

# Measuring and improving the quality of supports for people with IDD

The system of supports for people with intellectual and developmental disabilities (IDD) has changed tremendously over the last few decades. States are striving to provide a range of person-centered, community-based services—and gauge their impact.

## What's National Core Indicators®?

National Core Indicators (NCI) is used across states to assess the quality and outcomes of Developmental Disability (DD) services provided to individuals with IDD and their families. NCI offers valid, reliable, person-centered measures that states use to demonstrate how publicly funded supports are impacting people's lives and to determine where they can improve the quality of those supports. A total of 46 states and the District of Columbia participated in NCI in 2019-20. Some states, including California, also use NCI to collect data at a regional level.

Participating states use the data to:

- ★ Assess individual satisfaction and experience with supports
- ★ Track key outcomes across multiple years
- ★ Compare outcomes to other states and to the average across states
- ★ Improve DD system performance

## What does NCI measure?

NCI surveys help states measure important elements of person-centered planning, outcomes, and satisfaction in domains such as:

**Self Determination**

**Service Coordination & Access**

**Relationships & Community Inclusion**

**Rights, Choices, & Decision-making**

**Employment Status & Goals**

**Health, Welfare, & Safety**



Standardized suite of surveys; states can customize by adding state-pertinent questions



Sampling guidance and data collection protocols designed for inclusivity, to amplify the voices of *all* service users



Designed with input from service users and extensive input from public DD managers



Training and technical assistance to ensure the validity and integrity of the data



Secure data collection and analysis platform



National, state-level, and user-friendly reports for wide audiences



Interactive online chart-generator

## How do states gather the data?

States use the NCI Adult In-Person Survey to collect information on outcomes experienced by adults receiving publicly funded DD supports.

States can also use NCI Family Surveys to understand how DD supports are impacting the lives of families.



### Adult In-Person Survey

*Previously called the Adult Consumer Survey*

Respondents are adults age 18 and over who receive supports from the state. This survey is administered face-to-face.



### Family Surveys

These surveys are administered via mail. Respondents are family members of people with IDD receiving DD supports from the state:

**Adult Family Survey:** Respondents have an adult family member with IDD (18+) **living with them in the family home.**

**Family Guardian Survey:** Respondents have an adult family member with IDD (18+) **living outside of the family home.** Respondents may also be non-family legal guardians, as long as they don't live with the person receiving supports.

**Child Family Survey:** Respondents have a child with IDD (under age 18) **living with them in the family home.**

*Assessing outcomes through NCI became a critical element of our continuous quality improvement strategy. The value of such a robust national data set is immeasurable and supported person-centered systems change in South Dakota, ensuring people were achieving personal outcomes.*

—Dan Lusk, former Director for the Division of Developmental Disabilities (DDD), South Dakota

In 2015, the National Core Indicators for Aging and Disabilities (NCI-AD) began surveying seniors and adults with physical disabilities. For information on NCI-AD, please visit [www.nci-ad.org](http://www.nci-ad.org).

## Who analyzes the data?

NCI staff analyze and report on the data. Each year, NCI produces national and state-specific reports detailing the data aggregated at the state level. The reports are available on the NCI website at [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org).

NCI also provides publicly available tools to help states understand and report on their data. The NCI website features an online Chart Generator that can be used to explore the data.

NCI also produces user-friendly versions of the yearly reports; these can be shared with survey respondents and others who might appreciate plain-language versions of the results.

### CHART GENERATOR

#### 1.) Select a State

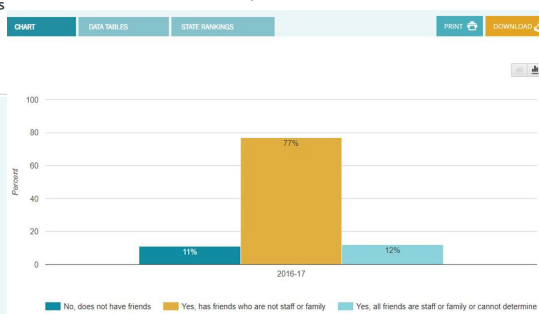
NCI Average

#### 2.) Select a Measure

- Descriptive
- Health, Welfare, and Rights
- Individual Outcomes
- System Performance

#### Do you have friends you like to talk to or do things with?

The proportion of people who reported they have friends who are not staff or family members



### Selected peer reviewed articles with NCI findings:

Hiersteiner, D., Bradley, V., Ne'eman, A., Bershadsky, J. & Bonardi, A. (2017) **Putting the research in context: The life experience and outcomes of adults on the autism spectrum.** Inclusion 5(1) 45-59.

Hsieh, K., Heller, T., Bershadsky, J., & Taub, S. (2015). **Impact of adulthood stage and social-environmental context on body mass index and physical activity of individuals with intellectual disability.** Intellectual and Developmental Disabilities, 53(2), 100-113.

Bershadsky, J., Hiersteiner, D., Fay, M.L., Bradley, V. (2014) **Race/Ethnicity and the Use of Preventive Health Care Among Adults with Intellectual and Developmental Disabilities.** Medical Care 52(10)Suppl 3. S25-S31

Stancliffe, R. J., Tichá, R., Larson, S. A., Hewitt, A. S., & Nord, D. (2015). **Responsiveness to self-report interview questions by adults with intellectual and developmental disability.** Intellectual and Developmental Disabilities, 53(3), 163-181

Bershadsky, J., Taub, S., Bradley, V., Engler, J., Moseley, C., Lakin, K. C., Stancliffe, R. J., Larson, S., Ticha, R. & Bailey, C. (2012). **Place of residence and preventive health care for developmental disabilities services recipients in twenty states.** Public Health Reports, 127, 475-485.

## For more information:

Visit [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)

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National Core Indicators began in 1997 as a collaborative effort between the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute.



Human Services  
Research Institute

# NASDDDS

National Association of State Directors of Developmental Disabilities Services