



**NATIONAL CORE
INDICATORS[®]**
NASDDDS & HSRI

**National Core Indicators[®]-
Intellectual and
Developmental Disabilities
2020–21 At-A-Glance Report**



Human Services
Research Institute

NASDDDS

National Association of State Directors of Developmental Disabilities Services



What is National Core Indicators®-Intellectual and Developmental Disabilities (NCI®-IDD)?

Since 1997, state developmental disability service systems have used the NCI-IDD 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-IDD'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-IDD findings from all participating states for quick and easy reading.

Does something catch your eye?

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



Where are the statistics in this report from?

This report includes selected findings from the NCI-IDD 2020–21 surveys. A brief description of each survey is on the following page.

Weighted NCI-IDD averages

The data shown in this report are **weighted NCI-IDD 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-IDD average. For more information, see the Methodology section of the NCI-IDD survey reports.

How are NCI-IDD reports used?

The NCI-IDD team produces reports that inform state efforts to strengthen long-term services and supports (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-IDD Reports from 2020–21, 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 the Background Information section, which gathers data about the person from agency records, and an in-person survey, which is gathered face-to-face with the person receiving services.

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 Survey

The **Staff Stability Survey** is an online 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 support professional workforce, employed by agencies. Agencies receive the survey through an email invitation (address provided by State) and respond directly into the data entry system (ODESA).

COVID-19 Supplement data

In response to the COVID-19 pandemic, NCI-IDD added COVID-19 Supplements to all NCI Surveys. States could opt not to participate in the supplements. This report shows select outcomes from those supplements. **Note: Not every state implemented the COVID-19 Supplements.**

2020-2021 In-Person Survey (IPS)

19,991 adults with
IDD participated
across 26 states*

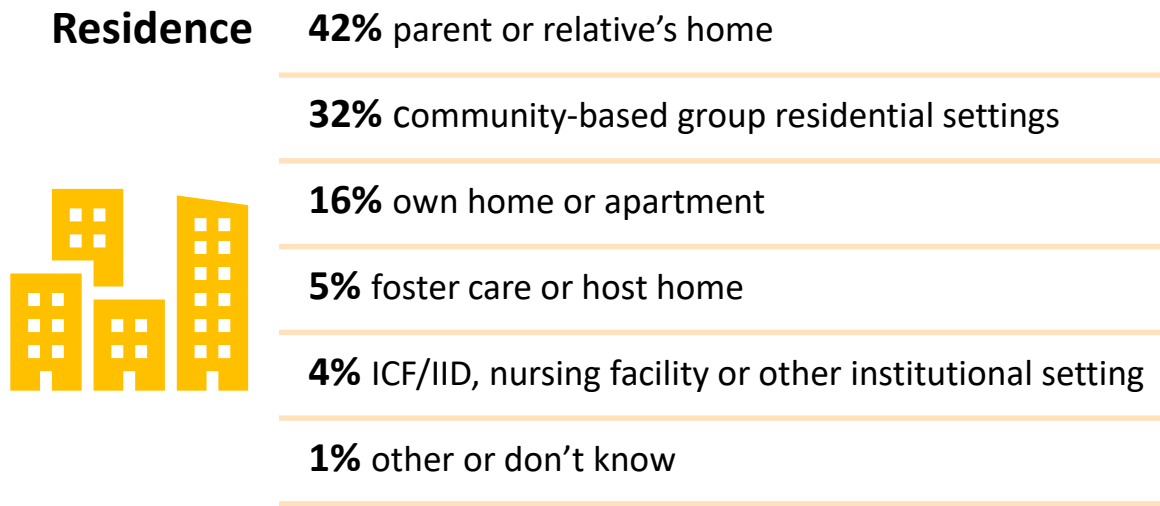
NCI-IDD averages:

- Include all participating states
- Data are weighted

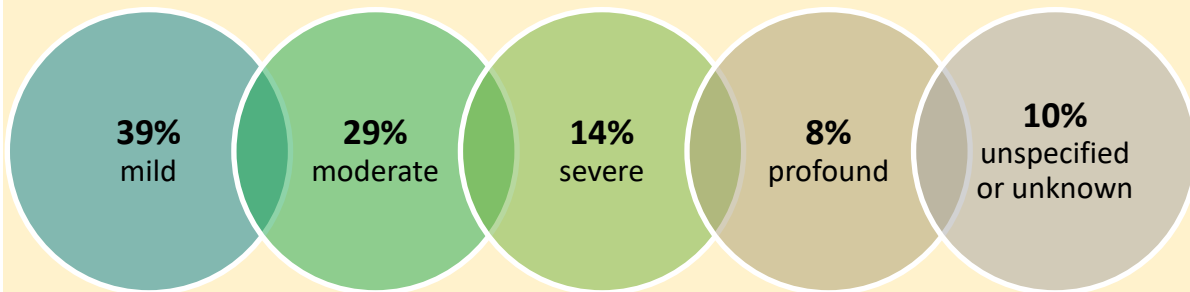
*2018-19 IPS participating states were: AL, AR, CA, CO, FL, GA, HI, IL, IN, KS, KY, MI, MN, MO, NE, NV, NH, NJ, NC, OH, OR, PA, SD, TN, VA, WI

Respondents

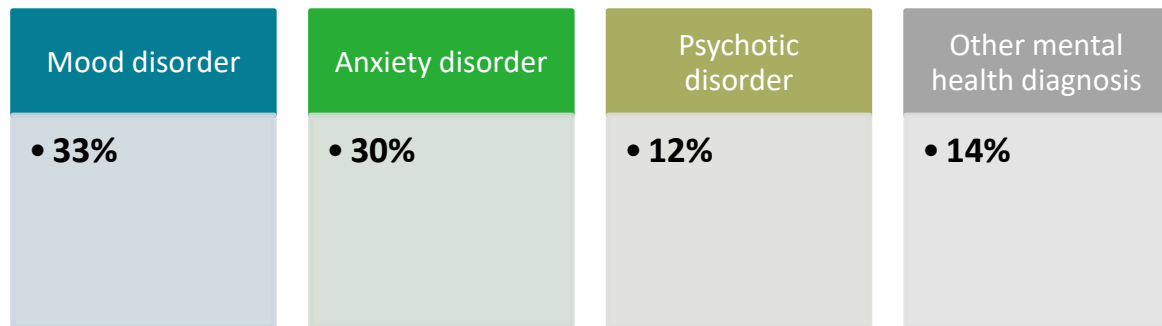
Adults with IDD age 18 and older receiving at least one service (in addition to case management) from the state DD service system. Proxy respondents were allowed for some questions



86% have an ID diagnosis...



Mental Health Diagnoses



59%
male



41
average age



45%
had a guardian

2020-21 In-Person Survey



96%
reported
having taken
part in last
service
planning
meeting or
chose not to



79%
understood
what was
being talked
about at last
planning
meeting



76%
reported
that they
chose
services gets
as part of
service plan



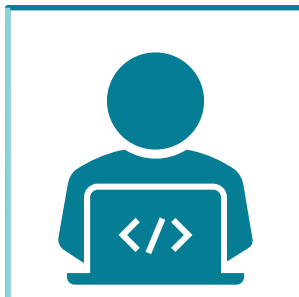
83%
know who to
ask to make
changes to
service plan

77%
report having
friends who are
not staff or family

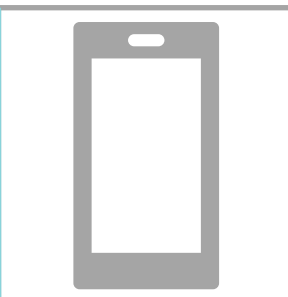
69%
report that they
can see friends
when they want

87%
report having
other ways of
communicating
with friends when
cannot see them

46%
want more help
to make or keep
in contact with
friends



92%
report being able
to use phone or
internet when
wanted



65%
report having a
cell phone or
smartphone

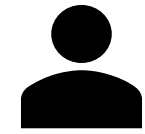


47%
of those who do
not have a cell
phone or
smartphone want
a cell phone or
smartphone

Respondents

Family members and/or guardians of adults who have IDD 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 . . .



12%

are over age 75



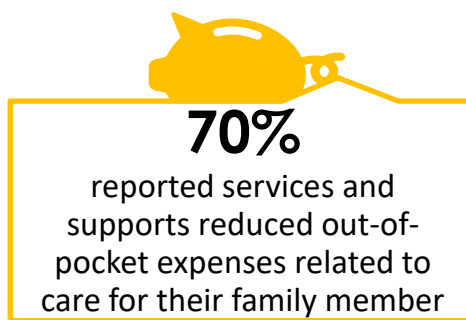
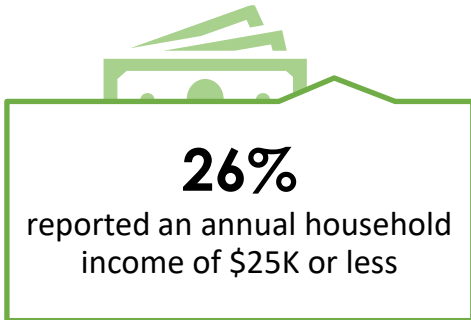
39%

say they or a family member provide paid support to their family member receiving services



24%

can always get and use respite services they need



Family member with IDD . . .



58 %
are male

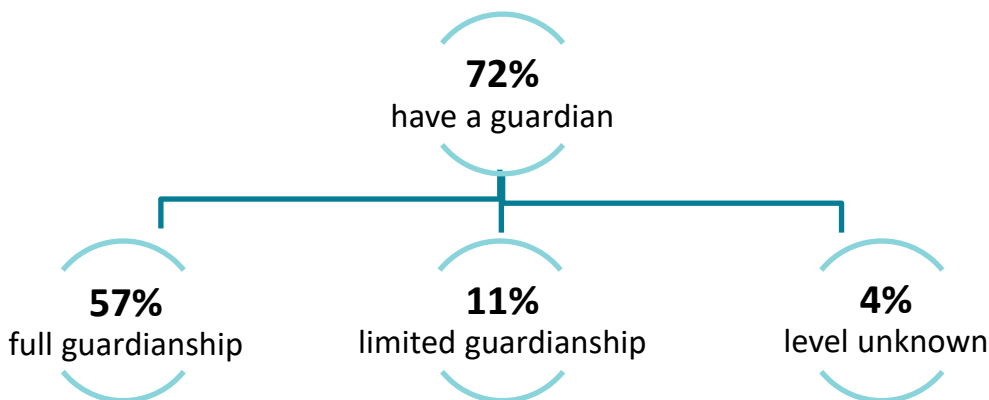


36
average age

79%
take part in community activities



62%
have friends other than family or paid staff



2020–21 Adult Family Survey (AFS)

4,952 families
participated across
12 states*

NCI-IDD averages:

- Include all participating states
- Data are weighted

*2020–21 AFS participating states were: AZ, DE, FL, GA, LA, MD, MN, MO, NJ, OK, PA, and VA



73%

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



17%

take part in family-to-family networks



95%

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

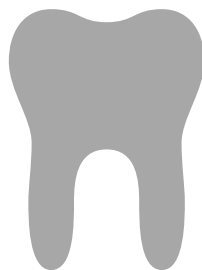


63% say their family member with IDD helped make the service plan



74%

family member can *always* see health professionals when needed



65%

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



51%

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

Respondents

Family members and/or guardians of adults who have IDD 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 . . .



23% are age 75 or older



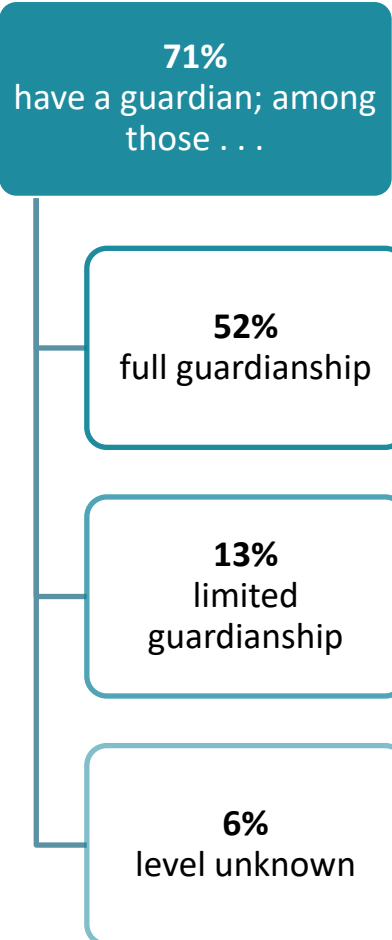
65% say they visited their family member with IDD 12 or more times in the past year

Family member with IDD . . .

Where family member lives . . .



- 11%** specialized facility for people with IDD
- 67%** group home or agency-operated apartment
- 14%** own home or apartment
- 5%** adult foster care or host home
- 3%** other



47 average age

58% male



82% take part in community activities

62% have friends other than family or paid staff



2020–21 Family/Guardian Survey (FGS)

3,118 families participated across **8** states*

NCI-IDD averages:

- Include all participating states
- Data are weighted

*2020–21 FGS participating states were: AZ, DE, GA, IN, KY, MD, NJ, and PA



44%

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



73%

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



95%

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



37% say they *always* get enough information to help plan services



38% say services and supports *always* change when their family's needs change



79% say they or another family member helped make the service plan



61% say their family member with IDD helped make the service plan



74%

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



63%

know how to file a complaint about provider agencies or staff



62%

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

Respondents

Family members and/or guardians of children who have IDD 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 . . .



15%

are under age 35



35%

say they or a family member provide paid support to their child receiving services



32%

can always get and use respite services they need



30%

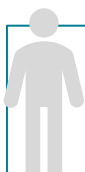
reported an annual household income of \$25K or less



75%

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

Child with IDD . . .



67%
male



11
average age



70%
child takes part in community activities



84%
child spends time with children without DD



77%
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

2020–21 Child Family Survey (CFS)

4,693 families participated across **10** states*

NCI-IDD averages:

- Include all participating states
- Data are weighted

*2020–21 CFS participating states were AZ, CO, MN, MO, NC, OR, SD, TX, VA, and WI



74%

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



49%

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



93%

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



37% *always* get enough information to help plan services



40% say services and supports *always* change when their family's needs change



90% say they or another family member helped make the service plan



18% say their child with IDD helped make the service plan



66%

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



65%

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



80%

say their child's service providers work together to provide support


2020-21 Child Family Survey

NCI-IDD

2020 Staff Stability Survey Results

Representing a total of **2,987** providers from **27** states

Data refer to the workforce of Direct Support Professionals (DSPs) supporting adults with IDD in 2020



Across states, the **average DSP turnover rate** in 2020 was **44%**
State turnover rates ranged from **27%** to **80%**

Among DSPs who were employed as of December 31, 2020:

- **30%** had been employed **12 months or less**

Among DSPs who had **separated** from employment in 2020:

- **48%** had been employed **12 months or less**



Across all service types, agencies paid a **median hourly wage of \$13.36**

Across the 22 states that included the COVID-19 Supplement, respondents reported the following about their pandemic experience:

33% of agencies reported closing locations/sites

15% reported paying family members to serve as support providers during the pandemic

47% reported stopping the delivery of some supports, either temporarily or permanently

To retain DSPs during the pandemic . . .

38% reported implementing at least one wage bonus for all DSPs

26% reported implementing temporary wage increases for all DSPs

25% reported no wage bonuses or wage increases were implemented



COVID-19 Supplements

- In response to the COVID-19 pandemic, NCI-IDD added COVID-19 Supplements to all NCI Surveys. States could opt not to participate in the supplements. The data from these supplements can support the understanding of the experience of people with disabilities and their families at the beginning of the COVID-19 pandemic and their interactions with services during that time.
- The following pages show select outcomes from the NCI-IDD COVID-19 Supplement reports. **Note: Not every state implemented the COVID-19 Supplements.**

In-Person Survey (IPS) COVID-19 Supplement

IPS COVID-19

Supplement

participating states

were: AL, AR, CA, CO,

FL, GA, HI, IL, IN, KS,

KY, MI, MO, NC, NE,

NH, NJ, NV, OH, OR,

PA, SD, TN, VA, and WI

NCI-IDD averages:

- Include all participating states
- Data are weighted

Proxy respondents were allowed for some questions

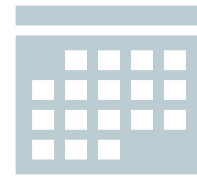
The most common changes to routine or daily schedule during the COVID-19 pandemic



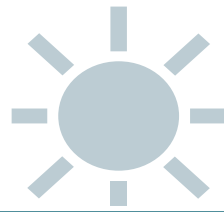
82% went into the community less often or stopped going altogether



59% saw family or friends (who don't live with person) less often or stopped seeing them in person



38% stopped going to an in-person day program, workshop, or other unpaid day or community



17% went fewer hours to a day program, workshop, or other unpaid day or community activity

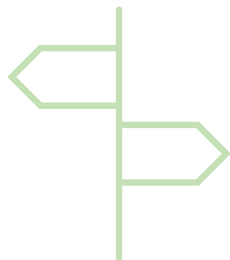
Respondents reported liking the following changes to their lives and daily routines that they experienced during the COVID-19 pandemic

33% staying home more

28% using technology more

22% talking with friends and family more

16% started a new activity that they liked or did activities they enjoy often



If there were changes in daily schedule, who chose person's new daily schedule?

44% person chose

33% person had help choosing

23% someone else chose

During the COVID-19 pandemic in 2020



83%
talked to a
case
manager or
service
coordinator
enough



85%
reported all
staff always
used
personal
protective
equipment
(PPE)



37%
reported
being more
worried,
scared,
anxious, or
sad than
before



23%
reported
wanting
more help
to feel less
worried,
scared,
anxious, or
sad

Technology



88% have a computer, tablet, or smartphone they can use in the home



83% report internet always works and connection is good at home



57% have ever talked to a case manager/service coordinator using videoconferencing or telehealth



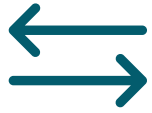
51% have ever talked to a health professional using videoconferencing or telehealth

Services done using videoconferencing since COVID-19 started . . .

- **18%** social groups organized by day program
- **16%** exercises or physical activity
- **12%** life skills (cooking, other self-care)
- **4%** job coaching, job skills, other employment-related activities



During the COVID-19 pandemic in 2020, respondents . . .



73%

report that their family members had changes, cancellations, or reductions in service



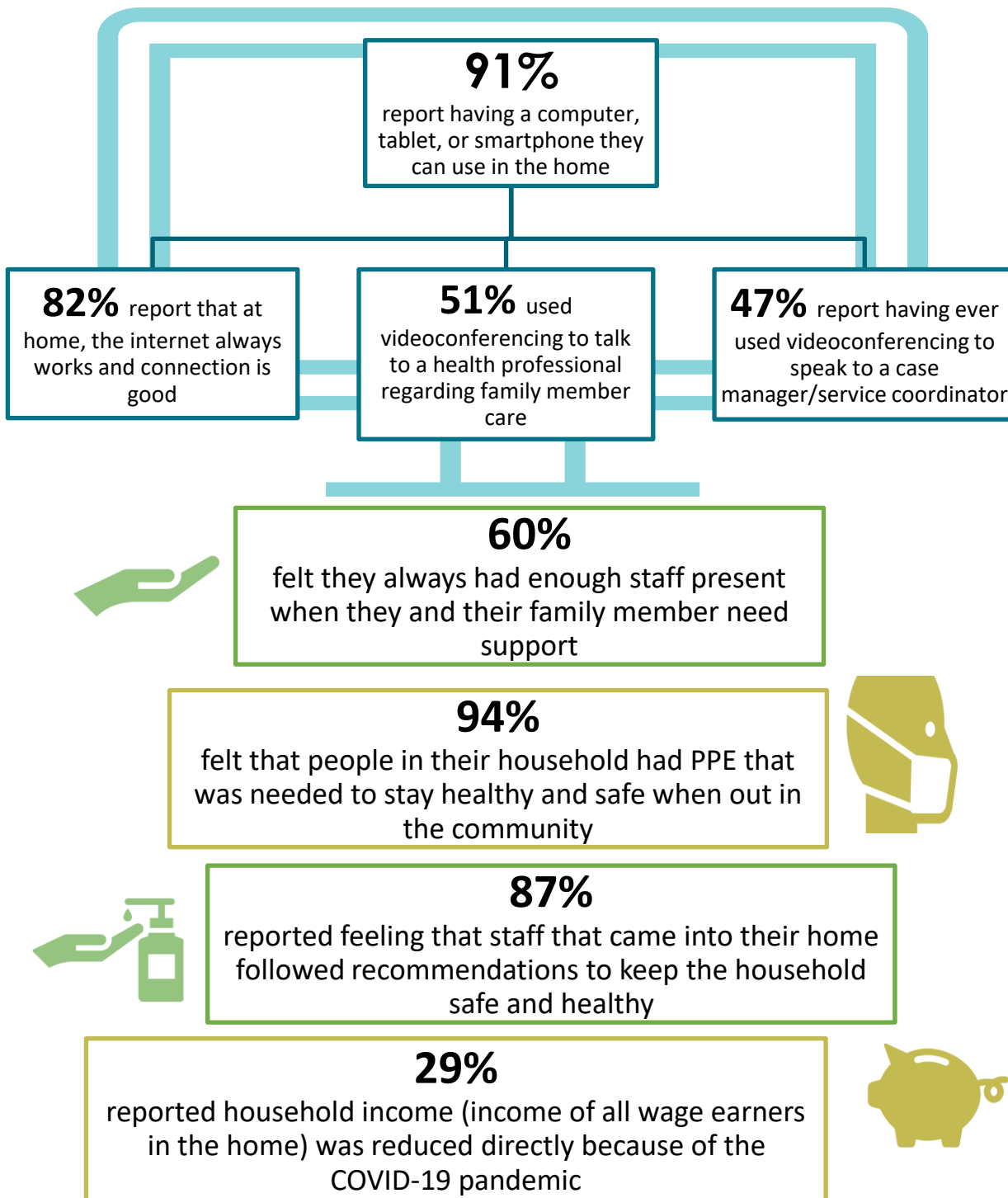
81%

received enough information about changes, cancellations, or reductions in service



56%

report that their family members' staff or case manager/service coordinator helped to adjust to those changes



Adult Family Survey (AFS) COVID-19 Supplement

AFS COVID-19

Supplement

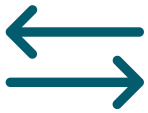
participating states

were: AZ, DE, FL, GA, LA, MD, MN, MO, NJ, PA, and VA

Respondents

Family members and/or guardians of adults who have IDD 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.

During the COVID-19 pandemic in 2020, respondents . . .



80%

report that their family members had changes, cancellations, or reductions in service during COVID-19



79%

received enough information about changes, cancellations, or reductions in service



70%

report that their family members' staff or case manager/service coordinator helped to adjust to those changes

Family/ Guardian Survey (FGS) COVID-19 Supplement

FGS COVID-19

Supplement

participating states

*were: AZ, DE, GA, IN,
KY, MD, NJ, and PA*

Respondents

Family members and/or guardians of adults who have IDD 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.

91%

report having a computer, tablet, or smartphone they can use in the home

88% report that at home, the internet always works and connection is good

30% used

videoconferencing to talk to a health professional regarding family member care

50% used

videoconferencing to speak to a case manager/service coordinator



73%

felt they've gotten to talk to their family member's case manager/service coordinator enough

71%

felt they always had enough staff present when they or family members need support



93%

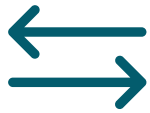
felt that people in their household had PPE that was needed to stay healthy

17%

reported household income (income of all wage earners in the home) was reduced directly because of the COVID-19 pandemic



During the COVID-19 pandemic in 2020, respondents . . .



74%

report that their child had changes, cancellations, or reductions in service during COVID-19



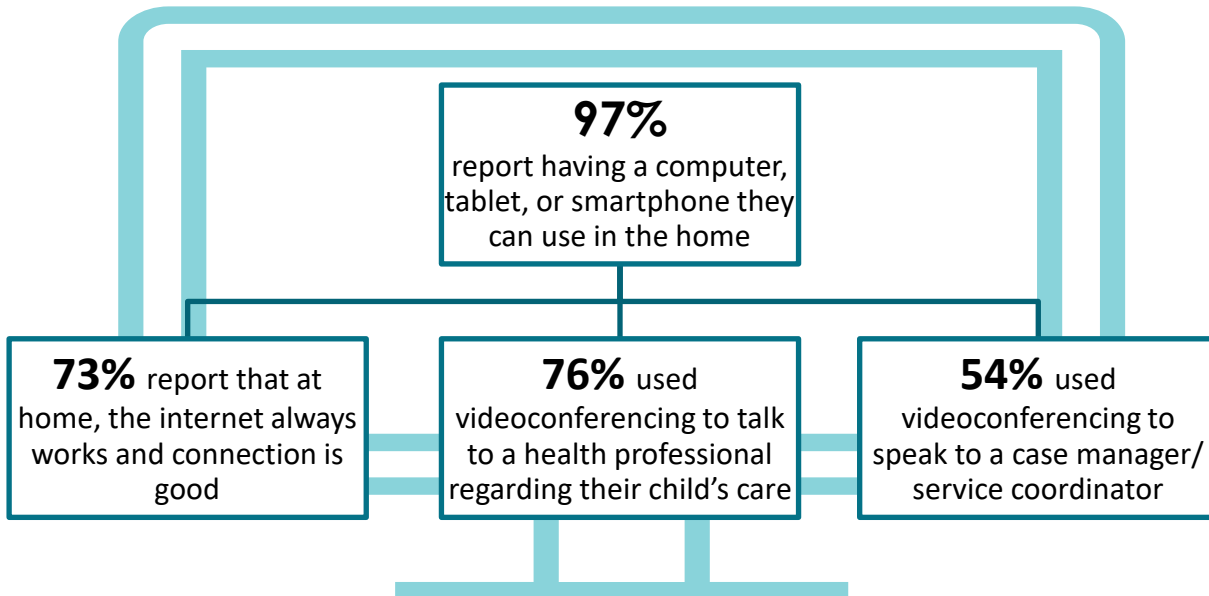
79%

received enough information about changes, cancellations, or reductions in service



56%

report that their child's staff or case manager/service coordinator helped to adjust to those changes



77%

felt they have gotten to talk with their child's case manager/service coordinator enough

52%

felt they always have enough staff present when they or their child need support



89%

report feeling that staff that came into their home followed recommendations to keep the household safe and healthy

42%

of respondents report that household income (income of all wage earners in the home) was reduced directly because of the COVID-19 pandemic



Child Family Survey (CFS) COVID-19 Supplement

CFS COVID-19

Supplement

participating states

were: AZ, CO, MN, MO, NC, OR, SD, TX, VA, and WI

Respondents

Family members and/or guardians of children who have IDD 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.



NATIONAL CORE INDICATORS®

NASDDDS & HSRI

NCI-IDD National Team Members

Stephanie Giordano
HSRI Co-Director of NCI
sgjordano@hsri.org

Laura Vegas
NASDDDS Director of NCI-IDD
lvegas@nasddds.org

Dorothy Hiersteiner
HSRI Co-Director of NCI
dhiersteiner@hsri.org

Alexandra Bonardi
abonardi@hsri.org

Valerie Bradley
vbradley@hsri.org

Henan Li
hli@hsri.org

Cheryl Sartori
csartori@hsri.org

Karen Gruber
kgruber@hsri.org

Eric Lam
elam@hsri.org

For more information about NCI, visit: www.nationalcoreindicators.org
Comments or questions, email: dhiersteiner@hsri.org