



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 Brookes- LaSure,

On behalf of The Coalition for Kidney Health (C4KH) and the kidney community, we would like to express our appreciation for the opportunity to provide comments on the "Medicaid Program; Ensuring Access to Medicaid Services; Proposed Rule - CMS-2442-P."

The C4KH is a multi-stakeholder group of partners with an interest in early detection and management of chronic kidney disease (CKD). 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 hope you take into consideration the following recommendations in our comments below to strengthen the proposed rule. As the leading voice for the kidney community in the nation, we would like to offer our recommendations, and insights on behalf of the kidney community.

The Burden of Kidney Disease

Chronic Kidney Disease (CKD) is a major public health issue in the United States, affecting approximately 37 million adults, or more than one in seven American adults. Though it ranks as the 10th leading cause of death in the country, as many as 9 out of 10 American adults with CKD are unaware of their condition. Commonly known as a **"silent killer,"** the symptoms of CKD often do not appear until kidney function has been significantly impaired, and for more than 120,000 annually, it progresses to End-Stage Renal Disease (ESRD), requiring dialysis or kidney transplantation. CKD also imposes a substantial burden on the quality of life of affected individuals, as well as their families and caregivers.

Major risk factors for kidney disease include uncontrolled diabetes, high blood pressure, and a family history of kidney failure. CKD due to these major risk factors affects one in three American adults. In the United States, CKD is the tenth leading cause of death with a five-year survival rate for the average dialysis patient of only 35 percent¹. CKD is a disease multiplier, often exacerbating comorbidities such as

¹ CDC <https://www.cdc.gov/kidneydisease/publications-resources/ckd-national-facts.html#:~:text=More%20than%201%20in%207,are%20estimated%20to%20have%20CKD>.



diabetes and heart failure and putting CKD patients at increased risk for hospitalization and complications, including reentry to the hospital, higher death rates, longer inpatient stays, and worsening kidney function.

At its onset, CKD is asymptomatic, and only preventive screening for high-risk populations such as diabetes and hypertension can identify it in its earliest stages. Even among at-risk populations, such as those with diabetes and hypertension, CKD often goes undetected until its later stages. Approximately half of CKD stage 3 patients are undiagnosed and, as a result, are less likely to access guideline-concordant care for delaying and managing CKD. More troubling, as many as thirty-eight percent of patients with end-stage kidney disease learn of their diagnosis only after their kidneys have failed, requiring them to initiate dialysis in the emergency room in what is known as a “crash” start. As much as sixty-three percent of patients begin unplanned, emergent dialysis. Crashing into dialysis is traumatic for patients, increases mortality, and creates an economic burden.

CKD disproportionately affects certain populations, including older adults, racial and ethnic minorities, and those with lower socioeconomic status. It is essential to address the significant disparities in health insurance coverage and access faced by Black and Hispanic adults within the Medicaid program. African Americans and Hispanics have a higher prevalence of CKD and are more likely to progress to ESRD compared to non-Hispanic Whites. While Black/African American people represent 13 percent of the U.S. population, they represent 35 percent of those with kidney failure². Efforts should be made to eliminate barriers to coverage and ensure equitable access to preventive services, early detection, disease management, and transplantation for these vulnerable populations.

We recognize that each State faces a unique set of challenges related to the resumption of its normal program activities after the end of the COVID–19 public health emergency (PHE). However, Medicaid should expand coverage to include comprehensive care for individuals with Chronic Kidney Disease. CKD screening can easily be integrated into primary care practice. Physicians can use non-invasive, cost-effective testing to assess kidney function via eGFR and albumin-to-creatinine ratio (uACR), a crucial step towards improving American population health.³

Finally, to address disparities and improve access, targeted outreach and education initiatives should be implemented to reach underserved communities. Culturally appropriate educational resources and materials should be developed and disseminated to increase awareness, promote kidney health, and encourage individuals at high risk for kidney disease to seek appropriate care and support. Medicaid programs should invest in CKD prevention programs and initiatives that reduce the progression of kidney disease, decrease healthcare costs, and improve patient outcomes.

Medicaid Advisory Committee (MAC) and Beneficiary Access Group (BAG)

² Norris KC, Beech BM. Social Determinants of Kidney Health: Focus on Poverty. *Clin J Am Soc Nephrol.* 2021;16(5):809-811. doi:10.2215/CJN.12710820

³ Nikita Stempniewicz, Joseph A. Vassalotti, John K. Cuddeback, Elizabeth Ciemins, ect; Chronic Kidney Disease Testing Among Primary Care Patients With Type 2 Diabetes Across 24 U.S. Health Care Organizations. *Diabetes Care* 1 September 2021; 44 (9): 2000–2009. <https://doi.org/10.2337/dc20-2715>



The creation of the Medicaid Advisory Committee (MAC) and Beneficiary Access Group (BAG) provides an opportunity for meaningful stakeholder engagement, including individuals with lived experience in Medicaid, such as beneficiaries, family members, or caregivers. We support the proposed changes to update the current Medical Care Advisory Committee (MCAC) structure in Medicaid. Given the unique healthcare needs and challenges faced by individuals with kidney disease, it is essential to ensure their active representation within these committees. It is imperative to include individuals with kidney disease, kidney transplant recipients, nephrologists, and representatives from patient advocacy organizations with a specific focus on kidney health. This ensures that the perspectives and needs of the kidney community are considered in decision-making processes.

The current regulations include no provisions around the transparency of MCACs. As a result, we strongly support the proposed transparency requirements, including the development and publication of recruitment processes, bylaws, meeting schedules, and meeting minutes. Transparency fosters trust and accountability within the MAC and BAG, ensuring that the interests of the kidney community and Medicaid beneficiaries are adequately represented and addressed. While we applaud that 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 proposed rule also adds requirements for states to support the recruitment of MAC and BAG members, planning meetings, producing meeting minutes and state response lists, and providing information and research. We support the expanded obligations, as state support for MAC and BAG processes and policy development is critical for these stakeholder committees to achieve their mission. We also 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 MAC 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.

Home and Community-Based Services (HCBS)

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 a caregiver or guardian) can represent the beneficiary throughout the process. We also support CMS’ proposed Incident Management System, and specifically support the broad definition of “critical incidents” to include a range of harmful things enrollees may experience.

We commend the proposed requirement for states to establish grievance procedures for Medicaid beneficiaries receiving certain HCBS services. Individuals with kidney disease receiving HCBS services, such as home dialysis or in-home support, should have a mechanism to express concerns about compliance with person-centered planning and the home and community-based settings rule. This provision will empower individuals with kidney disease to advocate for their rights and ensure high-quality care.

We strongly support the proposal requiring states to report on 1915(c) waiver waiting lists. This reporting provision is critical for identifying the unmet need for HCBS services among individuals with kidney disease, allowing policymakers, advocates, and stakeholders to better understand the challenges faced by the kidney community. Furthermore, we recommend extending this reporting requirement to 1905(a) state plan services, such as home health aides and personal care services, which are essential for individuals with kidney disease.

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 kidney disease who depend upon timely access to a wide range of providers to achieve their optimal health. Our coalition applauds CMS’ 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.

We applaud the proposed requirement for states to post all fee-for-service (FFS) rates on a publicly available website. This transparency measure ensures that individuals with kidney disease, their caregivers, and healthcare providers have access to information regarding reimbursement rates. Additionally, we support the comparison of base Medicaid FFS rates to Medicare rates for primary care, obstetrical and gynecological (OB/GYN) services, outpatient behavioral health, and certain HCBS services. However, we strongly recommend expanding this rate comparison analysis to include specialty care services specific to kidney diseases, such as nephrology consultations, dialysis-related services, and transplantation-related care. According to the United States Renal Data System (USRDS), spending for Medicare beneficiaries with CKD was \$85.4B in 2020, representing 23.5% of total Medicare fee for service expenditures⁴. Treatment costs for kidney failure (also known as end-stage renal disease or ESRD) are even more exorbitant. Individuals with ESRD represent only 1 percent of Medicare beneficiaries but account for 6 percent of Medicare fee-for-service expenditures.

⁴ USRDS 2022 Annual Report: <https://usrds-adr.niddk.nih.gov/2022/chronic-kidney-disease/6-healthcare-expenditures-for-persons-with-ckd>



Adequate reimbursement is vital to ensure access to high-quality care for individuals with kidney disease. We support the review of reimbursement rates for nephrology services to ensure they accurately reflect the complexity and time-intensive nature of kidney disease management. Inadequate reimbursement rates can impede access to specialized care and compromise patient outcomes. Medicaid programs should establish fair and sustainable reimbursement policies that incentivize nephrologists to deliver comprehensive care to individuals with kidney disease.

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. While we are supportive of CMS' 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).

Conclusion

In conclusion, the Coalition for Kidney Health (C4KH) and the kidney community commend the Centers for Medicare and Medicaid Services for their commitment to improving access to Medicaid services through the proposed rule, "Medicaid Program; Ensuring Access to Medicaid Services; Proposed Rule - CMS-2442-P." We emphasize the need for specific considerations related to kidney disease, including adequate reimbursement for nephrology services, targeted interventions for addressing disparities and comprehensive approaches to kidney disease management.

As representatives of the kidney community, we are committed to collaborating with CMS and other stakeholders to ensure that individuals with kidney disease have access to high-quality, affordable healthcare services. We appreciate the opportunity to provide these comprehensive comments and look forward to continued engagement in shaping policies that promote kidney health and improve the lives of individuals with kidney disease. If you have any questions, please contact Ignacio Alvarez with the National Kidney Foundation at ignacio.alvarez@kidney.org.

Thank you for your attention.

Sincerely,

Coalition for Kidney Health