



NATIONAL CORE INDICATORS[®]

NASDDDS & HSRI



2018-19 At-A-Glance Report



Human Services
Research Institute

NASDDDS

National Association of State Directors of Developmental Disabilities Services



What is National Core Indicators (NCI)?

Since 1997, state developmental disability service systems have used the National Core Indicators™ (NCI™) surveys to gather information about the satisfaction, quality of life, and critical life outcomes of those they support. States use this information to track their own performance over time and to compare results across states. NCI's outcome data contributes key information to states seeking to improve services that support people with IDD to live and contribute as valued members of their communities.

What is the At-A-Glance Report?

This report uses graphics and icons to demonstrate selected NCI findings from all participating states for quick and easy reading.

Does something catch your eye?

Visit www.nationalcoreindicators.org for more info on NCI.

Cover Art:

Charlene Murphy was born in Massachusetts and spent most of her young adult life at Fernald State School.

While in her 20s, Murphy was placed at Gateway Arts as one of the original 8 Gateway artists over 40 years ago. Murphy loves to draw and paint, and primarily creates works in the fabric, paper, and folk art production studios. Murphy historically depicts men and women in the simplest form; however, her focus recently has turned to drawing and painting whimsical animals.

For more info, visit: <https://www.gatewayarts.org/>



Where are the statistics in this report from?

This report includes selected findings from the National Core Indicators 2018-19 Surveys. A brief description of each survey is on the following page.

Weighted NCI Averages

The data shown in this report are **weighted NCI averages**. This means that the calculations reflect the relative population sizes of participating states and their survey sample sizes. This way, a state that provides services to a larger number of people but uses a sample similar in size to other states has a greater influence on the overall NCI average. For more information, see the Methodology section of the NCI survey reports.

How are NCI reports used?

The NCI Team produces reports that inform state efforts to strengthen LTSS policy, inform quality improvement activities, evaluate programs and policies, and compare state system performance with national norms. For more information on National Core Indicators, please visit www.nationalcoreindicators.org.

Want to learn more about data in this report?

For detailed information on samples, weighting, methodology and administration, please see the National NCI Reports from 2018-19, available at:

<https://www.nationalcoreindicators.org/resources/reports/>.

In-Person Survey

This survey is completed with adults with IDD 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 person 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 IDD 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 IDD 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 IDD 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.

Staff Stability Report

The **Staff Stability Survey** is an on-line survey of provider agencies supporting adults with ID/DD in residential, employment, day services and other in-home or community inclusion programs. The survey captures information about wages, benefits, and turnover of the direct care professional workforce, hired by agencies.

Agencies receive the survey through an email invitation (address provided by State) and agencies respond directly into ODESA.



2018-19

In-Person

Survey

(IPS)

22,009 adults

with IDD

participated

across 37

states*

NCI Averages:

•Include all participating states

•Data are weighted

*2018-19 IPS participating states were: AL, AR, AZ, CO, CT, DE, FL, GA, HI, IN, KS, KY, ME, MI, MN, MO, NC, NE, NH, NJ, NV, NY, OH, OK, OR, PA, RI, SC, SD, TN, TX, UT, VA, VT, WA, WI, WY

Respondents*

Adults with IDD age 18 and older receiving at least one service (in addition to case management) from the state DD service system.

Residence 38% parent or relative's home

32% community-based group residential settings

18% own home or apartment

7% foster care or host home

4% ICF/ID or other institutional setting

2% other or don't know



39% mild

29% moderate

12% severe

8% profound

12% unspecified or unknown

Mental Health Diagnoses

32%

• mood disorder

27%

• anxiety disorder

11%

• psychotic disorder

11%

• other mental health diagnosis



58% male



43 average age



53% under guardianship

*proxy respondents were allowed for some questions

2018-19 In-Person Survey



96%
reported having taken part in last service planning meeting



81%
understood what was being talked about at last planning meeting



94%
reported that they chose or had input in services gets as part of service plan



83%
know who to ask to make changes to service plan

79%
report having friends who are not staff or family

79%
report that they can see friends when they want

81%
report having other ways of talking or chatting with friends when cannot see them

48%
want more help to make or keep in contact with friends



89%
report being able to use phone or internet when wanted



56%
report having a cell phone or smartphone



44%
of those who do not have a cell phone or smartphone want a cell phone or smartphone

Respondents

Family members and/or guardians of adults who have I/DD and receive at least one service in addition to case management from the state DD service system. The respondent lives with the adult receiving services.

Respondents....



11%
are over
age 75



36%
say they or a
family
member
provide paid
support



33%
always have
the respite
services they
need



28%
reported an annual household
income of \$25K or less



73%
reported services and supports
reduced out-of-pocket
expenses related to care for
their family member

Family member with IDD....

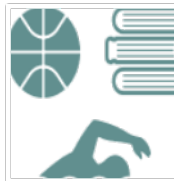


60%
are male

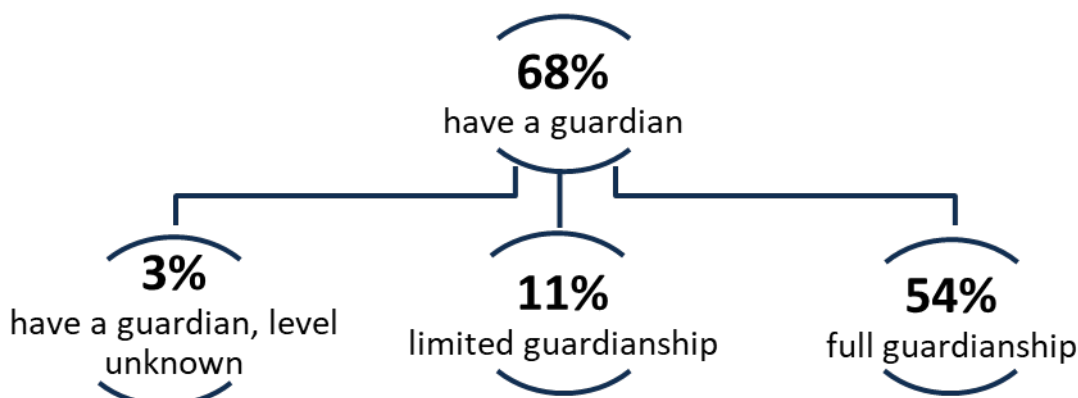


34
average age

88%
take part in
community activities



68%
have friends other
than family or paid
staff



2018-19

Adult Family Survey (AFS)

4,836 families
participated
across
12 states*

NCI Averages:

- Include all participating states
- Data are weighted

*2018-19 AFS participating states were: AZ, GA, LA MD, MN, MO, NC, OH, OK, PA, UT, VA



79%

have resources in the community the family can use



15%

take part in family-to-family networks



96%

feel services and supports have made a positive difference for their family member

39%

say they *always* get enough information to help plan services

41%

say services and supports *always* change when their family's needs change

85%

say they or another family member helped make the service plan

64%

say their family member with IDD helped make the service plan



78%

family member can *always* see health professionals when needed



68%

family member can *always* go to the dentist when needed



53%

crisis or emergency services were provided in the past year when needed

Respondents

Family members and/or guardians of adults who have I/DD and receive at least one service in addition to case management from the state DD service system. The respondent *does not live* with the adult receiving services.

Respondents....

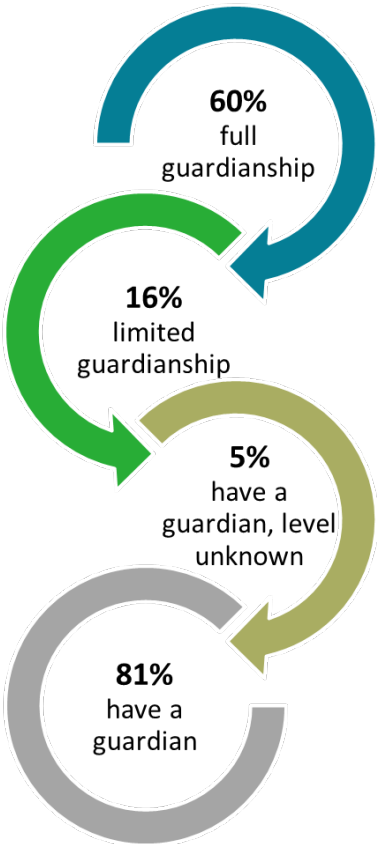


Family member with IDD....

Where family member lives...



- 14%** specialized facility for people with ID
- 65%** group home or agency-operated agency
- 11%** own home or apartment
- 7%** adult foster care or host home
- 3%** other



2018-19

**Family/
Guardian
Survey**

(FGS)

2,709 families
participated
across
9 states*

NCI Averages:

- Include all participating states
- Data are weighted

**2018-19 AFS participating states were: AZ, GA, KY, LA, MD, NC, OH, PA, VA*



46%

always kept informed by staff or residential agency about how family member is doing



74%

services are *always* delivered in a way that is respectful of family's culture



96%

feel services and supports have made a positive difference for their family member

43%

always get enough information to help plan services

44%

services and supports *always* change when their family's needs change

81%

say they or another family member helped make the service plan

62%

family member with IDD helped make the service plan

81%

know how to report abuse or neglect related to their family member

71%

know how to file a complaint about provider agencies or staff

76%

who filed a complaint in the past year were satisfied with the way it was handled and resolved

2018-19 Family/Guardian Survey

Respondents

Family members and/or guardians of children who have I/DD and receive at least one public service in addition to case management from the state DD agency. The respondent lives with the child receiving services.

Respondents....



14%

are under age 35



33%

say they or a family member provide paid support



39%

always have the respite services they need



39%

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



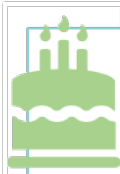
73%

reported services and supports reduced out-of-pocket expenses related to care for their child

Child with IDD....



69%
male



11
average age



81%
child takes part in community activities



88%
child spends time with children without DD



81%
have resources in the community the family can use



21%
take part in family-to-family networks

2018-19

Child Family Survey

(CFS)

14,816 families participated across **12** states*

NCI Averages:

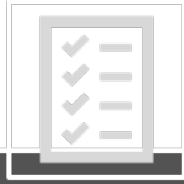
- Include all participating states
- Data are weighted

*2018-19 CFS participating states were: AZ, CA, CO, LA, MN, MO, NC, OH, OR, SD, WA, WI



69%

case manager/service coordinator *always* respects family's choices and opinions



43%

support workers *always* have the right information and skills to meet family's needs



92%

feel services and supports have made a positive difference for their child

30%

always get enough information to help plan services

31%

services and supports *always* change when their family's needs change

83%

say they or another family member helped make the service plan

18%

child with IDD helped make the service plan



73%

child's service providers work together to provide support



50%

family can *always* choose or change their child's support workers



50%

family can *always* choose or change the agency that provides services

2018-19 Child Family Survey

Staff Stability Survey

A total of **4,400** providers from **26** states and the **District of Columbia** participated in the 2018 NCI Staff Stability Survey

Across states, the weighted **average turnover rate** for DSPs

in 2018 was **51.3%**

States ranged from **30.7%** to **62.7%**



Full-Time Vacancy Rate:

11.9%

Part-Time Vacancy Rate:

18.1%



Across all service types, agencies paid a **median hourly wage of \$12.00**

Among DSPs who were employed as of 12/31/18...

- **19.6%** were employed **less than 6 mos.**
- **14.7%** were employed **6-12 mos.**
- **65.7%** were employed **12 mos. or longer**

Among DSPs separated from employment in 2018...

- **34.7%** were employed **less than 6 mos.**
- **20.3%** were employed **6-12 mos.**
- **33.7%** were employed **12 mos. or longer**

For more info on the survey and methodology, see the 2018 Staff Stability Report available here:

<https://www.nationalcoreindicators.org/staff-stability-survey/>



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