

# Adult Family Survey (AFS) State Report

Missouri (MO) Report

## Contents

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

| Table 17. Family Member's Activities in the Past Two Weeks Included School  | 14 |
|---|----|
| Table 18. Family Member's Activities in the Past Two Weeks Included Stays at Home                                   | 14 |
| Table 19. Family Member's Activities in the Past Two Weeks Included Other Activities                                | 15 |
| Table 20. Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors                | 15 |
| Table 21. Family Member's Level of Help Needed With Personal Care Activities (e.g., bathing, dressing, eating)      | 15 |
| Table 22. Family Member's Need for Help With Other Daily Activities (e.g., scheduling, managing money, or shopping) | 15 |
| Demographics of Respondents   | 16 |
| Table 23. Language Usually Spoken at Home   | 17 |
| Table 24. Respondent's Age  | 17 |
| Table 25. Respondent's Health   | 17 |
| Table 26. Respondent's Relationship to Family Member  | 17 |
| Table 27. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services               | 17 |
| Table 28. Number of Adults in Household (Not Including Family Member Receiving Services)                            | 18 |
| Table 29. Number of Children (Under 18 Years Old) in Household  | 18 |
| Table 30. Respondent's Highest Level of Education   | 18 |
| Table 31. Total Taxable Household Income of Wage Earners in the Past Year   | 18 |
| Table 32. Residential Designation (Urban, Suburban, or Rural)   | 18 |
| Services and Supports Received  | 19 |
| Table 33. Services and Supports Received From ID/DD Agency  | 20 |
| Table 34. Additional Services and Supports Received (Not From the I/DD Agency)                                      | 20 |
| Adult Family Survey Results   | 21 |
| Information and Planning Charts   | 22 |
| Information and Planning Tables   | 28 |
| Table Q1. Do you get enough information to take part in planning services for your family member?                   | 29 |
| Table Q2. Is the information you get about services and supports easy to understand?                                | 29 |
| Table Q3. Does the case manager/service coordinator respect your family's choices and opinions?                     | 29 |

| 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.)?   | 29  |
| Table Q5. Do you need help planning for your family member's future with respect to any of the following?   | 30  |
| Table Q6. If you asked for crisis or emergency services during the past year, were services provided when needed?   | 30  |
| Table Q7. Does your family member have a service plan?  | 30  |
| Table Q8. Does the service plan include all the services and supports your family member needs?   | 30  |
| Table Q9. Does your family member get all of the services listed in the service plan?   | 30  |
| Table Q10. Did you or someone else in your family (besides your family member with a disability) help make the service plan?  | 31  |
| Table Q11. Did your family member help make the service plan?   | 31  |
| Table Q12. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member's lasservice planning meeting?                                   |     |
| Table Q13. If your family member left school services during the past year, did s/he have a transition plan?  | 31  |
| Table Q14. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?   | 31  |
| Table Q15. Does your family member have enough supports (for example, support workers, community resources) to work or voluntee the community?  |     |
| 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?  |     |
| ccess and Delivery of Services and Supports Charts  | 33  |
| ccess and Delivery of Services and Supports Tables  | 40  |
| Table Q17. Are you or your family member able to contact his/her support workers when you want?   | 41  |
| Table Q18. Are you or your family member able to contact his/her case manager/service coordinator when you want?  | 41  |
| Table Q19. Do support workers come and go when they are supposed to?  | 41  |
| Table Q20. Do services and supports change when your family's needs change?   | 41  |
| Table Q21. Do support workers speak to you in a way you understand?   | 41  |
| Table Q22. Are services delivered in a way that is respectful of your family's culture?   | 41  |
| Table Q23. If your family member does not communicate verbally (for example, uses gestures or sign language, or a communication air are there support workers who can communicate with him/her? | • • |
| Table Q24. Do support workers have the right information and skills to meet your family's needs?  | 42  |

| Table Q25. Does your family member have the special equipment or accommodations that s/he needs?   | 42 |
|--|----|
| Table Q26. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?   | 42 |
| Table Q27. Does your family member's primary care doctor understand your family member's needs related to his/her disability?  | 42 |
| Table Q28. Does your family member go to the dentist when needed?  | 42 |
| Table Q29. Does your family member's dentist understand your family member's needs related to his/her disability?  | 43 |
| Table Q30. If your family member takes medications, do you know what they're for?  | 43 |
| Table Q31. Do you, your family member, or someone else in your family know what is needed to safely take the medications (when should be taken, how much to take, and the potential side effects)? |    |
| Table Q32. If your family member uses mental health services, does the mental health professional understand your family member related to his/her disability?                                     |    |
| Table Q33. If you need respite services, are you able to get/use them?   | 43 |
| Table Q34. If you have used respite services in the past year, were you satisfied with the quality of the respite services?  | 43 |
| Table Q35. Does your family get the supports and services it needs?  | 44 |
| Table Q36. If your family does not get the support and services needed, what additional services does your family need?  | 44 |
| Choice, Decision Making and Control Charts   | 45 |
| Choice, Decision Making and Control Tables   | 48 |
| Table Q37. Can your family choose or change the agency that provides your family member's services?  | 49 |
| Table Q38. Can your family choose or change your family member's support workers?  | 49 |
| Table Q39. Does your family directly manage support staff?   | 49 |
| Table Q40. Do service providers for your family member work together to provide support?   | 49 |
| Table Q41. Did you, your family member, or someone else in your family choose your family member's case manager/service coord  |    |
| Involvement in the Community Charts  | 50 |
| Involvement in the Community Tables  | 53 |
| Table Q42. Does your family member take part in activities in the community?   | 54 |
| Table Q43. For your family member, what makes it hard to take part in activities in the community?   | 54 |
| Table Q44. Does your family member have friends other than paid support workers or family?   | 54 |

|   | recreational programs, community housing, library programs, religious groups, etc.)?   | 54      |
|---|--|---------|
|   | Table Q46. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks)?  |         |
| S | atisfaction With Services and Supports Charts  | 55      |
| S | atisfaction With Services and Supports Tables  | 59      |
|   | Table Q47. Overall, are you satisfied with the services and supports your family member currently receives?  | 60      |
|   | Table Q48. Do you know how to file a complaint or grievance about provider agencies or staff?  | 60      |
|   | 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  | 1? . 60 |
|   | Table Q50. Do you know how to report abuse or neglect related to your family member?   | 60      |
|   | Table Q51. Within the past year, was a report of abuse or neglect filed on behalf of your family member?   | 60      |
|   | Table Q52. Do you feel that services and supports have made a positive difference in the life of your family member?   | 61      |
|   | Table Q53. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?  | 61      |
|   | Table Q54. Have the services or supports that your family member received during the past year been reduced, suspended, or terminate   |         |
|   | Table Q55. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change is services affect your family member negatively? |         |
|   | Table Q56. Have the services or supports that your family member received been increased in the past year?   | 61      |
|   | Table Q57. Are services and supports helping your family member to live a good life?   | 61      |

## What is NCI?

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

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:

- Outcomes where the state is significantly above the NCI average are denoted with an up arrow **\( \( \)**; 1.
- 2. Outcomes where the state is significantly below the NCI average are denoted with a down arrow  $\nabla$ .

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.

<u>Important note on responses:</u> 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     |
|-------------|-----|-----|-------|
| MO          | 14% | 86% | 299   |
| NCI         | 13% | 87% | 4,689 |

Table 2. Family Member's Age

| State v NCI | Average Age | N     |
|-------------|-------------|-------|
| MO          | 34.3        | 304   |
| NCI         | 34.1        | 4,800 |

**Table 3. Family Member's Gender** 

| State v NCI | Male | Female | N     |
|-------------|------|--------|-------|
| MO          | 57%  | 43%    | 302   |
| 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<br>Indian or<br>Alaska<br>Native | Asian | Black or<br>African<br>American | Pacific<br>Islander | White | Hispanic or<br>Latino | Other |
|-------------|---|-------|---------------------------------|---------------------|-------|-----------------------|-------|
| MO          | 3%  | 3%    | 7%                              | 1%                  | 89%   | 2%                    | 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<br>Disability | Mood<br>Illness or<br>Psychiatric<br>Disorder | Autism<br>Spectrum<br>Disorder | Cerebral<br>Palsy | Limited or<br>No Vision | Severe or<br>Profound<br>Hearing Loss |
|-------------|----------------------------|---|--------------------------------|-------------------|-------------------------|---------------------------------------|
| MO          | 63%                        | 26%   | 36%                            | 21%               | 11%                     | 5%                                    |
| 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<br>Disorder or<br>Neurological<br>Problem | Chemical<br>Dependency | Down<br>Syndrome | Prader-Willi<br>Syndrome | Fetal Alcohol<br>Spectrum<br>Disorder | Other |
|-------------|--------------|---|------------------------|------------------|--------------------------|---------------------------------------|-------|
| MO          | 12%          | 38%   | 1%                     | 10%              | 0%                       | 1%                                    | 24%   |
| 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<br>Disease | Diabetes | Cancer | High Blood<br>Pressure | High<br>Cholesterol |
|-------------|---------------------------|----------|--------|------------------------|---------------------|
| MO          | 12%                       | 17%      | 5%     | 24%                    | 21%                 |
| 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<br>Ulcers | Alzheimer's<br>Disease or<br>Other<br>Dementia | Oral Health or<br>Dental<br>Problems | Sleep Apnea | Other |
|-------------|-----------|--------------------|--|--------------------------------------|-------------|-------|
| MO          | 13%       | 6%                 | 3%   | 14%                                  | 21%         | 29%   |
| NCI         | 12%       | 4%                 | 3%   | 12%                                  | 20%         | 25%   |

**Table 7. Family Member's Preferred Means of Communication** 

| State v NCI | Spoken | Gestures or<br>Body<br>Language | Sign<br>Language<br>or Finger<br>Spelling | Communication<br>Aid or Device | Other | N     |
|-------------|--------|---------------------------------|---|--------------------------------|-------|-------|
| MO          | 77%    | 15%                             | 2%  | 2%                             | 4%    | 293   |
| 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<br>Guardianship | Limited | Full | Has<br>Guardianship<br>but Level Is<br>Unknown | N     |
|-------------|--------------------|---------|------|--|-------|
| MO          | 26%                | 8%      | 65%  | 1%   | 293   |
| NCI         | 32%                | 11%     | 54%  | 3%   | 4,537 |

**Table 9. Guardian or Conservator Relationship to Family Member** 

| State v NCI | Family | Friend | State<br>Employee or<br>Guardianship<br>Agency | Other | N     |
|-------------|--------|--------|--|-------|-------|
| MO          | 98%    | 0%     | 0%   | 1%    | 208   |
| NCI         | 98%    | 1%     | 0%   | 1%    | 2,965 |

Table 10. Family Member's Highest level of Education

| State v NCI | Did Not<br>Complete<br>High School<br>(and Not<br>Currently<br>Enrolled) | Currently<br>Enrolled in<br>High<br>School | High School<br>Certification | High School<br>Diploma or<br>GED | Vocational<br>School or<br>Certificate<br>Program | Some College | College<br>Degree<br>or<br>Higher | N     |
|-------------|--|--|------------------------------|----------------------------------|---|--------------|-----------------------------------|-------|
| MO          | 15%  | 2%   | 30%                          | 42%                              | 3%  | 5%           | 4%                                | 281   |
| 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<sup>1</sup>

Response options changed from previous years

| State v NCI | Yes | No  | N     |
|-------------|-----|-----|-------|
| MO          | 11% | 89% | 302   |
| NCI         | 16% | 84% | 4,700 |

<sup>&</sup>lt;sup>1</sup> 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<sup>2</sup>

Response options changed from previous years

| State v NCI | Yes | No  | N     |
|-------------|-----|-----|-------|
| MO          | 6%  | 94% | 300   |
| 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*<sup>3</sup>

Response options changed from previous years

| State v NCI | Yes | No  | N     |
|-------------|-----|-----|-------|
| MO          | 5%  | 95% | 296   |
| NCI         | 8%  | 92% | 4,630 |

## Table 14. Family Member's Activities in the Past Two Weeks Included Unpaid Activity in the Community<sup>4</sup>

Response options changed from previous years

| State v NCI | Yes | No  | N     |
|-------------|-----|-----|-------|
| MO          | 33% | 67% | 298   |
| NCI         | 33% | 67% | 4,595 |

<sup>&</sup>lt;sup>2</sup> 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).

<sup>&</sup>lt;sup>3</sup> 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.

<sup>&</sup>lt;sup>4</sup> 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<sup>5</sup>

Response options changed from previous years

| State v NCI | Yes | No  | N     |
|-------------|-----|-----|-------|
| MO          | 18% | 82% | 297   |
| NCI         | 18% | 82% | 4,637 |

## Table 16. Family Member's Activities in the Past Two Weeks Included Unpaid Activity in a Facility-based Setting<sup>6</sup>

Response options changed from previous years

| State v NCI | Yes | No  | N     |
|-------------|-----|-----|-------|
| MO          | 27% | 73% | 292   |
| 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     |
|-------------|-----|-----|-------|
| MO          | 6%  | 94% | 301   |
| 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     |
|-------------|-----|-----|-------|
| MO          | 55% | 45% | 287   |
| NCI         | 48% | 52% | 4,452 |

<sup>&</sup>lt;sup>5</sup> 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.

<sup>&</sup>lt;sup>6</sup> 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     |
|-------------|-----|-----|-------|
| MO          | 35% | 65% | 134   |
| 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     |
|-------------|-----------|------|------|-------|
| MO          | 14%       | 29%  | 57%  | 295   |
| 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     |
|-------------|-----------|------|------|-------|
| MO          | 43%       | 31%  | 26%  | 301   |
| 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     |
|-------------|-----------|------|------|-------|
| MO          | 80%       | 17%  | 3%   | 298   |
| 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     |
|-------------|---------|---------|-------|-------|
| MO          | 99%     | 0%      | 1%    | 303   |
| NCI         | 97%     | 2%      | 1%    | 4,764 |

### Table 24. Respondent's Age

| State v NCI | Under 35 | 35-54 | 55-74 | 75 and Older | N     |
|-------------|----------|-------|-------|--------------|-------|
| MO          | 2%       | 25%   | 64%   | 9%           | 298   |
| NCI         | 2%       | 23%   | 64%   | 11%          | 4,795 |

## Table 25. Respondent's Health

| State v NCI | Excellent | Very Good | Fairly<br>Good | Poor | N     |
|-------------|-----------|-----------|----------------|------|-------|
| MO          | 10%       | 41%       | 42%            | 7%   | 302   |
| NCI         | 15%       | 46%       | 36%            | 4%   | 4,777 |

## Table 26. Respondent's Relationship to Family Member

| State v NCI | Parent | Sibling | Spouse | Grandparent | Other | N     |
|-------------|--------|---------|--------|-------------|-------|-------|
| MO          | 89%    | 5%      | 0%     | 2%          | 3%    | 300   |
| 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<br>Family<br>Provides<br>Paid Support | Respondent<br>Provides<br>Paid<br>Support | Other<br>Family<br>Member<br>Provides<br>Paid<br>Support | N     |
|-------------|---|---|--|-------|
| MO          | 81%   | 10%                                       | 10%  | 301   |
| 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     |
|-------------|-----|-----|-------|--------------|-------|
| MO          | 5%  | 29% | 49%   | 17%          | 303   |
| 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<br>More | N     |
|-------------|------|-----|-----|-------|-----------------|-------|
| MO          | 88%  | 7%  | 3%  | 1%    | 1%              | 302   |
| NCI         | 87%  | 8%  | 3%  | 1%    | 1%              | 4,775 |

Table 30. Respondent's Highest Level of Education

| State v NCI | No High<br>School<br>Diploma or<br>GED | High<br>School<br>Diploma or<br>GED | Vocational<br>School or<br>Certificate<br>Program | Some College | College<br>Degree or<br>Higher | N     |
|-------------|--|-------------------------------------|---|--------------|--------------------------------|-------|
| MO          | 3%                                     | 26%                                 | 6%  | 21%          | 43%                            | 295   |
| 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<br>Income | Up to<br>\$15,000 | \$15,001-<br>\$25,000 | \$25,001-<br>\$50,000 | \$50,001-<br>\$75,000 | Over \$75,000 | Prefer<br>Not to<br>Say | N     |
|-------------|---------------------|-------------------|-----------------------|-----------------------|-----------------------|---------------|-------------------------|-------|
| MO          | 12%                 | 9%                | 9%                    | 17%                   | 18%                   | 16%           | 20%                     | 294   |
| NCI         | 10%                 | 8%                | 10%                   | 18%                   | 13%                   | 20%           | 21%                     | 4,647 |

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

| State v NCI | Urban or<br>suburban<br>(in or near a<br>city or large<br>town) | Rural<br>(outside of<br>a city or<br>town) | N     |
|-------------|---|--|-------|
| MO          | 66%   | 34%  | 297   |
| 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      | MO  | NCI |
|--|-----|-----|
| Financial Support                              | 15% | 14% |
| In-home Support                                | 35% | 41% |
| Out of Home Respite                            | 26% | 29% |
| Day or Employment Supports                     | 46% | 54% |
| Transportation                                 | 58% | 61% |
| Other  | 21% | 27% |
| Self-direction or Fiscal Intermediary Services | 39% | 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

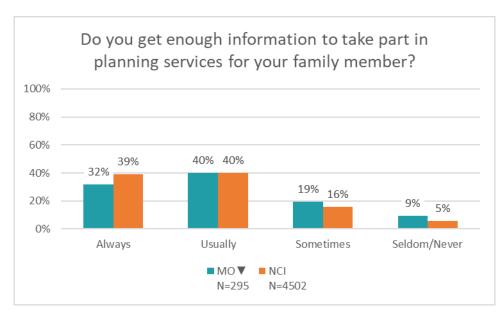
| Additional Services and Supports Received                 | MO  | NCI |
|---|-----|-----|
| Social Security Payments (SSI/SSB)                        | 94% | 93% |
| Services or Supports From Other Agencies or Organizations | 38% | 30% |

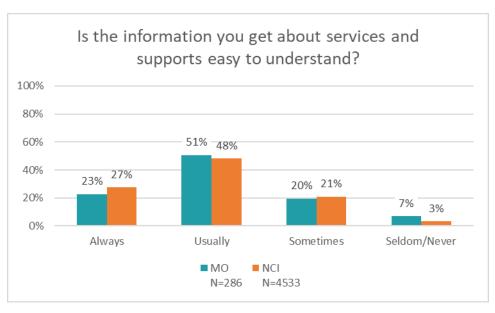
## Adult Family Survey Results

## *Information and Planning Charts*

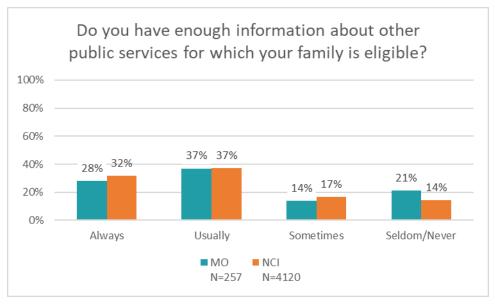
Families and family members with disabilities have the information and support necessary to plan for their services and supports.

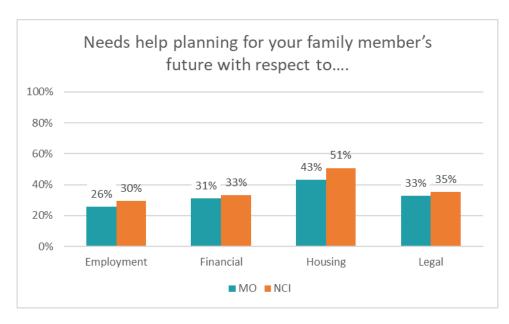
The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.



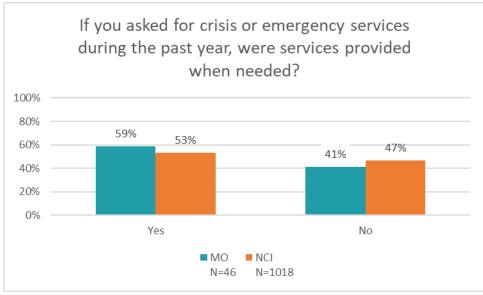


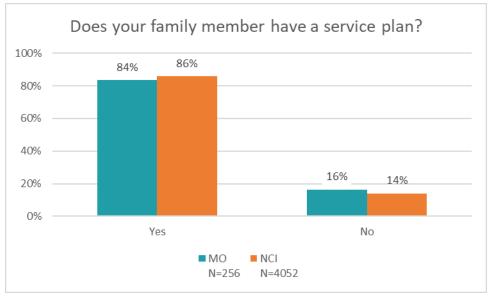


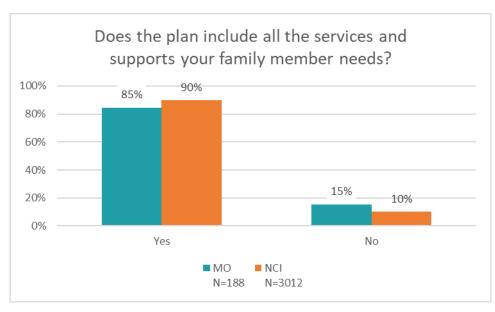


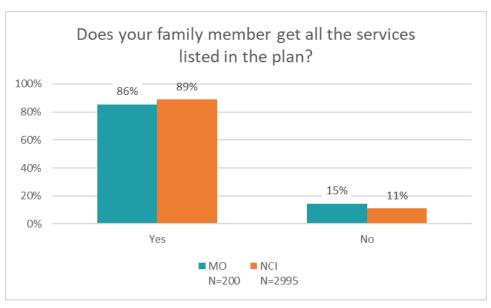


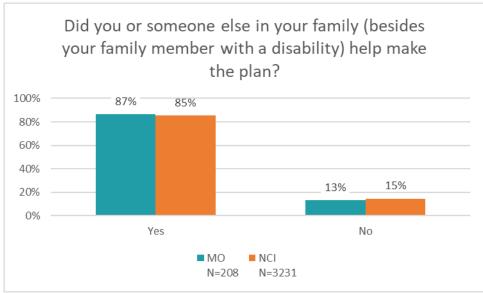


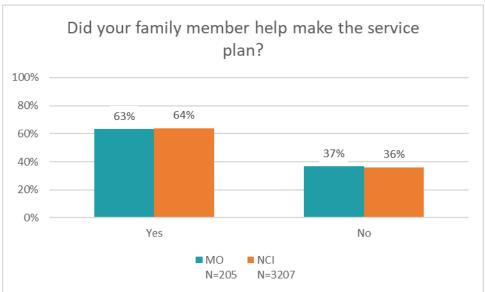


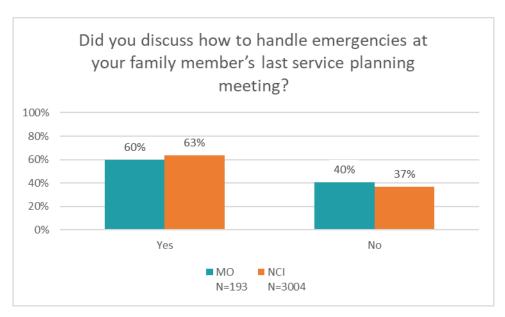


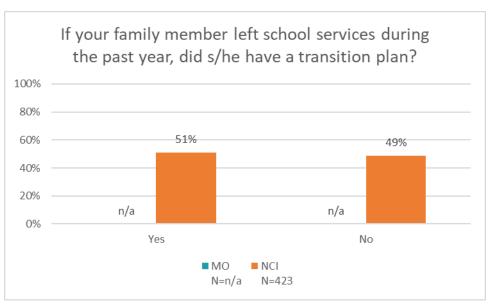


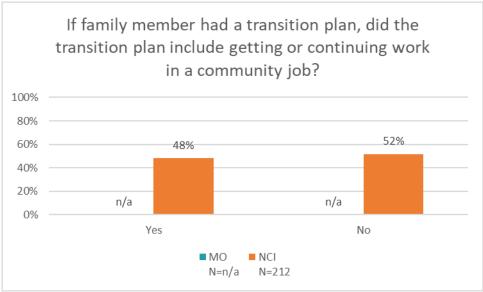


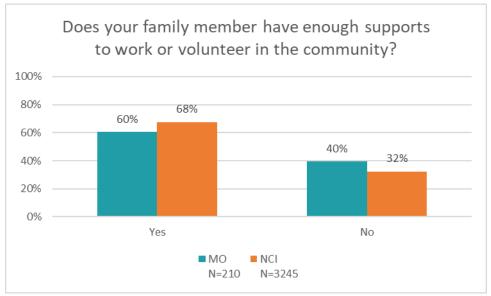


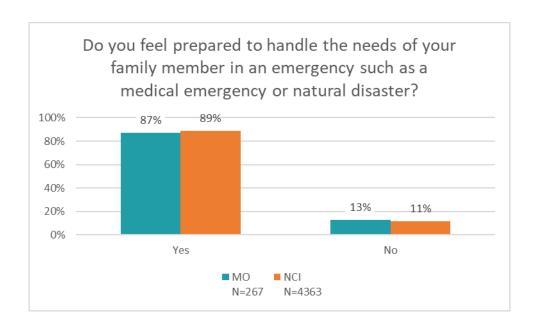












## Information and Planning Tables

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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO▼         | 32%    | 40%     | 19%       | 9%           | 295   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 23%    | 51%     | 20%       | 7%           | 286   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 64%    | 28%     | 5%        | 3%           | 290   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 28%    | 37%     | 14%       | 21%          | 257   |
| 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 | МО  | NCI |
|-------------------------|-----|-----|
| Employment              | 26% | 30% |
| Financial               | 31% | 33% |
| Housing                 | 43% | 51% |
| Legal                   | 33% | 35% |
| Medical                 | 29% | 31% |
| Social or Relationships | 28% | 32% |
| Transition from School  | 10% | 9%  |
| Recreation, Having Fun  | 34% | 36% |
| Other                   | 8%  | 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     |
|-------------|-----|-----|-------|
| MO          | 59% | 41% | 46    |
| NCI         | 53% | 47% | 1,018 |

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

| State v NCI | Yes | No  | N     |
|-------------|-----|-----|-------|
| MO          | 84% | 16% | 256   |
| 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     |
|-------------|-----|-----|-------|
| MO          | 85% | 15% | 188   |
| 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     |
|-------------|-----|-----|-------|
| MO          | 86% | 15% | 200   |
| 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     |
|-------------|-----|-----|-------|
| MO          | 87% | 13% | 208   |
| NCI         | 85% | 15% | 3,231 |

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

| State v NCI | Yes | No  | N     |
|-------------|-----|-----|-------|
| MO          | 63% | 37% | 205   |
| 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     |
|-------------|-----|-----|-------|
| MO          | 60% | 40% | 193   |
| 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   |
|-------------|-----|-----|-----|
| MO          | n/a | n/a | n/a |
| 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   |
|-------------|-----|-----|-----|
| MO          | 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     |
|-------------|-----|-----|-------|
| MO          | 60% | 40% | 210   |
| NCI         | 68% | 32% | 3,245 |

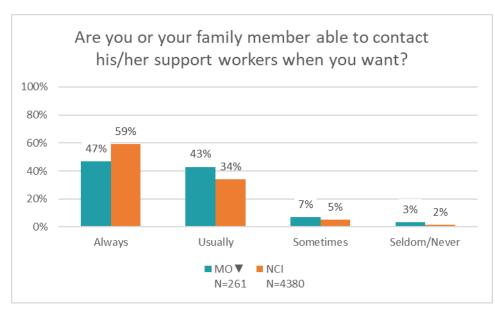
## Table Q16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

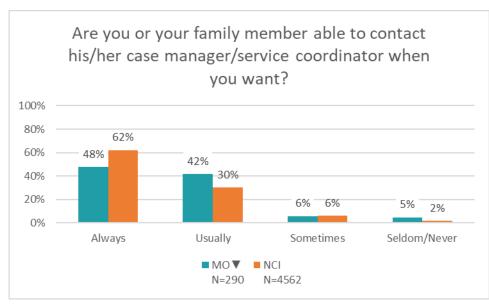
| State v NCI | Yes | No  | N     |
|-------------|-----|-----|-------|
| MO          | 87% | 13% | 267   |
| NCI         | 89% | 11% | 4,363 |

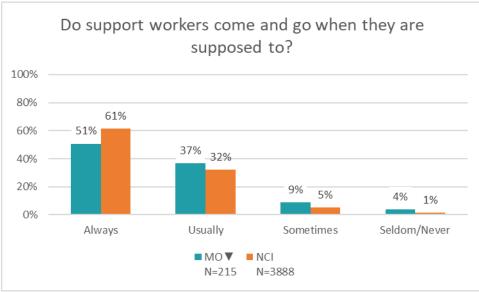
## Access and Delivery of Services and Supports Charts

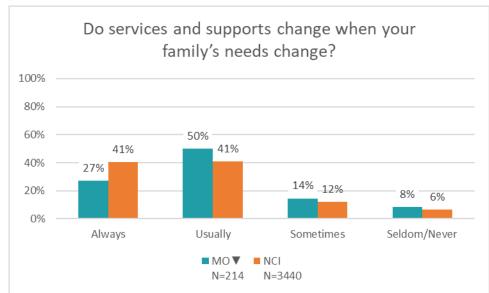
Families and family members with disabilities get the services and supports they need.

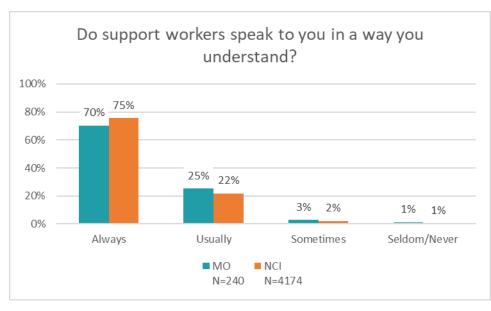
The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.

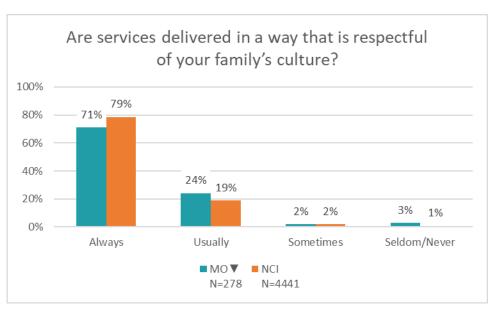


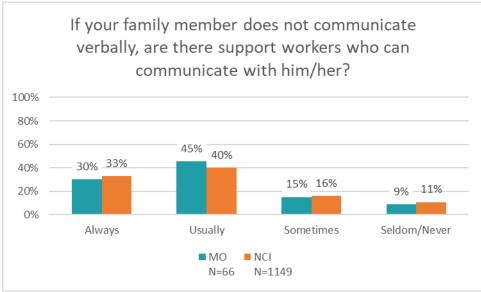


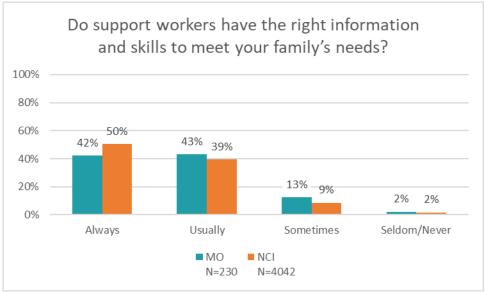


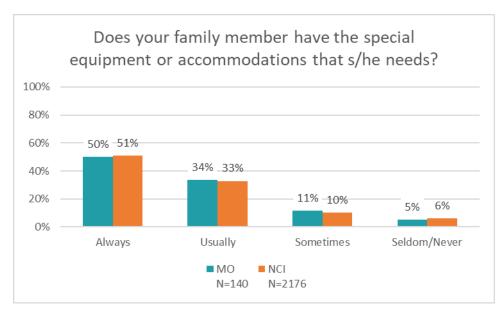


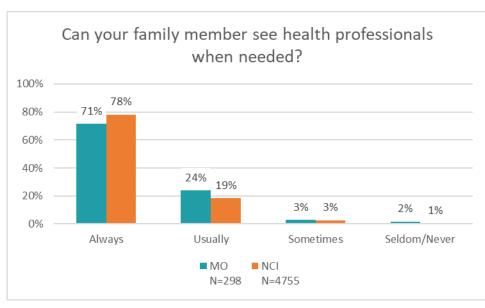


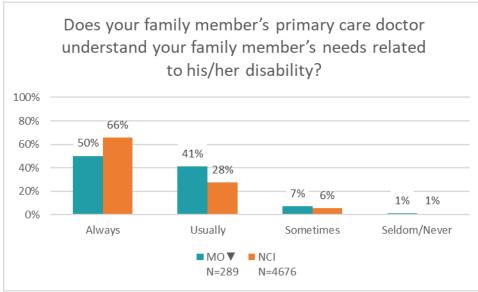


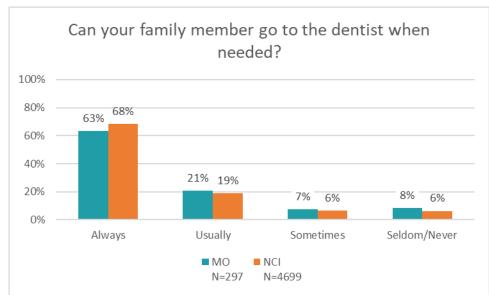


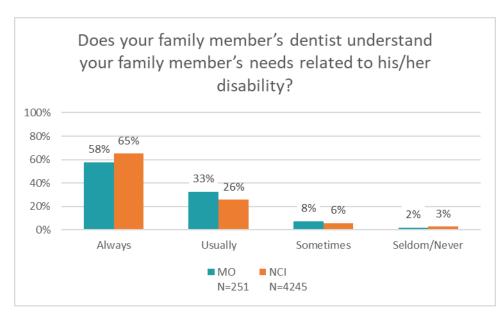


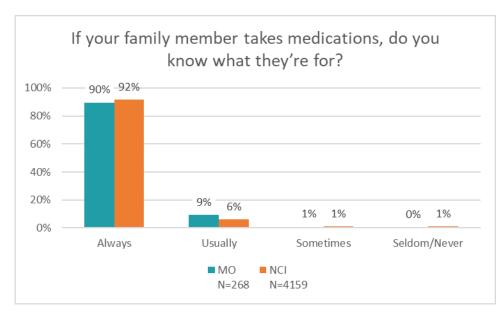


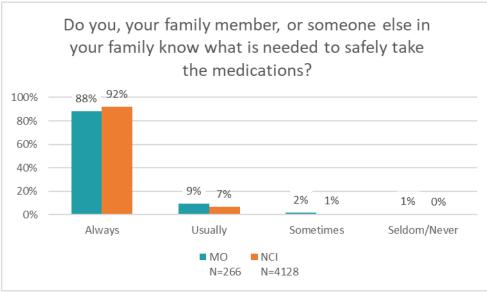


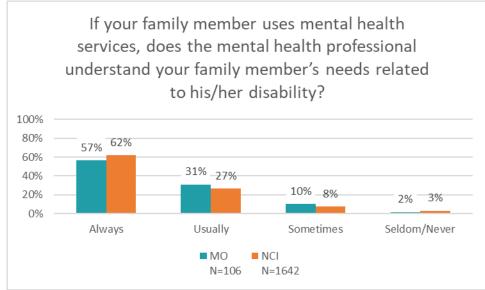


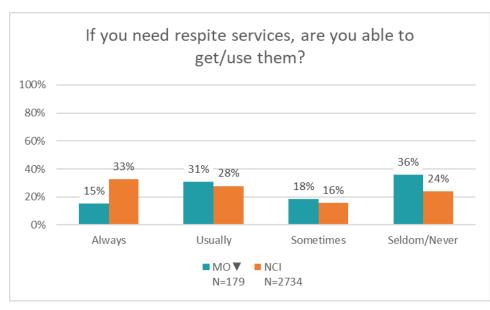


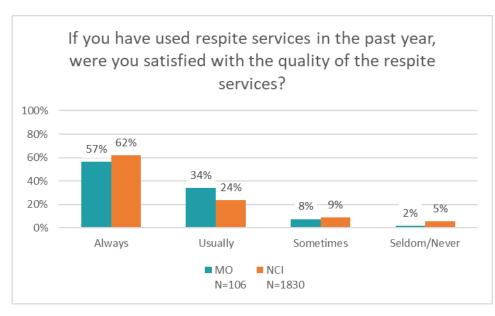


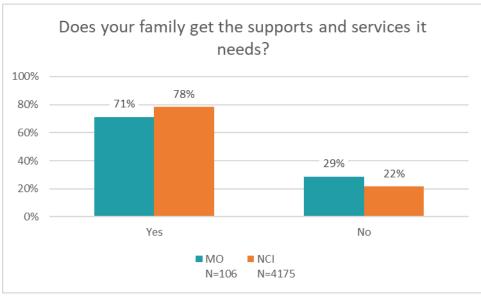


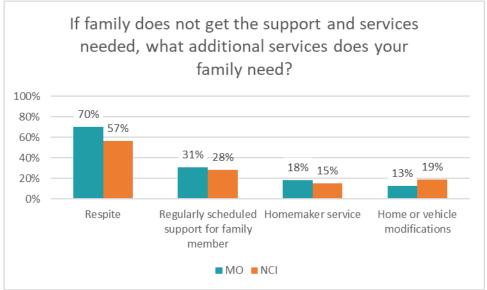


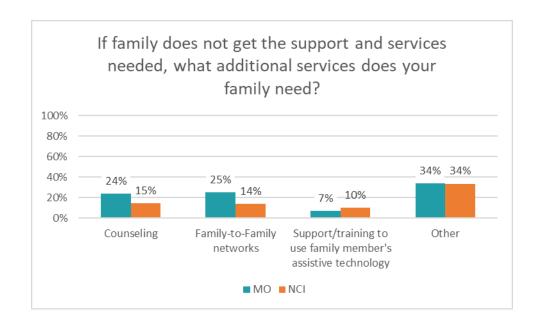












# Access and Delivery of Services and Supports Tables

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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO▼         | 47%    | 43%     | 7%        | 3%           | 261   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO▼         | 48%    | 42%     | 6%        | 5%           | 290   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO▼         | 51%    | 37%     | 9%        | 4%           | 215   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO▼         | 27%    | 50%     | 14%       | 8%           | 214   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 70%    | 25%     | 3%        | 1%           | 240   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO▼         | 71%    | 24%     | 2%        | 3%           | 278   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 30%    | 45%     | 15%       | 9%           | 66    |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 42%    | 43%     | 13%       | 2%           | 230   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 50%    | 34%     | 11%       | 5%           | 140   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 71%    | 24%     | 3%        | 2%           | 298   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO▼         | 50%    | 41%     | 7%        | 1%           | 289   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| МО          | 63%    | 21%     | 7%        | 8%           | 297   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 58%    | 33%     | 8%        | 2%           | 251   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 90%    | 9%      | 1%        | 0%           | 268   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 88%    | 9%      | 2%        | 1%           | 266   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 57%    | 31%     | 10%       | 2%           | 106   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO▼         | 15%    | 31%     | 18%       | 36%          | 179   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 57%    | 34%     | 8%        | 2%           | 106   |
| 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     |
|-------------|-----|-----|-------|
| MO          | 71% | 29% | 254   |
| 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?

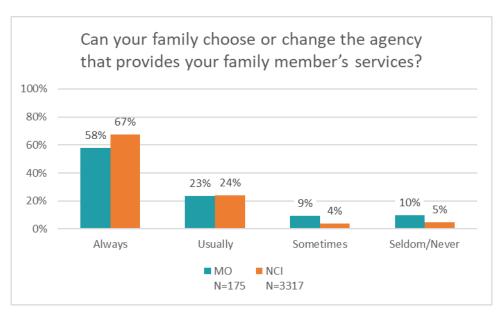
Categories are not mutually exclusive, therefore N is not shown

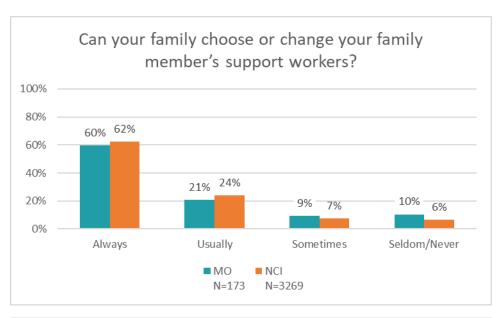
| Additional service needed                                    | MO  | NCI |
|--|-----|-----|
| Respite  | 70% | 57% |
| Regularly scheduled support for family member                | 31% | 28% |
| Homemaker service  | 18% | 15% |
| Home or vehicle modifications                                | 13% | 19% |
| Counseling   | 24% | 15% |
| Family-to-Family networks                                    | 25% | 14% |
| Support/training to use family member's assistive technology | 7%  | 10% |
| Other  | 34% | 34% |

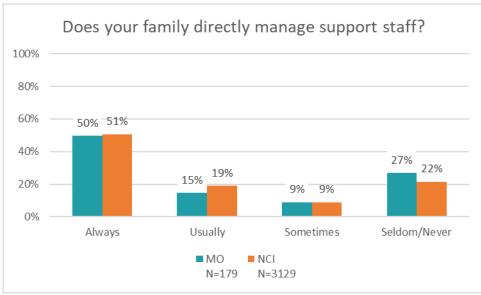
## Choice, Decision Making and Control Charts

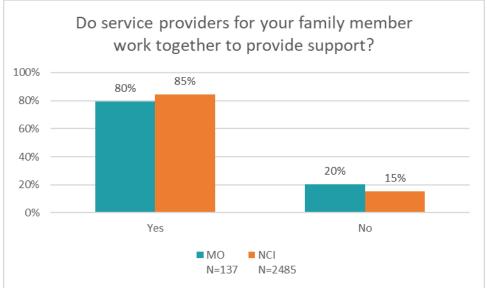
Families and family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.

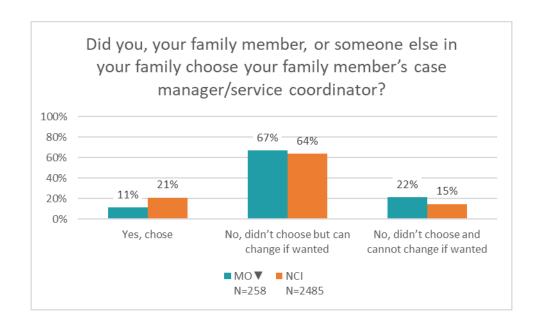
The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.











# 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 58%    | 23%     | 9%        | 10%          | 175   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 60%    | 21%     | 9%        | 10%          | 173   |
| 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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO          | 50%    | 15%     | 9%        | 27%          | 179   |
| 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     |
|-------------|-----|-----|-------|
| MO          | 80% | 20% | 137   |
| NCI         | 85% | 15% | 2,485 |

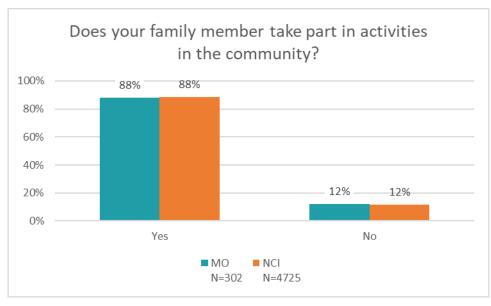
### Table Q41. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

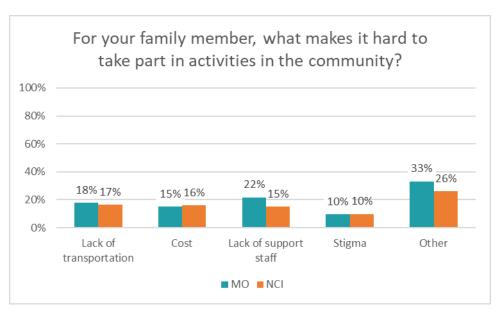
| Chose case manager/service coordinator        | MO▼ | MO N | NCI | NCI N |
|---|-----|------|-----|-------|
| Yes, chose                                    | 11% | 258  | 21% | 3,845 |
| No, didn't choose but can change if wanted    | 67% | 258  | 64% | 3,845 |
| No, didn't choose and cannot change if wanted | 22% | 258  | 15% | 3,845 |

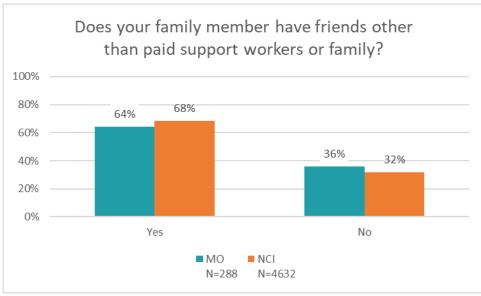
## Involvement in the Community Charts

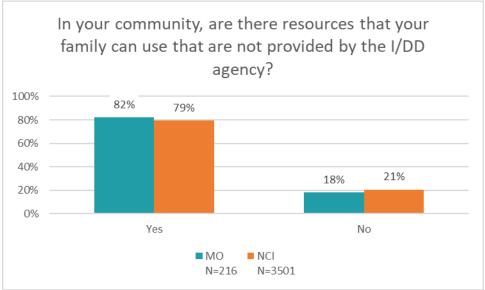
Family members with disabilities use integrated community services and participate in everyday community activities.

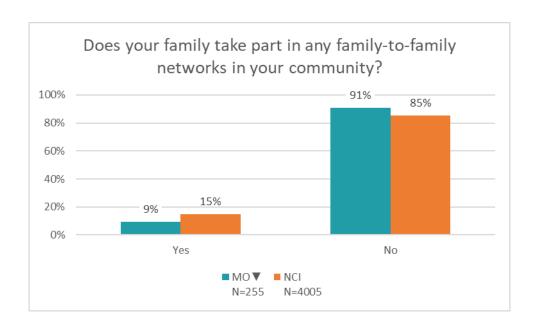
The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.











# 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     |
|-------------|-----|-----|-------|
| MO          | 88% | 12% | 302   |
| 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  | МО  | NCI |
|------------------------|-----|-----|
| Lack of transportation | 18% | 17% |
| Cost                   | 15% | 16% |
| Lack of support staff  | 22% | 15% |
| Stigma                 | 10% | 10% |
| Other                  | 33% | 26% |

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

| State v NCI | Yes | No  | N     |
|-------------|-----|-----|-------|
| MO          | 64% | 36% | 288   |
| 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     |
|-------------|-----|-----|-------|
| MO          | 82% | 18% | 216   |
| NCI         | 79% | 21% | 3,501 |

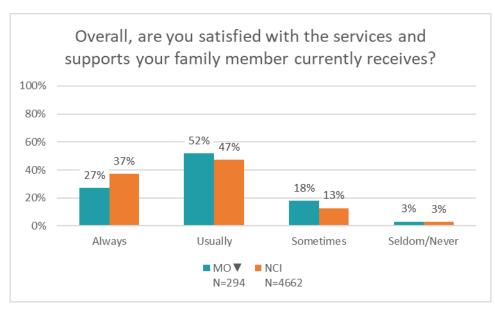
Table Q46. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?

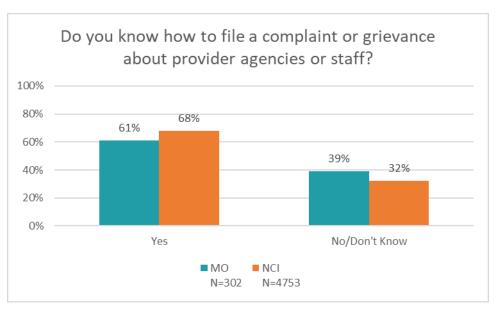
| State v NCI | Yes | No  | N     |
|-------------|-----|-----|-------|
| MO▼         | 9%  | 91% | 255   |
| NCI         | 15% | 85% | 4,005 |

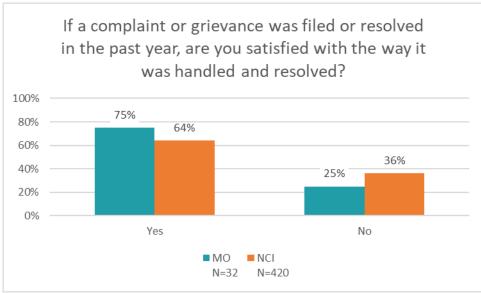
## Satisfaction With Services and Supports Charts

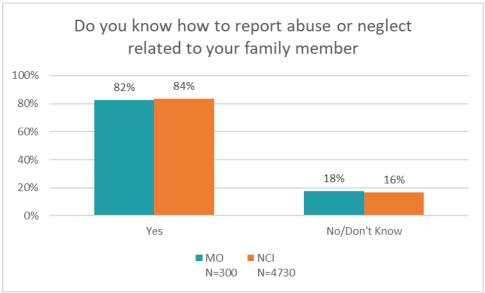
Families and family members with disabilities receive adequate and satisfactory supports.

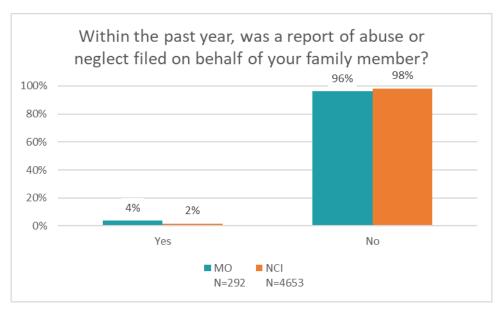
The following pages contain charts depicting the results. The same data are repeated in the accessible tables that follow.

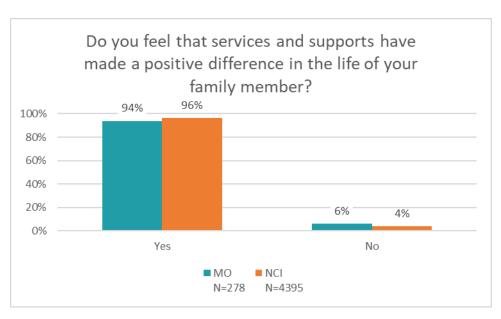


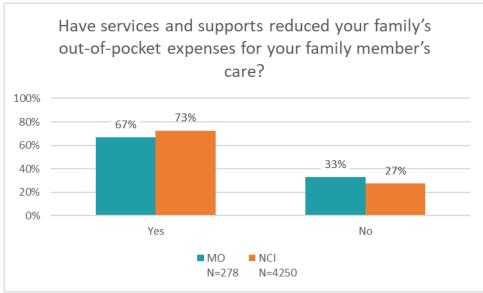


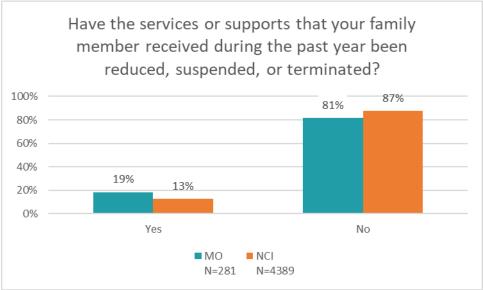


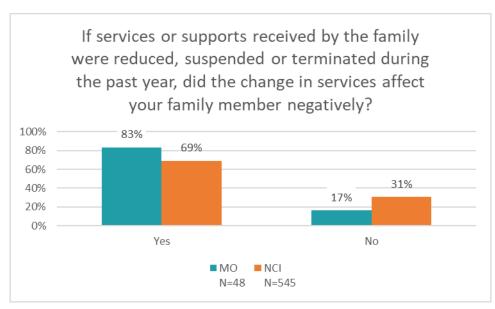


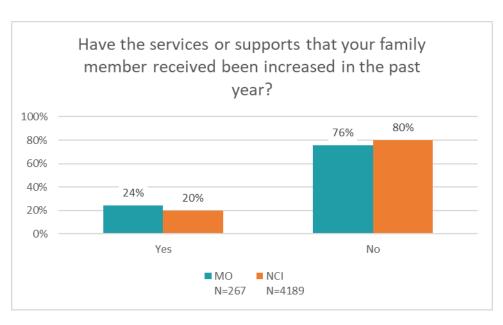


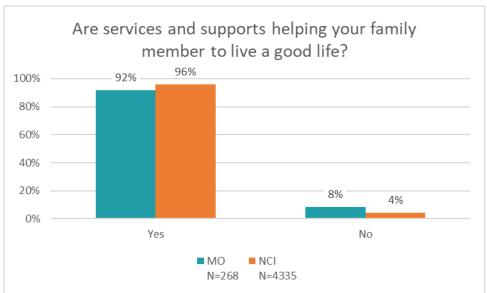












# Satisfaction With Services and Supports Tables

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     |
|-------------|--------|---------|-----------|--------------|-------|
| MO▼         | 27%    | 52%     | 18%       | 3%           | 294   |
| NCI         | 37%    | 47%     | 13%       | 3%           | 4,662 |

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

| State v NCI | Yes | No  | N     |
|-------------|-----|-----|-------|
| MO          | 61% | 39% | 302   |
| 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   |
|-------------|-----|-----|-----|
| MO          | 75% | 25% | 32  |
| 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     |
|-------------|-----|-----|-------|
| MO          | 82% | 18% | 300   |
| 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     |
|-------------|-----|-----|-------|
| MO          | 4%  | 96% | 292   |
| NCI         | 2%  | 98% | 4,653 |

<sup>&</sup>lt;sup>7</sup> Don't Know' responses were included in 'No' responses for this question.

<sup>&</sup>lt;sup>8</sup> 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     |
|-------------|-----|----|-------|
| MO          | 94% | 6% | 278   |
| 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     |
|-------------|-----|-----|-------|
| MO          | 67% | 33% | 278   |
| 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     |
|-------------|-----|-----|-------|
| MO          | 19% | 81% | 281   |
| 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   |
|-------------|-----|-----|-----|
| MO          | 83% | 17% | 48  |
| 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     |
|-------------|-----|-----|-------|
| MO          | 24% | 76% | 267   |
| 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     |
|-------------|-----|----|-------|
| MO          | 92% | 8% | 268   |
| NCI         | 96% | 4% | 4,335 |