



Nothing about us without us!

July 3, 2022

The Honorable Xavier Becerra
Secretary of Health and Human Services
U.S. Department of Health and Human Services
200 Independence Avenue SW
Washington, DC 20201

The Honorable Chiquita Brooks-LaSure
Administrator Centers for Medicare and Medicaid Services
U.S. 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 Autistic Self Advocacy Network (ASAN) is grateful for the opportunity to provide information and comments on the Center of Medicare and Medicaid Services proposed Rule, "Medicaid Program; Ensuring Access to Medicaid Services".

ASAN is a national disability rights organization that serves autistic adults. We advocate for policies that support the needs of autistic individuals, including access to health care and supportive services that meet our needs. A significant ASAN priority is ensuring that members of the intellectually and developmentally disabled community have access to culturally competent home and community-based services that meet individual support

needs. ASAN works to ensure that these services are provided in non-restrictive community settings. ASAN has had substantial prior engagement with this issue, including advocacy on HCBS Settings Rule implementation through public comments and communication with CMS on continued federal actions our community needs to ensure that HCBS is delivered in an accountable manner that protects our rights. ASAN has produced resources for self-advocates on this topic, such as “This Rule Rules!: The HCBS Settings Rule and You.”¹

ASAN is grateful for many provisions in the proposed Rule.. We are excited to note that the Access Rule addresses many concerns that HCBS stakeholders have raised about accountability, quality monitoring, and grievance processes. These provisions provide much-needed oversight and enforcement authority that builds upon and advances the commitments laid out in the recently-implemented HCBS Settings Rule. Our hope is that these regulations mark the beginning of a robust state HCBS oversight process that will expand access to services and ensure that those services are consistent with Olmstead and the Settings Rule in practice- not merely on paper. Please find our detailed feedback on the provisions of the proposed Rule as follows.

Medical Care Advisory Committees (MCAC)

ASAN generally supports strengthening beneficiary engagement and representation through the proposed Medicaid Advisory Committee (MAC) with dedicated beneficiary representation. We similarly support HHS’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. It is critical that beneficiaries and advocates be centered in this advisory process as those ultimately most directly affected by the Medicaid decision-making process. We further believe these representation groups can be expanded as follows:

¹ Autistic Self Advocacy Network, This Rule Rules! The HCBS Settings Rule and You Available at <https://autisticadvocacy.org/policy/toolkits/hcbsRule/#this-Rule-Rules-the-hcbs-settings-Rule-and-you>

Recommendations:

Increase beneficiary representation.

We recognize that there are many stakeholders who need to be part of the MAC to ensure a comprehensive set of perspectives and expertise, but a 25% representation requirement for Beneficiary Advisory Group participants is too low. The proposed Rule notes that the Beneficiary Advisory Group would not consist entirely of Medicaid beneficiaries but also include people with direct experience supporting beneficiaries. While these perspectives are important, they represent a distinct constituency of interest from beneficiaries themselves. If direct support providers, administrators and case managers are not included in the MAC under separate criteria, the proportion of BAG participation in the MAC should be expanded to allow for sufficient beneficiary representation. In addition, CMS should ensure adequate representation of beneficiaries across a wide range of Medicaid services, including waiver service recipients. Medicaid beneficiaries who rely on waiver services are more likely to have relevant knowledge and experience around the limitations and challenges of Medicaid access and administration. It is essential that their perspectives are directly represented.

Include broader stakeholder representation categories.

We recommend the expansion of the stakeholders represented in the MAC. In particular, we suggest including Protection and Advocacy (P&A) agencies for the states. The role that P&As play as independent agencies defending the rights of disabled beneficiaries makes them a critical stakeholder group to include in the MAC process. CMS has acknowledged that P&A agencies play an essential role in addressing beneficiary complaints when rights are violated and has frequently expressed that the P&A system is essential for identifying and reporting failures of compliance with regulations such as the HCBS Settings Rule. P&A representation in the MAC is critical for addressing shortcomings of state Medicaid implementation that impact vulnerable communities and endanger our civil rights and safety.

We also recommend that HHS ensure that states include a wide range of Medicaid stakeholder groups, including reproductive justice advocates, disability rights advocates,

aging and elder law organizations, medical-legal partnerships, racial justice organizations, reentry groups, people living with HIV/AIDS, LGBTQIA+ groups, and others who are actively engaged with Medicaid and with communities who rely on Medicaid. Ensuring that these populations are fairly represented in the stakeholder process is essential to ensuring that states address issues addressing disparities in access and care experienced by many marginalized and vulnerable communities, as well as ensuring that many Medicaid waiver populations are fully represented in the process.

Ensure that MAC proceedings are accessible and transparent to the public.

All MAC meetings should be open to members of the public, with accessible notifications made to the public in advance of meetings as well as an accommodations request policy for members of the public who attend. Meetings should reserve time to provide an opportunity for input and questions from members of the public.

Home and Community-Based Services

ASAN welcomes provisions of the proposed Rule that aim to address concerns around quality, incident management, grievance processes, payment adequacy and person-centered plans. These provisions are essential for ensuring that the HCBS system is able to deliver on the promises of Olmstead. Before and after its March 17, 2023 implementation date, ASAN has raised a number of concerns with CMS about oversight and accountability measures to ensure compliance with the HCBS Settings Rule. Our community needs these provisions to ensure compliance with the Settings Rule so that the rights of recipients of Home and Community-Based Services will be protected.

We similarly support the application of this Rule to HCBS provided through 1115 Medicaid demonstration programs in addition to services provided under 1915(c), and 1915(i), (j), and (k) state plans. ASAN is concerned about the use of 1115 waiver demonstrations in contexts and capacities that would override the rights of individuals with disabilities, particularly uses that would allow people to be put into restrictive

settings disallowed under other authorities. For example, a waiver of the IMD exclusion is a common element of Section 1115 waivers for mental health and SUD programs. We believe this application of demonstration authority is counter to the intent of the proposed Rule.

Recommendation:

Extend the HCBS provisions under the Access Rule to 1905(a) mental health rehabilitation services.

It is important to ensure that HCBS is available to all people with disabilities in need of these services. To this end, the provisions of this Rule should be extended to those individuals who rely on 1905 (a) mental health rehabilitation services. The American Rescue Plan has included a broader definition of “home and community based services” than the one employed in this Rule, and expressly included services for people with mental health disabilities. The more restrictive definition in the proposed Rule will exclude individuals with mental health disabilities from receiving the same protections regarding person-centered planning requirements, grievance systems, incident management systems, payment adequacy, reporting requirements, transparency regarding waiting lists for services, and quality measures and assurance systems.

Person-centered plans

We support HHS’s proposed approach of enhancing structure, oversight, and accountability for HCBS provision. Person-centered plan fidelity is essential for ensuring that HCBS services follow beneficiaries’ identified service needs rather than replicating coercive, one-size-fits-all approaches that have often failed people with disabilities. This is especially important for ensuring state compliance with the rights of beneficiaries to community-based services, including those under the recently-implemented HCBS Settings Rule.

We also support the requirement to reassess person-centered plans based on changes in needs or at the request of the individual. In our stakeholder engagement and research around person-centered planning, we have heard many concerns relating to the fidelity of person-centered plans to the expressed needs and goals of the individual. A frequent

recommendation was the annual review of person-centered plans and timely reassessment of plans at the request of the individual. We are glad to see both of these recommendations reflected in the proposed Rule. People with disabilities are not static. Our needs, goals, and plans change over time. So too do our supports. For this reason, it is essential that HCBS recipients can initiate changes to a person-centered plan when new services are needed or when previously sought services prove unhelpful. It is especially important to ensure that person-centered plans.

We welcome language clarifying that waiver participants may not require an authorized representative in the person-centered planning process by substituting “if applicable” language. We are concerned that the absence of this language could undermine the waiver participant’s role as the center of the person-centered planning process should it be interpreted to require a representative where the service recipient does not want one. If the service recipient desires a representative or advocate, it is critical to ensure that that is a representative of the individual’s choosing and that a representative is only utilized in cases where an individual determines that such a representative would enable them to engage more effectively with the planning process.

ASAN has grave concerns with the proposed three-year implementation timeline. Delayed implementation of this Rule will harm service quality for many members of our community. This apprehension is compounded by our experiences advocating for service recipients impacted by the Settings Rule. The Settings Rule was first proposed on May 3, 2012 and finalized on January 16, 2014, with an effective date of March 17th, 2014. The finalized Rule allowed for a five-year state transition period. The expectation was that states would be prepared for full compliance with the Rule by March of 2019². However, this is not how the implementation timeline unfolded in practice. Instead, this process was delayed, first in May 2017, when CMS issued an informational bulletin announcing its intent to extend the implementation period until 2022,³ then in July 2020, when CMS issued a State Medicaid Director Letter extending the transition period for an additional year.⁴ Together, these extensions ballooned the state transition period to

² 79 C.F.R. § 2947 .

³ <https://www.medicaid.gov/federal-policy-guidance/downloads/cib050917.pdf>

⁴ <https://www.medicaid.gov/Federal-Policy-Guidance/Downloads/smd20003.pdf>

almost twice the length countenanced in the final Rule. Almost a decade passed between the final Rule and its implementation date. These delays prolonged the period during which HCBS recipients were not guaranteed the right to receive services in community settings where their rights to privacy, dignity, independence, and community integration were respected but did little to bring states closer to compliance at the end of the transition period.

We recognize the constraints imposed by the COVID-19 public health emergency and accompanying provider crisis. However, had states been diligent in pursuing compliance, they would have achieved it before the public health emergency. Because states had fallen behind on their obligations, the public health emergency compounded the problems of the drawn-out transition period. Consequently, few states were prepared for full compliance as of the final implementation date of March 17, 2023. CMS has responded with flexibility, allowing preemptive corrective action plans for states unable to reach compliance by this date. This has turned the final implementation of the Settings Rule into a soft launch rather than a firm deadline. Service recipients continue to wait for full enforcement of their rights often without transparent, accessible means to remain informed about the status of compliance efforts or address grievances.

These facts leave us skeptical of the value of any extended timeline for states to achieve compliance with the Access Rule. We are concerned that an excessive implementation period will delay service recipients' exercise of their rights, perpetuate low-quality service provision, and harm members of our community's quality of life. States should be able to implement many of the Rule's data collection and reporting requirements promptly. Many of these provisions are things states should have been developing as part of their HCBS settings compliance, which calls for a grievance process, quality reporting, and person-centered planning. Delay in the implementation of these provisions risks creating a lapse in HCBS oversight, frustrating compliance and keeping services low-quality and unaccountable for too many in our community.

Recommendation:

Reduce the implementation period for person-centered planning provisions to two years. We encourage HHS to enact a two-year implementation period for the person-centered planning provisions of the Access Rule instead of the three years proposed in the Notice. We recognize that states may need some time to implement regulatory changes, but states should already have adequate infrastructure in place to promptly comply with the data collection and reporting requirements under this provision of the Rule. These are systems that states should have been developing for years, and while this Rule may require state legislative or regulatory actions, these should not require more than two years to enact. Given the near-decade in which disabled individuals have waited to receive the rights afforded them under prior Rulemaking, it is critical that oversight measures such as those present in the Rule be introduced as expeditiously as possible.

Grievance system

We support the provision that would establish a grievance procedure for 1915(c) waiver recipients regarding person-centered planning, service plan requirements, and HCBS settings requirements. As discussed in the Proposed Rule, this is an area of continued concern for waiver service recipients and advocates. The lack of clear, transparent, and accessible grievance procedures makes it difficult to address failures to comply with the above requirements. A grievance procedure would give HCBS recipients recourse when their rights are violated.

Recommendation:

Shorten the response time for grievances to 45 days.

Some grievances will be in response to serious violations of service recipients' rights. This is especially true of the person-centered planning process and HCBS Settings Rule compliance. When serious violations occur, 90 days is too long to wait for resolution. While we appreciate the inclusion of an expedited review process for issues that pose a substantial risk to the health, safety, and welfare of the beneficiary, there are many subjects of grievances that would not meet these criteria but still constitute serious

violations of beneficiaries' rights. If someone is not receiving services, denied the ability to control their own schedules, or denied privacy in their homes, they should not need to wait three months -during which time they continue to experience lack of services or rights violations- for resolution.

Recommendation: Apply grievance procedure requirements to 1905(a) mental health rehabilitation services.

As discussed previously, we recommend that the HCBS provisions under this Rule include 1905(a) mental health rehabilitation services. These are understood to be HCBS provisions under the ACA. As the Rule notes, these services are provided to a large number of Medicaid recipients with mental health needs. Failure to extend these requirements leaves many Medicaid recipients with mental health disabilities without recourse if their rights are violated.

Incident Management System

We endorse the provisions in the proposed Rule which provide a standardized definition for critical incidents. As the regulation notes, there have been long-standing state compliance issues with federal requirements on critical incident monitoring and reporting. The provisions of this Rule offer an opportunity to enforce state obligations to develop and implement comprehensive incident reporting systems. We expect that the proposed 90% performance level minimum without additional "good cause" exceptions will be beneficial. The 90% threshold should provide any necessary leeway in cases of unexpected occurrences. As noted in the proposed Rule, lapses in compliance are associated with significant harm to beneficiaries. When states fail to swiftly and completely report cases of harm, misconduct and abuse they allow these abuses to continue, and leave disabled people in unsafe and abusive conditions. Even in exceptional circumstances, failure to reach this 90% performance threshold is evidence that disabled people are being harmed. We discourage the use of a longer timeline for the implementation of incident management systems. These are processes states should already have the infrastructure to implement. Further delays in compliance put the health and safety of beneficiaries at risk.

Recommendation: Require providers to report critical incidents to state Protection & Advocacy (P&A) agencies when reporting to the states.

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.”⁵ A requirement to report critical incidents to P&As can ensure that the state responds appropriately in cases where there is a risk of further harm. This proposal is consistent with requirements to report serious incidents in psychiatric residential treatment facilities to the P&A before the close of the following business day.⁶

HCBS Payment Adequacy

We encourage HHS’s efforts to ensure that HCBS direct support workers receive fair pay for their work. Direct support workers provide essential support to individuals with disabilities. They have long suffered from underpayment and lack of labor protections. The HCBS workforce is predominantly composed of women of color. Current statistics indicate that nearly 85% of HCBS direct support workers are women, 27% are Black, and 23% are Hispanic or Latinx⁷. Direct support workers are disproportionately low-income, with 43% of the workforce living in low-income households. More than 40% of direct support workers rely on publicly provided health coverage, primarily Medicaid, while 16% have no health coverage at all.

Direct support workers’ financial precarity is not itself a mistake of labor markets. Rather, it is the product of policy choices to exclude domestic workers, including home health aides, from labor protections. These policies date to the early 20th century. Inextricable from the history of American racism, they reflect the deliberate exclusion of jobs predominantly performed by people of color from efforts to improve blue collar working conditions. This legacy of racism persists through the present day. It harms both direct

⁵ 42 U.S.C. § 15043.

⁶ 42 C.F.R. § 483.374(b).

⁷ PHI, *direct support Workers in the United States: Key Facts* 6 (2022)

<https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-3/>.

support workers and the individuals with disabilities they support. The financial precarity experienced by direct support workers as a result of these policies forces many workers to exit the workforce for other employment, disrupting the stability of services available to individuals with disabilities. Those who continue to provide direct support are in turn left unable to provide the best quality service possible due to their own economic burdens, as well as disincentives on provider agencies to properly train and support workers due to these high rates of workforce turnover.

Inadequate staffing causes delays in accessing supportive services. For this reason, individuals often go without needed supports for months or years. Without these supports, many individuals are not able to participate in their communities as fully as possible and can find themselves in more restrictive settings than they would if their needs were met. Poor work conditions, wages, and benefits contribute to substantial staff turnover. This impedes effective service delivery to individuals with disabilities, making it difficult for individuals and families to build relationships with support staff and establish clear understandings of service recipients' needs, goals, and means of communicating. It also diminishes the quality of care, as high levels of staff turnover erode training and experience in best practices to support service recipients' autonomy and self-determination. When agencies lose training and experience to turnover, disabled people suffer. When staff cannot afford to continue to provide support, or experience poor health or burnout due to financial stress and lack of employer supports, disabled people suffer along with them.

Addressing the workforce crisis requires multiple simultaneous approaches. We support HHS's proposal of a pass-through mechanism to ensure that HCBS funding directed to worker compensation actually reaches workers. However, this is one of many measures needed to solve the problem. Without additional rate increases, pass-through risks reducing providers' funds, causing them to cut critical elements of service provision, including training, oversight, and transportation, or to shut down entirely. CMS should provide a thorough and transparent accounting of its rate determination methodology both to ensure that all components of direct support service are adequately funded and

to verify that the factual basis for HHS' chosen pass-through rate is established in the administrative record.

Thank you for the opportunity to provide our comments and feedback on the HCBS Access Rule as well as for your continued efforts to promote access to these essential services and supports for our community. This Rule provides many critical reporting frameworks and accountability mechanisms which stakeholders and service recipients have been seeking for years. The Access Rule is a crucial companion to prior Rulemaking and will be instrumental in ensuring that the rights of disabled people who receive HCBS services will be protected in practice, not just in concept.

If you have any questions, feel free to contact Gregory Robinson at grobinson@autisticadvocacy.org