



Family/Guardian Survey (FGS) 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) Family/Guardian Survey is administered to families who have an adult family member (18 years or older) with an intellectual or developmental disability who does not live in the family home and receives at least one service other than case management. Not all states that participate in NCI-IDD administer the Family/Guardian Survey on an annual basis. Of the 48 states, the District of Columbia and 22 sub-state entities that were members of NCI-IDD during the 2023-24 data collection cycle, 11 states submitted a valid sample of Family/Guardian Survey data: Arizona (AZ), California (CA), Delaware (DE), Georgia (GA), Indiana (IN), Maryland (MD), Minnesota (MN), North Dakota (ND), New Jersey (NJ), New Hampshire (NH), and Pennsylvania (PA). This Final Report provides results based on data submitted by June 30, 2024.

What is the NCI-IDD Family/Guardian Survey?

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

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

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

What is included in this report?

This report includes this state's Family/Guardian Survey data compared to the NCI-IDD Average. 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 Family/Guardian Survey, data analysis and state samples, check out the [National Family/Guardian 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.

- Demographic results are shown in table form showing state outcomes and the NCI-IDD Average. Outcomes are shown by accessible tables showing state outcomes and the NCI-IDD Average.
- 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.
- 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.
- 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.
- **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 1a. Family Member's Residence

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

State	Specialized Facility for People with Intellectual Disabilities	Group Home or Agency Operated Apartment	Independent Home or Apartment	N
PA	8%	81%	7%	537
Weighted NCI-IDD Average	12%	59%	21%	8419

Table 1b. Family Member's Residence (continued)

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

State	Adult Foster Care or Host Family Home	Nursing Home	Homeless	Other	N
PA	4%	0%	0%	1%	537
Weighted NCI-IDD Average	4%	1%	0%	4%	8419

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

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

State	Less than One Year	One to Three Years	Four to Five Years	Over Five Years	N
PA	12%	25%	11%	53%	530
Weighted NCI-IDD Average	9%	21%	11%	59%	8397

Table 3. Family Member's Residential Designation

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

State	Urban or Suburban (In or Near a City or Large Town)	Rural (Outside of a City or Town)	N
PA	70%	30%	523
Weighted NCI-IDD Average	85%	15%	8302

Table 4. Family Member's Age

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

State	Age	N
PA	47.8	537
Weighted NCI-IDD Average	47.4	8581

Table 5. Family Member's Gender

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

State	Male	Female	Other	N
PA	59%	41%	0%	537
Weighted NCI-IDD Average	59%	41%	0%	8587

Table 6. 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%	1%	7%	0%	89%	2%	0%	2%
Weighted NCI-IDD Average	2%	4%	7%	0%	81%	6%	1%	2%

Table 7a. Family Member's Conditions

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

State	Intellectual Disability	Mood Illness/Psychiatric Diagnosis	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision – Legally Blind
PA	89%	43%	36%	16%	9%
Weighted NCI-IDD Average	78%	36%	33%	16%	8%

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	Hearing Loss – Severe or Profound	Brain Injury	Seizure or Neurological Disorder	Chemical Dependency
PA	6%	8%	27%	0%
Weighted NCI-IDD Average	6%	8%	25%	0%

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

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

State	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder (FASD)	Other
PA	11%	1%	2%	12%
Weighted NCI-IDD Average	10%	1%	1%	12%

Table 8a. Family Member's Health Conditions

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

State	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
PA	12%	19%	6%	29%	27%
Weighted NCI-IDD Average	9%	19%	6%	31%	31%

Table 8b. Family Member's Health Conditions (continued)

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

State	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Dementia	Oral Health Problems	Sleep Apnea
PA	16%	2%	5%	18%	17%
Weighted NCI-IDD Average	11%	2%	4%	16%	16%

Table 8c. Family Member's Health Conditions (continued)

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

State	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	11%	3%	4%	1%	22%
Weighted NCI-IDD Average	11%	4%	4%	1%	23%

Table 9. Family Member's Preferred Means of Communication

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

State	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
PA	80%	12%	1%	1%	6%	532
Weighted NCI- IDD Average	82%	12%	1%	1%	4%	8450

Table 10. 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	98%	0%	0%	0%	0%	0%	1%	532
Weighted NCI-IDD Average	96%	1%	0%	0%	0%	1%	2%	8489

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

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

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

State	No Guardianship or Conservatorship	Limited Guardianship or Conservatorship	Full Guardianship or Conservatorship	Has Guardianship or Conservatorship but Level is Unknown	N
PA	36%	19%	40%	6%	486
Weighted NCI-IDD Average	29%	19%	46%	5%	8065

Table 12. Guardian or Conservator Relationship to Family Member

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

State	Family	Friend	Employee of State or Guardianship or Conservatorship Agency	Other	N
PA	86%	1%	11%	2%	271
Weighted NCI-IDD Average	87%	2%	8%	3%	5185

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

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

State	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	30%	1%	30%	504
Weighted NCI-IDD Average	30%	0%	32%	8127

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

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

State	High School Diploma/GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
PA	36%	2%	1%	0%	504
Weighted NCI-IDD Average	27%	2%	4%	4%	8127

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

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

State	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	31%	40%	28%	523
Weighted NCI-IDD Average	37%	38%	25%	8327

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

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

State	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	22%	39%	39%	530
Weighted NCI-IDD Average	24%	39%	37%	8457

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

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

State	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	2%	15%	83%	532
Weighted NCI-IDD Average	3%	21%	76%	8475

Respondents

This section provides information about the survey respondent.

Table 17. Language Usually Spoken at Home

State	English	Spanish	Chinese	Tagalog	Vietnamese	American Sign Language	Other	N
PA	99%	0%	0%	0%	0%	0%	1%	530
Weighted NCI-IDD Average	97%	1%	0%	0%	0%	0%	1%	8447

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

Table 18. Respondent’s Age

State	18 - 34	35 - 54	55 - 74	75 or Older	N
PA	1%	9%	65%	25%	530
Weighted NCI-IDD Average	1%	9%	61%	28%	8473

Table 19. Respondent’s Health

State	Excellent	Very good	Good	Fair	Poor	N
PA	14%	34%	34%	15%	3%	528
Weighted NCI-IDD Average	15%	36%	34%	14%	2%	8507

Table 20. Respondent’s Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Public Guardian	Private Guardian	Other	N
PA	64%	32%	0%	2%	1%	1%	1%	531
Weighted NCI-IDD Average	64%	23%	0%	1%	2%	3%	7%	8481

Table 21. Respondent's Frequency of Visits with Family Member Past 12 Months

State	Did Not Visit	1 to 3 Times	4 to 6 Times	7 to 12 Times	More Than 12 Times	N
PA	3%	12%	11%	11%	63%	533
Weighted NCI-IDD Average	4%	11%	11%	11%	63%	8508

Table 22. Respondent's Highest Level of Education

State	No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
PA	2%	27%	8%	17%	46%	526
Weighted NCI-IDD Average	3%	16%	6%	20%	55%	8395

Table 23. Total Taxable Household Income of Wage Earners in the Last Year

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

State	No Earned Income	Up to \$15,000	\$15,001 to \$25,000	\$25,001 to \$50,000	\$50,001 to \$75,000	Over \$75,000	Prefer Not to Say	N
PA	10%	4%	5%	12%	10%	20%	40%	512
Weighted NCI-IDD Average	9%	4%	5%	12%	12%	24%	34%	8155

Services and Supports Received

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

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

Table 24a. Services and Supports Received from IDD Agency

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

State	Financial Support	In-Home Support	Residential Supports	Day or Employment Supports
PA	26%	31%	94%	52%
Weighted NCI-IDD Average	34%	42%	79%	63%

Table 24b. Services and Supports Received from IDD 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 or Behavioral Health Care or Other Treatments or Therapies	Self-Direction or Fiscal Intermediary Services
PA	94%	67%	11%
Weighted NCI-IDD Average	82%	52%	20%

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

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

State	Social Security (SSI or SSB)	Services or Supports from Other Agencies or Organizations
PA	97%	33%
Weighted NCI-IDD Average	94%	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 26. Do you get enough information to take part in planning services for your family member?

State	Always	Usually	Sometimes	Seldom or Never	N
PA	37%	39%	17%	7%	479
Weighted NCI-IDD Average	39%	36%	17%	8%	7769

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	40%	47%	10%	3%	480
Weighted NCI-IDD Average	39%	45%	12%	3%	7636

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	93%	4%	1%	3%	517
Weighted NCI-IDD Average	90%	5%	1%	3%	8086

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	55%	31%	10%	4%	506
Weighted NCI-IDD Average	58%	28%	9%	5%	7751

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	45%	34%	14%	7%	516
Weighted NCI-IDD Average	46%	30%	15%	9%	7871

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

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

State	Employment	Financial	Housing	Legal	Medical
PA	25%	33%	36%	33%	43%
Weighted NCI-IDD Average	28%	34%	40%	28%	44%

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

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

State	Social or Relationships	Transition From School	Recreation or Having Fun	Other
PA	37%	5%	43%	14%
Weighted NCI-IDD Average	36%	4%	42%	16%

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

State	Yes	No	N
PA	51%	49%	374
Weighted NCI-IDD Average	54%	46%	6560

Table note: Alternatives to guardianship or 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 33. Does your family member have a service plan?

State	Yes	No	N
PA ↑	98%	2%	487
Weighted NCI-IDD Average	92%	8%	6930

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

State	Yes	No	N
PA ↑	94%	6%	436
Weighted NCI-IDD Average	90%	10%	5633

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

State	Yes	No	N
PA	79%	21%	447
Weighted NCI-IDD Average	82%	18%	5948

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

State	Yes	No	N
PA	63%	37%	426
Weighted NCI-IDD Average	66%	34%	5804

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

State	Yes	No	N
PA	89%	11%	431
Weighted NCI-IDD Average	89%	11%	5651

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

State	Yes	No	N
PA	2%	98%	515
Weighted NCI-IDD Average	2%	98%	7915

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

State	Yes	No	N
PA	n/a	n/a	n/a
Weighted NCI-IDD Average	60%	40%	135

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.

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

State	Yes	No	N
PA	n/a	n/a	n/a
Weighted NCI-IDD Average	59%	41%	60

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.

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

State	Yes	No	N
PA	89%	11%	405
Weighted NCI-IDD Average	88%	12%	5360

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

State	Yes	No	N
PA	90%	10%	471
Weighted NCI-IDD Average	88%	12%	7254

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

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

State	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home and/or Vehicle Modifications
PA	3%	28%	15%	10%
Weighted NCI-IDD Average	10%	30%	19%	8%

Table 43b. If your family does not get the support and services needed, what additional services does your family need? (continued)*Categories are not mutually exclusive; therefore N is not shown.*

State	Counseling	Family to Family Networks	Support or Training to Use Assistive Technology	Other
PA	13%	15%	20%	55%
Weighted NCI-IDD Average	26%	14%	16%	46%

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	43%	38%	14%	5%	342
Weighted NCI-IDD Average	39%	41%	14%	6%	5563

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

State	Yes	No	N
PA	68%	32%	294
Weighted NCI-IDD Average	66%	34%	4937

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	69%	26%	3%	2%	303
Weighted NCI-IDD Average	63%	28%	6%	3%	4261

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	52%	37%	8%	3%	494
Weighted NCI-IDD Average	50%	37%	9%	4%	7511

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	57%	33%	7%	3%	499
Weighted NCI-IDD Average	55%	32%	8%	4%	7879

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

State	Yes	No	N
PA ↑	96%	4%	370
Weighted NCI-IDD Average	93%	7%	5546

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	75%	21%	3%	1%	502
Weighted NCI-IDD Average	75%	21%	3%	1%	7523

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

State	Yes	No	N
PA ↓	20%	80%	476
Weighted NCI-IDD Average	28%	72%	7724

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

State	Yes	No	N
PA	90%	10%	511
Weighted NCI-IDD Average	91%	9%	8183

Table 53. 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%	12%	5%	486
Weighted NCI-IDD Average	86%	11%	3%	7907

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	56%	38%	5%	1%	323
Weighted NCI-IDD Average	52%	41%	6%	2%	5363

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	77%	20%	3%	0%	500
Weighted NCI-IDD Average	72%	23%	4%	1%	7400

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	44%	45%	8%	3%	213
Weighted NCI-IDD Average	44%	40%	12%	5%	3041

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	42%	45%	11%	2%	471
Weighted NCI-IDD Average	40%	45%	13%	3%	7050

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

State	Yes	No	N
PA	44%	56%	424
Weighted NCI-IDD Average	42%	58%	6372

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

State	Yes	No	N
PA ↑	94%	6%	489
Weighted NCI-IDD Average	88%	12%	7079

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	61%	24%	5%	10%	292
Weighted NCI-IDD Average	61%	22%	6%	12%	4855

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	26%	20%	12%	43%	267
Weighted NCI-IDD Average	32%	19%	13%	37%	4519

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↓	8%	7%	4%	82%	304
Weighted NCI-IDD Average	15%	9%	7%	70%	4538

Table 63. 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	23%	50%	27%	402
Weighted NCI-IDD Average	20%	55%	25%	6569

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

State	Yes	No	N
PA ↑	91%	9%	501
Weighted NCI-IDD Average	87%	13%	7943

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

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

State	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
PA	11%	11%	25%	11%	27%
Weighted NCI-IDD Average	20%	17%	27%	9%	25%

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

State	Yes	No	N
PA	61%	39%	466
Weighted NCI-IDD Average	63%	37%	7578

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

State	Yes	No	N
PA	84%	16%	301
Weighted NCI-IDD Average	79%	21%	5511

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

State	Yes	No	N
PA	16%	84%	426
Weighted NCI-IDD Average	15%	85%	7009

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	79%	16%	2%	3%	504
Weighted NCI-IDD Average	75%	20%	3%	3%	7999

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	61%	34%	5%	0%	479
Weighted NCI-IDD Average	60%	33%	6%	1%	7564

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↑	77%	17%	4%	2%	504
Weighted NCI-IDD Average	68%	22%	6%	4%	8016

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	68%	28%	3%	1%	446
Weighted NCI-IDD Average	65%	28%	5%	2%	6799

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	66%	25%	7%	2%	475
Weighted NCI-IDD Average	70%	22%	6%	2%	7335

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA ↓	68%	25%	4%	3%	438
Weighted NCI-IDD Average	74%	20%	3%	3%	7003

Table 75. 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 ↑	62%	22%	7%	9%	412
Weighted NCI-IDD Average	55%	25%	8%	13%	6310

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	59%	32%	9%	1%	380
Weighted NCI-IDD Average	58%	31%	7%	3%	5363

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

State	Yes	No	N
PA	78%	22%	110
Weighted NCI-IDD Average	79%	21%	2161

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

State	Yes	No	N
PA	80%	20%	422
Weighted NCI-IDD Average	81%	19%	7078

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

State	Yes	No	N
PA	46%	54%	492
Weighted NCI-IDD Average	48%	52%	7788

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

State	Yes	No or Don't Know	N
PA	60%	40%	525
Weighted NCI-IDD Average	56%	44%	8333

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

State	Yes	No	N
PA	60%	40%	58
Weighted NCI-IDD Average	57%	43%	883

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

State	Yes	No or Don't Know	N
PA	71%	29%	514
Weighted NCI-IDD Average	69%	31%	8325

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

State	Yes	No	N
PA	9%	91%	494
Weighted NCI-IDD Average	6%	94%	7842

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

State	Yes	No	N
PA	81%	19%	42
Weighted NCI-IDD Average	77%	23%	309

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	44%	45%	10%	1%	526
Weighted NCI-IDD Average	44%	43%	11%	3%	8223

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

State	Yes	No	N
PA ↑	97%	3%	488
Weighted NCI-IDD Average	95%	5%	7827

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	45%	37%	13%	5%	428
Weighted NCI-IDD Average	48%	32%	12%	8%	6437

Table 88. 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 ↓	7%	93%	472
Weighted NCI-IDD Average	10%	90%	7298

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

State	Yes	No	N
PA	83%	17%	24
Weighted NCI-IDD Average	84%	16%	667

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

State	Yes	No	N
PA	21%	79%	399
Weighted NCI-IDD Average	21%	79%	6228

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

State	Yes	No	N
PA ↑	98%	2%	475
Weighted NCI-IDD Average	95%	5%	7617