

National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD)



National Report 2024-25

Pennsylvania

Family/Guardian Survey (FGS)





Human Services Research Institute

Human Services Research Institute (HSRI)

2336 Massachusetts Avenue

Cambridge, MA 02140



NASDDDS

National Association of State Directors
of
Developmental Disabilities Services

National Association of State Directors of Developmental Disabilities Services (NASDDDS)

301 N Fairfax Street, Suite 101

Alexandria, VA 22314

June 2026

Questions/Comments: nci@nationalcoreindicators.org

List of Acronyms Used in This Report

CMS Centers for Medicare & Medicaid Services

FGS Family/Guardian Survey HCBS – Home and Community-Based Services

HSRI Human Services Research Institute

IDD Intellectual and developmental disabilities

NASDDDS National Association of State Directors of Developmental Disabilities Services

NCI National Core Indicators

Table of Contents

Executive Summary	9
Results	11
Presentation of the Data	12
Demographics.....	13
Family Member.....	14
Table 1a. Family Member’s Residence	15
Table 1b. Family Member’s Residence (continued).....	15
Table 2. Family Member’s Time Living In Current Residence.....	15
Table 3. Family Member’s Residential Designation.....	16
Table 4. Family Member’s Age.....	16
Table 5. Family Member’s Gender.....	16
Table 6. Family Member’s Race/Ethnicity.....	17
Table 7a. Family Member’s Conditions.....	17
Table 7b. Family Member’s Conditions (continued)	18
Table 7c. Family Member’s Conditions (continued).....	18
Table 8a. Family Member’s Health Conditions	18
Table 8b. Family Member’s Health Conditions (continued).....	19
Table 8c. Family Member’s Health Conditions (continued).....	19
Table 9. Family Member’s Preferred Means of Communication.....	20
Table 10. Family Member’s Preferred Language	20
Table 11. Family Member Has Legal Court Appointed Guardian or Conservator.....	21
Table 12. Guardian or Conservator Relationship to Family Member.....	21
Table 13a. Family Member’s Highest Level of Education	21
Table 13b. Family Member’s Highest Level of Education (continued).....	22
Table 14. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors.....	22
Table 15. Family Member’s Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating).....	23
Table 16. Family Member’s Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping).....	23
Respondents	24
Table 17. Language Usually Spoken at Home.....	25
Table 18. Respondent’s Age.....	25
Table 19. Respondent’s Health	26

Table 20. Respondent's Relationship to Family Member	26
Table 21. Respondent's Frequency of Visits with Family Member Past 12 Months.....	27
Table 22. Respondent's Highest Level of Education.....	27
Table 23. Total Taxable Household Income of Wage Earners in the Last Year	27
Services and Supports Received.....	28
Table 24a. Services and Supports Received from IDD Agency.....	29
Table 24b. Services and Supports Received from IDD Agency (continued)	29
Table 25. Additional Services and Supports Received (not from the IDD Agency)	29
Main Survey Results	30
Information and Planning	31
Table 26. Do you get enough information to take part in planning services for your family member?	32
Table 27. Is the information you get about services and supports easy to understand?	32
Table 28. Do you get information about services and supports in your preferred language? ...	32
Table 29. Does the case manager or service coordinator listen to your family's choices and opinions?	32
Table 30. Do staff or the residential agency keep you informed about how your family member is doing?.....	33
Table 31a. Do you need help planning for your family member's future in any of these areas?...	33
Table 31b. Do you need help planning for your family member's future in any of these areas? (continued)	33
Table 32. Has your family learned about alternatives to guardianship/conservatorship?	33
Table 33. Does your family member have a service plan?	34
Table 34. Does the service plan include all the services and supports your family member needs?.....	34
Table 35. Did you or someone else in your family (besides your family member with a disability) help make the service plan?	34
Table 36. Did your family member help make the plan?	34
Table 37. Do you feel like your family had enough say or input in making the plan?	35
Table 38. Did your family member leave school services and begin adult services during the past 12 months?	35
Table 39. If your family member left school services during the past 12 months, did your family member have a transition plan?	35
Table 40. If your family member had a transition plan, did the transition plan include getting or continuing work in a community job?.....	35
Access and Delivery of Services and Supports.....	36
Table 41. Does your family member get all the services listed in the plan?	37

Table 42. Does your family get the supports and services it needs?.....	37
Table 43a. If your family does not get the support and services needed, what additional services does your family need?.....	37
Table 43b. If your family does not get the support and services needed, what additional services does your family need? (continued)	38
Table 44. Do services and supports change when your family’s needs change?.....	38
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).....	38
Table 46. Does your family member have the special equipment or accommodations that they need?	38
Table 47. Are you or your family member able to contact support workers when you want? ...	39
Table 48. Are you or your family member able to contact the case manager or service coordinator when you want?	39
Table 49. Do service providers for your family member work together to provide support?.....	39
Table 50. Are services delivered in a way that is respectful of your family’s culture?.....	39
Table 51. Does your family member use technology in their everyday life to help them do things on their own?.....	40
Table 52. Is there a computer, tablet (iPad or similar), or smartphone that you can use in your home?	40
Table 53. How well does the internet work in your home?	40
Workforce	41
Table 54. Do support workers come and go when they are supposed to?.....	42
Table 55. Do support workers speak to you in a way you understand?	42
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?	42
Table 57. Do support workers have the right information and skills to meet your family’s needs?	43
Table 58. Do your family member’s support workers change too often? Is there too much “turnover” of support workers?.....	43
Table 59. Is there always a staff person available to support your family member when support is needed?	43
Choice, Decision Making and Control.....	44
Table 60. Can someone in your family choose or change the provider agency that provides your family member’s services?	45
Table 61. Can someone in your family choose or change your family member’s support workers?	45

Table 62. Can someone in your family directly manage support staff?	45
Table 63. Did you, your family member, or someone else in your family choose your family member's case manager or service coordinator?	45
Community Connections	46
Table 64. Does your family member do things in the community?	47
Table 65. For your family member, what makes it hard to do things in the community?.....	47
Table 66. Does your family member have friends other than paid support workers or family?.	47
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?.....	48
Table 68. Does your family take part in any family-to-family networks in your community?	48
Health, Welfare and Safety	49
Table 69. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?	50
Table 70. Does your family member's primary care provider (doctor, registered nurse, etc.) understand your family member's needs related to their disability?	50
Table 71. Can your family member go to the dentist when needed?	50
Table 72. Does your family member's dentist understand your family member's needs related to their disability?	50
Table 73. If your family member takes prescription medications, do you know what they're for?	51
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)?.....	51
Table 75. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling.).....	51
Table 76. Does your family member's mental or behavioral health professional understand your family member's needs related to their disability?	51
Table 77. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?	52
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?	52
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?	52
Table 80. Do you know how to file a complaint or grievance about provider agencies or staff?	52
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?	53
Table 82. Do you know how to report abuse or neglect related to your family member?	53

Table 83. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?53

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?53

Family Satisfaction 54

Table 85. Overall, are you satisfied with the services and supports your family member currently receives?.....55

Table 86. Do you feel that services and supports have made a positive difference in the life of your family member?55

Table 87. Does the agency providing residential services to your family member involve them in important decisions?.....55

Table 88. Have the services or supports that your family member received during the past 12 months been reduced, suspended, or terminated?55

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?56

Table 90. Have the services or supports that your family member received been increased in the past 12 months?56

Table 91. Are services and supports helping your family member to live a good life?56

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 2024-25 data collection cycle, 4 states submitted a valid sample of Family/Guardian Survey data: Arizona, Maryland, New Jersey, Pennsylvania. This Final Report provides results based on data submitted by June 30, 2025.

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.

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.
- For 2024-25, due to the number of participating states, state averages were not tested to examine the significance of the difference 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.
- **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	7%	73%	16%	295
Weighted NCI-IDD Average	6%	74%	15%	1302

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	1%	1%	0%	1%	295
Weighted NCI-IDD Average	2%	0%	0%	2%	1302

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	8%	23%	9%	60%	291
Weighted NCI-IDD Average	9%	24%	10%	57%	1296

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	72%	28%	292
Weighted NCI-IDD Average	78%	22%	1288

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	47.6	298
Weighted NCI-IDD Average	46.6	1,315

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	N
PA	60%	40%	298
Weighted NCI-IDD Average	61%	39%	1315

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%	5%	0%	91%	2%	0%	2%
Weighted NCI-IDD Average	1%	2%	7%	0%	85%	3%	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 or Psychiatric Diagnosis	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision – Legally Blind
PA	88%	41%	34%	18%	10%
Weighted NCI-IDD Average	83%	38%	38%	17%	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	8%	9%	27%	0%
Weighted NCI-IDD Average	7%	9%	26%	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 Disabilities
PA	9%	1%	1%	10%
Weighted NCI-IDD Average	9%	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	8%	23%	5%	30%	39%
Weighted NCI-IDD Average	9%	21%	6%	30%	37%

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 or Dental Problems	Sleep Apnea
PA	15%	2%	4%	13%	22%
Weighted NCI-IDD Average	11%	2%	4%	15%	19%

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)
PA	6%	8%	3%	1%
Weighted NCI-IDD Average	5%	8%	4%	1%

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%	14%	2%	2%	2%	293
Weighted NCI-IDD Average	80%	14%	2%	2%	3%	1285

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%	1%	2%	294
Weighted NCI-IDD Average	97%	0%	0%	0%	0%	1%	2%	1291

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%	12%	44%	8%	268
Weighted NCI-IDD Average	30%	12%	52%	6%	1244

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	90%	0%	8%	2%	162
Weighted NCI-IDD Average	91%	1%	6%	2%	867

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	25%	0%	28%	283
Weighted NCI-IDD Average	26%	0%	31%	1261

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	40%	1%	1%	4%	283
Weighted NCI-IDD Average	33%	2%	2%	5%	1261

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	30%	44%	26%	280
Weighted NCI-IDD Average	31%	41%	27%	1257

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	19%	39%	42%	290
Weighted NCI-IDD Average	18%	39%	42%	1287

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	1%	15%	84%	293
Weighted NCI-IDD Average	1%	15%	84%	1290

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%	1%	0%	0%	0%	0%	0%	288
Weighted NCI-IDD Average	99%	0%	0%	0%	0%	0%	1%	1265

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%	8%	68%	23%	295
Weighted NCI-IDD Average	1%	9%	66%	24%	1296

Table 19. Respondent's Health

State	Excellent	Very Good	Good	Fair	Poor	N
PA	12%	30%	37%	19%	1%	292
Weighted NCI-IDD Average	11%	36%	36%	16%	1%	1285

Table 20. Respondent's Relationship to Family Member

State	Parent	Sibling	Spouse	Grandparent	Public Guardian	Private Guardian	Other	N
PA	63%	32%	0%	1%	1%	1%	1%	293
Weighted NCI-IDD Average	65%	28%	0%	1%	1%	1%	3%	1293

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	4%	12%	8%	12%	64%	294
Weighted NCI-IDD Average	3%	10%	9%	12%	66%	1299

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	3%	25%	5%	14%	52%	291
Weighted NCI-IDD Average	2%	18%	4%	17%	59%	1278

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	11%	4%	5%	16%	10%	19%	34%	280
Weighted NCI-IDD Average	10%	3%	4%	13%	10%	25%	35%	1253

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 Supports	Residential Supports	Day or Employment Supports
PA	26%	46%	83%	55%
Weighted NCI-IDD Average	29%	41%	84%	65%

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	93%	63%	16%
Weighted NCI-IDD Average	93%	63%	18%

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 payments (SSI or SSB)	Services or Supports from other Agencies or Organizations
PA	98%	31%
Weighted NCI-IDD Average	96%	29%

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.

“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	39%	36%	20%	5%	259
Weighted NCI-IDD Average	40%	38%	17%	6%	1218

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	39%	45%	15%	2%	262
Weighted NCI-IDD Average	36%	47%	14%	3%	1212

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	96%	2%	1%	2%	278
Weighted NCI-IDD Average	93%	4%	1%	2%	1266

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%	28%	13%	5%	275
Weighted NCI-IDD Average	59%	26%	11%	4%	1234

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	49%	24%	18%	10%	282
Weighted NCI-IDD Average	46%	27%	18%	9%	1231

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	26%	27%	30%	25%	35%
Weighted NCI-IDD Average	27%	33%	36%	27%	41%

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	41%	5%	45%	16%
Weighted NCI-IDD Average	39%	3%	44%	14%

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

State	Yes	No	N
PA	55%	45%	213
Weighted NCI-IDD Average	54%	46%	1061

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%	266
Weighted NCI-IDD Average	96%	4%	1104

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

State	Yes	No	N
PA	92%	8%	237
Weighted NCI-IDD Average	90%	10%	956

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

State	Yes	No	N
PA	78%	22%	244
Weighted NCI-IDD Average	84%	16%	987

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

State	Yes	No	N
PA	67%	33%	233
Weighted NCI-IDD Average	67%	33%	967

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

State	Yes	No	N
PA	88%	12%	235
Weighted NCI-IDD Average	90%	10%	964

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

State	Yes	No	N
PA	1%	99%	288
Weighted NCI-IDD Average	1%	99%	1260

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

Due to the low N overall, the measure is not reported

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

Due to the low N overall, the measure is not reported

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.

“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	87%	13%	223
Weighted NCI-IDD Average	87%	13%	906

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

State	Yes	No	N
PA	92%	8%	261
Weighted NCI-IDD Average	89%	11%	1143

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	10%	30%	15%	15%
Weighted NCI-IDD Average	14%	23%	15%	14%

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	Assistive Technology Training and Support	Other
PA	20%	15%	10%	60%
Weighted NCI-IDD Average	23%	15%	12%	55%

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	41%	43%	13%	4%	197
Weighted NCI-IDD Average	38%	44%	14%	4%	901

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	76%	24%	177
Weighted NCI-IDD Average	68%	32%	795

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	67%	22%	7%	4%	155
Weighted NCI-IDD Average	64%	25%	8%	4%	675

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	60%	31%	8%	1%	274
Weighted NCI-IDD Average	54%	35%	9%	2%	1198

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	59%	31%	7%	3%	271
Weighted NCI-IDD Average	59%	31%	7%	3%	1212

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

State	Yes	No	N
PA	92%	8%	193
Weighted NCI-IDD Average	92%	8%	897

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	78%	17%	4%	1%	274
Weighted NCI-IDD Average	75%	20%	3%	1%	1198

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	24%	76%	262
Weighted NCI-IDD Average	26%	74%	1180

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

State	Yes	No	N
PA	92%	8%	274
Weighted NCI-IDD Average	93%	7%	1224

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

State	The Internet Always Works, The Connection Is Good	The Internet Rarely or Never Works, The Connection is Bad or I Do Not Have Internet in My Home	The Internet Sometimes Works, The Connection is Sometimes Good	N
PA	85%	4%	11%	265
Weighted NCI-IDD Average	87%	3%	10%	1196

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.

“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	57%	37%	5%	2%	194
Weighted NCI-IDD Average	54%	39%	5%	2%	870

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	79%	18%	1%	1%	274
Weighted NCI-IDD Average	74%	21%	3%	2%	1192

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	57%	31%	8%	4%	118
Weighted NCI-IDD Average	48%	37%	11%	5%	517

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	46%	41%	10%	3%	261
Weighted NCI-IDD Average	40%	44%	13%	3%	1148

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	48%	52%	239
Weighted NCI-IDD Average	47%	53%	1062

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

State	Yes	No	N
PA	91%	9%	260
Weighted NCI-IDD Average	82%	18%	1132

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.

“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	65%	21%	3%	11%	164
Weighted NCI-IDD Average	62%	21%	5%	12%	806

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	32%	17%	18%	33%	153
Weighted NCI-IDD Average	30%	17%	15%	38%	734

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	10%	6%	6%	79%	163
Weighted NCI-IDD Average	12%	6%	6%	76%	771

Table 63. Did you, your family member, or someone else in your family choose your family member's case manager or 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%	47%	30%	213
Weighted NCI-IDD Average	28%	47%	25%	1025

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.

“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%	264
Weighted NCI-IDD Average	90%	10%	1186

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	16%	13%	28%	10%	24%
Weighted NCI-IDD Average	18%	14%	29%	10%	26%

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

State	Yes	No	N
PA	67%	33%	259
Weighted NCI-IDD Average	62%	38%	1153

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	80%	20%	179
Weighted NCI-IDD Average	78%	22%	855

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

State	Yes	No	N
PA	17%	83%	224
Weighted NCI-IDD Average	17%	83%	1061

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.

“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%	18%	1%	1%	271
Weighted NCI-IDD Average	78%	18%	2%	1%	1196

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	69%	28%	3%	0%	259
Weighted NCI-IDD Average	64%	31%	5%	1%	1145

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	73%	21%	4%	2%	273
Weighted NCI-IDD Average	70%	22%	4%	3%	1203

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

State	Always	Usually	Sometimes	Seldom or Never	N
PA	70%	23%	7%	0%	233
Weighted NCI-IDD Average	67%	25%	6%	2%	1055

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	69%	21%	7%	3%	251
Weighted NCI-IDD Average	73%	19%	6%	2%	1109

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	76%	18%	3%	4%	242
Weighted NCI-IDD Average	76%	18%	3%	3%	1080

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	66%	24%	2%	9%	217
Weighted NCI-IDD Average	59%	26%	5%	10%	1004

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	72%	23%	5%	1%	199
Weighted NCI-IDD Average	63%	30%	6%	2%	860

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	85%	15%	72
Weighted NCI-IDD Average	82%	18%	329

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

State	Yes	No	N
PA	76%	24%	233
Weighted NCI-IDD Average	77%	23%	1051

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	47%	53%	260
Weighted NCI-IDD Average	44%	56%	1163

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	66%	34%	276
Weighted NCI-IDD Average	60%	40%	1213

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	65%	35%	34
Weighted NCI-IDD Average	55%	45%	181

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	76%	24%	270
Weighted NCI-IDD Average	72%	28%	1213

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	11%	89%	257
Weighted NCI-IDD Average	10%	90%	1153

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%	21
Weighted NCI-IDD Average	73%	27%	82

Family Satisfaction

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

“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	48%	40%	8%	4%	273
Weighted NCI-IDD Average	43%	44%	10%	3%	1213

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

State	Yes	No	N
PA	94%	6%	265
Weighted NCI-IDD Average	94%	6%	1171

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	52%	28%	13%	7%	224
Weighted NCI-IDD Average	49%	29%	13%	9%	1012

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	9%	91%	245
Weighted NCI-IDD Average	10%	90%	1118

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	n/a	n/a	n/a
Weighted NCI-IDD Average	81%	19%	91

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

State	Yes	No	N
PA	18%	82%	218
Weighted NCI-IDD Average	18%	82%	1009

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

State	Yes	No	N
PA	95%	5%	254
Weighted NCI-IDD Average	95%	5%	1137