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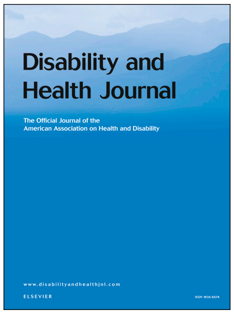

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Measuring Nonmedical, Person-Centered Outcomes for Home and Community-Based Service Participants: Selecting and Defining Concepts

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Abbreviations

ADA	Americans with Disability Act
CMS	Centers for Medicare and Medicaid Services
HCBS	Home- and community-based services
NQF	National Quality Forum

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ABSTRACT

Background: Quality measures can monitor whether home- and community-based services (HCBS) are delivered effectively and support the outcomes desired by persons served. Nonmedical, person-centered quality measures complement Medicaid's HCBS Quality Measure Set.

Objectives: (1) Determine the aspects of quality most important to HCBS recipients, (2) identify aspects of quality not included in quality outcome instruments, and (3) select and define aspects for new quality outcome measures.

Methods: A Participant Council representing HCBS recipients identified aspects of quality important to them. We reviewed person-centered instruments to identify gaps in coverage of concepts related to the National Quality Forum's HCBS quality domains of choice and control, community inclusion, and holistic health and function. Focusing on concepts prioritized by the Participant Council, we identified gaps in current instruments defined as: (1) no instrument addresses the concept; (2) measures not person-centered; (3) measures not outcome-focused; or (4) measures lack evidence of adequate reliability and validity across HCBS populations.

Results: We defined 18 concepts for which adequate measures are lacking and selected nine for further development, including choice and control over (1) living arrangement, (2) how time is spent, (3) money, (4) important relationships, (5) personal expression (6) food and nutrition, and (7) healthcare and health; as well as (8) dignity of risk; and (9) community engagement.

Conclusions: Despite the existence of many HCBS instruments, there remains a need for nonmedical, person-centered concepts to complement Medicaid's HCBS Quality Measure Set. Next steps are to develop and test items that measure these nine concepts.

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INTRODUCTION

Home- and community-based services (HCBS) help people with disabilities live in the community rather than in institutional settings.[1] These services include assistance with activities of daily living such as bathing, dressing, eating, and preparing meals, as well as supports such as transportation and employment which help people to engage in their communities. In accordance with the Americans with Disabilities Act of 1990 (ADA),[2] HCBS supports the goal of optimal independence for people with disabilities. Further, the Olmstead decision[3] requires that states provide community supports to enable people with disabilities to live in the most integrated settings possible. In accordance with the ADA and Olmstead, and with consumer advocacy, there is increasing emphasis on the provision of person-centered HCBS services which are intended to "assist the individual in achieving personally defined outcomes."[1] The recently enacted HCBS Access Rule incorporates a requirement for person-centered services and requires states to report HCBS quality measures.[4]

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Quality measures assess whether services are high quality, including whether services are effective and support the outcomes desired by the persons served.[5] Quality outcome measures, which reflect the results of delivered services, can assess different aspects of service outcomes, including medical and functional outcomes, as well as nonmedical outcomes desired by the individual receiving HCBS. Quality measures assess the quality of services provided. They can provide feedback to measured entities to encourage system-level quality improvement activities.

In 2017, the National Quality Forum (NQF) developed a framework for HCBS quality that includes 11 domains and 40 subdomains for measures.[6] NQF specified criteria for HCBS quality measures, including that quality measures should be evidence-based, tested to show validity and reliability, measured in ways that can identify opportunities for quality improvement, and feasible to collect allowing opportunity to hold programs accountable.[5] While many HCBS quality measures have been developed, some of which are in use by a number of states and providers (e.g., National Core

Indicators (NCI) - Intellectual and Developmental Disabilities; NCI - Aging and Disabilities,[7] the Council on Quality and Leadership's Personal Outcome Measures,[8] and HCBS CAHPS[9]), there are few quality measures in some NQF-identified domains. Further, many of the items and instruments that measure these domains do not meet one or more of the NQF criteria. Thus, there is a need to develop additional item sets that measure person-centered outcomes valued by HCBS recipients that are evidence-based. This report describes the initial phases of our research to develop measures of nonmedical, person-centered outcomes for HCBS users that meet NQF's criteria and address gaps in coverage of NQF domains.

METHODS

We conducted three activities to address two research questions, laying the foundation for item set development to address gaps in current measures: (1) Determine important concepts, (2) Identify gaps in outcome measurement instruments, and (3) Prioritize and select the most important concepts for instrument development. The questions were:

1. What aspects of life are most important to HCBS users that can be supported by HCBS services?
2. Where are the gaps in non-medical, person-centered measures that address these key concepts?

Our work is guided by the understanding that "person-centered values . . . are dedicated to the idea that individuals should have the power to define and pursue their own vision for a good life,"[10] choosing what they consider meaningful in creating the life they want. The need for autonomy is a basic tenet of self-determination theory.[11]

Participant Council

Informed by principles of participatory action research,[12] we assembled a Participant Council comprised of 13 individuals with various types of disabilities who receive HCBS to support alignment of the project with the priorities of people who receive HCBS. We recruited members at the start of the

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study and convened virtually to seek their input. We identified potential Council members using professional contacts of research team members and identifying experts who participated on other research panels. We used purposive sampling methods to assure representation across disability populations, including intellectual and developmental (n=3), mental health (n=3), physical (n=7), and age-related disabilities including dementia (n=2). Many of the Council members hold professional positions in the disability field, including self-advocates (n=10), employment with (n=7) and/or board membership (n=4) of disability advocacy organizations and HCBS provider organizations. With the Council, we determined and defined important concepts for person-centered HCBS measures; identified gaps in existing measures for those concepts; and prioritized concepts for item set development.

Determine Important Concepts

The objective of the first Participant Council meeting was to identify nonmedical, person-centered concepts that the members believed to be important aspects of quality and that could be supported by HCBS. We sought concepts within NQF's HCBS Quality Measure Framework's domains of Choice and Control, Community Inclusion, Holistic Health and Functioning and Safety.[6,13] These domains address outcomes rather than processes or structures as defined by Donabedian's Structure-Process-Outcome Model of quality.[14] These domains provided the foundation for discussion and identifying specific concepts important to the Participant Council members.

Research team members reviewed meeting notes and transcripts and identified concepts suggested by the Council for measurement. We drafted definitions of those concepts using the notes and transcripts from the Council meeting to describe what the concepts mean to the individuals.

Identify Gaps in Outcome Measurement Instruments

The research team examined coverage of the 21 concepts identified by the Participant Council, to determine where gaps existed. We reviewed HCBS instrument items, to identify gaps. We defined a gap when existing items addressing the concept did not exist, or when the items were not person-

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centered, were not outcome-focused, and/or were not evaluated for psychometric standards of validity and reliability in multiple disability populations. We deemed measures to be person-centered if they addressed the desires or priorities of the individual receiving services, provided opportunities for choice, and/or allowed for dignity of risk for the individual to act upon choices. We deemed items to reflect outcomes if they addressed the situation resulting from the structures and processes of services.

Using an online database of HCBS measurement instruments maintained by the Rehabilitation Research and Training Center on HCBS Outcomes at the University of Minnesota,[15] we identified over 150 instruments classified as person-centered and related to the NQF domains of choice and control, community inclusion, and holistic health and function, and aligned with the concepts identified by the Participant Council.[13] Two research team members independently extracted items from each instrument related to the identified concepts and reviewed each instrument to assess whether the items in instruments met our criteria (person-centered, outcome-focused, evidence of reliability and validity in multiple disability populations). Reviewers discussed disagreements, and the full research team reconciled disagreements. Based on this activity, we identified concepts that aligned with the Council members' comments for which items used in instruments collectively met the identified criteria.

Prioritize and Select Most Important Concepts for Instrument Development

Using a nominal group technique,[14] Council members discussed and ranked the importance of the 18 concepts for which gaps were identified. This process consisted of one meeting, a concept rating survey, a focus group, and a concept ranking survey to achieve consensus.

First, the Participant Council met to review the measure concepts and the nominal group procedures. Second, we distributed an online survey to the Council and asked members to rate the importance of each measure concept on a 5-point scale ranging from not at all important to extremely important. We shared the average scores for each concept in a subsequent focus group and provided time for Council members to discuss and explain their perspectives about the importance of the

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concepts. Next, we asked Council members to rank each concept in terms of importance. Council members had 10 points to distribute across the concepts, with points assigned to the concepts they believed to be most important. They could assign 10 points to one concept or one point across 10 concepts. The results of the rating and ranking exercises and reviews of the focus group (Zoom teleconference software) informed the selection of the final concepts for instrument development and updates to the concept definitions.

Institutional Review Board

[blinded for review]’s IRB approved the protocol for selecting and defining concepts using the nominal group technique. Council members provided consent before participating. Continued participation in the Council was independent of their decision regarding research participation.

RESULTS

Determine Important Concepts

The Participant Council identified 21 concepts \across choice and control, community inclusion, and holistic health and functioning during its first meeting. Figure 1 lists the concepts across each step.

Gaps in HCBS Outcome Measurement Instruments

Our review of the HCBS instrument database identified 236 items from instruments related to the 21 concepts identified by the Council. The items from these instruments did not meet the criteria for any of the 21 concepts; therefore, we did not have adequate evidence to exclude any concepts based on our criteria alone. Table 1 summarizes results from the gap analysis. We learned that researchers at the University of Minnesota were developing quality measures for three of these concepts: choice and control over daily life, choice and control over services and support, and employment.[16] Therefore, we excluded these concepts to avoid duplication of effort, leaving 18 concepts for further consideration.

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Selection of Final Concepts

We shared these 18 concepts with the Participant Council for ranking and discussion. Results from the rating and ranking surveys are summarized in Figure 1. After the Council members who took part in the focus group ranked these 18 concepts, the full Council discussed the concept rankings. Some concepts were combined, as Council members believed that the original list represented various aspects of a single concept. For example, they viewed the concepts of community leadership, developing communities, volunteerism, community contribution, choice and control over communities of connection, and engagement with communities of choice as best represented by a single concept of community engagement. They believed that a combined concept reflects variation in how individuals may prefer to be engaged in communities. For example, some people may seek leadership roles, while some may seek to contribute to a community by volunteering, and yet others want to attend community events as participants. Additionally, Choice and Control over health -information and related accommodations was revised to Choice and Control over Healthcare and Health to reflect the discussion and definition from the Council.

One of the concepts not selected for development but which generated considerable discussion was the concept of safety. Several participants described this concept as being “weaponized” against people with disabilities, preventing them from living how they would choose and in conflict with the concept of dignity of risk. However, Council members recognized that safety may be a critical issue for some people, particularly for groups experiencing discrimination and exclusion. The Council viewed this concept to not be a person-centered outcome, but rather an aspect of care. Consequently, we selected nine concepts as priorities for development.

Definitions for Final Concepts

We developed definitions of each of the quality concepts prioritized by the Participant Council based on their input. We reviewed these definitions with the Council members, and revised definitions

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in accordance with their feedback. Seven of the nine concept areas address choice and control over aspects of life. Before defining specific concepts, the Council members discussed definitions of “choice and control.” Council members agreed that choice and control in HCBS should not mean a choice between narrow options not tailored to the individual. Rather, choice and control exists when “a person [is] free to make any decision they feasibly want to. . . Services should facilitate people making their own individual choices in the community.” This definition informed the specific concepts related to choice and control.

Choice and Control over Living Arrangement

Choice and control over living arrangements reflects the extent to which individuals have choice and control over the space where they live. A living arrangement includes the location and setting of where people live, who they live and share their space with, as well as how their space is used. It recognizes that people may value distinct aspects of a living arrangement, and their values may reflect their culture and background. Living arrangements include living alone or with others, and the type of communal setting. The living environment is distinct from the living arrangement and includes the attitudes and beliefs of others in a shared living environment as they affect the individual (e.g., cultural biases/prejudices). Individuals may consider the living environment as part of their choice of their living arrangements.

Dignity of Risk

Dignity of Risk is the level to which an individual makes and acts upon decisions, regardless of the risk that others believe such decisions pose. Dignity of risk includes receiving the information and support needed to assess risk and to act on the decisions one makes, even when others believe the decision is unwise. Dignity of risk incorporates situations that present a possible danger to oneself or others, and also includes pursuing goals that could be very promising, such as applying for a job or

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promotion, developing an emotional relationship, marrying, having a child, managing money, pursuing physically risky activities, and other activities. Dignity of risk reflects who has control of decision making.

Choice and Control Over How Time Is Spent

Choice and Control Over How Time is Spent reflects the extent to which an individual makes and acts upon choices about how to spend time, including the types of activities in which one engages and decisions to spend time in solitary activities. Control over how to spend time requires flexibility, such that a person can choose to do different activities at various times, as they prefer. It recognizes that some people like consistent schedules, while others prefer spontaneity in their routines.

Choice and Control over Money

Choice and Control over Money reflects the extent to which individuals make choices and have control over how their money is spent. Financial control may include having and exercising budget authority (i.e., control over how HCBS funds are allocated, including wages of staff, or decisions to purchase supplies); purchasing, owning, using, and selling goods or other assets; decisions over the appointment and direction of a financial power of attorney; and other decisions related to how one spends income and assets.

Choice and Control over Important Relationships

This concept is defined as the extent to which an individual makes and acts on choices about forming, maintaining and ending close, intimate relationships with individuals or communities of one’s choosing. Relationships may be physical, sexual, or emotional. They may be with friends, family, or workers. People also may have meaningful relationships with service animals or pets.

Choice and Control Over Personal Expression

This concept measures the extent to which an individual makes and acts on decisions about personal expression and style. That concept includes aspects such as how one dresses, decorates one’s living space, the music one listens to, how the person wears their hair, and other forms of personal

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expression. These choices may reflect one’s culture of origin, religion, sexual or gender identity, or other affiliations.

Choice and Control over Food and Nutrition

Like conversations that addressed several of the other concepts, discussion of diet and nutrition highlighted the importance of cultural identification. As one Council member said, “Sometimes we don't have a lot of control to the foods in our communities…dietary choices for communities of color [are] also significant issues.” That consideration is reflected in the definition developed by the Council members.

This concept is defined as the extent to which an individual makes and exercises choices about what and how much they eat. These choices may reflect health, financial, cultural, religious, political, or personal preferences. People should have choice and control even when others believe that foods may be unhealthy. People may receive information to assist with their choices but have the control to make unwise choices. These decisions are an expression of dignity of risk in diet and nutrition.

Community Engagement

Council members developed a concept of Community Engagement to combine several preliminary concepts. These included concepts of choice of communities of connection, engagement with communities or individuals, community leadership, community contribution, and developing communities. They combined these concepts because people may choose to engage in their communities in diverse ways, or to engage with different communities in distinct types of ways. As one Council member stated, “[community engagement is] kind of an aspirational goal, because when we are a part of a community, we take care of each other. When we’re actually responsible for our actions, but we also support other people in the community.”

Council members defined Community Engagement as the extent to which individuals are engaged with and integrated into communities of their choosing. Communities may be defined by culture, religion, sexuality, disability, or other shared interests or identities. The level and nature of

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engagement reflects individuals' preferences. Forms of engagement include developing communities, organizations, or activities; participating in the activities of a group; assuming a leadership role in a group; volunteering to contribute to a group's activities; developing and maintaining friendships; and other ways in which the person wishes to be engaged.

Choice and Control over Healthcare and Health

During discussions with the Council, the preliminary concept of "accessible health information and accommodation" evolved to become Choice and Control over Healthcare. While they deemed accessible information and accommodation to be important, Council members understood this information and accommodation as reflecting the structures and processes of care, rather than person-centered outcomes. The revised concept is defined as the extent to which HCBS consumers are enabled to make informed decisions about healthcare. People are enabled when they have information that is provided in accessible forms, and they can access resources such as physically accessible exam tables and testing equipment. People have the right to make choices about healthcare or to designate someone to assist in decision making. Decisions should not be made for them without their consent and meaningful input. While not specifically included in the concept definition, Council members discussed the importance of Choice and Control over Healthcare within a cultural context. "I also wanted to include [as part of this concept] non-traditional practices, historical practices from traditional healers or cultural healers…[Non-traditional] services are really important because we have such a diverse community."

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DISCUSSION

Importance of the HCBS Users' Voices

Members of the Participant Council identified nine concepts that are important to HCBS users for measuring the quality of nonmedical, person-centered HCBS outcomes after we provided a list of person-centered outcome-oriented measure topics. These concepts are aligned with NQF's framework for HCBS quality measurement. The nine concepts are choice and control over (1) living arrangement, (2) how time is spent, (3) money, (4) important relationships, (5) personal expression (6) food and nutrition, and (7) healthcare and health; as well as (8) dignity of risk; and (9) community engagement. The importance of choice and control reflects a cultural value on personal agency, personal freedom, self-expression, pursuit of happiness, and social mobility.

The HCBS Access Rule requires states to report HCBS quality measures with measures to be reviewed and updated every two years, in recognition of the evolving nature of HCBS quality measurement.[4] The initial HCBS measure set uses several data collection methods and sources, including CAHPS surveys, case management records, administrative data and NCI-AD and NCI-IDD surveys. The quality measure concepts covered by these data sources include choosing services, community inclusion, personal safety and respect, reliability and helpfulness of staff, staff listening and communicating well, transportation, unmet needs, documentation of a person-centered plan, risk assessment, facility admission, making choices in life, social connectedness, and respect for personal space. Beyond these measures, there is a need for additional nonmedical, person-centered, and outcome focused HCBS quality measures. Our study sought to close some of the gaps in concept coverage in existing measures. We brought the voice of HCBS users to this endeavor, identifying what HCBS outcomes are important for measurement. Once finalized, measures developed as part of this project could be important additions to this measure set, which should be reviewed and updated every two years.

Next Steps for Instrument Development

This study is the first step in a larger project that will develop item sets for each concept that operationalize measurement of these nine concepts. This first step identified and defined concepts important to HCBS consumers. Subsequent steps include development and testing of items sets for each concept, and assessing the validity, reliability, and feasibility of the items across multiple disability

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groups receiving HCBS. These steps include continued consultation with the Participant Council. Their input is essential to assuring that questions are person-centered and meaningful to the range of individuals who receive HCBS across waivers. Testing of the developed items sets includes cognitive testing to ensure that items are understood as intended. Pilot testing the item sets will allow us to evaluate reliability, validity, and feasibility across Medicaid waiver populations. We are guided throughout this work by the Participant Council. Future research is needed to evaluate how these item sets measure the quality of HCBS services, which would require consideration of exclusion criteria, risk-adjustment and reliability and validity at the provider or state level.[17]

Two limitations of the research to note are the limited number of participants on the Council, and development of only nine of the 18 concepts. The small size of the Council facilitated in-depth conversations, but the priorities identified by the group may not be generalizable. Future studies should engage a larger group of HCBS participants to confirm that the concepts reflect the priorities of a broader group of stakeholders. Due to limited resources, we were only able to develop half of the concepts. Future adoption by state agencies and HCBS providers would require successful pilot testing and industry consensus that these new measures reflect valued outcomes.

CONCLUSIONS

Quality measurement of HCBS is evolving. HCBS quality measurement should focus on whether services help improve outcomes that are meaningful to the person served. HCBS users identified priority measure concepts that focus on choice and control over several aspects of day-to-day life, as well as dignity of risk and community engagement. Continued research is needed - and is on-going - to operationalize these concepts.

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Declaration of Generative AI and AI-assisted technologies in the writing process

Authors did not use generative AI to develop the methodology, results, or production of this manuscript.

Table and Figure Legends

Figure 1. Important Concepts of Person-Centered Outcomes Identified by the Participant Council

Caption: This figure shows the conception selection process undergone with the project Participant Council. Each list of concepts outlines a step in the process, including the method(s) used and concepts that carried over into the next stage. The final list displays the final concepts to be developed and tested.

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Table 1. Gaps in HCBS Measurement Instrument Items

Gap Assessed	*Number of Items*
Person-Centered	58
Outcome-Focused	44
Person-Centered and Outcome Focused	34
Populations Tested*	
Intellectual and Developmental Disabilities	6
Age-Related Disability	6
Physical Disability	4
Mental Health Disability	3

Note. n= 236 items.
*Not all Instruments reported psychometric testing.

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REFERENCES CITED

1. Centers for Medicare and Medicaid Services. Home- and community-based services. Centers for Medicare & Medicaid Services. Accessed December 3, 2023, https://www.cms.gov/outreach-and-education/american-indian-alaska-native/aian/ltss-ta-center/info/hcbs
2. U.S. Congress. Americans with Disabilities Act, 1990. 42 USC 12101 et seq1990.
3. Ginsburg R.B. and the Supreme Court of the United States. Olmstead v. L.C. In: Court USS, editor. US Reports 527 US 581. Washington, DC1998.
4. Centers for Medicare and Medicaid Services. Ensuring Access to Medicaid Services Final Rule (CMS-2442-F). CMS,. Updated May 10, 2024. Accessed May 12, 2024, https://www.federalregister.gov/documents/2024/05/10/2024-08363/medicaid-program-ensuring-access-to-medicaid-services
5. National Quality Forum. Home and Community-Based Services Quality. National Quality Forum. Accessed May 12, 2024, https://www.qualityforum.org/ProjectDescription.aspx?projectID=77692
6. National Quality Forum. Person-centered Planning and Practice Final Report. Accessed December 3, 2023, http://www.qualityforum.org/Person_Centered_Planning_and_Practice.aspx
7. National Core Indicators. National Core Indicators - Aging and Disabilities. NCI-AD. Accessed May 12, 2024, https://nci-ad.org/
8. The Council on Quality and Leadership. Accreditation. Accessed October 26, 2023, https://www.c-q-l.org/accreditation
9. Centers for Medicare and Medicaid Services. CAHPS Home and Community-Based Services Survey. CMS. Accessed May 12, 2024, https://www.medicaid.gov/medicaid/quality-of-care/quality-of-care-performance-measurement/cahps-home-and-community-based-services-survey/index.html
10. National Center on Advancing Person-Centered Practices and Systems. Person-Centered Thinking, Planning, and Practice: A National Environmental Scan of Foundational Resources and Approaches.

Journal Pre-proof

Accessed March 4, 2023, https://ncapps.acl.gov/docs/NCAPPS_ResourcesApproaches_NationalEnvironmentalScan_December2019.pdf

11. Ryan RM, Deci EL. *Self-Determination Theory: Basic Psychological Needs in Motivation, Development, and Wellness*. Guilford Publications; 2018.
12. Reason P, Bradbury H. *The Sage Handbook of Action Research: Participative Inquiry and Practice*. 2nd ed. Sage; 2008.
13. National Quality Forum. Quality in Home and Community-Based Services to Support Community Living: Addressing Gaps in Performance Measurement Accessed January 17, 2024, https://www.qualityforum.org/Publications/2016/09/Quality_in_Home_and_Community-Based_Services_to_Support_Community_Living__Addressing_Gaps_in_Performance_Measurement.aspx
14. Donabedian A. *Explorations in Quality Assessment and Monitoring. Vol.1. The Definition of Quality and Approaches to Its Assessment*. vol 1. Health Administration Press; 1980.
15. Institute on Community Integration. Rehabilitation and Research Training Center on Outcome Measurement (RTC-OM) Website. University of Minnesota. https://rtcom.umn.edu/database
16. Roberts MA, Abery BH. A person-centered approach to home and community-based services outcome measurement. *Front Rehabil Sci*. 2023;4:1056530. doi:10.3389/fresc.2023.1056530
17. Partnership for Quality Measurement. Endorsement and Maintenance (E&M) Guidebook. Batelle. Accessed October 24, 2024, https://p4qm.org/sites/default/files/2024-08/Del-3-6-Endorsement-and-Maintenance-Guidebook-Final_0.pdf

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Concepts generated in first meeting	Concepts for NGT	Ranking position	Rating position	NGT Score (Combined)	Final Concepts Selected
Choice & Control Over Living Arrangement	Choice and control over living arrangement	1	1	81	Choice and control over living arrangement
Dignity of Risk	Dignity of risk	2	3	79	Dignity of risk
Choice & Control Over How Time Is Spent	Choice and control over how time is spent	3	5	72	Choice and control over how time is spent
Choice & Control Over finances	Choice and control over finances	4	4	72	Choice and control over finances
Choice & Control Over Personal Expression	Choice and control over personal expression	6	1	71	Choice and control over personal expression
Choice & Control Over Intimate Relationships	Choice and control of intimate relationships	5	7	68	Meaningful relationships
Meaningful Relationships	Meaningful relationships	8	5	66	
Accessible Health Information and Related Accommodations	Accessible health-information and related accommodations	9	8	63	Choice and Control Over Healthcare & Health
Choice & Control Over Food and Nutrition	Choice and control of diet and nutrition	7	13	61	Choice and control of diet and nutrition
Choice of Community of Connections	Choice and control over communities of connections	11	10	61	Community Engagement
Engagement with Communities or Individuals of Choice	Engagement with communities or individuals of choice	12	11	59	
Volunteerism	Volunteerism	12	16	53	
Community Leadership	Community leadership	12	17	52	
Community Contribution	Community contribution	17	14	52	
Developing Communities	Developing communities	18	18	44	
Safety	Safety	9	8	63	[redacted]
Wellbeing	Well-being	15	11	58	
Choice & Control Over Educational Opportunities	Choice and control over educational	16	14	54	
Choice & Control Over Services/Supports	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]
Employment	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]
Control Over Daily Life	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]

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