



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 Consortium for Constituents with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance.

The undersigned members of CCD's Long Term Services and Supports (LTSS) and Health Task Forces appreciate the opportunity to comment on the proposed regulations. We greatly appreciate CMS's attention and commitment to improving access to Medicaid services and supports necessary for people with disabilities to access health care and live in the community. We have asked CMS to create more accountability and oversight for Home and Community-Based Services (HCBS) for years, in numerous previous comments on the Access Rule.<sup>1</sup> We are incredibly supportive of CMS's work to seriously address problems with HCBS access in the proposed rules.

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<sup>1</sup> See Consortium for Constituents with Disabilities, *Comments on Request for Information: Access to Coverage and Care in Medicaid & CHIP* (April 18, 2022), [https://www.c-c-d.org/fichiers/CCD-HealthLTSSCoChairComments-CMS-Access-RFI\\_4-18-22.pdf](https://www.c-c-d.org/fichiers/CCD-HealthLTSSCoChairComments-CMS-Access-RFI_4-18-22.pdf).

While we appreciate the detailed attention given to access to HCBS, we are concerned that many of the proposed provisions will not benefit people with mental health disabilities.<sup>2</sup> Mental health rehabilitative services are how most Medicaid enrollees receive community mental health services, and most Medicaid enrollees receiving rehabilitation services are people with mental health and behavioral health-related disabilities.<sup>3</sup> Accordingly, to exclude Medicaid state plan rehabilitative services from the proposed Access Rule provisions related to HCBS amounts to excluding people with mental health and behavioral health disabilities from those protections.

## **I. Medical Advisory Committee and Beneficiary Advisory Group § 431.12**

CCD supports the strengthening of stakeholder engagement and representation through the establishment of the proposed Medicaid Advisory Committee (MAC) with dedicated enrollee representation.

We support the broadening of engagement from the medical care advisory committee's prior review of health and medical services to the MAC's expanded purview into policy development and administration. Not only will this better allow for discussion on social determinants of health, but it will support states to integrate an equity focus more comprehensively and effectively into rulemaking. It may also allow for early recognition of access violations and opportunity to address systemic barriers to access through policy changes.

We also support the establishment of minimum requirements for enrollee representation on the MAC and opportunities for enrollees to meet separately from the MAC. The perspective of enrollees relying on Medicaid services is critical to ensuring policy development and administration is accessible to and serves the needs of those seeking

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<sup>2</sup> Medicaid Program; Ensuring Access to Medicaid Services, 88 Fed. Reg. 27, 960 (proposed May 5, 2023) (to be codified at 42 C.F.R. pts. 431, 438, 441 & 447), <https://www.govinfo.gov/content/pkg/FR-2023-05-03/pdf/2023-08959.pdf> [hereinafter Proposed Rule]. Specifically, we are referring to provisions relating to: person-centered planning (II.B.1), grievance systems (II.B.2), incident management systems (II.B.3), payment adequacy (II.B.5), reporting requirements (II.B.7.e).

<sup>3</sup> For example, “[in] 2004, 73 percent of Medicaid beneficiaries receiving rehabilitation services were individuals with mental health needs, and these beneficiaries were responsible for 79 percent of rehabilitation spending under the option.” SUBSTANCE ABUSE & MENTAL HEALTH SERVS. ADMIN., MEDICAID HANDBOOK: INTERFACE WITH BEHAVIORAL HEALTH SERVICES 3-5 (2013), <https://store.samhsa.gov/sites/default/files/d7/priv/sma13-4773.pdf> [hereinafter SAMHSA Medicaid Handbook].

support. However, we have concerns that the proposed name, Beneficiary Advisory Group, and corresponding acronym does not adequately capture the importance of this representation.

**RECOMMENDATION:** We recommend CMS consider a different name for enrollee representation on the MAC. We also recommend requiring all MAC meetings to be open to the public with a dedicated time during the meeting for the public to make comments. We further recommend added requirements to ensure equitable representation across the MAC, including but not limited to, appropriate tribal representation for each geographic area. We also recommend including procedural requirements which are transparent and accessible to the public on how the MAC and enrollee representation will be selected and serve, including allowing a process for at-cause removal if necessary.

Finally, we recommend ensuring the MAC provides advice to the state on each of the listed topics at minimum, with the opportunity to expand into other issues determined by the MAC, enrollee representation, and states. Stakeholder representation is critical to each of the listed topics from changes to services to cultural competency and health equity. We also recommend CMS leverage the Administration for Community Living and other HHS divisions to support implementation. For example, the Developmental Disabilities Councils, RAISE Family Caregiving Advisory Council, and SAMHSA administered state mental health councils can serve as models and resources for MACs and BAGs.

## **II. Home and Community Based Services (HCBS)**

### **A. Person-Centered Services Plans § 441.301(c)**

CCD supports a new minimum threshold of 90% for ensuring functional needs assessments are conducted at least annually and that plans are adjusted accordingly. Functional redeterminations are often incredibly opaque and completed with great subjectivity. Requiring annual assessments without improving the way assessments are conducted could lead to loss of services if assessments are done incorrectly. This is particularly true in managed care, since Managed Care Organizations (MCOs) often have a financial incentive to conduct inaccurate assessments to reduce service costs

below the capitated rates.<sup>4</sup> Therefore, we recommend additional guidance to ensure assessments are conducted in accordance with objective and unbiased standards.<sup>5</sup>

Person-centered service plans (PCSPs) are all too often just a checklist of items addressed during the care planning meeting, with limited opportunity to go beyond these completion checks. Therefore, we propose PCSP include a thorough qualitative assessment of the plan's content, ensuring its alignment with the HCBS Settings rule, and provide significant opportunity to detail the enrollee's preferences and desires.

The proposed changes also do not strengthen the cultural competency requirements in PCSP. Currently, § 441.301 requires service plans to reflect "cultural considerations" and that the plans are provided in an accessible manner. Section 435.905(b) adds additional language around the communication of materials. While these accessibility issues are crucial, cultural competency should go beyond language and communication access. We propose adding as part of the cultural considerations in the service plan, if and how the religious and cultural observances of the enrollee impacts how they receive services. These include food choices and preparations, style of dress, and holiday observances. Several of these cultural competency considerations were added to the 2023 Surveyors guidelines for nursing home residents' care plans, and should be adopted for HCBS enrollees' service plans.<sup>6</sup>

Additionally, CCD supports not including any good cause exceptions as the 90% threshold provides enough flexibility to address factors outside the state's control that would impact compliance with the requirement. We also support the proposed changes applying evenly across Fee-for-Service (FFS) and managed care delivery systems. As previously stated, MCOs have often failed to provide transparency in their assessment

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<sup>4</sup> U.S. GOV'T ACCOUNTABILITY OFF., GAO-18-103, CMS SHOULD TAKE ADDITIONAL STEPS TO IMPROVE ASSESSMENTS OF INDIVIDUALS' NEEDS FOR HOME- AND COMMUNITY- BASED SERVICES 15, 19 (2017), <https://www.gao.gov/assets/gao-18-103.pdf> (also noting this conflict of interest is mentioned in the preamble to the report).

<sup>5</sup> A review of California's HCBS programs found biases embedded in assessment criteria, including those designed by algorithms. See Amber Christ & Hagar Dickman, Justice in Aging, *An Equity Framework for Evaluating California's Medi-Cal Home and Community-Based Services for Older Adults and People with Disabilities* (Dec. 2022), <https://justiceinaging.org/wp-content/uploads/2022/12/An-Equity-Framework-for-Evaluating-CAs-HCBS-System.pdf>

<sup>6</sup> U.S. DEP'T OF HEALTH AND HUM. SERVS., CENTER FOR MEDICARE & MEDICAID SERVS., STATE OPERATIONS MANUAL APPENDIX PP - GUIDANCE TO SURVEYORS FOR LONG TERM CARE FACILITIES (REV. 2023), <https://www.cms.gov/medicare/provider-enrollment-and-certification/guidanceforlawsandregulations/downloads/appendix-pp-state-operations-manual.pdf>.

process and may have financial incentives to reduce services through functional redeterminations and service plans. We encourage CMS to issue more rules to prevent enrollees from biased assessments through managed care systems.

CCD recommends less than 3 years for implementing the new performance measures. States are required to conduct annual assessments and service plan adjustments, so the proposed rule is not creating a new obligation. Rather, the proposed changes add a monitoring and reporting requirement for states. Two years should be sufficient for states to comply with this new requirement. Further, the revised requirements should apply to § 1915(i), (j), and (k) programs to ensure consistency across LTSS programs.

The NPRM identified several obstacles to applying the proposed changes to other programs like § 1905(a) medical assistance, state plan personal care, home health, and case management services. However, we recommend CMS issue some standards for states to conduct timely assessments and service plan adjustments for these programs not covered by the current NPRM. We also specifically recommend that CMS apply PCSP standards to appropriate 1905(a) mental health rehabilitative services. First, states should have sufficient data collection and reporting capabilities as a result of CMS requiring states to report quarterly American Rescue Plan Act (ARPA) spending related to HCBS, including mental health rehabilitative services, for the past several years.<sup>7</sup> For any states that lack capabilities, CMS should require states to build capacity and provide effective dates that allow states time to do so. Second, mental health rehabilitative services are person-centered by design.<sup>8</sup> To the extent § 1905(a) services do not yet have explicit person-centered service plan requirements, we recommend CMS establish such requirements so “that States implement person-centered planning process[es] for all HCBS,”<sup>9</sup> including rehabilitative services.

Lastly, 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 enrollee’s

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<sup>7</sup> U.S. Dep’t of Health and Hum. Servs., Center for Medicare & Medicaid Servs., Dear State Medicaid Director Letter (May 13, 2021) (SMD # 21-003) (RE: *Implementation of American Rescue Plan Act of 2021 Section 9817: Additional Support for Medicaid Home and Community-Based Services During the COVID-19 Emergency*), <https://www.medicaid.gov/federal-policy-guidance/downloads/smd21003.pdf>.

<sup>8</sup> Rehabilitative services allow programs to tailor service plans to each consumer’s needs, strengths, and preferences for services, settings, and providers. SAMHSA Medicaid Handbook, *supra* note 3, at 3-5. Rehabilitative services can be delivered in a variety of settings, including the consumer’s own home; by a variety of providers, including peers; and can be used to attain life skills such as peer support, skills training, and supported employment.

<sup>9</sup> Proposed Rule, Section II.B.1, 88 Fed. Reg. 27272-75.

assessment and person-centered service plan within twelve months, the enrollee should not be penalized and their 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.***

#### **B. Grievance System § 441.301(c)(7)**

We recommend that the response time for grievances be shortened to 45 days. Enrollees may grieve about violations of essential rights, such as a failure to follow the person-centered planning process or a violation of the home and community based settings rule. Ninety days is too long for an individual to wait for resolution if they are experiencing a serious violation of their rights or access to services, particularly if they have been denied their request for expedited resolution.

We additionally recommend CMS apply the grievance system requirements to mental health rehabilitative services. As the proposed rule notes, the HCBS delivered under § 1905(a) goes to "large numbers" of Medicaid enrollees with mental health needs.<sup>10</sup> Indeed, as noted above, most Medicaid enrollees receiving rehabilitation services are people with mental health and substance use-related disabilities.

#### **C. Incident Management System § 441.302(a)(6)**

We support the proposed incident management system, including the uniform definition of "critical incidents." We also support the application of this provision to both managed care and FFS delivery systems. We agree that from the enrollee perspective there is no meaningful difference between abuse, neglect, or exploitation perpetrated by a provider paid via managed care or a provider paid via FFS.

We appreciate CMS increasing the minimum performance level for this metric to 90%. Because 90% already gives states leeway for unexpected occurrences, and because the expectation should be that states comply with this 100% of the time, we do not support any "good cause exceptions" to this metric.<sup>11</sup>

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<sup>10</sup> *Id.* at 27975.

<sup>11</sup> *Id.* at 27981.

We emphasize that an incident management system should prevent harm as much as possible. The proposed language, however, focuses heavily on data collection and after-the-fact evaluation of that data. We recommend that the requirements in § 441.302(a)(6)(i) be revised to instruct a state to address critical incidents to protect and benefit enrollees to the extent possible. To ensure meaningful action by states, these instructions should include adequate detail.

We appreciate CMS noting that additional measures are needed to ensure that all critical incidents are reported. In addition to the measures that CMS proposes, we suggest two additional strategies.

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 should have the option to 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) that states:

***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 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.”<sup>12</sup> 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. Furthermore, this proposal has precedent– it is consistent with the requirement for psychiatric residential treatment facilities (PRTFs)

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<sup>12</sup> 42 U.S.C. § 15043.

that such facilities report “serious occurrences” to the P&A, which has now been implemented for over a decade.<sup>13</sup> P&As have experience receiving such reports, and have appropriate processes in place to receive such reports and address any confidentiality concerns.

**RECOMMENDATION:** Amend § 441.301(a)(7) to add a new subparagraph after subparagraph (D) that states:

***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.***

Regarding tracking, trending and analysis of data, we recommend that incident management systems be required to enable identification of the provider. Provider-specific information could be vital for identifying problems and improving care delivery.

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 section 1905(a) State plan authorities.”<sup>14</sup>

First, the percentage of HCBS nationally that is delivered via state plan authorities is not negligible. According to the Kaiser Family Foundation, in 2020, state plan home health and personal care services constituted approximately 19% of total HCBS spending.<sup>15</sup> Children in particular are more likely to receive state plan services, because CMS has repeatedly stated that pursuant to the Early and Periodic Screening, Diagnostic, and Treatment mandate, if a service can be authorized under the state plan, it may not be

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<sup>13</sup> 42 C.F.R. § 483.374(b).

<sup>14</sup> 88 Fed. Reg. at 27975.

<sup>15</sup> See Kaiser Family Found., *Medicaid HCBS Spending, By Authority* (2020), <https://www.kff.org/health-reform/state-indicator/home-health-expenditures/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>. KFF defines “total HCBS spending” as the total spent for home health services, state plan personal care services, §§ 1915(k), 1915(i) state plan services, and §§ 1915(c) and 1115 waivers. *Id.*



authorized under a waiver.<sup>16</sup> Thus, for children in particular, it is important to include state plan services to ensure the health and welfare of children,

Second, while most 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 disabilities.<sup>17</sup> As of 2020, of the 267 different 1915(c) and 1115 HCBS waivers in existence, only 14 of them – or 5% of the total– targeted individuals with mental illness.<sup>18</sup>

Instead, we propose that for incident reporting, CMS adhere to the definition of HCBS in the American Rescue Plan Act.<sup>19</sup> While this may create some burden on states that are not already collecting data on 1905(a) HCBS state plan services, if CMS does not require the states to develop these systems, that barrier will remain. Again, for an enrollee who has been harmed, it matters very little whether their services are funded via state plan authority or some 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 additional time to implement the requirement for § 1905(a) services.

#### **E. HCBS Payment Adequacy § 441.302(k)**

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.

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<sup>16</sup> U.S. DEP'T OF HEALTH AND HUM. SERVS., CENTER FOR MEDICARE & MEDICAID SERVS., APPLICATION FOR A §1915(C) HOME AND COMMUNITY-BASED WAIVER: INSTRUCTIONS, TECHNICAL GUIDE AND REVIEW CRITERIA 26 (2019), [https://wms-mmdl.cms.gov/WMS/help/35/Instructions\\_TechnicalGuide\\_V3.6.pdf](https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf).

<sup>17</sup> Medicare & Medicaid Payment Access Comm., *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/> (referencing 2015 data and noting that enrollment in most of those waivers are small).

<sup>18</sup> Molly O'Malley Watts, Kaiser Family 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>.

<sup>19</sup> American Rescue Plan of 2021, Pub. L. No. 117-2, § 9817 (2021), <https://www.congress.gov/bill/117th-congress/house-bill/1319/text>

The HCBS workforce is composed primarily of Black, Indigenous, and people of color (BIPOC) women.<sup>20</sup> 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.<sup>21</sup> Over 40% of direct care workers rely on public health coverage, primarily Medicaid, while 16% have no health insurance.<sup>22</sup> 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.<sup>23</sup> These racist exclusions, promoted at the time in an attempt to preserve the legacy of slavery, have contributed to the low wages and difficult working conditions that still exist today.<sup>24</sup>

HCBS direct care workers often work for low-wages and limited benefits, while turnover is typically very high.<sup>25</sup> Medicaid's typically low reimbursement rates suppress wages and impede recruitment and retention.<sup>26</sup> This directly contributes to chronic workforce shortages that negatively affect the availability and quality of care.

Though the demand for HCBS services continues to grow, workforce shortages have forced many providers to cut services and turn away clients.<sup>27</sup> High rates of turnover in

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<sup>20</sup> PHI, *Direct Care Workers in the United States: Key Facts* 6 (2022) <https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-3/>.

<sup>21</sup> *Id.* at 6-7.

<sup>22</sup> *Id.* at 10.

<sup>23</sup> 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>.

<sup>24</sup> Marc Linder, *Farm Workers and the Fair Labor Standards Act: Racial Discrimination in the New Deal*. 65 TEX. L. REV. 1335, 1335-1393 (1987), <https://iro.uiowa.edu/esploro/outputs/9983557330902771?skipUsageReporting=true>.

<sup>25</sup> 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].

<sup>26</sup> 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](https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF) [hereinafter Report to the President 2017].

<sup>27</sup> MACPAC HCBS Issue Brief, *supra* note 25, at 4.

direct support staffing threaten the health and safety of individuals with I/DD.<sup>28</sup> Inconsistent staffing can lead to gaps in care and reduce the independence and overall quality of life for individuals receiving services.<sup>29</sup> 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 adverse outcomes.<sup>30</sup> Conversely, continuity of HCBS direct care staff has been shown to improve quality of care.<sup>31</sup> 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.<sup>32</sup> 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.<sup>33</sup>

Fixing the direct care worker crisis requires two necessary components. States must create rates that build in fair compensation for workers and reasonable and transparent ancillary administrative and program support expenses.<sup>34</sup> Raising overall rates will prevent squeezing providers into the red or forcing them to cut costs in other key areas, like transportation. Additionally, there must 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

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<sup>28</sup> 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>.

<sup>29</sup> Report to the President 2017, *supra* note 26, at 20.

<sup>30</sup> 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>.

<sup>31</sup> 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>.

<sup>32</sup> 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].

<sup>33</sup> 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>.

<sup>34</sup> *Id.*

HCBS direct care workers.<sup>35</sup> Recently, New York’s legislature passed a bill that raises the minimum wage for direct care workers to \$18/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.<sup>36</sup> 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.

We support a pass through mechanism, but we recognize that this proposal will not work without a strong interested parties advisory group (IPAG) and true willingness of states to engage in meaningful negotiations with providers, direct care workers and enrollees to remedy longstanding access issues. Therefore, we strongly encourage CMS to ensure that the proposed regulations related to the IPAG and rate-setting are as robust as possible.

Additionally, we urge CMS to include transparent rate accounting to ensure that other necessary components of direct care service – such as transportation, supervision, and program support – are sufficient, even as workers’ compensation increases. We support a fully transparent accounting of all components of the rate structure and encourage CMS to use this opportunity to bolster collection and dissemination of data on rate setting, including uniform definitions of the components included in each rate category. Currently, state rates vary considerably in how they define different components of their rates, and often these components are not clearly defined. These variations, coupled with the lack of available public data on Medicaid HCBS rates, makes it very hard to determine an appropriate compensation percentage for workers, though for the three services included we agree that a large share of the rate should be dedicated to worker compensation.

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<sup>35</sup> 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.” Health Affairs Rescue Plan Funding Raises, *supra* note 32.

<sup>36</sup> 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/>.

We also encourage CMS to provide technical assistance to ensure states build their overall HCBS service rates such that other components of the service rate (travel, productive billable time, programming, and administration) are adequately incorporated so as not to create unintended consequences that inhibit HCBS participants' access to care.

HHS requests feedback on whether to apply the proposed payment adequacy provisions to "state plan" services which they should. Issues with access and quality span all authorities. From the enrollee's perspective, there is little reason not to apply these regulations to all the ways in which a state may authorize personal care services (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." However, in 2020, state plan home health and personal care services constituted approximately 19% of total HCBS spending.<sup>37</sup> In some states, it is much higher: in Texas, 50% of all HCBS expenditures are for state plan services; in Indiana, it is 46%; and in Massachusetts it is 43%.<sup>38</sup> This is not negligible. Furthermore, as noted above, children are much more likely to receive services via 1905(a), as are people with mental health disabilities. To ensure the benefit of the proposed rule accrues across states and populations, the proposed payment adequacy provisions should apply to 1905(a) state plan PCS and home health aide benefits.

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<sup>37</sup> Kaiser Family Foundation defines "total HCBS spending" as the total spent for home health services, state plan personal care services, 1915(k), 1915(i) state plan services, and 1915(c) and section 1115 waivers. Kaiser Family Found., *Medicaid HCBS Spending By Authority* (2020) <https://www.kff.org/health-reform/state-indicator/home-health-expenditures/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

<sup>38</sup> *Id.* Other states, such as New York and California, spend a large proportion of total HCBS expenditures (23% and 18%) on home health aide and personal care services authorized via 1905(a) authority. Note that these percentages are the percent of state plan PCA and state plan home health aides out of all HCBS services, which includes services beyond home health aide and PCS offered via 1915(c) and section 1115 waivers. 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.

## **F. Compliance Reporting § 441.311(b)**

### **1. Incident Management Assessment System**

We support the requirement that states report every 24 months on the incident management system, and every 60 months for systems that are deemed in compliance. As noted above in our comments to proposed § 441.30(a)(7), we are proposing that CMS require providers to report critical incidents to the designated P&A system for the state when such incidents are reported to the state. If CMS accepts this suggestion, CMS should require states to track whether critical incidents are reported to the designated P&A system at the same time the incident was reported to the state.

### **2. Critical Incidents**

We also 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 within 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 tracking 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.

### **3. Person Centered Service Plan reporting**

CMS should allow states to use a random sample for purposes of PCSP reporting requirements only if that sample truly represents the diversity of HCBS beneficiaries and is able to capture if a particular set of providers are constantly in non-compliance. We also recommend annual reporting to more quickly capture if states are not conducting assessments timely as required.<sup>39</sup>

## **G. Reporting on the Home and Community Based Services (HCBS) Quality § 441.311(c) and § 441.312**

We support the proposal to develop and maintain an HCBS core measure set and to phase in required reporting of measures. 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. The HCBS core measure framework CMS shared in July 2022 will improve transparency and help standardize HCBS measure

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<sup>39</sup> See 42 C.F.R. § 441.301(c)(3).

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 that measure 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 make them even stronger.

First, we recommend that CMS expand the basis and scope of HCBS core measure quality reporting to include § 1905(a) HCBS services, as appropriate. As written, the rule would leave out millions 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. We realize incorporating state plan HCBS may require a slightly longer phase in for authorities that may require more serious data infrastructure development.

Second, HCBS measures should be updated and reported annually, 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. 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.

Third, the final regulations should accelerate the phase in of stratified measure reporting. 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. 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. The Framework's first priority is to collect, report on, and analyze programs by demographic data to understand the different impacts and aspects of CMS efforts on different communities. The second priority is to assess causes of disparities within CMS programs and address inequities. Throughout the proposed rule, CMS reiterates its commitment to working toward health equity. It 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.

In light of these commitments, we are disappointed with the extended seven-year phase-in of requirements for states to report HCBS measures by key demographic characteristics. 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. The timelines for other quality measure reporting systems are far more ambitious. 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. Adult and Child Core Set measures for Medicaid and CHIP will be implemented on a phased-in timeline of five years (which we suggested was too long). The proposed every other year reporting further delays implementation of this crucial step in monitoring and reducing health inequities. We recommend that CMS shift to annual reporting and phase in all measure stratification within four years after finalization.

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 intellectual or developmental disabilities has separate surveys validated for use with adults with IDD and for children with IDD. 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.<sup>40</sup> We support explicitly listing the requirement that states would have to implement at least one appropriate experience-of-care survey tool for each major disability group covered by the state’s § 1915(c) programs in these regulations.

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 HCBS measures derived from the survey. We fully support using robust oversampling to cover typically underserved HCBS populations (race/ethnicity, sex, preferred language, age, sexual orientation, sex characteristics, gender identity, disability type, and setting type) while increasing the sample size more

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<sup>40</sup> CMS, Dear State Medicaid Director (July 21, 2022) (SMD # 22-003), <https://www.medicaid.gov/federal-policy-guidance/downloads/smd22003.pdf>.



generally to provide more specific, actionable 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 on selecting measures for stratification only discusses weighing potential barriers to stratification instead of balancing the costs against the potential benefits. We recommend removing unnecessary specifics in this provision and reorganizing it to reflect the value of stratification to meeting CMS's health equity-related quality goals. To this end, there is no reason not to expect that every HCBS core measure will eventually be reported stratified by key demographics, and so we recommend removing unnecessary language referring to a "subset" of HCBS core measures in (d)(5).

The new regulations should align with expectations for our future demographic data needs. 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 § 441.312(d)(5), states will have to distinguish claims by disability type, but current capabilities do not even adequately capture all Medicaid enrollees who have disabilities. Stratifying by disability eligibility categories leaves 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, sexual characteristics, gender identity, or other demographic characteristics. Having a 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.

We also urge CMS to include sexual orientation, gender identity, and sex characteristics (SOGISC) in its list of demographic factors to consider for stratification. 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 Individual, and the priorities named in the Federal Evidence Agenda for LGBTQI+ Equity. CMS must remain committed to the work of 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.

**RECOMMENDATION:** Modify proposed § 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 sex 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:** Modify proposed § 441.312(f) as follows:

(d)(7) *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.

**H. Access Reporting on Waiting Lists and Access to Homemaker Services, Home Health Aide, and Personal Care, § 441.311(d)**

CCD commends CMS for seeking to improve public transparency and processes in HCBS waiver lists and increase standardized reporting on HCBS access. However, CCD strongly recommends that CMS require states to report more specific information. According to Kaiser Family Foundation (KFF), waiting list enrollment totals nearly 820,000 people nationally, but individuals on waiting lists ultimately may not be eligible for waiver services.<sup>41</sup> Notably, eight states that do not screen for waiver eligibility before

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<sup>41</sup> KFF reports waiting list enrollment totals nearly 820,000 people nationally with an average wait time of 39 months. MaryBeth Musumeci, et. al., Kaiser Family Found., *Key*

placing an individual on a waiting list comprise 61% of the total waiting list population. As a result, people are waiting for care that they will never receive.

To provide further transparency for enrollees, CMS should require states to publicly report criteria they use to determine placement and movement within the list. Currently, CMS only provides high-level guidance on waiting list management. In the previous Medicaid RFI, we implored the agency to get more granular and establish a baseline set of standards that CMS expects all waiting lists to meet. We again urge CMS to consider this request. The agency must go beyond publicly reporting the number of people on waiting lists by disaggregating data by demographics and disability to monitor or assess the equity impact of certain waiting list structures. It is currently impossible to monitor the disproportionate impact within and across states because public disaggregated data is not available.

To improve waitlist accuracy, we strongly urge CMS to require all states to conduct screening before placing individuals on the waiting list, so as to not offer services to individuals who are ineligible. Because of the various approaches states use to establish and report waitlist data, it is impossible to determine how many eligible people are going without care. Across the country, each state operates a unique HCBS program with different eligibility criteria and services offered. A disabled individual who received HCBS in one state may not be eligible for services in another state. At the very least, CMS can ensure that no individual is waiting for services that they cannot receive.

CCD also asks that states report the number of eligibility screens performed on each individual on the waiting list in the past year, list why a rescreen was performed, and provide data on how many individuals who were rescreened were deemed ineligible and removed from the waiting list. In the same manner, many disabled individuals not receiving HCBS are unaware of their eligibility and are not actively seeking this level of care. To increase the number of eligible individuals who receive care, CMS should facilitate state-wide data-sharing across means tested programs, including Supplemental Nutrition Assistance Program (SNAP), Temporary Assistance for Needy Families (TANF), Supplemental Security Income (SSI), and others to ensure that all families on each of these programs have access to the others.

Compounding this issue is the fact that many individuals who wait for HCBS are also receiving care through another waiver program that does not meet all of their needs. Anecdotal reporting from our networks suggests that many people with disabilities are

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*State Policy Choices about Medicaid Home and Community- Based Services* (Feb 2020) <https://www.kff.org/medicaid/issue-brief/key-state-policy-choices-about-medicaid-home-and-community-based-services/>.

not approved for the number of hours they need and must fill in gaps with family caregivers or go without care. It is difficult to assess how many people on waiting lists are actually going without any HCBS because states do not track how individuals meet their care needs while on the waitlist.<sup>42</sup> We ask CMS to require states to specify the number of individuals on the waiting list who are also receiving care through another state waiver program and track what needs are not being met while an individual sits on a waiting list. CMS should use this data as metrics to measure unmet HCBS needs and work to close these gaps.

CCD approves of CMS's proposal to track the time it takes between approval to delivery of homemaker, home health aide, and personal care services as an appropriate way to measure the timely delivery of HCBS programs; however, we express concerns on how states may use the data. While we support tracking the unmet needs and unfulfilled hours of care for individuals who are authorized to receive HCBS, we caution against states using information about unfilled hours to infer whether or not authorized services are necessary. There are a multitude of reasons as to why an individual would be unable to receive authorized care on a particular day, especially for disabled populations who are prone to chronic pain and bouts of ill health that can limit their ability to fully participate in their treatment plan. Likewise, unfulfilled hours are also not always under the control of the individual receiving services. The service provider may have been unavailable or there may have been confusion around when and what services were to be delivered on that day. Ultimately, CCD hesitates to support a proposal that could result in more limited access to care for the enrollee, unless there are sufficient assurances that the proposal will not limit access to care.

To prevent states from using this measure to decide whether authorized services are necessary, CCD encourages states to track and report why an individual turns away a service.

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<sup>42</sup> For example, "Stakeholders noted that beneficiaries may get their LTSS needs met through state plan services or support from family caregivers while they wait for an HCBS waiver slot to become available. It is difficult to judge how many people on waiting lists are actually going without any HCBS because states do not track how individuals meet their care needs while waiting for waiver services." MEDICAID & CHIP PAYMENT & ACCESS COMM'N, *Issue Brief State Management of Home- and Community-Based Services Waiver Waiting Lists* (Aug. 2020), at p. 2 <https://www.macpac.gov/wp-content/uploads/2020/08/State-Management-of-Home-and-Community-Based-Services-Waiver-Waiting-Lists.pdf>.

### **I. Payment Adequacy § 441.311(e)**

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, and 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 fee-for-service.

The value of the information for future rate-setting purposes outweighs any burden. Providers likely readily have this information, 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.

### **J. Effective Date § 441.311(f)**

We support the effective date of three years for most measures and four years for reporting on the requirements in § 441.311(e). However, as noted above, we 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).

### **K. Website Transparency § 441.313**

CCD supports posting new reporting requirements around PCSPs and reassessments on a publicly accessible website to make it easier for stakeholders to assess the state's compliance with regulations. However, due to the "digital divide" many enrollees do not have easy access to the internet. Therefore, we recommend an additional requirement from state agencies or MCOs to share the information posted on the website in an alternative format at the enrollee's request.

To avoid confusion by having several different links to several different MCOs and provider entities, we recommend that each state have the basic information available on one centralized webpage, with the opportunity to filter by provider, managed care plan, or locality, in addition to links to the MCOs for more detailed reporting requirements.

CCD recommends less than 3 years for compliance with the website transparency requirements, at least as it pertains to PCSP. States should be conducting annual redeterminations and service plan adjustments -- the rule simply adds a reporting

requirement. Given that states just need to report what they should already be doing, we recommend a time period of 2 years from the date the final rule is published.

#### **L. 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 an excellent example of that proactive approach to oversight and should not be limited to managed care delivery systems. Last, we commend CMS for the mandatory Medicaid and CHIP core quality measure set. We ask that CMS affirmatively and clearly state that the Medicaid core measures apply to all Medicaid HCBS recipients, as they are Medicaid enrolled individuals.

### **III. Documentation of Access to Care and Service Payment Rates §§ 447.203-204**

#### **A. Payment Transparency**

We appreciate the efforts CMS has made within this proposed rule to support transparency of payment rates. Requiring states to publish their rates in a clearly accessible, public location on the state's website with the date the rates were last updated will help stakeholders identify when rates have stagnated without adjustment for inflation, cost of living, and increased costs of service delivery. Further, we support the proposed requirements that trigger additional analysis and rationale for rate reduction or restructuring which could diminish access and urge CMS to require this level of analysis for any reduction or restructuring which results in a decreased expenditure of any kind.

Though publication of existing rates is a positive step, it can be difficult to interpret without additional information about the service rate model (i.e. underlying cost factors and assumptions which compose the rate) and the frequency of rate review (i.e. how often the rate is assessed for adequacy against current expenses). States are currently required through CMS's technical guidance to review their rate setting methodology, at minimum, every five years to ensure that rates are adequate to maintain an ample provider base and to ensure quality of services. Moreover, their report to CMS is

required to include when rates were initially set and last reviewed, how the state measures rate sufficiency and compliance with §1902(a)(30)(A), the rate review method(s) used, and the frequency of rate review activities.

This information, alongside the underlying rate model, is critically important for stakeholders to assess risks and threats to access. The service rate model should account for and provide for each cost component intrinsic to providing the service, including but not limited to: wages, employee-related expenses, program-related expenses, and general and administrative expenses. Each of these cost components should be broken further into separate measures ranging from travel and training to quality oversight and reporting. In a comprehensive system of rate review, at minimum, each component is assessed against current service requirements and necessary expenses to assess appropriate adjustments to each cost element.

However, changes to rates are often conducted without comprehensive review and assessment against the underlying rate model. This can lead to confusion in the community as to whether an increase or cut is applied to a single component or applied proportionately across each component. Furthermore, if a state has conducted a comprehensive rate review which recommends increases in each component, the impact to the underlying rate model is unclear and distorted if the rate is only partially funded. Ensuring transparency of these issues would allow stakeholders to better assess the impact reimbursement rates have on access to quality services.

This is especially apparent in the discussion of direct care wages which are inextricably linked to adequacy of reimbursement rates. Transparency of the underlying rate model would allow stakeholders the opportunity to assess the sufficiency of the wage, benefits, and other employee related expenses assessed within the rate. Moreover, it would allow discussion within the MAC and interested parties advisory group to assess whether the rate model appropriately values the policy requirements of the position and remains competitive with the needs of the workforce.

**RECOMMENDATION:** Amend § 447.203(b)(1) to include the following language:

***The agency is required to include the date when rates were initially set with hyperlink to the underlying rate model, the last rate review method(s) used and any corresponding adjustment to the underlying rate model, and schedule of rate review activities not to exceed two (2) years from the date of last review.***

## **B. Interested Parties Advisory Group**

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 at least 25% of seats in the group are reserved for Medicaid enrollees and their representatives, 25% for direct care workers and their representatives, and 25% of seats in the group are reserved for providers employing direct care workers and their representatives.

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 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.

Last, the state should be required to publish a public response to the advisory group's recommendations, 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.

We encourage CMS to keep the Medicaid Advisory Committee (MAC) and the interested parties advisory group separate. They could have overlapping membership and coordinated meetings, but the work required merits two groups. 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). This is not to suggest however, that the MAC should not review and establish recommendations related to reimbursement rate adequacy and



frequency of rate reviews across Medicaid services. We urge CMS to ensure the MAC has opportunities to advise states on the appropriateness of its broad-scale frequency of rate review schedules and adjustment to underlying rate models. This will allow for better integration of policy recommendations against any increased funding needs.

**C. Medicaid Provider Participation and Public Process to Inform Access to Care § 447.204**

We support the proposal to make technical changes to this section to appropriately cross-reference the analysis that CMS proposes to require under § 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:** We recommend that CMS amend § 447.204(a)(2) as follows:

§ 447.204(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.

Thank you for considering these comments, and for your ongoing commitment to improving access to critical services and supports for people with disabilities. If you have any questions, please feel free to reach out Jennifer Lav at [lav@healthlaw.org](mailto:lav@healthlaw.org).

Sincerely,

Access Ready  
Allies for Independence  
American Association of People with Disabilities  
American Association on Health and Disability  
American Music Therapy Association  
American Occupational Therapy Association  
American Physical Therapy Association

American Speech-Language-Hearing Association  
American Therapeutic Recreation Association  
Amputee Coalition  
Association of Assistive Technology Act Programs  
Association of University Centers on Disabilities  
Autism Society of America  
Autistic People of Color Fund (APOC)  
Autistic Self Advocacy Network  
Autistic Women & Nonbinary Network  
Bazelon Center for Mental Health Law  
Brain Injury Association of America  
Caring Across Generations  
Disability Rights Education and Defense Fund (DREDF)  
Epilepsy Foundation  
Family Voices  
Justice in Aging  
Lakeshore Foundation  
National Academy of Elder Law Attorneys  
National Association of Councils on Developmental Disabilities  
National Center for Parent Leadership, Advocacy, and Community Empowerment  
(National PLACE)  
National Disability Rights Network (NDRN)  
National Health Law Program  
National Multiple Sclerosis Society  
National Respite Coalition  
SourceAmerica  
The Kelsey