National Core Indicators (NCI) is a collaborative effort between NASDDDS and HSRI. The purpose of the program, which began in 1997, is to support State Developmental Disabilities agencies to gather a standard set of performance and outcome measures they can use to track performance over time, to compare results across states, and to establish national benchmarks.
Where do these statistics come from?

This report includes selected findings from the National Core Indicators™ 2014-15 Surveys listed below. The data shown here are averages of all responses regardless of state—unlike typical NCI reporting, where NCI averages are calculated as averages of all state averages. So these results may differ from those in other NCI reports.

**The Adult Consumer Survey**

This survey is completed with individuals age 18 and older who receive at least one paid service (in addition to case management) from a state DD agency. The survey instrument includes a Background Information Section, which gathers data about the consumer from agency records, and an in-person survey. The in-person survey is composed of two sections: Section I includes subjective questions that can only be answered by the person receiving services from the state. Section II includes objective, fact-based questions that can be answered by the person or, if needed, a proxy respondent who knows the person well.

The NCI Project Team interprets each state’s data and produces reports that can support state efforts to strengthen LTSS policy, inform quality improvement activities, evaluate programs and policies and compare their performance with national norms.

**Family Surveys**

The **Adult Family Survey** is completed with families who have an adult family member (age 18 or older) with I/DD living in the family home. The family member receives at least one paid service (in addition to case management) from the state DD agency. This survey is mailed out to families.

The **Family/Guardian Survey** is completed with families or guardians who have an adult family member (age 18 or older) with I/DD living outside the family home. The family member receives at least one paid service (in addition to case management) from the state DD agency. This survey is mailed out to families or guardians.

The **Child Family Survey** is completed with a minimum of 400 families who have a child (under age 18) with I/DD living in the family home. The child receives at least one paid service (in addition to case management) from the state DD agency. This survey is mailed out to families.

For more information on the National Core Indicators project, please see [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org). For detailed information on samples, methodology and administration, please see the NCI Reports from 2014-15, available at [http://www.nationalcoreindicators.org/resources/reports/](http://www.nationalcoreindicators.org/resources/reports/).
LOOKING AT THE 2014-15 ADULT CONSUMER SURVEY DATA

Who are the people using state DD services and what are their experiences like?

25,820 Adult Consumers Interviewed

- 58% Men
- 42% Women

Average Age 42

Level of ID

- Mild 35%
- Moderate 26%
- Severe 13%
- Profound 12%
- Not Known 6%
- No ID 8%

Co-occurring Diagnosis

- Mood Disorder 29%
- Anxiety Disorder 25%
- Psychotic Disorder 12%
- Other Mental Illness 9%

Other Co-Occurring Conditions

- Behavior Challenges 30%
- Seizure Disorder 29%
- Cerebral Palsy 17%
- Autism Spectrum Disorder 17%
- Down Syndrome 10%
- Brain Injury 6%

Race & Ethnicity

- White 65%
- Black or African American 17%
- Asian 4%
- American Indian or Alaska Native 1%
- Other 13%

The 2014-15 NCI Adult Consumer Survey Report includes data from: AR, CO, CT, DE, FL, GA, HI, IL, IN, KS, KY, LA, ME, MI, Mid-East Ohio Regional Council (MEORC), MN, MO, NH, NJ, NY, NC, OH, OK, PA, SC, SD, TN, TX, UT, VT, VA, DC
**LOOKING AT THE 2014-15 ADULT CONSUMER SURVEY DATA**

### Residence Type

- Parent/Relatives’ Home: 40%
- Group Home: 30%
- Independent Home/Apt.: 14%
- ICF: 9%
- Foster Care/Host Home: 5%
- Other: 2%

### Guardianship Status

- Independent of Guardianship: 53%
- Full Guardianship: 31%
- Limited Guardianship: 11%
- Not Known: 5%

### Paid Community Job

- No, 86%
- Yes, 14%

### By Residence Type

- Ind. Home/Apt.: 26%
- Group Home: 23%
- Parent/Relative: 40%

### Safety

- 84% Never Feel Scared at Home
- 84% Never Feel Scared in Neighborhood
- 89% Never Feel Scared at Work or Day Program

### Service Coordination

- 86% Helped Make Service Plan

### Relationships

- Do you...
  - Have a best friend? 77% YES, 23% NO
  - Have friends who are not staff or family? 74% YES, 26% NO
  - Ever feel lonely? 62% YES, 38% NO

### Can you...

- See family whenever you want? 81% YES
- See friends whenever you want? 79% YES
- Date without restriction (or are you married)? 70% YES

Source: 2014-15 NCI Adult Consumer Survey
LOOKING AT THE 2014-15 ADULT CONSUMER SURVEY DATA

Who are the people using state DD services and what are their experiences like?

Did you choose or have some input in choosing your...

- Roommates
- Staff
- Day Activity
- Schedule
- Free Time Activities
- What to Buy

In the past month, did you go out for...

- Shopping
- Errands
- Entertainment
- Out to Eat
- Religious Service
- Exercise

Source: 2014-15 NCI Adult Consumer Survey
LOOKING AT THE 2014-15 FAMILY SURVEY DATA

What do families think about the services their family member receives?

Demographics

<table>
<thead>
<tr>
<th>Category</th>
<th>Families of Adults in Family Home</th>
<th>Families of Adults Outside Family Home</th>
<th>Families of Child in Family Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Age</td>
<td>34</td>
<td>47</td>
<td>11</td>
</tr>
<tr>
<td>Gender</td>
<td>58% Male</td>
<td>58% Male</td>
<td>67% Male</td>
</tr>
</tbody>
</table>

Family Member’s Disability Type

- Intellectual Disability: 82% 86%
- Autism Spectrum Disorder: 60%
- Mental Illness/Psychiatric Diagnosis: 40% 42%
- Seizure Disorder/Neurological Problem: 34% 27%
- Cerebral Palsy: 20% 22%
- Down Syndrome: 15% 17%
- Brain Injury: 14% 18%

Health Services

If your family member lives in the family home, does s/he get needed...

- Physical health services? 98% 98%
- Dental services? 86% 95%
- Medication? 99% 98%
- Mental health services? 90% 90%

Support Staff

Do your family member’s support workers have the proper training to meet your family member’s needs?

- Support Staff 56% Yes 55% Yes 49% Yes

Do you have control over the hiring and management of support workers?

- Adult in Family Home: 57% Yes
- Adult Outside Family Home: 61% Yes

Source: 2014-15 NCI Family Surveys
LOOKING AT THE 2014-15 FAMILY SURVEY DATA

Access to Services
Does your family member...

Receive all the services listed in their plan?
- Yes: 89%, 92%, 87%

Always see a change in their services and supports when their needs change?
- Yes: 42%, 58%, 37%

Choice and Control
Do you...

Know how much money the DD agency spends on your family member’s behalf?
- Yes: 36%, 35%

Have a say in how DD agency money is spent on your family member’s behalf?
- Yes: 56%, 55%

Have the information you need to decide how agency money is spent?
- Yes: 90%, 87%

Notably, 1/3 of families surveyed reported an annual household income of $25,000 or less

Source: 2014-15 NCI Family Surveys
EXPANDING NCI PARTICIPATION
NCI continued to expand its membership during 2014-15 thanks in part to funding from the Administration on Intellectual and Developmental Disabilities (AIDD). In 2010, AIDD awarded the National Association of State Directors of Developmental Disabilities Services (NASDDDS) a contract to expand NCI, making funds available for several new states to join each year for five years. Two new states joined NCI in 2014-15: Vermont and Rhode Island.

In 2014-15, NCI membership included 41 states, Washington D.C., and 22 sub-state entities. Four new states joined for the 15-16 survey cycle, and as of printing of this report, one additional state had joined for the 2016-17 survey cycle. Not every participating NCI state administers each survey every year, so survey samples may not include all states.

In collaboration with the National Association of States United on Aging and Disabilities (NASUAD), NCI continued the pilot implementation of the National Core Indicators for Aging and Disabilities (NCI-AD) Survey. The NCI-AD project was conceived in response to growing concern about the limited information currently available to help states assess the quality of long-term services and supports (LTSS) for seniors, adults with physical disabilities, and caregivers.

CHANGES TO TOOLS
NCI staff revised the NCI Staff Stability Survey to provide more comprehensive and relevant information on staff turnover, vacancy rates, wages, and benefits. In 2014-15, the new survey was rolled out in 10 states. The resulting report was released in November 2015.
SHARING THE DATA

In addition to producing NCI reports, NCI staff disseminated results in a variety of formats, including presentations, posters, webinars, and data briefs. Staff wrote and presented on such topics as health disparities, respect given to people’s rights, self-direction, and NCI and the new HCBS rules. All presentations listed below can be found at http://www.nationalcoreindicators.org/resources/presentations/.

- April 2015: Data brief entitled What NCI Data Reveal About Service Delivery and the Respect Given to the Rights of People with I/DD. This data brief was followed by a Sarah Taub NCI Webinar on Rights and Respect with special guest Jonathan Martinis, Legal Director at the Quality Trust for Individuals with Disabilities, who presented on Supported Decision-Making.
- May 2015: At the Real Lives Advisory Board in Massachusetts, Valerie Bradley presented Self-Determination: Are We There Yet? A Brief Status Report from the US and Beyond.
- June 2015: American Association on Intellectual and Developmental Disabilities (AAIDD) Annual Meeting:
  - Quality of Life Data and Trends
  - New Federal HCBS Expectations: HCBS Setting Transition Plans and Data for Tracking Systemic Compliance
  - Friendship Matters! Improving Health and Well-Being by Supporting Relationships
  - Systems Change to Promote Rights: A Supported Decision-Making Initiative and National Core Indicators Data

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Be the first to hear when we post new reports, data briefs, or other publications! Subscribe to our mailing list.
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2014-2015

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