

## HCBS Quality Measures Issue Brief

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# Person-Reported Outcome Measures for Home and Community-Based Services

The National Quality Forum (NQF) defines home and community-based services (HCBS) as “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” (NQF 2016). More than 4.5 million people with disabilities used Medicaid-funded HCBS in 2017 (Musumeci et al. 2019). This number is expected to grow as the population ages and as advances in medical technology allow people with disabilities to live longer.

State Medicaid programs are primary payers for long-term services and supports (LTSS), including HCBS. State program managers need reliable measures to assess the quality of Medicaid HCBS provided to beneficiaries and to identify areas that need improvement. Among the most

important measures are those that gauge whether the services and supports provided to Medicaid HCBS beneficiaries are person-centered and meet their needs and goals (AGS 2016). The best way to measure these outcomes is to ask beneficiaries about their views on these matters (NQF 2013;

### About this series

In the last five years, the Centers for Medicare & Medicaid Services (CMS), the National Quality Forum (NQF), and private sector groups have issued reports that describe HCBS quality measure frameworks, inventories of HCBS quality measures now in use, and key measure gaps. CMS, other federal agencies, and measure developers have also developed and rigorously tested new HCBS quality measures, several of which recently became available to state Medicaid agencies.

This issue brief series describes recent HCBS quality measure developments, covering three critical processes and outcomes of high quality care:

1. Person-centered assessments and care plans
2. Person-reported outcomes, including choice and decision making, community participation, and experience of care
3. Rebalancing the long-term services and supports (LTSS) system toward HCBS

These briefs are intended to orient state Medicaid agencies to the measures currently available to: monitor, improve, and evaluate HCBS quality; inform the selection of appropriate measures for different HCBS programs and populations; and highlight current measure gaps.

Simon-Rusinowitz 2018). Known as “person-reported outcome measures,” these types of quality measures can help states determine how well HCBS structures and processes meet individuals’ goals and improve their quality of life.

This brief describes recent advances in **person-reported outcome measures** for Medicaid HCBS beneficiaries. It focuses on three outcomes of particular importance to these individuals: (1) choice and decision making, (2) community participation, and (3) experience of care. The brief reviews the history and evolution of measures in these areas, development of new measures, considerations for using these measures with different types of Medicaid HCBS programs and population groups, and remaining measure gaps. Several key points emerge from this review:

- State Medicaid agencies and state departments of aging and disability have used myriad measures to evaluate the quality of HCBS in the past 40 years, including person-reported outcome measures. Until recently, the only nationally standardized measures that allowed consumers, providers, and program managers to compare state performance to national benchmarks or performance in other states were measures designed for people with intellectual and developmental disabilities (IDD). These measures are derived from beneficiary surveys, such as the Personal Outcomes Measures and the National Core Indicators for people with IDD.
- In the past few years, new sets of nationally standardized person-reported outcome measures have become available, generated from new surveys:
  - In 2017, the Centers for Medicare & Medicaid Services (CMS) released a set of 19 person-reported experience-of-care measures, constructed from beneficiary responses to the Home and Community-Based Services Consumer Assessment of Healthcare Providers and Systems (HCBS CAHPS®) Survey. These measures meet accepted standards for

reliability and validity and can be used to compare the experience of care across multiple groups of adults with disabilities, including frail elderly, individuals with physical disabilities, persons with IDD, those with acquired brain injury, and persons with severe mental illness, even when these populations are served by different Medicaid HCBS programs.

- In addition, the National Core Indicators - Aging and Disabilities (NCI-AD), developed in 2015, complement the NCI by providing measures specifically tailored to adults over age 65 and people with physical disabilities.
- Despite this progress, gaps in person-reported outcome measures remain in many domains of the HCBS quality framework defined by NQF. Several efforts are currently underway to fill those gaps by developing and testing new survey questions and new approaches for eliciting beneficiaries’ views on an ongoing basis.

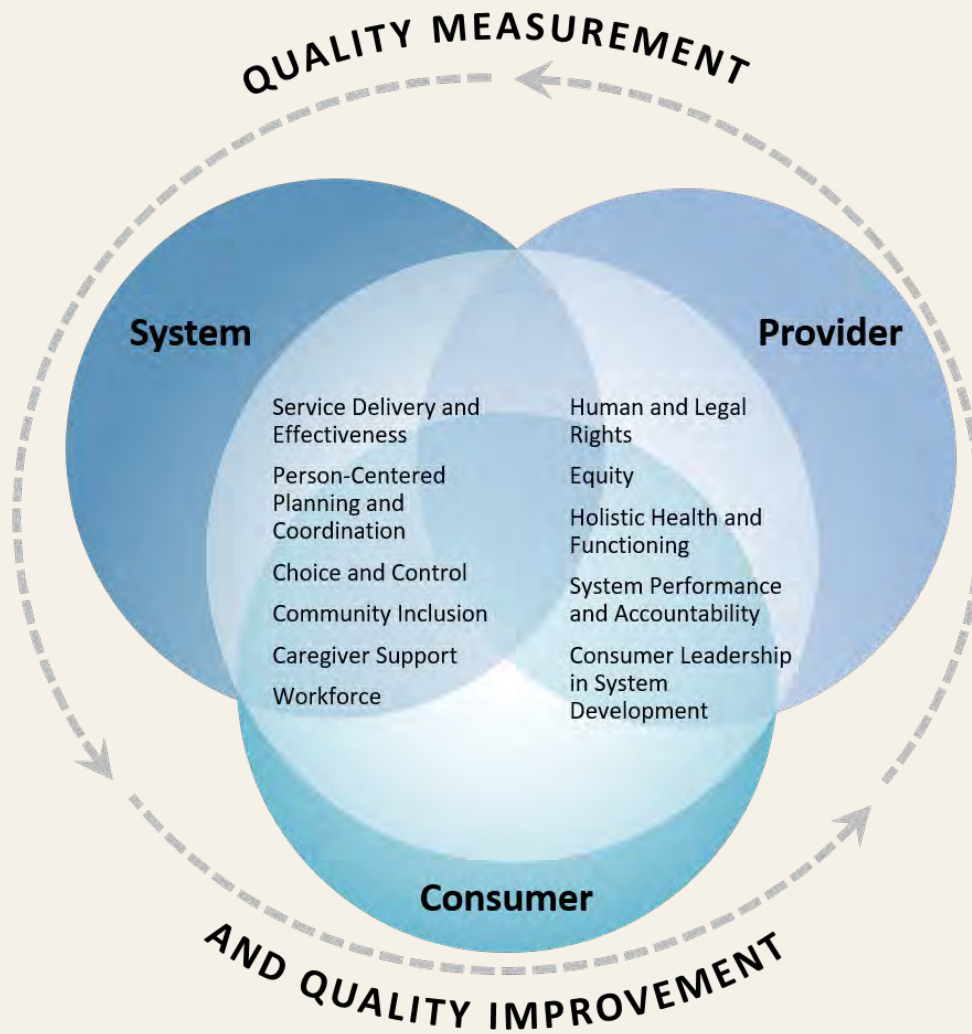
### **1. Importance of person-reported outcome measures**

Person-reported outcome measures concerning individual choice and decision making, community participation, and experience of care address 3 of the 11 quality domains of the NQF HCBS Quality Measurement Framework (see Exhibit 1). NQF defines these 3 domains as follows:

**Choice and Control** – the level to which people 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. This domain includes four subdomains: personal choices and goals, choice of services and supports, personal freedoms and dignity of risk, and self direction, a delivery model that gives beneficiaries decision-making authority over which services they receive and who provides them.

**Community Inclusion** – the level to which people who use HCBS are integrated into their communities and are socially connected, in accordance with personal preferences. This domain

**Exhibit 1. National Quality Forum home and community-based services quality measurement framework**



Source: National Quality Forum. *Quality in Home- and Community-based Services to Support Community Living: Addressing Gaps in Performance Measurement Final Report*. September 2016.

includes three subdomains: social connectedness and relationships, meaningful activity, and resources and settings to facilitate inclusion.

**Service Delivery and Effectiveness** – the level to which services are provided in a manner consistent with each person’s needs, goals, and preferences

and help the person to achieve desired outcomes. It includes two subdomains: delivery (including timely initiation of services and the degree to which the services and supports provided correspond with the plan of care), and meeting each person’s needs and achieving their goals.

Federal statutes reinforce the importance of choice and control, community inclusion, and person-centered service delivery. The Supreme Court's Olmstead decision was a landmark case that affirmed the right of people with disabilities to receive services in the most integrated setting, and Section 2402(a) of the Affordable Care Act required the establishment of processes to ensure service plans are developed in a way that reflects individual preferences and needs.<sup>1</sup> In addition, federal rules require certain programs that serve Medicaid beneficiaries with disabilities to collect information from beneficiaries about their quality of life and community integration. For example, the Medicaid managed care rules issued in 2016 required states to identify and report standard performance measures relating to quality of life and community integration for individuals receiving LTSS through managed care plans [42 CFR 438.330(c)(1)(ii)].

## 2. History and evolution of person-reported outcome measures

### HCBS quality measures vary by state and program.

States have used myriad measures to evaluate the quality of HCBS services. Federal rules governing Section 1915(c) HCBS waiver programs, which serve the largest number of HCBS beneficiaries, allow each state to develop its own performance indicators for each waiver program. States can also develop their own quality measures for HCBS programs operating under state plan options, such as Section 1915(k) Community First Choice and Section 1915(j) self-directed personal assistance services authorities. States that operate Medicaid managed LTSS (MLTSS) programs (see Exhibit 2) have similar flexibility to develop their own quality and performance measures.

One consequence of granting states leeway to develop their own HCBS quality measures is that HCBS programs lack a single, standardized set of quality measures (NQF 2016). HCBS performance measures now number in the hundreds nationwide, including those designed to assess choice and control, community participation, quality of life, and

experience of care. This latitude allows states to tailor the measures they use to each program, but it hinders efforts by consumers, CMS, and the public to compare state performance against national benchmarks, across states, and within states over time.

### Exhibit 2. Growth of Medicaid managed long-term services and supports (MLTSS)

Historically, state Medicaid agencies covered LTSS by paying providers directly on a fee-for-service (FFS) basis. However, Medicaid delivery and payment systems have undergone a sea change in the past 10 years. In 2018, nearly two dozen states contracted with private managed care plans to cover LTSS, paying each plan a fixed monthly amount for each Medicaid enrollee. In exchange for these capitated payments, MLTSS plans deliver services to enrollees through networks of providers, such as nursing homes, home health agencies, adult day centers, residential care homes, and personal care aides.

In addition to Medicaid MLTSS programs, several integrated care programs for people eligible for both Medicare and Medicaid also cover HCBS benefits, such as the Medicare-Medicaid Financial Alignment Initiative capitated model demonstration, and the Program of All-Inclusive Care for the Elderly (PACE). Each of these programs has unique federal reporting requirements and performance measures, which often vary by state (Giovannetti et al. 2013).

### Origins of person-reported outcome measures.

Since the early 1990s, numerous consumer surveys have been developed, tested, and fielded with HCBS beneficiaries, most of them designed for use with specific populations with disabilities. Exhibit 3 summarizes key features of the six most widely used instruments, discussed in more detail below.

**Exhibit 3. Person-reported outcome surveys: target HCBS populations, survey modes, and measures by domain**

	Survey	POMs	NCI	PES	MFP QoL	NCI-AD	HCBS CAHPS®
<b>HCBS populations</b>	Year begun	1993	1997	2003	2006	2015	2016
	Individuals with IDD	X	X	X	X		X
	Individuals with serious behavioral health conditions	X			X		X
	Adults under age 65 with physical disabilities			X	X	X	X
	Frail adults over age 65			X	X	X	X
<b>Survey administration mode</b>	In person	X	X <sup>a</sup>	X	X	X	X
	Telephone				X		X
	Other		X <sup>b</sup>				
<b>Domain(s)</b>	Choice and control of providers and services	X	X	X	X	X	X
	Choice and control over everyday life decisions					X	X
	Satisfaction with services and/or residential setting	X	X		X	X	X
	Treated with dignity and respect	X	X	X	X	X	X
	Community integration/social inclusion	X	X	X	X	X	X
	Access to transportation		X			X	X
	Unmet need for care or services		X	X	X	X	X
	Overall satisfaction with life		X		X		
	Realize personal goals	X				X <sup>c</sup>	
	Personal safety and security					X	X
	Access to employment					X	X <sup>d</sup>

<sup>a</sup> The NCI Adult In-Person Survey collects data in person.

<sup>b</sup> The NCI Family Surveys collect data via mail or online surveys and the NCI Staff Stability Survey collects data via online surveys.

<sup>c</sup> The NCI-AD measures whether the services provided meet individuals' goals.

<sup>d</sup> HCBS-CAHPS® has a supplemental employment module.

HCBS-CAHPS® = Home and Community-Based Services Consumer Assessment of Healthcare Providers and Systems; MFP QoL = Money Follows the Person Quality of Life; NCI = National Core Indicators; NCI-AD = National Core Indicators–Aging and Disabilities; PES = Participant Experience Survey; POMs = Personal Outcome Measures.

By 2008, nearly all state Medicaid, aging, and disability agencies were using at least one of the following surveys to measure person-reported outcomes for some groups of people with disabilities using HCBS. The surveys have been continuously updated, refined, and validated, and the measures derived from each survey have been repeatedly tested and revised:

- 1. Personal Outcomes Measures® (POMs).** In the early 1990s, the Council on Quality and Leadership (CQL) began holding focus groups with people with IDD, people with psychiatric disabilities, family members, and key stakeholders to identify the factors important to them about the services and care they received. Based on the results, they developed an interview tool that systematically addressed these factors and a set of indicators in the following domains: personal goals, choice, social inclusion, relationships, rights, dignity and respect, health, environment, security, and satisfaction. In the 25 years since the POMs survey was first developed, CQL has conducted extensive research on the results, and the current POMs contain 21 indicators organized into five categories: human security, community, relationships, choices, and goals (CQL 2017; Friedman 2018). For more information, see <https://www.c-q-l.org/the-cql-difference/personal-outcome-measures>.
- 2. National Core Indicators (NCI).** In the late 1990s, the Human Services Research Institute (HSRI), in collaboration with the National Association of State Directors of Developmental Disabilities Services, developed a survey to evaluate system performance in achieving key outcomes, including quality of life, for people with IDD. The survey was standardized to allow each state to compare its performance to national benchmarks and other states. NCI currently includes approximately 150 indicators, organized into five domains: individual outcomes; health, welfare, and rights; system performance; staff stability; and family outcomes. Three NCI survey tools are available for beneficiaries, family caregivers, and guardians, and the survey for

consumers has been validated for use with individuals who are nonverbal and those with cognitive disability, allowing for interview of proxies as needed. As of 2019, 46 states and the District of Columbia administer the NCI survey, as well as many sub-state regions and counties. HSRI maintains a database with results from all participating entities. State agencies use the survey results to guide quality improvement efforts, to meet Section 1915(c) waiver program reporting requirements, and for public reporting. For more information, see <https://www.nationalcoreindicators.org/>.

- 3. Participant Experience Survey (PES).** Starting in 2003, many states began using the Participant Experience Survey (PES) to assess the experiences of older adults and adults with physical disabilities participating in Section 1915(c) waiver programs. Originally developed by MedStat under a contract from CMS, the survey includes questions addressing four key domains: access to care, choice and control, respect and dignity, and community integration. Survey responses were used to calculate 33 indicators for older adults and people with physical disabilities, and 51 indicators for people with IDD (CMS and MedStat 2003). Another version of the survey was developed in 2005 for people with brain injuries.<sup>2</sup> For more information, see <http://www.nasuad.org/hcbs/article/participant-experience-survey-pes-tools>.
- 4. Money Follows the Person Quality of Life Survey.** The Deficit Reduction Act of 2005 created the Money Follows the Person (MFP) demonstration. Its goal was to test new approaches to assist long-term residents of institutions to transition to a home or other community residence if desired. As part of a contract to evaluate the MFP demonstration, Mathematica designed the MFP Quality of Life (QoL) survey to measure changes in QoL reported by people participating in the demonstration. The QoL survey was fielded three times: once before the person transitioned out of an institution, and then one year and two years after transition. It covered seven domains: living

situation, choice and control, access to personal care, respect/dignity, community integration and inclusion, overall life satisfaction, and health status. Many of the questions in the MFP QoL survey were based on the Participant Experience Survey, and others were drawn from other survey instruments, including NCI, a survey used in the Cash and Counseling Demonstration<sup>3</sup> evaluation, and the Nursing Home CAHPS® (Sloan and Irvin 2007). Several states continue to administer the MFP QoL survey, because it provides useful information for quality assurance and improvement purposes.<sup>4</sup>

The measures and indicators of beneficiary outcomes in these four surveys share many of the same domains (see Exhibit 3). A comprehensive environmental scan of HCBS quality measures conducted in 2006 for the Agency for Healthcare Research and Quality (AHRQ) summarized these measures in one overarching domain called “client experience” (Galantowicz 2008).

### 3. New person-reported outcome measures

During the past few years, program managers and researchers have developed and validated new surveys and survey items to evaluate quality from the perspective of people with disabilities, often building on existing survey instruments. Several factors have driven these efforts:

- **Evolving concepts of disability and quality of life.** Advances in the field of disability over the past two decades have led to broader understanding of what quality of life means to people with disabilities. In the past, disabilities were often viewed from a medical perspective, as conditions to be managed. In 2001, the World Health Organization (WHO) revised the International Classification of Functioning, Disability, and Health by reframing disability “as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors” (WHO 2001). This new definition focused greater attention on collective actions that help

to facilitate full participation of people with disabilities in society. Newer disability frameworks also put more emphasis on the physical and social environment, which can serve as barriers (such as inaccessible buildings) or facilitators (such as ramps or wheelchair-accessible public transportation) to community participation for people with disabilities (Stineman and Streim 2010). As understanding of the factors that contribute to community inclusion and quality of life has expanded, surveys for people with disabilities have been modified as well to cover additional domains central to quality of life, such as choice and satisfaction with residential setting, and employment opportunities.

- **Changes in service delivery.** Service delivery systems have also changed in the past 20 years. As noted earlier, many state Medicaid agencies have switched from providing HCBS through traditional FFS models to providing such services through contracts with managed care plans. In addition, self-directed options have become widespread, allowing individuals to choose the providers and set of services they wish to receive. Self-direction can be implemented via employer authority models, in which individuals can hire or fire personal care workers, or budget authority models, in which individuals decide what mix of services and supports they wish to receive within a fixed budget. The emergence of these service delivery approaches has led to the development of new survey questions tailored to these models.
- **Interest in cross-disability surveys.** New initiatives to develop person-centered outcome measures have also been prompted by interest in cross-disability surveys that permit comparison of outcomes for all Medicaid HCBS beneficiaries participating in HCBS programs, regardless of the waiver program or delivery system they participate in or their disability type. Cross-disability surveys have been designed to compare outcomes common to people with any type of disability, including frail elderly and people with physical disabilities, IDD, acquired brain injury, or severe mental illness.

**HCBS CAHPS.**<sup>®</sup> These trends led CMS to create an experience-of-care survey specifically designed for people using HCBS. Sponsored by AHRQ, a set of experience-of-care surveys called Consumer Assessment of Healthcare Providers and Systems (CAHPS<sup>®</sup>) ask individuals receiving services to report on and evaluate their experience with health plans, providers, and health care facilities. There are currently more than a dozen CAHPS<sup>®</sup> surveys for individuals who receive care from different types of providers, have different health conditions, are enrolled in different types of health plans, or receive care in different types of health care facilities.<sup>5</sup>

The HCBS CAHPS<sup>®</sup> survey instrument consists of 69 core items. These items were used to derive 19 measures, consisting of 7 scale measures, 6 global rating and recommendations measures, and 6 individual measures (see Exhibit 4). For example, the questions ask respondents to rate how well they are treated by care manager staff and personal care assistants, availability of transportation to get to medical appointments, and physical safety, among other areas. Employment-related questions are part of a supplemental survey module, which states or other survey sponsors can use if they wish. In 2016, the survey qualified to receive the CAHPS trademark, and NQF endorsed the 19 measures derived from the survey. For more information, see <https://www.medicaid.gov/medicaid/quality-of-care/performance-measurement/cahps-hcbs-survey/index.html>.

**National Core Indicators—Aging and Disabilities (NCI-AD).** In 2014, HSRI partnered with the National Association of State Units on Aging and Disability (NASUAD) (now, known as ADvancing States) to expand the NCI for use with people with physical disabilities and older adults. The survey was piloted in three states in 2015, launched in 2016, and as of 2018–2019, about 25 states had administered it.<sup>6</sup> The NCI-AD was designed to assess quality of life and outcomes for people who use any publicly funded LTSS service, including Medicaid, Older Americans Act, Programs of All-inclusive Care for the Elderly (PACE), nursing homes, or state-funded

## Exhibit 4. HCBS CAHPS<sup>®</sup> measures, endorsed by the National Quality Forum

### Scale Measures (composed of 2 or more survey items)

1. Staff are reliable and helpful
2. Staff listen and communicate well
3. Case manager is helpful
4. Choosing the services that matter to you
5. Transportation to medical appointments
6. Personal safety and respect
7. Planning your time and activities

### Global Ratings Measures

8. Global rating of personal assistance and behavioral health staff
9. Global rating of homemaker
10. Global rating of case manager

### Recommendations Measures

11. Would recommend personal assistance/behavioral health staff to family and friends
12. Would recommend homemaker to family and friends
13. Would recommend case manager to family and friends

### Unmet Needs Measures

14. Unmet need in dressing/bathing due to lack of help
15. Unmet need in meal preparation/eating due to lack of help
16. Unmet need in medication administration due to lack of help
17. Unmet need in toileting due to lack of help
18. Unmet need with household tasks due to lack of help

### Physical Safety Measure

19. Hit or hurt by staff



**Exhibit 5. Comparison of HCBS-CAHPS® and NCI-AD survey features**

Feature	HCBS CAHPS®	NCI-AD™
Availability	Publicly available (free)	Proprietary, copyrighted (cost to use)
Endorsement or recognition by national organizations	Measures endorsed by the National Quality Forum (NQF)	
Eligible population	Medicaid HCBS beneficiaries with any type of disability <sup>a</sup>	People receiving LTSS through any publicly funded program; excludes people with intellectual and development disabilities (captured by NCI™) or severe mental illness
Technical assistance available to states	Supporting data submission to HCBS CAHPS® national database (free), and facilitating access and use of other HCBS CAHPS® database reporting products for quality improvement and research	Planning and implementing the survey, sampling strategy, data analysis, submitting results to the national database, interviewer training (for an annual fee)

Note: A comparison of additional features is available at: [https://nci-ad.org/images/uploads/NCI-AD\\_and\\_HCBS\\_CAHPS\\_Comparison.pdf](https://nci-ad.org/images/uploads/NCI-AD_and_HCBS_CAHPS_Comparison.pdf).

<sup>a</sup> Although the HCBS CAHPS® survey was designed and tested with Medicaid beneficiaries using HCBS, states may use it with non-Medicaid HCBS programs if they offer homemaker, personal assistant, and/or case manager services. HCBS-CAHPS® = Home and Community-based Services-Consumer Assessment of Healthcare Providers and Systems; NCI-AD = National Core Indicators-Aging and Disabilities.

programs. The NCI-AD survey must be administered through in-person interviews; telephone interviews are not permitted. NCI-AD measures outcomes in 18 domains, comprising about 50 indicators in total. Although most indicators correspond to one survey question, some are calculated based on responses to a set of related questions. For more information, see <https://nci-ad.org/>.

Although the HCBS CAHPS® and NCI-AD share many person-reported outcome measures, there are differences in how they organize the domains of care, and some core indicators in NCI-AD, such as questions about employment, are supplemental items in HCBS CAHPS®. Exhibit 5 compares other features of the two surveys.

**4. Selection and use of measures for state Medicaid HCBS programs and populations**

Because person-reported outcome measures are critical indicators of HCBS quality, most states use at least one of the surveys described in this brief. With many surveys to choose from, state program managers should make sure any survey selected meets three key criteria:

- 1. Scientifically validated.** The survey instrument, questions, and the measures derived from them should be tested for reliability and validity. Reliability is the degree to which the answers to questions are consistent and reproducible, so that differences in measure scores across states

or programs reflect true differences rather than being due to chance. Validity ensures that survey questions are stated clearly and objectively, and the measures accurately assess the concepts they were intended to measure. All of the surveys described in this brief have been tested and validated, and the results are regarded as reliable as long as the interviewers are trained in accordance with established standards.

**2. Nationally standardized questions.** Using national surveys that ask a common set of questions allows states to compare the results for beneficiaries in their state to national benchmarks and results in other states. Such cross-state comparisons can help identify areas for improvement. States may add supplemental questions for their own research and evaluation purposes, but the results for those questions will not be comparable to survey results in other states.

**3. Risk-adjusted scores.** If survey results are used to compare scores across programs or across states, the scores should be risk adjusted by participant characteristics that affect the results. For example, the HCBS CAHPS® measures are risk adjusted by general health rating, mental health rating, age, gender, whether the survey respondent lives alone, and response option (direct versus proxy). The NCI-AD indicators are risk adjusted using 15 characteristics, including age, gender, race, whether the survey respondent lives alone and/or in a rural area, mobility, amount of assistance needed for everyday activities, and other factors.

Beyond these foundational criteria, additional considerations may influence states' choice of beneficiary surveys. For example:

- **Preference for cross-disability or disability-specific measures.** As Exhibit 3 shows, the HCBS CAHPS® and MFP QoL surveys are designed for use with Medicaid beneficiaries with any type of disability, although the MFP QoL survey was designed for people who are transitioning from institutions to the community. In contrast, the

NCI, NCI-AD, and POMs are geared toward certain groups of HCBS beneficiaries: people with IDD for NCI and POMs, and older adults and people with physical disabilities for the NCI-AD. Some people prefer cross-disability surveys because they are useful for comparing outcomes across all HCBS programs, while others prefer disability-specific surveys because they include particular topics and questions that are especially relevant to individuals with specific needs and priorities. NCI-AD can be used in any publicly funded LTSS program, whereas HCBS CAHPS® applies only to participants in Medicaid HCBS programs (that is, it excludes nursing facility residents, for whom another CAHPS® survey is available).

### Measure selection technical assistance for states

The Administration for Community Living recently established a **National Center for Advancing Person-Centered Practices and Systems** to serve as a central clearinghouse for information about person-centered care. The center provides technical assistance to states in selecting and implementing structural, process, and outcome measures to incentivize and evaluate the impact of person-centered practices. The National Center for Advancing Person-Centered Practices and Systems is jointly funded by CMS and the Administration for Community Living. For more information, see <https://ncapps.acl.gov/>.

- **Survey mode, costs, and response rates.**

Interviews for the NCI, NCI-AD, and POMs are conducted in person, while HCBS CAHPS® and MFP QoL interviews can be done either in person or by telephone. The mode of survey administration affects costs, since in-person interviews can cost at least twice as much as interviews conducted by telephone. Those who advocate for conducting survey interviews in person say that it is important to communicate

with people who may have difficulty with hearing or speech and to establish trust. However, telephone interviews can also work well if interviewers are trained to address communication barriers. Telephone surveys generally have lower response rates and require larger sample sizes to ensure those who do respond are representative of the HCBS population served, with regard to age, gender, race/ethnicity, and types of disability. Survey mode, cost, and response rate are interrelated; in-person surveys cost more but generally have higher response rates, whereas telephone surveys cost less but generally have lower response rates, requiring more contacts to yield the minimum sample size (number of completed responses) to achieve a reasonable level of reliability.

- **Ability to use state/program terms and supplemental modules.** Some surveys can be modified to substitute terms and language that particular respondents will understand. For example, some surveys ask about how program staff respond to beneficiaries' requests; in such cases, the wording of the question can be tailored to fit the staff titles used by each state or program. Some surveys also allow states to add a few questions to the survey, such as to obtain feedback on state- or program-specific issues. In addition, some surveys have supplemental modules; for example, the HCBS CAHPS® survey has an optional set of questions that address employment opportunities for certain beneficiary groups for whom work is an important aspect of community participation. State officials interested in tailoring nationally standardized surveys to state-specific needs should explore these options with each survey sponsor.
- **MLTSS versus FFS.** All of the surveys described in this brief can be used with both MLTSS program enrollees and HCBS beneficiaries who receive services through FFS delivery models. However, to calculate measures at the MLTSS health plan level, the measure denominators are defined as the number of survey respondents from each plan,

rather than the total number of survey respondents for each state publicly funded LTSS or HCBS program. States may also consider requiring the sample of MLTSS enrollees be limited to those who have been continuously enrolled for a minimum period of time, to ensure they have received HCBS for long enough to have experienced the care arranged by the MLTSS plan. To be eligible for the HCBS CAHPS® survey sample, respondents must have received HCBS services for three months or longer. To be eligible for the NCI-AD survey sample, respondents must receive publicly funded LTSS at least two to three times a week.

- **Public reporting.** National reporting of survey results allows states to compare their performance with that of other states. Currently, NCI and NCI-AD make national and state-specific reports available on their websites, and the national reports display state scores, weighted by the number of survey respondents, relative to the overall national weighted average. In addition, CMS included NCI in the 2020 Adult Core Set, which is a tool that states can use to monitor and improve the quality of health care provided to adult Medicaid and CHIP beneficiaries. States that use HCBS CAHPS® are encouraged to participate at no cost in a new HCBS CAHPS® Database, currently under development by AHRQ, which will provide standardized comparisons of performance across states and programs. The database is expected to be operational in 2020. Aggregate summary results will be publicly available on AHRQ's CAHPS® Database website, and de-identified data files will be made available for approved research purposes.

## 5. Remaining measure gaps and additional measures under development

The NQF HCBS quality report (NQF 2016) identified measure gaps in all 11 domains of the HCBS quality framework, including aspects of systems and service delivery that are best evaluated through person-reported outcome measures. For example, in the choice and control domain, NQF recommended

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

To fill some measure gaps in the NQF HCBS quality framework, in 2016 the National Institute on Disability, Independent Living, and Rehabilitation Research funded a Research and Training Center on HCBS Outcome Measurement (RTC/OM) at the University of Minnesota. Its goal is to refine and develop measures to assess the impact of HCBS on the lives of people with disabilities in the community. The project has six phases that span the measure development lifecycle, from identifying measure concepts that are meaningful to people with disabilities, to developing and validating measures and supporting measure implementation.

The RTC/OM began by conducting a series of meetings with stakeholders representing five groups of people with disabilities, including IDD, physical disabilities, traumatic brain injury, aging-related disabilities, and psychiatric disability. In addition to individuals with these disabilities, the project team met with family members, providers, and state program administrators. The groups were asked to review the domains and sub-domains of the NQF HCBS quality framework and identify areas that were missing, were not sufficiently emphasized, or even areas that they thought did not belong. Researchers then compared the results to existing HCBS measures to identify gaps.

Based on the advice of a national advisory committee and several technical expert panels, the project team identified several person-reported outcome measure concepts to fill measure gaps, which fall into three domains of the NQF HCBS quality framework (see Exhibit 6). The RTC/OM team is conducting psychometric testing of the questions that will form the basis for measures; this testing is being conducted with participants from all five disability groups. Testing is expected to last until the end of 2020. If the measures meet standard thresholds for reliability and validity and

demonstrate usability and feasibility, the project team will provide guidance on how to measure change over time and how to use the measures to improve the quality of services.

### **Exhibit 6. New person-reported outcome measures under development by the RTC/OM, by NQF HCBS Quality Framework Domain**

#### **Community inclusion and meaningful activity**

- Social connectedness
- Employment experiences of people who are employed, seeking employment, and no longer seeking employment
- Availability of transportation to community events

#### **Choice and control**

- Personal life and daily activities
- Services and supports
- Types of services received and who provides the services (for people who self-direct)

#### **Human rights**

- Freedom from abuse and neglect

RTC/OM = Research and Training Center on HCBS Outcome Measurement at the University of Minnesota. For more information, see <https://rtcom.umn.edu/>.

**New approaches to collecting person-reported outcome measures.** Although new person-reported outcome measures will enhance states' ability to monitor and evaluate HCBS quality, challenges remain. Nearly all of the surveys described in this brief are administered to a small sample of HCBS beneficiaries and, in most cases, conducted annually. Therefore, even if the survey respondents

are representative of the HCBS population overall, the results do not capture the experience and perceptions of all beneficiaries on an ongoing basis. For this reason, some state program managers and MLTSS health plan quality assurance staff say that person-reported outcome measures derived from surveys are not as useful as they could be for quality improvement in real time.

One alternative to surveys is to embed questions about individuals' personal goals into regular interactions between case managers and beneficiaries so that beneficiaries can rate progress in achieving their goals over time. For example, a recent study compared the use of a goal attainment scale to person-reported outcome measures with a sample of older adults. Results indicated that the study participants expressed a range of personalized outcomes important to them, some of which were not captured through current person-reported outcome measures. On average, about three-quarters of the participants achieved the goal they had selected over

six months and the results varied across the study organizations (Giovannetti et al. 2018).

The 2016 NQF HCBS quality report suggested another way to address the limitations of surveys for producing person-reported outcome measures. NQF recommended developing and implementing electronic quality data systems, integrated with other systems that capture assessment, service planning and authorization, and service utilization data. Integrated data systems would "facilitate 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" (NQF 2016, pp. 13–14). NQF also emphasized the need to link quality outcomes to the structures and processes that produce such outcomes, to give program managers real-time data needed to improve quality. In doing so, NQF reaffirmed the importance of all three types of measures—structure, process, and outcome—to support ongoing quality improvement (Exhibit 7).

**Exhibit 7. Types of quality measures and HCBS example**



**Structure**

Case managers receive ongoing training in person-centered planning



**Process**

Services and supports are arranged and delivered pursuant to person-centered assessment and care plans



**Outcome**

Services and supports meet individuals' needs, and achieve their care goals, ensure choice and control, and enhance community participation

## Conclusion

For more than two decades, state Medicaid agencies have conducted surveys of people who use Medicaid HCBS to understand their experience of care, evaluate the quality of services and supports provided, and determine how well the structures and processes used to provide person-centered care meet individual needs and goals. The person-reported outcome measures produced by the surveys described in this brief provide critical information to program managers about how well they are performing and how they can improve.

Survey developers continue to validate, update, and add questions to existing surveys to ensure that their surveys remain relevant to changing definitions of quality of care, quality of life, and community inclusion and what these concepts mean to people with disabilities. New surveys, such as HCBS CAHPS®, have also been developed to enable comparisons of person-reported experience and outcomes across diverse groups of individuals with disabilities. As more states administer these surveys and share results with national organizations, states can compare their performance to national benchmarks and to other states, and identify areas for improvement.

New person-reported outcome measures are now under development. As more nationally standardized and validated measures become available and new systems and approaches are used to track beneficiaries' views, state program managers will benefit from an expanded set of tools for assessing whether HCBS are meeting the needs of individuals and the extent to which their state's system design and implementation delivers high quality services.

## References

- American Geriatrics Society (AGS) Expert Panel on Person-Centered Care. "Person-Centered Care: A Definition and Essential Elements." *Journal of the American Geriatrics Society*, vol. 64, 2016, pp. 15–18. Available at <https://onlinelibrary.wiley.com/doi/epdf/10.1111/jgs.13866>.
- Centers for Medicare & Medicaid Services (CMS) and MedStat. "Development and Testing Overview for the Participant Experience Survey Tools." Version 1.0, August 1, 2003. Available at [http://www.nasuad.org/sites/nasuad/files/hcbs/files/28/1386/2\\_Summary.pdf](http://www.nasuad.org/sites/nasuad/files/hcbs/files/28/1386/2_Summary.pdf).
- Coughlin, R., J. Ward, N. Denny-Brown, B. Hagen, K. Maurer, E. Morris, J. Smoot, A. Steiner, and B. Perez. "Money Follows the Person Demonstration: Overview of State Grantee Progress, January to December 2016." Cambridge, MA: Mathematica Policy Research. September 2017. <https://www.mathematica-mpr.com/download-media?MediaItemId={96C0D313-A6E8-4314-8E4B-C762F7347C6A}>
- Council on Quality and Leadership (CQL). "Personal Outcome Measures® 2017: Measuring Outcomes Now and Into the Future." 2017. Available at <https://www.c-q-l.org/files/2017Documents/CQL-Personal-Outcome-Measures-Validation-Report-2017.pdf>.
- Friedman, C. "The Personal Outcome Measures®." *Disability and Health Journal*, vol. 11, no. 3, July 2018, pp. 351–358. Available at <https://www.sciencedirect.com/science/article/pii/S1936657417302273?via%3Dihub>.
- Galantowicz, S. "Environmental Scan of Measures for Medicaid Title XIX Home and Community-Based Services." Rockville, MD: Agency for Healthcare Research and Quality (AHRQ), March 2008. Available at <https://www.ahrq.gov/patient-safety/settings/long-term-care/resource/hcbs/report/index.html> See also "Appendix III: Compendium of Measures and Tools." Available at <https://www.ahrq.gov/professionals/systems/long-term-care/resources/hcbs/hcbsreport/hcbsapiii.html#intro>.
- Giovannetti, E., J. Briefer-French, E. Anderson, D. Rey, and D. Lipson. "Development of Assessment and Care Planning Measures for Use in Medicaid Managed Long Term Services and Supports (MLTSS) Programs." Including Appendix 1, Environmental Scan of Assessment and Care Planning Quality Measures. National Committee for Quality Assurance and Mathematica Policy Research. Prepared for the Centers for Medicare & Medicaid Services (CMS), September 2013.
- Giovannetti, E., B. Sandberg, B. Angelia, S. Baird, C. Clair, and S. Scholle, "What Matters Most: A Pilot Study to Develop Quality Measures for Older Adults with Complex Needs." Presentation at the 2018 Gerontological Society of America Annual Scientific Meeting. *Innovation in Aging*, vol. 2, S1, 2018

Musumeci, M.B., P. Chidambaram, and M. O'Malley Watts. "Medicaid Home and Community-Based Services Enrollment and Spending." Issue Brief. Kaiser Family Foundation, April 2019. Available at <http://files.kff.org/attachment/Issue-Brief-Medicaid-Home-and-Community-Based-Services-Enrollment-and-Spending>.

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

National Quality Forum (NQF). "Patient Reported Outcomes (PROs) in Performance Measurement." January 10, 2013. Available at <http://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdIdentifier=id&ItemID=72537>

Simon-Rusinowitz, L. "When Person-Centered Services Stop at My Mother's Nursing Home Door: Views from a Daughter and Champion of Person-Centered Care." 2018. Available at <https://www.healthinnovation.org/news/newsletter/health-innovation-highlights-december-20-2018#eldercare>.

Sloan, Matt, and Carol Irvin. "Money Follows the Person Quality of Life Survey." Prepared for Centers for Medicare and Medicaid Services (CMS). Washington, DC: Mathematica Policy Research, 2007.

Stineman, M.G., and J.E. Streim. "The Biopsychological Paradigm: A Foundational Theory for Medicine." *Physical Medicine and Rehabilitation*, vol. 2, no. 11, 2010, pp. 1035–1045. Available at <https://www.sciencedirect.com/science/article/abs/pii/S1934148210005149>

World Health Organization (WHO). "International Classification of Functioning, Disability and Health." Geneva, Switzerland: WHO, 2001.

## Endnotes

<sup>1</sup> The U.S. Department of Health and Human Services issued guidance in June 2014 regarding the process for operationalizing person-centered planning in: "Guidance to HHS Agencies for Implementing Principles of Section 2402(a) of the Affordable Care Act: Standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services Programs," available at: <https://acl.gov/sites/default/files/news%202016-10/2402-a-Guidance.pdf>.

<sup>2</sup> Because the HCBS CAHPS survey largely supplanted the Personal Experience Survey, only a few states currently use PES.

<sup>3</sup> Cash and Counseling was a federal demonstration, conducted in three states, that provided individuals with a monthly allowance to hire their choice of workers including family members, and to purchase other services and goods (as permitted by states). For more information on the Cash and Counseling Demonstration, see <https://aspe.hhs.gov/terms/cash-and-counseling-demonstration> and <https://www.mathematica.org/relatedcontent?itemID={54E78D4C-07D6-427A-B17A-B0630DA4AEEA}&relatedcontent=Related%20Publications>.

<sup>4</sup> A copy of the "Money Follows the Person Quality of Life Survey" is available online at [http://www.mathematica-mpr.com/~media/publications/PDFs/health/MFP\\_QoL\\_Survey.pdf](http://www.mathematica-mpr.com/~media/publications/PDFs/health/MFP_QoL_Survey.pdf).

<sup>5</sup> A list of CAHPS® surveys is available online at: <https://www.ahrq.gov/cahps/surveys-guidance/index.html>.

<sup>6</sup> The number of states administering the NCI-AD survey each year varies because many do not conduct the survey every year. Sixteen states collected data in the 2018-2019 cycle of the NCI-AD Adult Consumer Survey.

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