



**CONSORTIUM FOR CITIZENS  
WITH DISABILITIES**

November 18, 2020

**CCD Comments on HCBS Recommended Core Measure Set RFI**

Submitted electronically to [HCBSMeasuresRFI@cms.hhs.gov](mailto:HCBSMeasuresRFI@cms.hhs.gov)

**Re: Request for Information: Recommended Measure Set for Medicaid-Funded Home and Community-Based Services (HCBS)**

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations advocating together 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. We, the undersigned members of the CCD Health and Long Term Services and Supports Task Forces, thank you for the opportunity to comment on the proposed 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 essential to ensure 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. Moreover, it will help improve HCBS quality and may provide HCBS participants with data they can use to choose health plans (and eventually providers).

Still, we need much more. Given how critical HCBS is to people with disabilities and older adults, and given that HCBS now represents nearly one quarter of fee-for-service Medicaid spending (with additional spending in managed care), a CMS recommended HCBS core measures is long overdue.<sup>1</sup> We urge CMS to move more swiftly to adopt a mandatory core set of HCBS measures. This could parallel the transition to required state reporting of the child core

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<sup>1</sup> MACPAC, *FactSheet, Medicaid Home- and Community-Based Services: Characteristics and Spending of High-Cost Users*, 1 (June 2018). See also, MACPAC, *MACStats: Medicaid and CHIP Data Book*, 57 (Dec. 2019).

set and adult behavioral health measures by FY 2024.<sup>2</sup> In the meantime, we ask that CMS continue to support the development and implementation of measures that help address some of the many gaps identified in this RFI, including especially *outcome* measures and a commitment to reporting measures stratified by key population demographics.

More immediately, we submit the following recommendations based on the proposed HCBS core measure set (Each is explored in greater detail below.):

- 1) **Report and make decisions with transparency and community input**
  - Post annual reports on CMS’s website based on state results from the base and extended measure sets; and
  - Review and revise the recommended measure set annually, using a process that involves extensive engagement with HCBS participants and advocates. We also include several other process recommendations in our detailed comments.
- 2) **Develop more measures that can be meaningfully implemented at the provider level.**
  - Provider level data is arguably the most readily actionable level for addressing care quality and would still provide a base for evaluating performance upstream at the plan or state level. Provider-level data also would more effectively inform ongoing monitoring of HCBS settings.
- 3) **Strengthen the base measures related community integration.** The ability to live fully integrated in the community is critical to quality of life for people with disabilities, but is underdeveloped in key proposed measure set domains such as “community inclusion” and “choice and control.”
- 4) **Elevate health equity** in every measure by emphasizing the importance of stratification and cross-tabulation of data by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary language/expressive means, rural/urban environment, and service setting for all core measures. Provide states with technical support and, where possible, financial resources to expand stratification, including on all measures.<sup>3</sup>
- 5) **Fill in key measure gaps**
  - Reinforce the importance of caregiver supports by encouraging states to require care managers or health plans to assess and respond to the identified needs of family caregivers. This promising practice can temporarily fill in for the lack of measures on caregiver supports.
  - Prioritize measure development related to workforce gaps that result in low-quality care. Suggest that states track and report ratios of support workers to participants and worker turnover.
- 6) **Align core measures with elements of the HCBS settings rule to streamline oversight and encourage states to take up core measures.** States already have to do ongoing monitoring of their HCBS settings, and aligning core measures with this other oversight regime could reduce administrative burden for states and encourage core measure uptake.

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<sup>2</sup> See MACPAC, *Chapter 2: State Readiness to Report Mandatory Core Set Measures*, 68 (Mar. 2020), <https://www.macpac.gov/wp-content/uploads/2020/03/State-Readiness-to-Report-Mandatory-Core-Set-Measures.pdf>.

<sup>3</sup> "Expressive means" includes the use of natural speech and/or augmentative and alternative communication.

Following are our more detailed comments:

## 1) Ensure Public Transparency in Review and Reporting

We recommend CMS **publicly disclose – at least annually -- all state reported results** from core and extended measures, similar to the way CMS currently posts annual reports of the adult and child core measure set results. Without that transparency, consumers will not be able to use quality data for plan or provider selection. To the extent that states use proprietary tools (such as National Core Indicators (NCI) or National Core Indicators – Aging and Disability (NCI-AD)) to collect core measure data, CMS should work to ensure data will be publicly available at no charge for quality measure reporting, with minimal data lag.

We also recommend that CMS **annually review and refine the HCBS measure set** and how the measure set has helped identify and improve service outcomes. The review process should **prioritize the voices of consumers and consumer advocates** and include plain language materials accessible by HCBS users, including those with intellectual and developmental disabilities. Annual review would mirror the review of adult and child core measures, and is especially important given the ongoing measure development in HCBS, including the critical work at the University of Minnesota’s Institute on Community Integration on outcomes measures.<sup>4</sup>

Generally, we urge CMS to **prioritize “Importance of the Measure” and “Usability and Use”** as the most important criteria in measure selection. Overall, we agree with the five selection criteria: 1) Importance to Measure and Report; 2) Scientific Acceptability of the Measure Properties; 3) Feasibility; 4) Usability and Use; and 5) Related and Competing Measures. But we believe assessing the “importance of the measure” to people receiving HCBS and “usability” of the data by these individuals should be primary. While feasibility is important, this should not exclude measures that require the collection of survey-based, person-reported outcome measures. While survey-based measures can be labor intensive and there are financial costs for states and/or health plans, these surveys are often the only way to assess meaningful HCBS outcomes. Given the current shortage of endorsed HCBS measures, we agree with CMS’s approach to allow temporary inclusion of promising measures that might not yet meet strict guidelines for scientific acceptability and feasibility.

## 2) Encourage More Reporting at the Provider Level

Many of the questions in the core measure set derive from HCBS CAHPS or NCI/NCI-AD. These survey tools are among the best we currently have to get a clear picture of the quality of HCBS services in Medicaid. However, few states have dedicated the resources to administer a

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<sup>4</sup> The UM-ICI receives federal funding through several HHS agencies, including the Administration on Community Living and the Administration on Intellectual and Developmental Disabilities, and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

large enough sample to give any kind of clear statistical picture of care quality at the provider level and can really only inform state or perhaps plan level performance.

Over the long run, we believe that a structure that focuses at the provider level and then aggregates provider results to paint a broader plan or state-wide picture would be the best approach. For example, Council on Quality and Leadership's Personal Outcome Measures (POM) is a provider-level focused instrument and several states (e.g., NY, ND, SD) have aggregated these provider foci into larger analyses at state level. Even if states do not use POMS, it provides a useful model to consider how a provider-level focused core set might usefully function.

We realize that in many cases the data infrastructure for collecting and reporting measures at the provider level may be lacking. For example, many state case management records systems have limited functionality and may still rely on mail, fax, or phone for some data transfers.<sup>5</sup> Given the positive reliance in the draft measure set on HCBS participant survey data – such as NCI and HCBS CAHPS – we encourage CMS to **support states in using larger samples that enable measurement at the provider level**, which is important for participants and for state oversight purposes.

A stronger provider-level focus would also more readily allow the HCBS core measures to inform oversight and monitoring of important Medicaid HCBS regulatory requirements, such as the HCBS Settings Rule, person-centered planning, and the Medicaid managed care regulations. The HCBS Settings Rule, in particular, requires ongoing monitoring of individual providers. While state or program-level data from a participant experience survey may prove useful as an indirect validation of provider-level monitoring, having a large enough sample to reach to the provider level could allow synergies between HCBS quality reporting and on-going monitoring of HCBS settings.<sup>6</sup>

### **3) Strengthen the Base Measures on Community Integration**

Community inclusion, and choice and control over one's life, are core to why HCBS are so important. The availability and quality of these services are essential to maximizing independence, autonomy, and quality of life for older people and people with disabilities. To know we are achieving meaningful community inclusion, we need to measure it.

Critical aspects of community inclusion overlap with other NQF domains like "choice and control" and "person-centered planning." For example, the composite Community Inclusion measure from HCBS CAHPS is listed under Choice and Control. Even incorporating the measures in those domains, however, the base measures in the proposed set are

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<sup>5</sup> Lewin Group, *Home and Community-Based Services Systems Map Report*, 6 (Sept. 12, 2018), <https://www.medicaid.gov/sites/default/files/2020-01/hcbs-systems-map-report.pdf>.

<sup>6</sup> Several of the common participant experience survey questions have already been cross-walked to the Setting Rule.

underrepresented and underdeveloped. We recommend shifting the following measures to this domain:

- HCBS CAHPS (this is current under Choice & Control)
  - Community Inclusion and Empowerment Composite Measure (Q 75, 77, 78, 79, 80, 81)
- NCI-AD (these are currently in the extended set)
  - NCI-AD-1: Percentage of people who are as active in their community as they would like to be
  - NCI-AD-2: Percentage of people who get to do things they enjoy outside of their home as much as they want to
  - NCI-AD-7: Percentage of people who are able to see or talk to their friends and family when they want to

We also recommend shifting the HCBS CAHPS Transportation to Medical Appointments Composite Measure from this domain, since it fits better in other domains.

We note that several measures in other domains are essential for assessing community inclusion, including CAHPS HCBS Q 56, 57: Choosing the Services That Matter to You Composite Measure, and NCI 50: The percentage of people who say they were able to choose the services they get as part of their service plan.

These changes would help align the measure set with requirements of the Medicaid HCBS Settings Rule, and draw from recommendations in a recent white paper<sup>7</sup> to focus on measuring the following outcomes:

- increased number of HCBS participants deciding what to do and with whom; increased number of HCBS participants having relationships with community members who are not paid to provide support or services; and
- increased number of HCBS participants having access to transportation or other support to access to community activities of choice.

While progress has been made in developing robust measures to gauge the extent and authenticity of community inclusion, we remain far from realizing strong measures that reflect the level of day-to-day choice and control an individual has over their life and daily schedule. In addition to incorporating all possible measures thereof from the extended set into the base set, we urge CMS to work with the Administration to encourage more measure development in this area.

It is critical that CMS ensure that the HCBS core measures inform oversight and monitoring of important Medicaid HCBS regulatory requirements, such as the HCBS Settings Rule, person-

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<sup>7</sup> HCBS Advocacy Coalition and the Community Living Policy Center at the Lurie Institute for Disability Policy at Brandeis University, "Tracking Progress and Success of Implementation of the HCBS Settings Rule: Potential Outcomes and Measurements" (available at <https://hcbadvocacy.org/2020-outcomes-paper/>)

centered planning, and the Medicaid managed care regulations. The purpose of the HCBS Settings Rule as set forth in the preamble is to ensure that all HCBS participants receive the full benefits of community living. Thus, a core measure set that aligns with and reinforces the HCBS Settings Rule will help streamline administrative oversight and increase public transparency. Several measures included in the base and extended sets directly align with elements of the HCBS settings rule measuring whether people have choice of roommates, ability to eat when they want and host visitors at any time, control over their daily schedule, lockable doors, and more.<sup>8</sup>

Finally, we also think it is crucial that CMS identify and include a measure that gauges whether every individual has been offered the option of choosing a non-disability specific setting to receive their HCBS. This is a key element of the HCBS Settings Rule that is also a bedrock condition for successful community integration and could also be utilized by managed care to measure rebalancing efforts, one of the three required quality domains. Moreover, documenting the answer to this simple question would paint a clearer picture of provider capacity levels in the state and could help determine where to direct HCBS resources to bolster community supports. But availability of non-disability specific options is not a measure well reflected in the proposed core measure set.

#### **4) Elevate Health Equity as a Quality Priority, Including More Data Stratification**

COVID-19 has painfully reexposed the deep inequities in our healthcare system. COVID's terrible impact on older adults and people with disabilities – particularly those in congregate settings – is frequently in the news. A second dominant narrative highlights COVID's disparate impact on communities of color. In reality, these two narratives should be intertwined. We know already that racial and ethnic health disparities common in acute care settings have also been found in HCBS.<sup>9</sup> Direct care workers who provide HCBS are also disproportionately Black or other women of color.<sup>10</sup> But nine months into this pandemic, we still have lots of reports of specific outbreaks but very little systemic data on the full extent of COVID-19's effect on people of disabilities, let alone people of color with disabilities and the workforce that supports them. 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. Medicaid should be ground zero for this change.

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8 These include NCI 50, NCI 33 and 34, NCI 92, NCI-AD 16, NCI-AD 28-30, NCI-AD 32, and several composite measures from the HCBS CAHPS survey.

9 See, e.g., CD Fabius et al., *Racial Disparities in Medicaid Home and Community-Based Service Utilization and Expenditures among Persons with Multiple Sclerosis*, 18 BMC Health Servs. Res. 773 (2018).

10 Stephen Campbell, *Racial and Gender Disparities within the Direct Care Workforce: Five Key Findings*, 8, PHI (Nov. 2017), <https://phinational.org/wp-content/uploads/2017/11/Racial-and-Gender-Disparities-in-DCW-PHI-2017.pdf>. See also, Michael Martz, 'Us Against Them': Workers Cite Racial Divide on Front Line of Long-term-care Fight Against COVID-19, RICHMOND TIMES-DISPATCH, Aug. 14, 2020, [https://richmond.com/news/virginia/us-against-them-workers-cite-racial-divide-on-front-line-of-long-term-care-fight/article\\_225839e0-82f1-5668-9da0-a92ced009e1a.html](https://richmond.com/news/virginia/us-against-them-workers-cite-racial-divide-on-front-line-of-long-term-care-fight/article_225839e0-82f1-5668-9da0-a92ced009e1a.html).

Health equity should be at the forefront of any 2020 Medicaid quality measurement endeavor, particularly one involving older adults and people with disabilities. CMS's national quality strategy, finalized in 2016, sets four "foundational principles" that guide the agency's efforts to improve health and healthcare. The very first principle is to eliminate racial and ethnic disparities.<sup>11</sup> The strategy 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.<sup>12</sup>

The proposed HCBS core measure set in this RFI includes one domain for measures related to health equity, but that domain includes just a single measure (in the extended set) – an NCI-AD question on receiving services in their preferred language. The extended set also suggests that states should attempt to stratify data from "one or more measures (to be determined) by race, ethnicity, rural/urban, population type, dual-eligible status, etc."<sup>13</sup> Aside from this brief reference, the words "disparity" and "equity" appear nowhere else in the RFI main text or questions asked. This is a missed opportunity to fulfill CMS's stated quality principles.

Stratifying core quality data by key demographics deserves a much higher priority in this document and in Medicaid quality reporting more generally. To understand the complexities of disparate health care access for people with disabilities, policymakers need data broken down by key demographic groups for all reported measures, not just one. 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. Measure stewards should build this capability into the measure development process. Data stratification must become a basic expectation for quality data reporting.

We recommend CMS specify that the state reporting on each core measure include stratified data by race, ethnicity, disability status, age, sex, sexual orientation, gender identity, primary language/expressive means, rural/urban environment, and service setting. Where possible, such data should also be cross-tabulated, for example, showing the interaction between race and disability status. This data is essential to identify health inequities, target interventions at the communities or populations that need them most, and track progress in reducing or eliminating them.

We also recommend CMS provide states with technical assistance and enhanced administrative match to update computer systems to facilitate reporting each HCBS measure (as well as adult

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11 CMS, *CMS Quality Strategy 2016*, 5 (2016), <http://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/QualityInitiativesGenInfo/Downloads/CMS-Quality-Strategy.pdf>.

12 *Id.* at 10.

13 RFI, at 32.



and child measures) by key demographic groups. Stratifying data is not nearly as challenging if it is included as a basic design expectation from the beginning.

### *Holistic Health and Data Stratification*

Relatedly, we note that the NQF domain on holistic health and functioning would also benefit from a larger emphasis on data stratification. The RFI proposal includes just a handful of MLTSS measures in the extended measure set, including the proportion of HCBS enrollees who received a flu shot, who are screened for fall risk, and who have all-cause readmissions to hospitals within 30 days of discharge. These three measures would hardly capture the full range of holistic health quality for people using HCBS.

Policymakers, advocates, and enrollees would get a much clearer picture of the dimensions of holistic health for people using HCBS if states reported standard adult and child core measures stratified by disability and other key demographic characteristics. This would not require adding separate measures to the HCBS core measure set, but would help identify health disparities affecting people with disabilities and older adults related to common chronic conditions, behavioral health issues, BMI, and other health issues already included in the existing core measure sets (at least to the extent that HCBS users are already included in data reporting for the adult and child core sets).

We recommend that CMS retain the proposed measures related to exercise, fall risk, and hospital discharge remain in the extended measure set.

## **5) Develop New Measures and Approaches to Fill Gaps**

### *Assessing caregiver needs*

We call attention to the lack of any measures of caregiver supports in the draft measure set. This gap is particularly troubling, given the major role that 53 million adults play in providing unpaid LTSS to family and friends, and given that nearly one-quarter report caregiving is worsening their own health and one-fifth report caregiving is straining their finances.<sup>14</sup> While measures are being developed, 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.<sup>15</sup>

### *Addressing workforce gaps*

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14 AARP and National Alliance for Caregiving, *Caregiving in the United States 2020*, Washington, DC: AARP, (May 2020), <https://doi.org/10.26419/ppi.00103.001>.

15 AARP Public Policy Institute, *Recognition of Family Caregivers in Managed Long-Term Services and Supports*, (Apr. 2020), <https://www.aarp.org/content/dam/aarp/ppi/2020/04/recognition-of-family-caregivers.doi.10.26419-2Fppi.00090.001.pdf>.



The proposed measures on workforce focus do not include any that address the low-quality care that results from workforce gaps, particularly in direct care. We urge CMS to support development of these 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).<sup>16</sup> In the meantime, we urge CMS to recommend states track and report ratios of support workers to participants and staff turnover.

## **Conclusion**

Thank you again for moving the ball forward on HCBS quality measurement. We hope these recommendations will help inform your next steps in developing and strengthening the HCBS Core measure set.

If you have any questions regarding these comments, please contact David Machledt, Health Task Force co-chair (machledt@healthlaw.org).

Sincerely,

American Association on Health and Disability  
American Network of Community Options & Resources (ANCOR)  
American Physical Therapy Association (APTA)  
American Therapeutic Recreation Association  
Association of University Centers on Disabilities (AUCD)  
Autistic Self Advocacy Network  
Autism Society of America  
Bazelon Center  
Center for Public Representation  
CommunicationFIRST  
Disability Rights Education and Defense Fund (DREDF)  
Easterseals  
Epilepsy Foundation  
Justice in Aging  
Lakeshore Foundation  
National Association of Councils on Developmental Disabilities  
National Council on Independent Living (NCIL)  
National Disability Rights Network  
National Down Syndrome Congress

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16 National Quality Forum, *Quality in Home and Community-Based Services to Support Community Living: Addressing Gaps in Performance Measurement*, (Sept. 2016), [http://www.qualityforum.org/Publications/2016/09/Quality\\_in\\_Home\\_and\\_Community-Based\\_Services\\_to\\_Support\\_Community\\_Living\\_Addressing\\_Gaps\\_in\\_Performance\\_Measurement.aspx](http://www.qualityforum.org/Publications/2016/09/Quality_in_Home_and_Community-Based_Services_to_Support_Community_Living_Addressing_Gaps_in_Performance_Measurement.aspx).

National Health Law Program  
National Respite Coalition  
TASH  
The Arc of the United States  
The National Multiple Sclerosis Society  
World Institute on Disability (WID)