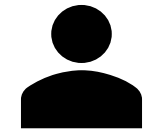


Respondents

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



26%

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



70%

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

Family member with IDD . . .



58 %

are male



36

average age

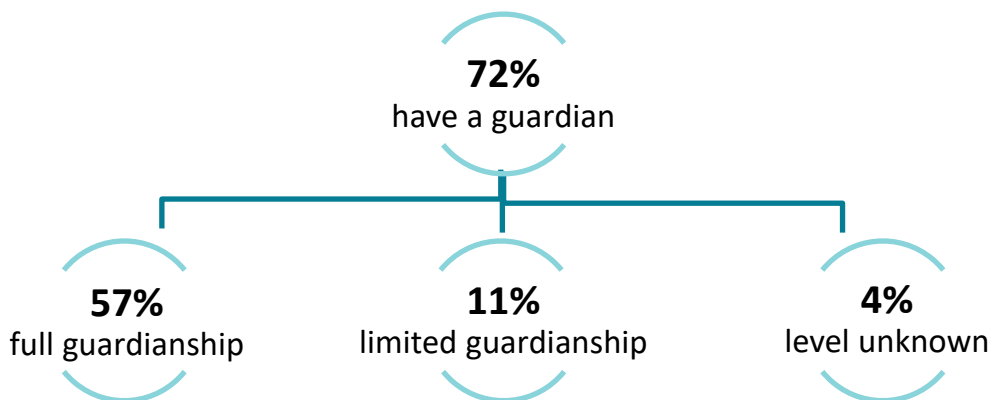
79%

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

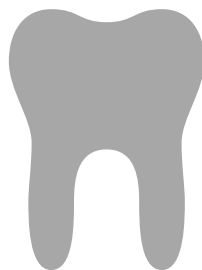


63% say their family member with IDD helped make the service plan



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

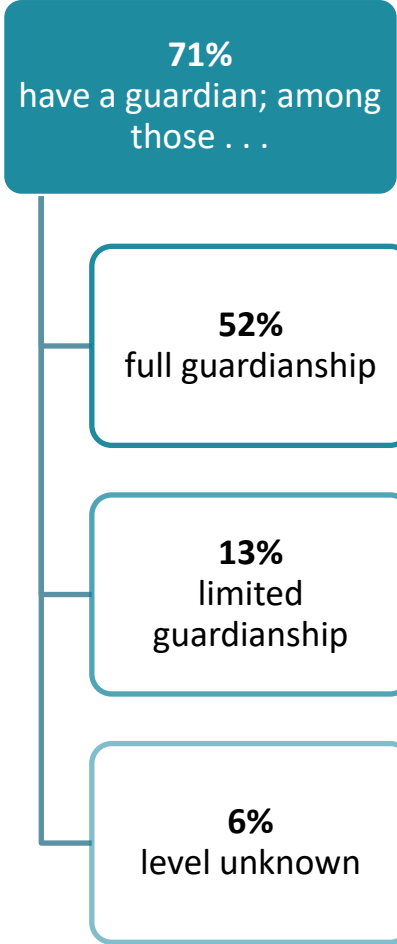
2020–21 Family/Guardian Survey (FGS)

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



47 average age

58% male



82% take part in community activities

62% have friends other than family or paid staff





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%

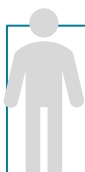
reported an annual household income of \$25K or less



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