NATIONAL QUALITY FORUM
Driving measurable health improvements together

Memo

November 30, 2021

To: Consensus Standards Approval Committee (CSAC)

From: Patient Experience and Function Project Team

Re: Patient Experience and Function Spring 2021 Cycle

CSAC Action Required

The CSAC will review recommendations from the Patient Experience and Function project at its November 30 - December 1, 2021, meeting, and vote on whether to uphold the recommendations from the Committee.

This memo includes a summary of the project, measure recommendations, themes identified, responses to the public and member comments, and results from NQF member expression of support. The following document accompany this memo:

- **Patient Experience and Function Draft Report**. The draft report has been updated to reflect the changes made following the Standing Committee's discussion of public and member comments. The complete draft report and supplemental materials are available on the project webpage.

Background

Patient experience and function encompasses patient functional status, satisfaction, and experience of care, as well as issues related to care coordination. Central to the concepts associated with a patient's experience of their overall care is the patient's health-related quality of life and the factors influencing it, including communication, care coordination, transitions of care, and use of health information technology.

Appropriate service planning is a critical process for selecting and organizing the services and supports that an older adult or person with a disability may need to live in the community. Medicaid will cover home- and community-based services as an alternative to institutional living provided that a person-centered service plan is in place that addresses the beneficiary's long-term care needs.[1] Measuring the quality of such plans and the extent to which individuals' needs and priorities are addressed is a key priority.

During the spring 2021 cycle, the 24-person Patient Experience and Function Standing Committee reviewed one new measure against NQF's standard evaluation criteria: NQF #3622 *National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures*.

The Standing Committee recommended the following measure:

- **#3622** National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home and Community-Based Services (HCBS) Measures (Human Services Research Institute) (new)

Draft Report

The Patient Experience and Function draft report presents the results of the evaluation of one measure considered under the Consensus Development Process (CDP). This measure is recommended for endorsement.

The measures were evaluated against the 2019 version of the measure evaluation criteria.

Measures under Review	Maintenance	New	Total
Measures under review	0	1	1
Measures recommended for endorsement	0	1	1
Measures not recommended for endorsement or trial use	0	0	0
Reasons for not recommending	Importance – 0 Scientific Acceptability -0 Use - 0 Overall - 0 Competing Measure - 0	Importance - 0 Scientific Acceptability - 0 Use - 0 Overall - 0 Competing Measure - 0	0

CSAC Action Required

Pursuant to the CDP, the CSAC is asked to consider endorsement of one candidate measure.

Measures Recommended for Endorsement

- **#3622** National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home and Community-Based Services (HCBS) Measures (Human Services Research Institute)

  Overall Suitability for Endorsement: Yes-13; No-2 (denominator = 15)

Comments and Their Disposition

NQF received 13 comments from 13 organizations (including 0 member organizations) and individuals pertaining to the draft report and to the measures under review.

A narrative of comments submitted during the comment period, with the responses to each comment and the actions taken by the Standing Committee and measure developers, is posted to the Patient Experience and Function project webpage.

Comment Themes and Committee Responses

Comments about specific measure specifications and rationale were forwarded to the developers, who were invited to respond.

The Standing Committee reviewed all the submitted comments (general and measure specific) and developer responses. Committee members focused their discussion on measures or topic areas with the most significant and recurring issues.

Member Expression of Support

Throughout the 16-week continuous public commenting period, NQF members had the opportunity to express their support ('support' or 'do not support') for the measure submitted for endorsement consideration to inform the Committee's recommendations. No NQF members provided expressions of support or non-support. Appendix C details the expression of support

References

1 Home and Community Based Services | CMS. https://www.cms.gov/newsroom/fact-sheets/home-and-community-based-services. Last accessed November 2021.

Appendix A: CSAC Checklist

The table below lists the key considerations to inform the CSAC's review of the measures submitted for endorsement consideration.

Key Consideration	Yes/No	Notes
Were there any process concerns raised during the CDP project? If so, briefly explain.	No	*
Did the Standing Committee receive requests for reconsideration? If so, briefly explain.	No	*
Did the Standing Committee overturn any of the Scientific Methods Panel's ratings of Scientific Acceptability? If so, state the measure and why the measure was overturned.	Yes	The SMP was consensus not reached on validity. In their analysis, the SMP noted several issues regarding data element validity testing, including incomplete information and the structure of the measure. After reviewing the SMP's concerns, the developer's responses to the concerns, and a discussion on potential missing data and the use of proxies, the Standing Committee agreed the additional information provided by the developer indicated the measure was valid.
If a recommended measure is a related and/or competing measure, was a rationale provided for the Standing Committee's recommendation? If not, briefly explain.	Yes	*
Were any measurement gap areas addressed? If so, identify the areas.	Yes	This measure examines the use of home- and community-based services specifically by those with intellectual or developmental disabilities.
Are there additional concerns that require CSAC discussion? If so, briefly explain.	Yes	The Standing Committee was unable to achieve 50% attendance during the scheduled meeting time so a second meeting was scheduled. Sufficient attendance was also not achieved at the second meeting, so NQF conferred with the co-chairs and determined that the comment in question and the proposed Standing Committee response could be reviewed by the Standing Committee via email since there were no concerns being presented in the comment that had not been previously discussed by the Standing Committee.

* Cell left intentionally blank

Appendix B: Measures Not Recommended for Endorsement

The Patient Experience and Function Standing Committee recommended the candidate measure for endorsement.

Appendix C: NQF Member Expression of Support Results

No NQF members provided their expression of support or non-support.

Appendix D: Details of Measure Evaluation

Rating Scale: H=High; **M**=Moderate; **L**=Low; **I**=Insufficient; **NA**=Not Applicable; **Y**=Yes; **N**=No

Vote totals may differ between measure criteria and between measures as Standing Committee members often have to join calls late or leave calls early. NQF ensures that quorum is maintained for all live voting. All voting outcomes are calculated using the number of Standing Committee members present during the meeting for that vote as the denominator. Denominator vote counts may vary throughout the criteria due to intermittent Standing Committee attendance fluctuation. The vote totals reflect members present and eligible to vote at the time of the vote. Quorum (a minimum of 15 out of 22 active Standing Committee members present) was reached and maintained for the duration of the measure evaluation meeting.

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

Submission

Description: The National Core Indicators for Intellectual and Developmental Disabilities Home- and Community-Based Services Measures ("NCI for ID/DD HCBS Measures" hereafter) originate from the NCI(R) In-Person Survey (IPS), an annual, multistate, and cross-sectional survey of adult recipients of state developmental disabilities systems' supports and services. First developed in 1997 by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in collaboration with the Human Services Research Institute (HSRI), the main aims of NCI for ID/DD HCBS Measures were to evaluate person-reported outcomes and assess state developmental disabilities service systems performance in various domains and subdomains accordingly. The unit of analysis is "the state," and the accountable entity is the state-level entity responsible for providing and managing developmental disabilities services. Currently, 46 states and the District of Columbia are members of the NCI program. To align with member states' fiscal schedules, the annual survey cycle typically starts on July 1 and ends on June 30 of the following year.

Gathering subjective information and data from people with ID/DD poses unique challenges due to potential intellectual and developmental limitations experienced by the population. As such, extensive work went into the processes of developing NCI IPS administration methods, survey methodology, and measure design and revisions. The original development built on direct consultation with members of the target population and their advocates, as well as extensive literature review and testing.

The NCI for ID/DD HCBS Measures consist of 14 measures in total:

Five measures in the HCBS Domain: Person-Centered Planning (PCP) and Coordination

- #PCP-1 The proportion of people who express they want a job who have a related goal in their service plan (Community Job Goal)
- #PCP-2 The proportion of people who report their service plan includes things that are important to them (Person-Centered Goals)
- #PCP-3 The proportion of people who express they want to increase independence in functional skills (activities of daily living [ADLs]) who have a related goal in their service plan (ADL Goal)
- #PCP-4 The proportion of people who report they are supported to learn new things (Lifelong Learning)
- #PCP-5 The proportion of people who report satisfaction with the level of participation in community inclusion activities (Satisfaction With Community Inclusion Scale)

Four measures in the HCBS Domain: Community Inclusion

- #CI-1 The proportion of people who reported that they do not feel lonely often (Social Connectedness)
- #CI-2 The proportion of people who reported that they have friends who are not staff or family members (Has Friends)
- #CI-3 The proportion of people who report adequate transportation (Transportation Availability Scale)

- #CI-4 The proportion of people who engage in activities outside the home (Community Inclusion Scale)

Four measures in the HCBS Domain: Choice and Control

- #CC-1 The proportion of people who reported they chose or were aware they could request to change their staff (Chose Staff)
- #CC-2 The proportion of people who reported they could change their case manager/service coordinator (Can Change Case Manager)
- #CC-3 The proportion of people who live with others who report they can stay home if they choose when others in their house/home go somewhere (Can Stay Home When Others Leave)
- #CC-4 The proportion of people who report making choices (independently or with help) in life decisions (Life Decisions Scale)

One measure in the HCBS Domain: Human and Legal Rights

- #HLR-1 The proportion of people who report that their personal space is respected in the home (Respect for Personal Space Scale)

Numerator Statement: The NCI for ID/DD HCBS Measures use values between 0 and 1 as the scores. Typically, the numerator is the number of respondents who selected the most positive response category (e.g., "yes", "always"). The attached file SuppTable_Measures_210420_508.xlsx lists what constituted the most positive response categories for each measure item, as well as other detailed information as relevant for S.2b.

Denominator Statement: For each measure, the denominator is the number of respondents (i.e., adult recipients of state developmental disabilities services) who provided valid answers to the respective survey question, except those that meet the exclusion criteria (see S.8. below for details).

If the denominator for a state is fewer than 20, the measure score is censored to protect the confidentiality of respondents.

Exclusions: At the end of Section I, the surveyor assesses whether the respondent appears to understand at least one question and answers in a cohesive manner. This assessment is the only subjective process in the exclusion determination process, but it is not done on an arbitrary or state-by-state basis. Rather, it is based on a protocol, included in the survey manual and reviewed during surveyor trainings, that apply uniformly to all surveyors across different participating states. The protocol is straightforward—the section must be marked “valid” if at least one question in the section was answered in a manner that the basic level of comprehension was shown, and a clear response given either verbally (e.g., yes/no) or nonverbally (nodding/shaking head). NCI and participating states routinely conduct surveyor training and surveyor shadowing and reviewing processes that ensure, among other things, that surveyors are applying this assessment (whether or not Section I was valid) strictly based on the protocol. If the surveyor´s assessment is that Section I is not valid, the respondent´s Section I data are flagged for exclusion from the numerators and denominators. However, the individual is not removed from the data set.

If Section I data are excluded, Section II data are flagged for exclusion from the numerators and denominators, unless a proxy respondent was used in Section II. If the respondent or proxy did not answer any questions in Section II, the survey is removed from the denominators of Section II items.

Responses are excluded from numerators and denominators for Section I items if:

(a) the surveyor indicated that the respondent did not give consistent and valid responses; or

(b) all questions in Section I were left blank or marked "not applicable" or "don’t know".

Responses are excluded from numerators and denominators for Section II items if:

(a) the individual receiving supports was marked as the sole respondent to all questions in Section II, but Section I was deemed invalid; or

(b) all questions in Section II were left blank or marked "not applicable" or "don’t know".

For each measure item, missing responses and responses indicating "not applicable" or "don’t know" were excluded from denominators. The distribution of exclusions among states is shown in Testing Attachment 2b2.2. Please see S.9. for more details on denominator exclusions.

Adjustment/Stratification: Other Statistical risk model and stratification. Risk-adjusted Life Decisions and Community Inclusion Scales are further stratified by 5 residential setting categories:

Category #1 - Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID), nursing facility, or other institutional setting

Category #2 - Group residential setting (e.g., group home)

Category #3 - Own home or apartment

Category #4 - Parents' or relatives' home

Category #5 - Foster care or host home

There are both conceptual/policy and empirical reasons for this stratification. Conceptually, the need for types and mixes of HCBS supports vary by residential setting, impacting the interpretation and program/policy implications of outcomes. Providing scores for each residential setting separately provides states with meaningful information about the outcomes of these different service/support strategies, offering detailed, actionable recommendations for improvement. Further, risk-adjusted measures significantly vary by residential setting, providing empirical support for the informational value of reporting these measures separately for the 5 settings.

The constructed variable, res_type5, was used as the stratification variable. Res_type5 is recoded from background information (administrative records) variable TYPEHOME18, Type of Residence.

The included response TYPEHOME18 categories were:

res_type5 category #1 - ICF/IID, nursing facility or other institutional setting:

1. ICF/IID, 4-6 residents with disabilities
2. ICF/IID, 7-15 residents with disabilities
3. ICF/IID, 16 or more residents with disabilities
4. Nursing facility
5. Other specialized institutional facility
6. res_type5 category #2 - Group residential setting
7. Group living setting, 2-3 people with disabilities
8. Group living setting, 4-6 people with disabilities
9. Group living setting, 7-15 people with disabilities
10. res_type5 category #3 - Own home or apartment
11. Lives in own home or apartment; may be owned or rented, or may be sharing with roommate(s) or spouse
12. res_type5 category #4 - Parent/relative's home
13. Parent/relative's home (may include paid services to family for residential supports)
14. res_type5 category #5 - Foster or host home
15. Foster care or host home (round-the-clock services provided in a single-family residence where two or more people with a disability live with a person or family who furnishes services)
16. Foster care or host home (round-the-clock services provided in a single-family residence where only one person with a disability lives with a person or family who furnishes services—sometimes called shared living); Other

The TYPEHOME18 categories excluded from res_type5 were:

13. Homeless or crisis bed placement
14. Other (specify):____
99. Don't know

Level of Analysis: Population: Regional and State

Setting of Care: Other

Type of Measure: Outcome: PRO-PM

Data Source: Instrument-Based Data

Measure Steward: Human Services Research Institute

STANDING COMMITTEE MEETING June 30, 2021

1. Importance to Measure and Report: <u>The measure meets the Importance criteria.</u>

(1a. Evidence, 1b. Performance Gap)

1a. Evidence**: Total votes=15; Y-14; N-1**; 1b. Performance Gap: **Total votes= 15; H-3**; **M-10**; **L-2**; **I-0**

Rationale

- The Standing Committee noted that while the evidence varied across the 14 components of the measures, overall, the evidence demonstrated the measure was meaningful to measure, and reporting of NCI-submitted measures across various states and regions can lead to improved outcomes for HCBS recipients.
- The Standing Committee expressed concern with the wide variation among performance gap for the 14 components and between states. While the performance gap for certain components and some states was low, some components and/or states were performing very well. The Standing Committee questioned whether this measure was needed when some components and/or states could potentially be "topped out" and unable to improve further. The Standing Committee also noted that the differences between racial and ethnic groups were relatively minor and did not necessarily imply that a gap existed.
- The developer noted that due to the structure of the measure and the natural variation between states, this variation is expected and will continue to evaluate the measure for potential improvements.
- The Standing Committee agreed this level of variation was acceptable, and the measure passed on performance gap.

2. Scientific Acceptability of Measure Properties: <u>The measure meets the Scientific Acceptability criteria.</u>

(2a. Reliability - precise specifications, testing; 2b. Validity - testing, threats to validity)

2a. Reliability: **Total votes: 15; Y-15**; **N-0 (Accept SMP moderate rating);** 2b. Validity: **Total votes: 15; H-2**; **M-11**; **L-1**; **I-1**

Rationale

- This measure was reviewed by the Scientific Methods Panel (SMP). It passed with a moderate rating on reliability (Total votes: 9; H-3, M-3, L-2, I-1), but did not reach consensus on validity (Total votes: 7; H-0, M-4, L-0, I-3).
- The Standing Committee noted that reliability testing was conducted at the data element level through multiple data element analyses, some from previous work conducted, and others based on a relatively recent sample of In-Person Surveys (IPS) of the National Core Indicators (NCI). The sample includes 37 states and a total of 22,000 completed surveys.
- Reliability testing was also conducted at the score level through an analysis of variance (ANOVA) to assess between-state variance in relationship to within-state variance and assessed inter-unit reliability (IUR).
- The Standing Committee expressed concerns regarding whether the samples were representative of state-to-state and racial/ethnical differences. One member questioned why each state must have a sample size that will support a 95 percent confidence interval with a 5 percent margin of error. The developer explained that this sample size requirement was created based on the state's service populations and assisted with removing the potential for skewing the results due to sample size issues, thus making the sample representative of the populations they were evaluating.
- The Standing Committee also questioned whether the developer had observed any trends among the 37 participating states. The developer noted that the participating states varied each year, and certain states only participate every few years either due to budgetary issues or other logistical issues. A total of 47 states were members that participated at their own desired interval. The developer cautioned against using the 37 states to represent the whole nation due to this result and stated that the information gathered would assist in better understanding how the service systems are doing across the country.
- The Standing Committee ultimately accepted the SMP's reliability vote of moderate (Total votes: 15; Y-15; N-0)
- The Standing Committee noted that validity testing was conducted at the data element level using seven studies that investigated the relationships among NCI data elements and testing

hypotheses about expected associations and at the measure score level through a Pearson Product Moment Correlation Coefficient.

- The SMP was unable to reach consensus on validity (Total votes: 7; H-0, M-4, L-0, I-3). In their preliminary analyses, the SMP noted that the submission was incomplete in the data element validity testing, as the developer had only listed references to studies without appropriately summarizing their results; hence, the SMP reviewers did not conduct a data element validity evaluation. It was noted that none of the risk factors for this risk-adjusted measure were tested. Furthermore, the SMP noted the developer's testing of performance score validity at the state level was not optimal because all of the constructs are estimated based on the same survey, suggesting that any validity issues that affect the entire survey in a consistent manner are likely to lead to exaggerated correlations.
- In response to the SMP's feedback, the developer reported results of a confirmatory factor analysis evaluating the factor structure of the five multi-item measures, with results indicating that the data fit well. The developer also expanded their presented analysis to include external measures of quality (not just between the 14 survey items) with results that were directionally appropriate, statistically significant, and of moderate to high strength in the association.
- The Standing Committee expressed concerns about states selecting only the best results to share. The developer noted that survey strategies in the states are designed by third parties through workplans. This precludes states from picking successful sites or programs for interviewing.
- The Standing Committee noted that the measure's skip pattern could lead to missing data. The developer replied that the different components of the measure may have different response rates, thus leading to missing data; however, deleting responses would be discounting the person's voice for the sake of consistency.
- The Standing Committee requested more information on the use of proxies to respond to questions. The developer noted proxies were only allowed for section 1 of the survey, which was more subjective. Section 2, which was more factual, had to be filled out by the actual patient. The developer further clarified that follow-up questions were asked as needed, and the proxy was documented.
- The Standing Committee agreed the additional information provided by the developer indicated that the measure was valid and passed the measure on the validity criterion (Total votes: 15; H-2; M-11; L-1; I-1).

3. Feasibility: Total votes = 15; H-2; M-8; L-4; I-1

(3a. Clinical data generated during care delivery; 3b. Electronic sources; 3c. Susceptibility to inaccuracies/ unintended consequences identified 3d. Data collection strategy can be implemented)

Rationale

- The Standing Committee noted challenges with feasibility, including challenges with data collection for the 38 states collecting NCI data for ID/DD HCBS measures and data confidentiality/data access for states that are under contract with external administrative entities as well as sample identification challenges facing states that elect to oversample or stratify data by population. However, most states reported that the identified challenges had been overcome once processes and protocols were established and subsequently repeated.
- The Standing Committee inquired about the annual membership fee of $15,000 and an unspecified cost for data access. The developer clarified the annual membership fee was for states, and they would have access to their data without any additional fees. The data access fee was for institutions that would like to use the data for research purposes.
- The Standing Committee emphasized that potential burden could not be the only reason to not endorse a measure that would be filling an important gap and agreed the measure was feasible.

4. Use and Usability

(4a. Use; 4a1. Accountability and transparency; 4a2. Feedback on the measure by those being measured and others; 4b. Usability; 4b1. Improvement; 4b2. The benefits to patients outweigh evidence of unintended negative consequences to patients)

4a**. Use: total votes = 15; Pass-12; No Pass-3** 4b. Usability: **Total votes = 15; H-2; M-9; L-2; I-2**

Rationale

- The Standing Committee noted that the measure was currently in use in several programs, including the Medicaid Adult Core Health Care Quality Measure Set, Connecticut Medicaid 1915(c) HCBS Waiver Assurances, Indiana Family and Social Services Administration Medicaid 1915(c) HCBS Waiver Assurances, Arizona Community and Supported Employment initiatives, Massachusetts Department of Developmental Services programs, and the Kentucky Division of Developmental and Intellectual Disabilities programs.
- The Standing Committee also noted that users of the measure were able to provide feedback and had provided generally positive feedback so far.
- The Standing Committee highlighted that the data demonstrated increased state- and user-level engagement and that no unintended consequences had been identified.
- The Standing Committee agreed the measure was in use and usable.

5. Related and Competing Measures

- One measure was identified as related:
    - #2967 CAHPS® Home- and Community-Based Services Measures
- The Standing Committee did not express any concerns with the relationship between this measure and the measure under review.

6. Standing Committee Recommendation for Endorsement: **Total votes = 15; Y-13**; **N-2**

7. Public and Member Comment

- Ten public comments received were supportive of the measure. Two comments were supportive of the measure and contained suggestions for future improvements to the PROM. One comment was supportive of the measure and contained suggestions for the PROM, as well as expressing concerns with one element of the measure to which the Standing Committee responded:
    - "The Standing Committee thanks the commenter for their comment and accepts the response provided by the measure developer. The residential categorization of concern is explained in full in the measure submission and accounts for unrepresented response options. The Standing Committee also had questions about feasibility and diversity in the sample population and discussed these items at length during the measure evaluation meeting. In evaluating these measures against NQF's endorsement criteria, the Standing Committee agreed the measure fills an important measurement gap and meets all NQF criteria. The Standing Committee ultimately recommends this measure for endorsement."

8. Consensus Standards Approval Committee (CSAC) Vote: Y-X; N-X

9. Appeals

Patient Experience and Function Spring 2021 Review Cycle

CSAC Review

November 30 – December 1, 2021
Funded by the Centers for Medicare & Medicaid Services under contract HHSM-500-2017-00060I Task Order HHSM-500-T0001

NATIONAL QUALITY FORUM
Driving measurable health improvements together

Patient Experience and Function Standing Committee Recommendations

- **One measure reviewed for Spring 2021**
  - **One measure reviewed by the Scientific Methods Panel**
    - **#3622** passed SMP on reliability. SMP did not reach consensus on validity
- **One measure recommended for endorsement**
  - **#3622** National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home and Community-Based Services (HCBS) Measures (Human Services Research Institute) (new)

Patient Experience and Function: Public and Member Comment and Member Expressions of Support

- 13 comments received for **#3622** National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home and Community-Based Services (HCBS) Measures (Human Services Research Institute)
  - 10 in support of measure under review
  - Two comments were supportive of the measure but contained future suggestions for improving the PROM
  - One comment was supportive and included suggestions for improving the PROM and one comment for the Standing Committee to consider

- No NQF members provided expressions of support or non-support

NATIONAL QUALITY FORUM
Driving measurable health improvements together

Patient Experience and Function Team Contact Information

- NQF Project Team:
  - Tamara H. Funk, MPH, Director
  - Erin Buchanan, MPH, Manager
  - Yemsrach Kidane, PMP, Project Manager
  - Hannah Ingber, MPH, Senior Analyst
  - Sean Sullivan, MA, Coordinator
- Project Webpage: https://www.qualityforum.org/Patient_Experience_and_Function.aspx
- Project email address: patientexperience@qualityforum.org

NATIONAL QUALITY FORUM
Driving measurable health improvements together

Patient Experience and Function, Spring 2021 Cycle: CDP Report

DRAFT REPORT FOR CSAC REVIEW
AUGUST 19, 2021

This report is funded by the Centers for Medicare & Medicaid Services under contract HHSM-500-2017-00060I Task Order HHSM-500-TO001.

https://www.qualityforum.org

Content

Executive Summary

Patient experience and function (PEF) is an important measure topic area that encompasses patient functional status, satisfaction, and experience of care, as well as issues related to care coordination. Central to the concepts associated with patient experience with their overall care is the patient's health-related quality of life (HRQoL) and the factors influencing it, including communication, care coordination, transitions of care, and use of health information technology (IT).

The National Quality Forum (NQF) PEF Standing Committee was established to evaluate measures within this topic area for NQF endorsement. NQF has 50 endorsed measures in the PEF portfolio addressing patient assessments of care, mobility and self-care, shared decision making, patient activation, and care coordination. Most of the measures within this portfolio are patient-reported outcome performance measures (PRO-PMs), including measures of patient experience, patient satisfaction, and functional status.

The Standing Committee reviewed one new measure during the spring 2021 cycle against NQF's standard evaluation criteria: NQF #3622 *National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures*. The Standing Committee recommended the measure for endorsement.

A brief summary of the measure currently under review is included in the body of the report; a detailed summary of the Standing Committee's discussion and ratings of the criteria for each measure is in Appendix A.

Introduction

Patient experience and function is a critical topic area that includes quality metrics associated with patient satisfaction and experience of care, patient-reported outcome measures (PROMs), and care coordination. While it is a desirable outcome unto itself, positive patient experience of care has also shown to be associated with other positive clinical outcomes.[1,2] This led the United States (U.S.) healthcare system to increasingly embrace the idea of ensuring each person and family is engaged within a care partnership, which is critical to achieving better patient outcomes.[3] Care coordination measures also signify an important element needed for the success of this integrated approach. Care coordination spans the continuum of care and promotes quality care delivery, better patient experiences, and more meaningful outcomes.[4–6] Well-coordinated care includes effective communication among all patients and providers across the care spectrum and ensures accountable structures and processes are in place for the integration of comprehensive plans of care across providers and settings.[7–9]

NQF Portfolio of Performance Measures for Patient Experience and Function Conditions

The PEF Standing Committee (Appendix C) oversees NQF's portfolio of Patient Experience and Function measures (Appendix B), which includes measures for functional status, communication, shared decision making, care coordination, patient experience, and long-term services and supports. This portfolio contains 50 measures: four process measures, one composite measure, and 45 outcome measures, of which 27 are PRO-PMs (see table below).

Table 1. NQF Patient Experience and Function Portfolio of Measures

	Process	Outcome/Resource Use	Composite
Functional Status Change and Assessment	2	23	0
Shared Decision Making	0	3	0
Care Coordination	2	5	0
Patient Experience	0	10	1
Long-Term Services and Supports	0	4	0
Total	4	45	1

Additional measures have been assigned to other portfolios. These include healthcare-associated infection measures (Patient Safety), care coordination measures (Geriatrics and Palliative Care), imaging efficiency measures (Cost and Efficiency), and a variety of condition- or procedure-specific outcome measures (Cardiovascular, Cancer, Renal, etc.).

Patient Experience and Function Measure Evaluation

On June 30, 2021, the PEF Standing Committee evaluated one new measure against NQF's standard measure evaluation criteria.

Table 2. Patient Experience and Function Measure Evaluation Summary

Measure Summary	Maintenance	New	Total
Measures under consideration	0	1	1
Measures recommended for endorsement	0	1	1

Comments Received Prior to Standing Committee Evaluation

NQF accepts comments on endorsed measures on an ongoing basis through the Quality Positioning System (QPS). In addition, NQF solicits comments for a continuous 16-week period during each evaluation cycle via an online tool located on the project webpage. For this evaluation cycle, the commenting period opened on April 30, 2021, and closed on September 20, 2021. As of June 10, no comments were submitted and shared with the Standing Committee prior to the measure evaluation meeting (Appendix F).

Comments Received After Committee Evaluation

The continuous 16-week public commenting period with NQF member support closed on September 17, 2021. Following the Committee's evaluation of the measures under review, NQF received 13 comments from 12 organizations (including zero member organizations) and individuals pertaining to the draft report and to the measures under review (Appendix G). All comments for each measure under review have also been summarized in Appendix A.

Throughout the 16-week continuous public commenting period, NQF members had the opportunity to express their support ("support" or "do not support") for each measure submitted for endorsement consideration to inform the Committee's recommendations during the commenting period. This expression of support (or not) during the commenting period replaces the member voting opportunity that was previously held subsequent to committee deliberations no NQF members expressed that they are in support of the measure. This information can be found in Appendix A of the post comment memo.

Summary of Measure Evaluation

The following brief summary of the measure evaluation highlights the major issues that the Standing Committee considered. Details of the Standing Committee's discussion and ratings of the criteria for the measure are included in Appendix A.

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures (Human Services Research Institute): Recommended

Description: The National Core Indicators for Intellectual and Developmental Disabilities Home- and Community-Based Services Measures ("NCI for ID/DD HCBS Measures" hereafter) originate from the NCI(R) In-Person Survey (IPS), an annual, multistate, and cross-sectional survey of adult recipients of state developmental disabilities systems' supports and services. First developed in 1997 by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in collaboration with the Human Services Research Institute (HSRI), the main aims of NCI for ID/DD HCBS Measures were to evaluate person-reported outcomes and assess state developmental disabilities service systems performance in various domains and subdomains accordingly. The unit of analysis is "the state," and the accountable entity is the state-level entity responsible for providing and managing developmental disabilities services. Currently, 46 states and the District of Columbia are members of the NCI program. To align with member states' fiscal schedules, the annual survey cycle typically starts on July 1 and ends on June 30 of the following year. Gathering subjective information and data from people with ID/DD poses unique challenges due to potential intellectual and developmental limitations experienced by the population. As such, extensive work went into the processes of developing NCI IPS administration methods, survey methodology, and measure design and revisions. The original development built on direct consultation with members of the target population and their advocates, as well as extensive literature review and testing. The NCI for ID/DD HCBS Measures consist of 14 measures in total:

Five measures in the HCBS Domain: Person-Centered Planning (PCP) and Coordination

- #PCP-1 The proportion of people who express they want a job who have a related goal in their service plan (Community Job Goal)
- #PCP-2 The proportion of people who report their service plan includes things that are important to them (Person-Centered Goals)
- #PCP-3 The proportion of people who express they want to increase independence in functional skills (activities of daily living [ADLs]) who have a related goal in their service plan (ADL Goal)
- #PCP-4 The proportion of people who report they are supported to learn new things (Lifelong Learning)
- #PCP-5 The proportion of people who report satisfaction with the level of participation in community inclusion activities (Satisfaction With Community Inclusion Scale)

Four measures in the HCBS Domain: Community Inclusion

- #CI-1 The proportion of people who reported that they do not feel lonely often (Social Connectedness)
- #CI-2 The proportion of people who reported that they have friends who are not staff or family members (Has Friends)
- #CI-3 The proportion of people who report adequate transportation (Transportation Availability Scale)
- #CI-4 The proportion of people who engage in activities outside the home (Community Inclusion Scale)

Four measures in the HCBS Domain: Choice and Control

- #CC-1 The proportion of people who reported they chose or were aware they could request to change their staff (Chose Staff)
- #CC-2 The proportion of people who reported they could change their case manager/service coordinator (Can Change Case Manager)
- #CC-3 The proportion of people who live with others who report they can stay home if they choose when others in their house/home go somewhere (Can Stay Home When Others Leave)
- #CC-4 The proportion of people who report making choices (independently or with help) in life decisions (Life Decisions Scale)

One measure in the HCBS Domain: Human and Legal Rights

- #HLR-1 The proportion of people who report that their personal space is respected in the home (Respect for Personal Space Scale)

Measure Type: Outcome: PRO-PM; **Level of Analysis**: Population: Regional and State; **Setting of Care**: Other; **Data Source**: Instrument-Based Data

This is a new outcome PRO-PM measure at the population (i.e., regional and state) level that aims to assess the performance of ID/DD HCBS Measures in various domains and sub-domains based on the NCI. The Standing Committee noted that evidence varied across the 14 components of the measures; nonetheless, there was sufficient evidence to support this measure. The Standing Committee also expressed concern with the wide variation among performance gap for the 14 components and between states, with some components/states performing well and others not performing as well. The Standing Committee questioned whether this measure was needed if some components and/or states could potentially be "topped out" and unable to improve further. The developer noted that due to the structure of the measure and the natural variation between states, this variation is expected, and they will continue to evaluate the measure for potential improvements. The Standing Committee passed the measure on the performance gap criterion based on this feedback. The Scientific Methods Panel (SMP) reviewed this measure and passed it with a moderate rating but did not reach consensus on validity. The Standing Committee expressed concerns regarding whether the samples were representative of state-to-state and racial/ethnical differences. Following a discussion on sample size requirements and any observable trends on commonalities between the states that were not doing well, the Standing Committee accepted the SMP's reliability vote of moderate. In their preliminary analyses, the SMP noted several issues regarding data element validity testing, including incomplete information and the structure of the measure. After reviewing the SMP's concerns, the developer's responses to the concerns, and a discussion on potential missing data and the use of proxies, the Standing Committee agreed the additional information provided by the developer indicated the measure was valid. The Standing Committee noted some implementation challenges pertaining to the potential burden of data collection and fees associated with the data; nevertheless, it agreed the measure was feasible, in use, and usable. Ultimately, the measure was recommended for endorsement.

NQF attempted to hold the post-comment call on October 20 and again on October 25 but did not achieve sufficient Standing Committee attendance either day to hold the meeting. Instead, the Standing Committee reviewed and responded to one comment that contained concerns via email and determined that all items of concern had been thoroughly discussed by the Standing Committee during the measure evaluation meeting. The Standing Committee's response to this comment is contained in Appendix G.

References

1 Manary MP, Boulding W, Staelin R, et al. The Patient Experience and Health Outcomes. *N Engl J Med*. 2013;368(3):201-203.

2 Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open*. 2013;3(1):e001570.

3 Majid U. The Dimensions of Tokenism in Patient and Family Engagement: A Concept Analysis of the Literature. *J Patient Exp*. 2020;7(6):1610-1620.

4 Tricco AC, Antony J, Ivers NM, et al. Effectiveness of quality improvement strategies for coordination of care to reduce use of health care services: a systematic review and meta-analysis. *CMAJ*. 2014;186(15):E568-E578.

5 Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems. *Pediatrics*. 2014;133(5):e1451-e1460.

6 Pronovost P, Weast B, Schwarz M, et al. Medication reconciliation: a practical tool to reduce the risk of medication errors. *J Crit Care*. 2003;18(4):201-205.

7 Gnanasakthy A, Mordin M, Evans E, et al. A Review of Patient-Reported Outcome Labeling in the United States (2011-2015). *Value Health*. 2017;20(3):420-429.

8 Shay LA, Lafata JE. Where is the evidence? A systematic review of shared decision making and patient outcomes. *Med Decis Making*. 2015;35(1):114-131.

9 Berkowitz SA, Parashuram S, Rowan K, et al. Association of a Care Coordination Model With Health Care Costs and Utilization: The Johns Hopkins Community Health Partnership (J-CHiP). *JAMA Netw Open*. 2018;1(7):e184273.

Appendix A: Details of Measure Evaluation

Rating Scale: H=High; **M**=Moderate; **L**=Low; **I**=Insufficient; **NA**=Not Applicable

Note: Vote totals may differ between measure criteria and between measures as Standing Committee members often have to join calls late or leave calls early. NQF ensures that quorum is maintained for all live voting. All voting outcomes are calculated using the number of Standing Committee members present for that vote as the denominator. Quorum (15 out of 22 Standing Committee members) was reached and maintenance during the measure evaluation meeting.

Measures Recommended

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

Measure Worksheet | Specifications

Description: The National Core Indicators for Intellectual and Developmental Disabilities Home- and Community-Based Services Measures ("NCI for ID/DD HCBS Measures" hereafter) originate from the NCI(R) In-Person Survey (IPS), an annual, multistate, and cross-sectional survey of adult recipients of state developmental disabilities systems' supports and services. First developed in 1997 by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in collaboration with the Human Services Research Institute (HSRI), the main aims of NCI for ID/DD HCBS Measures were to evaluate person-reported outcomes and assess state developmental disabilities service systems performance in various domains and subdomains accordingly. The unit of analysis is "the state," and the accountable entity is the state-level entity responsible for providing and managing developmental disabilities services. Currently, 46 states and the District of Columbia are members of the NCI program. To align with member states' fiscal schedules, the annual survey cycle typically starts on July 1 and ends on June 30 of the following year.

Gathering subjective information and data from people with ID/DD poses unique challenges due to potential intellectual and developmental limitations experienced by the population. As such, extensive work went into the processes of developing NCI IPS administration methods, survey methodology, and measure design and revisions. The original development built on direct consultation with members of the target population and their advocates, as well as extensive literature review and testing.

The NCI for ID/DD HCBS Measures consist of 14 measures in total:

Five measures in the HCBS Domain: Person-Centered Planning (PCP) and Coordination

- #PCP-1 The proportion of people who express they want a job who have a related goal in their service plan (Community Job Goal)
- #PCP-2 The proportion of people who report their service plan includes things that are important to them (Person-Centered Goals)
- #PCP-3 The proportion of people who express they want to increase independence in functional skills (activities of daily living [ADLs]) who have a related goal in their service plan (ADL Goal)
- #PCP-4 The proportion of people who report they are supported to learn new things (Lifelong Learning)
- #PCP-5 The proportion of people who report satisfaction with the level of participation in community inclusion activities (Satisfaction With Community Inclusion Scale)

Four measures in the HCBS Domain: Community Inclusion

- #CI-1 The proportion of people who reported that they do not feel lonely often (Social Connectedness)
- #CI-2 The proportion of people who reported that they have friends who are not staff or family members (Has Friends)

- #CI-3 The proportion of people who report adequate transportation (Transportation Availability Scale)
- #CI-4 The proportion of people who engage in activities outside the home (Community Inclusion Scale)

Four measures in the HCBS Domain: Choice and Control

- #CC-1 The proportion of people who reported they chose or were aware they could request to change their staff (Chose Staff)
- #CC-2 The proportion of people who reported they could change their case manager/service coordinator (Can Change Case Manager)
- #CC-3 The proportion of people who live with others who report they can stay home if they choose when others in their house/home go somewhere (Can Stay Home When Others Leave)
- #CC-4 The proportion of people who report making choices (independently or with help) in life decisions (Life Decisions Scale)

One measure in the HCBS Domain: Human and Legal Rights

- #HLR-1 The proportion of people who report that their personal space is respected in the home (Respect for Personal Space Scale)

Numerator Statement: The NCI for ID/DD HCBS Measures use values between 0 and 1 as the scores. Typically, the numerator is the number of respondents who selected the most positive response category (e.g., "yes", "always"). The attached file SuppTable_Measures_210420_508.xlsx lists what constituted the most positive response categories for each measure item, as well as other detailed information as relevant for S.2b.

Denominator Statement: For each measure, the denominator is the number of respondents (i.e., adult recipients of state developmental disabilities services) who provided valid answers to the respective survey question, except those that meet the exclusion criteria (see S.8. below for details).

If the denominator for a state is fewer than 20, the measure score is censored to protect the confidentiality of respondents.

Exclusions: At the end of Section I, the surveyor assesses whether the respondent appears to understand at least one question and answers in a cohesive manner. This assessment is the only subjective process in the exclusion determination process, but it is not done on an arbitrary or state-by-state basis. Rather, it is based on a protocol, included in the survey manual and reviewed during surveyor trainings, that apply uniformly to all surveyors across different participating states. The protocol is straightforward—the section must be marked “valid” if at least one question in the section was answered in a manner that the basic level of comprehension was shown, and a clear response given either verbally (e.g., yes/no) or nonverbally (nodding/shaking head). NCI and participating states routinely conduct surveyor training and surveyor shadowing and reviewing processes that ensure, among other things, that surveyors are applying this assessment (whether or not Section I was valid) strictly based on the protocol. If the surveyor´s assessment is that Section I is not valid, the respondent´s Section I data are flagged for exclusion from the numerators and denominators. However, the individual is not removed from the data set.

If Section I data are excluded, Section II data are flagged for exclusion from the numerators and denominators, unless a proxy respondent was used in Section II. If the respondent or proxy did not answer any questions in Section II, the survey is removed from the denominators of Section II items.

Responses are excluded from numerators and denominators for Section I items if:

(a) the surveyor indicated that the respondent did not give consistent and valid responses; or

(b) all questions in Section I were left blank or marked "not applicable" or "don’t know".

Responses are excluded from numerators and denominators for Section II items if:

(a) the individual receiving supports was marked as the sole respondent to all questions in Section II, but Section I was deemed invalid; or

(b) all questions in Section II were left blank or marked "not applicable" or "don’t know".

For each measure item, missing responses and responses indicating "not applicable" or "don't know" were excluded from denominators. The distribution of exclusions among states is shown in Testing Attachment 2b2.2. Please see S.9. for more details on denominator exclusions.

Adjustment/Stratification: Other Statistical risk model and stratification. Risk-adjusted Life Decisions and Community Inclusion Scales are further stratified by 5 residential setting categories:

Category #1 - Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID), nursing facility, or other institutional setting

Category #2 - Group residential setting (e.g., group home)

Category #3 - Own home or apartment

Category #4 - Parents' or relatives' home

Category #5 - Foster care or host home

There are both conceptual/policy and empirical reasons for this stratification. Conceptually, the need for types and mixes of HCBS supports vary by residential setting, impacting the interpretation and program/policy implications of outcomes. Providing scores for each residential setting separately provides states with meaningful information about the outcomes of these different service/support strategies, offering detailed, actionable recommendations for improvement. Further, risk-adjusted measures significantly vary by residential setting, providing empirical support for the informational value of reporting these measures separately for the 5 settings.

The constructed variable, res_type5, was used as the stratification variable. Res_type5 is recoded from background information (administrative records) variable TYPEHOME18, Type of Residence.

The included response TYPEHOME18 categories were:

res_type5 category #1 - ICF/IID, nursing facility or other institutional setting:

1. ICF/IID, 4-6 residents with disabilities
2. ICF/IID, 7-15 residents with disabilities
3. ICF/IID, 16 or more residents with disabilities
4. Nursing facility
5. Other specialized institutional facility
6. res_type5 category #2 - Group residential setting
7. Group living setting, 2-3 people with disabilities
8. Group living setting, 4-6 people with disabilities
9. Group living setting, 7-15 people with disabilities
10. res_type5 category #3 - Own home or apartment
11. Lives in own home or apartment; may be owned or rented, or may be sharing with roommate(s) or spouse
12. res_type5 category #4 - Parent/relative's home
13. Parent/relative's home (may include paid services to family for residential supports)
14. res_type5 category #5 - Foster or host home
15. Foster care or host home (round-the-clock services provided in a single-family residence where two or more people with a disability live with a person or family who furnishes services)
16. Foster care or host home (round-the-clock services provided in a single-family residence where only one person with a disability lives with a person or family who furnishes services—sometimes called shared living); Other

The TYPEHOME18 categories excluded from res_type5 were:

13. Homeless or crisis bed placement
14. Other (specify):____
99. Don't know

Level of Analysis: Population: Regional and State

Setting of Care: Other

Type of Measure: Outcome: PRO-PM

Data Source: Instrument-Based Data

Measure Steward: Human Services Research Institute

STANDING COMMITTEE MEETING June 30, 2021

1. Importance to Measure and Report: The measure meets the Importance criteria.

(1a. Evidence, 1b. Performance Gap)

1a. Evidence**: Total votes=15; Y-14; N-1**; 1b. Performance Gap: **Total votes= 15; H-3**; **M-10**; **L-2**; **I-0**

Rationale

- The Standing Committee noted that while the evidence varied across the 14 components of the measures, overall, the evidence demonstrated the measure was meaningful to measure, and reporting of NCI-submitted measures across various states and regions can lead to improved outcomes for HCBS recipients.
- The Standing Committee expressed concern with the wide variation among performance gap for the 14 components and between states. While the performance gap for certain components and some states was low, some components and/or states were performing very well. The Standing Committee questioned whether this measure was needed when some components and/or states could potentially be "topped out" and unable to improve further. The Standing Committee also noted that the differences between racial and ethnic groups were relatively minor and did not necessarily imply that a gap existed.
- The developer noted that due to the structure of the measure and the natural variation between states, this variation is expected and will continue to evaluate the measure for potential improvements.
- The Standing Committee agreed this level of variation was acceptable, and the measure passed on performance gap.

2. Scientific Acceptability of Measure Properties: The measure meets the Scientific Acceptability criteria.

(2a. Reliability - precise specifications, testing; 2b. Validity - testing, threats to validity)

2a. Reliability: **Total votes: 15; Y-15**; **N-0 (Accept SMP moderate rating);** 2b. Validity: **Total votes: 15; H-2**; **M-11**; **L-1**; **I-1**

Rationale

- This measure was reviewed by the Scientific Methods Panel (SMP). It passed with a moderate rating on reliability (Total votes: 9; H-3, M-3, L-2, I-1), but did not reach consensus on validity (Total votes: 7; H-0, M-4, L-0, I-3).
- The Standing Committee noted that reliability testing was conducted at the data element level through multiple data element analyses, some from previous work conducted, and others based on a relatively recent sample of In-Person Surveys (IPS) of the National Core Indicators (NCI). The sample includes 37 states and a total of 22,000 completed surveys.
- Reliability testing was also conducted at the score level through an analysis of variance (ANOVA) to assess between-state variance in relationship to within-state variance and assessed inter-unit reliability (IUR).
- The Standing Committee expressed concerns regarding whether the samples were representative of state-to-state and racial/ethnical differences. One member questioned why each state must have a sample size that will support a 95 percent confidence interval with a 5 percent margin of error. The developer explained that this sample size requirement was created based on the state's service populations and assisted with removing the potential for skewing the results due to sample size issues, thus making the sample representative of the populations they were evaluating.
- The Standing Committee also questioned whether the developer had observed any trends among the 37 participating states. The developer noted that the participating states varied each year, and certain states only participate every few years either due to budgetary issues or other logistical issues. A total of 47 states were members that participated at their own desired interval. The developer cautioned against using the 37 states to represent the whole nation due to this result and stated that the information gathered would assist in better understanding how the service systems are doing across the country.

- The Standing Committee ultimately accepted the SMP's reliability vote of moderate (Total votes: 15; Y-15; N-0)
- The Standing Committee noted that validity testing was conducted at the data element level using seven studies that investigated the relationships among NCI data elements and testing hypotheses about expected associations and at the measure score level through a Pearson Product Moment Correlation Coefficient.
- The SMP was unable to reach consensus on validity (Total votes: 7; H-0, M-4, L-0, I-3). In their preliminary analyses, the SMP noted that the submission was incomplete in the data element validity testing, as the developer had only listed references to studies without appropriately summarizing their results; hence, the SMP reviewers did not conduct a data element validity evaluation. It was noted that none of the risk factors for this risk-adjusted measure were tested. Furthermore, the SMP noted the developer's testing of performance score validity at the state level was not optimal because all of the constructs are estimated based on the same survey, suggesting that any validity issues that affect the entire survey in a consistent manner are likely to lead to exaggerated correlations.
- In response to the SMP's feedback, the developer reported results of a confirmatory factor analysis evaluating the factor structure of the five multi-item measures, with results indicating that the data fit well. The developer also expanded their presented analysis to include external measures of quality (not just between the 14 survey items) with results that were directionally appropriate, statistically significant, and of moderate to high strength in the association.
- The Standing Committee expressed concerns about states selecting only the best results to share. The developer noted that survey strategies in the states are designed by third parties through workplans. This precludes states from picking successful sites or programs for interviewing.
- The Standing Committee noted that the measure's skip pattern could lead to missing data. The developer replied that the different components of the measure may have different response rates, thus leading to missing data; however, deleting responses would be discounting the person's voice for the sake of consistency.
- The Standing Committee requested more information on the use of proxies to respond to questions. The developer noted proxies were only allowed for section 1 of the survey, which was more subjective. Section 2, which was more factual, had to be filled out by the actual patient. The developer further clarified that follow-up questions were asked as needed, and the proxy was documented.
- The Standing Committee agreed the additional information provided by the developer indicated that the measure was valid and passed the measure on the validity criterion (Total votes: 15; H-2; M-11; L-1; I-1).

3. Feasibility: Total votes = 15; H-2; M-8; L-4; I-1

(3a. Clinical data generated during care delivery; 3b. Electronic sources; 3c. Susceptibility to inaccuracies/ unintended consequences identified 3d. Data collection strategy can be implemented)

Rationale

- The Standing Committee noted challenges with feasibility, including challenges with data collection for the 38 states collecting NCI data for ID/DD HCBS measures and data confidentiality/data access for states that are under contract with external administrative entities as well as sample identification challenges facing states that elect to oversample or stratify data by population. However, most states reported that the identified challenges had been overcome once processes and protocols were established and subsequently repeated.
- The Standing Committee inquired about the annual membership fee of $15,000 and an unspecified cost for data access. The developer clarified the annual membership fee was for states, and they would have access to their data without any additional fees. The data access fee was for institutions that would like to use the data for research purposes.
- The Standing Committee emphasized that potential burden could not be the only reason to not endorse a measure that would be filling an important gap and agreed the measure was feasible.

4. Use and Usability

(4a. Use; 4a1. Accountability and transparency; 4a2. Feedback on the measure by those being measured and others; 4b. Usability; 4b1. Improvement; 4b2. The benefits to patients outweigh evidence of unintended negative consequences to patients)

4a**. Use: total votes = 15; Pass-12; No Pass-3** *4b. Usability:* ***Total votes = 15;*** **H-2; M-9; L-2; I-2**

Rationale

- The Standing Committee noted that the measure was currently in use in several programs, including the Medicaid Adult Core Health Care Quality Measure Set, Connecticut Medicaid 1915(c) HCBS Waiver Assurances, Indiana Family and Social Services Administration Medicaid 1915(c) HCBS Waiver Assurances, Arizona Community and Supported Employment initiatives, Massachusetts Department of Developmental Services programs, and the Kentucky Division of Developmental and Intellectual Disabilities programs.
- The Standing Committee also noted that users of the measure were able to provide feedback and had provided generally positive feedback so far.
- The Standing Committee highlighted that the data demonstrated increased state- and user-level engagement and that no unintended consequences had been identified.
- The Standing Committee agreed the measure was in use and usable.

5. Related and Competing Measures

- One measure was identified as related:
  - #2967 CAHPS® Home- and Community-Based Services Measures
- The Standing Committee did not express any concerns with the relationship between this measure and the measure under review.

6. Standing Committee Recommendation for Endorsement: **Total votes = 15; Y-13**; **N-2**

7. Public and Member Comment

- Ten public comments received were supportive of the measure. Two comments were supportive of the measure and contained suggestions for future improvements to the PROM. One comment was supportive of the measure and contained suggestions for the PROM, as well as expressing concerns with one element of the measure to which the Standing Committee responded:
  - "The Standing Committee thanks the commenter for their comment and accepts the response provided by the measure developer. The residential categorization of concern is explained in full in the measure submission and accounts for unrepresented response options. The Standing Committee also had questions about feasibility and diversity in the sample population and discussed these items at length during the measure evaluation meeting. In evaluating these measures against NQF's endorsement criteria, the Standing Committee agreed the measure fills an important measurement gap and meets all NQF criteria. The Standing Committee ultimately recommends this measure for endorsement."

8. Consensus Standards Approval Committee (CSAC) Vote: Y-X; N-X

9. Appeals

Appendix B: Patient Experience and Function Portfolio—Use in Federal Programs[a]

NQF #	Title	Federal Programs: Finalized or Implemented as of June 30, 2021
0005	CAHPS Clinician & Group Surveys (CG-CAHPS)-Adult, Child	Physician Compare (Implemented 2013) Merit-Based Incentive Payment System (MIPS) Program (Implemented 2018)
0006	Consumer Assessment of Healthcare Providers and Systems (CAHPS) Health Plan Survey, Version 5.0 (Medicaid and Commercial)	Marketplace Quality Rating System (QRS) (Implemented 2015)
0166	HCAHPS	Hospital Compare (Implemented 2015) Hospital Inpatient Quality Reporting (IQR) (Implemented 2010) Hospital Value-Based Purchasing (HVBP) (Implemented 2012) Prospective Payment System (PPS)-Exempt Cancer Hospital Quality Reporting (PCHQR) (Implemented 2015)
0258	CAHPS In-Center Hemodialysis Survey	End-Stage Renal Disease Quality Incentive Program (ESRD QIP) (Implemented 2016) Dialysis Facility Compare (Implemented 2020)
0422	Functional Status Change for Patients With Knee Impairments	MIPS Program (Implemented 2018) Physician Compare (Implemented 2013)
0423	Functional Status Change for Patients With Hip Impairments	MIPS Program (Implemented 2018) Physician Compare (Implemented 2018)
0424	Functional Status Change for Patients With Foot and Ankle Impairments	MIPS Program (Implemented 2018)
0425	Functional Status Change for Patients With Lumbar Impairments	MIPS Program (Implemented 2018) Physician Compare (Implemented 2018)
0426	Functional Status Change for Patients With Shoulder Impairments	MIPS Program (Implemented 2018)
0427	Functional Status Change for Patients With Elbow, Wrist, and Hand Impairments	MIPS Program (Implemented 2018) Physician Compare (Implemented 2018)
0428	Functional Status Change for Patients With General Orthopedic Impairments	None
0517	CAHPS® Home Health Care Survey (Experience With Care)	Home Health Quality Reporting Program (HH QRP) (Implemented 2012)
1741	Patient Experience With Surgical Care Based on the Consumer Assessment of	None

[a] Per CMS Measures Inventory Tool as of 07/01/2021

NQF #	Title	Federal Programs: Finalized or Implemented as of June 30, 2021
	Healthcare Providers and Systems (CAHPS)® Surgical Care Survey	
2286	Functional Change: Change in Self-Care Score	None
2287	Functional Change: Change in Motor Score	None
2321	Functional Change: Change in Mobility Score	None
2483	Gains in Patient Activation (PAM) Scores at 12 Months	None
2548	Child Hospital CAHPS (HCAHPS)	None
2612	CARE: Improvement in Mobility	None
2613	CARE: Improvement in Self-Care	None
2614	CoreQ: Short Stay Discharge Measure	None
2615	CoreQ: Long-Stay Resident Measure	None
2616	CoreQ: Long-Stay Family Measure	None
2631	Percent of Long-Term Care Hospital (LTCH) Patients With an Admission and Discharge Functional Assessment and a Care Plan That Addresses Function	Long-Term Care Hospital Quality Reporting (LTCH QRP) (Implemented 2017) Inpatient Rehabilitation Facility Compare (Implemented 2015) Long-Term Care Hospital Compare (Implemented 2015)
2632	Long-Term Care Hospital (LTCH) Functional Outcome Measure: Change in Mobility Among Patients Requiring Ventilator Support	LTCH QRP (Implemented 2017)
2633	Inpatient Rehabilitation Facility (IRF) Functional Outcome Measure: Change in Self-Care Score for Medical Rehabilitation Patients	Inpatient Rehabilitation Facility Quality Reporting (IRF QRP) (Implemented 2017) Inpatient Rehabilitation Facility Compare (Implemented 2015)
2634	Inpatient Rehabilitation Facility (IRF) Functional Outcome Measure: Change in Mobility Score for Medical Rehabilitation Patients	IRF QRP (Implemented 2017) Inpatient Rehabilitation Facility Compare (Implemented 2015)
2635	Inpatient Rehabilitation Facility (IRF) Functional Outcome Measure:	IRF QRP (Implemented 2017)

NQF #	Title	Federal Programs: Finalized or Implemented as of June 30, 2021
	Discharge Self-Care Score for Medical Rehabilitation Patients	Inpatient Rehabilitation Facility Compare (Implemented 2015)
2636	Inpatient Rehabilitation Facility (IRF) Functional Outcome Measure: Discharge Mobility Score for Medical Rehabilitation Patients	IRF QRP (Implemented 2017) Inpatient Rehabilitation Facility Compare (Implemented 2015)
2643	Average Change in Functional Status Following Lumbar Spine Fusion Surgery	MIPS Program (Implemented 2020)
2653	Average Change in Functional Status Following Total Knee Replacement Surgery	MIPS Program (Implemented 2020)
2769	Functional Change: Change in Self-Care Score for Skilled Nursing Facilities	None
2774	Functional Change: Change in Mobility Score for Skilled Nursing Facilities	None
2775	Functional Change: Change in Motor Score for Skilled Nursing Facilities	None
2776	Functional Change: Change in Motor Score in Long-Term Acute Care Facilities	None
2777	Functional Change: Change in Self Care Score for Long-Term Acute Care Facilities	None
2778	Functional Change: Change in Mobility Score for Long-Term Acute Care Facilities	None
2958	Informed, Patient Centered (IPC) Hip and Knee Replacement Surgery	None
2962	Shared Decision Making Process	None
2967	CAHPS® Home- and Community-Based Services Measures	Medicaid (Implemented 2017)
3227	CollaboRATE Shared Decision Making Score	None
3420	CoreQ: AL Resident Satisfaction Measure	None
3422	CoreQ: AL Family Satisfaction Measure	None
3455	Timely Follow-Up After Acute Exacerbations of Chronic Conditions	None
3461	Functional Status Change for Patients With Neck Impairments	MIPS Program (Finalized 2019)

NQF #	Title	Federal Programs: Finalized or Implemented as of June 30, 2021
3477	Discharge to Community-Post Acute Care Measure for Home Health Agencies	HH QRP (Implemented 2018) Home Health Compare (Implemented 2020)
3479	Discharge to Community-Post Acute Care Measure for Inpatient Rehabilitation Facilities	IRF QRP (Implemented 2017) Inpatient Rehabilitation Facility Compare (Implemented 2016)
3480	Discharge to Community-Post Acute Care Measure for Long-Term Care Hospitals	LTCH QRP (Implemented 2017) Long-Term Care Hospital Compare (Implemented 2016)
3481	Discharge to Community-Post Acute Care Measure for Skilled Nursing Facilities	Skilled Nursing Facility Quality Reporting (SNF QRP) (Implemented 2017)
3559	Hospital-Level, Risk-Standardized Patient-Reported Outcomes Following Elective Primary Total Hip and/or Total Knee Arthroplasty (THA/TKA) ((CMS)/Yale New Haven Health Services Corporation/Center for Outcomes Research and Evaluation (YNHHSC/CORE))	None
3593	Identifying Personal Priorities for Functional Assessment Standardized Items (FASI) Needs	None

Appendix C: Patient Experience and Function Standing Committee and NQF Staff

STANDING COMMITTEE

Gerri Lamb, PhD, RN, FAAN (Co-Chair)
Associate Professor, Arizona State University
Tucson, AZ

Christopher Stille, MD, MPH, FAAP (Co-Chair)
University of Colorado School of Medicine
Aurora, Colorado

Richard Antonelli, MD, MS
Medical Director for Integrated Care, Boston Children's Hospital, Harvard Medical School
Boston, Massachusetts

Adrienne Boissy, MD, MA
Chief Experience Officer, Cleveland Clinic
Cleveland, Ohio

Desiree Collins Bradley
ATW Health Solutions
Fresno, Texas

Donald Casey, MD, MPH, MBA, FACP, FAHA, FAAPL, DFACMQ
President, American College of Medical Quality (ACMQ)
Chicago, Illinois

Ariel Cole, MD
Clerkship Director for Geriatrics, Florida State University College of Medicine Orlando Campus
Winter Park, Florida

Ryan Coller, MD, MPH
Division Chief, Pediatric Hospital Medicine, University of Wisconsin-Madison
Madison, Wisconsin

Sharon Cross, LISW-S
Patient/Family Centered Care Program Director, The Ohio State University Wexner Medical Center
Columbus, Ohio

Christopher Dezii, MBA, RN, CPHQ
Lead, Healthcare Quality & Performance Measures, Bristol-Myers Squibb Company
Lawrenceville, New Jersey

Shari Erickson, MPH
Vice President, Governmental & Regulatory Affairs, American College of Physicians (ACP)
Washington, District of Columbia

Dawn Hohl, RN, BSN, MS, PhD
Sr. Director of Transitions and Patient Experience, Johns Hopkins Home Care Group
Baltimore, Maryland

Sherrie Kaplan, PhD, MPH
University of California Irvine School of Medicine
Irvine, California

Brenda A. Leath, DPS, MHSA, PMP
President/CEO, Leath & Associates, Inc.
Washington, District of Columbia

Brian Lindberg, BSW, MMHS
Executive Director, Consumer Coalition for Quality Health Care
Washington, District of Columbia

Lisa Morrise, MA
Patient & Family Engagement Affinity Group National Partnership for Patients
Salt Lake City, Utah

Kirk Munsch
Patient Advocacy Manager, Rare Patient Voice
Colorado Springs, Colorado

Randi Oster, MBA
President, Help Me Health
Fairfield, Connecticut

Charissa Pacella, MD
Chief of Emergency Services and Medical Staff, University of Pittsburgh Medical Center (UPMC)
Pittsburgh, Pennsylvania

Lenard Parisi, RN, MA, CPHQ, FNAHQ
Senior Operational Consultant, Strategic Quality Solutions, LLC
New York, New York

Debra Saliba, MD, MPH
Professor of Medicine, UCLA/JH Borun Center, VA GRECC, RAND Health
Los Angeles, California

Ellen Schultz, MS
American Institutes for Research
Chicago, Illinois

Lisa Suter, MD
Assistant Professor and Associate Director, Yale School of Medicine, and Yale/CORE
New Haven, Connecticut

Peter Thomas, JD
Principal, Powers, Pyles, Sutter & Verville, P.C.
Washington, District of Columbia

NQF STAFF

Kathleen Giblin, RN
Acting Senior Vice President, Quality Measurement

Tricia Elliott, MBA, CPHQ, FNAHQ
Senior Managing Director, Quality Measurement

Tamara H. Funk, MPH
Director

Erin Buchanan, MPH
Manager

Hannah Ingber, MPH
Senior Analyst

Sean Sullivan, MA
Coordinator

Poonam Bal, MHSA
Senior Director

Oroma Igwe, MPH
Manager

Yemsrach Kidane, PMP
Project Manager

Gus Zimmerman, MPP
Coordinator

Appendix D: Measure Specifications

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

STEWARD

Human Services Research Institute

DESCRIPTION

National Core Indicators for Intellectual and Developmental Disabilities Home- and Community-Based Services Measures ("NCI for ID/DD HCBS Measures" hereafter) originate from NCI(R) In-Person Survey (IPS), an annual multi-state cross-sectional survey of adult recipients of state developmental disabilities systems' supports and services. First developed in 1997 by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in collaboration with Human Services Research Institute (HSRI), the main aims of NCI for ID/DD HCBS Measures were to evaluate person-reported outcomes and assess state developmental disabilities service systems performance in various domains and sub-domains accordingly. The unit of analysis is "the state", and the accountable entity is the state-level entity responsible for providing and managing developmental disabilities services. Currently, 46 states and the District of Columbia are members of the NCI program. To align with member states' fiscal schedules, the annual survey cycle typically starts on July 1 and ends on June 30 of the following year.

Gathering subjective information and data from people with ID/DD poses unique challenges due to potential intellectual and developmental limitations experienced by the population. As such, extensive work went into the processes of developing NCI IPS administration methods, survey methodology and measure design and revisions. The original development built on direct consultation with members of the target population and their advocates, as well as extensive literature review and testing.

The NCI for ID/DD HCBS Measures consist of 14 measures in total, including:

Five measures in the HCBS Domain: Person-Centered Planning (PCP) and Coordination

#PCP-1 The proportion of people who express they want a job who have a related goal in their service plan (Community Job Goal)

#PCP-2 The proportion of people who report their service plan includes things that are important to them (Person-Centered Goals)

#PCP-3 The proportion of people who express they want to increase independence in functional skills (ADLs) who have a related goal in their service plan (ADL Goal)

#PCP-4 The proportion of people who report they are supported to learn new things (Lifelong Learning)

#PCP-5 The proportion of people who report satisfaction with the level of participation in community inclusion activities (Satisfaction with Community Inclusion Scale)

Four measures in the HCBS Domain: Community Inclusion

#CI-1 The proportion of people who reported that they do not feel lonely often (Social Connectedness)

#CI-2 The proportion of people who reported that they have friends who are not staff or family members (Has Friends)

#CI-3 The proportion of people who report adequate transportation (Transportation Availability Scale)

#CI-4 The proportion of people who engage in activities outside the home (Community Inclusion Scale)

Four measures in the HCBS Domain: Choice and Control

#CC-1 The proportion of people who reported they chose or were aware they could request to change their staff (Chose Staff)

#CC-2 The proportion of people who reported they could change their case manager/service coordinator (Can Change Case Manager)

#CC-3 The proportion of people who live with others who report they can stay home if they choose when others in their house/home go somewhere (Can Stay Home When Others Leave)

#CC-4 The proportion of people who report making choices (independently or with help) in life decisions (Life Decisions Scale)

And one measure in the HCBS Domain: Human and Legal Rights

#HLR-1 The proportion of people who report that their personal space is respected in the home (Respect for Personal Space Scale)

TYPE

Outcome: PRO-PM

DATA SOURCE

Instrument-Based Data NCI IPS data are collected using the copyrighted survey tools. Up until the 2018-19 survey cycle, the only mode of data collection was a face-to-face, in-person survey. Due to the COVID-19 pandemic, remote surveying (via video conferencing) were allowed when following appropriate protocols. NCI IPS is generally administered in English or Spanish.

LEVEL

Population: Regional and State

SETTING

Other State Home- and Community-Based Services (HCBS) settings

NUMERATOR STATEMENT

The NCI for ID/DD HCBS Measures use values between 0 and 1 as the scores. Typically, the numerator is the number of respondents who selected the most positive response category (e.g. "yes", "always"). The attached file SuppTable_Measures_210420_508.xlsx lists what constituted the most positive response categories for each measure item, as well as other detailed information as relevant for S.2b.

NUMERATOR DETAILS

The attached file SuppTable_Measures_210420_508.xlsx lists detailed information as relevant for S.2b.

Numerators:

-Paid Community Job Goal: The number of respondents who report that community employment is a goal in person's service plan

-Person-Centered Goals: The number of respondents who report their service plan includes things that are important to them

-ADL Goal: The number of respondents in whose service plan there is a goal to increase independence or improve functional skill performance in activities of daily living (ADLs)

-Lifelong Learning: The number of respondents who report they are supported to learn new things

-Satisfaction With Community Inclusion Scale: This is a multi-item measure; therefore, it does not have a simple form for the numerator and denominator.

-Social Connectedness: The number of respondents who report that they do not feel lonely often

-Has Friends: The number of respondents who report that they have friends who are not staff or family members

-Transportation Availability Scale: This is a multi-item measure; therefore, it does not have a simple form for the numerator and denominator

-Community Inclusion Scale: This is a multi-item measure; therefore, it does not have a simple form for the numerator and denominator

-Chose Staff: The number of respondents who report they chose or were aware they could request to change their staff

-Chose Case Manager: The number of respondents who report they could change their case manager/service coordinator

-Can Stay Home When Others Leave: The number of respondents who report they can stay home if they choose when others in their house/home go somewhere

-Life Decisions Scale: This is a multi-item measure; therefore, it does not have a simple form for the numerator and denominator

-Respect for Personal Space Scale: This is a multi-item measure; therefore, it does not have a simple form for the numerator and denominator

DENOMINATOR STATEMENT

For each measure, the denominator is the number of respondents (adult recipients of state developmental disabilities services) who provided valid answers to the respective survey question, except those that meet the exclusion criteria (see S.8. below for details).

If the denominator for a state is fewer than 20, the measure score is censored to protect the confidentiality of respondents.

DENOMINATOR DETAILS

The NCI IPS consists of two main sections, denoted by Roman numerals I and II. Section I of the survey contains questions about personal experiences and therefore may only be answered by the individual receiving developmental disabilities services. Section II of the survey---featuring questions about topics such as community involvement, choices, rights, and access to services—allows for responses from a “proxy,” defined as a person who knows the individual well (such as a family member or friend).

Generally speaking, the denominators are the numbers of respondents who are eligible to respond and gave a valid response. Specifically:

#PCP-1: The number of respondents with a valid Section I, who reported that they do not have a job and would like a paid job in the community

#PCP-2: The number of respondents with a valid Section I

#PCP-3: The number of respondents with a valid Section I, who indicated "yes" to the question about desire to increase independence in ADL.

#PCP-4: The number of respondents with a valid Section I

#PCP-5: This is a multi-item measure; therefore, it does not have a simple form for the numerator and denominator

#CI-1: Social Connectedness: The number of respondents with a valid Section I

#CI-2: Has Friends: The number of respondents with a valid Section I

#CI-3: This is a multi-item measure; therefore, it does not have a simple form for the numerator and denominator

#CI-4: This is a multi-item measure; therefore, it does not have a simple form for the numerator and denominator

#CC-1: The number of respondents with a valid Section II

#CC-2: The number of respondents with a valid Section II

#CC-3 The number of respondents with a valid Section I

#CC-4: This is a multi-item measure; therefore, it does not have a simple form for the numerator and denominator

#HLR-1: This is a multi-item measure; therefore, it does not have a simple form for the numerator and denominator

Exclusion criteria apply. Please see S.8. and S.9. for more details.

EXCLUSIONS

At the end of Section I, the surveyor assesses whether the respondent appears to understand at least one question and answers in a cohesive manner. This assessment is the only subjective process in the exclusion determination process, but it is not done on an arbitrary or state-by-state basis. Rather, it is based on a protocol, included in the survey manual and reviewed during surveyor trainings, that apply uniformly to all surveyors across different participating states. The protocol is straightforward—the section must be marked “valid” if at least one question in the section was answered in a manner that the basic level of comprehension was shown, and a clear response given either verbally (e.g. yes/no) or non-verbally (nodding/shaking head). NCI and participating states routinely conduct surveyor training and surveyor shadowing and reviewing processes that ensure, among other things, that surveyors are applying this assessment (whether or not Section I was valid) strictly based on the protocol. If the surveyor´s assessment is that Section I is not valid, the respondent´s Section I data are flagged for exclusion from the numerators and denominators. However, the individual is not removed from the dataset.

If Section I data are excluded, Section II data are flagged for exclusion from the numerators and denominators -unless- a proxy respondent was used in Section II. If the respondent or proxy did not answer any questions in Section II, the survey is removed from the denominators of Section II items.

Responses are excluded from numerators and denominators for Section I items if:

(a) The surveyor indicated that the respondent did not give consistent and valid responses, or

(b) All questions in Section I were left blank, or marked "not applicable" or "don’t know".

Responses are excluded from numerators and denominators for Section II items if:

(a) the individual receiving supports was marked as the sole respondent to all questions in Section II but Section I was deemed invalid, or

(b) All questions in Section II were left blank, or marked "not applicable" or "don’t know".

For each measure item, missing responses and responses indicating "not applicable" or "don’t know" were excluded from denominators. The distribution of exclusions among states is shown in Testing Attachment 2b2.2. Please see S.9. for more details on denominator exclusions.

EXCLUSION DETAILS

In general, missing responses and responses indicating "not applicable" or "don't know" were excluded from denominators. Denominator exclusions for each measure:

-Paid Community Job Goal: Respondents with an invalid Section I (as defined in S.8.), and those who responded "not applicable" or "don´t know" to the survey question "Would you like to have a job in the community?" are excluded

-Person-Centered Goals: Respondents with an invalid Section I are excluded

-ADL Goal: Respondents with an invalid Section I, and those who did not indicate "yes" to the question about desire to increase independence in ADL are excluded

-Lifelong Learning: Respondents with an invalid Section I are excluded

-Satisfaction with Community Inclusion Scale: Respondents with an invalid Section I are excluded

-Social Connectedness: Respondents with an invalid Section I are excluded

-Has Friends: Respondents with an invalid Section I are excluded

-Transportation Availability Scale: Respondents with an invalid Section I are excluded

-Community Inclusion Scale: Respondents with an invalid Section II are excluded

-Chose Staff: Respondents with an invalid Section II are excluded

-Chose Case Manager: Respondents with an invalid Section II are excluded

-Can Stay Home When Others Leave: Respondents with an invalid Section I are excluded

-Life Decisions Scale: Respondents with an invalid Section II are excluded

-Respect for Personal Space Scale: Respondents with an invalid Section I are excluded

There are no pre-screening procedures prior to the survey. Participation is voluntary, and individual surveys are de-identified. Exclusion of responses occurs at the time of data analysis by HSRI, based on the criteria described above. There is no threshold of number of answers to be met for a "complete" survey.

RISK ADJUSTMENT

Other Statistical risk model and stratification

STRATIFICATION

Risk-adjusted Life Decisions and Community Inclusion Scales are further stratified by 5 residential setting categories:

category #1 - Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID), nursing facility, or other institutional setting

#2 - Group residential setting (e.g., group home)

#3 - Own home or apartment

#4 - Parents' or relatives' home

#5 - Foster care or host home

There are both conceptual/policy and empirical reasons for this stratification. Conceptually, the need for types and mixes of HCBS supports vary by residential setting, impacting the interpretation and program/policy implications of outcomes. Providing scores for each residential setting separately provides states with meaningful information about the outcomes of these different service/support strategies, offering detailed, actionable recommendations for improvement. Further, risk-adjusted measures significantly vary by residential setting, providing empirical support for the informational value of reporting these measures separately for the 5 settings.

The constructed variable res_type5 was used as the stratification variable. Res_type5 is recoded from background information (administrative records) variable TYPEHOME18, Type of Residence:

The included response TYPEHOME18 categories were:

res_type5 category #1 - ICF/IID, nursing facility or other institutional setting:

1. ICF/IID, 4-6 residents with disabilities
2. ICF/IID, 7-15 residents with disabilities
3. ICF/IID, 16 or more residents with disabilities
4. Nursing facility
5. Other specialized institutional facility

res_type5 category #2 - Group residential setting

6. Group living setting, 2-3 people with disabilities
7. Group living setting, 4-6 people with disabilities
8. Group living setting, 7-15 people with disabilities

res_type5 category #3 - Own home or apartment

9. Lives in own home or apartment; may be owned or rented, or may be sharing with roommate(s) or spouse

res_type5 category #4 - Parent/relative's home

10. Parent/relative's home (may include paid services to family for residential supports)

res_type5 category #5 - Foster or host home

11. Foster care or host home (round-the-clock services provided in a single-family residence where two or more people with a disability live with a person or family who furnishes services)
12. Foster care or host home (round-the-clock services provided in a single-family residence where only one person with a disability lives with a person or family who furnishes services—sometimes called shared living) Other

The TYPEHOME18 categories excluded from res_type5 were:

13. Homeless or crisis bed placement
14. Other (specify):____
99. Don't know

TYPE SCORE

Rate/proportion better quality = higher score

ALGORITHM

Please see attached file SuppTable_Measures_210420_508.xlsx for details. 145711| 141882| 143853

COPYRIGHT / DISCLAIMER

enhance, or otherwise modify the NCI measures and specifications or associated materials. Anyone desiring to use or reproduce the contents of reports, inclusive of data results, without modification for a non-commercial purpose, may do so without obtaining approval from NCI. The use or reproduction of NCI survey instruments and questions requires prior approval by the NASDDDS and HSRI. All commercial uses or requests for alteration of the measures and specifications must be approved by NASDDDS/HSRI and are subject to a license at the discretion of NASDDDS/HSRI. NCI measures and specifications are not clinical or disability services guidelines, do not establish a standard of medical care, nor a standard for disability services and are not intended or tested for all potential applications.

The measures and specifications are provided “as is” without warranty of any kind. NASDDDS and HSRI make no representations, warranties, or endorsements about the suitability or utility of any product, test, or protocol identified as deriving from or based on an NCI measure or specification. NCI also makes no representations, warranties, or endorsements about the quality of any agency of a state, contractor of a state agency, or other organization who uses, applies, or reports NCI performance measures. NASDDDS/HSRI has no liability to anyone who relies on NCI measures and specifications or data reflective of performance under such measures and specifications.

Appendix E: Related and Competing Measures

Measure Specifications

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures
#2967 CAHPS® Home- and Community-Based Services Measures

Steward

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

Human Services Research Institute

#2967 CAHPS® Home- and Community-Based Services Measures

Centers for Medicare & Medicaid Services

Description

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

National Core Indicators for Intellectual and Developmental Disabilities Home- and Community-Based Services Measures ("NCI for ID/DD HCBS Measures" hereafter) originate from NCI(R) In-Person Survey (IPS), an annual multi-state cross-sectional survey of adult recipients of state developmental disabilities systems' supports and services. First developed in 1997 by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in collaboration with Human Services Research Institute (HSRI), the main aims of NCI for ID/DD HCBS Measures were to evaluate person-reported outcomes and assess state developmental disabilities service systems performance in various domains and sub-domains accordingly. The unit of analysis is "the state", and the accountable entity is the state-level entity responsible for providing and managing developmental disabilities services. Currently, 46 states and the District of Columbia are members of the NCI program. To align with member states' fiscal schedules, the annual survey cycle typically starts on July 1 and ends on Jun 30 of the following year.

Gathering subjective information and data from people with ID/DD poses unique challenges due to potential intellectual and developmental limitations experienced by the population. As such, extensive work went into the processes of developing NCI IPS administration methods, survey methodology and measure design and revisions. The original development built on direct consultation with members of the target population and their advocates, as well as extensive literature review and testing.

The NCI for ID/DD HCBS Measures consist of 14 measures in total, including:

Five measures in the HCBS Domain: Person-Centered Planning (PCP) and Coordination

#PCP-1 The proportion of people who express they want a job who have a related goal in their service plan (Community Job Goal)

#PCP-2 The proportion of people who report their service plan includes things that are important to them (Person-Centered Goals)

#PCP-3 The proportion of people who express they want to increase independence in functional skills (ADLs) who have a related goal in their service plan (ADL Goal)

#PCP-4 The proportion of people who report they are supported to learn new things (Lifelong Learning)

#PCP-5 The proportion of people who report satisfaction with the level of participation in community inclusion activities (Satisfaction with Community Inclusion Scale)

Four measures in the HCBS Domain: Community Inclusion

#CI-1 The proportion of people who reported that they do not feel lonely often (Social Connectedness)

#CI-2 The proportion of people who reported that they have friends who are not staff or family members (Has Friends)

#CI-3 The proportion of people who report adequate transportation (Transportation Availability Scale)

#CI-4 The proportion of people who engage in activities outside the home (Community Inclusion Scale)

Four measures in the HCBS Domain: Choice and Control

#CC-1 The proportion of people who reported they chose or were aware they could request to change their staff (Chose Staff)

#CC-2 The proportion of people who reported they could change their case manager/service coordinator (Can Change Case Manager)

#CC-3 The proportion of people who live with others who report they can stay home if they choose when others in their house/home go somewhere (Can Stay Home When Others Leave)

#CC-4 The proportion of people who report making choices (independently or with help) in life decisions (Life Decisions Scale)

And one measure in the HCBS Domain: Human and Legal Rights

#HLR-1 The proportion of people who report that their personal space is respected in the home (Respect for Personal Space Scale)

#2967 CAHPS® Home- and Community-Based Services Measures

The Home and Community-Based Services (HCBS) Consumer Assessment of Healthcare Providers and Systems (CAHPS) measures derive from a cross-disability survey to elicit feedback from adult Medicaid participants (aged 18 years and older) receiving HCBS about their experience with the long-term services and supports they receive in the community delivered through a Medicaid-funded HCBS program. The unit of analysis for NQF 2967 is the Medicaid HCBS program, and the accountable entity is the operating body responsible for managing and overseeing delivery of a specific HCBS program within a given state.

The measures consist of 7 scale measures, 6 global rating and recommendation measures, and 6 individual measures:

Scale Measures (7 Measures Based on 34 Survey Items)

1. Staff are reliable and helpful—Top-box score composed of 6 survey items.
2. Staff listen and communicate well—Top-box score composed of 11 survey items.
3. Case manager is helpful—Top-box score composed of 3 survey items.
4. Choosing the services that matter to you—Top-box score composed of 2 survey items.
5. Transportation to medical appointments—Top-box score composed of 3 survey items.
6. Personal safety and respect—Top-box score composed of 3 survey items.

7. Planning your time and activities—Top-box score composed of 6 survey items.

Global Ratings Measures (3 Measures Based on 3 Survey Items)

8. Global rating of personal assistance and behavioral health staff—Top-box score on a 0–10 scale.

9. Global rating of homemaker—Top-box score on a 0–10 scale.

10. Global rating of case manager—Top-box score on a 0–10 scale.

Recommendations Measures (3 Measures Based on 3 Survey Items)

11. Would recommend personal assistance/behavioral health staff to family and friends—Top-box score on a 1–4 scale (Definitely No, Probably No, Probably Yes, or Definitely Yes).

12. Would recommend homemaker to family and friends—Top-box score on a 1–4 scale (Definitely No, Probably No, Probably Yes, or Definitely Yes).

13. Would recommend case manager to family and friends—Top-box score on a 1–4 scale (Definitely No, Probably No, Probably Yes, or Definitely Yes).

Unmet Needs Measures (5 Measures Based on 5 Survey Items)

14. Unmet need in dressing/bathing due to lack of help—Top-box score on a Yes or No scale.

15. Unmet need in meal preparation/eating due to lack of help—Top-box score on a Yes or No scale.

16. Unmet need in medication administration due to lack of help—Top-box score on a Yes or No scale.

17. Unmet need in toileting due to lack of help—Top-box score on a Yes or No scale.

18. Unmet need with household tasks due to lack of help—Top-box score on a Yes or No scale.

Physical Safety Measure (1 Measure Based on 1 Survey Item)

19. Hit or hurt by staff—Top-box score on a Yes or No scale.

Type

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

Outcome: PRO-PM

#2967 CAHPS® Home- and Community-Based Services Measures

Outcome: PRO-PM

Data Source

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

Instrument-Based Data NCI IPS data are collected using the copyrighted survey tools. Up until the 2018-19 survey cycle, the only mode of data collection was face-to-face, in-person survey. Due to the COVID-19 pandemic, remote surveying (via video conferencing) were allowed when following appropriate protocols. NCI IPS is generally administered in English or Spanish.

Available in attached appendix at A.1 Attachment SuppTable_Measures_210420_508.xlsx

#2967 CAHPS® Home- and Community-Based Services Measures

Instrument-Based Data CAHPS Home- and Community-Based Services Survey

In-person and phone

English and Spanish

Available in attached appendix at A.1 No data dictionary

Level

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

Population : Regional and State

#2967 CAHPS® Home- and Community-Based Services Measures

Other

Setting

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

Other State Home- and Community-Based Services (HCBS) settings

#2967 CAHPS® Home- and Community-Based Services Measures

Other Home and Community-Based Services Program

Numerator Statement

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

The NCI for ID/DD HCBS Measures use values between 0 and 1 as the scores. Typically, the numerator is the number of respondents who selected the most positive response category (e.g. "yes", "always"). The attached file SuppTable_Measures_210420_508.xlsx lists what constituted the most positive response categories for each measure item, as well as other detailed information as relevant for S.2b.

#2967 CAHPS® Home- and Community-Based Services Measures

The CAHPS Home and Community-Based Services measures are created using top-box scoring. This refers to the percentage of respondents that give the most positive response. Details regarding the definition of the most positive response are noted below. HCBS service experience is measured in the following areas:

Scale Measures

1. Staff are reliable and helpful—Average proportion of respondents that gave the most positive response on 6 survey items.

2. Staff listen and communicate well—Average proportion of respondents that gave the most positive response on 11 survey items.

3. Case manager is helpful—Average proportion of respondents that gave the most positive response on 3 survey items.

4. Choosing the services that matter to you—Average proportion of respondents that gave the most positive response on 2 survey items.

5. Transportation to medical appointments—Average proportion of respondents that gave the most positive response on 3 survey items.

6. Personal safety and respect—Average proportion of respondents that gave the most positive response on 3 survey items.

7. Planning your time and activities—Average proportion of respondents that gave the most positive response on 6 survey items.

Global Rating Measures

8. Global rating of personal assistance and behavioral health staff—Proportion of respondents that gave the most positive response of 9 or 10 on a 0–10 scale.

9. Global rating of homemaker—Proportion of respondents that gave the most positive response of 9 or 10 on a 0–10 scale.

10. Global rating of case manager—Proportion of respondents that gave the most positive response of 9 or 10 on a 0–10 scale.

Recommendation Measures

11. Would recommend personal assistance/behavioral health staff to family and friends—Proportion of respondents that gave the most positive response of Definitely Yes on a 1–4 scale (Definitely No, Probably No, Probably Yes, or Definitely Yes).

12. Would recommend homemaker to family and friends—Proportion of respondents that gave the most positive response of Definitely Yes on a 1–4 scale (Definitely No, Probably No, Probably Yes, or Definitely Yes).

13. Would recommend case manager to family and friends—Proportion of respondents that gave the most positive response of Definitely Yes on a 1–4 scale (Definitely No, Probably No, Probably Yes, or Definitely Yes).

Unmet Needs Measures

14. Unmet need in dressing/bathing due to lack of help—Proportion of respondents that gave the most positive response of No on a 1–2 scale (Yes or No).

15. Unmet need in meal preparation/eating due to lack of help—Proportion of respondents that gave the most positive response of No on a 1–2 scale (Yes or No).

16. Unmet need in medication administration due to lack of help—Proportion of respondents that gave the most positive response of No on a 1–2 scale (Yes or No).

17. Unmet need in toileting due to lack of help—Proportion of respondents that gave the most positive response of Yes on a 1–2 scale (Yes or No). Please note that, unlike the other Unmet Needs measures, this measure is not reverse coded.

18. Unmet need with household tasks due to lack of help—Proportion of respondents that gave the most positive response of No on a 1–2 scale (Yes or No).

Physical Safety Measure

19. Hit or hurt by staff—Proportion of respondents that gave the most positive response of No on a 1–2 scale (Yes or No).

Numerator Details

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

The attached file SuppTable_Measures_210420_508.xlsx lists detailed information as relevant for S.2b.

Numerators:

-Paid Community Job Goal: The number of respondents who report that community employment is a goal in person's service plan

-Person-Centered Goals: The number of respondents who report their service plan includes things that are important to them

-ADL Goal: The number of respondents in whose service plan there is a goal to increase independence or improve functional skill performance in activities of daily living (ADLs)

-Lifelong Learning: The number of respondents who report they are supported to learn new things

-Satisfaction with Community Inclusion Scale: This is a multi-item measure, therefore it does not have a simple form for the numerator and denominator

-Social Connectedness: The number of respondents who report that they do not feel lonely often

-Has Friends: The number of respondents who report that they have friends who are not staff or family members

-Transportation Availability Scale: This is a multi-item measure, therefore it does not have a simple form for the numerator and denominator

-Community Inclusion Scale: This is a multi-item measure, therefore it does not have a simple form for the numerator and denominator

-Chose Staff: The number of respondents who report they chose or were aware they could request to change their staff

-Chose Case Manager: The number of respondents who report they could change their case manager/service coordinator

-Can Stay Home When Others Leave: The number of respondents who report they can stay home if they choose when others in their house/home go somewhere

-Life Decisions Scale: This is a multi-item measure, therefore it does not have a simple form for the numerator and denominator

-Respect for Personal Space Scale: This is a multi-item measure, therefore it does not have a simple form for the numerator and denominator

#2967 CAHPS® Home- and Community-Based Services Measures

To calculate the program-level scores:

Score each item using the top box method; calculate a mode adjusted score for each respondent; calculate case mix adjusted scores for each program; and calculate means for the scale measures.

Scale Measures:

For each survey item, the top-box numerator is the number of respondents who selected the most positive response category.

Staff are reliable and helpful—Survey items 13, 14, 15, 19, 37, and 38

13: In the last 3 months, how often did {personal assistance/behavioral health staff} come to work on time?

14: In the last 3 months, how often did {personal assistance/behavioral health staff} work as long as they were supposed to?

15: In the last 3 months, when staff could not come to work on a day that they were scheduled, did someone let you know that {personal assistance/behavioral health staff} could not come that day?

19: In the last 3 months, how often did {personal assistance/behavioral health staff} make sure you had enough personal privacy when you dressed, took a shower, or bathed?

37: In the last 3 months, how often did {homemakers} come to work on time?

38: In the last 3 months, how often did {homemakers} work as long as they were supposed to?

Staff listen and communicate well—Survey items 28, 29, 30, 31, 32, 33, 41, 42, 43, 44, and 45

28: In the last 3 months, how often did {personal assistance/behavioral health staff} treat you with courtesy and respect?

29: In the last 3 months, how often were the explanations {personal assistance/behavioral health staff} gave you hard to understand because of an accent or the way {personal assistance/behavioral health staff} spoke English?

30: In the last 3 months, how often did {personal assistance/behavioral health staff} treat you the way you wanted them to?

31: In the last 3 months, how often did {personal assistance/behavioral health staff} explain things in a way that was easy to understand?

32: In the last 3 months, how often did {personal assistance/behavioral health staff} listen carefully to you?

33: In the last 3 months, did you feel {personal assistance/behavioral health staff} knew what kind of help you needed with everyday activities, like getting ready in the morning, getting groceries, or going places in your community?

41: In the last 3 months, how often did {homemakers} treat you with courtesy and respect?

42: In the last 3 months, how often were the explanations {homemakers} gave you hard to understand because of an accent or the way the {homemakers} spoke English?

43: In the last 3 months, how often did {homemakers} treat you the way you wanted them to?

44: In the last 3 months, how often did {homemakers} listen carefully to you?

45: In the last 3 months, did you feel {homemakers} knew what kind of help you needed?

Case manager is helpful—Survey items 49, 51, and 53

49: In the last 3 months, could you contact this {case manager} when you needed to?

51: In the last 3 months, did this {case manager} work with you when you asked for help with getting or fixing equipment?

53: In the last 3 months, did this {case manager} work with you when you asked for help with getting other changes to your services?

Choosing the services that matter to you—Survey items 56 and 57

56: In the last 3 months, did your [program-specific term for “service plan”] include . . .

57: In the last 3 months, did you feel {personal assistance/behavioral health staff} knew what’s on your [program-specific term for “service plan”], including the things that are important to you?

Transportation to medical appointments—Survey items 59, 61, and 62

59: Medical appointments include seeing a doctor, a dentist, a therapist, or someone else who takes care of your health. In the last 3 months, how often did you have a way to get to your medical appointments?

61: In the last 3 months, were you able to get in and out of this ride easily?

62: In the last 3 months, how often did this ride arrive on time to pick you up?

Personal safety and respect—Survey items 64, 65, and 68

64: In the last 3 months, was there a person you could talk to if someone hurt you or did something to you that you didn't like?

65: In the last 3 months, did any {personal assistance/behavioral health staff, homemakers, or your case managers} take your money or your things without asking you first?

68: In the last 3 months, did any {staff} yell, swear, or curse at you?

Planning your time and activities—Survey items 75, 77, 78, 79, 80, and 81

75: In the last 3 months, when you wanted to, how often could you get together with these family members who live nearby?

77: In the last 3 months, when you wanted to, how often could you get together with these friends who live nearby?

78: In the last 3 months, when you wanted to, how often could you do things in the community that you like?

79: In the last 3 months, did you need more help than you get from {personal assistance/behavioral health staff} to do things in your community?

80: In the last 3 months, did you take part in deciding what you do with your time each day?

81: In the last 3 months, did you take part in deciding when you do things each day—for example, deciding when you get up, eat, or go to bed?

Global Ratings Measures:

The numerator for each global measure includes the number of respondents who answered 9 or 10 for the item (on a scale of 0 to 10).

Global rating of personal assistance and behavioral health staff—Survey item 35

35: Using any number from 0 to 10, where 0 is the worst help from {personal assistance/behavioral health staff} possible and 10 is the best help from {personal assistance/behavioral health staff} possible, what number would you use to rate the help you get from {personal assistance/behavioral health staff}?

Global rating of homemaker—Survey item 46

46: Using any number from 0 to 10, where 0 is the worst help from {homemakers} possible and 10 is the best help from {homemakers} possible, what number would you use to rate the help you get from {homemakers}?

Global rating of case manager—Survey item 54

54: Using any number from 0 to 10, where 0 is the worst help from {case manager} possible and 10 is the best help from {case manager} possible, what number would you use to rate the help you get from {case manager}?

Recommendation Measures:

The numerator for each recommendation measure includes the number of respondents who answered Definitely Yes for the item (on a scale of Definitely No, Probably No, Probably Yes, or Definitely Yes). Item numbers and item text are listed below.

Would recommend personal assistance/behavioral health staff to family and friends—Survey item 36

36: Would you recommend the {personal assistance/behavioral health staff} who help you to your family and friends if they needed help with everyday activities? Would you say you recommend the {personal assistance/behavioral health staff}?

Would recommend homemaker to family and friends—Survey item 47

47: Would you recommend the {homemakers} who help you to your family and friends if they needed {program-specific term for homemaker services}? Would you say you recommend the {homemakers}?

Would recommend case manager to family and friends—Survey item 55

55: Would you recommend the {case manager} who helps you to your family and friends if they needed {program-specific term for case-management services}? Would you say you recommend the {case manager}?

Unmet Needs Measures:

The numerator for each unmet needs measure includes the number of respondents who answered No for that item (these items are then reverse coded so that higher scores reflect a better experience). Item numbers and item text are listed below.

Unmet need in dressing/bathing due to lack of help—Survey item 18

18: In the last 3 months, was this because there were no {personal assistance/behavioral health staff} to help you?

Unmet need in meal preparation/eating due to lack of help—Survey item 22

22: In the last 3 months, was this because there were no {personal assistance/behavioral health staff} to help you?

Unmet need in medication administration due to lack of help—Survey item 25

25: In the last 3 months, was this because there were no {personal assistance/behavioral health staff} to help you?

Unmet need in toileting due to lack of help—Survey item 27

27: In the last 3 months, did you get all the help you needed with toileting from {personal assistance/behavioral health staff} when you needed it? (not reverse coded).

Unmet need with household tasks due to lack of help—Survey item 40

40: In the last 3 months, was this because there were no {homemakers} to help you?

Physical Safety Measure:

The numerator for the following physical safety measure includes the number of respondents who answered No for this item (this item is then reverse coded so that higher scores reflect a better experience). The item number and item text is listed below.

Hit or hurt by staff—Survey item 71

71: In the last 3 months, did any {staff} hit you or hurt you?

Denominator Statement

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

For each measure, the denominator is the number of respondents (adult recipients of state developmental disabilities services) who provided valid answers to the respective survey question, except those that meet the exclusion criteria (see S.8. below for details).

If the denominator for a state is fewer than 20, the measure score is censored to protect the confidentiality of respondents.

#2967 CAHPS® Home- and Community-Based Services Measures

The denominator for all measures is the number of survey respondents. Individuals eligible for the CAHPS Home and Community-Based Services survey include Medicaid participants who are at least 18 years of age in the sample period, and have received HCBS services for three months or longer and their proxies. Eligibility is further determined using three cognitive screening items, administered during the interview:

1: Does someone come into your home to help you? (Yes, No)

2: How do they help you?

3: What do you call them?

Individuals who are unable to answer these cognitive screening items are excluded. Some measures also have topic-specific screening items as well. Additional detail is provided in S.9.

Individuals who are more likely to be good proxy respondents during the CAHPS Home and Community-Based Services survey data collection are: (a) those who are willing to respond on behalf of the participant; (b) unpaid caregivers, family members, friends, and neighbors; and (c) those who know the participant well enough that he or she is familiar with the services and supports the participants is receiving, having regular, ongoing contact with the participant. Examples of circumstances that increase the likelihood that someone has knowledge about the participant and their care situation include living with the participant, managing the participant's in-home care for a majority of the day, having regular conversations with the participant about the services they receive, in-person visits with the participant, and being present when services/supports are delivered. Individuals who are less likely to be good proxy respondents are: (a) those with paid responsibilities for providing services/supports to the participant, including family members and friends who are paid to help the participant; and (b) guardians or conservators whose only responsibility is to oversee the participant's finances. Due to the nature of data being collected through CAHPS, individuals who are paid to deliver HCBS services are discouraged from acting as a proxy.

Denominator Details

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

The NCI IPS consists of two main sections, denoted by Roman numerals I and II. Section I of the survey contains questions about personal experiences and therefore may only be answered by the individual receiving developmental disabilities services. Section II of the survey---featuring questions about topics such as community involvement, choices, rights,

and access to services—allows for responses from a “proxy,” defined as a person who knows the individual well (such as a family member or friend).

Generally speaking, the denominators are the numbers of respondents who are eligible to respond and gave a valid response. Specifically:

#PCP-1: The number of respondents with a valid Section I, who reported that they do not have a job and would like a paid job in the community

#PCP-2: The number of respondents with a valid Section I

#PCP-3: The number of respondents with a valid Section I, who indicated "yes" to the question about desire to increase independence in ADL.

#PCP-4: The number of respondents with a valid Section I

#PCP-5: This is a multi-item measure, therefore it does not have a simple form for the numerator and denominator

#CI-1: Social Connectedness: The number of respondents with a valid Section I

#CI-2: Has Friends: The number of respondents with a valid Section I

#CI-3: This is a multi-item measure, therefore it does not have a simple form for the numerator and denominator

#CI-4: This is a multi-item measure, therefore it does not have a simple form for the numerator and denominator

#CC-1: The number of respondents with a valid Section II

#CC-2: The number of respondents with a valid Section II

#CC-3 The number of respondents with a valid Section I

#CC-4: This is a multi-item measure, therefore it does not have a simple form for the numerator and denominator

#HLR-1: This is a multi-item measure, therefore it does not have a simple form for the numerator and denominator

Exclusion criteria apply. Please see S.8. and S.9. for more details.

#2967 CAHPS® Home- and Community-Based Services Measures

While Medicaid programs provide a range of HCBS from different provider types (which vary by state) for participants with long-term services and supports needs, the proposed provider-related measures in this submission focus on the most common provider types for adults receiving Medicaid HCBS. These include personal assistance providers, behavioral health staff, homemakers, and case managers.

Personal care services and homemaker services typically involve assistance with activities of daily living (ADL), bathing, dressing, grooming, toileting, eating, mobility and instrumental activities of daily living (IADL), meal preparation, housework, laundry, food shopping. Case management is an integral component of Medicaid HCBS programs; the role of the case manager includes working with the participant to assess his/her need for services/supports and developing a person-centered care/service plan, referring individuals to needed services, monitoring service delivery, and responding to the individual’s changing needs and circumstances.

Not all HCBS participants receive all services. Questions 4, 6, 8, and 11 assess which services the participant receives. Participants are then eligible for different survey questions based on these responses.

These questions are:

4: In the last 3 months, did you get {program specific term for personal assistance} at home?

6: In the last 3 months, did you get {program specific term for behavioral health specialist services} at home?

8: In the last 3 months, did you get {program specific term for homemaker services} at home?

11: In the last 3 months, did you get help from {program specific term for case manager services} to help make sure that you had all the services you needed?

In addition to only including those eligible for the relevant survey questions based on a Yes response to one or more of the questions above, only individuals who provided a valid response to the individual survey items are included in each measure's denominator (i.e., participants for whom a Don't Know or Refused, or those for whom an unclear response was recorded, are not counted in a measure's denominator).

Scale Measure 1: Staff are reliable and helpful

13: The number of surveys completed by all those who responded Yes to screener 4 or 6

14: The number of surveys completed by all those who responded Yes to screener 4 or 6

15: The number of surveys completed by all those who responded Yes to screener 4 or 6

19: The number of surveys completed by all those who responded Yes to screener 4 or 6

37: The number of surveys completed by all those who responded Yes to screener 8

38: The number of surveys completed by all those who responded Yes to screener 8

Scale Measure 2: Staff listen and communicate well

28: The number of surveys completed by all those who responded Yes to screener 4 or 6

29: The number of surveys completed by all those who responded Yes to screener 4 or 6

30: The number of surveys completed by all those who responded Yes to screener 4 or 6

31: The number of surveys completed by all those who responded Yes to screener 4 or 6

32: The number of surveys completed by all those who responded Yes to screener 4 or 6

33: The number of surveys completed by all those who responded Yes to screener 4 or 6

41: The number of surveys completed by all those who responded Yes to screener 8

42: The number of surveys completed by all those who responded Yes to screener 8

43: The number of surveys completed by all those who responded Yes to screener 8

44: The number of surveys completed by all those who responded Yes to screener 8

45: The number of surveys completed by all those who responded Yes to screener 8

Scale Measure 3: Case manager is helpful

49: The number of surveys completed by all those who responded Yes to screener 11

51: The number of surveys completed by all those who responded Yes to screener 11

53: The number of surveys completed by all those who responded Yes to screener 11

Scale Measure 4: Choosing the services that matter to you

56: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

57: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

Scale Measure 5: Transportation to medical appointments

59: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

61: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

62: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

Scale Measure 6: Personal safety and respect

64: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

65: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

68: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

Scale Measure 7: Planning your time and activities

75: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

77: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

78: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

79: The number of surveys completed by all those who responded Yes to screener 4 or 6

80: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

81: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

Global Rating Measures:

Global rating of personal assistance and behavioral health staff

35: The number of surveys completed by all those who responded Yes to screener 4 or 6

Global rating of homemaker

46: The number of surveys completed by all those who responded Yes to screener 8

Global rating of case manager

54: The number of surveys completed by all those who responded Yes to screener 11

Recommendation Measures:

Recommendation of personal assistance and behavioral health staff to family and friends

36: The number of surveys completed by all those who responded Yes to screener 4 or 6

Recommendation of homemaker to family and friends

47: The number of surveys completed by all those who responded Yes to screener 8

Recommendation of case manager to family and friends

55: The number of surveys completed by all those who responded Yes to screener 11

Unmet Needs Measures:

Unmet need in dressing/bathing due to lack of help

18: The number of surveys completed by all those who responded Yes to 16 and No to 17

Unmet need in meal preparation/eating due to lack of help

22: The number of surveys completed by all those who responded Yes to 20 and No to 21

Unmet need in medication administration due to lack of help

25: The number of surveys completed by all those who responded Yes to 23 and No to 24

Unmet need in toileting due to lack of help

27: The number of surveys completed by all those who responded Yes to 26

Unmet need with household tasks due to lack of help

40: The number of surveys completed by all those who responded No to 39

Physical Safety Measures:

Hit or hurt by staff

71: The number of surveys completed by all those who responded Yes to screener 4, 6, 8, or 11

Exclusions

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

At the end of Section I, the surveyor assesses whether the respondent appears to understand at least one question and answers in a cohesive manner. This assessment is the only subjective process in the exclusion determination process, but it is not done on an arbitrary or state-by-state basis. Rather, it is based on a protocol, included in the survey manual and reviewed during surveyor trainings, that apply uniformly to all surveyors across different participating states. The protocol is straightforward—the section must be marked “valid” if at least one question in the section was answered in a manner that the basic level of comprehension was shown, and a clear response given either verbally (e.g. yes/no) or non-verbally (nodding/shaking head). NCI and participating states routinely conduct surveyor training and surveyor shadowing and reviewing processes that ensure, among other things, that surveyors are applying this assessment (whether or not Section I was valid) strictly based on the protocol. If the surveyor´s assessment is that Section I is not valid, the respondent´s Section I data are flagged for exclusion from the numerators and denominators. However, the individual is not removed from the dataset.

If Section I data are excluded, Section II data are flagged for exclusion from the numerators and denominators -unless- a proxy respondent was used in Section II. If the respondent or proxy did not answer any questions in Section II, the survey is removed from the denominators of Section II items.

Responses are excluded from numerators and denominators for Section I items if:

(a) The surveyor indicated that the respondent did not give consistent and valid responses, or

(b) All questions in Section I were left blank, or marked "not applicable" or "don’t know".

Responses are excluded from numerators and denominators for Section II items if:

(a) the individual receiving supports was marked as the sole respondent to all questions in Section II but Section I was deemed invalid, or

(b) All questions in Section II were left blank, or marked "not applicable" or "don't know".

For each measure item, missing responses and responses indicating "not applicable" or "don't know" were excluded from denominators. The distribution of exclusions among states is shown in Testing Attachment 2b2.2. Please see S.9. for more details on denominator exclusions.

#2967 CAHPS® Home- and Community-Based Services Measures

Individuals less than 18 years of age and individuals that have not received HCBS services for at least 3 months should be excluded. During survey administration, additional exclusions include individuals for whom a qualifying response was not received for the Cognitive Screening Questions mentioned in the denominator statement below.

In CMS's sample, 48 participants did not pass the cognitive screener (39 older adults and individuals with physical disabilities; 6 with an intellectual disability or developmental disability [ID/DD], and 3 with an acquired brain injury [ABI].

Exclusion Details

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

In general, missing responses and responses indicating "not applicable" or "don't know" were excluded from denominators. Denominator exclusions for each measure:

-Paid Community Job Goal: Respondents with an invalid Section I (as defined in S.8.), and those who responded "not applicable" or "don´t know" to the survey question "Would you like to have a job in the community?" are excluded

-Person-Centered Goals: Respondents with an invalid Section I are excluded

-ADL Goal: Respondents with an invalid Section I, and those who did not indicate "yes" to the question about desire to increase independence in ADL are excluded

-Lifelong Learning: Respondents with an invalid Section I are excluded

-Satisfaction with Community Inclusion Scale: Respondents with an invalid Section I are excluded

-Social Connectedness: Respondents with an invalid Section I are excluded

-Has Friends: Respondents with an invalid Section I are excluded

-Transportation Availability Scale: Respondents with an invalid Section I are excluded

-Community Inclusion Scale: Respondents with an invalid Section II are excluded

-Chose Staff: Respondents with an invalid Section II are excluded

-Chose Case Manager: Respondents with an invalid Section II are excluded

-Can Stay Home When Others Leave: Respondents with an invalid Section I are excluded

-Life Decisions Scale: Respondents with an invalid Section II are excluded

-Respect for Personal Space Scale: Respondents with an invalid Section I are excluded

There are no pre-screening procedures prior to the survey. Participation is voluntary, and individual surveys are de-identified. Exclusion of responses occurs at the time of data analysis by HSRI, based on the criteria described above. There is no threshold of number of answers to be met for a "complete" survey.

#2967 CAHPS® Home- and Community-Based Services Measures

Individuals who do not provide an answer for one or more of the following cognitive screening items should be excluded. If the respondent does not answer (e.g., provides an invalid response, does not respond, or indicates "I don't know"), the interviewer should end the interview.

1: Does someone come into your home to help you? (Yes or No)

2: How do they help you? Open-Ended Response

Examples of correct responses include:

- "Helps me get ready every day"
- "Cleans my home"
- "Works with me at my job"
- "Helps me to do things"
- "Drives me around"

3: What do you call them? Open-Ended Response

Examples of sufficient responses include:

- "My worker"
- "My assistant"
- Names of staff ("Jo", "Dawn", etc.)

Risk Adjustment

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

Other Statistical risk model and stratification

#2967 CAHPS® Home- and Community-Based Services Measures

Statistical risk model

Stratification

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

Risk-adjusted Life Decisions and Community Inclusion Scales, are further stratified by 5 residential setting categories:

category #1 - Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID), nursing facility, or other institutional setting

#2 - Group residential setting (e.g., group home)

#3 - Own home or apartment

#4 - Parents' or relatives' home

#5 - Foster care or host home

There are both conceptual/policy and empirical reasons for this stratification. Conceptually, the need for types and mixes of HCBS supports vary by residential setting, impacting the interpretation and program/policy implications of outcomes. Providing scores for each residential setting separately provides states with meaningful information about the outcomes of these different service/support strategies, offering detailed,

actionable recommendations for improvement. Further, risk-adjusted measures significantly vary by residential setting, providing empirical support for the informational value of reporting these measures separately for the 5 settings.

The constructed variable res_type5 was used as the stratification variable. Res_type5 is recoded from background information (administrative records) variable TYPEHOME18, Type of Residence:

The included response TYPEHOME18 categories were:

res_type5 category #1 - ICF/IID, nursing facility or other institutional setting:

1. ICF/IID, 4-6 residents with disabilities
2. ICF/IID, 7-15 residents with disabilities
3. ICF/IID, 16 or more residents with disabilities
4. Nursing facility
5. Other specialized institutional facility

res_type5 category #2 - Group residential setting

6. Group living setting, 2-3 people with disabilities
7. Group living setting, 4-6 people with disabilities
8. Group living setting, 7-15 people with disabilities

res_type5 category #3 - Own home or apartment

9. Lives in own home or apartment; may be owned or rented, or may be sharing with roommate(s) or spouse

res_type5 category #4 - Parent/relative's home

10. Parent/relative's home (may include paid services to family for residential supports)

res_type5 category #5 - Foster or host home

11. Foster care or host home (round-the-clock services provided in a single-family residence where two or more people with a disability live with a person or family who furnishes services)
12. Foster care or host home (round-the-clock services provided in a single-family residence where only one person with a disability lives with a person or family who furnishes services—sometimes called shared living) Other

The TYPEHOME18 categories excluded from res_type5 were:

13. Homeless or crisis bed placement
14. Other (specify):____
99. Don't know

#2967 CAHPS® Home- and Community-Based Services Measures

The intended primary unit of analysis is the Medicaid HCBS program. However, states may wish to stratify by sub-state agencies such as counties or regional entities with program operational and budgetary authority. In some instances, a state may wish to stratify by case-management agency as well, given they are typically viewed as having substantial responsibility for developing beneficiary service and support plans as well as monitoring whether the service/support plan addresses the person's needs and meet their goals.

States are increasingly moving users of Medicaid long-term services and supports, including HCBS, into managed care arrangements (typically referred to as Managed Long-

Term Services and Supports or MLTSS) where the managed care organization (MCO) is the primary accountable entity for ensuring HCBS beneficiary, health, welfare and quality of life. As such, we also anticipate some states may want to stratify based on (MCO).

Type Score

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

Rate/proportion better quality = higher score

#2967 CAHPS® Home- and Community-Based Services Measures

Other (specify): Case-mix adjusted top box score better quality = higher score

Algorithm

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

Please see attached file SuppTable_Measures_210420_508.xlsx for details.

#2967 CAHPS® Home- and Community-Based Services Measures

Scoring specifications for the measures will follow the same general scoring approach as used by other CAHPS surveys that use the CAHPS analysis program. The measures are based on case-mix adjusted top box scores. The research team suggests general health rating, mental health rating, age, education, gender, whether respondent lives alone, and response option as case- mix adjusters for these measures. We also recommend including survey mode as an additional adjustment variable and proxy status if proxy responses are permitted. More information about case-mix adjustment is available in Instructions for Analyzing Data from CAHPS Surveys (available from the downloadable zip file at http://www.ahrq.gov/cahps/surveys-guidance/cg/instructions/index.html).

To create scores for each scale measure:

1. Calculate the score for each item using the top box method.
2. Calculate a mode adjusted score for each item.
3. Calculate case-mix adjusted scores for each program.
4. Calculate means for the scale measures weighting each item equally.

The steps for user-defined calculations of risk-adjusted scores can be found in Instructions for Analyzing Data from CAHPS Surveys: Using the CAHPS Analysis Program Version 4.1 available from the downloadable zip file at http://www.ahrq.gov/cahps/surveys-guidance/cg/instructions/index.html.

To create scores for each global rating and individual item measure, follow steps 1-3 above.

Submission items

#3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures

5.1 Identified measures: 2967 : CAHPS® Home- and Community-Based Services Measures

5a.1 Are specs completely harmonized? No

5a.2 If not completely harmonized, identify difference, rationale, impact: NQF 2967 - CAHPS Home and Community Based Services Measures could be used to survey the same

population as it is described as a cross-population survey. NCI for ID/DD HCBS Measures, on the other hand, were specifically designed to survey the target population of adults with intellectual or developmental disabilities who are receiving HCBS. That said, the NCI for ID/DD HCBS Measures do not have the same focus as HCBS-CAHPS measures. One area which merits mention is the transportation item because it may appear to be related with a similar focus. The Transportation availability scale that is in this measure set includes a measure of having transportation available when needed. This is not the same measure as the "Transportation to Medical Appointments" scale that exists as part of HCBS-CAHPS, which only focuses on medical appointments. Home and Community Based Services (HCBS) are intended to support people to live a life in the community that extends beyond merely medical appointments, therefore a measure of broader access to transportation is important to have.

5b.1 If competing, why superior or rationale for additive value: We do not know of any NQF-endorsed measures that conceptually address both the same measure focus and the same target population.

#2967 CAHPS® Home- and Community-Based Services Measures

5.1 Identified measures:

5a.1 Are specs completely harmonized?

5a.2 If not completely harmonized, identify difference, rationale, impact: Not applicable.

5b.1 If competing, why superior or rationale for additive value: Not applicable.

Appendix F: Pre-Evaluation Comments

No comments were received as of June 10, 2021.

Appendix G: Post-Evaluation Comments

NQF #3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures, Comment #7750

Standing Committee Recommendation: Measure Recommended for Endorsement

Comment ID#: 7750

Commenter: Submitted by Mary McGurran

Council / Public: Public

Comment Period: Post-Evaluation Public and Member Commenting

Date Comment was Submitted: 9/1/2021

Developer Response Required? Yes

Level of Support: N/A

Theme: Generally supportive with recommendations for improvement

Comment

Health, welfare, safety. In Minnesota reports of suspected vulnerable maltreatment are confidential and reporter identity protected. Reporters are notified on if report was accepted. Reporters not required to notify family. This encourages reporting to discover and respond. Family may be reported by someone outside family. Family notification may not be in the person's interests/wishes. Limited information sharing protects person's privacy. Investigation of licensed providers are public. Suggest: If a report of abuse, neglect or financial exploitation was filed by a family respondent in the past 12 months, the percentage of family respondents who identify they were notified of the outcome of the report in a timely manner. If a report of abuse, neglect or financial exploitation was filed by a family respondent in the past 12 months, the percentage of family respondents who identify services and supports were offered to stop the abuse, neglect or financial exploitation.

Developer Response

Thank you for pointing out the importance of measures about abuse or neglect and of monitoring the timing and quality of responses to reports of maltreatment. Although not as part of #3622, National Core Indicators (NCI) does collect this information through the NCI Family Surveys, administered to family members of Home- and Community-Based Services (HCBS) recipients. For example, in the Adult Family Survey (one of NCI Family Surveys), family respondents are asked the following questions:

“Within the past year, was a report of abuse or neglect filed on behalf of your family member?

If yes, did the appropriate people respond to the report? If someone outside of your family reported abuse or neglect, were you notified of the report in a timely manner?”

The two measures suggested in your comment appeared similar to those Adult Family Survey questions. Here is a recent report featuring results from these Adult Family Survey questions.

Notably, NCI Family Surveys are entirely different in terms of respondent and methodology from the NCI In-Person Survey (IPS), which the 14 measures submitted as part of #3622 were based on. IPS is person-reported, person-centered and focused on key HCBS domains identified by the NQF report entitled "Quality in Home and Community-Based Services to Support Community Living: Addressing Gaps in Performance Measurement". We hope this clarification is helpful and would love to continue the conversation with you and answer any additional questions about IPS and Family Surveys. Many thanks for taking the time to comment on #3622.

NQF Response

Thank you for your comment.

NQF Committee Response

N/A

NQF #3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures, Comment #7780

Standing Committee Recommendation: Measure Recommended for Endorsement

Comment ID#: 7780

Commenter: Lauren Agoratus, Family Voices NJ; Submitted by Lauren Agoratus

Council / Public: Public

Comment Period: Post-Evaluation Public and Member Commenting

Date Comment was Submitted: 9/16/2021

Developer Response Required? Yes

Level of Support: N/A

Theme: Generally supportive but with specific concerns

Comment

We strongly support the 5 measures on PCP (person-centered planning), particularly community inclusion. We also support the 4 measures on community inclusion specifically. In addition, we support the 4 measures regarding choice and control. #CC-4 needs more details: choice regarding what (e.g. when/what to eat, when to sleep, roommates, etc.) Although we support the domain on human rights, this encompasses so much more than personal space. Self-advocates need to know how to appeal denials of services and programs such as SSI (supplemental security income), how to get insurance, how to appeal denied claims, etc. We would recommend a measure addressing ADLs (activities of daily living). We would also recommend a measure regarding necessary medical supports (including respite for family caregivers), as well as behavioral health, which allows individuals with disabilities to remain in their communities. This could include out-of-state authorizations and direct support during hospitalization.

Further, under adjustment/stratification regarding residential placement, this list is not comprehensive. There is supported housing, supervised apartments, independent living apartments, etc. We note that there were concerns regarding diversity in sample populations. We also not that while reliability/ validity testing was done, there were concerns with feasibility. We agree that some CAHPS (consumer assessment of health providers and systems) measures may be considered “competing measures” and will be discussed by the committee in the post-comment call. We specifically note the CAHPS measure regarding physical safety/harm as the issue of restraints and injuries still exists, particularly in congregate setting, and institutional abuse is another reason HCBS is so essential.

Developer Response

Thank you for your support of the fourteen #3622 items and your suggestions of additional items.

We appreciate your strong support of the 5 PCP measures and the 4 Community Inclusion measures. Regarding #CC-4 Life Decisions Scale, indeed there were more details included with the original submission that were not part of the PEF Draft Report. Here are the survey items that make up the scale:

- Who chose the place where you live?
- Did you choose the people you live with?
- [Ask only if person has a job] Who chose the place you work?
- [Ask only if person attends a day program] Who chose your day program or workshop?
- Do you choose your staff?

We recognize the importance of the domain on Human Rights and agree that more items should be included in this domain in the future. We did not intend for #HLR-1 Respect for Personal Space Scale to represent the entire domain.

Regarding residence types, we would like to clarify that the survey instrument provides response options for 14 types of residence arrangements, including an "Other: Please specify ____" option (0.7% of responses). As explained on Page 12 of the PEF Draft Report, we summarized the data gathered from the 14-category variable into the condensed 5-category variable for stratification based on conceptual and methodological considerations. Considering that less than 1% of the responses are in the "Other" category, we think that most respondents find the 14 categories sufficiently inclusive of the range of possible residential arrangements.

Regarding feasibility, we have previously provided clarifications both via written responses and in prior meetings. A summary can be read on Page 14 of the PEF Draft Report. We would welcome any additional discussions on any specific concerns regarding feasibility.

Last but not least, regarding "diversity in the sample population", we would like to better understand if there are any specific concerns. As a principle, we recognize and embrace various types of diversity – age, gender, race/ethnicity, disability, language, preferred communication methods, etc., which is well-reflected in our survey questions and protocols. The NCI sample is randomly drawn from all adult recipients of Home- and Community-Based Services with IDD in the participating states, precisely to capture the full range of diversity of the population they were drawn from.

We hope this response is helpful in addressing the concerns raised and look forward to further discussion.

NQF Response

N/A

NQF Committee Response

The Standing Committee thanks the commenter for their comment and accepts the response provided by the measure developer. The residential categorization of concern is explained in full in the measure submission and accounts for unrepresented response options. The Standing Committee also had questions about feasibility and diversity in the sample population and discussed these items at length during the measure evaluation meeting. In evaluating these measures against NQF's endorsement

criteria, the Standing Committee agreed the measure fills an important measurement gap and meets all NQF criteria. The Standing Committee ultimately recommends this measure for endorsement.

NQF #3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures, Comment #7797

Standing Committee Recommendation: Measure Recommended for Endorsement

Comment ID#: 7797

Commenter: Submitted by Desiree Kameka

Council / Public: Public

Comment Period: Post-Evaluation Public and Member Commenting

Date Comment was Submitted: 9/21/2021

Developer Response Required? Yes

Level of Support: N/A

Theme: Generally supportive with recommendations for improvement

Comment

In the last decade, research has demonstrated what we knew intrinsically to be true: health starts at home. Furthermore, when individuals, even those with the most complex needs, are supported to make decisions about where and with whom they live, and from whom they receive support, we can improve services, reduce costs, increase efficiency and, most importantly, improve their quality of life. It is why we partnered with Arizona State University's Morrison Institute to develop A Place In The World: Fueling Housing and Community Options For Adults With Autism and Other Neurodiversities (APITW) in order to present a wide spectrum of possibilities for housing and community development to meet the needs of the neurodiverse population. APITW provides the foundational nomenclature for housing and service delivery models with the goal to further define market segments, establishes best practices and guiding principles, and helps drive crucial partnerships that address pressing needs resulting from the current housing crisis. Additionally, APITW includes a Policy Paper, funded by the Daniel Jordan Fiddle Foundation, which reviewed the historical evolution of federal policies that influence housing and long-term services and supports (LTSS) for adults with autism and/or intellectual/developmental disabilities (I/DD). Over the next decade, 707,000 to 1,116,000 teens diagnosed with autism will turn 18. Many of these individuals will age out of school support systems but will be deemed ineligible for HCBS. They will continue to need LTSS in their homes and communities, which will enable them to engage in work activities, lead healthy and self-directed lives.Federal programs are seriously limited in their scope and capacity to provide necessary housing assistance for adults with autism, resulting in a shortage of affordable housing and persistent fears from self-advocates and families about homelessness or displacement. Time is limited for millions of adults with autism and/or I/DD who are living with aging caregivers, as well as the significant increase in those transitioning to adulthood annually. APITW identified the data gaps needed to calculate the total unmet housing need, to expand the definition of accessibility to address the needs of this population and to make this population a public policy priority.We reviewed the NCI-IDD measures and believe the data collected will truly offer a glimpse into

the everyday lives of HCBS recipients. In the future, we hope that states can also incorporate segmentation as defined in the APITW nomenclature such as levels of support need, service delivery model used -- whether the person lives in a provider-controlled or consumer-controlled setting.The following indicators should be ranked among the Top 5 for impact on quality of life measurement:

- % of people who do the things they like in their communities as much as they want
- % of people who do things in the community with the people they want
- % of people who feel that they belong to the group, organization or community they take part in: they can be themselves and feel included
- Of those who do not live in the family home, % of people who reported having input in choosing where they live
- % of people who report having input in choosing their daily schedule

We are concerned that the framing of some questions is ableist and may harm those being asked by neurotypical or able-bodied facilitators that underscore the value to an HCBS recipient that their relationships with non-disabled peers is more valuable than those who have a disability, thus they are perceived as not having as much value as their peers without disabilities. This is a direct ableist assumption being asked of the minority without considering how much time they want to spend with people who do not have disabilities. For example, to ask an individual who is African-American how much time they have spent with their caucasian peers would be underscoring the racist assumption that its best to have causcasion friends because they can potentially extend their privileges to you, the minority. Indicators of concern of which we hope the facilitators have been thoroughly trained to thwart ableist bias to prevent harm:

- The percentage of people who report they participated in specific integrated activities in the past month.
- The percentage of people who report that some or all of the groups, organizations, and communities they take part in include people without disabilities.This can be mitigated by first asking if they are able to spend the time they want with friends who are not in HCBS services with them or do not have disabilities. Asking the barriers to access would also be tremendous and underscore that the question is not ableist, but ensuring they are supported to be with people who are not part of the HCBS programming if they desire.

Without a doubt, the majority of the NCI-IDD measures will add invaluable data to assist policymakers and stakeholders to assess the support and services provided to individuals with IDD as well as other HCBS recipients. We are committed to continuing to develop properties and opportunities, and support others as well, to develop initiatives which place a premium on consumer-controlled settings and consumer-directed supports, we wholeheartedly endorse the inclusion of these NCI-IDD data measures in the NQF PEF.

Thank you for your consideration of our comments,

Developer Response

Thank you for the extensive comment—we have reviewed it carefully and appreciate the opportunity to respond. Here are some points of clarification for your consideration.

We agree that the framing of the questions is vitally important, and we take your concern regarding framing very seriously.

The indicators of concern that you quoted were:

- "The percentage of people who report they participated in specific integrated activities in the past month"
- "The percentage of people who report that some or all of the groups, organizations, and communities they take part in include people without disabilities"

We recognize that these are National Core Indicators In-Person Survey (IPS) indicators. The purposes of those indicators are as population-level quality measures. From a population- or systems-level perspective, it is important to understand whether there are state differences or trends on these indicators that suggest limited opportunities for integrated community engagement. To clarify, these two indicators were not in the 14 measures we submitted for consideration.

These indicators are related to our submitted measure PCP-5, and especially PCP-5.4 (bolded below):

- Question PCP-5.1. Think about how often you went out for entertainment in the past month. Would you like to go out for entertainment more, less, or the same amount as now?
- Question PCP-5.2. Think about how often you went to a restaurant or coffee shop in the past month. Would you like to go out to a restaurant or coffee shop more, less, or the same amount as now?
- Question PCP-5.3. Think about how often you went to a religious service or spiritual practice in the past month. Would you like to go to religious services or spiritual practices more, less, or the same amount as now?
- **Question PCP-5.4. Do you want to be a part of more groups in your community?**

For each of the questions listed above, the framing is Person-Centered Planning and Practice—it matters most what the survey respondent deemed satisfactory or unsatisfactory, important or unimportant. No assumption is placed on any of frequency or preference options for any of the listed activities. Just because these activities are mentioned does not mean they are endorsed. For example, the fact that "coffee shops" were mentioned does not mean the measure endorses coffee shops over other types of establishments. Similarly, in Question PCP-5.4, the mention of "groups in the community"— which may be interpreted to be inclusive (people with and without disabilities) rather than exclusive— does not mean the respondent should favor one way or another. The focus of the question was the respondent's preference. The question that precedes PCP-5.4 in the survey instrument and describes what would be considered a community group is carefully worded to refrain from implying that any type of group is preferable to any other: "Are you a part of any community groups? (This includes church groups, book clubs, knitting groups or any other formal or informal community group in an inclusive setting.)" It is our survey protocol to present all questions and response options equally without bias or preference. Surveyors are trained to avoid implicit or explicit value judgments in response to participants' answers. At the beginning of the survey, respondents are reminded that there are no right or wrong answers. For Question PCP-5.4, the same applies. We recognize and respect the full range of opinions regarding these questions.

Thank you for bringing APITW to our attention. We will review the policy paper and look into the nomenclature for levels of support needs and service delivery models.

In summary, we greatly appreciate your input and your support of #3622. Hope this response is helpful in addressing your points of concern. We are always open to opportunities to further improve our measures and your comment is highly valued.

NQF Response

Thank you for your comment.

NQF Committee Response

N/A

NQF #3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures, Comment #7748

Standing Committee Recommendation: Measure Recommended for Endorsement

Comment ID#: 7748

Commenter: Submitted by Patricia Sastoque

Council / Public: Public

Comment Period: Post-Evaluation Public and Member Commenting

Date Comment was Submitted: 8/31/2021

Developer Response Required? No

Level of Support: N/A

Theme: Supportive

Comment

I am writing to support the endorsement of the NCI measure by the National Quality Forum. I believe that the endorsement of this NCI measure is essential to ensure sound measurement of a key facet of long term supports and services and will contribute positively to efforts to monitor and improve quality supports for people with intellectual and developmental disability. Endorsement of these measures is an important addition to NQF's limited set of endorsed measures of quality in Home and Community Based Supports.

Thank you for the opportunity to provide comment and support for the endorsement of the NCI measures. Inclusion of these in the NQF measures will begin to address an important gap in measures of community based LTSS and will be essential to ensure that the supports and services provided result in positive outcomes for individuals receiving support.

Developer Response

N/A

NQF Response

Thank you for your comment.

NQF Committee Response

N/A

NQF #3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures, Comment #7764

Standing Committee Recommendation: Measure Recommended for Endorsement

Comment ID#: 7764

Commenter: Submitted by Julia Walsh

Council / Public: Public

Comment Period: Post-Evaluation Public and Member Commenting

Date Comment was Submitted: 9/9/2021

Developer Response Required? No

Level of Support: N/A

Theme: Additional considerations, PROM

Comment

I am writing to support the endorsement of the NCI measure by the National Quality Forum.

- Endorsement of these measures is an important addition to NQF's limited set of endorsed measures of quality in Home and Community Based Supports.
- NCI measures are tailored to capture quality information directly from the population with intellectual and developmental disabilities.
- The National Core Indicators measure under consideration by NQF supports a vision of quality, recognizes the essential role that HCBS plays in people's lives, and prioritizes quality monitoring and quality improvement to achieve efficient, effective, equitable supports for people with disabilities.
- The specific domains covered in the NCI measure that is under review: person centered planning, community inclusion, choice and control, and human rights are particularly in need and are indicators of high-quality service outcomes.
- I believe that the endorsement of this NCI measure is essential to ensure sound measurement across the life span for supports and services and will contribute positively to efforts to monitor and improve quality supports for people with intellectual and developmental disability.

Thank you for the opportunity to provide comment and support for the endorsement of the NCI measures. Inclusion of these in the NQF measures will begin to address an important gap in measures of community based LTSS and will be essential to ensure that the supports and services provided result in positive outcomes for individuals receiving support.

Developer Response

N/A

NQF Response

Thank you for your comment.

NQF Committee Response

N/A

NQF #3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures, Comment #7776

Standing Committee Recommendation: Measure Recommended for Endorsement

Comment ID#: 7776

Commenter: Tara Giberga, PA Office of Developmental Programs; Submitted by Tara Giberga

Council / Public: Public

Comment Period: Post-Evaluation Public and Member Commenting

Date Comment was Submitted: 9/13/2021

Developer Response Required? No

Level of Support: N/A

Theme: Supportive

Comment

Pennsylvania's Office of Developmental Programs (ODP) is thankful for the opportunity to provide comments in support of endorsing the 14 quality indicators of services and supports for people with intellectual and developmental disabilities (IDD), submitted by NCI for state IDD systems (NCI-IDD), to the National Quality Forum (NQF). ODP currently uses numerous NCI measures to evaluate service system performance.

Domains covered by the NCI indicators under review include person-centered planning, community inclusion, choice and control, and human rights, and represent high priority needs, and therefore indicators of high-quality service outcomes. NCI measures are crafted to capture quality information directly from the IDD population and thus the measures under consideration by NQF support a vision for quality that recognizes the value of inclusion and input from the IDD population and the critical role that HCBS play in lives. Inclusion of the NCI measures in NQF is a great start at addressing critical gaps and this unprecedented opportunity to have meaningful indicators of person-centeredness and service quality for this population of people, by this esteemed body, is very exciting!

Developer Response

N/A

NQF Response

Thank you for your comment.

NQF Committee Response

N/A

NQF #3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures, Comment #7777

Standing Committee Recommendation: Measure Recommended for Endorsement

Comment ID#: 7777

Commenter: Cathy Lerza, Kentucky Division of Developmental and Intellectual Disabilties; Submitted by Cathy Lerza

Council / Public: Public

Comment Period: Post-Evaluation Public and Member Commenting

Date Comment was Submitted: 9/15/2021

Developer Response Required? No

Level of Support: N/A

Theme: Supportive

Comment

The Kentucky Division of Developmental and Intellectual Disabilities supports the endorsement of the NCI-ID/DD measures by the National Quality Forum. Kentucky is one of 46 states currently using the measures. While most states use NCI for measuring quality, NQF currently has few endorsed measures of quality in Home and Community Based Supports. These NCI measures are particularly useful to us because they are specifically designed to gather information directly from people with intellectual and developmental disabilities.

Developer Response

N/A

NQF Response

Thank you for your comment.

NQF Committee Response

N/A

NQF #3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures, Comment #7778

Standing Committee Recommendation: Measure Recommended for Endorsement

Comment ID#: 7778

Commenter: Kim Opsahl, State of Indiana/FSSA/DDRS; Submitted by Shelly Thomas

Council / Public: Public

Comment Period: Post-Evaluation Public and Member Commenting

Date Comment was Submitted: 9/16/2021

Developer Response Required? No

Level of Support: N/A

Theme: Supportive

Comment

On behalf of the Division of Disability and Rehabilitative Services in the State of Indiana, we are writing to support the endorsement of the NCI measure by the National Quality Forum. Over 30,000 individuals with intellectual and developmental disabilities are currently being supported by a Home and Community Based Services waiver in Indiana. Including their voice is an essential component in assessing long term supports and services. Below are additional areas of importance:

- Endorsement of these measures is an important addition to NQF's limited set of endorsed measures of quality in Home and Community Based Services.
- NCI measures are tailored to capture quality information directly from the population with intellectual and developmental disabilities.
- The National Core Indicators measure under consideration by NQF supports a vision of quality and recognizes the essential role that HCBS plays in people's lives, and prioritizes quality monitoring and quality improvement to achieve efficient, effective, equitable supports for people with disabilities.
- The specific domains covered in the NCI measure that is under review: person centered planning, community inclusion, choice and control, and human rights are particularly in need and are indicators of high quality service outcomes.
- I believe that the endorsement of this NCI measure is essential to ensure sound measurement of a key facet of long term supports and services and will contribute positively to efforts to monitor and improve quality supports for people with intellectual and developmental disability.

Thank you for the opportunity to provide comment and support for the endorsement of the NCI measures. Inclusion of these in the NQF measures will begin to address an important gap in measures of community based LTSS and will be essential to ensure that the supports and services provided result in positive outcomes for individuals receiving support.

Developer Response

N/A

NQF Response

Thank you for your comment.

NQF Committee Response

N/A

NQF #3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures, Comment #7782

Standing Committee Recommendation: Measure Recommended for Endorsement

Comment ID#: 7782

Commenter: Christina Wu, National MLTSS Health Plan Association; Submitted by Christina Wu

Council / Public: Public

Comment Period: Post-Evaluation Public and Member Commenting

Date Comment was Submitted: 9/16/2021

Developer Response Required? No

Level of Support: N/A

Theme: Supportive

Comment

The National MLTSS Health Plan Association represents health plans that contract with states to provide long-term services and supports (LTSS) to beneficiaries through the Medicaid program. Our members currently cover the large majority of all enrollees in MLTSS plans and assist states with delivering high-quality LTSS at the same or lower cost as the fee-for-service system with a focus on ensuring beneficiaries' quality of life and ability to live as independently as possible. Member organizations include Aetna Inc., AmeriHealth Caritas, Anthem, Centene Corp., Commonwealth Care Alliance, Inclusa Inc., L.A. Care Health Plan, Lakeland Care, Molina Healthcare, UPMC Health Plan and VNSNY CHOICE.

The National MLTSS Health Plan Association supports the endorsement of the 14 NCI-ID/DD measures by the National Quality Forum. Many of the measures under consideration mirror the NCI-AD (Aging and Disabilities) measures, which the MLTSS Association supports. These measures are crafted to capture information on person-centered outcomes and service quality directly from the population with ID/DD (e.g., the service plan includes things that are important to the member). The specific domains covered in the proposed NCI measure (i.e., person-centered planning and coordination, community inclusion, choice and control, and human and legal rights) are important and appropriate indicators of high-quality

outcomes for home and community-based services (HCBS). Given the current dearth in standardized quality measures for HCBS, inclusion of these NCI-ID/DD measures in NQF-endorsed measures will begin to address this critical gap and drive the field towards greater consistency across payers and states, and improve overall consumer choice, quality expectations, and policy advancement.

Developer Response

N/A

NQF Response

Thank you for your comment.

NQF Committee Response

N/A

NQF #3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures, Comment #7783

Standing Committee Recommendation: Measure Recommended for Endorsement

Comment ID#: 7783

Commenter: Barbara Palmer, Agency for Persons with Disabilities - Florida; Submitted by Edwin DeBardeleben

Council / Public: Public

Comment Period: Post-Evaluation Public and Member Commenting

Date Comment was Submitted: 9/16/2021

Developer Response Required? No

Level of Support: N/A

Theme: Additional considerations

Comment

To Whom It May Concern:

I am writing to support the addition of the new measures developed by the National Core Indicators' (NCI) to be used by the National Quality Forum (NQF). Endoresement of these measures is an important addition to NQF's limited set of endorsed quality measures of Home and Community Based Services (HCBS). The NCI measures are tailored to capture quality information directly from the population with intellectual and developmental disabilties.

The NCI measures under consideration by NQF supports a vision of quality, recognizes the essential role that HCBS plays in people's lives, and prioritizes quality monitoring and improvement to achieve efficient, effective, equitable supports for people with disabilities. The specific domains covered in the NCI measures that are under review are: person centered planning, community inclusion, choice and control, and human rights.

I believe that the endoresment of NCI measures is essential to ensure sound measurement of a key facet of long-term supports and services and will contribute positively to efforts to monitor and improve quality supports for people with intellectual and developmental disability.

Thank you for the opportunity to provide comment and support for the endorsement of the NCI measures. Inclusion of these in the NQF measures will begin to address an important gap in measures of community-based long-term servics and supports and will be essential to ensure that the supports and services provided result in positive outcomes for individuals receiving supports.

Sincerely,

Barbara Palmer

Director

Developer Response

N/A

NQF Response

Thank you for your comment.

NQF Committee Response

N/A

NQF #3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures, Comment #7784

Standing Committee Recommendation: Measure Recommended for Endorsement

Comment ID#: 7784

Commenter: Submitted by Leslie Morrison

Council / Public: Public

Comment Period: Post-Evaluation Public and Member Commenting

Date Comment was Submitted: 9/16/2021

Developer Response Required? No

Level of Support: N/A

Theme: Supportive

Comment

The California Department of Developmental Services supports the endorsement of the five National Core Indicator (NCI) measures by the National Quality Forum (NQF). We serve over 355,000 indiividuals with intellectual and developmental disabilities on a monthly basis. Including their perspective is an essential component of evaluating long term supports and services.

These measures would add critical, focused, consumer-centered measures to the NQF's existing endorsed measures of quality for Home and Community Based Services. These measures would enable consideration of the actual voices of people with intellectual and developmental disabilities regarding their ability to make life choices and achieve community inclusion and participation. This information would complement other available administrative and fiscal information about long-term services and supports. NQF's endorsement would provide an important push forward for efforts to achieve efficient, effective, and equitable supports for people with intellectual and developmental disabilities. Thank you for the opportunity to provide comment and support for the endorsement of these NCI measures.

Developer Response

N/A

NQF Response

Thank you for your comment.

NQF Committee Response

N/A

NQF #3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures, Comment #7787

Standing Committee Recommendation: Measure Recommended for Endorsement

Comment ID#: 7787

Commenter: Submitted by Robin Wilmoth

Council / Public: Public

Comment Period: Post-Evaluation Public and Member Commenting

Date Comment was Submitted: 9/17/2021

Developer Response Required? No

Level of Support: N/A

Theme: Supportive

Comment

I am writing from Tennessee to strongly support the endorsement of the NCI measure by the National Quality Forum. I have worked with NCI over the past years and found their work to be of great value. Their work has assisted within our state with the advancement of knowledge of the field of disabilities to a wide variety of stakeholders.

- Endorsement of these measures is an important addition to NQF's limited set of endorsed measures of quality in Home and Community Based Supports.
- NCI measures are tailored to capture quality information directly from the population with intellectual and developmental disabilities
- The National Core Indicators measure under consideration by NQF supports a vision of quality recognizes the essential role that HCBS plays in people's lives, and prioritizes quality monitoring and quality improvement to achieve efficient, effective, equitable supports for people with disabilities.
- The specific domains covered in the NCI measure that is under review: person centered planning, community inclusion, choice and control, and human rights are particularly in need and are indicators of high quality service outcomes.
- I believe that the endorsement of this NCI measure is essential to ensure sound measurement of a key facet of long term supports and services and will contribute positively to efforts to monitor and improve quality supports for people with intellectual and developmental disability.

Thank you for the opportunity to allow me to provide comment and support for the endorsement of the NCI measures. Inclusion of these in the NQF measures will begin to address an important gap in measures of community based LTSS and will be essential to ensure that the supports and services provided result in positive outcomes for individuals receiving support.

Robin Wilmoth

Department of Intellectual and Developmental Disabilities Tennessee

Developer Response

N/A

NQF Response

Thank you for your comment.

NQF Committee Response

N/A

NQF #3622 National Core Indicators for Intellectual and Developmental Disabilities (ID/DD) Home- and Community-Based Services (HCBS) Measures, Comment #7788

Standing Committee Recommendation: Measure Recommended for Endorsement

Comment ID#: 7788

Commenter: Submitted by Carol Batangan-Rivera

Council / Public: Public

Comment Period: Post-Evaluation Public and Member Commenting

Date Comment was Submitted: 9/17/2021

Developer Response Required? No

Level of Support: N/A

Theme: Supportive

Comment

I am writing to support the endorsement of the NCI measure by the National Quality Forum (NQF).

The NCI foundational principle includes that the individual with intellectual and developmental disabilities is the "most important informant regarding the performance of public services and supports." Having NQF consider the NCI measures supports the value that the consumer's input is important towards improving long-term services and support (LTSS).

The endorsement of the specific domains covered in the NCI measure under review: person-centered planning, community inclusion, choice and control, and human rights provide information on the consumer's experience. These measures align with the HCBS quality measure framework that covers the three critical processes and outcomes of a vision of high-quality care in the areas of choice and decision making, community participation, and experience of care.

The addition of NCI measures will improve the monitoring of supports experienced by people with intellectual and developmental disabilities to achieve their person-centered goals and outcomes of living a good life.

Lastly, the NCI survey is updated to remain relevant to the changing initiatives regarding the quality of care, quality of life, and community inclusion. The NCI measures will add and/or complement the NQF/ HCBS quality framework for assessing HCBS services and support and the design of the system to deliver quality services.

Thank you for the opportunity to provide comment and support for the endorsement of the NCI measures.

Developer Response

N/A

NQF Response

Thank you for your comment.

NQF Committee Response

N/A

National Quality Forum
1099 14th Street NW, Suite 500
Washington, DC 20005
http://www.qualityforum.org