UCLA CENTER FOR RACIAL & DISABILITY JUSTICE

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Mehmet Oz, MD
Centers for Medicare & Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, Maryland 21244-1850

RE: Medicaid Program; 2028 Medicaid Home and Community-Based Services Quality Measure Set

Dear Administrator Oz,

The Center for Racial and Disability Justice (CRDJ) at UCLA School of Law welcomes the opportunity to submit this comment in response to the Centers for Medicare & Medicaid Services proposed 2028 Medicaid Home and Community-Based Services (HCBS) Quality Measure Set (CMS-2453-NC). CRDJ is a research center focused on advancing justice at the intersection of race and disability through interdisciplinary research, policy analysis, community-engaged knowledge mobilization, and support for disability justice movements. These comments are co-authored by Dr. Hope Sparks, Disability Policy Research Fellow at Northwestern University, whose research centers on guardianship policy and alternatives to guardianship.

We recognize the importance of nationally standardized HCBS quality measurement. HCBS are central to community living, autonomy, family life, safety, economic security, and self-determination for disabled people, older adults, and others who rely on Medicaid-funded services and supports [1-3]. A national quality measure set can provide important infrastructure for transparency, quality improvement, and accountability across state Medicaid programs [4]. However, there are areas where the proposed *2028 HCBS Quality Measure Set* should be strengthened to assess equity, quality, and accountability more effectively. The central concern is that a national HCBS quality framework that does not require meaningful equity stratification, disaggregated reporting, lived-experience measures, material-access measures, and co-production with people receiving HCBS will be insufficient for assessing whether Medicaid-funded HCBS are equitably supporting community living, self-determination, safety, and access to needed services. We propose the following recommendations:

- **Equity Stratification Is Necessary to Establish a Meaningful Baseline:** The first years of mandatory reporting will shape how future HCBS quality and disparities are understood. Baseline data that does not capture race, ethnicity, language, disability, and other equity dimensions will provide an incomplete foundation for quality improvement.

- **Geographic Stratification Alone Cannot Capture HCBS Inequities:** Geography is important, but it cannot substitute for race, ethnicity, disability type, language, age, rurality, and other factors relevant to understanding how HCBS systems operate for different communities.
- **Aggregate Reporting Obscures Program, Plan & Population-Level Gaps:** Statewide aggregate data may conceal disparities within specific waivers, HCBS authorities, managed care plans, provider networks, regions, or service systems.
- **Self-Determination, Safety & Community Are Core Measures of Quality:** Measures that assess service navigation, complaint access, safety, choice, community participation, and personal goals are central to HCBS quality.
- **Documentation Measures Must Be Paired with Material Access Measures:** Assessments and person-centered plans matter, but they do not by themselves show whether people receive needed services, equipment, mental health supports, communication access, transportation, or community-based supports.
- **Co-Production Is Necessary for Equity-Centered Measure Development:** Measure development, stratification categories, implementation, interpretation, and quality improvement should be informed by the lived expertise of people receiving HCBS, particularly racialized and multiply marginalized disabled people.

BACKGROUND

CMS proposes the *2028 HCBS Quality Measure Set* as part of a broader effort to standardize quality measurement for Medicaid-funded HCBS. The notice states that HCBS allow people to receive services in their homes and communities rather than in institutional settings and that Medicaid-covered HCBS may include both medical and non-medical services, including case management, personal care, homemaker services, adult day health, habilitation, and respite care. CMS also states that in fiscal year 2023, 8.4 million Medicaid beneficiaries received HCBS, with HCBS accounting for $145.9 billion in Medicaid expenditures [5].

CMS is seeking comment on the proposed mandatory and voluntary measures, how states should collect and report data, which measures should require stratified reporting, the proposed stratification factors, reporting populations, attribution rules, reporting schedules, and small-number exemptions.

We recognize the value of consistent quality measurement across states, as standardized measures can help identify gaps, support quality improvement, and make it easier to compare HCBS performance across systems. However, standardization alone is not sufficient. A quality measure set that does not meaningfully capture race, ethnicity, language, disability, program-level differences, delivery-system differences, and the lived experiences of people receiving

HCBS may produce the appearance of accountability while leaving systemic inequities unmeasured [6-10].

EQUITY STRATIFICATION IS NECESSARY TO ESTABLISH A MEANINGFUL BASELINE

The 2028 measure set will do more than initiate reporting. It will establish the baseline against which future HCBS quality, disparities, and improvements are measured. If the first years of mandatory reporting do not capture race, ethnicity, language, disability type, and other relevant equity dimensions, the baseline itself will be incomplete and unable to serve as an adequate baseline for HCBS quality.

Without these data, CMS and states may be able to report statewide averages, but they will not be able to determine whether those averages reflect equitable access, service quality, safety, self-determination, or community living outcomes across different groups of people receiving HCBS. Apparent statewide improvement could mask persistent or worsening disparities for racialized disabled people as well as those with limited English proficiency, psychiatric disabilities, intellectual and developmental disabilities (I/DD), complex support needs, older adults, and people living in institutional settings.

This is especially important in HCBS because quality is shaped by factors that are not evenly distributed across communities, including provider availability, language access, assessment practices, care coordination, access to assistive technology and equipment, transportation, complaint pathways, managed care authorization practices, and availability of culturally responsive services [11-21]. If these differences are not captured in the baseline, they may remain invisible in future quality reporting and quality improvement efforts.

CMS is soliciting comment on requiring stratified data for five mandatory measures in 2028: LTSS-1, LTSS-2, LTSS-6, LTSS-7, and LTSS-8. CMS further states that it is soliciting comment on stratification by geography and is not proposing to require stratification for any other factors. That limitation raises significant concerns. A measure set that captures only aggregate statewide performance or geography-based differences will not be able to show whether HCBS systems are serving different communities equitably.

We recommend that the final measure set:

- Require stratification of LTSS-6, LTSS-7, and LTSS-8 by race and ethnicity beginning in 2028 where existing data systems permit reliable reporting.
- Require stratification of LTSS-1 and LTSS-2 by race, ethnicity, disability type, language, age, and other relevant factors where state assessment or case management systems permit.
- Require states to submit an equity stratification implementation plan for any required stratification factor they cannot report in 2028, including barriers, timelines, and planned data-system improvements.

- Treat 2028 as the beginning of mandatory equity stratification, not merely a preliminary period before equity stratification begins.

GEOGRAPHIC STRATIFICATION ALONE CANNOT CAPTURE HCBS INEQUITIES

Geographic stratification is important. Rurality, regional provider availability, transportation infrastructure, and local workforce conditions can significantly shape whether people receiving HCBS can access needed services [11, 12, 19]. CMS's proposal to consider geographic stratification therefore addresses one meaningful dimension of HCBS access. However, geography alone is not an equity framework. It cannot substitute for race, ethnicity, disability type, language, age, sex/gender, and other factors needed to understand whether HCBS systems are operating equitably across communities [22-25]. Geographic stratification may show that one region has different outcomes than another, but it will not show which communities within that region are underserved, excluded, delayed, or denied meaningful choice [13, 23, 26].

Geographic stratification may also obscure intersectional disparities. For example, a rural region may show lower access to HCBS overall, but the data may still fail to show which racialized communities, language communities, or types of disability face the greatest barriers. Similarly, a state may appear to perform well overall while specific groups experience delayed assessments, limited provider choice, lack of culturally and linguistically responsive services, inaccessible complaint processes, or pressure toward institutional settings [13, 21, 27-29].

CMS also proposes allowing states to suppress measure components with small numbers and requests comment on whether higher suppression thresholds should be permitted. While privacy protections are essential, particularly for small communities and groups that may face stigma or retaliation, suppression rules can also erase smaller communities from public reporting if they are not paired with equity-preserving alternatives. This is especially important for Indigenous and Pacific Island communities, rural racialized disabled people, disabled people in smaller language communities, LGBTQ+ disabled people, and other multiply marginalized groups [23, 29-34].

We recommend that CMS require stratification beyond geography beginning in 2028, including stratification by race, ethnicity, language, disability type, age, and other relevant demographic and programmatic factors. Where states cannot yet report these data reliably, CMS should require states to identify the relevant data limitations, describe the steps needed to improve demographic and disability data collection, and provide a timeline for implementation. CMS should also develop guidance on stratification categories in consultation and co-production with directly impacted people receiving HCBS. Privacy protections should be designed in ways that protect individuals without removing smaller communities from equity analysis. To that end, CMS should consider approaches such as data pooling, multi-year reporting, carefully designed aggregation, or secure federal analysis. When data are suppressed, states should be required to explain why suppression was necessary and how CMS and the state will continue to assess equity for smaller populations.

AGGREGATE REPORTING OBSCURES PROGRAM, PLAN & POPULATION-LEVEL GAPS

We are concerned that aggregate reporting will obscure the specific systems, programs, and delivery structures wherein inequities occur. CMS is soliciting comment on whether state reporting on each mandatory and voluntary measure should be in the aggregate across applicable HCBS programs. In so doing, it states that CMS is not proposing to require states to report separately by each HCBS program or authority, nor separately by delivery system or managed care plan, although it may allow optional reporting at those levels.

A statewide aggregate rate is not sufficient for equity accountability. HCBS are not experienced only at the statewide level. People receiving HCBS experience services through specific waiver programs, managed care plans, provider networks, case management systems, regional systems, assessment processes, and administrative structures [4, 35, 36]. Inequities often occur at precisely these levels [19, 21, 37]. Aggregate reporting can make a state appear to perform adequately while specific programs or delivery systems produce inequitable outcomes [17, 38, 39].

CMS's interest in reducing reporting demands is understandable, particularly during early implementation. But when reporting is too broad, the data may not identify the system-level problems that quality measurement is supposed to reveal [4, 17, 35]. Aggregate reporting should not become the default substitute for meaningful equity analysis [9, 39, 40].

We recommend that the final measure set require reporting by HCBS program, waiver authority, delivery system, managed care plan, and population where feasible. Aggregate reporting may be useful for statewide comparison, but it should not be treated as sufficient when it may obscure program-level, plan-level, regional, or population-level disparities. CMS should require states to identify when aggregate data may mask meaningful differences across HCBS systems and to report separate fee-for-service and managed care measure versions where applicable. States should also be required to include an equity analysis explaining whether aggregate performance differs from performance for particular populations, programs, plans, or regions.

SELF-DETERMINATION, SAFETY & COMMUNITY ARE CORE MEASURES OF QUALITY

HCBS quality cannot be measured solely by whether an assessment occurred or whether a plan was updated. HCBS quality must also measure whether people receiving services have meaningful choice, control, safety, access to complaint pathways, ability to change services, and opportunities to participate in community life [1, 6, 7, 36].

CMS proposes to retain several participant-reported experience-of-care measures in the 2028 mandatory measure set, including measures from the Home and Community-Based Services Consumer Assessment of Healthcare Providers and Systems survey (HCBS CAHPS), National Core Indicators–Aging and Disabilities survey (NCI-AD), National Core Indicators–Intellectual and Developmental Disabilities survey (NCI-IDD), and Personal Outcome Measures (POM). These measures capture important domains that administrative data alone cannot show, including

choice of services, personal safety and respect, transportation, community inclusion, social connection, freedom from abuse and neglect, and personal goals [6, 36, 41, 42].

At the same time, CMS proposes to narrow or limit several measures that are directly relevant to self-determination and community living. CMS is **not** requiring two measures that Money Follows the Person grantees must report in 2026: HCBS CAHPS "Planning Your Time and Activities" and POM "People Live in Integrated Environments." CMS is also **not** adding four measures that were recommended by the *HCBS Quality Measure Set Review Workgroup* related to access to mental health services, needed assistive equipment and devices, knowing whom to contact with a complaint, and knowing whom to talk to if a person wants to change services. These measures go directly to whether people receiving HCBS can navigate service systems, exercise choice, and seek help when services do not meet their needs [6, 7, 36, 43].

Knowing whom to contact to change services is not merely a satisfaction measure. It helps assess whether a person has the information, support, and practical ability to seek changes in services. For people subject to guardianship, substituted decision-making, institutional pressure, or service systems that restrict choice, the ability to know whom to contact to change services is central to self-determination [44-46]. Similarly, knowing whom to contact with a complaint is not merely an administrative issue. Complaint access is a safety, rights, and accountability issue. People receiving HCBS must be able to raise concerns about services, support workers, service plans, providers, managed care plans, and case management systems without fear of retaliation, service disruption, or dismissal [47-49].

CMS states that while POM may be used as an interim measure for 2028, it may be removed from the 2030 measure set. We are also deeply concerned about removing or weakening POM without an adequate replacement. POM includes indicators related to freedom from abuse and neglect, choice of services, participation in community life, and personal goals. These domains are directly relevant to whether HCBS are supporting self-determination, safety, and meaningful community living [1, 6, 42, 50].

We recommend that CMS include the Workgroup-recommended measures. CMS should also prioritize development of comparable service-change and complaint-access measures across HCBS CAHPS, NCI-AD, NCI-IDD, and other relevant instruments. Before removing POM-based measures from future measure sets, CMS should develop cross-survey equivalents that preserve the core domains captured by POM, including freedom from abuse and neglect, choice of services, community participation, personal goals, and respect for people's preferences. Moreover, these participant-reported measures should also be stratified by race, ethnicity, disability type, language, age, geography, and other equity factors where feasible, so that CMS and states can assess whether self-determination, safety, service navigation, and community life are being supported equitably.

DOCUMENTATION MUST BE PAIRED WITH MATERIAL ACCESS

Comprehensive assessments and person-centered service plans are critical components in identifying support needs, documenting preferences, coordinating services, and protecting rights [36, 51]. However, documentation is not the same as access. A person-centered plan on paper does not guarantee that a person receives adequate personal care, communication support, assistive technology, transportation, mental health services, culturally responsive care, or safe and reliable support [2, 15, 16, 52].

CMS notes that the Workgroup recommended removing LTSS-1, LTSS-2, and LTSS-3, which relate to comprehensive assessment, person-centered planning, and shared person-centered plans. We in no way want to suggest that assessment and planning are unimportant. Rather, our concern is that process measures can become substitutes for outcome, access, and rights-related measures if they are not paired with measures that show whether people actually receive the supports identified in assessments and plans [6, 15, 36, 51].

For racialized and multiply marginalized disabled people, a narrow focus on documentation can give rise to additional problems. A service plan may exist while the person still lacks providers who speak their language, cannot access needed equipment, cannot get transportation outside the home, cannot obtain mental health supports, cannot safely raise concerns, or cannot exercise meaningful choice over services [2, 13, 15, 16, 19, 29, 34, 52]. A plan may state that services are person-centered while people continue to experience unmet needs, stigmatizing care, social isolation, unsafe support arrangements, or pressure toward institutional settings [2, 15, 28, 29, 53, 54].

The Workgroup-recommended measures on access to mental health services and needed assistive equipment and devices are particularly important. These measures should not be treated as secondary simply because they raise comparability challenges. Where comparable measures do not yet exist across instruments, CMS can require available measures now and develop cross-survey equivalents for future cycles.

CRDJ recommends that the final measure set include measures of access to mental health services and needed assistive equipment and devices as mandatory measures where these measures are currently available. Where comparable measures do not yet exist across survey instruments, CMS should develop cross-survey equivalents for material-access measures across HCBS CAHPS, NCI-AD, NCI-IDD, and other relevant instruments. CMS should also pair LTSS-1 and LTSS-2 with measures that assess whether people actually receive the supports identified in assessments and person-centered plans. States should be required to analyze whether documented person-centered plans correspond to timely service delivery, provider availability, communication access, transportation, and community participation. State reporting capacity and survey comparability are important implementation considerations, but they should not be treated as sufficient reasons to exclude measures that capture core dimensions of community living and access to needed supports.

CO-PRODUCTION IS NECESSARY FOR EQUITY-CENTERED MEASURE DEVELOPMENT

CMS held a public call for measures and convened an independent Workgroup, recognizing the value of public input and expert review. However, it is vital that CMS create ongoing structures for not just consultation, but also meaningful co-production with people receiving HCBS, especially those most likely to experience systemic barriers [55-58].

Co-production is especially important for stratification categories. Categories developed without directly impacted communities can reproduce stigma, erase intersectional identities, or fail to capture the service experiences that matter most [22, 59-61]. People receiving HCBS should help shape which categories are collected, how they are defined, how privacy is protected, how data are interpreted, and how quality improvement plans respond to inequities [22, 33, 58, 62].

CMS should explain how it weighed the perspectives of people receiving HCBS against considerations such as state reporting burden, survey comparability, and implementation feasibility, particularly where the proposed measure set excludes measures that were recommended by the Workgroup that address service navigation, complaints, assistive equipment, and mental health access [6, 55-57, 63].

It is our recommendation that CMS establish and maintain an *HCBS Quality Measure Advisory Board* composed primarily of people receiving HCBS and people with lived experience navigating HCBS systems. The advisory board should include racialized disabled people, people with a variety of disabilities including I/DD and psychiatric disabilities, older adults, people with complex support needs, people with limited English proficiency, rural disabled people, LGBTQ+ disabled people, and people with experience living in institutional settings. Advisory board members should be compensated for their time, expertise, and access needs, and CMS should provide accessible materials, plain language and/or easy read summaries, language access, communication supports, and multiple participation formats. CMS and states should also be required to explain how feedback from directly impacted people shaped measure selection, stratification, reporting, and quality improvement expectations. In addition, CMS should create a process for people receiving HCBS to identify emerging gaps in the measure set between formal update cycles.

CONCLUSION

The *2028 HCBS Quality Measure Set* has the potential to become vital infrastructure for transparency, accountability, and quality improvement. But that infrastructure will remain incomplete unless it can identify the people, programs, systems, and conditions where inequities occur.

The proposed measure set should be strengthened in several key ways: equity stratification is necessary to establish a meaningful baseline; geographic stratification alone cannot capture HCBS inequities; aggregate reporting may obscure program, plan, and population-level gaps; self-determination, safety, and community life are core measures of quality; documentation

measures should be paired with material access measures; and co-production is necessary for equity-centered measure development.

A national HCBS quality measure set should help assess whether disabled people and older adults can live, receive support, and participate in their communities with dignity, autonomy, safety, and meaningful choice. For multiply marginalized disabled people, that requires more than standardized reporting. It requires equity-centered data, transparent accountability, and governance informed by the people whose lives are most impacted by HCBS policy decisions.

If you have any questions, please feel free to contact Dr. Kate Caldwell at caldwell@law.ucla.edu and Dr. Hope Sparks at hope.sparks@northwestern.edu.

Sincerely,

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