

2023-24

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 OF 2023-24 DATA

INTRODUCTION

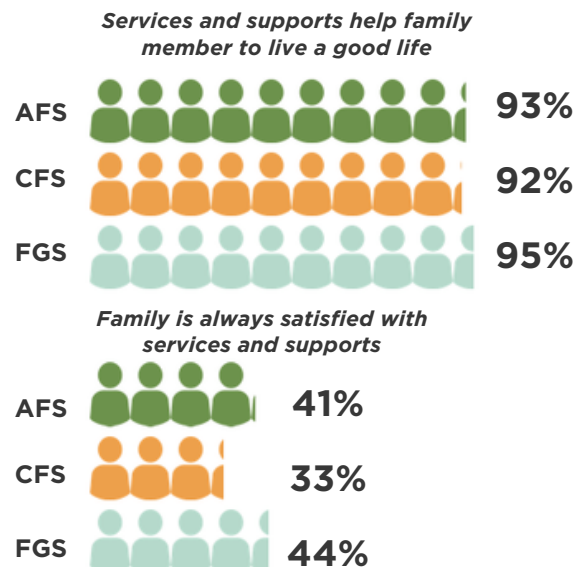
The **2023-24 Data at a Glance: Family Surveys** shows selected findings from National Core Indicators® Intellectual and Developmental Disabilities (NCI-IDD) suite of family surveys:

- **Adult Family Survey (AFS):** Respondents are families living with an adult family member who receives services from the state DD system
- **Child Family Survey (CFS):** Respondents are families living with a child who receives services from the state DD system
- **Family Guardian Survey (FGS):** 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 the person who responded to the survey. This person is a family member or guardian 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



Across the three surveys, more than **9 out of every 10 families** say that the services and supports they receive help their family member to live a good life.

At the same time, around **4 out of every 10 families of adults with IDD** say that they are always satisfied with the services and supports, while 3 out of every 10 families of children with IDD say this.

These data showcase that **Medicaid-funded services from state DD agencies are making a positive difference** in the lives of families of children and adults with IDD. These data also show that the quality of Medicaid-funded supports, as measured by user satisfaction, can be improved.

Service Planning and Coordination

Across the three surveys, about **8 or 9 out of every 10 families** say that service plan includes all the services and supports their family member needs.

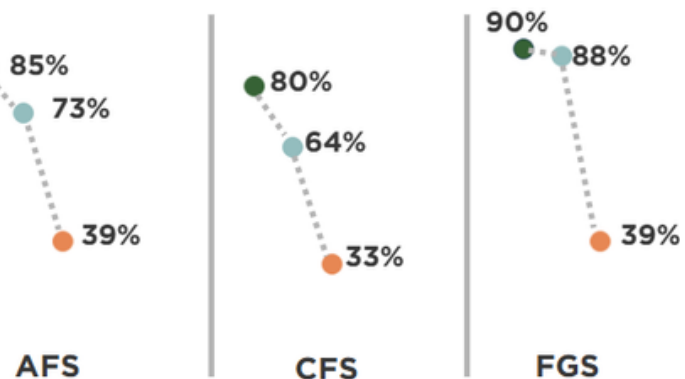
However, there is wide variation in respondents saying their family gets the supports and services they need, with averages ranging between 64% and 88%.

In addition, fewer than **4 out of every 10 families** say that services and supports always change when their family's needs change.

Plan includes all the services and supports family member needs

Family gets the supports and services it needs

Services and supports always change when family's needs change

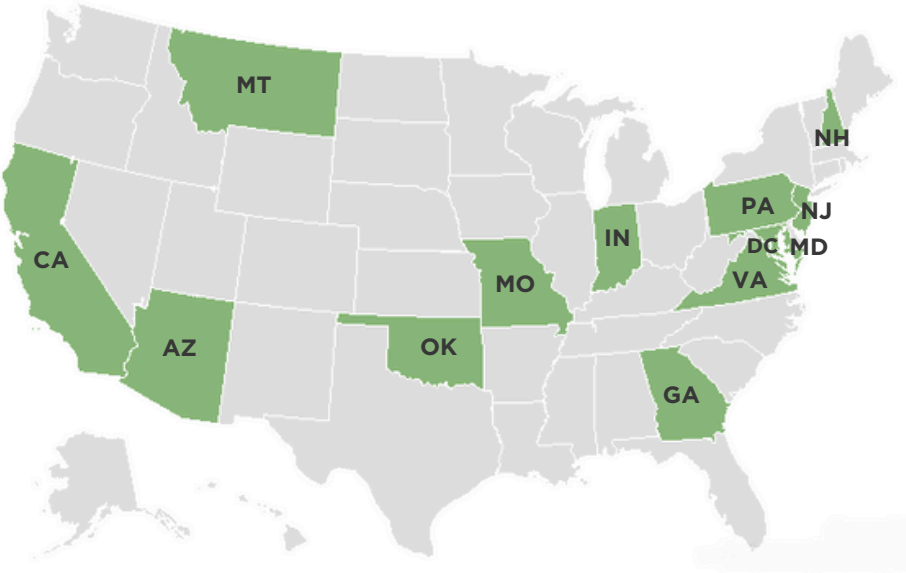


These data suggest that although service plans include all the services and supports children and adults with IDD require, the **families do not always get the support and services they need**. Further, the data underscore the need for **greater flexibility** with services to ensure they can be responsive to changing needs.

ADULT FAMILY SURVEY: 2023-24 SAMPLE DETAILS

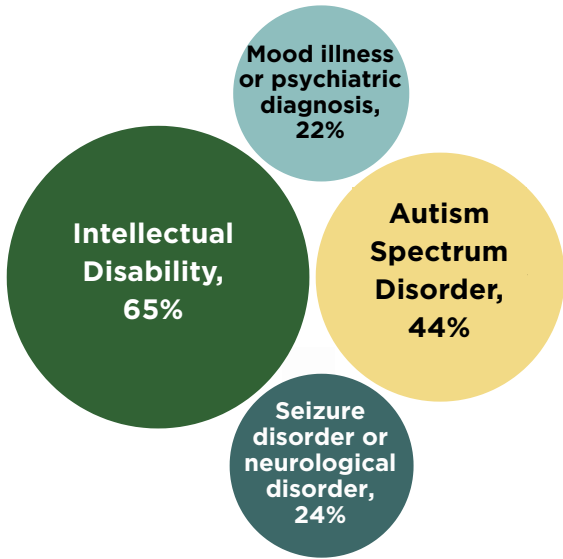
SAMPLE

18,724 respondents from 13 states



DIAGNOSIS OF FAMILY MEMBER

Note: Diagnoses are not mutually exclusive.



FAMILY MEMBER DEMOGRAPHICS

Race and Ethnicity

57% White
22% Hispanic
12% Black or African American
10% Asian
2% American Indian/Alaska Native
1% Pacific Islander
2% Other

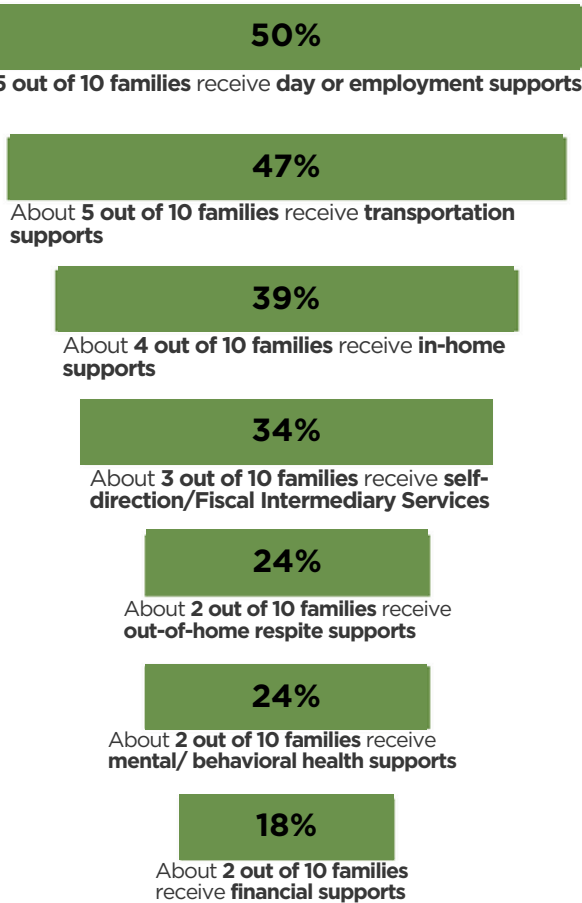
Age and Gender

34 years old (average)
62% Male
38% Female

Communication

19%
Family member with IDD uses non-spoken means to communicate

SERVICES RECEIVED FROM DD AGENCY



FAMILY CHARACTERISTICS



21% live in rural area
79% live in urban or suburban area



65% Family member has a guardian



49% Family provides paid support to family member



39% Total taxable household income \$50,000 or less

ADULT FAMILY SURVEY: 2023-24 OUTCOMES

ACCESS AND DELIVERY

Family member gets all services listed in plan **83%**

Family member does things in the community **83%**


Family member always has the special equipment or accommodations they need **49%**


Family member can always see primary care provider when needed **74%**


Family member can always see dentist when needed **67%**


Family member can always get mental or behavioral health supports when needed **46%**

WORKFORCE


 **35%** say family member's support workers change too often

 **75%** say there is **always** a staff person available to support family member when support is needed

 **48%** say support workers **always** have the right information and skills to meet family's needs


 **45%** say there are **always** support workers who can communicate with family members who use alternate forms of communication

INFORMATION AND PLANNING

 About 2 out of every 3 families (63%) say case manager/service coordinator **always** listens to family's choices and opinions

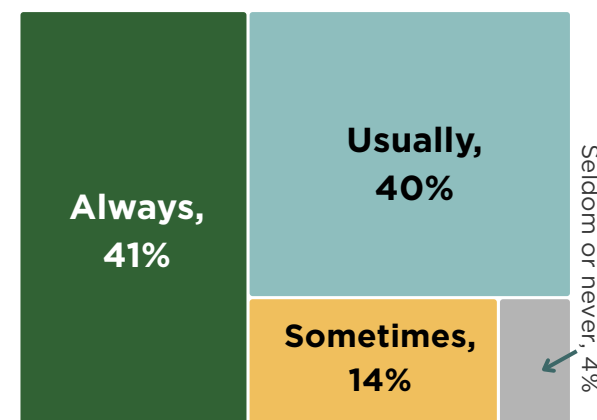
About 2 out of every 3 families (65%) say their family member with IDD helped make service plan



 About 1 out of every 3 families (33%) say they **always** get enough information to take part in planning services for family member


FAMILY SATISFACTION

Overall, are you **satisfied** with the services your family member currently receives?



CHOICE AND CONTROL

Someone in family can always choose or change family member's...

 **57%**
Support workers

 **62%**
Agency that provides services

 **85%**
Case manager/Service coordinator

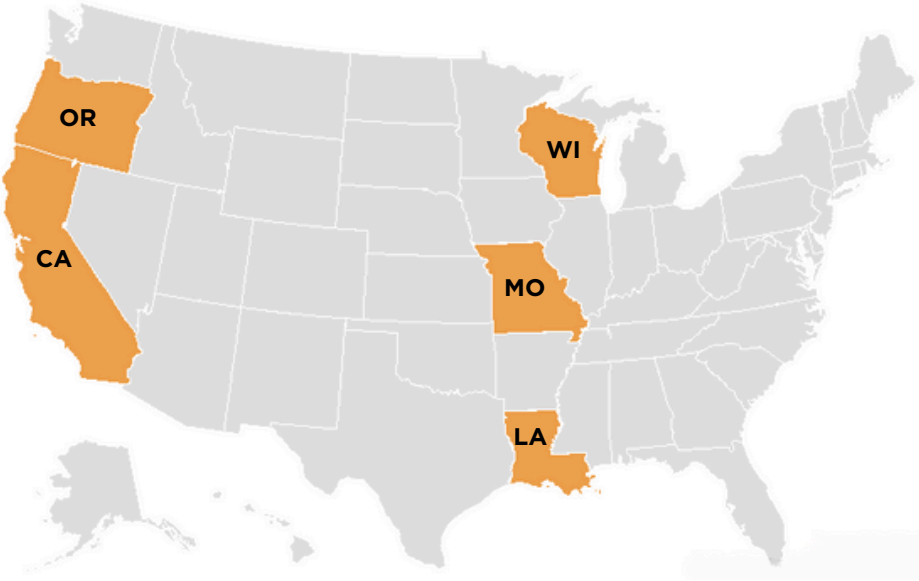
93%

Services and supports have made a **positive difference in the life** of family member

CHILD FAMILY SURVEY: 2023-24 SAMPLE DETAILS

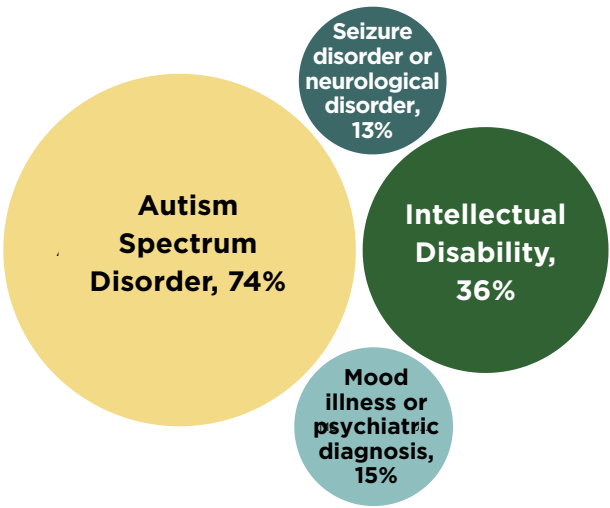
SAMPLE

10,050 respondents from 5 states



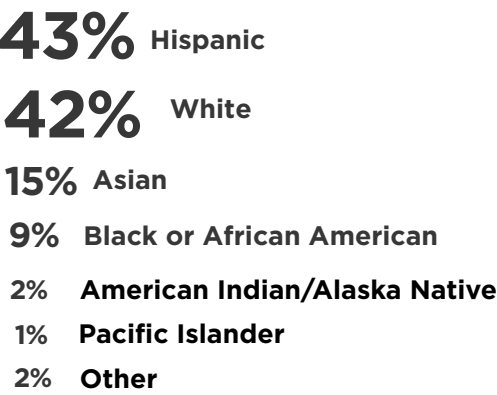
DIAGNOSIS OF CHILD

Note: Diagnoses are not mutually exclusive.

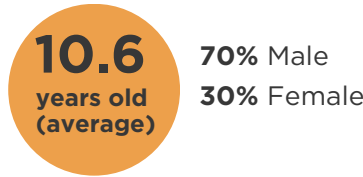


CHILD DEMOGRAPHICS

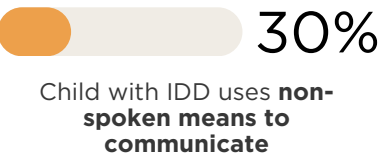
Race and Ethnicity



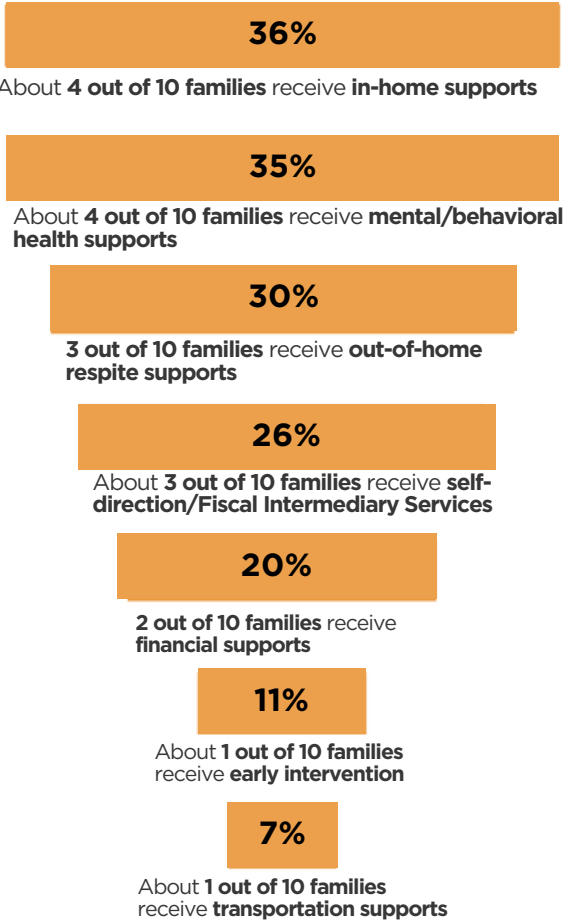
Age and Gender



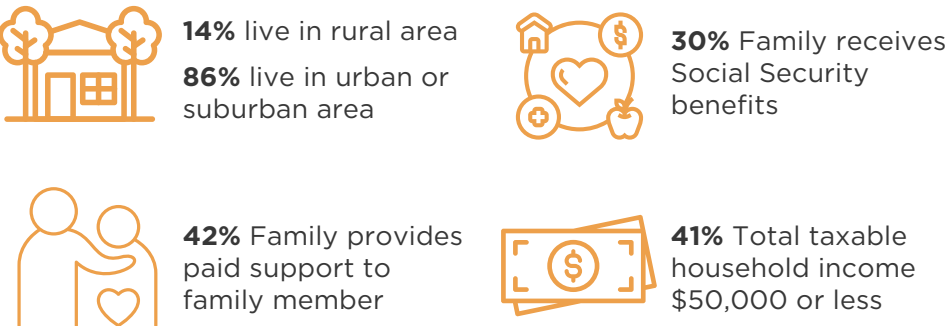
Communication



SERVICES RECEIVED FROM DD AGENCY

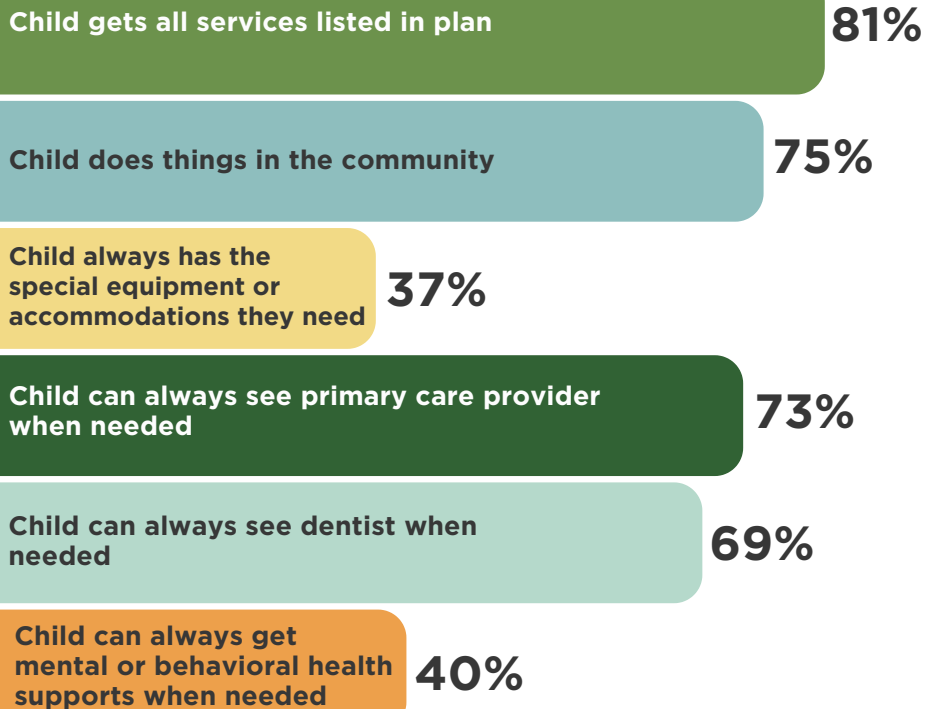


FAMILY CHARACTERISTICS



CHILD FAMILY SURVEY: 2023-24 OUTCOMES

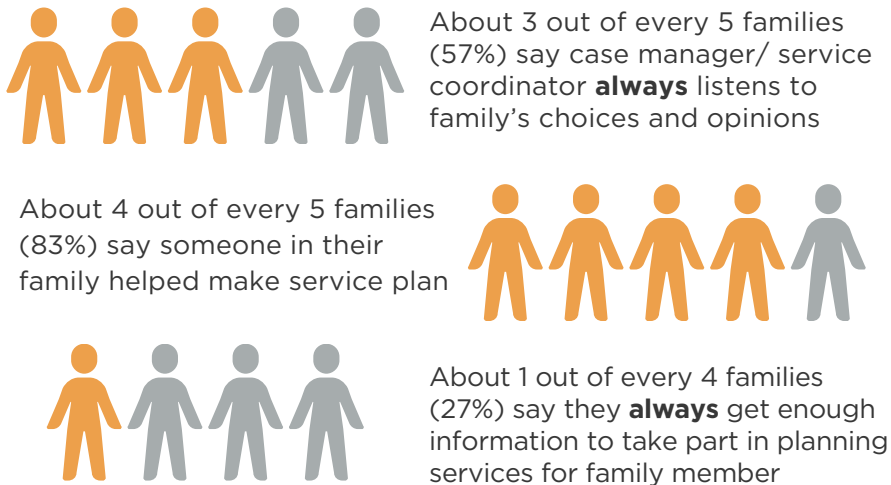
ACCESS AND DELIVERY



WORKFORCE

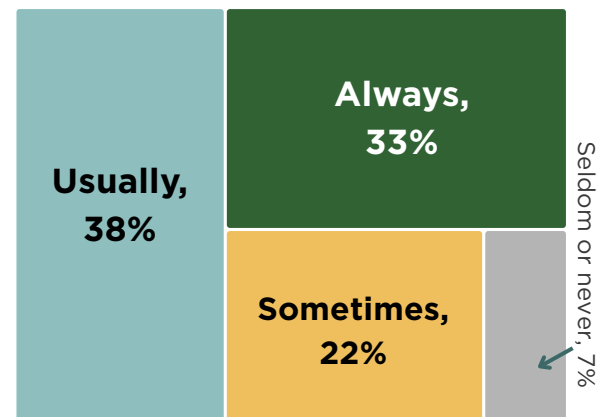


INFORMATION AND PLANNING



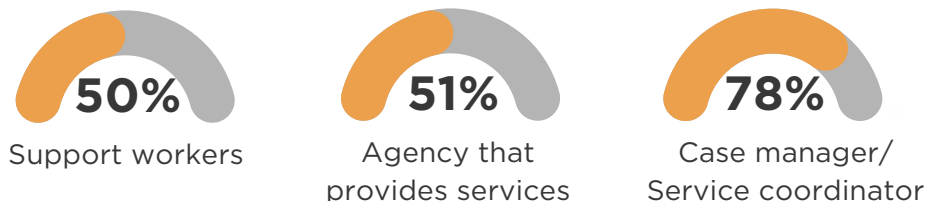
FAMILY SATISFACTION

Overall, are you **satisfied** with the services your child currently receives?



CHOICE AND CONTROL

Someone in family can always choose or change child's...



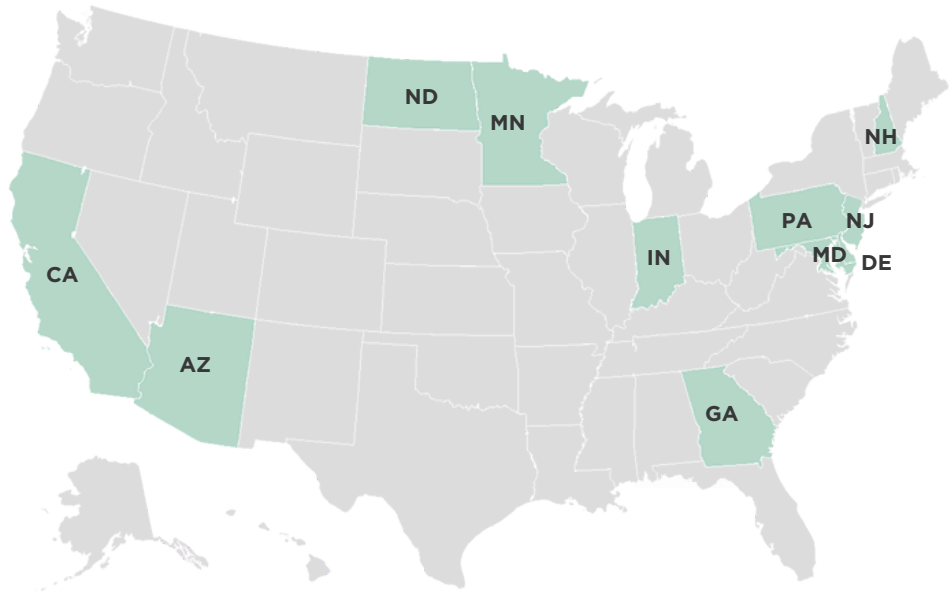
91%

Services and supports have made a **positive difference in the life** of child

FAMILY GUARDIAN SURVEY: 2023-24 SAMPLE DETAILS

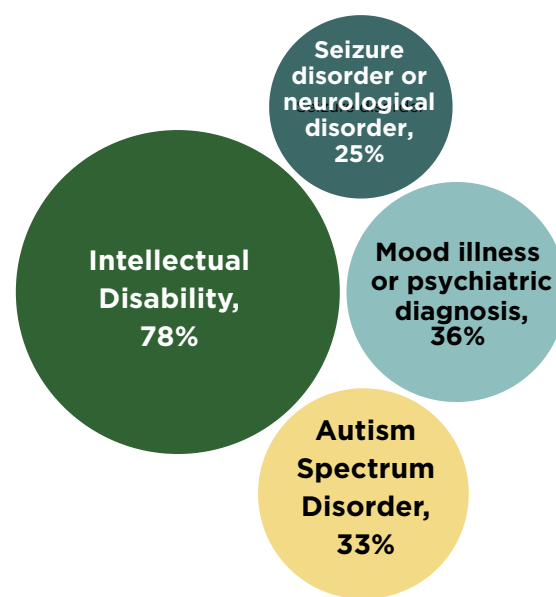
SAMPLE

8,614 respondents from 11 states



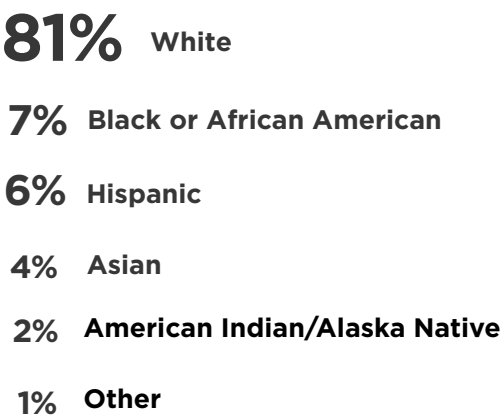
DIAGNOSIS OF FAMILY MEMBER

Note: Diagnoses are not mutually exclusive.

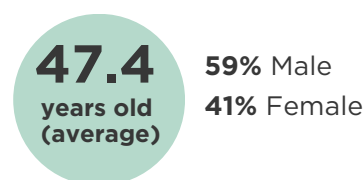


FAMILY MEMBER DEMOGRAPHICS

Race and Ethnicity



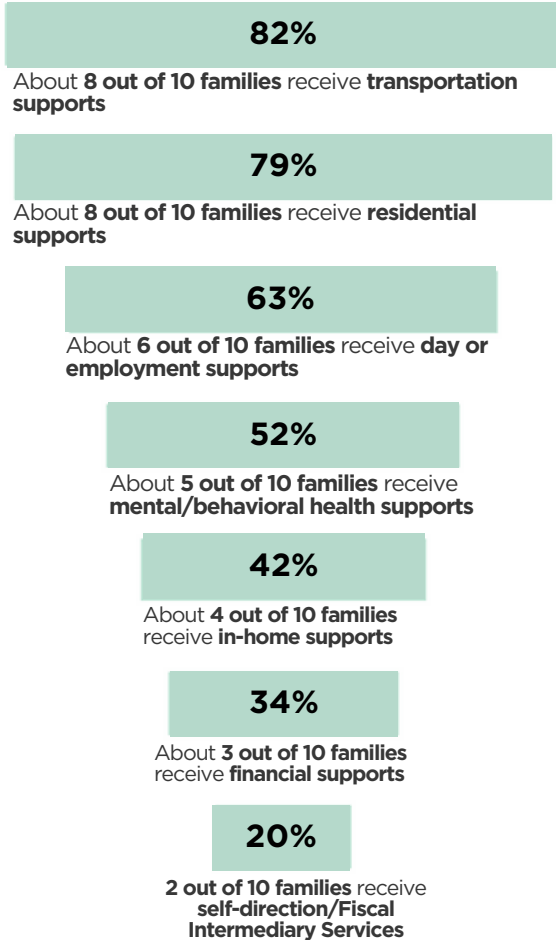
Age and Gender



Communication



SERVICES RECEIVED FROM DD AGENCY



FAMILY CHARACTERISTICS



FAMILY GUARDIAN SURVEY: 2023-24 OUTCOMES

ACCESS AND DELIVERY

Family member gets all services listed in plan **88%**

Family member does things in the community **87%**


Family member always has the special equipment or accommodations they need **63%**


Family member can always see primary care provider when needed **75%**


Family member can always see dentist when needed **68%**


Family member can always get mental or behavioral health supports when needed **55%**

WORKFORCE

 **42%** say family member's support workers change too often

 **88%** say there is **always** a staff person available to support family member when support is needed

 **40%** say support workers **always** have the right information and skills to meet family's needs

 **44%** say there are **always** support workers who can communicate with family members who use alternate forms of communication

INFORMATION AND PLANNING

 About 3 out of every 5 families (58%) say case manager/service coordinator **always** listens to family's choices and opinions

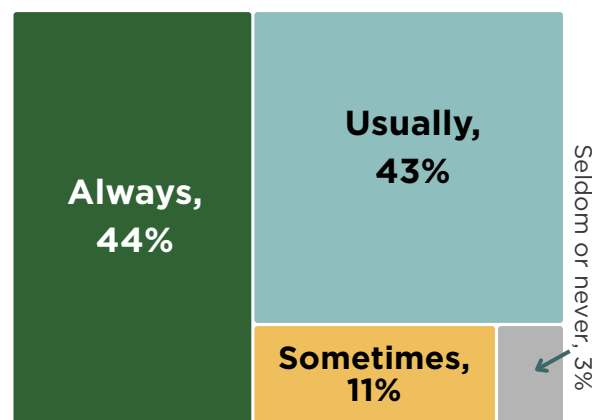
About 2 out of every 3 families (66%) say their family member with IDD helped make service plan



 About 2 out of every 5 families (39%) say they **always** get enough information to take part in planning services for family member

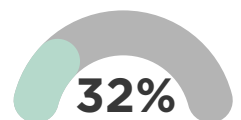
FAMILY SATISFACTION

Overall, are you **satisfied** with the services your family member currently receives?

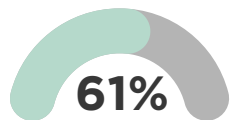


CHOICE AND CONTROL

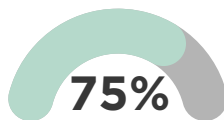
Someone in family can always choose or change family member's...



Support workers



Agency that provides services



Case manager/Service coordinator

95%

Services and supports have made a **positive difference in the life** of family member