

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

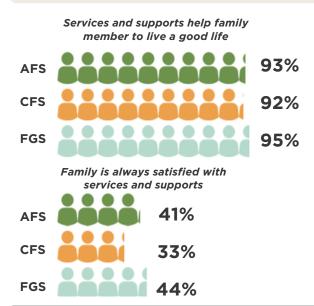
The **2023-24 Data at a Glance: Family Surveys** shows selected findings from National Core Indicators® Intellectual and Developmental Disabilities (NCI-IDD) suite of family surveys:

- 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 <u>AFS</u>, <u>CFS</u>, and <u>FGS</u> 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.

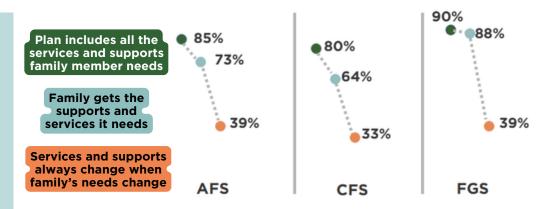
These data showcase that **Medicaid-funded services from state DD agencies are making a positive difference** in the lives of families of children and adults with IDD. These data also show that the quality of Medicaid-funded supports, as measured by user satisfaction, can be improved.

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.

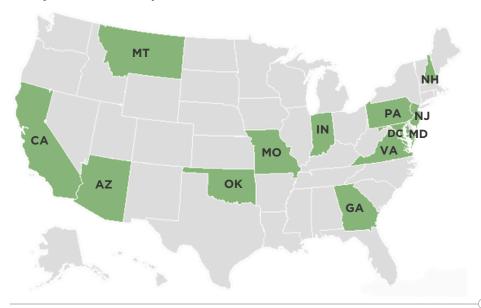


These data suggest that although service plans include all the services and supports children and adults with IDD require, the **families do not always get the support and services they need**. Further, the data underscore the need for **greater flexibility** with services to ensure they can be responsive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

ADULT FAMILY SURVEY: 2023-24 SAMPLE DETAILS

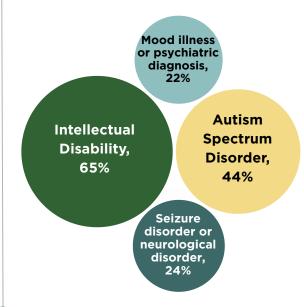
SAMPLE

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

American Indian/Alaska Native

1% **Pacific Islander**

2% Other

Age and Gender



62% Male 38% Female

Communication



Family member with IDD uses non-spoken means to communicate

SERVICES RECEIVED FROM DD **AGENCY**

50%

5 out of 10 families receive day or employment supports

47%

About 5 out of 10 families receive transportation supports

39%

About 4 out of 10 families receive in-home supports

34%

About 3 out of 10 families receive selfdirection/Fiscal Intermediary Services

24%

About 2 out of 10 families receive out-of-home respite supports

24%

About 2 out of 10 families receive mental/behavioral health supports

About 2 out of 10 families receive financial supports

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%

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

CHOICE AND CONTROL

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



62%

85%

Agency that provides services

Case manager/ Service coordinator

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



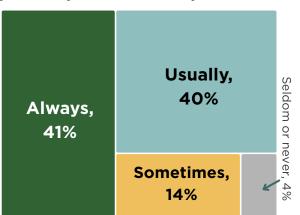
48% say support workers always have the right information and skills to meet family's needs



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

FAMILY SATISFACTION

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



93%

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

CHILD FAMILY SURVEY: 2023-24 SAMPLE DETAILS

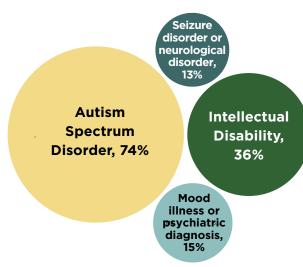
SAMPLE

10,050 respondents from 5 states



DIAGNOSIS OF CHILD

Note: Diagnoses are not mutually exclusive.



CHILD DEMOGRAPHICS

Race and Ethnicity

43% Hispanic

42% White

15% Asian

9% Black or African American

2% American Indian/Alaska Native

1% Pacific Islander

2% Other

Age and Gender

10.6 years old (average)

70% Male **30%** Female

Communication



30%

Child with IDD uses nonspoken means to communicate

SERVICES RECEIVED FROM DD AGENCY

36%

About 4 out of 10 families receive in-home supports

35%

About 4 out of 10 families receive mental/behavioral health supports

30%

3 out of 10 families receive out-of-home respite supports

26%

About 3 out of 10 families receive selfdirection/Fiscal Intermediary Services

20%

2 out of 10 families receive financial supports

11%

About 1 out of 10 families receive early intervention

7%

About 1 out of 10 families receive transportation supports

FAMILY CHARACTERISTICS



14% live in rural area

86% live in urban or suburban area



30% Family receives Social Security benefits



42% Family provides paid support to family member



41% Total taxable household income \$50,000 or less

CHILD FAMILY SURVEY: 2023-24 OUTCOMES

ACCESS AND DELIVERY

Child gets all services listed in plan

81%

Child does things in the community

75%

Child always has the special equipment or accommodations they need

37%

Child can always see primary care provider when needed

73%

Child can always see dentist when needed

69%

Child can always get mental or behavioral health supports when needed

40%

INFORMATION AND PLANNING



About 3 out of every 5 families (57%) say case manager/ service coordinator **always** listens to family's choices and opinions

About 4 out of every 5 families (83%) say someone in their family helped make service plan





About 1 out of every 4 families (27%) say they **always** get enough information to take part in planning services for family member

CHOICE AND CONTROL

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



51%

Agency that provides services



Case manager/ Service coordinator

WORKFORCE



36% say child's support workers change too often



70% say there is **always** a staff person available to support child when support is needed



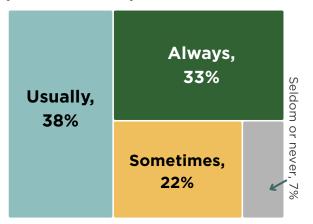
43% say support workers always have the right information and skills to meet family's needs



37% say there are **always** support workers who can communicate with child who uses alternate forms of communication

FAMILY SATISFACTION

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



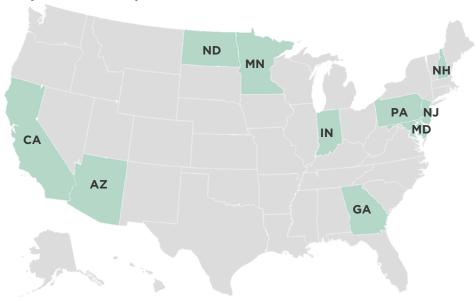
91%

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

FAMILY GUARDIAN SURVEY: 2023-24 SAMPLE DETAILS

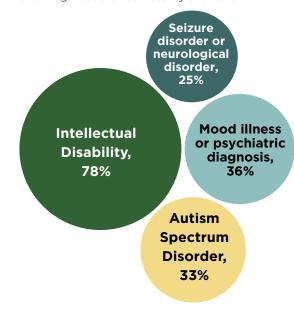
SAMPLE

8,614 respondents from **11 states**



DIAGNOSIS OF FAMILY MEMBER

Note: Diagnoses are not mutually exclusive.



FAMILY MEMBER DEMOGRAPHICS

Race and Ethnicity

81% White

7% Black or African American

6% Hispanic

4% Asian

2% American Indian/Alaska Native

1% Other

Age and Gender

47.4 years old (average)

59% Male41% Female

Communication



Family member with IDD uses non-spoken means to communicate

SERVICES RECEIVED FROM DD AGENCY

82%

About 8 out of 10 families receive transportation supports

79%

About 8 out of 10 families receive residential supports

63%

About 6 out of 10 families receive day or employment supports

52%

About 5 out of 10 families receive mental/behavioral health supports

42%

About 4 out of 10 families receive in-home supports

34%

About 3 out of 10 families receive financial supports

20%

2 out of 10 families receive self-direction/Fiscal Intermediary Services

FAMILY CHARACTERISTICS



15% live in rural area **85%** live in urban or suburban area



70% Family member has a guardian



94% Family receives Social Security benefits



30% Total taxable household income \$50,000 or less

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%

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

CHOICE AND CONTROL

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



61%

75%

Agency that provides services

Case manager/ Service coordinator

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



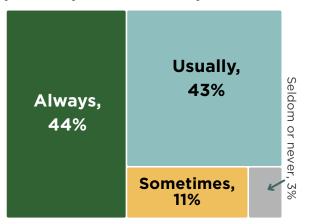
40% say support workers **always** have the right information and skills to meet family's needs



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

FAMILY SATISFACTION

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



95%

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