



Patient Experience and Function, Spring 2021 Cycle: CDP Report

**DRAFT REPORT FOR COMMENT
AUGUST 19, 2021**

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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

PEF 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 will close 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](#)).

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/ethnic 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.

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

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.

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)
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- #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

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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 06/30/2021

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

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

1a. Evidence: **Pass-14; No Pass-1**; 1b. Performance Gap: **H-3; M-10; L-0; I-0**

Rationale:

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NQF REVIEW DRAFT—Comments due by September 17, 2021, by 6:00 PM ET

- 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: **Y-15; N-0**; 2b. Validity: **H-2; M-11; L-1; I-1**

Rationale:

- This measure was reviewed by the Scientific Methods Panel (SMP).
- 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/ethnic 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.
- 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. 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.

3. Feasibility: 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: **Pass-12; No Pass-3** 4b. Usability: **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 discuss the related measure during the evaluation meeting and will discuss it during the post-comment call.

6. Standing Committee Recommendation for Endorsement: **Y-13; N-2**

7. Public and Member Comment

- None

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)

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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)

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Coordinator

Appendix D: Measure Specifications

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

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#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:

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(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

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Appendix E: Related and Competing Measures

#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)

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#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

NATIONAL QUALITY FORUM

NQF REVIEW DRAFT—Comments due by Month DD, YYYY by 6:00 PM ET.

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

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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.

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