

# 2021-22 PA Adult Family Survey State Report

## Table of Contents

<b>2021-22 PA Adult Family Survey State Report</b> .....	<b>1</b>
Introduction .....	7
Demographics.....	9
Family Member .....	9
Table 1. More Than One Person Living in the Home Has IDD .....	10
Table 2. Family Member’s Residential Designation.....	11
Table 3. Family Member’s Age.....	12
Table 4. Family Member’s Gender.....	13
Table 5. Family Member’s Race and Ethnicity.....	14
Table 6a. Family Member’s Conditions.....	15
Table 6b. Family Member’s Conditions (continued) .....	16
Table 7a. Family Member’s Health Conditions (continued) .....	17
Table 7b. Family Member’s Health Conditions (continued).....	18
Table 7c. Family Member’s Health Conditions (continued) .....	19
Table 8. Family Member’s Preferred Means of Communication .....	20
Table 9. Family Member’s Preferred Language.....	21
Table 10. Family Member Has Legal Court Appointed Guardian or Conservator .....	22
Table 11. Guardian or Conservator Relationship to Family Member.....	23
Table 12a. Family Member’s Highest Level of Education.....	24
Table 12b. Family Member’s Highest Level of Education (continued) .....	25
Table 13. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors .....	26
Table 14. Family Member’s Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating) .....	27
Table 15. Family Member’s Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping) .....	28

Respondents.....	29
Table 16. Language Usually Spoken at Home .....	30
Table 17. Respondent's Age.....	31
Table 18. Respondent's Health.....	32
Table 19. Respondent's Relationship to Family Member .....	33
Table 20. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services .....	34
Table 21. Number of Adults in Household (Not Including Family Member Receiving Services) .....	35
Table 22. Number of Children (Under 18 Years Old) in Household .....	36
Table 23. Respondent's Highest Level of Education .....	37
Table 24. Total Taxable Household Income of Wage Earners in the Past Year .....	38
Services and Supports Received .....	39
Table 25a. Services and Supports Received From ID/DD Agency.....	40
Table 25b. Services and Supports Received From ID/DD Agency (continued) .....	41
Table 26. Additional Services and Supports Received.....	42
Main Survey Results .....	43
Information and Planning.....	44
Table 27. Do you get enough information to take part in planning services for your family member? .....	45
Table 28. Is the information you get about services and supports easy to understand? .....	46
Table 29. Do you get information about services and supports in your preferred language? .....	47
Table 30. Does the case manager/service coordinator listen to your family's choices and opinions? .....	48
Table 31. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)? .....	49
Table 32. Do you need help planning for your family member's future with respect to any of the following areas? .....	50
Table 33. Has your family learned about alternatives to guardianship? .....	51

Table 34. Does your family member have a service plan?.....	52
Table 35. Does the plan include all the services and supports your family member needs? .....	53
Table 36. Did you or someone else in your family (besides your family member with a disability) help make the plan? .....	54
Table 37. Did your family member help make the plan?.....	55
Table 38. Do you feel like your family had enough say or input in making the plan? .....	56
Table 39. Did your family member leave school services and begin adult services during the past 12 months? .....	57
Table 40. If your family member left school services during the past year, did they have a transition plan? .....	58
Table 41. If family member had a transition plan, did the transition plan include getting or continuing work in a community job? .....	59
Access and Delivery of Services and Supports.....	60
Table 42. Does your family member get all the services listed in the plan?.....	61
Table 43. Does your family get the supports and services it needs? .....	62
Table 44a. "If your family does not get the support and services needed, what additional services does your family need?.....	63
Table 44b. If your family does not get the support and services needed, what additional services does your family need? (continued).....	64
Table 45. Do services and supports change when your family's needs change? .....	65
Table 46. Does your family member have enough supports to work or volunteer in the community?.....	66
Table 47. Does your family member have the special equipment or accommodations they need? .....	67
Table 48. If you need respite services, how often are you able to get them when needed?.....	68
Table 49. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services? .....	69
Table 50. Are you or your family member able to contact their support workers when you want?.....	70

Table 51. Are you or your family member able to contact their case manager/service coordinator when you want? .....	71
Table 52. Do service providers for your family member work together to provide support? .....	72
Table 53. Are services delivered in a way that is respectful of your family's culture? ...	73
Table 54. Does your family member use technology in their everyday life to help them do things on their own?.....	74
Table 55. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?.....	75
Table 56. How well does the internet work in your home? .....	76
Workforce (New in 2021-2022).....	77
Table 57. Do support workers come and go when they are supposed to? .....	78
Table 58. Do support workers speak to you in a way you understand? .....	79
Table 59. If your family member does not communicate verbally, are there support workers who can communicate with them? .....	80
Table 60. Do support workers have the right information and skills to meet your family's needs? .....	81
Table 61. Do your family member's support workers change too often? Is there too much "turnover" of support workers?.....	82
Table 62. Is there always a staff person available to support your family member when support is needed?.....	83
Choice, Decision Making and Control.....	84
Table 63. Can your family choose or change the agency that provides your family member's services? .....	85
Table 64. Can your family choose or change your family member's support workers? .....	86
Table 65. Can someone in your family directly manage support staff? .....	87
Table 66. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator? .....	88
Table 67. Does your family member do things in the community?.....	89
Table 68. For your family member, what makes it hard to do things in activities in the community?.....	90

Table 69. Does your family member have friends other than paid support workers or family?.....	91
Table 70. In your community, are there resources that your family can use that are not provided by the state (for example, recreational programs, community housing, library programs, religious groups, etc.)?.....	92
Table 71. Does your family take part in any family-to-family networks in your community?.....	93
Health, Welfare, and Safety (New in 2021-22) .....	94
Table 72. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?.....	95
Table 73. Does your family member's primary care doctor understand your family member's needs related to his/her disability?.....	96
Table 74. Can your family member go to the dentist when needed? .....	97
Table 75. Does your family member's dentist understand your family member's needs related to their disability?.....	98
Table 76. If your family member takes prescription medications, do you know what they're for?.....	99
Table 77. Do you, your family member, or someone else in your family know what is needed to safely take the medications?.....	100
Table 78. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)?.....	101
Table 79. If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability? .....	102
Table 80. If you asked for crisis or emergency services during the past 12 months, were services provided when needed? .....	103
Table 81. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?.....	104
Table 82. Have you talked about how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your family member's case manager/service coordinator?.....	105
Table 83. Do you know how to file a complaint or grievance about provider agencies or staff? .....	106

Table 84. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled? .....	107
Table 85. Do you know how to report abuse or neglect related to your family member? .....	108
Table 86. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member? .....	109
Table 87. If a report of abuse or neglect was filed on behalf of family member, were you notified of the report in a timely manner? .....	110
Family Satisfaction.....	111
Table 88. Overall, are you satisfied with the services and supports your family member currently receives?.....	112
Table 89. Do you feel that services and supports have made a positive difference in the life of your family member? .....	113
Table 90. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?.....	114
Table 91. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated? .....	115
Table 92. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?.....	116
Table 93. Have the services or supports that your family member received been increased in the past year?.....	117
Table 94. Are services and supports helping your family member to live a good life? 118	
COVID-19 Supplement .....	119
Table 95. Were your family member's services and supports changed, canceled, or reduced during COVID time? .....	120
Table 96. If yes, are those changes still in effect (still part of your family member's life)? .....	121
Table 97. If some or all of your family member's services have reopened or restarted: Did your family get enough information about the services reopening/restarting?... 122	
Table 98. If some or all of your family member's services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions? .....	123

Table 99. If staff support your family member in your family member's home: Do you feel that the staff follow recommendations to keep the household safe and healthy? ..... 124

Table 100. Do you feel that the people in your household have the personal protective equipment (PPE) they need to stay healthy and safe when going out in the community? ..... 125

Table 101. In preparation for the future, have you made or updated an emergency plan with your family member's case manager or with other staff? ..... 126

*Introduction*

**What is NCI-IDD**

The National Core Indicators® – Intellectual and Developmental Disabilities (NCI®-IDD) is a voluntary effort by state developmental disability agencies to track their performance using a standardized set of consumer and family/guardian surveys with nationally validated measures. The effort is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI).

In 2021-22, a total of 48 states, the District of Columbia and 22 sub-state entities participated in NCI-IDD.

**Where are the statistics in this report from?**

This report includes findings from the National Core Indicators 2021-22 Adult Family Survey (AFS). The NCI-IDD averages data shown are weighted. These data are comprised of 11, 989 valid surveys collected across 12 states: Alaska (AK), Arizona (AZ), California (CA), Georgia (GA), Indiana (IN), Louisiana (LA), Missouri (MO), Montana (MT), New Hampshire (NH), Oklahoma (OK), Pennsylvania (PA), and South Dakota (SD).

**What is the NCI-IDD Adult Family Survey?**

The NCI-IDD Adult Family Survey is used to gather data on family outcomes. It is mailed to families who have an adult family member who lives 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/service coordinator" is used throughout this report, the same role may also be referred to as "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.

### **Important note on Impact of COVID-19**

The 2021-22 NCI-IDD Family Survey data collection cycle began July 1, 2021 and ended June 30, 2022. As COVID-19 variants continued to impact communities across the United States, states were impacted in various ways throughout the year. Because the family surveys do not collect information on the date of survey completion, these data cannot fully assess what impact the pandemic had on data collected at different times throughout the year. While these data will serve as an important baseline, and meaningful way for states to understand the overall impact of services on families of individuals being served, these data should be read with caution. To help better understand the overall impact of COVID-19 on families, NCI-IDD added a state optional COVID-19 Supplement to all NCI-IDD Surveys. The COVID-19 Supplement is intended to support the understanding of the experience of people with disabilities and their families at the beginning of the COVID-19 pandemic, and their interactions with services during that time. Last year’s Family Survey COVID-19 Supplement can be found [here](#).

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

This report includes this state’s Adult Family Survey data compared to the NCI-IDD Average. State outcomes that are significantly higher or lower than the NCI-IDD Average are indicated with an arrow:

- Outcomes where the state is significantly above the NCI-IDD average are denoted with an up arrow ▲;
- Outcomes where the state is significantly below the NCI-IDD average are denoted with a down arrow ▼.

Significance is based on “Always” or “Yes” response.

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 Adult Family Survey, data analysis and state samples, check out the [National Adult Family Survey Report](#).



*Demographics*

Family Member

Table 1. More Than One Person Living in the Home Has IDD

State	Yes	No	N
PA	12%	88%	371
Weighted NCI-IDD Average	16%	84%	11521

Table 2. Family Member's Residential Designation

State	Urban or Suburban (In or Near a City or Large Town)	Rural (Outside of a City or Town)	N
PA	61%	39%	375
Weighted NCI-IDD Average	78%	22%	10853

Table 3. Family Member's Age

State	Age	N
PA	34.9	383
Weighted NCI-IDD Average	34.6	11350

Table 4. Family Member's Gender

State	Male	Female	Other	N
PA	62%	38%	0%	380
Weighted NCI-IDD Average	59%	41%	0%	11530

Table 5. Family Member's Race and Ethnicity

All data 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	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer Not to Say
PA	1%	2%	8%	0%	86%	4%	1%	0%
Weighted NCI-IDD Average	2%	10%	10%	0%	54%	27%	2%	2%

Table 6a. Family Member's Conditions

All data 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	Intellectual Disability	Mood Illness or psychiatric diagnosis	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Hearing loss (severe or profound)
PA	88%	33%	40%	15%	9%	8%
Weighted NCI-IDD Average	66%	24%	38%	17%	9%	6%

Table 6b. Family Member's Conditions (continued)

All data 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	Brain Injury	Seizure Or Neurological Disorder	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder (FASD)	Other
PA	9%	30%	0%	18%	0%	1%	20%
Weighted NCI-IDD Average	8%	26%	0%	15%	1%	1%	18%



Table 7a. Family Member's Health Conditions (continued)

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
PA	8%	14%	4%	19%	25%
Weighted NCI-IDD Average	9%	16%	4%	26%	28%

Table 7b. Family Member's Health Conditions (continued)

State	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Dementia	Oral Health Problems	Sleep Apnea
PA	10%	0%	1%	12%	18%
Weighted NCI- IDD Average	8%	2%	2%	12%	18%

Table 7c. Family Member's Health Conditions (continued)

State	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
PA	15%	6%	1%	0%	35%
Weighted NCI-IDD Average	18%	5%	3%	1%	26%

Table 8. Family Member's Preferred Means of Communication

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
PA	81%	10%	1%	1%	8%	379
Weighted NCI-IDD Average	81%	11%	1%	1%	5%	11701

Table 9. Family Member's Preferred Language

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
PA	97%	1%	0%	0%	0%	1%	2%	374
Weighted NCI-IDD Average	81%	10%	1%	0%	1%	1%	7%	11797

Table 10. Family Member Has Legal Court Appointed Guardian or Conservator

State	No Guardianship	Limited	Full	Has Guardianship but Level Is Unknown	N
PA	22%	20%	53%	5%	307
Weighted NCI-IDD Average	35%	20%	41%	4%	10936

Table 11. Guardian or Conservator Relationship to Family Member

State	Family	Friend	Employee or State Guardianship Agency	Other	N
PA	95%	1%	0%	4%	200
Weighted NCI-IDD Average	95%	1%	0%	4%	6416

Table 12a. Family Member's Highest Level of Education

State	Did Not Complete High School (and Not Currently Enrolled)	Currently Enrolled in High School	High School Certification	High School Diploma or GED	N
PA	7%	2%	27%	56%	367
Weighted NCI-IDD Average	17%	3%	34%	31%	11202



Table 12b. Family Member's Highest Level of Education (continued)

State	Vocational School or Certificate Program	Some College	College Degree or Higher	N
PA	3%	2%	2%	367
Weighted NCI-IDD Average	4%	6%	4%	11202

Table 13. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

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

State	None	Some	Extensive	N
PA	55%	31%	15%	370
Weighted NCI-IDD Average	53%	30%	17%	11315

Table 14. Family Member's Level of Help Needed with Personal Care Activities  
 (for example, bathing, dressing, eating)

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

State	None	Some	Extensive	N
PA	26%	44%	30%	379
Weighted NCI-IDD Average	26%	37%	37%	11583

Table 15. Family Member’s Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping)

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

State	None	Some	Extensive	N
PA	2%	18%	80%	377
Weighted NCI-IDD Average	6%	23%	71%	11569

## Respondents

This section provides demographic information about the respondent

Table 16. Language Usually Spoken at Home

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
PA	98%	1%	0%	0%	0%	0%	1%	381
Weighted NCI-IDD Average	77%	15%	1%	1%	1%	0%	5%	11803

Table 17. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
PA	1%	17%	71%	11%	378
Weighted NCI-IDD Average	6%	24%	59%	12%	11803

Table 18. Respondent's Health

State	Excellent	Very good	Good	Fair	Poor	N
PA	12%	38%	35%	13%	2%	378
Weighted NCI-IDD Average	11%	32%	37%	17%	2%	11820



Table 19. Respondent's Relationship to Family Member

For "Spouse", the percentages Weighted NCI-IDD Average are non-zero even though they are displayed as a rounded-down 0%.

State	Parent	Sibling	Spouse	Grandparent	Other	N
PA	89%	5%	0%	3%	3%	378
Weighted NCI-IDD Average	86%	7%	0%	2%	5%	11679

Table 20. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services

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

State	No	Yes, Respondent Is	Yes, Another Family Member Is	N
PA	6%	91%	3%	33
Weighted NCI-IDD Average	52%	36%	15%	11106

Table 21. Number of Adults in Household (Not Including Family Member Receiving Services)

State	One	Two	Three	Four or More	N
PA	5%	28%	51%	16%	376
Weighted NCI-IDD Average	8%	27%	44%	22%	11632

Table 22. Number of Children (Under 18 Years Old) in Household

State	One	Two	Three	Four or More	None	N
PA	8%	2%	1%	0%	90%	380
Weighted NCI-IDD Average	10%	4%	2%	1%	84%	11678

Table 23. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
PA	3%	31%	9%	19%	38%	382
Weighted NCI-IDD Average	13%	23%	7%	21%	36%	11603

Table 24. Total Taxable Household Income of Wage Earners in the Past 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	No Earned Income	Up to \$15,000	\$15,001 to \$25,000	\$25,001 to \$50,000	\$50,001 to \$75,000	Over \$75,000	Prefer Not to Say	N
PA	9%	5%	9%	23%	10%	24%	20%	371
Weighted NCI-IDD Average	12%	8%	9%	18%	12%	18%	22%	11376

## Services and Supports Received

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

Table 25a. Services and Supports Received From ID/DD Agency

All data 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	Financial Support	In-Home Support	Out of Home Respite Care	Day or Employment Supports
PA	15%	45%	25%	49%
Weighted NCI-IDD Average	16%	38%	24%	44%



Table 25b. Services and Supports Received From ID/DD Agency (continued)

All data 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	Transportation	Mental/behavioral health care or other treatments or therapies	Self-Direction or Fiscal Intermediary Services
PA	59%	27%	53%
Weighted NCI-IDD Average	43%	26%	32%

Table 26. Additional Services and Supports Received

All data 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	Social Security Payments (SSI or SSB)	Services or Supports from Other Agencies or Organizations
PA	96%	48%
Weighted NCI-IDD Average	87%	31%

## *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.

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

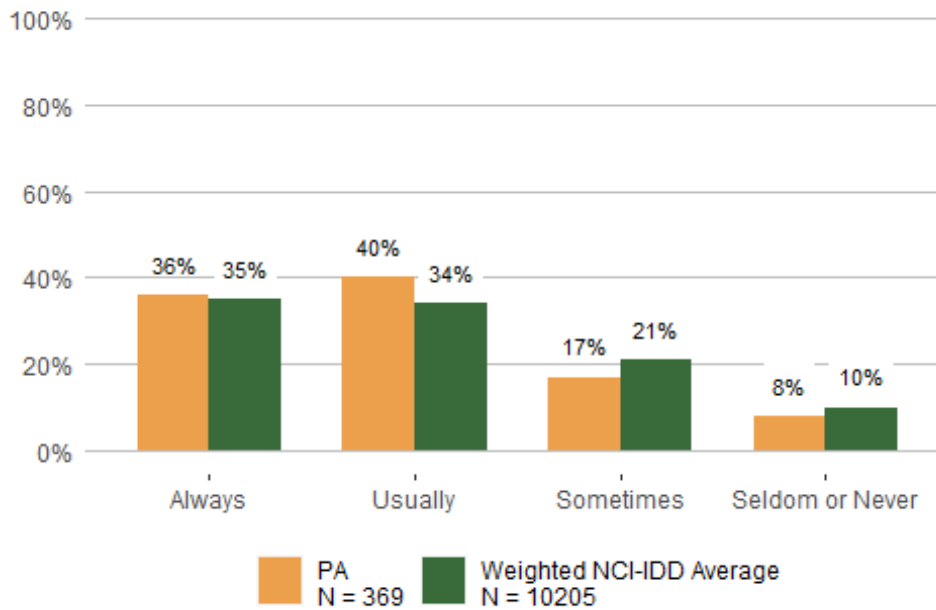


Table 27. Do you get enough information to take part in planning services for your family member?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	36%	40%	17%	8%	369
Weighted NCI-IDD Average	35%	34%	21%	10%	10205

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

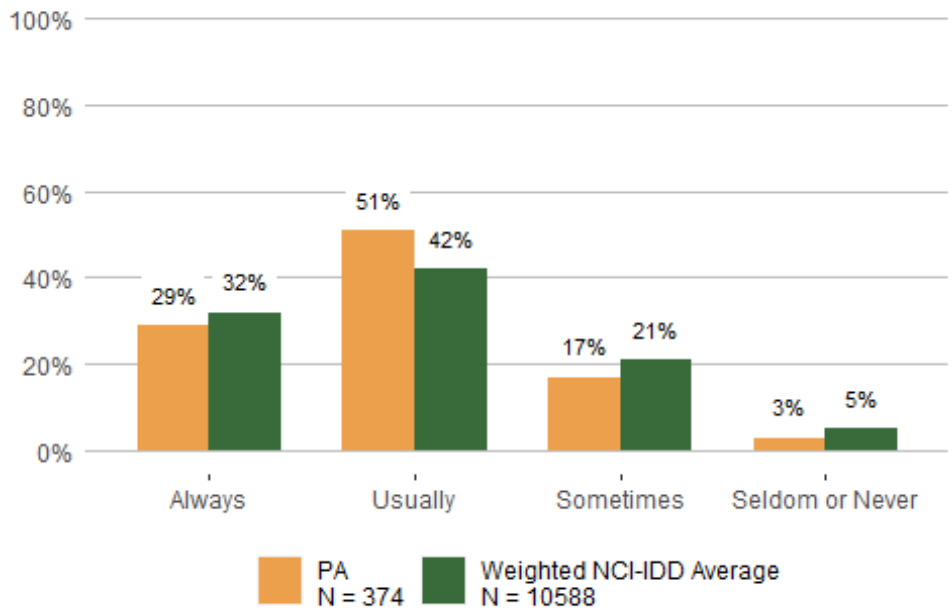


Table 28. Is the information you get about services and supports easy to understand?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	29%	51%	17%	3%	374
Weighted NCI-IDD Average	32%	42%	21%	5%	10588

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

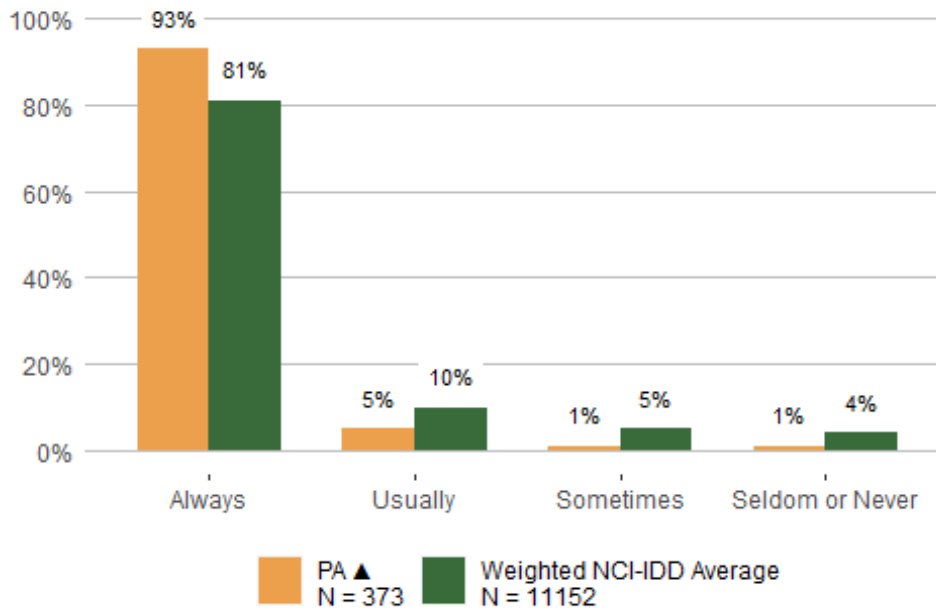


Table 29. Do you get information about services and supports in your preferred language?

New question in 2021-22

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	93%	5%	1%	1%	373
Weighted NCI-IDD Average	81%	10%	5%	4%	11152

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

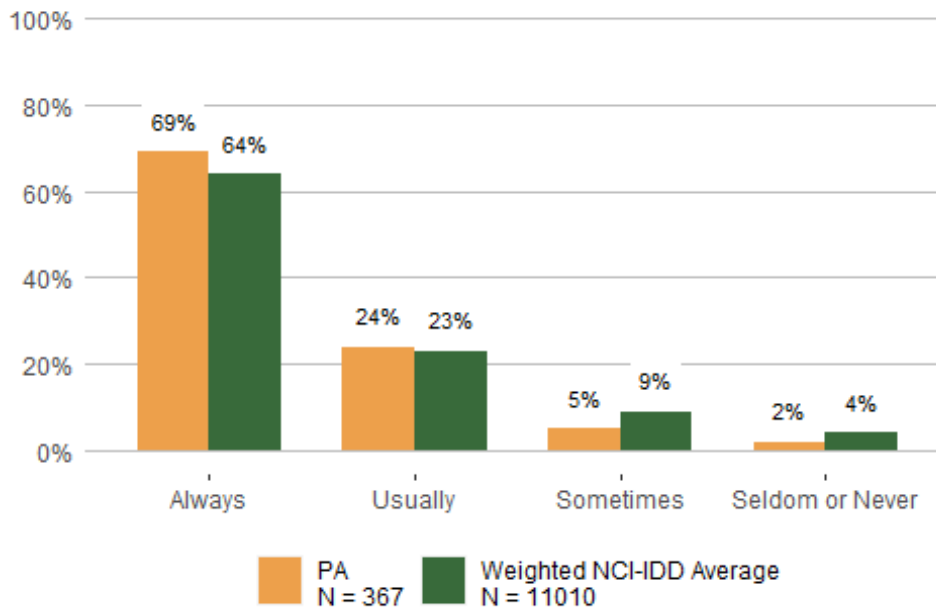


Table 30. Does the case manager/service coordinator listen to your family’s choices and opinions?

Question changed in 2021-22

State	Always	Usually	Sometimes	Seldom or Never	N
PA	69%	24%	5%	2%	367
Weighted NCI-IDD Average	64%	23%	9%	4%	11010



Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

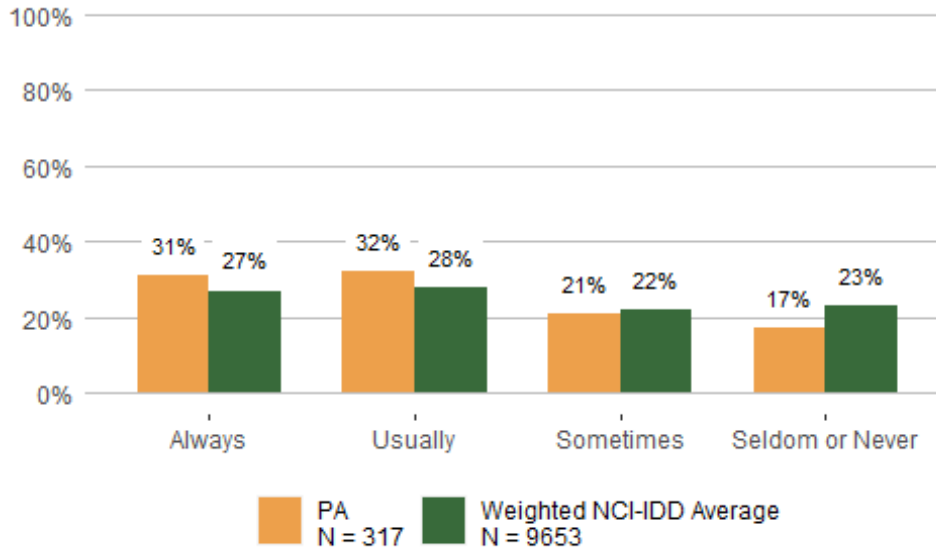


Table 31. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	31%	32%	21%	17%	317
Weighted NCI-IDD Average	27%	28%	22%	23%	9653

Do you need help planning for your family member's future with respect to any of the following areas?

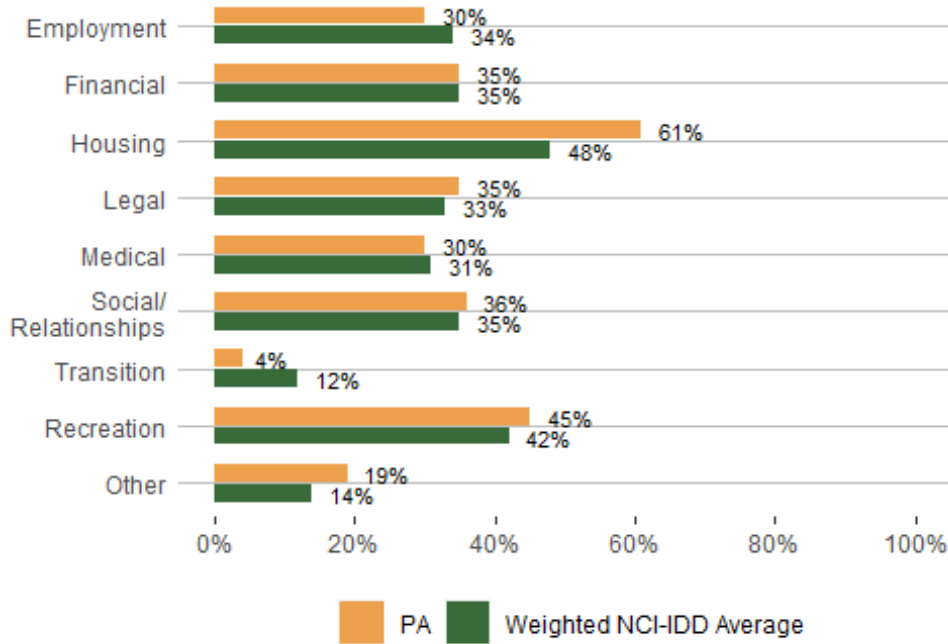


Table 32. Do you need help planning for your family member's future with respect to any of the following areas?

Categories are not mutually exclusive, therefore N is not shown

State	Employment	Financial	Housing	Legal	Medical	Social/Relationships	Transition	Recreation	Other
PA	30%	35%	61%	35%	30%	36%	4%	45%	19%
Weighted NCI-IDD Average	34%	35%	48%	33%	31%	35%	12%	42%	14%

Has your family learned about alternatives to guardianship?

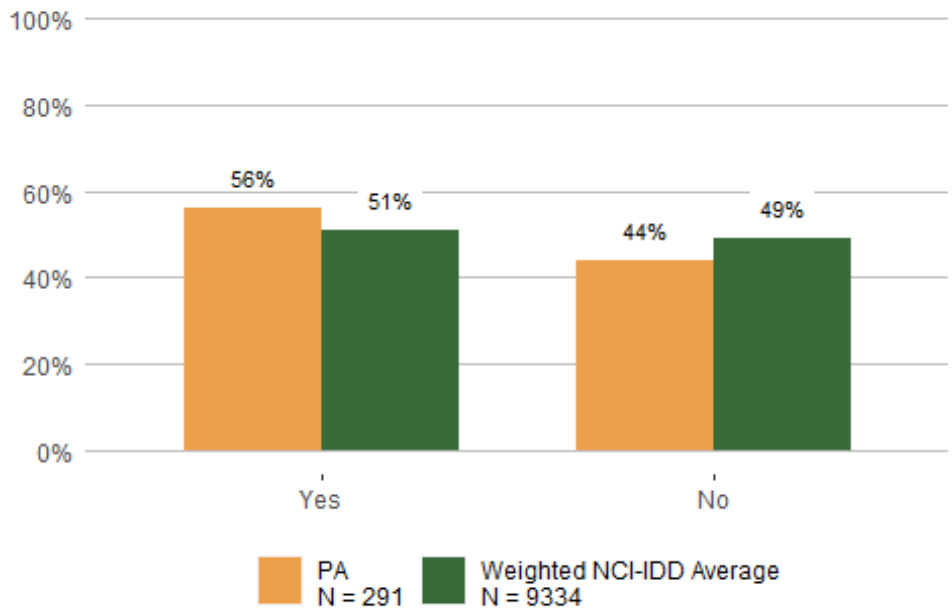


Table 33. Has your family learned about alternatives to guardianship?  
New question in 2021-22

State	Yes	No	N
PA	56%	44%	291
Weighted NCI-IDD Average	51%	49%	9334

Does your family member have a service plan?

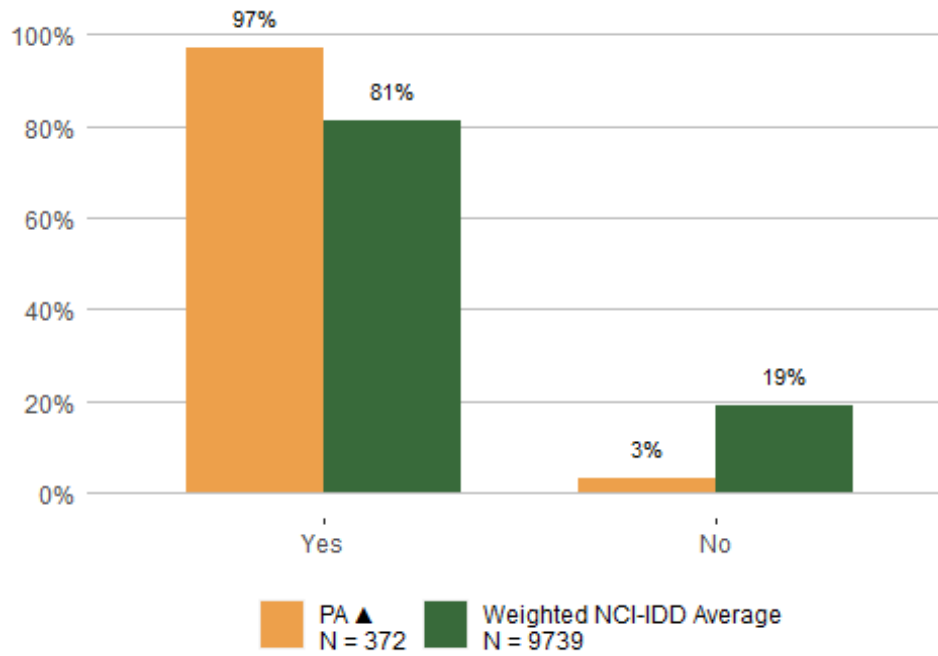


Table 34. Does your family member have a service plan?

State	Yes	No	N
PA ▲	97%	3%	372
Weighted NCI-IDD Average	81%	19%	9739

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

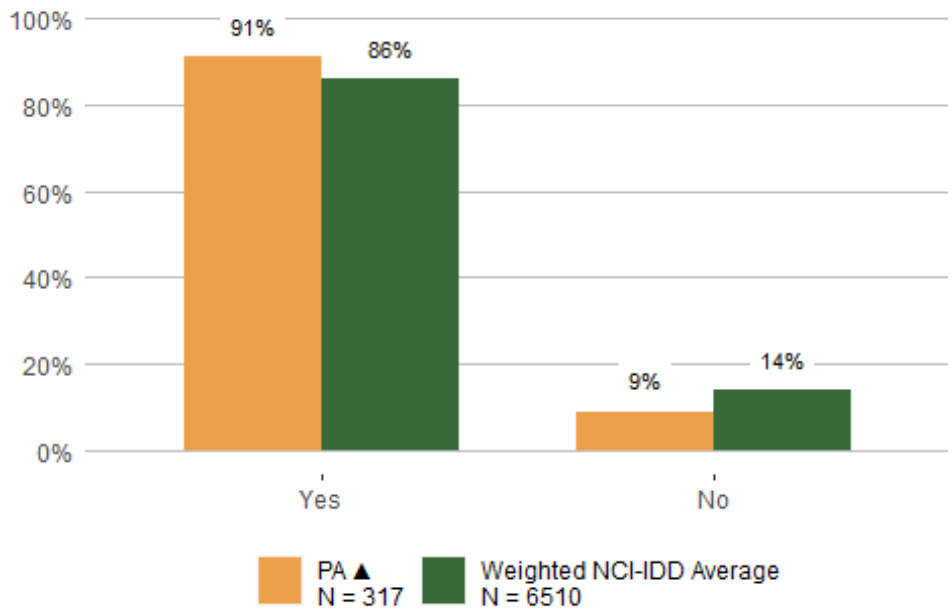


Table 35. Does the plan include all the services and supports your family member needs?

State	Yes	No	N
PA ▲	91%	9%	317
Weighted NCI-IDD Average	86%	14%	6510

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

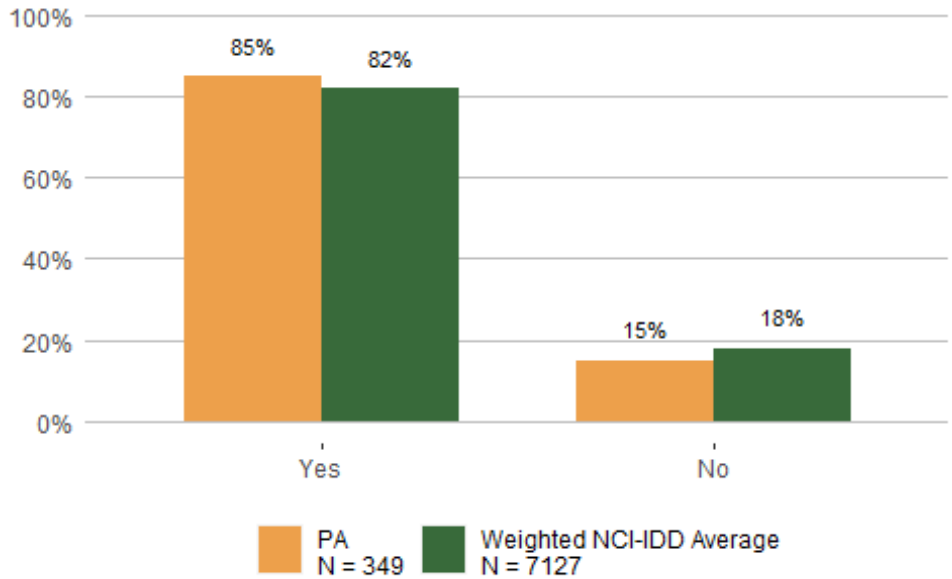


Table 36. Did you or someone else in your family (besides your family member with a disability) help make the plan?

State	Yes	No	N
PA	85%	15%	349
Weighted NCI-IDD Average	82%	18%	7127

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

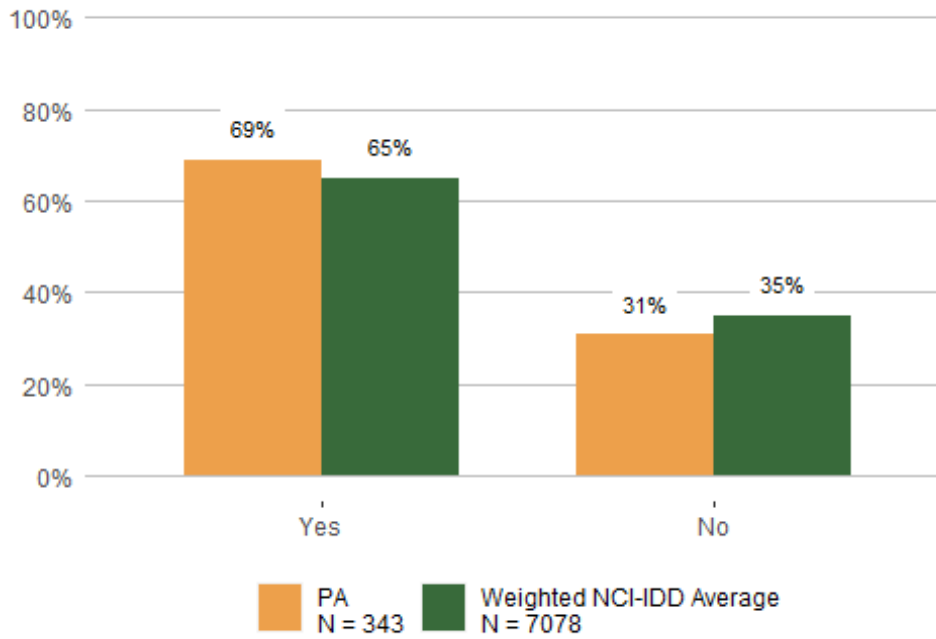


Table 37. Did your family member help make the plan?

State	Yes	No	N
PA	69%	31%	343
Weighted NCI-IDD Average	65%	35%	7078

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

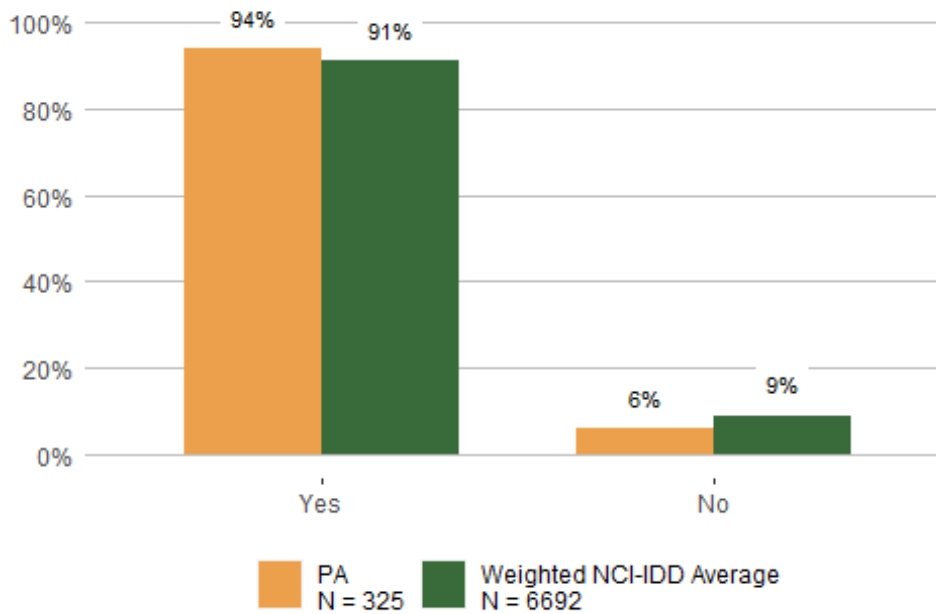


Table 38. Do you feel like your family had enough say or input in making the plan?  
New question in 2021-22

State	Yes	No	N
PA	94%	6%	325
Weighted NCI-IDD Average	91%	9%	6692



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

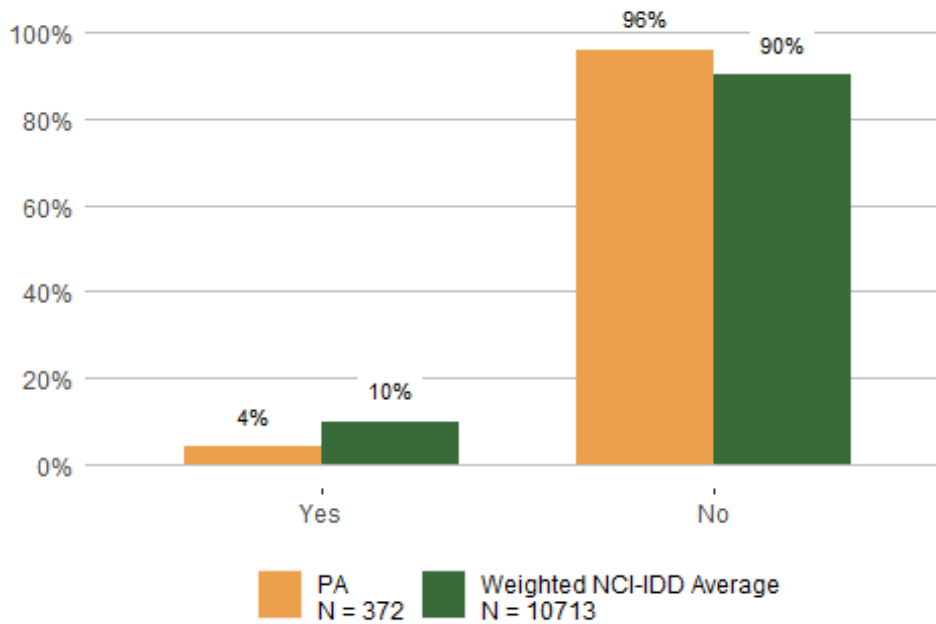


Table 39. Did your family member leave school services and begin adult services during the past 12 months?

State	Yes	No	N
PA	4%	96%	372
Weighted NCI-IDD Average	10%	90%	10713

If your family member left school services during the past year, did they have a transition plan?

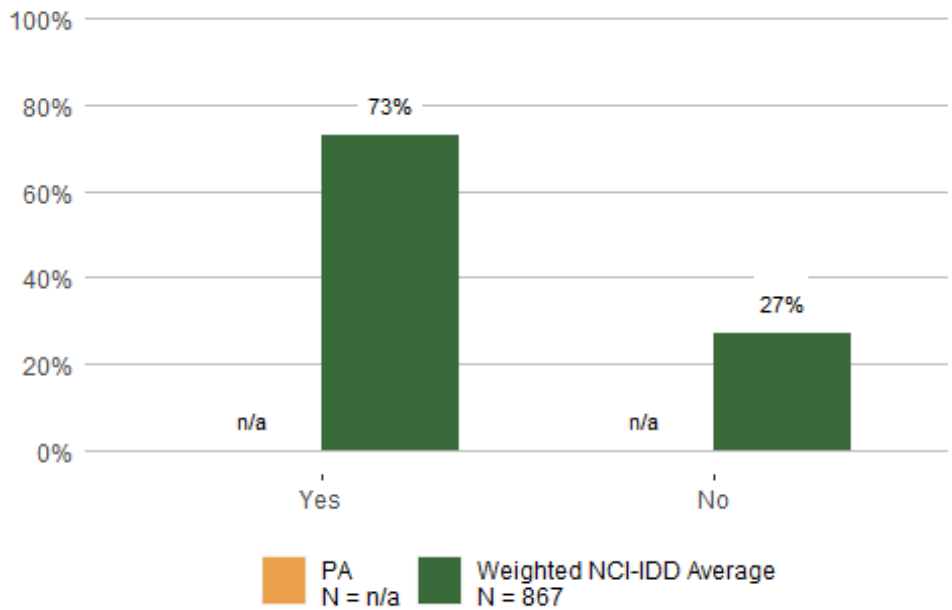


Table 40. If your family member left school services during the past year, did they have a transition plan?

State	Yes	No	N
PA	n/a	n/a	n/a
Weighted NCI-IDD Average	73%	27%	867

If family member had a transition plan, did the transition plan include getting or continuing work in a community job?

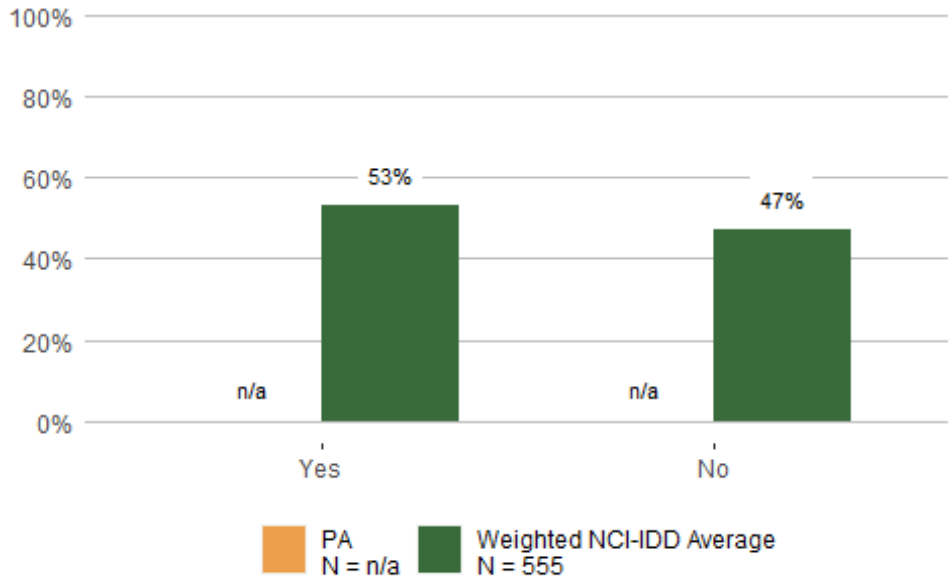


Table 41. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?

State	Yes	No	N
PA	n/a	n/a	n/a
Weighted NCI-IDD Average	53%	47%	555

## 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.

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

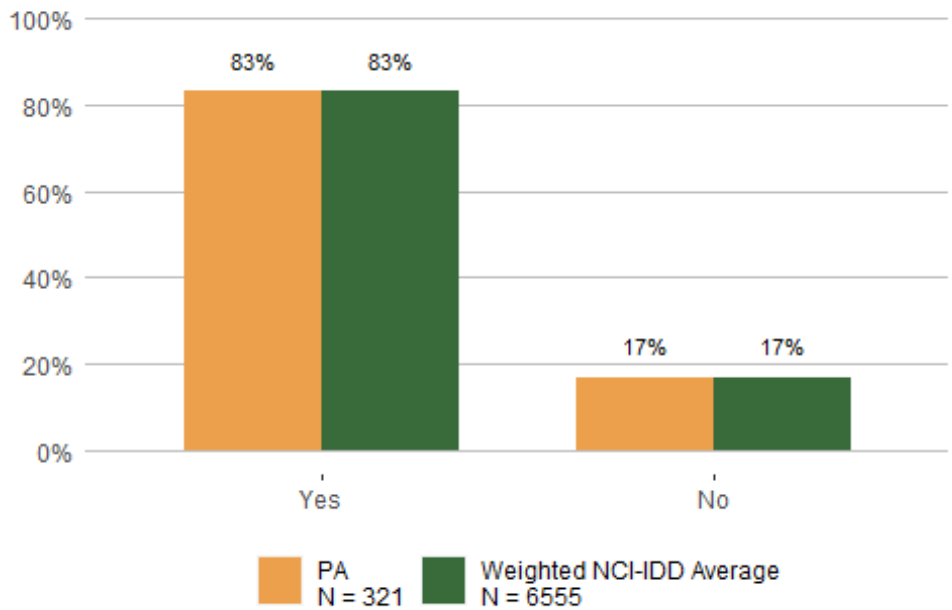


Table 42. Does your family member get all the services listed in the plan?

State	Yes	No	N
PA	83%	17%	321
Weighted NCI-IDD Average	83%	17%	6555

Does your family get the supports and services it needs?

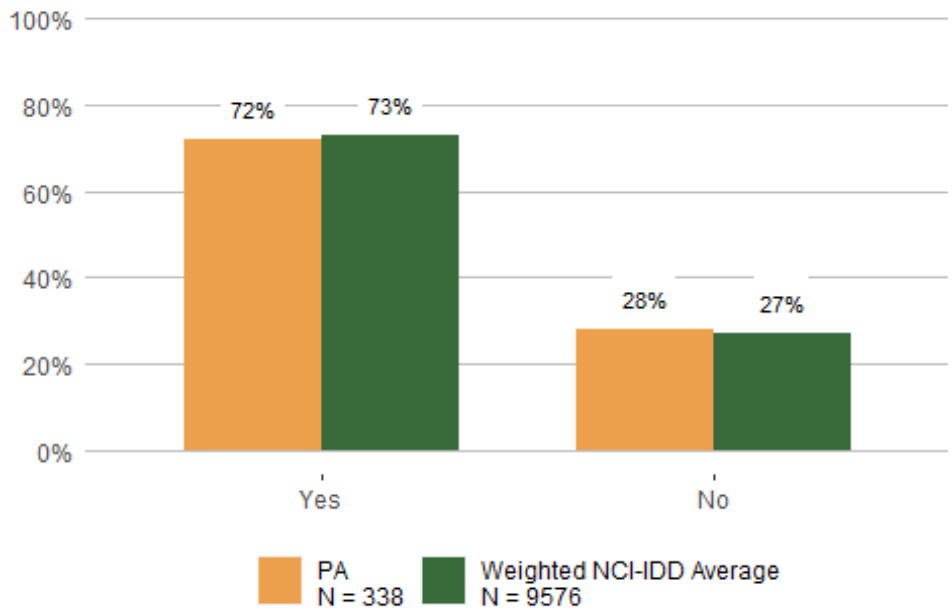


Table 43. Does your family get the supports and services it needs?

State	Yes	No	N
PA	72%	28%	338
Weighted NCI-IDD Average	73%	27%	9576

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

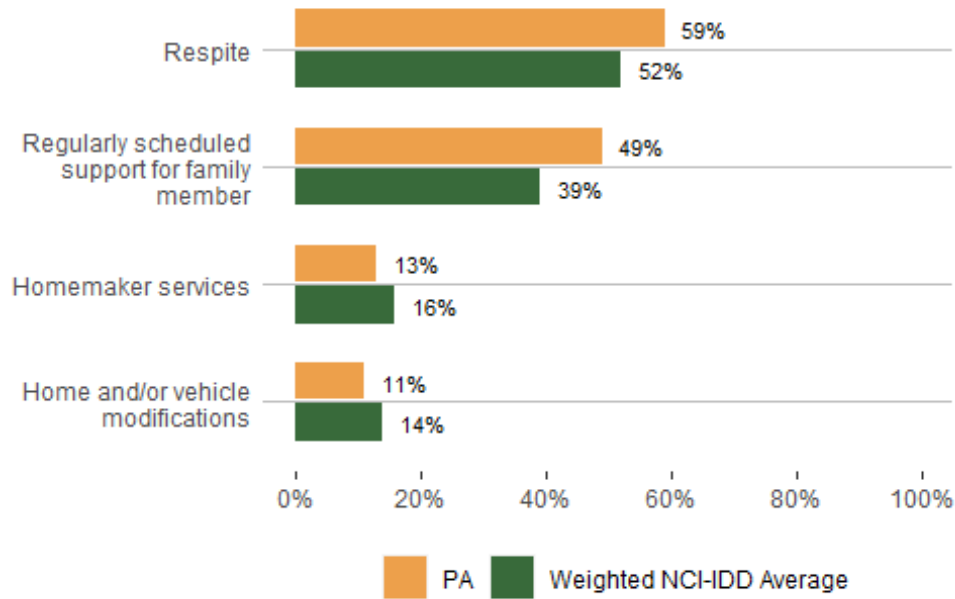


Table 44a. “If your family does not get the support and services needed, what additional services does your family need?”

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

State	Respite	Regularly scheduled support for family member	Homemaker services	Home and/or vehicle modifications
PA	59%	49%	13%	11%
Weighted NCI-IDD Average	52%	39%	16%	14%

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

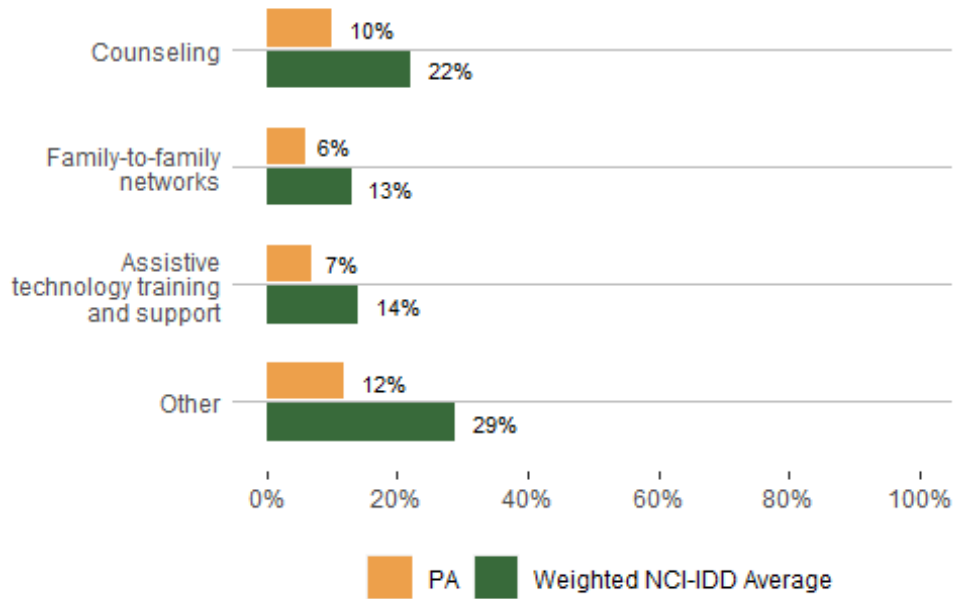


Table 44b. If your family does not get the support and services needed, what additional services does your family need? (continued)

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

State	Counseling	Family-to-family networks	Assistive technology training and support	Other
PA	10%	6%	7%	12%
Weighted NCI-IDD Average	22%	13%	14%	29%



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

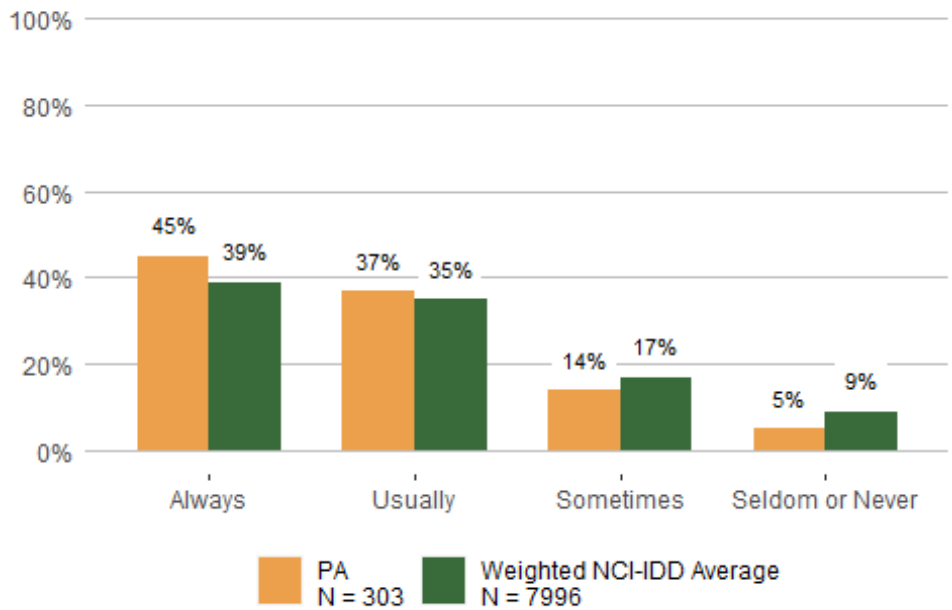


Table 45. Do services and supports change when your family's needs change?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	45%	37%	14%	5%	303
Weighted NCI-IDD Average	39%	35%	17%	9%	7996

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

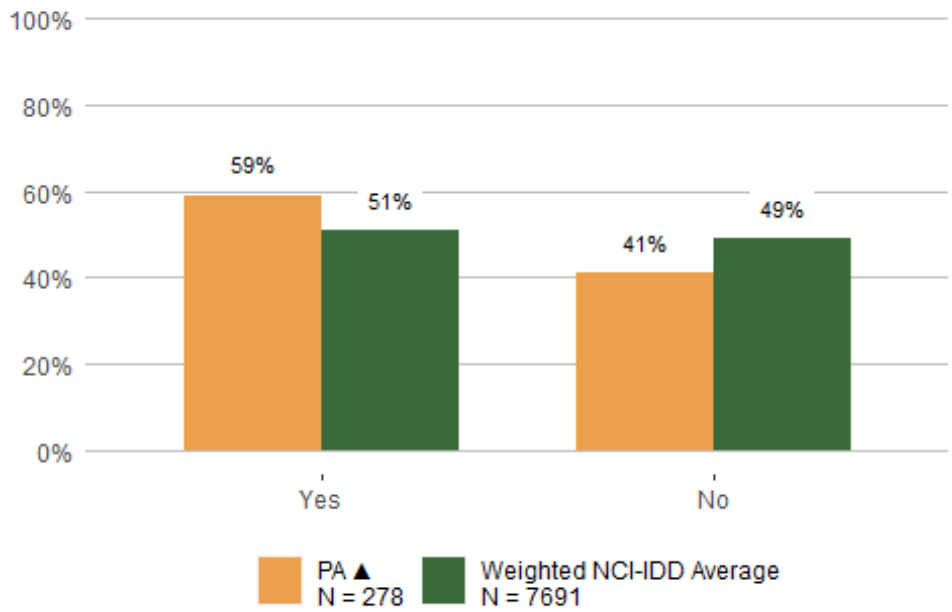


Table 46. Does your family member have enough supports to work or volunteer in the community?

State	Yes	No	N
PA ▲	59%	41%	278
Weighted NCI-IDD Average	51%	49%	7691

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

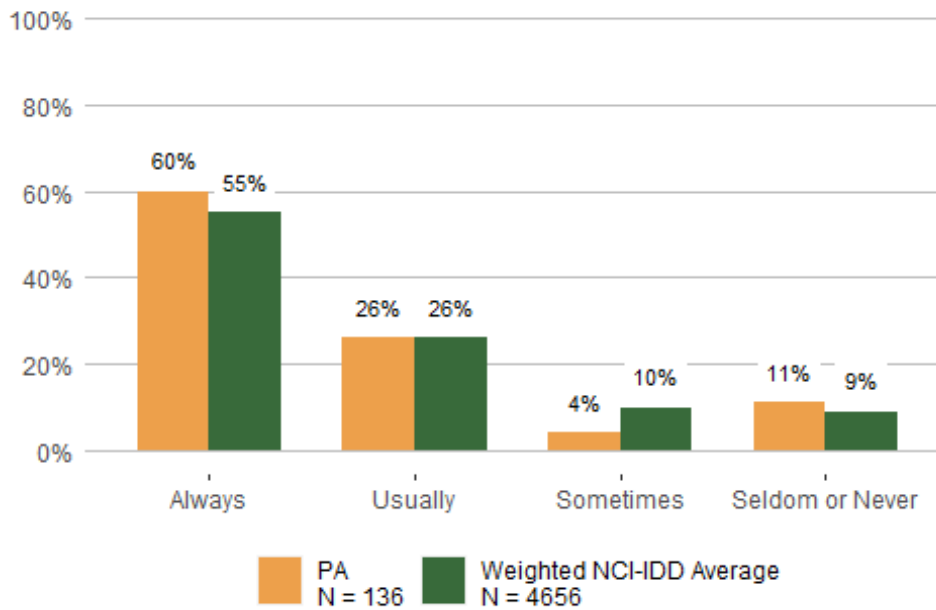


Table 47. Does your family member have the special equipment or accommodations they need?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	60%	26%	4%	11%	136
Weighted NCI-IDD Average	55%	26%	10%	9%	4656

If you need respite services, how often are you able to get them when needed?

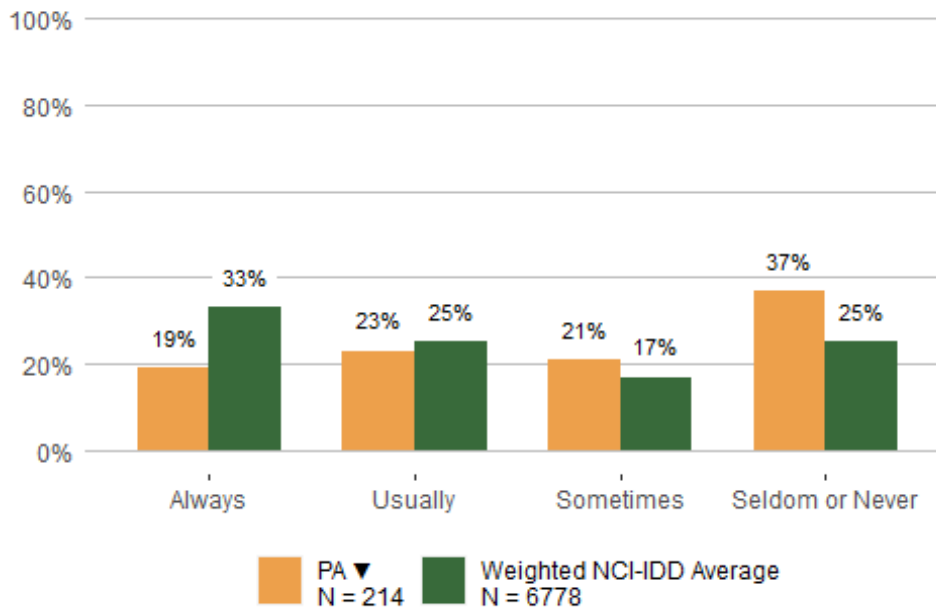


Table 48. If you need respite services, how often are you able to get them when needed?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▼	19%	23%	21%	37%	214
Weighted NCI-IDD Average	33%	25%	17%	25%	6778

If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?

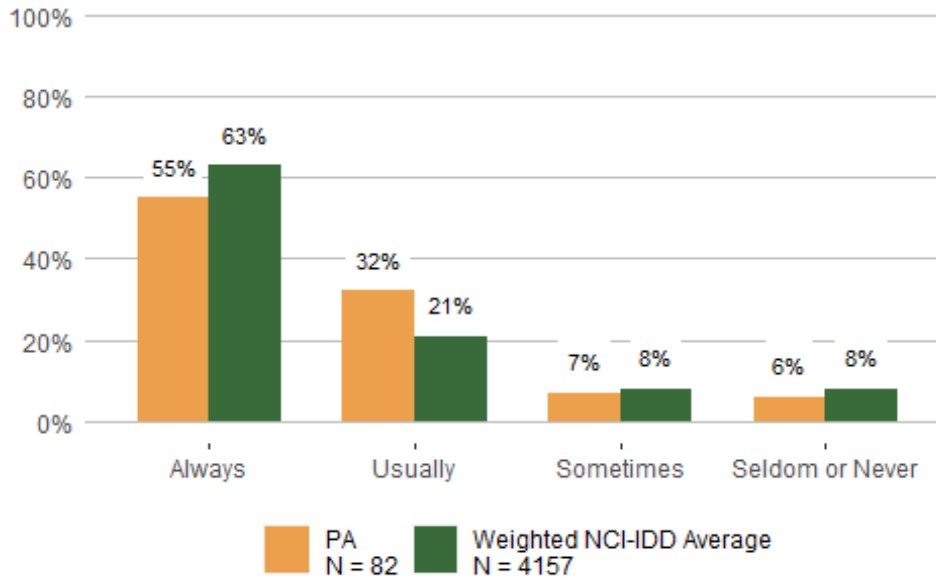


Table 49. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	55%	32%	7%	6%	82
Weighted NCI-IDD Average	63%	21%	8%	8%	4157

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

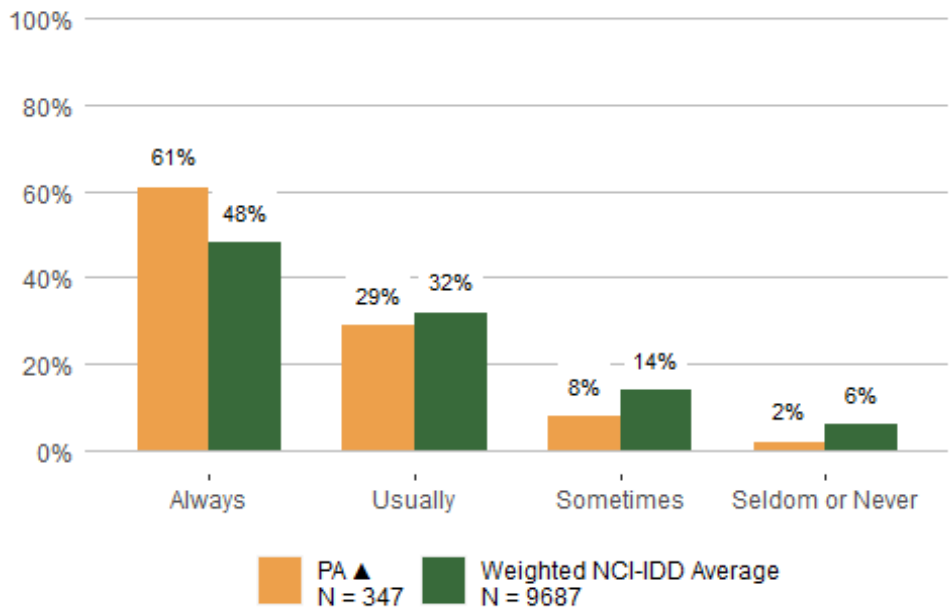


Table 50. Are you or your family member able to contact their support workers when you want?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	61%	29%	8%	2%	347
Weighted NCI-IDD Average	48%	32%	14%	6%	9687

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

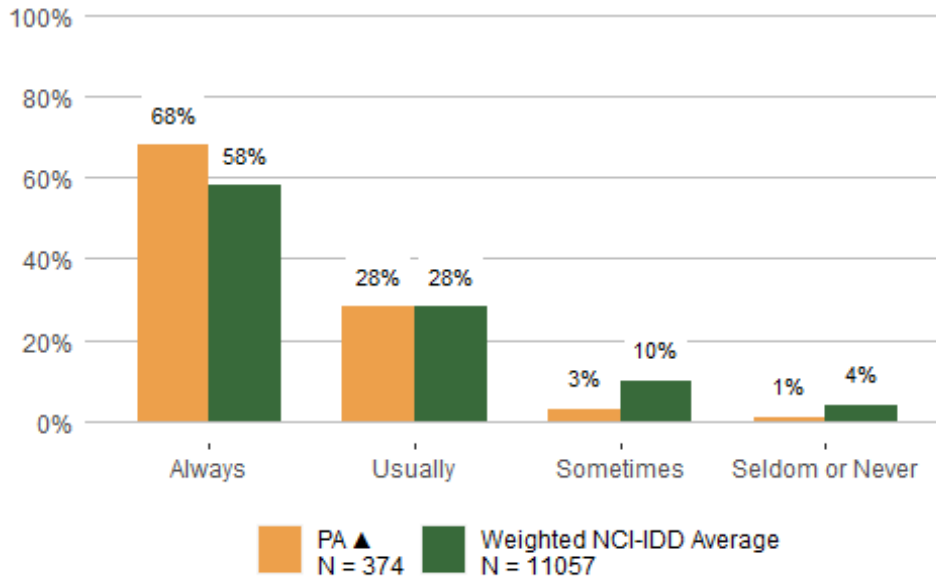


Table 51. Are you or your family member able to contact their case manager/service coordinator when you want?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	68%	28%	3%	1%	374
Weighted NCI-IDD Average	58%	28%	10%	4%	11057

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

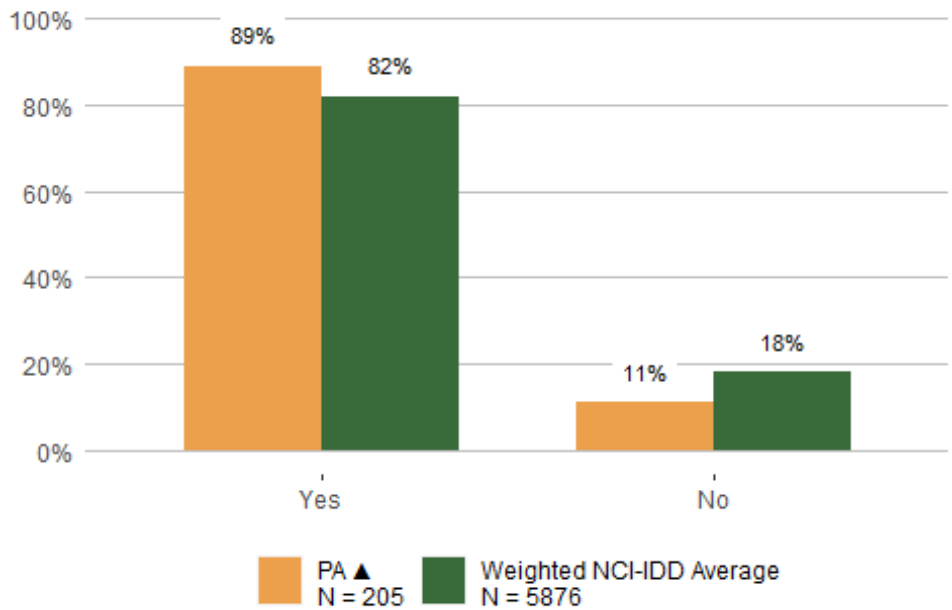


Table 52. Do service providers for your family member work together to provide support?

State	Yes	No	N
PA ▲	89%	11%	205
Weighted NCI-IDD Average	82%	18%	5876



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

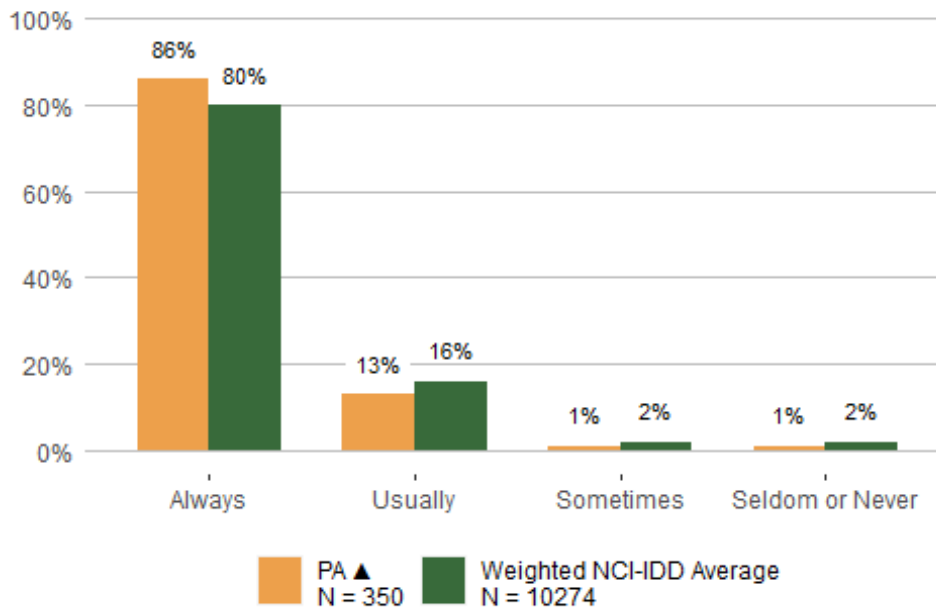


Table 53. Are services delivered in a way that is respectful of your family's culture?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	86%	13%	1%	1%	350
Weighted NCI-IDD Average	80%	16%	2%	2%	10274

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

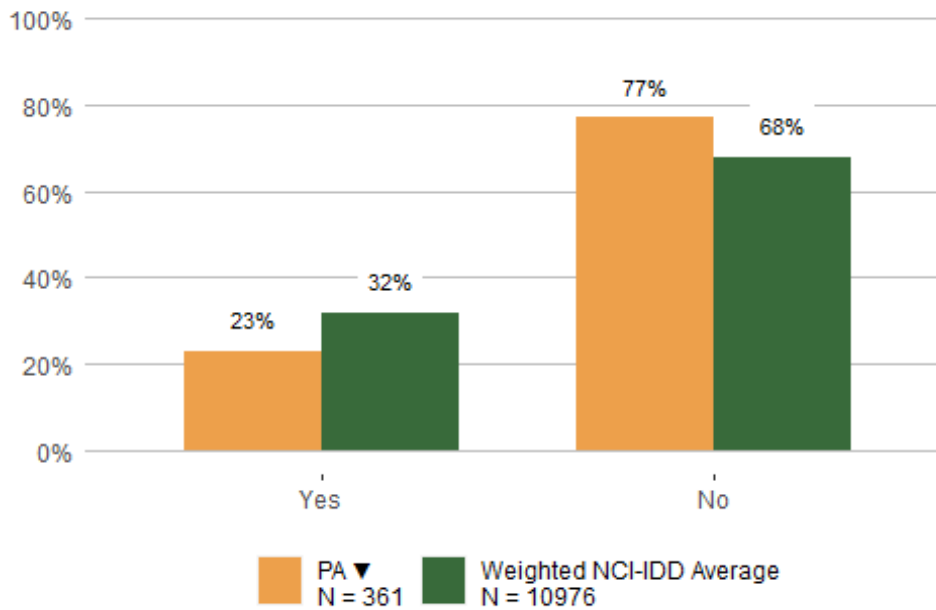


Table 54. Does your family member use technology in their everyday life to help them do things on their own?

New question in 2021-22

State	Yes	No	N
PA ▼	23%	77%	361
Weighted NCI-IDD Average	32%	68%	10976

Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?

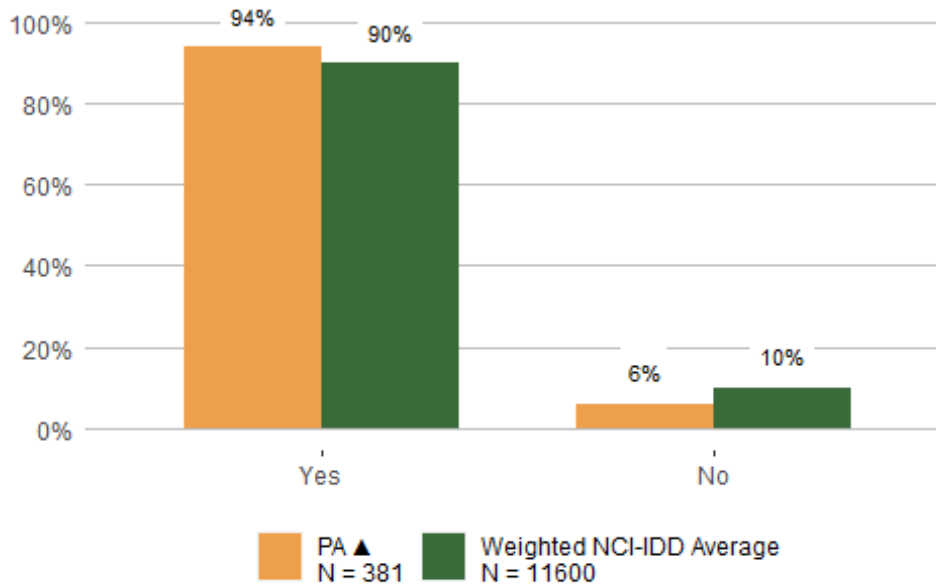


Table 55. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?

New question in 2021-22

State	Yes	No	N
PA ▲	94%	6%	381
Weighted NCI-IDD Average	90%	10%	11600

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

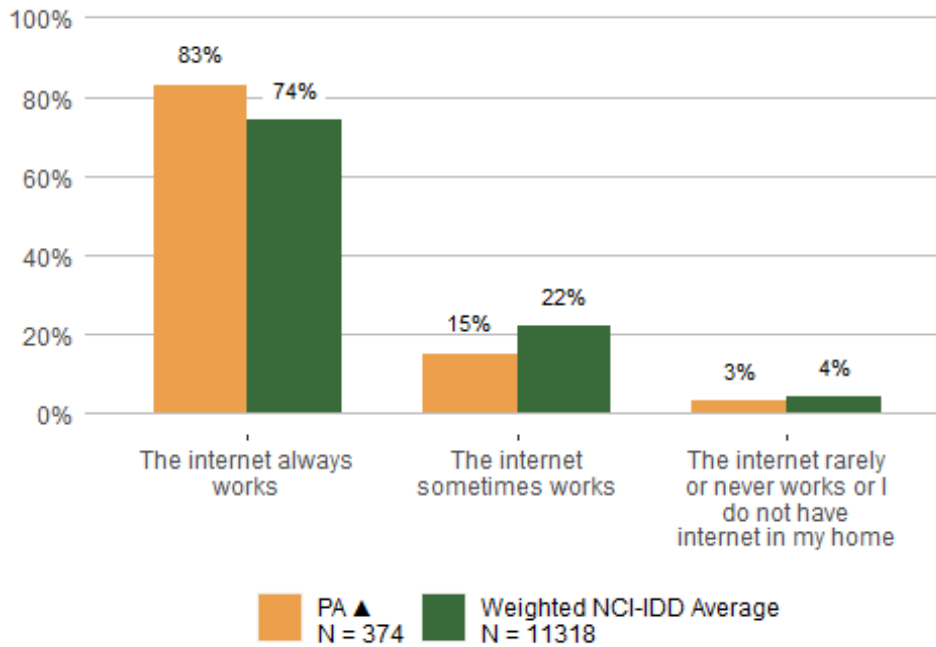


Table 56. How well does the internet work in your home?

New question in 2021-22

State	The internet always works	The internet sometimes works	The internet rarely or never works or I do not have internet in my home	N
PA ▲	83%	15%	3%	374
Weighted NCI-IDD Average	74%	22%	4%	11318

Workforce (New in 2021-2022)

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.

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

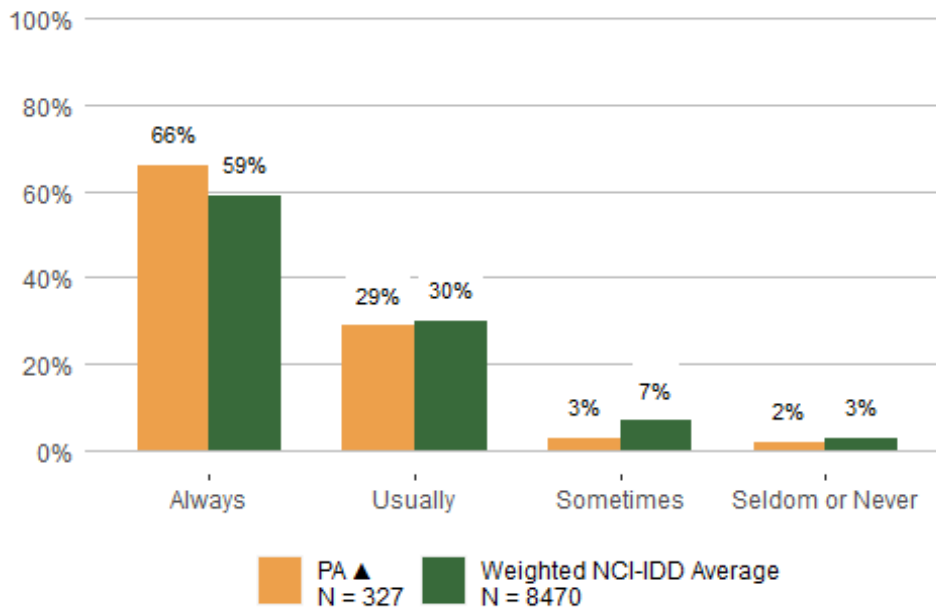


Table 57. Do support workers come and go when they are supposed to?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	66%	29%	3%	2%	327
Weighted NCI-IDD Average	59%	30%	7%	3%	8470

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

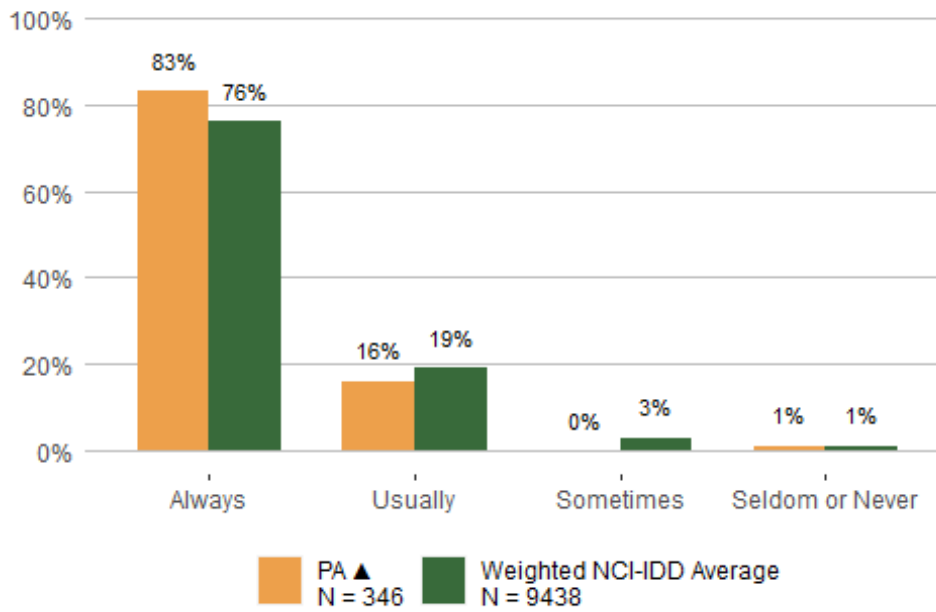


Table 58. Do support workers speak to you in a way you understand?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	83%	16%	0%	1%	346
Weighted NCI-IDD Average	76%	19%	3%	1%	9438

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

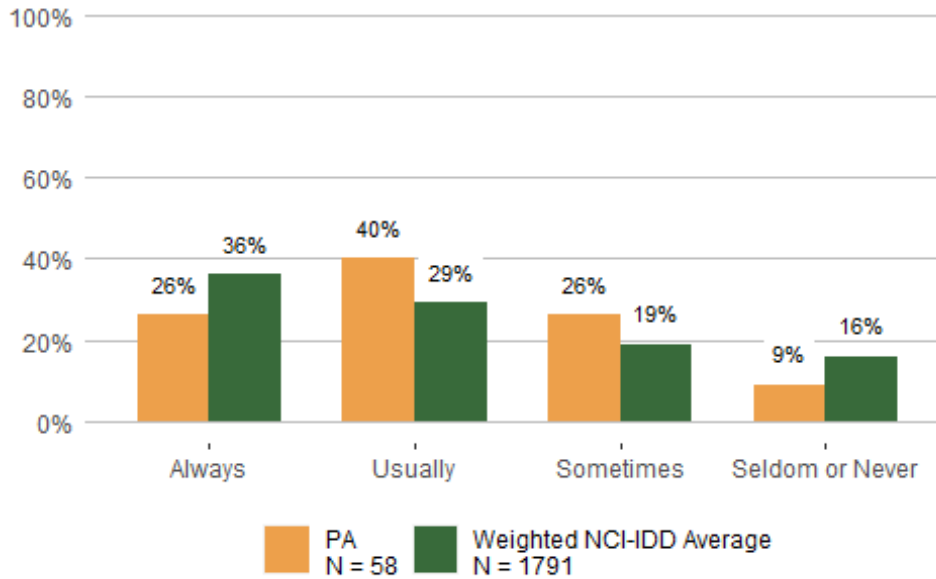


Table 59. If your family member does not communicate verbally, are there support workers who can communicate with them?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	26%	40%	26%	9%	58
Weighted NCI-IDD Average	36%	29%	19%	16%	1791



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

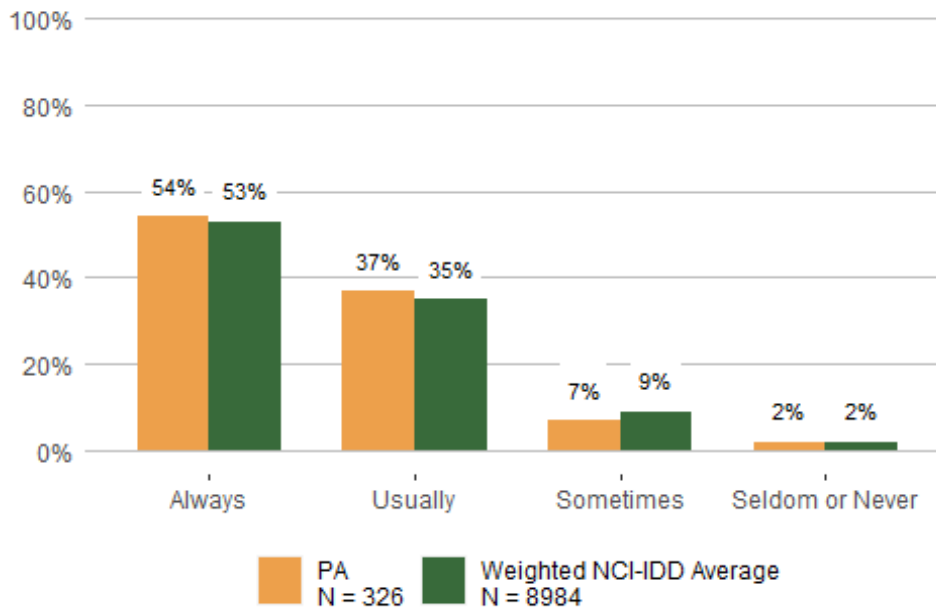


Table 60. Do support workers have the right information and skills to meet your family's needs?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	54%	37%	7%	2%	326
Weighted NCI-IDD Average	53%	35%	9%	2%	8984

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

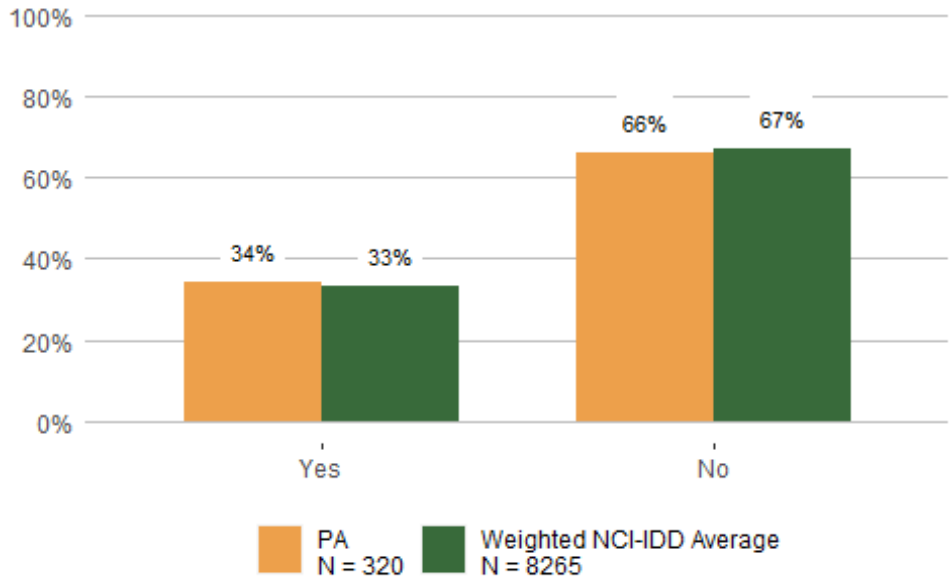


Table 61. Do your family member's support workers change too often? Is there too much "turnover" of support workers?

New question in 2021-22

State	Yes	No	N
PA	34%	66%	320
Weighted NCI-IDD Average	33%	67%	8265

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

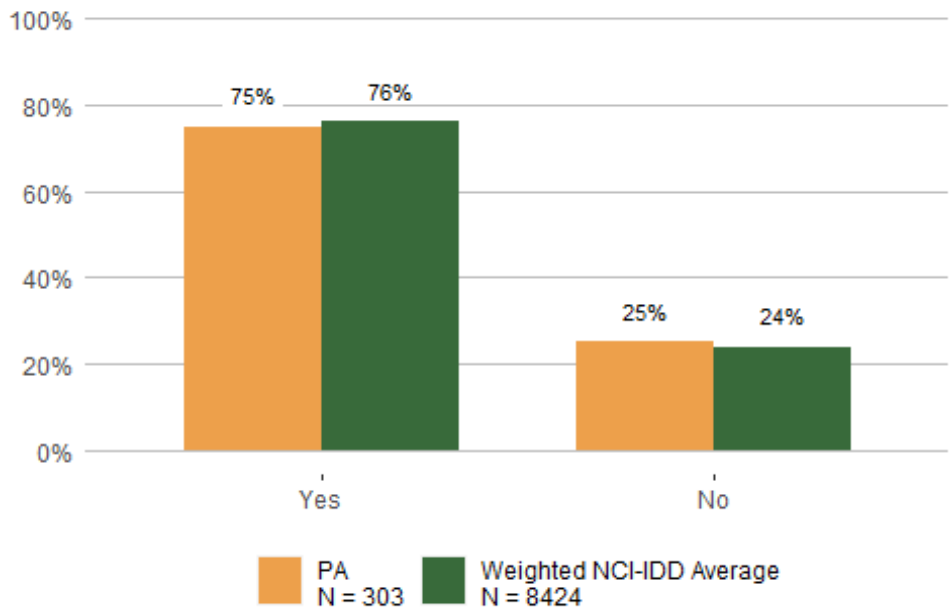


Table 62. Is there always a staff person available to support your family member when support is needed?

New question in 2021-22

State	Yes	No	N
PA	75%	25%	303
Weighted NCI-IDD Average	76%	24%	8424

## 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.**

Can your family choose or change the agency that provides your family member's services?

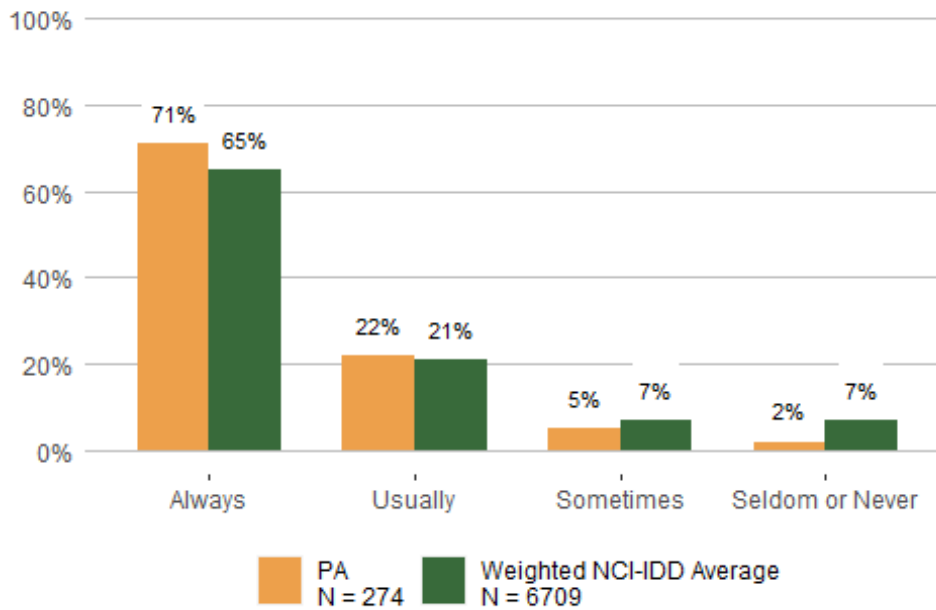


Table 63. Can your family choose or change the agency that provides your family member's services?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	71%	22%	5%	2%	274
Weighted NCI-IDD Average	65%	21%	7%	7%	6709

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

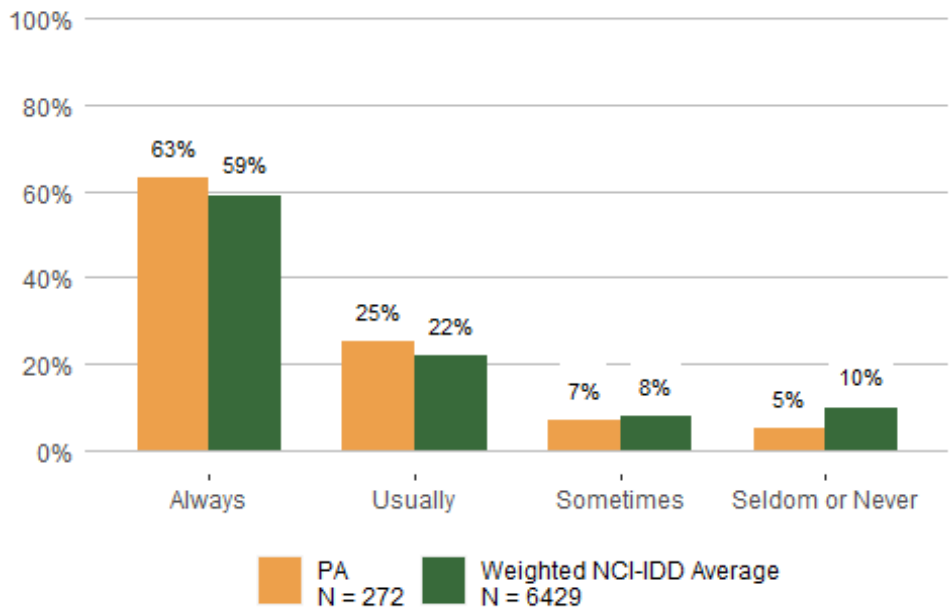


Table 64. Can your family choose or change your family member's support workers?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	63%	25%	7%	5%	272
Weighted NCI-IDD Average	59%	22%	8%	10%	6429

Can someone in your family directly manage support staff?

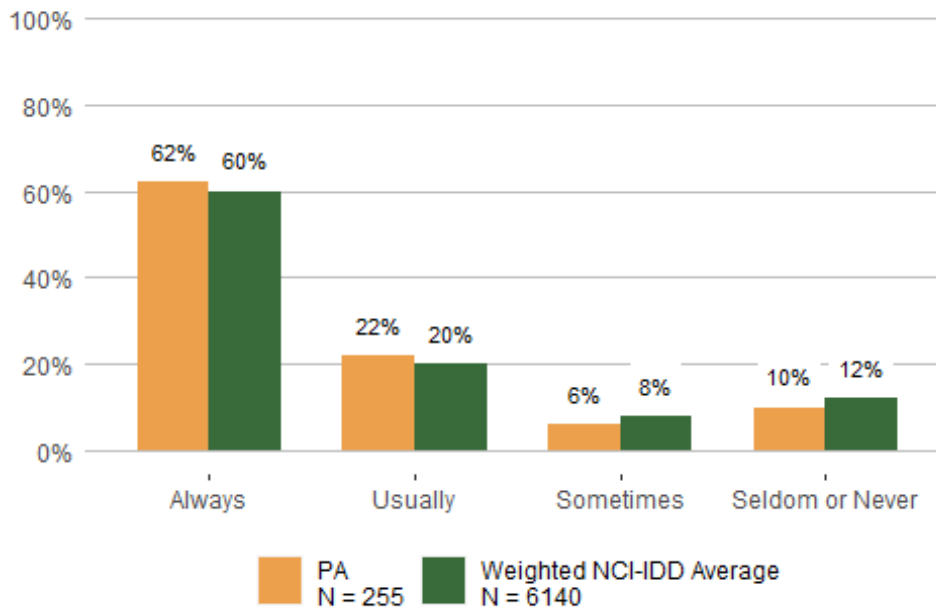


Table 65. Can someone in your family directly manage support staff?  
Question changed in 2021-22

State	Always	Usually	Sometimes	Seldom or Never	N
PA	62%	22%	6%	10%	255
Weighted NCI-IDD Average	60%	20%	8%	12%	6140

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

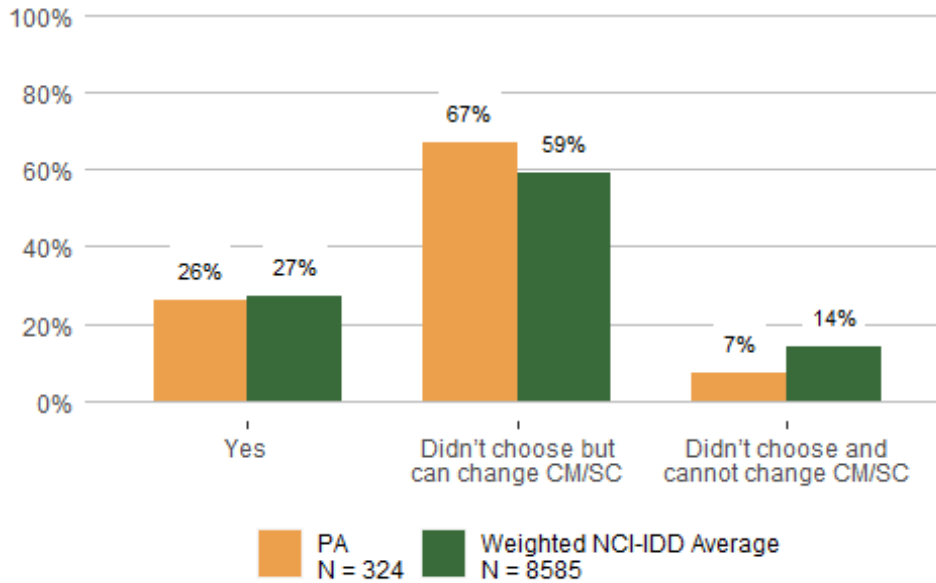


Table 66. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

State	Yes	Didn't choose but can change CM/SC	Didn't choose and cannot change CM/SC	N
PA	26%	67%	7%	324
Weighted NCI-IDD Average	27%	59%	14%	8585



Does your family member do things in the community?

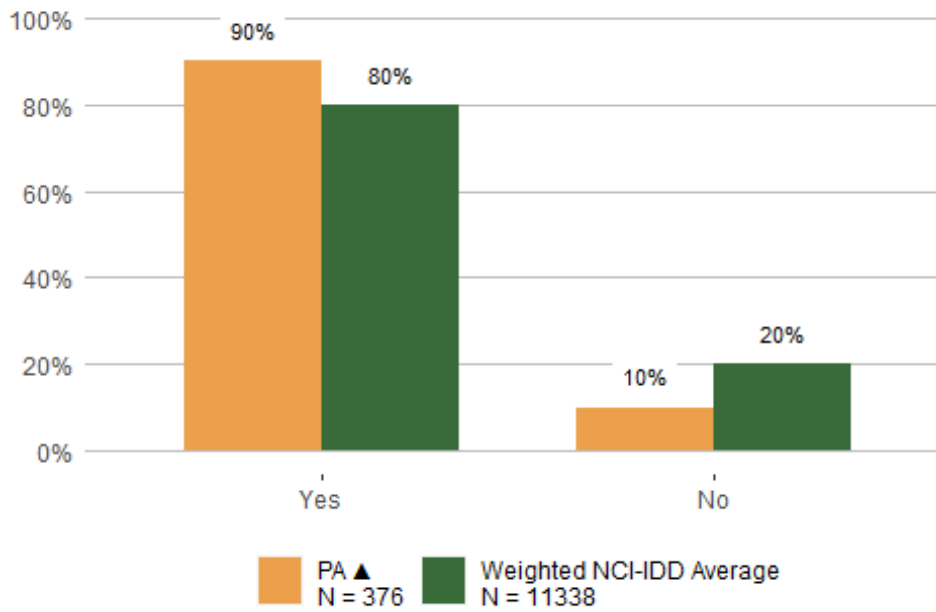


Table 67. Does your family member do things in the community?

State	Yes	No	N
PA ▲	90%	10%	376
Weighted NCI-IDD Average	80%	20%	11338

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

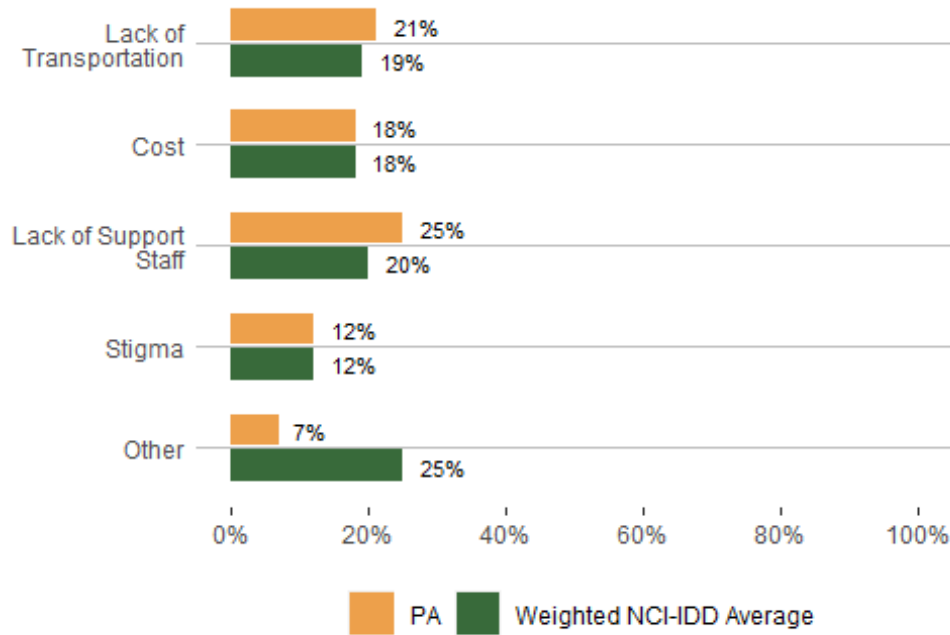


Table 68. For your family member, what makes it hard to do things in activities in the community?

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

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
PA	21%	18%	25%	12%	7%
Weighted NCI-IDD Average	19%	18%	20%	12%	25%

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

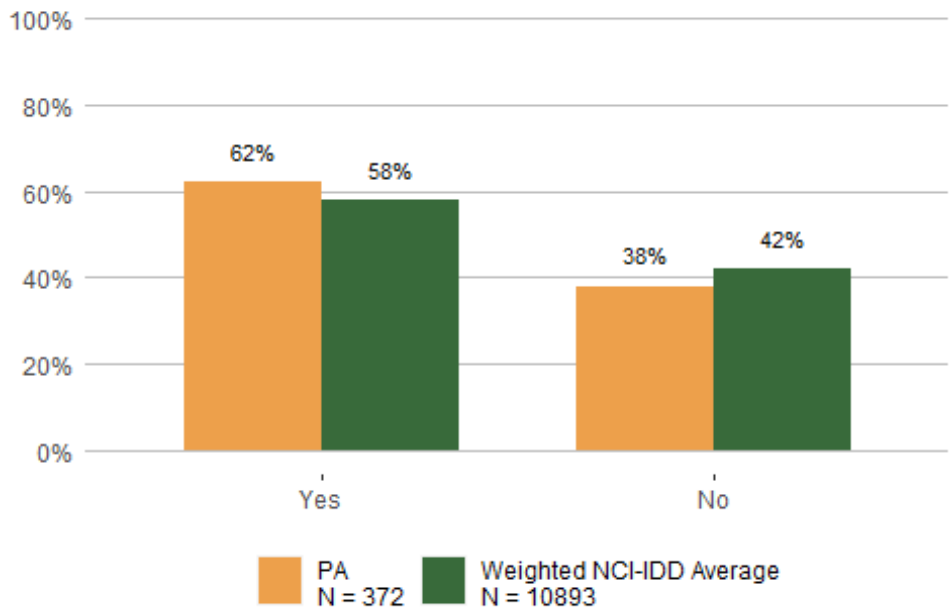


Table 69. Does your family member have friends other than paid support workers or family?

State	Yes	No	N
PA	62%	38%	372
Weighted NCI-IDD Average	58%	42%	10893

In your community, are there resources that your family can use that are not provided by the regional center (for example, recreational programs, community housing, library programs, religious groups, etc.)?

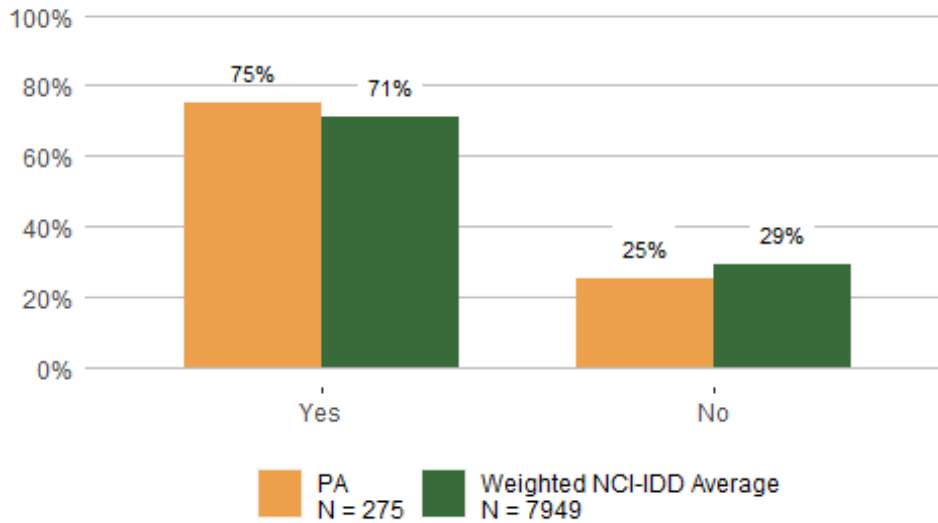


Table 70. In your community, are there resources that your family can use that are not provided by the state (for example, recreational programs, community housing, library programs, religious groups, etc.)?

Some NCI states provide services through a statewide ID/DD agency; those who used direct entry saw the question “In the community, are there resources or support that your family can use that are not provided by the I/DD agency?” Those who used the paper tool saw the question “In the community, are there resources or support that your family member can use that are not provided by the I/DD agency?”

State	Yes	No	N
PA	75%	25%	275
Weighted NCI-IDD Average	71%	29%	7949

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

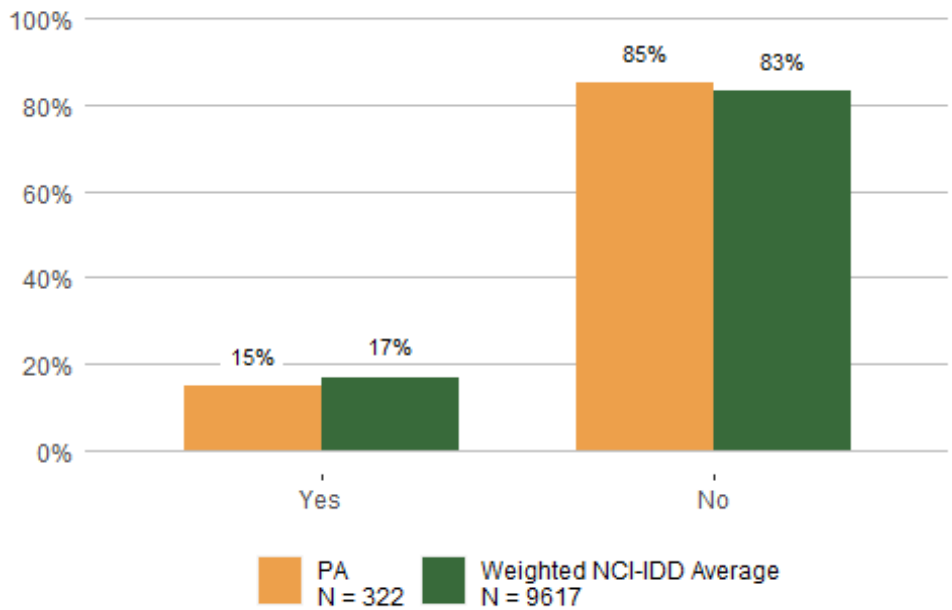


Table 71. Does your family take part in any family-to-family networks in your community?

State	Yes	No	N
PA	15%	85%	322
Weighted NCI-IDD Average	17%	83%	9617

Health, Welfare, and Safety (New in 2021-22)

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

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

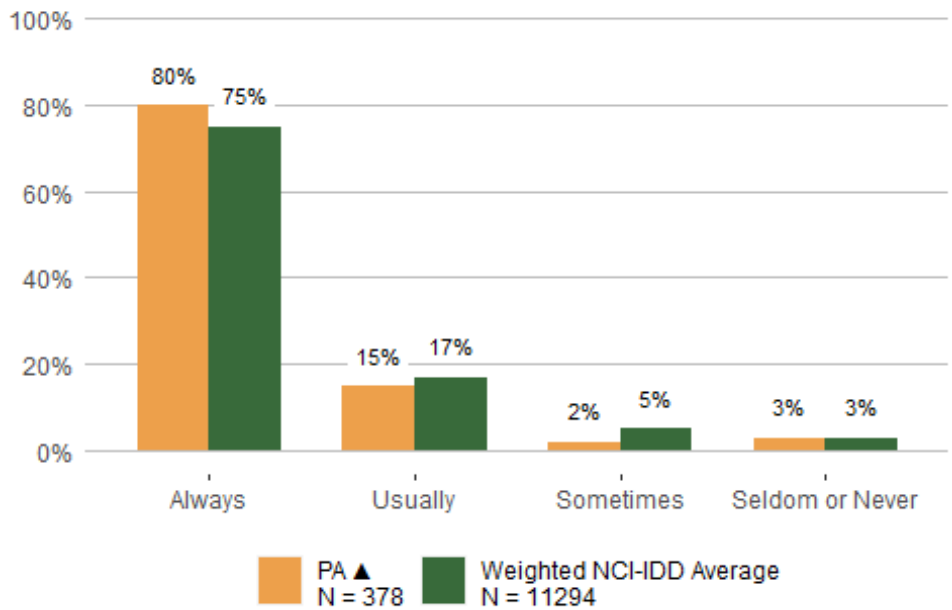


Table 72. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?

New question in 2021-22

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	80%	15%	2%	3%	378
Weighted NCI-IDD Average	75%	17%	5%	3%	11294

Does your family member's primary care doctor understand your family member's needs related to his/her disability?

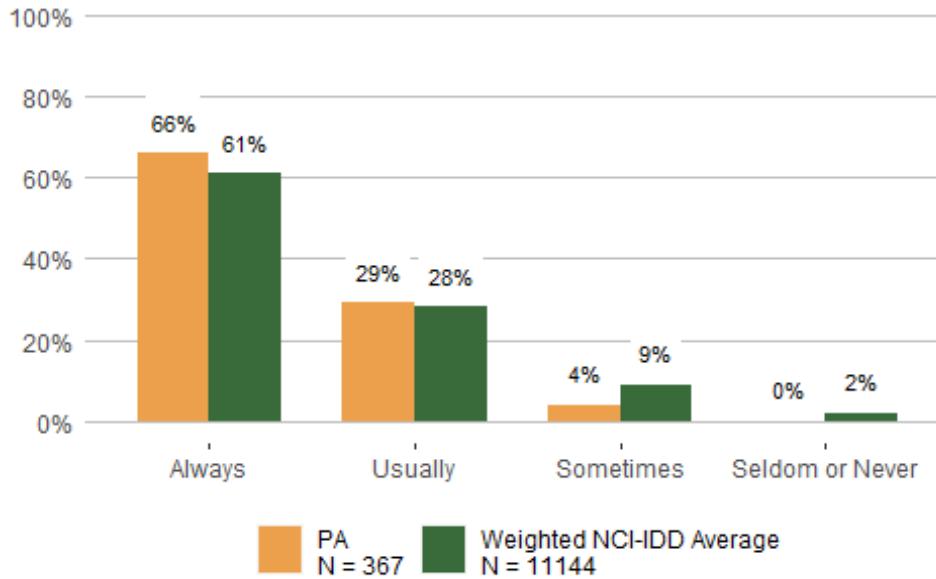


Table 73. Does your family member’s primary care doctor understand your family member’s needs related to his/her disability?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	66%	29%	4%	0%	367
Weighted NCI-IDD Average	61%	28%	9%	2%	11144



Can your family member go to the dentist when needed?

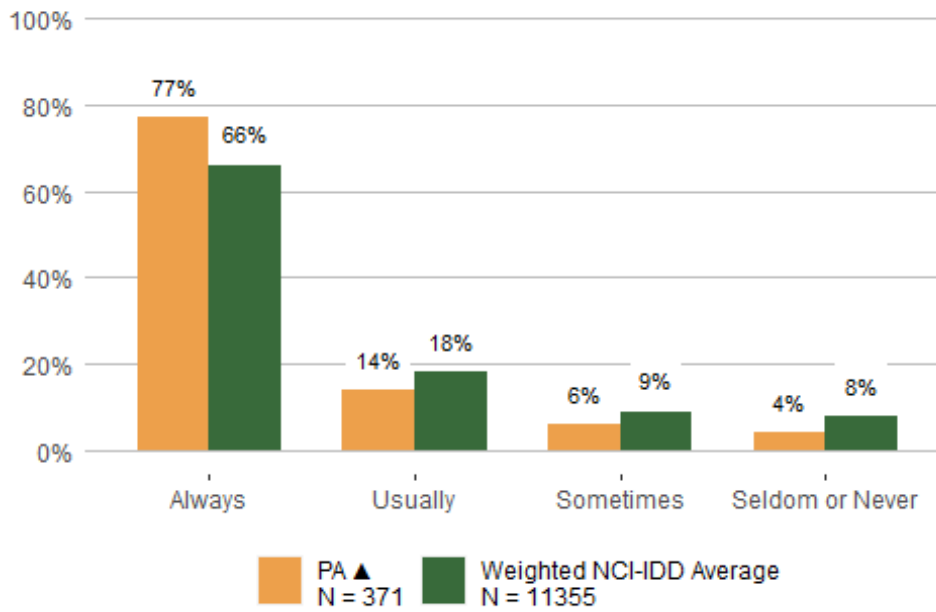


Table 74. Can your family member go to the dentist when needed?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	77%	14%	6%	4%	371
Weighted NCI-IDD Average	66%	18%	9%	8%	11355

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

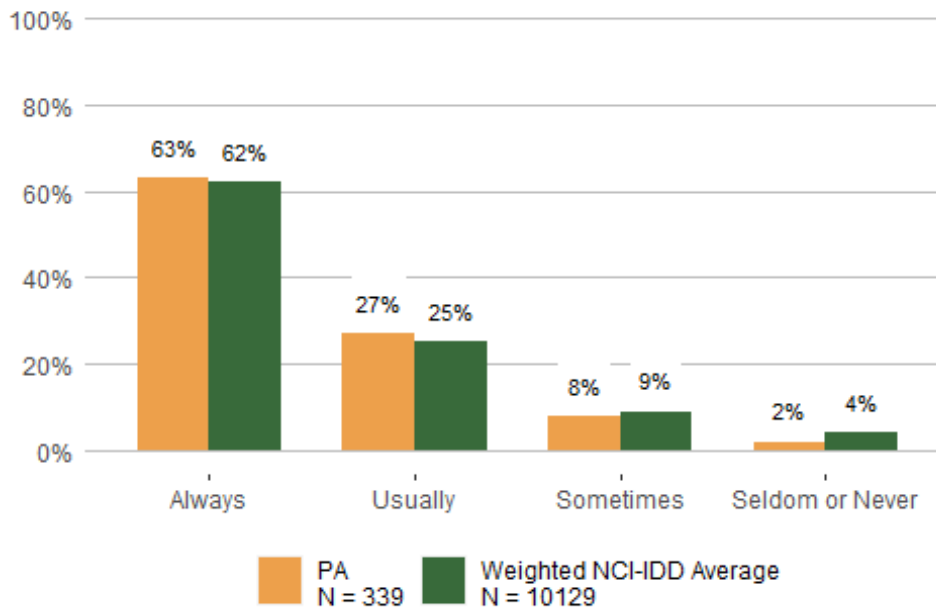


Table 75. Does your family member’s dentist understand your family member’s needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	63%	27%	8%	2%	339
Weighted NCI-IDD Average	62%	25%	9%	4%	10129

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

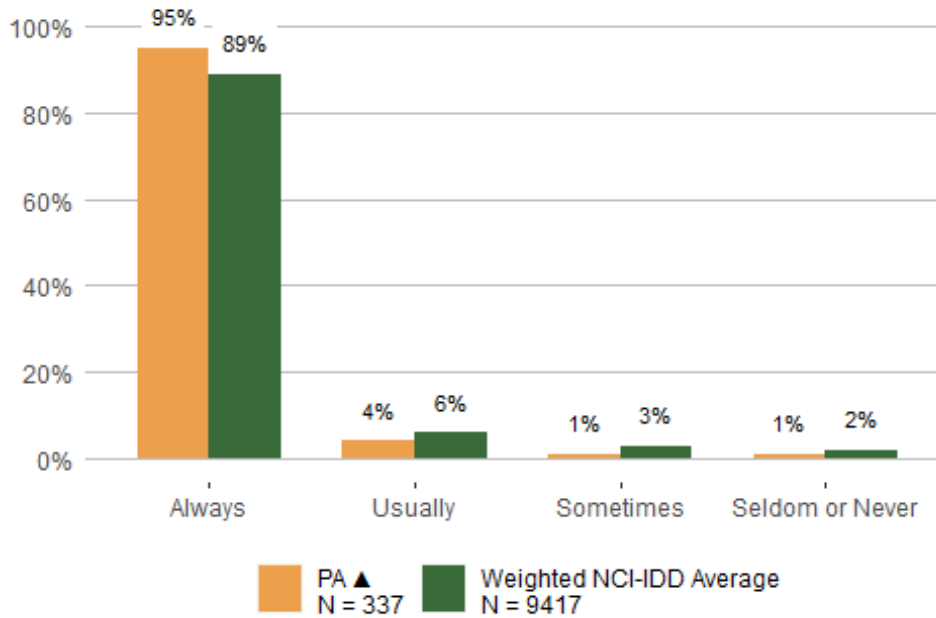


Table 76. If your family member takes prescription medications, do you know what they're for?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	95%	4%	1%	1%	337
Weighted NCI-IDD Average	89%	6%	3%	2%	9417

Do you, your family member, or someone else in your family know what is needed to safely take the medications?

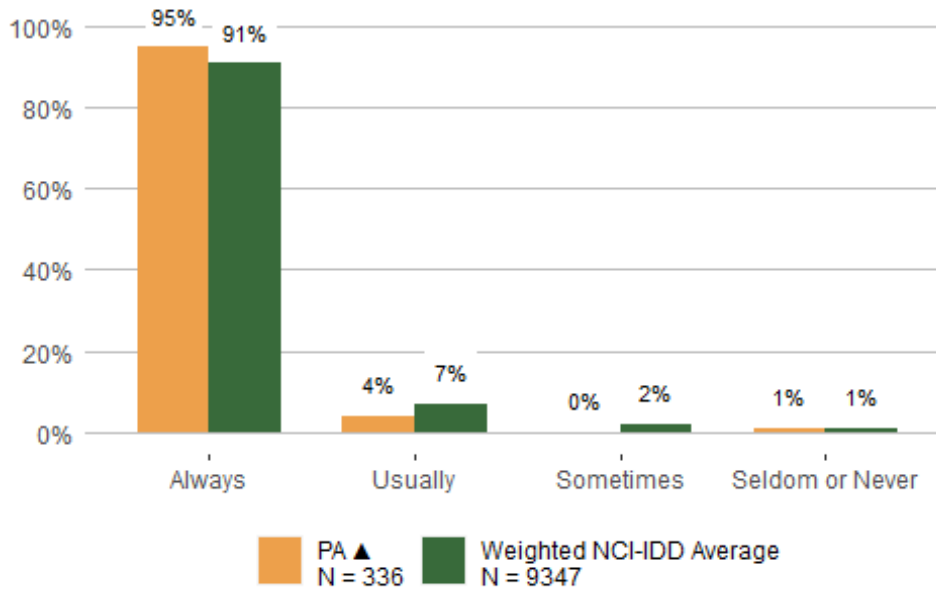


Table 77. Do you, your family member, or someone else in your family know what is needed to safely take the medications?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	95%	4%	0%	1%	336
Weighted NCI-IDD Average	91%	7%	2%	1%	9347

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

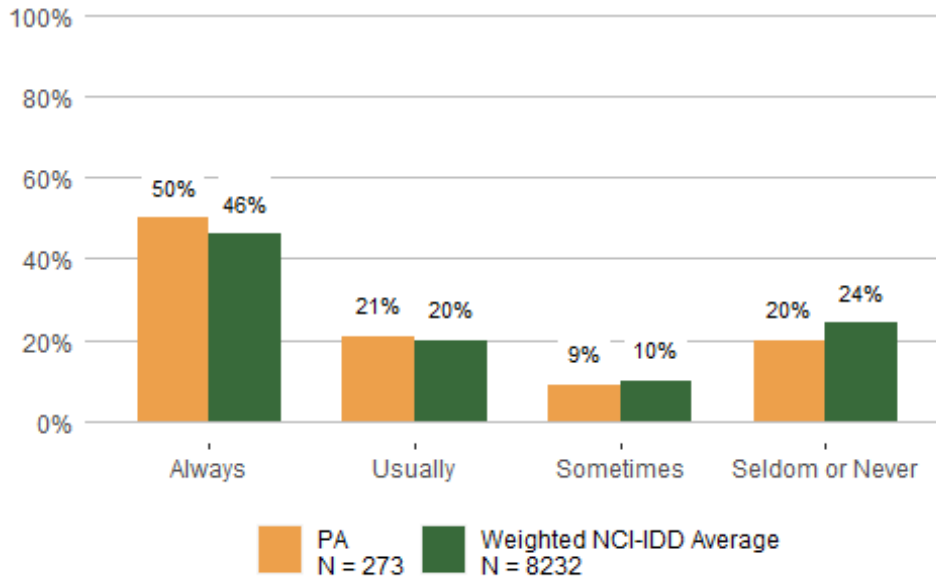


Table 78. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)?

New question in 2021-22

State	Always	Usually	Sometimes	Seldom or Never	N
PA	50%	21%	9%	20%	273
Weighted NCI-IDD Average	46%	20%	10%	24%	8232

If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability?

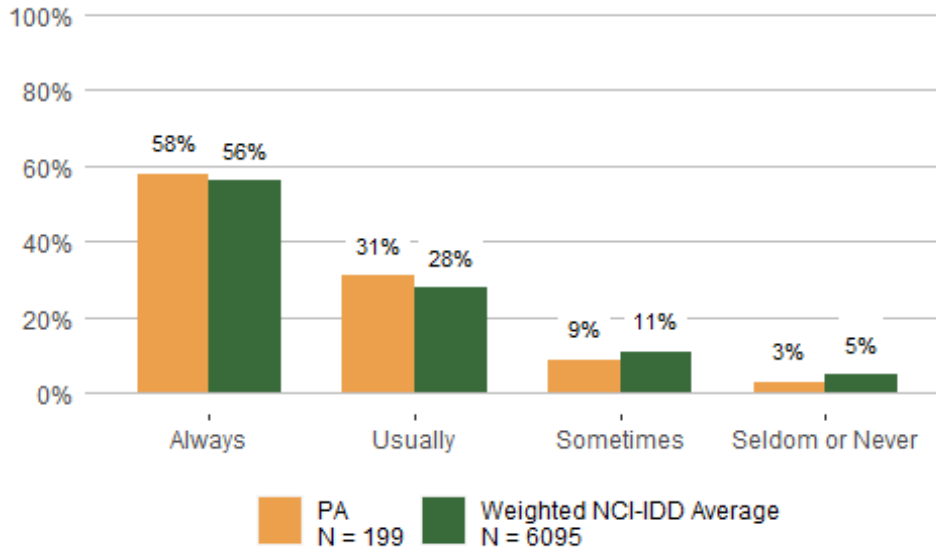


Table 79. If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	58%	31%	9%	3%	199
Weighted NCI-IDD Average	56%	28%	11%	5%	6095

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

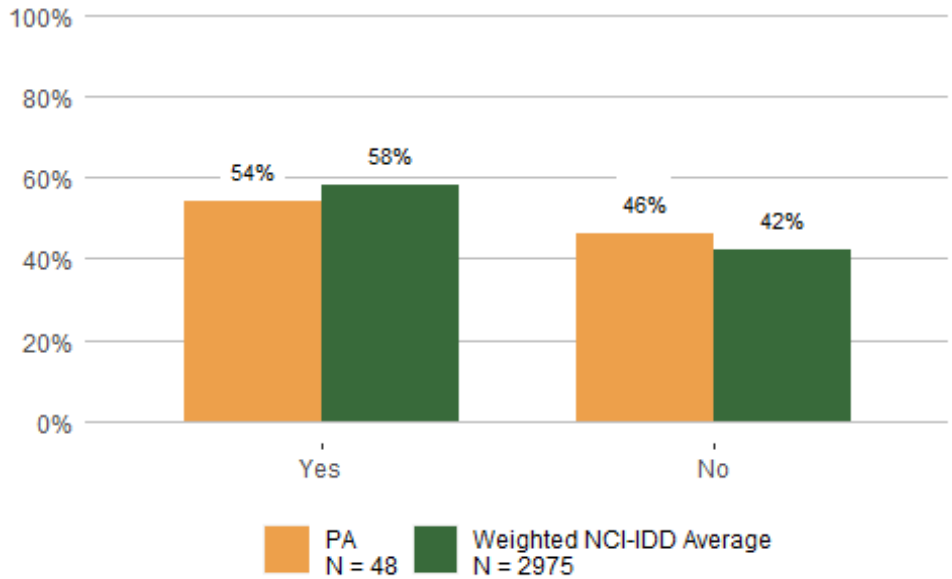


Table 80. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

State	Yes	No	N
PA	54%	46%	48
Weighted NCI-IDD Average	58%	42%	2975

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

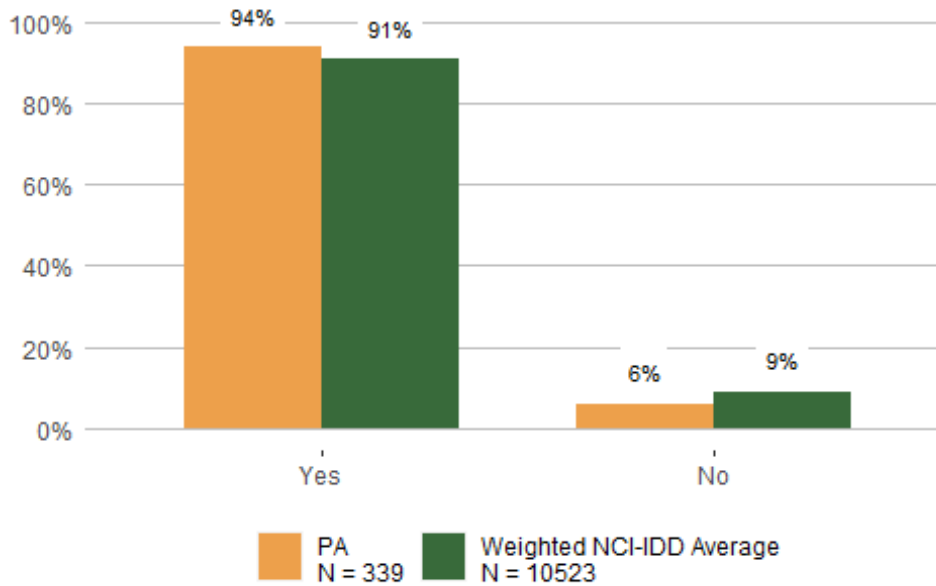


Table 81. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?

State	Yes	No	N
PA	94%	6%	339
Weighted NCI-IDD Average	91%	9%	10523



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

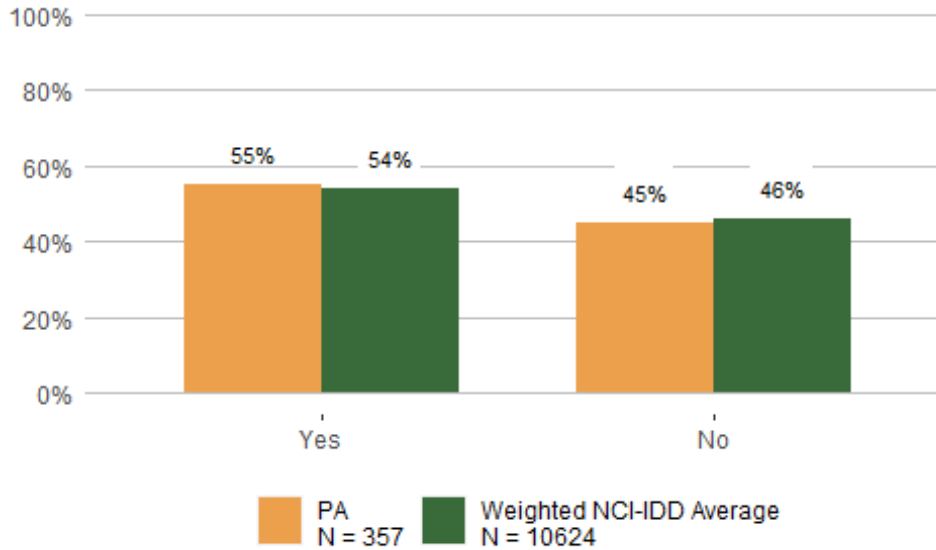


Table 82. Have you talked about how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your family member's case manager/service coordinator?

New question in 2021-22

State	Yes	No	N
PA	55%	45%	357
Weighted NCI-IDD Average	54%	46%	10624

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

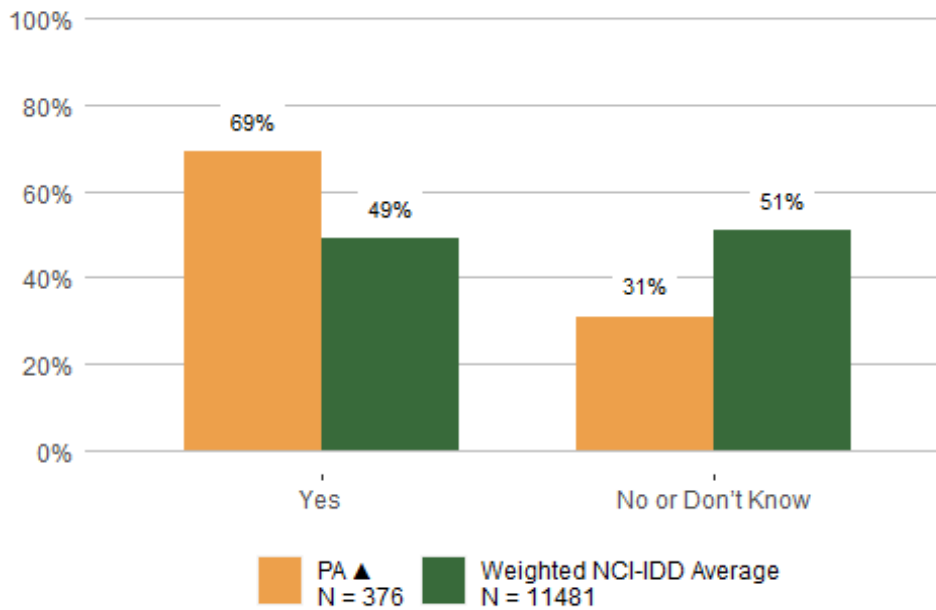


Table 83. Do you know how to file a complaint or grievance about provider agencies or staff?

State	Yes	No or Don't Know	N
PA ▲	69%	31%	376
Weighted NCI-IDD Average	49%	51%	11481

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

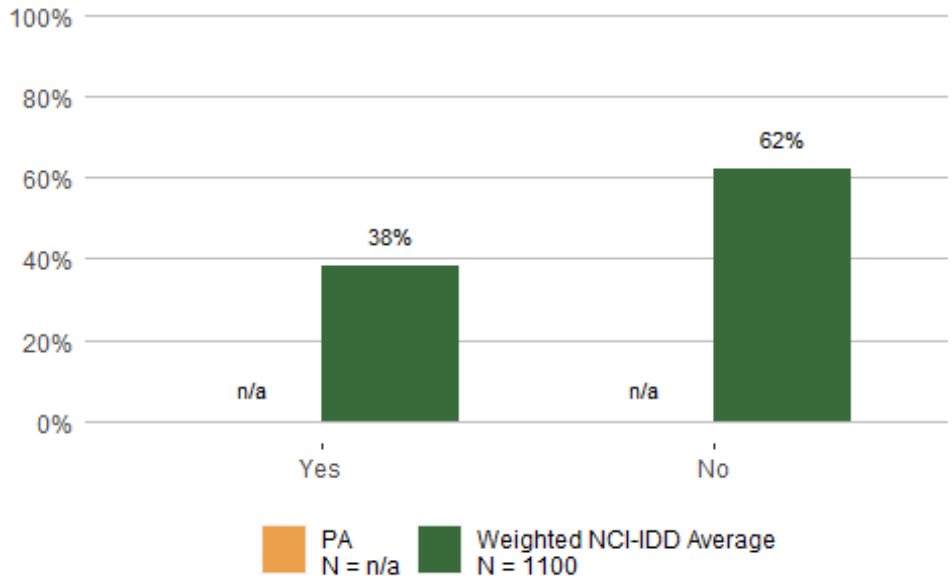


Table 84. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

State	Yes	No	N
PA	n/a	n/a	n/a
Weighted NCI-IDD Average	38%	62%	1100

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

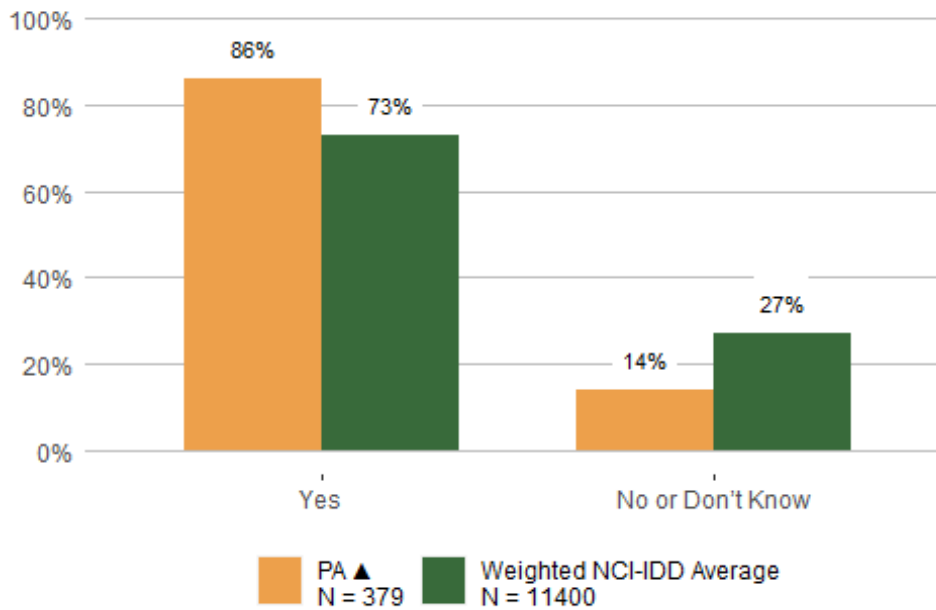


Table 85. Do you know how to report abuse or neglect related to your family member?

State	Yes	No or Don't Know	N
PA ▲	86%	14%	379
Weighted NCI-IDD Average	73%	27%	11400

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

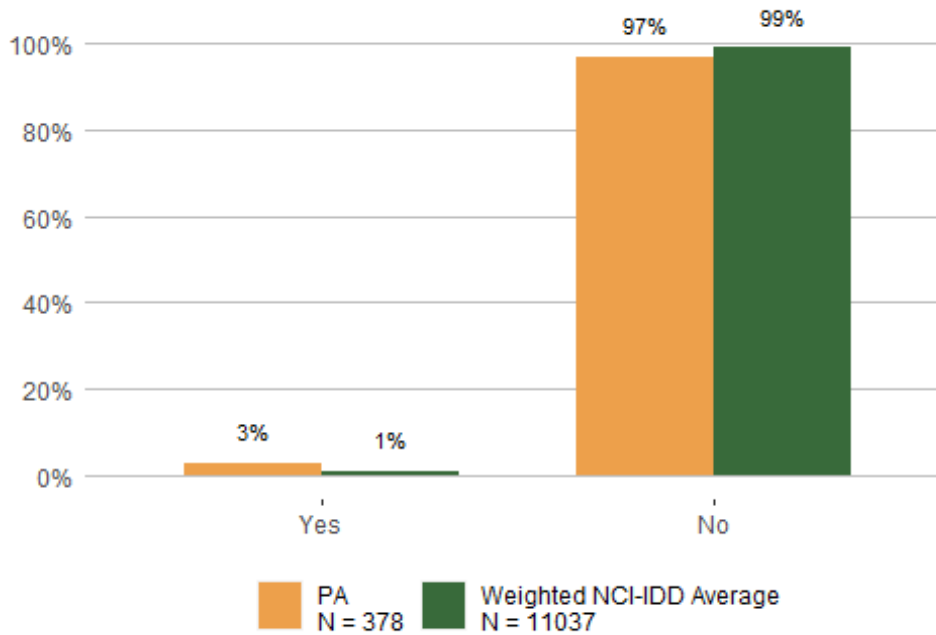


Table 86. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

State	Yes	No	N
PA	3%	97%	378
Weighted NCI-IDD Average	1%	99%	11037

If a report of abuse or neglect was filed on behalf of family member, were you notified of the report in a timely manner?

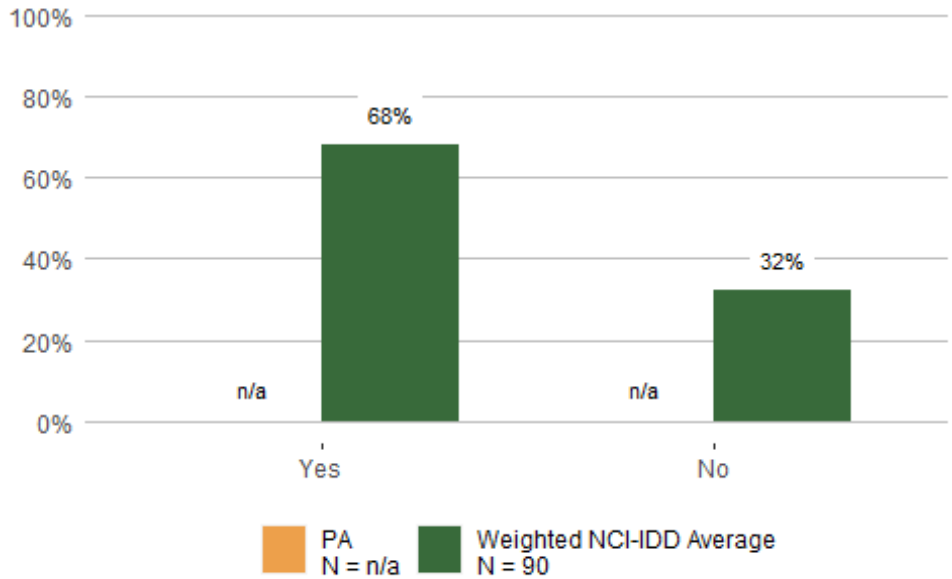


Table 87. If a report of abuse or neglect was filed on behalf of family member, were you notified of the report in a timely manner?

State	Yes	No	N
PA	n/a	n/a	n/a
Weighted NCI-IDD Average	68%	32%	90

## Family Satisfaction

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

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

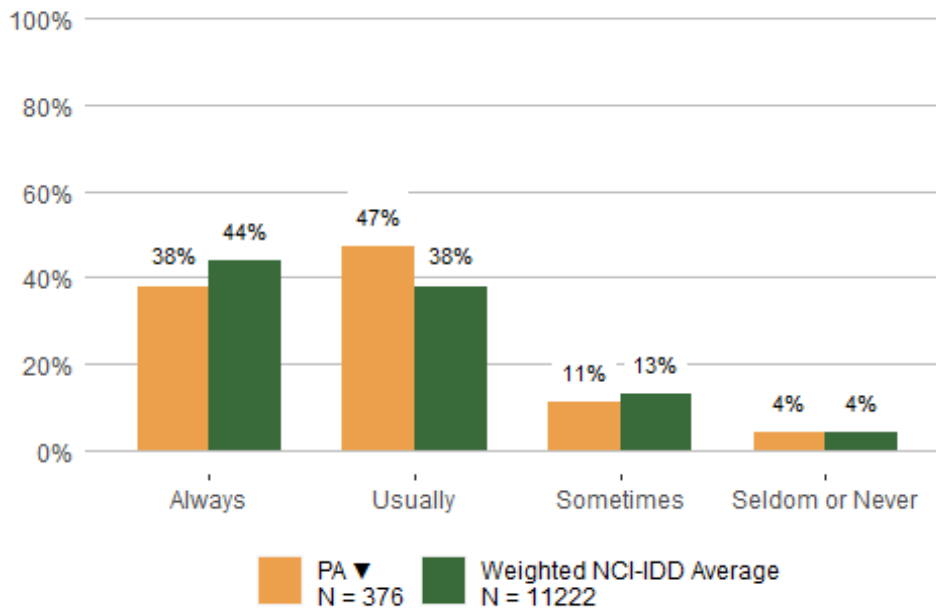


Table 88. Overall, are you satisfied with the services and supports your family member currently receives?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▼	38%	47%	11%	4%	376
Weighted NCI-IDD Average	44%	38%	13%	4%	11222



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

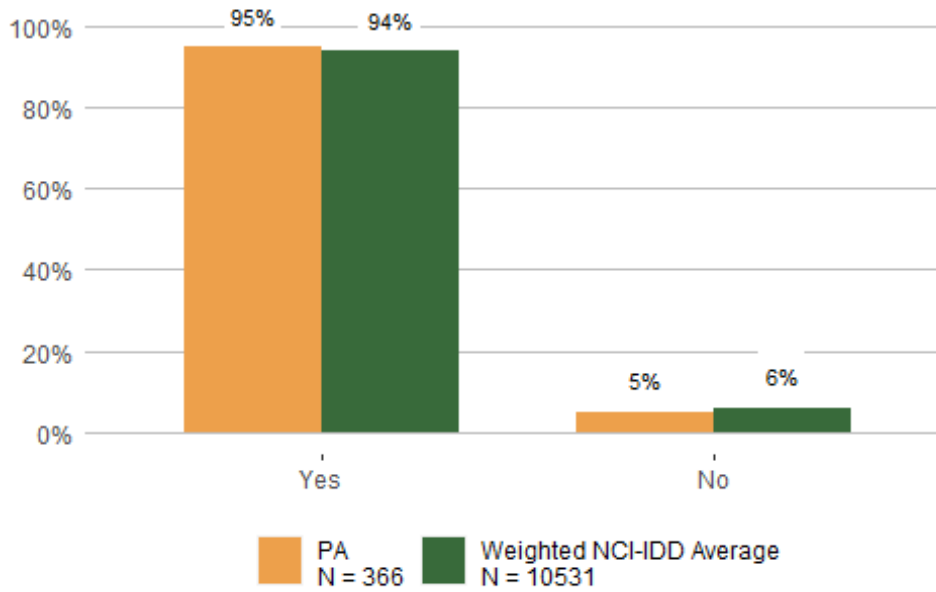


Table 89. Do you feel that services and supports have made a positive difference in the life of your family member?

State	Yes	No	N
PA	95%	5%	366
Weighted NCI-IDD Average	94%	6%	10531

Have services and supports reduced your family's out-of-pocket expenses for your family member's care?

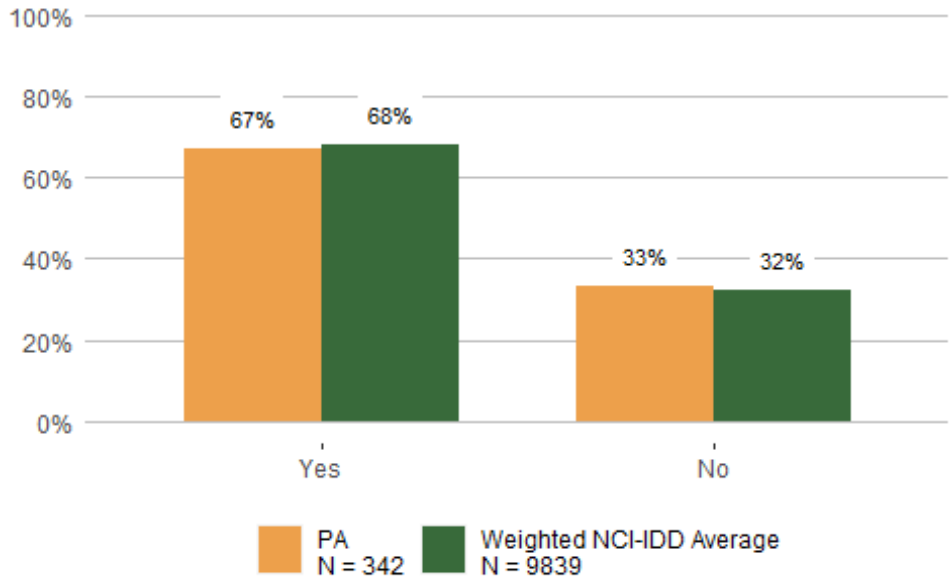


Table 90. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?

State	Yes	No	N
PA	67%	33%	342
Weighted NCI-IDD Average	68%	32%	9839

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

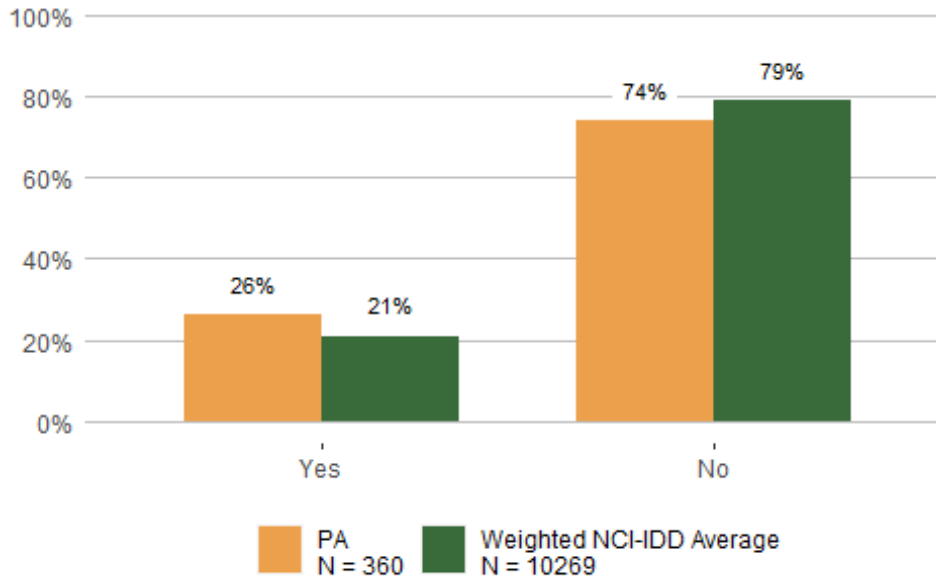


Table 91. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?

State	Yes	No	N
PA	26%	74%	360
Weighted NCI-IDD Average	21%	79%	10269

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

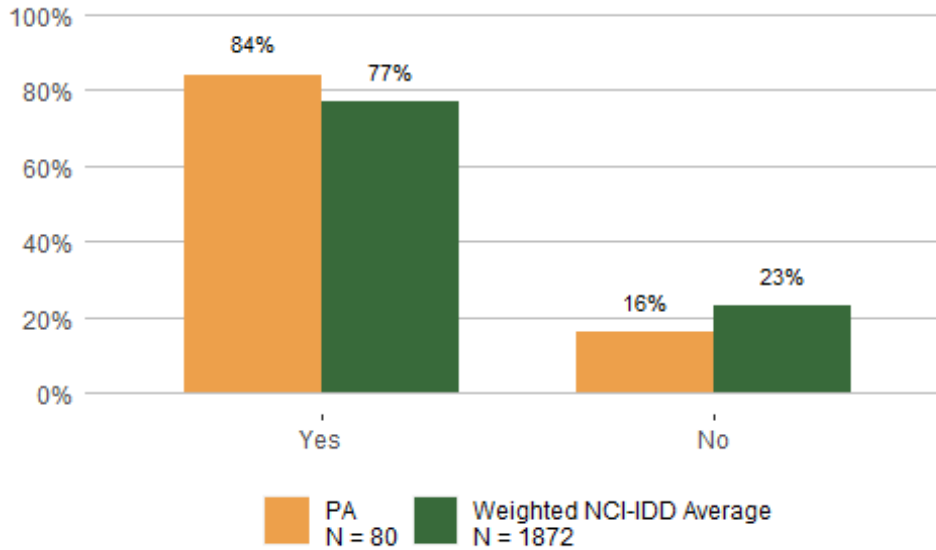


Table 92. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?

State	Yes	No	N
PA	84%	16%	80
Weighted NCI-IDD Average	77%	23%	1872

Have the services or supports that your family member received been increased in the past year?

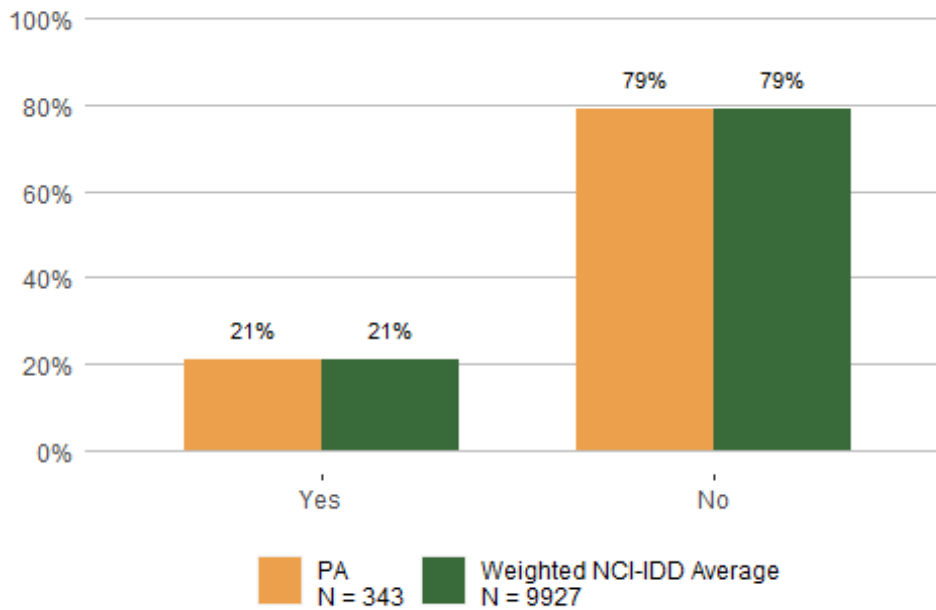


Table 93. Have the services or supports that your family member received been increased in the past year?

State	Yes	No	N
PA	21%	79%	343
Weighted NCI-IDD Average	21%	79%	9927

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

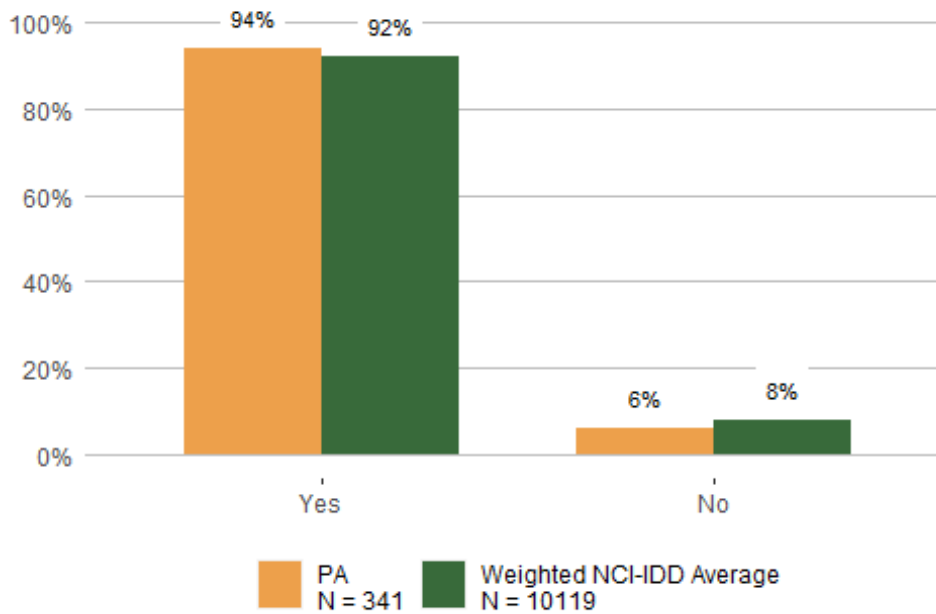


Table 94. Are services and supports helping your family member to live a good life?

State	Yes	No	N
PA	94%	6%	341
Weighted NCI-IDD Average	92%	8%	10119

## COVID-19 Supplement

The COVID-19 Supplement is intended to support an ongoing understanding of the continuing effects of the pandemic on people's lives and services. Note: the COVID-19 Supplement was state optional, one state chose not to administer the Supplement.

Were your family member's services and supports changed, canceled, or reduced during COVID time?

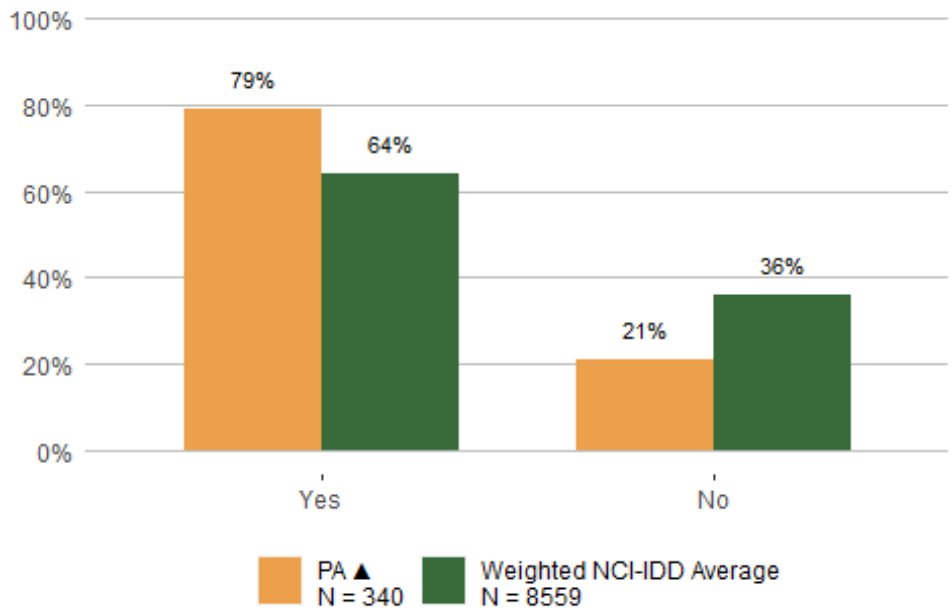


Table 95. Were your family member's services and supports changed, canceled, or reduced during COVID time?

State	Yes	No	N
PA ▲	79%	21%	340
Weighted NCI-IDD Average	64%	36%	8559



If yes, are those changes still in effect (still part of your family member's life)?

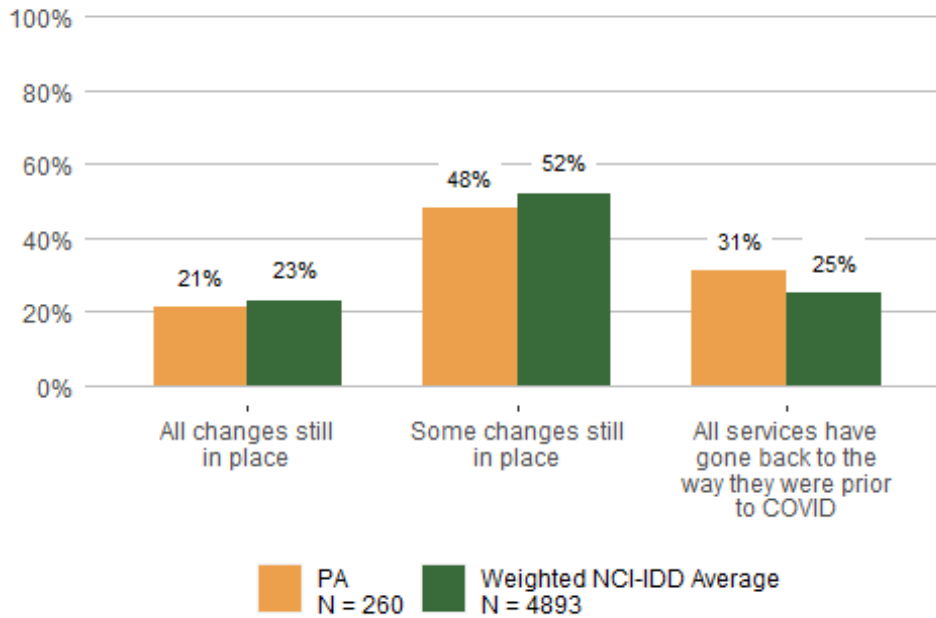


Table 96. If yes, are those changes still in effect (still part of your family member's life)?

State	All changes still in place	Some changes still in place	All services have gone back to the way they were prior to COVID	N
PA	21%	48%	31%	260
Weighted NCI-IDD Average	23%	52%	25%	4893

If some or all of your family member's services have reopened or restarted: Did your family get enough information about the services reopening/restarting?

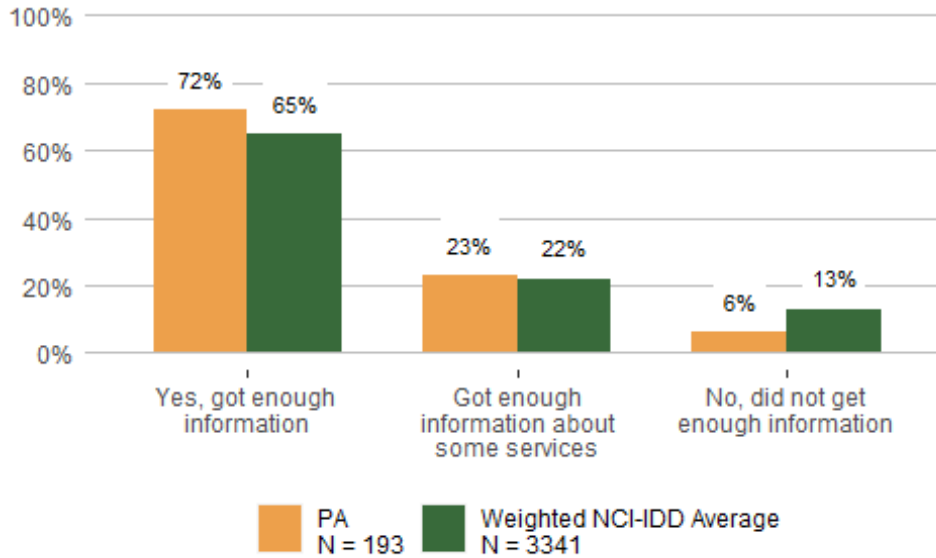


Table 97. If some or all of your family member’s services have reopened or restarted: Did your family get enough information about the services reopening/restarting?

State	Yes, got enough information	Got enough information about some services	No, did not get enough information	N
PA	72%	23%	6%	193
Weighted NCI-IDD Average	65%	22%	13%	3341

If some or all of your family member's services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions?

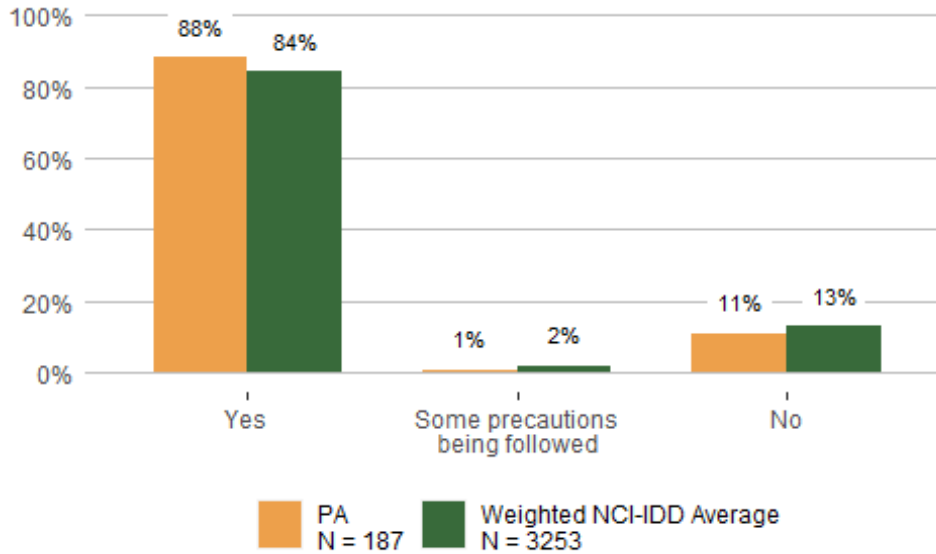


Table 98. If some or all of your family member’s services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions?

State	Yes	Some precautions being followed	No	N
PA	88%	1%	11%	187
Weighted NCI-IDD Average	84%	2%	13%	3253

If staff support your family member in your family member's home: Do you feel that the staff follow recommendations to keep the household safe and healthy?

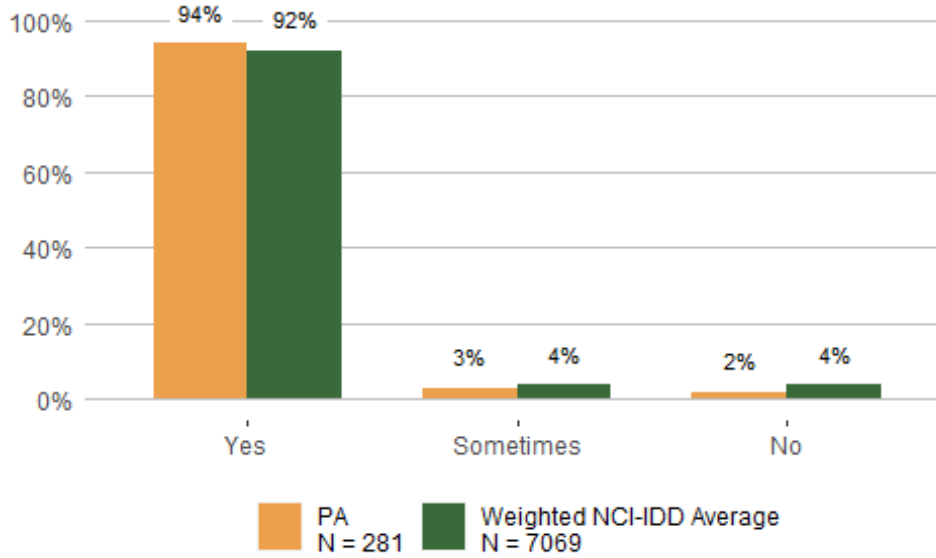


Table 99. If staff support your family member in your family member's home: Do you feel that the staff follow recommendations to keep the household safe and healthy?

State	Yes	Sometimes	No	N
PA	94%	3%	2%	281
Weighted NCI-IDD Average	92%	4%	4%	7069

Do you feel that the people in your household have the personal protective equipment (PPE) they need to stay healthy and safe when going out in the community?

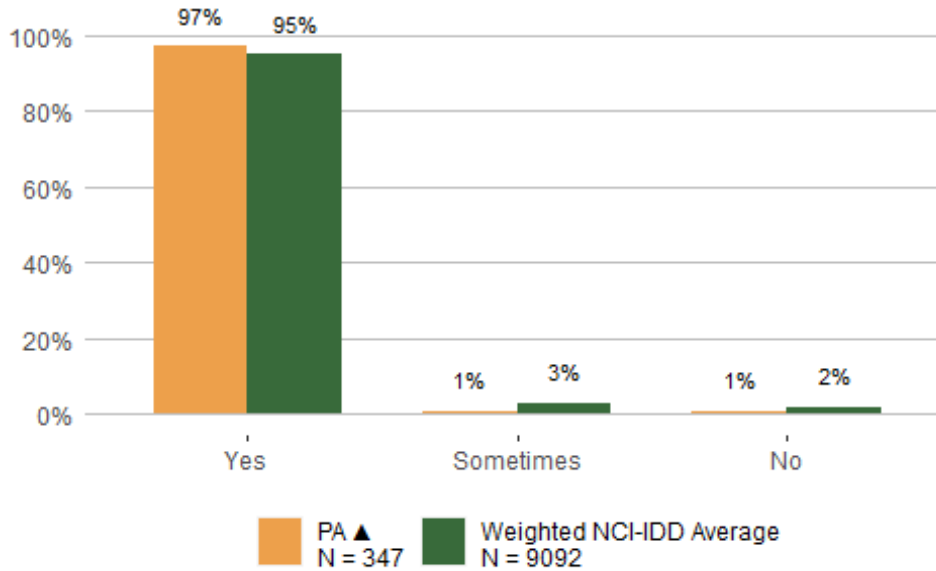


Table 100. Do you feel that the people in your household have the personal protective equipment (PPE) they need to stay healthy and safe when going out in the community?

State	Yes	Sometimes	No	N
PA ▲	97%	1%	1%	347
Weighted NCI-IDD Average	95%	3%	2%	9092

In preparation for the future, have you made or updated an emergency plan with your family member's case manager or with other staff?

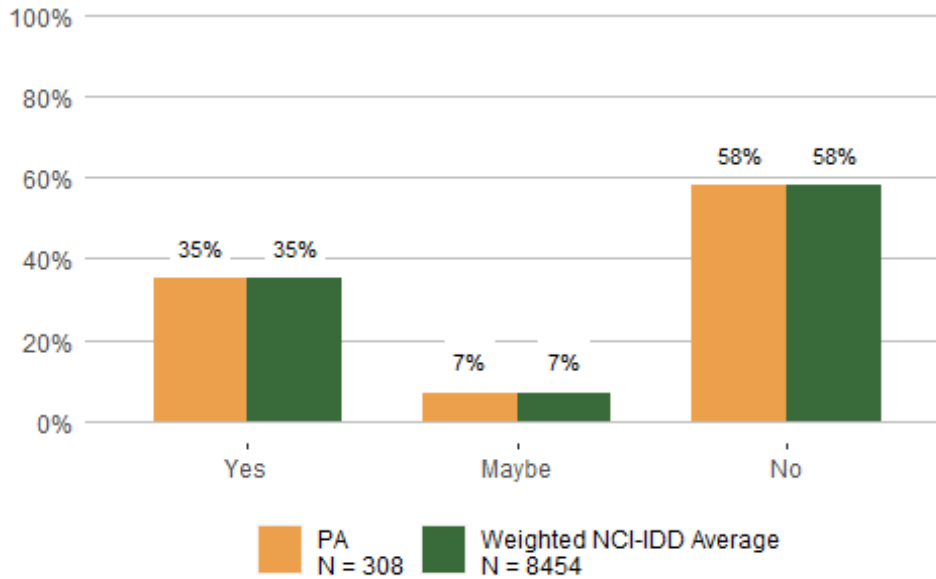


Table 101. In preparation for the future, have you made or updated an emergency plan with your family member's case manager or with other staff?

State	Yes	Maybe	No	N
PA	35%	7%	58%	308
Weighted NCI-IDD Average	35%	7%	58%	8454