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July 3, 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 & Medicaid Services
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

VIA ELECTRONIC TRANSMISSION

Re: Medicaid Program; Ensuring Access to Medicaid Services (CMS-2442-P)

Dear Secretary Becerra and Administrator Brooks-LaSure,

First Focus on Children appreciates the opportunity to comment on the Centers for Medicare & Medicaid Services' (CMS) proposed rule, **Ensuring Access to Medicaid Services** (hereinafter "Access Rule"). First Focus on Children is a bipartisan advocacy organization that prioritizes children and families in federal budget and policy decisions. We advocate for the over 42 million children covered by Medicaid and the Children's Health Insurance Program (CHIP) to ensure they have access to timely, affordable, and high-quality care. The proposed Access Rule, along with the Managed Care Rule, represent much needed steps toward improving the Medicaid program, especially for children.

In general, First Focus on Children supports CMS finalizing the Access Rule subject to our comments below that we believe will help further improve the proposals for children and families. We support CMS requiring compliance with the finalized version of these proposals at the soonest practicable dates.

Medicaid and CHIP provide health care coverage to more than 50% of children in the United States,¹ including foster youth, children with complex and special health care needs, and many children of color. As CMS works toward improving access to care, it must consider the unique needs of children. Unfortunately, having Medicaid or CHIP coverage is only one piece of the puzzle for children to be able to access care. The access component is often filled with barriers that prevent children from

¹ Centers for Medicare & Medicaid Services, Medicaid and CHIP Enrollment Trend Snapshot (March 2023), <https://www.medicare.gov/medicaid/national-medicare-chip-program-information/downloads/march-2023-medicare-chip-enrollment-trend-snapshot.pdf>.

accessing the care that they critically need. Some the best ways to tackle breakdowns in the Medicaid system for children, are to improve transparency and to look to the lived experienced of enrollees for input to approve access to and quality of care. This rule takes steps in the right direction utilizing those tools for improving Medicaid for children. Combined with Managed Care Access Proposed Rule, we applaud CMS for trying to set standards that attempt to tackle barriers to children's access to care and that are more comprehensive and consistent across delivery systems.

Fee-for-Service States

We recommend that CMS add additional 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 (e.g., behavioral health services). In its companion Managed Care proposed rule, CMS is proposing wait time standards, secret survey shopper requirements, and related publication requirements for certain services. We support CMS applying similar standards to services delivered via the FFS delivery system, including to assess geographic variation. Children enrolled in Medicaid have the same right to accessible services regardless of whether their states elect to deliver services via the FFS or managed care delivery system, and CMS should hold states accountable for assuring access to the same degree that CMS proposes to hold managed care organizations responsible for access.

Medicaid Advisory Committee and Beneficiary Advisory Group

CMS proposes to significantly strengthen requirements for Medical Care Advisory Committees (MCACs), which would be renamed Medicaid Advisory Committees (MACs) and include a new Beneficiary Advisory Group (BAG). First Focus on Children is happy to see these proposed regulations. They are welcome steps to meaningfully improve engagement of stakeholders, most importantly, the children and families with firsthand knowledge of the Medicaid effectiveness and deficiencies in their states.

Direct input from families with children enrolled in Medicaid offers several benefits for making better policy and improving care. Firstly, it provides a deeper understanding of the challenges faced by these families, helping policymakers and healthcare providers comprehend the realities of accessing healthcare for Medicaid-enrolled children. By highlighting gaps in care, such as access barriers and deficiencies in the healthcare system, families' insights can guide policymakers in addressing these issues effectively.

Moreover, family input enables policymakers to develop targeted policies that specifically address the needs of children enrolled in Medicaid, ensuring that solutions are realistic and impactful. This patient-centered approach, which considers the unique circumstances and preferences of families, fosters a stronger sense of ownership and accountability. Additionally, feedback from families helps in the implementation of Medicaid programs by streamlining processes, reducing administrative burdens, and enhancing the delivery of care.

Engaging families in the policymaking process not only promotes trust and satisfaction but also demonstrates the value placed on their input. Ultimately, incorporating direct input from Medicaid-enrolled families leads to more accessible, high-quality care and improved health outcomes for children.

While First Focus on Children supports the proposal MAC and BAG proposals overall, we offer the following suggestion to improve them to have the most positive impacts on children enrolled in Medicaid:

- Committees should include a broad array of key stakeholders with an open and transparent appointment process. We support CMS' proposal for the appointment of members on a rotating basis, which would help ensure continuity in MAC and BAG operations. However, we oppose imposing term limits for members, since in some jurisdictions the number of advocates, especially those dedicated to children's health issues, is limited.
- CMS must ensure families with children enrolled in Medicaid, including those with disabilities and special health care needs, are represented on each the MAC and BAG. We would encourage CMS to include requirements that BAG membership represent a cross section of families with children enrolled in Medicaid to ensure so that the unique health needs of infants through teens/young adults are represented in the input and policymaking process.
- Require representation on the MAC from providers and community organizations serving, meeting, and advocating for the needs of children's physical and behavioral health. Despite being a large proportion of enrollees in state Medicaid programs, children's unique health issues often get overshadowed by overarching policy. Requiring a fixed percentage of child-focused providers and community organizations can help ensure children are not overlooked.
- Engaging Medicaid enrollees and providing opportunities to meaningfully engage in BAG and MAC proceedings should be a priority. We support requirements to make MAC and BAG meetings accessible to people with disabilities and persons with Limited English Proficiency (LEP). State Medicaid agencies should provide staffing and other support for MAC and BAG proceedings. However, CMS should allow and require states to also provide independent support for members of the BAG to help ensure more meaningful input into the process that is not tainted by the bias toward a desired policy or program direction of state staff. We also urge CMS to further clarify and strengthen state requirements to engage families with children enrolled in Medicaid, including providing transportation assistance/reimbursement, childcare, financial reimbursement (for room, board, and any missed work), and varying meeting times and locations to allow participation of enrollees during working hours.
- We urge CMS to further clarify that the BAG may issue recommendations, reports, and other findings independently of the MAC.
- CMS should expressly provide for MAC subcommittees as determined by members, including Children's Health/Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit and others.
- Apply the requirements, or similar, to separate CHIP programs.
- The scope of MAC and BAG should extend to all aspects of a state's Medicaid program. We support CMS' proposal that MAC and BAG recommendations should not be limited to medical care, but includes other issues related to the effective administration of the program, including services, eligibility, care coordination, quality, communications, cultural

competencies, and other issues. CMS should make clear that the scope of MAC and BAG advisory authority should extend to all aspects of a state's Medicaid program.

- Require meetings between BAG members and the director of the single state agency on a quarterly basis;
- Provide for regular meetings between BAG and CMS regional authorities;
- CMS should post MAC/BAG reports on its website, with a directory and links to each state's MAC and BAG;
- Require all MAC meetings throughout the year to be public, rather than just two meetings as currently proposed.

Payment Transparency

Medicaid's equal access provision requires sufficient provider payments to ensure care availability. However, Medicaid payments to primary and subspecialty clinicians are much lower than Medicare and private insurance payments. This, along with delayed and confusing payments, limits provider participation and access to care for patients.

Transparent payment rates in both FFS and managed care are crucial to enforcing the equal access provision. This allows stakeholders to raise concerns when inadequate payment affects patient care.

While we support these changes, we are concerned that the CMS benchmark undervalues pediatrics and won't address inadequate payment to Medicaid providers effectively. The proposed access rule outlines a process for State access analyses, but it's only required when a State proposes to reduce payment rates or restructure payments.

To improve the proposal for children and families, First Focus on Children recommends:

- Increasing the proposed fee ratio threshold from 80 percent to 100 percent of Medicare. Additionally, the extensive access analysis outlined in 42 CFR 447.203(c)(2) should be required when proposed rate reductions would bring Medicaid payment below 100 percent of Medicare.
- The Medicaid-to-Medicare fee ratio threshold should be a federal floor for all SPA and waiver approvals, not just for rate reductions.
- States with a Medicaid-to-Medicare fee ratio below 100 percent for pediatric primary care and pediatric behavioral health services should demonstrate annually that they meet the equal access provision for children in Medicaid, both in FFS and managed care.
- All states, regardless of their fee ratio, should complete the comprehensive access analysis outlined in 42 CFR 447.203(c)(2) to establish a baseline measure of access to care for Medicaid beneficiaries. This analysis should cover both FFS and managed care, allowing for comparisons within and across delivery systems. The baseline analysis will serve as a reference point for future access monitoring.

Home and Community-based Services (HCBS)

Children in Medicaid have the right to receive home health care services, personal care services, and private duty nursing through EPSDT. However, access to and the quality of nursing and personal care for children through EPSDT is insufficient. Private health insurance rarely covers pediatric home health care, and even in states where services are available, there are often waiting lists and gaps in care. This places the burden on unpaid family caregivers.

We support CMS' proposed safeguards for HCBS, which aim to improve monitoring, quality measures, and support for the direct care workforce. To better meet the needs of children relying on HCBS, First Focus on Children recommends the following:

- Ensure payment adequacy provisions apply to home health care, personal care services, and private duty nursing, and work with states to ensure sufficient payment rates for HCBS.
- State HCBS waiting lists should include age breakdowns to capture the number of children waiting for waivers.
- Paid family caregivers should be explicitly mentioned in the payment adequacy provision or the definition of the direct care workforce.
- Pediatric-specific metrics should be included in the proposed HCBS quality measures.

Conclusion

First Focus on Children thanks you for your work and the opportunity to comment on these issues. Should you have any further questions, please contact Abuko Estrada, Vice President of Medicaid and Child Health Policy, at abukoe@firstfocus.org.

Respectfully,



Bruce Lesley
President, First Focus on Children