

*2017-18 FAMILY/GUARDIAN SURVEY*  
*MARYLAND REPORT*



# Contents

<b>What is NCI?</b> .....	<b>1</b>
<b>What is the NCI Family/Guardian Survey?</b> .....	<b>1</b>
Table A1. NCI Family Survey – Sub-Domains and Concern Statements .....	2
<b>How were people selected to participate?</b> .....	<b>3</b>
<b>Data Analysis</b> .....	<b>4</b>
<b>Weighting</b> .....	<b>4</b>
<b>Significance testing</b> .....	<b>5</b>
<b>Limitations of the data</b> .....	<b>5</b>
<b>What is contained in this report?</b> .....	<b>6</b>
<i>Family Member</i> .....	<i>7</i>
Table 1. Family member’s residence .....	8
Table 2. Family member’s residential designation .....	8
Table 3. Family member’s average age .....	8
Table 4. Family member’s gender .....	8
Table 5. Family member’s race and ethnicity (categories are not mutually exclusive) .....	9
Table 6. Family member’s disabilities (categories are not mutually exclusive) .....	9
Table 7. Family member’s disabilities (continued, categories are not mutually exclusive) .....	9
Table 8. Family member’s health conditions (categories are not mutually exclusive) .....	9
Table 9. Family member’s health conditions (continued, categories are not mutually exclusive) .....	10
Table 10. Family member’s preferred means of communication .....	10
Table 11. Family member has legal court appointed guardian or conservator .....	10
Table 12. Guardian or conservator relationship to family member .....	10
Table 13. Family member’s highest level of education .....	11
Table 14. Family member’s typical day activity .....	11
Table 15. Family member’s support needs .....	12
<i>Respondents</i> .....	<i>13</i>
Table 16. Respondent’s age .....	14
Table 17. Respondent’s health .....	14
Table 18. Respondent’s relationship to family member .....	14
Table 19. Respondent’s frequency of visits with family member last year .....	14
Table 20. Respondent’s highest level of education .....	15
Table 21. Past year total household taxable income of wage earners .....	15
<i>Services and Supports Received</i> .....	<i>16</i>
Table 22. Services and supports received from state (categories are not mutually exclusive) .....	17
Table 23. Services and supports received (not from IDD agency; categories are not mutually exclusive) .....	17

<i>Information and Planning</i> .....	18
Chart 1. Do you get enough information to take part in planning services for your family member? .....	20
Chart 2. Is the information you get about services and supports easy to understand? .....	20
Chart 3. Do staff or the residential agency keep you informed about how your family member is doing? .....	20
Chart 4. Does the case manager/service coordinator respect your family's choices and opinions? .....	20
Chart 5. Respondent's future planning needs .....	21
Chart 6. In the past year, did your family member move out of the family home for the first time? .....	21
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? .....	21
Chart 8. Does your family member have a service plan? .....	21
Chart 9. Does the plan include all the services and supports your family member needs? .....	22
Chart 10. Does your family member get all of the services listed in the plan? .....	22
Chart 11. Did you or another family member (besides your family member with a disability) help make the plan? .....	22
Chart 12. Did your family member help make the plan? .....	22
Chart 13. Did you discuss how to handle emergencies at your family member's last service planning meeting? .....	23
Chart 14. If your family member transitioned out of school services during the past year, did s/he have a transition plan? .....	23
Chart 15. Does your family member have enough supports to work or volunteer in the community? .....	23
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? .....	23
Table 24. Information and Planning .....	25
Table 25. Respondent Needs Help With Future Planning Needs .....	26
Table 26. Information and Planning (continued) .....	27
<i>Access and Delivery of Services and Supports</i> .....	28
Chart 17. Are you or your family member able to contact his/her support workers when you want to? .....	30
Chart 18. Are you or your family member able to contact his/her case manager/service coordinator when you want to? .....	30
Chart 19. Do support workers come and leave when they are supposed to? .....	30
Chart 20. Do services and supports change when your family's needs change? .....	30
Chart 21. Do support workers speak to you in a way that you understand? .....	31
Chart 22. Are services delivered in a way that is respectful of your family's culture? .....	31
Chart 23. If your family member does not communicate verbally, are there support workers who can communicate with him/her? .....	31
Chart 24. Do support workers have the right information and skills to meet your family's needs? .....	31
Chart 25. Does your family member have the special equipment or accommodations that s/he needs? .....	32
Chart 26. Can your family member see health professionals when needed? .....	32
Chart 27. Does your family member's primary care doctor understand his/her needs related to his/her disability? .....	32
Chart 28. Do you have access to dental services for your family member? .....	32
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? .....	33
Chart 30. If your family member takes medications, do you know what they're for? .....	33
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? .....	33
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? .....	33
Chart 33. Does your family get the supports and services needed? .....	34

Chart 34. Additional services or supports needed (categories are not mutually exclusive) .....	34
Table 27. Access and Delivery of Services and Supports .....	36
Table 28. Access and Delivery of Services and Supports (continued) .....	37
Table 29. Access and Delivery of Services and Supports (continued) .....	38
Table 30. Additional Services Needed (categories are not mutually exclusive) .....	38
<i>Choice, Decision Making and Control</i> .....	<i>39</i>
Chart 35. Does the agency providing residential services to your family member involve him/her in important decisions? .....	41
Chart 36. Can your family choose or change the agency that provides your family member's services? .....	41
Chart 37. Can your family choose or change your family member's support workers? .....	41
Chart 38. Does your family directly manage support workers? .....	41
Chart 39. Do service providers for your family member work together to provide support? .....	42
Chart 40. Did you or your family member choose the case manager/service coordinator? .....	42
Table 31. Choice and Control .....	44
Table 32. Choice and Control (continued) .....	44
Table 33. Chose Case Manager/Service Coordinator .....	44
<i>Involvement in the Community</i> .....	<i>45</i>
Chart 41. Does your family member take part in activities in the community? .....	47
Chart 42. Obstacles/Barriers to family member's participation in community activities (categories are not mutually exclusive) .....	47
Chart 43. Does your family member have friends other than paid support workers or family? .....	47
Chart 44. In your community, are there resources that your family can use that are not provided by the IDD agency? .....	47
Chart 45. Does your family take part in any family-to-family networks in your community? .....	48
Table 34. Involvement in the Community .....	50
Table 35. Obstacles to Family Member's Participation in Community Activities (categories are not mutually exclusive) .....	50
Table 36. Involvement in the Community (continued) .....	50
<i>Satisfaction With Services and Supports</i> .....	<i>51</i>
Chart 46. Overall, are you satisfied with the services and supports your family member currently receives? .....	53
Chart 47. Do you know how to file a complaint or grievance about provider agencies or staff? .....	53
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? .....	53
Chart 49. Do you know how to report abuse or neglect related to your family member? .....	53
Chart 50. In the past year, was a report of abuse or neglect filed on behalf of your family member? .....	54
Chart 51. If a report of abuse or neglect was filed on behalf of family member, did the appropriate people respond to the report? .....	54
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? .....	54
Chart 53. Do you feel that services and supports have made a positive difference in the life of your family member? .....	54
Chart 54. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated? .....	55
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? .....	55
Chart 56. Have the services or supports that your family member received been increased in the past year? .....	55
Chart 57. Are services and supports helping your family member to live a good life? .....	55
Table 37. Satisfaction With Service and Supports .....	57
Table 38. Satisfaction With Service and Supports (continued) .....	57

## 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.<sup>1</sup> 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.

---

<sup>1</sup> 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
<b>Information and Planning</b>	Families/family members with disabilities have the information and support necessary to plan for their services and supports.
<b>Access &amp; Support Delivery</b>	Families/family members with disabilities get the services and supports they need.
<b>Choice, Decision Making &amp; Control</b>	Families/family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.
<b>Involvement in the Community</b>	Family members with disabilities use integrated community services and participate in everyday community activities.
<b>Satisfaction</b>	Families/family members with disabilities receive adequate and satisfactory supports.
<b>Outcomes</b>	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.<sup>2</sup>

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%.

---

<sup>2</sup> 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.<sup>3</sup>

---

<sup>3</sup> 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.<sup>4</sup> 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.

---

<sup>4</sup> 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 Maryland (MD) 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 residence<sup>5</sup>**

		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	MD	10%	63%	8%	17%	1%	1%	0%	0%	1,104
	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	MD	76%	24%	1,097
	NCI	80%	20%	4,743

**Table 3. Family member's average age**

		Average Age	N
Family Member's Age	MD	47.7	1,094
	NCI	47.9	4,724

**Table 4. Family member's gender**

		Male	Female	N
Family Member's Gender	MD	58%	42%	1,119
	NCI	58%	42%	4,838

<sup>5</sup> 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	MD	1%	3%	17%	1%	80%	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	MD	75%	30%	23%	16%	9%	7%	12%
	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	MD	24%	1%	11%	1%	1%	7%
	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	MD	9%	21%	7%	37%	33%
	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	MD	10%	2%	6%	15%	11%	13%
	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	MD	76%	17%	3%	1%	3%	1,107
	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	MD	47%	18%	29%	7%	985
	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	MD	89%	2%	8%	1%	462
	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	MD	34%	1%	41%	13%	5%	3%	3%	1,044
	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	MD	19%	5%	76%	1,026
	NCI	15%	4%	82%	4,515
Paid Small Group Job in a Community-based Setting	MD	15%	6%	79%	1,014
	NCI	10%	4%	85%	4,436
Unpaid Activity in the Community	MD	18%	16%	66%	1,025
	NCI	18%	14%	68%	4,495
Paid Work in a Community Business That Primarily Hires People With Disabilities	MD	8%	5%	87%	1,005
	NCI	7%	3%	90%	4,459
Paid Activity in a Facility-based Setting	MD	23%	7%	70%	1,012
	NCI	19%	5%	76%	4,492
Unpaid Activity in a Facility-based Setting	MD	39%	8%	53%	1,024
	NCI	33%	6%	61%	4,495
School	MD	3%	3%	94%	1,013
	NCI	5%	2%	93%	4,460
Stays at Home	MD	20%	21%	59%	985
	NCI	28%	24%	47%	4,280
Other	MD	40%	8%	52%	301
	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	MD	26%	34%	41%	1,086
	NCI	29%	36%	35%	4,729
Family Member's Need for Help With Personal Care Activities	MD	37%	37%	26%	1,104
	NCI	42%	38%	20%	4,808
Family Member's Need for Help With Other Daily Activities	MD	76%	21%	3%	1,104
	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	MD	1%	10%	60%	29%	1,115
	NCI	2%	12%	63%	22%	4,788

Table 17. Respondent's health

		Excellent	Very Good	Fairly Good	Poor	N
Respondent's Health	MD	17%	42%	34%	7%	1,113
	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	MD	58%	27%	0%	2%	1%	1%	12%	1,105
	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	MD	4%	8%	10%	12%	66%	1,100
	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	MD	3%	19%	4%	22%	53%	1,101
	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	MD	9%	4%	8%	14%	12%	24%	30%	1,036
	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	MD	34%
	NCI	31%
In-home Support	MD	48%
	NCI	46%
Residential Supports	MD	87%
	NCI	90%
Day or Employment Supports	MD	75%
	NCI	65%
Transportation	MD	91%
	NCI	91%
Other	MD	55%
	NCI	60%
Self-direction or Fiscal Intermediary Services	MD	21%
	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)	MD	92%
	NCI	95%
Services or Supports From Other Agencies or Organizations	MD	31%
	NCI	32%

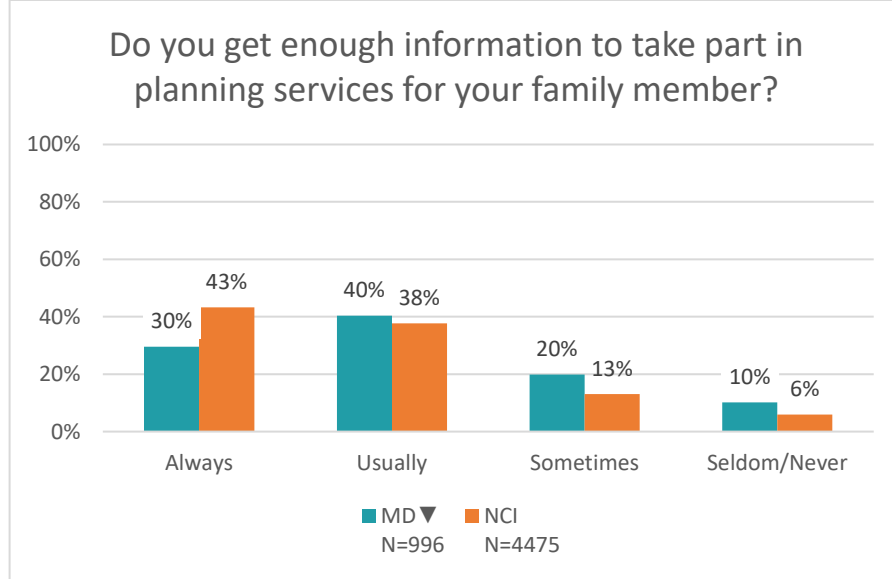
## Information and Planning

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

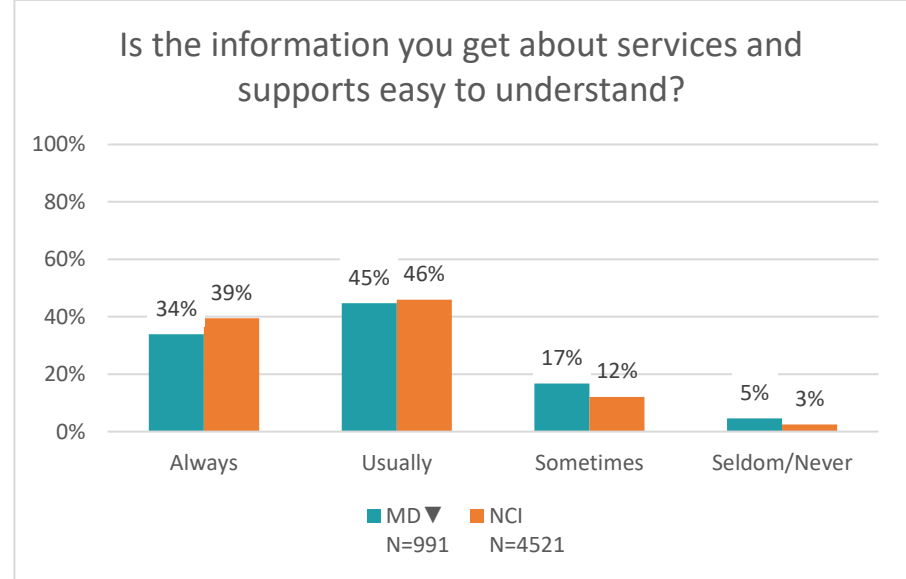
---

## *Charts for Information and Planning*

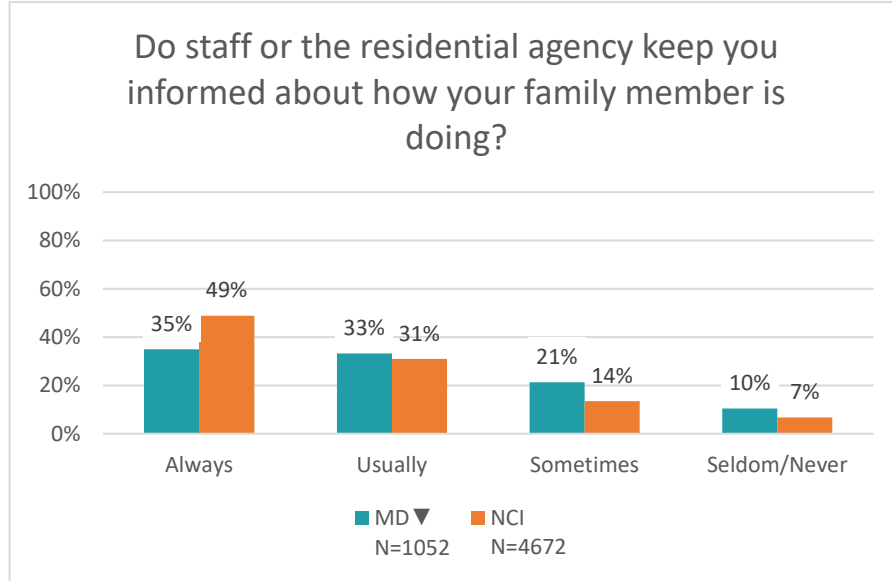
**Chart 1.** Do you get enough information to take part in planning services for your family member?



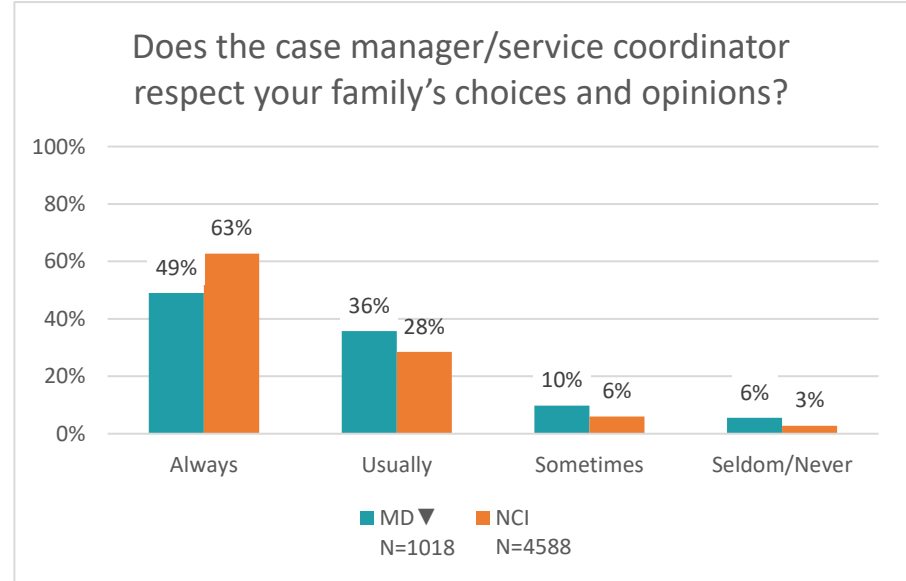
**Chart 2.** Is the information you get about services and supports easy to understand?



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

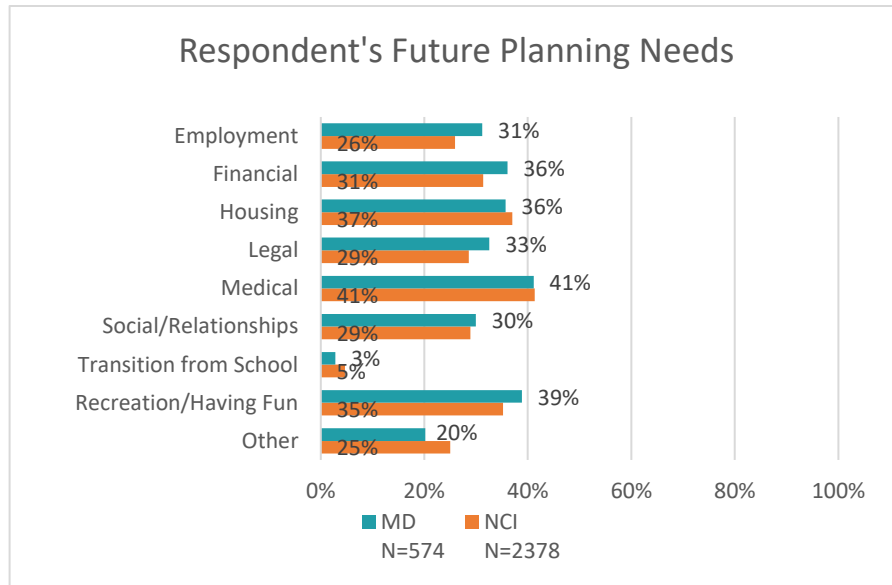


**Chart 4.** Does the case manager/service coordinator respect your family's choices and opinions?

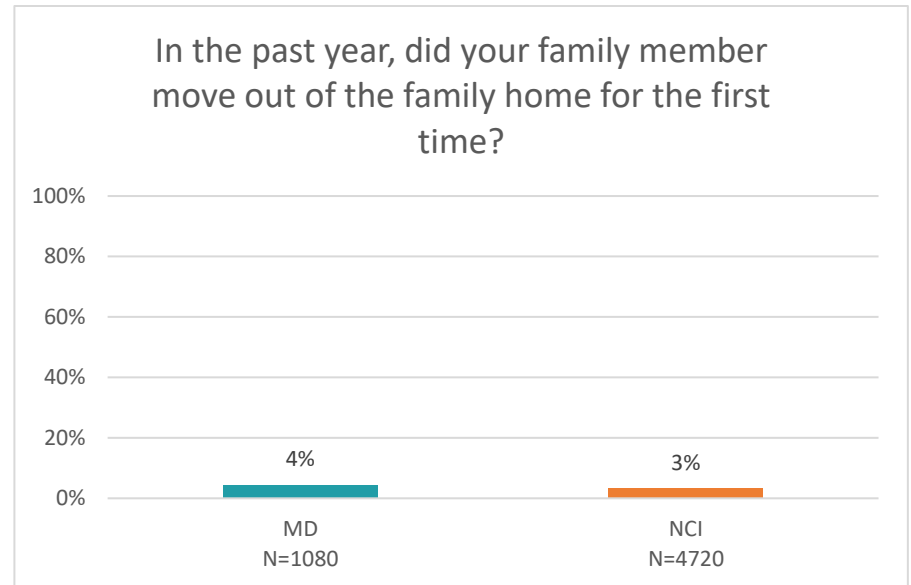




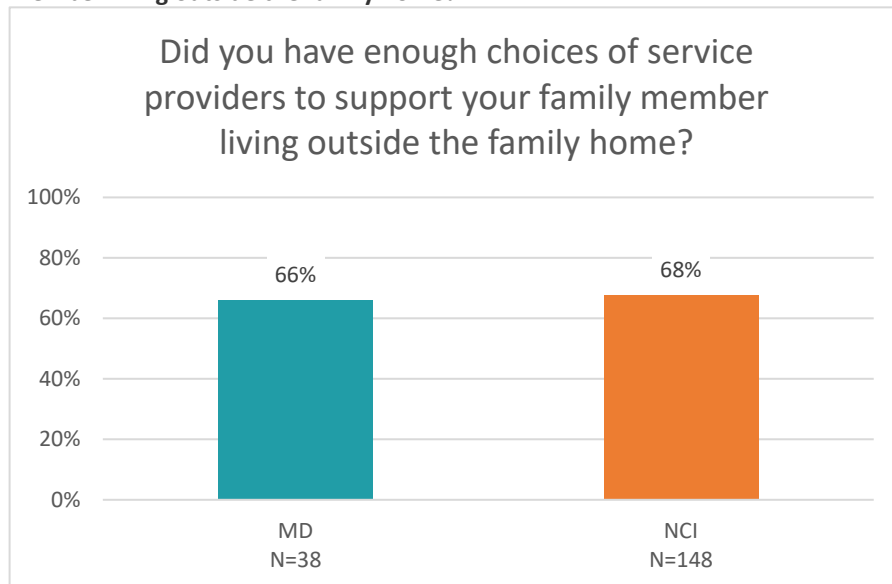
**Chart 5. Respondent's future planning needs**



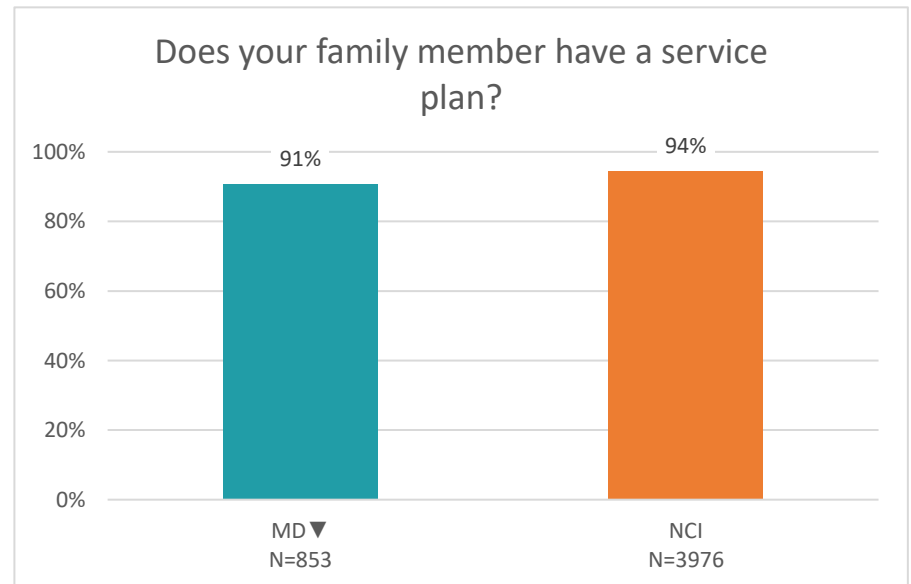
**Chart 6. In the past year, did your family member move out of the family home for the first time?**



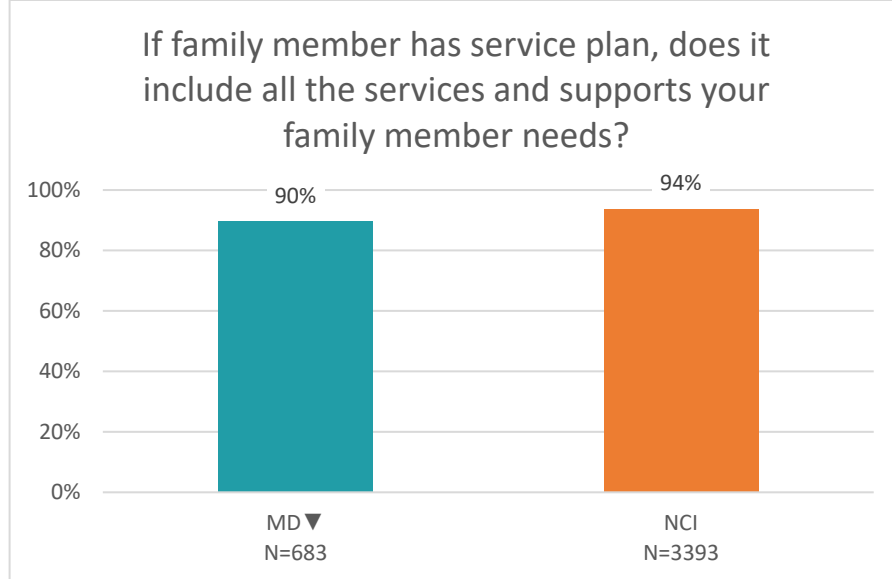
**Chart 7. If family member moved out of the home for the first time in the past year, did you have enough choices of service providers to support your family member living outside the family home?**



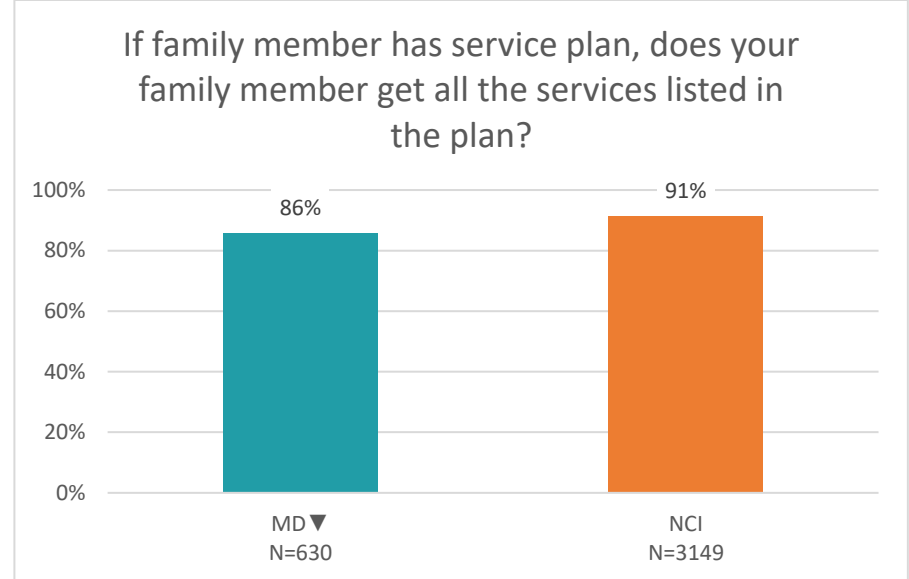
**Chart 8. Does your family member have a service plan?**



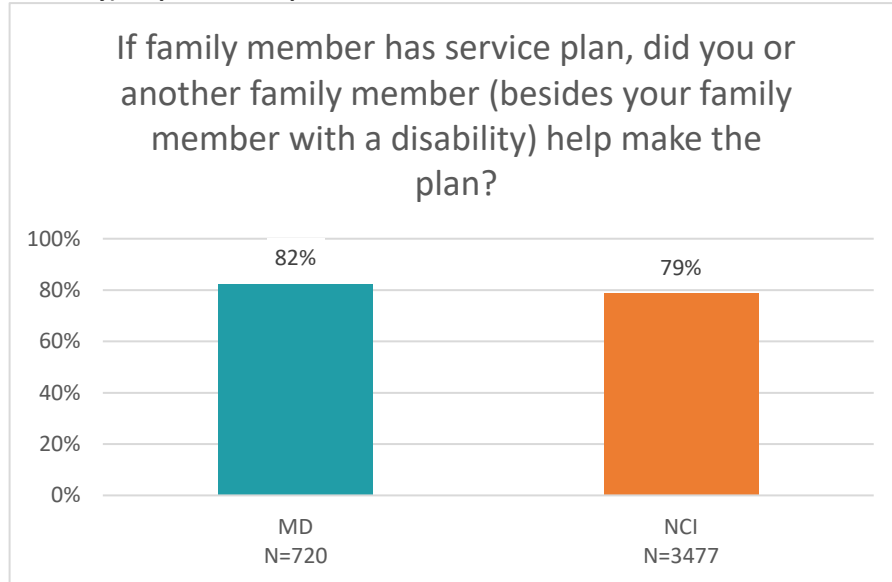
**Chart 9.** Does the plan include all the services and supports your family member needs?



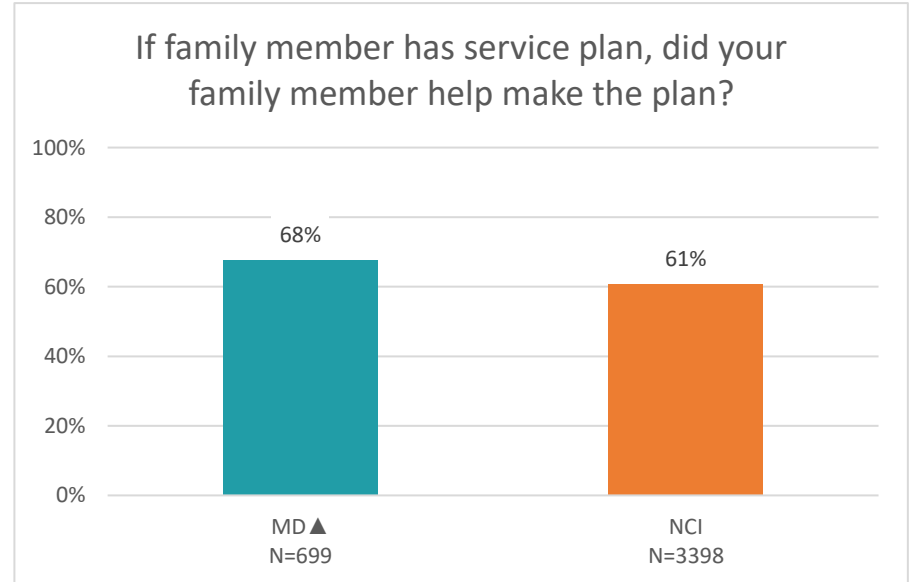
**Chart 10.** Does your family member get all of the services listed in the plan?



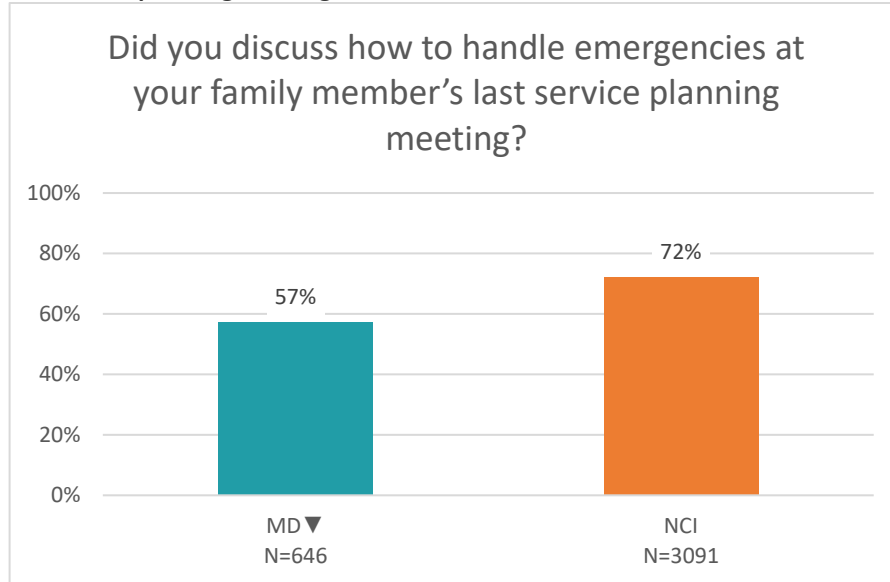
**Chart 11.** Did you or another family member (besides your family member with a disability) help make the plan?



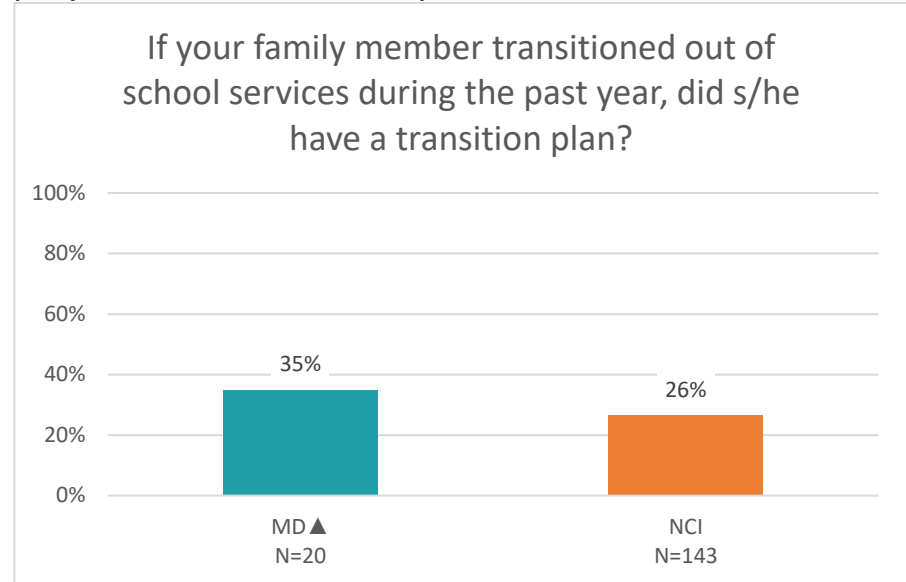
**Chart 12.** Did your family member help make the plan?



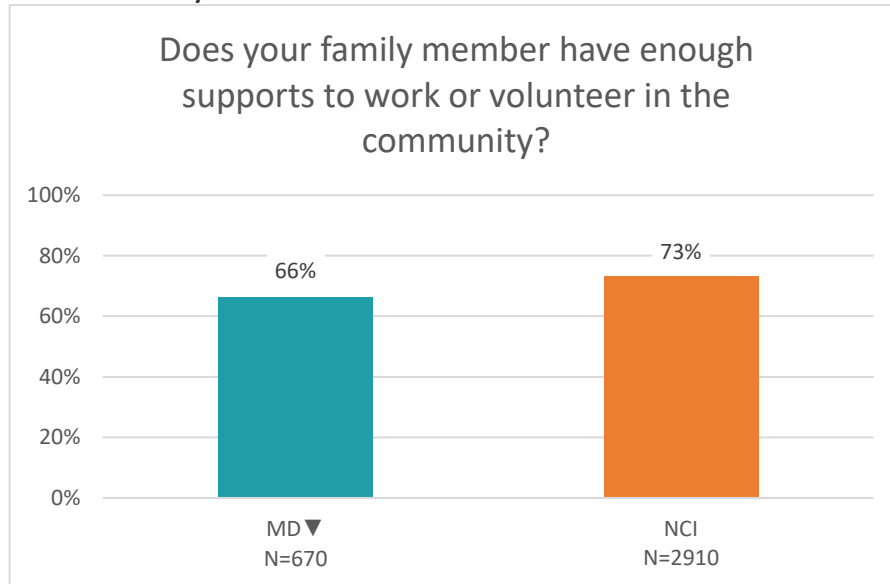
**Chart 13.** Did you discuss how to handle emergencies at your family member's last service planning meeting?



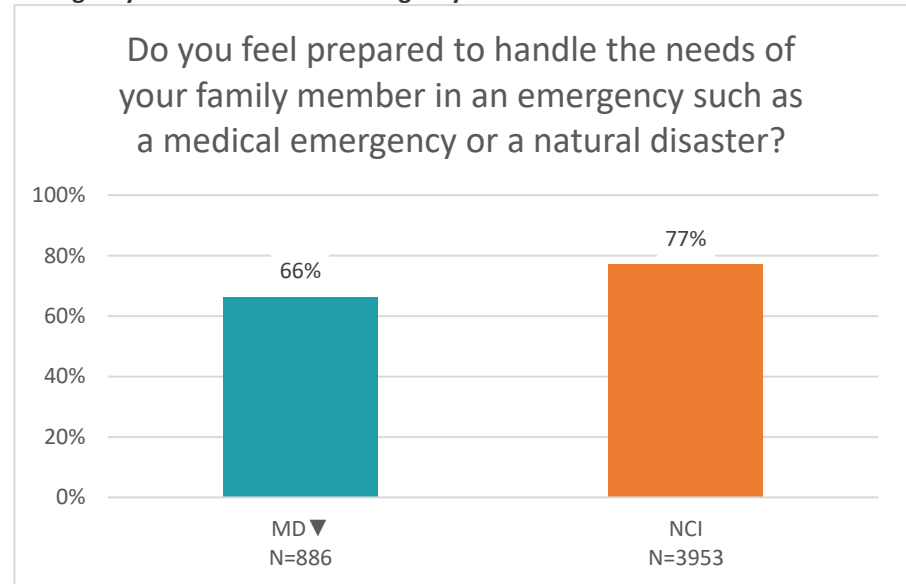
**Chart 14.** If your family member transitioned out of school services during the past year, did s/he have a transition plan?



**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?	MD ▼	30%	40%	20%	10%	996
	NCI	43%	38%	13%	6%	4,475
Is the information you get about services and supports easy to understand?	MD ▼	34%	45%	17%	5%	991
	NCI	39%	46%	12%	3%	4,521
Do staff or the residential agency keep you informed about how your family member is doing?	MD ▼	35%	33%	21%	10%	1,052
	NCI	49%	31%	14%	7%	4,672
Does the case manager/service coordinator respect your family's choices and opinions?	MD ▼	49%	36%	10%	6%	1,018
	NCI	63%	28%	6%	3%	4,588

Table 25. Respondent Needs Help With Future Planning Needs

		Yes
Employment	MD	31%
	NCI	26%
Financial	MD	36%
	NCI	31%
Housing	MD	36%
	NCI	37%
Legal	MD	33%
	NCI	29%
Medical	MD	41%
	NCI	41%
Social or Relationships	MD	30%
	NCI	29%
Transition from School	MD	3%
	NCI	5%
Recreation	MD	39%
	NCI	35%
Other	MD	20%
	NCI	25%
N	MD	574
	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?	MD	4%	96%	1,080
	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?	MD	66%	34%	38
	NCI	68%	32%	148
Does your family member have a service plan?	MD▼	91%	9%	853
	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?	MD▼	90%	10%	683
	NCI	94%	6%	3,393
Does your family member get all the services listed in the plan?	MD▼	86%	14%	630
	NCI	91%	9%	3,149
Did you or another family member (beside your family member with a disability) help make the plan?	MD	82%	18%	720
	NCI	79%	21%	3,477
Did your family member help make the plan?	MD▲	68%	32%	699
	NCI	61%	39%	3,398
Did you discuss how to handle emergencies at your family member's last service planning meeting?	MD▼	57%	43%	646
	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?	MD▲	35%	65%	20
	NCI	26%	74%	143
Does your family member have enough supports to work or volunteer in the community?	MD▼	66%	34%	670
	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?	MD▼	66%	34%	886
	NCI	77%	23%	3,953

## Access and Delivery of Services and Supports

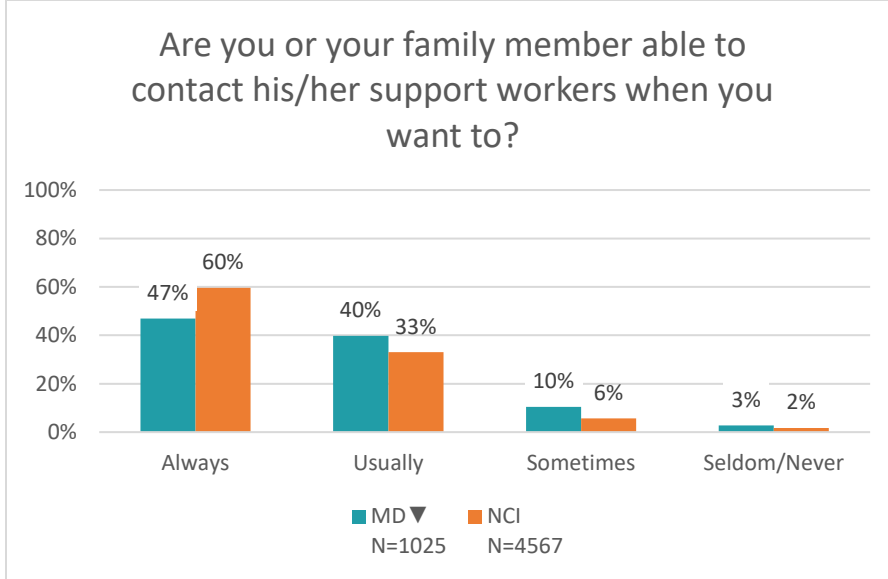
Families and family members with disabilities get the services and supports they need.

---

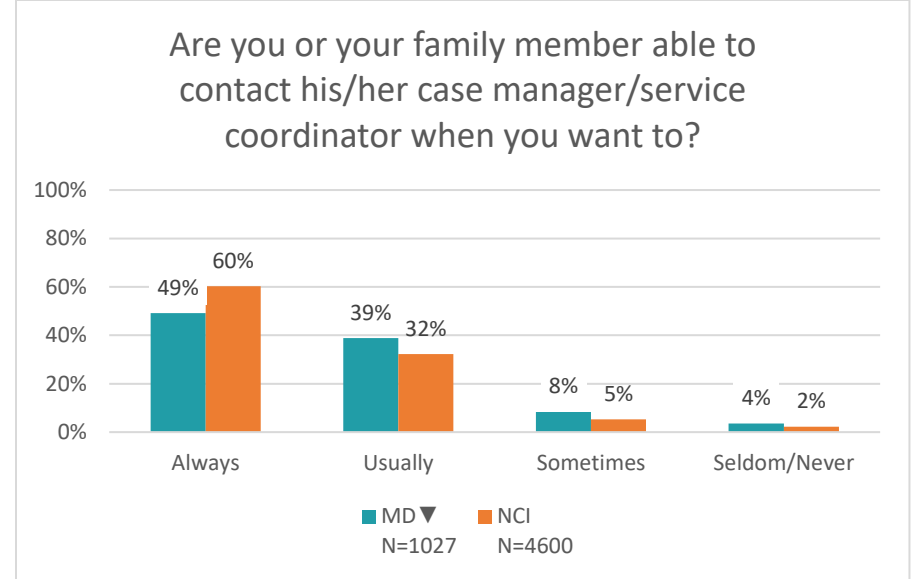


## *Charts for Access and Delivery of Services and Supports*

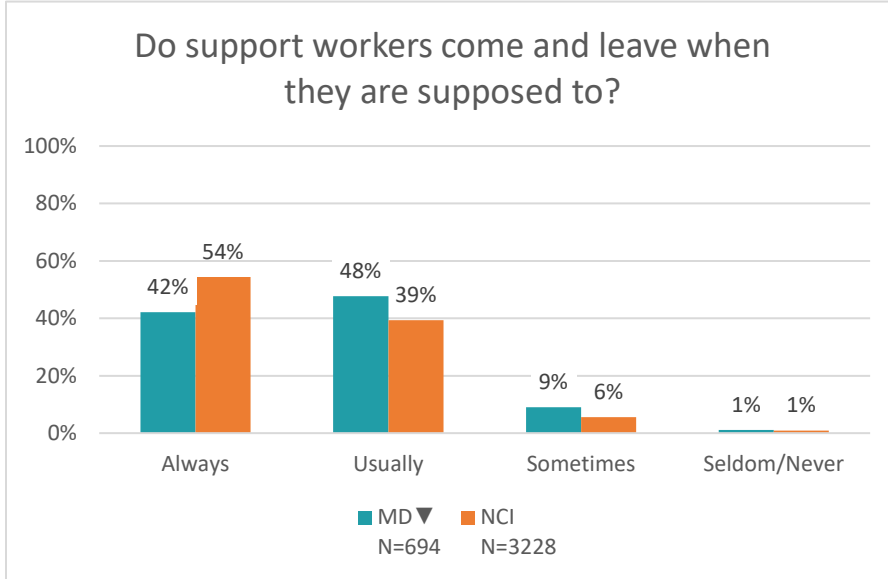
**Chart 17.** Are you or your family member able to contact his/her support workers when you want to?



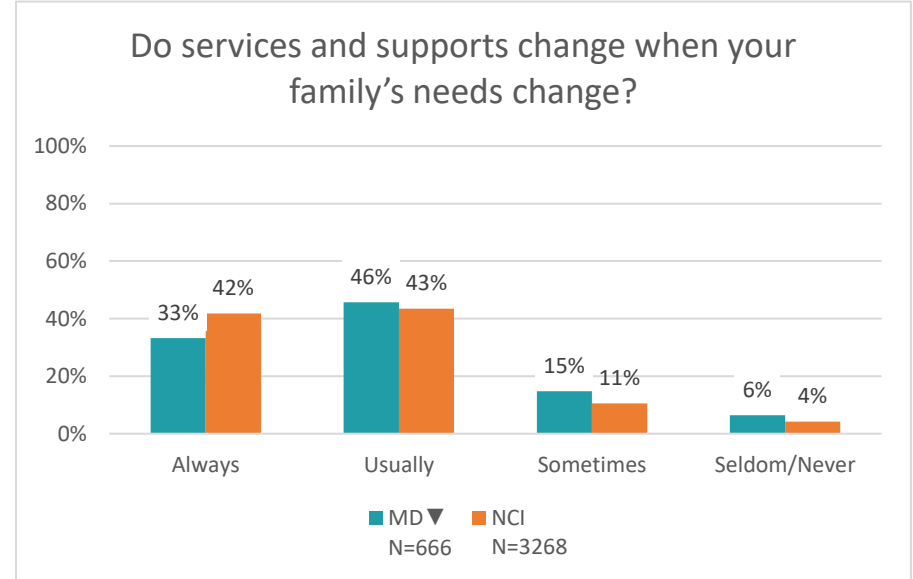
**Chart 18.** Are you or your family member able to contact his/her case manager/service coordinator when you want to?



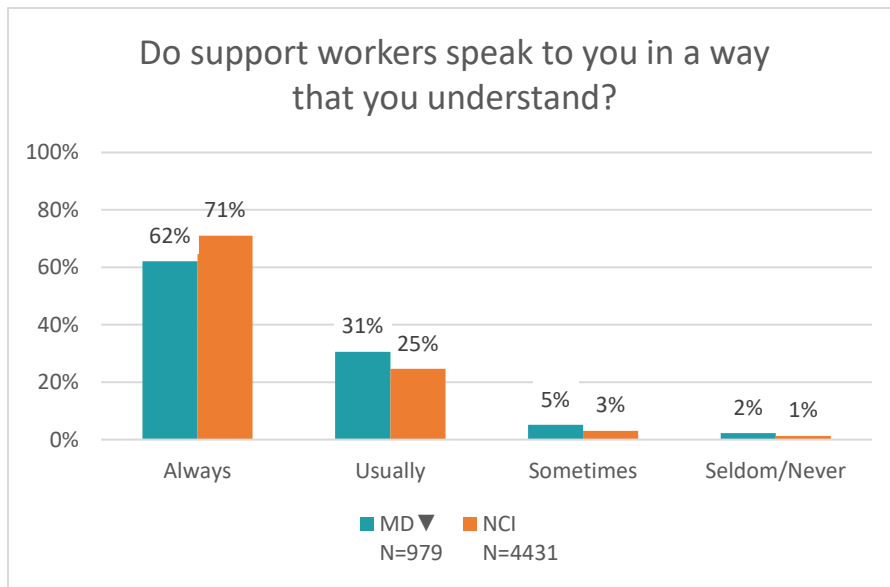
**Chart 19.** Do support workers come and leave when they are supposed to?



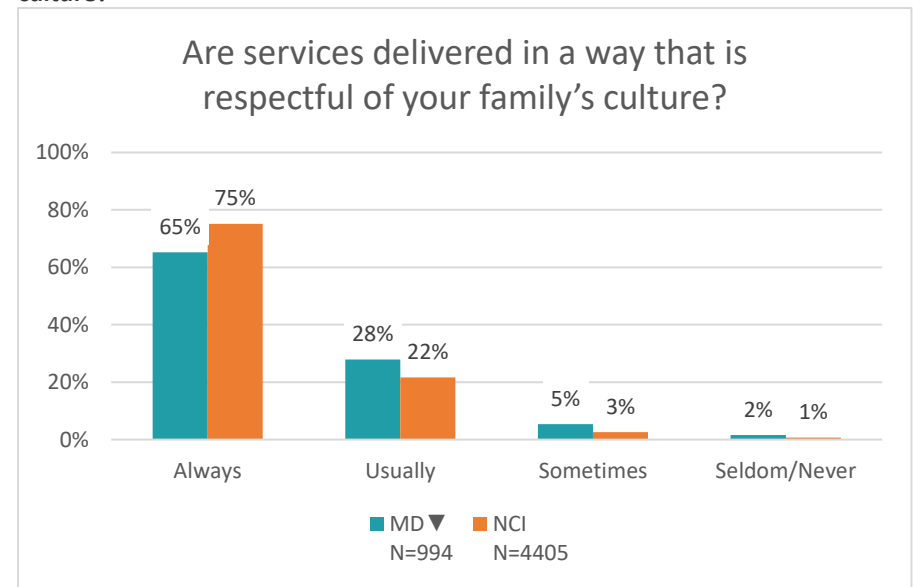
**Chart 20.** Do services and supports change when your family's needs change?



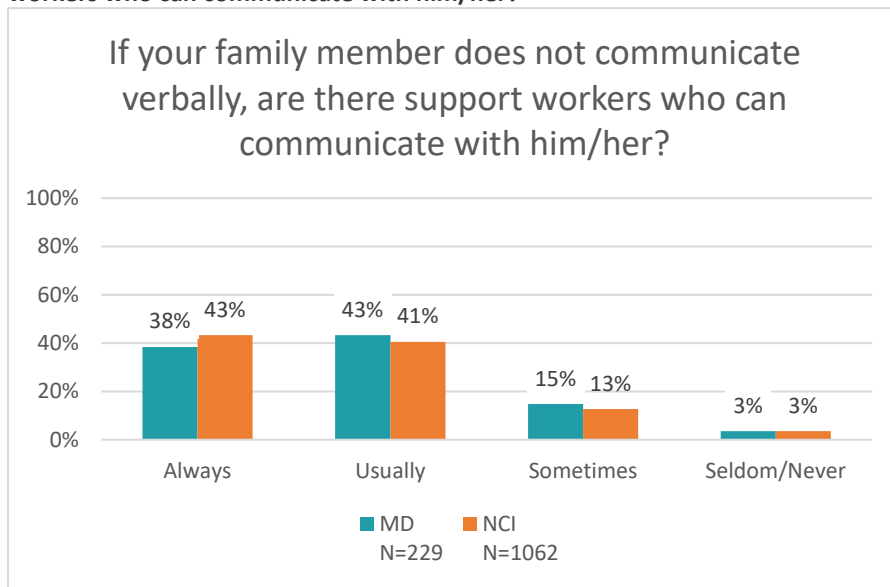
**Chart 21.** Do support workers speak to you in a way that you understand?



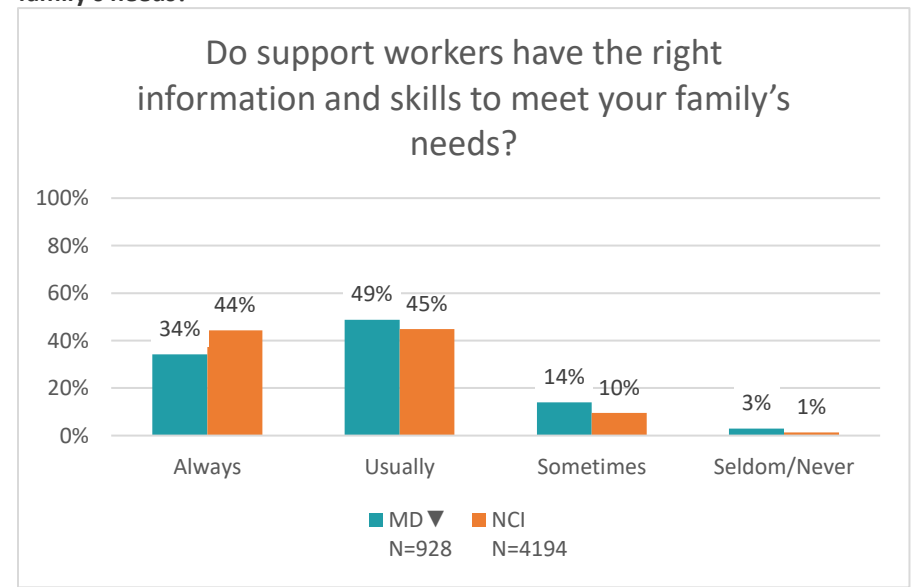
**Chart 22.** Are services delivered in a way that is respectful of your family's culture?



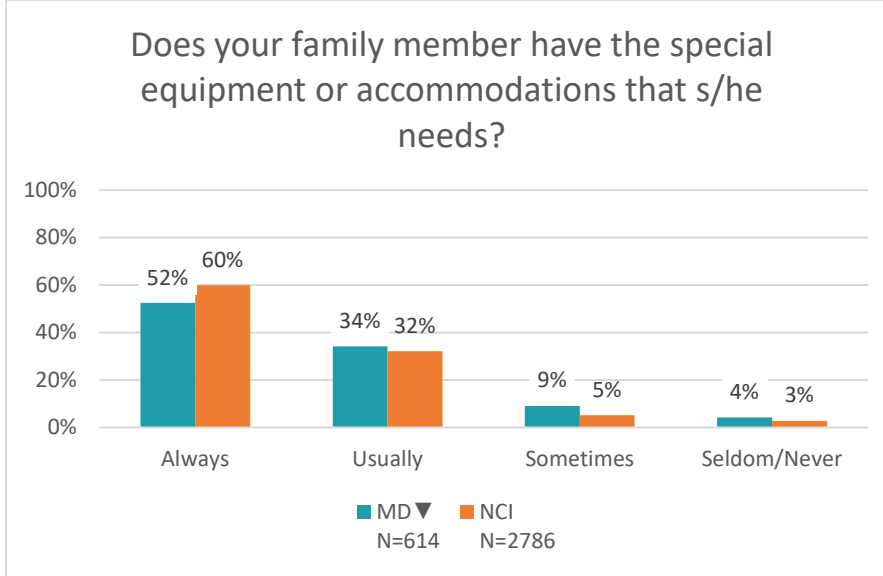
**Chart 23.** If your family member does not communicate verbally, are there support workers who can communicate with him/her?



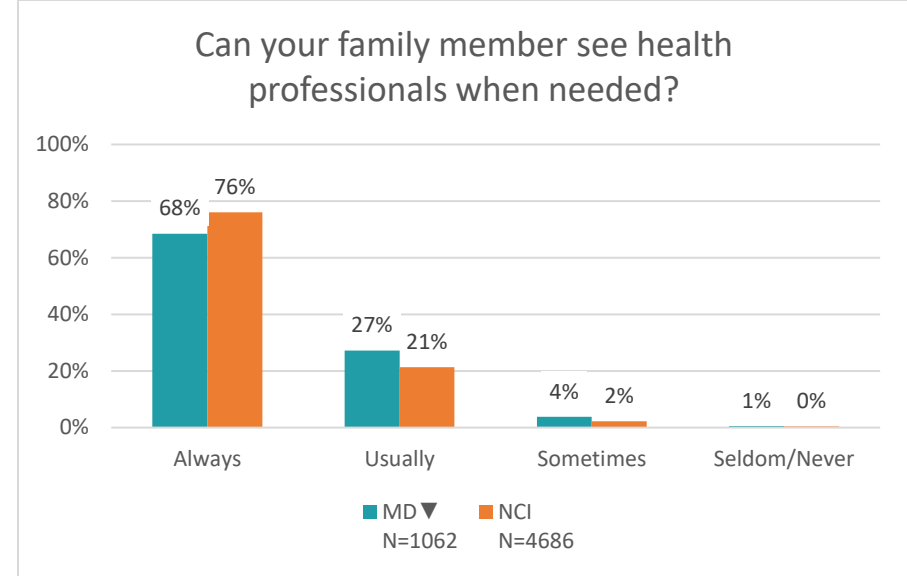
**Chart 24.** Do support workers have the right information and skills to meet your family's needs?



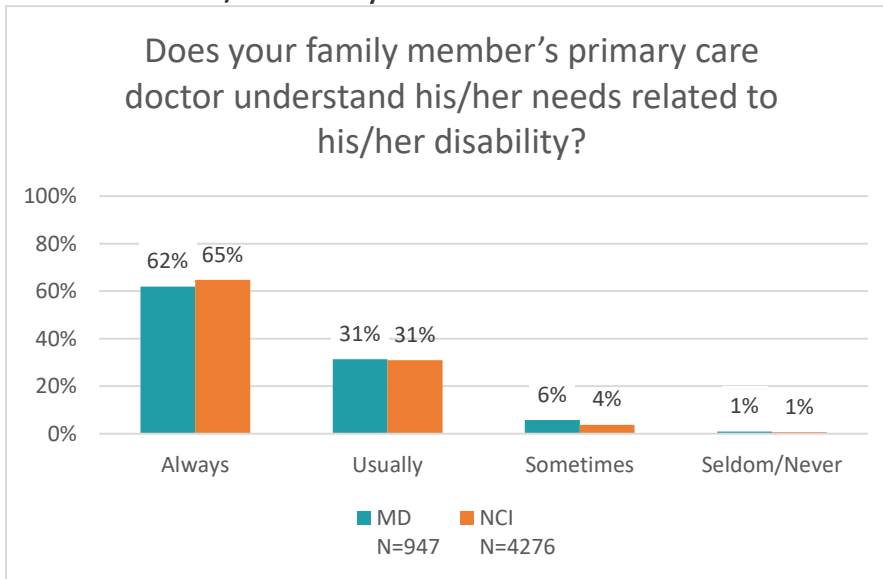
**Chart 25.** Does your family member have the special equipment or accommodations that s/he needs?



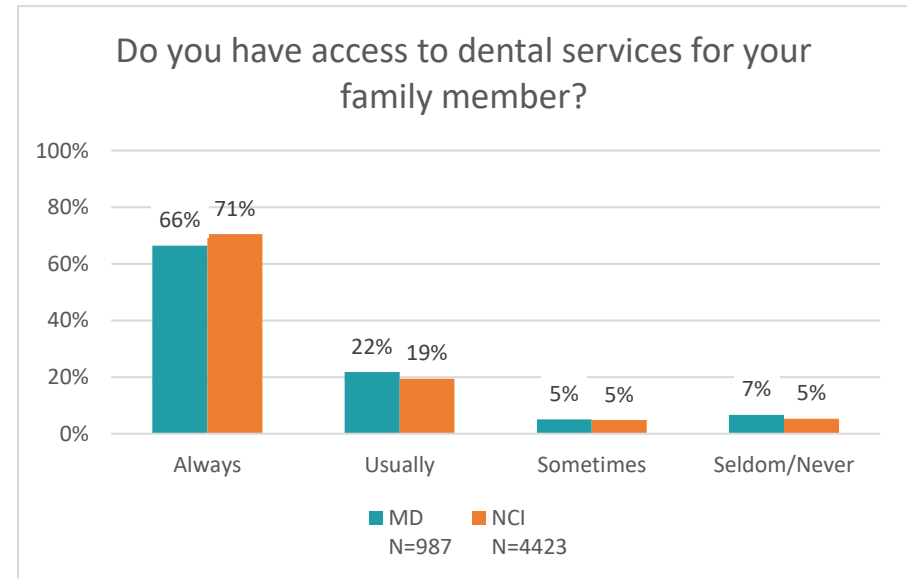
**Chart 26.** Can your family member see health professionals when needed?



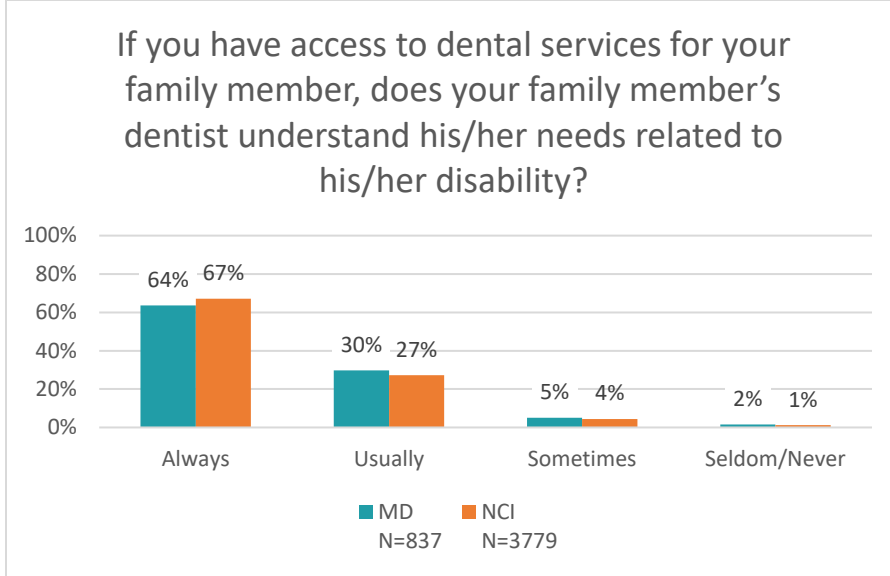
**Chart 27.** Does your family member's primary care doctor understand his/her needs related to his/her disability?



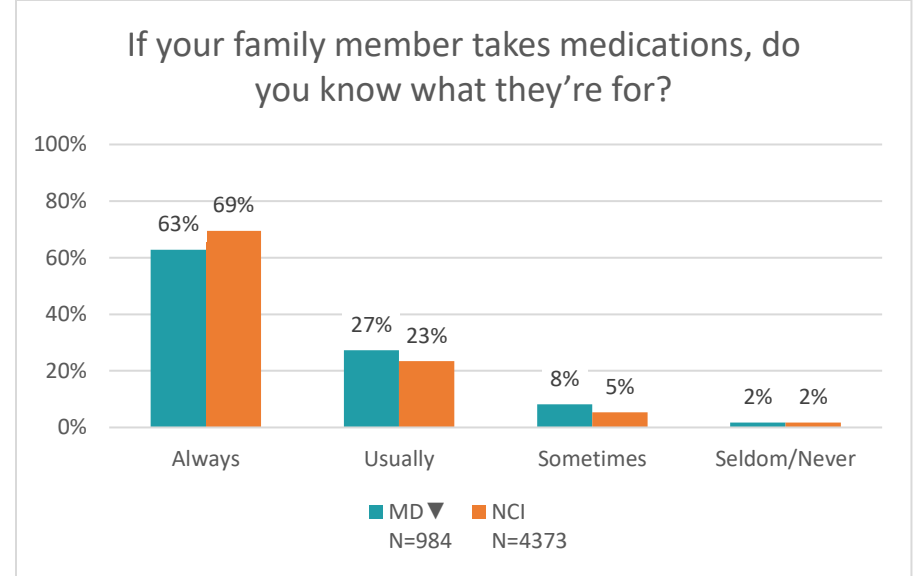
**Chart 28.** Do you have access to dental services for your family member?



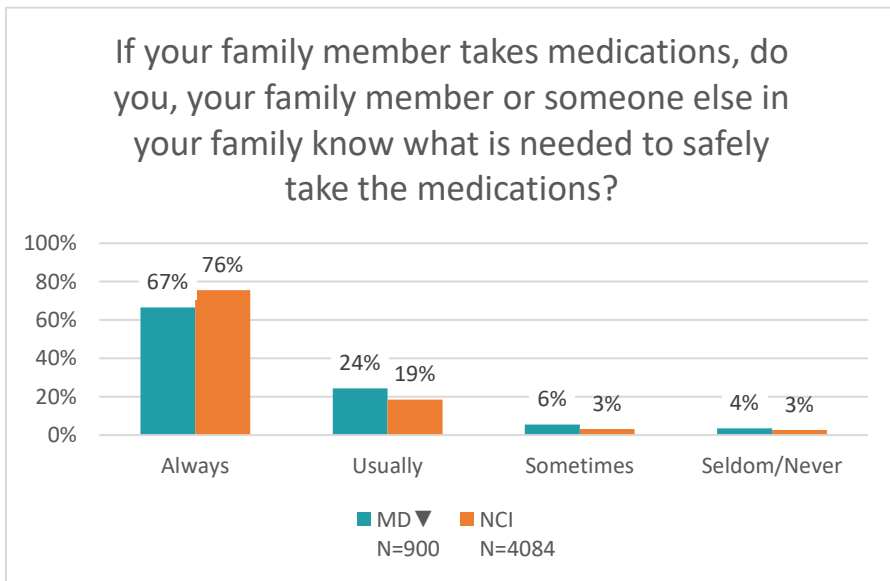
**Chart 29.** If you have access to dental services for your family member, does your family member’s dentist understand his/her needs related to his/her disability?



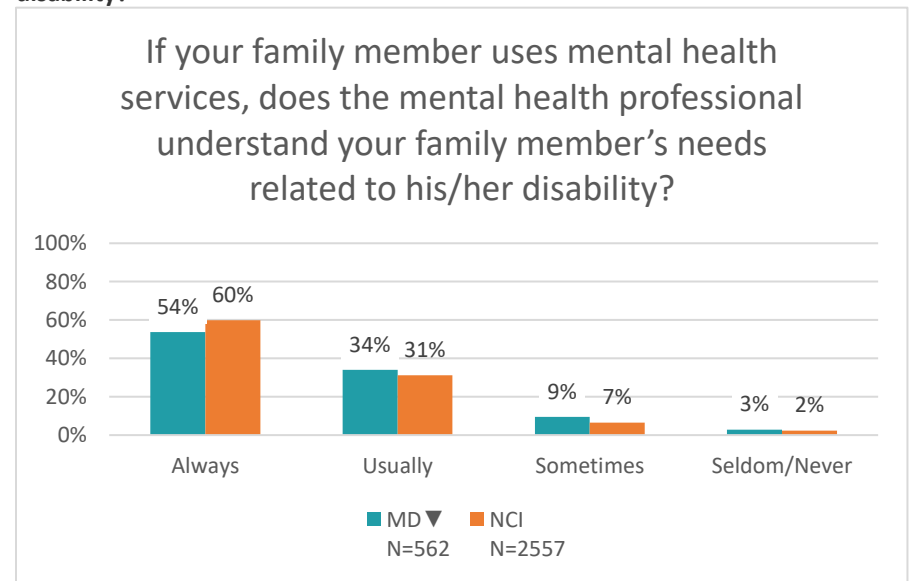
**Chart 30.** If your family member takes medications, do you know what they’re for?

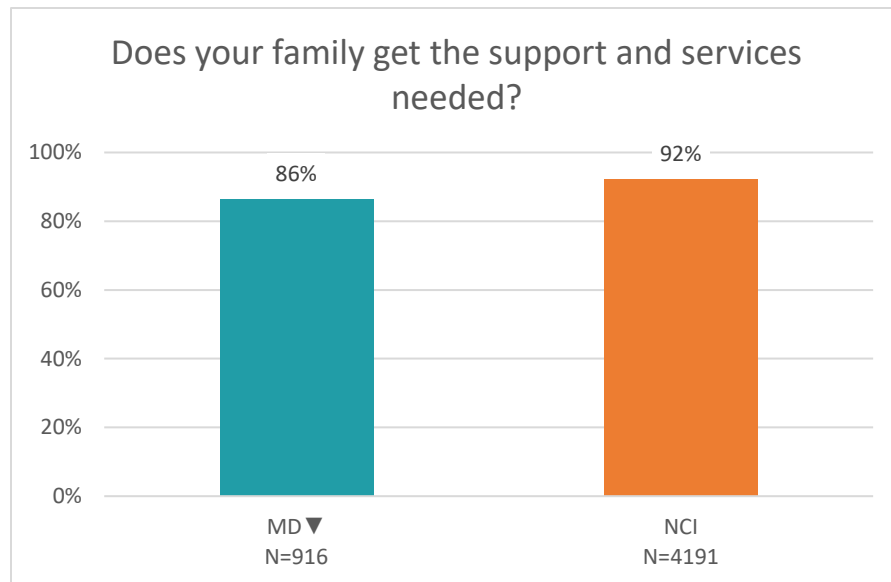
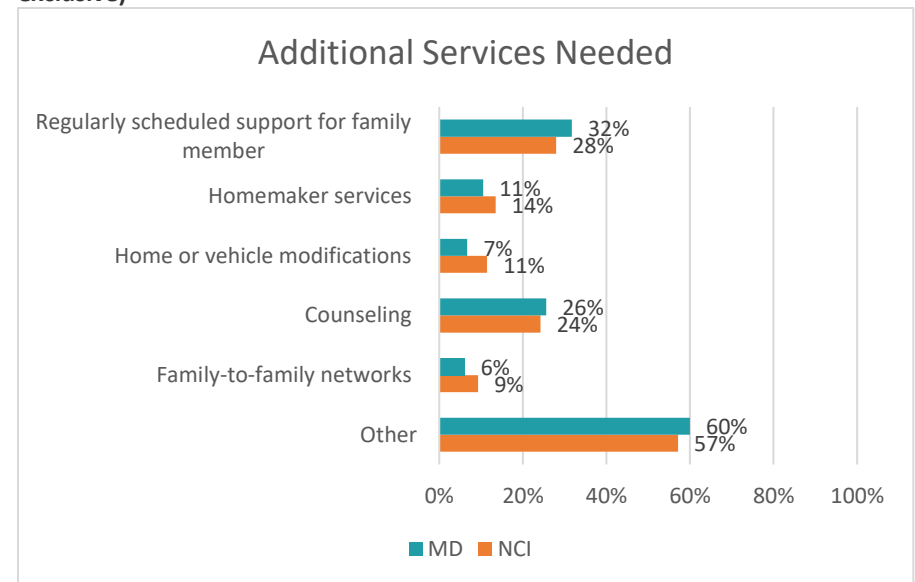


**Chart 31.** If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications?



**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?	MD ▼	47%	40%	10%	3%	1,025
	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?	MD ▼	49%	39%	8%	4%	1,027
	NCI	60%	32%	5%	2%	4,600
Do support workers come and leave when they are supposed to?	MD ▼	42%	48%	9%	1%	694
	NCI	54%	39%	6%	1%	3,228
Do services and supports change when your family's needs change?	MD ▼	33%	46%	15%	6%	666
	NCI	42%	43%	11%	4%	3,268
Do support workers speak to you in a way that you understand?	MD ▼	62%	31%	5%	2%	979
	NCI	71%	25%	3%	1%	4,431
Are services delivered in a way that is respectful of your family's culture?	MD ▼	65%	28%	5%	2%	994
	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?	MD	38%	43%	15%	3%	229
	NCI	43%	41%	13%	3%	1,062
Do support workers have the right information and skills to meet your family's needs?	MD ▼	34%	49%	14%	3%	928
	NCI	44%	45%	10%	1%	4,194
Does your family member have the special equipment or accommodations that s/he needs?	MD ▼	52%	34%	9%	4%	614
	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?	MD ▼	68%	27%	4%	1%	1,062
	NCI	76%	21%	2%	0%	4,686
Does your family member's primary care doctor understand his/her needs related to his/her disability?	MD	62%	31%	6%	1%	947
	NCI	65%	31%	4%	1%	4,276
Do you have access to dental services for your family member?	MD	66%	22%	5%	7%	987
	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?	MD	64%	30%	5%	2%	837
	NCI	67%	27%	4%	1%	3,779
If your family member takes medications, do you know what they're for?	MD ▼	63%	27%	8%	2%	984
	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?	MD ▼	67%	24%	6%	4%	900
	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?	MD ▼	54%	34%	9%	3%	562
	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?	MD ▼	86%	14%	916
	NCI	92%	8%	4,191

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

		Needs Service
Regularly scheduled support for family member	MD	32%
	NCI	28%
Homemaker services	MD	11%
	NCI	14%
Home or vehicle modifications	MD	7%
	NCI	11%
Counseling	MD	26%
	NCI	24%
Family-to-family networks	MD	6%
	NCI	9%
Other	MD	60%
	NCI	57%

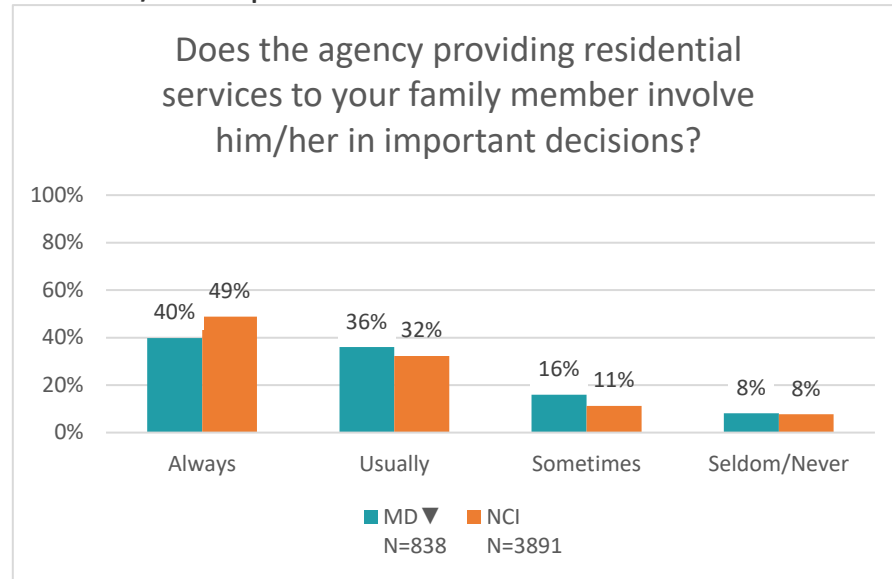
## **Choice, Decision Making and Control**

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

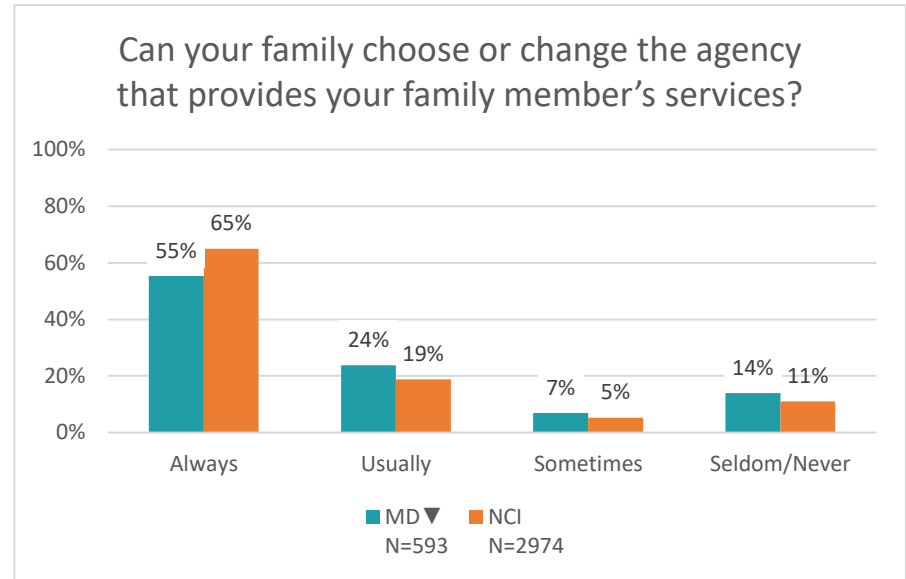
---

## *Charts for Choice, Decision Making and Control*

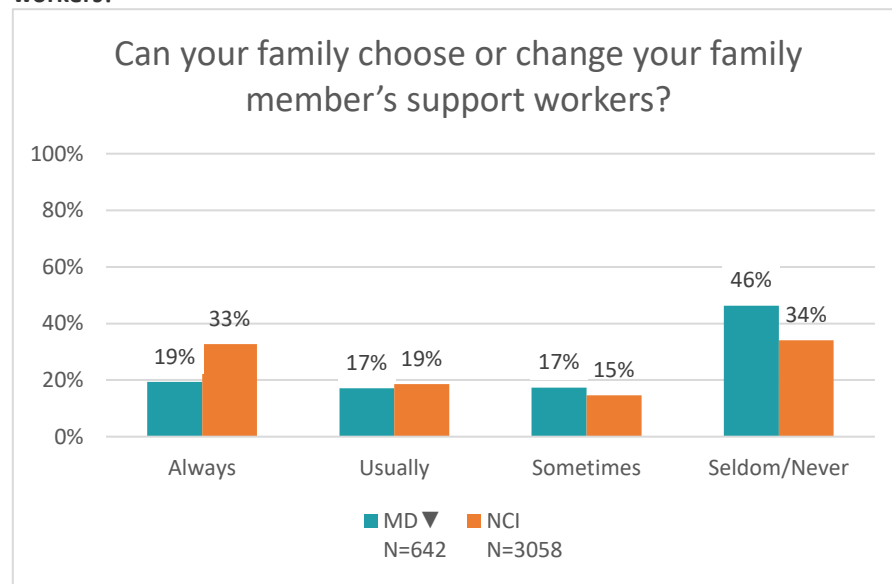
**Chart 35.** Does the agency providing residential services to your family member involve him/her in important decisions?



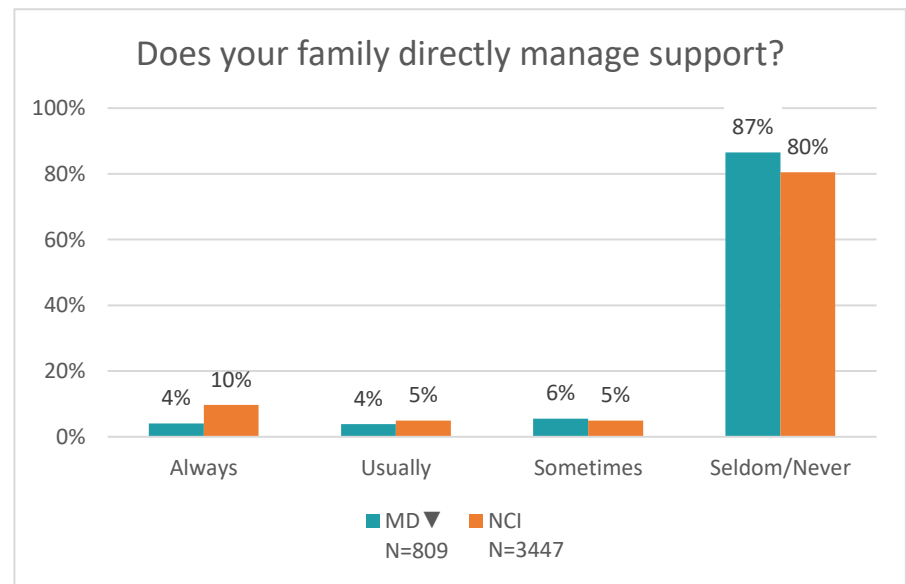
**Chart 36.** Can your family choose or change the agency that provides your family member's services?



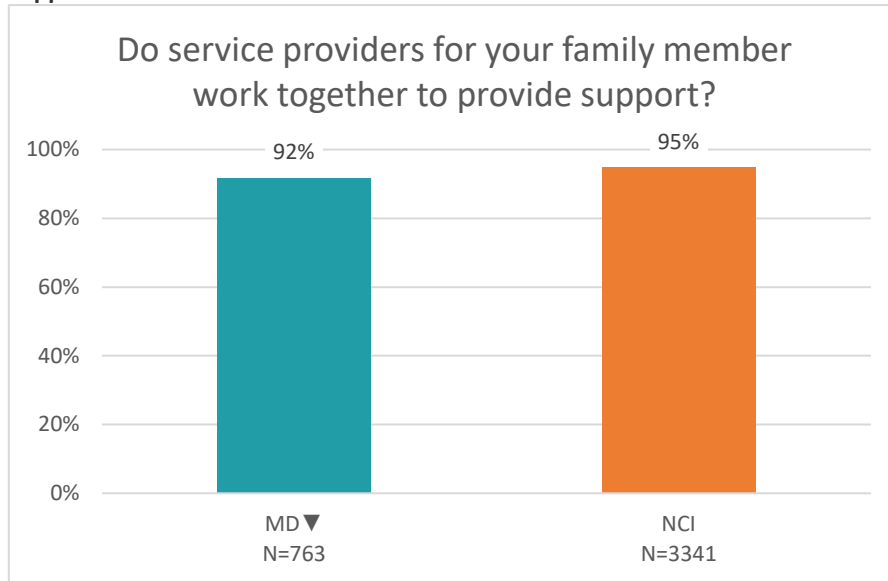
**Chart 37.** Can your family choose or change your family member's support workers?



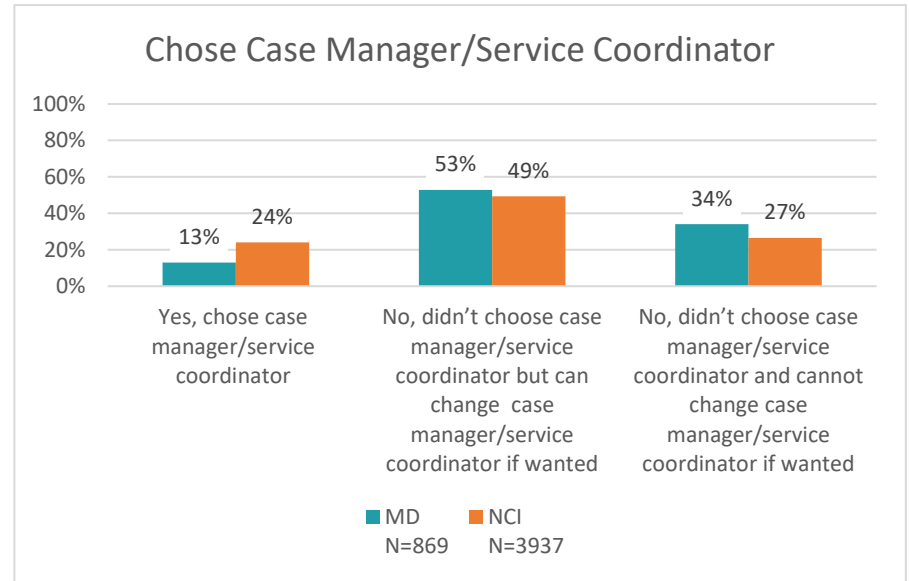
**Chart 38.** Does your family directly manage support workers?



**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?	MD ▼	40%	36%	16%	8%	838
	NCI	49%	32%	11%	8%	3,891
Can your family choose or change the agency that provides your family member's services?	MD ▼	55%	24%	7%	14%	593
	NCI	65%	19%	5%	11%	2,974
Can your family choose or change the individual staff that provide the services for your family member?	MD ▼	19%	17%	17%	46%	642
	NCI	33%	19%	15%	34%	3,058
Does your family directly manage support?	MD ▼	4%	4%	6%	87%	809
	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?	MD ▼	92%	8%	763
	NCI	95%	5%	3,341

Table 33. Chose Case Manager/Service Coordinator

		Chose Case Manager/Service Coordinator
Yes, chose case manager/service coordinator	MD	13%
	NCI	24%
No, didn't choose case manager/service coordinator but can change case manager/service coordinator if wanted	MD	53%
	NCI	49%
No, didn't choose case manager/service coordinator and cannot change case manager/service coordinator if wanted	MD	34%
	NCI	27%
N	MD	869
	NCI	3,937



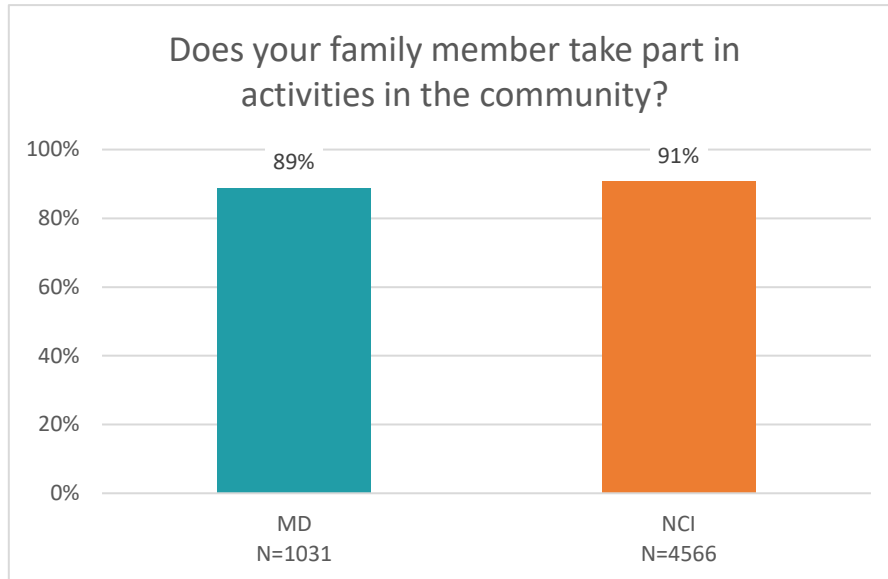
## Involvement in the Community

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

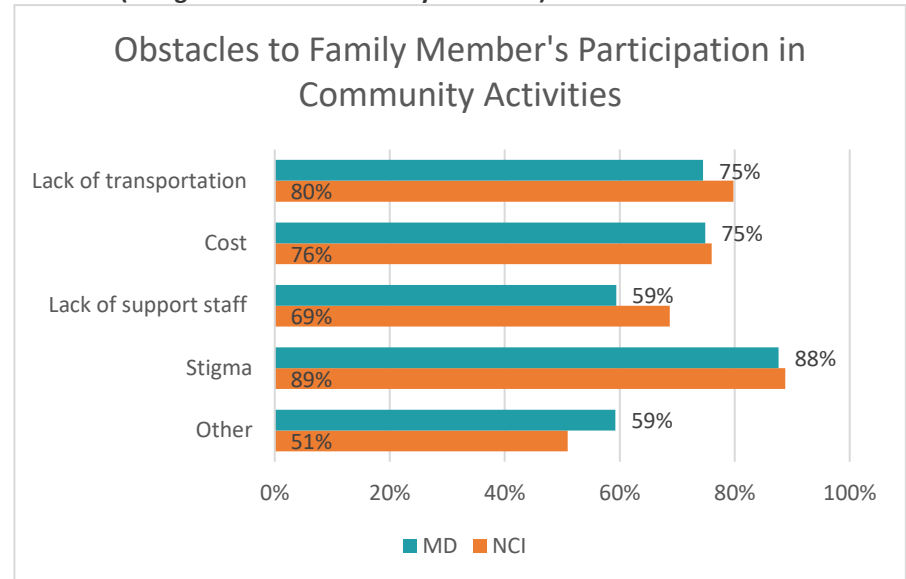
---

## *Charts for Involvement in the Community*

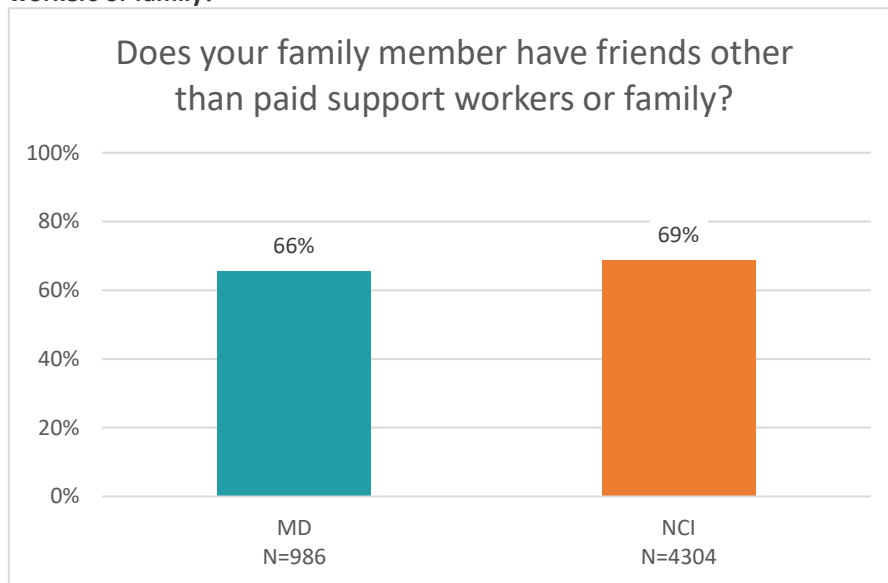
**Chart 41.** Does your family member take part in activities in the community?



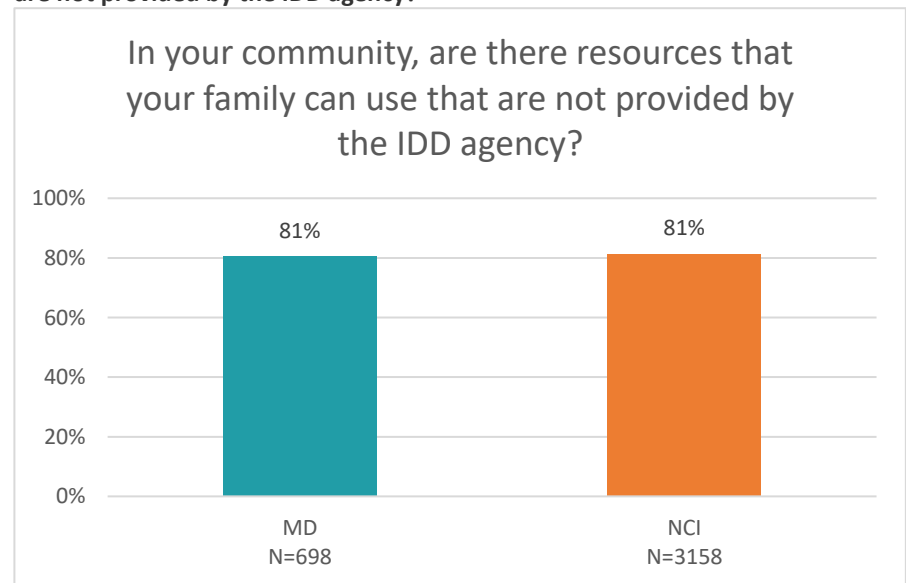
**Chart 42.** Obstacles/Barriers to family member's participation in community activities (categories are not mutually exclusive)



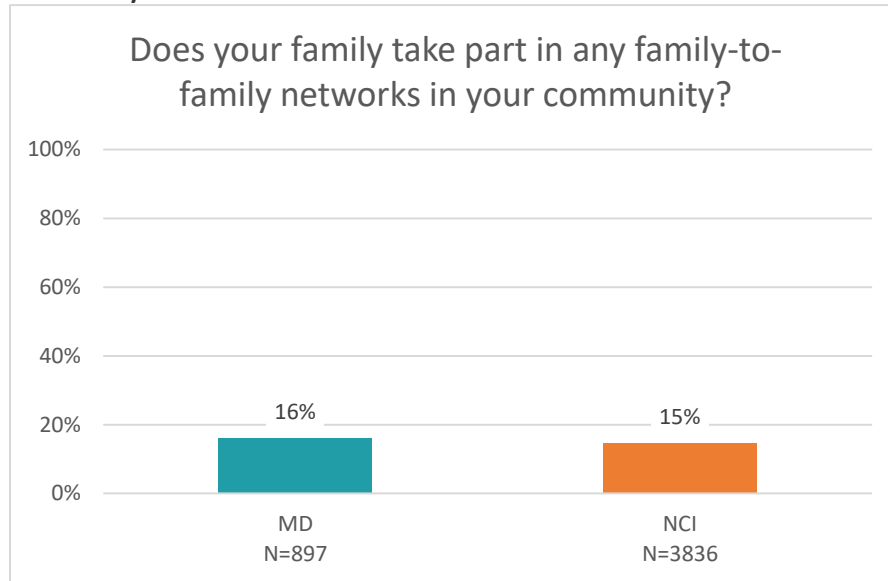
**Chart 43.** Does your family member have friends other than paid support workers or family?



**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?	MD	89%	11%	1,031
	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	MD	75%
	NCI	80%
Cost	MD	75%
	NCI	76%
Lack of support staff	MD	59%
	NCI	69%
Stigma	MD	88%
	NCI	89%
Other	MD	59%
	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?	MD	66%	34%	986
	NCI	69%	31%	4,304
In your community, are there resources that your family can use that are not provided by the IDD agency?	MD	81%	19%	698
	NCI	81%	19%	3,158
Does your family take part in any family-to-family networks in your community?	MD	16%	84%	897
	NCI	15%	85%	3,836

## Satisfaction With Services and Supports

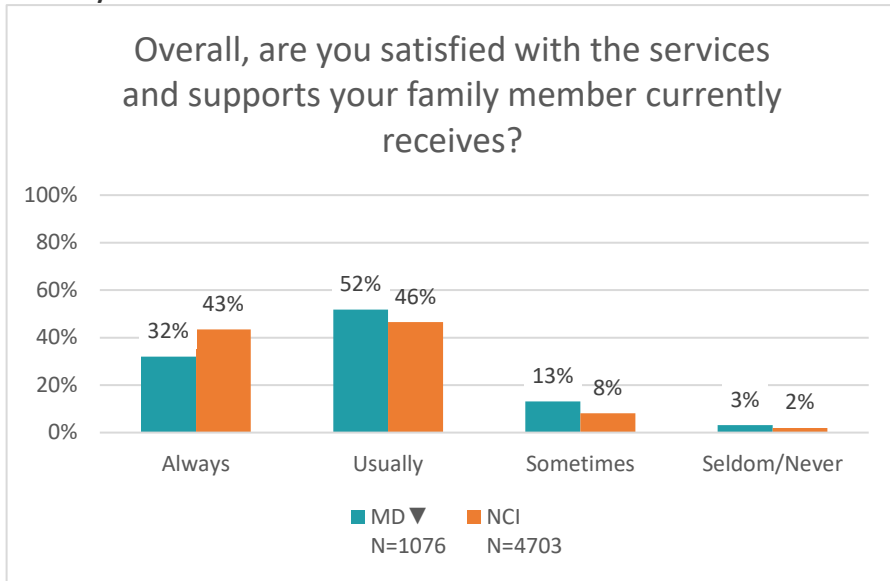
Families and family members with disabilities receive adequate and satisfactory supports.

---

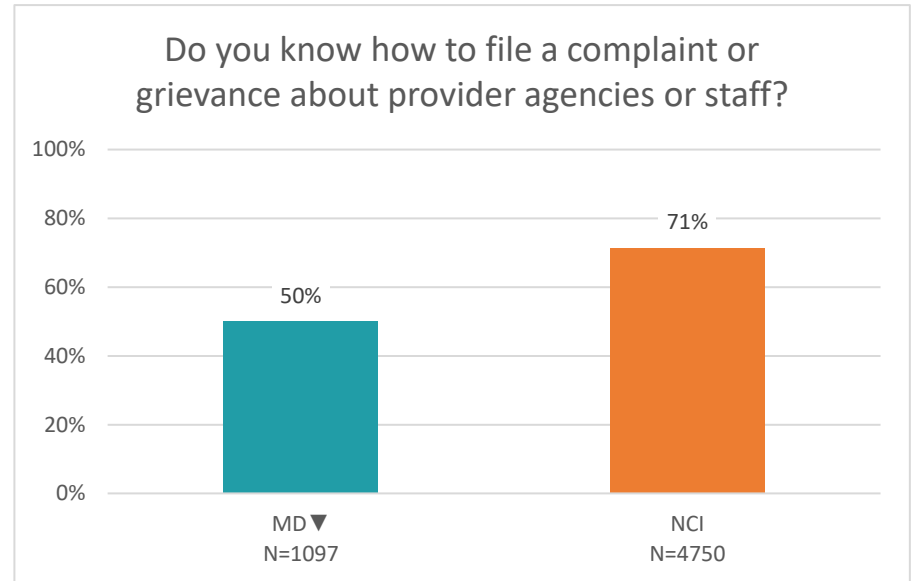
## *Charts for Satisfaction With Services and Supports*



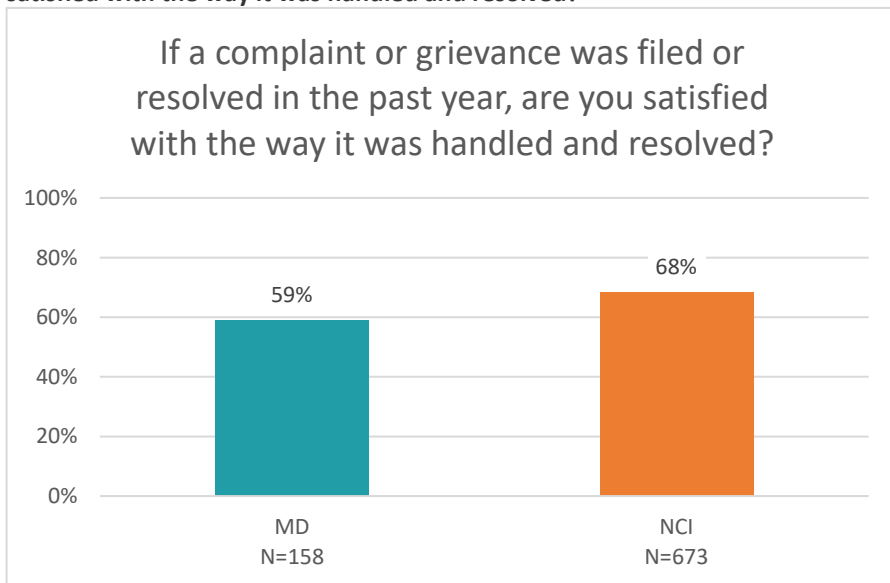
**Chart 46.** Overall, are you satisfied with the services and supports your family member currently receives?



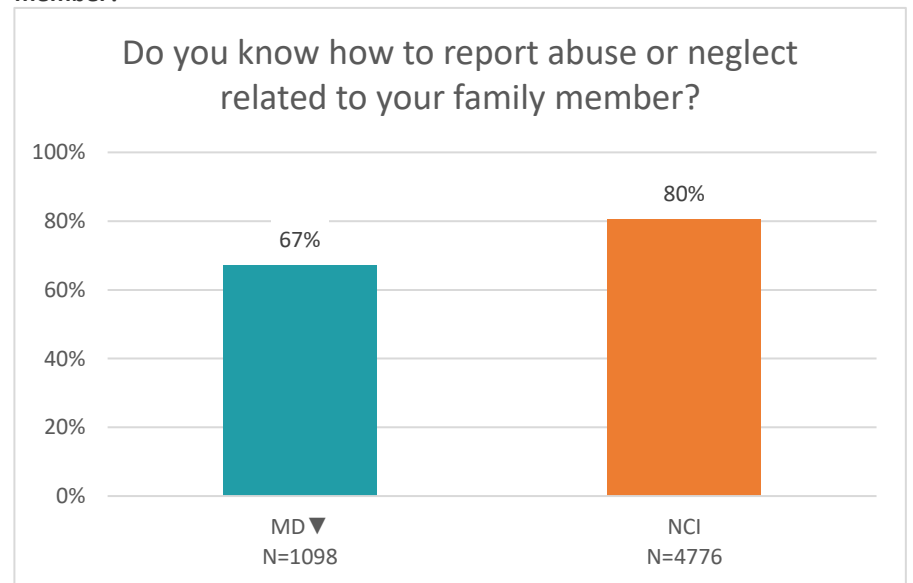
**Chart 47.** Do you know how to file a complaint or grievance about provider agencies or staff?\*



**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?

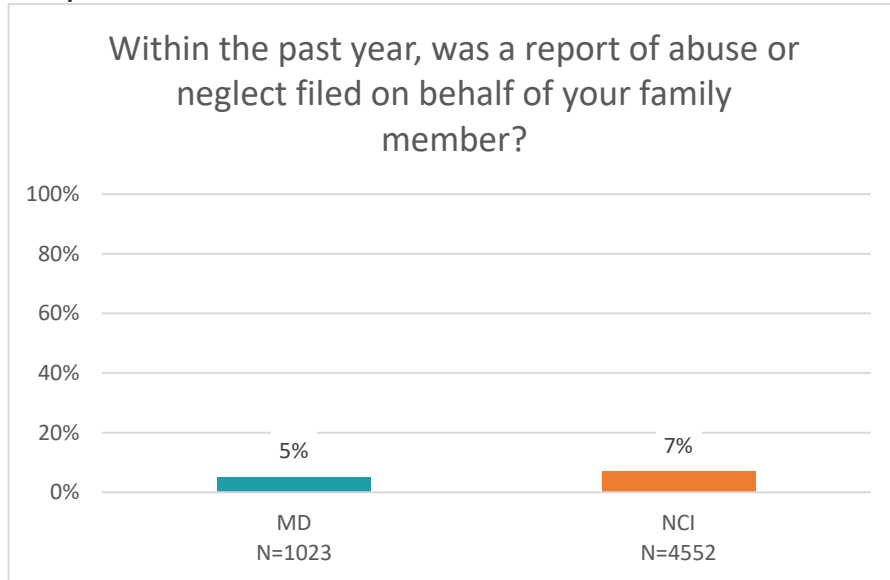


**Chart 49.** Do you know how to report abuse or neglect related to your family member?\*

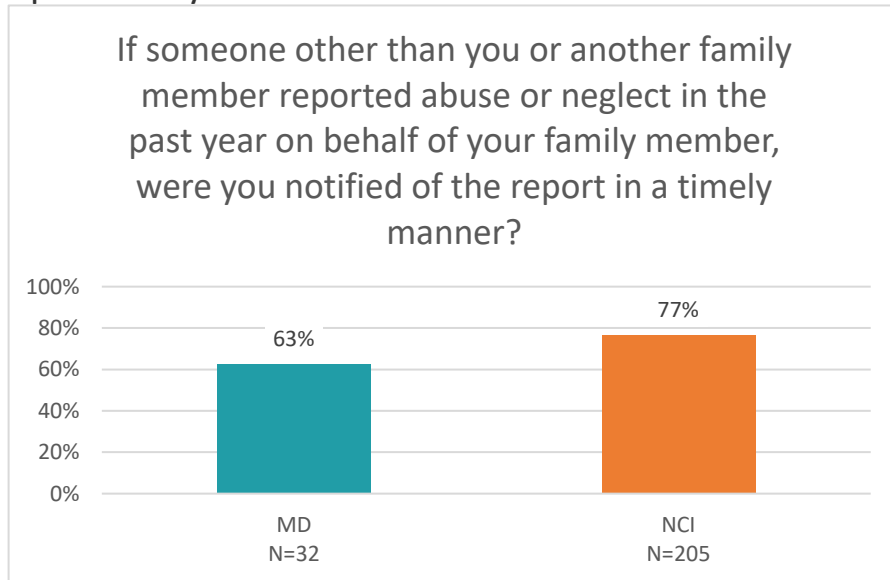


\*No and don't know responses are combined

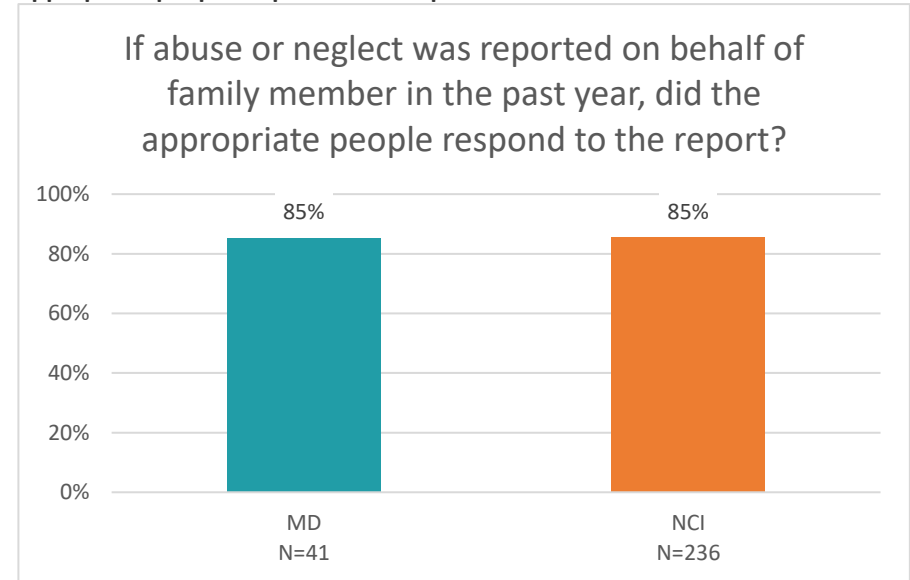
**Chart 50.** In the past year, was a report of abuse or neglect filed on behalf of your family member?



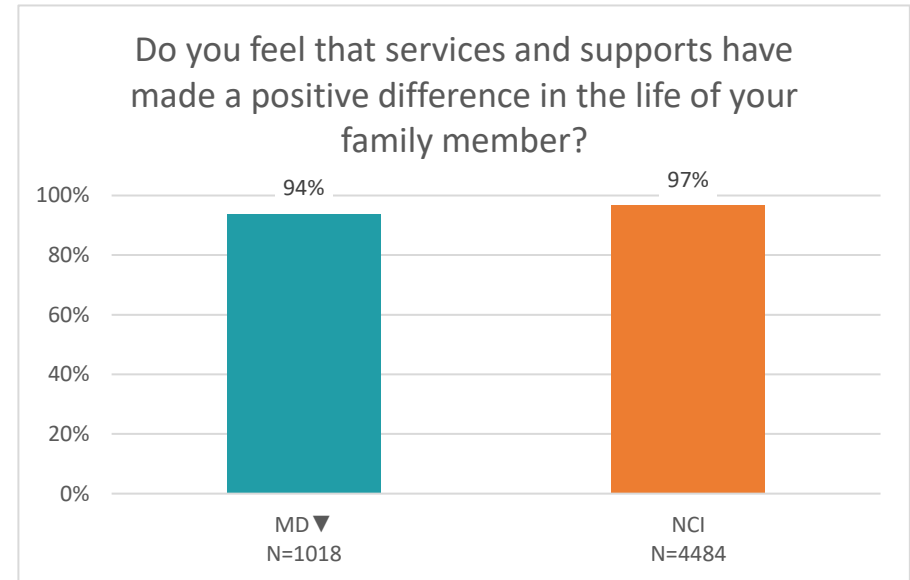
**Chart 52.** If someone other than you or another family member reported abuse or neglect in the past year on behalf of your family member, were you notified of the report in a timely manner?



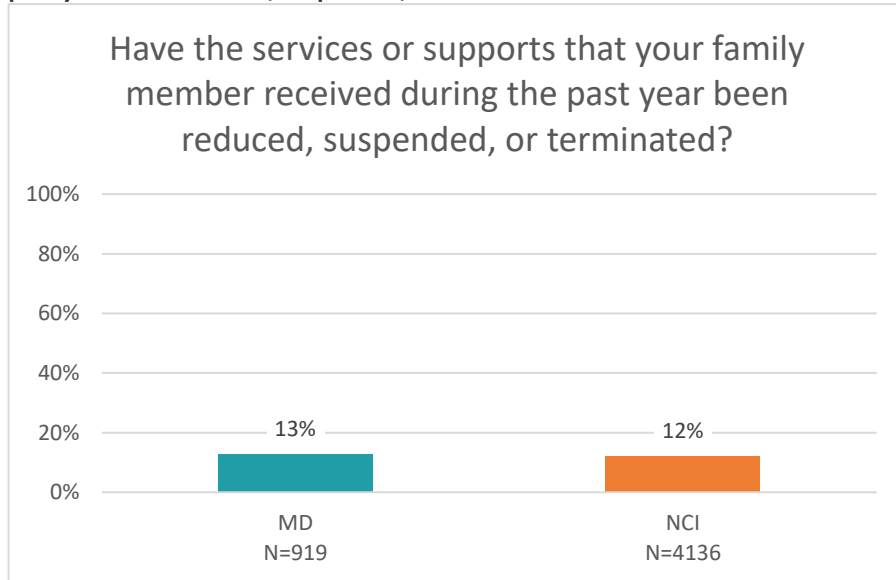
**Chart 51.** If a report of abuse or neglect was filed on behalf of family member, did the appropriate people respond to the report?



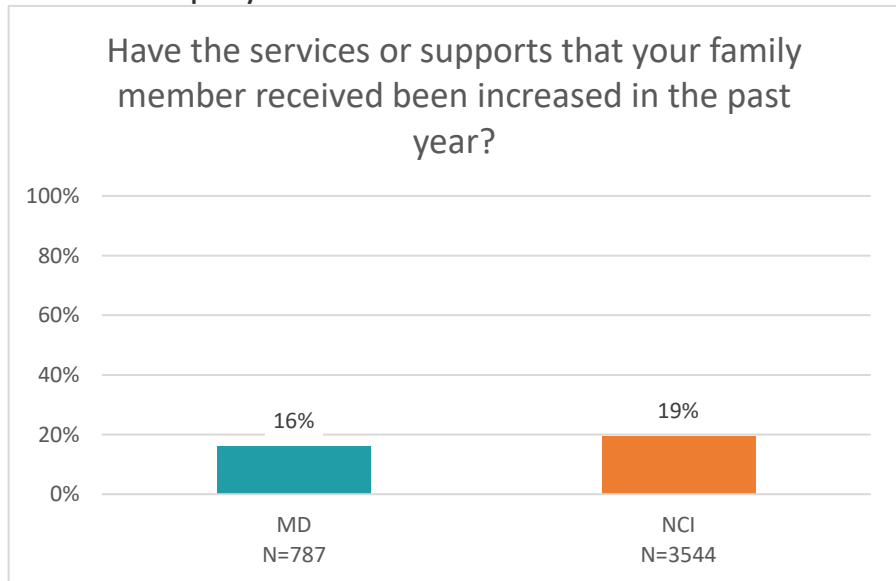
**Chart 53.** Do you feel that services and supports have made a positive difference in the life of your family member?



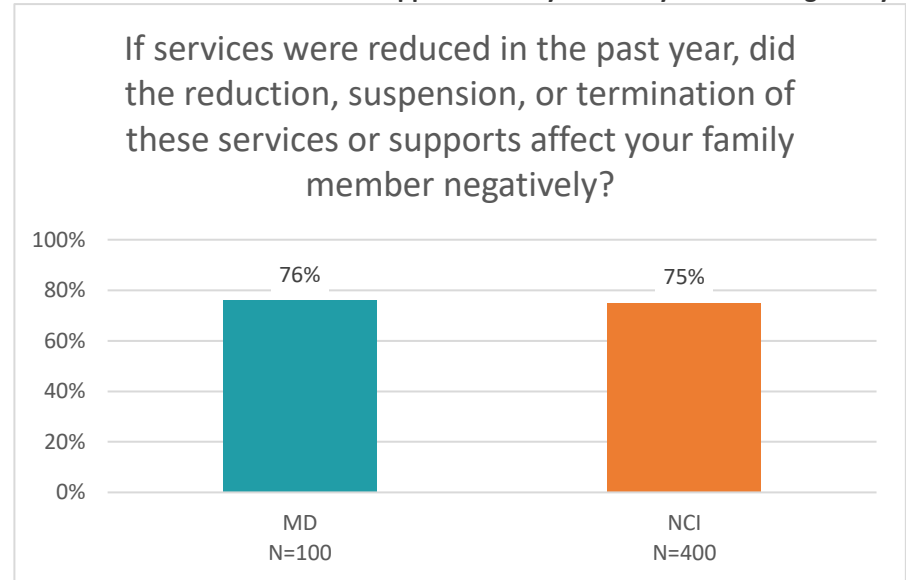
**Chart 54.** Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?



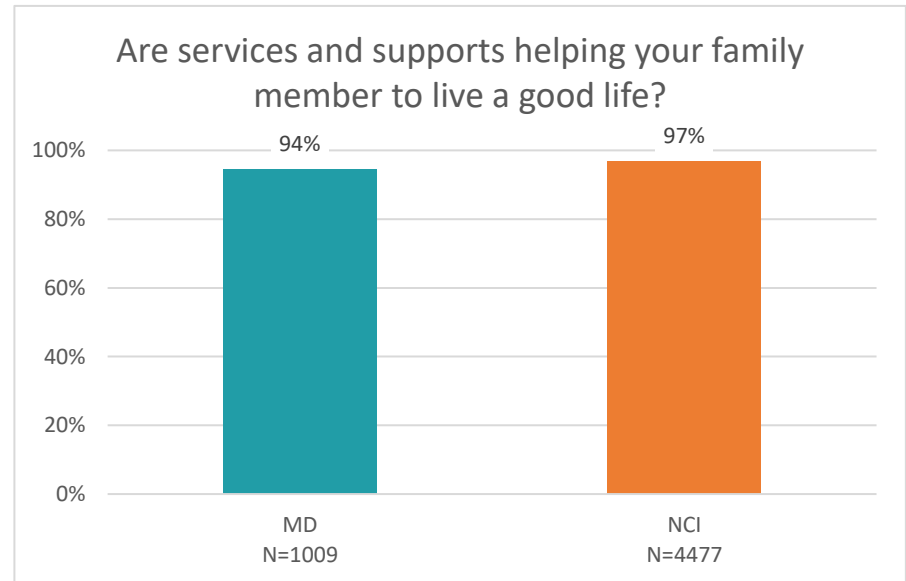
**Chart 56.** Have the services or supports that your family member received been increased in the past year?



**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?	MD ▼	32%	52%	13%	3%	1,076
	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?*	MD ▼	50%	37%	1,097
	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?	MD	59%	41%	158
	NCI	68%	32%	673
Do you know how to report abuse or neglect related to your family member?*	MD ▼	67%	22%	1,098
	NCI	80%	13%	4,776
Within the past year, was a report of abuse or neglect filed on behalf of your family member?	MD	5%	95%	1,023
	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?	MD	85%	15%	41
	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?	MD	63%	38%	32
	NCI	77%	23%	205
Do you feel that services and supports have made a positive difference in the life of your family member?	MD ▼	94%	6%	1,018
	NCI	97%	3%	4,484
Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?	MD	13%	87%	919
	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?	MD	76%	24%	100
	NCI	75%	25%	400
Have the services or supports that your family member received been increased in the past year?	MD	16%	84%	787
	NCI	19%	81%	3,544
Are services and supports helping your family member to live a good life?	MD	94%	6%	1,009
	NCI	97%	3%	4,477

\*No and don't know responses are combined