



## **Family Guardian Survey (FGS) State Report**

### **2022-2023 Pennsylvania Report**

## Table of Contents

Executive Summary.....	8
Results .....	10
Presentation of the Data.....	11
Demographics.....	12
Family Member .....	13
Table 1a. Family Member’s Residence .....	14
Table 1b. Family Member’s Residence (Continued).....	15
Table 2. Family Member’s Time Living In Current Residence .....	16
Table 3. Family Member’s Residential Designation .....	17
Table 4. Family Member’s Age .....	18
Table 5. Family Member’s Gender .....	19
Table 6a. Family Member’s Race/Ethnicity .....	20
Table 6b. Family Member’s Race/Ethnicity (continued) .....	21
Table 7a. Family Member’s Conditions.....	22
Table 7b. Family Member’s Conditions (Continued) .....	23
Table 7c. Family Member’s Conditions (Continued).....	24
Table 8a. Family Member’s Health Conditions.....	25
Table 8b. Family Member’s Health Conditions (Continued) .....	26
Table 8c. Family Member’s Health Conditions (Continued).....	27
Table 9. Family Member’s Preferred Means of Communication .....	28
Table 10a. Family Member’s Preferred Language.....	29
Table 10b. Family Member’s Preferred Language (continued) .....	30
Table 11. Family Member Has Legal Court Appointed Guardian or Conservator	31
Table 12. Guardian or Conservator Relationship to Family Member .....	32
Table 13a. Family Member’s Highest Level of Education.....	33
Table 13b. Family Member’s Highest Level of Education (Continued) .....	34
Table 14. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors.....	35
Table 15. Family Member’s Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating).....	36
Table 16. Family Member’s Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping) .....	37

Respondents .....	38
Table 17a. Language Usually Spoken at Home .....	39
Table 17b. Language Usually Spoken at Home (continued).....	40
Table 18. Respondent’s Age .....	41
Table 19. Respondent’s Health.....	42
Table 20a. Respondent’s Relationship to Family Member .....	43
Table 20b. Respondent’s Relationship to Family Member (continued).....	44
Table 21. Respondent’s Frequency of Visits with Family Member In The Past 12 Months .....	45
Table 22. Respondent’s Highest Level of Education.....	46
Table 23a. Total Taxable Household Income of Wage Earners in the last year ...	47
Table 23b. Total Taxable Household Income of Wage Earners in the last year (continued).....	48
Services and Supports Received .....	49
Table 24a. Services and Supports Received from IDD Agency .....	50
Table 24b. Services and Supports Received from State (continued) .....	51
Table 25. Additional Services and Supports Received (not from the IDD Agency) .....	52
Main Survey Results.....	53
Information and Planning .....	54
Table 26. Do you get enough information to take part in planning services for your family member?.....	55
Table 27. Is the information you get about services and supports easy to understand?.....	56
Table 28. Do you get information about services and supports in your preferred language? .....	57
Table 29. Does the case manager or service coordinator listen to your family’s choices and opinions?.....	58
Table 30. Do staff or the residential agency keep you informed about how your family member is doing? .....	59
Table 31a. Do you need help planning for your family member’s future in any of these areas? .....	60
Table 31b. Do you need help planning for your family member’s future in any of these areas? (Continued).....	61
Table 32. Has your family learned about alternatives to guardianship? .....	62

Table 33. Does your family member have a service plan? .....	63
Table 34. Does the plan include all the services and supports your family member needs? .....	64
Table 35. Did you or someone else in your family (besides your family member with a disability) help make the plan? .....	65
Table 36. Did your family member help make the plan? .....	66
Table 37. Do you feel like your family had enough say or input in making the plan?.....	67
Table 38. Did your family member leave school services and begin adult services during the past 12 months? .....	68
Table 39. If your family member left school services during the past 12 months, did your family member have a transition plan? .....	69
Table 40. If your family member had a transition plan, did the transition plan include getting or continuing work in a community job .....	70
Access and Delivery of Services and Supports .....	71
Table 41. Does your family member get all the services listed in the plan? .....	72
Table 42. Does your family get the supports and services it needs? .....	73
Table 43a. If your family does not get the support and services needed, what additional services does your family need?.....	74
Table 43b. If your family does not get the support and services needed, what additional services does your family need? (Continued) .....	75
Table 44. Do services and supports change when your family's needs change? 76	
Table 45. Does your family member have enough supports to work or volunteer in the community? (These types of supports might include support workers, community resources, transportation) .....	77
Table 46. Does your family member have the special equipment or accommodations that they need? .....	78
Table 47. Are you or your family member able to contact support workers when you want? .....	79
Table 48. Are you or your family member able to contact the case manager or service coordinator when you want? .....	80
Table 49. Do service providers for your family member work together to provide support?.....	81
Table 50. Are services delivered in a way that is respectful of your family's culture? .....	82

Table 51. Does your family member use technology in their everyday life to help them do things on their own? .....	83
Table 52. Is there a computer, tablet (iPad or similar), or smartphone that you can use in your home? .....	84
Table 53. How well does the internet work in your home? .....	85
Workforce .....	86
Table 54. Do support workers come and go when they are supposed to? .....	87
Table 55. Do support workers speak to you in a way you understand? .....	88
Table 56. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them? .....	89
Table 57. Do support workers have the right information and skills to meet your family's needs?.....	90
Table 58. Do your family member's support workers change too often? Is there too much "turnover" of support workers? .....	91
Table 59. Is there always a staff person available to support your family member when support is needed?.....	92
Choice, Decision Making and Control.....	93
Table 60. Can someone in your family choose or change the provider agency that provides your family member's services? .....	94
Table 61. Can someone in your family choose or change your family member's support workers? .....	95
Table 62. Can someone in your family directly manage support staff? .....	96
Table 63. Did you, your family member, or someone else in your family choose your family member's case manager or service coordinator?.....	97
Community Connections.....	98
Table 64. Does your family member do things in the community? .....	99
Table 65. For your family member, what makes it hard to do things in the community? .....	100
Table 66. Does your family member have friends other than paid support workers or family? .....	101
Table 67. In your community, are there resources or support that your family member can use that are not provided by the I/DD agency? .....	102
Table 68. Does your family take part in any family-to-family networks in your community?.....	103
Health, Welfare and Safety.....	104

Table 69. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed? .....	105
Table 70. Does your family member’s primary care provider (doctor, registered nurse, etc.) understand your family member’s needs related to their disability? .....	106
Table 71. Can your family member go to the dentist when needed? .....	107
Table 72. Does your family member’s dentist understand your family member’s needs related to their disability? .....	108
Table 73. If your family member takes prescription medications, do you know what they’re for? .....	109
Table 74. Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?.....	110
Table 75. Can your family member get mental or behavioral health supports when needed (Like see a therapist, go to group counseling)? .....	111
Table 76. Does your family member’s mental or behavioral health professional understand your family member’s needs related to their disability?.....	112
Table 77. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?.....	113
Table 78. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency, pandemic or natural disaster? .....	114
Table 79. Have you talked about how to handle emergencies (such as a medical emergency, pandemic, or natural disaster) with your family member’s case manager or service coordinator? .....	115
Table 80. Do you know how to file a complaint or grievance about provider agencies or staff? .....	116
Table 81. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?.....	117
Table 82. Do you know how to report abuse or neglect related to your family member?.....	118
Table 83. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member? .....	119
Table 84. If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?.....	120
Family Satisfaction .....	121

Table 85. Overall, are you satisfied with the services and supports your family member currently receives? ..... 122

Table 86. Do you feel that services and supports have made a positive difference in the life of your family member? ..... 123

Table 87. Does the agency providing residential services to your family member involve them in important decisions? ..... 124

Table 88. Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated? ..... 125

Table 89. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively? ..... 126

Table 90. Have the services or supports that your family member received been increased in the past 12 months? ..... 127

Table 91. Are services and supports helping your family member to live a good life? ..... 128

## Executive Summary

The National Core Indicators®-Intellectual and Developmental Disabilities (NCI-IDD) are standard measures used across states to assess the outcomes of services provided to individuals with intellectual/developmental disabilities and their families. Indicators address key areas of concern such as employment, respect/rights, service planning, community inclusion, choice, and health and safety. The data that result from NCI-IDD surveys are often used to inform strategic planning, produce legislative reports, and prioritize quality improvement initiatives. Many states also share the data with stakeholder groups such as Quality Councils and use the stakeholder feedback to help set priorities and establish policy direction.

The National Core Indicators (NCI) Family/Guardian Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who does not live in the family home and receives at least one service other than case management. Not all states that participate in NCI-IDD administer the Family/Guardian Survey on an annual basis. Of the 48 states, the District of Columbia and 22 sub-state entities that were members of NCI-IDD during the 2022-23 data collection cycle, five states submitted a valid sample of Family/Guardian Survey data: Arizona (AZ), Georgia (GA), Maryland (MD), New Jersey (NJ), and Pennsylvania (PA). This Final Report provides a summary of results based on data submitted by June 30, 2023.

### ***What is the NCI-IDD Family/Guardian Survey?***

The NCI-IDD Family/Guardian Survey is used to gather data on family outcomes. It is mailed to families or guardians who have an adult family member who does not live with the respondent and receives at least one service in addition to case management from the state DD agency. The survey collects demographic information on both the individual receiving services (“family member”) as well as the person who fills out the survey (the ‘respondent’) and information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable.

Please note that while the term “case manager” is used throughout this report, the same role may also be referred to as “service coordinator” or “supports coordinator” depending on the state.

Important note on responses: All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses, and personal characteristics.

### **What is included in this report?**

This report includes this state’s Family/Guardian Survey data compared to the NCI-IDD Average.



The charts in this document, grouped by subdomain, display the state results alongside the average across states (NCI-IDD average). The charts are followed by accessible tables containing the same information.

To find out more about the development of the Family/Guardian Survey, data analysis and state samples, check out the National Family/Guardian Survey Report.

# Results

## Presentation of the Data

In addition to basic demographic questions and questions on services received, the survey contains six groupings of questions that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes.

- Each question is constructed so the respondent selects from either four possible responses (“always”, “usually”, “sometimes”, “seldom/never”) or two responses (“yes” or “no”). Respondents also have the option to indicate that they don’t know the answer to a question or that the question is not applicable.
- Demographic results are shown in table form.
- States with 20 or fewer respondents to a question are not included in tables; however, their data **are** included in the NCI-IDD Average.
- **Note on NCI-IDD Averages:** The NCI-IDD averages contained in this report are “weighted” means; their calculations reflect the relative population sizes of participating states and the states’ sample sizes. Prior to 2016-17, NCI-IDD averages were calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”), so comparisons to past reports should be made with caution. See more about weighting in the Methodology section.
- **Note on language used in this report:** “You” and “Respondent” refers to the person (usually a parent or guardian) filling out the survey. “Family Member” refers to the person receiving services whom the respondent is answering questions about in this survey.
- **Note on responses:** All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

## Demographics

**Note on responses:** All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

**Note on responses:** Some pages in this section are in landscape orientation because some table headers cannot be displayed in full in portrait orientation.

## Family Member

This section provides demographic information about the family member receiving services.

**Please note:** All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

Table 1a. Family Member’s Residence

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Specialized facility for people with intellectual disabilities	Group home or agency-operated apartment	Independent home or apartment	N
<b>PA</b>	<b>11%</b>	<b>82%</b>	<b>2%</b>	<b>649</b>
Weighted NCI-IDD Average	10%	74%	10%	2135

*Table Note: Specialized Facility for People With Intellectual Disabilities refers to Intermediate Care Facilities (ICF), state-run or other institutional setting. Independent Home or Apartment refers to housing that is not operated by an agency, and one where the individual may or may not live with a roommate*

Table 1b. Family Member’s Residence (Continued)

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Adult foster care or host family home	Nursing Home	Homeless	Other	N
<b>PA</b>	<b>3%</b>	<b>0%</b>	<b>0%</b>	<b>1%</b>	<b>649</b>
Weighted NCI-IDD Average	3%	0%	0%	1%	2135

Table 2. Family Member’s Time Living In Current Residence

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Less than one year	One to three years	Four to five years	Over five years	N
<b>PA</b>	<b>4%</b>	<b>20%</b>	<b>12%</b>	<b>64%</b>	<b>640</b>
Weighted NCI-IDD Average	8%	24%	13%	55%	2111



Table 3. Family Member’s Residential Designation

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	N
<b>PA</b>	<b>71%</b>	<b>29%</b>	<b>638</b>
Weighted NCI-IDD Average	78%	22%	2083

Table 4. Family Member's Age

*Please note: All data in this section are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Age	N
<b>PA</b>	<b>44.8</b>	<b>650</b>
Weighted NCI-IDD Average	44.6	2132

Table 5. Family Member’s Gender

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Male	Female	Other	N
<b>PA</b>	<b>61%</b>	<b>39%</b>	<b>0%</b>	<b>650</b>
Weighted NCI-IDD Average	60%	39%	0%	2139

Table 6a. Family Member’s Race/Ethnicity

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.*

State (names abbreviated)	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander
<b>PA</b>	<b>2%</b>	<b>1%</b>	<b>5%</b>	<b>0%</b>
Weighted NCI-IDD Average	2%	2%	10%	0%

Table 6b. Family Member’s Race/Ethnicity (continued)

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.*

State (names abbreviated)	White	Hispanic or Latino	Other	Prefer not to say
<b>PA</b>	<b>89%</b>	<b>3%</b>	<b>1%</b>	<b>1%</b>
Weighted NCI-IDD Average	81%	4%	2%	2%

Table 7a. Family Member’s Conditions

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.*

State (names abbreviated)	Intellectual disability	Mood illness or psychiatric diagnosis	Autism spectrum disorder	Cerebral palsy
<b>PA</b>	<b>88%</b>	<b>45%</b>	<b>35%</b>	<b>15%</b>
Weighted NCI-IDD Average	82%	41%	37%	15%

Table 7b. Family Member’s Conditions (Continued)

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.*

State (names abbreviated)	Limited or No Vision	Hearing loss (severe or profound)	Brain injury	Seizure or neurological disorder	Chemical dependency
<b>PA</b>	<b>10%</b>	<b>7%</b>	<b>10%</b>	<b>30%</b>	<b>0%</b>
Weighted NCI-IDD Average	9%	6%	9%	27%	0%

Table 7c. Family Member’s Conditions (Continued)

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.*

State (names abbreviated)	Down syndrome	Prader-Willi Syndrome	Fetal alcohol spectrum disorder (FASD)	Other
<b>PA</b>	<b>10%</b>	<b>2%</b>	<b>2%</b>	<b>10%</b>
Weighted NCI-IDD Average	9%	2%	2%	12%



Table 8a. Family Member’s Health Conditions

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.*

State (names abbreviated)	Cardiovascular disease	Diabetes	Cancer	High blood pressure	High cholesterol
<b>PA</b>	<b>9%</b>	<b>18%</b>	<b>5%</b>	<b>29%</b>	<b>33%</b>
Weighted NCI-IDD Average	8%	18%	5%	32%	35%

Table 8b. Family Member’s Health Conditions (Continued)

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.*

State (names abbreviated)	Dysphagia	Pressure ulcers	Alzheimer's disease or dementia	Oral health problems	Sleep apnea
<b>PA</b>	<b>17%</b>	<b>4%</b>	<b>4%</b>	<b>17%</b>	<b>17%</b>
Weighted NCI-IDD Average	13%	2%	4%	16%	14%

Table 8c. Family Member’s Health Conditions (Continued)

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.*

State (names abbreviated)	Asthma	Other pulmonary diagnosis (e.g., COPD, bronchitis, emphysema)	Chronic kidney disease	Long-term health problems associated with COVID-19 (also known as Long COVID)	Other
<b>PA</b>	<b>7%</b>	<b>4%</b>	<b>5%</b>	<b>1%</b>	<b>22%</b>
Weighted NCI-IDD Average	9%	4%	4%	1%	23%

Table 9. Family Member’s Preferred Means of Communication

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Spoken	Gestures or body language	Sign language or finger spelling	Communication aid or device	Other	N
<b>PA</b>	<b>74%</b>	<b>17%</b>	<b>2%</b>	<b>1%</b>	<b>6%</b>	<b>646</b>
Weighted NCI-IDD Average	76%	16%	2%	2%	5%	2104

Table 10a. Family Member’s Preferred Language

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	English	Spanish	Chinese	N
<b>PA</b>	<b>96%</b>	<b>1%</b>	<b>0%</b>	<b>646</b>
Weighted NCI-IDD Average	96%	1%	0%	2109

*Table Note: “Chinese” includes Mandarin, Cantonese, and Hokkien.*

Table 10b. Family Member’s Preferred Language (continued)

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Tagalog	Vietnamese	American Sign Language	Other	N
<b>PA</b>	<b>0%</b>	<b>0%</b>	<b>1%</b>	<b>2%</b>	<b>646</b>
Weighted NCI-IDD Average	0%	0%	1%	2%	2109

*Table Note: “Tagalog” includes Filipino.*

Table 11. Family Member Has Legal Court Appointed Guardian or Conservator

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	No guardianship	Limited guardianship	Full guardianship	Has guardianship but level unknown	N
<b>PA</b>	<b>30%</b>	<b>12%</b>	<b>53%</b>	<b>5%</b>	<b>600</b>
Weighted NCI-IDD Average	28%	11%	55%	5%	1993

Table 12. Guardian or Conservator Relationship to Family Member

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Family	Friend	Employee of state or guardianship agency	Other	N
<b>PA</b>	<b>92%</b>	<b>1%</b>	<b>5%</b>	<b>2%</b>	<b>395</b>
Weighted NCI-IDD Average	92%	1%	4%	3%	1353



Table 13a. Family Member’s Highest Level of Education

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Did not complete high school – Not currently in school	Currently enrolled in high school	High school certificate (NOT a high school diploma or GED)	N
<b>PA</b>	<b>26%</b>	<b>1%</b>	<b>33%</b>	<b>611</b>
Weighted NCI-IDD Average	26%	1%	35%	2027

Table 13b. Family Member’s Highest Level of Education (Continued)

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	N
<b>PA</b>	<b>36%</b>	<b>3%</b>	<b>1%</b>	<b>1%</b>	<b>611</b>
Weighted NCI- IDD Average	29%	3%	3%	4%	2027

Table 14. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	No support needed; no issues with managing behavior	Some support needed; requires only occasional assistance or monitoring	Extensive support needed; frequent or severe enough to require regular assistance	N
<b>PA</b>	<b>28%</b>	<b>41%</b>	<b>31%</b>	<b>630</b>
Weighted NCI- IDD Average	32%	39%	29%	2053

Table 15. Family Member’s Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	No support needed; no issues with personal care activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed; frequent or severe enough to require regular assistance	N
<b>PA</b>	<b>17%</b>	<b>40%</b>	<b>43%</b>	<b>640</b>
Weighted NCI- IDD Average	20%	39%	41%	2090

Table 16. Family Member’s Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping)

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	No support needed; no issues with other daily activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed; frequent or severe enough to require regular assistance	N
<b>PA</b>	<b>1%</b>	<b>14%</b>	<b>85%</b>	<b>644</b>
Weighted NCI- IDD Average	1%	16%	83%	2100

## **Respondents**

This section provides information about the survey respondent.

Table 17a. Language Usually Spoken at Home

State (names abbreviated)	English	Spanish	Chinese	N
<b>PA</b>	<b>98%</b>	<b>0%</b>	<b>0%</b>	<b>639</b>
Weighted NCI-IDD Average	98%	1%	0%	2074

*Table Note: "Chinese" includes Mandarin, Cantonese, and Hokkien.*

Table 17b. Language Usually Spoken at Home (continued)

State (names abbreviated)	Tagalog	Vietnamese	American Sign Language	Other	N
<b>PA</b>	<b>0%</b>	<b>0%</b>	<b>0%</b>	<b>1%</b>	<b>639</b>
Weighted NCI-IDD Average	0%	0%	0%	1%	2074

*Table Note: "Tagalog" includes Filipino.*



Table 18. Respondent's Age

State (names abbreviated)	18 – 34	35 – 54	55 – 74	75 or older	N
<b>PA</b>	<b>0%</b>	<b>10%</b>	<b>67%</b>	<b>23%</b>	<b>631</b>
Weighted NCI-IDD Average	1%	9%	67%	24%	2088

Table 19. Respondent’s Health

State (names abbreviated)	Excellent	Very good	Good	Fair	Poor	N
<b>PA</b>	<b>14%</b>	<b>35%</b>	<b>34%</b>	<b>13%</b>	<b>3%</b>	<b>634</b>
Weighted NCI-IDD Average	15%	35%	35%	13%	3%	2091

Table 20a. Respondent’s Relationship to Family Member

State (names abbreviated)	Parent	Sibling	Spouse	Grandparent	N
<b>PA</b>	<b>70%</b>	<b>22%</b>	<b>0%</b>	<b>2%</b>	<b>640</b>
Weighted NCI-IDD Average	69%	21%	0%	1%	2101

Table 20b. Respondent’s Relationship to Family Member (continued)

State (names abbreviated)	Public guardian	Private guardian	Other	N
<b>PA</b>	<b>1%</b>	<b>3%</b>	<b>3%</b>	<b>640</b>
Weighted NCI-IDD Average	1%	2%	6%	2101

Table 21. Respondent’s Frequency of Visits with Family Member In The Past 12 Months

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Did not visit	1 to 3 times	4 to 6 times	7 to 12 times	More than 12 times	N
<b>PA</b>	<b>3%</b>	<b>9%</b>	<b>12%</b>	<b>14%</b>	<b>61%</b>	<b>646</b>
Weighted NCI-IDD Average	3%	9%	11%	13%	64%	2105

Table 22. Respondent’s Highest Level of Education

State (names abbreviated)	No high school diploma or GED	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	N
<b>PA</b>	<b>3%</b>	<b>22%</b>	<b>7%</b>	<b>18%</b>	<b>50%</b>	<b>632</b>
Weighted NCI-IDD Average	3%	17%	5%	19%	57%	2068

Table 23a. Total Taxable Household Income of Wage Earners in the last year

*Please note: Respondents did not respond if they were a public guardian/administrator, or if they represent a financial institution or guardianship agency. Does not include state/federal benefits such as SSI, SSDI etc.*

State (names abbreviated)	No earned income	Up to \$15,000	\$15,001– \$25,000	\$25,001– \$50,000	N
<b>PA</b>	<b>10%</b>	<b>4%</b>	<b>5%</b>	<b>15%</b>	<b>613</b>
Weighted NCI-IDD Average	10%	4%	5%	12%	2028

Table 23b. Total Taxable Household Income of Wage Earners in the last year (continued)

*Please note: Respondents did not respond if they were a public guardian/administrator, or if they represent a financial institution or guardianship agency. Does not include state/federal benefits such as SSI, SSDI etc.*

State (names abbreviated)	\$50,001–\$75,000	Over \$75,000	Prefer not to say	N
<b>PA</b>	<b>9%</b>	<b>18%</b>	<b>38%</b>	<b>613</b>
Weighted NCI-IDD Average	10%	23%	36%	2028



## Services and Supports Received

This section provides information about the services and supports received by the family from the state IDD agency.

**Please note:** All data in this section are reported by the respondent based on their understanding of their family member's services and supports received.

Table 24a. Services and Supports Received from IDD Agency

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Financial support	In-home support	Residential supports	Day or employment supports
<b>PA</b>	<b>27%</b>	<b>31%</b>	<b>96%</b>	<b>56%</b>
Weighted NCI-IDD Average	29%	36%	90%	65%

Table 24b. Services and Supports Received from State (continued)

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Transportation	Mental or behavioral health care or other treatments or therapies	Self-direction or fiscal intermediary services
<b>PA</b>	<b>95%</b>	<b>68%</b>	<b>13%</b>
Weighted NCI-IDD Average	93%	63%	18%

Table 25. Additional Services and Supports Received (not from the IDD Agency)

*Please note: All data in this section are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.*

State (names abbreviated)	Social Security (SSI or SSB)	Services or supports from other agencies or organizations
<b>PA</b>	<b>98%</b>	<b>29%</b>
Weighted NCI-IDD Average	97%	25%

# Main Survey Results

## Information and Planning

Families have the information and support needed to take part in planning supports and services for their family member receiving services and supports from the state developmental disabilities system.

**“You”** and **“Respondent”** refers to the person (usually a parent or guardian) filling out the survey.

**“Family Member”** refers to the person receiving services whom the respondent is answering questions about in this survey.

**Do you get enough information to take part in planning services for your family member?**

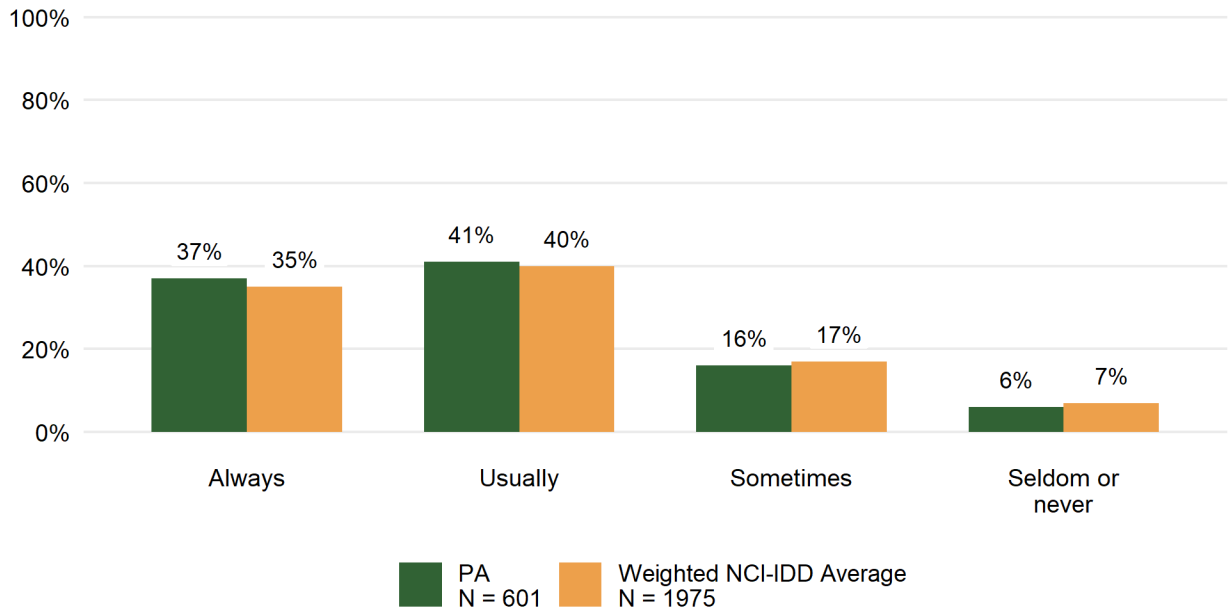


Table 26. Do you get enough information to take part in planning services for your family member?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>37%</b>	<b>41%</b>	<b>16%</b>	<b>6%</b>	<b>601</b>
Weighted NCI-IDD Average	35%	40%	17%	7%	1975

**Is the information you get about services and supports easy to understand?**

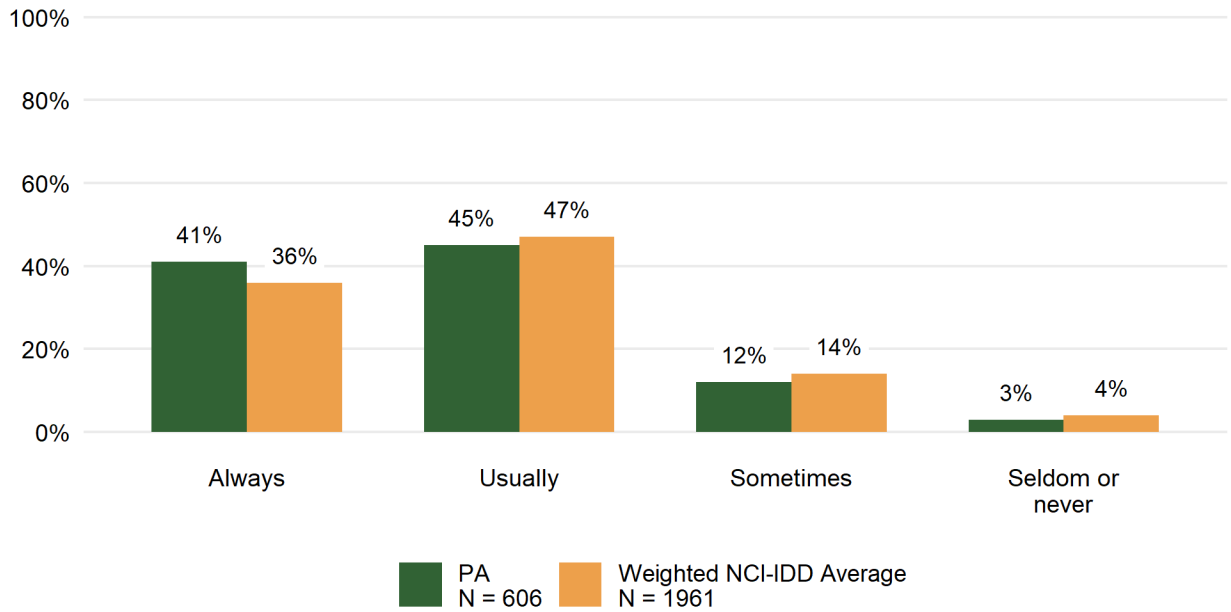


Table 27. Is the information you get about services and supports easy to understand?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>41%</b>	<b>45%</b>	<b>12%</b>	<b>3%</b>	<b>606</b>
Weighted NCI-IDD Average	36%	47%	14%	4%	1961



**Do you get information about services and supports in your preferred language?**

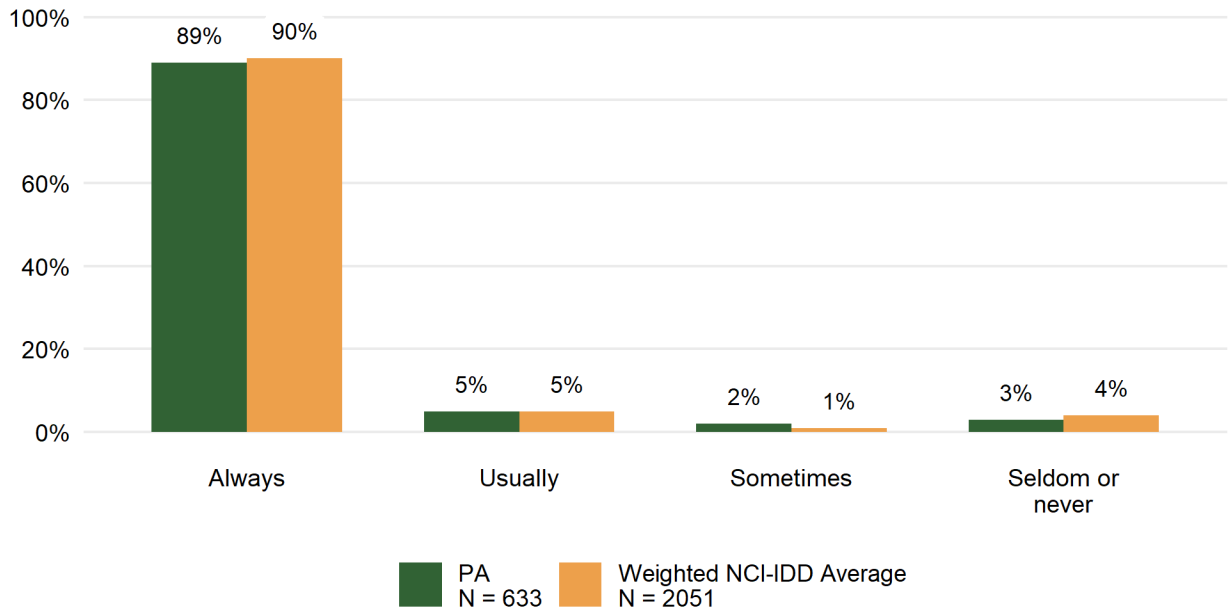


Table 28. Do you get information about services and supports in your preferred language?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>89%</b>	<b>5%</b>	<b>2%</b>	<b>3%</b>	<b>633</b>
Weighted NCI-IDD Average	90%	5%	1%	4%	2051

**Does the case manager or service coordinator listen to your family's choices and opinions?**

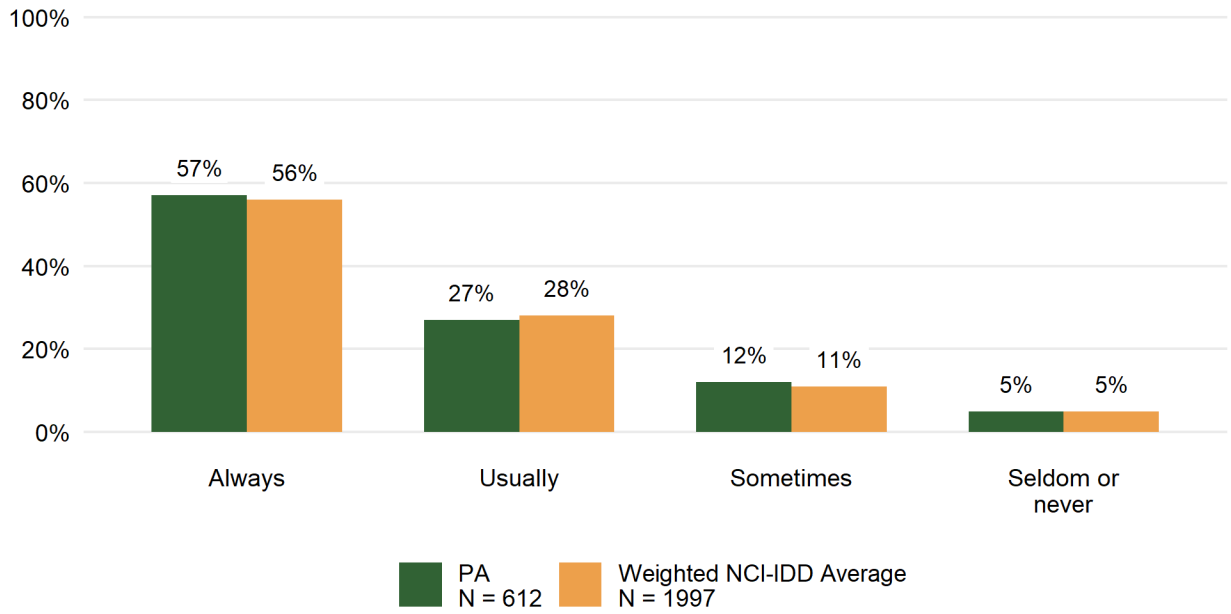


Table 29. Does the case manager or service coordinator listen to your family's choices and opinions?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>57%</b>	<b>27%</b>	<b>12%</b>	<b>5%</b>	<b>612</b>
Weighted NCI-IDD Average	56%	28%	11%	5%	1997

**Do staff or the residential agency keep you informed about how your family member is doing?**

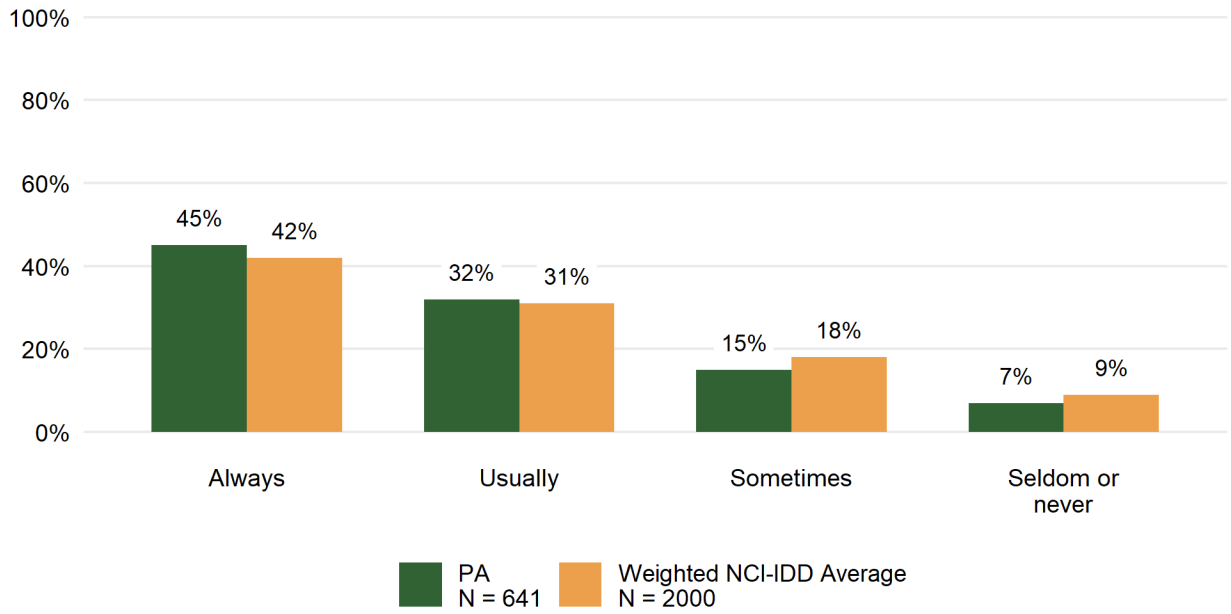


Table 30. Do staff or the residential agency keep you informed about how your family member is doing?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>45%</b>	<b>32%</b>	<b>15%</b>	<b>7%</b>	<b>641</b>
Weighted NCI-IDD Average	42%	31%	18%	9%	2000

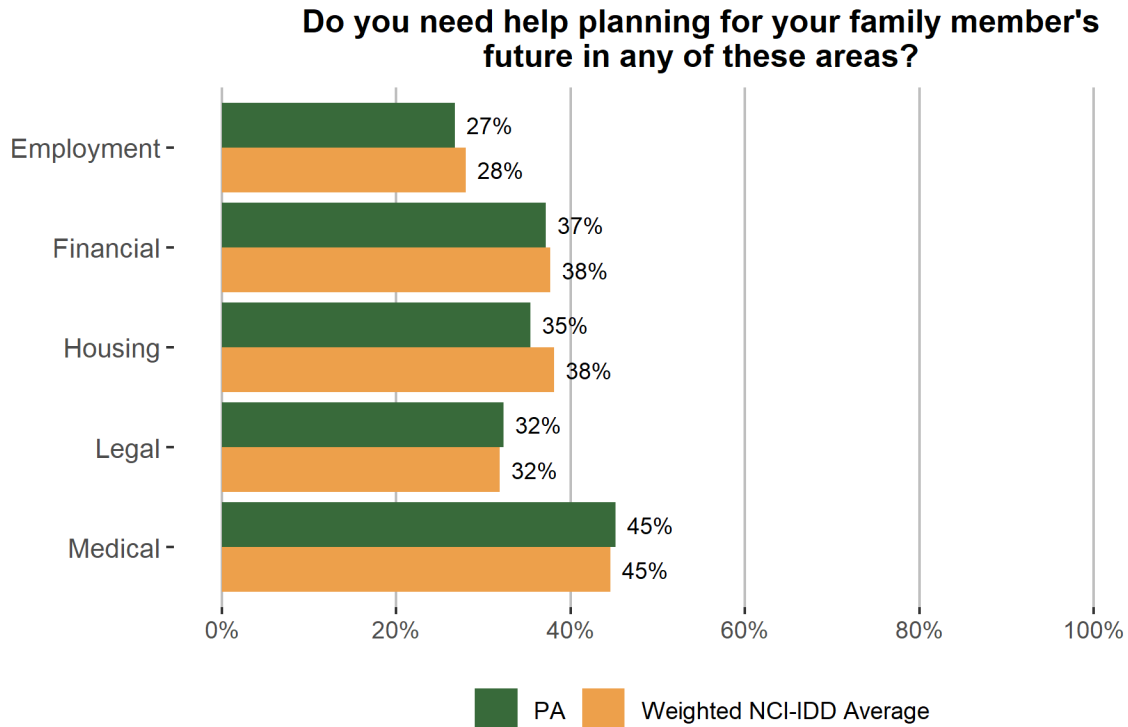


Table 31a. Do you need help planning for your family member’s future in any of these areas?

*Categories are not mutually exclusive, therefore N is not shown.*

State (names abbreviated)	Employment	Financial	Housing	Legal	Medical
<b>PA</b>	<b>27%</b>	<b>37%</b>	<b>35%</b>	<b>32%</b>	<b>45%</b>
Weighted NCI-IDD Average	28%	38%	38%	32%	45%

**Do you need help planning for your family member's future in any of these areas? (Continued)**

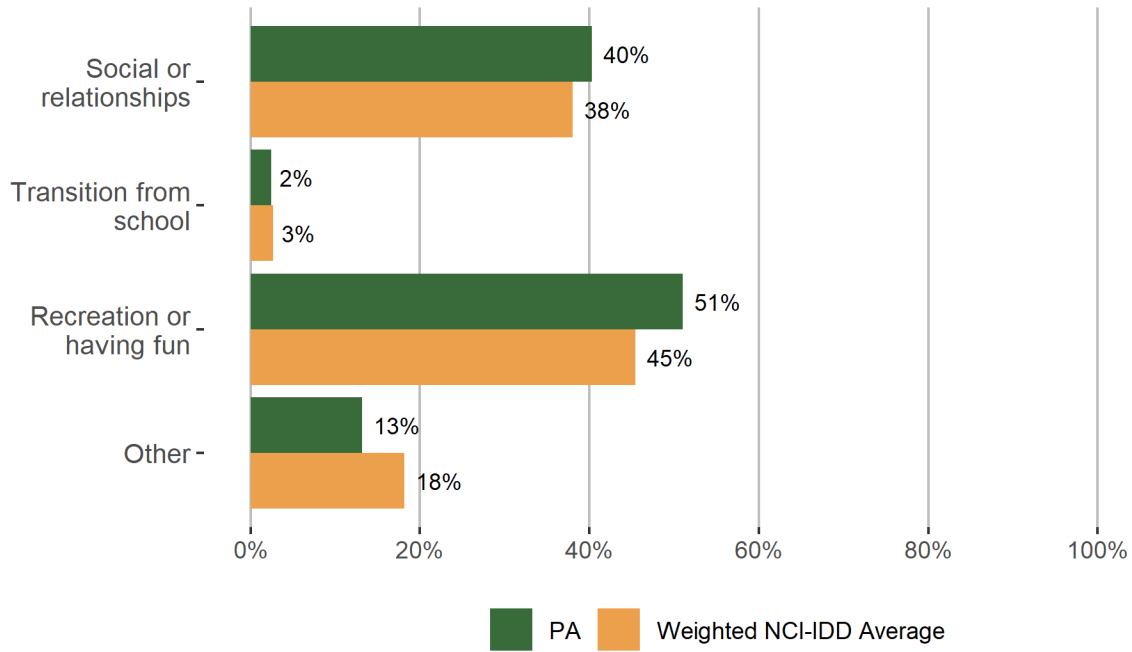


Table 31b. Do you need help planning for your family member's future in any of these areas? (Continued)

Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Social or relationships	Transition from school	Recreation or having fun	Other
PA	40%	2%	51%	13%
Weighted NCI-IDD Average	38%	3%	45%	18%

### Has your family learned about alternatives to guardianship?

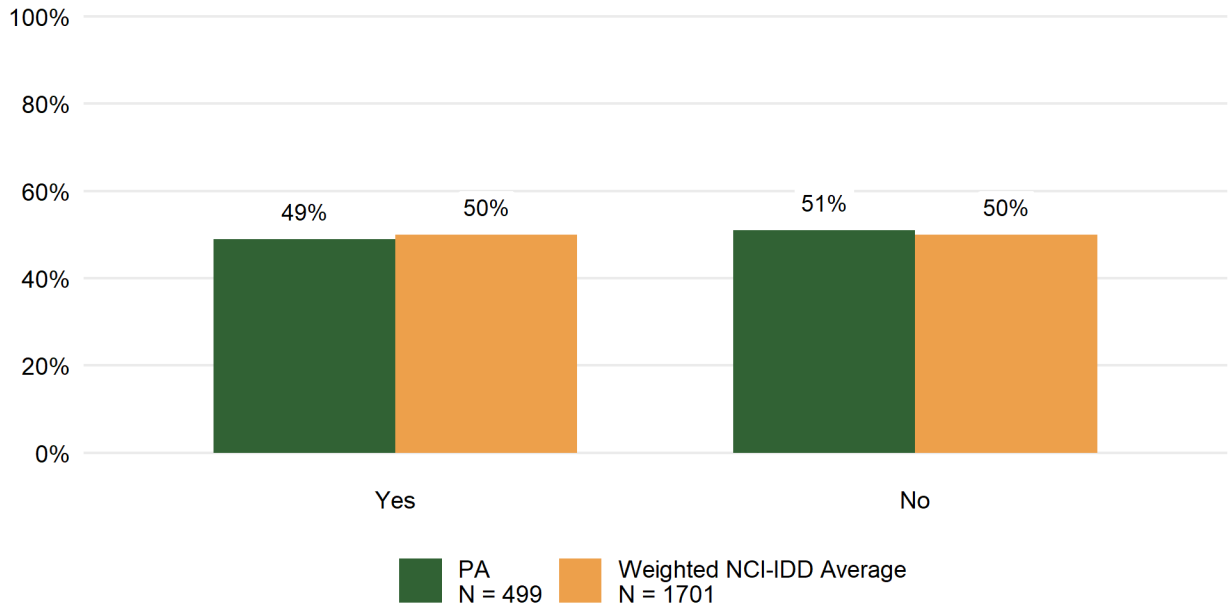


Table 32. Has your family learned about alternatives to guardianship?

State (names abbreviated)	Yes	No	N
PA	49%	51%	499
Weighted NCI-IDD Average	50%	50%	1701

*Table Note: Alternatives to guardianship let a family member make more decisions for themselves, with or without the help of others. This might include “**Supported Decision Making (SDM)**”, allows a person with a disability to make their own decisions with the help of people they trust. “**Other decision-making supports**”, like health-care proxies, advance directives, powers of attorney, notarized statements, representation agreements, etc.*

**Does your family member have a service plan?**

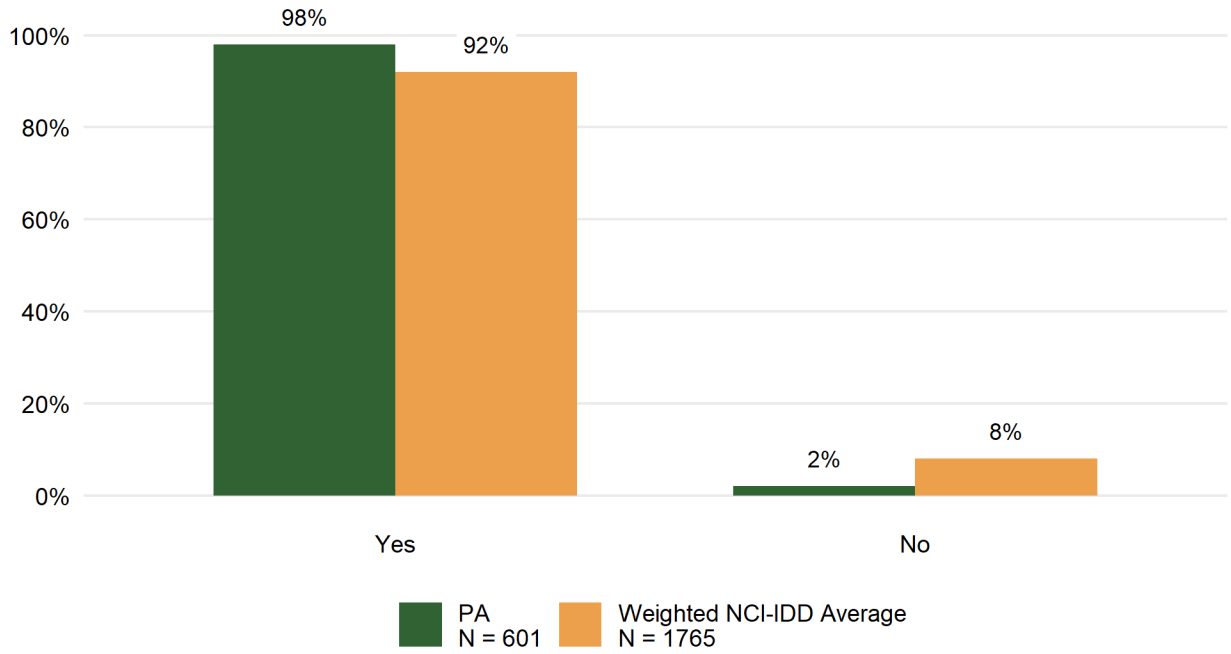


Table 33. Does your family member have a service plan?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>98%</b>	<b>2%</b>	<b>601</b>
Weighted NCI-IDD Average	92%	8%	1765

*Table Note: Data for this question are reported by the respondent based on their understanding of their family member’s services and supports.*

**Does the plan include all the services and supports your family member needs?**

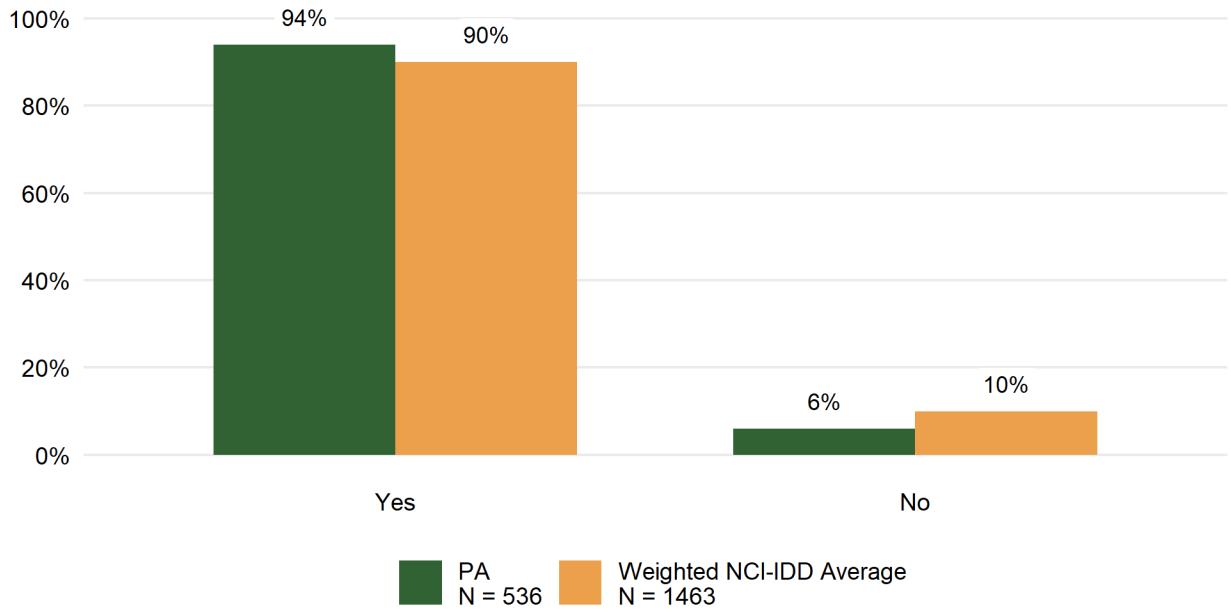


Table 34. Does the plan include all the services and supports your family member needs?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>94%</b>	<b>6%</b>	<b>536</b>
Weighted NCI-IDD Average	90%	10%	1463



**Did you or someone else in your family (besides your family member with a disability) help make the plan?**

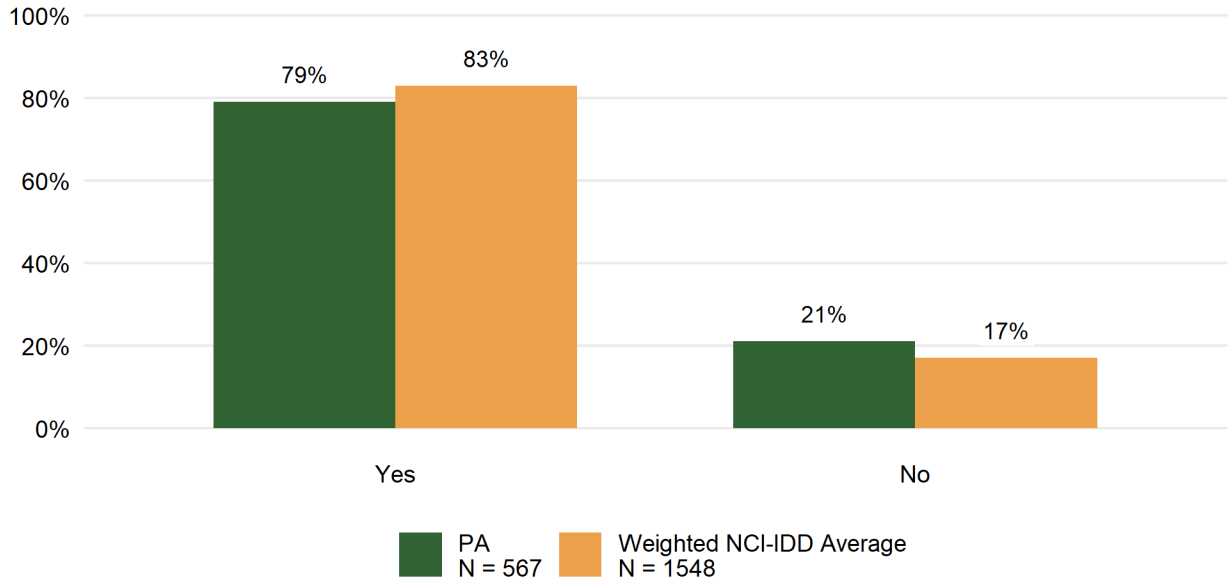


Table 35. Did you or someone else in your family (besides your family member with a disability) help make the plan?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>79%</b>	<b>21%</b>	<b>567</b>
Weighted NCI-IDD Average	83%	17%	1548

### Did your family member help make the plan?

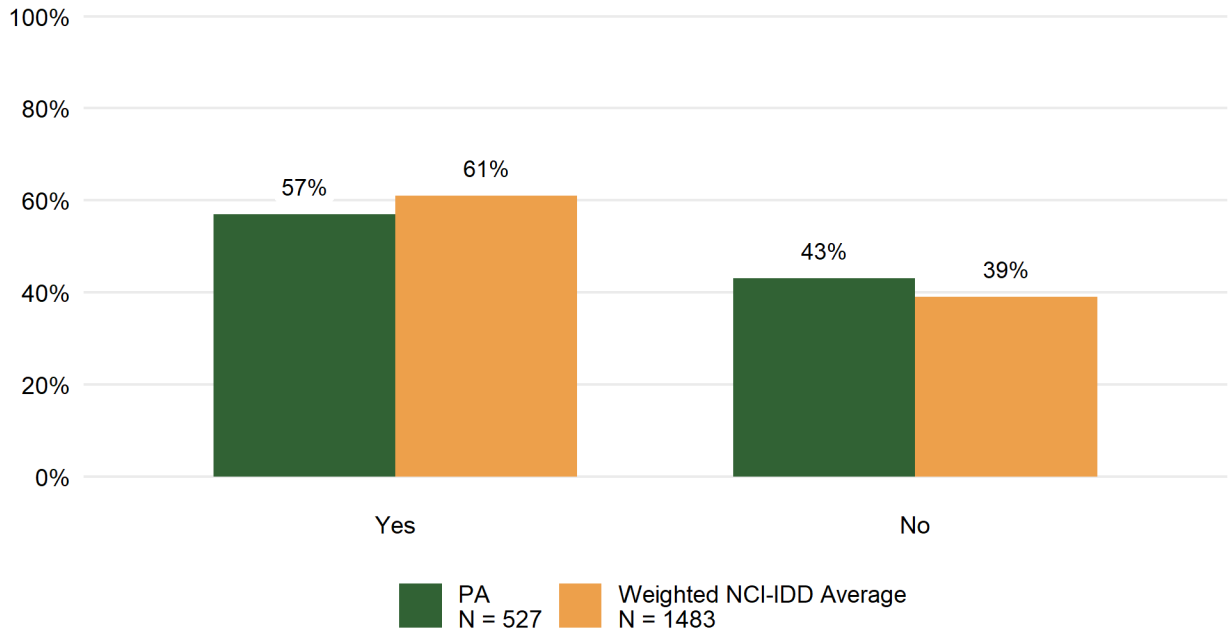


Table 36. Did your family member help make the plan?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>57%</b>	<b>43%</b>	<b>527</b>
Weighted NCI-IDD Average	61%	39%	1483

**Do you feel like your family had enough say or input in making the plan?**

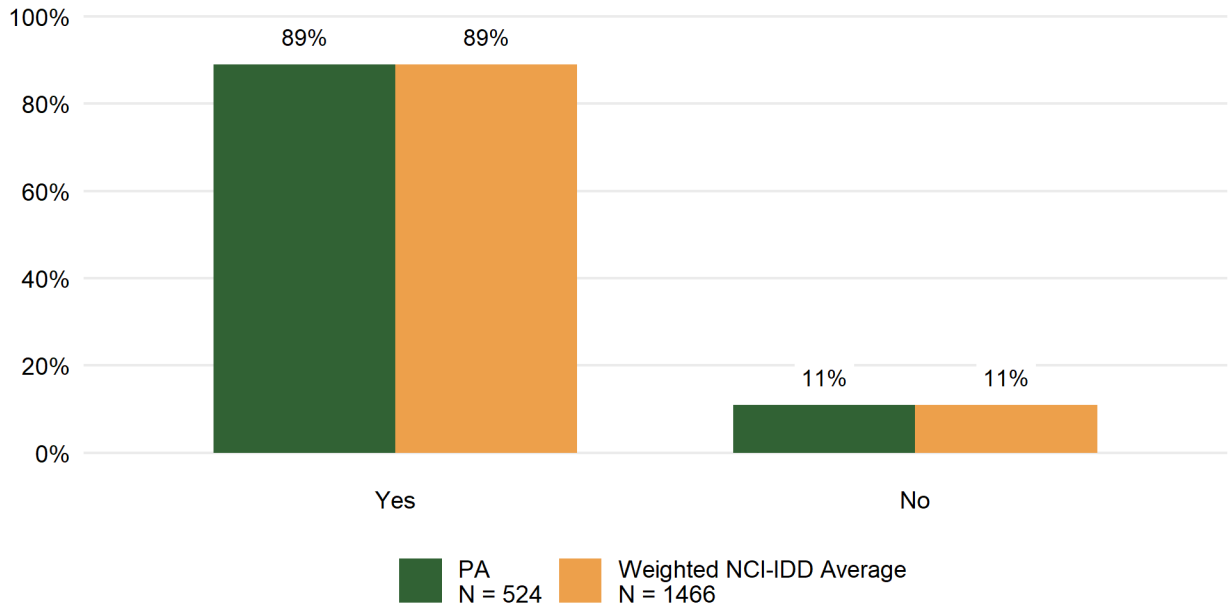


Table 37. Do you feel like your family had enough say or input in making the plan?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>89%</b>	<b>11%</b>	<b>524</b>
Weighted NCI-IDD Average	89%	11%	1466

**Did your family member leave school services and begin adult services during the past 12 months?**

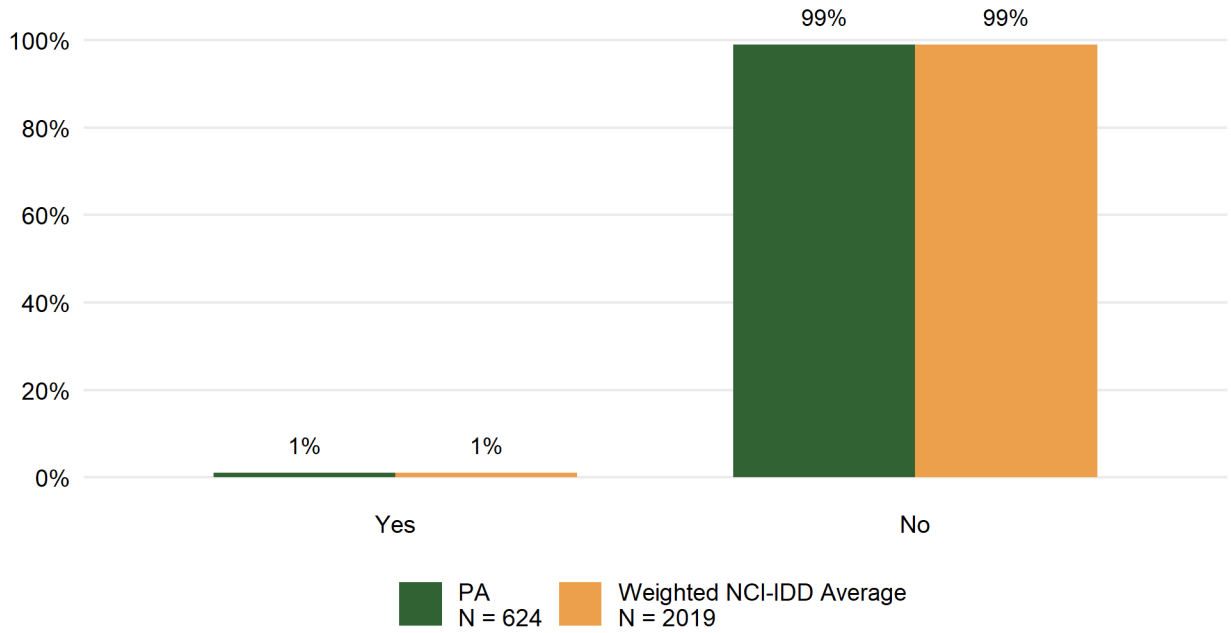


Table 38. Did your family member leave school services and begin adult services during the past 12 months?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>1%</b>	<b>99%</b>	<b>624</b>
Weighted NCI-IDD Average	1%	99%	2019

**If your family member left school services during the past 12 months, did your family member have a transition plan?**

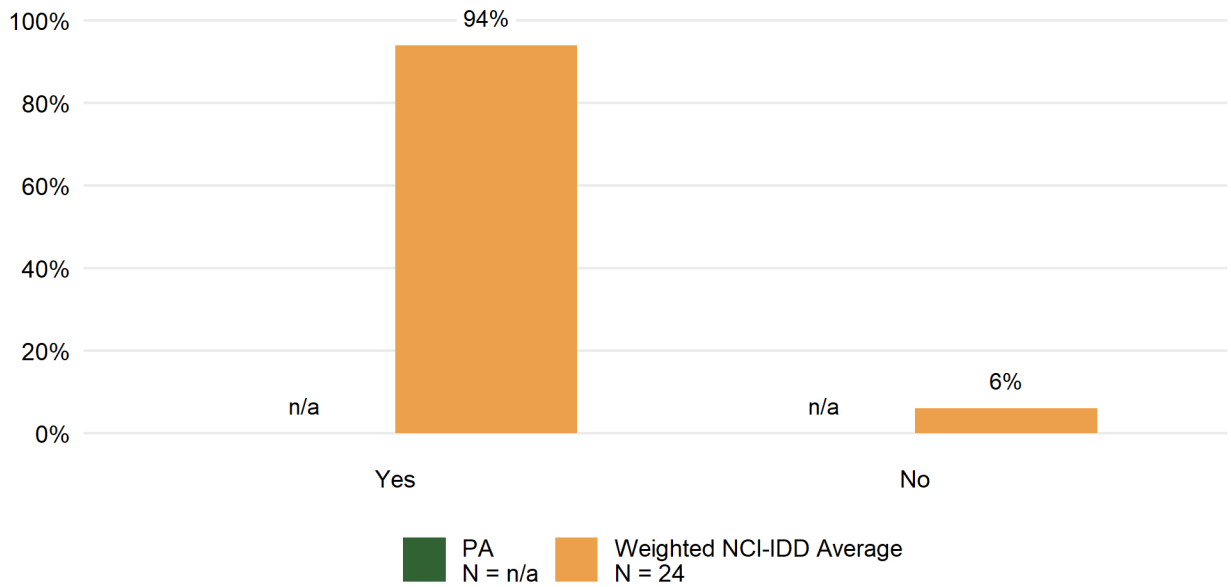


Table 39. If your family member left school services during the past 12 months, did your family member have a transition plan?

State (names abbreviated)	Yes	No	N
PA	n/a	n/a	n/a
Weighted NCI-IDD Average	94%	6%	24

Table 40. If your family member had a transition plan, did the transition plan include getting or continuing work in a community job

*Observed N overall was less than 20. Table and chart not reported.*

### **Access and Delivery of Services and Supports**

Families receive services and supports that are appropriate to the needs of the family and the family member receiving services and supports from the state developmental disabilities system.

**“You”** and **“Respondent”** refers to the person (usually a parent or guardian) filling out the survey.

**“Family Member”** refers to the person receiving services whom the respondent is answering questions about in this survey.

**Does your family member get all the services listed in the plan?**

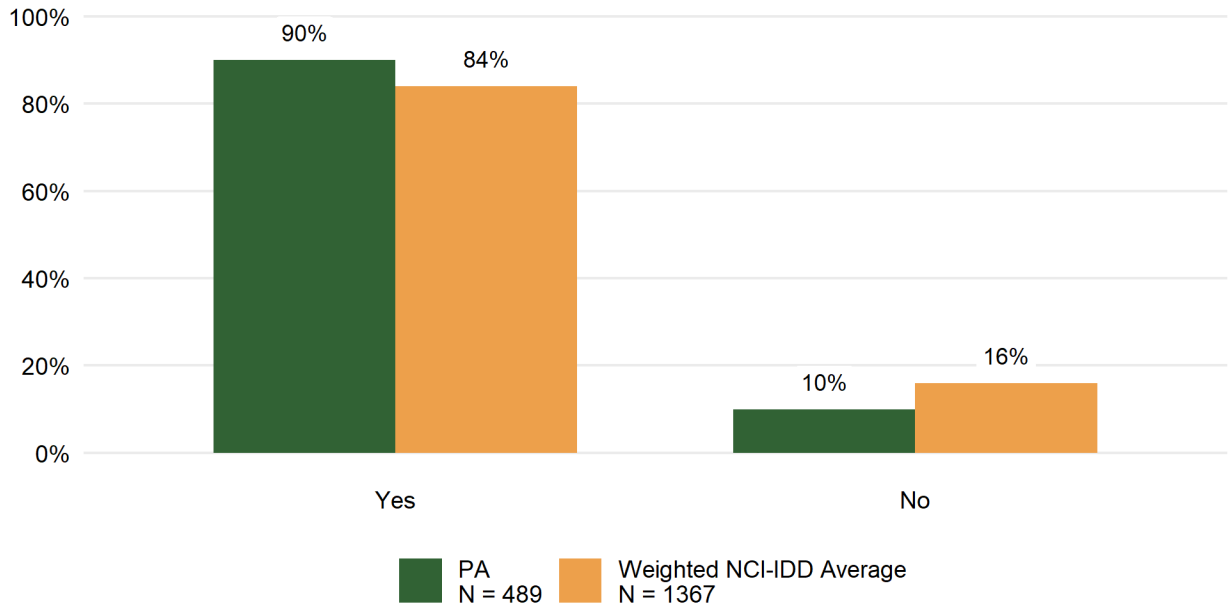


Table 41. Does your family member get all the services listed in the plan?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>90%</b>	<b>10%</b>	<b>489</b>
Weighted NCI-IDD Average	84%	16%	1367



**Does your family get the supports and services it needs?**

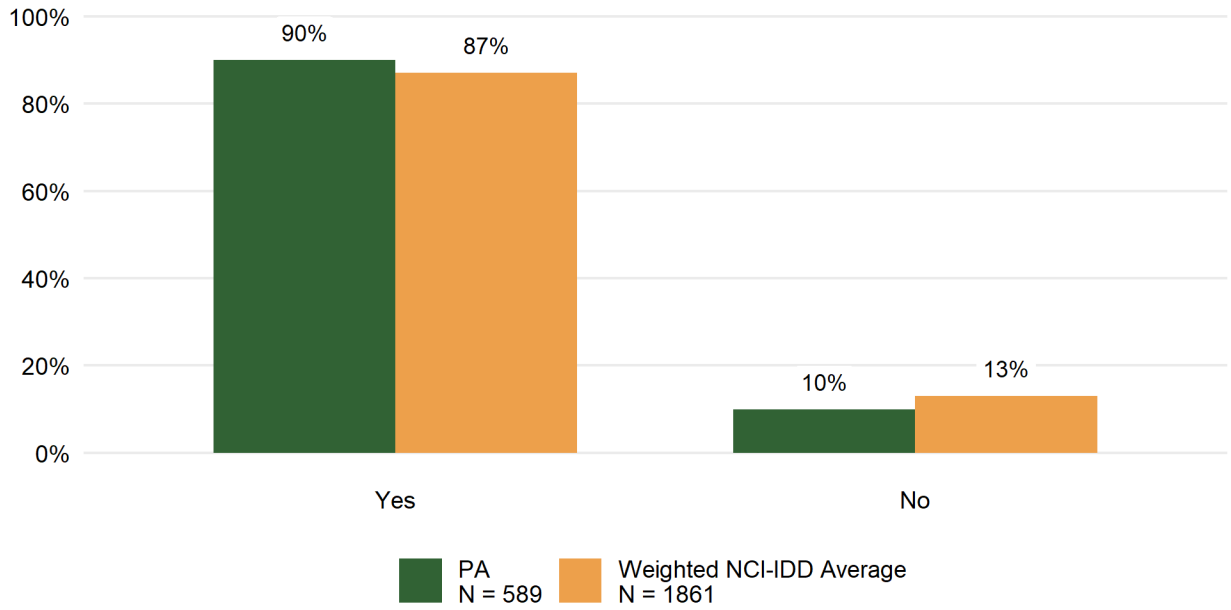


Table 42. Does your family get the supports and services it needs?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>90%</b>	<b>10%</b>	<b>589</b>
Weighted NCI-IDD Average	87%	13%	1861

**If your family does not get the support and services needed, what additional services does your family need?**

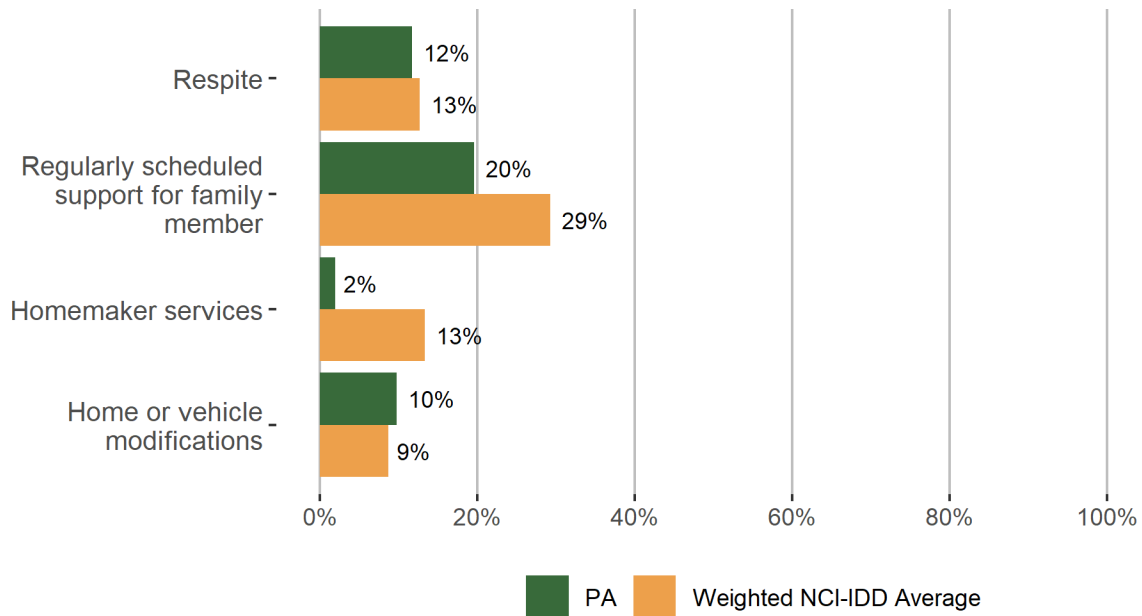


Table 43a. If your family does not get the support and services needed, what additional services does your family need?

Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Respite	Regularly scheduled support for family member	Homemaker services	Home or vehicle modifications
PA	12%	20%	2%	10%
Weighted NCI-IDD Average	13%	29%	13%	9%

**If your family does not get the support and services needed, what additional services does your family need? (Continued)**

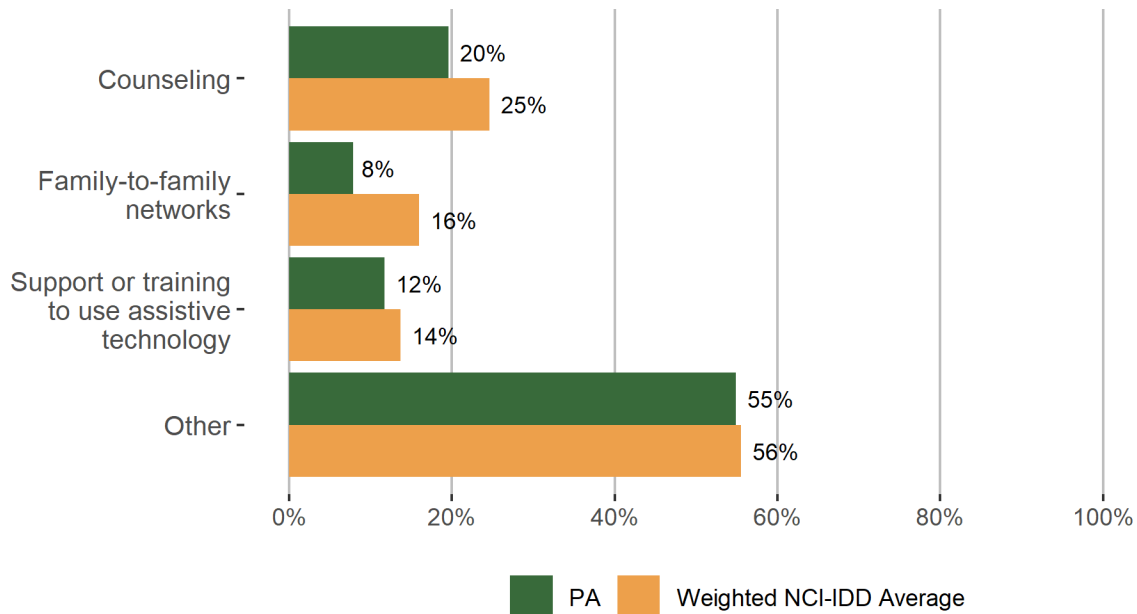


Table 43b. If your family does not get the support and services needed, what additional services does your family need? (Continued)

Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Counseling	Family-to-family networks	Support or training to use assistive technology	Other
PA	20%	8%	12%	55%
Weighted NCI-IDD Average	25%	16%	14%	56%

**Do services and supports change when your family's needs change?**

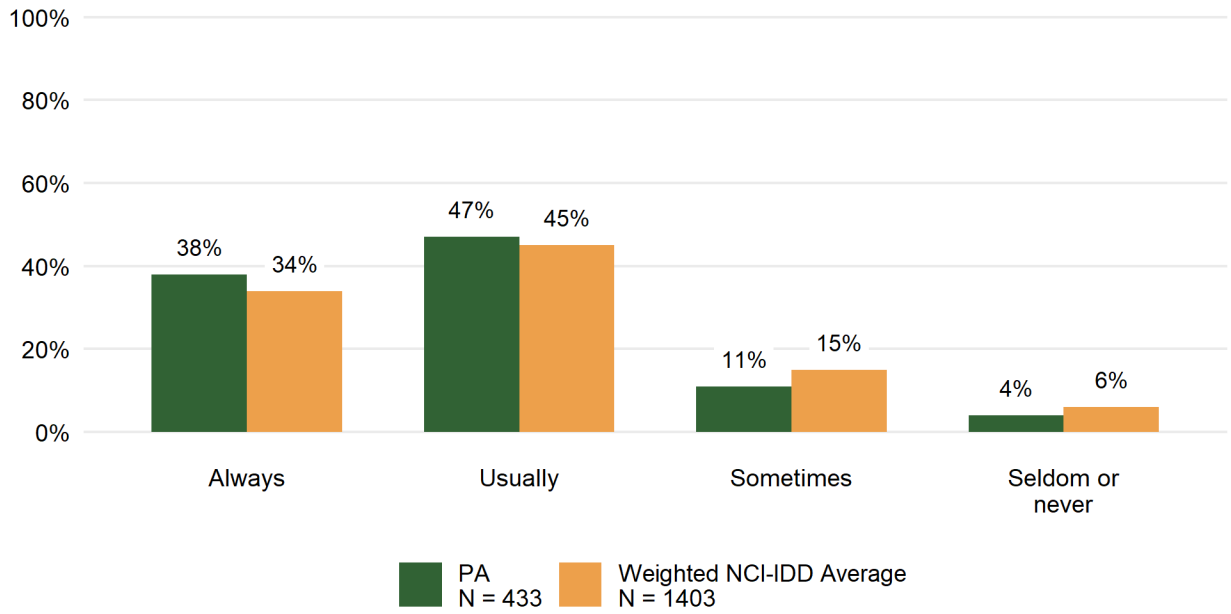


Table 44. Do services and supports change when your family's needs change?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>38%</b>	<b>47%</b>	<b>11%</b>	<b>4%</b>	<b>433</b>
Weighted NCI-IDD Average	34%	45%	15%	6%	1403

**Does your family member have enough supports to work or volunteer in the community?**

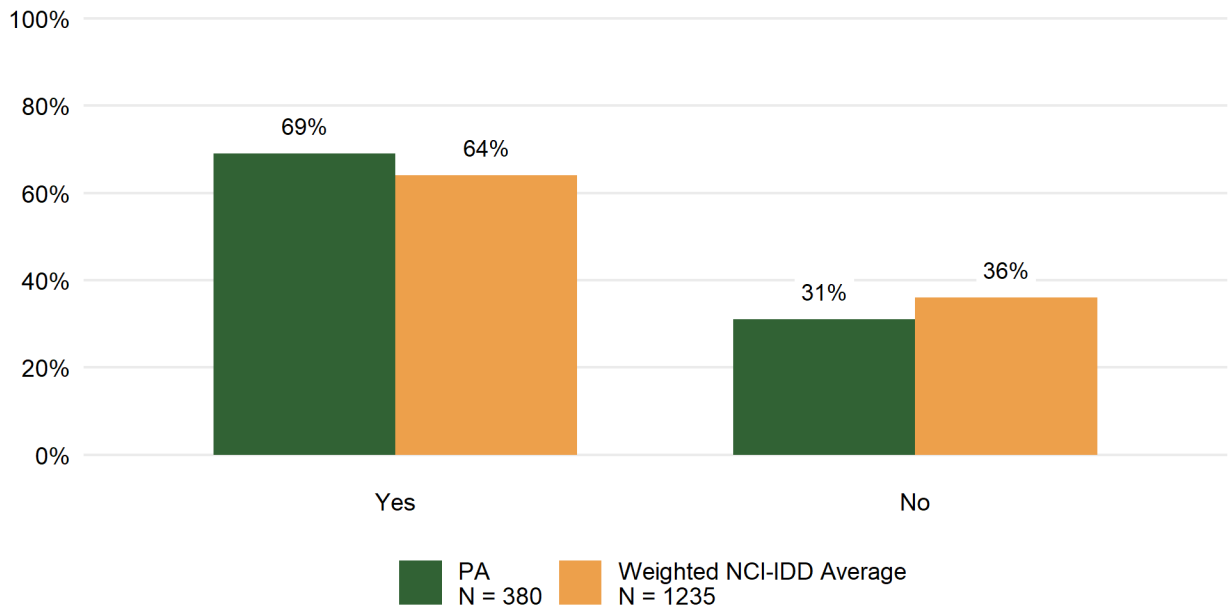


Table 45. Does your family member have enough supports to work or volunteer in the community? (These types of supports might include support workers, community resources, transportation)

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>69%</b>	<b>31%</b>	<b>380</b>
Weighted NCI-IDD Average	64%	36%	1235

**Does your family member have the special equipment or accommodations that they need?**

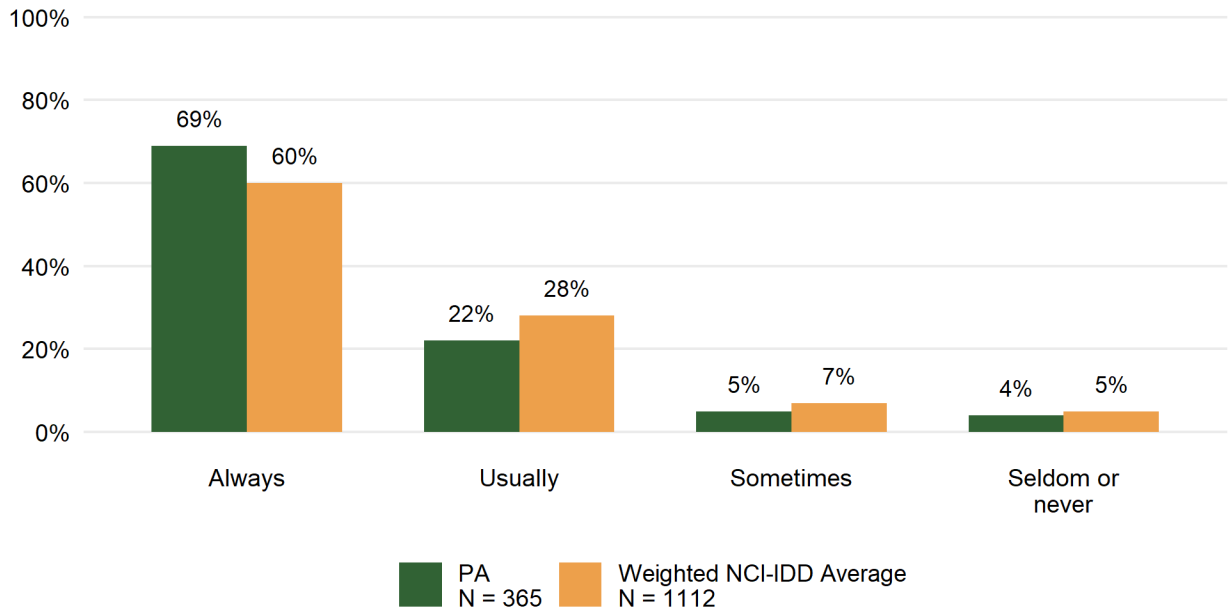


Table 46. Does your family member have the special equipment or accommodations that they need?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>69%</b>	<b>22%</b>	<b>5%</b>	<b>4%</b>	<b>365</b>
Weighted NCI-IDD Average	60%	28%	7%	5%	1112

**Are you or your family member able to contact support workers when you want?**

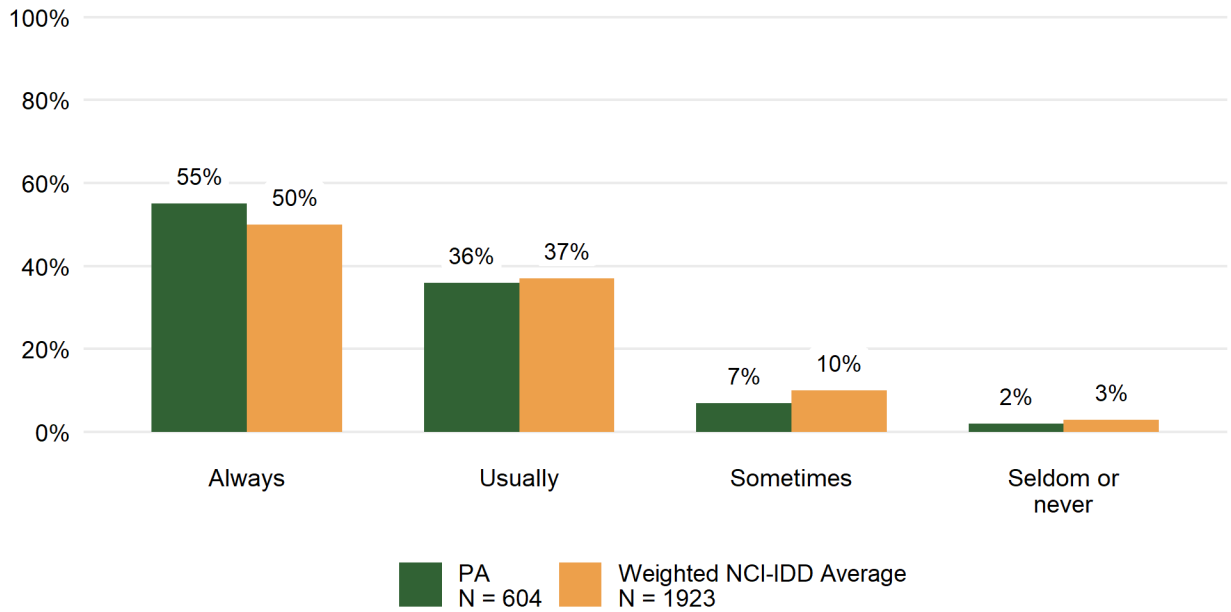


Table 47. Are you or your family member able to contact support workers when you want?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>55%</b>	<b>36%</b>	<b>7%</b>	<b>2%</b>	<b>604</b>
Weighted NCI-IDD Average	50%	37%	10%	3%	1923

**Are you or your family member able to contact the case manager or service coordinator when you want?**

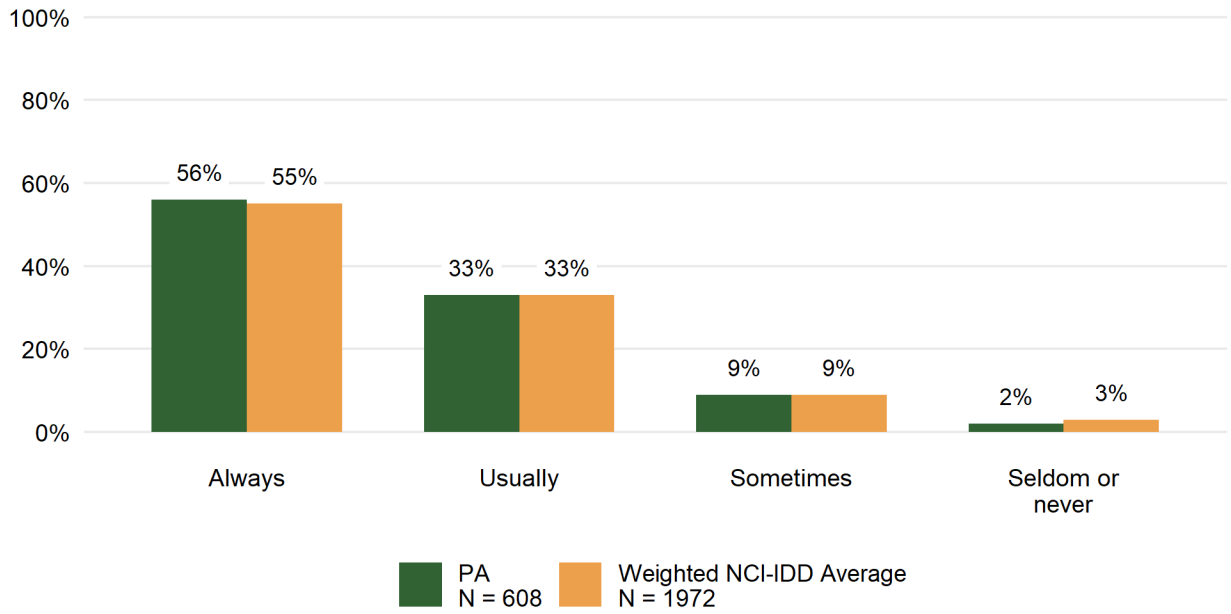


Table 48. Are you or your family member able to contact the case manager or service coordinator when you want?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>56%</b>	<b>33%</b>	<b>9%</b>	<b>2%</b>	<b>608</b>
Weighted NCI-IDD Average	55%	33%	9%	3%	1972



**Do service providers for your family member work together to provide support?**

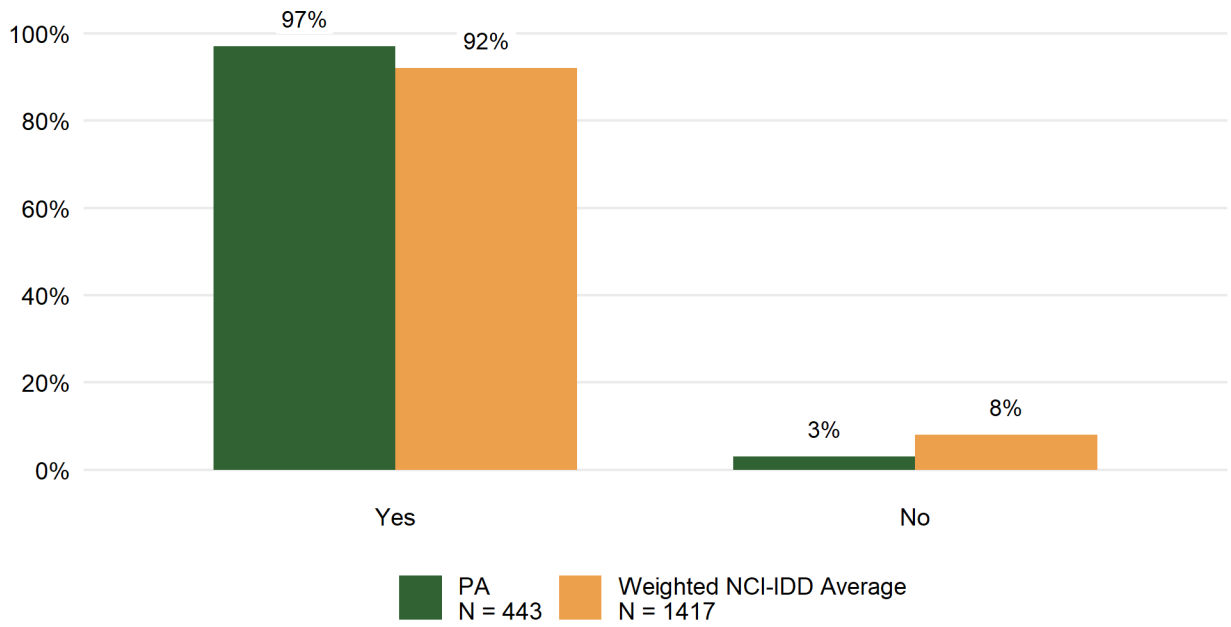


Table 49. Do service providers for your family member work together to provide support?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>97%</b>	<b>3%</b>	<b>443</b>
Weighted NCI-IDD Average	92%	8%	1417

**Are services delivered in a way that is respectful of your family's culture?**

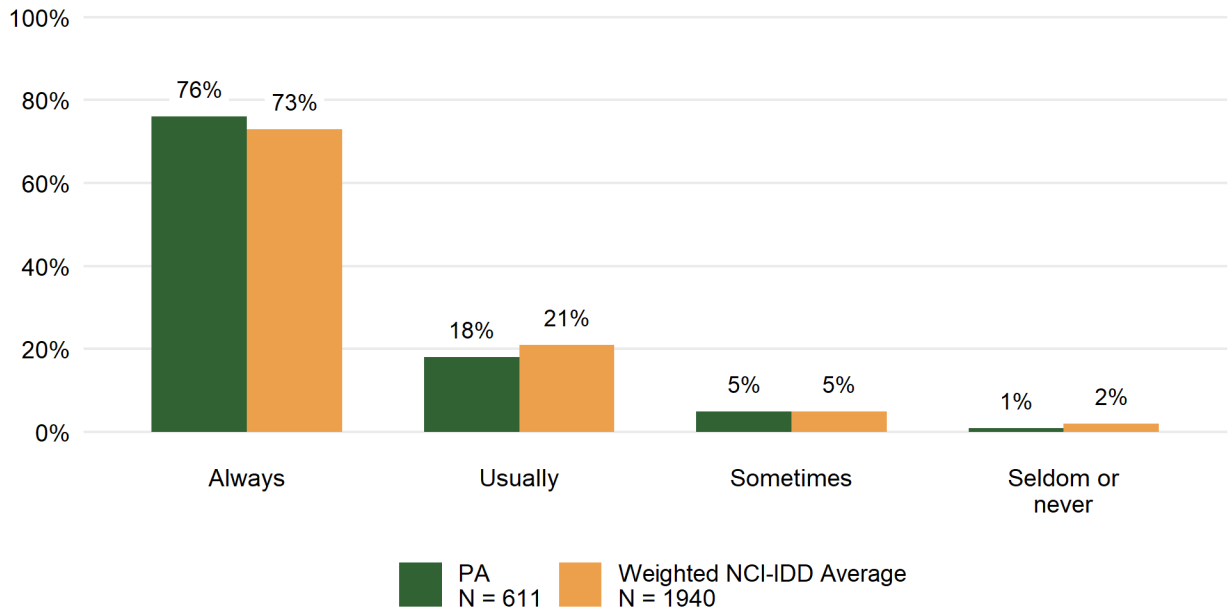


Table 50. Are services delivered in a way that is respectful of your family's culture?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>76%</b>	<b>18%</b>	<b>5%</b>	<b>1%</b>	<b>611</b>
Weighted NCI-IDD Average	73%	21%	5%	2%	1940

**Does your family member use technology in their everyday life to help them do things on their own?**

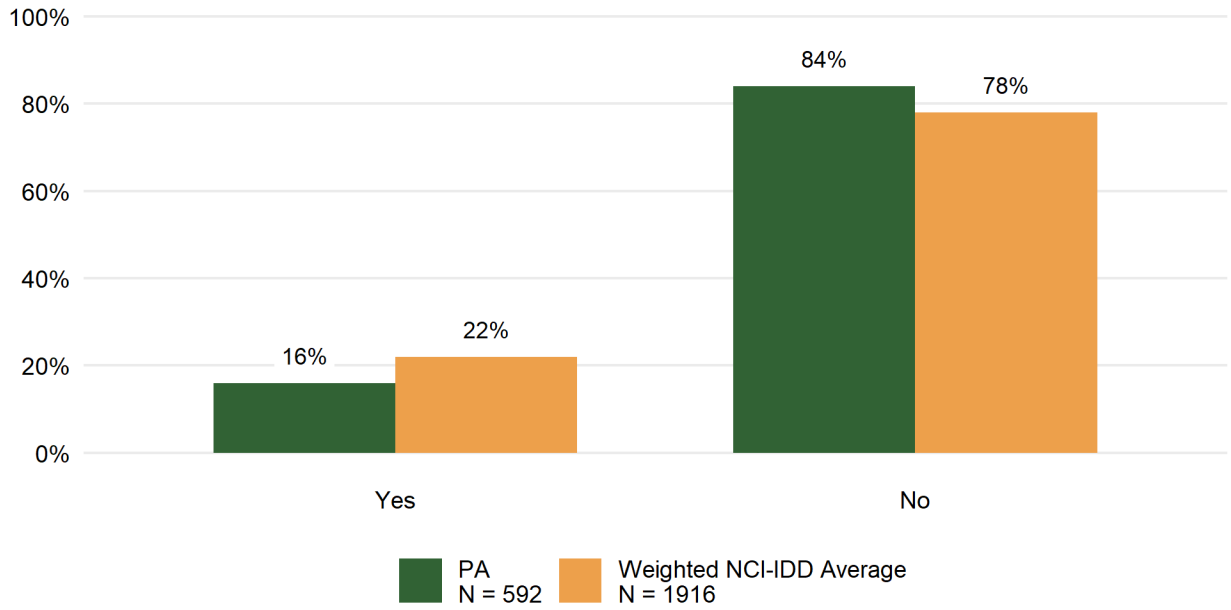


Table 51. Does your family member use technology in their everyday life to help them do things on their own?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>16%</b>	<b>84%</b>	<b>592</b>
Weighted NCI-IDD Average	22%	78%	1916

**Is there a computer, tablet (iPad or similar), or smartphone that you can use in your home?**

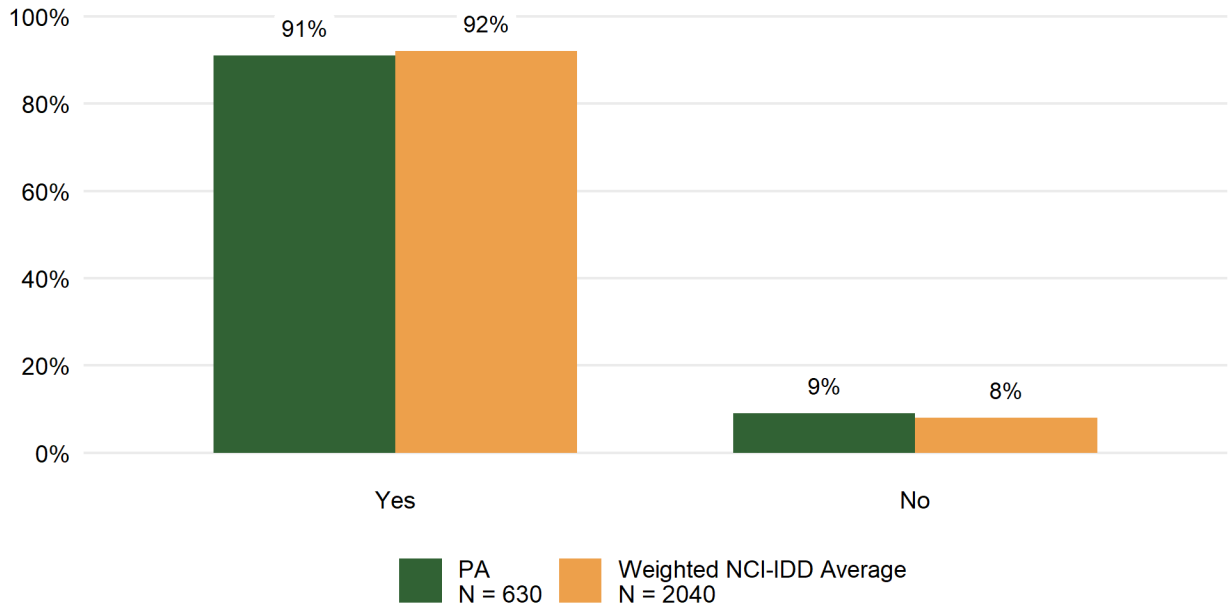


Table 52. Is there a computer, tablet (iPad or similar), or smartphone that you can use in your home?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>91%</b>	<b>9%</b>	<b>630</b>
Weighted NCI-IDD Average	92%	8%	2040

### How well does the internet work in your home?

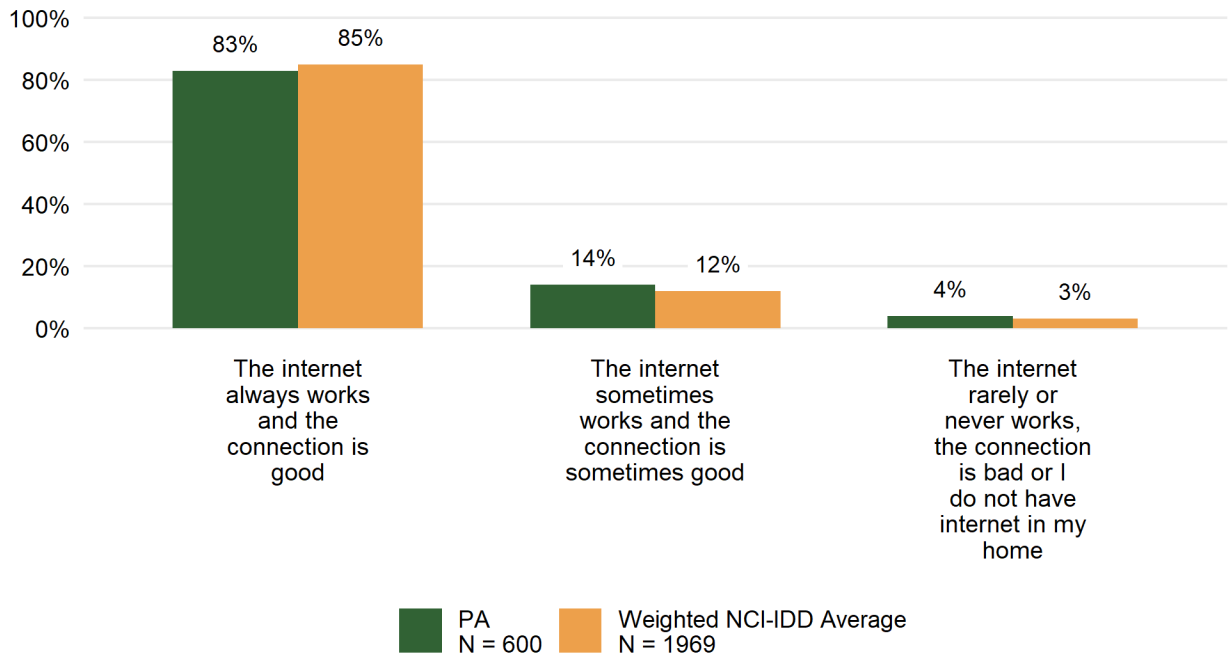


Table 53. How well does the internet work in your home?

State (names abbreviated)	The internet always works and the connection is good	The internet sometimes works and the connection is sometimes good	The internet rarely or never works, the connection is bad or I do not have internet in my home	N
PA	83%	14%	4%	600
Weighted NCI-IDD Average	85%	12%	3%	1969

## Workforce

There is stable and sufficient workforce to meet demand. People are supported by staff who demonstrate respect for what is important to the person in their day-to-day life. Staff have the right skills to support people.

“**You**” and “**Respondent**” refers to the person (usually a parent or guardian) filling out the survey.

“**Family Member**” refers to the person receiving services whom the respondent is answering questions about in this survey.

**Do support workers come and go when they are supposed to?**

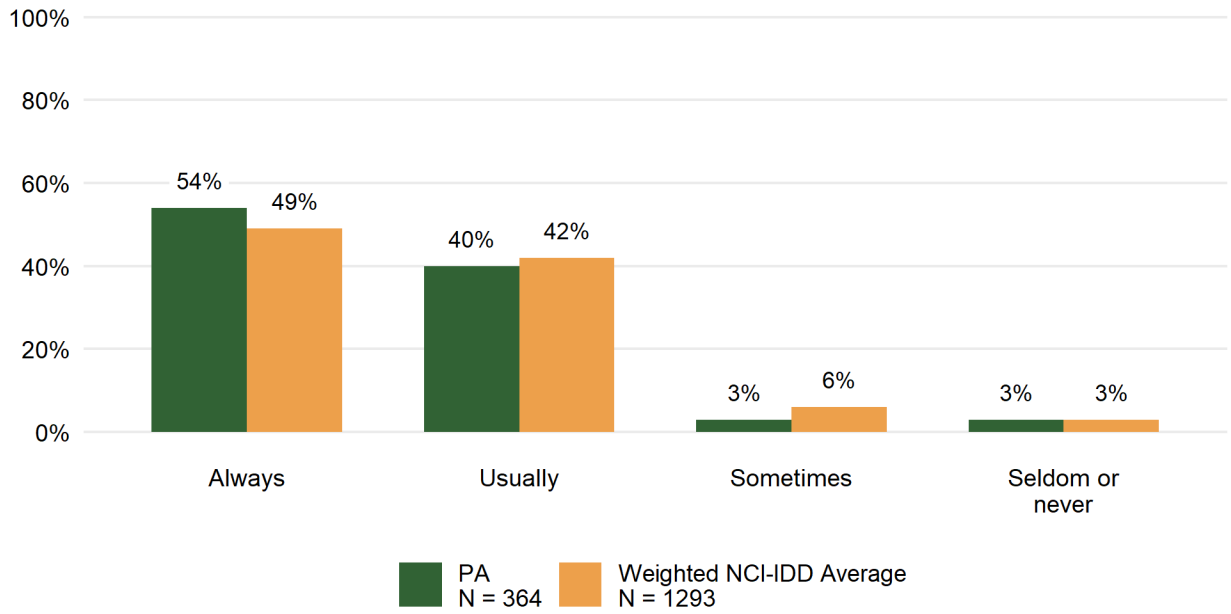


Table 54. Do support workers come and go when they are supposed to?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>54%</b>	<b>40%</b>	<b>3%</b>	<b>3%</b>	<b>364</b>
Weighted NCI-IDD Average	49%	42%	6%	3%	1293

**Do support workers speak to you in a way you understand?**

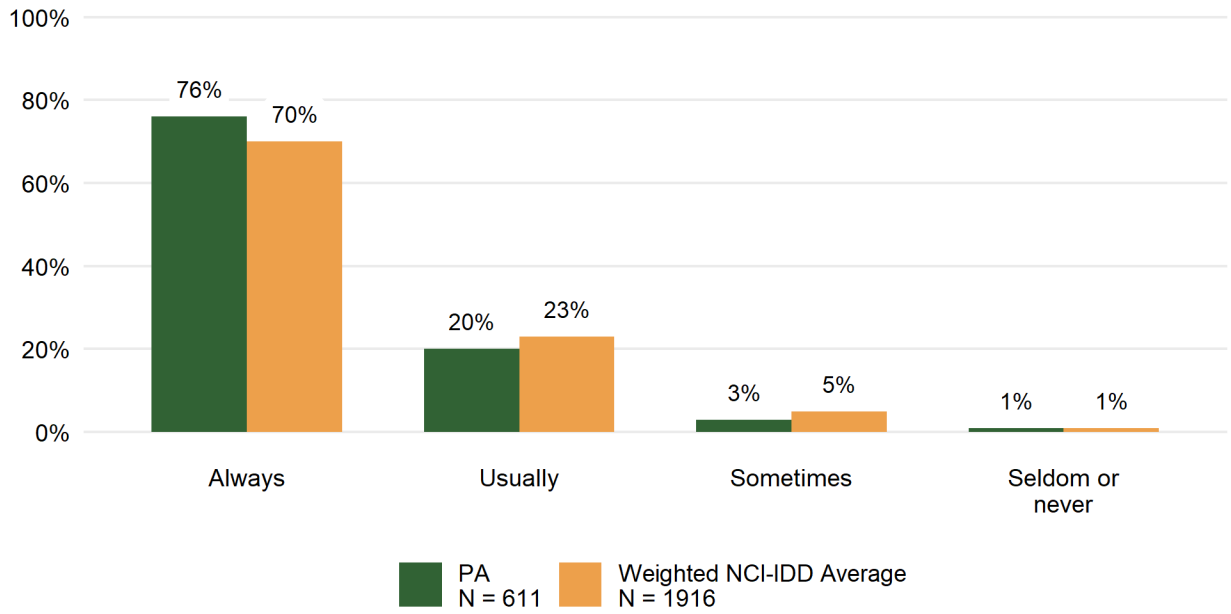


Table 55. Do support workers speak to you in a way you understand?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>76%</b>	<b>20%</b>	<b>3%</b>	<b>1%</b>	<b>611</b>
Weighted NCI-IDD Average	70%	23%	5%	1%	1916



**If your family member does not communicate verbally, are there support workers who can communicate with them?**

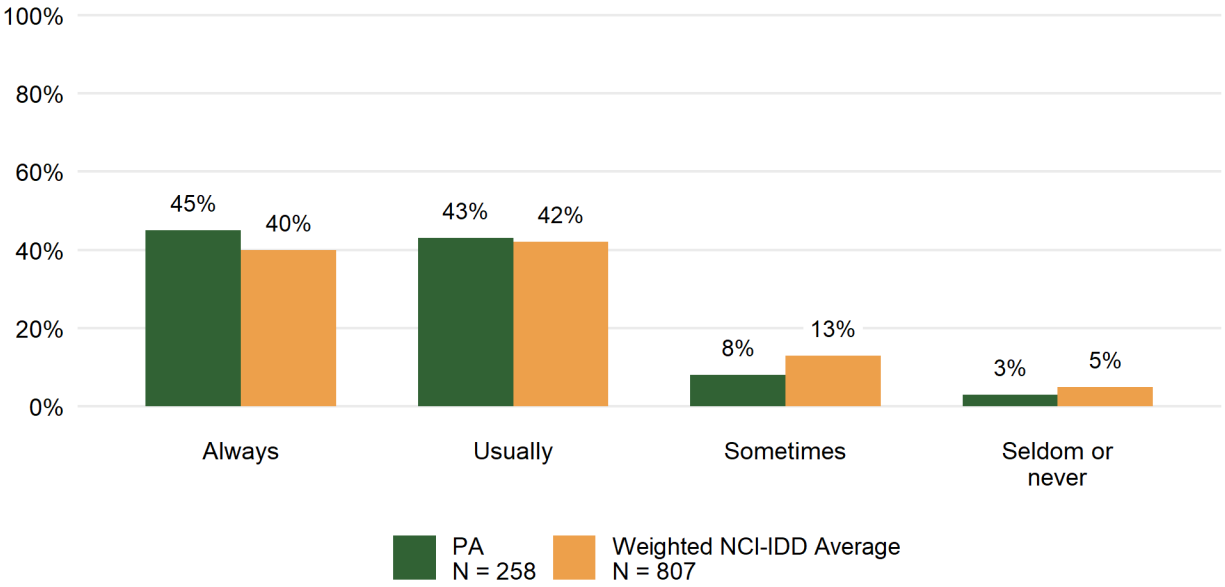


Table 56. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>45%</b>	<b>43%</b>	<b>8%</b>	<b>3%</b>	<b>258</b>
Weighted NCI-IDD Average	40%	42%	13%	5%	807

**Do support workers have the right information and skills to meet your family's needs?**

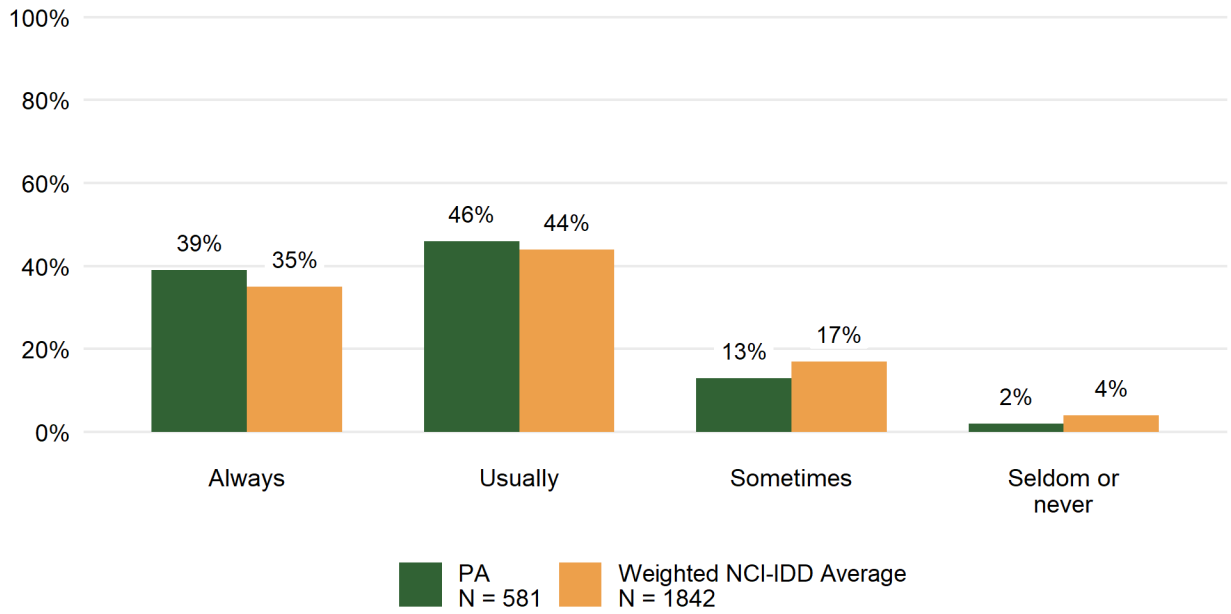


Table 57. Do support workers have the right information and skills to meet your family's needs?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>39%</b>	<b>46%</b>	<b>13%</b>	<b>2%</b>	<b>581</b>
Weighted NCI-IDD Average	35%	44%	17%	4%	1842

**Do your family member's support workers change too often? Is there too much "turnover" of support workers?**

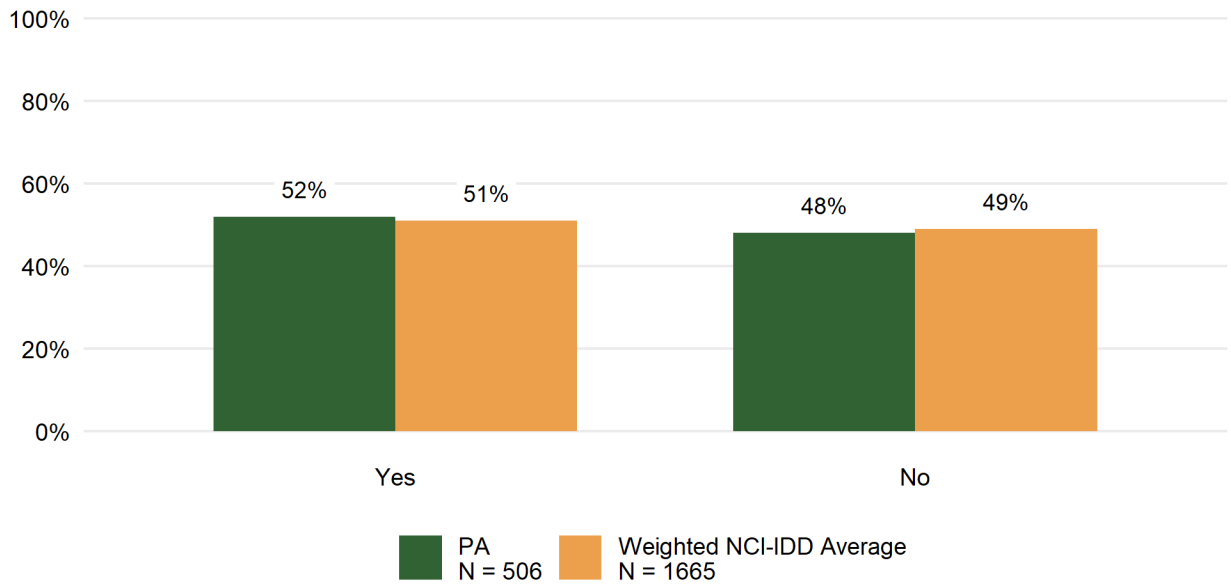


Table 58. Do your family member’s support workers change too often? Is there too much “turnover” of support workers?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>52%</b>	<b>48%</b>	<b>506</b>
Weighted NCI-IDD Average	51%	49%	1665

**Is there always a staff person available to support your family member when support is needed?**

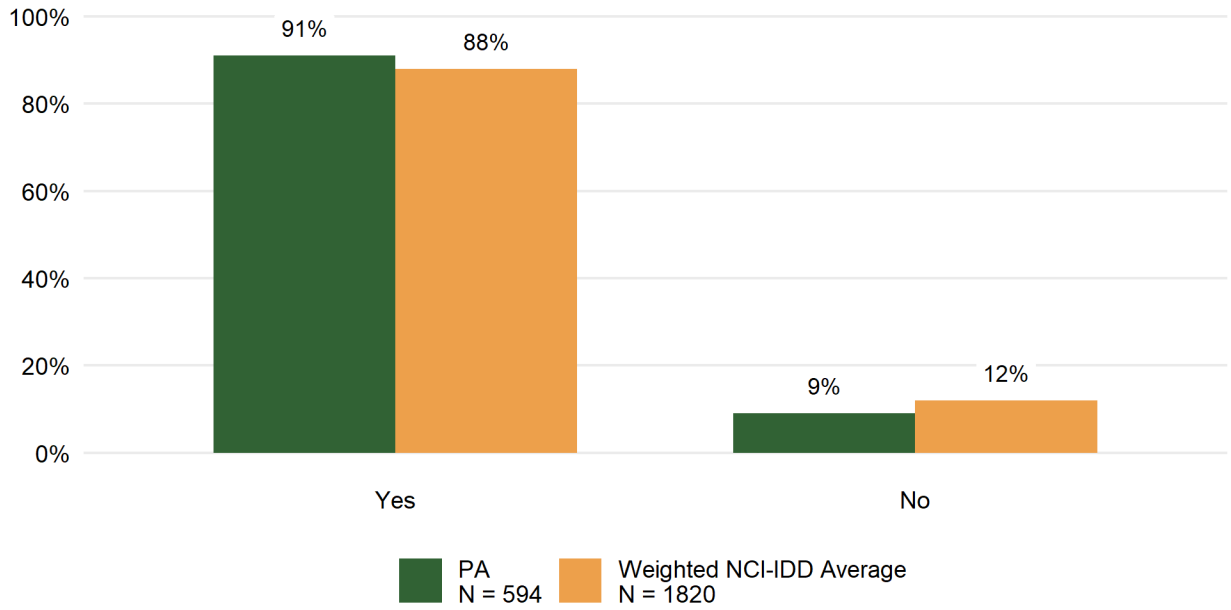


Table 59. Is there always a staff person available to support your family member when support is needed?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>91%</b>	<b>9%</b>	<b>594</b>
Weighted NCI-IDD Average	88%	12%	1820

### **Choice, Decision Making and Control**

Families and family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.

**“You”** and **“Respondent”** refers to the person (usually a parent or guardian) filling out the survey.

**“Family Member”** refers to the person receiving services whom the respondent is answering questions about in this survey.

**Can someone in your family choose or change the provider agency that provides your family member's services?**

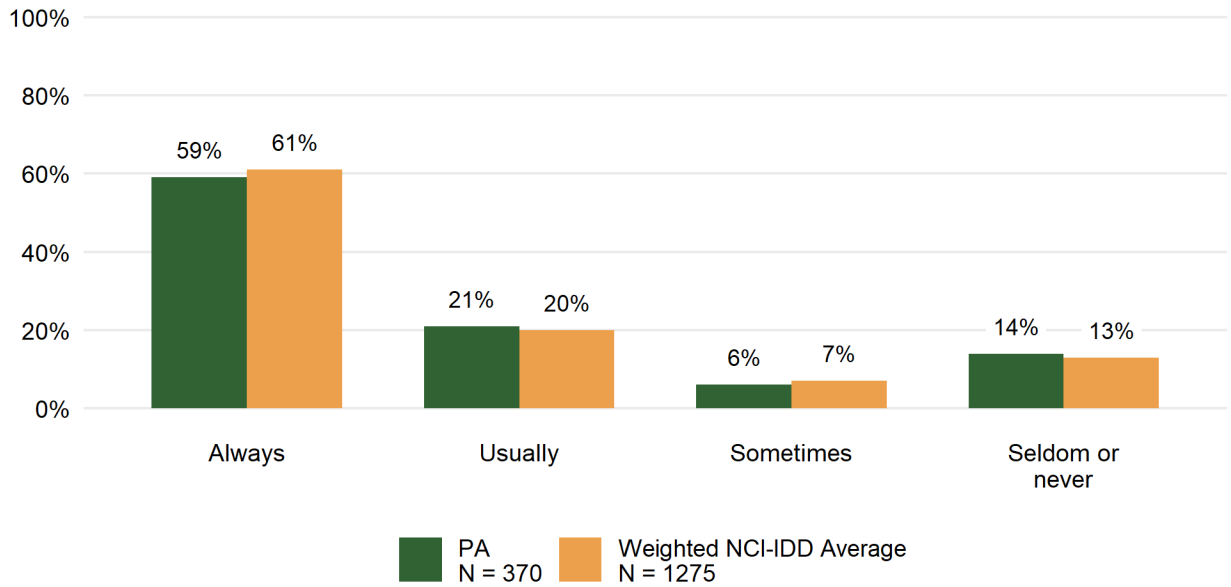


Table 60. Can someone in your family choose or change the provider agency that provides your family member's services?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>59%</b>	<b>21%</b>	<b>6%</b>	<b>14%</b>	<b>370</b>
Weighted NCI-IDD Average	61%	20%	7%	13%	1275

**Can someone in your family choose or change your family member's support workers?**

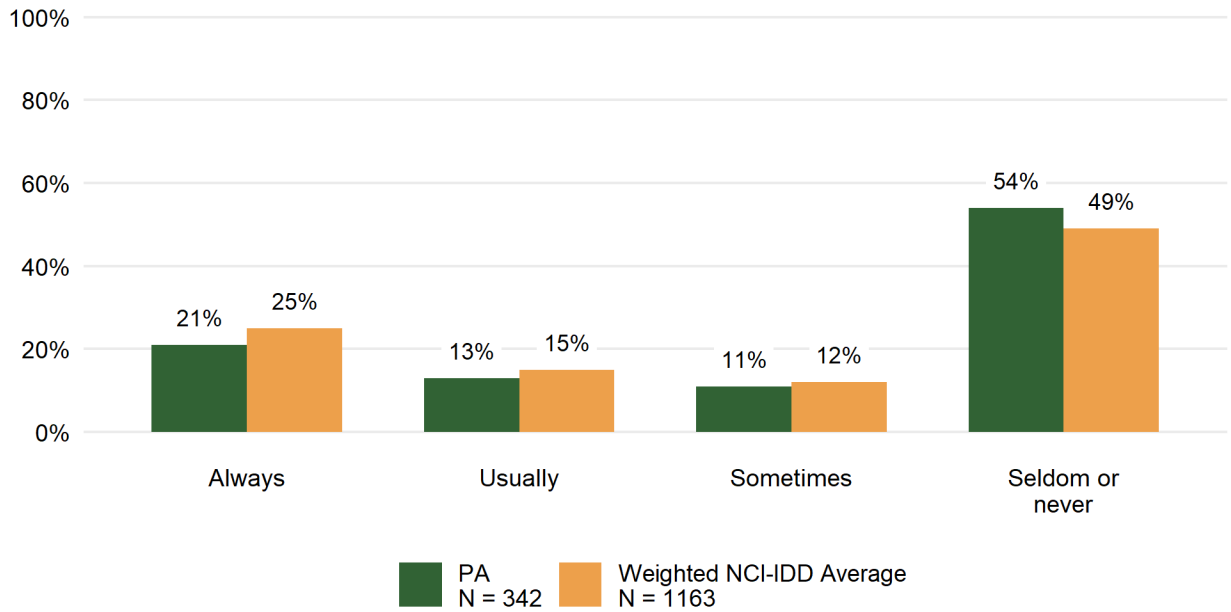


Table 61. Can someone in your family choose or change your family member’s support workers?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>21%</b>	<b>13%</b>	<b>11%</b>	<b>54%</b>	<b>342</b>
Weighted NCI-IDD Average	25%	15%	12%	49%	1163

**Can someone in your family directly manage support staff?**

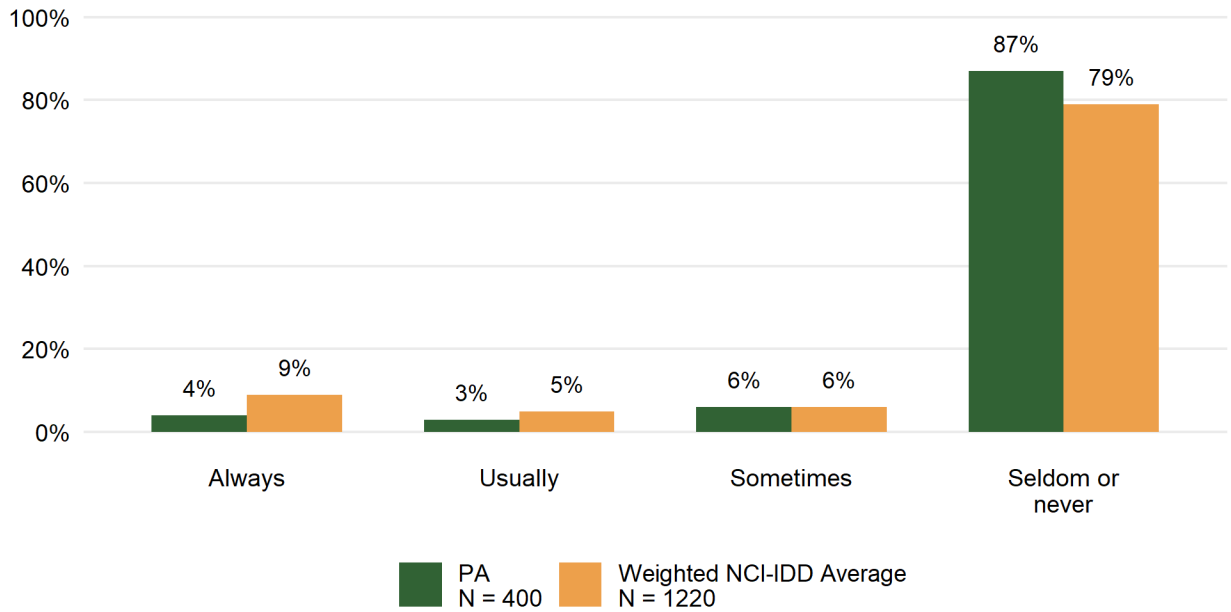


Table 62. Can someone in your family directly manage support staff?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>4%</b>	<b>3%</b>	<b>6%</b>	<b>87%</b>	<b>400</b>
Weighted NCI-IDD Average	9%	5%	6%	79%	1220



**Did you, your family member, or someone else in your family choose your family member's case manager or service coordinator?**

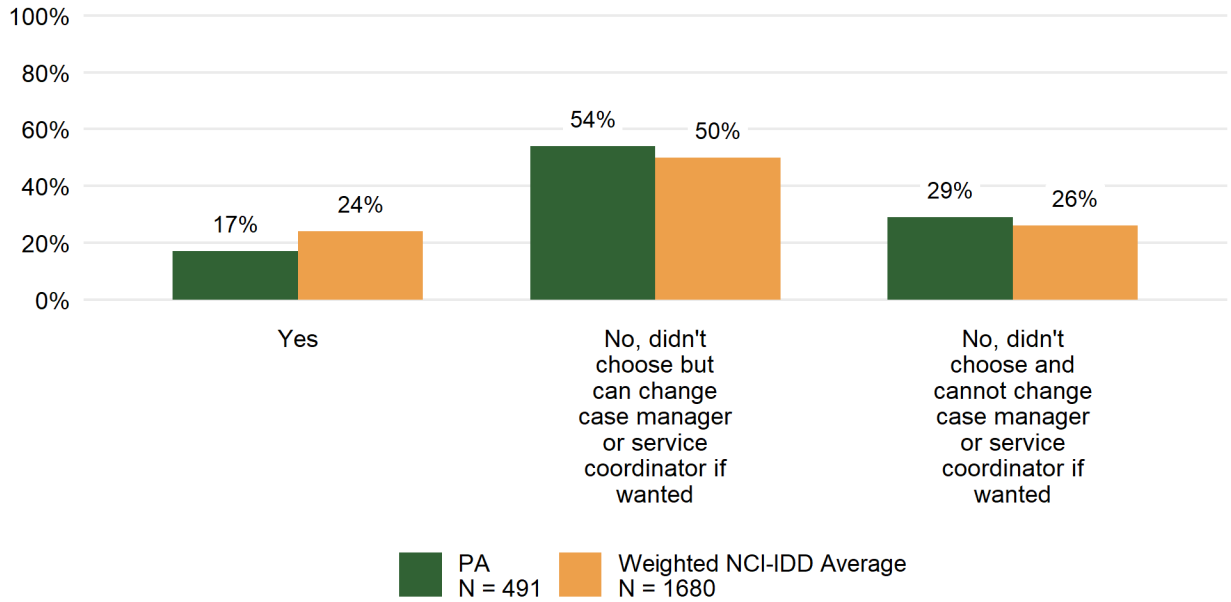


Table 63. Did you, your family member, or someone else in your family choose your family member's case manager or service coordinator?

State (names abbreviated)	Yes	No, didn't choose but can change case manager or service coordinator if wanted	No, didn't choose and cannot change case manager or service coordinator if wanted	N
PA	17%	54%	29%	491
Weighted NCI-IDD Average	24%	50%	26%	1680

## Community Connections

Family members receiving services and supports from the state Developmental disabilities system are meaningfully engaged as members of their communities and have strong relationships. Families can use supports in their community.

**“You”** and **“Respondent”** refers to the person (usually a parent or guardian) filling out the survey.

**“Family Member”** refers to the person receiving services whom the respondent is answering questions about in this survey.

**Does your family member do things in the community?**

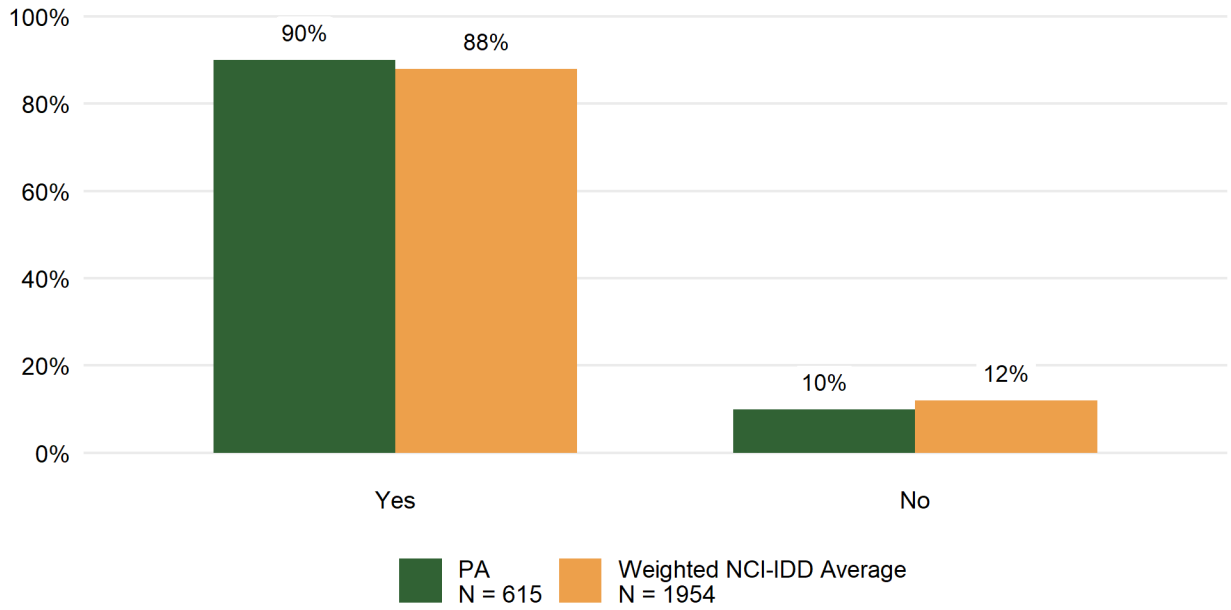


Table 64. Does your family member do things in the community?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>90%</b>	<b>10%</b>	<b>615</b>
Weighted NCI-IDD Average	88%	12%	1954

**For your family member, what makes it hard to do things in the community?**

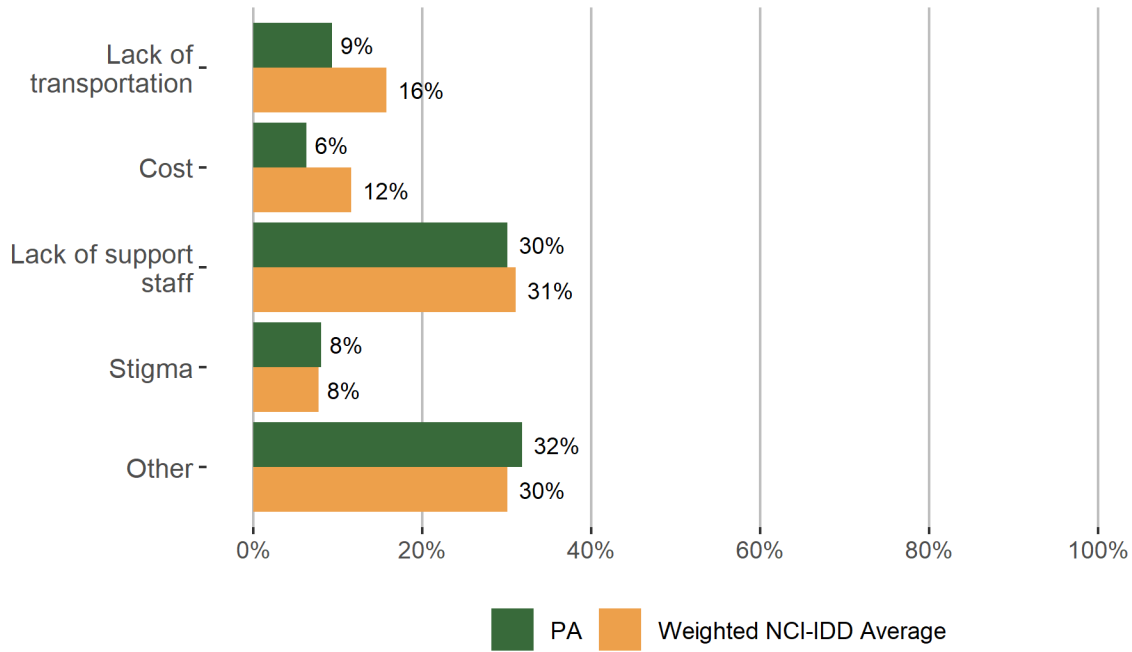


Table 65. For your family member, what makes it hard to do things in the community?

Categories are not mutually exclusive, therefore N is not shown.

State (names abbreviated)	Lack of transportation	Cost	Lack of support staff	Stigma	Other
<b>PA</b>	<b>9%</b>	<b>6%</b>	<b>30%</b>	<b>8%</b>	<b>32%</b>
Weighted NCI-IDD Average	16%	12%	31%	8%	30%

**Does your family member have friends other than paid support workers or family?**

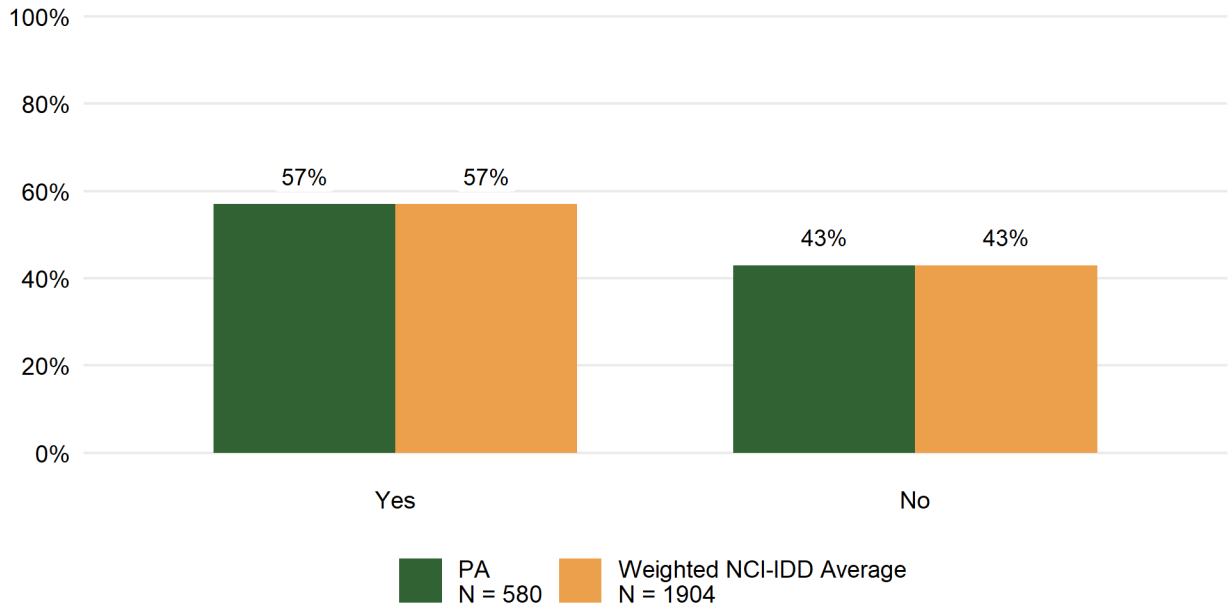


Table 66. Does your family member have friends other than paid support workers or family?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>57%</b>	<b>43%</b>	<b>580</b>
Weighted NCI-IDD Average	57%	43%	1904

**In your community, are there resources or support that your family member can use that are not provided by the I/DD agency?**

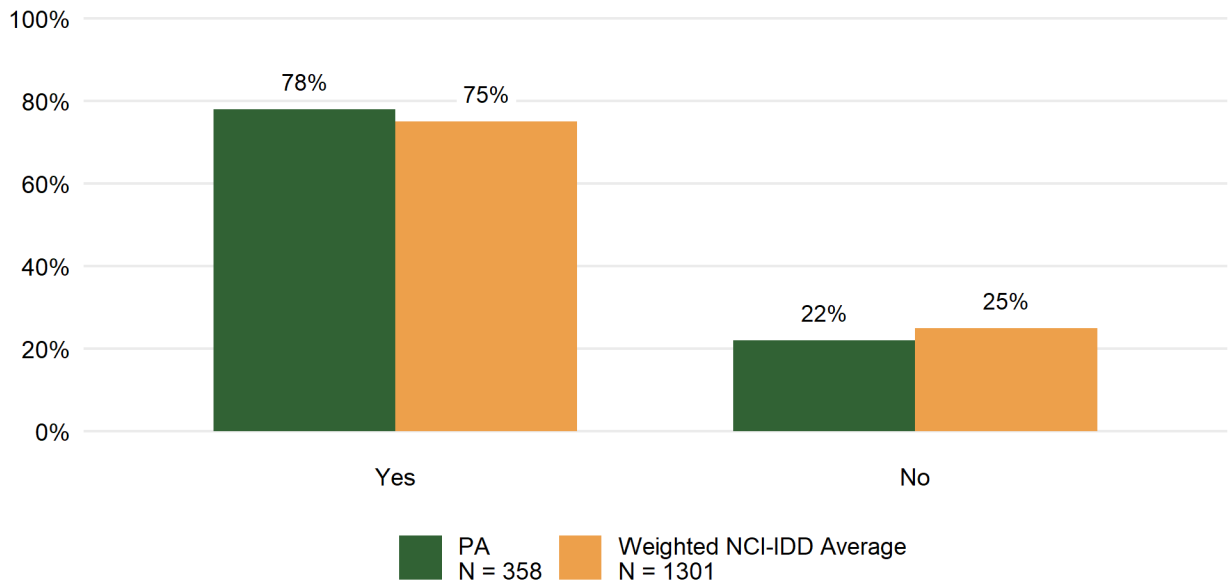


Table 67. In your community, are there resources or support that your family member can use that are not provided by the I/DD agency?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>78%</b>	<b>22%</b>	<b>358</b>
Weighted NCI-IDD Average	75%	25%	1301

**Does your family take part in any family-to-family networks in your community?**

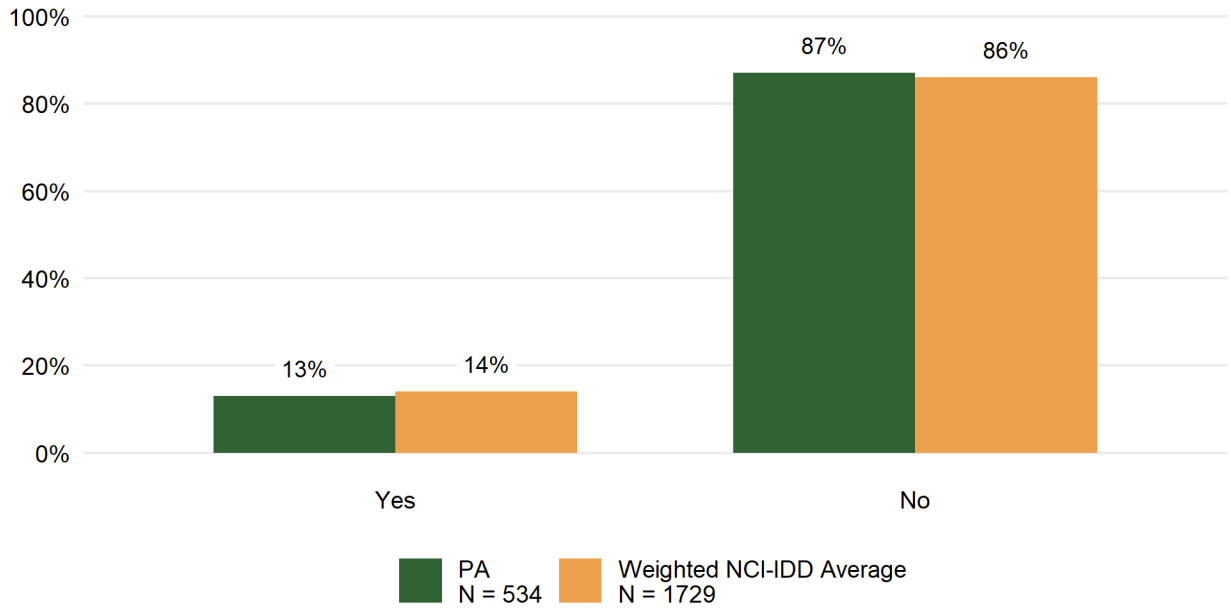


Table 68. Does your family take part in any family-to-family networks in your community?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>13%</b>	<b>87%</b>	<b>534</b>
Weighted NCI-IDD Average	14%	86%	1729

### Health, Welfare and Safety

Families are supported to ensure the health, welfare, and safety of their family member receiving services and supports from the state developmental disabilities system.

**“You”** and **“Respondent”** refers to the person (usually a parent or guardian) filling out the survey.

**“Family Member”** refers to the person receiving services whom the respondent is answering questions about in this survey.



**Can your family member see a primary care provider when needed?**

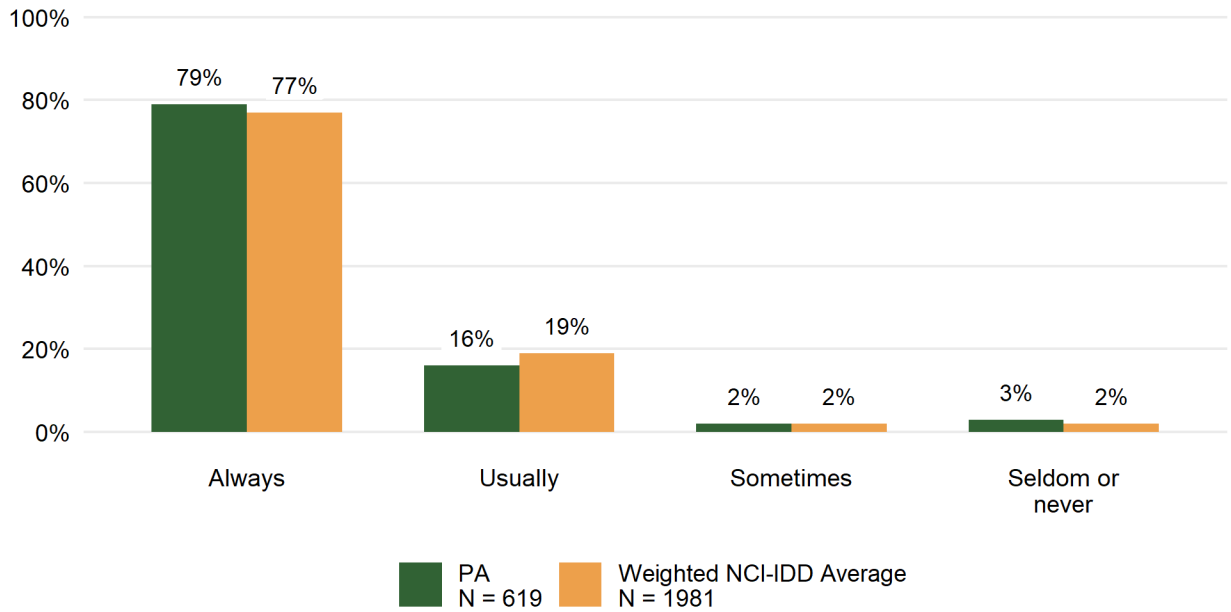


Table 69. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>79%</b>	<b>16%</b>	<b>2%</b>	<b>3%</b>	<b>619</b>
Weighted NCI-IDD Average	77%	19%	2%	2%	1981

**Does your family member's primary care provider understand your family member's needs related to their disability?**

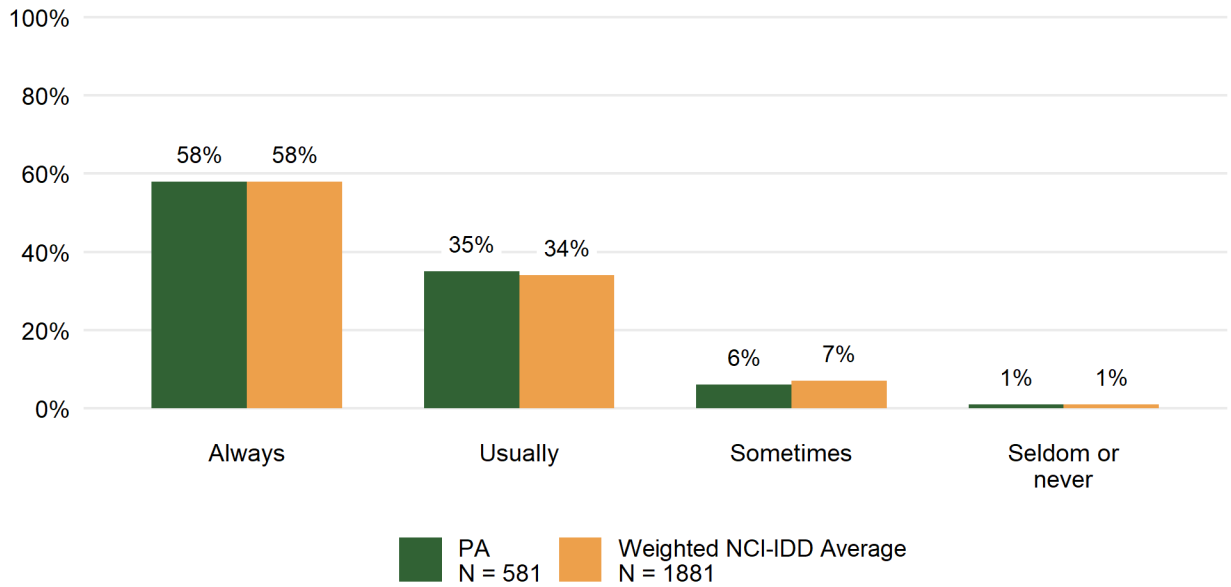


Table 70. Does your family member’s primary care provider (doctor, registered nurse, etc.) understand your family member’s needs related to their disability?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>58%</b>	<b>35%</b>	<b>6%</b>	<b>1%</b>	<b>581</b>
Weighted NCI-IDD Average	58%	34%	7%	1%	1881

**Can your family member go to the dentist when needed?**

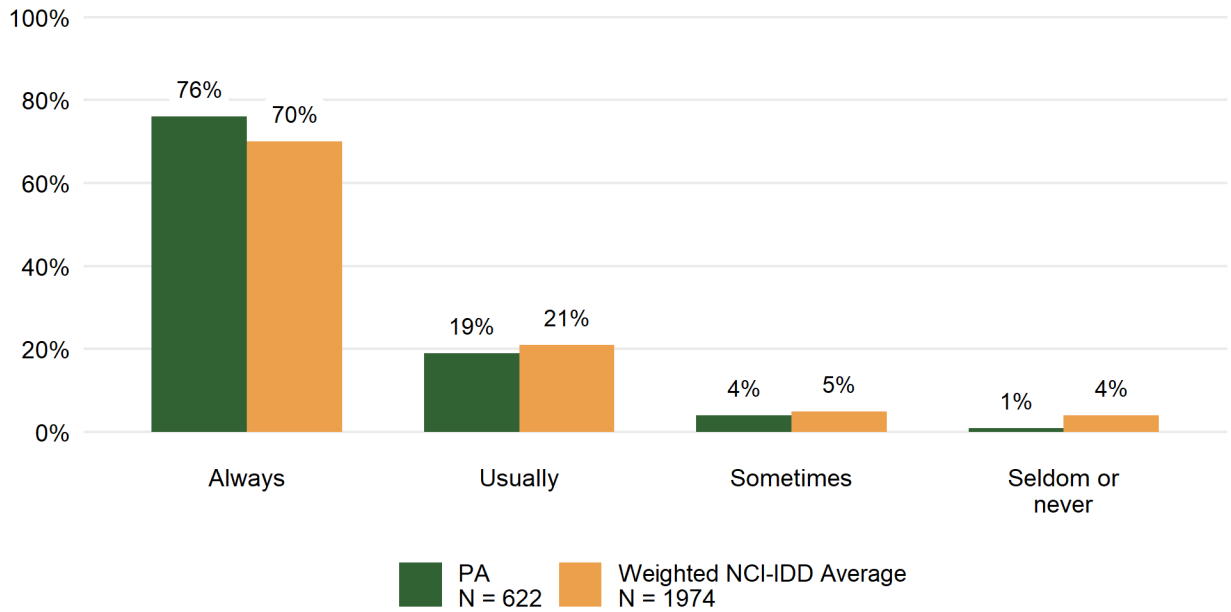


Table 71. Can your family member go to the dentist when needed?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>76%</b>	<b>19%</b>	<b>4%</b>	<b>1%</b>	<b>622</b>
Weighted NCI-IDD Average	70%	21%	5%	4%	1974

**Does your family member's dentist understand your family member's needs related to their disability?**

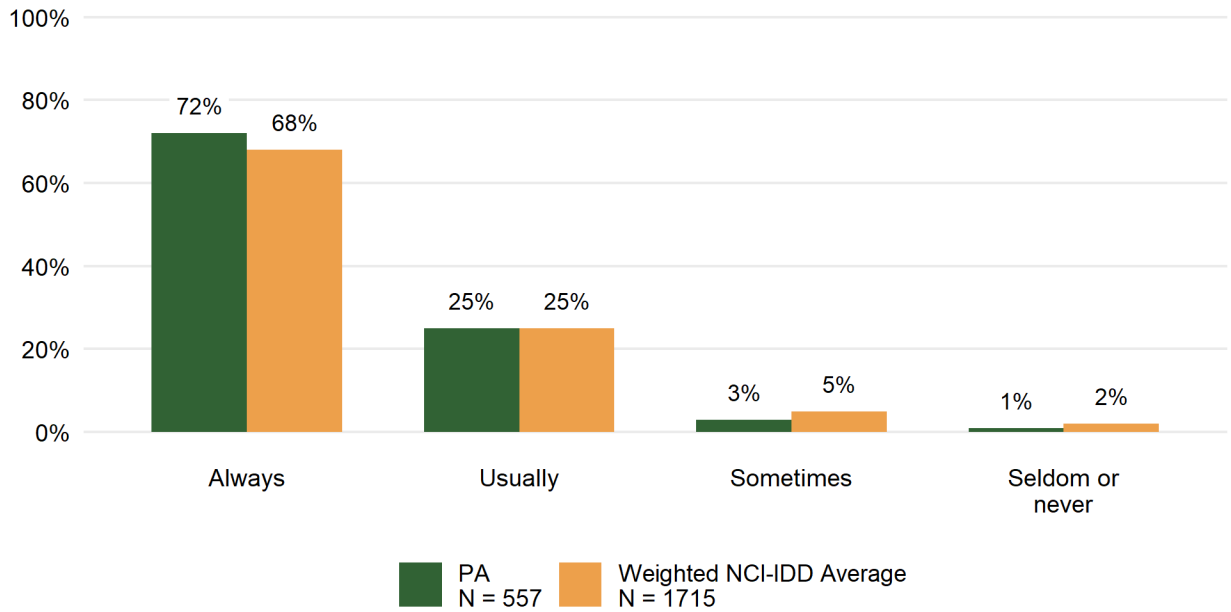


Table 72. Does your family member’s dentist understand your family member’s needs related to their disability?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>72%</b>	<b>25%</b>	<b>3%</b>	<b>1%</b>	<b>557</b>
Weighted NCI-IDD Average	68%	25%	5%	2%	1715

**If your family member takes prescription medications, do you know what they're for?**

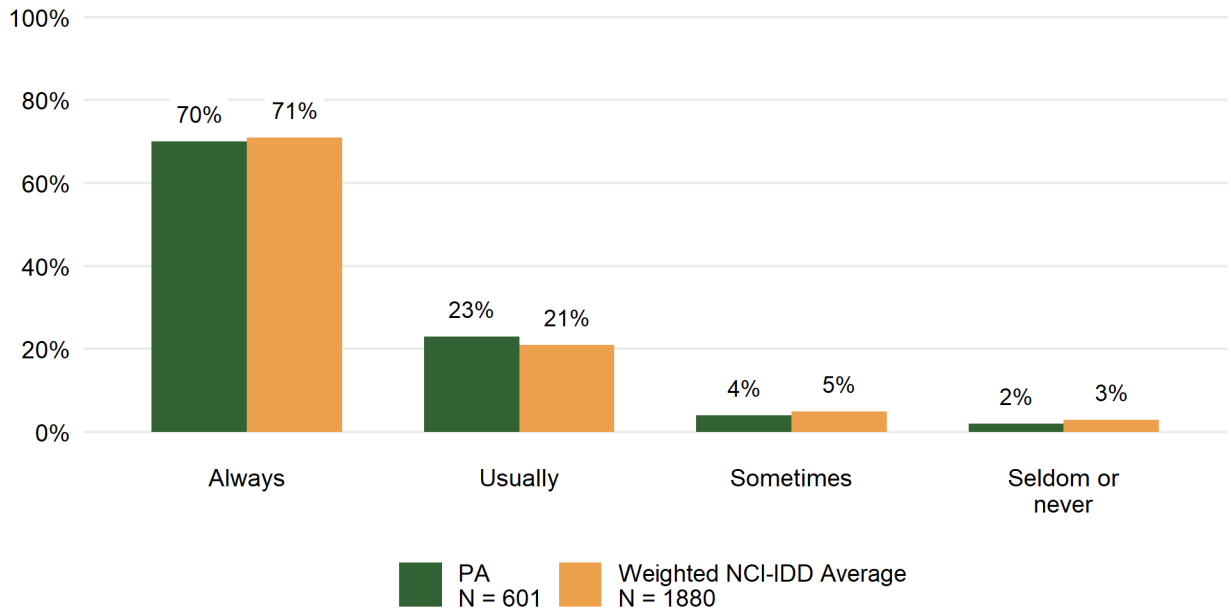


Table 73. If your family member takes prescription medications, do you know what they're for?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>70%</b>	<b>23%</b>	<b>4%</b>	<b>2%</b>	<b>601</b>
Weighted NCI-IDD Average	71%	21%	5%	3%	1880

**Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?**

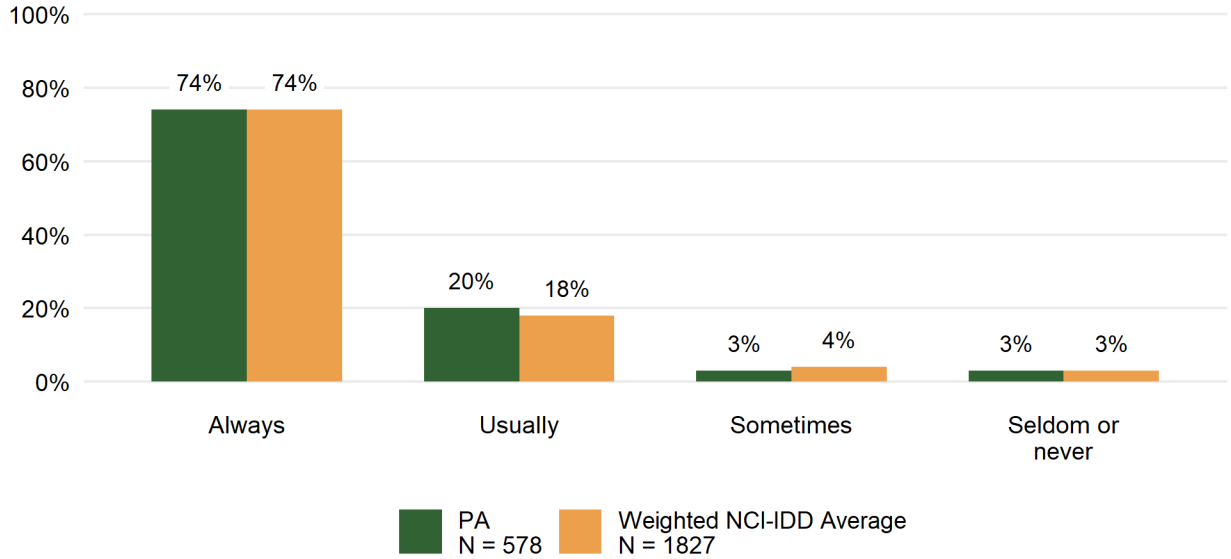


Table 74. Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>74%</b>	<b>20%</b>	<b>3%</b>	<b>3%</b>	<b>578</b>
Weighted NCI-IDD Average	74%	18%	4%	3%	1827

**Can your family member get mental or behavioral health supports when needed (Like see a therapist, go to group counseling)?**

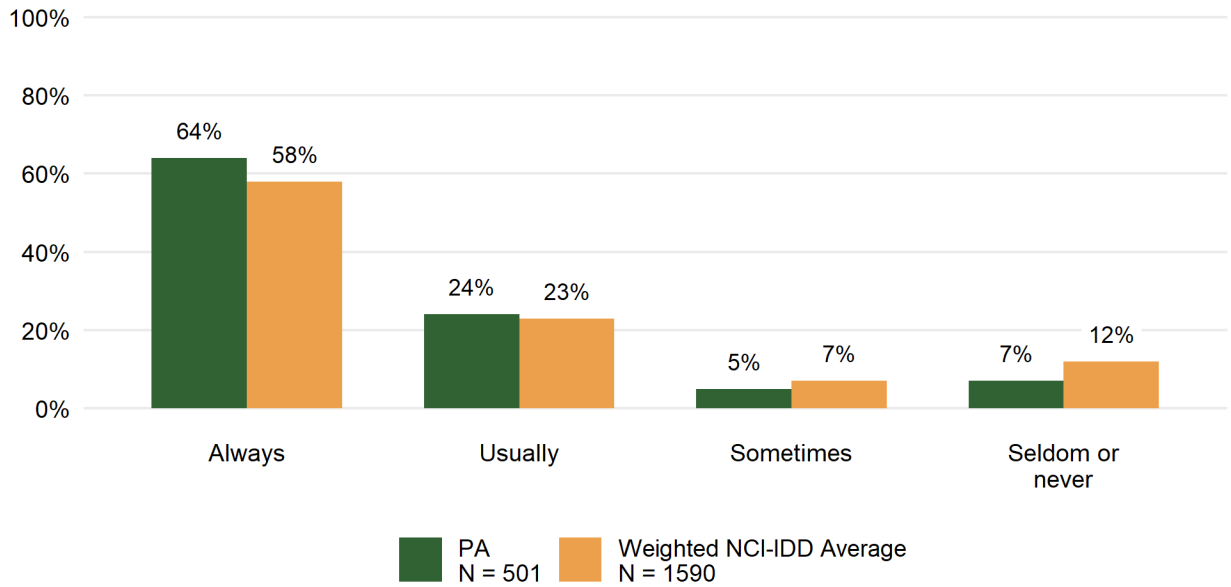


Table 75. Can your family member get mental or behavioral health supports when needed (Like see a therapist, go to group counseling)?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>64%</b>	<b>24%</b>	<b>5%</b>	<b>7%</b>	<b>501</b>
Weighted NCI-IDD Average	58%	23%	7%	12%	1590

**Does your family member's mental or behavioral health professional understand your family member's needs related to their disability?**

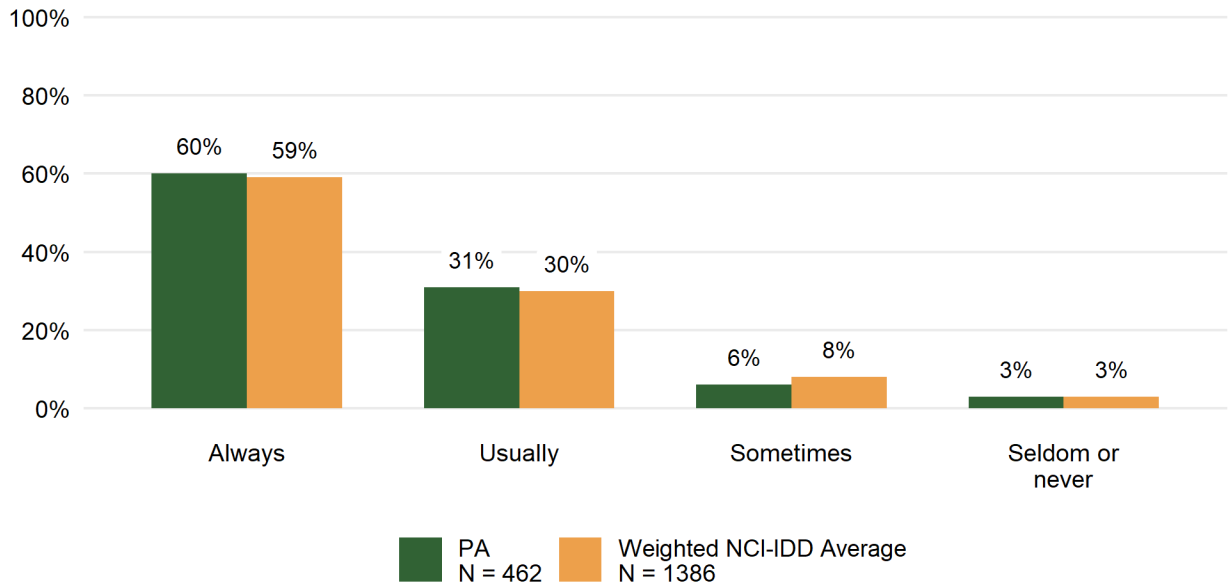


Table 76. Does your family member’s mental or behavioral health professional understand your family member’s needs related to their disability?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>60%</b>	<b>31%</b>	<b>6%</b>	<b>3%</b>	<b>462</b>
Weighted NCI-IDD Average	59%	30%	8%	3%	1386



**If you asked for crisis or emergency services during the past 12 months, were services provided when needed?**

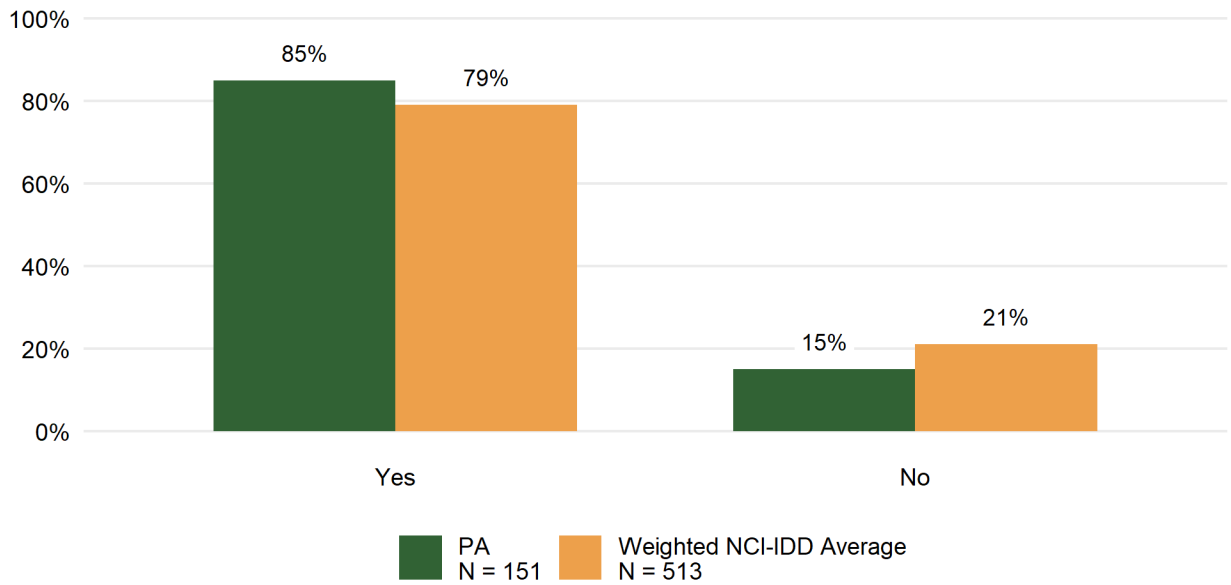


Table 77. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>85%</b>	<b>15%</b>	<b>151</b>
Weighted NCI-IDD Average	79%	21%	513

**Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency, pandemic or natural disaster?**

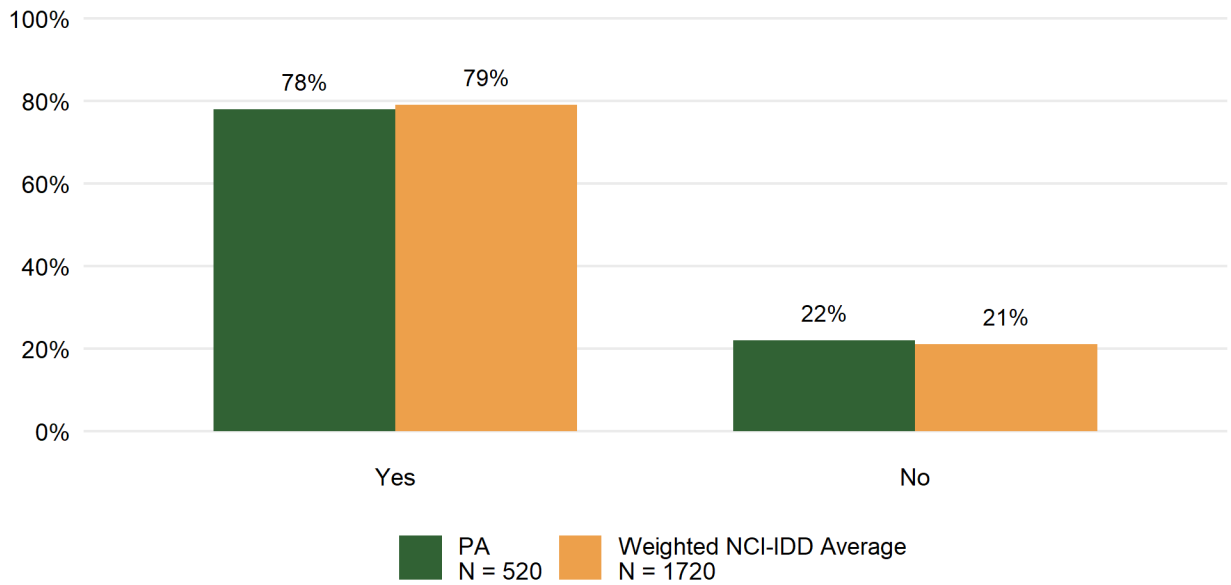


Table 78. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency, pandemic or natural disaster?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>78%</b>	<b>22%</b>	<b>520</b>
Weighted NCI-IDD Average	79%	21%	1720

**Have you talked about how to handle emergencies with your family member's case manager or service coordinator?**

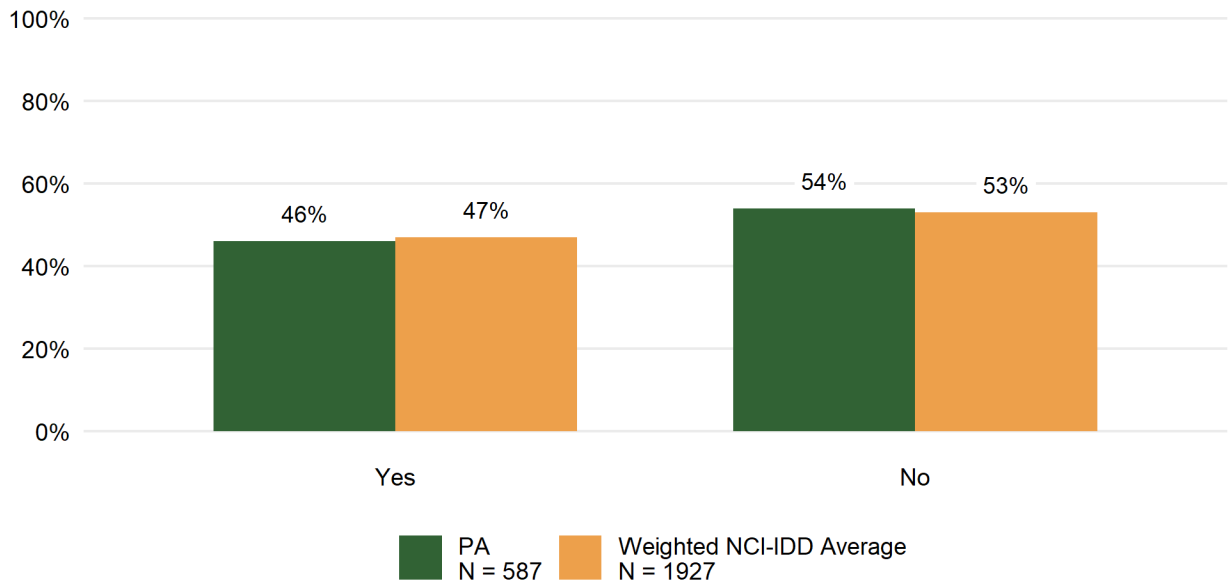


Table 79. Have you talked about how to handle emergencies (such as a medical emergency, pandemic, or natural disaster) with your family member’s case manager or service coordinator?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>46%</b>	<b>54%</b>	<b>587</b>
Weighted NCI-IDD Average	47%	53%	1927

**Do you know how to file a complaint or grievance about provider agencies or staff?**

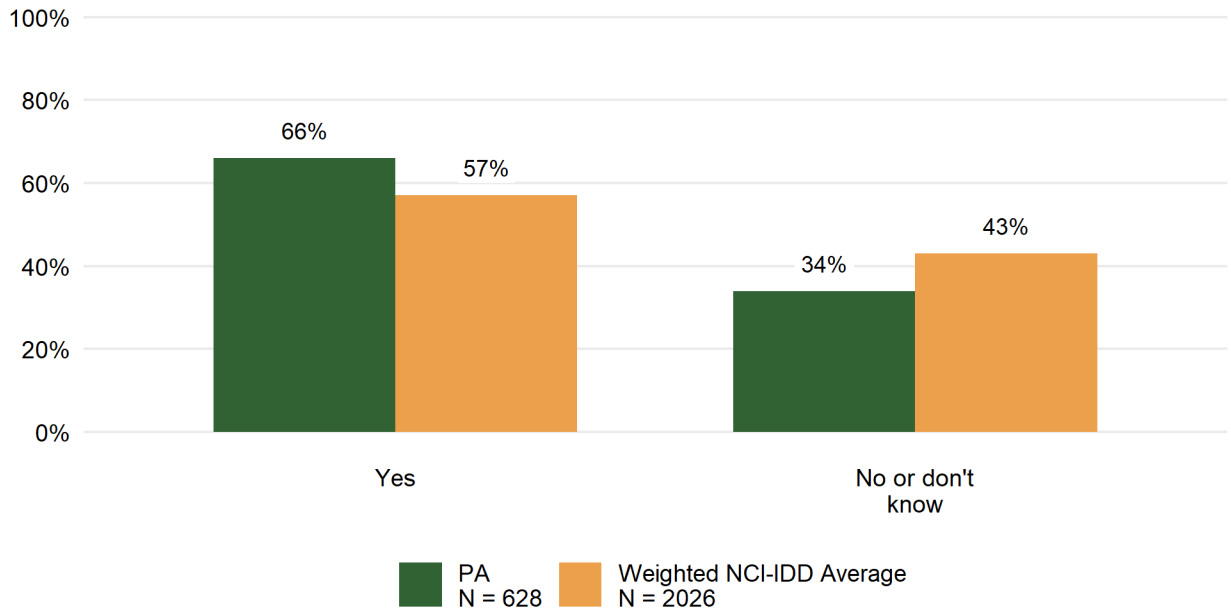


Table 80. Do you know how to file a complaint or grievance about provider agencies or staff?

State (names abbreviated)	Yes	No or don't know	N
<b>PA</b>	<b>66%</b>	<b>34%</b>	<b>628</b>
Weighted NCI-IDD Average	57%	43%	2026

**If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?**

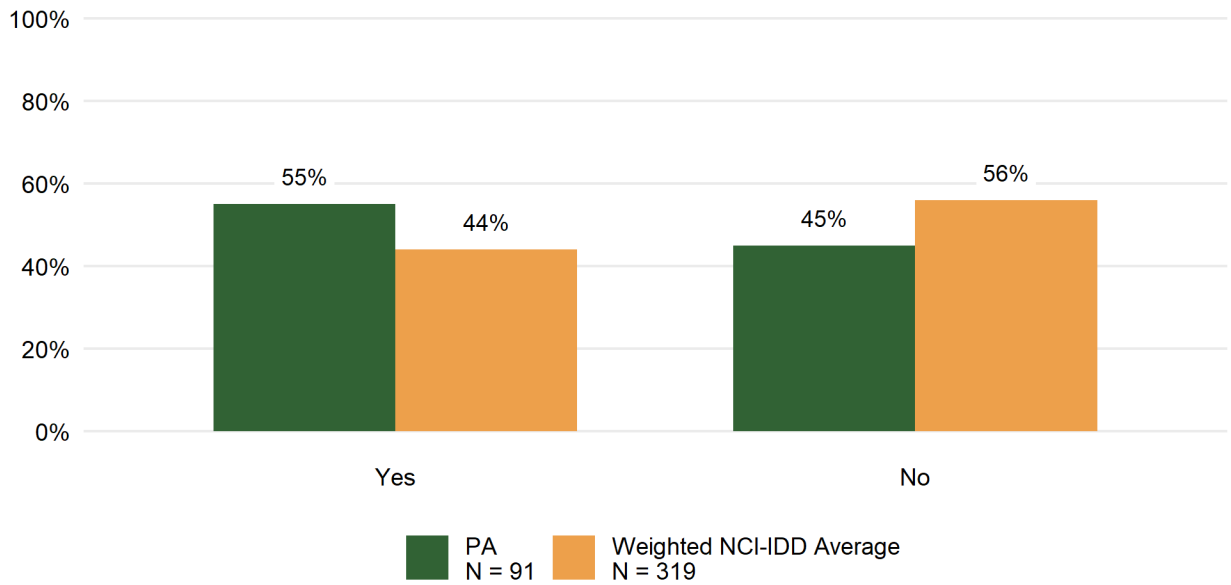


Table 81. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>55%</b>	<b>45%</b>	<b>91</b>
Weighted NCI-IDD Average	44%	56%	319

**Do you know how to report abuse or neglect related to your family member?**

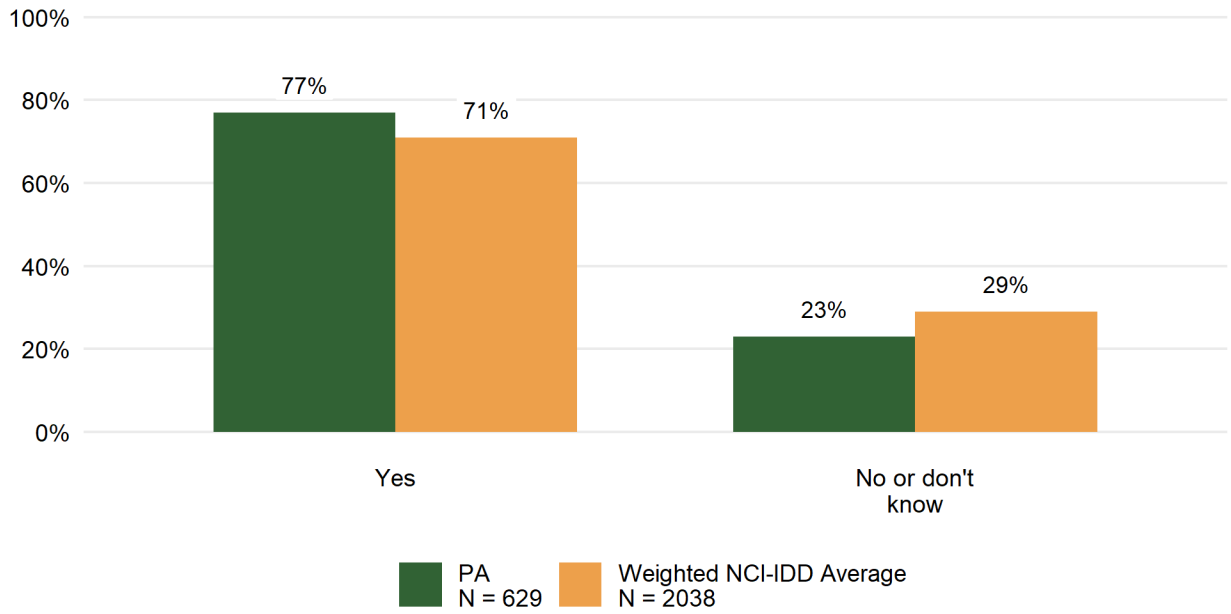


Table 82. Do you know how to report abuse or neglect related to your family member?

State (names abbreviated)	Yes	No or don't know	N
<b>PA</b>	<b>77%</b>	<b>23%</b>	<b>629</b>
Weighted NCI-IDD Average	71%	29%	2038

**Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?**

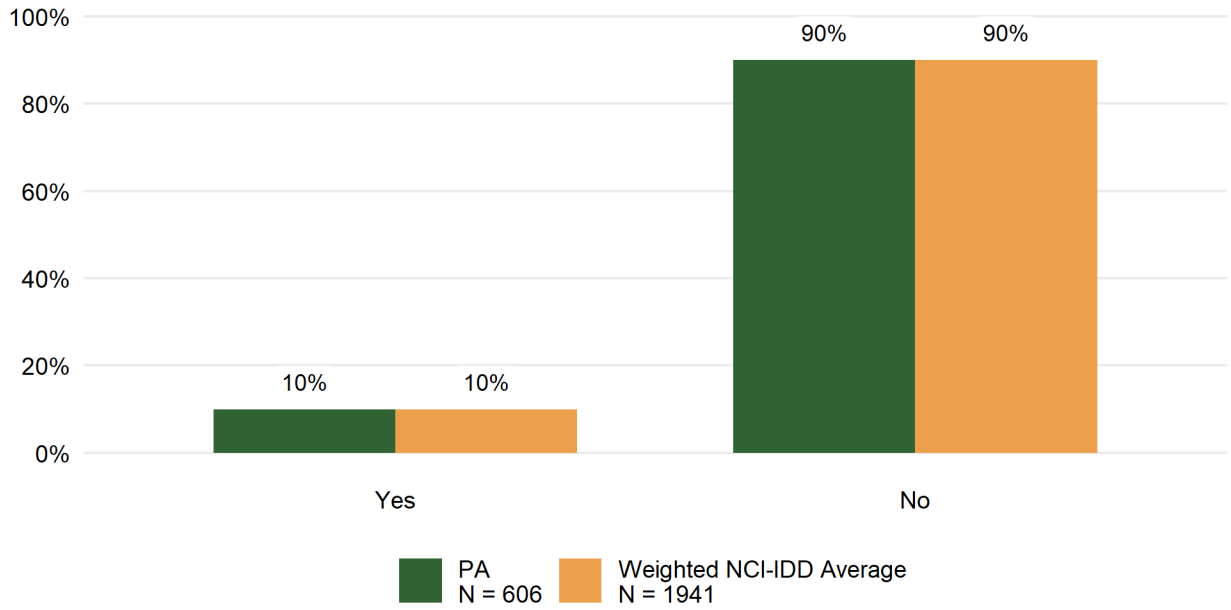


Table 83. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>10%</b>	<b>90%</b>	<b>606</b>
Weighted NCI-IDD Average	10%	90%	1941

**If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?**

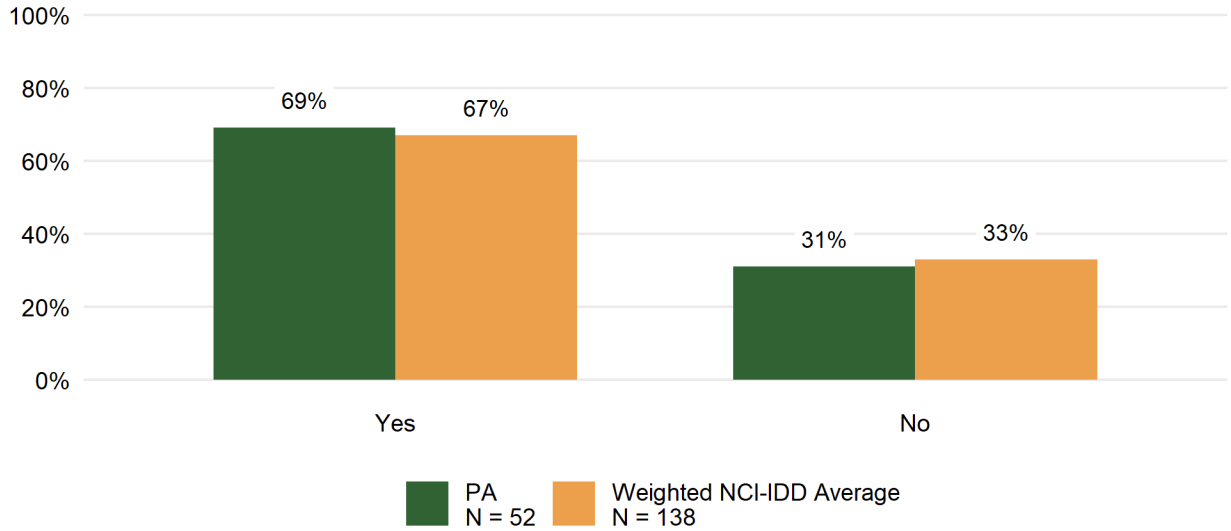


Table 84. If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?

State (names abbreviated)	Yes	No	N
PA	69%	31%	52
Weighted NCI-IDD Average	67%	33%	138



## Family Satisfaction

Services and supports lead to better lives for people with disabilities and their families.

“**You**” and “**Respondent**” refers to the person (usually a parent or guardian) filling out the survey.

“**Family Member**” refers to the person receiving services whom the respondent is answering questions about in this survey.

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

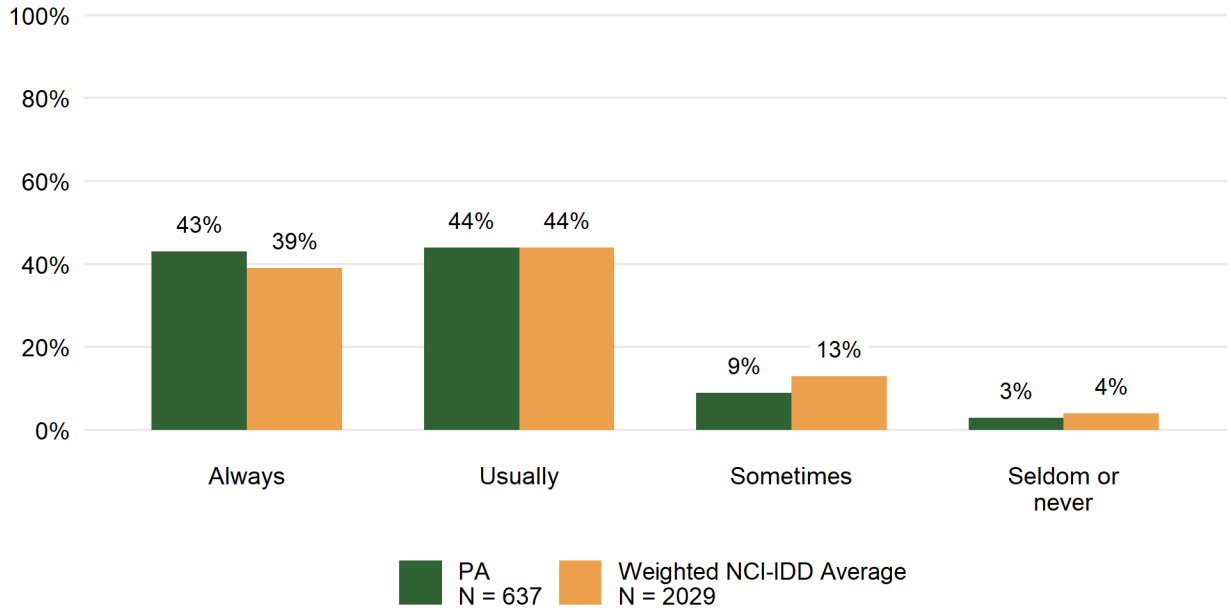


Table 85. Overall, are you satisfied with the services and supports your family member currently receives?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>43%</b>	<b>44%</b>	<b>9%</b>	<b>3%</b>	<b>637</b>
Weighted NCI-IDD Average	39%	44%	13%	4%	2029

**Do you feel that services and supports have made a positive difference in the life of your family member?**

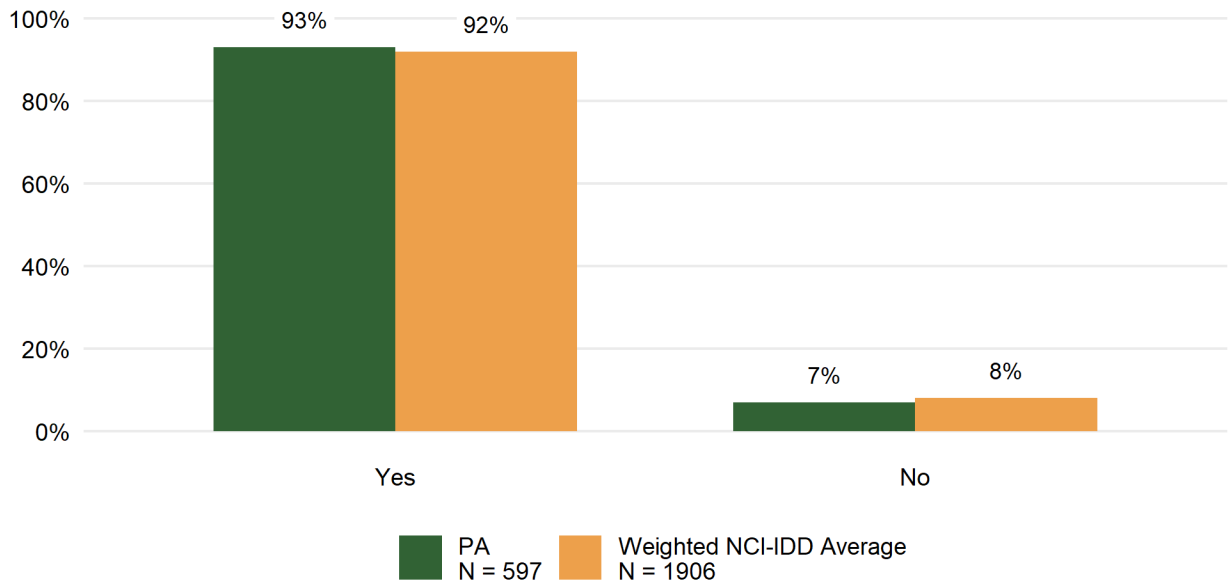


Table 86. Do you feel that services and supports have made a positive difference in the life of your family member?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>93%</b>	<b>7%</b>	<b>597</b>
Weighted NCI-IDD Average	92%	8%	1906

**Does the agency providing residential services to your family member involve them in important decisions?**

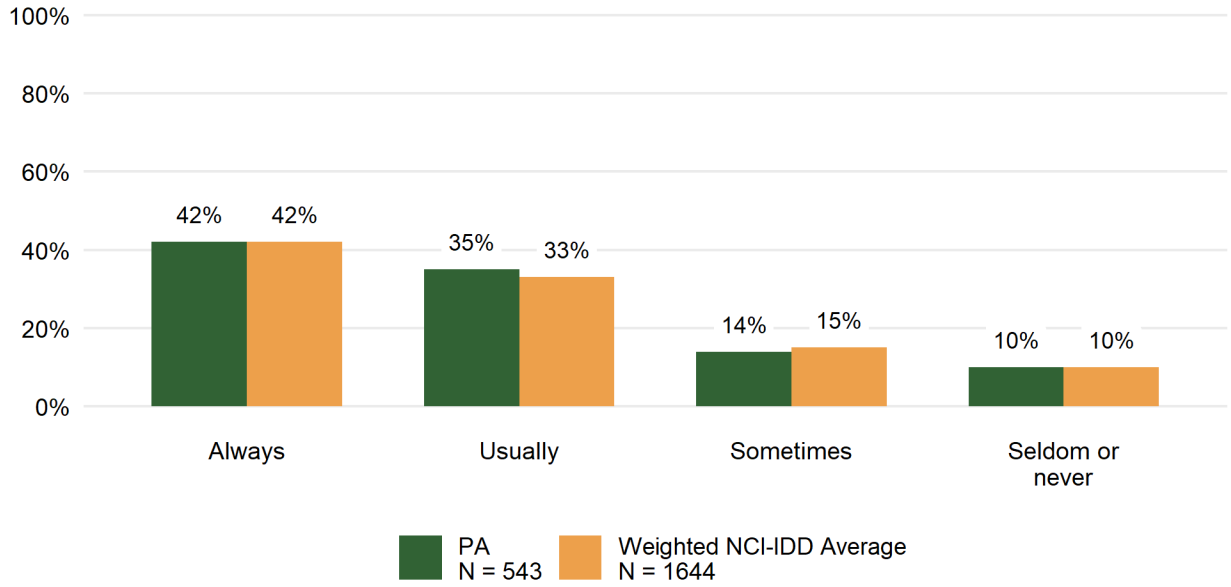


Table 87. Does the agency providing residential services to your family member involve them in important decisions?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
<b>PA</b>	<b>42%</b>	<b>35%</b>	<b>14%</b>	<b>10%</b>	<b>543</b>
Weighted NCI-IDD Average	42%	33%	15%	10%	1644

**Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?**

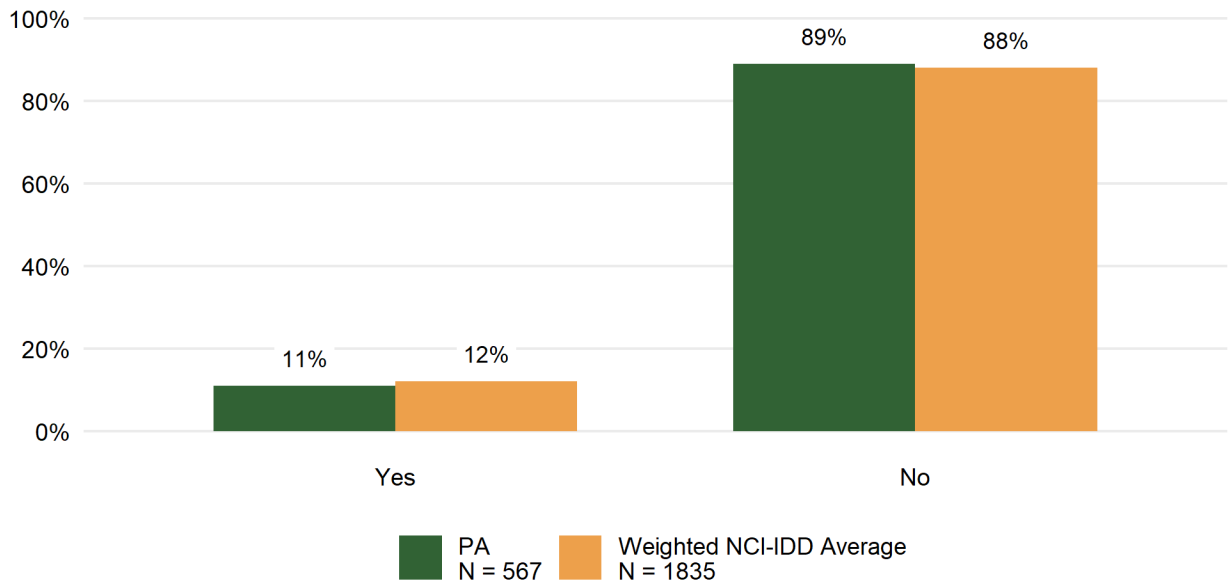


Table 88. Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>11%</b>	<b>89%</b>	<b>567</b>
Weighted NCI-IDD Average	12%	88%	1835

**If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively?**

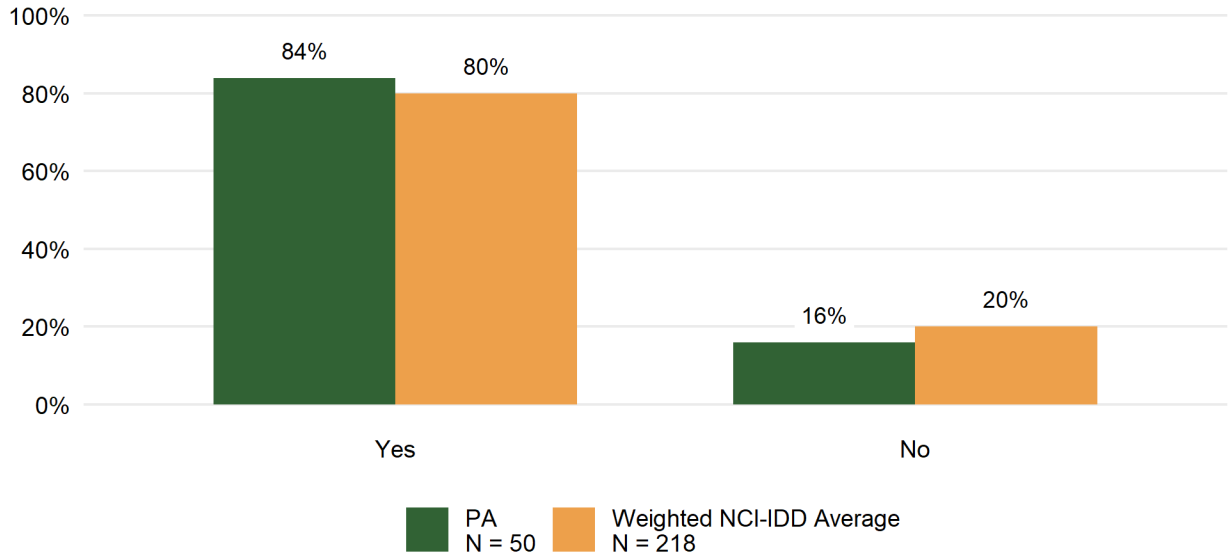


Table 89. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively?

State (names abbreviated)	Yes	No	N
PA	84%	16%	50
Weighted NCI-IDD Average	80%	20%	218

**Have the services or supports that your family member received been increased in the past 12 months?**

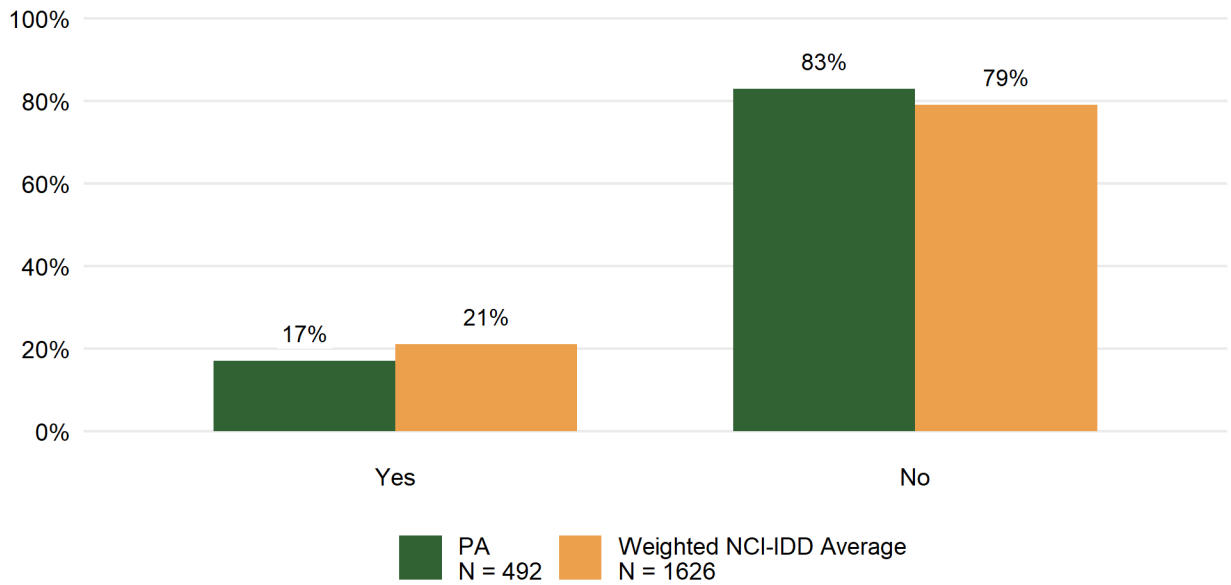


Table 90. Have the services or supports that your family member received been increased in the past 12 months?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>17%</b>	<b>83%</b>	<b>492</b>
Weighted NCI-IDD Average	21%	79%	1626

**Are services and supports helping your family member to live a good life?**

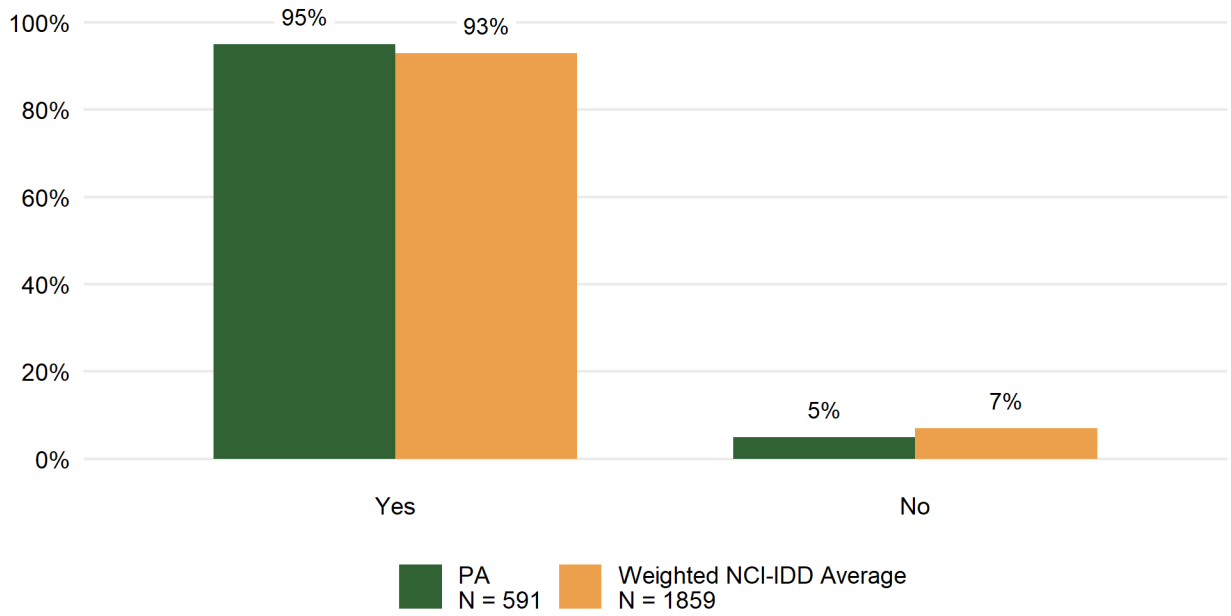


Table 91. Are services and supports helping your family member to live a good life?

State (names abbreviated)	Yes	No	N
<b>PA</b>	<b>95%</b>	<b>5%</b>	<b>591</b>
Weighted NCI-IDD Average	93%	7%	1859