

2021-2022 PA Family Guardian Survey State Report

Table of Contents

2021-2022 PA Family Guardian Survey State Report	1
Introduction	7
Demographics.....	9
Family Member	9
Table 1a. Residence.....	10
Table 1b. Residence (continued)	11
Table 2. Family Member's Time Living in Current Residence.....	12
Table 3. Family Member's Residential Designation.....	13
Table 4. Family Member's Age	14
Table 5. Family Member's Gender	15
Table 6. Family Member's Race and Ethnicity.....	16
Table 7a. Family Member's Conditions	17
Table 7b. Family Member's Conditions (continued)	18
Table 8a. Family Member's Other Health Conditions.....	19
Table 8b. Family Member's Other Health Conditions (continued)	20
Table 8c. Family Member's Other Health Conditions (continued)	21
Table 9. Family Member's Preferred Means of Communication	22
Table 10. Family Member's Preferred Language	23
Table 11. Family Member Has Legal Court Appointed Guardian or Conservator	24
Table 12. Guardian or Conservator Relationship to Family Member	25
Table 13a. Family Member's Highest level of Education	26
Table 13b. Family Member's Highest level of Education (continued)	27
Table 14. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	28

Table 15. Family Member's Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)	29
Table 16. Family Member's Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping)	30
Respondents.....	31
Table 17a. Language Usually Spoken at Home	32
Table 18. Respondent's Age.....	33
Table 19. Respondent's Health	34
Table 20. Respondent's Relationship to Family Member	35
Table 21. Respondent's Frequency of Visits With Family Member	36
Table 22. Respondent's Highest Level of Education	37
Table 23. Total Taxable Household Income of Wage Earners in the Past Year	38
Services and Supports Received.....	39
Table 24a. Services and Supports Received From State.....	40
Table 24b. Services and Supports Received From State (continued).....	41
Table 25. Additional Services and Supports Received	42
Family/Guardian Survey Results	43
Information and Planning	44
Table 26. Do you get enough information to take part in planning services for your family member?	45
Table 27. Is the information you get about services and supports easy to understand?	46
Table 28. Do you get information about services and supports in your preferred language?	47
Table 29. Does the case manager/service coordinator listen to your family's choices and opinions?	48
Table 30. Do staff or the residential agency keep you informed about how your family member is doing?	49
Table 31a. Do you need help planning for your family member's future in any of these areas?	50

Table 31b. Do you need help planning for your family member's future in any of these areas?	51
Table 32. Has your family learned about alternatives to guardianship?	52
Table 33. Does your family member have a service plan?	53
Table 34. Does the service plan include all the services and supports your family member needs?	54
Table 35. Did you or someone else in your family (besides your family member with a disability) help make the service plan?	55
Table 36. Did your family member help make the service plan?	56
Table 37. Do you feel like your family had enough say or input in making the plan?	57
Table 38. Did your family member leave school services and begin adult services during the past 12 months?	58
Table 39. If your family member left school services during the past year, did they have a transition plan?	59
Table 40. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?	60
Access and Delivery of Services and Supports.....	61
Table 41. Does your family member get all the services listed in the ISP?	62
Table 42. Does your family get the supports and services it needs?	63
Table 43a. If your family does not get the support and services needed, what additional services does your family need?	64
Table 43b. If your family does not get the support and services needed, what additional services does your family need? (continued)	65
Table 44. Do services and supports change when your family's needs change?	66
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)	67
Table 46. Does your family member have the special equipment or accommodations they need?	68
Table 47. Are you or your family member able to contact their support workers when you want?	69

Table 48. Are you or your family member able to contact their case manager/service coordinator when you want?	70
Table 49. Do service providers for your family member work together to provide support?	71
Table 50. Are services delivered in a way that is respectful of your family's culture? ...	72
Table 51. Does your family member use technology in their everyday life to help them do things on their own?	73
Table 52. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?	74
Table 53. How well does the internet work in your home?	75
Workforce (New in 2021-22)	76
Table 54. Do support workers come and go when they are supposed to?	77
Table 55. Do support workers speak to you in a way you understand?	78
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?	79
Table 57. Do support workers have the right information and skills to meet your family's needs?	80
Table 58. Do your family member's support workers change too often? Is there too much "turnover" of support workers?	81
Table 59. Is there always a staff person available to support your family member when support is needed?	82
Choice, Decision Making and Control	83
Table 60. Can someone in your family choose or change the provider agency that provides your family member's services?	84
Table 61. Can someone in your family choose or change your family member's support workers?	85
Table 62. Can someone in your family directly manage support staff?	86
Table 63. Did you, your family member, or someone else in your family choose your family member's case manager?	87
Community Connections	88
Table 64. Does your family member do things in the community?	89

Table 65. For your family member, what makes it hard to do things in the community?	90
Table 66. Does your family member have friends other than paid support workers or family?	91
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?	92
Table 68. 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 69. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?	95
Table 70. Does your family member's primary care provider understand your family member's needs related to their disability?	96
Table 71. Can your family member go to the dentist when needed?	97
Table 72. Does your family member's dentist understand your family member's needs related to their disability?	98
Table 73. If your family member takes prescription medications, do you know what they're for?	99
Table 74. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)?	100
Table 75. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)?	101
Table 76. Does your family member's mental or behavioral health professional understand your family member's needs related to their disability?	102
Table 77. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?	103
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?	104
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/service coordinator?	105

Table 80. Do you know how to file a complaint or grievance about provider agencies or staff?	106
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?	107
Table 82. Do you know how to report abuse or neglect related to your family member?	108
Table 83. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?	109
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?	110
Family Satisfaction.....	111
Table 85. Overall, are you satisfied with the services and supports your family member currently receives?.....	112
Table 86. Do you feel that services and supports have made a positive difference in the life of your family member?	113
Table 87. Does the agency providing residential services to your family member involve them in important decisions?	114
Table 88. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?	115
Table 89. 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 90. Have the services or supports that your family member received been increased in the past 12 months?.....	117
Table 91. Are services and supports helping your family member to live a good life?..	118
COVID-19 Supplement	119
Table 92. Were your family member's services and supports changed, canceled, or reduced during COVID time?	120
Table 93. If yes, are those changes still in effect (still part of your family member's life)?	121
Table 94. 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 95. 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 96. 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 97. In preparation for the future, have you made or updated an emergency plan with your family member's case manager/service coordinator or with other staff? ...	125

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 Family/Guardian Survey (FGS). The NCI-IDD averages data shown are weighted. These data are comprised of 8,050 valid surveys collected across 10 states: Arizona (AZ), California (CA), Delaware (DE), Georgia (GA), Indiana (IN), Minnesota (MN), New Hampshire (NH), Pennsylvania (PA), South Dakota (SD), and Washington (WA).

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.

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 Family/Guardian 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 Family/Guardian Survey Report](#).

Demographics

Family Member

Table 1a. Residence

State	Specialized Facility for People with Intellectual Disabilities	Group Home or Agency-Operated Apartment	Independent Home or Apartment	N
PA	18%	74%	3%	646
Weighted NCI- IDD Average	14%	52%	27%	7916

Table 1b. Residence (continued)

State	Adult Foster Care or Host Family Home	Nursing Home	Homeless	Other	N
PA	3%	1%	0%	1%	646
Weighted NCI-IDD Average	4%	1%	0%	1%	7916

Table 2. Family Member's Time Living in Current Residence

State	Less than one year	One to three years	Four to five years	Over five years	N
PA	2%	12%	7%	79%	596
Weighted NCI-IDD Average	7%	21%	11%	61%	7820

Table 3. 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	69%	31%	623
Weighted NCI-IDD Average	87%	13%	7755

Table 4. Family Member's Age

State	Age	N
PA	49.5	655
Weighted NCI-IDD Average	44.8	7813

Table 5. Family Member's Gender

State	Male	Female	Other	N
PA	58%	42%	0%	655
Weighted NCI-IDD Average	60%	40%	0%	7911

Table 6. 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.

State	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer Not to Say
PA	1%	1%	6%	0%	91%	2%	1%	0%
Weighted NCI-IDD Average	2%	5%	6%	0%	80%	8%	2%	2%

Table 7a. 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	86%	39%	30%	15%	11%	7%
Weighted NCI-IDD Average	74%	33%	34%	16%	8%	6%

Table 7b. 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	8%	31%	0%	9%	1%	1%	11%
Weighted NCI-IDD Average	9%	26%	1%	9%	1%	2%	11%

Table 8a. Family Member's Other Health 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	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
PA	7%	17%	4%	28%	25%
Weighted NCI-IDD Average	8%	18%	5%	28%	27%

Table 8b. Family Member's Other Health 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	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Dementia	Oral Health Problems	Sleep Apnea
PA	24%	2%	5%	13%	16%
Weighted NCI- IDD Average	12%	2%	4%	13%	17%

Table 8c. Family Member's Other Health 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	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	5%	3%	5%	1%	19%
Weighted NCI-IDD Average	10%	4%	4%	1%	24%

Table 9. 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	71%	18%	1%	2%	8%	648
Weighted NCI-IDD Average	80%	13%	2%	1%	4%	7738

Table 10. Family Member's Preferred Language

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
PA	97%	0%	0%	0%	0%	1%	2%	648
Weighted NCI-IDD Average	95%	1%	0%	0%	0%	1%	2%	7796

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

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

State	No Guardianship	Limited	Full	Has Guardianship but Level Is Unknown	N
PA	14%	22%	51%	12%	549
Weighted NCI-IDD Average	29%	21%	44%	6%	7312

Table 12. Guardian or Conservator Relationship to Family Member

State	Family	Friend	Employee or State Guardianship Agency	Other	N
PA	85%	2%	9%	3%	414
Weighted NCI-IDD Average	88%	2%	6%	3%	4676

Table 13a. 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	N
PA	39%	0%	25%	593
Weighted NCI-IDD Average	29%	1%	32%	7415

Table 13b. Family Member's Highest level of Education (continued)

State	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
PA	32%	1%	1%	2%	593
Weighted NCI-IDD Average	27%	2%	5%	4%	7415

Table 14. 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	27%	38%	34%	622
Weighted NCI-IDD Average	36%	38%	26%	7564

Table 15. 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	13%	39%	48%	642
Weighted NCI-IDD Average	26%	38%	36%	7708

Table 16. 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	1%	13%	87%	643
Weighted NCI-IDD Average	3%	25%	72%	7765

Respondents

This section provides demographic information about the respondent.

Table 17a. Language Usually Spoken at Home

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
PA	99%	0%	0%	0%	0%	0%	1%	650
Weighted NCI-IDD Average	95%	2%	1%	0%	0%	0%	2%	7803

Table 18. Respondent's Age

State	Under 35	35-54	55-74	75 or Older	N
PA	1%	8%	64%	27%	646
Weighted NCI-IDD Average	1%	11%	60%	28%	7797

Table 19. Respondent's Health

State	Excellent	Very good	Good	Fair	Poor	N
PA	13%	38%	29%	17%	3%	650
Weighted NCI-IDD Average	15%	36%	33%	14%	3%	7744

Table 20. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Public Guardian	Private Guardian	Other	N
PA	59%	32%	0%	1%	1%	1%	5%	650
Weighted NCI-IDD Average	73%	16%	0%	1%	2%	1%	7%	7745

Table 21. Respondent's Frequency of Visits With Family Member

State	Did Not Visit	1 to 3 Times	4 to 6 Times	7 to 12 Times	More Than 12 Times	N
PA	9%	16%	15%	12%	49%	646
Weighted NCI-IDD Average	6%	11%	11%	12%	61%	7736

Table 22. 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	4%	28%	7%	16%	43%	640
Weighted NCI-IDD Average	4%	17%	6%	22%	51%	7669

Table 23. 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	Up to \$15,000	\$15,001 to \$25,000	\$25,001 to \$50,000	\$50,001 to \$75,000	Over \$75,000	No Earned Income	Prefer Not to Say	N
PA	5%	8%	15%	12%	17%	12%	31%	620
Weighted NCI-IDD Average	5%	6%	12%	12%	22%	11%	32%	7386

Services and Supports Received

Table 24a. Services and Supports Received From State

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	Residential Supports	Day or Employment Supports
PA	26%	32%	94%	52%
Weighted NCI-IDD Average	40%	45%	75%	59%

Table 24b. Services and Supports Received From State (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	93%	68%	8%
Weighted NCI-IDD Average	76%	52%	19%

Table 25. 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	97%	25%
Weighted NCI-IDD Average	93%	27%

Family/Guardian 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?

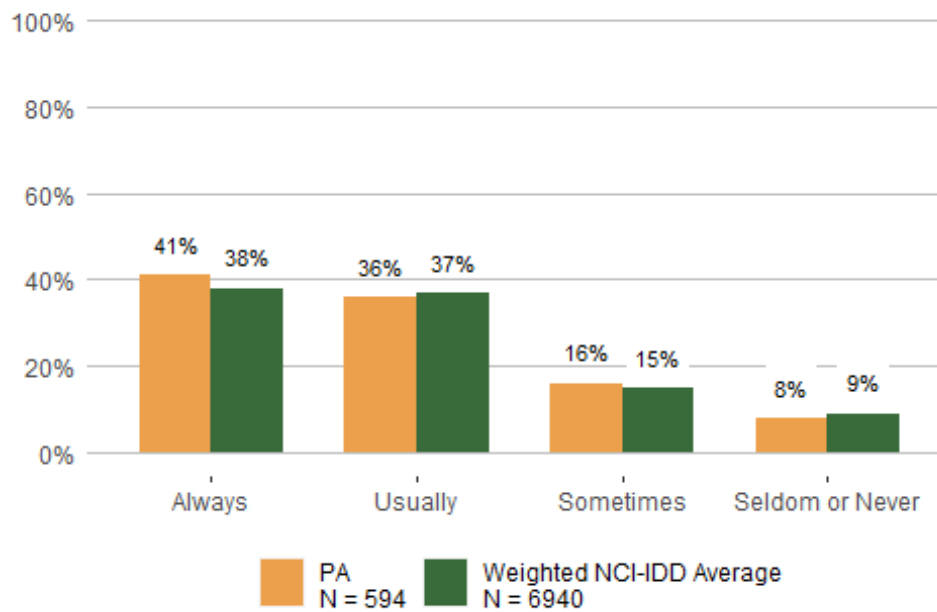


Table 26. Do you get enough information to take part in planning services for your family member?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	41%	36%	16%	8%	594
Weighted NCI-IDD Average	38%	37%	15%	9%	6940

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

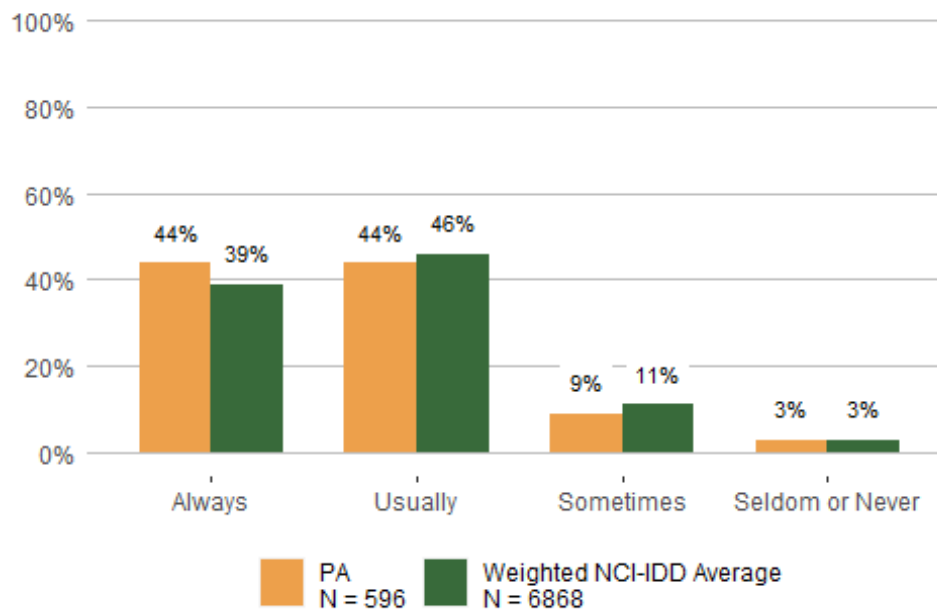


Table 27. Is the information you get about services and supports easy to understand?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	44%	44%	9%	3%	596
Weighted NCI-IDD Average	39%	46%	11%	3%	6868

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

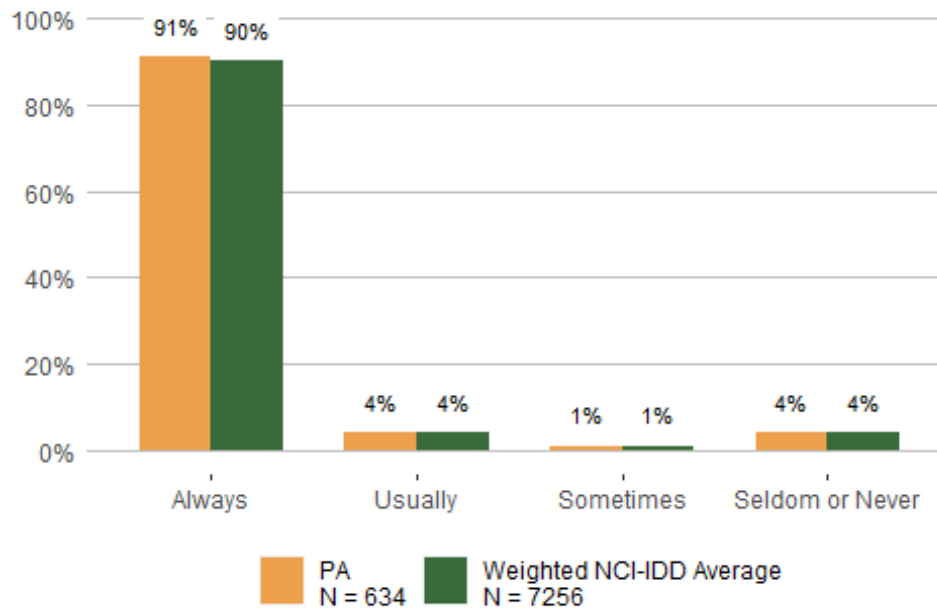


Table 28. Do you get information about services and supports in your preferred language?

New question in 2021-22

State	Always	Usually	Sometimes	Seldom or Never	N
PA	91%	4%	1%	4%	634
Weighted NCI-IDD Average	90%	4%	1%	4%	7256

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

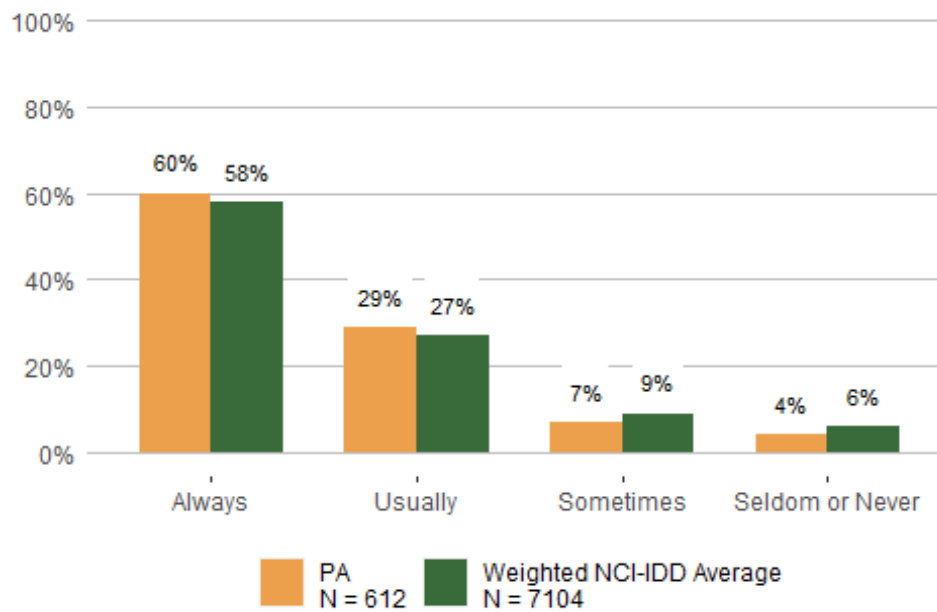


Table 29. Does the case manager/service coordinator listen to your family's choices and opinions?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	60%	29%	7%	4%	612
Weighted NCI-IDD Average	58%	27%	9%	6%	7104

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

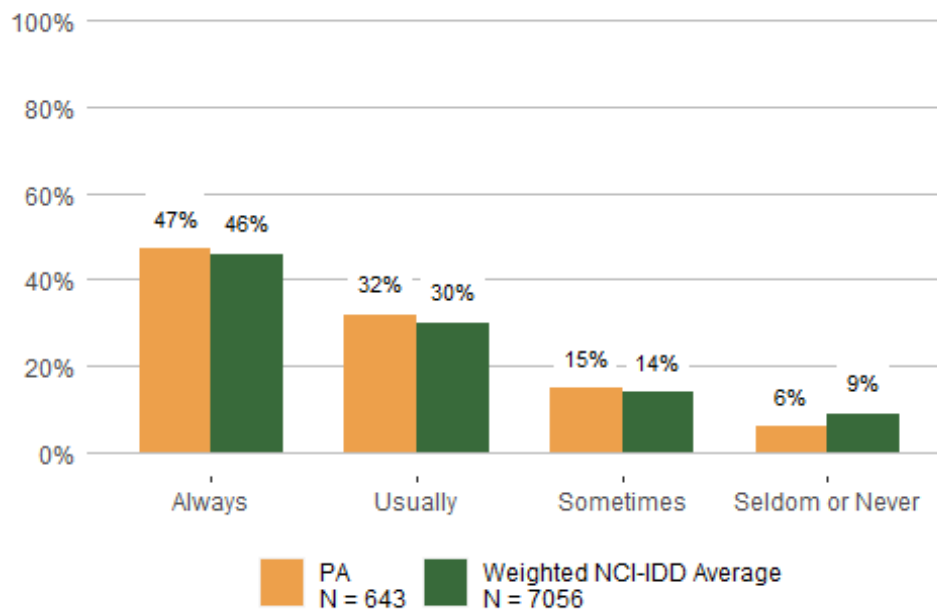


Table 30. Do staff or the residential agency keep you informed about how your family member is doing?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	47%	32%	15%	6%	643
Weighted NCI-IDD Average	46%	30%	14%	9%	7056

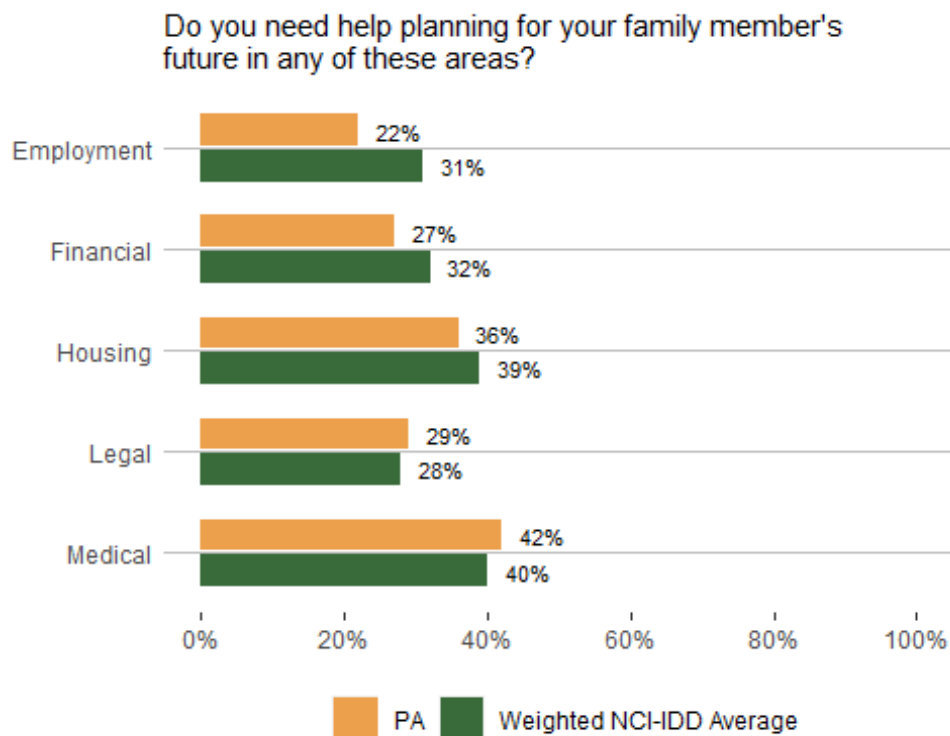


Table 31a. Do you need help planning for your family member's future in any of these areas?

Categories are not mutually exclusive, therefore N is not shown

State	Employment	Financial	Housing	Legal	Medical
PA	22%	27%	36%	29%	42%
Weighted NCI-IDD Average	31%	32%	39%	28%	40%

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

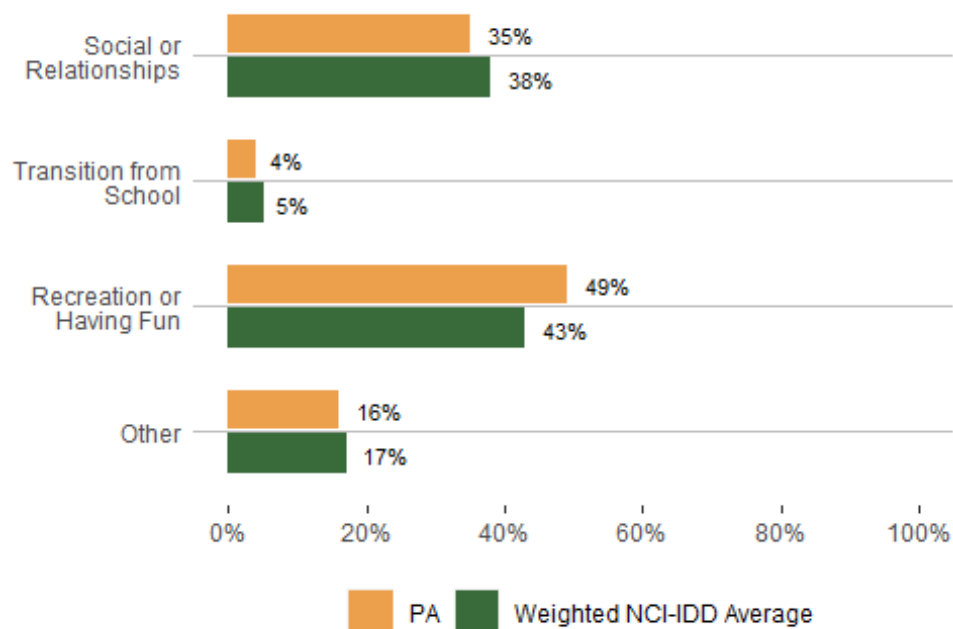


Table 31b. Do you need help planning for your family member's future in any of these areas?

Categories are not mutually exclusive, therefore N is not shown

State	Social or Relationships	Transition from School	Recreation or Having Fun	Other
PA	35%	4%	49%	16%
Weighted NCI-IDD Average	38%	5%	43%	17%

Has your family learned about alternatives to guardianship?

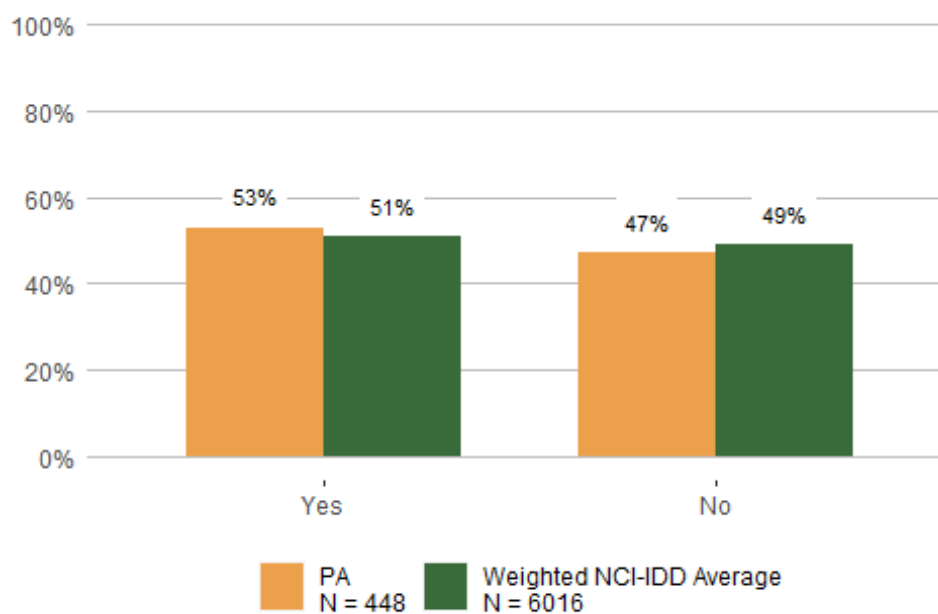


Table 32. Has your family learned about alternatives to guardianship?

State	Yes	No	N
PA	53%	47%	448
Weighted NCI-IDD Average	51%	49%	6016

Does your family member have a service plan?

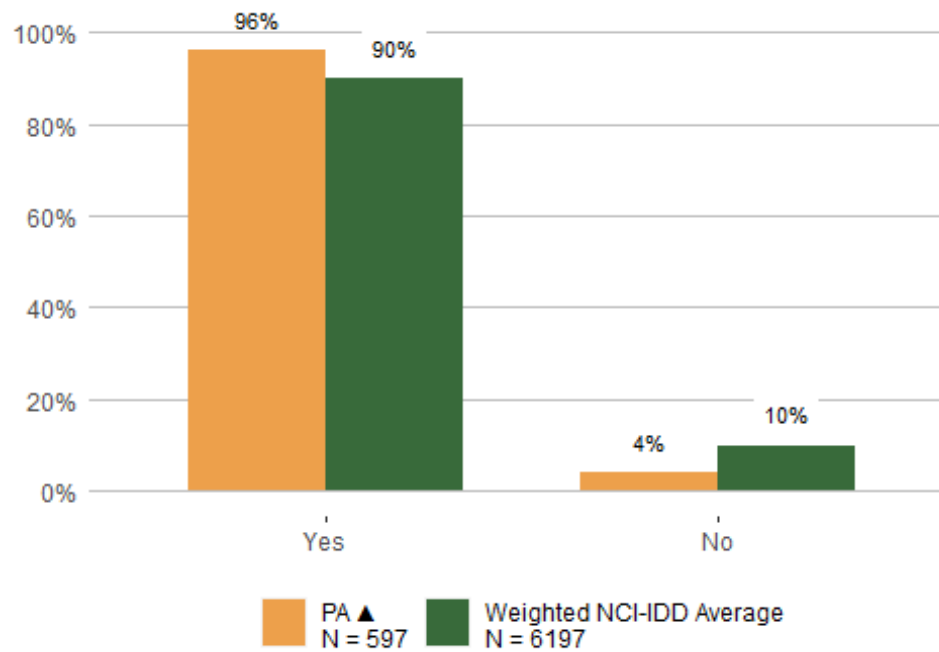


Table 33. Does your family member have a service plan?

State	Yes	No	N
PA ▲	96%	4%	597
Weighted NCI-IDD Average	90%	10%	6197

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

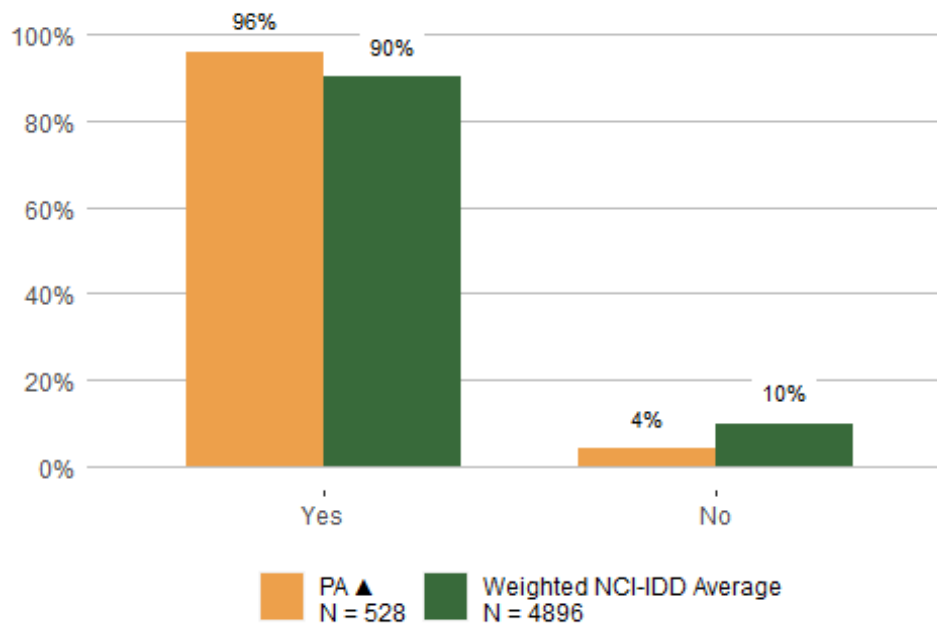


Table 34. Does the service plan include all the services and supports your family member needs?

State	Yes	No	N
PA ▲	96%	4%	528
Weighted NCI-IDD Average	90%	10%	4896

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

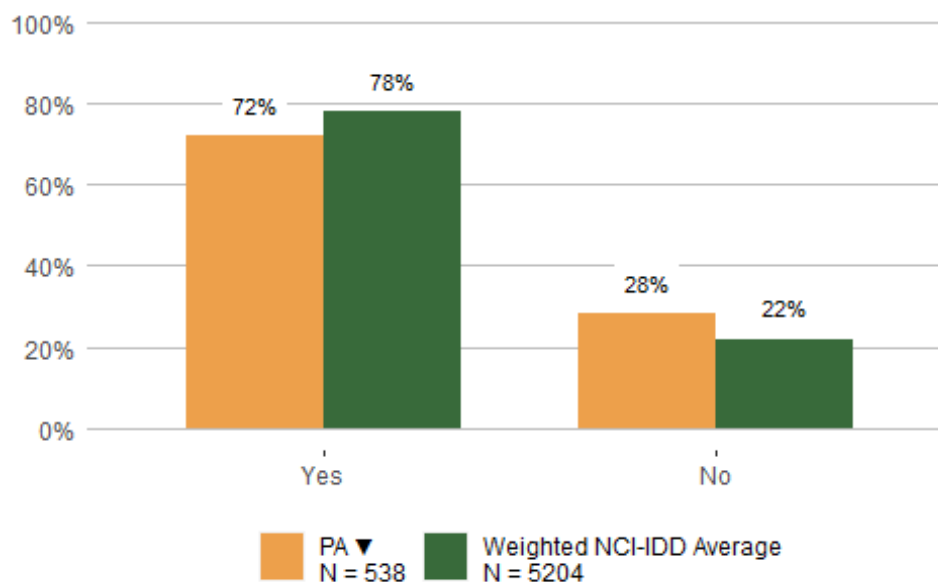


Table 35. Did you or someone else in your family (besides your family member with a disability) help make the service plan?

State	Yes	No	N
PA ▼	72%	28%	538
Weighted NCI-IDD Average	78%	22%	5204

Did your family member help make the service plan?

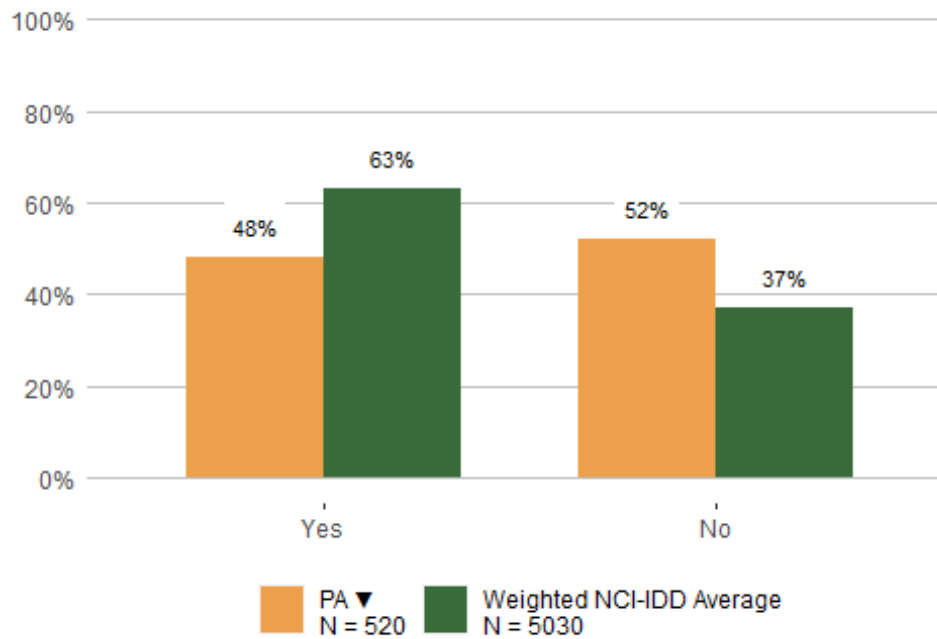


Table 36. Did your family member help make the service plan?

State	Yes	No	N
PA ▼	48%	52%	520
Weighted NCI-IDD Average	63%	37%	5030

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

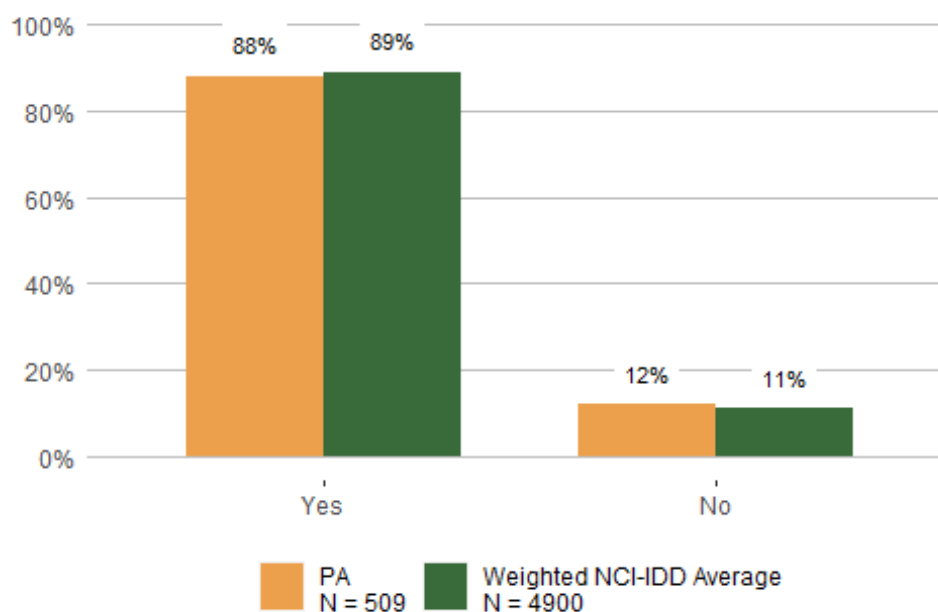


Table 37. Do you feel like your family had enough say or input in making the plan?
New question in 2021-22

State	Yes	No	N
PA	88%	12%	509
Weighted NCI-IDD Average	89%	11%	4900

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

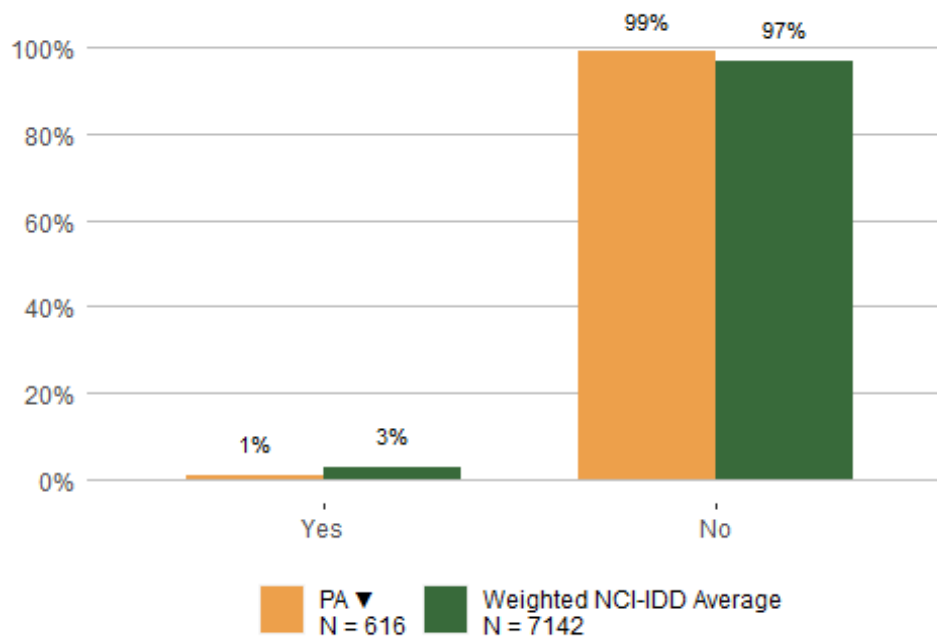


Table 38. Did your family member leave school services and begin adult services during the past 12 months?

State	Yes	No	N
PA ▼	1%	99%	616
Weighted NCI-IDD Average	3%	97%	7142

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

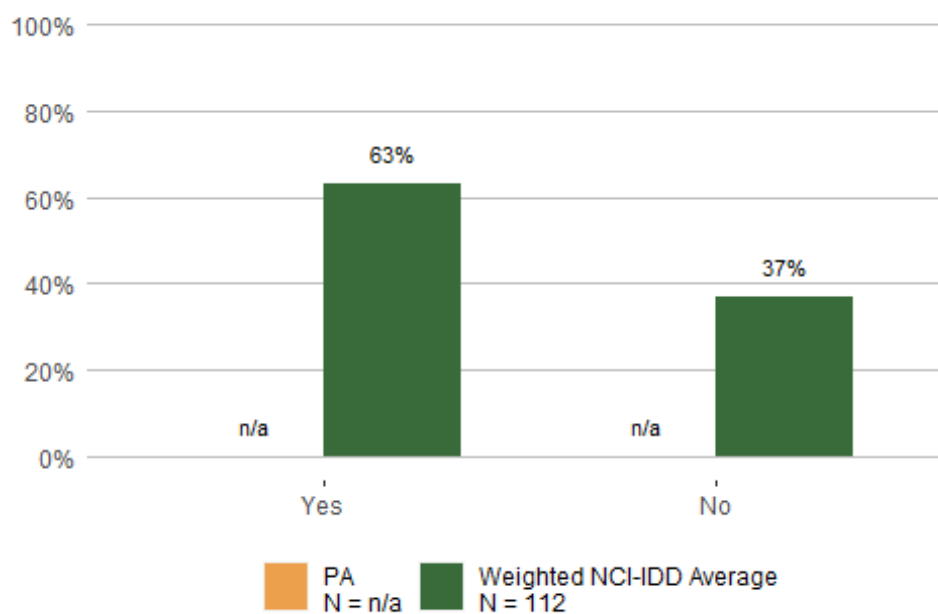


Table 39. If your family member left school services during the past year, did they have a transition plan?

State	Yes	No	N
PA	n/a	n/a	n/a
Weighted NCI-IDD Average	63%	37%	112

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

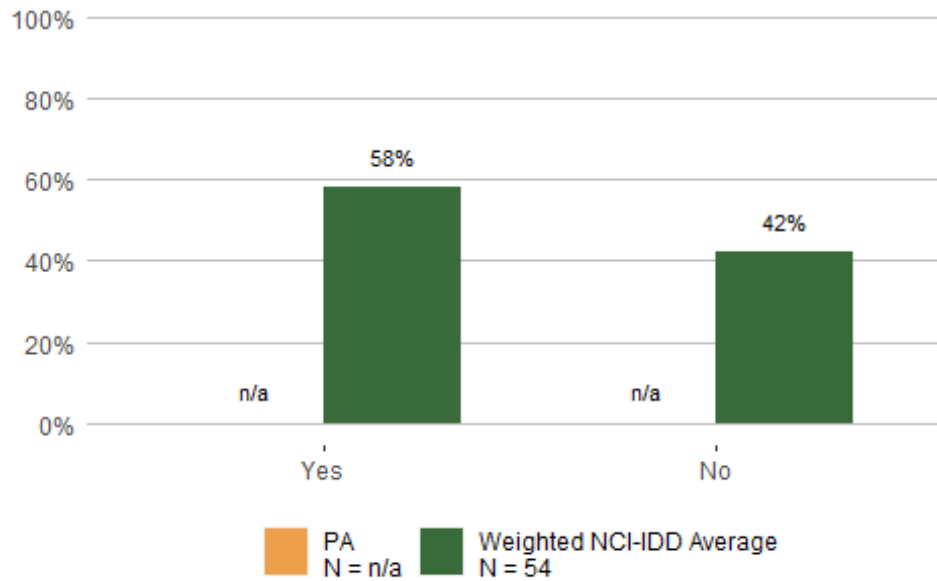


Table 40. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?

State	Yes	No	N
PA	n/a	n/a	n/a
Weighted NCI-IDD Average	58%	42%	54

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 ISP?

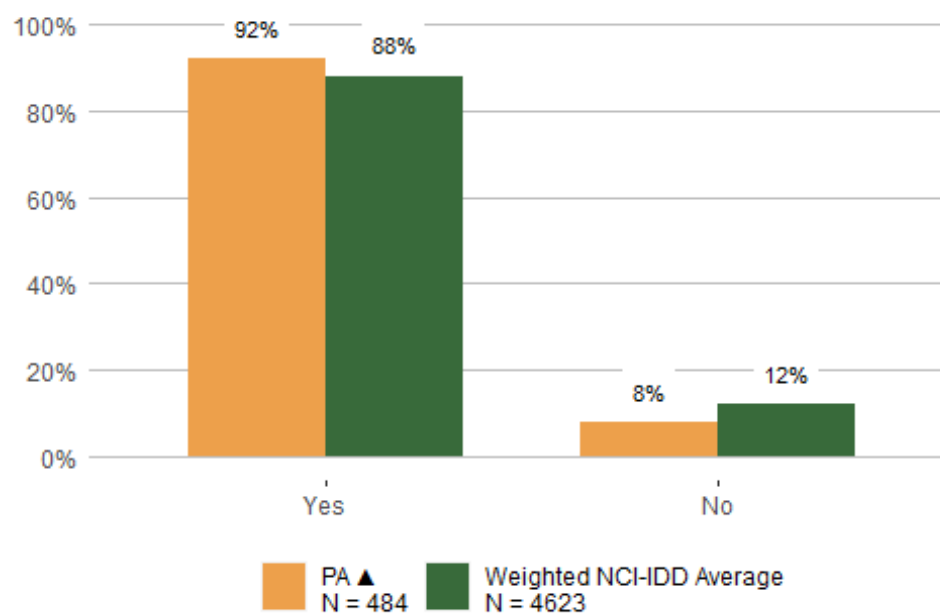


Table 41. Does your family member get all the services listed in the ISP?

State	Yes	No	N
PA ▲	92%	8%	484
Weighted NCI-IDD Average	88%	12%	4623

Does your family get the supports and services it needs?

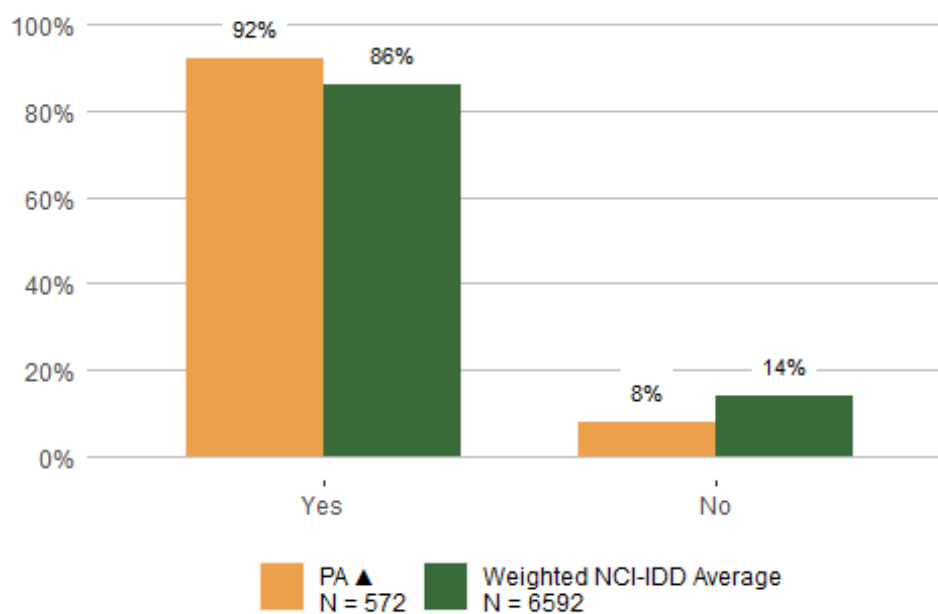


Table 42. Does your family get the supports and services it needs?

State	Yes	No	N
PA ▲	92%	8%	572
Weighted NCI-IDD Average	86%	14%	6592

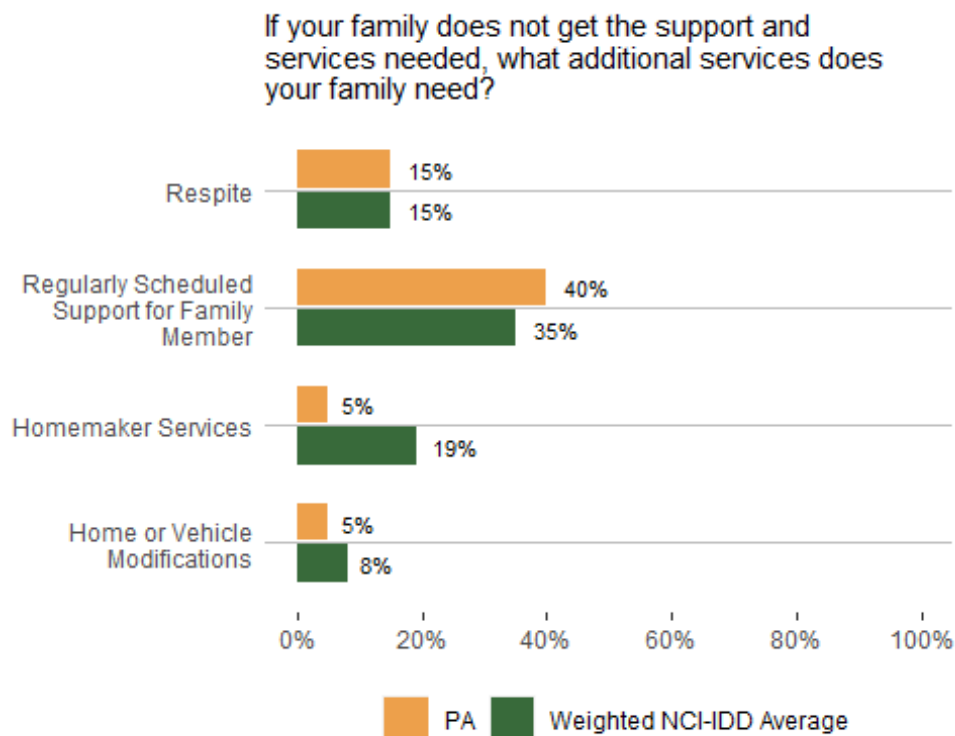


Table 43a. If your family does not get the support and services needed, what additional services does your family need?

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

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications
PA	15%	40%	5%	5%
Weighted NCI-IDD Average	15%	35%	19%	8%

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

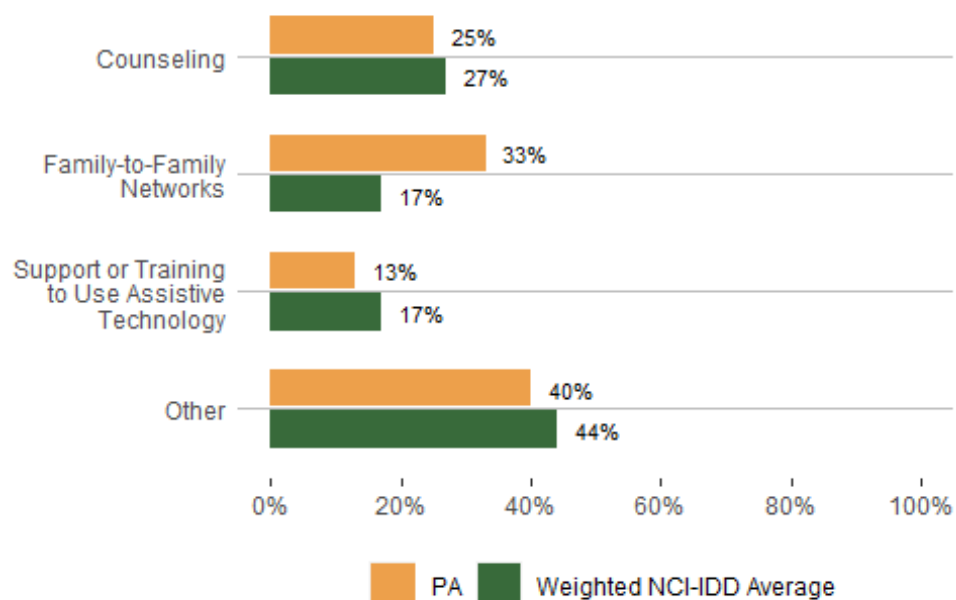


Table 43b. If your family does not get the support and services needed, what additional services does your family need? (continued)

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

State	Counseling	Family-to-Family Networks	Support or Training to Use Assistive Technology	Other
PA	25%	33%	13%	40%
Weighted NCI-IDD Average	27%	17%	17%	44%

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

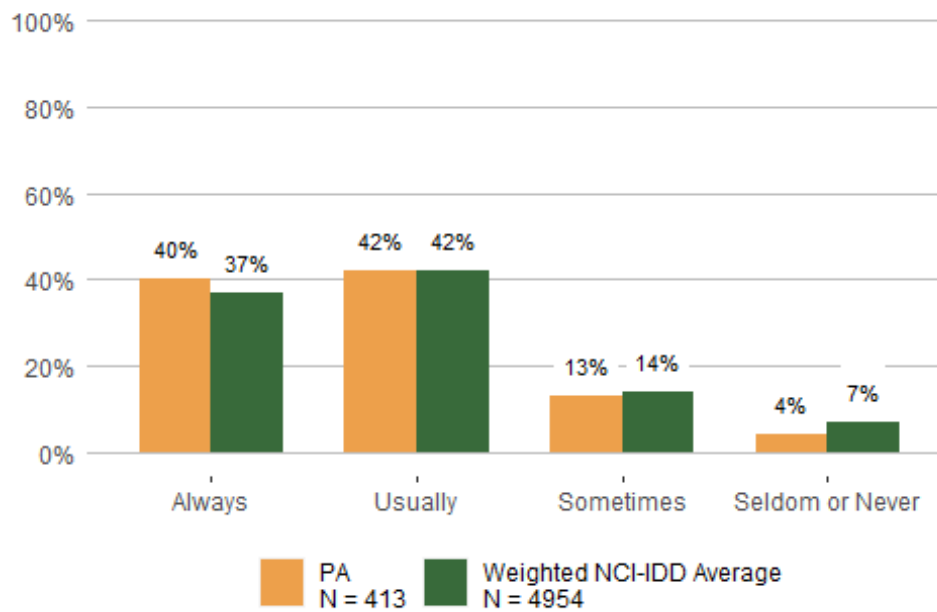


Table 44. Do services and supports change when your family's needs change?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	40%	42%	13%	4%	413
Weighted NCI-IDD Average	37%	42%	14%	7%	4954

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)

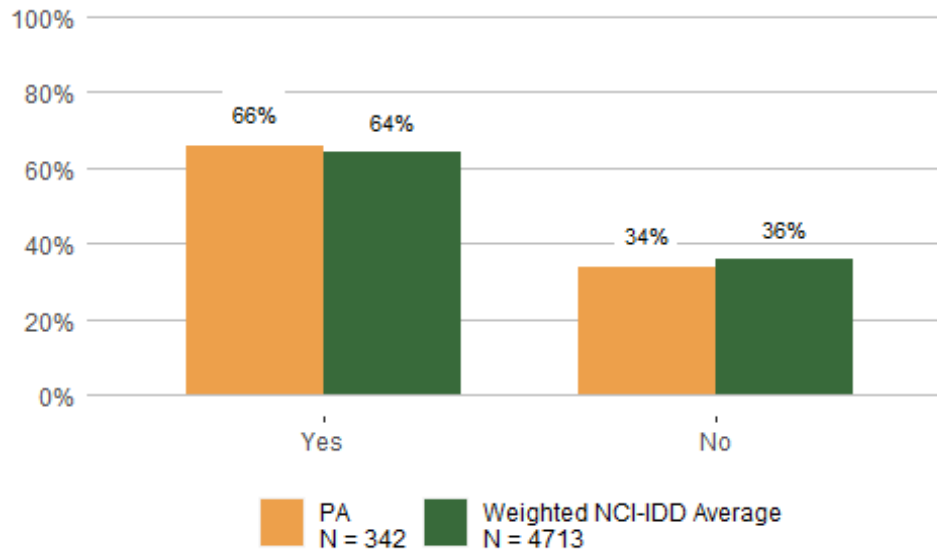


Table 45. Does your family member have enough supports to work or volunteer in the community? (These types of supports might include support workers, community resources, transportation)

State	Yes	No	N
PA	66%	34%	342
Weighted NCI-IDD Average	64%	36%	4713

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

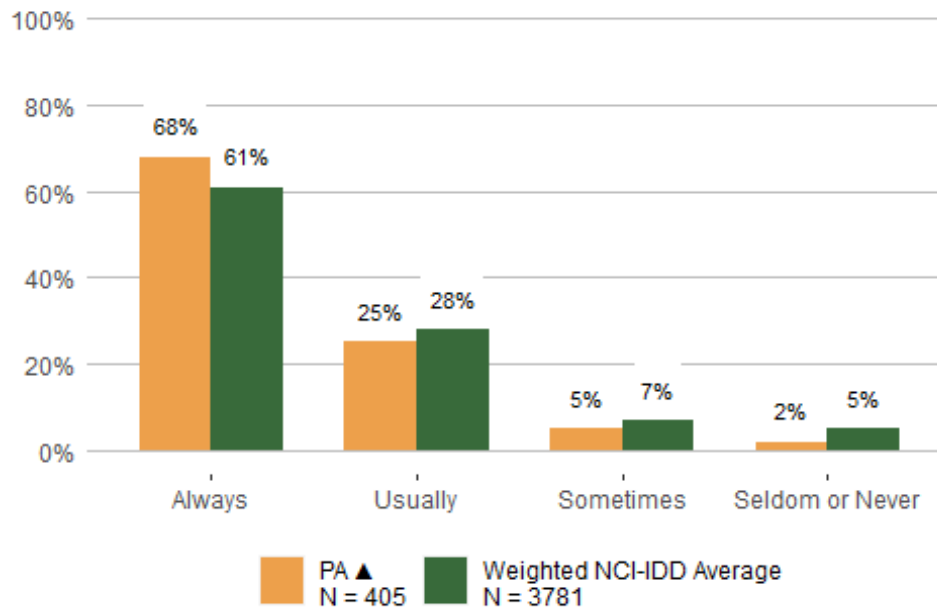


Table 46. Does your family member have the special equipment or accommodations they need?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	68%	25%	5%	2%	405
Weighted NCI-IDD Average	61%	28%	7%	5%	3781

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

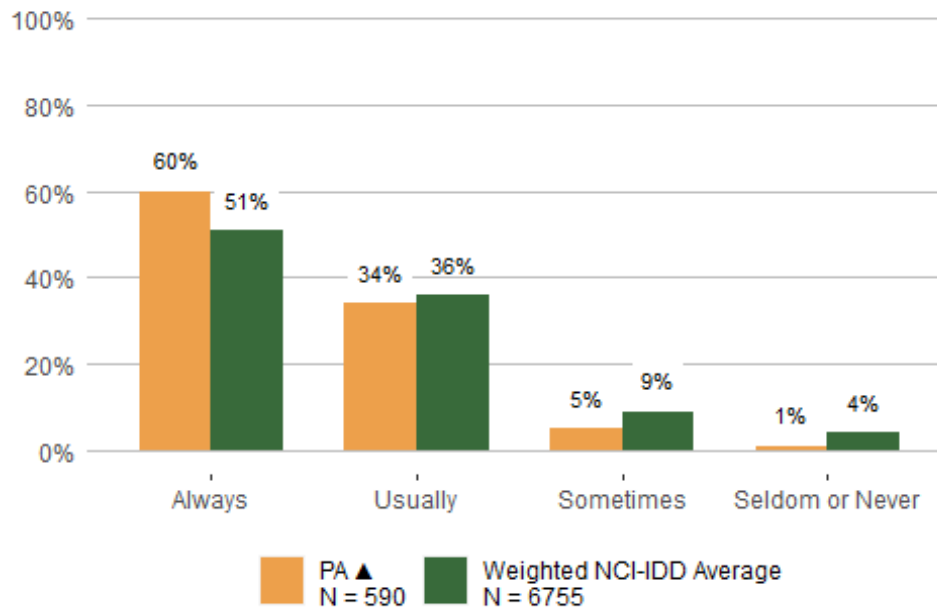


Table 47. Are you or your family member able to contact their support workers when you want?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	60%	34%	5%	1%	590
Weighted NCI-IDD Average	51%	36%	9%	4%	6755

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

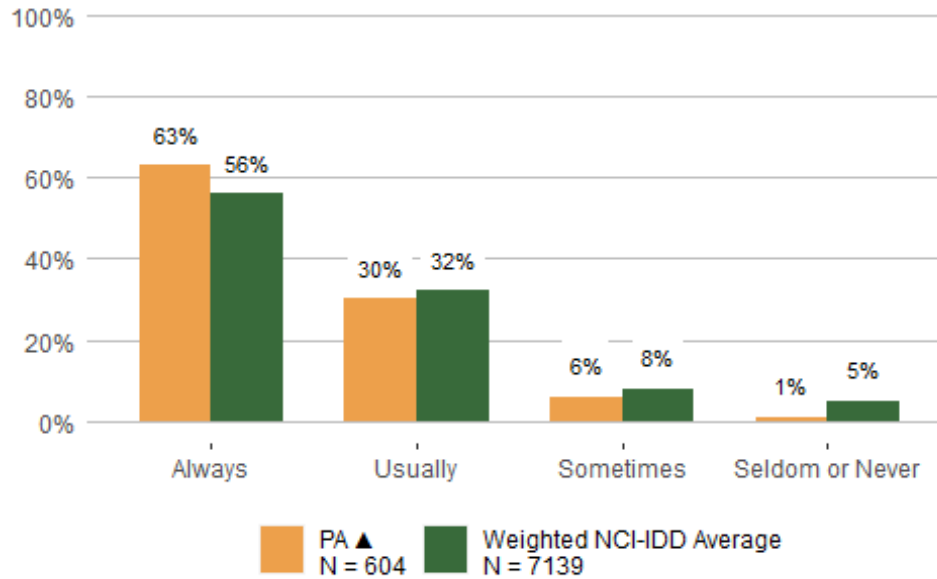


Table 48. Are you or your family member able to contact their case manager/service coordinator when you want?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	63%	30%	6%	1%	604
Weighted NCI-IDD Average	56%	32%	8%	5%	7139

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

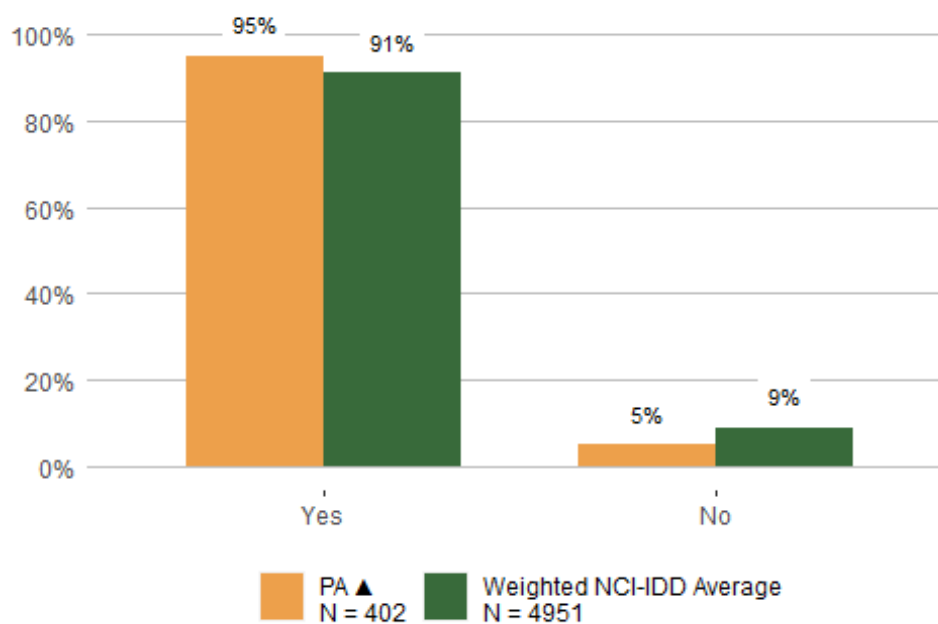


Table 49. Do service providers for your family member work together to provide support?

State	Yes	No	N
PA ▲	95%	5%	402
Weighted NCI-IDD Average	91%	9%	4951

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

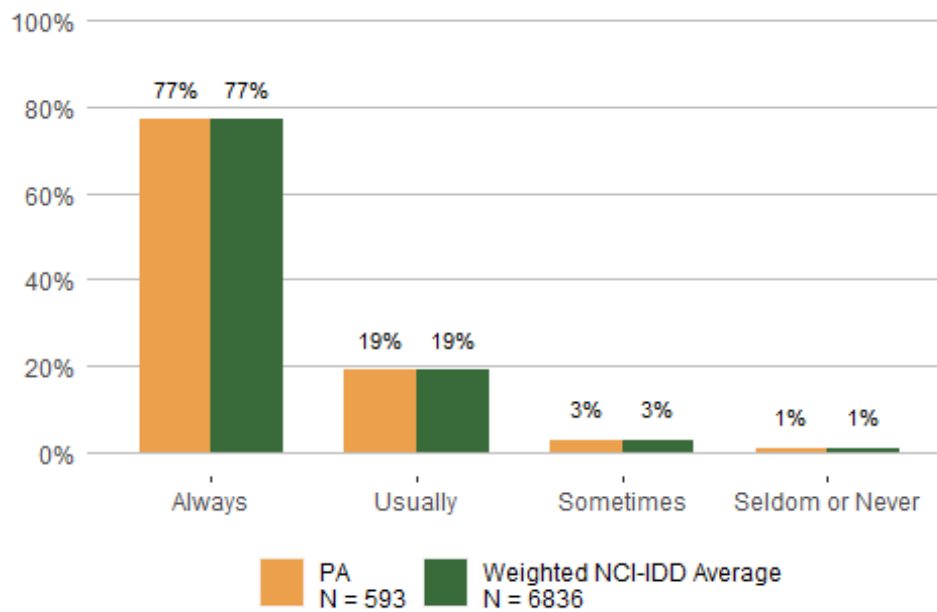


Table 50. Are services delivered in a way that is respectful of your family's culture?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	77%	19%	3%	1%	593
Weighted NCI-IDD Average	77%	19%	3%	1%	6836

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

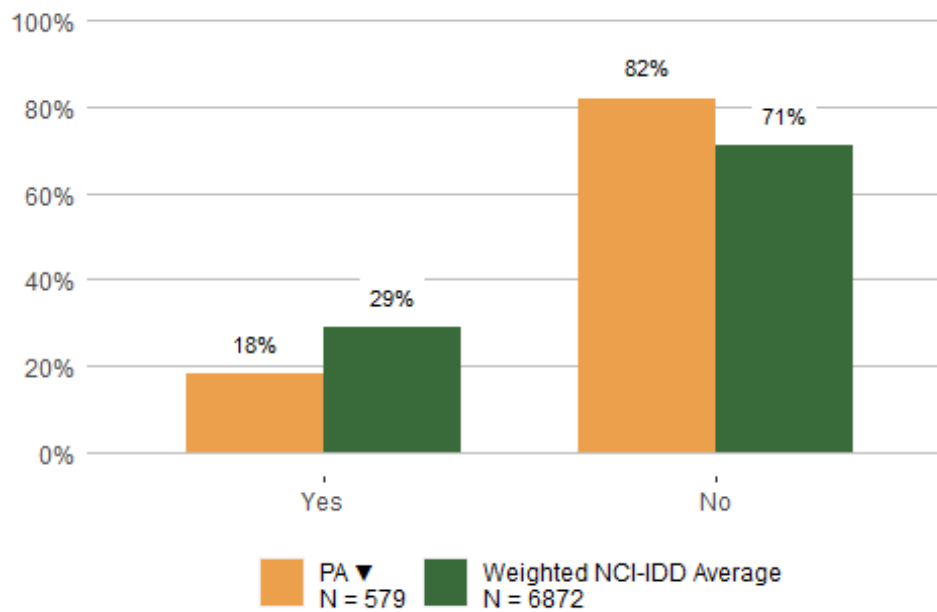


Table 51. Does your family member use technology in their everyday life to help them do things on their own?

New question in 2021-22

State	Yes	No	N
PA ▼	18%	82%	579
Weighted NCI-IDD Average	29%	71%	6872

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

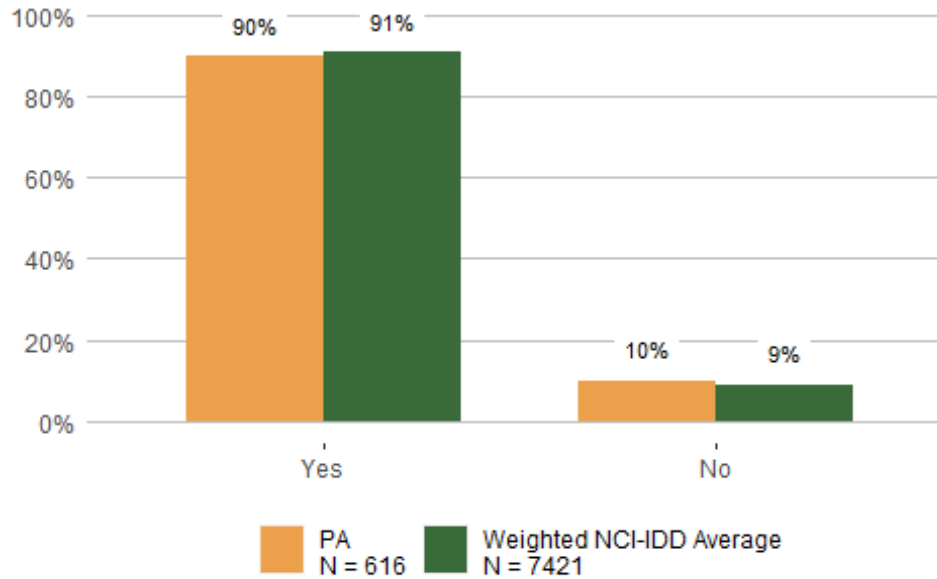


Table 52. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?

New question in 2021-22

State	Yes	No	N
PA	90%	10%	616
Weighted NCI-IDD Average	91%	9%	7421

How well does the internet work in your home?

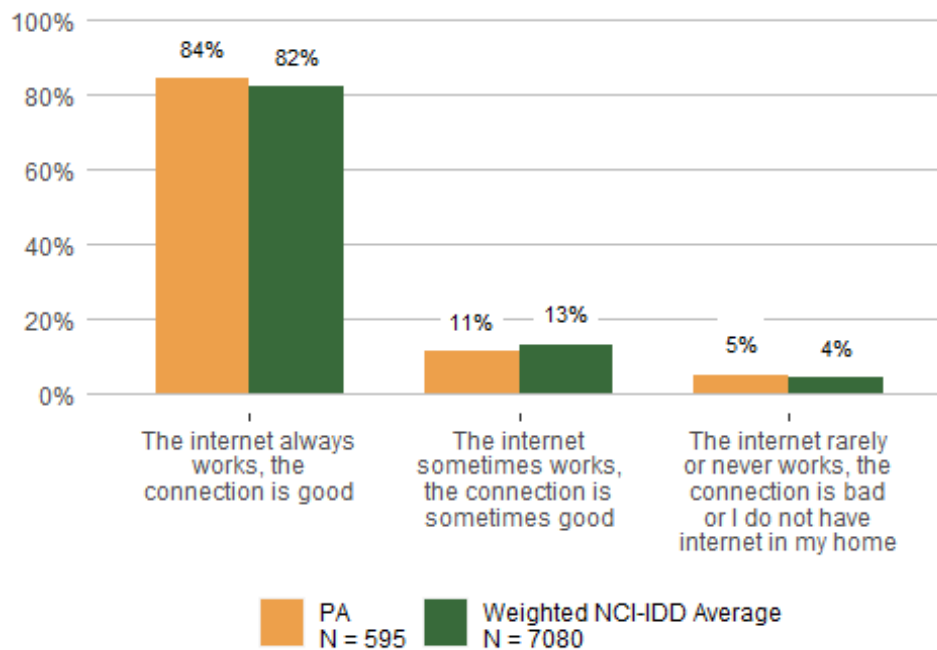


Table 53. How well does the internet work in your home?

New question in 2021-22

State	The internet always works, the connection is good	The internet sometimes works, 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	84%	11%	5%	595
Weighted NCI-IDD Average	82%	13%	4%	7080

Workforce (New in 2021-22)

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?

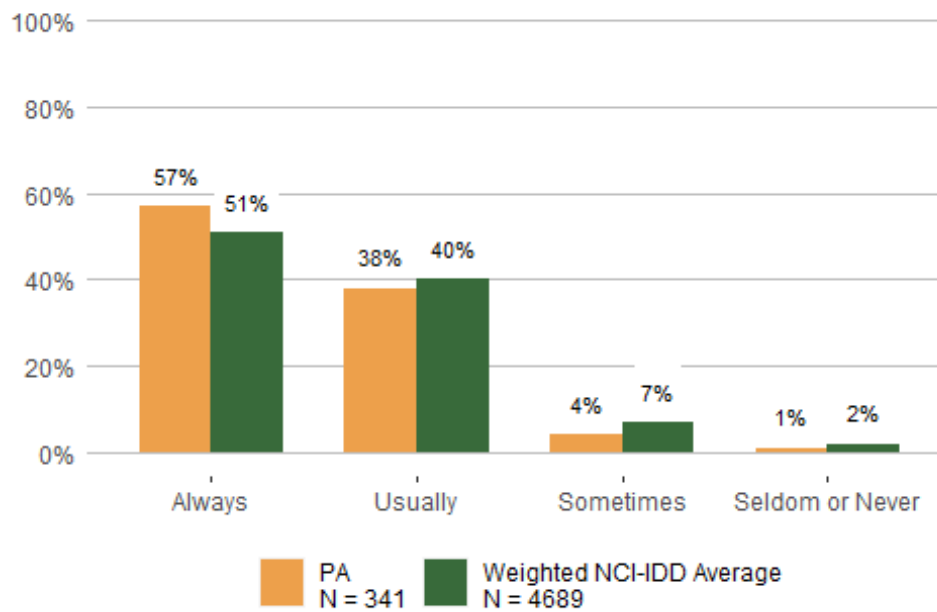


Table 54. Do support workers come and go when they are supposed to?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	57%	38%	4%	1%	341
Weighted NCI-IDD Average	51%	40%	7%	2%	4689

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

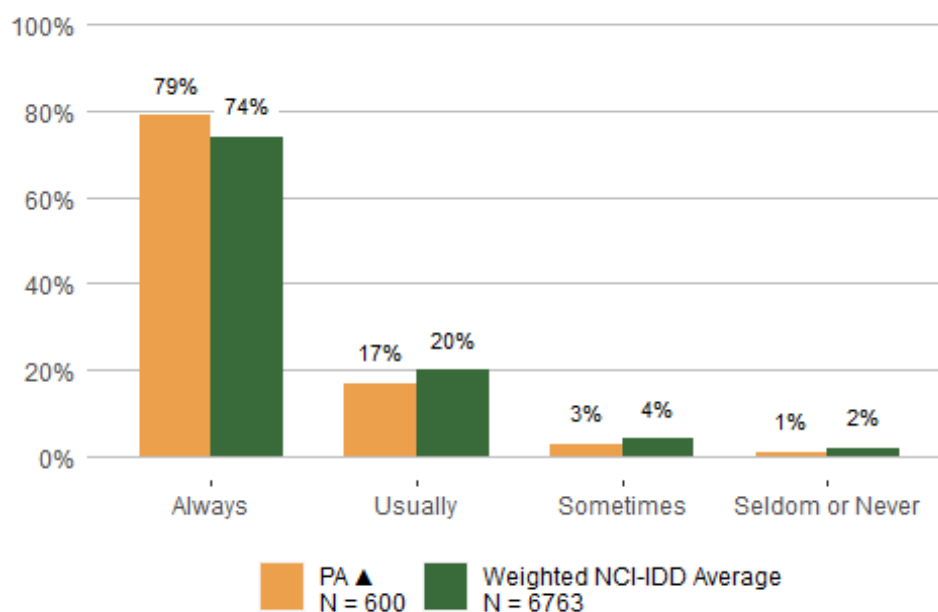


Table 55. Do support workers speak to you in a way you understand?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	79%	17%	3%	1%	600
Weighted NCI-IDD Average	74%	20%	4%	2%	6763

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?

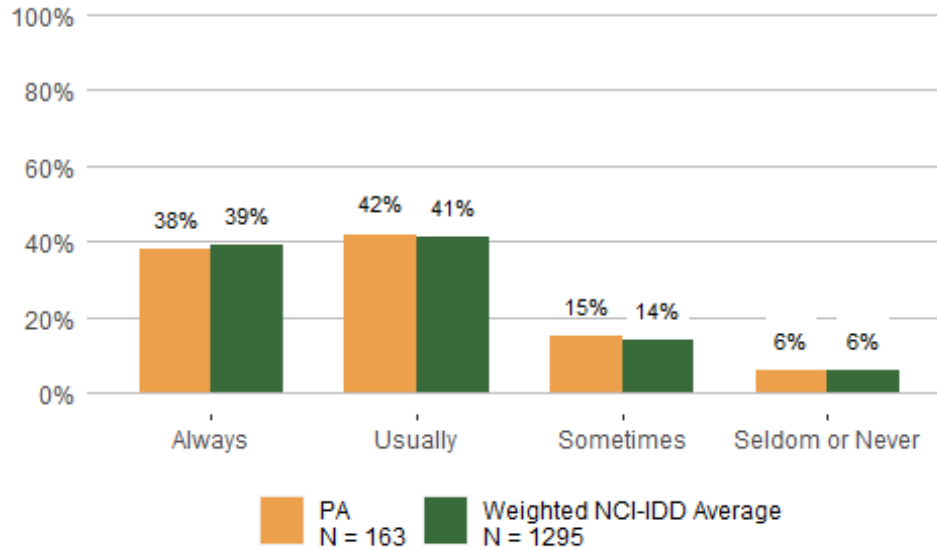


Table 56. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	38%	42%	15%	6%	163
Weighted NCI-IDD Average	39%	41%	14%	6%	1295

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

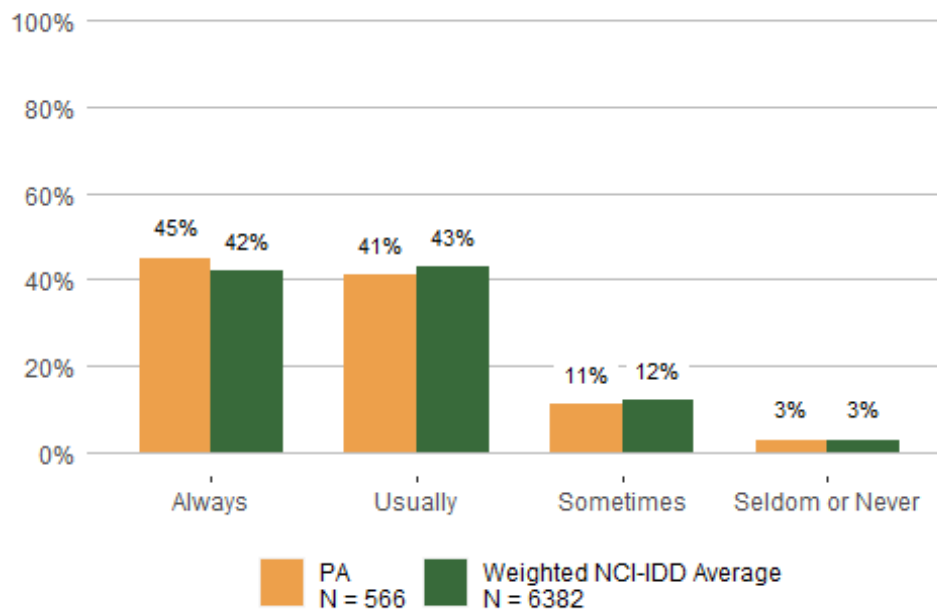


Table 57. Do support workers have the right information and skills to meet your family's needs?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	45%	41%	11%	3%	566
Weighted NCI-IDD Average	42%	43%	12%	3%	6382

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

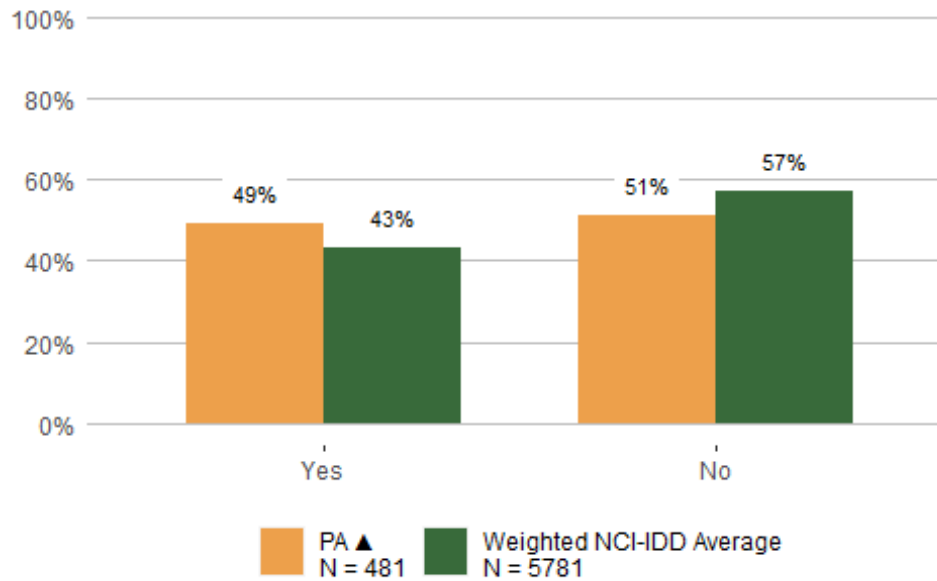


Table 58. Do your family member's support workers change too often? Is there too much "turnover" of support workers?

New question in 2021-22

State	Yes	No	N
PA ▲	49%	51%	481
Weighted NCI-IDD Average	43%	57%	5781

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

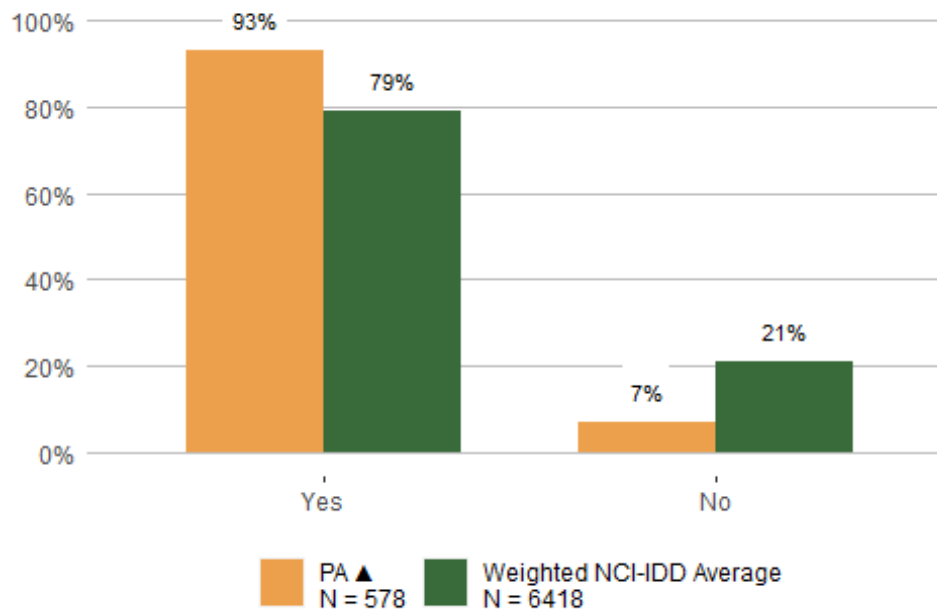


Table 59. Is there always a staff person available to support your family member when support is needed?

New question in 2021-22

State	Yes	No	N
PA ▲	93%	7%	578
Weighted NCI-IDD Average	79%	21%	6418

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

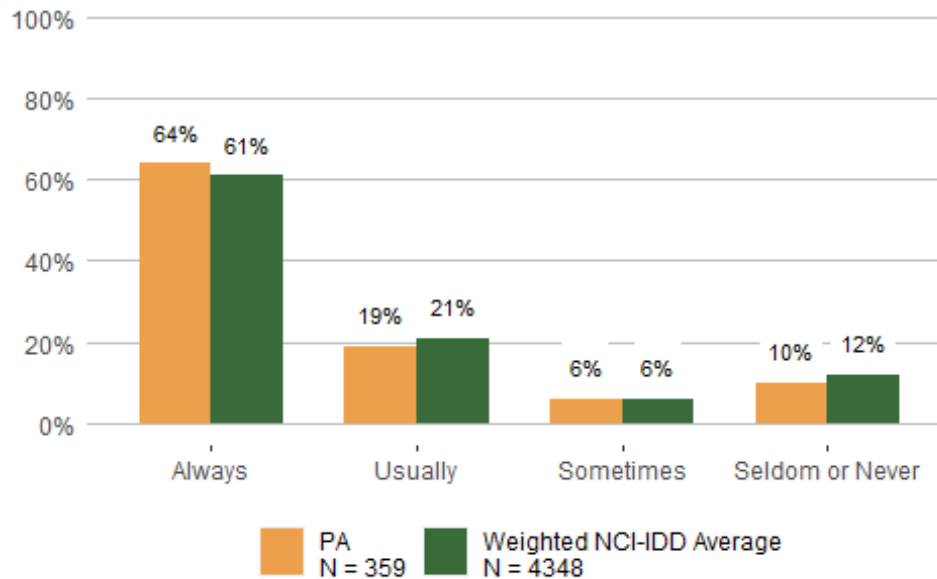


Table 60. Can someone in your family choose or change the provider agency that provides your family member's services?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	64%	19%	6%	10%	359
Weighted NCI-IDD Average	61%	21%	6%	12%	4348

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

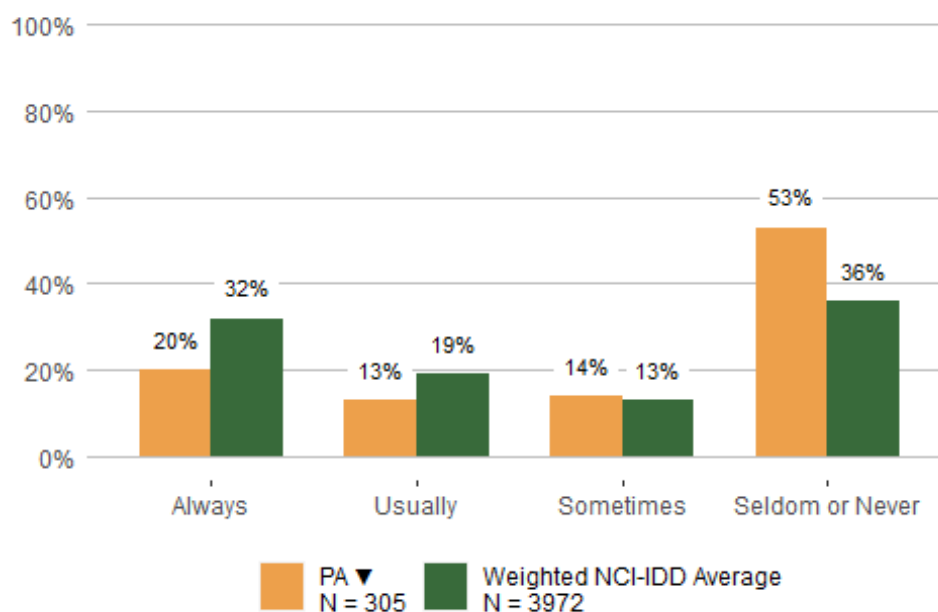


Table 61. Can someone in your family choose or change your family member's support workers?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▼	20%	13%	14%	53%	305
Weighted NCI-IDD Average	32%	19%	13%	36%	3972

Can someone in your family directly manage support staff?

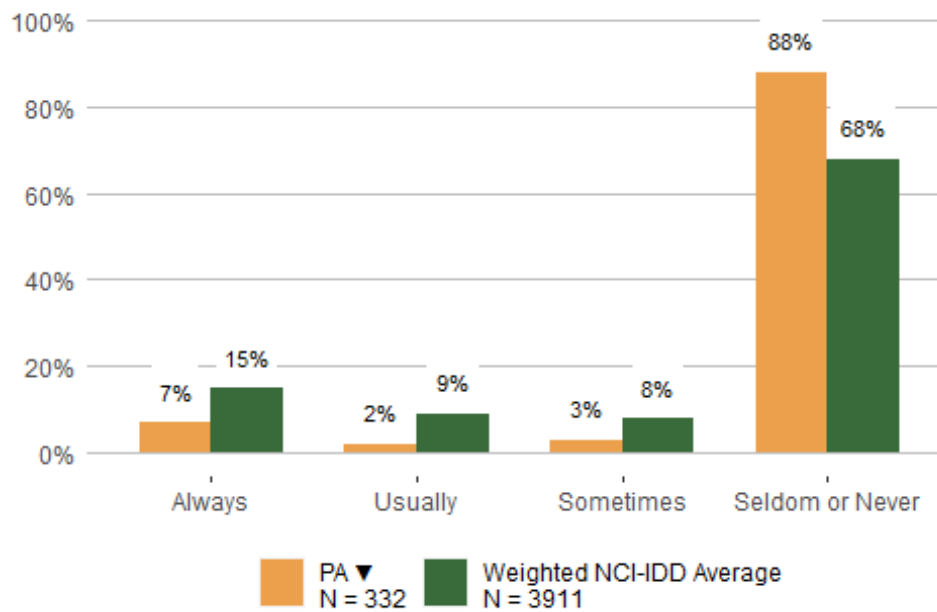


Table 62. Can someone in your family directly manage support staff?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▼	7%	2%	3%	88%	332
Weighted NCI-IDD Average	15%	9%	8%	68%	3911

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

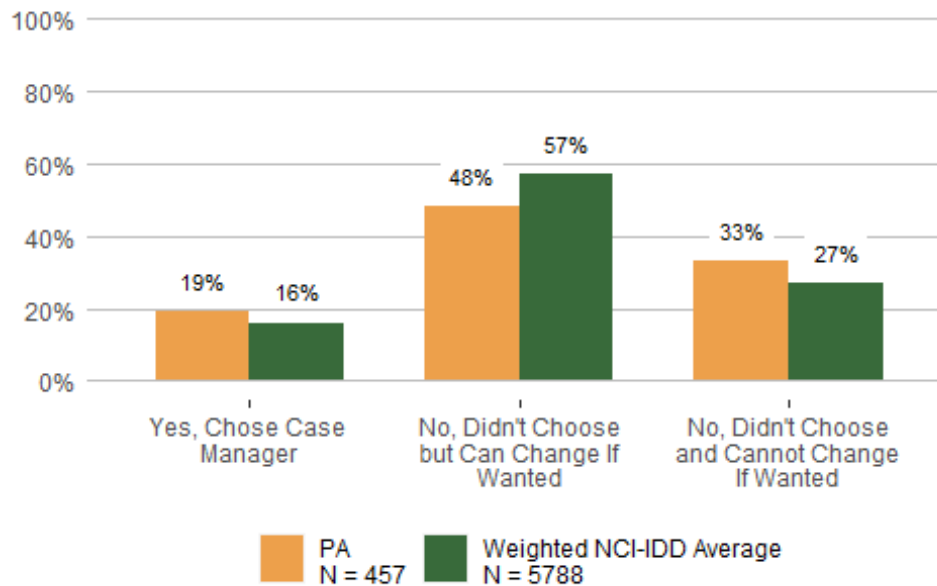


Table 63. Did you, your family member, or someone else in your family choose your family member's case manager?

State	Yes, Chose Case Manager	No, Didn't Choose but Can Change If Wanted	No, Didn't Choose and Cannot Change If Wanted	N
PA	19%	48%	33%	457
Weighted NCI-IDD Average	16%	57%	27%	5788

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.

Does your family member do things in the community?

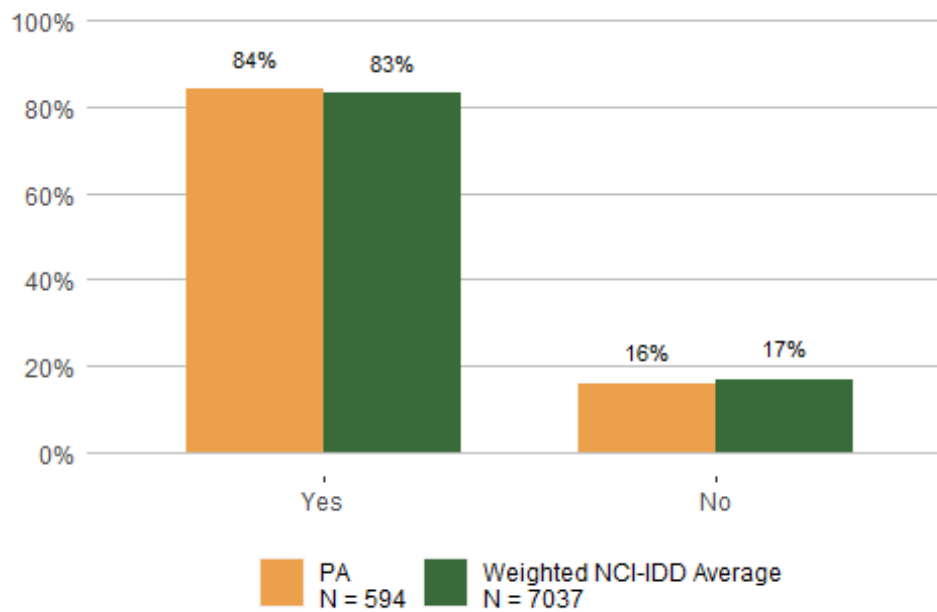


Table 64. Does your family member do things in the community?

State	Yes	No	N
PA	84%	16%	594
Weighted NCI-IDD Average	83%	17%	7037

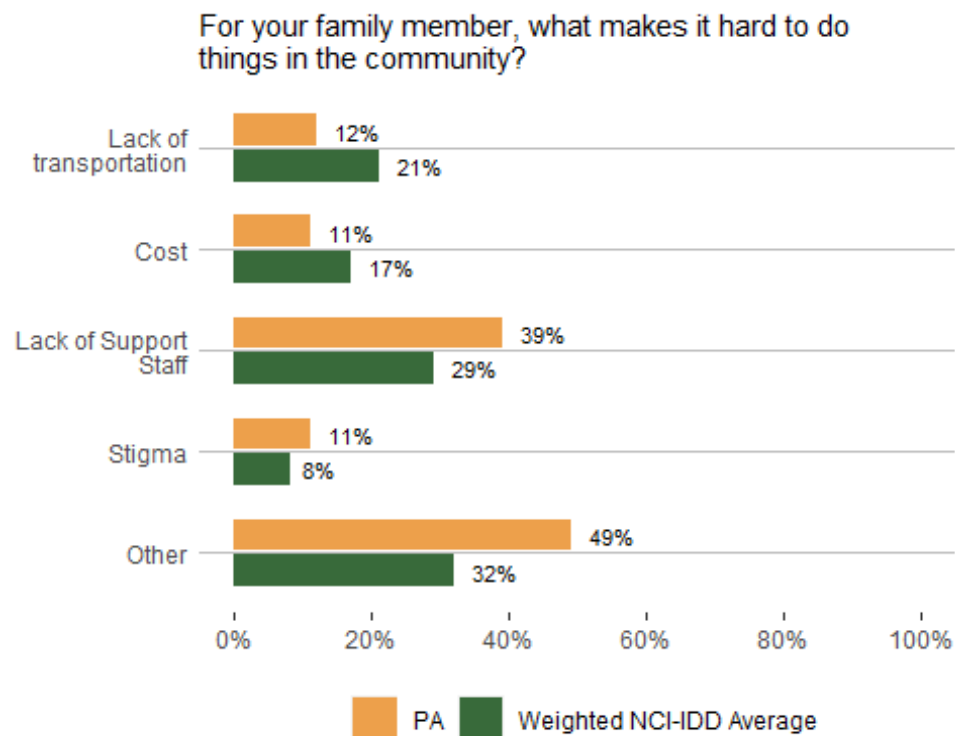


Table 65. For your family member, what makes it hard to do things in the community?

State	Lack of transportation	Cost	Lack of Support Staff	Stigma	Other
PA	12%	11%	39%	11%	49%
Weighted NCI-IDD Average	21%	17%	29%	8%	32%

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

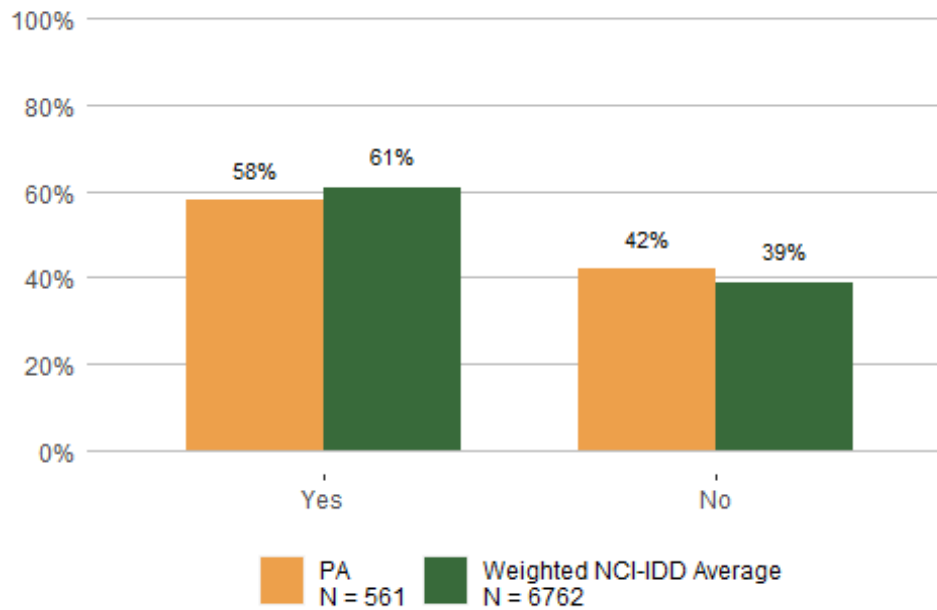


Table 66. Does your family member have friends other than paid support workers or family?

State	Yes	No	N
PA	58%	42%	561
Weighted NCI-IDD Average	61%	39%	6762

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

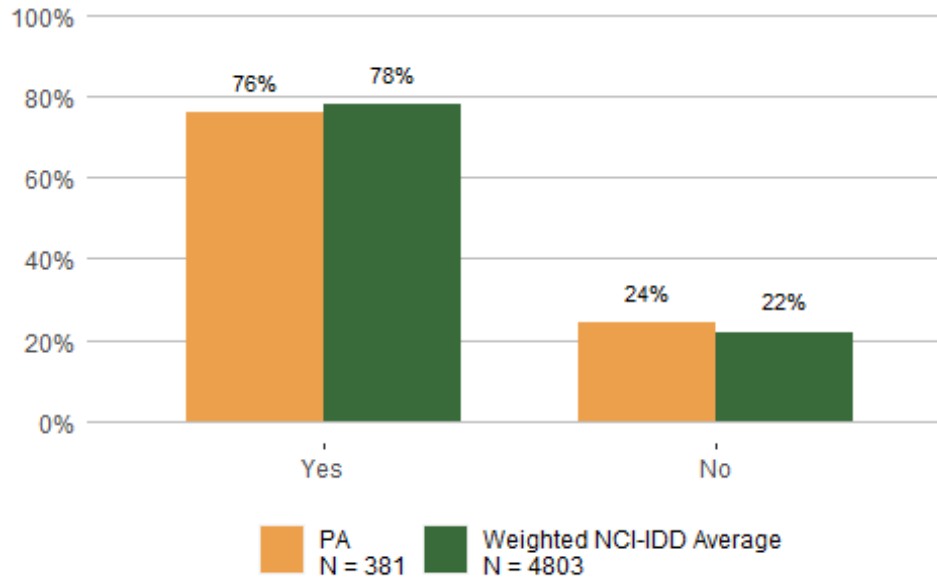


Table 67. In your community, are there resources or support that your family member can use that are not provided by the I/DD agency?

State	Yes	No	N
PA	76%	24%	381
Weighted NCI-IDD Average	78%	22%	4803

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

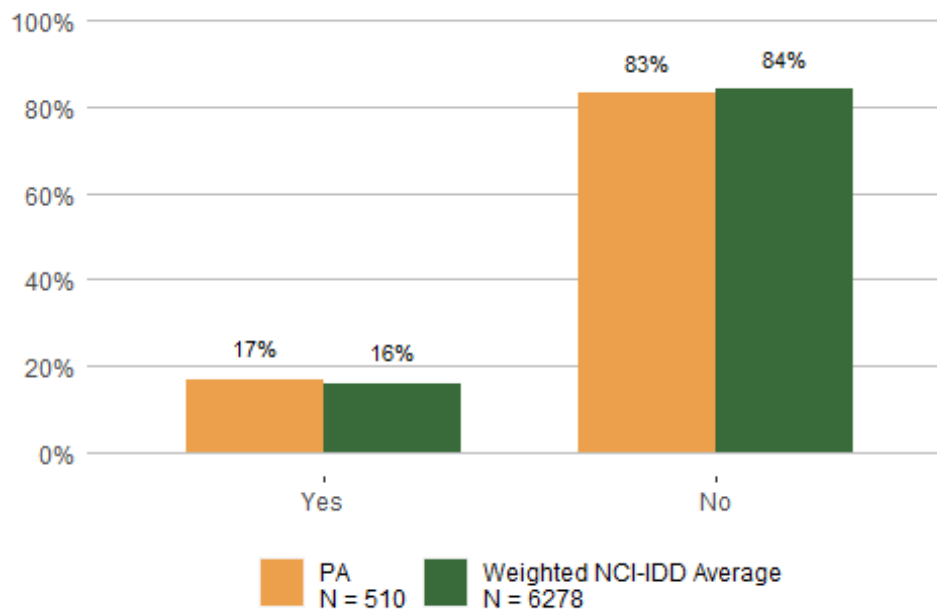


Table 68. Does your family take part in any family-to-family networks in your community?

State	Yes	No	N
PA	17%	83%	510
Weighted NCI-IDD Average	16%	84%	6278

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?

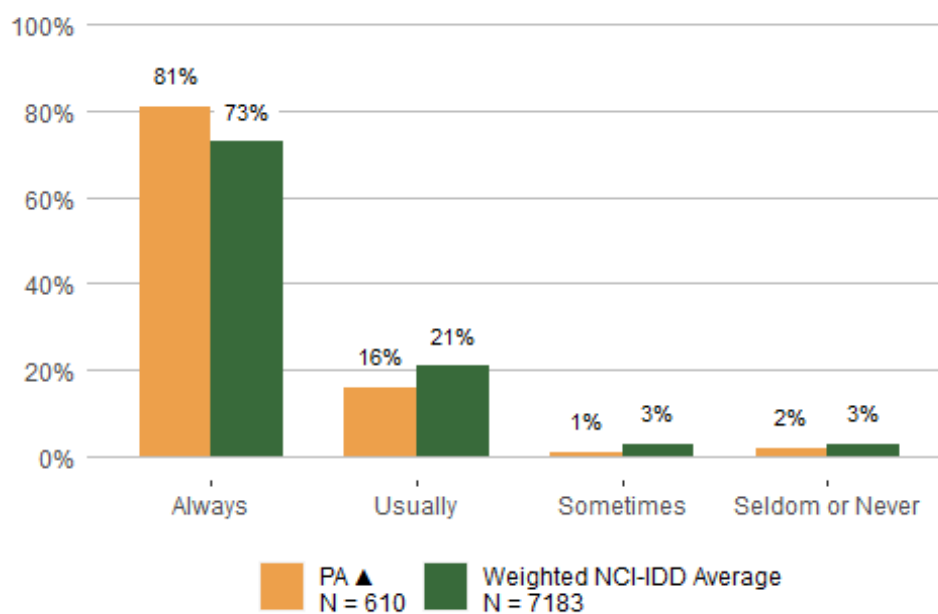


Table 69. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?

New question in 2021-22

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	81%	16%	1%	2%	610
Weighted NCI-IDD Average	73%	21%	3%	3%	7183

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

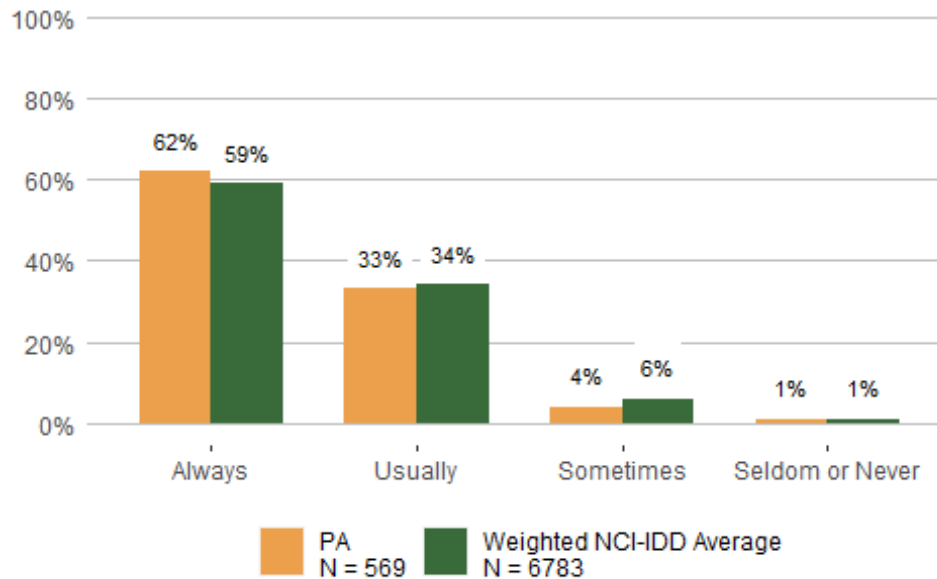


Table 70. Does your family member's primary care provider understand your family member's needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	62%	33%	4%	1%	569
Weighted NCI-IDD Average	59%	34%	6%	1%	6783

Can your family member go to the dentist when needed?

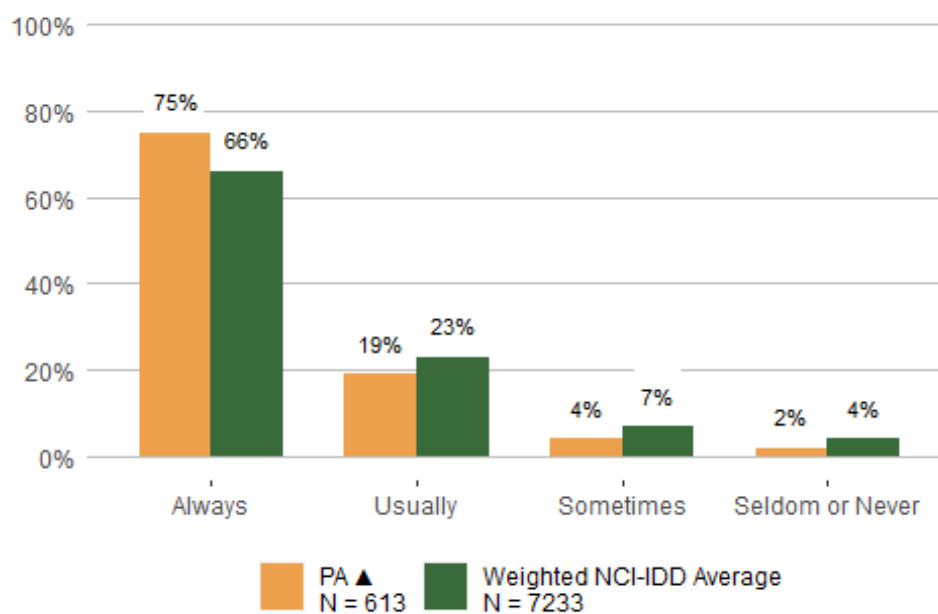


Table 71. Can your family member go to the dentist when needed?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	75%	19%	4%	2%	613
Weighted NCI-IDD Average	66%	23%	7%	4%	7233

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

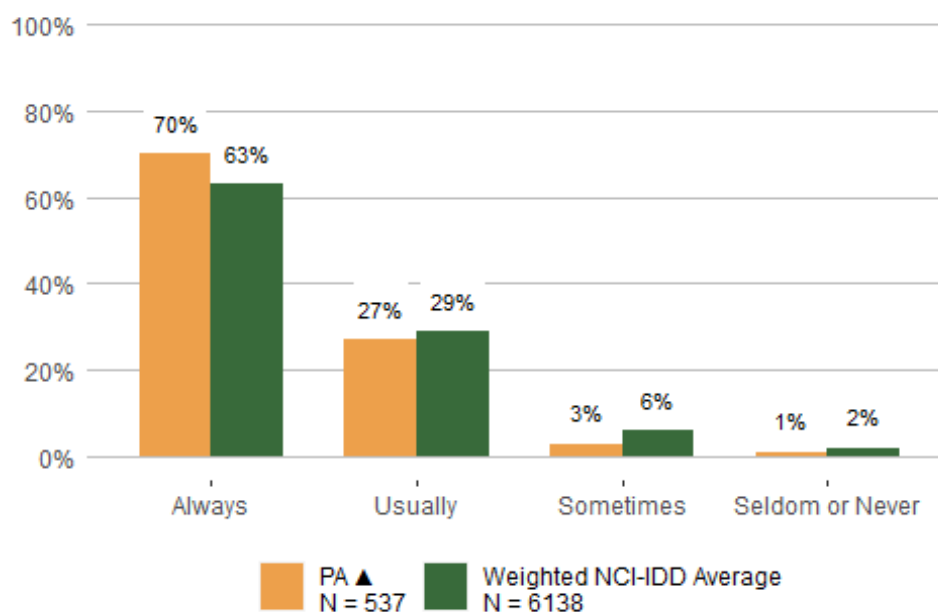


Table 72. Does your family member's dentist understand your family member's needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	70%	27%	3%	1%	537
Weighted NCI-IDD Average	63%	29%	6%	2%	6138

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

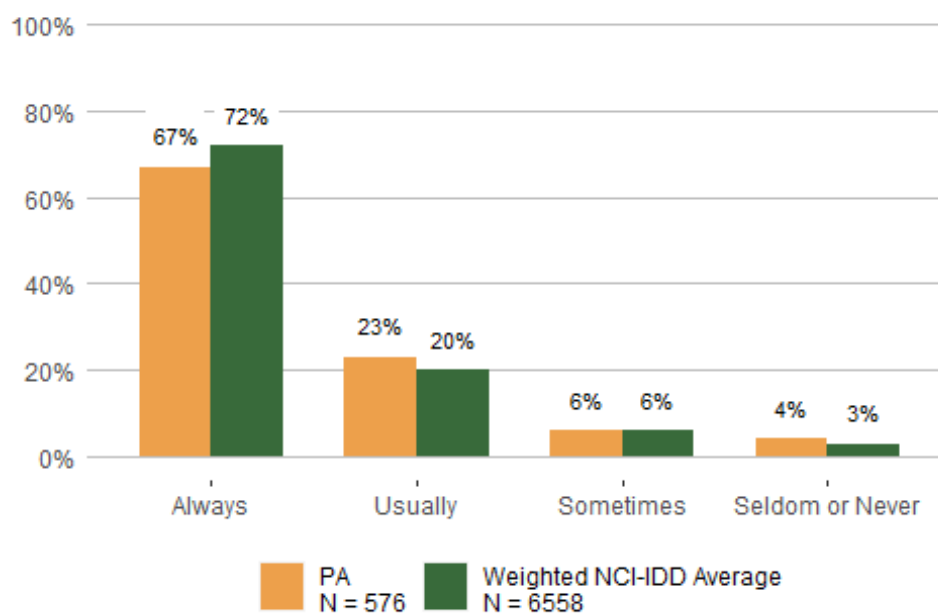


Table 73. If your family member takes prescription medications, do you know what they're for?

Question changed in 2021-22

State	Always	Usually	Sometimes	Seldom or Never	N
PA	67%	23%	6%	4%	576
Weighted NCI-IDD Average	72%	20%	6%	3%	6558

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

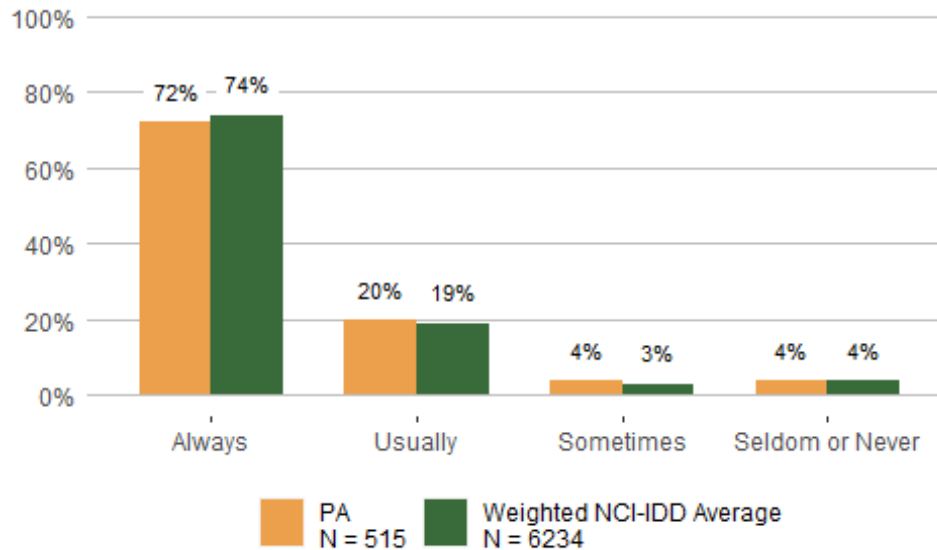


Table 74. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	72%	20%	4%	4%	515
Weighted NCI-IDD Average	74%	19%	3%	4%	6234

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

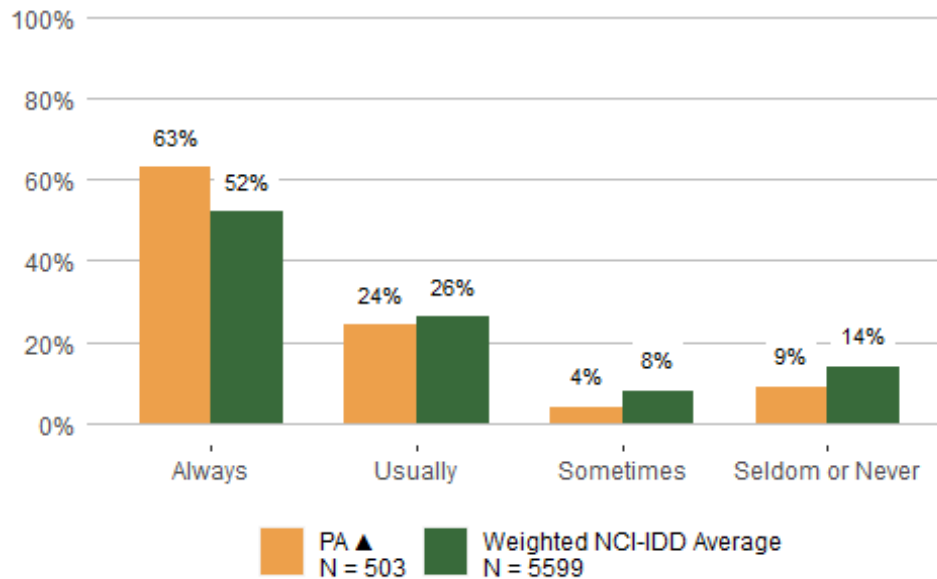


Table 75. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)?

New question in 2021-22

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	63%	24%	4%	9%	503
Weighted NCI-IDD Average	52%	26%	8%	14%	5599

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

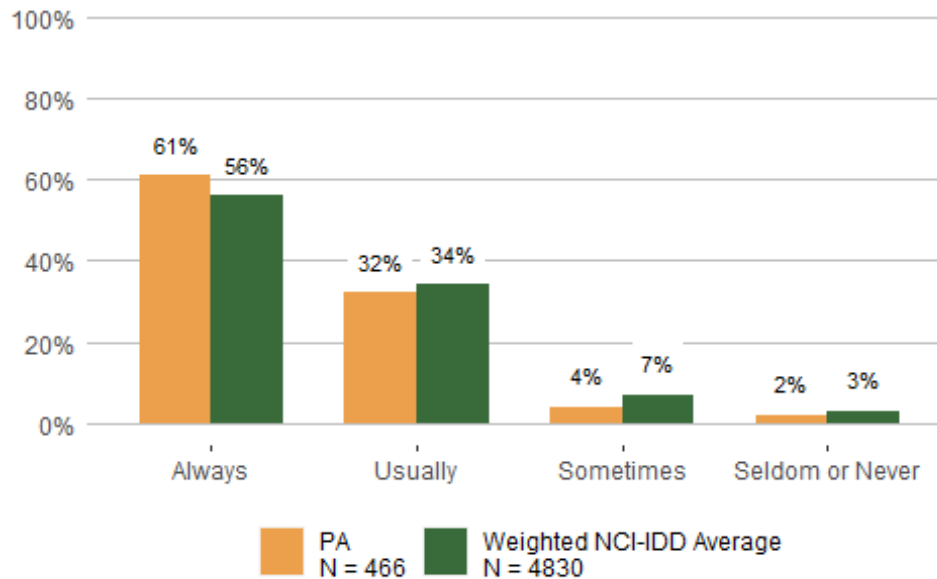


Table 76. Does your family member's mental or behavioral health professional understand your family member's needs related to their disability?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	61%	32%	4%	2%	466
Weighted NCI-IDD Average	56%	34%	7%	3%	4830

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

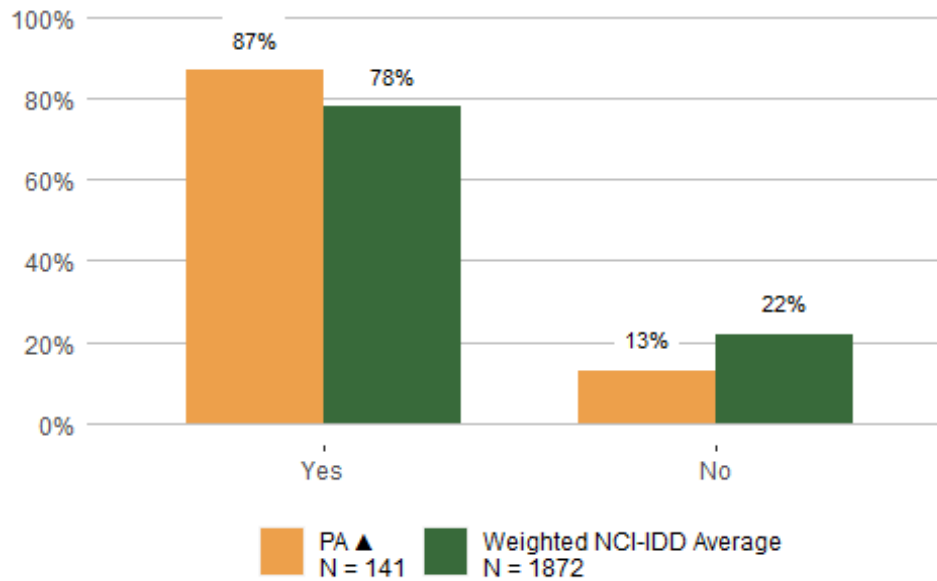


Table 77. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

State	Yes	No	N
PA ▲	87%	13%	141
Weighted NCI-IDD Average	78%	22%	1872

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

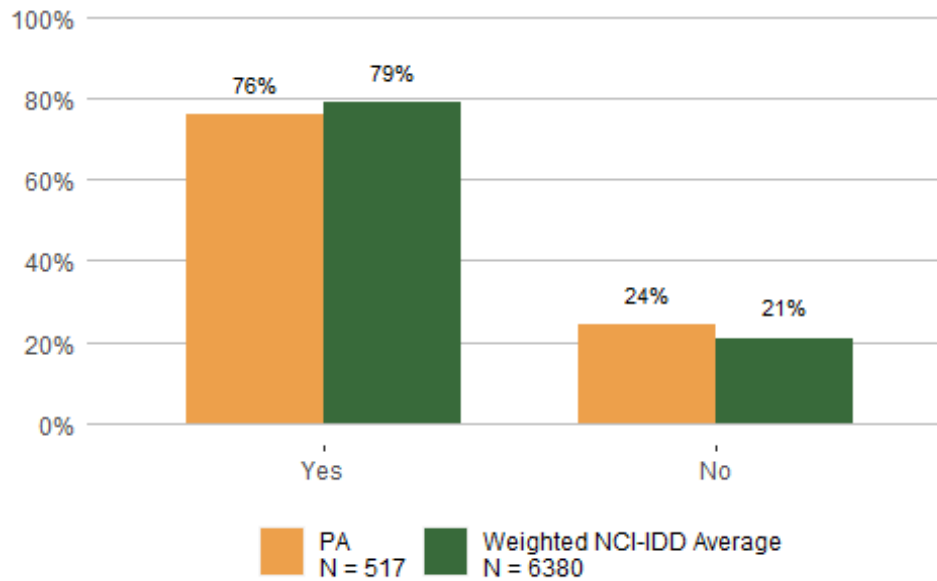


Table 78. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency, pandemic or natural disaster?

State	Yes	No	N
PA	76%	24%	517
Weighted NCI-IDD Average	79%	21%	6380

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?

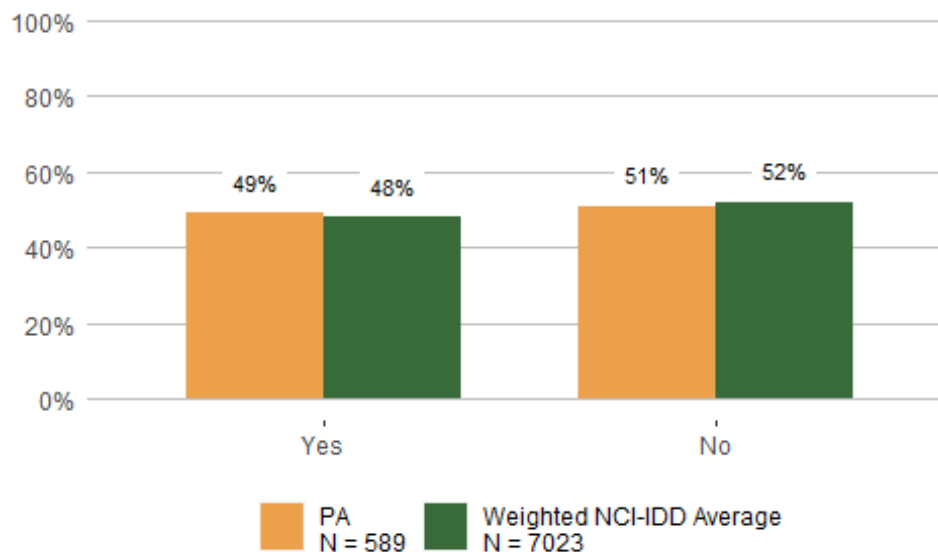


Table 79. Have you talked about how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your family member's case manager/service coordinator?

New question in 2021-22

State	Yes	No	N
PA	49%	51%	589
Weighted NCI-IDD Average	48%	52%	7023

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

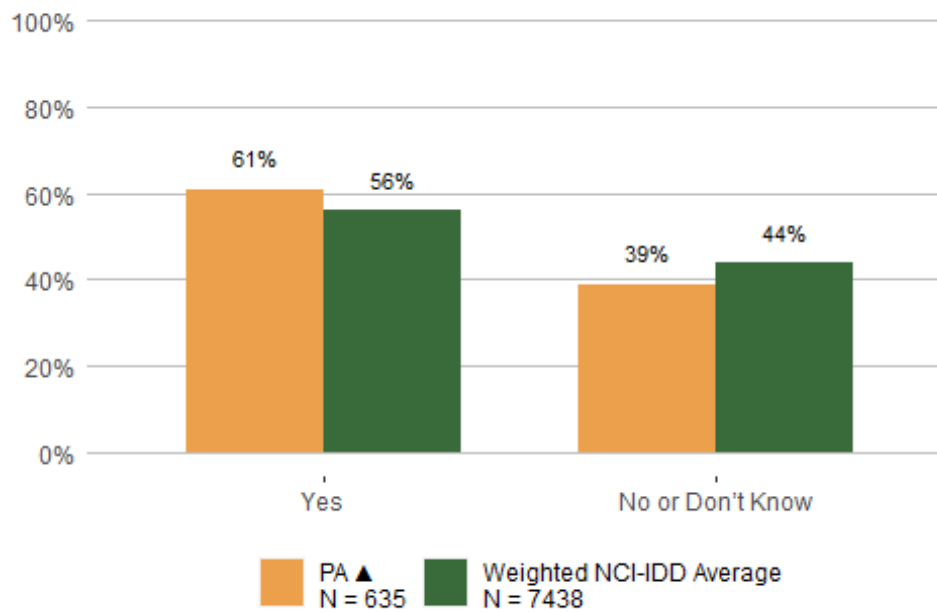


Table 80. Do you know how to file a complaint or grievance about provider agencies or staff?

State	Yes	No or Don't Know	N
PA ▲	61%	39%	635
Weighted NCI-IDD Average	56%	44%	7438

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

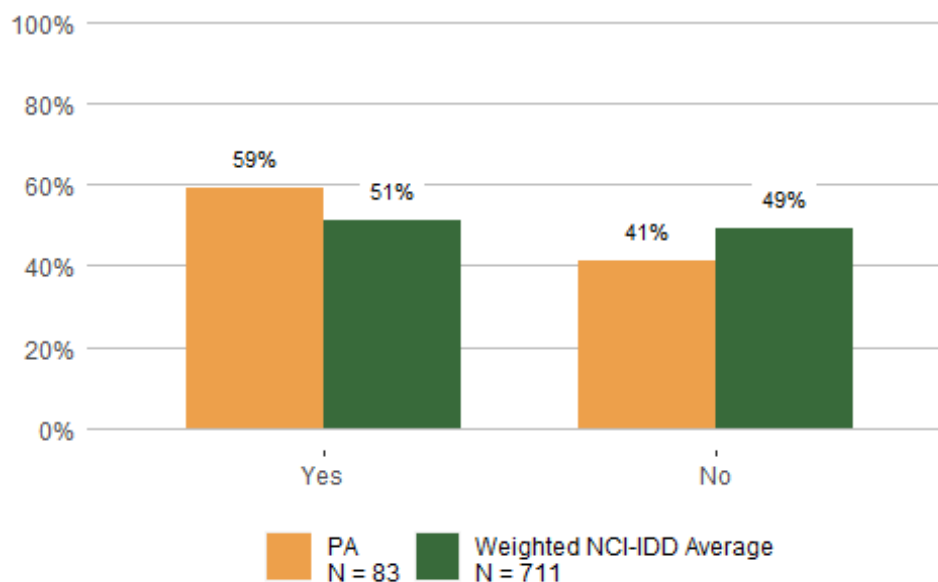


Table 81. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

State	Yes	No	N
PA	59%	41%	83
Weighted NCI-IDD Average	51%	49%	711

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

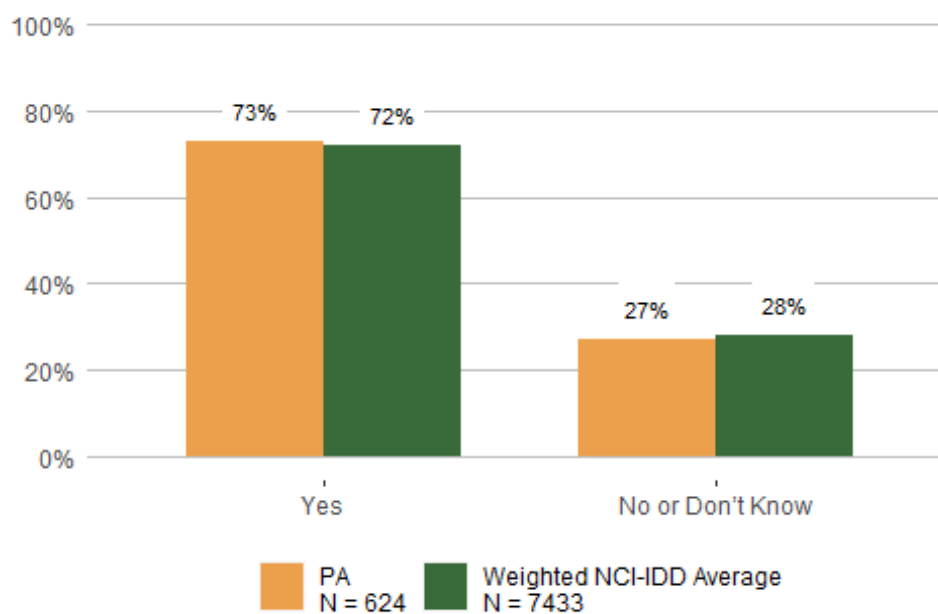


Table 82. Do you know how to report abuse or neglect related to your family member?

State	Yes	No or Don't Know	N
PA	73%	27%	624
Weighted NCI-IDD Average	72%	28%	7433

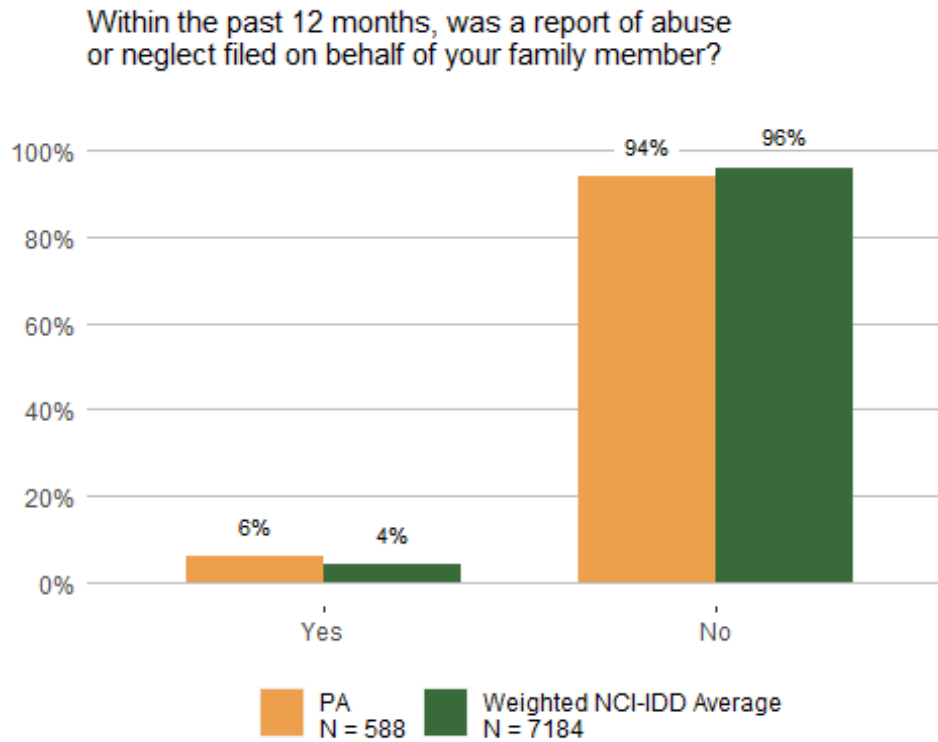


Table 83. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

State	Yes	No	N
PA	6%	94%	588
Weighted NCI-IDD Average	4%	96%	7184

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?

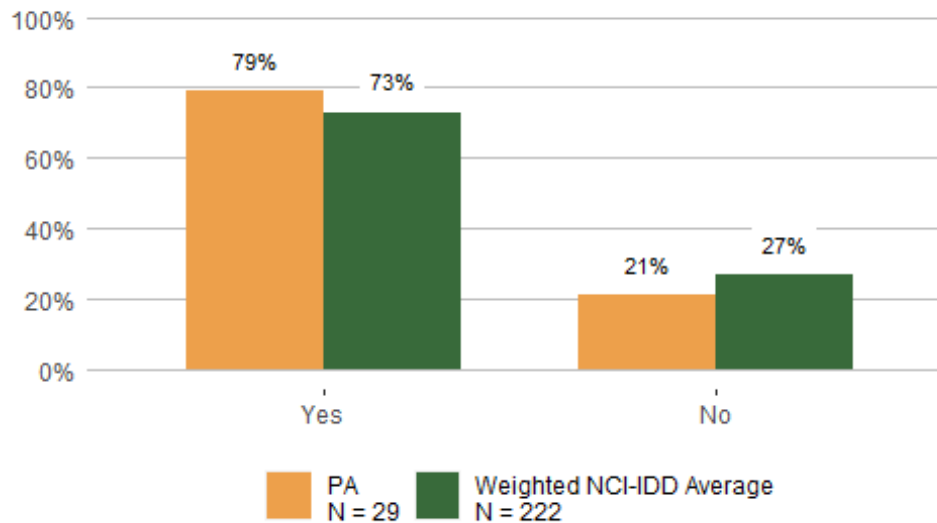


Table 84. If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?

State	Yes	No	N
PA	79%	21%	29
Weighted NCI-IDD Average	73%	27%	222

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?

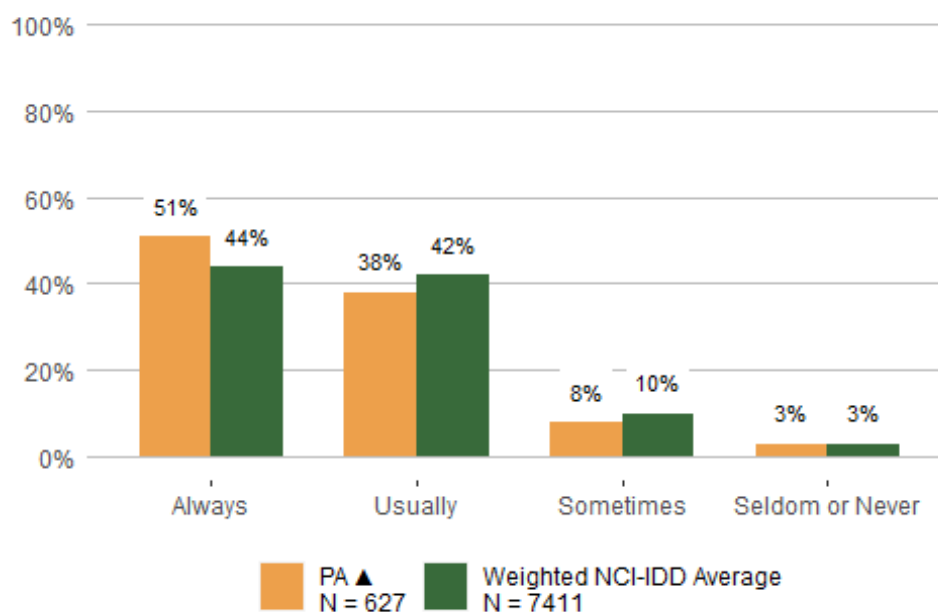


Table 85. Overall, are you satisfied with the services and supports your family member currently receives?

State	Always	Usually	Sometimes	Seldom or Never	N
PA ▲	51%	38%	8%	3%	627
Weighted NCI-IDD Average	44%	42%	10%	3%	7411

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

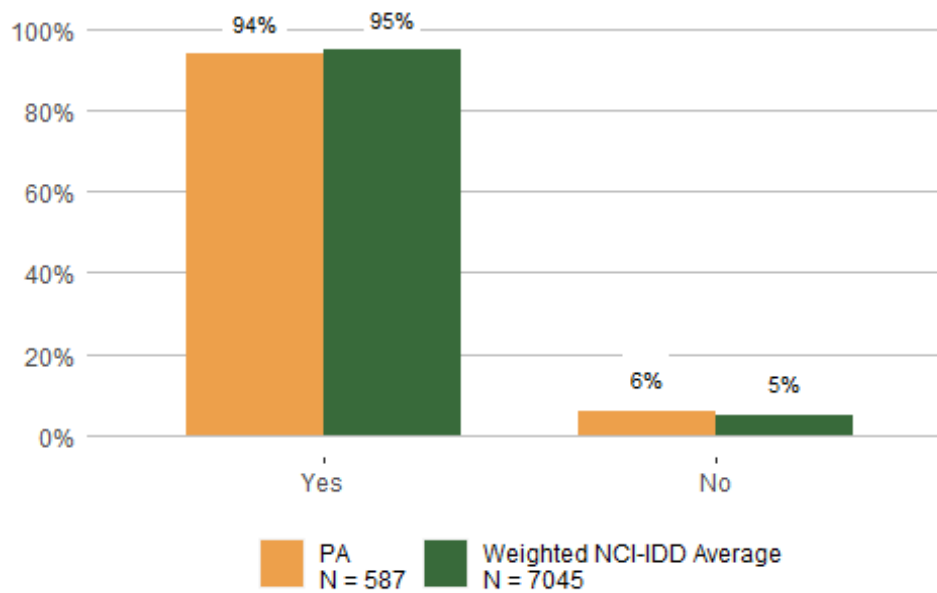


Table 86. Do you feel that services and supports have made a positive difference in the life of your family member?

State	Yes	No	N
PA	94%	6%	587
Weighted NCI-IDD Average	95%	5%	7045

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

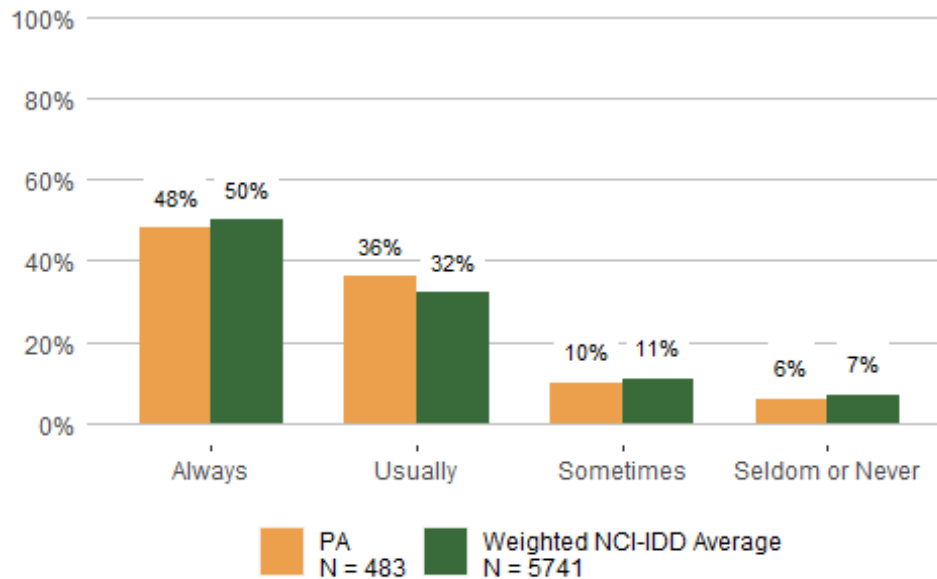


Table 87. Does the agency providing residential services to your family member involve them in important decisions?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	48%	36%	10%	6%	483
Weighted NCI-IDD Average	50%	32%	11%	7%	5741

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

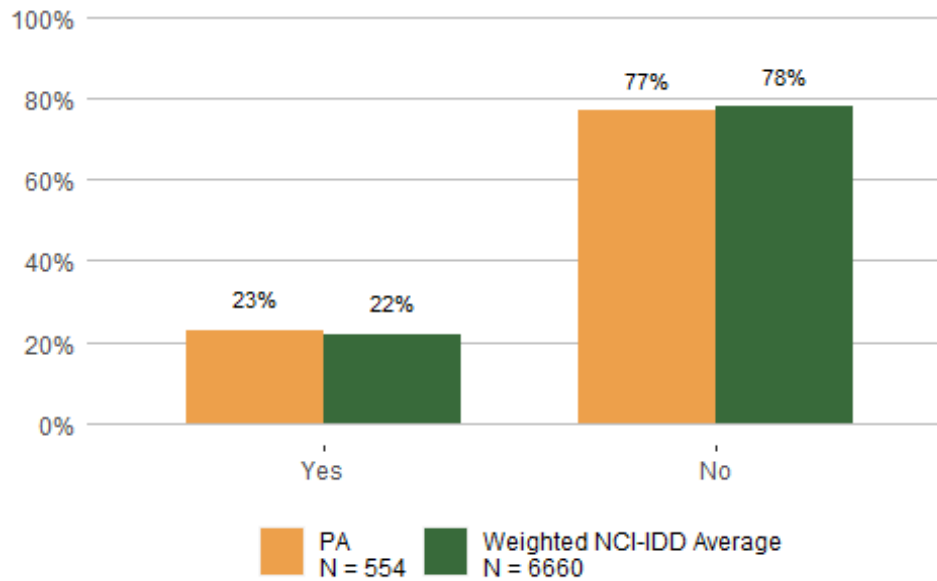


Table 88. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?

State	Yes	No	N
PA	23%	77%	554
Weighted NCI-IDD Average	22%	78%	6660

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?

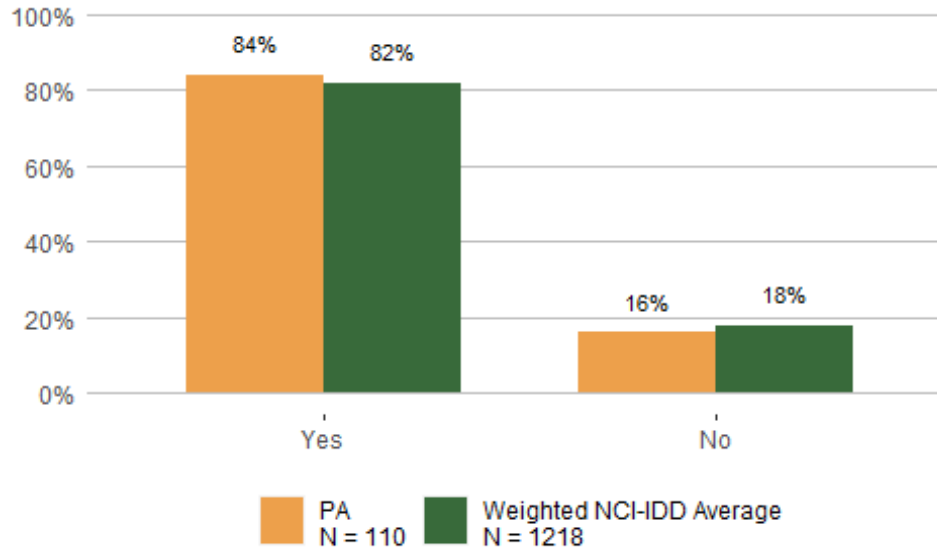


Table 89. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?

State	Yes	No	N
PA	84%	16%	110
Weighted NCI-IDD Average	82%	18%	1218

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

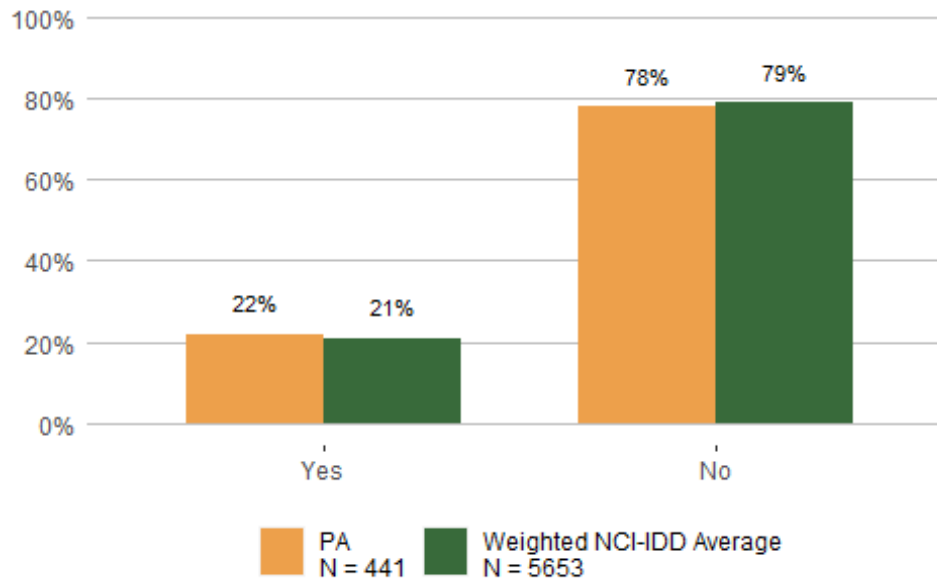


Table 90. Have the services or supports that your family member received been increased in the past 12 months?

State	Yes	No	N
PA	22%	78%	441
Weighted NCI-IDD Average	21%	79%	5653

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

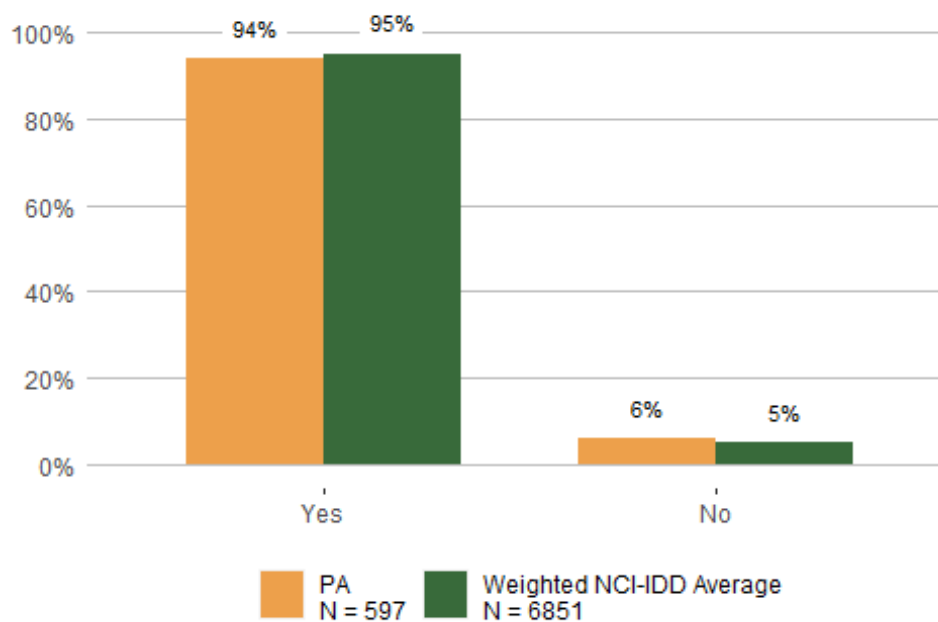


Table 91. Are services and supports helping your family member to live a good life?

State	Yes	No	N
PA	94%	6%	597
Weighted NCI-IDD Average	95%	5%	6851

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?

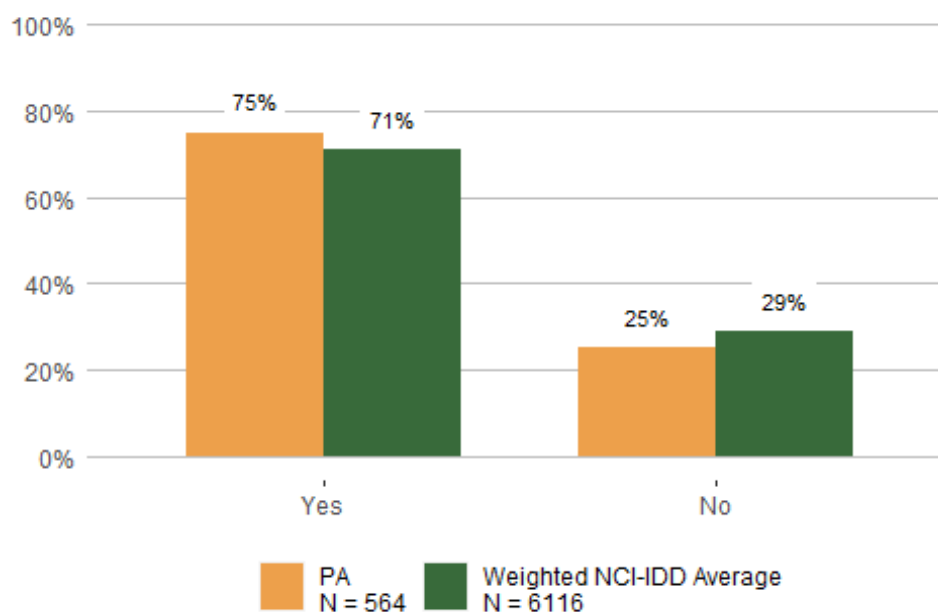


Table 92. Were your family member's services and supports changed, canceled, or reduced during COVID time?

State	Yes	No	N
PA	75%	25%	564
Weighted NCI-IDD Average	71%	29%	6116

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

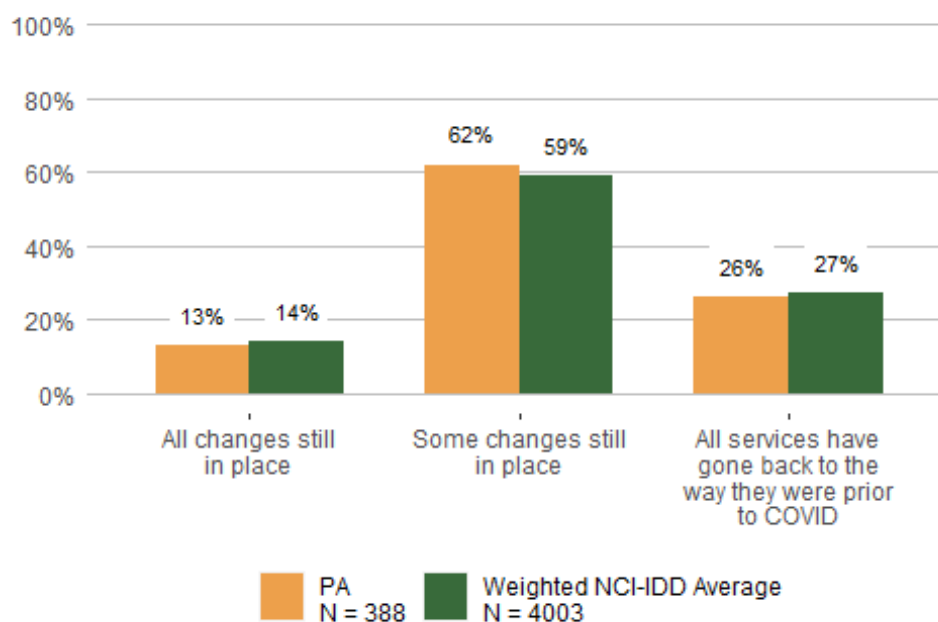


Table 93. If yes, are those changes still in effect (still part of your family member's life)?

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	13%	62%	26%	388
Weighted NCI-IDD Average	14%	59%	27%	4003

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?

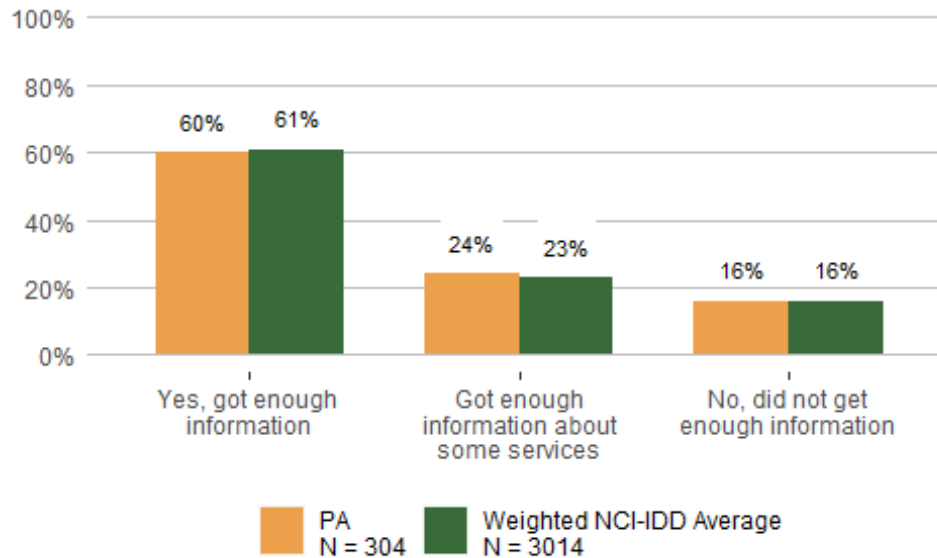


Table 94. If some or all of your family member's services have reopened or restarted: Did your family get enough information about the services reopening/restarting?

State	Yes, got enough information	Got enough information about some services	No, did not get enough information	N
PA	60%	24%	16%	304
Weighted NCI-IDD Average	61%	23%	16%	3014

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?

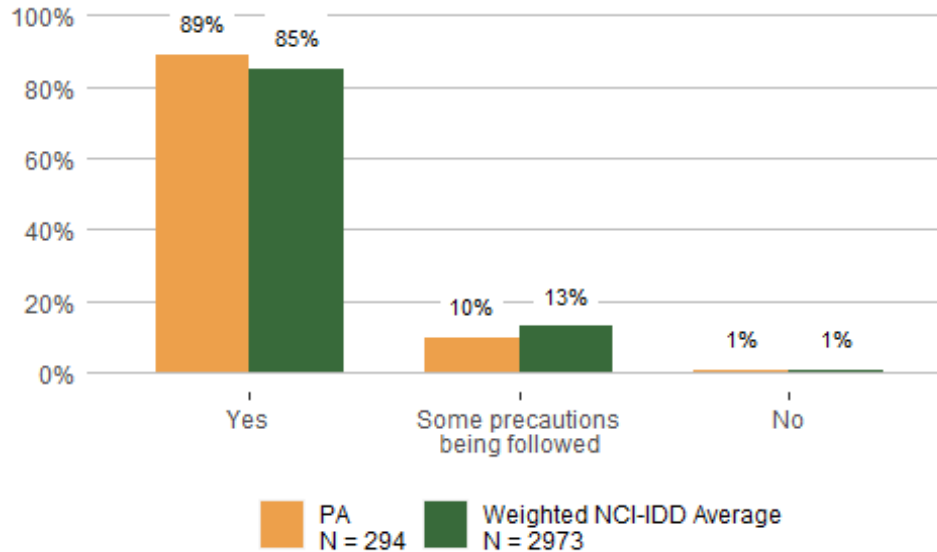


Table 95. If some or all of your family member's services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions?

State	Yes	Some precautions being followed	No	N
PA	89%	10%	1%	294
Weighted NCI-IDD Average	85%	13%	1%	2973

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?

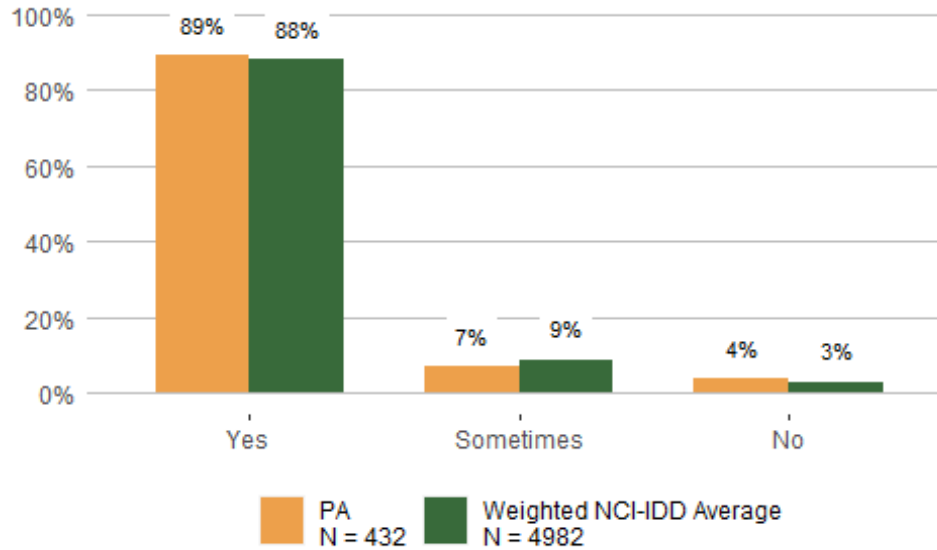


Table 96. If staff support your family member in your family member's home: Do you feel that the staff follow recommendations to keep the household safe and healthy?

State	Yes	Sometimes	No	N
PA	89%	7%	4%	432
Weighted NCI-IDD Average	88%	9%	3%	4982

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

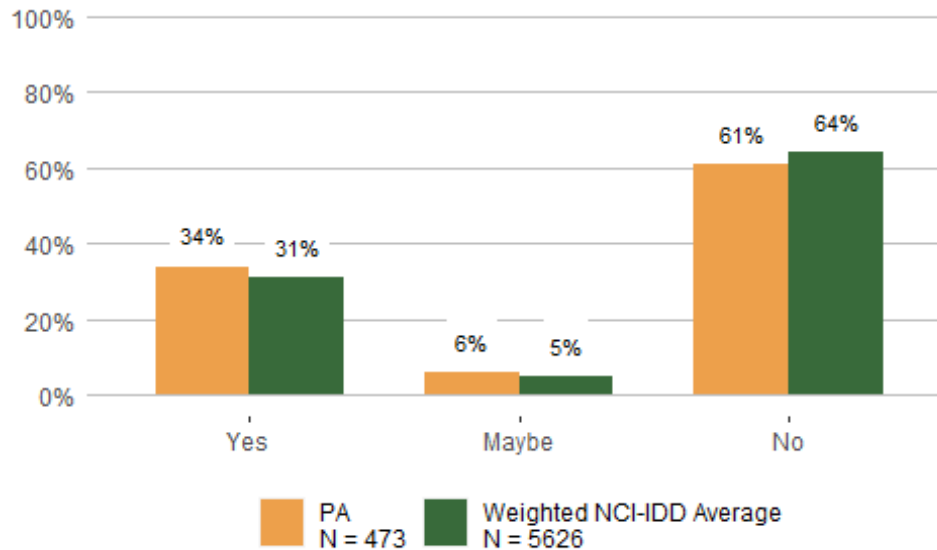


Table 97. In preparation for the future, have you made or updated an emergency plan with your family member's case manager/service coordinator or with other staff?

State	Yes	Maybe	No	N
PA	34%	6%	61%	473
Weighted NCI-IDD Average	31%	5%	64%	5626