

NCI Family/Guardian Survey Outcomes

Pennsylvania Report

2012-2013 Data



**NATIONAL CORE
INDICATORS**

A Collaboration of
the National Association of State Directors of
Developmental Disabilities Services
and Human Services Research Institute

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What is NCI?

The National Core Indicators (NCI) program is a voluntary effort by state developmental disability agencies to gauge and track their own performance using a common and nationally validated set of performance measures. The effort is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in collaboration with the Human Services Research Institute (HSRI). NCI has developed a set of more than 100 standard performance measures (or “indicators”) that states use to assess the outcomes of services provided to individuals and their families. These indicators focus on areas such as: employment, rights, service planning, community inclusion, choice, health, and safety. During the 2012-13 data collection cycle, 33 states and 22 sub-state entities participated in NCI.

What is the NCI Family/Guardian Survey?

The NCI Family/Guardian Survey is a mail-in survey sent to the families who have a family member living outside of the home who receives services from the State DD Agency. The survey is used to gather data on family outcomes, and it is refined and tested to ensure that it is valid and reliable. The survey collects demographic information on the individual receiving services and the survey respondent (usually a parent) as well as information on services and supports received. It contains six groupings of questions that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes. Respondents also have the option of writing open-ended comments concerning their family’s participation in the service system.

What topics are covered by the survey?

The National Core Indicators are organized by topic or “domain.” Each domain consists of sub-domains, and each sub-domain is associated with a particular area of concern. The NCI Family/Guardian Survey includes items to measure the Family Outcomes domain. The table on the following page lists the NCI Family Surveys sub-domains and concerns.

TABLE 1. NCI FAMILY SURVEY INDICATORS –SUB-DOMAINS AND CONCERN STATEMENTS

Sub-Domain	Concern
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 & Control	Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.
Community Connections	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.
Family 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 Family/Guardian Survey by selecting a random sample of at least 1,000 families and guardians who had an adult with a developmental disability living outside of the family's home and who received at least one direct service or support other than service coordination.

All states mailed out a paper survey to families selected in their sample. A sample size of 1,000 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000

families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a $\pm 5\%$ margin of error and a 95% confidence level when interpreting the results. Both the confidence interval and margin of error used are widely acceptable 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 $\pm 7\%$.

Limitations of Data

The NCI Family/Guardian Survey tool is not intended to be used for monitoring individuals or providers, but rather for assessing system-wide performance. The NCI Statewide Average should not be interpreted as necessarily defining “acceptable” levels of performance or satisfaction, nor does it provide benchmarks for acceptable or unacceptable levels of performance for each indicator. Instead, it describes average levels of performance or satisfaction across the State. It is up to public managers, policy-makers, and other stakeholders to decide what is an acceptable or unacceptable result (i.e., percentage of individuals achieving the indicated outcome).

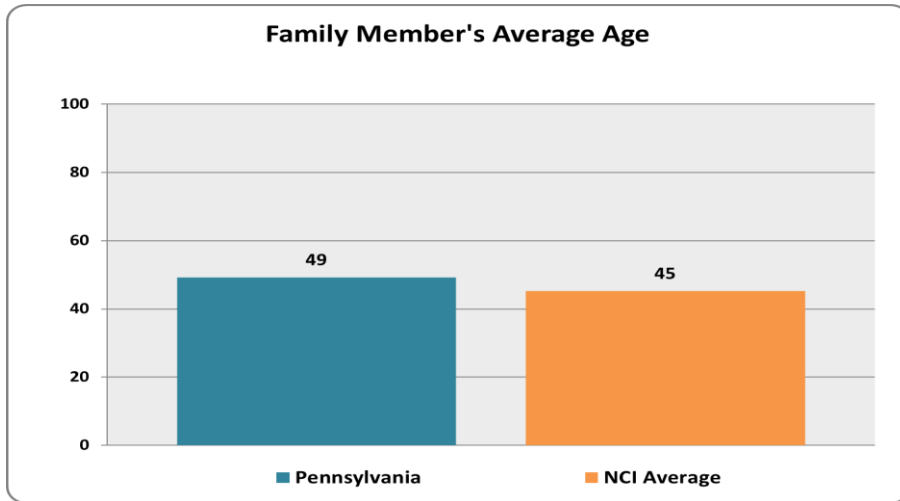
What is contained in this report?

This report illustrates 2012-2013 NCI Family/Guardian Survey demographic and outcome results from Pennsylvania compared to the NCI Average (the average of all state averages). In 2012-13, 11 states conducted the Family/Guardian Survey. All results are shown in chart form along with descriptive text to the right of each outcome chart. Charts do not display the number of respondents to each question. Some questions may have a low response rate, particularly questions about knowledge and use of ID/DD money, reporting grievances, and abuse or neglect. States with less than 20 responses to a particular question were excluded from analysis for that question. The number of responses per each question are included in the national reports. All state and national data results for this survey can be found online at <http://www.nationalcoreindicators.org/resources/reports/>.

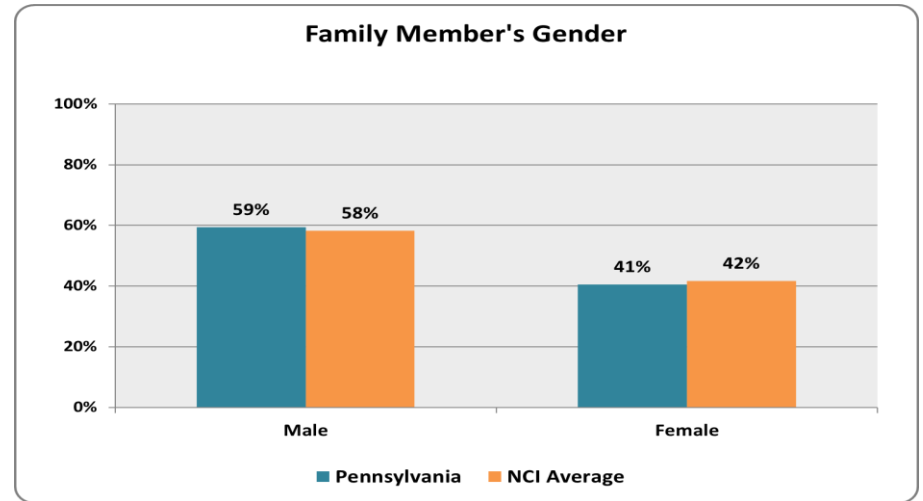
Results: Demographics of Family Member

ILLUSTRATES THE DEMOGRAPHIC PROFILE OF FAMILY MEMBER FOR WHOM THE SURVEY WAS COMPLETED

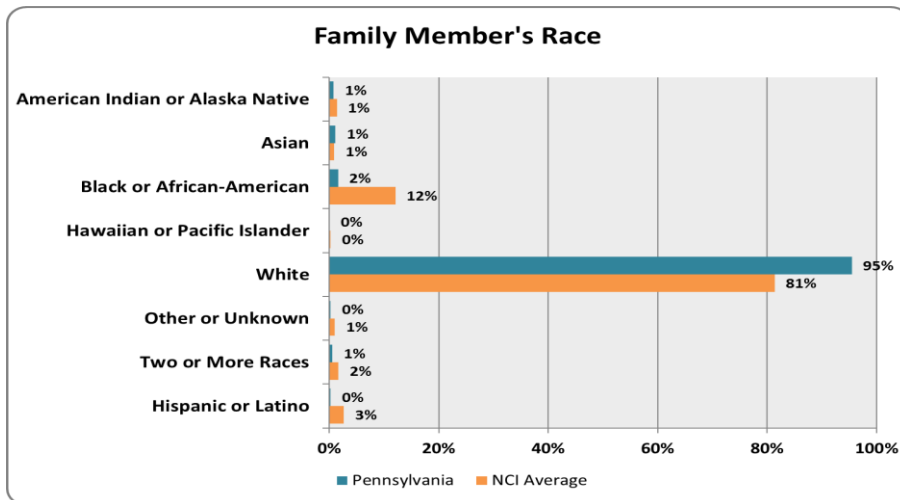
GRAPH 1. FAMILY MEMBER'S AVERAGE AGE



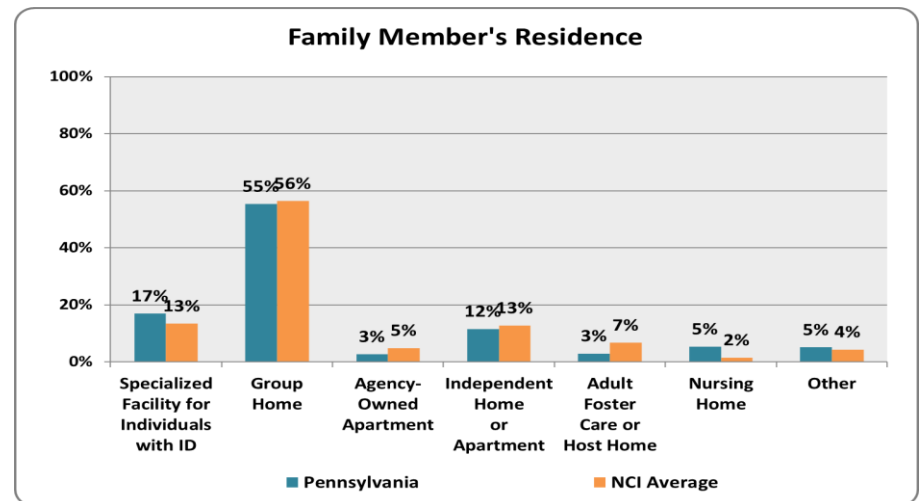
GRAPH 2. GENDER



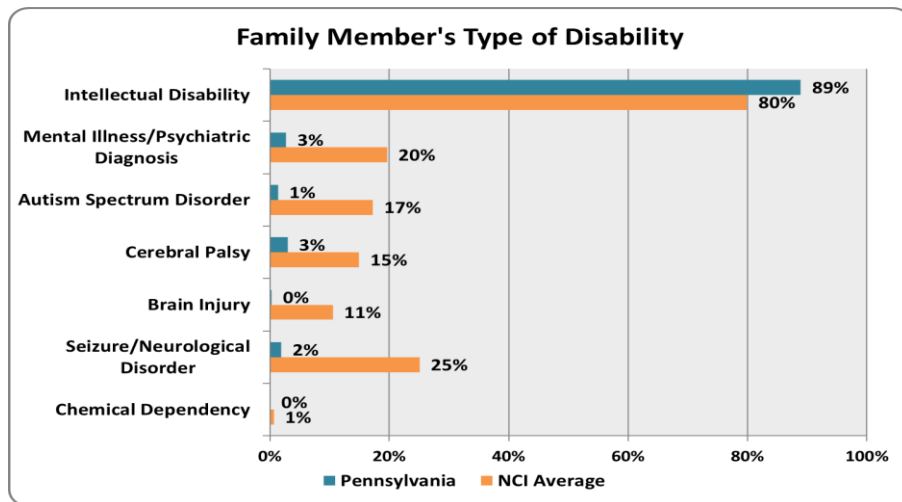
GRAPH 3. RACE



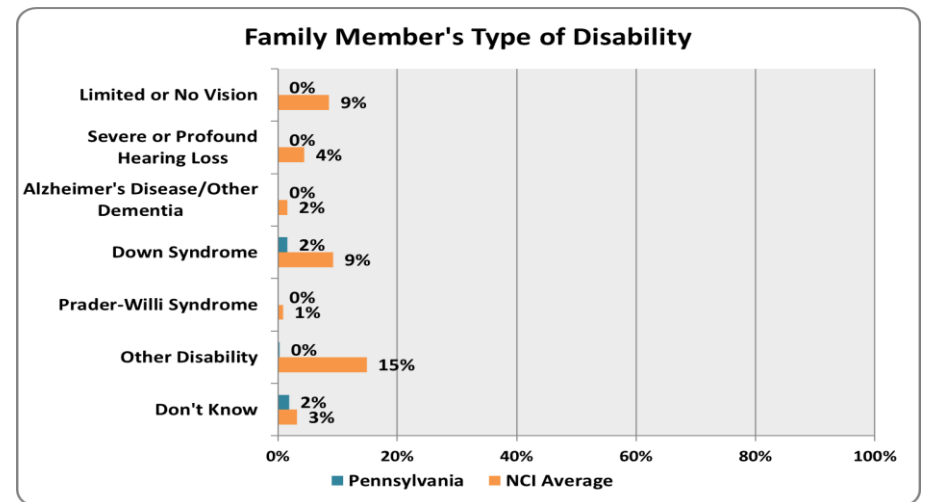
GRAPH 4. FAMILY MEMBER'S RESIDENCE



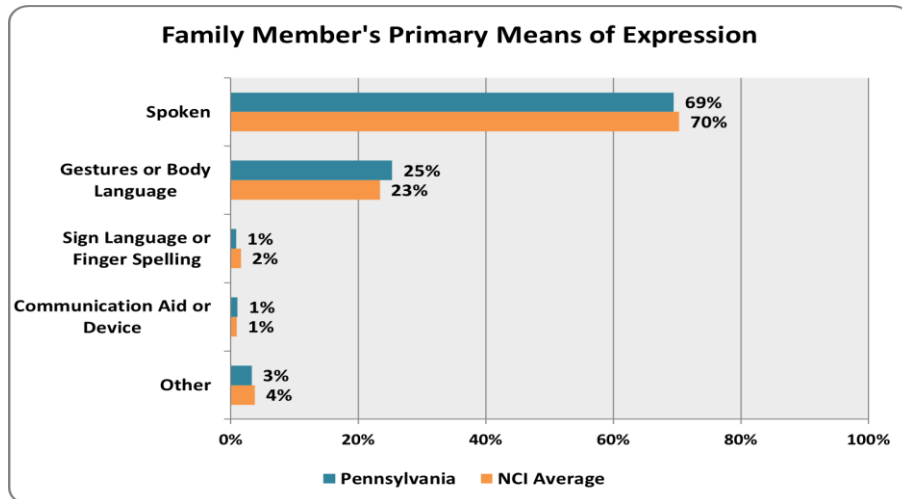
GRAPH 5. TYPE OF DISABILITIES (NOT MUTUALLY EXCLUSIVE)



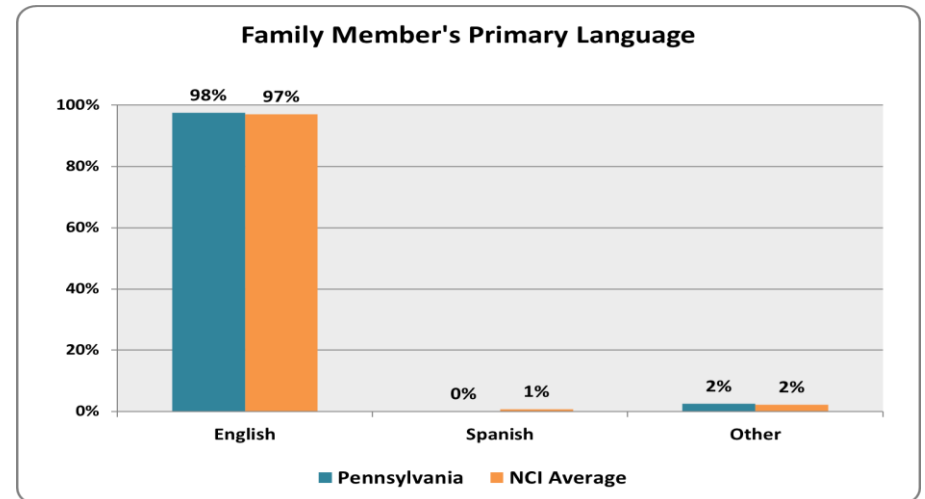
GRAPH 6. TYPE OF DISABILITIES, CONTINUED (NOT MUTUALLY EXCLUSIVE)



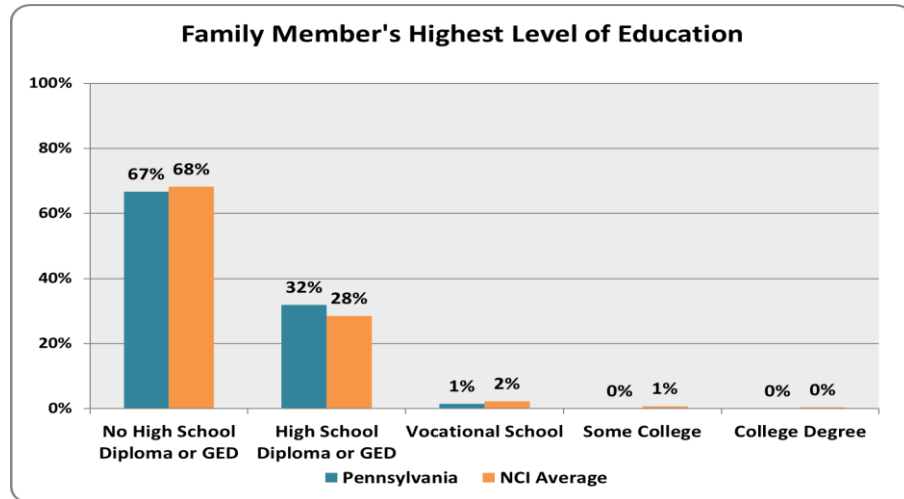
GRAPH 7. PRIMARY MEANS OF EXPRESSION



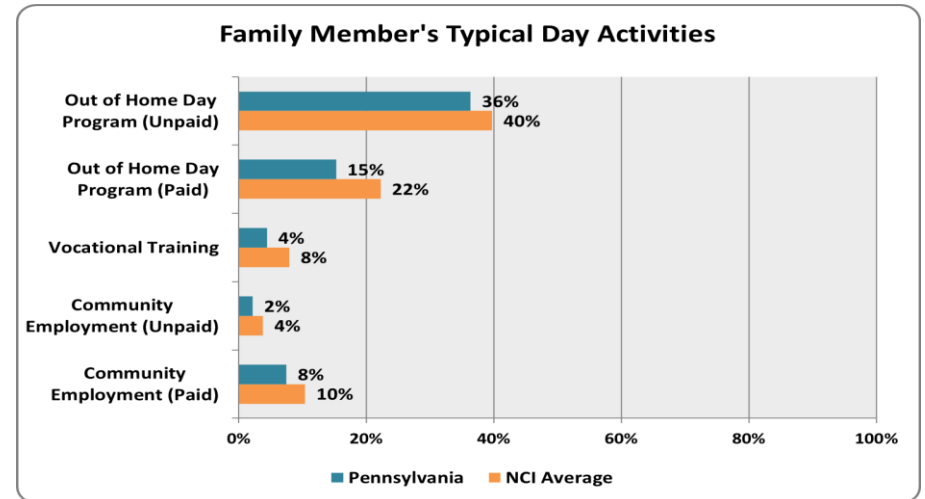
GRAPH 8. PRIMARY LANGUAGE



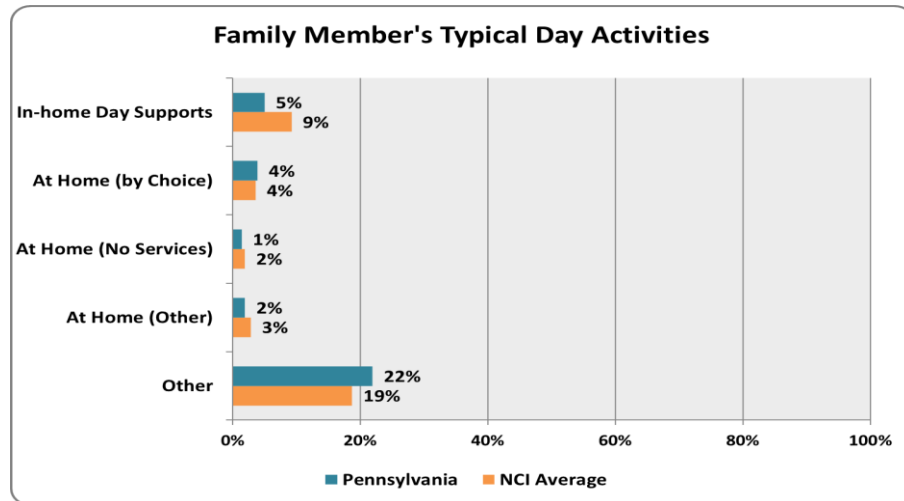
GRAPH 9. FAMILY MEMBER'S EDUCATION LEVEL



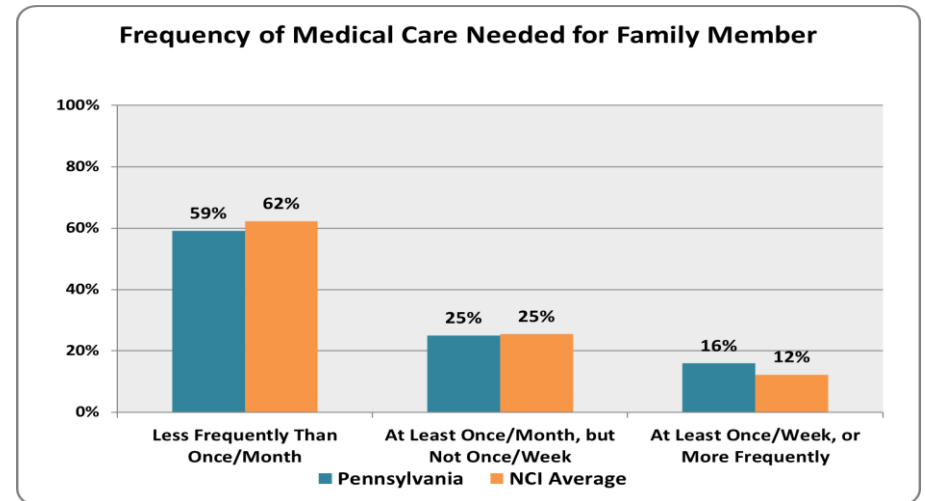
GRAPH 10. TYPICAL DAY ACTIVITIES



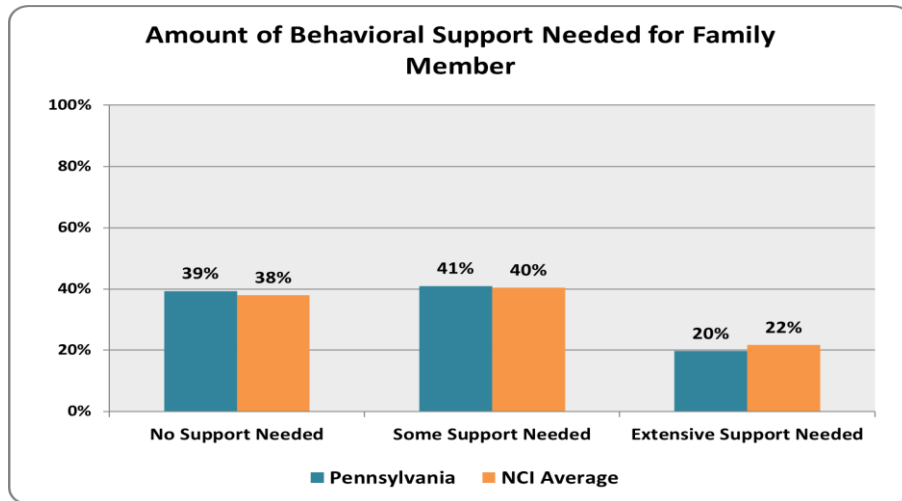
GRAPH 11. TYPICAL DAY ACTIVITIES, CONTINUED



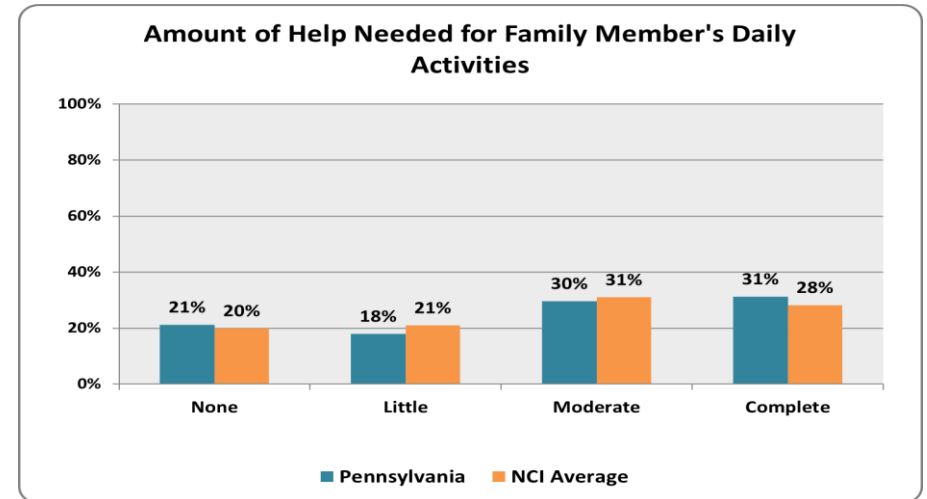
GRAPH 12. FREQUENCY OF MEDICAL CARE NEEDED FOR FAMILY MEMBER



GRAPH 13. AMOUNT OF BEHAVIORAL SUPPORT NEEDED FOR FAMILY MEMBER



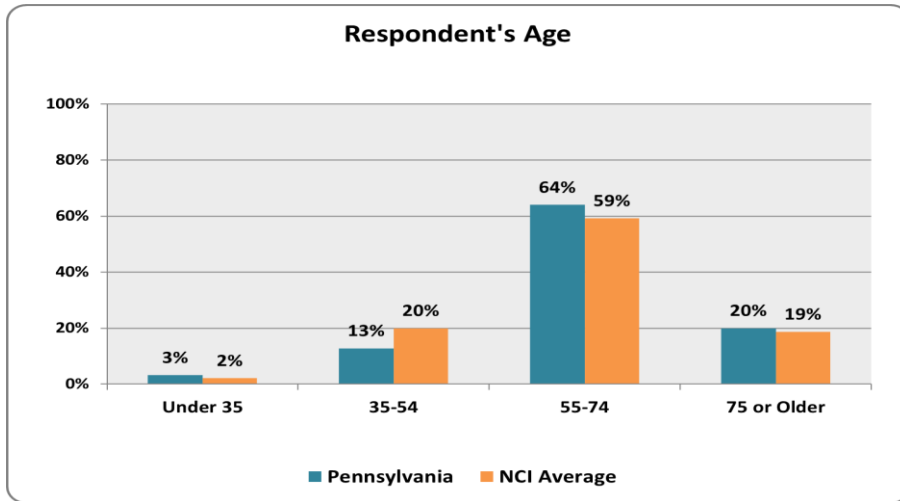
GRAPH 14. HELP NEEDED WITH DAILY ACTIVITIES



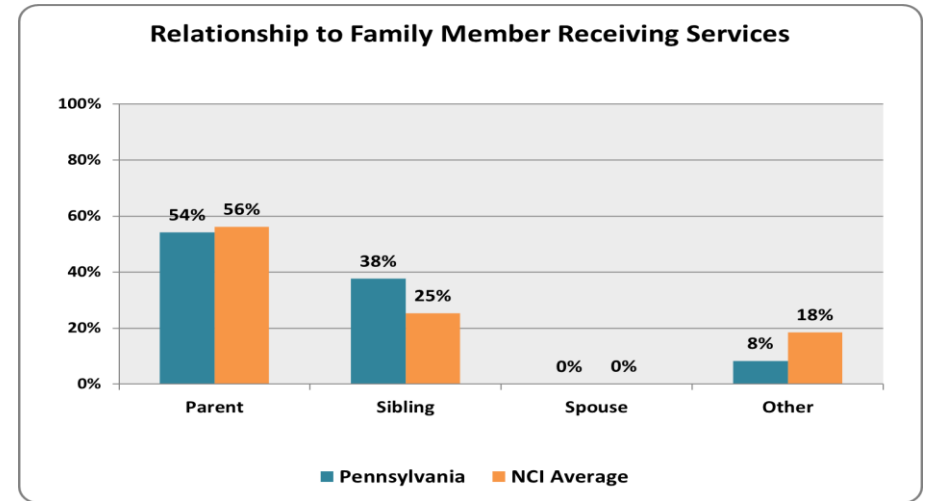
Results: Demographics of Respondent

ILLUSTRATES THE DEMOGRAPHIC PROFILE OF THE SURVEY RESPONDENTS

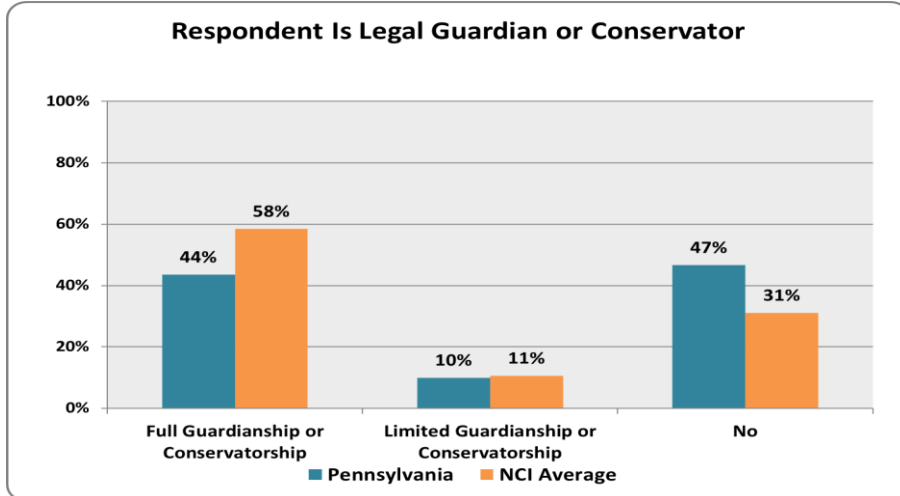
GRAPH 15. RESPONDENT'S AGE



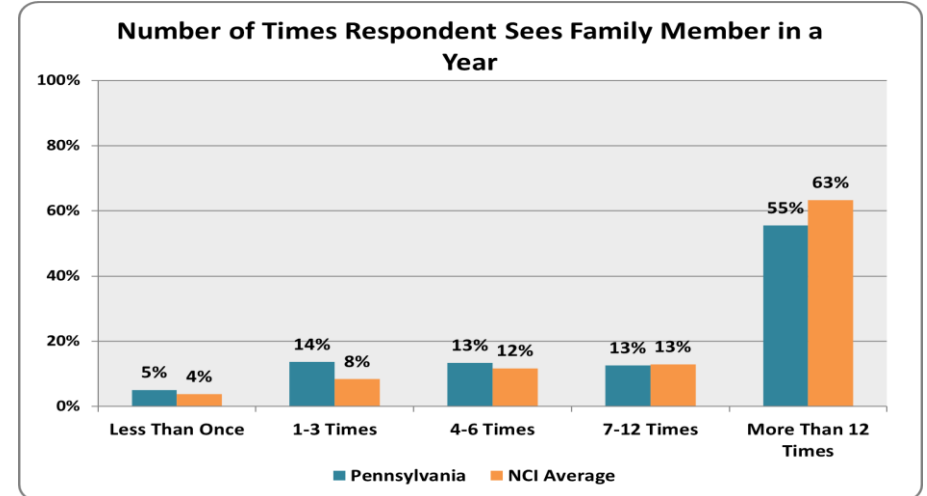
GRAPH 16. RELATIONSHIP TO FAMILY MEMBER



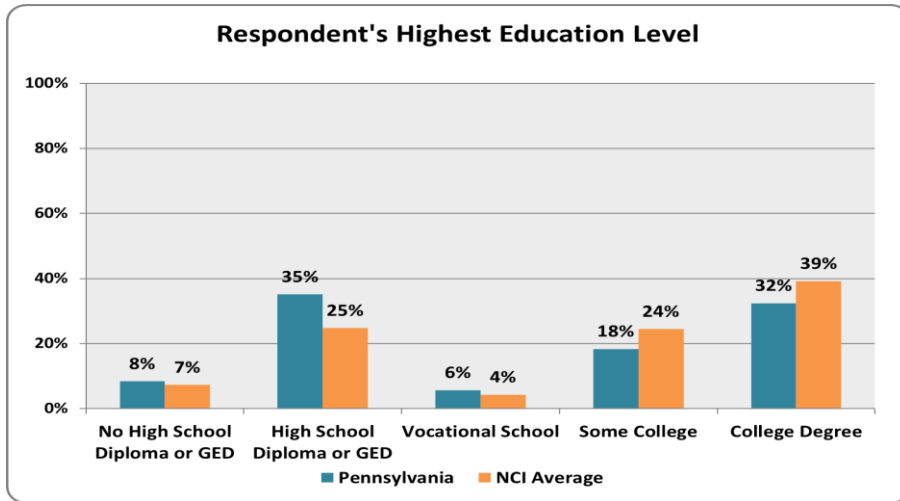
GRAPH 17. LEGAL GUARDIAN OR CONSERVATOR



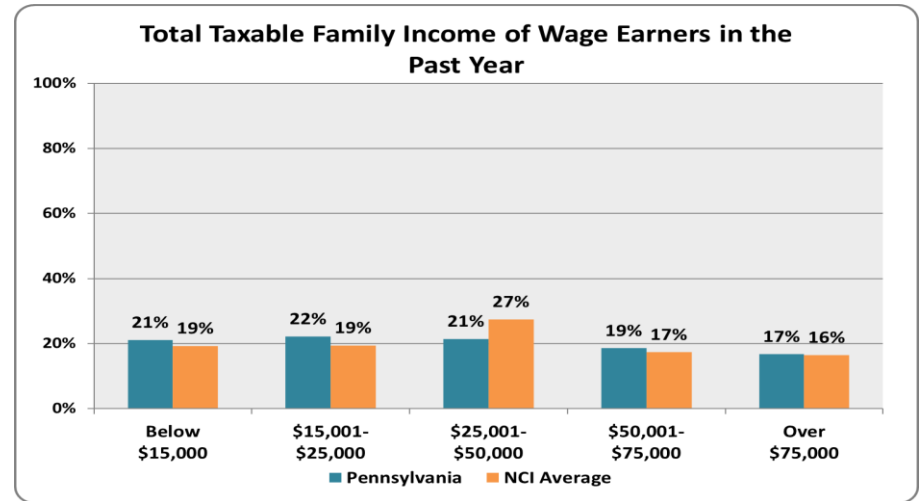
GRAPH 18. FREQUENCY OF VISITS EACH YEAR



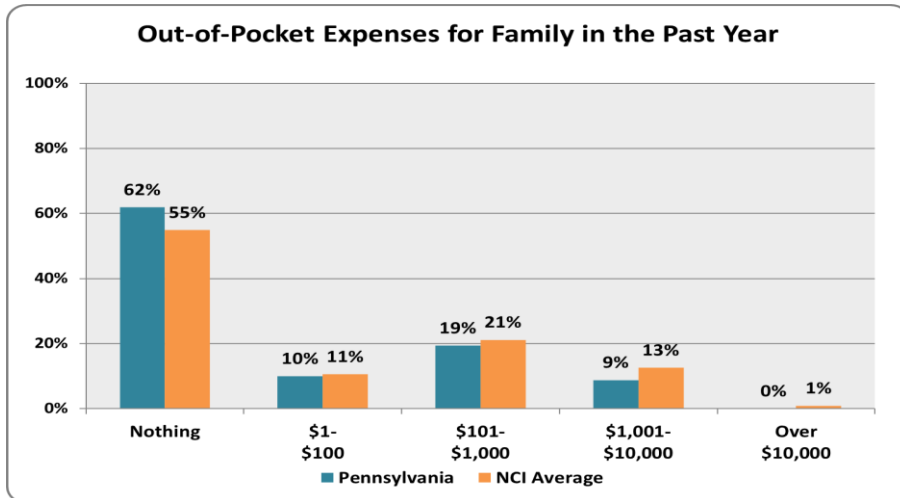
GRAPH 19. RESPONDENT'S HIGHEST LEVEL OF EDUCATION



GRAPH 20. INCOME LEVEL



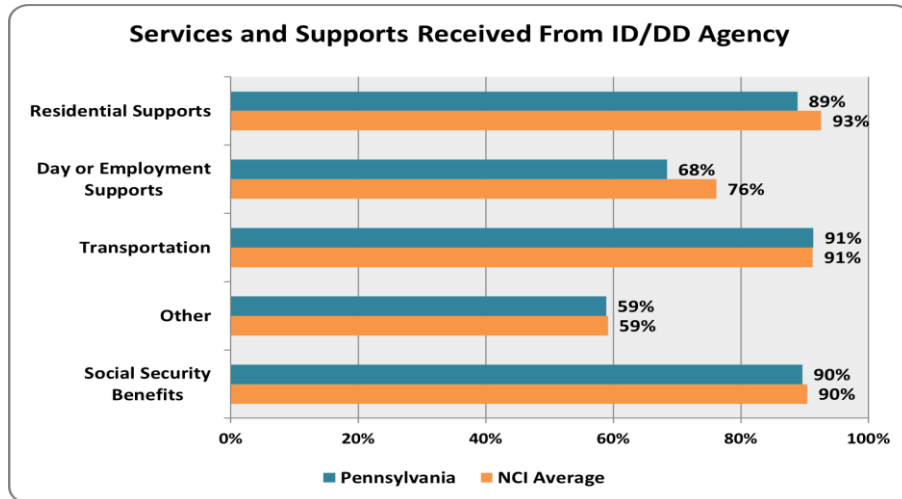
GRAPH 21. OUT-OF-POCKET EXPENSES



Services and Supports Received

ILLUSTRATES THE SERVICES AND SUPPORTS RECEIVED BY FAMILY MEMBERS

GRAPH 22. SERVICES AND SUPPORTS RECEIVED¹

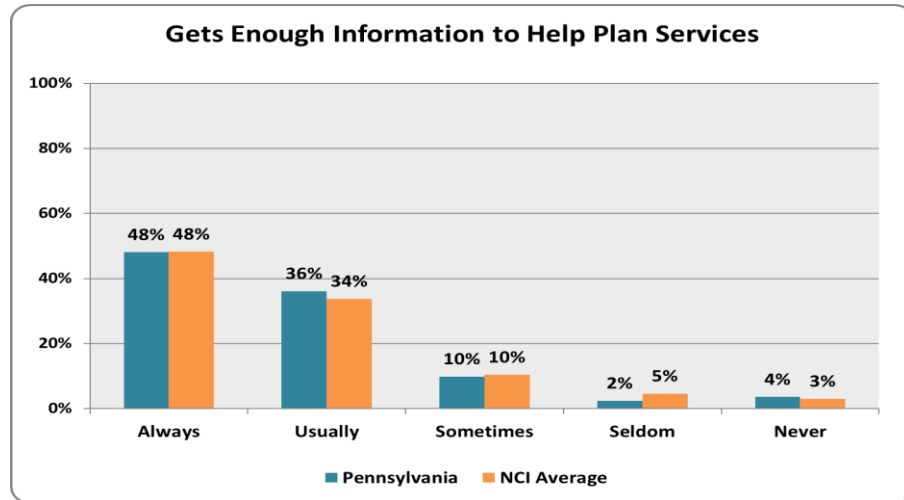


¹ All services and supports are received from the ID/DD Agency **except** social security benefits.

Information and Planning

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES HAVE THE INFORMATION AND SUPPORT NECESSARY TO PLAN FOR THEIR SERVICES AND SUPPORTS

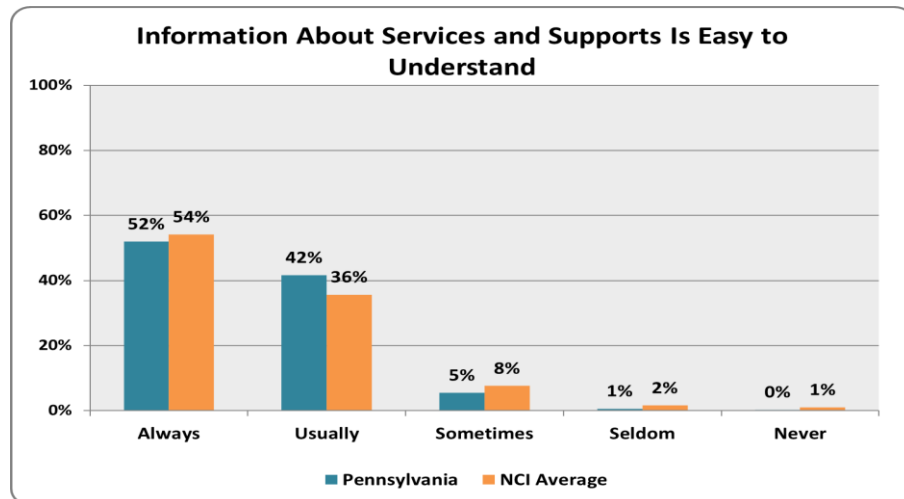
GRAPH 23. DO YOU GET ENOUGH INFORMATION TO HELP YOU PARTICIPATE IN PLANNING SERVICES FOR YOUR FAMILY MEMBER?



This graph illustrates that respondents from Pennsylvania and across all NCI states receive enough information to help plan services: always 48% and 48%, usually 36% and 34%, sometimes 10% and 10%, seldom 2% and 5%, and never 4% and 3%.

Across NCI states, percentage of "always" responses ranged between 62% and 37%

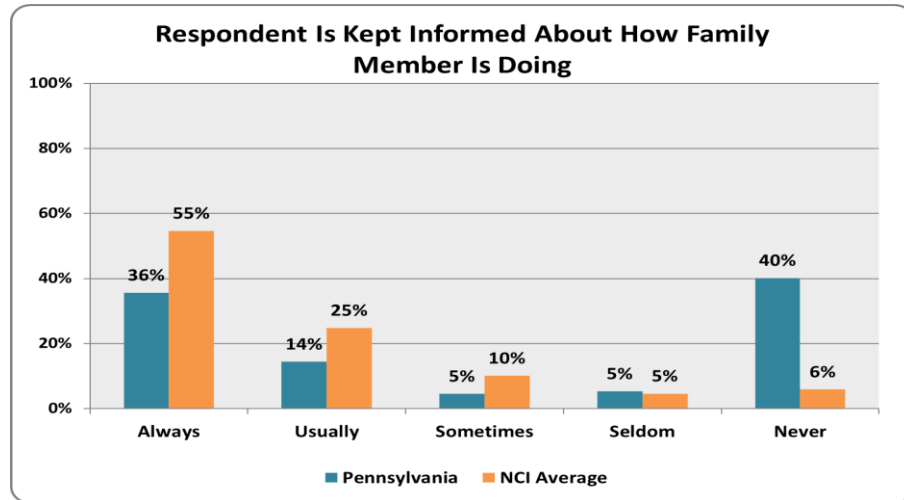
GRAPH 24. IS THE INFORMATION YOU RECEIVE EASY TO UNDERSTAND?



This graph illustrates that respondents from Pennsylvania and across all NCI states say the information they receive is easy to understand: always 52% and 54%, usually 42% and 36%, sometimes 5% and 8%, seldom 1% and 2%, and never 0% and 1%.

Across NCI states, percentage of "always" responses ranged between 66% and 43%.

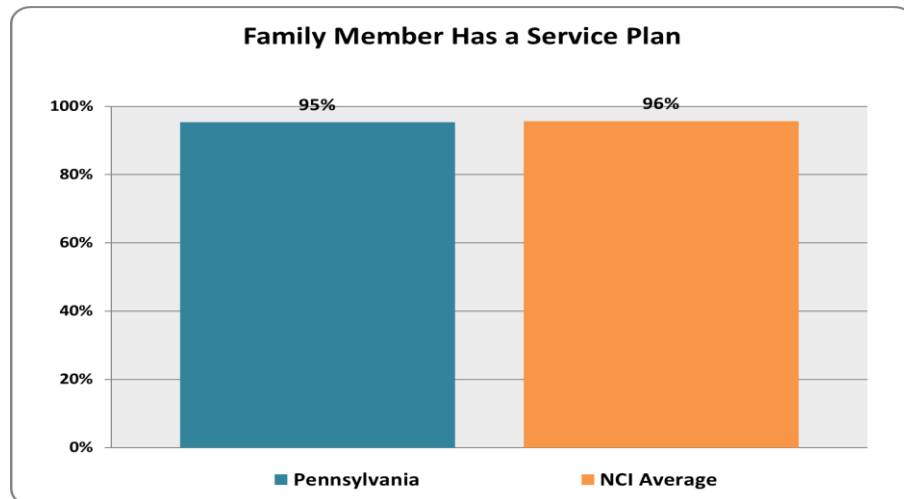
GRAPH 25. ARE YOU KEPT INFORMED ABOUT HOW YOUR FAMILY MEMBER IS DOING?



This graph illustrates that respondents from Pennsylvania and across all NCI states are kept informed about how their family member is doing: always 36% and 55%, usually 14% and 25%, sometimes 5% and 10%, seldom 5% and 5%, and never 40% and 6%.

Across NCI states, percentage of "always" responses ranged between 71% and 36%.

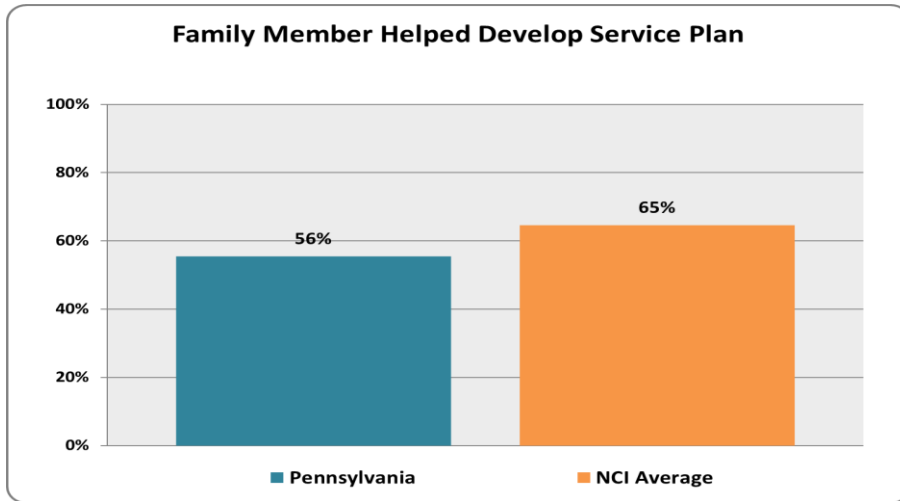
GRAPH 26. DOES YOUR FAMILY MEMBER HAVE A SERVICE PLAN?



This graph illustrates that 95% of respondents from Pennsylvania and 96% from across all NCI states say their family member has a service plan.

Across NCI states, percentage of "yes" responses ranged between 99% and 92%.

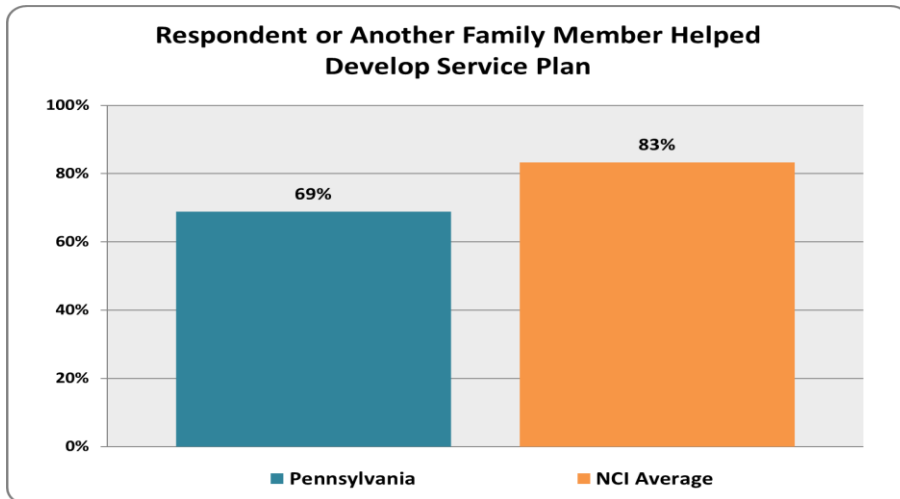
GRAPH 27. DID YOUR FAMILY MEMBER HELP DEVELOP THE PLAN?



This graph illustrates that among respondents whose family member has a service plan, 56% from Pennsylvania and 65% from across all NCI states say their family member helped develop the plan.

Across NCI states, percentage of "yes" responses ranged between 78% and 51%.

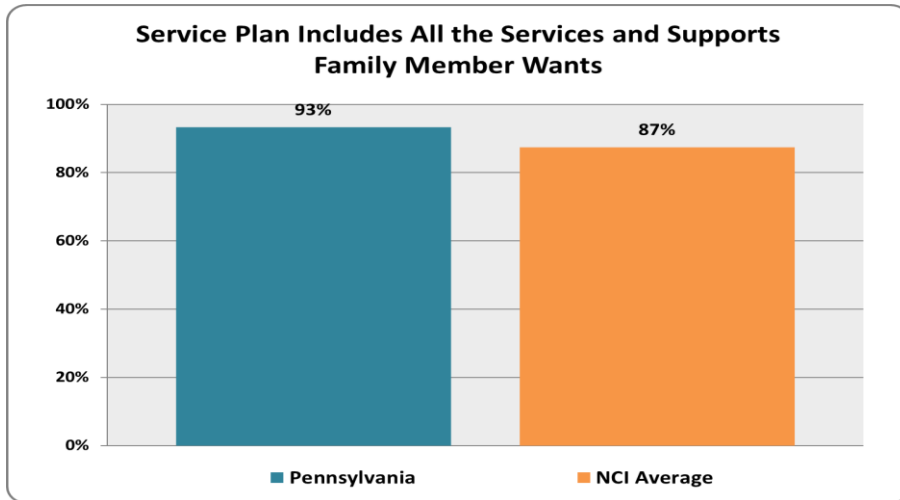
GRAPH 28. DID YOU OR ANOTHER FAMILY MEMBER HELP DEVELOP THE PLAN?



This graph illustrates that among respondents whose family member has a service plan, 69% from Pennsylvania and 83% from across all NCI states say they or another family member helped develop the plan.

Across NCI states, percentage of "yes" responses ranged between 90% and 69%.

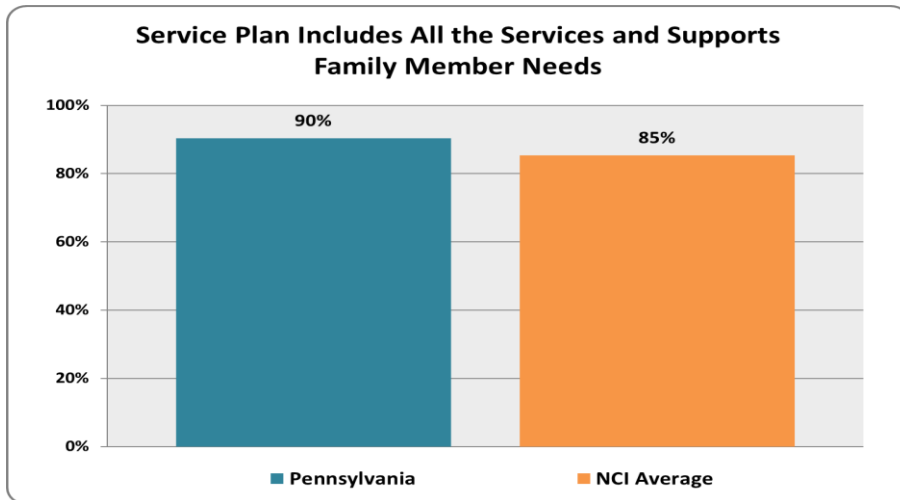
GRAPH 29. DOES THE PLAN INCLUDE ALL THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER WANTS?



This graph illustrates that among respondents whose family member has a service plan, 93% from Pennsylvania and 87% from across all NCI states say the plan includes all the services and supports their family member wants.

Across NCI states, percentage of "yes" responses ranged between 95% and 78%.

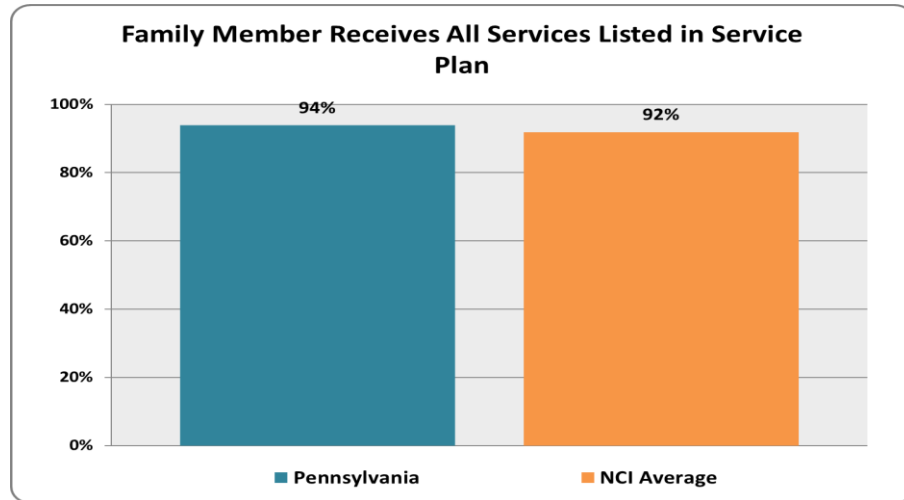
GRAPH 30. DOES THE PLAN INCLUDE ALL THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER NEEDS?



This graph illustrates that among respondents whose family member has a service plan, 90% from Pennsylvania and 85% from across all NCI states say the plan includes all the services and supports their family member needs.

Across NCI states, percentage of "yes" responses ranged between 96% and 73%.

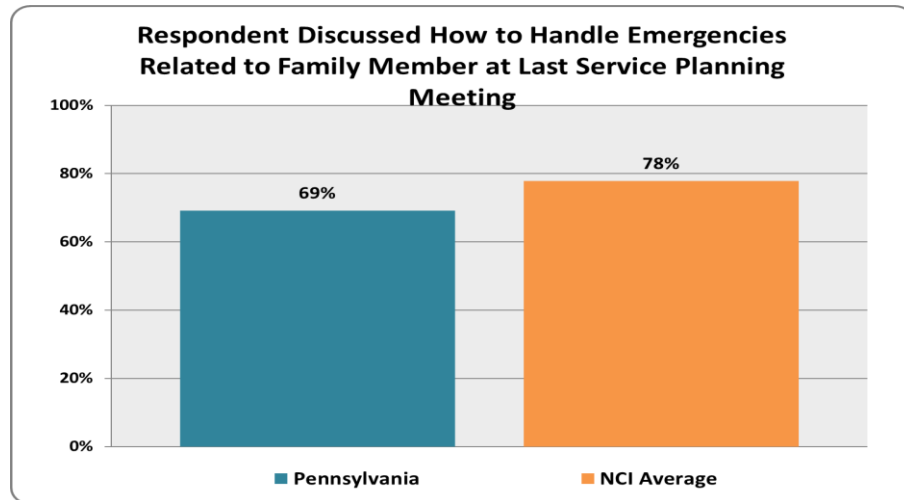
GRAPH 31. DOES YOUR FAMILY MEMBER RECEIVE ALL OF THE SERVICES LISTED IN THE PLAN?



This graph illustrates that among respondents whose family member has a service plan, 94% from Pennsylvania and 92% from across all NCI states say their family member receives all the services listed in the plan.

Across NCI states, percentage of "yes" responses ranged between 97% and 82%.

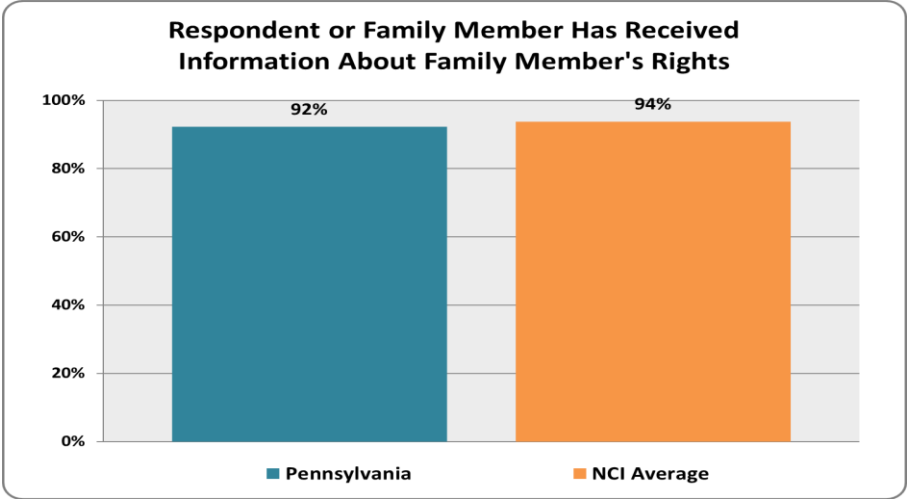
GRAPH 32. DID YOU DISCUSS HOW TO HANDLE EMERGENCIES RELATED TO YOUR FAMILY MEMBER AT THE LAST SERVICE PLANNING MEETING?



This graph illustrates that among respondents whose family member has a service plan, 69% from Pennsylvania and 78% from across all NCI states discussed how to handle emergencies related to the family member at the last planning meeting.

Across NCI states, percentage of "yes" responses ranged between 90% and 65%.

GRAPH 33. HAVE YOU OR YOUR FAMILY MEMBER RECEIVED INFORMATION ABOUT HIS/HER RIGHTS?



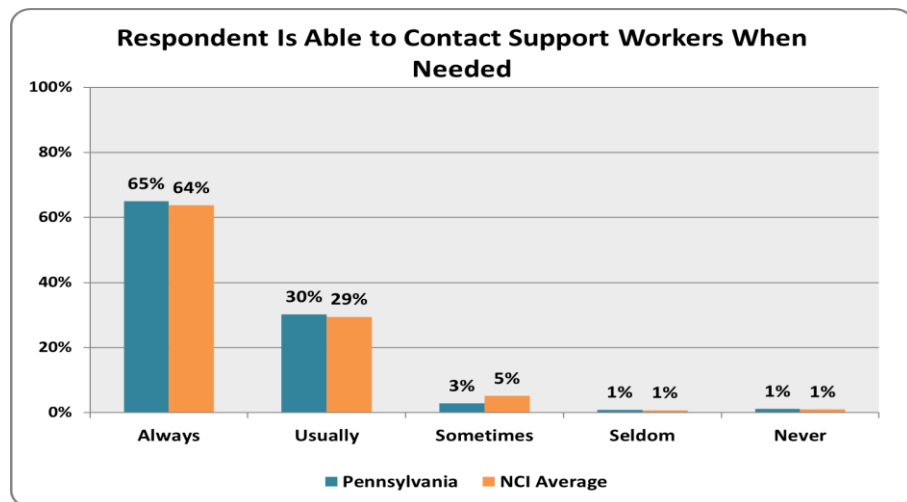
This graph illustrates that 92% of respondents from Pennsylvania and 94% from across all NCI states say they or their family member received information their family member's rights.

Across NCI states, percentage of "yes" responses ranged between 98% and 86%.

Access and Delivery

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES GET THE SERVICES AND SUPPORTS THEY NEED

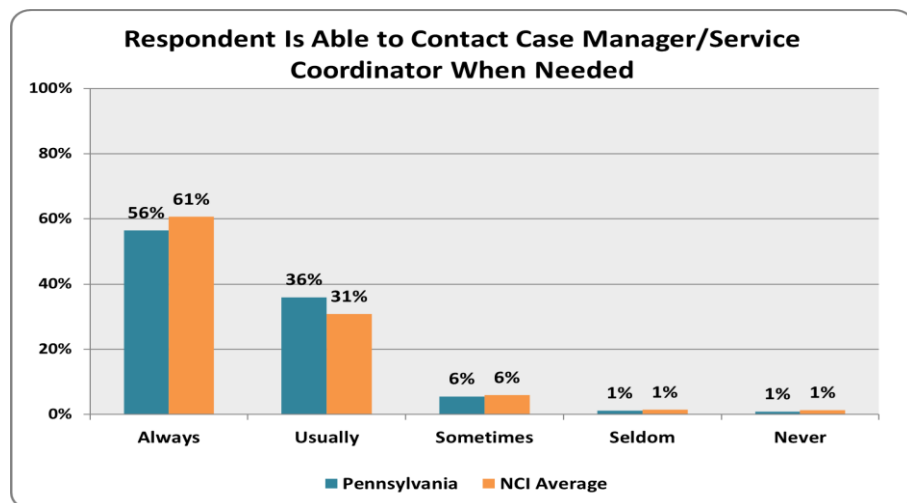
GRAPH 34. ARE YOU ABLE TO CONTACT YOUR FAMILY MEMBER'S SUPPORT WORKERS WHEN YOU NEED TO?



This graph illustrates that respondents from Pennsylvania and across all NCI states are able to contact their family member's support workers when needed: always 65% and 64%, usually 30% and 29%, sometimes 3% and 5%, seldom 1% and 1%, and never 1% and 1%.

Across NCI states, percentage of "always" responses ranged between 78% and 53%.

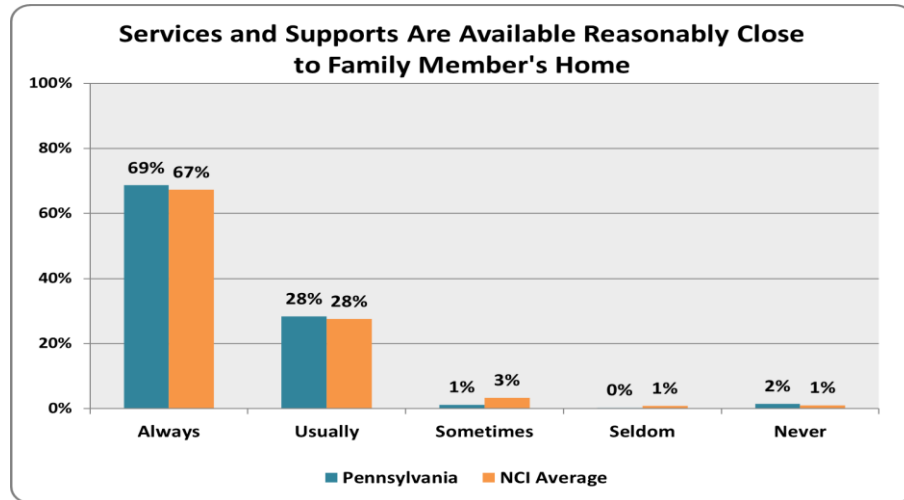
GRAPH 35. ARE YOU ABLE TO CONTACT YOUR FAMILY MEMBER'S CASE MANAGER/SERVICE COORDINATOR WHEN YOU NEED TO?



This graph illustrates that respondents from Pennsylvania and across all NCI states are able to contact their family member's case manager/service coordinator when needed: always 56% and 61%, usually 36% and 31%, sometimes 6% and 6%, seldom 1% and 1%, and never 1% and 1%.

Across NCI states, percentage of "always" responses ranged between 72% and 53%.

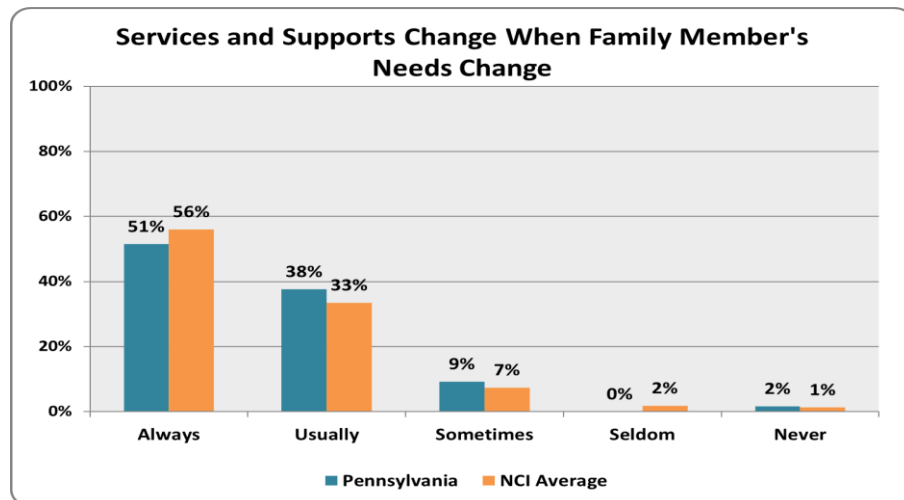
GRAPH 36. ARE SERVICES AND SUPPORTS AVAILABLE WITHIN A REASONABLE DISTANCE FROM YOUR FAMILY MEMBER'S HOME?



This graph illustrates that respondents from Pennsylvania and across all NCI states say services and supports are available within a reasonable distance from their family member's home: always 69% and 67%, usually 28% and 28%, sometimes 1% and 3%, seldom 0% and 1%, and never 2% and 1%.

Across NCI states, percentage of "always" responses ranged between 82% and 62%.

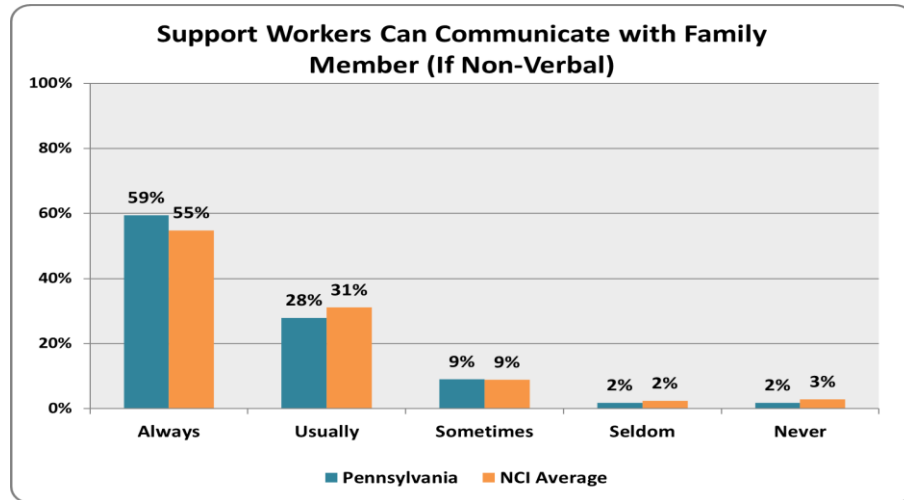
GRAPH 37. DO THE SERVICES AND SUPPORTS CHANGE WHEN YOUR FAMILY MEMBER'S NEEDS CHANGE?



This graph illustrates that respondents from Pennsylvania and across all NCI states say services and supports change when their family member's needs change: always 51% and 56%, usually 38% and 33%, sometimes 9% and 7%, seldom 0% and 2%, and never 2% and 1%.

Across NCI states, percentage of "always" responses ranged between 72% and 50%.

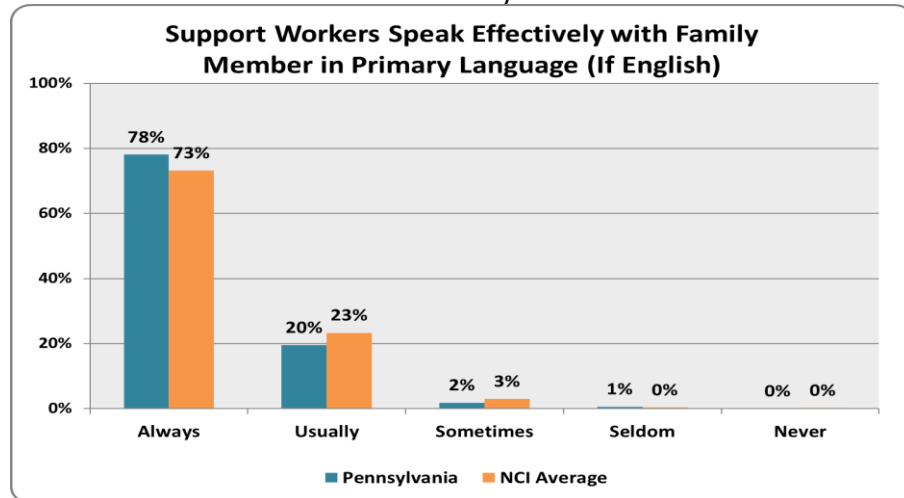
GRAPH 38. IF YOUR FAMILY MEMBER DOES NOT COMMUNICATE VERBALLY (FOR EXAMPLE, USES GESTURES OR SIGN LANGUAGE), ARE THERE SUPPORT WORKERS WHO CAN COMMUNICATE WITH HIM/HER?



This graph illustrates that among respondents from Pennsylvania and across all NCI states whose family member does not communicate verbally, support workers are able to communicate with him/her: always 59% and 55%, usually 28% and 31%, sometimes 9% and 9%, seldom 2% and 2%, and never 2% and 3%.

Across NCI states, percentage of "always" responses ranged between 74% and 40%.

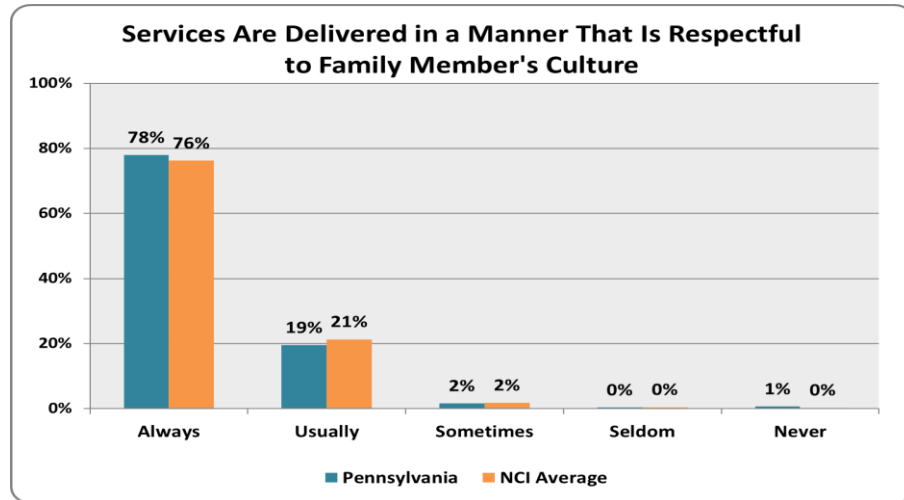
GRAPH 39. IF ENGLISH IS YOUR FAMILY MEMBER'S PRIMARY LANGUAGE, DO THE SUPPORT WORKERS SPEAK TO HIM/HER EFFECTIVELY?



This graph illustrates that among respondents from Pennsylvania and across all NCI states whose family member's primary language is English, workers speak with their family member effectively: always 78% and 73%, usually 20% and 23%, sometimes 2% and 3%, seldom 1% and 0%, and never 0% and 0%.

Across NCI states, percentage of "always" responses ranged between 80% and 67%.

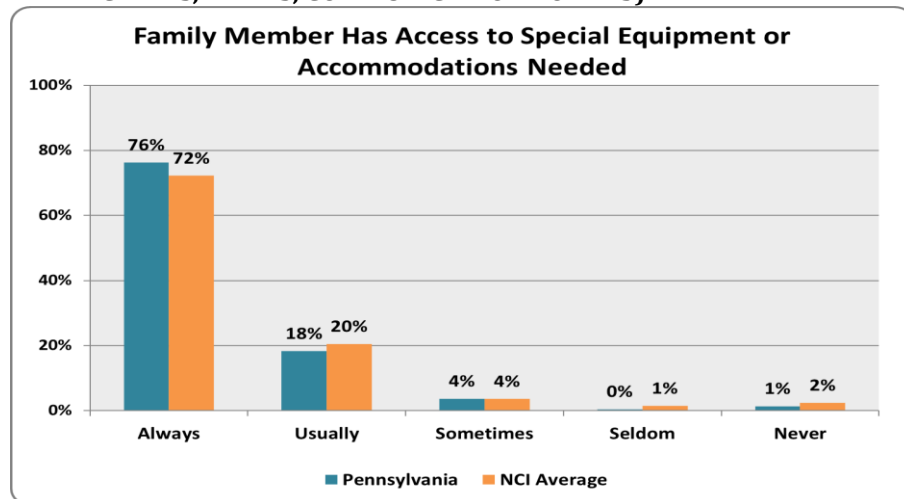
GRAPH 40. ARE SERVICES DELIVERED IN A WAY THAT IS RESPECTFUL TO YOUR FAMILY MEMBER'S CULTURE?



This graph illustrates that respondents from Pennsylvania and across all NCI states say services are delivered in a manner that is respectful of their family member's culture: always 78% and 76%, usually 19% and 21%, sometimes 2% and 2%, seldom 0% and 0%, and never 1% and 0%.

Across NCI states, percentage of "always" responses ranged between 90% and 72%.

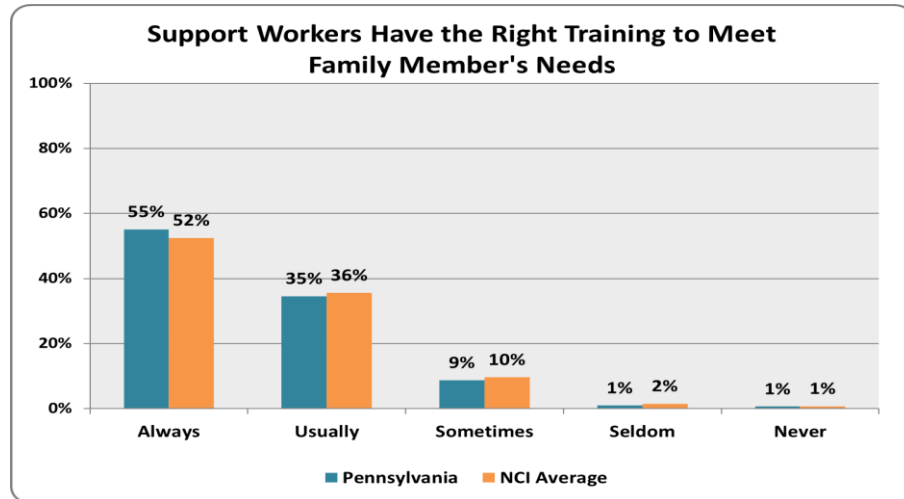
GRAPH 41. DOES YOUR FAMILY MEMBER HAVE ACCESS TO THE SPECIAL EQUIPMENT OR ACCOMMODATIONS THAT HE/SHE NEEDS (FOR EXAMPLE, WHEELCHAIRS, RAMPS, COMMUNICATION BOARDS)?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their family member has access to special equipment or accommodations needed: always 76% and 72%, usually 18% and 20%, sometimes 4% and 4%, seldom 0% and 1%, and never 1% and 2%.

Across NCI states, percentage of "always" responses ranged between 88% and 65%.

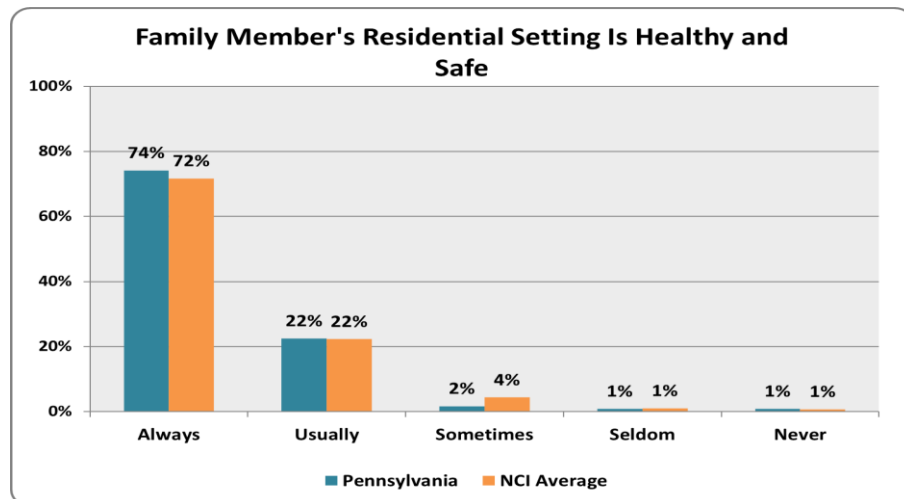
GRAPH 42. DO SUPPORT WORKERS HAVE THE RIGHT TRAINING TO MEET YOUR FAMILY MEMBER'S NEEDS?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their family member's support workers have the right training to meet their family member's needs: always 55% and 52%, usually 35% and 36%, sometimes 9% and 10%, seldom 1% and 2%, and never 1% and 1%.

Across NCI states, percentage of "always" responses ranged between 60% and 43%.

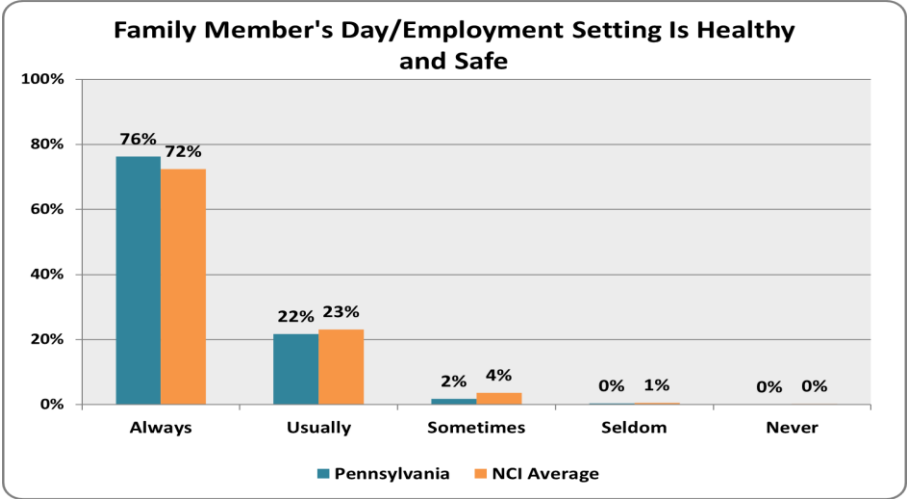
GRAPH 43. DO YOU FEEL THAT YOUR FAMILY MEMBER'S RESIDENTIAL SETTING IS A HEALTHY AND SAFE ENVIRONMENT?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their family member's residential setting is healthy and safe: always 74% and 72%, usually 22% and 22%, sometimes 2% and 4%, seldom 1% and 1%, and never 1% and 1%.

Across NCI states, percentage of "always" responses ranged between 79% and 65%.

GRAPH 44. DO YOU FEEL THAT YOUR FAMILY MEMBER'S DAY/EMPLOYMENT SETTING IS A HEALTHY AND SAFE ENVIRONMENT?



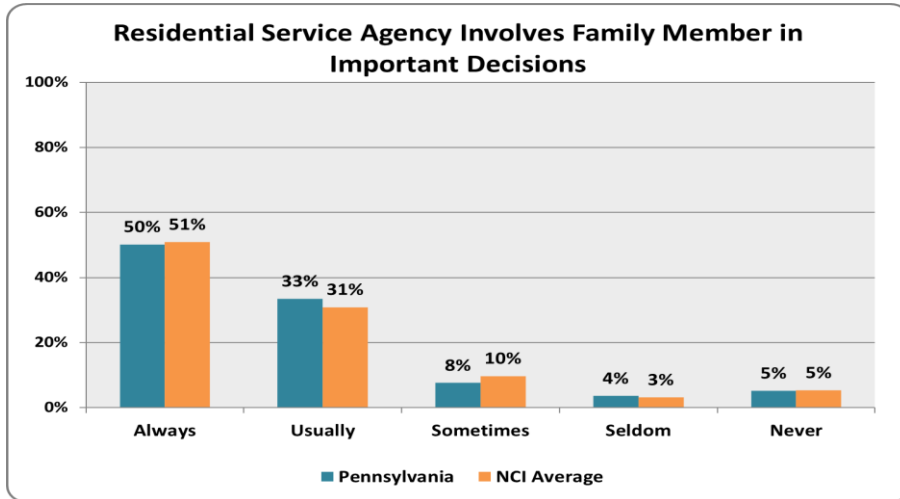
This graph illustrates that respondents from Pennsylvania and across all NCI states say their family member's day or employment setting is healthy and safe: always 76% and 72%, usually 22% and 23%, sometimes 2% and 4%, seldom 0% and 1%, and never 0% and 0%.

Across NCI states, percentage of "always" responses ranged between 84% and 66%.

Choice and Control

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES DETERMINE THE SERVICES AND SUPPORTS THEY RECEIVE AND THE INDIVIDUALS OR AGENCIES WHO PROVIDE THEM

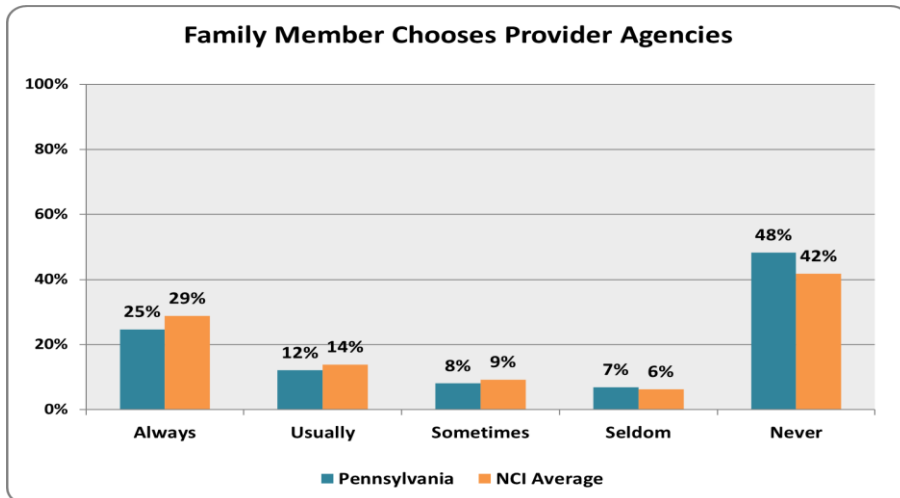
GRAPH 45. DOES THE AGENCY PROVIDING RESIDENTIAL SERVICES TO YOUR FAMILY MEMBER INVOLVE HIM/HER IN IMPORTANT DECISIONS?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their family member's residential service agency involves their family member in important decisions: always 50% and 51%, usually 33% and 31%, sometimes 8% and 10%, seldom 4% and 3%, and never 5% and 5%.

Across NCI states, percentage of "always" responses ranged between 59% and 45%.

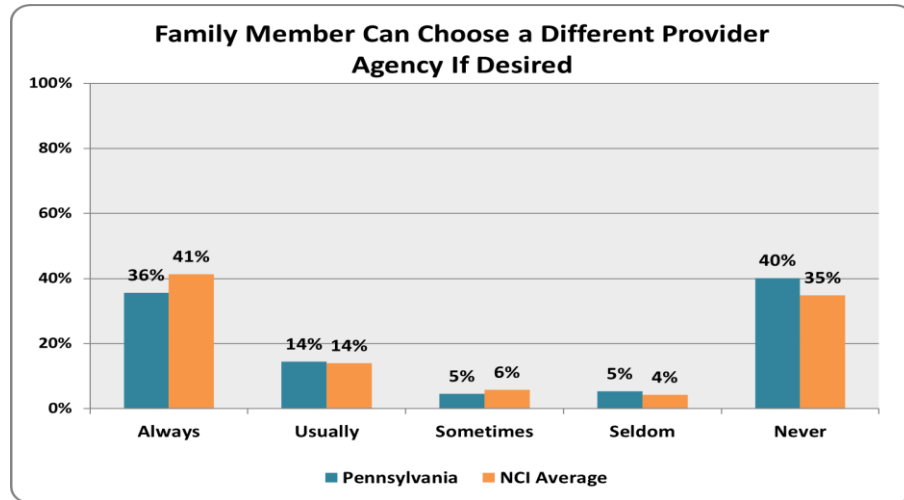
GRAPH 46. DOES YOUR FAMILY MEMBER CHOOSE THE PROVIDER AGENCIES THAT WORK WITH HIM OR HER?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their family member chooses the provider agencies that work with him/her: always 25% and 29%, usually 12% and 14%, sometimes 8% and 9%, seldom 7% and 6%, and never 48% and 42%.

Across NCI states, percentage of "always" responses ranged between 36% and 25%.

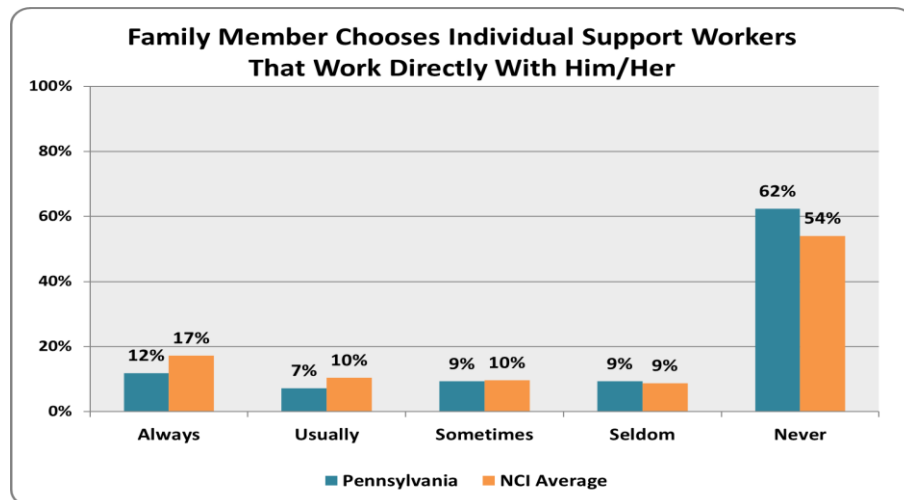
GRAPH 47. CAN YOUR FAMILY MEMBER CHOOSE A DIFFERENT PROVIDER AGENCY IF S/HE WANTS TO?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their family member can choose a different provider agency if he/she wants: always 36% and 41%, usually 14% and 14%, sometimes 5% and 6%, seldom 5% and 4%, and never 40% and 35%.

Across NCI states, percentage of "always" responses ranged between 55% and 29%.

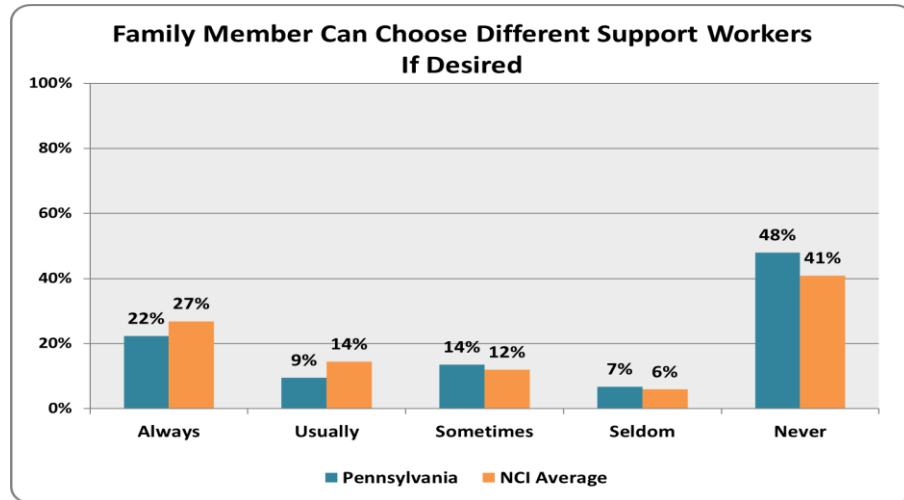
GRAPH 48. DOES YOUR FAMILY MEMBER CHOOSE THE INDIVIDUAL SUPPORT WORKERS WHO WORK DIRECTLY WITH HIM/HER?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their family member chooses the individual support workers who work with him/her: always 12% and 17%, usually 7% and 10%, sometimes 9% and 10%, seldom 9% and 9%, and never 62% and 54%.

Across NCI states, percentage of "always" responses ranged between 33% and 9%.

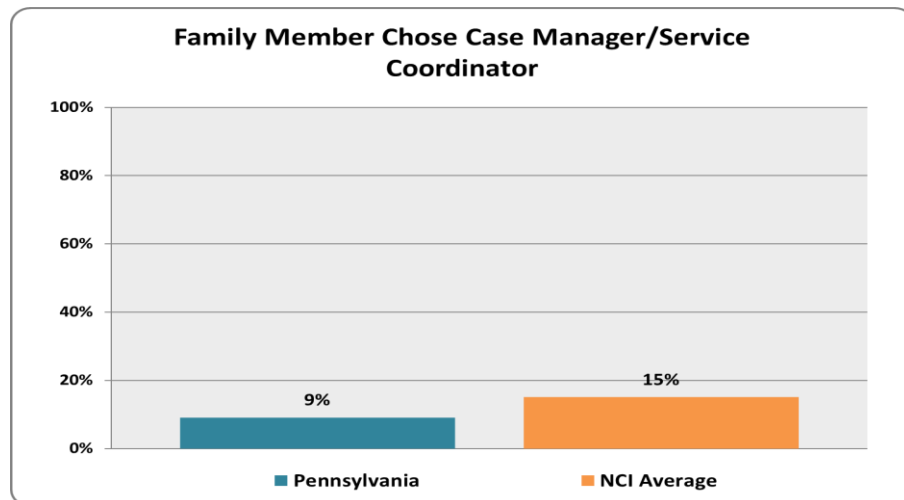
GRAPH 49. CAN YOUR FAMILY MEMBER CHOOSE DIFFERENT SUPPORT WORKERS IF S/HE WANTS TO?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their family member can choose different individual support workers if he/she wants: always 22% and 27%, usually 9% and 14%, sometimes 14% and 12%, seldom 7% and 6%, and never 48% and 41%.

Across NCI states, percentage of "always" responses ranged between 42% and 17%.

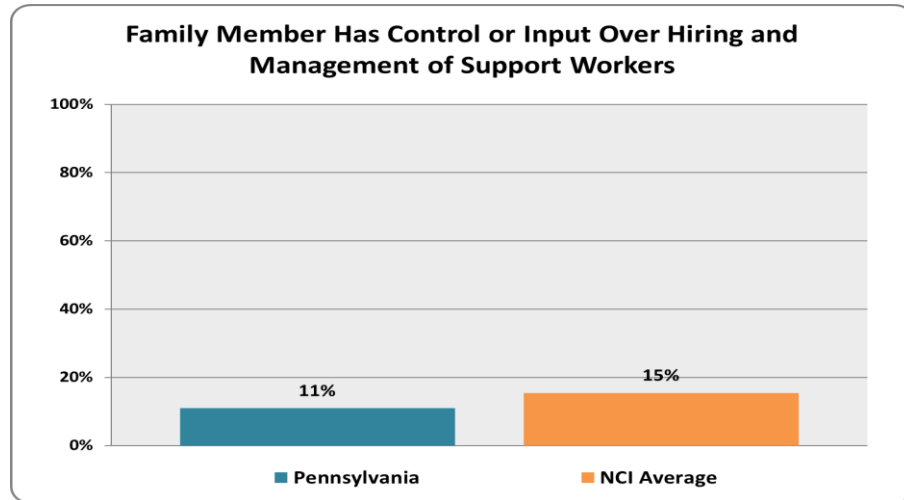
GRAPH 50. DID YOUR FAMILY MEMBER CHOOSE HIS/HER CASE MANAGER/SERVICE COORDINATOR?



This graph illustrates that 9% of respondents from Pennsylvania and 15% across all NCI states say their family member chose their case manager/service coordinator.

Across NCI states, percentage of "yes" responses ranged between 43% and 6%.

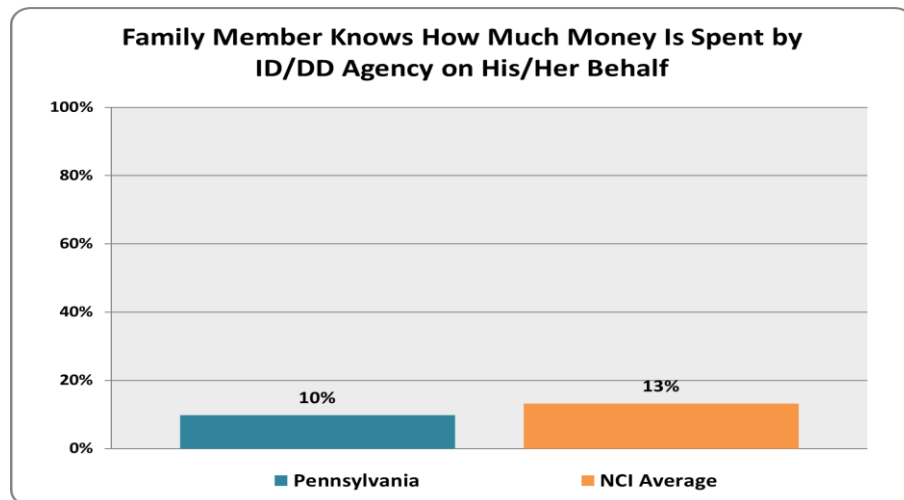
GRAPH 51. DOES YOUR FAMILY MEMBER HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF HIS/HER SUPPORT WORKERS?



This graph illustrates that 11% of respondents from Pennsylvania and 15% across all NCI states say their family member has control and input over the hiring and management of support workers.

Across NCI states, percentage of "yes" responses ranged between 40% and 6%.

GRAPH 52. DOES YOUR FAMILY MEMBER KNOW HOW MUCH MONEY IS SPENT BY THE ID/DD AGENCY ON HIS/HER BEHALF?*

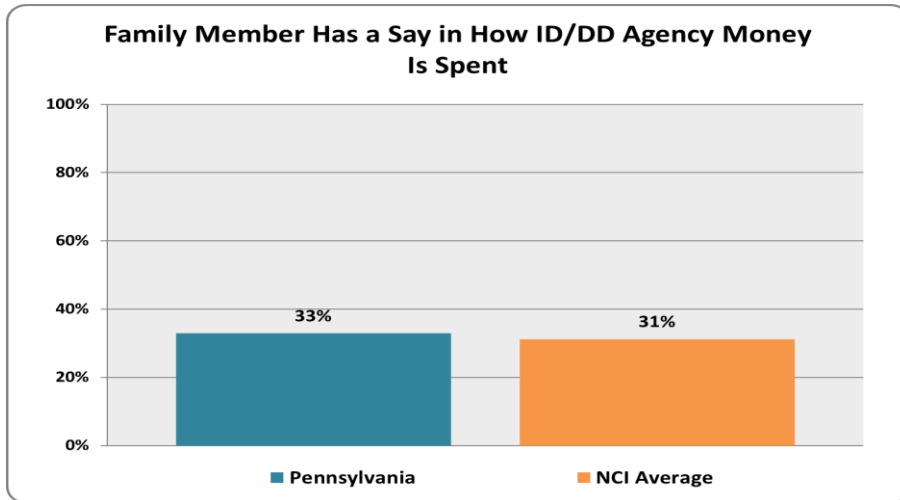


This graph illustrates that 10% of respondents from Pennsylvania and 13% across all NCI states say their family member knows how much money is spent by the ID/DD agency on his/her behalf.

Across NCI states, percentage of "yes" responses ranged between 28% and 6%.

*Don't know' responses are included with 'no' responses.

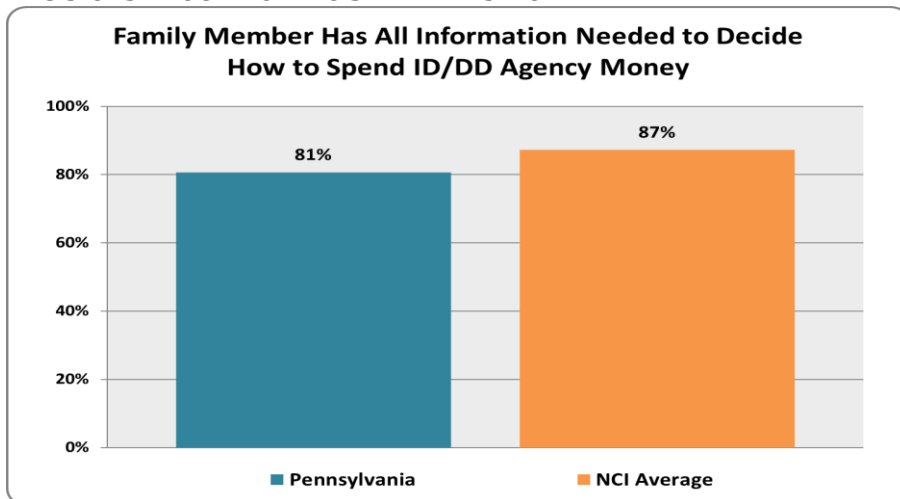
GRAPH 53. DOES YOUR FAMILY MEMBER HAVE A SAY IN HOW ID/DD AGENCY MONEY IS SPENT ON HIS/HER BEHALF?



This graph illustrates that 33% of respondents from Pennsylvania and 31% across all NCI states say their family member has a say in how ID/DD agency money is spent on his/her behalf.

Across NCI states, percentage of "yes" responses ranged between 42% and 16%.

GRAPH 54. IF YOUR FAMILY MEMBER HAS A SAY IN HOW ID/DD AGENCY MONEY IS SPENT, DOES S/HE HAVE ALL THE INFORMATION NEEDED TO MAKE DECISIONS ABOUT HOW TO SPEND THIS MONEY?



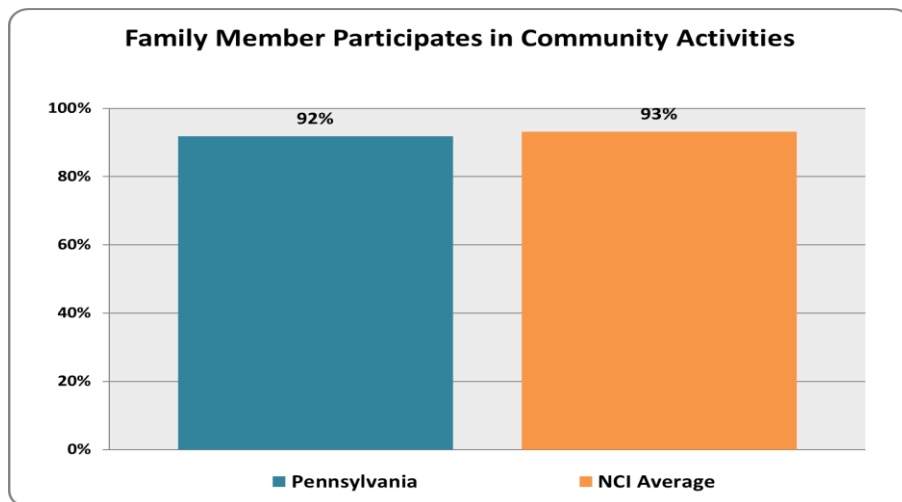
This graph illustrates that among respondents whose family member has a say in how ID/DD agency money is spent, 81% of respondents from Pennsylvania and 87% across all NCI states say their family member has all the information needed to make those determinations.

Across NCI states, percentage of "yes" responses ranged between 96% and 81%.

Community Connections

FAMILY MEMBERS WITH DISABILITIES USE INTEGRATED COMMUNITY SERVICES AND PARTICIPATE IN EVERYDAY COMMUNITY ACTIVITIES

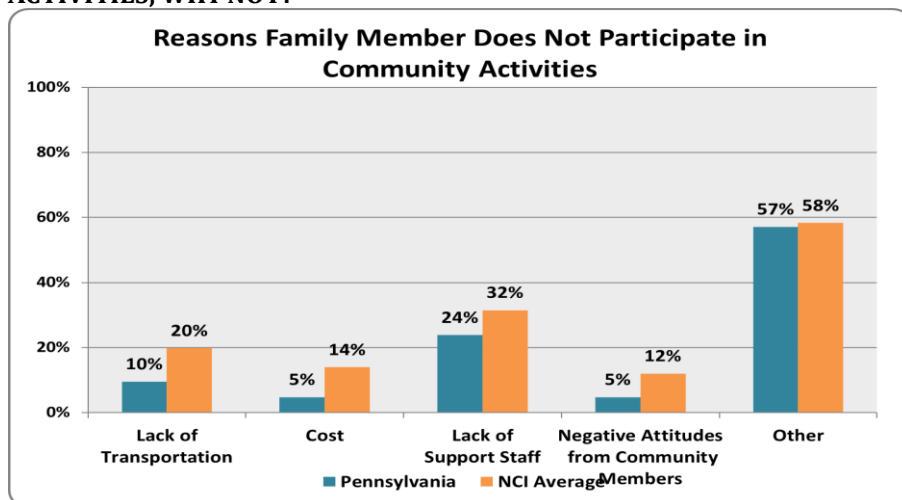
GRAPH 55. DOES YOUR FAMILY MEMBER PARTICIPATE IN COMMUNITY ACTIVITIES (SUCH AS GOING OUT TO A RESTAURANT, MOVIE, OR SPORTING EVENT)?



This graph illustrates that 92% of respondents from Pennsylvania and 93% across all NCI states say their family member participates in community activities.

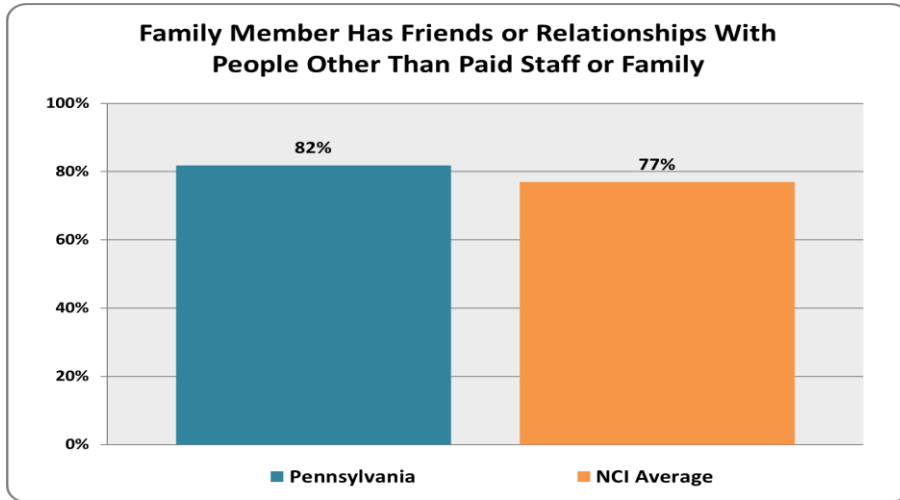
Across NCI states, percentage of "yes" responses ranged between 96% and 89%.

GRAPH 56. IF YOUR FAMILY MEMBER DOESN'T PARTICIPATE IN COMMUNITY ACTIVITIES, WHY NOT?



This graph illustrates that among respondents from Pennsylvania and across NCI states whose family member does not participate in community activities, the reasons given were: 10% and 20% lack of transportation, 5% and 14% cost, 24% and 32% lack of support staff, 5% and 12% negative attitudes from community members, 57% and 58% other.

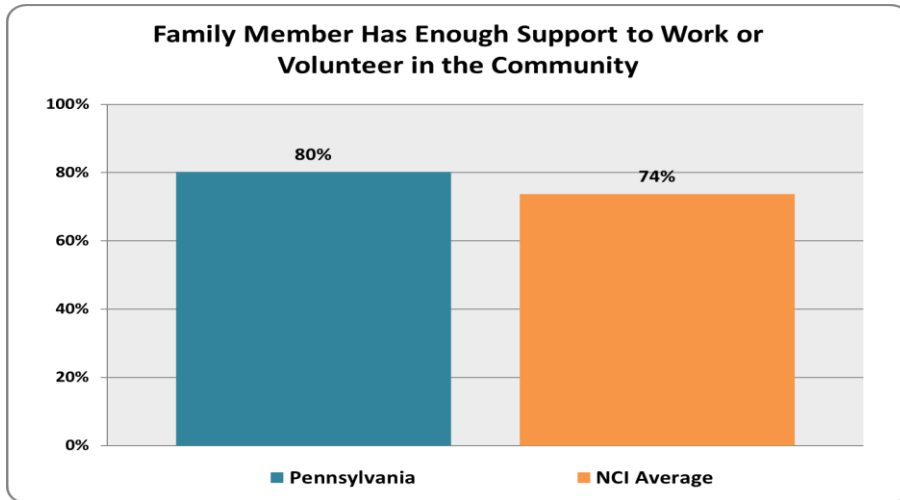
GRAPH 57. DOES YOUR FAMILY MEMBER HAVE FRIENDS OR RELATIONSHIPS WITH PERSONS OTHER THAN PAID STAFF OR FAMILY?



This graph illustrates that 82% of respondents from Pennsylvania and 77% across all NCI states say their family member has relationships with people other than paid staff or family.

Across NCI states, percentage of "yes" responses ranged between 83% and 73%.

GRAPH 58. DOES YOUR FAMILY MEMBER HAVE ENOUGH SUPPORT (FOR EXAMPLE, SUPPORT WORKERS, COMMUNITY RESOURCES) TO WORK OR VOLUNTEER IN THE COMMUNITY?



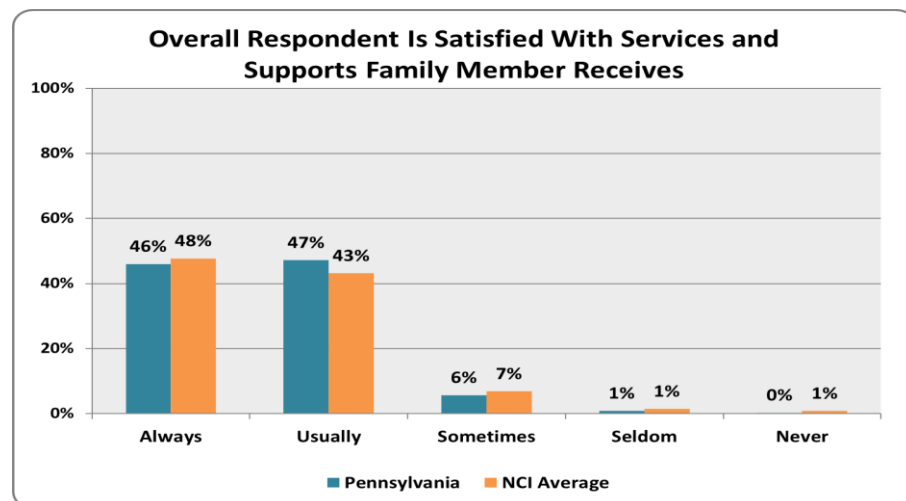
This graph illustrates that 80% of respondents from Pennsylvania and 74% across all NCI states say their family member has enough supports (e.g., support workers or community resources) to work or volunteer in the community.

Across NCI states, percentage of "yes" responses ranged between 80% and 66%.

Satisfaction

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES RECEIVE ADEQUATE AND SATISFACTORY SUPPORTS

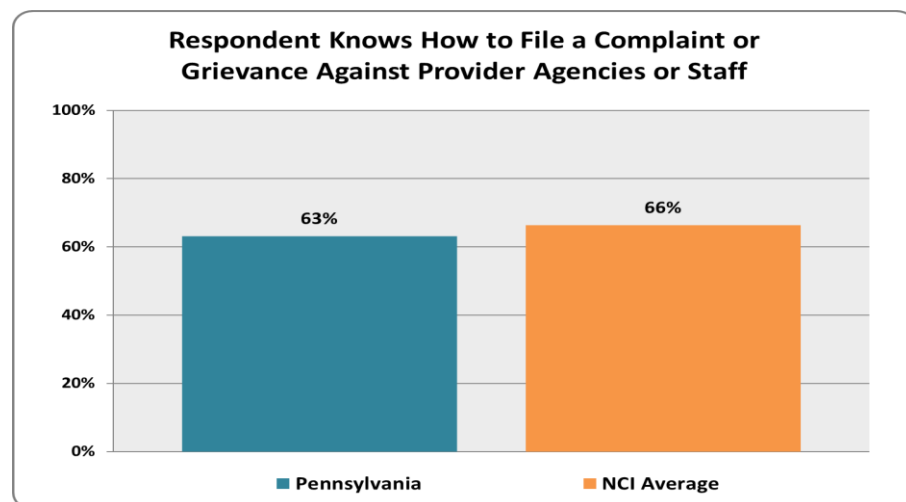
GRAPH 59. OVERALL, ARE YOU SATISFIED WITH THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER CURRENTLY RECEIVES?



This graph illustrates that respondents from Pennsylvania and across all NCI states are satisfied with the services and supports their family member receives: always 46% and 48%, usually 47% and 43%, sometimes 6% and 7%, seldom 1% and 1%, and never 0% and 1%.

Across NCI states, percentage of "always" responses ranged between 62% and 39%.

GRAPH 60. DO YOU KNOW THE PROCESS FOR FILING A COMPLAINT OR GRIEVANCE AGAINST PROVIDER AGENCIES OR STAFF?*

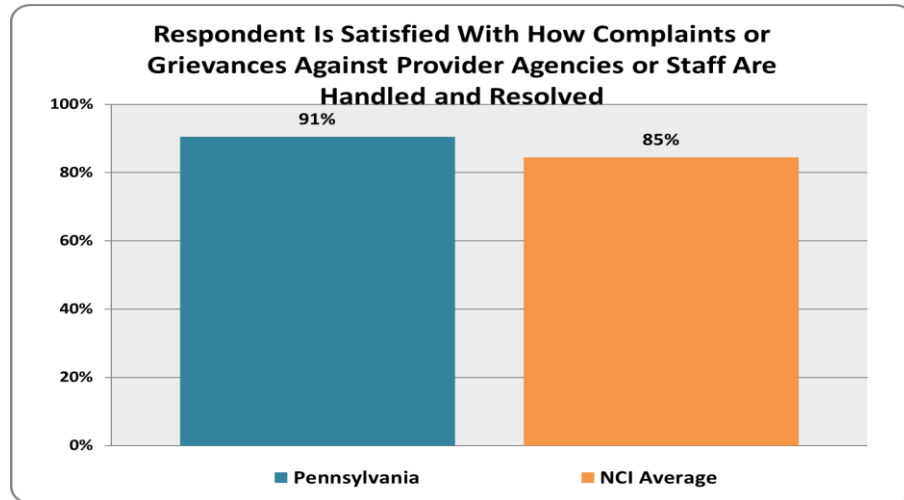


This graph illustrates that 63% of respondents from Pennsylvania and 66% across all NCI states know the process for filing a complaint or grievance against provider agencies or staff.

Across NCI states, percentage of "yes" responses ranged between 80% and 48%.

*Don't know' responses are included with 'no' responses.

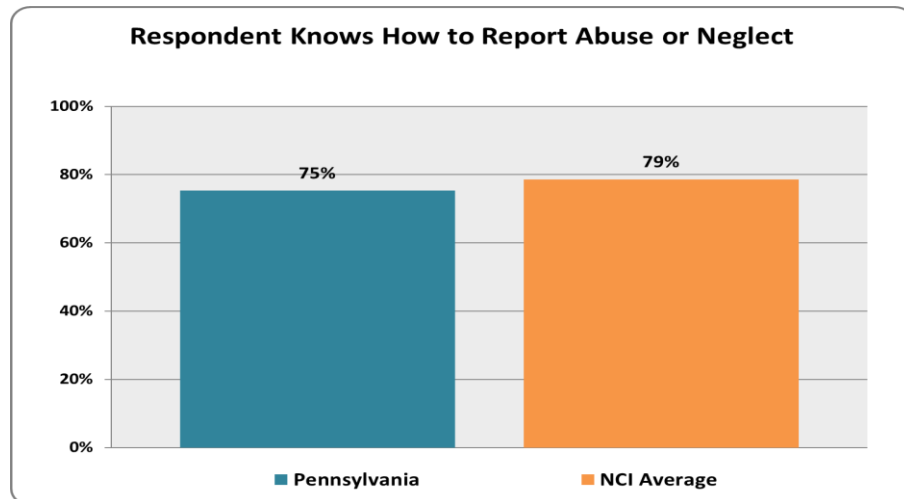
GRAPH 61. ARE YOU SATISFIED WITH THE WAY COMPLAINTS OR GRIEVANCES AGAINST PROVIDER AGENCIES OR STAFF ARE HANDLED AND RESOLVED?



This graph illustrates that 91% of respondents from Pennsylvania and 85% across all NCI states are satisfied with the way complaints or grievances against provider agencies or staff are handled and resolved.

Across NCI states, percentage of "yes" responses ranged between 91% and 72%.

GRAPH 62. DO YOU KNOW HOW TO REPORT ABUSE OR NEGLECT?*

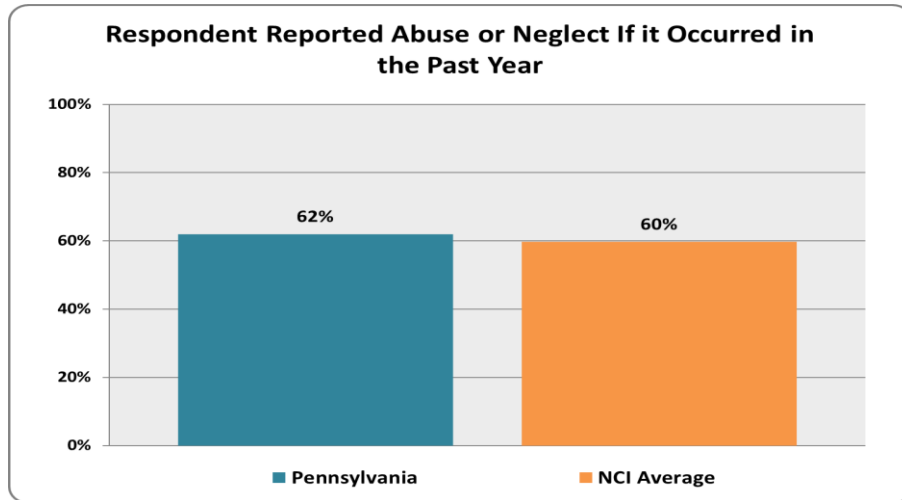


This graph illustrates that 75% of respondents from Pennsylvania and 79% across all NCI states know how to report abuse or neglect.

Across NCI states, percentage of "yes" responses ranged between 87% and 60%.

*Don't know' responses are included with 'no' responses.

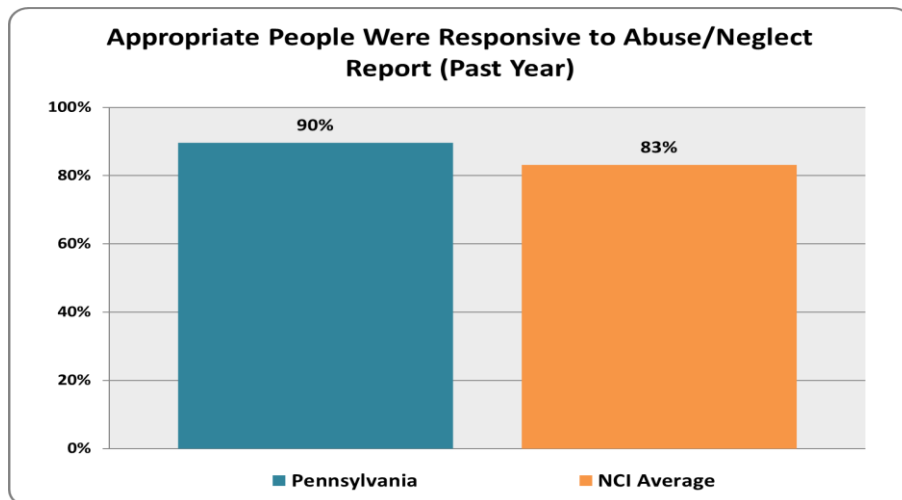
GRAPH 63. WITHIN THE PAST YEAR, IF ABUSE OR NEGLECT OCCURRED, DID YOU REPORT IT?



This graph illustrates that 62% of respondents from Pennsylvania and 60% across all NCI states reported abuse or neglect if it occurred in the past year.

Across NCI states, percentage of "yes" responses ranged between 74% and 48%.

GRAPH 64. IF YOU REPORTED ABUSE OR NEGLECT IN THE PAST YEAR, WERE THE APPROPRIATE PEOPLE RESPONSIVE TO YOUR REPORT?



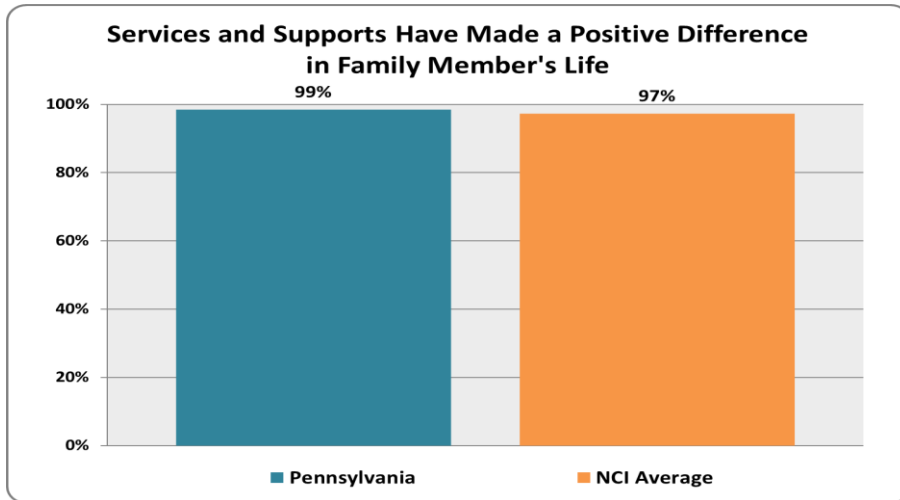
This graph illustrates that among respondents who reported abuse or neglect in the past year, 90% from Pennsylvania and 83% across all NCI states say the appropriate parties were responsive to their report.

Across NCI states, percentage of "yes" responses ranged between 93% and 70%.

Family Outcomes

INDIVIDUAL AND FAMILY SUPPORTS MAKE A POSITIVE DIFFERENCE IN THE LIVES OF FAMILIES

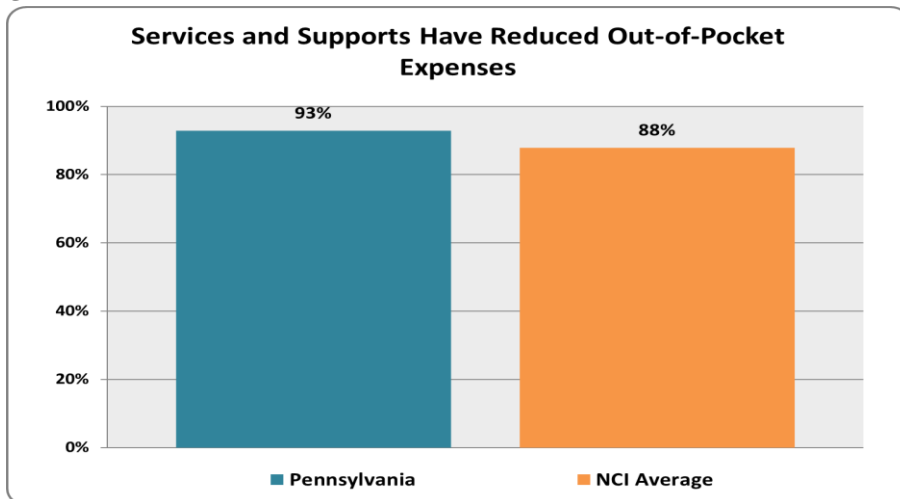
GRAPH 65. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE MADE A POSITIVE DIFFERENCE IN THE LIFE OF YOUR FAMILY MEMBER?



This graph illustrates that 99% of respondents from Pennsylvania and 97% across all NCI states say services and supports have made a positive difference in the life of their family member.

Across NCI states, percentage of "yes" responses ranged between 99% and 95%.

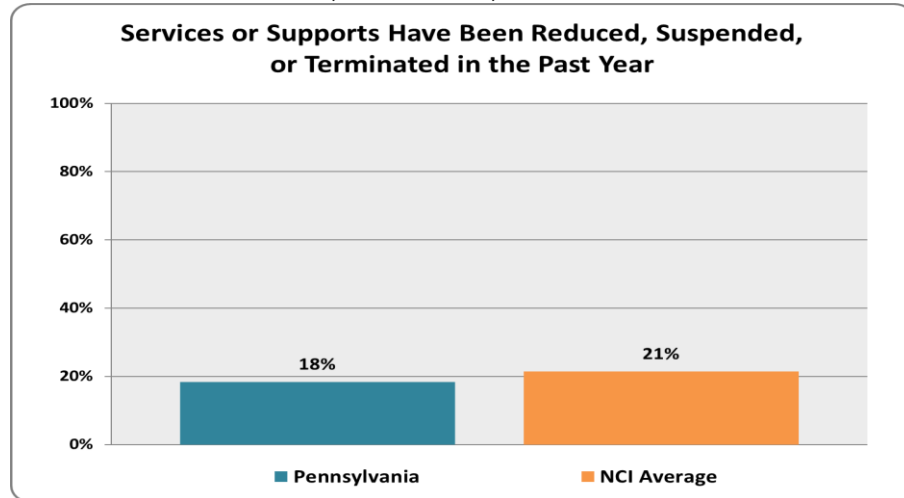
GRAPH 66. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE REDUCED YOUR FAMILY'S OUT-OF-POCKET EXPENSES FOR YOUR FAMILY MEMBER'S CARE?



This graph illustrates that 93% of respondents from Pennsylvania and 88% across all NCI states say services and supports reduced the family's out-of-pocket expenses for their family member's care.

Across NCI states, percentage of "yes" responses ranged between 93% and 84%.

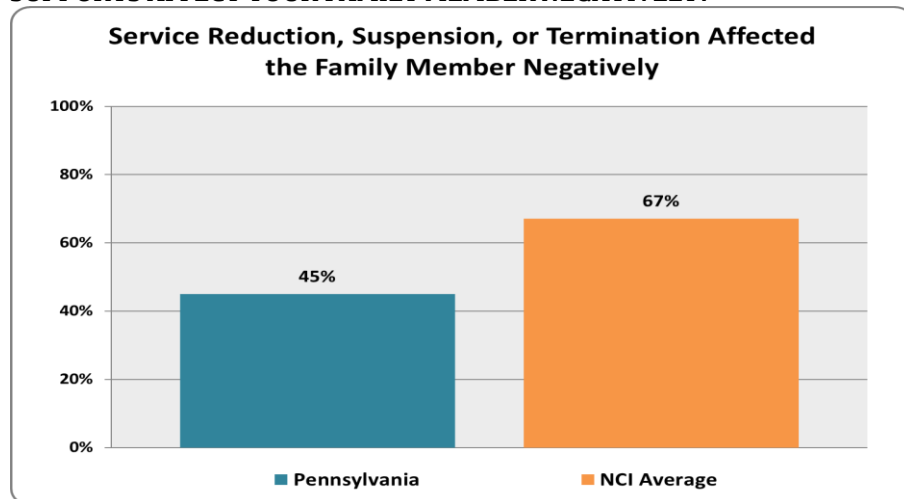
GRAPH 67. HAVE THE SERVICES OR SUPPORTS THAT YOUR FAMILY MEMBER RECEIVED BEEN REDUCED, SUSPENDED, OR TERMINATED IN THE PAST YEAR?



This graph illustrates that 18% of respondents from Pennsylvania and 21% across all NCI states say services and supports were reduced, suspended, or terminated in the past year.

Across NCI states, percentage of "yes" responses ranged between 59% and 11%.

GRAPH 68. IF SERVICES OR SUPPORTS RECEIVED BY YOUR FAMILY MEMBER WERE REDUCED, SUSPENDED, OR TERMINATED IN THE PAST YEAR, DID THE REDUCTION, SUSPENSION, OR TERMINATION OF THESE SERVICES OR SUPPORTS AFFECT YOUR FAMILY MEMBER NEGATIVELY?



This graph illustrates that among respondents whose family member's services were reduced, suspended, or terminated in the past year, 45% from Pennsylvania and 67% across all NCI states say this change affected their family member negatively.

Across NCI states, percentage of "yes" responses ranged between 84% and 45%.