



## American Association on Health & Disability

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**AAHD** - *Dedicated to better health for people with disabilities through health promotion and wellness*



# LAKESHORE

April 18, 2022

### **Re: Access to Care and Coverage for People Enrolled in Medicaid and CHIP: CMS RFI**

American Association on Health and Disability (AAHD) ([www.aahd.us](http://www.aahd.us))

Lakeshore Foundation ([www.lakeshore.org](http://www.lakeshore.org))

The American Association on Health and Disability (AAHD) ([www.aahd.us](http://www.aahd.us)) is a national non-profit organization of public health professionals, both practitioners and academics, with a primary concern for persons with disabilities. The AAHD mission is to advance health promotion and wellness initiatives for persons with disabilities. AAHD is specifically dedicated to integrating public health and disability into the overall public health agenda.

The Lakeshore Foundation ([www.lakeshore.org](http://www.lakeshore.org)) mission is to enable people with physical disability and chronic health conditions to lead healthy, active, and independent lifestyles through physical activity, sport, recreation and research. Lakeshore is a U.S. Olympic and Paralympic Training Site; the UAB/Lakeshore Research Collaborative is a world-class research program in physical activity, health promotion and disability linking Lakeshore's programs with the University of Alabama, Birmingham's research expertise.

Comments are consistent with, many times identical to, those submitted by the Consortium for Citizens with Disabilities (CCD).

Thank you for the opportunity to comment. If you have any questions please contact Clarke Ross at [clarkeross10@comcast.net](mailto:clarkeross10@comcast.net).

Sincerely,



**E. Clarke Ross, D.P.A.**

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***Objective 3: Whether care is delivered through fee-for-service or managed care, Medicaid and CHIP beneficiaries have access to timely, high-quality, and appropriate care in all payment systems, and this care will be aligned with the beneficiary's needs as a whole person. CMS is seeking feedback on how to establish minimum standards or federal "floors" for equitable and timely access to providers and services, such as targets for the number of days it takes to access services. These standards or "floors" would help address differences in how access is defined, regulated, and monitored across delivery systems, value-based payment arrangements, provider type (e.g., behavioral health, pediatric subspecialties, dental, etc.), geography (e.g., by specific state regions and rural versus urban), language needs, and cultural practices.***

***1. What would be the most important areas to focus on if CMS develops minimum standards for Medicaid and CHIP programs related to access to services? For example, should the areas of focus be at the national level, the state level, or both? How should the standards vary by delivery system, valuebased payment arrangements, geography (e.g., sub-state regions and urban/rural/frontier areas), program eligibility (e.g., dual eligibility in Medicaid and Medicare), and provider types or specialties?***

### **Minimum Standards for HCBS and LTSS**

It is incredibly important for CMS to develop minimum standards for access to services for HCBS. These standards should reflect a federal floor that states can build on.

Measuring access to long-term services and supports (LTSS) and home and community based services (HCBS) is different from measuring access to other clinical services and states are significantly "behind the curve" when it comes to measuring access due to a dearth of metrics

<https://clpc.ucsf.edu/publications/managed-long-term-services-and-supports-assessing-provider-network-adequacy>). The most frequently used access criteria such as time and distance standards are generally inappropriate to services provided in a fixed home, community, or institutional location. Additionally, LTSS and HCBS services have (1) a wider range of amount, duration, and scope variations (for example, home attendant services that may be prescribed for 7 hours per week, or 17 hours, or 27 hours, etc.) and (2) a wide range of unique conditions that may complicate providing services (such as travel time to an individual's home or very particular skills needed for at-home care for a specific individual). Given these factors, access to HCBS required for individuals' health, inclusion is less reliable. To help ensure access to LTSS and HCBS, CMS should develop metrics to evaluate:

- If needed services are being prescribed. HCBS is not a medical service. However, in LTSS and HCBS, it is all too common to evaluate need based on provider and system capacity rather than actual individual need. In this process, individuals are routinely pressured into accepting far less services and support, which can lead to serious and sometime deadly consequences.
- If provider capacity is sufficient. (The more typical network adequacy analysis).
- What proportion of prescribed hours is *actually* being filled. One of the most pervasive problems in LTSS and HCBS is that many individuals only receive a fraction of the services they need even, though they *have* an approved prescription for the services (for example, they may receive only 20 of their 40 hours prescribed), especially due to provider shortages.
- The number of providers identified during the planning process/provider change period who were actually willing to accept the beneficiary for all needed services. how assessed "need" is being inappropriately influenced, for example, basing need on extraordinary services and supports from friends or family, or unreasonable expectations on service recipients themselves.

CMS should also develop methods to stratify metric data to identify how aggregated access data may mask serious access difference among the extremely diverse population relying on these services.

While Medicaid requires states to ensure that payments are sufficient to enlist enough providers so that services are available at least to the extent that such services are available to the general population, there is often no identifiable comparison in Medicare or private insurance for these services. Access standards for HCBS are underdeveloped.

To address inadequate rates, we recommend that CMS amend the equal access rule to expressly include HCBS waivers and managed care. Specifically, CMS' distinction between state plan services and services provided via HCBS waivers makes little sense as a matter of statutory

interpretation, and it is bad policy. Nothing in 42 U.S.C. § 1396a (a)(30)(A) restricts its application to a narrow set of “state plan services.”

While states are required to report on their rate methodology when they request a new HCBS waiver, CMS could add additional safeguards to ensure that this analysis of rates will meet the needs of participants. This look-behind could include any number of factors that would inform the sufficiency of rates, including an analysis of individuals who had hours of waiver services approved but unstaffed or understaffed, a requirement that states analyze direct service provider turnover and capacity, and that states explain if their rates are adjusted for inflation, and if not, how that impacts availability of services. We also recommend including additional factors to ensure that rates are sufficient to meet the needs of people who may need staff with special training or skills, such as the ability to use assistive technology; require one or more forms of AAC to effectively communicate with others; ASL or other language skills; the training and skills to handle complex behavior needs without abuse, neglect, or over medication; and other needed cultural competency skills. If such needs are not part of the rate planning, people with complex needs will continue to be denied care or have limited access and disparities in access to HCBS will worsen.

### **Minimum Standards for Behavioral Health**

For specialty behavioral health, any minimum standards developed related to access to services must be measured by more specific categories than simply “behavioral health.” Simply measuring access to “inpatient” and “outpatient” behavioral health care is insufficient. Instead, access to sub-specialty behavioral health services should be monitored separately.

As a starting point, it is important to disaggregate SUD providers and mental health providers, to avoid situations where a plan meets the defined access standard by only providing mental health but not SUD services, or vice versa.

*3. How could CMS consider the concepts of whole person care or care coordination across physical health, behavioral health, long-term services and supports (LTSS), and health-related social needs when establishing minimum standards for access to services? For example, how can CMS and its partners enhance parity compliance within Medicaid for the provision of behavioral health services, consistent with the Mental Health Parity and Addiction Equity Act? How can CMS support states in providing access to care for pregnant and postpartum women with behavioral health conditions and/or substance use disorders? What are other ways that CMS can promote whole person care and care coordination?*

### **Enhancing Compliance with the Mental Health Parity and Addictions Equity Act**

Medicaid is the largest payer of mental health services in the United States and plays a vital role in ensuring access to behavioral health services for Medicaid's more than eighty million low-income enrollees (<https://www.medicaid.gov/medicaid/benefits/behavioral-health-services/index.html>). Current federal parity protections apply only to Medicaid Managed Care Organizations (MCOs), Medicaid Alternative Benefit Plans (ABPs) and the Children's Health Insurance Program (CHIP), but not to fee-for-service Medicaid. To truly strengthen behavioral health coverage in Medicaid, federal parity protections should also extend to fee-for-service Medicaid. CMS should work with Congress to extend parity requirements.

Much work remains to truly enforce the existing promises of the Mental Health Parity and Addictions Equity Act (MHPAEA) within Medicaid and CHIP. To improve parity compliance, CMS must take a more proactive role in enforcing MHPAEA. Under current regulations, parity analysis is left primarily to states or MCOs (42 C.F.R. § 438.920). States also need support and guidance from federal enforcement agencies to be able to conduct thorough parity analysis. CMS should mandate disclosure and transparency requirements for all health plans that enables ready analysis.

Parity enforcement system remains largely complaint driven, with the onus placed on individuals to file appropriate appeals and complaints, and there is no clear way to file a complaint for Medicaid or CHIP. Navigating this patchwork system of enforcement is confusing and overwhelming. To improve this, CMS should coordinate with other parity enforcement agencies to create a centralized, easily accessible, public complaint process. Further enforcement agencies should work together to produce easy-to-understand educational materials for the general public. These materials should include clear examples of what parity violations look like and should be part of an ongoing outreach campaign to provide up-to-date support, information, and resources on behavioral health parity.

***Objective 4: CMS has data available to measure, monitor, and support improvement efforts related to access to services (i.e., potential access; realized access; and beneficiary experience with care across states, delivery systems, and populations). CMS is interested in feedback about what new data sources, existing data sources (including Transformed Medicaid Statistical Information System [T-MSIS], Medicaid and CHIP Core Sets, and home and community based services (HCBS) measure set), and additional analyses could be used to meaningfully monitor and encourage equitable access within Medicaid and CHIP programs.***

***1. What should CMS consider when developing an access monitoring approach that is as similar as possible across Medicaid and CHIP delivery systems (e.g., fee-for-service and managed care programs) and programs (e.g., HCBS programs and dual eligibility in Medicaid and Medicare) and across services/benefits? Would including additional levels***

*of data reporting and analyses (e.g., by delivery system or by managed care plan, etc.) make access monitoring more effective? What type of information from CMS would be useful in helping states identify and prioritize resources to address access issues for their beneficiaries? What are the most significant gaps where CMS can provide technical or other types of assistance to support states in standardized monitoring and reporting across delivery systems in areas related to access?*

*2. What measures of potential access, also known as care availability, should CMS consider as most important to monitor and encourage states to monitor (e.g., provider networks, availability of service providers such as direct service workers, appointment wait times, grievances and appeals based on the inability to access services, etc.)? How could CMS use data to monitor the robustness of provider networks across delivery systems (e.g., counting a provider based on a threshold of unique beneficiaries served, counting providers enrolled in multiple networks, providers taking new patients, etc.)?*

### **Managed Care and Managed LTSS Network Access**

Some beneficiaries in managed care spend untold hours searching for available providers for services they need, and many give up after fruitlessly wading through wrong numbers, outdated listings, and providers who are not accepting new patients. Others end up with surprise bills for out-of-network services due to errors in provider directories, or simply cannot find a listed provider at all.

States must work to eliminate the burden of this bureaucratic red tape, and one of the best ways to do that is transparency. CMS could build on some of the provider directory accuracy provisions from the 2021 Consolidated Appropriations Act and require states to update MCO and FFS provider directories at least every quarter, respond to consumer network questions promptly, and hold Medicaid beneficiaries harmless if they obtain services from an out-of-network provider listed as in-network. CMS could require states to publish periodic (at least annual) scorecards for accuracy and typical appointment wait times for different services in FFS and MCO networks. Such scorecards would need to include benchmarks with [enforceable standards](#) to incentivize states and plans to comply.

The 2016 Managed Care rule update created a new mandatory EQR activity to validate network adequacy, and the preamble to that rule suggested that CMS was looking at increasing direct testing of provider networks. The protocol laying out how states should conduct this new required activity has not yet been released, but evidence collected in the intervening years has continued to accumulate reinforcing the importance of actively auditing MCO's assurances about their provider networks and directories.

In 2014 HHS' Office of the Inspector General [conducted secret shopper surveys](#) of Medicaid plans that found over half the provider directory entries were incorrect or not available for appointments. Since then, a number of states have also found that direct testing of networks and provider directories through mechanisms like secret shopper surveys helps identify consumer access barriers. States including Texas, Maryland, Missouri, New Hampshire, and Ohio have conducted surveys that revealed massive error rates in provider directories and documented long wait times to obtain a scheduled appointment. Maryland's [extensive survey of on-line and paper provider directories](#) led to nine corrective action plans for MCOs in 2019. Texas' [EQRO study](#), which only successfully contacted 52% of providers in 2018, includes a list of best practices for more accurate provider directories.

Until the new CMS protocol is released, states that do not validate network adequacy face no penalties. Enhanced match for activities related to required network adequacy validation is also contingent on the new protocol. States may be able to classify direct testing of this kind under existing optional EQR activities that qualify for enhanced match. CMS should promote these active auditing with states, including through technical assistance that advertises how states can obtain higher 75% FMAP for conducting MCO provider network availability surveys through EQR. The TA should detail common problems designing and conducting these surveys to ensure that data collected is actionable.

CMS should also recommend how to design these surveys to account for potential differences in accessibility for medically underserved groups, including people with disabilities, people with limited English proficiency, and people of color. Such individuals should be involved from the beginning on designing, implementing and conducting this survey research. For example, many people with disabilities still struggle when network providers lack the equipment necessary to provide services that accommodate their unique needs.

### **HCBS Core Measure Set**

We have long advocated for robust, meaningful, publicly reported home-and-community-based services (HCBS) quality measures in Medicaid. HCBS quality measures are an essential component of a broader oversight system to ensure that Medicaid enrollees, including people with disabilities and older adults receive services that meet their needs, goals and preferences and help them thrive in the community. In our work as a coalition, we see the need for these measures as an assurance that people who use HCBS have access to the quality services they need to enjoy the full benefits of community living.

We appreciate that the Centers for Medicare and Medicaid Services (CMS) has recognized the urgency and importance of creating a recommended set of HCBS measures. The HCBS core measure set will raise expectations for states and health plans to prioritize HCBS measurement and promote standardized methodologies that make it easier to create benchmarks and compare

across states. In the future, a robust measure set may provide HCBS participants with data they can use to choose health plans (and eventually providers).

Still, we need much more and faster. Given how critical HCBS is to people with disabilities and older adults, and given the large share of Medicaid spending dedicated to HCBS, a CMS recommended HCBS core measures set is long overdue. (MACPAC, *FactSheet, Medicaid Home- and Community-Based Services: Characteristics and Spending of High-Cost Users*, 1 (June 2018).) We urge CMS to implement an HCBS core set and move toward mandatory reporting. This could parallel the transition to required state reporting of the child core set and adult behavioral health measures by FY 2024 (<https://www.macpac.gov/wp-content/uploads/2020/03/State-Readiness-to-Report-Mandatory-Core-Set-Measures.pdf>). In the meantime, we ask that CMS continue to support the development and implementation of measures that help address some of the many gaps, including especially *outcome* measures, provider-level measures, and a commitment to reporting key measures stratified by key population demographics.

Most of the available metrics for HCBS depend on surveys of individuals' experience of care. Survey instruments like National Core Indicators (NCI), NCI-AD, CMS's HCBS CAHPS survey, and the Council on Quality and Leadership's Personal Outcome Measures tool, provide rich data across many important areas, including autonomy, community integration, care quality, and person-centered planning. These are some of the best data sources we have, but they are also limited. Because of small sample sizes in many states, the results provide only the broadest overview of quality and may not pick up on important variations across populations, geography, plans, or providers. Due to the infrequent implementation – every other year in some states – they also may miss changes over time.

To the extent that the core measure set depends largely on these survey instruments, CMS should make clear the expectation that states broaden their sample size to allow for more fine-grained analysis of performance. Moreover, CMS should take steps to fast track other approaches to measuring HCBS access, such as using T-MSIS claims data, that can provide more timely results at the provider level. Two areas of particular need are:

- Assessing caregiver needs. 53 million adults play key roles in providing unpaid LTSS to family and friends. Nearly one-quarter report that caregiving is worsening their own health and one-fifth report caregiving is straining their finances. We recommend that CMS urge states to require care managers or health plans to conduct assessments of the physical, emotional, mental, social, and financial needs of family caregivers or natural supports, and address the needs identified. This is a promising practice that at least six states require of managed care plans.
- Addressing workforce gaps. Workforce gaps, particularly in direct care, lead directly to low quality care. We urge CMS to support development of measures, including measures



of cultural competence (defined by the National Quality Forum as the degree to which the workforce delivers services aligned with the cultural background, values, and principles of the HCBS consumer). In the meantime, we urge CMS to recommend states track and report ratios of support workers to participants and staff turnover.

Finally, people with disabilities and older adults who receive these services should be involved in the design, development, implementation, and selection of such measures.

### **Workforce Measures**

The role of the direct-care workforce in the availability of and access to HCBS is especially crucial. There is also a lack of basic data on the HCBS workforce at the state and federal levels (PHI 2021). This makes tracking the workforce and addressing fundamental workforce issues difficult. “State officials and beneficiary advocates whom we interviewed shared that this lack of data is particularly challenging because, without the data, they cannot accurately estimate the size of the workforce or the average income.” (MACPAC 2022).

We urge CMS to establish required reporting on measures and metrics related to workforce volume, workforce stability, and compensation.

### **Measuring Equity**

If there is one urgent lesson to take away from the tragedy of this pandemic, it is that the U.S. health system has to do much more to promote health equity. Health equity should be at the forefront of Medicaid quality measurement endeavors. CMS’s national quality strategy, which sets racial and ethnic health equity as a “foundational principle,” identifies specific actions that could help states improve health equity, two of which relate directly to data collection:

- stratifying quality reporting by race, ethnicity, disability, and primary language/expressive means to help identify health inequities; and
- building IT infrastructure that can readily incorporate such demographic data.

The proposed HCBS core measure set must build on these recommendations to set an expectation that all states stratify core quality data by key demographic categories – including race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary language/expressive means, urban/rural environment, and service setting.

In accordance with the national quality strategy, CMS should provide states with technical assistance and enhanced administrative match to update computer systems to be able to report each core measure (including the adult and child sets) by key demographic groups.