

NCI Adult Family 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 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 Adult Family Survey?

The NCI Adult Family Survey is a mail-in survey sent to families who have a family member living in 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 (often the individual’s 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 Adult Family Survey includes items to measure the Family Outcomes domain. The table on the following page lists the NCI Family Surveys sub-domains and concern statements.

TABLE 1. NCI FAMILY SURVEY INDICATORS – 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 & 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 Adult Family Survey by selecting a random sample of at least 1,000 families of an adult with a developmental disability living in 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 $\pm 5\%$ 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 Adult Family 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).

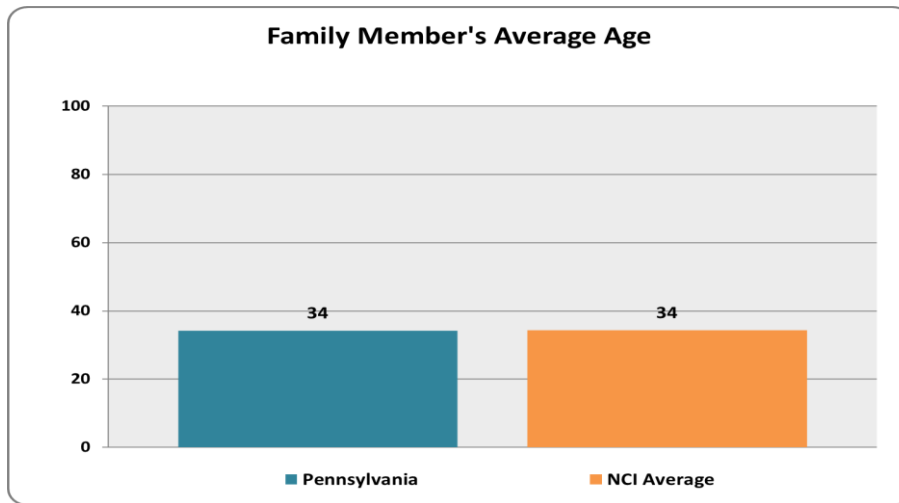
What is contained in this report?

This report illustrates 2012-2013 NCI Adult Family Survey demographic and outcome results from Pennsylvania compared to the NCI Average (the average of all state averages). In 2012-13, thirteen states conducted the Adult Family 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/>.

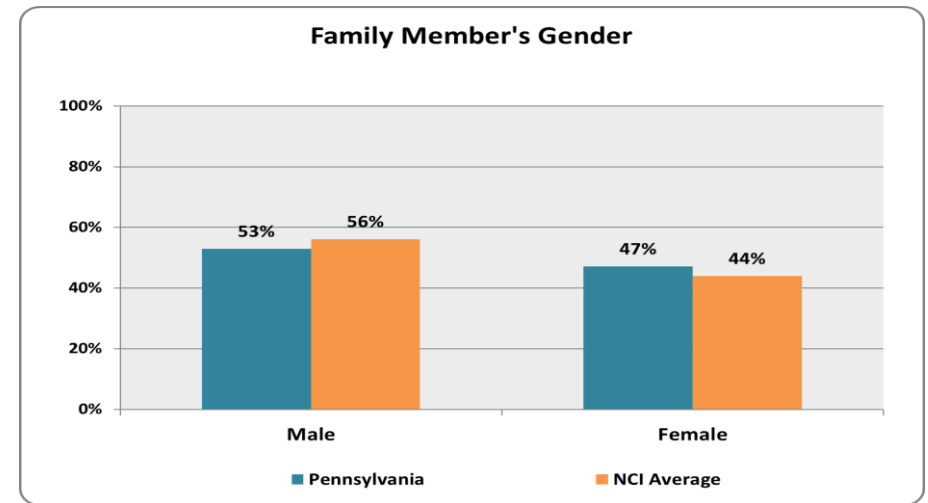
Results: Demographics of Family Member

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

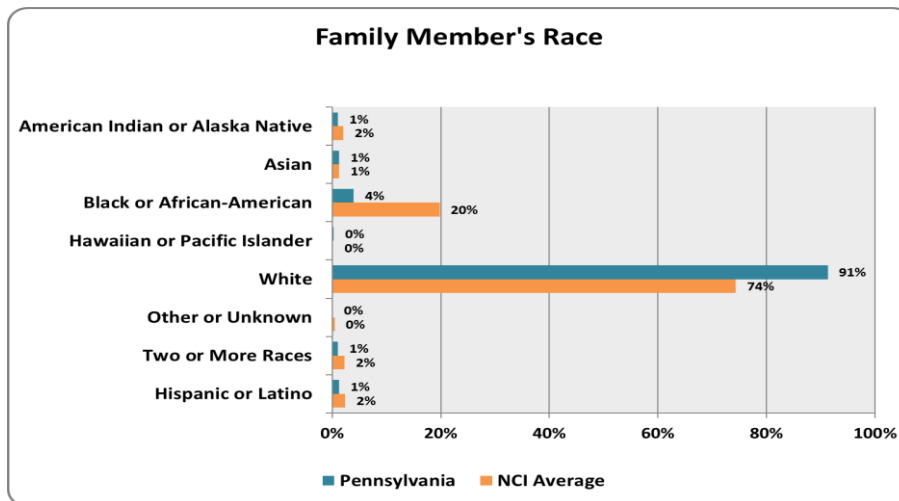
GRAPH 1. FAMILY MEMBER'S AVERAGE AGE



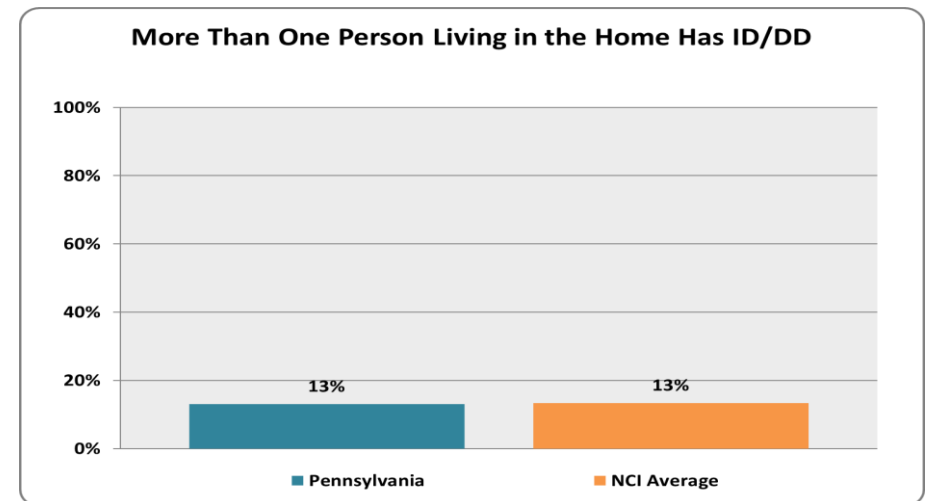
GRAPH 2. FAMILY MEMBER'S GENDER



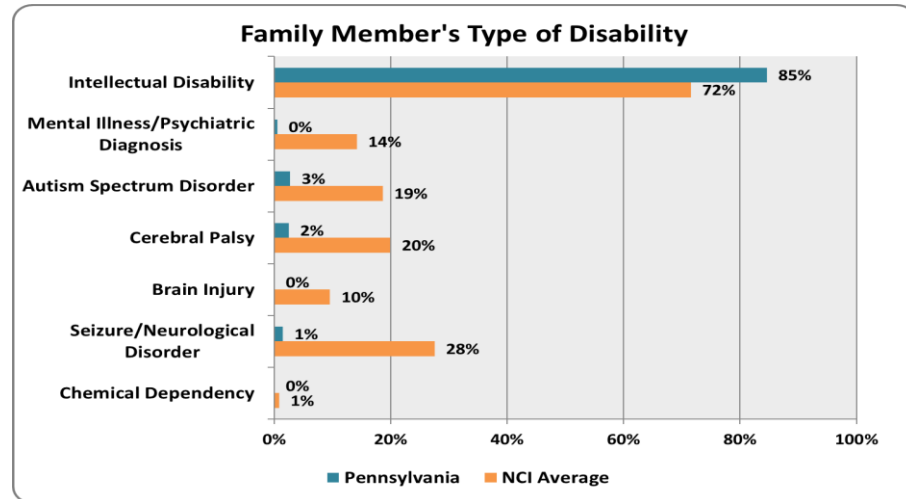
GRAPH 3. FAMILY MEMBER'S RACE



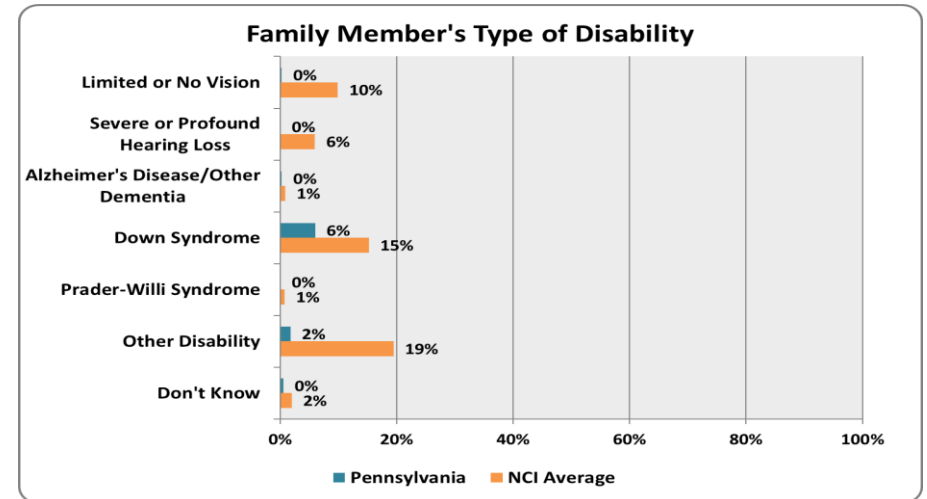
GRAPH 4. MORE THAN ONE PERSON LIVING IN THE HOME HAS ID/DD



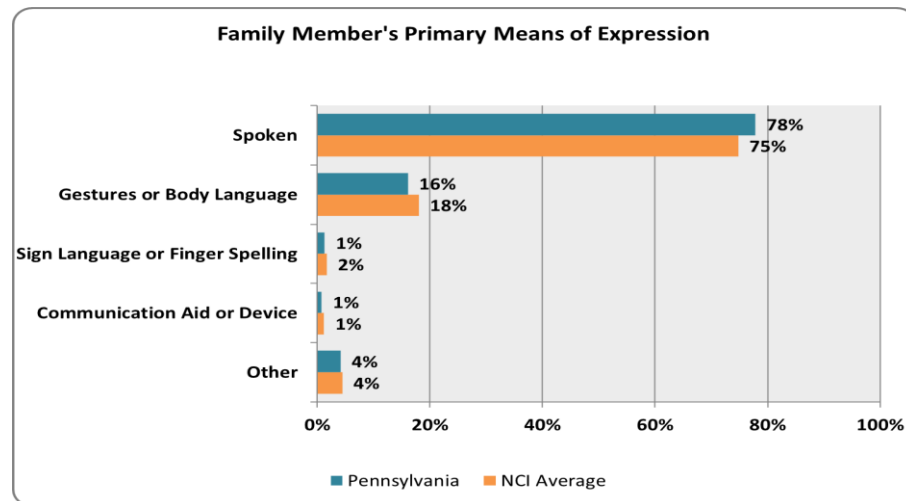
**GRAPH 5. FAMILY MEMBER'S TYPE OF DISABILITY
(NOT MUTUALLY EXCLUSIVE)**



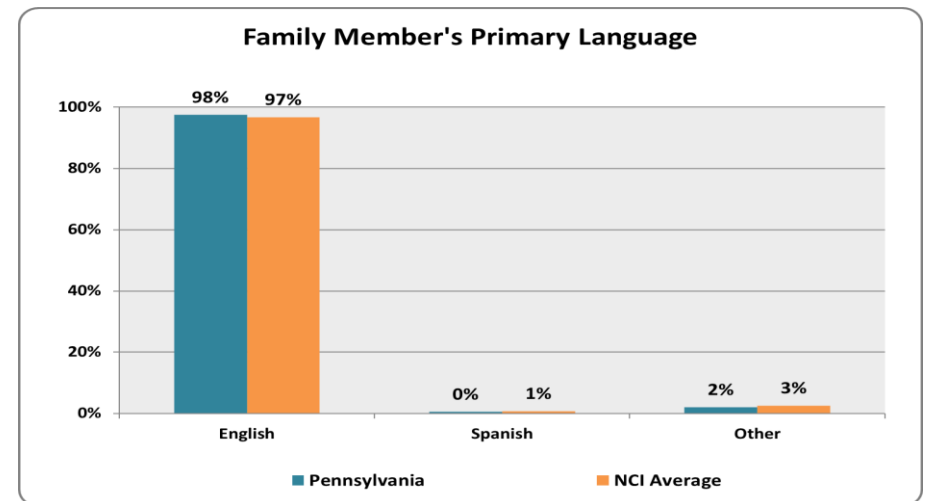
**GRAPH 6. FAMILY MEMBER'S TYPE OF DISABILITY, CONTINUED
(NOT MUTUALLY EXCLUSIVE)**



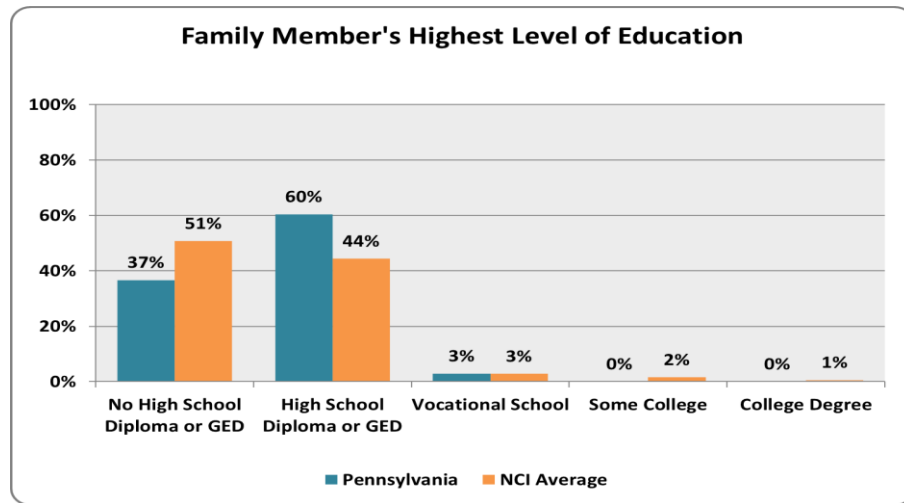
GRAPH 7. FAMILY MEMBER'S PRIMARY MEANS OF EXPRESSION



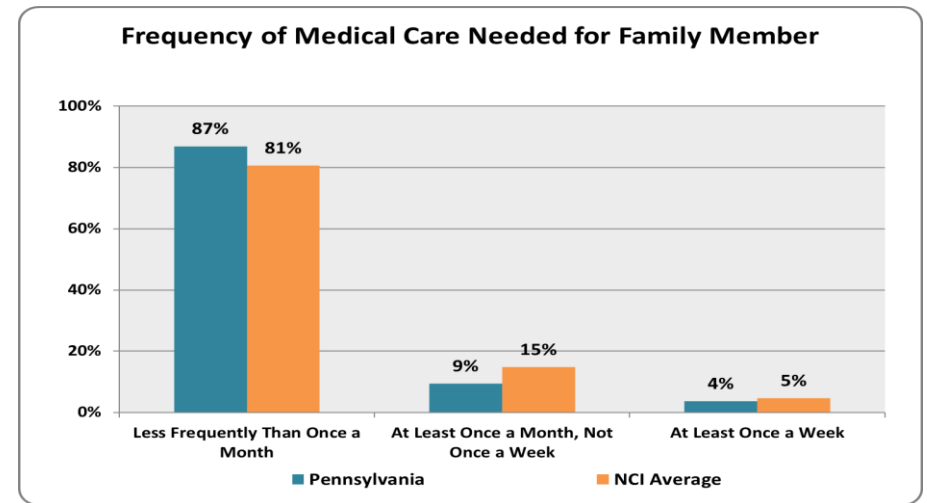
GRAPH 8. FAMILY MEMBER'S PRIMARY LANGUAGE



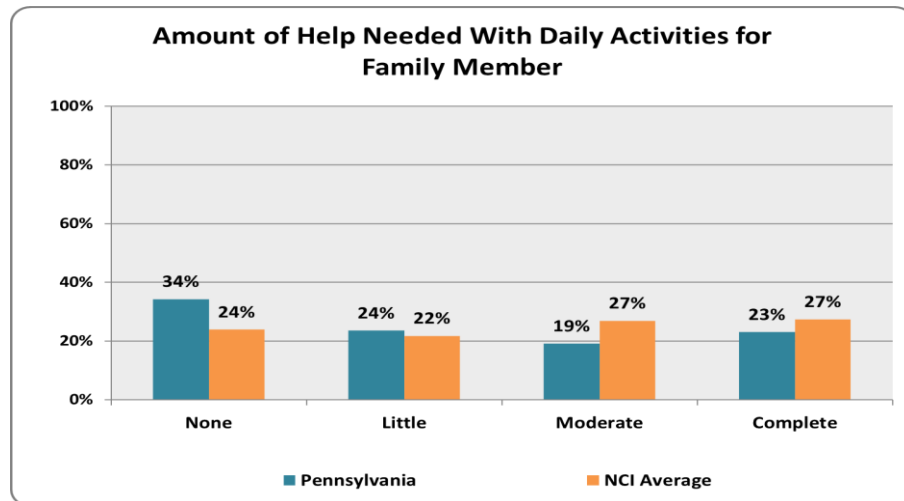
GRAPH 9. FAMILY MEMBER'S EDUCATION LEVEL



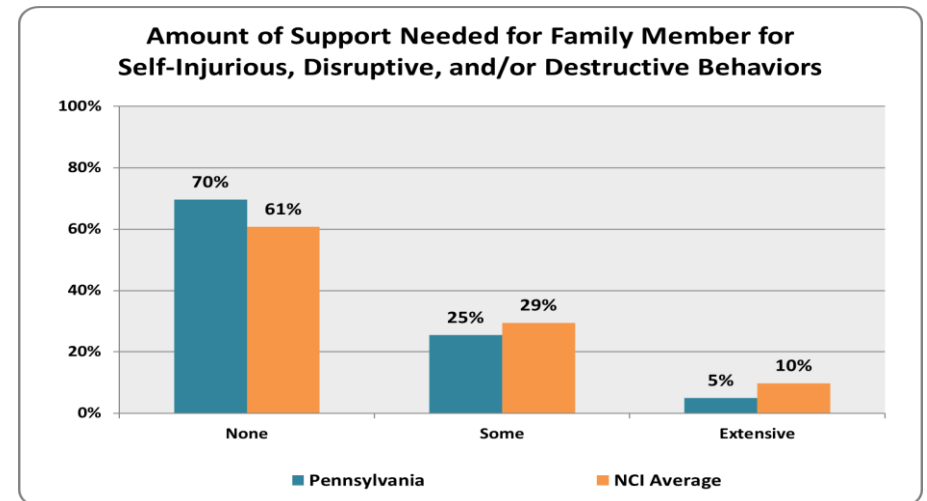
GRAPH 10. FREQUENCY OF MEDICAL CARE NEEDED FOR FAMILY MEMBER



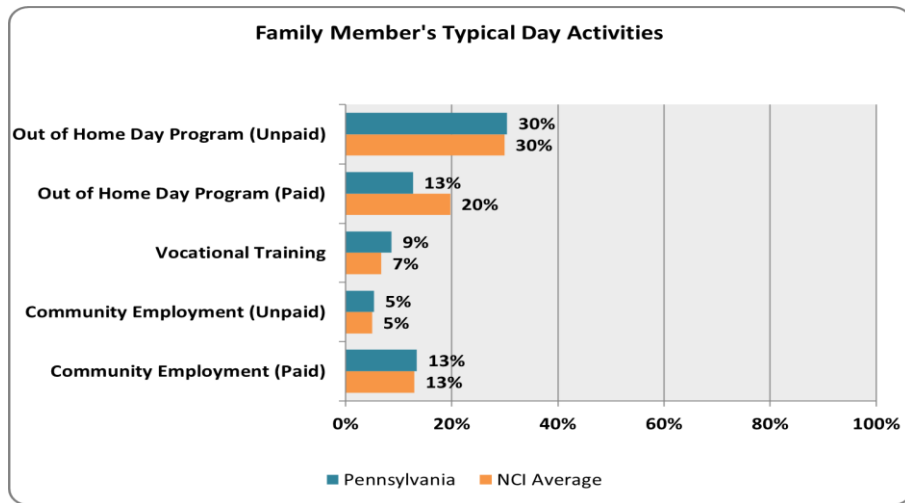
GRAPH 11. AMOUNT OF HELP NEEDED WITH DAILY ACTIVITIES FOR FAMILY MEMBER



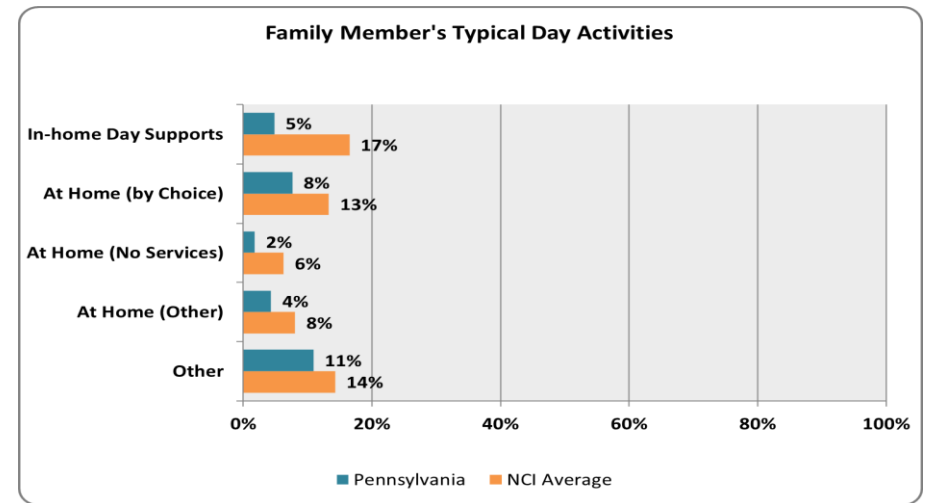
GRAPH 12. AMOUNT OF SUPPORT NEEDED FOR FAMILY MEMBER FOR SELF-INJURIOUS, DISRUPTIVE, AND/OR DESTRUCTIVE BEHAVIORS



GRAPH 13. FAMILY MEMBER'S TYPICAL DAY ACTIVITIES



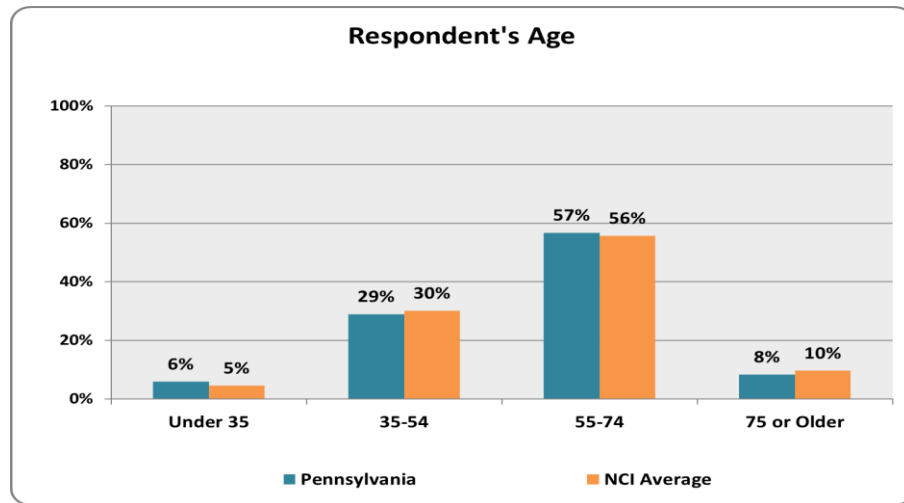
GRAPH 14. FAMILY MEMBER'S TYPICAL DAY ACTIVITIES, CONTINUED



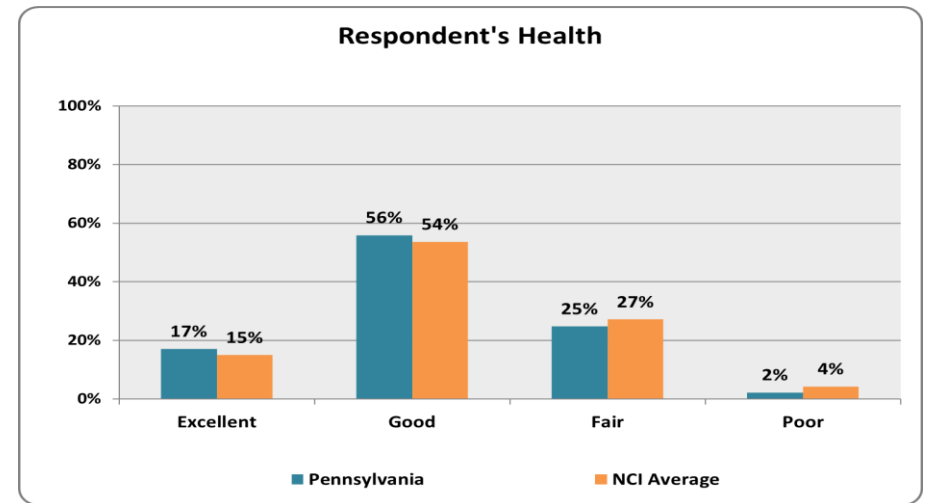
Results: Demographics of Respondent

ILLUSTRATES THE DEMOGRAPHIC PROFILE OF THE SURVEY RESPONDENTS

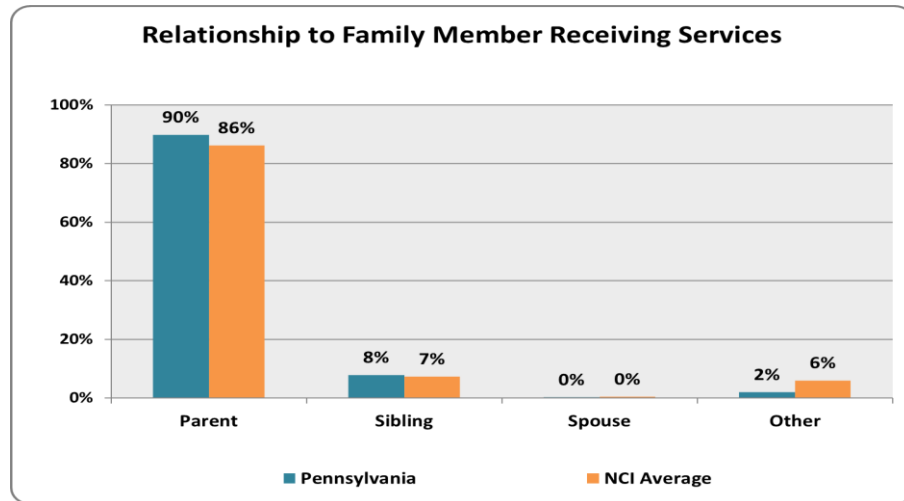
GRAPH 15. RESPONDENT'S AGE



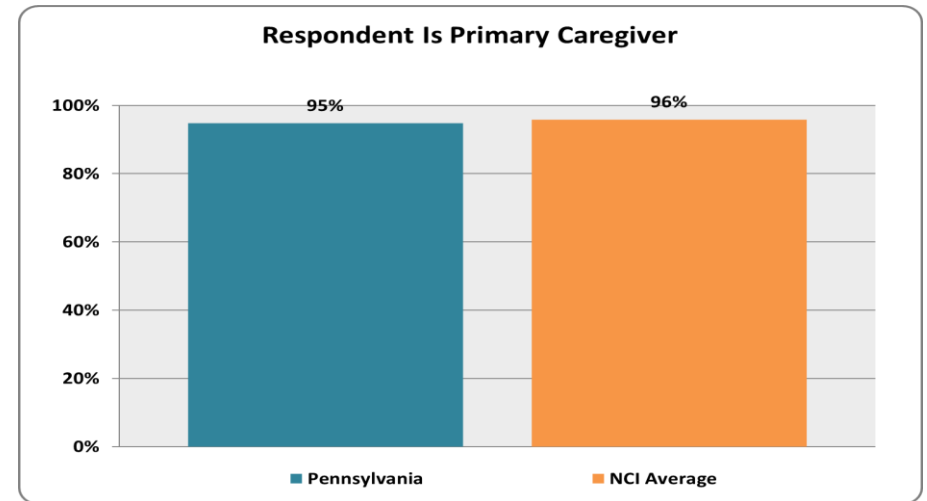
GRAPH 16. RESPONDENT'S HEALTH



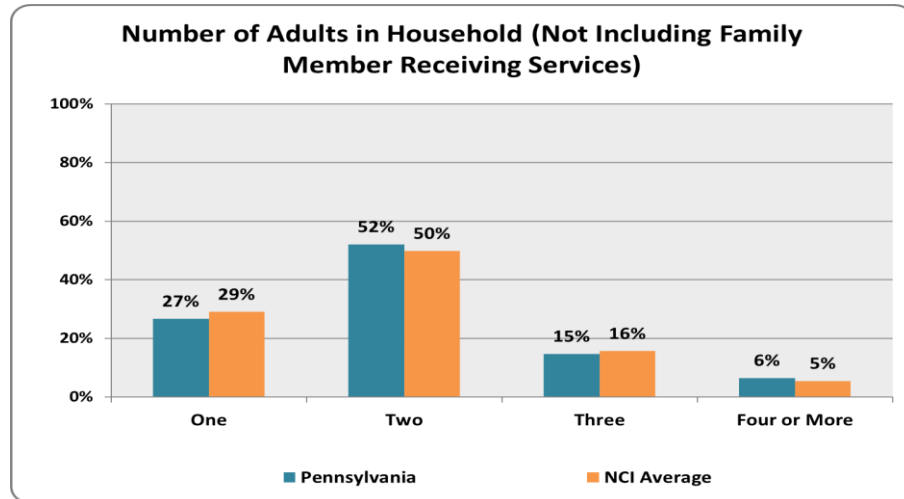
GRAPH 17. RELATIONSHIP TO FAMILY MEMBER RECEIVING SERVICES



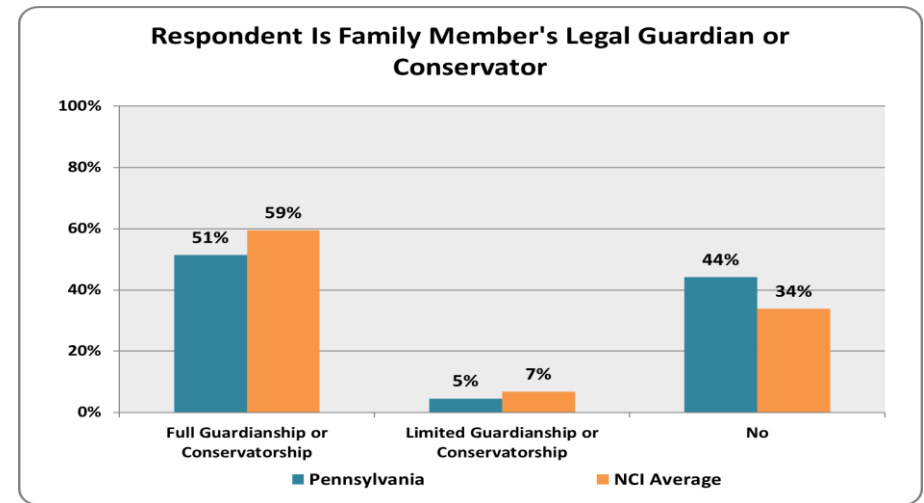
GRAPH 18. RESPONDENT IS PRIMARY CAREGIVER



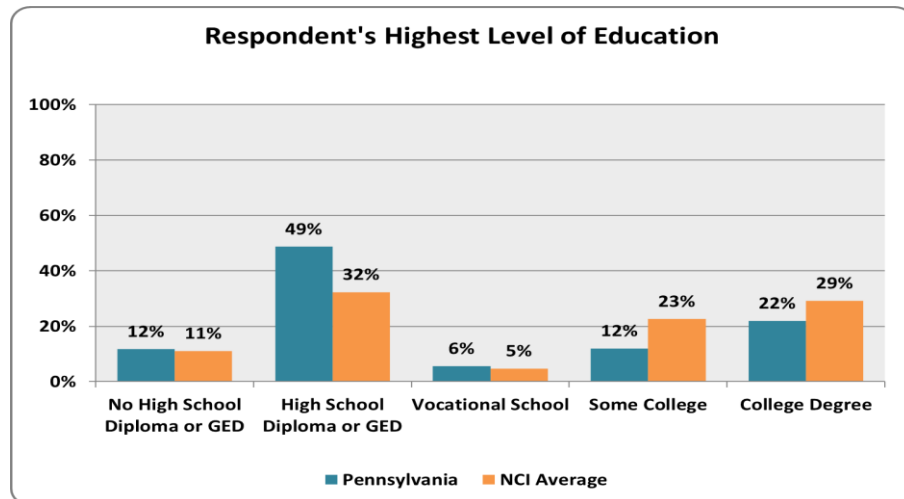
GRAPH 19. NUMBER OF ADULTS IN HOUSEHOLD (NOT INCLUDING FAMILY MEMBER RECEIVING SERVICES)



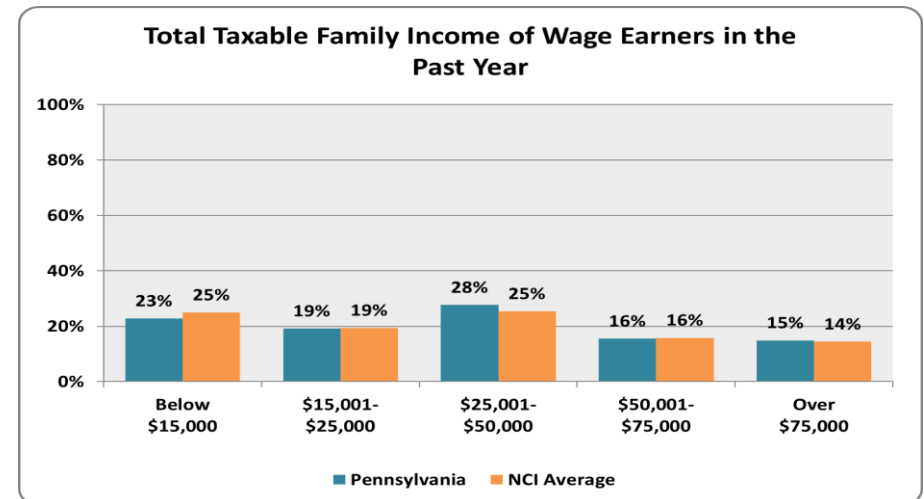
GRAPH 20. RESPONDENT IS FAMILY MEMBER'S LEGAL GUARDIAN OR CONSERVATOR



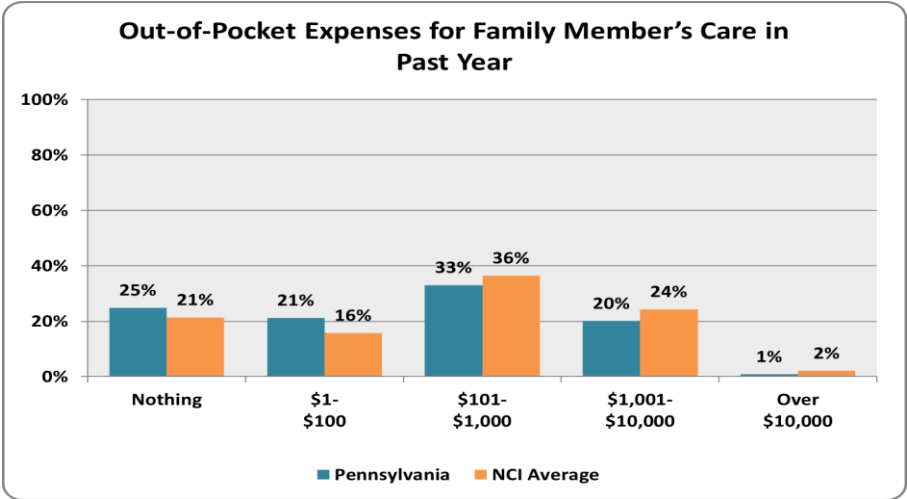
GRAPH 21. RESPONDENT'S HIGHEST LEVEL OF EDUCATION



GRAPH 22. TOTAL TAXABLE FAMILY INCOME OF WAGE EARNERS IN THE PAST YEAR



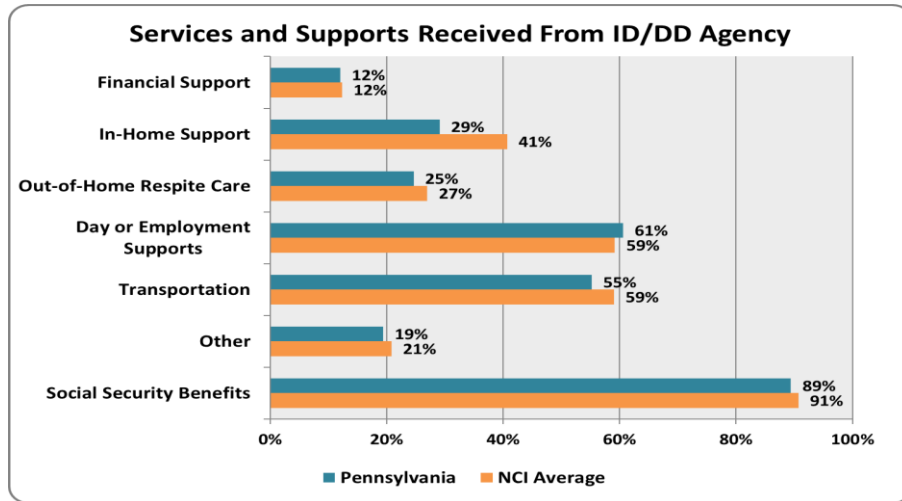
GRAPH 23. OUT-OF-POCKET EXPENSES FOR FAMILY MEMBER'S CARE IN PAST YEAR



Services and Supports Received

ILLUSTRATES THE SERVICES AND SUPPORTS RECEIVED BY FAMILIES AND FAMILY MEMBERS

GRAPH 24. SERVICES AND SUPPORTS RECEIVED¹

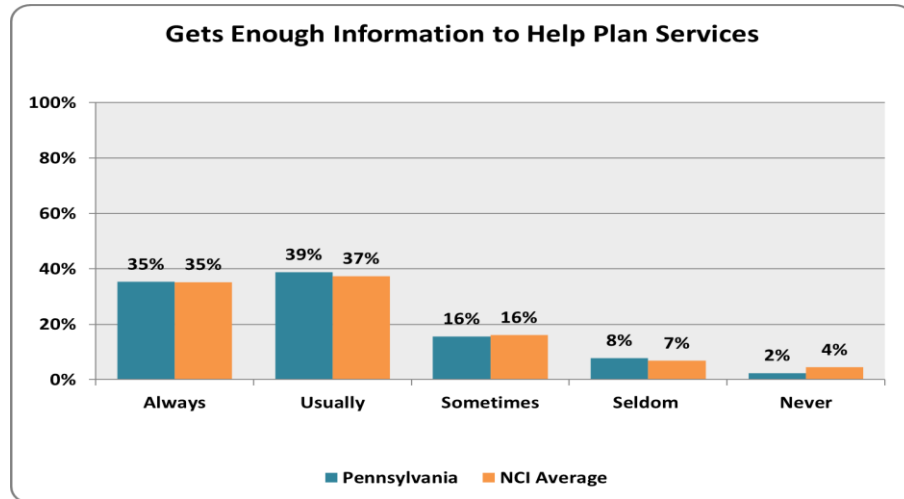


¹ All services and supports are received from the ID/DD Agency **except** social security benefits.

Information and Planning

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

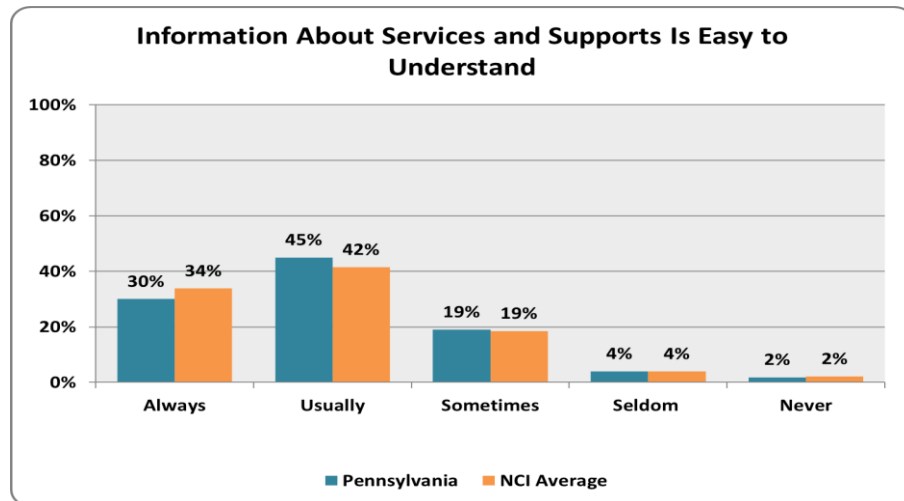
GRAPH 25. DO YOU GET ENOUGH INFORMATION TO HELP YOU PARTICIPATE IN PLANNING SERVICES FOR YOUR FAMILY?



This graph illustrates that respondents from Pennsylvania and across all NCI states receive enough information to help plan services: always 35% and 35%, usually 39% and 37%, sometimes 16% and 16%, seldom 8% and 7%, and never 2% and 4%.

Across NCI states, percentage of "always" responses ranged between 45% and 24%.

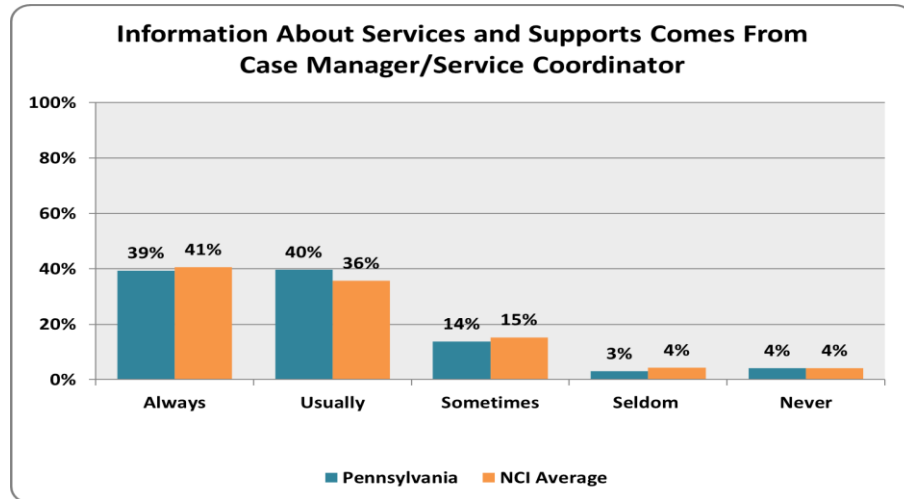
GRAPH 26. IS THE INFORMATION YOU RECEIVE EASY TO UNDERSTAND?



This graph illustrates that respondents from Pennsylvania and across all NCI states say the information they receive is easy to understand: always 30% and 34%, usually 45% and 42%, sometimes 19% and 19%, seldom 4% and 4%, and never 2% and 2%.

Across NCI states, percentage of "always" responses ranged between 48% and 28%.

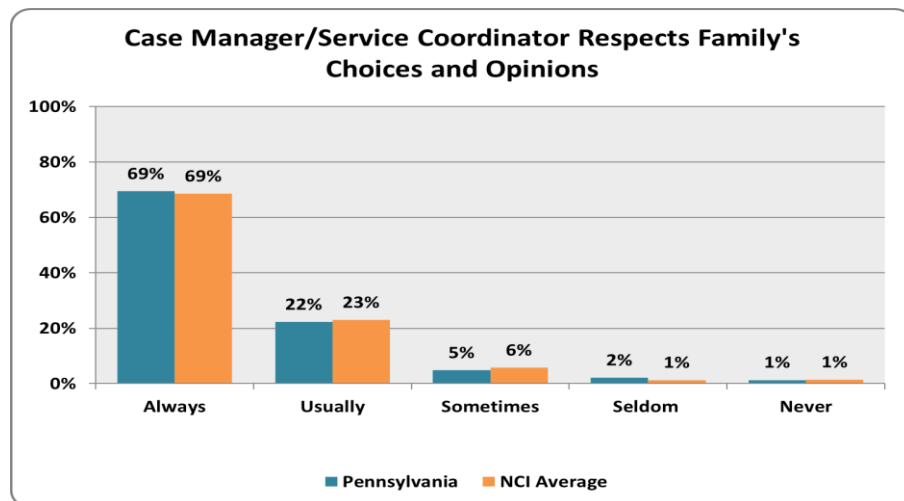
GRAPH 27. DOES THE INFORMATION YOU RECEIVE COME FROM YOUR CASE MANAGER/SERVICE COORDINATOR?



This graph illustrates that respondents from Pennsylvania and across all NCI states say the information they receive about services and supports comes from their case manager/service coordinator: always 39% and 41%, usually 40% and 36%, sometimes 14% and 15%, seldom 3% and 4%, and never 4% and 4%.

Across NCI states, percentage of "always" responses ranged between 49% and 27%.

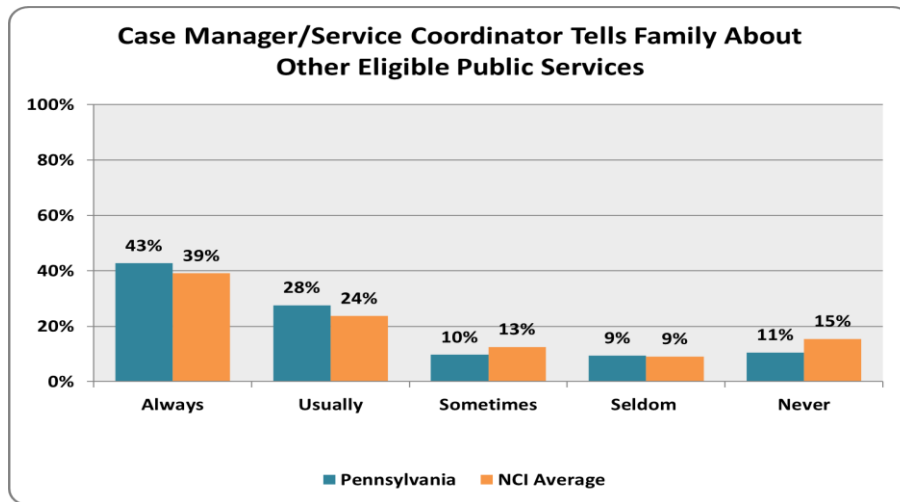
GRAPH 28. DOES THE CASE MANAGER/SERVICE COORDINATOR RESPECT YOUR FAMILY'S CHOICES AND OPINIONS?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their case manager/service coordinator respects the family's choices and opinions: always 69% and 69%, usually 22% and 23%, sometimes 5% and 6%, seldom 2% and 1%, and never 1% and 1%.

Across NCI states, percentage of "always" responses ranged between 83% and 58%.

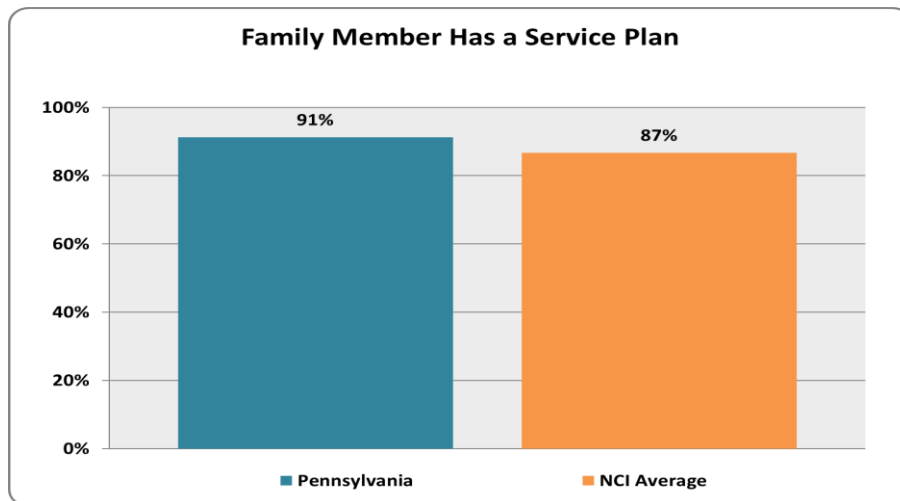
GRAPH 29. DOES THE CASE MANAGER/SERVICE COORDINATOR TELL YOU ABOUT OTHER PUBLIC SERVICES YOUR FAMILY IS ELIGIBLE FOR (FOOD STAMPS, SUPPLEMENTAL SECURITY INCOME [SSI], HOUSING SUBSIDIES, ETC.)?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their case manager/service coordinator tells the family about the public services they are eligible for: always 43% and 39%, usually 28% and 24%, sometimes 10% and 13%, seldom 9% and 9%, and never 11% and 15%.

Across NCI states, percentage of "always" responses ranged between 50% and 26%.

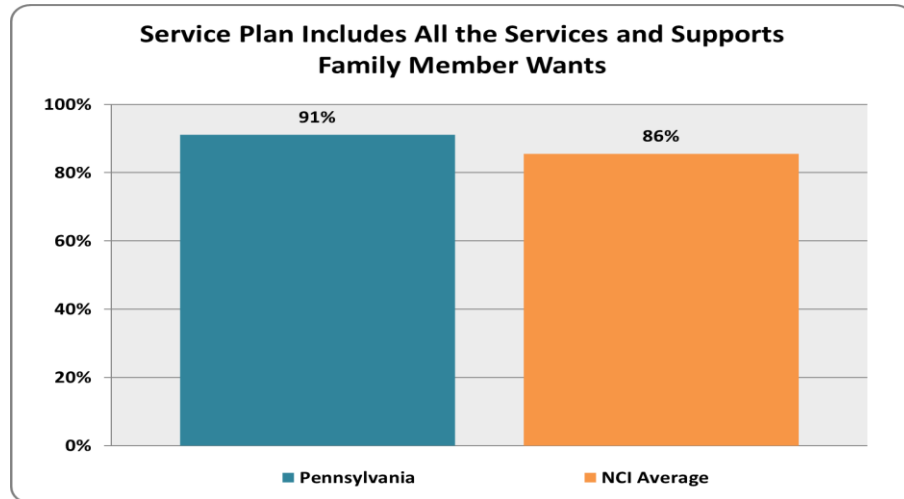
GRAPH 30. DOES YOUR FAMILY MEMBER HAVE A SERVICE PLAN?



This graph illustrates that 91% of respondents from Pennsylvania and 87% from across all NCI states say their family member has a service plan.

Across NCI states, percentage of "yes" responses ranged between 95% and 76%.

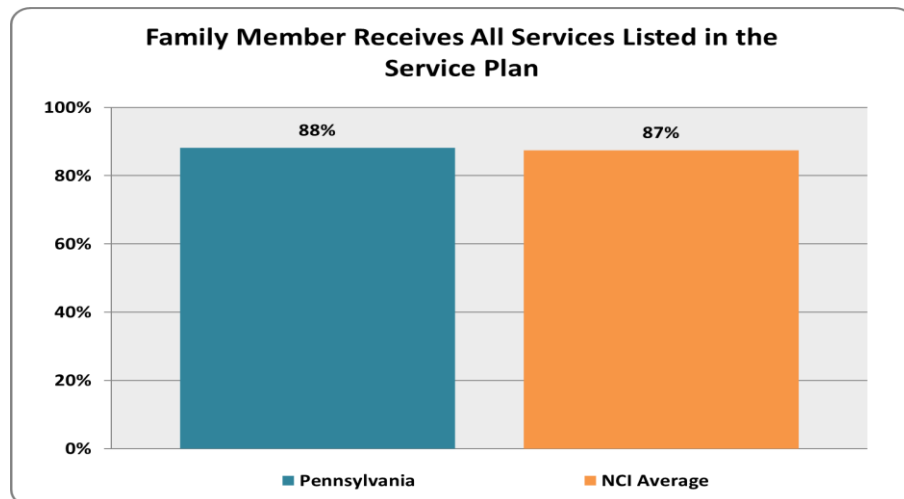
GRAPH 31. DOES THE PLAN INCLUDE ALL THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER WANTS?



This graph illustrates that among respondents whose family member has a service plan, 91% from Pennsylvania and 86% from across all NCI states say the plan includes all the services and supports the family member wants.

Across NCI states, percentage of "yes" responses ranged between 94% and 76%.

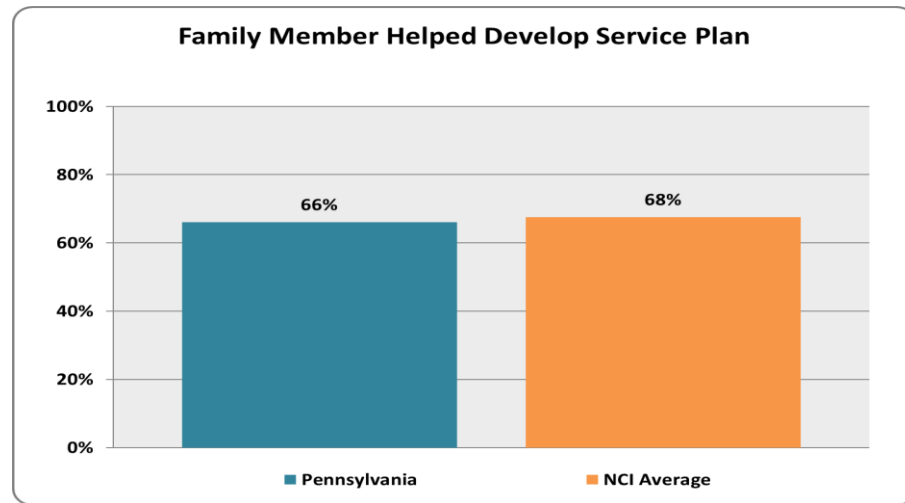
GRAPH 32. DOES YOUR FAMILY MEMBER RECEIVE ALL THE SERVICES LISTED IN THE PLAN?



This graph illustrates that among respondents whose family member has a service plan, 88% from Pennsylvania and 87% 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 93% and 81%.

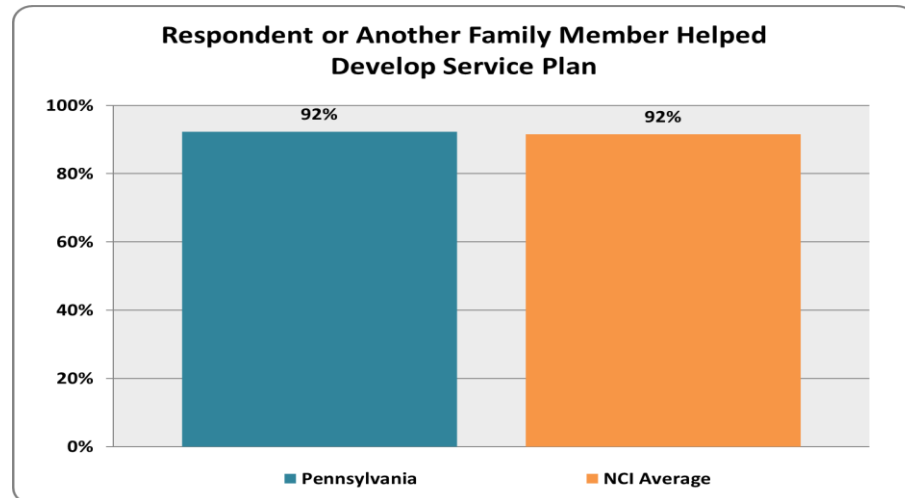
GRAPH 33. DID YOUR FAMILY MEMBER HELP DEVELOP THE PLAN?



This graph illustrates that among respondents whose family member has a service plan, 66% from Pennsylvania and 68% from across all NCI states say their family member helped develop the plan.

Across NCI states, percentage of "yes" responses ranged between 78% and 54%.

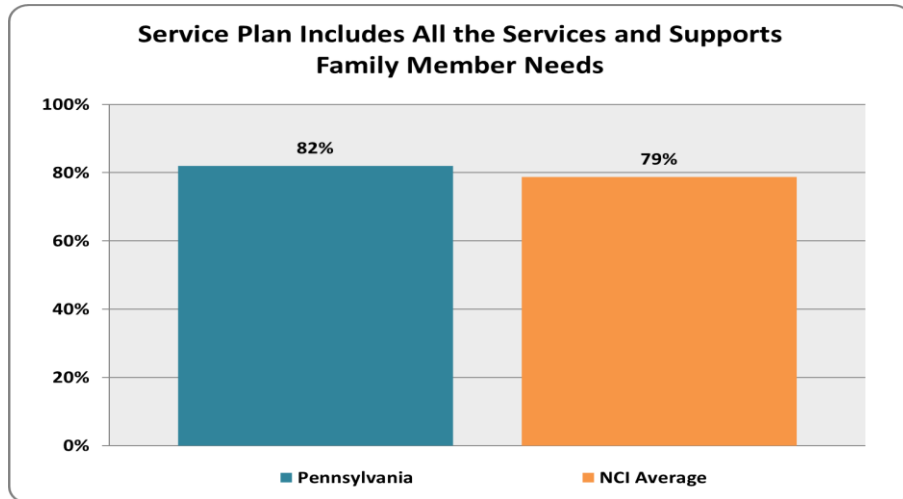
GRAPH 34. DID YOU OR ANOTHER FAMILY MEMBER HELP DEVELOP THE PLAN?



This graph illustrates that among respondents whose family member has a service plan, 92% from Pennsylvania and 92% from across all NCI states say they or another family member helped develop the plan.

Across NCI states, percentage of "yes" responses ranged between 99% and 82%.

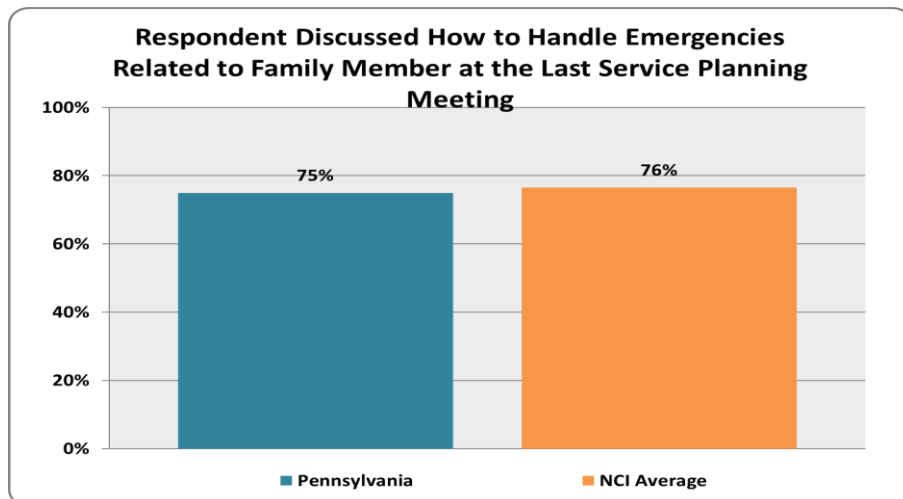
GRAPH 35. DOES THE PLAN INCLUDE ALL THE SERVICES AND SUPPORTS YOUR FAMILY MEMBER NEEDS?



This graph illustrates that among respondents whose family member has a service plan, 82% from Pennsylvania and 79% 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 91% and 67%.

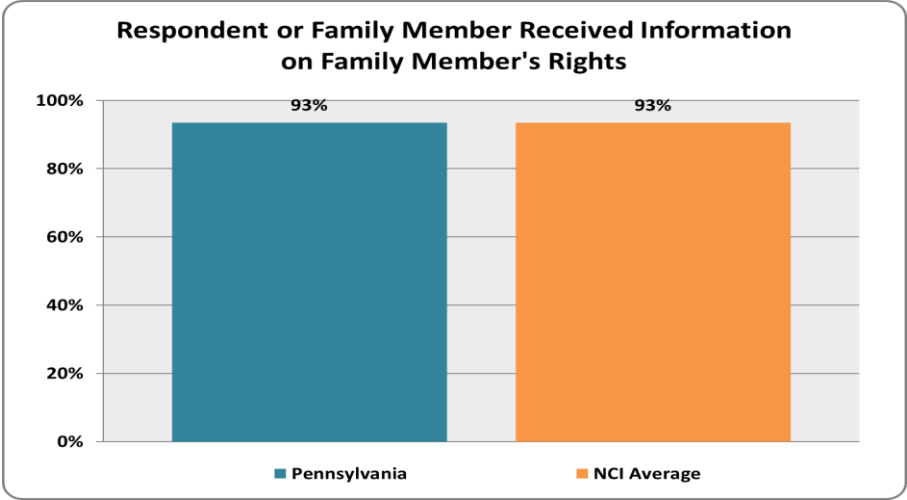
GRAPH 36. DID YOU DISCUSS HOW TO HANDLE EMERGENCIES RELATED TO YOUR FAMILY MEMBER AT THE LAST SERVICE PLANNING MEETING?



This graph illustrates that among respondents whose family member has a service plan, 75% from Pennsylvania and 76% 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 93% and 58%.

GRAPH 37. HAVE YOU OR YOUR FAMILY MEMBER RECEIVED INFORMATION ABOUT HIS/HER RIGHTS?



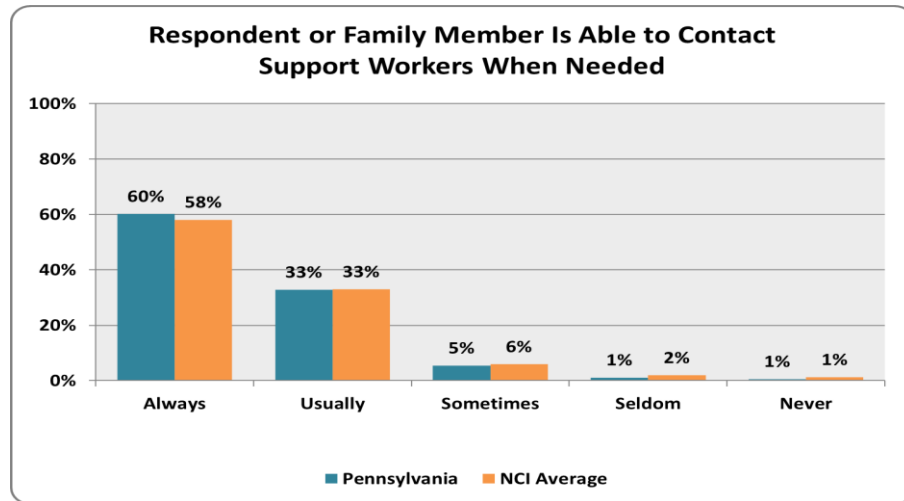
This graph illustrates that 93% of respondents from Pennsylvania and 93% from across all NCI states say they or their family member received information about their family member's rights.

Across NCI states, percentage of "yes" responses ranged between 98% and 88%.

Access and Delivery

PEOPLE MAKE CHOICES ABOUT THEIR LIVES AND ARE ACTIVELY ENGAGED IN PLANNING THEIR SERVICES AND SUPPORTS

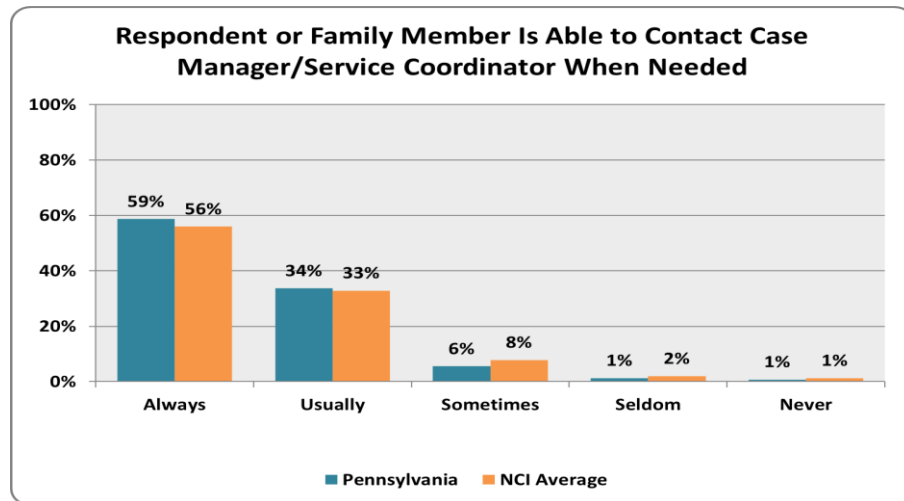
GRAPH 38. ARE YOU OR YOUR FAMILY MEMBER ABLE TO CONTACT HIS/HER SUPPORT WORKERS WHEN YOU NEED TO?



This graph illustrates that respondents from Pennsylvania and across all NCI states say they or their family member are able to contact their family member's support workers when needed: always 60% and 58%, usually 33% and 33%, sometimes 5% and 6%, seldom 1% and 2%, and never 1% and 1%.

Across NCI states, percentage of "always" responses ranged between 74% and 47%.

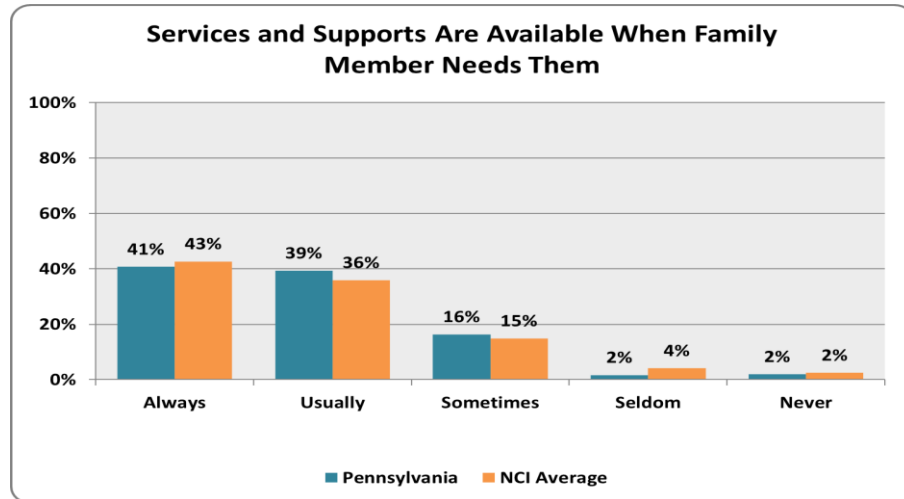
GRAPH 39. ARE YOU OR YOUR FAMILY MEMBER ABLE TO CONTACT HIS/HER CASE MANAGER/SERVICE COORDINATOR WHEN YOU NEED TO?



This graph illustrates that respondents from Pennsylvania and across all NCI states say they or their family member are able to contact their family member's case manager/service coordinator when needed: always 59% and 56%, usually 34% and 33%, sometimes 6% and 8%, seldom 1% and 2%, and never 1% and 1%.

Across NCI states, percentage of "always" responses ranged between 68% and 37%.

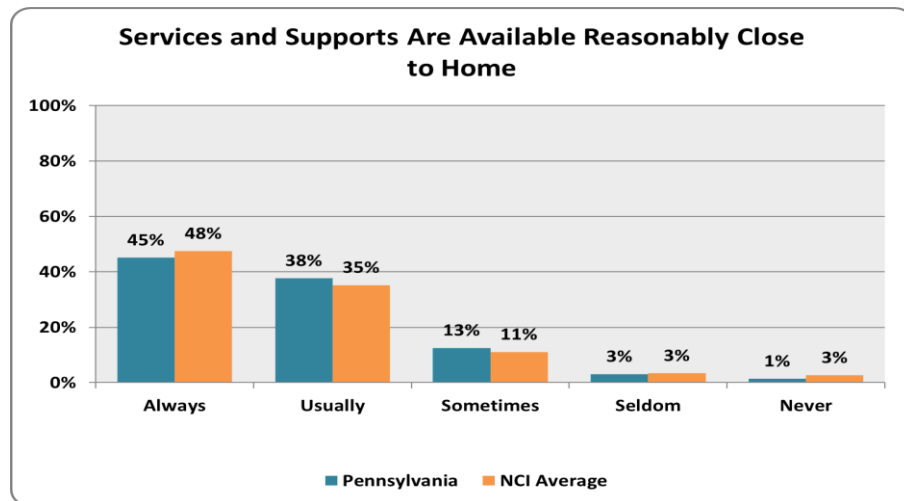
GRAPH 40. ARE SERVICES AND SUPPORTS AVAILABLE WHEN YOUR FAMILY MEMBER NEEDS THEM?



This graph illustrates that respondents from Pennsylvania and across all NCI states say that services and supports are available when their family member needs them: always 41% and 43%, usually 39% and 36%, sometimes 16% and 15%, seldom 2% and 4%, and never 2% and 2%.

Across NCI states, percentage of "always" responses ranged between 61% and 29%.

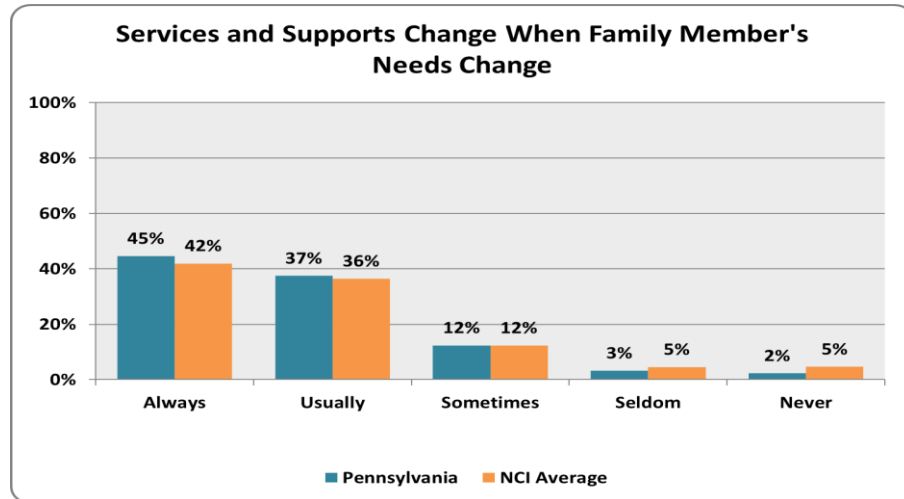
GRAPH 41. ARE SERVICES AND SUPPORTS AVAILABLE WITHIN A REASONABLE DISTANCE FROM YOUR HOME?



This graph illustrates that respondents from Pennsylvania and across all NCI states say that services and supports are available within a reasonable distance from home: always 45% and 48%, usually 38% and 35%, sometimes 13% and 11%, seldom 3% and 3%, and never 1% and 3%.

Across NCI states, percentage of "always" responses ranged between 66% and 40%.

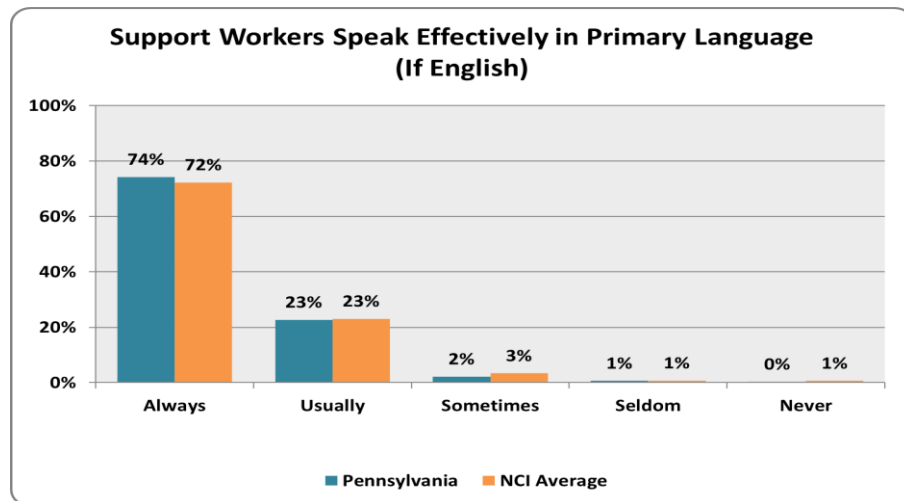
GRAPH 42. DO THE SERVICES AND SUPPORTS CHANGE WHEN YOUR FAMILY MEMBER'S NEEDS CHANGE?



This graph illustrates that respondents from Pennsylvania and across all NCI states say that services and supports change when their family member's needs change: always 45% and 42%, usually 37% and 36%, sometimes 12% and 12%, seldom 3% and 5%, and never 2% and 5%.

Across NCI states, percentage of "always" responses ranged between 57% and 30%.

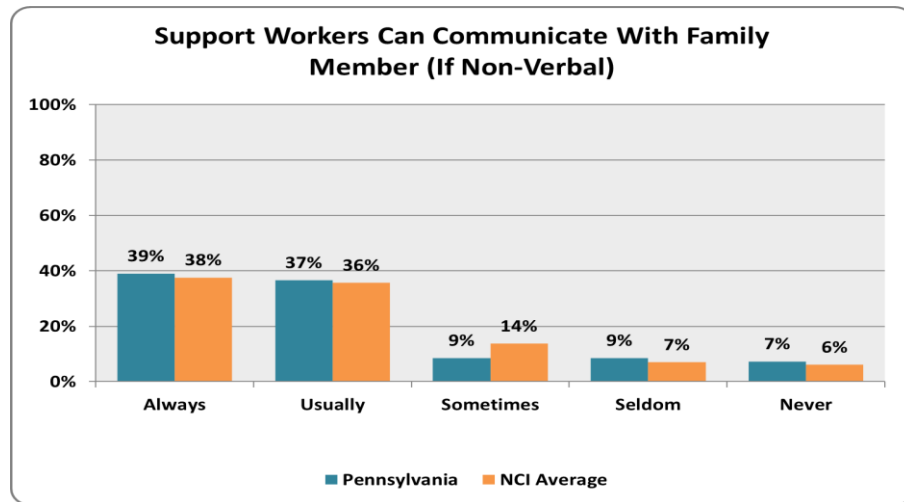
GRAPH 43. IF ENGLISH IS YOUR PRIMARY LANGUAGE, DO SUPPORT WORKERS SPEAK TO YOU EFFECTIVELY?



This graph illustrates that among respondents from Pennsylvania and across all NCI states whose primary language is English, support workers speak with their family member effectively: always 74% and 72%, usually 23% and 23%, sometimes 2% and 3%, seldom 1% and 1%, and never 0% and 1%.

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

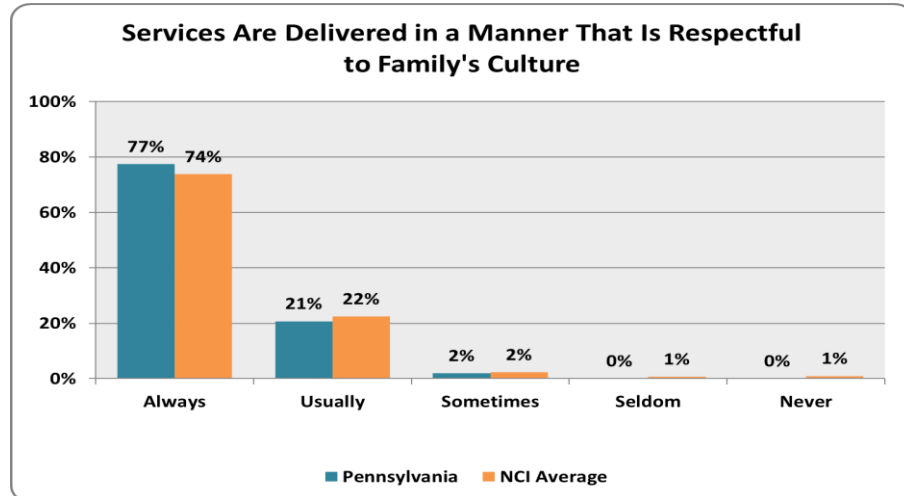
GRAPH 44. IF YOUR FAMILY MEMBER DOES NOT COMMUNICATE VERBALLY (FOR EXAMPLE, USES GESTURES OR SIGN LANGUAGE), ARE THERE SUPPORT WORKERS WHO CAN COMMUNICATE WITH HIM/HER?



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 their family member: always 39% and 38%, usually 37% and 36%, sometimes 9% and 14%, seldom 9% and 7%, and never 7% and 6%.

Across NCI states, percentage of "always" responses ranged between 52% and 25%.

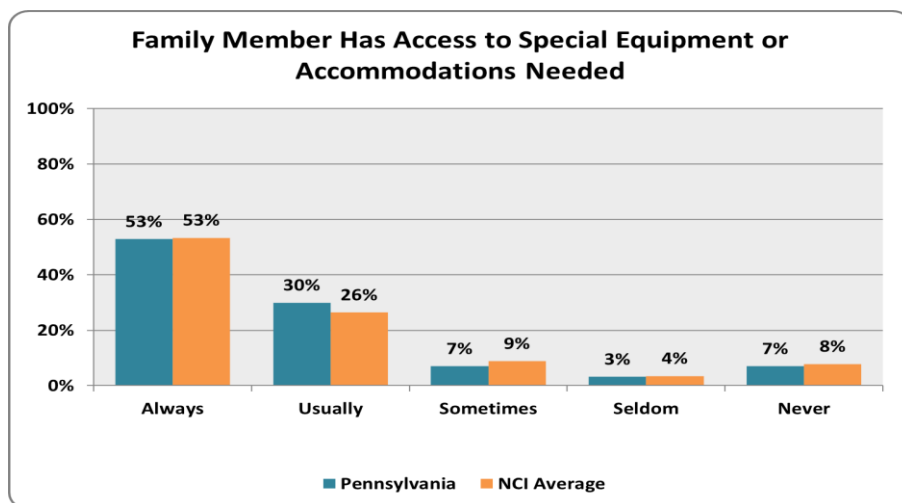
GRAPH 45. ARE SERVICES DELIVERED IN A WAY THAT IS RESPECTFUL TO YOUR FAMILY'S CULTURE?



This graph illustrates that respondents from Pennsylvania and across all NCI states say services are delivered in a manner that is respectful of the family's culture: always 77% and 74%, usually 21% and 22%, sometimes 2% and 2%, seldom 0% and 1%, and never 0% and 1%.

Across NCI states, percentage of "always" responses ranged between 88% and 61%.

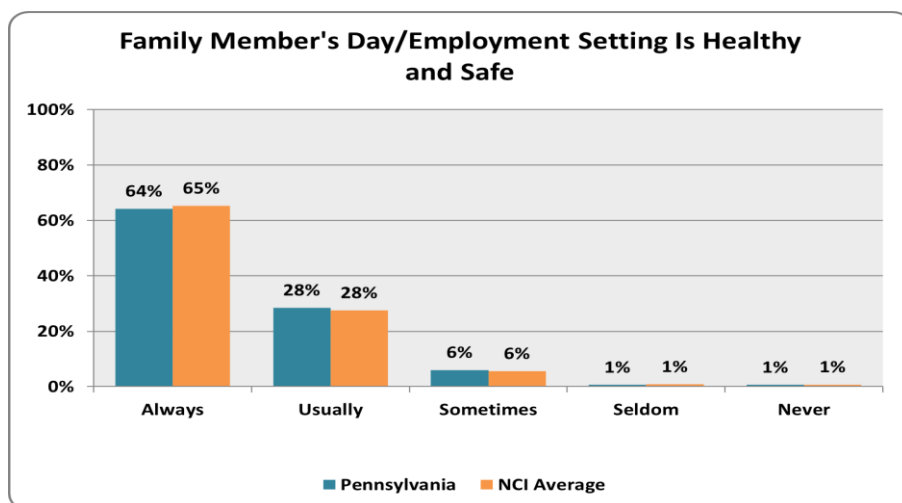
GRAPH 46. DOES YOUR FAMILY MEMBER HAVE ACCESS TO THE SPECIAL EQUIPMENT OR ACCOMMODATIONS THAT S/HE NEEDS (FOR EXAMPLE, WHEELCHAIR, RAMP, COMMUNICATION BOARD)?



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 53% and 53%, usually 30% and 26%, sometimes 7% and 9%, seldom 3% and 4%, and never 7% and 8%.

Across NCI states, percentage of "always" responses ranged between 75% and 44%.

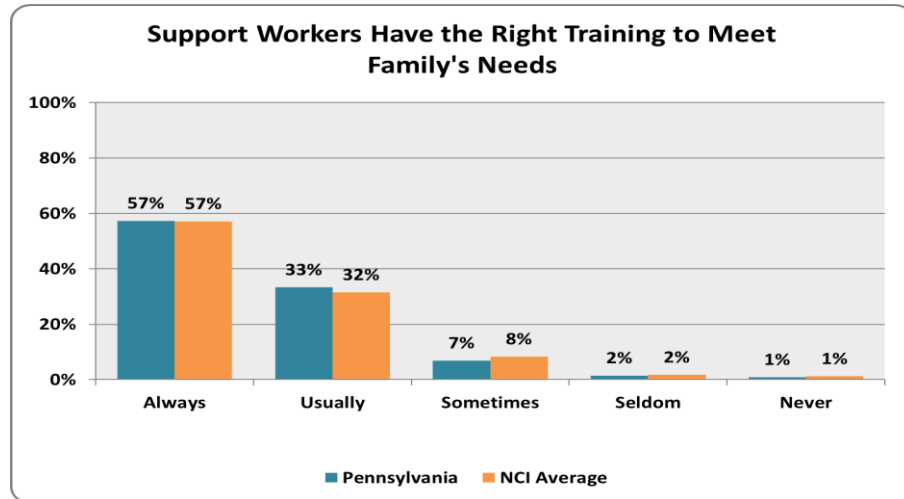
GRAPH 47. DO YOU FEEL THAT YOUR FAMILY MEMBER'S DAY/EMPLOYMENT SETTING IS A HEALTHY AND SAFE ENVIRONMENT?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their family member's day and employment setting is healthy and safe: always 64% and 65%, usually 28% and 28%, sometimes 6% and 6%, seldom 1% and 1%, and never 1% and 1%.

Across NCI states, percentage of "always" responses ranged between 81% and 54%.

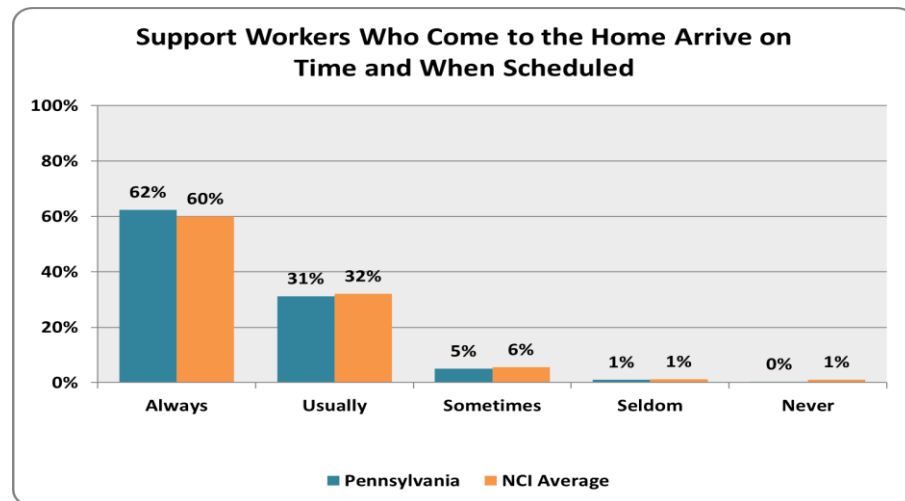
GRAPH 48. DO SUPPORT WORKERS HAVE THE RIGHT TRAINING TO MEET YOUR FAMILY'S NEEDS?



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 the family's needs: always 57% and 57%, usually 33% and 32%, sometimes 7% and 8%, seldom 2% and 2%, and never 1% and 1%.

Across NCI states, percentage of "always" responses ranged between 68% and 49%.

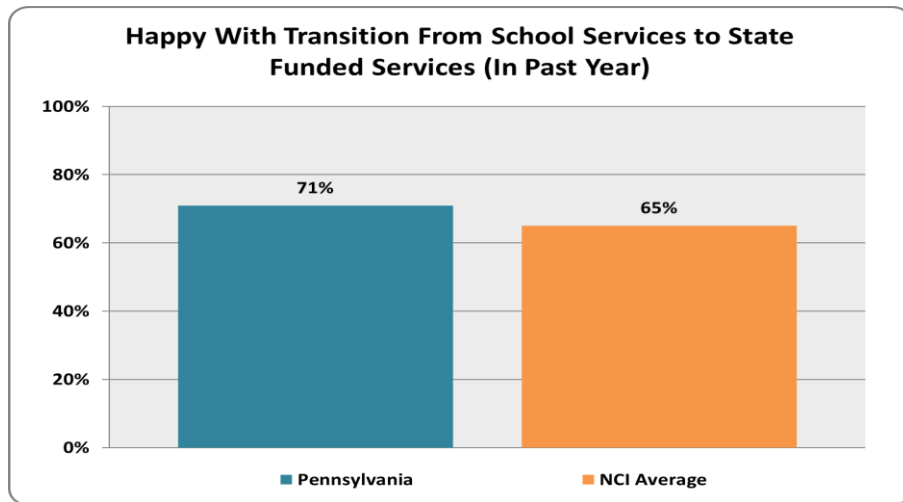
GRAPH 49. DO THE SUPPORT WORKERS WHO COME TO YOUR HOME ARRIVE ON TIME AND WHEN SCHEDULED?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their family member's support workers arrive on time and when scheduled: always 62% and 60%, usually 31% and 32%, sometimes 5% and 6%, seldom 1% and 1%, and never 0% and 1%.

Across NCI states, percentage of "always" responses ranged between 77% and 51%.

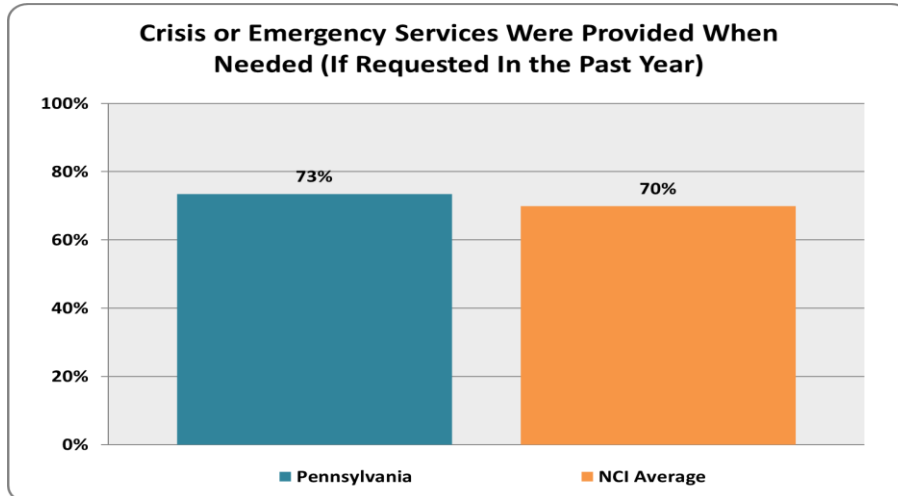
GRAPH 50. IF YOUR FAMILY MEMBER TRANSITIONED FROM SCHOOL SERVICES TO STATE FUNDED SERVICES IN THE PAST YEAR, WERE YOU HAPPY WITH THE TRANSITION PROCESS?



This graph illustrates that among respondents whose family member transitioned from school to State funded services in the past year, 71% of respondents from Pennsylvania and 65% across all NCI states were happy with the transition process.

Across NCI states, percentage of "yes" responses ranged between 73% and 45%.

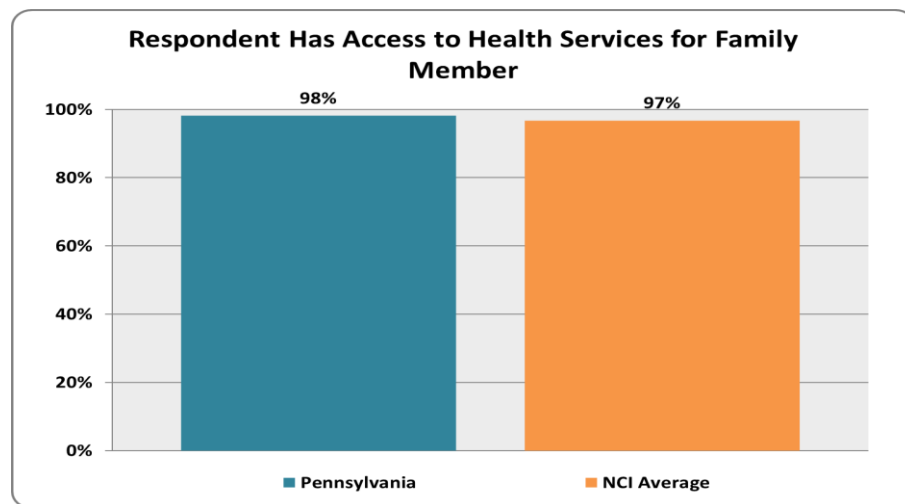
GRAPH 51. IF YOU ASKED FOR CRISIS OR EMERGENCY SERVICES IN THE PAST YEAR, WERE SERVICES PROVIDED WHEN NEEDED?



This graph illustrates that among respondents who asked for crisis or emergency services in the past year, 73% from Pennsylvania and 70% across all NCI states say the services were provided when needed.

Across NCI states, percentage of "yes" responses ranged between 85% and 53%.

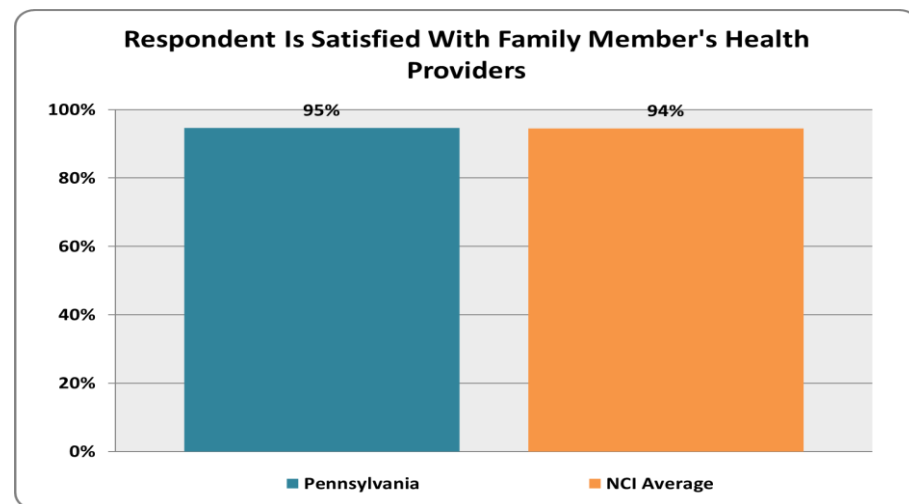
GRAPH 52. DO YOU HAVE ACCESS TO HEALTH SERVICES FOR YOUR FAMILY MEMBER?



This graph illustrates that 98% of respondents from Pennsylvania and 97% across all NCI states have access to health services for their family member.

Across NCI states, percentage of "yes" responses ranged between 99% and 91%.

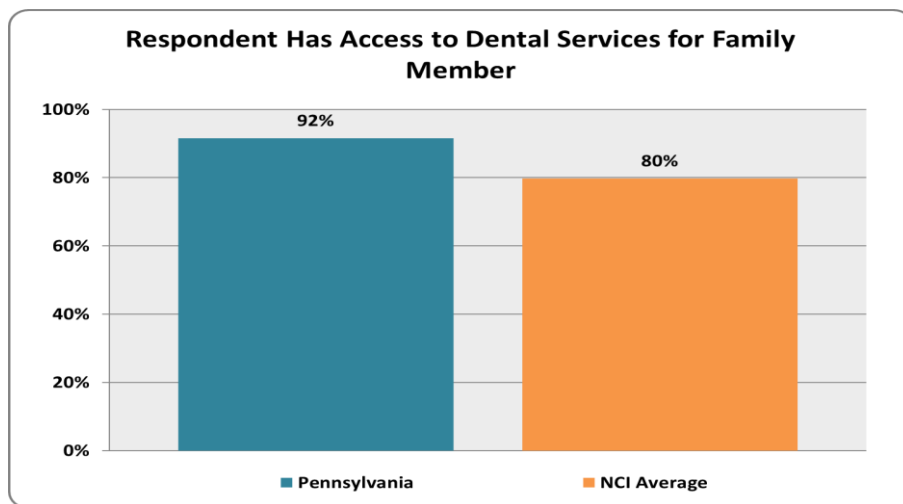
GRAPH 53. IF YOU HAVE ACCESS TO HEALTH SERVICES FOR YOUR FAMILY MEMBER, ARE YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



This graph illustrates that among respondents with access to health services for their family member, 95% from Pennsylvania and 94% across all NCI states are satisfied with the quality of those providers.

Across NCI states, percentage of "yes" responses ranged between 97% and 88%.

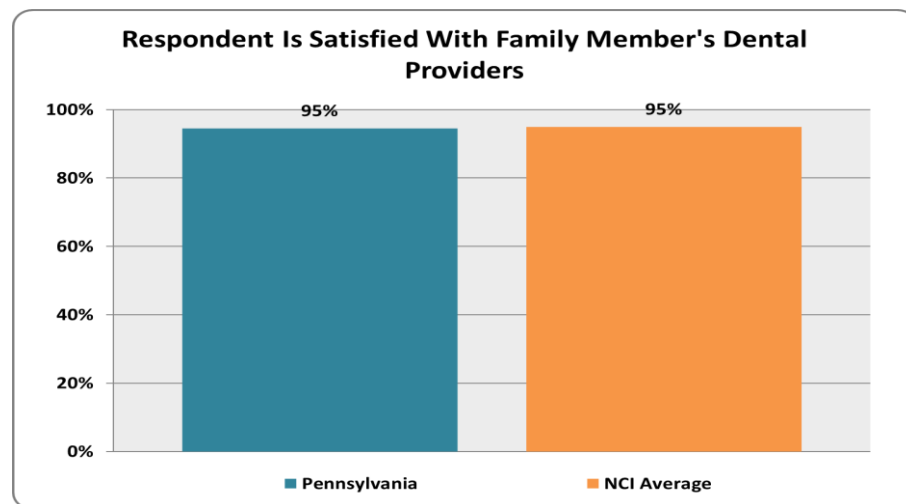
GRAPH 54. DO YOU HAVE ACCESS TO DENTAL SERVICES FOR YOUR FAMILY MEMBER?



This graph illustrates that 92% of respondents from Pennsylvania and 80% across all NCI states have access to dental services for their family member.

Across NCI states, percentage of "yes" responses ranged between 93% and 66%.

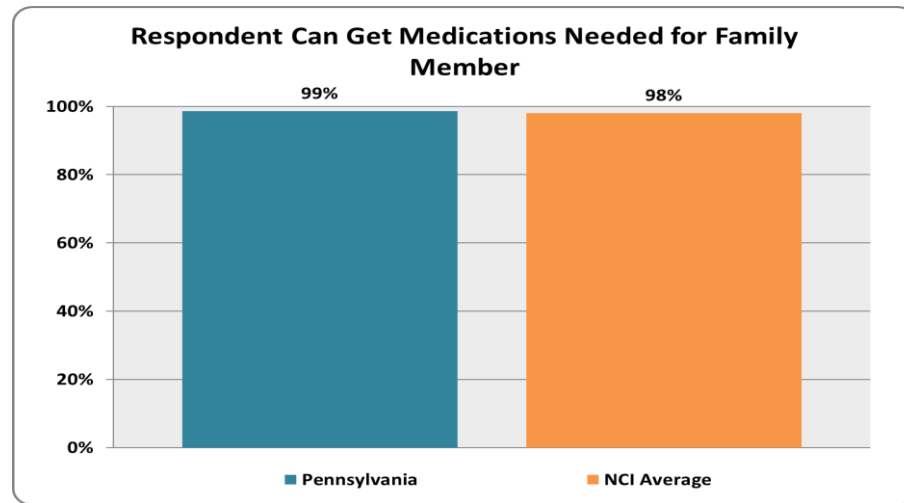
GRAPH 55. IF YOU HAVE ACCESS TO DENTAL SERVICES FOR YOUR FAMILY MEMBER, ARE YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



This graph illustrates that among respondents with access to dental services for their family member, 95% from Pennsylvania and 95% across all NCI states are satisfied with the quality of those providers.

Across NCI states, percentage of "yes" responses ranged between 97% and 91%.

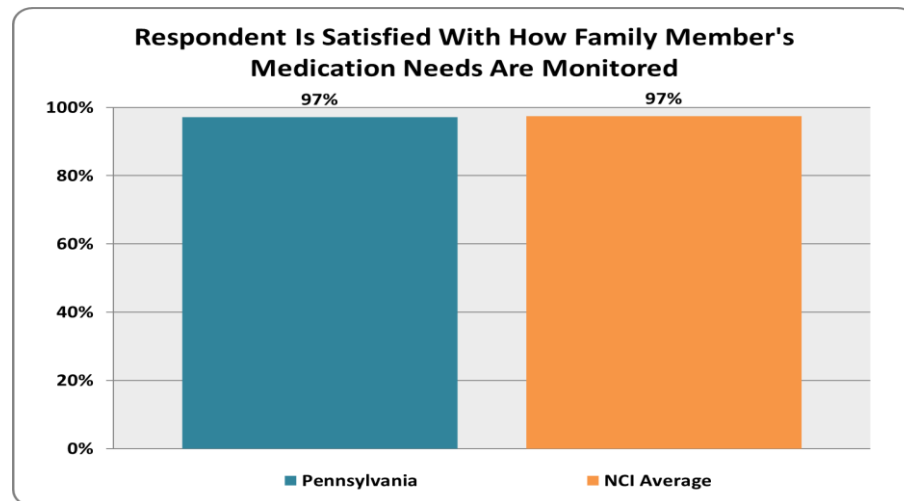
GRAPH 56. ARE YOU ABLE TO GET MEDICATIONS NEEDED FOR YOUR FAMILY MEMBER?



This graph illustrates that 99% of respondents from Pennsylvania and 98% across all NCI states can get medications needed for their family member.

Across NCI states, percentage of "yes" responses ranged between 99% and 96%.

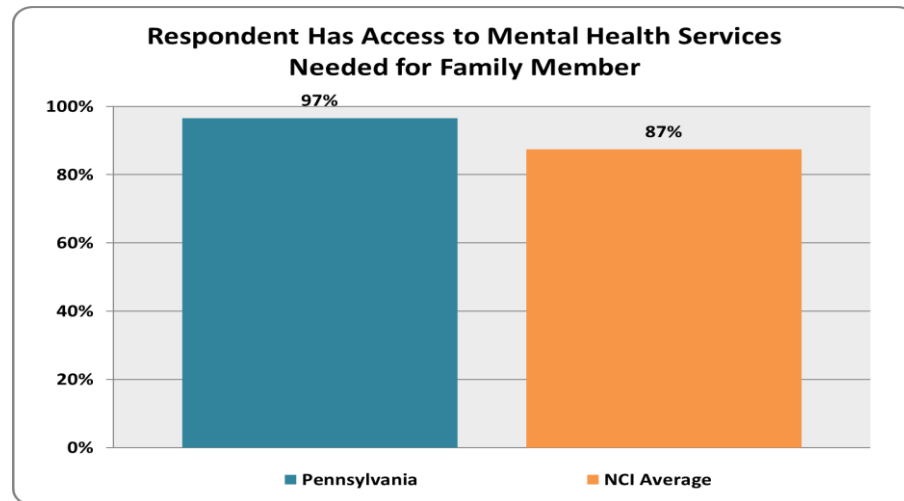
GRAPH 57. IF YOU ARE ABLE TO GET MEDICATIONS NEEDED FOR YOUR FAMILY MEMBER, ARE YOU SATISFIED WITH HOW YOUR FAMILY MEMBER'S MEDICATION NEEDS ARE MONITORED?



This graph illustrates that among respondents with access to medication needed for their family member, 97% from Pennsylvania and 97% across all NCI states are satisfied with how medications are monitored.

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

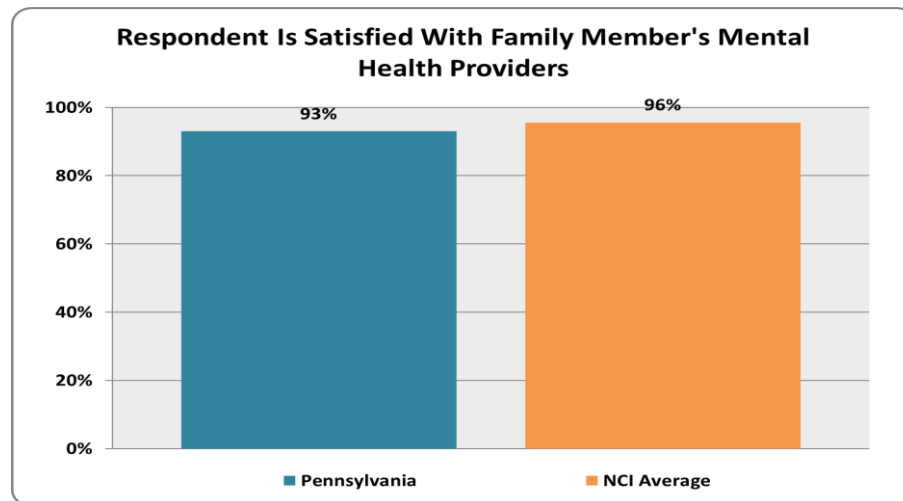
GRAPH 58. IF NEEDED, DO YOU HAVE ACCESS TO MENTAL HEALTH SERVICES FOR YOUR FAMILY MEMBER?



This graph illustrates that 97% of respondents from Pennsylvania and 87% across all NCI states say they have access to mental health services needed for their family member if needed.

Across NCI states, percentage of "yes" responses ranged between 97% and 78%.

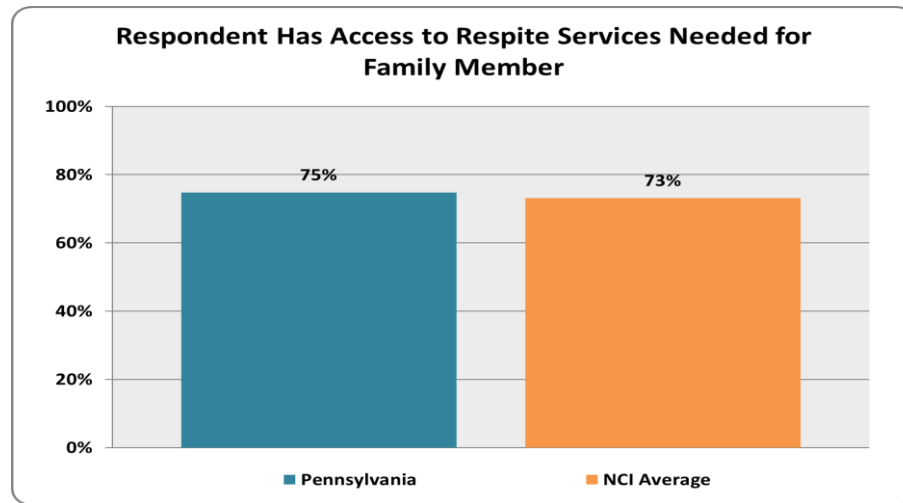
GRAPH 59. IF YOU HAVE ACCESS TO MENTAL HEALTH SERVICES NEEDED FOR YOUR FAMILY MEMBER, ARE YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



This graph illustrates that among respondents with access to mental health services needed for their family member, 93% from Pennsylvania and 96% across all NCI states are satisfied with the quality of those providers.

Across NCI states, percentage of "yes" responses ranged between 99% and 93%.

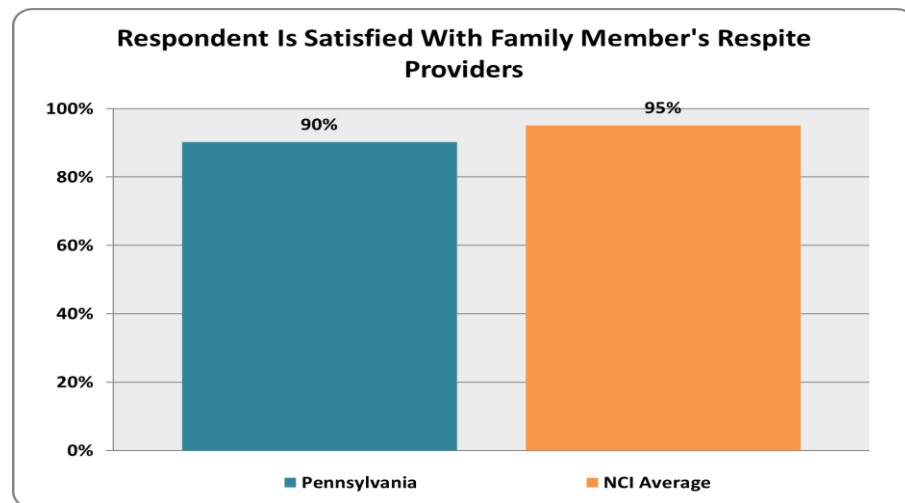
GRAPH 60. IF YOU NEED RESPITE SERVICES, DO YOU HAVE ACCESS TO THEM?



This graph illustrates that 75% of respondents from Pennsylvania and 73% across all NCI states have access to respite services if needed.

Across NCI states, percentage of "yes" responses ranged between 91% and 52%.

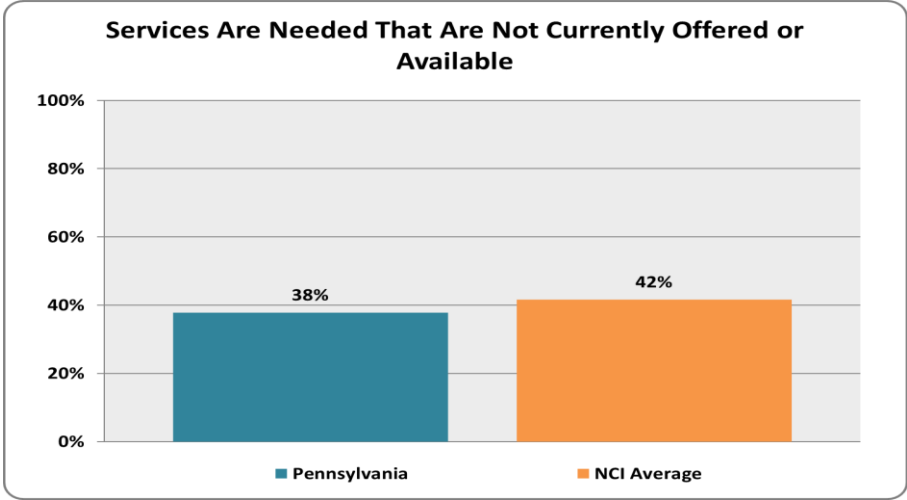
GRAPH 61. IF YOU HAVE ACCESS TO RESPITE SERVICES NEEDED, ARE YOU SATISFIED WITH THE QUALITY OF THOSE PROVIDERS?



This graph illustrates that among respondents with access to respite services for their family member, 90% from Pennsylvania and 95% across all NCI states are satisfied with the quality of those providers.

Across NCI states, percentage of "yes" responses ranged between 99% and 90%.

GRAPH 62. ARE THERE SERVICES YOUR FAMILY MEMBER NEEDS THAT ARE NOT CURRENTLY OFFERED OR AVAILABLE?



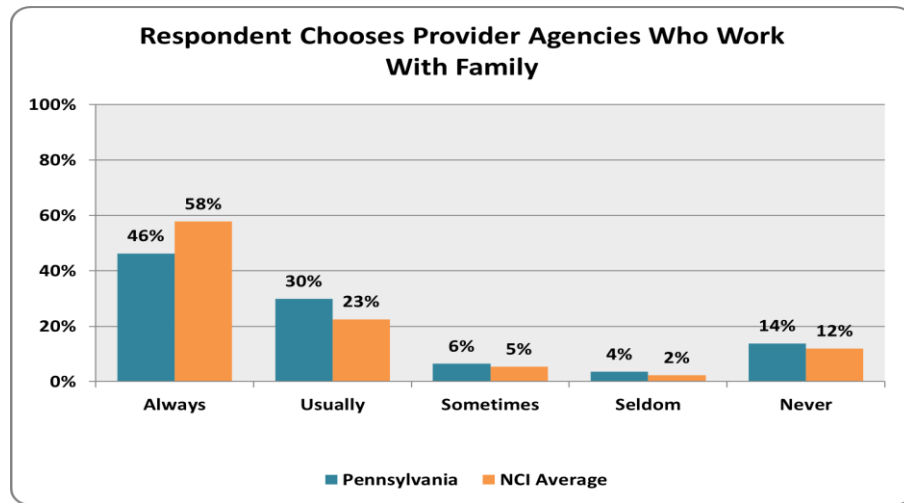
This graph illustrates that 38% of respondents from Pennsylvania and 42% across all NCI states say there are services needed that are not currently offered or available.

Across NCI states, percentage of "yes" responses ranged between 57% and 15%.

Choice and Control

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

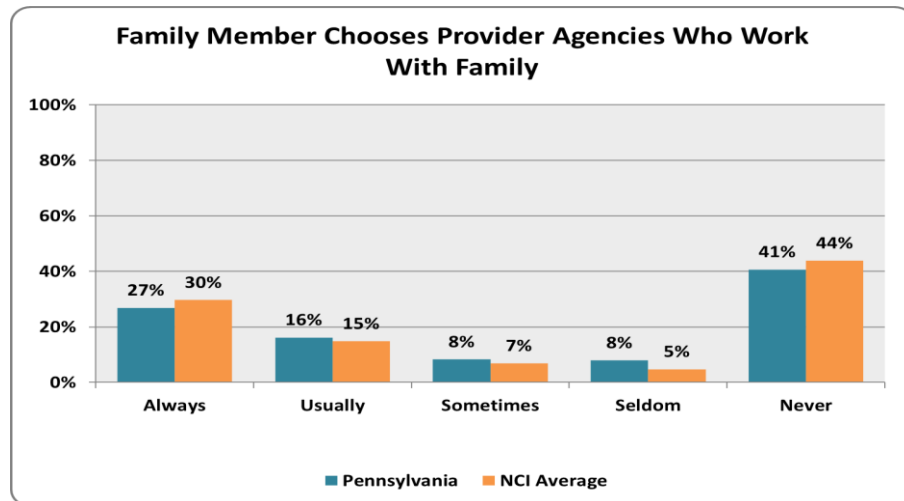
GRAPH 63. DO YOU CHOOSE THE PROVIDER AGENCIES WHO WORK WITH YOUR FAMILY?



This graph illustrates that respondents from Pennsylvania and across all NCI states choose the provider agencies that work with their family: always 46% and 58%, usually 30% and 23%, sometimes 6% and 5%, seldom 4% and 2%, and never 14% and 12%.

Across NCI states, percentage of "always" responses ranged between 72% and 46%.

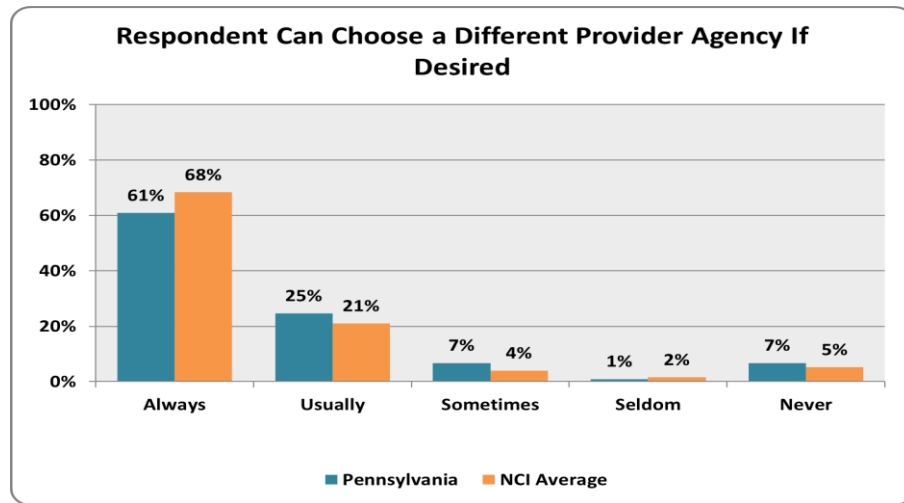
GRAPH 64. DOES YOUR FAMILY MEMBER CHOOSE THE PROVIDER AGENCIES WHO WORK WITH YOUR FAMILY?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their family member chooses the provider agencies that work with their family: always 27% and 30%, usually 16% and 15%, sometimes 8% and 7%, seldom 8% and 5%, and never 41% and 44%.

Across NCI states, percentage of "always" responses ranged between 40% and 22%.

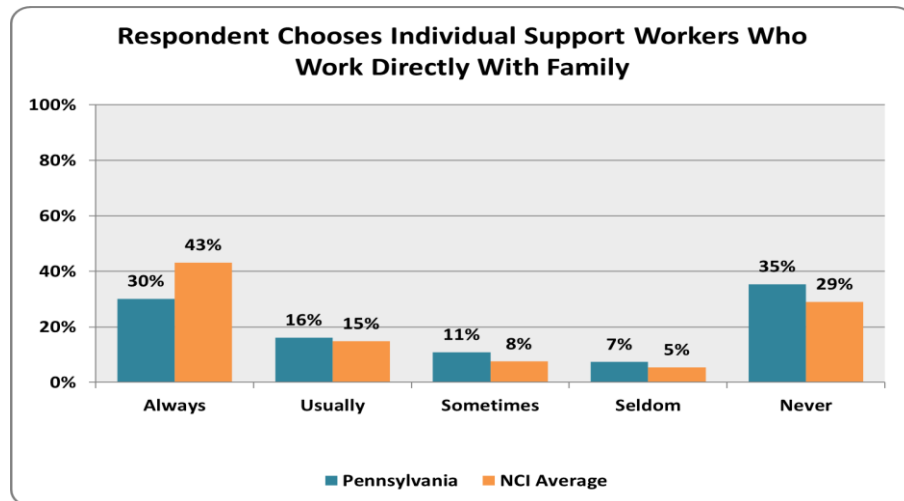
GRAPH 65. CAN YOU CHOOSE A DIFFERENT PROVIDER AGENCY IF YOU WANT TO?



This graph illustrates that respondents from Pennsylvania and across all NCI states can choose a different provider agency if they want: always 61% and 68%, usually 25% and 21%, sometimes 7% and 4%, seldom 1% and 2%, and never 7% and 5%.

Across NCI states, percentage of "always" responses ranged between 80% and 58%.

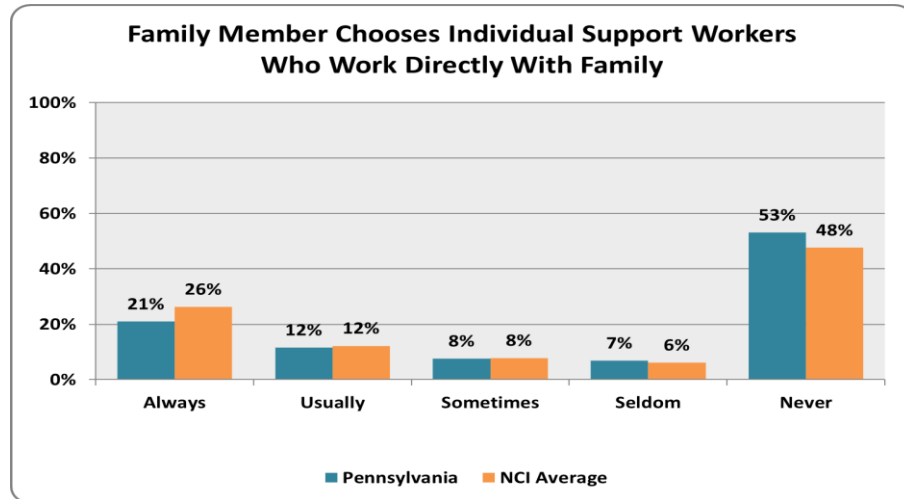
GRAPH 66. DO YOU CHOOSE THE INDIVIDUAL SUPPORT WORKERS WHO WORK DIRECTLY WITH YOUR FAMILY?



This graph illustrates that respondents from Pennsylvania and across all NCI states choose the individual support workers who work with their family: always 30% and 43%, usually 16% and 15%, sometimes 11% and 8%, seldom 7% and 5%, and never 35% and 29%.

Across NCI states, percentage of "always" responses ranged between 61% and 15%.

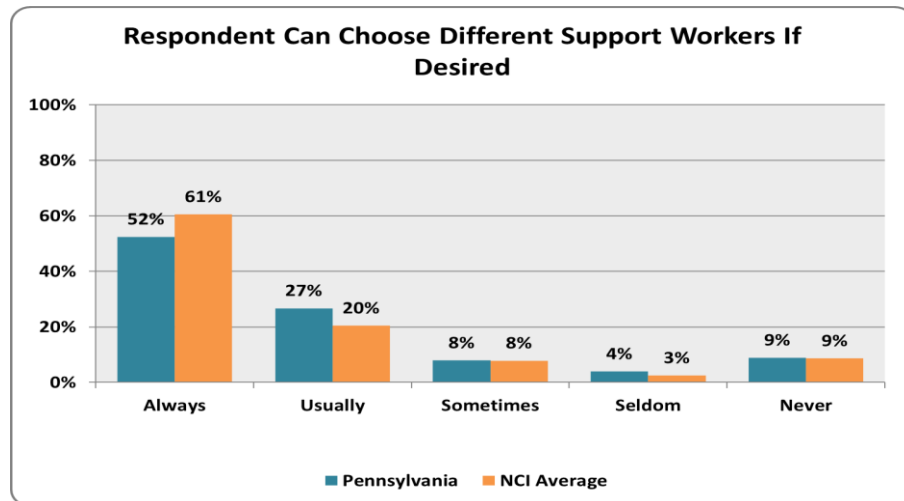
GRAPH 67. DOES YOUR FAMILY MEMBER CHOOSE THE INDIVIDUAL SUPPORT WORKERS WHO WORK DIRECTLY WITH YOUR FAMILY?



This graph illustrates that respondents from Pennsylvania and across all NCI states say their family member chooses the individual support workers who work with their family: always 21% and 26%, usually 12% and 12%, sometimes 8% and 8%, seldom 7% and 6%, and never 53% and 48%.

Across NCI states, percentage of "always" responses ranged between 41% and 11%.

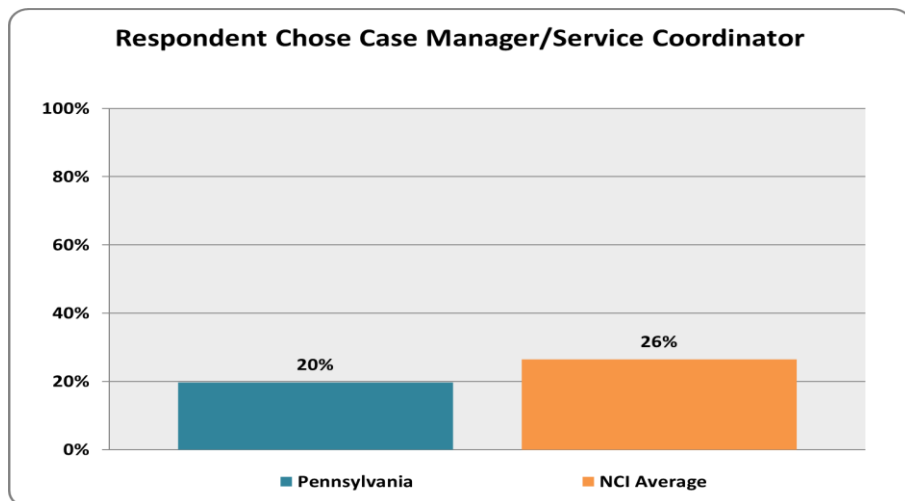
GRAPH 68. CAN YOU CHOOSE DIFFERENT SUPPORT WORKERS IF YOU WANT TO?



This graph illustrates that respondents from Pennsylvania and across all NCI states can choose different support workers if they want: always 52% and 61%, usually 27% and 20%, sometimes 8% and 8%, seldom 4% and 3%, and never 9% and 9%.

Across NCI states, percentage of "always" responses ranged between 72% and 41%.

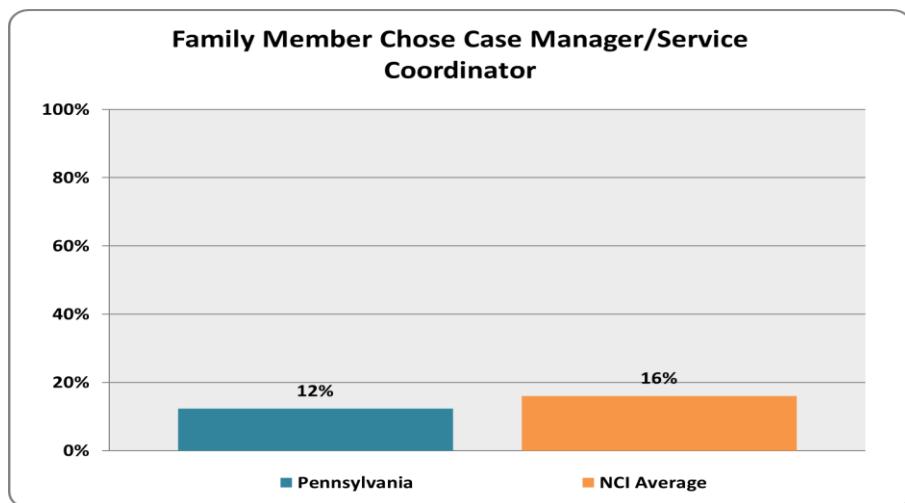
GRAPH 69. DID YOU CHOOSE YOUR FAMILY MEMBER'S CASE MANAGER/SERVICE COORDINATOR?



This graph illustrates that 20% of respondents from Pennsylvania and 26% across all NCI states chose their family member's case manager/service coordinator.

Across NCI states, percentage of "yes" responses ranged between 67% and 10%.

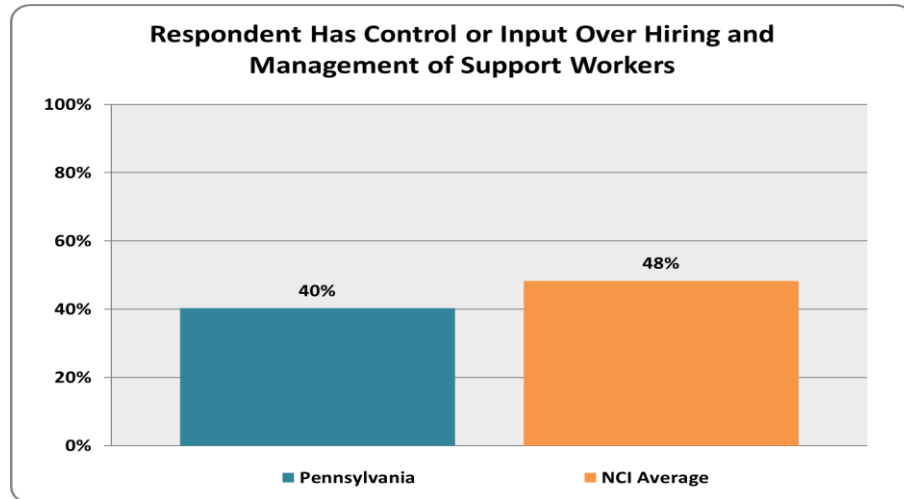
GRAPH 70. DID YOUR FAMILY MEMBER CHOOSE HIS/HER CASE MANAGER/SERVICE COORDINATOR?



This graph illustrates that 12% of respondents from Pennsylvania and 16% across all NCI states say their family member chose his or her own case manager/service coordinator.

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

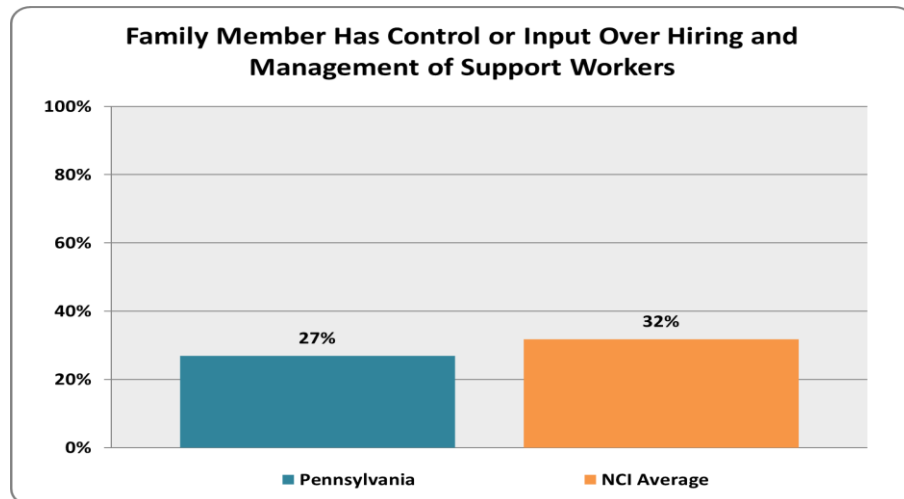
GRAPH 71. DO YOU HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF YOUR FAMILY MEMBER'S SUPPORT WORKERS?



This graph illustrates that 40% of respondents from Pennsylvania and 48% across all NCI states have control and input over the hiring and management of support workers.

Across NCI states, percentage of "yes" responses ranged between 77% and 25%.

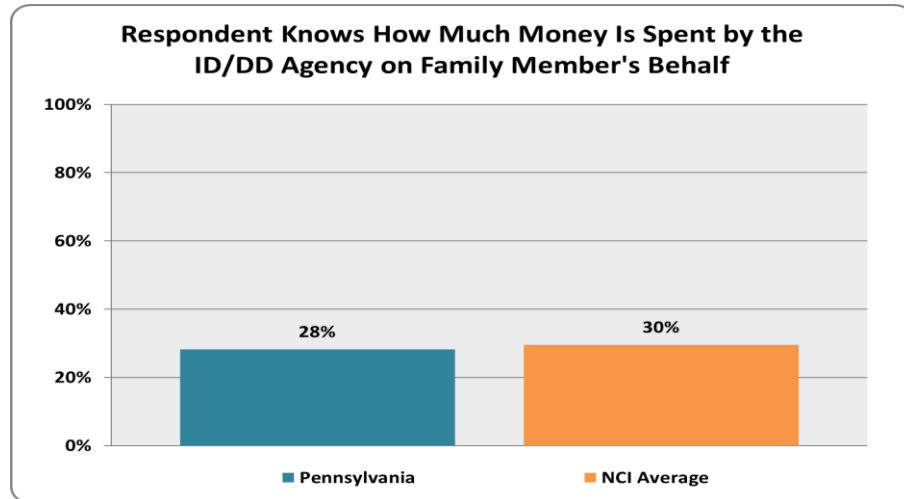
GRAPH 72. DOES YOUR FAMILY MEMBER HAVE CONTROL AND/OR INPUT OVER THE HIRING AND MANAGEMENT OF HIS/HER SUPPORT WORKERS?



This graph illustrates that 27% of respondents from Pennsylvania and 32% 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 54% and 17%.

GRAPH 73. DO YOU KNOW HOW MUCH MONEY IS SPENT BY THE ID/DD AGENCY ON BEHALF OF YOUR FAMILY MEMBER WITH A DEVELOPMENTAL DISABILITY?*

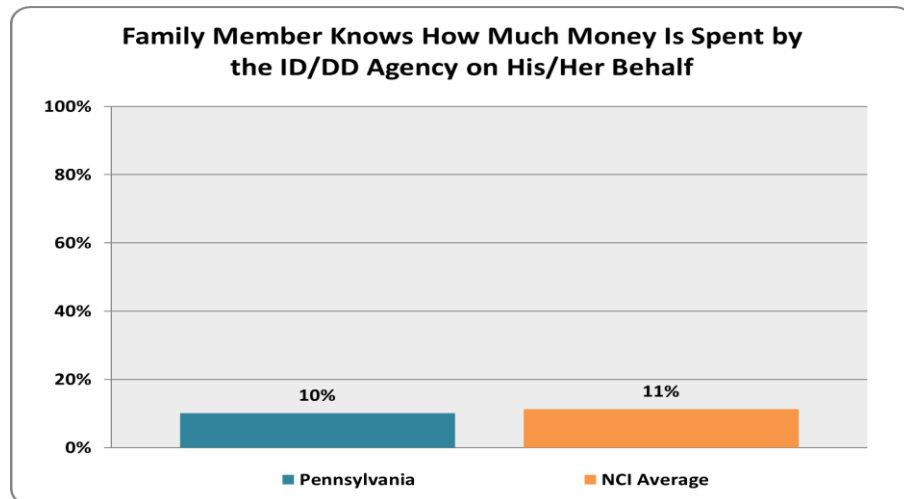


This graph illustrates that 28% of respondents from Pennsylvania and 30% across all NCI states know how much money is spent by the ID/DD agency on their family member's behalf.

Across NCI states, percentage of "yes" responses ranged between 62% and 15%.

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

GRAPH 74. DOES YOUR FAMILY MEMBER KNOW HOW MUCH MONEY IS SPENT BY THE ID/DD AGENCY ON HIS/HER BEHALF?*

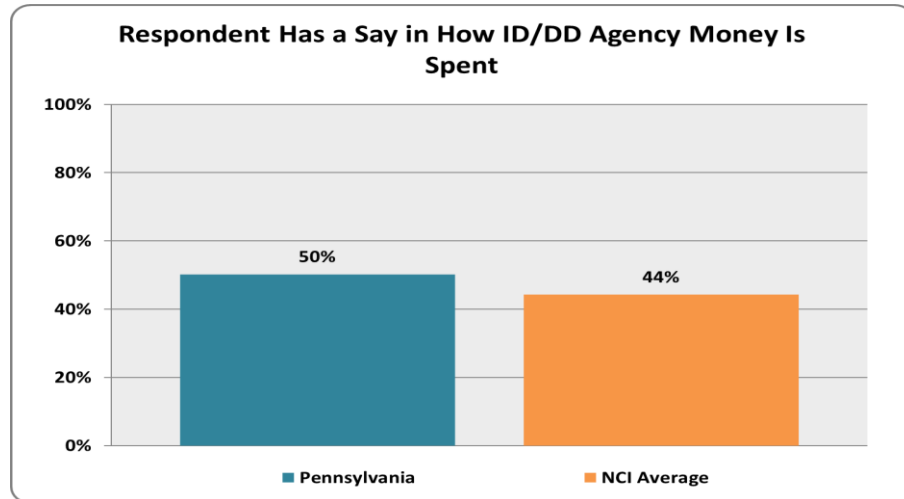


This graph illustrates that 10% of respondents from Pennsylvania and 11% across all NCI states say their family member knows how much money is spent by the ID/DD agency on his/her behalf.

Across NCI states, percentage of "yes" responses ranged between 30% and 4%.

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

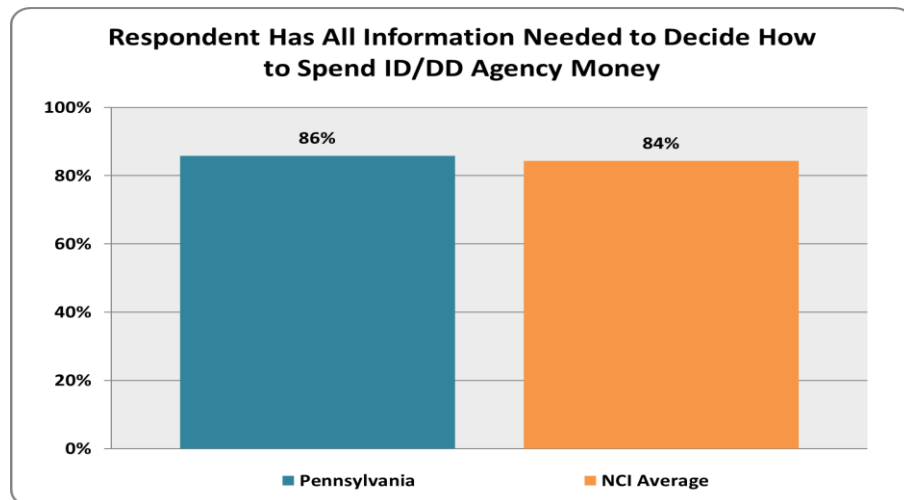
GRAPH 75. DO YOU HAVE A SAY IN HOW ID/DD AGENCY MONEY IS SPENT ON YOUR FAMILY MEMBER'S BEHALF?



This graph illustrates that 50% of respondents from Pennsylvania and 44% across all NCI states have a say in how ID/DD agency money is spent on behalf of their family member.

Across NCI states, percentage of "yes" responses ranged between 75% and 22%.

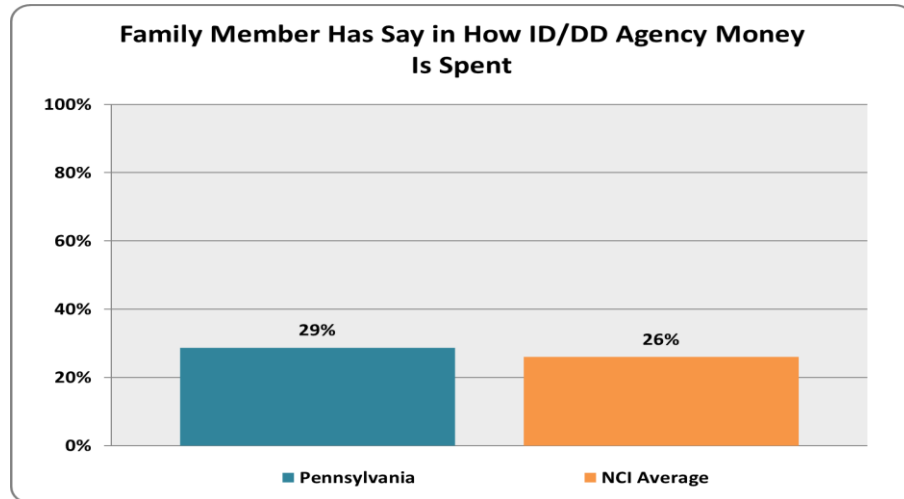
GRAPH 76. IF YOU HAVE A SAY IN HOW ID/DD AGENCY MONEY IS SPENT, DO YOU HAVE ALL THE INFORMATION YOU NEED TO MAKE DECISIONS ABOUT HOW TO SPEND THIS MONEY?



This graph illustrates that among respondents with a say in how ID/DD agency money is spent on behalf of their family member, 86% from Pennsylvania and 84% across all NCI states have all the information needed to make those determinations.

Across NCI states, percentage of "yes" responses ranged between 93% and 72%.

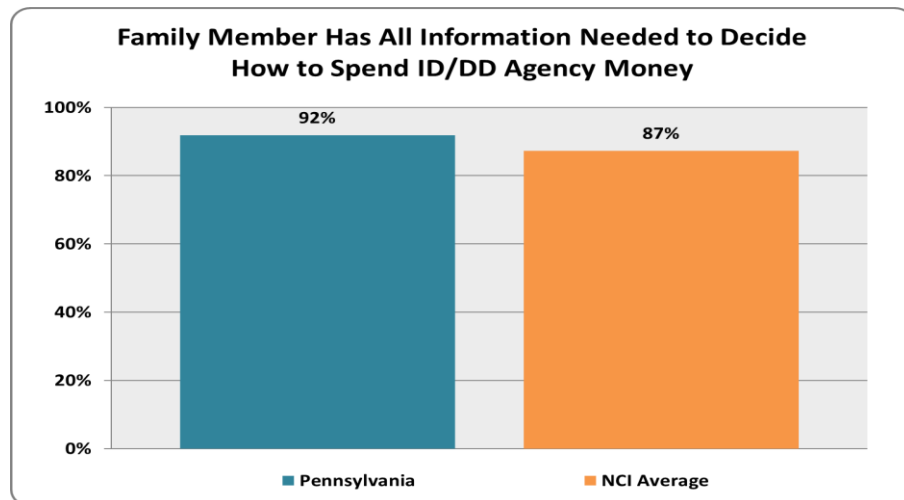
GRAPH 77. DOES YOUR FAMILY MEMBER HAVE A SAY IN HOW ID/DD AGENCY MONEY IS SPENT ON HIS/HER BEHALF?



This graph illustrates that 29% of respondents from Pennsylvania and 26% 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 15%.

GRAPH 78. IF YOUR FAMILY MEMBER HAS A SAY IN HOW ID/DD AGENCY MONEY IS SPENT, DOES YOUR FAMILY MEMBER HAVE ALL THE INFORMATION S/HE NEEDS TO MAKE DECISIONS ABOUT HOW TO SPEND THIS MONEY?



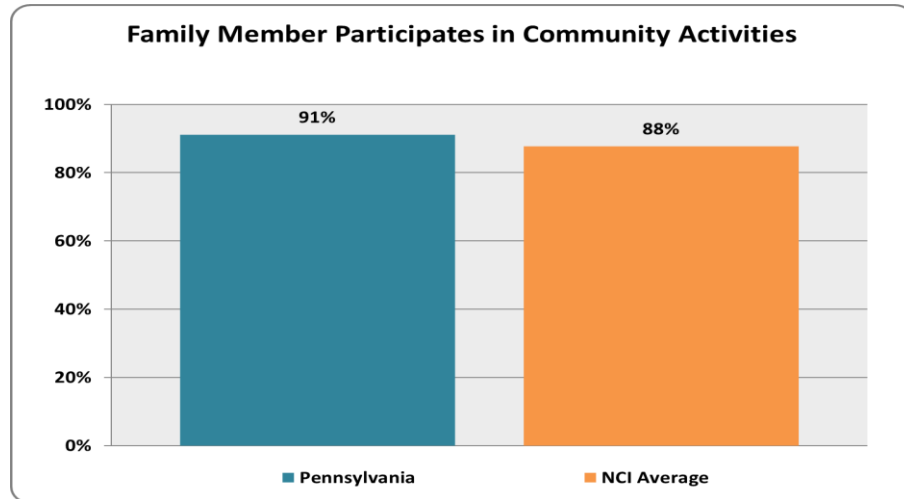
This graph illustrates that among respondents whose family member has a say in how ID/DD agency money is spent, 92% from Pennsylvania and 87% across all NCI states say their family member has all the information needed to make those determinations.

Across NCI states, percentage of "yes" responses ranged between 96% and 74%.

Community Connections

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

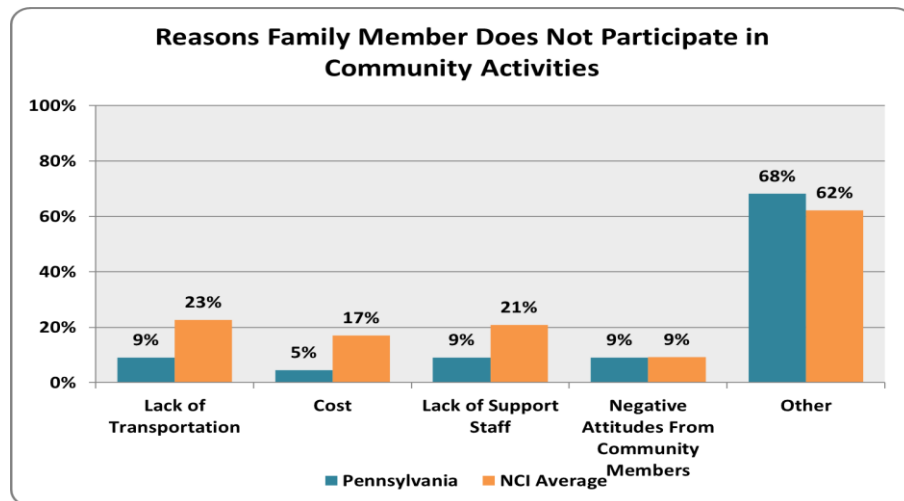
GRAPH 79. DOES YOUR FAMILY MEMBER PARTICIPATE IN COMMUNITY ACTIVITIES (SUCH AS GOING OUT TO A RESTAURANT, MOVIE, OR SPORTING EVENT)?



This graph illustrates that 91% of respondents from Pennsylvania and 88% across all NCI states say their family member participates in community activities.

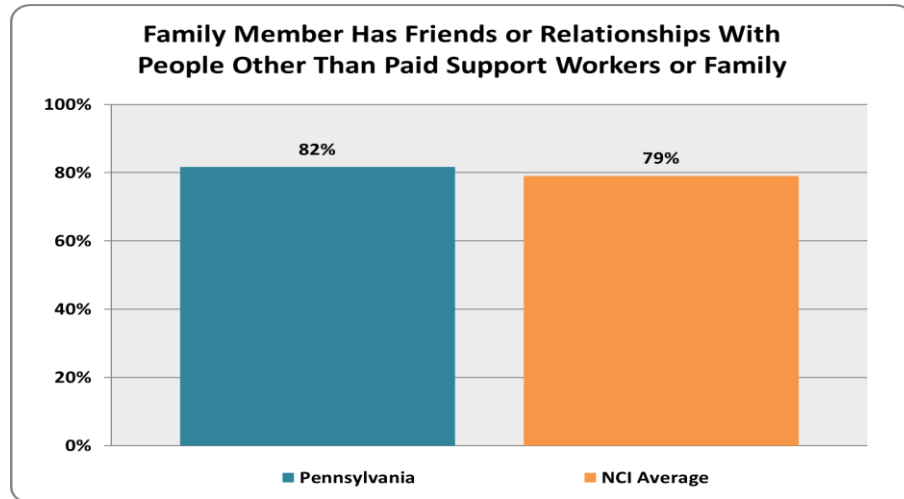
Across NCI states, percentage of "yes" responses ranged between 95% and 78%.

GRAPH 80. 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: 9% and 23% lack of transportation, 5% and 17% cost, 9% and 21% lack of support staff, 9% and 9% negative attitudes from community members, 68% and 62% other.

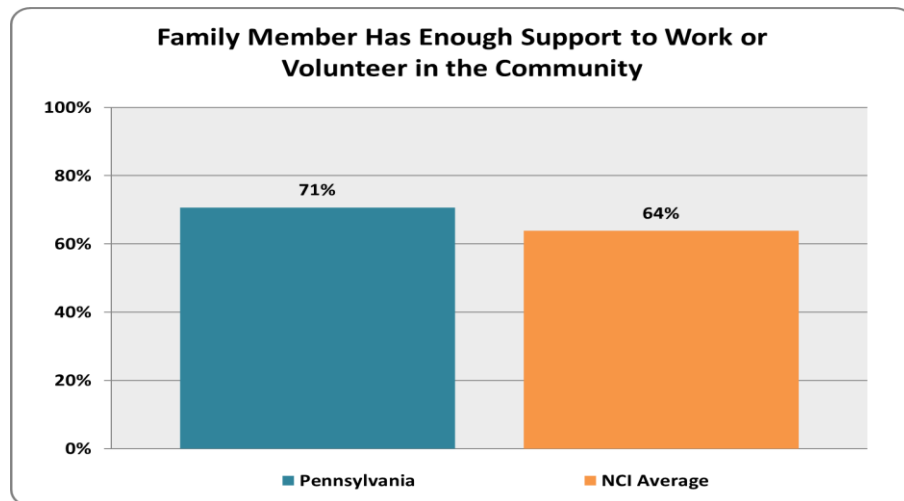
GRAPH 81. DOES YOUR FAMILY MEMBER HAVE FRIENDS OR RELATIONSHIPS WITH PERSONS OTHER THAN PAID SUPPORT WORKERS OR FAMILY?



This graph illustrates that 82% of respondents from Pennsylvania and 79% across all NCI states say their family member has relationships with people other than family or paid staff.

Across NCI states, percentage of "yes" responses ranged between 86% and 73%.

GRAPH 82. DOES YOUR FAMILY MEMBER HAVE ENOUGH SUPPORTS (E.G., SUPPORT WORKERS, COMMUNITY RESOURCES) TO WORK OR VOLUNTEER IN THE COMMUNITY?



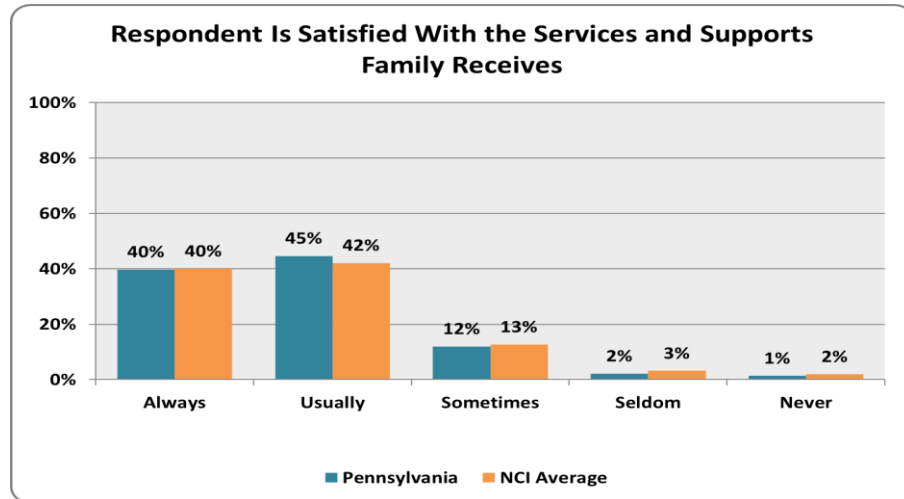
This graph illustrates that 71% of respondents from Pennsylvania and 64% across all NCI states say their family member has enough supports (e.g., support workers or community resources) to work or volunteer in the community.

Across NCI states, percentage of "yes" responses ranged between 72% and 51%.

Satisfaction

FAMILIES AND FAMILY MEMBERS WITH DISABILITIES RECEIVE ADEQUATE AND SATISFACTORY SUPPORTS

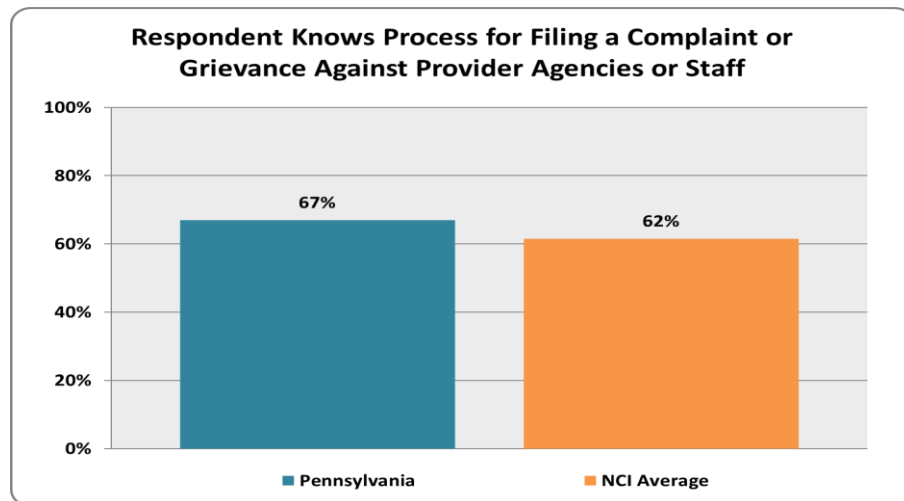
GRAPH 83. OVERALL, ARE YOU SATISFIED WITH THE SERVICES AND SUPPORTS YOUR FAMILY CURRENTLY RECEIVES?



This graph illustrates that respondents from Pennsylvania and across all NCI states are satisfied with the services and supports their family receives: always 40% and 40%, usually 45% and 42%, sometimes 12% and 13%, seldom 2% and 3%, and never 1% and 2%.

Across NCI states, percentage of "always" responses ranged between 58% and 30%.

GRAPH 84. DO YOU KNOW THE PROCESS FOR FILING A COMPLAINT OR GRIEVANCE AGAINST PROVIDER AGENCIES OR STAFF?*

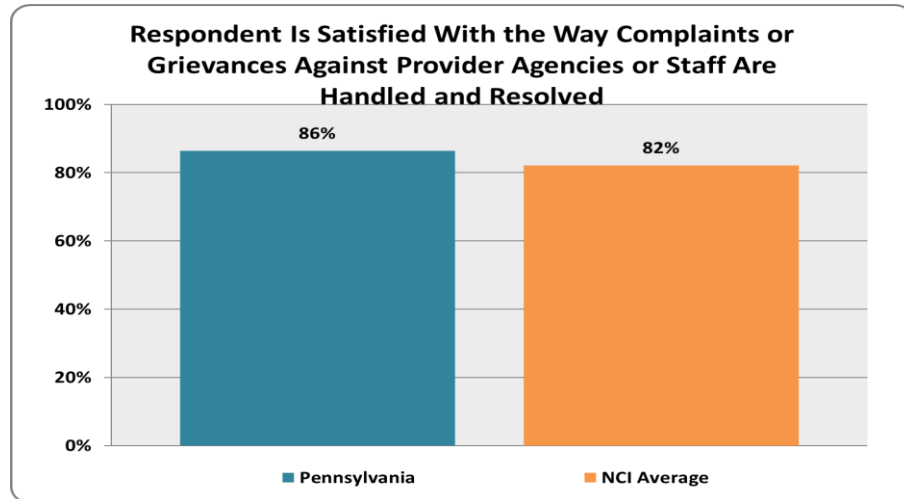


This graph illustrates that 67% of respondents from Pennsylvania and 62% across all NCI states know the process for filing a complaint or grievance against provider agencies or staff.

Across NCI states, percentage of "yes" responses ranged between 84% and 34%.

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

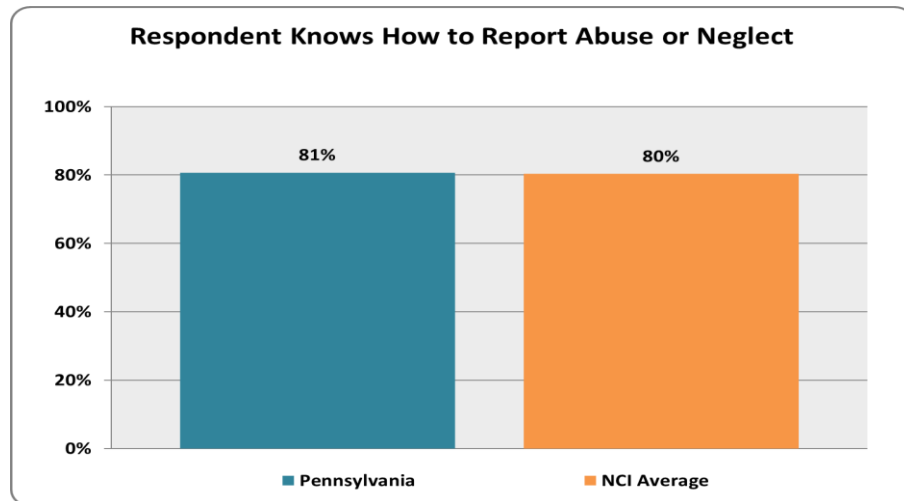
GRAPH 85. ARE YOU SATISFIED WITH THE WAY COMPLAINTS OR GRIEVANCES AGAINST PROVIDER AGENCIES OR STAFF ARE HANDLED AND RESOLVED?



This graph illustrates that 86% of respondents from Pennsylvania and 82% 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 90% and 65%.

GRAPH 86. DO YOU KNOW HOW TO REPORT ABUSE OR NEGLECT?*

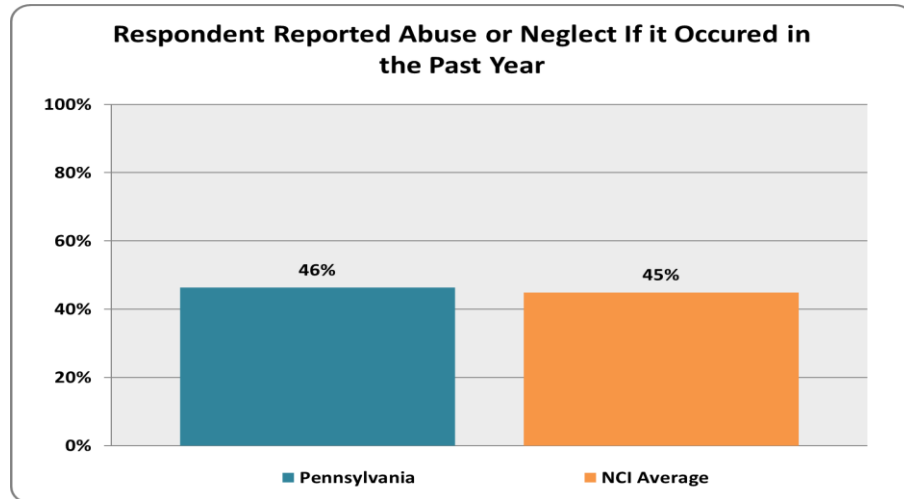


This graph illustrates that 81% of respondents from Pennsylvania and 80% across all NCI states know how to report abuse or neglect.

Across NCI states, percentage of "yes" responses ranged between 93% and 59%.

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

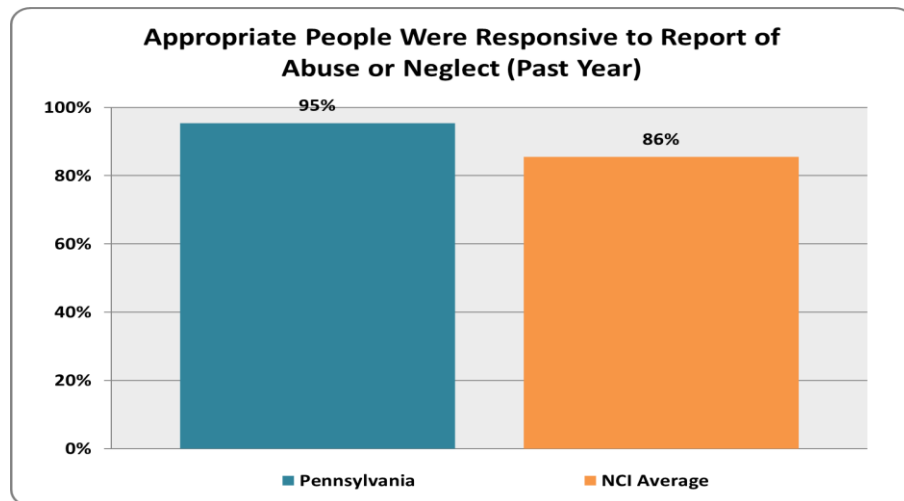
GRAPH 87. WITHIN THE PAST YEAR, IF ABUSE OR NEGLECT OCCURRED, DID YOU REPORT IT?



This graph illustrates that 46% of respondents from Pennsylvania and 45% across all NCI states reported abuse or neglect if it occurred in the past year.

Across NCI states, percentage of "yes" responses ranged between 76% and 29%.

GRAPH 88. IF YOU REPORTED ABUSE OR NEGLECT IN THE PAST YEAR, WERE THE APPROPRIATE PEOPLE RESPONSIVE TO YOUR REPORT?



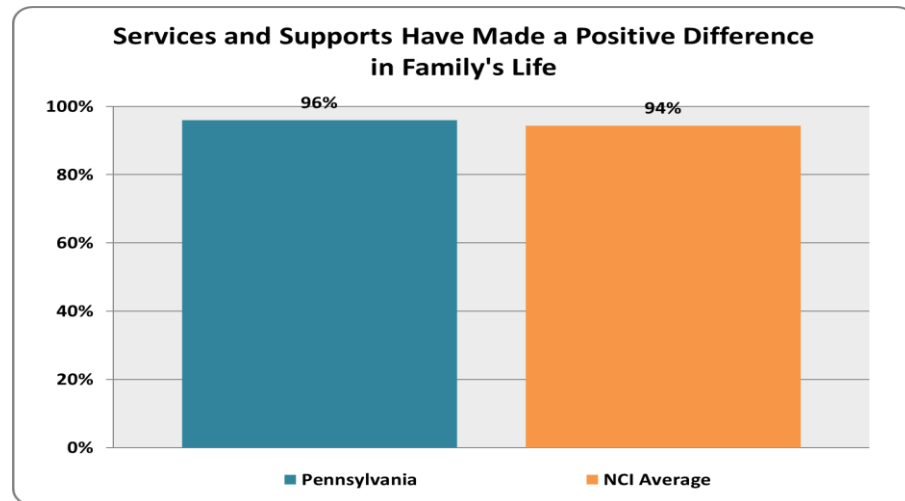
This graph illustrates that among respondents who reported abuse or neglect in the past year, 95% from Pennsylvania and 86% across all NCI states say that appropriate parties were responsive to their report.

Across NCI states, percentage of "yes" responses ranged between 95% and 68%.

Family Outcomes

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

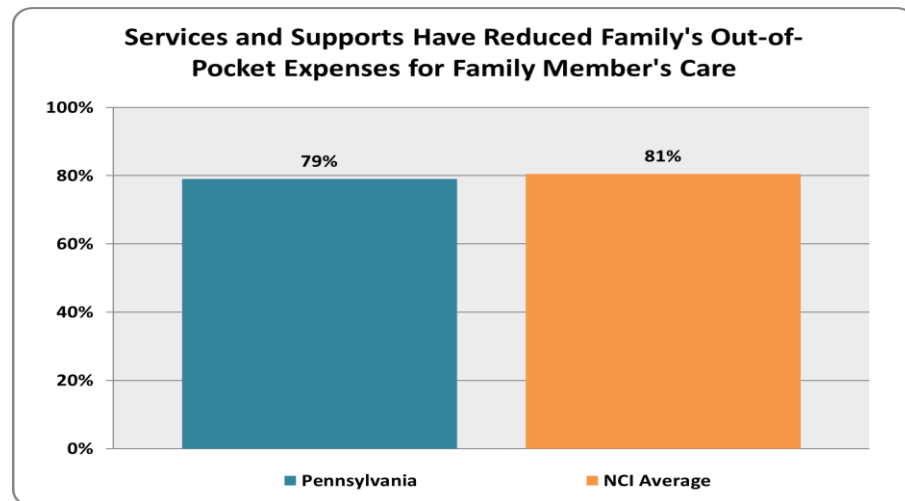
GRAPH 89. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE MADE A POSITIVE DIFFERENCE IN THE LIFE OF YOUR FAMILY?



This graph illustrates that 96% of respondents from Pennsylvania and 94% across all NCI states say that services and supports have made a positive difference in the life of their family.

Across NCI states, percentage of "yes" responses ranged between 99% and 91%.

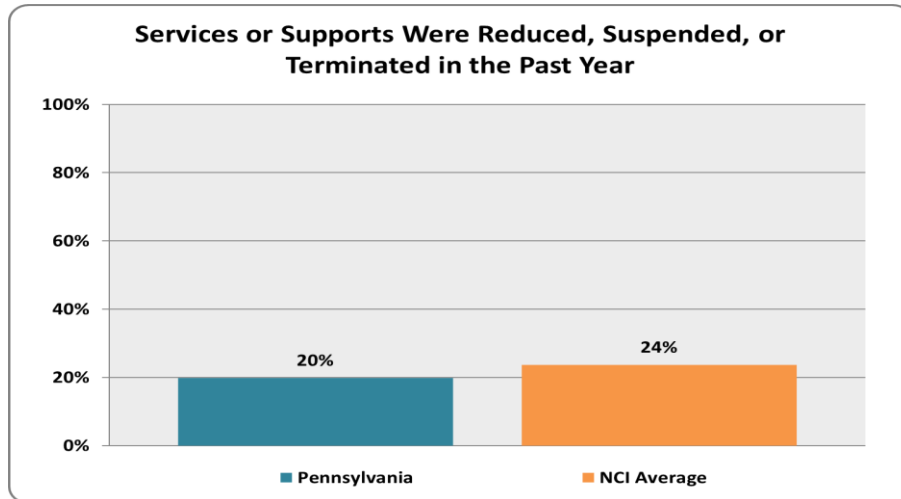
GRAPH 90. DO YOU FEEL THAT SERVICES AND SUPPORTS HAVE REDUCED YOUR FAMILY'S OUT-OF-POCKET EXPENSES FOR YOUR FAMILY MEMBER'S CARE?



This graph illustrates that 79% of respondents from Pennsylvania and 81% across all NCI states say that 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 70%.

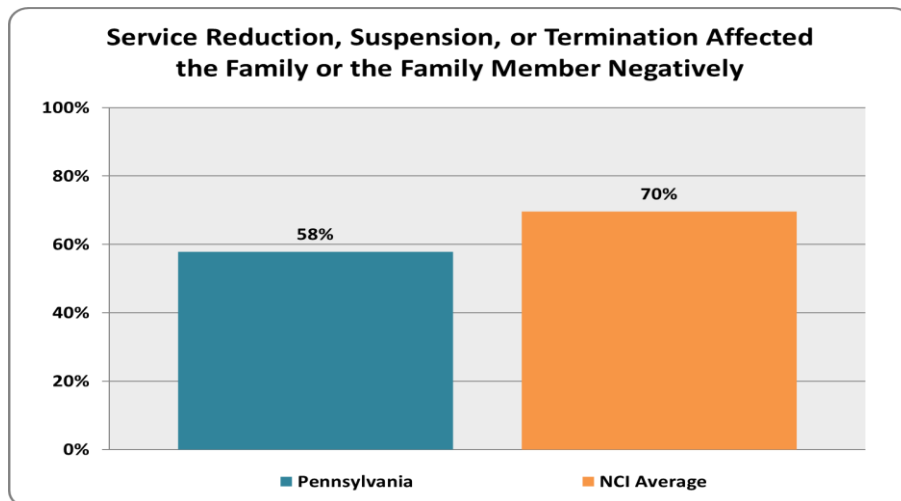
GRAPH 91. HAVE THE SERVICES OR SUPPORTS THAT YOU OR YOUR FAMILY MEMBER RECEIVED BEEN REDUCED, SUSPENDED, OR TERMINATED IN THE PAST YEAR?



This graph illustrates that 20% of respondents from Pennsylvania and 24% across all NCI states say that services and supports were reduced, suspended, or terminated in the past year.

Across NCI states, percentage of "yes" responses ranged between 58% and 10%.

GRAPH 92. IF SERVICES OR SUPPORTS RECEIVED BY THE FAMILY WERE REDUCED, SUSPENDED OR TERMINATED DURING THE PAST YEAR, DID THIS CHANGE AFFECT YOUR FAMILY OR YOUR FAMILY MEMBER NEGATIVELY?



This graph illustrates that among respondents whose services were reduced, suspended, or terminated in the past year 58% from Pennsylvania and 70% across all NCI states say the change affected their family or family member negatively.

Across NCI states, percentage of "yes" responses ranged between 87% and 53%.