd7f-c2f9-4112-aaa6-f54d690d6e65/ppc-coalition-principles-final.pdf>.

² <https://www.cff.org/sites/default/files/2022-04/PPC-Response-to-Medicaid-Access-RFI.pdf>

The current regulations include no provisions around transparency of MCACs. As CMS transitions to the dual structure, our organizations appreciate the new transparency requirements. Specifically, we support the requirements for the state to develop and publish processes to recruit and appoint committee members, bylaws for committee governance, committee member lists, the meeting schedule, and past meeting minutes and attendee lists. While we are pleased the proposed rule requires (at least) quarterly MAC meetings, we recommend that all MAC meetings should be open to the public (the proposed rule would require only two public meetings). The BAG should retain flexibility to make its meetings public at the BAG's choice, as it may be necessary for beneficiaries to have a private forum for difficult conversations, and beneficiaries may be private individuals who do not wish to have public exposure.

The proposed rule adds requirements for states to support the recruitment of MAC and BAG members, planning of meetings, producing meeting minutes and state response lists, and to provide information and research. We support the expanded obligations as state support for MAC and BAG processes and policy development is critical to the bodies being able to achieve their mission. However, we believe the regulation should go further in providing support to BAG members. First, states should be required to reimburse BAG members for reasonable costs related to participating (travel, lodging, etc.) without BAG members having to demonstrate need for reimbursement and BAG members should be compensated for their time participating in MAC and BAG activities. Second, CMS should require states to allow BAGs to have an independent (i.e., not affiliated to the state) counsel or policy organization, selected by the BAG, to support it in any capacity the BAG chooses.

We agree with the proposed requirement for states to take reasonable steps to make MAC and BAG meetings accessible to people with disabilities and limited English proficiency, including allowing participation virtually or by phone. We also agree with the proposal that requires states to select meeting times and locations to maximize attendance.

Finally, we appreciate CMS broadening the role for the MAC and BAG. Current regulations only require states to rely on the MCAC for advice on "health and medical care services," which could be construed narrowly to only allow input on service issues. The proposed rule would expand the role of the MAC and BAG to provide recommendations on all elements of state Medicaid programs, including services, eligibility and enrollment processes, communications, and quality of care, among other policy development topics. We support this proposal and the requirement for the state to support the MAC in the development of an annual report discussing MAC activities and recommendations, including a summary of BAG recommendations and state follow-up. However, we recommend that CMS explicitly consider ways that states should be required to consult with the MAC and BAG in policy development. For example, CMS should require that state Medicaid application designs and notice templates (including those used for managed care), should be provided to the BAG for comment prior to completion.

Home and Community-Based Services

As the primary payer of home and community-based services (HCBS) in the U.S., Medicaid plays a critical role in meeting the needs of individuals receiving long-term services and supports at home and in the community. Ensuring sufficient consumer protections and timely access to home and community-based services is essential to meeting the needs of Medicaid enrollees, including individuals with chronic illnesses.

Our organizations support the proposed rule requiring states to establish grievance procedures for Medicaid beneficiaries receiving certain HCBS services. Individuals in FFS Medicaid must have a way to express concerns about compliance with the state or a provider's compliance with the person-centered planning process and the home and community-based settings rule. However, we recommend that CMS shorten the timeframe for grievance resolution from 90 days to 45 days and specify that another individual or entity (such as caregiver or guardian) can represent the beneficiary throughout the process. We also support CMS's proposed Incident Management System, and specifically support the broad definition of "critical incidents" to include a range of harmful things enrollees may experience.

We support the proposal requiring states to report to CMS on 1915(c) waiver waiting lists, including all the reporting details such as the number of people on the list who are waiting to enroll and the average amount of time individuals newly enrolled in the waiver program waited to enroll. This information could help advocates, policymakers, and other stakeholders better understand the unmet need in the state and would allow individuals and families to plan for their future. These reporting provisions should also apply to 1905(a) state plan services for home health aides and personal care services and other HCBS services as identified by the Secretary.

Finally, we also recommend that CMS require states to break out all access reporting by disability, functional status, diagnoses, and age to better understand which populations may be disproportionately at risk.

Documentation of Access to Care and Service Payment Rates

Medicaid law requires that state Medicaid programs assure that payments are sufficient to enable access to providers for Medicaid enrollees. This requirement is particularly important to individuals with chronic illnesses who depend upon timely access to a wide range of providers to achieve their optimal health. Our organizations applaud CMS's broad proposal to replace Access Monitoring Review Plans with a new framework, including improved rate transparency and analysis and a two-tiered system for reviewing state requests to reduce or restructure Medicaid payment rates.

Transparency and Analysis

We support the proposed requirement for all states to post all FFS rates on a publicly available website by January 1, 2026. Even in states with high Medicaid managed care penetration rates, the FFS rate schedule is often a starting point or factor in negotiated provider payment rates and therefore the FFS rates should be posted in all states as proposed. We also support the proposed requirement for states to compare base Medicaid FFS rates to Medicare rates for primary care, obstetrical and gynecological (OB/GYN) services, and outpatient behavioral health for calendar year 2025 by January 1, 2026. We appreciate CMS requiring states to disclose the Medicaid payment amount for certain HCBS (personal care, home health aide, and homemaker services), for calendar year 2025 by January 1, 2026. While we acknowledge that Medicare is not a perfect comparator, we agree that it is a useful starting place because Medicare rates are publicly available on a national basis.

We urge CMS to extend this analysis to specialty care. Patients with chronic illness depend on the care provided by specialists and need timely access to providers. We also recommend that CMS develop a method for comparisons where Medicaid services have no equivalent Medicare rate or are provided very infrequently in Medicare so as to not be a reliable proxy.

Our organizations support requiring states to establish an Interested Parties Advisory Group (IPAG). The IPAG would advise and consult with the Medicaid agency on current and proposed direct care worker payment rates along with related access to care metrics and submit recommendations to the state at

least every two years. It is critical for Medicaid programs to evaluate rates and access for HCBS services, especially considering the unique market power of Medicaid for HCBS infrastructure and the current challenges in staffing these services. We advise that the IPAG and MAC should be separate entities. Furthermore, the IPAG should include sufficient and balanced representation from direct care workers, beneficiaries, and their authorized representatives, as well as other interested parties. The IPAG should be provided with sufficient data and states should be required to provide written, public responses to the IPAG's recommendations.

Rate Reductions

For rate reductions, CMS proposes a two-tiered approach that would provide a streamlined process for rate reductions or restructuring. A state seeking approval for a rate reduction/restructuring would have to show that the new rates would meet new, proposed standards: (1) new Medicaid rate at least 80% of comparable Medicare rate, (2) total rate reduction under 4% in aggregate FFS Medicaid expenditures, and (3) the required public process yielded no significant access concerns that the state was unable to address. We support this structure with some modifications:

1. **80 percent of the most recently published Medicare rates for comparable services.** We support this concept but recommend that CMS reconsider the 80% threshold and instead increase it to 100% of Medicare. As the preamble states, many providers are already paid at 80% of Medicare and thus it seems appropriate to select a higher standard by which to assess whether a reduction would diminish access. We are also concerned that CMS's proposed "aggregate" standard – reviewing rates across a benefit category rather than at the service-specific level – will mean that some Medicaid services are paid below the percentage threshold even if the overall benefit category achieves the threshold. CMS should consider setting the threshold on a disaggregated basis to avoid permitting states to obscure low payment rates and to truly protect access to key services.
2. **No more than a 4 percent reduction in aggregate FFS expenditures for each benefit category.** A four percent standard – or even a lower standard like one percent – would in most cases be reducing a rate which is already far below Medicare levels, therefore we ask CMS to remove this prong. Given the operation of inflation over time, there are very few goods or services that will truly decrease in value, and for the few that do decrease in value states should be easily able to document and justify the basis for their rate reductions. We support CMS's proposal to assess such rate reductions on a cumulative basis over the course of a state fiscal year. If, against our recommendation, CMS implements some version of this prong we urge CMS to consider designing a limit to ensure that states could not implement a deep cut (say 20%) to a particular service by analyzing the service within a broader category of services which, as a whole, does not exceed the four percent (or similar) threshold. CMS could also consider disaggregating service analysis in future rulemaking.
3. **No evident access concerns raised through the required public processes.** We strongly support this provision since developing robust mechanisms for states to hear feedback from providers and stakeholders about access concerns will be critical to assuring that this proposed provision has its intended effect. We believe CMS should further consider formalizing a specific role for the MAC/BAG in this process.

For states that do need to conduct enhanced analysis of rates that could result in diminished access, we support the standards that CMS has specified. However, we urge CMS to require states to publicly post the enhanced analysis, including data submissions, and that CMS ensure these submissions are public to ensure full transparency.

While we are supportive of CMS's approach to addressing rate reductions, we note that some states have on-going rates that are well below Medicare levels. CMS should consider using its authority to encourage states toward a national floor for rates. For example, CMS could phase in an explicit regulatory floor or implement standards tying improvements in Medicaid rates to approvals of related Medicaid flexibilities, such as section 1115 approvals, SDPs, etc. (as CMS has already done for some 1115 approvals for health-related social needs).

Finally, in its companion proposed rule on managed care, CMS is proposing new access criteria which are not proposed for FFS, including wait time standards, secret survey shopper requirements, and related publication requirements for certain services. To promote alignment and improve access, CMS should apply these requirements to most FFS states, or allow an exception for states that provide a de minimis level of FFS coverage.

Conclusion

Thank you for the opportunity to provide these comments. We look forward to continuing to partner with you on the implementation of these critical policies to improve access to care in Medicaid. If you have any questions, please contact Theresa Alban with the Cystic Fibrosis Foundation at talban@cff.org.

Sincerely,

Alpha-1 Foundation
American Cancer Society Cancer Action Network
American Heart Association
American Kidney Fund
American Lung Association
Arthritis Foundation
Asthma and Allergy Foundation of America
CancerCare
Child Neurology Foundation
Chronic Disease Coalition
Cystic Fibrosis Foundation
Epilepsy Foundation
Hemophilia Federation of America
Immune Deficiency Foundation
Lupus Foundation of America
Muscular Dystrophy Association
National Alliance on Mental Illness (NAMI)
National Eczema Association
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