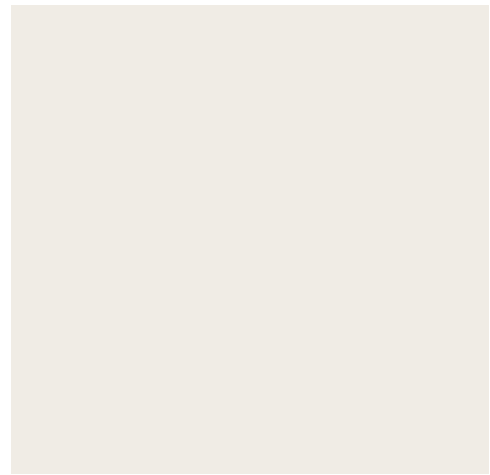


2022-23 DATA AT A GLANCE: FAMILY SURVEYS

Selected Findings from National Core Indicators® Intellectual and Developmental Disabilities
Adult Family Survey (**AFS**), Family Guardian Survey (**FGS**), and Child Family Survey (**CFS**)



FAMILY SURVEYS: OVERVIEW

INTRODUCTION

The 2022-23 Data at a Glance: Family Surveys shows selected findings from National Core Indicators® Intellectual and Developmental Disabilities (NCI-IDD) suite of family surveys:

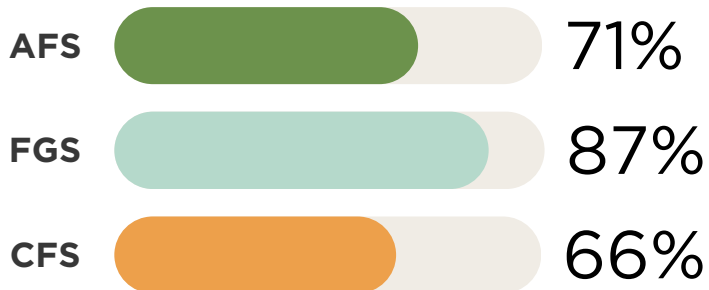
- Adult Family Survey (AFS): Respondents are families living with an adult family member who receives services from the state DD system
- Family Guardian Survey (FGS): Respondents are families living with a child who receives services from the state DD system
- Child Family Survey (CFS): Respondents are families/guardians whose family member receiving services does not live with them

While reviewing this resource it is important to note the following:

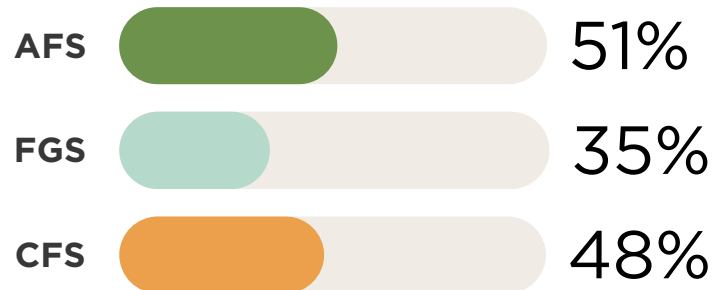
- "Family member" refers to children or adults with intellectual or developmental disabilities who use long-term services and supports.
- "Respondent" refers to family members or guardians of the person using services.
- Data displayed in this resource are *weighted*, and reflect a selection of key outcomes. Please refer to the [AFS](#), [CFS](#), and [FGS](#) reports to learn about other important outcomes.

CROSS FAMILY SURVEY COMPARISONS

Does your family get the services and supports it needs?

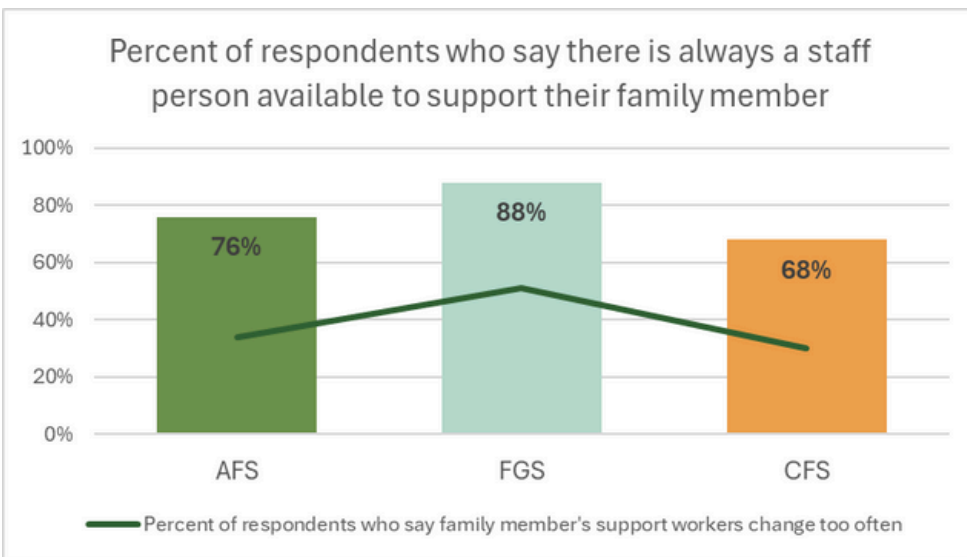


Do support workers always have the right information and skills to meet your family's needs?



Across the three surveys, there is wide variation in respondents saying their family gets the supports and services they need and support workers always have the right information and skills to meet family needs. Of note, AFS and CFS respondents, who have family members with IDD who live at home, have lower rates of reporting their family gets the services and supports it needs than FGS respondents; in contrast, AFS and CFS respondents have higher rates of reporting that support workers always have the right information and skills to meet their family's needs.

Workforce Stability and Availability



The graph (left) shows the percent of respondents in each survey that indicate there is always a staff person available to support their family member. The green line shows the percent of respondents in each survey who say their family member's support workers change too often.

Of note, AFS and CFS respondents, who have family members with IDD who live at home, have lower rates than FGS respondents of reporting that a staff person is always available, but they also have lower rates than FGS respondents of support workers changing too often. This may be related to different living arrangements and service coordination experiences among the samples.

Taken together, these data show that there may be different experiences in key outcomes for respondents with a family member with IDD living at home compared to those who do not live at home. **Services systems may need to explore different solutions to enhance the workforce to better support the diversity of families with children and adults with IDD.**

ADULT FAMILY SURVEY: SAMPLE DETAILS

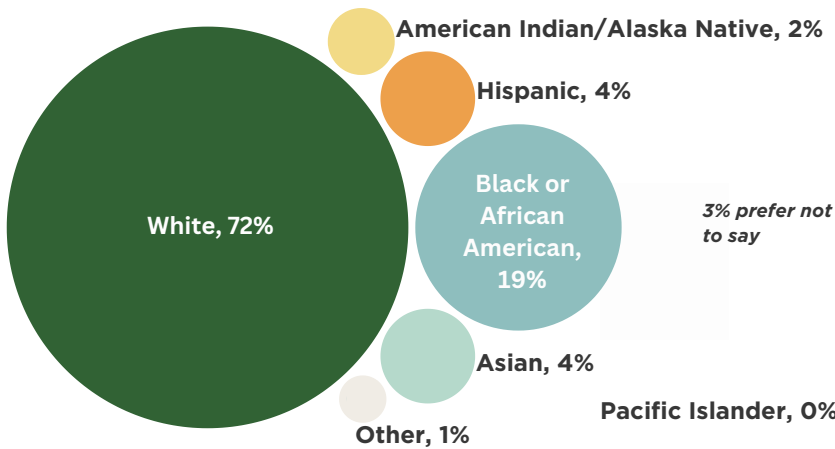
SAMPLE SIZE

4,988 total respondents

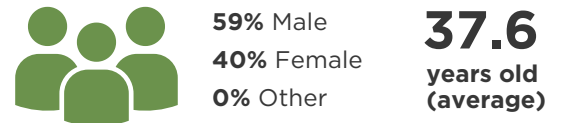
STATES INCLUDED



RACE AND ETHNICITY OF FAMILY MEMBER



GENDER AND AGE OF FAMILY MEMBER

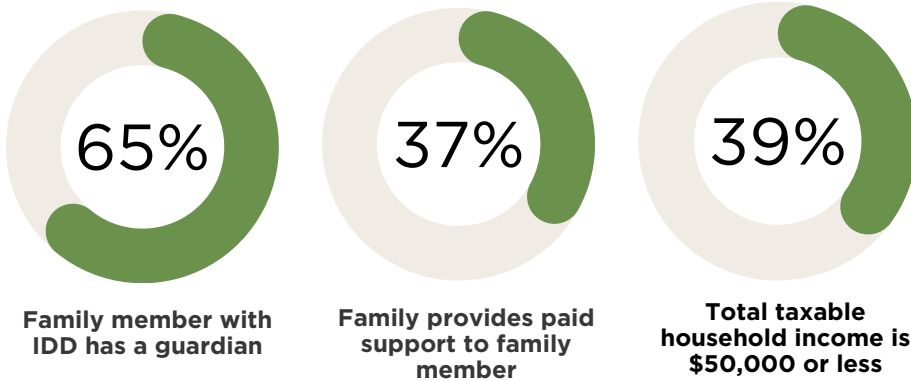


LOCATION

36% live in rural area
64% live in urban or suburban area

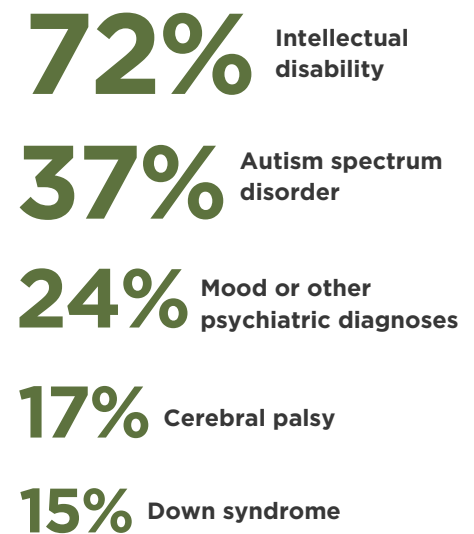


FAMILY CHARACTERISTICS

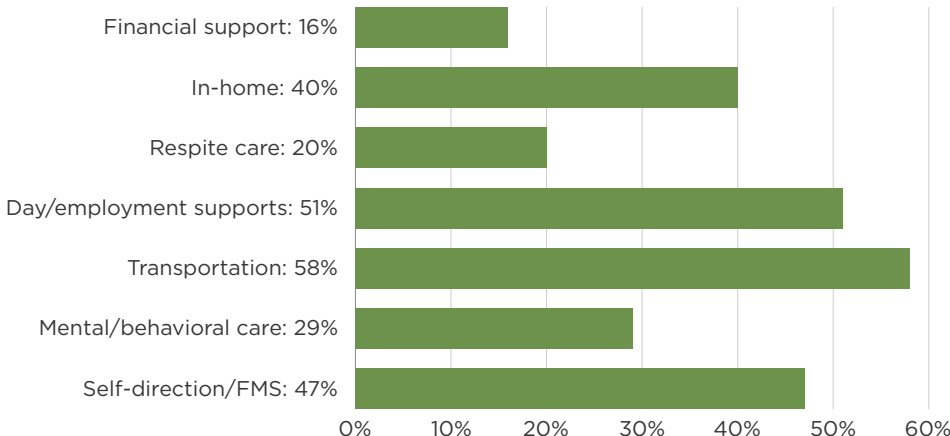


DIAGNOSIS OF FAMILY MEMBER

Note: Diagnoses are not mutually exclusive.



SERVICES RECEIVED FROM DD AGENCY



PREFERRED MEANS OF COMMUNICATION OF FAMILY MEMBER



ADULT FAMILY SURVEY: OUTCOMES

FAMILY SATISFACTION

94% say services and supports are helping their family member to live a good life

42% say they are **always** satisfied overall with the services and supports their family member currently receives



INFORMATION AND PLANNING

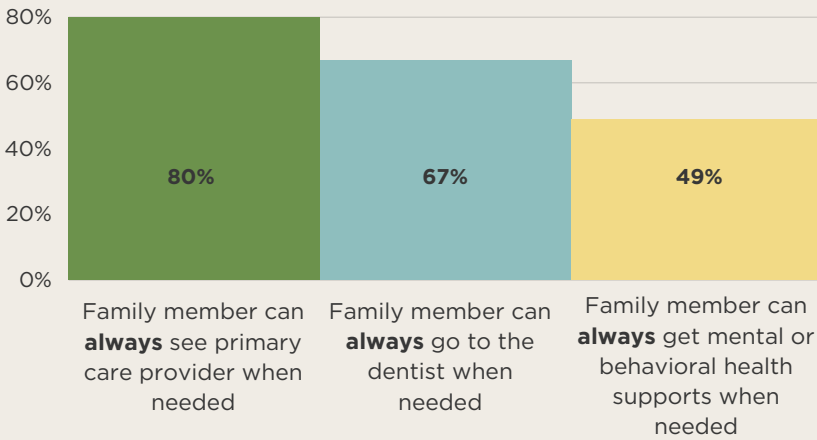
68% Say case manager/service coordinator **always** listens to family's choices and opinions

88% Say plan includes **all** the services and supports family member needs

64% Say family member with IDD helped make service plan

50% Say family has learned about alternatives to guardianship

HEALTH AND SAFETY



ACCESS AND DELIVERY

86% say family member gets **all** the services listed in the plan, but **71%** say family gets all the services it needs

81% say services are **always** delivered in a way that is respectful of family's culture

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

34% say family member's support workers change too often

22% say family was **always** able to get respite services when needed (If family needed respite services)

COMMUNITY CONNECTIONS

64% Say family member has friends other than paid support workers or family

18% Say family takes part in any family-to-family networks in their community

CHOICE AND CONTROL

38% say they, their family member, or someone else in the family chose their family member's case manager/service coordinator



62% say someone in the family can **always** choose or change their family member's support workers

CHILD FAMILY SURVEY: SAMPLE DETAILS

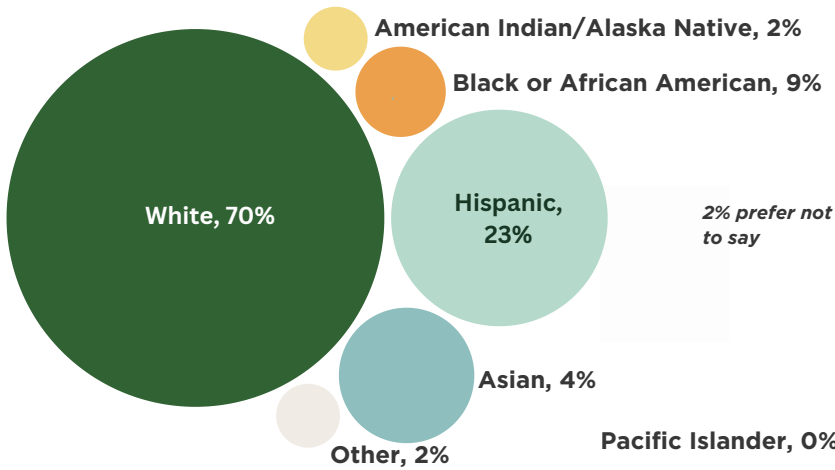
SAMPLE SIZE

3,760 total respondents

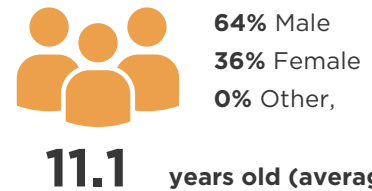
STATES INCLUDED



RACE AND ETHNICITY OF CHILD



GENDER AND AGE OF CHILD

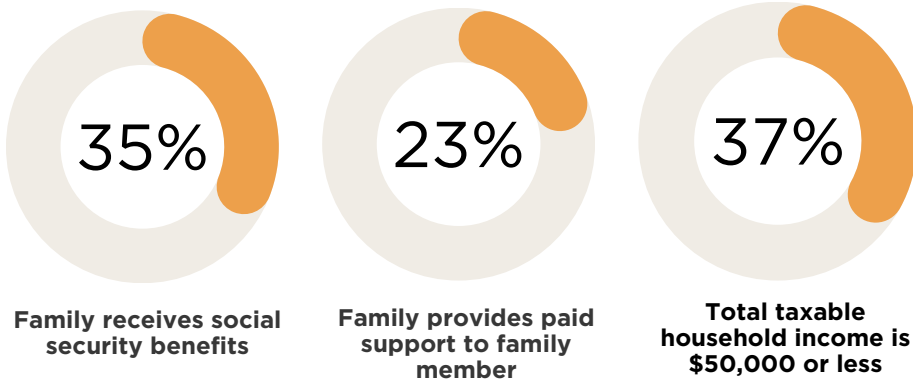


LOCATION

27% live in rural area
73% live in urban or suburban area

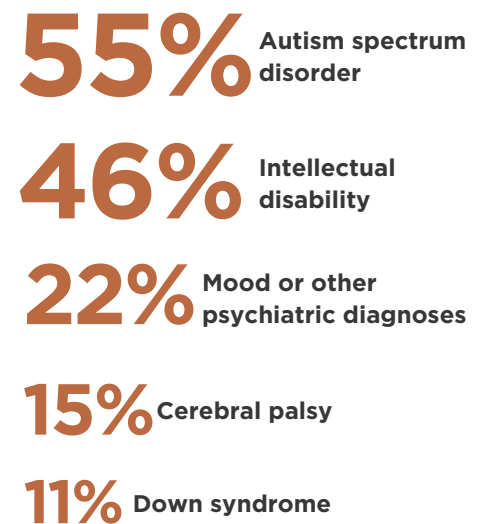


FAMILY CHARACTERISTICS

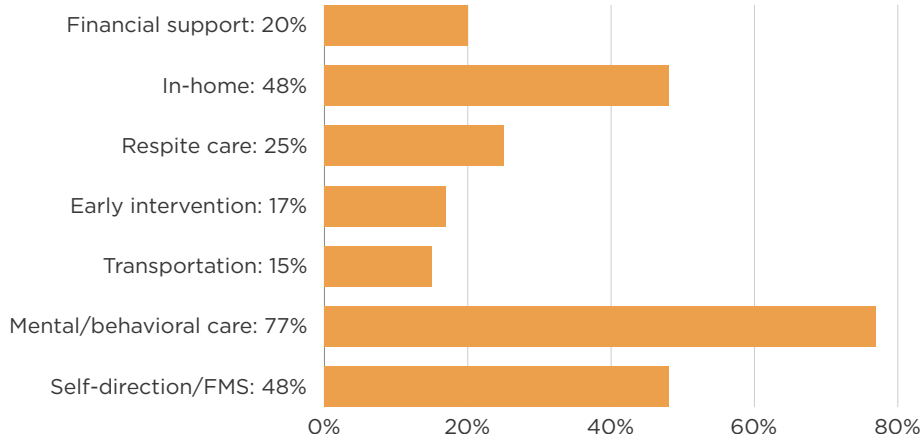


DIAGNOSIS OF CHILD

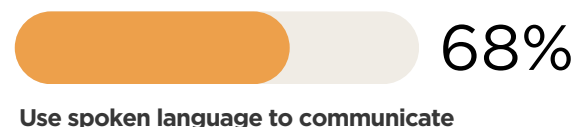
Note: Diagnoses are not mutually exclusive.



SERVICES RECEIVED FROM DD AGENCY



PREFERRED MEANS OF COMMUNICATION OF CHILD



Other forms of communication used include gestures, sign language, or communication aids

CHILD FAMILY SURVEY: OUTCOMES

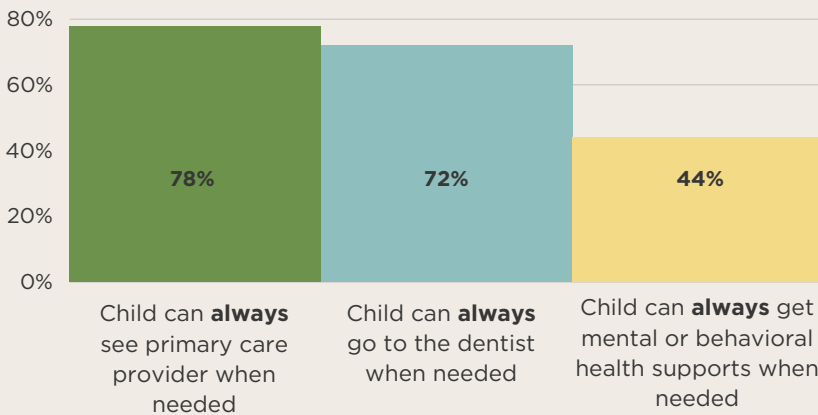
FAMILY SATISFACTION

94% say services and supports are helping their child to live a good life

38% say they are **always** satisfied overall with the services and supports their child currently receives



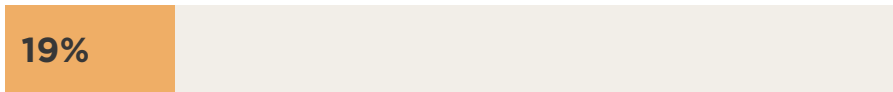
HEALTH AND SAFETY



COMMUNITY CONNECTIONS



Say child spends time with children who do not have DD



Say family takes part in any family-to-family networks in their community

CHOICE AND CONTROL

27% say they, their child, or someone else in the family chose their family member's case manager/service coordinator



63% say someone in the family can **always** choose or change their family member's support workers

INFORMATION AND PLANNING



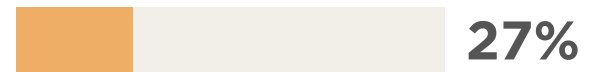
Say case manager/service coordinator **always** listens to family's choices and opinions



Say plan includes **all** the services and supports child needs



Say child with IDD helped make service plan



Say family has learned about alternatives to guardianship

ACCESS AND DELIVERY



82% say child gets **all** the services listed in the plan, but **66%** say family gets all the services it needs



82% say services are **always** delivered in a way that is respectful of family's culture



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



30% say child's support workers change too often



22% say family was **always** able to get respite services when needed (If family needed respite services)

FAMILY GUARDIAN SURVEY: SAMPLE DETAILS

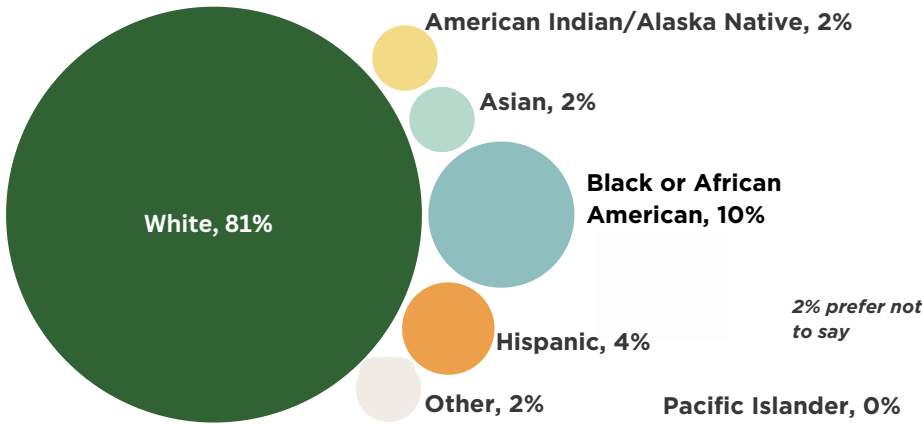
SAMPLE SIZE

2,145 total respondents

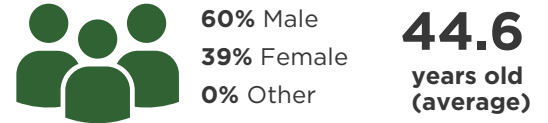
STATES INCLUDED



RACE AND ETHNICITY OF FAMILY MEMBER



GENDER AND AGE OF FAMILY MEMBER

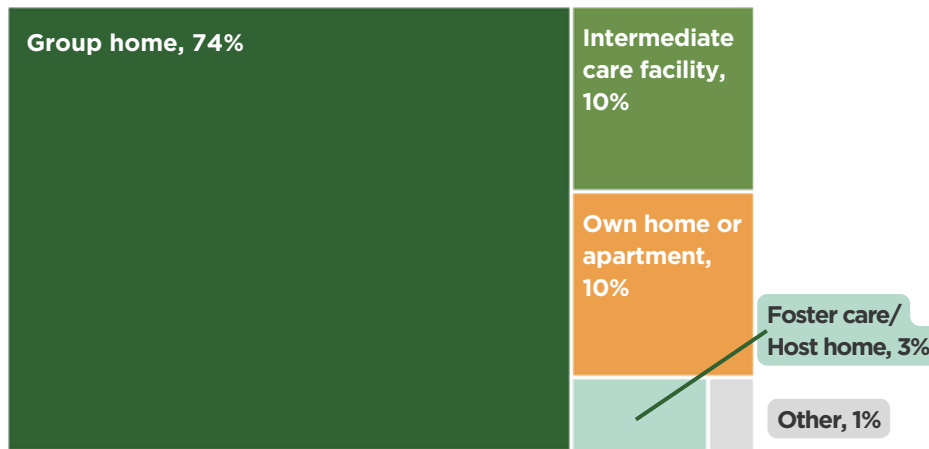


LOCATION

22% live in rural area
78% live in urban or suburban area

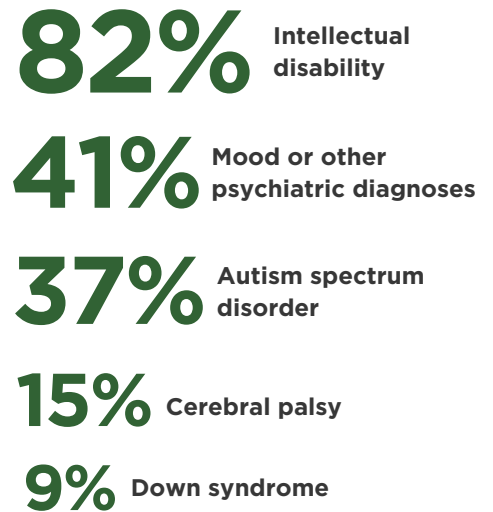


RESIDENCE OF FAMILY MEMBER

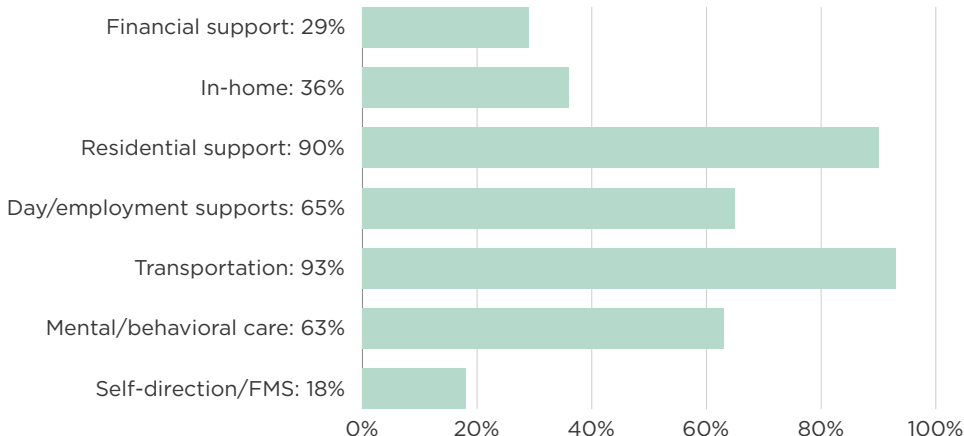


DIAGNOSIS OF FAMILY MEMBER

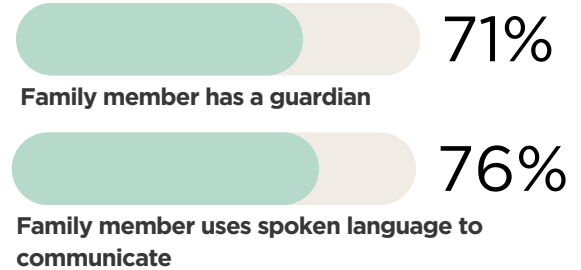
Note: Diagnoses are not mutually exclusive.



SERVICES RECEIVED FROM DD AGENCY



OTHER CHARACTERISTICS



Other forms of communication used include gestures, sign language, or communication aids

FAMILY GUARDIAN SURVEY: OUTCOMES

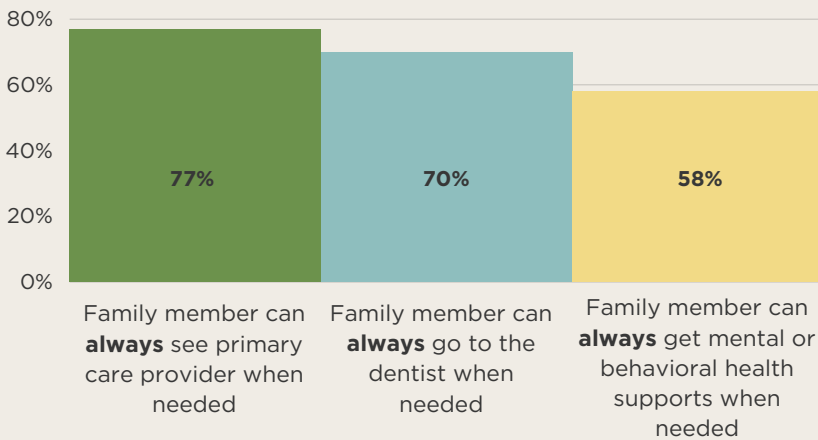
FAMILY SATISFACTION

93% say services and supports are helping their family member to live a good life

39% say they are **always** satisfied overall with the services and supports their family member currently receives



HEALTH AND SAFETY



COMMUNITY CONNECTIONS

57%

Say family member has friends other than paid support workers or family

14%

Say family takes part in any family-to-family networks in their community

CHOICE AND CONTROL

24%

say they, their family member, or someone else in the family chose their family member's case manager/service coordinator



25%

say someone in the family can **always** choose or change their family member's support workers

INFORMATION AND PLANNING

56%

Say case manager/service coordinator **always** listens to family's choices and opinions

90%

Say plan includes **all** the services and supports family member needs

61%

Say family member with IDD helped make service plan

50%

Say family has learned about alternatives to guardianship

ACCESS AND DELIVERY



84% say family member gets **all** the services listed in the plan, and **87%** say family gets all the services it needs



73% say services are **always** delivered in a way that is respectful of family's culture



34% say services and supports always change when family's needs change



51% say family member's support workers change too often



40% say there are **always** support workers who can communicate with them (If family does not communicate verbally)