National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD)

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National Report 2022-23

Overview and Methodology

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National Core Indicators®—Intellectual and Developmental Disabilities (NCI®-IDD) History and Activities

Overview of National Core Indicators—Intellectual and Developmental Disabilities

In December 1996, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), in collaboration with the Human Services Research Institute (HSRI), launched the Core Indicators Project (CIP). The aim of the project was to support state developmental disabilities operating agencies in the development and implementation of performance and outcome indicators—and related data collection strategies—so that they could measure service delivery system performance. This effort, now called National Core Indicators—Intellectual and Developmental Disabilities (NCI-IDD), strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families. Moreover, NASDDDS' active sponsorship of NCI-IDD facilitates pooled knowledge, expertise, and resources among the states.

In 1997, 15 states convened to discuss the scope and content of a potential performance measurement framework. Directors and staff from these 15 states worked to identify the major domains and sub-domains of performance, indicators, measures, and data sources. The original 61 indicators, developed through a consensus process, were intended to provide a system-level "snapshot" of how well each state was performing. The states were guided by a set of criteria that was designed to select indicators that were:

1. Measurable
2. Related to issues the states had some ability to influence
3. Important to all individuals they served, regardless of level of disability or residential setting.

During this initial phase, data collection protocols were developed and field-tested, including a face-to-face In-Person Survey[1] (for individuals aged 18 and older who were receiving services) and a mail-out Adult Family Survey (for families who have an adult family member living at home). Seven states volunteered to pilot test the indicators. Eight additional states served on the Steering Committee.

Since the initial field test, NCI-IDD has expanded its scope to include outcomes of services for children with intellectual and developmental disabilities and their families and data on the workforce supporting adults with IDD. In addition, NCI-IDD continues to develop and refine the indicators and expand state participation. For more information about NCI-IDD states, technical reports, and other resources, please visit idd.nationalcoreindicators.org.

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[1] Formerly named 'Adult Consumer Survey'

The Core Indicators

The Core Indicators are the standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern, including employment, respect/rights, service planning, community inclusion, choice, and health and safety. To see the entire list of Core Indicators, please visit this page.

Each survey instrument is designed to measure certain Core Indicators. While most indicators correspond to a single survey question, a few refer to clusters of related questions. For example, the indicator that measures Community Inclusion (the proportion of people who regularly participate in everyday integrated activities in their communities) is measured by several survey questions that ask about several separate community activities.

The current set of performance indicators includes approximately 100 consumer, family, system, and health and safety outcomes—outcomes that are important to understanding the overall health of public developmental disabilities agencies. Indicators are organized across domains: Individual Outcomes; Health, Welfare and Rights; System Performance. Each domain is broken down into sub-domains (see Figure B on the following page). Three data sources are used to assess outcomes: the In-person Survey, three Family Surveys, and a NCI State of the Workforce, IDD survey.

The indicators have remained generally consistent over the last several years and thus can be used to analyze system-level trends over time. However, the NCI-IDD program is a dynamic effort that allows for measures to be added, dropped, or changed to reflect current and future priorities of participating states.

The data collection tools used to gather indicator data are regularly refined and tested to ensure they remain valid, reliable, and applicable to current issues within the field.

Domains and Sub-Domains

The following table lists the domains and sub-domains covered by the NCI-IDD In-Person Survey indicators.

Figure B. In-person Survey Indicators: Domains and Sub-Domains

Individual Outcomes Domain

Sub-domain	Concern Statement
Employment	People have competitive paid jobs in community-based businesses. People's jobs reflect varied preferences for employment.
Community Inclusion and Belonging	People do things in their community they want to do. People feel lie they belong to the communities/groups of their choosing.
Community Participation	People participate in activities in their community.
Choice and Decision-Making	People are supported to make everyday choices and life decisions. Support for decision making includes necessary information and experiences.
Relationships	People are supported to build and maintain relationships that are important to them.
Satisfaction	People are satisfied with their everyday lives – where they live, work, the supports they receive and what they do during the day.

System Performance

Sub-domain	Concern Statement
Self-Direction	People who use a self-directed supports option have the information and support needed to actively participate in directing their own supports and services.
Service Coordination	Case managers/service coordinators are accessible and responsive to people. Case managers/service coordinators are knowledgeable about people's needs and the services/supports available to address those needs. Service plans reflect people's goals and needs and are modified as changes occur. People actively engage in the service planning process.
Workforce	There is stable and sufficient direct support workforce to meet demand. People are supported by staff who demonstrate respect for what is important to the person in their day-to-day life. Staff have the right skills to support people.
Access	Services and supports are available, accessible, and responsive to people's needs. People know the options available to them for services and supports...

Health, Welfare, and Rights

Sub-domain	Concern Statement
Safety	People feel safe at home and outside of the home. People know whom to talk to if they don't feel safe.
Health	People have access to and get recommended health services at the recommended frequencies.
Medications	Medications are used effectively and appropriately.
Wellness	People maintain healthy habits.
Respect/Rights	People's rights are respected, and people receive the same respect and protections as others in the community.

How NCI-IDD Data Are Used

The Core Indicators provide information for quality management and are intended to be used in conjunction with other state data sources, such as risk management information, regional level performance data, results of provider monitoring processes, and administrative information gathered at the individual service coordination level. States typically use the indicator data to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Some states use NCI-IDD as a data source for supplemental performance measures in their home and community-based services (HCBS) waiver quality management systems and include the information in support of evidentiary reports to the Centers for Medicare & Medicaid Services (CMS). Many states share the indicator data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction. It is also important to note that states do not use the information in a punitive way to sanction service providers, nor do they use the results to remediate

individual issues (unless specifically requested by the participant or required by law as in the case of suspected abuse, neglect, or mistreatment).

For more information on how to use these data for quality improvement, please see this handbook: Using National Core Indicators for Quality Improvement Initiatives.

Methodology

Check out the Frequently Asked Questions for more information on Methodology.

Administration

A key principle of NCI-IDD is the importance of gathering information directly from service recipients. The indicators are meant to apply to all individuals receiving services from the state developmental disabilities service system, regardless of disability type, and NCI-IDD administration protocols dictate that every person selected into the sample is given an opportunity to respond and no one is prescreened or predetermined to be unable to respond. Moreover, survey questions should not be marked "not applicable" on the basis of a person's level of ability.

Information for the In-Person Survey is collected via a direct conversation with the person receiving services. Additionally, background information is primarily collected from the individual's record. Section I questions, which pertain to personal experiences and require subjective responses, 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, respect and rights, and their access to services—allows for the use of "proxy" or other respondents who know the individual well (such as a family member or friend).

Proxy Respondents

Studies have found that the greatest discrepancies between individual and proxy responses occur when the information being collected is subjective (i.e., related to how a person feels; proxies would be aware of the correct answers only if the individual had previously expressed his or her feelings).[2] Questions relating to observable behaviors tend to have higher levels of agreement between the proxy and the individual. By excluding proxies, a large percentage of individuals (most of whom are unable to respond) would be unrepresented in the data. Thus, the NCI-IDD determined at the outset that proxy respondents would be used, though only for specific questions and only in situations where the individual surveyed either could not effectively communicate with the surveyor or chose to have a proxy respondent.

As mentioned, the use of proxy respondents for the NCI-IDD tool is limited to questions in Section II, which relates to observable and/or measurable items: Community Inclusion, Choices, Respect/Rights, and Access to Needed Services. These questions deal with everyday occurrences on which others may reliably report. State records are also used to report objective data on an individual's health status and exam history as well as employment status; this information is collected in the Background Section of the survey.

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[2] Magaziner, Jay, Sheryl Zimmerman, Ann L. Gruber-Baldini, J. Richard Hebel, and Kathleen M. Fox. "Proxy Reporting in Five Areas of Functional Status Comparison with Self-Reports and Observations of Performance." American Journal of Epidemiology 146.5 (1997): 418-28.

NCI-IDD has taken steps to ensure that the responses gathered are as accurate as possible. First, it is important to make the questions as accessible as possible to increase participation by all individuals. Surveyors are trained to make informed decisions about whether to include a proxy respondent. NCI-IDD attempts to make the language in the In-person Survey as easy to understand as possible and includes suggested rephrasing for questions that may be nuanced or more difficult to understand. The NCI-IDD surveys are also routinely revised based on feedback from states, self-advocates, families, and surveyors who are administering the tool. Secondly, it is important to establish a set of standards for proxy respondents. NCI-IDD aims to increase the reliability of proxy responses by allowing only those people who know the individual well (family, friends, staff, etc.) to serve as proxy respondents.

To avoid conflict, case managers/service coordinators are not allowed to respond as proxies. Further, if both the individual and a proxy respondent answer a question, the individual's answer is recorded so long as his/her answer is deemed reliable by the surveyor. Surveyors also keep track of who responds to each question—the individual or the proxy—and the proxy's relationship to the individual.

Surveyor Training

States employ a variety of individuals to conduct the face-to-face meetings for the NCI-IDD In-person Survey. To avoid conflict, surveys cannot be administered by the individual's service provider, relative, personal case manager, staff member, or other close contact. Given this constraint, states often use university students, state staff, private contractors, advocacy organizations, and individuals with disabilities and their families to conduct the surveys.

NCI-IDD National staff implements a required, standardized training for NCI-IDD surveyors each year. Training includes asynchronous and synchronous trainings that includes an in-depth review of the NCI-IDD program, survey administration protocol and procedures, and the survey tool. The goal of trainings is to provide a standardized training to ensure uniform application of the survey.

Additional training is available to review the process for entering survey data in the Online Data Entry Survey Application (ODESA).

Data Analysis

Criteria for Exclusion of Responses

All individuals selected in the survey sample are given an opportunity to participate in a face-to-face meeting. There are no prescreening procedures. Exclusion of responses occurs at the time of data analysis by HSRI, based on the criteria described below. There is no threshold of number of answers to be given in order to consider a survey complete.

Surveys are excluded from analysis of questions occurring in Section I if:

1. The surveyor indicated that the individual receiving supports did not respond validly to questions in Section I.
2. All questions in Section I were missing or marked n/a or Don't Know.

Surveys are excluded from analysis of questions occurring in Section II if:

1. The individual receiving supports was marked as the respondent to all questions in Section II but Section I was deemed invalid (for one of the reasons above).
2. No questions were answered in Section II.

The total number of valid In-Person Surveys included in this report for 2022-23 was 25,424.

Responses for Section I

Only individuals receiving services may answer questions in Section I. As shown in Figure C, 62% of individuals in the total 2022-23 sample responded to Section I of the direct meeting; valid responses by state ranged from 36% to 84%.

Responses for Section II

Section II allows for multiple respondents who know the individual well (e.g. family, friend, support worker) to provide answers. If an individual's responses were excluded from Section I in the final analysis, responses from Section II were also excluded if the individual was the only respondent to Section II. For 2022-23, the valid response rate (proxies included) to Section II was 99%.

Sampling

Each state is instructed to attempt to complete surveys with a sample of adults who are receiving at least one publicly funded service in addition to case management. A sample size of 400 guarantees valid comparisons to be made across states with a 95% confidence level and a margin of error of +/-5%, no matter how large the service population size. A 95% confidence level and a margin of error of +/-5% is mandatory for each state's sample to be included in this report. Most states sample more than 400 individuals to account for refusals and surveys that may be deemed invalid. Figure C presents the number of surveys completed by state. A more detailed description of each state's sampling strategy can be found in Appendix B.

Why do we ask states to collect 400 surveys?

When NCI-IDD asks states to pull a representative sample of 400 surveys, the aim is to compile a dataset that can provide a high level of statistical accuracy. This means that the goal is to create a dataset that can be used to make accurate inferences about the entire population of people using

public services in each state. In order to do this, we ask each participating state to pull a sample that reaches the 95% confidence level/5% margin of error threshold; for most states, this sample size is 400.

A sample size that reaches the 95% confidence level/5% margin of error threshold means that if you sampled that number of people from the same population several times, 95% of your responses would fall within 5% above or below the actual percentages. Using this sample size we can assume relative accuracy. The larger the sample size, the smaller the margin of error and the greater the accuracy.

Statistical accuracy is largely a function of sample size. The larger the sample size, the greater the statistical accuracy of results (lower margin of error). However, gains in statistical accuracy are not proportional to increases in sample size. There are diminishing returns. For example, for a large total population, if the sample size increases by 100, and then by another 100, and then by another 100, the statistical accuracy might increase by 5%, then by 3%, then by 1%.

As a result, the 400 sample size gives a statistical accuracy of ±5% and is considered the most "cost effective" sample size for large-scale surveys. Meaning, you could sample more people, but the increase in statistical accuracy those "extra" people would provide is minimal, and not worth the money.

To play around with this, take a look at www.raosoft.com/samplesize.html NCI-IDD requires a margin of error at most 5% and a 95% confidence level. As you increase the population size (in our case, this represents the service population), you'll see that the recommended sample size does not increase proportionally.

https://answersresearch.com/wp-content/uploads/2015/06/Answers-Research-Magic-400-062315.pdf
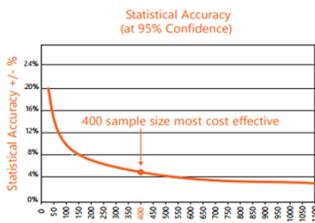
Figure C. Valid Surveys and Response Rates by State 2022-23

State	% Valid Answers to Section I	% Valid Answers to Section II	Number of Valid Surveys Completed
AL	57.2%	99.8%	479
AR	70.5%	99.8%	417
CA	68.6%	99.8%	8830
CT	55.5%	99.7%	602
DC	61.6%	99.4%	354
DE	57.3%	99.5%	419
FL	46.1%	99.6%	532
GA	54.4%	100.0%	406
HI	41.0%	100.0%	351
IL	56.8%	100.0%	400
IN	73.6%	99.6%	1080
KS	68.4%	100.0%	393
KY	46.5%	99.1%	439
MD	61.9%	99.6%	533
MI	55.4%	99.7%	670
MN	51.6%	99.8%	403
MO	65.0%	99.8%	403
MT	69.3%	97.0%	365
NC	59.6%	99.8%	594
NE	83.1%	96.7%	420
NH	52.6%	100.0%	399
NJ	52.6%	99.6%	460
NV	84.5%	98.6%	419
NY	56.3%	98.3%	1682
OK	62.8%	99.8%	400
OR	71.3%	100.0%	418
PA	55.0%	99.7%	718
SC	54.0%	100.0%	511
TX	49.8%	97.6%	420
UT	65.2%	96.4%	359
VA	50.7%	100.0%	762
WI	35.9%	98.9%	362
WY	63.0%	98.3%	424
Unweighted NCI-IDD	62.3%	99.5%	25424

Data Management and Analysis

HSRI coordinates the NCI-IDD data management and analysis. All states enter data into the Online Data Entry Survey Application (ODESA) system; HSRI staff subsequently download the data into an SPSS data file. This data file is then "cleaned" (reviewed for completeness and compliance with standard NCI-IDD formats) and invalid responses are eliminated. Files from individual states are then merged into a single SPSS file. The merged file from 2022-23 was used for all analyses in this report.

Below is a summary of the statistical procedures used to analyze the In-person Survey data.

Weighting

Statistically, the term "average" refers to a calculated central or middle value of a set of numbers. In NCI-IDD reports, we use "NCI-IDD average" to demonstrate the typical performance of all the states that conducted the survey. Prior to the 2016-17 survey cycle, the NCI-IDD average was calculated as the simple arithmetic mean of all state means (an approach known as "average of averages").

The NCI-IDD averages are "weighted" to reflect the states' relative population and sample sizes. We created the weights using the state's number of valid surveys and its total survey-eligible population. This way, a state that provides services to a larger number of people but uses a sample similar in size to other states has a greater influence on the overall NCI-IDD average (that is, its contribution is *proportional to its service population*).

When a state's sampling strategy is to identify and interview survey participants using simple random sampling or proportional stratified random sampling, each completed survey in the state gets assigned the same weight. In some cases, when a state's sampling strategy departs markedly from simple random or proportional, it may be necessary for completed surveys in the state to be assigned different weights based on which sampling strata they correspond to.

You can read more about each state's sample in Appendix B.

The number of respondents (N) for each question is not weighted.

Significance Testing

For most items in this report, each state's percentage was compared to the weighted NCI-IDD Average (described above), and the differences between the two were tested for both statistical significance as well as effect sizes. Effect sizes are used in addition to statistical significance because statistical significance of a state's result depends, in part, on the size of the state's sample: the larger the sample, the more likely it is that even a small difference will be found statistically significant. A statistically significant difference for a state with a large sample size, in and by itself, does not necessarily mean there is a practically significant difference. The inclusion of effect sizes as a new criterion allows us to present "meaningfully significant" results, which take into consideration the magnitude or size of the differences.

Many outcomes in this report are categorized into one of the three classes:

1. Significantly above the NCI-IDD average, where the difference between the state's percentage and the weighted NCI-IDD average a) was in favor of the state, b) was statistically significant (i.e., p <.01), and c) met the effect size criterion (i.e., Cohen's d > 0.2, see below for details);
2. Within the NCI-IDD average range, where the difference between the state's percentage and the weighted NCI-IDD average was a) not statistically significant (i.e., p ≥.01), or b) did not meet the effect size criterion (i.e., Cohen's d ≤ 0.2);
3. Significantly below the NCI-IDD average, where the difference between the state's percentage and the weighted NCI-IDD average a) was in favor of the NCI-IDD average, b) was statistically significant (i.e., p <.01), and c) met the effect size criterion (i.e., Cohen's d > 0.2).

Technical Details

The comparisons were done through one sample T-tests using the weighted NCI-IDD average as the benchmark. A conservative cut-off point (alpha) of $p < .01$ was used to detect statistically significant differences. Effect sizes are calculated using the formula: Cohen's $d = (2t)/(\sqrt{df})$. A cutoff point of Cohen's d= 0.2 was chosen for the effect size to be considered "meaningfully significant," following the standard interpretation offered by Cohen (1988) that Cohen's d of 0.8 = large, 0.5= moderate, and 0.2= at least a small effect.

Outcome Adjustment

Outcome adjustment, or "risk adjustment," is a statistical process used to control for differences in the individual characteristics of people who completed the NCI-IDD Survey across states. This procedure allows for more accurate state comparisons by effectively "leveling the playing field." This analysis helps account for the fact that states have different eligibility definitions for services and may have samples with different characteristics. Outcome adjustment produces a predicted value that one would expect to observe given the individual's characteristics. The state's average observed rate (i.e., the state average prior to risk-adjustment) is adjusted by the average predicted rate to produce the risk-adjusted rate. As a result of this procedure, state differences in adjusted values reflect true state differences rather than differences due to the demographic or characteristic makeup of state service populations.

In 2022, the NCI-IDD team underwent a systematic revision process to improve the outcome adjustment methodology. The team made significant updates based on recent data, reevaluating both the predictors and outcome-adjusted indicators taking into consideration the latest data cycle and evolving perspectives on equity and person-centered planning and services.

Key changes in our methodology include:

- The team narrowed down the risk-adjusted indicators to only two scales: the Community Inclusion Scale and the Life Decisions Scale. As a result, the remainder of the Choice section no longer undergoes outcome adjustment.
- The indicators are now adjusted using the following variables: age, level of intellectual disability, level of mobility, self-reported health status, preferred mode of communication, proxy use, and whether any behavioral supports are needed for disruptive or destructive behavior.

These updates ensure a more accurate representation of state differences in adjusted values, reflecting true variations in state performance rather than differences due to demographic or characteristic

makeup of state service populations. Unadjusted results for these indicators are presented in Appendix C.

Scale Development

Scales are a widely used research tool for measuring various constructs or concepts. The purpose of scales is to combine responses from multiple related questions into one variable, which can then be used to measure an overarching concept rather than the individual elements of that concept.

When creating a scale, it is essential to ensure that the multiple items included in it share common properties or measure the same underlying construct. This is important because including items that measure different constructs or properties can lead to an unreliable or invalid scale.

To create NCI-IDD scales, we performed factor analysis to identify the underlying dimensions or factors that are being measured by a set of items. In factor analysis, the correlations between the items are examined, and the items are grouped together based on their shared variance.

In addition to factor analysis, we also performed assessments of each scale's reliability using Cronbach's alpha. The scales had an adequate level of internal consistency and reliability.

In the 2022-23 IPS, we present six scales: Adequate Transportation (new), Respect for Personal Space (new), Satisfaction with Community Inclusion, Community Inclusion, Everyday Choices, and Life Decisions. In general, higher scale scores represent higher levels of desirable results or better system performance. For more information on each scale, please refer to the table notes accompanying each scale.