

*2017-18 ADULT FAMILY SURVEY*  
*PENNSYLVANIA 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).

NCI has developed more than 100 standard performance measures (or ‘indicators’) that states use to assess the outcomes of services for individuals and families, including outcomes in the areas of employment, rights, service planning, community inclusion, choice, health, and safety. In 2017-18 a total of 46 states, the District of Columbia and 22 sub-state entities participated in NCI.

## 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 in the family home 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 and the person who fills out the survey (the ‘respondent’) as well as information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable.

In 2017-18, a total of 5,221 Adult Family Surveys were completed across 12 states.<sup>1</sup> The survey contained six groupings of questions (“sub-domains”) that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes (see Table A1 on the following page). Respondents also had the option of writing open-ended comments concerning their family’s participation in the service system.

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<sup>1</sup> States that conducted the Adult Family Survey in 2017-18 were: AZ, DC, DE, FL, GA, MD, MO, NC, NH, OK, PA and WA.

Table A1. NCI Family Survey – Sub-Domains and Concern Statements

Sub-Domain	Concern Statement
<b>Information and Planning</b>	Families/family members with disabilities have the information and support necessary to plan for their services and supports.
<b>Access &amp; Support Delivery</b>	Families/family members with disabilities get the services and supports they need.
<b>Choice, Decision Making &amp; Control</b>	Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.
<b>Involvement in the Community</b>	Family members with disabilities use integrated community services and participate in everyday community activities.
<b>Satisfaction</b>	Families/family members with disabilities receive adequate and satisfactory supports.
<b>Outcomes</b>	Individual and family supports make a positive difference in the lives of families.

## How were people selected to participate?

States were asked to administer the survey to a random sample of at least 1,000 families, all of whom have an adult family member with a developmental disability who lives in the family home and receives at least one direct service or support other than service coordination.

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or both. In previous years, states only had the option to mail paper surveys. In 2017-18, a total of four states had at least a portion of surveys completed via direct entry mode.<sup>2</sup>

All states mailed out a paper survey to families selected in their sample. A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. Both the confidence level and margin of error used are widely accepted standards for reviewing results, regardless of population size. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we included in our national reports those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.

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<sup>2</sup> States that used the direct entry or mail and direct entry options were: DE, FL, NC and WA. For more information on response rates and mode, please see the Methodology section within the national edition of the 2017-18 Adult Family Survey Report.



## Data Analysis

Surveys received from the state were considered valid based on the following two criteria:

1. The respondent indicated the individual with an intellectual or developmental disability receiving services lived in the family home.
2. At least a portion of survey questions were answered aside from demographic information.

Questions left blank or marked ‘not applicable’ are not included in analysis. For most questions, ‘don’t know’ responses were excluded from analysis. Two questions in the Satisfaction section combine ‘no’ and ‘don’t know’ responses; those questions are denoted with an asterisk in the table. For all items shown, states receive an ‘n/a’ designation for a survey item if fewer than 20 people responded; however, their data are included in the NCI Average.

## Weighting

Prior to 2016-17, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). Beginning last year, the approach has been enhanced to take into account the relative numbers of people receiving services through participating states’ systems. The NCI averages contained in this report are “weighted” means. Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall NCI average—that is, the state’s contribution to the NCI average is proportional to its service population. The weights used in calculations for this report were developed using each participating state’s number of survey respondents and its total survey-eligible population.<sup>3</sup>

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<sup>3</sup> For more information on weighting and significance testing, see the Methodology section of the National Adult Family Survey Report.

## Significance testing

Statistical significance is shown in this report. The state's percentage was compared to the weighted NCI average (described above), and the differences between the two were tested for both **statistical significance** as well as **effect sizes**. Effect sizes are used in addition to statistical significance because statistical significance of a state's result depends, in part, on the size of the state's sample: the larger the sample, the more likely it is that even a small difference will be found *statistically* significant.

The t-test analyses established whether the state's percentage was:

1. Higher than the NCI average, and the difference was statistically significant (denoted in the report with an up arrow ▲);
2. Within the average range (i.e., not statistically different from the NCI Average); or
3. Lower than the NCI average, and the difference was statistically significant (denoted in the report with a down arrow ▼).

Statistical significance testing was conducted on each state's "yes" or "always" response compared to the NCI average; statistical significance was determined at the  $p \leq .01$  level.<sup>4</sup> Demographics data and data on services received were not tested for statistically significant differences.

## Limitations of the data

The NCI Adult Family Survey is a tool for assessing system-wide performance. It is not intended to be used to monitor individuals or providers. The NCI Statewide Average should not be interpreted as defining or providing a benchmark for "acceptable" levels of performance or satisfaction. Instead, it describes average levels of performance or satisfaction across the state; it is up to public managers, policymakers, and other stakeholders to use the data to determine programmatic and policy-related priorities.

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<sup>4</sup> For more information on weighting and significance testing, see the Methodology section of the National Adult Family Survey.

## What is contained in this report?

This report illustrates the 2017-18 NCI Adult Family Survey demographic and outcome results from Pennsylvania (PA) compared to the NCI Average. All results are shown first in charts by sub-domain and then in table form by sub-domain. Arrow symbols (▲ and ▼) are used to indicate areas where the state average was statistically higher or lower than the NCI Average. **Please note: items without the ▲ or ▼ arrow symbols indicate that the state was within the NCI Average range.** For most items, the total number of respondents (N) from the state and across NCI states is displayed in charts and tables. States with fewer than 20 responses to a question received an 'n/a' designation; however, their data are included in the NCI Average. All state and national data results for this survey can be found online at <http://www.nationalcoreindicators.org/resources/reports/>.

## Family Member

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

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**Table 1. More than one person living at home has IDD**

		Yes	No	N
More Than One Person Living in the Home Has IDD	PA	12%	88%	695
	NCI	13%	87%	5,034

**Table 2. Family member's age**

		Average Age	N
Family Member's Age	PA	40.6	731
	NCI	36.1	5,175

**Table 3. Family member's gender**

		Male	Female	N
Family Member's Gender	PA	56%	44%	724
	NCI	57%	43%	5,119

**Table 4. Family member's race and ethnicity (categories are not mutually exclusive)**

		American Indian or Alaska Native	Asian	Black or African-American	Hawaiian or Pacific Islander	White	Other or Unknown	Hispanic or Latino
Family Member's Race and Ethnicity	PA	1%	1%	7%	0%	91%	2%	1%
	NCI	2%	4%	13%	0%	77%	9%	1%

Table 5. Family member's disabilities (categories are not mutually exclusive)

		Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss	Brain Injury
Family Member's Disabilities	PA	84%	21%	20%	23%	11%	7%	10%
	NCI	71%	23%	29%	22%	11%	7%	10%

Table 6. Family member's disabilities (continued, categories are not mutually exclusive)

		Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
Family Member's Disabilities	PA	29%	0%	22%	0%	0%	18%
	NCI	31%	1%	18%	1%	1%	19%

Table 7. Family member's health conditions (categories are not mutually exclusive)

		Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
Family Member's Health Conditions	PA	15%	18%	4%	29%	30%
	NCI	13%	19%	5%	29%	29%

Table 8. Family member's health conditions (continued, categories are not mutually exclusive)

		Dysphagia	Pressure Ulcers	Alzheimer's Disease or Other Dementia	Oral Health or Dental Problems	Sleep Apnea	Other
Family Member's Health Conditions	PA	11%	2%	2%	10%	17%	28%
	NCI	10%	2%	3%	13%	19%	26%

**Table 9. Family member's preferred means of communication**

		Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
Family Member's Preferred Means of Communication	PA	77%	14%	2%	1%	6%	718
	NCI	74%	16%	2%	2%	6%	5129

**Table 10. Family member's level of guardianship**

		None	Limited	Full	Has Guardianship but Level Is Unknown	Don't know	N
Level of Guardianship or Conservatorship of Family Member	PA	39%	11%	39%	3%	8%	706
	NCI	32%	11%	49%	3%	5%	5,059

**Table 11. Guardian or conservator relationship to family member**

		Family	Friend	State Employee or Guardianship Agency	Other	N
Guardian or Conservator Relationship to Family Member	PA	96%	0%	0%	4%	333
	NCI	96%	0%	0%	4%	3,032

Table 12. Family member's highest level of education

		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
Family Member's Highest Level of Education	PA	16%	3%	29%	45%	4%	1%	2%	668
	NCI	16%	5%	35%	34%	4%	4%	3%	4,981

Table 13. Family member's typical day activity

		Usually/Often	Sometimes	Never	N
Paid Individual Job in the Community	PA	16%	3%	80%	690
	NCI	16%	3%	80%	4,868
Paid Small Group Job in a Community-based Setting	PA	11%	2%	87%	683
	NCI	9%	2%	89%	4,824
Unpaid Activity in the Community	PA	21%	13%	66%	692
	NCI	22%	13%	65%	4,904
Paid Work in a Community Business That Primarily Hires People With Disabilities	PA	6%	1%	92%	688
	NCI	6%	2%	92%	4,865
Paid Work in a Facility-based Setting	PA	26%	2%	72%	692
	NCI	17%	2%	81%	4,884
Unpaid Activity in a Facility-based Setting	PA	29%	5%	66%	686
	NCI	27%	5%	69%	4,870
School	PA	5%	1%	94%	678
	NCI	11%	2%	88%	4,800
Stays at Home	PA	47%	22%	31%	617
	NCI	51%	20%	28%	4,607
Other	PA	51%	5%	44%	173
	NCI	52%	7%	41%	1,218



**Table 14. Family member's support needs**

		None	Some	Extensive	N
Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	PA	61%	27%	11%	714
	NCI	57%	28%	15%	5,074
Family Member's Need for Help With Personal Care Activities	PA	31%	32%	38%	730
	NCI	25%	33%	42%	5,133
Family Member's Need for Help With Other Daily Activities	PA	3%	17%	79%	720
	NCI	4%	17%	79%	5,132

## Respondents

This section provides demographic information about the respondent.

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Table 15. Respondent's age

		Under 35	35-54	55-74	75+	N
Respondent's Age	PA	1%	12%	65%	22%	731
	NCI	2%	19%	65%	15%	5,143

Table 16. Respondent's health

		Excellent	Very Good	Fairly Good	Poor	N
Respondent's Health	PA	14%	44%	37%	5%	727
	NCI	15%	45%	35%	4%	5,156

Table 17. Respondent's relationship to family member

		Parent	Sibling	Spouse	Grandparent	Other	N
Respondent's Relationship to Family Member	PA	85%	12%	0%	1%	1%	729
	NCI	86%	9%	0%	2%	3%	5,149

**Table 18. Respondent (or other family member) provides paid support (categories are not mutually exclusive)**

		Respondent or Other Family Member Provides Paid Support to Family Member
No Family Member Provides Paid Support	PA	79%
	NCI	70%
Respondent Provides Paid Support	PA	11%
	NCI	20%
Other Family Member Provides Paid Support	PA	11%
	NCI	12%
N	PA	710
	NCI	5,092

**Table 19. Number of adults in household**

		One	Two	Three	Four or More	N
Number of Adults in Household (Not Including Family Member Receiving Services)	PA	10%	29%	46%	15%	717
	NCI	9%	30%	45%	15%	5,106

**Table 20. Number of children in household**

		None	One	Two	Three	Four or More	N
Number of Children in Household	PA	91%	5%	2%	1%	1%	724
	NCI	88%	7%	3%	1%	1%	5,143

Table 21. Respondent's highest level of education

		No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
Respondent's Highest Level of Education	PA	7%	38%	7%	17%	32%	719
	NCI	7%	29%	7%	21%	36%	5,140

Table 22. Past year total household taxable income of wage earners

		Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	No Earned Income	Prefer Not to Say	N
Total Taxable Income of Wage Earners in the Household in Past Year	PA	10%	12%	19%	10%	15%	12%	22%	673
	NCI	8%	12%	20%	13%	16%	11%	21%	4,915

Table 23. Family's residential setting

		Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	Don't know	N
Residential Setting	PA	64%	35%	1%	725
	NCI	67%	31%	2%	5,110

## Services and Supports Received

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

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**Table 24. Services and supports received from state (categories are not mutually exclusive)**

		Services and Supports Received From State
Financial Support	PA	16%
	NCI	18%
In-home Support	PA	35%
	NCI	40%
Out-of-home Respite	PA	30%
	NCI	32%
Day or Employment Supports	PA	65%
	NCI	55%
Transportation	PA	70%
	NCI	62%
Other	PA	23%
	NCI	26%
Self-direction or Fiscal Intermediary Services	PA	43%
	NCI	39%

**Table 25. Additional services and supports received (not from IDD agency; categories are not mutually exclusive)**

		Additional Services and Supports Received (Not From the IDD Agency)
Social Security Payments (SSI/SSB)	PA	95%
	NCI	94%
Services or Supports From Other Agencies or Organizations	PA	36%
	NCI	31%

## Information and Planning

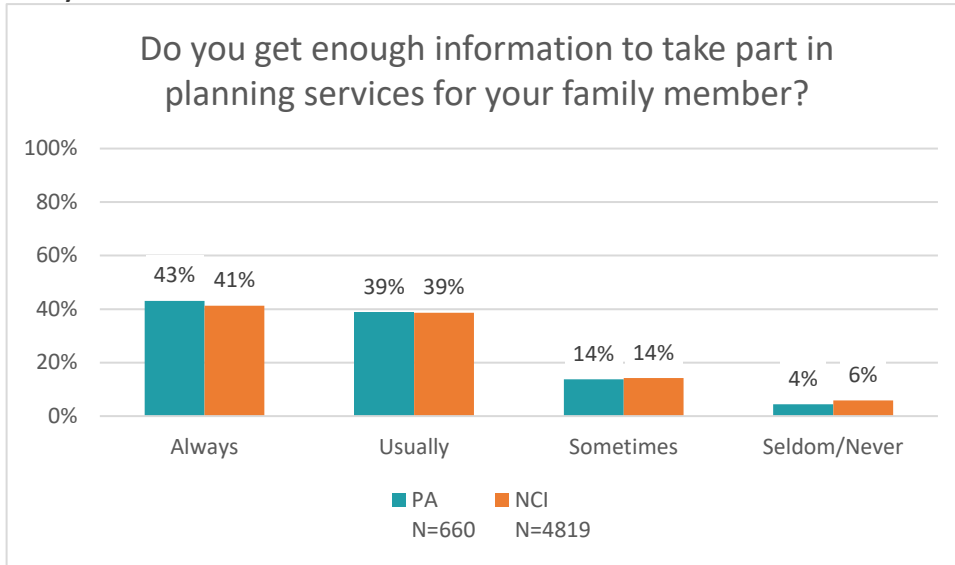
Families and family members with disabilities have the information and support necessary to plan for their services and supports.

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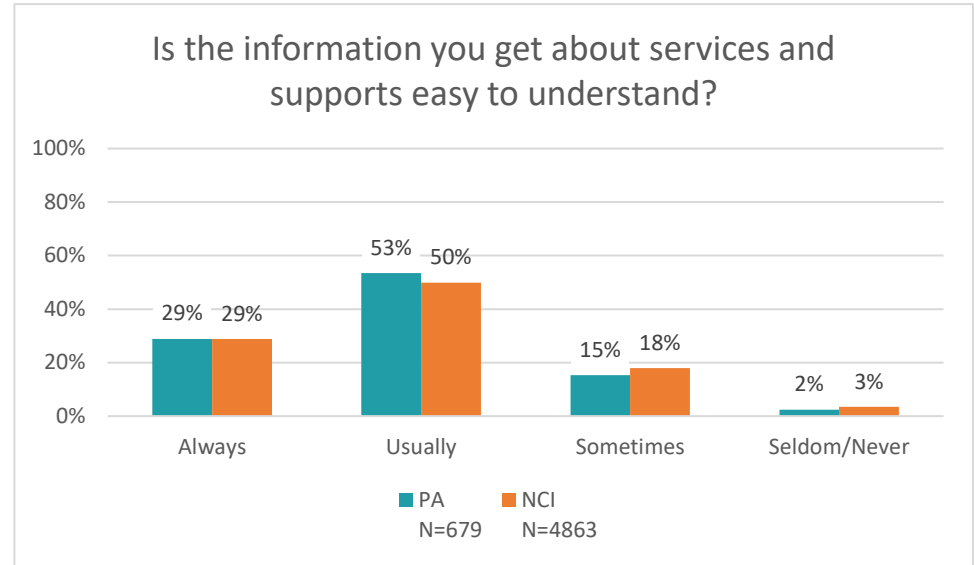


## *Charts for Information and Planning*

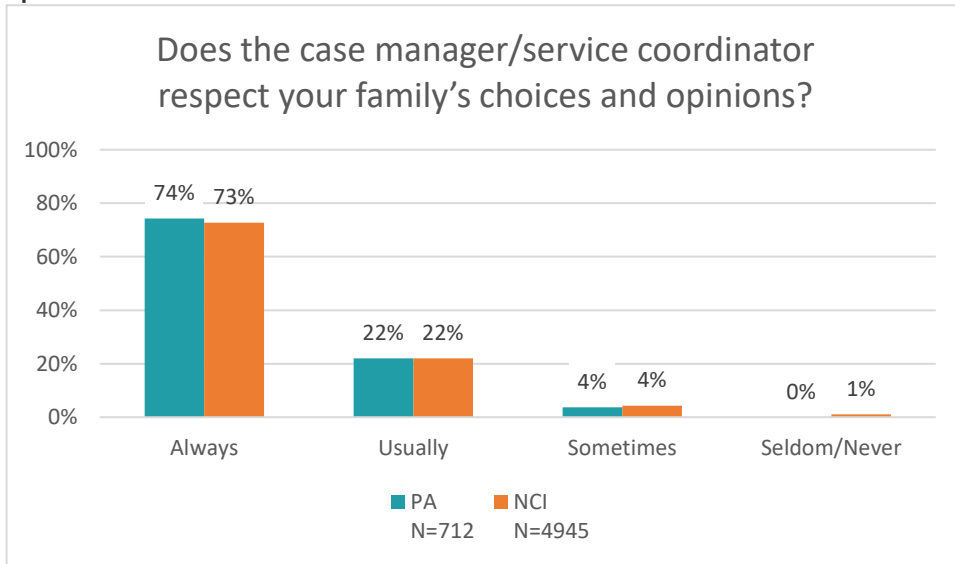
**Chart 1.** Do you get enough information to take part in planning services for your family member?



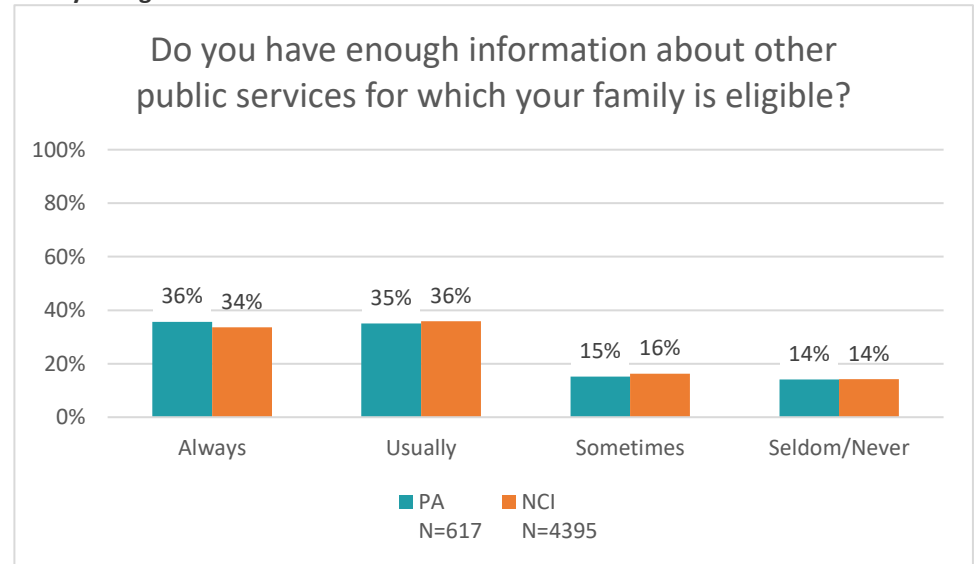
**Chart 2.** Is the information you get about services and supports easy to understand?



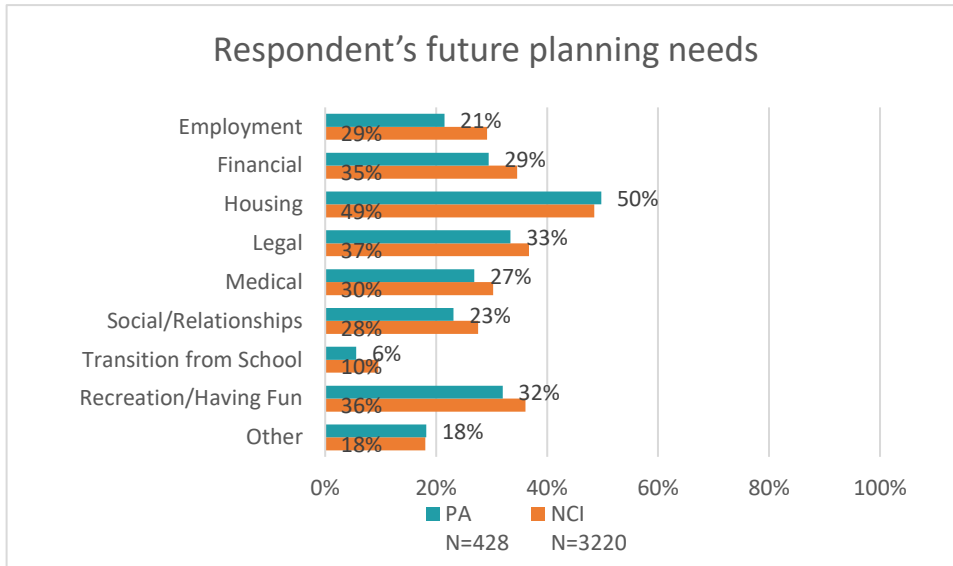
**Chart 3.** Does the case manager/service coordinator respect your family's choices and opinions?



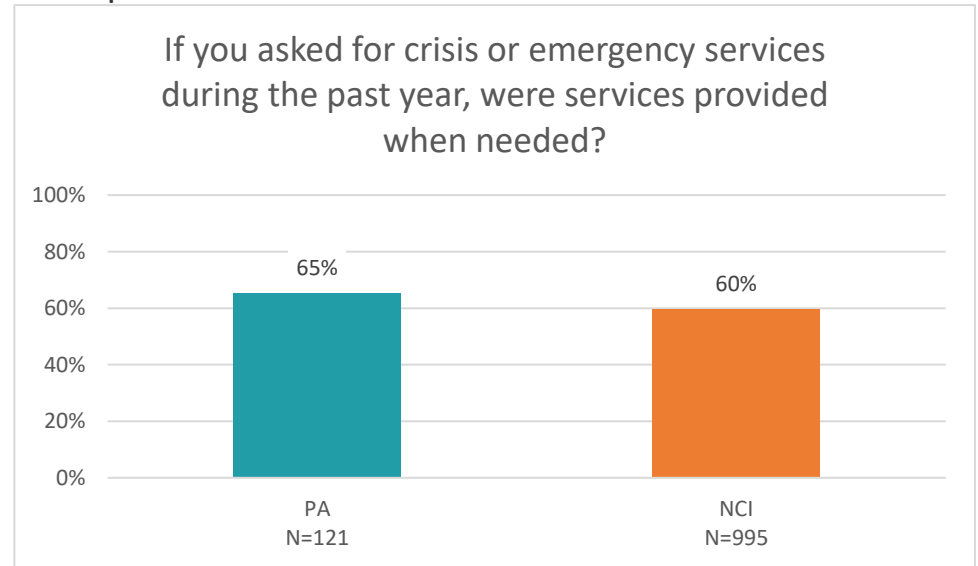
**Chart 4.** Do you have enough information about other public services for which your family is eligible?



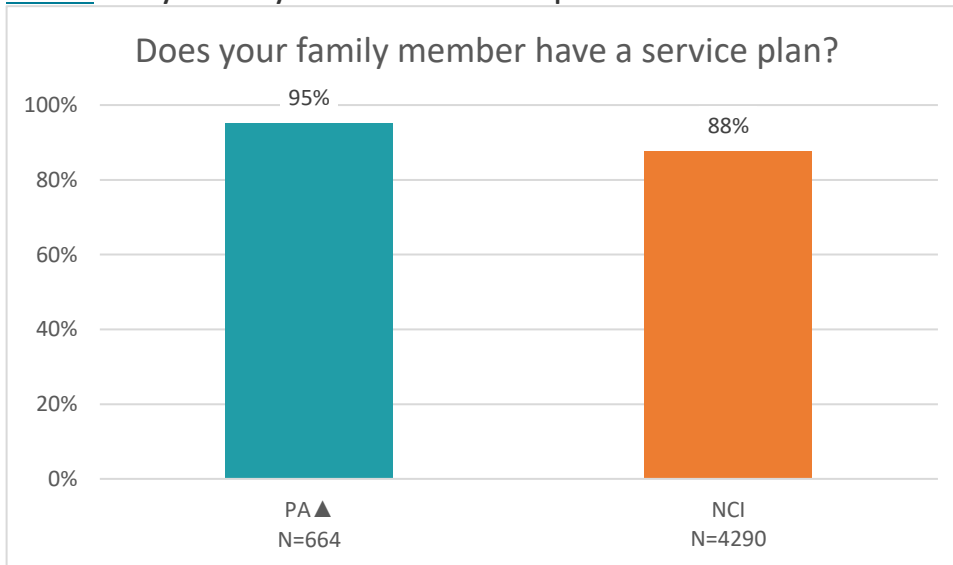
**Chart 5.** Respondent’s future planning needs



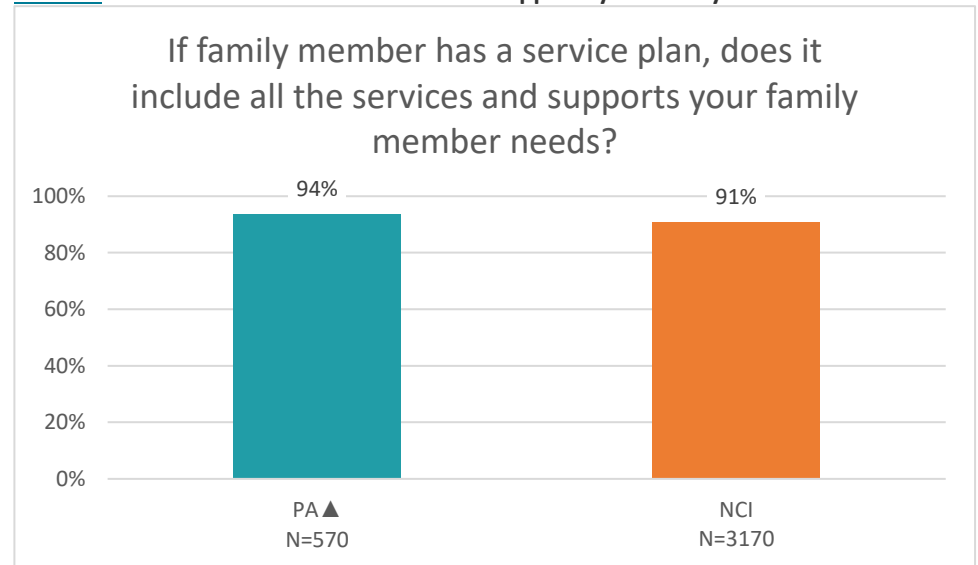
**Chart 6.** If you asked for crisis or emergency services during the past year, were services provided when needed?

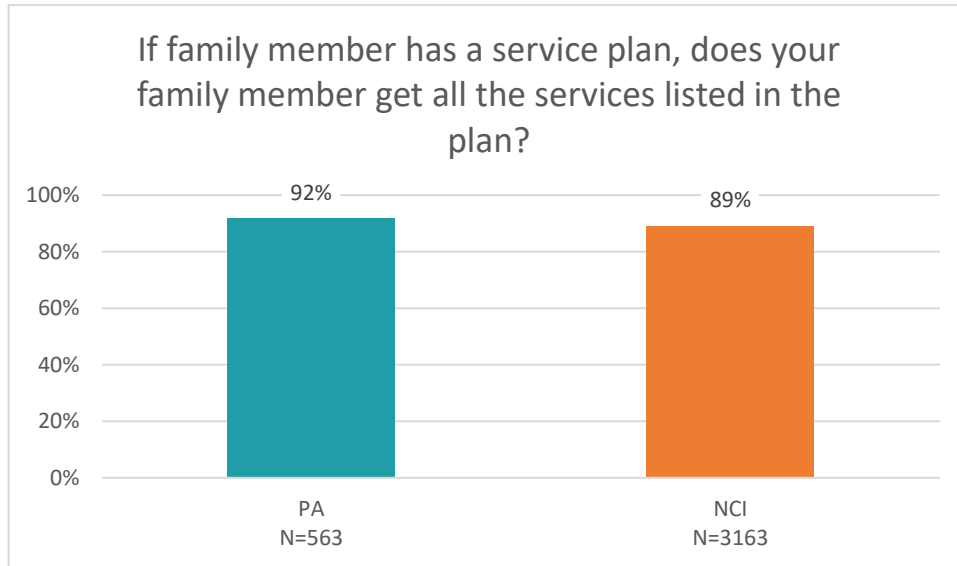
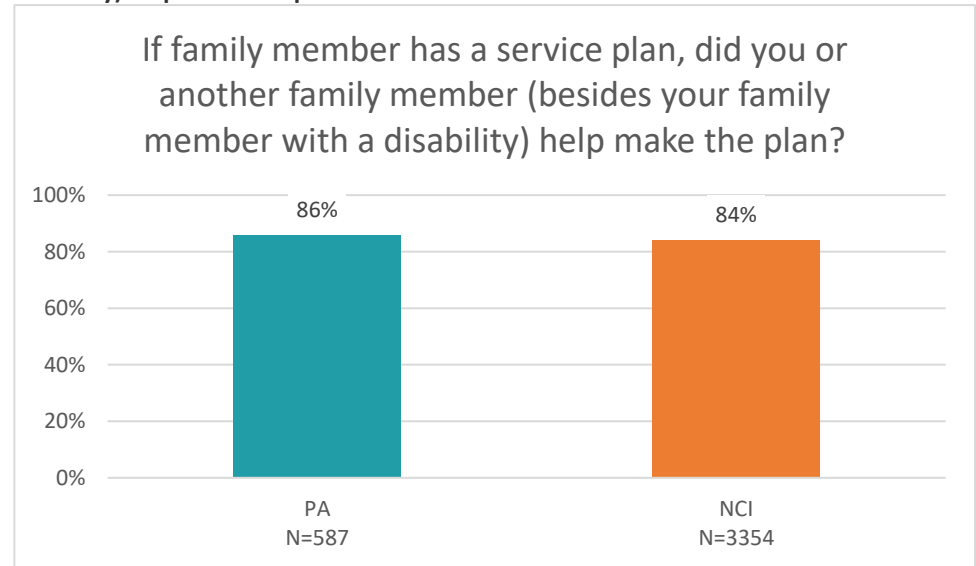
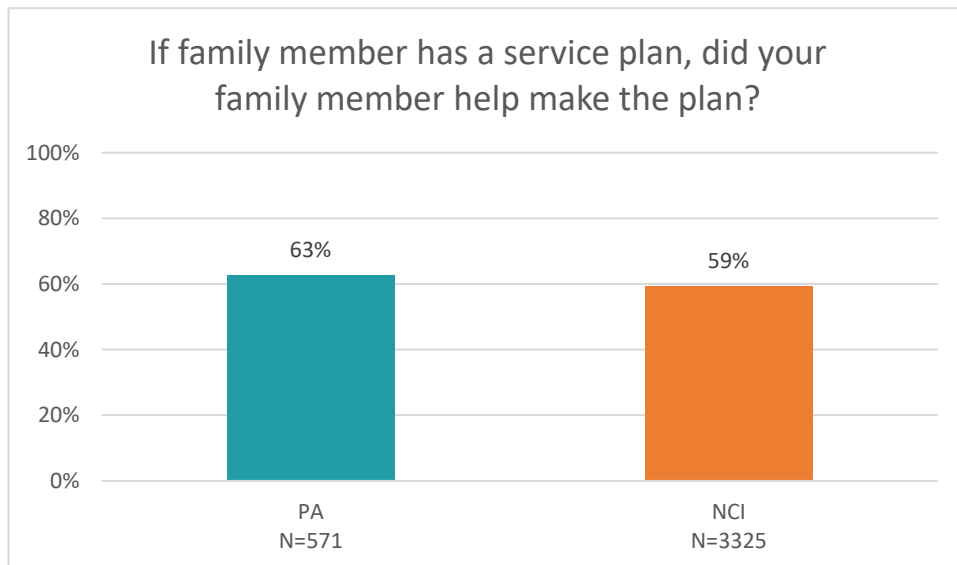
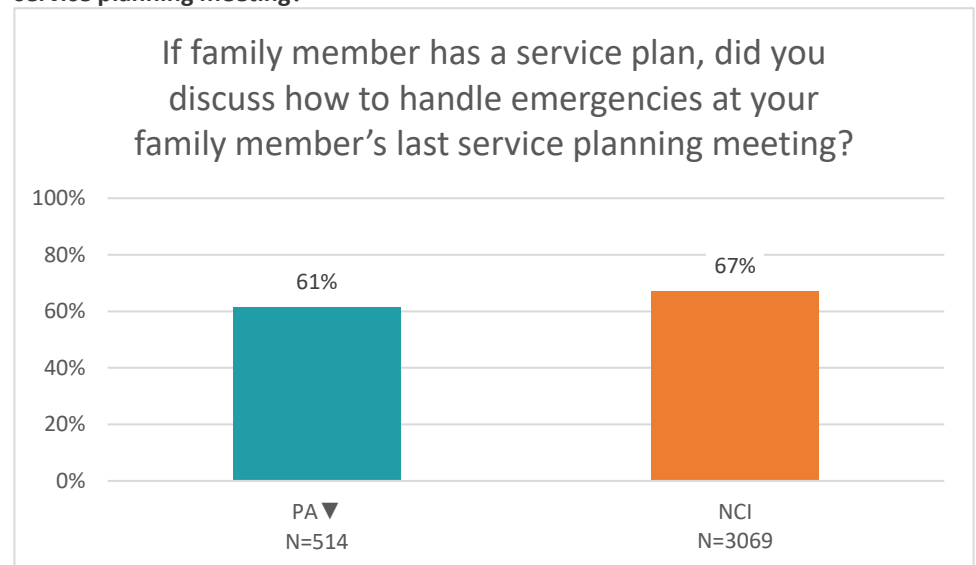


**Chart 7.** Does your family member have a service plan?

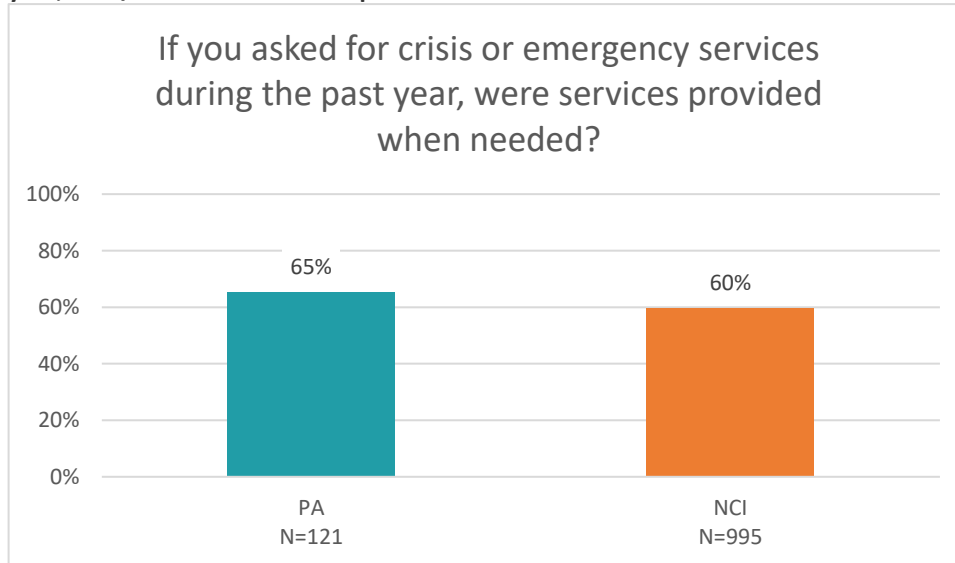


**Chart 8.** Does it include all the services and supports your family member needs?

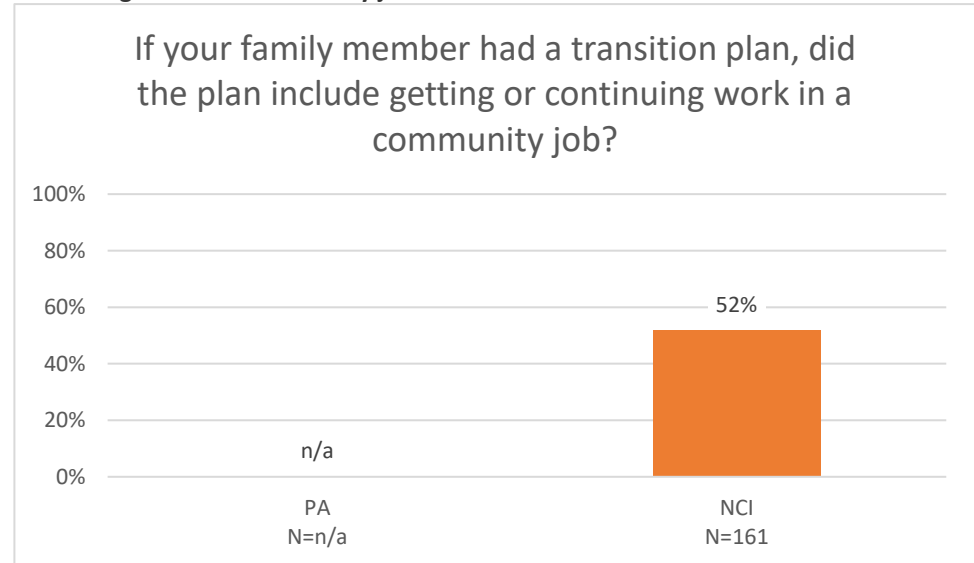


**Chart 9.** Does your family member get all the services listed in the plan?**Chart 10.** Did you or another family member (besides your family member with a disability) help make the plan?**Chart 11.** Did your family member help make the plan?**Chart 12.** Did you discuss how to handle emergencies at your family member's last service planning meeting?

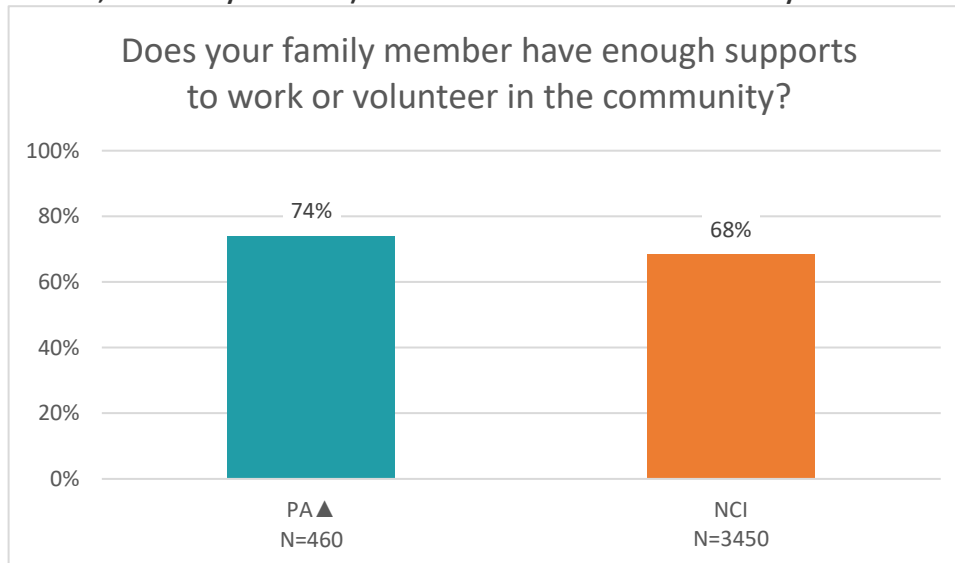
**Chart 13.** If your family member transitioned out of school services during the past year, did s/he have a transition plan?



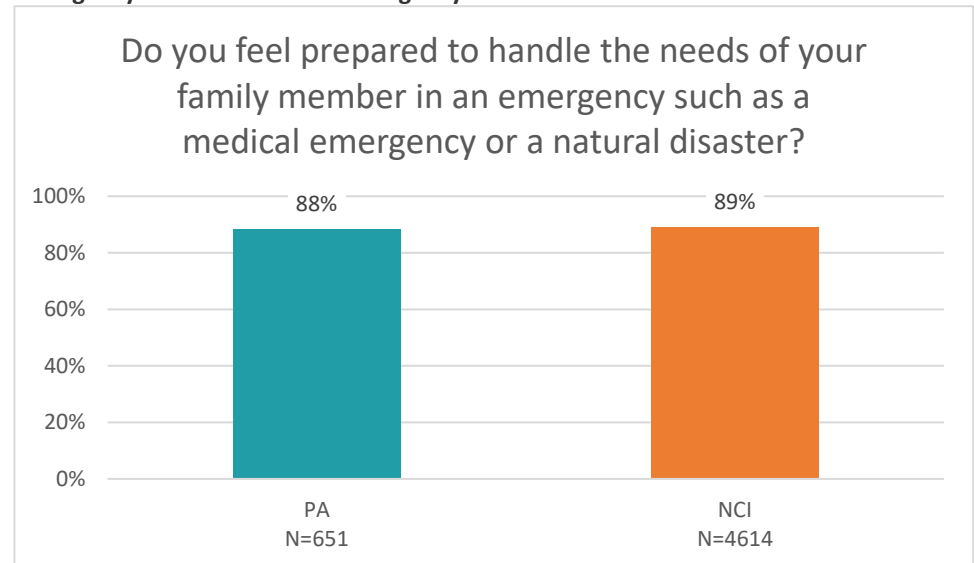
**Chart 14.** If your family member had a transition plan, did the plan include getting or continuing work in a community job?



**Chart 15.** Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?



**Chart 16.** Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?



## *Tables for Information and Planning*

Table 26. Information and Planning

		Always	Usually	Sometimes	Seldom/Never	N
Do you get enough information to take part in planning services for your family member?	PA	43%	39%	14%	4%	660
	NCI	41%	39%	14%	6%	4,819
Is the information you get about services and supports easy to understand?	PA	29%	53%	15%	2%	679
	NCI	29%	50%	18%	3%	4,863
Does the case manager/service coordinator respect your family's choices and opinions?	PA	74%	22%	4%	0%	712
	NCI	73%	22%	4%	1%	4,945
Do you have enough information about other public services for which your family is eligible?	PA	36%	35%	15%	14%	617
	NCI	34%	36%	16%	14%	4,395

**Table 27. Respondent's Future Planning Needs**

		Yes
Employment	PA	21%
	NCI	29%
Financial	PA	29%
	NCI	35%
Housing	PA	50%
	NCI	49%
Legal	PA	33%
	NCI	37%
Medical	PA	27%
	NCI	30%
Social or Relationships	PA	23%
	NCI	28%
Transition from School	PA	6%
	NCI	10%
Recreation	PA	32%
	NCI	36%
Other	PA	18%
	NCI	18%
N	PA	428
	NCI	3,220



Table 28. Information and Planning (continued)

		Yes	No	N
If you asked for crisis or emergency services during the past year, were services provided when needed?	PA	65%	35%	121
	NCI	60%	40%	995
Does your family member have a service plan?	PA ▲	95%	5%	664
	NCI	88%	12%	4,290
<b><i>If your family member has a service plan...</i></b>				
Does it include all the services and supports your family member needs?	PA ▲	94%	6%	570
	NCI	91%	9%	3,170
Does your family member get all the services listed in the plan?	PA	92%	8%	563
	NCI	89%	11%	3,163
Did you or another family member (besides your family member with a disability) help make the plan?	PA	86%	14%	587
	NCI	84%	16%	3,354
Did your family member help make the plan?	PA	63%	37%	571
	NCI	59%	41%	3,325
Did you discuss how to handle emergencies at your family member's last service planning meeting?	PA ▼	61%	39%	514
	NCI	67%	33%	3,069
If your family member transitioned out of school services during the past year, did s/he have a transition plan?	PA	70%	30%	30
	NCI	53%	47%	356
If your family member had a transition plan, did the plan include getting or continuing work in a community job?	PA	n/a	n/a	n/a
	NCI	52%	48%	161
Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?	PA ▲	74%	26%	460
	NCI	68%	32%	3,450
Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?	PA	88%	12%	651
	NCI	89%	11%	4,614

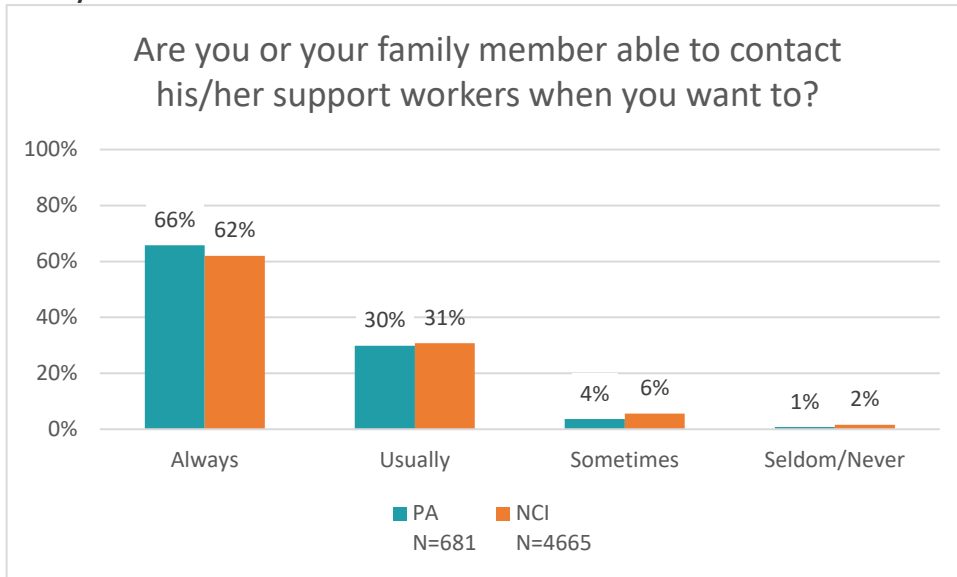
## **Access and Delivery of Services and Supports**

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

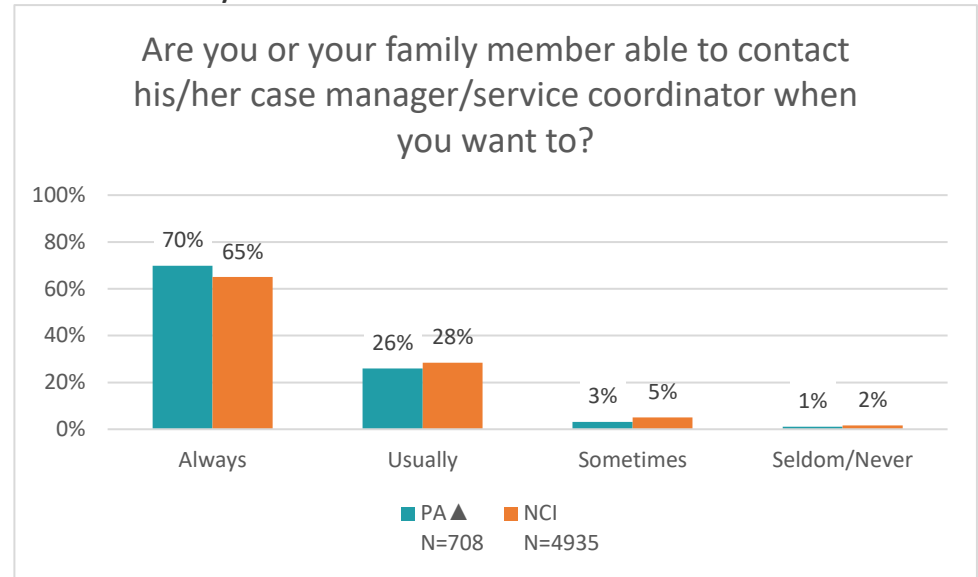
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## *Charts for Access and Delivery of Services and Supports*

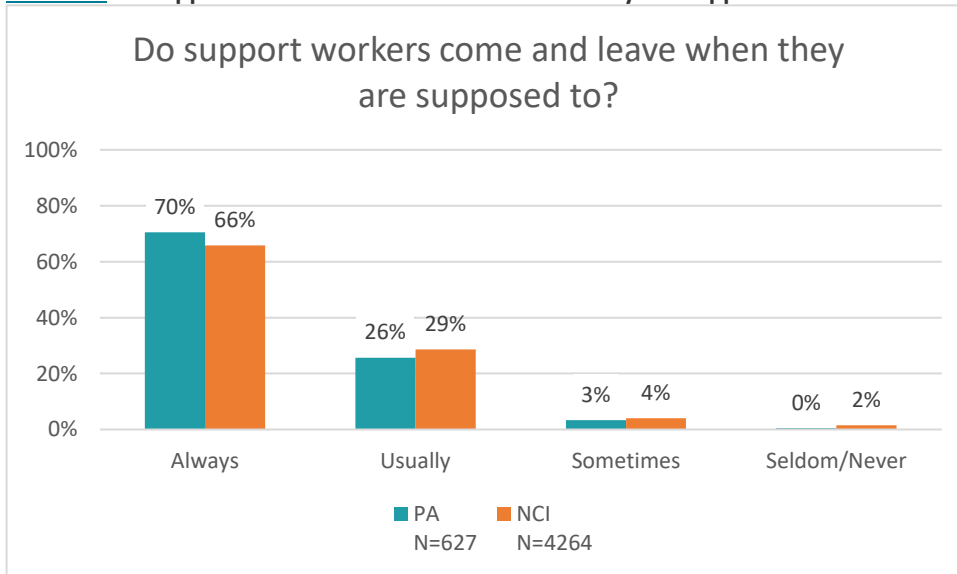
**Chart 17.** Are you or your family member able to contact his/her support workers when you want to?



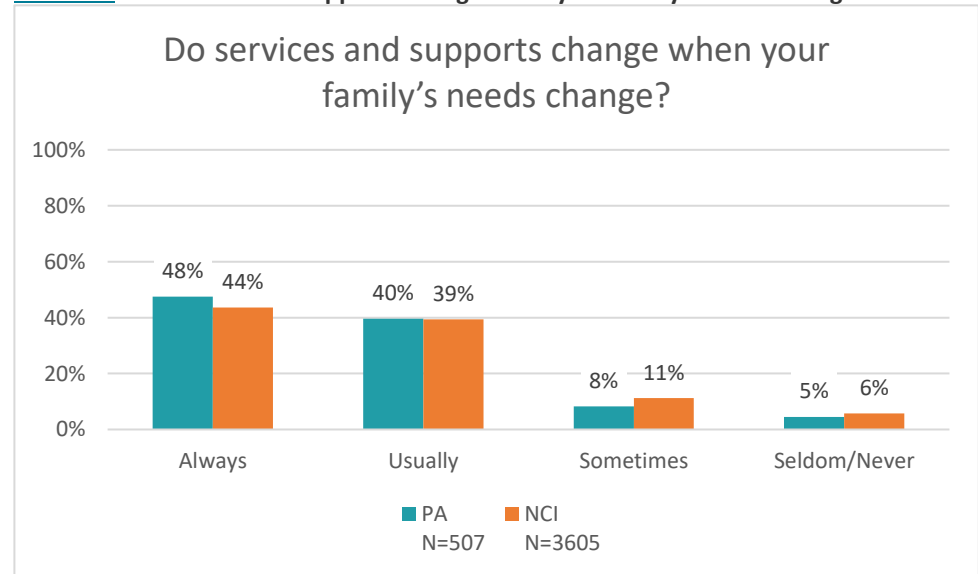
**Chart 18.** Are you or your family member able to contact his/her case manager/service coordinator when you want to?



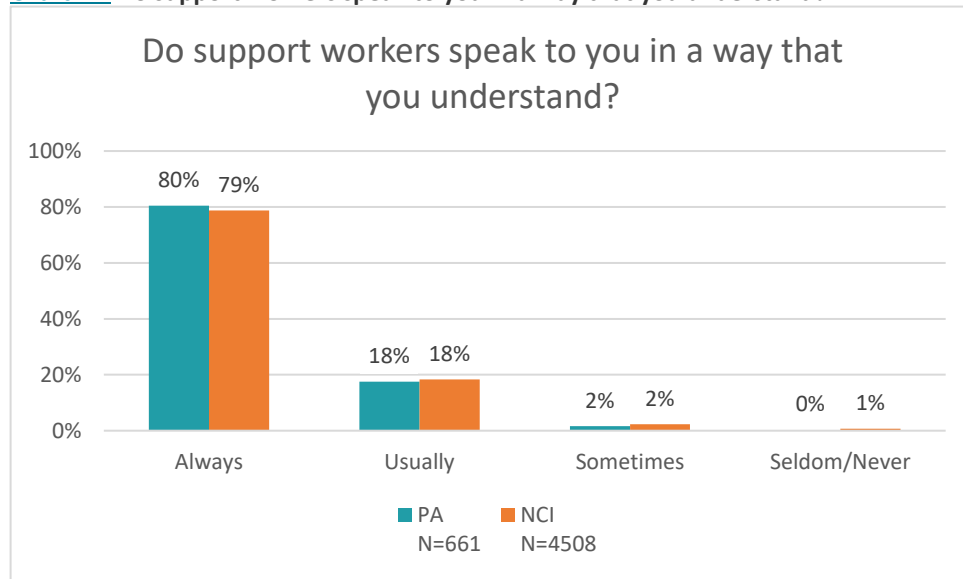
**Chart 19.** Do support workers come and leave when they are supposed to?



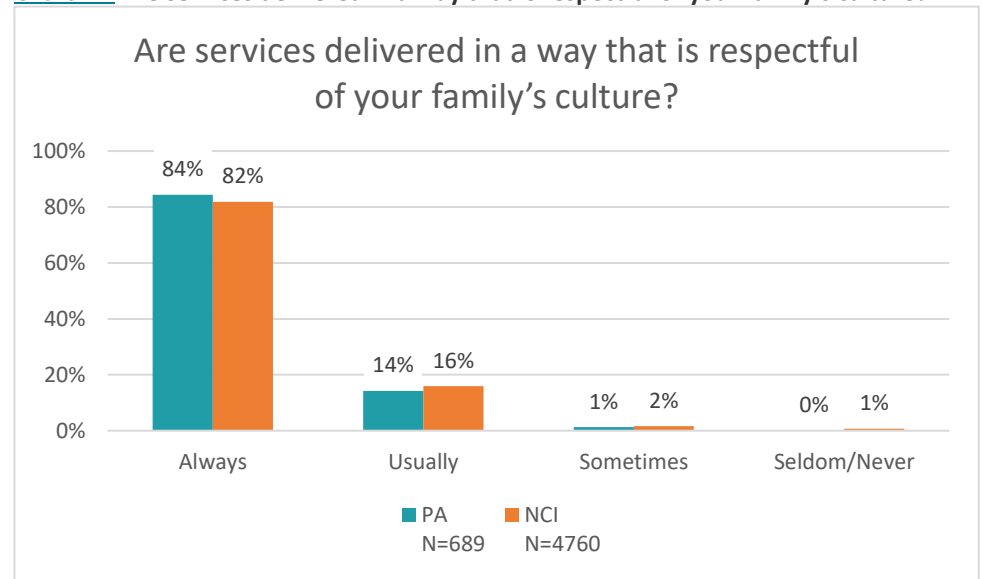
**Chart 20.** Do services and supports change when your family's needs change?



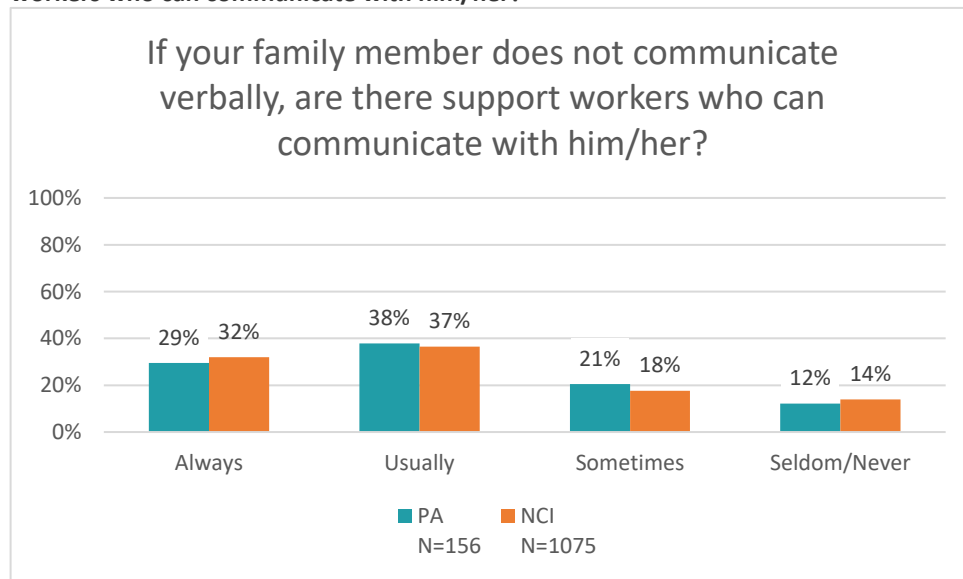
**Chart 21.** Do support workers speak to you in a way that you understand?



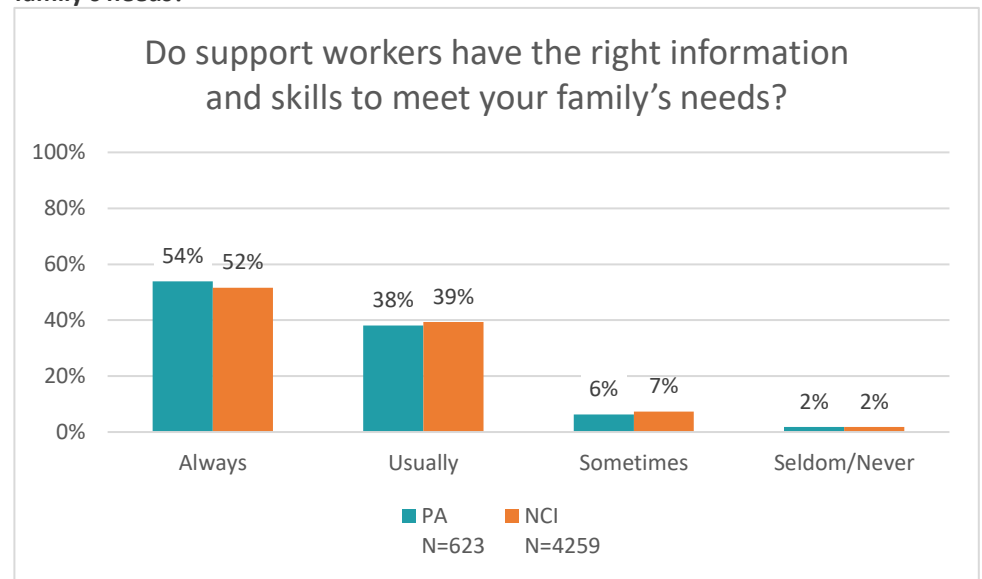
**Chart 22.** Are services delivered in a way that is respectful of your family's culture?



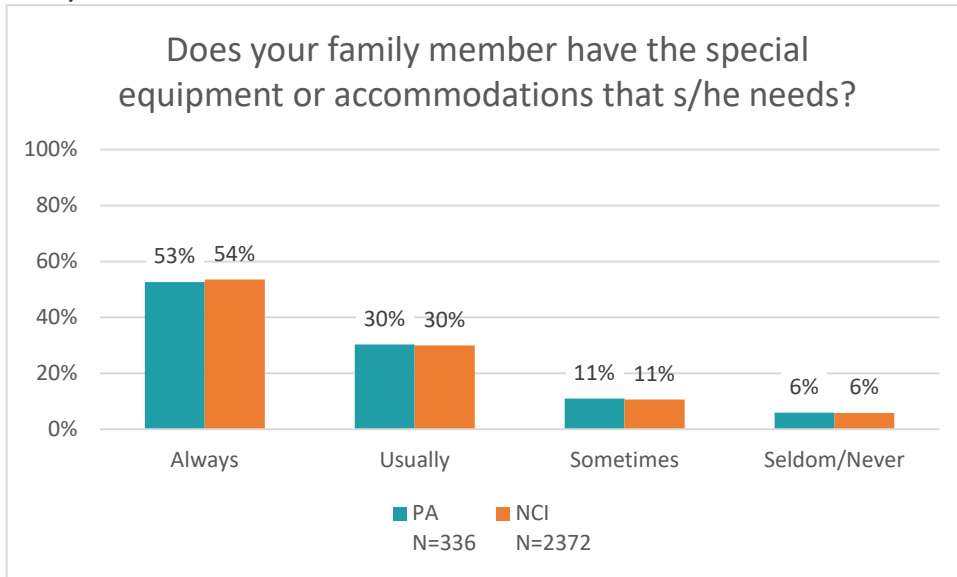
**Chart 23.** If your family member does not communicate verbally, are there support workers who can communicate with him/her?



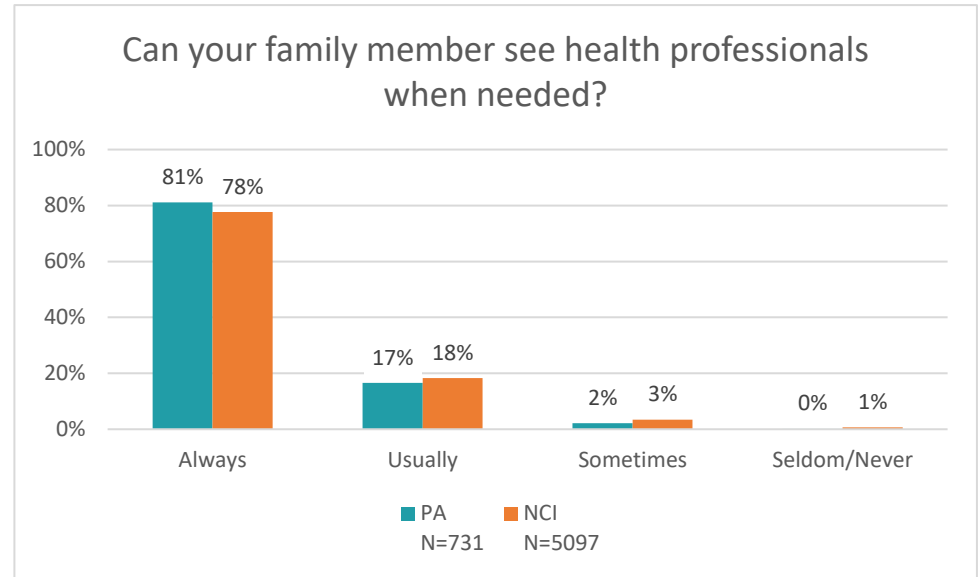
**Chart 24.** Do support workers have the right information and skills to meet your family's needs?



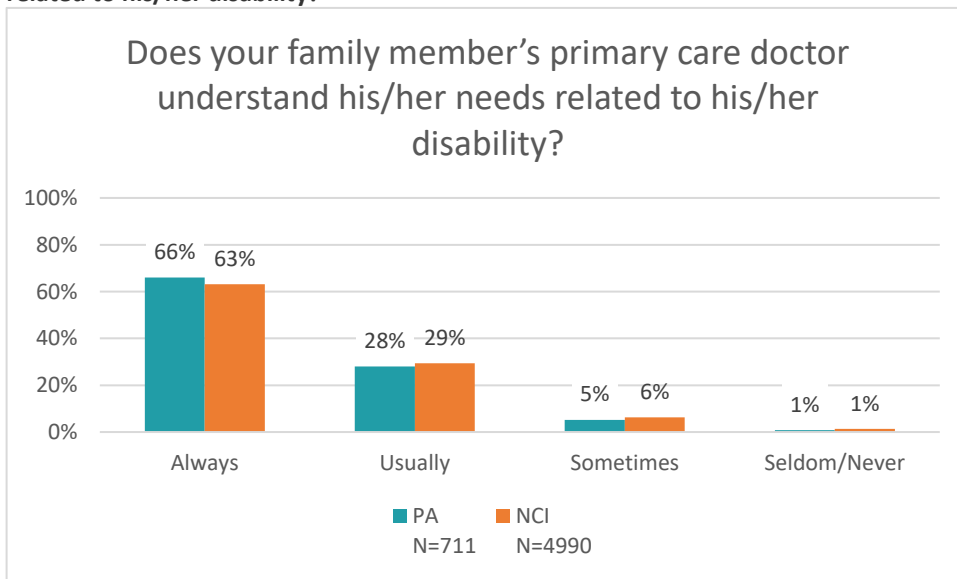
**Chart 25.** Does your family member have the special equipment or accommodations that s/he needs?



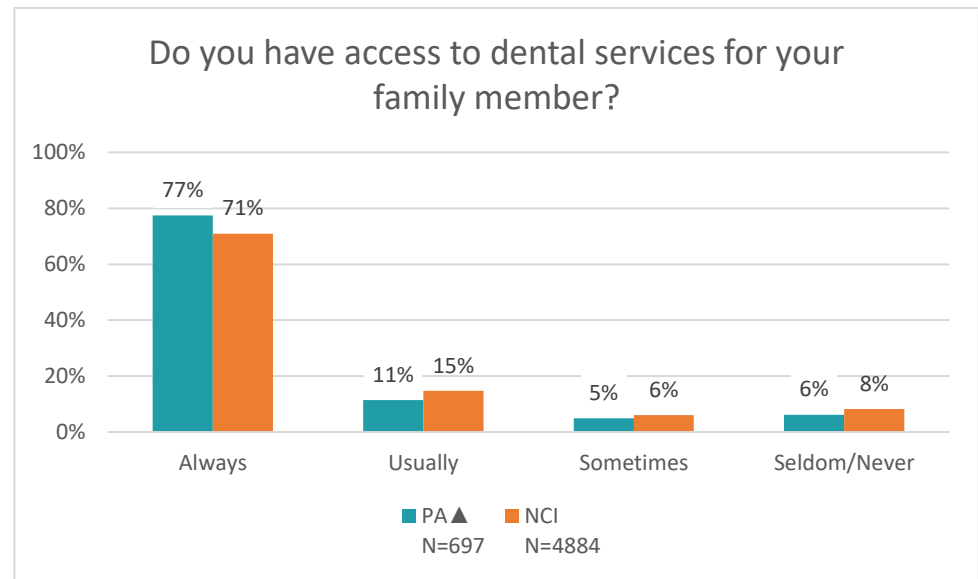
**Chart 26.** Can your family member see health professionals when needed?



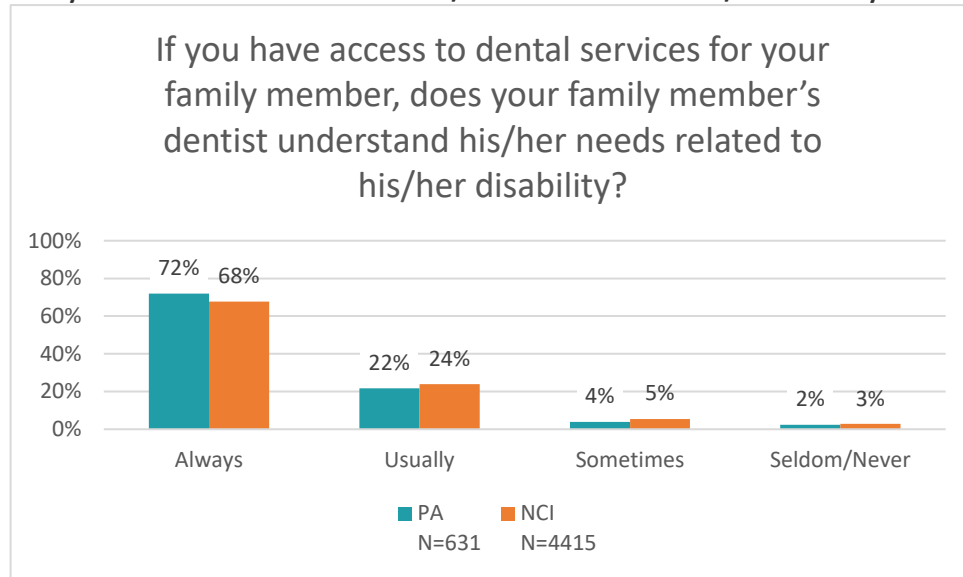
**Chart 27.** Does your family member's primary care doctor understand his/her needs related to his/her disability?



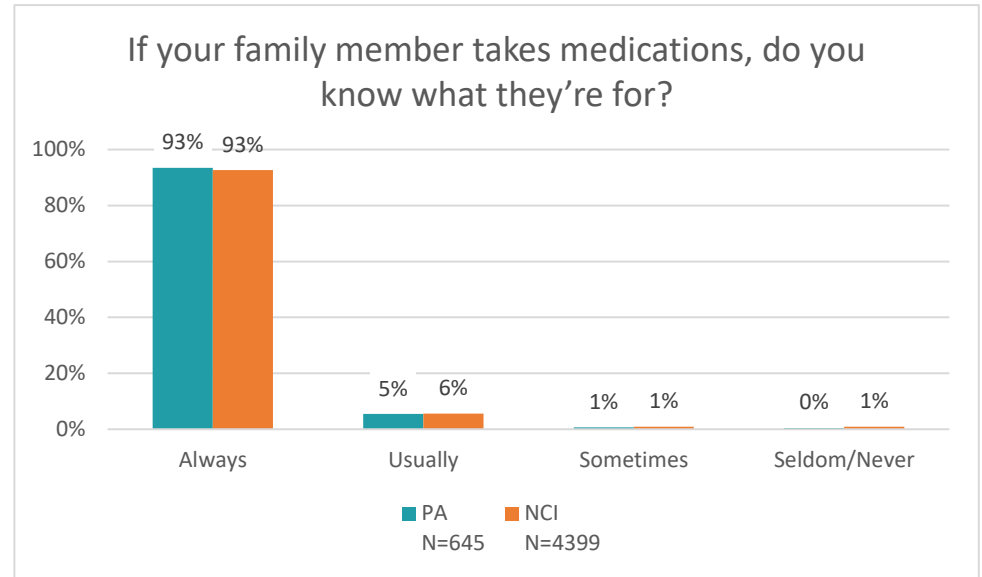
**Chart 28.** Do you have access to dental services for your family member?



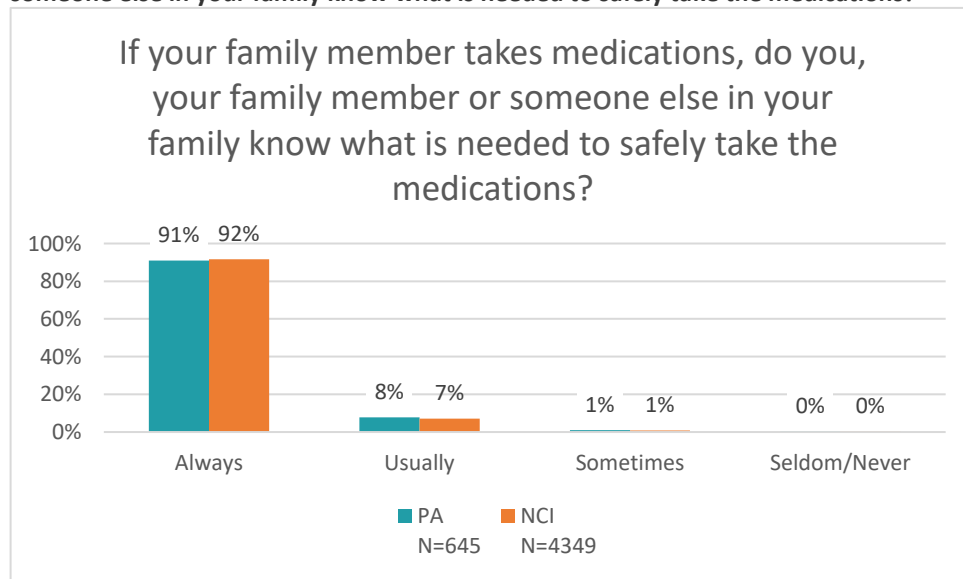
**Chart 29.** If you have access to dental services for your family member, does your family member’s dentist understand his/her needs related to his/her disability?



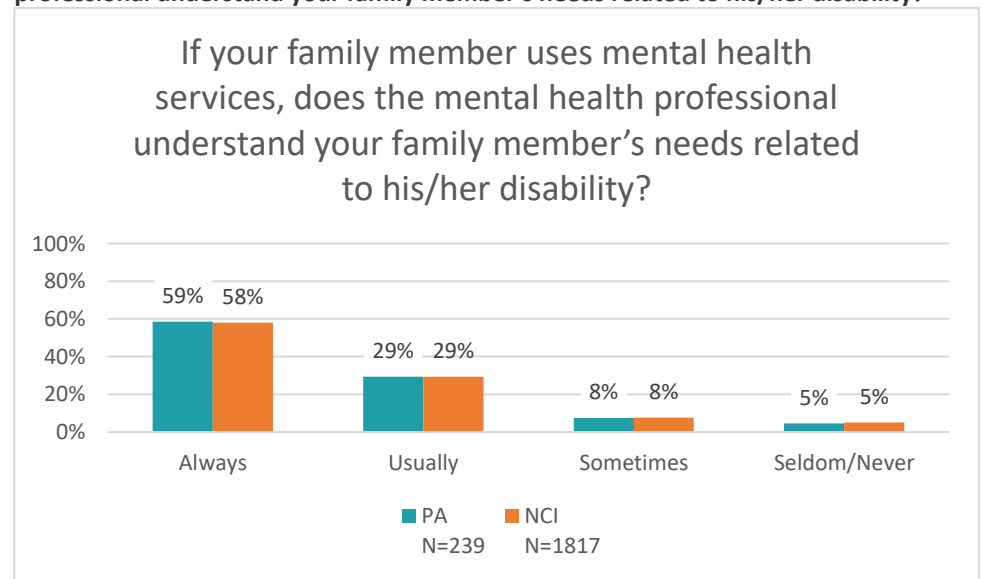
**Chart 30.** If your family member takes medications, do you know what they’re for?



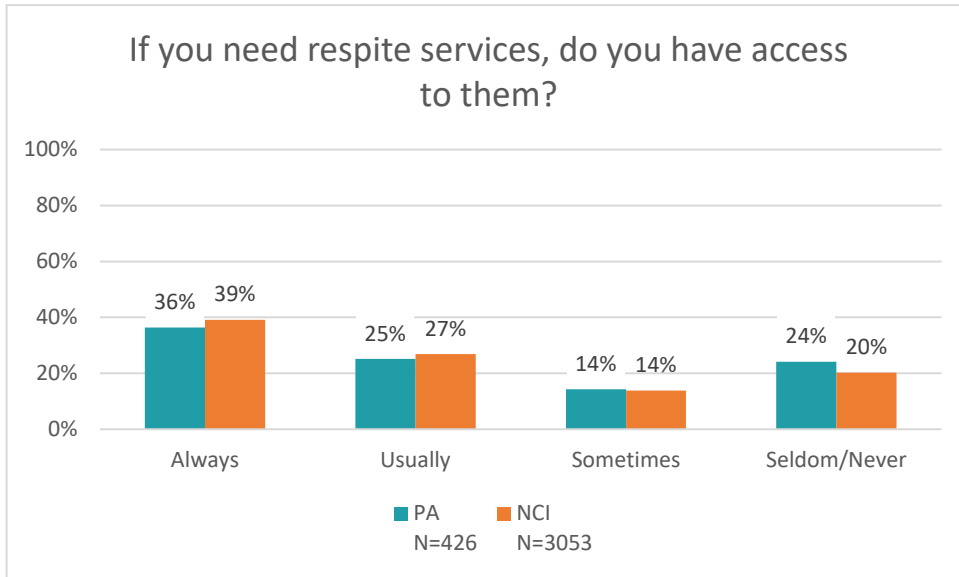
**Chart 31.** If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications?



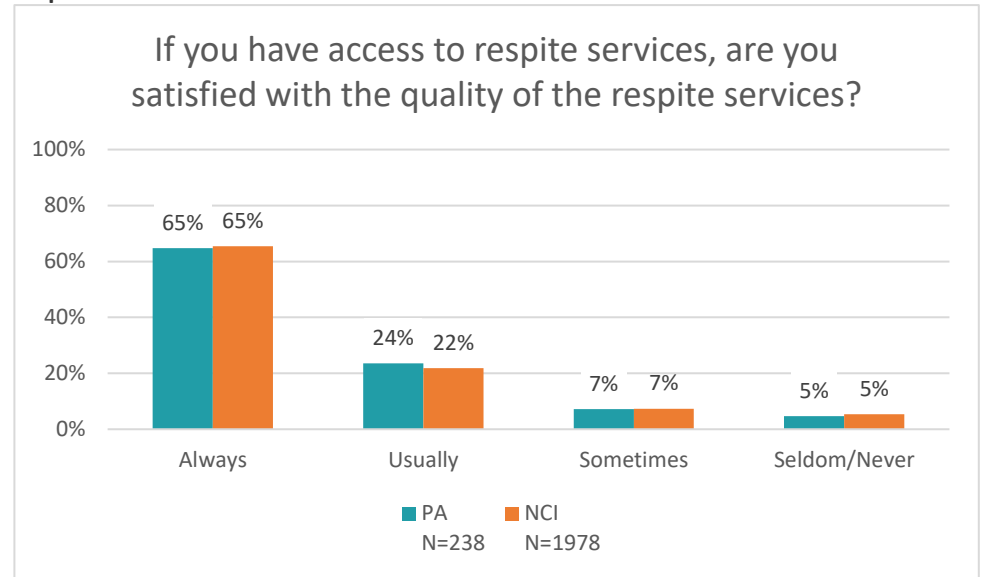
**Chart 32.** If your family member uses mental health services, does the mental health professional understand your family member’s needs related to his/her disability?



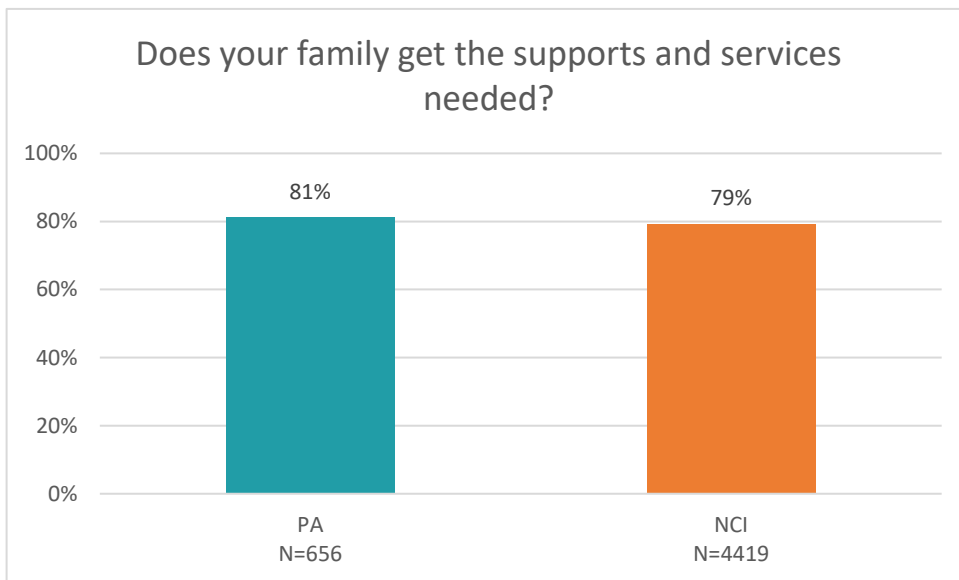
**Chart 33.** If you need respite services, do you have access to them?



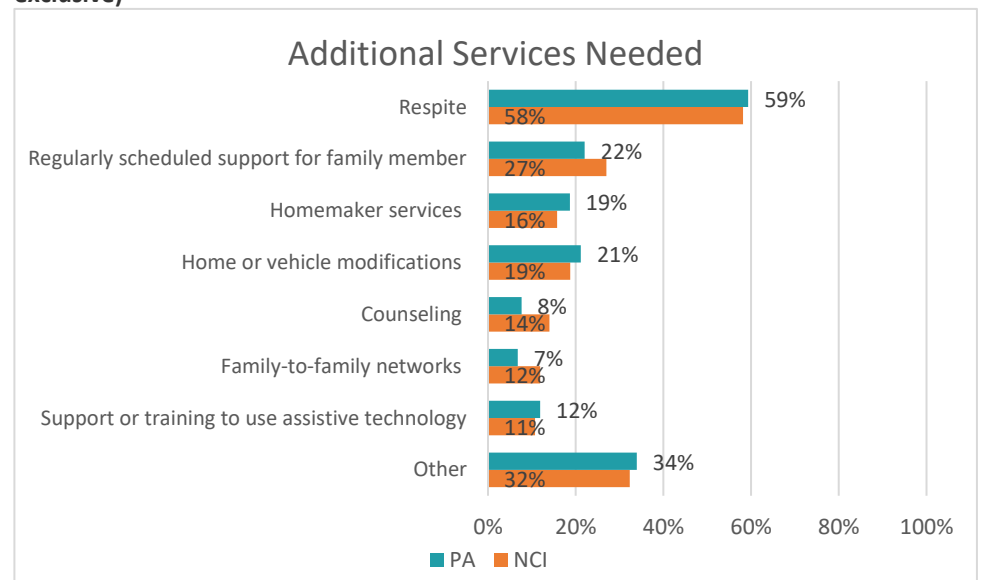
**Chart 34.** If you have access to respite services, are you satisfied with the quality of the respite services?



**Chart 35.** Does your family get the supports and services needed?



**Chart 36.** Additional services or supports needed (categories are not mutually exclusive)





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

Table 29. Access and Delivery of Services and Supports

		Always	Usually	Sometimes	Seldom/Never	N
Are you or your family member able to contact his/her support workers when you want to?	PA	66%	30%	4%	1%	681
	NCI	62%	31%	6%	2%	4,665
Are you or your family member able to contact his/her case manager/service coordinator when you want to?	PA▲	70%	26%	3%	1%	708
	NCI	65%	28%	5%	2%	4,935
Do support workers come and leave when they are supposed to?	PA	70%	26%	3%	0%	627
	NCI	66%	29%	4%	2%	4,264
Do services and supports change when your family's needs change?	PA	48%	40%	8%	5%	507
	NCI	44%	39%	11%	6%	3,605
Do support workers speak to you in a way that you understand?	PA	80%	18%	2%	0%	661
	NCI	79%	18%	2%	1%	4,508
Are services delivered in a way that is respectful of your family's culture?	PA	84%	14%	1%	0%	689
	NCI	82%	16%	2%	1%	4,760
If your family member does not communicate verbally, are there support workers who can communicate with him/her?	PA	29%	38%	21%	12%	156
	NCI	32%	37%	18%	14%	1,075
Do support workers have the right information and skills to meet your family's needs?	PA	54%	38%	6%	2%	623
	NCI	52%	39%	7%	2%	4,259
Does your family member have the special equipment or accommodations that s/he needs?	PA	53%	30%	11%	6%	336
	NCI	54%	30%	11%	6%	2,372

Table 30. Access and Delivery of Services and Supports (continued)

		Always	Usually	Sometimes	Seldom/Never	N
Can your family member see health professionals when needed?	PA	81%	17%	2%	0%	731
	NCI	78%	18%	3%	1%	5,097
Does your family member's primary care doctor understand his/her needs related to his/her disability?	PA	66%	28%	5%	1%	711
	NCI	63%	29%	6%	1%	4,990
Do you have access to dental services for your family member?	PA ▲	77%	11%	5%	6%	697
	NCI	71%	15%	6%	8%	4,884
If you have access to dental services for your family member, does your family member's dentist understand his/her needs related to his/her disability?	PA	72%	22%	4%	2%	631
	NCI	68%	24%	5%	3%	4,415
If your family member takes medications, do you know what they're for?	PA	93%	5%	1%	0%	645
	NCI	93%	6%	1%	1%	4,399
If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications?	PA	91%	8%	1%	0%	645
	NCI	92%	7%	1%	0%	4,349
If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?	PA	59%	29%	8%	5%	239
	NCI	58%	29%	8%	5%	1,817
If you need respite services, do you have access to them?	PA	36%	25%	14%	24%	426
	NCI	39%	27%	14%	20%	3,053
If you have access to respite services, are you satisfied with the quality of the respite services?	PA	65%	24%	7%	5%	238
	NCI	65%	22%	7%	5%	1,978

**Table 31. Access and Delivery of Services and Supports (continued)**

		Yes	No	N
Does your family get the supports and services needed?	PA	81%	19%	656
	NCI	79%	21%	4,419

**Table 32. Additional Services Needed (categories are not mutually exclusive)**

		Needs Service
Respite	PA	59%
	NCI	58%
Regularly scheduled support for family member	PA	22%
	NCI	27%
Homemaker services	PA	19%
	NCI	16%
Home or vehicle modifications	PA	21%
	NCI	19%
Counseling	PA	8%
	NCI	14%
Family-to-Family networks	PA	7%
	NCI	12%
Support/training to use family member's assistive technology	PA	12%
	NCI	11%
Other	PA	34%
	NCI	32%

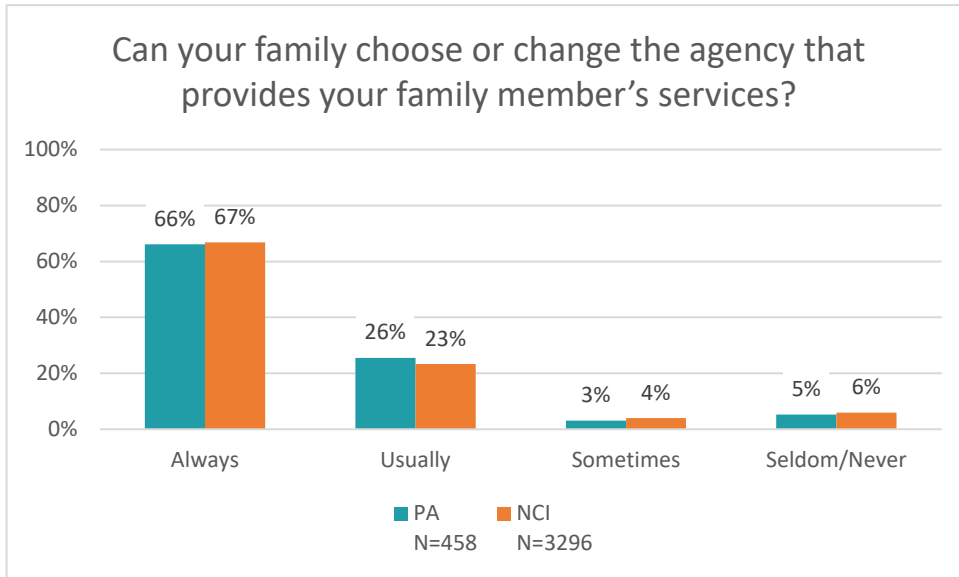
## **Choice, Decision Making and Control**

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

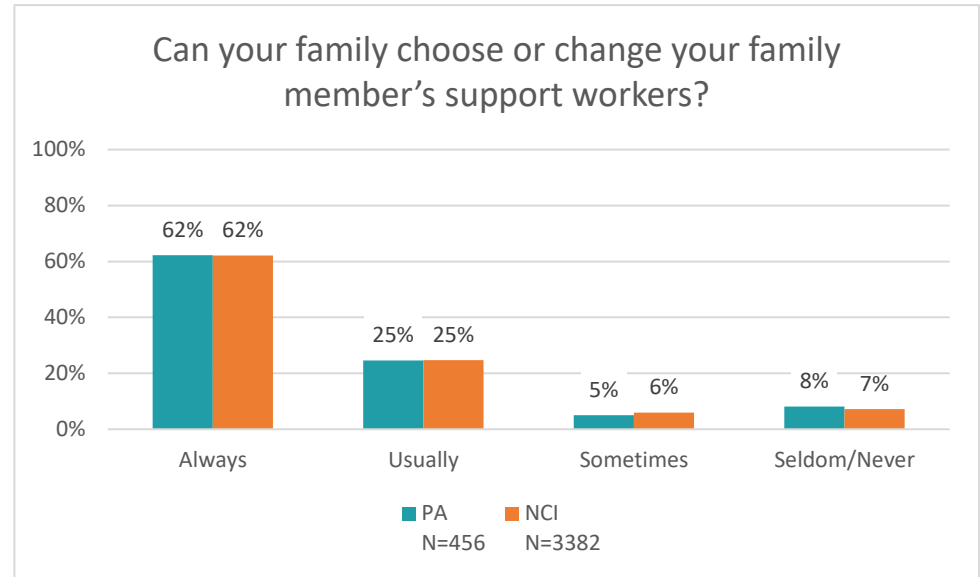
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## *Charts for Choice, Decision Making and Control*

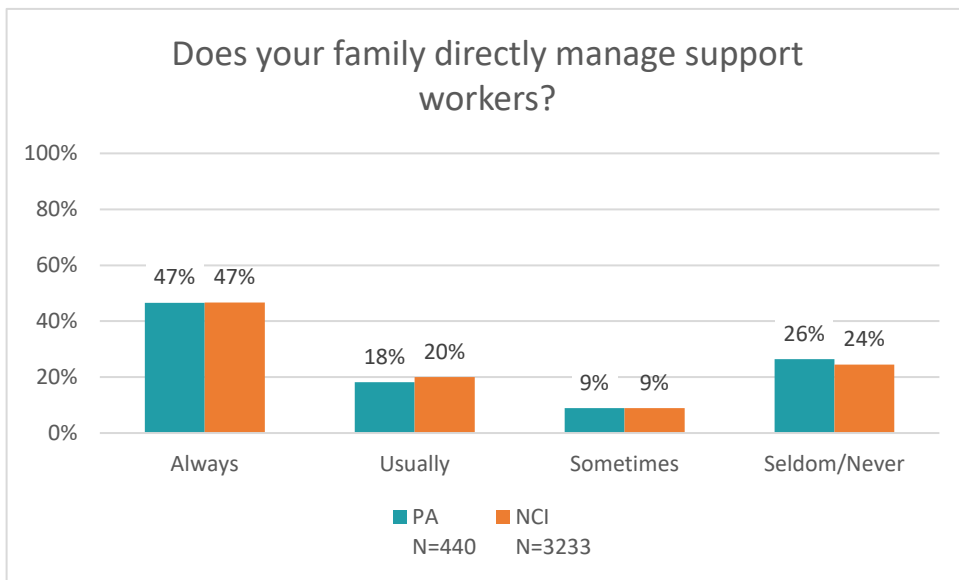
**Chart 37.** Can your family choose or change the agency that provides your family member's services?



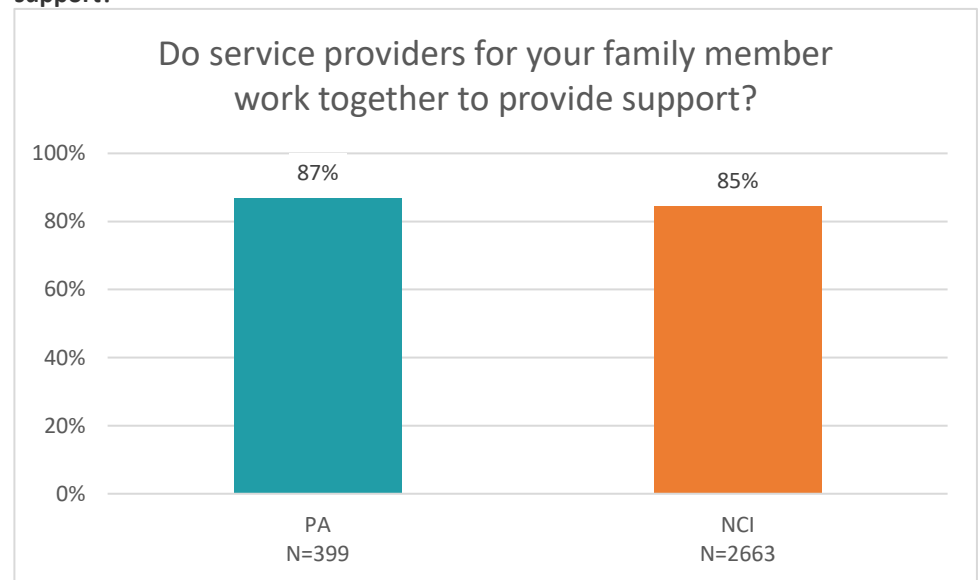
**Chart 38.** Can your family choose or change your family member's support workers?



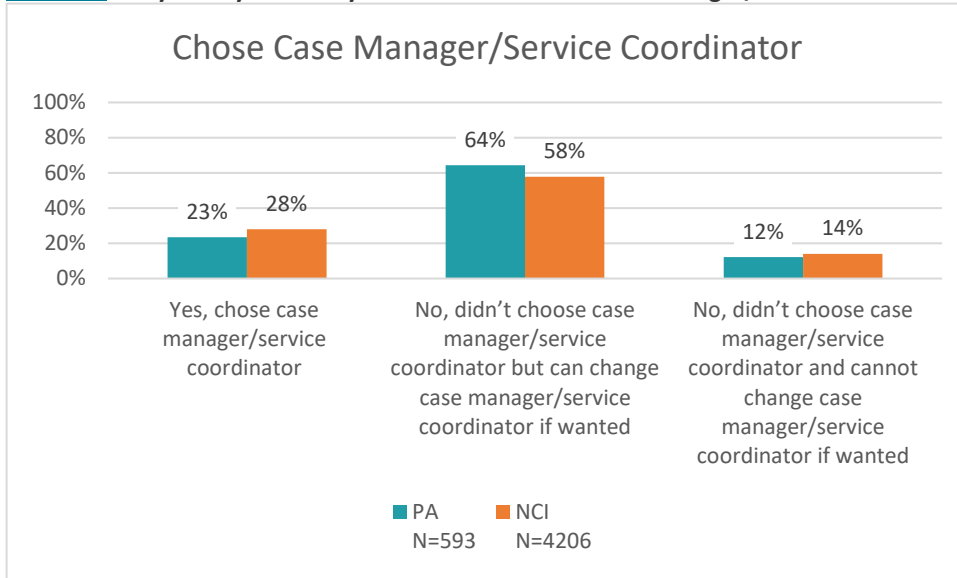
**Chart 39.** Does your family directly manage support workers?



**Chart 40.** Do service providers for your family member work together to provide support?



**Chart 41.** Did you or your family member choose the case manager/service coordinator





## *Tables for Choice, Decision Making and Control*

**Table 33. Choice and Control**

		Always	Usually	Sometimes	Seldom/Never	N
Can your family choose or change the agency that provides your family member's services?	PA	66%	26%	3%	5%	458
	NCI	67%	23%	4%	6%	3296
Can your family choose or change your family member's support workers?	PA	62%	25%	5%	8%	456
	NCI	62%	25%	6%	7%	3382
Does your family directly manage support workers?	PA	47%	18%	9%	26%	440
	NCI	47%	20%	9%	24%	3233

**Table 34. Choice and Control (continued)**

		Yes	No	N
Do service providers for your family member work together to provide support?	PA	87%	13%	399
	NCI	85%	15%	2663

Table 35. Chose Case Manager/Service Coordinator

		Chose Case Manager/ Service Coordinator
Yes, chose case manager/service coordinator	PA	23%
	NCI	28%
No, didn't choose case manager/service coordinator but can change case manager/service coordinator if wanted	PA	64%
	NCI	58%
No, didn't choose case manager/service coordinator and cannot change case manager/service coordinator if wanted	PA	12%
	NCI	14%
N	PA	593
	NCI	4,206

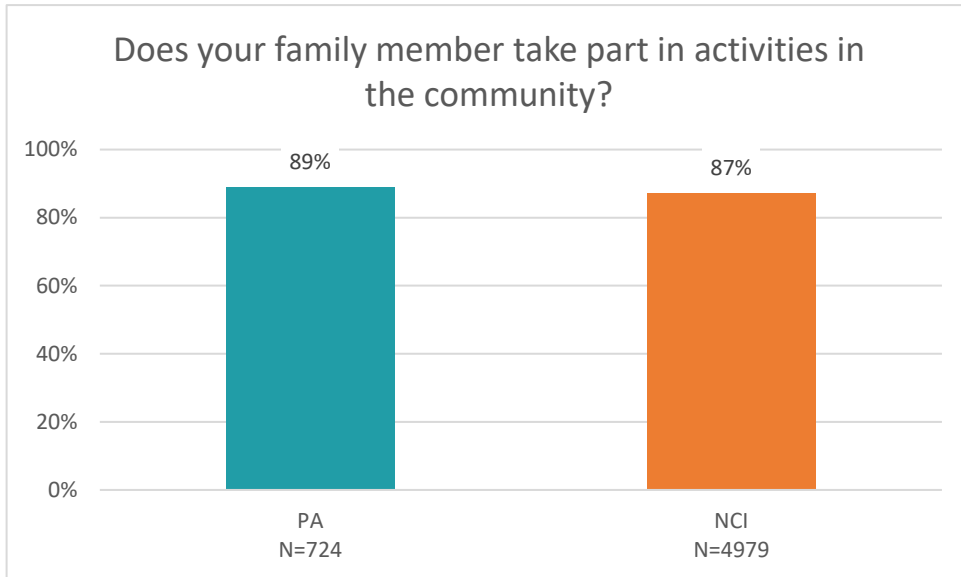
## **Involvement in the Community**

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

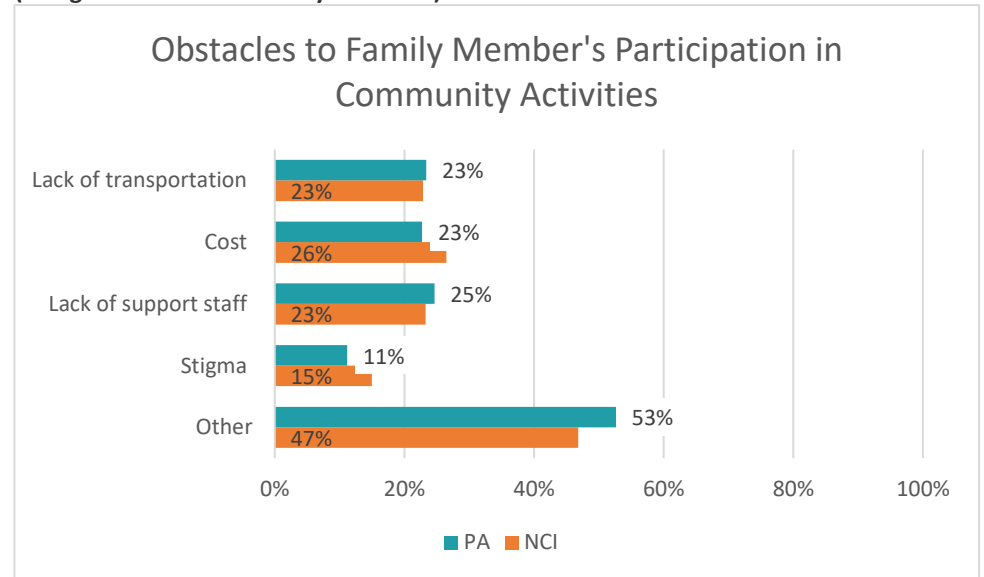
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## *Charts for Involvement in the Community*

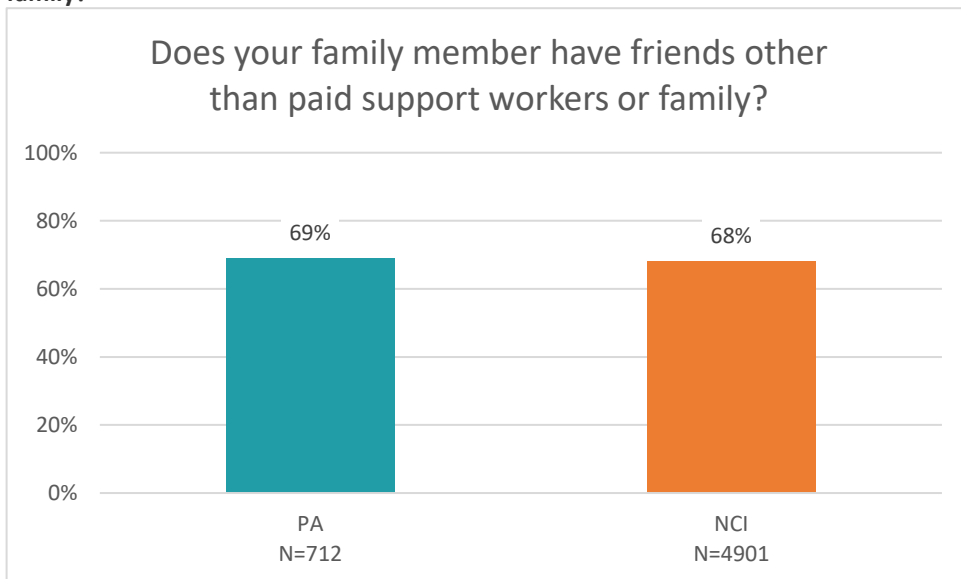
**Chart 42.** Does your family member take part in activities in the community?



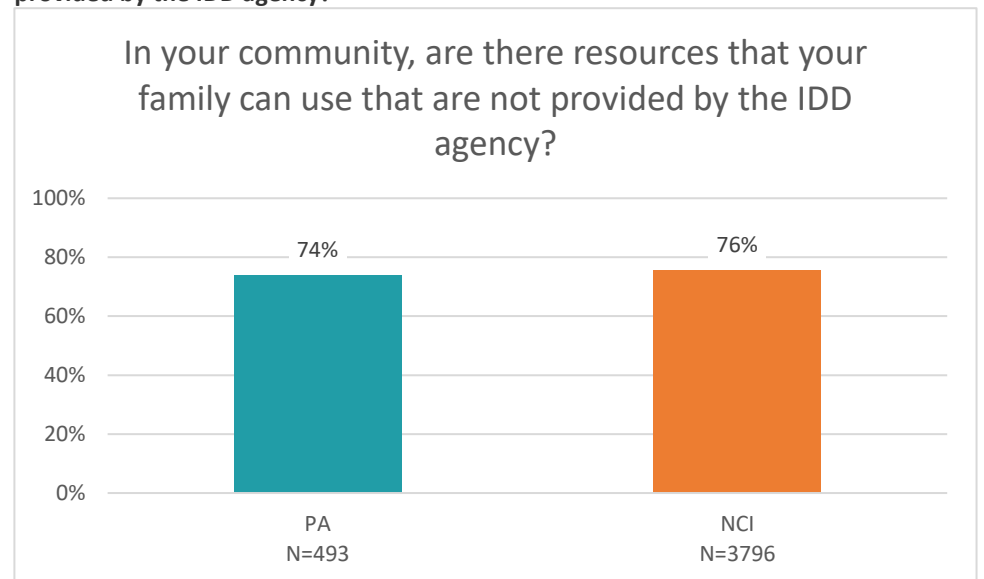
**Chart 43.** Obstacles/Barriers to family member's participation in community activities (categories are not mutually exclusive)



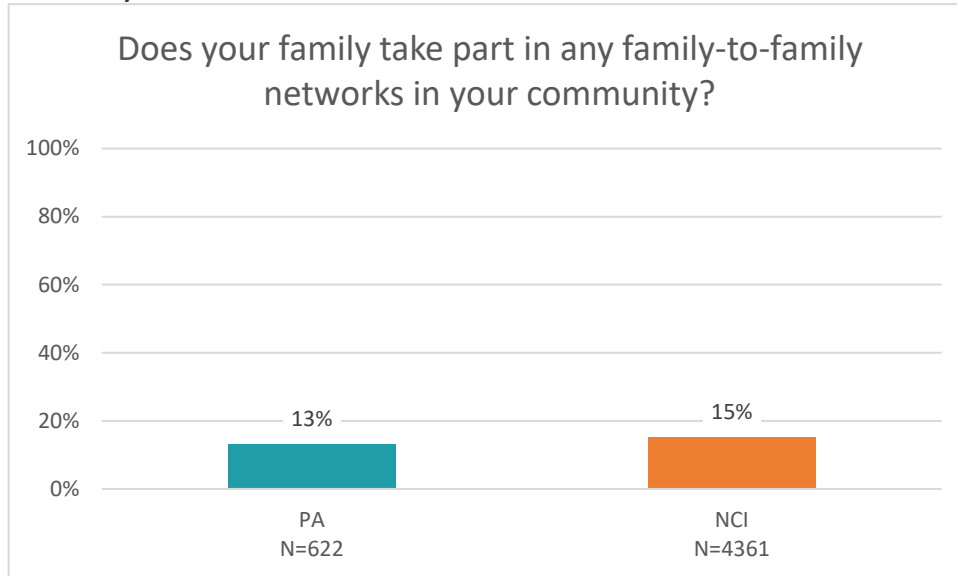
**Chart 44.** Does your family member have friends other than paid support workers or family?



**Chart 45.** In your community, are there resources that your family can use that are not provided by the IDD agency?



**Chart 46.** Does your family take part in any family-to-family networks in your community?



## *Tables for Involvement in the Community*



**Table 36. Involvement in the Community**

		Yes	No	N
Does your family member take part in activities in the community?	PA	89%	11%	724
	NCI	87%	13%	4,979

**Table 37. Obstacles to Family Member's Participation in Community Activities (categories are not mutually exclusive)**

		Obstacles/Barriers
Lack of transportation	PA	23%
	NCI	23%
Cost	PA	23%
	NCI	26%
Lack of support staff	PA	25%
	NCI	23%
Stigma	PA	11%
	NCI	15%
Other	PA	53%
	NCI	47%

**Table 38. Involvement in the Community (continued)**

		Yes	No	N
Does your family member have friends other than paid support workers or family?	PA	69%	31%	712
	NCI	68%	32%	4,901
In your community, are there resources that your family can use that are not provided by the IDD agency?	PA	74%	26%	493
	NCI	76%	24%	3,796
Does your family take part in any family-to-family networks in your community?	PA	13%	87%	622
	NCI	15%	85%	4,361

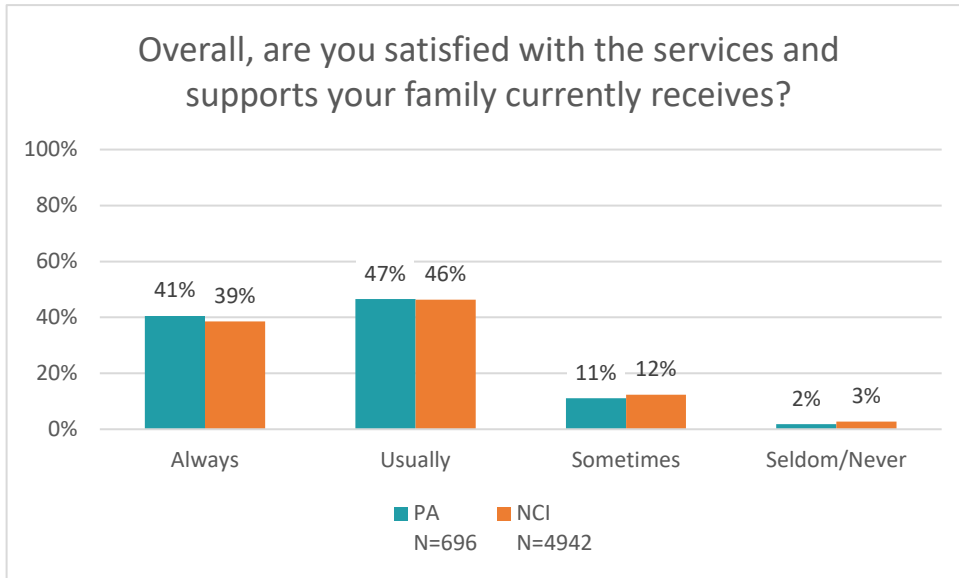
## Satisfaction With Services and Supports

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

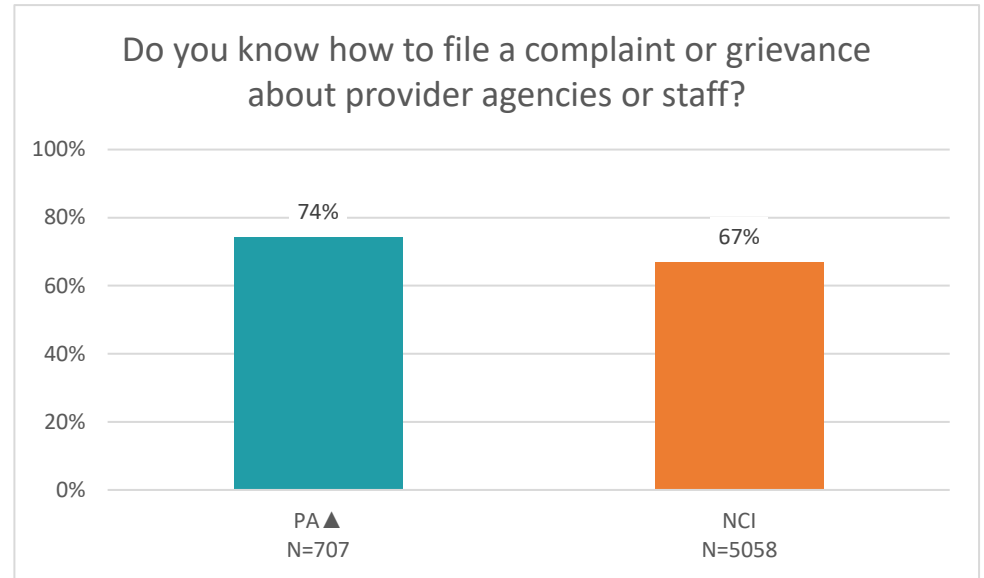
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## *Charts for Satisfaction With Services and Supports*

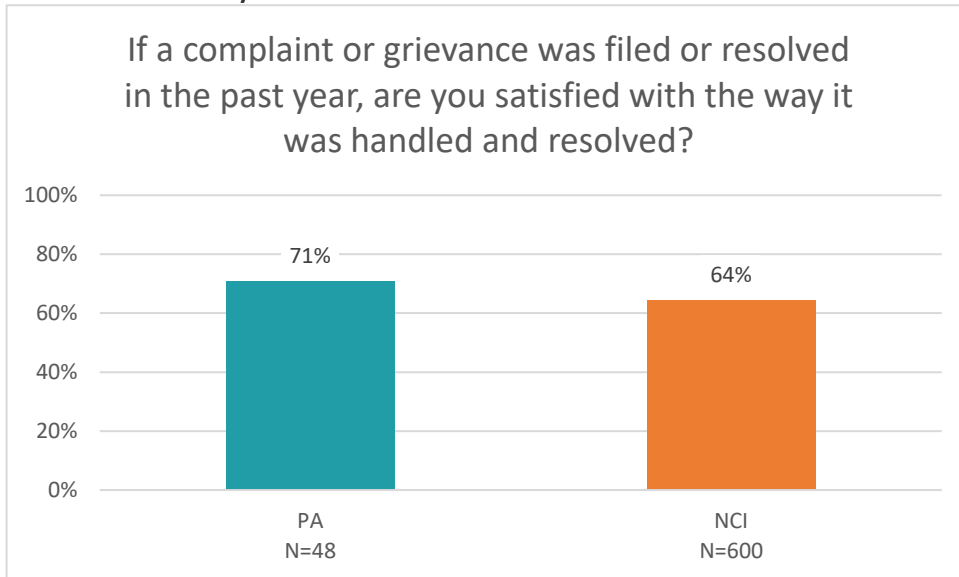
**Chart 47.** Overall, are you satisfied with the services and supports your family currently receives?



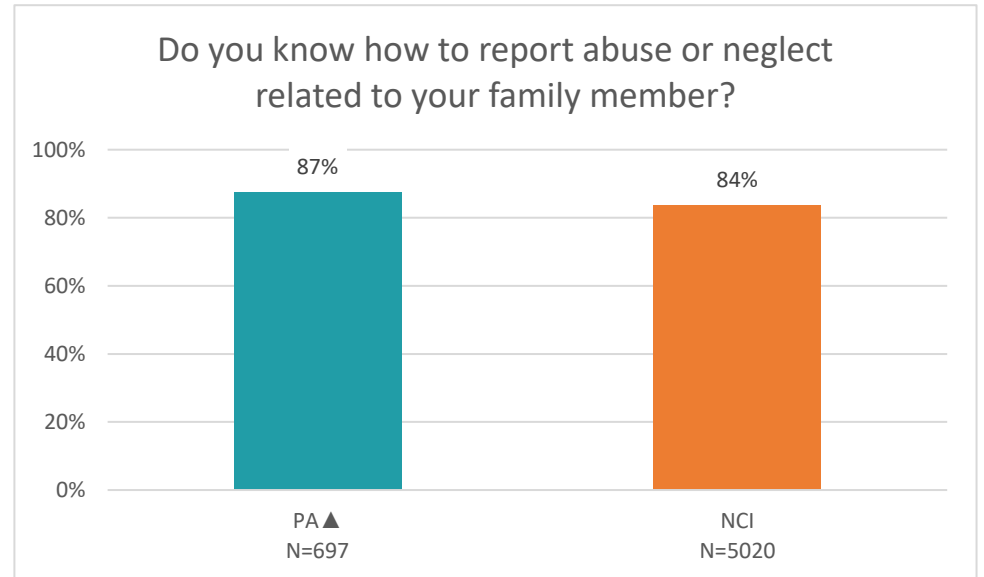
**Chart 48.** Do you know how to file a complaint or grievance about provider agencies or staff?\*



**Chart 49.** If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

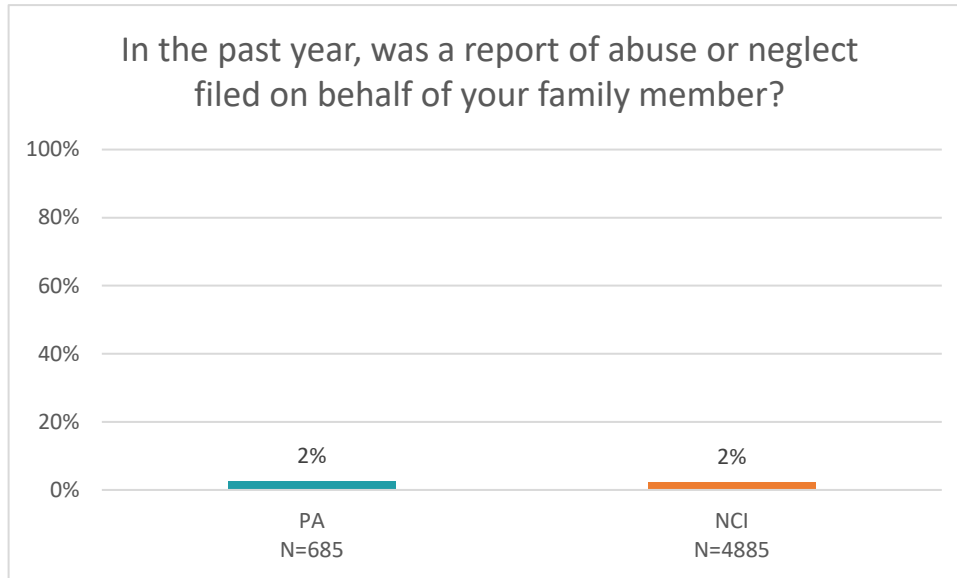


**Chart 50.** Do you know how to report abuse or neglect related to your family member?\*

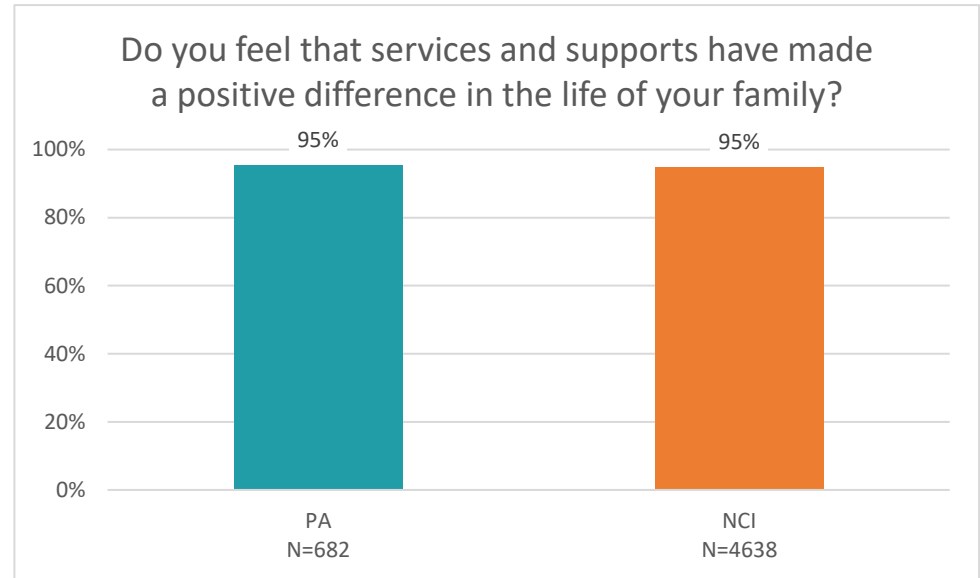


\*No and don't know responses are combine

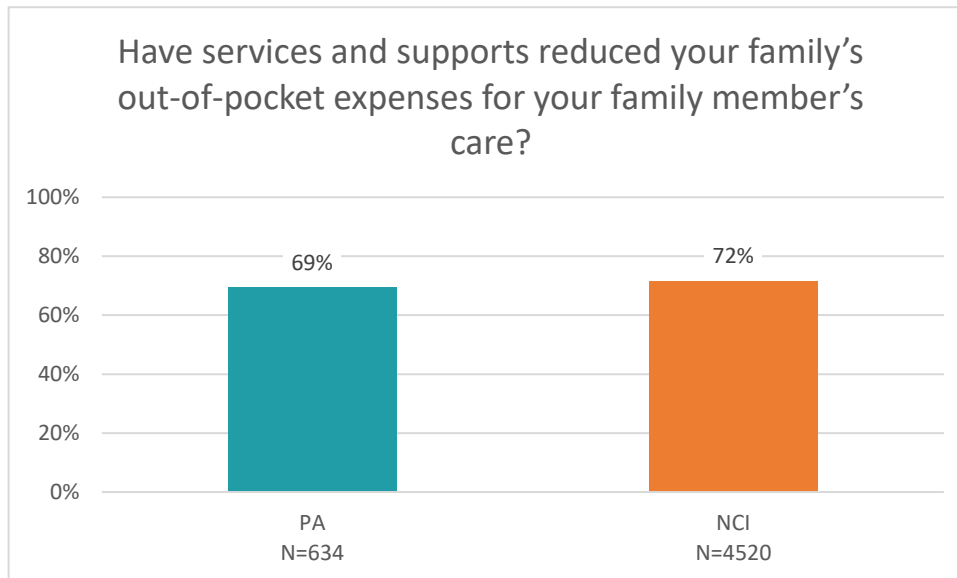
**Chart 51.** In the past year, was a report of abuse or neglect filed on behalf of your family member?



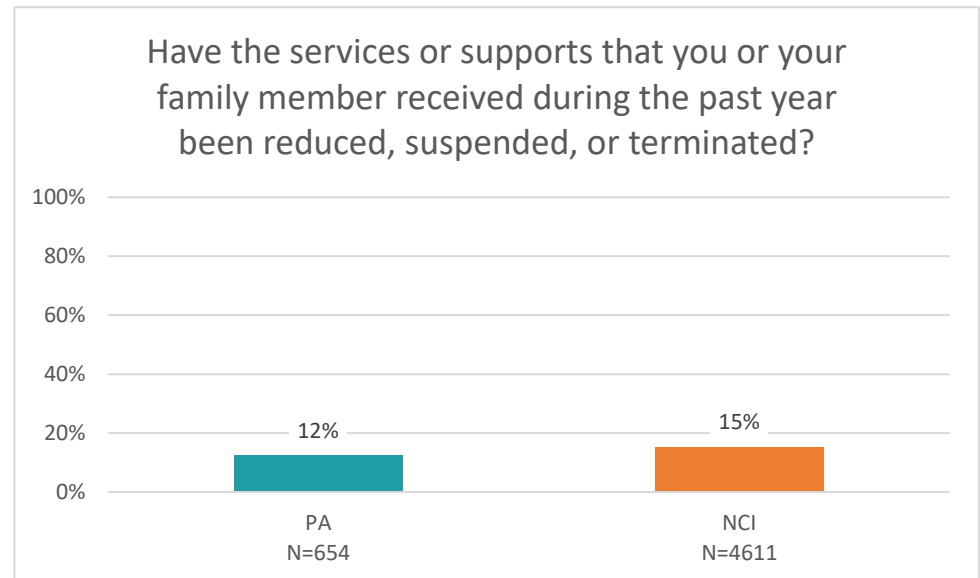
**Chart 52.** Do you feel that services and supports have made a positive difference in the life of your family?



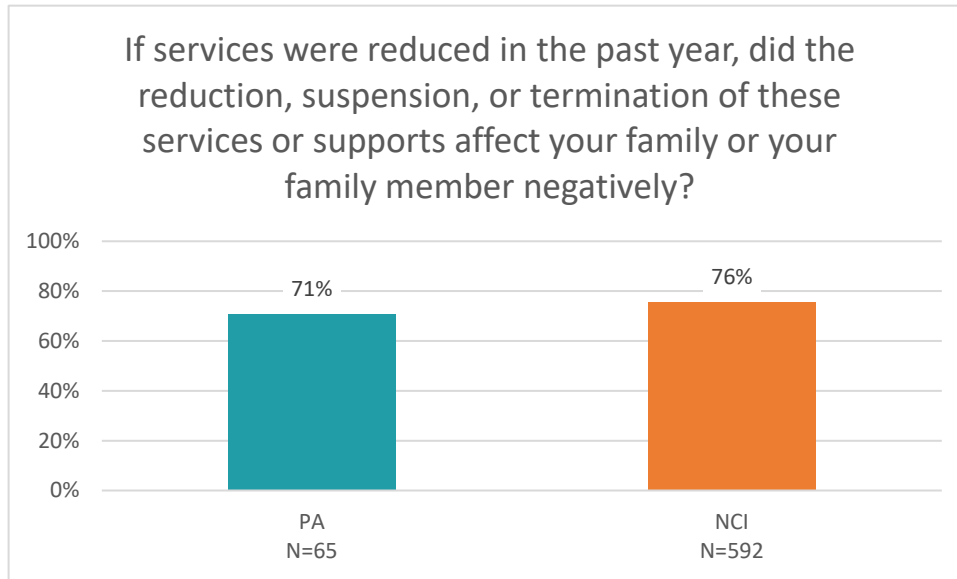
**Chart 53.** Have services and supports reduced your family's out-of-pocket expenses for your family member's care?



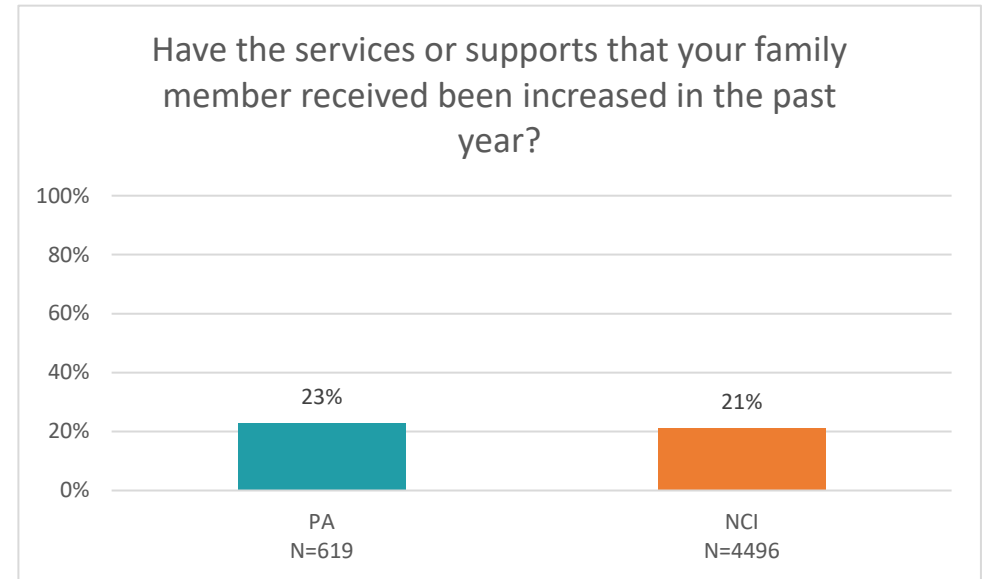
**Chart 54.** Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?



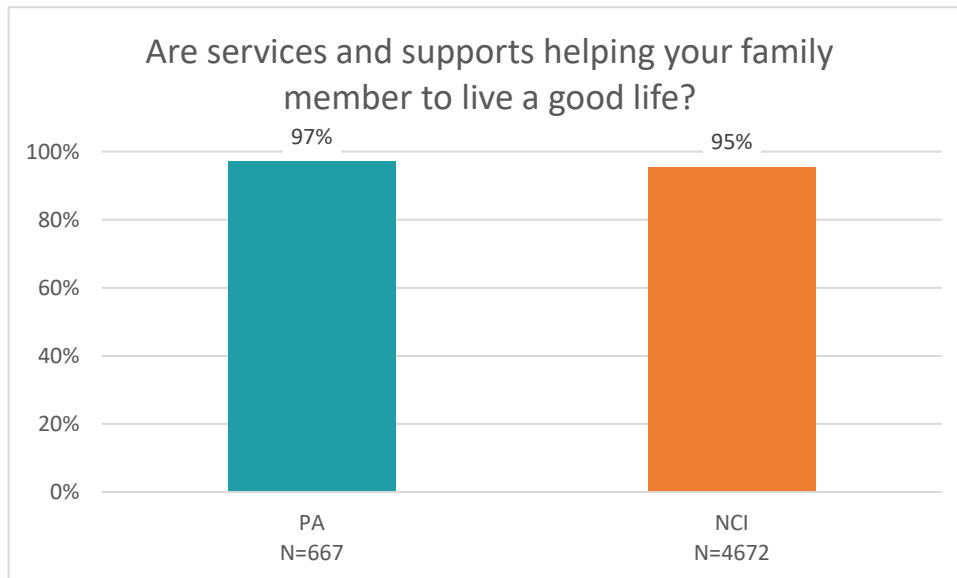
**Chart 55.** If services were reduced in the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?



**Chart 56.** Have the services or supports that your family member received been increased in the past year?



**Chart 57.** Are services and supports helping your family member to live a good life?



## *Tables for Satisfaction With Services and Supports*



**Table 39. Satisfaction With Service and Support**

		Always	Usually	Sometimes	Seldom/Never	N
Overall, are you satisfied with the services and supports your family currently receives?	PA	41%	47%	11%	2%	696
	NCI	39%	46%	12%	3%	4,942

**Table 40. Satisfaction With Service and Supports (continued)**

		Yes	No	N
Do you know how to file a complaint or grievance about provider agencies or staff? *	PA ▲	74%	18%	707
	NCI	67%	23%	5,058
If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?	PA	71%	29%	48
	NCI	64%	36%	600
Do you know how to report abuse or neglect related to your family member? *	PA ▲	87%	6%	697
	NCI	84%	10%	5,020
In the past year, was a report of abuse or neglect filed on behalf of your family member?	PA	2%	98%	685
	NCI	2%	98%	4,885

\*No and don't know responses are combine

Table 41. Satisfaction With Service and Supports (continued)

		Yes	No	N
Do you feel that services and supports have made a positive difference in the life of your family?	PA	95%	5%	682
	NCI	95%	5%	4,638
Have services and supports reduced your family's out-of-pocket expenses for your family member's care?	PA	69%	31%	634
	NCI	72%	28%	4,520
Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?	PA	12%	88%	654
	NCI	15%	85%	4,611
If services were reduced in the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?	PA	71%	29%	65
	NCI	76%	24%	592
Have the services or supports that your family member received been increased in the past year?	PA	23%	77%	619
	NCI	21%	79%	4,496
Are services and supports helping your family member to live a good life?	PA	97%	3%	667
	NCI	95%	5%	4,672