



2022 ADULT FAMILY SURVEY REPORT

FAMILY MEMBERS OVER THE AGE OF 18 WHO USE
MEDICAID DEVELOPMENTAL DISABILITY SERVICES

MAY 2023

PREPARED BY THE PARTNERSHIP FOR PEOPLE WITH DISABILITIES AT VIRGINIA COMMONWEALTH UNIVERSITY



VCU

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School of Education | **Partnership for
People with Disabilities**



Virginia Department of
Behavioral Health &
Developmental Services

This report includes information from a sample of families with family members of adults over 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. Family members responded to one of two surveys: a survey for families who have an adult family member over 18 who lives in the family home, or a survey for families who have an adult family member over 18 who lives outside of the family home.

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

The following terms will be used throughout the survey:

- "Respondent" is the person who completed the survey.
- "Family Member" is the person using services from the Building Independence (BI), Family and Individual Supports (FIS) and Community Living (CL) waivers.
- "Family" refers to the Respondent and Family Member.

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 and 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.

TOTAL NUMBER OF SURVEY RESPONSES:

Out of Family Home = 135

In Family Home = 129

"Out of Family Home" means that the adult family member over the age of 18 who uses Medicaid Developmental Disability Services lives outside of the family home, while "In Family Home" means that they live in the family home.

**Indicates a statistically significant difference between households with a person living out of the family home and households with a person living in the family home.*

AGE 55 OR OLDER

83%

Out of Family Home

82%

In Family Home

HAVE POOR OR FAIRLY GOOD HEALTH*

11%

Out of Family Home

32%

In Family Home

HAVE SOME COLLEGE OR A COLLEGE DEGREE*

76%

Out of Family Home

63%

In Family Home

ABOUT THE FAMILY MEMBER USING SERVICES

LIVES IN A RURAL AREA

30% Out of Family Home
41% In Family Home

AVERAGE AGE *

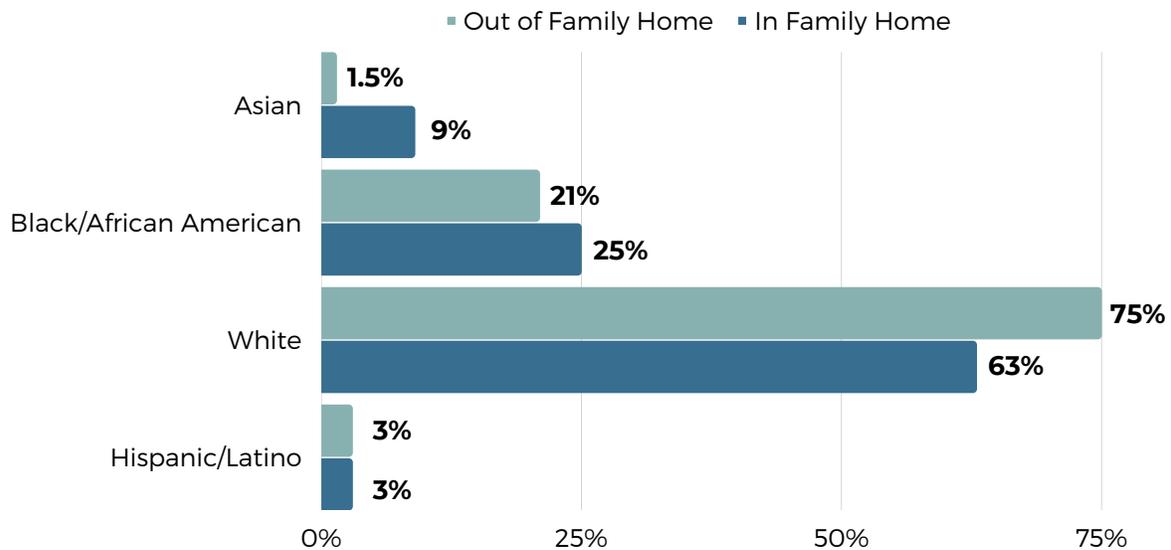
46 Out of Family Home
34 In Family Home

HAS A COURT-APPOINTED LEGAL GUARDIAN

79% Out of Family Home
77% In Family Home



RACE/ETHNICITY



*Indicates a statistically significant difference between households with a person living out of the family home and households with a person living in the family home.

ABOUT THE FAMILY MEMBER USING SERVICES



NEEDS SOME OR EXTENSIVE SUPPORT WITH DAILY ACTIVITIES



NEEDS SOME OR EXTENSIVE SUPPORT WITH PERSONAL ASSISTANCE



NEEDS SOME OR EXTENSIVE SUPPORT TO MANAGE BEHAVIORS*



*Indicates a statistically significant difference between households with a person living out of the family home and households with a person living in the family home.

"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

RESPONDENT ALWAYS/USUALLY GETS ENOUGH INFORMATION TO TAKE PART IN PLANNING SERVICES FOR THEIR FAMILY MEMBER

86% Out of Family Home

76% In Family Home

THE INFORMATION ABOUT SERVICES AND SUPPORTS IS ALWAYS/USUALLY EASY TO UNDERSTAND FOR THE RESPONDENT*

87% Out of Family Home

75% In Family Home

THE CASE MANAGER/SUPPORT COORDINATOR ALWAYS/ USUALLY RESPECTS FAMILY'S CHOICES AND OPINIONS

93% Out of Family Home

95% In Family Home

SERVICE PLAN INCLUDES ALL SERVICES/ SUPPORTS THE FAMILY MEMBER NEEDS

93% Out of Family Home

85% In Family Home

FAMILY MEMBER GETS ALL SERVICES IN THE SERVICE PLAN*

92% Out of Family Home

77% In Family Home



**Indicates statistically significant difference between households with person living out of the family home and households with person living in the family home.*

ACCESS & DELIVERY OF SUPPORTS

FAMILY IS ALWAYS/USUALLY ABLE TO CONTACT CASE MANAGER/ SUPPORT COORDINATOR



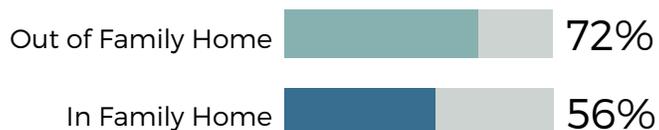
FAMILY IS ALWAYS/USUALLY ABLE TO CONTACT SUPPORT WORKERS



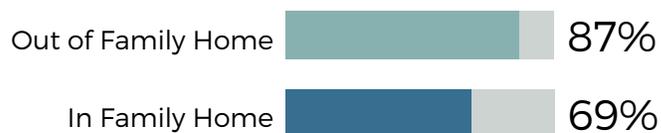
RESPONDENT KNOWS WHO TO TALK TO IF HAVING PROBLEMS WITH CASE MANAGER/ SUPPORT COORDINATOR



RESPONDENT KNOWS HOW TO FILE COMPLAINT/GRIEVANCE ABOUT PROVIDER AGENCIES/ STAFF*



FAMILY GETS THE SERVICES AND SUPPORTS NEEDED



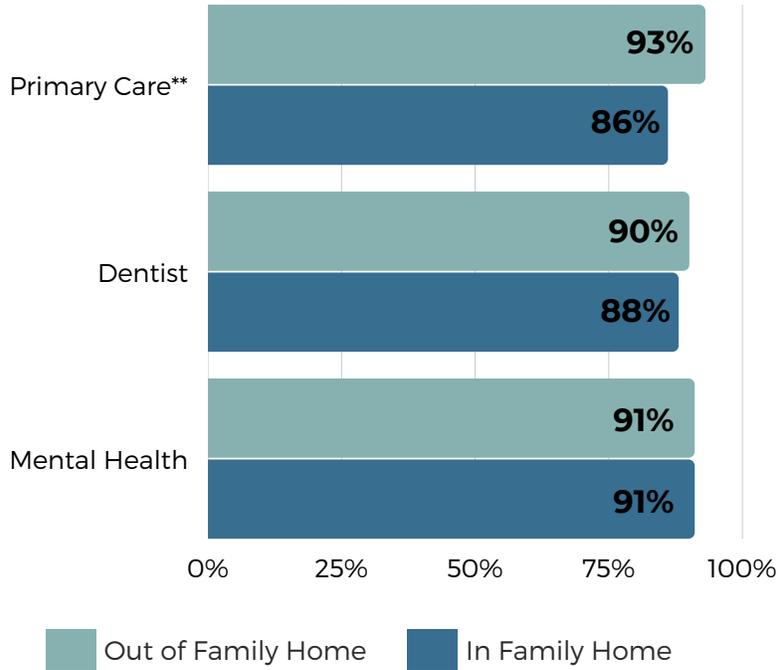
SERVICES AND SUPPORTS ALWAYS/USUALLY CHANGE WHEN FAMILY'S NEEDS CHANGE*



*Indicates statistically significant difference between households with person living out of the family home and households with person living in the family home.

HEALTH & SAFETY

PROVIDER ALWAYS/USUALLY UNDERSTANDS FAMILY MEMBER'S NEEDS RELATED TO THEIR DISABILITY



**Primary Care provider includes doctors, nurses, etc.

FAMILY MEMBER CHOSE THEIR PRIMARY CARE DOCTOR

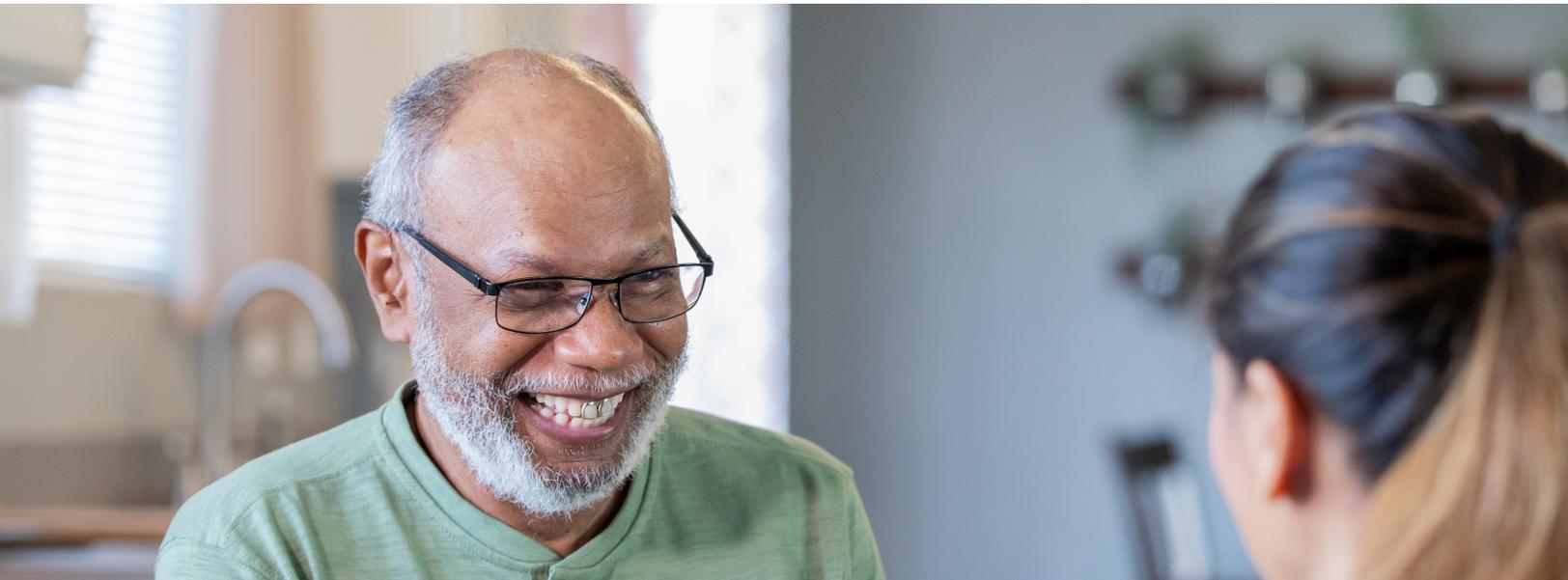
36% Out of Family Home
35% In Family Home

FAMILY MEMBER CAN ALWAYS/USUALLY SEE A PRIMARY CARE PROVIDER WHEN NEEDED

89% Out of Family Home
94% In Family Home

FAMILY MEMBER CAN ALWAYS/USUALLY GO TO THE DENTIST WHEN NEEDED*

92% Out of Family Home
82% In Family Home



**Indicates statistically significant difference between households with person living out of the family home and households with person living in the family home.*

COMMUNITY INVOLVEMENT



FAMILY MEMBER PARTICIPATES IN COMMUNITY ACTIVITIES

87%

Out of Family Home

84%

In Family Home

FAMILY PARTICIPATES IN FAMILY-TO-FAMILY NETWORKS IN COMMUNITY

22%

Out of Family Home

18%

In Family Home

FAMILY MEMBER HAS ENOUGH SUPPORTS TO WORK/VOLUNTEER IN THE COMMUNITY*

68%

Out of Family Home

43%

In Family Home

**Indicates statistically significant difference between households with person living out of the family home and households with person living in the family home.*



OUTCOMES & SATISFACTION

SERVICES AND SUPPORTS HAVE MADE A POSITIVE DIFFERENCE FOR FAMILY MEMBER

94%

Out of Family Home

87%

In Family Home

SERVICES AND SUPPORTS HELP FAMILY MEMBER LIVE A GOOD LIFE*

97%

Out of Family Home

86%

In Family Home

**Indicates statistically significant difference between households with person living out of the family home and households with person living in the family home.*