



In-Person Survey (IPS) State Report

2024-25 Pennsylvania Report



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The NCI-IDD average is weighted
In-Person Survey 2024-25 State Report

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The NCI-IDD average is weighted

What is National Core Indicators® – Intellectual and Developmental Disabilities (NCI-IDD)?

The National Core Indicators® – Intellectual and Developmental Disabilities (NCI-IDD) program is a voluntary effort by state developmental disability agencies to track their performance using a standardized set of consumer and family/guardian surveys with nationally validated measures. The effort is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI).

Where are the statistics in this report from?

This report includes findings from the National Core Indicators® 2024-25 In-Person Survey (IPS). The data shown are weighted NCI-IDD averages. These data are comprised of valid surveys collected across 39 states: AL, AZ, AR, CA, CO, CT, DE, DC, GA, HI, IL, IN, KS, KY, LA, MD, MI, MN, MO, MT, NE, NV, NH, NJ, NY, NC, ND, OH, OK, OR, PA, SC, SD, TX, UT, VA, WA, WI, WY.

What is the NCI-IDD In-Person Survey?

The NCI-IDD In-Person Survey is completed with adults with IDD age 18 and older receiving at least one paid service (in addition to case management) from the state DD service system. The survey instrument includes a “Background Information Section”, which gathers data about the consumer from agency records, and an In-Person Survey that is conducted face-to-face with the person receiving services, either in person or via videoconference. The In-Person Survey is composed of two sections: Section I includes subjective questions that can only be answered by the person receiving services from the state. Section II includes objective, fact-based questions that can be answered by the person or, if needed, a proxy respondent who knows the person well.

What is included in this report?

This report includes this state’s In-Person Survey data compared to the weighted NCI-IDD Average. State outcomes that are statistically significantly higher or lower than the NCI-IDD Average are indicated with an arrow:

1. Outcomes where the state is significantly above the NCI-IDD average are denoted with an up arrow ↑;
2. Outcomes where the state is significantly below the NCI-IDD average are denoted with a down arrow ↓.

Significance was set at $\alpha = .01$, with effect size considered. For more information about significance testing and effect size, please see the Methodology section of the National report.

The NCI-IDD average is weighted

Presentation of Data

Many questions in the IPS allow respondents to answer a question with “middle” response like “maybe”, “sometimes” or “in-between”. The data in this report are “collapsed” data. That means that two or more response options are grouped together if they are considered to reflect a positive outcome. The table titles explain which options were grouped. To see the breakout of responses for each option, please see Appendix C of the National In-Person Report.

The NCI-IDD averages are “weighted” to reflect the states’ relative population and sample sizes. We created the weights using the state’s number of valid surveys and its total survey-eligible population. This way, a state that provides services to a larger number of people but uses a sample similar in size to other states has a greater influence on the overall NCI-IDD average (that is, its contribution is *proportional to its service population*). To find out more about the development of In-Person Survey, data analysis and state samples, check out the National In-Person Survey Report.

The NCI-IDD average is weighted

Demographics

This section presents descriptive information of individuals surveyed.

Important note on data Several states had large amounts of missing data or data recorded as “don’t know.” Where 25% or more of a state’s sample had “don’t know” or missing responses, we used an asterisk (*) to indicate that state’s data should be interpreted with caution as it may not accurately represent the sample or service population.

The NCI-IDD average is weighted

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Table 1. Age

State	Age (Mean)	Minimum	Maximum	Standard Deviation	Age (Median)	N
PA	41.8	18	87	16.5	36	879
NCI-IDD	40.6	18	90	15.8	37	30790

Table 2. Age Group

State	18-22	23-34	35-54	55-74	75 and Older	Unknown	N
PA	6%	38%	28%	24%	3%	0%	882
NCI-IDD	10%	35%	33%	20%	3%	0%	30888

Table 3. Sex

Refers to individual's sex as assigned at birth.

State	Male	Female	Unknown	N
PA	58%	42%	0%	870
NCI-IDD	60%	40%	0%	30838

Table 4. Marital Status

Information may have been obtained through state records.

State	Single, never married	Married	Single, married in the past	Unknown	N
PA	97%	0%	2%	1%	846
NCI-IDD	94%	1%	2%	3%	30545

The NCI-IDD average is weighted

Table 5. Is This Person a Parent?

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

State	No, does not have a child	Yes, parent of a child or children under 18	Yes, parent of a child or children over 18	Yes, parent of a child or children, unknown age(s)	Unknown
PA	97%	1%	2%	0%	2%
NCI-IDD	97%	1%	2%	0%	10%

Table 6. Race and Ethnicity

Categories are not mutually exclusive; therefore, N is not shown; “Don’t Know” responses are included in the denominator, which is different from past years. In previous years, this variable was mutually exclusive.

State	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Don't Know
PA	0%	3%	15%	0%	77%	6%	1%	1%
NCI-IDD	1%	4%	17%	0%	65%	14%	2%	5%

Table 7. Residential Designation

Information based on residential designation defined by the USDA: <https://www.ers.usda.gov/data-products/rural-urban-commuting-area-codes.aspx>

State	Metropolitan	Micropolitan	Rural	Small town	N
PA	77%	13%	5%	6%	877
NCI-IDD	81%	11%	2%	5%	30695

Table 8. Type of Residence - ICFs/IID, Nursing Facilities or Other Specialized Institutional Settings

State	ICF/IID, 4-6 residents with disabilities	ICF/IID, 7-15 residents with disabilities	ICF/IID, 16 or more residents with disabilities	Nursing facility	Other specialized institutional facility	N
PA	0%	0%	1%	0%	0%	837
NCI-IDD	1%	1%	0%	0%	0%	30775

The NCI-IDD average is weighted

Table 9. Type of Residence - Group Residential Setting

State	Group living setting, 2-3 people with disabilities	Group living setting, 4-6 people with disabilities	Group living setting, 7-15 people with disabilities	N
PA	29%	6%	1%	837
NCI-IDD	8%	17%	3%	30775

Table 10. Type of Residence (continued)

State	Own home or apartment	Parent or relative's home	Foster care or host home (2 or more people with a disability)	Foster care, host home, or shared living (1 person with a disability)	Homeless or crisis bed placement	Other	Unknown	N
PA	10%	46%	1%	0%	0%	5%	0%	837
NCI-IDD	15%	48%	3%	1%	0%	1%	1%	30775

Table 11. Length of Time at Current Residence (if not homeless or in crisis bed placement)

State	Less than 1 year	1-3 years	4-5 years	Over 5 years	Unknown	N
PA	8%	18%	9%	58%	8%	811
NCI-IDD	8%	16%	8%	63%	5%	29297

Table 12. Person's Residence Owned or Controlled by Provider Agency

State	Yes	No	Unknown	N
PA	42%	56%	2%	833
NCI-IDD	35%	63%	2%	29329

The NCI-IDD average is weighted

Table 13. Person Is Named on the Lease or Other Legally Enforceable Rental Agreement

State	No	Yes, named on lease or deed	Yes, named on other legally enforceable rental agreement	Unknown	N
PA	69%	7%	9%	15%	826
NCI-IDD	46%	18%	7%	29%	19961

Table 14. Has Intellectual/Developmental Disability Diagnosis

State	Yes	No	Unknown	N
PA	94%	5%	1%	837
NCI-IDD	82%	17%	1%	29590

Table 15. Level of Intellectual/Developmental Disability

State	Mild	Moderate	Severe	Profound	Unspecified	Unknown	N
PA	47%	33%	9%	4%	6%	1%	779
NCI-IDD	39%	27%	11%	6%	15%	2%	25501

Table 16. Mood, Anxiety, Behavior, Psychotic, and Other Mental Illness

Categories are not mutually exclusive; therefore, N is not shown; “Don’t Know” responses are included in the denominator.

State	Mood disorder	Anxiety disorder	Behavior challenges	Psychotic disorder	Other mental illness or psychiatric diagnosis
PA	33%	36%	19%	8%	9%
NCI-IDD	23%	22%	20%	8%	8%

The NCI-IDD average is weighted

Table 17. Diagnoses Noted in Record

Categories are not mutually exclusive; therefore, N is not shown; “Don’t Know” responses are included in the denominator.

State	Autism spectrum disorder	Cerebral palsy	Brain injury	Seizure disorder	Chemical dependency
PA	29%	10%	2%	20%	0%
NCI-IDD	30%	15%	3%	23%	0%

Table 18. Diagnoses Noted in Record (continued)

Categories are not mutually exclusive; therefore, N is not shown; “Don’t Know” responses are included in the denominator.

State	Down syndrome	Prader-Willi syndrome	Fetal alcohol syndrome	Limited or no vision	Severe or profound hearing loss	Other disabilities not listed	No other disabilities other than ID
PA	8%	0%	1%	6%	4%	16%	14%
NCI-IDD	7%	0%	1%	5%	4%	15%	10%

Table 19. Other Conditions in Record

Categories are not mutually exclusive; therefore, N is not shown; “Don’t Know” responses are included in the denominator.

State	Cardiovascular disease	Diabetes	Cancer	High blood pressure	High cholesterol
PA	9%	19%	4%	25%	30%
NCI-IDD	9%	20%	3%	30%	25%

Table 20. Other Conditions in Record (continued)

Categories are not mutually exclusive; therefore, N is not shown; “Don’t Know” responses are included in the denominator.

State	Dysphagia	Pressure ulcers	Alzheimer's disease or other dementia	Oral health or dental problems	Sleep apnea
PA	11%	2%	4%	3%	10%
NCI-IDD	9%	1%	3%	4%	11%

The NCI-IDD average is weighted

Table 21. Other Conditions in Record (continued)

Categories are not mutually exclusive; therefore, N is not shown; “Don’t Know” responses are included in the denominator.

State	Asthma	Other pulmonary diagnosis	Chronic kidney disease	Long-term health problems associated with COVID-19	Other
PA	11%	3%	3%	0%	53%
NCI-IDD	13%	5%	3%	0%	53%

Table 22. Preferred Language

Information may have been obtained through state records.

State	English	Spanish	Chinese (including Mandarin, Cantonese and Hokkien)	Tagalog (including Filipino)	Vietnamese	American Sign Language (ASL)	Other	N
PA	97%	2%	0%	0%	0%	1%	0%	839
NCI-IDD	93%	6%	0%	0%	0%	0%	1%	30618

Table 23. Preferred Means of Communication

Information may have been obtained through state records.

State	Spoken	Gestures or body language	Sign language or finger spelling	Communication device	Other	Unknown	N
PA	80%	15%	1%	2%	1%	0%	838
NCI-IDD	80%	14%	1%	1%	4%	0%	29346

Table 24. Mobility

Information may have been obtained through state records.

State	Moves self around environment without aids	Moves self around environment with aids or uses wheelchair independently	Non-ambulatory and always needs assistance to move around environment	Unknown	N
PA	81%	11%	6%	2%	838
NCI-IDD	77%	13%	10%	1%	30538

The NCI-IDD average is weighted

Table 25. Support Needed to Manage Self-Injurious Behavior

State	None	Some	Extensive	Unknown	N
PA	73%	17%	5%	5%	813
NCI-IDD	74%	17%	5%	3%	28755

Table 26. Support Needed to Manage Disruptive Behavior

State	None	Some	Extensive	Unknown	N
PA	60%	29%	5%	6%	809
NCI-IDD	56%	26%	11%	8%	28814

Table 27. Support Needed to Manage Destructive Behavior

State	None	Some	Extensive	Unknown	N
PA	70%	20%	4%	6%	811
NCI-IDD	71%	16%	5%	9%	26820

Table 28. Level of Guardianship/Conservatorship

State	None	Limited guardianship/conservatorship	Full guardianship/conservatorship	Has guardian/conservator but unable to distinguish level	Unknown	N
PA	76%	2%	18%	2%	2%	860
NCI-IDD	49%	10%	28%	11%	2%	30720

Table 29. Guardian's/Conservator's Relationship to Person

State	Family	Friend	Public guardian/conservator or public administrator	Financial institution	N
PA	82%	2%	6%	0%	190
NCI-IDD	67%	2%	16%	0%	14215

The NCI-IDD average is weighted

Table 30. Guardian's/Conservator's Relationship to Person (continued)

State	Non-profit guardianship/conservatorship agency	For-profit guardianship/conservatorship agency	Unknown	Other	N
PA	4%	1%	4%	2%	190
NCI-IDD	2%	0%	8%	5%	14215

Table 31. Funding Source

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

State	ICF/IID	Medicaid HCBS waiver funded services	Medicaid state plan funded	LTC exclusively supported by state funds and no Medicaid	LTC exclusively supported by state funds, person has Medicaid for health	Unknown
PA	6%	87%	4%	1%	0%	4%
NCI-IDD	2%	86%	38%	0%	0%	2%

Table 32. Person Receives Medicare

State	Yes	No	Unknown	N
PA *	42%	36%	21%	814
NCI-IDD	49%	41%	10%	22020

Asterisk (*) indicates the state had more than 25% missing or don't know responses.

Table 33. Amount of Daily Support Received at Home

State	24-hour on-site support or supervision	Daily on-site support	Scheduled less frequent than daily support	As-needed visitation and phone contact	None of these options	Unknown	N
PA	45%	21%	25%	2%	5%	3%	830
NCI-IDD	42%	17%	23%	2%	6%	9%	20723

The NCI-IDD average is weighted

Table 34. Has Remote Supports

Remote supports combine technology and direct care to provide supports such as home-based sensors, cameras, and other devices.

State	No, none	Yes, 24-hour remote supports	Yes, less than 24-hour remote supports	Unknown	N
PA	93%	1%	1%	5%	831
NCI-IDD	78%	3%	3%	16%	20244

Table 35. Has Ever Been Diagnosed or Presumed Diagnosed with COVID-19

State	Yes	No	Unknown	N
PA	25%	39%	36%	811
NCI-IDD	40%	42%	18%	27359

Table 36. Has Ever Required In-Patient Hospitalization Due to COVID-19 (of those who had COVID-19)

State	Yes	No	Unknown	N
PA	9%	85%	6%	202
NCI-IDD	8%	90%	2%	11424

Table 37. Has Gotten the COVID-19 Vaccine

State	Yes, fully vaccinated and has received at least one booster	Yes, fully vaccinated	Partially vaccinated—received one of two doses of Pfizer-BioNTech or Moderna or Novavax	Not vaccinated at all	Unknown	N
PA	44%	15%	4%	8%	28%	811
NCI-IDD	50%	16%	6%	10%	18%	26985

The NCI-IDD average is weighted

Employment

Value statement: People have competitive paid jobs in community-based businesses. People's jobs reflect varied preferences for employment.

NCI-IDD reports on four types of paid community jobs: 1. Individual job without publicly funded supports—an individual job in which the person does not receive state or other funded supports; 2. Individual job with publicly funded supports— an individual job in which the person receives state or other funded supports; 3. Group-supported—a job that takes part in a community setting but is done with a group of individuals with disabilities (e.g., work crew). Group-supported jobs may or may not receive publicly funded supports; and 4. Community job in a business that primarily hires people with disabilities—a job where the employees with disabilities interact with the non-disabled population; this job is not in a traditional sheltered workshop and is NOT an enclave.

Important note on data Several states had large amounts of missing data or data recorded as “don’t know.” Where 25% or more of a state’s sample had “don’t know” or missing responses, we used an asterisk (*) to indicate that state’s data should be interpreted with caution as it may not accurately represent the sample or service population.

The NCI-IDD average is weighted

Table 38. Has a community job; individual, group and/or in a business that primarily hires people with disabilities

State	No	Yes	N
PA	80%	20%	793
NCI-IDD	83%	17%	27290

Table 39. Does not have paid community job and wants a paid community job

State	No	Yes	N
PA	62%	38%	261
NCI-IDD	55%	45%	10535

Table 40. Has community employment as a goal in their service plan

State	No	Yes	N
PA	72%	28%	768
NCI-IDD	75%	25%	18470

Table 41. Uses special technology to help do their job

State	Yes	No	N
PA	16%	84%	154
NCI-IDD	16%	84%	4682

The NCI-IDD average is weighted

Table 42. Does these activities at least once a week

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

State	Attends day program or workshop	Volunteers	Job training	School/ classes	Community activities with paid support	Other	No activities	Unknown
PA	31%	18%	4%	3%	43%	19%	18%	4%
NCI-IDD	46%	20%	8%	10%	40%	22%	17%	3%

Table 43. Takes part in classes, training or skills building activities to gain skills to expand their job opportunities

State	No	Yes	N
PA	91%	9%	504
NCI-IDD	82%	18%	17301

Community Inclusion and Belonging

Value statement: People do things in their community they want to do. People feel like they belong to the communities/groups of their choosing.

The NCI-IDD average is weighted

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Table 44. Gets to go out and do the things likes to do in the community as much as wants to

State	Average	N
PA ↑	81%	487
NCI-IDD	71%	16914

Table 45. Does things in the community with the people they want

State	Average	N
PA ↑	88%	475
NCI-IDD	81%	16670

Table 46. Can be themselves when with others in groups, organizations, or communities the person takes part in (if person takes part in groups, organizations, or communities)

Proxy respondents were allowed for this question.

State	Average	N
PA	93%	229
NCI-IDD	92%	8123

Table 47. Others include them as part of the group in groups, organizations, or communities the person takes part in (if person takes part in groups, organizations, or communities)

Proxy respondents were allowed for this question.

State	Average	N
PA	92%	225
NCI-IDD	91%	8121

The NCI-IDD average is weighted

Table 48. Gets help to learn new things

State	Average	N
PA	76%	503
NCI-IDD	77%	16923

Choice and Decision Making

Value statement: People are supported to make everyday choices and life decisions. Support for decision-making includes necessary information and experiences.

Table 49. Chose or had some input in choosing where they live if not living in the family home

Proxy respondents were allowed for this question.

State	Average	N
PA	61%	379
NCI-IDD	57%	14383

Table 50. Chose or had some input in choosing their housemates if not living in the family home, or chose to live alone

Proxy respondents were allowed for this question.

State	Average	N
PA ↑	52%	390
NCI-IDD	44%	14534

Table 51. Decides or has help deciding their daily schedule

Proxy respondents were allowed for this question.

State	Average	N
PA ↑	93%	865
NCI-IDD	86%	30381

The NCI-IDD average is weighted

Table 52. Decides or has help deciding how to spend free time

Proxy respondents were allowed for this question; This is asking about who chooses how the person spends their time when they are not working, attending a day program, or doing other regular daily activity with or without supports.

State	Average	N
PA ↑	97%	863
NCI-IDD	93%	30337

Table 53. Has enough choice about what to do in free time

Proxy respondents were allowed for this question.

State	Average	N
PA ↑	96%	826
NCI-IDD	93%	29653

Table 54. Chose or had some help in choosing where they work (among those with a paid community job)

Proxy respondents were allowed for this question; Reported for those determined to have a paid community job based on Background Information section.

State	Average	N
PA	90%	134
NCI-IDD	89%	4055

The NCI-IDD average is weighted

Table 55. Chose or had some input in choosing day program or work program

Proxy respondents were allowed for this question; only includes those respondents determined to have an unpaid community activity, unpaid paid facility-based activity or paid facility-based activity in the Background Information section.

State	Average	N
PA ↑	74%	232
NCI-IDD	62%	8053

Table 56. Has input in choosing their regular day activities (in addition to or instead of a paid community job and/or day program/work program)

Proxy respondents were allowed for this question.

State	Average	N
PA ↑	90%	564
NCI-IDD	84%	18969

Table 57. Chooses or has help deciding what to buy or has set limits on what to buy with their spending money

Proxy respondents were allowed for this question.

State	Average	N
PA ↑	94%	838
NCI-IDD	89%	29440

The NCI-IDD average is weighted

Table 58. Chose staff or were aware they could request to change staff

Proxy respondents were allowed for this question.

State	Average	N
PA ↑	73%	717
NCI-IDD	63%	24758

Table 59. Can change their case manager/service coordinator if wants to

Proxy respondents were allowed for this question.

State	Average	N
PA ↑	81%	786
NCI-IDD	74%	28251

Table 60. Life Decisions Scale

Risk-adjusted. For more information on this scale, see the beginning of this chapter. Some states are not included due to variation in availability of data for risk adjustment.

State	Average	N
PA	67%	879
NCI-IDD	59%	27515

Table 61. Everyday Choices Scale

State	Average	N
PA	94%	875
NCI-IDD	89%	30645

The NCI-IDD average is weighted

Community Participation

Value statement: People participate in activities in their communities.

The NCI-IDD average is weighted

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Table 62. Went out shopping at least once in the past month (examples: groceries, clothing)

Proxy respondents were allowed for this question.

State	Average	N
PA	91%	855
NCI-IDD	89%	30126

Table 63. Went out on errands at least once in the past month (examples: banks, post office, hairdressers or barber)

Proxy respondents were allowed for this question.

State	Average	N
PA ↑	91%	843
NCI-IDD	84%	29697

Table 64. Went out for entertainment at least once in the past month (examples: go to the movies or attend plays, concerts, sporting events, going out dancing)

Proxy respondents were allowed for this question.

State	Average	N
PA	73%	845
NCI-IDD	75%	30038

Table 65. Went out to a restaurant or coffee shop at least once in the past month

Proxy respondents were allowed for this question.

State	Average	N
PA	86%	849
NCI-IDD	85%	30114

The NCI-IDD average is weighted

Table 66. Went out to religious service or spiritual practice at least once in the past month (examples: church, synagogue, study, or other place of worship)

Proxy respondents were allowed for this question.

State	Average	N
PA ↓	33%	849
NCI-IDD	39%	29934

Table 67. Takes part in groups, organizations or communities (in-person or virtually)

Proxy respondents were allowed for this question.

State	Average	N
PA	29%	852
NCI-IDD	29%	30098

Table 68. The groups, organizations or communities takes part in include people without disabilities

Proxy respondents were allowed for this question.

State	Average	N
PA	57%	222
NCI-IDD	57%	8005

The NCI-IDD average is weighted

Table 69. Community Inclusion Scale

Risk-adjusted. For more information on this scale, see the beginning of this chapter. Some states are not included due to variation in availability of data for risk adjustment.

State	Average	N
PA	84%	879
NCI-IDD	83%	27515

Relationships

Value statement: People are supported to build and maintain relationships that are important to them.

Table 70. Has friends who are not staff or family members

State	Average	N
PA	74%	511
NCI-IDD	76%	17638

Table 71. Has best friend (may be staff or family)

State	Average	N
PA	83%	405
NCI-IDD	81%	14944

Table 72. Wants help to make or keep in contact with friends

“Yes” and “Maybe” responses combined.

State	Average	N
PA ↓	46%	491
NCI-IDD	57%	17027

Table 73. Has friends (may be staff or family) and can meet with their friends in person when they want

State	Average	N
PA ↑	77%	408
NCI-IDD	68%	14812

The NCI-IDD average is weighted

Table 74. Has other ways of talking, chatting, or communicating with friends when cannot see them in person

State	Average	N
PA	81%	402
NCI-IDD	79%	14912

Table 75. Can see and/or talk with their family when they want (among those who do not live in the family home)
“Yes” and “Maybe” responses combined.

State	Average	N
PA	86%	175
NCI-IDD	84%	8894

Table 76. Often feels lonely

State	Average	N
PA ↓	9%	500
NCI-IDD	13%	17157

Table 77. Can go on a date or is married or living with partner

State	Average	N
PA	82%	360
NCI-IDD	78%	13225

The NCI-IDD average is weighted

Satisfaction

Value statement: People are satisfied with their everyday lives – where they live, work, the supports they receive, and what they do during the day.

Table 78. Likes home or where lives

State	Average	N
PA	92%	517
NCI-IDD	90%	18199

Table 79. Wants to live somewhere else

State	Average	N
PA ↓	22%	504
NCI-IDD	28%	17578

Table 80. Has enough things they like to do at home

State	Average	N
PA	88%	508
NCI-IDD	84%	17336

Table 81. Likes paid community job (if working in a paid community job)

Based on those reported to have a paid community job (from the Background Information Section).

State	Average	N
PA ↑	97%	113
NCI-IDD	90%	3624

The NCI-IDD average is weighted

Table 82. Wants to go out shopping more, less or the same amount as last month

Proxy respondents were allowed for this question.

State	More	Less	The same amount	N
PA	24%	5%	71%	825
NCI-IDD	34%	6%	60%	29633

Table 83. Wants to go out for entertainment more, less or the same amount as last month

Proxy respondents were allowed for this question.

State	More	Less	The same amount	N
PA	32%	2%	66%	818
NCI-IDD	44%	3%	53%	29600

Table 84. Wants to go out to a restaurant or coffee shop more, less or the same amount as last month

Proxy respondents were allowed for this question.

State	More	Less	The same amount	N
PA	30%	3%	68%	822
NCI-IDD	42%	4%	54%	29757

Table 85. Wants to go out to a religious service or spiritual practice more, less or the same amount as last month

Proxy respondents were allowed for this question.

State	More	Less	The same amount	N
PA	13%	2%	85%	772
NCI-IDD	21%	3%	76%	28554

The NCI-IDD average is weighted

Table 86. Person wants to be a part of more community groups

Proxy respondents were allowed for this question.

State	Yes	No	N
PA	29%	71%	777
NCI-IDD	36%	64%	28053

Table 87. Satisfaction with Community Inclusion Scale

State	Average	N
PA	71%	856
NCI-IDD	61%	30372

This scale measures respondents' satisfaction with their level of participation in community groups, as well as the frequency of outings during the past month, including shopping, entertainment, visits to restaurants or coffee shops, and attendance at religious services or engagement in spiritual practices.

Table 88. Likes how they usually spend time during the day

State	Average	N
PA ↑	90%	505
NCI-IDD	81%	17318

Table 89. Has used telehealth for healthcare services and like using it

Proxy respondents were allowed for this question.

State	Average	N
PA	57%	350
NCI-IDD	55%	13792

The NCI-IDD average is weighted

Table 90. Has accessed services and support using video conference technology and like using it

Proxy respondents were allowed for this question.

State	Average	N
PA	63%	150
NCI-IDD	59%	6815

Table 91. Have talked with their case manager/service coordinator using video conference technology and like using it

Proxy respondents were allowed for this question.

State	Average	N
PA	53%	257
NCI-IDD	57%	9658

Self-Direction

Value statement: People who use a self-directed supports option have the information and support needed to actively participate in directing their own supports and services.

Table 92. Using a self-directed supports option

Information may have been obtained through state records. AR, IN, NV, and WA do not offer self-direction.

State	Yes	No	N
PA	15%	85%	807
NCI-IDD	19%	81%	27890

Table 93. People who make decisions or have input in making decisions about the services that are self-directed

AR, IN, NV, and WA do not offer self-direction.

State	Person mostly makes decisions	Person has input, and family/friend helps	Family/friend makes decisions, person does not have input	Case manager/service coordinator or another professional employed by the state	N
PA	7%	39%	53%	1%	75
NCI-IDD	16%	41%	40%	4%	3453

Table 94. Can make changes to individual budget/services if needed

Proxy respondents were allowed for this question. AR, IN, NV, and WA do not offer self-direction.

State	Yes	No	In-between	N
PA	94%	3%	3%	64
NCI-IDD	90%	2%	8%	2984

Table 95. Has enough help deciding how to direct services

Proxy respondents were allowed for this question. AR, IN, NV, and WA do not offer self-direction.

State	Yes	No	In-between	N
PA	94%	3%	3%	62
NCI-IDD	86%	5%	8%	2988

The NCI-IDD average is weighted

Table 96. Has the amount of control wanted with the services that are self-directed

Proxy respondents were allowed for this question. AR, IN, NV, and WA do not offer self-direction.

State	Yes	No	In-between	N
PA	92%	2%	6%	62
NCI-IDD	85%	5%	10%	2988

Table 97. The services and supports they want to self-direct are always available. This includes things like having the services that they want available when they want them and having enough staff to hire.

Proxy respondents were allowed for this question. AR, IN, NV, and WA do not offer self-direction.

State	Yes	No	Sometimes	N
PA	77%	10%	13%	62
NCI-IDD	64%	17%	19%	2984

Table 98. Gets information about budget and services from financial management service (FMS)

Proxy respondents were allowed for this question. AR, IN, NV, and WA do not offer self-direction.

State	Yes	No	Sometimes	N
PA	80%	12%	8%	59
NCI-IDD	85%	10%	5%	2914

Table 99. Information from FMS is easy to understand

Proxy respondents were allowed for this question. AR, IN, NV, and WA do not offer self-direction.

State	Yes, easy to understand on own	No, not easy to understand and does not get help to understand	Some information is easy to understand or understands with help from others	N
PA	83%	2%	15%	46
NCI-IDD	68%	7%	25%	2301

The NCI-IDD average is weighted

Table 100. Frequency with which the person gets information from FMS

Proxy respondents were allowed for this question. AR, IN, NV, and WA do not offer self-direction.

State	At least every three months	About twice a year	Once a year or less	N
PA	67%	16%	16%	43
NCI-IDD	72%	13%	15%	2190

Table 101a. Needs help with these elements of self-direction

Proxy respondents were allowed for this question. Categories are not mutually exclusive; therefore, N is not shown. AR, IN, NV, and WA do not offer self-direction.

State	Help planning out service needs and setting a schedule for staff	Help getting staff paid	Help finding or keeping the staff they want	Help training staff	Help managing benefits for staff
PA	0%	2%	5%	0%	0%
NCI-IDD	9%	10%	24%	10%	7%

Table 101b. Needs help with these elements of self-direction (continued)

Proxy respondents were allowed for this question. Categories are not mutually exclusive; therefore, N is not shown. AR, IN, NV, and WA do not offer self-direction.

State	Help understanding information gets from FMS	More information about what services and supports they can get	Other	Don't Know
PA	5%	19%	0%	8%
NCI-IDD	16%	31%	13%	2%

The NCI-IDD average is weighted

Service Coordination

Value statement: Case managers/service coordinators are accessible and responsive to people. Case managers/service coordinators are knowledgeable about people's needs and the services/supports available to address those needs. Service plans reflect people's goals and needs and are modified as changes occur. People actively engage in the service planning process.

Table 102. Has met or spoken with case manager/service coordinator

State	Average	N
PA	95%	491
NCI-IDD	93%	16961

Table 103. Case manager/service coordinator knows what is important to person

State	Average	N
PA	92%	439
NCI-IDD	90%	14932

Table 104. Able to contact case manager/service coordinator when wants

State	Average	N
PA ↑	89%	425
NCI-IDD	85%	14817

Table 105. Case manager/service coordinator has talked to them about technology that may help them in their everyday life

Proxy respondents were allowed for this question.

State	Average	N
PA ↑	38%	705
NCI-IDD	33%	27104

The NCI-IDD average is weighted

Table 106. Was at last service planning meeting, or had the opportunity to be but chose not to

State	Average	N
PA	98%	448
NCI-IDD	97%	15787

Table 107. Knew what was being talked about at last service planning meeting

State	Average	N
PA	81%	417
NCI-IDD	81%	14630

Table 108. Last service planning meeting included people person wanted to be there

State	Average	N
PA	96%	437
NCI-IDD	94%	15239

Table 109. Person helped make the service plan

Proxy respondents were allowed for this question.

State	Average	N
PA	75%	761
NCI-IDD	74%	29273

The NCI-IDD average is weighted

Table 110. Case manager/service coordinator reviews their service plan with them throughout the year, when needed

Proxy respondents were allowed for this question.

State	Average	N
PA ↑	93%	777
NCI-IDD	87%	29442

Table 111. The service plan includes things that are important to person

State	Average	N
PA ↑	97%	385
NCI-IDD	94%	13237

Table 112. Knows who to ask if wants to change something about services

Proxy respondents were allowed for this question.

State	Average	N
PA ↑	87%	793
NCI-IDD	80%	29743

Table 113. Of those who say they want to learn to perform ADLs more independently, the percentage who have a related goal in the service plan

State	Average	N
PA	81%	32
NCI-IDD	74%	1861

The NCI-IDD average is weighted

Table 114. Of those who say they want a paid job in the community (and do not currently have one), the percentage who have community employment as a goal in the service plan

State	Average	N
PA	44%	96
NCI-IDD	34%	2672

Workforce

Value statement: There is stable and sufficient direct support 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.

Table 115. Staff are respectful of person's culture

State	Average	N
PA	97%	207
NCI-IDD	94%	9611

Table 116. Staff treat person with respect

State	Average	N
PA ↑	97%	220
NCI-IDD	92%	9903

Table 117. Person can talk or communicate with staff in their preferred language

State	Average	N
PA	98%	220
NCI-IDD	96%	9827

Table 118. Staff do things the way person wants them done

State	Average	N
PA ↑	94%	213
NCI-IDD	86%	9640

The NCI-IDD average is weighted

Table 119. When in the community, staff support person in the way they want

State	Average	N
PA ↑	97%	212
NCI-IDD	91%	9594

Table 120. Staff come and leave when they are supposed to

State	Average	N
PA ↑	95%	205
NCI-IDD	89%	9067

Table 121. Person's staff change too often

“Yes, staff do change too often” and “Sometimes or some staff” responses combined.

State	Average	N
PA	34%	206
NCI-IDD	40%	9440

Table 122. Staff have the right training to meet person's needs

Proxy respondents (who were not staff) were allowed for this question.

State	Average	N
PA ↑	97%	514
NCI-IDD	89%	19747

The NCI-IDD average is weighted

Access

Value statement: Services and supports are available, accessible, and responsive to people's needs People know the options available to them for services and supports.

Table 123. Able to get places when wants to do something outside of home like going out to see friends, for entertainment, or to do something fun

State	Average	N
PA ↑	89%	505
NCI-IDD	82%	17313

Table 124. Has a way to get places needs to go (like work, appointments, etc.)

State	Average	N
PA	95%	510
NCI-IDD	94%	17403

Table 125. Has access to the internet

Proxy respondents were allowed for this question.

State	Average	N
PA	85%	862
NCI-IDD	86%	30315

Table 126. Internet always works at home

Proxy respondents were allowed for this question.

State	Average	N
PA ↑	94%	619
NCI-IDD	89%	22007

The NCI-IDD average is weighted

Table 127. Frequency uses internet

Proxy respondents were allowed for this question.

State	Everyday	Several times a week	Several times a month	Several times a year	Not at all	N
PA	72%	9%	4%	2%	13%	722
NCI-IDD	70%	10%	3%	1%	15%	26234

Table 128. Uses technology in everyday life to help them do more things on their own

“Using technology in everyday life” refers to things like using a smartphone app to help get places, setting automatic alerts or reminders to do things like take medication, and using apps to show how to do things like preparing meals; proxy respondents were allowed for this question.

State	Yes	No	N
PA	34%	66%	828
NCI-IDD	35%	65%	29793

Table 129. Has enough help to use the technology and devices that help them in their everyday life (if uses technology that helps them do more things on their own)

Proxy respondents were allowed for this question.

State	Average	N
PA	93%	269
NCI-IDD	92%	10241

Table 130. Knows who to talk to if there are issues with the technology and devices that help them in their everyday life (if uses technology that helps them do more things on their own)

Proxy respondents were allowed for this question.

State	Average	N
PA	96%	271
NCI-IDD	94%	10283

Table 131. Has used telehealth to talk with a health professional

Proxy respondents were allowed for this question.

State	Average	N
PA ↓	45%	829
NCI-IDD	51%	29609

Table 132. Accessed services or supports using videoconference technology

Proxy respondents were allowed for this question.

State	Average	N
PA ↓	19%	834
NCI-IDD	24%	29536

Table 133. Has talked with their case manager/service coordinator using videoconference technology

Proxy respondents were allowed for this question.

State	Average	N
PA	33%	830
NCI-IDD	36%	29445

The NCI-IDD average is weighted

Table 134. Has a cell phone or smartphone

State	Average	N
PA	69%	510
NCI-IDD	73%	17567

Table 135. Wants a cell phone or smartphone (if does not have one)

State	Yes	No	N
PA	33%	67%	144
NCI-IDD	45%	55%	4232

Table 136. Reasons for not having a cell phone or smartphone despite wanting one

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

State	Cost	Not allowed	Lost/broke my old phone	Other
PA	29%	3%	26%	46%
NCI-IDD	36%	12%	21%	36%

Table 137a. Additional services needed

Categories are not mutually exclusive; therefore, N is not shown. Proxy respondents were allowed for this question.

State	Help finding a new place to live	Changes or modifications to home	Staff support to help at home	Help working on job skills
PA	7%	4%	7%	11%
NCI-IDD	12%	10%	16%	19%

The NCI-IDD average is weighted

Table 137b. Additional services needed (continued)

Categories are not mutually exclusive; therefore, N is not shown. Proxy respondents were allowed for this question.

State	Help finding or signing up for classes	Help finding something different to do during the day (not including paid community job)	Help finding more reliable transportation
PA	10%	10%	5%
NCI-IDD	19%	20%	15%

Table 137c. Additional services needed (continued)

Categories are not mutually exclusive; therefore, N is not shown. Proxy respondents were allowed for this question.

State	Help getting or using tech to help in everyday life	Help with healthcare	Help understanding medication
PA	5%	3%	3%
NCI-IDD	13%	9%	8%

Table 137d. Additional services needed (continued)

Categories are not mutually exclusive; therefore, N is not shown. Proxy respondents were allowed for this question.

State	Help finding, getting or setting up mental health or behavioral health	Anything else	Does not need additional supports	Don't Know
PA	4%	10%	57%	3%
NCI-IDD	10%	17%	44%	1%

The NCI-IDD average is weighted

Safety

Value statement: People feel safe at home and outside of the home. People know whom to talk to if they don't feel safe.

Table 138. Feels afraid in their home, neighborhood, transport, workplace, day program/at other daily activity and/or other places

State	Average	N
PA ↓	18%	500
NCI-IDD	22%	17260

Table 139. Has someone to go to for help when they feel afraid

State	Average	N
PA	95%	497
NCI-IDD	93%	17372

Health

Value statement: People have access to and get recommended health services at the recommended frequencies.

Important note on data Several states had large amounts of missing data or data recorded as “don’t know.” Where 25% or more of a state’s sample had “don’t know” or missing responses, we used an asterisk (*) to indicate that state’s data should be interpreted with caution as it may not accurately represent the sample or service population.

Table 140. Has a primary care doctor or practitioner

Information may have been obtained through state records.

State	Average	N
PA	97%	820
NCI-IDD	97%	30141

Table 141. In poor health

Proxy respondents were allowed for this question.

State	Average	N
PA ↓	1%	862
NCI-IDD	2%	30337

Table 142. Had a complete physical exam in the past year (this refers to a routine exam, not a visit for a specific problem or illness)

Information may have been obtained through state records.

State	Average	N
PA ↑	92%	805
NCI-IDD	89%	28280

Table 143. Had a routine dental exam in the past year

Information may have been obtained through state records.

State	Average	N
PA	83%	741
NCI-IDD	80%	27492

The NCI-IDD average is weighted

Table 144. Had an eye exam/vision screening in the past year

Information may have been obtained through state records.

State	Average	N
PA ↑	69%	666
NCI-IDD	59%	25677

Table 145. Had a hearing test in the past five years

Information may have been obtained through state records.

State	Average	N
PA * ↑	85%	401
NCI-IDD	48%	20811

Asterisk (*) indicates the state had more than 25% missing or don't know responses.

Table 146. Had a Pap test in the past three years (among women 21 and older)

Information may have been obtained through state records.

State	Average	N
PA ↑	66%	174
NCI-IDD	44%	8209

The NCI-IDD average is weighted

Table 147. Had a mammogram test in the past two years (among women 40 and over)

Information may have been obtained through state records. The U.S. Preventive Services Task Force (USPSTF) recommends that all women get screened every other year starting at age 40 to reduce their risk of dying from breast cancer. For more information, please visit [USPSTF's page on breast cancer screening](#).

State	Average	N
PA ↑	89%	82
NCI-IDD	73%	2918

Table 148. Last colorectal cancer screening (among people 45 to 75)

Categories are not mutually exclusive; therefore, N is not shown. Information may have been obtained through State records, “Don’t Know” included in denominator.

State	Colonoscopy within the past 10 years	Sigmoidoscopy within the past 5 years	Fecal Occult Blood Test (FOBT) or Fecal Immunochemical Test (FIT) in the past year	Never had exam or screening	Don't Know
PA	33%	0%	6%	8%	53%
NCI-IDD	32%	1%	10%	22%	36%

Table 149. Had a flu vaccine in the past 12 months

Information may have been obtained through state records.

State	Average	N
PA *	62%	445
NCI-IDD	67%	25294

Asterisk (*) indicates the state had more than 25% missing or don't know responses.

Table 150. Went to the emergency room for any reason to get care for themselves in the past 12 months

Proxy respondents were allowed for this question.

State	Yes	No	N
PA	28%	72%	854
NCI-IDD	27%	73%	30073

Table 151. Had an unexpected hospital admission due to dehydration, bowel obstruction, seizure, aspiration, or GERD, in the past year

Categories are not mutually exclusive; therefore, N is not shown. Information may have been obtained through State records.

State	Dehydration	Bowel obstruction	Seizure	Aspiration	Gastroesophageal Reflux Disease (GERD)
PA	6%	15%	34%	21%	28%
NCI-IDD	13%	17%	41%	18%	23%

Table 152. Fell and hurt themselves in the past six months

Proxy respondents were allowed for this question.

State	No	Yes	N
PA	85%	15%	857
NCI-IDD	86%	14%	30196

The NCI-IDD average is weighted

Medications

Value statement: Medications are used effectively and appropriately.

Important note on data Several states had large amounts of missing data or data recorded as “don’t know.” Where 25% or more of a state’s sample had “don’t know” or missing responses, we used an asterisk (*) to indicate that state’s data should be interpreted with caution as it may not accurately represent the sample or service population.

Table 153. Takes at least one medication for mood, anxiety, psychotic disorder, and/or behavioral challenges

Information may have been obtained through state records.

State	Average	N
PA ↑	63%	753
NCI-IDD	51%	26362

Table 154. Takes medication for mood, anxiety, and/or psychotic disorders

Information may have been obtained through state records.

State	Average	N
PA ↑	60%	752
NCI-IDD	46%	26434

Table 155. Number of medications taken for at least one of the following: mood disorders, anxiety, or psychotic disorders

Information may have been obtained through state records.

State	One or two medications	Three or four medications	Five to ten medications	Eleven or more medications	N
PA	60%	29%	10%	0%	445
NCI-IDD	66%	26%	8%	0%	9194

Table 156. Takes medication for behavioral challenges

Information may have been obtained through state records.

State	Average	N
PA	24%	751
NCI-IDD	24%	26202

The NCI-IDD average is weighted

Table 157. Number of medications taken for behavioral challenges if taking at least one for this purpose

State	One or two medications	Three or four medications	Five to ten medications	Eleven or more medications	N
PA	76%	18%	5%	1%	172
NCI-IDD	75%	19%	5%	0%	4906

Table 158. Has behavior plan

Information may have been obtained through state records.

State	Average	N
PA ↑	31%	767
NCI-IDD	25%	20372

Table 159. Has behavior plan (among those who take medication for a behavior challenge)

Information may have been obtained through state records.

State	Average	N
PA	57%	171
NCI-IDD	55%	5246

Wellness

Value statement: People are supported to engage in and maintain healthy habits and lifestyles.

Important note on data Several states had large amounts of missing data or data recorded as “don’t know.” Where 25% or more of a state’s sample had “don’t know” or missing responses, we used an asterisk (*) to indicate that state’s data should be interpreted with caution as it may not accurately represent the sample or service population.

Table 160. Person uses nicotine or tobacco products

Information may have been obtained through state records.

State	Average	N
PA	6%	753
NCI-IDD	5%	29489

Table 161. Body mass index (BMI) category (BMI calculated using data on weight and height)

Information may have been obtained through state records.

State	Underweight	Normal	Overweight	Obese	N
PA	5%	31%	31%	33%	510
NCI-IDD	5%	29%	27%	39%	27335

Table 162. Exercises or does physical activity at least once per week for 10 minutes or more at a time

Proxy respondents were allowed for this question.

State	Average	N
PA	79%	854
NCI-IDD	83%	30186

Table 163. Exercises or does physical activity at least once per week that makes the muscles in arms, legs, back, and/or chest work hard

Proxy respondents were allowed for this question.

State	Average	N
PA	29%	851
NCI-IDD	33%	30027

The NCI-IDD average is weighted

Rights and Respect

Value statement: People's rights are respected and people receive the same respect and protections as others in the community.

Important note on data Several states had large amounts of missing data or data recorded as “don’t know.” Where 25% or more of a state’s sample had “don’t know” or missing responses, we used an asterisk (*) to indicate that state’s data should be interpreted with caution as it may not accurately represent the sample or service population.

Table 164. Has attended a self-advocacy group, meeting, conference or event or had the opportunity and chose not to

Proxy respondents were allowed for this question.

State	Average	N
PA ↓	28%	763
NCI-IDD	34%	28369

Table 165. Has ever voted in local, state, or federal election, or had the opportunity and chose not to

Proxy respondents were allowed for this question.

State	Average	N
PA ↑	73%	826
NCI-IDD	50%	29401

Table 166. Has a place to be alone in the home

State	Average	N
PA	98%	521
NCI-IDD	97%	17730

Table 167. Has a key to the home

Proxy respondents were allowed for this question.

State	Average	N
PA	60%	857
NCI-IDD	56%	30267

The NCI-IDD average is weighted

Table 168. Wants a key to the home (if does not have one)

Proxy respondents were allowed for this question.

State	Yes	Maybe, not sure	No	N
PA	13%	3%	84%	294
NCI-IDD	13%	7%	79%	11714

Table 169. Can lock bedroom if wants

Proxy respondents were allowed for this question.

State	Average	N
PA	63%	781
NCI-IDD	60%	28005

Table 170. Others (who do not live in the home) let person know before entering home

State	Average	N
PA ↑	94%	486
NCI-IDD	88%	17154

Table 171. Others let person know before coming into person’s bedroom

State	Average	N
PA ↑	87%	498
NCI-IDD	80%	17393

The NCI-IDD average is weighted

Table 172. Others read person's mail or email without asking

State	Average	N
PA ↓	6%	471
NCI-IDD	11%	15626

Table 173. There are no rules for using phone or internet

State	Average	N
PA ↑	88%	456
NCI-IDD	83%	16106

Table 174. There are rules about having friends or visitors in the home

State	Average	N
PA ↓	20%	450
NCI-IDD	29%	16011

Table 175. Can stay at home if others in the house go somewhere

Proxy respondents were allowed for this question.

State	Average	N
PA	47%	788
NCI-IDD	45%	28085

The NCI-IDD average is weighted

Table 176. Respect for Personal Space Scale

State	Average	N
PA	93%	513
NCI-IDD	88%	17749