
2019-2020

AT-A-GLANCE REPORT

Selected Findings From NCI Surveys



Human Services
Research Institute

NASDDDS

National Association of State Directors of Developmental Disabilities Services



ABOUT NATIONAL CORE INDICATORS

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.

Visit nationalcoreindicators.org for more information.

THE DATA

This report includes selected findings from the National Core Indicators 2019-2020 Surveys. The surveys are described on the next page.

The data shown in this report are weighted NCI averages. This means 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 size similar to other states has a greater influence on the overall NCI average. For more information, see the Methodology section of the NCI survey reports.

OBJECTIVES & PLANS

States use the NCI reports to inform their efforts to strengthen LTSS policy, inform quality improvement activities, evaluate programs and policies, and compare state system performance with national norms.



THE SURVEYS

FAMILY SURVEYS

These surveys are mailed out to families (or where applicable, to guardians) of people who receive at least one paid service from the state DD agency in addition to case management.



ADULT FAMILY SURVEY

Families of adults (age 18+) with IDD living in the family home



CHILD FAMILY SURVEY

Families of children with IDD who live in the family home



FAMILY GUARDIAN SURVEY

Families or guardians of adults (age 18+) with IDD living outside the family home

THE IN-PERSON SURVEY

Direct surveys of people with IDD (age 18+) who receive at least one paid service (in addition to case management) from the state DD agency.



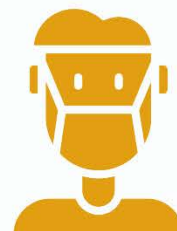
THE STAFF STABILITY SURVEY

An online survey of provider agencies supporting adults with IDD 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 these agencies. Agencies are emailed a link to the survey. (State staff provide the email addresses of the agencies.) And agencies respond directly into ODESA.



COVID-19 AND IN-PERSON SURVEYING

The 2019-2020 in-person surveys ended early due to COVID-19; all data collection was halted on April 15, 2020. Very few states had completed data collection by that date. For this reason, NCI decided not to publicly report these data.



2019-2020 ADULT FAMILY SURVEY

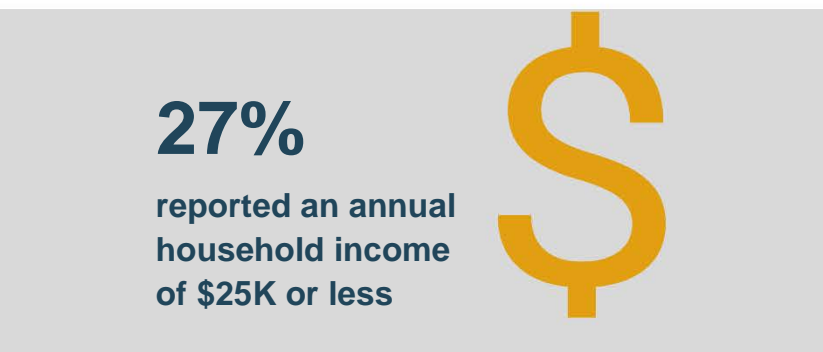
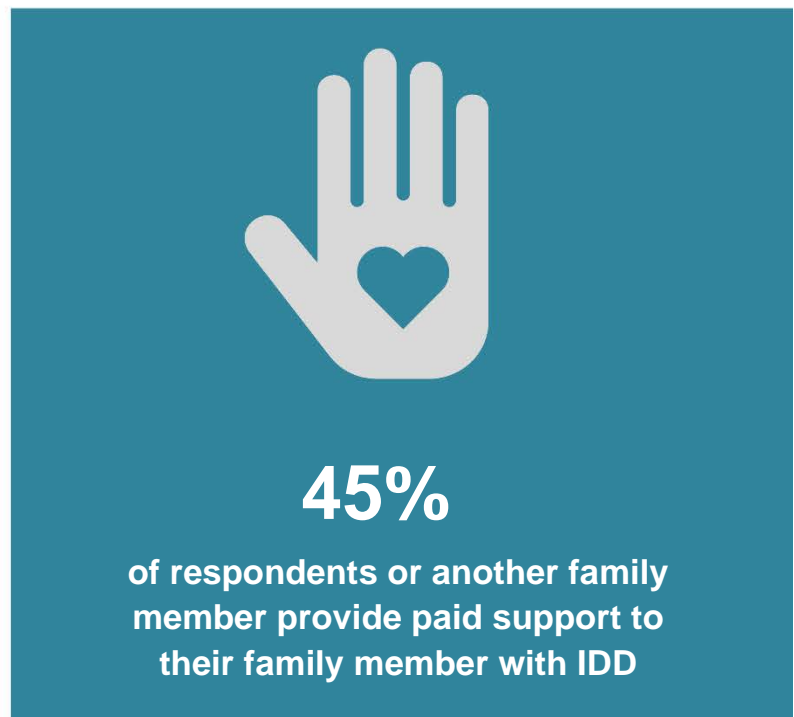
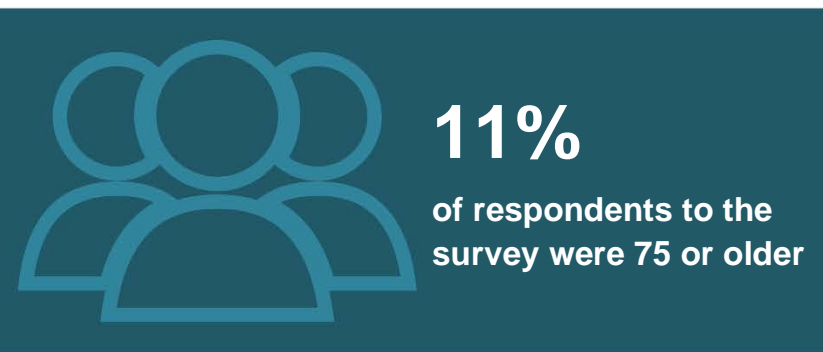
STATES THAT PARTICIPATED:

14

AZ, CA, DE, DC, FL, GA, MD, MO, NH, NC, OK, PA, SD, WA

FAMILIES THAT RESPONDED:

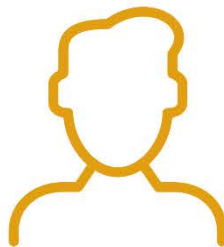
19,183



Family member with IDD...



34
average age



61%
are male



63%
have a guardian

2019-2020 ADULT FAMILY SURVEY



38%

always get enough information to help plan services



38%

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

81%

reported they or another family member helped make the service plan



65%

reported their family member with IDD helped make the service plan



78%

have resources in the community the family can use that are not provided by the IDD agency



19%

take part in family-to-family networks



34%

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

2019-2020 FAMILY/GUARDIAN SURVEY

STATES THAT PARTICIPATED:

11

AZ, CA, FL, GA, MD, MN, NH, NC, PA, SD, UT

FAMILIES THAT RESPONDED:

9,435



24%

of survey respondents were 75 or older



65%

visited their family member with IDD more than 12 times in the past year

Family member with IDD...



45

average age



60%

are male

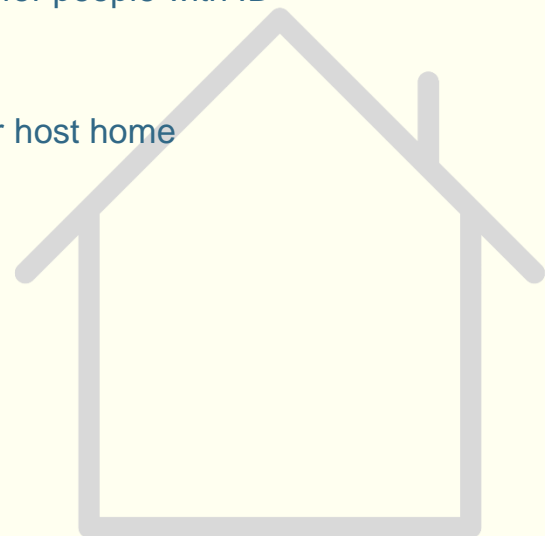


73%

have a guardian

Where family member lives...

- **59%** group home or agency-operated apartment
- **19%** own home or apartment
- **12%** specialized facility for people with ID
- **8%** adult foster care or host home
- **1%** nursing home
- **2%** other



2019-2020 FAMILY/GUARDIAN SURVEY



42%

always get enough information to help plan services

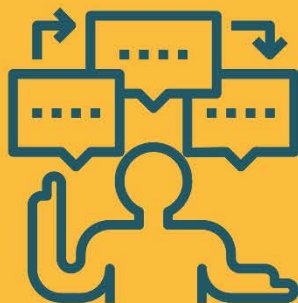


41%

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

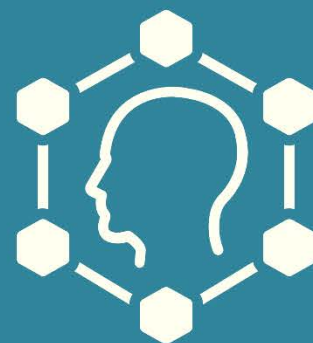
80%

reported they or another family member helped make the service plan



60%

reported their family member with IDD helped make the service plan



82%

have resources in the community the family can use that are not provided by the IDD agency



14%

take part in family-to-family networks



77%

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

2019-2020 CHILD FAMILY SURVEY


STATES THAT PARTICIPATED:

8

AZ, CO, LA, MO, NC, OR, UT, WI

FAMILIES THAT RESPONDED:

3,056



12%
of respondents to the survey were 35 or younger



22%
reported they or another family member provide paid support to their child



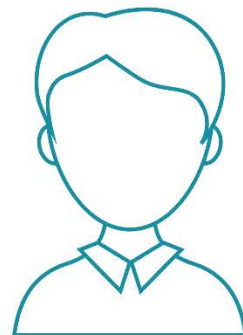
24%
reported an annual household income of \$25K or less

Child with IDD...



12

average age



67%

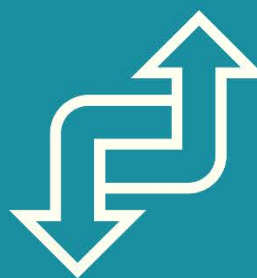
are male

2019-2020 CHILD FAMILY SURVEY



33%

always get enough information to help plan services

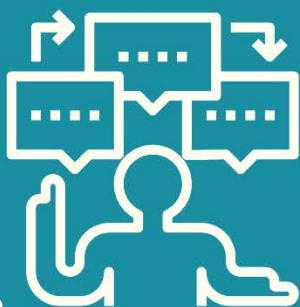


32%

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

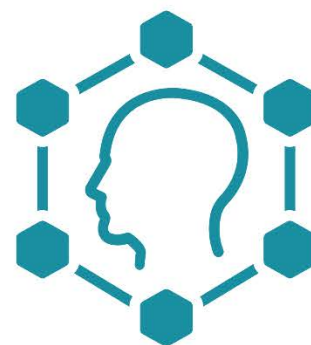
92%

reported they or another family member helped make the service plan



18%

reported their child with IDD helped make the service plan



81%

have resources in the community the family can use that are not provided by the IDD agency



20%

take part in family-to-family networks



77%

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

2019 STAFF STABILITY SURVEY

3,604 providers participated from across 26 states including the District of Columbia

8.5%

FULL-TIME DSP
VACANCY RATE

11.2%

PART-TIME DSP
VACANCY RATE



\$12

MEDIAN HOURLY
WAGE
FOR DIRECT SUPPORT
PROFESSIONALS

42.8%

WEIGHTED AVERAGE
TURNOVER RATE
FOR
DIRECT SUPPORT PROFESSIONALS



STATE TURNOVER RANGE

23.8%

TO

64.8%

Length of employment of the DSPs who **left** in 2019...

- 32.7% less than 6 months
- 17.8% 6-12 months
- 32.4% 12 months or longer



Length of employment for DSPs employed as of 12/31/19...

- 17.7% less than 6 months
- 16.4% 6-12 months
- 65.9% 12 months or longer



NCI NATIONAL TEAM MEMBERS

Alexandra Bonardi
HSRI Director of NCI
abonardi@hsri.org

Laura Vegas
NASDDDS Director of NCI
Lvegas@nasddds.org

Valerie Bradley
vbradley@hsri.org

Rachel Fink
rfink@hsri.org

Stephanie Giordano
sgjordano@hsri.org

Karen Gruber
kgruber@hsri.org

Henan Li
hli@hsri.org

Dorothy Hiersteiner
dhiersteiner@hsri.org

Eric Lam
elam@hsri.org

Cheryl Sartori
csartori@hsri.org

For more information about NCI, visit nationalcoreindicators.org.

Comments or questions, email dhiersteiner@hsri.org.

Cover Art: Gilberto Palacios (1959-2017) was born and raised in Havana, Cuba, where he spent hours creating compositions based on the costumes and makeup observed on the streets of Havana. Having traveled to the United States by boat in 1980 and moving to Boston in 1999, Palacios found Gateway Arts in 2003 where he worked to develop his “Afro Cuban Style.” His dense, colorful works filled with faces, figures, and patterns became popular and highly collected. Palacios died in Miami, Florida in 2017. His artwork has been shown in galleries across Massachusetts, New York, and England. For more information, visit gatewayarts.org.