



# Adult Family Survey (AFS) State Report

Pennsylvania (PA) Report

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## What is NCI?

The National Core Indicators (NCI) 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).

In 2018-19 a total of 46 states, the District of Columbia and 22 sub-state entities participated in NCI.

## Where are the statistics in this report from?

This report includes findings from the National Core Indicators™ 2018-19 Adult Family Survey (AFS). The data shown are weighted NCI averages. These data are comprised of 4,836 valid surveys collected across 12 states: AZ, GA, LA, MD, MN, MO, NC, OH, OK, PA, UT and VA.

## What is the NCI Adult Family Survey?

The NCI Adult Family Survey is used to gather data on family outcomes. It is mailed to families who have an adult family member who *lives with* the respondent and receives at least one service other than case management from the state DD agency. The survey collects demographic information on both the individual receiving services ('family member') as well as the person who fills out the survey (the 'respondent') and information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable.

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

## What is included in this report?

This report includes this state's Adult Family Survey data compared to the NCI Average. State outcomes that are significantly higher or lower than the NCI Average are indicated with an arrow:

1. Outcomes where the state is significantly above the NCI average are denoted with an up arrow ▲;
2. Outcomes where the state is significantly below the NCI average are denoted with a down arrow ▼.

Significance is based on "Always" or "Yes" response.

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

To find out more about the development of the Adult Family Survey, data analysis and state samples, check out the National Adult Family Report: <https://www.nationalcoreindicators.org/resources/reports/#reports-family-survey-final-reports>.

## Demographics



## *Demographics of Family Member Receiving Services*

*This section provides demographic profiles of the family member about whom the survey was completed.*

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

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

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

State v NCI	Yes	No	N
PA	14%	86%	662
NCI	13%	87%	4,689

**Table 2. Family Member's Age**

State v NCI	Average Age	N
PA	35.3	677
NCI	34.1	4,800

**Table 3. Family Member's Gender**

State v NCI	Male	Female	N
PA	56%	44%	673
NCI	60%	40%	4,770

**Table 4. Family Member's Race and Ethnicity**

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

State v NCI	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other
PA	2%	2%	11%	0%	83%	5%	1%
NCI	3%	2%	14%	0%	78%	6%	1%

**Table 5a. Family Member's Disabilities (not mutually exclusive)**

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

State v NCI	Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss
PA	82%	26%	27%	16%	7%	7%
NCI	71%	25%	32%	20%	9%	6%

**Table 5b. Family Member's Disabilities (continued)**

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

State v NCI	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
PA	10%	29%	1%	18%	1%	1%	3%
NCI	10%	30%	1%	16%	1%	1%	15%

**Table 6a. Family Member's Health Conditions**

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

State v NCI	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
PA	10%	20%	5%	28%	26%
NCI	11%	17%	4%	28%	25%

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

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

State v NCI	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Other Dementia	Oral Health or Dental Problems	Sleep Apnea	Other
PA	10%	2%	2%	11%	22%	17%
NCI	12%	4%	3%	12%	20%	25%

**Table 7. Family Member's Preferred Means of Communication**

State v NCI	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
PA	78%	14%	2%	3%	3%	659
NCI	77%	16%	2%	2%	3%	4,695

**Table 8. Family Member Has Legal Court Appointed Guardian or Conservator**

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

State v NCI	No Guardianship	Limited	Full	Has Guardianship but Level Is Unknown	N
PA	49%	9%	39%	3%	609
NCI	32%	11%	54%	3%	4,537

**Table 9. Guardian or Conservator Relationship to Family Member**

State v NCI	Family	Friend	State Employee or Guardianship Agency	Other	N
PA	97%	1%	0%	2%	292
NCI	98%	1%	0%	1%	2,965

**Table 10. Family Member's Highest level of Education**

State v NCI	Did Not Complete High School (and Not Currently Enrolled)	Currently Enrolled in High School	High School Certification	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
PA	11%	4%	25%	49%	5%	3%	3%	655
NCI	14%	5%	32%	38%	3%	4%	5%	4,604

**Table 11. Family Member's Activities in the Past Two Weeks Included *Individual Paid Job in the Community*<sup>1</sup>**

Response options changed from previous years

State v NCI	Yes	No	N
PA	19%	81%	657
NCI	16%	84%	4,700

<sup>1</sup> An individual job is defined as work at an individual job in a local business alongside peers who do not have disabilities. Job is part of the typical labor market (for example, competitive employment).

**Table 12. Family Member's Activities in the Past Two Weeks Included *Paid Small Group Job in a Community-based Setting*<sup>2</sup>**

Response options changed from previous years

State v NCI	Yes	No	N
PA	11%	89%	644
NCI	12%	88%	4,633

**Table 13. Family Member's Activities in the Past Two Weeks Included *Paid Work in a Community Job That Primarily Hires People With Disabilities*<sup>3</sup>**

Response options changed from previous years

State v NCI	Yes	No	N
PA	9%	91%	647
NCI	8%	92%	4,630

**Table 14. Family Member's Activities in the Past Two Weeks Included *Unpaid Activity in the Community*<sup>4</sup>**

Response options changed from previous years

State v NCI	Yes	No	N
PA	36%	64%	644
NCI	33%	67%	4,595

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<sup>2</sup> A small group job is defined as work in an integrated setting, as part of a group of not more than 8 people with disabilities (for example, enclave, work crew).

<sup>3</sup> Paid work in a community job that primarily hires people with disabilities is defined as work in a setting where the person interacts with the non-disabled population; this is NOT in a traditional sheltered workshop and NOT enclave.

<sup>4</sup> Unpaid work in the community includes: volunteering, skills training, and staff-supported community connections.

**Table 15. Family Member's Activities in the Past Two Weeks Included *Paid Activity in a Facility-based Setting*<sup>5</sup>**

Response options changed from previous years

State v NCI	Yes	No	N
PA	20%	80%	643
NCI	18%	82%	4,637

**Table 16. Family Member's Activities in the Past Two Weeks Included *Unpaid Activity in a Facility-based Setting*<sup>6</sup>**

Response options changed from previous years

State v NCI	Yes	No	N
PA	27%	73%	625
NCI	27%	73%	4,556

**Table 17. Family Member's Activities in the Past Two Weeks Included *School***

Response options changed from previous years

State v NCI	Yes	No	N
PA	5%	95%	644
NCI	11%	89%	4,616

**Table 18. Family Member's Activities in the Past Two Weeks Included *Stays at Home***

Response options changed from previous years

State v NCI	Yes	No	N
PA	46%	54%	627
NCI	48%	52%	4,452

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<sup>5</sup> Paid work performed in a facility-based setting is defined as work at a location developed specifically to provide work activity exclusively for people with disabilities; may be paid sub-minimum wage. Examples include traditional sheltered workshops or work activity centers.

<sup>6</sup> An unpaid activity in a facility-based setting includes day habilitation, senior programs, or drop-in centers.

**Table 19. Family Member's Activities in the Past Two Weeks Included *Other Activities***

Response options changed from previous years

State v NCI	Yes	No	N
PA	43%	57%	230
NCI	39%	61%	1,867

**Table 20. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors**

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

State v NCI	Extensive	Some	None	N
PA	11%	28%	61%	658
NCI	14%	29%	56%	4,708

**Table 21. Family Member's Level of Help Needed With Personal Care Activities (e.g., bathing, dressing, eating)**

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

State v NCI	Extensive	Some	None	N
PA	30%	36%	35%	671
NCI	36%	38%	26%	4,772

**Table 22. Family Member's Need for Help With Other Daily Activities (e.g., scheduling, managing money, or shopping)**

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

State v NCI	Extensive	Some	None	N
PA	72%	23%	6%	671
NCI	74%	21%	5%	4,751



## *Demographics of Respondents*

*This section provides demographic information about the respondent.*

**Table 23. Language Usually Spoken at Home**

New question in 2018-19

State v NCI	English	Spanish	Other	N
PA	98%	2%	1%	673
NCI	97%	2%	1%	4,764

**Table 24. Respondent's Age**

State v NCI	Under 35	35-54	55-74	75 and Older	N
PA	2%	20%	65%	13%	673
NCI	2%	23%	64%	11%	4,795

**Table 25. Respondent's Health**

State v NCI	Excellent	Very Good	Fairly Good	Poor	N
PA	12%	45%	38%	4%	670
NCI	15%	46%	36%	4%	4,777

**Table 26. Respondent's Relationship to Family Member**

State v NCI	Parent	Sibling	Spouse	Grandparent	Other	N
PA	92%	6%	0%	1%	1%	672
NCI	87%	6%	0%	3%	3%	4,785

**Table 27. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services**

State v NCI	No One in Family Provides Paid Support	Respondent Provides Paid Support	Other Family Member Provides Paid Support	N
PA	73%	14%	13%	660
NCI	67%	21%	15%	4,731

**Table 28. Number of Adults in Household (Not Including Family Member Receiving Services)**

State v NCI	One	Two	Three	Four or More	N
PA	6%	21%	48%	25%	666
NCI	8%	27%	46%	18%	4,763

**Table 29. Number of Children (Under 18 Years Old) in Household**

State v NCI	None	One	Two	Three	Four or More	N
PA	91%	6%	2%	1%	0%	667
NCI	87%	8%	3%	1%	1%	4,775

**Table 30. Respondent's Highest Level of Education**

State v NCI	No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
PA	5%	37%	7%	19%	31%	664
NCI	6%	27%	6%	22%	38%	4,726

**Table 31. Total Taxable Household Income of Wage Earners in the Past Year**

State v NCI	No Earned Income	Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	Prefer Not to Say	N
PA	13%	7%	8%	18%	12%	18%	22%	654
NCI	10%	8%	10%	18%	13%	20%	21%	4,647

**Table 32. Residential Designation (Urban, Suburban, or Rural)**

State v NCI	Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	N
PA	59%	41%	656
NCI	65%	35%	4,693

## *Services and Supports Received*

*This section provides information about the services and supports received by the family from the state ID/DD agency.*

**Table 33. Services and Supports Received From ID/DD Agency**

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

Services and Supports Received From State	PA	NCI
Financial Support	14%	14%
In-home Support	36%	41%
Out of Home Respite	30%	29%
Day or Employment Supports	55%	54%
Transportation	58%	61%
Other	25%	27%
Self-direction or Fiscal Intermediary Services	41%	41%

**Table 34. Additional Services and Supports Received (Not From the I/DD Agency)**

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

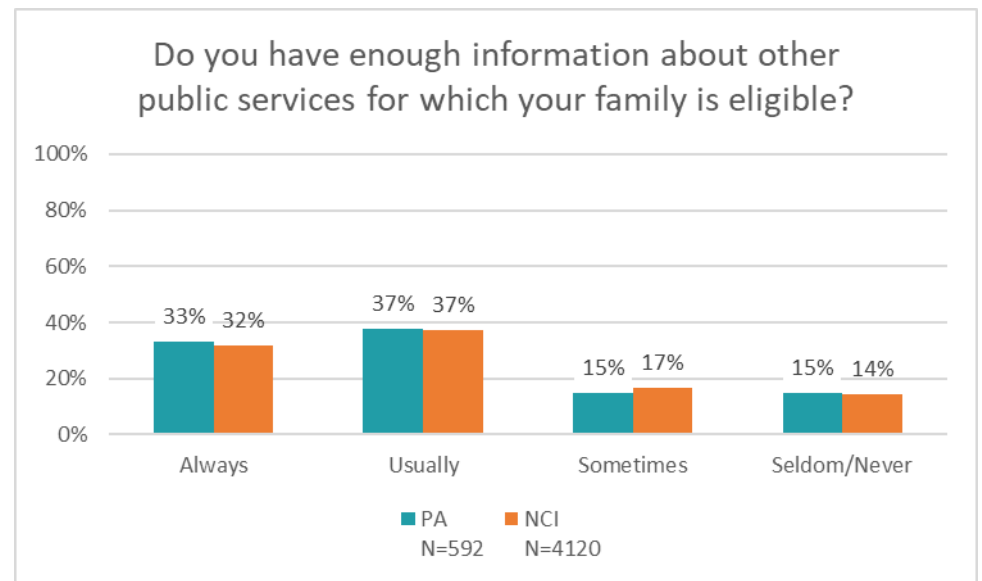
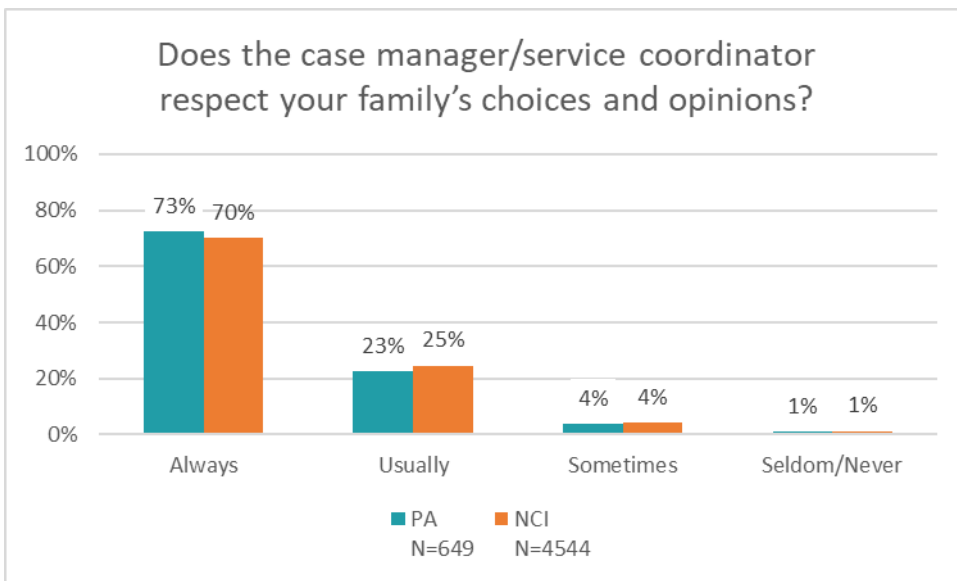
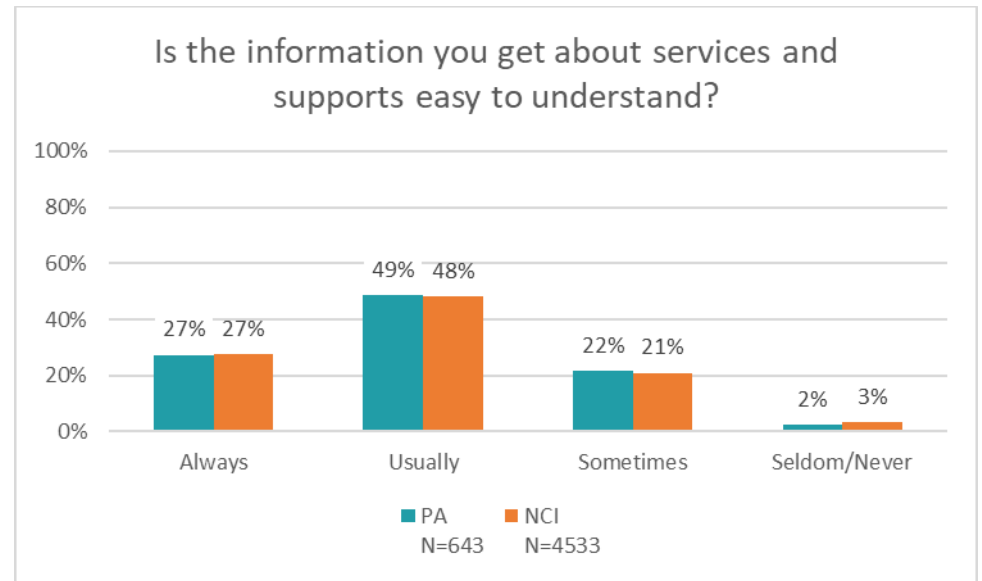
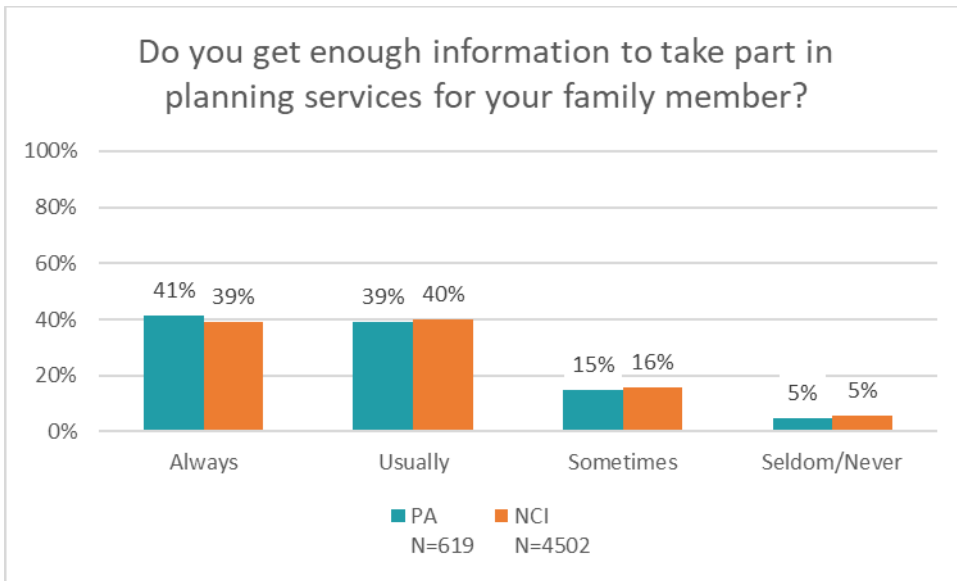
Additional Services and Supports Received	PA	NCI
Social Security Payments (SSI/SSB)	93%	93%
Services or Supports From Other Agencies or Organizations	35%	30%

## Adult Family Survey Results

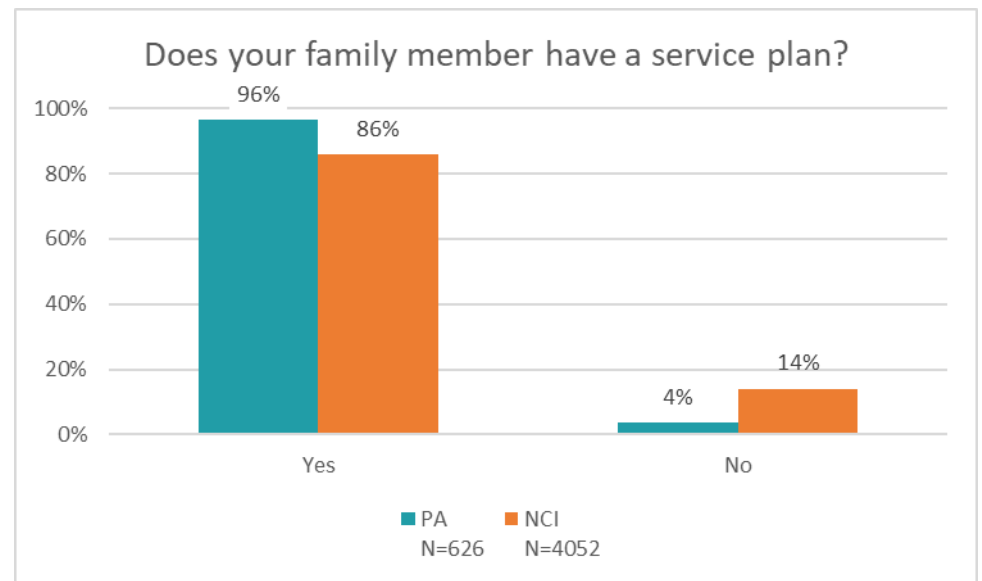
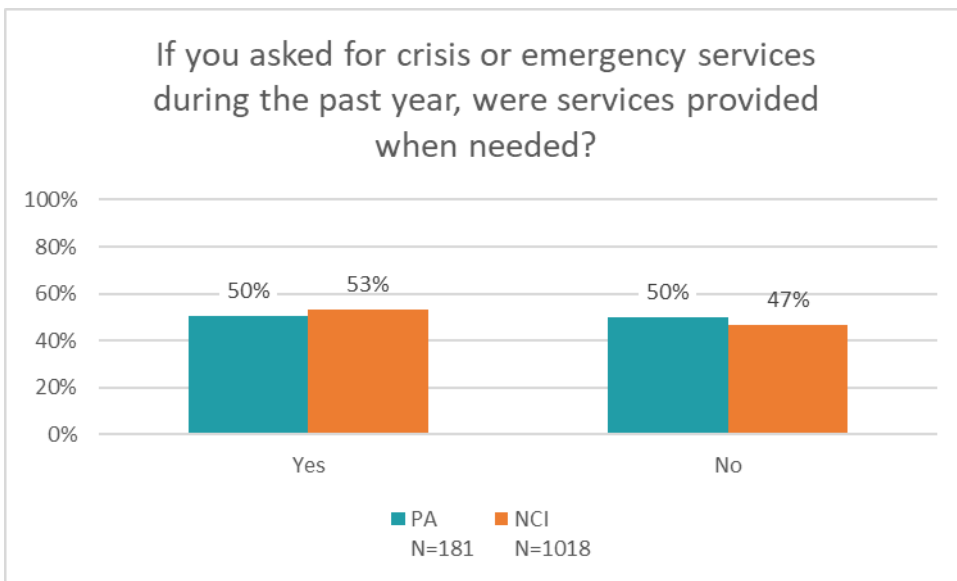
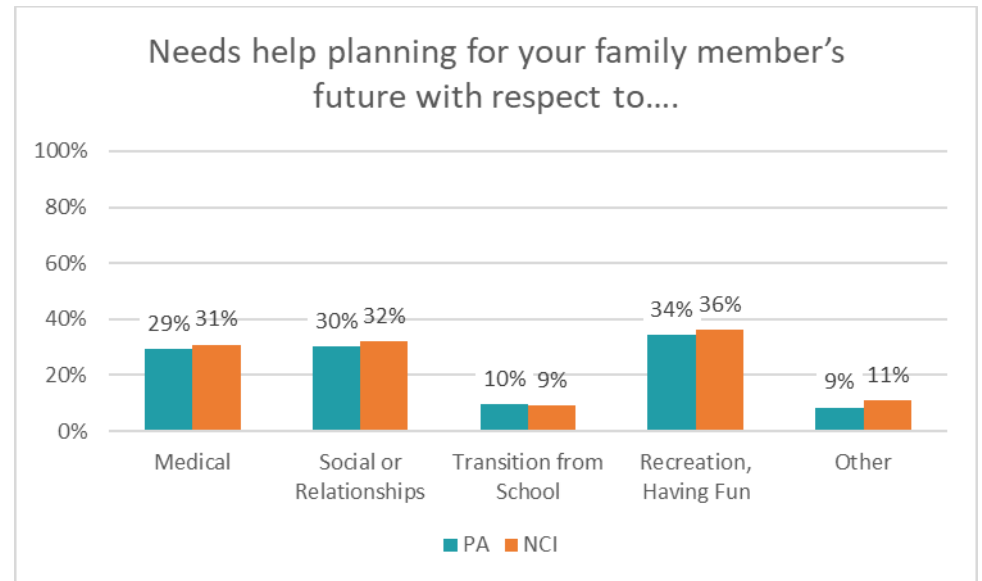
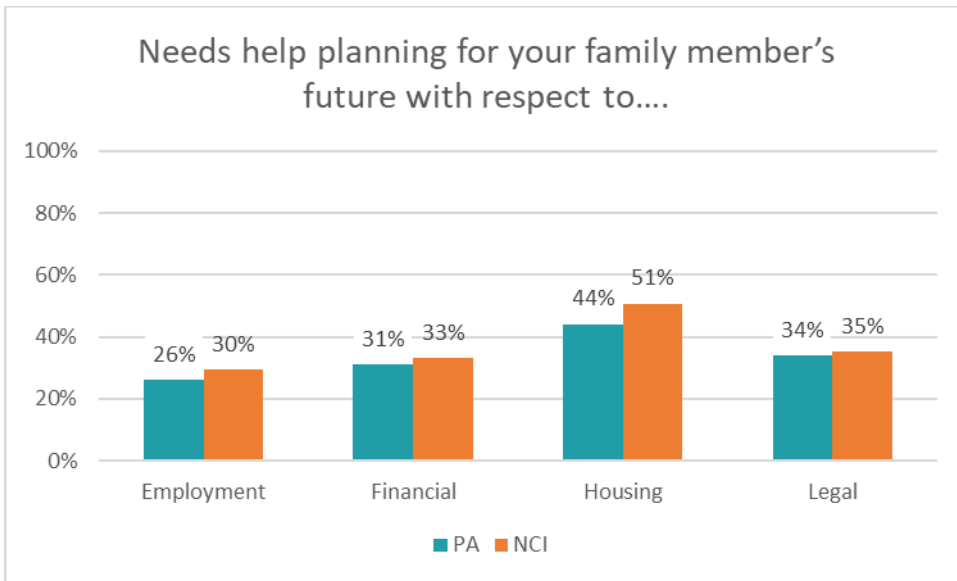
## *Information and Planning Charts*

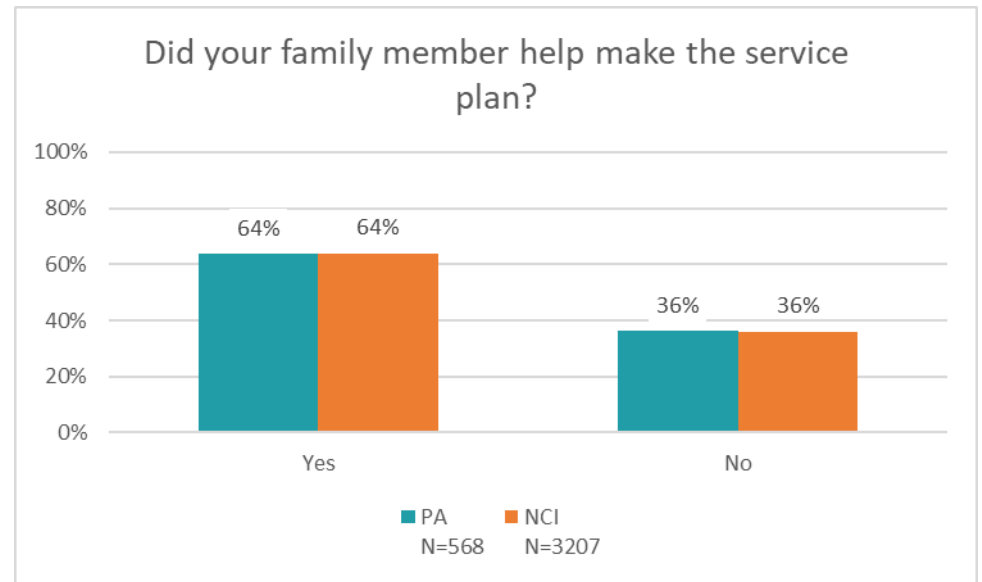
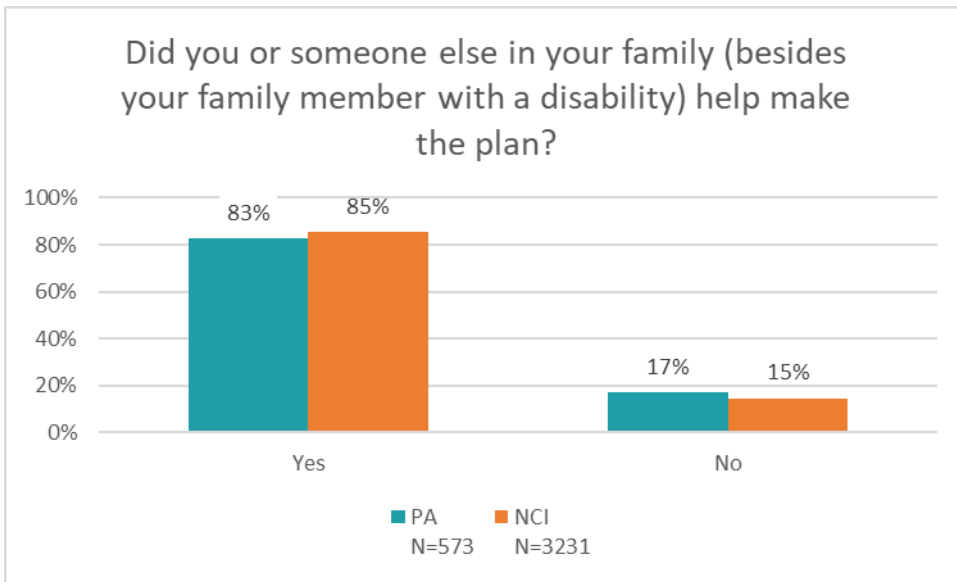
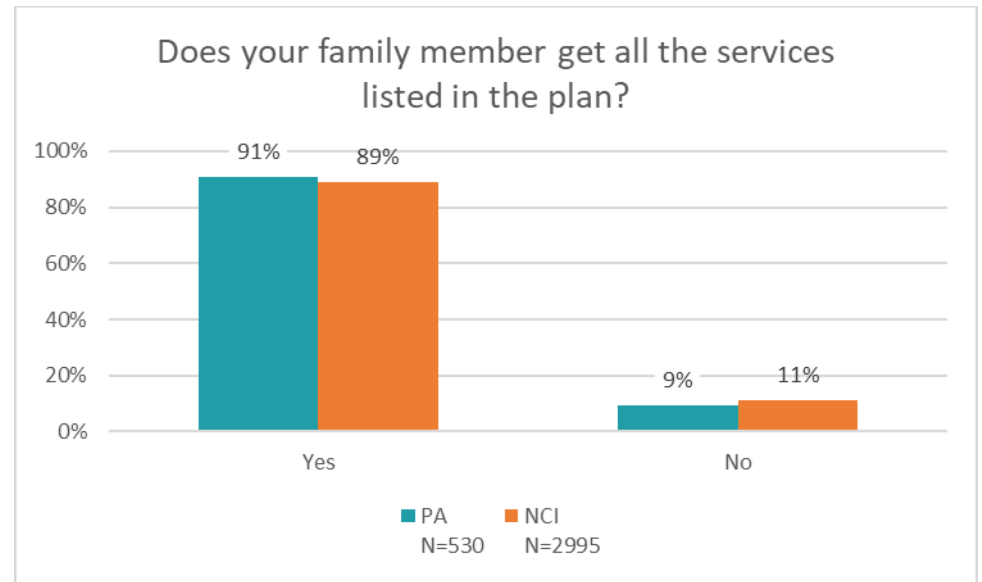
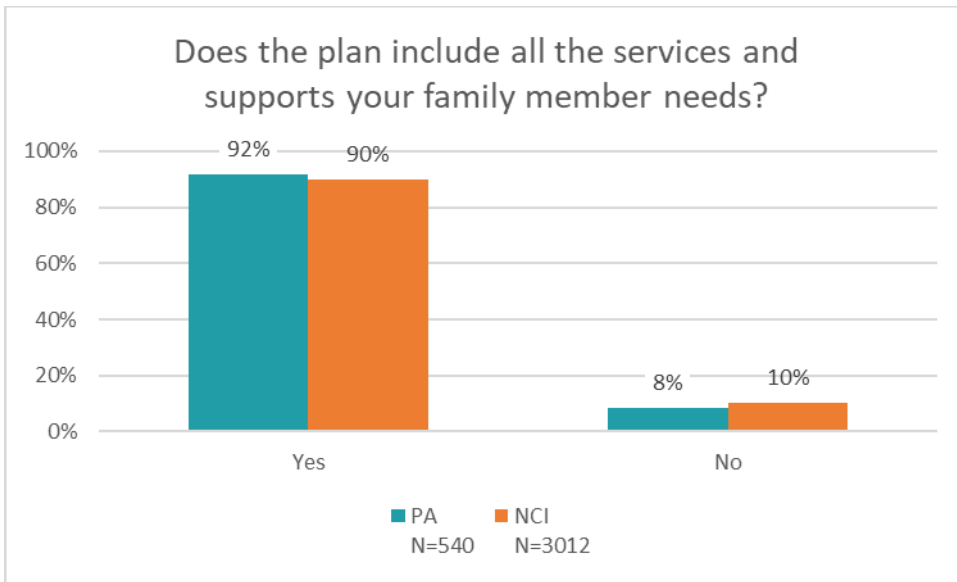
*Families and family members with disabilities have the information and support necessary to plan for their services and supports.*

The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.

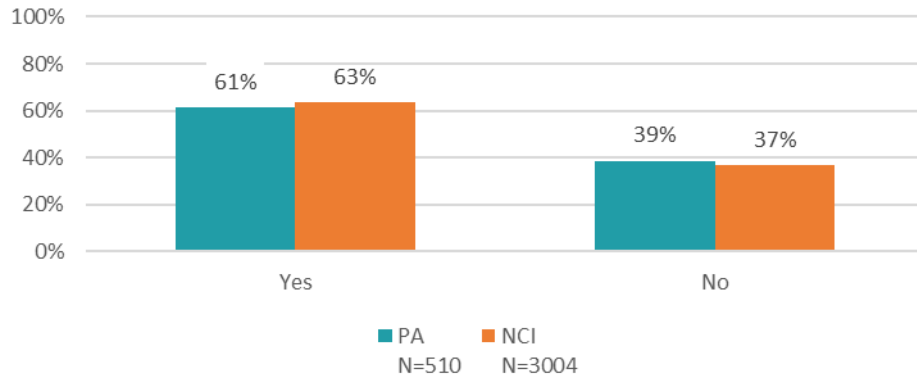




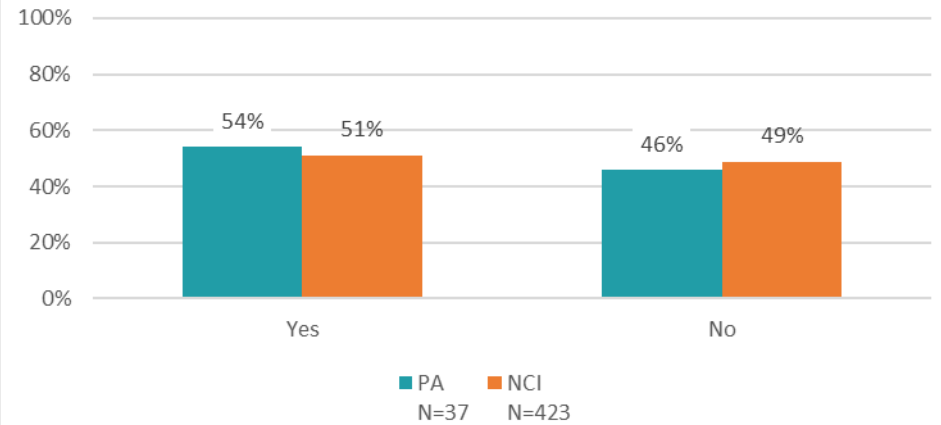




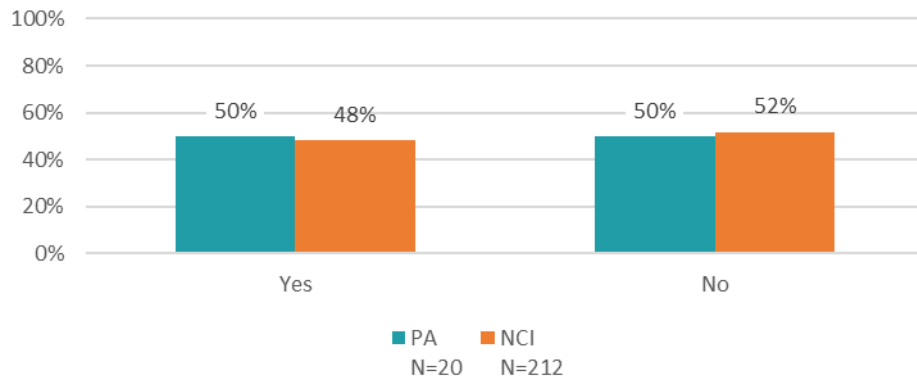
Did you discuss how to handle emergencies at your family member's last service planning meeting?



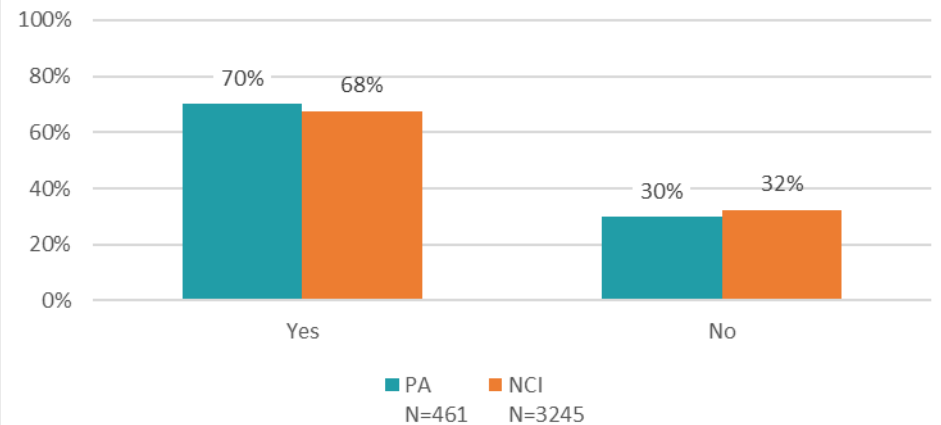
If your family member left school services during the past year, did s/he have a transition plan?

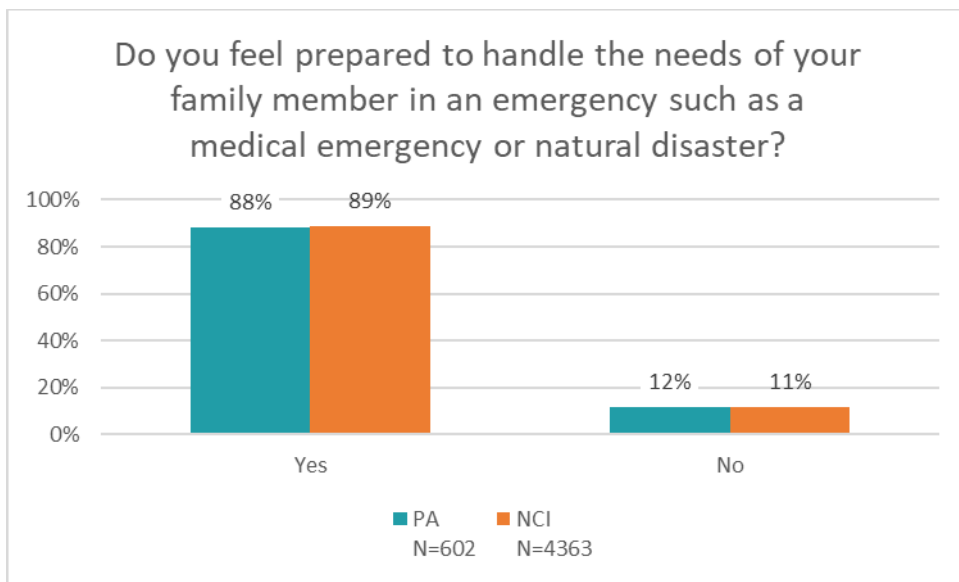


If family member had a transition plan, did the transition plan include getting or continuing work in a community job?



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





## *Information and Planning Tables*

*Families and family members with disabilities have the information and support necessary to plan for their services and supports.*

**Table Q1. Do you get enough information to take part in planning services for your family member?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	41%	39%	15%	5%	619
NCI	39%	40%	16%	5%	4,502

**Table Q2. Is the information you get about services and supports easy to understand?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	27%	49%	22%	2%	643
NCI	27%	48%	21%	3%	4,533

**Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	73%	23%	4%	1%	649
NCI	70%	25%	4%	1%	4,544

**Table Q4. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	33%	37%	15%	15%	592
NCI	32%	37%	17%	14%	4,120

**Table Q5. Do you need help planning for your family member's future with respect to any of the following?**

Categories are not mutually exclusive, therefore N is not shown

Needs help planning for...	PA	NCI
Employment	26%	30%
Financial	31%	33%
Housing	44%	51%
Legal	34%	35%
Medical	29%	31%
Social or Relationships	30%	32%
Transition from School	10%	9%
Recreation, Having Fun	34%	36%
Other	9%	11%

**Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?**

State v NCI	Yes	No	N
PA	50%	50%	181
NCI	53%	47%	1,018

**Table Q7. Does your family member have a service plan?**

State v NCI	Yes	No	N
PA▲	96%	4%	626
NCI	86%	14%	4,052

**Table Q8. Does the service plan include all the services and supports your family member needs?**

State v NCI	Yes	No	N
PA	92%	8%	540
NCI	90%	10%	3,012

**Table Q9. Does your family member get all of the services listed in the service plan?**

State v NCI	Yes	No	N
PA	91%	9%	530
NCI	89%	11%	2,995

**Table Q10. Did you or someone else in your family (besides your family member with a disability) help make the service plan?**

State v NCI	Yes	No	N
PA	83%	17%	573
NCI	85%	15%	3,231

**Table Q11. Did your family member help make the service plan?**

State v NCI	Yes	No	N
PA	64%	36%	568
NCI	64%	36%	3,207

**Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's last service planning meeting?**

State v NCI	Yes	No	N
PA	61%	39%	510
NCI	63%	37%	3,004

**Table Q13. If your family member left school services during the past year, did s/he have a transition plan?**

State v NCI	Yes	No	N
PA	54%	46%	37
NCI	51%	49%	423

**Table Q14. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?**

State v NCI	Yes	No	N
PA	50%	50%	20
NCI	48%	52%	212

**Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?**

State v NCI	Yes	No	N
PA	70%	30%	461
NCI	68%	32%	3,245



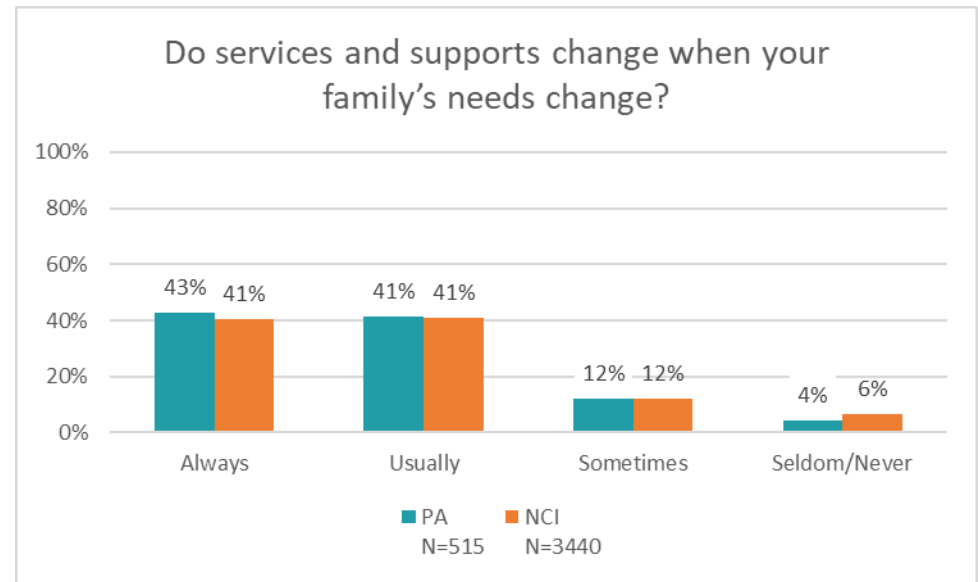
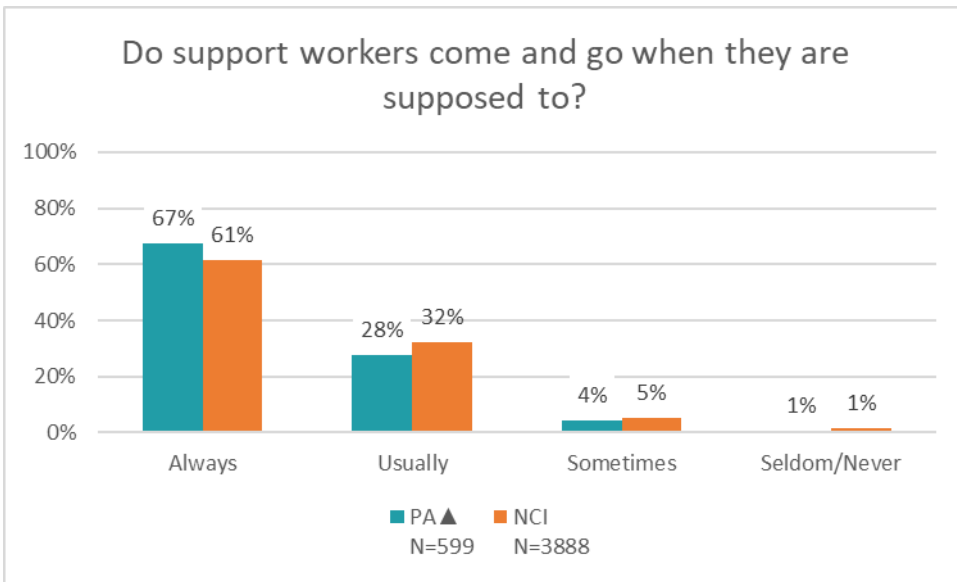
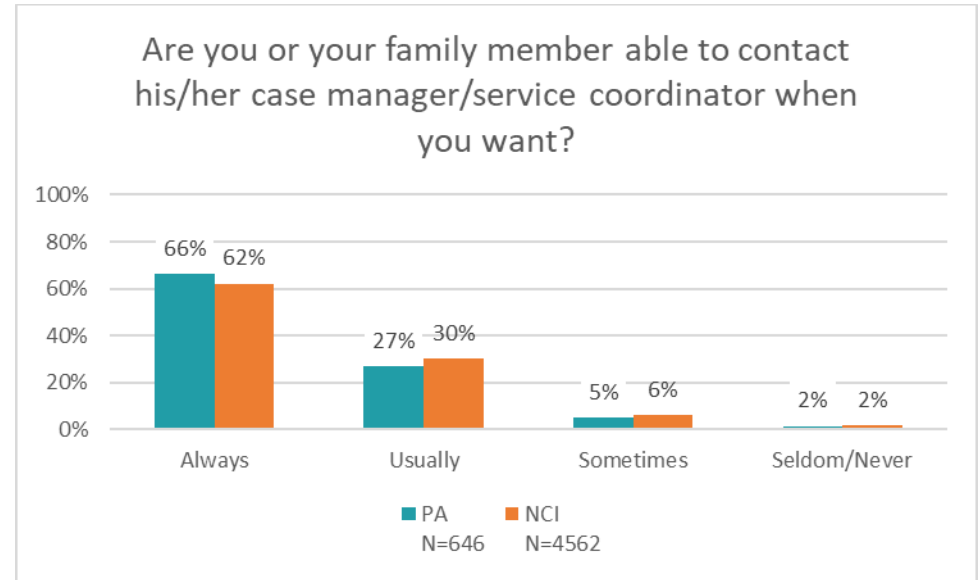
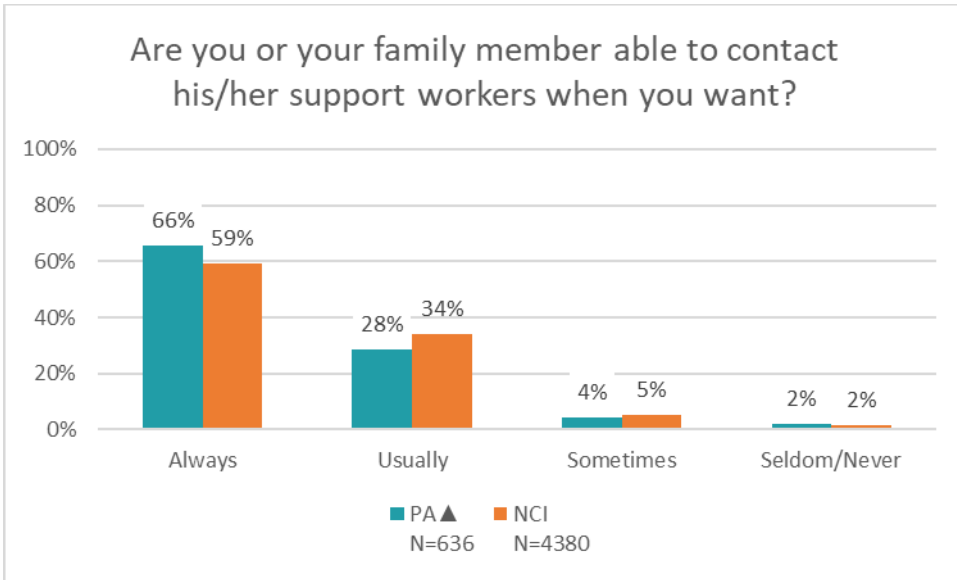
**Table Q16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?**

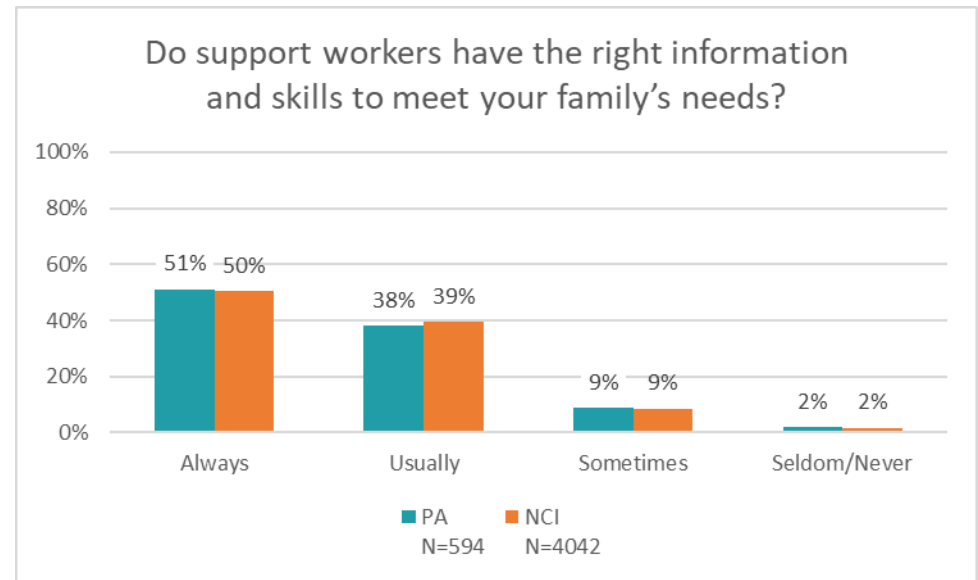
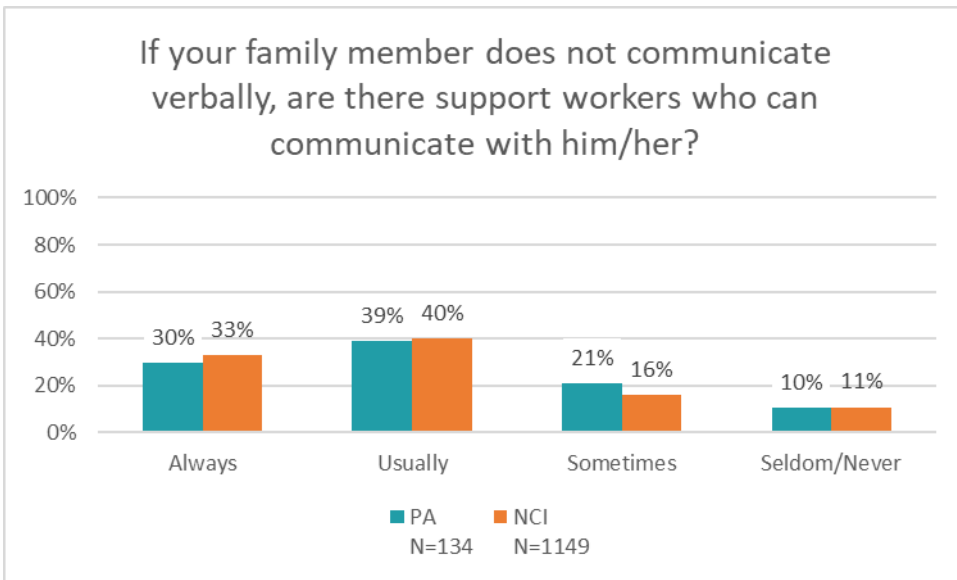
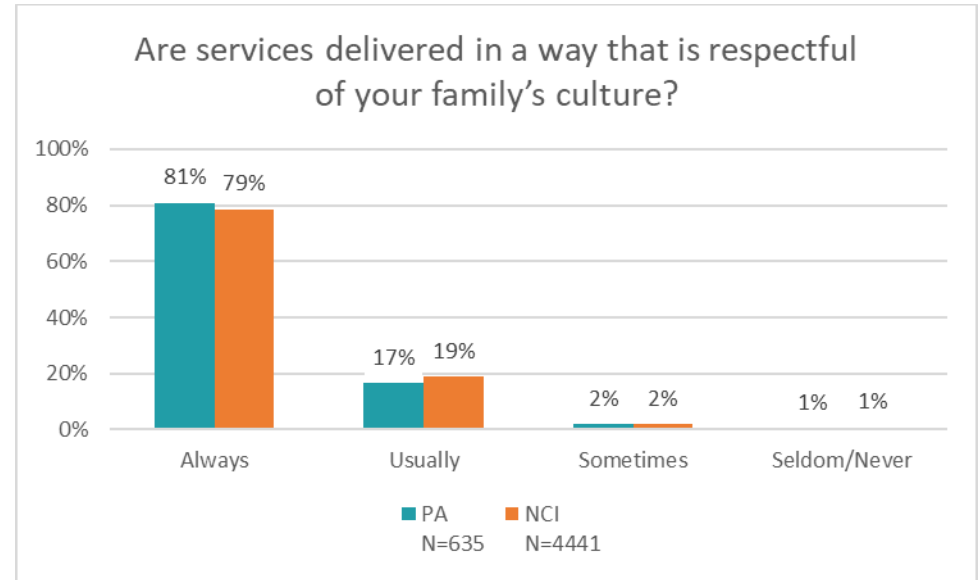
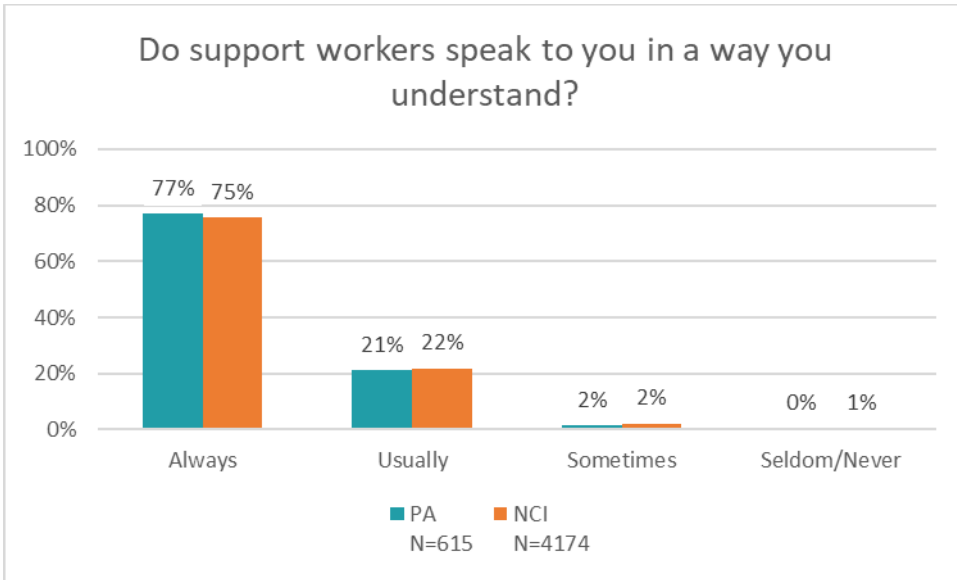
State v NCI	Yes	No	N
PA	88%	12%	602
NCI	89%	11%	4,363

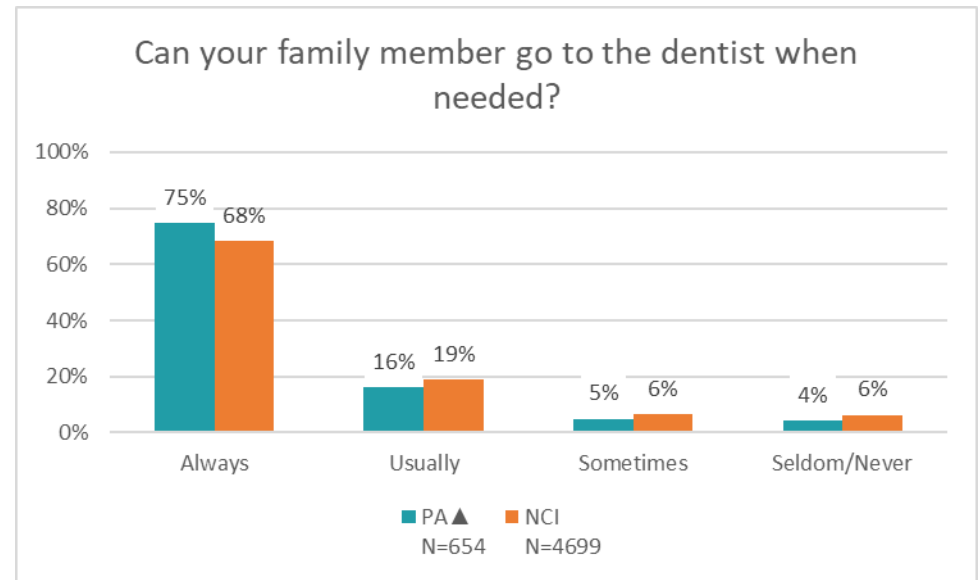
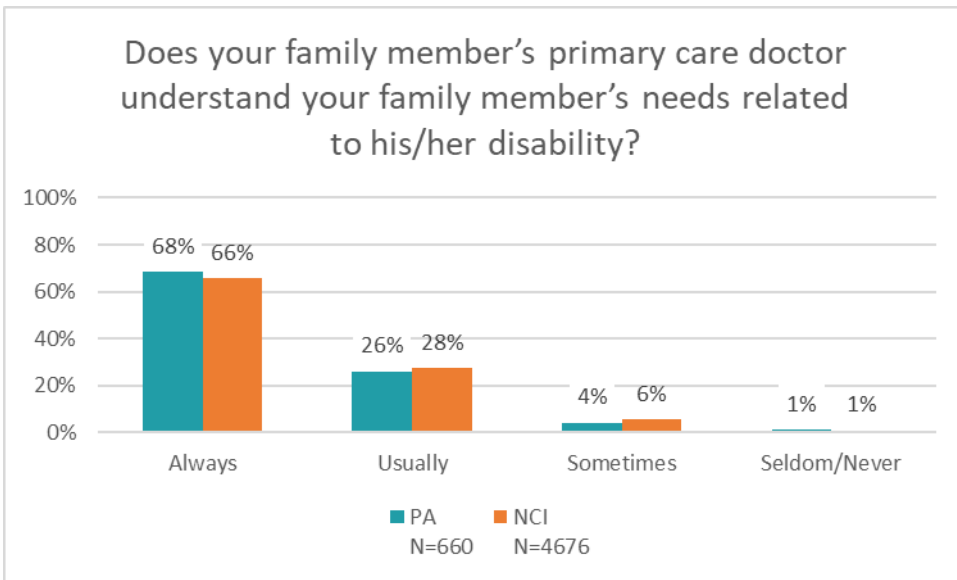
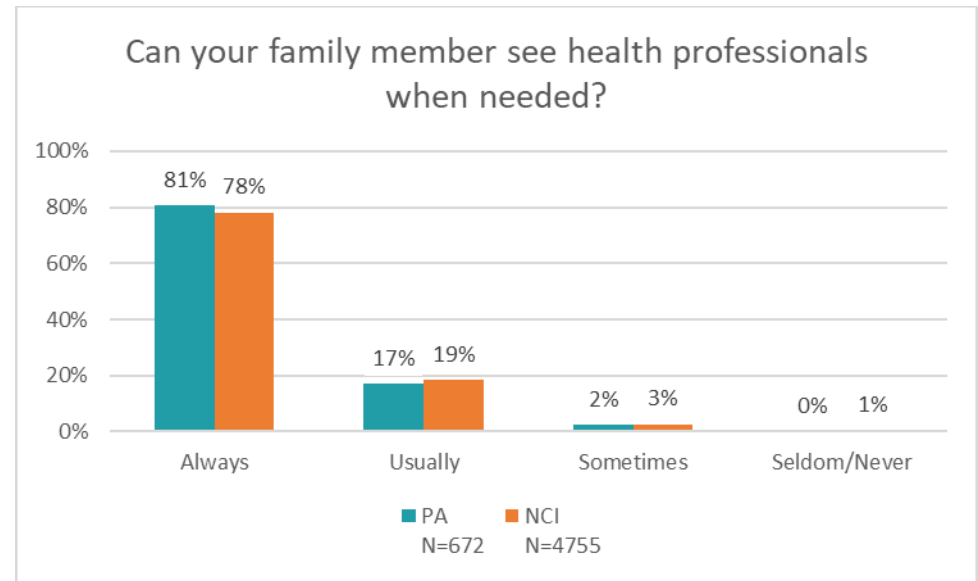
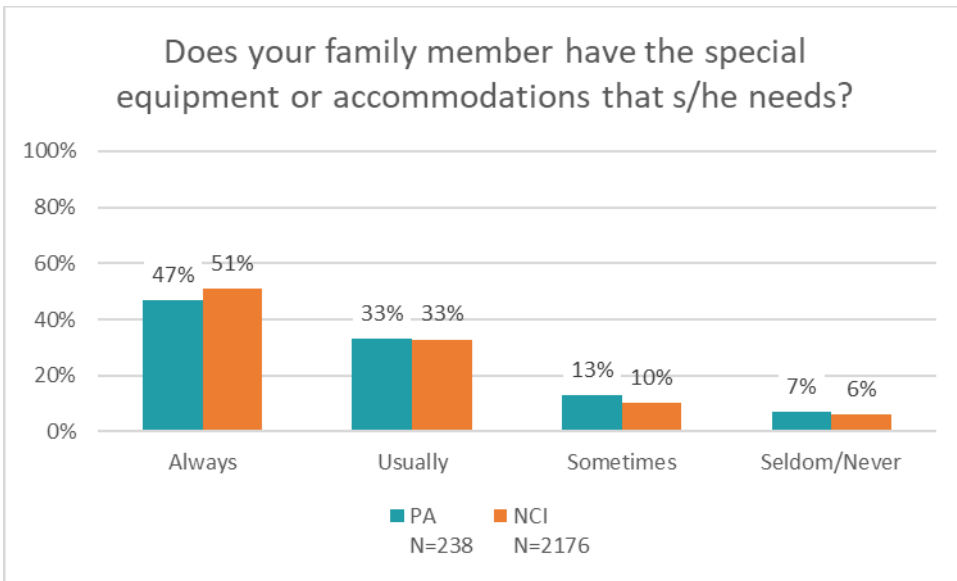
## *Access and Delivery of Services and Supports Charts*

*Families and family members with disabilities get the services and supports they need.*

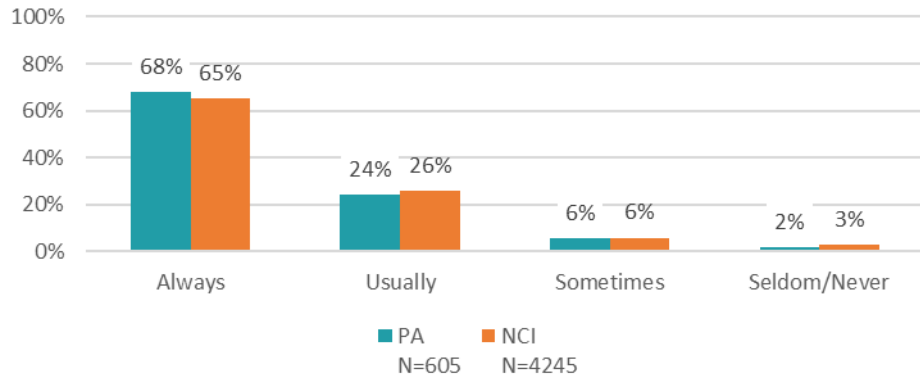
The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.



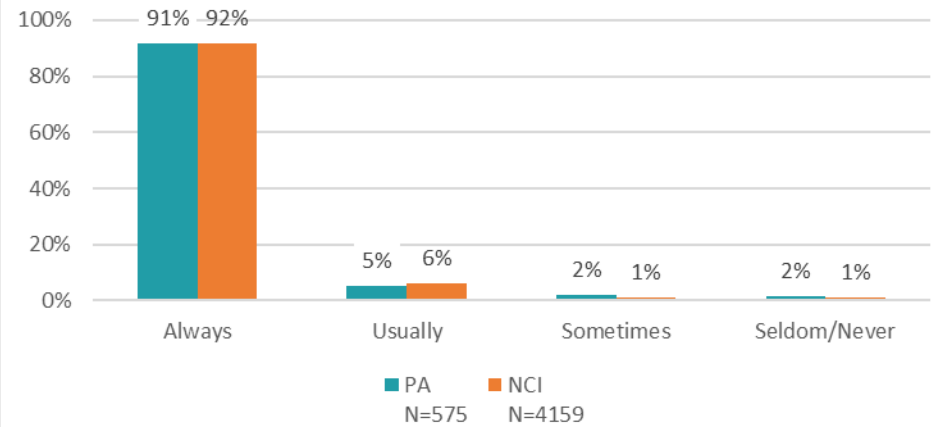




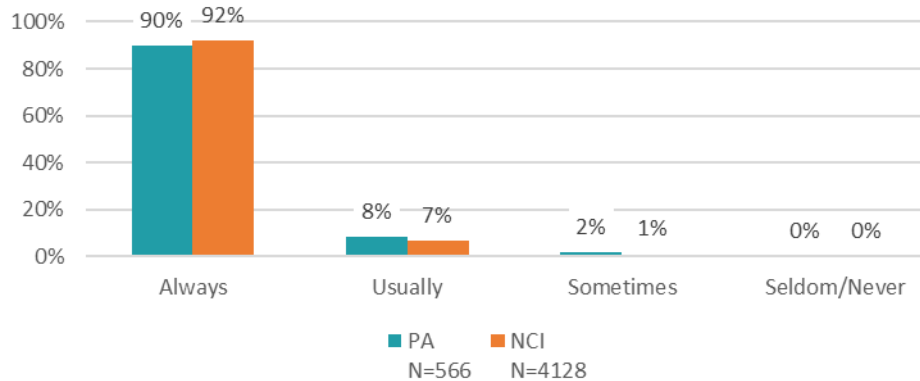
Does your family member's dentist understand your family member's needs related to his/her disability?



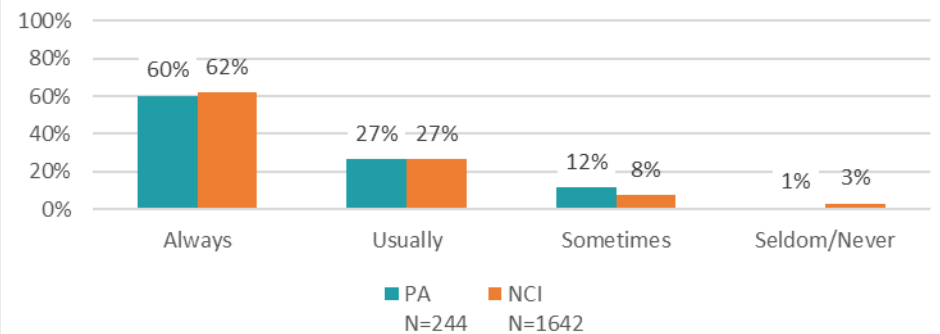
If your family member takes medications, do you know what they're for?

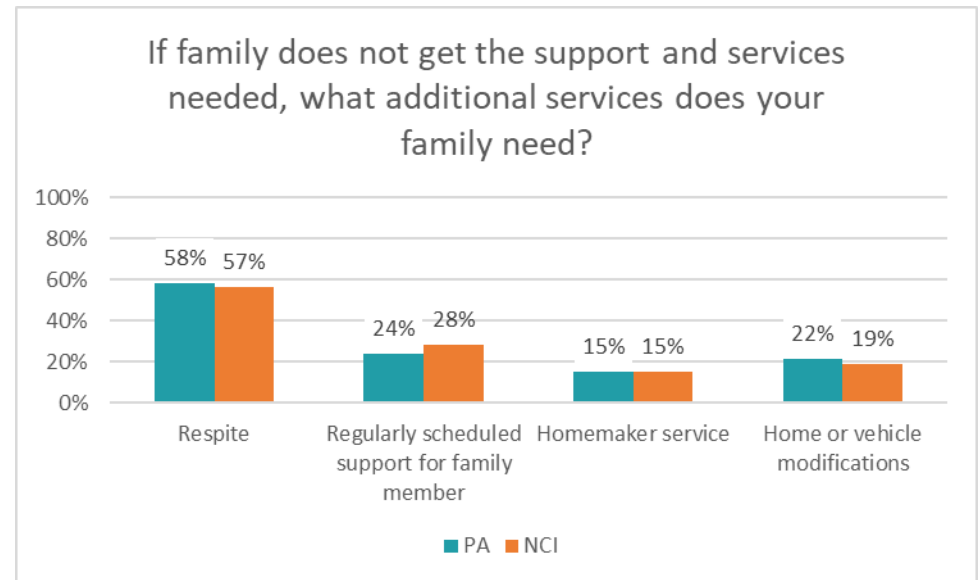
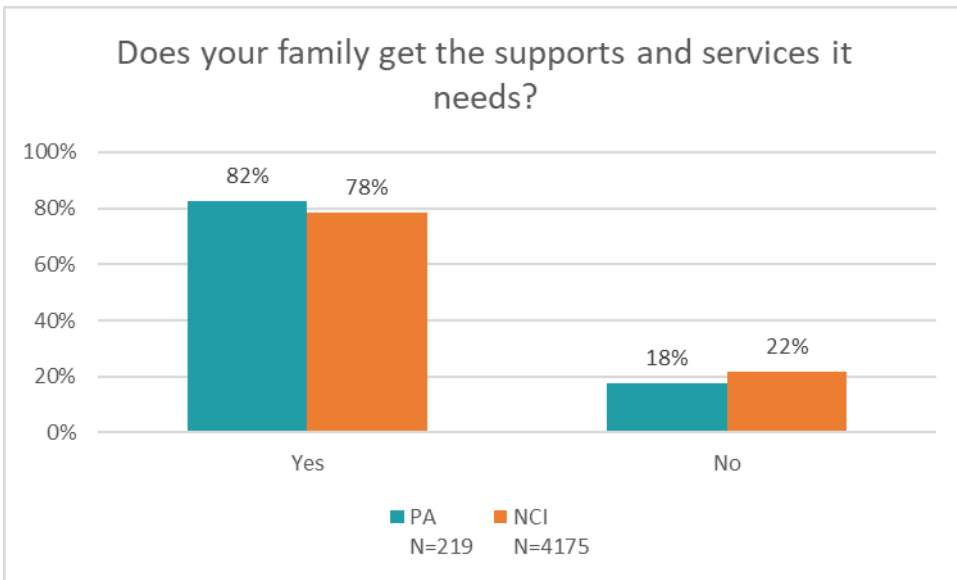
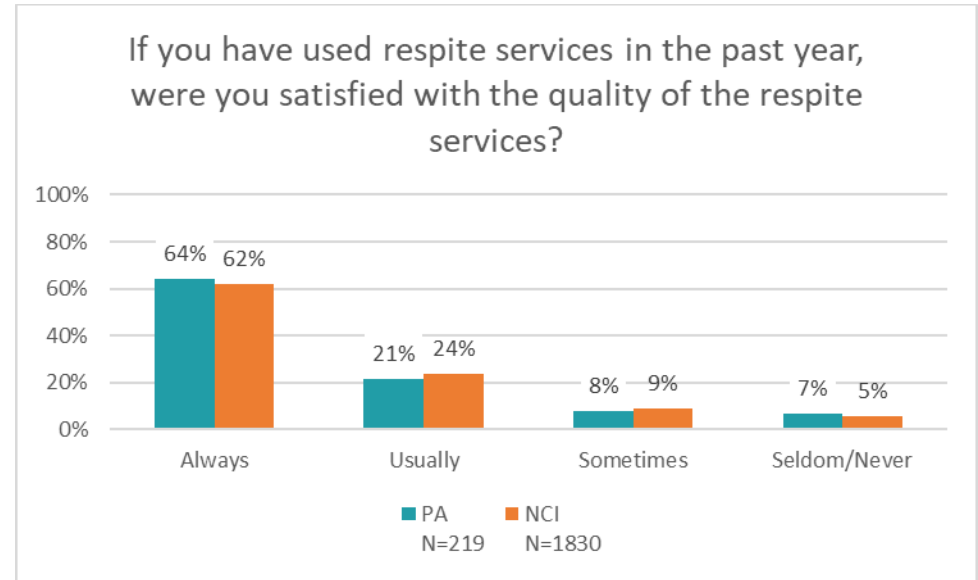
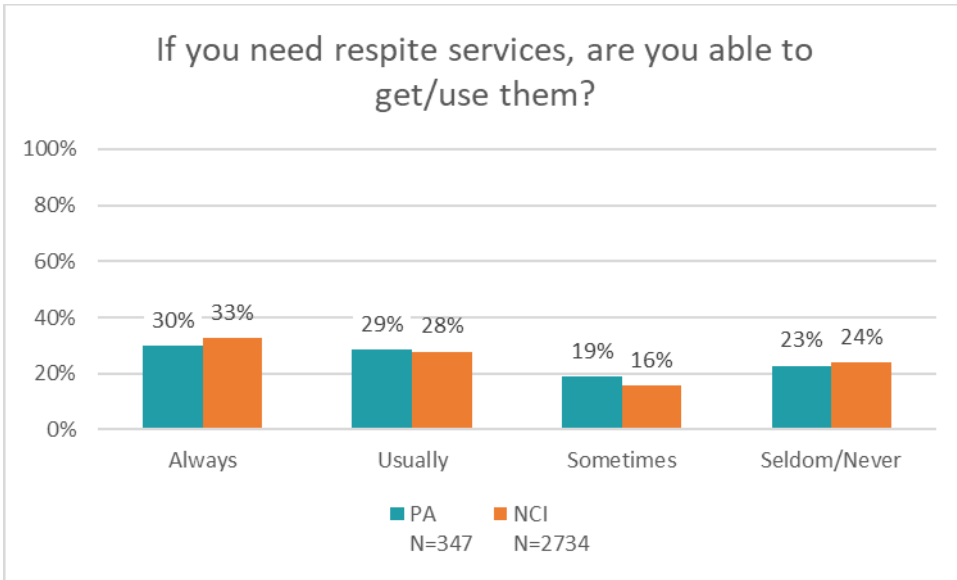


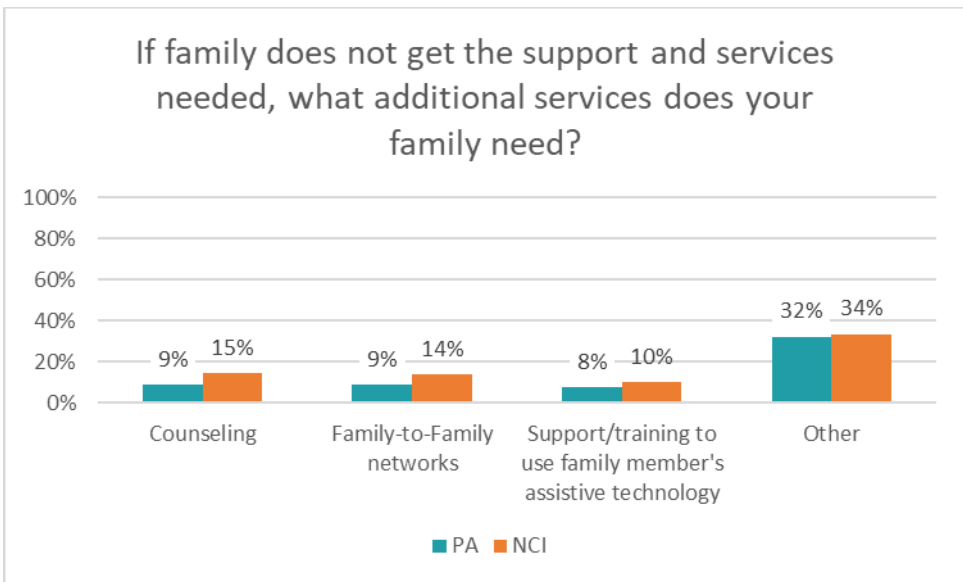
Do you, your family member, or someone else in your family know what is needed to safely take the medications?



If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?









## *Access and Delivery of Services and Supports Tables*

*Families and family members with disabilities get the services and supports they need.*

**Table Q17. Are you or your family member able to contact his/her support workers when you want?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA▲	66%	28%	4%	2%	636
NCI	59%	34%	5%	2%	4,380

**Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	66%	27%	5%	2%	646
NCI	62%	30%	6%	2%	4,562

**Table Q19. Do support workers come and go when they are supposed to?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA▲	67%	28%	4%	1%	599
NCI	61%	32%	5%	1%	3,888

**Table Q20. Do services and supports change when your family's needs change?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	43%	41%	12%	4%	515
NCI	41%	41%	12%	6%	3,440

**Table Q21. Do support workers speak to you in a way you understand?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	77%	21%	2%	0%	615
NCI	75%	22%	2%	1%	4,174

**Table Q22. Are services delivered in a way that is respectful of your family's culture?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	81%	17%	2%	1%	635
NCI	79%	19%	2%	1%	4,441

**Table Q23. If your family member does not communicate verbally (for example, uses gestures or sign language, or a communication aid), are there support workers who can communicate with him/her?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	30%	39%	21%	10%	134
NCI	33%	40%	16%	11%	1,149

**Table Q24. Do support workers have the right information and skills to meet your family's needs?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	51%	38%	9%	2%	594
NCI	50%	39%	9%	2%	4,042

**Table Q25. Does your family member have the special equipment or accommodations that s/he needs?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	47%	33%	13%	7%	238
NCI	51%	33%	10%	6%	2,176

**Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	81%	17%	2%	0%	672
NCI	78%	19%	3%	1%	4,755

**Table Q27. Does your family member's primary care doctor understand your family member's needs related to his/her disability?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	68%	26%	4%	1%	660
NCI	66%	28%	6%	1%	4,676

**Table Q28. Does your family member go to the dentist when needed?**

Question changed from previous years

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA ▲	75%	16%	5%	4%	654
NCI	68%	19%	6%	6%	4,699

**Table Q29. Does your family member's dentist understand your family member's needs related to his/her disability?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	68%	24%	6%	2%	605
NCI	65%	26%	6%	3%	4,245

**Table Q30. If your family member takes medications, do you know what they're for?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	91%	5%	2%	2%	575
NCI	92%	6%	1%	1%	4,159

**Table Q31. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	90%	8%	2%	0%	566
NCI	92%	7%	1%	0%	4,128

**Table Q32. If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	60%	27%	12%	1%	244
NCI	62%	27%	8%	3%	1,642

**Table Q33. If you need respite services, are you able to get/use them?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	30%	29%	19%	23%	347
NCI	33%	28%	16%	24%	2,734

**Table Q34. If you have used respite services in the past year, were you satisfied with the quality of the respite services?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	64%	21%	8%	7%	219
NCI	62%	24%	9%	5%	1,830

**Table Q35. Does your family get the supports and services it needs?**

State v NCI	Yes	No	N
PA	82%	18%	576
NCI	78%	22%	4,175

**Table Q36. If your family does not get the support and services needed, what additional services does your family need?**

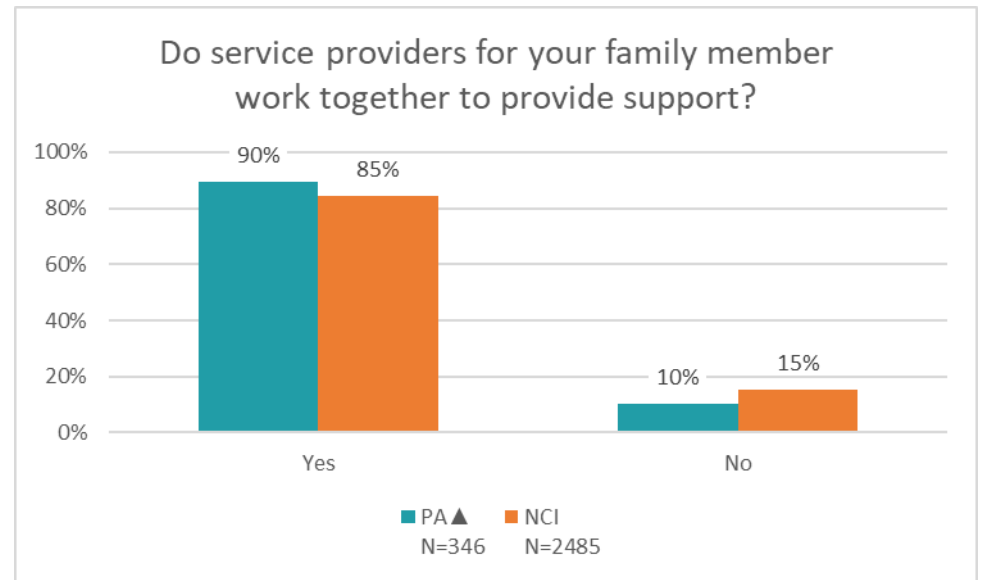
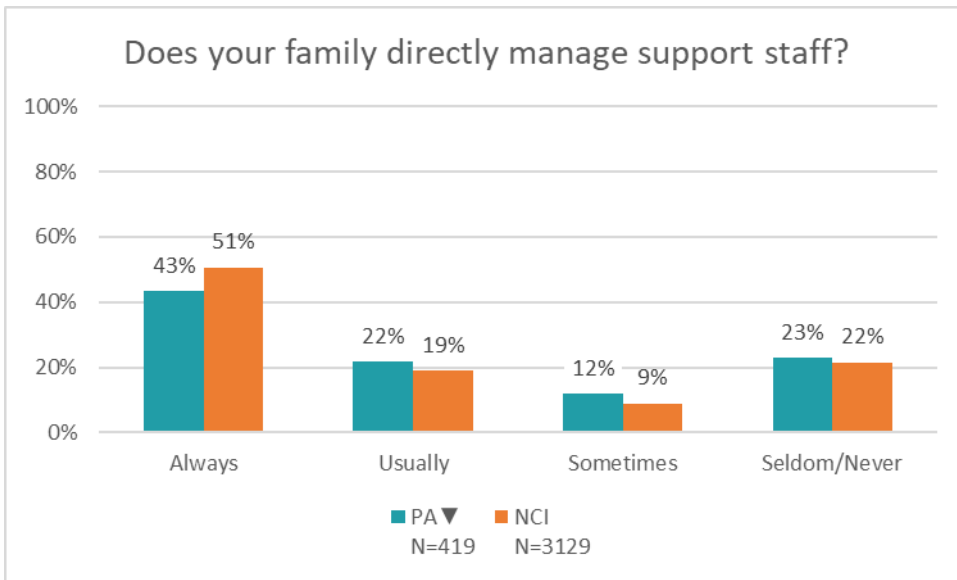
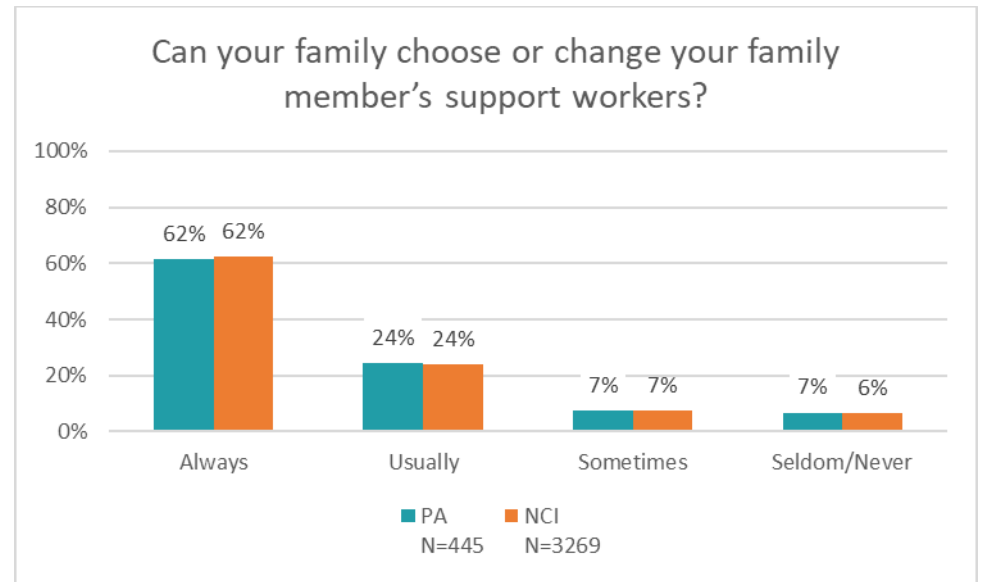
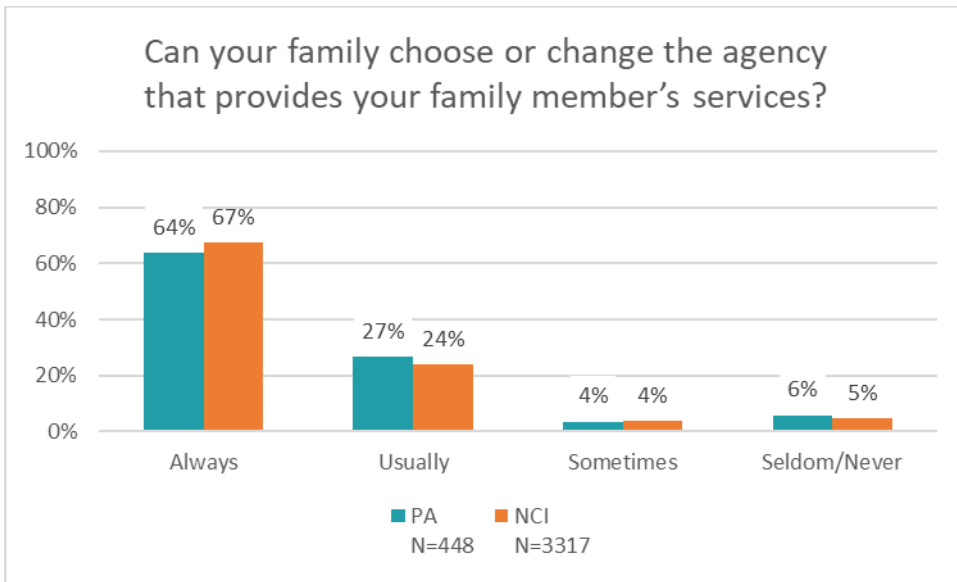
Categories are not mutually exclusive, therefore N is not shown

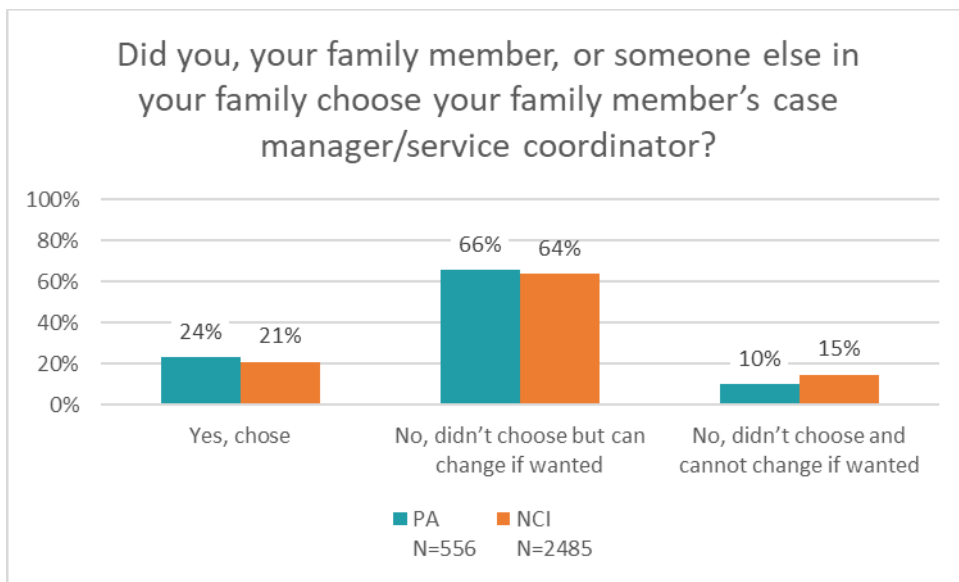
Additional service needed...	PA	NCI
Respite	58%	57%
Regularly scheduled support for family member	24%	28%
Homemaker service	15%	15%
Home or vehicle modifications	22%	19%
Counseling	9%	15%
Family-to-Family networks	9%	14%
Support/training to use family member's assistive technology	8%	10%
Other	32%	34%

## *Choice, Decision Making and Control Charts*

*Families and family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.*

The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.







## *Choice, Decision Making and Control Tables*

*Families and family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.*

**Table Q37. Can your family choose or change the agency that provides your family member's services?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	64%	27%	4%	6%	448
NCI	67%	24%	4%	5%	3,317

**Table Q38. Can your family choose or change your family member's support workers?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	62%	24%	7%	7%	445
NCI	62%	24%	7%	6%	3,269

**Table Q39. Does your family directly manage support staff?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA ▼	43%	22%	12%	23%	419
NCI	51%	19%	9%	22%	3,129

**Table Q40. Do service providers for your family member work together to provide support?**

State v NCI	Yes	No	N
PA ▲	90%	10%	346
NCI	85%	15%	2,485

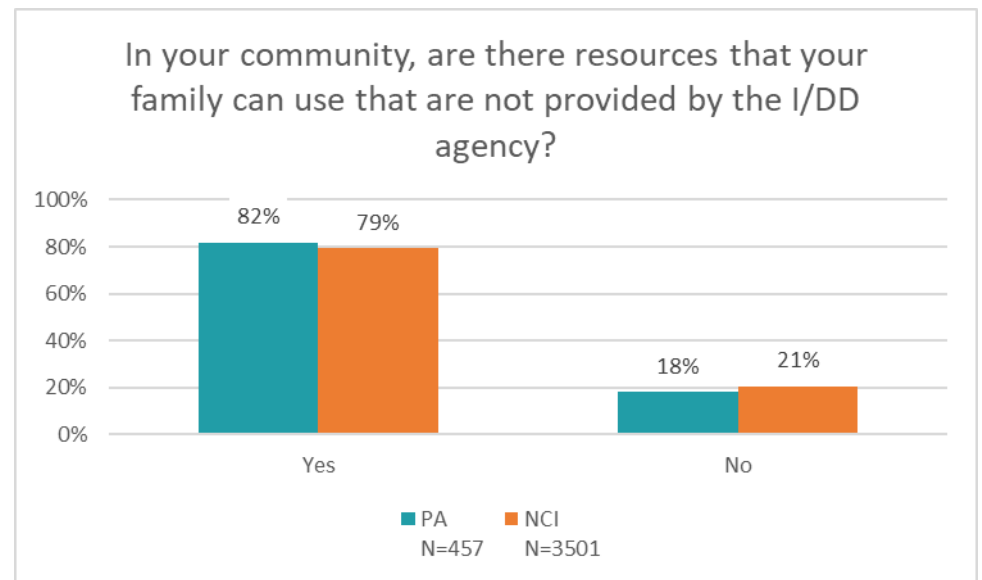
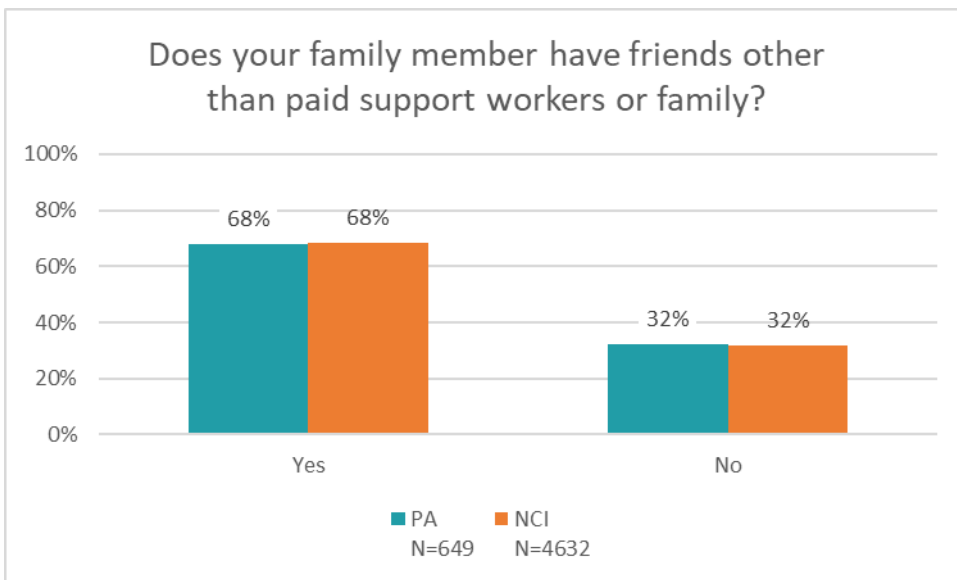
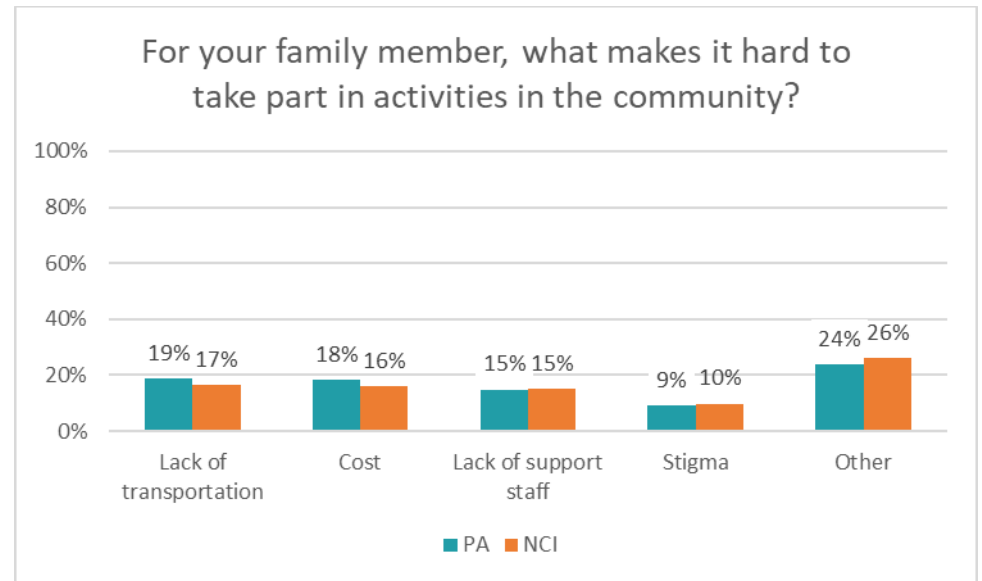
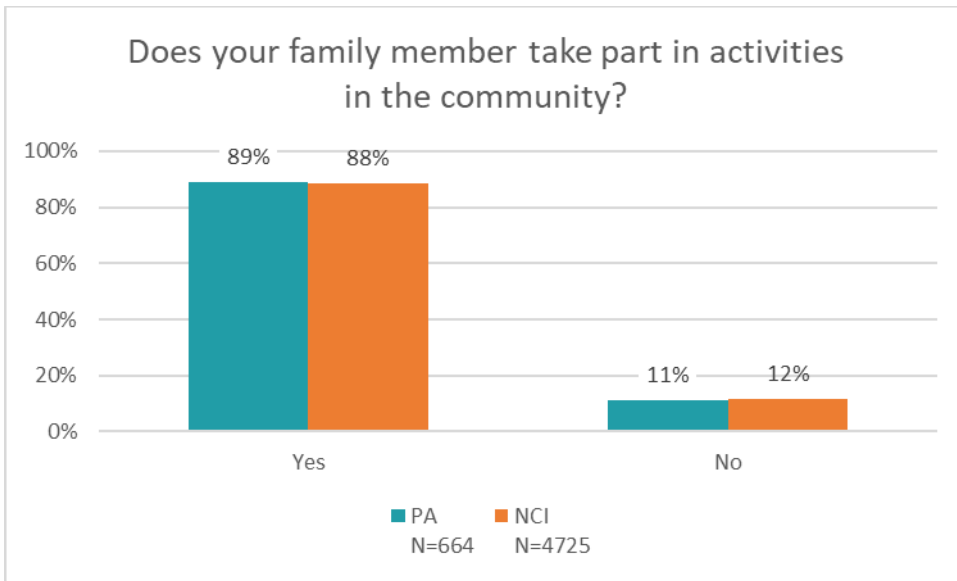
**Table Q41. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?**

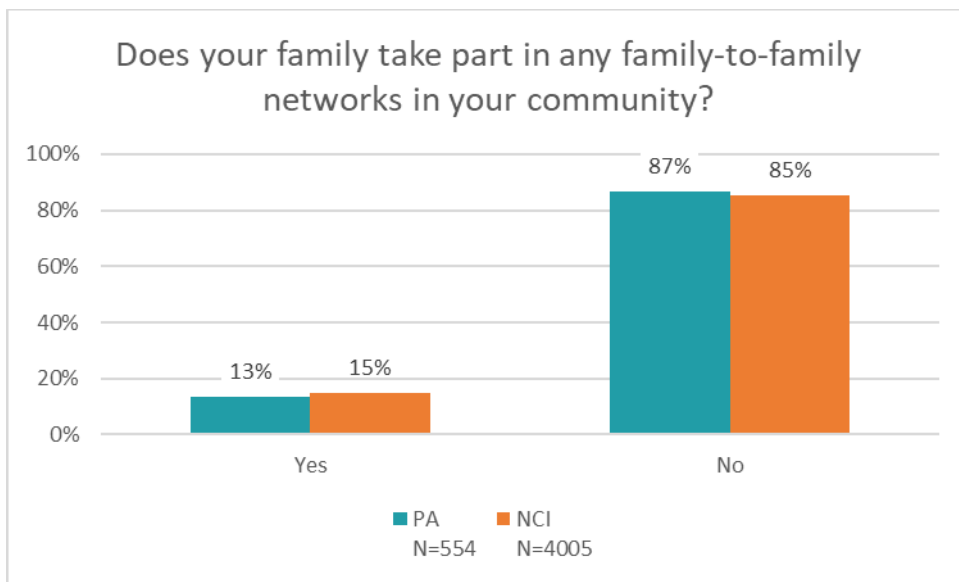
Chose case manager/service coordinator	PA	PA N	NCI	NCI N
Yes, chose	24%	556	21%	3,845
No, didn't choose but can change if wanted	66%	556	64%	3,845
No, didn't choose and cannot change if wanted	10%	556	15%	3,845

## *Involvement in the Community Charts*

*Family members with disabilities use integrated community services and participate in everyday community activities.*

The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.





## *Involvement in the Community Tables*

*Family members with disabilities use integrated community services and participate in everyday community activities.*

**Table Q42. Does your family member take part in activities in the community?**

State v NCI	Yes	No	N
PA	89%	11%	664
NCI	88%	12%	4,725

**Table Q43. For your family member, what makes it hard to take part in activities in the community?**

Question is rephrased from previous years; categories are not mutually exclusive, therefore N is not shown

Obstacles or barriers...	PA	NCI
Lack of transportation	19%	17%
Cost	18%	16%
Lack of support staff	15%	15%
Stigma	9%	10%
Other	24%	26%

**Table Q44. Does your family member have friends other than paid support workers or family?**

State v NCI	Yes	No	N
PA	68%	32%	649
NCI	68%	32%	4,632

**Table Q45. In your community, are there resources that your family can use that are not provided by the I/DD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?**

State v NCI	Yes	No	N
PA	82%	18%	457
NCI	79%	21%	3,501

**Table Q46. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?**

State v NCI	Yes	No	N
PA	13%	87%	554
NCI	15%	85%	4,005

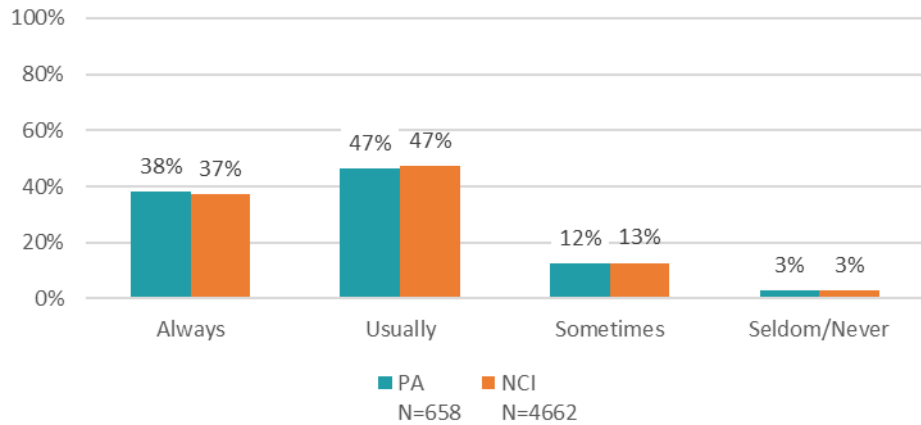
## *Satisfaction With Services and Supports Charts*

*Families and family members with disabilities receive adequate and satisfactory supports.*

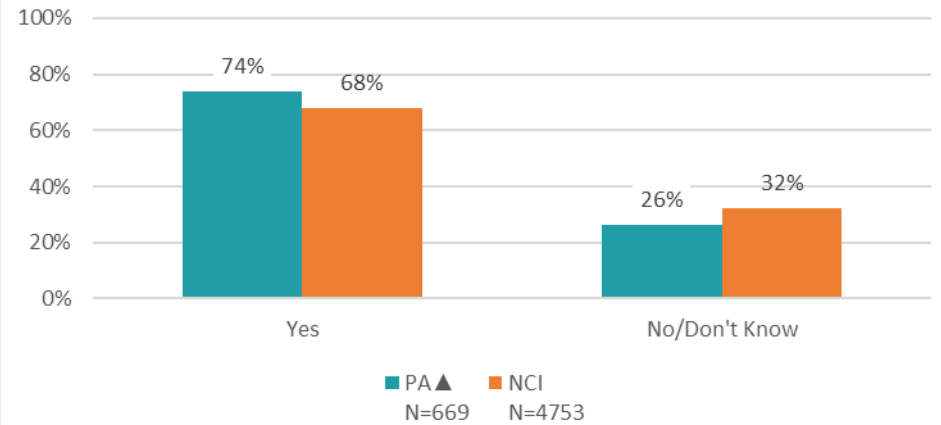
The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.



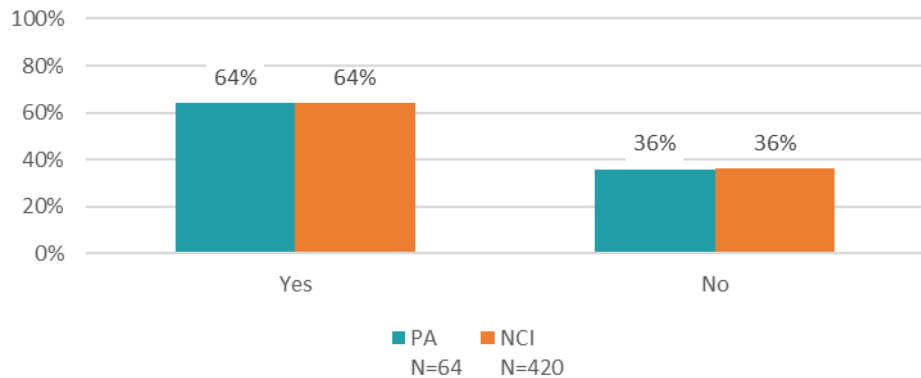
Overall, are you satisfied with the services and supports your family member currently receives?



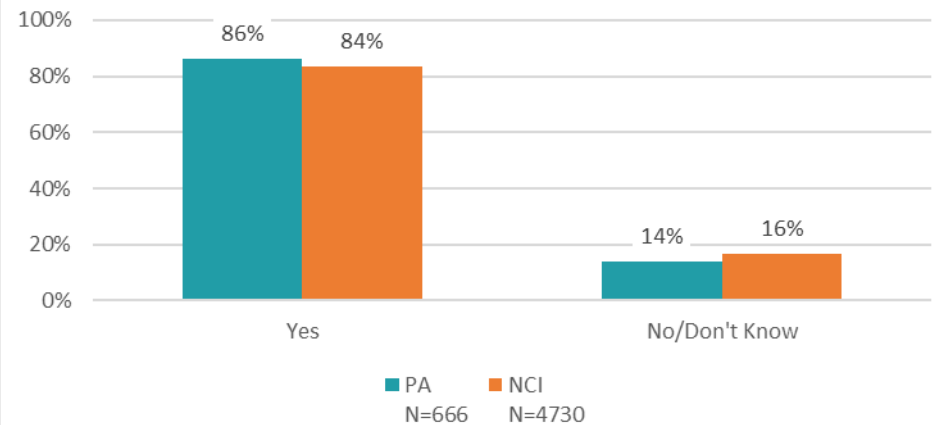
Do you know how to file a complaint or grievance about provider agencies or staff?

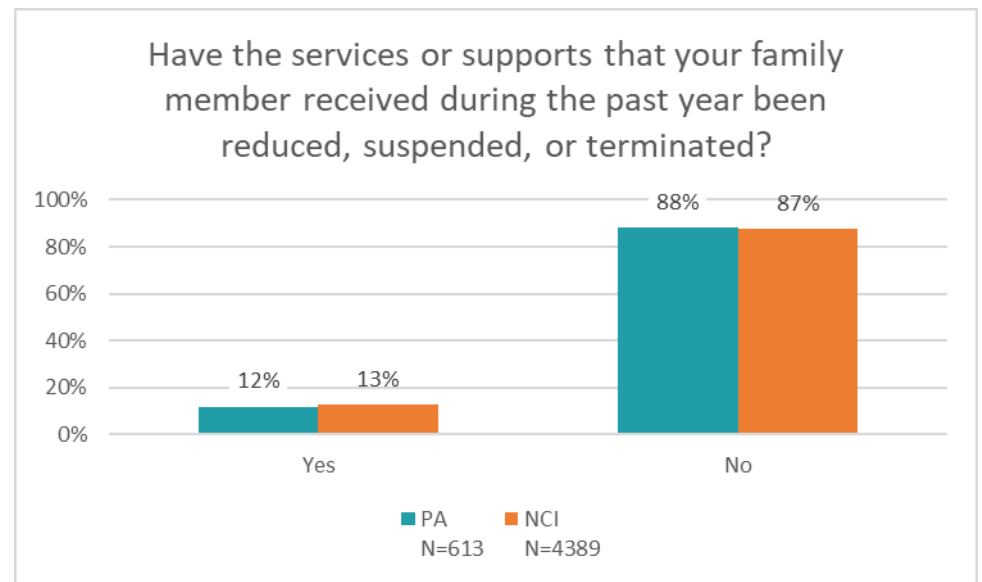
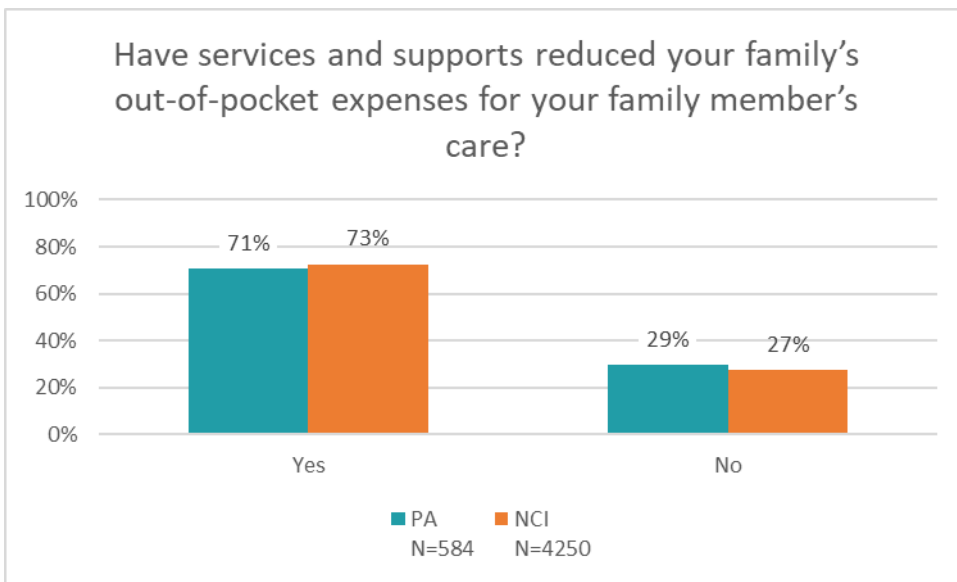
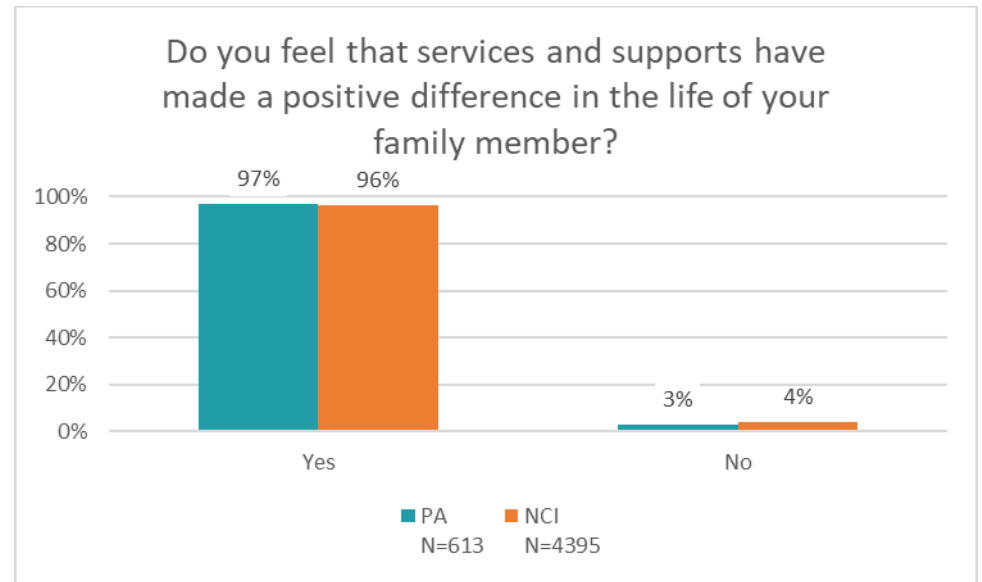
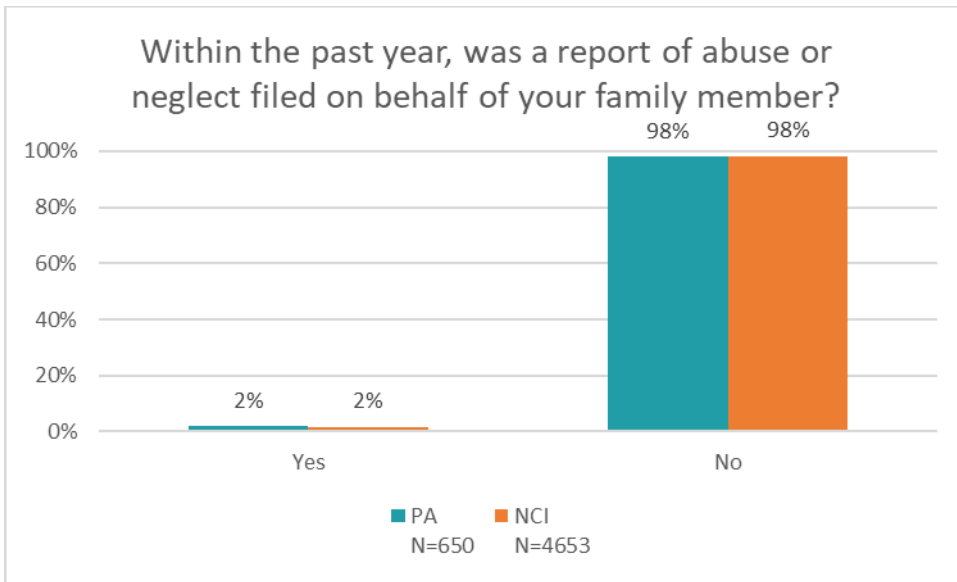


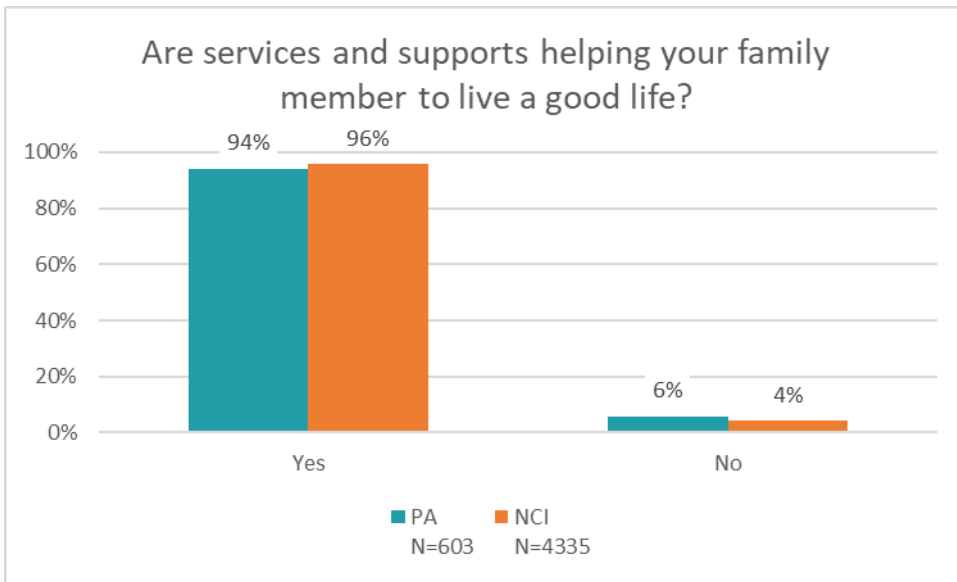
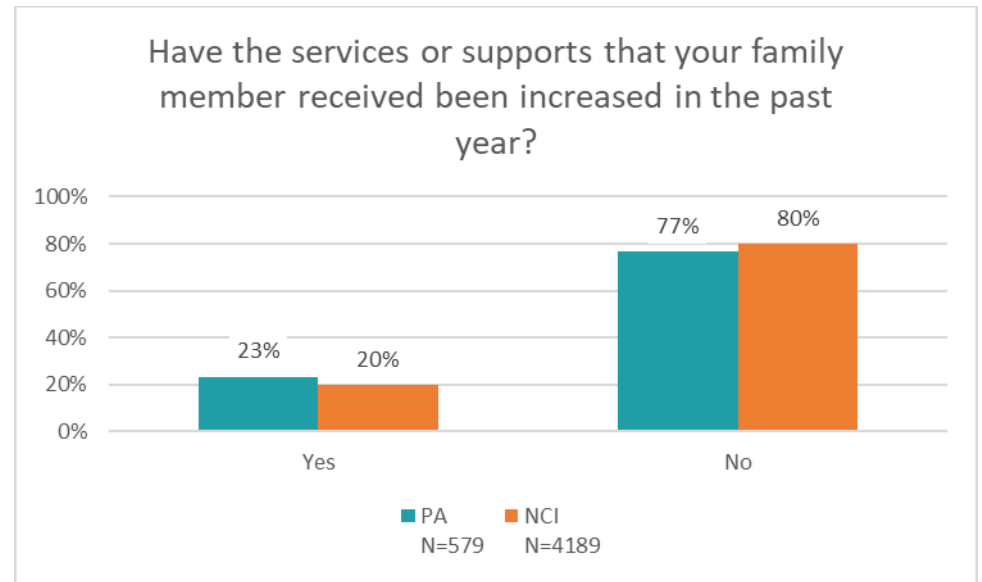
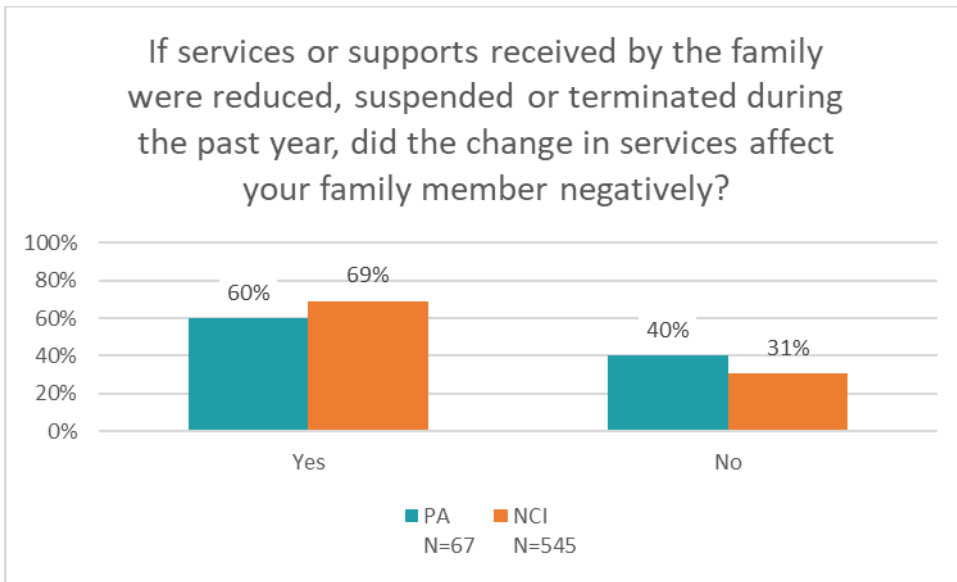
If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?



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







## *Satisfaction With Services and Supports Tables*

*Families and family members with disabilities receive adequate and satisfactory supports.*

**Table Q47. Overall, are you satisfied with the services and supports your family member currently receives?**

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	38%	47%	12%	3%	658
NCI	37%	47%	13%	3%	4,662

**Table Q48. Do you know how to file a complaint or grievance about provider agencies or staff?<sup>7</sup>**

State v NCI	Yes	No	N
PA▲	74%	26%	669
NCI	68%	32%	4,753

**Table Q49. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?**

State v NCI	Yes	No	N
PA	64%	36%	64
NCI	64%	36%	420

**Table Q50. Do you know how to report abuse or neglect related to your family member?<sup>8</sup>**

State v NCI	Yes	No	N
PA	86%	14%	666
NCI	84%	16%	4,730

**Table Q51. Within the past year, was a report of abuse or neglect filed on behalf of your family member?**

State v NCI	Yes	No	N
PA	2%	98%	650
NCI	2%	98%	4,653

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<sup>7</sup> Don't Know' responses were included in 'No' responses for this question.

<sup>8</sup> Don't Know' responses were included in 'No' responses for this question.

**Table Q52. Do you feel that services and supports have made a positive difference in the life of your family member?**

State v NCI	Yes	No	N
PA	97%	3%	613
NCI	96%	4%	4,395

**Table Q53. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?**

State v NCI	Yes	No	N
PA	71%	29%	584
NCI	73%	27%	4,250

**Table Q54. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?**

State v NCI	Yes	No	N
PA	12%	88%	613
NCI	13%	87%	4,389

**Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?**

State v NCI	Yes	No	N
PA	60%	40%	67
NCI	69%	31%	545

**Table Q56. Have the services or supports that your family member received been increased in the past year?**

State v NCI	Yes	No	N
PA	23%	77%	579
NCI	20%	80%	4,189

**Table Q57. Are services and supports helping your family member to live a good life?**

State v NCI	Yes	No	N
PA	94%	6%	603
NCI	96%	4%	4,335