National Patient
Advocate Foundation

July 28, 2026

Centers for Medicare and Medicaid Services
7500 Security Blvd
Baltimore, MD 21244

**RE: Medicaid Program; Community Engagement Requirement (CER) for Certain Individuals-Interim Final Rule with Comment Period (IFC)**

Submitted electronically via www.regulations.gov

National Patient Advocate Foundation (NPAF) appreciates the opportunity to submit comments on this IFC.

NPAF is a national nonprofit organization and policy affiliate of the Patient Advocate Foundation (PAF) working at the system level to influence public policy and drive change in healthcare—with the mission of making the healthcare system work for all of us. Our work is directly informed by listening and responding to the needs of patients and caregivers.

PAF is the nation's first comprehensive nonprofit dedicated to helping patients navigate, access, and afford their care while improving the healthcare system for all. It provides financial assistance to help patients afford treatment and cost of living needs, personalized case management to navigate complex healthcare and social needs challenges, and a wide array of resources to empower people to take charge of their health.

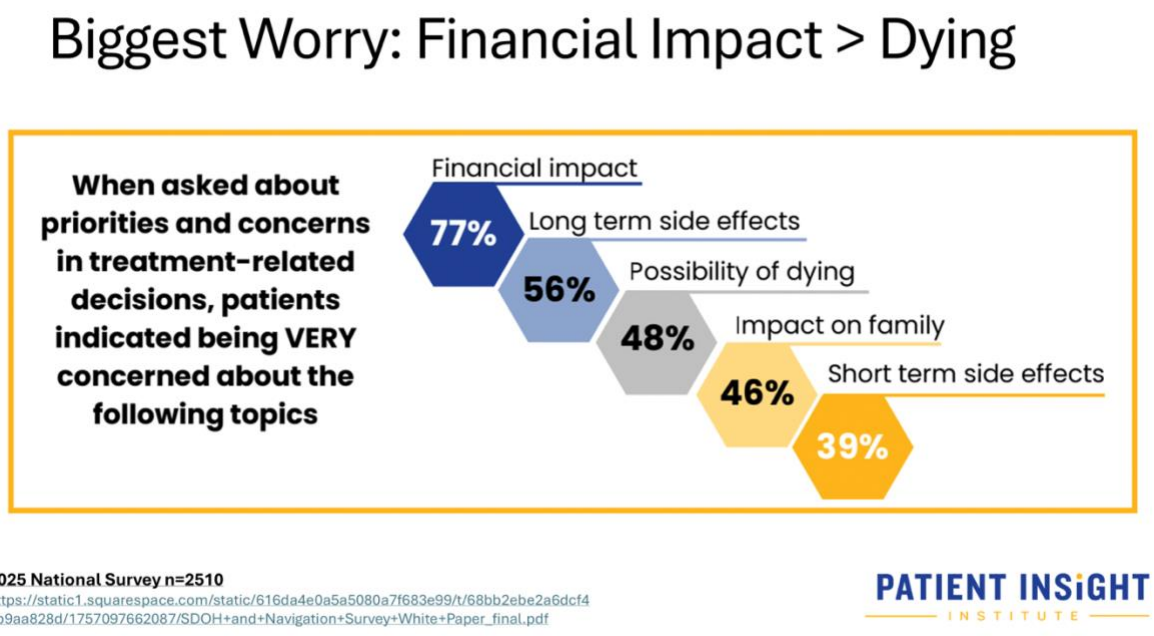
**Background**

NPAF prioritizes policies responsive to unmet financial needs articulated by patients and caregivers coping with complex and chronic conditions. For most of them, financial distress is a common consequence of serious illness. This is true even for individuals with health insurance. Costs of medical and other care escalate quickly and often overwhelm even the best planned household budgets, hurting individuals' economies, health, and quality of life. Patients and family caregivers in our vast national grassroots advocate network consistently tell us that preserving financial stability alongside medical and mental health must be considered as integral aspects of high-quality healthcare, and NPAF is positioned to pursue this objective through evidence-supported, system-level reforms.

Our direct patient services counterpart, PAF, delivers a hands-on “Needs Navigation” model to ease cost concerns for patients experiencing financial hardship and help reduce the stress they and their caregivers experience in successfully completing the complex administrative processes required to access care and benefits. In 2025, PAF distributed over $259 million in financial support and provided direct, sustained assistance to more than 186,000 patients. The population PAF served last year alone represented 758 distinct diagnoses and 434 rare diseases from all 50 states, Puerto Rico, Guam, and the U.S. Virgin Islands, reaching patients in 92% of all U.S. counties.

Since PAF’s and NPAF’s founding in 1996—and joining forces with the Patient Access Network (PAN) Foundation in 2026— we have helped more than 3.8 million people access and navigate care, granted over $7 billion in financial assistance, provided personalized case management support to over 350,000 patients, and elevated the patient’s voice to drive improvements in the healthcare system.

A 2025 survey conducted by PAF’s Patient Insight Institute of 2500 people PAF served found their top health concern was financial hardship. This was higher even than their fear of death:




Subsequently, as the economy has worsened, we are hearing more and more concerning stories from our patient network, such as Janet Marx who received vital assistance previously from PAF helping with medication copays yet had to sell her house this year to be able to afford the cost spike she confronted in her health care premiums.

**Our comments on this IFC**

NPAF is deeply concerned that the IFC's community engagement framework will fall hardest on Medicaid beneficiaries already experiencing health conditions and financial hardship as well as the family caregivers who help them stay connected to coverage and care. For people living with unstable wages, irregular schedules, intermittent housing insecurity, limited internet or phone access, and frequent changes in address, these administrative demands are not minor program conditions; they are predictable coverage barriers that harm health and well-being.

The IFC itself recognizes the magnitude of this burden. CMS estimates that roughly 44 percent of approximately 20 million applicable beneficiaries, or 8.8 million people, will need to submit information to the state because compliance, exception, or exclusion cannot be verified, and estimates that this process will take an average of two hours every six months. In aggregate, CMS estimates 35.2 million hours of annual beneficiary burden and $454.784 million in annual beneficiary costs associated with providing documentation and information to satisfy the requirement. Those estimates underscore the practical reality that the IFC shifts substantial administrative responsibility onto low-income people, many of whom are experiencing health challenges themselves or in their home, and whose time, transportation, device access, data plans, and workplace flexibility are already constrained.

For people facing financial hardship, the most consequential effect of this IFC is likely to be loss of coverage for procedural reasons rather than a true failure to work or engage in the community. The IFC acknowledges that earlier Medicaid community engagement initiatives in Arkansas and Georgia demonstrated how beneficiary awareness, clarity of requirements, accessibility of reporting mechanisms, and overall administrative complexity influence participation and compliance. That implementation history matters here because beneficiaries with low incomes and health conditions often cycle among unstable employment, short-term jobs, caregiving obligations, and periods of crisis that are difficult to document in real time even when they are continuously striving to meet basic needs.

Low-income workers are especially vulnerable because the IFC appears built around documentation and reporting structures that fit stable, formal employment and associated healthcare coverage better than the realities of low-wage labor often lacking important benefits. Many people in the adult group work fluctuating hours, cobble together multiple part-time jobs, rely on seasonal work, or experience sudden reductions in hours without advance notice. When eligibility turns on repeated demonstrations of compliance, individuals with the least predictable employment are also the ones most likely to be tripped up by paperwork, deadline confusion, outdated address/contact information, or mismatches between state data

and their actual circumstances. In that setting, Medicaid ceases to function as a stabilizing support during periods of economic volatility and instead becomes another source of instability.

The burden extends beyond beneficiaries themselves to caregivers, who are often the invisible administrative backbone of Medicaid participation and in-home care. The IFC does recognize an exclusion for a parent, guardian, caretaker relative, or family caregiver of a dependent child age 13 and under or a disabled individual, and CMS explains that these categories are intended to align with existing Medicaid concepts where possible. That exclusion is important, but it does not fully address the realities of caregiving in financially strained households coping with health conditions. Many caregivers provide substantial help with transportation, paperwork, medication management, providing health care services themselves, language interpretation, appointment scheduling, and crisis response for relatives who may not satisfy the IFC's definitions of a disabled individual or qualifying dependent child yet still depend on unpaid support to maintain employment and health coverage. Others move in and out of caregiving roles as household composition, work schedules, health circumstances and family needs change. Without simple, durable pathways to recognize these circumstances, the IFC will continue to place substantial documentation burdens on households already stretched thin.

The IFC also acknowledges that some beneficiaries or individuals acting on their behalf will need to request short-term hardship exceptions, including where an individual receives institutional or hospital services or must travel outside the community for treatment. CMS estimates 300,000 such requests annually at one hour each. But short-term hardship pathways are not a sufficient safeguard for people facing chronic financial precarity alongside health conditions. Financial hardship does not typically present as a single isolated event. It is often an ongoing condition marked by transportation breakdowns, housing instability, domestic violence, caregiving disruptions, temporary job loss, lack of paid leave, and inability to secure records from employers or third parties. A framework centered on discrete exception requests still assumes a level of administrative capacity that many struggling households do not have.

The notice architecture in the IFC raises additional concern. CMS estimates that states will send tens of millions of notices annually and must use at least two modalities for outreach, while also generating noncompliance notices that provide at least 30 calendar days to respond before adverse action. While outreach is necessary, volume does not equal comprehension nor does it confirm a beneficiary's receipt where the person currently resides. Beneficiaries with limited English proficiency, low health literacy, inconsistent mailing addresses, or intermittent access to online accounts can easily miss or misunderstand notices, particularly where communications are layered onto renewal forms, requests for information, and other Medicaid correspondence. Financially distressed households often prioritize immediate crises over paperwork that appears technical or duplicative, even when the consequence is loss of health coverage. Moreover,

updating contact information to reach all these beneficiaries at their current address or email is not realistically addressed or accounted for in the proposed outreach approach.

Coverage interruptions caused by these procedural burdens can have severe downstream effects for people with financial hardship even when they are not ill. Medicaid supports access to primary care, behavioral health care, prescription drugs, preventive services, home and community-based services and treatment that helps beneficiaries remain able to work, search for work, care for family members, and manage chronic but non-disabling conditions. When coverage is terminated because documentation is late, incomplete, or not successfully matched, the result can be delayed care, unaffordable out-of-pocket costs, medical debt, and worsening economic instability. For caregivers, the same loss of coverage can reduce their own capacity to continue providing unpaid care and can shift costs and stress across the entire household and to the health system itself.

These concerns are intensified by the IFC's own recognition that administrative complexity can shape whether people successfully comply. If nearly half of affected beneficiaries are expected to submit paperwork and information manually, then the central policy risk is not isolated error but systemic procedural churn. In practice, people with the fewest financial resources are least able to absorb that churn. They may lack printer access, broadband, scanner capability, paid time off, reliable mail delivery, or a single point of contact with the state. Each additional verification point increases the chance that an otherwise eligible person will lose coverage because the system was not designed around the realities of poverty and harms of gaps in coverage.

Finally, the rule's addition of a "significant impairment" test to medical frailty standards will further complicate and reduce coverage in cases where individuals need it most. The Act does not require proof that a condition significantly impairs work capacity for a patient to be deemed "medically frail." NPAF urges caution where the IFC adds a narrowing "significant impairment" element that is not in the statute's text. This restrictive approach will particularly and negatively affect vulnerable populations such as people coping with serious illness and disability, and also unnecessarily exacerbates the administrative burden on beneficiaries and states.

CMS should therefore revise implementation and oversight of this IFC to minimize foreseeable harm to beneficiaries coping with complex and chronic conditions, people facing financial hardship, and the caregivers who support them. At a minimum, the final policy should:

1) Maximize verification and sharply limit requests for beneficiary-submitted documentation, including by requiring states to use all available wage, SNAP, TANF, unemployment insurance, and other reliable administrative data before contacting the individual for more information.

2) Require a robust good-cause standard for late or missing documentation whenever a beneficiary reports barriers such as unstable housing, loss of phone or internet access, transportation problems, limited English proficiency, domestic violence, caregiving disruption, or inability to obtain employer records.
3) Prohibit disenrollment for a first instance of alleged noncompliance unless the state has completed multiple outreach attempts across modalities, including verifying current address updates for outreach, documented actual consideration of good cause, and provided person-centered assistance to resolve missing information.
4) Extend response time beyond 30 days where mail is returned, electronic contact fails, or the beneficiary indicates hardship, because financially strained households often need additional time to secure records and respond.
5) Create a simple self-attestation pathway, subject to post-enrollment verification when needed, for individuals with unstable work schedules, intermittent earnings, or temporary crises that make contemporaneous documentation difficult.
6) Broaden caregiver protections by instructing states to recognize caregiving responsibilities functionally, not only formally, and by minimizing repeated documentation for households with ongoing caregiving demands.
7) Require all notices, scripts, and online workflows to be written in plain language, translated into prevalent languages, accessible for people with disabilities, and tested with beneficiaries who have low literacy and limited digital access. PAF's Patient Insight Institute is a helpful messaging resource for CMS to provide patient-resonant, understandable language input and we would be happy to make that resource available to you.
8) Require states to report transparently on procedural denials, disenrollments, call-center wait times, returned mail, fair hearing requests, and reinstatements so CMS and the public can distinguish true noncompliance from administrative and outreach failure.
9) Establish prompt reinstatement and retroactive coverage protections when beneficiaries are disenrolled for failure to document compliance, but later demonstrate that they met the requirement, qualified for an exception or exclusion, or did not receive effective notice.
10) Not include the added "significant impairment" requirement as it is not supported by statute.

Additional protections are warranted for caregivers. CMS should direct states to adopt streamlined processes that allow caregivers to establish excluded status once and remain excluded for a reasonable period absent a known change in circumstances, rather than

requiring repeated resubmission of the same information. CMS should also clarify that individuals assisting a beneficiary with compliance or paperwork may serve as authorized representatives through simplified methods, because many low-income beneficiaries with health conditions rely on family members to manage notices, portals, and communications with the agency. These operational changes would better reflect how coverage is actually maintained in medically and financially stressed households.

In finalizing this policy, CMS should judge success not by the volume of notices sent or the number of verifications completed, but by whether eligible people retain coverage and healthcare continuity without avoidable procedural loss. The IFC's own burden estimates demonstrate that millions of beneficiaries will be exposed to repeated documentation demands and that states will administer a notice-and-verification regimen of enormous scale. Without substantially stronger protections, those burdens will predictably fall on people with the least financial flexibility and on the caregivers whose unpaid labor helps keep vulnerable households and health systems functioning.

**Conclusion**

NPAF appreciates the opportunity to comment on this proposed IFC. We close our comments with this compelling patient testimonial submitted by an NPAF grassroots advocate, Yvonne R. from Georgia:

*"I qualified for Medicaid by a single dollar and had to prove it before a judge twice. That experience was overwhelming. One of those judges didn't even know what documentation was required. At that time, I had several overlapping diagnoses. I used a walker and I couldn't even put a sentence together. Managing my health became my full-time job. I understand the importance of oversight and reducing fraud — but we can't isolate the people who legitimately need Medicaid. I couldn't have made it without it."*

Please contact me at Rebecca.kirch@npaf.org if NPAF can provide further details about these IFC comments.

Respectfully submitted,

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