

# NATIONAL CORE INDICATORS™

AT-A-GLANCE REPORT • 2016-17



## SELECTED FINDINGS FROM THE 2016-17 SURVEYS

Human Services Research Institute (HSRI)

National Association of State Directors of  
Developmental Disabilities Services (NASDDDS)





*Cover art by*  
**Betty Antoine**

Born in Boston, Massachusetts in 1987, **Betty Antoine** is emerging as an artist with a strong sensibility for needlecraft and traditions. Antoine works tirelessly with a colorful palette, be it painting, drawing, or crocheting. Throughout the studios she can be found crocheting or knitting at any given time. These traditional crafts have been passed down in her family, and they are very important to her.

Antoine appreciates the tactile qualities of many objects and translates that detail into imagery she paints or draws. She has a great understanding of portraiture and has developed a unique style of representing textiles within the composition. Through marked persistence Antoine successfully evokes the texture of fabric and detail in the imagery she chooses to paint. Painting, like crocheting, provides her with a meditative process, presenting her with time for reflection. Antoine's fine art and crochet crafts have been recognized in many exhibitions throughout Massachusetts including exhibitions at the Gateway Gallery and Drive-By Projects in Watertown, MA.

See more at [www.gatewayarts.org](http://www.gatewayarts.org)

## Where are the statistics in this report from?

This report includes selected findings from the National Core Indicators™ 2016-17 Surveys listed below. **The data shown are weighted NCI averages\*.**

### The Adult Consumer Survey

This survey is completed with adults with I/DD age 18 and older receiving at least one paid service (in addition to case management) from the 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.

### Family Surveys

The **Adult Family Survey** is completed by 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 to families.

The **Family/Guardian Survey** is completed by 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 to families or guardians.

The **Child Family Survey** is completed by families who have a child 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 to families.

The NCI Team produces reports that inform state efforts to strengthen LTSS policy, inform quality improvement activities, evaluate programs and policies, and compare their performance with national norms. For more information on National Core Indicators, please see [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org). For detailed information on samples, methodology and administration, please see the NCI Reports from 2016-17, available at <http://www.nationalcoreindicators.org/resources/reports/>.

*\*Beginning this year, the NCI averages contained in this report are “weighted” means: the calculations reflect the relative population sizes of participating states and their survey sample sizes. For more information, please see the 2016-17 Adult Consumer Survey Report at <http://www.nationalcoreindicators.org/resources/reports/>.*

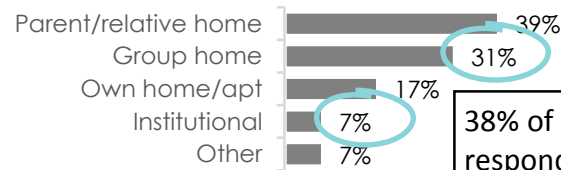
# 2016-17 Adult Consumer Survey

**NCI  
Average  
Data**  
(all participating  
states)

## 21,548 adults with I/DD participated in the 2016-17 survey in 38 states\* and the District of Columbia.

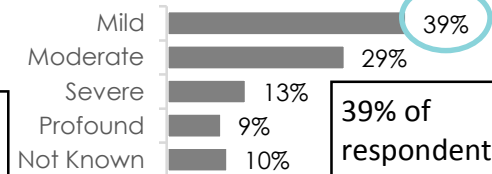
Respondents are adults with I/DD age 18 and older receiving at least one paid service (in addition to case management) from the state DD agency.

### Residence



38% of respondents live in group homes or institutional settings

### Level of Intellectual Disability



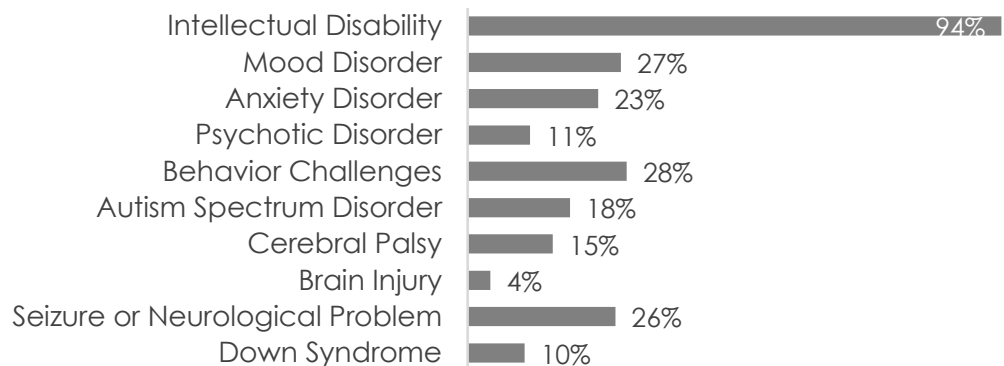
39% of respondents are reported to have mild ID

- 58% are male
- 94% have ID
- 42 is the average age
- 19% have a paying job in the community
- 46% want a paying job in the community

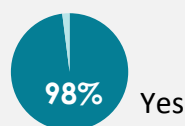


### Diagnoses

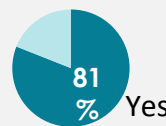
Not mutually exclusive; 'Don't know' responses included in denominator



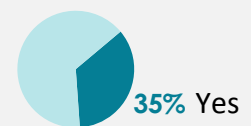
#### Have a primary care doctor



#### Visited dentist in the past year



#### Reported to be under full guardianship



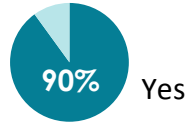
\*AL, AR, CO, CT, DC, DE, FL, GA, HI, ID, IL, IN, KS, KY, LA, ME, MI, MN, MO, MS, NC, NE, NH, NJ, NV, NY, OH, OK, OR, PA, RI, SD, TN, TX, UT, VA, VT, WI, WY.

# Respondents are adults with I/DD age 18 and older receiving at least one paid service (in addition to case management) from the state DD agency.

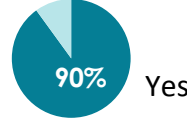
Like their home



Like their paid job in the community



Feel services are helping them live a good life



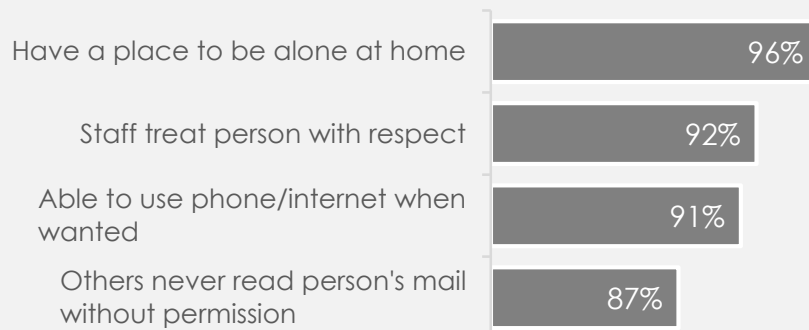
- 77% have friends who are not staff or family
- 79% can see friends when they want

- 41% want more help to make or keep in contact with friends
- 11% often feel lonely

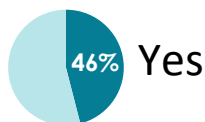
## Access and Inclusion

- 93% have the **transportation** they need to get where they **need** to go
- 84% have the **transportation** they need to get where they **want** to go
- 86% are able to go out and **do the things they like to do**
- 78% get to **do things they like to do as much as they want**
- 84% have **enough** things they **enjoy doing when at home**

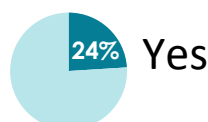
## Privacy and Respect



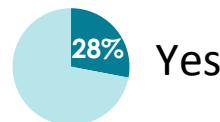
Would like paid job in the community



Take classes/trainings to get job/better job



Have paid community employment as goal in service plan



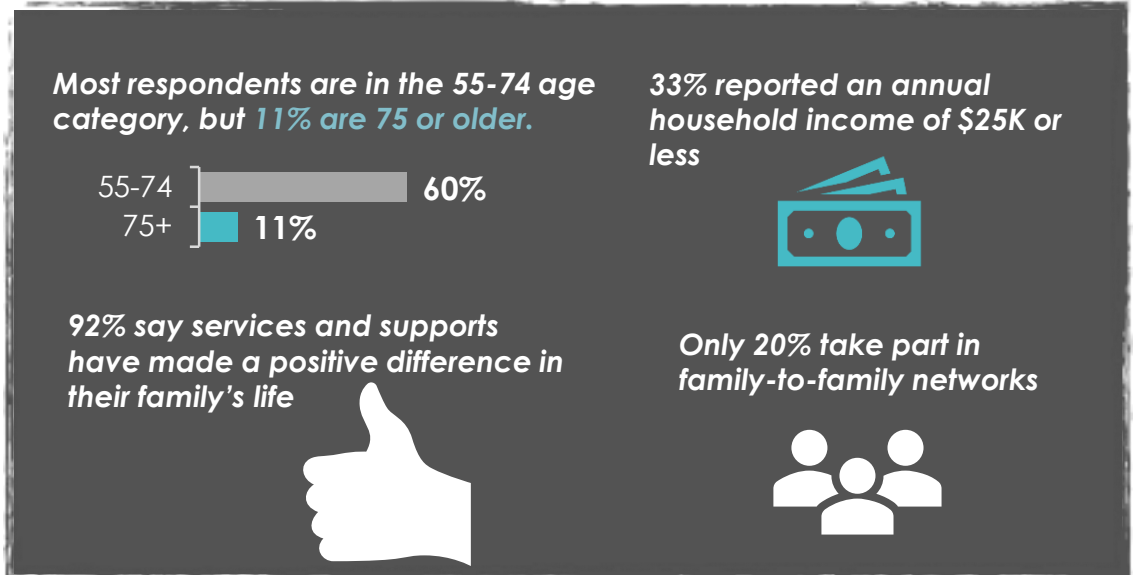
# 2016-17 Adult Family Survey

NCI  
Average  
Data  
(all participating  
states)

## 11,419 families participated in the 2016-17

### Adult Family Survey in 16 states\*

Respondents are family members and/or guardians who share a home with an adult who has I/DD and receives one public service in addition to case management from the state DD agency.



### The family member with I/DD . . .



**58% are male**



**34 is the average age**

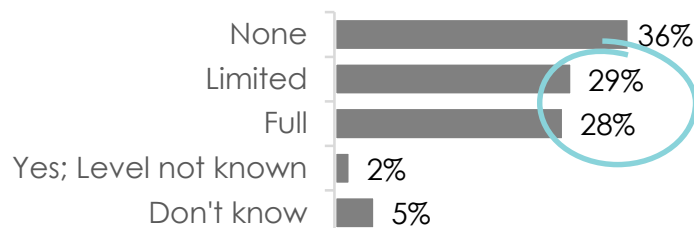


**87% take part in community activities**



**77% can always see a health professional when needed**

### Legal Guardianship



57% of respondents' family members with I/DD are reported to be under limited or full guardianship

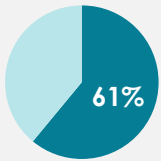
\* CA, DC, DE, FL, GA, KY, LA, MD, MN, MO, MS, NC, NJ, OK, PA, UT

# Respondents are families and/or

**guardians** who share a home with an adult who has I/DD and receives one public service in addition to case management from the state DD agency.

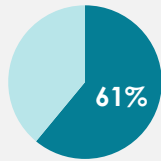
2016-17  
Adult Family  
Survey

Can choose or  
change support workers



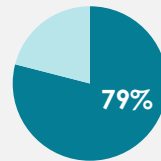
Yes

Can choose or change  
provider agency



Yes

Service workers work together  
to provide support



Yes



**85%** feel prepared to handle the needs of their family member in an emergency



**68%** report that the case manager/service coordinator always respects their family's choices and opinions



**81%** Say services are delivered in a way that respects their family's culture



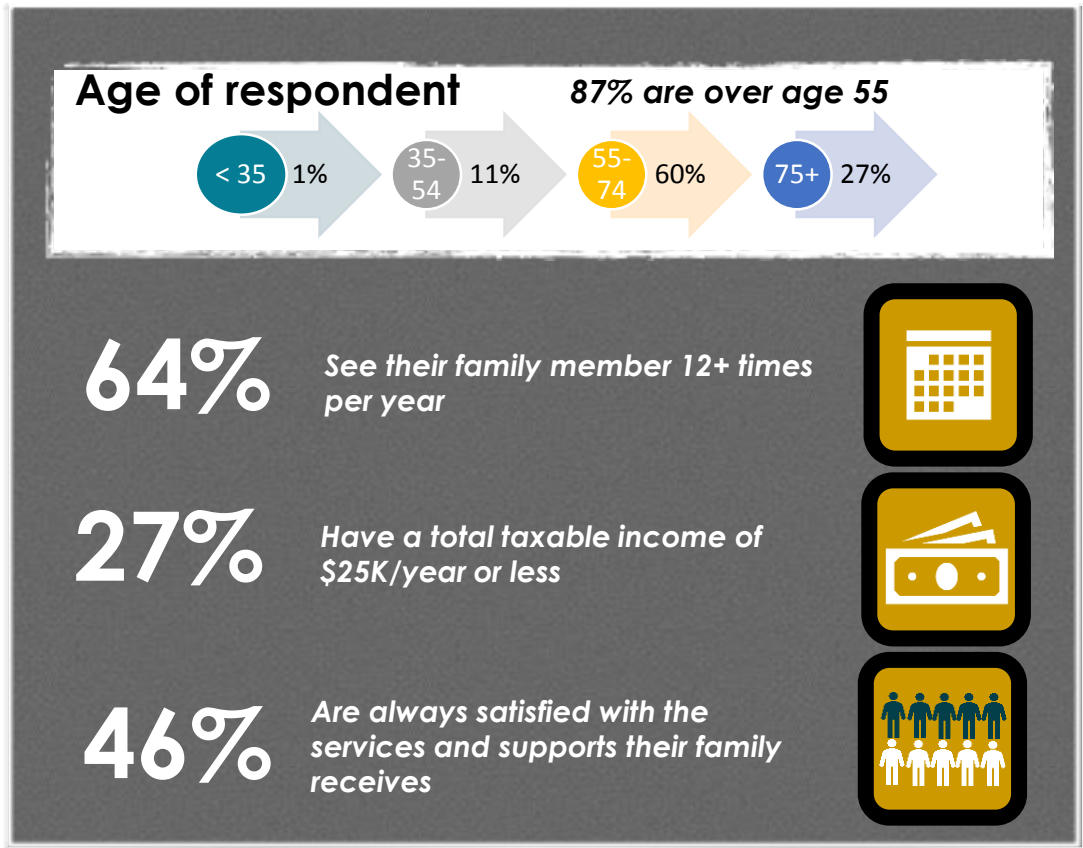
**67%** Say support workers arrive on time and leave when they're supposed to

# 2016-17 Family Guardian Survey

NCI  
Average  
Data  
(all participating  
states)

## 9,194 families/guardians participated in the 2016-17 Family Guardian Survey in 12 states\*

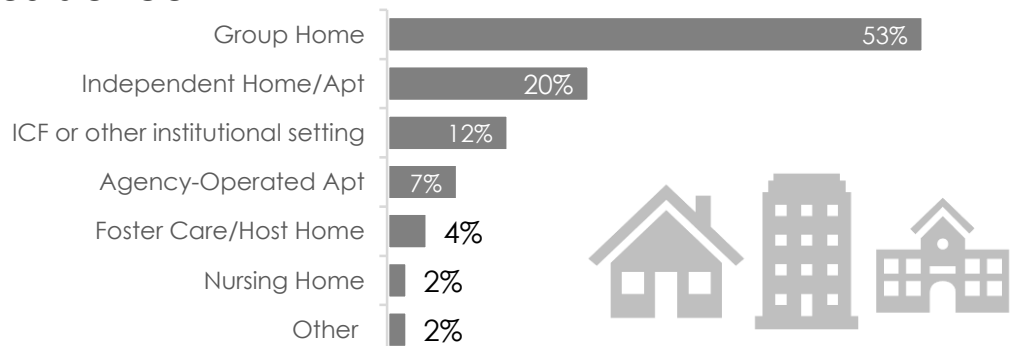
Respondents are families and/or guardians of an adult with I/DD who lives somewhere other than the family home and receives at least one public service in addition to case management from the state DD agency.



### According to respondents, the family member with I/DD . . .



### Residence



\* AZ, CA, FL, GA, KY, LA, MD, NC, NJ, PA, SD, VA; NCI Average is weighted



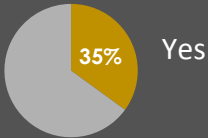
# Respondents are families and/or

# guardians

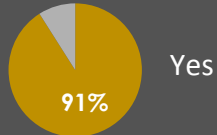
of an adult with I/DD who lives somewhere other than the family home and receives at least one public service in addition to case management from the state DD agency.

2016-17  
Family  
Guardian  
Survey

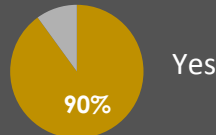
Can choose or  
change support  
workers



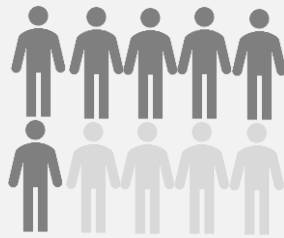
Family member's  
service plan includes  
all services and  
supports needed



Family gets supports and  
services needed



60%



Can always reach their family  
member's case manager  
when they want to



67%

Say their family member  
has enough support to  
work or volunteer in the  
community



61%

Say support workers  
arrive on time and  
leave when they're  
supposed to



78%

Say services are  
delivered in a way that  
respects their family's  
culture



67%

Have friends other than  
paid staff or family

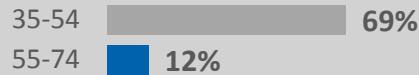
# 2016-17 Child Family Survey

NCI  
Average  
Data  
(all participating  
states)

**3,352 families/guardians** participated in the 2016-17 Child Family Survey in 9 states\*.

Respondents are families and/or guardians who share a home with a child who has I/DD and receives at least one public service in addition to case management from the state DD agency.

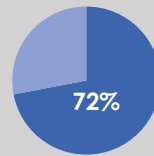
Most respondents are in the 35-54 age category, but 12% are 55+.



27% reported an annual household income of \$25K or less



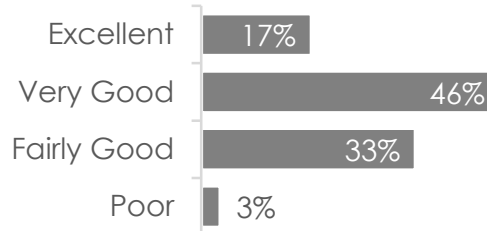
72% say their family gets needed supports



32% say they're always satisfied with services and supports



## Self-Reported Health Status of Respondents

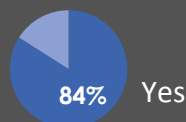


The child family member with I/DD . . .

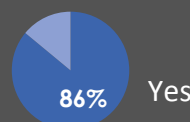
**67%** are male

**11** is the average age

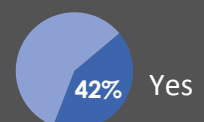
Child takes part in community activities



Child spends time with children without I/DD



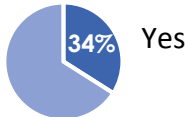
Child always has access to special equipment/accommodations



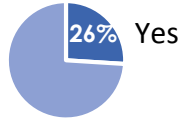
\*AZ, LA, MN, MO, NC, OR, SD, WA, WI; NCI Average is weighted

# Respondents are families and/or guardians who share a home with a child who has I/DD and receives at least one public service in addition to case management from the state DD agency.

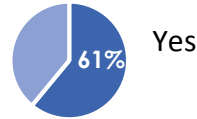
Always receive enough info to help plan services for their child



Say the info they receive is always easy to understand

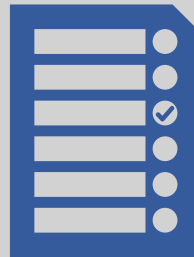


Can always choose or change the agency that provides supports



61%

Say support workers arrive on time and leave when they're supposed to



79%

Say their child gets all services listed in the service plan



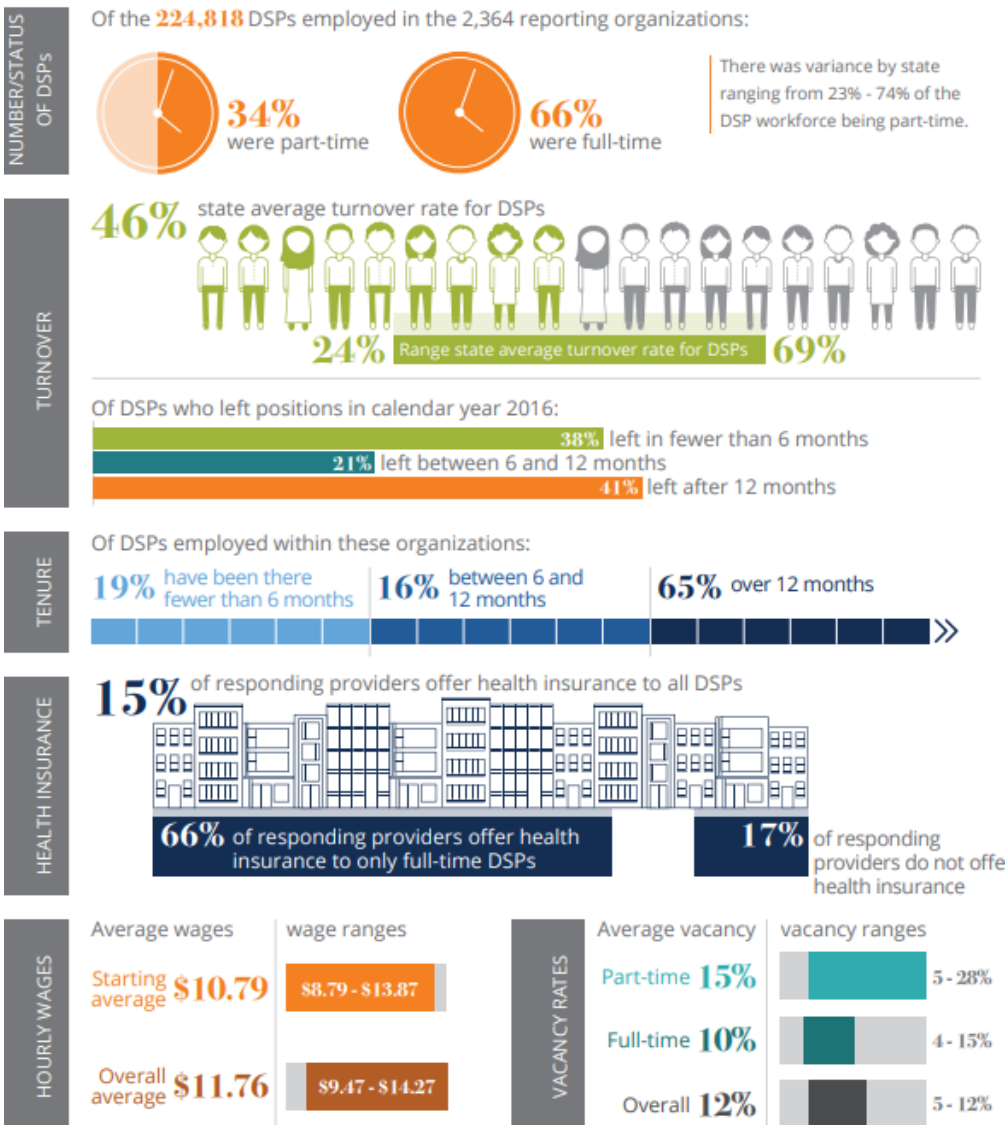
79%

Say services are always delivered in a way that respects their family's culture

# Spotlight on... The 2016 NCI Staff Stability Survey

Around the country, state developmental disability agencies continue to focus on **improving the quality and stability of the workforce of direct support professionals (DSPs) who assist adults with intellectual and developmental disabilities.**

## SNAPSHOT OF DIRECT SUPPORT WORKFORCE CHALLENGES IN THE UNITED STATES (NCI, 2018)



These efforts come at a time of escalating demand for long-term services and supports in home and community-based settings. Importantly, states also seek to reduce the costs associated with staff turnover at provider agencies and to reduce the impact of turnover on the quality of supports and outcomes for consumers.

National Core Indicators™ (NCI™) works with member states to collect comprehensive data on the workforce of DSPs providing supports to adults (age 18 and over) with intellectual and developmental disabilities. The goal is to help states benchmark their workforce data to those of other states so they can measure improvements made through policy or programmatic changes.

U.S. Department of Health and Human Services (2006). The supply of direct support professionals serving individuals with intellectual disabilities and other developmental disabilities: Report to Congress. Retrieved from <http://aspe.hhs.gov/daltcp/reports/2006/DSPsupply.htm>

\*Ohio examined DSPs providing ICF/ID funded supports separately from those providing HCBS waiver funded supports. These are treated as separate entities in the 2016 NCI Staff Stability Report.

Larson, S.A., Hewitt, A. & Lakin, K.C. (2004). A multi-perspective analysis of effects on recruitment and retention challenges on outcomes for persons with intellectual and developmental disabilities and their families. *American Journal on Mental Retardation*.

*Spotlight on...*

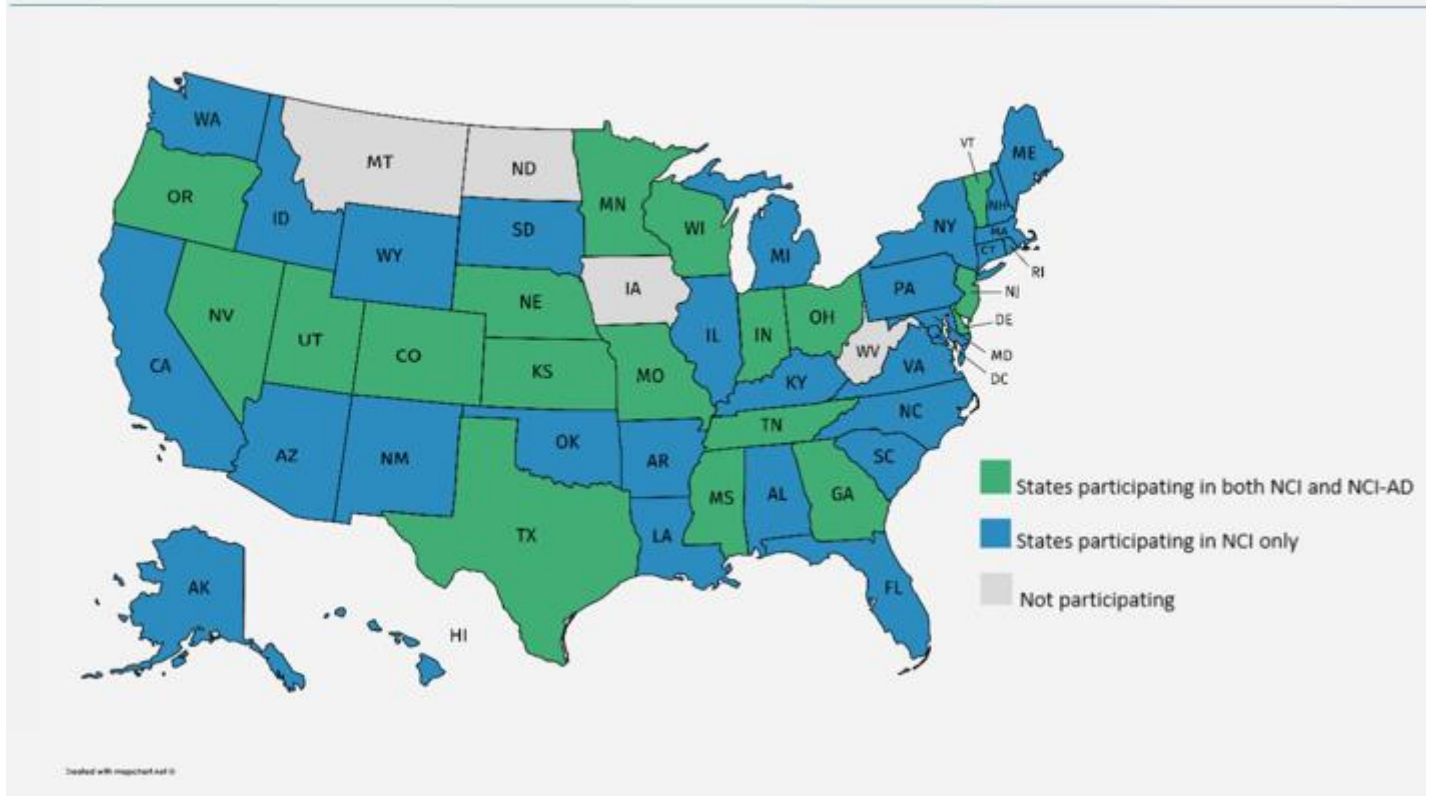
## National Core Indicators for Aging and Disabilities (NCI-AD)

A newer project related to NCI, the **National Core Indicators for Aging and Disabilities (NCI-AD)**, has been implemented in a number of states since 2015. NCI-AD is a collaboration between HSRI and the National Association of States United for Aging and Disabilities (NASUAD) and grew out of NCI's experience and the recognition that the amount and type of information available to states for assessing quality of their LTSS for seniors and adults with physical disabilities was extremely limited.



June 1, 2018 kicked off NCI-AD's fourth year of data collection, with more than 20 states nationwide participating. For more information on NCI-AD, see [www.NCI-AD.org](http://www.NCI-AD.org).

### 2016-17 NCI and NCI-AD State Participation







## Staff

**Mary Lou Bourne**  
NASDDDS Project Director of NCI  
[mlbourne@nasddds.org](mailto:mlbourne@nasddds.org)

**Valerie Bradley**  
[vbradley@hsri.org](mailto:vbradley@hsri.org)

**Laura Vegas**  
[lvegas@nasddds.org](mailto:lvegas@nasddds.org)

**Stephanie Giordano**  
[sgiordano@hsri.org](mailto:sgiordano@hsri.org)

**Henan Li**  
[hli@hsri.org](mailto:hli@hsri.org)

**Sarah Weidlein**  
[sweidlein@hsri.org](mailto:sweidlein@hsri.org)

**Alexandra Bonardi**  
HSRI Project Director of NCI  
[abonardi@hsri.org](mailto:abonardi@hsri.org)

**Dorothy Hiersteiner**  
[dhiersteiner@hsri.org](mailto:dhiersteiner@hsri.org)

**Julie Bershinsky**  
[jbershadsky@hsri.org](mailto:jbershadsky@hsri.org)

**Cheryl Sartori**  
[csartori@hsri.org](mailto:csartori@hsri.org)

**Rachel Fink**  
[rfink@hsri.org](mailto:rfink@hsri.org)

## 2018 NASDDDS RESEARCH COMMITTEE MEMBERS

### NASDDDS Members

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Comments or questions:  
[dhiersteiner@hsri.org](mailto:dhiersteiner@hsri.org)



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