



2017-18 ADULT FAMILY SURVEY

DELAWARE REPORT



Contents

What is NCI?	1
What is the NCI Adult Family Survey?	1
Table A1. NCI Family Survey – Sub-Domains and Concern Statements	2
How were people selected to participate?	3
Data Analysis	4
Weighting	4
Significance testing	5
Limitations of the data	5
What is contained in this report?	6
<i>Family Member</i>	<i>7</i>
Table 1. More than one person living at home has IDD	8
Table 2. Family member’s age	8
Table 3. Family member’s gender	8
Table 4. Family member’s race and ethnicity (categories are not mutually exclusive)	8
Table 5. Family member’s disabilities (categories are not mutually exclusive)	9
Table 6. Family member’s disabilities (continued, categories are not mutually exclusive)	9
Table 7. Family member’s health conditions (categories are not mutually exclusive)	9
Table 8. Family member’s health conditions (continued, categories are not mutually exclusive)	9
Table 9. Family member’s preferred means of communication	10
Table 10. Family member’s level of guardianship.....	10
Table 11. Guardian or conservator relationship to family member.....	10
Table 12. Family member’s highest level of education	11
Table 13. Family member’s typical day activity	11
Table 14. Family member’s support needs	12
<i>Respondents</i>	<i>13</i>
Table 15. Respondent’s age	14
Table 16. Respondent’s health	14
Table 17. Respondent’s relationship to family member.....	14
Table 18. Respondent (or other family member) provides paid support	15
Table 19. Number of adults in household	15
Table 20. Number of children in household.....	15
Table 21. Respondent’s highest level of education	16
Table 22. Past year total household taxable income of wage earners.....	16

Table 23. Family's residential setting	16
<i>Services and Supports Received</i>	17
Table 24. Services and supports received from state (categories are not mutually exclusive).....	18
Table 25. Additional services and supports received (not from IDD agency; categories are not mutually exclusive)	18
<i>Information and Planning</i>	19
Chart 1. Do you get enough information to take part in planning services for your family member?	21
Chart 2. Is the information you get about services and supports easy to understand?	21
Chart 3. Does the case manager/service coordinator respect your family's choices and opinions?.....	21
Chart 4. Do you have enough information about other public services for which your family is eligible?	21
Chart 5. Respondent's future planning needs	22
Chart 6. If you asked for crisis or emergency services during the past year, were services provided when needed?.....	22
Chart 7. Does your family member have a service plan?.....	22
Chart 8. Does it include all the services and supports your family member needs?.....	22
Chart 9. Does your family member get all the services listed in the plan?.....	23
Chart 10. Did you or another family member (besides your family member with a disability) help make the plan?	23
Chart 11. Did your family member help make the plan?.....	23
Chart 12. Did you discuss how to handle emergencies at your family member's last service planning meeting?	23
Chart 13. If your family member transitioned out of school services during the past year, did s/he have a transition plan?	24
Chart 14. If your family member had a transition plan, did the plan include getting or continuing work in a community job?.....	24
Chart 15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?	24
Chart 16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?.....	24
Table 26. Information and Planning.....	26
Table 27. Respondent's Future Planning Needs.....	27
Table 28. Information and Planning (continued)	28
<i>Access and Delivery of Services and Supports</i>	29
Chart 17. Are you or your family member able to contact his/her support workers when you want to?.....	31
Chart 18. Are you or your family member able to contact his/her case manager/service coordinator when you want to?	31
Chart 19. Do support workers come and leave when they are supposed to?	31
Chart 20. Do services and supports change when your family's needs change?	31
Chart 21. Do support workers speak to you in a way that you understand?	32
Chart 22. Are services delivered in a way that is respectful of your family's culture?	32
Chart 23. If your family member does not communicate verbally, are there support workers who can communicate with him/her?.....	32
Chart 24. Do support workers have the right information and skills to meet your family's needs?	32
Chart 25. Does your family member have the special equipment or accommodations that s/he needs?	33
Chart 26. Can your family member see health professionals when needed?.....	33
Chart 27. Does your family member's primary care doctor understand his/her needs related to his/her disability?	33

Chart 28. Do you have access to dental services for your family member?	33
Chart 29. If you have access to dental services for your family member, does your family member's dentist understand his/her needs related to his/her disability?	34
Chart 30. If your family member takes medications, do you know what they're for?	34
Chart 31. If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications?	34
Chart 32. If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?	34
Chart 33. If you need respite services, do you have access to them?	35
Chart 34. If you have access to respite services, are you satisfied with the quality of the respite services?	35
Chart 35. Does your family get the supports and services needed?	35
Chart 36. Additional services or supports needed (categories are not mutually exclusive)	35
Table 29. Access and Delivery of Services and Supports	37
Table 30. Access and Delivery of Services and Supports (continued)	38
Table 31. Access and Delivery of Services and Supports (continued)	39
Table 32. Additional Services Needed (categories are not mutually exclusive)	39
<i>Choice, Decision Making and Control</i>	<i>40</i>
Chart 37. Can your family choose or change the agency that provides your family member's services?	42
Chart 38. Can your family choose or change your family member's support workers?	42
Chart 39. Does your family directly manage support workers?	42
Chart 40. Do service providers for your family member work together to provide support?	42
Chart 41. Did you or your family member choose the case manager/service coordinator?	43
Table 33. Choice and Control	45
Table 34. Choice and Control (continued)	45
Table 35. Chose Case Manager/Service Coordinator	46
<i>Involvement in the Community</i>	<i>47</i>
Chart 42. Does your family member take part in activities in the community?	49
Chart 43. Obstacles/Barriers to family member's participation in community activities (categories are not mutually exclusive)	49
Chart 44. Does your family member have friends other than paid support workers or family?	49
Chart 45. In your community, are there resources that your family can use that are not provided by the IDD agency?	49
Chart 46. Does your family take part in any family-to-family networks in your community?	50
Table 36. Involvement in the Community	52
Table 37. Obstacles to Family Member's Participation in Community Activities (categories are not mutually exclusive)	52
Table 38. Involvement in the Community (continued)	53
<i>Satisfaction With Services and Supports</i>	<i>54</i>
Chart 47. Overall, are you satisfied with the services and supports your family currently receives?	56
Chart 48. Do you know how to file a complaint or grievance about provider agencies or staff?	56

Chart 49. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?.....	56
Chart 50. Do you know how to report abuse or neglect related to your family member?	56
Chart 51. In the past year, was a report of abuse or neglect filed on behalf of your family member?.....	57
Chart 52. Do you feel that services and supports have made a positive difference in the life of your family?	57
Chart 53. Have services and supports reduced your family’s out-of-pocket expenses for your family member’s care?	57
Chart 54. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?	57
Chart 55. If services were reduced in the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?	58
Chart 56. Have the services or supports that your family member received been increased in the past year?	58
Chart 57. Are services and supports helping your family member to live a good life?	58
Table 39. Satisfaction With Service and Support.....	60
Table 40. Satisfaction With Service and Supports (continued)	60
Table 41. Satisfaction With Service and Supports (continued).....	61

What is NCI?

The National Core Indicators (NCI) program is a voluntary effort by state developmental disability agencies to track their performance using a standardized set of consumer and family/guardian surveys with nationally validated measures. The effort is coordinated by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI).

NCI has developed more than 100 standard performance measures (or ‘indicators’) that states use to assess the outcomes of services for individuals and families, including outcomes in the areas of employment, rights, service planning, community inclusion, choice, health, and safety. In 2017-18 a total of 46 states, the District of Columbia and 22 sub-state entities participated in NCI.

What is the NCI Adult Family Survey?

The NCI Adult Family Survey is used to gather data on family outcomes. It is mailed to families who have an adult family member who lives in the family home and receives at least one service other than case management from the state DD agency. The survey collects demographic information on both the individual receiving services and the person who fills out the survey (the ‘respondent’) as well as information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable.

In 2017-18, a total of 5,221 Adult Family Surveys were completed across 12 states.¹ The survey contained six groupings of questions (“sub-domains”) that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes (see Table A1 on the following page). Respondents also had the option of writing open-ended comments concerning their family’s participation in the service system.

¹ States that conducted the Adult Family Survey in 2017-18 were: AZ, DC, DE, FL, GA, MD, MO, NC, NH, OK, PA and WA.

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

Sub-Domain	Concern Statement
Information and Planning	Families/family members with disabilities have the information and support necessary to plan for their services and supports.
Access & Support Delivery	Families/family members with disabilities get the services and supports they need.
Choice, Decision Making & Control	Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.
Involvement in the Community	Family members with disabilities use integrated community services and participate in everyday community activities.
Satisfaction	Families/family members with disabilities receive adequate and satisfactory supports.
Outcomes	Individual and family supports make a positive difference in the lives of families.

How were people selected to participate?

States were asked to administer the survey to a random sample of at least 1,000 families, all of whom have an adult family member with a developmental disability who lives in the family home and receives at least one direct service or support other than service coordination.

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or both. In previous years, states only had the option to mail paper surveys. In 2017-18, a total of four states had at least a portion of surveys completed via direct entry mode.²

All states mailed out a paper survey to families selected in their sample. A sample size of 1,000 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 level and margin of error used are widely accepted standards for reviewing results, regardless of population size. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we included in our national reports those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.

² States that used the direct entry or mail and direct entry options were: DE, FL, NC and WA. For more information on response rates and mode, please see the Methodology section within the national edition of the 2017-18 Adult Family Survey Report.

Data Analysis

Surveys received from the state were considered valid based on the following two criteria:

1. The respondent indicated the individual with an intellectual or developmental disability receiving services lived in the family home.
2. At least a portion of survey questions were answered aside from demographic information.

Questions left blank or marked ‘not applicable’ are not included in analysis. For most questions, ‘don’t know’ responses were excluded from analysis. Two questions in the Satisfaction section combine ‘no’ and ‘don’t know’ responses; those questions are denoted with an asterisk in the table. For all items shown, states receive an ‘n/a’ designation for a survey item if fewer than 20 people responded; however, their data are included in the NCI Average.

Weighting

Prior to 2016-17, the NCI average was calculated as the simple arithmetic mean of all state means (an approach known as “average of averages”). Beginning last year, the approach has been enhanced to take into account the relative numbers of people receiving services through participating states’ systems. The NCI averages contained in this report are “weighted” means. Applying statistical weights allows a state that provides services to a larger number of people (but is represented in the data by a sample of the same size as other states) to have a higher influence on the overall NCI average—that is, the state’s contribution to the NCI average is proportional to its service population. The weights used in calculations for this report were developed using each participating state’s number of survey respondents and its total survey-eligible population.³

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

Significance testing

Statistical significance is shown in this report. The state's percentage was compared to the weighted NCI average (described above), and the differences between the two were tested for both **statistical significance** as well as **effect sizes**. Effect sizes are used in addition to statistical significance because statistical significance of a state's result depends, in part, on the size of the state's sample: the larger the sample, the more likely it is that even a small difference will be found *statistically* significant.

The t-test analyses established whether the state's percentage was:

1. Higher than the NCI average, and the difference was statistically significant (denoted in the report with an up arrow ▲);
2. Within the average range (i.e., not statistically different from the NCI Average); or
3. Lower than the NCI average, and the difference was statistically significant (denoted in the report with a down arrow ▼).

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

Limitations of the data

The NCI Adult Family Survey is a tool for assessing system-wide performance. It is not intended to be used to monitor individuals or providers. The NCI Statewide Average should not be interpreted as defining or providing a benchmark for "acceptable" levels of performance or satisfaction. Instead, it describes average levels of performance or satisfaction across the state; it is up to public managers, policymakers, and other stakeholders to use the data to determine programmatic and policy-related priorities.

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

What is contained in this report?

This report illustrates the 2017-18 NCI Adult Family Survey demographic and outcome results from Delaware (DE) compared to the NCI Average. All results are shown first in charts by sub-domain and then in table form by sub-domain. Arrow symbols (▲ and ▼) are used to indicate areas where the state average was statistically higher or lower than the NCI Average. **Please note: items without the ▲ or ▼ arrow symbols indicate that the state was within the NCI Average range.** For most items, the total number of respondents (N) from the state and across NCI states is displayed in charts and tables. States with fewer than 20 responses to a question received an 'n/a' designation; however, their data are included in the NCI Average. All state and national data results for this survey can be found online at <http://www.nationalcoreindicators.org/resources/reports/>.

Family Member

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

Table 1. More than one person living at home has IDD

		Yes	No	N
More Than One Person Living in the Home Has IDD	DE	19%	81%	187
	NCI	13%	87%	5,034

Table 2. Family member's age

		Average Age	N
Family Member's Age	DE	29.9	190
	NCI	36.1	5,175

Table 3. Family member's gender

		Male	Female	N
Family Member's Gender	DE	65%	35%	189
	NCI	57%	43%	5,119

Table 4. Family member's race and ethnicity (categories are not mutually exclusive)

		American Indian or Alaska Native	Asian	Black or African-American	Hawaiian or Pacific Islander	White	Other or Unknown	Hispanic or Latino
Family Member's Race and Ethnicity	DE	2%	5%	20%	0%	74%	4%	3%
	NCI	2%	4%	13%	0%	77%	9%	1%

Table 5. Family member's disabilities (categories are not mutually exclusive)

		Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss	Brain Injury
Family Member's Disabilities	DE	63%	22%	42%	6%	5%	3%	5%
	NCI	71%	23%	29%	22%	11%	7%	10%

Table 6. Family member's disabilities (continued, categories are not mutually exclusive)

		Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
Family Member's Disabilities	DE	17%	0%	20%	1%	1%	20%
	NCI	31%	1%	18%	1%	1%	19%

Table 7. Family member's health conditions (categories are not mutually exclusive)

		Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
Family Member's Health Conditions	DE	12%	12%	7%	14%	27%
	NCI	13%	19%	5%	29%	29%

Table 8. Family member's health conditions (continued, categories are not mutually exclusive)

		Dysphagia	Pressure Ulcers	Alzheimer's Disease or Other Dementia	Oral Health or Dental Problems	Sleep Apnea	Other
Family Member's Health Conditions	DE	2%	0%	4%	5%	20%	37%
	NCI	10%	2%	3%	13%	19%	26%

Table 9. Family member's preferred means of communication

		Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
Family Member's Preferred Means of Communication	DE	90%	4%	1%	2%	3%	189
	NCI	74%	16%	2%	2%	6%	5129

Table 10. Family member's level of guardianship

		None	Limited	Full	Has Guardianship but Level Is Unknown	Don't know	N
Level of Guardianship or Conservatorship of Family Member	DE	54%	7%	31%	3%	5%	189
	NCI	32%	11%	49%	3%	5%	5,059

Table 11. Guardian or conservator relationship to family member

		Family	Friend	State Employee or Guardianship Agency	Other	N
Guardian or Conservator Relationship to Family Member	DE	100%	0%	0%	0%	78
	NCI	96%	0%	0%	4%	3,032

Table 12. Family member's highest level of education

		Did Not Complete High School (and Not Currently Enrolled)	Currently Enrolled in High School	High School Certification	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
Family Member's Highest Level of Education	DE	13%	7%	44%	25%	4%	5%	2%	187
	NCI	16%	5%	35%	34%	4%	4%	3%	4,981

Table 13. Family member's typical day activity

		Usually/Often	Sometimes	Never	N
Paid Individual Job in the Community	DE	30%	5%	65%	175
	NCI	16%	3%	80%	4,868
Paid Small Group Job in a Community-based Setting	DE	11%	3%	86%	166
	NCI	9%	2%	89%	4,824
Unpaid Activity in the Community	DE	26%	17%	57%	171
	NCI	22%	13%	65%	4,904
Paid Work in a Community Business That Primarily Hires People With Disabilities	DE	9%	3%	88%	168
	NCI	6%	2%	92%	4,865
Paid Work in a Facility-based Setting	DE	9%	4%	88%	164
	NCI	17%	2%	81%	4,884
Unpaid Activity in a Facility-based Setting	DE	24%	5%	71%	170
	NCI	27%	5%	69%	4,870
School	DE	20%	2%	78%	171
	NCI	11%	2%	88%	4,800
Stays at Home	DE	42%	21%	36%	165
	NCI	51%	20%	28%	4,607
Other	DE	38%	10%	52%	52
	NCI	52%	7%	41%	1,218

Table 14. Family member's support needs

		None	Some	Extensive	N
Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	DE	71%	17%	12%	186
	NCI	57%	28%	15%	5,074
Family Member's Need for Help With Personal Care Activities	DE	47%	38%	15%	188
	NCI	25%	33%	42%	5,133
Family Member's Need for Help With Other Daily Activities	DE	8%	28%	64%	191
	NCI	4%	17%	79%	5,132

Respondents

This section provides demographic information about the respondent.

Table 15. Respondent's age

		Under 35	35-54	55-74	75+	N
Respondent's Age	DE	2%	31%	59%	8%	190
	NCI	2%	19%	65%	15%	5,143

Table 16. Respondent's health

		Excellent	Very Good	Fairly Good	Poor	N
Respondent's Health	DE	17%	51%	31%	1%	191
	NCI	15%	45%	35%	4%	5,156

Table 17. Respondent's relationship to family member

		Parent	Sibling	Spouse	Grandparent	Other	N
Respondent's Relationship to Family Member	DE	86%	7%	0%	6%	2%	191
	NCI	86%	9%	0%	2%	3%	5,149

Table 18. Respondent (or other family member) provides paid support (categories are not mutually exclusive)

		Respondent or Other Family Member Provides Paid Support to Family Member
No Family Member Provides Paid Support	DE	95%
	NCI	70%
Respondent Provides Paid Support	DE	3%
	NCI	20%
Other Family Member Provides Paid Support	DE	3%
	NCI	12%
N	DE	190
	NCI	5,092

Table 19. Number of adults in household

		One	Two	Three	Four or More	N
Number of Adults in Household (Not Including Family Member Receiving Services)	DE	7%	27%	46%	21%	188
	NCI	9%	30%	45%	15%	5,106

Table 20. Number of children in household

		None	One	Two	Three	Four or More	N
Number of Children in Household	DE	84%	12%	3%	1%	1%	189
	NCI	88%	7%	3%	1%	1%	5,143

Table 21. Respondent's highest level of education

		No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
Respondent's Highest Level of Education	DE	4%	21%	3%	22%	49%	189
	NCI	7%	29%	7%	21%	36%	5,140

Table 22. Past year total household taxable income of wage earners

		Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	No Earned Income	Prefer Not to Say	N
Total Taxable Income of Wage Earners in the Household in Past Year	DE	6%	7%	16%	14%	25%	7%	24%	189
	NCI	8%	12%	20%	13%	16%	11%	21%	4,915

Table 23. Family's residential setting

		Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	Don't know	N
Residential Setting	DE	58%	40%	2%	189
	NCI	67%	31%	2%	5,110

Services and Supports Received

This section provides information about the services and supports received by the family from the state IDD agency.

Table 24. Services and supports received from state (categories are not mutually exclusive)

		Services and Supports Received From State
Financial Support	DE	8%
	NCI	18%
In-home Support	DE	3%
	NCI	40%
Out-of-home Respite	DE	19%
	NCI	32%
Day or Employment Supports	DE	52%
	NCI	55%
Transportation	DE	59%
	NCI	62%
Other	DE	21%
	NCI	26%
Self-direction or Fiscal Intermediary Services	DE	9%
	NCI	39%

Table 25. Additional services and supports received (not from IDD agency; categories are not mutually exclusive)

		Additional Services and Supports Received (Not From the IDD Agency)
Social Security Payments (SSI/SSB)	DE	81%
	NCI	94%
Services or Supports From Other Agencies or Organizations	DE	45%
	NCI	31%

Information and Planning

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

Charts for Information and Planning

Chart 1. Do you get enough information to take part in planning services for your family member?

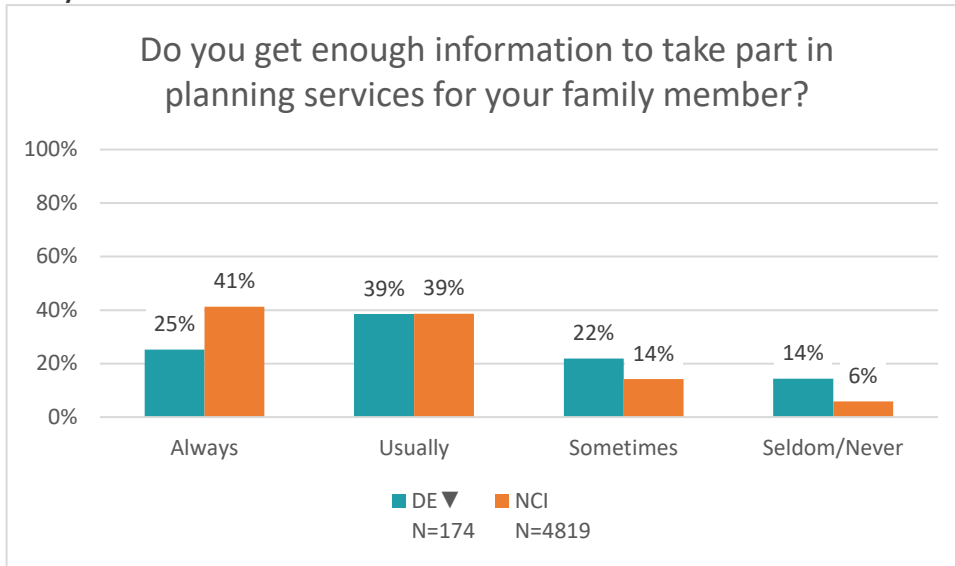


Chart 2. Is the information you get about services and supports easy to understand?

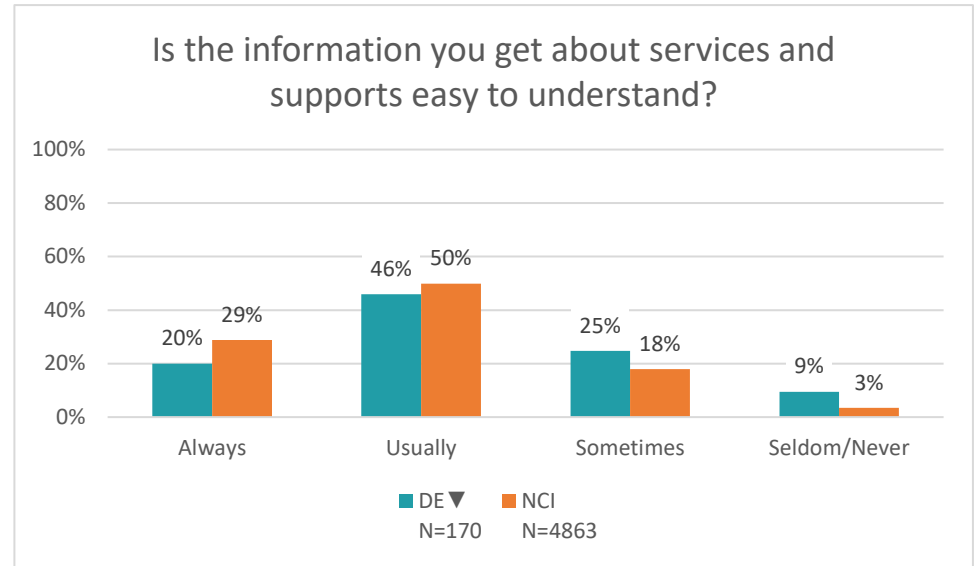


Chart 3. Does the case manager/service coordinator respect your family's choices and opinions?

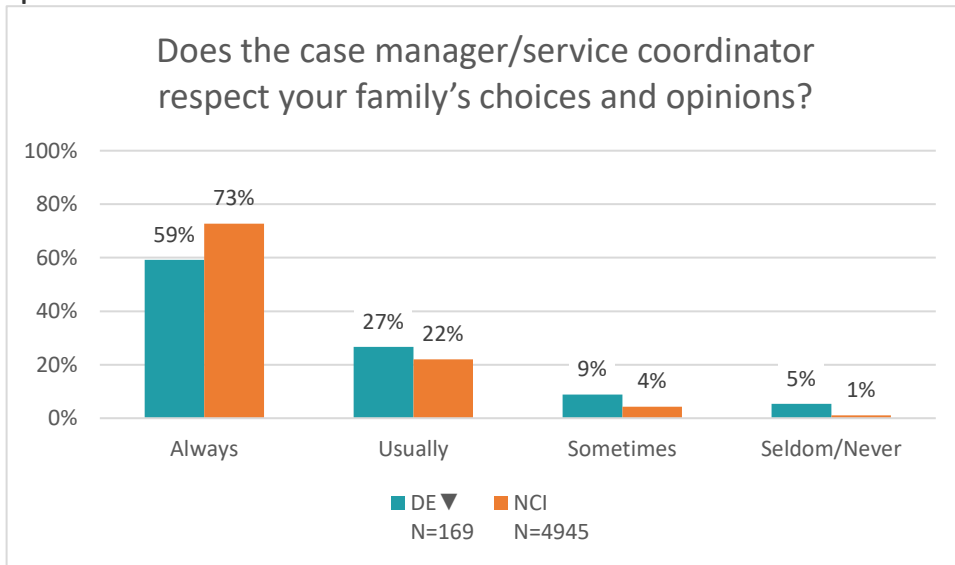


Chart 4. Do you have enough information about other public services for which your family is eligible?

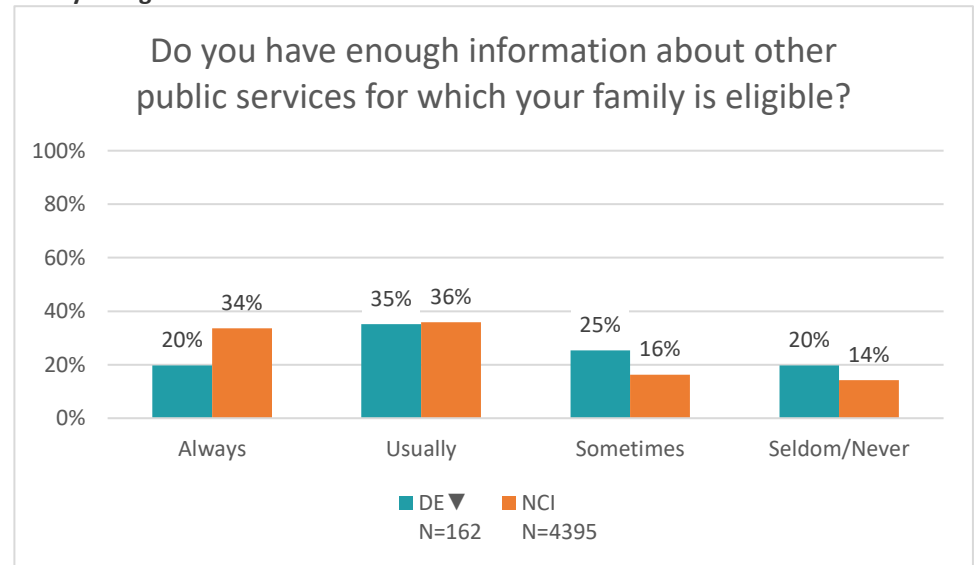


Chart 5. Respondent's future planning needs

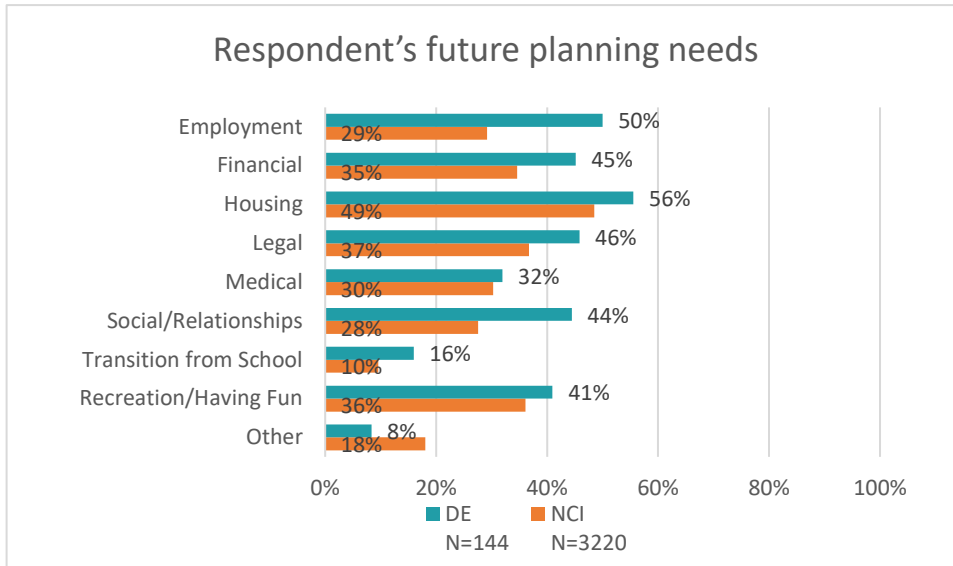


Chart 6. If you asked for crisis or emergency services during the past year, were services provided when needed?

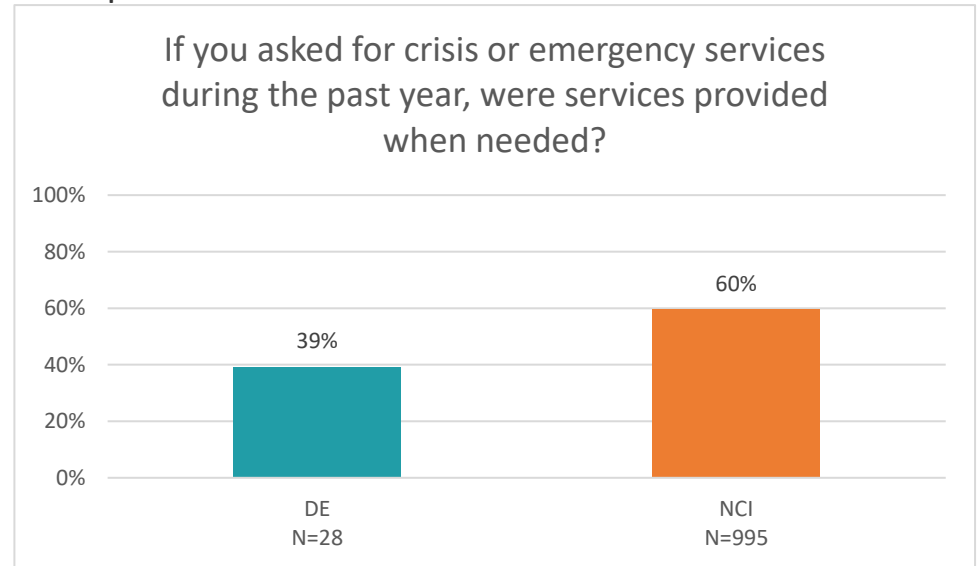


Chart 7. Does your family member have a service plan?

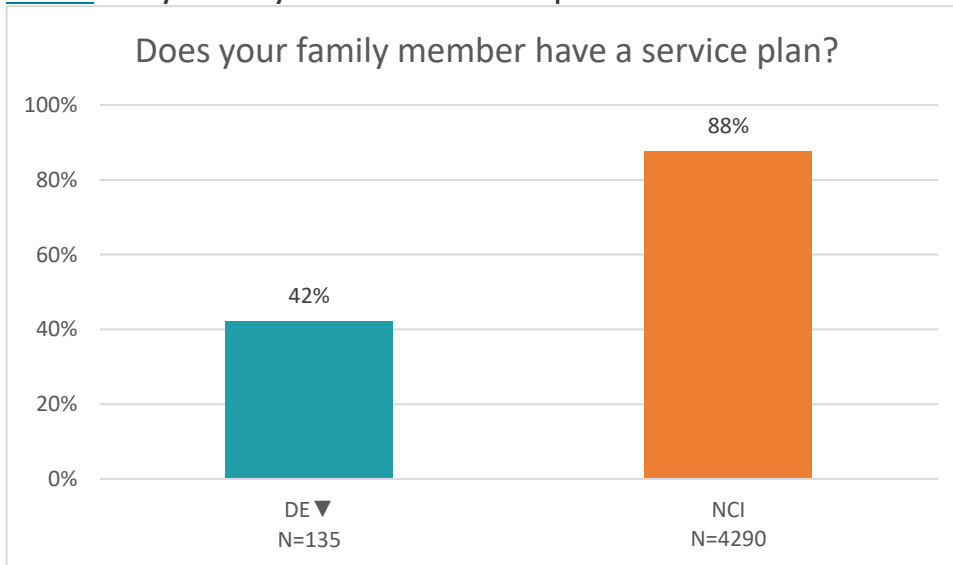


Chart 8. Does it include all the services and supports your family member needs?

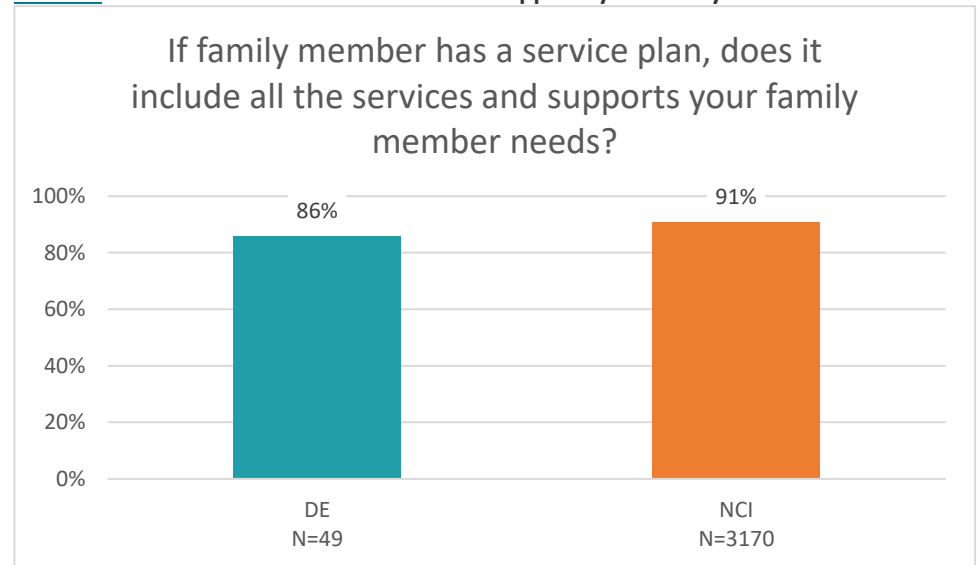


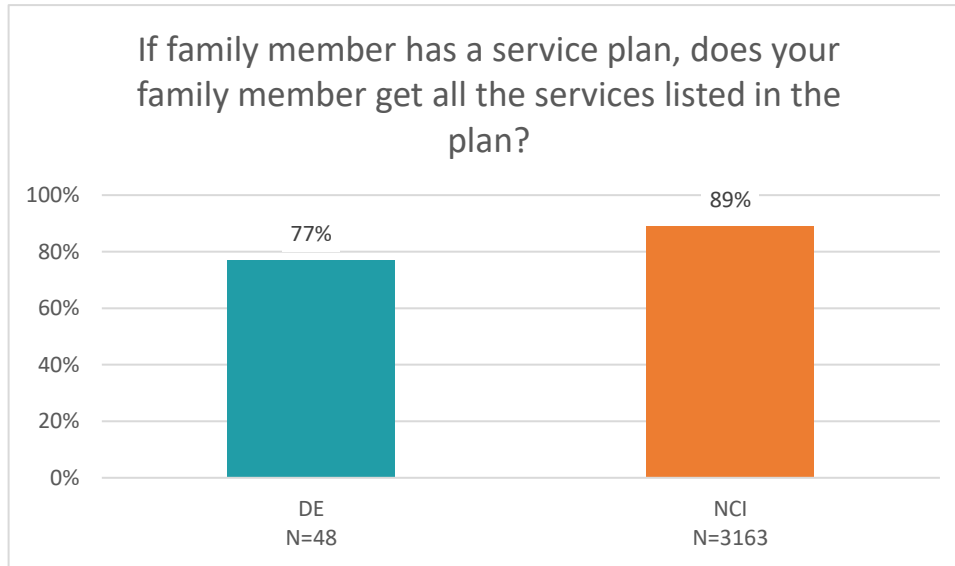
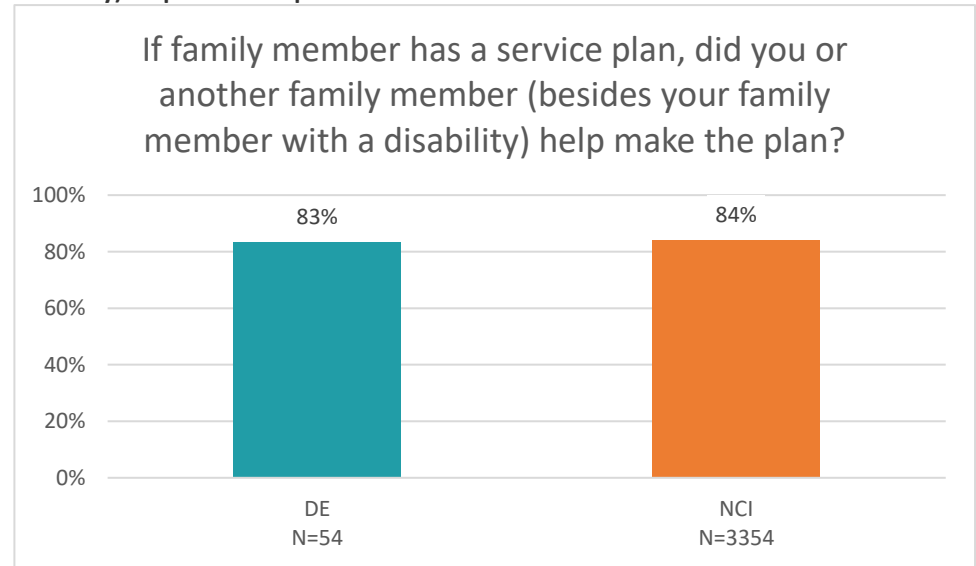
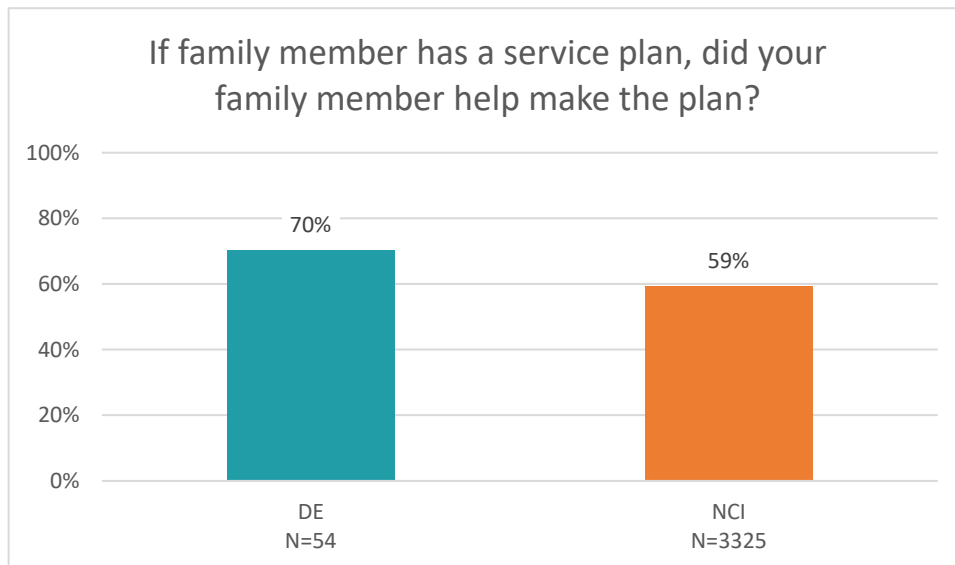
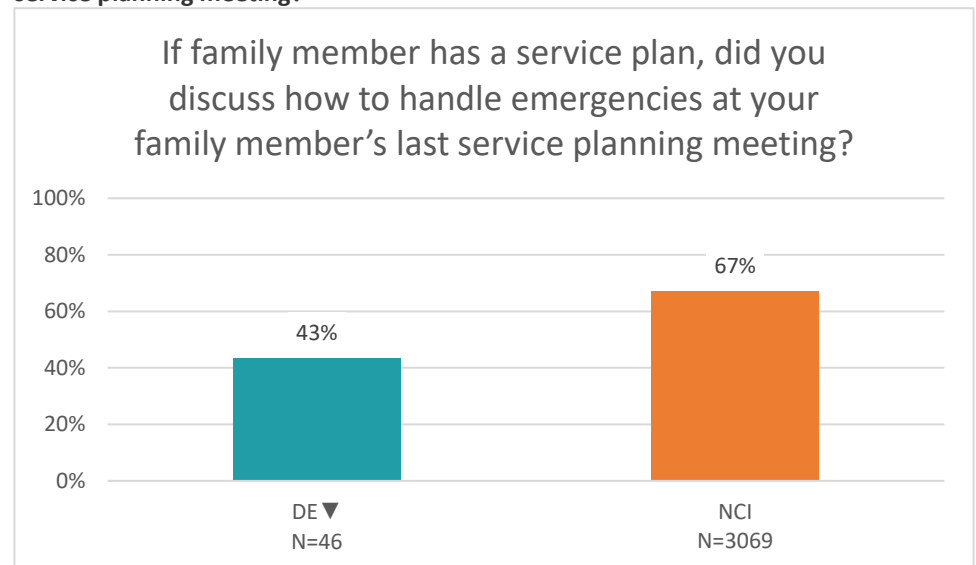
Chart 9. Does your family member get all the services listed in the plan?**Chart 10.** Did you or another family member (besides your family member with a disability) help make the plan?**Chart 11.** Did your family member help make the plan?**Chart 12.** Did you discuss how to handle emergencies at your family member's last service planning meeting?

Chart 13. If your family member transitioned out of school services during the past year, did s/he have a transition plan?

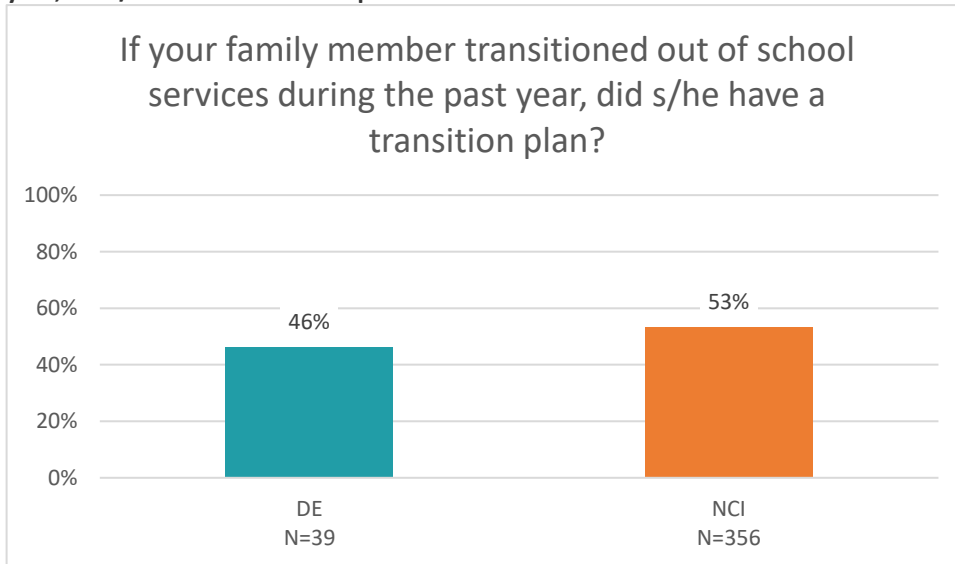


Chart 14. If your family member had a transition plan, did the plan include getting or continuing work in a community job?

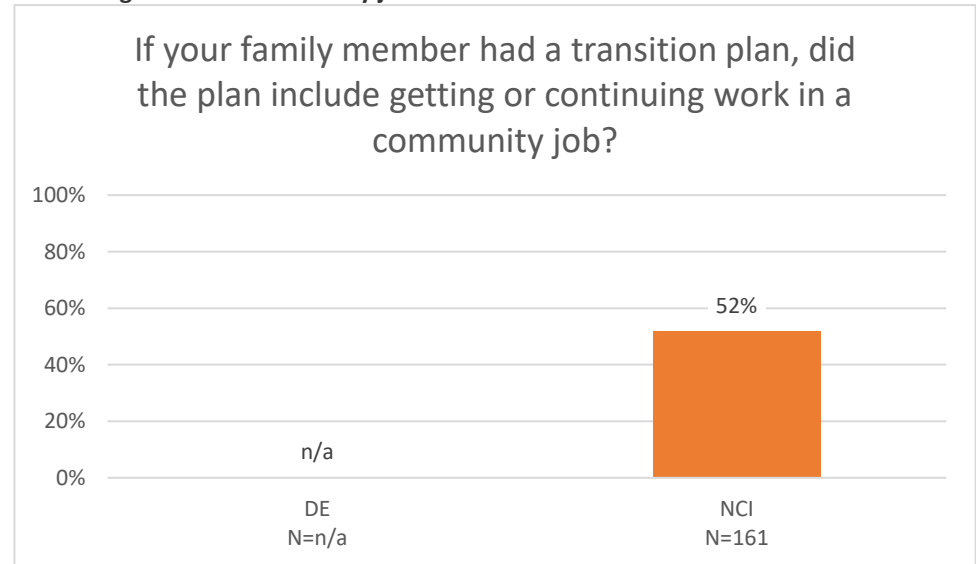


Chart 15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

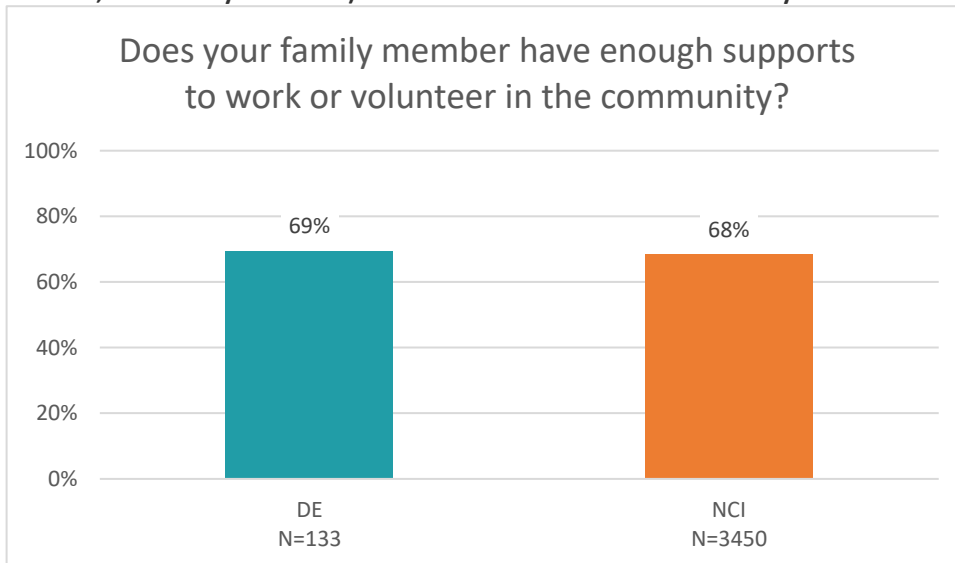
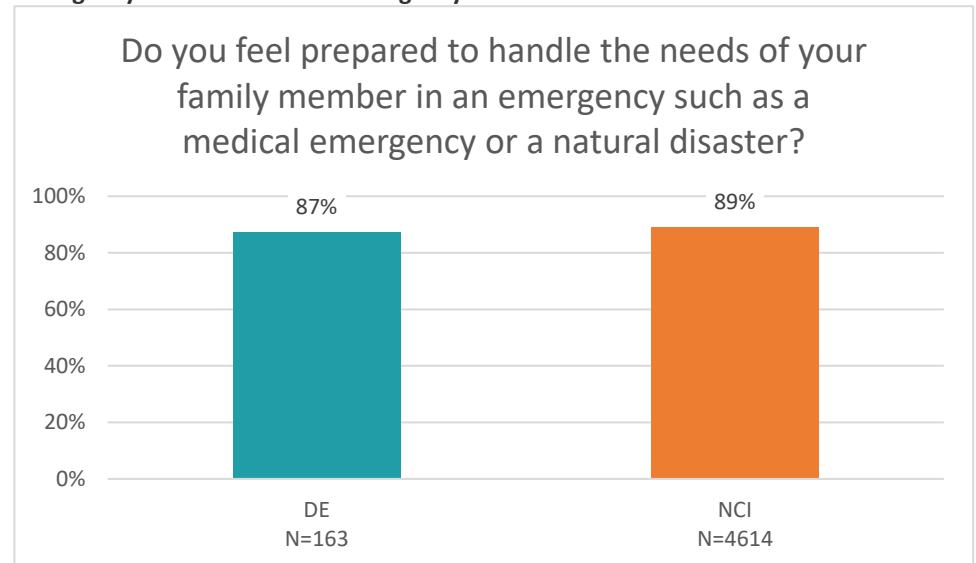


Chart 16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?



Tables for Information and Planning

Table 26. Information and Planning

		Always	Usually	Sometimes	Seldom/Never	N
Do you get enough information to take part in planning services for your family member?	DE ▼	25%	39%	22%	14%	174
	NCI	41%	39%	14%	6%	4,819
Is the information you get about services and supports easy to understand?	DE ▼	20%	46%	25%	9%	170
	NCI	29%	50%	18%	3%	4,863
Does the case manager/service coordinator respect your family's choices and opinions?	DE ▼	59%	27%	9%	5%	169
	NCI	73%	22%	4%	1%	4,945
Do you have enough information about other public services for which your family is eligible?	DE ▼	20%	35%	25%	20%	162
	NCI	34%	36%	16%	14%	4,395

Table 27. Respondent's Future Planning Needs

		Yes
Employment	DE	50%
	NCI	29%
Financial	DE	45%
	NCI	35%
Housing	DE	56%
	NCI	49%
Legal	DE	46%
	NCI	37%
Medical	DE	32%
	NCI	30%
Social or Relationships	DE	44%
	NCI	28%
Transition from School	DE	16%
	NCI	10%
Recreation	DE	41%
	NCI	36%
Other	DE	8%
	NCI	18%
N	DE	144
	NCI	3,220

Table 28. Information and Planning (continued)

		Yes	No	N
If you asked for crisis or emergency services during the past year, were services provided when needed?	DE	39%	61%	28
	NCI	60%	40%	995
Does your family member have a service plan?	DE ▼	42%	58%	135
	NCI	88%	12%	4,290
<i>If your family member has a service plan...</i>				
Does it include all the services and supports your family member needs?	DE	86%	14%	49
	NCI	91%	9%	3,170
Does your family member get all the services listed in the plan?	DE	77%	23%	48
	NCI	89%	11%	3,163
Did you or another family member (besides your family member with a disability) help make the plan?	DE	83%	17%	54
	NCI	84%	16%	3,354
Did your family member help make the plan?	DE	70%	30%	54
	NCI	59%	41%	3,325
Did you discuss how to handle emergencies at your family member's last service planning meeting?	DE ▼	43%	57%	46
	NCI	67%	33%	3,069
If your family member transitioned out of school services during the past year, did s/he have a transition plan?	DE	46%	54%	39
	NCI	53%	47%	356
If your family member had a transition plan, did the plan include getting or continuing work in a community job?	DE	n/a	n/a	n/a
	NCI	52%	48%	161
Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?	DE	69%	31%	133
	NCI	68%	32%	3,450
Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?	DE	87%	13%	163
	NCI	89%	11%	4,614

Access and Delivery of Services and Supports

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

Charts for Access and Delivery of Services and Supports

Chart 17. Are you or your family member able to contact his/her support workers when you want to?

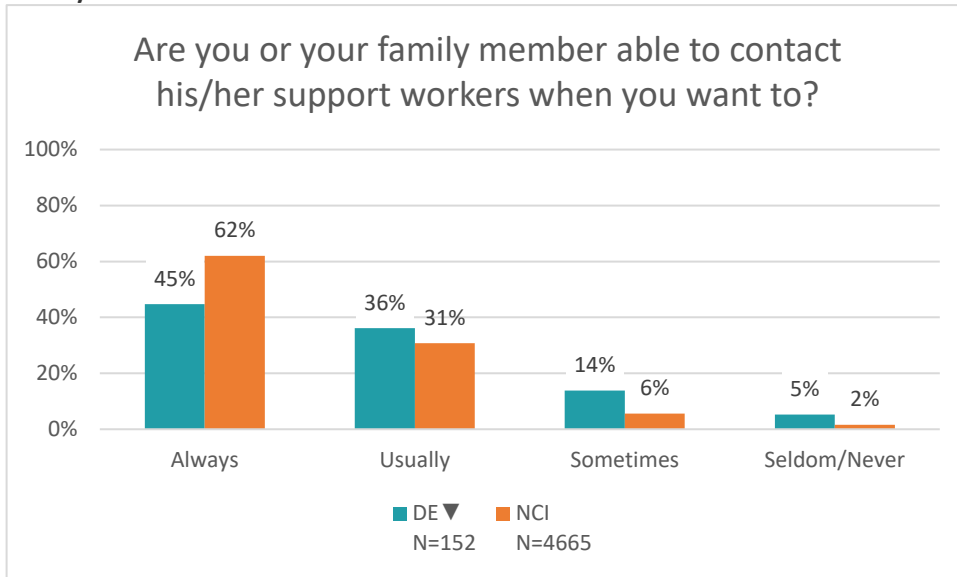


Chart 18. Are you or your family member able to contact his/her case manager/service coordinator when you want to?

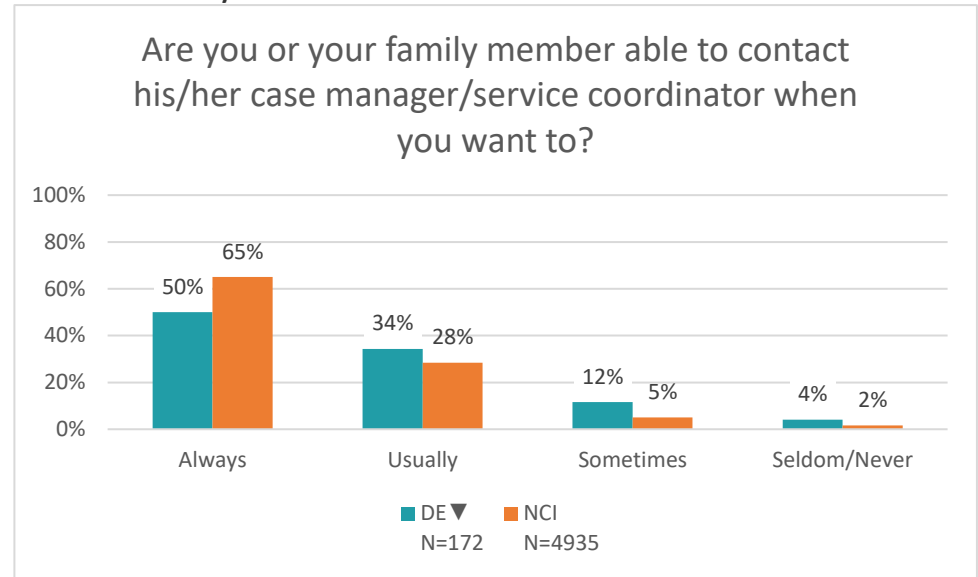


Chart 19. Do support workers come and leave when they are supposed to?

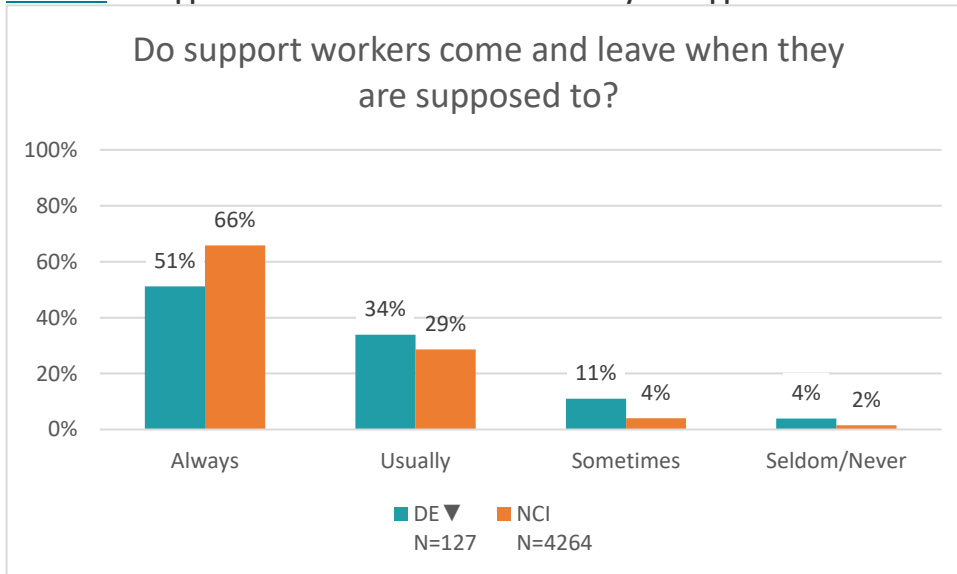


Chart 20. Do services and supports change when your family's needs change?

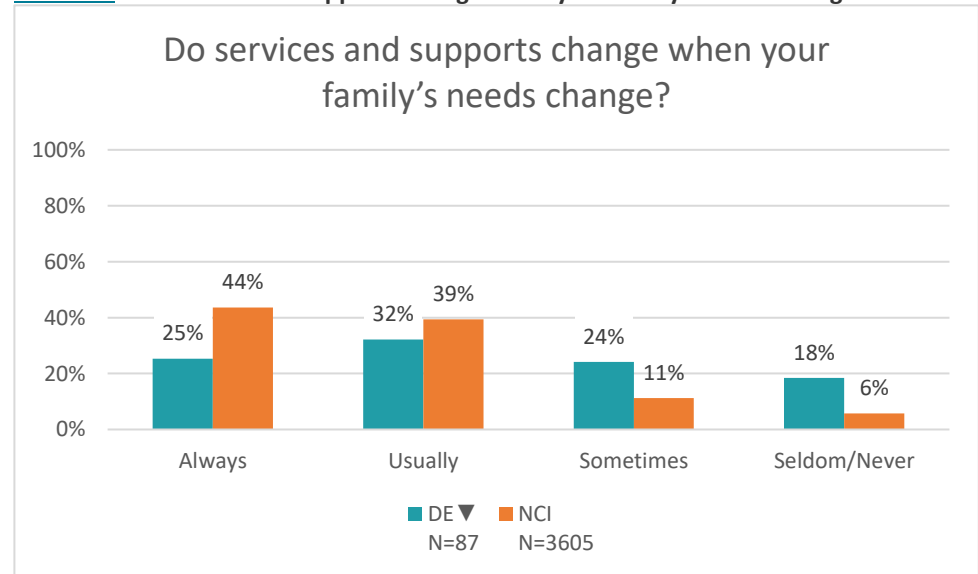


Chart 21. Do support workers speak to you in a way that you understand?

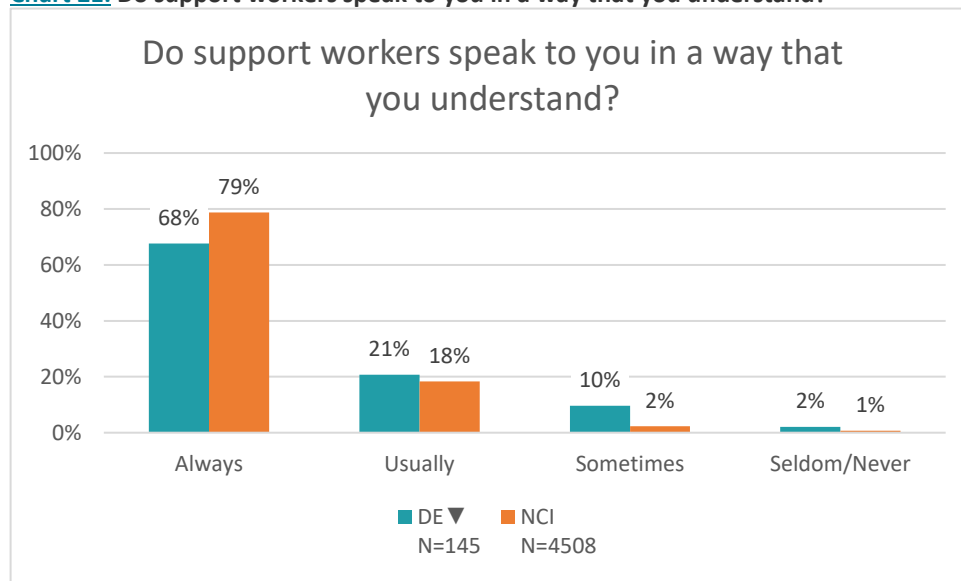


Chart 22. Are services delivered in a way that is respectful of your family's culture?

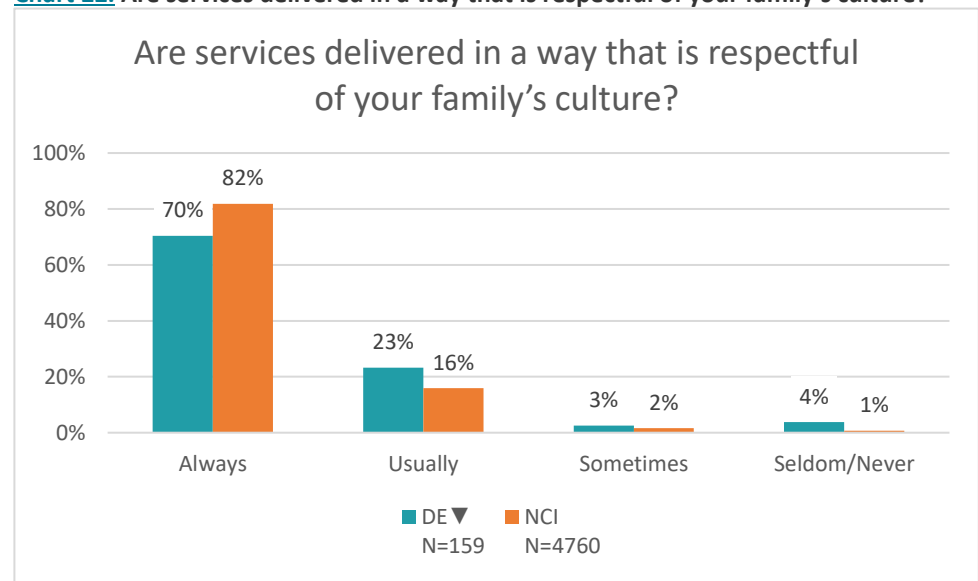


Chart 23. If your family member does not communicate verbally, are there support workers who can communicate with him/her?

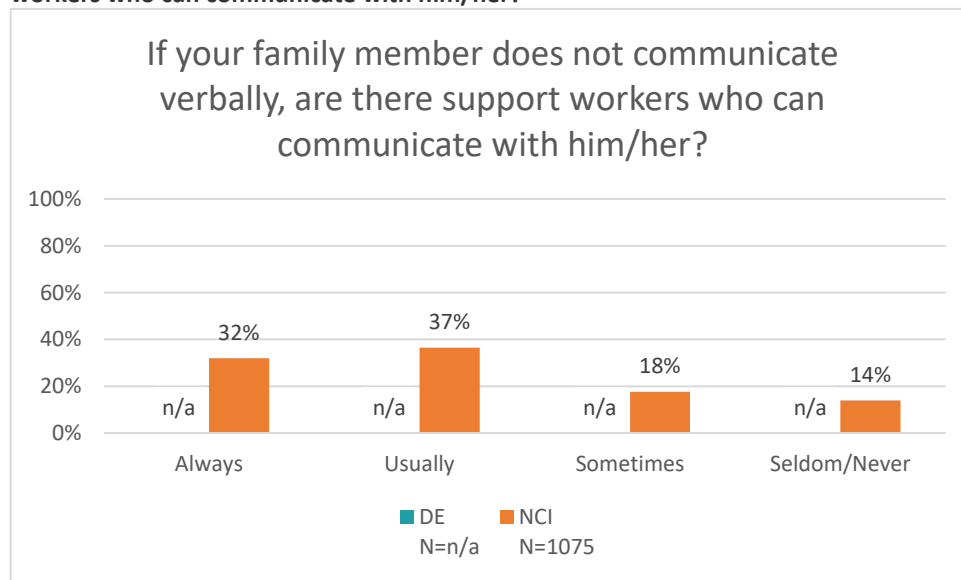


Chart 24. Do support workers have the right information and skills to meet your family's needs?

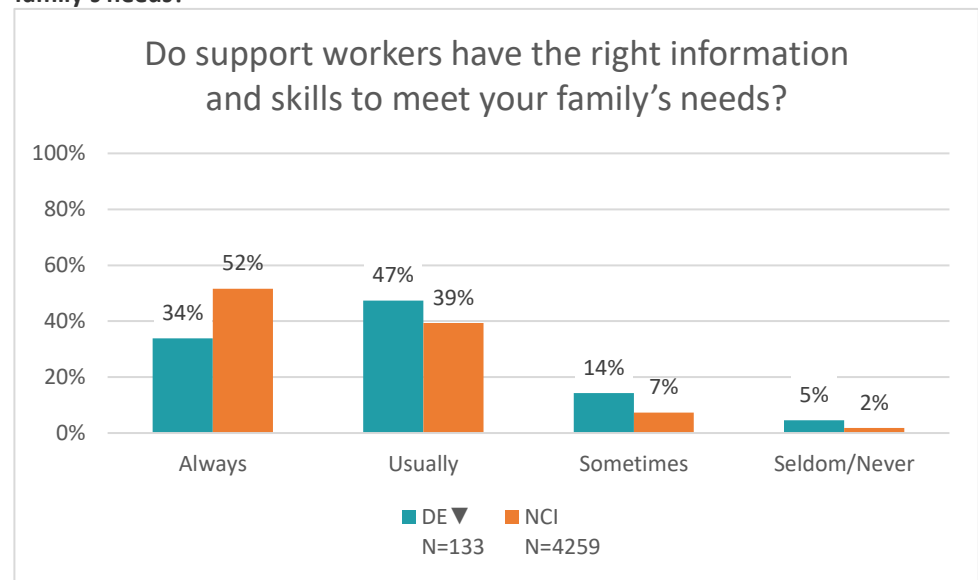


Chart 25. Does your family member have the special equipment or accommodations that s/he needs?

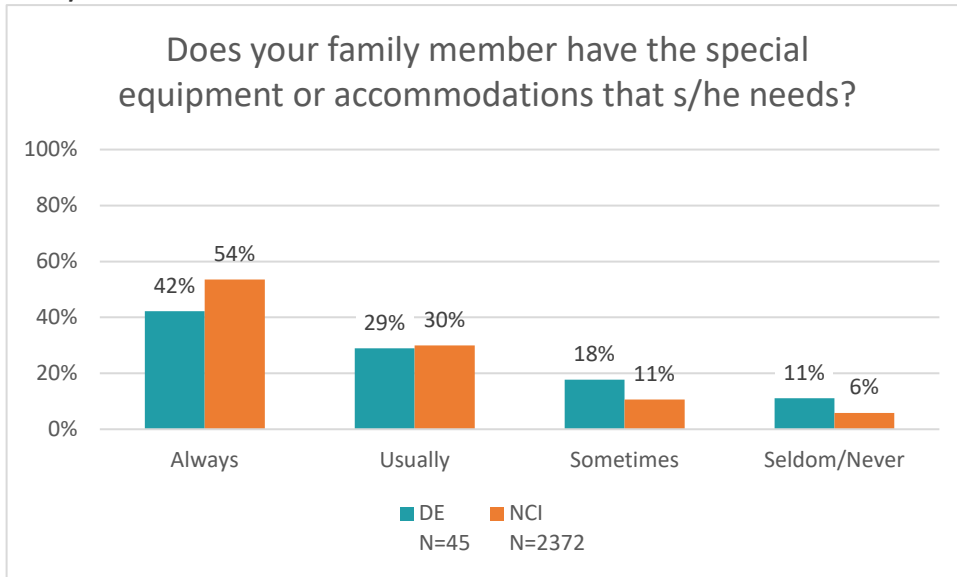


Chart 26. Can your family member see health professionals when needed?

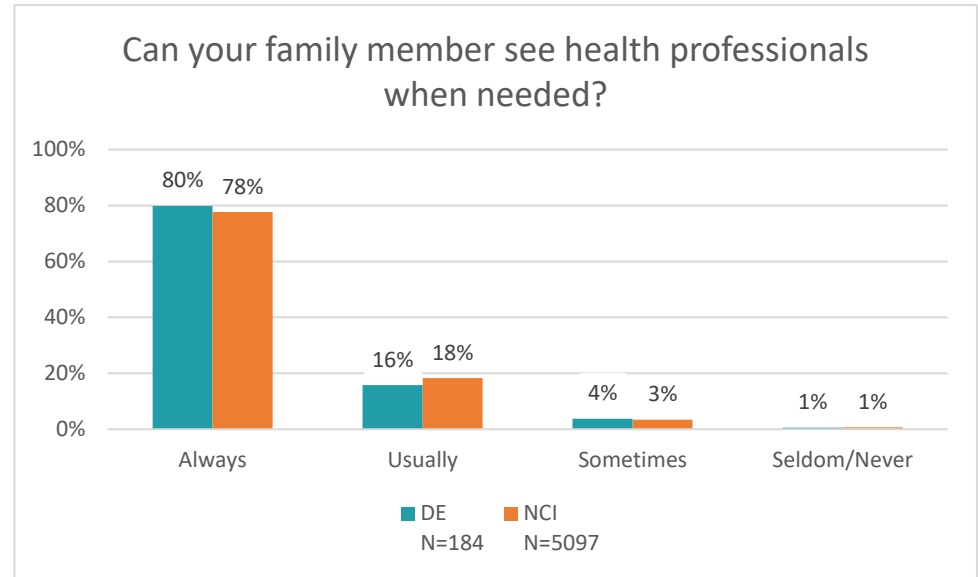


Chart 27. Does your family member's primary care doctor understand his/her needs related to his/her disability?

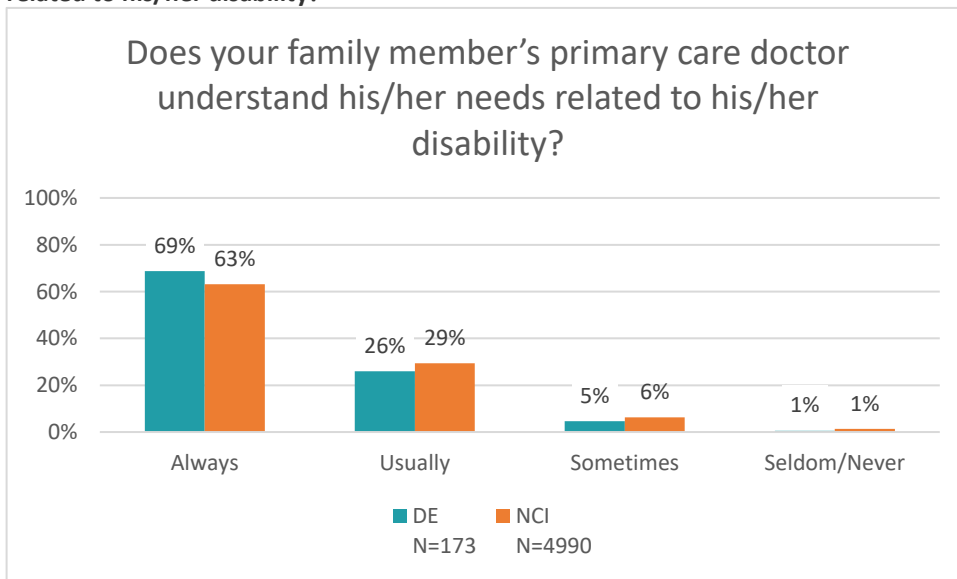


Chart 28. Do you have access to dental services for your family member?

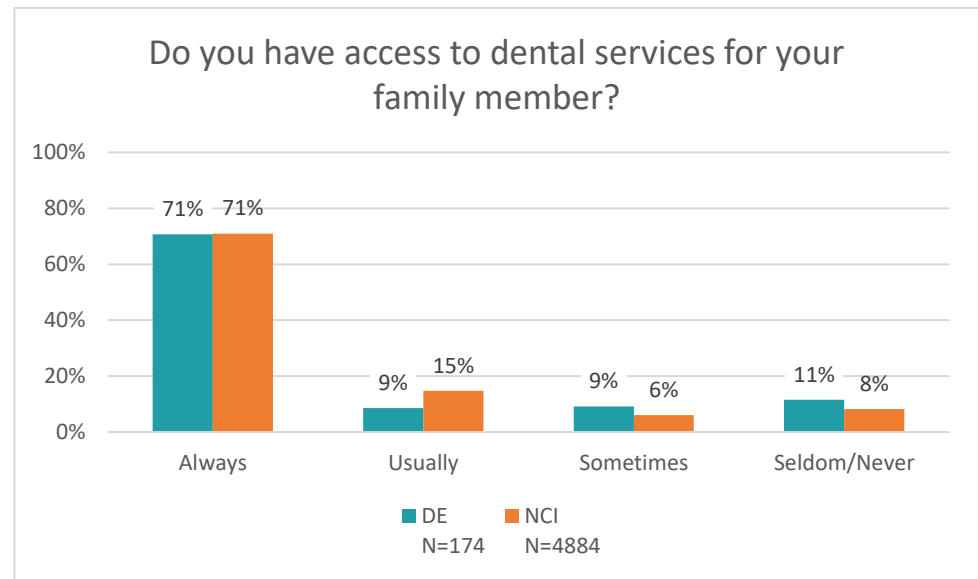


Chart 29. If you have access to dental services for your family member, does your family member’s dentist understand his/her needs related to his/her disability?

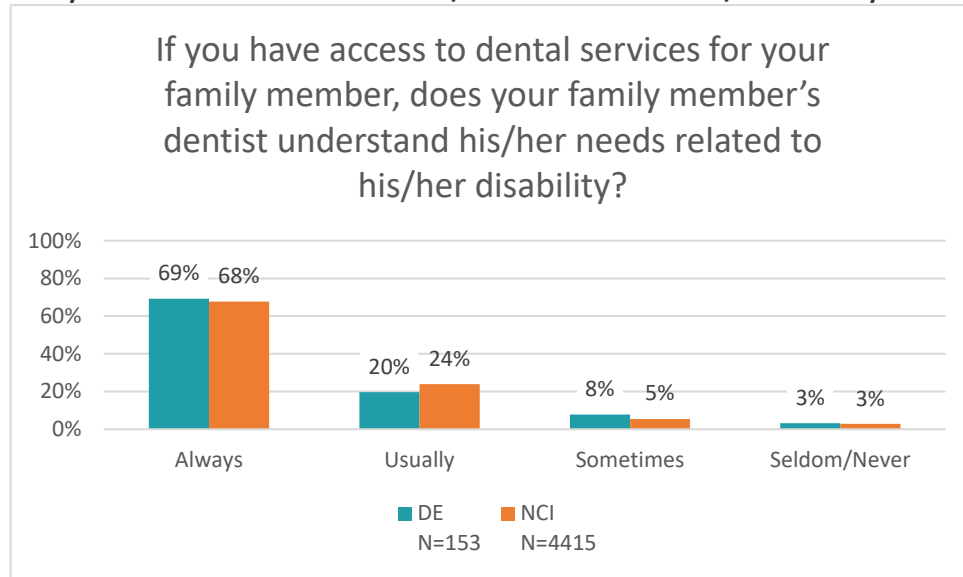


Chart 30. If your family member takes medications, do you know what they’re for?

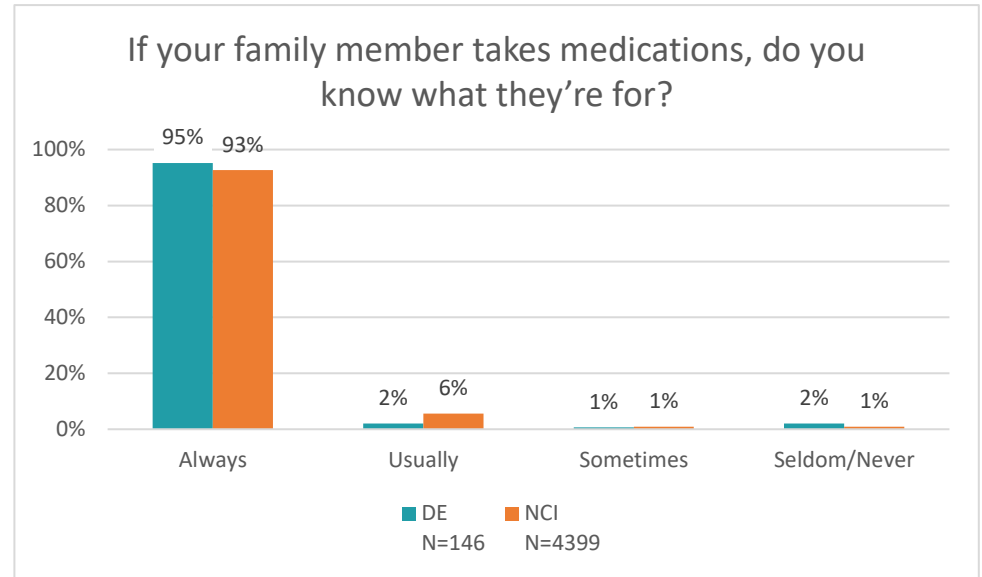


Chart 31. If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications?

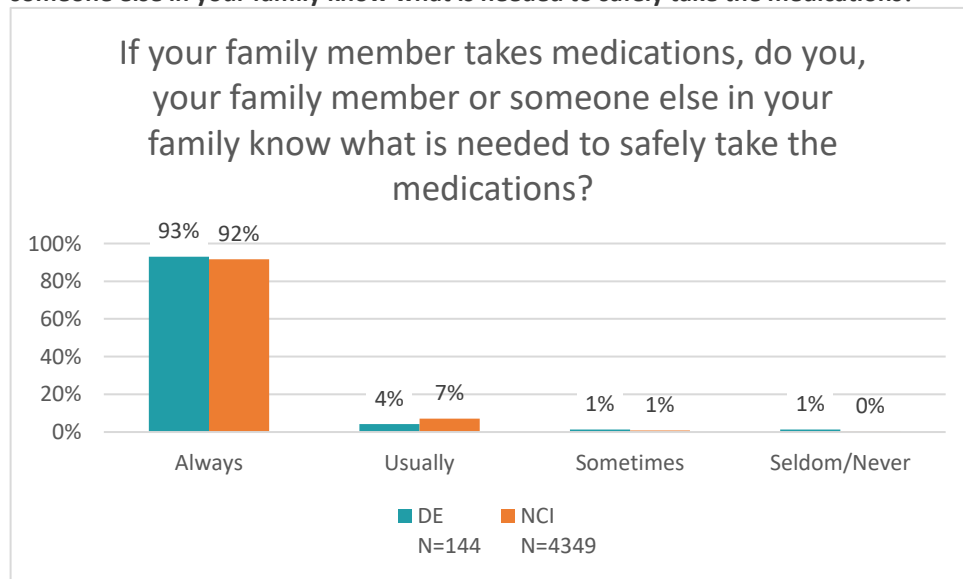


Chart 32. If your family member uses mental health services, does the mental health professional understand your family member’s needs related to his/her disability?

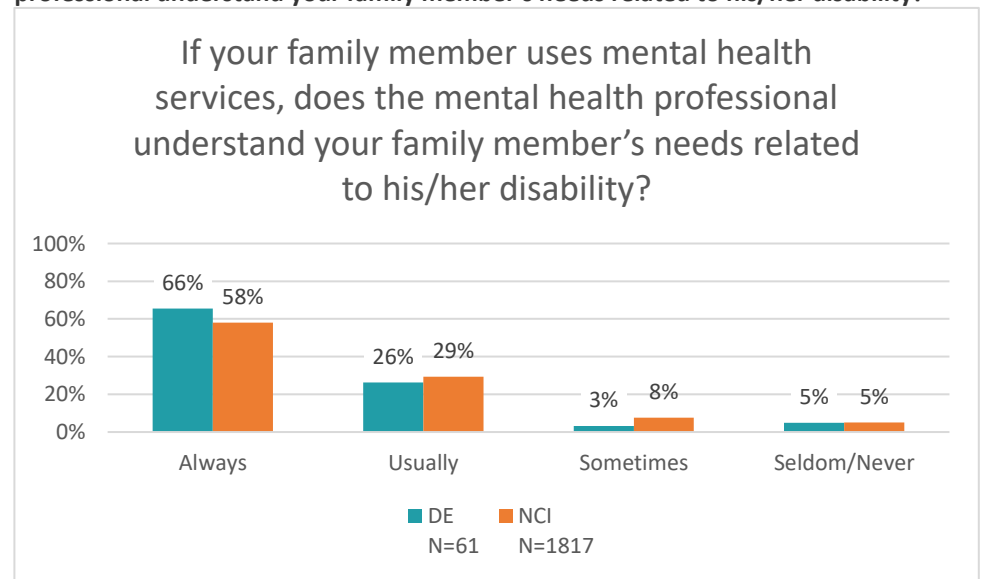


Chart 33. If you need respite services, do you have access to them?

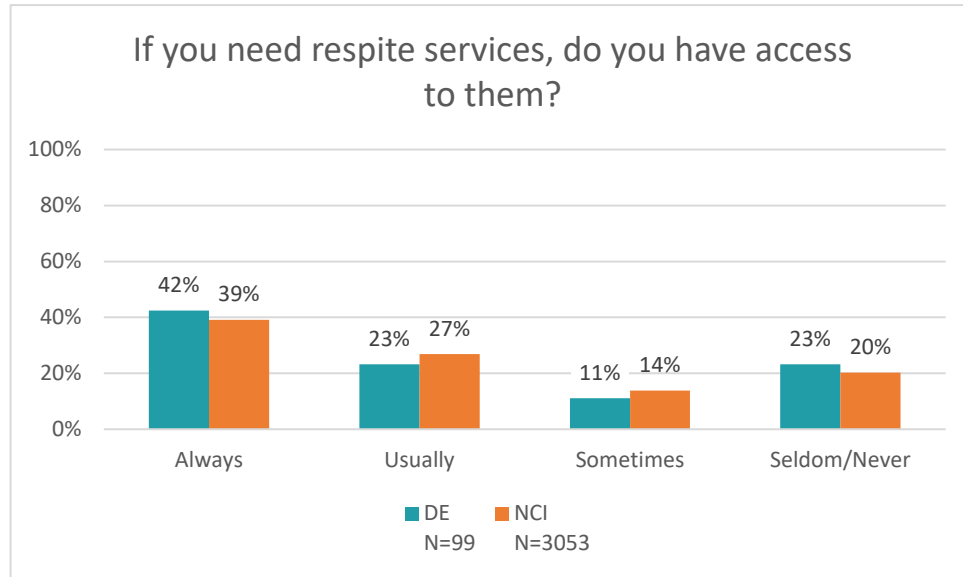


Chart 34. If you have access to respite services, are you satisfied with the quality of the respite services?

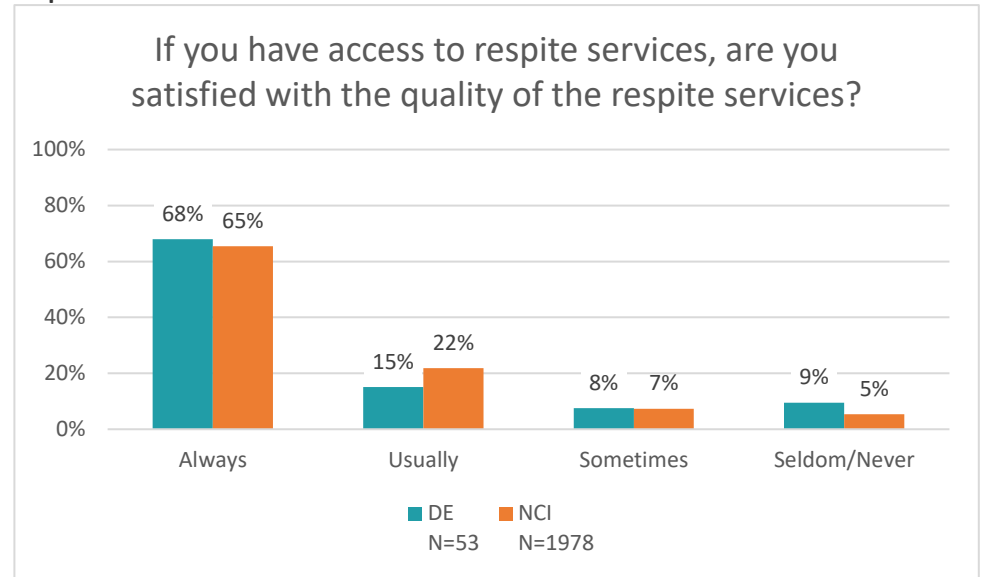


Chart 35. Does your family get the supports and services needed?

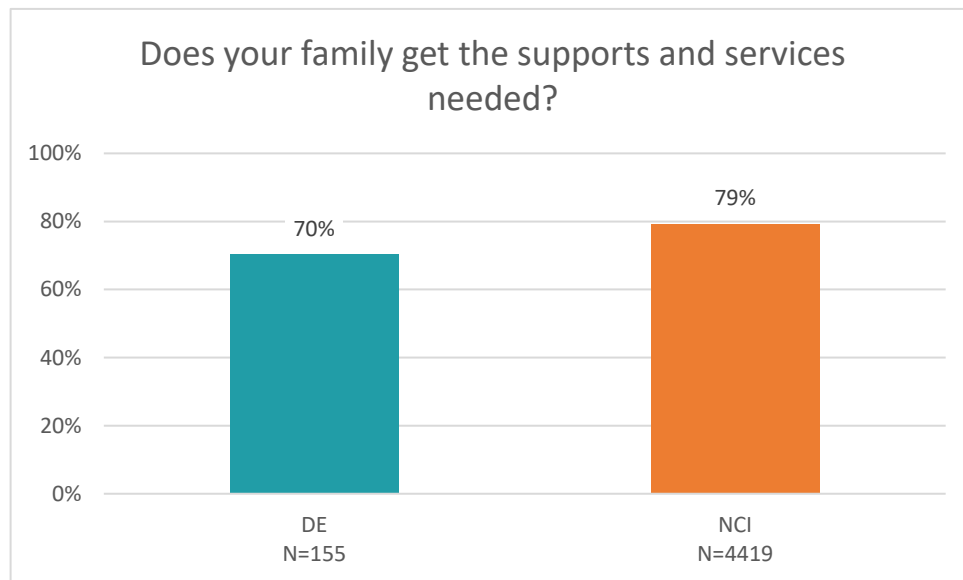
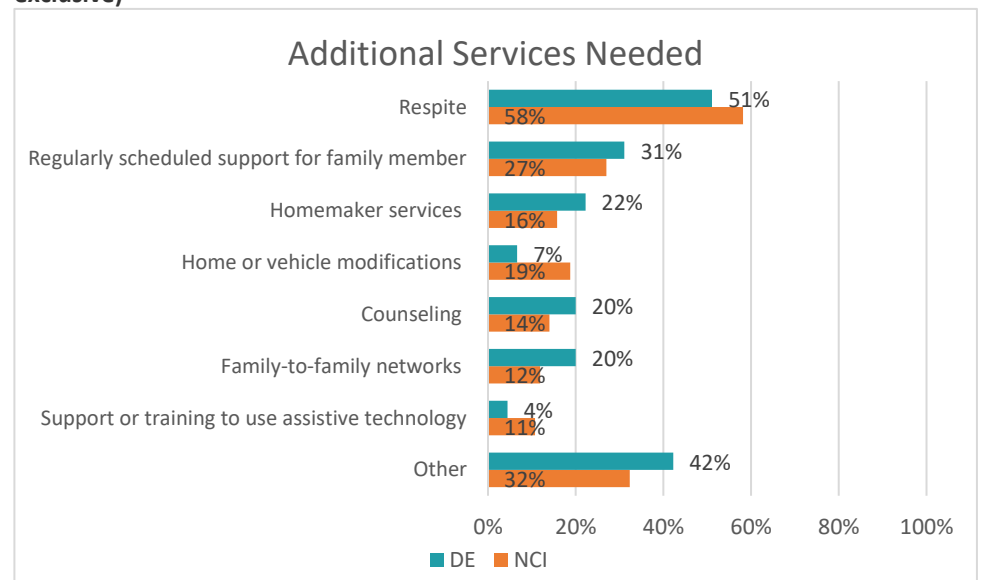


Chart 36. Additional services or supports needed (categories are not mutually exclusive)



Tables for Access and Delivery of Services and Supports

Table 29. Access and Delivery of Services and Supports

		Always	Usually	Sometimes	Seldom/Never	N
Are you or your family member able to contact his/her support workers when you want to?	DE ▼	45%	36%	14%	5%	152
	NCI	62%	31%	6%	2%	4,665
Are you or your family member able to contact his/her case manager/service coordinator when you want to?	DE ▼	50%	34%	12%	4%	172
	NCI	65%	28%	5%	2%	4,935
Do support workers come and leave when they are supposed to?	DE ▼	51%	34%	11%	4%	127
	NCI	66%	29%	4%	2%	4,264
Do services and supports change when your family's needs change?	DE ▼	25%	32%	24%	18%	87
	NCI	44%	39%	11%	6%	3,605
Do support workers speak to you in a way that you understand?	DE ▼	68%	21%	10%	2%	145
	NCI	79%	18%	2%	1%	4,508
Are services delivered in a way that is respectful of your family's culture?	DE ▼	70%	23%	3%	4%	159
	NCI	82%	16%	2%	1%	4,760
If your family member does not communicate verbally, are there support workers who can communicate with him/her?	DE	n/a	n/a	n/a	n/a	n/a
	NCI	32%	37%	18%	14%	1,075
Do support workers have the right information and skills to meet your family's needs?	DE ▼	34%	47%	14%	5%	133
	NCI	52%	39%	7%	2%	4,259
Does your family member have the special equipment or accommodations that s/he needs?	DE	42%	29%	18%	11%	45
	NCI	54%	30%	11%	6%	2,372

Table 30. Access and Delivery of Services and Supports (continued)

		Always	Usually	Sometimes	Seldom/Never	N
Can your family member see health professionals when needed?	DE	80%	16%	4%	1%	184
	NCI	78%	18%	3%	1%	5,097
Does your family member's primary care doctor understand his/her needs related to his/her disability?	DE	69%	26%	5%	1%	173
	NCI	63%	29%	6%	1%	4,990
Do you have access to dental services for your family member?	DE	71%	9%	9%	11%	174
	NCI	71%	15%	6%	8%	4,884
If you have access to dental services for your family member, does your family member's dentist understand his/her needs related to his/her disability?	DE	69%	20%	8%	3%	153
	NCI	68%	24%	5%	3%	4,415
If your family member takes medications, do you know what they're for?	DE	95%	2%	1%	2%	146
	NCI	93%	6%	1%	1%	4,399
If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications?	DE	93%	4%	1%	1%	144
	NCI	92%	7%	1%	0%	4,349
If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?	DE	66%	26%	3%	5%	61
	NCI	58%	29%	8%	5%	1,817
If you need respite services, do you have access to them?	DE	42%	23%	11%	23%	99
	NCI	39%	27%	14%	20%	3,053
If you have access to respite services, are you satisfied with the quality of the respite services?	DE	68%	15%	8%	9%	53
	NCI	65%	22%	7%	5%	1,978

Table 31. Access and Delivery of Services and Supports (continued)

		Yes	No	N
Does your family get the supports and services needed?	DE	70%	30%	155
	NCI	79%	21%	4,419

Table 32. Additional Services Needed (categories are not mutually exclusive)

		Needs Service
Respite	DE	51%
	NCI	58%
Regularly scheduled support for family member	DE	31%
	NCI	27%
Homemaker services	DE	22%
	NCI	16%
Home or vehicle modifications	DE	7%
	NCI	19%
Counseling	DE	20%
	NCI	14%
Family-to-Family networks	DE	20%
	NCI	12%
Support/training to use family member's assistive technology	DE	4%
	NCI	11%
Other	DE	42%
	NCI	32%

Choice, Decision Making and Control

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

Charts for Choice, Decision Making and Control

Chart 37. Can your family choose or change the agency that provides your family member's services?

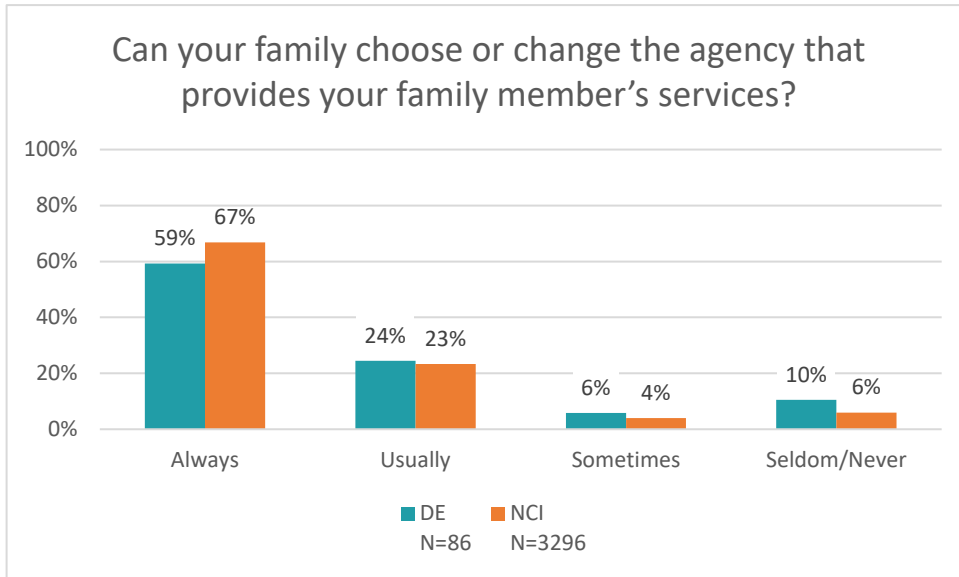


Chart 38. Can your family choose or change your family member's support workers?

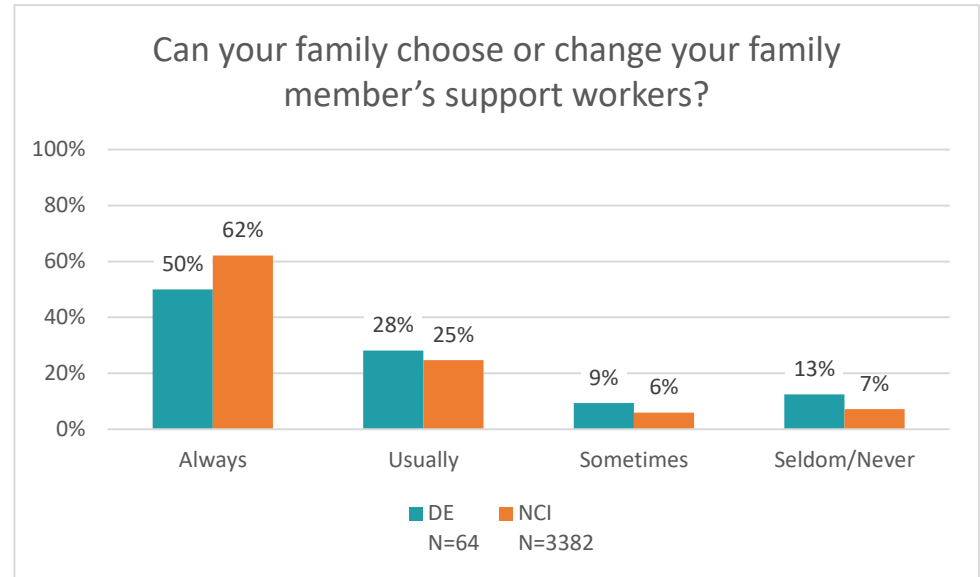


Chart 39. Does your family directly manage support workers?

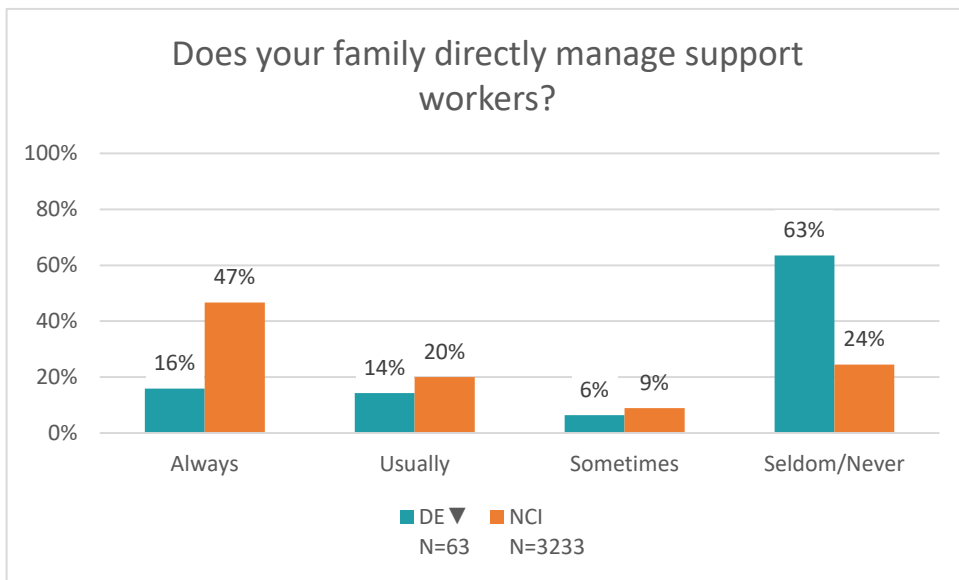


Chart 40. Do service providers for your family member work together to provide support?

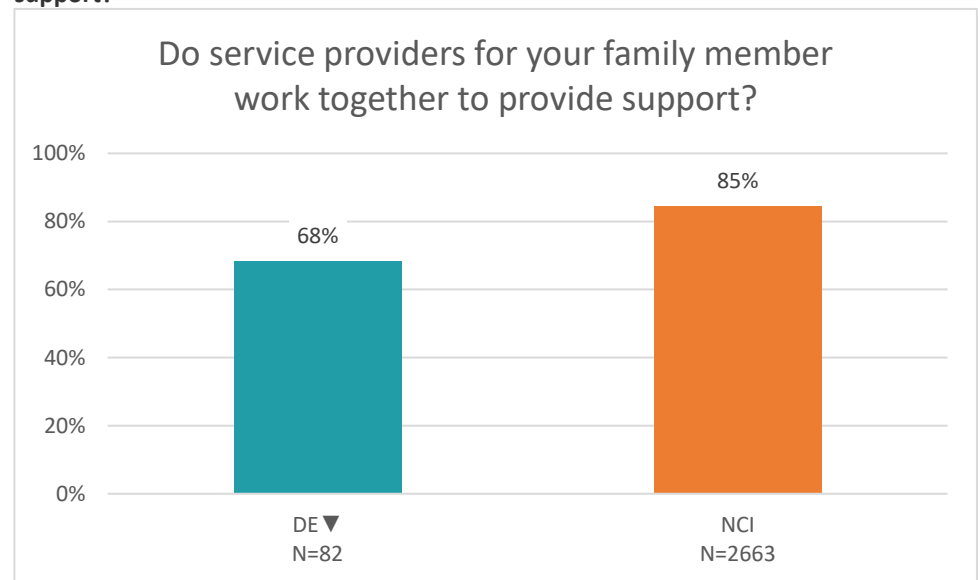
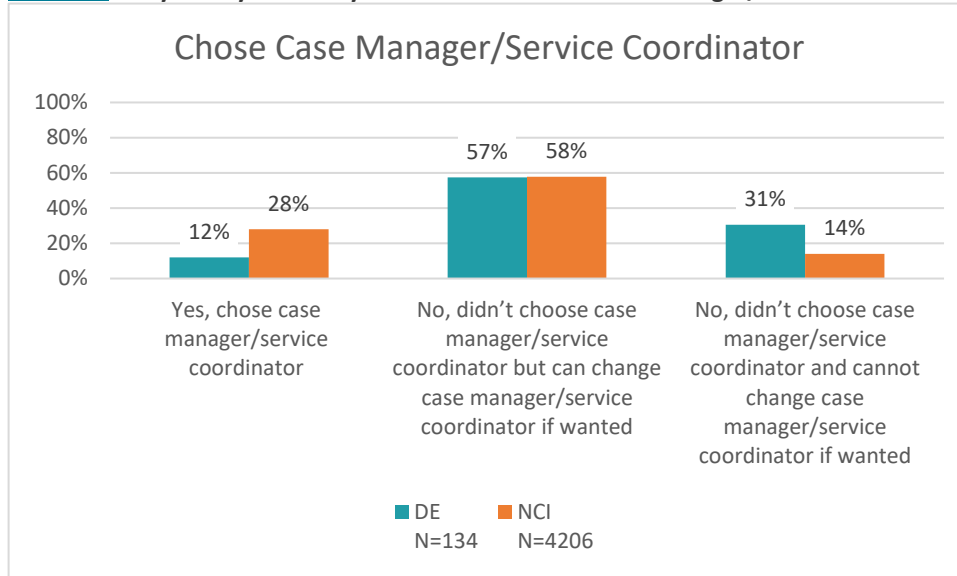


Chart 41. Did you or your family member choose the case manager/service coordinator

Tables for Choice, Decision Making and Control

Table 33. Choice and Control

		Always	Usually	Sometimes	Seldom/Never	N
Can your family choose or change the agency that provides your family member's services?	DE	59%	24%	6%	10%	86
	NCI	67%	23%	4%	6%	3296
Can your family choose or change your family member's support workers?	DE	50%	28%	9%	13%	64
	NCI	62%	25%	6%	7%	3382
Does your family directly manage support workers?	DE ▼	16%	14%	6%	63%	63
	NCI	47%	20%	9%	24%	3233

Table 34. Choice and Control (continued)

		Yes	No	N
Do service providers for your family member work together to provide support?	DE ▼	68%	32%	82
	NCI	85%	15%	2663

Table 35. Chose Case Manager/Service Coordinator

		Chose Case Manager/ Service Coordinator
Yes, chose case manager/service coordinator	DE	12%
	NCI	28%
No, didn't choose case manager/service coordinator but can change case manager/service coordinator if wanted	DE	57%
	NCI	58%
No, didn't choose case manager/service coordinator and cannot change case manager/service coordinator if wanted	DE	31%
	NCI	14%
N	DE	134
	NCI	4,206

Involvement in the Community

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

Charts for Involvement in the Community

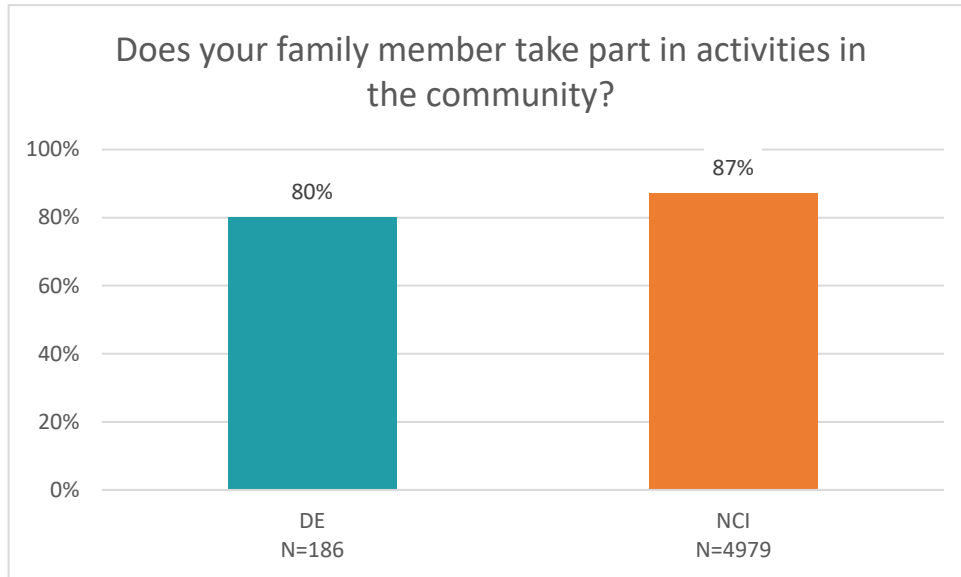
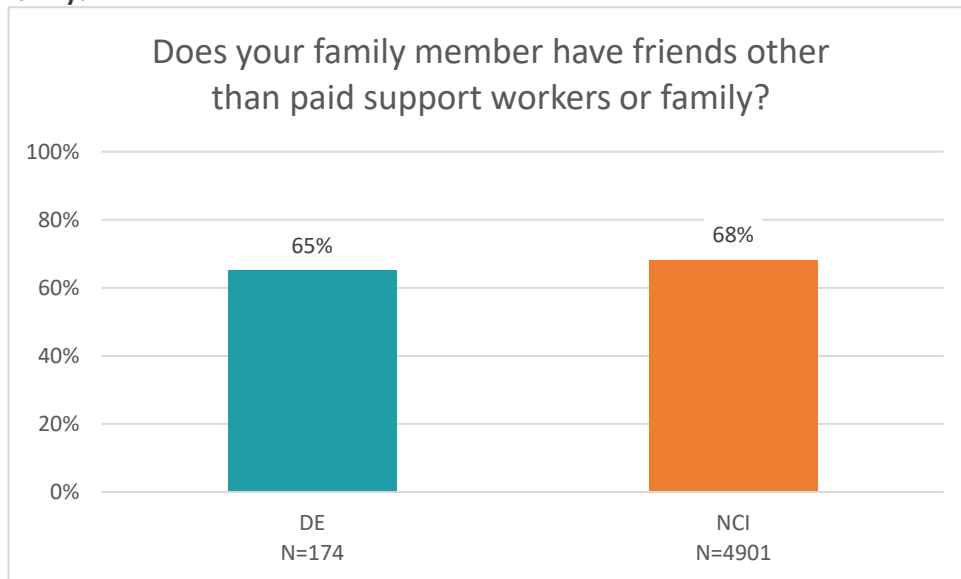
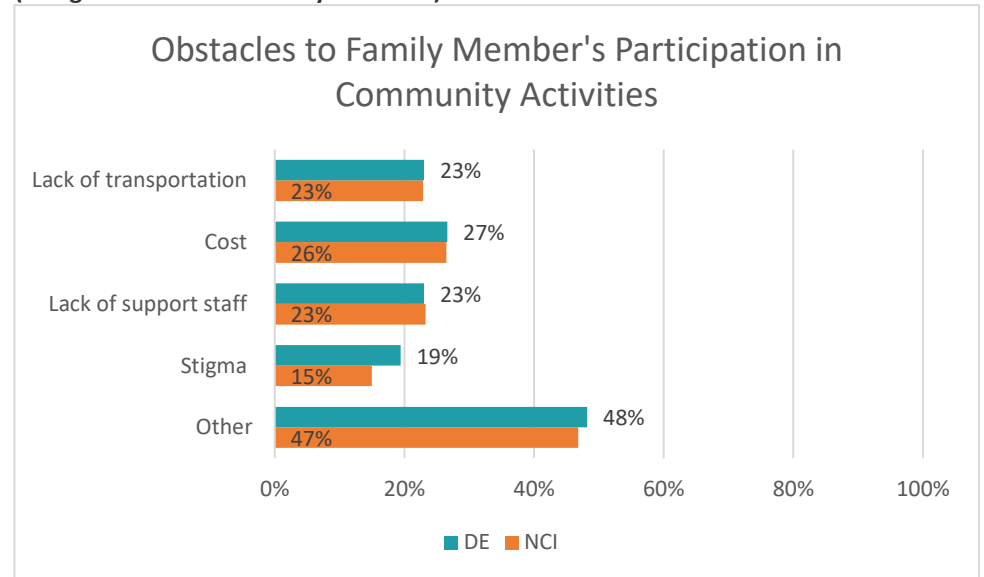
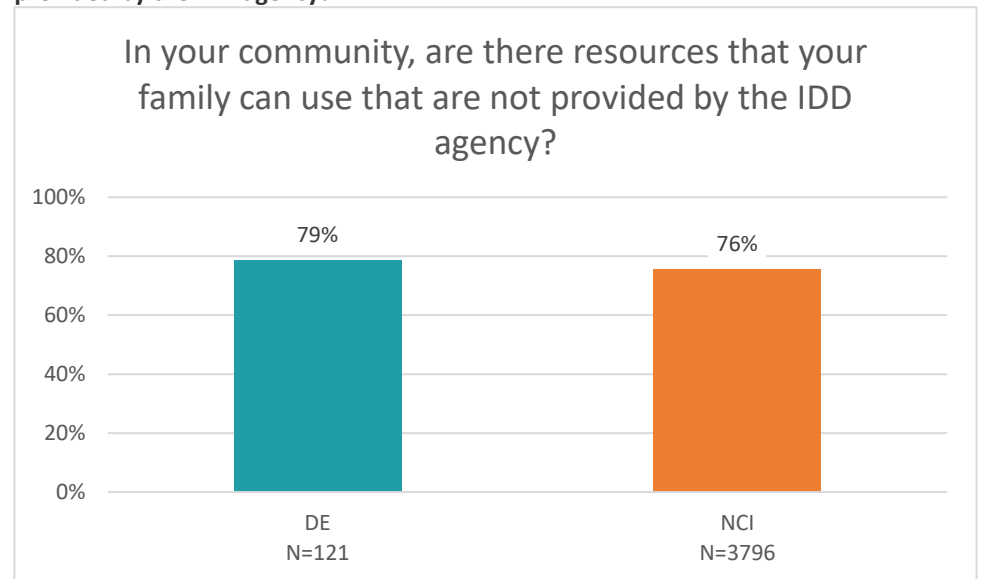
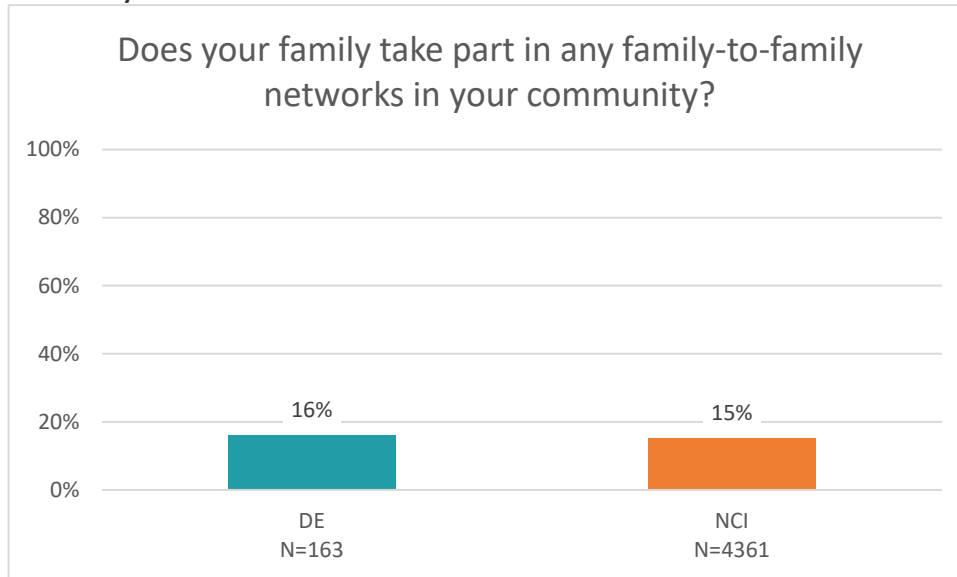
Chart 42. Does your family member take part in activities in the community?**Chart 44.** Does your family member have friends other than paid support workers or family?**Chart 43.** Obstacles/Barriers to family member's participation in community activities (categories are not mutually exclusive)**Chart 45.** In your community, are there resources that your family can use that are not provided by the IDD agency?

Chart 46. Does your family take part in any family-to-family networks in your community?



Tables for Involvement in the Community

Table 36. Involvement in the Community

		Yes	No	N
Does your family member take part in activities in the community?	DE	80%	20%	186
	NCI	87%	13%	4,979

Table 37. Obstacles to Family Member's Participation in Community Activities (categories are not mutually exclusive)

		Obstacles/Barriers
Lack of transportation	DE	23%
	NCI	23%
Cost	DE	27%
	NCI	26%
Lack of support staff	DE	23%
	NCI	23%
Stigma	DE	19%
	NCI	15%
Other	DE	48%
	NCI	47%

Table 38. Involvement in the Community (continued)

		Yes	No	N
Does your family member have friends other than paid support workers or family?	DE	65%	35%	174
	NCI	68%	32%	4,901
In your community, are there resources that your family can use that are not provided by the IDD agency?	DE	79%	21%	121
	NCI	76%	24%	3,796
Does your family take part in any family-to-family networks in your community?	DE	16%	84%	163
	NCI	15%	85%	4,361

Satisfaction With Services and Supports

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

Charts for Satisfaction With Services and Supports

Chart 47. Overall, are you satisfied with the services and supports your family currently receives?

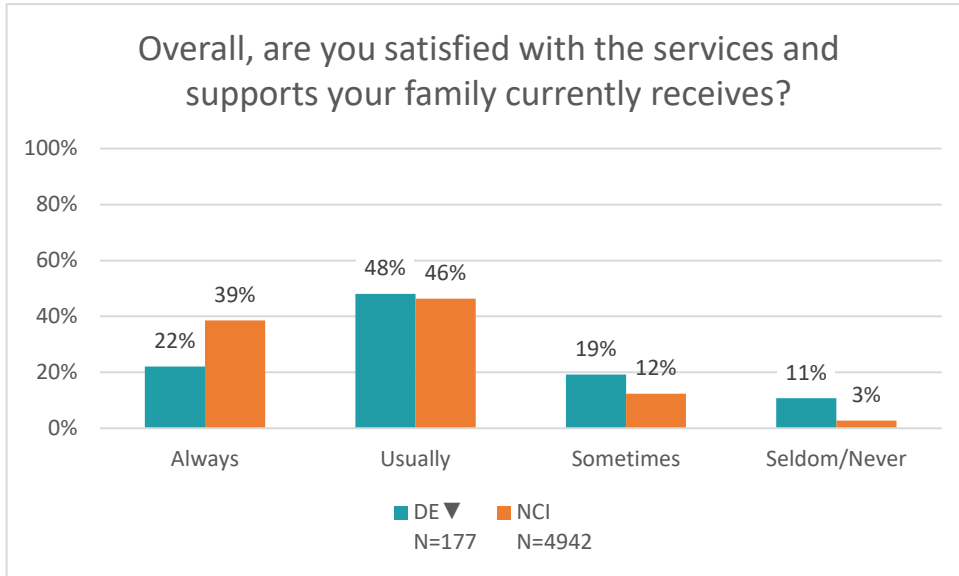


Chart 48. Do you know how to file a complaint or grievance about provider agencies or staff?*

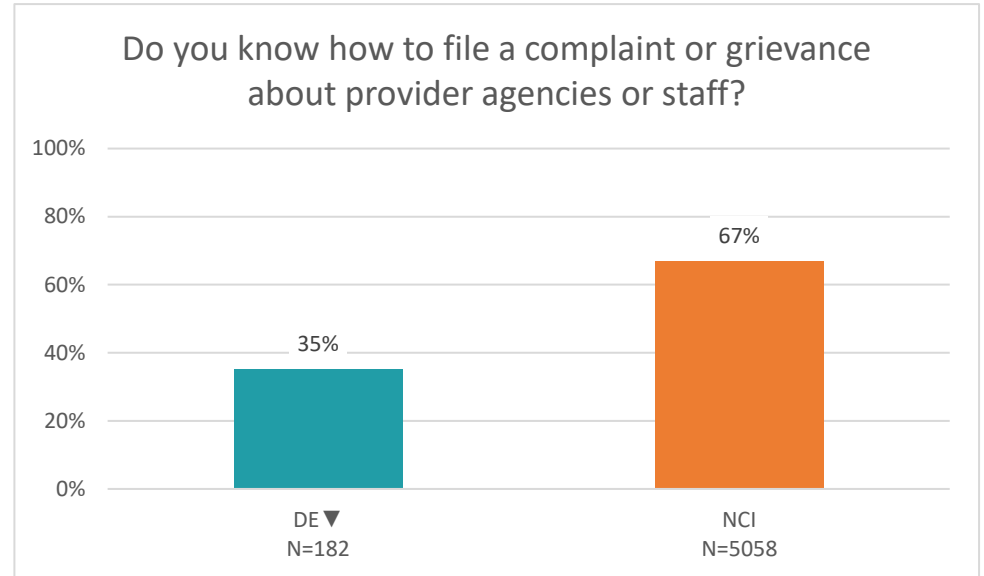


Chart 49. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

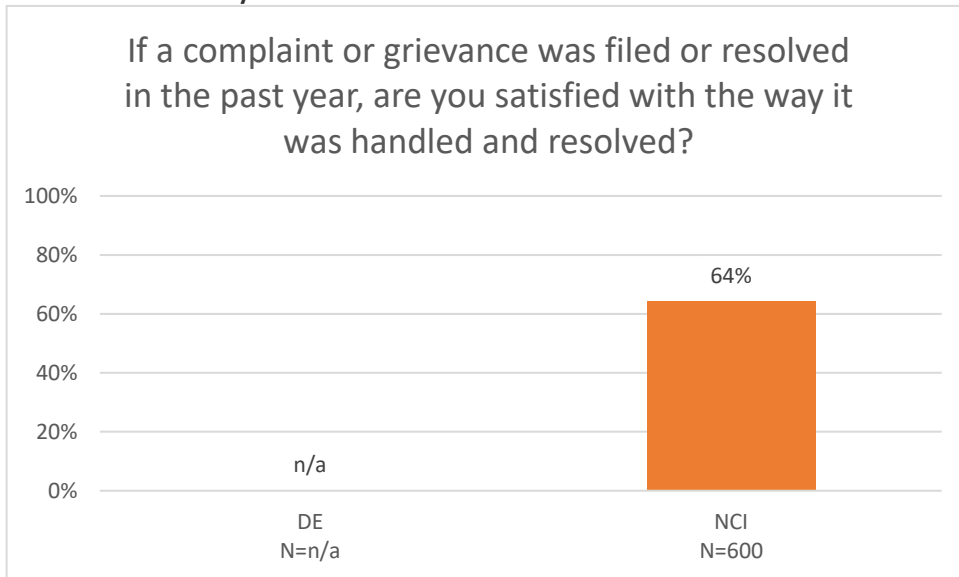
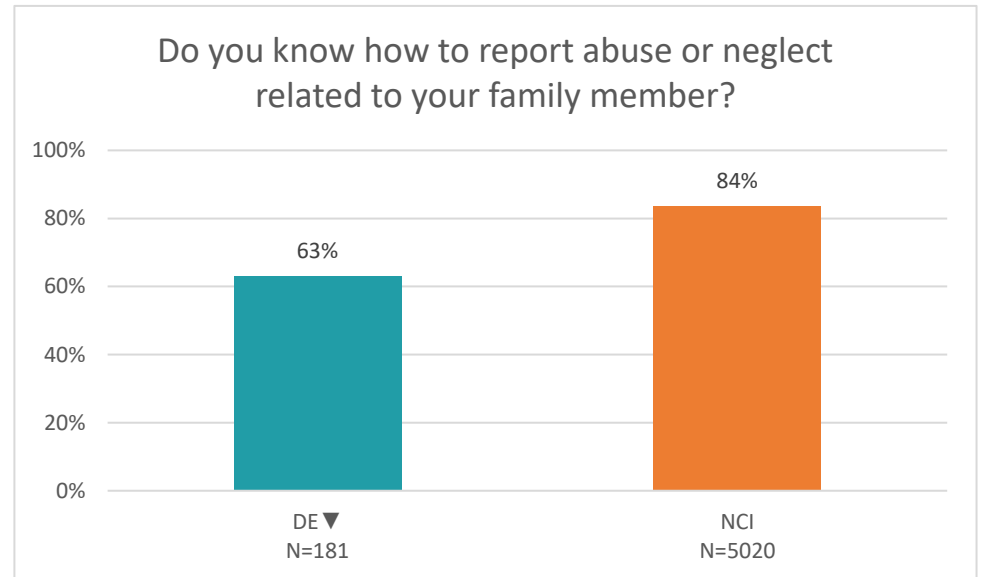


Chart 50. Do you know how to report abuse or neglect related to your family member?*



*No and don't know responses are combined

Chart 51. In the past year, was a report of abuse or neglect filed on behalf of your family member?

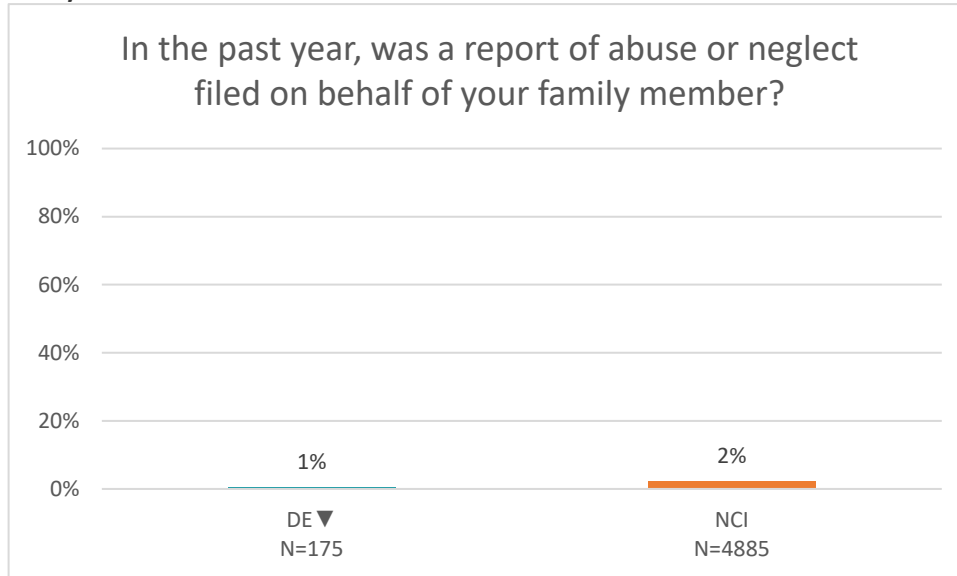


Chart 52. Do you feel that services and supports have made a positive difference in the life of your family?

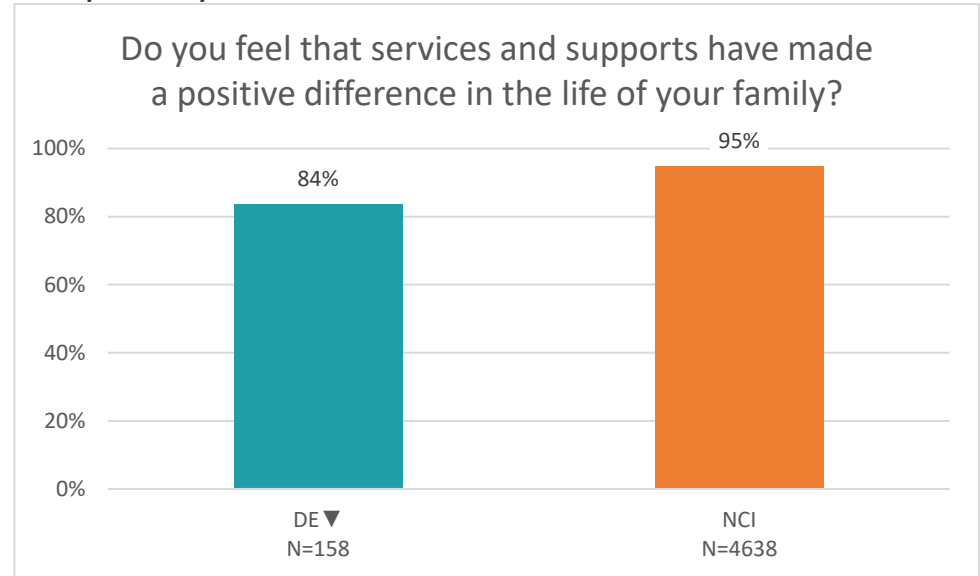


Chart 53. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?

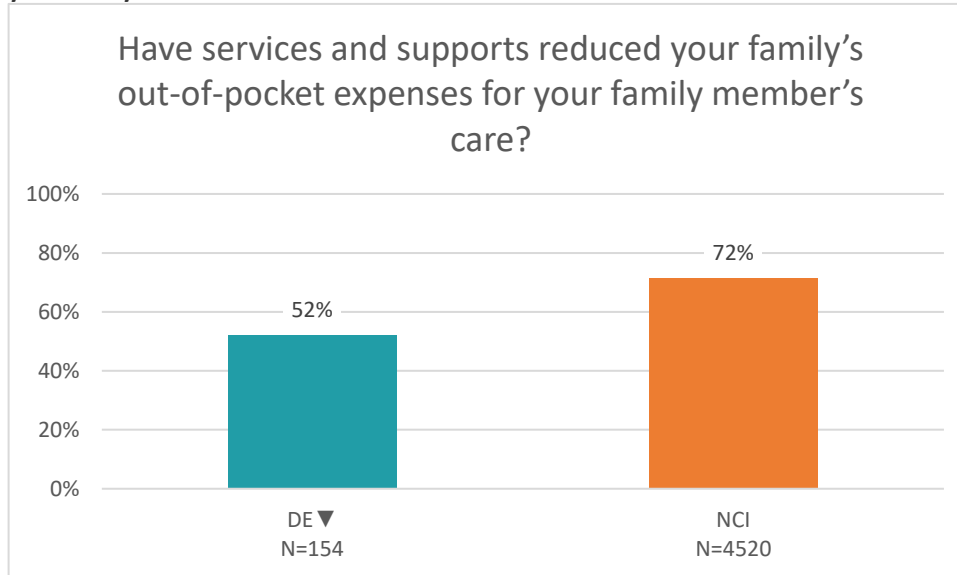


Chart 54. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?

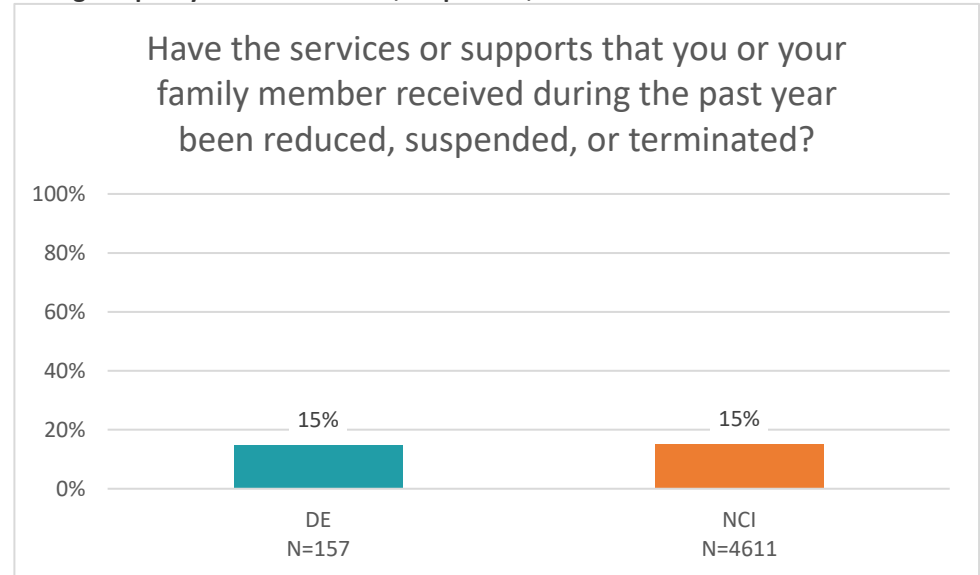


Chart 55. If services were reduced in the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?

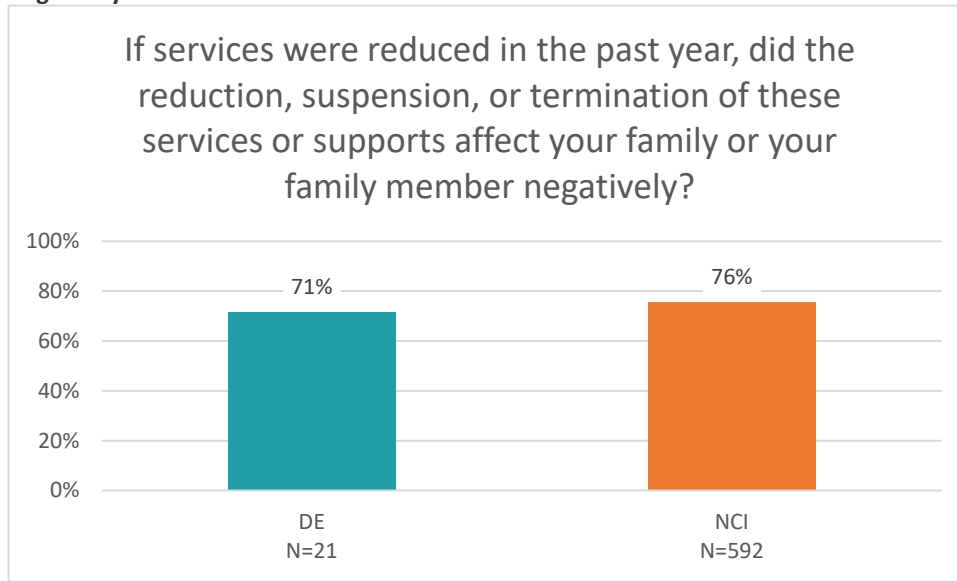


Chart 56. Have the services or supports that your family member received been increased in the past year?

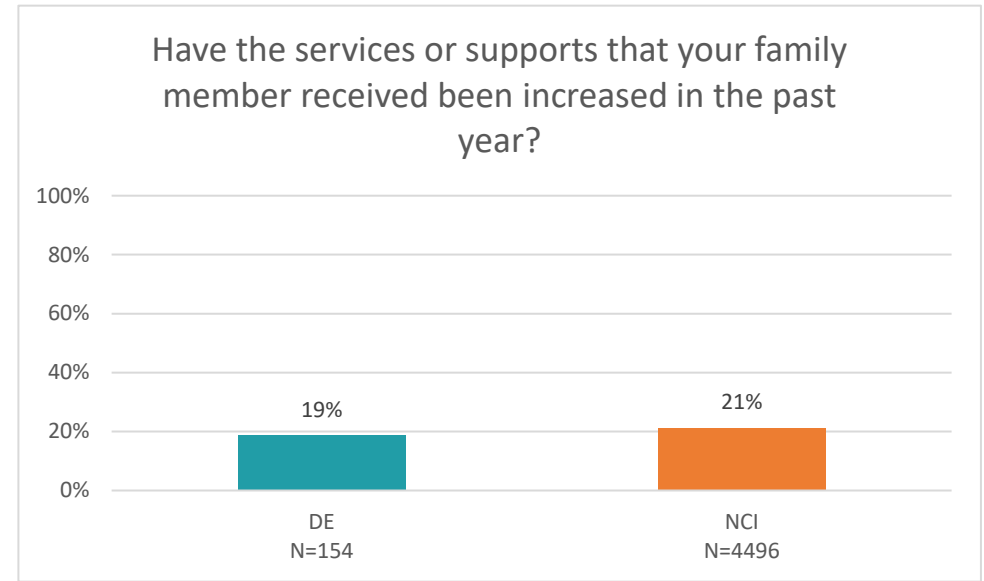
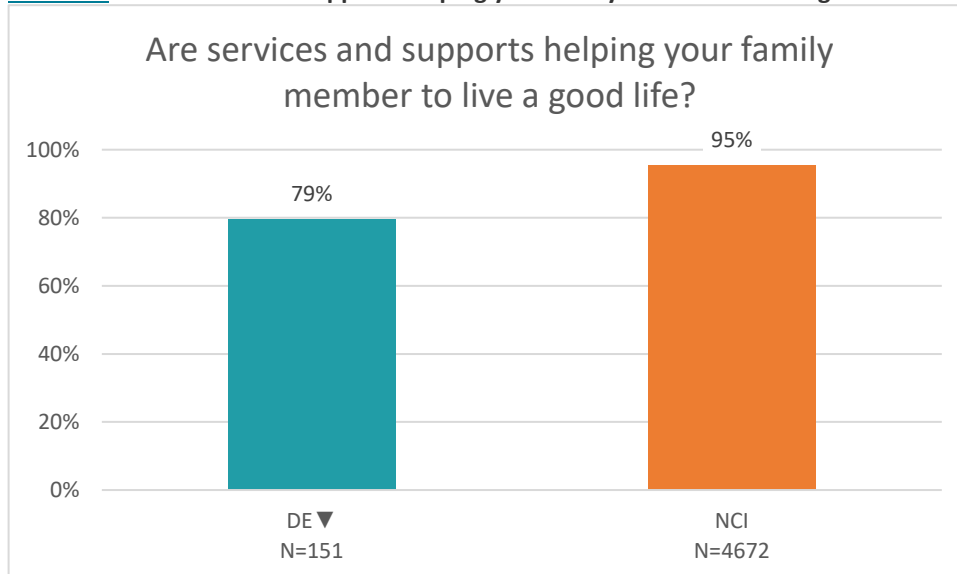


Chart 57. Are services and supports helping your family member to live a good life?



Tables for Satisfaction With Services and Supports

Table 39. Satisfaction With Service and Support

		Always	Usually	Sometimes	Seldom/Never	N
Overall, are you satisfied with the services and supports your family currently receives?	DE ▼	22%	48%	19%	11%	177
	NCI	39%	46%	12%	3%	4,942

Table 40. Satisfaction With Service and Supports (continued)

		Yes	No	N
Do you know how to file a complaint or grievance about provider agencies or staff? *	DE ▼	35%	49%	182
	NCI	67%	23%	5,058
If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?	DE	n/a	n/a	n/a
	NCI	64%	36%	600
Do you know how to report abuse or neglect related to your family member? *	DE ▼	63%	26%	181
	NCI	84%	10%	5,020
In the past year, was a report of abuse or neglect filed on behalf of your family member?	DE ▼	1%	99%	175
	NCI	2%	98%	4,885

*No and don't know responses are combined

Table 41. Satisfaction With Service and Supports (continued)

		Yes	No	N
Do you feel that services and supports have made a positive difference in the life of your family?	DE ▼	84%	16%	158
	NCI	95%	5%	4,638
Have services and supports reduced your family's out-of-pocket expenses for your family member's care?	DE ▼	52%	48%	154
	NCI	72%	28%	4,520
Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?	DE	15%	85%	157
	NCI	15%	85%	4,611
If services were reduced in the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?	DE	71%	29%	21
	NCI	76%	24%	592
Have the services or supports that your family member received been increased in the past year?	DE	19%	81%	154
	NCI	21%	79%	4,496
Are services and supports helping your family member to live a good life?	DE ▼	79%	21%	151
	NCI	95%	5%	4,672