



In Person Survey (IPS) State Report

2021-22 Pennsylvania Report

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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® 2021-22 In-Person Survey (IPS). The data shown are weighted NCI-IDD averages. These data are comprised of valid surveys collected across 27 states: AR, CO, CT, DE, FL, GA, IL, IN, KS, KY, MA, MI, MN, MO, NE, NV, NJ, NY, NC, OH, OK, OR, PA, SC, UT, VA, WI.

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 is taken a .01 and account for *effect size*. For more information about significance testing and effect sized, please see [the Methodology section of the National report](#).

Presentation of Data

The charts in this document, grouped by subdomain, display the state results alongside the weighted average across states (NCI-IDD average). The charts are followed by accessible tables containing the same information.

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](#).

Demographics

This section presents descriptive information of individuals surveyed.

Important notes 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 1. Age

State v NCI	Mean	Min	Max	Standard Deviation	Median	N
PA	44.1	19	93	16.3	41.0	648
NCI-IDD	42	18	100	16	39	13,416

Table 2. Age Group

State v NCI	18-22	23-34	35-54	55-74	75 and older	Unknown	N
PA	5%	30%	31%	26%	3%	5%	680
NCI-IDD	8%	33%	33%	23%	3%	1%	13,559

Table 3. Gender

State v NCI	Male	Female	Other	N
PA	59%	41%	0%	651
NCI-IDD	60%	40%	0%	13,484

Table 4. Marital Status

State v NCI	Single, Never Married	Married	Single, Married in the Past	Don't Know	N
PA	95%	1%	2%	2%	631
NCI-IDD	95%	1%	2%	2%	13,245

Table 5. Person is a parent

Categories are not mutually exclusive, therefore N is not shown

State v NCI	No, does not have a child	Yes, parent of a child or children under 18	Yes, parent of a child or children over 18	Don't Know
PA	97%	1%	2%	2%
NCI-IDD	96%	2%	2%	21%

Table 6. Race and Ethnicity

State v NCI	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Two or More	Don't Know	N
PA	0%	1%	11%	0%	84%	2%	1%	0%	0%	645
NCI-IDD	1%	2%	16%	0%	71%	5%	2%	1%	3%	13,337

Table 7. Residential Designation¹

State v NCI	Metropolitan	Micropolitan	Rural	Small Town	N
PA	77%	15%	3%	5%	639
NCI-IDD	78%	13%	3%	7%	13,428

¹ Information based on residential designation defined by the USDA: <https://www.ers.usda.gov/dataproducts/rural-urban-commuting-area-codes.asp>

Table 8. Type of Residence – ICFs/ID, Nursing facilities or other specialized institutional settings

State v NCI	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	2%	1%	2%	1%	0%	642
NCI-IDD	1%	2%	1%	0%	0%	13,296

Table 9. Type of Residence – Group Residential Setting

State v NCI	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	36%	9%	1%	642
NCI-IDD	10%	19%	6%	13,296

Table 10. Type of Residence – Other Home Settings

State v NCI	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	Don't Know	N
PA	10%	32%	1%	4%	0%	1%	0%	642
NCI-IDD	15%	39%	3%	2%	0%	1%	1%	13,296

Table 11. Length of Time at Current Residence (If Not Homeless or in Crisis Bed Placement)

State v NCI	Less Than 1 Year	1-3 Years	3-5 Years	Over 5 Years	Don't Know	N
PA	7%	20%	7%	58%	7%	627
NCI-IDD	8%	20%	8%	58%	5%	13,113

Table 12. Person's residence owned or controlled by provider agency

State v NCI	No	Yes	Don't Know	N
PA	45%	52%	3%	635
NCI-IDD	60%	37%	3%	13,119

Table 13. Person is named on the lease or other legally enforceable rental agreement

State v NCI	No	Yes, named on lease or deed	Yes, named on other legally enforceable rental agreement	Don't Know	N
PA	74%	8%	4%	15%	639
NCI-IDD	60%	18%	8%	15%	12,710

Table 14. Has ID Diagnosis

State v NCI	No	Yes	Don't Know	N
PA	3%	96%	1%	678
NCI-IDD	12%	87%	1%	13,392

Table 15. Level of ID (if the person has an ID diagnosis)

State v NCI	Mild	Moderate	Severe	Profound	Unspecified	Unknown	N
PA	42%	30%	10%	7%	11%	1%	655
NCI-IDD	38%	29%	12%	7%	12%	1%	11,965

Table 16. Mood, Anxiety, Behavior, Psychotic, and Other Mental Illness²

State v NCI	Mood Disorder	Anxiety Disorder	Behavior Challenges	Psychotic Disorder	Other Mental Illness or Psychiatric Diagnosis
PA	41%	32%	23%	10%	12%
NCI-IDD	31%	27%	22%	10%	10%

² ('Don't Know' responses are included in the denominator) (Categories are not mutually exclusive therefore N is not shown)

Table 17. Diagnoses noted in record

State v NCI	Autism Spectrum Disorder	Cerebral Palsy	Brain Injury	Seizure Disorder	Chemical Dependency
PA	21%	12%	1%	24%	0%
NCI-IDD	26%	15%	4%	24%	1%

Table 18. Diagnoses noted in record (continued)

State v NCI	Down Syndrome	Prader-Willi	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%	5%	11%	9%
NCI-IDD	8%	0%	1%	9%	5%	18%	9%

Table 19. Other conditions in record³

State v NCI	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
PA *	10%	17%	3%	28%	29%
NCI-IDD	10%	17%	3%	29%	24%

³ Added response categories in 2021-22; categories are not mutually exclusive, therefore N is not shown; 'don't know' responses are included in the denominator

Table 20. Other conditions in record (continued)

State v NCI	Dysphagia	Pressure Ulcers	Alzheimer's	Oral Health or Dental Problems	Sleep Apnea
PA *	13%	1%	4%	5%	11%
NCI-IDD	8%	1%	3%	4%	9%

Table 21. Other conditions in record (continued)⁴

State v NCI	Asthma	Other pulmonary diagnosis	Chronic kidney disease	Long-term health problems associated with COVID-19	Other
PA *	7%	3%	3%	1%	56%
NCI-IDD	11%	4%	12%	0%	55%

Table 22. Preferred form of Communication

State v NCI	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Device	Other	Don't know	N
PA	81%	15%	0%	1%	2%	0%	637
NCI-IDD	80%	13%	2%	1%	4%	1%	13,031

⁴ Added response categories in 2021-22; categories are not mutually exclusive, therefore N is not shown; 'don't know' responses are included in the denominator

Table 23. Primary Language

Information may have been obtained in the field

State v NCI	English	Spanish	Chinese (including Mandarin, Cantonese, and Hokkien)	Tagalog (including Filipino)	Vietnamese	American Sign Language (ASL)	Other	N
PA	98%	0%	0%	0%	0%	0%	1%	633
NCI-IDD	97%	2%	0%	0%	0%	0%	1%	12,987

Table 24. Mobility

Information may have been collected in the field

State v NCI	Moves Self Around Environment Without Aids	Moves Self Around Environment With Aids or Uses Wheelchair Independently	Non-Ambulatory, Always Needs Assistance to Move Around Environment	Don't Know	N
PA	76%	13%	10%	1%	635
NCI-IDD	75%	16%	8%	1%	13,263

Table 25. Support Needed to Manage Self-Injurious Behavior

State v NCI	None	Some	Extensive	Don't Know	N
PA	76%	18%	4%	2%	629
NCI-IDD	76%	16%	5%	2%	12,397

Table 26. Support Needed to Manage Disruptive Behavior

State v NCI	None	Some	Extensive	Don't Know	N
PA	59%	34%	5%	2%	634
NCI-IDD	56%	28%	8%	9%	12,423

Table 27. Support Needed to Manage Destructive Behavior

State v NCI	None	Some	Extensive	Don't Know	N
PA	75%	19%	4%	3%	637
NCI-IDD	67%	18%	5%	9%	12,447

Table 28. Level of Guardianship

State v NCI	None	Limited Guardianship	Full Guardian	Has Guardian, but Unable to Distinguish Level	Don't Know	N
PA	77%	2%	14%	2%	4%	640
NCI-IDD	46%	5%	36%	11%	2%	13,420

Table 29. Guardian's Relationship to Person

State v NCI	Family	Friend	Public Guardian or Public Administrator	Financial Institution	Non-profit Guardianship Agency	For-profit Guardianship Agency	Other	Don't Know	N
PA	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
NCI-IDD	74%	2%	9%	0%	3%	1%	1%	9%	6,772

Table 30. Funding Source

State v NCI	ICF/IID	Medicaid HCBS Waiver Funded Services	Medicaid State Plan funded	Exclusively supported by state funds	State Plan only	Don't know	N
PA	5%	82%	5%	1%	3%	6%	680
NCI-IDD	4%	86%	36%	1%	1%	3%	13,405

Table 31. Person receives Medicare

State v NCI	Yes	No	Don't know	N
PA *	26%	52%	23%	630
NCI-IDD	42%	51%	7%	13,184

Table 32. Amount of daily support received at home

State v NCI	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	Don't know	N
PA	57%	14%	18%	2%	8%	1%	635
NCI-IDD	51%	17%	18%	2%	9%	4%	12,622

Table 33. Has remote supports

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

State v NCI	No, none	Yes, 24-hour remote supports	Yes, less than 24-hour remote supports	Don't know	N
PA	89%	1%	4%	6%	638
NCI-IDD	84%	3%	3%	10%	12,334

Table 34. Has ever been diagnosed or presumed diagnosed with COVID-19

State v NCI	No	Yes	Don't know	N
PA	70%	21%	9%	622
NCI-IDD	69%	22%	9%	11,502

Table 35. Has ever required in-patient hospitalization due to COVID-19 (of those who had COVID-19)

State v NCI	No	Yes	Don't know	N
PA *	82%	14%	4%	127
NCI-IDD	86%	11%	2%	2,520

Table 36. Required intubation (if has ever required in-patient hospitalization due to COVID-19)

State v NCI	No	Yes	Don't know	N
PA *	n/a	n/a	n/a	n/a
NCI-IDD	78%	12%	10%	283

Table 37. Person was sent to Intensive Care Unit (ICU)

State v NCI	No	Yes	Don't know	N
PA *	n/a	n/a	n/a	n/a
NCI-IDD	60%	25%	15%	283

Table 38. Where person went after being hospitalized due to COVID-19 (if has ever required in-patient hospitalization due to COVID-19)

State v NCI	Returned to the home where they lived prior to hospitalization	Their family home	A different group home/provider operated residential setting than where they lived prior to hospitalization	Nursing home	Rehabilitation facility	Other	Don't know	N
PA *	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
NCI-IDD	77%	2%	1%	6%	7%	2%	5%	286

Table 39. Has gotten the COVID-19 vaccine⁵

State v NCI	No	Yes, fully vaccinated	Partially—received first of two doses	Don't know	N
PA	10%	77%	4%	9%	625
NCI-IDD	10%	77%	4%	9%	11,230

⁵ At the time of survey implementation vaccine boosters were not in use

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.

Please note: The following states are not included in some of the tables due to low N (<20), but their responses are included in the NCI Average: AL, HI, KY, MN and WI. State data with at least 25% “don’t knows” and missing data are denoted with an asterisk ()*

WI captured employment information differently from other states; their data are not comparable to other states and are therefore denoted with a sign (≠).

Table 40. Has a paid community job individual group and or in a business that primarily hires people with disabilities (Also known as “competitive employment”)

Information may have been obtained through state records

State v NCI	Average	N
PA	19%	599
NCI-IDD	16%	11,888

Table 41. Type of paid community job (of those with paid community job)

State v NCI	Individual without publicly funded supports	Individual with publicly funded supports	N	Group with or without publicly funded supports	N	Paid work in a community business that primarily hires people with disabilities	N
PA	25%	45%	105	29%	102	8%	102
NCI-IDD	38%	38%	1,724	18%	1,931	11%	1,896

Table 42. Average number of biweekly hours by type of community job

State v NCI	Individual with publicly funded supports	N	Individual without publicly funded supports	N	Group with or without publicly funded supports	N	Paid work in a community business that primarily hires people with disabilities	N
PA	26.7	39	26.8	21	24.2	21	n/a	n/a
NCI-IDD	27.5	548	31.1	572	30	301	25.3	202

Table 43. Average biweekly hourly wage by type of community job

State v NCI	Individual with publicly funded supports	N	Individual without publicly funded supports	N	Group with or without publicly funded supports	N	Paid work in a community business that primarily hires people with disabilities	N
PA	\$9.61	24	n/a	n/a	n/a	n/a	n/a	n/a
NCI-IDD	\$12.05	466	\$12.15	503	\$10.07	257	\$10.24	168

Table 44. Job industries of those with paid community jobs

State v NCI	Food prep and food service	Building and grounds cleaning or maintenance	Personal care provider	Retail	General office and support	Farming fishing forestry worker	N
PA	35%	28%	0%	12%	1%	0%	108
NCI-IDD	27%	18%	1%	24%	3%	1%	1,893

Table 44B. Job industries of those with paid community jobs (continued)

State v NCI	Construction or repair	Assembly, manufacturing, or packaging	Materials handling, mail distribution	Management, business or financial operations	Professional or technical occupation	Other	N
PA	0%	6%	0%	0%	1%	12%	108
NCI-IDD	0%	6%	2%	0%	1%	15%	1,893

Table 45. Does not have paid community job and wants a paid community job

State v NCI	Average	N
PA ▼	34%	190
NCI-IDD	47%	4,661

Table 46. Has community employment as a goal in their service plan

Information may have been obtained through state records

State v NCI	Average	N
PA	26%	623
NCI-IDD	25%	11,947

Table 47. Uses special technology to help do their job

State v NCI	Yes	No	N
PA	11%	89%	115
NCI-IDD	14%	86%	2,194

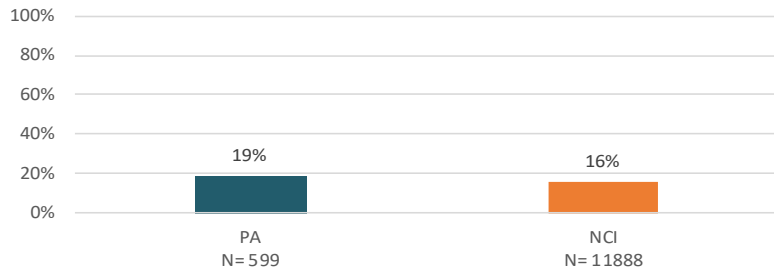
Table 48. Does these activities at least once a week

State v NCI	Attends day program or workshop	Volunteers	Job training	School/ classes	Community activities with paid support	Other	No activities	N
PA	30%	15%	3%	2%	33%	15%	27%	396
NCI-IDD	43%	16%	8%	7%	35%	18%	23%	8,227

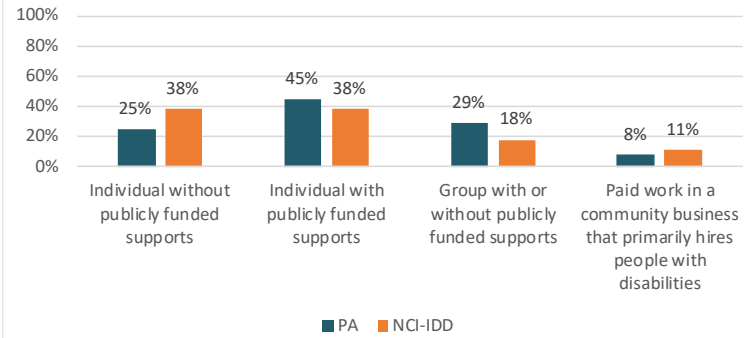
Table 49. Takes part in classes training or skills building activities to gain skills to expand their job

State v NCI	Average	N
PA ▼	10%	377
NCI-IDD	17%	7,967

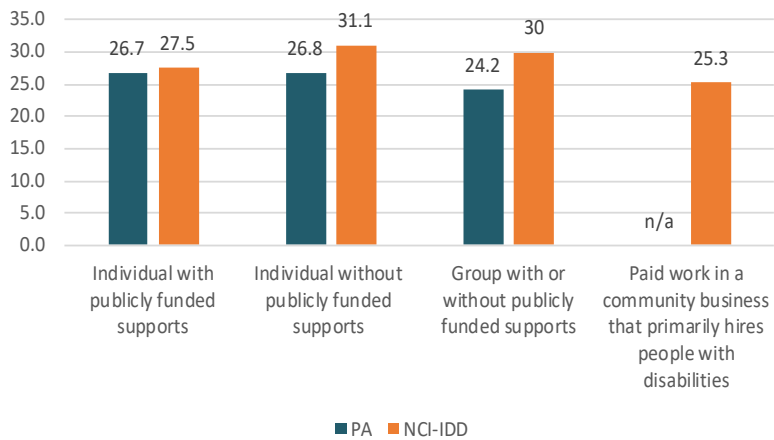
Has a paid community job; individual, group, and/or in a business that primarily hires people with disabilities (Also known as “competitive employment”)



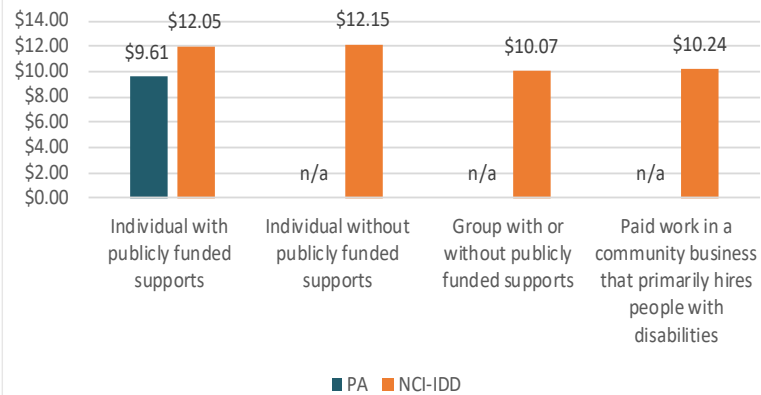
Type of paid community job (of those with paid community job)



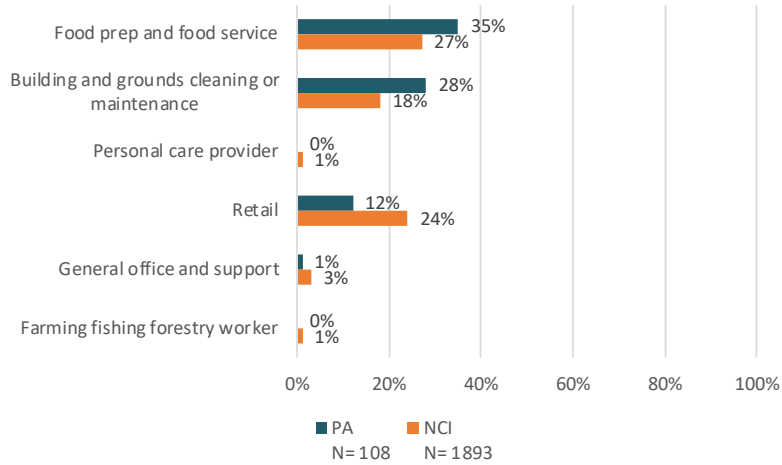
Average number of biweekly hours by type of community job



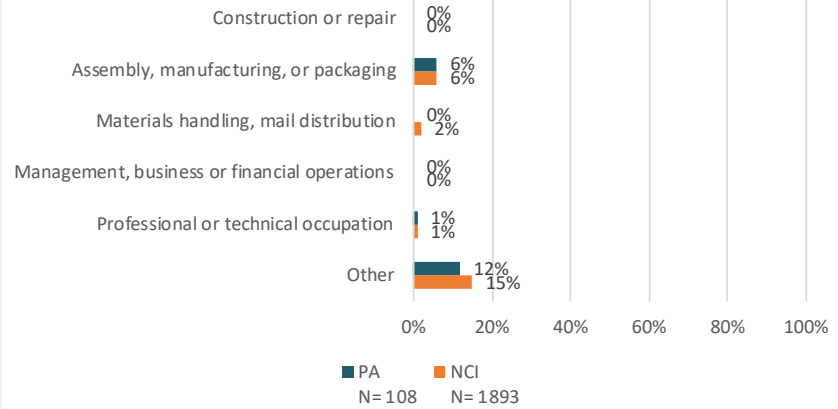
Average biweekly hourly wage by type of community job



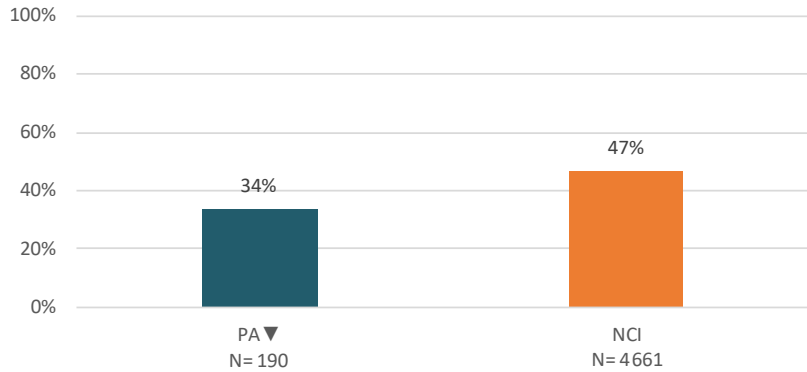
Job industries of those with paid community jobs



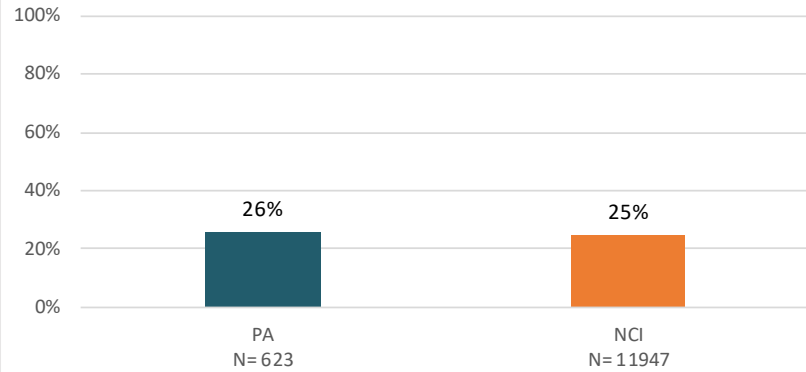
Job industries of those with paid community jobs (continued)



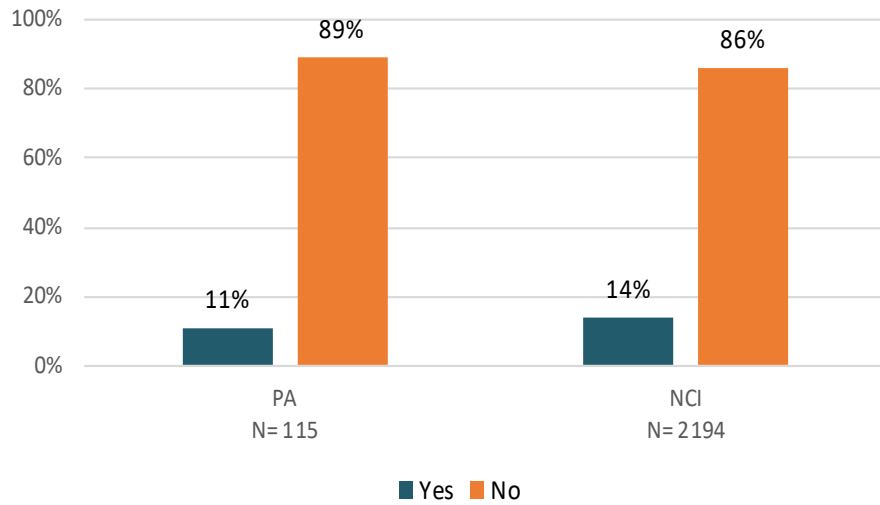
Does not have paid community job and wants a paid community job



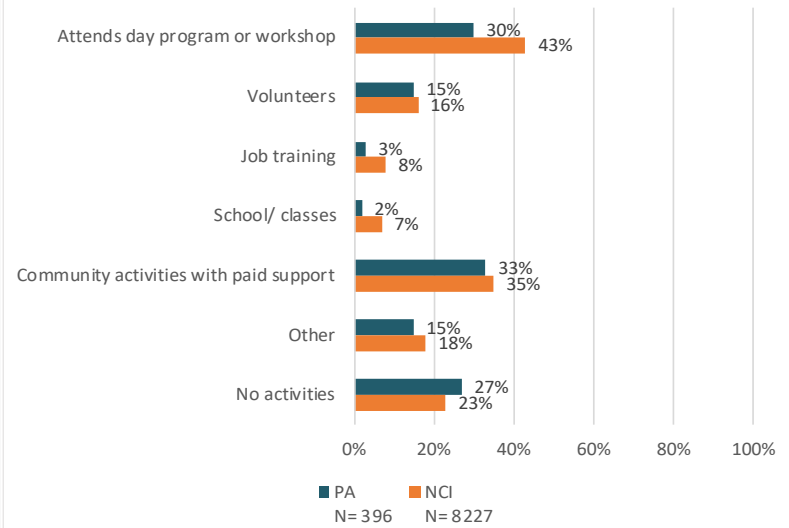
Has community employment as a goal in their service plan



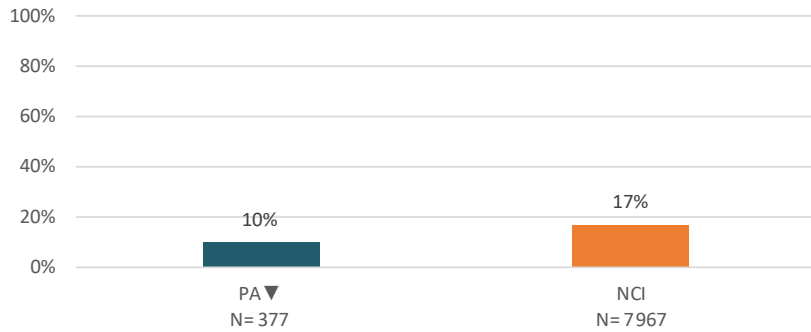
Uses special technology to help do their job



Does these activities at least once a week.



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



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.

Table 50. Gets to do things they like to do in the community as much as wants

State v NCI	Average	N
PA ▲	82%	360
NCI-IDD	69%	7,771

Table 51. Does things in the community with the people they want

State v NCI	Average	N
PA ▲	89%	349
NCI-IDD	81%	7,653

Table 52. 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 v NCI	Average	N
PA	95%	149
NCI-IDD	92%	3,161

Table 53. 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)

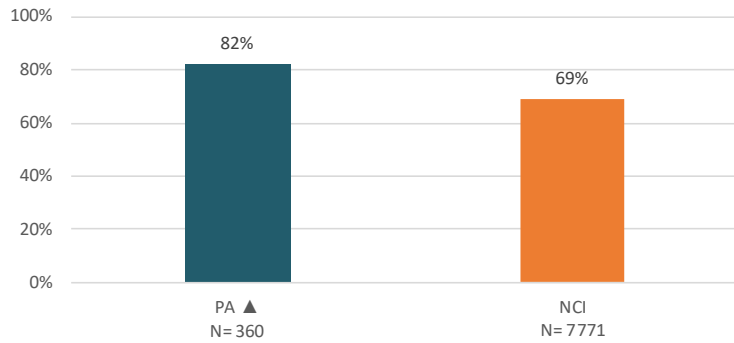
Proxy respondents were allowed for this question

State v NCI	Average	N
PA ▲	95%	142
NCI-IDD	90%	3,176

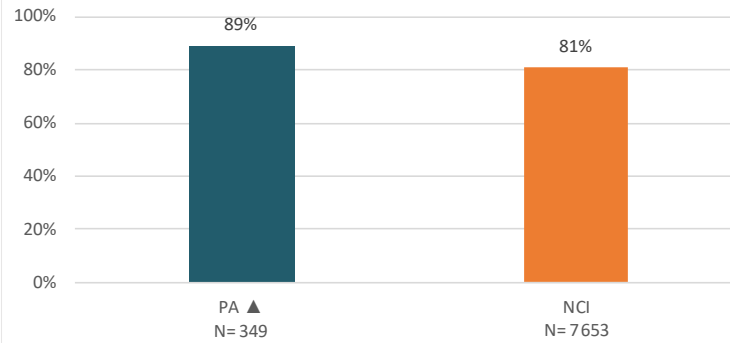
Table 54. Gets help to learn new things

State v NCI	Average	N
PA	81%	374
NCI-IDD	80%	7,771

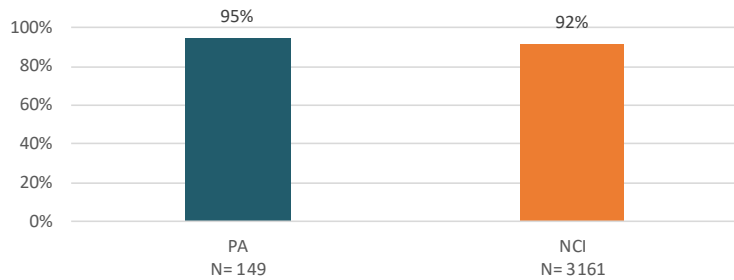
Gets to do things likes to do in the community as much as wants



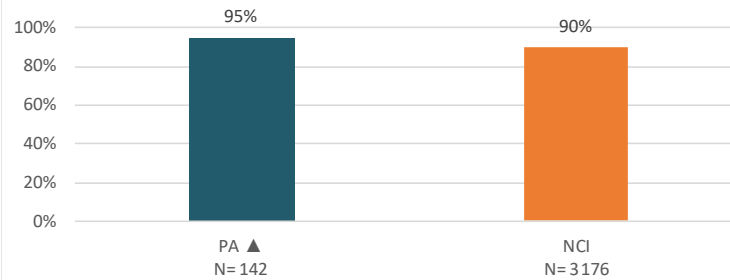
Does things in the community with the people they want



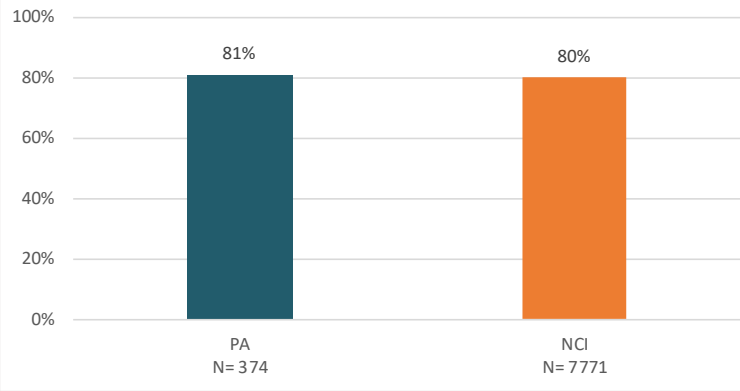
Can be themself when with others in groups, organizations, or communities the person takes part in (if person takes part in groups, organizations, or communities)



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)



Gets help to learn new things



Community Participation

Value statement: People participate in activities in their communities

Table 55. Went out shopping at least once in the past month
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	83%	656
NCI-IDD	82%	13,056

Table 56. Went out on errands at least once in the past month
Proxy respondents were allowed for this question

State v NCI	Average	N
PA ▲	89%	641
NCI-IDD	81%	12,877

Table 57. Went out for entertainment at least once in the past month

State v NCI	Average	N
PA	60%	642
NCI-IDD	62%	12,997

Table 58. Went out to a restaurant or coffee shop at least once in the past month
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	74%	652
NCI-IDD	77%	13,040

Table 59. Went out to religious service or spiritual practice at least once in the past month
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	29%	641
NCI-IDD	32%	12,979

Table 60. Takes part in groups, organizations or communities (in-person or virtually)
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	26%	640
NCI-IDD	26%	12,969

Table 61. The groups, organizations or communities takes part in include people without disabilities

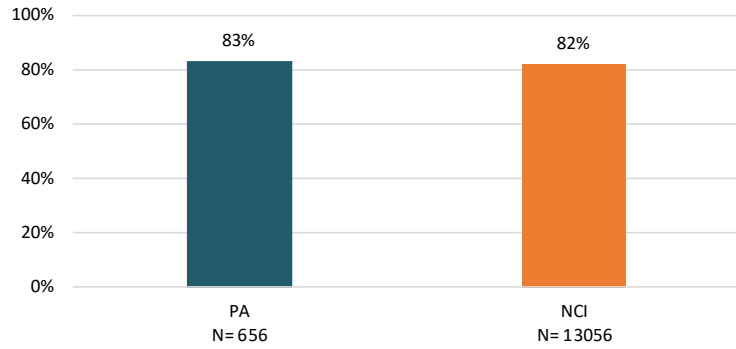
State v NCI	Average	N
PA	64%	131
NCI-IDD	58%	3,138

Table 62. Community Inclusion Scale⁶

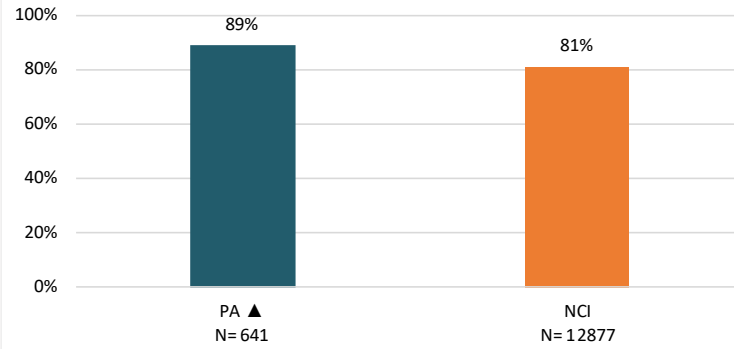
State v NCI	Average	N
PA	77%	671
NCI-IDD	75%	11,712

⁶ Risk adjusted. Scale was produced by using data from four variables; variables related to shopping, errands, entertainment and eating out in the community.

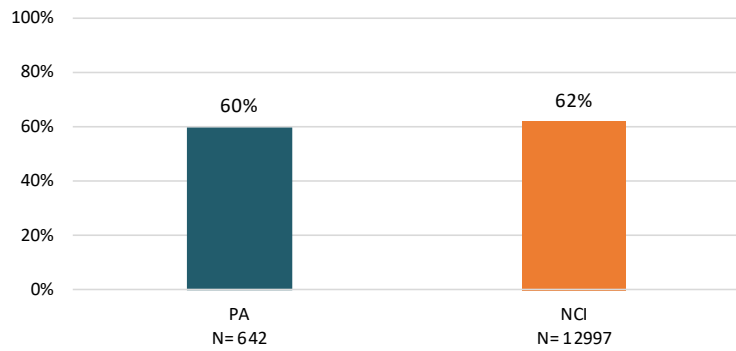
Went out shopping at least once in the past month



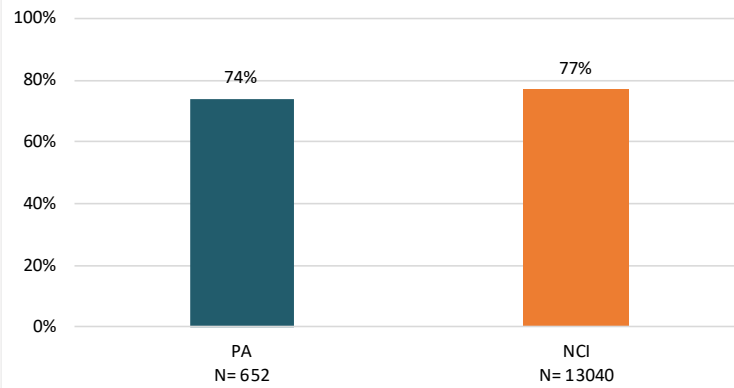
Went out on errands at least once in the past month



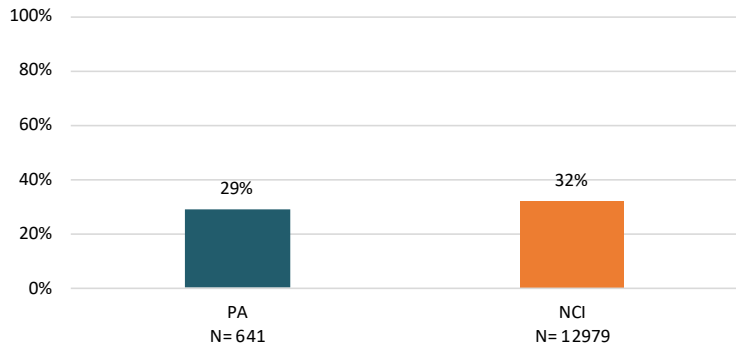
Went out for entertainment at least once in the past month



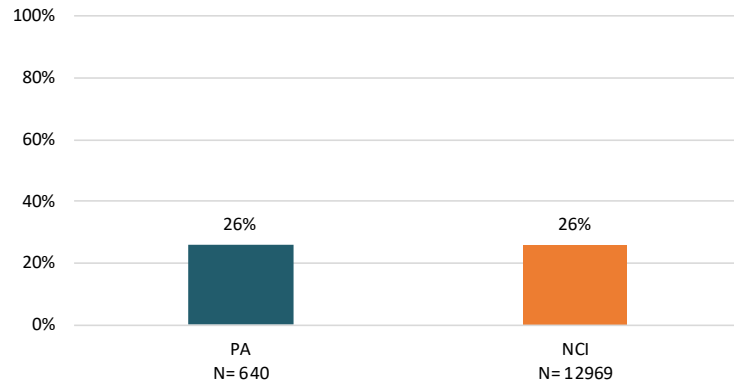
Went out to eat at least once in the past month



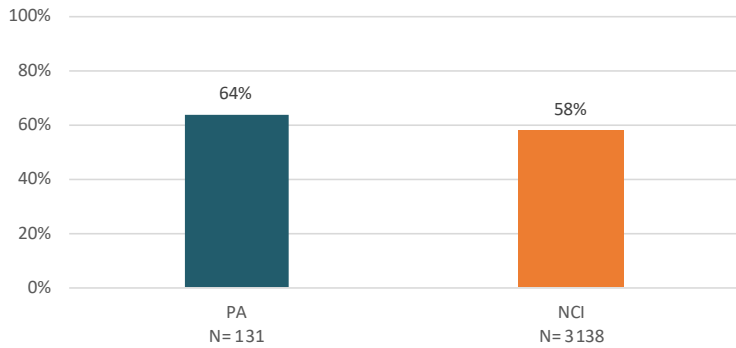
Went out to religious service or spiritual practice at least once in the past month



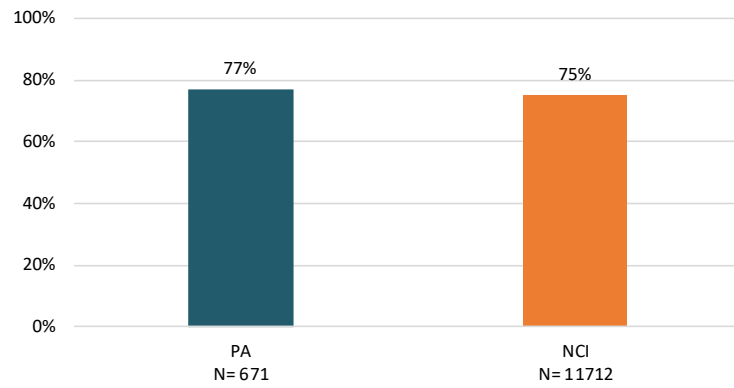
Participated as a member in community group



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



Community Inclusion Scale



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 63. 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 v NCI	Average	N
PA	54%	367
NCI-IDD	57%	7,355

Table 64. 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 v NCI	Average	N
PA	44%	362
NCI-IDD	44%	7,384

Table 65. Decides or has help deciding their daily schedule
Proxy respondents were allowed for this question

State v NCI	Average	N
PA ▲	94%	653
NCI-IDD	88%	13,099

Table 66. Decides or has help deciding how to spend free time⁷
Proxy respondents were allowed for this question

State v NCI	Average	N
PA ▲	97%	654
NCI-IDD	95%	13,093

⁷ 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

Table 67. Has enough choice about what to do in free time
Proxy respondents were allowed for this question

State v NCI	Average	N
PA ▲	98%	639
NCI-IDD	94%	12,706

Table 68. Chose or had some help in choosing where they work (among those with a paid community job)
Reported for those determined to have a paid community job based on Background Information section

Proxy respondents were allowed for this question

State v NCI	Average	N
PA	93%	86
NCI-IDD	90%	1,794

Table 69. Chose or had some input in choosing day program or workshop
Only includes those respondents determined to have a unpaid community activity, unpaid paid facility based activity or paid facility based activity in the Background Information section

Proxy respondents were allowed for this question

State v NCI	Average	N
PA	69%	185
NCI-IDD	64%	4,752

Table 70. Has input in choosing their regular day activities (in addition to or instead of a paid community job and/or day program/workshop)
Proxy respondents were allowed for this question

State v NCI	Average	N
PA ▲	91%	315
NCI-IDD	86%	7,443

Table 71. 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 v NCI	Average	N
PA ▲	96%	645
NCI-IDD	90%	12,718

Table 72. Chose staff or were aware they could request to change staff
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	59%	543
NCI-IDD	63%	11,237

Table 73. Can change their case manager/service coordinator if wants to
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	78%	548
NCI-IDD	74%	12,049

Table 74. Life Decisions Scale⁸
Risk Adjusted

State v NCI	Average	N
PA	58%	671
NCI-IDD	59%	11,712

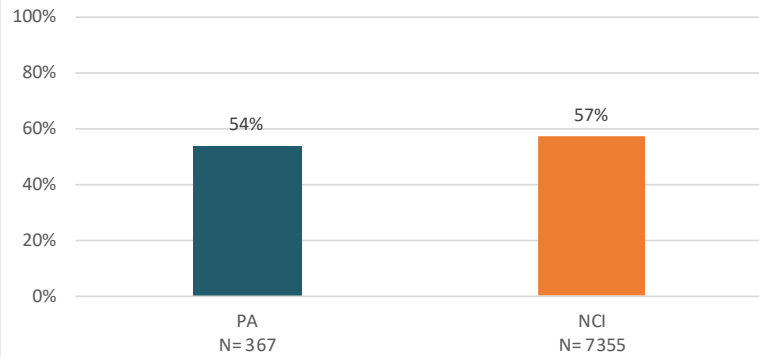
⁸ (The Life Decisions includes choice of: residence, work, day activity, staff, and roommates.)

Table 75. Everyday Choices Scale⁹

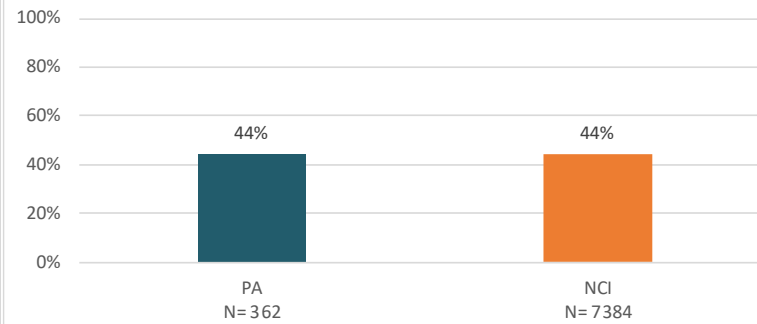
State v NCI	Average	N
PA	96%	677
NCI-IDD	91%	13,270

⁹ (The Everyday Choices scale includes choice of: daily schedule, how to spend money, and free time activities.)

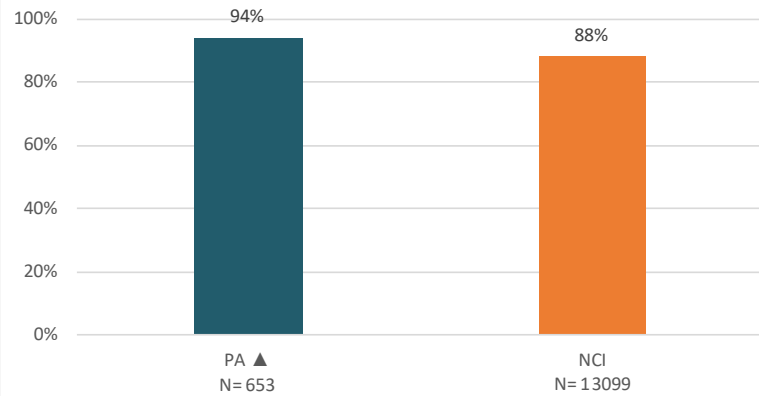
Chose or had some input in choosing where they live if not living in the family home



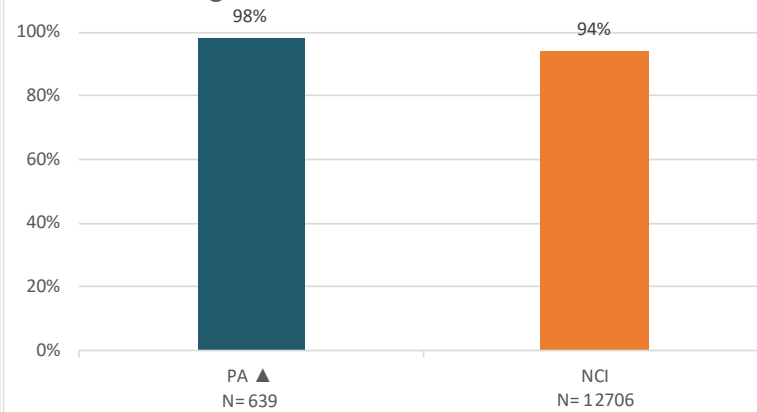
Chose or had some input in choosing their housemates if not living in the family home, or chose to live alone



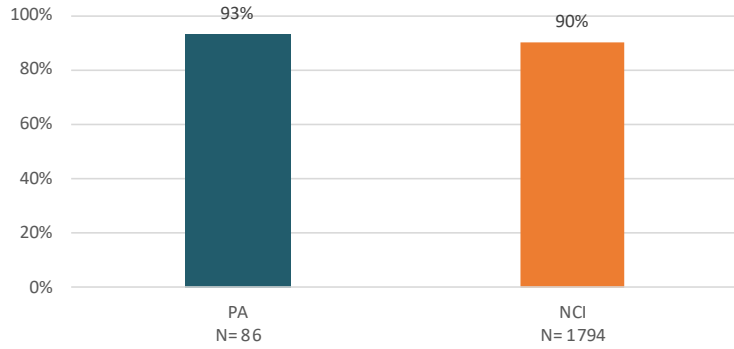
Decides or has help deciding their daily schedule



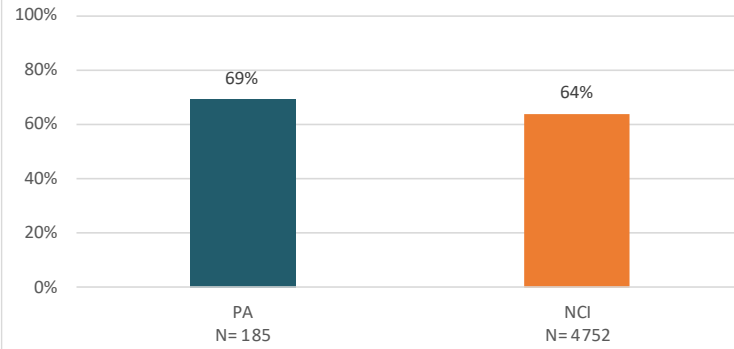
Has enough choice about what to do in free time



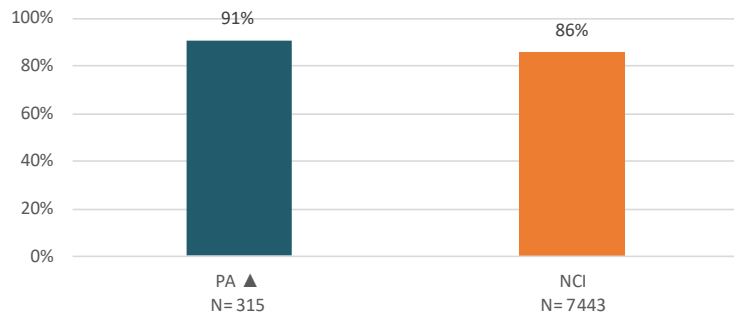
Chose or had some help in choosing where they work (among those with a paid community job)



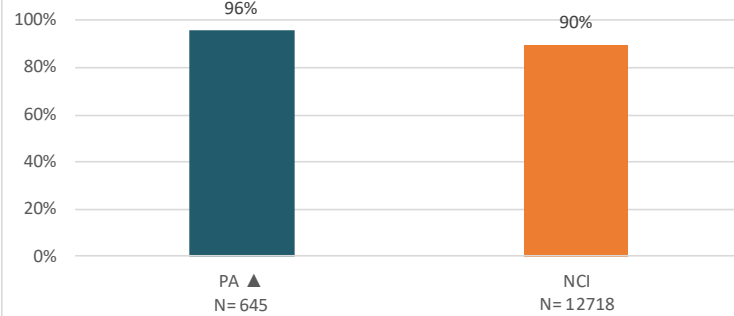
Chose or had some input in choosing day program or workshop



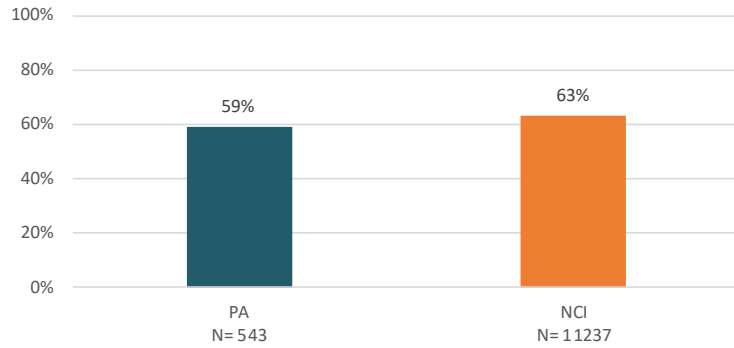
Has input in choosing their regular day activities (in addition to or instead of a paid community job and/or day program/workshop)



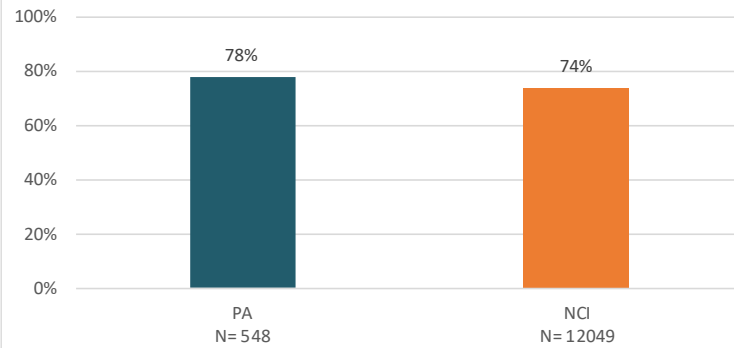
Chooses or has help deciding what to buy or has set limits on what to buy with their spending money



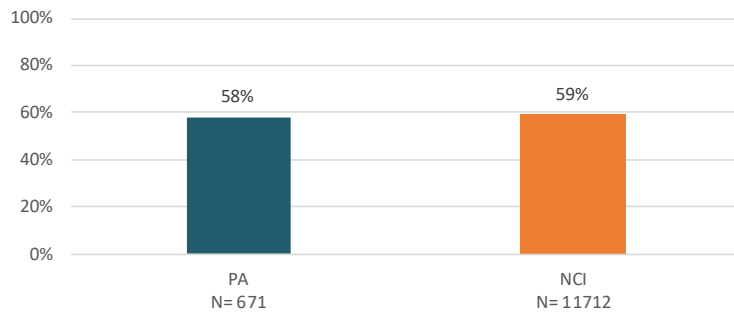
Chose staff or were aware they could request to change staff



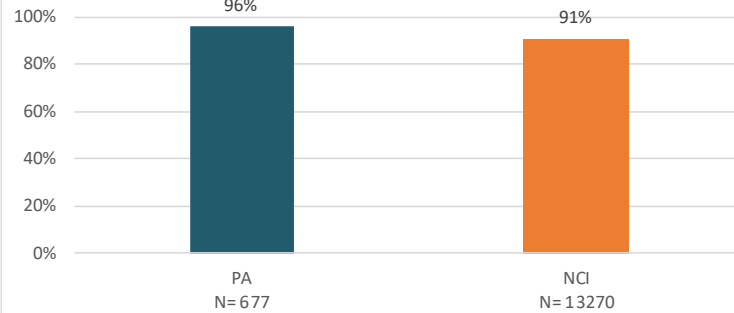
Can change their case manager/service coordinator if wants to



Life Decisions Scale (The Life Decisions includes choice of: residence, work, day activity, staff, and roommates.)



Everyday Choices Scale (The Everyday Choices scale includes choice of: daily schedule, how to spend money, and free time activities.)



Relationships

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

Table 76. Has friends who are not staff or family members

State v NCI	Average	N
PA	74%	396
NCI-IDD	78%	8,134

Table 77. Has best friend (may be staff or family)

State v NCI	Average	N
PA	82%	323
NCI-IDD	81%	7,015

Table 78. Wants more help to meet or keep in contact with friends.
“Yes” and “Maybe” responses combined

State v NCI	Average	N
PA ▼	40%	365
NCI-IDD	56%	7,787

Table 79. Has friends (may be staff or family) and can see their friends in person when they want

State v NCI	Average	N
PA ▲	77%	319
NCI-IDD	68%	7,007

Table 80. Has other ways of talking chatting or communicating with friends when cannot see them in person

State v NCI	Average	N
PA	83%	320
NCI-IDD	81%	7,042

Table 81. Can see or communicate with their family when they want (among those who do not live in the family home)

State v NCI	Average	N
PA	85%	198
NCI-IDD	83%	4,708

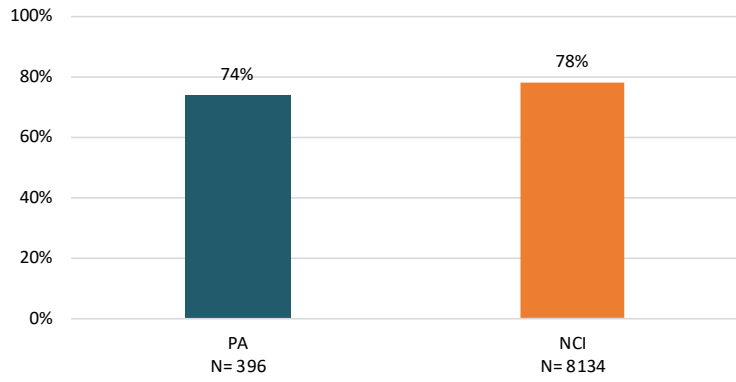
Table 82. Often feels lonely

State v NCI	Average	N
PA ▼	8%	382
NCI-IDD	11%	7,865

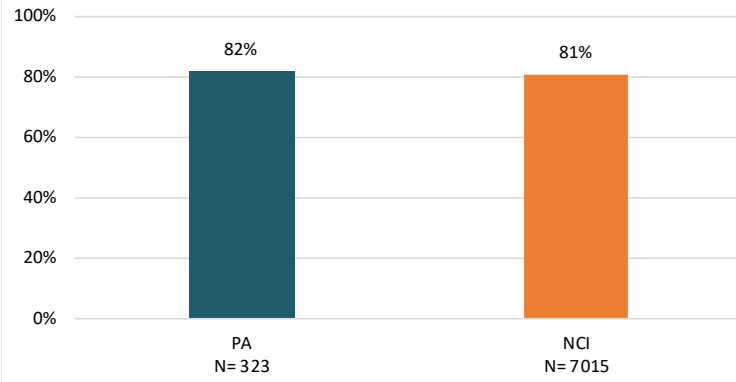
Table 83. Can go on a date or is married or living with partner

State v NCI	Average	N
PA ▲	85%	275
NCI-IDD	77%	6,270

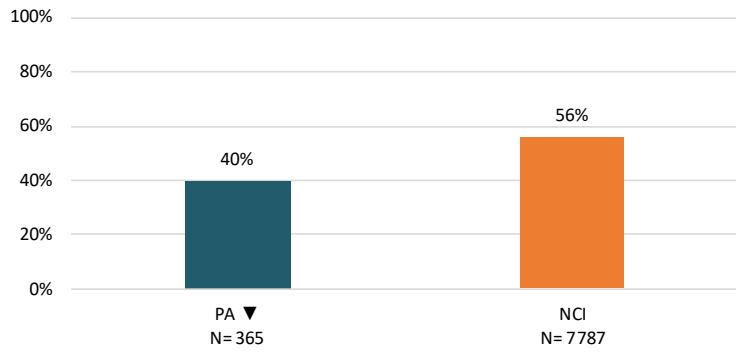
Has friends who are not staff or family members



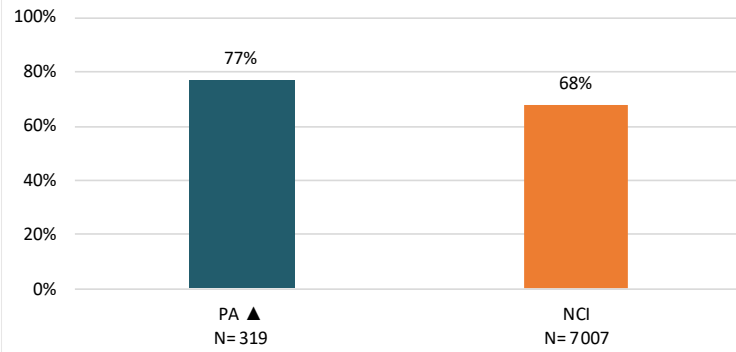
Has best friend (may be staff or family)



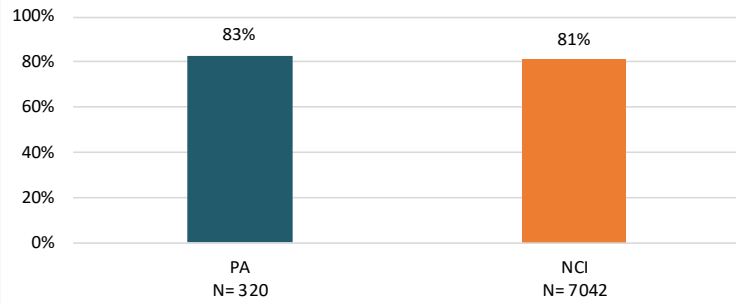
Wants more help to make or keep in contact with friends (Yes and Maybe responses combined)



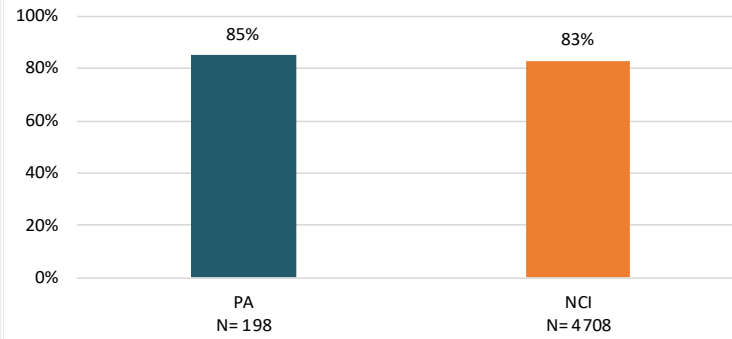
Has friends (may be staff or family) and can see them when they want



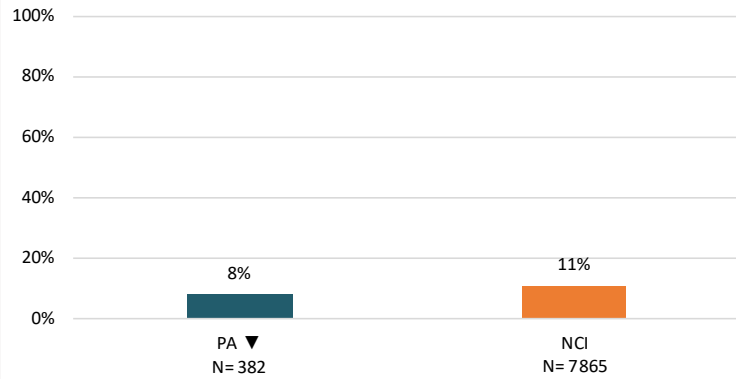
Has other ways of talking chatting or communicating with friends when cannot see them in person



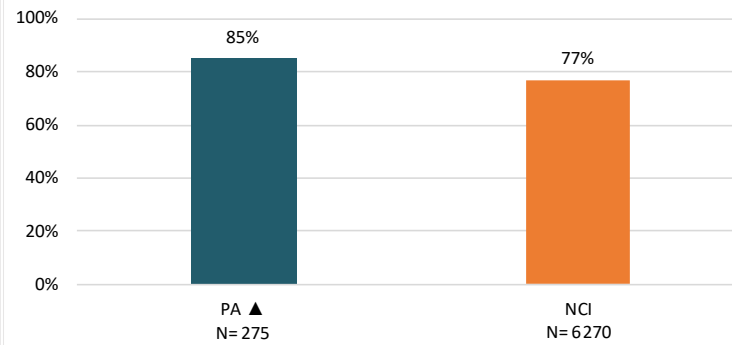
Can see and communicate with their family when they want if not living with family



Often feels lonely



Can go on a date or is married or living with partner



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 84. Likes home or where lives

State v NCI	Average	N
PA	93%	405
NCI-IDD	89%	8,276

Table 85. Wants to live somewhere else

State v NCI	Average	N
PA ▼	21%	379
NCI-IDD	29%	8,027

Table 86. Has enough things they like to do at home

State v NCI	Average	N
PA ▲	93%	393
NCI-IDD	83%	7,964

Table 87. Likes paid community job (if working in a paid community job)¹⁰

State v NCI	Average	N
PA	93%	84
NCI-IDD	91%	1,568

¹⁰ Based on those reported to have a paid community job (from the Background Information Section)

Table 88. Wants to go out shopping more, less or the same amount as last month
Proxy respondents were allowed for this question

State v NCI	More	Less	Same	N
PA	33%	5%	62%	617
NCI-IDD	39%	5%	56%	12,673

Table 89. Wants to go out for entertainment more, less or the same amount as last month
Proxy respondents were allowed for this question

State v NCI	More	Less	Same	N
PA	45%	2%	53%	587
NCI-IDD	53%	2%	45%	12,579

Table 90. 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 v NCI	More	Less	Same	N
PA	41%	2%	56%	601
NCI-IDD	49%	3%	48%	12,739

Table 91. 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 v NCI	More	Less	Same	N
PA	20%	2%	79%	550
NCI-IDD	27%	2%	71%	12,076

Table 92. Person wants to be a part of more community groups
Proxy respondents were allowed for this question

State v NCI	Average	No	N
PA	66%	34%	577
NCI-IDD	61%	39%	12,040

Table 93. Satisfaction with community inclusion scale¹¹

State v NCI	Average	N
PA	63%	637
NCI-IDD	56%	13,030

¹¹ The scale includes the following items: • Person is satisfied with how often they went on shopping in the past month • Person is satisfied with how often they went out for entertainment in the past month • Person is satisfied with how often they went to a restaurant or coffee shop in the past month • Person is satisfied with how often they went to a religious service or spiritual practice in the past month • Person is satisfied with the level of community group participation

Table 94. Likes how they usually spend time during the day

State v NCI	Average	N
PA ▲	89%	389
NCI-IDD	81%	7,976

Table 95. Has used telehealth for healthcare services and like using it
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	62%	313
NCI-IDD	58%	6,967

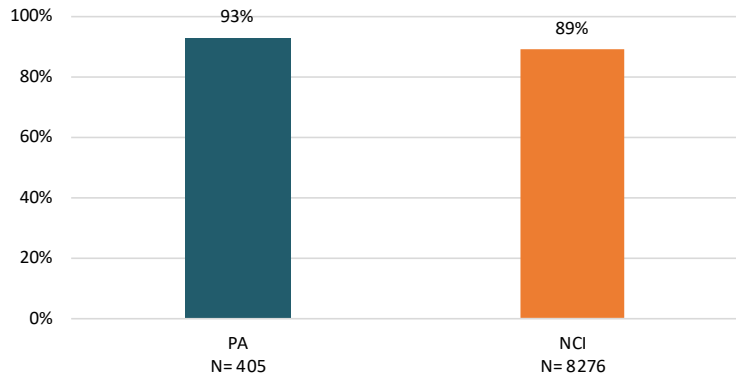
Table 96. Has accessed services and support using video conference technology and like using it
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	66%	204
NCI-IDD	61%	3,607

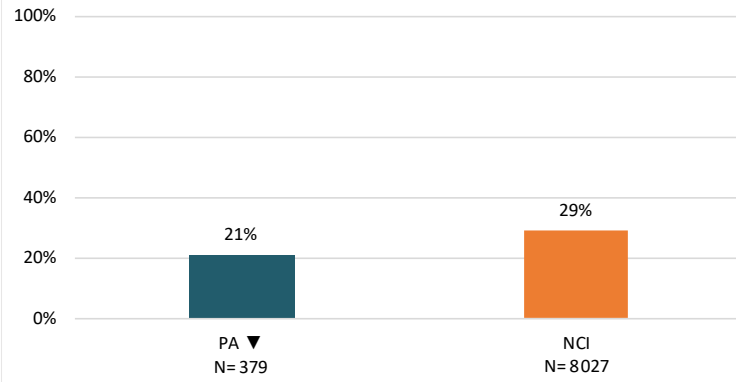
Table 97. Have talked with their case manager using video conference technology and like using it
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	67%	390
NCI-IDD	63%	7,059

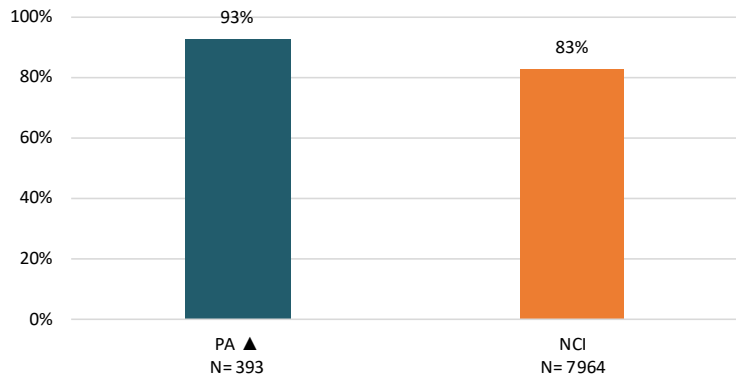
Likes home or where he/she lives



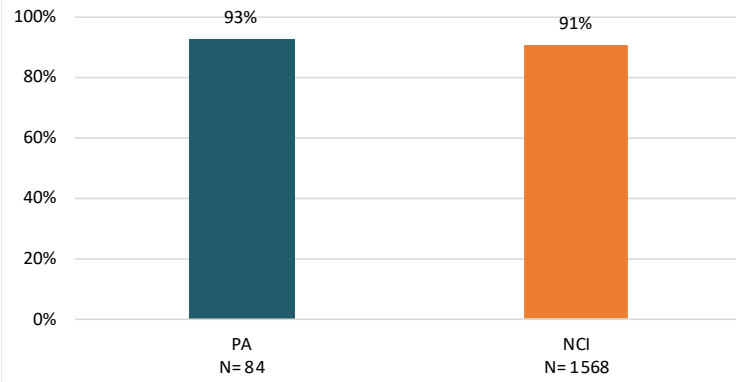
Wants to live somewhere else



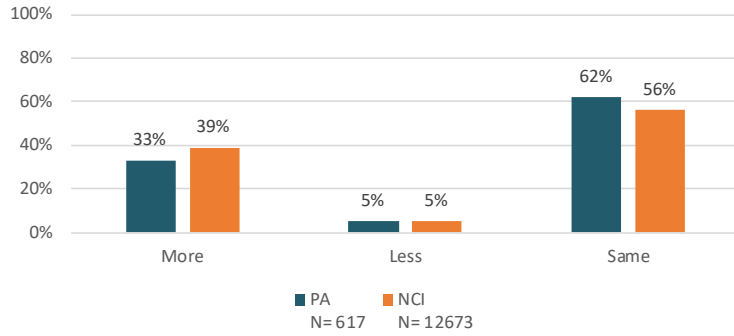
Has enough things they like to do at home



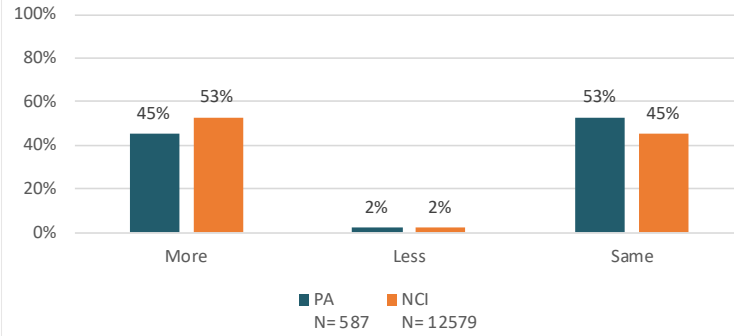
Likes paid community job



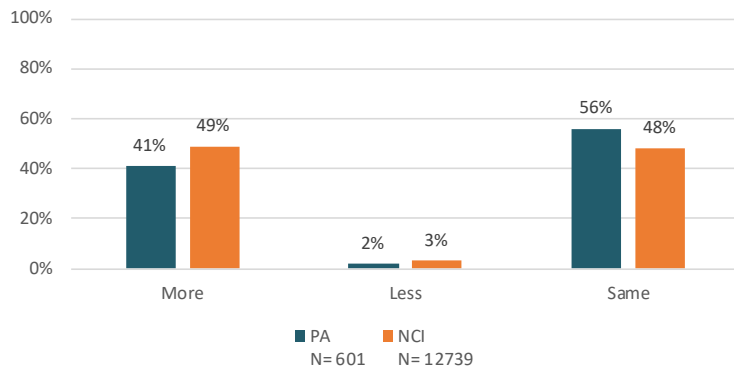
Person wants to go out for shopping more, less or the same amount as last month



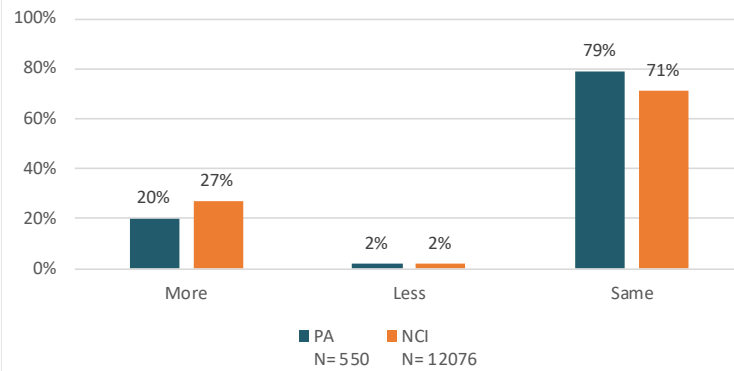
Person wants to go out for entertainment more, less or the same amount as last month



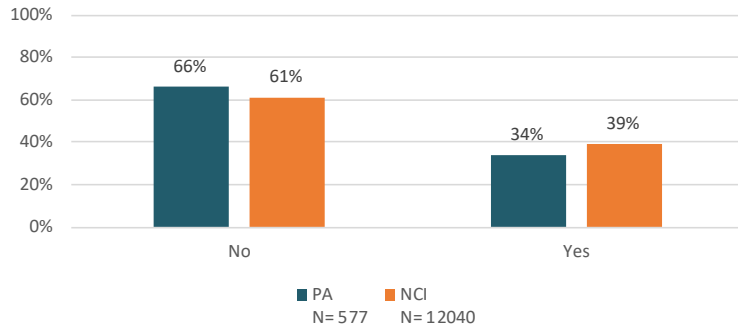
Person wants to go out to a restaurant or coffee shop more, less or the same amount as last month



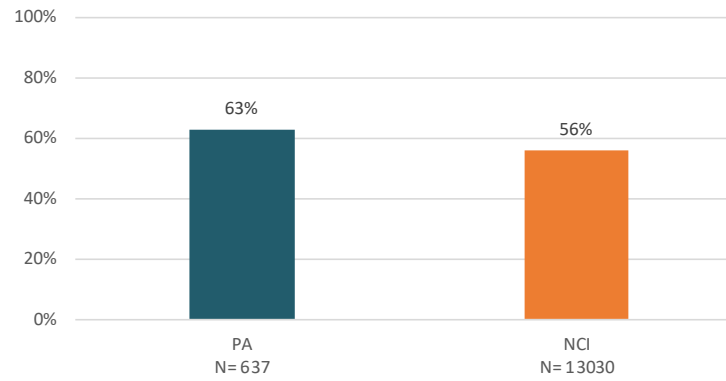
Person wants to go out to a religious service or spiritual practice more, less or the same amount as last month



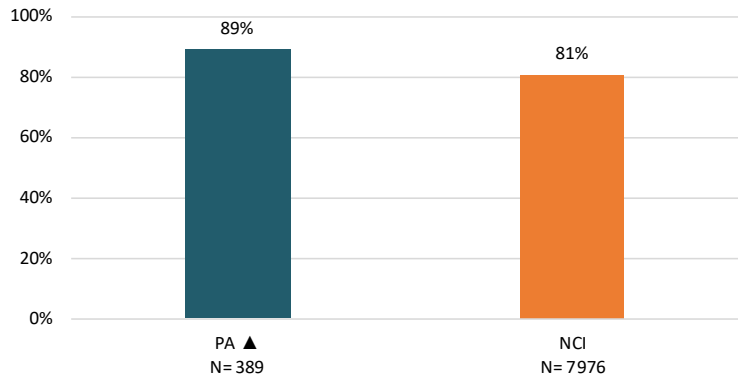
Person wants to be a part of more community groups



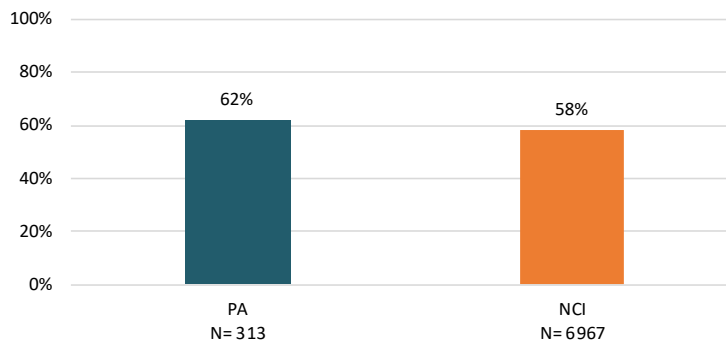
Satisfaction with community inclusion



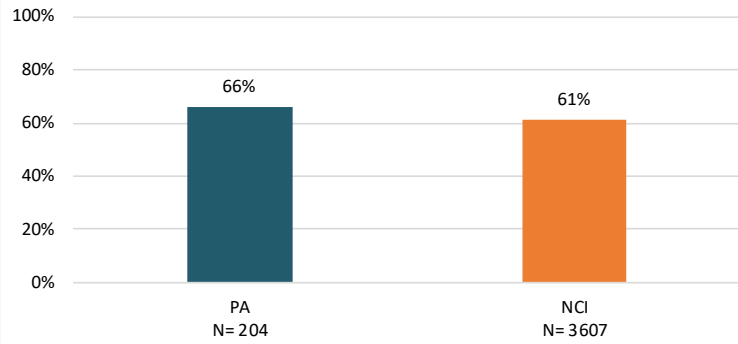
Likes how they usually spend time during the day



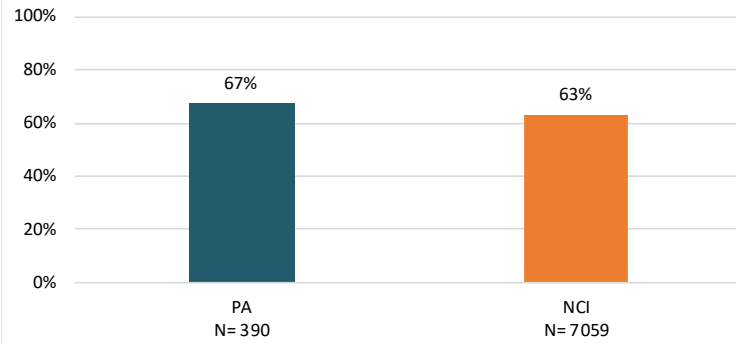
Has used telehealth for healthcare services and liked using it



Has accessed services and support using video conference technology and like using it



Have talked with their case manager using video conference technology and liked using it



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.

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. Additionally, many states have very low rates of individuals who were surveyed and were reported to use a self-directed supports option. **Significance testing was not conducted on these items.**

PLEASE NOTE: The data in this section may reflect the perspective of the person receiving services or that of friends/family who participate in decisions about the self-directed supports option.

Table 98. Using a self-directed supports option
Information may have been obtained through state records

State v NCI	No	Yes	N
PA	91%	9%	622
NCI-IDD	81%	19%	10,679

Table 99. People who make decisions or have input in making decisions about the services that are self-directed

State v NCI	Person mostly makes decisions	Person has input, and family/friend helps	Family/friend makes decisions, person does not have input	Decisions about what services are received are made by a case manager or another professional employed by the state	N
PA	19%	33%	44%	3%	36
NCI-IDD	13%	45%	36%	5%	1,698

Table 100. Can make changes to individual budget/services if needed

State v NCI	Yes	No	In-between	N
PA	97%	0%	3%	30
NCI-IDD	92%	2%	6%	1,381

Table 101. Has enough help deciding how to direct services

State v NCI	Yes	No	In-between	N
PA	93%	3%	3%	29
NCI-IDD	87%	5%	8%	1,393

Table 102. Has the amount of control wanted with the services that are self-directed

State v NCI	Yes	No	In-between	N
PA	89%	4%	7%	28
NCI-IDD	84%	4%	12%	1,387

Table 103. The services and supports they want to self-direct are always available

State v NCI	Yes	No	In-between	N
PA	67%	20%	13%	30
NCI-IDD	64%	16%	19%	1,385

Table 104. Gets information about budget and services from financial management service (FMS)

State v NCI	Yes	No	In-between	N
PA	93%	7%	0%	30
NCI-IDD	76%	14%	11%	1,350

Table 105. Information from FMS is easy to understand

State v NCI	Yes	No	In-between	N
PA	61%	18%	21%	28
NCI-IDD	67%	5%	28%	997

Table 106. Frequency with which the person gets information from FMS¹²

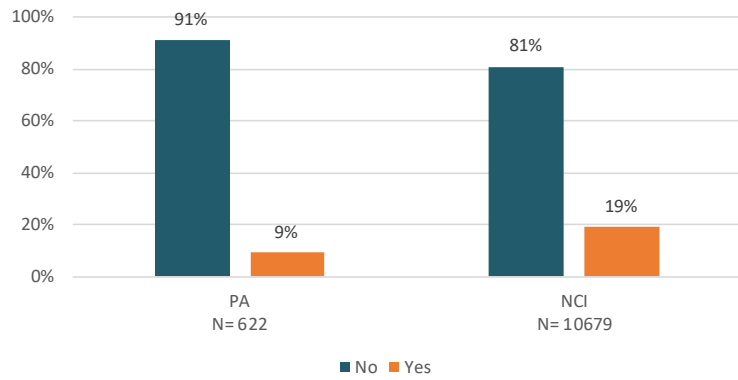
State v NCI	At Least Every Three Months	About Twice a Year	Once a Year or Less	N
PA	59%	32%	9%	22
NCI-IDD	70%	18%	12%	927

Table 107. Needs help with these elements of self-direction

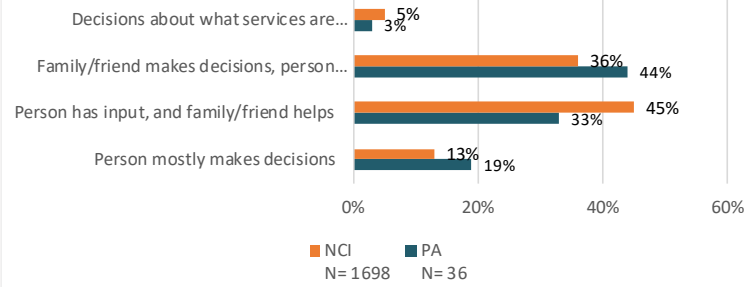
State v NCI	Help planning out service needs and setting a schedule for staff	Help getting staff paid	Help finding or keeping the staff they want	Help training staff	Help managing benefits for staff	Help understanding information gets from the FMS	More information about what services and supports can get	Other	Don't know, no response, unclear response	N
PA	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a
NCI-IDD	14%	15%	30%	14%	10%	22%	45%	25%	16%	907

¹² Please note: OR replaced “FMS” with “CME”

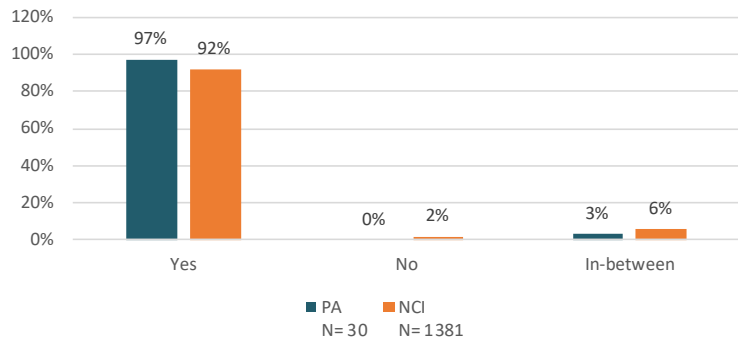
Using a self directed supports option



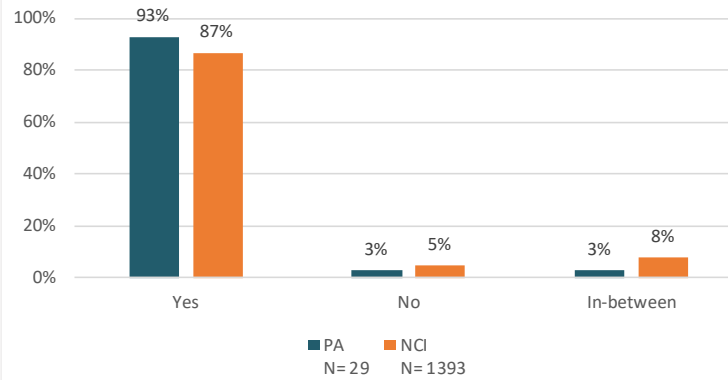
People who make decisions or have input in making decisions about the services that are self directed



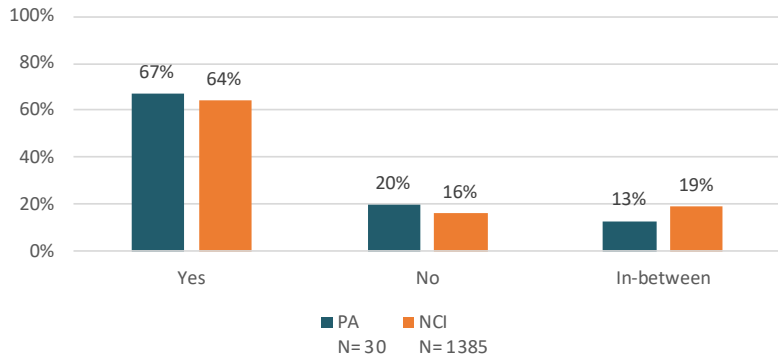
Can make changes to individual budget/services if needed



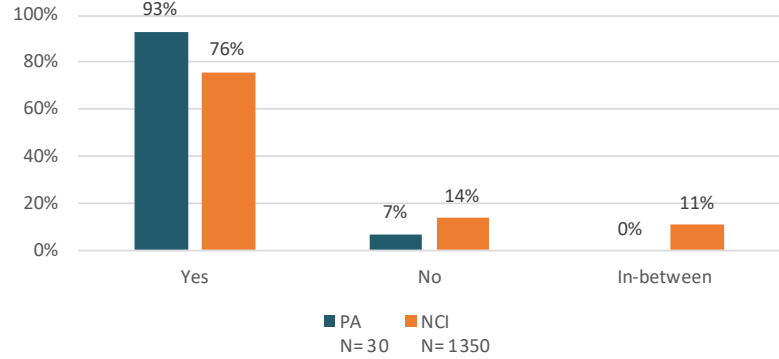
Has enough help deciding how to direct services



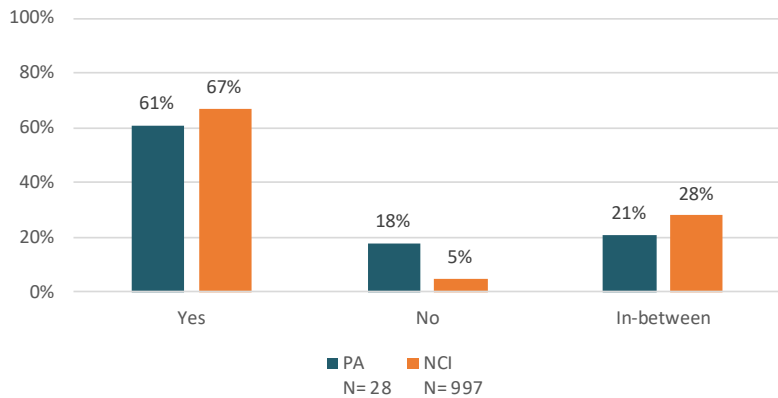
The services and supports they want to self-direct are always available



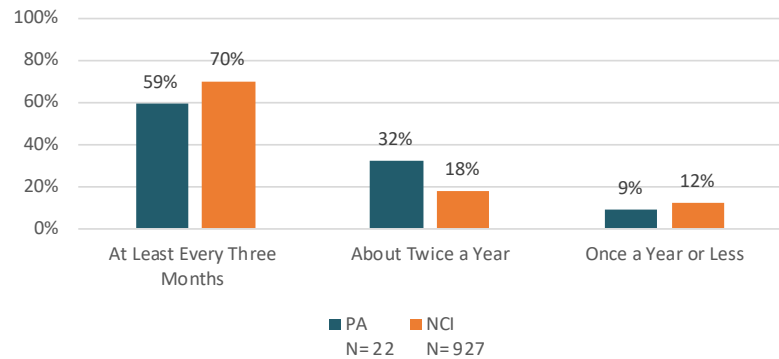
Gets information about budget and services from financial management service (FMS)



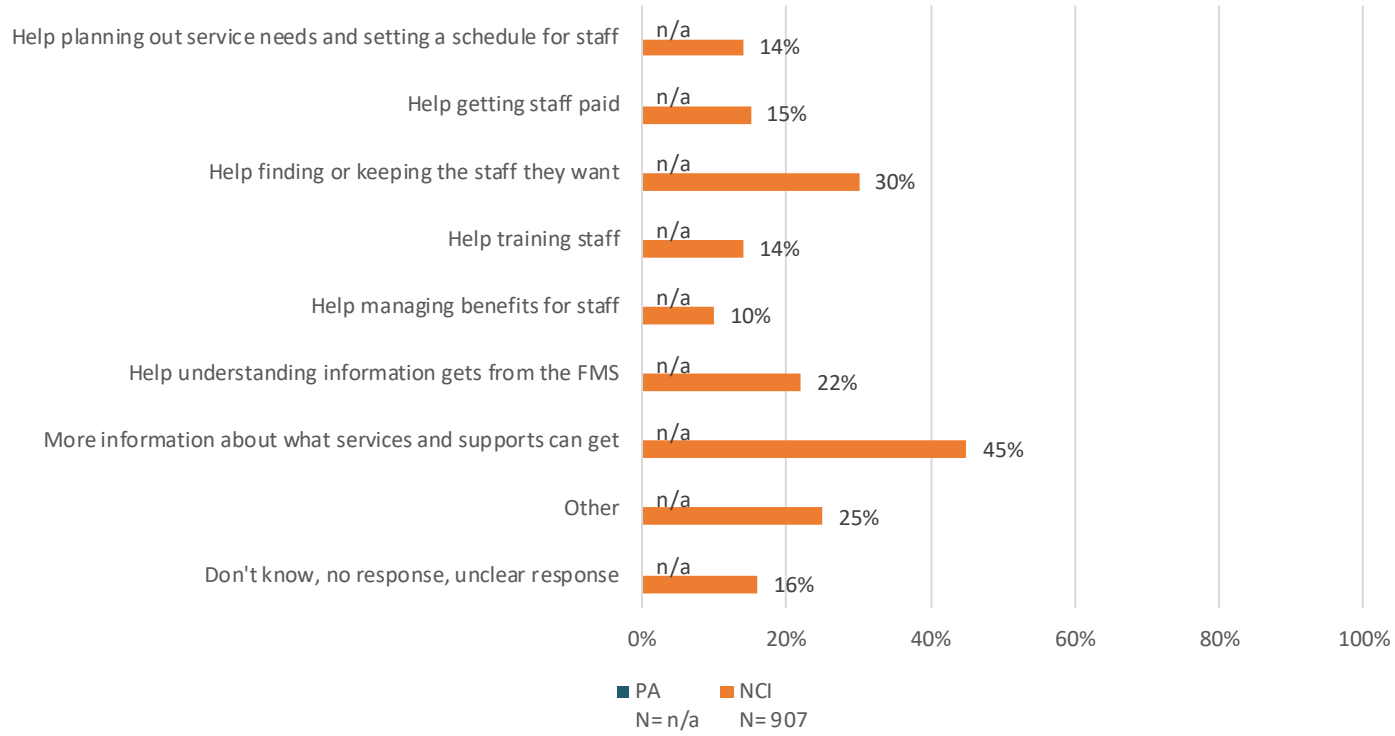
Information from FMS is easy to understand



Frequency with which the person gets information from FMS



Needs help with these elements of self direction



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 108. Has met or spoken with case manager/service coordinator

State v NCI	Average	N
PA	93%	367
NCI-IDD	93%	7,779

Table 109. Case manager/service coordinator knows what is important to person

State v NCI	Average	N
PA	93%	322
NCI-IDD	91%	6,913

Table 110. Able to contact case manager/service coordinator when wants

State v NCI	Average	N
PA ▲	93%	326
NCI-IDD	86%	6,909

Table 111. Case manager/service coordinator has talked to them about technology that may help them in their everyday life

State v NCI	Average	N
PA	40%	520
NCI-IDD	38%	11,482

Table 112. Was at last service planning meeting, or had the opportunity to be but chose not to

State v NCI	Average	N
PA	98%	342
NCI-IDD	97%	7,238

Table 113. Knew what was being talked about at last service planning meeting

State v NCI	Average	N
PA	78%	309
NCI-IDD	82%	6,626

Table 114. Last service planning meeting included people respondent wanted to be there

State v NCI	Average	N
PA ▲	99%	328
NCI-IDD	94%	6,880

Table 115. Person helped make service plan
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	74%	589
NCI-IDD	75%	12,446

Table 116. Case manager/service coordinator reviews their service plan with them throughout the year, when needed
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	90%	582
NCI-IDD	88%	12,478

Table 117. Service plan includes things that are important to person

State v NCI	Average	N
PA ▲	98%	286
NCI-IDD	95%	6,145

Table 118. Knows who to ask if wants to change something about services
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	85%	589
NCI-IDD	82%	12,723

Table 119. Of those who say they want to learn to perform ADLs more independently, the percentage who have a related goal in the service plan¹³

State v NCI	Average	N
PA	82%	28
NCI-IDD	73%	1,302

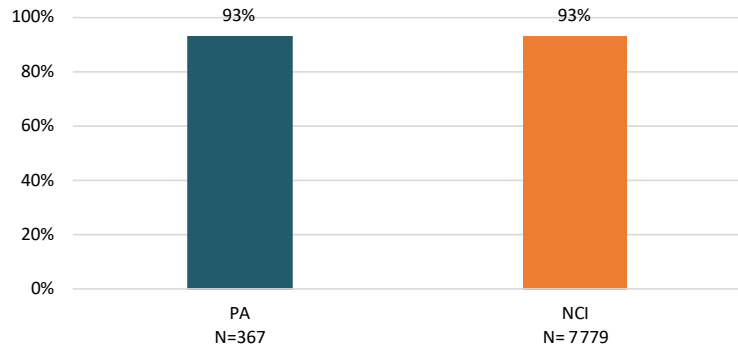
Table 120. Of those who say they want a paid job in the community (and do not currently have one), the percentage who have community employment as a goal in the service plan¹⁴

State v NCI	Average	N
PA	38%	63
NCI-IDD	35%	2,064

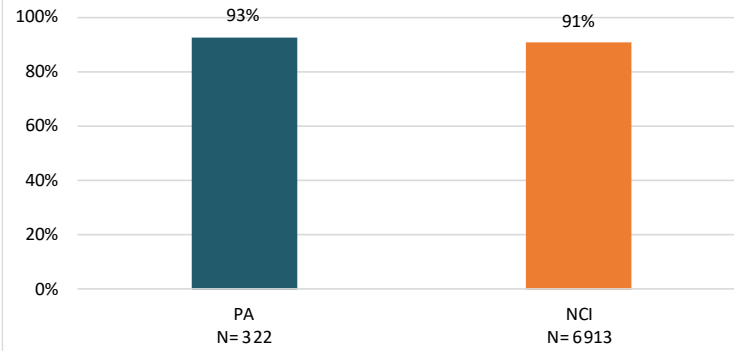
¹³ Please note: “ADL” refers to Activities of Daily Living. A related goal in the service plan refers to goals to increase independence or improve function skill performance in ADL. This analysis combines two questions that come from two different sources 1. Whether there is a goal in service plan to increase independence or improve functional skill performance in ADLs obtained through administrative records; and, 2. Whether the person wants to learn to do more ADLs on their own is asked during the face-to-face meeting with the person receiving services and can only be answered by that person.

¹⁴ Please note: This analysis combines two questions that come from two different sources 1. Whether community employment is a goal in service plan; and 2. Whether the person wants a job is asked during the face-to-face meeting with the person receiving services and can only be answered by that person

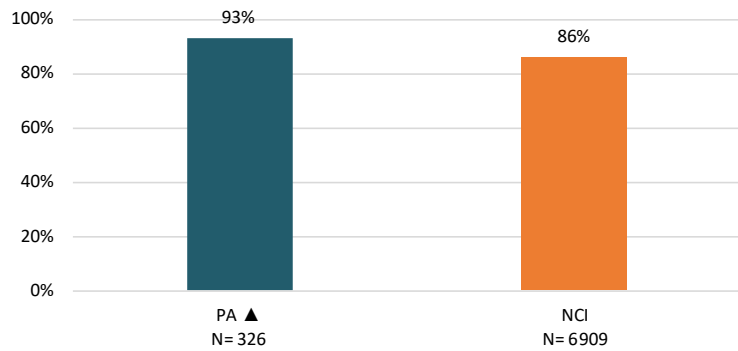
Has met or spoken with case manager/service coordinator



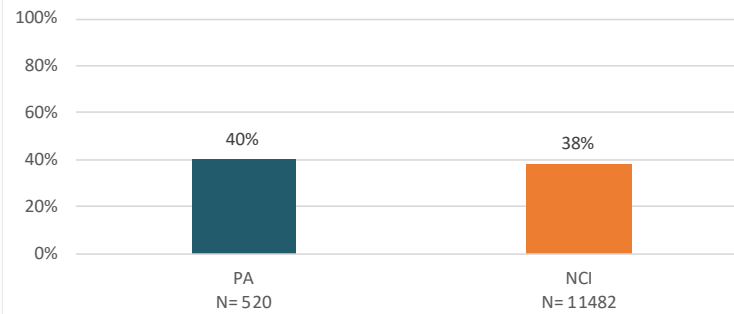
Case manager/service coordinator knows what is important to person



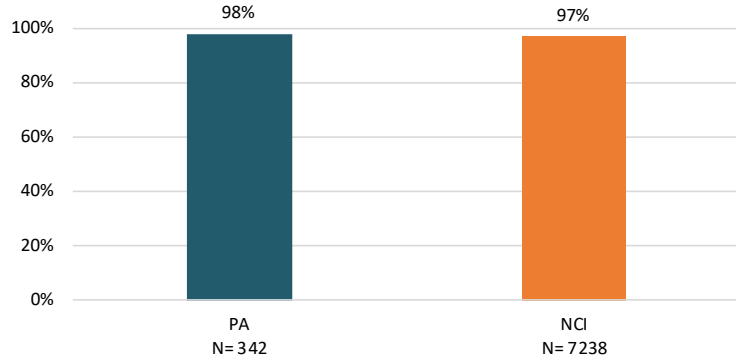
Able to contact case manager/service coordinator when wants



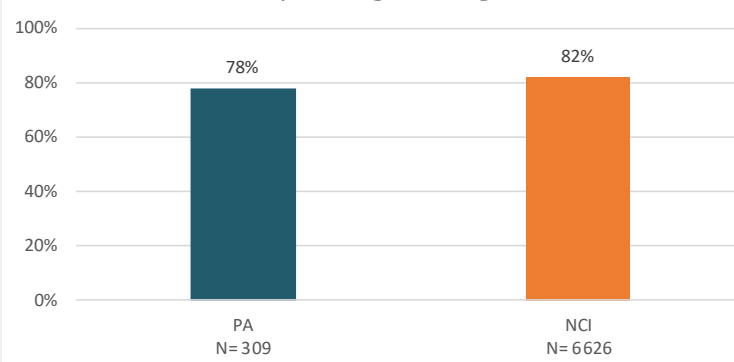
Case manager/service coordinator has talked to them about technology that may help them in their everyday life



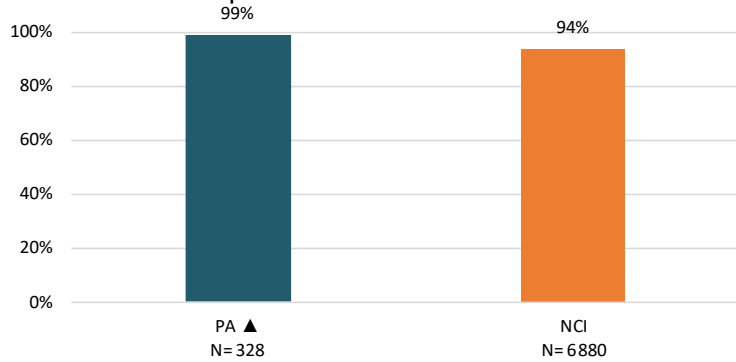
Was at last service planning meeting, or had the opportunity to be but chose not to



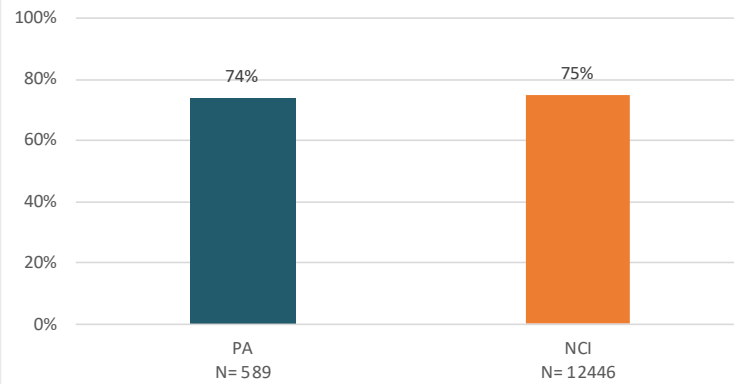
Knew what was being talked about at last service planning meeting



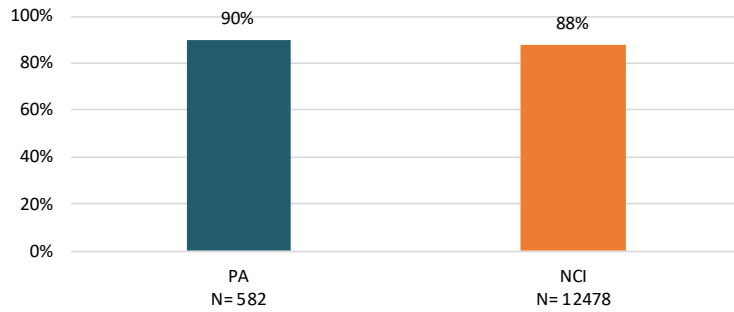
Last service planning meeting included people respondent wanted to be there



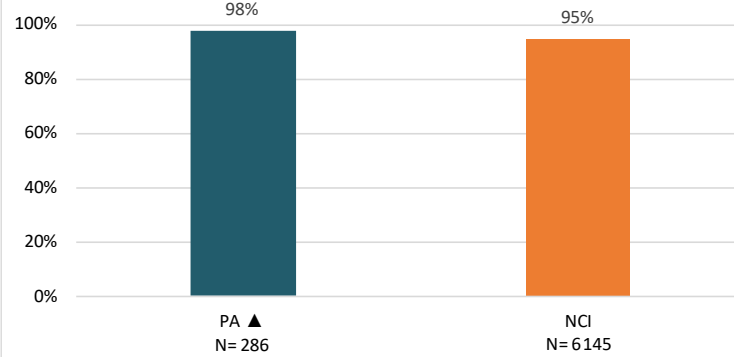
Person helped make service plan



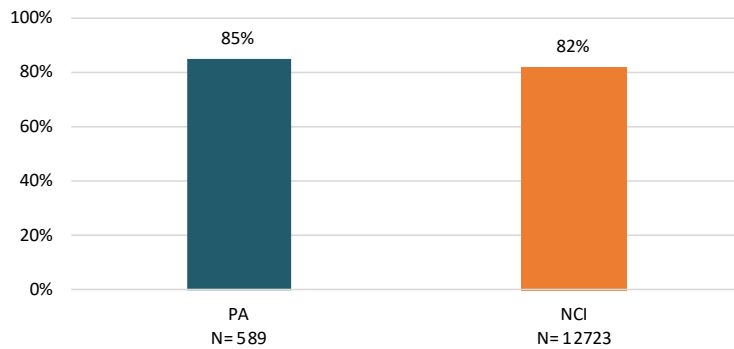
Case manager/service coordinator reviews their service plan with them throughout the year, when needed



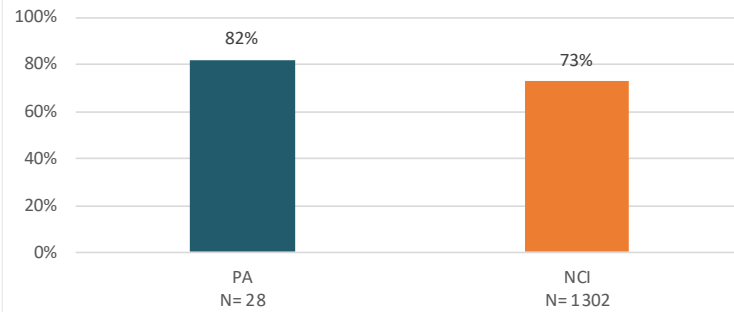
Service plan includes things that are important to person



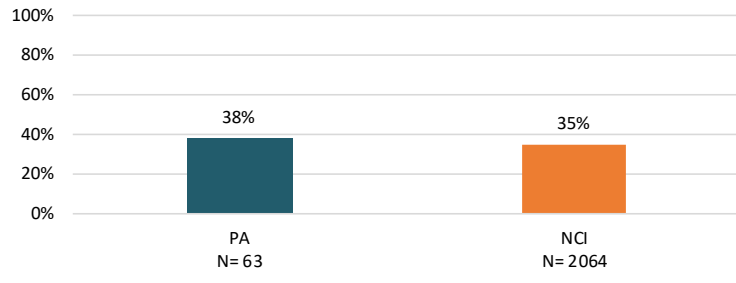
Knows who to ask if wants to change something about services



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



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



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 121. Staff are respectful of person's culture

State v NCI	Average	N
PA	97%	114
NCI-IDD	95%	4,433

Table 122. Staff treat person with respect

State v NCI	Average	N
PA	96%	131
NCI-IDD	92%	4,554

Table 123. Person can talk or communicate with staff in their preferred language

State v NCI	Average	N
PA	100%	121
NCI-IDD	98%	4,499

Table 124. Staff do things the way person wants them done

State v NCI	Average	N
PA ▲	95%	129
NCI-IDD	86%	4,440

Table 125. When in the community, staff support person in the way they want

State v NCI	Average	N
PA	93%	123
NCI-IDD	91%	4,414

Table 126. Staff come and leave when they are supposed to

State v NCI	Average	N
PA ▲	96%	114
NCI-IDD	90%	4,349

Table 127. Person's staff change too often

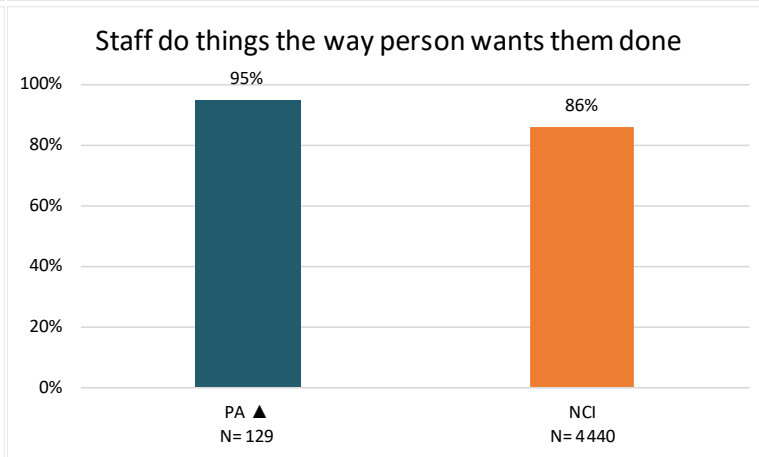
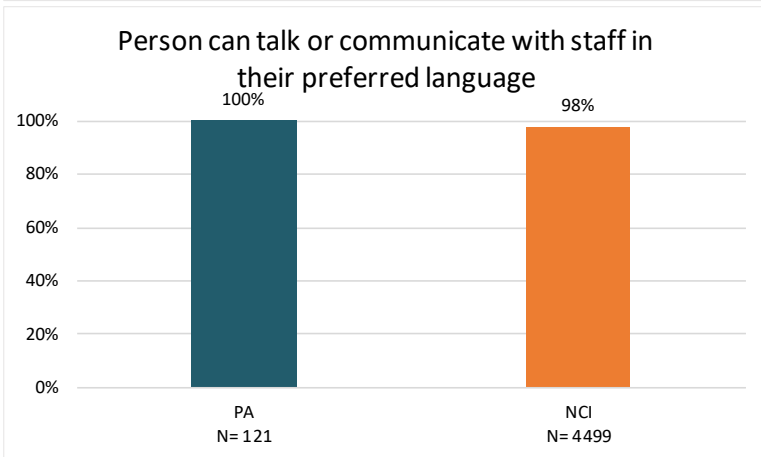
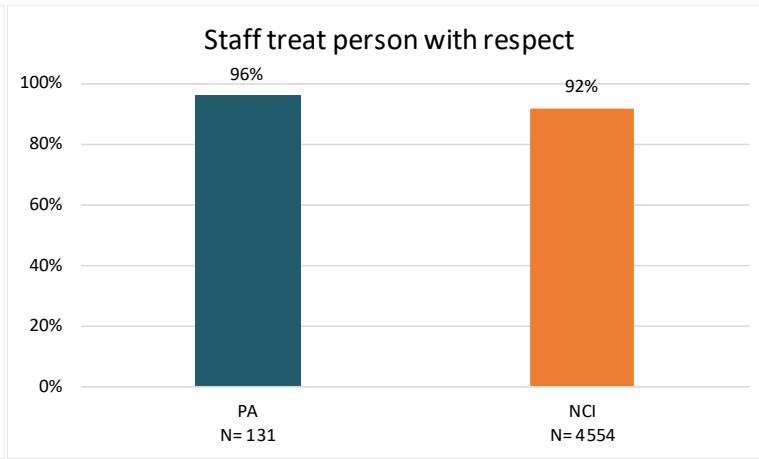
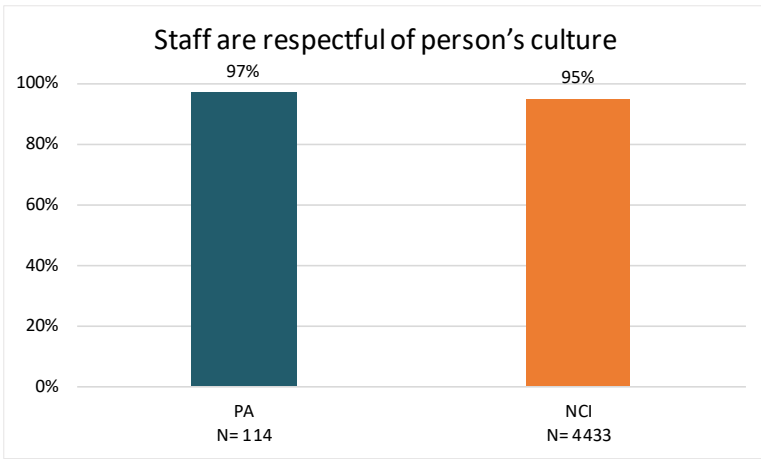
A higher percentage may not indicate a more positive result for this item

State v NCI	Average	N
PA	37%	118
NCI-IDD	40%	4,323

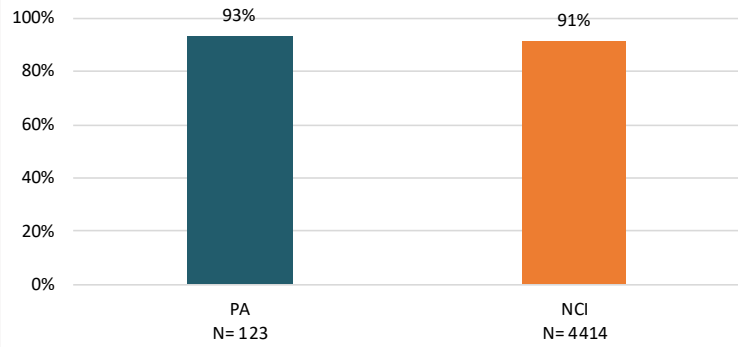
Table 128. Staff have the right training to meet person's needs

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

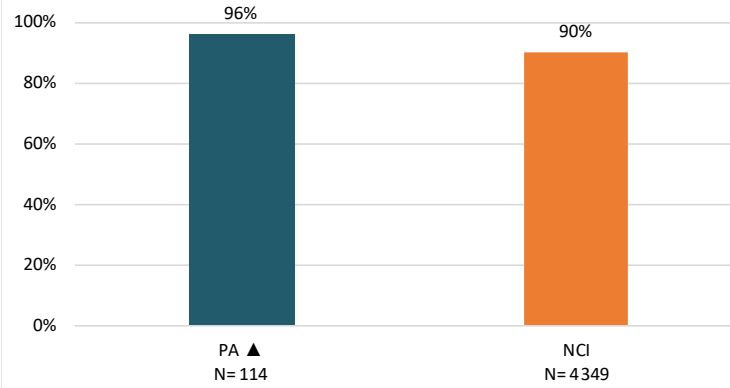
State v NCI	Average	N
PA	93%	338
NCI-IDD	90%	8,503



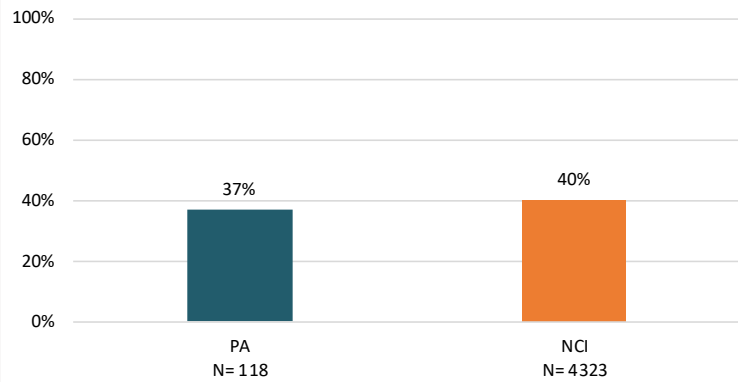
When in the community, staff support person in the way they want



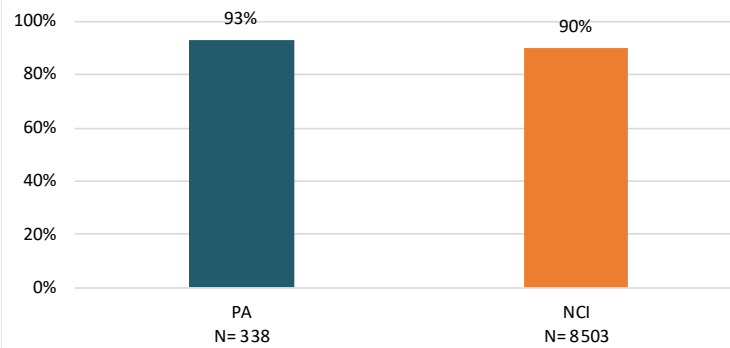
Staff come and leave when they are supposed to



Person's staff change too often



Staff have the right training to meet person's needs



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 129. 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 v NCI	Average	N
PA ▲	90%	387
NCI-IDD	78%	7,939

Table 130. Has a way to get places they need to go (like work, appointments, etc.)

State v NCI	Average	N
PA ▲	97%	386
NCI-IDD	93%	7,994

Table 131. Adequate Transportation Scale¹⁵

State v NCI	Average	N
PA	94%	379
NCI-IDD	86%	7,834

Table 132. Has access to the internet¹⁶

Proxy respondents were allowed for this question

State v NCI	Average	N
PA ▲	87%	663
NCI-IDD	83%	13,054

¹⁵This scale was produced by using data from variables related to having transportation when wants and needs it

¹⁶ This may be in the home, using a smartphone, in a local coffee shop, or somewhere the person spends time during the day

Table 133. Internet always works at home
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	88%	437
NCI-IDD	85%	8,453

Table 134. Frequency Uses Internet
Proxy respondents were allowed for this question

State v NCI	Everyday	Several times a week	Several times a month	Several times a year	Not at all	N
PA	47%	13%	11%	7%	22%	567
NCI-IDD	56%	14%	6%	3%	20%	10,870

Table 135. Uses technology in everyday life to help them do more things on their own
Proxy respondents were allowed for this question

State v NCI	Yes	No	N
PA	32%	68%	628
NCI-IDD	32%	68%	12,795

Table 136. 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 v NCI	Average	N
PA	91%	192
NCI-IDD	91%	3,890

Table 137. 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 v NCI	Average	N
PA	95%	195
NCI-IDD	93%	3,881

Table 138. Has used telehealth to talk with a health professional

Proxy respondents were allowed for this question

State v NCI	Average	N
PA	56%	632
NCI-IDD	59%	12,757

Table 139. Accessed services or supports using videoconference technology¹⁷

Proxy respondents were allowed for this question

State v NCI	Average	N
PA	35%	633
NCI-IDD	32%	12,748

¹⁷ This could be doing job coaching, attending a day program, or doing other activities through a provider using videoconference.

Table 140. Has talked with their case manager/service coordinator using videoconference technology
Proxy respondents were allowed for this question

State v NCI	Average	N
PA ▲	69%	622
NCI-IDD	59%	12,680

Table 141. Has a cell phone or smartphone

State v NCI	Average	N
PA	64%	385
NCI-IDD	66%	8,039

Table 142. Wants a cell phone or smartphone (if does not have one)

State v NCI	Yes	No	N
PA	35%	65%	110
NCI-IDD	47%	53%	2,582

Table 143. Reasons does not have cell phone or smartphone¹⁸

State v NCI	Cost	Not Allowed	Lost/Broke my old phone	Other
PA	37%	11%	4%	52%
NCI-IDD	31%	10%	17%	47%

¹⁸Categories are not mutually exclusive, therefore N is not shown

Table 144. Additional services needed

Proxy respondents were allowed for this question

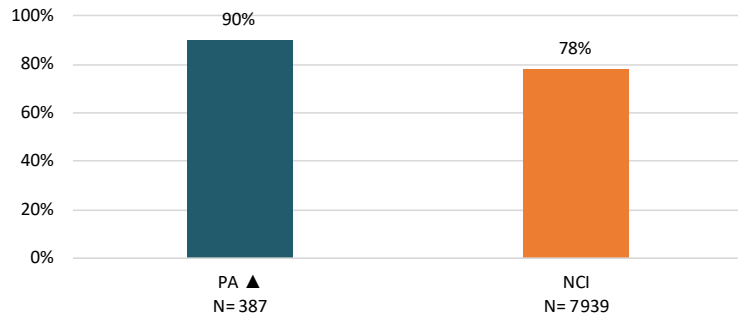
State v NCI	Help finding a new place to live	Changes, modifications to home	Staff support to help at home	Help working on job skills	Help finding or signing up for classes	Help to find something different to do during the day (not including paid work)	Help finding more reliable transportation
PA	5%	3%	6%	10%	8%	8%	6%
NCI-IDD	11%	7%	15%	17%	15%	17%	13%

Table 145. Additional services needed (continued)

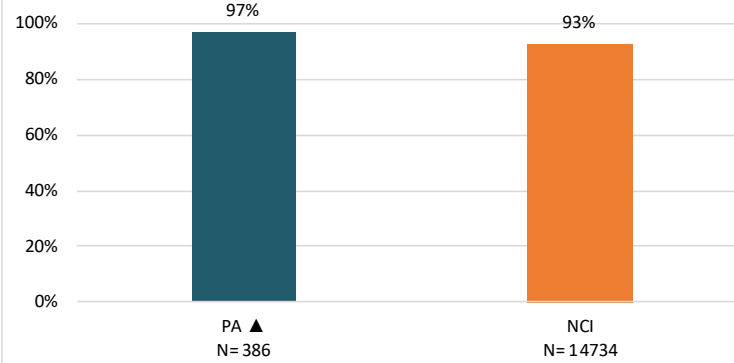
Proxy respondents were allowed for this question

State v NCI	Help getting or using tech to help in everyday life	Help with healthcare	Help understanding medication	Help finding, getting or setting up mental health or behavioral health supports	Anything else	Does not need additional supports	Don't know
PA	5%	3%	4%	5%	6%	66%	4%
NCI-IDD	12%	8%	7%	8%	14%	49%	2%

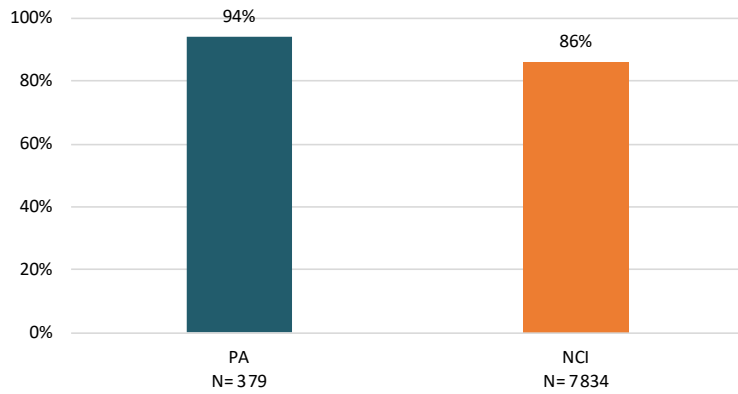
Able to get places when wants to do something outside of home like going out to see friends, for entertainment, or to do something fun



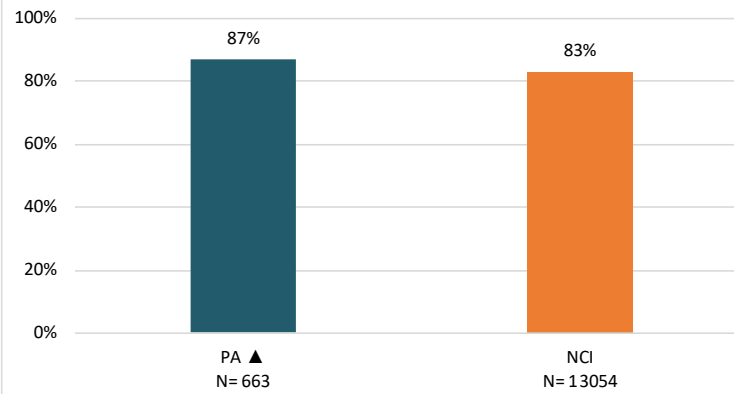
Has a way to get places she needs to go (like work, appointments, etc.)



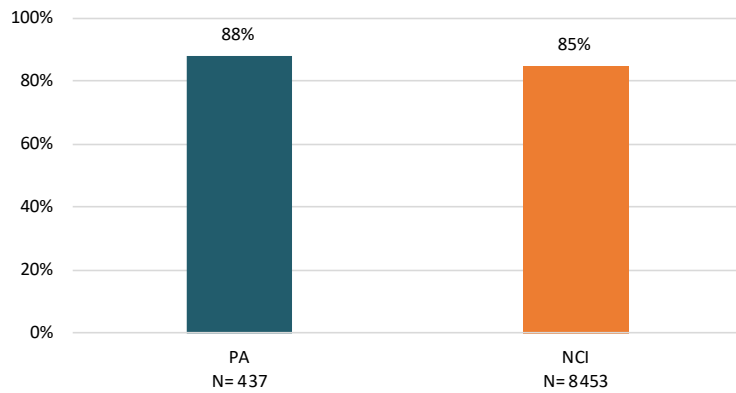
Adequate Transportation Scale



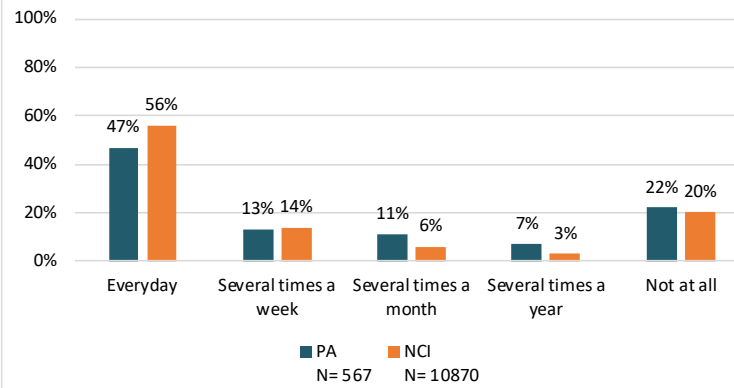
Has access to the internet



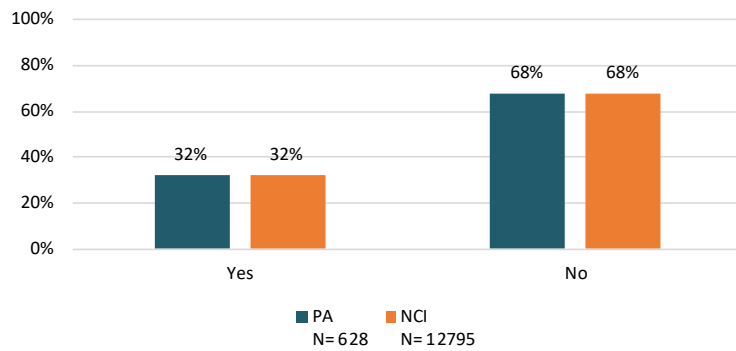
Internet always works at home



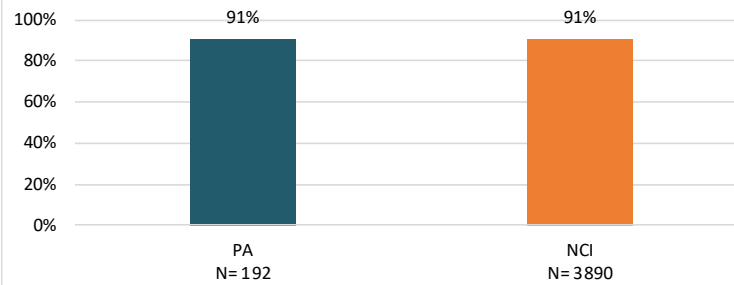
Frequency Uses Internet



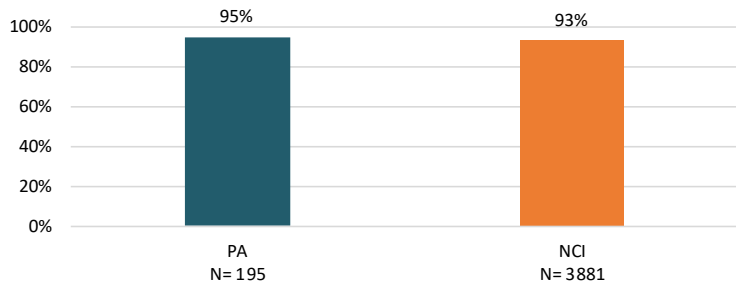
Uses technology in everyday life to help them do more things on their own



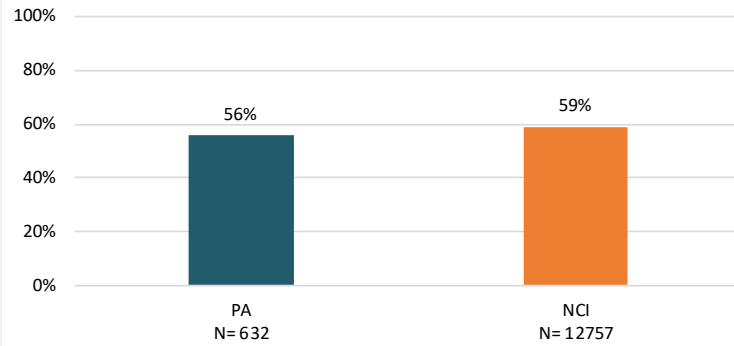
Has enough help to use the technology and devices that help them in their everyday life (if uses technology that helps them do more things on their own)



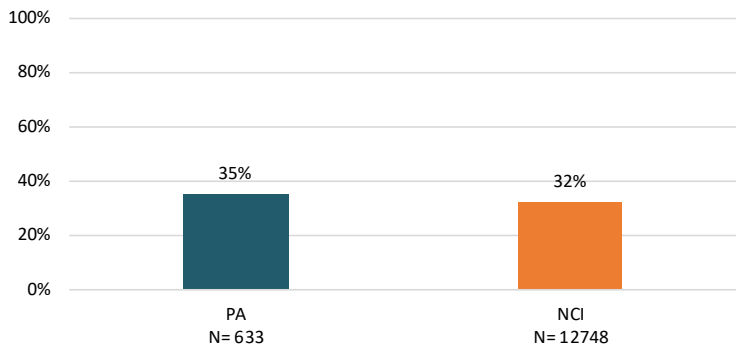
Knows who to talk to if there are issues with the technology and devices that help them in their everyday life (if uses technology that helps them do more things on their own)



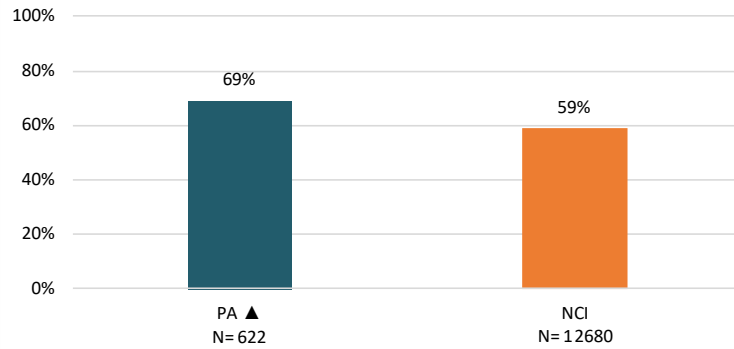
Has used telehealth to talk with a health professional.



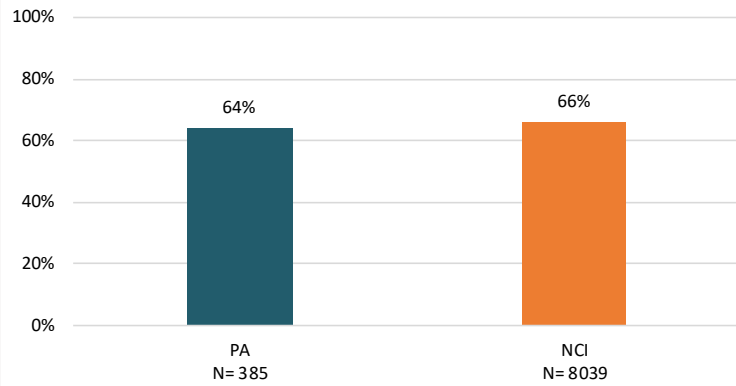
Accessed services or supports using videoconference technology



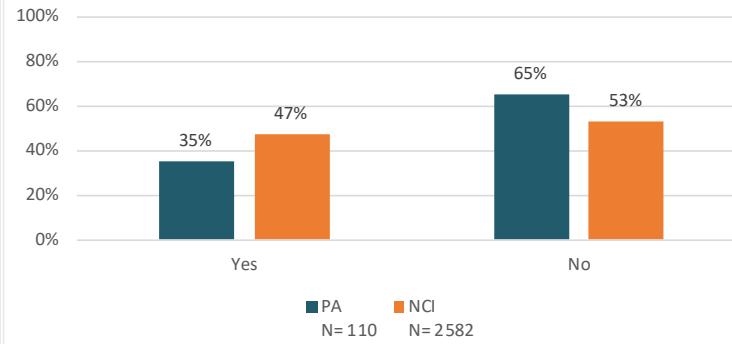
Has talked with their case manager/service coordinator using videoconference technology



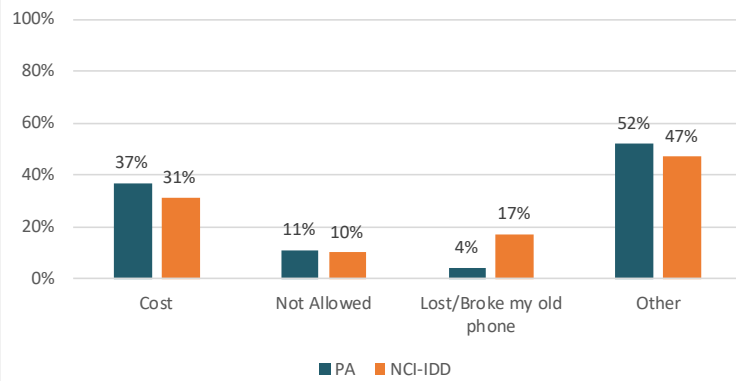
Has a cell phone or smartphone



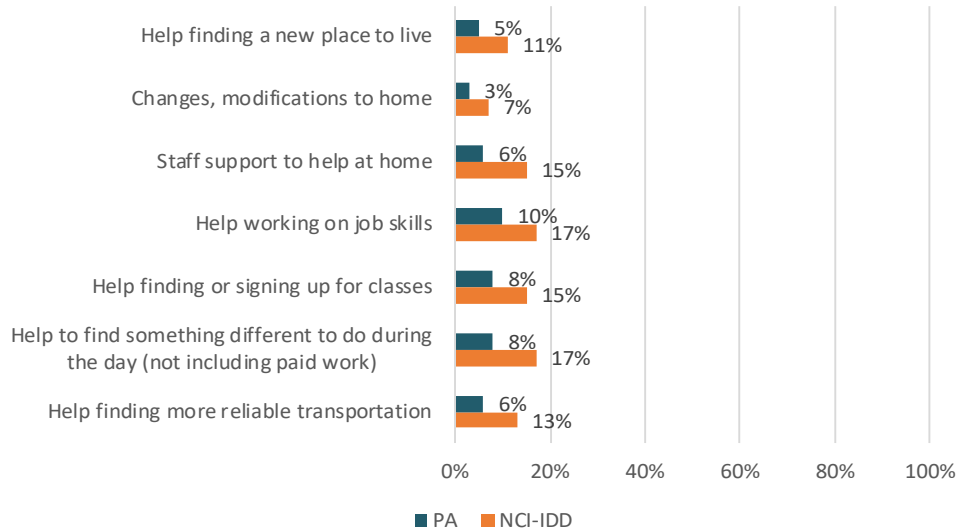
Wants a cell phone or smartphone (if does not have one)



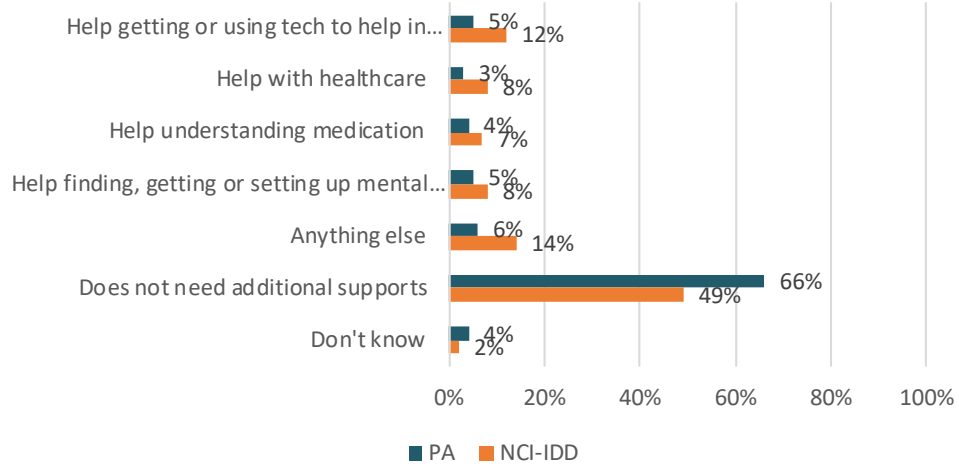
Reasons does not have cell phone or smartphone



Additional services needed



Additional services needed (continued)



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.

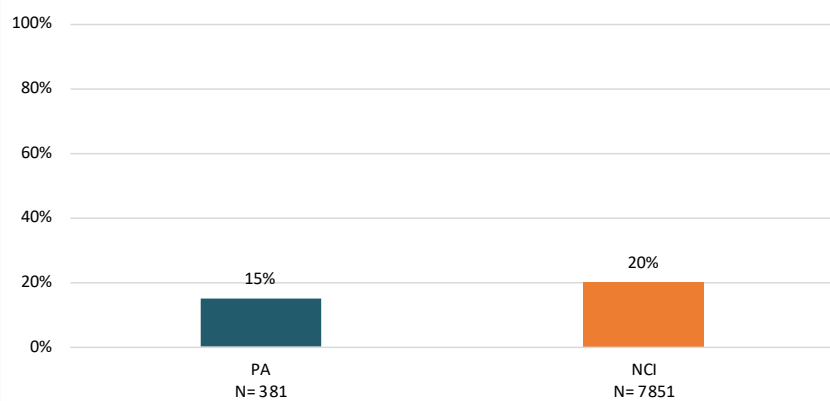
Table 146. Feels afraid in their home, neighborhood, transport, workplace, day program/at other daily activity and/or other places

State v NCI	Average	N
PA	15%	381
NCI-IDD	20%	7,851

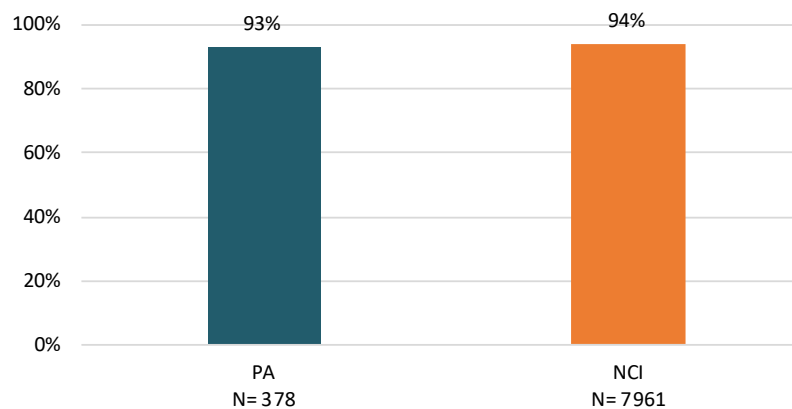
Table 147. Has someone to go to for help when they feel afraid

State v NCI	Average	N
PA	93%	378
NCI-IDD	94%	7,961

There is at least one place where the person feels afraid or scared in home day program work walking in the community in transport or other place



Has someone to go to for help if they ever feel scared



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 148. Has a primary care doctor or practitioner
Information may have been obtained through state records

State v NCI	Average	N
PA	96%	624
NCI-IDD	94%	12,954

Table 149. In poor health
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	1%	651
NCI-IDD	2%	13,118

Table 150. Had a complete physical exam in the past year
Information may have been obtained through state records

State v NCI	Average	N
PA ▲	89%	601
NCI-IDD	85%	12,007

Table 151. Had a routine dental exam in the past year
Information may have been obtained through state records

State v NCI	Average	N
PA ▲	81%	577
NCI-IDD	75%	11,276

Table 152. Had an eye exam/vision screening in the past year
Information may have been obtained through state records

State v NCI	Average	N
PA ▲	67%	529
NCI-IDD	56%	9,765

Table 153. Had a hearing test in the past five years
Information may have been obtained through state records

State v NCI	Average	N
PA *▲	88%	338
NCI-IDD	51%	7,273

Table 154. Had a Pap test in the past three years (among women 21 and older)
Information may have been obtained through state records

State v NCI	Average	N
PA *▲	71%	143
NCI-IDD	55%	3,025

Table 155. Had a mammogram test in the past two years (among women age 50 and over)
Information may have been obtained through state records

State v NCI	Average	N
PA ▲	89%	96
NCI-IDD	74%	1,313

Table 156. Last colorectal cancer screening (among people age 45 to 75)
Information may have been obtained through state records

State v NCI	Colonoscopy in past 10 years	Flexible sigmoidoscopy in past 5 years	Fecal occult blood test or fecal immunochemical test in the past year	Never had exam or screening	N
PA *	35%	0%	3%	9%	267
NCI-IDD	32%	1%	5%	20%	4,884

Table 157. Had a flu vaccine in the past 12 months
Information may have been obtained through state records

State v NCI	Average	N
PA *	77%	379
NCI-IDD	73%	9,681

Table 158. 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 v NCI	Went to ER in past 12 months	Did not go to ER in past 12 months	N
PA	26%	74%	635
NCI-IDD	26%	74%	12,934

Table 159. Had an unexpected hospital admission due to dehydration, bowel obstruction, seizure, aspiration, or GERD, in the past year¹⁹
Information may have been obtained through state records

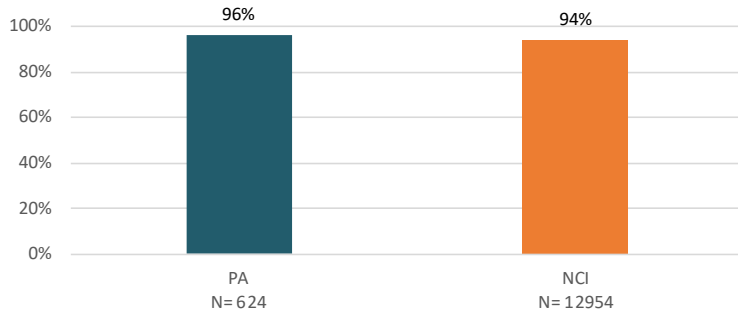
State v NCI	Dehydration	Bowel obstruction	Seizure	Aspiration	Gastro- Esophageal Reflux Disease	N
PA	8%	17%	40%	25%	30%	53
NCI-IDD	12%	14%	38%	15%	23%	739

Table 160. Fell and hurt themselves in the past six months
Proxy respondents were allowed for this question

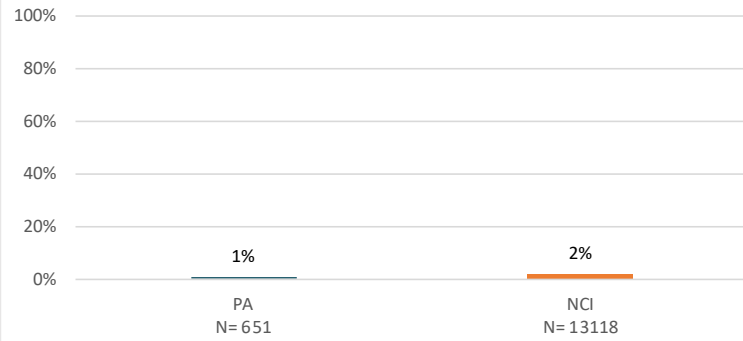
State v NCI	Fell and hurt themselves in past 6 months	Did not fall and hurt themselves in past 6 months	N
PA	16%	84%	638
NCI-IDD	14%	86%	12,970

¹⁹ Percentage shows “Of those with an unexpected hospital admission due to dehydration, bowel obstruction, seizure, aspiration, or GERD, in the past year, the percent that were hospitalized for each condition.”

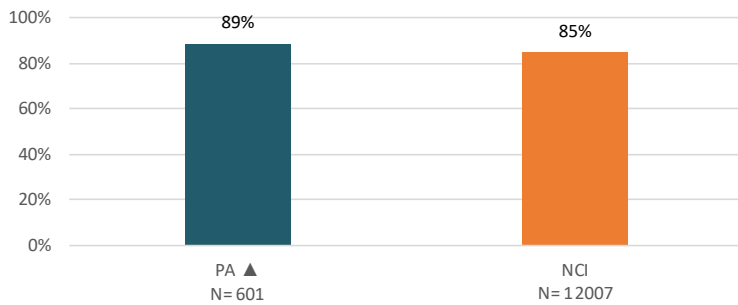
Has a primary care doctor or practitioner
(information may have been obtained through
state records)



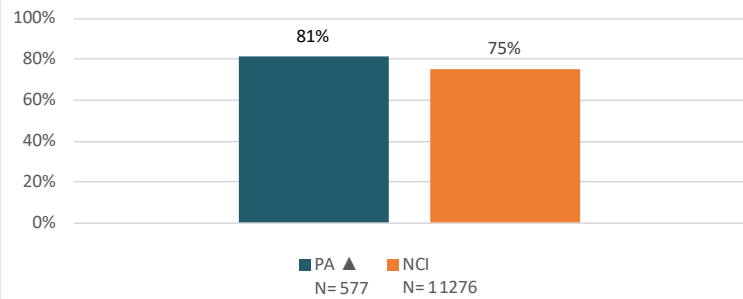
In poor health (proxy respondents were allowed
for this question)



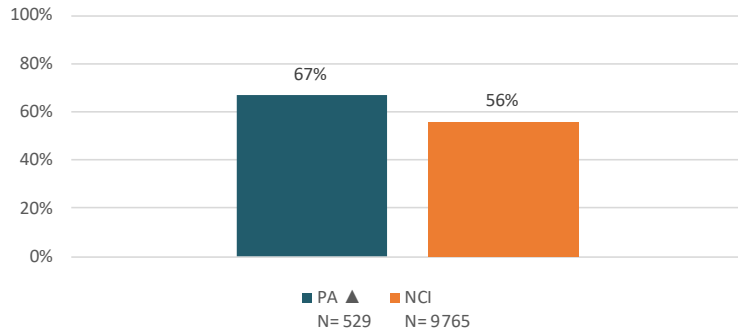
Had a complete physical exam in the past year
(information may have been obtained through
state records)



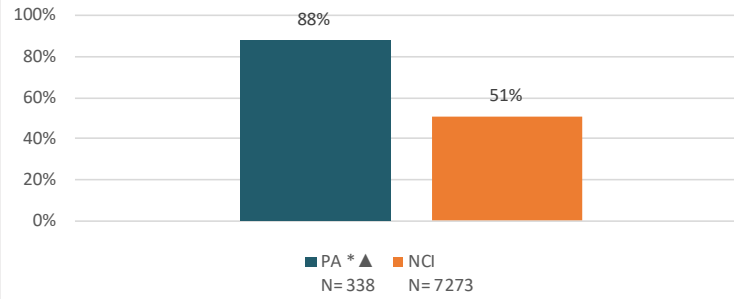
Had a routine dental exam in the past year
(information may have been obtained through
state records)



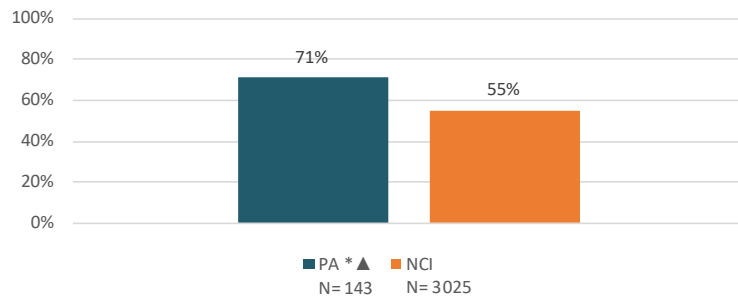
Had an eye exam in the past year (information may have been obtained through state records)



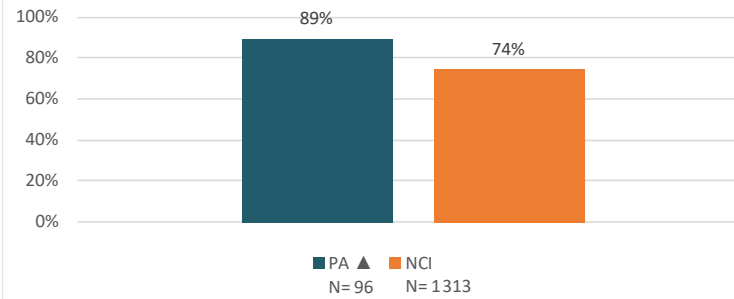
Had a hearing test in the past five years (information may have been obtained through state records)



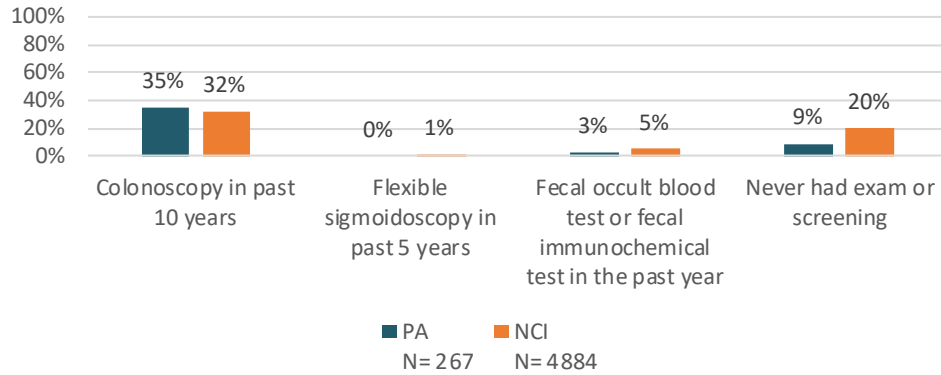
Had a Pap test in the past three years women 21 and older (information may have been obtained through state records)



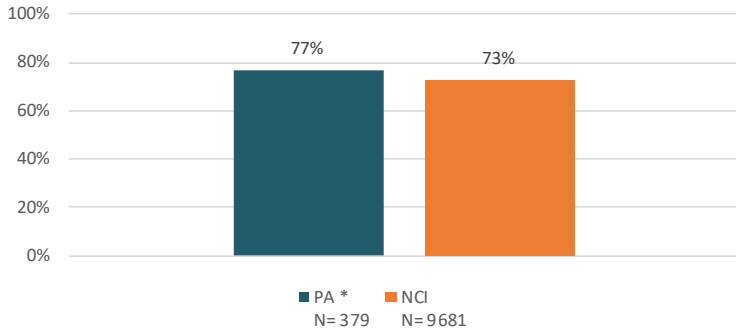
Had a mammogram test in the past two years women 40 and older (information may have been obtained through state records)



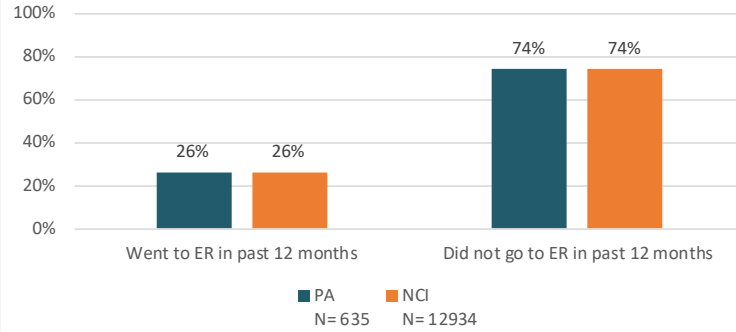
Last colorectal cancer screening (people 45 through 75; information may have been obtained through state records)



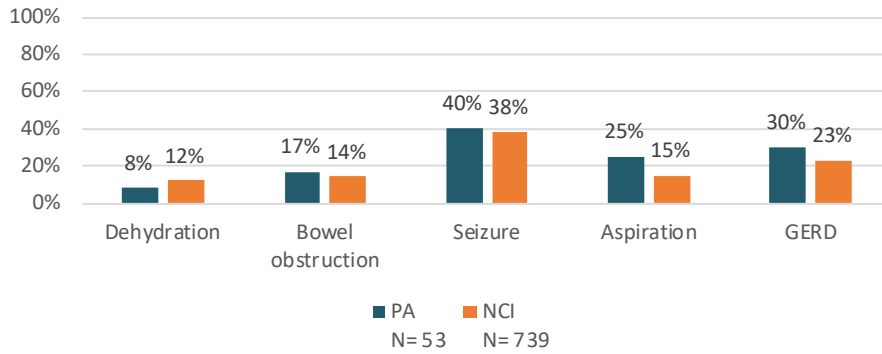
Had a flu vaccine in the past year (information may have been obtained through state records)



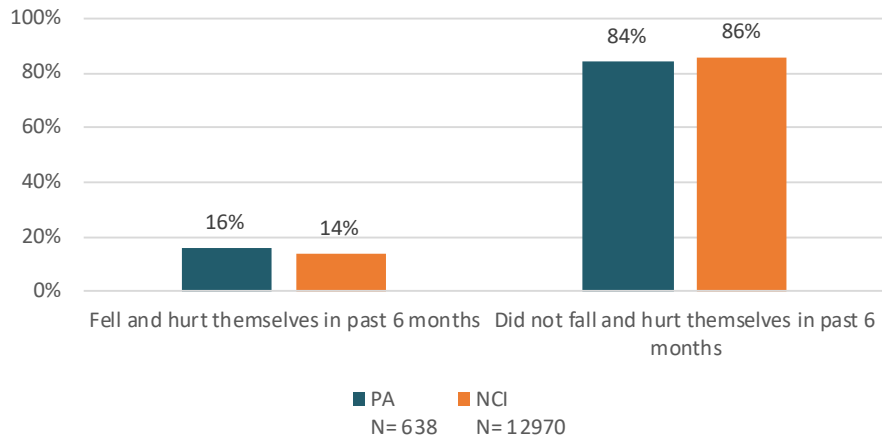
Went to the emergency room for any reason to get care for themselves in the past 12 months



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



Fell and hurt themselves in the past 6 months



Medication

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 161. Takes at least one medication for mood, anxiety, psychotic disorder, and/or behavioral challenges
Information may have been obtained through state records

State v NCI	Average	N
PA ▲	62%	614
NCI-IDD	56%	11,808

Table 162. Takes medication for mood, anxiety, and/or psychotic disorders
Information may have been obtained through state records

State v NCI	Average	N
PA ▲	59%	620
NCI-IDD	53%	11,844

Table 163. 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 v NCI	1-2 Medications	3-4 Medications	5-10 Medications	11 or More Medications	N
PA	56%	30%	13%	0%	362
NCI-IDD	66%	27%	7%	0%	5,996

Table 164. Takes medication for behavior challenges
Information may have been obtained through state records

State v NCI	Average	N
PA	24%	611
NCI-IDD	26%	11,689

Table 165. Number of medications taken for behavior challenges if taking at least one for this purpose
Information may have been obtained through state records

State v NCI	1-2 Medications	3-4 Medications	5-10 Medications	11 or More Medications	N
PA	81%	17%	3%	0%	139
NCI-IDD	77%	19%	4%	0%	2,958

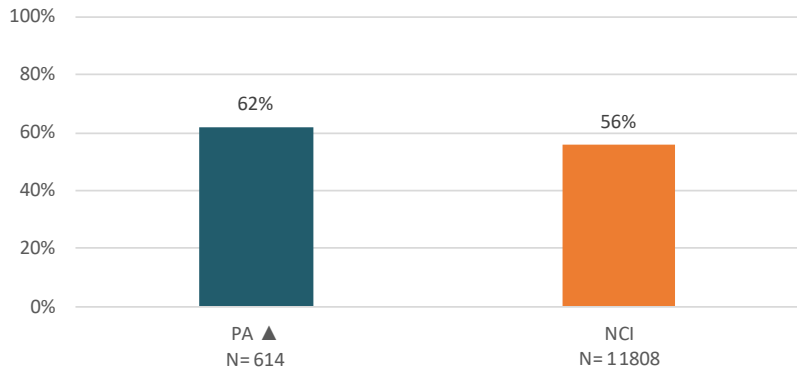
Table 166. Has behavior plan
Information may have been obtained through state records

State v NCI	Average	N
PA ▲	41%	625
NCI-IDD	27%	12,568

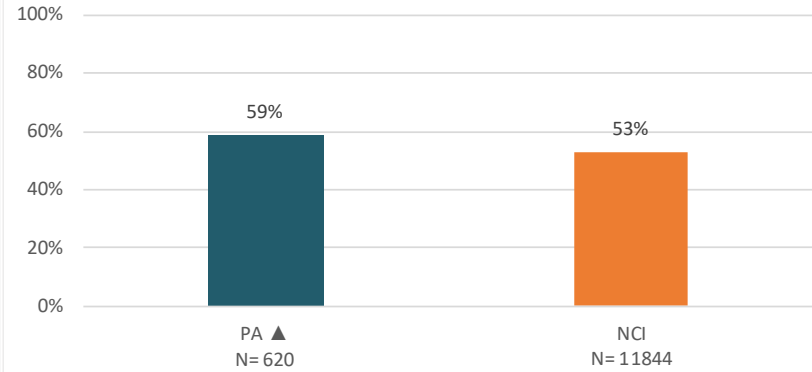
Table 167. Has behavior plan (among those who take medication for a behavior challenge)
Information may have been obtained through state records

State v NCI	Average	N
PA ▲	73%	145
NCI-IDD	58%	3,102

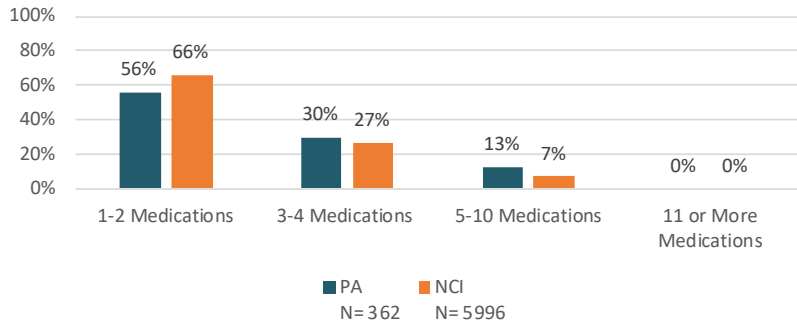
Takes at least one medication for mood anxiety psychotic disorder and/or behavioral challenges



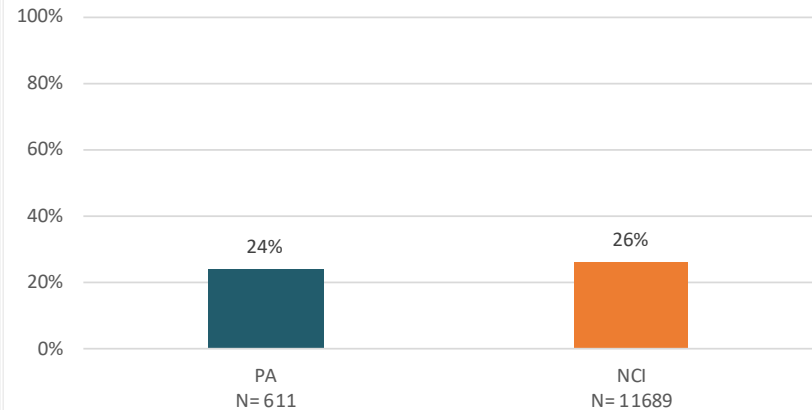
Takes medication for mood anxiety and/or psychotic disorders



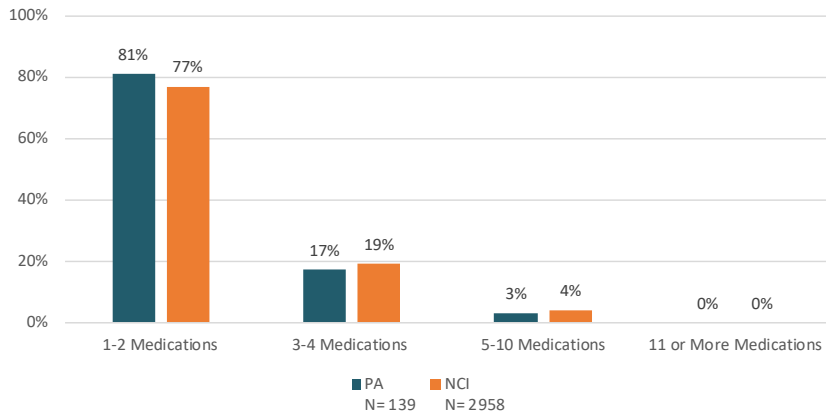
Number of medications taken for at least one of the following mood disorders anxiety or psychotic disorders



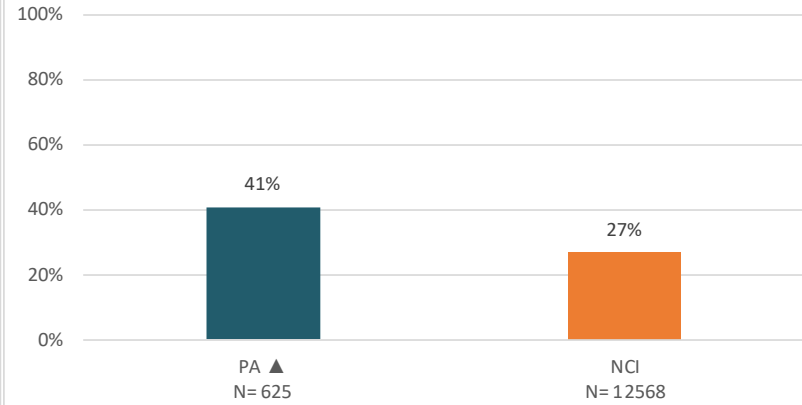
Takes medication for behavior challenges



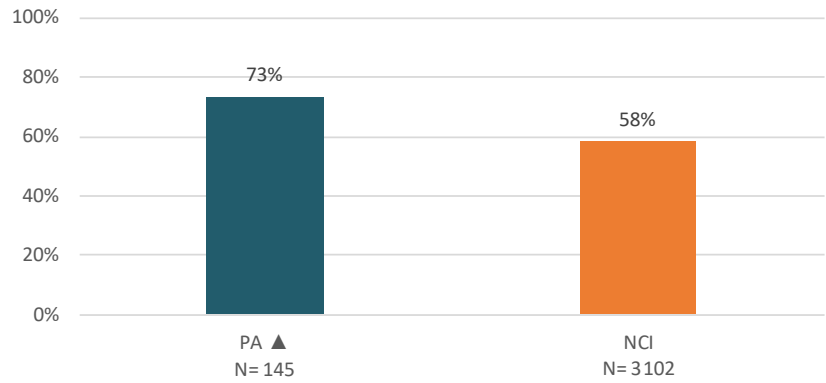
Number of medications taken for behavior challenges



Has a behavior plan



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



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 168. Uses tobacco products²⁰

Information may have been obtained through state records

State v NCI	Average	N
PA	8%	589
NCI-IDD	7%	12,664

Table 169. Body Mass Index (BMI) category²¹

Information may have been obtained through state records

State v NCI	Underweight	Normal	Overweight	Obese	N
PA *	4%	30%	32%	34%	332
NCI-IDD	5%	30%	28%	37%	10,701

Table 170. 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 v NCI	Average	N
PA	76%	641
NCI-IDD	80%	13,008

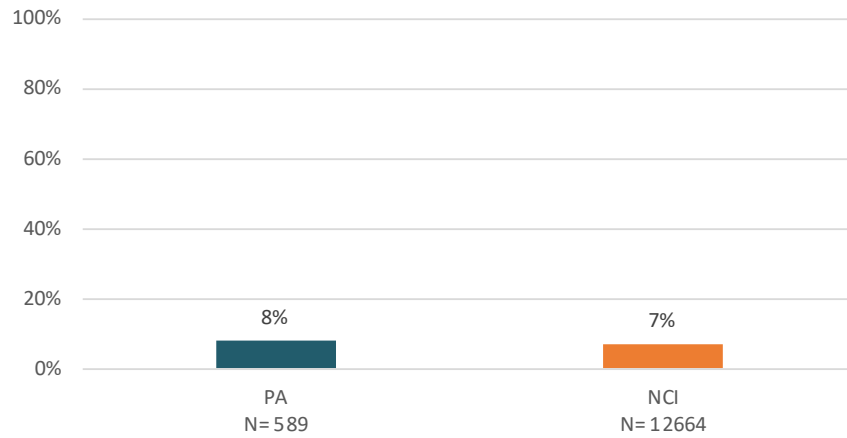
²⁰ A higher percentage for this item may not indicate a more positive result

²¹ BMI calculated using data on weight and height

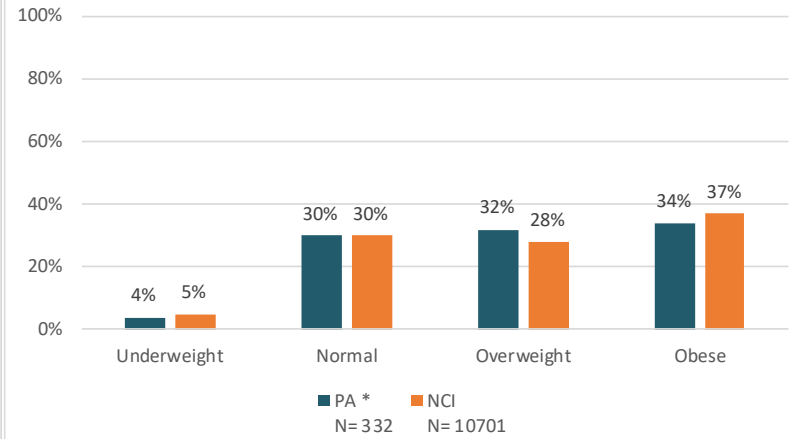
Table 171. Exercises or does physical activity at least once per week that makes the muscles in arms, legs, back, and/or chest work hard
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	34%	643
NCI-IDD	33%	12,967

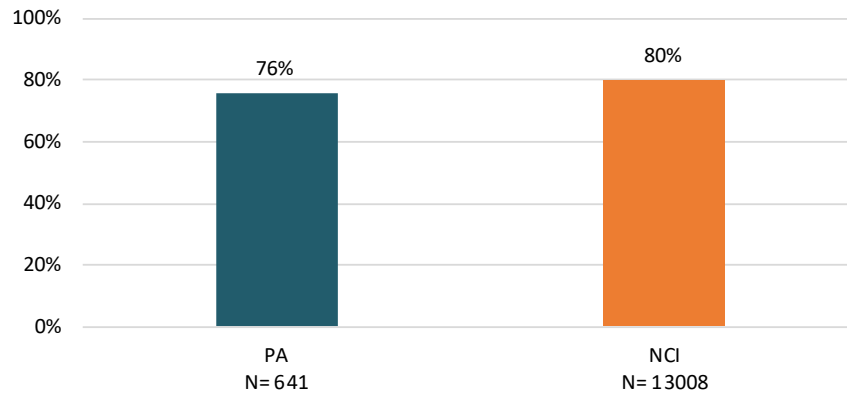
Uses tobacco products



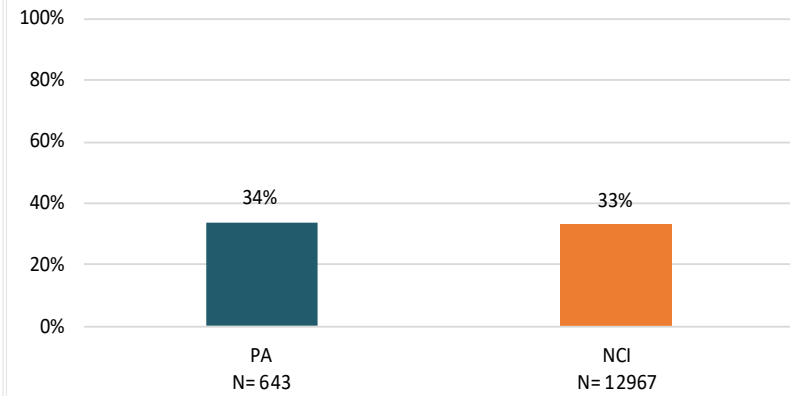
Body Mass Index (BMI) category



Exercises or does physical activity at least once a week at least 10 minutes at a time



Exercises for the muscles in arms legs back and/or chest



Rights and Respect

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

Table 172. 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 v NCI	Average	N
PA	30%	536
NCI-IDD	34%	12,078

Table 173. 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 v NCI	Average	N
PA ▲	69%	631
NCI-IDD	54%	12,551

Table 174. Has a place to be alone in the home

State v NCI	Average	N
PA	97%	396
NCI-IDD	97%	8,100

Table 175. Has a key to the home
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	51%	653
NCI-IDD	51%	13,084

Table 176. Wants a key to the home (if does not have one)
Proxy respondents were allowed for this question

State v NCI	Yes	Maybe	No	N
PA	9%	4%	86%	246
NCI-IDD	17%	9%	74%	5,669

Table 177. Can lock bedroom if wants
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	60%	579
NCI-IDD	59%	12,158

Table 178. Others (who do not live in the home) let person know before entering home

State v NCI	Average	N
PA ▲	92%	364
NCI-IDD	88%	7,899

Table 179. Others let person know before coming into person's bedroom

State v NCI	Average	N
PA ▲	88%	371
NCI-IDD	82%	7,936

Table 180. Others read person's mail or email without asking
A higher average for this item may not reflect a more positive result

State v NCI	Average	N
PA	11%	370
NCI-IDD	12%	7,297

Table 181. There are no rules for using phone or internet

State v NCI	Average	N
PA ▲	89%	352
NCI-IDD	82%	7,390

Table 182. There are rules about having friends or visitors in the home

State v NCI	Average	N
PA	27%	340
NCI-IDD	31%	7,315

Table 183. Can stay at home if others in the house go somewhere²²
Proxy respondents were allowed for this question

State v NCI	Average	N
PA	49%	584
NCI-IDD	48%	12,111

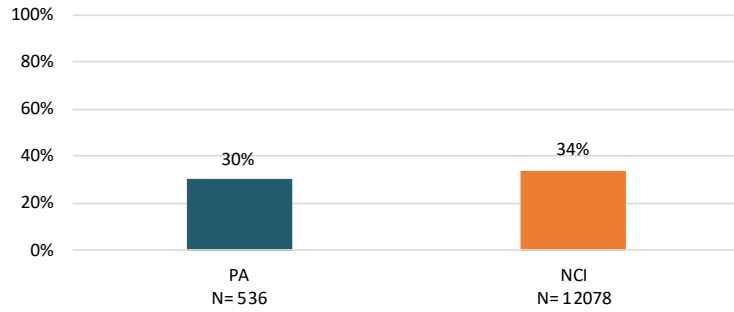
²² Please note: The denominator for this item does not exclude people who live at home, which differs from past NCI-IDD reporting.

Table 184. Respect for Personal Space Scale²³

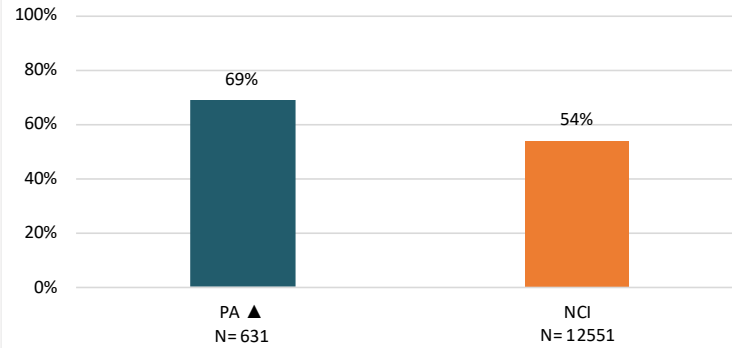
State v NCI	Average	N
PA	92%	382
NCI-IDD	89%	8,120

²³ The scale includes: • Other people let respondents know before they come into their home • Other people let respondents know before coming into their bedroom • Respondent has a place to be alone in their home

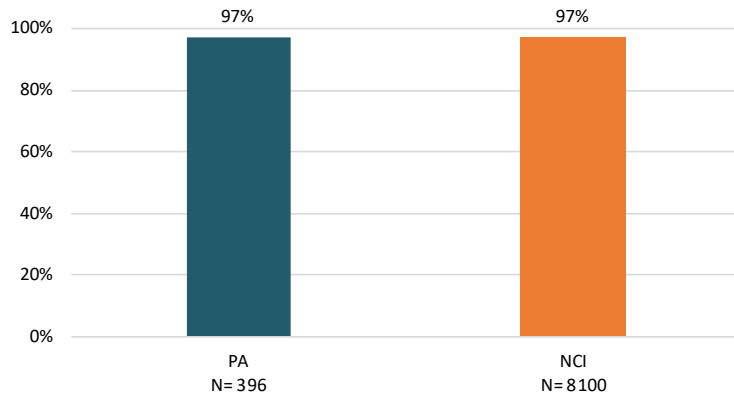
Has attended a self-advocacy group, meeting, conference or event or had the opportunity and chose not to



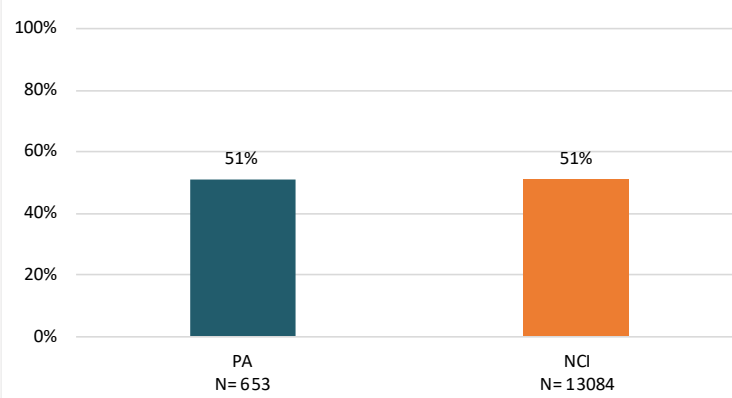
Has voted in local state or federal election or had the opportunity and chose not to



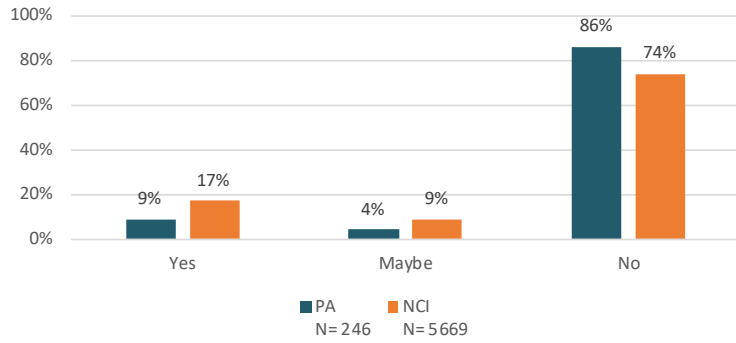
Has a place to be alone in the home



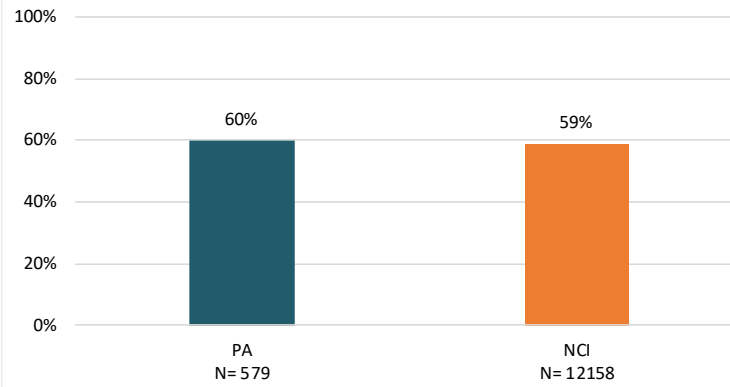
Has a key to the home



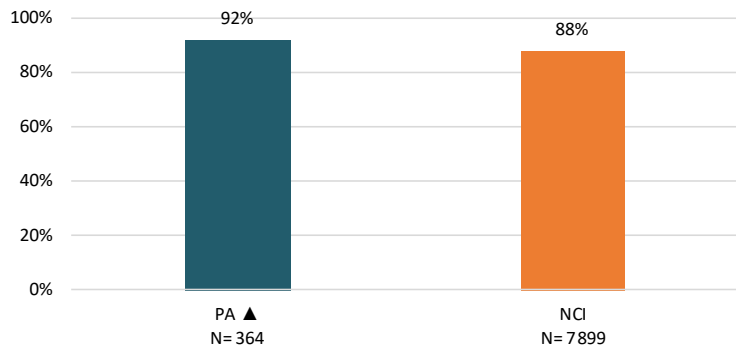
Wants a key to the home (if respondent does not have one)



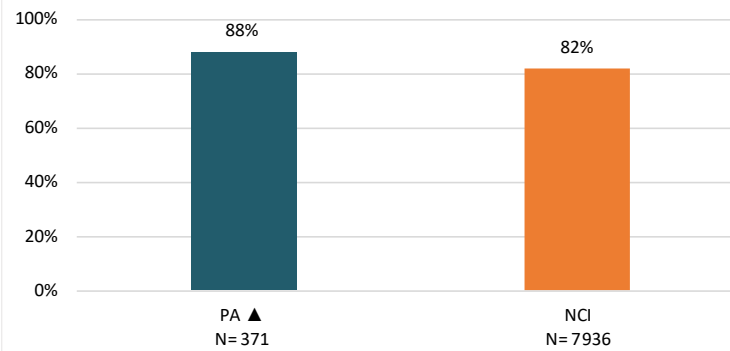
Can lock bedroom



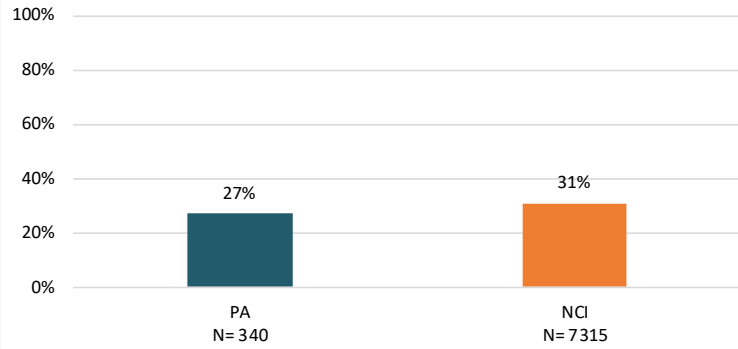
Others (who do not live in the home) let person know before entering home



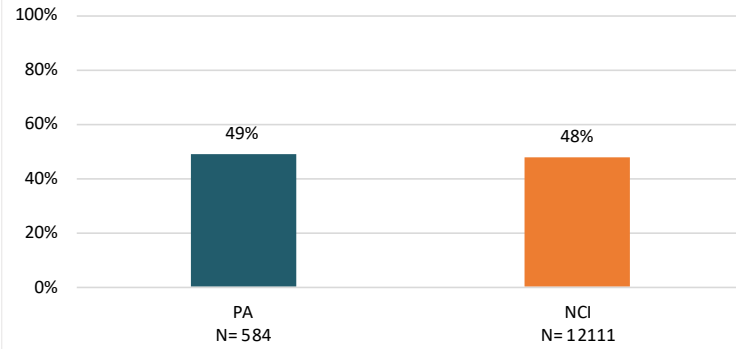
Others let the person know before entering person's bedroom



There are rules about having friends or visitors at home



Can stay at home if others in the house go somewhere if not living alone



Respect for Personal Space Scale

