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June 30, 2023

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

Re: CMS-2442-P, Medicaid Program; Ensuring Access to Medicaid Services

Dear Administrator Brooks-LaSure:

The National Health Law Program (NHeLP) is a public interest law firm that works to advance equitable access to health care and protect the health rights of people with low incomes and underserved populations. For over fifty years, we have litigated, advocated, and educated at the federal and state levels to advance health and civil rights in the United States. Consistent with our mission, we strongly believe that health care is a human right. Every individual should have access to high quality, affordable, and comprehensive health care and be able to achieve their own highest attainable standard of health.

We appreciate the opportunity to comment on these proposed rules. Below, please find comments stressing our support for the proposed changes to the Medicaid Advisory Committee and Beneficiary Advisory Group, the proposed improvements to assuring equal access and to home and community-based services (HCBS), and to promoting transparency and adequate payment for fee-for-service Medicaid. In areas where we believe the proposed language can be strengthened or clarified, we have indicated this.

§ 431.12 Medicaid Advisory Committee and Beneficiary Advisory Group

CMS proposes to significantly strengthen requirements for Medical Care Advisory Committees (MCACs), which would be renamed Medicaid Advisory Committee (MAC) and the new Beneficiary Advisory Group (BAG). We strongly support these changes. Although MCACs have been federally required for nearly 40 years, some states have seriously underutilized this important opportunity to monitor and improve their Medicaid programs. States vary widely in how they have implemented current MCAC requirements. In some states (Wyoming, Tennessee), there is no evidence of an MCAC. Other states, such as Pennsylvania, have robust MCACs that effectively engage Medicaid enrollees in state policymaking.

Given the ongoing threats to Medicaid services and eligibility at the state level and to judicial enforcement in federal and state courts, these revisions will reinvigorate state MCACs so that it becomes a vital, functioning two-way channel of communication between Medicaid policy makers and the individuals and providers who participate in the Medicaid program.

The proposed regulations are a welcome step to meaningfully engage Medicaid enrollees who have firsthand knowledge of the program's effectiveness and deficiencies. We offer the additional following comments and suggestions on how CMS might further improve these proposals.

A. §§ 431.12(a) BASIS AND PURPOSE; (b) STATE PLAN REQUIREMENT

We support requiring states to establish MACs to advise the state Medicaid agency on policy development and matters related to the effective administration of the Medicaid program. We strongly agree with CMS that because of “the lack of specificity in the current regulations specificity, these regulations have not been consistently implemented across States.”¹

State agencies have long had a poor track record engaging Medicaid enrollees and other stakeholders in program in planning, implementation, and oversight.² Accordingly, we welcome proposals to establish clear requirements for membership, operations, responsibilities, and transparency and aligning requirements for the MAC and BAG, consistent with other CMS advisory groups. Robust standards, and CMS compliance monitoring and enforcement, will

¹ 88 Fed. Reg. 27963.

² See Jane Perkins & Sarah Somers, Nat'l Health Law Prog., *Fact Sheet: Medicaid Medical Care Advisory Committees* (Jan. 2005), https://www.ndrn.org/images/Documents/Issues/Medicare/Medicaid/NDRN_medicare_advisory_committees.pdf.



help ensure that the MAC and BAG can function as intended, as vital partners in program development and oversight.³

We do suggest renaming the “Beneficiary Advisory Group” to the “Medicaid Enrollee Advisory Group” (MEAG) or “Medicaid Enrollee Advisory Council.” We are concerned that “Beneficiary Advisory Group” and the corresponding acronym “BAG” does not appropriately reflect the importance of the group.

B. § 431.12(c) APPOINTMENT OF MEMBERS

Committees should include a broad array of key stakeholders with an open and transparent appointment process. We support CMS’s proposal for the appointment of members on a rotating basis, which would help ensure continuity in MAC and BAG operations. We oppose imposing term limits for members, since in some jurisdictions, the number of advocates with Medicaid expertise is limited. We also support public posting requirements for member recruitment and information on the appointment process, set terms for MAC and BAG members, and for-cause removal. We further urge CMS to require members disclose actual or potential conflicts of interest.

CMS should specifically provide for set terms whereby members serve for the duration of their appointments, including “for cause” removal, with written notice and explanation of the ground of removal. Such a requirement would help prevent some of the most egregious state abuses of power. For example, in 2016 the District of Columbia Department of Health Care Finance (DHCF) removed the MCAC chair who had criticized the agency for application processing delays. Legal Aid DC recounted the events leading to the chair’s dismissal:

On December 14, 2015, Mr. Wesley Rivers, Policy Analyst with the D.C. Fiscal Policy Institute and then-Chair of MCAC, published a blog post expressing concern about the potential effect of Medicaid IT problems on beneficiaries’ ability to obtain and retain Medicaid coverage. See “DC Medicaid IT Problems Threaten to Leave Thousands of Residents Without Coverage, Unless Addressed Soon,” Dec. 14, 2015, <https://www.dcfpi.org/all/dc-medicaid-it-problems-threaten-to-leave-thousands-of-residents-without-coverage-unless-addressed-soon/>. As part of the blog post, Mr. Rivers summarized data regarding Medicaid applications and renewals that had been presented at prior MCAC meetings. On December 14, 2015, an article was also published in the Washington City Paper discussing Mr. Rivers’ blog post and quoting comments by him. See Andrew Giambrone, “Technical Problems May Soon

³ For example, in response to complaints from HIV/AIDS activists, Congress established minimum requirements for membership, conflict of interest, and transparency for the Part A Planning Councils under the Ryan White Act. See 42 U.S.C. § 300ff–12.



Leave Thousands of DC Residents Without Medicaid," Washington City Paper (Dec. 14, 2015), <https://washingtoncitypaper.com/article/444494/technical-problems-may-soon-leave-thousands-of-d-c-residents-without-medicaid/>.

On December 22, 2015, the law firm of Terris, Pravlik, & Millian, LLP filed a preliminary injunction motion in the long-running litigation of *Salazar v. District of Columbia*. Mr. Rivers, Legal Aid, and other MCAC members submitted declarations in support of the motion discussing Medicaid application and renewal problems that had impacted beneficiaries on whose behalf we advocate.

On January 21, 2016, Mr. Wayne Turnage, Director of DHCF, sent an email to all MCAC members informing them that Mr. Rivers was "no longer serving as chair of MCAC" and that DHCF would be "reshaping the Committee and revising operating procedures."⁴

DHCF then revamped the MCAC by-laws, adding a provision that "[m]embers serve at the pleasure of the Director," and allowing removal of members at any time, for any reason.⁵ Such a provision is entirely inconsistent with the law and the important role that MCACs should play – to advise the agency on matters of concern in the state's Medicaid program.

To prevent abuses like the one described above and to ensure that the MAC and BAG members can effectively advise the state Medicaid agency, federal regulatory protections are crucial. The removal of MAC and BAG members cannot be left to the discretion of state Medicaid agencies.

⁴ Letter from Jennifer Meazy, Supervising Attorney, Legal Aid Society of the District of Columbia, to Trina Dutta Special Projects Officer DC Department of Health Care Finance (Jul. 15, 2016), <https://dhcf.dc.gov/sites/default/files/dc/sites/dhcf/publication/attachments/Legal%20Aid%20Society%20of%20DC%20Comments%20on%20Proposed%20MCAC%20By-Laws.pdf>. Note that the National Health Law Program is co-counsel in *Salazar*.

⁵ District of Columbia Medical Care Advisory Committee, By-laws and Procedures, Revision adopted Jul. 27, 2016, Art. VI, § 6.1, https://dhcf.dc.gov/sites/default/files/dc/sites/dhcf/publication/attachments/MCAC%20ByLaws_Final-Approved_7-27-2016.pdf.



RECOMMENDATION: Amend subsection (c) as follows:

(c) Appointment **and removal** of members.

The agency director, or a higher State authority, must appoint members to the MAC and BAG on a rotating and continuous basis. The State must create a process for recruitment and appointment of members and publish this information on the States website as specified in paragraph (f). **Members shall serve set terms and may only be removed for cause. The State's by-laws shall specify grounds for removal, and the State must provide written notice stating the basis for removing a member.**

C. § 431.12(d) MAC MEMBERSHIP AND COMPOSITION

We support requiring at least 25% of MAC membership be Medicaid enrollees as part of the BAG. We also support CMS's proposed requirement to include representation from other stakeholders including state or local consumer advocacy groups, provider groups, managed care organizations, and other state agencies. CMS should encourage states to recruit MAC and BAG members representing a broad spectrum of Medicaid stakeholders, including elder law, racial justice organizations, disability rights advocates, people living with HIV/AIDS, LGBTQIA+ groups, reproductive justice advocates, and others who are actively engaged with Medicaid and with communities who rely on Medicaid.

CMS should expand the list of key Medicaid stakeholders who must be represented on a state's MAC to include legal services and protection and advocacy programs, as well as reproductive health providers.

1. MACs must include legal services providers and Protection & Advocacy system representatives

CMS should require MAC representation from legal services providers and the state's Protection & Advocacy organization, both of which play a crucial role enforcing the rights of Medicaid enrollees.

In 2021, legal aid offices financed by the Legal Services Corporation (LSC), the largest funder of civil legal aid for households at or below 125% of the federal poverty guidelines, served 1.8 million people.⁶ Legal services clients represent nearly every demographic (e.g., race, gender,

⁶ Legal Servs. Corp., What We Fund – Quick Facts, <https://www.lsc.gov/about-lsc/who-we-are/what-we-fund/quick-facts> (last visited June 25, 2023).



age, region), with concerted efforts made to reach agricultural workers, Native Americans, veterans, victims of domestic violence, and clients with limited-English proficiency.⁷

Legal aid attorneys and advocates have extensive experience representing Medicaid enrollees.⁸ These cases inform legal advocates of the issues affecting clients, most Medicaid eligible, and are the foundation for policy advocacy. In Ohio, legal advocates from Cincinnati's Children's Hospital's medical-legal partnership heard from pediatricians of crucial delays in newborn public benefit coverage in one particular county.⁹ Advocates, working in conjunction with state agencies and managed care plans, were able to streamline administrative processes to improve not only Medicaid eligibility determination but also SNAP and cash assistance. The new procedures are estimated to impact hundreds of eligibility determinations a year.¹⁰ Similarly, in Chester, Pennsylvania, advocates for the Health Education and Legal Assistance Project (HELP) worked with government agencies to provide notices in the preferred language of enrollees.¹¹ Additionally, they advocated for the expanded definition of "emergency" to include prenatal care for high-risk pregnancies resulting in additional health care coverage.¹²

Likewise, advocates from the Protection and Advocacy (P&A) network, a federally mandated system of agencies that advocate for the rights of people with disabilities, have unique experiences working with historically overlooked and harmed communities.¹³ Under federal law, P&As:

Have the authority to . . . pursue legal, administrative, and other appropriate remedies or approaches to ensure the protection of, and advocacy for, the rights of such individuals within the State who are or who may be eligible for treatment, services, or habilitation, or who are being considered for a change in living arrangements, with particular attention to members of ethnic and racial minority groups.¹⁴

⁷ Legal Servs. Corp., *By the Numbers*, <https://www.lsc.gov/our-impact/publications/numbers> (last visited June 25, 2023).

⁸ *Id.*

⁹ Kate Marple et al., Nat'l Ctr. for Med. Legal P'ship, *Increasing Nutritional Supports for Newborns* (2018) <https://medical-legalpartnership.org/wp-content/uploads/2018/04/Increasing-Nutritional-Supports-for-Newborns.pdf>.

¹⁰ *Id.*

¹¹ Daniel Atkins et al., *Medical-Legal Partnership and Healthy Start: Integrating Civil Legal Aid Services into Public Health Advocacy*, 35 J. LEGAL MED. 195 (2014).

¹² *Id.*

¹³ 42 U.S.C. § 15041; see Nat'l. Disability Rights Network, *About*, <https://www.ndrn.org/about/> (last visited Jun. 23, 2023).

¹⁴ 42 U.S.C. § 15043(A)(i).



The purpose of P&As is to “protect and advocate the rights of such individuals through activities to ensure the enforcement of the Constitution and Federal and State statutes.”¹⁵ Every state and U.S. territory houses a P&A agency making the network the largest provider of legal services for people with disabilities in the U.S.¹⁶ Annually, they serve tens of thousands of people with disabilities.¹⁷

Mandating the inclusion of legal advocates in MACs would further center the health and experiences of Medicaid enrollees. Attorneys have a legal and ethical obligation to zealously pursue their clients’ interests. Legal advocates have important perspective and insight to effectively advocate for low-income people on MACs. Moreover, because legal services providers and P&As rely on outside funding streams, they do not have a pecuniary interest in a state’s Medicaid policy.

2. MACs Should Include Representation from Providers of Reproductive Health Services

The proposed rule requires MAC representation by “clinical providers who are familiar with the health and social needs of Medicaid enrollees,” including providers of primary care, specialty care, and LTSS.¹⁸ We agree that providers can add value to discussions and should be represented on MACs. We understand the desire of some commenters who urge CMS to carve out mandatory MAC membership slots for various provider types.¹⁹ Medicaid is a key provider of important services including behavioral health services, oral health care, and services provided to low income children under the Early and Periodic Screening, Diagnostic, and Treatment program (EPSDT). However, if CMS were to carve out mandatory MAC slots for every key Medicaid provider type, it would bloat the size of the MAC and make it difficult to adhere to the 25% minimum for Medicaid enrollees. Mandatory inclusion on MACs for most Medicaid provider types is unwarranted.

¹⁵ 42 U.S.C. § 10801.

¹⁶ Nat’l Disability Rights Network, NDRN Member Agencies, <https://www.ndrn.org/about/ndrn-member-agencies/> (last visited Jun. 23, 2023).

¹⁷ Substance Abuse and Mental Health Serv. Admin, *The Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program Activities Report for Fiscal Years 2019 and 2020* (2022), <https://www.samhsa.gov/sites/default/files/paimi-activities-report-fy-19-20.pdf>; Admin. for Community Living, *Program Evaluations and Reports* (2023), <https://acl.gov/programs/program-evaluations-and-reports>.

¹⁸ Proposed § 431.12(d)(2)(B).

¹⁹ See, e.g., Letter from Ronald Benner, President, American Optometric Association to Chiquita Brooks-LaSure, Administrator, CMS (Jun. 14, 2023), <https://www.regulations.gov/comment/CMS-2023-0070-0273> (calling on CMS to establish a mandatory MAC slot for optometrists).



Although in most cases we do not see a need to carve out MAC slots for specific provider types, we think reproductive health providers are an exception. In many states, efforts are underway to undermine access to evidence-based sexual and reproductive health care. Therefore, we request that CMS require that MACs include *bona fide* reproductive health care providers.

Medicaid is an important provider of reproductive health services, covering more than 40% of U.S. women's births and 65% of Black women's' births.²⁰ It is the leading source of family planning coverage in the U.S.²¹ All states provide Medicaid coverage for breast and cervical cancer treatment, and many programs cover gender-affirming hormone therapy.²² Federal law requires that all states cover abortions that fall into the Hyde Amendment's exceptions of rape, incest, or endangerment of the pregnant person's life.²³

²⁰ MACPAC, *Medicaid's Role in Financing Maternity Care* (2020), <https://www.macpac.gov/wp-content/uploads/2020/01/Medicaid%E2%80%99s-Role-in-Financing-Maternity-Care.pdf>; Latoya Hill et al., *Racial Disparities in Maternal and Infant Health: Current Status and Efforts to Address Them*, Kaiser Fam. Found. (2022), <https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-disparities-in-maternal-and-infant-health-current-status-and-efforts-to-address-them/>. See also Madeline T. Morcelle, *Reforming Medicaid toward Reproductive Justice*, 48 (2–3) AM. J. LAW & MED. 223, 242–243 (2022), <https://www.cambridge.org/core/journals/american-journal-of-law-and-medicine/article/reforming-medicaid-coverage-toward-reproductive-justice/D8F29D78E4D6CC9273152A7267F1F47C>.

²¹ Usha Ranji et al., Kaiser Fam. Found., *Financing Family Planning Services for Low-Income Women: The Role of Public Programs* (2019), <https://www.kff.org/womens-health-policy/issue-brief/financing-family-planning-services-for-low-income-women-the-role-of-public-programs/>.

²² Kaiser Fam. Found., *State Eligibility for Medicaid Breast and Cervical Cancer Treatment Program* (2021), <https://www.kff.org/other/state-indicator/state-eligibility-for-medicaid-breast-and-cervical-cancer-treatment-program-bcctp/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>; Ivette Gomez, Kaiser Fam. Found., *Update on Medicaid Coverage of Gender-Affirming Health Services* (2022), <https://www.kff.org/womens-health-policy/issue-brief/update-on-medicaid-coverage-of-gender-affirming-health-services/> (As of 2022, half of states reported covering gender-affirming hormones).

²³ Pub.L. 117-103, Div. H, §§ 506–507; Madeline T. Morcelle, Nat'l Health Law Prog., *Fostering Equitable Access to Abortion Coverage: Reversing the Hyde Amendment 2* (2021), <https://healthlaw.org/resource/fostering-equitable-access-to-abortion-coverage-reversing-the-hyde-amendment/>; but see Madeline T. Morcelle & Cat Duffy, Nat'l Health Law Prog., *There's More That HHS Can (and Must) Do to Protect Abortion Access* (2022), <https://healthlaw.org/theres-more-that-hhs-can-and-must-do-to-protect-abortion-access/> (calling on HHS to enforce federal Medicaid abortion coverage requirements, which some states have violated for decades, endangering the health and lives of enrollees).



Unfortunately, Medicaid’s critical sexual, reproductive, and broader health care coverage have long made it a strategic target for those who wish to restrict access.²⁴ In an era in which many lawmakers are attacking sexual and reproductive health care access on every front, protecting and advancing Medicaid enrollees’ access is a health equity imperative. One way to advance that goal is to ensure representation by reproductive health providers on MACs.

We also ask that CMS place strong safeguards around who can represent Medicaid reproductive health providers. In particular, we are concerned that some states, and particularly those working to ban or restrict rather than promote abortion access, may select so-called “crisis pregnancy centers” (CPCs). CPCs are unregulated anti-abortion, anti-contraception, and anti-LGBTQI+ nonprofits that falsely and deliberately market themselves as comprehensive reproductive health care clinics.²⁵

Requiring MACs to include reproductive health providers is also consistent with Secretary Becerra’s pledge to leave no stone unturned in efforts to protect access to reproductive health care, including abortion.²⁶

RECOMMENDATION: Amend § 431.12(d)(2) as follows and reletter remaining subparagraphs (C), (D), and (F) accordingly:

- (2) The remaining committee members must include representation of at least one from each of the following categories:
 - (A) State or local consumer advocacy groups or other community-based organizations that represent the interests of, or provide direct service, to Medicaid beneficiaries.
 - (B) Free legal services providers and the state’s Protection and Advocacy system.**
 - (CB) Clinical providers or administrators who are familiar with the health and social needs of Medicaid beneficiaries and with the resources available and required for their

²⁴ *Id.*

²⁵ Melissa N. Montoya et al., *The Problems with Crisis Pregnancy Centers: Reviewing the Literature and Identifying New Directions for Future Research* 14 INT. J. WOMEN’S HEALTH 757 (2022), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9189146/>.

²⁶ HHS, Remarks by Secretary Xavier Becerra at the Press Conference in Response to President Biden’s Directive following Overturning of *Roe v. Wade* (2022) <https://www.hhs.gov/about/news/2022/06/28/remarks-by-secretary-xavier-becerra-at-the-press-conference-in-response-to-president-bidens-directive-following-overturning-of-roe-v-wade.html>; see also HHS, Statement by HHS Secretary Xavier Becerra on President Biden’s Executive Order to Protect Access to Reproductive Health Care (2022), <https://www.hhs.gov/about/news/2022/07/08/statement-hhs-secretary-xavier-becerra-president-bidens-executive-order-protect-access-reproductive-health-care.html>.



care. This includes providers or administrators of primary care, specialty care, and long-term care. **MACs must also include reproductive health organizations.**

D. §§ 431.12(e) BENEFICIARY ADVISORY GROUP; (h) STATE AGENCY STAFF ASSISTANCE, PARTICIPATION, AND FINANCIAL HELP

MACs should center the voices of enrollees and provide support to maximize their participation. Enrollee perspectives and lived experience should not only be considered, but centered when making policy decisions related to Medicaid programs. The concept of involving affected populations in policy development dates back to the early days of the HIV/AIDS pandemic, when a group of people with AIDS demanded they “be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.”²⁷

We strongly support CMS’s proposal to establish the BAG, comprised of Medicaid enrollees, family members, and caregivers, that meets separately, but also operates within MAC. We urge CMS to further clarify that the BAG may issue recommendations, reports, and other findings independently of the MAC.

Enrollee engagement is essential to developing an effective Medicaid program and best practices include continued enrollee feedback. The people who actually use Medicaid for their health care are the real experts on how well the program functions. Membership should reflect the cultural, linguistic and racial composition and disability status of the Medicaid population. Moreover, enrollee engagement has historically resulted in informed policy decision-making with positive results.²⁸ For example, in preparation for Medicaid expansion, Massachusetts and Washington made intentional efforts to hear from enrollees directly, resulting in feedback that touched on cultural competency, the need for robust provider networks, and simplified appeals and grievance systems.²⁹ Through engagement, enrollees are empowered to become more involved in Medicaid program design and build a constituency of low-income and historically underserved people motivated to develop a successful Medicaid program.

²⁷ The Denver Principles (1983), https://data.unaids.org/pub/externaldocument/2007/gipa1983denverprinciples_en.pdf; See also, Miriam Lewis Sabin, *How the Denver Principles changed health care for everyone*, 401 *The LANCET* 2099 (Jun. 24, 2023).

²⁸ See, e.g., Renée Markus Hodin, *The Secret Sauce Is...Consumer Stakeholder Engagement*, 37 *GENERATIONS* 88, 89-91 (2013).

²⁹ Jane M. Zhu et al., *Engaging Consumers in Medicaid Program Design: Strategies from the States*, 99 *MILIBANK QUARTERLY* 99 (2021); see Edward Alan & Cynthia Rudder, *Engaging Consumers in Medicaid Nursing Home Reimbursement Policy: Lessons From New York and Minnesota*, 53 *GERONTOLOGIST* 627 (2013).



Engaging Medicaid enrollees and providing opportunities to meaningfully engage in BAG and MAC proceedings should be a priority. We support requirements to make MAC and BAG meetings accessible to people with disabilities and limited English proficiency (LEP) persons. State Medicaid agencies should provide staffing and other support for MAC and BAG proceedings.

We urge CMS to further clarify and strengthen state requirements to engage Medicaid enrollees, including providing transportation assistance, childcare, financial reimbursement, and varying meeting times and locations to allow participation of enrollees. For example, Vermont’s Medicaid and Exchange Advisory Committee provides a per diem and travel reimbursement for members whose participation is not supported through their employment.³⁰ Medicaid enrollees under 300% FPL also receive reimbursement for childcare and other expenses to allow their participation.³¹

Minnesota’s Health Services Advisory Council (HSAC) provides an “honorarium of \$200 per meeting and reimbursement for mileage and parking shall be paid to each council member in attendance except the medical director.”³² In addition, this honorarium applies to HSAC’s subcommittee, the Dental Services Advisory Committee, which has thirteen committee members including one consumer. DSAC committee members are given a \$200 honorarium plus reimbursement for mileage and parking.³³ Under state law, HSAC and its subcommittee, DSAC, require consumers to be a part of their committees and the honorarium and travel reimbursement provided per meeting facilitate that participation, however, it is unclear whether there are any additional protections provided to ensure that the honorarium is not qualified as income that could potentially interfere with members’ eligibility for public benefits.

CMS should provide guidance and technical assistance to states to ensure that compensation for enrollee participation in MAC and BAG does not compromise a person’s eligibility for Medicaid and other public benefits. For example, compensation may be provided in the form of cash, gift cards or contributions to a tuition or retirement saving account, which are treated as income.³⁴ If a person elects to receive compensation in the form of cash, the person must be

³⁰ VT. STAT. ANN. tit. 33, § 402(b)(3).

³¹ *Id.*

³² MINN. STAT. § 256B.0625, subdiv. 3e (2022)

³³ MINN. STAT. § 256B.0625, subdiv. 3c (2022)

³⁴ See, e.g., 82nd Oregon Legislative Assembly – 2023 Regular Session, House Bill 2650 (Apr. 2023), <https://olis.oregonlegislature.gov/liz/2023R1/Downloads/MeasureDocument/HB2650/A-Engrossed> (directing Oregon Department of Administrative Services to establish program for compensating eligible members of informal workgroups and task forces).



informed that receipt of cash compensation may be treated as income, which could impact eligibility for public benefits.³⁵

We also recognize that engaging Medicaid enrollees and caregivers in the MAC and BAG may be a challenge for states. Members of communities which have been historically maligned and marginalized might be skeptical, or even suspicious, of this new found interest in enrollee engagement. For example, due to historical experiences of medical abuses, communities of color—especially African Americans—have been reluctant to participate in clinical research.³⁶ CMS should provide additional guidance, technical assistance, and other resources to help states proactively recruit BAG members from under-represented groups.

E. § 431.12(f) MAC AND BAG ADMINISTRATION

CMS proposes to strengthen transparency, participation, and accountability by requiring states to publicly post MAC information, including meeting times, agenda, minutes, bylaws, the appointment process, as well as requiring public meetings, and providing for public comments. We strongly support these proposals.

Based on our review, some states already do a good job posting MCAC information, but information posted is not always consistent and is sometimes missing key information. For example, North Carolina posts meeting schedules, bylaws, and membership, and meeting minutes.³⁷ By contrast, New Mexico provides very little information on its MCAC.³⁸

³⁵ Under IRS rules, reimbursements for travel and other expenses are not considered income. However, honoraria, stipends, and compensation for missed wages could be taxable income that could affect financial eligibility for insurance affordability and other public benefit programs. See generally IRS Pub. 525, *Taxable and Nontaxable Income* (Feb. 7, 2023), <https://www.irs.gov/pub/irs-pdf/p525.pdf>.

³⁶ Autumn Tamlyn et al., *At the Intersection of Trust and Mistrust: A Qualitative Analysis of Motivators and Barriers to Research Participation at a Safety-net Hospital*, 26 HEALTH EXPECTATIONS 1118,1119 (2023). See also Lisa Shea et al., *Improving Diversity in Study Participation: Patient Perspectives on Barriers, Racial Differences and the Role of Communities*, 25 HEALTH EXPECTATIONS 1979 (2022); Alexandra García et al., *Community Engagement as a Foundation for Improving Neighborhood Health*, 38 PUB. HEALTH NURSING 223 (2021).

³⁷ NC Div. of Health Benefits, Medical Care Advisory Committee, <https://medicaid.ncdhhs.gov/meetings-notices/committees-and-work-groups/medical-care-advisory-committee> (last visited Jun. 15, 2023).

³⁸ NM Human Servs. Dept., Medicaid Advisory Committee, https://www.hsd.state.nm.us/about_the_department/medicaid-advisory-committee-overview/ (last visited Jun. 15, 2023).



Public participation in MAC and BAG regular and special meetings is one way to ensure that these important advisory groups can fulfill their goals. CMS should ensure that states post public notice in a timely manner all regular and special meetings times and locations, as well as minutes, draft minutes, reports (including minority reports), recordings, and other documents. States must also ensure that information on MAC and BAG operations is up to date.

Several states provide training and onboarding materials for MCAC members. For example, Iowa provides a legal overview for new members of state boards and commissions, although it is not specific to MCACs.³⁹ Virginia provides its MCAC members with a glossary of Medicaid acronyms and terms.⁴⁰ We urge CMS to develop training and onboarding materials for MAC and BAG members that states can use. The Health Resources Services Administration (HRSA) developed training materials for participants in the Ryan White Part A Planning Councils.⁴¹ The North Carolina Justice Center developed effective training materials for its Member Advisory Committee, including *Using Enrollee Experiences to Improve Medicaid Plans* and *How to Plan and Run an Accessible and Inclusive Meeting*, as the state moved Medicaid enrollees to managed care.⁴² CMS should produce something similar that states can adapt for their MAC and BAG programs.

We agree with CMS's proposal that states should vary meeting times and locations will enable participation from a fuller range of Medicaid stakeholders. We also strongly support requiring states to make MAC and BAG proceeding accessible for persons with disabilities and LEP individuals. While in-person attendance may be preferred, ensuring that all meetings have teleconference capabilities will allow for greater participation. Moreover, easy accessibility of meetings and information promotes community trust and leadership.

We recognize the challenge that the need for public participation and transparency may be obviated by the need for closed-door meetings of MAC and BAG. This may be particularly true of some BAG meetings, where Medicaid enrollees and caregivers may wish to share intimate

³⁹ See Pamela Griebel, Assistant Attorney General Director, Licensing and Adm. Law Div., Iowa Dept. of Justice, *Legal Overview for New Board and Commission Members* (2015), [https://hhs.iowa.gov/sites/default/files/Legal Overview for New Board and Commission Members.pdf](https://hhs.iowa.gov/sites/default/files/Legal%20Overview%20for%20New%20Board%20and%20Commission%20Members.pdf).

⁴⁰ VA Dept. of Med. Assistance Servs., DMAS MAC Glossary (2022), <https://www.dmas.virginia.gov/media/4506/dmas-mac-glossary.pdf>.

⁴¹ EGM Consulting, LLC, *Training Guide for RWHAP Part A Planning Councils/Planning Bodies: A Member's First Planning Cycle* (Feb. 2020), <https://targethiv.org/planning-chatt/training-guide> (last visited June 25, 2023).

⁴² See North Carolina Justice Center, *Member Advisory Committee (MAC) Training for Medicaid Managed Care*, <https://www.ncjustice.org/mac-training/> (last visited Jun. 28, 2023).



details of their health status and medical care. In addition, most states have open meetings laws that may apply to MACs and BAGs.

States should specify in their by-laws what meetings may be closed to the public. In some states, laws requiring open meetings might apply. For example, the DC Open Meetings Act permits only very narrow topics to be discussed in closed sessions, such as discussion of collective bargaining negotiations, trade secrets, and disciplinary matters.⁴³ Once in closed session, only these matters may be discussed. In other words, the executive session may not convene for one of the purposes enumerated in Section 2-575(b) and then move on to discuss other topics.⁴⁴

While we strongly favor open meetings, we think CMS's proposal to require a minimum of two public meetings, and optional open BAG meetings strikes a reasonable balance. Moreover, we strongly favor requiring states to provide a public comment period at MAC meetings.

F. § 431.12(g) MAC AND BAG PARTICIPATION AND SCOPE

The scope of MAC and BAG should extend to all aspects of a state's Medicaid program. We support CMS's proposal that MAC and BAG recommendations should not be limited to medical care, but includes other issues related to the effective administration of the program, including services, eligibility, care coordination, quality, communications, cultural competencies, and other issues. CMS should make clear that the scope of MAC and BAG advisory authority should extend to all aspects of a state's Medicaid program.⁴⁵

The timing of consultation is also important. CMS should clarify that the state Medicaid agency must consult with the MAC and BAG prior to making significant changes. In a 2002 court case, for example, Medicaid recipients charged that a MCAC did not review significant changes to eligibility policies and procedures prior to their submission to CMS.⁴⁶ State agency personnel had met with advocacy groups to share information, and a state legislative committee had previewed and approved the changes prior to their submission to CMS. In addition, an advisory committee that did not include a Medicaid recipient had been consulted after the fact and had reviewed various policy suggestions. The court found these actions to be no substitute for consultation with a duly constituted MCAC, because "[t]he requirement of

⁴³ See D.C. Code § 2-575(b).

⁴⁴ *Id.* § 2-575(d) ("A public body that meets in closed session shall not discuss or consider matters other than those matters listed under subsection (b) of this section.").

⁴⁵ See *Morabito v. Blum*, 528 F. Supp. 252, 263-67 (S.D.N.Y. 1981) "the scope of [MCAC's] advisory authority is intended to cover the entire field of state decision-making with respect to the Medicaid program, and is not limited to discrete areas of concern."

⁴⁶ *Rosen v. Tennessee Com'r of Finance and Administration*, 280 F. Supp. 2d 743 (M.D. Tenn. 2002), opinion set aside on other grounds, 2003 WL 22383610 (M.D. Tenn. Oct 14, 2003),



consultation with persons knowledgeable about the needs of the beneficiary population is not a meaningless formality.”⁴⁷ The court held that the MCAC’s input had to be sought and received before the date of the action in question, not after the fact, and that the failure to properly consult the MCAC invalidated any attempt by the agency to effect the policy change.⁴⁸

Additional courts have found that, where consultation with the MCAC is required, the committee's input must be sought and received before the state action in question, not after the fact. As stated in *Morabito*: “The requirement of prior consultation is rooted in the fact that medical care advisory committees are purely advisory in nature, having no power either to ratify or to veto any action that the state Medicaid agency proposes to take”⁴⁹ The proposed rule helps clarify these issues which have been a source of litigation.

In addition to prior consultation, we urge CMS to specifically require MAC and BAG consultation with other Medicaid advisory groups. These include the member advisory committees required for states when long term services and supports (LTSS) are delivered through a managed care program, and of managed care entities LTSS.⁵⁰ The MAC and BAG should also consult with the proposed Parties Advisory Group.⁵¹ The MAC and BAG should coordinate with the state’s Drug Utilization Review Board and Medicaid Pharmacy and Therapeutics Committees.⁵² We also recommend that CMS address the intersection between

⁴⁷ 280 F. Supp. 2d at 823.

⁴⁸ *Id.* at 825.

⁴⁹ 528 F. Supp. at 264-65. See also, e.g., *Benton v. Rhodes*, 586 F.2d 1, 3 (6th Cir. 1978); *Jennings v. Alexander*, Medicare & Medicaid Guide (CCH), ¶ 30,735 (M.D.Tenn. Sept. 3, 1980); *Becker v. Toia*, 439 F. Supp. 324, 332-33 (S.D.N.Y. 1977); *Ho v. Chang*, Medicare & Medicaid Guide (CCH), ¶ 28,433 (D.Haw. Apr. 27, 1977); *Robinson v. Maher*, Medicare & Medicaid Guide (CCH), ¶ 27,707 (D.Conn. Jan. 19, 1976). See also *Visiting Nurse Ass’n of North Shore, Inc. v. Bullen*, 93 F.3d 997, 1010 n.14 (1st Cir.1996) (noting that case law under § 431.12 “suggests that States should undertake their [MCAC] consultations as early in the Plan amendment process as practicable, preferably before any final decision on proposed changes to their reimbursement methodologies,” and that it is reasonable to think that “[MCAC] consultation is sufficient as along [sic] as it occurs before final HCFA approval of the Plan amendment”). Compare *Mississippi Hosp. Ass’n v. Heckler*, 701 F2d. 511, 523 (5th Cir. 1983). (“Conceivably the complete absence of an MCAC or one that is improperly constituted or exists in name only, or in the failure to consult the committee on a fundamental policy change in a reimbursement plan, might contravene the vague requirement in 42 C.F.R. § 431.12(e) that “[t]he committee must have the opportunity for participation in policy development and program administration, including furthering the participation of recipient members in the agency program.”)

⁵⁰ 45 C.F.R. §§ 438.70, 110.

⁵¹ Proposed § 447.203(b)(b).

⁵² See 42 U.S.C. § 1396r-8(g)(3), authorizing the Drug Utilization Review Board; 42 U.S.C. § 1396r-8 (d)(4)(A), providing for the establishment of formularies. These committees are often called Pharmacy and Therapeutics (P&T) committees. See National Academy for State Health



the “Interested Parties Advisory Group” (IPAG) proposed in § 447.203(c)(1). As stated below, while we support the creation of two separate groups, the IPAG appears to have a relatively limited role to recommend and approve rates, while the BAG must be able to identify ongoing issues with access and request and receive corrective active when access barriers are identified.

CMS should also require meetings between BAG members and the director of the single state agency on a quarterly basis, and provide for regular meetings between BAG and CMS regional authorities.

RECOMMENDATION: Amend § 431.12(g) as follows

(g) MAC and BAG participation and scope. The MAC and BAG participants must have the opportunity to participate in and provide recommendations to the State agency on **any** matters-related to the **State’s Medicaid program, including** policy development and matters related to the effective administration of the Medicaid program. **The State shall consult with the MAC and BAC prior to making significant changes to the program.** At a minimum, the MAC and BAG must determine, in collaboration with the State, which topics to provide advice on related to--

G. § 431.12(i) ANNUAL REPORT

We support CMS’s proposal to require annual reports on MAC and BAG activities, produced with state support, and with state responses to recommendations. State Medicaid agencies should not lead reporting process or limit the recommendations of MAC and BAG members. CMS should hold states accountable to ensure that agencies fulfil the requirements related to MACs and BAGs. CMS should also conduct a readiness review to certify state compliance and implement a corrective action plan for states that fail to meet these requirements.

In addition, the annual MAC report should address compliance with these other responsibilities, including:

- reviewing Medicaid managed care marketing materials;⁵³
- reviewing the state’s Medicaid managed care program report;⁵⁴

Policy (NASHP), *State Experience in Creating Effective P&T Committees* (March 2006), https://eadn-wc03-6094147.nxedg.io/cdn/wp-content/uploads/sites/default/files/medicaid_pandt.pdf. See also 45 C.F.R. § 156.122(a)(3), requiring P&T Committees for plans subject to Essential Health Benefits.

⁵³ 42 U.S.C. § 1396u-2(d)(2)(A)(ii); 42 C.F.R. § 438.104(c).

⁵⁴ 42 C.F.R. § 438.66(e)(3)(ii).



- providing input on the state’s managed care quality rating system;⁵⁵
- drafting and revising the state’s quality strategy;⁵⁶ and
- public notice and hearing requirements for § 1115 demonstration projects.⁵⁷

§ 441.301(c)(1) Person-centered service plans

We support the proposal that states ensure reassessments of functional need and updates to the person-centered plan take place at least every twelve months. We also support the standard that the state must demonstrate that this must be done 90% of the time, but add that care must be taken to avoid “clustering.” A state should not be considered compliant if the same individuals do not receive timely evaluations or updated plans repeatedly. States should track whether this is the case, and if so, be required to implement corrective action.

To protect enrollees’ health and welfare, as well as their due process rights, the regulations should explicitly state that if a state fails to complete an assessment and person-centered service plan within twelve months, the enrollee’s services should continue. Services should not be suspended due to a state’s failure to comply with the person-centered service planning requirements.

RECOMMENDATION: Amend § 441.301(c)(3)(i) to insert the following language at the end of the sentence:

A beneficiary’s services shall not be reduced, suspended, or terminated due to the State’s failure to comply with the reassessment of functional need or review of the person-centered service plan within the specified timeframe.

We support the application of the person-centered planning requirements to §§ 1915(i), (j), and (k) authority. We agree that at this time it may be difficult to apply the twelve-month reassessment and planning timeframe to § 1905(a) services because of a lack of congruence in various assessment and planning requirements across § 1905(a) services. However, as noted elsewhere in these comments, § 1905(a) remains an important source of coverage for HCBS, particularly for children and individuals with psychiatric disabilities, and in certain states.⁵⁸ Therefore, we suggest that in the future CMS revisit the assessment and planning process for HCBS delivered under § 1905(a).

⁵⁵ 42 C.F.R. § 438.344(c)(2)(i).

⁵⁶ 42 C.F.R. § 438.340(c)(1)(i).

⁵⁷ 42 C.F.R. § 431.408(a)(3)(i).

⁵⁸ *Infra* at 21-23, discussion of proposed § 441.302(a)(6).



We propose an effective date of two years after the date of enactment, not three. The requirement to conduct assessments to update person-centered service plans is not new, and therefore states should already have systems in place to track the timeliness of assessments and the person-centered planning process.⁵⁹ CMS is simply updating the performance metric and ensuring consistent application of the person-centered planning requirement across states. States should be able to comply with this requirement in two years.

§ 441.301(c)(7) Grievance system

We support CMS’s proposals to mandate an HCBS grievance system, particularly the provisions of the proposed rule that call for protections from retribution, establish conflict of interest protections and a pathway for expedited resolutions, and require states to inform enrollees about their rights and the grievance process. We also support the references to ensuring the availability of language services and auxiliary aids and services, but the repeated references to the regulations at § 435.905(b) may suggest that these accessibility services might NOT be necessary outside of the specific provisions for which they are listed. Perhaps it would be more efficient to write a separate provision related to language and disability access under the general requirements for the grievance system and specify that it applies to all components of the grievance system.

We have several other recommendations to strengthen this grievance system proposal. First, we recommend that CMS clarify the difference between issues that are appropriate for a grievance and those that constitute an “adverse action” where a person has a right to a fair hearing.⁶⁰ In the managed care regulations, a grievance is defined as “an expression of dissatisfaction **about any matter other than an adverse benefit determination.** . . .”⁶¹ (emphasis supplied). We recommend adding language to the definition of a grievance in proposed 301(c)(7)(ii) to ensure that enrollees do not mistakenly file grievances about issues that are adverse benefit decisions and that entitle them to a fair hearing. We also suggest that if an enrollee mistakenly grieves an adverse benefit determination, that the grievance be treated as a fair hearing request unless the enrollee objects.

Second, we recommend shortening the response time for grievances to 45 days. Enrollees can grieve about essential rights, such as a failure to follow the person-centered planning process or a violation of the HCBS settings rule. Ninety days is too long for an individual to

⁵⁹ CMS, Modifications to Quality Measures and Reporting in § 1915(c) Home and Community-Based Waivers (March 12, 2014), https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/3-cmcs-quality-memo-narrative_0_133.pdf.

⁶⁰ 42 C.F.R. § 431.201.

⁶¹ 42 C.F.R. § 438.400(b)



wait for resolution, especially if they request an expedited decision and that request is not granted.

Finally, having a system in place to identify systemic problems from the ground up, and in real time, is a critical component of an effective oversight system. We have previously recommended that states implement HCBS ombuds programs that have the responsibility to address individual's problems while periodically identifying and publicly reporting systemic issues they encounter in the course of their work. While such a system may not yet be in place in fee for service (FFS) Medicaid, we believe that reporting on grievances would benefit from a qualitative, not just quantitative approach. For example, it would be valuable to have an independent evaluator periodically review the grievance process to identify common barriers, trends, participation rates, effectiveness of resolutions, and more. We would recommend this in addition to the proposed requirements for quantitative reporting.

There are provisions in this FFS grievance system—such as the expedited resolution pathway and the provision protecting enrollees from retribution—that are not available in the managed care grievance process. We appreciate that CMS's goal is to align HCBS beneficiary protections across Medicaid delivery systems. To avoid fragmentation, we strongly recommend that CMS update the managed care grievance process to include these protections in the managed care final rule, as well as any other inconsistencies CMS might identify in your review.

§ 441.302(a)(6) – Incident Management System

We support the proposed incident management system. An HCBS system that is responsive to the needs and choices of enrollees and maximizes access to the community must be a safe setting, free from abuse and neglect.

We support having a uniform definition of “critical incidents.” We additionally suggest that CMS define the term “neglect” to ensure the phrase is interpreted broadly. Neglect should encompass a failure to act or an omission that causes or is likely to cause emotional, physical, sexual, financial, or psychological harm.

We also support the application of this provision to both managed care and fee for service delivery systems. We agree that from the enrollee perspective there is no meaningful difference between abuse and neglect perpetrated by a provider paid via managed care or a provider paid via FFS. Furthermore, examples abound of problems in both managed care and FFS settings.⁶²

⁶² See generally, Gov't Accountability Office, *Medicaid Long-term Services and Supports: Access and Quality Problems in Managed Care Demand Improved Oversight* 19 (Nov. 2020)

We appreciate CMS increasing the minimum performance level for this metric to 90%. We agree that the expectation should be that states “meet State-specified timeframes for initiating investigation, completing investigations, and determining resolution, and completing corrective action plans for *all* critical incidents,” and do not support any “good cause exceptions” to this metric.⁶³

We recommend that CMS set minimum timeframes for state corrective action. The minimum timeframe should not be left completely to state discretion.

A. **STRATEGIES TO STRENGTHEN CRITICAL INCIDENT REPORTING, INVESTIGATION, RESOLUTION, AND CORRECTIVE ACTION**

It will continue to be challenging to ensure that all critical incidents are reported, because providers may be reluctant to report incidents where employees may have acted in a way that exposes them to liability. Because of this, we support the proposed requirement to use claims data, Medicaid fraud control unit data, and data from other state agencies to identify unreported critical incidents. However, we are still concerned that the provision relies too heavily on the provider self-reporting critical incidents, and therefore incidents may be underreported. We offer two additional suggestions to promote accurate reporting and resolution of critical incidents.

First, the regulations should clarify that a critical incident may be reported by anyone directly to the State. While providers *must* report critical incidents to the state, enrollees and other interested parties *may* report incidents directly, and the timeframes for compliance should be triggered by these direct reports. Such a process is particularly important for verifying that providers are reporting all critical incidents.

RECOMMENDATION: Amend § 441.302(a)(6) to add a new subparagraph after subparagraph (C), and reletter the remaining subparagraphs as necessary:

(audit finding that an Arizona MCO failed to report serious incidents like sexual assaults or attempted suicide), <https://www.gao.gov/assets/gao-21-49.pdf>; see also *KanCare MLTSS Review Corrective Action Plan* (2017), http://kslegislature.org/li_2018/b2017_18/committees/ctte_s_phw_1/documents/testimony/20170123_06.pdf (Kansas corrective action plan noting that the MCOs did not have processes in place to track the use of unauthorized restrictive interventions, that the three different MCOs defined critical incidents differently and reported highly varying numbers of incidents to the state, and that providers, advocates, and members indicated that they often did not receive solution regarding incidents).

⁶³ 88 Fed. Reg. at 27980.



The State must accept critical incident reports directly from beneficiaries or other interested parties. The State must establish a process to accept such reports, and the process must allow reports to be made orally or in writing. The State must acknowledge receipt of the report, and must ensure that punitive action is neither threatened nor taken against any individual who makes a report in good faith.

Second, we are concerned that states may not take corrective action when necessary. While we recognize that there is a requirement that states initiate an investigation within State-specified timeframes, we are concerned that states might have an incentive not to categorize incidents as “critical.” We therefore also suggest that providers report critical incidents to the designated Protection & Advocacy (P&A) system for the state when such incidents are reported to the state. Federal law establishes that P&As “have the authority to investigate incidents of abuse and neglect of individuals with developmental disabilities if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred.”⁶⁴ Reporting to the P&A helps ensure that the State responds appropriately and acts with sufficient urgency to prevent further harm.

This additional reporting should constitute a minimal burden on providers, and no additional burden for the state. This proposal has precedent—it is consistent with the requirement for psychiatric residential treatment facilities (PRTFs) that such facilities report “serious occurrences” to the P&A.⁶⁵ The PRTF reporting requirement has been implemented now for over a decade. P&As have experience receiving such reports, and have appropriate processes in place to receive such reports and address any confidentiality concerns.

RECOMMENDATION: Amend § 441.302(a)(7) to add a new subparagraph after subparagraph (D) as follows, and reletter the remaining subparagraphs as necessary:

Send critical incident reports to the State-designated Protection and Advocacy system at the same time such reports are submitted to the State. The notification to the P&A must at a minimum include the name of the beneficiary involved in the critical incident, a description of the incident, and the name, street address, and telephone number where the critical incident took place and where the beneficiary resides, and any other information submitted to the State.

⁶⁴ 42 U.S.C. § 15043; see also 42 U.S.C. § 10801 (“The purposes of this chapter are . . . to assist States to establish and operate a protection and advocacy system for individuals with mental illness which will . . . investigate incidents of abuse and neglect of individuals with mental illness if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred.”).

⁶⁵ 42 C.F.R. § 483.374(b).

B. APPLICATION OF CRITICAL INCIDENT REPORTING REQUIREMENT TO § 1905(A) STATE PLAN SERVICES

The proposed rule excludes from the incident management system § 1905(a) state plan services. We believe that the incident management system should encompass all HCBS, and not just those services delivered under §§ 1915(c), (i), (j) and (k). We disagree that § 1905(a) services should be excluded because “only a small percentage of HCBS nationally is delivered under § 1905(a) State plan authorities.”⁶⁶

First, in 2020, approximately 20% of all HCBS expenditures are for state plan personal care services (PCS) and home health aide services authorized under § 1905(a).⁶⁷ Twenty percent is not a small percentage. In that same timeframe, almost two million people received 1905(a) state plan home health aide and personal care services.⁶⁸

Furthermore, under Medicaid’s Early and Periodic Screening, Diagnostic and Treatment benefit for children, children should receive the vast majority of HCBS via § 1905(a). CMS has repeatedly stated that pursuant to the EPSDT mandate, if a service can be authorized under the state plan, it may not be authorized under a waiver.⁶⁹ Thus, for children in particular, it is important to include state plan services to ensure the health and welfare of children, who more likely receive services authorized via § 1905(a).

Second, while the majority of HCBS for individuals with intellectual disabilities, developmental disabilities, and physical disabilities may be authorized via §§ 1915(c), (i), (j), and (k), it is much rarer for states to use such authorities to authorize HCBS for individuals with psychiatric

⁶⁶ 88 Fed. Reg. at 27981.

⁶⁷ Kaiser Fam. Found, *State Health Facts: Medicaid HCBS Spending, By Authority* (\$, in thousands), <https://www.kff.org/health-reform/state-indicator/home-health-expenditures/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> (For purposes of this chart, “total HCBS spending” is defined as the total spent for 1905(a) home health services, 1905(a) personal care services, § 1915(k) services, § 1915(i) state plan services, and §§ 1915(c) and 1115 waivers) [hereinafter Kaiser HCBS Spending by Authority].

⁶⁸ Kaiser Fam. Found., *State Health Facts: People Receiving Medicaid HCBS, by Authority* (2020), <https://www.kff.org/health-reform/state-indicator/home-health-participants/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>.

⁶⁹ CMS, *EPSDT – A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents* 26 (2014), https://www.medicaid.gov/sites/default/files/2019-12/epsdt_coverage_guide.pdf; CMS, *Application for a § 1915(c) Home and Community-Based Waiver [Version 3.6, January 2019] Instructions, Technical Guide and Review Criteria* 131 (2019), https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf;



disabilities.⁷⁰ As of 2020, of the 267 § 1915(c) and § 1115 HCBS waivers in existence, only 14 of them—or 5% of the total—targeted individuals with mental illness.⁷¹ In 2020, only six states had § 1915(i) state plan amendments that target individuals with mental illness.⁷² Even though Medicaid is the biggest funder of mental health services, most of that funding does not flow through §§ 1915(c), (i), (j) or (k) authority.

Instead, many services for individuals with mental health conditions are provided under the category of “rehabilitative services,” pursuant to § 1905(a)(13). This is why the American Rescue Plan defined home and community-based services as including: “(vi) Rehabilitative services, including those related to behavioral health, described in section 1905(a)(13) of such Act.”⁷³

For incident reporting, CMS adhere to the definition of HCBS in § 9817 of the American Rescue Plan Act. We recognize that there may be some burden on states that do not already have systems in place to collect data and report on state plan services, but if CMS never requires a state to develop such reporting mechanisms, the argument is circular. Again, for an enrollee who has experienced a critical incident at the hands of a provider, it matters very little whether the service is provided via state plan or other authority. The risk of leaving out large groups of enrollees with disabilities—including most children and many adults with psychiatric disabilities—counsels against excluding § 1905(a) from critical incident reporting. Therefore, we recommend applying the requirement to § 1905(a) services, but allowing states to have an additional year to implement the requirement for § 1905(a) services.

⁷⁰ Medicaid & CHIP Payment & Access Comm’n, *Behavioral health services covered under HCBS waivers and 1915(i) SPAs*, <https://www.macpac.gov/subtopic/behavioral-health-services-covered-under-hcbs-waivers-and-spas/> (last visited June 19, 2023).

⁷¹ Molly O’Malley Watts et al., Kaiser Fam. Found., *State Policy Choices About Medicaid Home and Community-Based Services Amid the Pandemic* (2022), <https://www.kff.org/report-section/state-policy-choices-about-medicaid-home-and-community-based-services-amid-the-pandemic-issue-brief/#endnote-link-548748-14>.

⁷² *Id.* According to Kaiser Family Foundation, in fiscal year 2020, six states had § 1915(i) state plan amendments to support individuals with mental illness. These states are Arkansas, Idaho, Indiana, Iowa, Ohio, and Texas. In addition, Maryland has operated a § 1915(i) for children with serious emotional disturbance since 2014, and in 2020, North Dakota added a § 1915(i) state plan option to support adults with serious mental illness. See Maryland Medicaid State Plan, Attachment 3.1 (effective October 19, 2019), <https://health.maryland.gov/mmcp/Documents/State%20Plan/2023/Current%20Attachments%203.1B%20to%203.2%205%2031%2023.pdf>; North Dakota State Plan Amendment 20-0010 (effective October 1, 2020), <https://www.medicaid.gov/medicaid/spa/downloads/ND-20-0010.pdf>.

⁷³ The American Rescue Plan of 2021 § 9817, Pub. L. No. 117-2, 135 Stat. 4, <https://www.congress.gov/bill/117th-congress/house-bill/1319/text>.

§ 441.302(k) – HCBS payment adequacy

A. INTRODUCTION

We support the requirement that a percentage of total payments for certain services be spent on direct care worker compensation. HCBS direct care workers perform difficult, and extremely important, work. Ensuring fair wages is the best way to keep pace with the growing demand for high-quality HCBS care.

Historically, direct care services have been undervalued and undercompensated. HCBS direct care workers often work for low-wages and limited benefits, while turnover is typically very high.⁷⁴ In 2021, median hourly wages for an HCBS direct care worker were just \$14.09 an hour nationally, while turnover rates exceeded 60% in these positions.⁷⁵ Medicaid's typically low reimbursement rates suppress wages and impede recruitment and retention.⁷⁶ This directly contributes to chronic workforce shortages that negatively affect the availability and quality of care.

1. **Equity**

Poor wages and benefits for direct care workers stem from decades of discrimination and bias. Historically, labor laws have done very little to provide any protections for domestic workers, including home health workers, a pool composed primarily of women of color.⁷⁷ In 1938, the Fair Labor Standards Act (FLSA) established basic protections such as overtime pay, sick leave, and hazard pay, but excluded domestic and agricultural workers, a workforce that was

⁷⁴ Medicaid & CHIP Payment & Access Comm'n, *Issue Brief: State Efforts to Address Medicaid Home- and Community-Based Services Workforce Shortages* 1 (March 2022), <https://www.macpac.gov/wp-content/uploads/2022/03/MACPAC-brief-on-HCBS-workforce.pdf> [hereinafter MACPAC HCBS Issue Brief].

⁷⁵ PHI, *Direct Care Workers in the United States: Key Facts 2* (2022), <https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-3/> [hereinafter PHI Direct Care Workers 2022]; PHI, *Key Facts and FAQ: Understanding the Direct Care Workforce*, <https://www.phinational.org/policy-research/key-facts-faq/>.

⁷⁶ President's Comm. For People with Intellectual Disabilities, *Report to the President 2017: America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy* 20 (2017), https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF [hereinafter Report to the President 2017].

⁷⁷ Lisa I. Iezzoni et al., *Historical Mismatch Between Home-Based Care Policies And Laws Governing Home Care Workers*, 38 HEALTH AFF. 973 (2019), <https://www.healthaffairs.org/doi/10.1377/hlthaff.2018.05494>.



disproportionately made up of southern Black workers.⁷⁸ These racist exclusions, promoted at the time by white Southern Democrats in an attempt to preserve the legacy of slavery, have contributed to the low wages and difficult working conditions that still exist today.⁷⁹ The 1971 safety standards established by the Occupational Safety and Health Administration again excluded domestic workers from these basic protections, even though research demonstrates that direct care work can lead to frequent injuries.⁸⁰

The HCBS workforce is composed primarily of Black Indigenous and People of Color (BIPOC) women.⁸¹ Current statistics indicate that nearly 85% of HCBS direct care workers are women, 27% are Black, and 23% are Hispanic or Latino (any race). Over 30% are immigrants. Forty-three percent of the workforce lives in low-income households. Over 40% of direct care workers rely on public health coverage, primarily Medicaid, while 16% have no health insurance.⁸² In 2013, the Department of Labor's Home Care Rule finally extended the FLSA's minimum wage and overtime laws to domestic workers, including nearly 1.9 million HCBS direct care workers, effective January 1, 2015.⁸³ Despite the changes made by the Home Care Rule, a recent GAO report found that these changes have not improved HCBS direct care workers' earnings relative to other professions with similar educational requirements.⁸⁴

The COVID-19 pandemic was particularly difficult for HCBS direct care workers. Many direct care staff worked long hours, without adequate personal protective equipment (PPE), often serving clients who were isolated from family and friends.⁸⁵ The hands-on nature of direct-care

⁷⁸ *From Excluded to Essential: Tracing the Racist Exclusion of Farmworkers, Domestic Workers, and Tipped Workers from the Fair Labor Standards Act Before the Subcomm. on Workforce Protections of the H. Comm. on Educ. and the Workforce*, 117th Cong. 2-5 (2021) (statement of Rebecca Dixon, Executive Director, National Employment Law Project).

⁷⁹ Marc Linder, *Farm Workers and the Fair Labor Standards Act: Racial Discrimination in the New Deal*, 65 TEX. L. REV. 1335 (1987).

⁸⁰ See e.g., Eileen Borris, *When the Home is a Workplace*, DISSENT, (Apr. 16, 2020), https://www.dissentmagazine.org/online_articles/when-the-home-is-a-workplace; HHS, NIOSH Hazard Review: Occupational Hazards in Home Health Care (2010), <https://www.cdc.gov/niosh/docs/2010-125/pdfs/2010-125.pdf>.

⁸¹ PHI Direct Care Workers 2022, *supra* note 75, at 6.

⁸² PHI Direct Care Workers 2022, *supra* note 75, at 6.

⁸³ Application of the Fair Labor Standards Act to Domestic Service, 78 Fed. Reg. 60454 (Oct. 1, 2013).

⁸⁴ U.S. GOV'T ACCOUNTABILITY OFF., GAO-21-72, FAIR LABOR STANDARDS ACT: OBSERVATIONS ON THE EFFECTS OF THE HOME CARE RULE 5 (2020), <https://www.gao.gov/assets/gao-21-72.pdf>.

⁸⁵ Shaun Heasley, *COVID-19 Taking a Toll on Direct Support Professionals*, DISABILITY SCOOP (Aug. 14, 2020), <https://www.disabilityscoop.com/2020/08/14/covid-19-taking-a-toll-on-direct-support-professionals/28729/>; Eli Cahan, *Most Home Health Aides 'Can't Afford Not to Work' – Even When Lacking PPE*, KAISER HEALTH NEWS (Oct. 16, 2020), <https://khn.org/news/mostly-poor-minority-homehealth-aides-lacking-ppe-share-plight-of-vulnerable-covid-patients/>.

work made social distancing difficult and many became sick or had to quarantine. Additionally, many direct care workers who were parents struggled to find appropriate child care throughout the crisis.⁸⁶ As a result of the pandemic, many direct service workers reported anxiety, depression, difficulty sleeping and emotional burn-out.⁸⁷

HCBS direct care workers' labor keeps people with disabilities out of institutions and in their homes and communities. Demand for caregiving is increasing as our population ages, yet for far too long the value of these positions has not been properly recognized or compensated. The difficult conditions caused by low wages are hard on workers and can lead to poor outcomes for HCBS participants. Raising wages and benefits and improving working conditions represents a critical step to correct the historical exploitation of these workers and help ensure safe and high quality care for HCBS recipients.

2. **Insufficient rates are inextricably linked to poor access and quality**

Low wages and poor benefits are directly tied to both the availability and the quality of HCBS services. Though the demand for HCBS services continues to grow, workforce shortages have forced many providers to cut services and turn away clients.⁸⁸ High rates of turnover in direct support staffing threaten the health and safety of individuals with intellectual and developmental disabilities (I/DD).⁸⁹ Inconsistent staffing can lead to gaps in care and reduce the independence and overall quality of life for individuals receiving services.⁹⁰ Staffing instability can make it difficult for people with disabilities or older adults to form strong, ongoing relationships with their caregivers, requiring clients or families to constantly orient new staff and establish clear communication. Turnover can put clients at risk of inappropriate care and

⁸⁶ Elizabeth Edwards, David Machledt & Jenifer Lav, *Retaining Medicaid COVID-19 Changes to Support Community*, 14 ST. LOUIS U. J. HEALTH L. & POL'Y 391, 405 (2021), <https://scholarship.law.slu.edu/jhlp/vol14/iss2/10/>.

⁸⁷ ANCOR Foundation & United Cerebral Palsy, *The Case for Inclusion 2023* 14 (2023), https://caseforinclusion.org/application/files/7316/7753/8320/The_Case_for_Inclusion_2023_Making_Good_on_Our_Nations_Promise_of_Community_Inclusion_for_All.pdf.

⁸⁸ MACPAC Issue Brief, *supra* note 74, at 4.

⁸⁹ Carly Friedman, Council on Quality & Leadership, *The Impact of Direct Support Professional Turnover on the Health and Safety of People with Intellectual and Developmental Disabilities* 10-12 (2020), <https://www.c-q-l.org/wp-content/uploads/2021/03/CQL-2021-Research-DSP-Turnover-Impact-Health-Safety-Friedman.pdf>.

⁹⁰ Report to the President 2017, *supra* note 76, at 20.



adverse outcomes.⁹¹ Conversely, continuity of HCBS direct care staff has been shown to improve quality of care.⁹²

The only way to truly satisfy the growing demand for high-quality HCBS services is to increase wages for HCBS direct care workers to bolster recruitment and reduce turnover. Direct care workers frequently cite higher wages and improved benefits as the two most important factors in improving their jobs and helping to reduce constant turnover.⁹³ A recent study by Leading Age found that even a modest increase of around 15% in direct care workers' wages could significantly reduce staff turnover and improve continuity and quality of care.⁹⁴

B. THE PROPOSED DIRECT CARE WORKER MINIMUM COMPENSATION OF 80% IS REASONABLE

Despite broad and longstanding calls to increase pay for HCBS direct care workers, wages remain very low, only marginally outpacing inflation in the last decade. The inflation-adjusted median hourly wage increased from \$11.43 in 2011 to \$14.09 in 2021.⁹⁵

Guaranteeing a true living wage for direct care workers will require two necessary components. First, states need to build their rates based on living wage labor cost models that factor in reasonable and transparent ancillary administrative and program support expenses to arrive at a final rate.⁹⁶ Raising overall rates will prevent squeezing providers into the red or

⁹¹ Kezia Scales, *Meeting the Integration Mandate: The Implications of Olmstead for the Home Care Workforce*, 27 GEO. J. ON POVERTY L. & POL'Y 261, 277 (2020), <https://www.law.georgetown.edu/poverty-journal/wp-content/uploads/sites/25/2020/06/05-Scales.pdf>.

⁹² Joanne Spetz et al., *Home And Community-Based Workforce For Patients With Serious Illness Requires Support To Meet Growing Needs*, 38 HEALTH AFF. 902 (2019), <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2019.00021>.

⁹³ Mandar Bodas et al., *Will States Use 'Rescue Plan' Funding To Give Direct Care Workers A Raise?* HEALTH AFF, FOREFRONT (2021), <https://www.healthaffairs.org/content/forefront/states-use-rescue-plan-funding-give-direct-care-workers-raise> [hereinafter Health Affairs Rescue Plan Funding Raises].

⁹⁴ Christian Weller et al., Leading Age, *Making Care Work Pay: How Paying at Least a Living Wage to Direct Care Workers Could Benefit Care Recipients, Workers, and Communities* (2020), <https://leadingage.org/wp-content/uploads/drupal/Making%20Care%20Work%20Pay%20Report.pdf>.

⁹⁵ PHI Direct Care Workers 2022, *supra* note 75, at 9 (noting that this means HCBS direct care workers' wages have increased slightly more than the cost of goods and services in the last decade).

⁹⁶ Christian Weller et al., *Making Care Work Pay: How A Living Wage For LTSS Workers Benefits All*, HEALTH AFF, FOREFRONT (2020),



forcing them to cut costs in other key areas, like transportation. Second, there needs to be a mechanism to ensure that money directed to worker compensation actually makes its way into the workers' pockets. HCBS rate increases have not always resulted in corresponding higher wages for HCBS direct care workers.⁹⁷ While some states require 75 to -100% of rate increases pass through to direct care workers, others provide no such mandate at all.⁹⁸ Recently, New York's legislature passed a bill that raises the minimum wage for direct care workers to \$18 per hour in October 2023 and also increased the State's personal care rate, but providers have complained that managed care plans are pocketing that increase even as providers' labor costs have gone up.⁹⁹ For these reasons, we support a state-level requirement that a percentage of the total payments for a service be spent on direct care worker compensation, and we support transparent rate-building methodologies that reflect the true cost of delivering quality care.

1. States have already implemented similar policies

There may be other mechanisms to ensure that states' HCBS dollars are efficiently spent on actual service delivery, but setting a percentage wage threshold has been relatively well established. As the proposed rule notes, several states, including Minnesota and Illinois, have passed requirements to ensure that a set percentage of payments go directly to direct care worker compensation.¹⁰⁰ Since 2000, a voluntary program for home care providers in Texas provides an enhanced rate if the provider achieves a 90% threshold of funding going toward attendant compensation (including mileage reimbursement).¹⁰¹ Many more states have applied percentage pass through requirements to rate **increases**. Values range from 75% for HCBS

<https://www.healthaffairs.org/content/forefront/making-care-work-pay-living-wage-ltss-workers-benefits-all>.

⁹⁷ Health Affairs Rescue Plan Funding Raises (noting that, for example, “[w]hile 35 states have used Medicaid policy actions to increase payment rates for HCBS during the pandemic, provider rate increases do not necessarily get passed on to DCWs as an increase in pay or benefits.”);

⁹⁸ Ruqaiyah Yearby et al., Inst. for Healing Justice & Equity, *Direct Care Worker Wage Pass-Through Law Final Report* (2020), <https://ihje.org/wp-content/uploads/2020/12/Direct-Care-Worker-Wage-Pass-Through-Law-Final-Report-September-2020-Institute-of-Healing-Justice-and-Equity.pdf> (review and summary of 22 states that have wage pass-throughs).

⁹⁹ Patrick Filbin, *New York's Mandated Home Care Wage Increases 'Haven't Actually Addressed The Issue'*, HOME HEALTH CARE NEWS (2023),

<https://homehealthcarenews.com/2023/02/new-yorks-mandated-home-care-wage-increases-havent-actually-addressed-the-issue/>.

¹⁰⁰ 88 Fed. Reg. 27984 fn. 82.

¹⁰¹ Tex. Dept. Health & Human Servs., *Rate Enhancement Programs – Open Enrollment Presentation 13* (2022), <https://pfd.hhs.texas.gov/sites/rad/files/documents/long-term-svcs/2022/2022-enroll-trng-ppt.pdf>.



workers in Indiana and to the full value of the rate increase going to direct care worker compensation in California, Utah, and Rhode Island, with several states in between.¹⁰²

These examples show that the 80/20 percentage CMS has proposed is well within the range of percentages that states have already utilized to help ensure an appropriate share of service payments flow to direct care work. We therefore support the 80% threshold as a starting point, but also recognize that creating a rate model with a fair percentage will require transparent rate methodologies and attention to detail.

2. Wage pass-throughs based on percentages will only work with transparent data on the true costs of delivering homemaker, home health, and personal care services.

Publicly available rate models do not provide enough consistent data about non-compensation costs to provide a clear picture of what an aggregate percentage threshold would look like.¹⁰³ We recommend that in the final rule and future guidance CMS work to standardize definitions of what specific expenses fall into the buckets of transportation, administrative costs, and program support. Clearer definitions of these categories will make it easier for the interested parties advisory group to provide meaningful input into what is an adequate rate. It will also make rates easier to compare across states, to adjust the threshold percentage (if necessary), and above all avoid unintended consequences that could worsen access to HCBS services for people with disabilities.

¹⁰² Yearby et al., *supra* note 98. (ranges include 75% of increases (IN), 85% (CO, TX), up to 100% (CA)); See also, Nat'l Governors Ass'n., *Addressing Wages of the Direct Care Workforce through Medicaid Policies* (2022), <https://www.nga.org/publications/addressing-wages-of-the-direct-care-workforce-through-medicaid-policies/> (Utah required full HCBS rate increase to go to direct care worker compensation).

¹⁰³ Burns & Assocs., *Overview Proposed Rate Models for Intellectual and Developmental Disabilities Waiver Services—prepared for Nevada Department of Health and Human Services* (June 2021), https://dhcfp.nv.gov/uploadedFiles/dhcfp.nv.gov/content/Resources/Rates/Overview%20of%20Proposed%20Rates_2021-06-30.pdf; Burns & Assocs., *Rate and Payment Options Study Proposed Rates - prepared for Rhode Island Department of Behavioral Healthcare, Developmental Disabilities and Hospitals*, (Oct. 2022), https://bhddh.ri.gov/sites/g/files/xkqbur411/files/2022-10/Revised%20Rate-and-Payment-Options-Study_Recommendations_2022-10-14_Rev-1.pdf; see also Ralph Lollar & Dianne Kayala, CMS, *Fee Schedule HCBS Rate Setting: Developing a Rate for Direct Service Workers* (2016), <https://www.medicaid.gov/sites/default/files/2019-12/hcbs-1a-ffs-rate-setting.pdf> (CMS hypothetical rate models described in training webinar).

3. Definition of compensation

a. Wages and benefits

We strongly support CMS's proposals to include typical wages and benefits as direct care compensation, including the employer's share of payroll taxes. While these taxes may not end up in the worker's pocket, this is reasonably considered compensation.

We also agree that compensation should not be extended to include costs that have little direct benefit to workers. CMS asks if the costs of training should be included in compensation. Since workers will presumably be paid their hourly wages to attend training, those costs should be included as wages. That component of training appears to be typically folded into the productivity adjustment in many rate models. However, the cost of providing the training—such as paying for training instructors or training resources—is only indirectly beneficial to the worker and should be included in the category of program supports.

b. Transportation, travel and other costs

Most rate models we reviewed included some costs for transportation or mileage between clients. While many direct care workers have only one client per day and may not travel often at work, there are some who travel between multiple clients. Travel for personal care services typically amounted to under 3 to 5% of the total share of the rate, with somewhat higher costs in rural regions. This is not huge, but could be critical to determining the viability of the 80/20 split.

CMS should explain how transportation costs would factor into the payment pass-through calculation. Where such costs are directly included in the calculation of service rates, we would expect travel between clients (or with a client going into the community) to count toward program supports. We see value in keeping transportation as a separate line-item in the rate building process, but also recommend future guidance clarifying how providers and states should approach transportation costs. For example, if one provider does not reimburse a direct care worker for her between-client travel, those costs should be counted differently (reducing compensation) from another provider who correctly reimburses individuals for those expenses.

c. Program supports and administrative costs

In our review of several rate model studies, the program supports component was the least clearly defined and most variable by service. In Burns & Associates models, which are common, the program supports amounts ranged widely across HCBS services—from 1% to

37% of the total estimated rate, with an average of 14%.¹⁰⁴ CMS’s 2016 hypothetical rate model projected that these program supports represented just 2% of total payments.¹⁰⁵ With these large discrepancies in what constitutes program supports, it can confound the relationship between total rates and worker compensation, and defeat the whole purpose of the calculated percentage. CMS should issue further guidance clearly outlining what components of these services should be counted as administrative and programmatic supports, respectively.

In summary, we strongly support CMS’s proposal to help ensure adequate HCBS payment rates and to boost direct care worker compensation to boost recruitment and retention in this important job. The 80/20 split appears to be a reasonable starting standard, but we urge CMS to require more data collection on different components of actual HCBS payments, including median wage and compensation of direct care workers, so CMS, stakeholders in the interested party advisory group, and the public can better understand how their HCBS dollars are being spent.

C. THE MINIMUM COMPENSATION RATE SHOULD APPLY TO STATE PLAN PERSONAL CARE SERVICES AND HOME HEALTH AIDE SERVICES

HHS requests feedback on whether to apply the proposed payment adequacy provisions to “state plan” services. They should. Issues with access and quality span all authorities. From

¹⁰⁴ Burns & Assocs., *Overview Proposed Rate Models for Intellectual and Developmental Disabilities Waiver Services—prepared for Nevada Department of Health and Human Services* 23 (June 2021), https://dhcfp.nv.gov/uploadedFiles/dhcfpnavgov/content/Resources/Rates/Overview%20of%20Proposed%20Rates_2021-06-30.pdf (noting that “program support assumptions equate to between 1% and 38% of the proposed rates [and that] survey respondents reported a weighted average rate of 14%). See also Burns & Assocs., *Rate and Payment Options Study Proposed Rates - prepared for Rhode Island Department of Behavioral Healthcare, Developmental Disabilities and Hospitals* (Oct. 2022), https://bhddh.ri.gov/sites/g/files/xkqbur411/files/2022-10/Revised%20Rate-and-Payment-Options-Study_Recommendations_2022-10-14_Rev-1.pdf; The Hilltop Institute, UMBC, *Rate Methodology Study Pursuant to Section 2 of HB 1696* (Nov. 2018), <https://health.maryland.gov/mmcp/Documents/JCRs/2018/Report%20on%20REM%20Reimbursement%20Rates%20for%20Home-%20and%20Community-Based%20Care.pdf> (Maryland study of certain waiver and program rates); Burns & Assocs., *Virginia Department of Behavioral Health and Developmental Services, My Life, My Community Proposed Rate Models* (July 2021); https://www.burnshealthpolicy.com/wp-content/uploads/2021/08/VA-DBHDS-Proposed-Rate-Models_2021-07-30.pdf

¹⁰⁵ Ralph Lollar & Dianne Kayala, CMS, *Fee Schedule HCBS Rate Setting: Developing a Rate for Direct Service Workers* (2016), <https://www.medicaid.gov/sites/default/files/2019-12/hcbs-1a-ffs-rate-setting.pdf>.



the beneficiary’s perspective, there is little reason not to apply these regulations to all the ways in which a state may authorize PCS and home health aide benefits.

The proposed rule excludes PCS and home health aide services authorized under state plan services, asserting that “the vast majority of HCBS is delivered under section 1915(c), (i), (j), and (k), while only a small percentage of HCBS nationally is delivered under section 1905(a) State plan authorities.”¹⁰⁶

As noted above in our comments on the proposed incident management system (§ 441.302(a)(6)), we disagree that only a small percentage of HCBS nationally is delivered via state plan authorities. According to the Kaiser Family Foundation, in 2020, § 1905(a) state plan home health and personal care services constituted almost 20% of total HCBS spending.¹⁰⁷ This is not negligible.

Furthermore, the use of state plan services is not uniform across populations or states. If CMS does not amend the proposed regulation to include home health aide services and PCS via § 1905(a) state plan authority, CMS risks excluding pediatric populations and individuals who live in certain states from the increased access that the proposed regulation is intended to achieve.

1. Coverage of PCS and home health aide services is primarily through § 1905(a) state plan authority for children and youth under twenty-one

Children who receive PCS or home health aide services should overwhelmingly be relying on state plan services. As noted above, in comments on the incident management system, under Medicaid’s Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit for children, children have a right to PCS and home health aide services via state plan services. CMS has repeatedly stated that in such cases, if a service can be authorized under the state plan, it may not be authorized under a waiver.¹⁰⁸ Thus, it is important to include state plan services to ensure that any positive gains from this rule are shared equally by the pediatric population.

¹⁰⁶ 88 Fed. Reg. at 27985.

¹⁰⁷ Kaiser HCBS Spending by Authority, *supra* note 67.

¹⁰⁸ CMS, *EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents* 26 (2014), https://www.medicaid.gov/sites/default/files/2019-12/epsdt_coverage_guide.pdf.



2. States vary greatly in the proportion of expenditures for HCBS authorized via § 1905(a) state plan authority

While some spend almost no money on HCBS services via § 1905(a), others primarily fund HCBS via § 1905(a) authority. In Texas, 50% of **all** HCBS expenditures are for § 1905(a) state plan personal care services and home health aide services, in Indiana, it is 46%; for the District of Columbia, it is 63%; and in Massachusetts, it is approximately 43%.¹⁰⁹ For enrollees in states that rely more heavily on § 1905(a) authority to cover home health aides and PCS, applying the minimum compensation rate to § 1905(a) home health aides and PCS is of increased importance. While home health aide services is a mandatory benefit under § 1905(a), states vary greatly on the number of hours of home health aide services they will authorize via § 1905(a) authority, with some states only covering very short-term, intermittent needs, and others covering a large number of hours that could at least partially supplant the need for § 1915(c) waiver services.¹¹⁰ Additionally, at least 34 states cover PCS as a § 1905(a) state plan service, and those states vary greatly regarding the number of hours authorized and may also vary on eligibility criteria for the service.¹¹¹ While the definition of PCS is not uniform across authorities, these differences are inconsequential for most enrollees.

Because of the great variation across states and population of use of § 1905(a) state plan authority to cover PCS and home health aide services, we recommend that CMS extend the payment adequacy provisions to PCS and home health aide services provided under § 1905(a) state plan authority.

¹⁰⁹ Kaiser HCBS Spending by Authority, *supra* note 67 (note that these percentages are the percent of state plan PCS and state plan home health aide expenditures out of all HCBS expenditures, which includes services beyond home health aide and PCS offered via the § 1915(c) and § 1115 waivers, and §§ 1915(k) and 1915(i) state plan HCBS options included in the scope of this proposed rule. If only looking at the 3 services for which CMS proposes a minimum compensation rate, the percent of expenditures for state plan PCS and state plan home health aides would be even higher).

¹¹⁰ Kaiser Fam. Found., *State Health Facts: Medicaid Benefits: Home Health Services – Nursing Services, Home Health Aides, and Medical Supplies/Equipment* (2018), <https://www.kff.org/medicaid/state-indicator/home-health-services-includes-nursing-services-home-health-aides-and-medical-suppliesequipment/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> (for example, Mississippi only permits for 25 home health aide visits per year under the state plan benefit while other states allow for an unlimited number of visits with prior authorization).

¹¹¹ Kaiser Fam. Found., *State Health Facts: Medicaid Benefits: Personal Care Services* (2018), <https://www.kff.org/medicaid/state-indicator/personal-care-services/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>.

§ 441.311(b) Compliance reporting

A. INCIDENT MANAGEMENT ASSESSMENT SYSTEM

We support the requirement that States be required to report every 24 months on the incident management system, and every 60 months for systems that are deemed in compliance. We suggest that CMS add a requirement that requires States to track whether critical incidents are reported to the designated Protection & Advocacy program at the same time the incident was reported to the State. As noted above, we are proposing that CMS require providers to report critical incidents to the designated Protection & Advocacy (P&A) system for the state when such incidents are reported to the state. Federal law establishes that P&As “have the authority to investigate incidents of abuse and neglect of individuals with developmental disabilities if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred.”¹¹² Reporting to the P&A helps ensure that the State responds appropriately and acts with sufficient urgency to prevent further harm. If CMS requires reports to be sent to the P&A at the same time they are reported to the state, states should be required to track and report on compliance with this requirement.

B. CRITICAL INCIDENTS

We support CMS’s proposal that states report annually on number and percent of critical incidents for which an investigation was initiated within state-specified timeframes, number and percent that are investigated and resolved w/in state time frames, and the number of critical incidents requiring corrective action for which corrective action is completed within the time frames. We also suggest that CMS require tracking of the number of critical incidents requiring corrective action as a standalone measure. This information could help enrollees and advocates identify how often the state is taking action to ensure critical incidents do not repeat.

§ 441.311(c) Reporting on the HCBS Quality Measure Set

We support the proposal to require mandatory reporting of an HCBS core measure set with state options for additional measures.¹¹³ The proposal will enable states and CMS to accurately compare quality of plans and services from year to year, program to program, plan to plan (in the case of managed care), and state to state. Public reporting of quality data will also facilitate accountability in HCBS by centralizing information and making it accessible to consumers. Quality measure reporting can help states target resources to improve quality of

¹¹² 42 U.S.C. § 15043; see *also* 42 U.S.C. § 10805 (investigation authority under the Protection and Advocacy for Individuals with Mental Illness program).

¹¹³ 88 Fed. Reg. at 28082.



care and enable CMS and states to hold plans and programs accountable for disparities and inequities in HCBS.

We strongly suggest that CMS require annual reporting of HCBS quality measures, in line with the reporting timelines all the other Medicaid quality measure sets: the Quality Rating System, the mandatory Child Medicaid & CHIP Core Set, the Behavioral Health Core Set, and the Adult Core Set, as well as Medicare and Marketplace quality reporting.¹¹⁴ The timelines given to implement the HCBS, which would require states to begin reporting every two years starting in 2027, are too long. Reporting HCBS measures every other year will lock in data lags and lower expectations that can stymie HBCS innovation, delay oversight, and inhibit quality improvement interventions. In the proposed managed care rule, CMS acknowledges concerns about data lag by changing the External Quality Review annual reporting schedule so reports will be posted no more than one year after data collection.¹¹⁵ Why allow a much worse data lag here?

We realize that many measures in the recommended HCBS measure set depend on one of several HCBS experience of care measures, and that these survey tools can be expensive for states to implement. However, HCBS expenditures represent a substantial fraction of all Medicaid expenditures, and the consequences of poor quality care can be catastrophic. We believe that reasonable investments in HCBS quality oversight infrastructure are overdue and are more important than ever. Medicaid managed care plans routinely report Consumer Assessment of Health Providers and Systems (CAHPS) patient experience of care surveys annually, and CMS just proposed requiring annual enrollee surveys for every managed care plan.¹¹⁶ We see no reason that HCBS should not be held to the same standard.

RECOMMENDATION: Change all references in § 441.311(c) to refer to annual rather than “at least every other year” reporting.

§ 441.311(d) Access reporting

We support CMS’s commitment to developing a new set of measures to monitor HCBS participants’ access to key services. However, as a general matter, the access reporting requirements set by proposed § 441.311(d) do not fully reflect CMS’s commitments to health equity. Although CMS requires stratification of some quality measures to evaluate equity in

¹¹⁴ CMS, *Adult and Child Health Care Quality Measures*, <https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/adult-and-child-health-care-quality-measures/index.html> (last visited June 25, 2023).

¹¹⁵ CMS, Medicaid Program; Medicaid and Children’s Health Insurance Program (CHIP) Managed Care Access, Finance, and Quality, 88 Fed. Reg. 28092, 28180 (May 3, 2023).

¹¹⁶ *Id.* at 28243.



HCBS care, CMS does not require stratification of the access measures. Stratification of access measures is needed for many of the same reasons – to understand who accesses care and whether states, programs, and plans are meeting their civil rights obligations to HCBS applicants and enrollees. We recommend that the final rule set state expectations for stratifying relevant access measures as well.

A. WAIVER WAITING LISTS

The proposed rule requires states with HCBS waiting lists to report how they manage their lists. The information would include whether the state screens individuals for eligibility prior to placing them on the list, whether the state periodically screens individuals on the list for continued eligibility, and the frequency of rescreening, if applicable. States would also report on the number of people on the list who are waiting to enroll, and the average amount of time individuals newly enrolled in the waiver program in the past twelve months were on the waiting list.

We support this provision. This information could help advocates, policymakers, and other stakeholders better understand the unmet need in states with waiting lists, compare waiting list policies across states, and develop best practices and appropriate beneficiary protections to minimize harms from waiting lists. The data may also help individuals and families to make more informed decisions about accessing coverage as they plan for their future.

B. ACCESS TO HOMEMAKER SERVICES, HOME HEALTH AIDE, AND PERSONAL CARE

We appreciate the requirement to track the average amount of time from when services are authorized until they are provided and the percentage of authorized hours that are actually provided over a twelve-month period. People who are approved for HCBS often struggle to find staff to support them, leading to *de facto* denials. Measuring the percentage of authorized hours that are actually provided can also measure this unmet need, and we support its inclusion.

To be actionable, we believe the delivered services percentage metric should also track **why** such services were not provided. There are many reasons why authorized services may not be provided promptly, ranging from administrative burden and delays by the state, to a lack of providers, to access issues related to fiscal management agencies for self-directed services. Thus, it would be helpful to create simple reporting codes that identify and track common reasons for such delays or failure to provide all authorized services. CMS should require the state to specifically track the most common reasons why such hours were not filled, particularly for reasons related to a lack of providers or to providers not showing up.



§ 441.311(e) Payment Adequacy

We support the proposal that states report annually on the percent of payments for certain services that are spent on compensation. We agree that additional information about the median hourly wage and compensation by category would be helpful. We suggest that CMS include a requirement that states also report on travel expenditures, administrative and program support expenditures, and such other significant components that CMS deems relevant. We suggest that CMS include such a requirement in the final rule. This information should be stratified by delivery system and where applicable, by plan, to capture differences between managed long term services and supports and FFS. We further suggest that CMS ask states to report on direct care worker staff turnover to see the effects higher wages may have on retention and, ultimately, care quality.

The value of the information for future rate-setting purposes outweighs any burden. Providers likely readily have this information, because they know what they are paying employees and what their other expenses and obligations are, but direct care workers and other stakeholders may not. To allow for meaningful participation in the interested parties advisory group, information such as the median wages and compensation and historic trends should be equally available to all members of the public.

We also note that rate models we reviewed included certain assumptions for paid time off (vacation, holiday, and sick time) and wages that may not be consistent with actual paid time off and wages that providers offer to their workers. However, rate model **assumptions** are not **mandates**, and some rate models make clear providers were not bound to pay the amounts assumed in the rate model.¹¹⁷ While we understand that CMS intends to apply the payment adequacy calculation at the aggregate level for the whole state and not individual providers, if most providers refused to offer sick leave, for example, that portion of the rate model would look like it was covering worker benefits when actually it may be paying for program support or administrative expenses. We recommend that CMS clarify this potential slippage between rates and what providers (and health plans) actually pay, and clearly place the onus on states to ensure that aggregate direct care worker compensation meets the 80/20 goal. States must report **actual** expenditures on compensation for direct care workers, as specified in § 441.303(e), and not rely on rate models to assess compliance with this requirement.

¹¹⁷ Burns & Assocs., *Overview Proposed Rate Models for Intellectual and Developmental Disabilities Waiver Services—prepared for Nevada Department of Health and Human Services* 7 (June 30, 2021), https://dhcfp.nv.gov/uploadedFiles/dhcfpnvgov/content/Resources/Rates/Overview%20of%20Proposed%20Rates_2021-06-30.pdf.



As noted above in comments on HCBS Payment Adequacy and for the same reasons, these provisions should also apply to § 1905(a) state plan services for home health aides and personal care services.

§ 441.311(f) Effective Date

We support the effective date of three years for most measures, but recommend that states begin to report on person-centered planning within two years, to align with the proposed two-year effective date for compliance discussed above in comments on § 441.301(c)(1). We also support a four-year effective date for the reporting requirements of § 441.303(e), in recognition of the additional complexity of this provision. We also support the requirement to apply the reporting requirements to managed care. These reports measure essential protections for enrollees, and measuring and reporting on this progress should not be delayed.

§ 441.312 HCBS Quality Measure Set

We support the proposal to develop and maintain an HCBS core measure set and to phase in required reporting of measures over time. Medicaid is the national largest payer of HCBS, with expenditures exceeding \$100 billion in FY2016, and so represents a substantial share of all Medicaid spending.¹¹⁸ Although the number of validated HCBS measures has increased substantially in recent years, states reporting on new measures is highly variable. Only a few national level reports have even tried to identify disparities in quality and access across disability populations or race and ethnicity. The HCBS core measure framework CMS shared in July 2022 will improve transparency and help standardize HCBS measure collection and reporting. Importantly, it recognized the need for states to report measures such that they can identify and track racial and ethnic disparities as well as differences in outcomes for other important demographic groups.

These proposed regulations build on this framework by elevating transparency and public accountability, increasing opportunities for informed decision-making by Medicaid HCBS participants, and committing to actions that prioritize and lead toward a more equitable HCBS delivery system. We have several suggestions to strengthen parts of the proposal, centered around two main themes: adjusting the timeline for developing the measures and expanding the scope of data collection and reporting.

¹¹⁸ Caitlin Murray et al., Mathematica, *Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Years 2017 and 2018*, 5 (2021), <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures-2017-2018.pdf> (total LTSS expenditures for FY 2017 and 2018 did not include data from CA, NY, IL, and VA, so 2016 is a more complete estimate; over 57% of LTSS expenditures were for HCBS in 2016).



A. SHORTEN THE HCBS QUALITY MEASURE TIMELINES

First, HCBS measures should be updated annually alongside annual reporting, as is standard practice for other Medicaid core measure sets. Especially with a new and rapidly evolving field of HCBS measures, the current slow pace for updating the set will delay implementation of innovative approaches and inhibit CMS's ability to adjust the set to ensure it has the right measures to inform quality improvement interventions.¹¹⁹ At least in the first years as CMS gets the HCBS measure set established, annual reporting and updating will be essential to maximize the effectiveness of the measure set for CMS, state Medicaid agencies, plans, providers, advocates, and HCBS participants themselves.

Second, the final regulations should accelerate the phase in of stratified measure reporting proposed in § 441.312(f). We strongly support the proposed requirements in § 441.312(d) that states begin reporting HCBS quality measures by age, disability groups, delivery systems, dual eligibility, and other key demographic elements. Throughout the proposed rule, CMS reiterates its commitment to working toward health equity. Last year, CMS released its Framework for Health Equity, which sets priorities for demographic data collection and analysis, assessing causes of disparities, addressing inequities, and advancing language access, cultural competency, and accessibility.¹²⁰ The first priority of the Framework for Health Equity is to collect, report on, and analyze programs by demographic data to understand the different impacts and aspects of CMS efforts on different communities.¹²¹ The second priority is to assess causes of disparities within CMS programs and address inequities.¹²² The proposed rule also names the Biden-Harris Administration's priorities in Executive Order 13985 for advancing equity for underserved populations, including communities of color, LGBTQI+ communities, rural communities, and people with disabilities.¹²³

¹¹⁹ The success of CMS's proposals to report on disparities quality and access measures depends heavily on states' ability to collect and report on demographic data of HCBS applicants and enrollees. CMS's Data Quality Atlas shows that the most recent race and ethnicity data collected from Medicaid and CHIP enrollees and reported through T-MSIS is of low quality or unusable in twenty states. And while the preamble describes some recent successes imputing race and ethnicity in some Medicaid data, states need to hear a clear message that improving the quality of gold standard, self-reported demographic data remains a priority. We believe the biennial reporting and long phase-in of stratification only encourages states to continue to delay solving the data challenges that hinder this type of reporting.

¹²⁰ CMS, *Framework for Health Equity 2022-2032*, 5 (Apr. 2022), <https://www.cms.gov/files/document/cms-framework-health-equity-2022.pdf>.

¹²¹ *Id.* at 5.

¹²² *Id.*

¹²³ Exec. Order No. 13985 (Jan. 20, 2021).



In light of these commitments, we are disappointed with the extended phase-in of requirements for states to report HCBS measures by key demographic characteristics listed in proposed § 441.312(d)(7). Required reporting on potential health disparities has sat on the back burner far too long, and the long phase-in only encourages states to continue to delay solving the data challenges that hinder this type of reporting. CMS's proposed seven-year phase in for stratified reporting in § 441.312(f) lags behind the timelines for other quality measure reporting systems. For example, the National Committee for Quality Assurance (NCQA) began requiring plans to report results by race and ethnicity for five HEDIS measures in 2022, and requires plans to stratify 13 measures in 2023 and will add more in 2024.¹²⁴ The proposed phase-in for stratifying Adult and Child Core Set measures was five years (which we suggested was too long).¹²⁵ The proposed every other year reporting further delays implementation of this crucial step in monitoring and reducing health inequities. In short, the proposed rule sets expectations for analysis and application of both quality and access measures too low; it does not hold states accountable for collecting and improving quality of demographic data to conduct meaningful analysis. We recommend phasing in all required stratified measure within four years.

B. EXPAND THE SCOPE OF HCBS QUALITY REPORTING

First, we strongly recommend that CMS finalize this regulation with changes that expand the basis and scope of HCBS core measure quality reporting to include § 1905(a) HCBS services, as appropriate, even if it means a slightly longer phase in for authorities where states do not currently have capacity to report on these services. As written, the rule would leave large numbers of Medicaid HCBS users whose HCBS are authorized under § 1905(a) from access to important quality oversight. We noted above how important these services are for youth and adults. Leaving out these other authorities will only lead to ongoing fragmentation and confusion and may lead to poorer quality of care for individuals receiving these services.

Second, we also urge CMS to ensure that the implementation of HCBS experience of care surveys is robust enough to meet the requirements for stratified data collection and for providing meaningful quality data to cover all HCBS users in the state. HCBS experience of care surveys are validated for specific ages and populations, not for use across all people with disabilities who use HCBS. For example, the National Core Indicators (NCI) for people with

¹²⁴ National Committee for Quality Assurance (NCQA), *Using HEDIS to Improve Health Equity* (Oct. 2022), https://www.ncqa.org/wp-content/uploads/2022/10/20221006_Future-of-HEDIS_Using-HEDIS-to-Improve-Health-Equity_TRANSCRIPTSLIDES.pdf; NCQA, *Stratified Measures: How HEDIS Can Enhance Health Equity*, <https://www.ncqa.org/blog/stratified-measures-how-hedis-can-enhance-health-equity/> (last visited June 25, 2023).

¹²⁵ CMS, *Adult and Child Health Care Quality Measures*, <https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/adult-and-child-health-care-quality-measures/index.html> (last visited June 25, 2023).



Intellectual or developmental disabilities has separate surveys validated for use with adults with I/DD and for children with I/DD. NCI-Aging and Disability is designed for older adults and people with physical disabilities. In its State Medicaid Director letter releasing the first HCBS recommended core measure set, CMS set a reasonable expectation that states “ensure that all major population groups are assessed using the measures in the measure set,” and so may have to implement multiple experience of care surveys to fulfill this expectation.¹²⁶ We support the requirement that states implement at least one appropriate experience-of-care survey tool for each major disability group covered by the state’s § 1915(c) programs. The requirement should be explicit in these regulations.¹²⁷

We are also concerned that the language in the proposed regulation will make it too easy for states to avoid taking the necessary steps to report stratified HCBS quality data. In many states, the sample size for these surveys is extremely limited and only allows for a state-level analysis of survey-derived HCBS measures. NHeLP fully supports using robust oversampling to cover typically underserved HCBS populations (race/ethnicity, sex, preferred language, age, sexual orientation, gender identity, sex characteristics, disability type, and setting type) while increasing the sample size more generally to provide more specific quality data, including by plan in managed LTSS states. CMS should acknowledge that states may need to increase sample sizes to achieve satisfactory data to evaluate the quality of HCBS care in their states and to address disparities in care, even if it requires more resources to do so.

The proposed provision outlining how CMS will select measures for stratification only discusses weighing potential barriers to stratification, which may make it more difficult to require stratification. We recommend reorganizing this provision to reflect the need to balance the value of stratification—such as meeting CMS’s health equity-related quality goals—against potential risks, costs, and feasibility. NHeLP thinks some of the criteria listed in the regulation, such as whether the survey collects necessary demographic variables, are unnecessarily specific for regulation text.¹²⁸ Also, we see no reason not to expect that every HCBS core

¹²⁶ CMS, Dear State Medicaid Director Letter at 10 (July 21, 2022) (SMD # 22-003) (*re: Home and Community-Based Services Quality Measure Set*), <https://www.medicaid.gov/federal-policy-guidance/downloads/smd22003.pdf>.

¹²⁷ NHeLP also acknowledges that this requirement may not account for smaller § 1915(c) waiver programs that serve targeted populations, like acquired brain injuries or HIV/AIDS. CMS should build a pathway to include these populations in HCBS quality measure reporting as well.

¹²⁸ The proposed reference to the demographic data collection methods of various experience of care surveys, some of which are privately run, is unnecessary. CMS should set the expected data collection standard, and then work with the relevant HCBS measure developers to ensure that their survey tools meet CMS’s standards, rather than citing a tool’s idiosyncratic data collection methods as a barrier that may limit or prevent stratification. These surveys

measure will eventually be reported stratified by key demographics, and so we recommend removing language referring to a “subset” of HCBS core measures in (d)(7) that is unnecessarily self-limiting (see below).

Finally, the new regulations should align with expectations for our future demographic and quality data needs. In particular, we urge CMS to include sexual orientation, gender identity, and sex characteristics (SOGISC) in its list of suggested demographic factors to consider for stratification.¹²⁹ The absence is notable given the inclusion of sexual orientation and gender identity in CMS’s definition of health equity; the Executive Order on Advancing Equity for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals; and the priorities named in the Federal Evidence Agenda for LGBTQI+ Equity.¹³⁰ CMS must remain committed to inclusion by devoting resources and investing in the underserved communities it names in its commitment to health equity. The consequence of doing so will be to leave behind and further set back advancements in LGBTQI+ health.

Effective reporting on HCBS quality will also require more effective flags for disability in state and federal data systems. To satisfy the reporting requirements at proposed § 441.312(d)(5), states will have to distinguish claims by disability type, but current capabilities do not even adequately capture which Medicaid enrollees have disabilities. Disability eligibility categories leave out large swaths of participants who qualify for Medicaid through other eligibility pathways, like the adult Medicaid expansion. Medicaid application questions typically are not robust enough to accurately capture self-reported disabilities by type, and claims-based disability flags often fall short. We urge CMS to work with advocates to identify a common solution that will strengthen states’ and CMS’s capacity to report effectively on quality and access measure outcomes across the breadth of disabilities, including for people with disabilities who are also marginalized due to race, ethnicity, geography, age, language, sex, sexual orientation, gender identity, or other demographic characteristics. Having a

could also be a useful tool to cross-check against T-MSIS data for surveyed enrollees to fill missing information or test for accuracy.

¹²⁹ See, e.g., 88 Fed. Reg. at 27993 (“Identify the subset of measures that must be stratified by race, ethnicity, Tribal status, sex, age, rural/urban status, disability, language, or such other factors as may be specified by the Secretary.”).

¹³⁰ CMS, *Definition of Health Equity*, <https://www.cms.gov/pillar/health-equity> (last visited June 25, 2023), Exec. Order 14075, 87 Fed. Reg. 37189 (Jun. 21, 2022) (instructing HHS Secretary to “establish an initiative to address the health disparities facing LGBTQI+ youth and adults, take steps to prevent LGBTQI+ suicide, and address the barriers and exclusionary policies that LGBTQI+ individuals and families face in accessing quality, affordable, comprehensive health care, including mental health care, reproductive health care, and HIV prevention and treatment.”); Nat’l Science and Technology Council, *Federal Evidence Agenda on LGBTQI+ Equity* (Jan. 2023), <https://www.whitehouse.gov/wp-content/uploads/2023/01/Federal-Evidence-Agenda-on-LGBTQI-Equity.pdf>.



standardized flag for disability would also facilitate the stratification of other Medicaid core measure sets by disability to identify disparities in care quality and access to acute and preventive care for people with disabilities.

RECOMMENDATION: Amend § 441.311(d)(7) to remove unnecessary language and explicitly include SOGISC data:

(d)(7) “The subset of measures among the measures in the Home and community-Based Services Quality Measure Set that must be stratified by race, ethnicity, sex, **sexual orientation, gender identity, and sexual characteristics**, age, rural/urban status, disability, language, Tribal status, and such other factors as may be specified by the Secretary and informed by consultation every other year with States and interested parties in accordance with paragraph (b)(2) and subsection (g) of this section.”

RECOMMENDATION: Amend § 441.312(f) as follows:

(f) *Selection of measures for stratification.* In specifying which measures, and by which factors, States must report stratified measures consistent with paragraph (d)(7) of this section, the Secretary will take into account **weigh the potential benefits to advance health equity goals while ensuring statistical validity, protecting beneficiary privacy, and considering** whether stratification can be accomplished based on valid statistical methods and without risking a violation of beneficiary privacy and, for measures obtained from surveys, whether the original survey instrument collects the variables necessary to stratify the measures, and such other factors as the Secretary determines appropriate; the Secretary will require stratification of ~~25~~ **50** percent of the measures in the Home and Community-Based Services Quality Measure Set for which the Secretary has specified that reporting should be stratified by 3 years after the effective date of these regulations, ~~50~~ and **100** percent of such measures by ~~5~~ **4** years after the effective date of these regulations, and ~~100~~ percent of measures by ~~7~~ **5** years after the effective date of these regulations.

§ 441.313 Website Transparency

We strongly support the proposal to require states to post all their HCBS accountability, quality, and access data on a single, user-friendly, accessible website. User-testing for the Medicaid Quality Rating System (QRS) provided direct feedback that participants get frustrated when they have to navigate multiple websites to obtain information, and that same finding undoubtedly applies in the HCBS context as well.¹³¹

¹³¹ 88 Fed. Reg. at 28202.



We also support the proposal that CMS will report on its own website the results states report to it pursuant to proposed § 441.311. This will facilitate the process of comparing results across states and create a single source where enrollees, advocates, and policymakers can find a wealth of information about HCBS access.

While the website requirement provisions in this rule closely parallel similar transparency requirements in the Managed care proposed rule at § 438.10(c), we found discrepancies between the language access requirements described in the managed care rule at § 438.10(d) compared to in Medicaid FFS, at § 435.905(b). For example, the managed care requirements require states to do an analysis to determine the distribution and prevalence of different languages across the state and to provide written translations for critical materials in each prevalent language. Specifically, many states reporting on proposed § 441.311 will apply to Medicaid HCBS participants who receive services under managed LTSS. We recommend that proposed § 441.313(a) cross reference the language requirements in § 438.10(d), where applicable, in addition to § 435.905(b).

Prior to proposing the QRS web-based system, CMS pre-tested prototypes with Medicaid enrollees to identify approaches that work best for them. Then, CMS used the feedback to adjust its proposed policy. We wholeheartedly endorse this type of approach. This is a wise and obviously fruitful method to create more effective and responsive federal policy and we encourage its broader use in the future. We recommend that such user testing also include people with disabilities and those with limited English Proficiency to identify and address accessibility issues.

Alignment of Access and Managed Care Rule Provisions

We appreciate and strongly support that CMS is considering applying waiting time standards and direct testing of Medicaid FFS provider networks through annual independent secret shopper surveys. Due to relatively low provider rates across most services in FFS delivery systems, finding available providers can be extremely challenging even when freedom of choice of providers has not been waived. We have long encouraged CMS to build oversight and accountability mechanisms that are based on direct testing rather than relying on state assurances of compliance with federal Medicaid requirements. Secret shopper surveys and waiting time for appointments are excellent examples of that proactive approach to oversight and should not be limited to managed care delivery systems.

§ 447.203(b)(1) Payment Rate transparency

We commend and support CMS for requiring state agencies to publish all Medicaid FFS payment rates on a website developed and maintained by the single State agency that is accessible to the public, in addition to requiring states that pay varying rates by population,



provider type, and geographical location to identify this information. We also support requiring states to comply with accessibility requirements to ensure that people with disabilities and limited English proficiency are able to equitably access the information.

Furthermore, we appreciate CMS requiring that the website be easily reached from a hyperlink on the State Medicaid agency's website. It is important that such information is readily available to enrollees, advocates, and other interested parties.

§ 447.203(b)(2) Comparative payment rate analysis and rate disclosure

A. PRIMARY CARE PROVIDERS

We commend CMS for requiring primary care services as one of the proposed categories of services subject to the comparative payment rate analysis. Primary care providers are on the front lines of securing optimal health. Therefore, it is crucial that the payment rate for primary care providers are high enough to ensure that the doctor-patient relationship is effective and will positively impact the health of the patient.

We recommend that CMS keep the Access Monitoring Review Plan (AMRP) requirement to provide a separate analysis for each provider type and site of service for primary care services, including those provided by physician, Federally Qualified Health Center (FQHC), clinic, or dental care providers. We understand that this proposed rule would exclude the parenthetical description because it already includes rate analysis that is at the CPT or HCPCS code level. We also understand that this approach would require states to perform less sub-categorization of the data analysis, however we urge CMS not to categorically exclude from the analysis FQHCs and clinics. We understand the inherent challenges in performing a comparative analysis of rates paid on a Prospective Payment System (PPS) or encounter basis. However, we urge CMS to include clinics to the extent that they provide primary care paid on a procedure basis. In addition, we urge CMS to explore ways to analyze the impact of PPS and encounter rates on access in future rulemaking.

Moreover, CMS should make clear that the category is not limited to MD-level providers, but would also include Physician Assistants (PA), Nurse Practitioners (NP), etc. who also provide these services. We encourage CMS to clarify these distinctions in preamble language or other subregulatory guidance.

B. OB/GYN PROVIDERS

We support the proposed rule expanding and broadening the AMRP process to include both obstetrical and gynecological services. This proposal improves on current AMRP requirements only including pre- and post-natal obstetric services (including labor and delivery).



We agree that this proposal will more accurately capture a wider array of services for states and CMS to assess and ensure access to care in FFS, because OB/GYNs provide other important sexual and reproductive health services beyond pregnancy, including cervical and breast cancer screenings; screenings for Rh(D) incompatibility, syphilis infection, and hepatitis B virus in pregnant people; monitoring weight fluctuation during pregnancy; and screening for perinatal depression.

We recommend that CMS include other sexual and reproductive health services, including pelvic floor Physical Therapists (PTs) and Occupational Therapists (OTs), as well as urologists, and other providers who primarily serve the sexual and reproductive health needs of people assigned male at birth (AMAB). Because sexual and reproductive health includes numerous services and a broad range of providers, it is important that the analysis reflect the full panoply of necessary services. Moreover, CMS should clarify that the category of providers is not limited to MD-level providers, but would also include Physician Assistants (PAs), Nurse Practitioners (NPs), Midwives, pelvic floor PTs and OTs, etc. As more states incorporate doula coverage as a Medicaid benefit, it would be pertinent to also include doulas within the list of non-MD level providers. Finally, we recommend that CMS continue to use gender inclusive language when categorizing sexual and reproductive health services.

C. BEHAVIORAL HEALTH SERVICES

We appreciate that CMS proposes to require an analysis of rates paid to behavioral health providers. As discussed in more detail below, we are concerned that a comparative rate analysis of these services will be hampered by the fact that Medicare does not cover as many mental health and substance use disorder services as most Medicaid programs, and also does not cover the full range of provider types that may participate in Medicaid.¹³² We also note that certain integral mental health services, such as Assertive Community Treatment (ACT), are a singular team-based services. We ask that CMS distinguish team-based services from bundled rates, to ensure that states will not be required to identify the appropriate payment for each “constituent service” for team-based care.

¹³² See, e.g., Beth McGinty, The Commonwealth Fund, *Medicare’s Mental Health Coverage: What’s Included, What’s Changed, and What Gaps Remain* (2023), <https://www.commonwealthfund.org/publications/explainer/2023/mar/medicare-mental-health-coverage-included-changed-gaps-remain>; Meredith Freed et al., Kaiser Family Found., *Mental Health and Substance Use Disorder Coverage in Medicare Advantage Plans* (2023), <https://www.kff.org/medicare/issue-brief/mental-health-and-substance-use-disorder-coverage-in-medicare-advantage-plans>.



D. HCBS: PERSONAL CARE, HOME HEALTH AIDE, AND HOMEMAKER SERVICES

We also appreciate that CMS proposes to analyze rates paid to providers of three types of HCBS: personal care, home health aide, and homemaker services. We recommend that CMS clarify the language to make clear these services are subject to a rate analysis whether they are covered through a waiver or the state plan § 1905(a) authority.

In some states, for example, state plan PCS cover large proportions of the population receiving any kind of PCS, so if state plan services are not included the analysis will be geographically skewed. More importantly, for services provided pursuant to EPSDT, CMS has said repeatedly that waiver services are only supposed to supplement EPSDT services, but most EPSDT services should be provided through the state plan.¹³³

We want to emphasize how important it is for CMS to require states to measure and analyze rates paid for HCBS and access to these services. To date, only a few states have attempted to do so, making clear that more data in this area is needed. Some states, such as Rhode Island, have measured some aspects of access, including HCBS, but such studies have largely focused on geographic location and whether providers are currently accepting new patients.¹³⁴ While such factors, which are commonly used for measuring access to other services, are helpful, assessing access for HCBS has proven to be much more complex.

In addition to the service types enumerated in the proposed rule, we urge CMS to consider requiring states to measure and report on payment rates for specialty care. Many Medicaid FFS enrollees have chronic conditions and disabilities that require access to specialists such as cardiologists, endocrinologists, orthopedists, neurologists, and oncologists. Yet too often, access to these specialists is a major challenge for Medicaid enrollees.¹³⁵ In many locations, wait times of six or more months to see these specialists are common.¹³⁶ Thus, CMS should ensure that payment rates for specialty care are measured and monitored along with the other enumerated services.

¹³³ *Supra* at pages 31-32 (discussion of EPSDT and § 1905(a) state plan services).

¹³⁴ See Rhode Island Dept. Health, *2015 Statewide Health Inventory Utilization and Capacity Study*, 58-79 (2015), <http://www.health.ri.gov/publications/reports/2015HealthInventory.pdf>.

¹³⁵ See, e.g., Justin W. Timbie et al., *Specialty Care Access for Medicaid Enrollees in Expansion States*, 25 AM. J. MANAGED CARE 83 (2019); Joseph T. Labrum IV et al., *Does Medicaid Insurance Confer Adequate Access to Adult Orthopaedic Care in the Era of the Patient Protection and Affordable Care Act?*, 475 CLIN. ORTHOP. RELAT. RES. 1527 (2017).

¹³⁶ See, e.g., ANM Healthcare, *Survey of Physician Appointment Wait Times and Medicare and Medicaid Acceptance Rates* (2022), https://www.merrithawkins.com/uploadedFiles/MerrittHawkins/Content/News_and_Insights/Articles/mha-2022-wait-time-survey.pdf.



RECOMMENDATION: Amend § 447.203(b)(2)(i)-(v) as follows:

- (i) Primary care services (***provided by physician, FQHC, clinic, dental care, or other providers***).
- (ii) ~~Obstetrical and gynecological~~ ***Reproductive and sexual health*** services.
- (iii) Outpatient behavioral health services.
- (iv) ***Specialist services***.
- (v) Personal care, home health aide, and homemaker services, as specified in § 440.180(b)(2) through (4), provided by individual providers and providers employed by an agency, ***whether provided through the state plan or a waiver***.

§ 447.203(b)(3)(i) Comparative payment rate analysis and rate disclosure requirements for OB/GYN, primary care, outpatient behavioral health

We generally support the provision to require a comparative rate analysis and payment rate disclosure. We agree that the analysis should meet the requirements of:

- organizing by category of service;
- identifying the base Medicaid payment rates for each E/M CPT/HCPCS code identified by CMS under the applicable category of service, including if rates vary, separate ID of the payment rates by population, provider type, and geographic location;
- identifying the Medicare non-facility payment rates effective for the same time and geographical location that correspond to § 447.203(b)(3)(i)(B);
- identifying the Medicaid Base payment rate at a percentage of Medicare; and
- the number of Medicaid claims paid.

Although we agree with CMS that Medicare rates are an appropriate benchmark by which to evaluate payment rates for most key services in Medicaid, as mentioned above, we urge CMS to address situations where there is not a comparable Medicare payment rate for OB/GYN, primary care, and behavioral health services – *i.e.*, when Medicaid will pay for a particular CPT code that Medicare will not. While we think that the vast majority of these services subject to the comparative analysis will have a counterpart in Medicare, certain reproductive and sexual health services and behavioral health services may not. For behavioral health services, Medicare does not cover services that are essential for individuals with serious mental illness, such as peer support services or assertive community treatment, while Medicaid covers many of these services for dual-eligible enrollees. For reproductive and sexual health services, Medicare generally only covers contraception for non-contraceptive purposes. For example, Medicare does not cover Long-Acting Reversible Contraception (LARCs) but it is covered by



Medicaid. Moreover, many reproductive health providers who serve Medicaid enrollees are not Medicare providers. Because there is a lack of coverage in Medicare for these specific behavioral and reproductive health services, there will be a gap in the analysis when it comes to ensuring that payment rates meet accessibility standards.

Therefore, we encourage CMS to create a necessary approach or utilize the approach described in proposed § 447.203(b)(3)(ii) to account for the lack of a comparable rate when states are meeting the comparable analysis requirement.

§ 447.203(b)(3)(ii) Comparative payment rate analysis and rate disclosure requirements for HCBS

We commend CMS for proposing to require states, for the first time, to publish the rates paid to HCBS providers. We agree with CMS that requiring states to express the payment rates as an average hourly rate for each service is a straightforward way to conduct this analysis and will help to ensure that all stakeholders can understand and compare these rates.

As we have previously noted, access to HCBS services is greatly affected by rates and wages.¹³⁷ We further agree that states must separately identify the rates paid (to the extent different) to individual providers, providers employed by an agency, providers serving different populations (pediatric and adult), provider type, and geographical location. We suggest that to the extent that states pay different rates for other distinctions or have rate modifiers, states be required to report these different rates as well. For example, we are aware of states that pay higher rates for higher level of need or complexity due to a person's cognitive, behavioral, or mobility needs often using "tiers" within a service; for harder to fill hours, such as nights and weekends; or due to geographical area.¹³⁸ States should be required to report any rate distinctions or variations to allow comparison of rates, identify innovative practices, and issue spot deficiencies. Such information would be lost and analysis of access difficult if the state only reports an average rate for the service as a whole.

We further appreciate CMS proposing to require states to identify both the number of claims and the number of enrollees who have received one of the three identified HCBS in the calendar year. This provision is an important counterpart to the provisions at proposed § 441.311(d)(2)(ii) that will require states to evaluate the proportion of authorized HCBS hours that are actually provided. Taken together, these components will help states and CMS to obtain a fuller picture of whether Medicaid enrollees who need HCBS have access to the services they need, and if not, will provide an indication as to whether increasing payment

¹³⁷ *Supra* note 94.

¹³⁸ CMS, *Tiered Rates: Trends in Acuity-Based and Geography-Based Rate Variation* (2017), <https://www.medicaid.gov/sites/default/files/2019-12/tiered-rates.pdf>



rates will improve access. This data will also allow CMS and states to evaluate the number of providers available to provide HCBS in a particular geographic area from year to year; and the ratio of unique recipients to the number of unique participating providers per county, which will help paint a fuller picture of access, and identify gaps.

We note that services provided by natural supports, both paid and unpaid, may be relevant to questions of access as would assessments of the care providers.¹³⁹ For example, if a parent of an adult child is providing a significant number of hours, both paid and unpaid, this could be an indicator that the family cannot find a qualified provider for the services. In addition, an assessment of that parent's well-being could indicate that providing the services is not ideal and is impacting the parent's ability to otherwise support the individual and continue to provide services in the future. Additional access issues could be identified by surveying HCBS participants and their support systems as they would be able to identify with the most specificity the access issues and the perceived cause of such problems. We encourage CMS to explore these factors in future rulemaking.

§ 447.203(b)(4) Comparative payment rate analysis and payment rate disclosure timeframe

We support CMS requiring state agencies to publish the initial comparative payment rate analysis and payment rate disclosure of its Medicaid payments no later than January 1, 2026, with a retroactive analysis of payment rates that are in effect as of January 1, 2025. We also support updating the analysis every 2 years, by no later than January 1 of the second year following the most recent update. It is important that the information stays updated to ensure that provider rates remain sufficient. Moreover, we support the requirement that such publication and update remain consistent with the publication requirements described in proposed § 447.203(b)(1) for payment rate transparency data.

§ 447.203(b)(5) Compliance with payment rate transparency, comparative payment rate analysis, and payment rate disclosure requirements

We appreciate CMS's commitment to ensuring compliance. We agree with CMS that the existing procedures at part 430 are an appropriate mechanism to enforce compliance with these provisions.

We further encourage CMS, in future rulemaking, to consider establishing a process to resolve enrollee concerns regarding access to covered services. We are not aware of any state

¹³⁹ See Disability Rights Education & Defense Fund & Nat'l Senior Citizens Law Cntr., *Identifying and Selecting Long-Term Services and Supports Outcome Measures 28* (2013), <http://dredf.org/2013-documents/Guide-LTSS-Outcome-Measures.pdf>.



Medicaid program that has a statewide system of addressing access concerns in a FFS program. In some states, enrollees may occasionally find someone at their state or local Medicaid office who will assist them in finding a provider who accepts FFS Medicaid, but frequently enrollees are simply referred to the phone book.¹⁴⁰ Even the enrollees who do get help may be given a provider list that is full of inaccuracies.

As noted above, we encourage CMS to align the wait time standards and direct testing of Medicaid FFS provider networks through annual independent secret shopper surveys. In addition, we have previously recommended that CMS implement a grievance system and an ombuds program to ensure that there is a process outside of the fair hearing context to raise important issues and concerns.¹⁴¹ We encourage CMS to continue exploring options that allow enrollees to identify problems with access that will help states implement systemic resolutions.

§ 447.203(b)(6) Interested parties advisory group for rates paid for certain services

We strongly support the proposed requirement for the State agency to establish an advisory group for interested parties to advise and consult on provider rates with respect to PCS, home health aides, and homemaker services. The group includes direct care workers, enrollees and their authorized representatives, and other interested parties. We suggest that a majority of the seats be reserved for enrollees and direct care workers, with at least 25% of seats in the group are reserved for Medicaid enrollees and their representatives, and at least another 25% reserved for direct care workers and their representatives.

We also encourage CMS to keep the Medicaid Advisory Committee (MAC) and the interested parties advisory group separate. They could have coordinated meetings, but the work required merits two groups. It would be unreasonable to expect the MAC to fulfill its important obligations overseeing the entire Medicaid program and the particular issues related to the direct care workforce. In addition, while the MAC draws from a very broad cross-section of Medicaid stakeholders, the interested parties advisory group will need to draw from a much more specialized set of stakeholders (for example, stakeholders with disabilities and deep experience with specific HCBS delivered by direct care workers).

In addition to simply making the process by which the state selects group members and convenes its meetings clear, we also support a requirement that the state publicly recruit members. While we support leaving tenure of appointment determinations to the state, group

¹⁴⁰ See, e.g., Eric Steele, Medicaid patients face limited access, Bangor Daily News (Jan. 27, 1998), <http://archive.bangordailynews.com/1998/01/27/medicaid-patients-face-limited-access/>.

¹⁴¹ Nat'l Health Law Prog., *Comments on CMS Request for Information on Access to Coverage and Care in Medicaid & CHIP* 52 (Apr. 18, 2022), <https://healthlaw.org/resource/nhelp-comments-on-cms-request-for-information-on-access-to-coverage-and-care-in-medicaid-chip/>



members should serve for set terms and only be removed for cause. Set terms allow members to provide recommendations and constructive criticism of the State's Medicaid program without fear of reprisal, and prevent the State from disbanding an advisory group that disagrees with the rate determination. Similarly, the regulations should clarify that state employees are not permitted to serve on the advisory group. While state employees may provide information and support to advisory group members, allowing State employees to be appointed to the group defeats the purpose of having an independent advisory group.

We also recommend that the advisory group receive sufficient explanations and information as to how any proposed rates were calculated, in addition to the metrics required by the Payment Adequacy and Reporting Requirements sections. This information should include clear, consistent definitions of the cost elements that are considered in establishing a rate.

Rates are often based on rate studies, which are based on specific cost elements involved in providing these services. For example, a rate may be made up of the costs of employee compensation, travel, training, administration, and other components. If the definitions of these components are not clear and the basis for these calculations are not shared with sufficient granularity, then the advisory group will not be able to meaningfully comment. Similarly, if the definitions of the components that go into a rate study for these services vary considerably between rate studies, then meaningful comparisons from year to year or from state to state will not be possible.

Last, we urge CMS to ensure that the recommendations of the interested parties advisory group are given due consideration and appropriate action. In our experience, while imperfect, states already have ways of soliciting input from direct care workers, enrollees, enrollees' representatives and advocates about access problems in FFS Medicaid. Yet unless there is a mechanism to act on that input and correct the identified problems, that input has little meaning. At a minimum, the state should also be required to publish a public response to the advisory group's recommendations on rate setting, explaining the evidence used to make their final rate recommendations, whether they accepted the recommendations of the advisory group, and if the rates differ from the recommendations, explaining the State's reasoning. Ongoing access barriers could also be referred to the MAC for investigation and recommendations regarding corrective action.

§ 447.203(c)(1) Initial State analysis for rate reduction or restructuring

Generally, we oppose the two-tiered approach and believe that this approach is insufficient to ensure access. The two-tiered system would result in states implementing significant cuts to Medicaid rates without scrutiny for prolonged periods of time as long as they are exempt.



The proposed rule would provide that, if a state meets the following three criteria under its initial analysis, the State would not be required to provide a more detailed analysis to establish that the rate reduction proposal meets the access requirement:

- (1) services affected by the proposed reduction or restructuring would be paid at or above 80% of the most recently published Medicare rates for the same or comparable aggregate set of Medicare-covered services;
- (2) the proposed reductions or restructurings would result in no more than a 4% reduction in aggregate fee-for-service expenditures for each benefit category within a single state fiscal year; and
- (3) there are no evident access concerns raised through public processes set out in § 447.203(c)(4) and § 447.204.

Although we commend CMS for including the third criteria that centers the importance of public concerns about rate reductions or restructuring, we vehemently oppose CMS implementing an exemption method for states when inquiring on whether a state's rate reduction or restructuring proposal meets the access requirement. First, lowering the threshold to 80% would exempt many states from going through the scrutiny process when a rate reduction is proposed and such exemption would allow access for more Medicaid enrollees to go unchecked.

Additionally, a 4% cut is not nominal even in absolute terms when it is applied to rates that are already low. If Medicaid providers are already operating within thin margins, especially due to the effects of inflation, cuts at 4% are highly likely to result in access issues.

CMS's proposal fails to account for rates that have failed to keep up with inflation over time. When states fail to raise their rates as costs increase, and the rates paid by other payers increase, the rates stagnate, which may be equivalent to a significant rate cut. One study found that between 2008 and 2012, while Medicaid rates rose by an average of 5%, they still fell relative to Medicare rates—from 72% of Medicare to only 66%.¹⁴² As inflation has been particularly high over the last two years, these relative cuts are likely to be even higher. The fact that Medicaid rates are failing to keep up with inflation suggests that CMS should do more monitoring of rates, even when states are not proposing to cut them. We urge CMS to address ongoing monitoring of payment rates in future rulemaking and ongoing reviews.

Long-standing research has established that Medicaid enrollees with higher health care needs or chronic conditions are already more likely to experience access problems than their

¹⁴² Stephen Zuckerman & Dana Goin, The Urban Inst., *How Much Will Medicaid Physician Fees for Primary Care Rise in 2013? Evidence from a 2012 Survey of Medicaid Physician Fees* 6-7 (2012), <https://kaiserfamilyfoundation.files.wordpress.com/2013/01/8398.pdf>.

comparatively healthy counterparts.¹⁴³ Even if a relatively low proportion of enrollees experience access problems after a rate cut, the state has still violated its obligations under the Medicaid Act. If the access problems are concentrated among high-need enrollees that should draw more scrutiny from CMS, not less. Medicaid enrollees with disabilities and chronic conditions who continue to receive services on a fee-for-service basis could face diminished access without any meaningful oversight or opportunity for redress.

CMS notes that this newly proposed exemption process was crafted due to several states complaining about the administration of the present rule's being overly burdensome. We appreciate the importance of ensuring that states are not overburdened with administrative obligations, but this kind of oversight is necessary to ensure enrollee access. There are other steps CMS could take to assist states in creating their plans without exempting them from rigorous monitoring of access in their Medicaid programs, such as providing templates that states could use to report the requested data, and providing technical assistance to states to assist their compliance. No state should be exempt from monitoring and reporting, and CMS should not increase the number of states that could be exempt. Thus, we encourage CMS to require states to provide as much detailed information as possible proving that the rate reduction would not interfere with access.

§ 447.203(c)(2) Additional state rate analysis

We commend CMS for proposing to require states to provide detailed information about proposed rate reductions or restructuring. For the reasons described above, we strongly believe that states should be required to provide this information any time it proposes to reduce rates or restructure rates in a way that could result in diminished access. The information that CMS proposes to collect from states in these scenarios will provide rich information from which CMS can analyze a state's proposal regarding rates to understand its impact on beneficiary access to care. We recommend that, in addition to requiring states to provide summary information about proposed changes, and information about the rates in aggregate, CMS should require states to provide the specific range of rates, including any variation in rates (for example, regional differences, or differences based on provider specialty).

¹⁴³ See, e.g., Sharon K. Long, et al., Urban Inst., *National Findings on Access to Health Care and Service Use for Non-Elderly Adults Enrolled in Medicaid* 3 (2012), <https://www.macpac.gov/wp-content/uploads/2012/06/National-Findings-on-Access-to-Health-Care-and-Service-Use-for-Non-elderly-Adults-Enrolled-in-Medicaid.pdf>; Karen Davis et al., *Access to Health Care for the Poor: Does the Gap Remain?*, 2 ANN. REV. PUB. HEALTH 159, 160 (1981).

Again, we appreciate that CMS proposes to require states to provide essential details about rates when they propose to cut or restructure them, and we urge CMS to require this information for all proposed cuts or restructurings, rather than setting “safe harbors” under which states will not be subject to this level of scrutiny.

RECOMMENDATION: Amend § 447.203(c)(2) as follows:

~~(2)~~ **(1)** State rate analysis.

For any State plan amendment that proposes to reduce provider payment rates or restructure provider payments in circumstances when the changes could result in diminished access ~~where the requirements in paragraphs (c)(1)(i) through (iii) of this section are not met~~, the State must also provide the following to CMS as part of the State plan amendment submission as a condition of approval, ~~in addition to the information required under paragraph (c)(1) of this section~~, in a format prescribed by CMS:

* * *

(vi) *To the extent there is any variation in the provider payment rate that is being reduced or restructured (e.g., differences depending on geographic location or provider specialty), a complete description of both the current payment rates and the proposed new rates.*

(vii) A summary of, and the State's response to, any access to care concerns or complaints received from enrollees, providers, and other interested parties regarding the service(s) for which the payment rate reduction or restructuring is proposed as required under § 447.204(a)(2).

§ 447.203(c)(3) Compliance with requirements for state analysis for rate reduction or restructuring

We strongly support the proposed provisions that make clear that CMS may deny a requested State Plan Amendment to reduce or restructure rates if CMS determines, after reviewing the supporting materials, that the requested State Plan Amendment will result in decreased access to care. Enforcement, including denials of State Plan Amendments, where appropriate, is a crucial component of ensuring that the promise of access in the Medicaid Act, is realized.

We also appreciate that this section proposes to require states to monitor beneficiary access to care in an ongoing way and take action to address any decreases in access. We are concerned, however, that without more direction as to how access should be monitored, and how states are to determine whether access has decreased, these provisions will not be sufficient to ensure that enrollees have access to covered services. In addition, as discussed in more detail above, we continue to urge CMS to use the same measures for monitoring and ensuring access in FFS Medicaid that are used in Medicaid managed care.



Thus, we continue to recommend that CMS set a national core set of access to care measures and metrics in future rulemaking. This core set could initially be established through sub-regulatory guidance, though we encourage CMS to consider eventually encoding the measures and metrics in regulation. While individual states could be responsible for collecting and analyzing state-level data to evaluate compliance with national standards set by CMS, we urge CMS to require more uniformity in their reporting to allow it to more easily monitor states' efforts and enforce compliance if the data reveals access problems. A core set of measures would allow CMS to more efficiently obtain the information it needs to provide meaningful oversight of access in the Medicaid program since it could then readily apply lessons learned from engaging with one state's plan to another state. National measures are needed to ensure that standards do not vary too widely from one state to another, and that oversight by CMS is not fragmented.¹⁴⁴ We previously provided ample input to CMS on specific measures that it should consider including among the core measures on which states must measure and report.¹⁴⁵ We urge CMS to review our previous suggestions and reach out to us to discuss them further.¹⁴⁶

§ 447.203(c)(4) Mechanisms for ongoing beneficiary and provider input

We support the proposal that requires states to have ongoing mechanisms for beneficiary and provider input on access to care and to promptly respond to public input through these mechanisms citing specific access problems, with an appropriate investigation, analysis, and response. Additionally, we support requiring states to maintain a record of data on public input and how the State responded to this input, which will be made available to CMS upon request.

§ 447.203(c)(5) Addressing access questions and remediation of inadequate access to care

We support the proposal to require the State to submit a corrective action plan with specific steps and timelines to address any identified access deficiencies within ninety days after discovery. Additionally, we support the requirement that the access deficiency should be

¹⁴⁴ Cf. Suzanne Murrin, Dept. of Health & Human Servs., Office of Inspector General, *State Standards for Access to Care in Medicaid Managed Care* 19 (2014) (“CMS and States need to do more to ensure that all States have adequate access standards and strategies for assessing compliance.”), <http://oig.hhs.gov/oei/reports/oei-02-11-00320.pdf>.

¹⁴⁵ Letter from Elizabeth G. Taylor, Nat'l Health Law Prog., to Andy Slavitt, Ctrs. Medicare & Medicaid Servs. (Jan. 4, 2016) (responding to CMS's Request for Information (RFI)—Data Metrics and Alternative Processes for Access to Care in the Medicaid Program), <https://healthlaw.org/resource/medicaid-access-metrics-rfi-response>.

¹⁴⁶ *Id.*



remedied within twelve months, while emphasizing that the corrective action plan may include longer-term objectives.

§ 447.203(c)(6) Compliance actions for access deficiencies

We support the proposal to clarify that CMS may use the procedures set forth in § 430.35 when necessary to ensure compliance with access requirements.

§ 447.204 Medicaid provider participation and public process to inform access to care

We support the proposal to make technical changes to this section to appropriately cross-reference the analysis that CMS proposes to require under proposed § 447.203(c). In addition, we recommend that CMS strengthen subsection (a)(2) in this section, by requiring that states consult the interested parties advisory group, proposed to be established in § 447.203(b)(6). We suggest requiring states to consult this advisory group, in addition to stakeholders at large, when the state is considering a rate reduction or restructuring. We believe that the interested parties advisory group will have considerable expertise regarding the appropriateness of payment rates to ensure access to care, such that their input will be particularly valuable to states when determining the impact of a proposed rate cut.

RECOMMENDATION: Amend § 447.204(a)(2) as follows:

(a)(2) Input from ***the interested parties advisory group established pursuant to § 447.203(b)(6) of this chapter, in addition to*** beneficiaries, providers and other affected stakeholders on beneficiary access to the affected services and the impact that the proposed rate change will have, if any, on continued service access. The state should maintain a record of the public input and how it responded to such input.

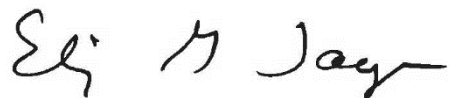
Conclusion

We have included numerous citations to supporting research, including direct links to the research. We direct CMS to each of the materials we have cited and made available through active links, and we request that the full text of each of the studies and articles cited, along with the full text of our comment, be considered part of the formal administrative record for purposes of the Administrative Procedure Act. If CMS is not planning to consider these materials part of the record as we have requested here, we ask that you notify us and provide us an opportunity to submit copies of the studies and articles into the record.



Thank you for consideration of these comments. If you have any questions or need any further information, please feel free to contact Jennifer Lav (lav@healthlaw.org).

Sincerely,

A handwritten signature in black ink that reads "Elizabeth G. Taylor". The signature is written in a cursive style with a long horizontal flourish at the end.

Elizabeth G. Taylor
Executive Director

