

**WWI-WWH Response to CMS RFI on Medicaid Access and Services
Submitted Online 4/18/2022**

https://cmsmedicaidaccessrfi.gov1.qualtrics.com/jfe/form/SV_6EYj9eLS9b74Npk

CMS Question. 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.

WWH-WWI Response

CMS should fully implement the ACA’s “no-wrong-door” requirement. The lack of coordination between multiple systems for publicly-administered and publicly-supported health care coverage – ACA health insurance marketplace policies, Medicaid, CHIP, Medicare, other systems - creates multiples gaps and inefficiencies and undermines statutory intent. CMS should return, as soon as possible, to the Obama Administration’s original proposed regulation requiring all marketplaces to not only assess the Medicaid and CHIP eligibility of applicants for marketplace coverage, but to actually enroll them in Medicaid or CHIP when appropriate.

CMS Question. 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?

WWH-WWI Response

Many people find the process of applying for and using health insurance overwhelming. Regardless of their education level, income, age, employment status, and other demographic factors, consumers need expert help to navigate health insurance options, enrollment, and post-

enrollment challenges. Navigators can help de-mystify the complexity of applying for and using health insurance. They can also help reduce health disparities by improving health literacy in rural and underserved communities, including Black, Indigenous, and other communities of color. Challenges with accessing care are not limited to eligibility and enrollment issues. And with many people seeking assistance in qualifying for Medicaid or government subsidies, issues are not limited to open-enrollment periods.

Insurance navigation services must be year-round services offered by trained experts, who can help consumers break down barriers and promote access and health insurance literacy. Navigator services requiring adequate funding include eligibility and enrollment, and any and all post-enrollment questions and challenges that consumers might face. Although the Affordable Care Act (ACA) recognized the critical role of navigators in providing these services, funding has been shrinking over the years – even though the need for these services continues and, in many ways, has increased. 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. The most effective navigators are trusted messengers in communities they serve, providing culturally competent, proactive and responsive assistance. Adequate funding for states to offer such services for navigators is critical to reducing barriers that have structurally and negatively impacted marginalized communities impacted by many structural barriers resulting in health disparities.

Adequate training of navigators is essential. Whitman-Walker is proud to have partnered with the DC Health Benefit Exchange for the original launch of DC Health Link in 2013 to serve as the training partner for all 200 Assister/Navigators from more than 35 community organizations. We provided comprehensive initial training and continuing education through the

first four open-enrollment periods. Our onboarding for our own navigators includes a multi-week intensive training program that includes substantive information on the various health insurance program options, eligibility and enrollment, coverage, and application procedures; motivational and trauma-informed counseling and interviewing skills, relationship building, customer service skills, de-escalation skills, and healthy boundaries; effectively using technology and importance of documentation; and workflow within our health center and community partners for how best to meet additional needs consumers may have. We suggest that CMS require entities to have training as part of their programs, and that CMS reinstate funding opportunities for training and technical assistance for navigation programs.

All of the target populations highlighted in the question – 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; people with disabilities; and people with mental health or substance use disorders – face significant barriers which 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 to reducing health disparities and improving health equity.

Authorities: Transform Health, *The Critical Role of Navigation in Health Care Delivery: Implications of Federal Funding Reductions to Navigator Programs* (August 2019), <https://www.transformhc.com/wp-content/uploads/2019/08/Funding-Navigation-Services-FINAL-8.27.19.pdf>; Julie Rovner, *First Step in Health Exchange Enrollment: Train the Helpers* (Oct. 1, 2013), National Public Radio, <https://www.npr.org/sections/health-shots/2013/10/01/226930768/first-step-in-health-exchange-enrollment-train-the-helpers>.

CMS Question. What key indicators of enrollment in coverage should CMS consider monitoring? For example, how can CMS use indicators to monitor eligibility determination

denial rates and the reasons for denial? Which indicators are more or less readily available based on existing data and systems? Which indicators would you prioritize?

WWH-WWI Response

While denial rates and the reasons for denials are important indicators, those indicators alone fail to account for key factors such as the lack of timely decision-making by the agency, the timeliness and clarity of notices provided to consumers, and the accessibility of agency services. These factors should also be measured and closely monitored. In addition, the status of all applications and renewals submitted at the 45-day required deadline for timely processing should be monitored. In addition, trends on Limited English Proficient consumers, age, ethnicity, race, disability, sex, gender identity and sexual orientation should be recorded and monitored to review whether denial or termination rates are significantly greater for any such demographic.

CMS Question. What actions could CMS take to promote continuity of coverage for beneficiaries transitioning between Medicaid, CHIP, and other insurance affordability programs; between different types of Medicaid and CHIP services/benefits packages; or to a dual Medicaid-Medicare eligibility status? For example, how can CMS promote coverage continuity for beneficiaries moving between eligibility groups (e.g., a child receiving Early and Periodic Screening, Diagnosis, and Treatment [EPSDT] qualified supports who transitions to other Medicaid services such as home and community based services [HCBS] at age 21, etc.); between programs (Medicaid, CHIP, Basic Health Program, Medicare, and the Marketplace); or across state boundaries? Which of these actions would you prioritize first?

WWH-WWI Response

CMS should provide more guidance to states about their obligations to promote continuity of coverage and provide affirmative/proactive assistance with transitions. Even when Whitman-Walker is aware of and proactively assists consumers with these transitions, there are inadequate mechanisms within the agency to support the transition smoothly. The transitions are cumbersome and often require multiple interactions with agency staff to ensure that new benefits

are coded accurately and with the correct effective date. For example, when a Medicaid beneficiary transitions to Medicare, often the consumer will remain eligible for Medicaid – as a full dual – and will need coding as a Qualified Medicare Beneficiary (QMB) to pay Medicare cost sharing and enroll them in Low Income Subsidy (LIS) for their Medicare Part D benefits. We see the coding leave either Medicaid or Q (for QMB) coding off their updated profile after the Medicare transition. We recommend a requirement that states publish their procedure/protocol manual to demonstrate the steps needed to effectuate benefits. Highlighting different scenarios to show who will be eligible and for what benefits they will receive would also be helpful. We see how this would be beneficial for eligibility staff at the Medicaid agency, as we find knowledge and understanding of the interaction between different programs often too limited. In addition, if a consumer within their Medicaid certification period becomes Medicare eligible (or under a different program), we recommend no additional application or documentation be required and the consumer be transitioned, and notice be sent. At the next certification /renewal period, the consumer may be asked as they would for any renewal for any needed information/verification. One of the most confusing issues is someone who has just completed a renewal and then must provide all the same information to effectuate their transition to another program. The process is overly bureaucratic and unnecessary.

Eligibility systems should be programmed to identify some basic transitions in advance: (1) turning 65 years for Medicare eligibility; (2) 29 months after receipt of Social Security Disability Insurance (SSDI) benefits for Medicare eligibility; and (2) turning 19, 20, 21 years depending on the state's eligibility categories and need for transition to another category with different income limits for Medicaid. Sixty to 90 days in advance of a transition, beneficiaries should receive notice about their upcoming transition, what the change may mean for how they

access care, and referral to the State Health Insurance Counseling Program (SHIP) for those transitioning to Medicare for assistance with programs for low-income Medicare beneficiaries and enrollment in a Medicare Part D prescription drug plan. Unless a renewal is due at the same time a transition is occurring, a transition should not require the beneficiary to complete an application or renewal to be enrolled in the new category of coverage. Only new information (not already collected information) should be requested or required. For example, for a beneficiary becoming Medicare eligible and potentially transitioning from one category of Medicaid to another or no longer qualifying for Medicaid but qualifying for Qualified Medicare Beneficiary (QMB) coverage, only a request to upload the Medicare card would be appropriate.

CMS Question. How could CMS consider the concepts of whole person care^[5] 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? *[5] Under a “whole-person” philosophy, individuals with chronic physical and/or behavioral health conditions are provided linkages to long-term community care services and supports, social services, and family services, as needed. State Medicaid Director Letter #10-024. Available at: <https://www.medicaid.gov/federal-policy-guidance/downloads/smd10024.pdf>*

WWI-WWH response

Persons on Medicaid, in our experience, have many socially and legally determined needs that affect their health directly and indirectly. These Social Determinants of Health require a team of specialists beyond the medical providers and medical support staff that are traditionally recognized by Medicaid programs and other insurers. We encourage CMS to think broadly in recognizing specialists who can help best care for and support Medicaid patients as part of the care team. Often health care is paid for primarily by component-based care – specifically,

medical, behavioral, and dental services that are eligible for payment based on their coding. Federally qualified health centers are paid differently – based on costs. However, none of these models adequately reimburse or encourage innovative care team approaches. CMS should extend the specialty model of care to other professionals who address key structural barriers and social determinants of health that impact patient needs and drive health care costs.

Whitman-Walker Health (WWH) has developed a highly integrated care model, which includes not only primary medical and HIV specialty care, dental services, behavioral health services (mental health and addiction treatment), medical adherence nurse case management, and care navigators, but also community health workers (health educators, HIV and STI testing and counseling specialists), public benefits and insurance navigators, and lawyers. Our staff are strained to work collaboratively across all services to screen for social determinants of health and health-harming issues in order to improve access to care and health outcomes for our patients.

Among our care specialists, whose vital services are not clinically reimbursable, are our lawyers and our Public Benefits and Insurance Navigators (PBINs). In operation since 1986, WWH's Legal Services Program is proud to be the oldest medical-legal partnership in the country. Our legal services team works collaboratively with all services to address health-affecting legal needs and structural barriers to improve access to care and patient health outcomes. To enhance our legal services, since 2007 WWH has provided patients with trained experts to help navigate insurance options and coverage – our PBINs. The PBIN team helps ensure access to care by ensuring that all eligible patients are enrolled in Medicaid, CHIP, ACA health insurance marketplace plans, the DC Health Care Alliance, Medicare, the AIDS Drug Assistance Program, or other applicable medical assistance programs. They also work with our

lawyers to identify other social and legal determinants of health, including immigration issues, identity documents, disability benefit needs, and workplace rights issues.

WWH has found that our legal services are a critical gateway to our clinical health services for many who otherwise would not connect to health care. One example is the transgender and non-binary community. Identification documents that accurately match one's gender identity and presentation facilitate one's access to work, health care, and community connections – and even one's safety on the street and in any public place – as we are all asked for our ID at medical appointments, when applying for jobs, when entering public buildings, when purchasing items in a store, and by the police. Our lawyers assist transgender persons to update their identity documents, which is often a first – yet transformative – step to care. With matching identification, transgender individuals feel more comfortable connecting with a health care provider – and a significant number of our transgender legal clients engage with the health care system through our legal services for the first time in many years. It also enables us to assist many individuals to enroll in health insurance – many of whom were previously uninsured. Many of our transgender legal clients report that WWH is the first professional, trans-friendly service provider they have ever encountered. We often see that legal barriers are the most pressing issues for our clients, and overcoming these issues opens doors and starts meaningful conversations about wellness and safety. Some clients were thrown out of their homes by parents, or recently released from prison, and are currently “couch surfing” among friends or acquaintances, and we strive to connect them to community resources. With the advent of our Name and Gender Change Legal Clinic, WWH saw our medical and behavioral health transgender patients grow exponentially. Today, WWH serves around 2,500 transgender medical patients annually and provides “legal care” to many of those individuals, including

immigration, discrimination, insurance and other benefits, and privacy issues as well as identity documents.

CMS Question. 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?

WWI-WWH response

There is a need for substantially greater LGBTQ cultural competency among Medicaid providers

Individuals who are lesbian, gay, bisexual, transgender or queer (LGBTQ+) other sexual and gender diverse persons of all races and ethnicities experience barriers in accessing and receiving equitable healthcare. Many such individuals people are multiply minoritized based on race, ethnicity, economic status, and other social factors. The lack of provider knowledge of their health issues and needs, and lack of provider comfort and skill in effectively communicating with such patients, are major barriers to health care for sexual- and gender-diverse patients. Lack of provider clinical and cultural competence results in failure to diagnose or misdiagnosis of health conditions, resulting in lack of effective treatment; and discourages LGBTQI people from seeking regular medical care and from full disclosure to health care providers.

Authorities: National Academies of Science, Engineering and Medicine, UNDERSTANDING THE WELLBEING OF LGBTQI+ POPULATIONS, at pp. 357-59 (Washington, DC: 2020). <https://www.nap.edu/catalog/25877/understanding-the-well-being-of-lgbtqi-populations>; American Association of Medical Schools, IMPLEMENTING CURRICULAR AND INSTITUTIONAL CLIMATE CHANGES TO IMPROVE HEALTH CARE FOR INDIVIDUALS WHO ARE LGBT, GENDER NONCONFORMING, OR BORN WITH DSD: A RESOURCE FOR MEDICAL EDUCATORS (2014). <http://offers.aamc.org/lgbt-dsd-health>; The Joint Commission, ADVANCING EFFECTIVE COMMUNICATION, CULTURAL COMPETENCE, AND PATIENT- AND FAMILY-CENTERED CARE FOR THE LESBIAN, GAY, BISEXUAL, AND TRANSGENDER (LGBT) COMMUNITY: A FIELD GUIDE (2011). <http://www.jointcommission.org/lgbt>; Lett E, Dowshen NL, Baker KE: Intersectionality and health inequities for gender minority blacks in the U.S. *Am. J. Prev. Med.* 2020; 59:639-647.

LGBTQ patients have identified the following desired characteristics of health care providers:

- comfort with LGBTQ patients
- ability to facilitate shared medical decisions
- non-heterosexist/cis-sexist assumptions
- ability to apply LGBTQ-specific knowledge
- acknowledgment and attention to the social context of health disparities
- ability to facilitate disclosure
- ability to identify and eliminate bias
- acceptance and promotion of acceptance

Authorities: Alpert, A. B., Cichoski-Kelly, E. M., & Fox, A. D. (2017). What lesbian, gay, bisexual, transgender, queer, and intersex patients say doctors should know and do: A qualitative study. *Journal of Homosexuality*, 64(10), 1368–1389.

<https://doi.org/10.1080/00918369.2017.1321376>; Eliason, M. J., & Dibble, S. L. (2015). Provider-patient issues for the LGBTQ cancer patient. In *Cancer and the LGBTQ Community* (pp. 187–202). Springer, Cham. https://doi.org/10.1007/978-3-319-15057-4_12.

Researchers have recommended that HCPs should be able to:

- use appropriate terminology, including identifiers suggested by the patient
- reconcile personal beliefs with their professional role
- create an inclusive healthcare environment
- understand the stages and functions of a medical interview
- attend to patients' physical comfort
- effectively communicate
- know resources to refer patients to after screening for risks

Authorities: Rossi, A. L., & Lopez, E. J. (2017). Contextualizing competence: Language and LGBTQ-based competency in health care. *Journal of Homosexuality*, 64(10), 1330–1349.

<https://doi.org/10.1080/00918369.2017.1321361>; Saha, S., Beach, M. C., & Cooper, L. A. (2008). Patient centeredness, cultural competence and healthcare quality. *Journal of the National Medical Association*, 100(11), 1275–1285. [https://doi.org/10.1016/S0027-9684\(15\)31505-4](https://doi.org/10.1016/S0027-9684(15)31505-4):

Garg, A., Boynton-Jarrett, R., & Dworkin, P. H. (2016). Avoiding the unintended consequences of screening for social determinants of health. *JAMA*, 316(8), 813–814.

<https://doi.org/10.1001/jama.2016.9282>.

As awareness has broadened regarding the importance of tailored healthcare for individuals minoritized based on sexual orientation, sexual attraction, gender identity, gender

expression, and differences in sex development, more jurisdictions and schools are requiring health professionals to undergo SGD cultural competency training.

Authorities: Obedin-Maliver J, Goldsmith ES, Stewart L, et al.: Lesbian, gay, bisexual, and transgender-related content in undergraduate medical education. *JAMA* 2011;306:971-977; Hollenbach, A.D., Eckstrand, K.L., Dreger, A.D. IMPLEMENTING CURRICULAR AND INSTITUTIONAL CLIMATE CHANGES TO IMPROVE HEALTH CARE FOR INDIVIDUALS WHO ARE LGBT, GENDER NONCONFORMING, OR BORN WITH DSD: A RESOURCE FOR MEDICAL EDUCATORS. Association of American Medical Colleges, 2014; Ard, K.L., Keuroghlian, A.S.: Training in sexual and gender minority health - expanding education to reach all clinicians. *N. Engl. J. Med.* 2018; 379: 2388-2391; Council of the District of Columbia. Code of the District of Columbia. 3–1205.10. Term and Renewal of Licenses, Registrations, or Certifications. 2021. <https://code.dccouncil.us/us/dc/council/code/sections/3-1205.10>.

It is particularly important that Medicaid programs and providers be educated about, and responsive to, the particular concerns and needs of LGBTQ patients, especially LGBTQ persons of color and those living at the intersections of other multiple marginalized identities. LGBT-identified persons are more likely to be lower-income, and more likely to depend on Medicaid, than the non-LGBT population. Moreover, LGBT people are more likely to be living with disabilities, and gay and bisexual men and transgender women are more likely to be living with HIV, and Medicaid is a major source of health care for these populations.

Authorities: National Academies of Science, Engineering and Medicine, UNDERSTANDING THE WELLBEING OF LGBTQI+ POPULATIONS, at pp. 354-55 (Washington, DC: 2020). <https://www.nap.edu/catalog/25877/understanding-the-well-being-of-lgbtqi-populations>; Choi S.K., Badgett, M.V.L., and Wilson, B.D.M. (2019). *State Profiles of LGBT Poverty in the United States*. Williams Institute. <https://williamsinstitute.law.ucla.edu/publications/state-lgbt-poverty-us/>; Rooney C., Whittington C., and Durso L.E. (2018). *Protecting Basic Living Standards for LGBTQ People*. Center for American Progress. <https://www.americanprogress.org/article/protecting-basic-living-standards-lgbtq-people/>.

There are a number of actions that CMS should take in order to promote LGBTQ cultural competency of State Medicaid programs and providers:

1. The agency should **re-issue and strengthen the nondiscrimination and access 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.

2. Moreover, CMS should **actively promote LGBTQ cultural competency training** of health care institutions, and individual Medicaid providers. There are a number of available resources which CMS should employ:

- Whitman-Walker Institute and the National LGBT Cancer Network, together with leading educators, researchers, health care providers and patient advocates from across the country, have issued recommended guidelines for cultural competency training of health care providers and staff. TRANSFORMING HEALTHCARE: A GUIDE TO BEST

PRACTICES IN LGBTQIA+ CULTURAL COMPETENCY TRAINING,
www.culturalcompetency.org.

- The Joint Commission released has recommendations for healthcare organizations to create an inclusive climate for SGD patients. The Joint Commission. ADVANCING EFFECTIVE COMMUNICATION, CULTURAL COMPETENCE, AND PATIENT- AND FAMILY CENTERED CARE FOR THE LESBIAN, GAY, BISEXUAL, AND TRANSGENDER (LGBT) COMMUNITY: A FIELD GUIDE. 2011. https://www.jointcommission.org/-/media/tjc/documents/resources/patient-safety-topics/health-equity/lgbtfieldguide_web_linked_verpdf.pdf?db=web&hash=FD725DC02CFE6E4F21A35EBD839BBE97&hash=FD725DC02CFE6E4F21A35EBD839BBE97.
- The Association of American Medical Colleges defined clinical competency recommendations for medical doctors. Hollenbach AD, Eckstrand KL, Dreger AD: IMPLEMENTING CURRICULAR AND INSTITUTIONAL CLIMATE CHANGES TO IMPROVE HEALTH CARE FOR INDIVIDUALS WHO ARE LGBT, GENDER NONCONFORMING, OR BORN WITH DSD: A RESOURCE FOR MEDICAL EDUCATORS. Association of American Medical Colleges, 2014, <https://store.aamc.org/implementing-curricular-and-institutional-climate-changes-to-improve-health-care-for-individuals-who-are-lgbt-gender-nonconforming-or-born-with-dsd-a-resource-for-medical-educators.html>.
- The American Psychological Association (APA) Task Force on Psychological Practice with Sexual Minority Persons has issued GUIDELINES FOR PSYCHOLOGICAL PRACTICE WITH SEXUAL MINORITY PERSONS, approved by the APA Council of Representatives (Feb. 2021), https://www.apa.org/about/policy/psychological-sexual-minority-persons.pdf?_ga=2.180293540.1082501276.1649692354-835657555.1649692354.

3. CMS should also **provide funding for medical, nursing and other health professional educational institutions** for education on LGBTQ health disparities and health care needs, and training to student knowledge, attitudes and skills in working with sexual and gender diverse patients. We also encourage the agency to **explore grant or loan waiver programs** to incentivize health professional students, and practicing providers, to undertake advance training in the health care needs of LGBTQ and other marginalized patient populations.

4. In addition, CMS should **require providers to undergo LGBTQ cultural competency training as part of Medicaid Conditions of Participation and Conditions of Coverage.**

CMS should increase funding for language interpreter services

Whitman-Walker is committed to providing full access to all of our health services for Limited English Proficiency patients, and invests considerable resources in hiring multi-lingual staff and in developing and implementing a language access program that exceeds federal and District of Columbia requirements. However, there is a significant need for additional interpreter services through Medicaid – including a need for increased reimbursement rates. Many LEP patients on Medicaid, who we refer for surgery or for specialist care, encounter significant delays in receiving care from the hospitals or specialists to who we refer them because of a lack of interpreters. Moreover, our LEP patients consistently report that at other facilities to which they are referred, relevant healthcare documentation or paperwork is rarely provided as a translated document in the language they understand. Even for in-person appointments, many health care facilities rely on telephone interpreters and may delay in calling the interpreter for the first few minutes, so the first several minutes of an appointment may be un-interpreted. Greater resources for on-site/in-person interpreters should be provided.

CMS Question. 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?

WWI-WWH response

CMS should take a number of actions to address the lack of gender-affirming care, particularly surgery

Transgender and non-binary persons on Medicaid needing gender-affirming care experience many barriers, due to (1) continuing exclusions and restrictions in many State Medicaid plans and Medicaid managed care organizations; and (2) a lack of qualified providers, especially surgeons, in many states. We will discuss these issues and their resolution in turn, although the problems are related – continuing exclusions and restrictions discourage providers and medical students from entering the field by suppressing demand and perpetuating outdated notions that “sex change” procedures are “cosmetic” and “fringe” rather than an essential component of care for a significant – and growing – population.

Continuing discriminatory Medicaid policies and practices. A significant number of State Medicaid programs still expressly exclude coverage of gender-affirming care for transgender persons, and States that do not categorically exclude all coverage vary substantially in the types of procedures that are covered.

Authorities: National Academies of Science, Engineering and Medicine, UNDERSTANDING THE WELLBEING OF LGBTQI+ POPULATIONS, at pp. 107, 362 (Washington, DC: 2020). <https://www.nap.edu/catalog/25877/understanding-the-well-being-of-lgbtqi-populations>; Zaliznyak, B.A., et al. (2021), Which U.S. states’ Medicaid programs provide coverage for gender-affirming hormone therapy and gender-affirming genital surgery for transgender patients? *J. Sex. Med.* 18:2; 410-422. [https://www.jsm.jsexmed.org/article/S1743-6095\(20\)31062-6/fulltext](https://www.jsm.jsexmed.org/article/S1743-6095(20)31062-6/fulltext); Mallory, C. and Tentindo, W. (2019). *Medicaid Coverage for Gender-Affirming Care*. Williams Institute. <https://williamsinstitute.law.ucla.edu/wp-content/uploads/Medicaid-Gender-Care-Oct-2019.pdf>; Movement Advancement Project,

Healthcare Laws and Policies: Medicaid Coverage for Transition-Related Care, <https://www.lgbtmap.org/img/maps/citations-medicaid.pdf>, www.lgbtmap.org/2020-tally-report (visited April 13, 2022).

Moreover, many plans that do not contain blanket exclusions of all “sex reassignment” procedures still exclude many essential types of surgeries related to gender transition, including facial or chest surgery, and plans that are more inclusive commonly exclude revision work (labiaplasty and glans reconstruction). In addition, many insurers deny coverage of other specific treatments needed to complete an individual’s transition on grounds that the procedure is “cosmetic” – either by relying on general plan language excluding cosmetic procedures or concluding that a procedure is not medically necessary. In many cases, plans specifically exclude procedures that are routinely considered cosmetic for most cisgender persons, but may be part of a medically recognized course of treatment for a transgender person. Examples of such procedures, which are categorically excluded as “cosmetic” in many plans and by many utilization reviewers, include:

- Surgeries of the head and face, such as hair transplant, scalp advancement, brow reduction, lip reduction or augmentation, rhinoplasty, cheek and chin contouring, jawline modification, blepharoplasty [eyelid repair], and other facial feminization techniques for transgender women.
- Laser hair removal and electrolysis, on the face and elsewhere on the body.
- Surgeries involving the neck, such as cartilage reduction (modification of the Adam’s Apple) and vocal feminization surgery.
- Breast augmentation and reduction.
- Other body contouring procedures, such as waist reduction, hip/buttocks implants, fat transfer, pectoral implants.
- Lessons/training to modify the vocal range.

CMS should address these continuing problems by promptly amending Medicaid nondiscrimination regulations that were undercut by the previous Administration to expressly

prohibit gender identity discrimination: 42 CFR §§ 438.3(d)(4), 438.206(c)(2), and 440.262.

CMS should also promptly issue a letter to State Medicaid Directors spelling out that policies and practices that single out gender-affirming procedures for exclusion or medically unwarranted restrictions violate federal law.

In addition, CMS should explore ways to amend Medicaid regulations to make clear that gender-affirming surgeries are essential services, medically necessary, and frequently life-saving.

Lack of qualified Medicaid providers of gender-affirming care, particularly surgery. Even when a surgical procedure is covered by Medicaid, in many if not most States there are critical shortages of qualified surgeons who accept Medicaid. And for many gender-affirming surgeries, there are very few surgeons with training and experience to perform many of these specific procedures. As a result, many transgender and non-binary Medicaid recipients are in effect denied essential care.

Although the District of Columbia Medicaid program is relatively progressive in its coverage policies, our Medicaid patients face many challenges receiving the surgeries they need.

Specifically:

- ***Mastectomy, Chest Reconstruction, Breast Augmentation, and Chest Reduction.*** Only 3 surgeons accept DC Medicaid; of the 3, one is only available for consultations once per month, and has even less availability for surgery; a second surgeon is based at a hospital that has severely limited her access to operating room time due to alleged “operational and staffing challenges” at the hospital. The third surgeon is also the only surgeon accepting DC Medicaid; so demand is high for his time. The bottom line: it takes more than 6 months to complete consultation and surgery. There is high demand for these services.
- ***Facial feminization*** (only 4 bones): There is only 1 plastic surgeon available, and he does not perform Tracheal Shaves, so he must coordinate with an ENT surgeon. Completion of consultation and surgery may take more than 6 months. There is high demand for these services.
- ***Phalloplasty.*** No surgeon is actively consulting or performing this procedure for people with DC Medicaid currently. The hospital that previously housed this practice has been

maintaining a waitlist since September 2021, and there is no end in sight. Some patients consulted more than 12 months ago, and have no idea when or if their surgery will be scheduled. Some patients have been on a waitlist even for a consultation for 7 months or longer.

- ***Vaginoplasty, Vulvoplasty.*** The situation is the same as for phalloplasty procedures. There is high demand for these procedures.
- ***Metoidioplasty.*** There is only 1 specialist available at this time. They have limited operating room time at the hospital where they have privileges due to alleged “operational and staffing challenges” at the hospital. Consultation and completion of surgery may take longer than 6 months.
- ***Hysterectomy.*** While access is not as limited as for a number of other procedures (there are 3 GYN surgeons we can refer DC Medicaid patients to), it still takes 3 – 6 months to complete consultation and surgery.
- ***Orchiectomy.*** Although access is not as limited as for a number of other procedures (there are 3 skilled urologists we can refer DC Medicaid patients to), it still takes 3 – 6 months to complete consultation and surgery.

In our experience at Whitman-Walker, our patients on Maryland Medicaid or Virginia Medicaid experience considerably less access and longer timelines for the surgeries they need.

These shortages cause many hardships for patients. For example:

“Renee”, a 39-year-old transgender woman, a long-time medical patient of Whitman-Walker with DC Medicaid, has been waiting since before 2018 to complete her vaginoplasty. In October 2017, she completed a gender-affirming orchiectomy with a Urologist at GWU as she was aware there were no in-network options for vaginoplasty at the time, and no surgeons nearby completing the procedure. By April 2018, Renee learned from her urologist that the urologist was partnering with a local plastic surgeon to perform vaginoplasty procedures in DC (the first vaginoplasty under DC Medicaid, to our knowledge, occurred in May 2018). Renee immediately worked to obtain the letters required for the surgery, including working with the surgical team to correct mistakes in the initial letters. Unfortunately, in the interim the plastic surgeon decided to stop participating with DC Medicaid. In early 2019, WWH attempted to refer Renee to Johns Hopkins who, at the time, was willing to accept DC Medicaid. However, the Johns Hopkins intake and consultation system was quite cumbersome and error-prone – many patients waited more than 9 months for a consultation and more than 12 months after that for surgery – so Renee was never scheduled. As of June 2021, she had been referred to the latest option – a surgeon at Medstar opened up consultations in DC (though the surgeon is normally based in Baltimore). Renee underwent preparations for surgery (including dilation and hair removal), but before the surgery Medstar cancelled scheduled procedures at its DC hospital and initiated a waitlist for all future consultations and procedures. Renee remains on the waitlist. We are requesting Medstar prioritize Single Case Agreements between DC Medicaid MedStar and their Baltimore surgical

facility where there is a provider so that patients who have already consulted may move forward to complete the procedure. There is not yet any resolution.

“Edgar”, a 34-year-old transgender man and medical patient of Whitman-Walker since 2014, was referred for gender-affirming hysterectomy in 2016 through [health system A] but was unable to complete the procedure due to [that health system’s] extensive “gatekeeper” process, where they screened and re-evaluated patients who had gone through screening and behavioral health evaluations elsewhere. By October 2017, while he was on DC Medicaid, Edgar was able to obtain a hysterectomy [elsewhere] with Whitman-Walker’s support. By May of 2018, he was healed and discussing options for phalloplasty with his provider. At that point, we’d been told that the surgical team – the first in DC to attempt vaginoplasty – believed that they would be ready for phalloplasty by the fall of 2018. Edgar consulted in late July 2018 with both the urologist and the private practice plastic surgeon. The team attempted their first phalloplasty, without supervision of another plastic surgeon, in September 2018. Within days, Edgar’s phallus failed due to poor nerve hookup (this procedure requires microsurgery skills which apparently neither surgeon possessed). He was left with substantial mental harm and physical disfigurement. Although the surgeons had assured Edgar and Whitman-Walker that they had enough training and could do the procedure, after his procedure they told us they would not attempt one again. At the time, the only hope for repair was a Single Case Agreement with [a hospital in Maryland] (as [that hospital] did not participate with DC Medicaid) to get the patient in urgently. With very careful coordination across both teams, he was referred to [the Maryland hospital] in January 2019, and ongoing coordination continued for a Single Case Agreement. His consult was scheduled for April 2019. Because Edgar was terrified of risking failure of Single Case Agreement efforts, he purchased Blue Cross Blue Shield coverage from the Exchange and completed revision corrective surgery in July 2019 at [the Maryland hospital]. The new surgeon confirmed that the initial procedure was performed poorly.

There are a number of actions that CMS can take to increase the number of qualified gender-affirming surgeons over time:

1. As discussed above, the agency should issue regulations and guidance to State Medicaid Directors to eliminate discriminatory exclusions of and restrictions on medically indicated gender-affirming surgeries, and explore ways to incorporate medically supported gender-affirming care into essential services required of all Medicaid programs.
2. Many surgeons are unwilling to take Medicaid patients because of the low reimbursement rates and administrative burdens of enrollment, utilization procedures, and claims processing. CMS should encourage State Medicaid agencies to increase compensation rates especially for gender-affirming surgeries where limited capacity already exists. Streamlined enrollment and

ease of access where single case agreements or limited enrollment to facilitate access to providers for Medicaid beneficiaries must be available. Streamlined utilization procedures and claims processing are also critical.

3. CMS should fund education/training programs in medical schools focused on gender-affirming care – surgery as well as hormone therapy. Academic medical centers can become leaders in gender-affirming care – CMS and other federal grantors should prioritize funding for gender-affirming medical education at interested academic centers. Specialized training programs and fellowships that should be investigated include programs at New York University, Johns Hopkins, and Oregon State University. These and other institutions may be appropriate candidates for financial support from CMS. Moreover, CMS should explore ways to incentivize surgeons to obtain specialized training and certification at such institutions, through educational loan relief and otherwise.

4. CMS should encourage State cross-reciprocity for gender-affirming surgery, to enable Medicaid recipients in a State that lacks any qualified surgeons able and willing to perform a needed procedure to obtain it from a qualified surgeon in a nearby State, with that surgeon reimbursed by the Medicaid program in the patient’s State of residence. Current Single Care Agreements in such circumstances are difficult to obtain and frequently unavailable.

Need to require Medicaid managed care organizations to include LGBTQ-competent providers in their networks

In assuring network adequacy, it is essential to consider whether a network includes providers who are clinically and culturally competent to serve LGBTQI patients. The lack of provider knowledge of the health issues and needs of lesbians, gay men, and bisexual persons; of transgender and gender nonbinary patients; and individuals with intersex traits; and lack of provider comfort and skill in effectively communicating with such patients, are major barriers to

health care for sexual- and gender-diverse patients. Lack of provider clinical and cultural competence results in failure to diagnose or misdiagnosis of health conditions, resulting in lack of effective treatment; and discourages LGBTQI people from seeking regular medical care and from full disclosure to health care providers.

Authorities: National Academies, UNDERSTANDING THE WELLBEING OF LGBTQI+ POPULATIONS, *supra* n.9, at pp. 357-59; American Association of Medical Schools, IMPLEMENTING CURRICULAR AND INSTITUTIONAL CLIMATE CHANGES TO IMPROVE HEALTH CARE FOR INDIVIDUALS WHO ARE LGBT, GENDER NONCONFORMING, OR BORN WITH DSD: A RESOURCE FOR MEDICAL EDUCATORS (2014), available at <http://offers.aamc.org/lgbt-dsd-health>; The Joint Commission, ADVANCING EFFECTIVE COMMUNICATION, CULTURAL COMPETENCE, AND PATIENT- AND FAMILY-CENTERED CARE FOR THE LESBIAN, GAY, BISEXUAL, AND TRANSGENDER (LGBT) COMMUNITY: A FIELD GUIDE (2011), available at <http://www.jointcommission.org/lgbt>.

CMS Question. 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?

WWI-WWH response

Achieving health equity depends on the collection of relevant demographic data and data on the social determinants of health applicable to the relevant communities. In particular, assessing and advancing health equity in LGBTQI populations requires collecting adequate data on sexual orientation, gender identity and variations in sex characteristics (also known as intersex traits). Comprehensive data collection is critical to advancing health equity and improving the healthcare delivery system for all patients, including patients from historically marginalized communities. A lack of data stymies policymakers' ability to identify systemic issues in access to coverage, claims denials, appeals, and other measures. Limited or inaccurate

data also makes it difficult to implement serious investments in improving quality of care for patients and reducing racial and ethnic health disparities. Comprehensive data is especially important to addressing disparities that are made worse when compounded with marginalized identities based on disability, gender identity, sexual orientation, and intersex traits.

CMS and its Center for Consumer Information and Insurance Oversight (CCIIO) can draw on several sources to inform this data collection. The recently-issued the National Academies of Science, Engineering and Medicine report, *Measuring Sex, Gender Identity, and Sexual Orientation*, lays out guiding principles and recommended measures for testing, including for administrative settings such as health plan enrollment. The report (at page 3-9) notes that

the Center for Medicare and Medicaid Innovation (2021) [available at <https://innovation.cms.gov/strategic-direction-whitepaper>] lists stratified performance data as a pillar in its strategy to advance health equity. Thus, collecting data on sex, gender identity, and sexual orientation in medical settings is important for quality improvement and the advancement of health equity.

Recognizing the importance of sexual and gender data to the provision of healthcare services, HHS recently adopted a new version of the US Core Data for Interoperability (USCDI) that includes sexual orientation and gender identity as core elements. Some insurers have also already developed new tools to leverage gender identity data elements to improve the experience of their diverse enrollees, such as the ability for transgender and nonbinary clients to include their authentic names, pronouns, and gender identities in their insurance record, and to avoid inappropriate denials of care for transgender, nonbinary, and intersex individuals based on sex coding. In addition, the National Association of Insurance Commissioners Special Committee on Race and Insurance has developed detailed, thoughtful guidance for insurance regulators and insurance companies on data collection methodologies that respect individual autonomy and protect privacy while providing essential information for policymakers.

Authorities: National Academies of Science, Engineering and Medicine. Measuring Sex, Gender Identity, and Sexual Orientation. (Washington, DC: 2022).

<https://nap.nationalacademies.org/catalog/26424/measuring-sex-gender-identity-and-sexual-orientation>; *HHS updates interoperability standards to support the electronic exchange of sexual orientation, gender identity and social determinants of health* (July 9, 2021),

<https://www.hhs.gov/about/news/2021/07/09/hhs-updates-interoperability-standards-to-support-electronic-exchange-of-sogi-sdoh.html>; Page Minemyer, *Oscar launches new functionality for transgender, nonbinary members*, Fierce Healthcare (July 14, 2021),

<https://www.fiercehealthcare.com/payer/oscar-launches-new-functionality-for-transgender-nonbinary-members>; *National Association of Insurance Commissioners Special Committee on Race and Insurance – Workstream 5 (Health), Principles for Data Collection, Draft 12/20/21*, available https://content.naic.org/cmte_ex_race_and_insurance.htm.