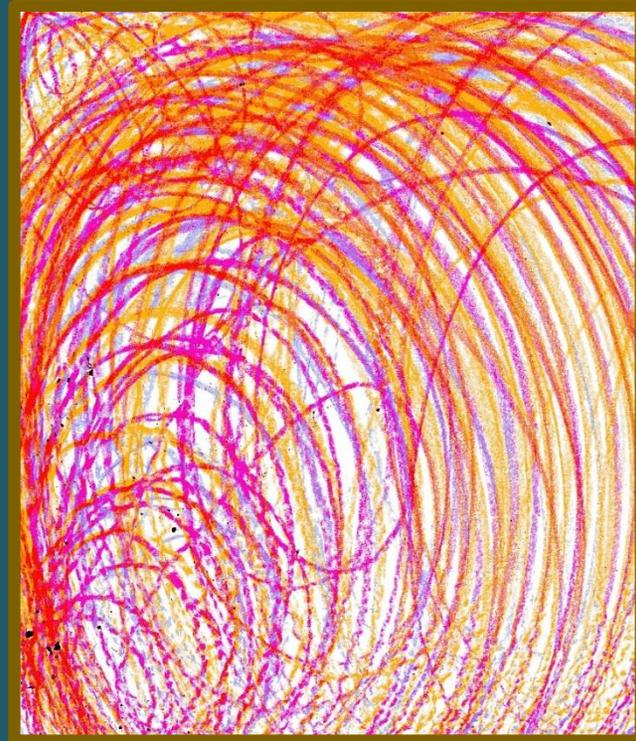


NCI AT-A- GLANCE



Selected Findings from the 2014-15 Surveys



www.nationalcoreindicators.org

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.



Human Services
Research Institute

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. For detailed information on samples, methodology and administration, please see the NCI Reports from 2014-15, available at <http://www.nationalcoreindicators.org/resources/reports/>.

About the Cover Art

Peter Rutledge is a Spotlight Studios artist. He was born in 1987 in Oklahoma City and spent his first four years in Ichikawa, Japan. He lives in Waltham, Massachusetts with his parents and has been developing his art through the program with Work, Community, and Independence. Peter loves motion and activity. His art reflects blowing wind, splashing water, and great swirls of motion and activity. The dynamic, energetic style of his process is clearly shown in his results.

[View his portfolio](#)

LOOKING AT THE 2014-15 ADULT CONSUMER SURVEY DATA

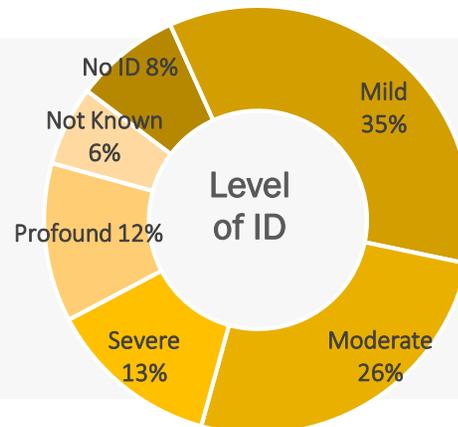
Who are the people using state DD services and what are their experiences like?

25,820 Adult Consumers Interviewed

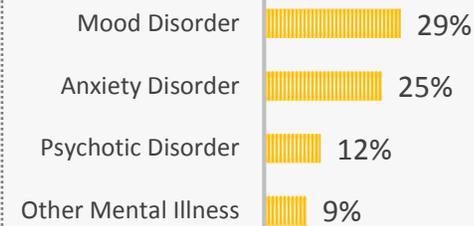
58% Men
42% Women



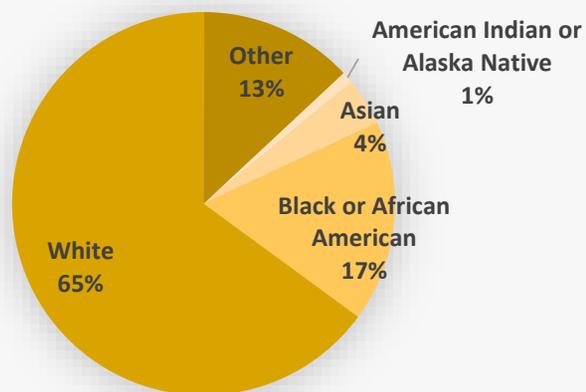
Average Age
42



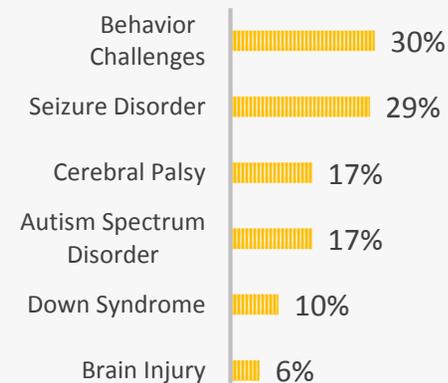
Co-occurring Diagnosis



Race & Ethnicity

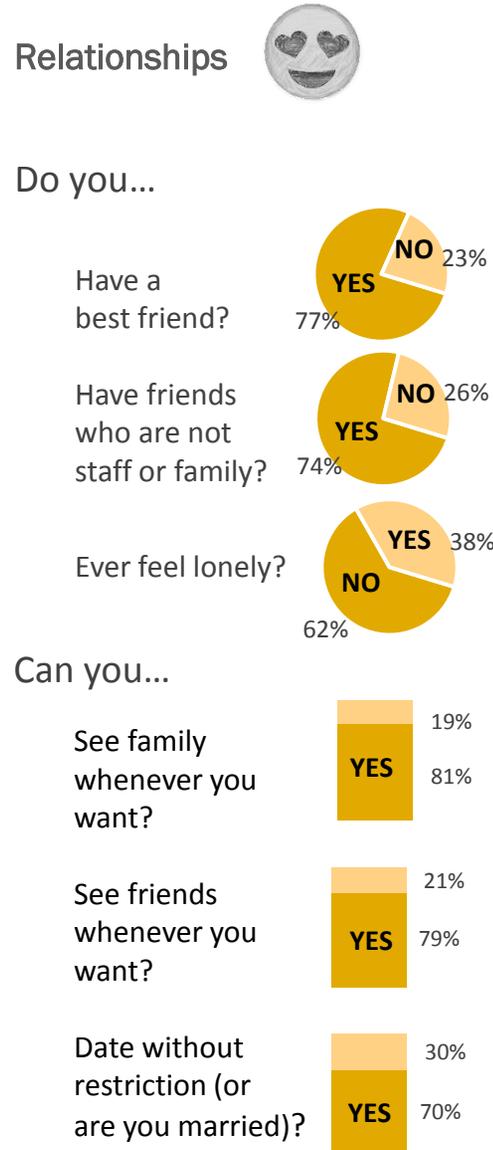
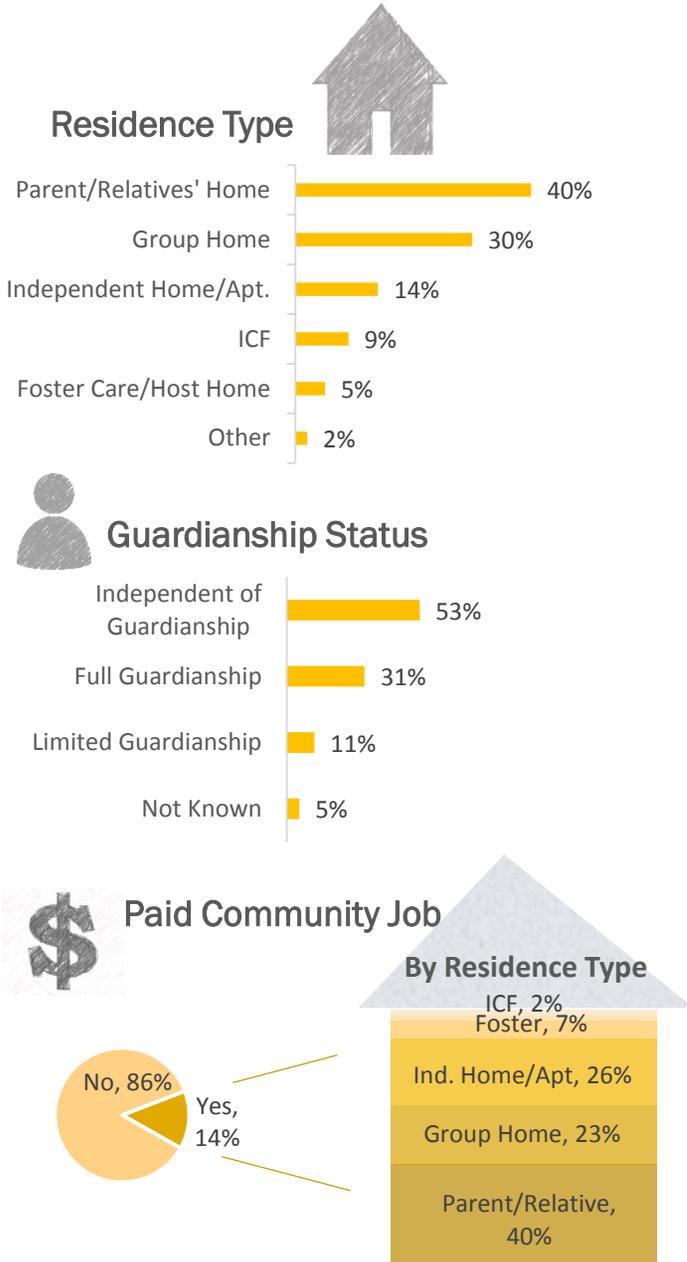


Other Co-Occurring Conditions



LOOKING AT THE 2014-15 ADULT CONSUMER SURVEY DATA

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

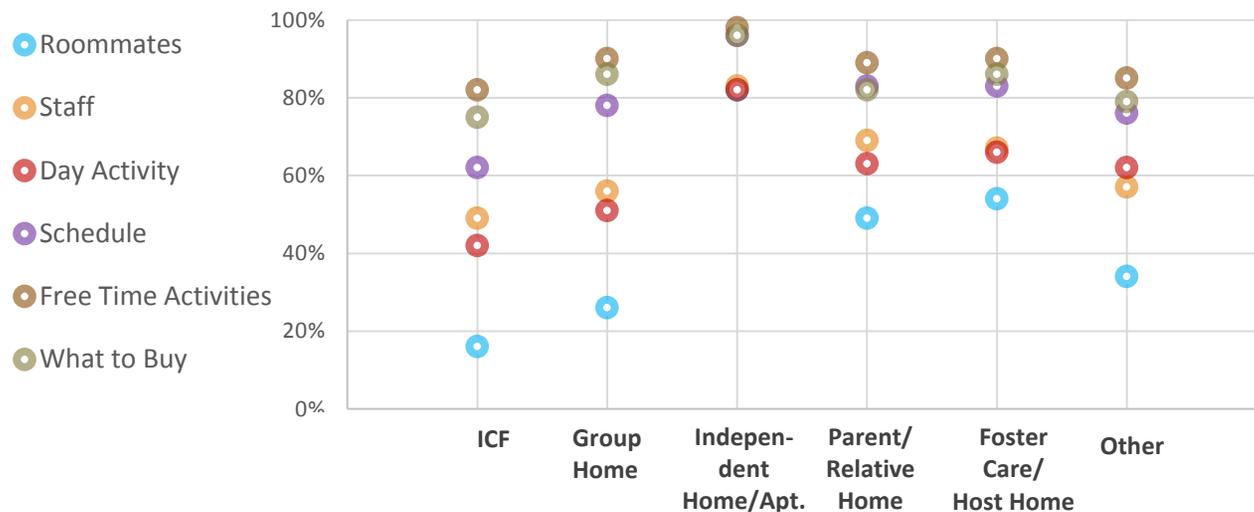


LOOKING AT THE 2014-15 ADULT CONSUMER SURVEY DATA

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

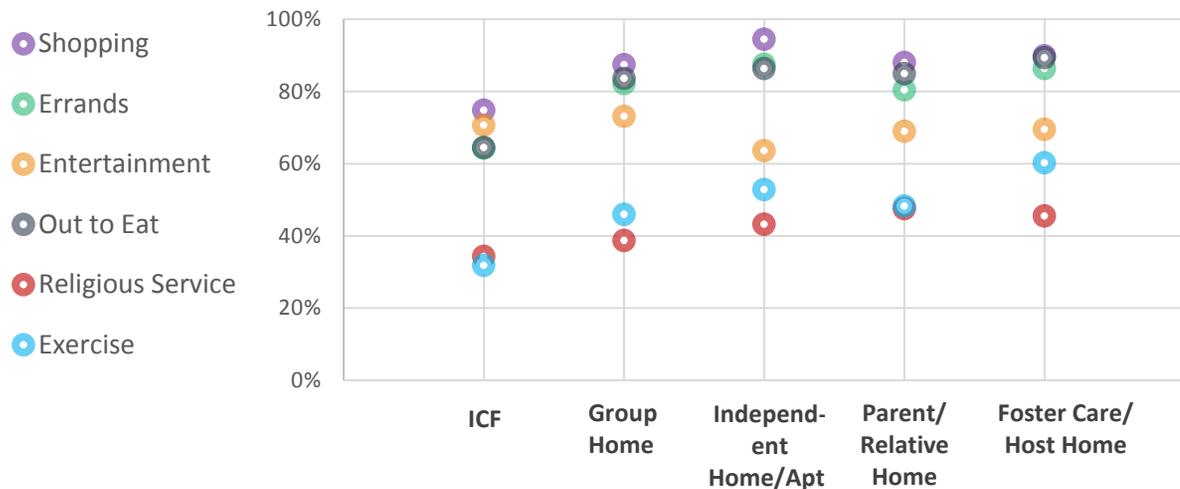
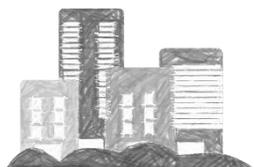
Did you choose or have some input in choosing your...

Choice



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

Community Inclusion

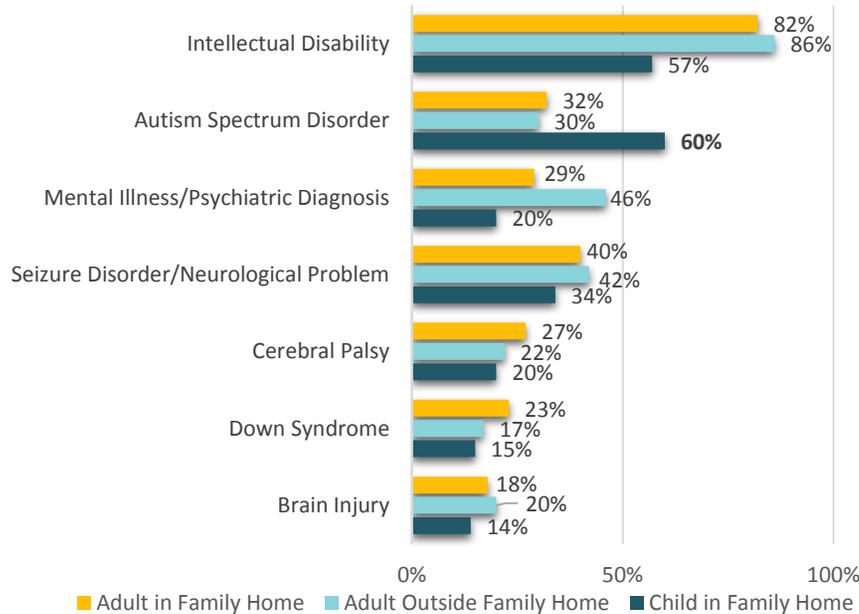


LOOKING AT THE 2014-15 FAMILY SURVEY DATA

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

Demographics	Families of Adult in Family Home N=5,595	Families of Adult Outside Family Home N=4,423	Families of Child in Family Home N=3,319
Average Age of the family member with a disability	34	47	11
Gender of the family member with a disability	58% Male	58% Male	67% Male

Family Member's Disability Type



Families of Adults in Family Home: CO, CT, FL, GA, KY, LA, MD, MN, NC, OK, PA, SD, UT, DC, WI; Families of Adults Outside the Family Home: AZ, CO, DE, FL, GA, KY, LA, MD, MI, NC, PA, SD, VA, WI; Families of Child in Family Home: AZ, HI, LA, MN, NC, SD, VA, WA, WI

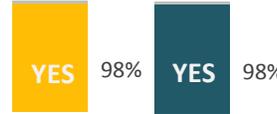
Source: 2014-15 NCI Family Surveys

Health Services

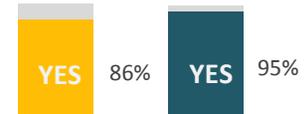
If your family member lives in the family home, does s/he get needed...

■ Families of adult in family home
■ Families of child in family home

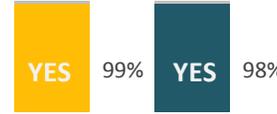
Physical health services?



Dental services?



Medication?



Mental health services?



Support Staff

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



■ Families of adult in family home
■ Families of adult outside family home
■ Families of child in family home

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



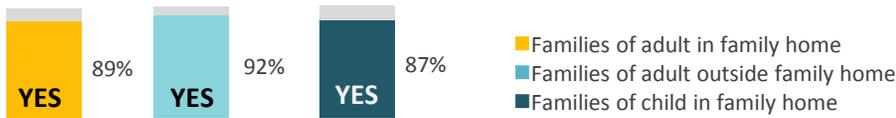
LOOKING AT THE 2014-15 FAMILY SURVEY DATA

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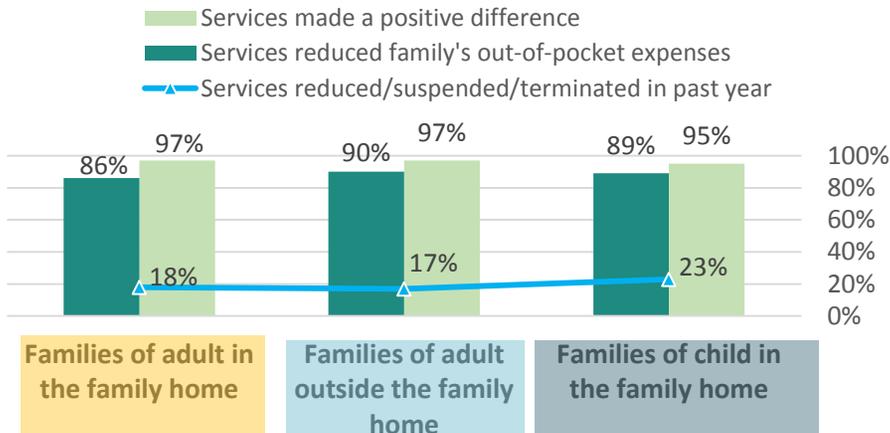
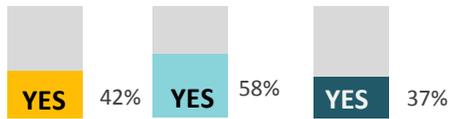
Access to Services

Does your family member...

Receive all the services listed in their plan?



Always see a change in their services and supports when their needs change?



Choice and Control

Do you...

Know how much money the DD agency spends on your family member's behalf?



Have a say in how DD agency money is spent on your family member's behalf?



Have the information you need to decide how agency money is spent?



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

LOOKING AT PAST-YEAR NCI ACTIVITIES

Who participates in NCI and what kinds of information and resources does NCI share?

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.

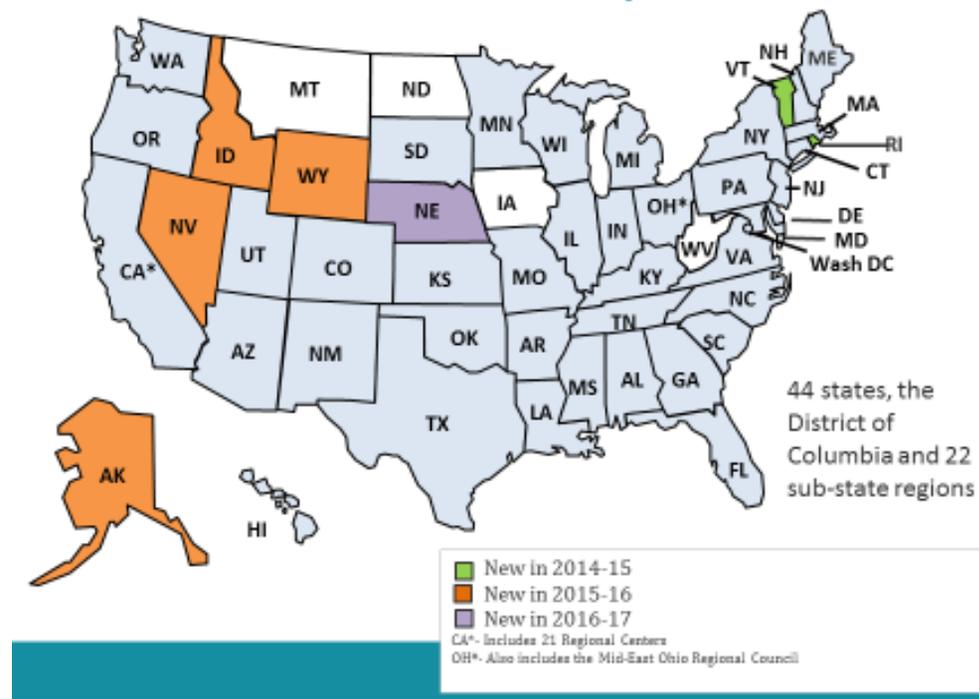
In 2014-15, NCI membership included 41 states, Washington D.C., and 22 sub-state entities. Four new states joined for the 15-16 survey cycle, and as of printing of this report, one additional state had joined for the 2016-17 survey cycle. Not every participating NCI state administers each survey every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

NCI State Participation



LOOKING AT PAST-YEAR NCI ACTIVITIES

Who participates in NCI and what kinds of information and resources does NCI share?

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/>

- **October 2014:** [National Core Indicators: Employment Trends for Adults with ID/DD and Suggestions for Policy Development](#) in a webinar sponsored by ANCOR (American Network of Community Options and Resources).
- **November 2014:** [Exploring Health Disparities Among People with Intellectual and Developmental Disabilities: What are the Issues and Do Race and Ethnicity Play a Role?](#) at the NASDDDS Annual Meeting.
- **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:** [HSRI and The National Core Indicators Staff Stability Survey](#) at the first National Association of Direct Support Professionals conference.
- **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](#)

Be the first to hear when we post new reports, data briefs, or other publications!

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Comments or questions:
dhiersteiner@hsri.org



Program Staff

Mary Lou Bourne
 NASDDDS Project Director of NCI
mlbourne@hsri.org

Valerie Bradley
vbradley@hsri.org

Dorothy Hiersteiner
dhiersteiner@hsri.org

Stephanie Giordano
sgiardano@hsri.org

Alexandra Bonardi
 HSRI Project Director of NCI
abonardi@hsri.org

Julie Bershadsky
jbbershadsky@hsri.org

Cheryl Sartori
csartori@hsri.org

Erica Hendricks
ehendricks@hsri.org

www.nationalcoreindicators.org

Comments or questions:
dhiersteiner@hsri.org

NASDDDS Research Committee

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