CBE ID

3622-3

Title

NCI for ID/DD HCBS: Satisfaction with Community Inclusion Scale

Project

Advanced Illness and Post-Acute Care

Endorsement Status

Endorsed

Is Under Review

Yes

Next Maintenance Cycle

Spring 2026

Previous Endorsement Cycle

Spring 2021

Steward

Human Services Research Institute

1.0 New or Maintenance

Maintenance

1.1 Measure Structure

Instrument + Derived Measure Set

1.1a Instrument or Derived Measure

Derived Measure

1.2 Associated Instrument Lookup

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

1.6 Measure 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, 48 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.

1.6 Measure Description (derived)

This measure assesses satisfaction with participation in community inclusion activities among people receiving home and community-based services. It calculates the the proportion of people who report satisfaction with the level of participation in community inclusion activities. The measure is derived from a series of National Core Indicators survey items that ask respondents whether they would like to participate more, less, or the same amount as they currently do in activities such as shopping, entertainment, going to restaurants or coffee shops, attending religious or spiritual practices, and participating in community groups. Responses are recoded to reflect satisfaction when individuals indicate that their current level of participation is about the same as desired.
This measure is intended to capture perceived adequacy of community participation and support evaluation of community inclusion outcomes within HCBS.

1.6a Material Specification Change(s)

No

1.7 Measure Type

Patient-reported Experience Performance Measure (PRE-PM)

1.8 Level of Analysis

Population or Geographic Area

1.8a Population or Geographic Area Level of Analysis

State

1.9 Care Setting

Home Health, Nursing Home/Skilled Nursing Facility, Other

1.9b Other Care Setting

Home- and Community-Based Services

1.10 Measure Rationale

National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD) is a national effort to measure and improve the performance of public developmental disabilities agencies. The measures in this submission are all derived from the NCI-IDD In-person Survey (IPS), which collects experience of care data from adults who receive case management and at least one other paid service from their state developmental disability program. These paid services, collectively known as home and community-based services (HCBS), are intended to support people with disabilities to live and engage in their communities. They include assistance with activities of daily living/instrumental activities of daily living (ADLs/IADLs), employment supports, transportation, support to participate in community life, occupational, physical and other therapies, residential services, behavioral health services, and family and caregiver supports, among others. More than one million people in the U.S. receive services from state developmental disability agencies (Administration for Community Living, n.d.). Medicaid is the predominant payer for HCBS for people with intellectual and developmental disabilities (U.S. Government Accountability Office, 2023). Medicaid-funded HCBS is required to follow person-centered service planning practices where service plans are built around the expressed, individual goals and preferences of the person receiving services.

A 2015 expert panel, which included individuals with disabilities, developed a framework for assessing HCBS quality that comprises 11 domains (National Quality Forum, 2016). The NCI IPS encompasses many of the domains from this national HCBS quality framework, including Person-Centered Planning and Coordination, Choice and Control, Community Inclusion, and Holistic Health and Functioning. Because many HCBS outcomes are individual to the service recipient, they are often best assessed from the person’s perspective. NCI measures provide representative data on whether services are person-centered and meet HCBS users’ needs, priorities, and goals. These data are rolled up to the system-level in state-specific reports. These system-level results, along with more granular data, can be and have been used for quality improvement activities to improve system performance.

Since NCI-IDD was first launched, 48 states have participated. State programs have used NCI-IDD measure results to monitor and improve program participants’ experience with services, including efforts to increase employment. For example, in Missouri, NCI-IDD data demonstrated low rates of people who express they want a job who have a related goal in their service plan. This led to improvement initiatives called Employment First Collaborative and Empowering Through Employment. As a result of these initiatives, significant increases in the number of service plans with employment authorizations occurred between 2016 and 2020. Several NCI-IDD measures are also included in the Centers for Medicare & Medicaid’s (CMS) HCBS Quality Measure Set (QMS). States using the NCI-IDD IPS for compliance with the QMS requirements are required to report on the measures included as QMS mandatory measures using either the 2024-25 or 2025-26 data.

References

Administration for Community Living (n.d.) *30 Years of Community Living for Individuals with Intellectual and/or Developmental Disabilities (1987-2017)* Retrieved from https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/30%20Years%207-13-21.pdf

CMCS (2024) *Informational Bulletin*. Retrieved from https://www.medicaid.gov/federal-policy-guidance/downloads/cib041124.pdf

CMCS (2024) *MFP Grant Note: Note to Money Follows the Person (MFP) Demonstration Grant Recipients: Updates to the Home and Community-Based Services (HCBS) Quality Measure Set (QMS) Reporting Requirements for the MFP Demonstration.* Retrieved from *MFP Supplemental Services Notice*

Missouri Department of Public Health (N.d.) *Employment Initiatives.* Retrieved from Employment Initiatives | dmh.mo.gov

Missouri Department of Public Health (2021) *MOQO and You: Daily Life & Employment .* Retrieved from MOQO & You: Daily Living & Employment Report | dmh.mo.gov

Missouri Department of Public Health (N.d.) *Empowering Through Employment.* Retrieved from *Empowering Through Employment | dmh.mo.gov*

National Quality Forum. (2016). *Quality in Home and Services to Support Community Living: Addressing Gaps in Performance Measurement.* Washington, DC. Retrieved from https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/HCBS_Final_Report.pdf

United States Government Accountability Office (GAO, 2023). *Medicaid: Characteristics of and Expenditures for Adults with Intellectual or Developmental Disabilities*. Retrieved from https://www.gao.gov/products/gao-23-105457

1.10 Measure Rationale (derived)

This measure assesses the proportion of people who report satisfaction with their level of participation in community inclusion activities. It includes five elements of community inclusion: shopping, entertainment, dining out, religious/spiritual activities, and group membership. Community inclusion is one of the 11 domains in the HCBS Quality Framework developed by an expert panel that included people with lived experience of disability and HCBS use (National Quality Forum, 2016). This measure is also included in the CMS HCBS Quality Measure Set. States who choose to use the NCI-IDD In-Person Survey for compliance with the Quality Measure Set requirements are required to report on the measures included as mandatory using either their 2024-25 or 2025-26 data.

There is considerable unmet demand for community-group participation among people with intellectual and developmental disabilities (Stancliffe, Pettingell, Houseworth, and Ticha, 2023). Person-centered service planning, which is a requirement of the CMS Settings Rule, includes identifying and addressing person-centered goals for community activities. Assessing whether these personal preferences and goals around community inclusion have been met allows programs to determine where any quality gaps exist. DD system programs can develop tailored quality improvement interventions related to service planning and provision along the five community inclusion domains.

References

National Quality Forum. (2016). *Quality in Home and Services to Support Community Living: Addressing Gaps in Performance Measurement.* Washington, DC. Retrieved from https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/HCBS_Final_Report.pdf

Stancliffe, R., Pettingell, S., Houseworth, J. and Ticha, R. (2023) Participation and companions for socially inclusive community activities by U.S. adults with intellectual and developmental disabilities *Intellectual and Developmental Disabilities* 61(4), 326-344 doi: 10.1352/1934-9556-61.4.326

1.13 Data Dictionary

Not attached. I attest that all information will be provided where codes and/or value sets are needed (1.14a - 1.15c).

1.14 Numerator

The numerator for this measure is defined using the following NCI-IDD In-Person Survey items that comprise the Satisfaction with Community Inclusion Scale. Q57 “Think about how often you went shopping in the past month. Would you like to go shopping more, less, or the same amount as now?” Q60 “Think about how often you went out for entertainment in the past month. Would you like to go out for entertainment more, less, or the same amount as now?” Q62 “Think about how often you went to a restaurant or coffee shop in the past month. Would you like to go out to a restaurant or coffee shop more, less, or the same amount as now?” Q64 “Think about how often you went to a religious service or spiritual practice in the past month. Would you like to go to religious services or spiritual practices more, less, or the same amount as now?” Q66 “Do you want to be a part of more groups in your community?” For Q57, Q60, Q62, and Q64, response options are 1 = More, 2 = Less, 3 = The same amount as now, and 99 = Don’t know, no response, or unclear response. Q66 has the response options of 2 = Yes and 1 = No. Responses of "3 = The same amount as now" (Q57, Q60, Q62, and Q64) and "2 Yes" (Q66) are used to construct the Satisfaction with Community Inclusion Scale numerator.

1.14a Numerator Details

The number of respondents who report wanting “About the same” level of activity as they experienced in the past month for four community activities and “No” to wanting to be a part of more community groups.

The numerator for this measure is defined using the following NCI-IDD In-Person Survey items that comprise the Satisfaction with Community Inclusion Scale.

Q57 “Think about how often you went shopping in the past month. Would you like to go shopping more, less, or the same amount as now?”

Q60 “Think about how often you went out for entertainment in the past month. Would you like to go out for entertainment more, less, or the same amount as now?”

Q62 “Think about how often you went to a restaurant or coffee shop in the past month. Would you like to go out to a restaurant or coffee shop more, less, or the same amount as now?”

Q64 “Think about how often you went to a religious service or spiritual practice in the past month. Would you like to go to religious services or spiritual practices more, less, or the same amount as now?”

Q66 “Do you want to be a part of more groups in your community?”

For Q57, Q60, Q62, and Q64, response options are 1 = More, 2 = Less, 3 = The same amount as now, and 99 = Don’t know, no response, or unclear response. Q66 has the response options of 2 = Yes and 1 = No.

Responses of "3 = The same amount as now" (Q57, Q60, Q62, and Q64) and "2 Yes" (Q66) are used to construct the Satisfaction with Community Inclusion Scale numerator.

1.15 Denominator

The denominator for the Satisfaction with Community Inclusion Scale includes adults receiving services who participate in the NCI-IDD In-Person Survey and respond to the items included in the scale (please refer to 1.14 Numerator for the list).

1.15a Denominator Details

The denominator for the Satisfaction with Community Inclusion Scale includes adults receiving services who participate in the NCI-IDD In-Person Survey and respond to the items included in the scale (please refer to **1.14 Numerator** for the list). Those with non-missing data for at least two of the five survey items were included.

1.15b Denominator Exclusions

In general, cases are excluded from the denominator when the surveyor indicates that the respondent did not appear to understand the questions or did not answer in a consistent manner. Cases are excluded from denominators when required survey responses are missing, declined, or otherwise not interpretable. This includes responses such as “don’t know,” refusals, or blanks. Only responses explicitly listed as valid response options are included in the denominator. For measures that depend on skip patterns or respondent eligibility, cases are excluded from denominators when prerequisite conditions are not met. For example, items that follow a screening question include only cases that affirmatively meet the screening criteria, and all other cases are excluded from the denominator.

1.15c Denominator Exclusions Details

- Cases are excluded from the denominator when the surveyor indicates that the respondent did not appear to understand the questions or did not answer in a consistent manner:
    - Excluded if INVL_CR2_15 = 1
- Cases are excluded from denominators when required survey responses are missing, declined, or otherwise not interpretable:
    - Excluded if PCP_SHOPPING_21, PCP_ENTERTAIN_21, PCP_EATOUT_21, PCP_RELIG_21 or PCP_COMM_GROUP_21 is missing or "Don't know"

1.15d Age Group

Adults (18-64 years), Older Adults (65 years and older)

1.16 Type of Score

Rate/proportion

1.16.0 Same Type of Score? (derived)

Different from instrument

1.17 Measure Score Interpretation

Better performance = Higher score

1.17.0 Same Measure Score Interpretation? (derived)

Same as instrument

1.18 Calculation of Measure Score

Please see attached 3622-1.18-Calculation-of-Measure-Score-Spring2026.docx

1.18 Calculation of Measure Score (derived)

Please see 3622-1.18-Calculation-of-Measure-Score-Spring2026.docx for detailed measure score calculations.

1.18.0 Same Calculation of Measure Score? (derived)

Different from instrument

1.18a Attach measure score calculation diagram

3622-1.18-Calculation-of-Measure-Score-Spring2026.pdf

1.19 Measure Stratification Details

Please see 3622-1.19-Measure-Stratification-Spring2026.xlsx for measure stratification details.

1.20 Types of Data Sources

Administrative Data, Patient-Reported Data and/or Survey Data

1.20c Format: Patient-Reported Data and/or Survey Data

Digital

1.21b Attach Data Collection Tool(s)

3622-1.21b-NCI-for-ID-DD-HCBS-Spring2026.pdf

1.22 Proxy Responses

Yes

1.23 Survey Respondent

Patient, Family or Other Caregiver, Other

1.23a Other Survey Respondent

Staff

1.24 Data Collection and Response Rate

The NCI-IDD® In-Person survey (IPS) was designed to collect information directly from individuals receiving developmental disability system services. The IPS offers valid, reliable, person-centered measures that states use to demonstrate how publicly funded supports are impacting people's lives and to determine where state systems can improve the quality of those supports.

However, gathering subjective information and data from people with IDD poses unique challenges due to potential intellectual and developmental limitations experienced by the population. NCI IPS administration methods, survey methodology and measure creation and revision were designed with the survey population in mind and are uniquely designed to collect data from this population.

Instructions for Data Collection:

IPS Patient-Reported Data and/or Survey Data are collected via a direct conversation with a person receiving support and services from the state's lead agency or accountable entity at the state level that administers services to people with intellectual and developmental disabilities (IDD).

The measured entity for all measures included in this submission is the state. In each member state, the lead agency or accountable entity at the state level that administers services to people with IDD is responsible for the state's IPS administration, in accordance with NCI's methodological standards.

NCI provides training and technical assistance at all stages of the effort from sampling design through standardized surveyor training and data collection and performs validity checks on the collected data. NCI allows, and has developed training and guidance for, survey administration via face-to-face survey or remote surveying via video conference. NCI offers the IPS survey tool translated into Spanish and written Chinese for trained surveyors who are bilingual. If a trained bilingual surveyor is not available, and/or the respondent requests a language for which there is not a translated survey tool available, NCI allows for the use of interpreters and provides surveyors with training and guidance on how to administer the survey with an interpreter.

Though eligibility for services varies by state, the population surveyed by the IPS includes individuals with IDD.

The IPS consists of two main sections, denoted by Roman numerals I and II.

Section I of the survey contains questions which pertain to personal experiences and require subjective responses; this section may only be answered by the individual receiving services.

Section II of the survey—which consists of objective questions on the individual's involvement in the community, their choices, rights, and their access to services—allows for responses from a "proxy," that is, a person who knows the individual well (such as a family member or friend). Surveyor training ensures that surveyors are able to identify acquiescence (e.g. all yes responses), and indicators of inability to understand and respond to questions.

At the end of Section I, the surveyor indicates whether the respondent appeared to understand the questions and answered them in a consistent manner. If the surveyor's response to this question is negative, Section I data are excluded from analysis. If Section I data are excluded from analysis based on the surveyor's assessment of inconsistent responses and potential lack of understanding, Section II data are also excluded for this case unless a proxy respondent was used.

A third part of IPS data, known as "Background information" or BI, comes from administrative records and is used to characterize the demographics of respondents. These data are not Patient-Reported Data and/or Survey Data. In some cases, BI data is used to determine whether a question is relevant for the respondent to answer.

Response rates:

The data analyzed for the most recent testing came from 39 states. Each state is instructed to construct a sample frame of adults (18 and over) who are receiving at least one publicly funded service in addition to case management from their state developmental disability service system. Based on this sample frame and the assumption of a middle response distribution (50%), each state is recommended to have a sample size that will support both (1) a 95% confidence level, and (2) a ±5% margin of error. States whose final sample of completed surveys does not include a number of completed surveys that reach this threshold will not be included in NCI reporting. Most states sample more than this minimum recommended size to account for refusals and surveys that may be deemed incomplete or invalid. Some states stratify their samples by factors such as region, program, or funding source.

Incomplete surveys are those that have no valid responses in Section I or Section II.

Surveys are deemed invalid based on the standard data validation and cleaning procedure. A standard data validation and cleaning procedure is applied to returned surveys to identify inconsistent responses and responses noted by the surveyor to be inconsistent or the result of the respondent's lack of understanding (see above paragraph for details). It should be noted that not all member states collect all of the data elements required to construct all of the proposed measures.

Ultimately, for each measure, the response rate is the number of valid responses to the underlying question. For composite measures, data are treated as missing following the protocols described in each measure-specific submission.

The NCI team offers many potential strategies for states to increase response rates, including designing the initial scheduling approach to ensure surveyors are emphasizing the importance of the survey and how states will use the data, producing resources to let people and families know in advance that they may be selected to participate, sharing the previous years' data in accessible and user-friendly formats, ensuring case managers and staff are aware and on-board with the survey, and can help prepare the participant, and more. Surveyors are flexible in the time and place where the survey is conducted.

1.25 Data Source Details

Measures 3622-1-m (NCI for ID/DD HCBS: Community Job Goal) and 3622-2-m (NCI for ID/DD HCBS: Activities of Daily Living (ADL) Goal) are both calculated by examining data collected in the Background Information Section of the survey on goals included in the persons Individualized Service Plan (ISP), and then contrasting that with whether the person has an expressed desire for that goal (Data collected during the survey).

The Background Information Section data are collected separately from the survey itself and come from existing administrative records. The Background Information data used for the above measures comes directly from the respondent's ISP. In some states, the Background Information data collectors do not have access to the respondent's ISP. In those cases, surveyors can contact the respondent's case manager to access this information, and the case manager should review the ISP.

To mitigate challenges related to differing languages used across states to refer to ADL and Community Job Goals, the survey questions are deliberately broad to encompass varying wordings or phrasing of goals in ISPs.

1.26 Minimum Sample Size

For each measure in the instrument, if the sample size of valid responses from the accountable entity is 20 or below, the data are not analyzed or reported at the accountable entity level for confidentiality protection.

1.26.0 Same Minimum Sample Size? (derived)

Same as instrument

2.1 Attach Logic Model

3622-2.1-LogicModel-Spring2026.docx

2.2 Evidence of Measure Importance

The NCI-IDD® IPS collects data from people receiving HCBS from state developmental disability programs about their services, including whether they are person-centered and reflect individual goals and needs. Person-centered service planning is an evidence-based practice (Chong and Caldwell, 2023; Isvan, Bonardi and Hiersteiner, 2023) required in Medicaid HCBS programs. Feedback on the extent to which public developmental disability programs are meeting individual goals and needs across a range of valued outcomes such as employment, functioning, and social connectedness enables states to monitor and address program efficacy and quality, though targeted quality improvement initiatives. It also supports assessing the value these systems are realizing from their investments.

The high level of NCI-IDD adoption and robust response rates are evidence of the value placed by service users and program officials on the measures and their importance. Further, NCI-IDD measures, including those in this submission, align with the 2016 HCBS Quality Framework (National Quality Forum, 2016) and selected NCI-IDD measures have been included in Centers for Medicare & Medicaid national reporting requirements for HCBS programs.

References

Chong, N. and Caldwell, J. (2023) The associations between person-centered planning and person-reported outcomes in home- and community-based services *Innovation in Aging* https://doi.org/10.1093/geroni/igad104.0808

CMCS (2024) *MFP Grant Note: Note to Money Follows the Person (MFP) Demonstration Grant Recipients: Updates to the Home and Community-Based Services (HCBS) Quality Measure Set (QMS) Reporting Requirements for the MFP Demonstration.* Retrieved from MFP Supplemental

Services Notice

Isvan, N., Bonardi, A., & Hiersteiner, D. (2023). Effects of person-centered planning and practices on the health and well-being of adults with intellectual and developmental disabilities: a multilevel analysis of linked administrative and survey data. *Journal of Intellectual Disability Research*, doi: 10.1111/jir. 13015. https://onlinelibrary.wiley.com/doi/10.1111/jir.13015

National Quality Forum. (2016). *Quality in Home and Services to Support Community Living: Addressing Gaps in Performance Measurement.* Washington, DC. Retrieved from https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/HCBS_Final_Report.pdf

2.2 Evidence of Measure Importance (derived)

People with intellectual and developmental disabilities value social inclusion (Stancliffe and Hall, 2023). DD system programs can support community inclusion through person-centered planning processes that align supports, such as transportation and personal assistance, with individual goals around when and how to engage in the community. Research has demonstrated that people who had control and could choose when to participate in community activities had more positive outcomes (Stancliff et al., 2022). Socially inclusive community participation is strongly associated with better friendship outcomes for people with IDD (Standcliffe, Pettingell, Houseworth, and Ticha, 2023). Social connections, including friendships, can have a protective effect on health status (Holt-Lunstad, 2022).

Furthermore, Community Inclusion is a domain of the NQF HCBS Quality Framework and identifying individual goals, such as those related to satisfaction with one’s level of community inclusion, is core to person-centered planning and coordination, one of the 11 domains in the HCBS Quality Framework (National Quality Forum, 2016).

References

Holt-Lunstad, J. (2022). Social connection as a public health issue: the evidence and a systemic framework for prioritizing the “social” in social determinants of health. *Annual Review of Public Health*, *43*(1), 193-213. doi: 10.1146/annurev-psych-122216-011902

National Quality Forum. (2016). *Quality in Home and Services to Support Community Living: Addressing Gaps in Performance Measurement.* Washington, DC. Retrieved from https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/HCBS_Final_Report.pdf

Stancliffe, R. J., & Hall, S. A. (2023). Social inclusion of adults with intellectual and developmental disabilities: Toward belonging. *International Review of Research in Developmental Disabilities* 64;253-306 doi: 10.1016/bs.irrdd.2023.06.002

Stancliffe, R., Pettingell, S., Berchadsky, J., Houseworth, J. and Ticha, R. (2022) Community participation and staying home if you want: US adults with intellectual and development disabilities *Journal of Applied Research in Intellectual Disabilities* 35:1199-1207 doi: 10.1111/jar.13014

Stancliffe, R., Pettingell, S., Houseworth, J. and Ticha, R. (2023) Participation and companions for socially inclusive community activities by U.S. adults with intellectual and developmental disabilities *Intellectual and Developmental Disabilities* 61(4), 326-344 doi: 10.1352/1934-9556-61.4.326

2.4 Performance Gap

The data used to create Table 1 come from the 2024-2025 NCI In-Person Survey. All respondents who provided valid responses to at least two of the five community engagement items were included in the calculations. The mean performance score can be interpreted as the average percentage of people who expressed satisfaction with their level of engaging in five community activities (shopping, entertainment, eating out, attending religious/spiritual gatherings, and belonging to a community organization). Overall, 61% of survey participants expressed satisfaction with their level of community engagement and 39% reported that they would like to either increase or decrease their current level of participation in community activities. The measure varies between 45% and 86% mean satisfaction across the 39 participating states. These numbers indicate considerable room for improvement in providers' efforts to get to know the individuals they serve, understand their preferences and priorities, and adjust community inclusion supports that they provide to meet individual preferences.

Table 1. Performance Scores by Decile

Table 1. Mean Performance Score by Decile, Accountable Entity, 2024-2025

	Overall	Min	Decile 1	Decile 2	Decile 3	Decile 4	Decile 5	Decile 6	Decile 7	Decile 8	Decile 9	Decile 10	Max
Mean Performance Score	**61.4%**	**42.1%**	**49.5%**	**54.1%**	**57.4%**	**59.1%**	**60.6%**	**62.1%**	**65.5%**	**66.7%**	**69.2%**	**77.5%**	**86.0%**
N of Entities	**39**	**1**	**4**	**4**	**4**	**4**	**4**	**3**	**4**	**4**	**4**	**4**	**1**
N of Persons / Encounters / Episodes	**30,372**	**810**	**2,295**	**3,404**	**1,732**	**1,828**	**9,910**	**1,566**	**2,409**	**2,254**	**2,826**	**2,148**	**408**

2.6 Meaningfulness to Target Population

Various groups of interested parties have been involved in efforts to identify quality measures for HCBS services, and the resulting measures have included reference to NCI measures, NCI concepts or specific NCI measures themselves. The inclusion of NCI measures in frameworks and measure development that relied heavily on stakeholder input demonstrates the importance of NCI measures to the target population.

For example, priorities defined by the target population and other stakeholders were brought forward through expert panelists who came together to establish the NQF framework for HCBS quality described earlier in this submission. A 2015 committee of 18 people including individuals with disabilities and caregivers, and seven Federal Advisors, developed this framework for assessing HCBS quality that comprises 11 domains (National Quality Forum, 2016).

Beyond inclusion in the NQF framework itself, evaluation and psychometric testing of the framework further demonstrated that concepts measured in NCI are valued by the target population. Researchers at University of Minnesota’s Rehabilitation Research and Training Center on Outcome Measures conducted a study to establish the content and social validity of the NQF HCBS Quality Framework with stakeholders. As described in their research center’s brief: “Involving Stakeholders to address challenges in HCBS Measure Development,” this was accomplished through a Participatory Planning and Decision-Making (PPDM) process. The PPDM process included meeting with all stakeholder groups and providing them with an opportunity to evaluate the NQF framework, add to it, and stipulate which personal outcomes and service characteristics were most important to measure. To obtain a nationally representative sample, PPDM groups were conducted across the country with each stakeholder group which included people with intellectual and developmental disabilities, mental health conditions, traumatic brain injury, physical disabilities, and a variety of age-related conditions.

Additional focus groups were organized for family members, HCBS support providers, and groups of public managers. The research center’s brief: “Involving Stakeholders to address challenges in HCBS Measure Development” does not specify the number of people included in the stakeholder groups.

Overall, results from PPDM groups conducted by the University of Minnesota indicated a high degree of stakeholder support for the content of the NQF HCBS Quality Framework, further validating the framework to support quality improvement work. Stakeholders prioritized measures of Person-Centered Planning and Coordination, Choice and Control, and Human and Legal Rights.

Stakeholders in the study did provide input resulting in recommendations for number of revisions or additions to the NQF Quality Framework. These included: (1) adding within the broad *community inclusion* domain a subdomain focused on access to and quality of *transportation*; (2) the addition of a stand-alone domain for *employment*; and (3) a greater focus on *the self-determination* of people with disabilities rather than the degree of choice and control they experience.

The NCI-IDD measures being submitted are entirely responsive to priorities identified by the stakeholders through this study. Measures of choice and control which are submitted can be viewed as core elements that are supportive of self-determination, as detailed in the logic model section above.

Some measures from this instrument are also part of the Centers for Medicare & Medicaid Services (CMS) HCBS Quality Measure Set QMS). To create the HCBS QMS, CMS published an RFI to solicit public comment from stakeholders on a draft set of quality measures. A goal of this stakeholder engagement was to ensure that the resulting measure set included measures that were important to and important for people receiving services. “Since releasing the RFI, CMS has also engaged with a broad range of stakeholders, including states, managed care plans, consumer advocates, quality measurement experts, researchers, and other federal agencies, to receive additional feedback on the draft measure set and on opportunities to support states with using the measure set, including to meet quality measurement and reporting requirements under various Medicaid HCBS authorities (Page 4).” The number of stakeholders consulted for this work is not specified. The following NCI-IDD measures submitted in this package are included as part of the HCBS QMS:

- Social Connectedness (3622-4-m)
- Satisfaction with Community Inclusion (3622-3-m)

Several states, including California and Kentucky, review NCI-IDD results with statewide groups of service users and families. For example, the Kentucky DD Services Quality Improvement Committee, made up of people receiving services, tracks performance of NCI-IDD measures across 3-year cycles. There were 11 members of the 2024 Quality Improvement Committee including people with disabilities, caregivers and other experts. They identify areas of priority for service users and produce a report. The 2024 Committee Recommendations Report includes priorities based on several measures being submitted in this maintenance package, such as community inclusion, relationships, and employment. The 2024 Committee Recommendations include specific interventions needed to accomplish improvement goals including enhanced information dissemination and service coordinator training.

References:

National Core Indicators. (2024). *2023-24 National Report: Relationships* Retrieved from 2023-24

NCI-IDD Relationships National Report

Kentucky National Core Indicators. (2024). Recommendations Report Retrieved from Kentucky National Core Indicators Recommendation Report 2024

National Quality Forum. (2016). *Quality in Home and Services to Support Community Living: Addressing Gaps in Performance Measurement.* Washington, DC. Retrieved from https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/HCBS_Final_Report.pdf

Rehabilitation Research and Training Center on HCBS Outcome Measurement (RTC/OM). (2020). *Brief 1: Involving stakeholders to address challenges in HCBS measure development: Toward person-centered measurement [Research Brief]*. Institute on Community Integration, University of Minnesota-Twin Cities. https://publications.ici.umn.edu/rtcom/briefs/brief-one-involving-stakeholders-to-address-challenges-in-hcbs-mesure-development

2.6 Meaningfulness to Target Population (derived)

This measure is reflective of the Person Centered Planning and Coordination domain and the Community Inclusion domain that were identified by stakeholders and expert panelists who came together to establish the NQF framework for HCBS quality. The development of the NQF framework included robust input from groups of various interested parties. A 2015 committee of 18 people including individuals with disabilities, caregivers, and seven Federal Advisors, developed this framework for assessing HCBS quality that comprises 11 domains (National Quality Forum, 2016). Additional information on the development process is available at the instrument level.

Researchers at University of Minnesota’s Rehabilitation Research and Training Center on Outcome Measures conducted a study to establish the content and social validity of the NQF Conceptual Framework for HCBS Outcome Measurement with stakeholders. As described in their research center’s brief: “Involving Stakeholders to address challenges in HCBS Measure Development”, this was accomplished through a Participatory Planning and Decision-Making (PPDM) process. The PPDM process included meeting with all stakeholder groups and providing them with an opportunity to evaluate the NQF framework, add to it, and stipulate which personal outcomes and service characteristics were most important to measure.

The research center’s brief: “Involving Stakeholders to address challenges in HCBS Measure Development” does not specify the number of people included in the stakeholder groups.

Additional information on the UMN brief and development process is available at the instrument level.

This measure is also part of the CMS HCBS Quality Measure Set. To create the HCBS QMS, CMS published an RFI to solicit public comment from stakeholders on a draft set of quality measures. A goal of this stakeholder engagement was to ensure that the resulting measure set included measures that were important to and important for people receiving services. “Since releasing the RFI, CMS has also engaged with a broad range of stakeholders, including states, managed care plans, consumer advocates, quality measurement experts, researchers, and other federal agencies, to receive additional feedback on the draft measure set and on opportunities to support states with using the measure set, including to meet quality measurement and reporting requirements under various Medicaid HCBS authorities (Page 4).” The number of stakeholders consulted for this work is not specified.

References

National Core Indicators. (2024). *2023-24 National Report: Relationships* Retrieved from 2023-24 NCI-IDD Relationships National Report

National Quality Forum. (2016). *Quality in Home and Services to Support Community Living: Addressing Gaps in Performance Measurement.* Washington, DC. Retrieved from https://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/HCBS_Final_Report.pdf

Rehabilitation Research and Training Center on HCBS Outcome Measurement (RTC/OM). (2020). *Brief 1: Involving stakeholders to address challenges in HCBS measure development: Toward person-centered measurement [Research Brief]*. Institute on Community Integration, University of Minnesota-Twin Cities. https://publications.ici.umn.edu/rtcom/briefs/brief-one-involving-stakeholders-to-address-challenges-in-hcbs-mesure-development

3.1 Contributions Towards Closing Care Gaps

This domain is optional for the Spring 2026 cycle

4.1a Data Structure and Availability

The Online Data Entry Survey Application (ODESA) is a web-based platform that all participating National Core Indicators (NCI) states use to enter survey data for the NCI Intellectual and Developmental Disabilities (NCI-IDD) (including data for the measures included in this package).

Every year, ODESA is updated to reflect the current year’s survey tools. The ODESA application resides on a secure server and requires unique login information for each user. ODESA contains built-in logic checks and skip patterns to standardize data entry across states and across data enterers. In addition to its data entry functions, the system includes administrative features to allow states to manage users and groups, track progress, and download the state's survey data.

Data are collected yearly, and structured state data exports are available to participating states throughout the data cycle. Cleaned state datasets in Excel, .csv and/or SPSS format are available upon request after the cycle's standard reports are released publicly. National datasets, with the state names deidentified, are available to researchers upon approval of a proposal and payment of a fee.

Datasets may include missing data due to skip patterns (which may render a question not-applicable to a particular respondent based on their answer to a previous question), unavailable data (in the case of data that are collected in the Background Information section) or the respondent's inability to, or desire not to respond to a specific question. Information on missing data on specific measures included in this package is included in each measure template.

NCI collects data on subjective experiences and the data reflect the individual's feelings and experiences, therefore these data cannot be "inaccurate". Data inaccuracies can potentially result for questions in Section II if a proxy respondent's responses do not reflect the individual's true feelings, or, for questions in both sections, if the individual (or proxy) do not correctly interpret the question. Data inaccuracies can also result if the data from the Background Information section are not gathered reliably.

The NCI In Person Survey is implemented in many states and has been in use for many years. As a result, inaccuracies at the state level can often be identified comparing data to previous years and comparing to other states' data.

There have not been any changes to the instrument or measure specifications since initial submission.

4.1b Implementation Costs and Burden

NCI-IDD data collection at the state level occurs in the context of an agreement between states that participate in the National Core Indicators, the National Association of State Directors of Developmental Disability Services (NASDDDS) and Human Services Research Institute (HSRI). An annual NCI participation fee is required to participate in the NCI-IDD data collection. For the 2025-26 data cycle, this fee was $19,300.

Along with the participation fee, states sign an agreement. As part of the agreement, NASDDDS and HSRI commit to being responsible for various NCI activities such as

- Program Direction and Management: Provide general oversight of NCI-IDD activities. Prepare, maintain, and ensure industry standard security protocols for the Online Data Entry Survey Application system (ODESA 2.0).
- Technical Assistance: Furnish a wide range of technical assistance to support states to administer NCI and use NCI data for performance measurement and systems improvement.
- Data Analysis, Management and Reporting: Prepare and distribute reports from the national data sets annually.

As part of the agreement, states commit to being responsible for various NCI activities and the costs incurred therein, such as general operational tasks necessary to gather and enter NCI-IDD data into the NCI data collection portal, staying current with NCI-IDD protocols and undertaking the procedures necessary to meet the national program requirements.

States may choose to hire a vendor to administer the NCI-IDD IPS survey or to use their own staff to collect data. NCI is not involved in payment discussions between states and vendors, and we have no information about the costs of these arrangements.

4.1c Confidentiality

The NCI-IDD IPS dataset, which includes the measures in this submission, does not include any PHI (Protected Health Information) or PII (Personally Identifiable Information). Data are maintained in a secure data collection platform. Data are de-identified and minimum threshold reporting requirements are in place. Participation in an NCI-IDD interview is voluntary.

4.3 Feasibility Informed Final Measure

The measure specifications have not changed. This was done to maintain consistency with the original specifications and ensure results remain comparable. There has also been no feedback or evidence suggesting a need for changes, such as concerns about burden or requests for revisions. As a result, the existing measure specifications were retained without change.

4.4 Proprietary Information

Proprietary measure or components with fees

4.4a Fees, Licensing, or Other Requirements

As noted in 4.1b above, an annual NCI participation fee is required to participate in the NCI-IDD data collection. For the 2025-26 data cycle, this fee was $19,300. Participating state agencies own their state’s data.

If a researcher would like to use NCI data for research, there is a fee required for access to the National datasets. Here is the basic fee framework:

Basic fee framework:

Undergraduate/Graduate students (unfunded single study, single survey type) Each additional survey type will cost $600 Support for IRB applications may increase fees.	$600
Undergraduate/Graduate students (funded research study, single study, single survey type) Each additional survey type will cost $600 Support for IRB applications may increase fees.	$1,500
Academic Institutions (participation in funding application, IRB as necessary, ongoing communication, single study, single survey type) Support for IRB applications may increase fees. This level of access will require additional discussion with the NCI team around terms, conditions and fees for additional surveys and any add-on analyses. Additional data proposal forms may be required if additional research is conducted beyond the aims expressed in this proposal, or if additional team members access the survey tools.	$12,500 and up
Other External Organizations Terms, conditions and fees are established based on review of proposed study and extent of support required	**Case-by-case**

5.1.1 Data Used for Testing

NCI-IDD In-Person Survey 2024-25 dataset with 39 participating states and 30,888 survey respondents in total.

5.1.1a Dates of Testing Data

July 2024 to June 2025.

5.1.2 Differences in Data

None.

5.1.3 Characteristics of Measured Entities

Measured Entities	Number of NCI-IDD IPS Respondents	Type
Alabama	601	State
Arizona	404	State
Arkansas	409	State

California	8614	State
Colorado	1025	State
Connecticut	611	State
Delaware	405	State
District of Columbia	374	State
Georgia	411	State
Hawaii	356	State
Illinois	417	State
Indiana	844	State
Kansas	1196	State
Kentucky	423	State
Louisiana	458	State
Maryland	408	State
Michigan	653	State
Minnesota	385	State
Missouri	403	State
Montana	468	State
Nebraska	420	State
Nevada	496	State
New Hampshire	360	State
New Jersey	505	State
New York	1750	State
North Carolina	451	State
North Dakota	426	State
Ohio	571	State
Oklahoma	396	State
Oregon	415	State
Pennsylvania	882	State
South Carolina	821	State
South Dakota	349	State
Texas	1246	State
Utah	366	State
Virginia	813	State
Washington	410	State
Wisconsin	944	State
Wyoming	402	State

5.1.4 Characteristics of Units of the Eligible Population

The unit of analysis is the individual respondent. Eligible units are adults with intellectual or developmental disabilities who receive Home- and Community-Based Services and who are able to participate in the NCI In-Person Survey, either independently or with needed communication supports. Individuals may have a range of disabilities, functional abilities, service types, and living arrangements, reflecting the diversity of the HCBS population served by participating state systems.

5.2.1 Reliability Testing Conducted (instrument)

Not applicable (person/encounter level reliability testing not conducted)

5.2.1a Why Testing Not Conducted

These measures have not been modified since original endorsement.

5.2.1 Accountable Entity Level Reliability Testing Conducted (derived)

Accountable entity level (i.e., measure score) (e.g., signal-to-noise analysis)

5.2.2 Method(s) of Accountable Entity Level Reliability Testing (derived)

Please see 3622-ReliabilityMethodology_Scale-Spring2026.docx

5.2.3 Accountable Entity Level Reliability Testing Results (derived)

Total Entities: 39

Overall Mean Performance Score: 61.4%

Overall IUR: 0.944

IUR Range: 0.915 (minimum) to 0.969 (maximum)

Median Split-half ICC: 0.970 ± SD 0.007 (CI 0.944 - 0.984)

Please see Tables 2a and 2b as well as 5.2.3a attachment for details.

5.2.3a Attach Additional Accountable Entity Level Reliability Testing Results (derived)

3622-3-m-5.2.3a-Additional-Reliability-Testing-Results-Spring2026.docx

Table 2a. Accountable Entity Level Reliability Testing Results by Denominator, Target Population Size

Table 2a. Reliability by Denominator Decile, Accountable Entity, 2024-2025

	Overall	Min	Decile 1	Decile 2	Decile 3	Decile 4	Decile 5	Decile 6	Decile 7	Decile 8	Decile 9	Decile 10	Max
Reliability	0.944	0.915	0.916	0.921	0.923	0.924	0.925	0.929	0.935	0.943	0.949	0.960	0.969

Mean Performance Score	0.614	0.569	0.633	0.587	0.699	0.591	0.690	0.641	0.544	0.555	0.656	0.627	0.596
N of Entities	39	1	4	4	4	4	4	3	4	4	4	4	1
N of Persons / Encounters / Episodes	30,372	337	1,381	1,531	1,583	1,608	1,645	1,366	2,140	2,859	3,609	12,650	8,533

Table 2b. Accountable Entity Level Reliability Testing Results by Reliability Score

Table 2b. Reliability by Decile, Accountable Entity Level, 2024-2025

	Overall	**Min**	**Decile 1**	**Decile 2**	**Decile 3**	**Decile 4**	**Decile 5**	**Decile 6**	**Decile 7**	**Decile 8**	**Decile 9**	**Decile 10**	**Max**
Reliability	**0.944**	**0.915**	**0.916**	**0.921**	**0.923**	**0.924**	**0.925**	**0.929**	**0.935**	**0.943**	**0.949**	**0.960**	**0.969**

5.2.4 Interpretation of Accountable Entity Level Reliability Results (derived)

The overall IUR indicates that 94% of the variability in the measure is attributable to differences between states rather than to random noise. All deciles have reliability around 0.9, well above the 0.7 threshold. These results suggest that the measure is successful in distinguishing between high- and low-performing states. We note that when IUR is too high (>0.9) in clinical measures, the last statement may be regarded as naïve, since the extremely high variability between entities may be a sign of unadjusted differences in case mix that the developer neglected to address through risk adjustment (Hartman et al., 2024). However, we would expect that where the entity is a state agency operating within state-level policies and funding practices that substantially vary across states, and the measure being tested represents experiences that are highly dependent on state policies, lack of case mix adjustment may not always be the reason for high variability. In this case, states vary widely in their funding of long-term services and supports, public program eligibility requirements, approaches to delivering home and community-based services, and level of commitment to person-centered service planning, all of which are strongly related to satisfaction with community inclusion among people with IDD. These factors could account for high variability across states in this measure while at the same time making this a useful measure for assessing the impacts of state policies on the experiences of people with IDD.

The exceptionally high and stable ICC suggests that the measure is highly consistent and minimally affected by random split-half variation.

Reference:

Hartman N, Shahinian VB, Ashby VB, Price KJ, and & He K. (2024). Limitations of the Inter-Unit Reliability: A Set of Practical Examples. *Health Services and Outcomes Research Methodology, 24*(2), 156-169. PMID: 39145149; PMCID: PMC11323040.

5.3.1 Validity Testing Conducted (instrument)

Not applicable (person/encounter level validity testing not conducted)

5.3.1a Why Testing Not Conducted (instrument)

These measures have not been modified since original endorsement.

5.3.2 Type of Accountable Entity Level Validity Testing Conducted (derived)

Empirical validity testing at the accountable entity-level (e.g., criterion validity, construct validity, known groups analysis)

5.3.3 Method(s) of Accountable Entity Level Validity Testing (derived)

Participation in community activities is a desired outcome for people receiving home and community-based services and supports. Available self-reported measures of this outcome typically comprise of a series of questions about the frequency with which the person engages in a list of community-based activities (e.g., shopping, eating out, attending religious gatherings). Although frequency of engagement could be a valid measure of community inclusion, it is not as valid a measure of person-centered services and supports. The reason is that the activities comprising the measure are not equally desirable to everyone. For example, some people dislike shopping and not everyone is equally interested in religious gatherings. The current measure of *satisfaction* with community inclusion was developed specifically to capture whether the person is engaging with community activities *at their preferred level*. For these reasons, we expected this measure to share more mechanisms of change with measures in the “Person-Centered Planning and Coordination” domain than with those in the “Community Inclusion” domain. Considering that person-centered planning and service provision involves specialized training for providers and additional time spent with the service user compared to a “one-size fits all” approach we expected states that allocate more funds to HCBS to score higher in this measure.

To test these hypotheses, we measured the correlation between the current measure and the following four measures:

1. **Community Inclusion Scale**. This is a composite of four NCI survey items of the form, “During the past month, how many times did you…[go shopping, go out on errands, go out for entertainment, go out to a café or restaurant]. The four response options are: Not at all, once or twice, 3 or 4 times, 5 or more times. This measure addresses three of the five items that comprise the *Satisfaction with Community Inclusion* measure; therefore, we expected some shared mechanisms. However, it doesn’t address the individual desirability of the activities, so we expected that the correlation would be limited.
2. **Free Time Decisions**. This measure is based on a single NCI survey item: “Do you decide or have help deciding how to spend your free time?” Response options: yes, no. Considering that having a say in leisure activities should increase the likelihood choosing desirable community activities, we expected this measure to have a strong correlation with

Satisfaction with Community Inclusion.

3. **Free Time Choice**. This measure is based on a single NCI survey item: "Do you have enough choice about what to do in your free time?" Response options: yes, no. This measure is the most proximate to *Satisfaction with Community Inclusion*. We therefore expected it to have the strongest correlation.
4. **HCBS Spending**. State-level data on HCBS spending per HCBS client in 2022 was obtained from the KFF State Health Facts Database.

Depending on the distributional properties of the hypothesized correlates and the shape of their association with the measure, we report either parametric (Pearson) or non-parametric (Spearman's Rho) correlation coefficients. We conducted one-tailed significance tests of the correlation coefficients in line with the nature of the hypothesized associations.

5.3.4 Accountable Entity Level Validity Testing Results (derived)

Table 5.3.4. Correlations between the *Satisfaction with Community Inclusion* Measure and Hypothesized Correlates

Hypothesized Correlate	N of States	Pearson Correlation (p-value)	Spearman's Correlation (p-value)
Community Inclusion Scale	39		0.114 (0.099)
Free Time Decisions	39		0.442 (0.002)
Free Time Choice	39		0.411 (0.006)
HCBS Spending	26	0.254 (0.105)	

5.3.4a Attach Additional Accountable Entity Level Validity Testing Results (derived)

3622-3-m-5.2.3a-Additional-Validity-Testing-Results-Spring2026.docx

5.3.5 Interpretation of Accountable Entity Level Validity Results (derived)

As expected, Community Inclusion Scale had the weakest correlation among the four correlates. This supports our expectation that *Satisfaction with Community Inclusion* does not fall within the Community Inclusion Domain. The strongest correlations were with having a say in planning free time and having enough choice in what to do during free time, both of which are within the Person-Centered Planning and Coordination Domain, supporting our belief that *Satisfaction with Community Inclusion* is a valid measure of person-centeredness. Having enough choice in free time activities has the largest conceptual overlap with *Satisfaction with Community Inclusion* – both are measures of the respondent's judgment about the alignment between individual preference and service delivery. As expected, this was the strongest correlate. The correlation with HCBS spending was also positive, supporting our hypothesis that states with more "generous" HCBS budgets are more likely to deliver person-centered services. These findings provide support for the measure's convergent validity in addition to its face validity.

These correlates conceptually precede our measure, suggesting a causal relationship. For HCBS Spending, it can be argued that increased funding leads to more person-centered training for direct service providers, lower caseloads, and more time spent interacting with service users, resulting in more person-centered services. This causal chain is also empirically supported since the spending data temporally precedes the survey by at least two years. Similarly, it can be argued that if a person has a say in free time planning, and sufficient choice in choosing leisure activities, then they will be more likely to engage in community activities *at the level they prefer*. However, to clearly establish causality, multilevel analysis would be needed to address confounders and circular causal directionality.

The magnitude of the correlations and their significance level are lower than the expected thresholds for establishing empirical validity. It should be noted, however, that the thresholds are more realistic for clinical indicators measured with less noise than is the case for self-reported LTSS experiences based on personal judgment. The sample size of 26-30 states is also too small to provide sufficient power to detect significant correlations. These results should be regarded with these caveats in mind.

5.4.1 Methods Used to Address Risk Factors

No risk adjustment or stratification

5.4.1b Rationale For No Adjustment or Stratification

There is an ongoing discussion about the pros and cons of risk adjustment for social and functional characteristics. While it is a useful tool in addressing case mix differences among providers in the context of value-based payment systems, authors have also pointed out that it raises concerns about the likelihood that it may mask meaningful disparities in the quality of care that are within the provider’s ability to address (ASPE Report to Congress, 2016; Joynt et al., 2017; NQF, 2021). To a large extent, the decision to risk-adjust for socioeconomic and functional factors depends on the purpose of the measure. For value-based payment purposes, adjustment may, indeed, reward providers with high-risk clients. However, if the purpose is continuous quality improvement, it may be preferable to use unadjusted measures that reveal, rather than mask disparities in the quality of care, this opening the way for improvements.

The purpose of this measure is to inform state DD agencies of the extent to which their services are providing positive experiences for participants. This information is used by officials to make adjustments to the state’s service system. Ideally, services should be tailored to provide equally positive experiences for all participants, regardless of their level of support need. Adjusting for case mix could mask the failure of the system to tailor services to certain categories of service users. In other words, it would reduce the measure’s usefulness to support continuous quality improvement and to address disparities in service experiences. We do report the measure separately for groups in different living arrangements to provide state planners with additional information about different experiences of services received in different settings. This could be regarded as a type of measure stratification.

References:

U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. (2016). Report to Congress: Social Risk Factors and Performance Under Medicare’s

Value-Based Purchasing Programs. https://aspe.hhs.gov/reports/report-congress-social-risk-factors-performance-under-medicares-value-based-purchasing-programs

Joynt, K. E., Zuckerman, R., & Epstein, A. M. (2017). Social risk factors and performance under Medicare's value-based purchasing programs. Circulation: Cardiovascular Quality and Outcomes, 10(5), e003587. https://doi.org/10.1161/CIRCOUTCOMES.117.003587

National Quality Forum. (2021). Developing and testing risk adjustment models for social and functional status-related risk within healthcare performance measurement: Draft technical guidance, version 2. https://www.aahd.us/wp-content/uploads/2021/07/NQFRiskAdjustment-06172021DraftRept-SocialFunctionalStatus-07192021_CommentDeadline.pdf

6.1.1 Current Status

In use

6.1.2.0 Same Current or Planned Use(s)? (derived)

Same as instrument

6.1.2 Current or Planned Use(s)

Public Reporting, Quality Improvement with Benchmarking (external benchmarking to multiple organizations), Quality Improvement (Internal to the specific organization)

6.1.3 Program Details

Name of the program and sponsor
CMS Home- and Community-Based Services (HCBS) Quality Measure Set
URL of the program
https://www.medicaid.gov/medicaid/quality-of-care/quality-improvement/measuring...
Purpose of the program

The Centers for Medicare & Medicaid Services' Home- and Community-Based Services (HCBS) Quality Measure Set (QMS) is a national framework for standardized quality reporting in Medicaid-funded HCBS programs. CMS sponsors the HCBS QMS to promote consistent measurement, transparency, and accountability across state HCBS delivery systems, with a particular emphasis on person-centered outcomes, access, health and safety, and equity for individuals receiving services in home- and community-based settings.

Geographic area and percentage of accountable entities and patients included

The HCBS Quality Measure Set is national in scope and applies to all state Medicaid agencies administering HCBS through waivers or state plan authorities. Participation is mandatory under the Ensuring Access to Medicaid Services final rule, with phased-in reporting requirements. The percentage of accountable entities and individuals included is expected to increase as states implement required reporting, beginning with Medicaid HCBS populations specified in CMS guidance.

Applicable level of analysis and care setting

Measures are applied at the state system level and are used to assess performance of Medicaid HCBS programs overall rather than individual providers. The applicable care setting is home- and community-based services delivered through Medicaid HCBS waivers and state plan options.

,
Name of the program and sponsor
California Statewide Quality Assessment Project, sponsored by the California Department of Developmental Services (DDS) in partnership with the State Council on Developmental Disabilities (SCDD)
URL of the program
https://scdd.ca.gov/qap/
Purpose of the program

NCI is used by the State of California as part of its statewide Quality Assessment Program for developmental disabilities services, administered by the California Department of Developmental Services in partnership with the State Council on Developmental Disabilities and Human Services Research Institute. The program uses National Core Indicators measures as a standardized tool for assessing outcomes experienced by individuals receiving services through California’s developmental disabilities system. The purpose of the program is to support oversight, policy development, and continuous quality improvement across the state’s developmental disabilities service system. NCI measures are used to evaluate person-reported outcomes related to community inclusion, choice, rights, health, safety, and service coordination, and to identify areas for system improvement at both the statewide and regional levels.

Geographic area and percentage of accountable entities and patients included

The program is statewide in scope and includes all regional centers responsible for coordinating developmental disabilities services in California. Data collection covers a representative sample of adults receiving publicly funded developmental disabilities services, with the goal of reflecting experiences across the entire service system.

Applicable level of analysis and care setting

Measures are analyzed and reported at the statewide and regional center levels. The applicable care setting includes home- and community-based services provided through California’s developmental disabilities system.

,
Name of the program and sponsor
CMS Adult Core Set of Health Care Quality Measures for Medicaid (Adult Core Set)
URL of the program
https://www.medicaid.gov/medicaid/quality-of-care/downloads/2025-adult-core-set...
Purpose of the program

The purpose of the Adult Core Set is to provide CMS and states with a consistent set of indicators that reflect priority areas in Medicaid quality, including access, experience of care, and outcomes for adult beneficiaries. Measures derived from National Core Indicators are used to address experience-of-care and person-centered outcome domains for adults receiving long-term services and supports through Medicaid, complementing clinical and administrative measures within the set.

Geographic area and percentage of accountable entities and patients included

The Adult Core Set is national in scope and applies to state Medicaid programs. While reporting has historically been voluntary, CMS has expanded required reporting for Adult Core Set measures over time, increasing participation across states. The population represented includes adult Medicaid beneficiaries, including adults receiving HCBS, as defined by CMS reporting specifications.

Applicable level of analysis and care setting

Measures are reported at the state Medicaid program level and used for system-level assessment rather than provider-level accountability. The relevant care setting for this measure within the Adult Core Set context is Medicaid-funded home- and community-based services.

,
Name of the program and sponsor
Pennsylvania Office of Developmental Programs (ODP) Independent Monitoring for Quality (IM4Q)
URL of the program
https://home.myodp.org/resources/independent-monitoring-for-quality-and-nationa…
Purpose of the program

The purpose of Pennsylvania’s use of NCI measures is to support statewide quality management, program oversight, and continuous quality improvement. NCI data are used to assess system performance in areas such as community inclusion, employment, choice and self-determination, health, safety, and service coordination, and to inform programmatic decisions, policy development, and targeted improvement initiatives within ODP-administered services.

Geographic area and percentage of accountable entities and patients included

The program operates statewide and includes individuals receiving services through Pennsylvania’s intellectual disability and autism service system. Data collection reflects a representative sample of adults served by the system, allowing for analysis of outcomes across the Commonwealth and over time as part of ongoing system monitoring.

Applicable level of analysis and care setting

Measures are used and reported at the state program level and, where applicable, at sub-state or provider network levels to support internal analysis and quality improvement. The applicable care setting is home- and community-based services delivered through Pennsylvania’s developmental disabilities service system.

,
Name of the program and sponsor
Employment First Collaborative, Missouri Department of Mental Health, Division of

Developmental Disabilities
URL of the program
https://dmh.mo.gov/dev-disabilities/programs/employment/initiatives
Purpose of the program

The Employment First Collaborative was developed in response to findings from National Core Indicators for Intellectual and Developmental Disabilities (NCI-IDD) data showing low rates of individuals who wanted employment but did not have employment goals included in their service plans. The initiative aimed to increase competitive integrated employment opportunities for individuals with intellectual and developmental disabilities receiving HCBS services in Missouri.

Geographic area and percentage of accountable entities and patients included

The initiative was implemented statewide in Missouri through the developmental disabilities service system. It targeted HCBS providers, care coordinators, and individuals receiving developmental disability services.

Applicable level of analysis and care setting

Level of analysis: State developmental disabilities system

Care setting:

- Home- and community-based services (HCBS)
- Community employment and vocational support settings

,
Name of the program and sponsor
Empowering Through Employment, Missouri Department of Mental Health, Division of Developmental Disabilities
URL of the program
https://dmh.mo.gov/dev-disabilities/programs/empowering-through-employment
Purpose of the program

Empowering Through Employment was created to expand employment supports and improve employment outcomes for individuals with intellectual and developmental disabilities. The initiative built on NCI-IDD findings and Missouri’s Employment First efforts by promoting employment authorizations and employment-focused service planning. Missouri reported significant increases in service plans containing employment authorizations between 2016 and 2020.

Geographic area and percentage of accountable entities and patients included

The initiative operated statewide across Missouri’s developmental disabilities HCBS system. It involved individuals receiving HCBS services and provider organizations participating in employment-related supports.

Applicable level of analysis and care setting

Level of analysis: State developmental disabilities system

Care setting:

- Home- and community-based services (HCBS)
- Community employment and vocational support settings

6.1.4 Attributes for Accountability Use

The primary target population includes adults (18+) who receive publicly funded long-term services and supports from their state ID/DD service systems.

The accountable entities are state ID/ DD service systems.

The care settings relevant to the measures are primarily home- and community-based settings. The measures may also capture services delivered in residential settings, such as group homes, supported living arrangements, intermediate care facilities for individuals with intellectual disabilities (ICFs/IID), and nursing facilities. The measures are not intended to assess episodic inpatient care.

Across the measures derived from this instrument, social risk factors are addressed primarily at the measure level through stratification. All IDMs are stratified to facilitate fair and meaningful comparisons across specific residential setting categories. For a small subset of measures, an additional case mix adjustment is applied using a defined risk model to level the playing field where outcomes are especially sensitive to underlying differences in individual support needs. For the remaining measures, adjustment is intentionally not applied, reflecting a person-centered measurement philosophy in which service systems are expected to align supports with individuals' needs.

These measures are best suited for use in a state-level quality accountability and improvement program for publicly funded long-term services and supports (LTSS) for individuals with intellectual and developmental disabilities (ID/DD). The measures align with system-level accountability frameworks that monitor and compare performance across states or within-state systems over time. Accordingly, the measures are most appropriate for public reporting, federal and state oversight (e.g., HCBS quality assurance). These measures are not appropriate for provider-level accountability because 1) the outcomes are shaped by system-level policies, care coordination, and individuals' long-term service environments, which cannot be validly or fairly attributed to a single provider, and 2) these measures are based on sampling strategies designed for state-level estimates rather than provider-level analyses, particularly given that individuals typically receive services from multiple provider types.

6.2.1 Actions of Measured Entities to Improve Performance

As a system performance measurement tool, the NCI-IDD In Person Survey (IPS) was designed to support state development disabilities (DD) service systems ("states") to benchmark, set goals, and compare to the NCI-IDD average and other systems' performance. Federal partners such as the Centers for Medicare & Medicaid Services (CMS) and The Administration on Community Living (ACL) explicitly recognize NCI as a core dataset for managing, funding, and improving DD systems. To achieve those goals, states can take the following steps:

- Systematically analyze IPS results across multiple years to identify trends and priorities for improvement.
    - This can be done through meetings of a quality improvement committee and should include the input of service users and other interested parties. Their input can drive decisions about what an ideal system looks like and where targeted improvement efforts might be focused.
    - This can include comparing state results to those of other states, and the NCI-IDD average.
- Once priority areas have been identified, states should work to translate findings into specific goals tied to policy or program design such as waiver strategy, provider expectations, training requirements, or other areas.
    - Plans should be made to set benchmarks to track improvement year to year, and review plans if benchmarks aren't met.
- NCI results and the review of the results can be built into agency strategic plans, quality strategies, or legislative/budget justifications.

There are potential challenges related to using NCI data for system performance improvement.

- States may have limited resources and capacity to examine the breadth of NCI data and/or convene groups to review the data.
- For some NCI measures, there are not straightforward, easily accessible "levers to pull" to make improvements. It can take some time and thought to understand the drivers of some outcomes.
- Outcomes of policy/programmatic changes can take years to appear in the data.
- Necessary improvements may include actions from other agencies/areas of government and coordination can be challenging.
- Challenges around "owning" poor performance metrics.

However, these challenges can be mitigated by:

- Ensuring state staff working on NCI and the resulting performance improvement are dedicated, and work cross-agency with program, waiver and fiscal staff. This can ensure multiple perspectives and diverse ideas drive change.
- Examining NCI data in tandem with administrative and claims data to bolster findings and potentially target root causes.
- Setting smaller goals within larger goals to demonstrate improvement over time, as opposed to rapid results of policy changes.
- Making sure NCI is not framed or used as a "scorecard" but instead as a planning tool, or a "road sign" indicating areas for examination and improvement. This can encourage the use of NCI data to improve services, and not as referendum on the operations of the system.

One example of this process comes from Ohio.

Ohio noted in their NCI-IDD data that respondents were often not receiving routine dental care at the recommended intervals. The state examined Medicaid claims data to validate this finding and found that about two-thirds of NCI respondents did not have dental claim with Medicaid within the recommended timeframe. Further work led to the finding that there is a lack of Medicaid dental providers and some providers had waitlists approaching two years.

After convening a quality council and using data to bolster advocacy efforts, IDD considerations were included in the State of Ohio's Oral Health Plan. This led to cross agency efforts such as:

- Funding for Ohio State's Developmental and Intellectual Disabilities Dental Certificate Program for Community Providers for postgraduates.
- Enhanced Medicaid reimbursement rates, including a behavior management code for dentists.
- Working towards permitting Ohio's primary care providers to use silver diamine fluoride for cavity management.

6.2.1 Actions of Measured Entities to Improve Performance (derived)

In addition to the actions specified at the instrument level, there are several steps state DD systems can take to improve satisfaction with the level of community inclusion experienced by those receiving services

- Ensure that, if a person has a goal related to level of community inclusion, this goal is identified. The state DD system can impact what is included in the plans in a few ways.
    - This might include the inclusion of questions directed at assessing the presence of this goal in service planning paperwork and/or IT systems
    - This will require that people receiving services know their options related to community inclusion and are able to communicate their goals effectively. This can include plain language resources, interpreters, trusted people included at service planning meetings.
- Ensure that, if the goal is present, it is translated into explicit service plan goals. This may mean breaking the goal down into steps, or benchmarks such as working on specific skills. These service plan goals should also include services that promote social interactions, like assistive technology, therapy or skills training. This might also include a focus on teaching and coaching instead of a goal of task completion. States can ensure this happens by implementing a process for service plan evaluation and review.

State systems might encounter challenges as they try to increase satisfaction with level of community inclusions:

- Staffing challenges make it so there isn't enough support to allow people to go into the community as frequently as they might want or stay home if they don't want to go out when

others do. Additionally, rate structures might not incentivize individual supports so people who want to do something different than others may not be able to have the support they need.
- People have different communication styles which may complicate the process for goals to be included in service plans.

These challenges might be mitigated with the following actions:

- Support providers with rate reform, technical assistance, and workforce initiatives linked to community inclusion outcomes.
- Recognize and incentivize technology as a participation facilitator (e.g., coordinating activities, maintaining social connections).
- Develop accessible resources for people and case managers to help inform them about community inclusion and how it can be achieved.

Here are some ways states have used NCI data related to community inclusion for performance measurement:

- The Kentucky DD Services Quality Improvement Committee tracks performance on the measure of across 3-year cycles. The 2025 Committee Recommendations include specific interventions needed to accomplish community inclusion goals including enhanced information dissemination, ensuring providers comply with the CMS Settings Rule, and working with a group of waiver recipients and other interested parties to improve community inclusion.
- The Colorado HCPF website includes an NCI Dashboard on Community Integration which reports employment status reported out by regions across the state for comparisons. See https://vitalresearch.clicdata.com/b/CO-NCI-IDD
- States may track the extent to which personal preferences are reflected in community inclusion activities. The state of Missouri monitors this measure as People Participate in Meaningful Daily Activities of their Choice

6.2.2 Feedback on Measure Performance

Each year, NCI has several methods to receive feedback on the survey.

- The NCI Annual Meeting brings together state representatives, people administering the survey, contractors and others to discuss survey implementation, troubleshoot challenges, examine how data are used and more.
    - The NCI Annual Meeting allows states to discuss how they’ve used data and any achievements they’ve made related to NCI.
- Yearly training processes allow for direct feedback from surveyors on challenges or potential improvements,
- NCI holds office hours to allow those administering surveys at the state level to hear about innovations, changes or other areas of interest. States ask questions and provide feedback.
- Some states solicit feedback directly from people who respond to the survey. Survey administrators then raise any ideas and/or concerns to the NCI team.

Every 6 years, NCI rolls out a survey that has undergone a “revisions cycle.” This work, that spans several years, includes the gathering of extensive feedback from interested parties in the form of online surveys, focus groups, an Advisory group and user groups. The goals of these revisions cycles are to:

- Ensure the survey gathers information that is most relevant and timely for state systems
- Ensure the survey gathers data that will help state systems support people to achieve their goals
- Ensure the survey reflects the latest research and innovations
- Ensure the survey reflects the feedback received through the above channels

6.2.2 Feedback on Measure Performance (derived)

Each year, NCI has several methods to receive feedback on the survey.

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- Some states solicit feedback directly from people who respond to the survey. Survey administrators then raise any ideas and/or concerns to the NCI team.

NCI has not received any specific feedback on this measure.

6.2.3 Consideration of Measure Feedback

Updated guidance allowing remote surveying was added after a pilot study/implementation. This change helped address implementation challenges, particularly during COVID-19, by providing a flexible alternative to in-person surveying. No additional updates have been made since then, and there has been no feedback indicating further changes are needed.

6.2.3 Consideration of Measure Feedback (derived)

This measure has not been revised since its original endorsement.

6.2.4 Progress on Improvement

We conducted trend analysis of the 32 state systems with reportable data in both 2022-23 and 2024-25. In a paired state-level comparison, we found that performance moved by +0.7

percentage points (60.1% vs 60.8%, p = .068); 6 state systems improved, 2 declined, and 24 were unchanged. These results suggest directional improvement, but the change was not statistically significant.

These modest results are expected. Improvements often take many years to show up in survey-based quality measures. This is because:

- Change takes time to implement, especially at the system-level. Changes often require redesigns of workflows, training, cultural change and policy changes.
- People’s perception often takes time to change. Sometimes it takes many years to shift.
- Workforce challenges across the system can impact the ability to make changes, as can other external influences like social and economic stressors.

In addition, the COVID-19 pandemic occurred between the two testing periods. COVID-19 impacted people’s ability and desire to be in the community, associate with other people, and changed service delivery due to workforce shortages, site closures and other delivery model modifications. It is possible that the minimal improvements seen in our data are related to COVID-era disruptions.

6.2.5 Unexpected Findings

There have been no adverse or unexpected findings from the administration and reporting of the NCI-IDD® In-Person Survey.

6.2.5 Unexpected Findings (derived)

There have been no unexpected findings related to this measure based on the data and time period reflected in this submission.

Developer POC email

hli@hsri.org

Measure Developer POC

Henan Li
Human Services Research Institute
Cambridge, MA
United States

Steward Address

Henan Li
Cambridge, MA
United States

Steward Organization

Human Services Research Institute

Steward Organization URL

https://hsri.org

Steward POC email

hli@hsri.org