



Adult Family Survey (AFS) State Report

Contents

What is NCI?.....	7
Where are the statistics in this report from?	7
What is the NCI Adult Family Survey?.....	7
What is included in this report?.....	7
Demographics	8
Demographics of Family Member Receiving Services	9
Table 1. More Than One Person Living in the Home Has IDD.....	10
Table 2. Family Member’s Age.....	10
Table 3. Family Member’s Gender.....	10
Table 4. Family Member’s Race and Ethnicity	10
Table 5a. Family Member’s Disabilities (not mutually exclusive).....	11
Table 5b. Family Member’s Disabilities (continued).....	11
Table 6a. Family Member’s Health Conditions.....	11
Table 6b. Family Member’s Health Conditions (continued)	12
Table 7. Family Member’s Preferred Means of Communication.....	12
Table 8. Family Member Has Legal Court Appointed Guardian or Conservator	12
Table 9. Guardian or Conservator Relationship to Family Member	13
Table 10. Family Member’s Highest level of Education.....	13
Table 11. Family Member’s Activities in the Past Two Weeks Included <i>Individual Paid Job in the Community</i>	13
Table 12. Family Member’s Activities in the Past Two Weeks Included <i>Paid Small Group Job in a Community-based Setting</i>	14
Table 13. Family Member’s Activities in the Past Two Weeks Included <i>Paid Work in a Community Job That Primarily Hires People With Disabilities</i>	14
Table 14. Family Member’s Activities in the Past Two Weeks Included <i>Unpaid Activity in the Community</i>	14
Table 15. Family Member’s Activities in the Past Two Weeks Included <i>Paid Activity in a Facility-based Setting</i>	15
Table 16. Family Member’s Activities in the Past Two Weeks Included <i>Unpaid Activity in a Facility-based Setting</i>	15

Table 17. Family Member’s Activities in the Past Two Weeks Included <i>School</i>	15
Table 18. Family Member’s Activities in the Past Two Weeks Included <i>Stays at Home</i>	15
Table 19. Family Member’s Activities in the Past Two Weeks Included <i>Other Activities</i>	16
Table 20. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	16
Table 21. Family Member's Level of Help Needed With Personal Care Activities (e.g., bathing, dressing, eating)	16
Table 22. Family Member’s Need for Help With Other Daily Activities (e.g., scheduling, managing money, or shopping)	16
Demographics of Respondents	17
Table 23. Language Usually Spoken at Home	18
Table 24. Respondent's Age	18
Table 25. Respondent's Health	18
Table 26. Respondent’s Relationship to Family Member	18
Table 27. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services.....	18
Table 28. Number of Adults in Household (Not Including Family Member Receiving Services)	19
Table 29. Number of Children (Under 18 Years Old) in Household	19
Table 30. Respondent's Highest Level of Education	19
Table 31. Total Taxable Household Income of Wage Earners in the Past Year	19
Table 32. Residential Designation (Urban, Suburban, or Rural)	19
Services and Supports Received	20
Table 33. Services and Supports Received From ID/DD Agency.....	21
Table 34. Additional Services and Supports Received (Not From the I/DD Agency)	21
Adult Family Survey Results	22
Information and Planning Charts	23
Information and Planning Tables	29
Table Q1. Do you get enough information to take part in planning services for your family member?	30
Table Q2. Is the information you get about services and supports easy to understand?	30
Table Q3. Does the case manager/service coordinator respect your family’s choices and opinions?	30

Table Q4. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?	30
Table Q5. Do you need help planning for your family member’s future with respect to any of the following?	31
Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?.....	31
Table Q7. Does your family member have a service plan?.....	31
Table Q8. Does the service plan include all the services and supports your family member needs?.....	31
Table Q9. Does your family member get all of the services listed in the service plan?	31
Table Q10. Did you or someone else in your family (besides your family member with a disability) help make the service plan?	32
Table Q11. Did your family member help make the service plan?.....	32
Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member’s last service planning meeting?	32
Table Q13. If your family member left school services during the past year, did s/he have a transition plan?	32
Table Q14. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?	32
Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?.....	32
Table Q16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?	33
Access and Delivery of Services and Supports Charts.....	34
Access and Delivery of Services and Supports Tables.....	41
Table Q17. Are you or your family member able to contact his/her support workers when you want?	42
Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want?.....	42
Table Q19. Do support workers come and go when they are supposed to?	42
Table Q20. Do services and supports change when your family’s needs change?.....	42
Table Q21. Do support workers speak to you in a way you understand?	42
Table Q22. Are services delivered in a way that is respectful of your family’s culture?	42
Table Q23. If your family member does not communicate verbally (for example, uses gestures or sign language, or a communication aid), are there support workers who can communicate with him/her?	43
Table Q24. Do support workers have the right information and skills to meet your family’s needs?.....	43

Table Q25. Does your family member have the special equipment or accommodations that s/he needs? 43

Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)? 43

Table Q27. Does your family member’s primary care doctor understand your family member’s needs related to his/her disability? 43

Table Q28. Does your family member go to the dentist when needed?..... 44

Table Q29. Does your family member’s dentist understand your family member’s needs related to his/her disability? 44

Table Q30. If your family member takes medications, do you know what they’re for? 44

Table Q31. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)? 44

Table Q32. If your family member uses mental health services, does the mental health professional understand your family member’s needs related to his/her disability? 44

Table Q33. If you need respite services, are you able to get/use them? 45

Table Q34. If you have used respite services in the past year, were you satisfied with the quality of the respite services?..... 45

Table Q35. Does your family get the supports and services it needs? 45

Table Q36. If your family does not get the support and services needed, what additional services does your family need? 45

Choice, Decision Making and Control Charts..... 46

Choice, Decision Making and Control Tables..... 49

Table Q37. Can your family choose or change the agency that provides your family member’s services? 50

Table Q38. Can your family choose or change your family member’s support workers?..... 50

Table Q39. Does your family directly manage support staff? 50

Table Q40. Do service providers for your family member work together to provide support?..... 50

Table Q41. Did you, your family member, or someone else in your family choose your family member’s case manager/service coordinator? 50

Involvement in the Community Charts..... 51

Involvement in the Community Tables..... 54

Table Q42. Does your family member take part in activities in the community? 55

Table Q43. For your family member, what makes it hard to take part in activities in the community?..... 55

Table Q44. Does your family member have friends other than paid support workers or family? 55

Table Q45. In your community, are there resources that your family can use that are not provided by the I/DD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)? 55

Table Q46. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)? 55

Satisfaction With Services and Supports Charts 56

Satisfaction With Services and Supports Tables 60

Table Q47. Overall, are you satisfied with the services and supports your family member currently receives? 61

Table Q48. Do you know how to file a complaint or grievance about provider agencies or staff? 61

Table Q49. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved? . 61

Table Q50. Do you know how to report abuse or neglect related to your family member? 61

Table Q51. Within the past year, was a report of abuse or neglect filed on behalf of your family member? 61

Table Q52. Do you feel that services and supports have made a positive difference in the life of your family member? 62

Table Q53. Have services and supports reduced your family’s out-of-pocket expenses for your family member’s care? 62

Table Q54. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated? 62

Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively? 62

Table Q56. Have the services or supports that your family member received been increased in the past year? 62

Table Q57. Are services and supports helping your family member to live a good life? 62

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).

In 2018-19 a total of 46 states, the District of Columbia and 22 sub-state entities participated in NCI.

Where are the statistics in this report from?

This report includes findings from the National Core Indicators™ 2018-19 Adult Family Survey (AFS). The data shown are weighted NCI averages. These data are comprised of 4,836 valid surveys collected across 12 states: AZ, GA, LA, MD, MN, MO, NC, OH, OK, PA, UT and VA.

What is the NCI Adult Family Survey?

The NCI Adult Family Survey is used to gather data on family outcomes. It is mailed to families who have an adult family member who *lives with* the respondent 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 ('family member') as well as the person who fills out the survey (the 'respondent') and information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable.

Important note on responses: All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

What is included in this report?

This report includes this state's Adult Family Survey data compared to the NCI Average. State outcomes that are significantly higher or lower than the NCI Average are indicated with an arrow:

1. Outcomes where the state is significantly above the NCI average are denoted with an up arrow ▲;
2. Outcomes where the state is significantly below the NCI average are denoted with a down arrow ▼.

Significance is based on "Always" or "Yes" response.

The charts in this document, grouped by subdomain, display the state results alongside the average across states (NCI average). The charts are followed by accessible tables containing the same information.

To find out more about the development of the Adult Family Survey, data analysis and state samples, check out the National Adult Family Report: <https://www.nationalcoreindicators.org/resources/reports/#reports-family-survey-final-reports>.

Demographics

Demographics of Family Member Receiving Services

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

Important note on responses: All data are reported by the respondent based on their understanding of their family member's demographics, diagnoses and personal characteristics.

Table 1. More Than One Person Living in the Home Has IDD

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State v NCI	Yes	No	N
MD	10%	90%	433
NCI	13%	87%	4,689

Table 2. Family Member’s Age

State v NCI	Average Age	N
MD	32.7	449
NCI	34.1	4,800

Table 3. Family Member’s Gender

State v NCI	Male	Female	N
MD	63%	37%	450
NCI	60%	40%	4,770

Table 4. Family Member’s Race and Ethnicity

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State v NCI	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other
MD	1%	4%	24%	0%	70%	4%	1%
NCI	3%	2%	14%	0%	78%	6%	1%

Table 5a. Family Member’s Disabilities (not mutually exclusive)

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State v NCI	Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss
MD	63%	18%	43%	16%	7%	6%
NCI	71%	25%	32%	20%	9%	6%

Table 5b. Family Member’s Disabilities (continued)

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State v NCI	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
MD	9%	26%	1%	16%	0%	0%	14%
NCI	10%	30%	1%	16%	1%	1%	15%

Table 6a. Family Member’s Health Conditions

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State v NCI	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
MD	9%	13%	2%	22%	25%
NCI	11%	17%	4%	28%	25%

Table 6b. Family Member’s Health Conditions (continued)

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State v NCI	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Other Dementia	Oral Health or Dental Problems	Sleep Apnea	Other
MD	8%	3%	3%	11%	18%	27%
NCI	12%	4%	3%	12%	20%	25%

Table 7. Family Member’s Preferred Means of Communication

State v NCI	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
MD	76%	16%	2%	2%	4%	449
NCI	77%	16%	2%	2%	3%	4,695

Table 8. Family Member Has Legal Court Appointed Guardian or Conservator

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown.

State v NCI	No Guardianship	Limited	Full	Has Guardianship but Level Is Unknown	N
MD	53%	13%	31%	3%	424
NCI	32%	11%	54%	3%	4,537

Table 9. Guardian or Conservator Relationship to Family Member

State v NCI	Family	Friend	State Employee or Guardianship Agency	Other	N
MD	92%	1%	1%	6%	180
NCI	98%	1%	0%	1%	2,965

Table 10. Family Member’s Highest level of Education

State v NCI	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
MD	12%	0%	58%	17%	3%	5%	6%	438
NCI	14%	5%	32%	38%	3%	4%	5%	4,604

Table 11. Family Member’s Activities in the Past Two Weeks Included *Individual Paid Job in the Community*¹

Response options changed from previous years

State v NCI	Yes	No	N
MD	23%	77%	441
NCI	16%	84%	4,700

¹ An individual job is defined as work at an individual job in a local business alongside peers who do not have disabilities. Job is part of the typical labor market (for example, competitive employment).

Table 12. Family Member’s Activities in the Past Two Weeks Included *Paid Small Group Job in a Community-based Setting*²

Response options changed from previous years

State v NCI	Yes	No	N
MD	14%	86%	437
NCI	12%	88%	4,633

Table 13. Family Member’s Activities in the Past Two Weeks Included *Paid Work in a Community Job That Primarily Hires People With Disabilities*³

Response options changed from previous years

State v NCI	Yes	No	N
MD	11%	89%	432
NCI	8%	92%	4,630

Table 14. Family Member’s Activities in the Past Two Weeks Included *Unpaid Activity in the Community*⁴

Response options changed from previous years

State v NCI	Yes	No	N
MD	44%	56%	432
NCI	33%	67%	4,595

² A small group job is defined as work in an integrated setting, as part of a group of not more than 8 people with disabilities (for example, enclave, work crew).

³ Paid work in a community job that primarily hires people with disabilities is defined as work in a setting where the person interacts with the non-disabled population; this is NOT in a traditional sheltered workshop and NOT enclave.

⁴ Unpaid work in the community includes: volunteering, skills training, and staff-supported community connections.

Table 15. Family Member’s Activities in the Past Two Weeks Included *Paid Activity in a Facility-based Setting*⁵

Response options changed from previous years

State v NCI	Yes	No	N
MD	15%	85%	435
NCI	18%	82%	4,637

Table 16. Family Member’s Activities in the Past Two Weeks Included *Unpaid Activity in a Facility-based Setting*⁶

Response options changed from previous years

State v NCI	Yes	No	N
MD	34%	66%	430
NCI	27%	73%	4,556

Table 17. Family Member’s Activities in the Past Two Weeks Included *School*

Response options changed from previous years

State v NCI	Yes	No	N
MD	5%	95%	432
NCI	11%	89%	4,616

Table 18. Family Member’s Activities in the Past Two Weeks Included *Stays at Home*

Response options changed from previous years

State v NCI	Yes	No	N
MD	38%	62%	422
NCI	48%	52%	4,452

⁵ Paid work performed in a facility-based setting is defined as work at a location developed specifically to provide work activity exclusively for people with disabilities; may be paid sub-minimum wage. Examples include traditional sheltered workshops or work activity centers.

⁶ An unpaid activity in a facility-based setting includes day habilitation, senior programs, or drop-in centers.

Table 19. Family Member’s Activities in the Past Two Weeks Included *Other Activities*

Response options changed from previous years

State v NCI	Yes	No	N
MD	24%	76%	179
NCI	39%	61%	1,867

Table 20. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State v NCI	Extensive	Some	None	N
MD	14%	26%	60%	444
NCI	14%	29%	56%	4,708

Table 21. Family Member's Level of Help Needed With Personal Care Activities (e.g., bathing, dressing, eating)

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State v NCI	Extensive	Some	None	N
MD	34%	35%	31%	448
NCI	36%	38%	26%	4,772

Table 22. Family Member’s Need for Help With Other Daily Activities (e.g., scheduling, managing money, or shopping)

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics.

State v NCI	Extensive	Some	None	N
MD	64%	30%	6%	447
NCI	74%	21%	5%	4,751

Demographics of Respondents

This section provides demographic information about the respondent.

Table 23. Language Usually Spoken at Home

New question in 2018-19

State v NCI	English	Spanish	Other	N
MD	96%	1%	2%	449
NCI	97%	2%	1%	4,764

Table 24. Respondent's Age

State v NCI	Under 35	35-54	55-74	75 and Older	N
MD	3%	12%	74%	11%	452
NCI	2%	23%	64%	11%	4,795

Table 25. Respondent's Health

State v NCI	Excellent	Very Good	Fairly Good	Poor	N
MD	15%	48%	34%	3%	449
NCI	15%	46%	36%	4%	4,777

Table 26. Respondent's Relationship to Family Member

State v NCI	Parent	Sibling	Spouse	Grandparent	Other	N
MD	92%	5%	1%	1%	2%	448
NCI	87%	6%	0%	3%	3%	4,785

Table 27. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services

State v NCI	No One in Family Provides Paid Support	Respondent Provides Paid Support	Other Family Member Provides Paid Support	N
MD	83%	10%	9%	444
NCI	67%	21%	15%	4,731

Table 28. Number of Adults in Household (Not Including Family Member Receiving Services)

State v NCI	One	Two	Three	Four or More	N
MD	6%	26%	49%	19%	448
NCI	8%	27%	46%	18%	4,763

Table 29. Number of Children (Under 18 Years Old) in Household

State v NCI	None	One	Two	Three	Four or More	N
MD	90%	7%	2%	0%	0%	450
NCI	87%	8%	3%	1%	1%	4,775

Table 30. Respondent's Highest Level of Education

State v NCI	No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
MD	3%	19%	3%	21%	55%	447
NCI	6%	27%	6%	22%	38%	4,726

Table 31. Total Taxable Household Income of Wage Earners in the Past Year

State v NCI	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
MD	7%	4%	5%	14%	13%	32%	24%	436
NCI	10%	8%	10%	18%	13%	20%	21%	4,647

Table 32. Residential Designation (Urban, Suburban, or Rural)

State v NCI	Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	N
MD	64%	36%	439
NCI	65%	35%	4,693

Services and Supports Received

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

Table 33. Services and Supports Received From ID/DD Agency

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown

Services and Supports Received From State	MD	NCI
Financial Support	13%	14%
In-home Support	33%	41%
Out of Home Respite	22%	29%
Day or Employment Supports	65%	54%
Transportation	75%	61%
Other	23%	27%
Self-direction or Fiscal Intermediary Services	28%	41%

Table 34. Additional Services and Supports Received (Not From the I/DD Agency)

All data are reported by the respondent based on their understanding of their family member’s demographics, diagnoses and personal characteristics. Categories are not mutually exclusive, therefore N is not shown

Additional Services and Supports Received	MD	NCI
Social Security Payments (SSI/SSB)	94%	93%
Services or Supports From Other Agencies or Organizations	28%	30%

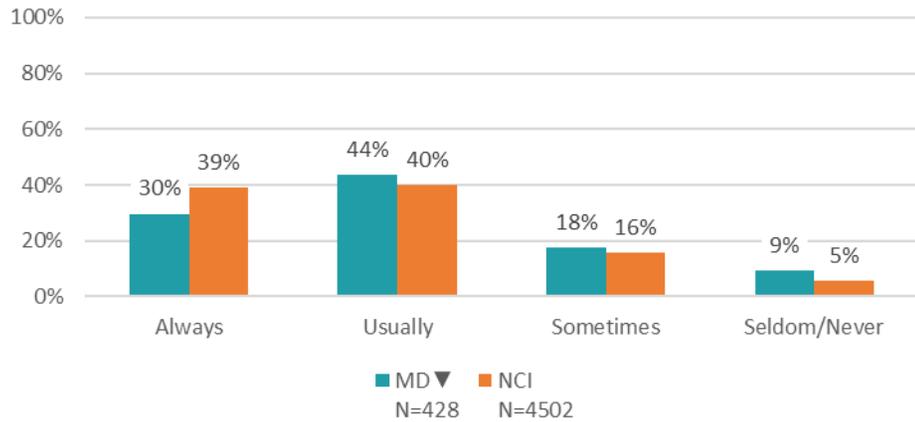
Adult Family Survey Results

Information and Planning Charts

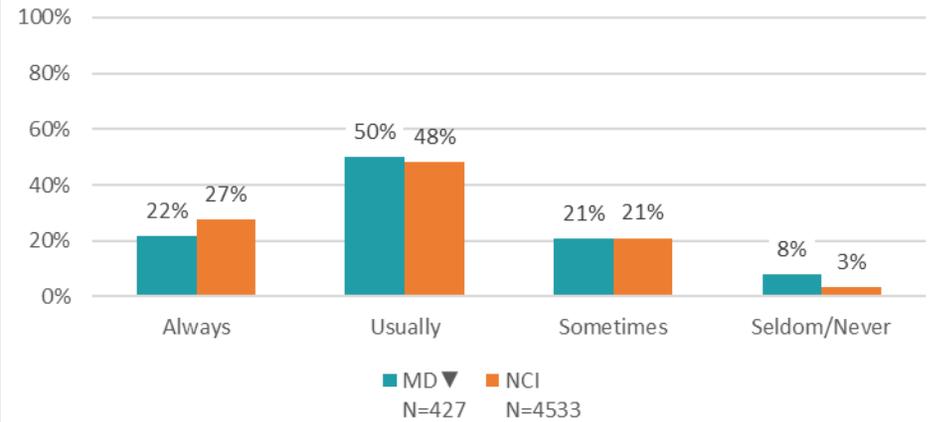
Families and family members with disabilities have the information and support necessary to plan for their services and supports.

The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.

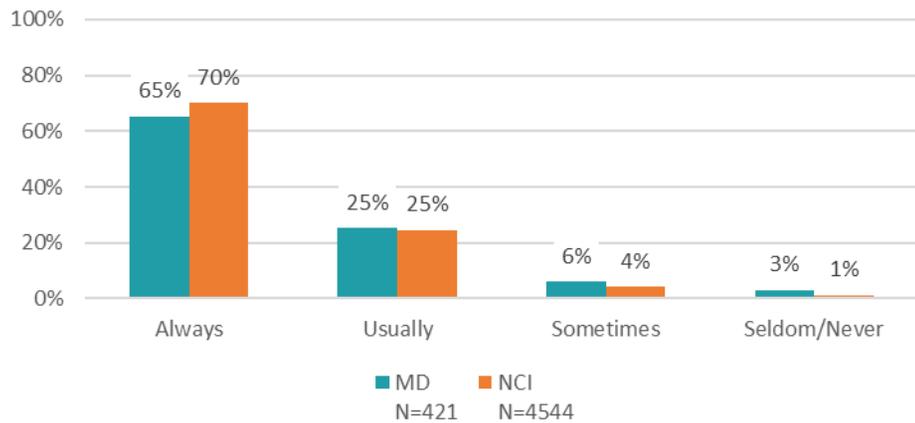
Do you get enough information to take part in planning services for your family member?



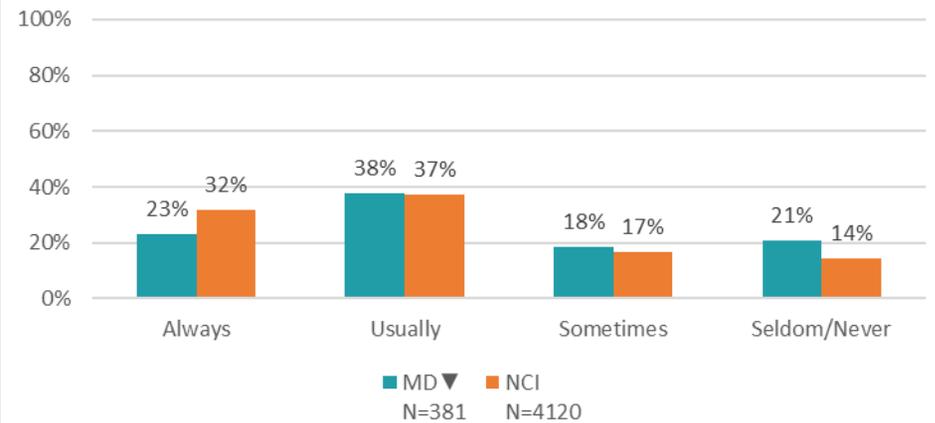
Is the information you get about services and supports easy to understand?

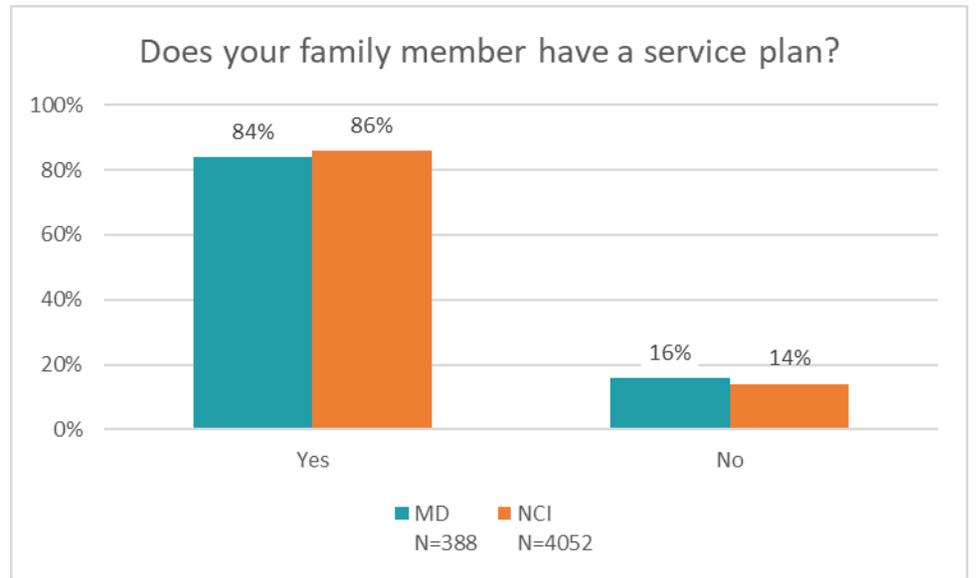
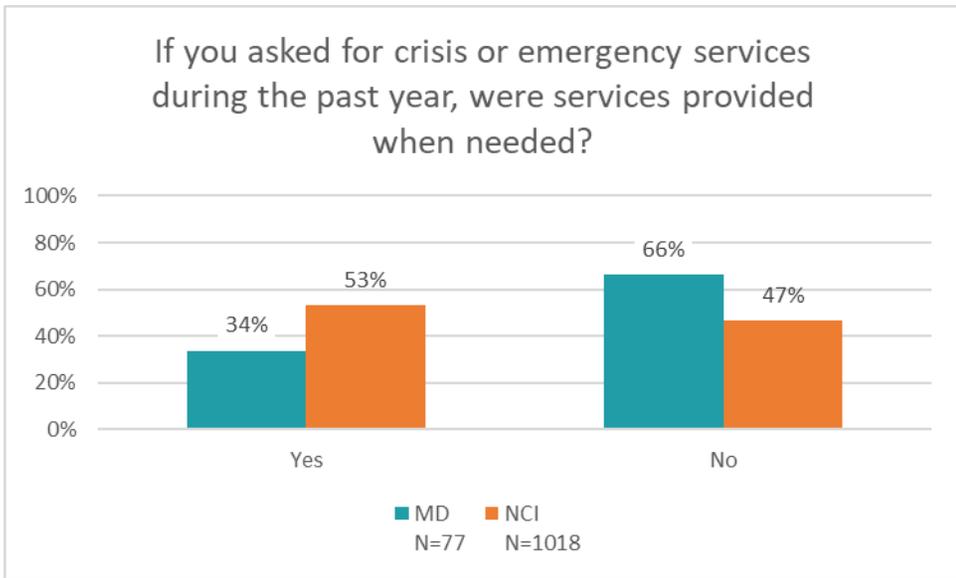
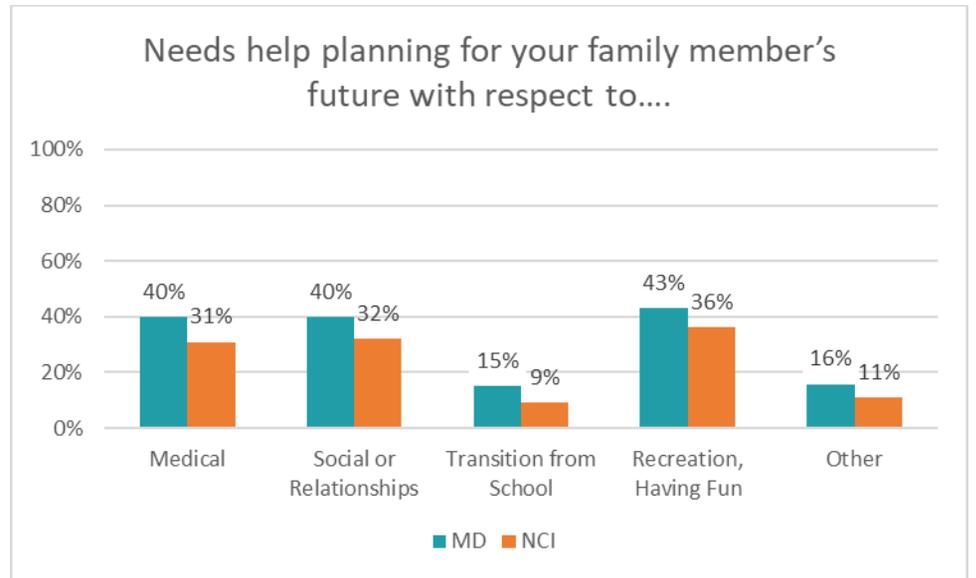
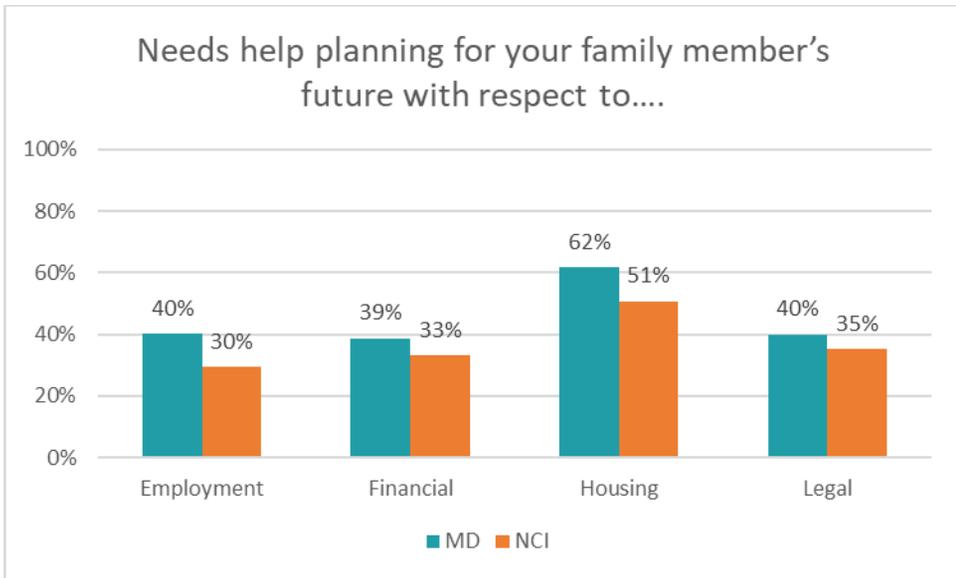


Does the case manager/service coordinator respect your family's choices and opinions?

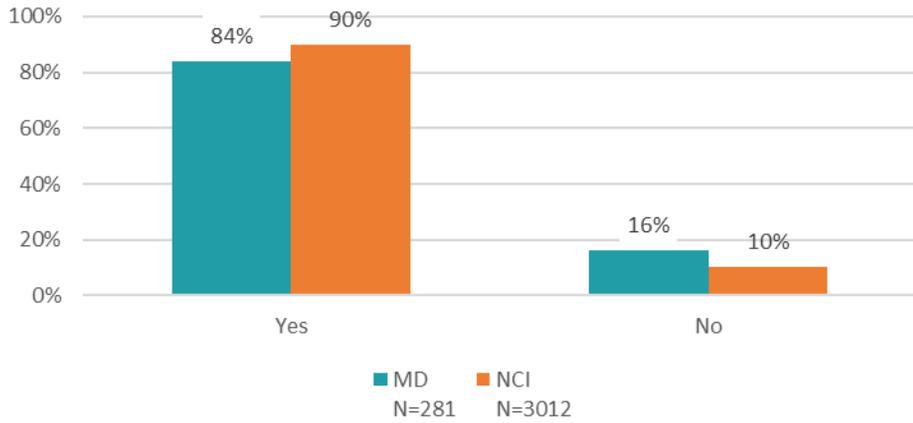


Do you have enough information about other public services for which your family is eligible?

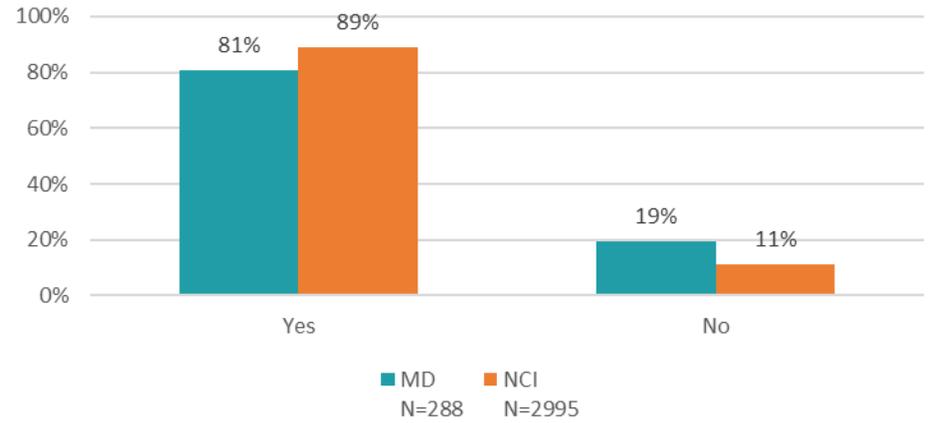




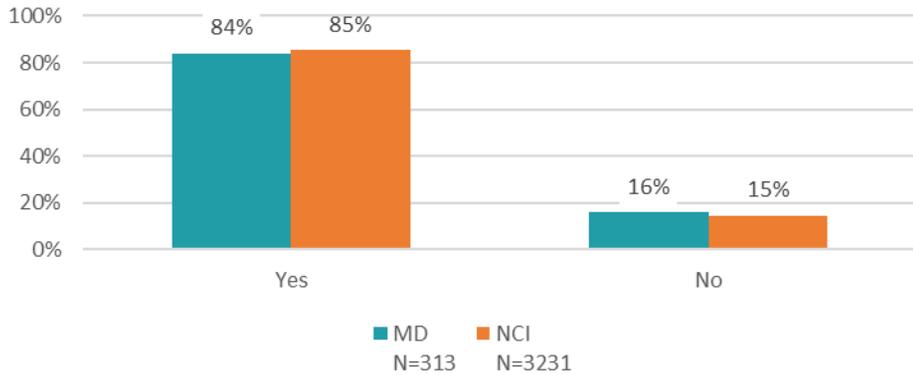
Does the plan include all the services and supports your family member needs?



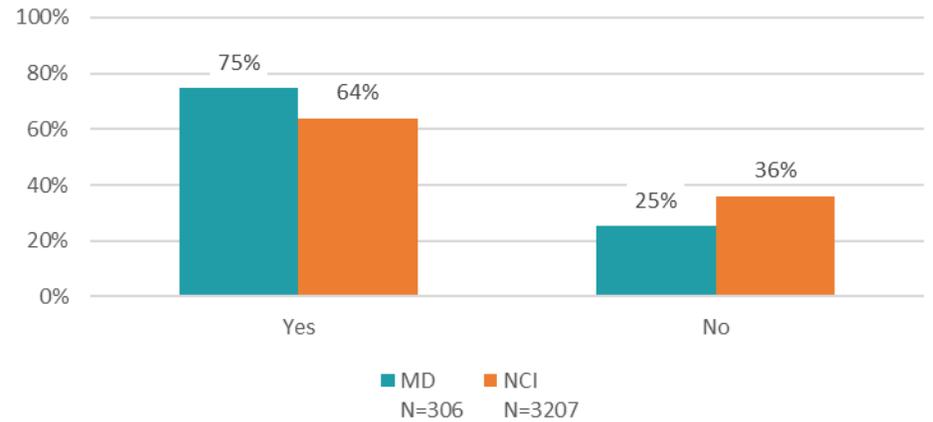
Does your family member get all the services listed in the plan?



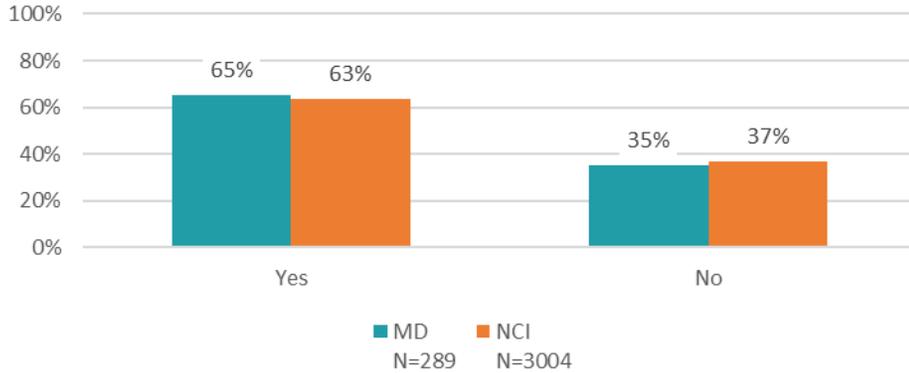
Did you or someone else in your family (besides your family member with a disability) help make the plan?



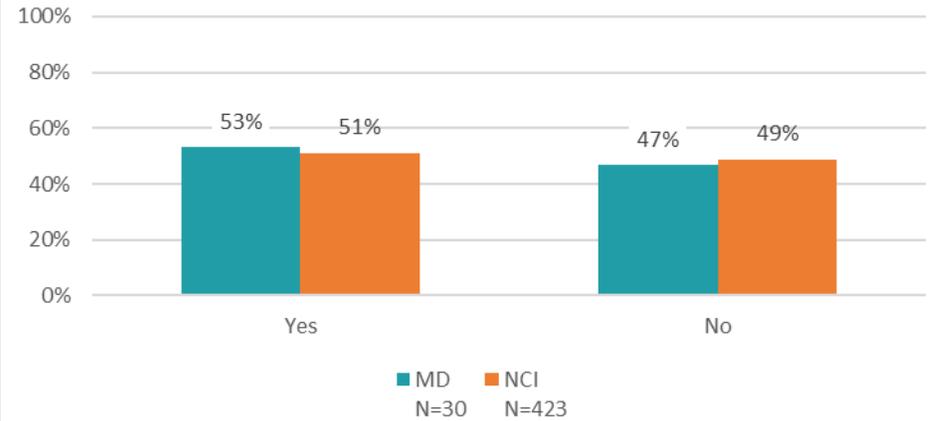
Did your family member help make the service plan?



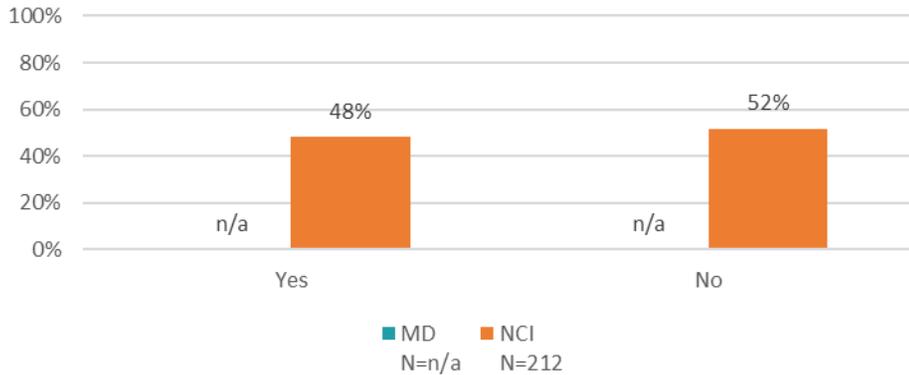
Did you discuss how to handle emergencies at your family member's last service planning meeting?



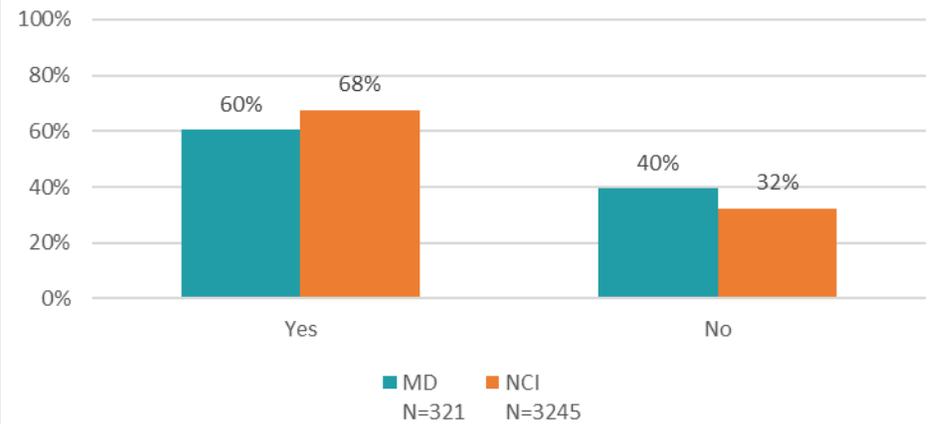
If your family member left school services during the past year, did s/he have a transition plan?



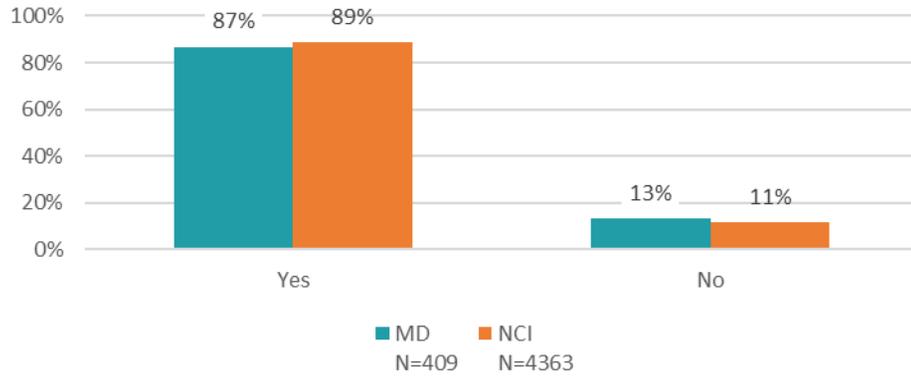
If family member had a transition plan, did the transition plan include getting or continuing work in a community job?



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



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



Information and Planning Tables

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

Table Q1. Do you get enough information to take part in planning services for your family member?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	30%	44%	18%	9%	428
NCI	39%	40%	16%	5%	4,502

Table Q2. Is the information you get about services and supports easy to understand?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	22%	50%	21%	8%	427
NCI	27%	48%	21%	3%	4,533

Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD	65%	25%	6%	3%	421
NCI	70%	25%	4%	1%	4,544

Table Q4. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	23%	38%	18%	21%	381
NCI	32%	37%	17%	14%	4,120

Table Q5. Do you need help planning for your family member’s future with respect to any of the following?

Categories are not mutually exclusive, therefore N is not shown

Needs help planning for...	MD	NCI
Employment	40%	30%
Financial	39%	33%
Housing	62%	51%
Legal	40%	35%
Medical	40%	31%
Social or Relationships	40%	32%
Transition from School	15%	9%
Recreation, Having Fun	43%	36%
Other	16%	11%

Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?

State v NCI	Yes	No	N
MD ▼	34%	66%	77
NCI	53%	47%	1,018

Table Q7. Does your family member have a service plan?

State v NCI	Yes	No	N
MD	84%	16%	388
NCI	86%	14%	4,052

Table Q8. Does the service plan include all the services and supports your family member needs?

State v NCI	Yes	No	N
MD ▼	84%	16%	281
NCI	90%	10%	3,012

Table Q9. Does your family member get all of the services listed in the service plan?

State v NCI	Yes	No	N
MD ▼	81%	19%	288
NCI	89%	11%	2,995

Table Q10. Did you or someone else in your family (besides your family member with a disability) help make the service plan?

State v NCI	Yes	No	N
MD	84%	16%	313
NCI	85%	15%	3,231

Table Q11. Did your family member help make the service plan?

State v NCI	Yes	No	N
MD▲	75%	25%	306
NCI	64%	36%	3,207

Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member’s last service planning meeting?

State v NCI	Yes	No	N
MD	65%	35%	289
NCI	63%	37%	3,004

Table Q13. If your family member left school services during the past year, did s/he have a transition plan?

State v NCI	Yes	No	N
MD	53%	47%	30
NCI	51%	49%	423

Table Q14. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?

State v NCI	Yes	No	N
MD	n/a	n/a	n/a
NCI	48%	52%	212

Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

State v NCI	Yes	No	N
MD▼	60%	40%	321
NCI	68%	32%	3,245

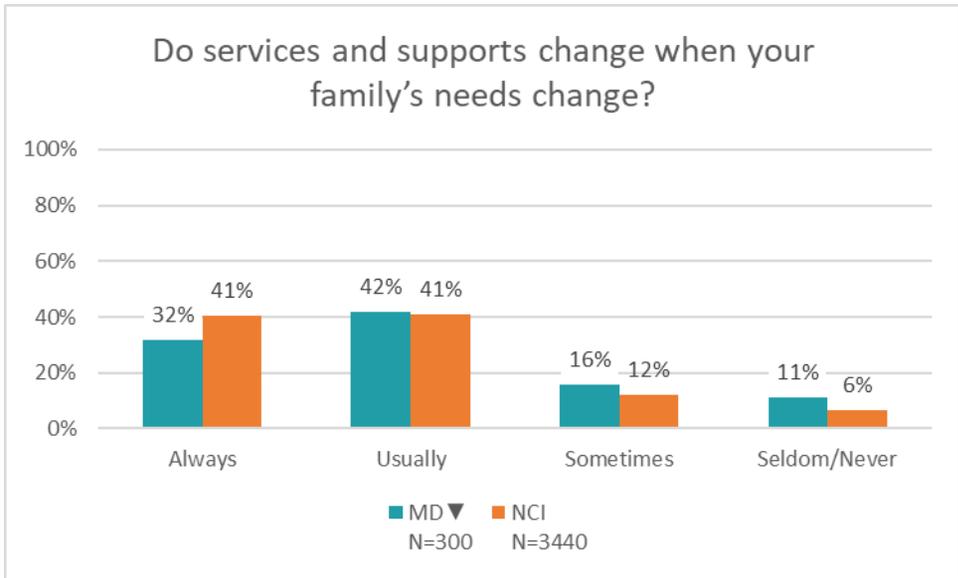
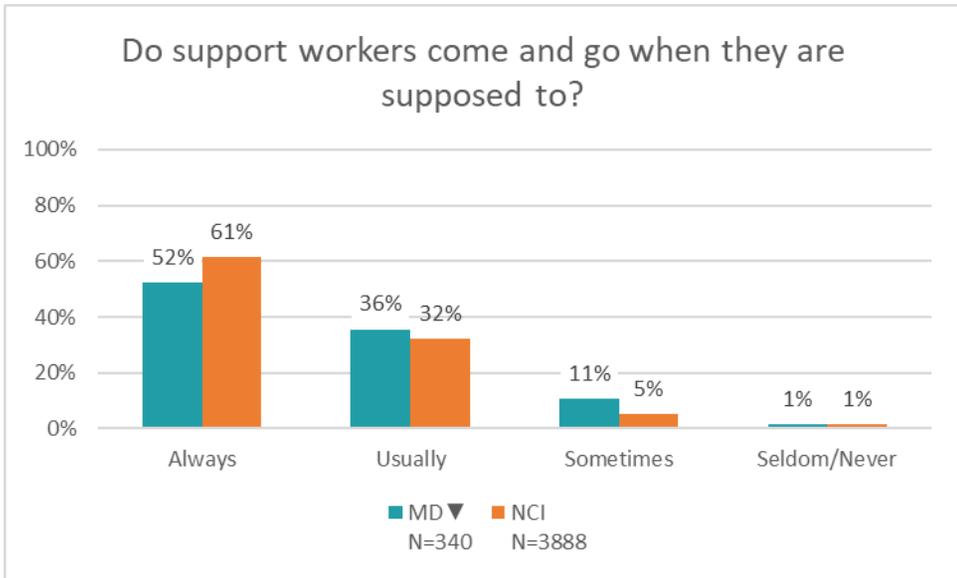
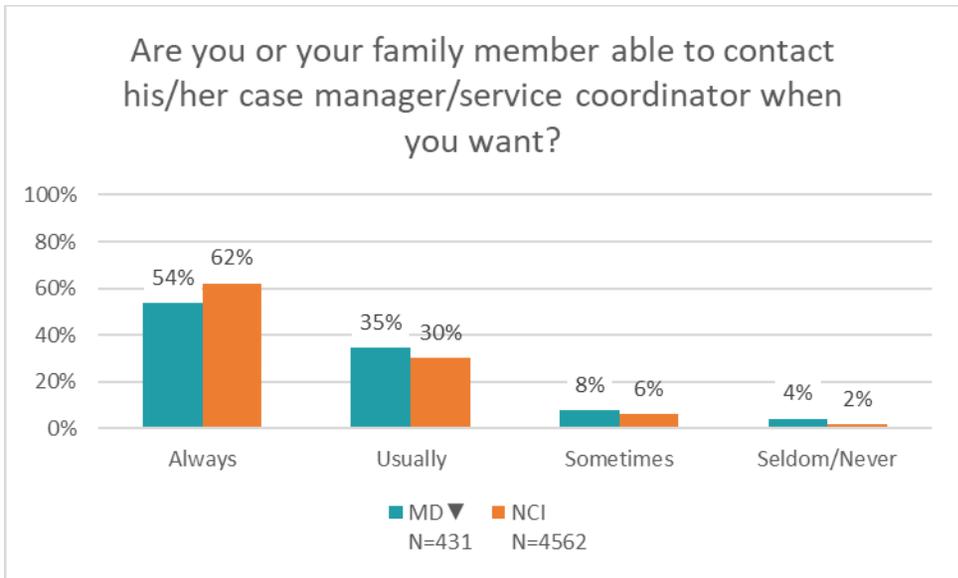
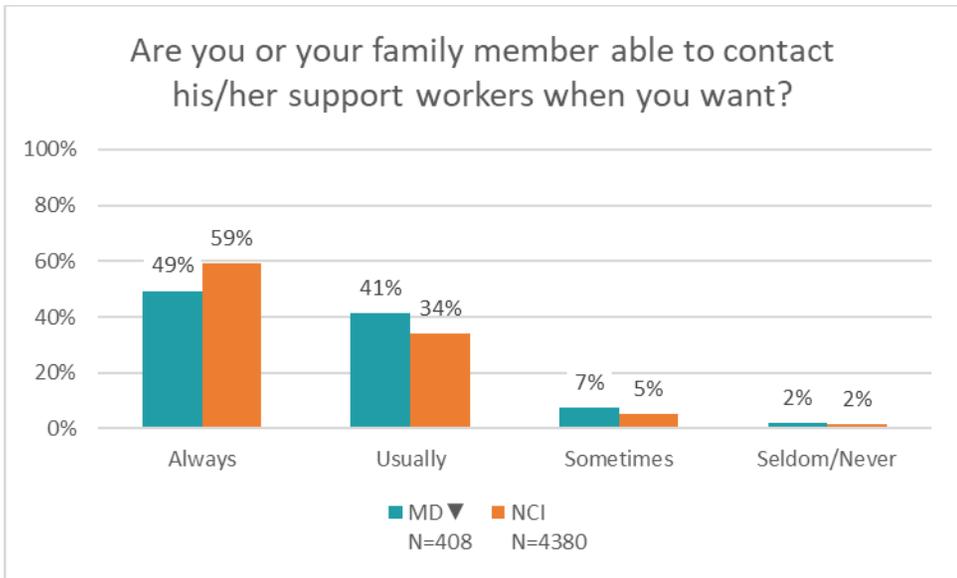
Table Q16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

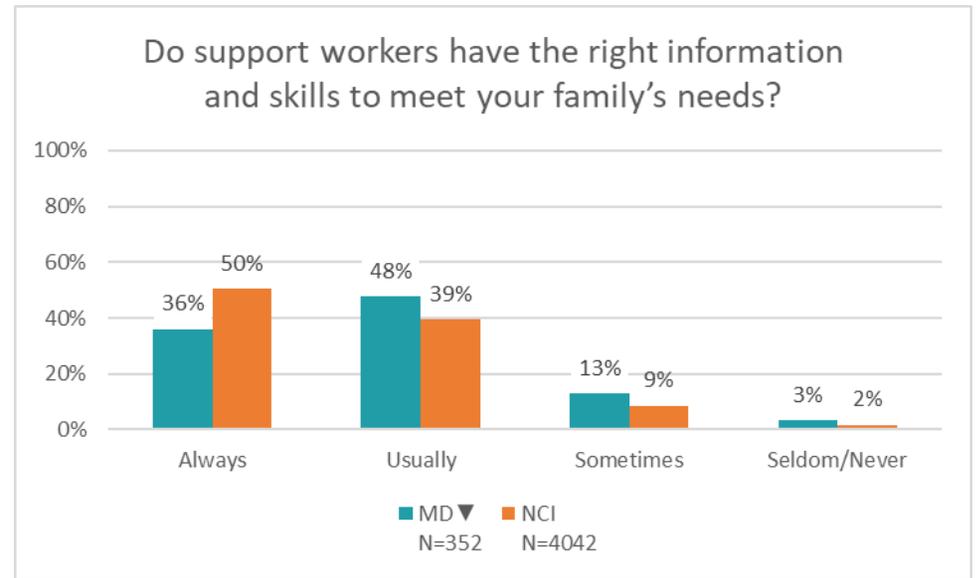
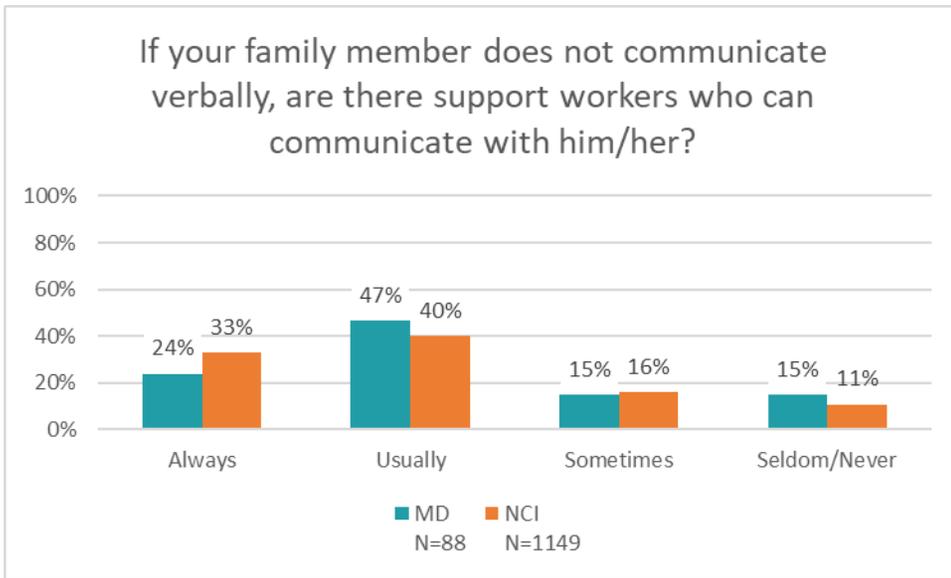
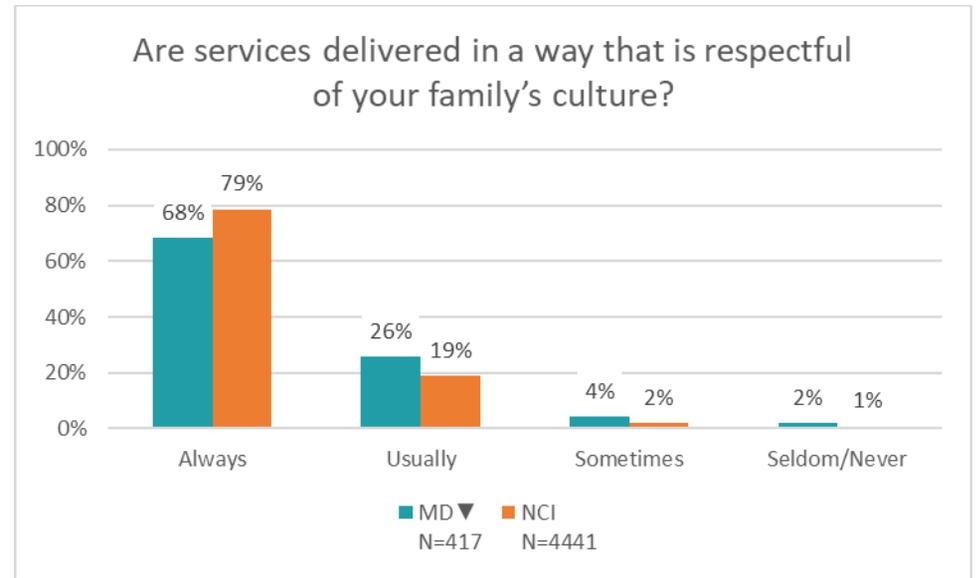
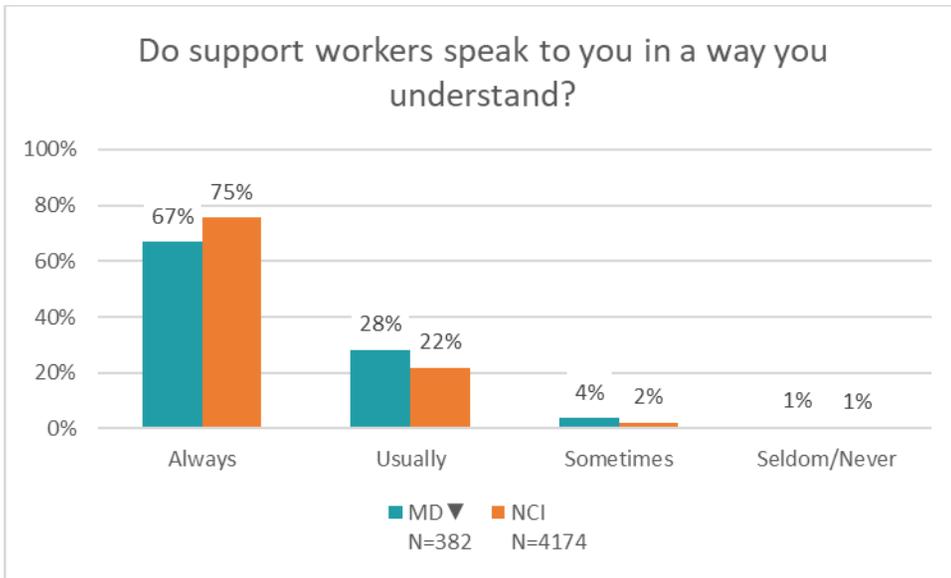
State v NCI	Yes	No	N
MD	87%	13%	409
NCI	89%	11%	4,363

Access and Delivery of Services and Supports Charts

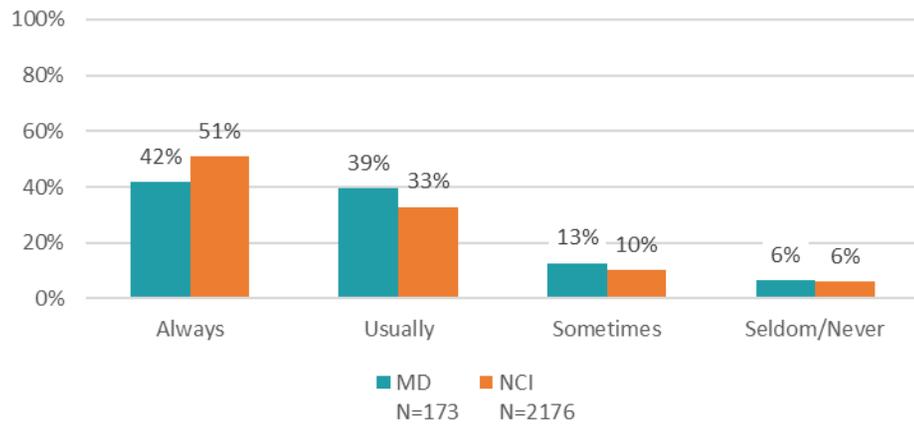
Families and family members with disabilities get the services and supports they need.

The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.

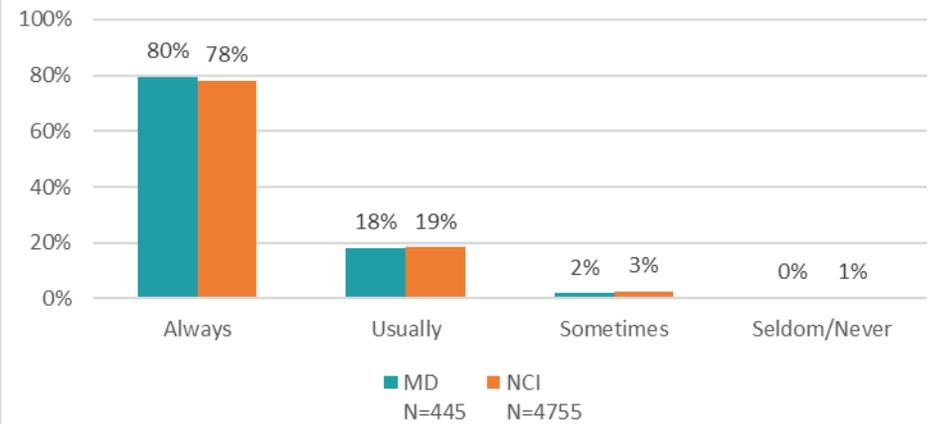




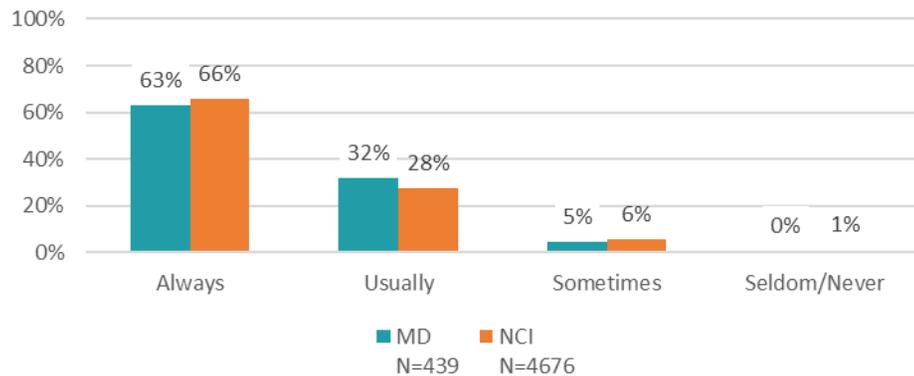
Does your family member have the special equipment or accommodations that s/he needs?



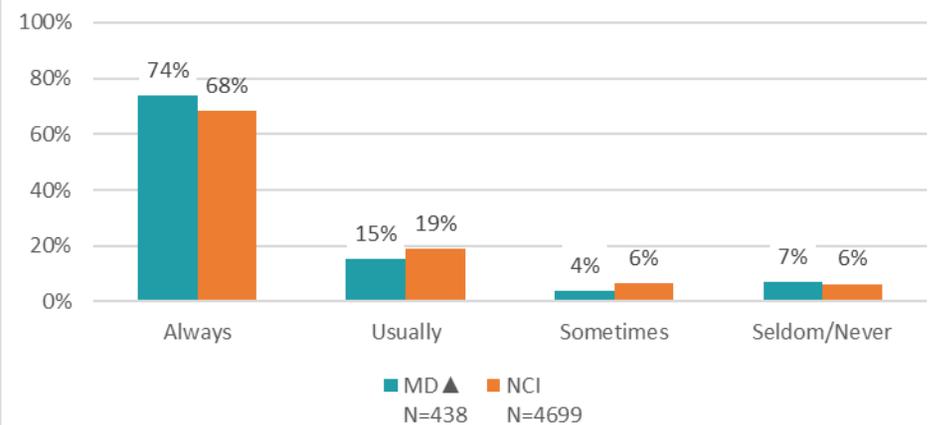
Can your family member see health professionals when needed?

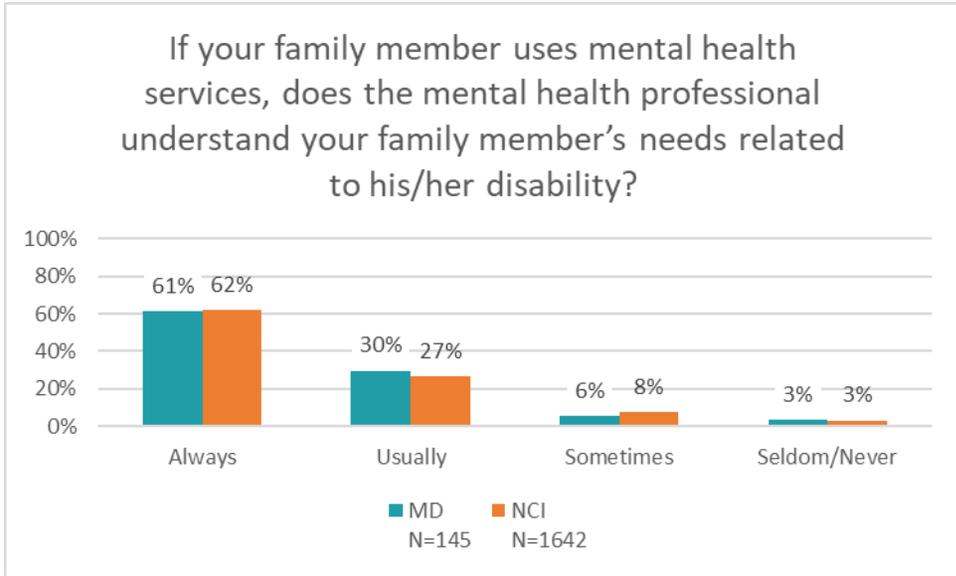
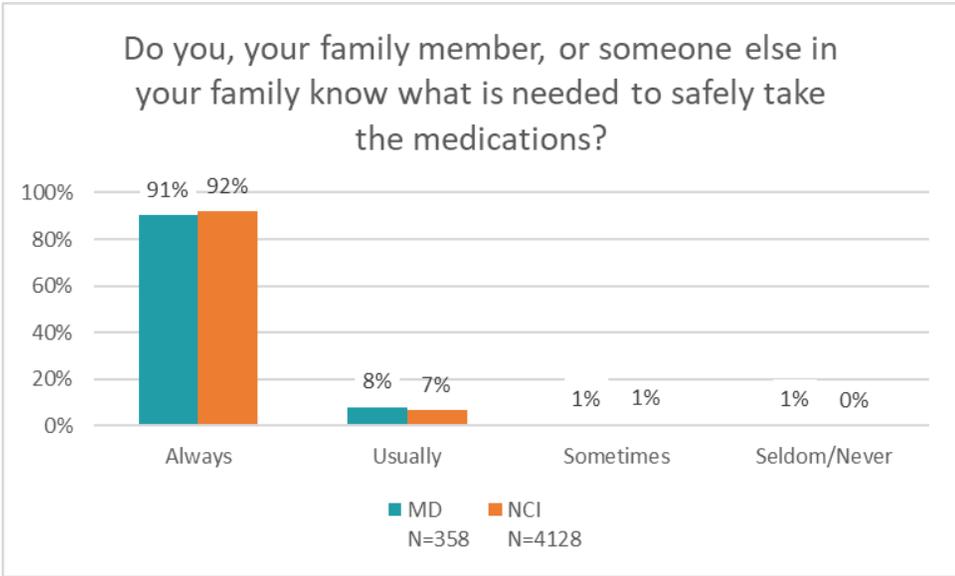
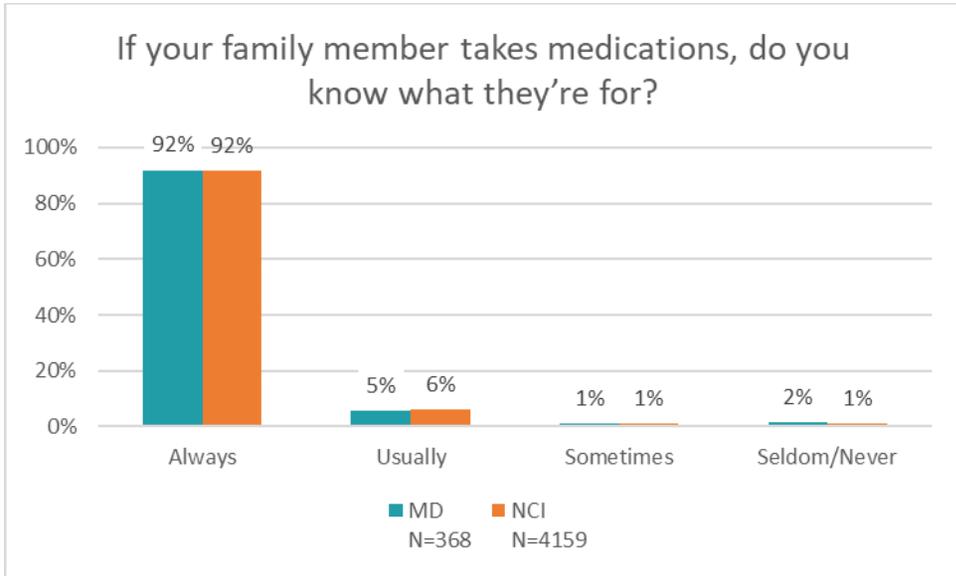
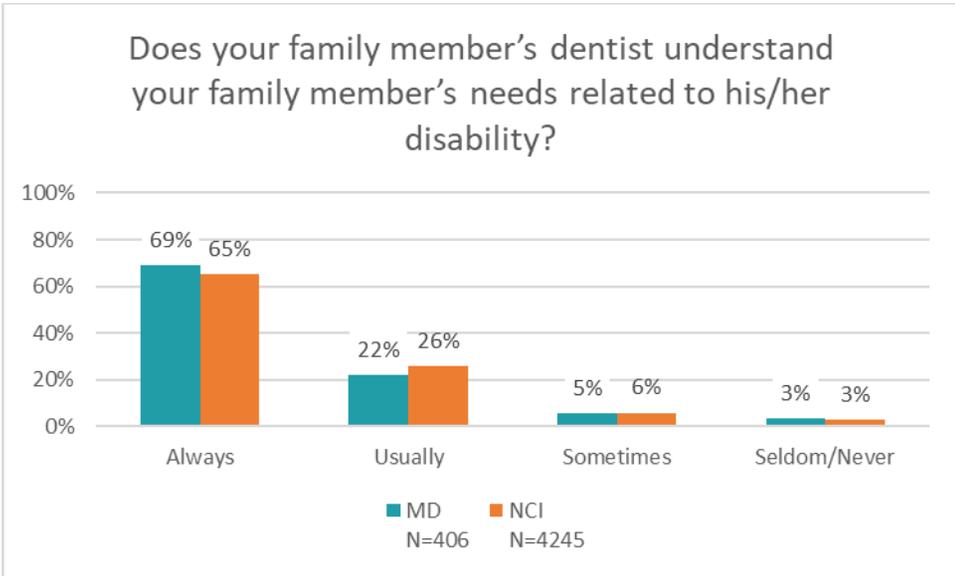


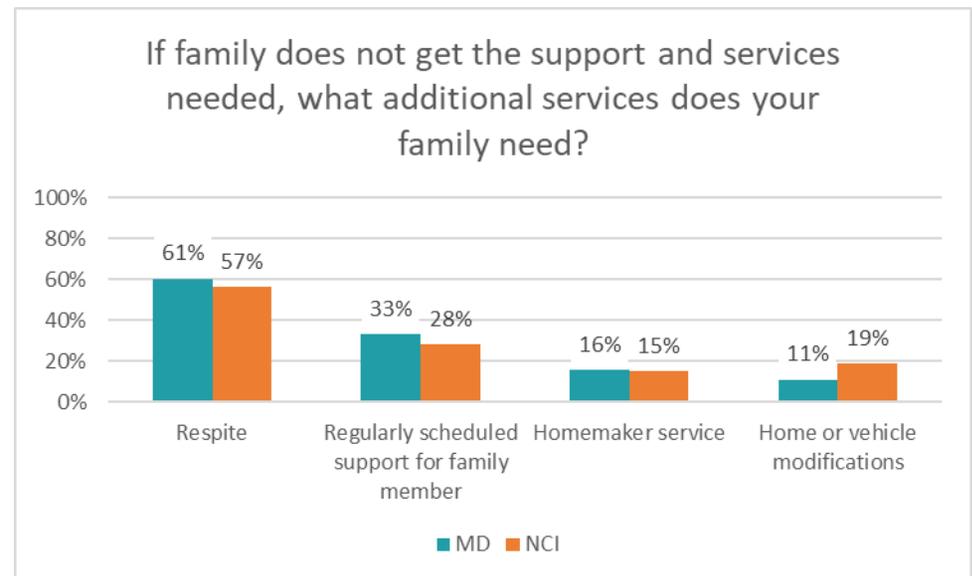
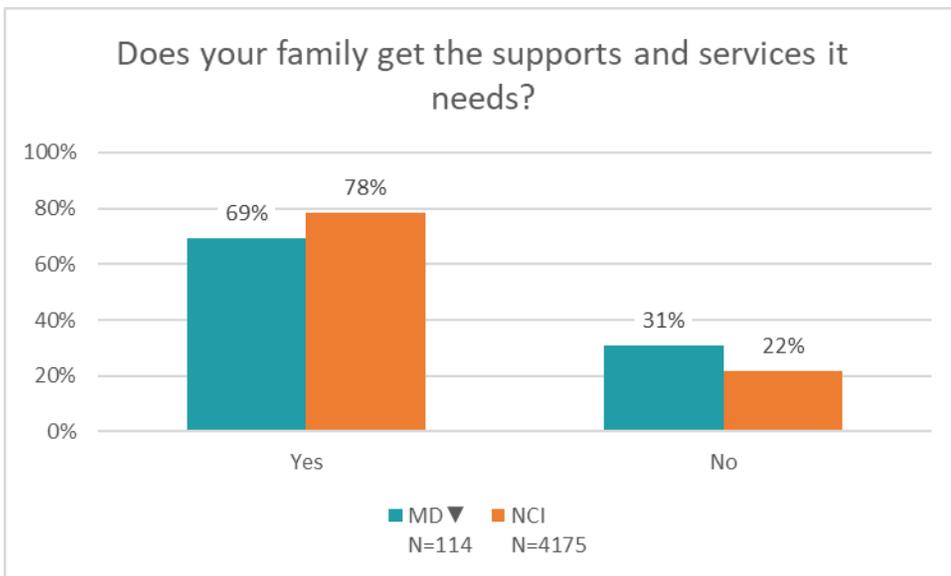
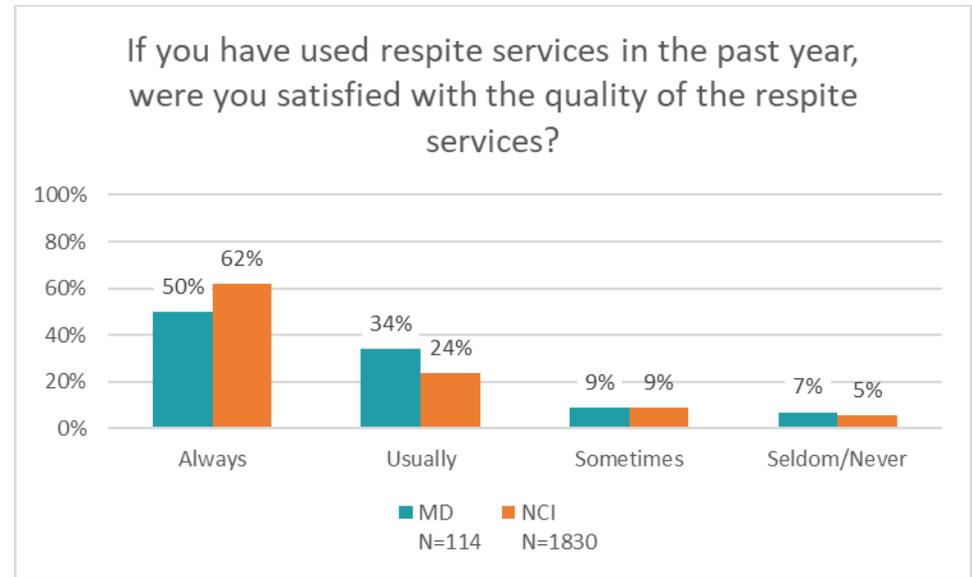
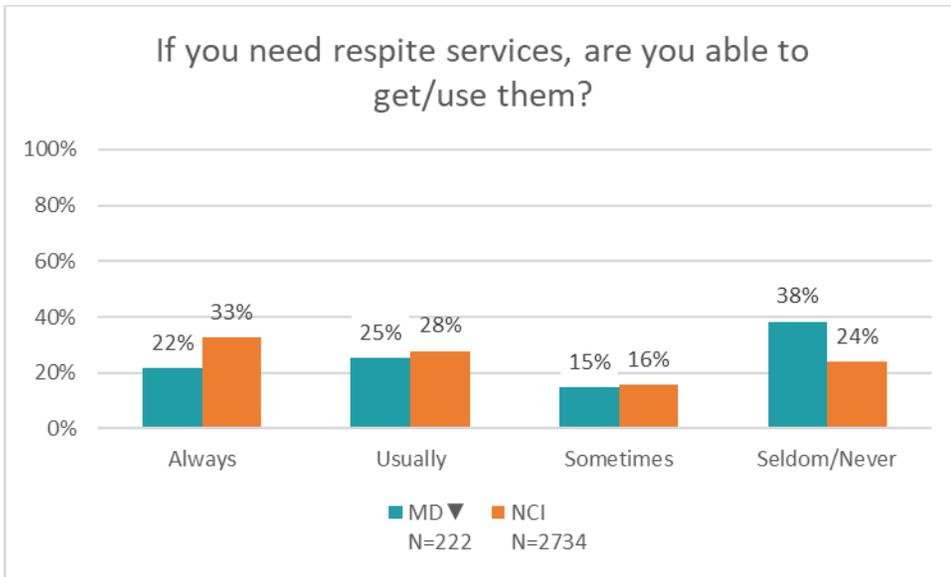
Does your family member's primary care doctor understand your family member's needs related to his/her disability?



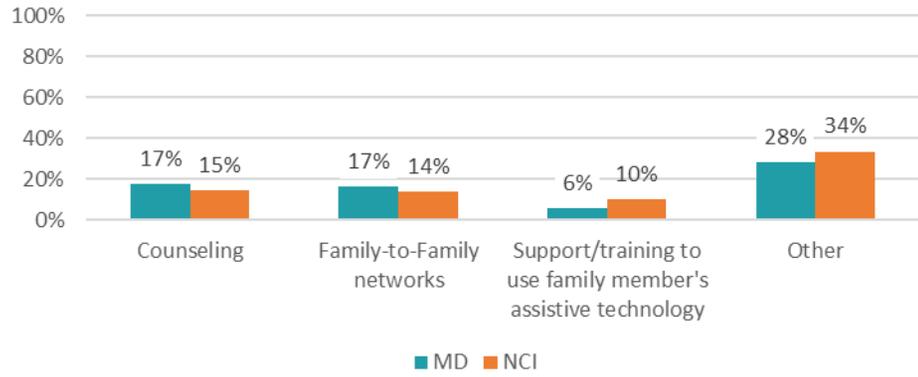
Can your family member go to the dentist when needed?







If family does not get the support and services needed, what additional services does your family need?



Access and Delivery of Services and Supports Tables

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

Table Q17. Are you or your family member able to contact his/her support workers when you want?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	49%	41%	7%	2%	408
NCI	59%	34%	5%	2%	4,380

Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	54%	35%	8%	4%	431
NCI	62%	30%	6%	2%	4,562

Table Q19. Do support workers come and go when they are supposed to?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	52%	36%	11%	1%	340
NCI	61%	32%	5%	1%	3,888

Table Q20. Do services and supports change when your family's needs change?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	32%	42%	16%	11%	300
NCI	41%	41%	12%	6%	3,440

Table Q21. Do support workers speak to you in a way you understand?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	67%	28%	4%	1%	382
NCI	75%	22%	2%	1%	4,174

Table Q22. Are services delivered in a way that is respectful of your family's culture?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	68%	26%	4%	2%	417
NCI	79%	19%	2%	1%	4,441

Table Q23. If your family member does not communicate verbally (for example, uses gestures or sign language, or a communication aid), are there support workers who can communicate with him/her?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD	24%	47%	15%	15%	88
NCI	33%	40%	16%	11%	1,149

Table Q24. Do support workers have the right information and skills to meet your family’s needs?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	36%	48%	13%	3%	352
NCI	50%	39%	9%	2%	4,042

Table Q25. Does your family member have the special equipment or accommodations that s/he needs?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD	42%	39%	13%	6%	173
NCI	51%	33%	10%	6%	2,176

Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD	80%	18%	2%	0%	445
NCI	78%	19%	3%	1%	4,755

Table Q27. Does your family member’s primary care doctor understand your family member’s needs related to his/her disability?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD	63%	32%	5%	0%	439
NCI	66%	28%	6%	1%	4,676

Table Q28. Does your family member go to the dentist when needed?

Question changed from previous years

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD▲	74%	15%	4%	7%	438
NCI	68%	19%	6%	6%	4,699

Table Q29. Does your family member's dentist understand your family member's needs related to his/her disability?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD	69%	22%	5%	3%	406
NCI	65%	26%	6%	3%	4,245

Table Q30. If your family member takes medications, do you know what they're for?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD	92%	5%	1%	2%	368
NCI	92%	6%	1%	1%	4,159

Table Q31. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when it should be taken, how much to take, and the potential side effects)?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD	91%	8%	1%	1%	358
NCI	92%	7%	1%	0%	4,128

Table Q32. If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD	61%	30%	6%	3%	145
NCI	62%	27%	8%	3%	1,642

Table Q33. If you need respite services, are you able to get/use them?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	22%	25%	15%	38%	222
NCI	33%	28%	16%	24%	2,734

Table Q34. If you have used respite services in the past year, were you satisfied with the quality of the respite services?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD	50%	34%	9%	7%	114
NCI	62%	24%	9%	5%	1,830

Table Q35. Does your family get the supports and services it needs?

State v NCI	Yes	No	N
MD ▼	69%	31%	378
NCI	78%	22%	4,175

Table Q36. If your family does not get the support and services needed, what additional services does your family need?

Categories are not mutually exclusive, therefore N is not shown

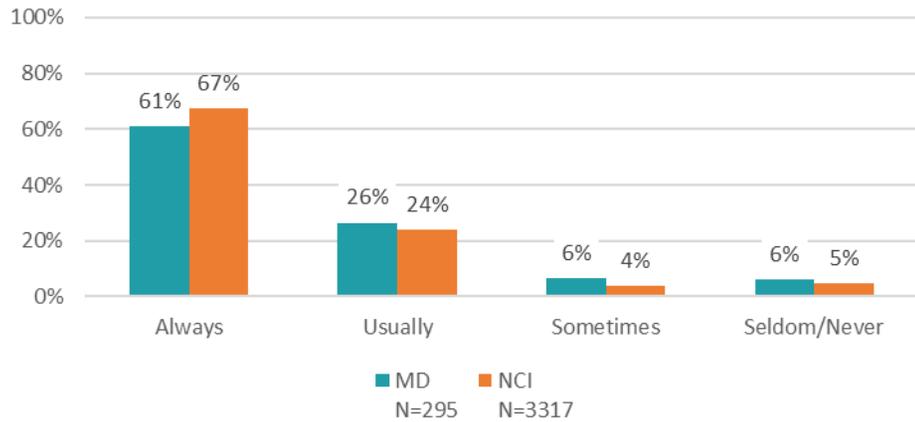
Additional service needed...	MD	NCI
Respite	61%	57%
Regularly scheduled support for family member	33%	28%
Homemaker service	16%	15%
Home or vehicle modifications	11%	19%
Counseling	17%	15%
Family-to-Family networks	17%	14%
Support/training to use family member's assistive technology	6%	10%
Other	28%	34%

Choice, Decision Making and Control Charts

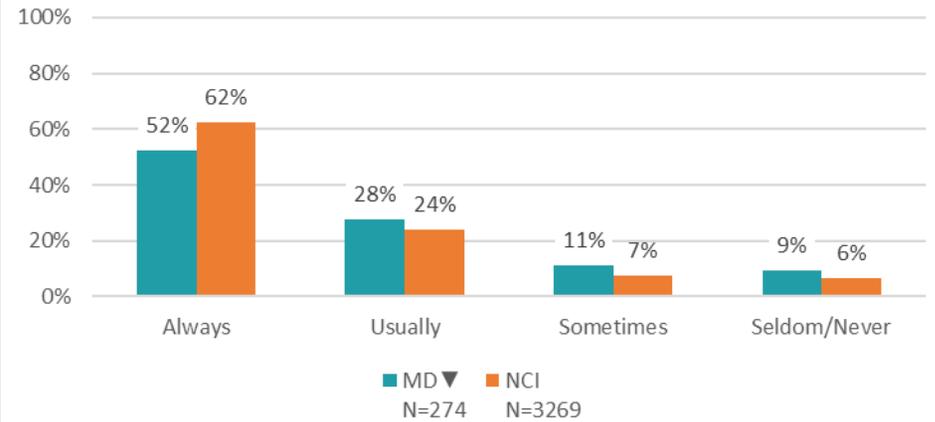
Families and family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.

The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.

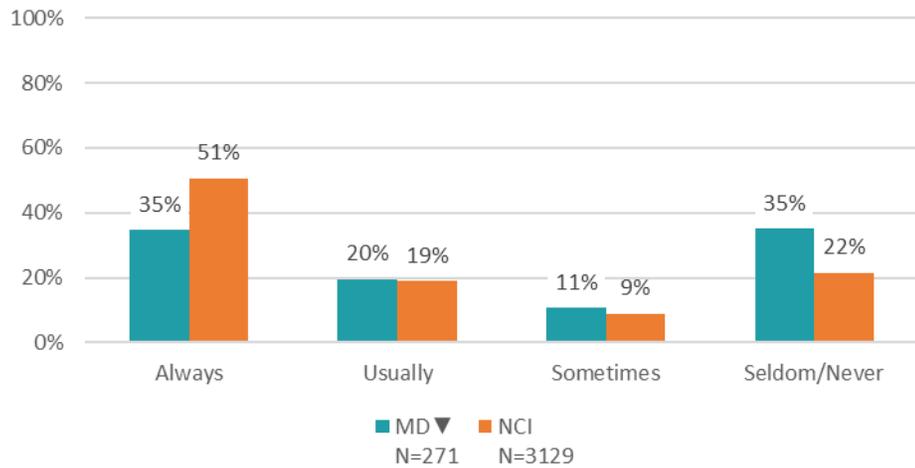
Can your family choose or change the agency that provides your family member's services?



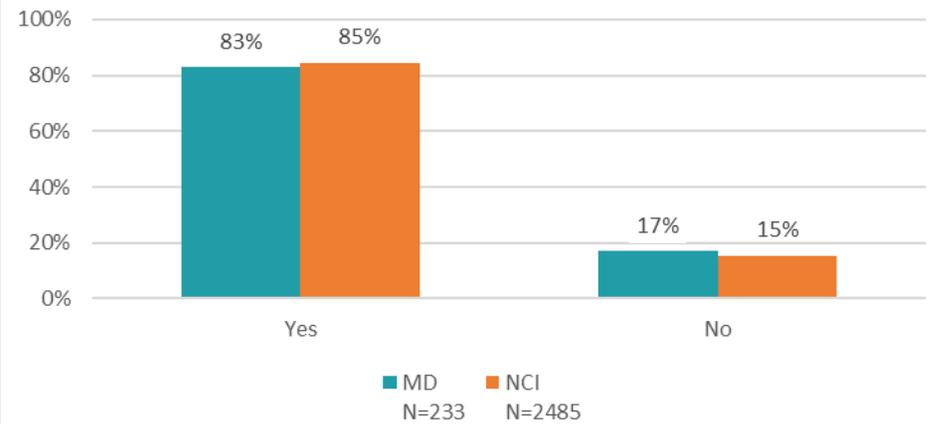
Can your family choose or change your family member's support workers?



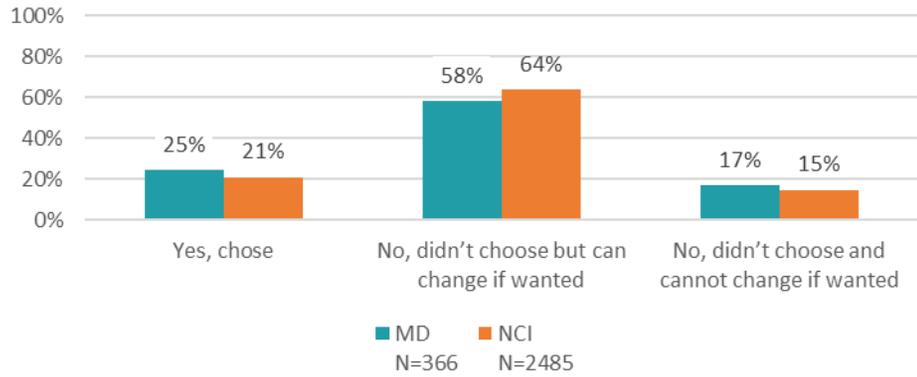
Does your family directly manage support staff?



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



Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?



Choice, Decision Making and Control Tables

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

Table Q37. Can your family choose or change the agency that provides your family member’s services?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD	61%	26%	6%	6%	295
NCI	67%	24%	4%	5%	3,317

Table Q38. Can your family choose or change your family member’s support workers?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	52%	28%	11%	9%	274
NCI	62%	24%	7%	6%	3,269

Table Q39. Does your family directly manage support staff?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	35%	20%	11%	35%	271
NCI	51%	19%	9%	22%	3,129

Table Q40. Do service providers for your family member work together to provide support?

State v NCI	Yes	No	N
MD	83%	17%	233
NCI	85%	15%	2,485

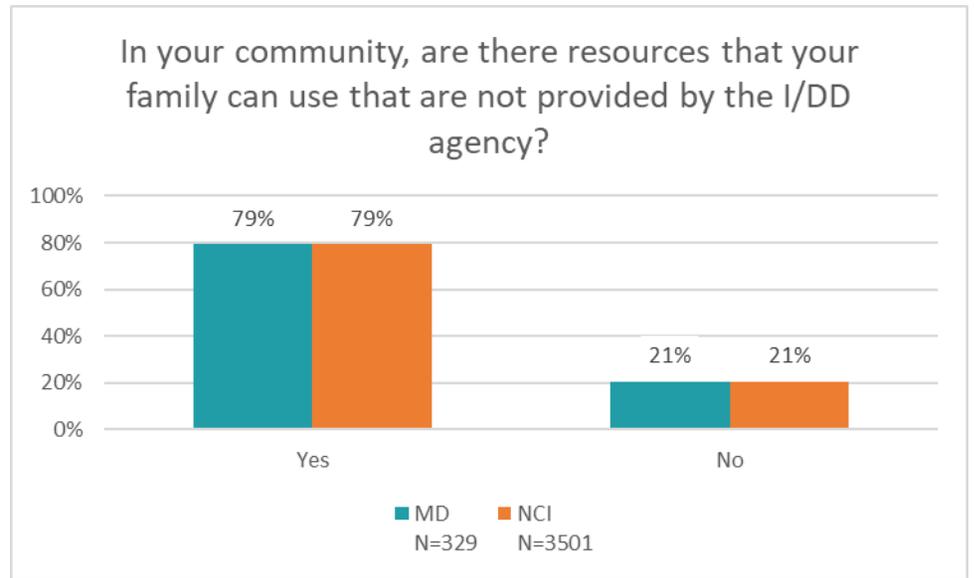
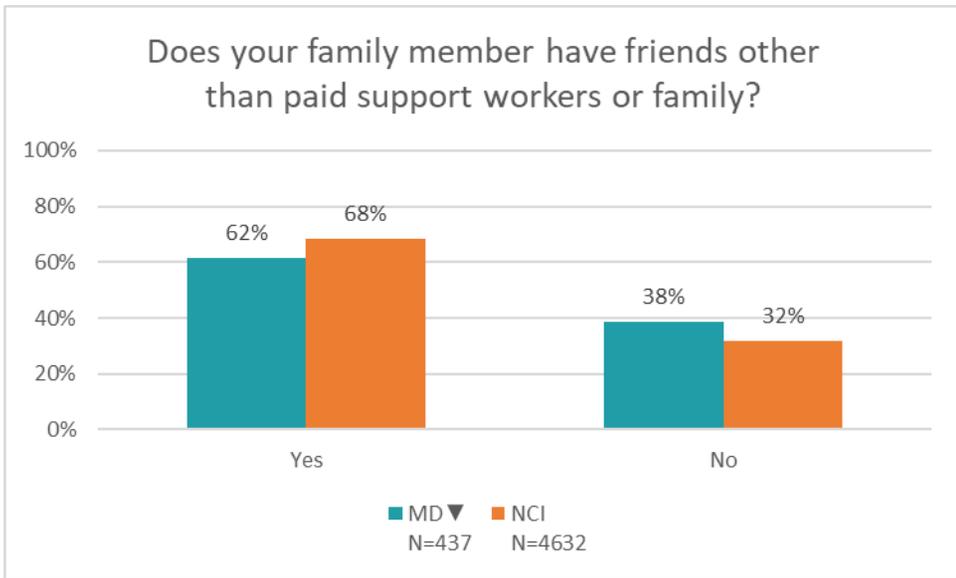
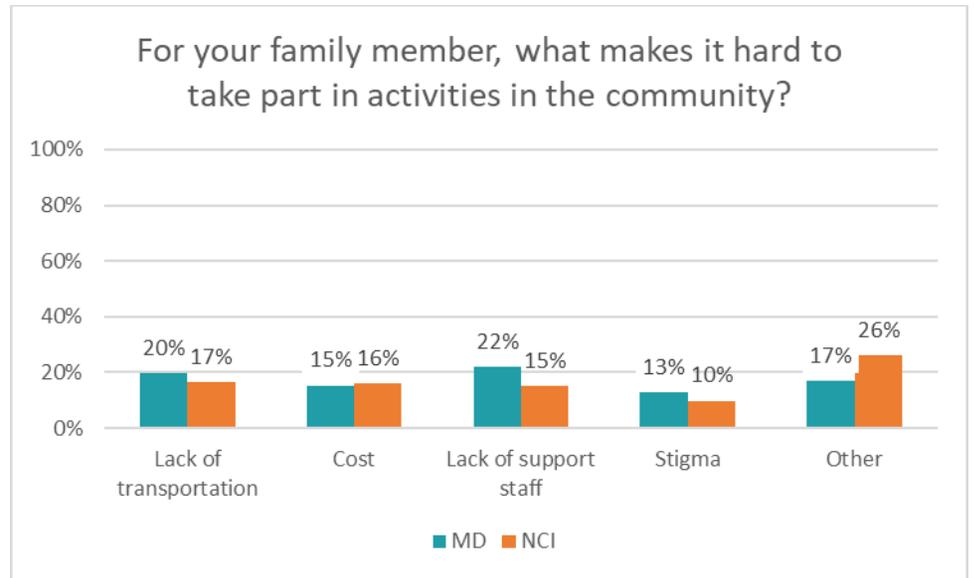
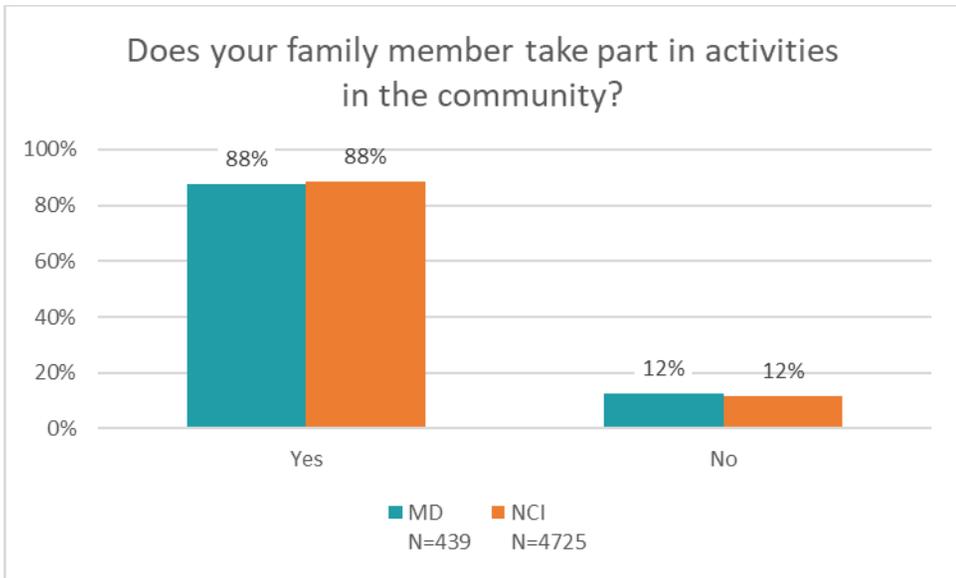
Table Q41. Did you, your family member, or someone else in your family choose your family member’s case manager/service coordinator?

Chose case manager/service coordinator	MD	MD N	NCI	NCI N
Yes, chose	25%	366	21%	3,845
No, didn’t choose but can change if wanted	58%	366	64%	3,845
No, didn’t choose and cannot change if wanted	17%	366	15%	3,845

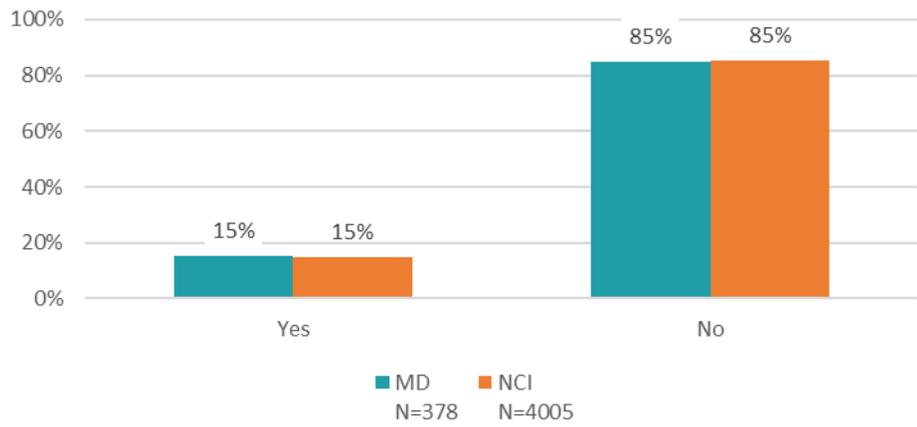
Involvement in the Community Charts

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

The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.



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



Involvement in the Community Tables

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

Table Q42. Does your family member take part in activities in the community?

State v NCI	Yes	No	N
MD	88%	12%	439
NCI	88%	12%	4,725

Table Q43. For your family member, what makes it hard to take part in activities in the community?

Question is rephrased from previous years; categories are not mutually exclusive, therefore N is not shown

Obstacles or barriers...	MD	NCI
Lack of transportation	20%	17%
Cost	15%	16%
Lack of support staff	22%	15%
Stigma	13%	10%
Other	17%	26%

Table Q44. Does your family member have friends other than paid support workers or family?

State v NCI	Yes	No	N
MD▼	62%	38%	437
NCI	68%	32%	4,632

Table Q45. In your community, are there resources that your family can use that are not provided by the I/DD agency (for example, recreational programs, community housing, library programs, religious groups, etc.)?

State v NCI	Yes	No	N
MD	79%	21%	329
NCI	79%	21%	3,501

Table Q46. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?

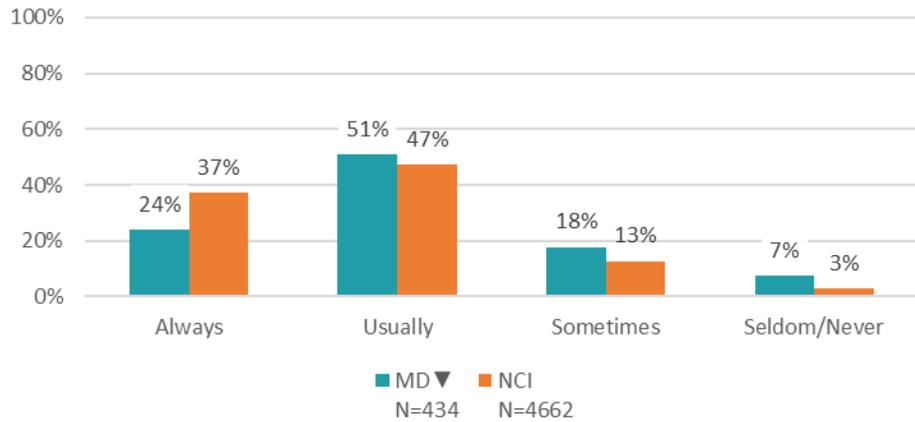
State v NCI	Yes	No	N
MD	15%	85%	378
NCI	15%	85%	4,005

Satisfaction With Services and Supports Charts

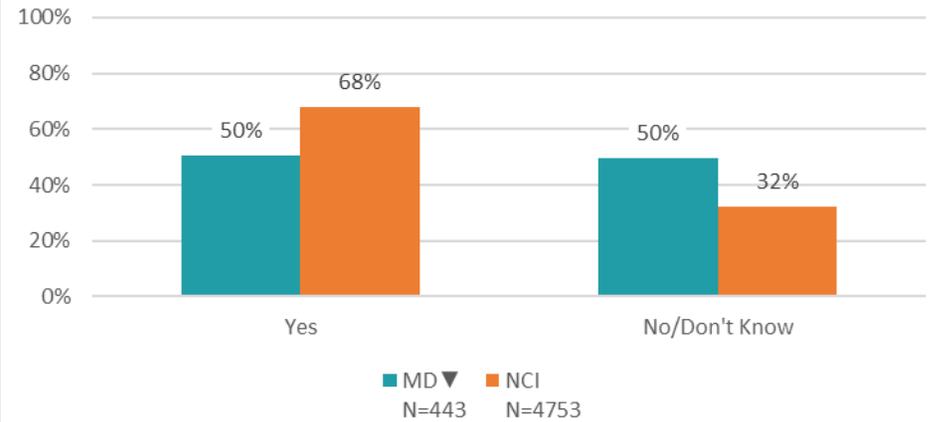
Families and family members with disabilities receive adequate and satisfactory supports.

The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.

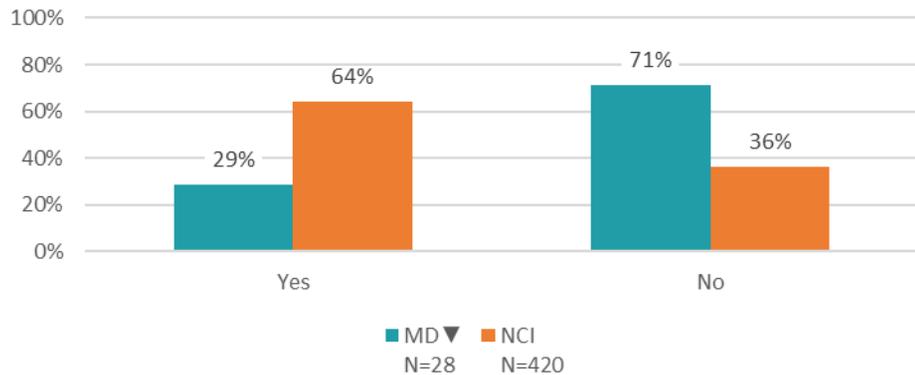
Overall, are you satisfied with the services and supports your family member currently receives?



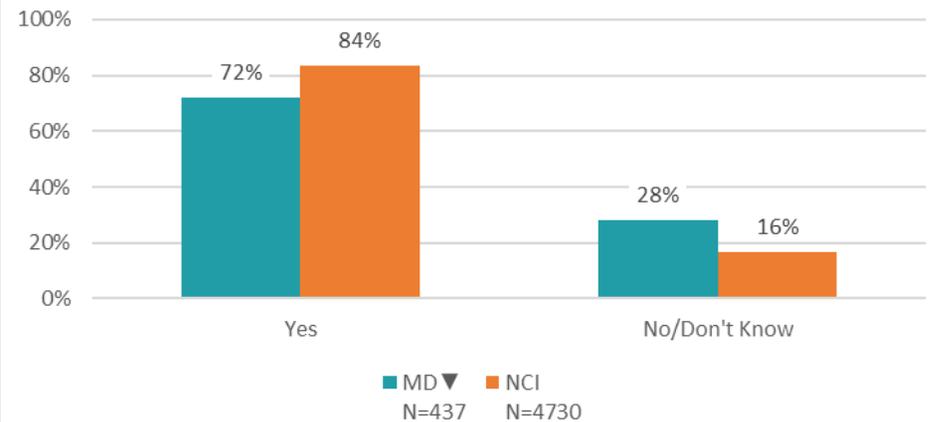
Do you know how to file a complaint or grievance about provider agencies or staff?

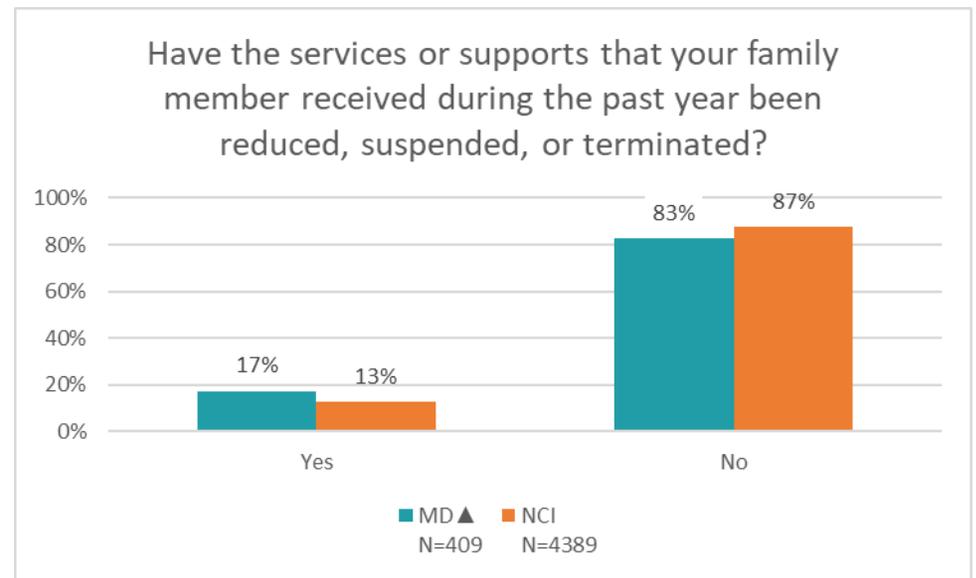
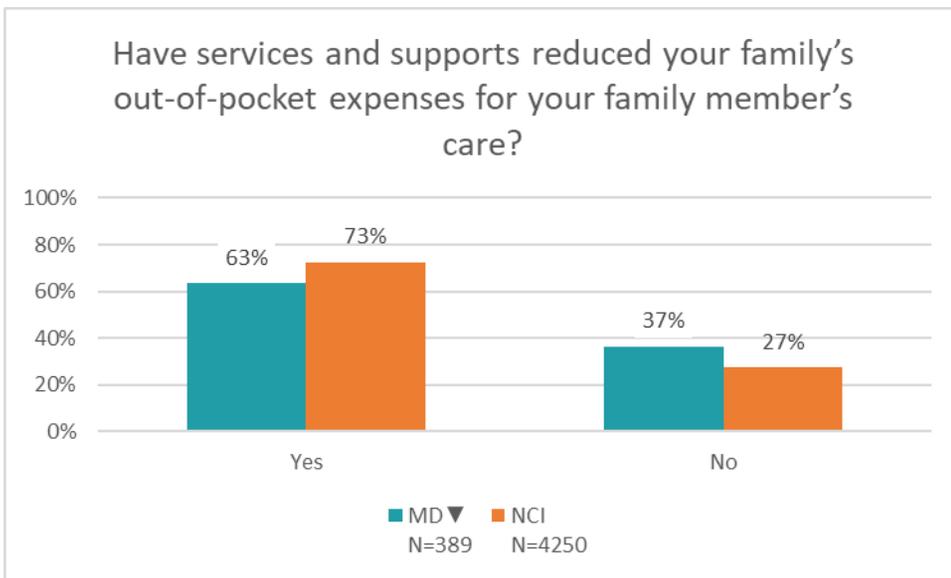
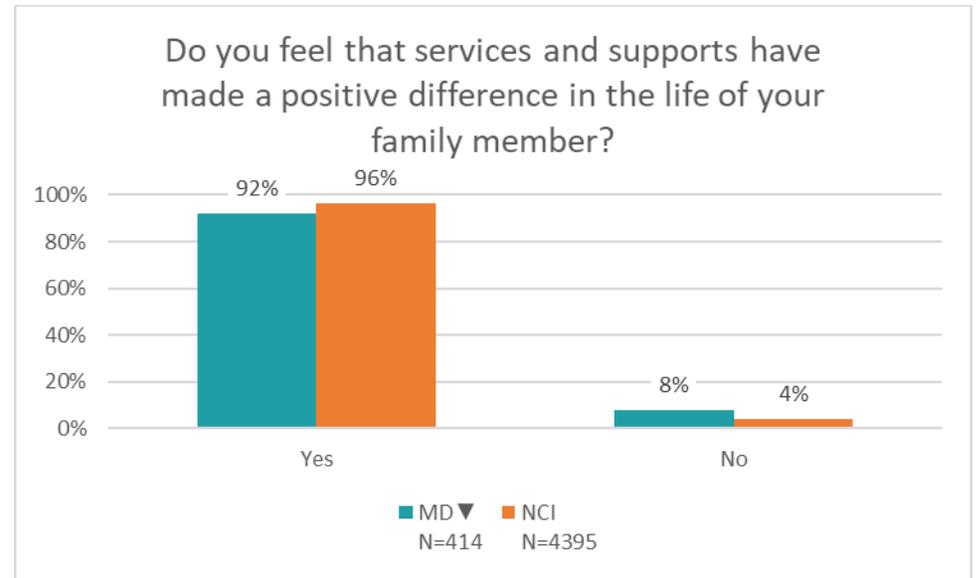
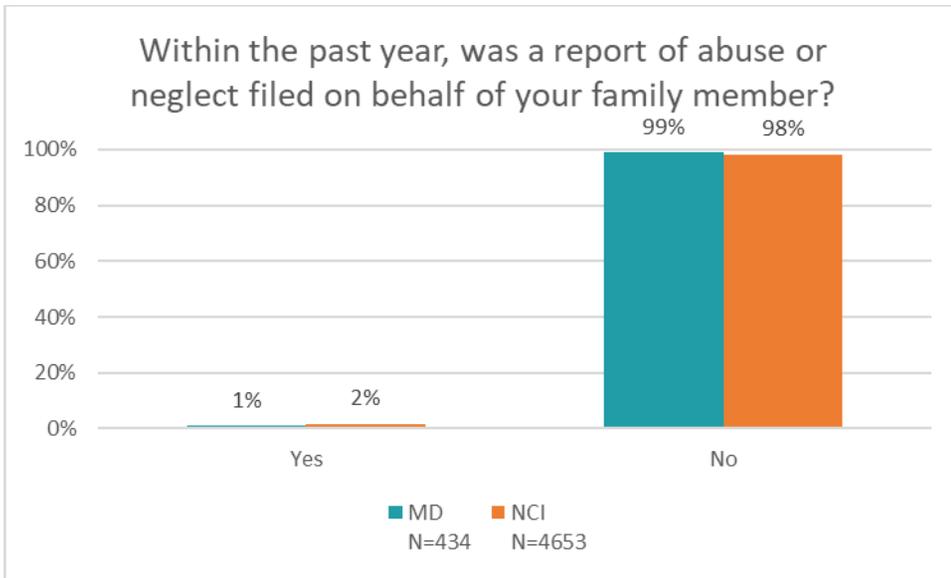


If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

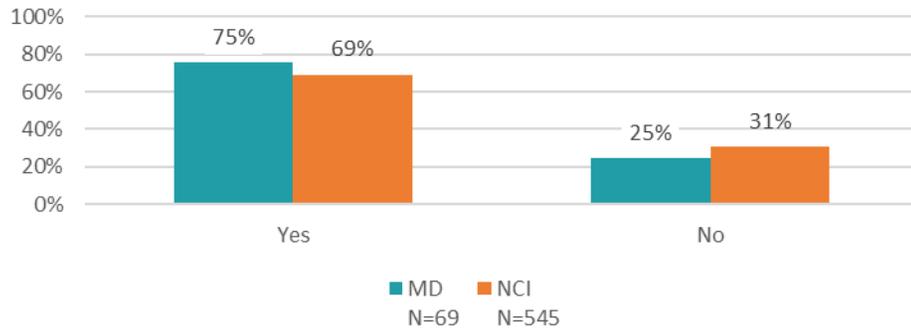


Do you know how to report abuse or neglect related to your family member?

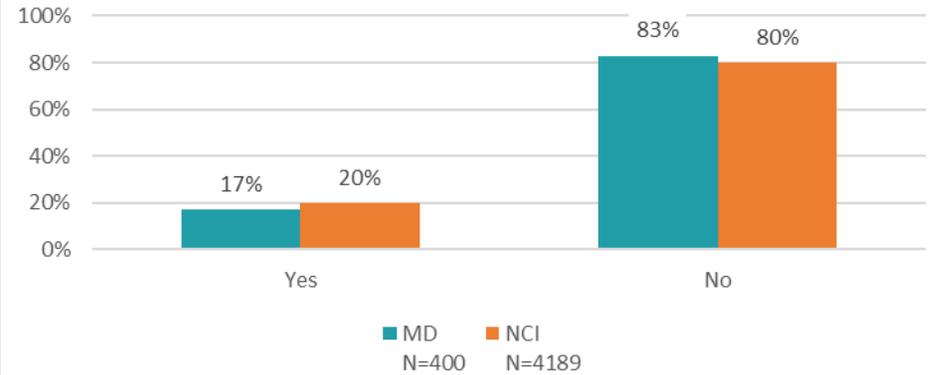




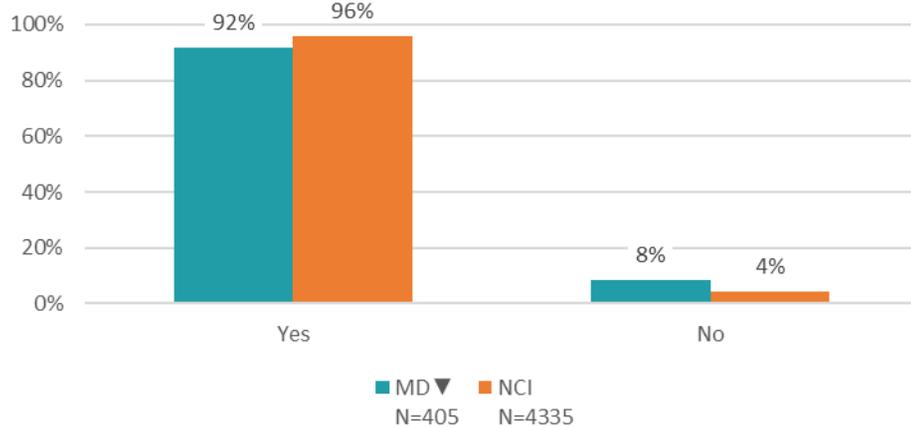
If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?



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



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



Satisfaction With Services and Supports Tables

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

Table Q47. Overall, are you satisfied with the services and supports your family member currently receives?

State v NCI	Always	Usually	Sometimes	Seldom/Never	N
MD ▼	24%	51%	18%	7%	434
NCI	37%	47%	13%	3%	4,662

Table Q48. Do you know how to file a complaint or grievance about provider agencies or staff?⁷

State v NCI	Yes	No	N
MD ▼	50%	50%	443
NCI	68%	32%	4,753

Table Q49. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?

State v NCI	Yes	No	N
MD ▼	29%	71%	28
NCI	64%	36%	420

Table Q50. Do you know how to report abuse or neglect related to your family member?⁸

State v NCI	Yes	No	N
MD ▼	72%	28%	437
NCI	84%	16%	4,730

Table Q51. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

State v NCI	Yes	No	N
MD	1%	99%	434
NCI	2%	98%	4,653

⁷ Don't Know' responses were included in 'No' responses for this question.

⁸ Don't Know' responses were included in 'No' responses for this question.

Table Q52. Do you feel that services and supports have made a positive difference in the life of your family member?

State v NCI	Yes	No	N
MD ▼	92%	8%	414
NCI	96%	4%	4,395

Table Q53. Have services and supports reduced your family’s out-of-pocket expenses for your family member’s care?

State v NCI	Yes	No	N
MD ▼	63%	37%	389
NCI	73%	27%	4,250

Table Q54. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?

State v NCI	Yes	No	N
MD ▲	17%	83%	409
NCI	13%	87%	4,389

Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?

State v NCI	Yes	No	N
MD	75%	25%	69
NCI	69%	31%	545

Table Q56. Have the services or supports that your family member received been increased in the past year?

State v NCI	Yes	No	N
MD	17%	83%	400
NCI	20%	80%	4,189

Table Q57. Are services and supports helping your family member to live a good life?

State v NCI	Yes	No	N
MD ▼	92%	8%	405
NCI	96%	4%	4,335