



Adult Family Survey (AFS) State Report

2023-24 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 2023-24 data collection cycle, 13 states submitted a valid sample of Adult Family Survey data: Arizona (AZ), California (CA), District of Columbia (DC), Georgia (GA), Indiana (IN), Maryland (MD), Missouri (MO), Montana (MT), New Jersey (NJ), New Hampshire (NH), Oklahoma (OK), Pennsylvania (PA), and Virginia (VA). This State Report provides results based on data submitted by June 30, 2024.

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.

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. So, 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.

The tables in this document, grouped by subdomain, display the state results alongside the average across states (NCI-IDD average). **Please note: the NCI-IDD averages shown throughout this report are weighted.** For more information see the [Methodology section](#).

"N" demonstrates the number of valid responses for each question. "N" can vary between questions. The N does not include missing responses, "don't know" responses or "not applicable" responses. For information on the total sample from each state, see Adult Family Survey Response Rates [here](#).

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

This section provides state and NCI-IDD results for demographic and survey outcomes data.

Presentation of the Data

- In addition to basic demographic questions and questions on services received, the survey contains seven groupings of questions that probe specific areas of quality service provision: information and planning, access and delivery of services, workforce, choice and control, community connections, health, welfare, and safety, and satisfaction.
- 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 have their data suppressed to only display "n/a"; 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 or conservator) filling out the survey. "Family Member" refers to the person receiving services whom the respondent is answering questions about in this survey.
- **Pennsylvania has been abbreviated throughout the report to PA.**
- **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.

Family Member

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

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

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

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	Yes	No	N
PA	15%	85%	639
Weighted NCI-IDD Average	15%	85%	18027

Table 2. Family Member's Residential Designation

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

State	Urban or Suburban (In or Near a City or Large Town)	Rural (Outside of a City or Town)	N
PA	59%	41%	628
Weighted NCI-IDD Average	79%	21%	17493

Table 3. Family Member's Age

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

State	Age	N
PA	33.1	662
Weighted NCI-IDD Average	34.1	18654

Table 4. Family Member's Gender

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

State	Male	Female	Other	N
PA	62%	38%	0%	640
Weighted NCI-IDD Average	62%	38%	0%	17861

Table 5. Family Member's Race/Ethnicity

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

State	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer Not to Say
PA	1%	5%	10%	0%	78%	6%	2%	2%
Weighted NCI-IDD Average	2%	10%	12%	1%	57%	22%	2%	3%

Table 6a. Family Member's Conditions

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

State	Intellectual Disability	Mood Illness/Psychiatric Diagnosis	Autism Spectrum Disorder	Cerebral Palsy
PA	81%	28%	44%	12%
Weighted NCI-IDD Average	65%	22%	44%	16%

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

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

State	Limited or No Vision – Legally Blind	Hearing Loss – Severe or Profound	Brain Injury	Seizure or Neurological Disorder
PA	5%	6%	5%	24%
Weighted NCI-IDD Average	7%	5%	7%	24%

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

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

State	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder (FASD)	Other
PA	0%	18%	0%	0%	16%
Weighted NCI-IDD Average	0%	14%	0%	1%	16%

Table 7a. Family Member's Health Conditions

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

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
PA	10%	16%	3%	21%	24%
Weighted NCI-IDD Average	9%	16%	4%	25%	29%

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

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

State	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Dementia	Oral Health Problems	Sleep Apnea
PA	8%	2%	2%	10%	20%
Weighted NCI-IDD Average	9%	2%	2%	11%	19%

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

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

State	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	19%	3%	2%	1%	32%
Weighted NCI-IDD Average	19%	5%	3%	1%	26%

Table 8. Family Member's Preferred Means of Communication

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

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
PA	85%	9%	2%	2%	2%	658
Weighted NCI-IDD Average	81%	11%	2%	2%	4%	18082

Table 9. 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	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
PA	96%	2%	0%	0%	0%	1%	1%	655
Weighted NCI-IDD Average	86%	8%	1%	0%	1%	1%	4%	18273

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

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

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

State	No Guardianship or Conservatorship	Limited Guardianship or Conservatorship	Full Guardianship or Conservatorship	Has Guardianship or Conservatorship but Level is Unknown	N
PA	48%	12%	35%	5%	596
Weighted NCI-IDD Average	35%	19%	42%	4%	17332

Table 11. Guardian or Conservator Relationship to Family Member

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

State	Family	Friend	Employee of State or Guardianship or Conservatorship Agency	Other	N
PA	94%	1%	1%	4%	287
Weighted NCI-IDD Average	96%	1%	0%	3%	9876

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

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

State	Did Not Complete High School, Not Currently in School	Currently Enrolled in High School	High School Certificate (NOT a High School Diploma/GED)	N
PA	6%	2%	24%	647
Weighted NCI-IDD Average	14%	2%	37%	17525

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

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

State	High School Diploma/GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
PA	59%	3%	4%	3%	647
Weighted NCI-IDD Average	31%	4%	7%	6%	17525

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

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

State	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
PA	57%	31%	12%	646
Weighted NCI-IDD Average	51%	30%	18%	17749

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

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

State	No Support Needed; No Issues with Personal Care Activities	Some Support Needed; Requires Only Occasional Assistance or Monitoring	Extensive Support Needed; Frequent or Severe Enough to Require Regular Assistance	N
PA	32%	41%	28%	651
Weighted NCI-IDD Average	25%	38%	37%	18212

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

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

State	No Support Needed; No Issues with Other Daily Activities	Some Support Needed; Requires Only Occasional Assistance or Monitoring	Extensive Support Needed; Frequent or Severe Enough to Require Regular Assistance	N
PA	3%	24%	73%	648
Weighted NCI-IDD Average	5%	22%	73%	18248

Respondents

This section provides information about the survey respondent.

Table 16. Language Usually Spoken at Home

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
PA	96%	2%	0%	0%	0%	0%	2%	652
Weighted NCI-IDD Average	83%	11%	1%	1%	1%	0%	4%	18260

Table note: Chinese” includes Mandarin, Cantonese, and Hokkien. “Tagalog” includes Filipino.

Table 17. Respondent’s Age

State	18 - 34	35 – 54	55 – 74	75 or Older	N
PA	4%	16%	70%	10%	652
Weighted NCI-IDD Average	5%	19%	64%	12%	18384

Table 18. Respondent’s Health

State	Excellent	Very good	Good	Fair	Poor	N
PA	13%	33%	36%	17%	2%	653
Weighted NCI-IDD Average	12%	32%	39%	15%	2%	18409

Table 19. Respondent's Relationship to Family Member

State	Parent (Biological, Adoptive, or Foster)	Sibling	Spouse	Grandparent	Other	N
PA	92%	5%	0%	2%	1%	658
Weighted NCI-IDD Average	88%	6%	0%	2%	3%	18498

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

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

State	No	Yes, Respondent Does	Yes, Another Family Member Does
PA	63%	26%	14%
Weighted NCI-IDD Average	51%	37%	16%

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	One	Two	Three	Four or More	N
PA	5%	27%	47%	21%	654
Weighted NCI-IDD Average	7%	27%	44%	22%	18353

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

State	One	Two	Three	Four or More	None	N
PA	5%	2%	1%	0%	92%	659
Weighted NCI-IDD Average	8%	3%	1%	1%	88%	18444

Table 23. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
PA	4%	31%	8%	14%	43%	656
Weighted NCI-IDD Average	10%	20%	6%	20%	44%	18130

Table 24. Total Taxable Household Income of Wage Earners in the Past Year

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

State	No Earned Income	Up to \$15,000	\$15,001–\$25,000	\$25,001–\$50,000	\$50,001–\$75,000	Over \$75,000	Prefer Not to Say	N
PA	10%	6%	7%	13%	13%	26%	26%	650
Weighted NCI-IDD Average	9%	6%	8%	16%	13%	25%	23%	17958

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	Financial Support	In Home Support	Out-of-Home Respite Care	Day or Employment Supports
PA	12%	41%	24%	54%
Weighted NCI-IDD Average	18%	39%	24%	50%

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	Transportation	Mental/Behavioral Health Care or Other Treatments or Therapies	Self-direction/Fiscal Intermediary Services
PA	57%	30%	40%
Weighted NCI-IDD Average	47%	24%	34%

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	Social Security SSI/SSB	Services or Supports from Other Agencies or Organizations
PA	95%	41%
Weighted NCI-IDD Average	88%	28%

Main Survey Results

Information and Planning

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

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.

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	38%	38%	19%	5%	620
Weighted NCI-IDD Average	33%	36%	21%	9%	16742

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	25%	51%	20%	4%	620
Weighted NCI-IDD Average	29%	44%	21%	5%	16807

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	90%	7%	2%	1%	633
Weighted NCI-IDD Average	82%	10%	4%	4%	17701

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	69%	23%	7%	1%	638
Weighted NCI-IDD Average	63%	25%	9%	3%	17230

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	27%	35%	23%	15%	546
Weighted NCI-IDD Average	25%	30%	23%	22%	15055

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	Employment	Financial	Housing	Legal
PA	29%	41%	59%	36%
Weighted NCI-IDD Average	34%	38%	51%	35%

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	Medical	Social or Relationships	Transition from School	Recreation or Having Fun	Other
PA	27%	34%	7%	40%	9%
Weighted NCI-IDD Average	32%	37%	11%	41%	11%

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

State	Yes	No	N
PA	52%	48%	551
Weighted NCI-IDD Average	51%	49%	14984

*Alternatives to guardianship/conservatorship 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.*

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

State	Yes	No	N
PA ↑	97%	3%	632
Weighted NCI-IDD Average	83%	17%	15776

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

State	Yes	No	N
PA ↑	92%	8%	549
Weighted NCI-IDD Average	85%	15%	10865

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

State	Yes	No	N
PA	86%	14%	588
Weighted NCI-IDD Average	83%	17%	12060

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

State	Yes	No	N
PA	70%	30%	574
Weighted NCI-IDD Average	65%	35%	11996

Table 38. Do you feel like your family had enough say or input in making the plan?

State	Yes	No	N
PA ↑	95%	5%	554
Weighted NCI-IDD Average	89%	11%	11308

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

State	Yes	No	N
PA ↓	6%	94%	633
Weighted NCI-IDD Average	11%	89%	16820

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

State	Yes	No	N
PA	85%	15%	26
Weighted NCI-IDD Average	71%	29%	1724

Table 41. If your family member had a transition plan, did the 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	48%	52%	1037

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.

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

State	Yes	No	N
PA	87%	13%	569
Weighted NCI-IDD Average	83%	17%	10970

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

State	Yes	No	N
PA	76%	24%	568
Weighted NCI-IDD Average	73%	27%	14789

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

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

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home and/or Vehicle Modifications
PA	65%	35%	15%	13%
Weighted NCI-IDD Average	52%	34%	18%	12%

Table 44b. If your family does not get the support and services needed, what additional services does your family need? (continued)*Categories are not mutually exclusive; therefore N is not shown.*

State	Counseling	Family-to-Family Networks	Assistive Technology Training and Support	Other
PA	9%	14%	5%	35%
Weighted NCI-IDD Average	23%	17%	14%	33%

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	45%	37%	13%	5%	523
Weighted NCI-IDD Average	39%	38%	16%	7%	12442

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

State	Yes	No	N
PA ↑	70%	30%	484
Weighted NCI-IDD Average	55%	45%	12095

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	49%	31%	12%	8%	225
Weighted NCI-IDD Average	49%	29%	11%	10%	6704

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↓	23%	28%	17%	33%	332
Weighted NCI-IDD Average	32%	28%	15%	25%	10692

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	51%	27%	10%	13%	156
Weighted NCI-IDD Average	61%	23%	8%	8%	7042

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	57%	35%	7%	1%	615
Weighted NCI-IDD Average	47%	35%	12%	5%	15009

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	63%	31%	5%	1%	642
Weighted NCI-IDD Average	55%	31%	10%	4%	17199

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

State	Yes	No	N
PA ↑	87%	13%	390
Weighted NCI-IDD Average	81%	19%	8992

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	85%	14%	1%	0%	627
Weighted NCI-IDD Average	78%	18%	2%	2%	15443

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

State	Yes	No	N
PA	28%	72%	624
Weighted NCI-IDD Average	32%	68%	17341

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

State	Yes	No	N
PA	92%	8%	648
Weighted NCI-IDD Average	91%	9%	18136

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

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 ↑	83%	15%	2%	639
Weighted NCI-IDD Average	79%	19%	3%	17869

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.

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	65%	28%	7%	1%	595
Weighted NCI-IDD Average	58%	32%	8%	3%	13056

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	79%	18%	2%	1%	604
Weighted NCI-IDD Average	74%	21%	4%	1%	14474

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	Always	Usually	Sometimes	Seldom or Never	N
PA	48%	34%	14%	5%	225
Weighted NCI-IDD Average	45%	32%	13%	10%	6942

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	56%	33%	10%	1%	585
Weighted NCI-IDD Average	48%	37%	12%	3%	13801

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

State	Yes	No	N
PA	35%	65%	557
Weighted NCI-IDD Average	35%	65%	12750

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

State	Yes	No	N
PA	77%	23%	546
Weighted NCI-IDD Average	75%	25%	12645

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.

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	66%	24%	5%	5%	496
Weighted NCI-IDD Average	62%	24%	7%	8%	10234

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	63%	22%	7%	7%	469
Weighted NCI-IDD Average	57%	24%	9%	10%	9896

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	63%	18%	7%	12%	413
Weighted NCI-IDD Average	59%	21%	7%	13%	9417

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

State	Yes	No, Didn't Choose but Can Change Case Manager/Service Coordinator if Wanted	No, Didn't Choose and Cannot Change Case Manager/Service Coordinator if Wanted	N
PA ↑	31%	57%	12%	566
Weighted NCI-IDD Average	26%	59%	16%	13687

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.

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

State	Yes	No	N
PA ↑	91%	9%	644
Weighted NCI-IDD Average	83%	17%	17917

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

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

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
PA	16%	18%	19%	10%	24%
Weighted NCI-IDD Average	20%	19%	19%	12%	24%

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

State	Yes	No	N
PA	62%	38%	628
Weighted NCI-IDD Average	59%	41%	17419

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	Yes	No	N
PA	76%	24%	474
Weighted NCI-IDD Average	74%	26%	12548

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

State	Yes	No	N
PA	15%	85%	560
Weighted NCI-IDD Average	18%	82%	15563

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.

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	82%	15%	2%	1%	641
Weighted NCI-IDD Average	74%	18%	4%	4%	17615

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	63%	30%	7%	1%	648
Weighted NCI-IDD Average	59%	30%	9%	2%	17304

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	73%	16%	6%	5%	648
Weighted NCI-IDD Average	67%	18%	7%	8%	17852

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	66%	25%	7%	2%	600
Weighted NCI-IDD Average	62%	26%	8%	4%	16129

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	92%	6%	1%	1%	545
Weighted NCI-IDD Average	89%	7%	2%	2%	14760

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	Always	Usually	Sometimes	Seldom or Never	N
PA	93%	7%	0%	0%	548
Weighted NCI-IDD Average	90%	8%	1%	1%	14623

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	53%	22%	8%	17%	484
Weighted NCI-IDD Average	46%	21%	9%	24%	13080

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	58%	31%	9%	2%	345
Weighted NCI-IDD Average	55%	29%	10%	6%	9624

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

State	Yes	No	N
PA	59%	41%	110
Weighted NCI-IDD Average	57%	43%	4376

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

State	Yes	No	N
PA ↑	96%	4%	602
Weighted NCI-IDD Average	92%	8%	16533

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	Yes	No	N
PA ↑	60%	40%	597
Weighted NCI-IDD Average	54%	46%	16420

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

State	Yes	No or Don't Know	N
PA ↑	70%	30%	637
Weighted NCI-IDD Average	50%	50%	18077

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

State	Yes	No	N
PA ↑	53%	47%	66
Weighted NCI-IDD Average	35%	65%	2508

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

State	Yes	No or Don't Know	N
PA ↑	93%	7%	606
Weighted NCI-IDD Average	82%	18%	16134

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

State	Yes	No	N
PA	3%	97%	621
Weighted NCI-IDD Average	2%	98%	17445

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	Yes	No	N
PA	n/a	n/a	n/a
Weighted NCI-IDD Average	70%	30%	160

Table note: PA had an N of less than 20, so their data is reported as n/a. They are included in the Weighted NCI-IDD Average.

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.

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	46%	41%	12%	2%	643
Weighted NCI-IDD Average	41%	40%	14%	4%	17756

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

State	Yes	No	N
PA ↑	97%	3%	616
Weighted NCI-IDD Average	93%	7%	16655

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

State	Yes	No	N
PA ↓	64%	36%	562
Weighted NCI-IDD Average	69%	31%	15649

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

State	Yes	No	N
PA	13%	87%	605
Weighted NCI-IDD Average	12%	88%	16464

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	Yes	No	N
PA	77%	23%	74
Weighted NCI-IDD Average	78%	22%	1756

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

State	Yes	No	N
PA	23%	77%	575
Weighted NCI-IDD Average	22%	78%	16050

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

State	Yes	No	N
PA ↑	96%	4%	590
Weighted NCI-IDD Average	93%	7%	16043