



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

NCI Family Surveys COVID-19 Supplement

National Report Special Edition

In response to the COVID-19 pandemic, NCI-IDD added a state-optional COVID-19 Supplement to all NCI Surveys. The COVID-19 Supplement is intended to 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. Data were collected between July 1, 2020 and June 30, 2021. This Special Edition Report shows individual state and overall national outcomes for the NCI-IDD COVID-19 Supplement questions.

(The 2021-22 NCI-IDD data cycle also contains a COVID-19 Supplement to support an ongoing understanding of the continuing effects of the pandemic on people's lives and services.)

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Executive Summary

Given the disruptions that have occurred and continue to occur on a global level due to the COVID-19 pandemic, policymakers and other stakeholders need to understand the consequences of these disruptions on families and people with intellectual and developmental disabilities (IDD), including the effectiveness of alternative accommodations, the flow of information and communication, and the health and safety of people with IDD and their families. To capture these experiences, NCI-IDD developed supplemental modules to the three family surveys – the Adult Family Survey (AFS), the Family Guardian Survey (FGS), and the Child Family Survey (CFS) – that were mailed and completed from July 2020 through the end of June 2021. Not all states that participated in the standard family surveys participated in the corresponding supplemental modules.

To solicit specific information regarding the impact of the pandemic, the COVID supplement was divided into four domains: Changes to Services; Technology; Support; and Household Health and Safety.

The data reported below provide a snapshot of the challenges that confronted and continue to confront families with a family member with IDD during the pandemic. They reflect the disruptions that families faced, the diminution of supports many of them experienced, the difficulties in adapting to new technology, and the threats that some families faced to their well-being do to the loss of jobs, income and the prospect of food insecurity.

Changes in Services

More than two-thirds of the families who responded to the AFS (families of adults with IDD living in the family home) noted that they experienced changes in services. Approximately 45% of families of adults living in the family home noted that these changes were “not good for my family.” About two-thirds of AFS and CFS families noted that their case manager/service coordinator or staff helped the family member/child adjust to changes. Three-quarters of FGS respondents (families whose family member lived elsewhere) indicated that support staff and/or the case manager/service coordinator was helpful in helping their family member adjust to changes. And although families reported changes in services, only a small number of families reported that their family member had to

WHAT ARE THE NCI-IDD FAMILY SURVEYS?

NCI-IDD family surveys are mail-out surveys 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. Respondents may complete the survey on paper or online.

There are three family surveys, and they vary slightly in their questions based on the living situation and whether the person with IDD is an adult or child:

- The Adult Family Survey (AFS) is mailed to families of adults (age 18+) with IDD living in the family home
- The Family/Guardian Survey (FGS) is mailed to families or guardians of adults (age 18+) with IDD living outside the family home
- The Child Family Survey (CFS) is mailed to families of children with IDD who live in the family home

leave the home or residential arrangement. According to the FGS, 7% of family members who were not living with the survey respondent had to move home during the pandemic.

Supports

During the pandemic, many states changed their rules to allow payments to families to provide support. Among family respondents to the AFS and CFS, approximately one-quarter reported that they were being paid by the state DD agency to provide supports to the family member at home. With respect to the adequacy of paid support staff, 40% of AFS respondents and 49% from the CFS noted that they did not or sometimes did not have enough staff present when the family or the family member needed support. When families were asked what other supports they and their family member needed, they most frequently cited social supports, supports for activities of daily living, positive behavior support, and someone to talk to if they feel lonely.

Technology

An important accommodation for families during the pandemic was the use of technology to communicate with case managers, health professionals, service providers, and friends and community organizations. Across surveys, respondents in large numbers indicated that they had a device that connected to the internet and that they had access to internet that always works with a good connection. However, only about one-half of families reported having used videoconferencing to talk with case managers/service coordinator during the pandemic; among those who did, the majority felt comfortable with the medium. With respect to use of technology for other services, some – but not most – took part in online social groups, job coaching, life skills, exercise and other services and supports. Some of the reasons that virtual services were not used included it not having been offered, disinterest or lack of engagement by the person with IDD, or lack of the appropriate device.

Family Health and Safety

The pandemic took a toll on the well-being of families. Of those respondents with a family member living at home (AFS and CFS), 28% and 35% respectively said that a wage earner in the household had lost a job or been furloughed. Of those with a member living outside the home (FGS), only 16% of respondents had lost a job.

Of the survey respondents who reported that a wage earner in the household had lost a job or been furloughed, the percentage who reported that their household income had been reduced directly because of the pandemic was roughly the same across all three surveys. A smaller but troubling number of families in the AFS and CFS – 16% and 30%, respectively – reported that since the pandemic started, it had become harder or sometimes harder to make sure the family had enough food to eat.

Presentation of Data

This report includes statewide and weighted NCI-IDD averages for all COVID Supplement data for each of the three NCI-IDD family surveys. Data are presented separately for each of the three surveys, each in its own chapter. Data are presented in a table format with states listed in alphabetical order.

The NCI averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the sample sizes.

Important Notes on FGS Data

Indiana (IN)

FGS COVID Supplement data from IN only come from respondents who completed the survey directly online. (The COVID Supplement was omitted from mailed copies of the survey.) Consequently, the data do not represent the complete sample of respondents represented in demographics and other outcomes to be reported in the National and State FGS reports.

Kentucky (KY)

The FGS COVID Supplement from KY was sent separately from the standard survey; therefore, the data for the COVID Supplement represent a different sample of respondents and are not connected to the demographics or other FGS outcomes to be reported in the National and State FGS reports.

Adult Family Survey

The Adult Family Survey is used to gather information on the experiences of family of adults with IDD. It is mailed to families who have an adult family member who *lives with the respondent* and receives at least one service in addition to case management from the state DD agency.

The following states chose to use the 2020-21 AFS COVID-19 Supplement: AZ, DE, FL, GA, LA, MD, MN, MO, NJ, PA, VA.

For the purpose of this survey, we defined “COVID time” as beginning March 2020.

During the COVID pandemic in 2020, respondents...



73%

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



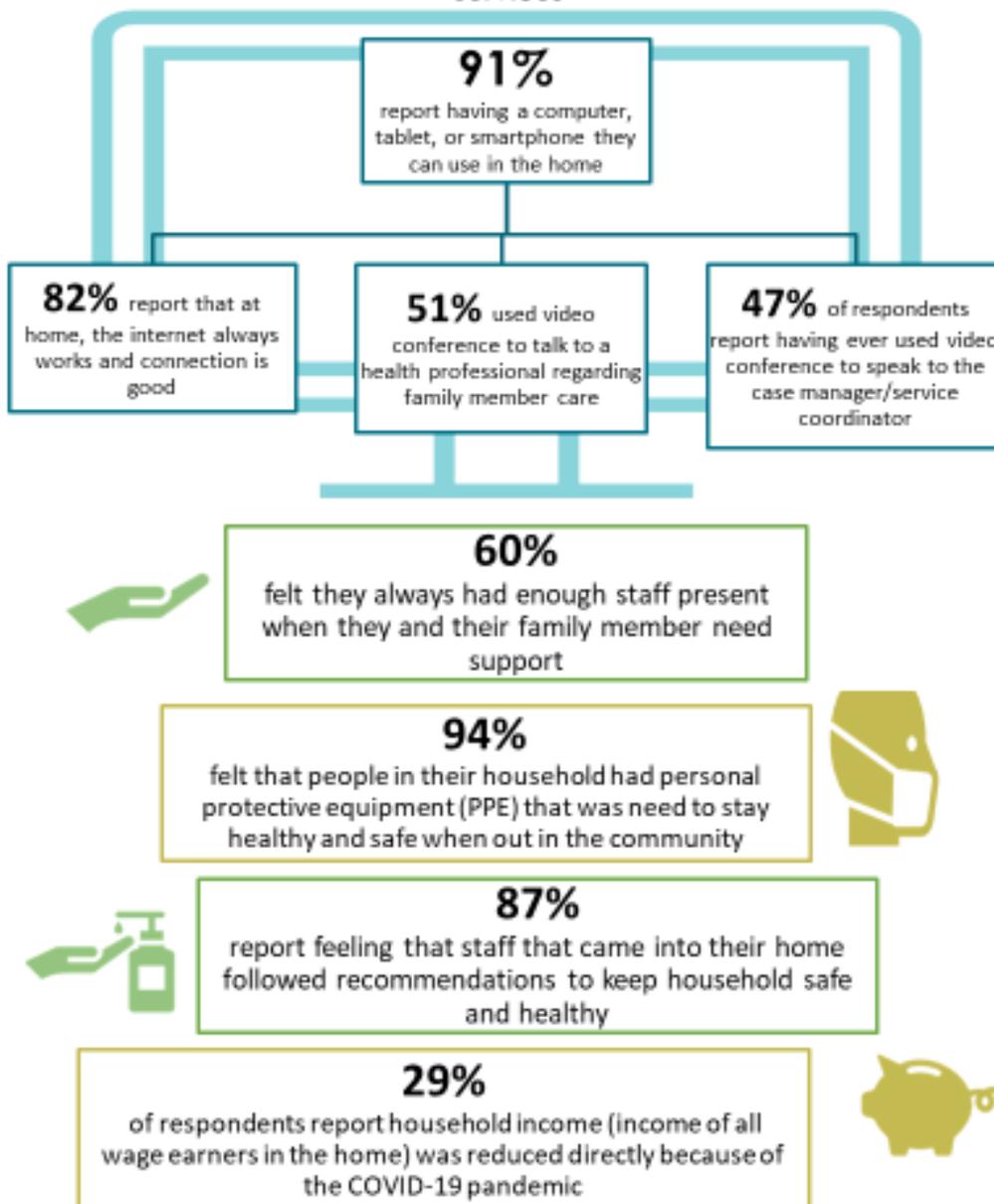
81%

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



56%

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



Adult Family Survey (AFS) COVID Supplement

AFS COVID Supplement participating states were: AZ, DE, FL, GA, LA, MD, MN, MO, NJ, PA, VA

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.

Changes to Services

Table AFS 1. Did your family member have any changes, cancellations or reductions in services during COVID time?

State	Yes	No	N
AZ	78%	22%	264
DE	79%	21%	139
FL	64%	36%	398
GA	43%	57%	394
LA	58%	42%	211
MD	80%	20%	1,082
MN	78%	22%	444
MO	75%	25%	249
NJ	88%	12%	249
PA	82%	18%	569
VA	76%	24%	140
Weighted NCI-IDD Average	73%	27%	4,139

Table AFS 2. If there were changes, cancellations or reductions in services during COVID time, how did the changes, cancellations or reductions in services affect your family?

State	The changes were mostly not good for my family	The changes were mostly good for my family	The changes were somewhat good, somewhat not good	The changes did not affect my family	N
AZ	43%	10%	38%	10%	199
DE	43%	1%	46%	10%	109
FL	41%	10%	35%	14%	243
GA	48%	11%	34%	7%	166
LA	39%	13%	40%	8%	120
MD	45%	13%	35%	7%	826
MN	49%	12%	34%	5%	329
MO	48%	7%	38%	7%	175
NJ	49%	7%	38%	6%	215
PA	45%	8%	35%	12%	437
VA	50%	7%	33%	10%	101
Weighted NCI-IDD Average	45%	9%	36%	10%	2,920

Table AFS 3. If any of your family member's services were changed, cancelled or reduced during COVID time, did you get enough information about changes, cancellations or reductions in services?

State	Yes	No	N
AZ	78%	22%	179
DE	86%	14%	101
FL	79%	21%	219
GA	85%	15%	160
LA	76%	24%	111
MD	76%	24%	789
MN	86%	14%	313
MO	84%	16%	170
NJ	75%	25%	203
PA	86%	14%	426
VA	87%	13%	98
Weighted NCI-IDD Average	81%	19%	2,769

Table AFS 4. If any of your family member's services were changed, cancelled or reduced during COVID time, did your family member's staff and/or case manager/service coordinator help him/her to adjust to those changes?

State	Yes	Maybe	No	N
AZ	52%	9%	39%	183
DE	43%	15%	42%	105
FL	63%	9%	28%	208
GA	57%	11%	32%	158
LA	52%	12%	36%	115
MD	51%	13%	36%	785
MN	48%	12%	40%	312
MO	43%	12%	45%	162
NJ	51%	11%	37%	203
PA	64%	8%	28%	419
VA	57%	11%	32%	98
Weighted NCI-IDD Average	56%	10%	34%	2,748

Table AFS 5. Did your family member change homes or move because of COVID?

State	Yes, my family member had to move	No	N
AZ	2%	98%	267
DE	2%	98%	142
FL	2%	98%	418
GA	0%	100%	410
LA	0%	100%	209
MD	1%	99%	1,085
MN	2%	98%	444
MO	0%	100%	265
NJ	0%	100%	250
PA	2%	98%	589
VA	0%	100%	140
Weighted NCI-IDD Average	1%	99%	4,219

Table AFS 6. During COVID time, if there was a change to your family’s/family member’s in-home supports, how was that decided?

State	My family member made the decision	Myself or our family made the decision	The provider made the decision and my family agreed	The provider made the decision and my family did not agree	N
AZ	15%	47%	30%	7%	137
DE	16%	24%	48%	12%	25
FL	19%	48%	27%	6%	188
GA	3%	54%	39%	4%	210
LA	18%	57%	20%	6%	107
MD	9%	35%	41%	15%	441
MN	12%	53%	28%	8%	214
MO	9%	49%	29%	14%	101
NJ	6%	49%	35%	11%	123
PA	8%	44%	41%	7%	259
VA	14%	43%	39%	3%	69
Weighted NCI-IDD Average	12%	47%	33%	7%	1,874

Technology

Table AFS 7. Is there a computer, tablet (iPad or similar) or smartphone that you can use in your home?

State	Yes	No	N
AZ	95%	5%	267
DE	92%	8%	141
FL	90%	10%	426
GA	83%	17%	397
LA	95%	5%	210
MD	95%	5%	1,086
MN	95%	5%	444
MO	90%	10%	263
NJ	99%	1%	241
PA	87%	13%	592
VA	87%	13%	142
Weighted NCI-IDD Average	91%	9%	4,209

Table AFS 8. If there is an internet-connected device that you can use in your home, how often can you connect to internet in your home?

State	The internet always works and the connection is good	The internet sometimes works and the connection is sometimes good	The internet rarely or never works, the connection is bad or I do not have internet in my home	N
AZ	84%	15%	2%	250
DE	91%	9%	0%	129
FL	84%	14%	3%	385
GA	64%	30%	5%	345
LA	76%	22%	2%	207
MD	85%	12%	2%	1,056
MN	83%	15%	2%	426
MO	79%	18%	3%	239
NJ	89%	11%	0%	247
PA	86%	12%	2%	510
VA	70%	26%	4%	129
Weighted NCI-IDD Average	82%	16%	2%	3,923

Table AFS 9. Have you ever used videoconference (Skype, Zoom, FaceTime, etc.) to speak to your family member’s case manager/service coordinator?

State	Yes	No	N
AZ	50%	50%	268
DE	48%	52%	143
FL	32%	68%	422
GA	25%	75%	394
LA	55%	45%	213
MD	60%	40%	1,074
MN	61%	39%	441
MO	60%	40%	258
NJ	39%	61%	250
PA	51%	49%	579
VA	66%	34%	145
Weighted NCI-IDD Average	47%	53%	4,187

Table AFS 10. If you’ve ever used video conference (Skype, Zoom, FaceTime, etc.) to speak to your family member’s case manager/service coordinator, how did you feel about using video conference for this communication?

State	I was very happy – I was comfortable and it was easy to use	It was ok – I would use it again, but I was not very comfortable or it was not that easy to use	I was not happy with it – I was not comfortable or it was not easy to use	N
AZ	70%	25%	6%	126
DE	83%	15%	2%	65
FL	70%	23%	7%	128
GA	65%	31%	4%	97
LA	70%	30%	0%	117
MD	72%	26%	3%	634
MN	72%	25%	3%	262
MO	66%	29%	5%	148
NJ	75%	24%	1%	97
PA	72%	26%	3%	285
VA	80%	18%	1%	92
Weighted NCI-IDD Average	72%	25%	3%	2,051

Table AFS 11. Have you ever used video conference (Skype, Zoom, FaceTime, etc.) to speak to health professionals regarding your family member’s care?

State	Yes	No	N
AZ	58%	42%	266
DE	60%	40%	138
FL	50%	50%	409
GA	32%	68%	390
LA	51%	49%	213
MD	62%	38%	1,071
MN	52%	48%	442
MO	51%	49%	260
NJ	62%	38%	246
PA	46%	54%	579
VA	50%	50%	145
Weighted NCI-IDD Average	51%	49%	4,159

Table AFS 12. If you’ve ever used video conference (Skype, Zoom, FaceTime, etc.) or telehealth to speak to health professionals regarding your family member’s care, how did you feel about it?

State	I was very happy – I was comfortable and it was easy to use	It was ok – I would use it again, but I was not very comfortable or it was not that easy to use	I was not happy with it – I was not comfortable or it was not easy to use	N
AZ	70%	25%	5%	148
DE	70%	26%	4%	80
FL	71%	25%	5%	194
GA	55%	41%	3%	119
LA	70%	26%	4%	108
MD	69%	27%	4%	640
MN	65%	29%	6%	225
MO	72%	22%	6%	125
NJ	69%	26%	5%	151
PA	68%	28%	4%	261
VA	76%	19%	4%	68
Weighted NCI-IDD Average	69%	27%	5%	2,119

Table AFS 13. Since COVID time started, has your family member taken part in any of the following services using video conference technology such as Skype, Zoom or FaceTime (or other)?

Categories are not mutually exclusive therefore N is not shown.

State	Job coaching, job skills, other employment- related activity	Social groups organized by day program	Exercise or physical activity	Life skills	Other	Don't know
AZ	11%	20%	19%	13%	25%	27%
DE	15%	28%	19%	6%	36%	22%
FL	5%	14%	13%	6%	39%	34%
GA	4%	57%	17%	10%	10%	25%
LA	4%	12%	12%	4%	16%	50%
MD	22%	49%	29%	22%	20%	18%
MN	19%	27%	20%	17%	29%	30%
MO	11%	28%	13%	6%	26%	36%
NJ	10%	58%	35%	19%	21%	12%
PA	9%	27%	21%	8%	27%	31%
VA	9%	22%	21%	13%	27%	22%
Weighted NCI-IDD Average	10%	30%	20%	12%	27%	28%

Table AFS 14. If your family member has not gotten any of the above services using video conference technology, why not?

Categories are not mutually exclusive therefore N is not shown.

State	This was not offered to my family member	It was at an inconvenient time	My family member did not want to participate	My family member did not have device needed	My family member has no internet access or poor internet access	My family member had trouble using the online platform and did not have support needed to participate	My family member had trouble engaging in online services	Other reason family member could not participate
AZ	38%	3%	24%	7%	4%	4%	11%	24%
DE	53%	3%	21%	5%	3%	10%	7%	10%
FL	49%	2%	18%	6%	6%	10%	16%	21%
GA	53%	2%	17%	16%	12%	4%	3%	15%
LA	52%	4%	20%	4%	4%	7%	13%	13%
MD	35%	6%	25%	11%	6%	13%	22%	19%
MN	39%	5%	28%	6%	2%	8%	12%	28%
MO	43%	1%	20%	14%	12%	11%	16%	20%
NJ	35%	5%	27%	1%	0%	8%	26%	17%
PA	34%	5%	24%	15%	11%	12%	18%	18%
VA	40%	0%	12%	15%	16%	11%	14%	25%
Weighted NCI-IDD Average	42%	3%	21%	10%	8%	9%	15%	20%

Support

Table AFS 15. Since COVID time started, do you feel that you’ve gotten to talk to your family member’s case manager/service coordinator enough?

State	Yes, we’ve talked enough	Sometimes I felt that it was enough, sometimes I would have liked to talk more	No, we haven’t talked enough	N
AZ	86%	5%	9%	265
DE	77%	9%	14%	134
FL	82%	9%	9%	408
GA	68%	22%	10%	389
LA	85%	9%	6%	210
MD	73%	14%	13%	1,036
MN	78%	10%	13%	427
MO	81%	7%	13%	243
NJ	83%	11%	7%	242
PA	84%	7%	9%	562
VA	84%	11%	5%	142
Weighted NCI-IDD Average	81%	10%	9%	4,058

Table AFS 16. Since COVID time started, have you or someone in your family started getting paid by the state DD agency to provide supports to your family member at home?

State	Yes	Sometimes	No	N
AZ	44%	1%	55%	259
DE	2%	0%	98%	132
FL	14%	0%	86%	399
GA	10%	0%	89%	391
LA	33%	1%	67%	200
MD	20%	1%	79%	1,026
MN	49%	0%	51%	417
MO	12%	0%	88%	235
NJ	40%	1%	59%	235
PA	20%	1%	79%	535
VA	33%	1%	66%	126
Weighted NCI-IDD Average	26%	1%	73%	3,955

Table AFS 17. Since COVID time started, do you feel you have always had enough staff present when you and your family member need support?

State	Yes	Sometimes	No	N
AZ	67%	14%	18%	203
DE	50%	19%	31%	58
FL	61%	11%	27%	324
GA	65%	19%	16%	285
LA	59%	16%	25%	169
MD	48%	16%	36%	728
MN	59%	14%	27%	362
MO	55%	14%	32%	154
NJ	48%	17%	36%	168
PA	65%	15%	20%	390
VA	58%	19%	23%	107
Weighted NCI-IDD Average	60%	15%	25%	2,948

Table AFS 18. Since COVID time started, has your family member’s case manager or staff spoken to you about having your family member use remote monitoring or remote support technology?

State	Yes	No	N
AZ	24%	76%	231
DE	15%	85%	123
FL	21%	79%	360
GA	16%	84%	371
LA	16%	84%	182
MD	31%	69%	927
MN	15%	85%	395
MO	18%	82%	221
NJ	29%	71%	217
PA	24%	76%	495
VA	22%	78%	118
Weighted NCI-IDD Average	22%	78%	3,640

Household health and safety

Table AFS 19. Since COVID time started, if staff have continued to support your family member in the home, do you feel that the staff follow recommendations to keep the household safe and healthy?

State	Yes	Sometimes	No	N
AZ	89%	6%	6%	178
DE	74%	7%	19%	57
FL	87%	6%	7%	301
GA	76%	15%	8%	297
LA	86%	10%	4%	168
MD	83%	5%	12%	622
MN	93%	6%	2%	320
MO	88%	6%	7%	138
NJ	85%	8%	7%	151
PA	91%	4%	6%	351
VA	84%	9%	7%	106
Weighted NCI-IDD Average	87%	7%	6%	2,689

Table AFS 20. Do you feel that the people in your household have the personal protective equipment (PPE) that is needed to stay healthy and safe when going out in the community?

State	Yes	Sometimes	No	N
AZ	92%	3%	5%	261
DE	97%	2%	1%	132
FL	92%	3%	5%	415
GA	89%	8%	3%	395
LA	90%	6%	4%	208
MD	94%	3%	4%	1,048
MN	96%	4%	1%	427
MO	95%	2%	2%	247
NJ	95%	3%	2%	239
PA	97%	1%	2%	569
VA	94%	2%	4%	135
Weighted NCI-IDD Average	94%	3%	3%	4,076

Table AFS 21. In preparation for the future, do you feel you need to make or update an emergency plan with your family member's case manager or with other staff?

State	Yes	Maybe	No	N
AZ	25%	13%	63%	248
DE	21%	15%	64%	125
FL	22%	17%	61%	397
GA	18%	9%	74%	388
LA	15%	9%	76%	202
MD	29%	17%	54%	1,003
MN	13%	17%	70%	419
MO	22%	21%	57%	247
NJ	21%	23%	56%	235
PA	19%	17%	64%	543
VA	17%	24%	59%	127
Weighted NCI-IDD Average	20%	16%	63%	3,934

Personal

Table AFS 22. Did you or any wage earner in your household become unemployed or furloughed (temporary suspension of employment) during the COVID-19 pandemic?

State	Yes	No	N
AZ	24%	76%	269
DE	38%	62%	139
FL	28%	72%	413
GA	11%	89%	397
LA	24%	76%	201
MD	29%	71%	1,066
MN	37%	63%	437
MO	26%	74%	249
NJ	34%	66%	241
PA	34%	66%	577
VA	24%	76%	135
Weighted NCI-IDD Average	28%	72%	4,124

Table AFS 23. Was your household income (the income of all wage earners in the home) reduced directly because of the COVID-19 pandemic?

State	Yes	Maybe	No	N
AZ	32%	5%	63%	261
DE	33%	4%	63%	136
FL	29%	4%	67%	408
GA	14%	6%	80%	388
LA	28%	2%	69%	202
MD	29%	4%	68%	1,054
MN	33%	5%	62%	439
MO	26%	3%	71%	252
NJ	40%	3%	57%	244
PA	30%	2%	68%	562
VA	26%	1%	73%	137
Weighted NCI-IDD Average	29%	3%	67%	4,083

Table AFS 24. Since the start of COVID time, has it become harder to make sure your family has enough food to eat?

State	Yes	Sometimes	No	N
AZ	7%	11%	82%	262
DE	12%	4%	84%	141
FL	11%	13%	76%	419
GA	5%	17%	78%	396
LA	6%	11%	83%	209
MD	6%	9%	85%	1,065
MN	3%	9%	88%	441
MO	6%	8%	87%	254
NJ	3%	7%	89%	241
PA	5%	8%	87%	581
VA	6%	11%	84%	141
Weighted NCI-IDD Average	6%	10%	83%	4,150

Table AFS 25. As a result of service changes due to COVID-19, does your family member need more help with the following?

Categories are not mutually exclusive therefore N is not shown.

State	Food or nutrition support	Medication administration support	Social support	Positive Behavior Support	Accessing telehealth healthcare and/or telehealth mental health services	Having someone to talk to if they feel lonely, stressed, anxious	Activities of daily living and/or instrumental activities of daily living	Respite services	Financial support	Other
AZ	20%	6%	46%	23%	10%	28%	19%	52%	13%	7%
DE	20%	7%	46%	24%	15%	36%	18%	39%	23%	9%
FL	23%	7%	37%	23%	11%	25%	27%	34%	17%	24%
GA	23%	6%	44%	24%	5%	20%	33%	31%	29%	14%
LA	21%	8%	36%	22%	11%	20%	24%	33%	22%	14%
MD	16%	6%	52%	25%	11%	30%	30%	39%	16%	16%
MN	16%	5%	49%	20%	10%	30%	29%	37%	11%	25%
MO	9%	7%	54%	28%	13%	29%	24%	38%	8%	11%
NJ	10%	3%	54%	31%	6%	23%	37%	42%	14%	15%
PA	12%	5%	53%	25%	8%	26%	24%	29%	8%	11%
VA	13%	5%	44%	31%	10%	25%	25%	32%	16%	19%
Weighted NCI-IDD Average	17%	6%	46%	25%	9%	26%	27%	37%	15%	16%

Family/Guardian Survey

The Family/Guardian Survey is used to gather information on the experiences of family and guardians of adults with IDD. It is mailed to families who have an adult family member who does not live with the respondent and receives at least one service in addition to case management from the state DD agency.

The following states chose to use the 2020-21 FGS COVID-19 Supplement: AZ, DE, GA, IN, KY, MD, NJ, PA.

For the purpose of this survey, we defined “COVID time” as beginning March 2020.

Important Notes on FGS Data

Indiana (IN)

FGS COVID Supplement data from IN only come from respondents who completed the survey directly online. (The COVID Supplement was omitted from mailed copies of the survey.) Consequently, the data do not represent the complete sample of respondents represented in demographics and other outcomes to be reported in the National and State FGS reports.

Kentucky (KY)

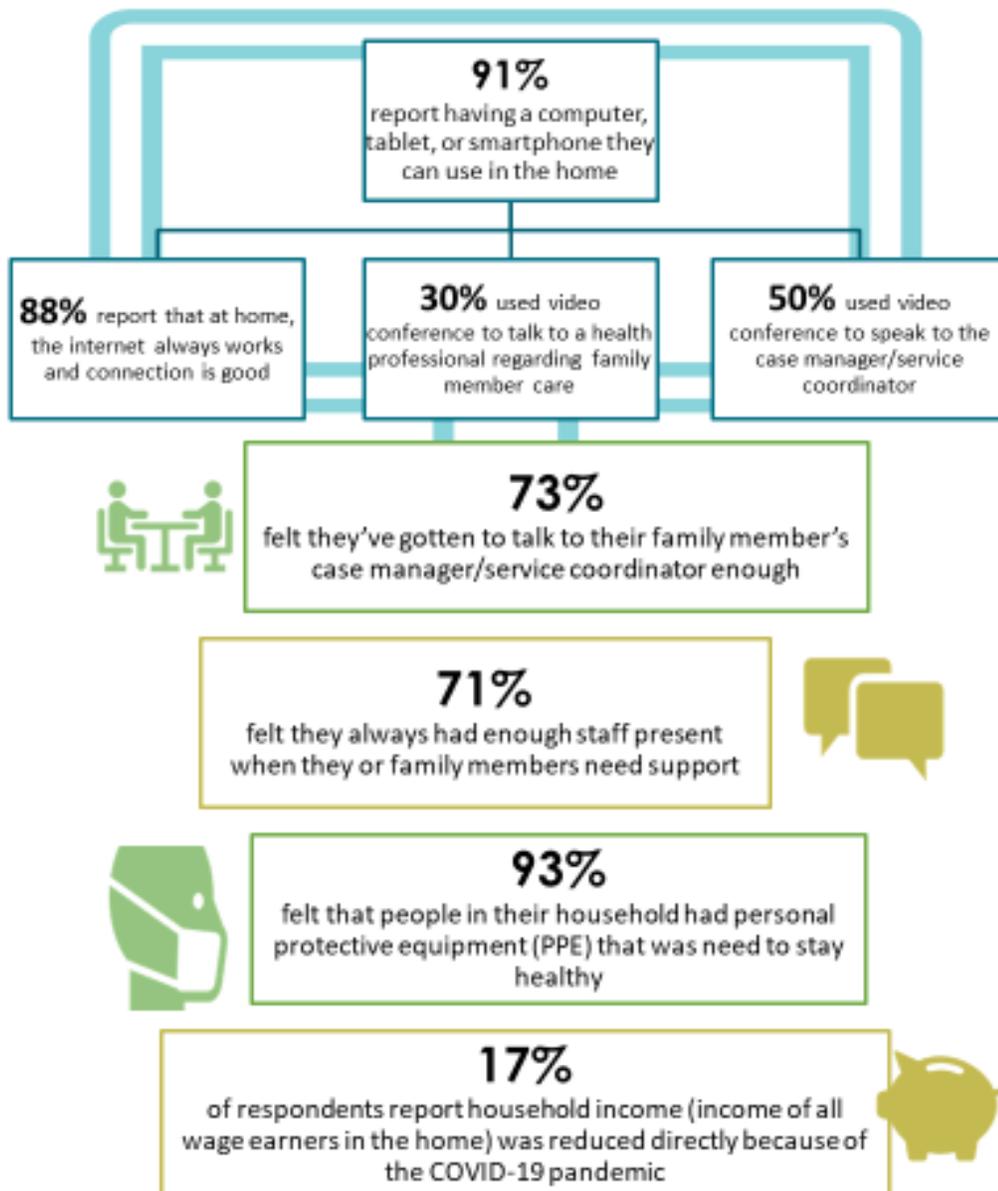
The FGS COVID Supplement from KY was sent separately from the standard survey; therefore, the data for the COVID Supplement represent a different sample of respondents and are not connected to the demographics or other FGS outcomes to be reported in the National and State FGS reports.

During the COVID pandemic in 2020, respondents ...


80%
 report that their family members had changes, cancellations, or reductions in service during COVID Time


79%
 received enough information about changes, cancellations, or reductions in services


70%
 report that their family members' staff or case manager/ service coordinator helped to adjust to those changes



Family/ Guardian Survey (FGS) COVID Supplement

*FGS COVID supplement participating states were: AZ, DE, GA, IN, KY, MD, NJ, PA

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.

Changes to Services

Table FGS 1. Did your family member have any changes, cancellations or reductions in services during COVID time?

State	Yes	No	N
AZ	83%	17%	244
DE	86%	14%	129
GA	61%	39%	296
IN	76%	24%	178
KY	77%	23%	130
MD	81%	19%	576
NJ	89%	11%	190
PA	82%	18%	453
Weighted NCI-IDD Average	80%	20%	2,196

Table FGS 2. If there were changes, cancellations or reductions in services during COVID time, how did the changes, cancellations or reductions in services affect your family?

State	The changes were mostly not good for my family	The changes were mostly good for my family	The changes were somewhat good, somewhat not good	The changes did not affect my family	N
AZ	38%	10%	39%	12%	195
DE	41%	15%	33%	12%	103
GA	51%	10%	33%	6%	169
IN	39%	13%	37%	11%	131
KY	51%	10%	28%	10%	96
MD	45%	15%	31%	10%	434
NJ	53%	8%	28%	11%	161
PA	45%	14%	27%	14%	336
Weighted NCI-IDD Average	45%	13%	31%	12%	1,625

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Table FGS 3. If any of your family member’s services were changed, cancelled or reduced during COVID time, did you get enough information about changes, cancellations or reductions in services?

State	Yes	No	N
AZ	81%	19%	189
DE	84%	16%	104
GA	82%	18%	169
IN	75%	25%	127
KY	83%	17%	93
MD	73%	27%	428
NJ	75%	25%	160
PA	83%	17%	344
Weighted NCI-IDD Average	79%	21%	1,614

Table FGS 4. If any of your family member’s services were changed, cancelled or reduced during COVID time, did your family member’s staff and/or case manager/service coordinator help him/her to adjust to those changes?

State	Yes	Maybe	No	N
AZ	72%	14%	13%	181
DE	71%	14%	16%	96
GA	78%	10%	13%	160
IN	71%	14%	14%	125
KY	73%	12%	16%	95
MD	63%	17%	20%	391
NJ	60%	22%	18%	154
PA	74%	17%	9%	325
Weighted NCI-IDD Average	70%	16%	14%	1,527

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Table FGS 5. If your family member lived in a provider-run setting during COVID time, do you feel you got enough information from the provider about how your family member was doing?

State	Yes	No	N
AZ	83%	17%	246
DE	81%	19%	130
GA	78%	22%	309
IN	77%	23%	123
KY	86%	14%	111
MD	75%	25%	467
NJ	75%	25%	160
PA	83%	17%	475
Weighted NCI-IDD Average	80%	20%	2,021

Table FGS 6. Did your family member change homes or move because of COVID?

State	Yes, my family member had to move	No	N
AZ	7%	93%	251
DE	5%	95%	137
GA	7%	93%	334
IN	2%	98%	184
KY	6%	94%	134
MD	7%	93%	612
NJ	9%	91%	193
PA	5%	95%	505
Weighted NCI-IDD Average	6%	94%	2,350

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Table FGS 7. Did your family member move into your home during COVID time?

State	Yes	No	N
AZ	6%	94%	255
DE	5%	95%	144
GA	7%	93%	340
IN	10%	90%	185
KY	11%	89%	136
MD	9%	91%	622
NJ	8%	92%	193
PA	6%	94%	510
Weighted NCI-IDD Average	7%	93%	2,385

Table FGS 8. If your family member is not living with you: Since the start of COVID time, do you feel you have gotten to talk to your family member enough?

State	Yes	No	N
AZ	82%	18%	220
DE	79%	21%	121
GA	86%	14%	308
IN	93%	7%	160
KY	85%	15%	119
MD	85%	15%	530
NJ	81%	19%	171
PA	81%	19%	449
Weighted NCI-IDD Average	83%	17%	2,078

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Table FGS 9. During COVID time, if there was a change to your family’s/family member’s in-home supports, how was that decided?

State	My family member made the decision	Myself or our family made the decision	The provider made the decision and my family agreed	The provider made the decision and my family did not agree	N
AZ	4%	13%	65%	18%	72
DE	7%	6%	76%	11%	54
GA	1%	20%	71%	8%	190
IN	10%	18%	57%	15%	111
KY	5%	25%	59%	11%	63
MD	7%	13%	62%	18%	237
NJ	3%	20%	59%	18%	101
PA	2%	8%	75%	15%	171
Weighted NCI-IDD Average	4%	13%	67%	15%	999

Technology

Table FGS 10. Is there a computer, tablet (iPad or similar) or smartphone that you can use in your home?

State	Yes	No	N
AZ	91%	9%	241
DE	90%	10%	141
GA	79%	21%	336
IN	97%	3%	177
KY	93%	7%	132
MD	93%	7%	611
NJ	99%	1%	185
PA	89%	11%	497
Weighted NCI-IDD Average	91%	9%	2,320

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Table FGS 11. If there is an internet connected device that you can use in your home, how often can you connect to internet in your home?

State	The internet always works and the connection is good	The internet sometimes works and the connection is sometimes good	The internet rarely or never works, the connection is bad or I do not have internet in my home	N
AZ	88%	10%	2%	219
DE	91%	8%	2%	116
GA	85%	13%	2%	274
IN	87%	12%	1%	170
KY	88%	12%	0%	118
MD	87%	11%	2%	580
NJ	93%	6%	1%	188
PA	89%	9%	2%	432
Weighted NCI-IDD Average	88%	10%	2%	2,097

Table FGS 12. Have you ever used video conference (Skype, Zoom, FaceTime, etc.) to speak to your family member’s case manager/service coordinator?

State	Yes	No	N
AZ	50%	50%	255
DE	48%	52%	143
GA	32%	68%	338
IN	70%	30%	180
KY	65%	35%	133
MD	58%	42%	626
NJ	51%	49%	192
PA	46%	54%	494
Weighted NCI-IDD Average	50%	50%	2,361

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Table FGS 13. If you've ever used video conference (Skype, Zoom, FaceTime, etc.) to speak to your family member's case manager/service coordinator, how did you feel about using video conference for this communication?

State	I was very happy – I was comfortable talking to the case manager on video conference and it was easy to use	It was ok – I would use it again, but I was not very comfortable talking to the case manager on video conference	I was not happy with it – I was not comfortable talking with the case manager or it was not easy to use	N
AZ	54%	38%	7%	125
DE	68%	32%	0%	62
GA	67%	27%	6%	103
IN	63%	33%	4%	123
KY	69%	24%	7%	85
MD	65%	29%	6%	333
NJ	70%	24%	5%	94
PA	67%	29%	4%	224
Weighted NCI-IDD Average	65%	30%	5%	1,149

Table FGS 14. Have you ever used video conference (For example, Skype, Zoom, FaceTime, etc.) to speak to health professionals regarding your family member's care?

State	Yes	No	N
AZ	31%	69%	249
DE	30%	70%	139
GA	34%	66%	333
IN	31%	69%	179
KY	34%	66%	134
MD	39%	61%	609
NJ	40%	60%	190
PA	21%	79%	501
Weighted NCI-IDD Average	30%	70%	2,334

Table FGS 15. If you’ve ever used video conference (Skype, Zoom, FaceTime, etc.) or telehealth to speak to health professionals regarding your family member’s care, how did you feel about it?

State	I was very happy – I was comfortable talking to health professionals on video conference and it was easy to use	It was ok – I would use it again, but I was not very comfortable talking to the case manager on video conference	I was not happy with it – I was not comfortable talking with the case manager or it was not easy to use	N
AZ	61%	31%	8%	75
DE	55%	39%	5%	38
GA	68%	25%	6%	110
IN	66%	25%	9%	56
KY	58%	31%	11%	45
MD	65%	31%	4%	226
NJ	64%	32%	4%	75
PA	71%	25%	4%	101
Weighted NCI-IDD Average	66%	29%	5%	726

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Table FGS 16. Since COVID time started, has your family member taken part in any of the following services using video conference technology such as Skype, Zoom or FaceTime (or other)?

Categories are not mutually exclusive therefore N is not shown.

State	Job coaching, job skills, other employment related activity	Social groups organized by day program	Exercise or physical activity	Life skills	Other	Don't know
AZ	2%	7%	5%	4%	16%	67%
DE	3%	6%	5%	3%	16%	69%
GA	9%	25%	13%	11%	11%	59%
IN	7%	14%	13%	6%	19%	55%
KY	9%	23%	10%	12%	20%	49%
MD	11%	26%	21%	13%	19%	45%
NJ	7%	36%	19%	10%	14%	39%
PA	3%	12%	10%	5%	13%	70%
Weighted NCI-IDD Average	6%	18%	13%	8%	16%	60%

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Table FGS 17. If your family member has not gotten any of the above services using video conference technology, why not?

Categories are not mutually exclusive therefore N is not shown.

State	This was not offered to my family member	It was at an inconvenient time	My family member did not want to participate	My family member did not have device needed	My family member has no internet access or poor internet access	My family member had trouble using the online platform and did not have support needed to participate	My family member had trouble engaging in online services	Other reason family member could not participate
AZ	34%	2%	14%	19%	10%	9%	20%	27%
DE	33%	1%	14%	16%	4%	7%	20%	36%
GA	38%	2%	13%	16%	6%	4%	9%	22%
IN	39%	2%	17%	14%	7%	6%	16%	20%
KY	42%	0%	18%	7%	9%	7%	24%	22%
MD	36%	5%	18%	16%	8%	10%	20%	29%
NJ	23%	0%	27%	9%	5%	11%	28%	30%
PA	29%	2%	18%	14%	6%	10%	23%	34%
Weighted NCI-IDD Average	32%	2%	17%	15%	7%	9%	21%	30%

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Support

Table FGS 18. Since COVID time started, do you feel that you’ve gotten to talk to your family member’s case manager/service coordinator enough?

State	Yes, we’ve talked enough	Sometimes I felt that it was enough, sometimes I would have liked to talk more	No, we haven’t talked enough	N
AZ	82%	7%	11%	247
DE	71%	14%	15%	135
GA	76%	13%	11%	331
IN	84%	9%	7%	173
KY	88%	8%	5%	133
MD	66%	12%	21%	591
NJ	72%	12%	16%	188
PA	72%	14%	14%	482
Weighted NCI-IDD Average	73%	12%	15%	2,280

Table FGS 19. Since COVID time started, have you or someone in your family started getting paid by the state DD agency to provide supports to your family member?

State	Yes	Sometimes	No	N
AZ	2%	0%	98%	236
DE	1%	0%	99%	126
GA	3%	0%	98%	320
IN	8%	1%	91%	171
KY	6%	0%	94%	121
MD	5%	1%	94%	573
NJ	3%	1%	96%	180
PA	3%	0%	97%	471
Weighted NCI-IDD Average	4%	0%	96%	2,198

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Table FGS 20. Since COVID time started, do you feel you have always had enough staff present when you and your family member need support?

State	Yes	Sometimes	No	N
AZ	79%	12%	9%	210
DE	74%	15%	11%	108
GA	71%	12%	17%	247
IN	52%	23%	25%	160
KY	71%	14%	15%	121
MD	65%	16%	20%	468
NJ	53%	21%	26%	145
PA	79%	10%	11%	376
Weighted NCI-IDD Average	71%	13%	16%	1,835

Table FGS 21. Since COVID time started, has your family member’s case manager or staff spoken to you about having your family member use remote monitoring or remote support technology?

State	Yes	No	N
AZ	20%	80%	219
DE	23%	77%	116
GA	29%	71%	323
IN	26%	74%	155
KY	27%	73%	106
MD	20%	80%	513
NJ	24%	76%	169
PA	17%	83%	419
Weighted NCI-IDD Average	21%	79%	2,020

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Household health and safety

Table FGS 22. Do you feel that the people in your household have the personal protective equipment (PPE) that is needed to stay healthy and safe when going out in the community?

State	Yes	Sometimes	No	N
AZ	93%	4%	4%	228
DE	97%	0%	3%	121
GA	76%	13%	11%	326
IN	95%	2%	2%	172
KY	97%	2%	2%	125
MD	95%	3%	3%	551
NJ	91%	5%	4%	176
PA	95%	2%	3%	443
Weighted NCI-IDD Average	93%	3%	4%	2,142

Table FGS 23. In preparation for the future, do you feel you need to make or update an emergency plan with your family member’s case manager or with other staff?

State	Yes	Sometimes	No	N
AZ	27%	18%	55%	233
DE	31%	23%	46%	121
GA	15%	11%	74%	306
IN	24%	16%	60%	172
KY	19%	15%	66%	122
MD	29%	22%	50%	555
NJ	22%	22%	56%	182
PA	21%	21%	58%	439
Weighted NCI-IDD Average	23%	19%	57%	2,130

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Personal

Table FGS 24. Did you or any wage earner in your household become unemployed or furloughed (temporary suspension of employment) during the COVID-19 pandemic?

State	Yes	No	N
AZ	16%	84%	247
DE	11%	89%	136
GA	12%	88%	328
IN	21%	79%	176
KY	18%	82%	131
MD	12%	88%	592
NJ	20%	80%	184
PA	18%	82%	484
Weighted NCI-IDD Average	16%	84%	2,278

Table FGS 25. Was your household income (the income of all wage earners in the home) reduced directly because of the COVID-19 pandemic?

State	Yes	Maybe	No	N
AZ	19%	2%	79%	243
DE	19%	3%	78%	138
GA	13%	8%	79%	326
IN	20%	2%	78%	170
KY	14%	0%	86%	131
MD	16%	2%	82%	582
NJ	21%	1%	79%	178
PA	17%	2%	80%	481
Weighted NCI-IDD Average	17%	3%	80%	2,249

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Table FGS 26. Since the start of COVID time, has it become harder to make sure your family has enough food to eat?

State	Yes	Sometimes	No	N
AZ	4%	13%	83%	250
DE	5%	7%	88%	136
GA	4%	15%	81%	326
IN	2%	6%	93%	178
KY	3%	4%	93%	132
MD	4%	5%	91%	588
NJ	2%	4%	94%	186
PA	2%	5%	93%	490
Weighted NCI-IDD Average	3%	7%	91%	2,286

Table FGS 27. As a result of service changes due to COVID-19, does your family member need more help with the following?

Categories are not mutually exclusive therefore N is not shown.

State	Food or nutrition support	Medication administration support	Social support	Positive Behavior Support	Accessing telehealth healthcare and/or telehealth mental health services	Having someone to talk to if they feel lonely, stressed, anxious	Activities of daily living and/or instrumental activities of daily living	Respite services	Financial support	Other
AZ	11%	8%	55%	36%	16%	33%	27%	6%	5%	16%
DE	17%	8%	56%	32%	13%	27%	27%	5%	8%	22%
GA	35%	8%	66%	31%	4%	49%	27%	10%	29%	15%
IN	24%	14%	60%	36%	18%	44%	28%	7%	9%	9%
KY	28%	8%	54%	45%	9%	22%	37%	11%	5%	17%
MD	23%	13%	60%	32%	13%	39%	35%	7%	7%	17%
NJ	19%	6%	56%	42%	11%	35%	45%	11%	7%	11%
PA	15%	10%	60%	36%	8%	31%	25%	4%	3%	17%
Weighted NCI-IDD Average	20%	10%	59%	35%	11%	35%	30%	6%	7%	16%

“Family” refers to the person completing the survey
 “Family member” references the person with IDD

Child Family Survey

The Child Family Survey is used to gather information on the experiences of family of children with IDD. It is mailed to families who have a child¹ with IDD who *lives with the respondent* and receives at least one service in addition to case management from the state DD agency.

The following states chose to use the 2020-21 CFS COVID-19 Supplement: AZ, CO, MN, MO, NC, OR, SD, TX, VA, WI.

For the purpose of this survey, we defined “COVID time” as beginning March 2020.

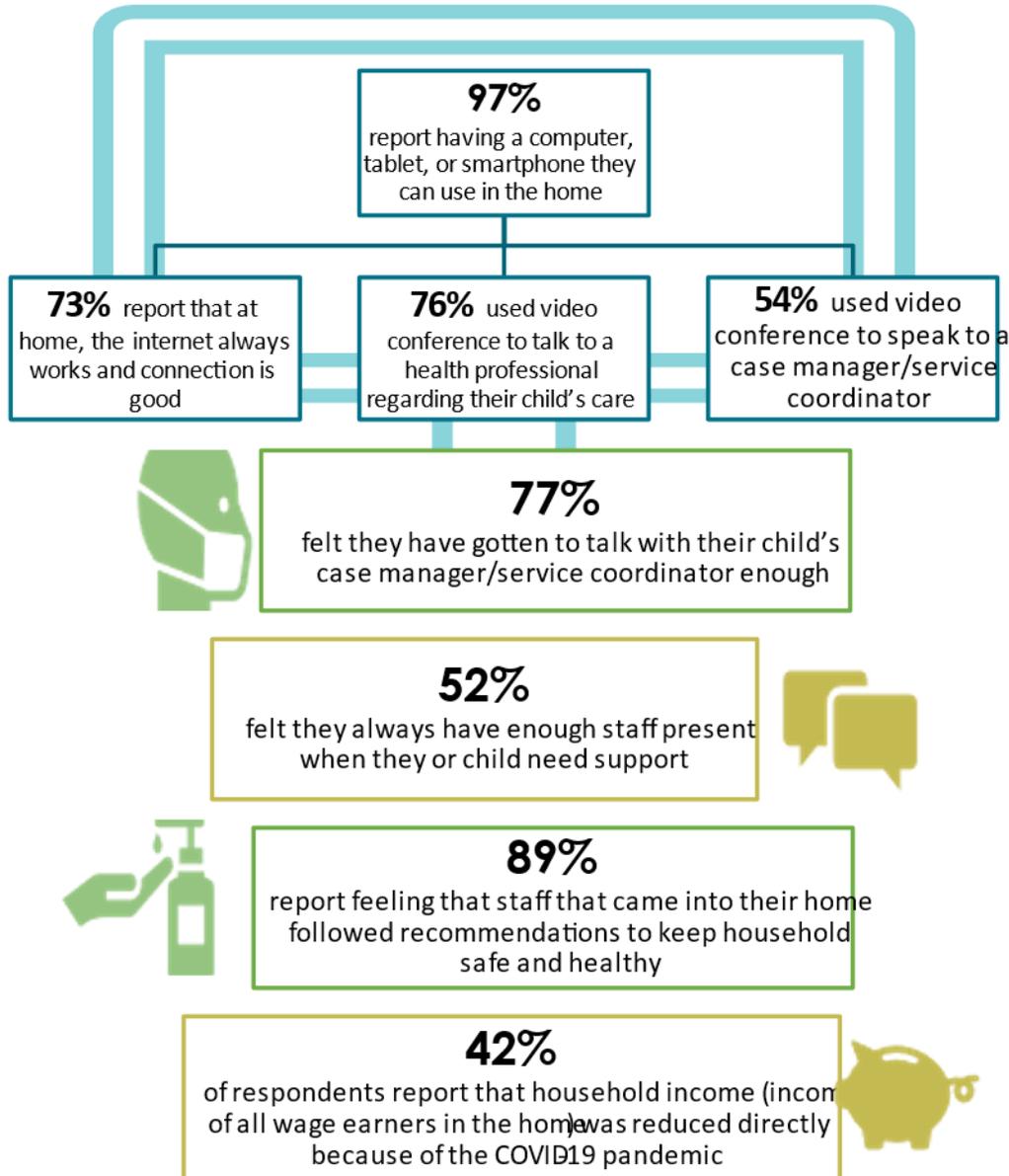
¹ Some states include people with IDD up to age 21 who receive “child” services

During the COVID pandemic in 2020, respondents ...


74%
 report that their child had changes, cancellations, or reductions in service during COVID Time


79%
 received enough information about changes, cancellations, or reductions in services


56%
 report that their child's staff or case manager /service coordinator helped to adjust to those changes



Child Family Survey (CFS) COVID Supplement

* CFS COVID supplement participating states were: AZ, CO, MN, MO, NC, OR, SD, TX, VA, WI

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.

Changes to Services

Table CFS 1. Did your child have any changes, cancellations or reductions in services during COVID time?

State	Yes	No	N
AZ	83%	17%	178
CO	86%	14%	97
MN	74%	26%	383
MO	78%	22%	161
NC	76%	24%	169
OR	63%	37%	615
SD	72%	28%	208
TX	64%	36%	1,531
VA	80%	20%	150
WI	77%	23%	769
Weighted NCI-IDD Average	74%	26%	4,261

Table CFS 2. If there were changes, cancellations or reductions in services during COVID time, how did the changes, cancellations or reductions in services affect your family?

State	The changes were mostly not good for my family	The changes were mostly good for my family	The changes were somewhat good, somewhat not good	The changes did not affect my family	N
AZ	42%	9%	42%	8%	142
CO	63%	5%	30%	1%	82
MN	56%	5%	33%	5%	277
MO	44%	10%	35%	10%	124
NC	43%	17%	35%	5%	127
OR	43%	10%	44%	2%	378
SD	41%	8%	43%	8%	143
TX	46%	6%	36%	12%	961
VA	50%	6%	41%	3%	117
WI	42%	7%	41%	9%	575
Weighted NCI-IDD Average	44%	10%	38%	8%	2,926

Table CFS 3. If any of your child’s services were changed, cancelled or reduced during COVID time, did you get enough information about changes, cancellations or reductions in services?

State	Yes	No	N
AZ	80%	20%	132
CO	85%	15%	78
MN	69%	31%	251
MO	76%	24%	120
NC	81%	19%	116
OR	79%	21%	355
SD	82%	18%	131
TX	77%	23%	939
VA	64%	36%	116
WI	82%	18%	535
Weighted NCI-IDD Average	79%	21%	2,773

Table CFS 4. If any of your child’s services were changed, cancelled or reduced during COVID time, did your child’s staff and/or case manager/service coordinator help him/her to adjust to those changes?

State	Yes	Maybe	No	N
AZ	62%	5%	33%	129
CO	54%	13%	34%	80
MN	41%	11%	49%	246
MO	46%	15%	39%	112
NC	55%	9%	35%	116
OR	50%	12%	38%	340
SD	50%	15%	35%	128
TX	56%	6%	38%	932
VA	44%	13%	43%	117
WI	58%	10%	32%	537
Weighted NCI-IDD Average	56%	8%	36%	2,737

“Family” refers to the person completing the survey
 “Child” references the person with IDD

Table CFS 5. Did your child change homes or move because of COVID?

State	Yes, my child had to move	No	N
AZ	3%	97%	181
CO	2%	98%	97
MN	1%	99%	376
MO	3%	97%	168
NC	4%	96%	174
OR	3%	97%	629
SD	3%	97%	214
TX	7%	93%	1,529
VA	1%	99%	153
WI	3%	97%	775
Weighted NCI-IDD Average	4%	96%	4,296

Table CFS 6. During COVID time, if there was a change to your family’s/ child’s in-home supports, how was that decided?

State	Myself or our family made the decision	The provider made the decision and my family agreed	The provider made the decision and my family did not agree	N
AZ	48%	41%	11%	120
CO	41%	45%	14%	80
MN	59%	26%	14%	197
MO	47%	37%	16%	73
NC	65%	27%	8%	113
OR	56%	31%	13%	293
SD	49%	35%	16%	51
TX	54%	34%	12%	833
VA	61%	20%	18%	103
WI	42%	45%	13%	415
Weighted NCI-IDD Average	53%	35%	11%	2,278

“Family” refers to the person completing the survey
 “Child” references the person with IDD

Technology

Table CFS 7. Is there a computer, tablet (iPad or similar) or smartphone that you can use in your home?

State	Yes	No	N
AZ	97%	3%	183
CO	100%	0%	95
MN	99%	1%	386
MO	99%	1%	169
NC	96%	4%	173
OR	98%	2%	630
SD	98%	2%	215
TX	95%	5%	1,533
VA	97%	3%	153
WI	98%	2%	777
Weighted NCI-IDD Average	97%	3%	4,314

Table CFS 8. If there is an internet connected device that you can use in your home, how often can you connect to internet in your home?

State	The internet always works and the connection is good	The internet sometimes works and the connection is sometimes good	The internet rarely or never works, the connection is bad or I do not have internet in my home	N
AZ	73%	23%	4%	180
CO	89%	11%	0%	96
MN	75%	24%	2%	388
MO	72%	23%	4%	166
NC	74%	25%	1%	173
OR	74%	24%	2%	624
SD	89%	11%	0%	209
TX	70%	26%	4%	1,484
VA	69%	27%	4%	153
WI	75%	23%	2%	774
Weighted NCI-IDD Average	73%	24%	3%	4,247

Table CFS 9. Have you ever used video conference (Skype, Zoom, FaceTime, etc.) to speak to your child’s case manager/service coordinator?

State	Yes	No	N
AZ	58%	42%	179
CO	80%	20%	96
MN	54%	46%	382
MO	58%	42%	166
NC	50%	50%	173
OR	66%	34%	621
SD	41%	59%	212
TX	44%	56%	1,521
VA	68%	32%	152
WI	63%	37%	772
Weighted NCI-IDD Average	54%	46%	4,274

Table CFS 10. If you’ve ever used video conference (Skype, Zoom, FaceTime, etc.) to speak to your child’s case manager/service coordinator, how did you feel about using video conference for this communication?

State	I was very happy – I was comfortable talking to the case manager on video conference and it was easy to use	It was ok – I would use it again, but I was not very comfortable talking to the case manager on video conference	I was not happy with it – I was not comfortable talking with the case manager or it was not easy to use	N
AZ	75%	24%	2%	102
CO	90%	9%	1%	77
MN	69%	26%	4%	204
MO	74%	22%	3%	94
NC	76%	19%	5%	84
OR	71%	26%	4%	398
SD	87%	13%	0%	78
TX	64%	30%	5%	666
VA	71%	24%	5%	101
WI	72%	24%	4%	480
Weighted NCI-IDD Average	72%	24%	4%	2,284

“Family” refers to the person completing the survey
 “Child” references the person with IDD

Table CFS 11. Have you ever used video conference (Skype, Zoom, FaceTime, etc.) to speak to health professionals regarding your child’s care?

State	Yes	No	N
AZ	81%	19%	180
CO	89%	11%	96
MN	75%	25%	390
MO	67%	33%	169
NC	78%	22%	172
OR	75%	25%	620
SD	57%	43%	211
TX	75%	25%	1,532
VA	78%	22%	154
WI	71%	29%	782
Weighted NCI-IDD Average	76%	24%	4,306

Table CFS 12. If you’ve ever used video conference (Skype, Zoom, FaceTime, etc.) or telehealth to speak to health professionals regarding your child’s care, how did you feel about it?

State	I was very happy – I was comfortable talking to the case manager on video conference and it was easy to use	It was ok – I would use it again, but I was not very comfortable talking to the case manager on video conference	I was not happy with it – I was not comfortable talking with the case manager or it was not easy to use	N
AZ	62%	32%	6%	141
CO	74%	23%	4%	84
MN	68%	29%	4%	284
MO	67%	29%	4%	109
NC	76%	19%	4%	135
OR	67%	27%	6%	442
SD	63%	30%	7%	117
TX	59%	34%	7%	1,134
VA	77%	19%	4%	118
WI	69%	26%	5%	553
Weighted NCI-IDD Average	67%	28%	5%	3,117

“Family” refers to the person completing the survey
 “Child” references the person with IDD

Table CFS 13. Since COVID time started, has your child taken part in any of the following services using video conference technology such as Skype, Zoom or FaceTime (or other)?

Categories are not mutually exclusive therefore N is not shown.

State	Job coaching, job skills, other employment related activity	Social groups organized by day program	Exercise or physical activity	Life skills	Other	Don't know
AZ	2%	7%	21%	9%	55%	18%
CO	0%	20%	41%	7%	43%	20%
MN	8%	15%	23%	13%	44%	24%
MO	5%	24%	13%	9%	44%	27%
NC	4%	16%	18%	9%	57%	18%
OR	4%	13%	24%	10%	51%	24%
SD	3%	9%	20%	4%	45%	33%
TX	8%	15%	40%	19%	64%	8%
VA	2%	6%	18%	7%	65%	16%
WI	4%	16%	19%	7%	35%	33%
Weighted NCI-IDD Average	5%	13%	25%	11%	53%	19%

“Family” refers to the person completing the survey
 “Child” references the person with IDD

Table CFS 14. If your child has not gotten any of the above services using video conference technology, why not?

Categories are not mutually exclusive therefore N is not shown.

State	This was not offered to my child	It was at an inconvenient time	My child did not want to participate	My child did not have device needed	My child has no internet access or poor internet access	My child had trouble using the online platform and did not have support needed to participate	My child had trouble engaging in online services	Other reason child could not participate
AZ	57%	9%	12%	2%	2%	8%	28%	22%
CO	55%	0%	16%	0%	0%	12%	37%	10%
MN	66%	3%	13%	1%	1%	9%	27%	12%
MO	55%	8%	29%	5%	5%	11%	23%	11%
NC	59%	6%	21%	6%	3%	11%	28%	14%
OR	62%	4%	18%	2%	1%	10%	22%	12%
SD	60%	2%	7%	3%	1%	5%	20%	17%
TX	51%	9%	21%	11%	9%	19%	31%	28%
VA	55%	5%	20%	6%	6%	14%	31%	20%
WI	52%	3%	15%	2%	3%	8%	29%	15%
Weighted NCI-IDD Average	56%	6%	18%	5%	4%	11%	28%	18%

“Family” refers to the person completing the survey
 “Child” references the person with IDD

Support

Table CFS 15. Since COVID time started, do you feel that you’ve gotten to talk to your child’s case manager/service coordinator enough?

State	Yes, we’ve talked enough	Sometimes I felt that it was enough, sometimes I would have liked to talk more	No, we haven’t talked enough	N
AZ	81%	8%	10%	178
CO	77%	9%	14%	95
MN	65%	21%	14%	379
MO	77%	7%	16%	158
NC	76%	10%	14%	159
OR	76%	16%	8%	610
SD	82%	9%	9%	204
TX	76%	11%	12%	1,517
VA	74%	18%	7%	152
WI	78%	14%	7%	768
Weighted NCI-IDD Average	77%	12%	11%	4,220

Table CFS 16. Since COVID time started, if staff have continued to support your child in the home, do you feel that the staff follow recommendations to keep the household safe and healthy?

State	Yes	Sometimes	No	N
AZ	91%	5%	4%	141
CO	95%	3%	3%	79
MN	90%	6%	5%	302
MO	86%	3%	11%	107
NC	80%	14%	6%	138
OR	90%	7%	3%	519
SD	86%	6%	7%	96
TX	91%	4%	4%	1,453
VA	86%	9%	6%	125
WI	91%	5%	3%	566
Weighted NCI-IDD Average	89%	7%	4%	3,526

“Family” refers to the person completing the survey
 “Child” references the person with IDD

Table CFS 17. Since COVID time started, have you or someone in your family started getting paid by the state DD agency to provide supports to your child at home?

State	Yes	Sometimes	No	N
AZ	26%	1%	73%	173
CO	44%	2%	54%	95
MN	58%	1%	42%	360
MO	5%	0%	95%	157
NC	33%	1%	66%	168
OR	28%	1%	71%	609
SD	6%	0%	95%	200
TX	11%	1%	88%	1,493
VA	38%	1%	61%	138
WI	14%	1%	85%	741
Weighted NCI-IDD Average	23%	1%	76%	4,134

Table CFS 18. Since COVID time started, do you feel you have always had enough staff present when you and your child need support?

State	Yes	Sometimes	No	N
AZ	57%	25%	18%	159
CO	37%	27%	36%	86
MN	41%	24%	35%	332
MO	36%	25%	39%	109
NC	45%	15%	40%	159
OR	45%	23%	32%	581
SD	52%	22%	25%	107
TX	63%	13%	23%	1,460
VA	43%	21%	36%	141
WI	47%	22%	31%	617
Weighted NCI-IDD Average	52%	20%	29%	3,751

“Family” refers to the person completing the survey
 “Child” references the person with IDD

Table CFS 19. Since COVID time started, has your child’s case manager or staff spoken to you about having your child use remote monitoring or remote support technology?

State	Yes	No	N
AZ	21%	79%	155
CO	31%	69%	87
MN	16%	84%	348
MO	22%	78%	146
NC	20%	80%	158
OR	17%	83%	556
SD	18%	82%	186
TX	31%	69%	1,470
VA	27%	73%	139
WI	25%	75%	667
Weighted NCI-IDD Average	23%	77%	3,912

Household health and safety

Table CFS 20. Do you feel that the people in your household have the personal protective equipment (PPE) that is needed to stay healthy and safe when going out in the community?

State	Yes	Sometimes	No	N
AZ	88%	6%	6%	173
CO	93%	2%	4%	92
MN	88%	9%	3%	379
MO	94%	3%	3%	162
NC	84%	7%	9%	170
OR	90%	6%	4%	603
SD	90%	5%	5%	209
TX	87%	6%	6%	1,507
VA	78%	12%	10%	149
WI	92%	4%	3%	758
Weighted NCI-IDD Average	88%	6%	6%	4,202

Table CFS 21. In preparation for the future, do you feel you need to make or update an emergency plan with your family member’s case manager or with other staff?

State	Yes	Sometimes	No	N
AZ	17%	23%	60%	170
CO	26%	13%	61%	95
MN	24%	20%	55%	357
MO	18%	22%	60%	158
NC	32%	16%	52%	159
OR	21%	21%	59%	581
SD	18%	13%	69%	193
TX	30%	10%	59%	1,491
VA	33%	21%	46%	145
WI	27%	19%	54%	712
Weighted NCI-IDD Average	25%	17%	57%	4,061

Personal

Table CFS 22. Did you or any wage earner in your household become unemployed or furloughed (temporary suspension of employment) during the COVID-19 pandemic?

State	Yes	No	N
AZ	36%	64%	177
CO	30%	70%	93
MN	35%	65%	377
MO	34%	66%	164
NC	31%	69%	172
OR	38%	62%	614
SD	24%	76%	210
TX	38%	62%	1,511
VA	35%	65%	150
WI	32%	68%	765
Weighted NCI-IDD Average	35%	65%	4,233

“Family” refers to the person completing the survey
 “Child” references the person with IDD

Table CFS 23. Was your household income (the income of all wage earners in the home) reduced directly because of the COVID-19 pandemic?

State	Yes	Maybe	No	N
AZ	49%	2%	48%	176
CO	35%	4%	61%	92
MN	36%	5%	59%	383
MO	36%	4%	60%	161
NC	33%	3%	64%	172
OR	42%	3%	55%	612
SD	34%	5%	61%	210
TX	50%	2%	48%	1,505
VA	36%	5%	60%	146
WI	37%	4%	59%	758
Weighted NCI-IDD Average	42%	3%	55%	4,215

Table CFS 24. Since the start of COVID time, has it become harder to make sure your family has enough food to eat?

State	Yes	Sometimes	No	N
AZ	13%	19%	68%	171
CO	5%	11%	84%	93
MN	11%	14%	74%	384
MO	5%	13%	82%	164
NC	12%	16%	72%	173
OR	9%	13%	77%	615
SD	9%	14%	77%	209
TX	27%	17%	56%	1,513
VA	12%	17%	71%	146
WI	9%	14%	77%	772
Weighted NCI-IDD Average	14%	16%	69%	4,240

“Family” refers to the person completing the survey
 “Child” references the person with IDD

Table CFS 25. As a result of service changes due to COVID 19, does your child need more help with the following?

Categories are not mutually exclusive therefore N is not shown.

State	Food or nutrition support	Medication administration support	Social support	Positive behavior support	Accessing telehealth healthcare and/or telehealth mental health services	Having someone to talk to if they feel lonely, stressed, anxious	Activities of daily living and/or instrumental activities of daily living (ADL and/or IADL) support	Respite services	Financial support	Other
AZ	30%	4%	63%	52%	7%	27%	23%	38%	18%	13%
CO	13%	1%	65%	52%	7%	23%	35%	53%	15%	9%
MN	19%	6%	60%	52%	14%	32%	42%	51%	15%	11%
MO	13%	4%	58%	57%	9%	36%	27%	51%	23%	4%
NC	26%	8%	61%	36%	9%	26%	40%	48%	17%	8%
OR	18%	6%	69%	47%	12%	34%	35%	39%	15%	9%
SD	14%	4%	49%	28%	5%	14%	15%	49%	25%	10%
TX	44%	26%	56%	55%	33%	47%	52%	51%	45%	8%
VA	25%	9%	62%	53%	13%	33%	49%	55%	15%	10%
WI	22%	5%	60%	48%	9%	24%	36%	48%	18%	6%
Weighted NCI-IDD Average	29%	10%	60%	48%	14%	32%	37%	46%	24%	9%

“Family” refers to the person completing the survey
 “Child” references the person with IDD

Questions? Comments?

For additional information on the National Core Indicators—Intellectual and Developmental Disabilities (NCI-IDD) initiative, public reports, and past data briefs, please visit: www.nationalcoreindicators.org.

If you want to discuss this report or have additional questions about the NCI-IDD, please contact Dorothy Hiersteiner (dhiersteiner@hsri.org) and Stephanie Giordano (sgiordano@hsri.org).