2023 CHILD FAMILY SURVEY REPORT
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.
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

CHILDS 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

69% Male
31% Female

AGE INFORMATION

Mean age: 14

7

Youngest Child

18

Oldest Child
ABOUT THE CHILDREN USING SERVICES

BEHAVIOR MANAGEMENT ASSISTANCE

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<th>Some</th>
<th>Extensive</th>
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<tr>
<td>Some</td>
<td>46%</td>
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<tr>
<td>Extensive</td>
<td>38%</td>
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PERSONAL CARE ACTIVITIES

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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".
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
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*

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<th>Barrier</th>
<th>Percentage</th>
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<tr>
<td>Lack of Transportation</td>
<td>15%</td>
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<tr>
<td>Cost</td>
<td>35%</td>
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<tr>
<td>Lack of Support Staff</td>
<td>34%</td>
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<tr>
<td>Stigma</td>
<td>37%</td>
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*More than one answer option could be selected

- Family gets the supports and services they need: 63%
- Services are delivered in a way that is respectful to the family’s culture: 97%
- Child has the special equipment accommodations that they need (for example wheelchair, ramp, communication board, etc.): 70%
- Services and supports change when the family’s needs change: 76%
- Support workers speak to them in a way that they understand: 96%
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