

**Objective 1: Medicaid and CHIP reaches people who are eligible and who can benefit from such coverage.**

1. What are the specific ways that CMS can support states in achieving timely eligibility determination and timely enrollment for both modified adjusted gross income (MAGI) and non-MAGI-based eligibility determinations? In your response, consider both eligibility determinations and redeterminations for Medicaid and CHIP coverage, and enrollment in a managed care plan, when applicable.

- **Access to technology:** Social workers at cystic fibrosis care centers report that people with CF consistently struggle to enroll in and renew Medicaid and CHIP coverage, and one of the main reasons is access to and understanding about how to use technology. While all states accept electronic applications, many people applying for Medicaid or CHIP do not have a home computer on which to complete their application or redetermination paperwork. Mobile friendly applications are an important option but people may still struggle to create electronic copies of their supporting documentation if they do not have access to a scanner.

These issues underscore the need to continue exploring additional enrollment pathways and improving those that already exist. For instance, one social worker reported that her state used to operate kiosks at which people could complete applications and scan documentation, eliminating the need for access to computers and scanners. Online applications and redeterminations should include instructions about how to use cell phones to take pictures and convert the images to acceptable file formats (e.g., PDFs) to further ease technology barriers.

- **Application assistance:** People with cystic fibrosis often have more support than other applicants because of the social workers that are embedded in multidisciplinary CF care teams—and yet they still overwhelmingly struggle to enroll in and maintain Medicaid and CHIP coverage. This underscores how much more application assistance is needed. To better understand this issue, CMS should monitor state data from Medicaid call centers and online assistance programs to assess call volume, average wait time, and call abandonment rate. Online assistance data should include the number of online chat requests initiated, the number completed, and the share that are deemed successfully resolved. We recommend states be required to disaggregate the statistics at a minimum by eligibility group and age and, where possible, by race/ethnicity. CMS should also explore ways to encourage states to adopt mobile friendly live chat options when possible.

3. In what ways can CMS support states in addressing barriers to enrollment and retention of eligible individuals among different groups, which include, but are not limited to: people living in urban or rural regions; people who are experiencing homelessness; people who are from communities of color; people whose primary language is not English; people who identify as lesbian, gay, bisexual, transgender, queer, or those who have other sexual orientations or gender identities (LGBTQ+); people with disabilities; and people with mental health or substance use disorders? Which activities would you prioritize first?

- **Plain language materials:** Social workers at CF care centers spoke about indecipherable Medicaid and CHIP applications and redetermination packages. Even as professionals familiar

with these programs, they still struggle to understand the requirements. CMS should support states in reviewing the accessibility of notices that require action by the enrollee or applicant and ensuring that all materials include taglines informing beneficiaries of their right to free language assistance and auxiliary aides. When states choose not to use the single streamlined application template released by CMS, CMS should ensure that the alternative application does not include extraneous questions and still meets plain language requirements. CMS could track if states are following accessibility requirements on the Medicaid and CHIP Scorecard.

- **Discriminatory behavior:** Social workers also said that some of their patients experience discriminatory behavior at state and municipal Medicaid/CHIP offices. CMS should require sensitivity training for Medicaid/CHIP employees and audit offices to ensure appropriate behavior toward applicants and enrollees.

**Objective 2: Medicaid and CHIP beneficiaries experience consistent coverage.**

*2. How should CMS consider setting standards for how states communicate with beneficiaries at-risk of disenrollment and intervene prior to a gap in coverage? For example, how should CMS consider setting standards for how often a state communicates with beneficiaries and what modes of communication they use? Are there specific resources that CMS can provide states to harness their data to identify eligible beneficiaries at-risk of disenrollment or of coverage gaps?*

- **Increase text communication:** Social workers reported that some people with CF were notified about missing documentation after the redetermination window had closed. CMS is well aware of the challenges with reaching transient populations who move frequently. CF social workers said that text message is often the best way to reach their patients and states should use text messages, in addition to other communication forms, whenever possible.
- **Plain language materials:** As described in question 3 under objective 1, social workers at CF care centers spoke about indecipherable Medicaid and CHIP applications and redetermination packages. Even as professionals familiar with these programs, they struggle to understand the requirements. CMS should support states in reviewing the accessibility of notices that require action by the enrollee or applicant and ensuring that all materials include taglines informing beneficiaries of their right to free language assistance and auxiliary aides. When states choose not to use the single streamlined application template released by CMS, CMS should ensure that the alternative application does not include extraneous questions and still meets plain language requirements. CMS could track if states are following accessibility requirements on the Medicaid and CHIP Scorecard.

**Objective 3: Whether care is delivered through fee-for-service or managed care, Medicaid and CHIP beneficiaries have access to timely, high-quality, and appropriate care in all payment systems, and this care will be aligned with the beneficiary's needs as a whole person.**

1. What would be the most important areas to focus on if CMS develops minimum standards for Medicaid and CHIP programs related to access to services? For example, should the areas of focus be at the national level, the state level, or both? How should the standards vary by delivery system, valuebased payment arrangements, geography (e.g., sub-state regions and urban/rural/frontier areas), program eligibility (e.g., dual eligibility in Medicaid and Medicare), and provider types or specialties?

- **Access to primary care and mental health providers:** People with CF enrolled in Medicaid or CHIP often struggle with access to primary care doctors and mental health specialists. This population generally has good access to CF care, as accredited CF care centers are usually housed within academic medical centers that accept Medicaid. However, people with CF enrolled in Medicaid report significant challenges finding a freestanding primary care providers and mental health specialists. This indicates that current network adequacy requirements related to these disciplines are insufficient for access to these services.

We also know that people with CF benefit more from mental health professionals with experience serving people with chronic conditions. As CMS considers ways to improve access to appropriate care, it should consider specialized mental health needs for people with chronic conditions.

- **Prescription drug limits:** Many states limit the number of prescription drugs that beneficiaries can access every month, and some of these limits are as low as three or four drugs a month. Adults with CF take seven prescriptions daily, on average, but can take up to 20 medications per day. While most of these states allow for medical necessity overrides, such policies add administrative burden for providers and patients, and create the potential for access delays. CMS should examine the impact of prescription drug limits and current override policies, and determine whether they are allowable under the requirement that Medicaid services be sufficient in amount, duration, and scope to reasonably achieve their purpose.
- **Coverage of inhaled hypertonic saline and vitamins A, D, E, and K:** Many state Medicaid programs do not cover inhaled hypertonic saline and vitamins A, D, E, and K—all of which are recommended by Cystic Fibrosis Foundation clinical consensus guidelines—due to confusion about whether these products qualify for federal matching funds.

CFF clinical consensus guidelines recommend use of inhaled hypertonic saline in individuals ages 6 and up for mucociliary clearance. Treatment with mucolytic products—including inhaled hypertonic saline solution—is shown to help clear mucus from the lungs, resulting in fewer lung infections, improved lung function, and better quality of life for people with CF.

People with cystic fibrosis also often have trouble absorbing nutrients, including fat-soluble vitamins, because of the thick, sticky mucus that blocks pancreatic ducts. CFF nutritional

guidelines therefore recommend the use of specially-designed supplements to ensure that people with CF receive adequate amounts of fat-soluble vitamins including A, D, E and K.

However, because these products are not FDA-approved, many states do not believe they are eligible for a federal match and do not cover them. We believe states may cover medically necessary products and receive matching funds without collecting rebates if the product is not eligible to qualify as a “covered outpatient drug.” Because vitamins A, D, E and K and inhaled hypertonic saline solution are not FDA-approved and do not require prescriptions, they are not eligible to qualify as covered outpatient drugs under SSA §1927 and can be covered by Medicaid without an applicable rebate agreement and are eligible for federal match. CMS should provide a state medical letter clarifying that states are able to receive a federal match for coverage of these critical products.

*3. How could CMS consider the concepts of whole person care or care coordination across physical health, behavioral health, long-term services and supports (LTSS), and health-related social needs when establishing minimum standards for access to services? For example, how can CMS and its partners enhance parity compliance within Medicaid for the provision of behavioral health services, consistent with the Mental Health Parity and Addiction Equity Act? How can CMS support states in providing access to care for pregnant and postpartum women with behavioral health conditions and/or substance use disorders? What are other ways that CMS can promote whole person care and care coordination?*

- Screening and referrals for social supports:** Given the increasing recognition about the importance of social determinants of health, CMS should explore ways to require all Medicaid managed care plans to screen for social risk factors, make referrals for support services, and track the outcomes of those referrals. Currently, about half of states require Medicaid MCOs to screen for social needs and make referrals based on screening results. Very few states track the outcomes of those referrals. It is important for plans to monitor enrollee use of referred services in order to better understand and address the barriers to access. This data will also help ensure that the referrals placed are for sustainable interventions.

*5. What are specific ways that CMS can support states to increase and diversify the pool of available providers for Medicaid and CHIP (e.g., through encouragement of service delivery via telehealth, encouraging states to explore cross-state licensure of providers, enabling family members to be paid for providing caregiving services, supporting the effective implementation of Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefits, implementing multi-payer value-based purchasing initiatives, etc.)? Which of these ways is the most important?*

- Remove telehealth licensing barriers:** CF providers report that licensing is a significant barrier to telehealth care for patients with a rare disease like CF who often seek care across state lines. Because CF care is highly specialized, many patients travel out-of-state for care and over 10 percent of people with CF receive care in a different state than their state of residence, according to the CF Foundation patient registry. People living with cystic fibrosis may seek care in another state for a variety of reasons, including geographic proximity or access to specialists

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with expertise in their specific CF-related complications. For example, those who harbor certain bacteria or have had a lung transplant may need to travel out-of-state to get appropriate care. In these cases, if physicians are not licensed in the patient's state of residence, remote care may be entirely inaccessible. CMS should work with Congress to remove licensing barriers to telehealth care.

**Objective 4: CMS has data available to measure, monitor, and support improvement efforts related to access to services (i.e., potential access; realized access; and beneficiary experience with care across states, delivery systems, and populations).**

2. *What measures of potential access, also known as care availability, should CMS consider as most important to monitor and encourage states to monitor (e.g., provider networks, availability of service providers such as direct service workers, appointment wait times, grievances and appeals based on the inability to access services, etc.)? How could CMS use data to monitor the robustness of provider networks across delivery systems (e.g., counting a provider based on a threshold of unique beneficiaries served, counting providers enrolled in multiple networks, providers taking new patients, etc.)?*

- Standardized reporting on benefits:** CMS should consider ways to provide more information about Medicaid and CHIP benefits by state. Currently, CMS mainly provides this information through links to state program documents, which can be long and difficult to understand, and are hard to compare across states. More visible information that is comparable across states is valuable for patients and researchers. For instance, in cystic fibrosis, coverage of specialized products and therapies—such as insulin testing supplies, feeding tubes, and inhaled hypertonic saline—can be critical elements of care. There is little national transparency into how each state treats these products. Such information would be a valuable resource in better understanding quality of care and access for all Medicaid and CHIP enrollees.

4. *How should CMS consider requiring states to report standardized data on Medicaid fair hearings, CHIP reviews, managed care appeals and grievances, and other appeal and grievance processes that address enrollment in coverage and access to services? How could these data be used to meaningfully monitor access?*

- State reporting on fair hearings, and appeals and grievances:** CMS should require all states to report standardized data on appeals and grievances and Medicaid fair hearings. Data should be disaggregated by demographic factors, provider type, service type, reason for denial, access to aid paid pending appeal, whether consumer was represented in the appeal, and disposition of grievance or appeal, including time to resolution and outcome. States contracting with MCOs should report information on an MCO-specific basis. States and CMS should review the data to identify and remediate potential access problems.