July 30, 2026

The Honorable Mehmet Oz, M.D., Administrator
Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services
P.O. Box 8016
Baltimore, MD 21244-8013

Subject: Medicaid Program; Community Engagement Requirement for Certain Individuals, CMS-2454-IFC

Dear Administrator Oz:

Children's Hospital of Philadelphia (CHOP) provides the following comments in response to the U.S. Department of Health and Human Services' Interim Final Rule on Community Engagement Requirement for Certain Individuals, CMS-2454-IFC.

In these comments, we focus on the unique needs of youth who are aging out of the comprehensive child coverage requirements in Medicaid known as EPSDT or Early Periodic Screening Diagnosis and Treatment into a differently defined set of benefits. For youth with special health care needs and chronic medical conditions, "aging out" can present particular health challenges. With this in mind, we focus on these youth, especially those who are likely shifting away from EPSDT to join the Medicaid expansion population, rather than those who might undergo a separate, and complex, application to receive Medicaid through a disability pathway.

CHOP cares for many medically complex youth who will be subject to but unable to satisfy the community engagement requirement. These children, along with their caregivers and providers, will need to document their medical frailty under the final rule. As drafted, CHOP believes there could be unintended consequences of the interim final rule on this vulnerable group, particularly as they move from pediatric to adult Medicaid coverage. We highlight these potential concerns, suggest ways to circumvent them and also share findings from research about the shift from pediatric to adult Medicaid coverage, and how this shift impacts health care access.

With nearly 20% of young adults enrolled in Medicaid, the impact of the interim final rule community engagement requirements on this group will be significant, so we respectfully request that CMS consider our comments below and:

1. Delay implementation of this rule so as to allow families, states and providers adequate time to prepare for new requirements;
2. Permit states to categorically exempt individuals with certain severe conditions, such as patients who are severely immunocompromised; have terminal diagnoses; or are receiving home intravenous nutrition or medication.
3. Minimize the administrative burden on families, states and providers by allowing the self-attestation option for medical frailty to become permanent;
4. If it is not possible for self-attestation to become a permanent methodology, allow states to develop strategies to minimize documentation requests and reduce the need for repeated documentation, especially in cases in which the medical frailty determination is likely to be ongoing.

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Current Risk of Coverage Gaps

The shift from pediatric to adult care and coverage is challenging, and many young adults become uninsured during this life stage. Young adults have the highest uninsurance rate of any age group, with an estimated 14% uninsured; disruptions in insurance coverage further exacerbate challenges in accessing healthcare. A recent study among young adult Medicaid enrollees found an increase in disenrollment as young adults become eligible through adult pathways; nearly one-third ultimately re-enroll suggesting continued eligibility. In this same study, the probability of disenrollment varied by population characteristics and state, which as suggested by the study authors, may be related to operational and eligibility differences in each state.

Approximately 25% of children and youth (more than 19 million children) have special health care needs. These youth are particularly vulnerable to gaps in coverage and care. Children and youth with special health care needs have or are at risk for having chronic physical, developmental, behavioral, or emotional conditions such as asthma, sickle cell disease, epilepsy, anxiety and autism. Some of these young adults will qualify for Medicaid not through a disability pathway but rather as adults in the expansion population. For these youth, moving from pediatric to adult care can be especially challenging, as it requires establishing care and coordinating across different specialists in addition to primary care. CHOP PolicyLab research examining the barriers and opportunities for youth with special health care needs illustrates the complexity of the transition for everyone involved, including pediatric providers, adult providers, young adults, and caregivers.

Young adults who lose coverage at this time - due to administrative burden, changed eligibility, or other reasons – may find that essential care for their conditions becomes inaccessible, leading to poor health outcomes. For example, youth with sickle cell disease who have gaps in coverage while transitioning to adult care have increased emergency room visits. Existing evidence suggests similar patterns will be seen among patients with congenital heart disease, childhood cancers, and other types of childhood medical complexity who lose coverage as they transition to adulthood.

Risk of Coverage Gaps from the Interim Final Rule

For young adults, especially those with special health care needs, the administrative and documentation requirements laid out in the Interim Final Rule will create additional complexities. It is well documented that young adults find navigating health coverage challenging, and this directly impacts their care. CHOP PolicyLab research with young adult cancer survivors found that 30% delayed or forwent survivorship care because they didn't understand their plan's coverage. Medicaid enrollees were even more likely than those with private coverage to report delaying care. CHOP PolicyLab researchers and other experts have also demonstrated that administrative burden decreases enrollment in benefits. With the Interim Final Rule's additional requirements related to documentation paired with more frequent eligibility determinations, more young adults are likely to lose Medicaid coverage not due to ineligibility, but rather due to administrative complexity.

Even for young people who technically remain eligible due to a medical frailty exemption, it will be challenging *to demonstrate* impaired ability to conduct work activities, especially while establishing care with new providers. Medicaid beneficiaries and their providers must prove not only that a patient has a serious condition (e.g., cancer), but that illness significantly impairs the

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person's ability to work 80 hours per month. The Interim Final Rule currently allows for states to accept self-attestation of medical frailty, but this provision expires after 2027.

Data limitations make it unlikely that medical frailty determinations will be automated after 2027, and states may need to rely on treating providers to verify not only a patient's condition, but their functional limitations in terms of community engagement. Providers who specialize in complex conditions and serve many Medicaid patients will face a large number of complex certification forms and will be forced to make repeated judgments about a patient's ability to work, often within tight schedules and compressed visit times. At CHOP, because patients come from all over the country for highly specialized care, the challenge will be magnified by different forms and deadlines from different states.

Given the burden on families, providers, and states, CHOP respectfully urges CMS to consider the recommendations listed above, and thereby minimize the loss of coverage among vulnerable young adults. Delayed implementation is a first necessary step, given the hurdles ahead for states and the affected populations.

Categorical exemption for certain diagnoses with clear inability to work over time will minimize the extra work for all parties, and ensure continuity of care for some of the sickest and most likely to deteriorate rapidly from coverage interruptions. A patient who requires ongoing intravenous nutrition or medications; a patient who is hospice eligible; or patients with other severe conditions that are unlikely to improve are going to be clearly exempt. Many of these patients will remain in the expansion population as their condition does not qualify them for a disability pathway, and yet their health is so poor (and will remain so poor) as to disqualify them for employment or community engagement. The documentation requirement should be eliminated for these patients, and either states or CMS should develop a methodology for doing so.

Finally, the self-attestation methodology, available in year one, will be the most sustainable approach for patients, their families, providers and for states. At a minimum, CMS should expand this provision for an additional year while the agency evaluates the impact and whether there is truly a justification for labor intensive documentation being currently being proposed.

CHOP urges CMS to consider implementing the law in a manner that preserves coverage for medically frail individuals who will have significant difficulty documenting their condition, including the many young adults who rely on Medicaid. The recommendations outlined in this letter would help to preserve coverage for this group. Clinical and policy experts at CHOP would be glad to provide additional information.

Thank you for your work on this important initiative.

Sincerely,



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