



April 18, 2022

We submitted comments in response to the Centers for Medicare & Medicaid Services' [request for information](#) on Access to Care and Coverage for People Enrolled in Medicaid and CHIP. These comments focus on the ways that the technology used to administer Medicaid — in particular, Medicaid Long-Term Services & Supports — can increase barriers to accessing care.

1-1: 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.

CMS can best support states by incentivizing proactive and comprehensive public auditing, testing, and maintenance of all current and future eligibility (re)determination technology systems. People are best served through systems that are not just “timely,” but thoroughly accessible and reliable. Automated systems may improve the processing time of determinations, but only if they are simple to use and correctly implement regulations and handle applications — otherwise, determinations may be swift but incorrect, and cause large-scale harm to people who need benefits. States must also recognize that automated systems cannot replace the need for human staff to help people at in-person offices or over the phone. Finally, states should assume continuation of eligibility as much as possible, as redeterminations often present an unnecessary burden on people receiving benefits.

Currently, there are major problems with the systems that facilitate eligibility determinations for various benefits programs. States often roll out these technology systems with known problems or without proper system testing, and people receiving benefits materially suffer from incorrect denials, terminations, or reductions in care. These problems of “broken” technology are unacceptable but can be prevented.

These technology issues have included problems due to standardized assessments and also with the basic functioning of the system, such as: improperly generated or late notices; system-wide bandwidth limits that don't match real-world capacity needs; file and document mishandling and loss; improperly handled user interface errors that leave users without clear directions; difficult-to-navigate user interface design; data-matching errors like wrongly condensing cases for different people with the same name, or the opposite — deciding that input with immaterial discrepancies like letter capitalization are different; lack of accessible design; and any direct mistranslations between regulations and design, or between design and implementation. People receiving benefits must not be forced to suffer from contractors' and states' mistakes.

Despite their preventability, most technology issues are only addressed after people lose benefits, and sometimes only after advocates file a lawsuit. This is because CMS and states do not consistently give advocates and people receiving benefits robust access to information or ways to participate in the contracting and development process for these systems, and because there is a lack of accountability for issues. Issues with broken benefits technology plague many benefits programs. For example, the Social Security Administration terminated people's SSI benefits for years due to a computer system error that allowed the system to check assets immediately after depositing benefits. This error meant that people's own SSI benefits were counted against them, incorrectly. The New York Legal Assistance Group was forced to [sue](#) the administration, as SSA was not taking action to prevent these issues.

People receiving benefits must not be the first people to sound the alarm on benefits technology problems. CMS must incentivize states to stop these issues before they occur, as prevention can have an enormous impact on increasing eligibility and avoiding cuts and terminations. For example, two states, Arkansas and Missouri, each created an assessment algorithm for determining the condition and needs of people requiring Long Term Services and Supports. Arkansas implemented their assessment in code, and rolled it out without input from people receiving benefits or other advocates. It had disastrous [effects](#) on people's care allocations despite their conditions remaining the same, and Legal Aid of Arkansas was forced to sue the state to overturn the use of the algorithm. Specifically, many of the people had conditions that were not contemplated by the algorithmic assessment, including cerebral palsy. The effects of the algorithm's allocation decisions forced many to consider institutional care settings, instead of their preferred home settings.

On the other hand, in Missouri, the Department of Health and Senior Services was proactively transparent, and published their proposed algorithm in late 2018. Advocates

were able to determine the likely impact of the new algorithm by using information from people currently receiving LTSS benefits, and found that 66% of them would have no longer been eligible. The state ended up pausing roll-out of the algorithm in 2021, as further public development and testing [showed](#) substantial negative impacts — and, so far, no one’s benefits have been terminated because of the new algorithm. This is the difference that proactive public auditing and testing of eligibility determination technology can have on people’s lives. If Missouri DHSS had not published the algorithm, and if advocates had not proactively evaluated the impact of the algorithm, advocates would have had a much more difficult time protecting the rights of the people relying on Medicaid, much like in Arkansas.

To support increased transparency and meaningful feedback from advocates, CMS must incentivize states to do their own proactive and comprehensive public testing of all new technology systems. There are two areas where testing must occur: before roll-out, testing of system components and functionality for all use cases and real-world circumstances; and throughout development and while the system is in use, audits of how the system impacts people’s eligibility. Each kind of testing is crucial in making sure the system works as specified and that system specifications do not have a disparate impact on certain populations or lead to a decrease in people’s eligibility for benefits.

Specifically, CMS should require that vendors and contractors robustly test the technology they produce. A way to facilitate this could be to tie payments to vendors with robust evidence that the system works well for all people using it to receive benefits. Currently, many states cannot even resolve technology problems that show up while the system is in use, because of contractual payment issues with vendors. This is a recurring issue for many states, who are forced to work with the small number of large technology vendors that are able to successfully navigate government procurement processes. CMS will not be able to meet timeliness or accessibility goals for programs like Medicaid while states are forced to work with vendors that continue to produce and get paid for broken technology systems.

CMS and states must also recognize that technology is not a panacea for all eligibility determination timeliness issues. Even when eligibility guidelines are implemented correctly, people can still lose or miss out on benefits if applications are burdensome or difficult to access. Many programs require frequent redeterminations that are difficult to keep up with, and states need to rethink whether redeterminations are even necessary in certain cases at all. CMS should encourage states to assume continuity of coverage and eligibility as much as possible. CMS should also prevent states from requiring people receiving benefits to respond on short notice or lose their benefits. Short response periods create unnecessary burdens for people receiving benefits and can result in erroneous

terminations, ultimately decreasing the timely enrollment in benefits, and generally have punitive effects.

For many, current technology is partially or completely inaccessible. Access to and ability to use devices, broadband internet, and unlimited data plans are not distributed evenly across race, class, and geography. CMS must strengthen paths of access for people who cannot easily use technology (like people with certain disabilities or many elderly people) and people who do not have access to the internet (like unhoused people, people who cannot afford internet access or technology, and people who live in rural areas where it is not available). CMS must also provide technical and non-technical accommodations for people with disabilities and people whose primary language is not English. This means designing all technology projects with non-technical users' needs in mind, especially when it comes to hiring staff to manage applications.

1-3: 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?

In this response, we focus on states' uses of standardized decision-making tools in the enrollment process for Medicaid Long-Term Services and Supports (LTSS), which have resulted in loss or denial of essential services, particularly in the context of Home and Community-Based Services (HCBS). The use of standardized decision-making tools for eligibility and allocation of HCBS can negatively impact people's ability to live in their communities and receive the services and supports they need. While the largest barriers to people getting the care they need through HCBS are inadequate funding and related difficulties in finding care workers, standardized decision-making tools can exacerbate these barriers when they arbitrarily allocate scarce resources and create friction and opacity in the enrollment process.

Some states have claimed that introducing standardized tools to determine eligibility and allocate services should make the process more fair and minimize bias in human decision-making about access to care. However, standardized decision-making tools for determining eligibility and allocating services actually introduce barriers and the potential for systemic discrimination based on race, disability, mental health, family situation, and

other factors. Of course, human decision-making is subject to these same biases, and generally enrollment processes involve a mix of human and algorithmic decision-making. Two risks, as states rely more on standardized decision-making tools, are that they have the illusion of objectivity and that because they are implemented at scale, any discriminatory effects will also be executed at scale. Using technical systems for the enrollment process also creates the opportunity to audit the process to identify biases and discrimination. Standardized decision-making tools will always work better for some people than others because they are designed to account for certain factors and to ignore others. Therefore, to minimize the harms of standardized decision-making in the enrollment process, programs need to be well-funded and CMS and states need to develop decision-making processes that account for the broadest possible range of needs; they also need to audit their processes to assess their impact and any discriminatory effects. In the typical assessment process for LTSS today, rather than asking people directly what supports they need, people are asked a series of 236 questions, a subset of which are then scored to decide whether people are eligible and, if so, how much funding they will get for care. This approach represents a lack of trust in disabled people, elderly people, and their support networks to directly articulate the supports they need; instead placing this trust in an algorithm, usually developed with minimal community input.

Some people have conditions that are not considered by a standardized decision-making tool used to determine eligibility or allocate care. For example, most assessment and scoring processes do not consider chronic pain and, as we will discuss below, states make choices about whether and how to factor things like cognition into their eligibility and allocation algorithms. In order to mitigate the potential harms of standardized decision-making tools, CMS should create more opportunities for input and oversight throughout the lifecycle of states' development and use of these tools. This should include CMS enabling states to monitor standardized tools for disparate impact based on demographic characteristics and other factors identified through public input, such as chronic pain and mental health, through enhanced data collection, auditing, and reporting.

The design and use of standardized decision-making tools always involves discretion and should be seen as regulatory in nature. While the introduction of new technology to administer Medicaid benefits has the potential to make it easier for people to access these benefits, the development of standardized tools to determine eligibility and to allocate care can have the opposite effect. Creating these tools requires states and vendors to make choices about how to measure eligibility factors that, despite being political in nature, are often hidden in the seemingly objective technology procurement and development process. However, these granular political choices about eligibility determination must be

treated like any other policy, with opportunities for public comment and other interventions. In the context of Medicaid eligibility, as well as in any other uses of technology to determine people's access to resources, the use of standardized decision-making tools for determining eligibility and allocating services introduce barriers and the potential for systemic discrimination based on race, disability, mental health, family situation, and other factors. Developing these tools requires discretionary choices about how to measure need that introduce the potential for bias and discrimination to be built into the system. These tools do not appear out of nowhere — from pre-procurement to procurement, then design and implementation, and finally to being in use, there are people making decisions at each phase. To identify potential barriers to access and mitigate their harmful effects, particularly on marginalized communities, CMS should help create the infrastructure for both public participation and federal oversight throughout the benefits technology lifecycle.

When states use standardized tools to determine whether people are eligible for benefits and how much support they should receive, they make choices about how to measure both financial and non-financial eligibility factors. Some of these measures are spelled out in laws and regulations, but translating the regulations into a rubric for a standardized tool or algorithm generally requires discretion about what to measure and how. In cases where the laws and regulations are less clear on how to measure eligibility factors, more discretion is given to the state agency employees involved in developing the algorithmic logic and to the vendors or contractors building the technology. This means that decisions that are effectively regulatory in nature can be hidden within the technology development process and not subject to public notice and comment even when they materially impact who is actually eligible for Medicaid services. State Medicaid agencies should not be able to make decisions about what factors are included in eligibility and allocation decisions without public input and without evaluating the impact of those decisions. Assessment processes should be designed to maximize the ability of people applying for care to define their circumstances and their needs.

In the context of Medicaid Long-Term Services and Supports, widely used tools like the InterRAI assessment use standardized measures to assess someone's needs. States then choose a subset of these standardized questions to include in a score that is used to determine whether an individual is eligible for services and how many hours of services they can receive. The decision of which questions to include in this subset varies state-by-state and has major impacts on eligibility. Of the 236 questions asked as part of the InterRAI Home-Care (InterRAI HC) assessment, a small subset are typically used to calculate an eligibility score and to determine the number of hours of care a person gets. In Washington, DC, for example, where the Department of Health Care Finance implemented

the InterRAI HC assessment in 2018, 32 questions are factored into the scoring logic for determining eligibility. None of the questions from the Cognition section of the assessment are factored into the eligibility score despite the fact that cognitive issues impact the amount of services and supports someone needs. In Missouri, however, a proposed eligibility scoring algorithm includes five of the ten questions that appear in the Cognition section of the InterRAI HC assessment, and one of the potential responses in the Cognition section results in 18 points, which is enough to automatically qualify someone for the program.

This relatively simple example of one area of difference between eligibility scoring of the same underlying assessment data in two states illustrates the arbitrariness of standardized decision making in determining eligibility for home and community based services (HCBS) through Medicaid LTSS. There are several ways CMS can counteract this arbitrariness to minimize the barriers standardized decision-making tools can introduce to Medicaid enrollment processes, especially for people who are most likely to be discriminated against when these tools are designed without input from advocates or people getting benefits, and are not subject to adequate oversight. CMS should require states to share information about proposed decision-making tools with stakeholders and the public and involve advocates and people using Medicaid in the development of these tools. CMS should also support states to have better data collection and reporting capabilities built into their systems so that they can monitor the impact of these systems during piloting and when the tools are in use.

Make information about enrollment systems publicly available and enable public input. Throughout the lifecycle of benefits technology there must be meaningful ways for legal advocates, researchers, community members, and others to get information and participate in decision-making about the technology that is being considered, developed, and used. Acknowledging that changes to algorithms used for benefits determinations (for example, logic used to develop eligibility scores) are in fact regulatory changes is one way to increase transparency and create opportunities for input in the form of public notice and comment.

CMS must incentivize states to do their own proactive and comprehensive public testing of all new and in-use technology systems. This includes public audits of the system's impact on people's eligibility, both before it is rolled out and on an ongoing basis once it is in use. CMS could provide guidance to states on how to write RFPs that include robust testing, piloting, and auditing and ensure that this is included in contracts with vendors. Testing and piloting new systems during development and implementation and conducting ongoing auditing when the tool is in use are essential foundations to identify

technology issues earlier — before they contribute to widespread loss of or lack of access to benefits. Making the results of these tests, pilots, and audits publicly available allows stakeholders to engage in the process of improving the design of these tools and mitigating their potential harms.

Ensure systems include robust data collection and reporting to enable auditing for demographic disparities in the enrollment process. States' use of technology to administer benefits programs gives them access to more data on their enrollment process — but this data is only useful if states design their systems to measure for and report helpful metrics. States need to be incentivized by CMS to look at indicators that actually measure people's access to care (not just timeliness of the application process) and that allow states and CMS to assess differences in eligibility and allocation across disability, mental health, family situations, and other demographic factors. It is important to consider the ways that some of these factors are more easily documented and measured than others and the inadequacies of standardized data in capturing the diversity of people's experiences, in particular with disability.

The Biden-Harris Administration's Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government recommends federal agencies collect data to measure and advance equity. Additionally, HHS's Strategic Goals 1 and 3 and CMS's recently identified Health Equity Challenges identify the need for standardized demographic data collection. CMS should ensure that state Medicaid agencies are able to assess disparities in the Medicaid enrollment process by: 1) providing guidance to states to get the right indicators and reporting built into their systems from the start; 2) requiring states to report demographic and other indicators of access to CMS and access for researchers and the public, accounting for privacy risks and risks of re-identification; and 3) incentivizing states to audit their benefits technology and proactively address impacts like benefits cuts, terminations, and denials, including any disparate impact on marginalized groups. Contracts with vendors should enable states to report on their indicators. State Medicaid agencies should not have to rely on vendors and spend additional funds in order to report on how their systems are functioning.

When disparities in enrollment are identified, CMS and states need to take action to address these disparities in policy and in the eligibility and allocation determination process, including any issues that arise from standardized decision-making tools. These indicators are also essential to look at in testing and piloting new tools and new logic before it is rolled out. As mentioned in our response to Objective 1: Question 1, proactive auditing in Missouri of their proposed eligibility algorithm for Medicaid LTSS HCBS

identified that 66% of people receiving benefits were at risk of loss of some or all of their benefits if the new system was implemented.