

Measure at a Glance

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

Survey Summary (Where does this survey seek to improve care?)

This yearly survey called the National Core Indicators In-Person Survey (NCI IPS), gathers information from adults who receive services for intellectual and developmental disabilities (ID/DD). The survey started in 1997, and 48 states and the District of Columbia currently use the survey. The survey usually runs from July 1 to June 30 each year.

The survey looks at how well state systems provide home- and community-based services (HCBS), which help people live and take part in their communities, to adults. The survey is not limited to a specific payer.

The information from the survey is used to calculate patient-reported experience performance measures (PRE-PM), meaning it uses information reported by people receiving services. A higher score on the PRE-PMs means better performance.

For the Spring 2026 cycle, the five PRE-PMs derived from this survey are:

- CBE #3622-1: NCI for ID/DD HCBS: Community Job Goal
- CBE #3622-2: NCI for ID/DD HCBS: Activities of Daily Living (ADL) Goal
- CBE #3622-3: NCI for ID/DD HCBS: Satisfaction with Community Inclusion Scale
- CBE #3622-4: NCI for ID/DD HCBS: Social Connectedness
- CBE #3622-5: NCI for ID/DD HCBS: Has Friends (Non-Staff, Non-Family)

Meaningfulness (Why does this matter to people with ID/DD, and how could it improve their care and services?)

This survey collects information about whether services are person-centered and reflect individual goals and needs. Person-centered planning means service plans, which identifies the type and amount of services a person needs to meet their goals and preferences, are built around a person's own goals and preferences. This approach is evidence-based practice (supported by research). The data, which includes information about employment, functioning, and social connectedness, help states monitor program performance and identify areas for improvement.

Many groups, including people with disabilities, caregivers, providers, and program leaders, helped identify what should be measured. These groups took part in developing a national framework with 11 areas of quality. Stakeholders said important areas include choice, control, and rights. Some suggested adding more focus on transportation, employment, and self-determination (a person's ability to make their own choices). The measures reflect priorities identified by stakeholders in the study.

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Usability (How will states use this survey to improve care delivery and services?)

States can use the PRE-PMs derived from the survey to:

- Review results and compare performance over time.
- Compare their results to other states and to the NCI average.
- Identify trends and areas for improvement.
- Set goals and inform decisions about programs, policies, and services.

States may include survey results in strategic plans, quality plans, and budget decisions.

They may also use the results with other data sources to better understand findings.

Feasibility (How can this survey be implemented and improve care and services without adding burden for states and people with ID/DD?)

This survey uses a system called the Online Data Entry Survey Application (ODESA), which is a web-based system that states use to enter survey data. The system is secure and requires a login. It includes built-in checks and skip patterns to support correct and consistent data entry. States can track progress, manage users, and download their data. States collect data every year, and they can access their data during and after the collection period.

States must pay a yearly fee to take part in the program. For the 2025-26 data cycle, the fee is \$19,300.

States also need to complete tasks such as collecting and entering data and following program rules. States may use their own staff or hire a vendor to collect the data. There can be challenges when using the data, such as limited resources or difficulty understanding some results.

Changes based on the data may take time. States may need to work with other agencies to address findings.

Because the survey has not changed, measure results are consistent over time.

There has been no feedback asking for changes or showing concerns about burden.

Impact (How will using this survey improve experiences and outcomes for people with ID/DD?)

This survey collects information about people's experiences with HCBS and whether such services are person-centered and reflect individual goals and needs.

States may use the data to assess system performance, support quality improvement efforts, and examine areas such as community inclusion, employment, and services that support daily life. States combine the data at the state level to assess system performance.

States can translate findings into specific goals tied to policy or program design. States may use results to identify areas where service goals are not aligned with individual goals and needs. States may use results to support improvement activities and increase focus on areas such as employment supports. Changes may take time to appear in the data and may require coordination across programs and agencies.

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CBE #3622-1: NCI for ID/DD HCBS: Community Job Goal

Measure Summary (Where does this measure seek to improve care?)

This measure looks at adults with intellectual and developmental disabilities (ID/DD) who receive state developmental disability services, say they want a job, and whether their service plan, which outlines the types and amounts of services they need to meet their goals and preferences and connect them to those services, includes a job goal. It uses data from the National Core Indicators (NCI) survey, which collects information from people receiving such services, including home- and community-based services (HCBS).

This measure applies to adults who receive publicly funded developmental disabilities services through state systems, regardless of payer type.

The percentage-based score divides the number of people with a job goal in their service plan (numerator) compared to the number of people who want a job but do not have one (denominator). A higher score means better performance (more people with a job goal).

Meaningfulness (Why does this matter to people with ID/DD, and how could it improve their care and services?)

This measure shows how often service plans include a job goal for people who say they want to work.

The data from the National Core Indicators (NCI) 2023-2024 survey, 2,118 of 5,042 people without a job (about 42%) said they wanted a paid job in the community. Among people who already had a paid job, 91% said they like their job (1,920 people). The findings show that many people want jobs but do not have them and most people who have jobs report that they like their work.

This measure also examines how well service plans reflect what people say they want, especially goals related to working. This relationship between what people say they want (such as a job) and whether their service plan includes that goal is part of person-centered planning and coordination and community inclusion, which are key areas used to assess service quality. Research shows that people who have a job goal in their service plan are much more likely to have competitive integrated employment (a paid job in the community where a person works alongside people without disabilities and earn wages similar to others doing the same work). Including a job goal in the service plan is an important step in helping people work toward employment if they want a job.

Usability (How will states use this measure to improve care delivery and services?)

This measure is used at the state level to monitor how well service plans include employment goals for people who say they want jobs, based on data collected through the NCI In-Person Survey. State developmental disabilities systems use this measure to track performance and compare results with other states. States can review results over time to identify trends and set priorities for improvement.

States can take specific actions to improve performance, including setting clear employment

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goal definitions, adding these goals to service plan templates, and training staff to understand participant goals. States can also update information systems to support goal tracking.

Impact (How will using this measure improve experiences and outcomes for people with ID/DD?)

This measure focuses on employment goals for people with intellectual and developmental disabilities. Employment is part of community inclusion.

Medicaid HCBS requires person-centered service planning, which means the plan reflects a person's goals and preferences. The measure allows state developmental disabilities systems to monitor whether service plans include employment goals for people who want jobs. Including employment goals shows whether service plans match a person's stated goal for work.

Research shows that people with an employment-related goal in their service plan have more than a four-fold increase in the odds of having competitive integrated employment. Employment is associated with economic stability, health, and quality of life. These findings show that including employment goals in service plans supports access to employment for people who want to work.

Performance Gap (Based on current performance, where and how much can services and care improve?)

The overall mean (average) score for this measure is 35% based on 2024-2025 NCI In-Person Survey data. The data include 30 states with valid results and 2,602 respondents in the measure population. State scores range from 12% (the lowest reporting state) to 61% (the highest reporting state).

The measure developer reports results by deciles. Deciles divide states into 10 equal parts based on scores. Decile 1 includes states with the lowest scores, and Decile 10 includes states with the highest scores. As states move up the deciles, performance improves. In these data, the mean (average) score for the lowest decile is about 13.9%. The mean score for the highest decile is about 58.0%.

These results show that, in many states, a large number of people who say they want a job do not have an employment goal in their service plan. The wide range in scores across states shows differences in how well service plans reflect people's stated employment goals. This gap suggests that some state systems may not fully align service plans with what people say they want, especially goals related to employment, and highlights an area where programs can focus quality improvement efforts.

CBE #3622-2: NCI for ID/DD HCBS: Activities of Daily Living (ADL) Goal

Measure Summary (Where does this measure seek to improve care?)

This measure looks at how well service plans match what people want. The measure focuses on adults who receive home- and community-based services, regardless of payer. It surveys whether people want to be more independent with activities of daily living (ADLs) and then checks if that goal is written in their service plan, which outlines the types and amounts of

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services they need to meet their goals and preferences and connect them to those services. ADLs include getting dressed, bathing, and brushing teeth.

The final score shows the percent of people who have a matching goal in their plan. A higher score means a greater percentage of people in the state have goals in their service plans that match what they want.

This measure focuses on person-centered planning (planning based on a person's own goals and choices). It looks at whether services reflect each person's preferences.

When plans include these goals, programs may support people who want more independence. When plans do not include these goals, the measure may show gaps between what people want and what their service plan includes.

Meaningfulness (Why does this matter to people with ID/DD, and how could it improve their care and services?)

This measure reflects what people say they want. It focuses on people who need help with daily activities and want more independence.

In 2024-25, 5,744 people reported needing help with ADLs, and 3,201 (57%) said they want to do more on their own. This information shows that independence in ADLs matters to many people receiving services.

The goal of the measure is to assess if service plans match what people say they want. The measure looks at person-centered planning, which means staff work with each person to create a service plan based on that person's own goals, choices, and needs related to daily functioning, including ADLs such as getting dressed, bathing, and brushing teeth. When people improve these skills, they may become more independent in their daily lives.

This measure shows how well service systems include personal goals in service plans. Providers and programs can use these results to see if they are helping people work toward skills that matter to them. The results can help programs identify gaps and improve how they plan services over time.

Usability (How will states use this measure to improve care delivery and services?)

States and programs can use this measure to review how well service plans match what people want. The measure reports a percentage that shows the number of people who want more independence in ADLs and have that goal in their service plan, which helps programs review and compare how well their service plans reflect what people want. Programs can compare their scores over time or compare them with other states. Using this information helps programs identify areas where service planning could better reflect personal goals.

States use these results for quality improvement. They can review trends, set goals, and create plans to address gaps. States may also use the measure to support discussions with staff, service users, and other groups. These discussions may help identify challenges and possible solutions, although programs may still need to review other data to fully understand gaps and actions for improvement.

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Impact (How will using this measure improve experiences and outcomes for people with ID/DD?)

This measure supports improvements in how service plans reflect what people want, especially goals related to independence in ADLs. When service plans include these goals, programs may help people build skills and increase independence over time. Programs can use the results to identify gaps in service planning and make changes to better align services with personal goals. These changes may include training staff, updating planning processes, or improving how staff learn about a person's preferences.

For people receiving services, this may lead to service plans that better reflect what they want and support them in developing everyday skills. Changes may take time because they often involve updates to systems, staff training, and how programs deliver services.

Performance Gap (Based on current performance, where and how much services and care can improve?)

The measure shows differences in how well service plans match what people want. The mean (average) score was 77% based on 2024-2025 data from 34 states. The lowest reported score for an individual state was about 16%. The highest reported score for an individual state was about 97%.

Scores are also grouped into deciles. Deciles divide states into 10 equal parts based on scores. The 1st decile includes states with the lowest scores, and the 10th decile includes states with the highest scores. As states move up in the deciles, performance improves. States in the lowest decile had an average score of about 35%, while states in the highest decile had an average score of about 95%.

Half of the states scored below 80%. This means at least 20% of people who want to be more independent in ADLs did not have this goal written in their service plan. These results show a gap in how well service plans reflect what people want.

CBE #3622-3: NCI for ID/DD HCBS: Satisfaction with Community Inclusion Scale

Measure Summary (Where does this measure seek to improve care?)

This measure looks at how satisfied adults with intellectual or developmental disabilities are with their level of participation in community activities. It applies to adults who receive home- and community-based services (HCBS) through state developmental disabilities service systems. HCBS are services that help people live and get care in their home or community. The measure is not limited to a specific payer.

The measure uses National Core Indicators (NCI) In-Person Survey questions about specific community activities, including shopping, going out for entertainment, eating at restaurants or coffee shops, attending religious or spiritual practices, and taking part in community groups. People answer questions about whether they want to do more, less, or the same amount of these activities. If they say they want the same amount, the measure counts them as satisfied.

The measure may help programs understand how well services match individual preferences.

Meaningfulness (Why does this matter to people with ID/DD, and how could it improve their care and services?)

This measure focuses on what matters to people receiving services. It looks at whether people feel satisfied with how often they take part in community activities. Research shows that people with intellectual and developmental disabilities value social inclusion, which means being part of community life. Programs can support this by using person-centered planning, which matches services such as transportation or personal help to a person's goals.

Studies show that people who can choose when to take part in activities tend to have more positive outcomes. Community participation is also linked to friendships, and social connections may help protect a person's health.

The measure reflects areas that stakeholders helped identify as important, including person-centered planning and coordination (services are planned and organized based on each person's goals, needs, and preferences) and community inclusion (people take part in community life in ways that matter to them, such as social, recreational, or group activities).

People with disabilities, caregivers, and experts worked together to shape the measure to ensure it reflects what matters most to the people receiving services.

Usability (How will states use this measure to improve care delivery and services?)

This measure supports program monitoring and improvement at the state level. States review results to understand whether services match people's preferences for community activities and to compare performance across states or over a period of time. States use the results to identify trends, set priorities, and guide decisions about policies and service planning. They may also review results with stakeholders, including people receiving services, to help improve services.

Impact (How will using this measure improve experiences and outcomes for adults with ID/DD?)

This measure focuses on how people feel about their level of community participation.

Changes in performance can be small and may take time to show. For example, results increased slightly from 60.1% in 2022-2023 to 60.8% in 2024-2025, but this change was not statistically significant (meaning it may be due to chance). External factors such as access to community services, service availability, or personal circumstances can also affect participation and influence results.

Performance Gap (Based on current performance, where and how much services and care can improve?)

This measure shows variation in how satisfied people are with their level of community participation. Data from the 2024-2025 NCI In-Person Survey show that:

- 61% of people reported satisfaction
- 39% said they wanted to increase or decrease their participation

These results reflect data from 39 states and about 30,372 respondents. Satisfaction scores ranged from 45% (the lowest reported score from a state) to 86% (the highest reported score

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from a state), showing wide differences in how people reported their level of community participation.

State results are also grouped into deciles. Deciles divide all states into 10 equal groups based on their scores. Decile 1 includes states with the lowest scores, and Decile 10 includes states with the highest scores. A higher decile means better performance.

In the lowest decile, the mean (average) satisfaction score is about 42.1%. In the highest decile, the mean satisfaction score is about 77.5%. The wide range and differences across deciles show that satisfaction with community participation varies across state systems.

CBE #3622-4: NCI for ID/DD HCBS: Social Connectedness

Measure Summary (Where does this measure seek to improve care?)

This measure looks at social connectedness (how connected a person feels to others) for people who receive home- and community-based services (HCBS). HCBS are services that help people live and take part in their communities.

The measure uses data from the National Core Indicators (NCI) survey for people with intellectual and developmental disabilities (ID/DD). The measure reports the percentage of people who answer a survey question by saying they do not feel lonely often or feel like they have no one to speak to. Responses of “no” or “sometimes” count as better results.

The measure includes adults who receive publicly funded HCBS through state developmental disability service systems and answer the survey question. It excludes people who do not understand the questions or do not give clear answers.

A higher score means better performance (more people reporting that they do not feel lonely often).

Meaningfulness (Why does this matter to adults receiving HCBS and how could it improve their care and services?)

This measure looks at social connectedness, which is important for people who receive HCBS. Data from the National Core Indicators (NCI) 2023-24 survey shows 55% of 9,499 respondents, said they want or may want help making or keeping friends.

A lack of social connectedness can lead to worse health outcomes and lower well-being. In addition, people with disabilities are more likely to feel lonely or socially isolated because of factors such as limited access to community activities, barriers to participation, and public health events such as the COVID-19 pandemic.

Person-centered service planning (such as creating a service plan based on a person’s own goals, preferences, and needs) may help improve community participation. Service providers, case managers, and sometimes family members or caregivers work with the person to develop the plan.

This measure may help states monitor social connectedness needs, identify gaps in social connectedness, and guide efforts to improve community participation and social support.

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Usability (How will states use this measure to improve care delivery and services?)

States use this measure to track and compare how well services support social connectedness. They can review survey results each year to find trends over time and compare their results to other states and national averages.

States may also use this information to identify areas where people feel more or less connected, such as how often they feel lonely, and guide quality improvement efforts, such as through setting goals and creating programs.

States may also combine these results with other data to better understand people's experiences.

Impact (How will using this measure improve experiences and outcomes for adults receiving HCBS?)

This measure focuses on social connectedness, which supports health and well-being. People who have low social connectedness often experience worse health outcomes and lower well-being. People with disabilities may be more likely to feel lonely or socially isolated.

Stakeholders may use this measure in different ways. States can use the results from this measure to identify people who report frequent loneliness and develop services that help increase social connections, such as adding goals for relationships or community participation in service plans and providing services that help people engage in their communities. Over time, these actions may improve social connectedness and support better health and quality of life for people receiving HCBS.

Performance Gap (Based on current performance, where and how much services and care can improve?)

This measure looks at how many people receiving state HCBS report that they do not feel lonely often. Data from the July 2024 to June 2025 NCI survey show a mean (average) score of 87% across states.

Results range from 81% (the lowest reported state value) to 98% (the highest reported state value) across 39 states, based on 17,157 survey respondents with valid responses. Scores are generally high, with remaining room for improvement.

The measure also reports results by decile. Deciles divide states into 10 equal parts based on scores. Decile 1 includes states with the lowest scores, and Decile 10 includes states with the highest scores, so being in a higher decile indicates better performance. The mean score for Decile 1 is about 82.7%, and the mean score for Decile 10 is about 95.2%.

CBE #3622-5: NCI for ID/DD HCBS: Has Friends (Non-Staff, Non-Family)

Measure Summary (Where does this measure seek to improve care?)

This measure looks at whether people receiving home- and community-based services (HCBS) have friends who are not staff or family. HCBS are services that help people live and take part in

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their community. The measure counts the percentage of people who report they have friends they like to talk to or spend time with who are not paid staff or family members.

This measure uses data from adults who receive state developmental disabilities services and participate in the National Core Indicators for Intellectual and Developmental Disabilities Home- and Community-Based Services (NCI-IDD HCBS) In-Person Survey, regardless of payer.

A higher score is better, indicating more people in the state report having friendships.

Meaningfulness (Why does this matter to people with ID/DD, and how could it improve their care and services?)

This measure looks at whether people have friends who are not family or staff. Data show that friendships are important to people who receive services.

The 2023 to 2024 NCI-IDD In-Person Survey collected responses from 9,499 people between July 2023 and June 2024, and 55% said they want or might want help making friends or staying in touch with friends.

Stakeholders and experts also identified social relationships as a key part of community inclusion.

Usability (How will states use this measure to improve care delivery and services?)

States can use this measure to:

- Understand how many people report having friends who are not family members or staff.
- Track progress over time to see patterns and set goals for improvement, such as in planning activities, quality improvement efforts, or program strategies.
- Compare their results to other states or to national averages.
- Decide where to focus efforts to support better social connections for people receiving services.

Using the data may require staff time and coordination across teams.

Results may take time to change because reported state scores reflect system improvements and personal outcomes, which develop gradually.

Impact (How will using this measure improve experiences and outcomes for people with ID/DD?)

This measure looks at how often people with intellectual and developmental disabilities (ID/DD) report having friends who are not family or staff. Friendships can have positive effects on health and well-being. However, people with ID/DD are less likely to have these types of friendships and may also experience exclusion from typical social relationships.

HCBS can help people build relationships (outside of paid staff and family) by supporting community participation and including goals in person-centered planning.

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Performance Gap (Based on current performance, where and how much services and care can improve?)

This measure shows how many people report having friends who are not family or staff. From July 2024-June 2025, 76% of survey respondents reported having these types of friends.

The analysis included 39 state systems and 17,638 respondents with valid responses. Scores varied across states, with results ranging from 44% (the lowest reported score from a state) to 91% (the highest reported score from a state). The mean (average) score was 75.6%.

The measure also groups states into deciles based on state performance scores. Deciles divide state systems into 10 equal parts based on their scores. Decile 1 includes states with the lowest scores, and decile 10 includes states with the highest scores, so being in a higher decile indicates better performance. In this measure, the mean (average) score for the states in the lowest decile was 55.2%, and the mean score for the states in the highest decile was 89.0%.

These differences suggest that state systems vary in how they support social relationships. The wide range of scores indicates there is room for improvement. Some people may not have access to services that help them build friendships outside of staff and family. This measure can help identify where systems may need to improve support for social connections.

Disclaimer: Battelle used generative artificial intelligence in the initial drafting of this document. Actual humans with relevant expertise subsequently validated and revised the content.