

Adult Family Survey (AFS) State Report

2022-23 Pennsylvania Report

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Executive Summary

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

The National Core Indicators (NCI) Adult Family Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who lives in the family home and receives at least one service other than case management. Not all states that participate in NCI-IDD administer the Adult Family Survey on an annual basis. Of the 48 states, the District of Columbia and 22 sub-state entities that were members of NCI-IDD during the 2022-23 data collection cycle, 10 states submitted a valid sample of Adult Family Survey data: Delaware (DE), District of Columbia (DC), Georgia (GA), Louisiana (LA), Maryland (MD), Missouri (MO), North Dakota (ND), New Jersey (NJ), Oklahoma (OK), and Pennsylvania (PA). This Final Report provides a summary of results based on data submitted by June 30, 2023.

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 or guardians 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" is used throughout this report, the same role may also be referred to as "service coordinator" or "supports coordinator" depending on the state.

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

What is included in this report?

This report includes this state's 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.

Results

Presentation of the Data

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

- Each question is constructed so the respondent selects from either four possible responses ("always", "usually", "sometimes", "seldom/never") or two responses ("yes" or "no"). Respondents also have the option to indicate that they don't know the answer to a question or that the question is not applicable.
- Demographic results are shown in table form.
- Statistical significance is taken to be at or below the .01 level. For those states that fall within the NCI-IDD Average range, their 'always' or 'yes' response was not statistically different from the NCI-IDD Average.
- States with 20 or fewer respondents to a question are not included in tables; however, their data *are* included in the NCI-IDD Average.
- Note on NCI-IDD Averages: The NCI-IDD averages contained in this report are "weighted" means; their calculations reflect the relative population sizes of participating states and the states' sample sizes. Prior to 2016-17, NCI-IDD averages were calculated as the simple arithmetic mean of all state means (an approach known as "average of averages"), so comparisons to past reports should be made with caution. See more about weighting in the Methodology section.
- Note on language used in this report: "You" and "Respondent" refers to the person (usually a parent or guardian) filling out the survey. "Family Member" refers to the person receiving services whom the respondent is answering questions about in this survey.
- **Note on responses:** All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

Demographics

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

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

Family Member

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

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

State (names abbreviated)	Yes	No	N
РА	13%	87%	642
Weighted NCI-IDD Average	12%	88%	4779

Table 2. Family Member's Residential Designation

State (names abbreviated)	Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	N
РА	58%	42%	637
Weighted NCI-IDD Average	64%	36%	4738

Table 3. Family Member's Age

State (names abbreviated)	Age	N
PA	41.8	670
Weighted NCI-IDD Average	37.6	4900

Table 4. Family Member's Gender

State (names abbreviated)	Male	Female	Other	N
РА	56%	44%	0%	664
Weighted NCI-IDD Average	59%	40%	0%	4788

Table 5a. Family Member's Race/Ethnicity

State (names abbreviated)	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander
PA	1%	1%	13%	0%
Weighted NCI-IDD Average	2%	4%	19%	0%

Table 5b. Family Member's Race/Ethnicity (continued)

State (names abbreviated)	White	Hispanic or Latino	Other	Prefer not to say
РА	82%	3%	1%	2%
Weighted NCI-IDD Average	72%	4%	1%	3%

Table 6a. Family Member's Conditions

State (names abbreviated)	Intellectual disability	Mood illness or psychiatric diagnosis	Autism spectrum disorder	Cerebral palsy
РА	82%	23%	28%	14%
Weighted NCI-IDD Average	72%	24%	37%	17%

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

State (names abbreviated)	Limited or no vision	Hearing loss (severe or profound)	Brain injury	Seizure or neurological disorder	
РА	10%	8%	7%	23%	
Weighted NCI-IDD Average	9%	6%	8%	27%	

Table 6c. Family Member's Conditions (Continued)

State (names abbreviated)	Chemical dependency	Down syndrome	Prader- Willi Syndrome	Fetal Alcohol Spectrum Disorder (FASD)	Other
PA	0%	18%	0%	0%	16%
Weighted NCI-IDD Average	0%	15%	0%	1%	17%

Table 7a. Family Member's Health Conditions

State (names abbreviated)	Cardiovascular Disease	Diabetes	Cancer	High blood pressure	High cholesterol
РА	12%	20%	4%	31%	34%
Weighted NCI-IDD Average	11%	17%	4%	29%	32%

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

State (names abbreviated)	Dysphagia	Pressure ulcers	Alzheimer's disease or dementia	Oral health problems	Sleep apnea
РА	8%	1%	2%	10%	15%
Weighted NCI-IDD Average	10%	1%	2%	11%	17%

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

State (names abbreviated)	Asthma	Other pulmonary diagnosis (e.g., COPD, bronchitis, emphysema)	Chronic kidney disease	Long-term health problems associated with COVID-19 (also known as Long COVID)	Other
РА	11%	4%	5%	1%	23%
Weighted NCI-IDD Average	14%	5%	5%	1%	26%

Table 8. Family Member's Preferred Means of Communication

State (names abbreviated)	Spoken	Gestures or body language	Sign language or finger spelling	Communication aid or device	Other	N
PA	82%	11%	2%	1%	3%	664
Weighted NCI-IDD Average	79%	13%	1%	2%	5%	4893

Table 9a. Family Member's Preferred Language

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

State (names abbreviated)	English	Spanish	Chinese	N
PA	96%	1%	0%	658
Weighted NCI-IDD Average	96%	1%	0%	4904

Table note: "Chinese" includes Mandarin, Cantonese, and Hokkien.

Table 9b. Family Member's Preferred Language (continued)

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

State (names abbreviated)	Tagalog	Vietnamese	American Sign Language	Other	N
PA	0%	0%	1%	1%	658
Weighted NCI-IDD Average	0%	0%	1%	2%	4904

Table note: "Tagalog" includes Filipino.

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

State (names abbreviated)	No guardianship	Limited guardianship	Full guardianship	Has guardianship but level unknown	Ν
PA	47%	9%	37%	6%	611
Weighted NCI-IDD Average	35%	10%	50%	5%	4626

Table 11. Guardian or Conservator Relationship to Family Member

State (names abbreviated)	Family	Friend	Employee of state or guardianship agency	Other	N
PA	95%	0%	0%	4%	288
Weighted NCI-IDD Average	96%	0%	0%	4%	2841

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

State (names abbreviated)	Did not complete high school – Not currently in school	Currently enrolled in high school	High school certificate (NOT a high school diploma or GED)	N
ΡΑ	17%	3%	19%	629
Weighted NCI- IDD Average	15%	2%	32%	4779

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

State (names abbreviated)	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	Ν
РА	54%	3%	2%	3%	629
Weighted NCI- IDD Average	40%	3%	4%	5%	4779

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

State (names abbreviated)	No support needed; no issues with managing behavior	Some support needed; requires only occasional assistance or monitoring	Extensive support needed; frequent or severe enough to require regular assistance	N
РА	63%	26%	10%	647
Weighted NCI- IDD Average	56%	29%	15%	4802

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

State (names abbreviated)	No support needed; no issues with personal care activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed	N
PA	31%	39%	30%	656
Weighted NCI- IDD Average	24%	37%	39%	4879

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

State (names abbreviated)	No support needed; no issues with other daily activities	Some support needed; requires only occasional assistance or monitoring	Extensive support needed	Ν
РА	5%	21%	74%	652
Weighted NCI- IDD Average	4%	19%	77%	4873

Respondents

This section provides information about the survey respondent.

Table 16a. Language Usually Spoken at Home

State (names abbreviated)	English	Spanish	Chinese	N
PA	97%	2%	0%	660
Weighted NCI-IDD Average	97%	1%	0%	4883

Table note: "Chinese" includes Mandarin, Cantonese, and Hokkien

Table 16b. Language Usually Spoken at Home (continued)

State (names abbreviated)	Tagalog	Vietnamese	American Sign Language	Other	N
РА	0%	0%	1%	1%	660
Weighted NCI-IDD Average	0%	0%	0%	1%	4883

Table note: "Tagalog" includes Filipino.

Table 17. Respondent's Age

State (names abbreviated)	18 – 34	35 – 54	55 – 74	75 or older	N
PA	2%	15%	65%	18%	657
Weighted NCI-IDD Average	2%	16%	68%	14%	4925

Table 18. Respondent's Health

State (names abbreviated)	Excellent	Very good	Good	Fair	Poor	N
РА	9%	32%	42%	16%	1%	658
Weighted NCI-IDD Average	11%	33%	39%	15%	2%	4919

Table 19. Respondent's Relationship to Family Member

State (names abbreviated)	Parent (biological, adoptive, or foster)	Sibling	Spouse	Grandparent	Other	N
РА	81%	16%	0%	1%	2%	666
Weighted NCI- IDD Average	86%	10%	0%	1%	3%	4938

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

State (names abbreviated)	No	Yes, respondent does	Yes, another family member does	N
РА	68%	20%	15%	656
Weighted NCI-IDD Average	63%	23%	17%	4880

Table note: Data combined from "select all that apply" questions and therefore might sum over 100%.

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

State (names abbreviated)	One	Two	Three	Four or more	N
РА	4%	32%	47%	17%	657
Weighted NCI-IDD Average	6%	28%	48%	18%	4890

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

State (names abbreviated)	One	Two	Three	Four or more	None	N
PA	4%	3%	0%	0%	93%	659
Weighted NCI-IDD Average	5%	2%	1%	0%	92%	4911

State (names abbreviated)	No high school diploma or GED	High school diploma or GED	Vocational school or certificate program	Some college	College degree or higher	Ν
PA	6%	39%	8%	18%	29%	661
Weighted NCI- IDD Average	5%	27%	7%	19%	43%	4856

Table 24a. Total Taxable Household Income of Wage Earners in the Past 12 Months

State (names abbreviated)	No earned income	Up to \$15,000	\$15,001–\$25,000	N
PA	14%	6%	9%	643
Weighted NCI-IDD Average	11%	5%	8%	4800

Table 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.

Table 24b. Total Taxable Household Income of Wage Earners in the Past 12 Months (continued)

State (names abbreviated)	\$25,001– \$50,000	\$50,001– \$75,000	Over \$75,000	Prefer not to say	N
РА	16%	11%	17%	26%	643
Weighted NCI-IDD Average	15%	12%	23%	25%	4800

Table 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.

Services and Supports Received

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

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

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

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

State (names abbreviated)	Financial support	In home support	Out-of-home respite care	Day or employment supports
PA	14%	38%	23%	48%
Weighted NCI-IDD Average	16%	40%	20%	51%

Table 25b. Services and Supports Received from ID/DD Agency (Continued)

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

State (names abbreviated)	Transportation	Mental or behavioral health care or other treatments or therapies	Self-direction or fiscal intermediary services
РА	59%	27%	44%
Weighted NCI-IDD Average	58%	29%	47%

Table 26. Additional Services and Supports Received (not from the IDD Agency)

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

State (names abbreviated)	Social Security (SSI or SSB)	Services or supports from other agencies or organizations
PA	94%	40%
Weighted NCI-IDD Average	94%	32%

Main Survey Results

Note on Significance: Statistical significance depends on both the amount by which a state differs from the average for a given item and the state's sample size for that item. There may be instances where State A's difference from the average is larger than State B's, but State B is shown as significantly different from the average whereas State A is not. The larger the sample size of a state, the smaller the difference needs to be for it to be statistically significant.

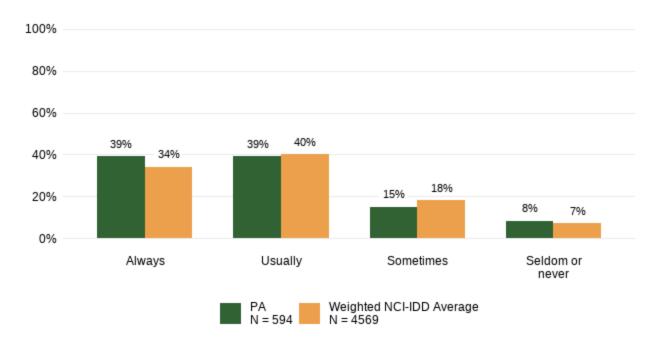
Information and Planning

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.

Note: Significance is based on "Always" or "Yes" response.

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

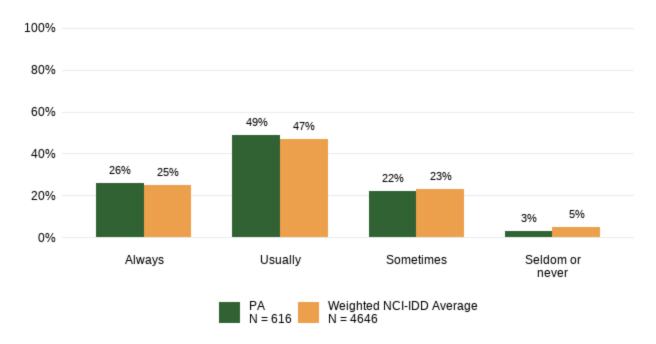
"Family Member" refers to the person receiving services whom the respondent is answering questions about in this survey.



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

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

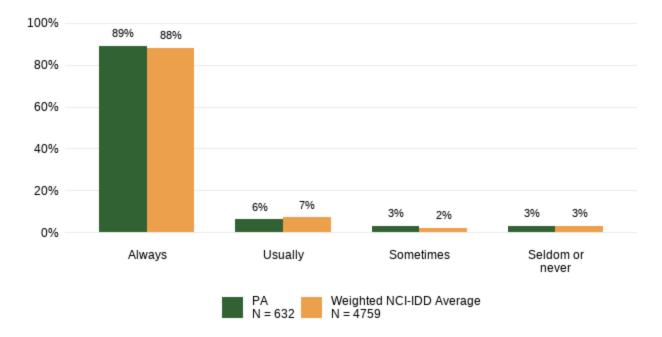
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
РА	39%	39%	15%	8%	594
Weighted NCI-IDD Average	34%	40%	18%	7%	4569



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?

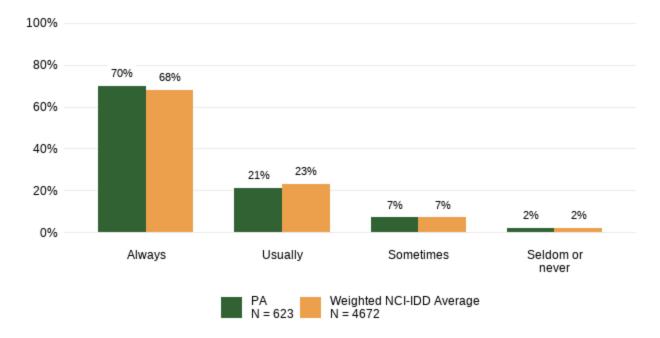
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
РА	26%	49%	22%	3%	616
Weighted NCI-IDD Average	25%	47%	23%	5%	4646



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?

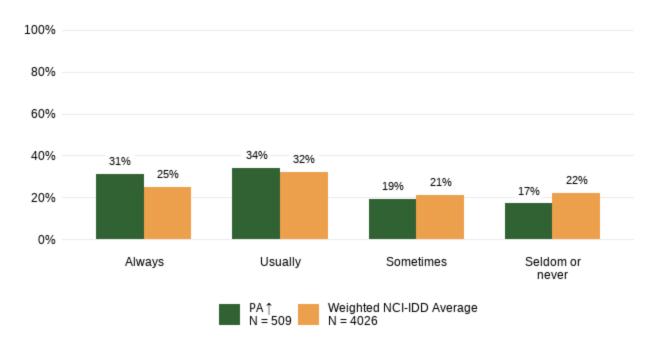
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
РА	89%	6%	3%	3%	632
Weighted NCI-IDD Average	88%	7%	2%	3%	4759



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?

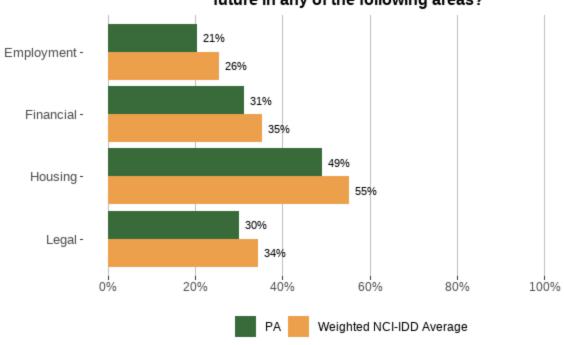
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
РА	70%	21%	7%	2%	623
Weighted NCI-IDD Average	68%	23%	7%	2%	4672



Do you have enough information about other public services for which your family is eligible?

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 (names abbreviated)	Always	Usually	Sometimes	Seldom or never	Ν
PA ↑	31%	34%	19%	17%	509
Weighted NCI-IDD Average	25%	32%	21%	22%	4026



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

Table 32a. Do you need help planning for your family member's future in any of the following areas? *Categories are not mutually exclusive, therefore N is not shown.*

State (names abbreviated)	Employment	Financial	Housing	Legal
РА	21%	31%	49%	30%
Weighted NCI-IDD Average	26%	35%	55%	34%

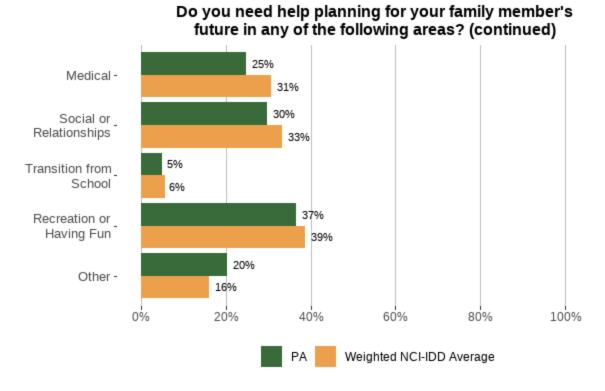
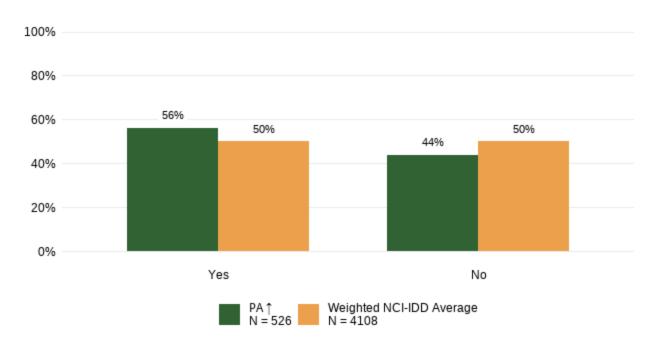


Table 32b. Do you need help planning for your family member's future in any of the following areas? (continued)

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

State (names abbreviated)	Medical	Social or Relationships	Transition from School	Recreation or Having Fun	Other
ΡΑ	25%	30%	5%	37%	20%
Weighted NCI-IDD Average	31%	33%	6%	39%	16%



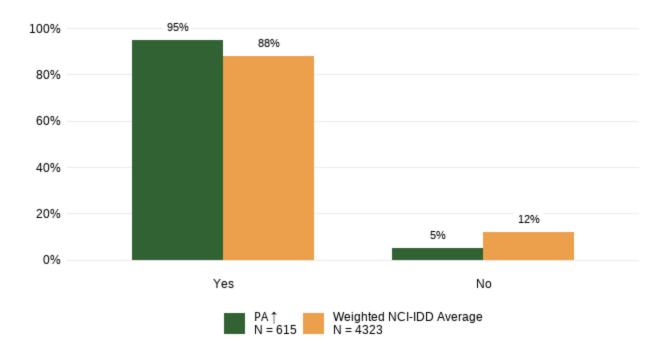
Has your family learned about alternatives to guardianship?

Table 33. Has your family learned about alternatives to guardianship?

If arrows are present, Key: Up Arrow (\uparrow) represents Significantly Above Average; down arrow (\downarrow) represents Significantly Below Average

State (names abbreviated)	Yes	No	N
PA ↑	56%	44%	526
Weighted NCI-IDD Average	50%	50%	4108

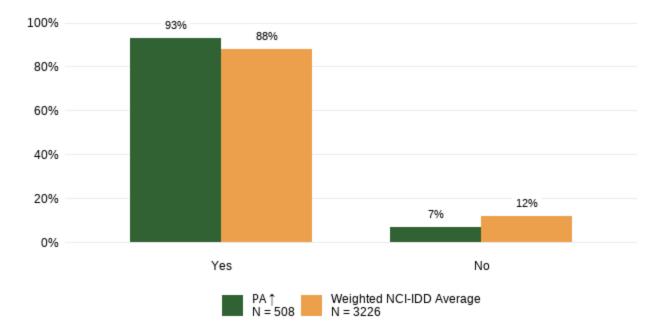
Table note: Alternatives to guardianship let a family member make more decisions for themselves, with or without the help of others. This might include: **"Supported Decision Making (SDM)"**, allows a person with a disability to make their own decisions with the help of people they trust. **"Other decision-making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



Does your family member have a service plan?

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

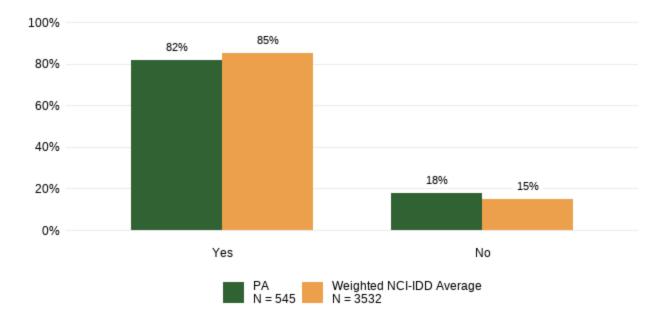
State (names abbreviated)	Yes	No	Ν
PA ↑	95%	5%	615
Weighted NCI-IDD Average	88%	12%	4323



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?

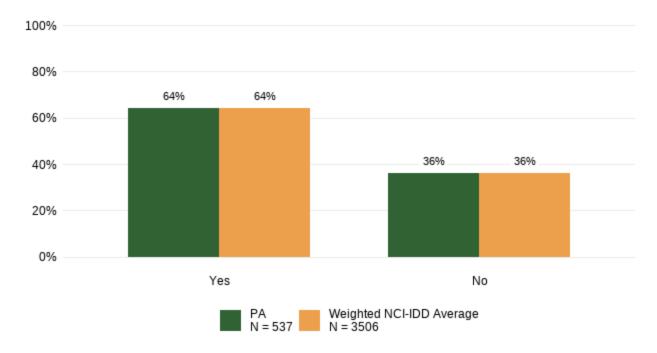
State (names abbreviated)	Yes	No	N
PA ↑	93%	7%	508
Weighted NCI-IDD Average	88%	12%	3226



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?

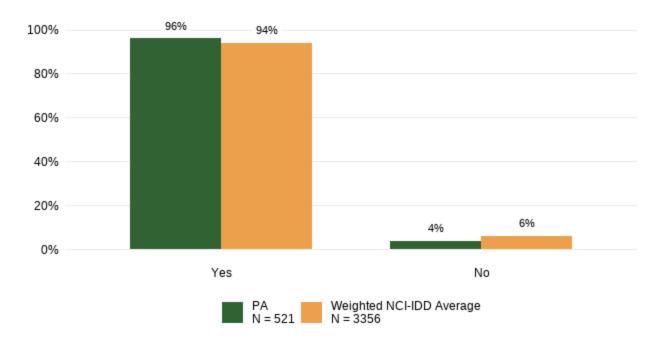
State (names abbreviated)	Yes	No	N
PA	82%	18%	545
Weighted NCI-IDD Average	85%	15%	3532



Did your family member help make the plan?

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

State (names abbreviated)	Yes	No	N
PA	64%	36%	537
Weighted NCI-IDD Average	64%	36%	3506



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?

State (names abbreviated)	Yes	No	N
PA	96%	4%	521
Weighted NCI-IDD Average	94%	6%	3356

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

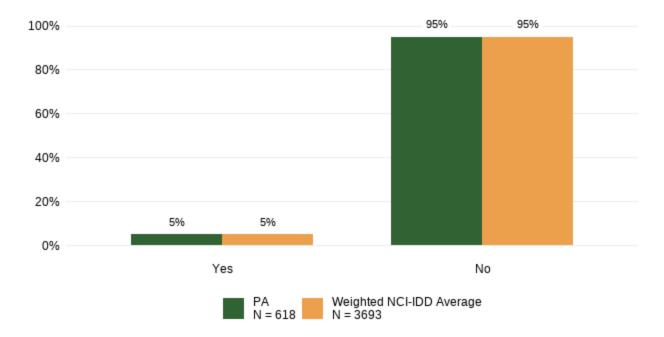
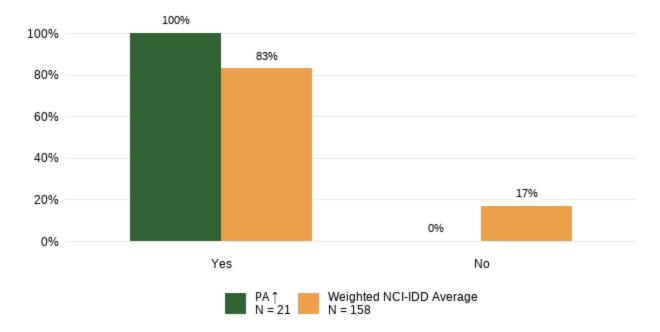


Table 39. Did your family member leave school services and begin adult services during the past 12 months?

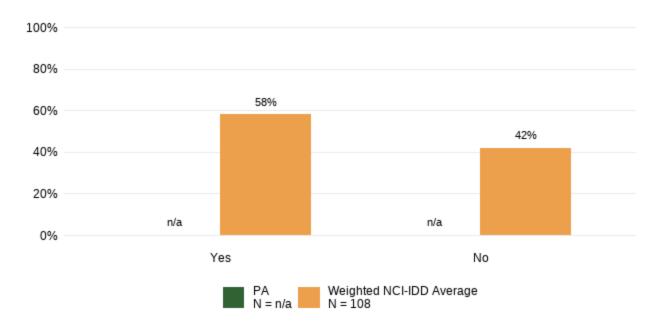
State (names abbreviated)	Yes	No	N
PA	5%	95%	618
Weighted NCI-IDD Average	5%	95%	3693



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

Table 40. If your family member left school services during the past 12 months, did they have a transition plan?

State (names abbreviated)	Yes	No	N
PA ↑	100%	0%	21
Weighted NCI-IDD Average	83%	17%	158



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

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

State (names abbreviated)	Yes	No	N
PA	n/a	n/a	n/a
Weighted NCI-IDD Average	58%	42%	108

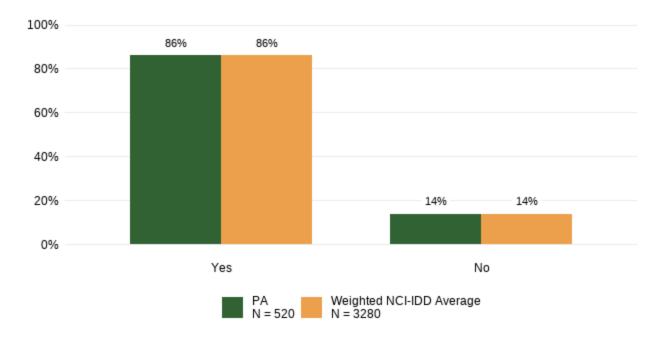
Access and Delivery of Services and Supports

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.

Note: Significance is based on "Always" or "Yes" response.

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

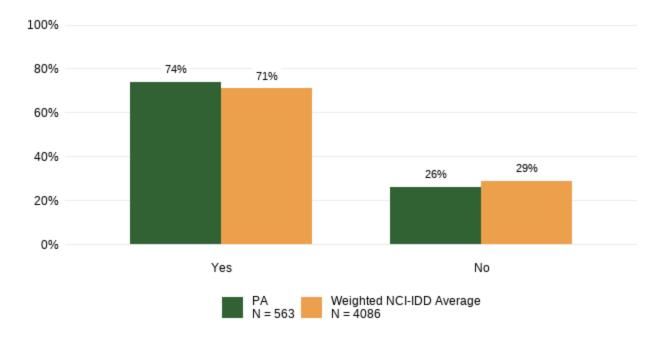
"Family Member" refers to the person receiving services whom the respondent is answering questions about in this survey.



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

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

State (names abbreviated)	Yes	No	N
PA	86%	14%	520
Weighted NCI-IDD Average	86%	14%	3280



Does your family get the supports and services it needs?

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

State (names abbreviated)	Yes	No	N
PA	74%	26%	563
Weighted NCI-IDD Average	71%	29%	4086

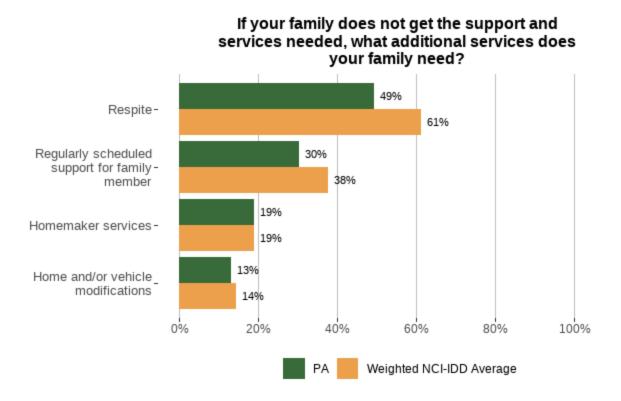


Table 44a. If your family does not get the support and services needed, what additional services does your family need?

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

State (names abbreviated)	Respite	Regularly scheduled support for family member	Homemaker services	Home and/or vehicle modifications
РА	49%	30%	19%	13%
Weighted NCI-IDD Average	61%	38%	19%	14%

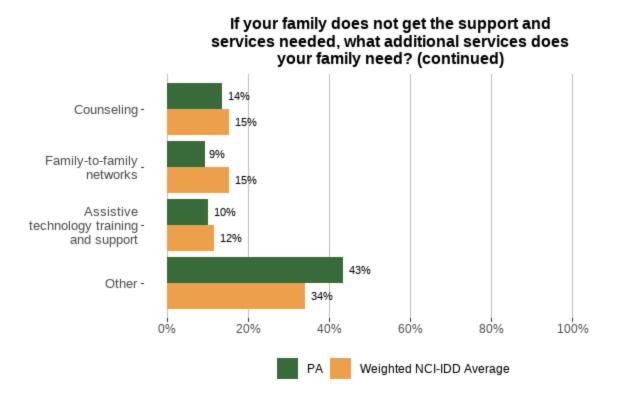
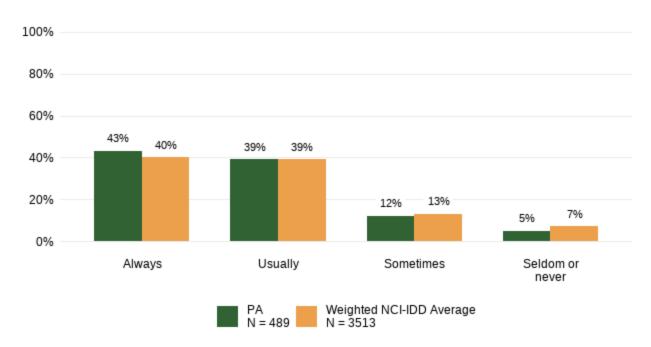


Table 44b. If your family does not get the support and services needed, what additional services does your family need? (continued)

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

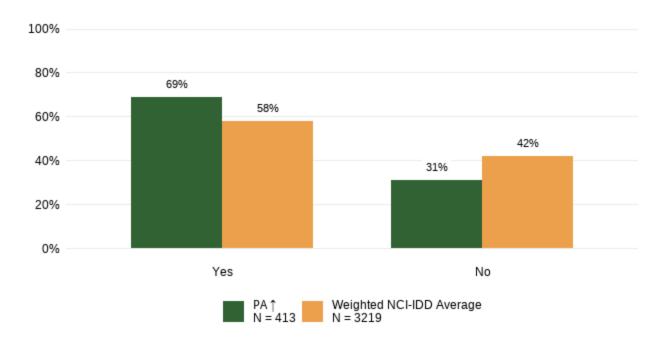
State (names abbreviated)	Counseling	Family-to-family networks	Assistive technology training and support	Other
PA	14%	9%	10%	43%
Weighted NCI-IDD Average	15%	15%	12%	34%



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

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

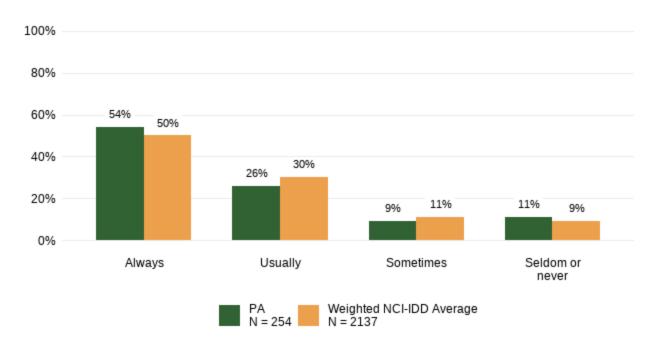
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
PA	43%	39%	12%	5%	489
Weighted NCI-IDD Average	40%	39%	13%	7%	3513



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?

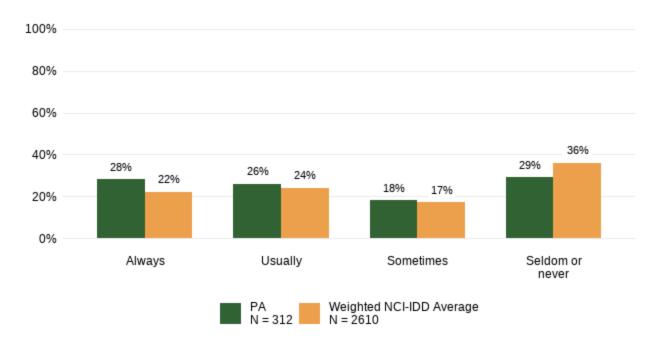
State (names abbreviated)	Yes	No	N
PA ↑	69%	31%	413
Weighted NCI-IDD Average	58%	42%	3219



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?

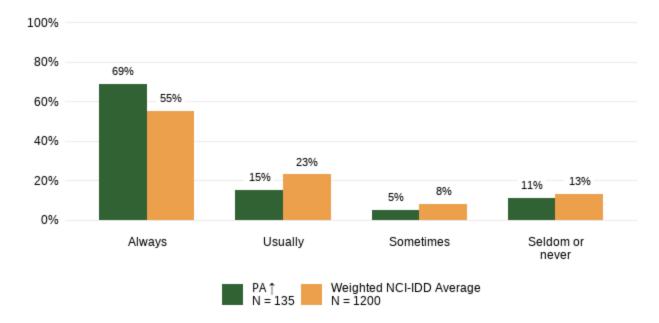
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
РА	54%	26%	9%	11%	254
Weighted NCI-IDD Average	50%	30%	11%	9%	2137



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?

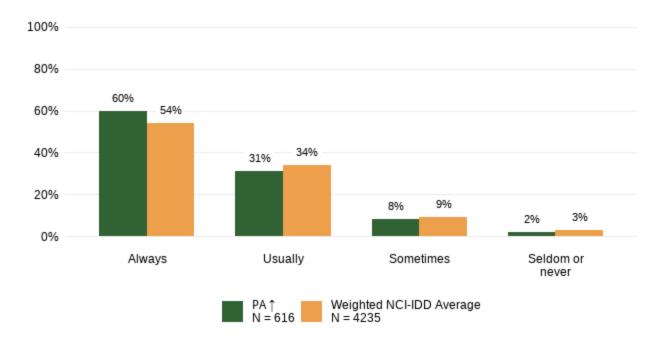
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
РА	28%	26%	18%	29%	312
Weighted NCI-IDD Average	22%	24%	17%	36%	2610



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?

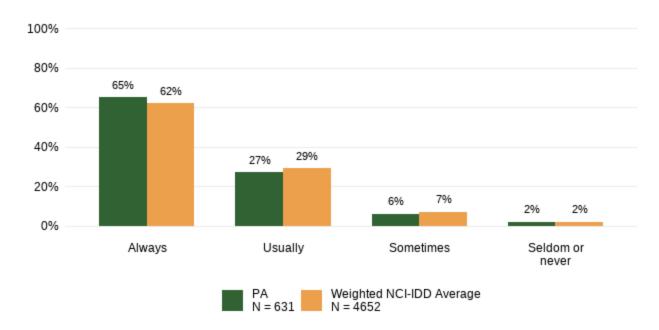
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	Ν
PA ↑	69%	15%	5%	11%	135
Weighted NCI-IDD Average	55%	23%	8%	13%	1200



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?

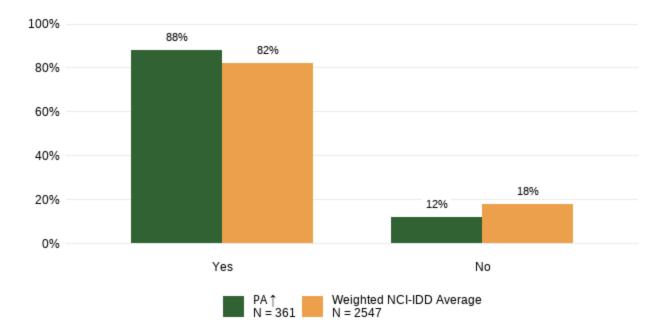
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
PA ↑	60%	31%	8%	2%	616
Weighted NCI-IDD Average	54%	34%	9%	3%	4235



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

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

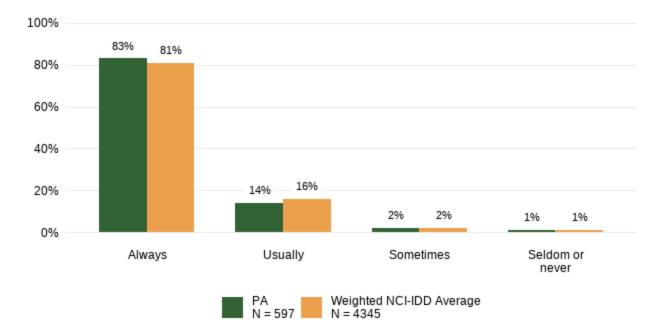
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	Ν
PA	65%	27%	6%	2%	631
Weighted NCI-IDD Average	62%	29%	7%	2%	4652



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 (names abbreviated)	Yes	No	N
PA ↑	88%	12%	361
Weighted NCI-IDD Average	82%	18%	2547



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 (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
PA	83%	14%	2%	1%	597
Weighted NCI-IDD Average	81%	16%	2%	1%	4345

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

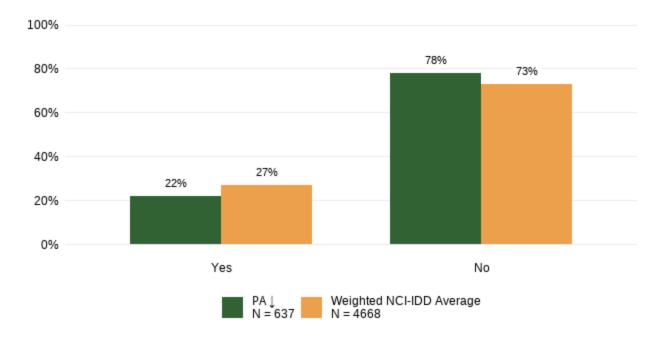
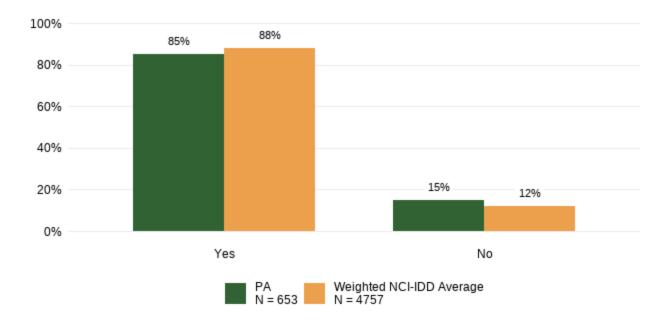


Table 54. Does your family member use technology in their everyday life to help them do things on their own?

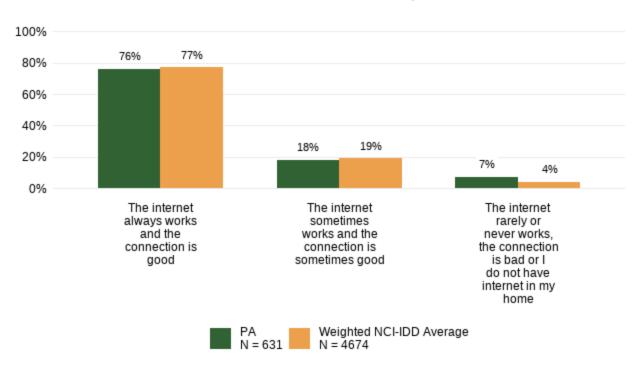
State (names abbreviated)	Yes	No	N
PA↓	22%	78%	637
Weighted NCI-IDD Average	27%	73%	4668



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?

State (names abbreviated)	Yes	No	N
PA	85%	15%	653
Weighted NCI-IDD Average	88%	12%	4757



How well does the internet work in your home?

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

State (names abbreviated)	The internet always works and the connection is good	The internet sometimes works and the connection is sometimes good	The internet rarely or never works, the connection is bad or I do not have internet in my home	N
РА	76%	18%	7%	631
Weighted NCI-IDD Average	77%	19%	4%	4674

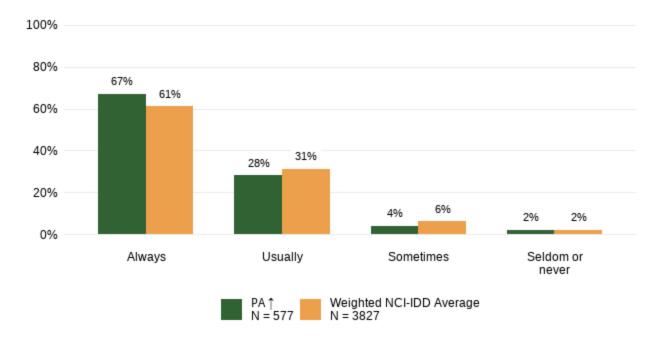
Workforce

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

Note: Significance is based on "Always" or "Yes" response.

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

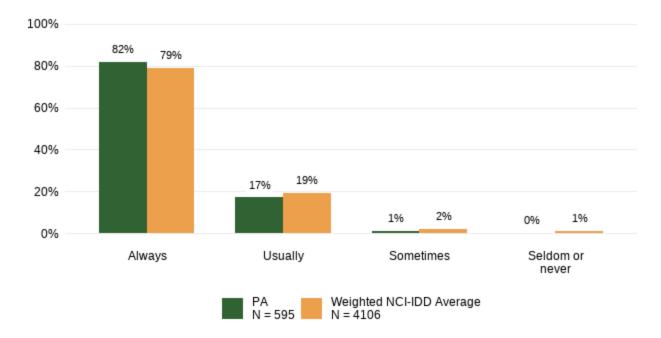
"Family Member" refers to the person receiving services whom the respondent is answering questions about in this survey.



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

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

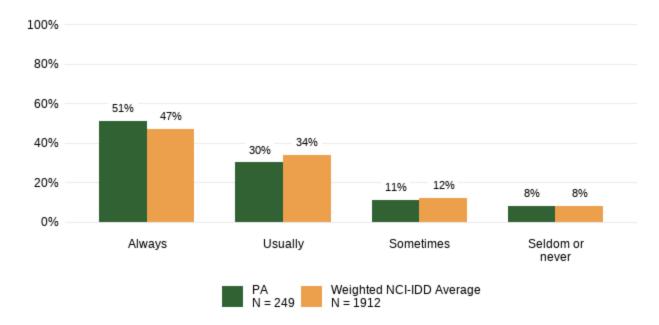
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
PA ↑	67%	28%	4%	2%	577
Weighted NCI-IDD Average	61%	31%	6%	2%	3827



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

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

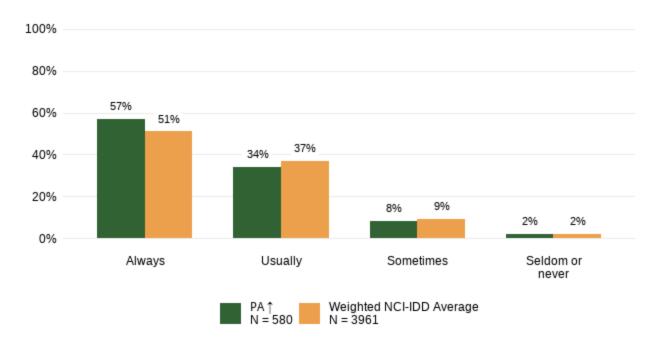
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
РА	82%	17%	1%	0%	595
Weighted NCI-IDD Average	79%	19%	2%	1%	4106



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 (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?

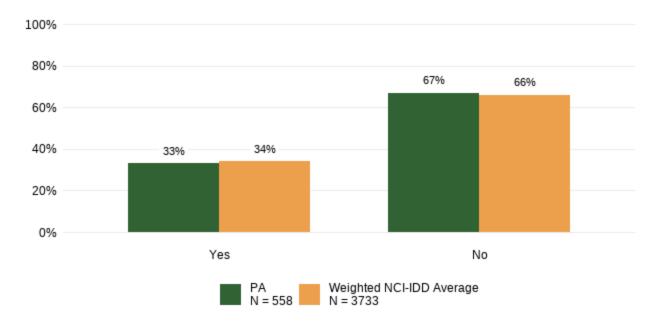
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	Ν
РА	51%	30%	11%	8%	249
Weighted NCI-IDD Average	47%	34%	12%	8%	1912



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?

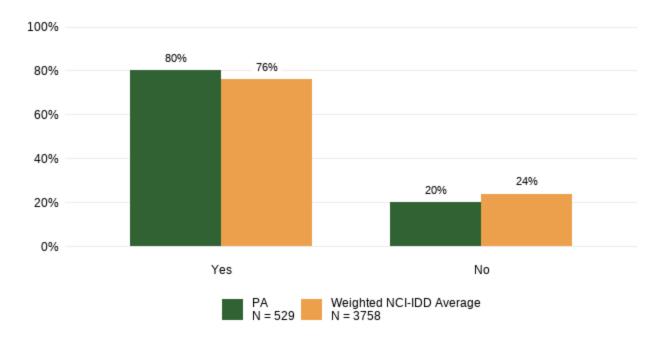
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
PA ↑	57%	34%	8%	2%	580
Weighted NCI-IDD Average	51%	37%	9%	2%	3961



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?

State (names abbreviated)	Yes	No	N
PA	33%	67%	558
Weighted NCI-IDD Average	34%	66%	3733



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?

State (names abbreviated)	Yes	No	N
PA	80%	20%	529
Weighted NCI-IDD Average	76%	24%	3758

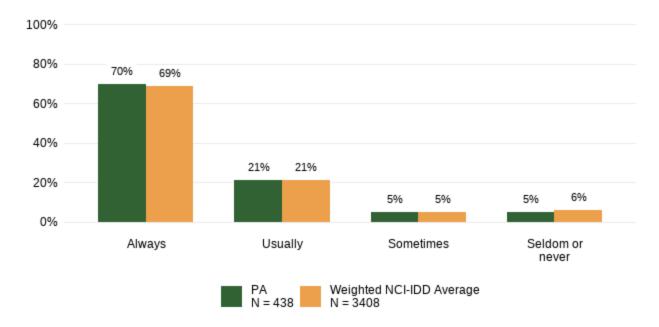
Choice, Decision Making and Control

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

Note: Significance is based on "Always" or "Yes" response.

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

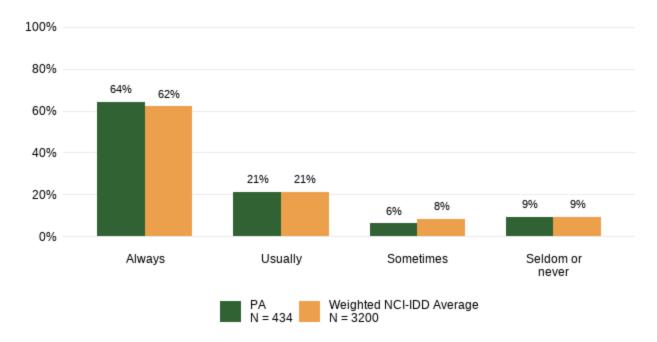
"Family Member" refers to the person receiving services whom the respondent is answering questions about in this survey.



Can someone in your family choose or change the 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?

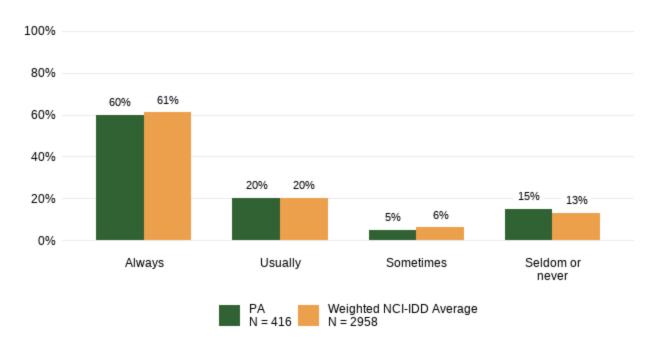
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
РА	70%	21%	5%	5%	438
Weighted NCI-IDD Average	69%	21%	5%	6%	3408



Can someone in 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?

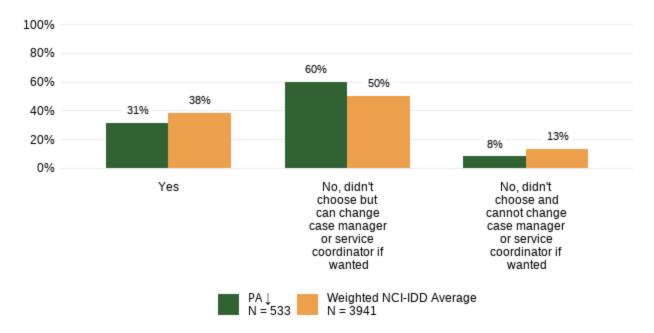
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
PA	64%	21%	6%	9%	434
Weighted NCI-IDD Average	62%	21%	8%	9%	3200



Can someone in your family directly manage support staff?

Table 65. Can someone in your family directly manage support staff?

State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
РА	60%	20%	5%	15%	416
Weighted NCI-IDD Average	61%	20%	6%	13%	2958



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 (names abbreviated)	Yes	No, didnt choose but can change case manager or service coordinator if wanted	No, didnt choose and cannot change case manager or service coordinator if wanted	Ν
PA↓	31%	60%	8%	533
Weighted NCI-IDD Average	38%	50%	13%	3941

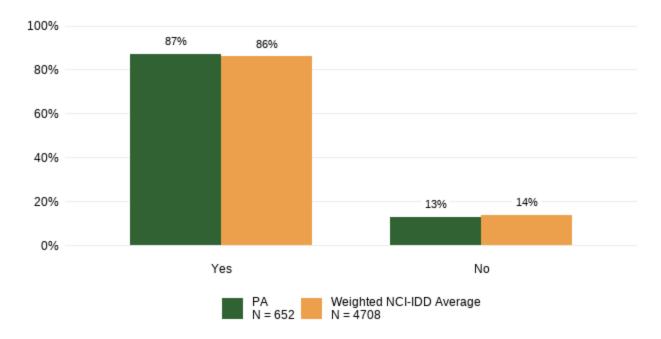
Community Connections

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.

Note: Significance is based on "Always" or "Yes" response.

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

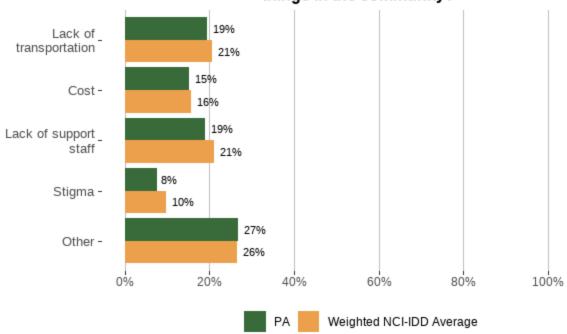
"Family Member" refers to the person receiving services whom the respondent is answering questions about in this survey.



Does your family member do things in the community?

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

State (names abbreviated)	Yes	No	N
PA	87%	13%	652
Weighted NCI-IDD Average	86%	14%	4708

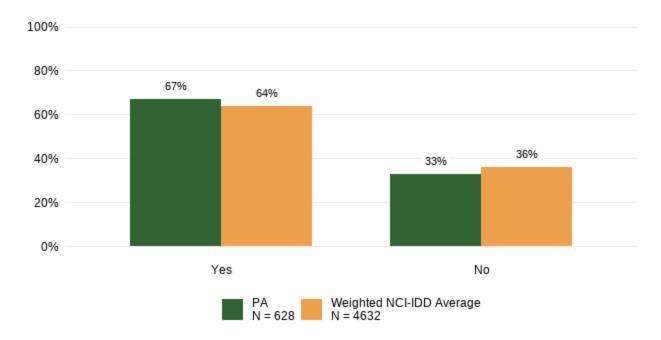


For your family member, what makes it hard to do things in the community?

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

Categories are not mutually e	exclusive, therefore N is not shown.
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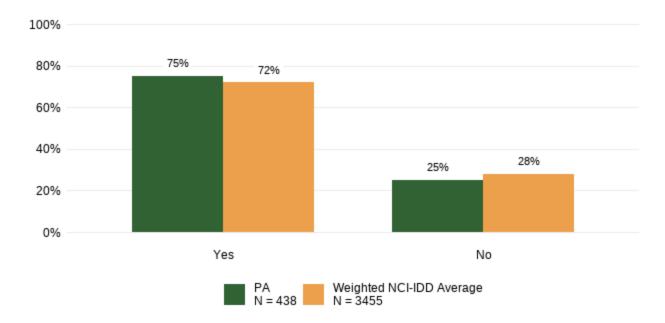
State (names abbreviated)	Lack of transportation	Cost	Lack of support staff	Stigma	Other
PA	19%	15%	19%	8%	27%
Weighted NCI-IDD Average	21%	16%	21%	10%	26%



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?

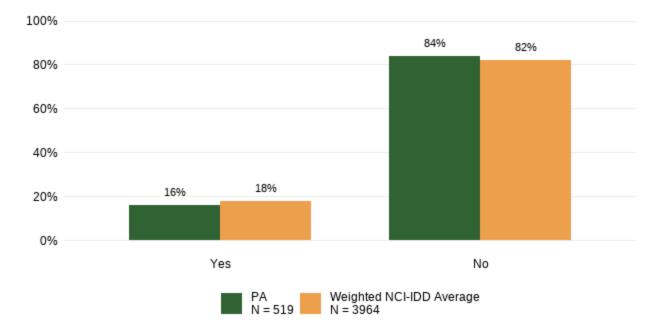
State (names abbreviated)	Yes	No	N
PA	67%	33%	628
Weighted NCI-IDD Average	64%	36%	4632



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

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

State (names abbreviated)	Yes	No	N
PA	75%	25%	438
Weighted NCI-IDD Average	72%	28%	3455



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 (names abbreviated)	Yes	No	N
PA	16%	84%	519
Weighted NCI-IDD Average	18%	82%	3964

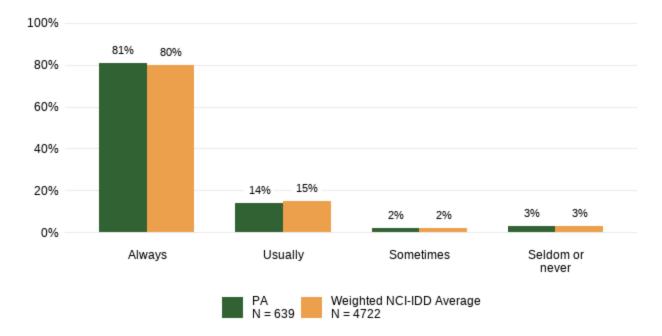
Health, Welfare, and Safety

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

Note: Significance is based on "Always" or "Yes" response.

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

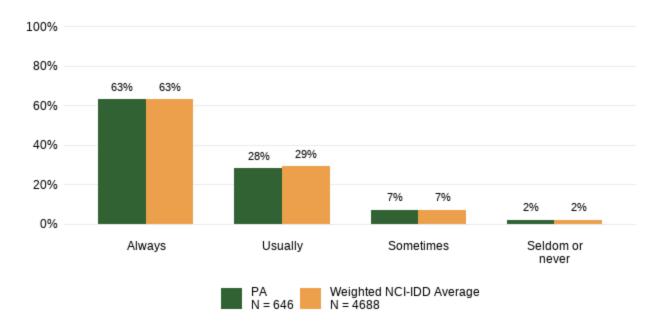
"Family Member" refers to the person receiving services whom the respondent is answering questions about in this survey.



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

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

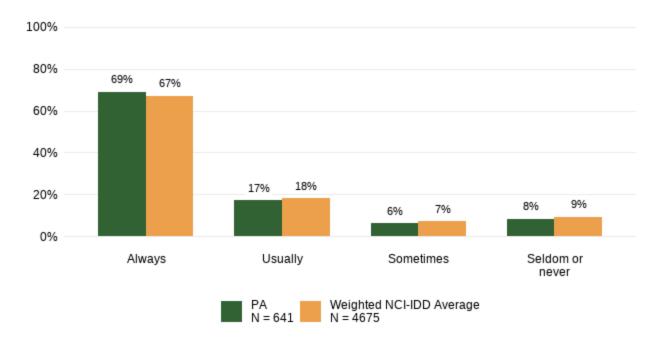
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
PA	81%	14%	2%	3%	639
Weighted NCI-IDD Average	80%	15%	2%	3%	4722



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

Table 73. Does your family member's primary care doctor understand your family member's needs related to their disability?

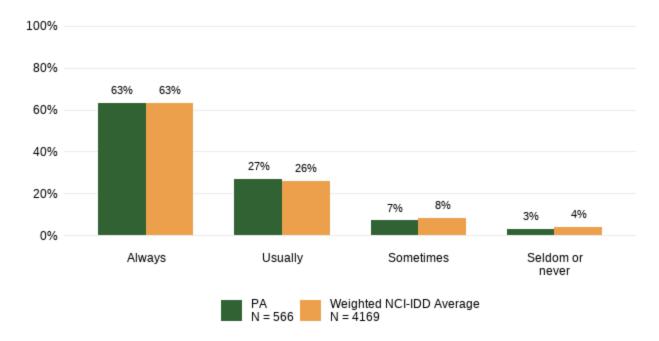
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	Ν
РА	63%	28%	7%	2%	646
Weighted NCI-IDD Average	63%	29%	7%	2%	4688



Can your family member go to the dentist when needed?

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

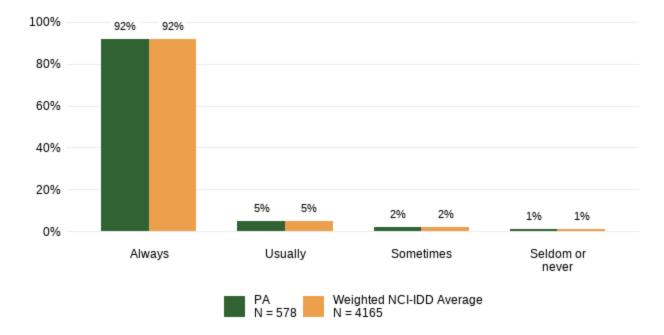
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
PA	69%	17%	6%	8%	641
Weighted NCI-IDD Average	67%	18%	7%	9%	4675



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?

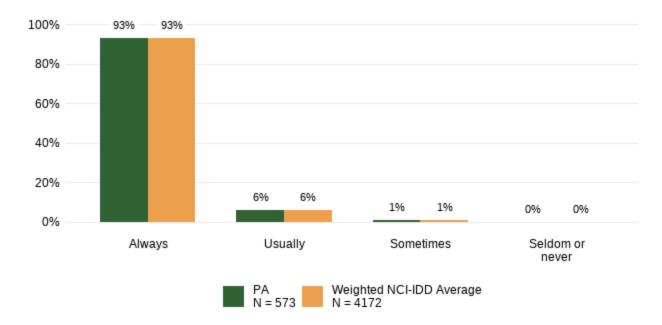
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	Ν
РА	63%	27%	7%	3%	566
Weighted NCI-IDD Average	63%	26%	8%	4%	4169



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?

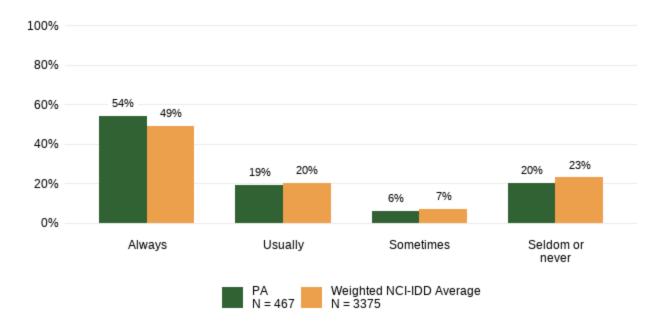
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
РА	92%	5%	2%	1%	578
Weighted NCI-IDD Average	92%	5%	2%	1%	4165



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

Table 77. Do you, your family member, or someone else in your family know what is needed to safely take the prescription medications (when it should be taken, how much to take, and the potential side effects)?

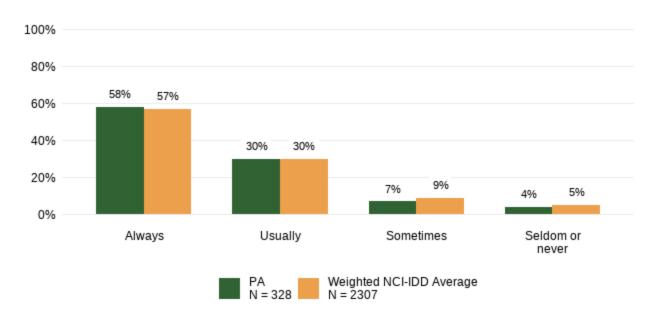
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	Ν
PA	93%	6%	1%	0%	573
Weighted NCI-IDD Average	93%	6%	1%	0%	4172



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)

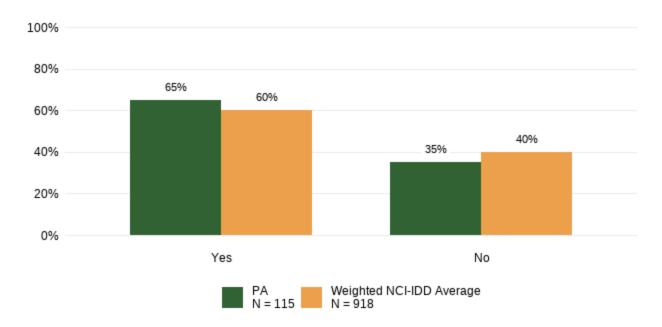
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	Ν
РА	54%	19%	6%	20%	467
Weighted NCI-IDD Average	49%	20%	7%	23%	3375



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?

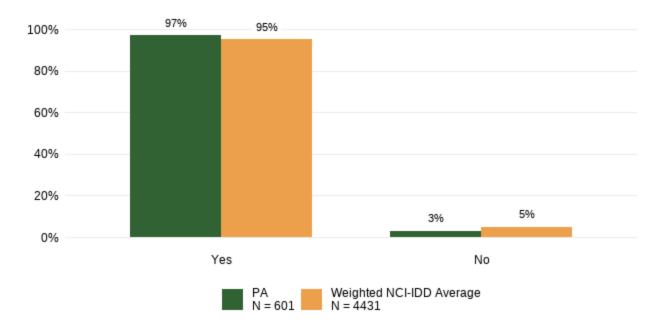
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	N
РА	58%	30%	7%	4%	328
Weighted NCI-IDD Average	57%	30%	9%	5%	2307



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?

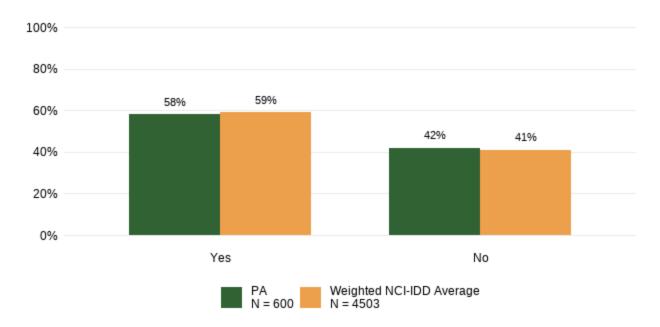
State (names abbreviated)	Yes	No	N
PA	65%	35%	115
Weighted NCI-IDD Average	60%	40%	918



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?

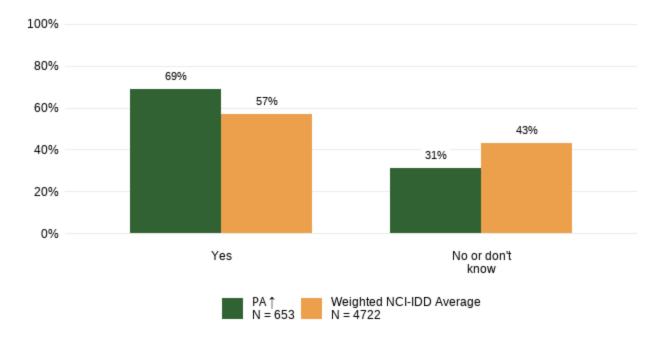
State (names abbreviated)	Yes	No	N
PA	97%	3%	601
Weighted NCI-IDD Average	95%	5%	4431



Have you talked about how to handle emergencies 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?

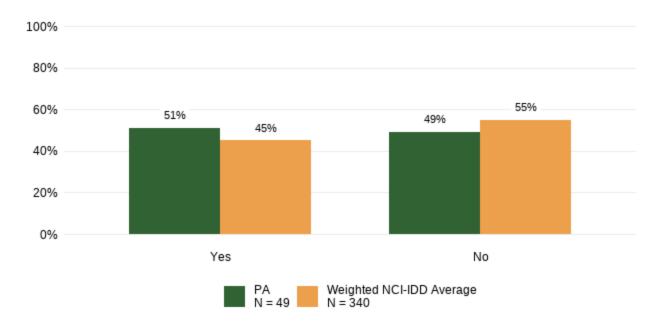
State (names abbreviated)	Yes	No	N
PA	58%	42%	600
Weighted NCI-IDD Average	59%	41%	4503



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?

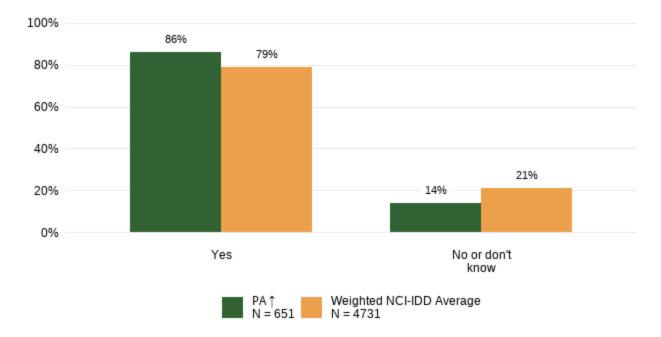
State (names abbreviated)	Yes	No or don't know	N
PA ↑	69%	31%	653
Weighted NCI-IDD Average	57%	43%	4722



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 (names abbreviated)	Yes	No	N
PA	51%	49%	49
Weighted NCI-IDD Average	45%	55%	340



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 (names abbreviated)	Yes	No or don't know	N
PA ↑	86%	14%	651
Weighted NCI-IDD Average	79%	21%	4731

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

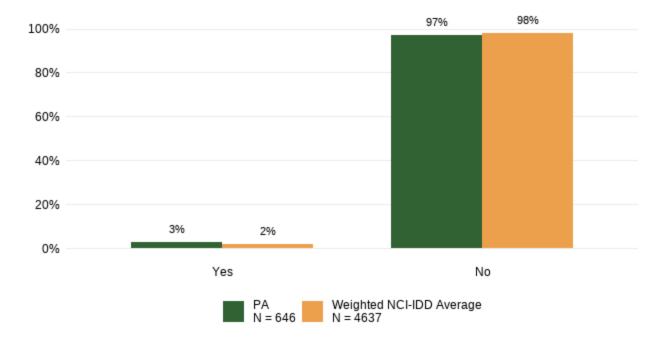
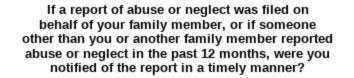


Table 86. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

State (names abbreviated)	Yes	No	N
PA	3%	97%	646
Weighted NCI-IDD Average	2%	98%	4637



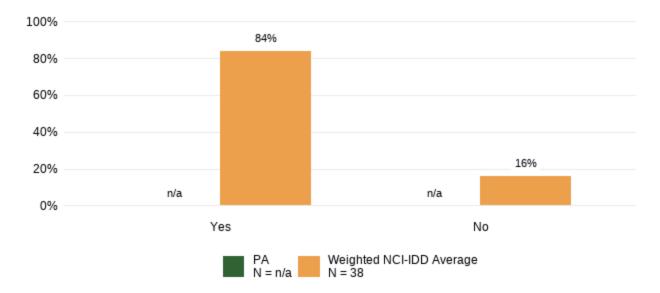


Table 87. If a report of abuse or neglect was filed on behalf of your family member, or if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?

State (names abbreviated)	Yes	No	Ν
PA	n/a	n/a	n/a
Weighted NCI-IDD Average	84%	16%	38

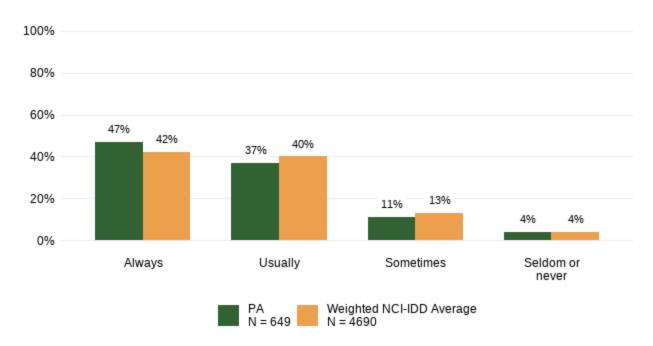
Family Satisfaction

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

Note: Significance is based on "Always" or "Yes" response.

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

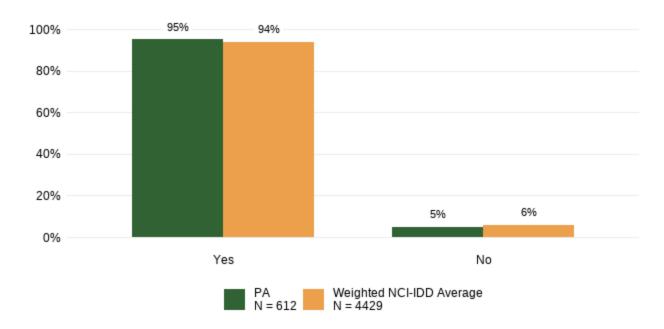
"Family Member" refers to the person receiving services whom the respondent is answering questions about in this survey.



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

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

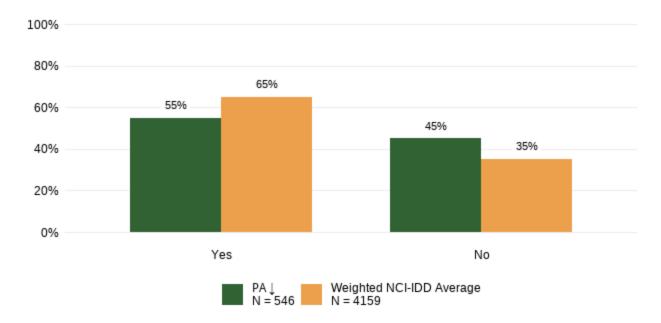
State (names abbreviated)	Always	Usually	Sometimes	Seldom or never	Ν
PA	47%	37%	11%	4%	649
Weighted NCI-IDD Average	42%	40%	13%	4%	4690



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?

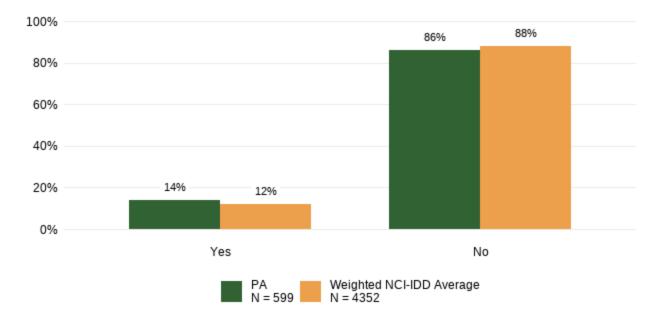
State (names abbreviated)	Yes	No	N
PA	95%	5%	612
Weighted NCI-IDD Average	94%	6%	4429



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?

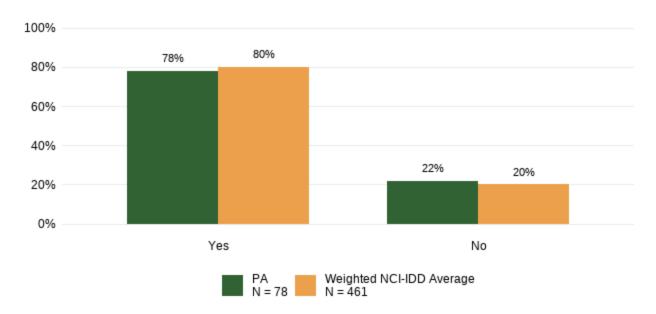
State (names abbreviated)	Yes	No	N
PA↓	55%	45%	546
Weighted NCI-IDD Average	65%	35%	4159



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

Table 91. Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?

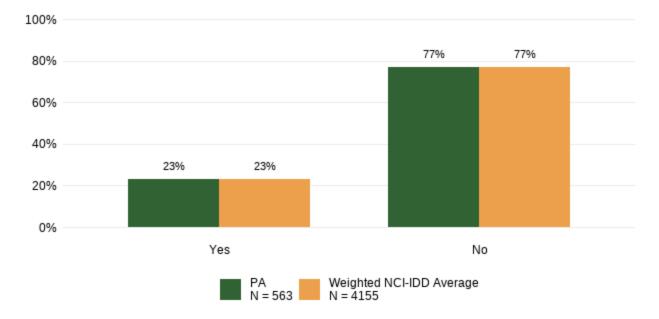
State (names abbreviated)	Yes	No	N
PA	14%	86%	599
Weighted NCI-IDD Average	12%	88%	4352



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

Table 92. If services or supports received by the family were reduced, suspended or terminated during the past 12 months, did the change in services affect your family member negatively?

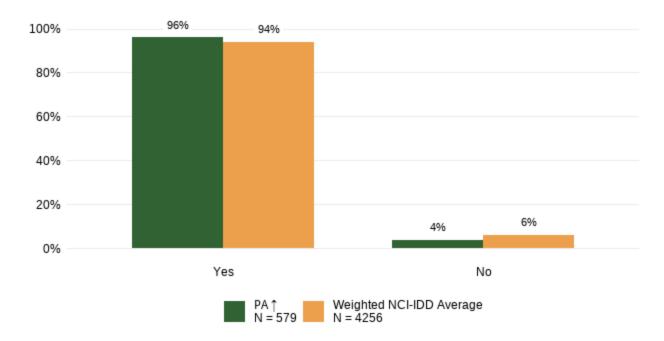
State (names abbreviated)	Yes	No	N
PA	78%	22%	78
Weighted NCI-IDD Average	80%	20%	461



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

Table 93. Have the services or supports that your family member received been increased in the past 12 months?

State (names abbreviated)	Yes	No	N
PA	23%	77%	563
Weighted NCI-IDD Average	23%	77%	4155



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 (names abbreviated)	Yes	No	N
PA ↑	96%	4%	579
Weighted NCI-IDD Average	94%	6%	4256