

2024-25

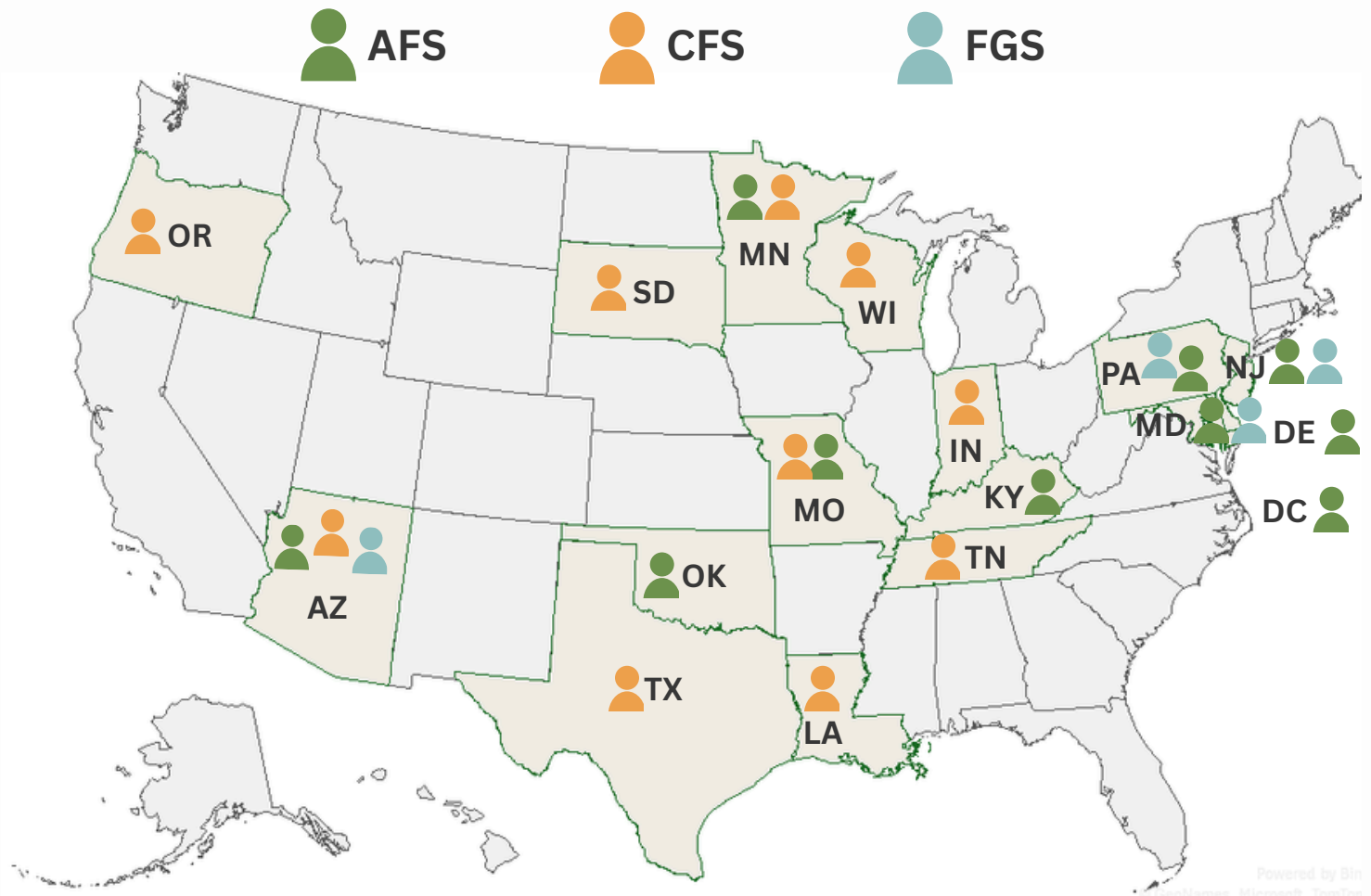
DATA AT A GLANCE:

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**).
The Family Surveys collect data from families of those receiving supports from their state Developmental Disabilities (DD) service system. The resulting data demonstrate how state (DD) systems are impacting families.

Respondents to each survey comprise:

- **AFS:** Families living with an adult family member who receives services from the state DD system
- **CFS:** Families living with a child who receives services from the state DD system
- **FGS:** Families/guardians whose family member receiving services does not live with them

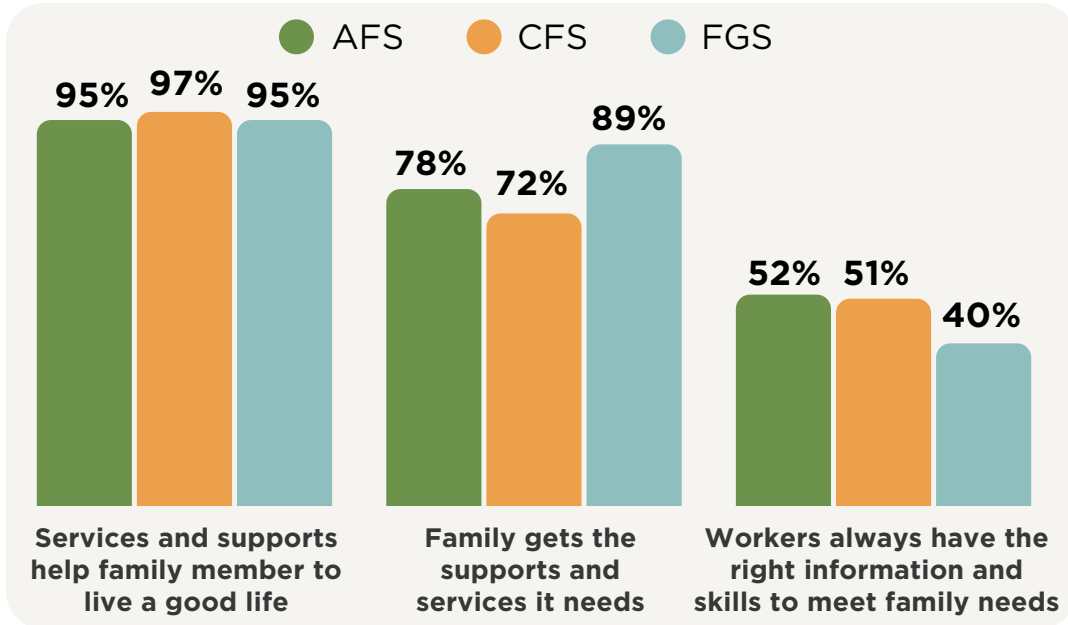


FAMILY SURVEYS: CROSS-SURVEY COMPARISONS OF 2024-25 DATA

INTRODUCTION

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.



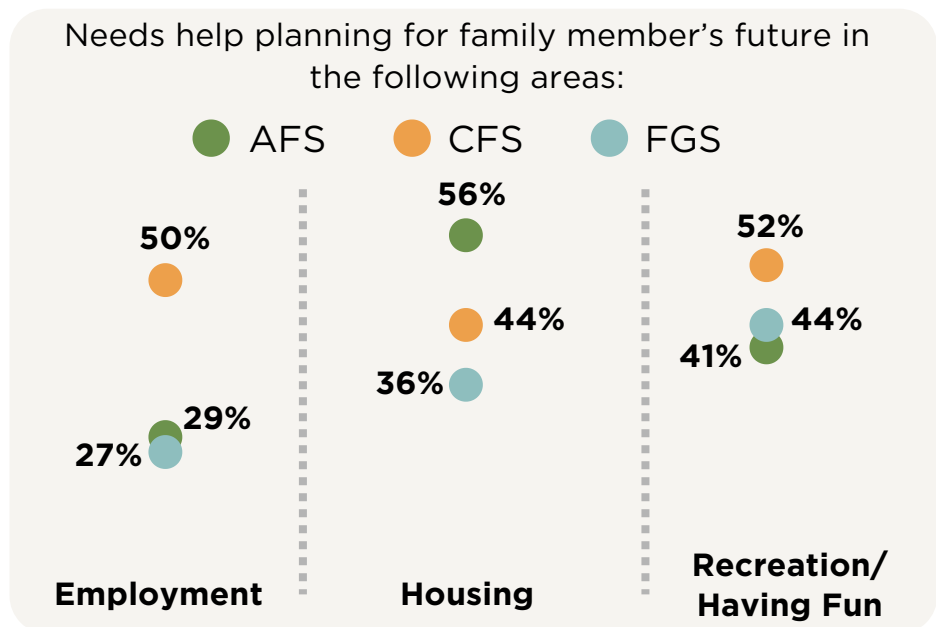
Across the family surveys, respondents overwhelmingly agree that the **services and supports they receive help their family member to live a good life.**

At the same time, **families still have unmet needs.** For example, between 72%-89% of respondents say their family gets all the services and supports they need; similarly, between 40%-52% of respondents say workers always have the right information and skills to meet family needs.

The Family Survey data can be used to look at areas where families need more support. The figure to the right shows three of the most common areas that respondents say they need help planning for their family member's future:

There are notable differences:

- 1 in every 2 **CFS respondents need help planning for employment**
- Over 1 in every 2 **AFS respondents need help planning for housing**
- More than 2 in every 5 **FGS respondents need help planning for recreation opportunities**

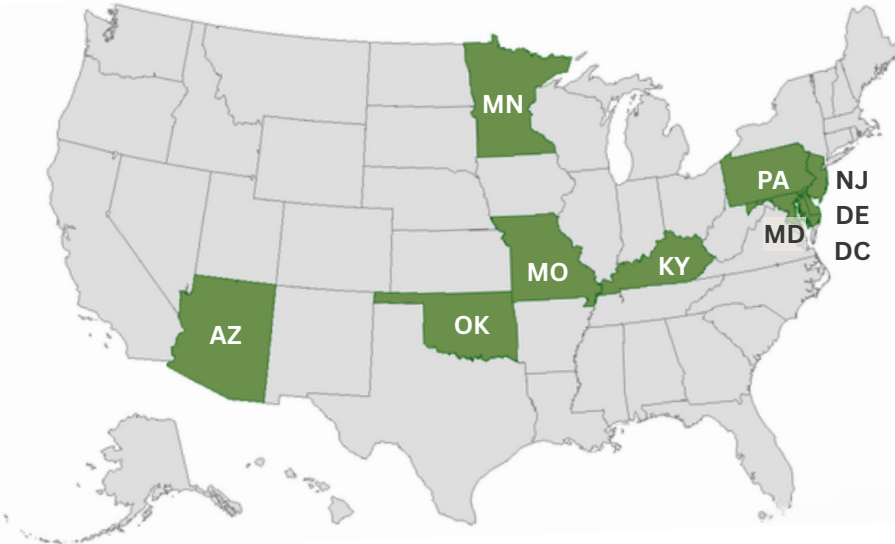


These data highlight how people throughout the lifespan have unique needs, and so do their families. For example, AFS respondents, who are family members to adults living at home, are often aging parents living with their aging child with IDD. Meanwhile, CFS respondents are parents to children and adolescents who are planning to transition from school to post-secondary service systems. As states work to strengthen services, **it is essential to use data to learn more about who uses services and what additional supports they need.**

ADULT FAMILY SURVEY: 2024-25 SAMPLE DETAILS

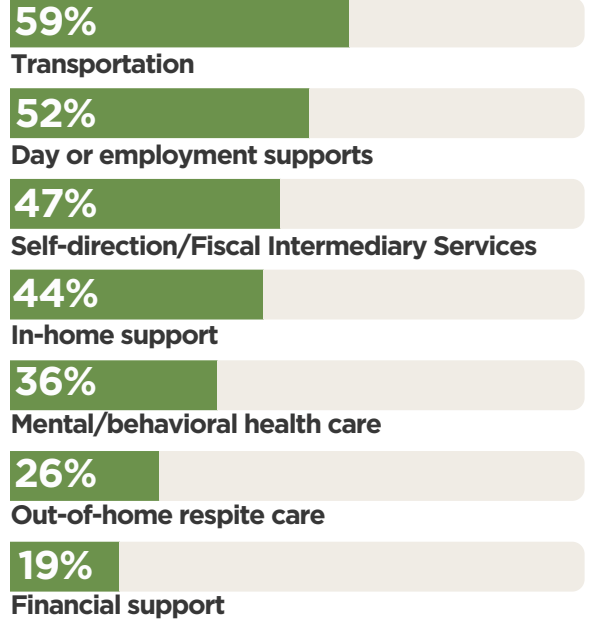
SAMPLE

3,185 respondents from **10 states**



Respondents are families living with an adult family member who receives services from the state DD system. All data are based on respondent report.

SERVICES FAMILIES REPORT RECEIVING FROM DD AGENCY

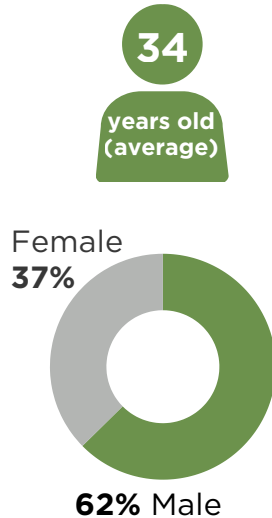


CHARACTERISTICS OF THE ADULT FAMILY MEMBER RECEIVING SERVICES

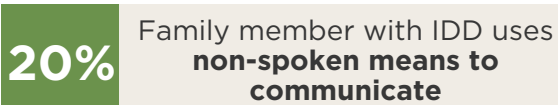
Race and Ethnicity

- 74%: White
- 11%: Black or African American
- 9%: Hispanic/Latino
- 5%: Asian
- 2%: American Indian/Alaska Native
- 1%: Other

Age and Gender

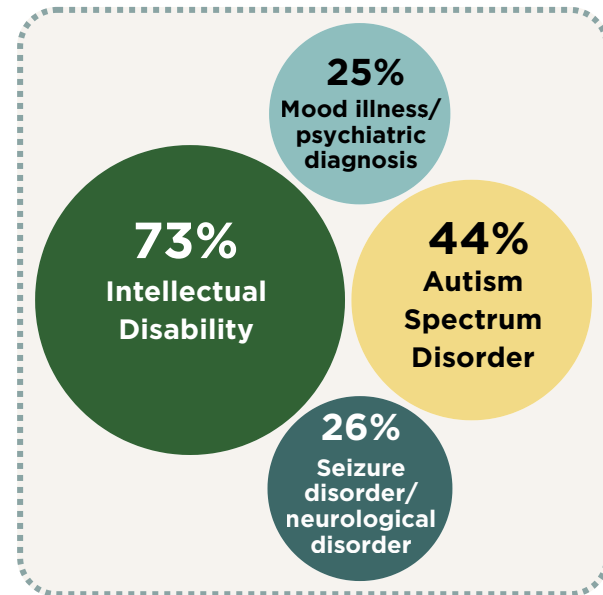


Communication



Diagnoses

Note: Diagnoses are not mutually exclusive.



FAMILY CHARACTERISTICS



33% live in rural area
67% live in urban or suburban area



51% Family provides paid support to family member



33% Total taxable household income \$50,000 or less



69% Family member has a legal guardian

ADULT FAMILY SURVEY: 2024-25 OUTCOMES

ACCESS AND DELIVERY



34% say family member uses technology in their everyday life to help them do things on their own



42% say services and supports always change when family's needs change



69% say family member with IDD helped make their service plan

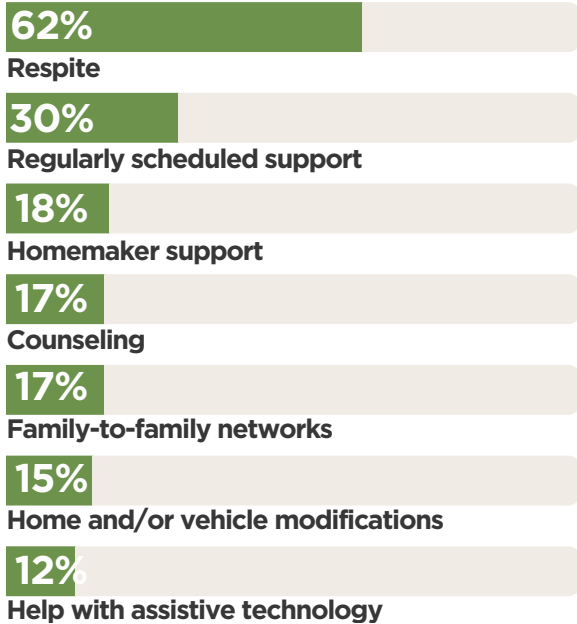


73% say case manager/service coordinator always listens to family's choices and opinions



78% say family gets the supports and services it needs

Additional services needed (among families that report that they do not get all the services they need)



HEALTH, WELFARE, AND SAFETY



Say family member can always see primary care provider when needed



Say family member can always see dentist when needed



Say family member can always get mental/behavioral health supports when needed

WORKFORCE



About 3 in every 4 families (**78%**) say there is **always** a staff person available to support family member when support is needed



About 2 in every 3 families (**64%**) can always choose or change family member's support workers



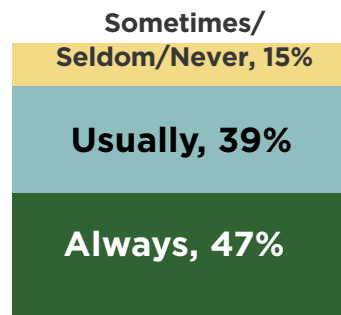
About 1 in every 2 families (**45%**) say there are **always** support workers who can communicate with family members *who do not communicate verbally*



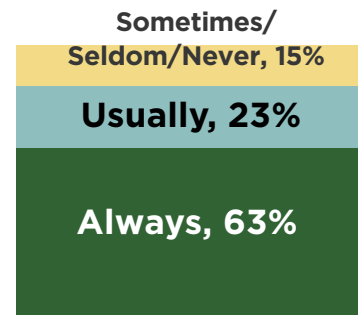
About 1 in 3 families (**34%**) say family member's support workers change too often

FAMILY SATISFACTION

96% say services and supports have made a positive difference in the life of family member



Satisfied with services and supports for family member

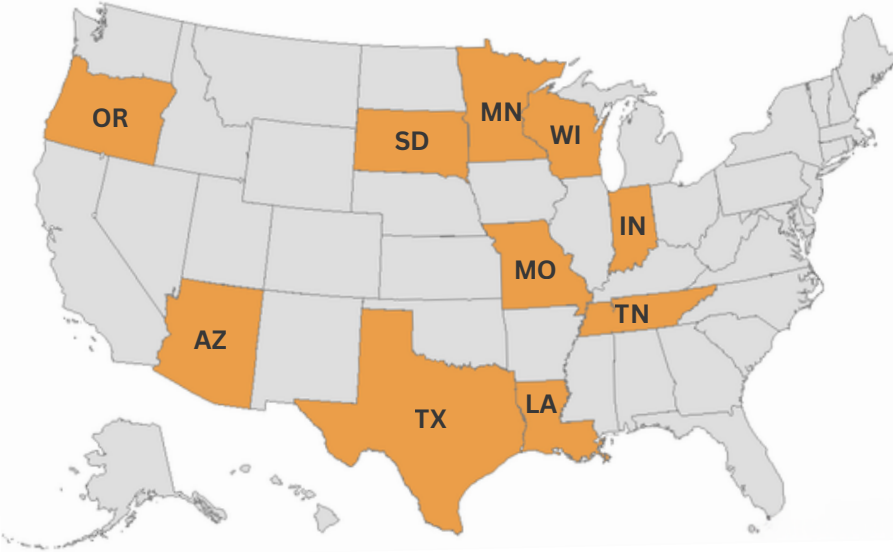


Satisfied with quality of respite care in past 12 months

CHILD FAMILY SURVEY: 2024-25 SAMPLE DETAILS

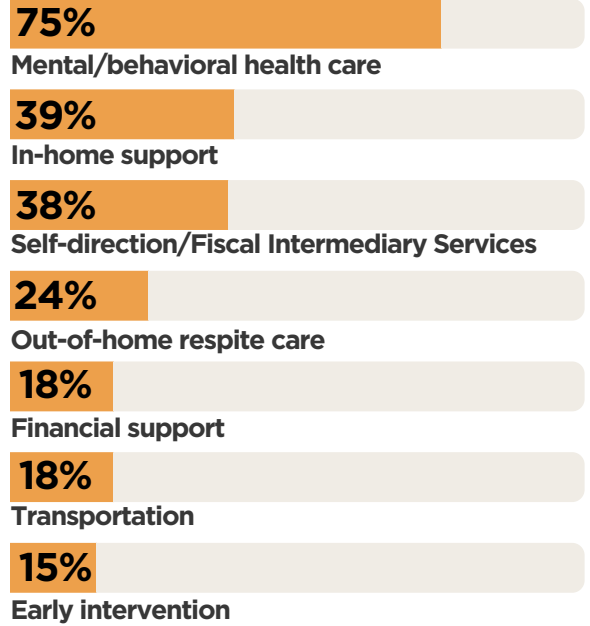
SAMPLE

4,113 respondents from **10 states**



Respondents are families living with a child who receives services from the state DD system. All data are based on respondent report.

SERVICES FAMILIES REPORT RECEIVING FROM DD AGENCY

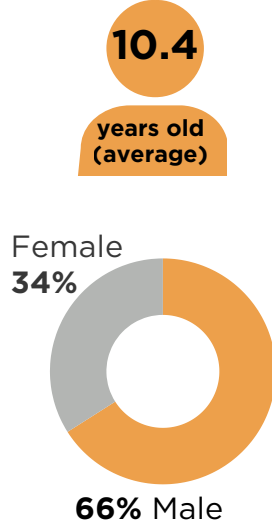


CHARACTERISTICS OF THE CHILD RECEIVING SERVICES

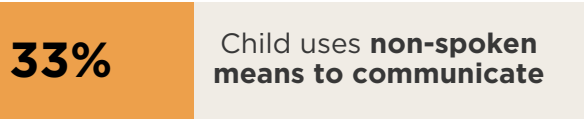
Race and Ethnicity

- 60%: White
- 28%: Hispanic/Latino
- 14%: Black or African American
- 5%: Asian
- 3%: American Indian/Alaska Native
- 1%: Pacific Islander
- 2%: Other

Age and Gender

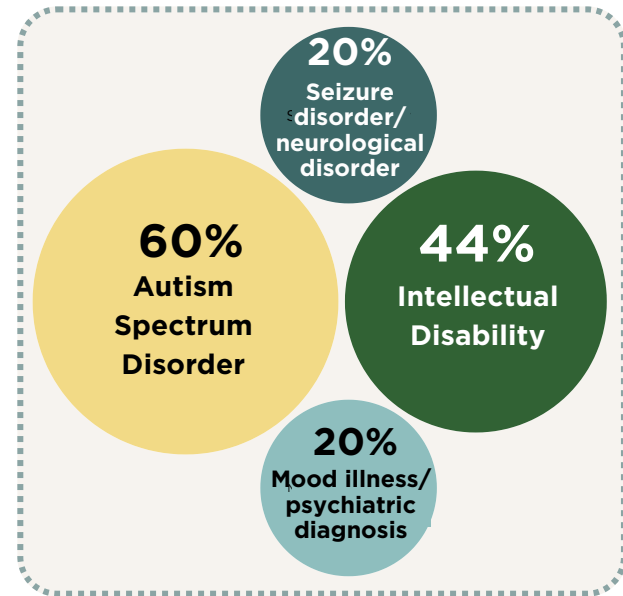


Communication



Diagnoses

Note: Diagnoses are not mutually exclusive.



FAMILY CHARACTERISTICS



26% live in rural area
74% live in urban or suburban area



32% Family provides paid support to family member



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



38% Family receives social security benefits

CHILD FAMILY SURVEY: 2024-25 OUTCOMES

ACCESS AND DELIVERY



21% say child with IDD helped make their service plan



44% say services and supports always change when family's needs change



44% say child uses technology in their everyday life to help them do things on their own

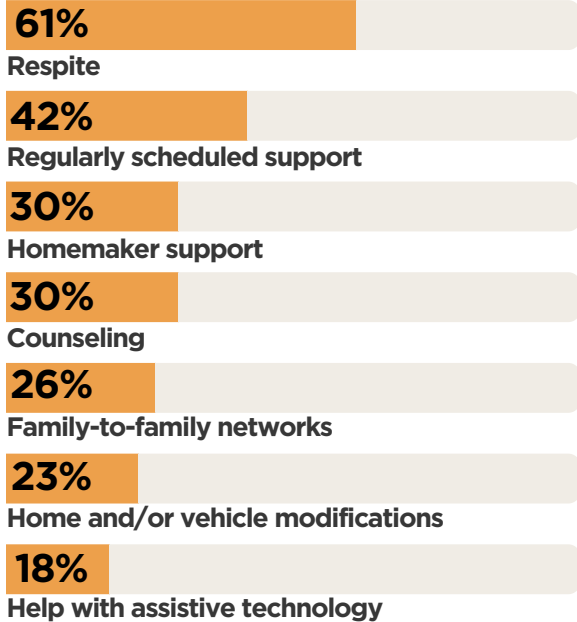


70% say case manager/service coordinator always listens to family's choices and opinions

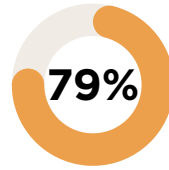


72% say family gets the supports and services it needs

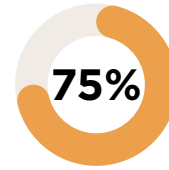
Additional services needed (among families that report that they do not get all the services they need)



HEALTH, WELFARE, AND SAFETY



Say family member can always see primary care provider when needed



Say family member can always see dentist when needed



Say family member can always get mental/behavioral health supports when needed

WORKFORCE



About 3 in every 4 families (**76%**) say there is **always** a staff person available to support child when support is needed



About 2 in every 3 families (**62%**) can always choose or change child's support workers



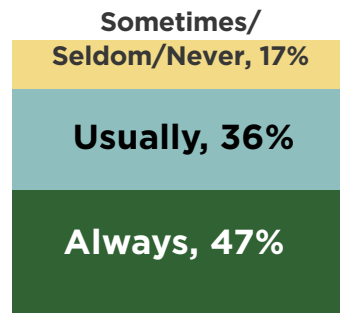
About 1 in every 2 families (**45%**) say there are **always** support workers who can communicate with child *who does not communicate verbally*



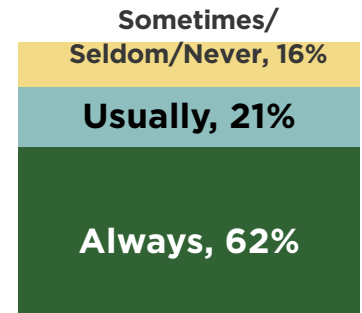
About 1 in 4 families (**28%**) say child's support workers change too often

FAMILY SATISFACTION

96% say services and supports have made a positive difference in the life of child



Satisfied with services and supports for child

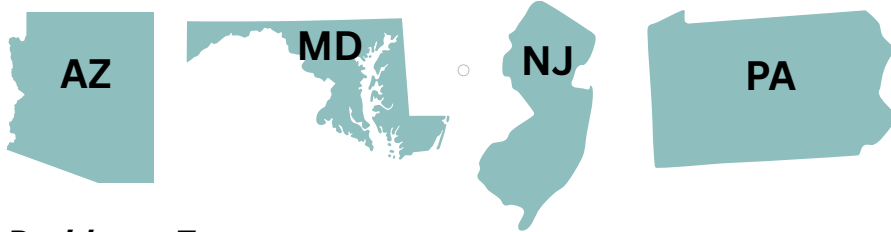


Satisfied with quality of respite care in past 12 months

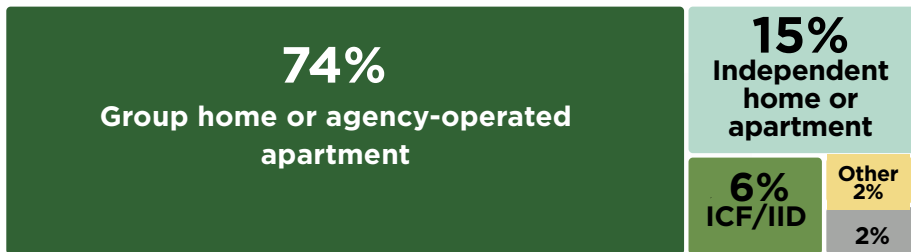
FAMILY GUARDIAN SURVEY: 2024-25 SAMPLE DETAILS

SAMPLE

1,315 respondents from **4 states**

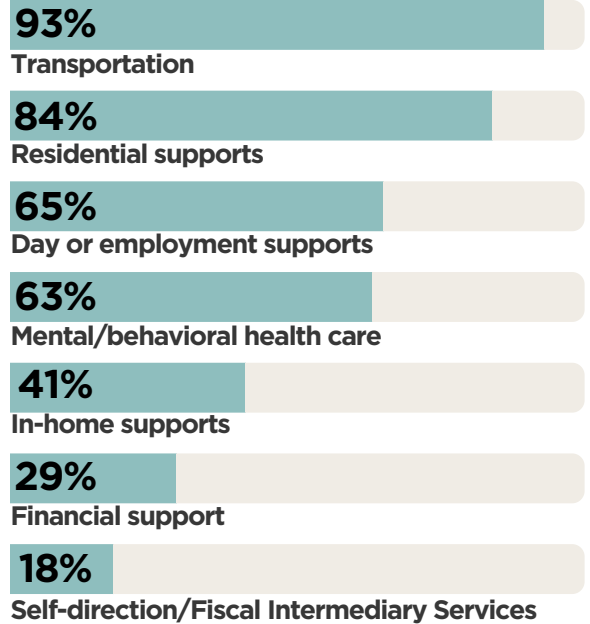


Residence Type



Respondents are families/guardians whose family member receiving services does not live with them. All data are based on respondent report.

SERVICES FAMILIES REPORT RECEIVING FROM DD AGENCY

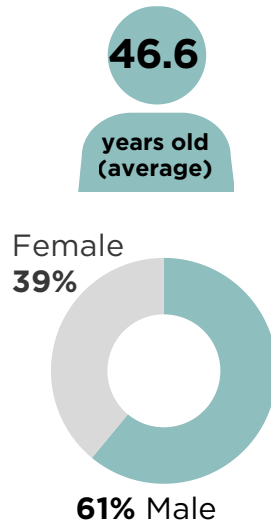


CHARACTERISTICS OF THE ADULT FAMILY MEMBER RECEIVING SERVICES

Race and Ethnicity

85%: White
7%: Black or African American
3%: Hispanic/Latino
2%: Asian
1%: American Indian/Alaska Native
1%: Other

Age and Gender

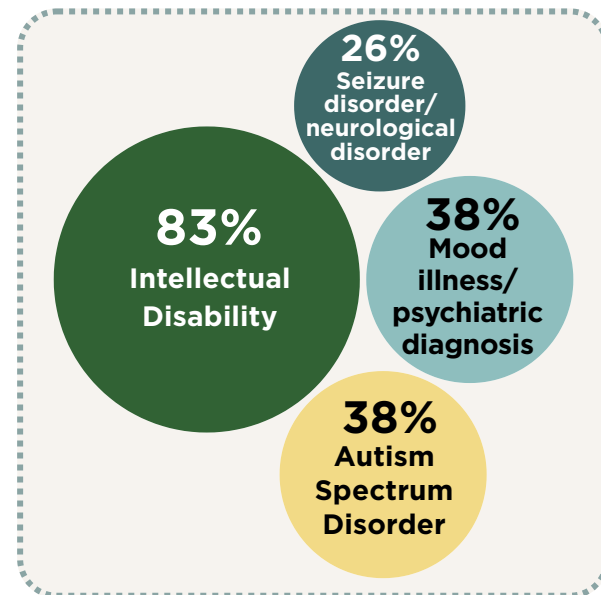


Communication

21% Family member with IDD uses non-spoken means to communicate

Diagnoses

Note: Diagnoses are not mutually exclusive.



OTHER CHARACTERISTICS



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



33% Family member's highest level of education is high school diploma/GED



96% Family member receives Social Security benefits



70% Family member has a legal guardian

FAMILY GUARDIAN SURVEY: 2024-25 OUTCOMES

ACCESS AND DELIVERY



26% say family member uses technology in their everyday life to help them do things on their own



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



59% say case manager/service coordinator always listens to family's choices and opinions



67% say family member with IDD helped make their service plan



89% say family gets the supports and services it needs

Additional services needed (among families that report that they do not get all the services they need)

23%
Regularly scheduled support

23%
Counseling

15%
Homemaker support

15%
Family-to-family networks

14%
Respite

14%
Home and/or vehicle modifications

12%
Help with assistive technology

HEALTH, WELFARE, AND SAFETY



Say family member can always see primary care provider when needed



Say family member can always see dentist when needed



Say family member can always get mental/behavioral health supports when needed

WORKFORCE



About 4 in 5 families (**82%**) say there is **always** a staff person available to support family member when support is needed



About 1 in every 2 families (**46%**) say agency always keeps them informed about how their family member is doing



About 1 in 2 families (**48%**) say there are **always** support workers who can communicate with family members *who do not communicate verbally*



About 1 in every 2 families (**47%**) say family member's support workers change too often

FAMILY SATISFACTION

94% say services and supports have made a positive difference in the life of family member

Sometimes/
Seldom/Never, 13%

Usually, 44%

Always, 43%

Satisfied with services and supports for family member

Sometimes/
Seldom/Never, 22%

Usually, 29%

Always, 49%

Agency providing residential supports involves family member in important decisions