



2023 CHILD FAMILY SURVEY REPORT

Prepared by the Partnership for People with
Disabilities & Virginia Commonwealth University



VCU Partnership for People
with Disabilities
School of Education



This report includes information from a sample of family members of children under the age of 18 with intellectual and developmental disabilities (IDD) who use services from the Building Independence (BI), Family and Individual Supports (FIS), and Community Living (CL) waivers.

Questions about this report should be referred to Parthy Dinora at padinora@vcu.edu.

For more information about NCI in Virginia, visit our website at: <https://nci.partnership.vcu.edu/>.

February 2024

The Partnership for People with Disabilities is a university center for excellence in developmental disabilities at Virginia Commonwealth University (VCU). VCU is an equal opportunity/affirmative action university providing access to education and employment without regard to age, race, color, national origin, gender, religion, sexual orientation, veteran's status, political affiliation, or disability. If alternative formats of this document are needed, please contact the Partnership at (804) 828-3876 or (800) 828-1120 (TTY Relay).

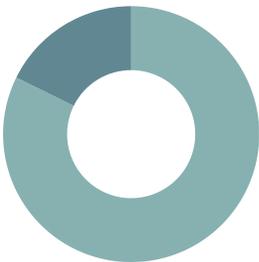


ABOUT THE RESPONDENTS

The survey results represent the opinions of those who responded and may not be representative of the experiences of all families across Virginia.

The total number of respondents was 161 with a 19% return rate.

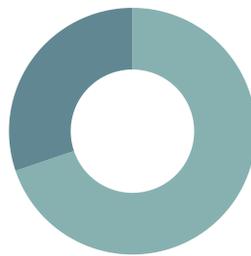
Relationship to Child



79% Parents
(biological, adoptive, or foster)

17% Grandparents

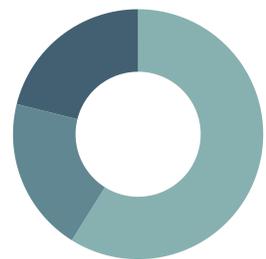
Age of Respondent



67% 35-54
years of age

29% 55-74
years of age

Highest Education Level



53% College degree
or higher

18% Some college

19% High school
diploma or GED

ABOUT THE RESPONDENTS

Self-reported Health



4%

Poor health

25%

Fair health

Children with Disabilities in Household



59%

Have more than one child with a disability

Geographical Area



65%

Urban/Suburban



35%

Rural

Out-of-Pocket Money Spent on Child's Services



27% \$101 - \$1,000

29% \$1,001 - \$10,000

Household Income



14% Under \$25,000

30% \$25,000-\$75,000

26% Over \$75,000



ABOUT THE CHILDREN USING SERVICES



CHILD'S RACE & ETHNICITY*

64% White

17% Black/African American

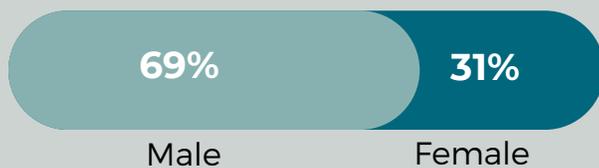
14% Asian

10% Hispanic/Latino

3% American Indian/Alaskan Native

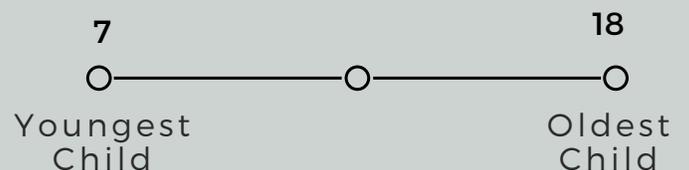
**More than one race or ethnicity could be selected*

CHILD'S GENDER



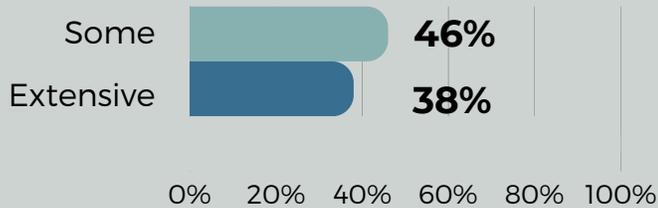
AGE INFORMATION

Mean age: 14

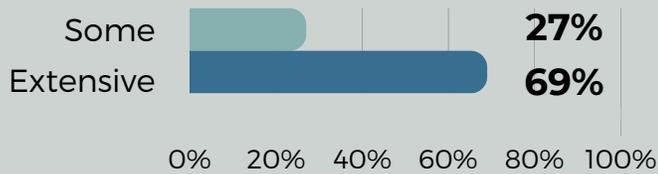


ABOUT THE CHILDREN USING SERVICES

BEHAVIOR MANAGEMENT ASSISTANCE



PERSONAL CARE ACTIVITIES



CHILD'S DISABILITIES*

- 71% Autism Spectrum Disorder
- 34% Intellectual Disability (ID)
- 29% Seizure Disorder and/or Neurological Problem
- 27% Mood Illness/Psychiatric Disorder
- 15% Cerebral Palsy

**More than one disability could be selected*

CHILD'S COMMUNICATION METHODS

- 56% Spoken
- 23% Gestures/body language
- 13% Communication aid/device
- 2% Sign language or finger spelling



"Some support" is defined as "requires only occasional assistance or monitoring" while "Extensive support" is defined as "frequent or severe enough to require regular assistance".

INFORMATION & PLANNING

63% Always/Usually have enough information to participate in planning

67% Say the information they get about services and supports is easy to understand

93% Feel their case manager/support coordinator respects their family's choices and opinions

93% Are able to contact their child's case manager/support coordinator when they want to

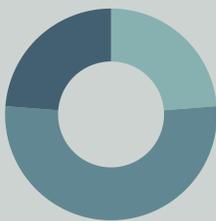
77% Know how to report abuse or neglect

SAID "YES" THEY NEED HELP PLANNING FOR CHILD'S FUTURE IN THESE AREAS*

Legal	70%
Financial	69%
Transition from School	69%
Employment	64%
Housing	60%
Social/Relationships	55%
Recreation/Having Fun	55%
Medical	51%

**More than one answer option could be selected*

DID ANYONE IN THE FAMILY CHOOSE THE CHILD'S CASE MANAGER/SUPPORT COORDINATOR?



24% Chose case manager/support coordinator

53% Did not choose case manager/support coordinator but can change if wanted

24% Did not choose case manager/support coordinator and cannot change if wanted



SERVICE PLANS

85%

Have a service plan for their child

80%

Say their service plan includes all the services and supports their child needs

88%

Helped make the child's service plan

44%

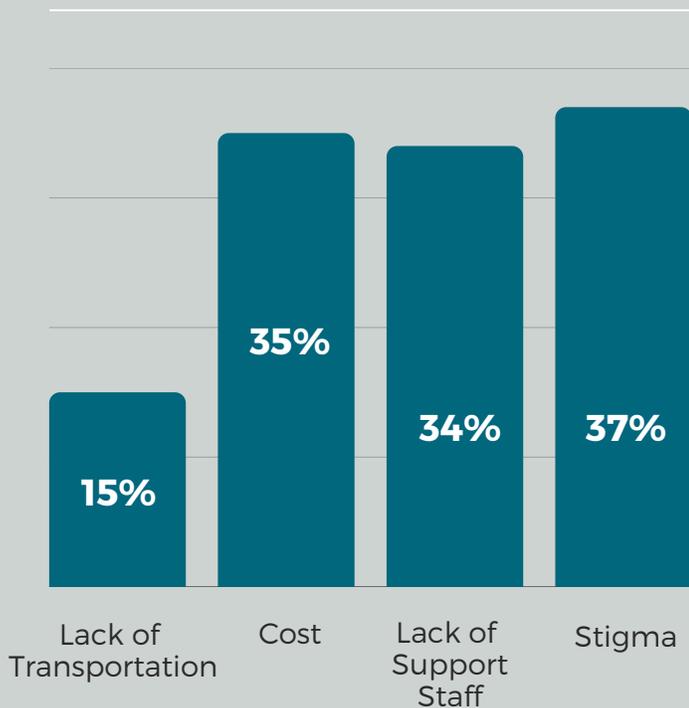
Have a transition plan for their child (ages 14 and above)

17%

Had the child with a disability help make the service plan

ACCESS & DELIVERY OF SUPPORTS

BARRIERS TO PARTICIPATING IN COMMUNITY ACTIVITIES*



*More than one answer option could be selected

Family gets the supports and services they need



Services are delivered in a way that is respectful to the family's culture



Child has the special equipment accommodations that they need (for example wheelchair, ramp, communication board, etc.)



Services and supports change when the family's needs change



Support workers speak to them in a way that they understand



ACCESS & DELIVERY OF SUPPORTS

92%

Child can see health professionals (for example a doctor, dentist, psychologist, etc.) when needed

89%

Child's primary care doctor understands the child's needs related to their disability

85%

Can go to the dentist when needed

83%

Dentist understands the child's needs related to their disability

80%

Mental health professionals understand the child's needs related to their disability (for example a psychologist, psychiatrist, counselor)

46%

Have access to respite services when needed





OUTCOMES

78%

Services and supports reduced out-of-pocket expenses

63%

Family gets the supports and services they need

90%

Services and supports help child live a good life

90%

Family supports improved ability to care for child

94%

Services and supports have made a positive difference