Quality in Home and Community-Based Services to Support Community Living:

Addressing Gaps in Performance Measurement

FINAL REPORT

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NATIONAL QUALITY FORUM

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FOREWORD
from the Members of the Committee

More than 12 million Americans need long-term services and supports (LTSS), a figure that is expected to increase to 27 million by 2050.[1] Of the more than 10 million living in their homes or other community settings, the vast majority receive unpaid help with daily activities, and a substantial fraction receive paid services funded by Medicaid, other government sources, and private payers including the individual and his or her family. More than 3 million people receive Medicaid-funded home and community-based services (HCBS), a figure that is expected to increase rapidly with the aging of the population and a continued shift away from institutional LTSS.[2] Yet there is little information collected about HCBS quality. When HCBS programs measure quality, the focus is typically on a narrow set of quality domains, the measures used are not comparable to those used in other states and programs, and the emphasis is not always on the needs and experiences of the people receiving services. Performance measures are needed to drive systems change, tie performance to outcomes, allow consumers to make informed choices, and compare the effectiveness of different models of HCBS and of HCBS versus institutional services. The continued expansion of HCBS, along with rapid changes in the healthcare delivery system, makes the need for comprehensive quality measurement in HCBS ever more urgent.

Recognizing the imperative to further conceptualize and promote measurement of HCBS quality, the U.S. Department of Health and Human Services (HHS) contracted with the National Quality Forum (NQF) to convene a national, multistakeholder Committee to reach consensus on a definition of HCBS and on the domains of HCBS quality, identify existing measures and measure concepts that are relevant to each domain, and make recommendations for future work. As members of that Committee, we represent advocacy organizations, state LTSS and Medicaid agencies, academic research centers, LTSS and healthcare providers, HCBS consumers, workers, caregivers, and other stakeholder groups. Some of us have expertise on certain populations, such as people with disabilities generally, older adults needing LTSS, or people with specific types of disabilities, while others have a deep understanding of LTSS-related public policy or of how the HCBS system works on the ground.

Unlike other aspects of the healthcare and social services system, HCBS lacks any standardized set of quality measures. There is also a lack of consensus as to what HCBS quality entails. For most Medicaid HCBS programs, the Centers for Medicare & Medicaid Services (CMS) requires states to assess quality and implement quality improvement efforts, but neither a precise definition of quality nor a specific set of measures is offered. As a consequence, states may use only pro forma measures that focus more on regulatory or contractual compliance; others use homegrown or borrowed measures of aspects of quality that can more readily be obtained through available administrative data or consumer surveys. Although there are many useful measures and measure concepts currently in the field, no state or program assesses quality across all of the domains identified by this Committee. Furthermore, public reporting by states of HCBS quality data is minimal and often nonexistent.

The shift to Medicaid managed LTSS has generated increased attention to the lack of a comprehensive HCBS quality system. As of July 2016, 23 states use managed care plans to deliver some, or all, HCBS to consumers, either through a Medicare-Medicaid alignment initiative or as a Medicaid-only design. In a managed LTSS system, states contract with managed care plans, which

take on much of the responsibility—and risk—for the delivery of LTSS, rather than managing the program directly with contracted providers. Appropriate oversight requires that states monitor both the quality and quantity of services provided, as well as the balance between HCBS and institutional services. The new Medicaid managed care regulations for the first time require states to assess HCBS quality in the areas of rebalancing, community integration, and quality of life. CMS indicated that it may provide future guidance and move toward development of a core set of measures.

Although the road to shared understanding and consensus has not always been easy, the Committee members are proud of what we have been able to accomplish in the relatively short period since our work began. While this report is by no means the final word on HCBS quality measurement, we believe that we have made a good start in framing the conversation about the imperative for HCBS quality measurement. Of particular value, we feel, are the Characteristics of High-Quality HCBS (see page 9), the extensive set of HCBS quality domains and subdomains (**Appendix D**), the global and domain-specific recommendations, and existing measure concepts that are relevant to those domains and subdomains. Despite high expectations among many outside observers for a definitive solution to HCBS quality measurement, this was not the Committee's charge, nor could such an objective have been achieved given the current state of the field.

Our work has been closely followed; there is tremendous collective interest in moving the state of HCBS quality measurement forward. This project has received a large amount of public comment, among the most ever received by NQF. This groundswell of interest leads us to hope that these organizations, including CMS, the Administration for Community Living, other agencies within HHS, and other measure developers will use our work as a starting point in developing a robust, comprehensive, and standardized system for measuring HCBS quality across states, programs, populations, and payers. In addition, we hope the report is also useful to states and advocates that are currently designing and implementing programs. For some quality domains, existing measures or measure concepts can be adapted if needed, further validated, and put into widespread use over the short term. For other domains and subdomains, further identification or development of appropriate measures is needed. In some subdomains, conceptual work in understanding how to operationalize the concepts of quality is needed before measure development can begin. We hope this report will provide guidance in furthering this work.

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EXECUTIVE SUMMARY

The Addressing Performance Measure Gaps in Home and Community-Based Services (HCBS) to Support Community Living Quality Project aimed 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 funding from federal, state, and local governments as well as private and third party payers 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 Services (HHS), convened a multistakeholder Committee to develop recommendations for the prioritization of measurement opportunities to address gaps in HCBS quality measurement. The project involved:

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, measure concepts, and instruments;
3. the identification of gaps in quality measurement based on the framework and scan; and
4. the drafting of recommendations for prioritization in measurement.

Over the course of this two-year project, three interim reports were published. 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 quality measurement in HCBS. The **second interim report** 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. The **third interim report** highlighted the work of the Committee in revising the domains and subdomains and drafting recommendations.

This final report details the Committee's recommendations for how to advance quality measurement in HCBS. Through Committee deliberations, the Committee members identified gaps in measurement within all of the domains and subdomains and discussed the barriers and challenges to measuring HCBS quality. These barriers and 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 across the numerous federal, state, local, and privately funded programs with respect to 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 global 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 Committee's global recommendations, which are elaborated upon in the body of this report, apply broadly to HCBS quality measurement. They are summarized as follows:

- supporting quality measurement across all domains and subdomains;
- building upon existing quality measurement efforts;
- developing and implementing a standardized approach to data collection, storage, analysis, and reporting;
- ensuring that emerging technology standards, development, and implementation are structured to facilitate quality measurement;
- triangulating the assessment of HCBS quality using an appropriate balance of measure types and units of analysis;
- developing a core set of standard measures for use across the HCBS system, along with a menu of supplemental measures that are tailorable to the population, setting, and program; and
- convening a standing panel of HCBS experts to evaluate and approve candidate measures.

In recognition of the state of measurement within each domain, the Committee categorized and grouped its domain-specific recommendations as follows:

- 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.
- 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.
- 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.

The accomplishments of the HCBS Committee mark an important milestone in the evolution of HCBS quality measurement. Nevertheless, much work lies ahead. The development of measures that capture the many facets of HCBS quality will need to be tested against NQF's evaluation criteria. The infrastructure supporting HCBS quality measurement will also need to be developed and strengthened. Such endeavors are time and resource intensive, but this work offers guidance—essential to those who use HCBS—to assure the highest quality of care and to help individuals achieve their goals of living healthy, meaningful lives in their own communities.

BACKGROUND AND CONTEXT

Home and community-based services (HCBS) play a vital role in empowering millions of Americans to live meaningful lives in the community of their choice. These services support individuals and their caregivers with daily self-care activities (e.g., walking, bathing, and dressing), medication management, food preparation, transportation, employment, and other activities that support community living. Individuals who use HCBS require these services due to disability, mental illness, and/or multiple chronic conditions. For the nearly 39 million Americans living with a disability, HCBS represent a resource through which individuals can create a network of services and supports that address their specific needs.[3]

The same is true for individuals with multiple chronic conditions, many of whom are older adults, who find it difficult to remain independent with functional limitations and challenges managing complex medication regimens. Projections show that 21 million individuals are expected to be living with multiple chronic conditions by 2040, and many will require long-term services and supports (LTSS) such as HCBS.[4] In addition, the number of people 65 years of age and older will exceed 70 million by 2030, accounting for 19 percent of the total United States population.[5] These numbers indicate that the population of HCBS consumers and demand for HCBS will continue to grow in the coming years.

HCBS are provided through a combination of unpaid caregivers, private providers, and public programs. Many people who use HCBS receive assistance from family members, friends, and volunteers in the form of unpaid caregiving. In the United States, the economic value of such care, specifically family caregiving, is valued at approximately $470 billion.[6] A growing portion of HCBS are also provided through a private-pay market, but the majority of services are offered through public programs. These programs are administered through government agencies such as the Centers for Medicare & Medicaid Services (CMS), the Veterans Health Administration, the Administration for Community Living, the Substance Abuse and Mental Health Services Administration, the Administration for Children and Families, and the Health Resources and Services Administration. In federal fiscal year (FY) 2014, HCBS accounted for a majority of Medicaid LTSS expenditures; $80.6 billion of the $152 billion spent by the federal government and state governments on LTSS was devoted to HCBS.[7] This represented a 7.7 percent increase in HCBS spending between FY 2013 and FY 2014.[8] This increase in spending has been accompanied by changes in the structure through which services are provided and paid for under Medicaid. States are increasingly contracting with managed care organizations (MCOs) operating under capitated payment structures to deliver services.[9] It is now the dominant structure for Medicaid programs in the United States with 38 states and the District of Columbia contracting with MCOs for the delivery of many services offered under Medicaid.[10]

Quality Measurement and HCBS

Quality measurement enables providers, organizations, health plans, health systems, payers, and, most importantly, consumers to gauge the quality of the services and supports being delivered. It also facilitates understanding of whether and how quality improvement activities enhance services and outcomes. These measures are quantitative indicators of the structures, processes, and outcomes of care that assess whether a desired goal is being achieved and allow for comparison between providers and entities. Previous as well as ongoing efforts have focused on strengthening quality measurement and quality improvement activities within HCBS. An early effort, for example, was the Deficit

Reduction Act (DRA) of 2005 (PL 109-171, Section 6086(b)), which 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 HCBS quality measures for the Medicaid program. The scan was AHRQ's first step to document the state of the science to support measure development and use in the realm of HCBS.[11]

More recently, in 2014, CMS awarded the Testing Experience and Functional Tools (TEFT) planning grants to nine states to test quality measurement tools and demonstrate e-health in Medicaid HCBS.[12] These efforts have led to the development of an HCBS consumer experience-of-care survey that has undergone field testing and been used to construct measures related to beneficiaries' experience with Medicaid services. Six states were also awarded TEFT grants to test the Functional Assessment Standardized Items (FASI) tool containing standardized functional assessment items in the domains of *functional abilities and goals*, *assistive devices*, *support needs*, and *caregiver assistance*.[13] Another component of TEFT is the identification of an electronic long-term services and supports service plan standard (eLTSS) that can enable electronic exchange of information relevant to the care of persons receiving HCBS.[14] The eLTSS plan standard will assess various ways of sharing LTSS data including secure email messaging and the adoption of personal health records for beneficiaries.[15]

As Medicaid is the largest funder of HCBS in the United States, the recently issued Medicaid Managed Care final rule will have a substantial impact on the field of HCBS quality measurement. In 2016, CMS issued the final rule, which includes regulations requiring states to address the quality of care provided via managed care. Specifically, the rule expands quality assessment and performance improvement programs (QAPIs) to implement a strategy for ensuring the quality of services provided through Prepaid Ambulatory Health Plans (PAHPs), Primary Care Case Management (PCCMs), and MCOs. States will be required to identify and report on standard measures related to quality of life, rebalancing, and community integration activities.[16]

In addition to efforts at the federal level, there has been a growing use of surveys at the state level to assess HCBS quality. These surveys are used to collect information directly from the individuals, families, and caregivers who use HCBS and focus on key topics such as employment, privacy, service planning, community inclusion, and choice of services and providers. For example, the National Core Indicators™ (NCI) surveys are commonly used in states' HCBS programs and include items related to health, welfare, protection, respect for individual rights, system performance, staff stability, and family satisfaction and support.[17] These surveys allow states to track the quality of services for adults and children with developmental disabilities, their families, adults with physical disabilities, and older adults. Other examples of surveys include the Money Follows the Person Quality of Life Survey, used by Medicaid Money Follows the Person programs, and the Health Outcomes Survey, used in the Program of All-Inclusive Care for the Elderly (PACE).[18,19]

While these many efforts represent valuable contributions to HCBS quality measurement and quality improvement, the availability and uptake of quality measures remain limited. The current environment reflects the fragmented nature of the system as well as a lack of consensus about the highest impact areas for future quality measurement efforts. HCBS stakeholders have called for a more unified measurement approach that addresses the various funding streams, regulators, extensive and diverse networks, providers, and service delivery models (e.g., self-direction) within the HCBS system.

PROJECT OVERVIEW

Under a contract with HHS, NQF convened a multistakeholder Committee (**Appendix B**) to develop recommendations for the prioritization of measurement opportunities to address gaps in HCBS quality measurement. NQF is an independent, nonprofit, membership organization that brings together stakeholders working to improve health and healthcare through quality measurement. Through the NQF endorsement process, quality measures are evaluated against five criteria: that they be based on evidence, demonstrate an opportunity for improvement, be clearly specified and scientifically tested, show that it is feasible to readily collect data for the calculation of the measure, and establish that the performance results can be used for both accountability and performance improvement. In addition to its endorsement process, NQF partners with stakeholders to address measurement science issues, particularly with respect to how to advance and strengthen quality measurement in areas where quality measurement may be in an earlier stage of development, such as HCBS. The Committee's recommendations are meant to provide a framework for HCBS measure development and use.

The project involved:

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, measure concepts, and instruments;
3. the identification of gaps in quality measurement based on the framework and scan; and
4. the drafting of recommendations for prioritization in measurement.

Over the course of this two-year project, three interim reports were published. 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 quality 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. Work to identify measures, measure concepts, and instruments continued throughout this project due to the growing use of measures or measure concepts in managed Medicaid programs and the multiple surveys in use in HCBS. The **third interim report** highlighted the work of the Committee in revising the definition of HCBS, domain and subdomain descriptions, and developing an initial set of recommendations for how to advance HCBS quality measurement

A 30-day public comment period followed the publication of each interim report. Comments were taken into consideration when planning subsequent project activities and drafting each interim report and this final report. Across all three public commenting periods, comments emphasized the importance of this work and the need for all measurement efforts to focus on improved consumer outcomes. Comments also acknowledged the many challenges facing HCBS quality measurement including the difficulty in testing measures and measure concepts in the many populations that use HCBS and determining the appropriate level of analysis and accountability. The public and NQF member comments received on the **first**, **second**, and **third** interim reports are summarized in **Appendix C**. This final report represents a culmination of the Committee's work and contains the final operational definition and conceptual framework, measurement domains and subdomains, global and domain-specific recommendations, and examples of measure concepts relevant to each domain.

OPERATIONAL DEFINITION AND CONCEPTUAL FRAMEWORK

The purpose of developing an operational definition and conceptual framework was three-fold. First, each contributed to establishing a common understanding of the services, settings, providers, and consumers of HCBS, and how quality measurement operates within the HCBS system. Second, this understanding informed the Committee's deliberations on what constitutes high-quality HCBS and the role of quality 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 measurement and improvement efforts for HCBS.

Operational Definition

In developing the operational definition, the Committee acknowledged 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. With these issues in mind, the Committee established an operational definition that is concise, positive in tone, and devoid of value statements.

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

Characteristics of High-Quality 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 consumer outcomes

Conceptual Framework: Measurement Domains and Subdomains

The Committee developed high-level measurement domains and more detailed subdomains to highlight the most important areas for quality measurement in HCBS. These domains form the foundation of the conceptual framework. The goals of constructing the domains and subdomains are to stimulate evidence-based research in support of quality measure development, guide quality improvement efforts, and highlight the important areas for measure development. The Committee identified 11 domains and 40 subdomains of measurement (**Appendix D**) after considering the current state of measurement and future opportunities for measure development. These domains closely correspond to the Committee's 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 services and supports.

SYNTHESIS OF EVIDENCE AND ENVIRONMENTAL SCAN

Using the conceptual framework as a guide, NQF staff, in consultation with the Committee and HHS, conducted an environmental scan to assess the current state of HCBS quality measurement. NQF categorized the measures found in the scan as measures, measure concepts, and instruments. For the purposes of the environmental scan, NQF staff defined a measure as a metric that has a specific numerator and denominator and has undergone scientific testing, a measure concept as a metric that has a specific numerator and denominator, but has *not* undergone testing, and an instrument as a psychometrically tested and validated survey, scale, or other measurement tool.

The scan was an iterative process that took place over life of the project. During the initial search, NQF found a total of 261 measures, 394 measure concepts, and 75 instruments (see **Appendix A**). These were included in a compendium featured in the second interim report. NQF staff also reviewed example state-level (Minnesota, Oregon, and Washington) and international (England, Canada, and Australia) quality measurement initiatives. Many of the measures found were healthcare focused and did not adequately capture the most important aspects of quality identified by the Committee. However, several instruments were found to be promising sources for measure development. The Committee expanded the scan, beyond sources identified in the initial search, and reviewed additional measure concepts contained in Medicaid MLTSS contracts and various surveys. Moreover, the public and NQF members, and Federal Advisory Group suggested other measures and measure concepts that were also considered by the Committee.

GAPS, PRIORITIZATION, AND RECOMMENDATIONS

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 recommendations. 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 the Committee's characteristics of high-quality HCBS;
- likelihood that measurement in the 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. 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

The Committee acknowledged several challenges to measurement in HCBS. First, the HCBS system is decentralized. Programs are often state- and population-specific 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. Adding additional responsibilities to the HCBS system may hinder 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 unique measures that apply to a specific context. In addition, the HCBS system as a whole lacks a systematic approach to the collection and reporting of the data needed for quality measurement. Development of quality measures requires time, financial support, and expertise. Continued prioritization will remain an essential aim as evidence-based practices evolve and new policies emerge.

Committee Recommendations to Advance HCBS Quality Measurement

Considering these challenges, the Committee developed recommendations to better assess the quality of HCBS. The Committee acknowledged measurement activities happening within many of the domains identified in the conceptual framework, but such activities often happen in silos. The Committee asserted that measurement within each domain is equally important and did not rank the domains. The global recommendations address current quality measurement challenges faced by the HCBS system as a whole and across all domains of measurement. Each domain-specific recommendation reflects the domain's current state of measurement and addresses how measurement within that domain can be improved. These recommendations, both global 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 for HHS. Nevertheless, these recommendations have wider applicability across the range of HCBS stakeholders, including measure developers, researchers, payers, delivery systems, and other stakeholders who use measures.

Global 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 recommendations.

- *Support quality measurement across all domains and subdomains.* Measurement should not stop with a few items, but instead measure development and identification should continue until all domains and subdomains identified in this report are addressed.

HCBS quality is a multifaceted concept, and measurement of domains is important to gain a true picture of the extent to which the HCBS system delivers high-quality services. However, the work must start somewhere, and the efforts that are needed to address these recommendations may span years. Priority measures and measure concepts, especially those capturing the experience of the people who use HCBS, can serve as a starting point to measure aspects of HCBS quality. Also in the short-term, investments should be made in measure identification and development to assist CMS, as the largest payer for HCBS, in specifying performance measures to be used in state managed LTSS programs. In the longer term, resources should be allocated to address domains and subdomains lacking appropriate measures, and to further identify and validate promising measures and measure concepts already in use.

- *Build upon existing quality measurement efforts*. It is not necessary to reinvent the wheel, and for many of the domains, there is substantial prior work that can be used as a starting point. Many states and programs have data collection and reporting systems that, though disparate, often contain promising measures and measure concepts, and approaches to quality measurement and reporting that should be considered for adoption or improvement. HCBS survey instruments also contain many items that can be, or are in the process of being, turned into useful quality measures.

- *Develop and implement a standardized approach to data collection, storage, analysis, and reporting*. HCBS quality is currently assessed in a fragmented and piecemeal manner, preventing comparisons across states, programs, populations, providers, and managed care organizations. Insufficient attention is paid to solving critical methodological issues, such as under what circumstances to allow proxy response, how to best facilitate self-response, and what data collection approaches are best suited to collecting sensitive information from a vulnerable population. Public reporting of quality data, when it happens at all, is neither comprehensive nor uniform, and it is not often accessible to or usable by HCBS consumers, families, and caregivers. Throughout the process from collection to reporting, a standardized, consistent, comprehensive approach is badly needed, one that cuts across data sources (e.g., surveys versus administrative records) and levels of analysis (the individual, the provider, the program, the state, etc.) and offers timely access to aggregate program data and—when needed for research or quality improvement purposes—de-identified individual records. When feasible, this quality data system should be integrated with other data systems that capture assessment, service planning and authorization, encounter, and other administrative data. With such a system, quality improvement efforts would more readily arise out of real-time program and quality data, and their implementation and progress toward goals could be more readily monitored.

- *Ensure that emerging technology standards, development, and implementation are structured to facilitate quality measurement*. As in other parts of the healthcare system, emerging technologies can help solve some of the challenges to quality assessment, or they can act as a barrier to collecting needed information. One example of a technology that might foster HCBS quality measurement is found in the Testing Experience and Functional Tools (TEFT) demonstration, components of which pilot the use of personal health records and create an electronic LTSS service plan standard. Such standards allow information to be exchanged among various providers and care coordinators. Collecting and reporting quality information in such a system, for

example, facilitates a standardized assessment of the service plan and the planning process, whether services are delivered according to the plan, and whether the individual's goals and objectives are achieved. Another example is the universal online assessment systems that have been implemented in a few states, which sometimes incorporate person-centered planning tools. These offer opportunities for standard consumer-focused measures to analyze the quality of the assessment process and the relationship between the assessment and the service plan.

- *Triangulate assessment of HCBS quality using an appropriate balance of measure types and units of analysis*. While the Committee recognizes the critical importance of measuring outcomes at the level of the individual receiving HCBS, person-level outcome measures derived from surveys must be supplemented by other measures to fully assess HCBS quality. Data must be collected, analyzed, and reported at various levels, including the individual, provider, managed care organization, HCBS program, the state and national HCBS system, and other accountable entities. Measures must capture not only outcomes, but also structures and processes. Measures of structure pertain to characteristics or capabilities of the system, such as the availability or training of providers or the processes in place to monitor service provision. Process measures refer to the actions of the system in relation to the consumer, such as how services are planned or delivered or how need is assessed. Although different domains and subdomains may require a different balance of levels of analysis and of structure, process, and outcome measures, it is generally important to assess not only whether the services benefit the individual, but also whether the system design and implementation lead to the provision of high-quality services and whether system practices adhere to established or emerging standards.
- *Develop a core set of standard measures for use across the HCBS system, along with a menu of supplemental measures that are tailorable to the population, setting, and program*. A prioritized set of core measures would allow for comparisons across programs and for uniform public reporting. HCBS programs should also be allowed some leeway to focus additional measures on identified areas for program-specific quality assessment and improvement, according to program objectives, stakeholder concerns, and the specific needs of the populations served. Development of supplemental measures that can be tailored to the specific circumstances, or chosen from a list of approximately equivalent versions, would balance a need for comparability with program-specific requirements and priorities.
- *Convene a standing panel of HCBS experts to evaluate and approve candidate measures.* CMS should establish a process by which candidate measures can be officially adopted to be used as standardized HCBS quality measures. At present, widespread use of promising measures and measure concepts is hampered by the absence of an official stamp of approval, such as the endorsement process used for healthcare quality measures. Currently established committees typically lack the HCBS expertise necessary to make appropriate decisions as to which measures have been demonstrated to be both useful and valid in the HCBS context.

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 domain varies, the Committee defined the domain-specific recommendation categories as follows:

- 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.

- 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.
- 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

Each subsection contains the domain and subdomain descriptions, the domain-specific recommendations, and a list of example measure concepts that are promising for further development. The measure concepts illustrate what the Committee envisioned when defining the domains and subdomains and are potential starting points for quality measure development within a given domain or subdomain. The Committee identified these measure concepts by reviewing items from surveys frequently utilized within HCBS programs (e.g., National Core Indicators-Adult Consumer Survey, Community Integration Survey), measure concepts contained in Medicaid MLTSS contracts, and measure concepts submitted by the public and NQF members during the 30-day public comment period for the third interim report. The source for each measure concept can be found in Appendix E.

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. Two subdomains were prioritized within this domain:

- **Delivery**: The level to which the individuals who use HCBS receive person-centered services and supports. 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, adequacy of the provider network to deliver needed services, and the capacity of the system to meet existing and future demands.
- **Person's needs met and goals realized:** The level to which individuals who use HCBS receive services and supports sufficient to meet their needs and to support them in achieving their goals.

RECOMMENDATIONS

Short-Term

- Expand the implementation of process measure concepts related to the person's needs met and goals realized subdomain.

Intermediate

- Support the development of quality measures for the delivery subdomain, with a focus on identifying specific aspects of service delivery that are important to HCBS consumers.
- Invest in developing person-centered outcome measures for this domain.

EXAMPLES OF MEASURE CONCEPTS RELEVANT TO EACH SUBDOMAIN:

Subdomain: Delivery	Source
Services are delivered in accordance with the service plan (SP), including in the type, scope, amount, duration, and frequency specified in the SP.	MLTSS NY, HI, others
Percent of survey respondents who reported receiving all services as specified in their service plan.	MLTSS KS
The number of service hours delivered minus the number of service hours approved.	MLTSS DE

Subdomain: Person's needs met and goals realized	Source
Percent responding yes to: Do the services you receive meet your needs and goals?	NCI-AD
Percent strongly agreeing with: As a direct result of the services I received, I am better able to do the things I want to do.	MHSIP-ACS
Proportion of Individualized Care Plans with goals unmet.	MLTSS NY
Percent responding yes to: Are services and supports helping you to live a good life?	NCI-ACS

General measures related to the domain	Source
Of the total number of scheduled [HCBS] visits for each service type, by provider type; the percent that were: on time, late, missed.	MLTSS TN
Of the total number of late/missed visits for each service type, by provider type; the percent that were: member initiated; provider-initiated; due to weather/natural disaster.	MLTSS TN

Person-Centered Planning and Coordination

This measurement domain is defined as an approach to assessment, planning, and coordination of services and supports that is focused on the individual's goals, needs, preferences, and values. The person directs the development of the plan, which describes the life they want to live in the community. Services and supports are coordinated across providers and systems to carry out the plan and ensure fidelity with the person's expressed goals, needs, preferences, and values. Three subdomains were prioritized within this domain.

- **Assessment**: The level to which the HCBS system and providers support the person in identifying their goals, needs, preferences, and values. This process should gather all of the information needed to inform the person-centered planning process. 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 and meeting needs the person deems important. The plan includes the role of the paid and unpaid services or supports needed to reach those goals.
- **Coordination**: The level to which the services and supports an individual receives across the healthcare and social service system are complementary, integrated, and fully supportive of the HCBS consumer in meeting his or her needs and achieving his or her goals.

RECOMMENDATIONS

Short-term

- Review existing measure concepts in the assessment subdomain to evaluate whether changes can be made to make them more generalizable.
- Expand the implementation of process measure concepts related to person-centered planning and coordination subdomains.

Intermediate

- Develop structure, process, and outcome measures for the coordination subdomain that address coordination of services across all aspects of healthcare and social service delivery, including LTSS, physical and behavioral health, and social support needs. Structure measures should focus on system-level requirements and infrastructure to support effective coordination at the individual level.
- Promote a balanced approach to development and use of system and individual-level measures for each subdomain.

EXAMPLES OF MEASURE CONCEPTS RELEVANT TO EACH SUBDOMAIN:

Subdomain: Assessment	Source
Number and percent of waiver participants with reassessment performed and ISP/IPs updated when needs/condition changed.	MLTSS HI
Percent responding yes to: Do you believe that the result of your “level of care assessment” identifies your real needs?	NMPQR

Subdomain: Person-Centered Planning	Source
Percent of members reporting that their care plan includes all of the things that are important to them.	MLTSS WI
Percent of participants reporting they are the primary deciders of what is in their service plan.	MLTSS MN
Percent of waiver individuals who have service plans that are adequate and appropriate to their needs and personal goals, as indicated in the assessment.	MLTSS NJ
Percent responding yes to: Do the services and/or supports focus on the person’s goals?	POMs

Subdomain: Coordination	Source
Percent HCBS members who report: Their service coordinators help them get what they need.	MLTSS HI
Percent responding yes to: Has a case manager helped you solve a problem that you have told them about?	MNCES
Percent responding yes to: Does your case manager help coordinate all the services you receive?	POMP-CMS

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, and are supported in making that 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.

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.
- Assess the evidence for and scientific acceptability of measure concepts and instruments that are currently in use.

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.

EXAMPLES OF MEASURE CONCEPTS RELEVANT TO EACH SUBDOMAIN:

Subdomain: Personal choices and goals	Source
Percent responding yes to: Can you see your friends when you want to?	NCI-ACS
Percent responding yes to: Can you get to the places you need to go, like work, shopping, or the doctor's office?	MFPQOL
Percent of HCBS members who report: They make choices about their everyday lives, including: housing, roommates, daily routines, case manager, support staff or providers, and social activities.	MLTSS HI
Percent responding "true" to: I have choices about the activities I want to do.	PART-E
Percent responding yes to: Does the person have options about where and with whom to live?	POMs
Percent responding that the consumer chose or helped choose: Who chose (or picked) the place where you work?	NCI-AD
Percent responding that the consumer chose or helped choose: Who chose (or picked) where you go during the day?	NCI-AD

Subdomain: Choice of services and supports	Source
Percent responding yes to: Do the people who are paid to help you do things the way you want them done?	NCI-AD
Percent responding yes to: Does your attendant provider pay attention to your choices, such as what you like to eat, where you want to go or what you want to do?	EAZI
Percent responding yes to: Can you make changes to your budget/services if you need to?	NCI-ACS
Percent responding yes to: Can you choose or change what kind of services you get and determine how often and when you get them?	NCI-AD
Percent of waiver participants whose record contains documentation indicating a choice of either self-directed or agency-directed care.	MLTSS KS
Percent of HCBS consumers who are self-directing their HCBS.	GA 1915(c) waiver

Subdomain: Personal freedoms and dignity of risk	Source
Percent responding "true" to: I have control over what I do and how I spend my time.	PART-E
Percent responding "true" to: I have the freedom to make my own decisions.	PART-E
Percent responding yes to: Are you free to take risks when you want to?	TXPES
Percent responding yes to: Does your attendant provider allow you to make your own mistakes?	EAZI

Subdomain: Self-direction	Source
Percent of members reporting that, in the last 12 months, they were offered the option to self-direct some or part of their services.	MLTSS WI
Percent of MLTSS members opting to use self-direction.	MLTSS NJ, SC, others
Participants who self-direct their supports and services do so with employer authority and/or budget authority.	MLTSS NY
Participants are able to make an informed choice on whether to self-direct their supports and services.	MLTSS NY
Change in the percent of dollars paid for consumer-directed community supports over time.	MLTSS MN
Members using self-directed arrangements through a fiscal intermediary.	MLTSS MI
Rate of increase for enrollees using self-directed arrangements.	MLTSS MI, TX, others

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.

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.

EXAMPLES OF MEASURE CONCEPTS RELEVANT TO EACH SUBDOMAIN:

Subdomain: Social connectedness and relationships	Source
Percent responding "always" to: I have someone who will listen to me when I need to talk.	PROMIS-ES
Percent responding "always" to: How often do you get the social and emotional support you need?	NHIS-01
Percent responding yes to: Is there someone you can count on in an emergency?	MNCES
Percent responding yes to: Generally, are you satisfied with the amount of contact you have with friends?	MNCES
Percent responding yes to: Generally, are you satisfied with the amount of contact you have with your family?	MNCES
Percent responding "always" to: When you want to, how often can you get together with these friends who live nearby?	HCBSEOC

Subdomain: Meaningful activity	Source
Proportion of individuals who do not have an integrated job in the community but would like one.	MLTSS NY
Proportion of individuals in sheltered workshops who transition to integrated community-based employment.	MLTSS NY
Proportion of individuals who have an integrated job in the community.	MLTSS NY
Percent responding "always" to: When you want to, how often can you do things in the community that you like?	HCBSEOC
Percent responding yes to: Do you like how you usually spend your time during the day?	NCI-AD
Percent responding yes to: Are you doing volunteer work or working without getting paid?	MFPQOL

Subdomain: Resources and settings to facilitate inclusion	Source
Percent HCBS members who report: They have adequate transportation when they want to go somewhere.	MLTSS HI
Percent responding “always” to: I have regular opportunities to be part of the community.	ORIES
Percent responding “always” to: Where I live makes it easy for me to get around in the community as I desire.	ORIES
Percent of HCBS members living in [group quarters] who report: They are able to see their families and friends when they want.	MLTSS HI
Percent of HCBS members living in [group quarters] who report: They are satisfied with where they live.	MLTSS HI

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

RECOMMENDATIONS

Short-Term

- Ensure that medical records and care plans include identification of family caregivers/ natural supports, with consent of the consumer as appropriate.
- Identify or develop measures of family caregiver/natural support involvement in service planning, assessment of family caregiver/natural support needs, impact of caregiving including employment, and availability of resources and training for family caregivers/natural supports.

Intermediate

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

Long-Term

- Support the development of the infrastructure needed for the collection and management of data related to the well-being, training, and involvement of the family caregiver/natural support and the availability and utilization of resources to support them.

EXAMPLES OF MEASURE CONCEPTS RELEVANT TO EACH SUBDOMAIN:

Subdomain: Family caregiver/natural support well-being	Source
Percent responding no to: During the past 12 months, has your overall health suffered because of your caregiving responsibilities?	GSS-CRR
Percent responding “rarely” or “never” to: In your experience as a caregiver, how often do you feel that caregiving interferes with your work?	POMP-CSS
Percent responding “rarely” or “never” to: In your experience as a caregiver, how often do you feel that caregiving causes you stress?	POMP-CSS
Percent responding yes to: In your experience as a caregiver, have you ever had a doctor, nurse, or social worker ask you about what you needed to take care of yourself?	CGUS
Percent of caregivers responding 4 or 5 on a 5-point scale to: How much of a financial strain would you say that caring for [person] is for you?	CGUS
Percent of caregivers responding yes to: Do your caregiving responsibilities make it difficult to meet your essential household expenses?	CGUS

Subdomain: Training and skill-building	Source
Percent responding yes to: Before [person] left the hospital or was discharged, did you receive clear instructions about any medical/nursing tasks you would need to perform for [person]?	CGUS
Percent responding yes to: In the last year, have you received any training to help you take care of [person]?	NSOC
Percent responding yes to: Have you received caregiver training or education, including participation in support groups, to help you make decisions and solve problems in your role as a caregiver?	POMP-CSS

Subdomain: Family caregiver/natural support involvement	Source
Percent responding yes to: Do you get enough information to take part in planning services for your family member?	NCI-AFS, NCI-FGS
Percent responding yes to: In your experience as a caregiver, have you ever had a doctor, nurse, or social worker ask you about what you needed to help care for [person]?	CGUS
Percent of HCBS consumers whose care plan identifies family/unpaid caregivers.	1915(c)
Percent of unpaid caregivers who report that they have been included in discussions about the HCBS consumer (with HCBS consumer’s consent).	International Measure

Subdomain: Access to resources	Source
Percent responding yes to: In the last year, have you used any service that took care of [person] so that you could take some time away from helping?	NSOC
Percent responding “not at all difficult” to: How difficult is it to get affordable services in [person’s] local area or community that could help you care for [person], like delivered meals, transportation, or in-home health services?	CGUS
Percent of caregivers responding yes to: In the last year, have you used any service that took care of [person] so that you could take some time away from helping?	NSOC

Workforce

The Committee defined this domain as the adequacy, availability, and appropriateness of the paid 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, benefits, and opportunities for skill development 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 when desired by the consumer; program development and evaluation; and the design, implementation, and evaluation of the HCBS system and policies.

RECOMMENDATIONS

Short-term

- Identify or develop measures of worker retention and turnover, worker wages and benefits, worker satisfaction, worker training and skill competency.

Intermediate

- Improve collection and use of administrative data for structure and process measures related to the workforce.
- Support the development of worker-focused outcome measures, e.g., worker satisfaction, satisfaction with preparation, quality of relationships with consumers and supervisors, level of support and engagement, opportunities for skill development and career advancement.
- CMS should collaborate with HRSA and the Department of Labor to identify means of improving and expanding data collection on the HCBS workforce.

Long-Term

- Establish the processes and infrastructure needed for collecting the above data related to the workforce.

EXAMPLES OF MEASURE CONCEPTS RELEVANT TO EACH SUBDOMAIN:

Subdomain: Person-centered approach to services	Source
Percent of members reporting that the people who help with personal care always treat them with courtesy and respect.	MLTSS WI
Percent responding yes to: In the past year, did the people who are paid to help you respect your privacy?	MNCES
Percent responding yes to: Do your workers make sure you have enough personal privacy when you dress, take a shower, or bathe?	HCBSEOC
Percent responding yes to: Do the people who are paid to help you do things for you the way you want them done?	NCI-AD
Percent responding yes to: Does your attendant provider listen to what you have to say?	EAZI

Subdomain: Demonstrated competencies, when appropriate	Source
Percent responding yes to: Do you feel your staff have the right training to meet your needs?	NCI-ACS
Percent of members reporting that the people who help them with personal care know what kind of help member needs.	MLTSS WI
Percent responding yes to: Do you feel your workers know what kind of help you need with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?	HCBSEOC
Proportion of direct support professionals that meet competencies.	MLTSS NY

Subdomain: Safety of and respect for the worker	Source
No measure concepts	

Subdomain: Sufficient workforce numbers, dispersion, and availability	Source
Percent responding no to: Is it difficult for you to find attendant providers for your care?	EAZI
Percent responding "not very hard" to: How hard was it, overall, for you to find someone to help that you were satisfied with?	C&C9MO
Number of home health and personal care aides per 1000 people with self-care and independent living disabilities.	LTSS Scorecard

Subdomain: Adequately compensated, with benefits	Source
No measure concepts	

Subdomain: Culturally competent	Source
Percent responding yes to: My worker is sensitive and responsive to customs and traditions of my culture or background.	MAHCSS
Percent responding yes to: Are services delivered in a way that is respectful of your family's culture?	NCI-AFS, NCI-FGS
Percent responding yes to: Do you communicate with your attendant provider in the language that you prefer?	EAZI

Subdomain: Workforce engagement and participation	Source
No measure concepts	

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.

RECOMMENDATIONS

Short-term

- Identify measures of human and legal rights currently in use in HCBS programs, assess their validity and reliability, and expand their use.

Intermediate

- Identify, validate, and expand the use of the most promising measures from among the process measure concepts currently in use to assess critical incident reporting and management.
- 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.

EXAMPLES OF MEASURE CONCEPTS RELEVANT TO EACH SUBDOMAIN:

Subdomain: Freedom from abuse and neglect	Source
Percent responding no to: Have you ever been physically hurt by any of the people who help you now?	MFPQOL
Percent responding no to: In the last year, has anyone taken (or stolen) money from you or put pressure on you to give them money?	MNCES
Percent responding no to: Are any of the people paid to help you now mean to you, or do they yell at you?	PES-E/D, MFPQOL
Member and/or caregivers receive education and information, annually at a minimum, about how to identify and report instances of abuse and neglect.	MLTSS RI
Percent of adverse event reports for abuse/ neglect/exploitation, deaths, falls, medication errors, pressure ulcers: by type; reported w/in required timeframe; reported to appropriate authorities if applicable; substantiated by type; investigated within the required timeframe; corrective action reviewed and verified within the required timeframe.	MLTSS HI
For members that report a critical incident, the Care Plan must demonstrate the completion of an updated risk assessment and mitigation plan.	MLTSS RI
Percent of critical incidents reported to the state within 30 days, including corrective actions taken.	MLTSS synthesis
Number of HCBS and other critical incidents, including unexpected death; physical, mental, sexual abuse or neglect; theft or exploitation; severe injury; medication error; unprofessional provider.	MLTSS DE
Percent of waiver individual's records with indications of abuse, neglect or exploitation documenting appropriate actions taken.	MLTSS VA
Percent responding no to: In the past 12 months, have you suspected that you've been abused, neglected, or exploited?	NMPQR
Percent of restraint applications, seclusion or other restrictive interventions that followed procedures as specified in the approved waiver.	MLTSS KS
Critical Incident reporting: per 1000 enrollees total and by population (HCBS and Institutional).	MLTSS DE

Subdomain: Optimizing the preservation of legal and human rights	Source
Percent of member records reviewed in which HCBS were denied, reduced, suspended, or terminated as evidenced in the Plan of Care and consequently, the member was informed of and afforded the right to request a Fair Hearing.	MLTSS TN
Percent responding "always" to: To what extent do you believe your rights are respected here?	PLQ
Percent of HCBS members who report: Their basic rights are respected by others.	MLTSS HI

Subdomain: Informed decisionmaking	Source
Percent strongly agreeing with: I felt comfortable asking questions about my treatment and medication.	MHSIP-ACS, CLMDP
Percent responding yes to: At the service planning meeting, did you know what was being talked about?	NCI-ACS
Percent strongly agreeing with: Staff helped me obtain the information I needed so that I could take charge of managing my illness.	MHSIP-ACS, CLMDP
Percent of managed LTSS members who received options counseling.	MLTSS NJ
Members receive options counseling as part of the comprehensive needs assessment.	MLTSS RI

Subdomain: Privacy	Source
Percent responding yes to: Do you have enough privacy at home?	NCI-ACS
Percent responding yes to: Are you able to be alone at home with visitors if you want to?	NCI-AD
Percent responding yes to: Staff respected my wishes about who is and who is not to be given information about my treatment.	MHSIP-ACS, CLMDP
Percent of HCBS members living in [group quarters] who report: Satisfaction with the amount of privacy they have.	MLTSS HI
Percent responding no to: Is personal information shared with others only at the request of, or with the consent of, the person or his/her legally authorized representative?	POMs

Subdomain: Supporting individuals in exercising their human and legal rights	Source
Scale based on whether the person exercises their rights as follows: (1) Right to voice their opinion, (2) right to vote, (3) right to move about the community, (4) right to associate with others, (5) right to practice their religion, (6) right to privacy, (7) right to access their possessions, (8) right to access food/refrigerator, (9) right to have visitors at any time, (10) right to access their money, (11) right for personal decision making, (12) right to fair wages, (13) right to non-discrimination at work, (14) right to dignity and respect, (15) right to freedom from coercion and restraint, (16) right to file complaints about services, (17) other rights that are important to the person.	POMs
Percent of enrollees with documented discussion of their rights and choices for providers.	MLTSS MI
Proportion of individuals who received information about their rights and the process to express concerns/objections in accordance with requirements.	MLTSS NY
Percent responding yes to: Is the person provided with the support needed to exercise his or her rights?	POMs

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. 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 polices 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.

RECOMMENDATIONS

Short-Term

- Identify equity measures currently in use in HCBS programs that examine differences in service delivery, utilization, and outcomes across age, gender, race/ethnicity, disability type, and other sociodemographic characteristics.
- Identify existing measures of housing, homelessness, and transportation and assess their validity and reliability and expand their use.

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.
- 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.

EXAMPLES OF MEASURE CONCEPTS RELEVANT TO EACH SUBDOMAIN:

Subdomain: Equitable access and resource allocation	Source
Percent of recipients using each service, compared by eligibility group.	MLTSS MN
Community health service utilization data for Enrollees, including number of units and units per 1,000 Enrollees by age group and gender categories, in the following summary categories: adult day health; home health; group adult foster care; hospice; homemaker, chore, respite and other non-medical residential support services; personal care attendant.	MLTSS MA
Percent of authorized units paid over time by eligibility group.	MLTSS MN
Percent responding "true" to: I am treated equally.	PART-E

Subdomain: Transparency and consistency	Source
No measure concepts	

Subdomain: Availability	Source
No measure concepts	

Subdomain: Reduction in health disparities and service disparities	Source
No measure concepts	

General measures related to the domain	Source
Centralized Enrollee Record contains data on race, ethnicity, preferred language, homelessness, and disability status and type.	MLTSS MA, MI, others

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.
- **Health promotion and prevention**: The level to which the HCBS system focuses on the prevention of adverse health and functional outcomes and promotes the highest levels of health and functioning, across all dimensions of holistic health.

RECOMMENDATIONS

Short-Term

- Identify reliable and valid health and functional assessment tools commonly used in community settings from which standardized quality measures could be developed.
- Identify existing outcome measures across all dimensions of holistic health, with particular focus on the dimensions of behavioral and social health and functioning.
- Expand the use of validated quality measures related to falls, medications, immunizations, and other quality measures focused on health promotion and prevention.

Intermediate

- Identify and develop standardized quality measures derived from health and functional assessment tools routinely used in community settings.
- 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 universal assessment tool for assessing and monitoring all dimensions of holistic health and functioning and generating a global health and functioning profile.

EXAMPLES OF MEASURE CONCEPTS RELEVANT TO EACH SUBDOMAIN:

Subdomain: Individual health & functioning	Source
Percent reporting that they feel lonely, sad, or depressed "not often," "almost never," or "never."	NCI-AD
Percent rating overall mental or emotional health as good or better.	HCBSEOC
Percent rating overall health as good or better.	HCBSEOC
Percentage of members who remained stable or improved in frequency of pain.	MLTSS NY
Percentage of members who remained stable or improved in experiencing depressive feelings over the follow-up period.	MLTSS NY
Percent responding "not at all" or "a little" to: To what extent do you feel that physical pain prevents you from doing what you need to do?	WHOQOL-BREF
Participants in the Demonstration who remained stable or improved in ADL functioning between previous assessment and most recent assessment.	MLTSS NY, AZ, others
Percent disagreeing with: Pain affects my well-being.	OPQOL
Percent of MLTSS members in HCBS/NF setting with selected mental health and substance abuse disorder diagnoses.	MLTSS NJ

Subdomain: Health promotion & prevention	Source
Percent of HCBS members who were re-admitted to the hospital within 30 days of last hospitalization	MLTSS NJ, NY
Percentage of members 18-85 years of age who had a diagnosis of hypertension and whose blood pressure was adequately controlled during the measurement year.	MLTSS CA
Percent of HCBS members who had ER utilization.	MLTSS NJ
Percentage of patients ages 18 years and older screened for clinical depression using a standardized tool and follow-up plan documented.	MLTSS CA
Percentage of members who had one or more falls in the last six months.	MLTSS NY
Percent of HCBS members who were admitted to the hospital.	MLTSS NJ
Moderate and high-risk members with a health risk assessment completed within 90 days of enrollment.	MLTSS IL
Percent of Enrollees with a problem falling, walking or balancing who discussed it with their practitioner and got treatment for it during the year.	MLTSS MI, IL, others
Percentage of members in long-term care who are at risk for falling who are seen by a practitioner and receive fall risk intervention.	MLTSS IA
Percent of plan members who discussed exercise with their doctor and were advised to start, increase or maintain their physical activity during the year.	MLTSS OH

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 infrastructure in place to increase the proportion of people served in home and community settings and 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.

RECOMMENDATIONS

Short-Term

- Expand the use of measures and measure concepts related to rebalancing, waiting lists, and unmet need.
- Conduct research on, validate, and standardize available structure and process measure concepts related to: (1) financing and service delivery, and (2) data management and use.

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.
- Develop a uniform measure of HCBS waiting lists.

Long-Term

- Evaluate promising practices in HCBS delivery through the lens of the Committee's HCBS quality framework.
- Require timely, periodic, standardized public reporting of HCBS participation, consumer outcomes, waiting lists, unmet needs, costs, and other elements related to system performance.
- Support the continued development and dissemination of evidence-based/research-validated practices and policies throughout HCBS and quality measures that assess the extent to which these practices are used across HCBS.

EXAMPLES OF MEASURE CONCEPTS RELEVANT TO EACH SUBDOMAIN:

Subdomain: Financing and service delivery structures	Source
Percent of individuals who are receiving HCBS versus institutional services.	MLTSS DE, others
Percent of MLTSS members who transitioned from nursing facility to the community.	MLTSS NJ, NM, others
Percent of HCBS members transitioning from the community to the NF for a stay of greater than 180 days.	MLTSS NJ
Percent of new members meeting Nursing Facility Level of Care criteria who opt for HCBS over Institutional placement.	MLTSS DE
Long-stay nursing home residents who returned to the community and were not reinstitutionalized for a long stay.	MLTSS NY
Of members who transitioned from a nursing facility, the percent who: are still in the community; returned to a nursing facility within 90 days after transition; returned to a nursing facility more than 90 days after transition.	MLTSS TN
Percent of new MLTSS members admitted to NFs during 12 month period.	MLTSS NJ
Members transitioned into the community are transitioned into a home and setting of their choice that is fully accessible on the day of transition.	MLTSS RI
Overall average cost per recipient of long-term care services by eligibility group, lead agency, and demographic group.	MLTSS MN

Subdomain: Evidence-based practice	Source
No measure concepts	

Subdomain: Data management and use	Source
NCQA/SNP Structure & Process Measures—Complex Case Management: Analyzing Effectiveness/Identifying Opportunities: Annual data collection using valid, clearly specified measures to assess goal achievement for an identified process or outcome, leading to identified opportunities for improvement.	MLTSS CA, MI, others

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.

RECOMMENDATIONS

Short-term

- Allocate resources necessary for developing consumer leadership reporting.
- Evaluate existing quality review teams with substantial participation of HCBS consumers who are effectively engaged in reviewing and making recommendations to improve HCBS programs.

Intermediate

- Develop structure, process, and outcome 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.

EXAMPLES OF MEASURE CONCEPTS RELEVANT TO EACH SUBDOMAIN:

Subdomain: System supports meaningful consumer involvement	Source
No measure concepts	

Subdomain: Evidence of meaningful consumer involvement	Source
Documentation in the form of stakeholder meeting agendas and meeting minutes that demonstrate the MCO response to significant concerns raised by stakeholder group participants.	MLTSS MN

Subdomain: Evidence of meaningful caregiver involvement	Source
No measure concepts	

CONCLUSION

Over the last two years, the HCBS Committee has developed the components of a strong foundation for HCBS quality measurement. These components include an operational definition, a list of characteristics of high-quality HCBS, and a conceptual framework for HCBS quality measurement. The accomplishments of this Committee mark an important milestone in the evolution of HCBS quality measurement. Nevertheless, much work lies ahead. Measures that capture the many facets of HCBS quality will need to be developed and tested. HCBS quality measures that are recommended for endorsement through NQF Consensus Development Process will need to be implemented by all payers and the infrastructure supporting HCBS quality measurement will need to be established or strengthened. Such endeavors are time and resource intensive.

Efforts currently taking place include the University of Minnesota's Rehabilitation Research and Training Center on Home and Community Based Services Outcome Measurement, which is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research to develop and refine measures related to HCBS, and other federally-funded activities (e.g., TEFT) continue their measure development and implementation work. The work and recommendations of the HCBS Committee offer guidance to these and other activities that are essential to assuring those who use HCBS that these services are of the highest quality and effective in helping them achieve their goals of living healthy, meaningful lives in their own communities.

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APPENDIX A:
Project Approach and Methods

General Approach and Timeline

NQF and the Committee used the approach and processes shown in Figure 1 and described below to complete this two-year project.

FIGURE 1. FIVE STEP PROCESS FOR HCBS QUALITY PROJECT

Step 1 Convene Multistakeholder Committee

Step 2 Identify a Conceptual Measurement Framework

Step 3 Conduct an Environmental Scan of Measures and Measure Concepts and Analysis of Gaps

Step 4 Develop Committee Recommendations and Priorities for Measure Development

Step 5 Obtain Public Comment and Finalize Recommendations

Convene Multistakeholder Committee

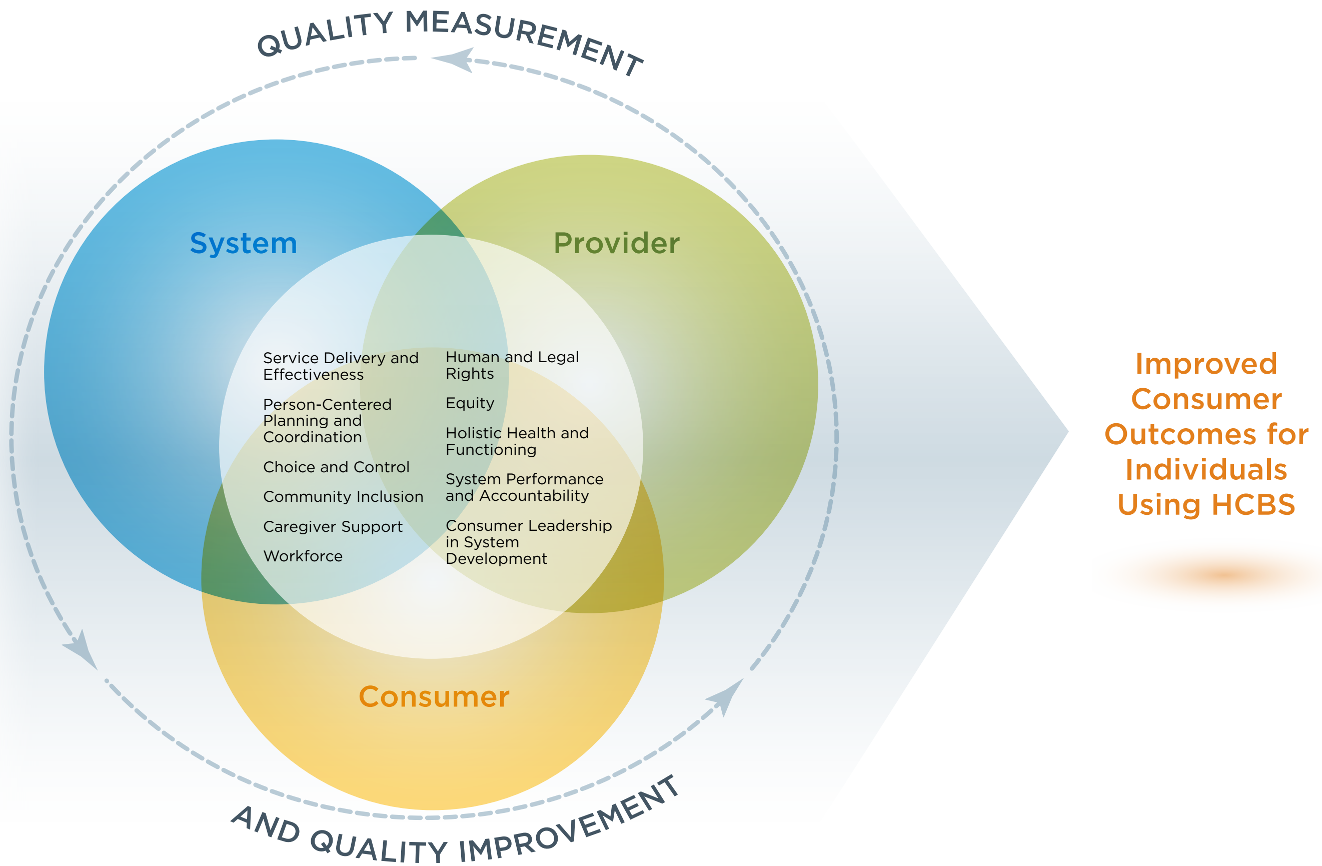
NQF convened a 22-member Committee with diverse representation and knowledge of the range of populations, services, settings, and payers of HCBS, including consumers and caregivers. A small multiagency Federal Advisory Group was formed upon contract award to provide guidance to NQF throughout the project. NQF met with the Federal Advisory Group and convened the multistakeholder Committee via a series of web meetings, in-person meetings, and conference calls throughout the project. Please see **Appendix B** for the full Committee roster and Federal Advisory Group members.

Identify a Conceptual Measurement Framework

The Committee drafted a conceptual framework for measurement comprised of an operational definition of HCBS, characteristics of high-quality HCBS, and measurement domains and subdomains that align with the characteristics of high-quality HCBS. The draft framework was informed by measurement domains described in the literature and Committee members' expert opinions. The Committee refined the operational definition and measurement domains and subdomains within the framework over the course of the project, informed by public and NQF member comment on the interim reports and during the web and in-person meetings.

The conceptual framework (Figure 2) shows how measurement and quality improvement in the domains at different levels of analysis leads to improved outcomes for HCBS consumers. The Committee's domains are shown in the center of a series of overlapping circles, which represent the levels at which measurement should 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 at the center where the levels overlap because measurement can be applied at multiple levels within the 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 2. HCBS QUALITY MEASUREMENT FRAMEWORK



Conduct an Environmental Scan and Analysis of Gaps

NQF staff completed an environmental scan of measures, measure concepts, and instruments that map to the domains and subdomains of the draft conceptual framework. For the purposes of the environmental scan, NQF staff defined a measure as a metric that has a specific numerator and denominator and has undergone scientific testing, a measure concept as a metric that has a specific numerator and denominator, but has *not* undergone testing, and an instrument as a psychometrically tested and validated survey, scale, or other measurement tool. The environmental scan aimed to identify measures, measure concepts, and instruments used across the range of populations that use or need HCBS, varied community settings, payers, delivery systems, and accountable entities.

With input from the Committee, the Federal Advisory Group, and the public and NQF members, NQF reviewed over 270 information sources (research publications, grey literature, measure repositories, and previous environmental scans). These sources are contained in an **annotated bibliography**. From these sources, NQF staff identified 261 measures, 394 measure concepts, and 75 instruments (see **Compendium of Measures).** Committee members reviewed the environmental scan findings to identify relevant performance measures, measure concepts, and instruments, and inform their deliberations on gaps in measurement and recommendations for quality measure development.

Many of the measures found were healthcare-focused and, from the Committee's perspective, did not adequately capture the most important aspects of HCBS quality. Many were process-focused and not meaningful to HCBS consumers and stakeholders. However, several instruments were found to be promising sources for quality measure development. The Committee expanded the scan, beyond sources identified in the initial search, and reviewed additional quality measures contained in Medicaid MLTSS contracts. Moreover, the public and NQF members suggested other measures that were also considered. Through these channels, the Committee selected examples of the types of measures and measure concepts that fall within the domains and subdomains of measurement.

Develop Committee Recommendations and Priorities for Measure Development

Following the second interim report in December 2015, the Committee began to identify gaps in measurement, prioritize areas for measurement development, and draft recommendations to advance measurement within each domain. At the Committee's January 2016 web 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 (for the early draft of the domains and subdomains, see the **first interim report**). The Committee divided into five workgroups based on Committee members' areas of expertise to identify the five most important subdomains within each domain, refine the domain definitions, and craft definitions for the prioritized subdomains. At the in-person meeting in March 2016, the full Committee discussed, refined, and came to consensus on the final list of domains and subdomains of HCBS quality measurement.

At this meeting, the Committee discussed critical challenges to measurement and barriers to implementation. They drafted general and domain-specific short-term, intermediate, and long-term recommendations to advance quality measurement in HCBS. The challenges and draft recommendations were identified in the third interim report.

Obtain Public Comment and Finalize Recommendations

Throughout the project, the public, NQF members, and the Federal Advisory Group submitted comments on the interim reports and Committee discussion during web and in-person meetings. The Committee members considered these comments in refining the operational definition, domains and subdomains, priorities for measure development, and recommendations to advance HCBS quality measurement. They engaged in Committee surveys and workgroup calls to discuss the public comments received on the third interim report, and to further refine and specify the operational definition, conceptual framework, and recommendations, including examples of measure concepts that align to the domains and subdomains of HCBS quality measurement.

APPENDIX B:
Committee Roster, Federal Advisory Group, and NQF Staff

Committee Members

Joe Caldwell, PhD (Co-chair)
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Andrew Anderson, MHSA
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Kim Ibarra, MS
Project Manager

Desmirra Quinnonez
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APPENDIX C: Summary of Public Comments Received on the Interim Reports

Overview of Comments Received on the First Interim Report

The National Quality Forum (NQF) received over 100 comments from federal and state agencies, associations, special interest groups, and individuals during the public comment period. Responses supported the Committee's work, approach, and consumer focus, and emphasized the urgency and importance of this work. Many individuals shared personal experiences highlighting critical HCBS concepts. The Committee discussed public comments at the August 28, 2015, web meeting, and worked to address these comments and questions in initial components of the conceptual framework.

Operational Definition of HCBS

Overall, there was support for a broad and inclusive definition of HCBS. Comments suggested revising, removing, or adding terms to the operational definition. The Committee discussed comments that the terms *independence* and *integrated* may not apply to all HCBS users and that *needs* may be too broad. The Committee was hesitant to remove *independence* and *integrated*, but agreed that *needs* was too broad. In general, the Committee supported suggestions to add *self-determination* and *community inclusion* to the definition, and refined the operational definition based on public feedback.

Characteristics of High-Quality HCBS

Comments received on the characteristics were positive overall. Many suggested modifying the language and terminology used, and adding terms that address the social determinants of health, meeting consumer needs, outcome-oriented data, and funding. In light of these comments, the Committee revised the *person-driven* characteristic to include life preferences and remove examples of goals. The Committee included *in accordance with individual preferences* to the social connectedness characteristic to reflect individual choices. Comments also highlighted the importance of the HCBS workforce. The Committee agreed that this characteristic should address skills and competencies, and acknowledged that the description of this characteristic needs more work in order to get to consensus. The Committee agreed with comments calling for engaging designated representatives and consumer advocates in HCBS design, implementation, and evaluation, but stressed that consumer voices should be most prominent.

Measurement Domains and Subdomains

Many comments supported the emphasis on consumer goals and the importance of caregivers. There were numerous suggested additions, and little to no comments that a concept was not important to measure. Based on public comments, the Committee agreed to add *supports for consumers in directing services*, *needs assessment*, and *transportation* as subdomains. The Committee also supported suggestions to remove *Providers* from the title of the Workforce/Providers domain and to remove *full* from the Full Community Inclusion domain. Given the breadth of comments on housing, the Committee considered a separate housing domain and decided that this issue needed further Committee discussion.

Conceptual Framework Illustration

There were a few comments on the illustration that suggested offering more detail on how quality measurement leads to improved consumer outcomes. Comments also related to the placement of specific domains in

the areas of measurement. The Committee discussed illustrating the intermediate step of quality improvement activities between quality measurement and improved consumer outcomes, and emphasized placing *Choice and Control* in the center of the Venn diagram given the Committee's long discussions about choice and control for persons receiving HCBS.

Overview of Comments Received on the Second Interim Report

The National Quality Forum (NQF) received over 50 comment submissions from advocacy and trade organizations, state agencies, special interest groups, researchers, and home and community-based services (HCBS) consumers and their family members or caregivers. NQF received general comments on the second interim report, and specific comments on the compendium of measures, review of selected quality measurement initiatives, and the annotated bibliography. Comments across these topics fell into three broad themes:

1. measurement domains and subdomains;
2. importance of and challenges facing HCBS quality measurement; and
3. balancing the breadth and depth of HCBS measures.

Comments generally supported the report and provided several suggestions for next steps. The Committee discussed these public comments at the January 29, 2016, web meeting. During this discussion, one major point of clarification was raised—the purpose of the compendium. Some comments appeared to interpret the compendium as a set of measures recommended for immediate implementation or representative of the "best" HCBS quality measures. Others suggested that the compendium is a representative sample of the current HCBS measurement landscape and its primary purpose is to be a tool for the Committee to use in identifying and prioritizing measurement gaps. The Committee used the compendium and incorporated the issues highlighted in the comments in the prioritization work that followed.

Measurement Domains and Subdomains

Comments pertaining to the measurement domains and subdomains focused on the distribution of measures across domains and the need for additional domain and subdomain refinement. Comments noted the lack of or very small number of measures in the Consumer Voice, Equity, Community Inclusion, Caregiver Support, and Human and Legal Rights domains. Some comments suggested that these domains should be prioritized for further measure development. Comments noted a need to delineate differences among domains and subdomains. The Committee discussed comments pertaining to the place of medically focused measures within the current set of domains and whether such measures were within the scope of HCBS. The Committee did not reach a final decision on this issue but did acknowledge that the issue should be discussed further and supported the need for greater domain and subdomain refinement.

Importance of and Challenges Facing HCBS Quality Measurement

Comments from HCBS consumers or their family members/caregivers strongly supported the importance of and need for assessing and monitoring HCBS quality, but emphasized that quality initiatives and measurements must be person-centered and warned against a one-size-fits-all approach. Other comments highlighted the complexities of capturing many of the concepts encompassed by the measurement domains and noted the dearth of valid and reliable measures for many of these complex concepts. The Committee acknowledged that there are many challenges to HCBS quality measurement, particularly the difficulty of determining what level of analysis is necessary and appropriate for a given measurement domain or subdomain. The Committee agreed that any approach to measurement must, at its core, be person-centered.

Balancing the Breadth and Depth of HCBS Measures

Given the large number of measures within the compendium, some comments called for the development of a smaller, harmonized set of measures, while others warned against taking a one-size-fits-all approach to quality measurement. The Committee discussed prioritization of cross-cutting or population/setting specific measures at the March 2016 in-person meeting.

Overview of Comments Received on the Third Interim Report

The National Quality Forum (NQF) received over 192 comments from advocacy groups, trade organizations, healthcare providers, insurers, state agencies, special interest groups, researchers, and home and community-based services (HCBS) consumers and their family members or caregivers. NQF received comments on the operational definition, the global recommendations, the domain-specific recommendations, and examples of measures/measure concepts relevant to each domain and subdomain of measurement identified by the NQF HCBS Committee. Comments were generally supportive. Many comments requested more specific recommendations and addressed some of most recent efforts to advance quality measurement in HCBS that the Committee should consider before finalizing its recommendations. The Committee discussed these comments at the August 4, 2016, web meeting. During the meeting, NQF requested the Committee's input on potential modifications and additions to various components of the third interim report. The Committee members did not discuss all of the comments received on the call, but they submitted additional feedback based on the public comments to NQF staff following the web meeting. The Committee continued to review and discuss the comments as they developed the final report.

Comments on the Operational Definition

Comments on the operational definition suggested rearranging the language, adding words that make the definition more precise, and removing words that may exclude certain populations that use HCBS or services that may be considered HCBS. Based on these comments, the Committee considered moving the portion of the definition that describes where HCBS is delivered closer the beginning. They also considered adding the term "health" to accompany "well-being" and changing the word "individual" to "person." The Committee discussed narrowing the definition to only people who have "limitations in function." However, to avoid a deficit-based definition, the Committee kept the language broad to encompass anyone with a long-term physical, cognitive, and/or behavioral health "need."

Global Recommendations

Comments on the global recommendations focused on increasing their specificity to ensure that there is enough information for stakeholders to take action. Several comments were related to prioritizing certain domains and subdomains. Many commenters expressed that the limited availability of resources increases the need for prioritization. There is a need to clarify the meaning of "consistent approach to quality measurement" in one of the seven global recommendations. A number of comments reiterated the importance of outcomes measures. Many comments called for more clarity on purpose, use, and importance of a menu of HCBS quality measures. The Committee refined and made these recommendations more specific in the final report.

Domain-Specific Recommendations and Example Measures/Measure Concepts

Comments on the domain-specific recommendations called for modifications to the domain and subdomain descriptions.

Many commenters suggested actionable short-term steps that can be taken in the domains where there were fewer or no short-term recommendations. There were also many suggested example measures/measure concepts that further illustrate the types of measures that could be found in the domains and subdomains. The Committee ultimately included example measure concepts in the final report. These comments informed the Committee's work as they finalized the domain and subdomain descriptions and recommendations during subsequent workgroup calls.

General Comments

Comments focused on reorganizing and consolidating domains that may have significant overlap. There were also suggestions to clarify important terms like "dignity of risk" and "community" and a call to not lose sight of individuals and families who use HCBS. Many comments requested that the Committee better align its recommendations to important ongoing related work that will affect quality measurement in HCBS in the future. Some comments suggested referencing populations that use HCBS that the third interim report may not have explicitly discussed.

APPENDIX D:
Final Domain Names, Definitions, and Prioritized Subdomains with Definitions

Domain Name and Definition	Prioritized Subdomains and Definitions
Service Delivery and Effectiveness: The level to which services and supports are provided in a manner consistent with a person's needs, goals, preferences, and values that help the person to achieve desired outcomes.	• **Delivery**: The level to which the individuals who use HCBS receive person-centered services and supports. 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, adequacy of the provider network to deliver needed services, and the capacity of the system to meet existing and future demands. • **Person's needs met and goals realized:** The level to which individuals who use HCBS receive services and supports sufficient to meet their needs and to support them in achieving their goals.
Person-Centered Planning and Coordination: An approach to assessment, planning, and coordination of services and supports that is focused on the individual's goals, needs, preferences, and values. The person directs the development of the plan, which describes the life they want to live in the community. Services and supports are coordinated across providers and systems to carry out the plan and ensure fidelity with the person's expressed goals, needs, preferences, and values.	• **Assessment**: The level to which the HCBS system and providers support persons in identifying their goals, needs, preferences, and values. This process should gather all of the information needed to inform the person-centered planning process. 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 and meeting needs that the person deems important. The plan includes the role of the paid and unpaid services or supports needed to reach those goals. • **Coordination**: The level to which the services and supports an individual receives across the healthcare and social service system are complementary, integrated, and fully support the HCBS consumer in meeting his or her needs and achieving his or her goals.
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.	• **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, and are supported in making that 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.
Community Inclusion: The level to which people who use HCBS are integrated into their communities and are socially connected, in accordance with personal preferences.	• **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.

Domain Name and Definition	Prioritized Subdomains and Definitions
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.	• **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.
Workforce: The adequacy, availability, and appropriateness of the paid HCBS workforce.	• **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, benefits, and opportunities for skill development 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 when desired by the consumer; program development and evaluation; and the design, implementation, and evaluation of the HCBS system and policies.

Domain Name and Definition	Prioritized Subdomains and Definitions
Human and Legal Rights: The level to which the human and legal rights of individuals who use HCBS are promoted and protected.	• **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.
Equity: The level to which HCBS are equitably available to all individuals who need long-term services and supports.	• **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.
Holistic Health and Functioning: The extent to which all dimensions of holistic health are assessed and supported.	• **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. • **Health promotion and prevention**: The level to which the HCBS system focuses on the prevention of adverse health and functional outcomes and promotes the highest levels of health and functioning, across all dimensions of holistic health.

Domain Name and Definition	Prioritized Subdomains and Definitions
System Performance and Accountability: The extent to which the system operates efficiently, ethically, transparently, and effectively in achieving desired outcomes.	• **Financing and service delivery structures**: The level to which the system is appropriately financed and has the infrastructure in place to increase the proportion of people served in home and community settings and 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.
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.	• **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:
Measure Concept Sources

From Survey Items

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- BSFC: Burden Scale for Family Caregivers, Short Version. http://www.psychiatrie.uk-erlangen.de/index.php?id=11049/
- CAHPS-HP: CAHPS Health Plan Survey 4.0, Supplemental items for the Adult Questionnaire. http://cahps.ahrq.gov/surveys-guidance/hp/instructions/medicaidsurveylist.html
- CCCQ: Client-Centered Care Questionnaire, English translation. http://link.springer.com/article/10.1007%2Fs11136-014-0650-7
- Channeling: National Long Term Care Channeling Evaluation, 1982-1984. Sample Member Follow-up Questionnaire. http://www.icpsr.umich.edu/cgi-bin/file?comp=none&study=8683&ds=5&file_id=142725
- CGUS: Caregiving in the U.S. 2015. http://www.caregiving.org/caregiving2015/
- CIQ: Community Integration Questionnaire. http://tbims.org/combi/ciq/ciqsyl.html
- CLMDP: SAMHSA's NOMs Client-Level Measures for Discretionary Programs Providing Direct Services, Adult Programs, Version 13 dated Oct. 2015. http://cmhs-gpra.samhsa.gov/TracPRD/View/docs/SVCS_AdultTool_v13_10_2015.pdf
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- MAHCSS: Massachusetts Home Care Satisfaction Survey 2008. http://www.nasuad.org/hcbs/article/participant-experience-survey
- MFPQOL: Money Follows the Person Quality of Life Survey. http://www.mathematica-mpr.com/~/media/publications/PDFs/health/MFP_QoL_Survey.pdf

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- MNCES: 2009 Elderly Waiver Consumer Experience Survey, Minnesota Department of Human Services. http://www.nasuad.org/hcbs/article/participant-experience-survey
- NCI-ACS: National Core Indicators Adult Consumer Survey, 2015-16.
- NCI-AD: National Core Indictors - Aging and Disabilities, 2015-16.
- NCI-AFS: National Core Indicators Adult Family Survey, 2015-16.
- NCI-FGS: National Core Indicators Family/Guardian Survey, 2015-16.
- NDPES: North Dakota Department of Human Services, Home and Community Based Services Participant Experience Survey. http://www.nasuad.org/hcbs/article/participant-experience-survey
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- PROMIS-GH: PROMIS v1.1 Global -Global Health. http://www.assessmentcenter.net/ (Registration required)
- PROMIS-PI: PROMIS Item Bank v. 1.1 -Pain Interference. http://www.assessmentcenter.net/ (Registration required)
- PROMIS-SPDSA: PROMIS Item Bank v. 1.0 -Satisfaction with Participation in Discretionary Social Activities. http://www.assessmentcenter.net/ (Registration required)
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- QOLS: Flanagan's Quality of Life Scale. http://hqlo.biomedcentral.com/articles/10.1186/1477-7525-1-60
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California

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Delaware

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Florida

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Hawaii

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Illinois

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Iowa

- Iowa High Quality Healthcare Initiative Request for Proposal: Attachment 1 - Scope of Work, 14.6

Kansas

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- KanCare Medicaid State Quality Strategy 2014, Appendices 4-10

Massachusetts

- Senior Care Options Contract 2015, 2.14
- MassHealth Managed Care Quality Strategy 2013, Table 7
- Medicare-Medicaid Capitated Financial Alignment Model Reporting Requirements 2014

Michigan

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Minnesota

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New Jersey

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New York

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- FIDA-IDD Three-Way Contract 2016, Figures 4.1 and 4.2
- Medicare-Medicaid Capitated Financial Alignment Model Reporting Requirements 2015
- State Quality Strategy 2015, Appendices 4 and 5

Ohio

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- Medicare-Medicaid Capitated Financial Alignment Model Reporting Requirements 2014
- MyCare Ohio Memorandum of Understanding with CMS 2012, Figures 6-3 and 6-4 and Table 7-C

Rhode Island

- Rhody Health Options Contract 2013, Attachments J and N
- Integrated Care Initiative Three-Way Contract, Exhibits 2 and 3
- Comprehensive Quality Strategy 2014, Chapter 7

South Carolina

- Healthy Connections Prime Three-Way Contract 2014, Exhibits 2 and 3 and Appendix L
- Medicare-Medicaid Capitated Financial Alignment Model Reporting Requirements 2015

Tennessee

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Texas

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Vermont

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