# 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 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.

<sup>&</sup>lt;sup>1</sup> 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.<sup>2</sup>

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.

<sup>&</sup>lt;sup>2</sup> 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.<sup>3</sup>

# 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 ▼).

<sup>&</sup>lt;sup>3</sup> 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.<sup>4</sup> 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 <a href="http://www.nationalcoreindicators.org/resources/reports/">http://www.nationalcoreindicators.org/resources/reports/</a>.

<sup>&</sup>lt;sup>4</sup> 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<br>facility for<br>people with<br>intellectual<br>disabilities<br>(ICF, state-<br>run or other<br>institutional<br>setting) | Group<br>Home | Agency<br>Operated<br>Apartment | Independent<br>Home or<br>Apartment |    | Nursing<br>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<br>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<br>Indian or<br>Alaska<br>Native | Asian | Black or<br>African-<br>American | Hawaiian<br>or Pacific<br>Islander | White | Other or<br>Unknown | Hispanic<br>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<br>Disability | Mood<br>Illness or<br>Psychiatric<br>Disorder | Autism<br>Spectrum<br>Disorder | Cerebral<br>Palsy | Limited<br>or No<br>Vision | Severe<br>or<br>Profound<br>Hearing<br>Loss | Brain<br>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<br>Disease | Diabetes | Cancer | High<br>Blood<br>Pressure | High<br>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<br>Ulcers | Alzheimer's<br>Disease or<br>Other<br>Dementia | Dental | Sleep<br>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<br>or Body<br>Language | Sign<br>Language<br>or Finger<br>Spelling | Communication<br>Aid or Device | Other | Ν     |
|---|-----|--------|---------------------------------|---|--------------------------------|-------|-------|
| Family Member's Preferred Means of<br>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<br>Guardianship<br>but Level Is<br>Unknown | Ν     |
|--|-----|------|---------|------|--|-------|
| Level of Guardianship or Conservatorship of Family<br>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<br>Employee or<br>Guardianship<br>Agency | Other | Ν     |
|--|-----|--------|--------|--|-------|-------|
| Guardian or Conservator Relationship to Family<br>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<br>Complete<br>High School<br>(and Not<br>Currently<br>Enrolled) | Currently<br>Enrolled<br>in High<br>School | High School<br>Certification | High<br>School<br>Diploma<br>or GED | Vocational<br>School or<br>Certificate<br>Program | Some<br>College | College<br>Degree or<br>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,<br>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<br>good | Fairly<br>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<br>Than<br>Once | 1-3<br>Times | 4-6 Times | 7-12<br>Times | 12 or<br>More<br>Times | N     |
|--|-----|----------------------|--------------|-----------|---------------|------------------------|-------|
| How Often Respondent Sees Family Member Each<br>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<br>School<br>Diploma<br>or GED | High<br>School<br>Diploma<br>or GED | Vocational<br>School or<br>Certificate<br>Program | Some<br>College | College<br>Degree<br>or<br>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<br>\$15,000 | \$15,001-<br>\$25,000 | \$25,001-<br>\$50,000 | \$50,001-<br>\$75,000 | Over<br>\$75,000 | No<br>Earned<br>Income | Prefer<br>Not to<br>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<br>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<br>and Supports Received<br>(Not From the IDD<br>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

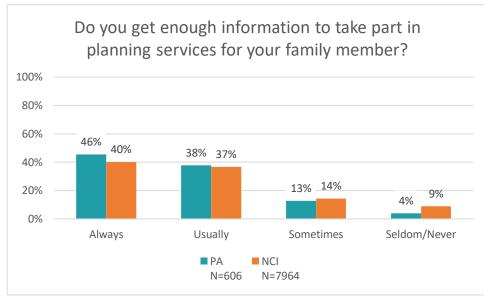
Families and family members with disabilities have the information and support necessary to plan for their services and supports.

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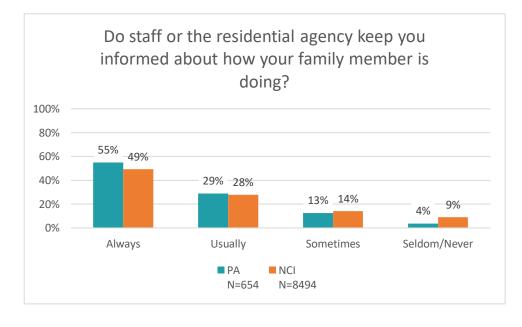
Charts for Information and Planning

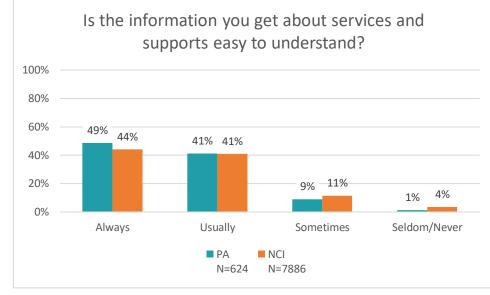
#### Chart 1.

#### Chart 2.

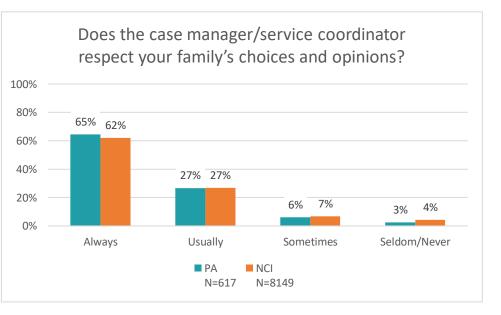


#### Chart 3.



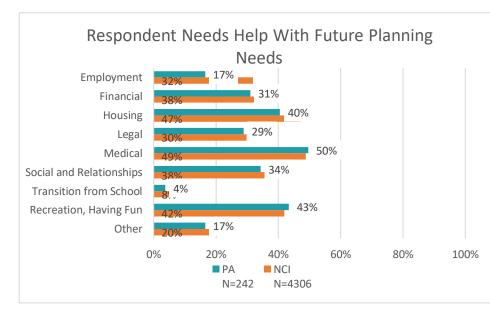


#### Chart 4.



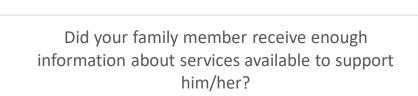
#### Chart 6.

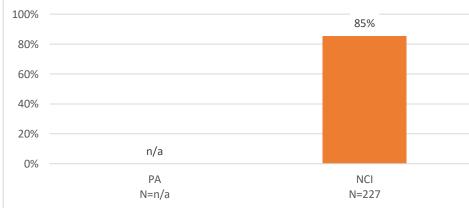
Chart 8.



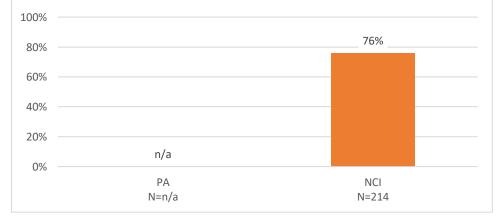
# In the past year, did your family member move out of the family home for the first time? 100% 80% 60% 40% 20% 3% 2% 0% PA NCI N=658 N=8699

#### Chart 7.





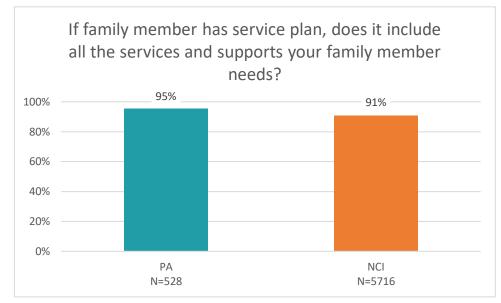
Did you have enough choices of service providers to support your family member living outside the family home?



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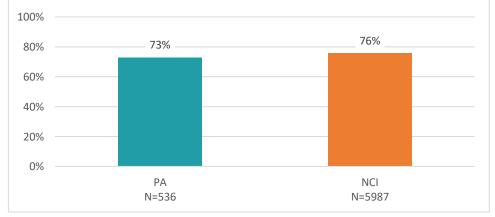
### Chart 5.

#### <u>Chart 10.</u>

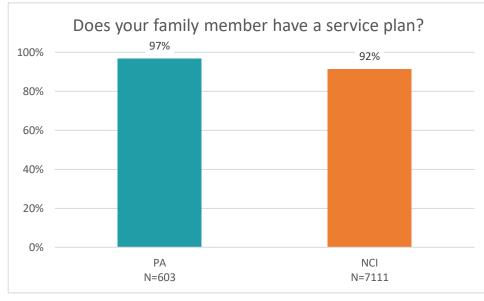


### <u>Chart 12.</u>

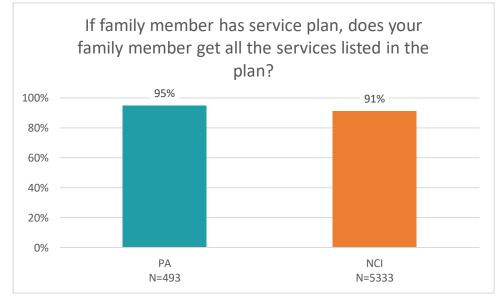
If family member has service plan, did you or another family member (beside your family member with a disability) help make the plan?



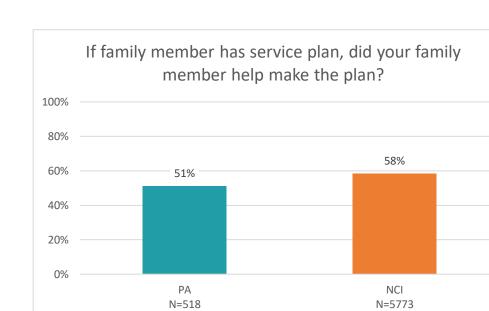
#### Chart 9.



#### <u>Chart 11.</u>

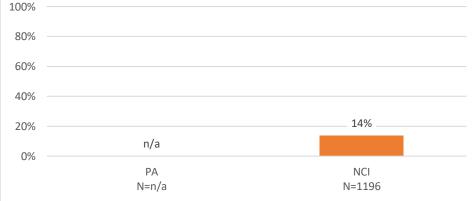


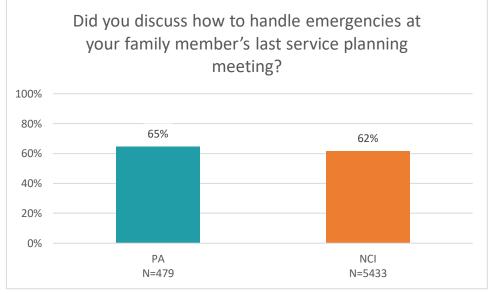
#### <u>Chart 14.</u>



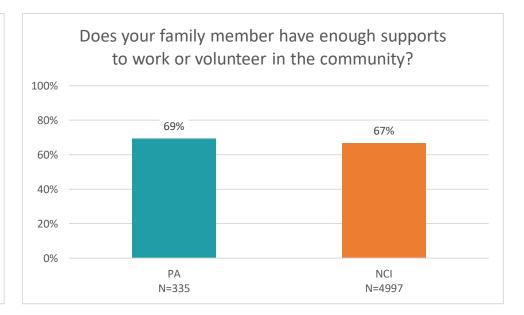
#### <u>Chart 15.</u>







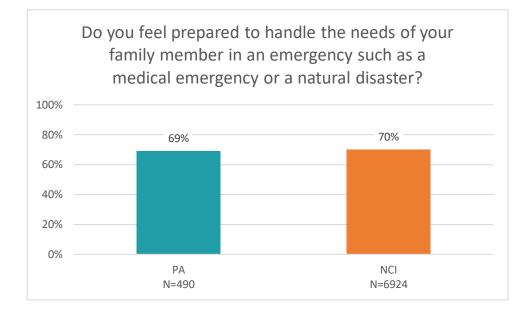
#### <u>Chart 16.</u>



#### <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

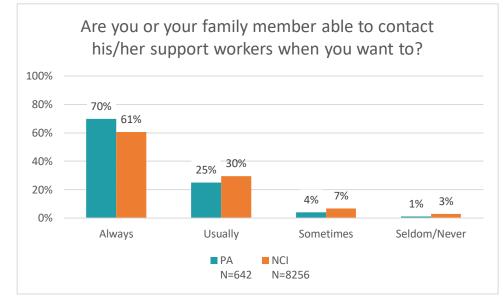
Families and family members with disabilities get the services and supports they need

National Core Indicators™

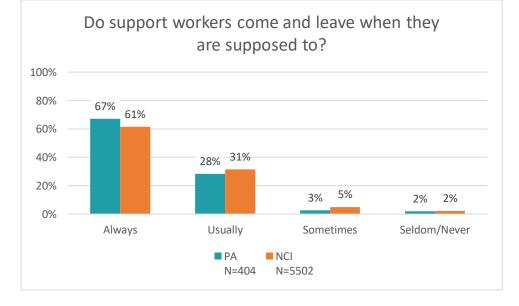
# Charts for Access and Delivery of Services and Supports

#### <u>Chart 18.</u>

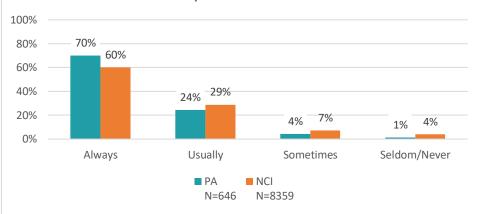
#### <u>Chart 19.</u>



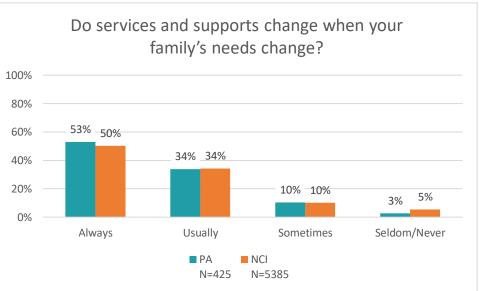
#### <u>Chart 20.</u>



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

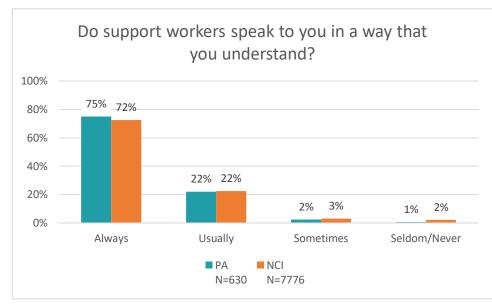


### <u>Chart 21.</u>



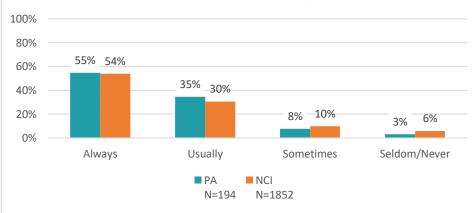
#### <u>Chart 22.</u>

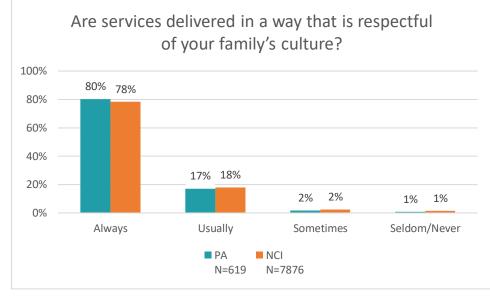




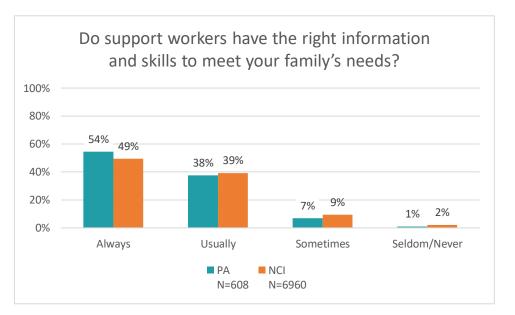
#### <u>Chart 24.</u>

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



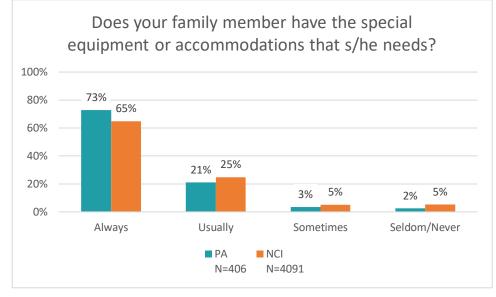


#### <u>Chart 25.</u>



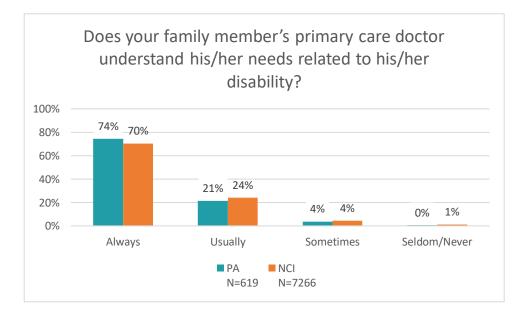
#### <u>Chart 26.</u>

#### <u>Chart 27.</u>

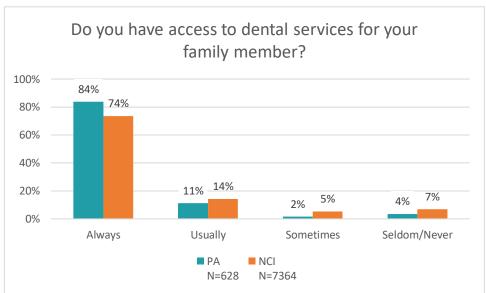


#### Can your family member see health professionals when needed? 100% 85% 76% 80% 60% 40% 20% 14% 20% 3% 1% 0% 1% 0% Seldom/Never Always Usually Sometimes PA NCI N=663 N=8020

#### <u>Chart 28.</u>



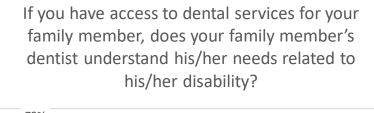
#### <u>Chart 29.</u>

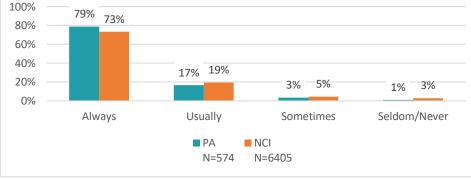


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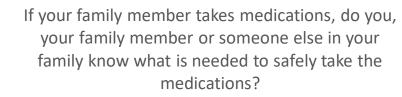
#### <u>Chart 30.</u>

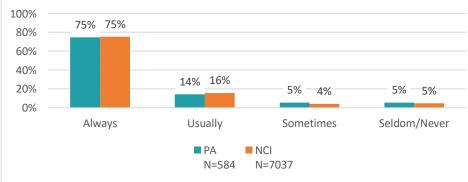
#### <u>Chart 31.</u>





#### <u>Chart 32.</u>





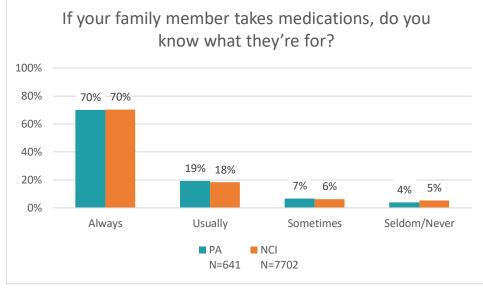
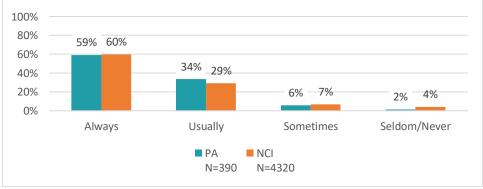
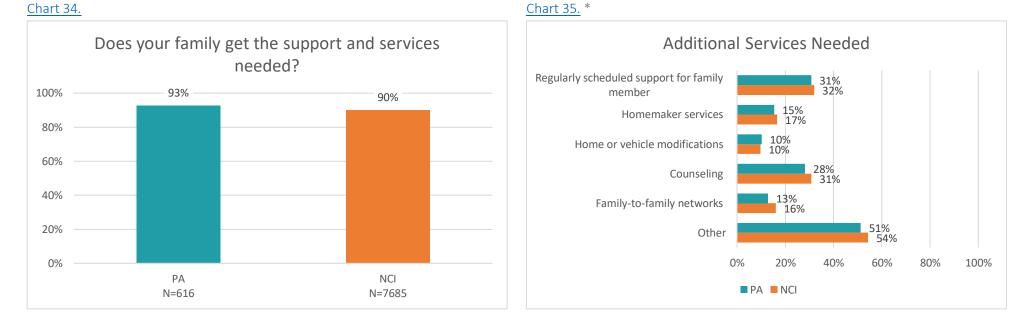


Chart 33.

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<br>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<br>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

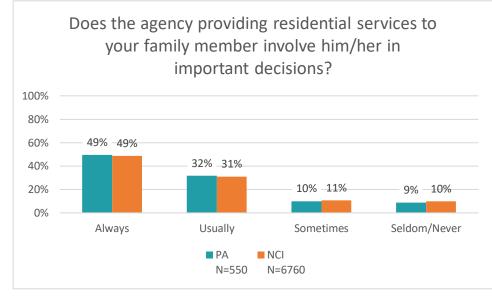
### Choice, Decision Making and Control

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

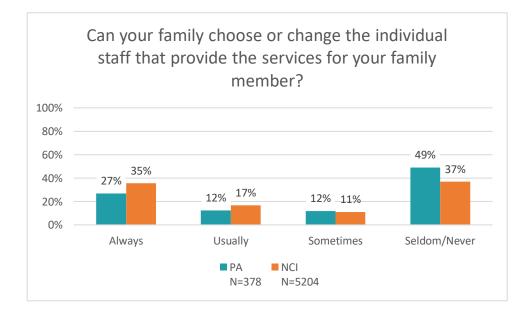
# Charts for Choice, Decision Making and Control

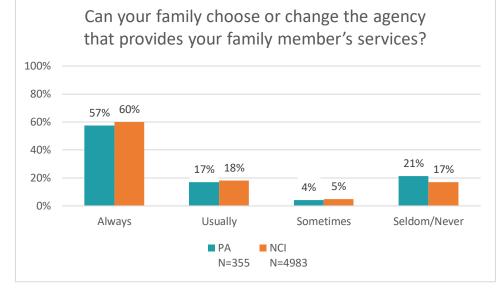
#### <u>Chart 36.</u>

#### <u>Chart 37.</u>

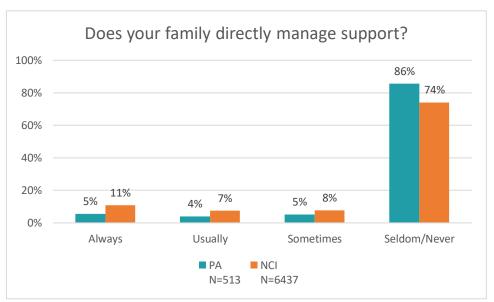


#### <u>Chart 38.</u>





#### <u>Chart 39.</u>

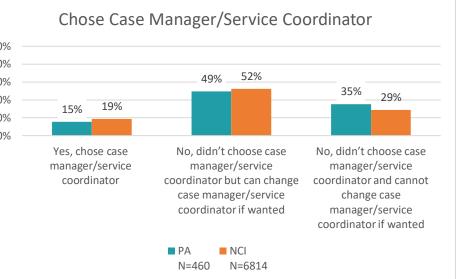


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#### <u>Chart 40.</u>

#### <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<br>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<br>Manager/Service<br>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

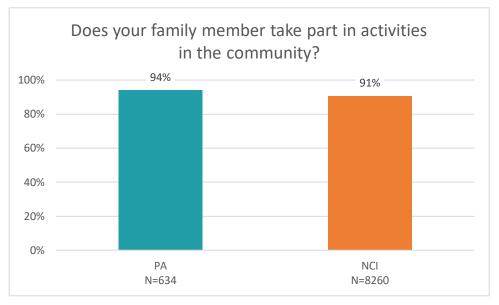
Family members with disabilities use integrated community services and participate in everyday community activities.

Charts for Involvement in the Community

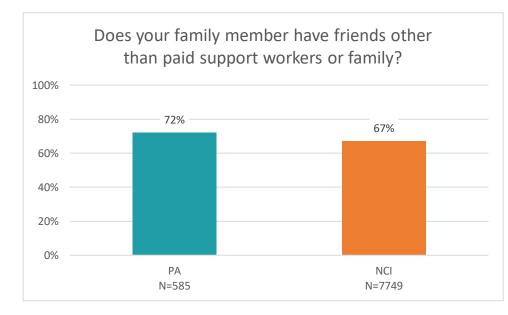
#### National Core Indicators<sup>™</sup>

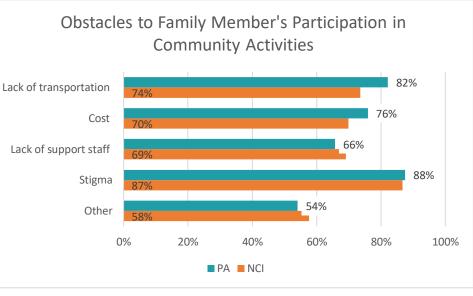
#### <u>Chart 42.</u>





#### <u>Chart 44.</u>





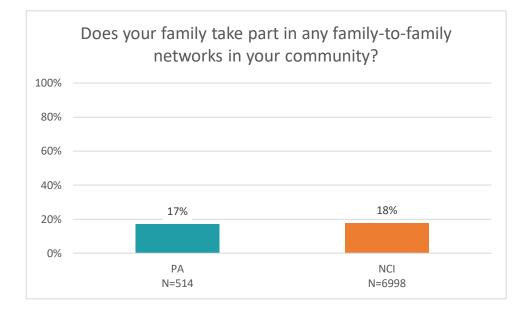
#### <u>Chart 45.</u>





\*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

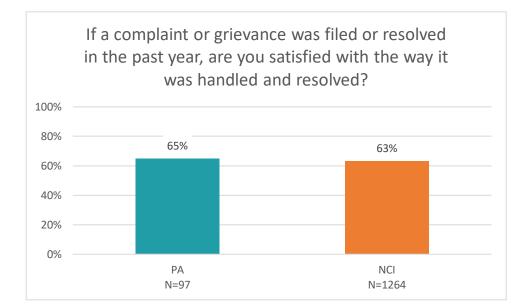
Families and family members with disabilities receive adequate and satisfactory supports.

# Charts for Satisfaction With Services and Supports

#### <u>Chart 47.</u>

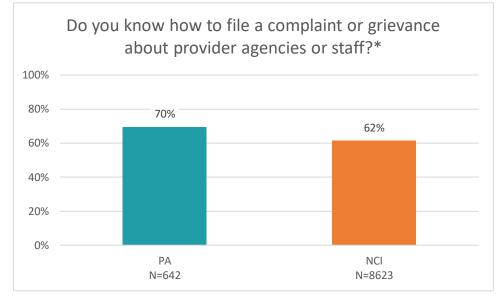
#### Overall, are you satisfied with the services and supports your family member currently receives? 100% 80% 51% 46% 60% 43% 42% 40% 20% 9% 6% 2% 1% 0% Seldom/Never Always Usually Sometimes PA NCI N=675 N=8705

#### <u>Chart 49.</u>

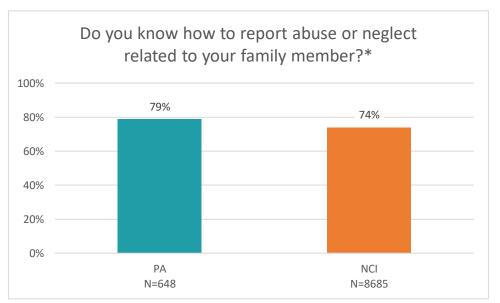


\*For this question, 'No' and 'Don't know' responses were combined.

<u>Chart 48.</u> \*

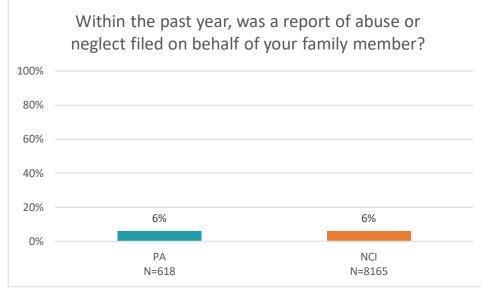


#### <u>Chart 50.</u> \*



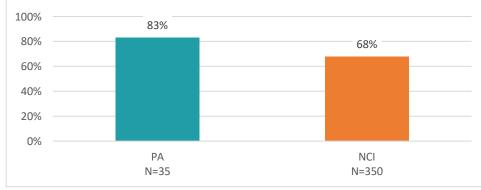
#### <u>Chart 51.</u>

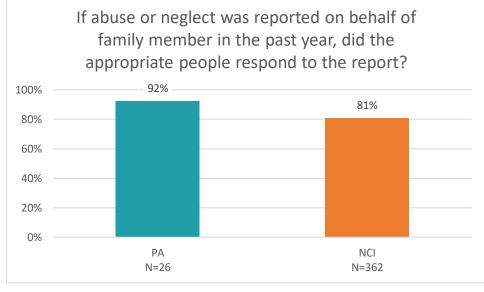
#### <u>Chart 52.</u>



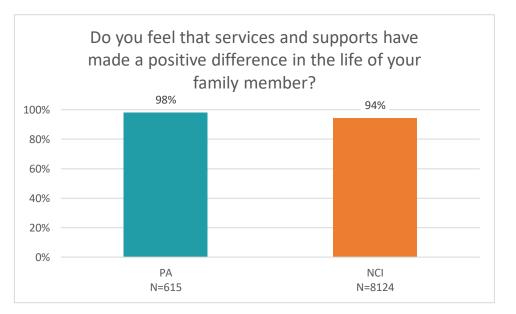
#### <u>Chart 53.</u>

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?



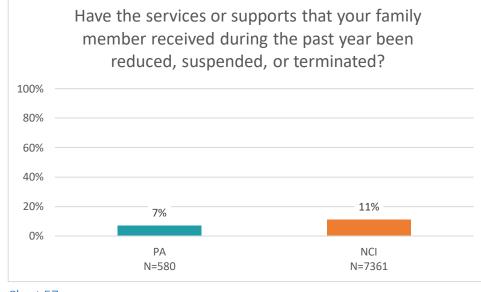


#### <u>Chart 54.</u>

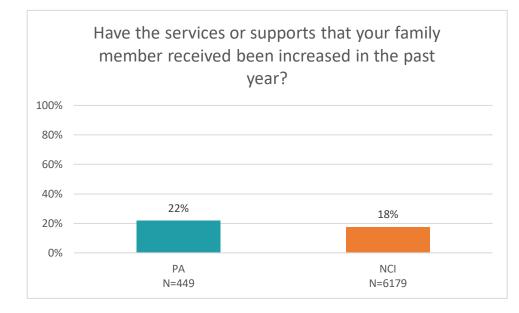


#### <u>Chart 56.</u>

<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?

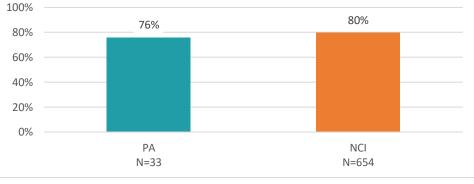
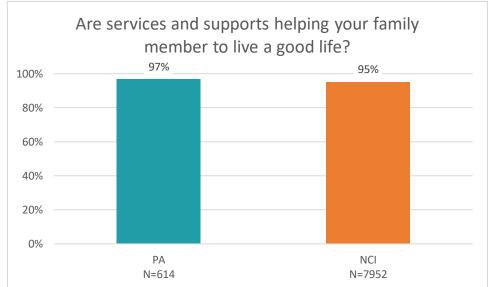


Chart 58.



Family/Guardian Survey State Results 2016-17 | 60

# 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<br>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 |