

Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living:

Priorities for Measure Development

INTERIM REPORT

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NATIONAL
QUALITY FORUM

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EXECUTIVE SUMMARY

The Addressing Performance Measure Gaps in Home and Community-Based Services (HCBS) to Support Community Living Project aims to develop a shared understanding and approach to assess the quality of HCBS; to identify gaps in current HCBS quality measurement; and to highlight high-leverage opportunities for measure development. Understanding the quality of HCBS becomes increasingly important as government funding shifts from institutional to community-based settings, and demand for HCBS rises. A growing number of programs offer services and supports to help individuals live independently in integrated community settings. However, despite this growth, there is a lack of standardized measurement of the quality of HCBS across payers and delivery systems.

To address this issue, the National Quality Forum (NQF), under a contract with the Department of Health and Human Service (HHS), convened a multistakeholder Committee to develop recommendations for the prioritization of measurement opportunities to address gaps in HCBS quality measurement. The two-year project involves:

1. the creation of a conceptual framework for measurement, including an operational definition of HCBS;
2. a synthesis of evidence and environmental scan for measures and measure concepts;
3. the identification of gaps in quality measurement based on the framework and scan; and
4. recommendations for prioritization in measurement.

The **first interim report** described the Committee's foundational work of creating an operational definition, identifying characteristics of high-quality HCBS, developing domains of measurement, and illustrating the function of performance measurement in HCBS. The **second interim report** for the project assessed the current HCBS quality measurement landscape, based on a synthesis of

evidence and environmental scan of measures, measure concepts, and instruments used or proposed for use in HCBS programs.

This third interim report details the Committee's work in identifying gaps in quality measurement and crafting recommendations for prioritization in measurement. Through review of the findings from the environmental scan and Committee deliberations, the Committee identified gaps in measurement within all of the domains and subdomains. In addition to identification of gaps, the Committee discussed the barriers and challenges to measuring HCBS quality. These challenges include:

- the lack of standardized measures across the country, which is exacerbated by the decentralized nature of the HCBS system;
- the lack of or limited access to timely data on HCBS programs;
- the variability of the numerous Federal, state, local, and privately funded programs with different reporting requirements and the flexibility offered to states and providers to establish their own quality measures to meet requirements; and

- the added administrative burden of data collection management, reporting, and incorporation into quality improvement activities.

With these gaps and challenges in mind, the Committee crafted cross-cutting and domain-specific recommendations for how resources should be invested to bring a systematic and standardized approach to quality measurement in HCBS. These recommendations are primarily intended for HHS, but have wider applicability across HCBS stakeholders.

The cross-cutting recommendations include:

- supporting quality measurement work across all domains and subdomains, rather than devoting resources to a few domains and subdomains;
- identifying and implementing a consistent approach to quality measurement (e.g., data collection, analysis, reporting, quality improvement activities);
- leveraging of technology for data collection, storage, analysis, and reporting of quality data;
- building on the existing quality measurement landscape when developing or expanding the use of quality measures across HCBS;
- utilizing both administrative and survey data to develop HCBS quality measures;
- supporting a balanced approach to HCBS quality measurement that acknowledges the

need for structure, process, and outcome measures in each domain; and

- developing a menu of HCBS quality measures that can be easily incorporated into existing HCBS programs in order to increase the use of similar reliable and valid measures throughout the HCBS system.

Appendix E lists all of the domain-specific recommendations. In recognition of the state of measurement, the Committee categorized and grouped its domain-specific recommendations as follows:

- **Group A:** Short-term recommendations correspond to areas where there are existing measures or measure concepts that have been tested or could be tested in HCBS populations.
- **Group B:** Intermediate recommendations correspond to areas where there are some existing measures or measure concepts, but more development is required because the existing measures do not assess all of the constructs that are important to measure within a given domain or subdomain.
- **Group C:** Long-term recommendations correspond to areas where there are few or no measures or measure concepts, and more research is needed, particularly around building an evidence base to support measure development.

BACKGROUND AND CONTEXT

Environmental Context

The United States is experiencing a major demographic shift with a rapid increase in the number of people who require long-term services and supports (LTSS). LTSS generally include assistance with daily self-care activities (e.g., walking, bathing, and dressing) and activities that support an independent lifestyle (e.g., food preparation, transportation, and managing medications). The broad category of LTSS also includes care and service coordination for people who live in their own home, a residential setting, a nursing facility, or other institutional setting. Home and community-based services (HCBS) are a subset of LTSS that functions outside of institutional care to maximize independence in the community. Both LTSS and HCBS include support provided by unpaid caregivers (e.g., family members, friends, and neighbors) to individuals with LTSS needs. Demand for these services is increasing and will continue to rise.

HCBS are essential for many older adults and people with disabilities. The Administration for Community Living (ACL) reports that the number of people 65 years of age and older will exceed 70 million by 2030, accounting for 19 percent of the population and doubling the total number of older Americans since 2000.¹ In 2013, 37 million people in the U.S. were classified as having a disability, with more than 50 percent of that total in their working years (18-64).² In addition, approximately 60 million Americans experience a mental illness annually, and 13.6 million people are currently living with chronic mental illness.³ Finally, projections show that 21 million individuals are expected to be living with multiple chronic conditions by 2040, many of whom will require LTSS.⁴ An increasing share of LTSS is comprised of HCBS, promoting independence and wellness in community settings.

In federal fiscal year (FY) 2014, HCBS accounted for a majority of Medicaid LTSS expenditures. Total

federal and state LTSS spending was \$152 billion, including \$80.6 billion for HCBS and \$71.2 billion for institutional LTSS.⁵ Moreover, researchers at the AARP Public Policy Institute estimated the economic value of family caregiving in the United States was approximately \$470 billion.⁶ These expenditures are expected to grow dramatically in concert with demand.⁷ Given the potential growth of HCBS, this is a critical time to better understand performance of these services and their contribution to the Department of Health and Human Services' (HHS) goals of building a health system that delivers better care, spends healthcare dollars more wisely, and makes individuals and communities healthier.

The Centers for Medicare & Medicaid Services (CMS) and states—via their federal-state partnership in providing the Medicaid HCBS benefit to eligible beneficiaries—are the dominant funders of HCBS. Most recently, states are partnering with CMS and are using managed care plans to deliver HCBS, with 16 states operating managed care long-term services and support programs in FY2015.⁸ As a result, CMS and states also drive much of the current quality monitoring and quality measurement activity for HCBS.

However, HCBS extends well beyond services purchased or reimbursed by Medicaid. First, a host of other federal, state, and local programs provide HCBS. These include ACL, the Substance Abuse and Mental Health Services Administration (SAMHSA), the Administration for Children and Families (ACF), the Health Resources and Services Administration (HRSA), and others. In addition, there is a large and growing private-pay market for HCBS. Finally, HCBS consumers receive assistance from family members, friends, and volunteers in the form of informal care, in addition to paid or formal services. As a quality measurement framework for HCBS continues to emerge, a number of issues must be considered. These include the relationships between various funding

streams, regulators, the extensive and diverse network of HCBS providers, service delivery models (e.g., self-direction), and the potential implications for how measurement systems will align across the evolving health and LTSS systems.

Related Efforts in HCBS and Measurement

There have been several ongoing and related efforts at the federal policy level and in the realm of quality measurement to support improvement in HCBS. For example, the Deficit Reduction Act (DRA) of 2005 (PL 109-171, Section 6086(b)) directed the Agency for Healthcare Research and Quality (AHRQ) to develop HCBS quality measures for the Medicaid program. To lay the groundwork for meeting these requirements, AHRQ contracted with Thomson Reuters (now Truven Health Analytics) to conduct an environmental scan of existing and potential measures.⁹ While the scan is now several years old, it was thorough and included more than 200 measure sources. NQF is updating and building upon this work and other previously completed efforts to identify measures, potential measure concepts, and instruments for HCBS.

CMS has sponsored the development of an HCBS taxonomy further explaining the types and uses of HCBS. Under Medicaid, a wide array of services and supports has been approved as HCBS; these include personal care, homemaker, habilitation, transportation, case management, supported employment, environmental modifications, respite care, and financial management services that support self-directed service delivery models.¹⁰ This taxonomy is to be implemented within the Transformed Medicaid Statistical Information System (T-MSIS), which gathers national eligibility, enrollment, program utilization, and expenditure data.

CMS has awarded Testing Experience and Functional Tools (TEFT) planning grants to nine states to test quality measurement tools and demonstrate e-health in Medicaid HCBS.¹¹ These efforts have led to the development of an HCBS consumer experience-of-care survey

that has been used to construct performance measures. These measures were submitted to NQF in spring 2016 for potential endorsement. In addition, a functional assessment of standardized items is in development for the assessment of self-care activities and activities that support an independent lifestyle as well as testing of an electronic LTSS health record, and a development of a personal health record.¹² Additionally, efforts to create measures for Medicaid Long-Term Services and Supports are ongoing.

Several measurement projects related to aging and disability are also currently underway. For example, the National Core Indicators (NCI)TM is now used in 31 states.¹³ These indicators assess key constructs such as employment, rights, service planning, community inclusion, choice, and health. The NCITM aims to collect and maintain valid data that allow states to improve services for older adults and individuals with disabilities. In addition, there is also new measurement research funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). This project aims to develop quality measures for HCBS that will eventually be submitted to NQF for potential endorsement. Additional information on the programs, measures, and instruments referenced in this report can be found in the [annotated bibliography](#).

Despite the existence of several established frameworks and/or lists of quality measurement domains for LTSS and HCBS, the availability and uptake of performance measures remain limited and lack uniformity across states and across other levels of analysis (e.g., provider, managed care organization). In light of the increasing use of HCBS nationally and the associated costs, there is a deficit in quality measurement. Stakeholders have called for more a standardized measurement approach for many years, but the current environment reflects the fragmented nature of the decentralized HCBS system as well as a historical lack of consensus about the best path forward for implementation of measurement.

PROJECT OVERVIEW

The demand for HCBS continues to grow; however, the quality of those services is not yet measured in a standardized way across the country. To address this issue, the National Quality Forum (NQF), under a contract with the Department of Health and Human Services (HHS), convened a multistakeholder Committee ([Appendix A](#)) to develop recommendations for the prioritization of measurement opportunities to address gaps in HCBS quality measurement. The two-year project involves:

1. the creation of a conceptual framework for measurement, including an operational definition of HCBS;
2. a synthesis of evidence and environmental scan for measures and measure concepts;
3. the identification of gaps in quality measurement based on the framework and scan; and
4. recommendations for prioritization in measurement.

This project builds upon previous and/or ongoing work related to HCBS quality in order to provide a unified picture of HCBS quality measurement and to identify opportunities for measure development. The project intends to provide a framework through which stakeholders can

align broader measure development efforts by ensuring that financial and human resources are purposefully targeted. The work is meant to quicken the pace of development and increase the use of national measures of HCBS that matter to consumers, families, caregivers, and stakeholders at all levels of the system.

The [first interim report](#) described the Committee's foundational work of creating an operational definition of HCBS, identifying characteristics of high-quality HCBS, developing domains of measurement, and illustrating the function of performance measurement in HCBS. The [second interim report](#) depicted the current HCBS quality measurement landscape, based on a synthesis of evidence and environmental scan of measures, measure concepts, and instruments used or proposed for use in HCBS. The Committee has continually refined each component of the project using feedback from the public and NQF members. This report describes the most recent iteration of the definition and framework, updates the analysis of the evidence synthesis and environmental scan, and refines the domains and subdomains. The majority of this report details the Committee's work in identifying gaps in quality measurement and crafting recommendations for prioritization in measurement.

OPERATIONAL DEFINITION AND CONCEPTUAL FRAMEWORK

The purpose of developing an operational definition and conceptual framework was three-fold. First, they create a common understanding of the services, settings, providers, and consumers of HCBS, and how the mechanism of performance measurement operates within HCBS. Second, this understanding informed the Committee's deliberations on what constitutes high-quality HCBS and the role of performance measurement in ensuring the delivery of high-quality services. And last, the operational definition and conceptual framework were developed to guide public and private payers alike in future quality and performance measurement efforts for HCBS.

Operational Definition

In developing the operational definition, the Committee discussed that the boundaries of HCBS are porous, even potentially subjective. Given the heterogeneity of people who use HCBS, the variety of services, and the many ways in which the services are funded, the Committee aimed to develop a definition that maintained a broad and inclusive orientation as to what might be considered part of HCBS. At the same time, the definition needed to be specific enough to be meaningful and consistent. With these issues in mind, the Committee established an operational definition that is positive in tone, devoid of value statements, plain-language, and concise. The definition of HCBS is:

The term “home and community-based services” (HCBS) refers to an array of services and supports that promote the independence, well-being, self-determination, and community inclusion of an individual of any age who has significant, long-term, physical, cognitive, and/or behavioral health needs and that are delivered in the home or other integrated community setting.

Characteristics of High-Quality HCBS

Stemming from the process of creating an operational definition of HCBS, the Committee identified specific characteristics of a high-quality HCBS system. This was necessary because the operational definition is more functional than aspirational, and it does not communicate the Committee's vision for what HCBS *should* be. Through extensive discussion, the Committee established that high-quality HCBS should be delivered in a manner that:

- Provides for a person-driven system that optimizes individual choice and control in the pursuit of self-identified goals and life preferences
- Promotes social connectedness and inclusion of people who use HCBS, in accordance with individual preferences
- Includes a flexible range of services that are sufficient, accessible, appropriate, effective, dependable, and timely to respond to individuals' strengths, needs, and preferences and that are provided in a setting of the individual's choosing
- Integrates healthcare and social services to promote well-being
- Promotes privacy, dignity, respect, and independence; freedom from abuse, neglect, exploitation, coercion, and restraint; and other human and legal rights
- Ensures each individual can achieve the balance of personal safety and dignity of risk that he or she desires
- Supplies and supports an appropriately skilled workforce that is stable and adequate to meet demand

- Supports family caregivers
- Engages individuals who use HCBS in the design, implementation, and evaluation of the system and its performance
- Reduces disparities by offering equitable access to, and delivery of, services that are developed, planned, and provided in a culturally sensitive and linguistically appropriate manner
- Coordinates and integrates resources to best meet the needs of the individual and maximize affordability and long-term sustainability
- Delivers—through adequate funding—accessible, affordable, and cost-effective services to those who need them
- Supplies valid, meaningful, integrated, aligned, accessible, outcome-oriented data to all stakeholders
- Fosters accountability through measurement and reporting of quality of care and recipient outcomes

Conceptual Framework

Measurement Domains and Subdomains

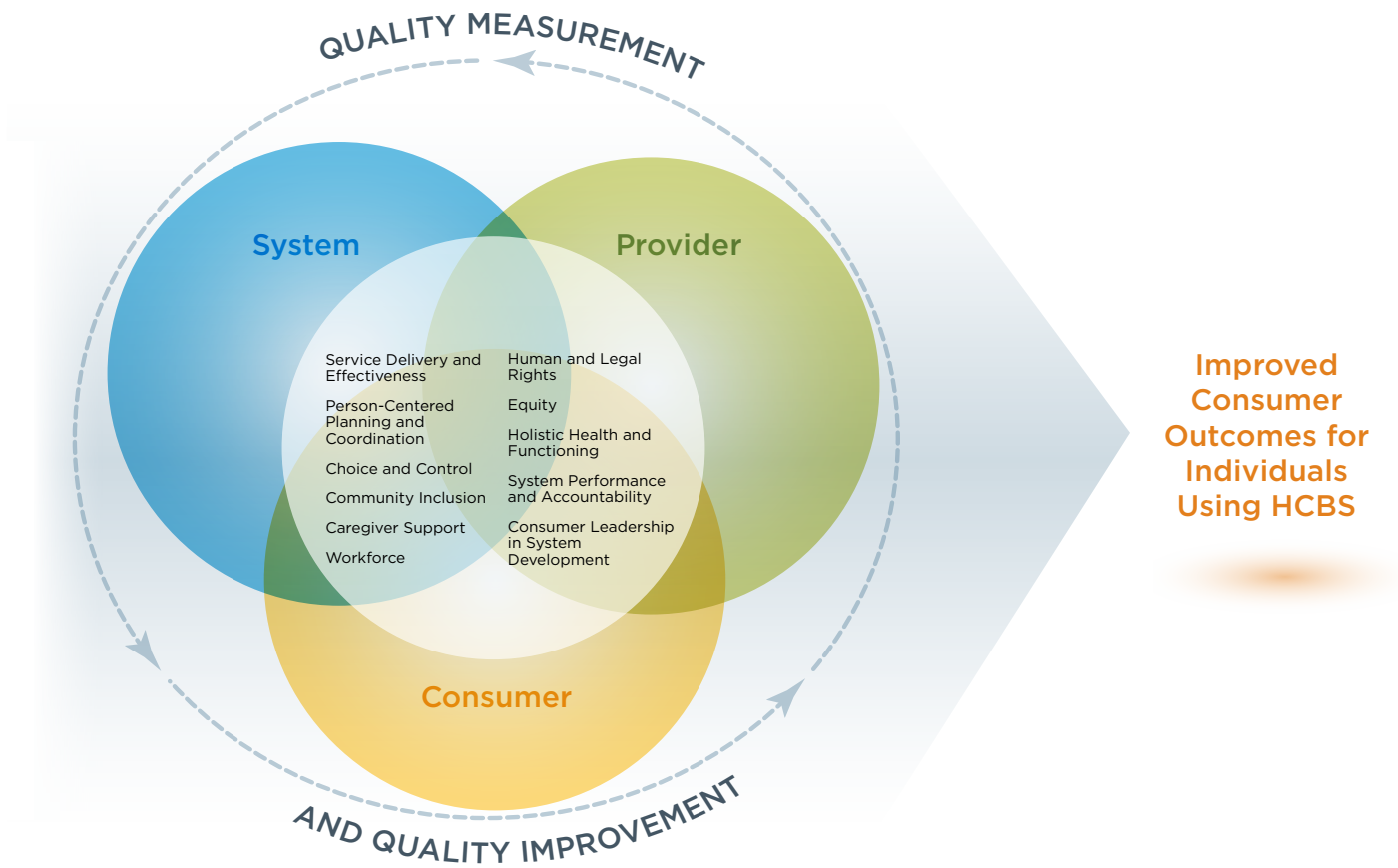
As part of the conceptual framework, the Committee developed high-level measurement domains and more detailed subdomains to highlight the most important areas for quality measurement in HCBS. The goals of constructing the domains and subdomains are to stimulate research, guide quality improvement efforts, and signal to measure developers the important areas for measure development. After consideration of the current measurement landscape and future opportunities for measure development, the Committee refined the initial list of domains

and subdomains ([Appendix C](#)). The revised list includes detailed definitions of the 11 domains and specific descriptions of the 41 subdomains that outline each domain's scope ([Appendix D](#)). These domains closely correspond to the previously outlined characteristics of high-quality HCBS, though they do not have a 1:1 relationship. The domains are also not mutually exclusive. They contain concepts and underlying premises that cut across multiple domains. For example, several domains include the concept of person-centered approaches that recognize and accept the role of individuals in directing their own care and supports.

HCBS Performance Measurement Illustration

The Committee developed an illustration of the conceptual framework to show how performance measurement works in HCBS (see Figure 1). The framework is intended to be nationally relevant, simple in style, and reflective of the primary importance of improved outcomes for individuals who use HCBS. Each circle in the framework represents a level at which measurement can be applied: to the broadest level of the system, to the intermediate level of accountability including providers and services, and to the most targeted level of individuals who use or are involved in HCBS. Measurement at each of these levels of analysis serves different purposes and responds to different information needs. The domains are placed in a circle at the center of the diagram where the levels overlap because measurement can be applied at multiple levels within many domains. The continuous arrows surrounding the four circles indicate the transmission of information necessary to operate a dynamic, learning system and the feedback loops between measurement and improvement efforts.

FIGURE 1. HCBS QUALITY MEASUREMENT FRAMEWORK



SYNTHESIS OF EVIDENCE AND ENVIRONMENTAL SCAN

Using the conceptual framework as a guide, NQF staff, in consultation with the Committee and HHS, completed a synthesis of evidence and environmental scan. The purpose of the scan and synthesis was to assess the current state of the HCBS quality measurement landscape. For the purposes of this work, NQF defined measures, measure concepts, and instruments as follows:

- A measure is a metric that has a specific numerator and denominator and has undergone scientific testing.
- A measure concept is a metric that has a specific numerator and denominator, but has *not* undergone testing.
- An instrument is a psychometrically tested and validated survey, scale, or other measurement tool.

NQF staff reviewed over 270 information sources to extract measures, measure concepts, and instruments that assess the quality of HCBS and map to the domains of HCBS measurement. NQF staff also reviewed example state-level (Minnesota, Oregon, and Washington) and international (England, Canada, and Australia) quality measurement initiatives. Within the U.S., there are several initiatives. For example, the Washington State Legislature has mandated the development and implementation of a statewide Common Measure Set for public and private healthcare providers as well as a measure set for contracted managed care and behavioral health organizations. In Oregon and Minnesota, state agencies are using new instruments (e.g., Oregon's Individual Experience Assessment and the National Core Indicator Survey) to evaluate consumers' experiences with HCBS. Similarly, governing bodies within England, Canada, and Australia are developing and implementing quality measurement frameworks and measure sets to assess the quality of their HCBS systems.

Environmental Scan Results

The environmental scan was an iterative process to identify measures that directly relate to the domains of measurement identified by the Committee. NQF cast a wide net and found a total of 261 measures, 394 measure concepts, and 75 instruments (see [Appendix D](#)). These were included in the compendium of measures featured in the second interim report. The Committee conducted a review of these measures after considering feedback from the public and NQF members and flagged 187 measures, 288 measure concepts, and 68 instruments that were most relevant to the domains. The number of measures, concepts, and instruments that assess constructs within each domain varies widely ([Appendix B](#)). Although many of the measures found were relevant, there were few in use that truly capture the characteristics of quality that matter most to stakeholders.

The Committee acknowledged example measures currently in use that most closely assess the constructs defined in the subdomains of measurement. The Committee identified instruments which have items that assess constructs that span multiple domains and could potentially be used or translated for broader use. For example, the Experience of Care survey has 19 measures that are developed for use across all HCBS populations. The National Core Indicators Survey (in use across 31 states), the National Core Indicators Survey - Aging and Disability (NCI-AD™),¹⁴ and the [Money Follows the Person Quality of Life Survey](#)¹⁵ are all surveys that include concepts, items, and questions that are widely in use, align with HCBS domains, and have potential for expanded development.

GAPS, PRIORITIZATION, AND RECOMMENDATIONS

Following the release of the second interim report in December 2015, the Committee took action to identify gaps in measurement, prioritize areas for measurement development, and draft recommendations to advance measurement within each domain. The Committee convened for a web meeting in January 2016 and reviewed public comments received on the second interim report. During this meeting, the discussion focused on the need for a more person-centered approach to HCBS quality measurement, as well as the need to further refine the domains and subdomains of the measurement framework. Following the web meeting, the Committee was divided into five workgroups based on Committee members' areas of expertise. Workgroups were tasked with refining the definition and subdomains and identifying promising measures for their assigned domains. Prior to convening each workgroup, members completed a refinement survey wherein they were asked to offer proposed edits to the domain definition, prioritize the five most relevant subdomains for the domain, and draft definitions for those prioritized subdomains. During the workgroup meetings, members discussed the survey results and drafted proposed final domain definitions and a list of prioritized subdomains with descriptions. This work laid the foundation for the in-person meeting in March.

The proposed domains and subdomains were discussed, revised, and accepted by the full Committee. Additionally, the Committee drafted cross-cutting and domain-specific recommendations. The recommendations were categorized by alphabetical groups. Group A are short-term recommendations, group B are intermediate term recommendations, and group C are long-term recommendations. Due to time constraints, the Committee was not able to discuss all recommendations by domain; however,

the workgroups for the domains not discussed met again and drafted recommendations for the remaining domains. A full listing of cross-cutting and domain-specific recommendations was then compiled into a validation survey and sent to the Committee for review and voting. Consensus was reached on the content of all the recommendations with some members suggesting edits as to the wording of some recommendations. These edits were reviewed and accepted after review of the survey results with the Committee co-chairs. For the short-term and intermediate term recommendations, NQF staff identified promising measures by reviewing the list of measures flagged as promising by two or more workgroup members and identified examples from this list that aligned to short-term and intermediate recommendations and cross-walked this list with measures identified in the validation survey.

Gaps in Measurement

The Committee examined the numbers and types of measures as well as the overall state of measurement within each domain to inform their deliberations about where measures should be developed. In an attempt to identify the highest priority measure gap areas, the Committee considered the impact that measurement in each domain would have on HCBS quality in terms of the:

- costs of poor quality to consumers, caregivers, natural supports, workers, communities, and the nation;
- extent of the performance gap between current practice and evidence-based practice;
- likelihood that measurement in each domain would close the gap; and

- extent to which measurement in the domain would benefit people of all ages, genders, socioeconomic statuses, ethnicities/races, in all populations across the spectrum of HCBS.

The Committee distinguished between different types of gaps in measurement. In some domains, many measures appear to be limited to only one population of HCBS users (e.g., individuals who are HIV-positive). In other domains, there are very few or no measures available that adequately assess the constructs described within a domain or its subdomains. There are also several domains that will require more research to develop a conceptual basis for measurement. The Committee developed recommendations based on gaps identified within each domain.

Considerations for Prioritizing Measurement

There is increasing recognition of the need to measure the quality of HCBS, but the approaches to quality measurement that have been successful in clinical and institutional settings likely will not be sufficient for assessing HCBS quality. Therefore, the Committee discussed the challenges to HCBS quality measurement. First, the HCBS system is decentralized. Many programs are often state- and population-centric and are highly variable in terms of measurement and quality improvement activities. Second, measuring the quality of HCBS necessitates the added administrative burden of data collection, management, and reporting. Many acknowledge that HCBS are often underfunded, under-staffed, and otherwise under-resourced. Adding further responsibilities to a system with very limited resources does not bode well for efforts to implement quality measurement and quality improvement activities. Third, there is the tension between the need for standardized measure sets that allow for comparisons across states, programs, populations, providers, and settings and the need for measures specific to these various aspects of HCBS. In addition, the HCBS system as a whole lacks a systematic

approach to the collection and reporting of the data needed for quality measurement as well as to provide guidance to HHS about future measure development. The Committee agreed that these challenges cut across the field of HCBS quality measurement and that measurement across all domains, regardless of the state of the science, should be prioritized so as to drive improvement in HCBS quality.

Draft Committee Recommendations to Advance HCBS Quality Measurement

Using the conceptual framework and findings from the synthesis of evidence and environmental scan, the Committee developed draft recommendations to better assess the quality of HCBS. The Committee acknowledged measurement activities occurring across many of the domains identified within the conceptual framework, but such activities often happen in silos. The Committee also asserted that measurement within each domain is equally important and thus did not attempt further prioritization of the measurement domains into any sort of ranking indicative of importance.

Cross-cutting recommendations address current quality measurement challenges faced by the HCBS system as a whole and across all domains of measurement. Domain-specific recommendations reflect a given domain's current state of measurement and address how measurement within that domain can be advanced. These recommendations, both cross-cutting and domain-specific, are intended to improve quality measurement in HCBS and increase the HCBS system's capacity for future measurement initiatives. In developing the recommendations, the Committee considered:

- the challenges to HCBS quality measurement, both across and within specific domains;
- where HHS should allocate resources to address these challenges; and

- what steps HHS could take or support to address these challenges.

As such, the Committee's recommendations are primarily made to HHS. Nevertheless, these recommendations have wider applicability across the range of HCBS stakeholders, including measure developers, researchers, payers, delivery systems, accountable entities, and other measure users.

Cross-Cutting Recommendations

Committee members emphasized that measurement in all domains should be person-centered, with the goal of improving consumer outcomes and promoting community living. Measurement should be approached at three levels: at the level of the person receiving HCBS, at the level of service provision, and at the systems level. With these ideas in mind, the Committee developed the following cross-cutting recommendations:

- supporting quality measurement work across all domains and subdomains, rather than devoting resources to a few domains and subdomains;
- identifying and implementing of a consistent approach to quality measurement (e.g., data collection, analysis, reporting, quality improvement activities);
- leveraging technology for data collection, storage, analysis, and reporting of quality data;
- building on the existing quality measurement landscape when developing or expanding the use of quality measures across HCBS;
- using both systemic and individual level data to develop HCBS quality measures;
- supporting a balanced approach to HCBS quality measurement that acknowledges the need for structure, process, and outcome measures in each domain; and
- developing a menu of tailorable HCBS quality

measures that can be easily incorporated into existing HCBS programs in order to increase the use of similar reliable and valid measures throughout the HCBS system.

Recognizing the importance of all the domains and subdomains within the conceptual framework, the Committee recommended supporting quality measurement work across all domains and subdomains. The Committee also recommended creating a standardized approach to quality measurement that leverages technology wherever possible. The approach should include identifying and implementing standard data collection, analysis, and reporting processes for HCBS quality measurement. Recent technology offers new approaches for measurement. For example, HCBS providers could use point-of-care products and applications to assess consumer experience immediately following service provision or collect data generated from social media to identify what matters most to consumers and caregivers. The Committee acknowledged that even though a concept may be difficult to measure given current technological and infrastructure limitations, it should not be ignored, as quality measurement in HCBS is an evolutionary process. Resources should be invested to discover innovative methods for assessing quality.

At the same time, future measurement initiatives should build upon the existing quality measurement landscape. Although the Committee identified deficiencies in the existing HCBS quality measures and gaps areas in measurement, it recognized the importance of previous efforts to develop measures that are in current use. The Committee recommended investing resources to test the psychometric properties of existing instruments, particularly those that are widely used. These instruments may be sources for quality measures that map to the Committee's measurement framework, particularly for domains for which very few quality measures currently exist (e.g., Caregiver Support; Consumer Leadership in System Development).

Additionally, the Committee cautioned against an overreliance on any one data source to create measures. Measure developers should attempt to balance use of administrative data with use of survey data. Survey data allows for the collection of a broader range of information (e.g., caregiver and consumer opinions, beliefs, preferences, etc.), but surveys are time and resource intensive. In contrast, administrative data may be less burdensome to collect and may be easier to use in the short term to accelerate quality measurement. The Committee cautioned that administrative data, given its limitations, may be better suited for use in process measures rather than outcome measures. In addition, within each domain, there should be a balance between each measure type (structure, process, outcome, etc.), where appropriate, to create a more complete picture of quality. The Committee was careful to clarify that this balance does not mean having an equal number of measure types within each domain.

Finally, the Committee emphasized that quality measures can be used for different purposes. Measures used for public reporting or to make comparisons about HCBS quality within and across states require standardization. Measures used to improve individual consumer quality of care or quality improvement within an agency may need to be more individualized. The Committee recommended the creation of a “menu” of performance measures that apply across populations. The menu would allow HCBS stakeholders to choose from a standard set of measures to fit their specific needs. These measures could be easily incorporated into existing public and private HCBS programs and would support standardization for comparing

performance across agencies and states. They would also allow public and private measure users the ability to select the measures that are most relevant and meaningful for their purposes.

Domain-Specific Recommendations

The Committee organized the recommendations into categories that represent the current state of measurement within each domain. Given that the state of measurement within each subdomain varies widely, the Committee defined its recommendation categories as follows:

- **Group A:** Short-term recommendations correspond to areas where there are existing measures or measure concepts that have been tested or could be tested in HCBS target populations.
- **Group B:** Intermediate recommendations correspond to areas where there are some existing measures or measure concepts, but more development is required because the existing measures do not assess all of the constructs that are important to measure within a given domain or subdomain.
- **Group C:** Long-term recommendations correspond to areas where there are few or no measures or measure concepts, and more research is needed, particularly around building an evidence

The domain specific recommendations are categorized and summarized in [Appendix E](#). For each domain, the domain definition, subdomain descriptions, and domain-specific recommendations are provided below.

Service Delivery and Effectiveness

This measurement domain is defined as the level to which services are provided in a manner consistent with a person's needs, goals, and preferences that help the person to achieve desired outcomes. Three subdomains were prioritized within this domain:

- **Delivery:** The level to which the HCBS system supplies person-centered services and supports to the individuals who use HCBS. Important aspects of delivery include timely initiation, the degree to which the delivered services and supports correspond with the plan of care, the ongoing assessment of the correlation of delivery and the plan of care, and the sufficiency of delivery in terms of the scope of services and the capacity to meet existing and future demands.
- **Person's needs met:** The level to which the HCBS system supplies services and supports sufficient to address the needs of the individual who uses HCBS.
- **Person's identified goals realized:** The level to which the HCBS system incorporates the HCBS consumer's goals into services and supports, and the individual who uses HCBS is able to achieve those goals through support of the HCBS system.

The Committee identified short-term and intermediate recommendations for this domain. The implementation of existing measure concepts

within the subdomains of Service Delivery and Effectiveness should be expanded. For example, measure concepts related to unmet service need, accessibility, and consumer experience could be used more widely by HCBS programs and providers for improving quality. Some illustrative examples of measures or measure concepts in use that could be built upon include: (1) measure concepts from the Washington State's Medicaid measure instrument that assesses the number and percent of HCBS beneficiaries who had all unmet activities of daily living (ADLs) and instrumental activities of daily living (IADLs) assigned to a paid provider and (2) Medicaid HCBS measure concepts used in Oregon that assess the number and percent of HCBS beneficiaries whose services are delivered in the type, scope, amount, durations, and frequency in accordance with the service plan.

RECOMMENDATIONS

Short-Term

- Expand the implementation of process measure concepts related to the person's goals identified and realized, unmet service need, accessibility, and consumer experience to improve quality.

Intermediate

- Support the development of quality measures for the delivery subdomain.
- Invest in developing person-centered outcome measures for this domain.

Person-Centered Planning and Coordination

This measurement domain is defined as the processes by which a person directs the development of a plan, based on his or her goals, needs, and preferences, and the coordination of services and supports across providers and systems to carry out the plan. Three subdomains were prioritized within this domain:

- **Assessment:** The level to which the HCBS system and providers ascertain the HCBS consumer's needs and goals. This process should be person-centered and re-assessments should occur on a regular basis to assure that changes in consumer goals and needs are captured and appropriate adjustments to services and supports are made.
- **Person-centered planning:** The level to which the planning process is directed by the person, with support as needed, and results in an executable plan for achieving goals the person deems important, including the paid and unpaid services or supports needed to reach those goals.
- **Coordination:** The level to which the HCBS system and health/other service providers collaborate to ensure delivery of individual services and supports that are complementary and work together to fully support the HCBS consumer in terms of his/her needs and goals.

The Committee identified short-term and intermediate recommendations for this domain. In the short-term, the implementation of measure concepts related to assessment and person-centered planning should be expanded. An example is a measure concept from the Washington State Individual and Family Services 1915c Waiver instrument that measures the percentage of waiver participants with personal goals identified at service planning, whose

personal goals were addressed in their service plan.

Few quality measures exist to assess coordination of HCBS. To address this, an intermediate recommendation is to invest in the development of quality measures for the coordination subdomain. Consumer surveys in use within various states should be explored for items that could be translated into quality performance measures related to coordination. The proposed CMS HCBS Experience of Care survey offers a measure that evaluates transportation to medical appointments. Washington State, for instance, measures the percentage of HCBS beneficiaries and family members responding to the National Core Indicators (NCI)TM survey who report satisfaction with the development and implementation of their individual support plans. These items are an example of how quality measures could be derived from an experience or satisfaction survey that is used across multiple HCBS populations. Another example is the Council on Quality and Leadership's (CQL) Personal Outcome Measures, which is an instrument that assesses whether an individual is supported in a way that achieves the outcomes that are most important to that individual.

RECOMMENDATIONS

Short-term

- Expand the implementation of process measure concepts related to assessment and person-centered subdomains.

Intermediate

- Support the development of quality measures for the coordination subdomain.
- Consumer surveys in use within various states should be explored for items that could be translated into quality measures.

Choice and Control

The Choice and Control domain is defined as the level to which individuals who use HCBS, on their own or with support, make life choices, choose their services and supports, and control how those services and supports are delivered. Four subdomains were prioritized within this domain:

- **Personal choices and goals:** The level to which services and plans describe, develop, and support individual choices and life goals.
- **Choice of services and supports:** The level to which individuals who use HCBS have a choice in selecting and self-directing their program delivery models, services and supports, provider(s), and setting(s).
- **Personal freedoms and dignity of risk:** The level to which individuals who use HCBS have personal freedoms and the ability to take risks.
- **Self-direction:** The level to which individuals who use HCBS, on their own or with support, have decisionmaking authority over their services and take direct responsibility to manage their services with the assistance of a system of available supports.

Within Choice and Control, the Committee developed short-term and intermediate recommendations. The Committee recommended testing and expanding the implementation of existing process and structure measure concepts capturing the personal choices and goals, choice of services and supports, and self-direction subdomains. Examples of such measure concepts include (1) those used within Medicaid managed long-term services and supports (MLTSS) such as the percent increase in enrollees who receive self-directed personal care or the percent increase in members who receive personal attendant and/or respite services through the self-directed services delivery model, and (2) the Oregon's Medicaid Community First Choice program measure of the

percentage of individuals who express that they are able to direct their services. These measure concepts capture data relevant to the subdomains of personal choice and goals, choice of services and supports, and self-direction and could be expanded to other public and private programs.

An intermediate recommendation from the Committee is to develop additional structure measures that capture best practices and assess whether the system offers and promotes choice and control. Members also recommended providing technical assistance to help operationalize and measure the four subdomains and testing the instruments that are currently used in various HCBS programs. The Committee noted that while some measures for this domain exist, the outcomes most meaningful to individual consumers are hard to measure. CMS's HCBS Experience of Care Survey is designed to elicit feedback from individuals who use HCBS contains performance measures that capture the subdomains of Choice and Control.

RECOMMENDATIONS

Short-term

- Validate and expand the use of process and structure measure concepts related to the personal choices and goals, choice of services and supports, and self-direction subdomains.

Intermediate

- Develop structure quality measures to assess program practices and designs that promote Choice and Control.
- Provide technical assistance to program officials to help operationalize and measure the subdomains of Choice and Control.
- Assess the evidence for and scientific acceptability of measure concepts and instruments that are currently in use.

Community Inclusion

This domain is defined as the level to which people who use HCBS are integrated into their communities and are socially connected, in accordance with personal preferences. Three subdomains were prioritized for this domain:

- **Social connectedness and relationships:**
The level to which individuals who use HCBS develop and maintain relationships with others.
- **Meaningful activity:** The level to which individuals who use HCBS engage in desired activities (e.g., employment, education, volunteering, etc.).
- **Resources and settings to facilitate inclusion:**
The level to which resources and involvement in community integrated settings are available to individuals who use HCBS.

The Committee identified short-term and intermediate recommendations for this domain. The Committee identified measurement challenges for community inclusion such as the availability of data, unclear accountability for community inclusion, and resource constraints to support community inclusion. To advance quality measurement within this domain, the Committee recommended testing of existing measure concepts within this domain and supporting efforts to further develop the construct of Community Inclusion and develop outcome measures. Illustrative examples of measure

concepts that could be tested and expanded in use include the proportion of adults with disabilities who participate in social, spiritual, recreational, community and civic activities to the degree that they wish and Medicaid MLTSS measures assessing the percent of people with mental illness or intellectual /developmental disabilities who are in competitive employment. Relevant performance measures could be developed using data from survey instruments such as CMS's Money Follows the Person Quality of Life survey and the National Core Indicators, which assesses the community participation of HCBS recipients, the percentage of HCBS recipients who have competitive work, and the average number of hours worked per week by individuals receiving HCBS.

RECOMMENDATIONS

Short-Term

- Test the scientific acceptability (e.g., validity and reliability) and expand the use of process and structure measure concepts related to the meaningful activity subdomain.

Intermediate

- Support efforts to further examine how to operationalize the construct of Community Inclusion and develop outcome quality measures for this domain.

Caregiver Support

The Caregiver Support domain is defined as the level of support (e.g., financial, emotional, technical) available to and received by family caregivers or natural supports of individuals who use HCBS. The Committee deliberated at length about the inclusion of the term ‘natural supports.’ Some of the issues discussed include who or what structures were encompassed by this term or replacing natural supports with ‘paid and unpaid caregivers.’ Others maintained that ‘natural supports’ is a term representing a variety of individuals (e.g., friend, neighbor, someone from a social club) who may provide support to an individual and its use would not overlap with the Workforce domain and cause confusion for those using the framework to inform their measurement activities. Four subdomains were prioritized for this domain:

- **Family caregiver/natural support well-being:** The level to which the family caregiver/natural support is assisted in terms of physical, emotional, mental, social, and financial well-being.
- **Training and skill-building:** The level to which the appropriate training and skill-building activities are available to caregivers/natural supports who desire such activities.
- **Family caregiver/natural support involvement:** The level to which family caregivers/natural supports are involved in developing and executing the HCBS consumer’s person-centered care plan in accordance with the preferences of the consumer and family caregiver/natural support. This involvement includes direct assessment of caregiver/natural support needs, not just their ability to provide care, and is an ongoing part of the provision of HCBS.
- **Access to resources:** The level to which the family caregiver/natural support is aware of and able to access resources (e.g., peer support, respite, crisis support, information and referral) that support overall well-being.

There is little data on caregivers and natural supports of HCBS consumers from which to develop quality measures. A small number of measures, measure concepts, or instruments that assess family caregivers or natural supports exist.

Moreover, family caregivers and natural supports are often overlooked or underrepresented in conversations about HCBS quality even though they play a major role in the provision of care and support to HCBS consumers.

The Committee identified intermediate and long-term recommendations for this domain. The Committee recommended that family caregiver and natural support assessments should be further developed and translated or modified into a format that can be more easily integrated into the existing HCBS programs. These assessments are not quality measures, but could be used to develop valid and reliable quality measures of caregiver support. For instance, the [Zarit Caregiver Burden Questionnaire](#) developed by the American Psychological Association is a 29-item instrument that assesses feelings of burden experienced by the caregivers of elderly persons with dementia, and the [Tailored Caregiver Assessment and Referral System](#) developed by the University of Wisconsin Milwaukee, a 32-item screening tool, identifies and categorizes caregivers’ level of burden to guide providers in understanding caregivers’ needs and care planning for the caregiver.^{16,17} Benchmarks for outcomes related to family caregiver and natural support well-being are also needed. In the long-term, an infrastructure and processes are needed to support data collection and management of family caregiver and natural support data that link with the consumer’s data. Currently, there is no way of accessing data on a consumer’s family caregiver or natural support, let alone tying these data back to the consumer.

RECOMMENDATIONS

Intermediate

- Further develop and disseminate family caregiver/natural support assessments and develop benchmarks for outcomes related to family caregiver/natural support well-being.

Long-Term

- Support the development of the processes and infrastructure needed for the collection and management of data related to the family caregiver/natural support.

Workforce

The Committee defined this domain as the adequacy, availability, and appropriateness of the HCBS workforce. Seven subdomains were prioritized for this domain:

- **Person-centered approach to services:** The level to which the workforce's approach to the delivery of services is tailored to the preferences and values of the consumer. This includes the use of good communication skills to solicit those preferences and values while also demonstrating respect for consumer privacy and boundaries.
- **Demonstrated competencies, when appropriate:** The level to which the workforce is able to demonstrate that services are provided in a skilled and competent manner. These skills and competencies are fostered in the workforce through the use of competency-based approaches to training and skill development.
- **Safety of and respect for the worker:** The level to which the HCBS delivery system monitors, protects, and supports the safety and well-being of the workforce.
- **Sufficient workforce numbers, dispersion, and availability:** The level to which the supply of and the demand for the HCBS workforce are aligned in terms of numbers, geographic dispersion, and availability.
- **Adequately compensated, with benefits:** The level to which the HCBS workforce is provided compensation, training, and benefits as a means for ensuring a stable supply of qualified workers to meet the service and support needs of HCBS consumers.
- **Culturally competent:** The level to which the workforce is able to deliver services that are aligned with the cultural background, values, and principles of the HCBS consumer (i.e., cultural competency of the workforce) and the level to which the HCBS system trains and supports the workforce in a manner that is aligned with the cultural background, values, and principles of the HCBS workforce (i.e., cultural competency of the HCBS system).

- **Workforce engagement and participation:** The level to which front-line workers and service providers have meaningful involvement in care planning and execution where appropriate, program development and evaluation, and the design, implementation, and evaluation of the HCBS system and policies.

Currently, there is no clear and consistent way to identify or access HCBS workers. There is limited data from which workforce measures can be constructed, resulting in few measures. The lack of measures is compounded by the lack of investment into workforce development and support.

The Committee developed intermediate and long-term recommendations for this domain. The Committee recommended examining the availability and feasibility of using existing data to develop structure and process measures related to workforce, such as the average turnover rate by setting and job title. A more long-term recommendation is to support the development of processes and infrastructure to collect data on the workforce and to link this data to the consumer receiving care. Investing resources into standardized data collection tools such as the National Core Indicators Staff Stability Survey¹⁸—designed to facilitate data collection by states on staffing levels, stability, wages, hours, benefits, recruitment, and retention of the direct support professional workforce—and assessments of the workforce will support the development of needed and meaningful structure, process, and outcome measures related to the workforce.

RECOMMENDATIONS

Intermediate

- Examine the availability and feasibility of using existing data to develop structure and process measures related to the workforce.
- Support the development of outcome measures related to the workforce.

Long-Term

- Support the development of the processes and infrastructure needed for the collection of data related to the workforce.

Human and Legal Rights

The Committee defined this domain as the level to which the human and legal rights of individuals who use HCBS are promoted and protected.

Within the domain, the Committee prioritized five subdomains:

- **Freedom from abuse and neglect:** The level to which the HCBS consumer is free from abuse and neglect and the HCBS system implements appropriate prevention and intervention strategies to ensure that the HCBS consumer is free from the threat of harm, actual harm, or disregard of basic needs.
- **Optimizing the preservation of legal and human rights:** The level to which the HCBS system ensures HCBS consumers are accorded their full legal and human rights and are afforded due process in the delivery of HCBS. The preservation of these rights includes the system's ability to detect and respond to potential violations in a timely and effective manner.
- **Informed decisionmaking:** The level to which HCBS consumers, on their own or with support, are provided sufficient, understandable information in order to make decisions.
- **Privacy:** The level to which the HCBS consumer is able to maintain the desired level of privacy in terms of information sharing, access to private space, and developing and maintaining private relationships.
- **Supporting individuals in exercising their human and legal rights:** The level to which the HCBS system supports individuals in exercising their human and legal rights.

Within this domain, the intermediate and long-term recommendations relate to the need to

test existing process measure concepts and develop outcome measures. Process measure concepts in use include Oregon state measures of the number and percent of HCBS beneficiaries and/or guardians who are informed about the ways to identify and report abuse, neglect, and exploitation, and a California Community First Choice measure on the percent of statewide cases involving critical incidents. Administrative data is a potential source for developing measures that assess privacy. Outcome measures related to human and legal rights may be derived from existing surveys such as CMS's Money Follows the Person Quality of Life Survey or the National Core Indicators surveys. A long-term recommendation is to develop the evidence base for the processes that the HCBS system can implement to optimize HCBS consumers' privacy, preservation of their human and legal rights, and ability to exercise their rights.

RECOMMENDATIONS

Intermediate

- Validate existing process measure concepts related to human and legal rights.
- Develop outcome quality measures related to all of the subdomains of human and legal rights.
- Examine the use of administrative data in developing measures for the privacy subdomain.

Long-Term

- Develop the evidence base for the processes that the HCBS system can implement to optimize HCBS consumers' privacy, preservation of their human and legal rights, and ability to exercise their rights.

Equity

After a robust discussion on the difference between equality and equity, the Committee agreed that consumers and communities should be treated fairly and justly, and services should be available and accessible according to need, rather than every individual getting the same services regardless of need. The Committee also distinguished between availability and accessibility by noting that a service or support must exist before it can be accessed by those who need it.

As such, the Committee defined the Equity domain as the level to which HCBS are equitably available to all individuals who need long-term services and supports. Four subdomains were prioritized for this domain:

- **Equitable access and resource allocation:** The extent to which consumers of HCBS have equitable access and ability to obtain needed services and supports (e.g., housing, transportation, employment services) and the extent to which the HCBS system is able to support that access through equitable allocation of resources and minimization of barriers (e.g., environmental, geographic) to access.
- **Transparency and consistency:** The extent to which laws, regulations, and policies are equitably administered and information is publicly available.
- **Availability:** The extent to which a service or support is equitably available to individuals seeking or receiving HCBS.
- **Reduction in health disparities and service disparities:** The extent to which the HCBS system minimizes disparities in health outcomes and services.

The Committee provided short-term, intermediate, and long-term recommendations for this domain. In the short term, the Committee recommended assessing the scientific acceptability of measure concepts related to housing and homelessness, for example, the percentage of people with identified homelessness or housing instability, the percentage of adults with a serious and persistent mental illness who report having a place to live that is comfortable for them, or the percentage of persons with an HIV

diagnosis who were homeless or unstably housed in the 12-month measurement period.

Intermediate recommendations include the investment of resources that enable access to existing program data (e.g., number of consumers served, waitlist times) and facilitate the translation of that program data into quality measures related to transparency and consistency. The Committee recommended development and expansion of population-focused measures on service availability to all HCBS consumers. Administrative data should be leveraged to obtain information related to race/ethnicity, age, gender, and spoken language to facilitate measurement of equity, and in particular, reduction in health and service disparities.

A long-term recommendation for this domain is to leverage technological innovations to develop systems for monitoring indicators of disparities (e.g., geo-mapping of resource distribution, hot-spotting).

RECOMMENDATIONS

Short-Term

- Assess the scientific acceptability and expand the use of existing quality measures related to housing and homelessness.

Intermediate

- Invest in methods for enabling access to existing program data and developing those data into quality measures related to transparency.
- Improve standardization and reporting of waiting list data for HCBS in order to improve accuracy and develop quality measures.
- Further develop and expand the population focus of existing HIV-specific quality measures related to service availability.
- Examine the use of administrative data for obtaining information on race/ethnicity, age, gender, languages spoken, and other information for examining equity.

Long-Term

- Leverage technological innovations to develop systems for monitoring various indicators of health and service disparities.

Holistic Health and Functioning

The Committee re-named the Health and Well-Being domain as Holistic Health and Functioning and defined this domain as the extent to which all dimensions of holistic health are assessed and supported. Two subdomains were prioritized for this domain:

- **Individual health and functioning:** The level to which all aspects of an HCBS consumer's health and functioning (including physical, emotional, mental, behavioral, cognitive, and social) are assessed and supported.
- **Population health and prevention:** The level to which the HCBS consumer is supported in preventing poor health outcomes (e.g., falls, malnutrition) and achieving the highest levels of health and functioning across all dimensions of holistic health.

This domain has short-term, intermediate, and long-term recommendations. The Committee's short-term recommendations are to refine and expand the use of quality measures derived from assessment tools routinely used in community settings, and expand the use of validated quality measures related to falls, medication management, immunizations, and other quality measures focused on population health. Some examples of such measures include the percentage of consumers aged 65 years and older who were screened for future fall risk at least once within 12 months; the percentage of consumers who need urgent, unplanned medical care due to an injury caused by fall; and the percentage of Programs of All-Inclusive Care for the Elderly (PACE) beneficiaries who received the pneumococcal immunization in the last 10 years.

The intermediate recommendations are to develop outcome measures across all dimensions of holistic

health, with particular focus on behavioral and social health and functioning.

The long-term recommendations are to develop, test, and disseminate a universal assessment tool that includes all dimensions of holistic health and functioning, and to leverage technological innovations to develop systems for monitoring various indicators of population health (e.g., rates of falls and immunizations). The TEFT Functional Assessment Standardized Items (FASI) is currently being tested and offers promise for use across populations of HCBS.

RECOMMENDATIONS

Short-Term

- Refine and expand the use of quality measures derived from assessment tools routinely used in community settings.
- Expand the use of validated quality measures related to falls, medications, immunizations, and other quality measures focused on population health.

Intermediate

- Develop outcome measures across all dimensions of holistic health, with particular focus on the dimensions of behavioral and social health and functioning.

Long-Term

- Develop, test, and disseminate a method for assessing and monitoring (e.g., a universal assessment tool) all dimensions of holistic health and functioning.
- Leverage technological innovations to develop systems for monitoring various indicators of population health.

System Performance and Accountability

The Committee voted to add “accountability” to the name of this domain and defined the domain as the extent to which the system operates efficiently, ethically, transparently, and effectively in achieving desired outcomes. Three subdomains were prioritized and defined:

- **Financing and service delivery structures:** The level to which the system is appropriately financed and has the appropriate infrastructure in place to meet the needs of consumers.
- **Evidence-based practice:** The level to which services are delivered in a manner that is consistent with the best available evidence.
- **Data management and use:** The level to which the system collects data in a manner that is consistent with best practices (i.e., complete, reliable, and valid), makes data publicly available, and uses data for performance improvement.

The recommendations for measure development within this domain are short-term, intermediate, and long-term. The Committee discussed measures and measure concepts related to Medicaid rebalancing between institutional and community care, waiting lists for HCBS provided by Medicaid, and unmet need that could be expanded in use and implemented nationally in the short term. Examples include the percentage of Medicaid LTSS expenditures devoted to HCBS, the relative distribution of LTSS recipients in home and community settings compared to institutional settings, relative spending on HCBS compared to institutional services, the proportion of all people receiving and waiting for LTSS, transitions from the community to institutional settings and from institutions back to the community, and the percentage of plans where expenditures are consistent with assessed needs.

For the intermediate term, the Committee recommended building on current measure development projects such as the TEFT demonstration project and continuing to develop states’ data infrastructure to enable efficient and effective data management and use.

In the long term, resources need to be invested in researching and sharing evidence-based practices within HCBS and developing quality measures that assess the extent to which these practices are used across HCBS.

RECOMMENDATIONS

Short-Term

- Expand the use of measures and measure concepts related to rebalancing, waiting lists, and unmet need.
- Refine available structure and process measure concepts related to: (1) financing and service delivery structures, and (2) data management and use through standardization, testing, and research.

Intermediate

- Build upon current measure development projects (e.g., Medicaid’s Testing Experience and Functional Tools [TEFT] grant), and continue developing states’ data infrastructures to enable efficient and effective data management and use.

Long-Term

- Support the continued development and dissemination of evidence-based practices throughout HCBS and provide resources for the development of quality measures that assess the extent to which these practices are used across HCBS.

Consumer Leadership in System Development

The Committee re-named this domain—previously called Consumer Voice—as Consumer Leadership in System Development to reflect the Committee’s intended meaning. This domain is defined as the level to which individuals who use HCBS are well supported to actively participate in the design, implementation, and evaluation of the system at all levels. The Committee underscored the importance of having HCBS consumers actively participate in developing the HCBS system. For example, a measure that merely assesses whether or not an HCBS consumer sits on a policymaking board would not adequately measure active participation. Three subdomains were prioritized and defined:

- **System supports meaningful consumer involvement:** The level to which the HCBS system facilitates and provides supports for active consumer participation in the design, implementation, and evaluation of the HCBS system.
- **Evidence of meaningful consumer involvement:** The level to which individuals who use HCBS have meaningful involvement in the design, implementation, and evaluation of the HCBS system.
- **Evidence of meaningful caregiver involvement:** The level to which family caregivers/natural supports of individuals who use HCBS have meaningful involvement in the design, implementation, and evaluation of the HCBS system.

The environmental scan did not identify any measures, measure concepts, or instruments

that aligned to this domain. The Committee recommended intermediate measure development and long-term research.

New managed Medicaid care regulations require consumer advisory committees at the provider, state, and health plan levels which could be a source of data for measure development. The Committee noted that there are few examples of what good consumer leadership in system development looks like. One Committee member cited an example of states that have built systems that have tried to incorporate elements of person-outcome based consumer interviews to inform quality councils at regional and state levels to interpret and make HCBS program and policy recommendations based on available data. The Committee recommended devoting resources to studying how the system can support meaningful consumer involvement in the design, implementation, and evaluation of the HCBS system and how to capture such involvement via quality measurement.

RECOMMENDATIONS

Intermediate

- Develop structure and process measures to assess the subdomains of consumer leadership in system development.

Long-term

- Devote resources to research how the system can support meaningful consumer involvement in the design, implementation, and evaluation of the HCBS system and how to capture such involvement via quality measures.

NEXT STEPS

The Committee's recommendations are a call to action intended to stimulate and guide measure development and implementation across the field using a consensus-based framework. While this is the final interim report, the recommendations, as well as all other work completed to date, are considered a draft. This report will be posted for a 30-day comment period to allow members of

the public to share their thoughts and opinions on these recommendations. These comments will be made publicly available. Committee members will review the comments received and use them to inform their work going forward. The final report for this project will be available in September 2016 and will be a culmination of the three preceding interim reports.

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APPENDIX A:

Committee Roster, HHS Advisory Group, and NQF Staff

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APPENDIX B: Environmental Scan Results

NQF staff identified measures, measure concepts, and instruments using the draft domains and subdomains defined by the Committee in the first interim report. They found 261 measures, 394 measure concepts, and 75 instruments (see [Compendium of Measures](#)). The Committee members used the scan results to identify promising items for further development and to inform its discussion of performance measurement gaps, challenges, priorities, and recommendations.

TABLE B1. DOMAINS OF HCBS QUALITY MEASUREMENT: MEASURES, MEASURE CONCEPTS, AND INSTRUMENTS^{a,b}

Domains for Measurement	Measures, n=261	Measure Concepts, n=394	Instruments, n=75
Service Delivery	75	173	8
System Performance	42	166	3
Effectiveness/Quality of Services	111	13	25
Choice and Control	17	61	34
Health and Well-Being	60	6	16
Workforce	10	65	6
Human and Legal Rights	4	28	1
Community Inclusion	4	15	7
Caregiver Support	4	3	11
Equity	4	4	0
Consumer Voice	0	0	0

TABLE B2. DOMAINS OF HCBS QUALITY MEASUREMENT AND PROMISING MEASURES, MEASURE CONCEPTS, AND INSTRUMENTS^{a,b}

Domains for Measurement	Promising Measures	Promising Measure Concepts	Promising Instruments
Service Delivery	17	115	2
Effectiveness/Quality of Services	59	7	16
Choice and Control	2	19	14
Community Inclusion	3	10	5
Caregiver Support	1	2	7
Workforce	4	11	9
Human and Legal Rights	4	26	0
Equity	4	4	0
Health and Well-Being	58	4	14
System Performance	35	90	1
Consumer Voice	0	0	0

^a NQF staff deleted duplicate measures and measure concepts to the extent possible; however, due to retrieval and extraction from numerous sources, identifying and deleting duplicates from the measure scan was not straightforward, and some duplicates may exist.

^b In some cases, measures constructed from instrument items were extracted and included as measures, and the instrument as a whole is included under instruments.

APPENDIX C:

Initial Domains and Subdomains of HCBS Quality Measurement

Domains for Measurement	Subdomains Corresponding to Each Domain
Service Delivery	Accessibility (e.g., geographic, economic, physical, and public and private awareness or linkage); appropriate (e.g., services aligned with needs and preferences, whether goals are assessed); sufficiency (e.g., scope of services, capacity to meet existing and future demands); dependable (e.g., coverage, timeliness, workforce continuity, knowledge of needs and preferences, and competency); timely initiation of services; coordination (e.g., comprehensive assessment, development of a plan, information exchange between all members of the care team, implementation of the plan, and evaluation of the plan)
Effectiveness/Quality of Services	Goals and needs realized; preferences met; health outcomes achieved; technical skills assessed and monitored; technical services delivered; team performance; rebalancing
Choice and Control	Choice of program delivery models and provider(s) including self-direction, agency, particular worker(s), and setting(s); personal freedoms and dignity of risk; achieving individual goals and preferences (i.e., individuality, person-centered planning); self-direction; shared accountability
Full Community Inclusion	Enjoyment or fun; employment, education, or productivity; social connectedness and relationships; social participation; resources to facilitate inclusion; choice of setting; accessibly built environment
Caregiver Support	Training and skill-building; access to resources (e.g., respite, crisis support); caregiver well-being (e.g., stress reduction, coping); caregiver and/or family assessment and planning; compensation
Workforce/Providers	Sufficient numbers and appropriately dispersed; dependability; respect for boundaries, privacy, consumer preferences, and values; skilled; demonstrated competencies when appropriate; culturally competent, sensitive, and mindful; adequately compensated, with benefits; safety of the worker; teamwork, good communications, and value-based leadership
Human and Legal Rights	Delivery system promotes dignity and respect; privacy; informed consent; freedom from abuse and neglect; optimizing the preservation of legal and human rights; sense of safety; system responsiveness
Equity	Reduction in health and service disparities; transparency of resource allocation; access or waiting list; safe, accessible, and affordable housing; availability; timeliness; consistency across jurisdictions
Health and Well-Being	Physical, emotional, and cognitive functioning; social well-being, spirituality; safety and risk as defined by the consumer; freedom from abuse, neglect, and exploitation; health status and wellness (e.g., prevention, management of multiple chronic conditions); behavioral health
System Performance	Consumer engagement; participatory program design; reliability; publicly available data; appropriate and fair resource allocation based on need; primarily judged by the aggregate of individual outcomes; waiting lists; backlog; financing and service delivery structures; availability of services; efficiency and evidence-based practices; data integrity
Consumer Voice	Meaningful mechanism for input (e.g., design, implementation, evaluation); consumer-driven system; breadth and depth of consumer participation; level of commitment to consumer involvement; diversity of consumer and workforce engagement; and outreach to promote accessible consumer engagement

APPENDIX D:

Revised Domain Names, Definitions, and Prioritized Subdomains with Definitions

Domain Name and Definition	Prioritized Subdomains and Definitions
<p>Service Delivery and Effectiveness: The level to which services are provided in a manner consistent with a person's needs, goals, and preferences that help the person to achieve desired outcomes</p>	<ul style="list-style-type: none"> • Delivery: The level to which the HCBS system supplies person-centered services and supports to the individuals who use HCBS. Important aspects of delivery include timely initiation, the degree to which the delivered services and supports correspond with the plan of care, the ongoing assessment of the correlation of delivery and the plan of care, and the sufficiency of delivery in terms of the scope of services and the capacity to meet existing and future demands. • Person's needs met: The level to which the HCBS system supplies services and supports sufficient to address the needs of the individual who uses HCBS. • Person's identified goals realized: The level to which the HCBS system incorporates the HCBS consumer's goals into services and supports and the individual who uses HCBS is able to achieve those goals through support of the HCBS system.
<p>Person-Centered Planning and Coordination: The processes by which a person directs the development of a plan, based on his or her goals, needs, and preferences, and the coordination of services and supports across providers and systems to carry out the plan</p>	<ul style="list-style-type: none"> • Assessment: The level to which the HCBS system and providers ascertain the HCBS consumer's needs and goals. This process should be person-centered and re-assessments should occur on a regular basis to assure that changes in consumer goals and needs are captured and appropriate adjustments to services and supports are made. • Person-centered planning: The level to which the planning process is <i>directed</i> by the person, with support as needed, and results in an executable plan for achieving goals that the person deems important, including paid and unpaid services or supports needed to reach those goals. • Coordination: The level to which HCBS system and health/other service providers collaborate to ensure delivery of individual services and supports are complementary and work together to fully support the HCBS consumer in terms of their needs and goals.
<p>Choice and Control: The level to which individuals who use HCBS, on their own or with support, make life choices, choose their services and supports, and control how those services and supports are delivered</p>	<ul style="list-style-type: none"> • Personal choices and goals: The level to which services and plans describe, develop, and support individual choices and life goals. • Choice of services and supports: The level to which individuals who use HCBS have a choice in selecting and self-directing their program delivery models, services and supports, provider(s), and setting(s). • Personal freedoms and dignity of risk: The level to which individuals who use HCBS have personal freedoms and the ability to take risks. • Self-direction: The level to which individuals who use HCBS, on their own or with support, have decisionmaking authority over their services and take direct responsibility to manage their services with the assistance of a system of available supports.

Domain Name and Definition	Prioritized Subdomains and Definitions
<p>Community Inclusion: The level to which people who use HCBS are integrated into their communities and are socially connected, in accordance with personal preferences</p>	<ul style="list-style-type: none"> • Social connectedness and relationships: The level to which individuals who use HCBS develop and maintain relationships with others. • Meaningful activity: The level to which individuals who use HCBS engage in desired activities (e.g., employment, education, volunteering, etc.). • Resources and settings to facilitate inclusion: The level to which resources and involvement in community integrated settings are available to individuals who use HCBS.
<p>Caregiver Support: The level of support (e.g., financial, emotional, technical) available to and received by family caregivers or natural supports of individuals who use HCBS</p>	<ul style="list-style-type: none"> • Family caregiver/natural support well-being: The level to which the family caregiver/natural support is assisted in terms of physical, emotional, mental, social, and financial well-being. • Training and skill-building: The level to which the appropriate training and skill-building activities are available to family caregivers/natural supports who desire such activities. • Family caregiver/natural support involvement: The level to which family caregivers/natural supports are involved in developing and executing the HCBS consumer's person-centered care plan in accordance with the preferences of the consumer and family caregiver/natural support. This involvement includes direct assessment of caregiver/natural support needs, not just their ability to provide care, and is an ongoing part of the provision of HCBS. • Access to resources: The level to which the family caregiver/natural support is aware of and able to access resources (e.g., peer support, respite, crisis support, information and referral) that support overall well-being.

Domain Name and Definition	Prioritized Subdomains and Definitions
<p>Workforce: The adequacy, availability, and appropriateness of the HCBS workforce</p>	<ul style="list-style-type: none"> • Person-centered approach to services: The level to which the workforce's approach to the delivery of services is tailored to the preferences and values of the consumer. This includes the use of good communication skills to solicit those preferences and values while also demonstrating respect for consumer privacy and boundaries. • Demonstrated competencies, when appropriate: The level to which the workforce is able to demonstrate that services are provided in a skilled and competent manner. These skills and competencies are fostered in the workforce through the use of competency-based approaches to training and skill development. • Safety of and respect for the worker: The level to which the HCBS delivery system monitors, protects, and supports the safety and well-being of the workforce. • Sufficient workforce numbers, dispersion, and availability: The level to which the supply of and the demand for the HCBS workforce are aligned in terms of numbers, geographic dispersion, and availability. • Adequately compensated, with benefits: The level to which the HCBS workforce is provided compensation, training, and benefits as a means for ensuring a stable supply of qualified workers to meet the service and support needs of participants. • Culturally competent: The level to which the workforce is able to deliver services that are aligned with the cultural background, values, and principles of the HCBS consumer (i.e., cultural competency of the workforce) and the level to which the HCBS system trains and supports the workforce in a manner that is aligned with the cultural background, values, and principles of the HCBS workforce (i.e., cultural competency of the HCBS system). • Workforce engagement and participation: The level to which front-line workers and service providers have meaningful involvement in care planning and execution where appropriate, program development and evaluation, and the design, implementation, and evaluation of the HCBS system and policies.
<p>Human and Legal Rights: The level to which the human and legal rights of individuals who use HCBS are promoted and protected</p>	<ul style="list-style-type: none"> • Freedom from abuse and neglect: The level to which the HCBS consumer is free from abuse and neglect and the HCBS system implements appropriate prevention and intervention strategies to ensure that the HCBS consumer is free from the threat of harm, actual harm, or disregard of basic needs. • Optimizing the preservation of legal and human rights: The level to which the HCBS system ensures HCBS consumers are accorded their full legal and human rights and are afforded due process in the delivery of HCBS. The preservation of these rights includes the system's ability to detect and respond to potential violations in a timely and effective manner. • Informed decisionmaking: The level to which the HCBS consumer, on their own or with support, is provided sufficient, understandable information in order to make decisions. • Privacy: The level to which the HCBS consumer is able to maintain the desired level of privacy in terms of information sharing, access to private space, and developing and maintaining private relationships. • Supporting individuals in exercising their human and legal rights: The level to which the HCBS system supports individuals in exercising their human and legal rights.

Domain Name and Definition	Prioritized Subdomains and Definitions
<p>Equity: The level to which HCBS are equitably available to all individuals who need long-term services and supports</p>	<ul style="list-style-type: none"> • Equitable access and resource allocation: The extent to which consumers of HCBS have equitable access and ability to obtain needed services and supports (e.g., housing, transportation, employment services) and the extent to which the HCBS system is able to support that access through equitable allocation of resources and minimization of barriers (e.g., environmental, geographic) to access. • Transparency and consistency: The extent to which laws, regulations, and policies are equitably administered and information is publicly available. • Availability: The extent to which a service or support is equitably available to individuals seeking or receiving HCBS. • Reduction in health disparities and service disparities: The extent to which the HCBS system minimizes disparities in health outcomes and services
<p>Holistic Health and Functioning: The extent to which all dimensions of holistic health are assessed and supported</p>	<ul style="list-style-type: none"> • Individual health and functioning: The level to which all aspects of an HCBS consumer's health and functioning (including physical, emotional, mental, behavioral, cognitive, and social) are assessed and supported. • Population health and prevention: The level to which the HCBS consumer is supported in preventing poor health outcomes (e.g., falls, malnutrition) and achieving the highest levels of health and functioning across all dimensions of holistic health.
<p>System Performance and Accountability: The extent to which the system operates efficiently, ethically, transparently, and effectively in achieving desired outcomes</p>	<ul style="list-style-type: none"> • Financing and service delivery structures: The level to which the system is appropriately financed and has the appropriate infrastructure in place to meet the needs of consumers. • Evidence-based practice: The level to which services are delivered in a manner that is consistent with the best available evidence. • Data management and use: The level to which the system collects data in a manner that is consistent with best practices (i.e., complete, reliable, and valid), makes data publicly available, and uses data for performance improvement.
<p>Consumer Leadership in System Development: The level to which individuals who use HCBS are well supported to actively participate in the design, implementation, and evaluation of the system at all levels</p>	<ul style="list-style-type: none"> • System supports meaningful consumer involvement: The level to which the HCBS system facilitates and provides supports for active consumer participation in the design, implementation, and evaluation of the HCBS system. • Evidence of meaningful consumer involvement: The level to which individuals who use HCBS have meaningful involvement in the design, implementation, and evaluation of the HCBS system. • Evidence of meaningful caregiver involvement: The level to which family caregivers/natural supports of individuals who use HCBS have meaningful involvement in the design, implementation, and evaluation of the HCBS system.

APPENDIX E: Domain-Specific Recommendations

Group A: Short-Term Recommendations

Domain	Recommendations
Service Delivery and Effectiveness	<ul style="list-style-type: none"> Expand the implementation of process measure concepts related to the person's goals identified and realized, unmet service need, accessibility, and consumer experience to improve quality.
Person-Centered Planning and Coordination	<ul style="list-style-type: none"> Expand the implementation of process measure concepts related to assessment and person-centered subdomains.
Choice and Control	<ul style="list-style-type: none"> Validate and expand the use of process and structure measure concepts related to the personal choices and goals, choice of services and supports, and self-direction subdomains.
Community Inclusion	<ul style="list-style-type: none"> Test the scientific acceptability (e.g., validity and reliability) and expand the use of process and structure measure concepts related to the meaningful activity subdomain.
Equity	<ul style="list-style-type: none"> Assess the scientific acceptability and expand the use of existing quality measures related to housing and homelessness.
Holistic Health and Functioning	<ul style="list-style-type: none"> Refine and expand the use of quality measures derived from assessment tools routinely used in community settings. Expand the use of validated quality measures related to falls, medications, immunizations, and other quality measures focused on population health.
System Performance and Accountability	<ul style="list-style-type: none"> Expand the use of measures and measure concepts related to rebalancing, waiting lists, and unmet need. Refine available structure and process measure concepts related to: (1) financing and service delivery structures, and (2) data management and use through standardization, testing, and research.

Group B: Intermediate Recommendations

Domain	Recommendations
Service Delivery and Effectiveness	<ul style="list-style-type: none"> Support the development of quality measures for the delivery subdomain. Invest in developing person-centered outcome measures for this domain.
Person-Centered Planning and Coordination	<ul style="list-style-type: none"> Support the development of quality measures for the coordination subdomain. Consumer surveys in use within various states should be explored for items that could be translated into quality measures.
Choice and Control	<ul style="list-style-type: none"> Develop structure quality measures to assess program practices and designs that promote Choice and Control. Provide technical assistance to program officials to help operationalize and measure the subdomains of Choice and Control. Assess the evidence for and scientific acceptability of measure concepts and instruments that are currently in use.
Community Inclusion	<ul style="list-style-type: none"> Support efforts to further examine how to operationalize the construct of Community Inclusion and develop outcome quality measures for this domain.

Domain	Recommendations
Caregiver Support	<ul style="list-style-type: none"> • Further develop and disseminate family caregiver/natural support assessments and develop benchmarks for outcomes related to family caregiver/natural support well-being.
Workforce	<ul style="list-style-type: none"> • Examine the availability and feasibility of using existing data to develop structure and process measures related to the workforce. • Support the development of outcome measures related to the workforce.
Human and Legal Rights	<ul style="list-style-type: none"> • Validate existing process measure concepts related to human and legal rights. • Develop outcome quality measures related to all of the subdomains of human and legal rights. • Examine the use of administrative data in developing measures for the privacy subdomain.
Equity	<ul style="list-style-type: none"> • Invest in methods for enabling access to existing program data and developing those data into quality measures related to transparency. • Improve standardization and reporting of waiting list data for HCBS in order to improve accuracy and develop quality measures. • Further develop and expand the population focus of existing HIV-specific quality measures related to service availability. • Examine the use of administrative data for obtaining information on race/ethnicity, age, gender, languages spoken, and other information for examining equity.
Holistic Health and Functioning	<ul style="list-style-type: none"> • Develop outcome measures across all dimensions of holistic health, with particular focus on the dimensions of behavioral and social health and functioning.
System Performance and Accountability	<ul style="list-style-type: none"> • Build upon current measure development projects (e.g., Medicaid's Testing Experience and Functional Tools [TEFT] grant), and continue developing states' data infrastructures to enable efficient and effective data management and use.
Consumer Leadership in System Development	<ul style="list-style-type: none"> • Develop structure and process measures to assess the subdomains of consumer leadership in system development.

Group C: Long-Term Recommendations

Domain	Recommendations
Caregiver Support	<ul style="list-style-type: none"> • Support the development of the processes and infrastructure needed for the collection and management of data related to the family caregiver/natural support.
Workforce	<ul style="list-style-type: none"> • Support the development of the processes and infrastructure needed for the collection of data related to the workforce.
Human and Legal Rights	<ul style="list-style-type: none"> • Develop the evidence base for the processes that the HCBS system can implement to optimize HCBS consumers' privacy, preservation of their human and legal rights, and ability to exercise their rights.
Equity	<ul style="list-style-type: none"> • Leverage technological innovations to develop systems for monitoring various indicators of health and service disparities.
Holistic Health and Functioning	<ul style="list-style-type: none"> • Develop, test, and disseminate a method for assessing and monitoring (e.g., a universal assessment tool) all dimensions of holistic health and functioning. • Leverage technological innovations to develop systems for monitoring various indicators of population health.
System Performance and Accountability	<ul style="list-style-type: none"> • Support the continued development and dissemination of evidence-based practices throughout HCBS and provide resources for the development of quality measures that assess the extent to which these practices are used across HCBS.
Consumer Leadership in System Development	<ul style="list-style-type: none"> • Devote resources to research how the system can support meaningful consumer involvement in the design, implementation, and evaluation of the HCBS system and how to capture such involvement via quality measures.

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