2016-17 FAMILY/GUARDIAN 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 2016-17 a total of 45 states, the District of Columbia and 22 sub-state entities participated in NCI.

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 and guardians who have an adult family member who does not live 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 2016-17, a total of 9,194 Family/Guardian Surveys were completed across 12 states¹. 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.

¹ States that conducted the Family/Guardian Survey in 2016-17 were: AZ, CA, FL, GA, KY, LA, MD, NC, NJ, PA, SD and VA.

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

Sub-Domain	Concern Statement
Information and Planning	Families/family members with disabilities have the information and
	support necessary to plan for their services and supports.
Access & Support Delivery	Families/family members with disabilities get the services and supports
	they need.
Choice, Decision Making &	Families/family members with disabilities determine the services and
Control	supports they receive and the individuals or agencies who provide them.
Involvement in the Community	Family members with disabilities use integrated community services and
	participate in everyday community activities.
Satisfaction	Families/family members with disabilities receive adequate and
	satisfactory supports.
Outcomes	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 1,200 families, all of whom have an adult family member with an intellectual or developmental disability who lives somewhere other than 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. A total of five states had at least a portion of surveys completed via direct entry mode.²

All states mailed out a paper survey to families selected in their sample. A sample size of 1,200 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%.

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 somewhere other than the family home.
- 2. At least a portion of survey questions were answered aside from demographic information.

² States that used the direct entry or mail and direct entry options were: KY, LA, NC, NJ, and SD. For more information on response rates and mode, please see the Methodology section within the national edition of the 2016-17 Family/Guardian Survey Report.

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 in table presentations for a survey item if fewer than 20 people responded; however, their data are included in the NCI Average.

Weighting

In previous years, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as "average of averages"). This year, the approach has been enhanced to take into account the relative numbers of people receiving services through participating states' systems. Beginning this year, 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.³

Significance testing

Starting this survey cycle (2016-17), 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 ▼).

³ For more information on weighting and significance testing, see the Methodology section of the National Family/Guardian Survey.

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

Limitations of the data

The NCI Family/Guardian 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, policy-makers, and other stakeholders to use the data to determine programmatic and policy-related priorities.

What is contained in this report?

This report illustrates the 2016-17 NCI Family/Guardian Survey demographic and outcome results from Pennsylvania (PA) compared to the NCI Average. All results are shown first in charts and then in table form, and arrow symbols (\blacktriangle and \checkmark) are used to indicate areas where the state average was statistically higher or lower than the NCI Average. **Please note: items without the** \blacktriangle or \lor 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 were excluded from analysis for that question. All state and national data results for this survey can be found online at http://www.nationalcoreindicators.org/resources/reports/.

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

Family Member

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

Table 1. Family member's residence

		Specialized facility for people with intellectual disabilities (ICF, state- run or other institutional setting)	Group Home	Agency Operated Apartment	Independent Home or Apartment		Nursing Home	Homeless	Other	Ν
Family Member's Residence	PA	16%	61%	6%	9%	4%	3%	0%	1%	682
	NCI	12%	53%	7%	20%	4%	2%	0%	2%	8,945

Table 2. Family member's residential setting

		Urban or suburban	Rural	N
Family Member's Residential Setting	PA	71%	29%	676
	NCI	85%	15%	8,879

Table 3. Family member's age

		Mean	N
Family Member's Age	PA	51.3	676
	NCI	46.3	8,964

Table 4. Family member's gender

		Male	Female	N
Family Member's Gender	PA	55%	45%	687
	NCI	59%	41%	9,067

Table 5. Family member's race and ethnicity

		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%	5%	0%	93%	1%	1%
· · ·	NCI	2%	4%	10%	0%	79%	2%	7%

Table 6a. Family member's disabilities *

		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%	38%	20%	17%	12%	7%	13%
	NCI	74%	33%	25%	17%	9%	7%	11%

Table 6b. Family member's disabilities (continued)*

		Seizure	Chemical	Down	Prader-	Fetal	Other
		Disorder or	Dependency	Syndrome	Willi	Alcohol	
		Neurological			Syndrome	Spectrum	
		Problem				Disorder	
Family Member's Disabilities	PA	32%	1%	13%	1%	0%	13%
	NCI	28%	1%	9%	1%	1%	13%

Table 7a. Family member's health conditions *

		Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
Family Member's Health Conditions	PA	10%	15%	6%	26%	30%
	NCI	9%	19%	5%	30%	31%

Table 7b. Family member's health conditions (continued) *

		Dysphagia	Pressure Ulcers	Alzheimer's Disease or Other Dementia	Dental	Sleep Apnea	Other
Family Member's Health Conditions	PA	20%	2%	8%	15%	12%	30%
	NCI	12%	2%	5%	16%	12%	33%

*Categories are not mutually exclusive; therefore N is not shown

Table 8. Family member's preferred means of communication

		Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	Ν
Family Member's Preferred Means of Communication	PA	69%	25%	1%	1%	3%	679
	NCI	74%	19%	2%	1%	4%	9,027

Table 9. Family member's level of guardianship

		None	Limited	Full	Has Guardianship but Level Is Unknown	Ν
Level of Guardianship or Conservatorship of Family Member	ΡΑ	29%	17%	44%	10%	610
	NCI	32%	10%	32%	26%	8,415

Table 10. Guardian or conservator's relationship to family member

		Family	Friend	State Employee or Guardianship Agency	Other	Ν
Guardian or Conservator Relationship to Family Member	PA	87%	2%	7%	3%	368
	NCI	86%	2%	8%	4%	5,071

Table 11. 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	Ν
Family Member's Highest Level of Education	PA	44%	0%	23%	26%	3%	1%	2%	578
	NCI	39%	1%	28%	19%	3%	5%	5%	8,169

Table 12. Family member's typical day activity

		Usually/Often	Sometimes	Never	N
Paid Individual Job in the Community	PA	9%	2%	89%	530
	NCI	14%	4%	82%	6,442
Paid Small Group Job in a Community-based Setting	PA	9%	2%	89%	521
	NCI	14%	5%	81%	6,205
Unpaid Activity in the Community	PA	17%	10%	73%	517
	NCI	19%	14%	67%	6,180
Paid Activity in a Facility-based Setting	PA	27%	4%	69%	555
alu Activity in a Facility-based Setting	NCI	24%	7%	70%	6,463
Unpaid Activity in a Facility-based Setting	PA	36%	6%	57%	534
	NCI	39%	7%	54%	6,423
School	PA	5%	1%	95%	413
	NCI	10%	3%	87%	5,030
Stays at Home	PA	30%	21%	49%	395
	NCI	31%	21%	48%	4,947
Other	PA	76%	10%	14%	72
	NCI	58%	9%	32%	1,373

Table 13. Family member's support needs

		Extensive	Some	None	Ν
Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	PA	32%	38%	31%	664
	NCI	30%	37%	33%	8,715
Family Member's Need for Help With Personal Care Activities	PA	48%	36%	17%	669
	NCI	40%	37%	23%	8,987
Family Member's Need for Help With Other Daily Activities	PA	84%	14%	2%	658
	NCI	76%	21%	3%	8,901

Respondents

This section provides demographic information about the respondent.

Table 14. Respondent's age

		Under 35	35-54	55-74	75+	Ν
Respondent's Age	PA	1%	9%	62%	29%	672
	NCI	1%	11%	60%	27%	9,048

Table 15. Respondent's health

		Excellent	Very good	Fairly good	Poor	N
Respondent's Health	PA	12%	42%	40%	6%	667
	NCI	15%	42%	38%	6%	9,014

Table 16. Respondent's relationship to family member

		Parent	Sibling	Spouse	Grandparent	Public	Private	Other	Ν
						Guardian	Guardian		
Respondent's Relationship to Family Member	PA	57%	38%	0%	1%	0%	2%	2%	675
	NCI	67%	21%	0%	1%	2%	3%	7%	9,083

Table 17. How often respondent sees family member each year

		Less Than Once	1-3 Times	4-6 Times	7-12 Times	12 or More Times	N
How Often Respondent Sees Family Member Each Year	PA	4%	8%	11%	12%	65%	687
	NCI	4%	10%	10%	12%	64%	9,052

Table 18. 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	3%	34%	6%	19%	38%	677
	NCI	5%	19%	5%	24%	47%	8,936

Table 19. Total taxable income of wage earners in household in the past year

		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	5%	10%	18%	9%	12%	14%	32%	529
	NCI	6%	10%	17%	11%	18%	11%	27%	7,120

Services and Supports Received

This section provides information about the services and supports received by the family.

Table 20. Services and Supports Received From ID/DD Agency *

		Services and Supports Received From State
Financial Support	PA	23%
	NCI	33%
In-home Support	PA	30%
	NCI	36%
Residential Supports	PA	88%
	NCI	84%
Day or Employment Supports	PA	67%
	NCI	68%
Transportation	PA	89%
	NCI	82%
Other	PA	63%
	NCI	52%
Self-direction or Fiscal Intermediary Services	PA	19%
· ·	NCI	20%

Table 21. Additional Services and Supports Received *

		Additional Services and Supports Received (Not From the IDD Agency)
Social Security Dovements (SSL/SSD)	PA	96%
Social Security Payments (SSI/SSB)		
	NCI	94%
Services or Supports From Other Agencies or	PA	36%
Organizations		
	NCI	28%

*Categories are not mutually exclusive; therefore N is not shown

Information and Planning

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

National Core Indicators™

Charts for Information and Planning

Chart 1.

Chart 2.

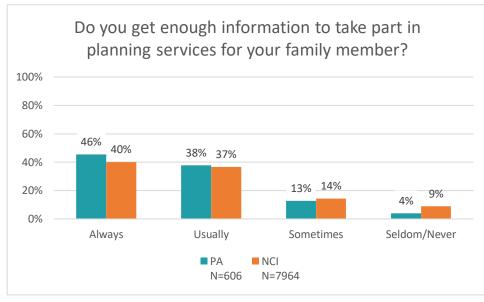
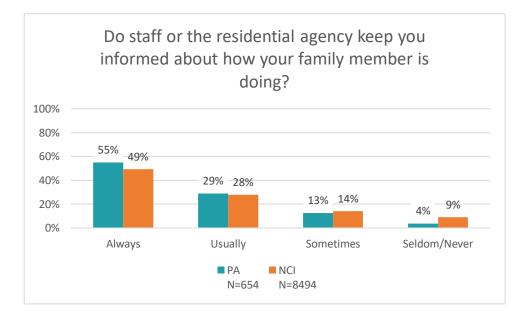


Chart 3.



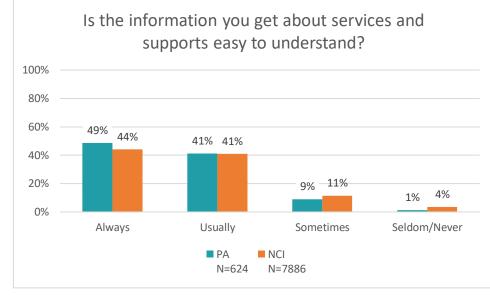


Chart 4.

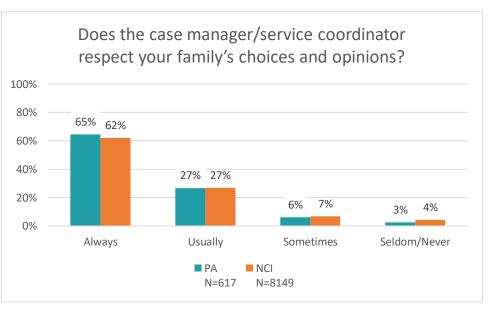
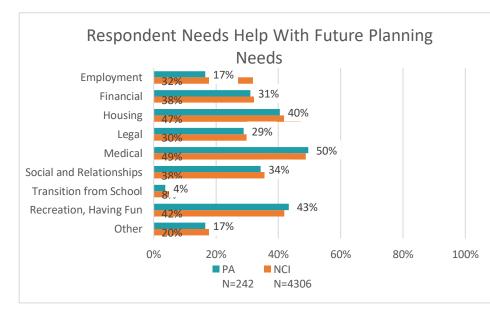


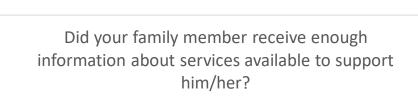
Chart 6.

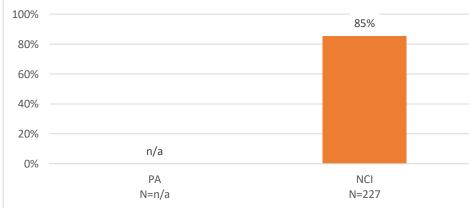
Chart 8.



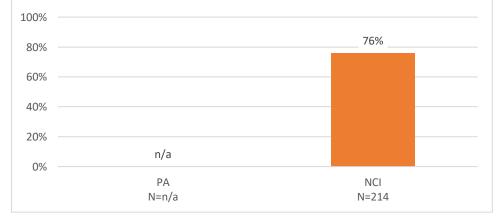
In the past year, did your family member move out of the family home for the first time? 100% 80% 60% 40% 20% 3% 2% 0% PA NCI N=658 N=8699

Chart 7.





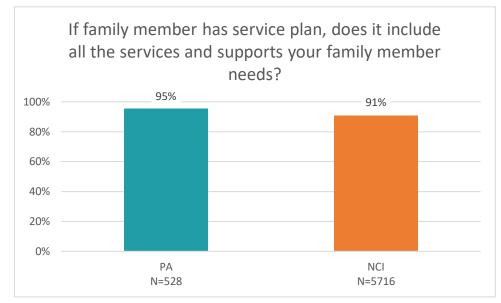
Did you have enough choices of service providers to support your family member living outside the family home?



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Chart 5.

<u>Chart 10.</u>



<u>Chart 12.</u>

If family member has service plan, did you or another family member (beside your family member with a disability) help make the plan?

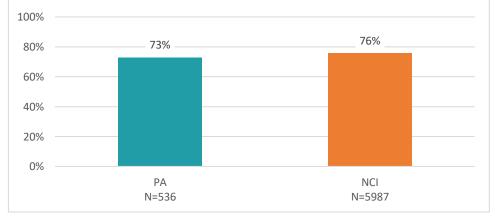
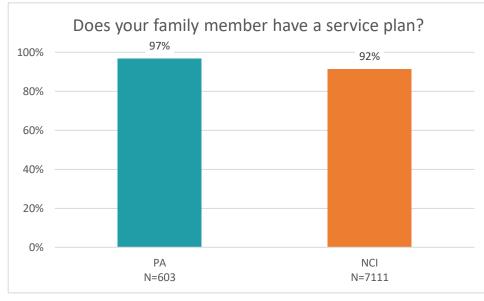
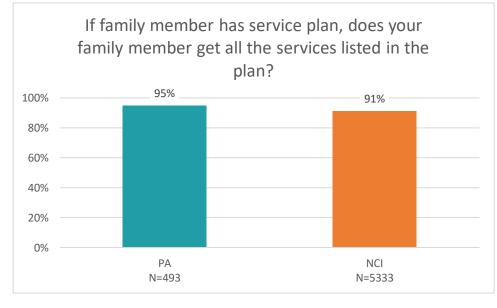


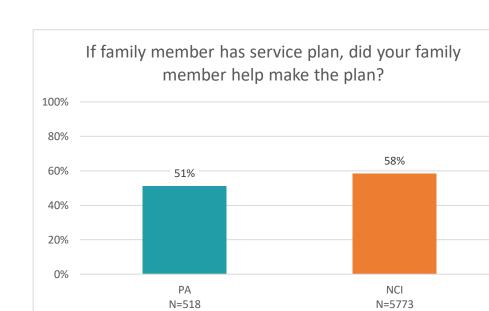
Chart 9.



<u>Chart 11.</u>

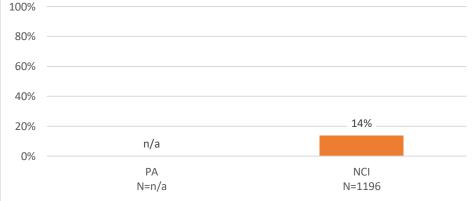


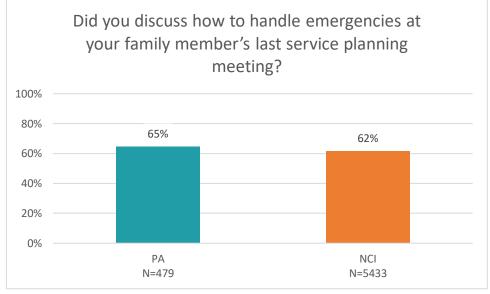
<u>Chart 14.</u>



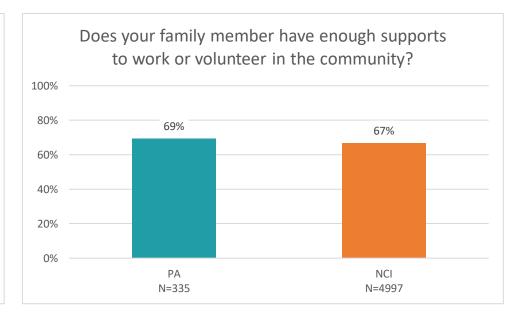
<u>Chart 15.</u>







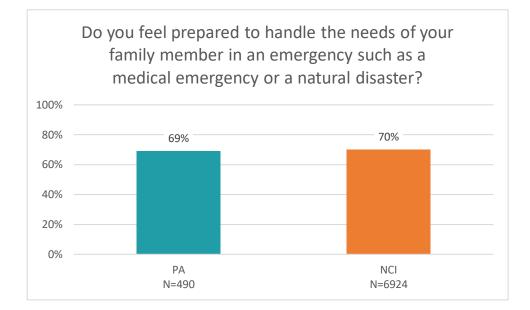
<u>Chart 16.</u>



<u>Chart 13.</u>

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<u>Chart 17.</u>



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Tables for Information and Planning

Table 22. Information and Planning—Always Responses

		Always	Usually	Sometimes	Seldom/Never	N
Do you get enough information to take part in planning services for your family member?	PA 🛦	46%	38%	13%	4%	606
	NCI	40%	37%	14%	9%	7,964
Is the information you get about services and supports easy to understand?	PA	49%	41%	9%	1%	624
	NCI	44%	41%	11%	4%	7,886
Do staff or the residential agency keep you informed about how your family member is doing?	PA 🛦	55%	29%	13%	4%	654
	NCI	49%	28%	14%	9%	8,494
Does the case manager/service coordinator respect your family's choices and opinions?	PA	65%	27%	6%	3%	617
	NCI	62%	27%	7%	4%	8,149

Table 23. Respondent Needs Help With Future Planning Needs

		Yes
Employment	РА	17%
	NCI	32%
Financial	PA	31%
	NCI	38%
Housing	PA	40%
	NCI	47%
Legal	PA	29%
	NCI	30%
Medical	PA	50%
	NCI	49%
Social and Relationships	PA	34%
	NCI	38%
Transition from School	PA	4%
	NCI	8%
Recreation, Having Fun	РА	43%
	NCI	42%
Other	РА	17%
	NCI	20%
Ν	РА	242
	NCI	4,306

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Table 24. Information and Planning—No Responses

		Yes	No	Ν
In the past year, did your family member move out of the family home for the first time?	PA▼	2%	98%	658
	NCI	3%	97%	8,699
If family member moved out of the family home for the first time in the past year				
Did your family member receive enough information about services available to support him/her?	PA	n/a	n/a	n/a
	NCI	85%	15%	227
Did you have enough choices of service providers to support your family member living outside the family home?	РА	n/a	n/a	n/a
	NCI	76%	24%	214
Does your family member have a service plan?	PA 🛦	97%	3%	603
	NCI	92%	9%	7,111
If your family member has a service plan				
Does it include all the services and supports your family member needs?	PA 🛦	95%	5%	528
	NCI	91%	9%	5,716
Does your family member get all the services listed in the plan?	PA 🛦	95%	5%	493
	NCI	91%	9%	5,333
Did you or another family member (beside your family member with a disability) help make the plan?	PA	73%	27%	536
	NCI	76%	24%	5,987
Did your family member help make the plan?	PA▼	51%	49%	518
	NCI	58%	42%	5,773
Did you discuss how to handle emergencies at your family member's last service planning meeting?	PA	65%	35%	479
	NCI	62%	38%	5,433
If your family member transitioned out of school services during the past year, did s/he have a transition plan?	РА	n/a	n/a	n/a
	NCI	14%	86%	1,196
Does your family member have enough supports to work or volunteer in the community?	PA	69%	31%	335
	NCI	67%	33%	4,997
Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?	РА	69%	31%	490
	NCI	70%	30%	6,924

Access and Delivery of Services and Supports

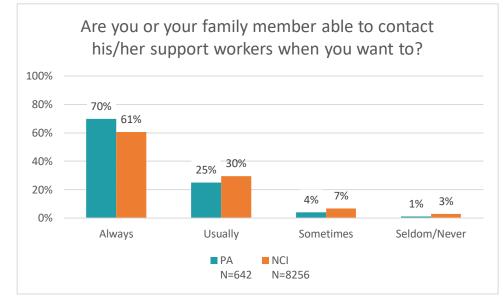
Families and family members with disabilities get the services and supports they need

National Core Indicators™

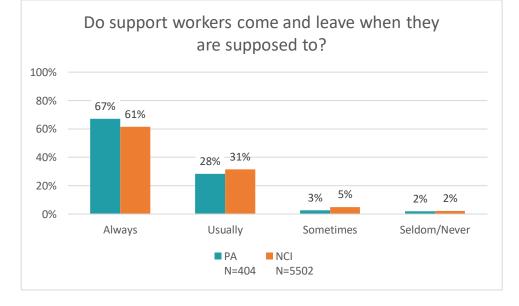
Charts for Access and Delivery of Services and Supports

<u>Chart 18.</u>

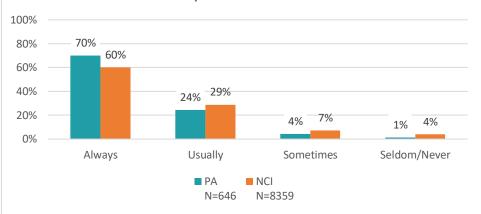
<u>Chart 19.</u>



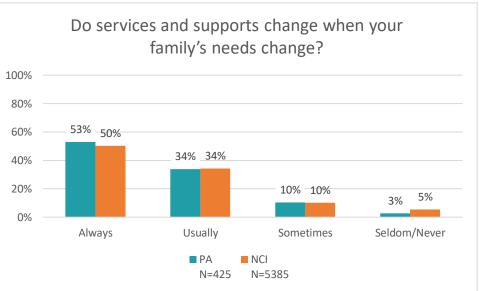
<u>Chart 20.</u>



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

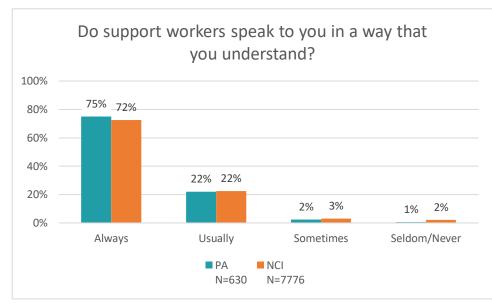


<u>Chart 21.</u>



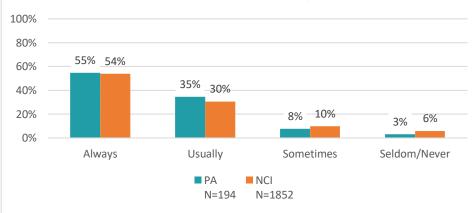
<u>Chart 22.</u>

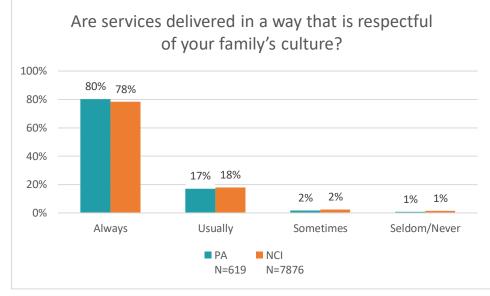




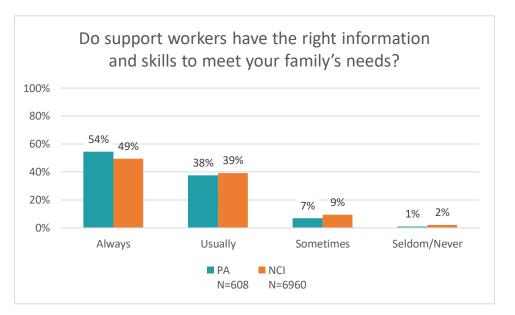
<u>Chart 24.</u>

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



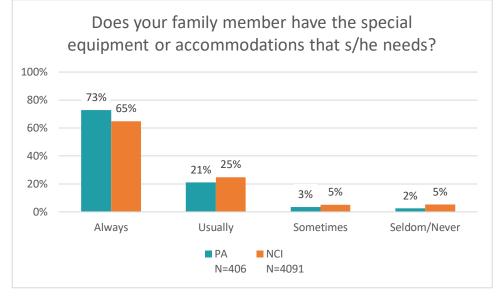


<u>Chart 25.</u>



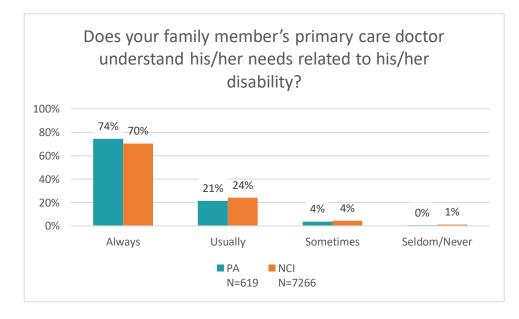
<u>Chart 26.</u>

<u>Chart 27.</u>

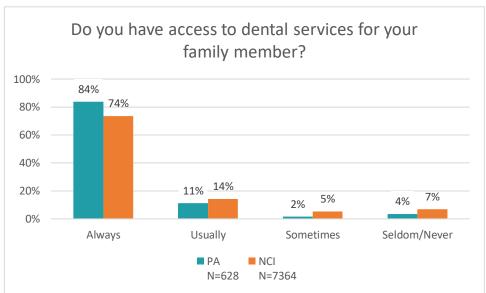


Can your family member see health professionals when needed? 100% 85% 76% 80% 60% 40% 20% 14% 20% 3% 1% 0% 1% 0% Seldom/Never Always Usually Sometimes PA NCI N=663 N=8020

<u>Chart 28.</u>



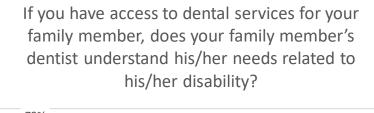
<u>Chart 29.</u>

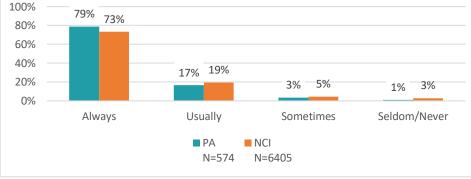


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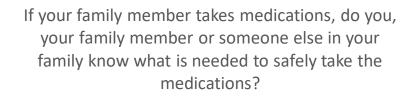
<u>Chart 30.</u>

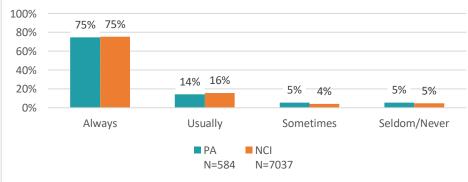
<u>Chart 31.</u>





<u>Chart 32.</u>





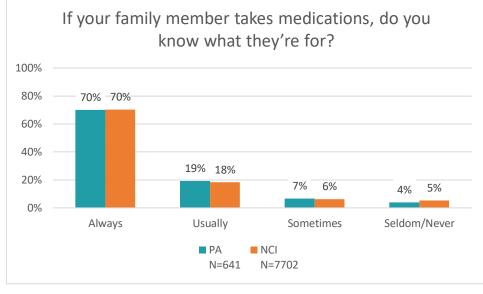
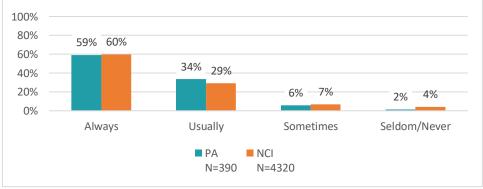
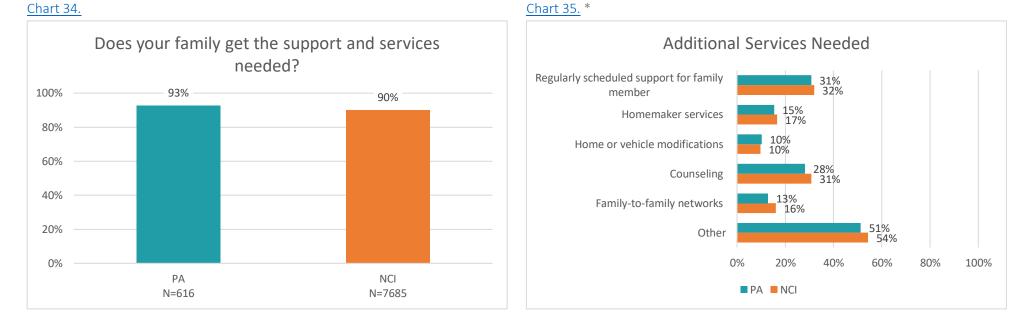


Chart 33.

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





*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

Tables for Access and Delivery of Services and Supports

Table 25. Access and Delivery of Services and Supports—Always Responses

		Always	Usually	Sometimes	Seldom/Never	N
Are you or your family member able to contact his/her support workers when you want to?	PA 🛦	70%	25%	4%	1%	642
	NCI	61%	30%	7%	3%	8,256
Are you or your family member able to contact his/her case manager/service coordinator when you want to?	PA 🛦	70%	24%	4%	1%	646
	NCI	60%	29%	7%	4%	8,359
Do support workers come and leave when they are supposed to?	PA	67%	28%	3%	2%	404
	NCI	61%	31%	5%	2%	5,502
Do services and supports change when your family's needs change?	PA	53%	34%	10%	3%	425
	NCI	50%	34%	10%	5%	5,385
Do support workers speak to you in a way that you understand?	PA	75%	22%	2%	1%	630
	NCI	72%	22%	3%	2%	7,776
Are services delivered in a way that is respectful of your family's culture?	PA	80%	17%	2%	1%	619
	NCI	78%	18%	2%	1%	7,876
If your family member does not communicate verbally, are there support workers who can communicate with him/her?	PA	55%	35%	8%	3%	194
	NCI	54%	30%	10%	6%	1,852
Do support workers have the right information and skills to meet your family's needs?	PA	54%	38%	7%	1%	608
	NCI	49%	39%	9%	2%	6,960
Does your family member have the special equipment or accommodations that s/he needs?	PA 🛦	73%	21%	3%	2%	406
	NCI	65%	25%	5%	5%	4,091

Table 26. Access and Delivery of Services and Supports—Always Responses (continued)

		Always	Usually	Sometimes	Seldom/Never	N
Can your family member see health professionals when needed?	PA▲	85%	14%	1%	0%	663
	NCI	76%	20%	3%	1%	8,020
Does your family member's primary care doctor understand his/her needs related to his/her disability?	PA	74%	21%	4%	0%	619
	NCI	70%	24%	4%	1%	7,266
Do you have access to dental services for your family member?	PA 🛦	84%	11%	2%	4%	628
	NCI	74%	14%	5%	7%	7,364
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 🛦	79%	17%	3%	1%	574
	NCI	73%	19%	5%	3%	6,405
If your family member takes medications, do you know what they're for?	PA	70%	19%	7%	4%	641
	NCI	70%	18%	6%	5%	7,702
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	75%	14%	5%	5%	584
	NCI	75%	16%	4%	5%	7,037
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%	34%	6%	2%	390
	NCI	60%	29%	7%	4%	4,320

Table 27. Access and Delivery of Services and Supports—Yes Responses

		Yes	No	N
Does your family get the support and services needed?	PA	93%	7%	616
	NCI	90%	10%	7,685
able 28. Additional Services Needed *				
		Needs Service		
Regularly scheduled support for family member	PA	31%		
	NCI	32%		
Homemaker services	PA	15%		
	NCI	17%		
Home or vehicle modifications	PA	10%		
	NCI	10%		
Counseling	PA	28%		
-	NCI	31%		
Family-to-family networks	PA	13%		
	NCI	16%		
Other	PA	51%		
	NCI	54%		

*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

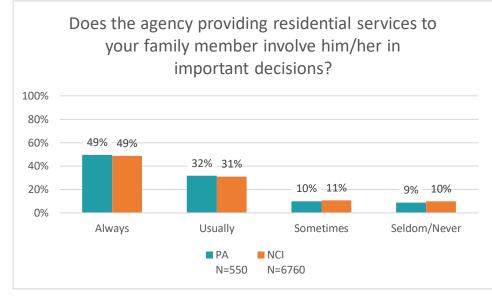
Choice, Decision Making and Control

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

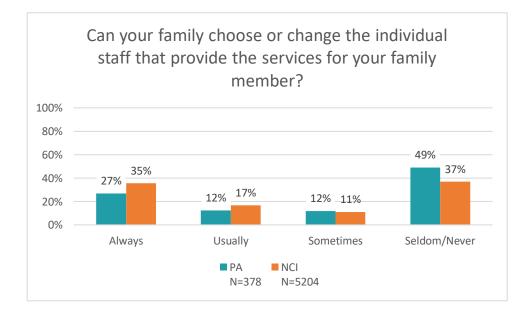
Charts for Choice, Decision Making and Control

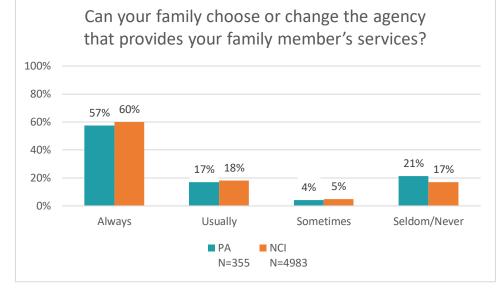
<u>Chart 36.</u>

<u>Chart 37.</u>

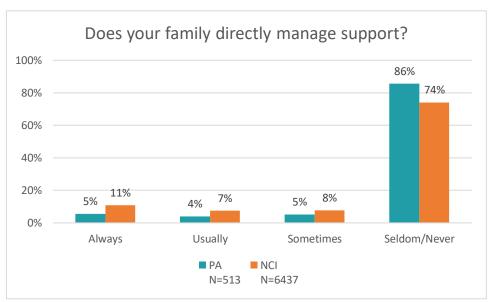


<u>Chart 38.</u>





<u>Chart 39.</u>

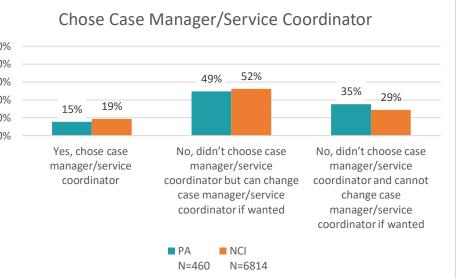


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<u>Chart 40.</u>

<u>Chart 41.</u>





Tables for Choice, Decision Making and Control

Table 29. Choice and Control — Always Responses

		Always	Usually	Sometimes	Seldom/Never	Ν
Does the agency providing residential services to your family member involve him/her in important decisions?	PA	49%	32%	10%	9%	550
	NCI	49%	31%	11%	10%	6,760
Can your family choose or change the agency that provides your family member's services?	PA	57%	17%	4%	21%	355
	NCI	60%	18%	5%	17%	4,983
Can your family choose or change the individual staff that provide the services for your family member?	PA▼	27%	12%	12%	49%	378
	NCI	35%	17%	11%	37%	5,204
Does your family directly manage support?	PA▼	5%	4%	5%	86%	513
	NCI	11%	7%	8%	74%	6,437

Table 30. Choice and Control —Yes Responses

		Yes	No	N
Do service providers for your family member work together to provide support?	PA 🛦	96%	4%	439
	NCI	94%	6%	5,750

Table 31. Family member, or someone else in your family chose case manager/service coordinator

		Chose Case Manager/Service Coordinator
Yes, chose case manager/service coordinator	PA	15%
	NCI	19%
No, didn't choose case manager/service coordinator but can change case manager/service coordinator if wanted	PA	49%
	NCI	52%
No, didn't choose case manager/service coordinator and cannot change case manager/service coordinator if wanted	РА	35%
	NCI	29%
Ν	PA	460
	NCI	6,814

Involvement in the Community

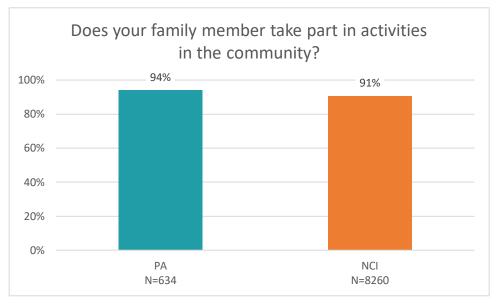
Family members with disabilities use integrated community services and participate in everyday community activities.

Charts for Involvement in the Community

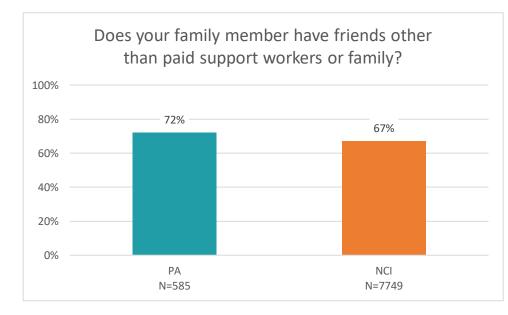
National Core Indicators[™]

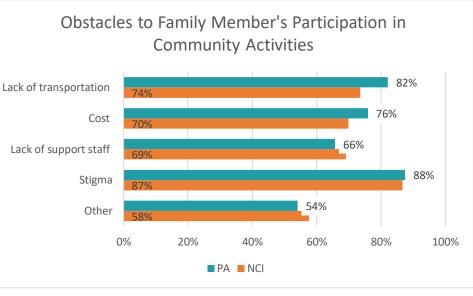
<u>Chart 42.</u>





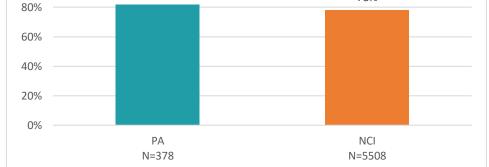
<u>Chart 44.</u>





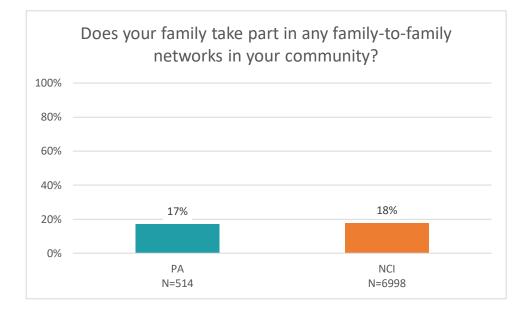
<u>Chart 45.</u>





*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

<u>Chart 46.</u>



Tables for Involvement in the Community

Table 32. Involvement in the Community

		Yes	No	N
Does your family member take part in activities in the community?	PA 🔺	94%	6%	634
	NCI	91%	9%	8,260

Table 33. Obstacles to Family Member's Participation in Community Activities *

	Ob	stacles/Barriers
Lack of transportation	PA	82%
	NCI	74%
Cost	PA	76%
	NCI	70%
Lack of support staff	PA	66%
	NCI	69%
Stigma	PA	88%
	NCI	87%
Other	PA	54%
	NCI	58%

Table 34. Involvement in the Community—Yes Responses

		Yes	No	N
Does your family member have friends other than paid support workers or family?	PA 🔺	72%	28%	585
	NCI	67%	33%	7,749
In your community, are there resources that your family can use that are not provided by the I/DD agency?	PA	82%	18%	378
	NCI	78%	22%	5 <i>,</i> 508
Does your family take part in any family-to-family networks in your community?	PA	17%	83%	514
	NCI	18%	82%	6,998

*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

Satisfaction With Services and Supports

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

Charts for Satisfaction With Services and Supports

<u>Chart 47.</u>

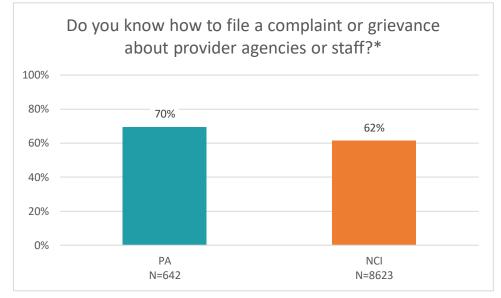
Overall, are you satisfied with the services and supports your family member currently receives? 100% 80% 51% 46% 60% 43% 42% 40% 20% 9% 6% 2% 1% 0% Seldom/Never Always Usually Sometimes PA NCI N=675 N=8705

<u>Chart 49.</u>

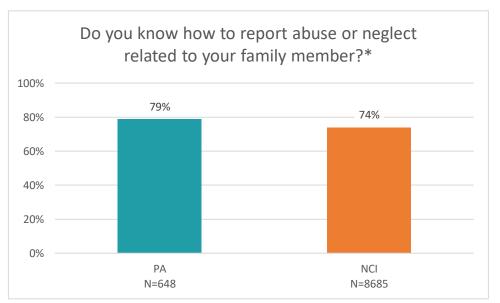


*For this question, 'No' and 'Don't know' responses were combined.

<u>Chart 48.</u> *

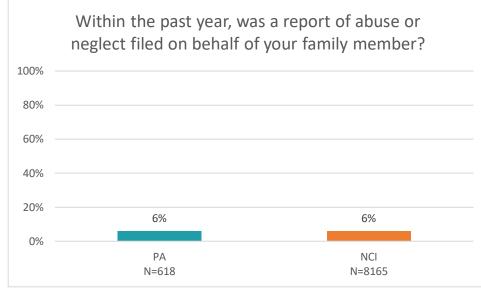


<u>Chart 50.</u> *



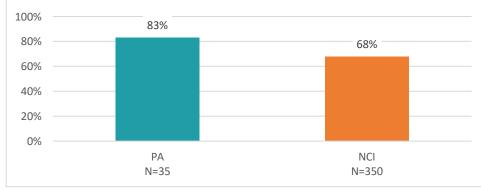
<u>Chart 51.</u>

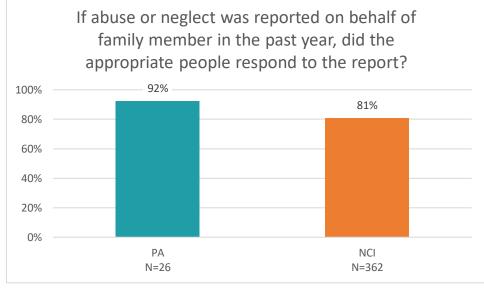
<u>Chart 52.</u>



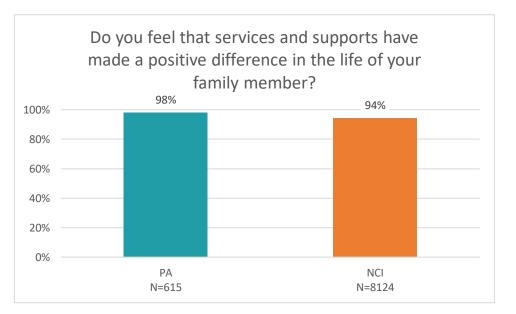
<u>Chart 53.</u>

If abuse or neglect was reported on behalf of family member in the past year by someone other than you or another family member, were you notified of the report in a timely manner?



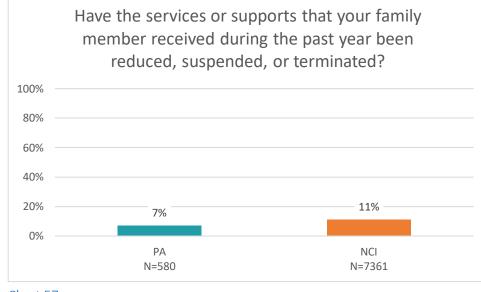


<u>Chart 54.</u>

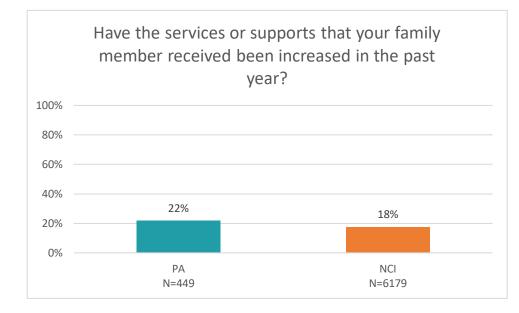


<u>Chart 56.</u>

<u>Chart 55.</u>



<u>Chart 57.</u>



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?

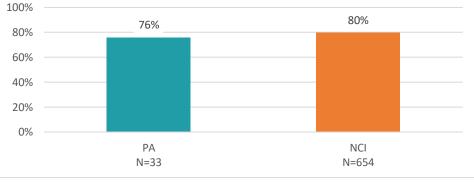
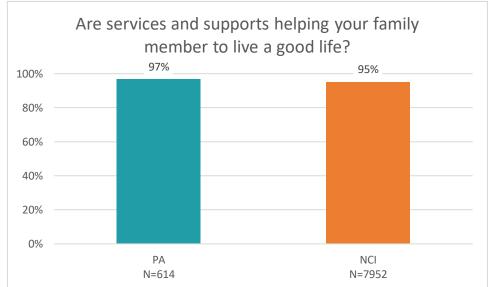


Chart 58.



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Tables for Satisfaction With Services and Supports

Table 35. Satisfaction—Always Responses

		Always	Usually	Sometimes	Seldom/Never	Ν
Overall, are you satisfied with the services and supports your family member currently receives?	PA	51%	43%	6%	1%	675
	NCI	46%	42%	9%	2%	8,705

Table 36. Satisfaction—Yes Responses

		Yes	No	N
Do you know how to file a complaint or grievance about provider agencies or staff? *	PA 🔺	70%	30%	642
	NCI	62%	38%	8,623
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	65%	35%	97
	NCI	63%	37%	1,264
Do you know how to report abuse or neglect related to your family member? *	PA 🛦	79%	21%	648
	NCI	74%	26%	8,685
Within the past year, was a report of abuse or neglect filed on behalf of your family member?	PA	6%	94%	618
	NCI	6%	94%	8,165
If a report of abuse or neglect was filed on behalf of family member in the past year				
Did the appropriate people respond to the report?	PA	92%	8%	26
	NCI	81%	19%	362
If someone other than you or another family member made the report, were you notified of the report in a timely manner?	РА	83%	17%	35
	NCI	68%	32%	350

*For this question, 'No' and 'Don't know' responses were combined.

Table 37. Satisfaction— Yes Responses (continued)

		Yes	No	N
Do you feel that services and supports have made a positive difference in the life of your family member?	PA 🛦	98%	2%	615
	NCI	94%	6%	8,124
Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?	PA▼	7%	93%	580
	NCI	11%	89%	7,361
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	76%	24%	33
	NCI	80%	20%	654
Have the services or supports that your family member received been increased in the past year?	PA	22%	78%	449
	NCI	18%	82%	6,179
Are services and supports helping your family member to live a good life?	PA	97%	3%	614
	NCI	95%	5%	7,952