



Family/Guardian Survey (FGS) State Report

Pennsylvania (PA) Report

Contents

What is NCI?.....	6
Where are the statistics in this report from?	6
What is the NCI Family/Guardian Survey?.....	6
What is included in this report?.....	6
Demographics	7
Demographics of Family Member Receiving Services	8
Table 1. Family Member’s Residence	9
Table 2. Family Member’s Residential Designation	9
Table 3. Family Member’s Age.....	9
Table 4. Family Member’s Gender	9
Table 5. Family Member’s Race and Ethnicity	10
Table 6a. Family Member’s Disabilities (not mutually exclusive)	10
Table 6b. Family Member’s Disabilities (continued).....	10
Table 7a. Family Member’s Health Conditions	11
Table 7b. Family Member’s Health Conditions (continued)	11
Table 8. Family Member’s Preferred Means of Communication.....	11
Table 9. Family Member Has Legal Court Appointed Guardian or Conservator	12
Table 10. Guardian or Conservator Relationship to Family Member	12
Table 11. Family Member’s Highest level of Education.....	12
Table 12. Family Member’s Activities in the Past Two Weeks Included <i>Individual Paid Job in the Community</i>	13
Table 13. Family Member’s Activities in the Past Two Weeks Included <i>Paid Small Group Job in a Community-based Setting</i>	13
Table 14. Family Member’s Activities in the Past Two Weeks Included <i>Paid Work in a Community Job That Primarily Hires People With Disabilities</i>	13
Table 15. Family Member’s Activities in the Past Two Weeks Included <i>Unpaid Activity in the Community</i>	14
Table 16. Family Member’s Activities in the Past Two Weeks Included <i>Paid Activity in a Facility-based Setting</i>	14

Table 17. Family Member’s Activities in the Past Two Weeks Included <i>Unpaid Activity in a Facility-based Setting</i>	14
Table 18. Family Member’s Activities in the Past Two Weeks Included <i>School</i>	15
Table 19. Family Member’s Activities in the Past Two Weeks Included <i>Stays at Home</i>	15
Table 20. Family Member’s Activities in the Past Two Weeks Included <i>Other Activities</i>	15
Table 21. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	15
Table 22. Family Member’s Level of Help Needed With Personal Care Activities (e.g., bathing, dressing, eating)	16
Table 23. Family Member’s Need for Help With Other Daily Activities (e.g., scheduling, managing money, or shopping)	16
Demographics of Family Member Receiving Services	17
Table 24. Language Spoken at Home	18
Table 25. Respondent’s Age	18
Table 26. Respondent’s Health	18
Table 27. Respondent’s Relationship to Family Member	18
Table 28. Respondent’s Frequency of Visits With Family Member Last Year	18
Table 29. Respondent’s Highest Level of Education	19
Table 30. Total Taxable Household Income of Wage Earners in the Past Year	19
Services and Supports Received	20
Table 30. Services and Supports Received From ID/DD Agency	21
Table 31. Additional Services and Supports Received (Not From the I/DD Agency)	21
Family/Guardian Survey Results	22
Information and Planning Charts	23
Information and Planning Tables	28
Table Q1. Do you get enough information to take part in planning services for your family member?	29
Table Q2. Is the information you get about services and supports easy to understand?	29
Table Q3. Do staff or the residential agency keep you informed about how your family member is doing?	29
Table Q4. Does the case manager/service coordinator respect your family’s choices and opinions?	29
Table Q5. Do you need help planning for your family member’s future with respect to any of the following?	30

Table Q6. In the past year, did your family member move out of the family home for the first time?.....	30
Table Q7. Does your family member have a service plan?.....	30
Table Q8. Does the service plan include all the services and supports your family member needs?.....	30
Table Q9. Does your family member get all of the services listed in the service plan?	31
Table Q10. Did you or someone else in your family (besides your family member with a disability) help make the service plan?	31
Table Q11. Did your family member help make the service plan?.....	31
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?	31
Table Q13. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?.....	31
Table Q14. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?.....	32
Access and Delivery of Services and Supports Charts.....	33
Access and Delivery of Services and Supports Tables.....	39
Table Q16. Are you or your family member able to contact his/her case manager/service coordinator when you want to?	40
Table Q17. Do support workers come and go when they are supposed to?	40
Table Q18. Do services and supports change when your family’s needs change?.....	40
Table Q19. Do support workers speak to you in a way you understand?	40
Table Q20. Are services delivered in a way that is respectful of your family’s culture?	41
Table Q21. 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?	41
Table Q22. Do support workers have the right information and skills to meet your family’s needs?.....	41
Table Q23. Does your family member have the special equipment or accommodations that s/he needs?	41
Table Q24. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?.....	41
Table Q25. Does your family member’s primary care doctor understand your family member’s needs related to his/her disability?	42
Table Q26. Does your family member go to the dentist when needed?.....	42
Table Q27. Does your family member’s dentist understand your family member’s needs related to his/her disability?	42

Table Q28. If your family member takes medications, do you know what they're for?	42
Table Q29. 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)?	42
Table Q30. If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?	43
Table Q31. Does your family get the supports and services it needs?	43
Table Q32. If your family does not get the support and services needed, what additional services does your family need?	43
Choice, Decision Making and Control Charts.....	44
Choice, Decision Making and Control Tables.....	47
Table Q33. Does the agency providing residential services to your family member involve him/her in important decisions?.....	48
Table Q34. Can your family choose or change the agency that provides your family member's services?	48
Table Q35. Can your family choose or change the individual staff that provide the services for your family member?	48
Table Q36. Does your family directly manage support staff?	48
Table Q37. Do service providers for your family member work together to provide support?.....	49
Table Q38. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?	49
Involvement in the Community Charts.....	50
Involvement in the Community Tables.....	53
Table Q39. Does your family member take part in activities in the community?	54
Table Q40. For your family member, what makes it hard to take part in activities in the community?.....	54
Table Q41. Does your family member have friends other than paid support workers or family?.....	54
Table Q42. In your community, are there resources that your family can use that are not provided by the IDD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?	54
Table Q43. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?	55
Satisfaction With Services and Supports Charts	56
Satisfaction With Services and Supports Tables	60
Table Q44. Overall, are you satisfied with the services and supports your family member currently receives?	61

Table Q45. Do you know how to file a complaint or grievance about provider agencies or staff?	61
Table Q46. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved? .	61
Table Q47. Do you know how to report abuse or neglect related to your family member?	61
Table Q48. Within the past year, was a report of abuse or neglect filed on behalf of your family member?	62
Table Q49. If a report of abuse or neglect was filed on behalf of your family member in the past year, did the appropriate people respond to the report?.....	62
Table Q50. If someone outside of your family reported abuse or neglect on behalf of your family member in the past year, were you notified of the report in a timely manner?.....	62
Table Q51. Do you feel that services and supports have made a positive difference in the life of your family member?	62
Table Q52. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?	62
Table Q53. 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?	63
Table Q54. Have the services or supports that your family member received been increased in the past year?	63
Table Q55. Are services and supports helping your family member to live a good life?	63

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 Family/Guardian Survey (FGS). The data shown are weighted NCI averages. These data are comprised of 2,664 valid surveys collected across nine states: AZ, GA, KY, LA, MD, NC, OH, PA and VA.

What is the NCI Family/Guardian Survey?

The NCI Family/Guardian Survey is used to gather data on family outcomes. It is mailed to families who have an adult family member who *does not live 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 Family/Guardian Survey data compared to the NCI Average. State outcomes that are significantly higher or lower than the NCI Average are indicated with an arrow:

- Outcomes where the state is significantly above the NCI average are denoted with an up arrow ▲;
- 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 Family/Guardian Survey, data analysis and state samples, check out the National Family/Guardian 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. Family Member's Residence

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

State v. NCI	Specialized facility for people with intellectual disabilities	Group home or agency-operated apartment	Independent home or apartment	Adult foster care/host family home	Nursing home	Homeless	Other	N
PA	12%	68%	13%	4%	1%	0%	1%	552
NCI	14%	65%	11%	7%	1%	0%	2%	2,657

Table 2. Family Member's Residential Designation

State v. NCI	Urban or Suburban	Rural	N
PA	73%	27%	545
NCI	76%	24%	2,618

Table 3. Family Member's Age

State v. NCI	Average Age	N
PA	48.3	560
NCI	47.5	2,664

Table 4. Family Member's Gender

State v. NCI	Male	Female	N
PA	56%	44%	556
NCI	60%	40%	2,693

Table 5. 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	Hawaiian or Pacific Islander	White	Hispanic or Latino	Other
PA	1%	1%	7%	1%	90%	1%	0%
NCI	2%	2%	13%	0%	81%	2%	2%

Table 6a. 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	Brain Injury
PA	82%	37%	21%	18%	9%	7%	10%
NCI	79%	40%	26%	17%	11%	7%	10%

Table 6b. 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	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
PA	30%	0%	11%	1%	1%	10%
NCI	30%	0%	9%	1%	1%	12%

Table 7a. 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	12%	17%	6%	29%	31%
NCI	9%	21%	6%	33%	30%

Table 7b. 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	20%	4%	8%	12%	16%	19%
NCI	14%	2%	7%	15%	13%	24%

Table 8. 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	76%	17%	2%	2%	4%	552
NCI	71%	22%	3%	1%	3%	2,658

Table 9. 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	None	Limited	Full	Has Guardianship but Level Is Unknown	N
PA	36%	15%	41%	8%	491
NCI	19%	16%	60%	5%	2,533

Table 10. Guardian or Conservator Relationship to Family Member

State v. NCI	Family	Friend	State Employee or Guardianship Agency	Other	N
PA	84%	1%	10%	4%	298
NCI	74%	2%	20%	5%	1,928

Table 11. 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	38%	0%	23%	30%	4%	2%	3%	529
NCI	42%	0%	29%	19%	3%	2%	4%	2,460

Table 12. Family Member's Activities in the Past Two Weeks Included *Individual Paid Job in the Community*¹

Response options changed from previous years

State v. NCI	No	Yes	N
PA	88%	12%	522
NCI	89%	11%	2,530

Table 13. Family Member's Activities in the Past Two Weeks Included *Paid Small Group Job in a Community-based Setting*²

Response options changed from previous years

State v. NCI	No	Yes	N
PA	91%	9%	511
NCI	89%	11%	2,459

Table 14. Family Member's Activities in the Past Two Weeks Included *Paid Work in a Community Job That Primarily Hires People With Disabilities*³

Response options changed from previous years

State v. NCI	No	Yes	N
PA	96%	4%	517
NCI	95%	5%	2,494

¹ 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).

² 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).

³ 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.

Table 15. Family Member's Activities in the Past Two Weeks Included *Unpaid Activity in the Community*⁴

Response options changed from previous years

State v. NCI	No	Yes	N
PA	73%	27%	488
NCI	72%	28%	2,406

Table 16. Family Member's Activities in the Past Two Weeks Included *Paid Activity in a Facility-based Setting*⁵

Response options changed from previous years

State v. NCI	No	Yes	N
PA	75%	25%	521
NCI	77%	23%	2,491

Table 17. Family Member's Activities in the Past Two Weeks Included *Unpaid Activity in a Facility-based Setting*⁶

Response options changed from previous years

State v. NCI	No	Yes	N
PA	66%	34%	497
NCI	54%	46%	2,414

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

⁵ 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.

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

Table 18. Family Member's Activities in the Past Two Weeks Included *School*

Response options changed from previous years

State v. NCI	No	Yes	N
PA	96%	4%	518
NCI	97%	3%	2,469

Table 19. Family Member's Activities in the Past Two Weeks Included *Stays at Home*

Response options changed from previous years

State v. NCI	No	Yes	N
PA	69%	31%	505
NCI	78%	22%	2,434

Table 20. Family Member's Activities in the Past Two Weeks Included *Other Activities*

Response options changed from previous years

State v. NCI	No	Yes	N
PA	47%	53%	214
NCI	59%	41%	998

Table 21. 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	None	Some	Extensive	N
PA	32%	41%	28%	549
NCI	30%	42%	29%	2,654

Table 22. 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	None	Some	Extensive	N
PA	25%	36%	39%	553
NCI	17%	39%	44%	2,666

Table 23. 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	None	Some	Extensive	N
PA	3%	22%	75%	551
NCI	2%	17%	81%	2,659

Demographics of Family Member Receiving Services

This section provides demographic information about the respondent.

Table 24. Language Spoken at Home

New question in 2018-19

State v. NCI	English	Spanish	Other	N
PA	99%	0%	1%	545
NCI	98%	0%	1%	2,664

Table 25. Respondent's Age

State v. NCI	Under 35	35-54	55-74	75 and Older	N
PA	0%	10%	65%	24%	547
NCI	4%	16%	62%	19%	2,665

Table 26. Respondent's Health

State v. NCI	Excellent	Very Good	Fairly Good	Poor	N
PA	16%	46%	36%	3%	541
NCI	16%	45%	34%	4%	2,657

Table 27. Respondent's Relationship to Family Member

State v. NCI	Parent	Sibling	Spouse	Grandparent	Public Guardian	Private Guardian	Other	N
PA	59%	31%	0%	2%	1%	1%	6%	544
NCI	51%	24%	0%	1%	11%	4%	8%	2,660

Table 28. Respondent's Frequency of Visits With Family Member Last Year

State v. NCI	Did Not Visit	1-3 Times	4-6 Times	7-12 Times	12 or More Times	N
PA	4%	8%	11%	14%	63%	547
NCI	3%	8%	21%	11%	57%	2,657

Table 29. 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%	29%	7%	19%	41%	550
NCI	3%	19%	5%	20%	52%	2,664

Table 30. 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	12%	7%	9%	17%	11%	14%	29%	457
NCI	9%	5%	7%	17%	13%	18%	31%	2,171

Services and Supports Received

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

Table 30. 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	25%	31%
In-home Support	43%	44%
Residential Supports	89%	92%
Day or Employment Supports	64%	73%
Transportation	91%	94%
Other	62%	61%
Self-direction or Fiscal Intermediary Services	23%	24%

Table 31. 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

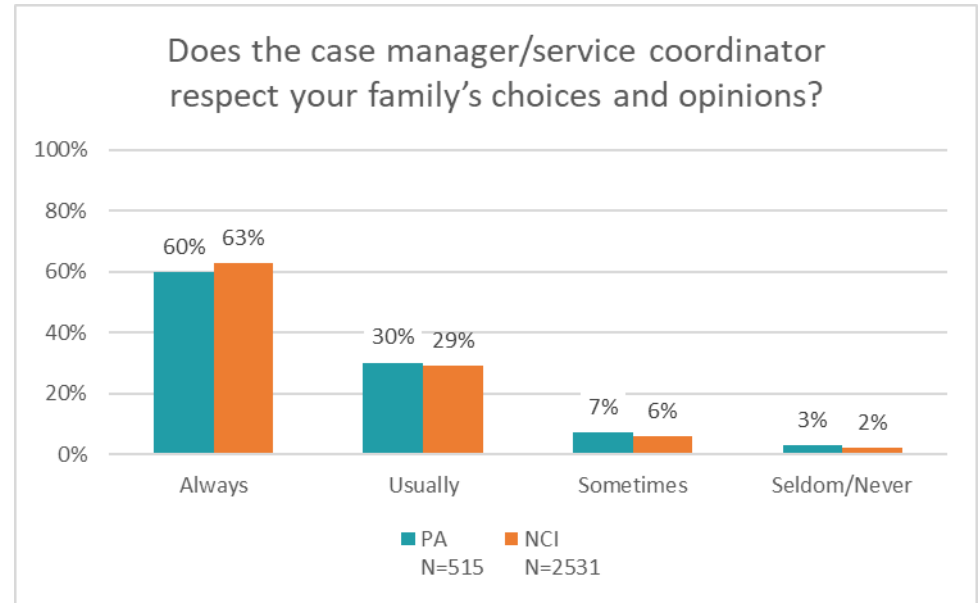
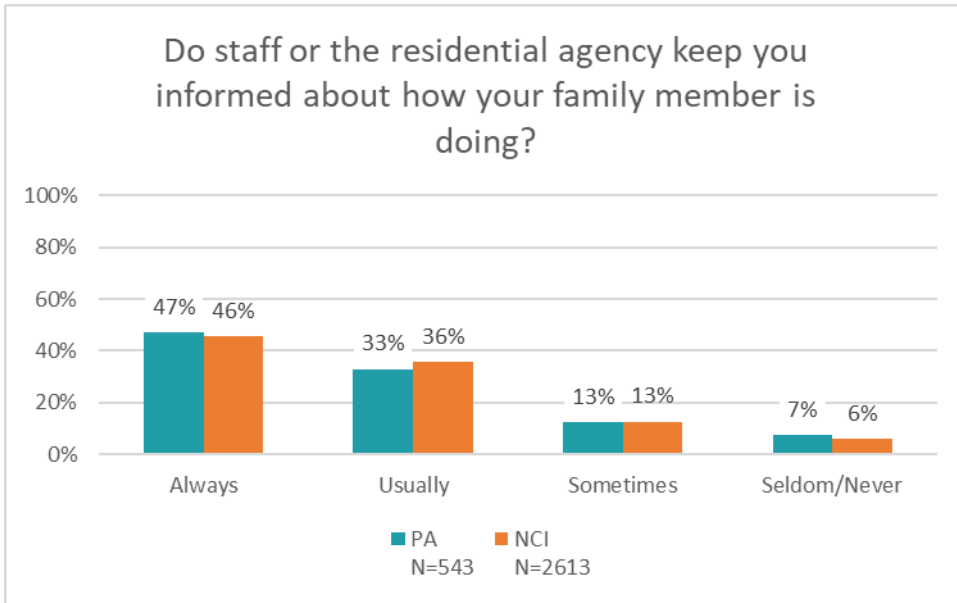
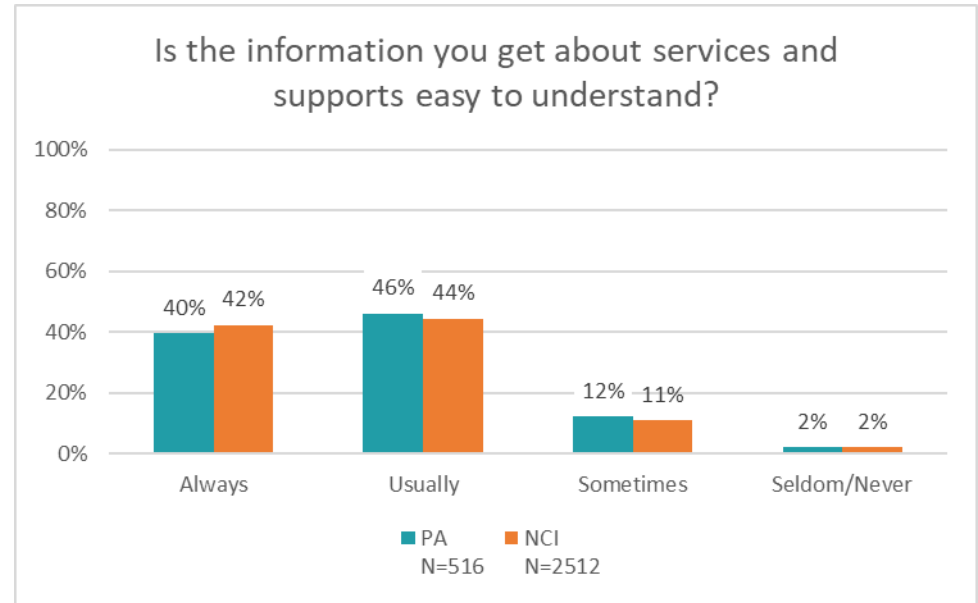
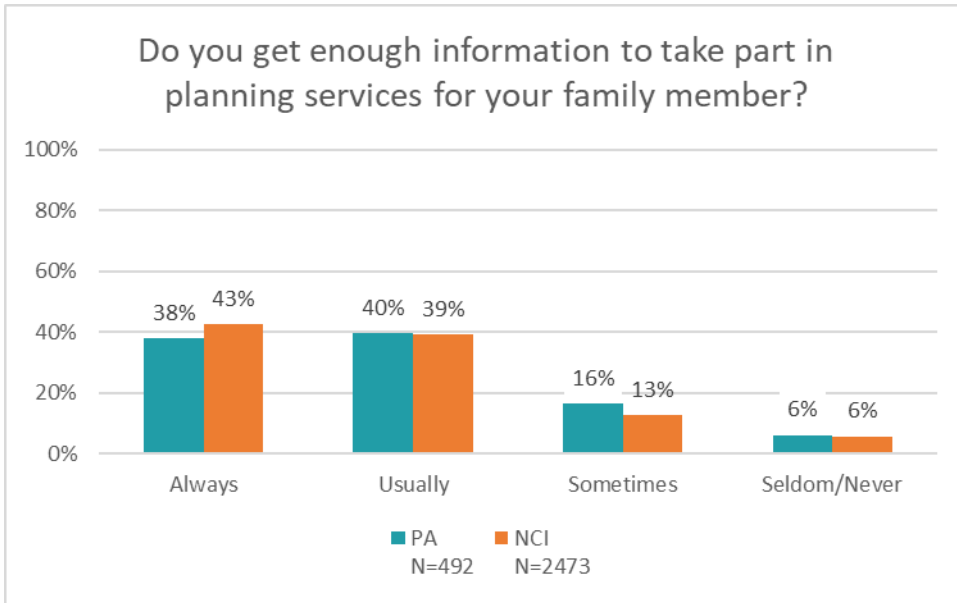
Additional Services and Supports Received	PA	NCI
Social Security Payments (SSI/SSB)	97%	96%
Services or Supports From Other Agencies or Organizations	32%	32%

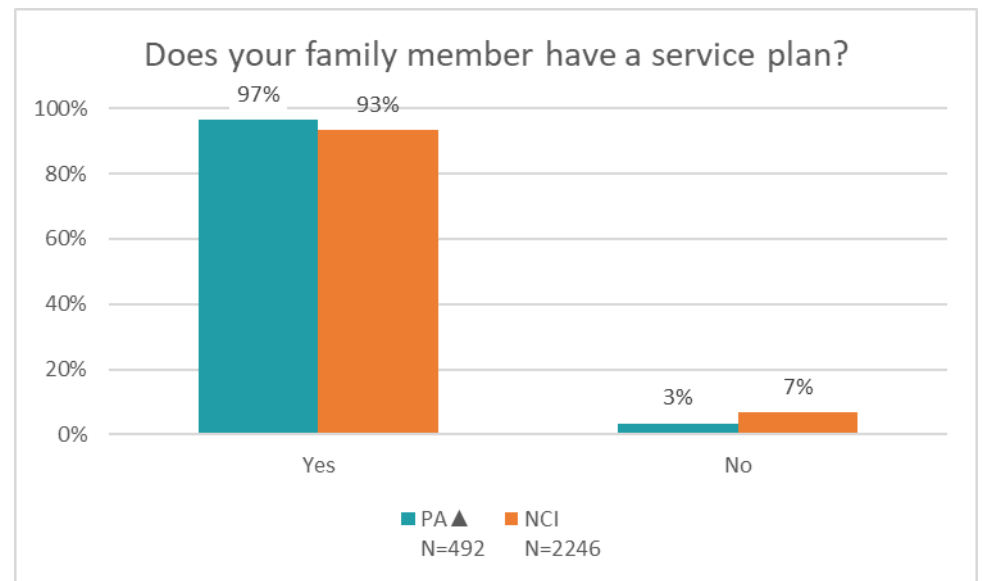
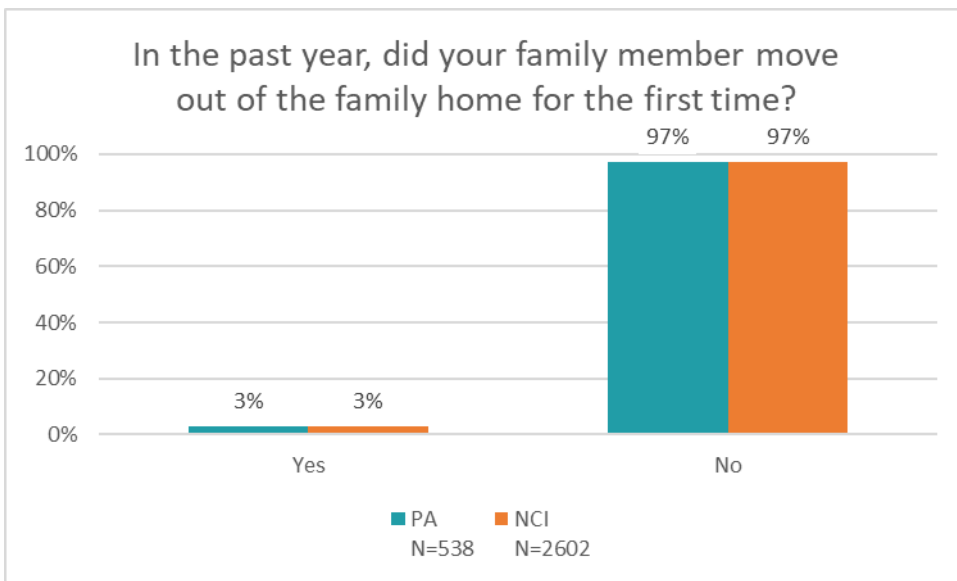
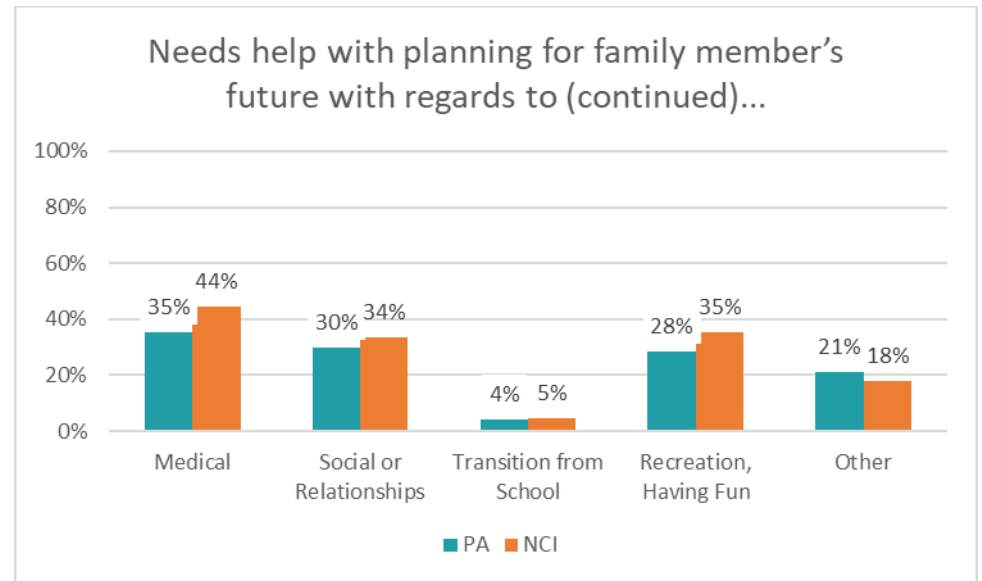
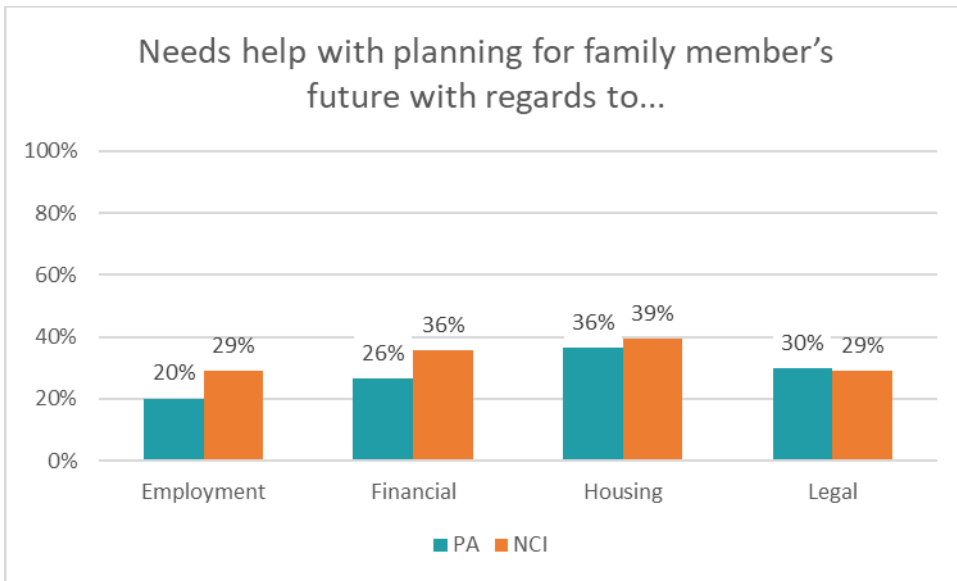
Family/Guardian Survey Results

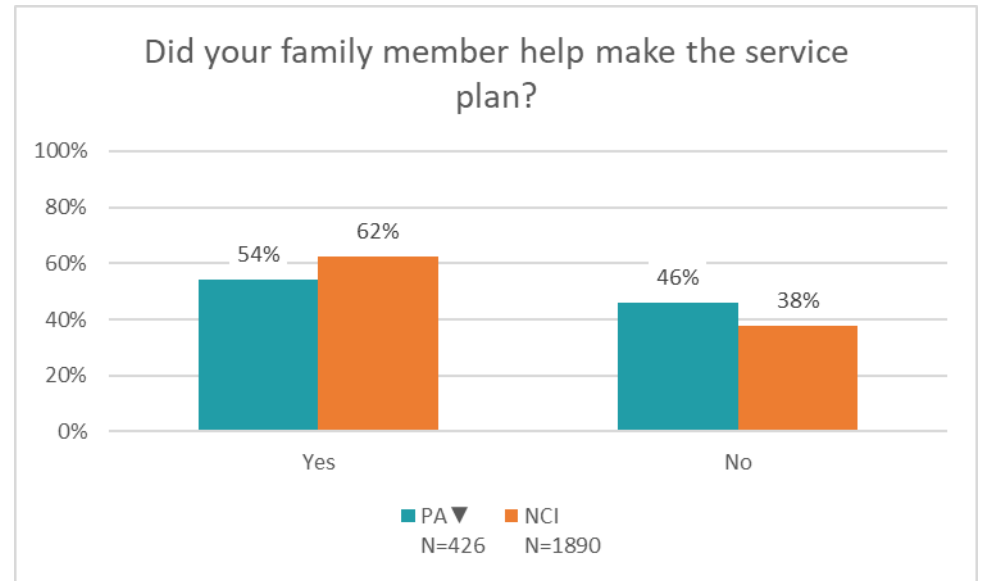
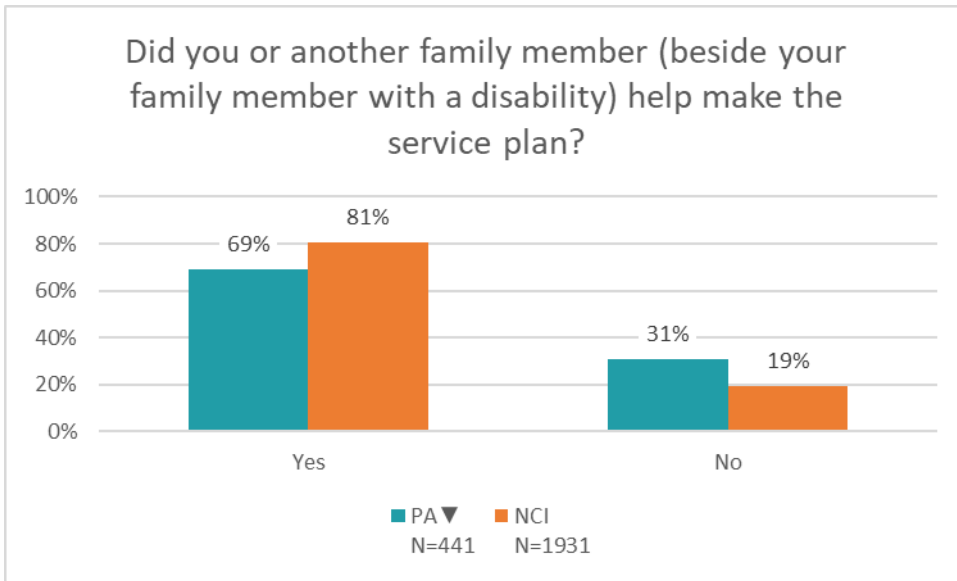
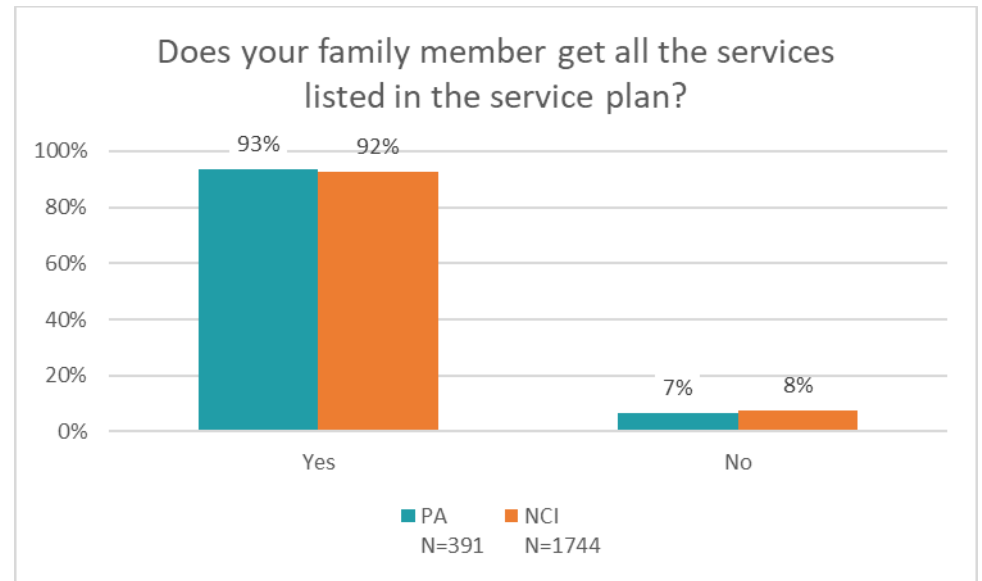
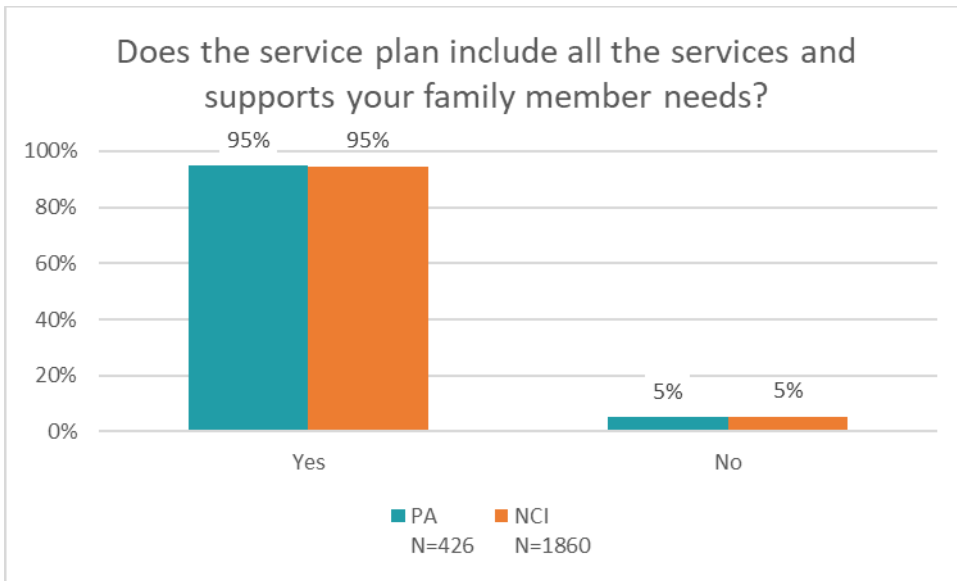
Information and Planning Charts

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

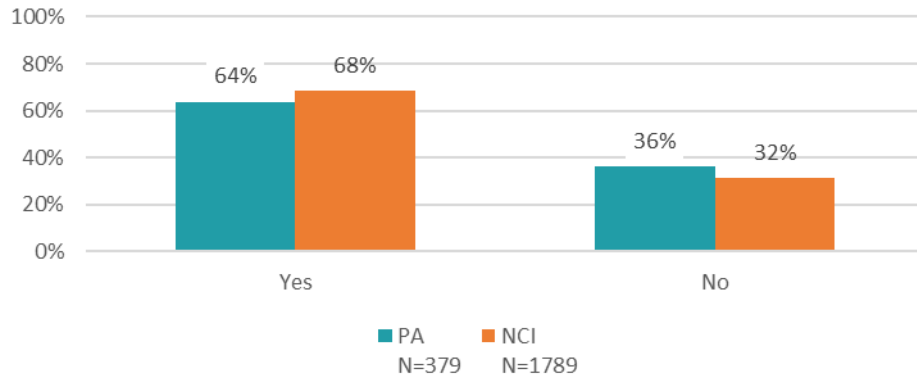
The following pages contain charts depicting the results. The same data is repeated in the tables that follow.



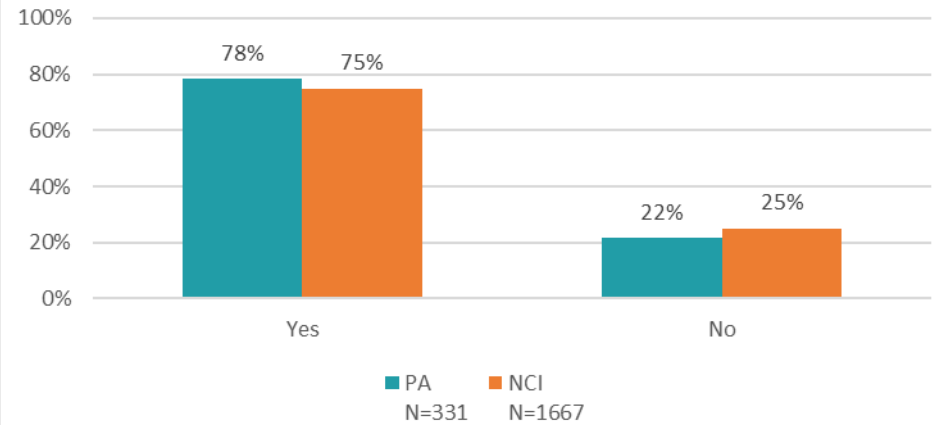




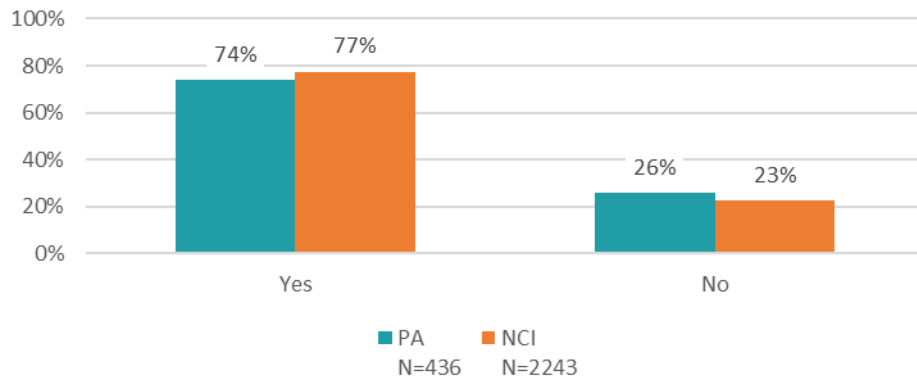
Did you discuss how to handle emergencies at your family member's last service planning meeting?



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



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



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	38%	40%	16%	6%	492
NCI	43%	39%	13%	6%	2,473

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

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	40%	46%	12%	2%	516
NCI	42%	44%	11%	2%	2,512

Table Q3. Do staff or the residential agency keep you informed about how your family member is doing?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	47%	33%	13%	7%	543
NCI	46%	36%	13%	6%	2,613

Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	60%	30%	7%	3%	515
NCI	63%	29%	6%	2%	2,531

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	20%	29%
Financial	26%	36%
Housing	36%	39%
Legal	30%	29%
Medical	35%	44%
Social or Relationships	30%	34%
Transition from School	4%	5%
Recreation, Having Fun	28%	35%
Other	21%	18%

Table Q6. In the past year, did your family member move out of the family home for the first time?

State v. NCI	Yes	No	N
PA	3%	97%	538
NCI	3%	97%	2,602

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

State v. NCI	Yes	No	N
PA▲	97%	3%	492
NCI	93%	7%	2,246

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

State v. NCI	Yes	No	N
PA	95%	5%	426
NCI	95%	5%	1,860

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

State v. NCI	Yes	No	N
PA	93%	7%	391
NCI	92%	8%	1,744

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 ▼	69%	31%	441
NCI	81%	19%	1,931

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

State v. NCI	Yes	No	N
PA ▼	54%	46%	426
NCI	62%	38%	1,890

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	64%	36%	379
NCI	68%	32%	1,789

Table Q13. 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	78%	22%	331
NCI	75%	25%	1,667

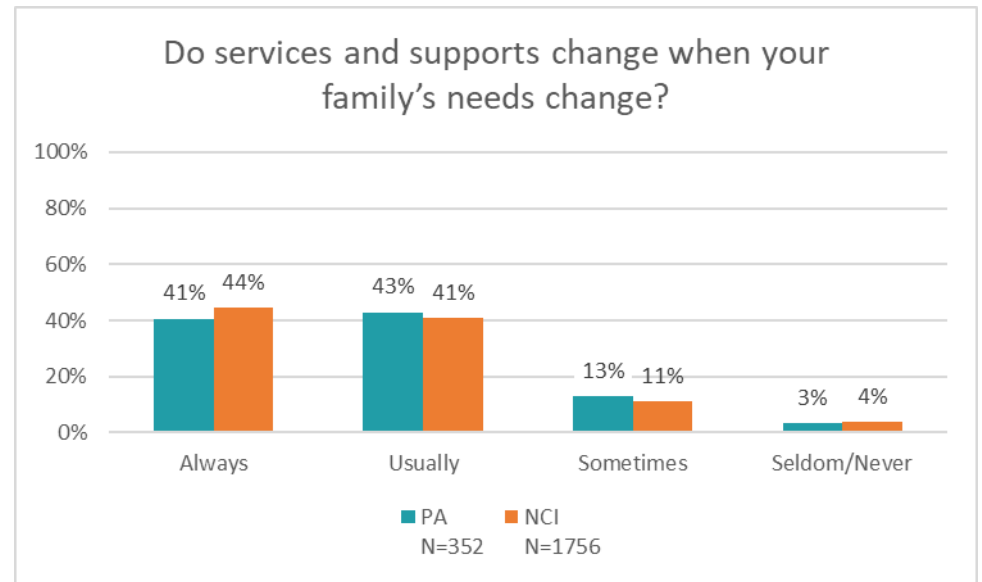
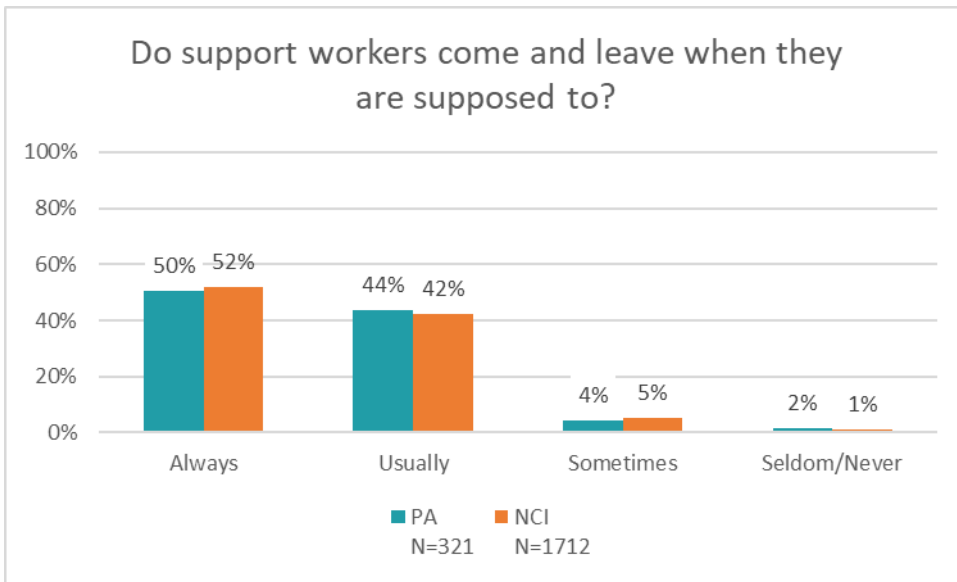
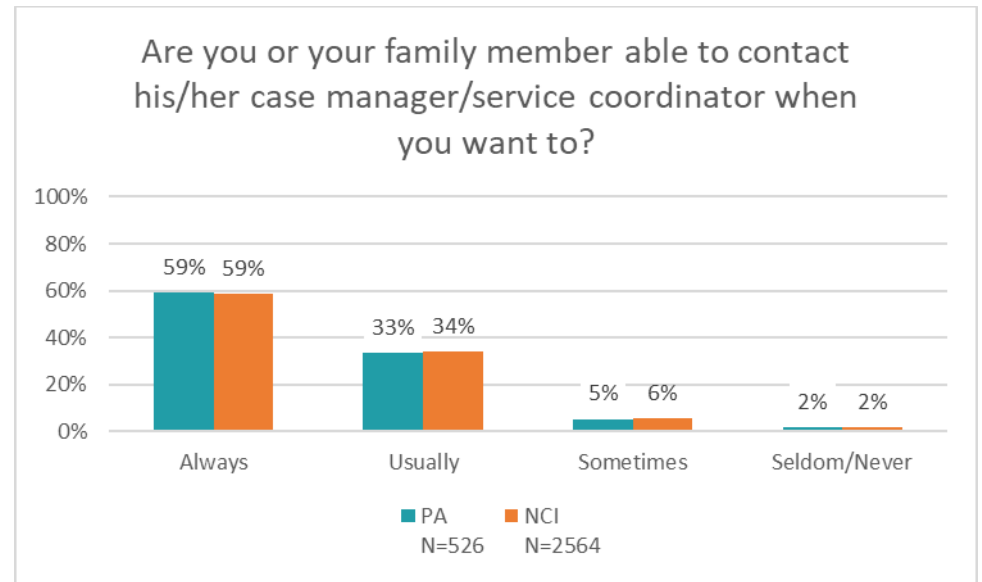
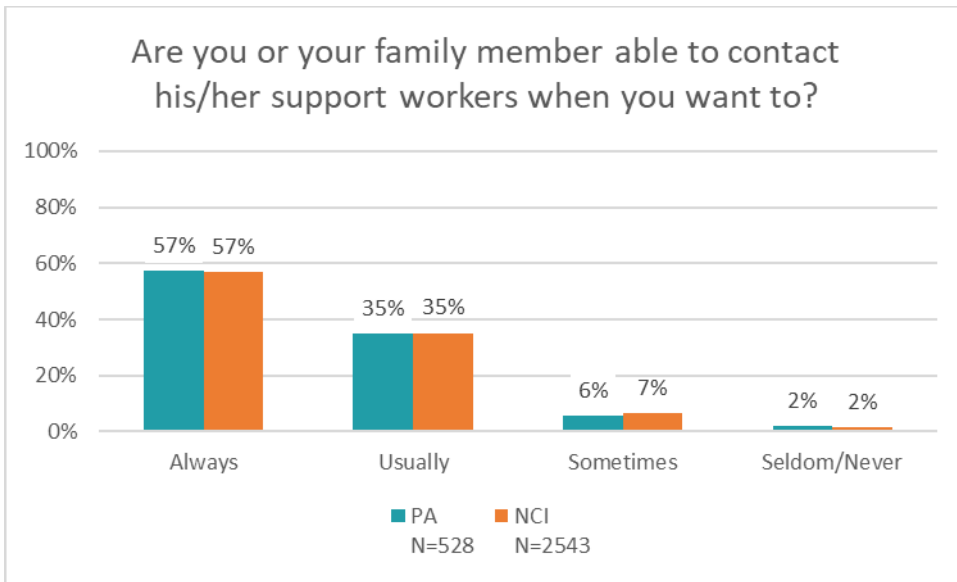
Table Q14. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

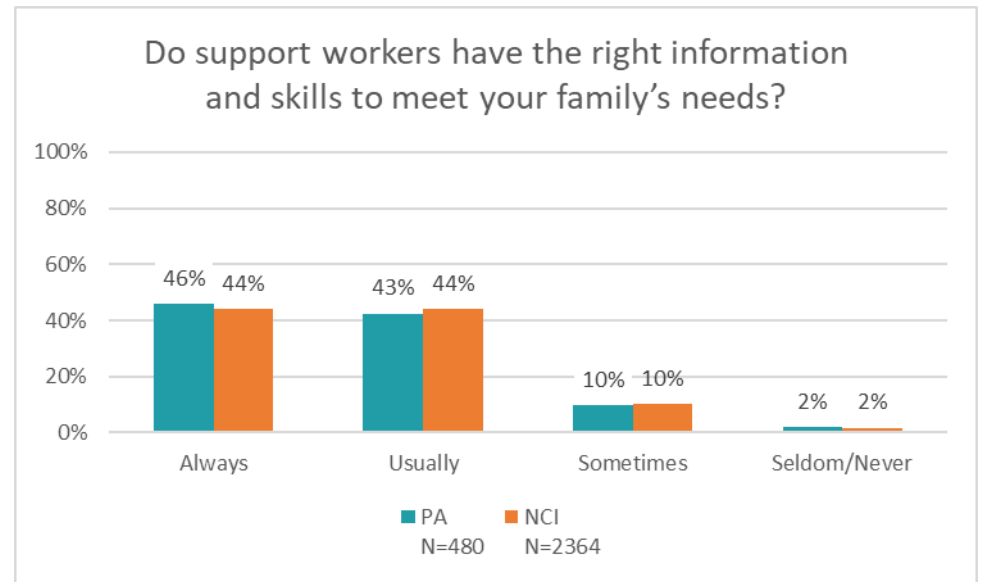
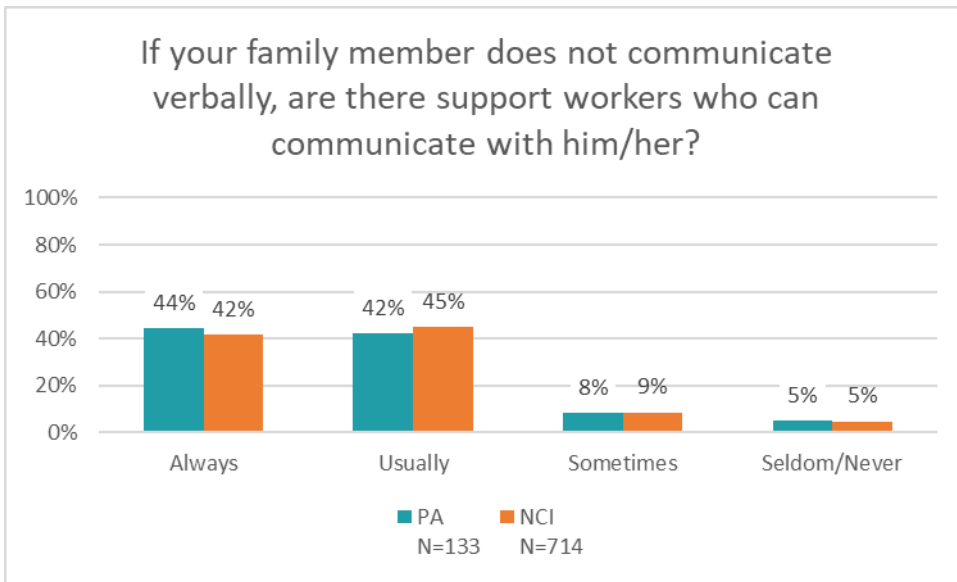
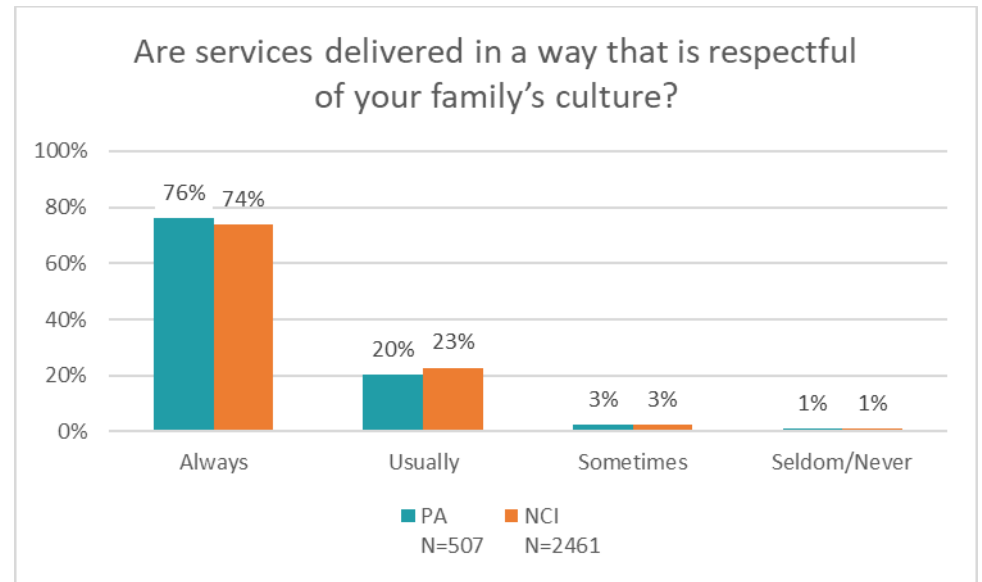
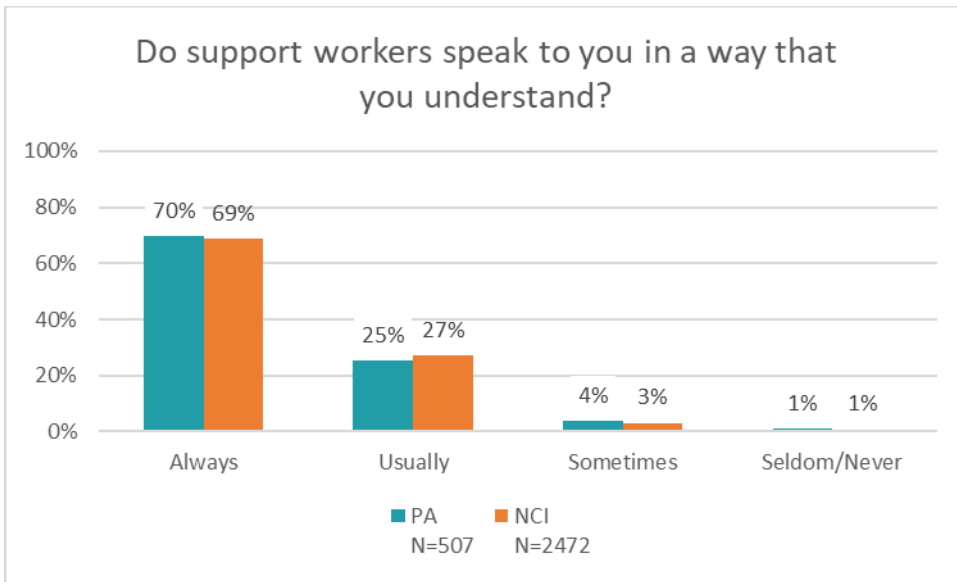
State v. NCI	Yes	No	N
PA	74%	26%	436
NCI	77%	23%	2,243

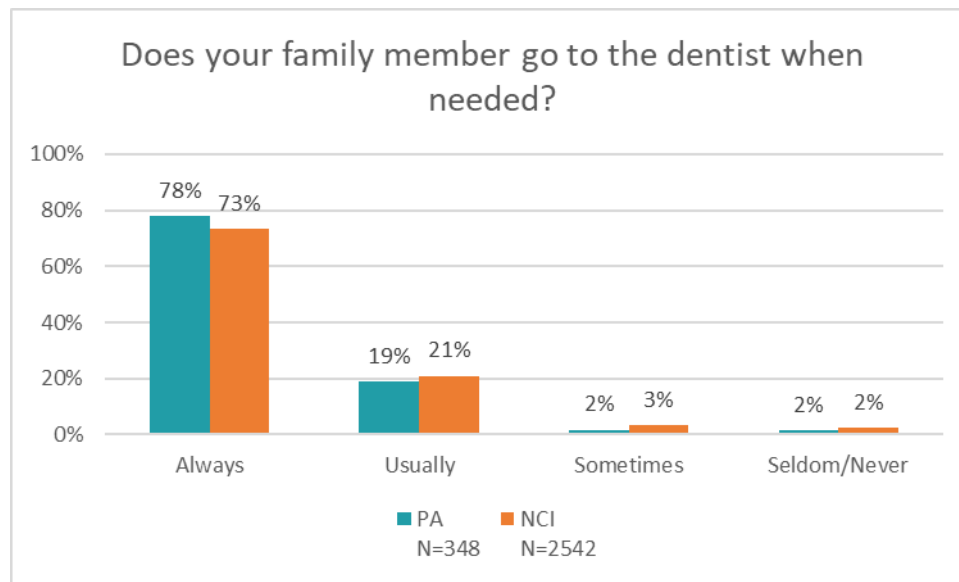
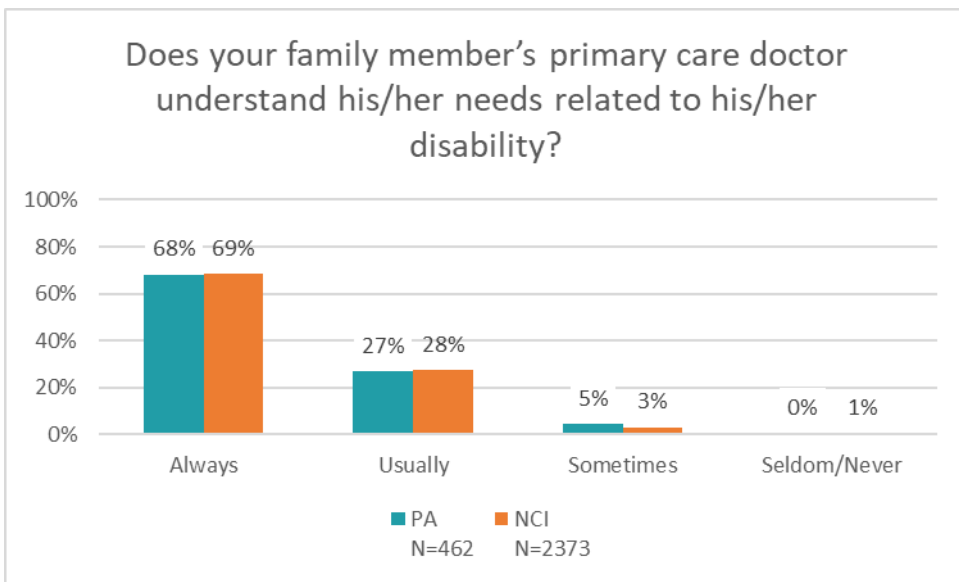
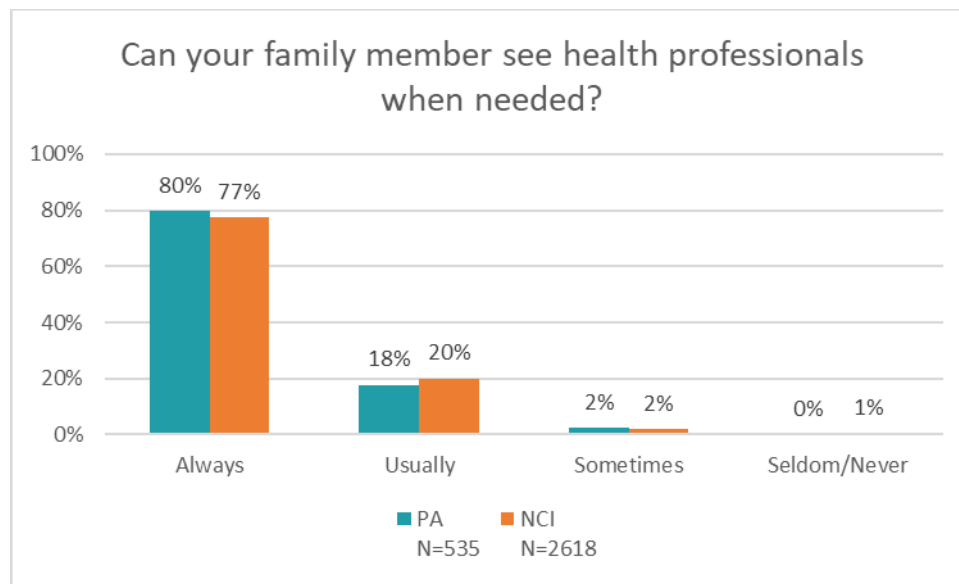
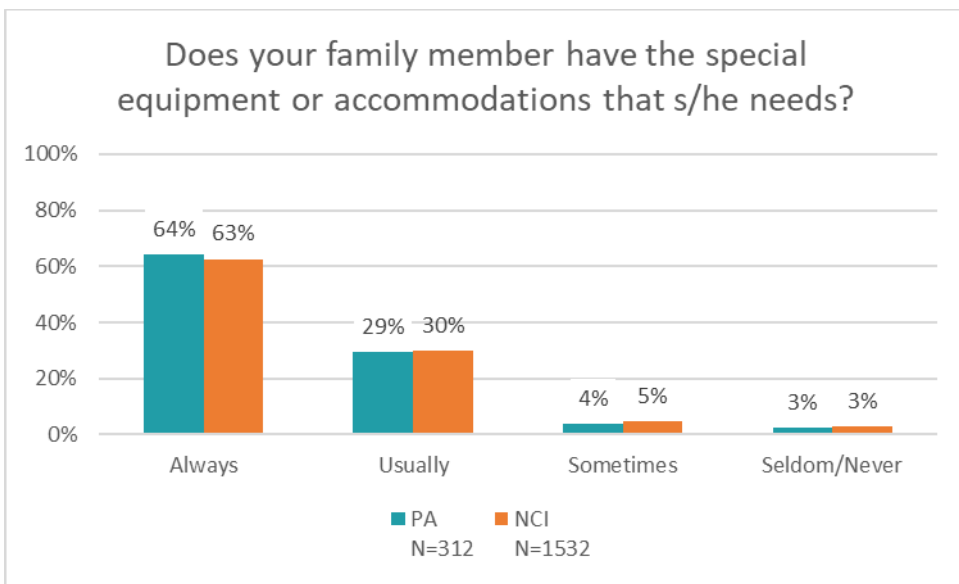
Access and Delivery of Services and Supports Charts

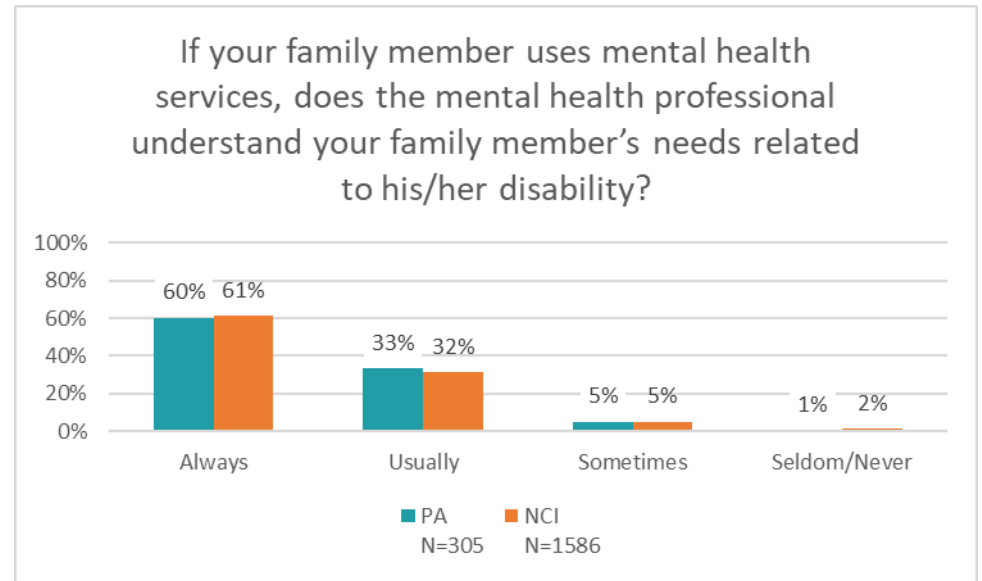
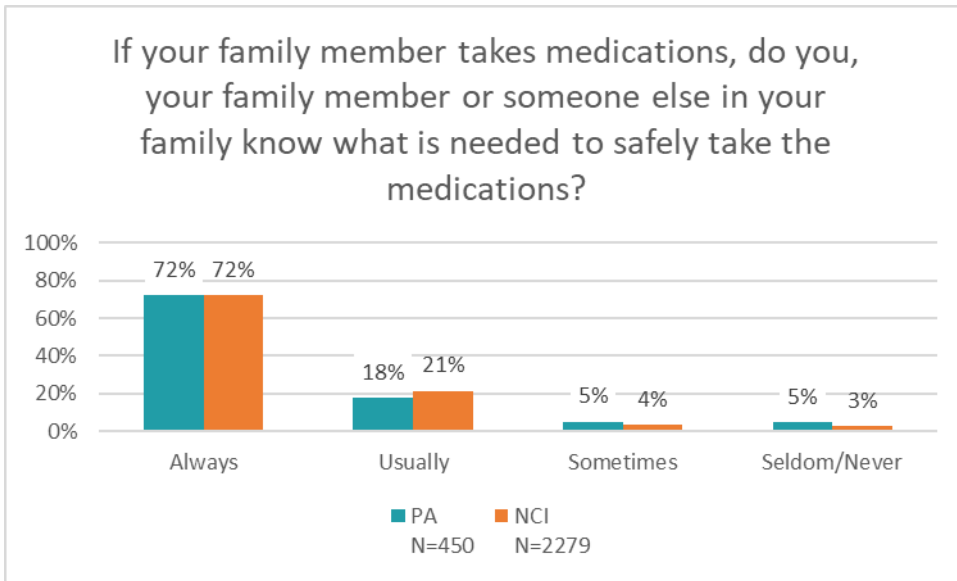
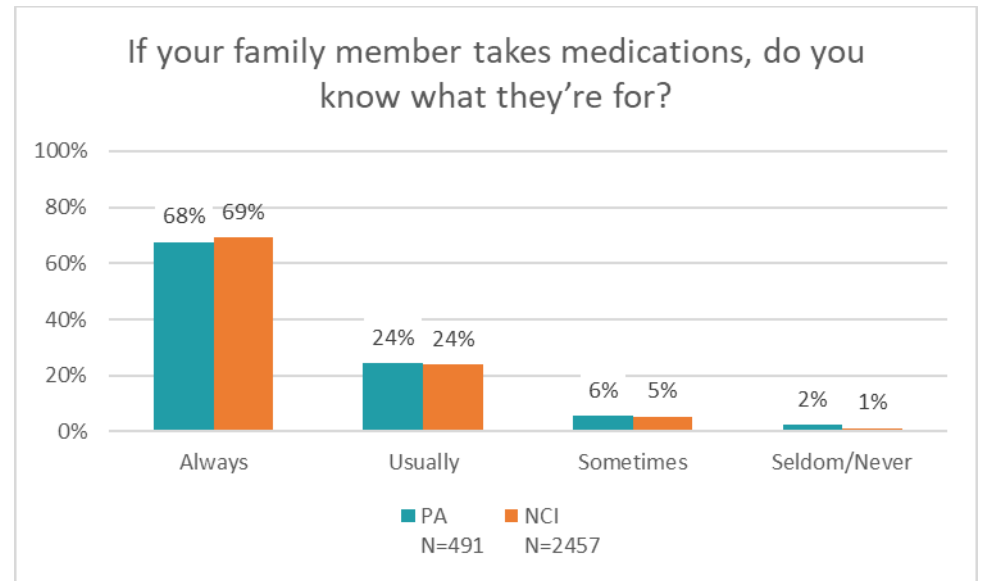
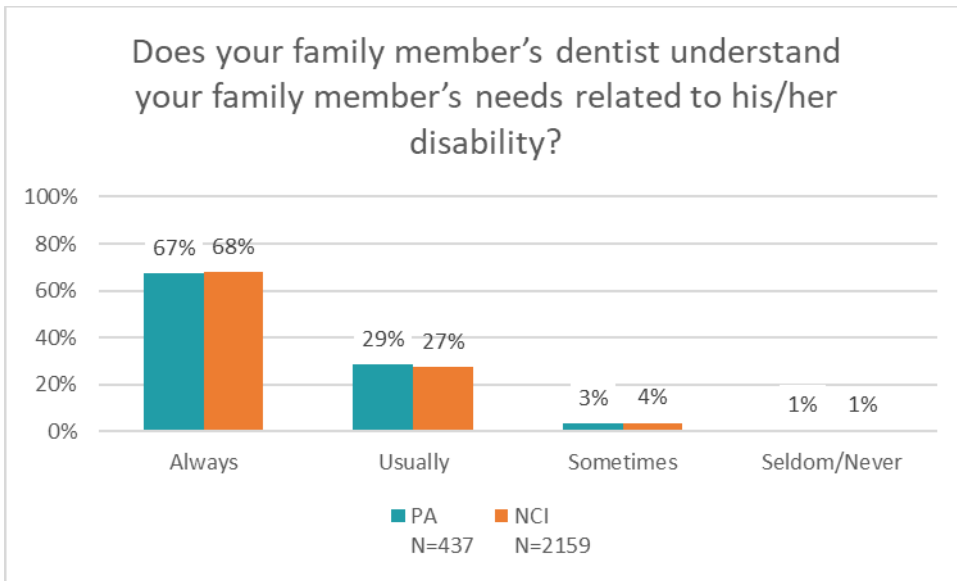
Families and family members with disabilities get the services and supports they need.

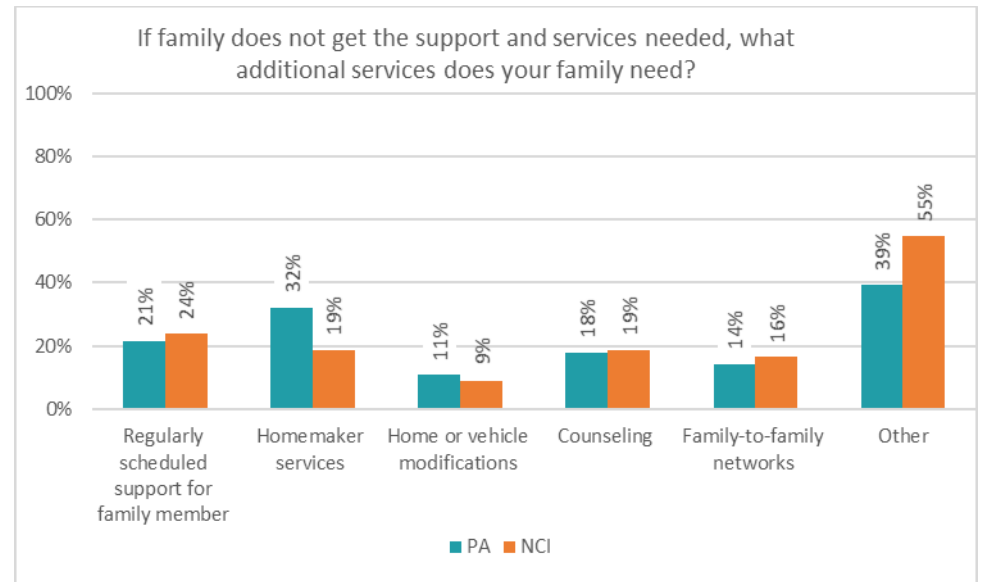
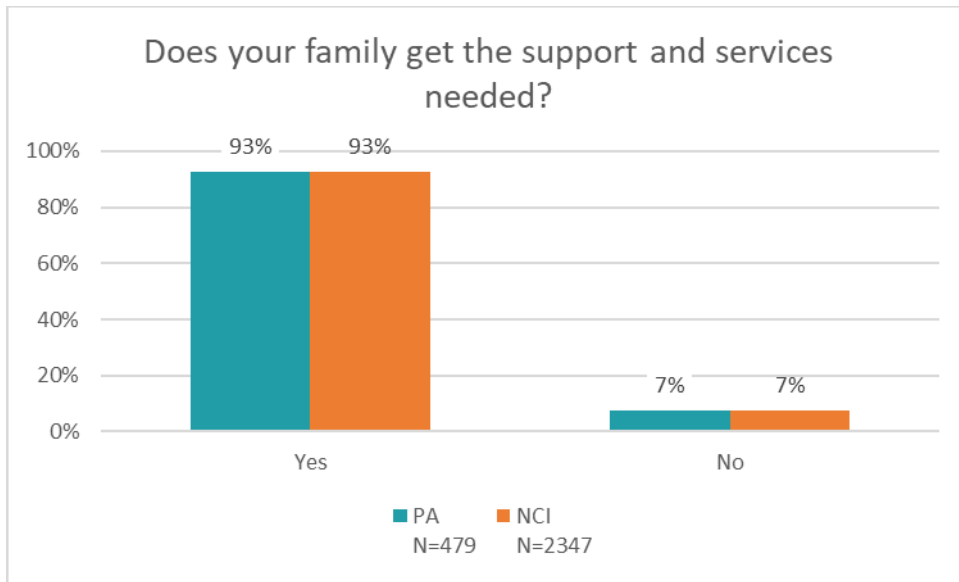
The following pages contain charts depicting the results. The same data is repeated in the tables that follow.











Access and Delivery of Services and Supports Tables

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

Table Q15. Are you or your family member able to contact his/her support workers when you want to?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	57%	35%	6%	2%	528
NCI	57%	35%	7%	2%	2,543

Table Q16. Are you or your family member able to contact his/her case manager/service coordinator when you want to?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	59%	33%	5%	2%	526
NCI	59%	34%	6%	2%	2,564

Table Q17. Do support workers come and go when they are supposed to?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	50%	44%	4%	2%	321
NCI	52%	42%	5%	1%	1,712

Table Q18. Do services and supports change when your family's needs change?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	41%	43%	13%	3%	352
NCI	44%	41%	11%	4%	1,756

Table Q19. Do support workers speak to you in a way you understand?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	70%	25%	4%	1%	507
NCI	69%	27%	3%	1%	2,472

Table Q20. Are services delivered in a way that is respectful of your family's culture?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	76%	20%	3%	1%	507
NCI	74%	23%	3%	1%	2,461

Table Q21. 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	44%	42%	8%	5%	133
NCI	42%	45%	9%	5%	714

Table Q22. 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	46%	43%	10%	2%	480
NCI	44%	44%	10%	2%	2,364

Table Q23. Does your family member have the special equipment or accommodations that s/he needs?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	64%	29%	4%	3%	312
NCI	63%	30%	5%	3%	1,532

Table Q24. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	80%	18%	2%	0%	535
NCI	77%	20%	2%	1%	2,618

Table Q25. 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%	27%	5%	0%	462
NCI	69%	28%	3%	1%	2,373

Table Q26. 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	78%	19%	2%	2%	348
NCI	73%	21%	3%	2%	2,542

Table Q27. 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	67%	29%	3%	1%	437
NCI	68%	27%	4%	1%	2,159

Table Q28. If your family member takes medications, do you know what they're for?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	68%	24%	6%	2%	491
NCI	69%	24%	5%	1%	2,457

Table Q29. 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	72%	18%	5%	5%	450
NCI	72%	21%	4%	3%	2,279

Table Q30. 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%	33%	5%	1%	305
NCI	61%	32%	5%	2%	1,586

Table Q31. Does your family get the supports and services it needs?

State v. NCI	Yes	No	N
PA	93%	7%	479
NCI	93%	7%	2,347

Table Q32. If your family does not get the support and services needed, what additional services does your family need?

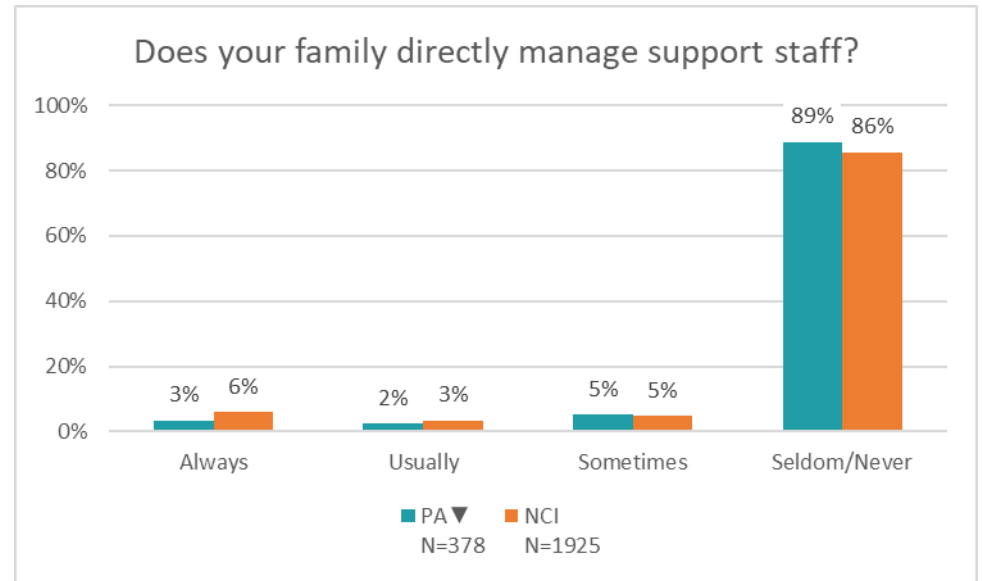
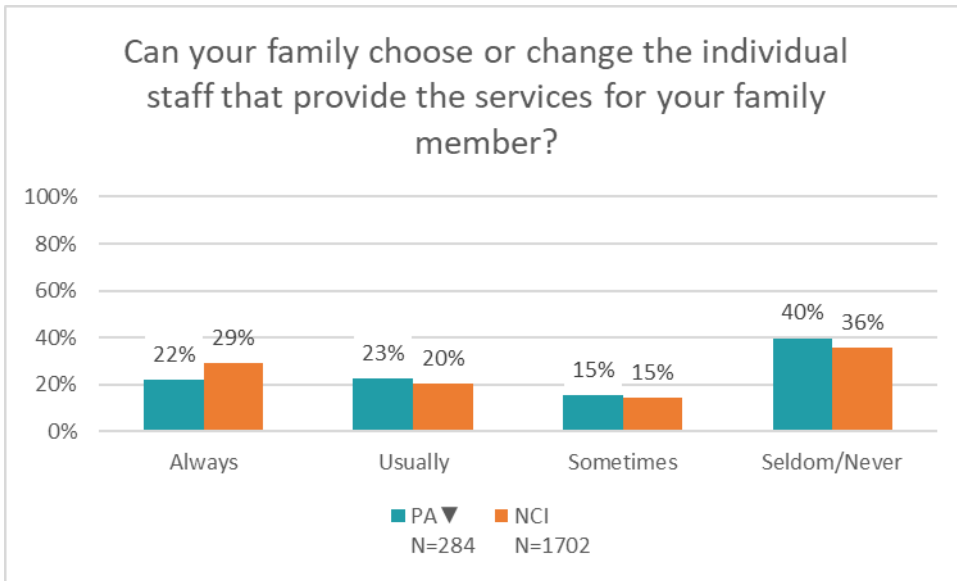
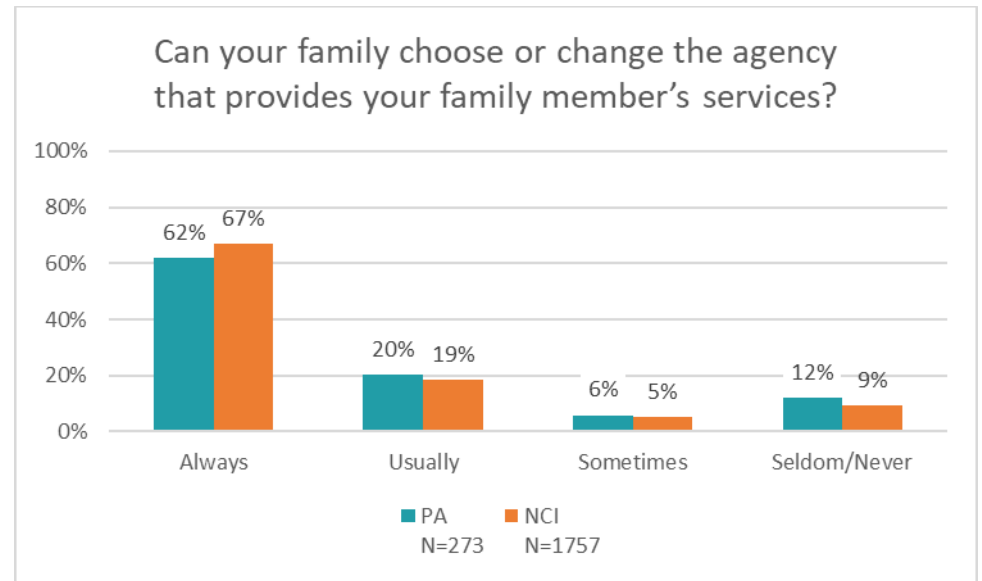
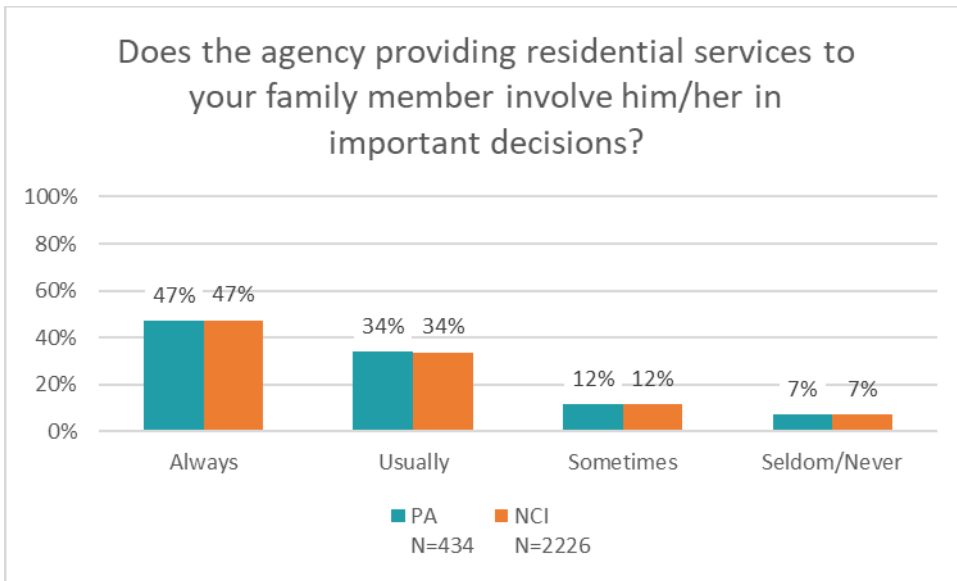
Categories are not mutually exclusive, therefore N is not shown

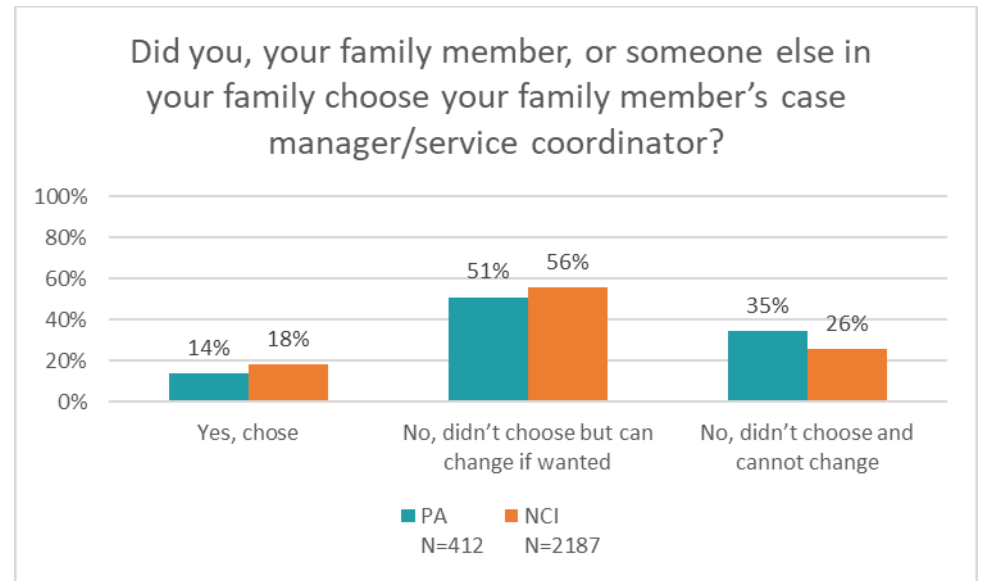
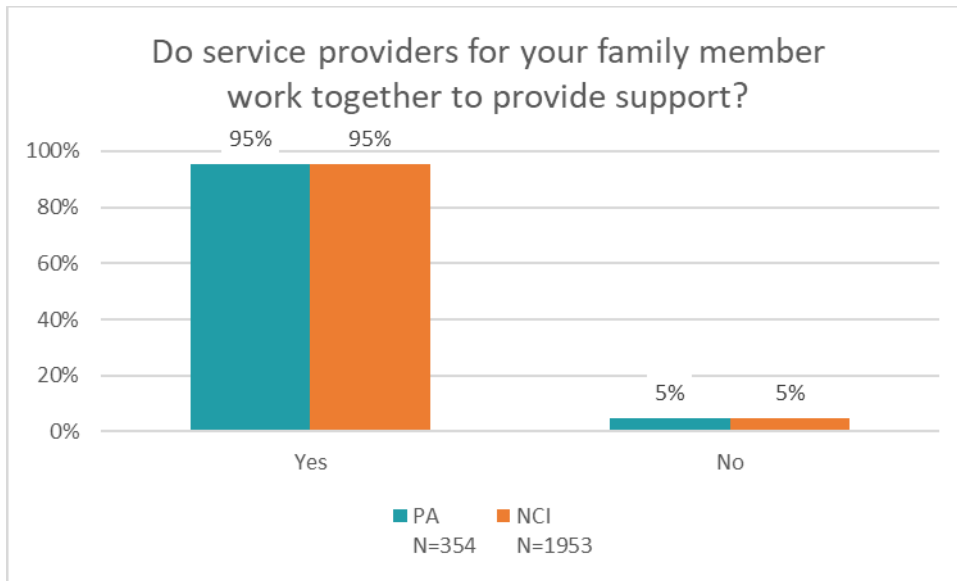
Additional services needed...	PA	NCI
Regularly scheduled support for family member	21%	24%
Homemaker services	32%	19%
Home or vehicle modifications	11%	9%
Counseling	18%	19%
Family-to-family networks	14%	16%
Other	39%	55%

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 is repeated in the 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 Q33. Does the agency providing residential services to your family member involve him/her in important decisions?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	47%	34%	12%	7%	434
NCI	47%	34%	12%	7%	2,226

Table Q34. 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	62%	20%	6%	12%	273
NCI	67%	19%	5%	9%	1,757

Table Q35. Can your family choose or change the individual staff that provide the services for your family member?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA ▼	22%	23%	15%	40%	284
NCI	29%	20%	15%	36%	1,702

Table Q36. Does your family directly manage support staff?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA ▼	3%	2%	5%	89%	378
NCI	6%	3%	5%	86%	1,925

Table Q37. Do service providers for your family member work together to provide support?

State v. NCI	Yes	No	N
PA	95%	5%	354
NCI	95%	5%	1,953

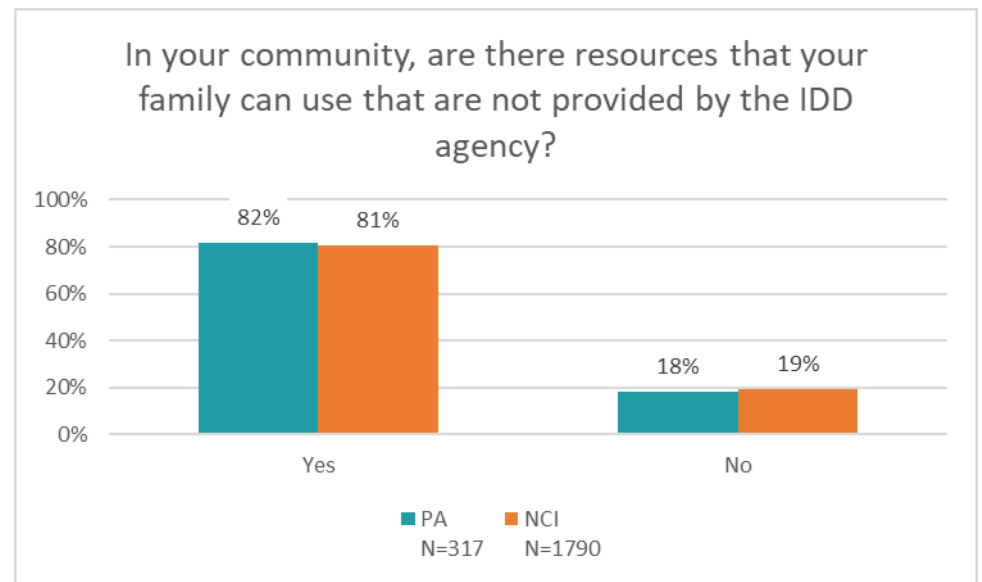
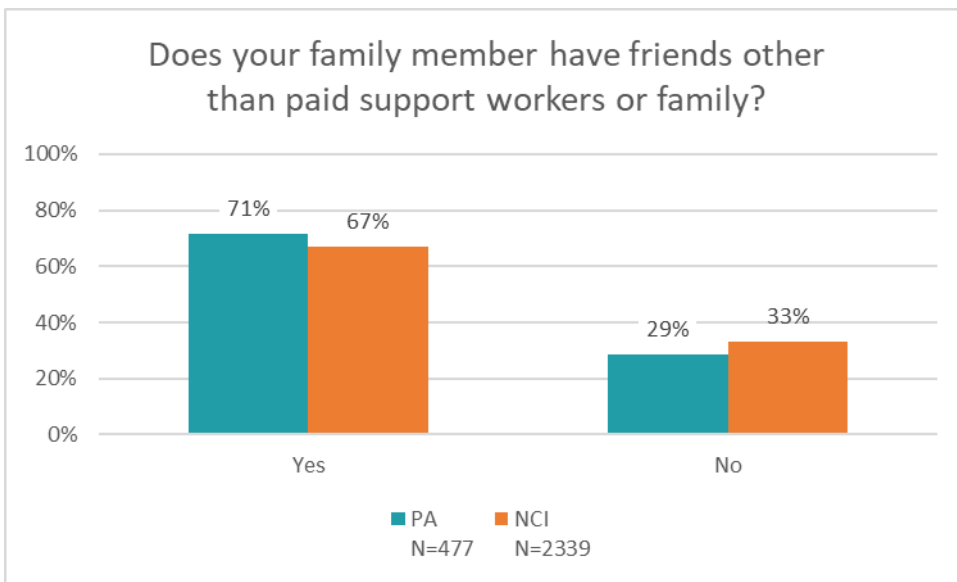
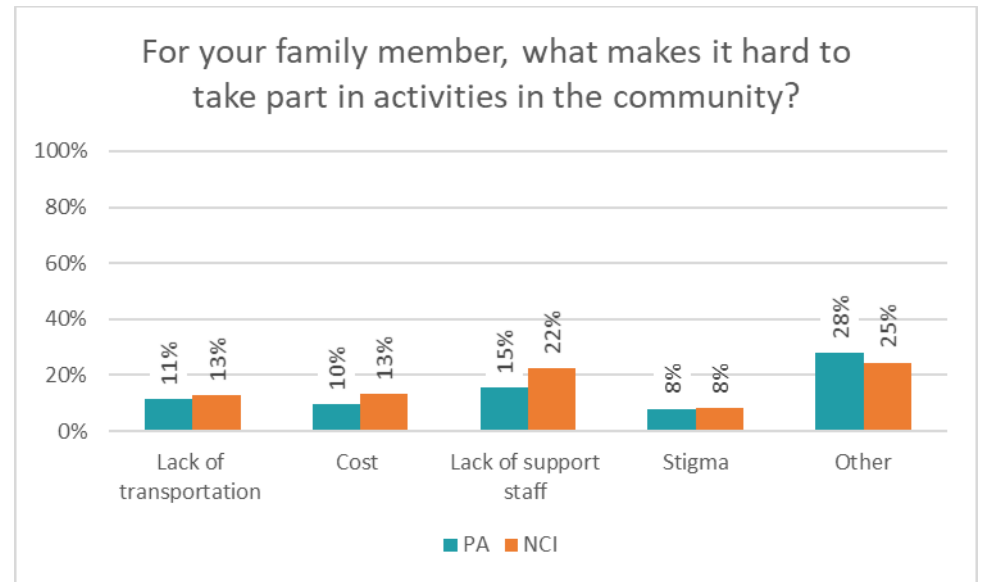
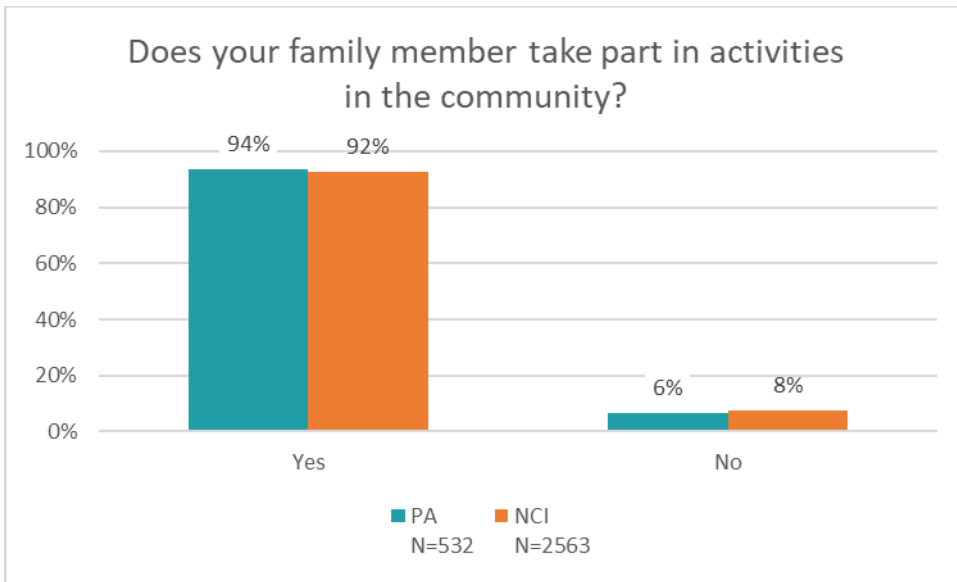
Table Q38. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

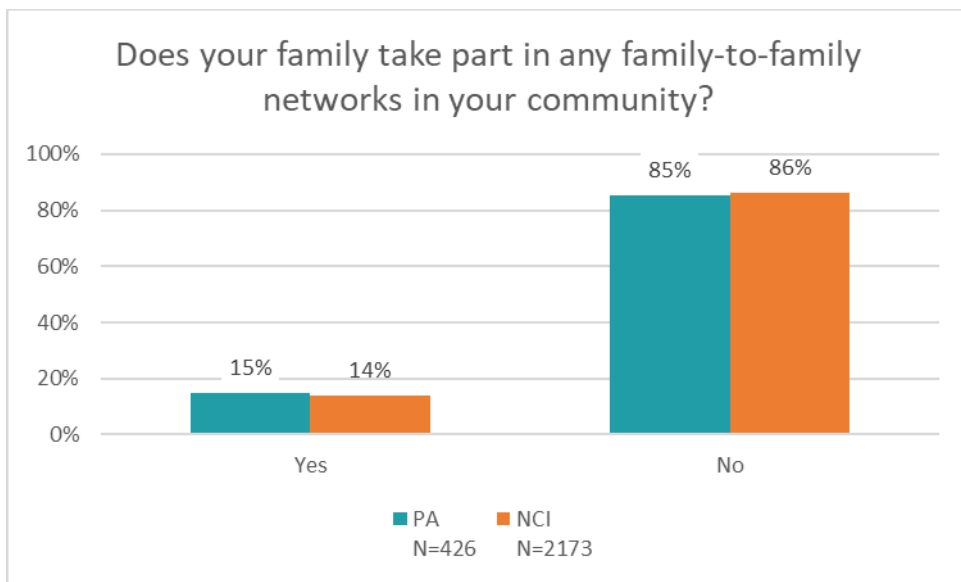
Chose case manager...	PA	PA N	NCI	NCI N
Yes, chose case manager/service coordinator	14%	412	18%	2,187
No, didn't choose case manager/service coordinator but can change case manager/service coordinator if wanted	51%	412	56%	2,187
No, didn't choose case manager/service coordinator and cannot change case manager/service coordinator if wanted	35%	412	26%	2,187

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 is repeated in the tables that follow.





Involvement in the Community Tables

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

Table Q39. Does your family member take part in activities in the community?

State v. NCI	Yes	No	N
PA	94%	6%	532
NCI	92%	8%	2,563

Table Q40. For your family member, what makes it hard to take part in activities in the community?

Question is rephrased from previous years

Obstacles or barriers...	PA	NCI
Lack of transportation	11%	13%
Cost	10%	13%
Lack of support staff	15%	22%
Stigma	8%	8%
Other	28%	25%

Table Q41. Does your family member have friends other than paid support workers or family?

State v. NCI	Yes	No	N
PA	71%	29%	477
NCI	67%	33%	2,339

Table Q42. In your community, are there resources that your family can use that are not provided by the IDD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?

State v. NCI	Yes	No	N
PA	82%	18%	317
NCI	81%	19%	1,790

Table Q43. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?

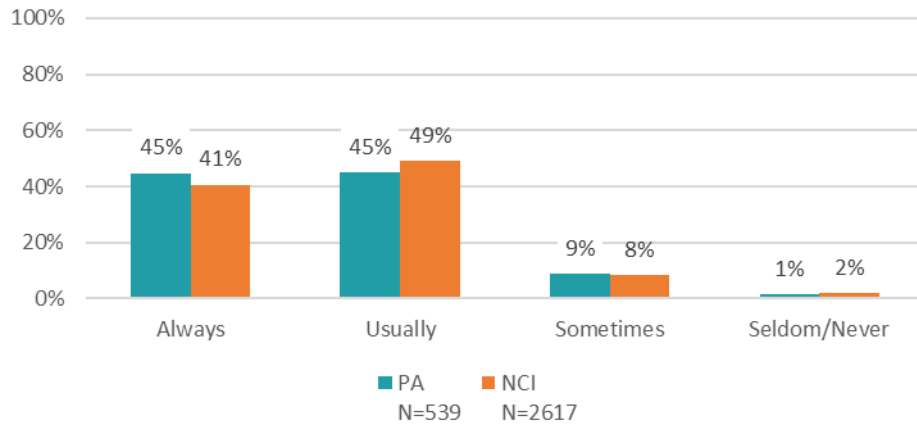
State v. NCI	Yes	No	N
PA	15%	85%	426
NCI	14%	86%	2,173

Satisfaction With Services and Supports Charts

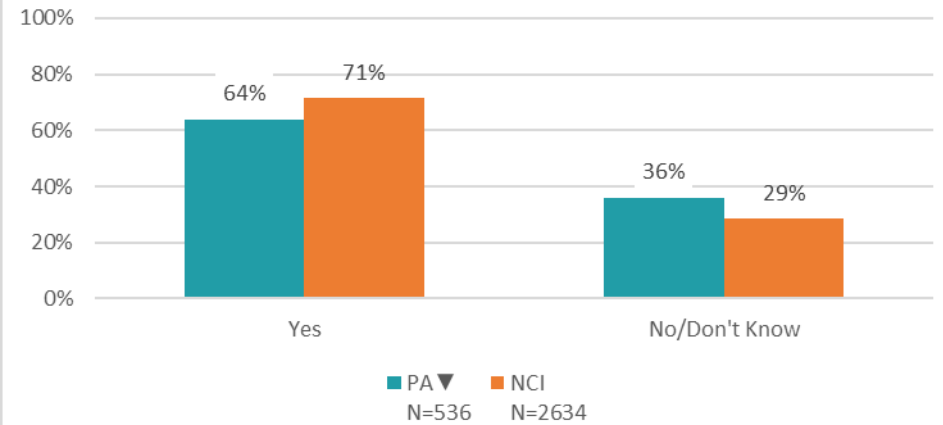
Families and family members with disabilities receive adequate and satisfactory supports.

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

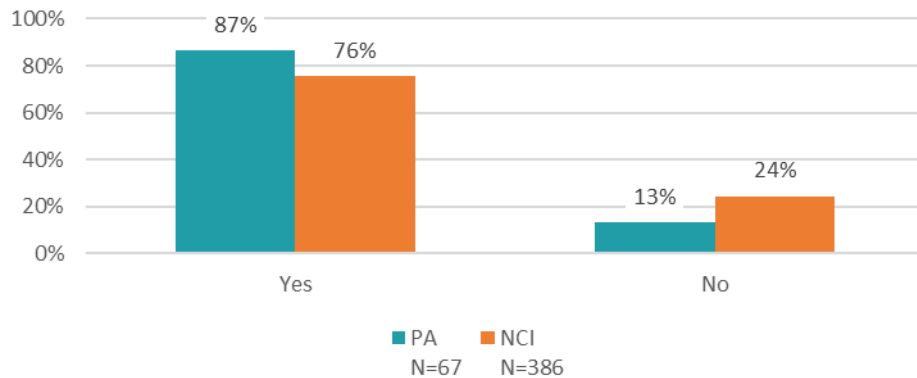
Overall, are you satisfied with the services and supports your family member currently receives?



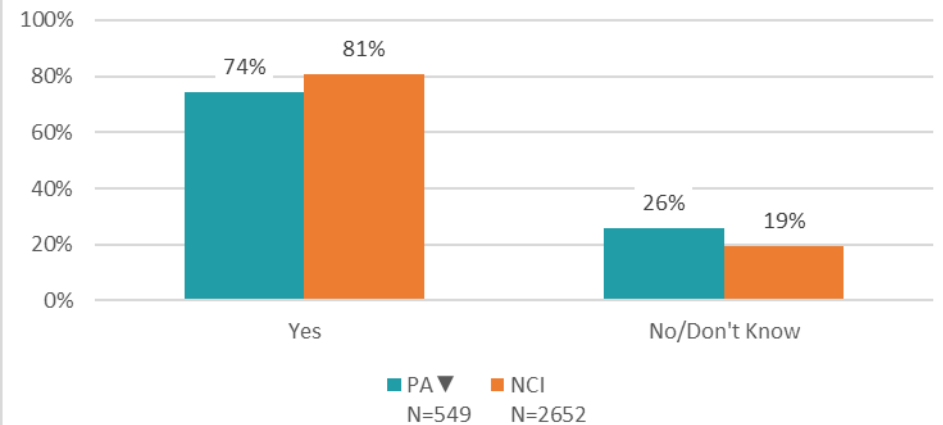
Do you know how to file a complaint or grievance about provider agencies or staff?

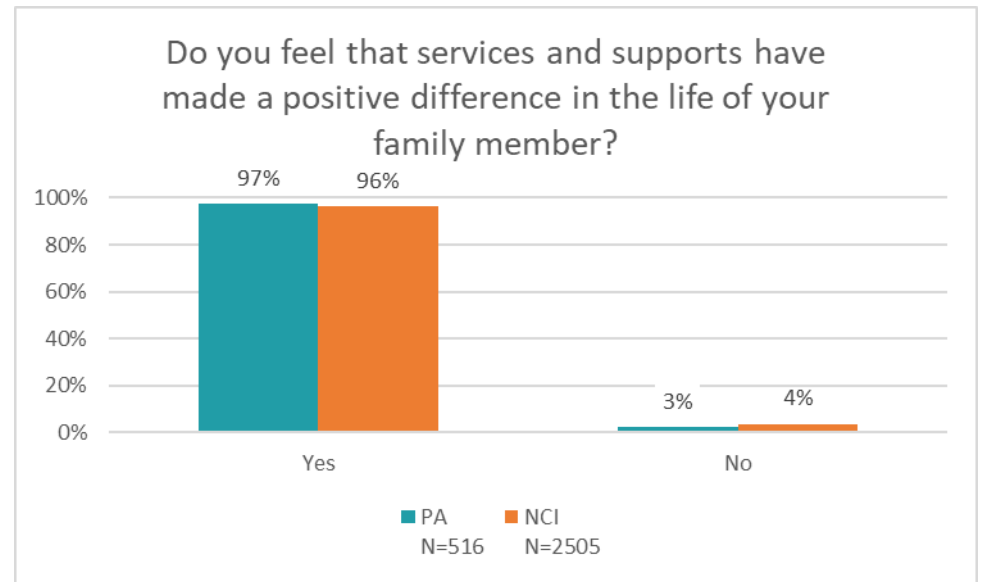
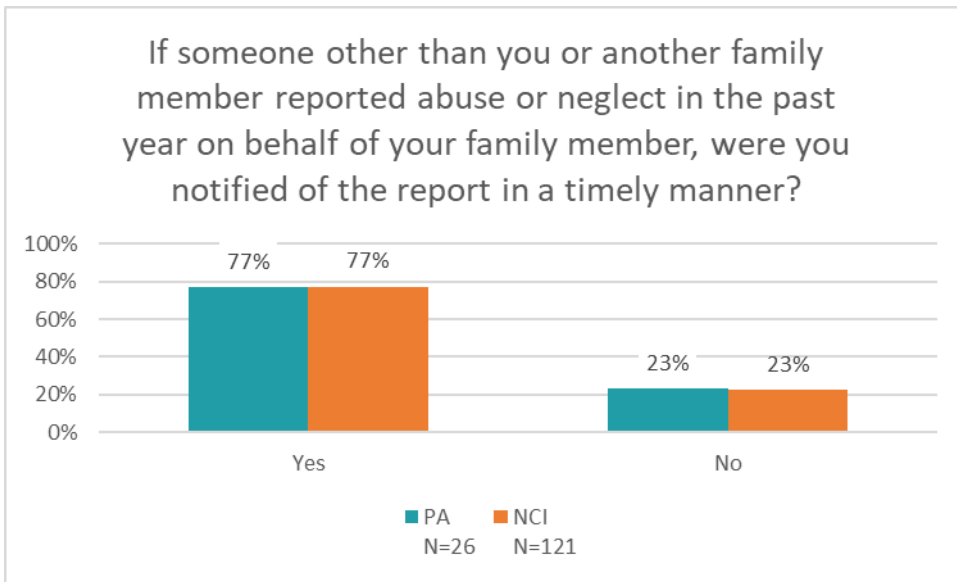
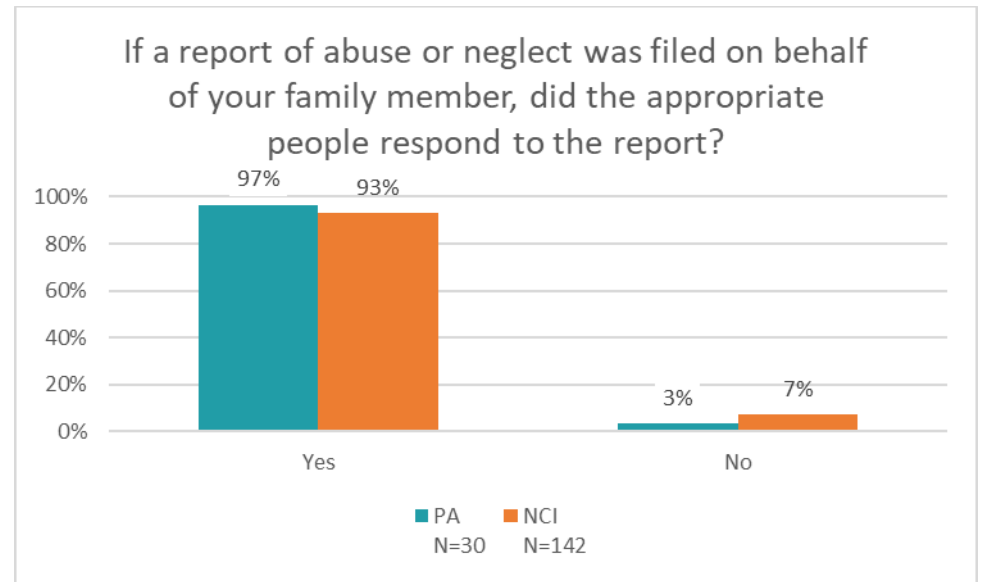
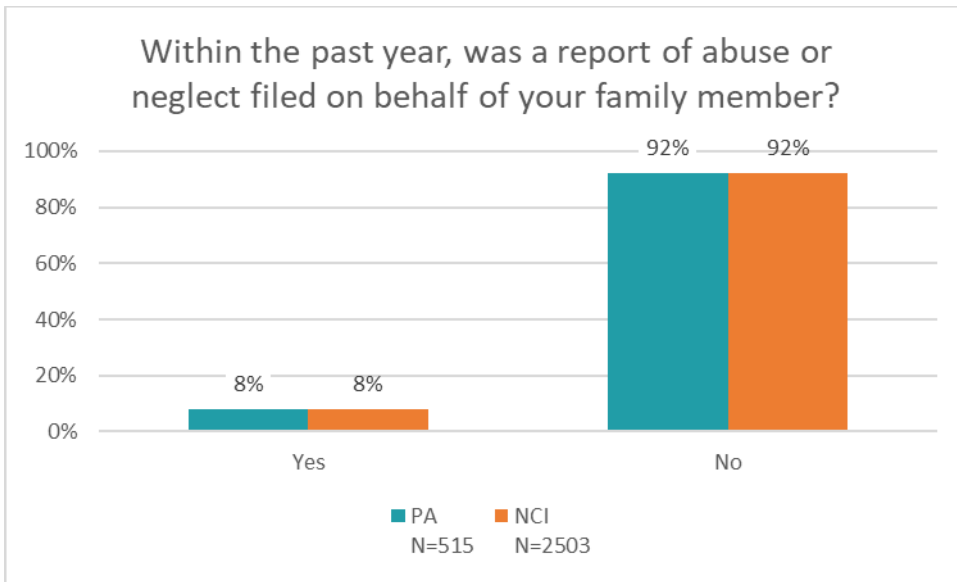


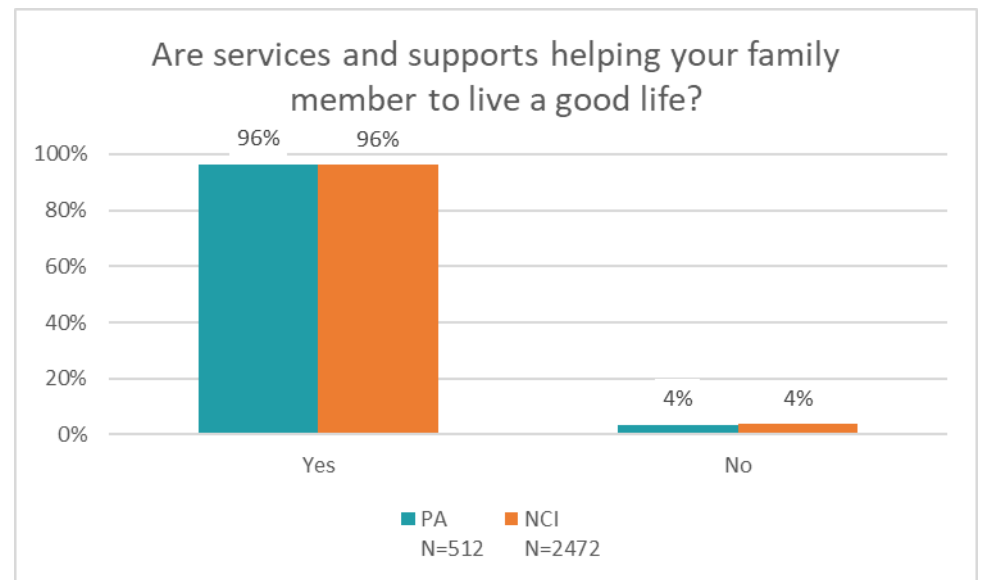
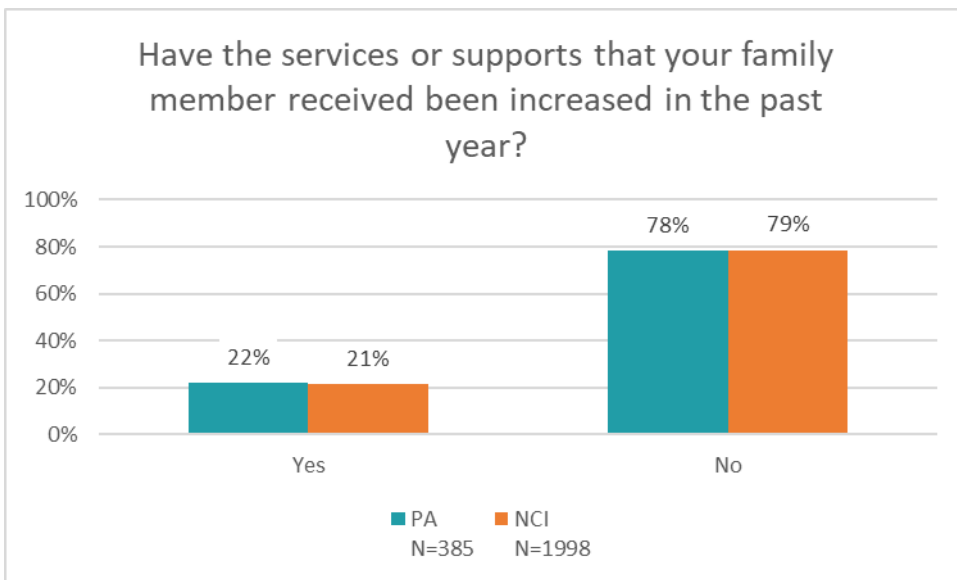
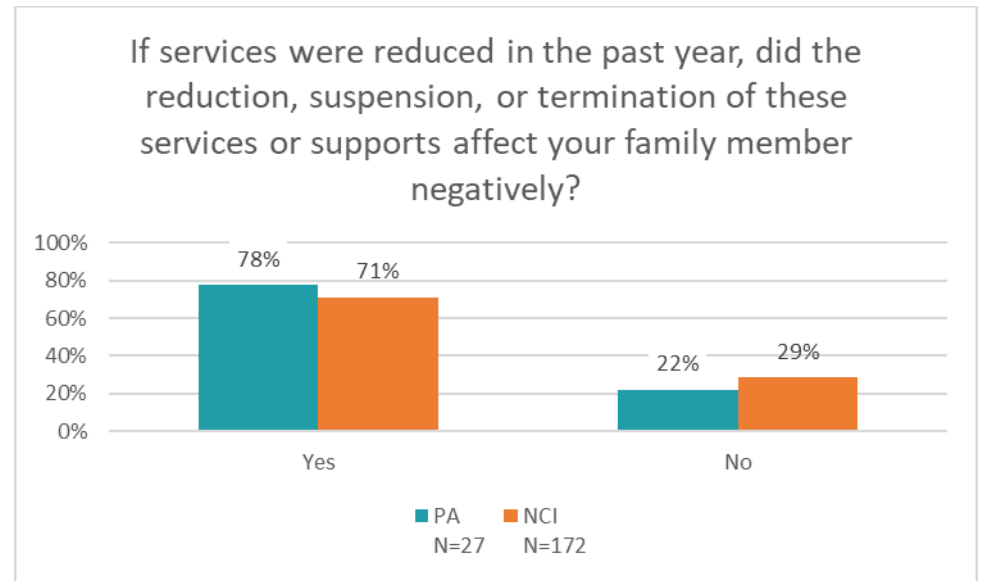
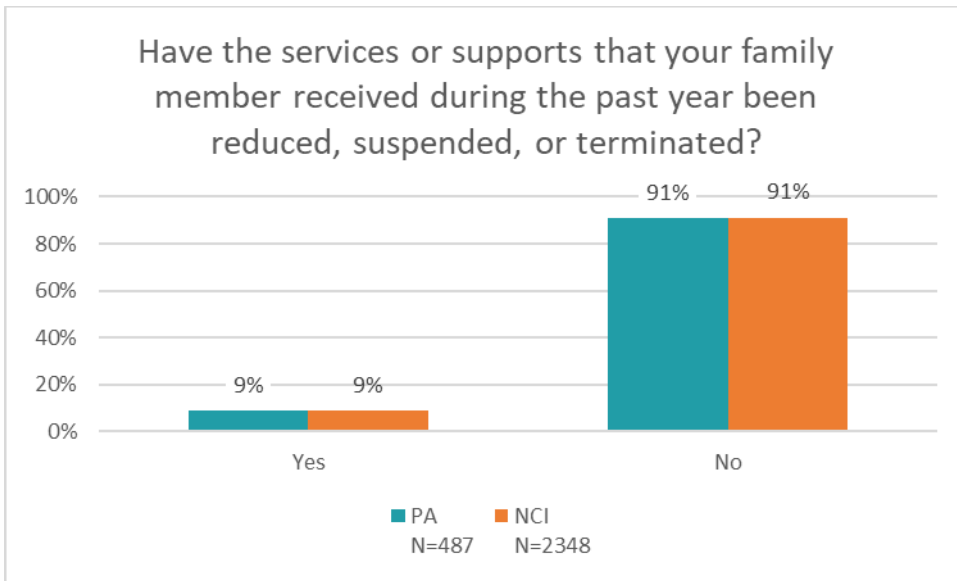
If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?



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 Q44. Overall, are you satisfied with the services and supports your family member currently receives?

State v. NCI	Always	Usually	Sometimes	Seldom/Never	N
PA	45%	45%	9%	1%	539
NCI	41%	49%	8%	2%	2,617

Table Q45. Do you know how to file a complaint or grievance about provider agencies or staff?⁷

State v. NCI	Yes	No	N
PA ▼	64%	36%	536
NCI	71%	29%	2,634

Table Q46. 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	87%	13%	67
NCI	76%	24%	386

Table Q47. Do you know how to report abuse or neglect related to your family member?⁸

State v. NCI	Yes	No	N
PA ▼	74%	26%	549
NCI	81%	19%	2,652

⁷ Don't Know' responses were included in 'No' responses for this question.

⁸ Don't Know' responses were included in 'No' responses for this question.

Table Q48. 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	8%	92%	515
NCI	8%	92%	2,503

Table Q49. If a report of abuse or neglect was filed on behalf of your family member in the past year, did the appropriate people respond to the report?

State v. NCI	Yes	No	N
PA	97%	3%	30
NCI	93%	7%	142

Table Q50. If someone outside of your family reported abuse or neglect on behalf of your family member in the past year, were you notified of the report in a timely manner?

State v. NCI	Yes	No	N
PA	77%	23%	26
NCI	77%	23%	121

Table Q51. 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%	516
NCI	96%	4%	2,505

Table Q52. 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	9%	91%	487
NCI	9%	91%	2,348

Table Q53. 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	78%	22%	27
NCI	71%	29%	172

Table Q54. Have the services or supports that your family member received been increased in the past year?

State v. NCI	Yes	No	N
PA	22%	78%	385
NCI	21%	79%	1,998

Table Q55. Are services and supports helping your family member to live a good life?

State v. NCI	Yes	No	N
PA	96%	4%	512
NCI	96%	4%	2,472