

NCI at 20

Two Decades of Measuring the Performance of State Intellectual and Developmental Disabilities Systems

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What is National Core Indicators?

For 20 years, National Core Indicators™—a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS), the Human Services Research Institute (HSRI), and participating states—has been supporting states to measure the performance of public intellectual and developmental disabilities (IDD) systems. Using standardized measures, NCI uses participant and family surveys—as well as surveys of working conditions for direct support professionals—to generate data that illuminate how publicly funded IDD services affect people’s lives and well-being. In addition to tracking system performance, states use the data to demonstrate compliance with federal regulations, compare their performance with other jurisdictions, and target quality improvement efforts. A key aspect of NCI is the transparency of the data, which is freely available to the public.

Other key features of NCI include:

- In addition to health, safety, and service delivery, the measures examine important social, community, and person-centered goals and quality of life
- The data collection instruments and protocols are specifically designed for inclusivity; no one is ever presumed to be incapable of voicing their opinion
- The results represent the experience of people served by the system, so states can base policy and system decisions on high-quality data rather than anecdotal reports

Three types of surveys are circulated in member states:



Adult Survey – in-person survey of at least 400 adults receiving services in each data collection cycle (yearly for some states, biannually or triennially for others).



Family surveys – mailed survey to families whose family member is receiving services including families with children, adults living at home, and an adult living outside the home.



Staff stability survey – mail survey of provider agencies to garner information on staff turnover, recruitment, salaries, and other workforce indicators.

Individual Outcomes: Domains

	Work
	Community Inclusion
	Choice and Decision Making
	Self Determination
	Relationships
	Satisfaction
	Service Coordination
	Health
	Medications
	Wellness
	Respect/Rights
	Safety

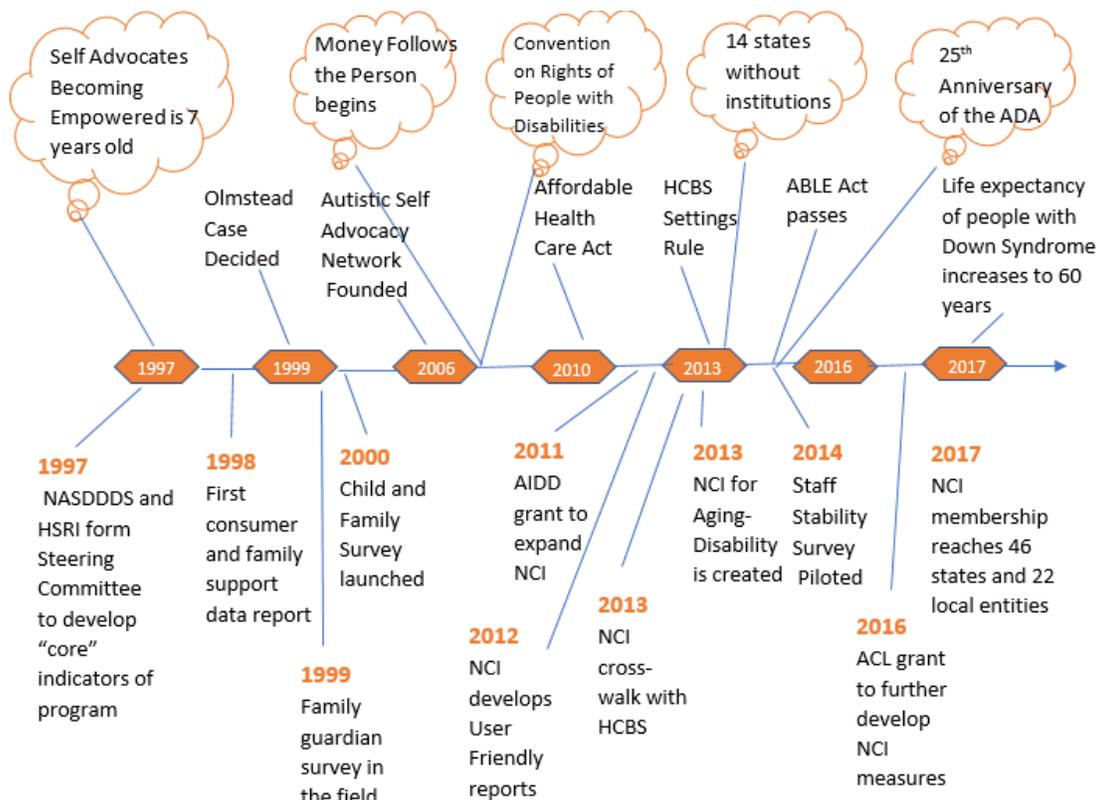


How did it develop?

In 1997, 15 states convened to discuss a potential performance measurement framework. Today, 46 states, including the District of Columbia, and 22 sub-state entities participate in NCI. While primarily funded by state membership fees, the growth of HSRI has also been supported by period grants and contracts from the Administration on Intellectual and Developmental Disabilities, and the Administration on Community Living. NCI has also enjoyed productive and mutually beneficial collaborations with the Institute on Community Integration at the University of Minnesota and Institute on Community Inclusion at the University of Massachusetts.

In 1997-98, a total of 5,426 service users and family members responded to NCI surveys; by 2007-08, that number had grown to 25,918; in 2016-17, an estimated 36,400 responded to NCI surveys.

NCI: 20 Year Timeline



What has NCI meant to self-advocates and public managers?

The availability of valid and reliable data reflecting the quality of life of people receiving services and supports has contributed to quality enhancement and has highlighted important findings in such areas as employment, friendships, behavior challenges, psychotropic medications and outcomes for people on the autism spectrum.

Self-Advocates

NCI has given people with IDD the ability to tell their stories and give input on the services and supports provided by the state. Recently, some self-advocates in California were interviewed to find out what they thought of NCI. Eduardo said, “It helps people by asking ‘are you sure you like your job?’ ‘are your relationships well right now?’ ‘are your families being healthy?’ ‘are you being healthy?’” Lisa said, “the NCI is important so the [agency] knows what services are working out for the consumers.” Ester observed that NCI is important because “The NCI is important because they can collect data to find out how the services of people with developmental disabilities are working and what the [agency] can work better on. Finally, Eugenia noted that “The data can be used for future things we might need.” See full video here: <https://www.youtube.com/watch?v+gfkUrshNQ18>



Managers

NCI, which was developed by managers responsible for oversight of IDD systems, has been used to enhance the quality of services and supports across the country. A former DD director from South Dakota, Dan Lusk, reinforced this point:

“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.”

What have we learned from NCI?

The availability of NCI data has made it possible to explore a variety of issues affecting people with IDD. Some of the more interesting findings over the past 20 years of NCI have included the fact that psychotropic medication use is tied to obesity, that outcomes for people with autism are not as robust as those for people not on the spectrum, that there is a connection between better health outcomes and friendship, and that many individuals who want to work do not have employment in their individual plans. A number of publications and data briefs showcasing NCI data have been prepared over the past two decades on issues such as health disparities, outcomes for people with behavioral challenges, and the choices enjoyed by people who are self-directing. The following graphs display some of these findings from NCI surveys completed in 2015-2016.

Selected NCI Findings 2015-2016

36 states (including the District of Columbia)¹: Total sample: 17,682

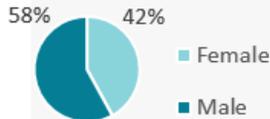
Demographics and personal characteristics of the sample

Average Age
43 years old

Race/Ethnicity:

70% -- White
18% -- Black/African American
3% -- Hispanic
7% -- Other**
1% -- Don't know

Gender



**Includes American Indian, Asian, Pacific Islander, two or more and other

Residence Type

Parent/Relative's Home

35%

Group Residential Setting
(e.g., Group Home)

32%

Own Home or
Apartment

20%

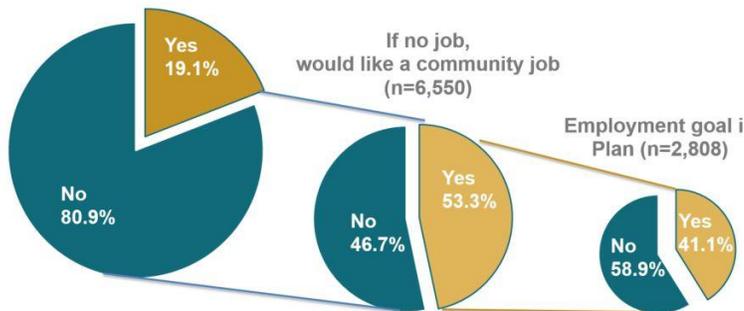
Other (including
foster care and
those without a
home)

8%

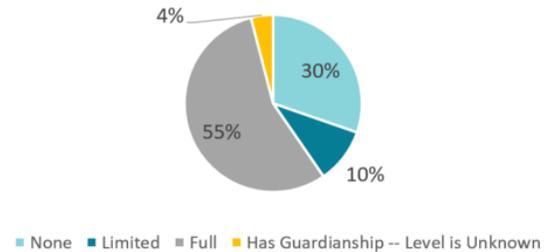
ICF/ID nursing facility
or other institutional
setting

5%

Has a job in the community
(n=16,375)



Legal guardianship arrangement for adult with disabilities



Percentage of people who report that they did the following at least once in the past month



Choice, Decision-making and control

Adjusted variables



¹ AL, AR, AZ, CO, CT, DC, DE, FL, GA, HI, IL, IN, KS, KY, LA, MA, ME, MI, MN, MO, MS, NC, NV, NY, OH, OK, PA, RI, SD, TN, UT, VA, VT, WA, WI, WY

Sharing NCI Results

NCI staff regularly produce data briefs, presentations, webinars, and blog posts to share timely NCI findings. They also publish articles in peer-reviewed journals. Recent articles include

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

Stancliffe, R. J., Lakin, K. C., Larson, S. A., Engler, J., Taub, S., Fortune, J., & Bershadsky, J. (2012). Demographic characteristics, health conditions, and residential service use in adults with Down syndrome in twenty-five U.S. states. *Intellectual and Developmental Disabilities*, 50(2), 92–108. DOI: 10.1352/1934-9556-50.2.92

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.

Going forward

Over the next several years, NASDDDS and HSRI will continue to ensure that NCI remains relevant and responsive to a changing landscape including the advent of managed care, an emphasis on value based purchasing, and the growing number of cross population health data sets. As in the past, the NCI partners will continue to improve the validity and reliability of surveys tools to ensure that public managers are able to make confident data-based decisions.

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