

2017-18 FAMILY/GUARDIAN SURVEY
SOUTH DAKOTA REPORT



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What is NCI?

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

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

What is the NCI Family/Guardian Survey?

The NCI Family/Guardian Survey is used to gather data on family outcomes. It is mailed to families who have an adult family member who lives somewhere other than 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 4,890 Family/Guardian Surveys were completed across ten 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 Family/Guardian Survey in 2017-18 were: AZ, FL, GA, MD, NH, NC, PA, SD, UT 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 1,200 families, all of whom have an adult family member with a developmental disability who lives somewhere other than the family home and receives at least one direct service or support other than service coordination.

Beginning in 2016-17, states had a choice of mailing paper surveys to families selected in their sample, sending a URL link for families to complete surveys online (referred to as “direct entry”), or both. In previous years, states only had the option to mail paper surveys. In 2017-18, a total of three 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: 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 Family/Guardian 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 somewhere other than 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 Family/Guardian 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 Family/Guardian Survey is a tool for assessing system-wide performance. It is not intended to be used to monitor individuals or providers. The NCI Statewide Average should not be interpreted as defining or providing a benchmark for "acceptable" levels of performance or satisfaction. Instead, it describes average levels of performance or satisfaction across the state; it is up to public managers, 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 Report.

What is contained in this report?

This report illustrates the 2017-18 NCI Family/Guardian Survey demographic and outcome results from South Dakota (SD) 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. Family member's residence⁵

		Specialized Facility for People With ID	Group Home	Agency Operated Apartment	Independent Home or Apartment	Adult Foster Care or Host Family Home	Nursing Home	Homeless	Other	N
Family Member's Residence	SD	18%	45%	23%	13%	0%	0%	0%	1%	487
	NCI	11%	57%	7%	15%	7%	1%	0%	3%	4,791

Table 2. Family member's residential designation

		Urban or Suburban	Rural	N
Family Member's Residential Setting	SD	97%	3%	484
	NCI	80%	20%	4,743

Table 3. Family member's average age

		Average Age	N
Family Member's Age	SD	43.9	481
	NCI	47.9	4,724

Table 4. Family member's gender

		Male	Female	N
Family Member's Gender	SD	55%	45%	496
	NCI	58%	42%	4,838

⁵ Specialized Facility for People With ID includes ICF, state-run or other institutional settings

Table 5. 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	Hispanic or Latino	Other or Unknown
Family Member's Race and Ethnicity	SD	10%	2%	1%	0%	90%	1%	0%
	NCI	3%	2%	10%	0%	84%	3%	1%

Table 6. 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	SD	73%	37%	19%	15%	9%	10%	9%
	NCI	78%	36%	22%	18%	9%	7%	10%

Table 7. 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	SD	25%	1%	12%	1%	4%	10%
	NCI	28%	1%	11%	1%	2%	12%

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

		Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
Family Member's Health Conditions	SD	10%	22%	4%	25%	17%
	NCI	10%	19%	7%	32%	32%

Table 9. 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	SD	17%	2%	6%	14%	20%	18%
	NCI	13%	3%	6%	15%	12%	21%

Table 10. 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	SD	81%	13%	3%	2%	1%	480
	NCI	76%	17%	2%	1%	4%	4,806

Table 11. Family member has legal court appointed guardian or conservator

		None	Limited	Full	Has Guardianship but Level Is Unknown	N
Level of Guardianship or Conservatorship of Family Member	SD	2%	12%	79%	6%	493
	NCI	25%	17%	52%	6%	4,559

Table 12. Guardian or conservator relationship to family member

		Family	Friend	State Employee or Guardianship Agency	Other	N
Guardian or Conservator Relationship to Family Member	SD	89%	3%	6%	1%	476
	NCI	83%	3%	9%	4%	3,279

Table 13. 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	SD	43%	0%	28%	23%	2%	2%	2%	466
	NCI	39%	1%	32%	20%	3%	2%	3%	4,503

Table 14. Family member's typical day activity

		Usually/Often	Sometimes	Never	N
Paid Individual Job in the Community	SD	22%	6%	72%	472
	NCI	15%	4%	82%	4,515
Paid Small Group Job in a Community-based Setting	SD	16%	8%	76%	463
	NCI	10%	4%	85%	4,436
Unpaid Activity in the Community	SD	13%	29%	58%	466
	NCI	18%	14%	68%	4,495
Paid Work in a Community Business That Primarily Hires People With Disabilities	SD	12%	5%	82%	465
	NCI	7%	3%	90%	4,459
Paid Activity in a Facility-based Setting	SD	30%	13%	57%	470
	NCI	19%	5%	76%	4,492
Unpaid Activity in a Facility-based Setting	SD	24%	10%	66%	463
	NCI	33%	6%	61%	4,495
School	SD	2%	1%	97%	469
	NCI	5%	2%	93%	4,460
Stays at Home	SD	30%	25%	44%	455
	NCI	28%	24%	47%	4,280
Other	SD	73%	21%	6%	33
	NCI	48%	10%	42%	1,196

Table 15. Family member's support needs

		Extensive	Some	None	N
Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	SD	22%	41%	36%	488
	NCI	29%	36%	35%	4,729
Family Member's Need for Help With Personal Care Activities	SD	32%	40%	27%	496
	NCI	42%	38%	20%	4,808
Family Member's Need for Help With Other Daily Activities	SD	72%	26%	2%	496
	NCI	82%	16%	2%	4,807

Respondents

This section provides demographic information about the respondent.

Table 16. Respondent's age

		Under 35	35-54	55-74	75+	N
Respondent's Age	SD	1%	17%	65%	18%	482
	NCI	2%	12%	63%	22%	4,788

Table 17. Respondent's health

		Excellent	Very Good	Fairly Good	Poor	N
Respondent's Health	SD	18%	48%	33%	1%	483
	NCI	18%	45%	33%	5%	4,790

Table 18. Respondent's relationship to family member

		Parent	Sibling	Spouse	Grandparent	Public Guardian	Private Guardian	Other	N
Respondent's Relationship to Family Member	SD	61%	22%	0%	2%	5%	3%	6%	486
	NCI	54%	27%	0%	1%	4%	5%	8%	4,804

Table 19. Respondent's frequency of visits with family member last year

		Less Than Once	1-3 Times	4-6 Times	7-12 Times	12 or More Times	N
How Often Respondent Sees Family Member Each Year	SD	4%	10%	12%	15%	58%	488
	NCI	4%	9%	11%	13%	63%	4,794

Table 20. 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	SD	4%	25%	11%	23%	37%	482
	NCI	4%	22%	6%	23%	45%	4,762

Table 21. Past year total household taxable income of wage earners

		No Earned Income	Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	Prefer Not to Say	N
Total Taxable Income of Wage Earners in the Household in Past Year	SD	8%	5%	9%	23%	17%	12%	27%	467
	NCI	11%	5%	10%	17%	13%	17%	28%	4,535

Services and Supports Received

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

Table 22. Services and supports received from state (categories are not mutually exclusive)

		Services and Supports Received From State
Financial Support	SD	25%
	NCI	31%
In-home Support	SD	32%
	NCI	46%
Residential Supports	SD	94%
	NCI	90%
Day or Employment Supports	SD	65%
	NCI	65%
Transportation	SD	92%
	NCI	91%
Other	SD	63%
	NCI	60%
Self-direction or Fiscal Intermediary Services	SD	32%
	NCI	30%

Table 23. 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)	SD	97%
	NCI	95%
Services or Supports From Other Agencies or Organizations	SD	26%
	NCI	32%

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?

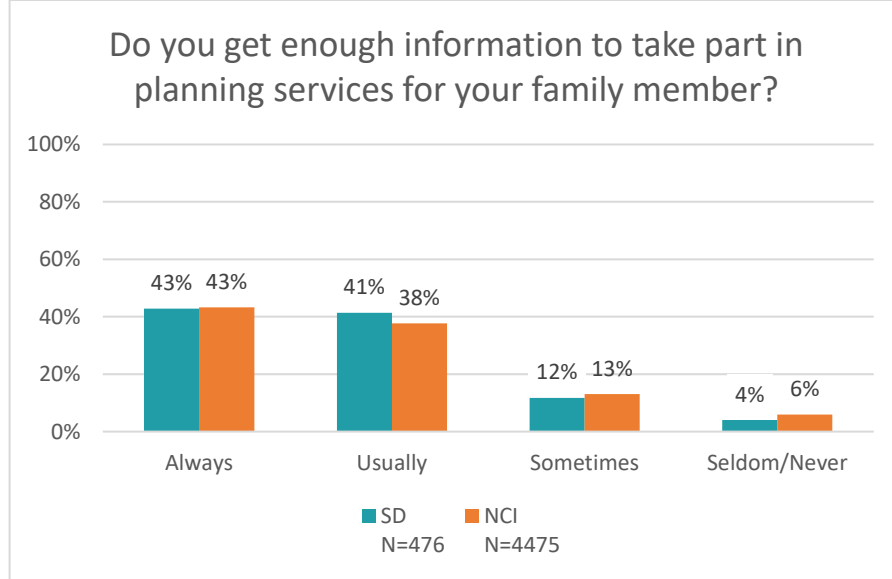


Chart 2. Is the information you get about services and supports easy to understand?

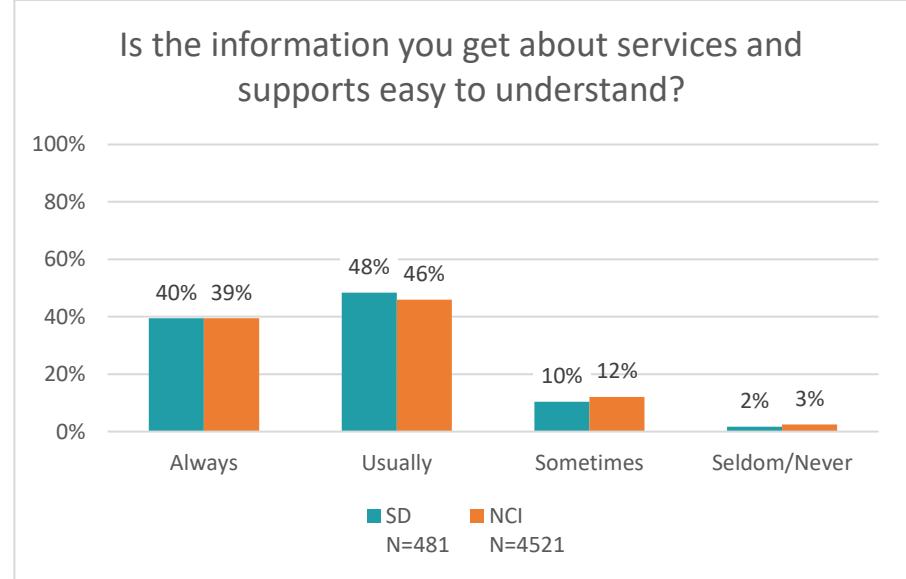


Chart 3. Do staff or the residential agency keep you informed about how your family member is doing?

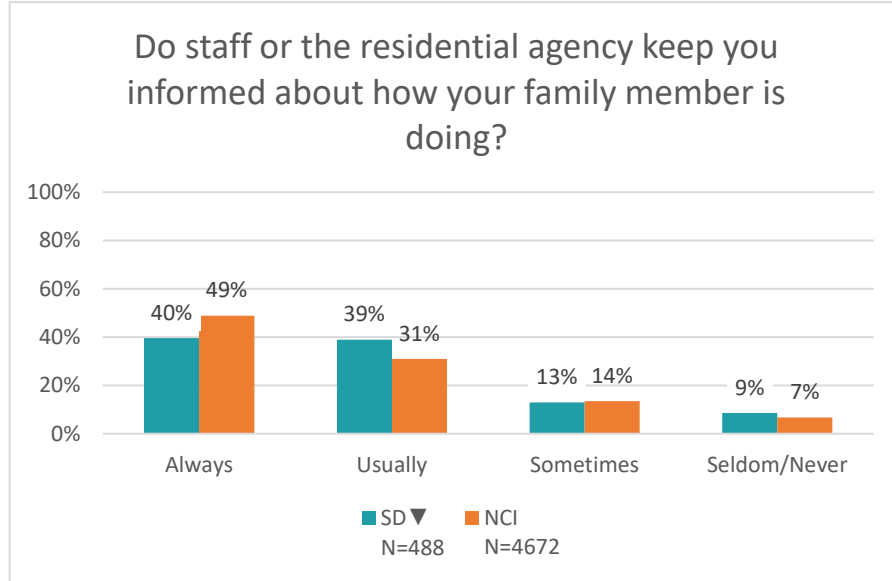


Chart 4. Does the case manager/service coordinator respect your family's choices and opinions?

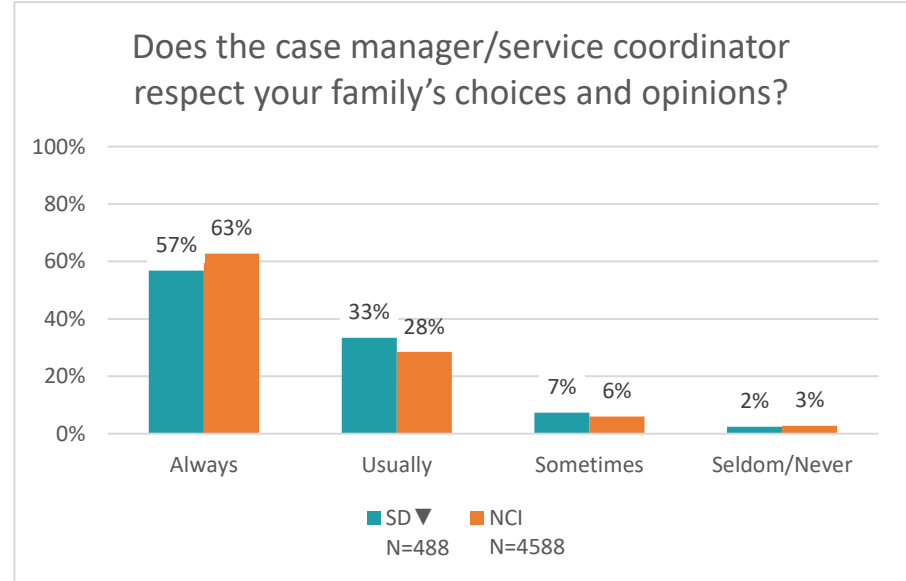


Chart 5. Respondent's future planning needs

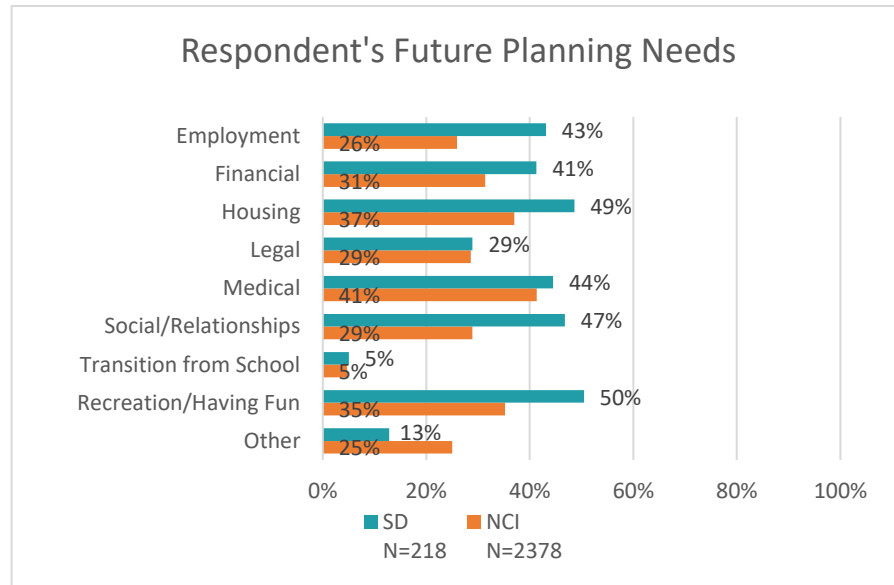


Chart 6. In the past year, did your family member move out of the family home for the first time?

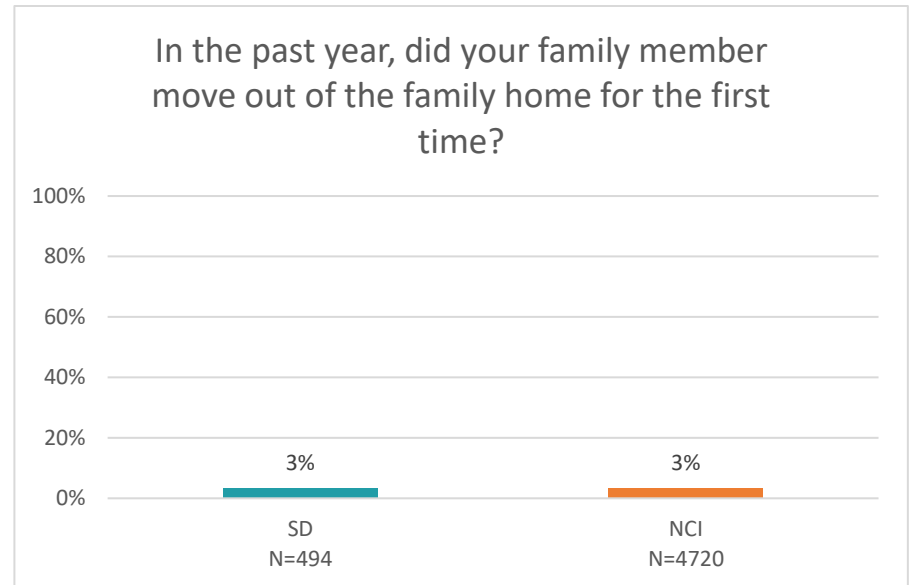


Chart 7. If family member moved out of the home for the first time in the past year, did you have enough choices of service providers to support your family member living outside the family home?

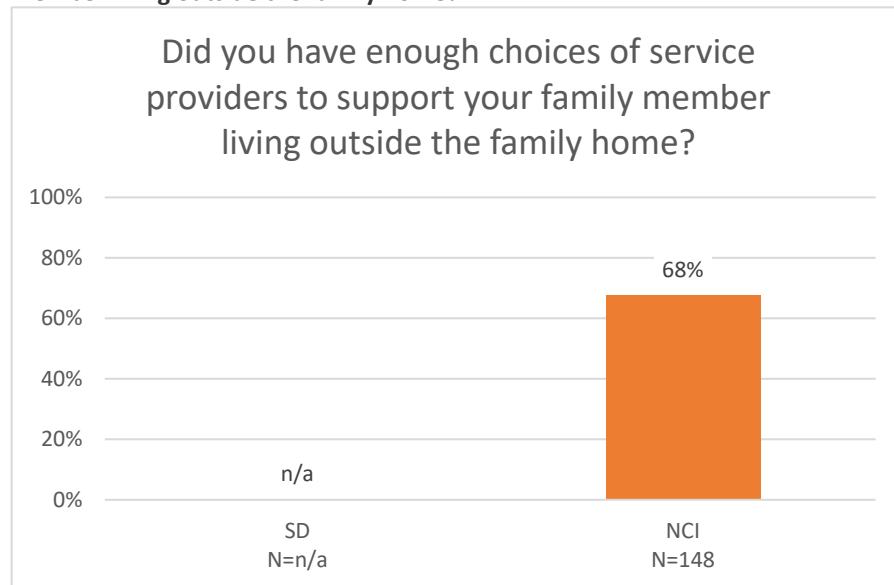


Chart 8. Does your family member have a service plan?

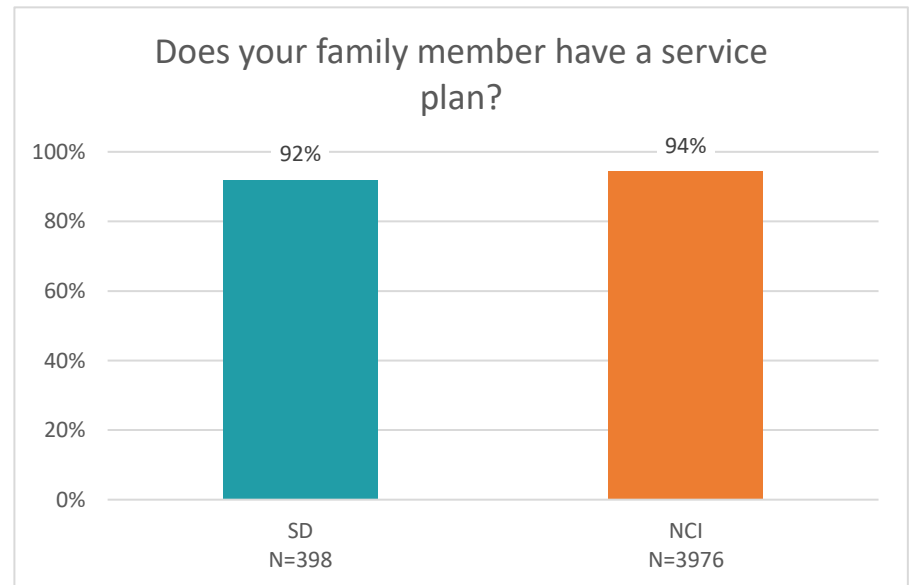


Chart 9. Does the plan include all the services and supports your family member needs?

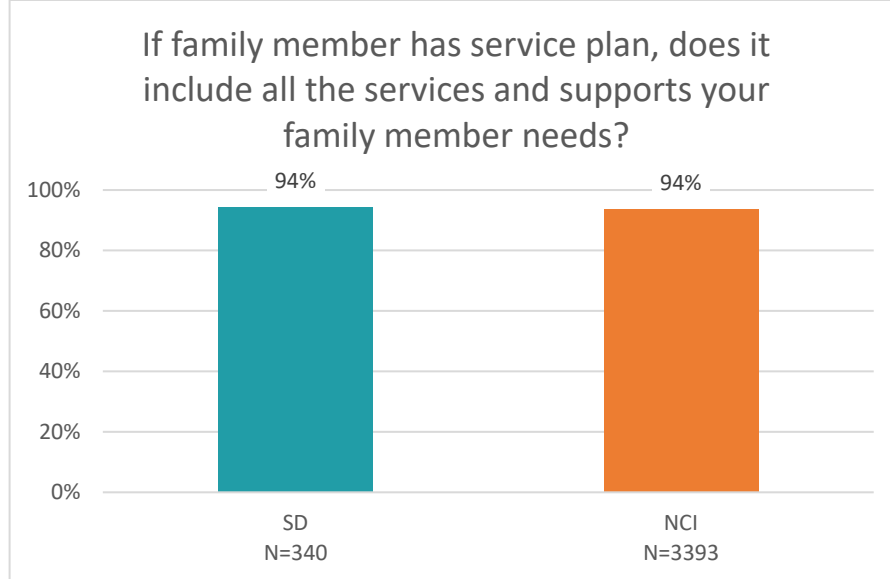


Chart 10. Does your family member get all of the services listed in the plan?

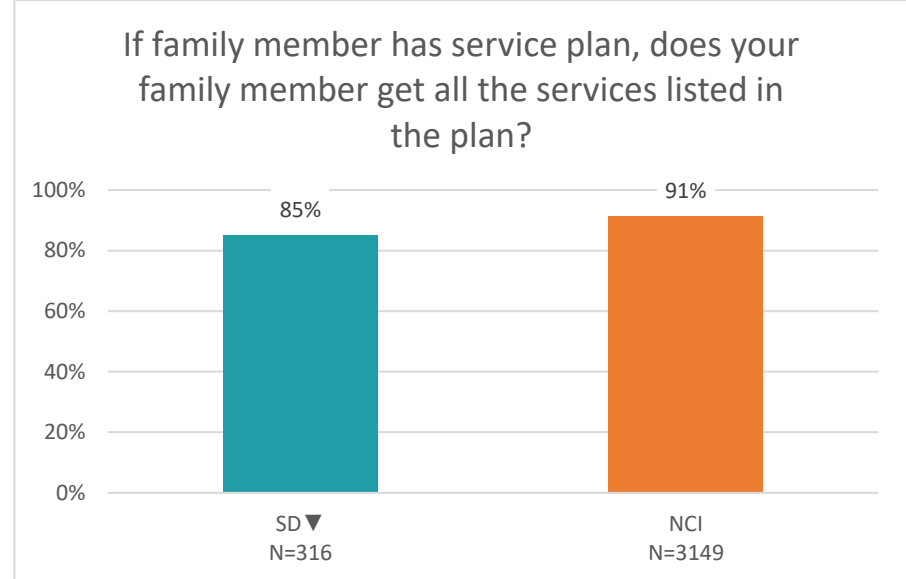


Chart 11. Did you or another family member (besides your family member with a disability) help make the plan?

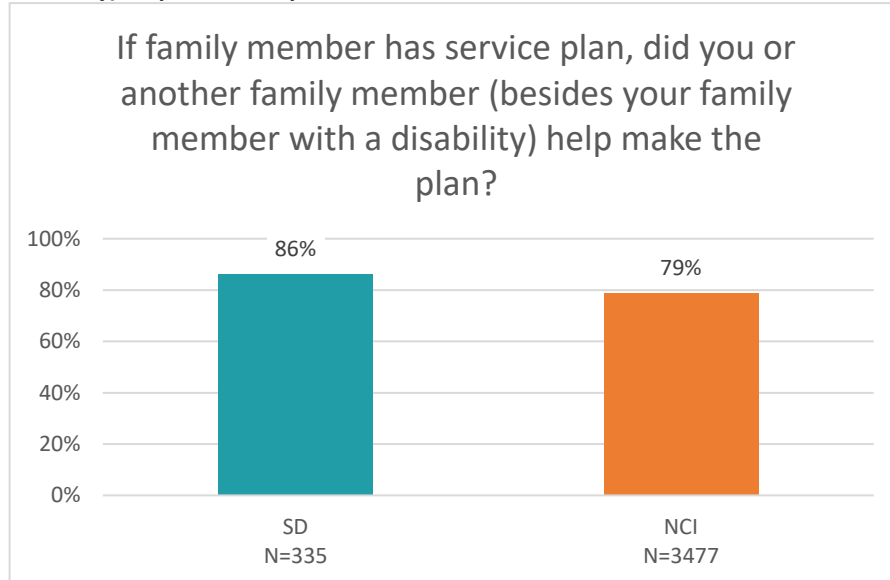


Chart 12. Did your family member help make the plan?

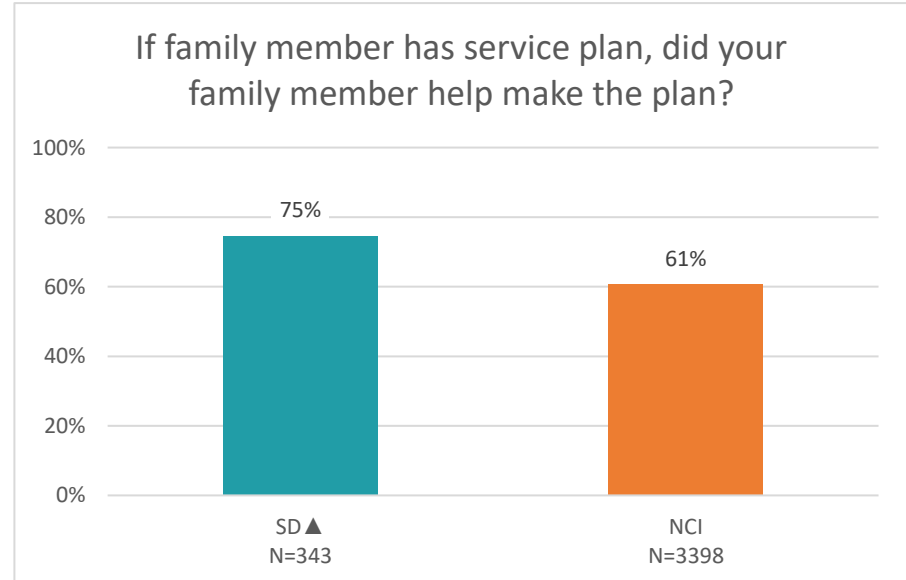


Chart 13. Did you discuss how to handle emergencies at your family member's last service planning meeting?

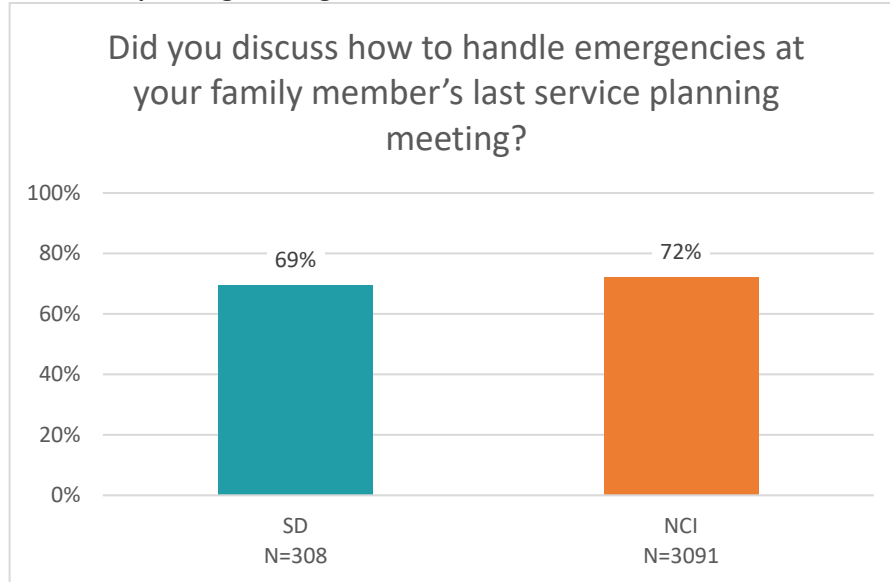


Chart 14. If your family member transitioned out of school services during the past year, did s/he have a transition plan?

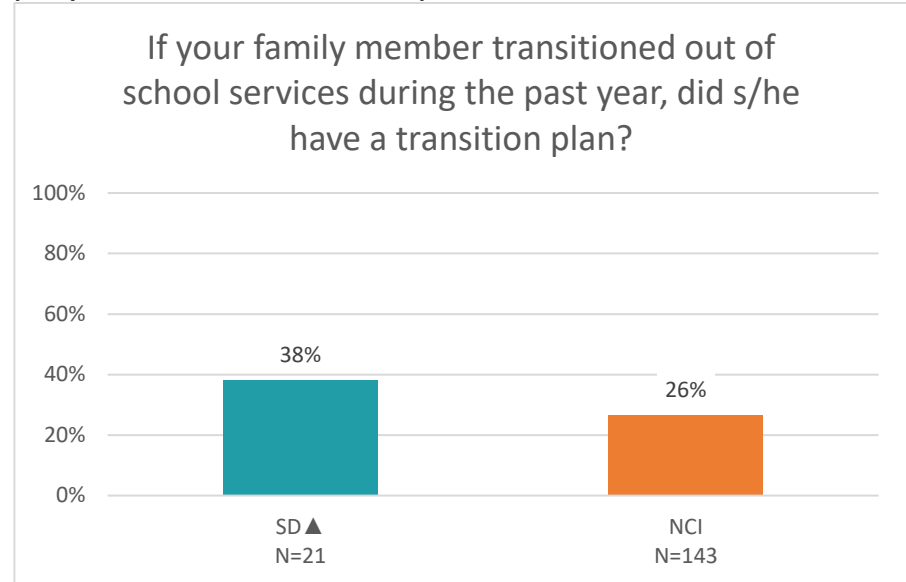


Chart 15. Does your family member have enough supports to work or volunteer in the community?

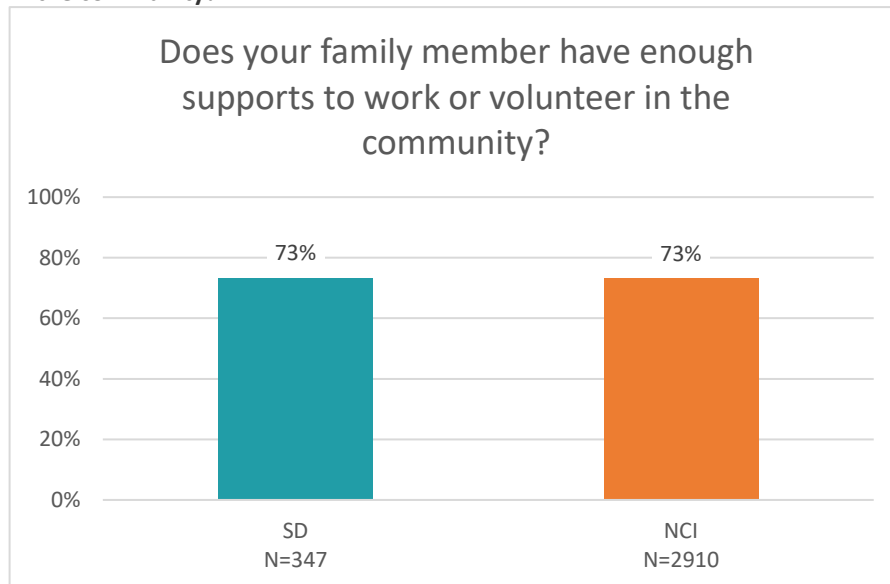
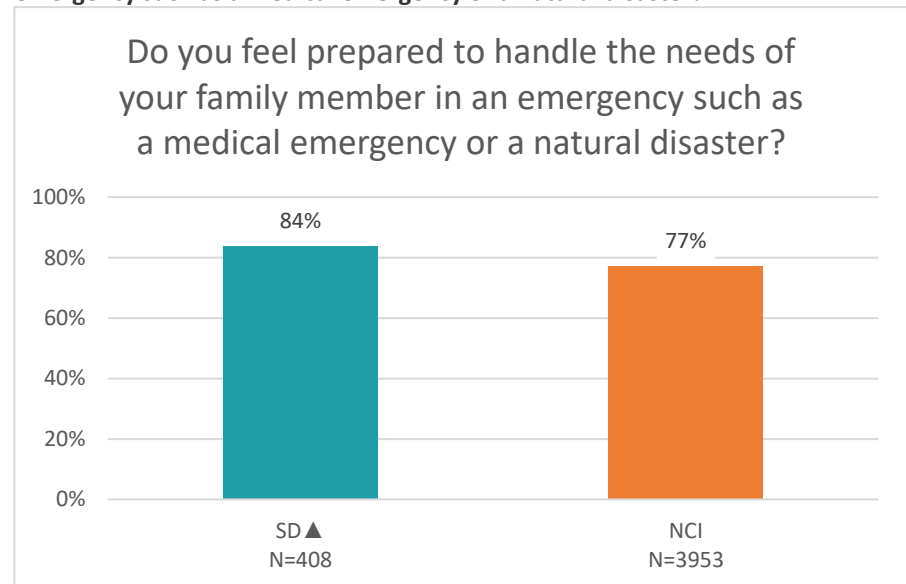


Chart 16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?



Tables for Information and Planning

Table 24. Information and Planning

		Always	Usually	Sometimes	Seldom/Never	N
Do you get enough information to take part in planning services for your family member?	SD	43%	41%	12%	4%	476
	NCI	43%	38%	13%	6%	4,475
Is the information you get about services and supports easy to understand?	SD	40%	48%	10%	2%	481
	NCI	39%	46%	12%	3%	4,521
Do staff or the residential agency keep you informed about how your family member is doing?	SD ▼	40%	39%	13%	9%	488
	NCI	49%	31%	14%	7%	4,672
Does the case manager/service coordinator respect your family's choices and opinions?	SD ▼	57%	33%	7%	2%	488
	NCI	63%	28%	6%	3%	4,588

Table 25. Respondent Needs Help With Future Planning Needs

		Yes
Employment	SD	43%
	NCI	26%
Financial	SD	41%
	NCI	31%
Housing	SD	49%
	NCI	37%
Legal	SD	29%
	NCI	29%
Medical	SD	44%
	NCI	41%
Social or Relationships	SD	47%
	NCI	29%
Transition from School	SD	5%
	NCI	5%
Recreation	SD	50%
	NCI	35%
Other	SD	13%
	NCI	25%
N	SD	218
	NCI	2,378

Table 26. Information and Planning (continued)

		Yes	No	N
In the past year, did your family member move out of the family home for the first time?	SD	3%	97%	494
	NCI	3%	97%	4,720
If family member moved out of the family home for the first time in the past year...				
Did you have enough choices of service providers to support your family member living outside the family home?	SD	n/a	n/a	n/a
	NCI	68%	32%	148
Does your family member have a service plan?	SD	92%	8%	398
	NCI	94%	6%	3,976
If your family member has a service plan...				
Does it include all the services and supports your family member needs?	SD	94%	6%	340
	NCI	94%	6%	3,393
Does your family member get all the services listed in the plan?	SD▼	85%	15%	316
	NCI	91%	9%	3,149
Did you or another family member (beside your family member with a disability) help make the plan?	SD	86%	14%	335
	NCI	79%	21%	3,477
Did your family member help make the plan?	SD▲	75%	25%	343
	NCI	61%	39%	3,398
Did you discuss how to handle emergencies at your family member's last service planning meeting?	SD	69%	31%	308
	NCI	72%	28%	3,091
If your family member transitioned out of school services during the past year, did s/he have a transition plan?	SD▲	38%	62%	21
	NCI	26%	74%	143
Does your family member have enough supports to work or volunteer in the community?	SD	73%	27%	347
	NCI	73%	27%	2,910
Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?	SD▲	84%	16%	408
	NCI	77%	23%	3,953

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?

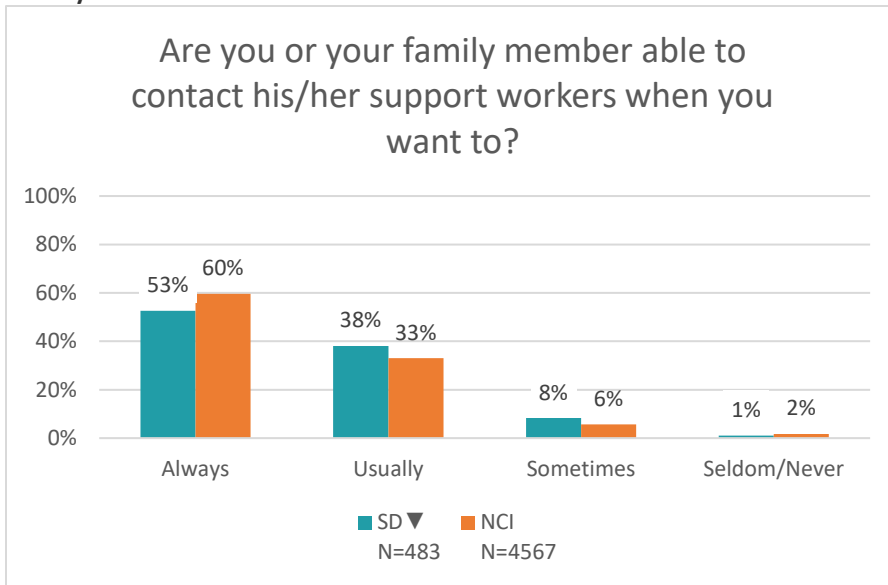


Chart 18. Are you or your family member able to contact his/her case manager/service coordinator when you want to?

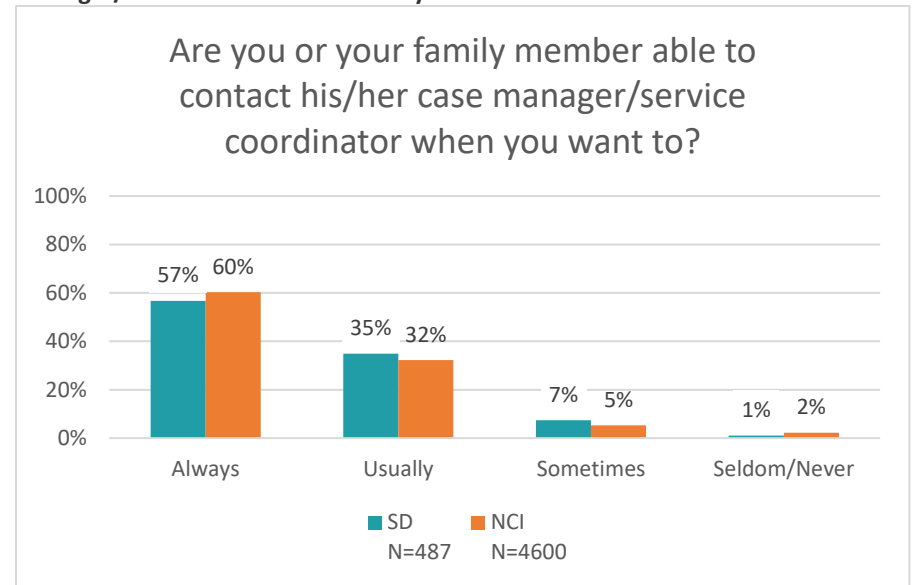


Chart 19. Do support workers come and leave when they are supposed to?

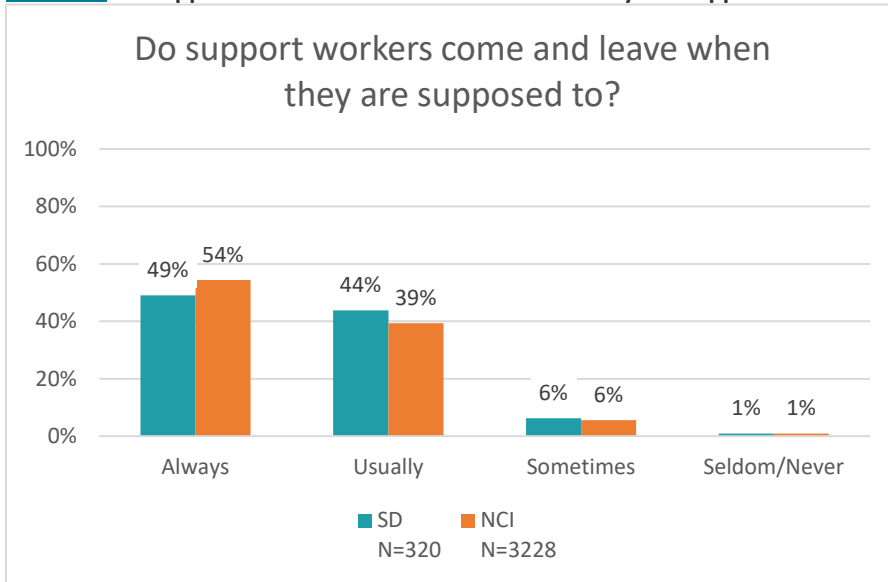


Chart 20. Do services and supports change when your family's needs change?

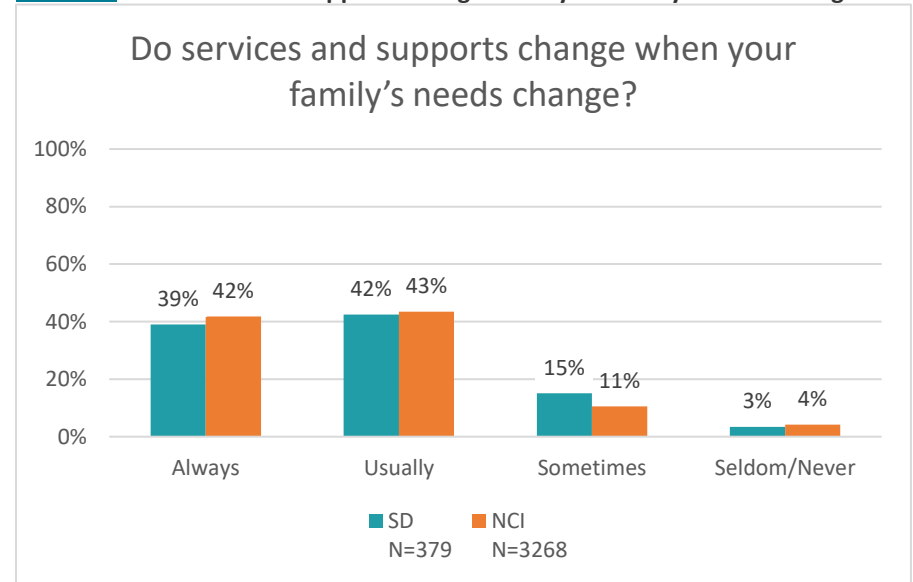


Chart 21. Do support workers speak to you in a way that you understand?

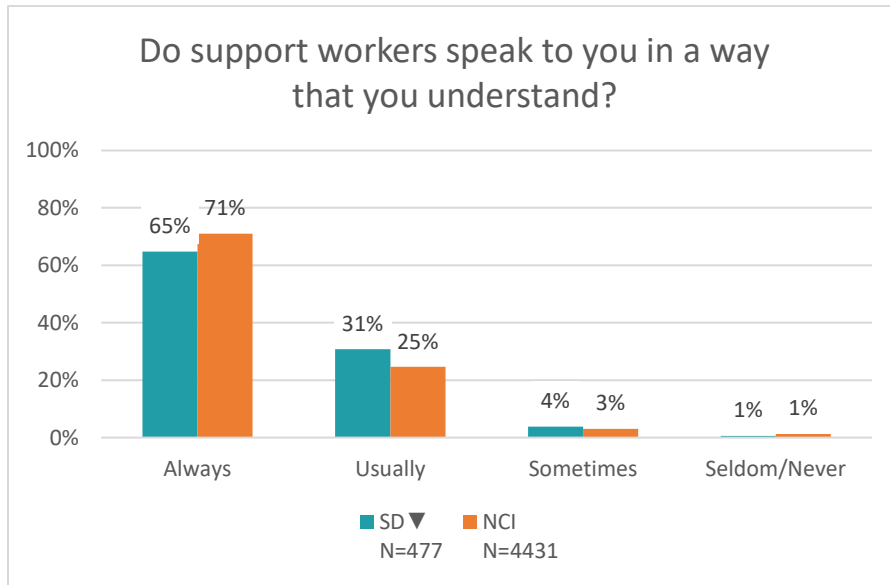


Chart 22. Are services delivered in a way that is respectful of your family's culture?

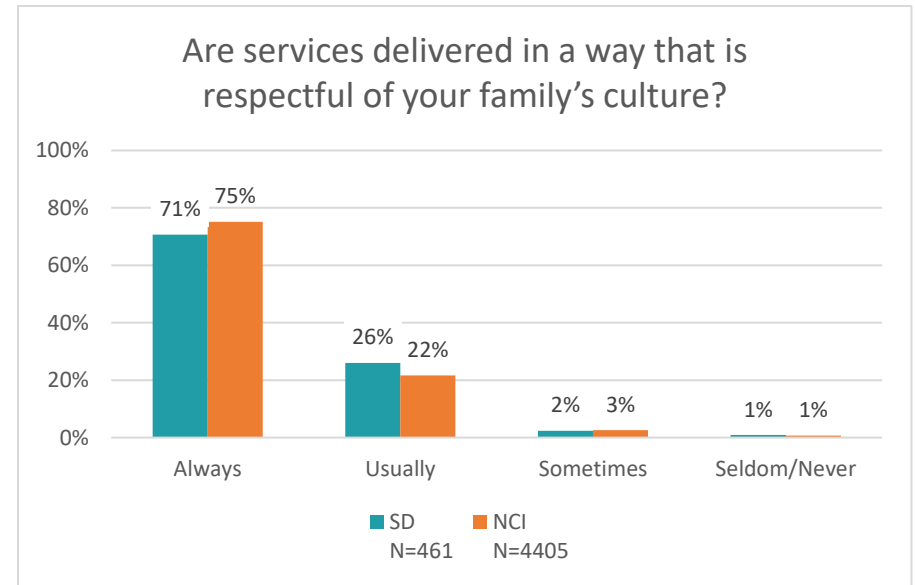


Chart 23. If your family member does not communicate verbally, are there support workers who can communicate with him/her?

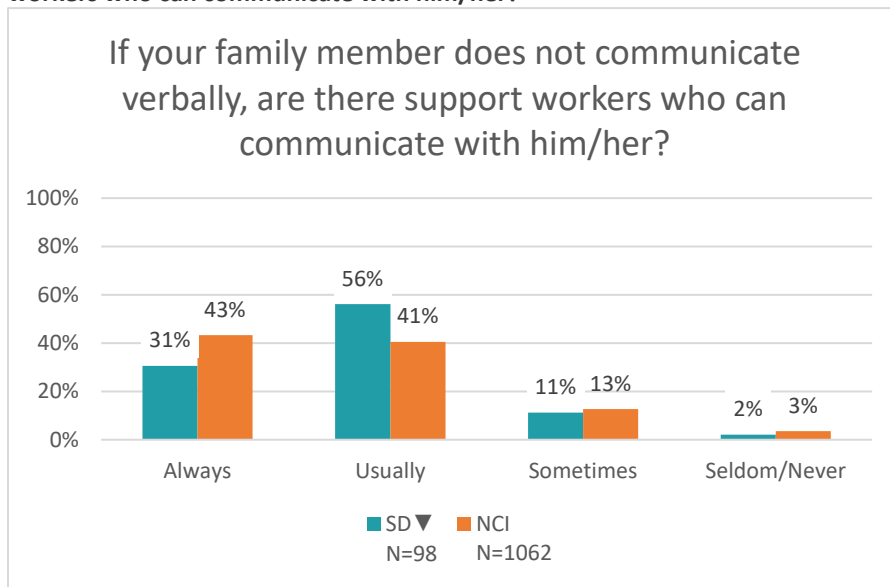


Chart 24. Do support workers have the right information and skills to meet your family's needs?

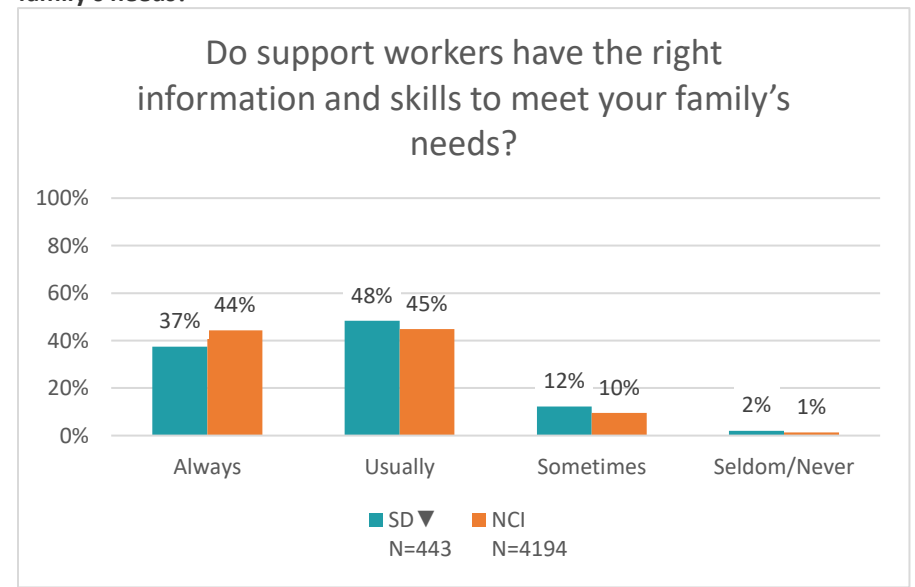


Chart 25. Does your family member have the special equipment or accommodations that s/he needs?

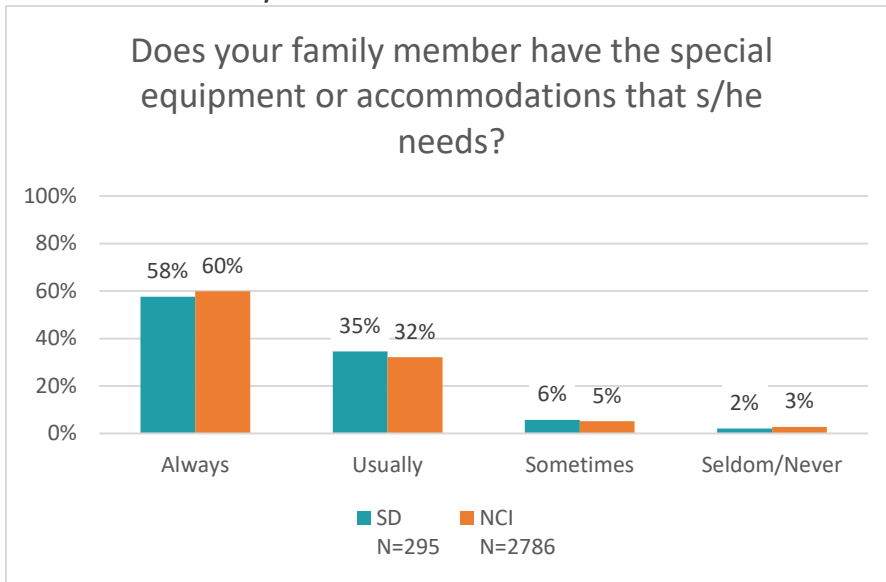


Chart 26. Can your family member see health professionals when needed?

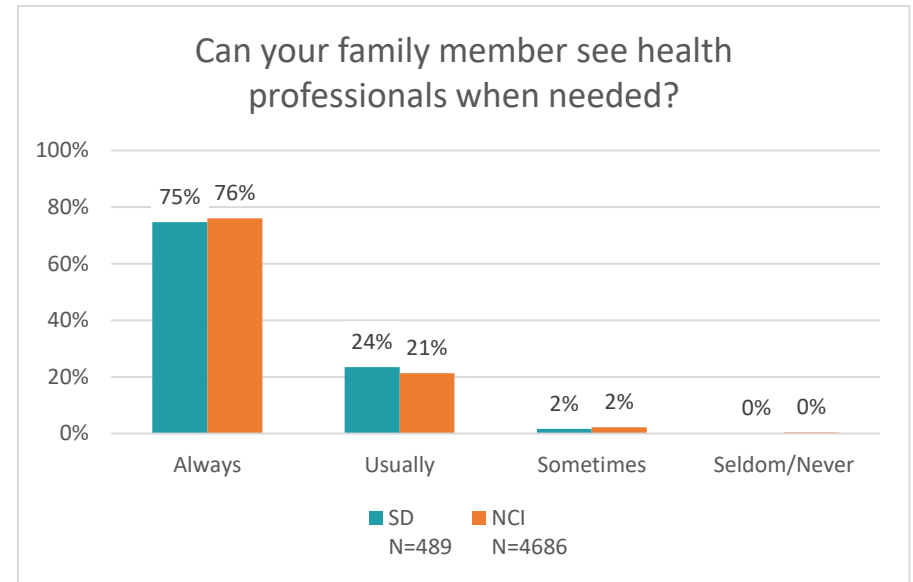


Chart 27. Does your family member's primary care doctor understand his/her needs related to his/her disability?

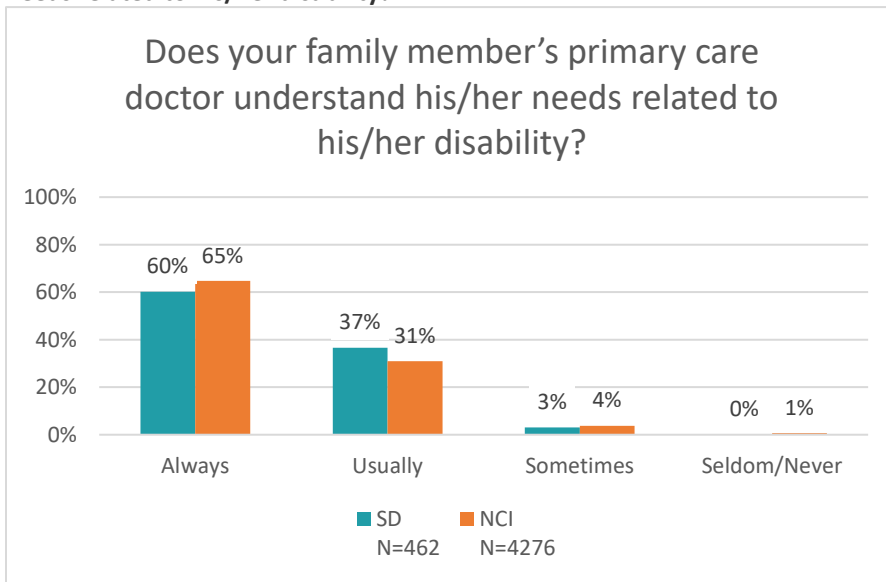


Chart 28. Do you have access to dental services for your family member?

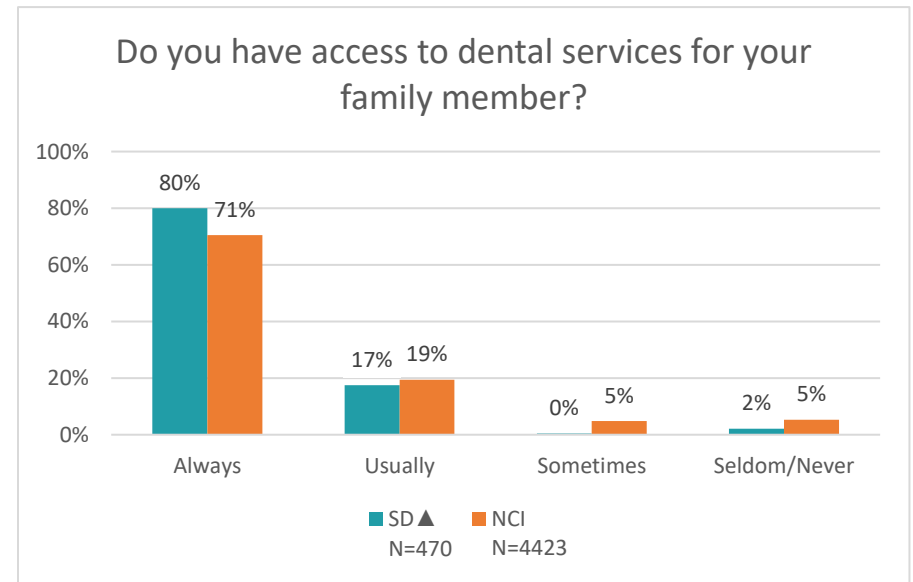


Chart 29. If you have access to dental services for your family member, does your family member’s dentist understand his/her needs related to his/her disability?

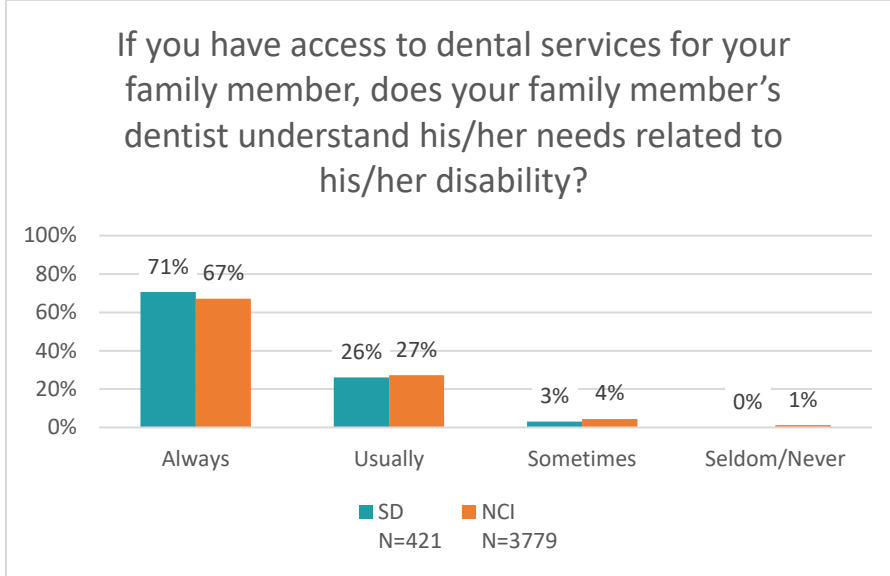


Chart 30. If your family member takes medications, do you know what they’re for?

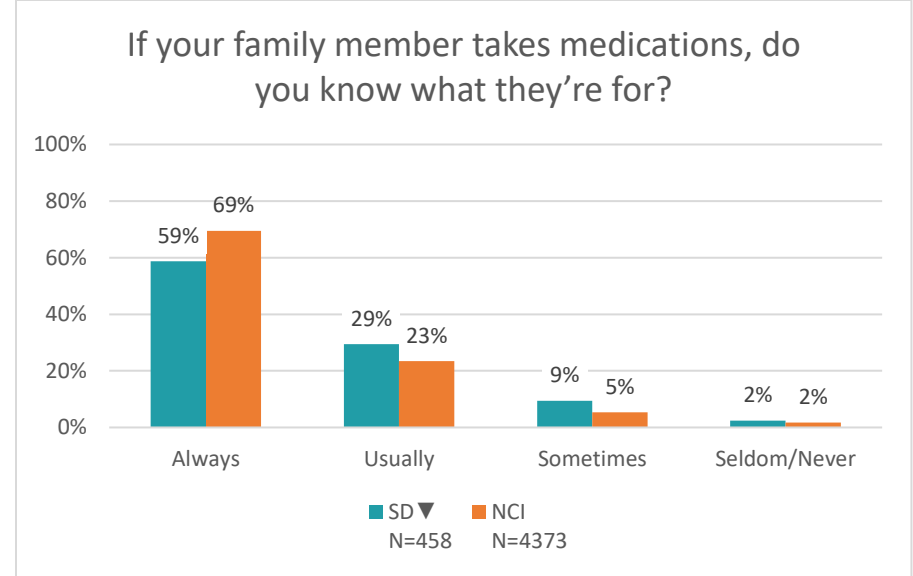


Chart 31. If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications?

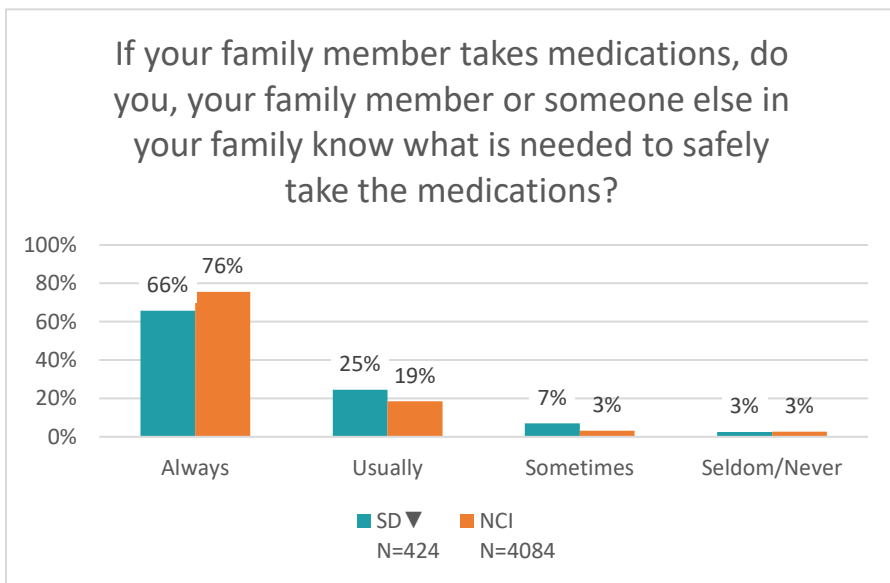


Chart 32. If your family member uses mental health services, does the mental health professional understand your family member’s needs related to his/her disability?

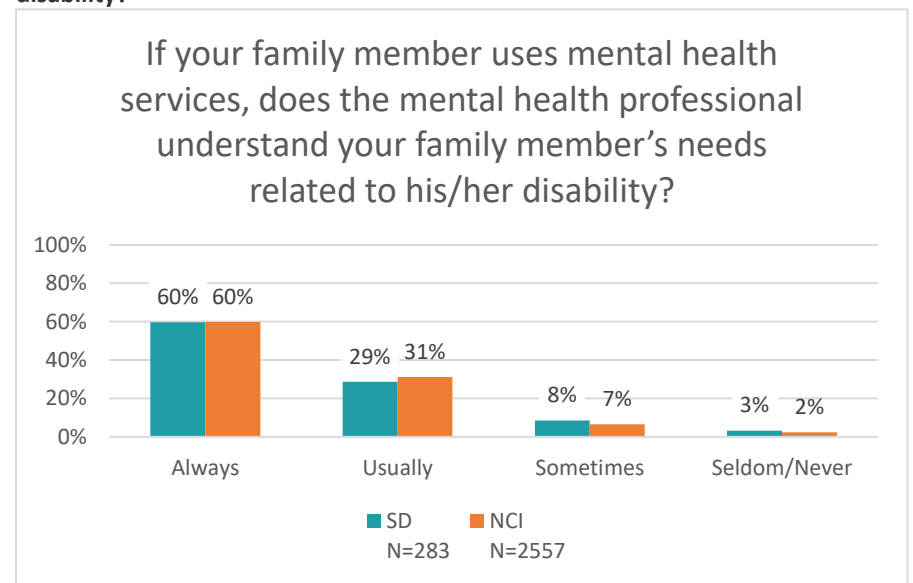


Chart 33. Does your family get the supports and services needed?

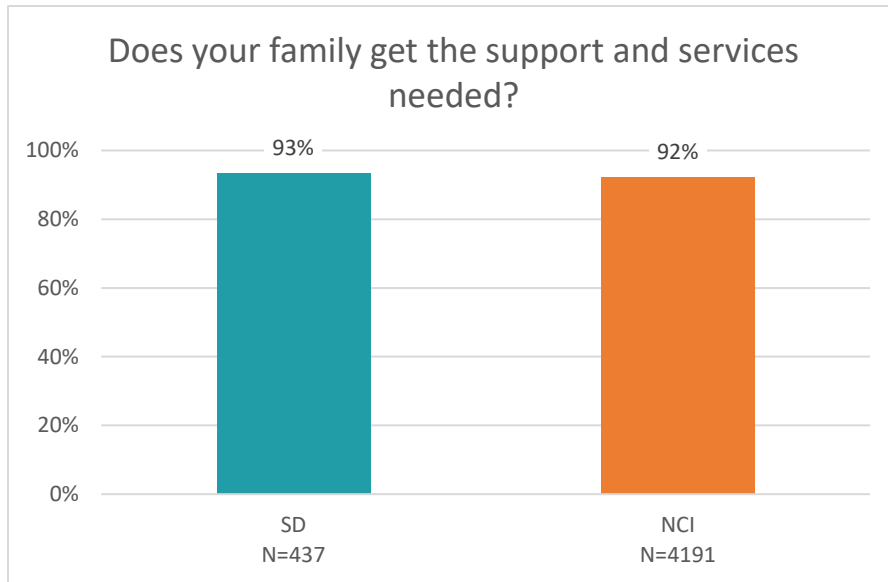
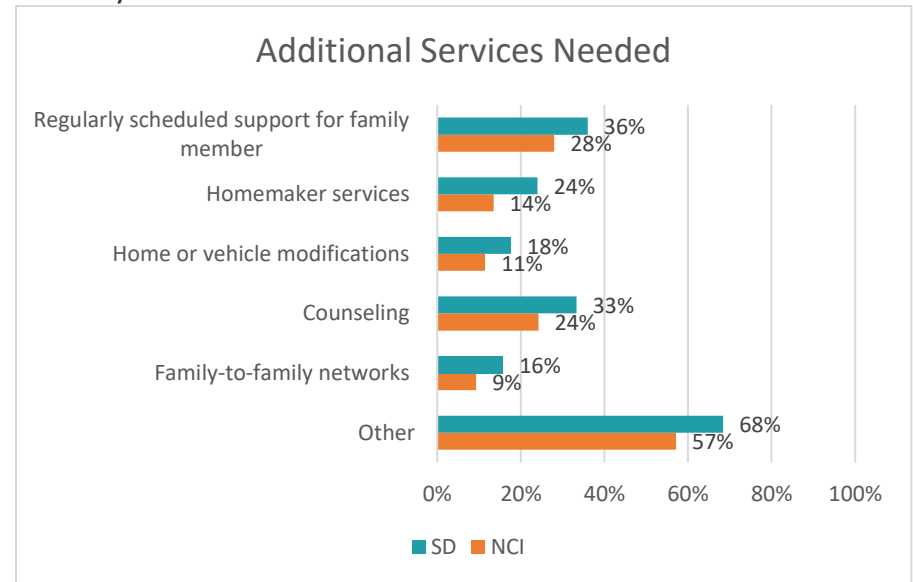


Chart 34. Additional services or supports needed (categories are not mutually exclusive)



Tables for Access and Delivery of Services and Supports

Table 27. 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?	SD ▼	53%	38%	8%	1%	483
	NCI	60%	33%	6%	2%	4,567
Are you or your family member able to contact his/her case manager/service coordinator when you want to?	SD	57%	35%	7%	1%	487
	NCI	60%	32%	5%	2%	4,600
Do support workers come and leave when they are supposed to?	SD	49%	44%	6%	1%	320
	NCI	54%	39%	6%	1%	3,228
Do services and supports change when your family's needs change?	SD	39%	42%	15%	3%	379
	NCI	42%	43%	11%	4%	3,268
Do support workers speak to you in a way that you understand?	SD ▼	65%	31%	4%	1%	477
	NCI	71%	25%	3%	1%	4,431
Are services delivered in a way that is respectful of your family's culture?	SD	71%	26%	2%	1%	461
	NCI	75%	22%	3%	1%	4,405
If your family member does not communicate verbally, are there support workers who can communicate with him/her?	SD ▼	31%	56%	11%	2%	98
	NCI	43%	41%	13%	3%	1,062
Do support workers have the right information and skills to meet your family's needs?	SD ▼	37%	48%	12%	2%	443
	NCI	44%	45%	10%	1%	4,194
Does your family member have the special equipment or accommodations that s/he needs?	SD	58%	35%	6%	2%	295
	NCI	60%	32%	5%	3%	2,786

Table 28. Access and Delivery of Services and Supports (continued)

		Always	Usually	Sometimes	Seldom/Never	N
Can your family member see health professionals when needed?	SD	75%	24%	2%	0%	489
	NCI	76%	21%	2%	0%	4,686
Does your family member's primary care doctor understand his/her needs related to his/her disability?	SD	60%	37%	3%	0%	462
	NCI	65%	31%	4%	1%	4,276
Do you have access to dental services for your family member?	SD▲	80%	17%	0%	2%	470
	NCI	71%	19%	5%	5%	4,423
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?	SD	71%	26%	3%	0%	421
	NCI	67%	27%	4%	1%	3,779
If your family member takes medications, do you know what they're for?	SD▼	59%	29%	9%	2%	458
	NCI	69%	23%	5%	2%	4,373
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?	SD▼	66%	25%	7%	3%	424
	NCI	76%	19%	3%	3%	4,084
If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?	SD	60%	29%	8%	3%	283
	NCI	60%	31%	7%	2%	2,557

Table 29. Access and Delivery of Services and Supports (continued)

		Yes	No	N
Does your family get the support and services needed?	SD	93%	7%	437
	NCI	92%	8%	4,191

Table 30. Additional Services Needed (categories are not mutually exclusive)

		Needs Service
Regularly scheduled support for family member	SD	36%
	NCI	28%
Homemaker services	SD	24%
	NCI	14%
Home or vehicle modifications	SD	18%
	NCI	11%
Counseling	SD	33%
	NCI	24%
Family-to-family networks	SD	16%
	NCI	9%
Other	SD	68%
	NCI	57%

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 35. Does the agency providing residential services to your family member involve him/her in important decisions?

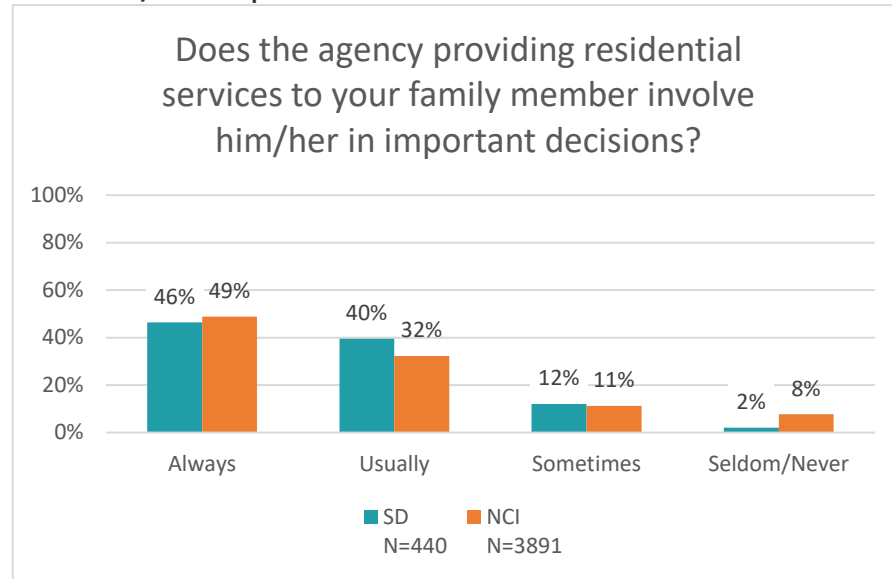


Chart 36. Can your family choose or change the agency that provides your family member's services?

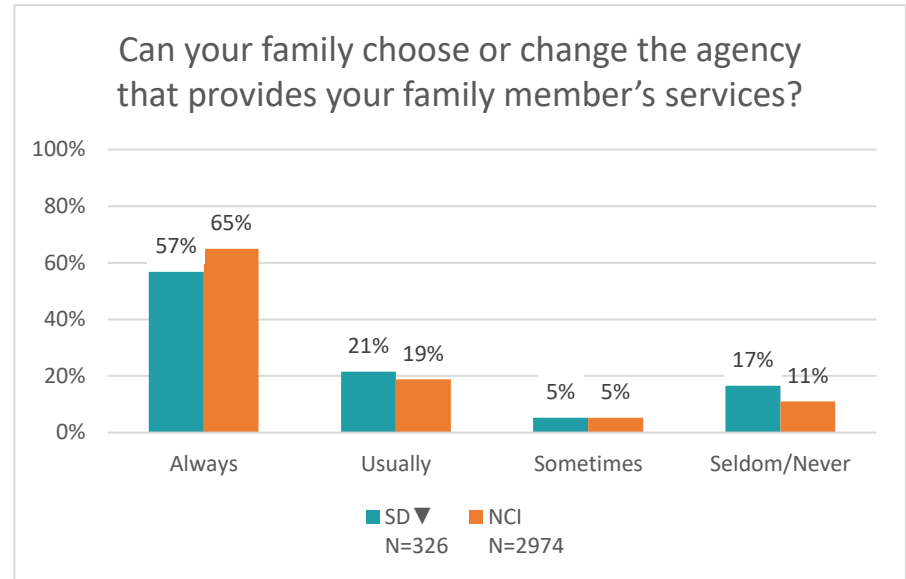


Chart 37. Can your family choose or change your family member's support workers?

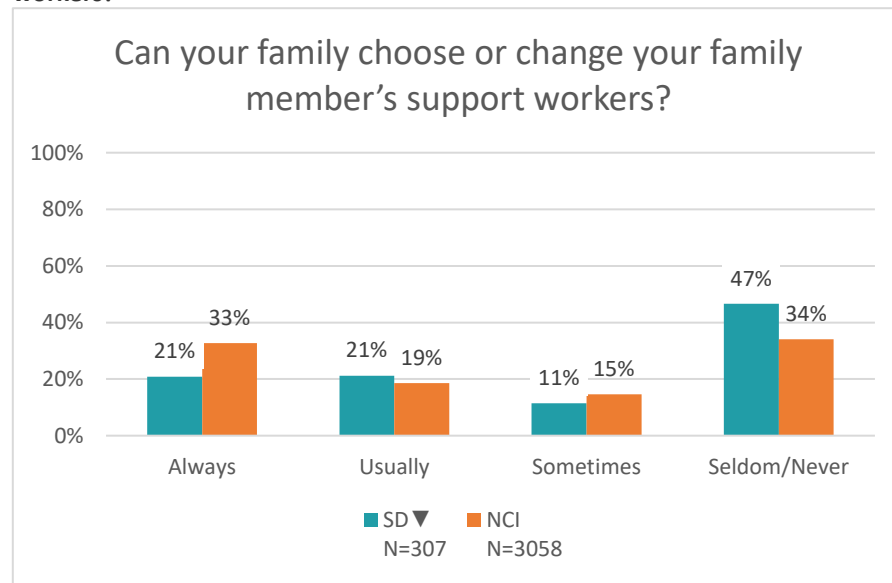


Chart 38. Does your family directly manage support workers?

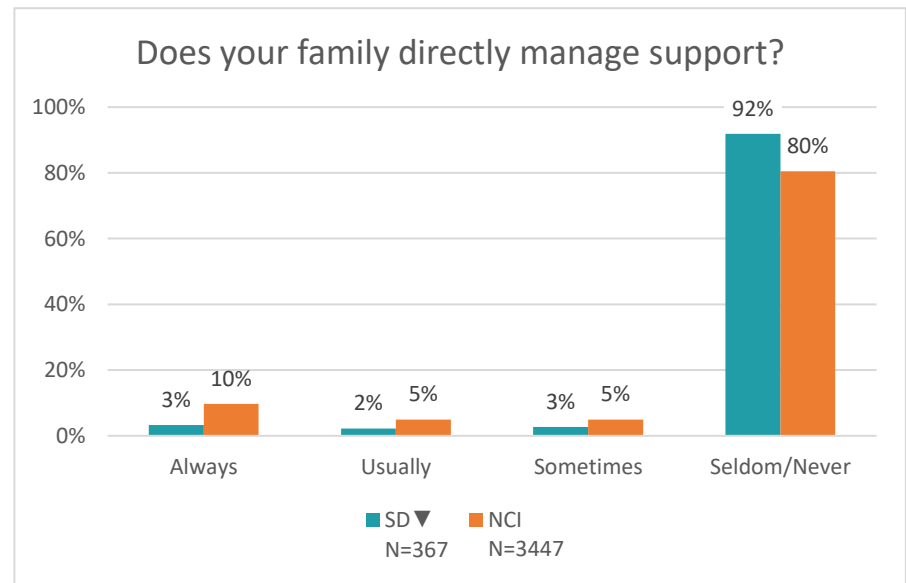


Chart 39. Do service providers for your family member work together to provide support?

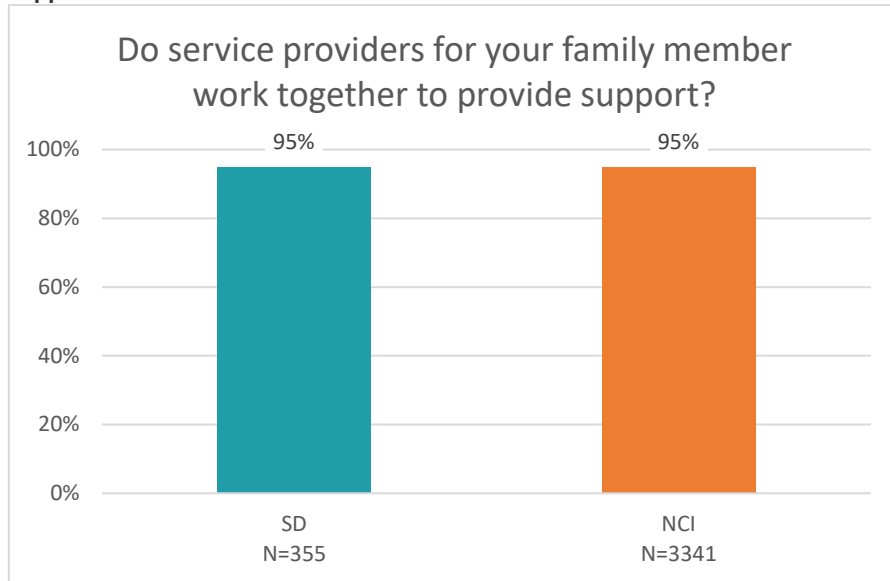
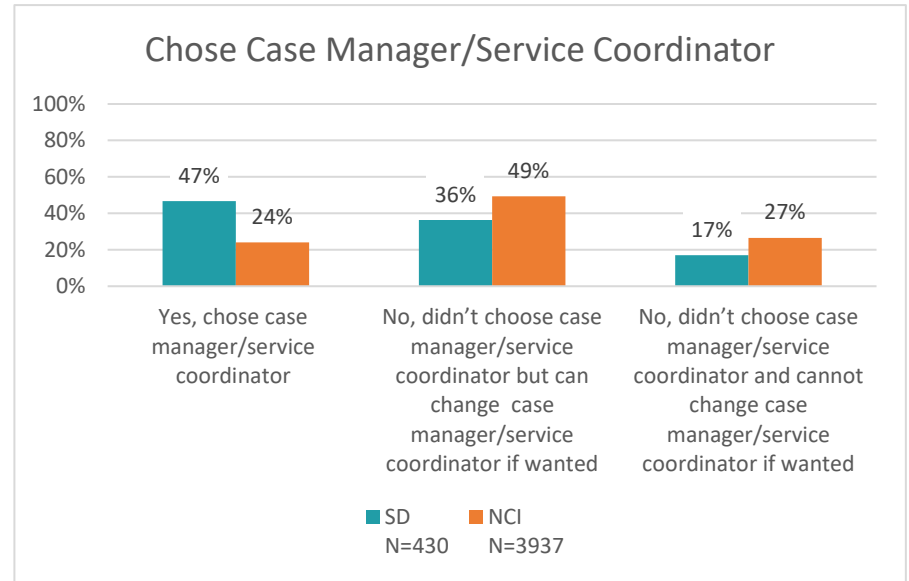


Chart 40. Did you or your family member choose the case manager/service coordinator?



Tables for Choice, Decision Making and Control

Table 31. Choice and Control

		Always	Usually	Sometimes	Seldom/Never	N
Does the agency providing residential services to your family member involve him/her in important decisions?	SD	46%	40%	12%	2%	440
	NCI	49%	32%	11%	8%	3,891
Can your family choose or change the agency that provides your family member's services?	SD ▼	57%	21%	5%	17%	326
	NCI	65%	19%	5%	11%	2,974
Can your family choose or change the individual staff that provide the services for your family member?	SD ▼	21%	21%	11%	47%	307
	NCI	33%	19%	15%	34%	3,058
Does your family directly manage support?	SD ▼	3%	2%	3%	92%	367
	NCI	10%	5%	5%	80%	3,447

Table 32. Choice and Control (continued)

		Yes	No	N
Do service providers for your family member work together to provide support?	SD	95%	5%	355
	NCI	95%	5%	3,341

Table 33. Chose Case Manager/Service Coordinator

		Chose Case Manager/Service Coordinator
Yes, chose case manager/service coordinator	SD	47%
	NCI	24%
No, didn't choose case manager/service coordinator but can change case manager/service coordinator if wanted	SD	36%
	NCI	49%
No, didn't choose case manager/service coordinator and cannot change case manager/service coordinator if wanted	SD	17%
	NCI	27%
N	SD	430
	NCI	3,937

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 41. Does your family member take part in activities in the community?

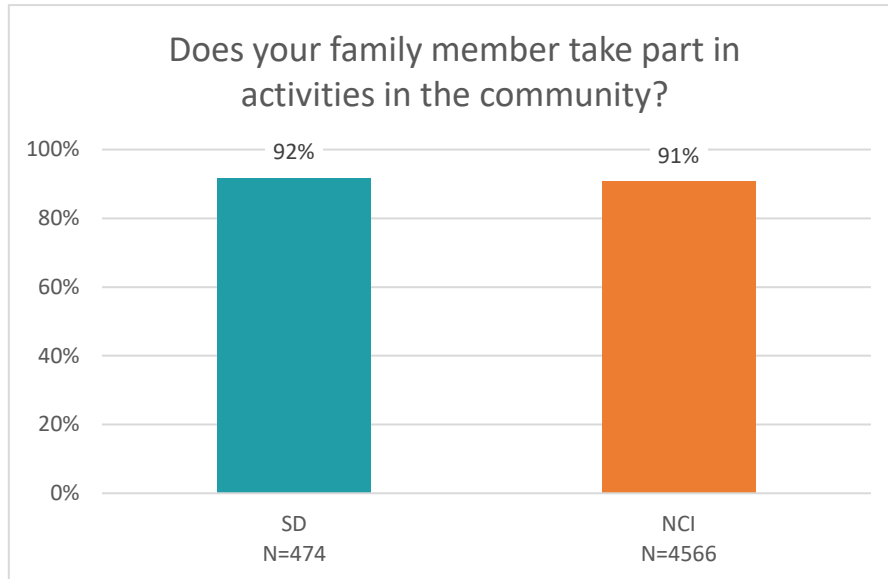


Chart 42. Obstacles/Barriers to family member’s participation in community activities (categories are not mutually exclusive)

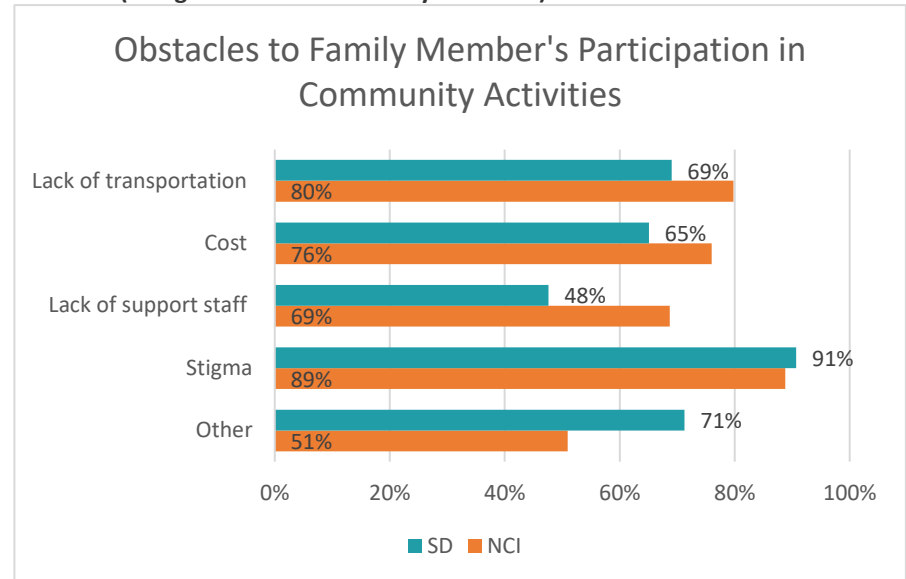


Chart 43. Does your family member have friends other than paid support workers or family?

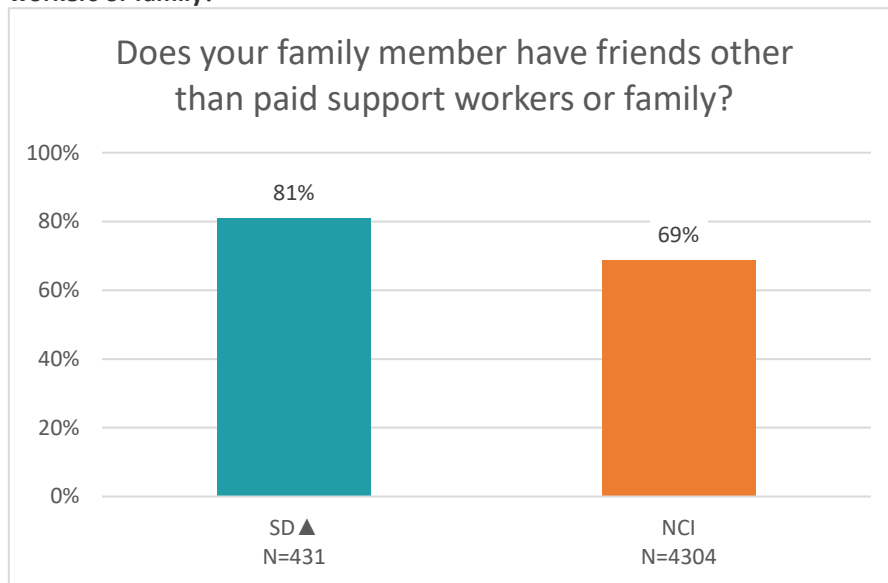


Chart 44. In your community, are there resources that your family can use that are not provided by the IDD agency?

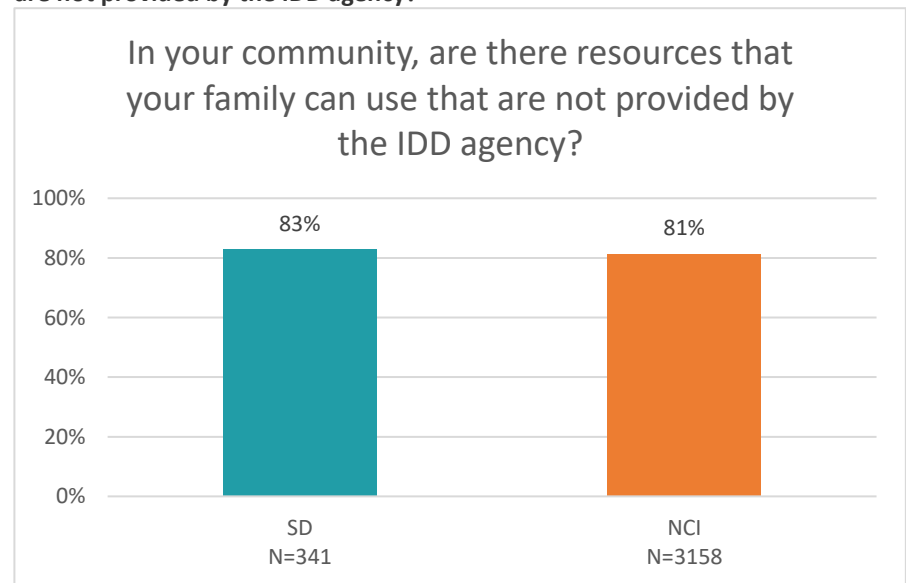
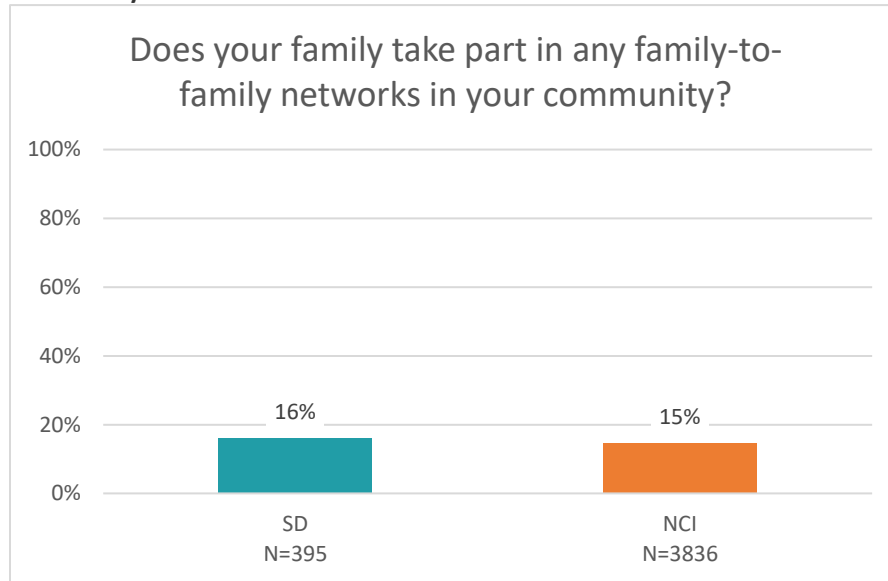


Chart 45. Does your family take part in any family-to-family networks in your community?



Tables for Involvement in the Community

Table 34. Involvement in the Community

		Yes	No	N
Does your family member take part in activities in the community?	SD	92%	8%	474
	NCI	91%	9%	4,566

Table 35. Obstacles to Family Member's Participation in Community Activities (categories are not mutually exclusive)

	Obstacles/Barriers	
Lack of transportation	SD	69%
	NCI	80%
Cost	SD	65%
	NCI	76%
Lack of support staff	SD	48%
	NCI	69%
Stigma	SD	91%
	NCI	89%
Other	SD	71%
	NCI	51%

Table 36. Involvement in the Community (continued)

		Yes	No	N
Does your family member have friends other than paid support workers or family?	SD▲	81%	19%	431
	NCI	69%	31%	4,304
In your community, are there resources that your family can use that are not provided by the IDD agency?	SD	83%	17%	341
	NCI	81%	19%	3,158
Does your family take part in any family-to-family networks in your community?	SD	16%	84%	395
	NCI	15%	85%	3,836

Satisfaction With Services and Supports

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

Charts for Satisfaction With Services and Supports

Chart 46. Overall, are you satisfied with the services and supports your family member currently receives?

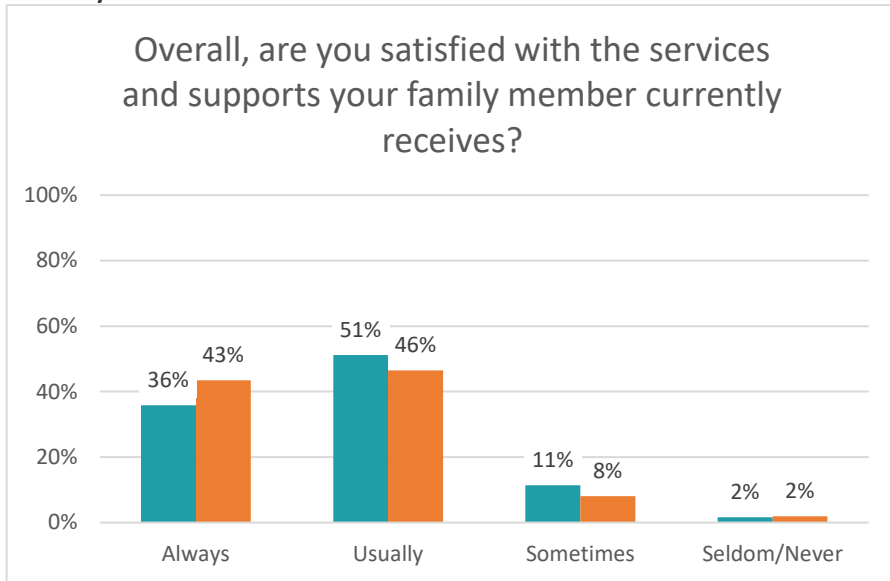


Chart 47. Do you know how to file a complaint or grievance about provider agencies or staff?*

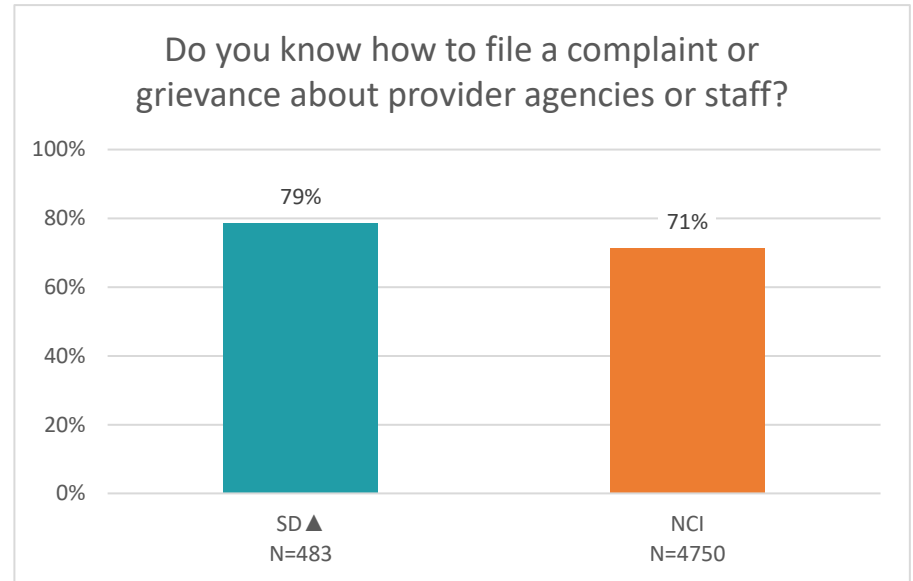


Chart 48. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

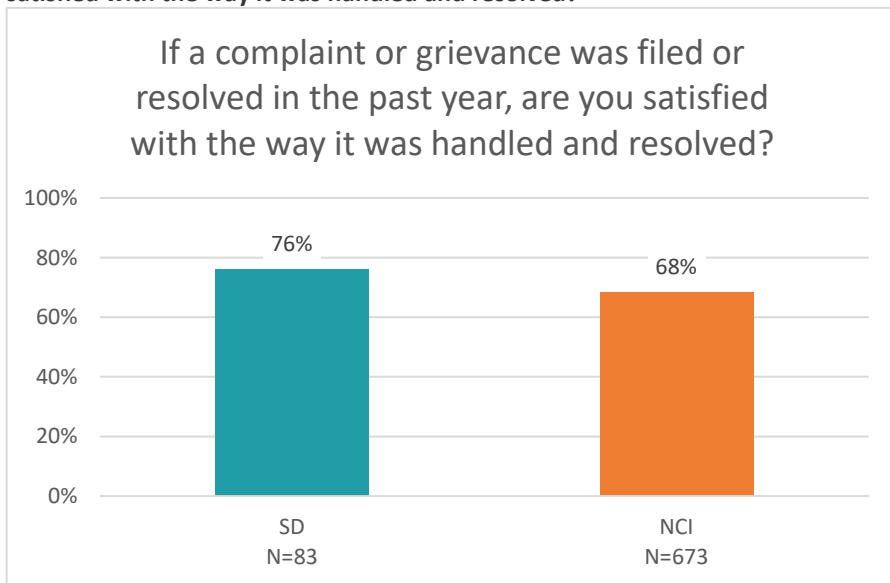
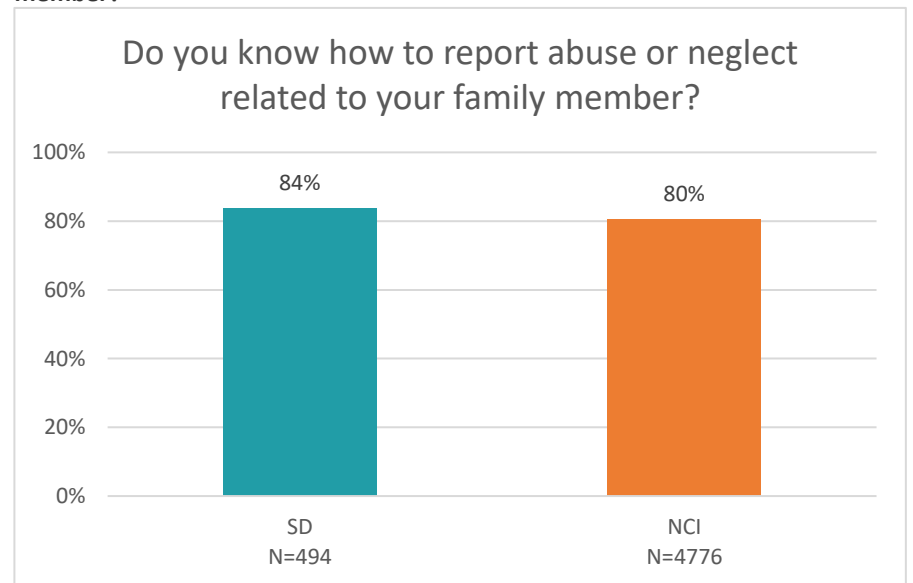


Chart 49. Do you know how to report abuse or neglect related to your family member?*



*No and don't know responses are combined

Chart 50. In the past year, was a report of abuse or neglect filed on behalf of your family member?

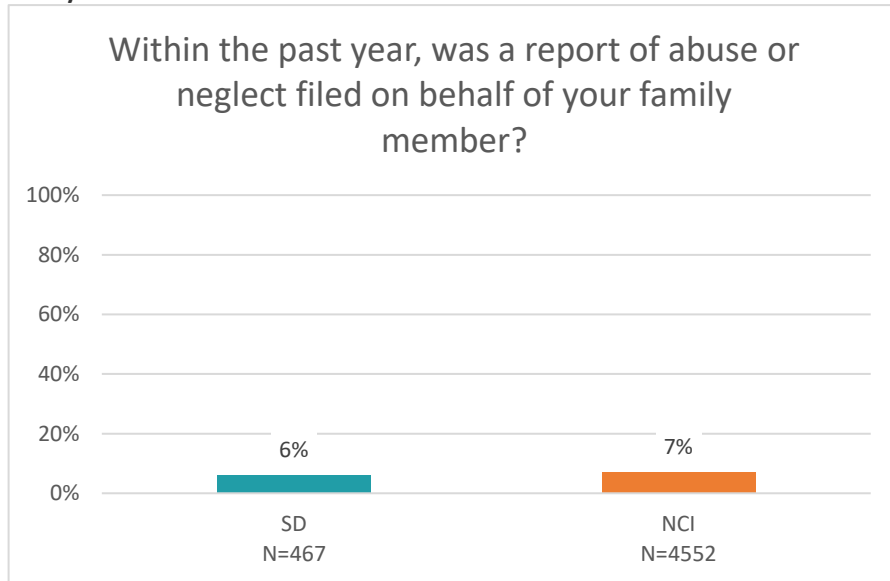


Chart 52. If someone other than you or another family member reported abuse or neglect in the past year on behalf of your family member, were you notified of the report in a timely manner?

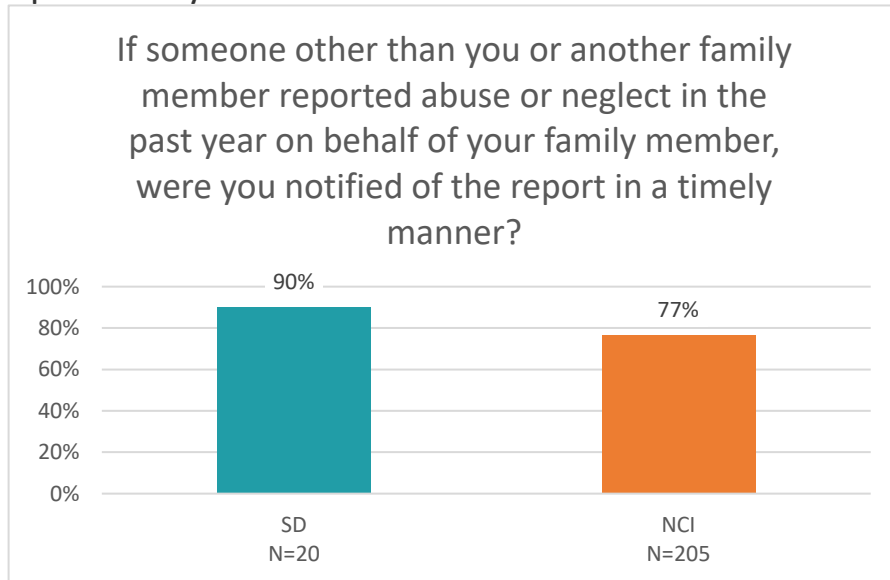


Chart 51. If a report of abuse or neglect was filed on behalf of family member, did the appropriate people respond to the report?

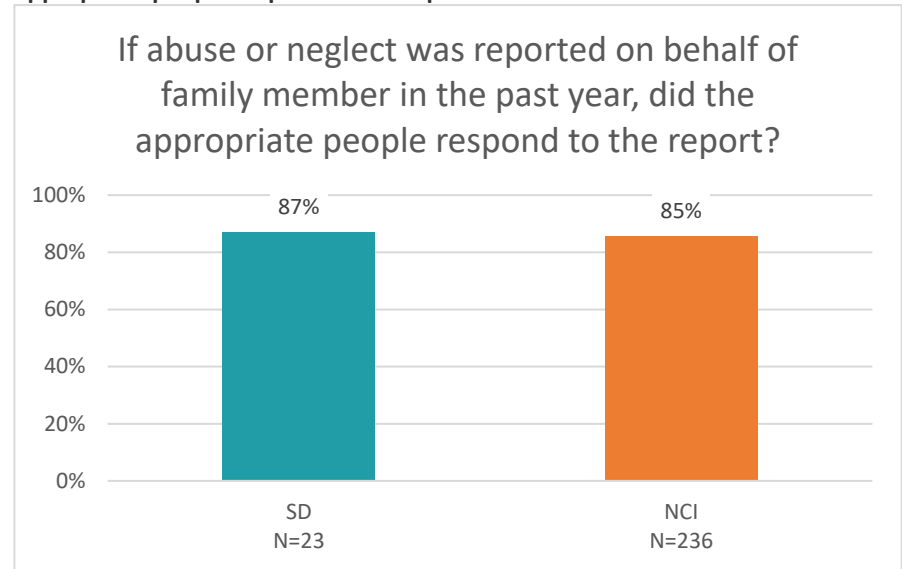


Chart 53. Do you feel that services and supports have made a positive difference in the life of your family member?

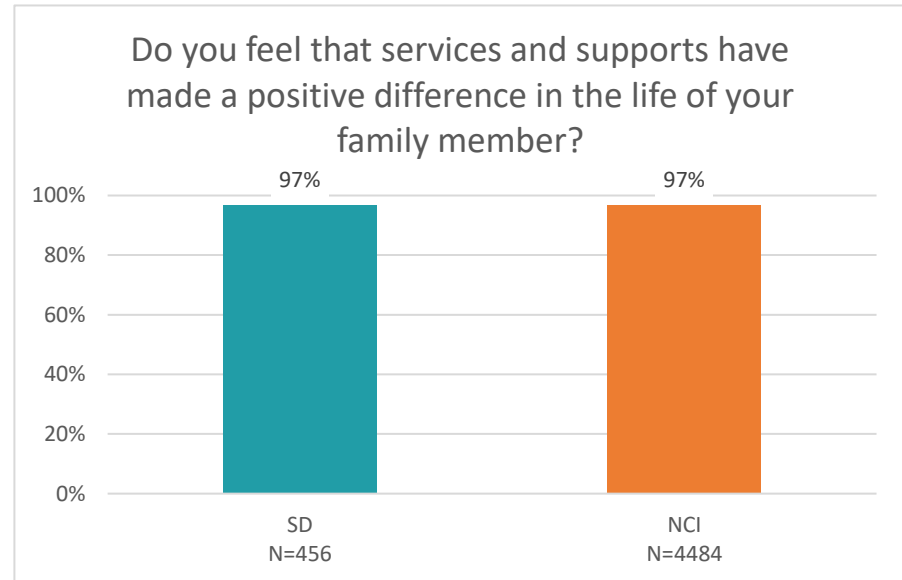


Chart 54. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?

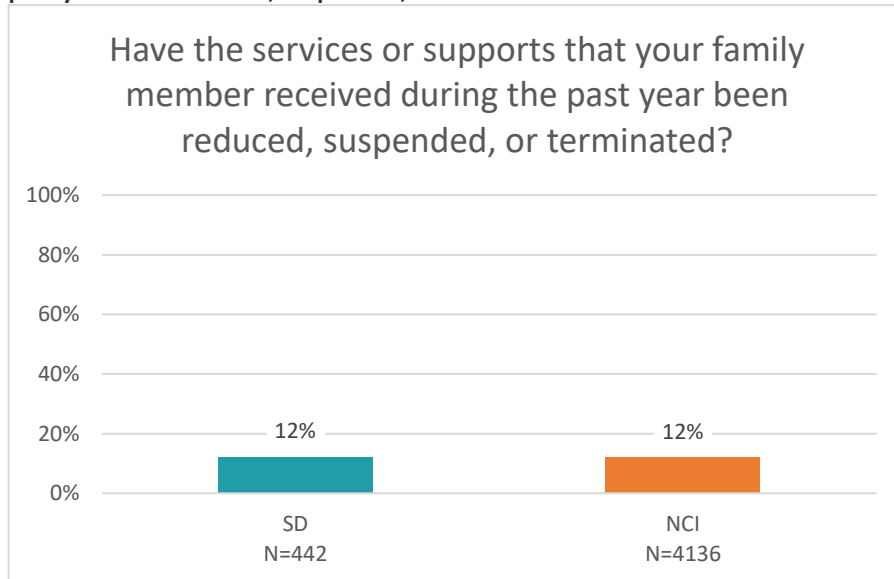


Chart 56. Have the services or supports that your family member received been increased in the past year?

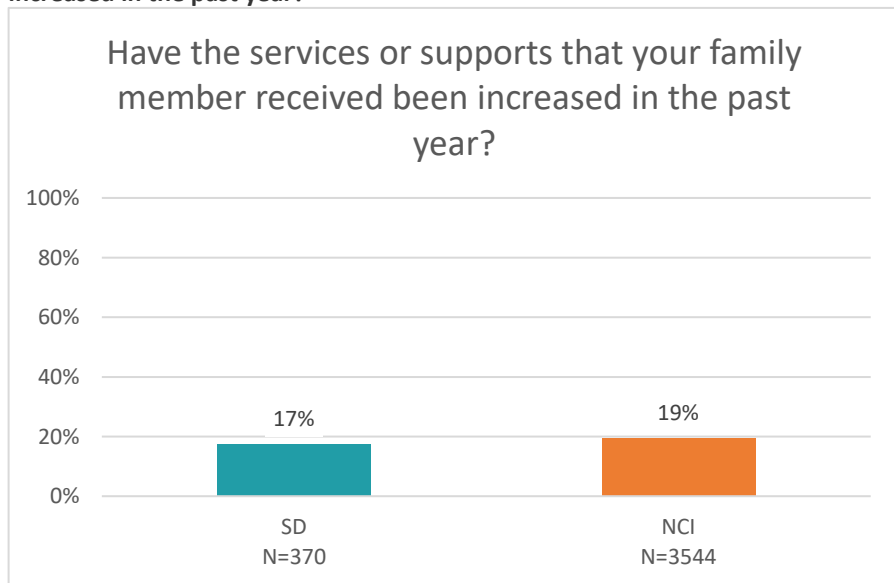


Chart 55. If services were reduced in the past year, did the reduction, suspension, or termination of these services or supports affect your family member negatively?

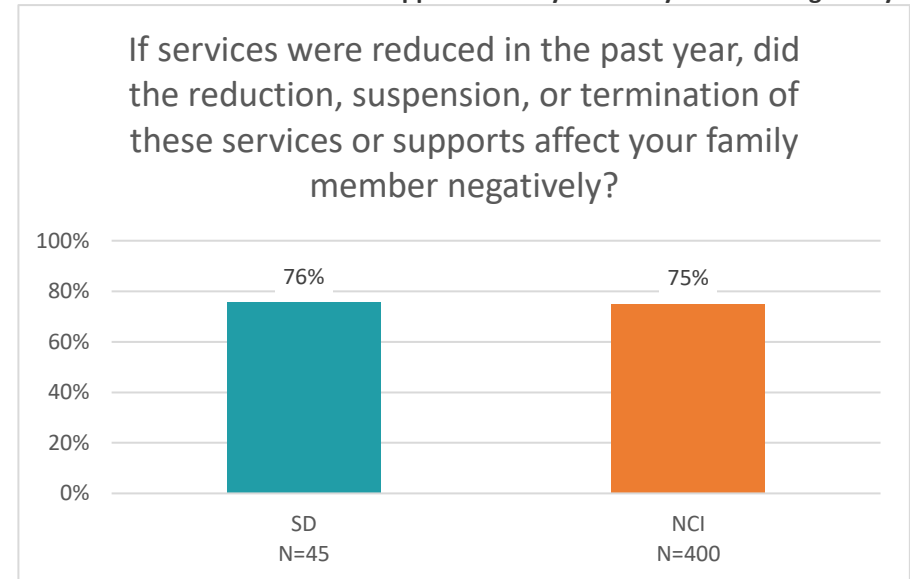
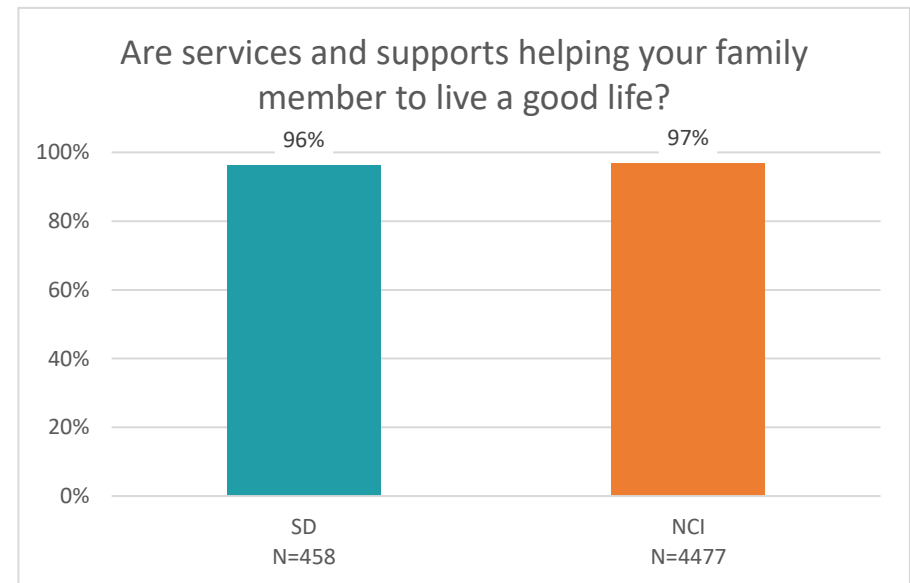


Chart 57. Are services and supports helping your family member to live a good life?



Tables for With Services and Supports

Table 37. Satisfaction With Service and Supports

		Always	Usually	Sometimes	Seldom/Never	N
Overall, are you satisfied with the services and supports your family member currently receives?	SD ▼	36%	51%	11%	2%	483
	NCI	43%	46%	8%	2%	4,703

Table 38. Satisfaction With Service and Supports (continued)

		Yes	No	N
Do you know how to file a complaint or grievance about provider agencies or staff?*	SD ▲	79%	14%	483
	NCI	71%	21%	4,750
If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?	SD	76%	24%	83
	NCI	68%	32%	673
Do you know how to report abuse or neglect related to your family member?*	SD	84%	9%	494
	NCI	80%	13%	4,776
Within the past year, was a report of abuse or neglect filed on behalf of your family member?	SD	6%	94%	467
	NCI	7%	93%	4,552
If a report of abuse or neglect was filed on behalf of your family member, did the appropriate people respond to the report?	SD	87%	13%	23
	NCI	85%	15%	236
If someone other than you or another family member reported abuse or neglect in the past year on behalf of your family member, were you notified of the report in a timely manner?	SD	90%	10%	20
	NCI	77%	23%	205
Do you feel that services and supports have made a positive difference in the life of your family member?	SD	97%	3%	456
	NCI	97%	3%	4,484
Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?	SD	12%	88%	442
	NCI	12%	88%	4,136
If services were reduced in the past year, did the reduction, suspension, or termination of these services or supports affect your family member negatively?	SD	76%	24%	45
	NCI	75%	25%	400
Have the services or supports that your family member received been increased in the past year?	SD	17%	83%	370
	NCI	19%	81%	3,544
Are services and supports helping your family member to live a good life?	SD	96%	4%	458
	NCI	97%	3%	4,477

*No and don't know responses are combined