

NCI Family/Guardian Survey Outcomes

Pennsylvania Report

2013-14 Data



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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 2013-14 data collection cycle, 39 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 a mail-in survey sent to 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 – 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 of an adult with a developmental disability living outside of the respondent’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 +/- 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 +/- 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?

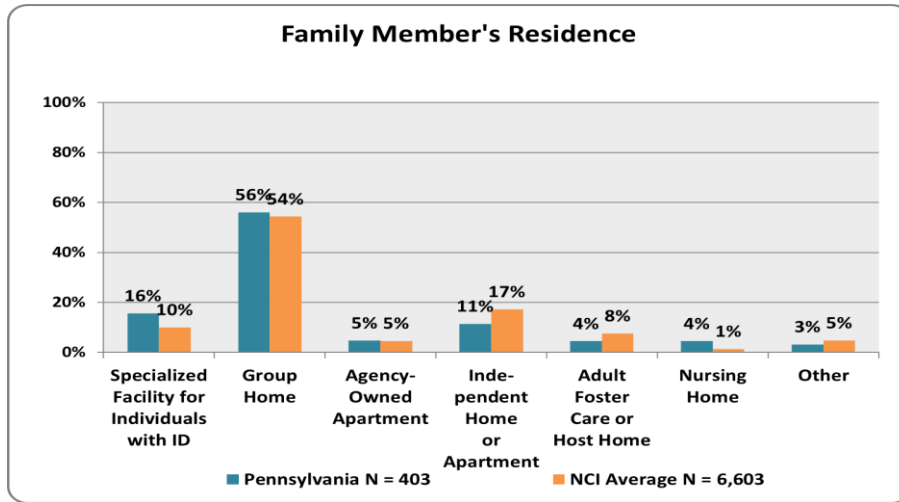
This report illustrates 2013-14 NCI Family/Guardian Survey demographic and outcome results from Pennsylvania compared to the NCI Average (the average of all state averages). In 2013-14, 12 states conducted the Family/Guardian Survey. All results are shown in chart form. Some questions may have a low 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 by state and across NCI states are included in each chart. All state and national data results for this survey can be found online at <http://www.nationalcoreindicators.org/resources/reports/>.

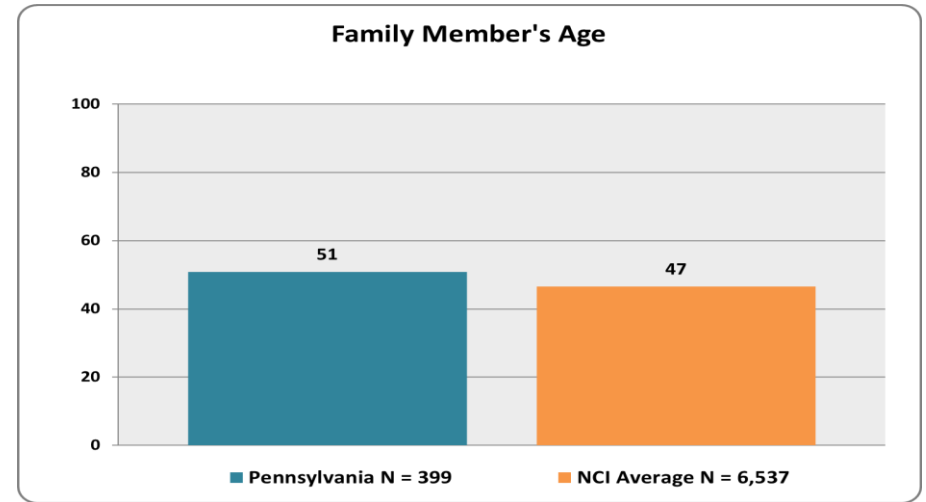
Results: Demographics of Family Member

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

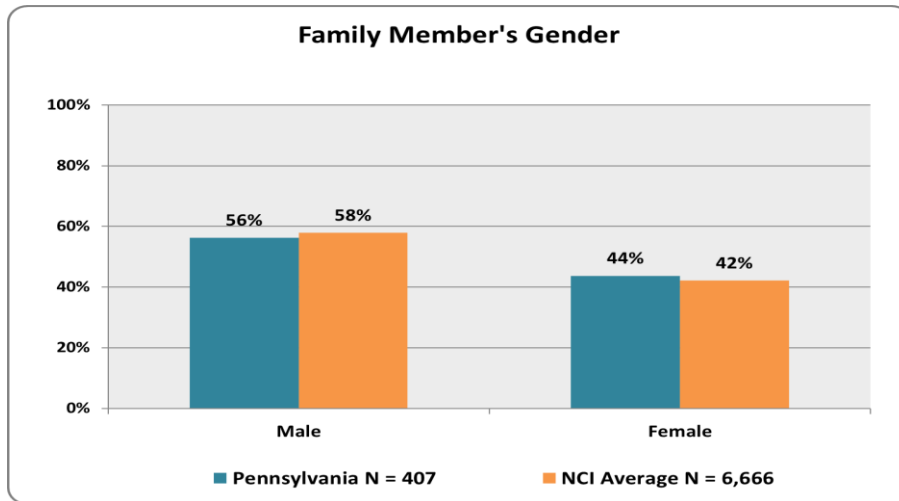
GRAPH 1. FAMILY MEMBER'S RESIDENCE



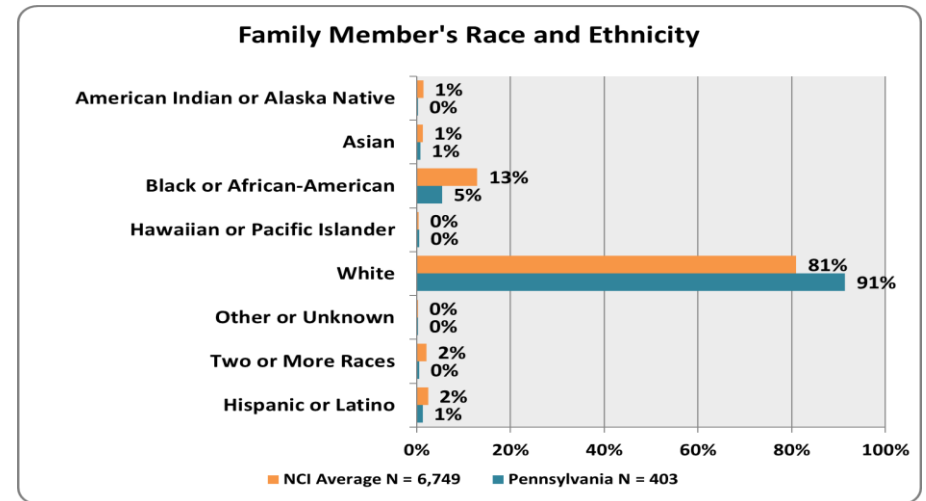
GRAPH 2. FAMILY MEMBER'S AVERAGE AGE



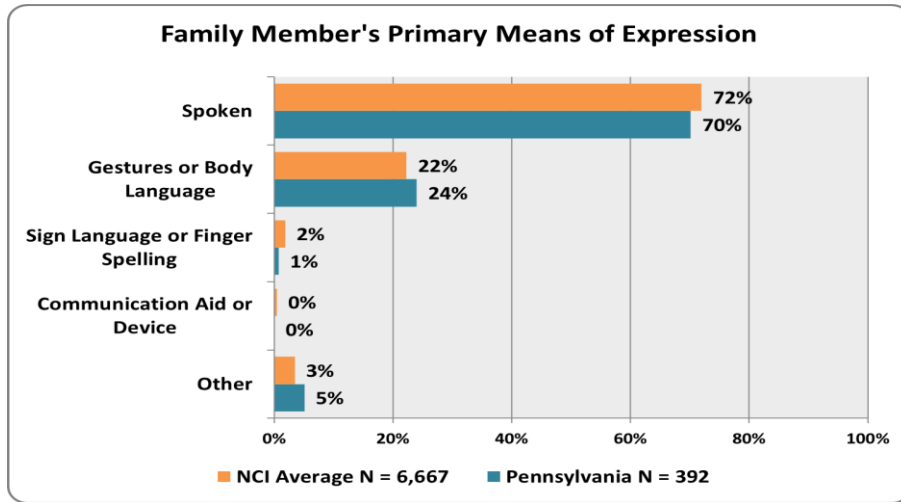
GRAPH 3. GENDER



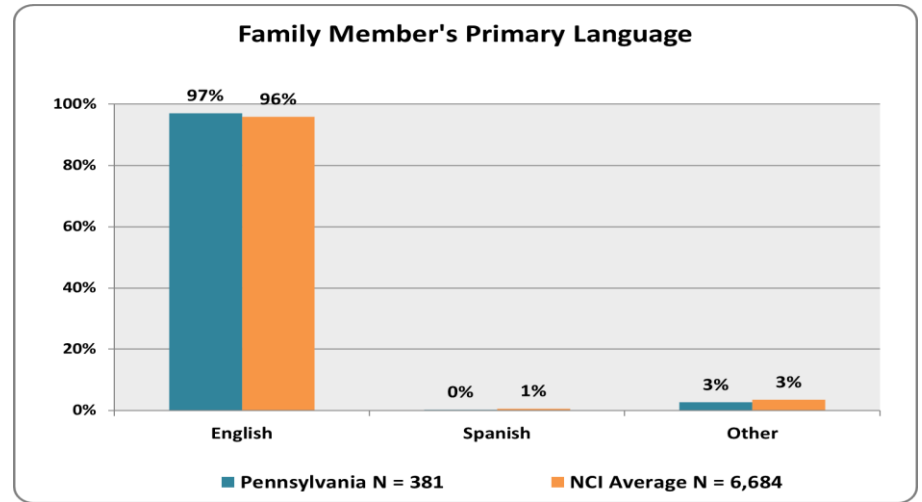
GRAPH 4. RACE AND ETHNICITY



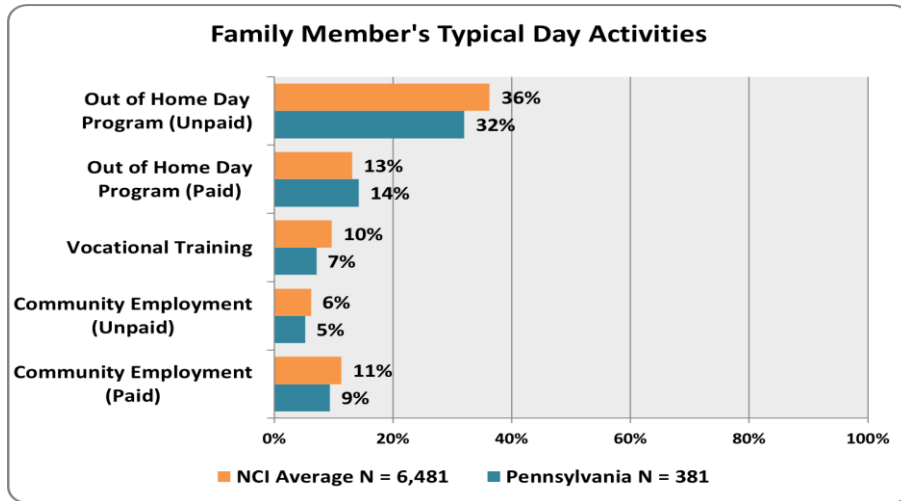
GRAPH 5. PRIMARY MEANS OF EXPRESSION



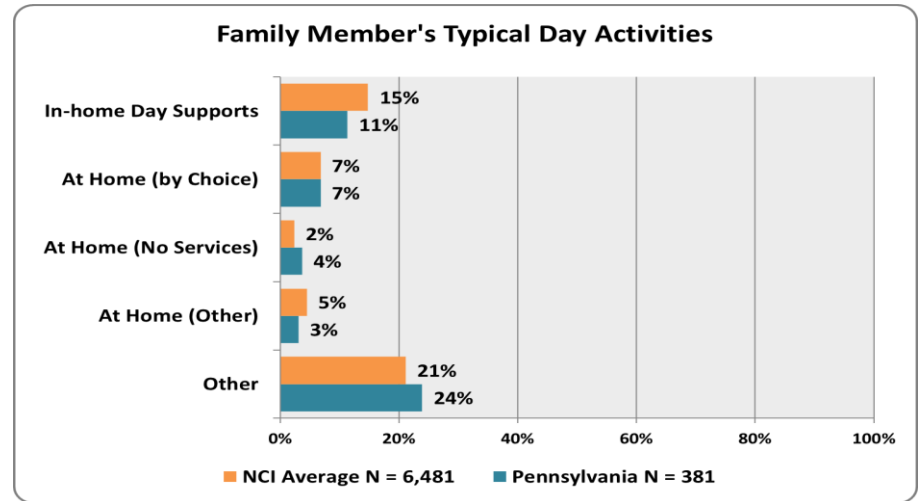
GRAPH 6. PRIMARY LANGUAGE



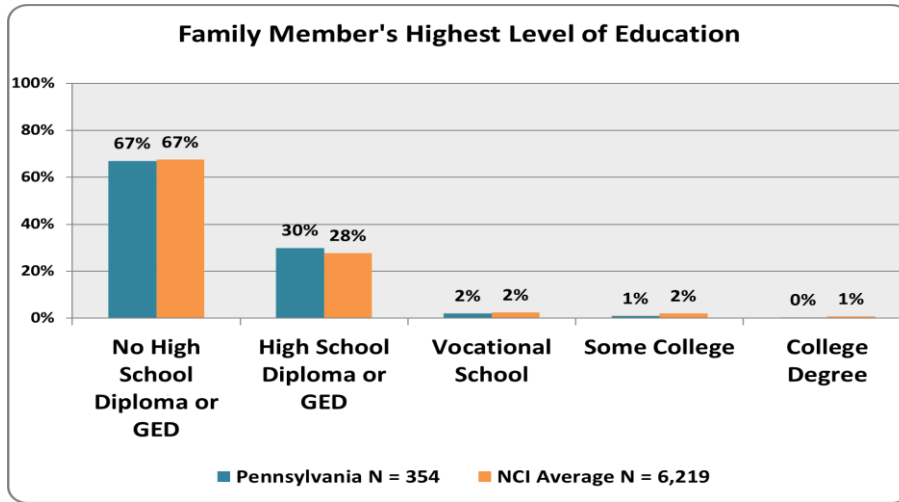
GRAPH 7. TYPICAL DAY ACTIVITIES



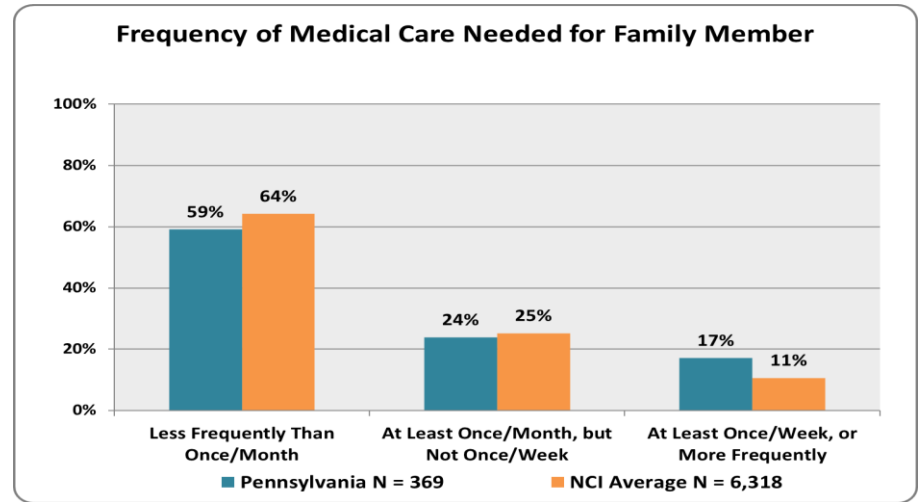
GRAPH 8. TYPICAL DAY ACTIVITIES, CONTINUED



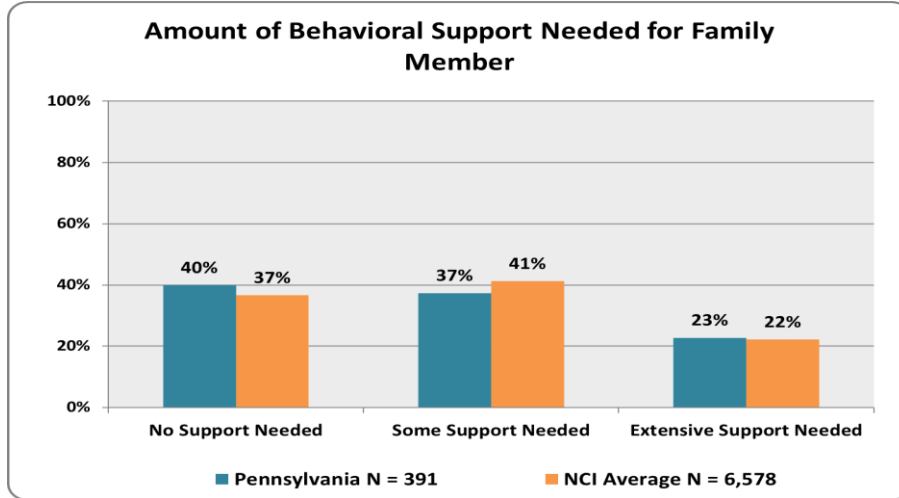
GRAPH 9. FAMILY MEMBER'S HIGHEST LEVEL OF EDUCATION



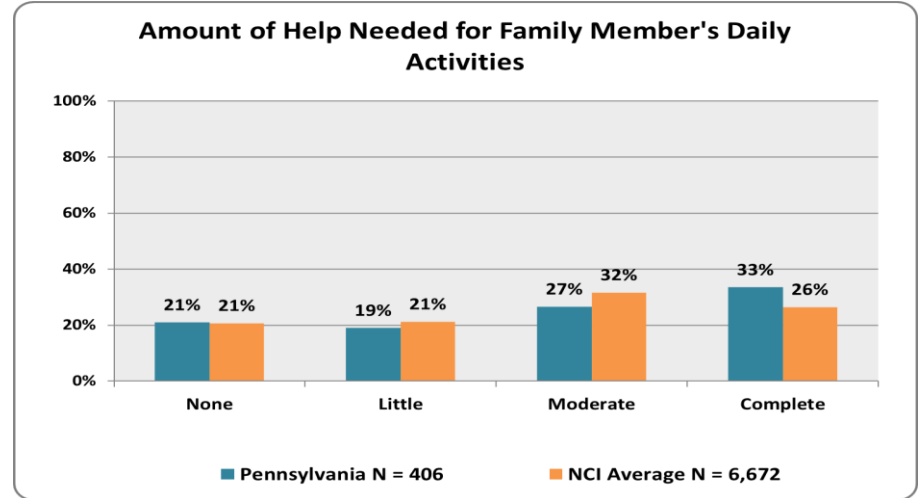
GRAPH 10. FREQUENCY OF MEDICAL CARE NEEDED FOR FAMILY MEMBER



GRAPH 11. AMOUNT OF BEHAVIORAL SUPPORT NEEDED FOR FAMILY MEMBER



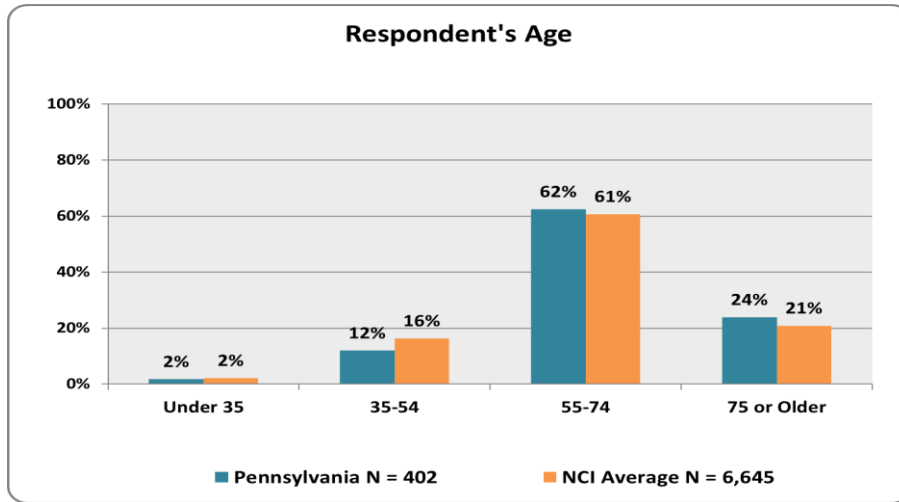
GRAPH 12. HELP NEEDED WITH DAILY ACTIVITIES



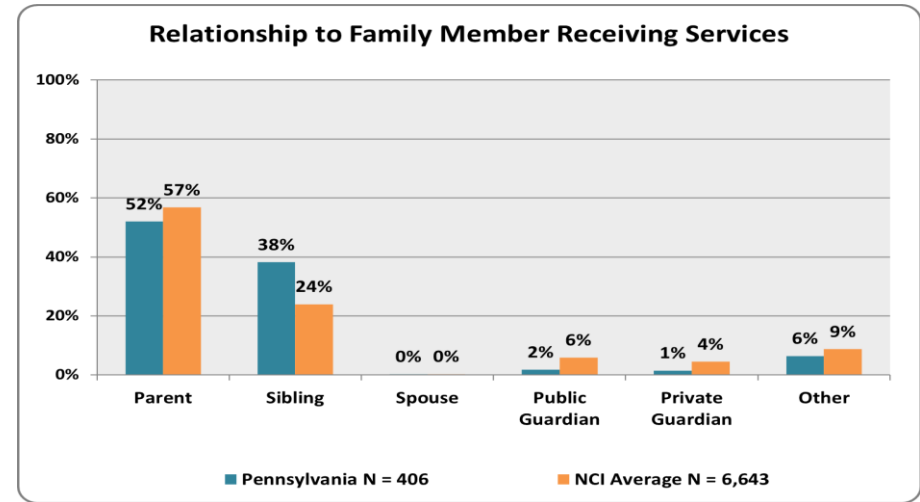
Results: Demographics of Respondent

ILLUSTRATES THE DEMOGRAPHIC PROFILE OF THE SURVEY RESPONDENTS

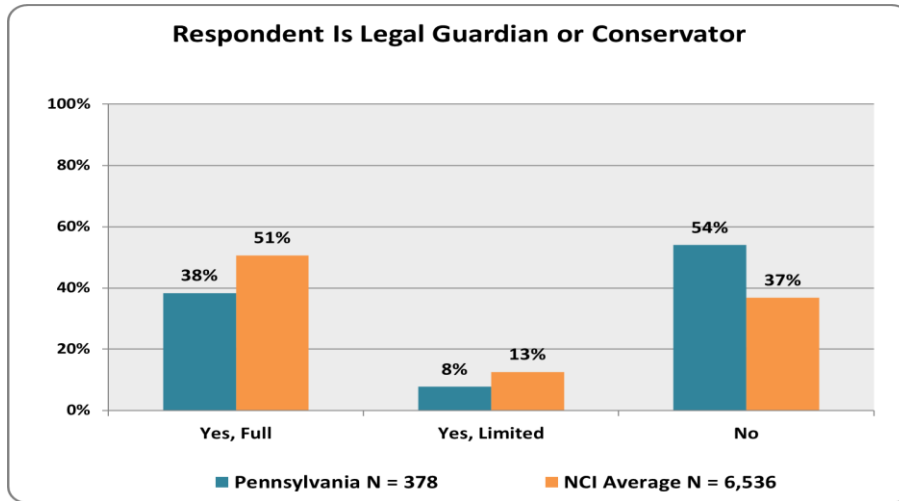
GRAPH 13. RESPONDENT'S AGE



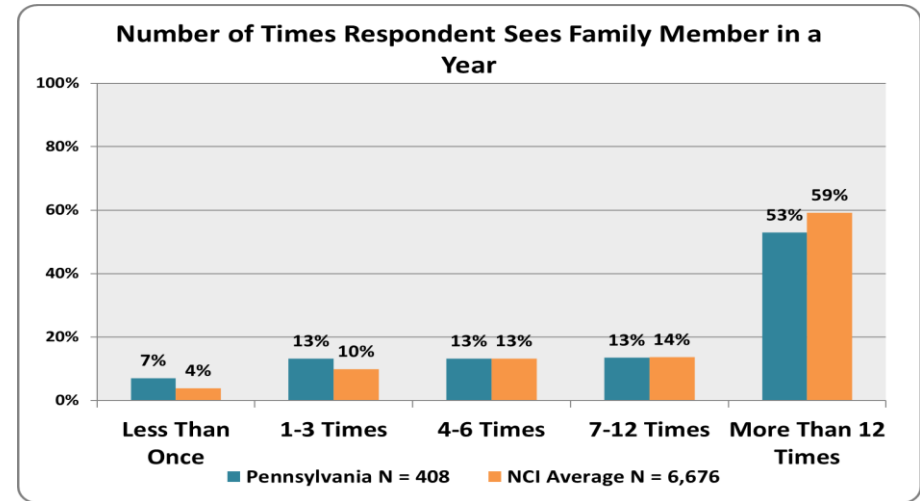
GRAPH 14. RELATIONSHIP TO FAMILY MEMBER



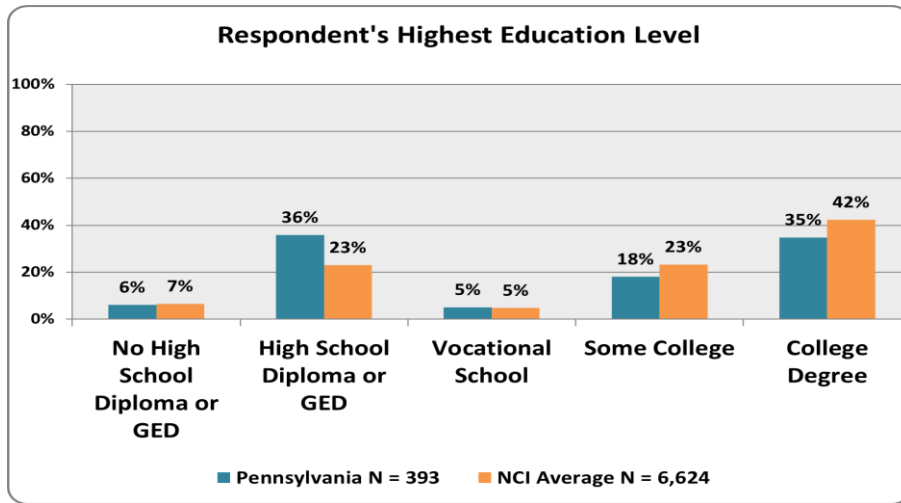
GRAPH 15. LEGAL GUARDIAN OR CONSERVATOR



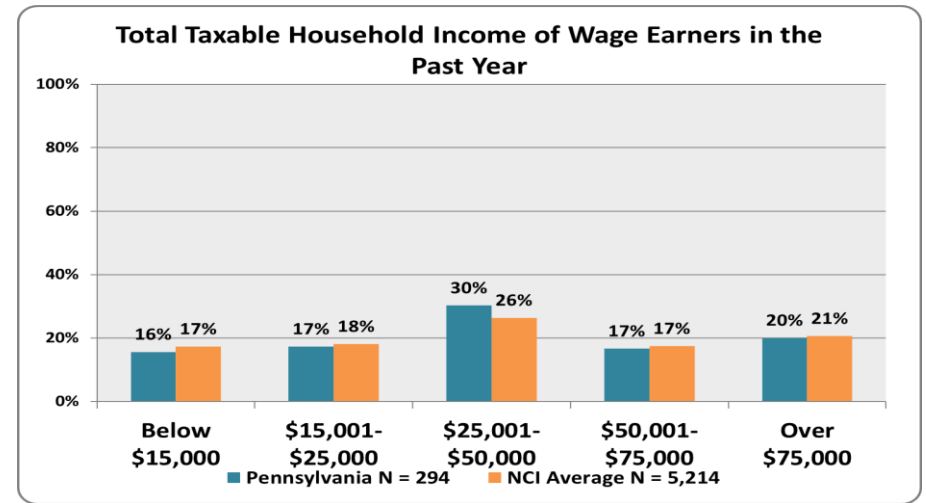
GRAPH 16. FREQUENCY OF VISITS EACH YEAR



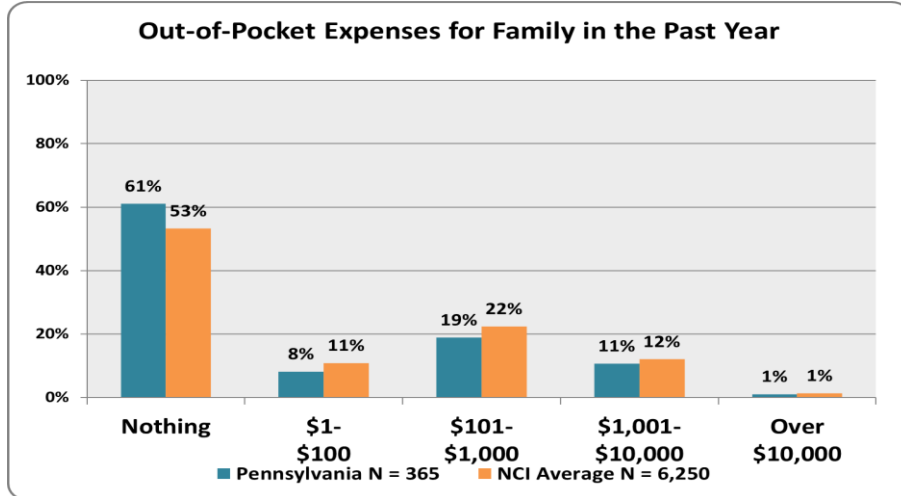
GRAPH 17. RESPONDENT'S HIGHEST LEVEL OF EDUCATION



GRAPH 18. TOTAL TAXABLE HOUSEHOLD INCOME OF WAGE EARNERS IN THE PAST YEAR



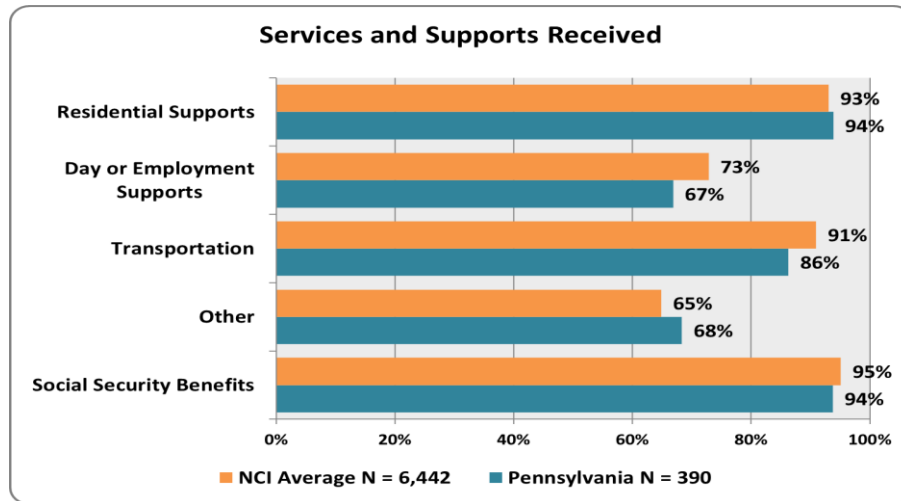
GRAPH 19. OUT-OF-POCKET EXPENSES



Services and Supports Received

ILLUSTRATES THE SERVICES AND SUPPORTS RECEIVED BY FAMILY MEMBERS

GRAPH 20. SERVICES AND SUPPORTS RECEIVED¹

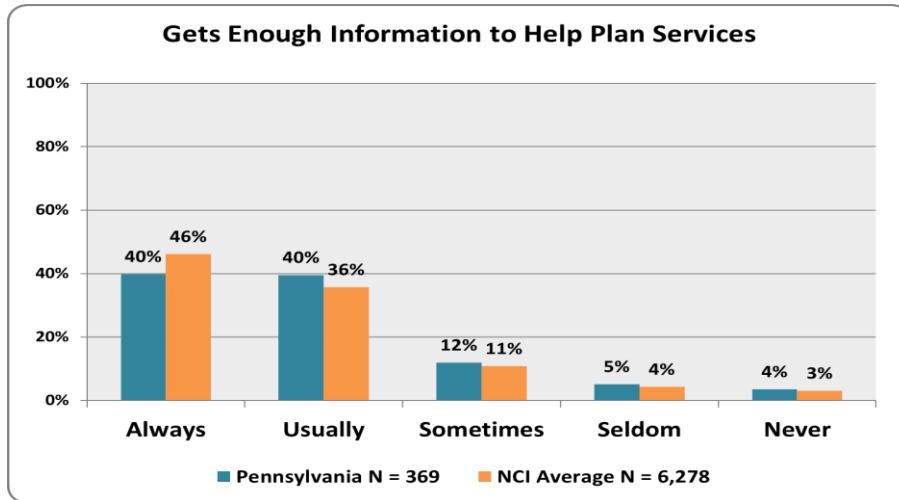


¹ All services and supports are received from the ID/DD Agency **except** social security benefits.

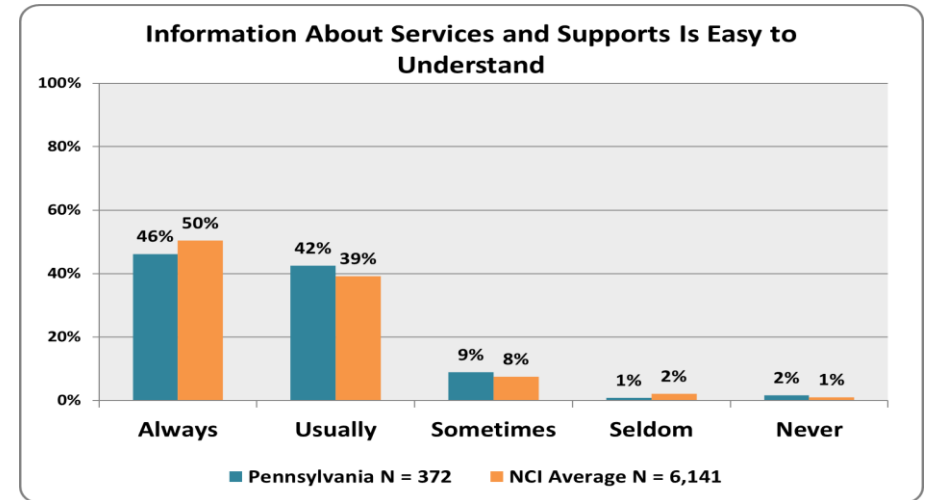
Information and Planning

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

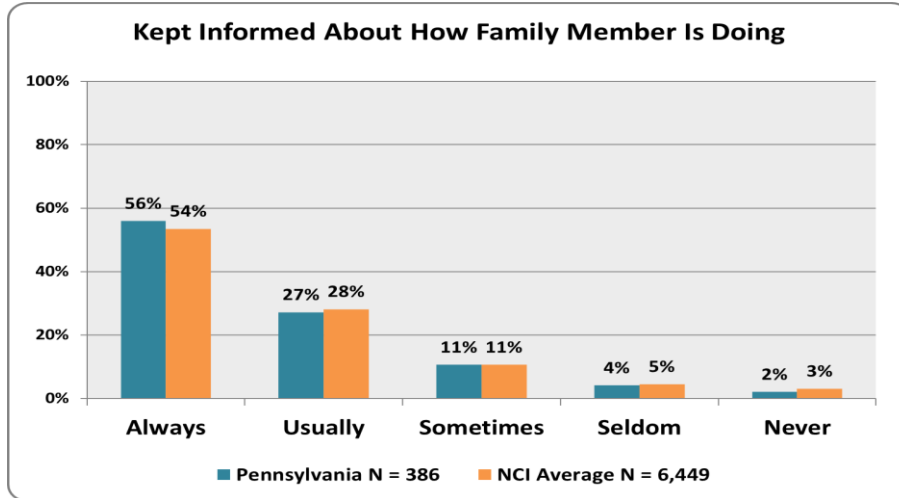
GRAPH 21. DO YOU GET ENOUGH INFORMATION TO HELP YOU PARTICIPATE IN PLANNING SERVICES FOR YOUR FAMILY MEMBER?



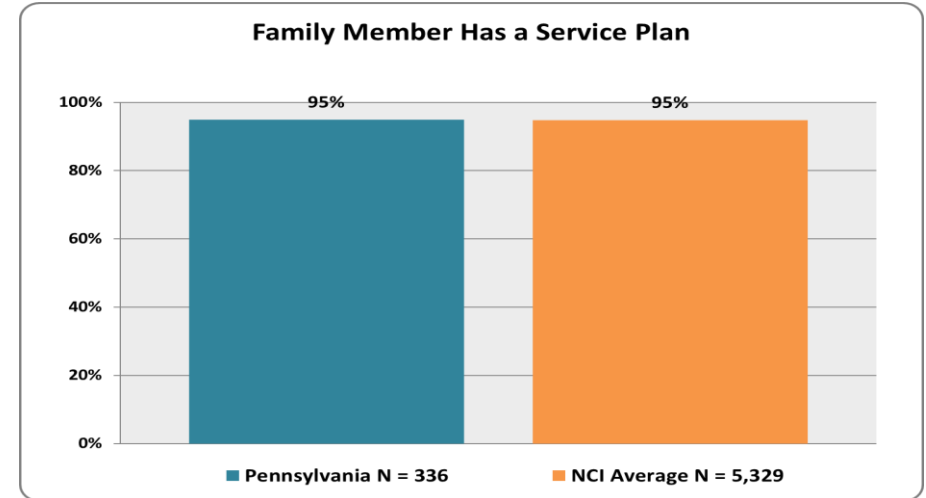
GRAPH 22. IS THE INFORMATION YOU RECEIVE EASY TO UNDERSTAND?



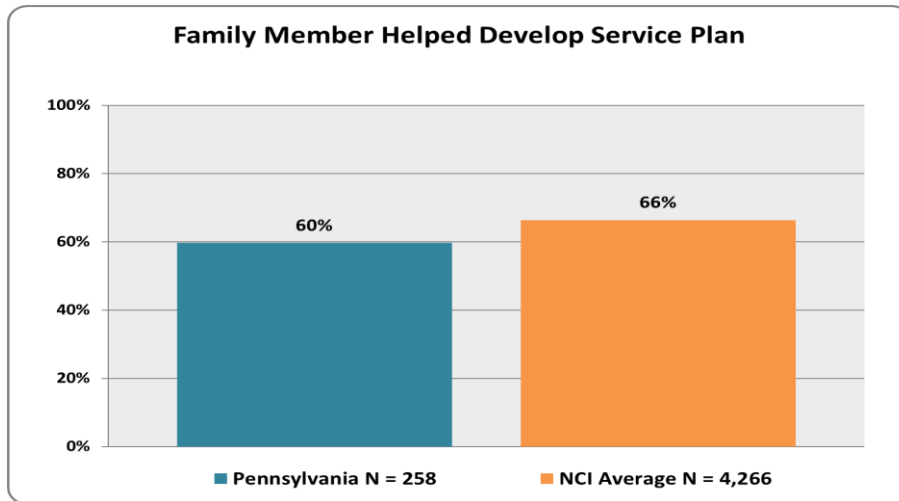
GRAPH 23. ARE YOU KEPT INFORMED ABOUT HOW YOUR FAMILY MEMBER IS DOING?



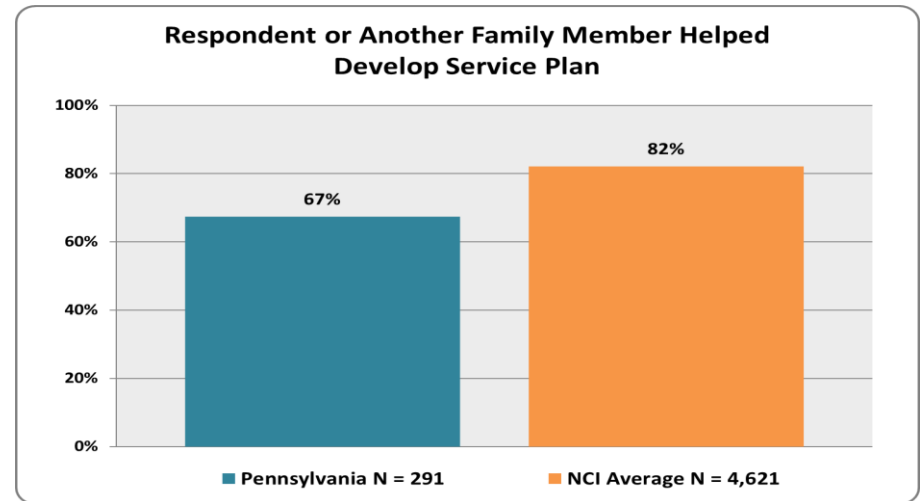
GRAPH 24. DOES YOUR FAMILY MEMBER HAVE A SERVICE PLAN?



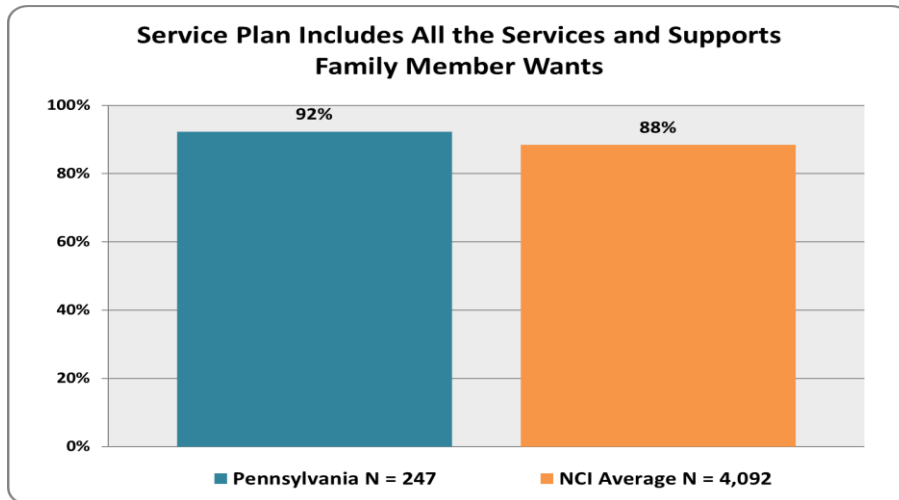
GRAPH 25. DID YOUR FAMILY MEMBER HELP DEVELOP THE SERVICE PLAN?



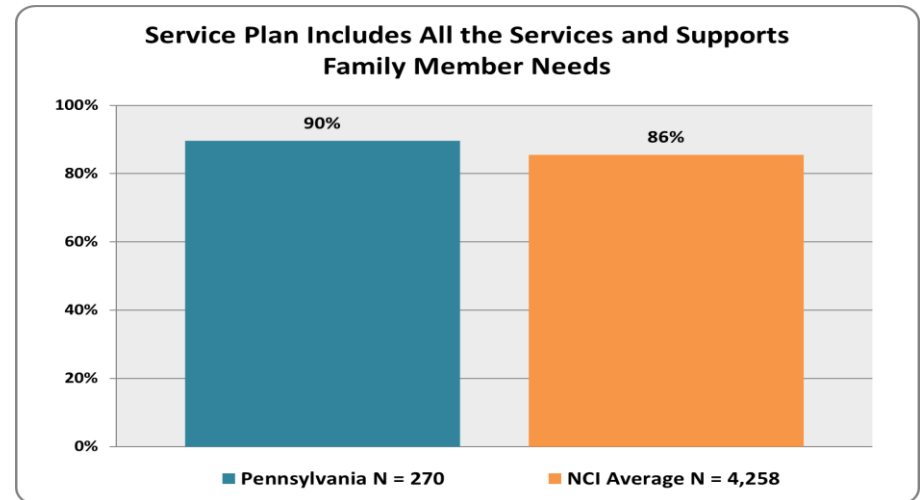
GRAPH 26. DID YOU OR ANOTHER FAMILY MEMBER HELP DEVELOP THE SERVICE PLAN?



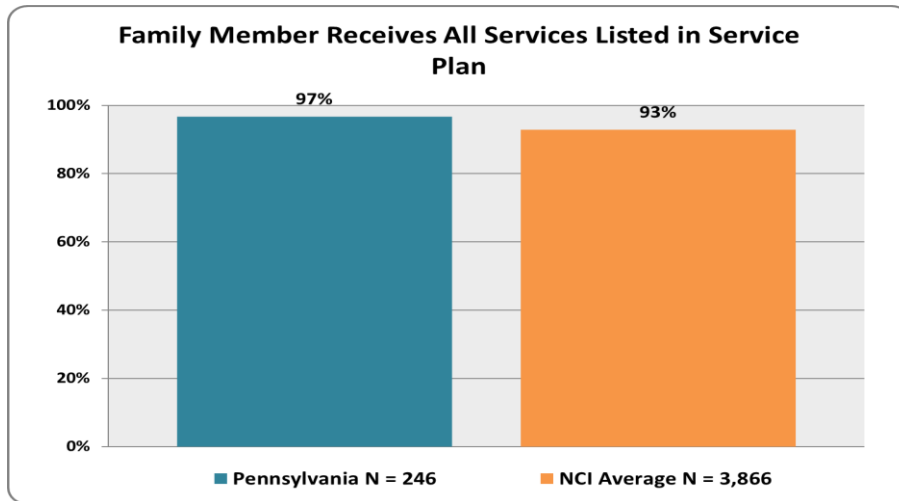
GRAPH 27. DOES THE SERVICE PLAN INCLUDE ALL THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER WANTS?



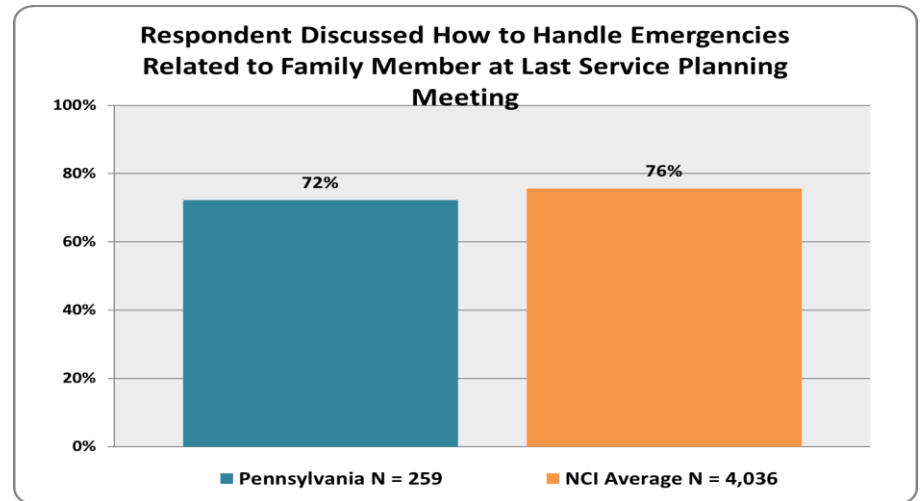
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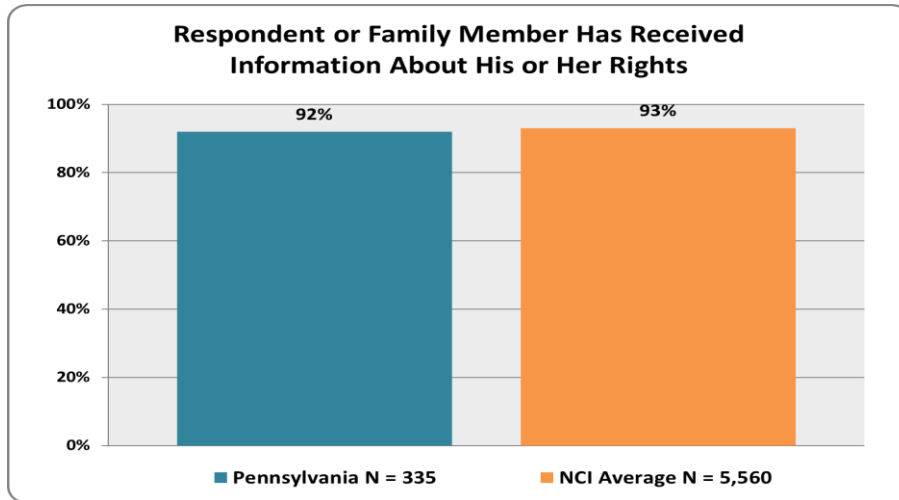
GRAPH 29. DOES YOUR FAMILY MEMBER RECEIVE ALL OF THE SERVICES LISTED IN THE SERVICE PLAN?



GRAPH 30. DID YOU DISCUSS HOW TO HANDLE EMERGENCIES RELATED TO YOUR FAMILY MEMBER AT THE LAST SERVICE PLANNING MEETING?



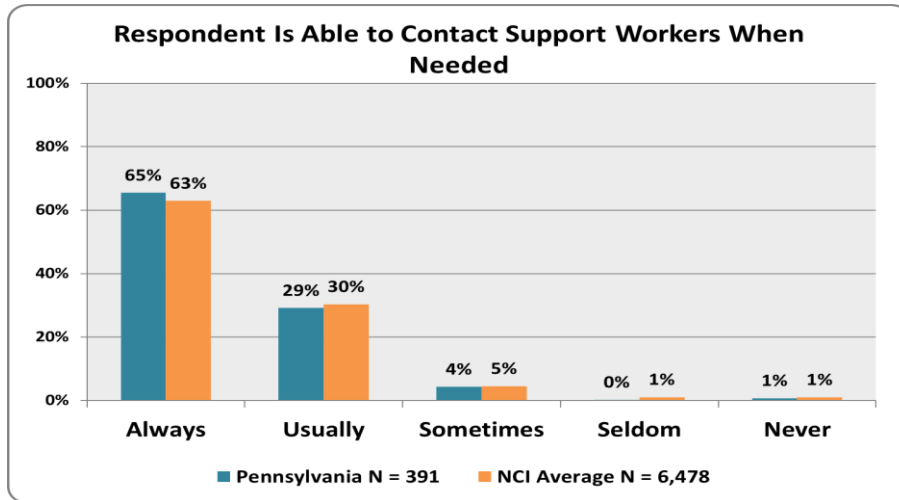
GRAPH 31. HAVE YOU OR YOUR FAMILY MEMBER RECEIVED INFORMATION ABOUT HIS/HER RIGHTS?



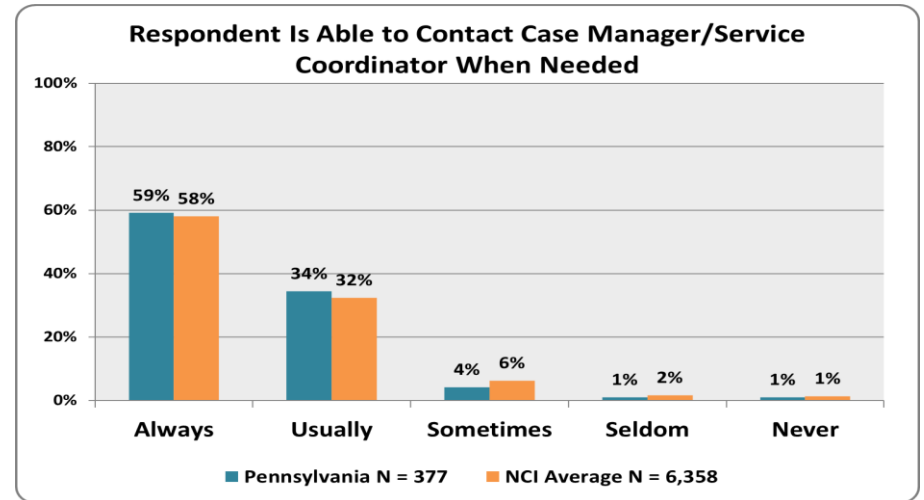
Access and Delivery

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

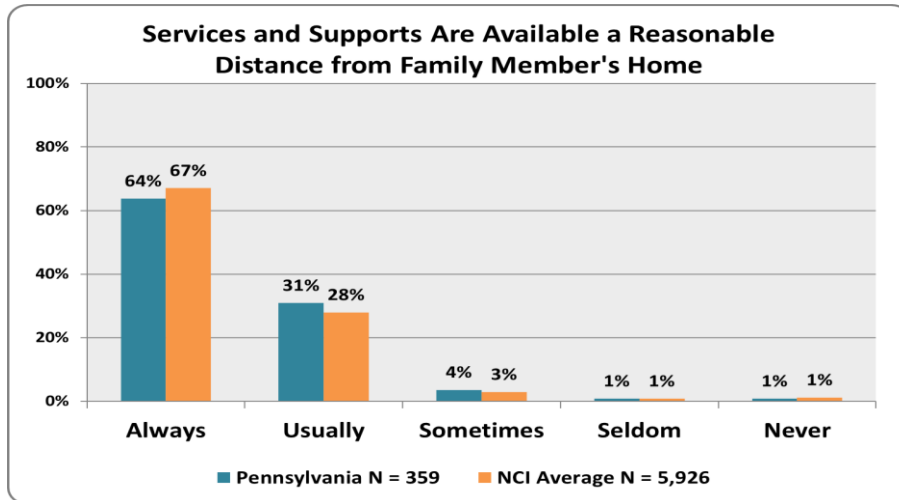
GRAPH 32. ARE YOU ABLE TO CONTACT YOUR FAMILY MEMBER'S SUPPORT WORKERS WHEN YOU NEED TO?



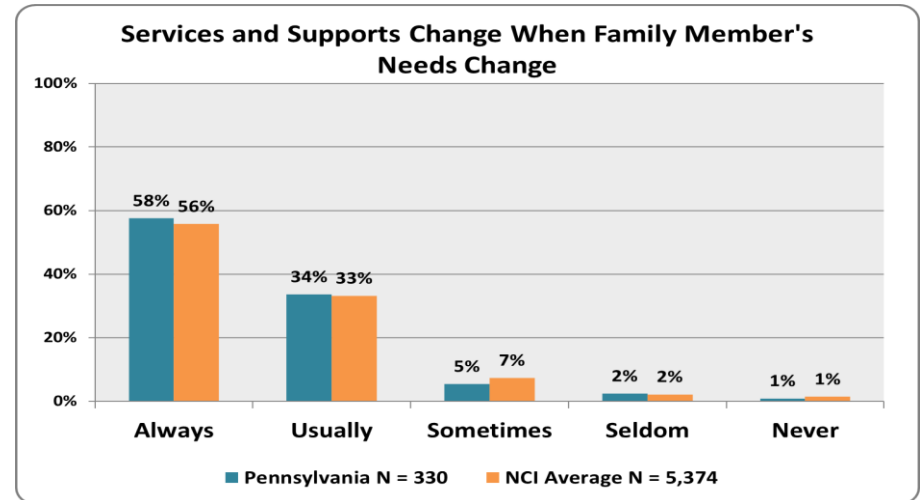
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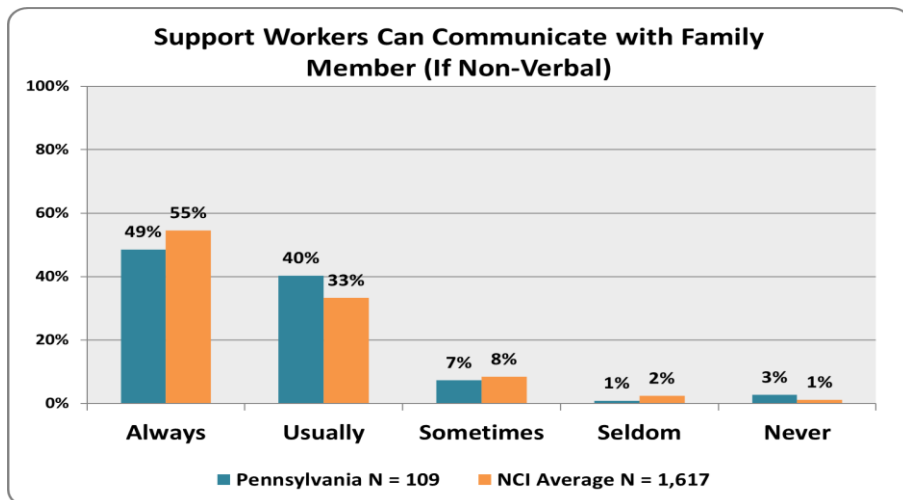
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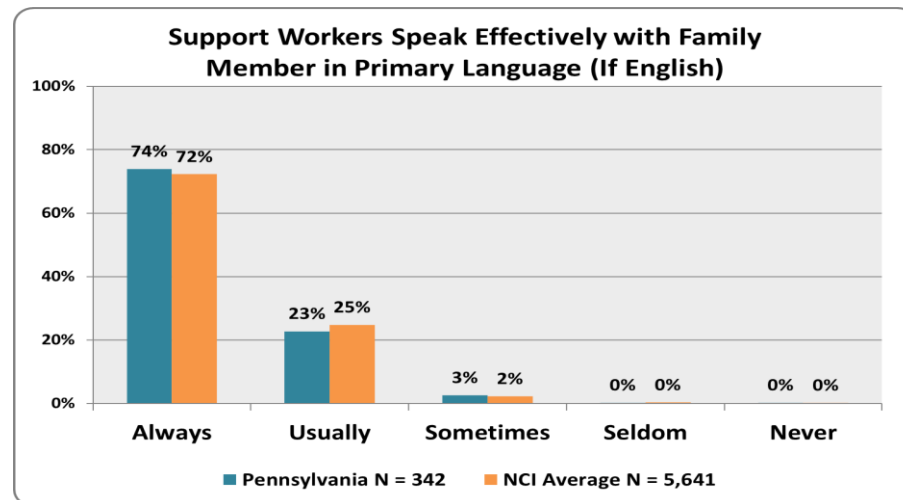
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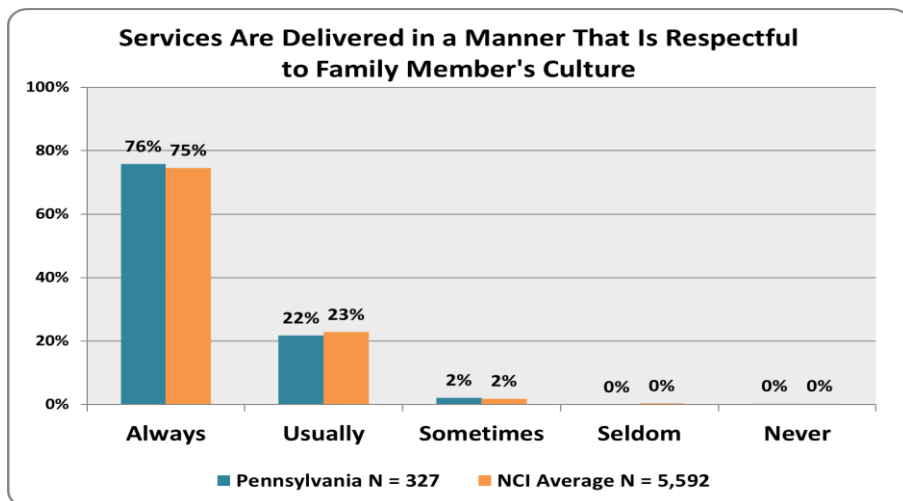
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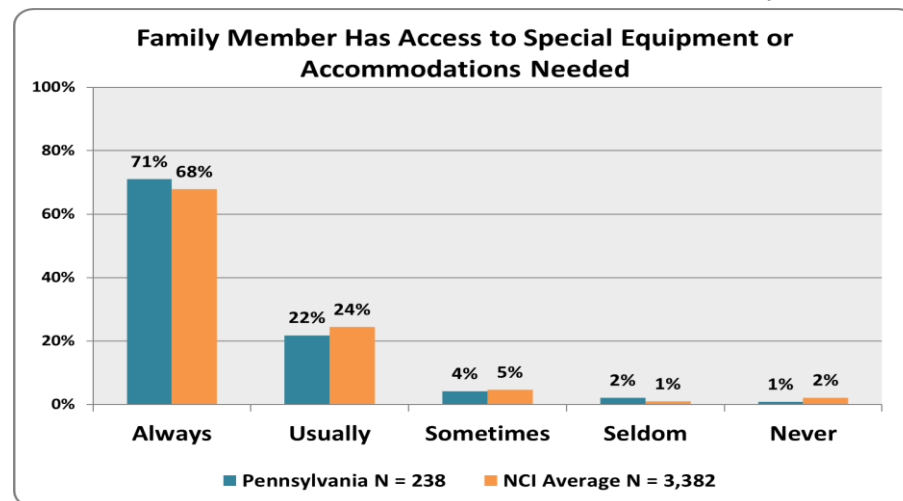
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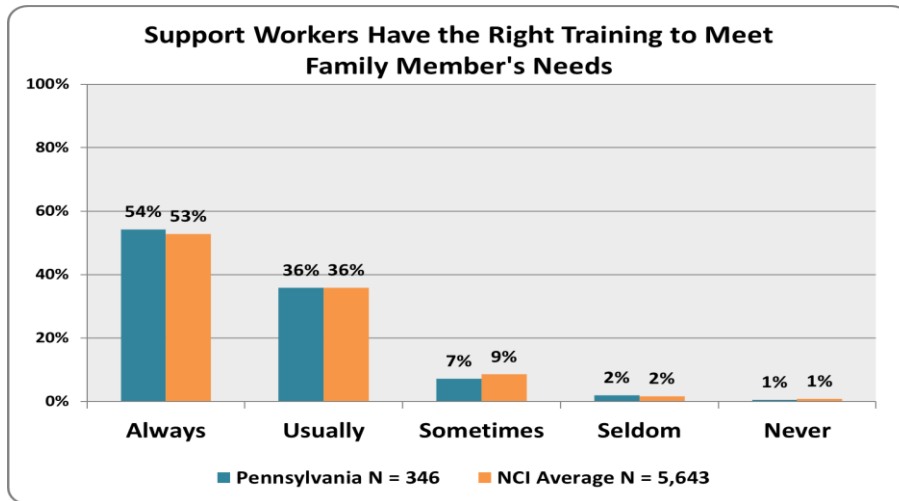
GRAPH 38. ARE SERVICES DELIVERED IN A WAY THAT IS RESPECTFUL TO YOUR FAMILY MEMBER'S CULTURE?



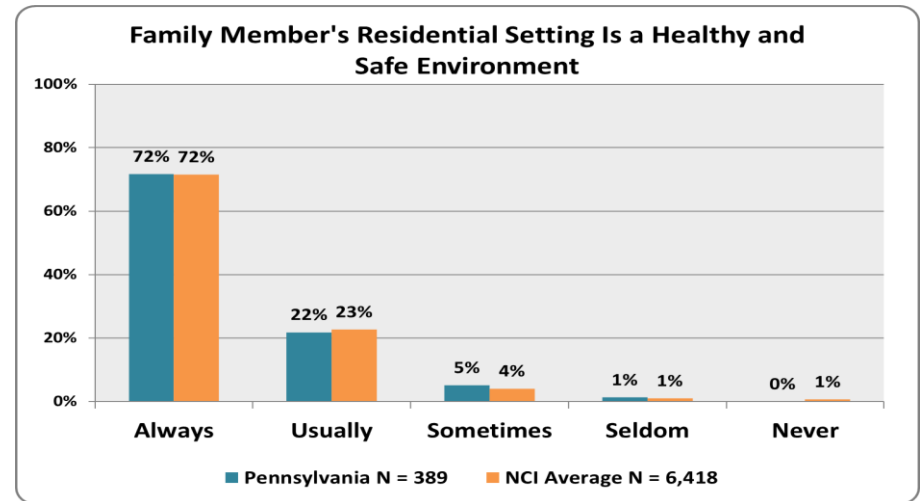
GRAPH 39. DOES YOUR FAMILY MEMBER HAVE ACCESS TO THE SPECIAL EQUIPMENT OR ACCOMMODATIONS THAT HE/SHE NEEDS (FOR EXAMPLE, WHEELCHAIRS, RAMPS, COMMUNICATION BOARDS)?



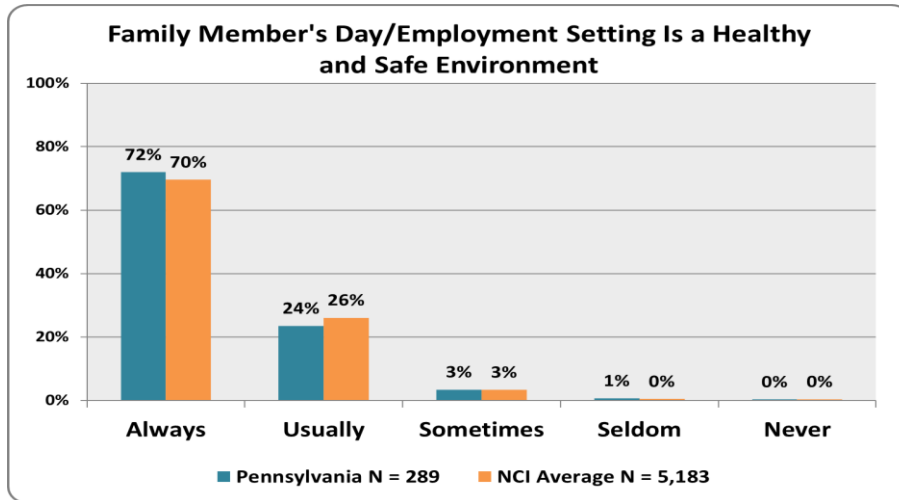
GRAPH 40. DO SUPPORT WORKERS HAVE THE RIGHT TRAINING TO MEET YOUR FAMILY MEMBER'S NEEDS?



GRAPH 41. DO YOU FEEL THAT YOUR FAMILY MEMBER'S RESIDENTIAL SETTING IS A HEALTHY AND SAFE ENVIRONMENT?



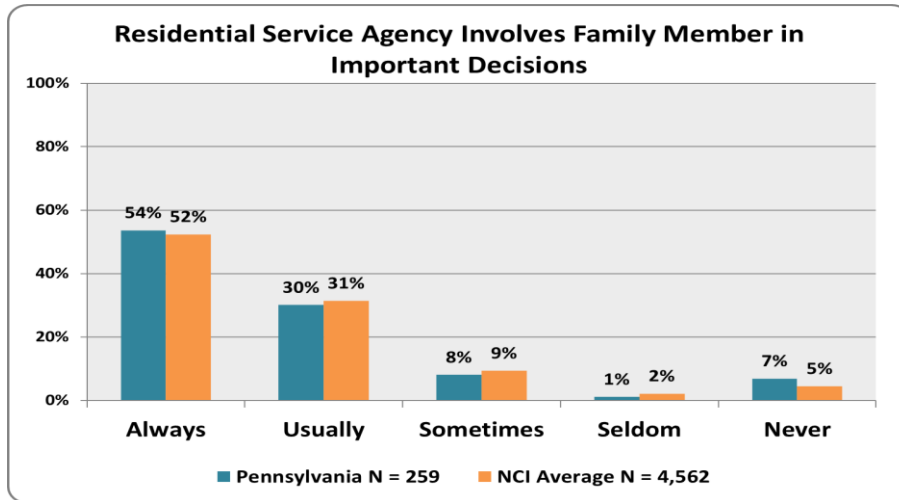
GRAPH 42. DO YOU FEEL THAT YOUR FAMILY MEMBER'S DAY/EMPLOYMENT SETTING IS A HEALTHY AND SAFE ENVIRONMENT?



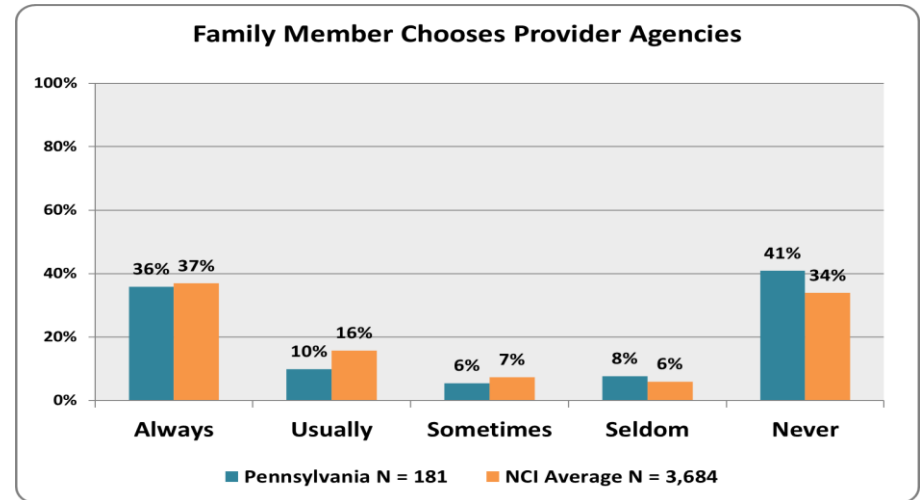
Choice and Control

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

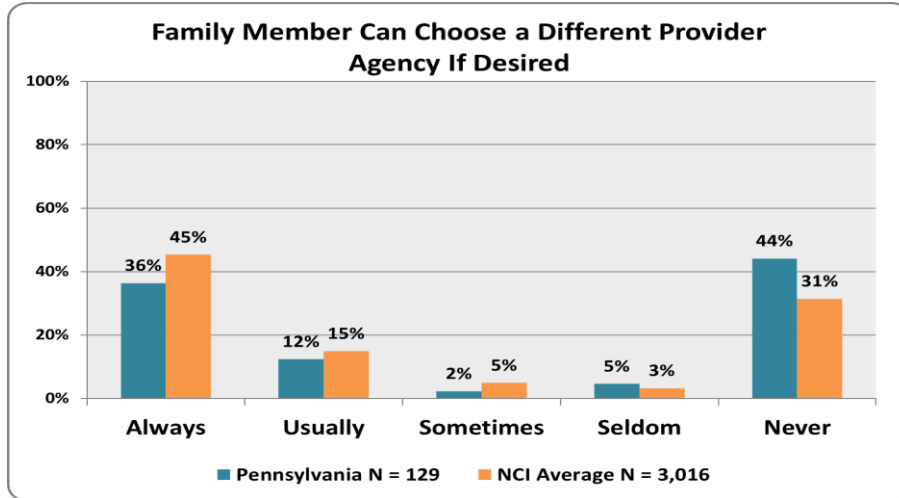
GRAPH 43. DOES THE AGENCY PROVIDING RESIDENTIAL SERVICES TO YOUR FAMILY MEMBER INVOLVE HIM/HER IN IMPORTANT DECISIONS?



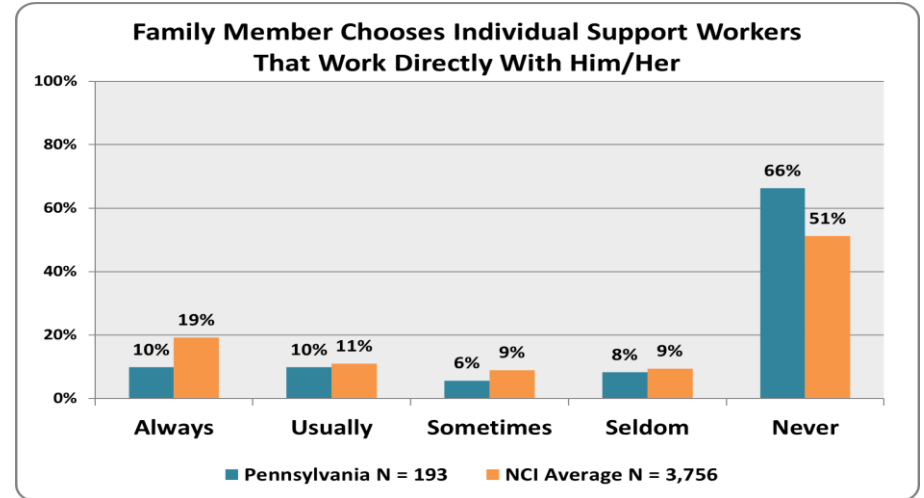
GRAPH 44. DOES YOUR FAMILY MEMBER CHOOSE THE PROVIDER AGENCIES THAT WORK WITH HIM OR HER?



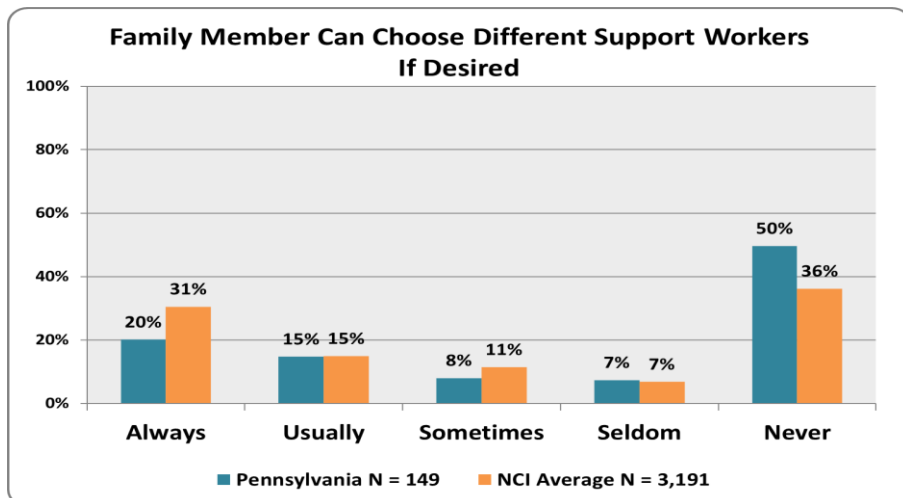
GRAPH 45. CAN YOUR FAMILY MEMBER CHOOSE A DIFFERENT PROVIDER AGENCY IF S/HE WANTS TO?



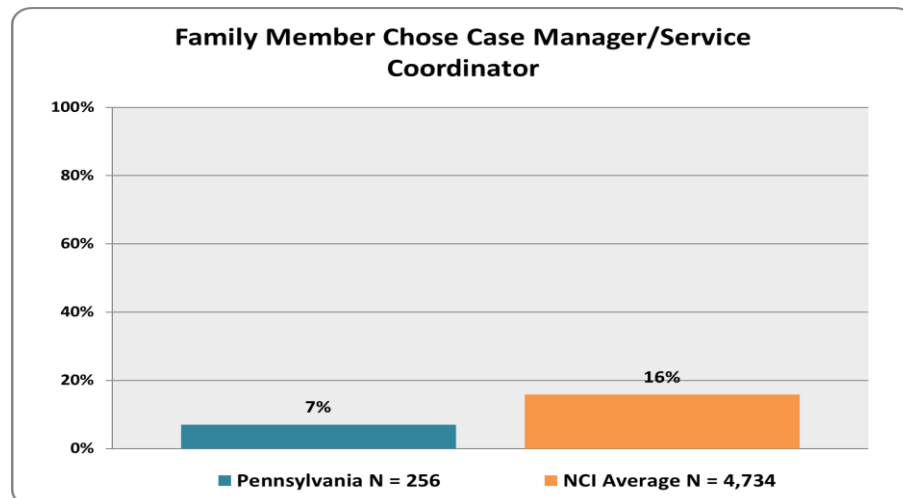
GRAPH 46. DOES YOUR FAMILY MEMBER CHOOSE THE INDIVIDUAL SUPPORT WORKERS WHO WORK DIRECTLY WITH HIM/HER?



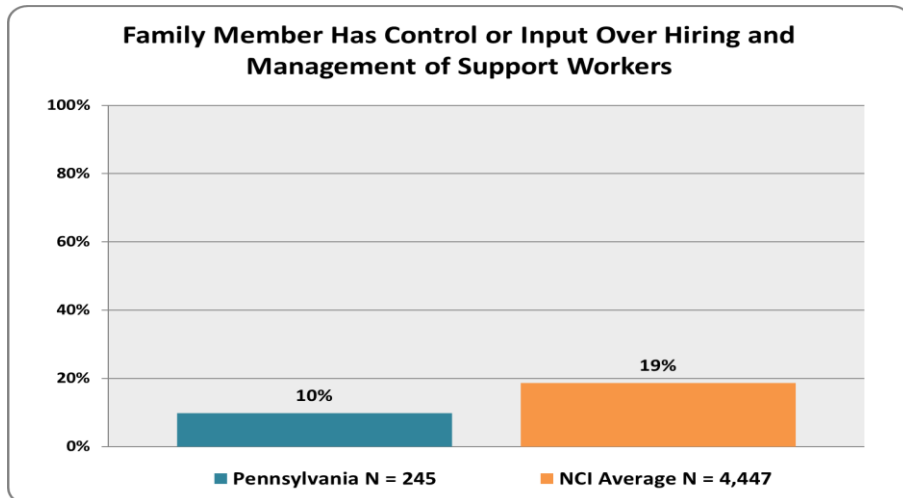
GRAPH 47. CAN YOUR FAMILY MEMBER CHOOSE DIFFERENT SUPPORT WORKERS IF S/HE WANTS TO?



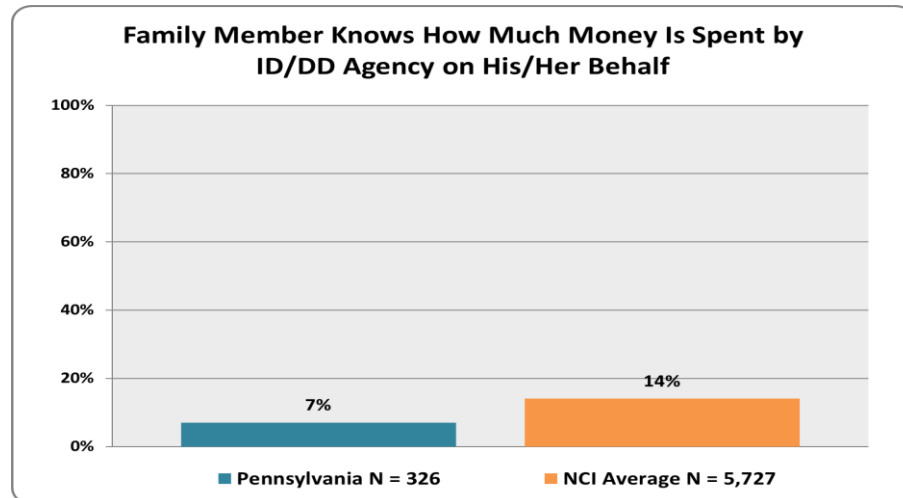
GRAPH 48. DID YOUR FAMILY MEMBER CHOOSE HIS/HER CASE MANAGER/SERVICE COORDINATOR?



GRAPH 49. DOES YOUR FAMILY MEMBER HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF HIS/HER SUPPORT WORKERS?

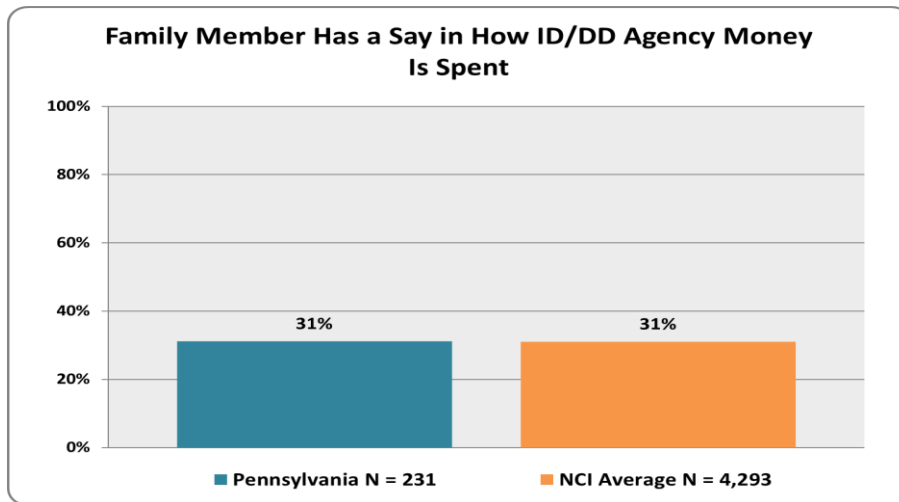


GRAPH 50. DOES YOUR FAMILY MEMBER KNOW HOW MUCH MONEY IS SPENT BY THE ID/DD AGENCY ON HIS/HER BEHALF?*

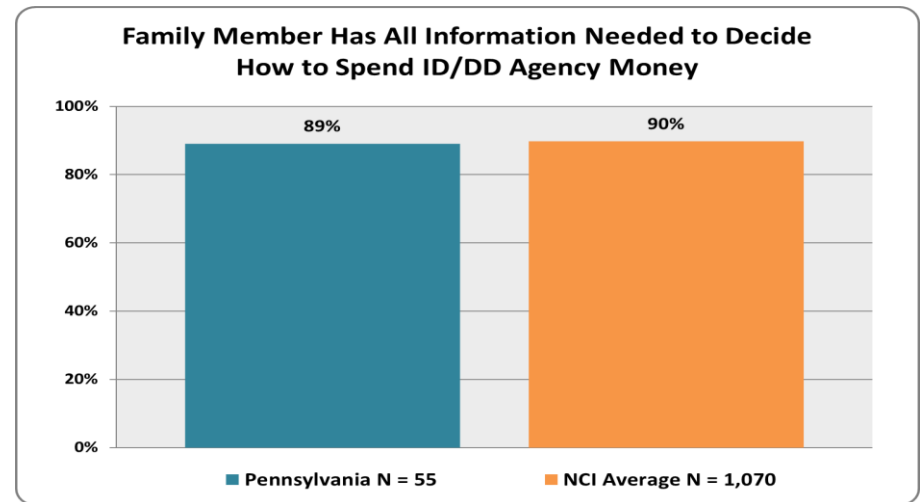


*'Don't Know' responses were included in 'No' responses for this question.

GRAPH 51. DOES YOUR FAMILY MEMBER HAVE A SAY IN HOW ID/DD AGENCY MONEY IS SPENT ON HIS/HER BEHALF?



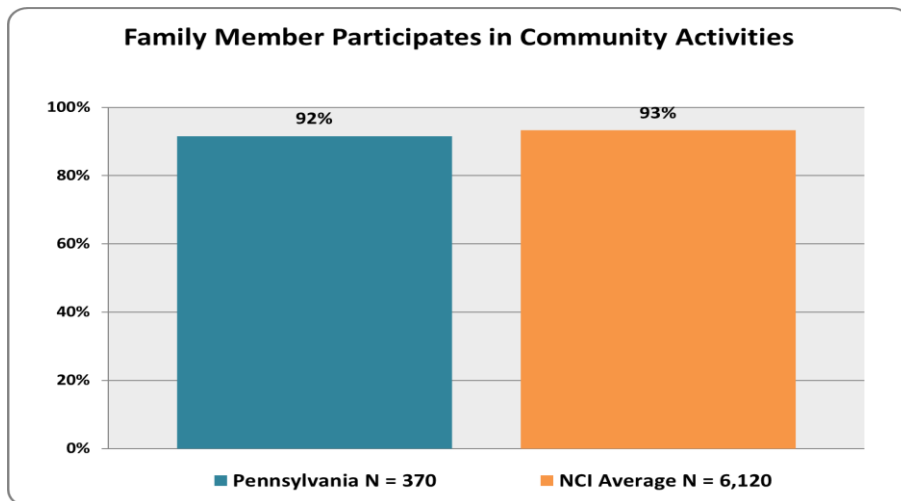
GRAPH 52. IF YOUR FAMILY MEMBER HAS A SAY IN HOW ID/DD AGENCY MONEY IS SPENT, DOES S/HE HAVE ALL THE INFORMATION NEEDED TO MAKE DECISIONS ABOUT HOW TO SPEND THIS MONEY?



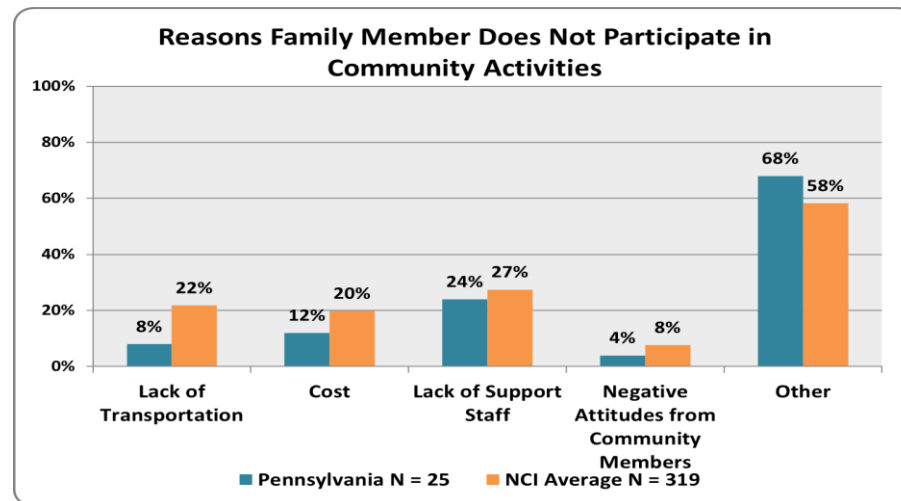
Community Connections

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

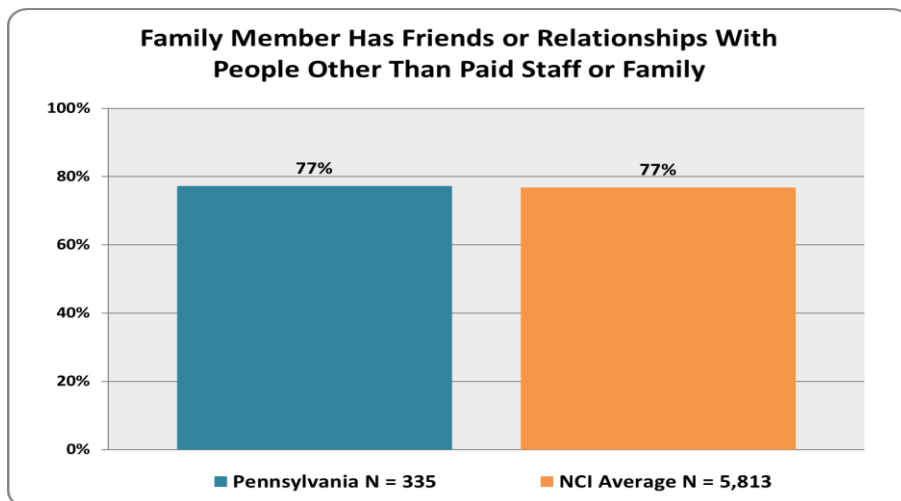
GRAPH 53. DOES YOUR FAMILY MEMBER PARTICIPATE IN COMMUNITY ACTIVITIES (SUCH AS GOING OUT TO A RESTAURANT, MOVIE, OR SPORTING EVENT)?



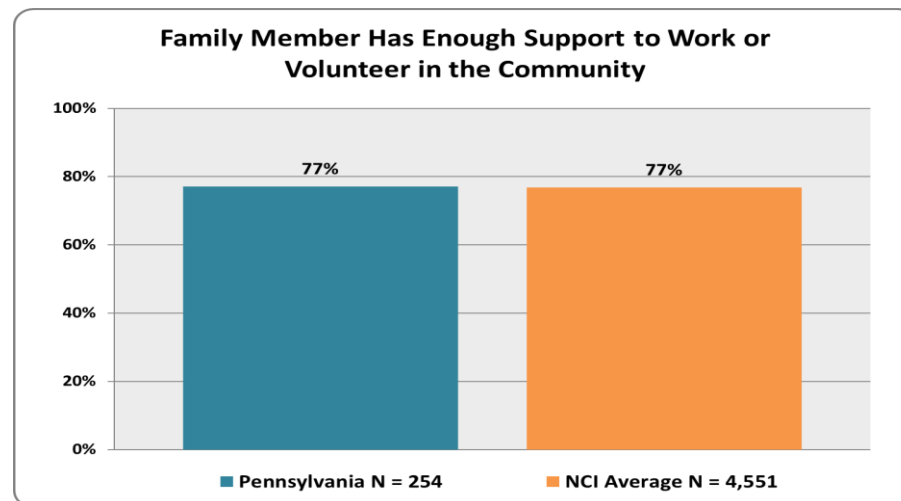
GRAPH 54. IF YOUR FAMILY MEMBER DOESN'T PARTICIPATE IN COMMUNITY ACTIVITIES, WHY NOT?



GRAPH 55. DOES YOUR FAMILY MEMBER HAVE FRIENDS OR RELATIONSHIPS WITH PERSONS OTHER THAN PAID STAFF OR FAMILY?



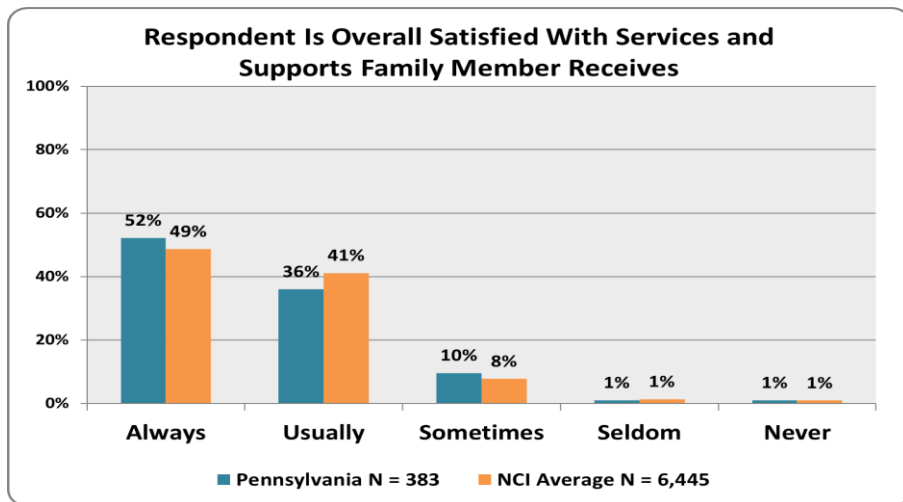
GRAPH 56. DOES YOUR FAMILY MEMBER HAVE ENOUGH SUPPORT (FOR EXAMPLE, SUPPORT WORKERS, COMMUNITY RESOURCES) TO WORK OR VOLUNTEER IN THE COMMUNITY?



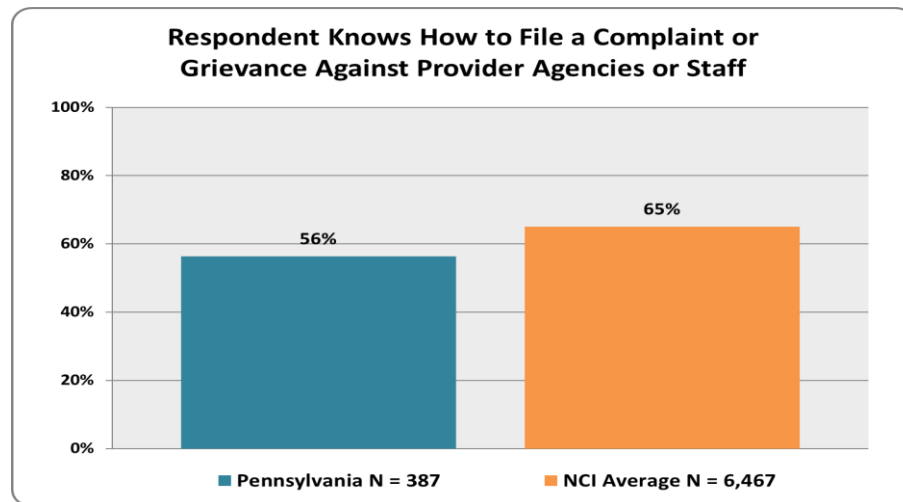
Satisfaction

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES RECEIVE ADEQUATE AND SATISFACTORY SUPPORTS

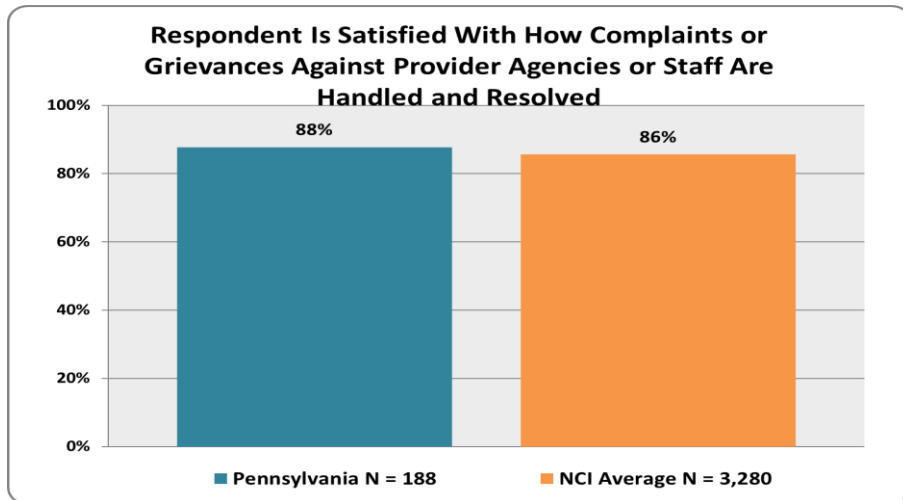
GRAPH 57. OVERALL, ARE YOU SATISFIED WITH THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER CURRENTLY RECEIVES?



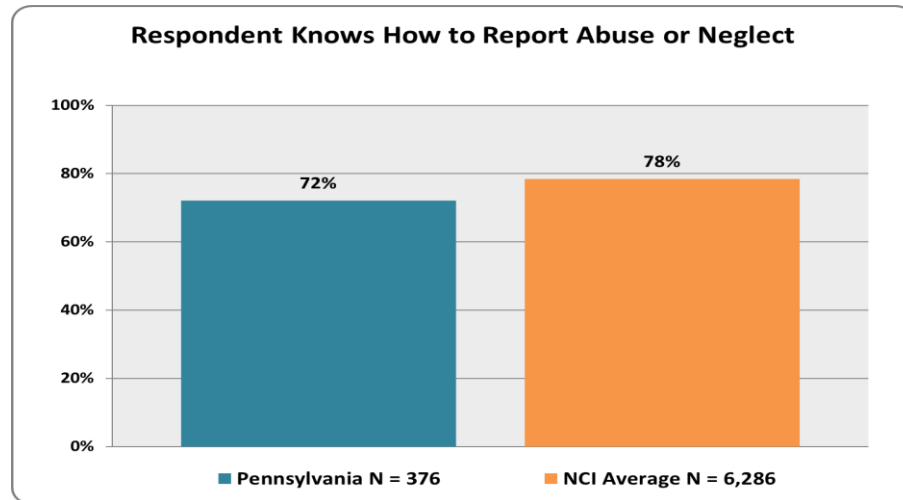
GRAPH 58. DO YOU KNOW THE PROCESS FOR FILING A COMPLAINT OR GRIEVANCE AGAINST PROVIDER AGENCIES OR STAFF?*



GRAPH 59. ARE YOU SATISFIED WITH THE WAY COMPLAINTS OR GRIEVANCES AGAINST PROVIDER AGENCIES OR STAFF ARE HANDLED AND RESOLVED?

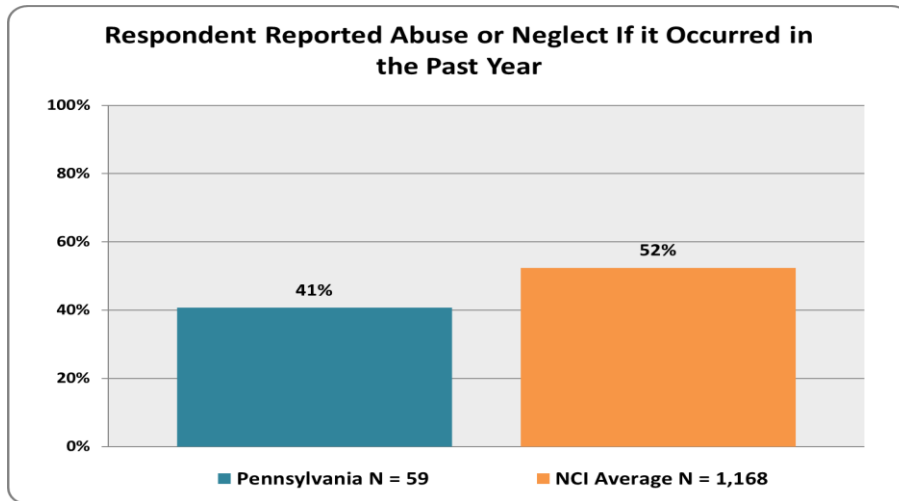


GRAPH 60. DO YOU KNOW HOW TO REPORT ABUSE OR NEGLECT?*

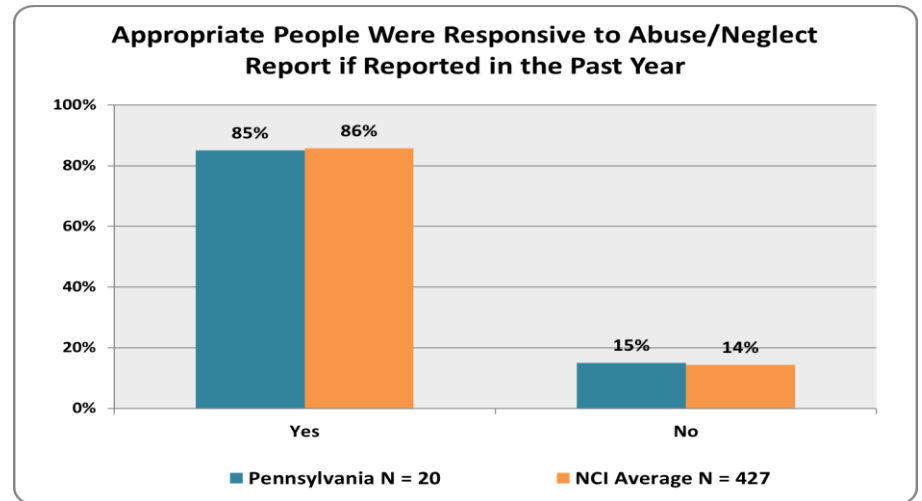


*'Don't Know' responses were included in 'No' responses for this question.

GRAPH 61. WITHIN THE PAST YEAR, IF ABUSE OR NEGLECT OCCURRED, DID YOU REPORT IT?



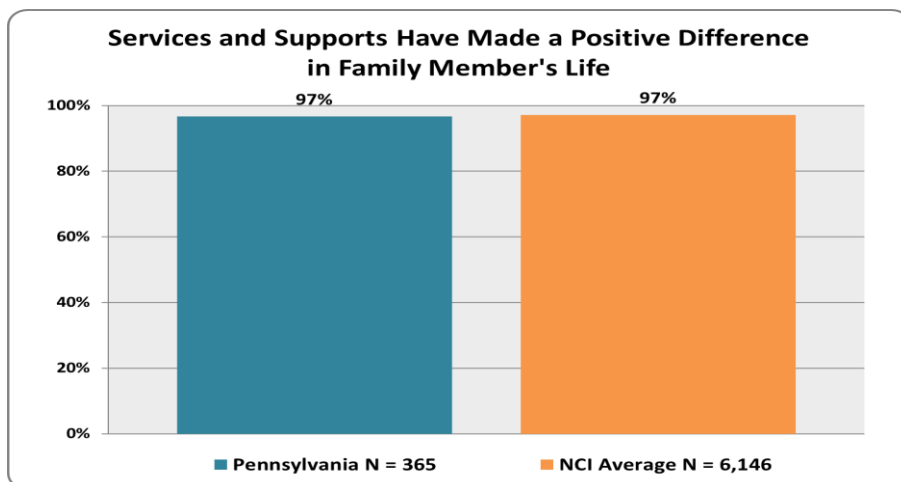
GRAPH 62. IF YOU REPORTED ABUSE OR NEGLECT IN THE PAST YEAR, WERE THE APPROPRIATE PEOPLE RESPONSIVE TO YOUR REPORT?



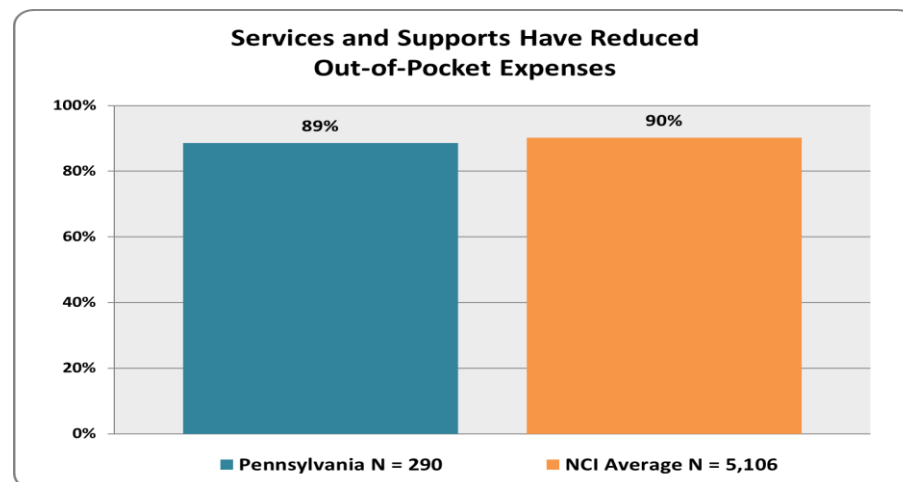
Family Outcomes

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

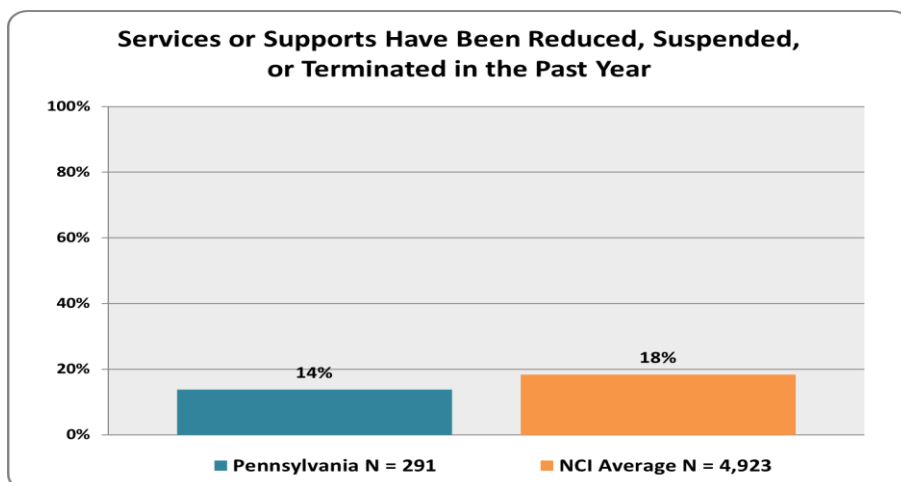
GRAPH 63. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE MADE A POSITIVE DIFFERENCE IN THE LIFE OF YOUR FAMILY MEMBER?



GRAPH 64. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE REDUCED YOUR FAMILY'S OUT-OF-POCKET EXPENSES FOR YOUR FAMILY MEMBER'S CARE?



GRAPH 65. HAVE THE SERVICES OR SUPPORTS THAT YOUR FAMILY MEMBER RECEIVED BEEN REDUCED, SUSPENDED, OR TERMINATED IN THE PAST YEAR?



GRAPH 66. 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?

