April 18, 2022

RE: CMS Request for Information on Access to Coverage and Care in Medicaid and CHIP

Submitted via comment portal at: https://cmsmedicaidaccessrfi.gov1.qualtrics.com/jfe/form/SV_6EYj9eLS9b74Npk

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 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 people living in urban or rural regions; people who are experiencing homelessness identities (LGBTQ+); people with disabilities; and people with mental health or substance use disorders? Which activities would you prioritize first?

At Howard Brown, we have a team of 6 full-time and 1 part-time insurance navigators to assist both established patients and community members enroll in and maintain health insurance coverage. During Open Enrollment in 2021, we helped over 1200 patients enroll in health insurance, including 558 patients enrolling in Medicaid. From our experience, we know how critical insurance navigation services are to enrollment and retention in health insurance. Many people find the process of applying for and using health insurance to be complicated and overwhelming. For marginalized communities in particular, history of medical mistreatment and lack of culturally affirming resources to improve health literacy create additional barriers to enrollment in health insurance. Insurance specialists can help to demystify the complexity of applying for and using health insurance, and they can help reduce health disparities by improving health literacy in rural and underserved communities, including Black, Indigenous, and other communities of color.

In recognition of the critical role that insurance navigators play in reducing disparities in accessing health insurance, CMS should increase funding for states to hire, train, and retain navigators year round. In recent years, funding for insurance navigation services has been shrinking, even though the need for these services continues and, in many ways, has increased with the onset of the COVID-19 pandemic. Qualified navigators need expertise in a wide range of issues, including eligibility and enrollment, the details of each health plan’s coverage, the health care delivery system, and patient counseling and communication skills, as well as cultural humility. Additionally, resources aimed at recruiting and training navigators from underrepresented communities can help to build trust with marginalized communities, which is essential for reducing disparities that we see in health insurance coverage and access. For example, our Spanish-speaking and Latinx navigators noted that it was especially important for them to assist our Latinx patients who do not speak English as
a primary language and were hesitant about enrolling in Medicaid due to the previous Administration’s Public Charge rule. Additionally, each of our navigators is also trained in LGBTQ-affirming service and care so that they are best able to assist our LGBTQ+ patients in accessing and navigating insurance. Similarly, all of the target populations highlighted in the question face significant barriers that can be addressed in part by trained navigators who are recruited from and connected to the community or communities in question. Community-based, trained and adequately funded and supported health care navigators are vital to improving Medicaid enrollment and retention and advancing health equity.

**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?

Due to the prevalence of anti-LGBTQ+ bias in our society, LGBTQ+ people experience a range of disparities that can negatively impact their ability to access affirming and affordable healthcare, safe housing, stable employment, steady income, and food stability. Care coordination from a well-trained team is especially helpful for LGBTQ+ people in navigating a complex and confusing system of support resources for a population that has historically experienced harm and discrimination in these settings.

At Howard Brown Health, we have care coordination teams to ensure that our patients get the highest quality of care. For example, our patient navigators and case managers support patients living with HIV with treatment adherence and care engagement by helping patients to thrive independently. Aside from health care referrals, our case managers support our patients by providing assistance in applying for social security or public aid, helping patients in understanding complex health insurance issues, advocating for public benefits and assistance in securing emergency financial aid, food, housing, utilities and transportation assistance.

Care coordinators, case managers, and insurance navigators play an integral role in connecting patients to services and reducing barriers to accessing care, especially for marginalized populations. Effective care coordination requires significant investment, training, and resources so that the navigators are well-versed in the complexities of the healthcare and insurance landscape and also trained to provide affirming service to all patients. CMS should ensure that adequate funding is provided for the states to offer such...
It is important that care coordinators who engage with the LGBTQ+ population are trained and knowledgeable about LGBTQ+ health and LGBTQ+ bias. CMS can promote whole person care by developing a training on implicit bias, affirming care, and harm-reduction measures for all Medicaid grantees, including care coordination professionals and providers.

Some helpful training and educational resources can be found at:

- [https://www.lgbtqiahealtheducation.org/](https://www.lgbtqiahealtheducation.org/)
- [https://soee.oakpoint.edu/product?catalog=Providing_Affirmative_Care_for_LGBTQ_Patients](https://soee.oakpoint.edu/product?catalog=Providing_Affirmative_Care_for_LGBTQ_Patients)
- [http://www.nursesheale.org/](http://www.nursesheale.org/)

In addition to existing legal obligations, how should CMS address cultural competency and language preferences in establishing minimum access standards? What activities have states and other stakeholders found the most meaningful in identifying cultural and language gaps among providers that might impact access to care?

LGBTQ+ people often experience challenges in accessing medical and behavioral health services that are affirming and inclusive. For example, a 2017 survey conducted by the Center for American Progress found that 8% of LGB respondents and 29% of transgender respondents had been refused medical care in the past year due to their sexual orientation or gender identity. Given the prevalence of non-affirming and discriminatory care, it is no wonder that LGBTQ+ people prefer to seek out services in spaces that are affirming, but those spaces are often difficult to find. One major contributor to the lack of affirming healthcare spaces is lack of education and training on LGBTQ+ health specifically. A 2018 study of students at medical schools across New England found that 80% of students felt “not competent” or “somewhat not competent” in treating LGBTQ+ patients. This lack of training extends beyond medical schools and highlights a need for continuing education for healthcare providers in providing culturally responsive care for LGBTQ+ patients. Studies show that LGBTQ+ patients want their healthcare providers to be comfortable with LGBTQ+ patients, able to facilitate shared medical decisions, hold non-heterosexist/cissexist assumptions, have ability to apply LGBTQ-specific knowledge, have awareness to the social context of health disparities, be able to facilitate disclosure and promote acceptance.

Due to the shortage of LGBTQ-competent care providers, CMS should establish and require regular cultural responsiveness training for all Medicare and Medicaid providers that addresses the intersectionality of race, ethnicity, LGBTQ+, HIV, language, and disabilities. This training could be included as part of the Medicaid Conditions of Participation and
Conditions of Coverage. This training should be regularly revised and updated, and should include feedback from marginalized communities to ensure that the training is accurate and helpful. We recommend CMS provide funding opportunities, such as innovation grants, to involve community members and experts in designing, implementing, and evaluating any cultural responsiveness training or educational resources. Additionally, CMS should consider the development of statewide or regional collaborative networks and multidisciplinary teams that can focus on improving and supporting diversity in healthcare settings.

At Howard Brown Health, we offer trainings on LGBTQ+ healthcare best practices. This includes:

Health Education About LGBTQ+ Elders (HEALE) which offers training on:

- Health Disparities and Barriers to Care
- Sex and Sexuality in for LGBTQ Older Adults
- Legal and Financial Barriers to Care
- Transgender and Gender Non-conforming Elders
- Aging with HIV

LGBTQ+ Care Core Four:

- Foundations of Care: Working with Patients who Identify as LGBTQ
- Foundations of Care: Working with Transgender and Gender Non-Conforming (TGNC) Patients
- Gender Appropriate Language: Practical Skill Development
- Sexual Orientation and Gender Identity Data Collection: Best Practices and Skill Development

Urgently, CMS should also re-issue and strengthen nondiscrimination regulations that the previous Administration undercut in 2020. In its Final Rule issued under Section 1557 of the Affordable Care Act in 2020, HHS deleted “sexual orientation and gender identity” from the following regulations:

- 42 CFR § 438.3(d)(4), providing that managed care and other covered entities “will not discriminate against individuals eligible to enroll on the basis of race, color, national origin, sex, or disability and will not use any policy or practice that has the effect of discriminating on the basis of race, color, or national origin, sex, or disability.”
- §438.206(c)(2), requiring that State contracts with managed care and other covered entities ensure that such entities “participate[] in the State’s efforts to promote the delivery of services in a culturally competent manner to all enrollees, including
those with limited English proficiency and diverse cultural and ethnic backgrounds, disabilities, and regardless of sex.”

- §440.262, providing: “The State must have methods to promote access and delivery of services in a culturally competent manner to all beneficiaries, including those with limited English proficiency, diverse cultural and ethnic backgrounds, disabilities, and regardless of sex. These methods must ensure that beneficiaries have access to covered services that are delivered in a manner that meets their unique needs.”

- §460.98(b)(3), providing that organizations participating in the Program for All-Inclusive Care for the Elderly (PACE) “may not discriminate against any participant in the delivery of required PACE services based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, or source of payment.”

- §460.112(a), which provides, in part: “Each participant [in the PACE Program] has the right not to be discriminated against in the delivery of required PACE services based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, or source of payment.”

Each of these regulations should be promptly amended to add “sexual orientation and gender identity,” consistent with the regulations prior to the unwarranted 2020 amendments.

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?

There are immense benefits to having a diverse workforce: studies show that patients who share a similar background or identity to their providers report higher levels of satisfaction and better quality of care. However, there is a lack of diversity in medical and behavioral health settings that can result in limited perspectives, poor communication, and unchallenged bias that far too often results in worse health outcomes for patients with marginalized identities. That is why it is imperative to address the unequal distribution of resources and opportunities to become healthcare providers resulting from historic and systematic racism and bias.

We recommend that CMS provide adequate funding and incentives to maximize recruitment and retention of Medicaid providers to address the healthcare provider
shortage, especially for medically underserved patients. Loan forgiveness programs have proven to be effective in attracting and retaining medical providers in high-need and medically underserved areas. CMS should consider implementing a loan forgiveness program and other financial incentives or tuition assistance programs for a wide array of healthcare professionals who provide care to medically underserved patients, including LGBTQ+ people and people living with HIV. We recommend that CMS provide funding and mentorship opportunities to recruit and develop staff from underrepresented communities. We recommend that CMS provide longer grant cycles to support organizations that work with underserved communities, to allow for more consistent programming and evaluation of community needs regarding a lack of provider diversity.

Beyond addressing the shortage of diversity in the healthcare workforce, we recommend that CMS encourage more community providers to accept Medicaid by adjusting the reimbursement rates to align with other insurers and streamlining the reimbursement process. While many healthcare organizations would like to expand care offerings for low-income people, the organizations cannot accept Medicaid because it is not financially sustainable to do so. Additionally, for many states, Medicaid reimbursement is a slow and cumbersome process. This along with the low reimbursement rates make it difficult for many providers, especially smaller, community-based practices, to sustain their operations financially if they accepted Medicaid clients.

In areas where there is a shortage of culturally competent providers, telehealth is a vital tool in expanding access to affirming care, particularly for LGBTQ+ people in rural settings. As a provider of LGBTQ-affirming telehealth, we have seen how telehealth has helped patients from all over Illinois access our services. CMS should continue to embrace telehealth, and in particular cross-state telehealth, as a solution to expanding access to care for marginalized populations. Providing telehealth across state lines is extremely complex and burdensome to navigate, but we know that it would benefit many patients from neighboring states that have no access to affirming healthcare. CMS should investigate strategies to make cross-state licensure and reimbursement for telehealth less burdensome and easier to navigate both for patients and providers.

Lastly, there are a number of actions CMS can take to increase the pool of Medicaid providers able to provide gender-affirming care. A significant number of states still expressly exclude coverage for gender-affirming care in Medicaid. In states where there aren’t blanket exclusions for gender-affirming care, there are wide variations in the types of care that are covered. Many procedures that are medically necessary and often life-saving for transgender people—including laser hair removal, breast augmentation, and facial surgeries—are usually considered “cosmetic” for cisgender people, and as such, are often categorically excluded in state Medicaid plans. CMS can help to address this issue and expand the pool of Medicaid providers for gender-affirming care by reinstating...
nondiscrimination regulations that were undercut by the previous Administration, and by issuing guidance to state Medicaid directors stating that exclusions for medically necessary gender-affirming care are discriminatory. CMS should also investigate ways to update Medicaid regulations to clarify that procedures that are routinely considered cosmetic may be medically necessary for transgender people.

What should CMS consider when developing an access monitoring approach that is as similar as possible across Medicaid and CHIP delivery systems (e.g., fee-for-service and managed care programs) and programs (e.g., HCBS programs and dual eligibility in Medicaid and Medicare) and across services/benefits? Would including additional levels of data reporting and analyses (e.g., by delivery system or by managed care plan, etc.) make access monitoring more effective? What type of information from CMS would be useful in helping states identify and prioritize resources to address access issues for their beneficiaries? What are the most significant gaps where CMS can provide technical or other types of assistance to support states in standardized monitoring and reporting across delivery systems in areas related to access?

When considering how CMS could develop a monitoring approach, a major barrier is the lack of guidance and standardization on how data is collected across Medicaid and CHIP programs. There is no singular guidance from CMS on how data should be collected, what agencies should help with monitoring that collection of data, or how to train healthcare workers and providers to collect that data. Comprehensive data collection is imperative in improving CMS monitoring systems.

The current monitoring criteria collects information on provider access, patient utilization, and perceptions of care. However, the current dataset doesn’t contain enough disaggregated demographic data to meaningfully discern who is accessing care and where there may be gaps in service. Some of this disaggregated demographic data is collected by in-person interviews with patients, but it is often left to the states or in some cases smaller, less centralized systems such as hospitals or home-care systems to decide how they collect and report this data. CMS does require states to report specific incidents data, care delivery, and fee-for-service data, but it is up to states to determine how often and in what format these incidents are reported. Some information that could be critical to monitor in real-time, such as grievances or critical incidents and access to services, may be reflected years after interventions are needed and not accurately reflected to CMS. CMS should consider issuing guidance to state Medicaid programs on how to standardize, collect, and report important patient data back to CMS in a timely manner.

CMS should also require the collection of sexual orientation or gender identity (SOGI) data alongside other routinely collected demographic data as part of their data collection
process. LGBTQ+ communities experience higher levels of poverty and are more likely to rely on Medicaid for health insurance compared to the general population. LGBTQ+ communities also historically experience discrimination that acts as a barrier to accessing healthcare and health insurance. If CMS collected SOGI data from Medicaid applicants, for example, it would provide insights on whether or not LGBTQ+ people are accessing Medicaid given higher rates of income instability among this marginalized population. While the National Institute of Health and other federal and state governments have begun to standardize and recommend the collection of SOGI data, there is still much needed guidance from these agencies on the how to collect SOGI so that states and other agencies have a uniform understanding of what SOGI data is and its importance. Providing guidance directly to states on how to collect SOGI data can help remove the barriers that LGBTQ+ people experience in accessing Medicaid and CHIP.

In what ways can CMS promote a more standardized effort to monitor access in long-term services and supports (LTSS), including HCBS programs? For example, how could CMS leverage the draft HCBS measure set, grievances and appeals, or states’ comparisons of approved Person-Centered Service Plans to encounter or billing data in managed care or fee-for-service to ensure appropriate services are being received? Which activities would you prioritize first?

CMS should prioritize creating a more uniform system for compiling paperwork, feedback, and demographic data to better assess potential gaps in service. The various HCBS state regulations can make it difficult to create a singular set of reporting tools. While the HCBS measure set does indicate streamlining wavier forms across services and compiling multiple waivers from a singular patient into a single report, this “bundling” should be expanded to reporting of all activities, requests, and feedback from patients. This standardization effort should also include a standard set of questionnaires, trainings for medical professionals administering surveys, and guidance on how to create uniform standardized billing systems, when possible, to aid the collection of data. Guidance from CMS on how to compile patient information will help states better recognize and address barriers to accessing certain services.

CMS should also investigate the use of additional modalities for how data is collected to gain a better understanding of when services are being rendered. Much of this data is collected using in-person interviews and questionnaires and while having person-to-person interaction is often preferred for a variety of reasons, allowing patients to self-report, including through online reporting, can help some patients feel more comfortable in disclosing information about themselves and in turn provide more accurate and timely data. Self-report can be especially helpful for gathering sensitive or stigmatizing data, including SOGI data.
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?

While CMS provides overarching definitions of critical incidents, appeals, and grievances, there remains a need for more specific guidance for states and plans on how to categorize the reasons why reports are filed and how to report this critical information to CMS. This can make it difficult to meaningfully analyze and standardize critical incident data to assess issues with coverage and access to services from state to state. In order for CMS to report standardized critical incident data across states, CMS must work with state programs to develop common definitions and protocol for classifying and measuring critical incidents that are applied consistently. This data can be used to compare rates of critical incidents, grievances, and appeals nationally in order to identify disparities or gaps in service. CMS should require states to send report standardized data associated with appeals, grievances, and critical incidents, and provide a clear mechanism for data reporting.

We would also recommend that critical incident data be reported alongside demographic data, including sexual orientation and gender identity (SOGI) data, whenever possible. This demographic data will help CMS get a clearer idea of who is experiencing critical incidents and grievances and what the outcomes of potential appeals or hearings are for different communities. This can help to address barriers that marginalized communities experience in access care, such as geographic access, discrimination, monetary barriers, and neglect. For example, LGBTQ+ communities historically experience discrimination and financial barriers in seeking access to health care. LGBTQ+ patients face discrimination based on HIV status, sexual orientation and perceived gender expression. LGBTQ+ patients statistically are low income and have high rates of enrollment in Medicaid. By implementing SOGI data collection when patients appeal a decision or report a grievance, CMS and state Medicaid program can gain a better understanding of potential discriminatory practices or other barriers preventing LGBTQ+ people from fully accessing or benefiting from Medicaid services.