



# 2016-17 ADULT FAMILY SURVEY

CALIFORNIA REPORT



# Contents

What is NCI? .....	1
What is the NCI Adult Family Survey? .....	1
Table A1. NCI Family Survey – Sub-Domains and Concern Statements.....	2
How were people selected to participate?.....	3
Data Analysis.....	3
Weighting.....	4
Significance testing .....	4
Limitations of the data .....	5
What is contained in this report?.....	5
Family Member .....	6
Table 1. More than one person living at home has IDD.....	7
Table 2. Family member’s age .....	7
Table 3. Family member’s gender.....	7
Table 4. Family member’s race and ethnicity .....	7
Table 5a. Family member’s disabilities * .....	8
Table 5b. Family member’s disabilities (continued) * .....	8
Table 6a. Family member’s health conditions * .....	8
Table 6b. Family member’s health conditions (continued) * .....	8
Table 7. Family member’s preferred means of communication .....	9

Table 8. Family member’s level of guardianship.....	9
Table 9. Guardian or conservator relationship to family member .....	9
Table 10. Family member’s highest level of education .....	10
Table 11. Family member’s typical day activity.....	10
Table 12. Family member’s support needs .....	11
Respondents.....	12
Table 13. Respondent’s age.....	13
Table 14. Respondent's health .....	13
Table 15. Respondent’s relationship to family member .....	13
Table 16. Respondent (or other family member) provides paid support .....	13
Table 17. Number of adults in household .....	14
Table 18. Number of children in household .....	14
Table 19. Respondent's highest level of education .....	14
Table 20. Past year total household taxable income of wage earners .....	14
Table 21. Family’s residential setting .....	15
Services and Supports Received .....	16
Table 22. Services and supports received from state * .....	17
Table 23. Services and supports received (not from IDD agency) * .....	17
Information and Planning.....	18
Charts for Information and Planning .....	19

Chart 1. Do you get enough information to take part in planning services for your family member? .....	20
Chart 2. Is the information you get about services and supports easy to understand?.....	20
Chart 3. Does the case manager/service coordinator respect your family’s choices and opinions? .....	20
Chart 4. Do you have enough information about other public services for which your family is eligible?.....	20
Chart 5. Respondent needs help with future planning.....	21
Chart 6. If you asked for crisis or emergency services during the past year, were services provided when needed?.....	21
Chart 7. Does your family member have a service plan? .....	21
Chart 8. Does it include all the services and supports your family member needs?.....	21
Chart 9. Does your family member get all the services listed in the plan? .....	22
Chart 10. Did you or another family member (besides your family member with a disability) help make the plan? .....	22
Chart 11. Did your family member help make the plan? .....	22
Chart 12. Did you discuss how to handle emergencies at your family member’s last service planning meeting?.....	22
Chart 13. If your family member transitioned out of school services during the past year, did s/he have a transition plan? .....	23
Chart 14. If your family member had a transition plan, did the plan include getting or continuing work in a community job? .....	23
Chart 15. Does your family member have enough supports to work or volunteer in the community? .....	23
Chart 16. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster? .....	23
Tables for Information and Planning .....	24
Table 24. Information and Planning—Always Responses.....	25
Table 25. Respondent Needs Help With Future Planning Needs .....	26
Table 26. Information and Planning—Yes Responses.....	27

Access and Delivery of Services and Supports .....	28
Charts for Access and Delivery of Services and Supports .....	29
Chart 17. Are you or your family member able to contact his/her support workers when you want to? .....	30
Chart 18. Are you or your family member able to contact his/her case manager/service coordinator when you want to?.....	30
Chart 19. Do support workers come and leave when they are supposed to? .....	30
Chart 20. Do services and supports change when your family's needs change? .....	30
Chart 21. Do support workers speak to you in a way that you understand?.....	31
Chart 22. Are services delivered in a way that is respectful of your family's culture? .....	31
Chart 23. If your family member does not communicate verbally, are there support workers who can communicate with him/her? .....	31
Chart 24. Do support workers have the right information and skills to meet your family's needs?.....	31
Chart 25. Does your family member have the special equipment or accommodations that s/he needs?.....	32
Chart 26. Can your family member see health professionals when needed? .....	32
Chart 27. Does your family member's primary care doctor understand his/her needs related to his/her disability? .....	32
Chart 28. Do you have access to dental services for your family member? .....	32
Chart 29. If you have access to dental services for your family member, does your family member's dentist understand his/her needs related to his/her disability?.....	33
Chart 30. If your family member takes medications, do you know what they're for?.....	33
Chart 31. If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications?.....	33
Chart 32. If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability? .....	33

Chart 33. If you need respite services, do you have access to them?.....	34
Chart 34. If you have access to respite services, are you satisfied with the quality of the respite services? .....	34
Chart 35. Does your family get the supports and services needed?.....	34
Chart 36. *Additional services needed .....	34
Tables for Access and Delivery of Services and Supports.....	35
Table 27. Access and Delivery of Services and Supports—Always Responses.....	36
Table 28. Access and Delivery of Services and Supports—Always Responses (continued) .....	37
Table 29. Access and Delivery of Services and Supports—Yes Responses.....	38
Table 30. Additional Services Needed * .....	38
Choice, Decision Making and Control.....	39
Charts for Choice, Decision Making and Control .....	40
Chart 37. Can your family choose or change the agency that provides your family member’s services? .....	41
Chart 38. Can your family choose or change your family member’s support workers? .....	41
Chart 39. Does your family directly manage support workers? .....	41
Chart 40. Do service providers for your family member work together to provide support? .....	41
Chart 41. Chose case manager/service coordinator .....	42
Tables for Choice, Decision Making and Control .....	43
Table 31. Choice and Control—Always Responses .....	44
Table 32. Choice and Control—Yes Responses .....	44
Table 33. Family member, or someone else in your family chose case manager/service coordinator .....	45

Involvement in the Community .....	46
Charts for Involvement in the Community .....	47
Chart 42. Does your family member take part in activities in the community? .....	48
Chart 43. *Obstacles/Barriers to family member’s participation in community activities .....	48
Chart 44. Does your family member have friends other than paid support workers or family? .....	48
Chart 45. In your community, are there resources that your family can use that are not provided by the IDD agency? .....	48
Chart 46. Does your family take part in family-to-family networks in your community? .....	49
Tables for Involvement in the Community .....	50
Table 34. Involvement in the Community .....	51
Table 35. Obstacles to Family Member's Participation in Community Activities * .....	51
Table 36. Involvement in the Community—Yes Responses .....	52
Satisfaction With Services and Supports .....	53
Charts for Satisfaction With Services and Supports .....	54
Chart 47. Overall, are you satisfied with the services and supports your family currently receives? .....	55
Chart 48. *Do you know how to file a complaint or grievance about provider agencies or staff? .....	55
Chart 49. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved? .....	55
Chart 50. *Do you know how to report abuse or neglect related to your family member? .....	55
Chart 51. In the past year, was a report of abuse or neglect filed on behalf of your family member? .....	56
Chart 52. Do you feel that services and supports have made a positive difference in the life of your family? .....	56
Chart 53. Have services and supports reduced your family’s out-of-pocket expenses for your family member’s care? .....	56

Chart 54. Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?.....	56
Chart 55. If services were reduced in the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively? .....	57
Chart 56. Have the services or supports that your family member received been increased in the past year?.....	57
Chart 57. Are services and supports helping your family member to live a good life?.....	57
Tables for Satisfaction With Services and Supports .....	58
Table 37. Satisfaction—Always Responses.....	59
Table 38. Satisfaction—Yes Responses.....	59
Table 39. Satisfaction—Yes Responses (continued) .....	60



## What is NCI?

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

NCI has developed more than 100 standard performance measures (or ‘indicators’) that states use to assess the outcomes of services for individuals and families, including outcomes in the areas of employment, rights, service planning, community inclusion, choice, health, and safety. In 2016-17 a total of 45 states, the District of Columbia and 22 sub-state entities participated in NCI.

## What is the NCI Adult Family Survey?

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

In 2016-17, a total of 11,419 Adult Family Surveys were completed across 16 states.<sup>1</sup> The survey contained six groupings of questions (“sub-domains”) that probe specific areas of quality service provision: information and planning, access and delivery of services, choice and control, community connections, satisfaction, and outcomes (see Table A1 on the following page). Respondents also had the option of writing open-ended comments concerning their family’s participation in the service system.

---

<sup>1</sup> States that conducted the Adult Family Survey in 2016-17 were: CA, DC, DE, FL, GA, KY, LA, MD, MN, MO, MS, NC, NJ, OK, PA, and UT.

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

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

## How were people selected to participate?

States were asked to administer the survey to a random sample of at least 1,200 families, all of whom have an adult family member with a developmental disability who lives in the family home and receives at least one direct service or support other than service coordination.

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

All states mailed out a paper survey to families selected in their sample. A sample size of 1,200 was recommended with the expectation of a 40% return rate or greater (yielding 400 or more usable responses per state). However, most states decided to sample more than 1,000 families, expecting a lower response rate than 40%. A final sample size of 400 would guarantee a +/- 5% margin of error and a 95% confidence level when interpreting the results. Both the confidence level and margin of error used are widely accepted standards for reviewing results, regardless of population size. States with fewer than 1,000 potential respondent families were instructed to send surveys to all eligible families. With response rates lower than expected, we included in our national reports those states that submitted fewer than 400 surveys up to a margin of error of no greater than +/- 7%.

## Data Analysis

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

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

Questions left blank or marked ‘not applicable’ are not included in analysis. For most questions, ‘don’t know’ responses were excluded from analysis. Two questions in the Satisfaction section combine ‘no’ and ‘don’t know’ responses, those questions are denoted with an asterisk in

---

<sup>2</sup> States that used the direct entry or mail and direct entry options were: DE, KY, LA, MO, MS, NC, and NJ. For more information on response rates and mode, please see the Methodology section within the national edition of the 2016-17 Adult Family Survey Report.

the table. For all items shown, states receive an ‘n/a’ designation in table presentations for a survey item if fewer than 20 people responded; however, their data are included in the NCI Average.

## Weighting

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

## Significance testing

Starting this survey cycle (2016-17), statistical significance is shown in this report. The state’s percentage was compared to the weighted NCI average (described above), and the differences between the two were tested for both **statistical significance** as well as **effect sizes**. Effect sizes are used in addition to statistical significance because statistical significance of a state’s result depends, in part, on the size of the state’s sample: the larger the sample, the more likely it is that even a small difference will be found *statistically* significant.

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

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

---

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

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

## Limitations of the data

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

## What is contained in this report?

This report illustrates the 2016-17 NCI Adult Family Survey demographic and outcome results from California (CA) compared to the NCI Average. All results are shown first in charts and then in table form, and arrow symbols (▲ and ▼) are used to indicate areas where the state average was statistically higher or lower than the NCI Average. **Please note: items without the ▲ or ▼ arrow symbols indicate that the state was within the NCI Average range.** For most items, the total number of respondents (N) from the state and across NCI states is displayed in charts and tables. States with fewer than 20 responses to a question were excluded from analysis for that question. All state and national data results for this survey can be found online at <http://www.nationalcoreindicators.org/resources/reports/>.

---

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

## Family Member

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

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

		Yes	No	N
More Than One Person Living in the Home Has IDD	CA	16%	84%	4,737
	NCI	14%	86%	11,046

Table 2. Family member's age

		Mean	N
Family Member's Age	CA	32.9	4,830
	NCI	33.8	11,245

Table 3. Family member's gender

		Male	Female	N
Family Member's Gender	CA	60%	40%	4,818
	NCI	58%	41%	11,220

Table 4. Family member's race and ethnicity

		American Indian or Alaska Native	Asian	Black or African-American	Hawaiian or Pacific Islander	White	Other or Unknown	Hispanic or Latino
Family Member's Race and Ethnicity	CA	3%	14%	9%	1%	45%	2%	37%
	NCI	2%	8%	14%	0%	61%	2%	20%

Table 5a. Family member's disabilities \*

		Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss	Brain Injury
Family Member's Disabilities	CA	61%	21%	33%	18%	9%	6%	10%
	NCI	65%	22%	31%	20%	10%	7%	10%

Table 5b. Family member's disabilities (continued) \*

		Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
Family Member's Disabilities	CA	24%	2%	15%	0%	1%	16%
	NCI	28%	1%	16%	0%	1%	19%

Table 6a. Family member's health conditions \*

		Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
Family Member's Health Conditions	CA	9%	17%	4%	27%	29%
	NCI	10%	16%	4%	26%	28%

Table 6b. Family member's health conditions (continued) \*

		Dysphagia	Pressure Ulcers	Alzheimer's Disease or Other Dementia	Oral Health or Dental Problems	Sleep Apnea	Other
Family Member's Health Conditions	CA	7%	2%	3%	16%	16%	34%
	NCI	9%	2%	3%	15%	16%	37%

\*Categories are not mutually exclusive; therefore N is not shown



Table 7. Family member's preferred means of communication

		Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
Family Member's Preferred Means of Communication	CA	81%	12%	2%	1%	4%	4,728
	NCI	77%	14%	2%	1%	5%	11,053

Table 8. Family member's level of guardianship

		None	Limited	Full	Has Guardianship but Level Is Unknown	Don't know	N
Level of Guardianship or Conservatorship of Family Member	CA	44%	50%	0%	0%	6%	4,647
	NCI	36%	29%	28%	2%	5%	10,940

Table 9. Guardian or conservator relationship to family member

		Family	Friend	State Employee or Guardianship Agency	Other	N
Guardian or Conservator Relationship to Family Member	CA	97%	1%	1%	2%	2,153
	NCI	96%	1%	1%	3%	5,848

Table 10. Family member's highest level of education

		Did Not Complete High School (and Not Currently Enrolled)	Currently Enrolled in High School	High School Certification	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
Family Member's Highest Level of Education	CA	20%	4%	34%	24%	5%	9%	5%	4,478
	NCI	18%	3%	35%	28%	4%	6%	5%	10,650

Table 11. Family member's typical day activity

		Usually/Often	Sometimes	Never	N
Paid Individual Job in the Community	CA	13%	5%	82%	3,666
	NCI	14%	4%	82%	8,811
Paid Small Group Job in a Community-based Setting	CA	15%	6%	79%	3,597
	NCI	12%	4%	84%	8,504
Unpaid Activity in the Community	CA	22%	13%	66%	3,616
	NCI	22%	14%	65%	8,562
Paid Activity in a Facility-based Setting	CA	17%	5%	79%	3,576
	NCI	19%	4%	77%	8,655
Unpaid Activity in a Facility-based Setting	CA	22%	6%	72%	3,459
	NCI	27%	5%	68%	8,380
School	CA	30%	5%	65%	2,917
	NCI	22%	4%	75%	7,017
Stays at Home	CA	50%	19%	31%	2,748
	NCI	51%	21%	28%	6,963
Other	CA	65%	8%	27%	842
	NCI	63%	9%	27%	1,946

Table 12. Family member's support needs

		Extensive	Some	None	N
Family Member's Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	CA	21%	30%	49%	4,590
	NCI	19%	31%	50%	10,819
Family Member's Need for Help With Personal Care Activities	CA	36%	36%	29%	4,773
	NCI	39%	35%	25%	11,187
Family Member's Need for Help With Other Daily Activities	CA	65%	28%	7%	4,736
	NCI	72%	23%	5%	11,123

## Respondents

*This section provides demographic information about the respondent.*

Table 13. Respondent's age

		Under 35	35-54	55-74	75+	N
Respondent's Age	CA	5%	28%	57%	11%	4,837
	NCI	4%	25%	60%	11%	11,264

Table 14. Respondent's health

		Excellent	Very good	Fairly good	Poor	N
Respondent's Health	CA	15%	39%	41%	5%	4,819
	NCI	14%	41%	40%	5%	11,238

Table 15. Respondent's relationship to family member

		Parent	Sibling	Spouse	Grandparent	Other	N
Respondent's Relationship to Family Member	CA	87%	8%	0%	2%	3%	4,837
	NCI	86%	8%	0%	2%	3%	11,266

Table 16. Respondent (or other family member) provides paid support

		Respondent or Other Family Member Provides Paid Support to Family Member
No Family Member Provides Paid Support	CA	58%
	NCI	66%
Respondent Provides Paid Support	CA	32%
	NCI	24%
Other Family Member Provides Paid Support	CA	11%
	NCI	12%
N	CA	4,732
	NCI	11,116

Table 17. Number of adults in household

		One	Two	Three	Four or More	N
Number of Adults in Household (Not Including Family Member Receiving Services)	CA	10%	28%	39%	22%	4,730
	NCI	9%	30%	42%	19%	11,069

Table 18. Number of children in household

		One	Two	Three	Four or More	None	N
Number of Children in Household	CA	12%	5%	2%	1%	80%	4,733
	NCI	10%	4%	1%	1%	84%	11,078

Table 19. Respondent's highest level of education

		No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
Respondent's Highest Level of Education	CA	20%	19%	6%	23%	32%	4,704
	NCI	14%	23%	6%	23%	35%	11,083

Table 20. Past year total household taxable income of wage earners

		Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	No Earned Income	Prefer Not to Say	N
Total Taxable Income of Wage Earners in the Household in Past Year	CA	11%	12%	19%	11%	15%	11%	21%	4,484
	NCI	10%	11%	19%	12%	16%	12%	20%	10,610

Table 21. Family's residential setting

		Urban or suburban (in or near a city or large town)	Rural (outside of a city or town)	Don't know	N
Residential Setting	CA	81%	13%	6%	4,687
	NCI	72%	24%	5%	11,041

## Services and Supports Received

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



Table 22. Services and supports received from state \*

		Services and Supports Received From State
Financial Support	CA	14%
	NCI	14%
In-home Support	CA	32%
	NCI	39%
Out-of-home Respite	CA	21%
	NCI	25%
Day or Employment Supports	CA	54%
	NCI	54%
Transportation	CA	49%
	NCI	55%
Other	CA	15%
	NCI	19%
Self-direction or Fiscal Intermediary Services	CA	11%
	NCI	23%

Table 23. Services and supports received (not from IDD agency) \*

		Additional Services and Supports Received (Not From the IDD Agency)
Social Security Payments (SSI/SSB)	CA	86%
	NCI	91%
Services or Supports From Other Agencies or Organizations	CA	24%
	NCI	26%

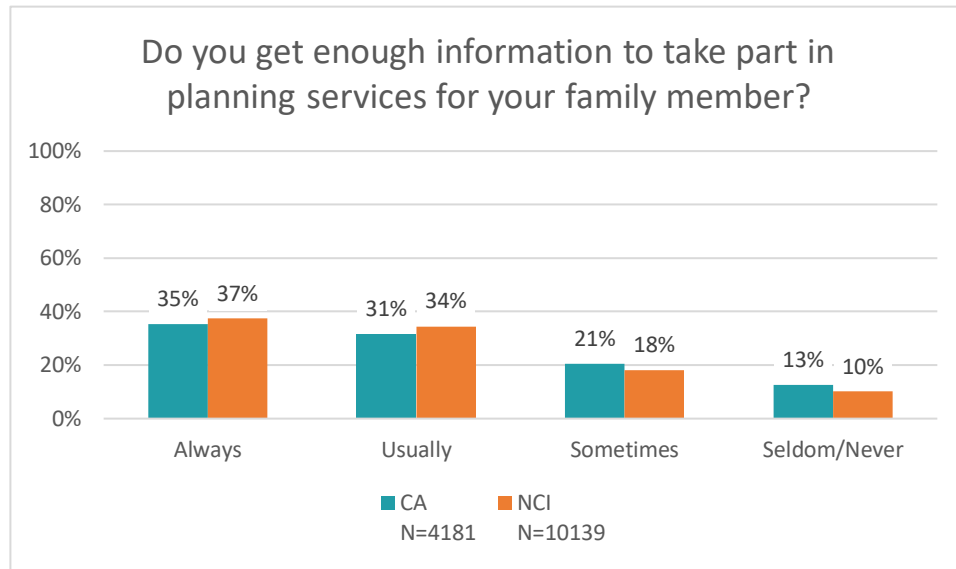
\*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

## Information and Planning

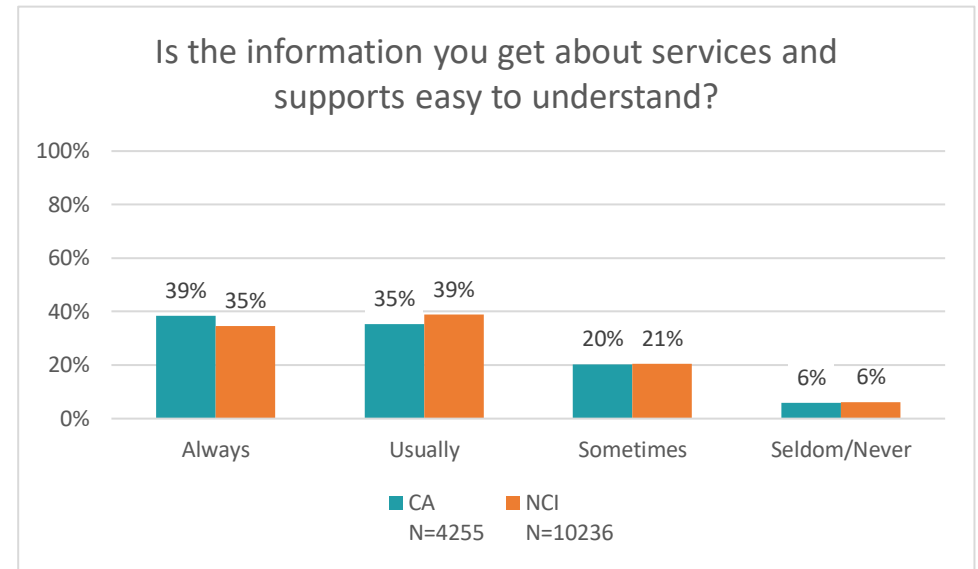
*Families and family members with disabilities have the information and support necessary to plan for their services and supports.*

*Charts for Information and Planning*

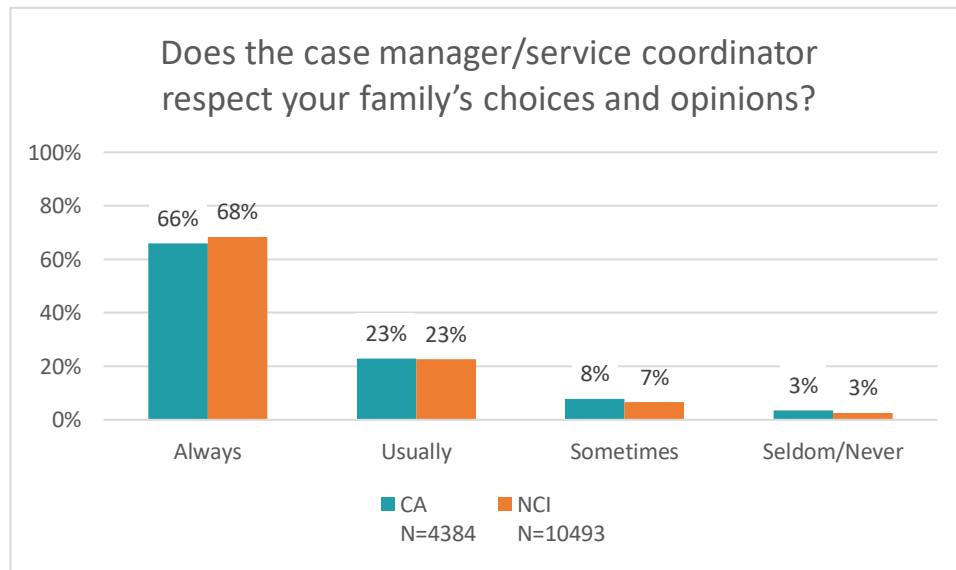
[Chart 1.](#)



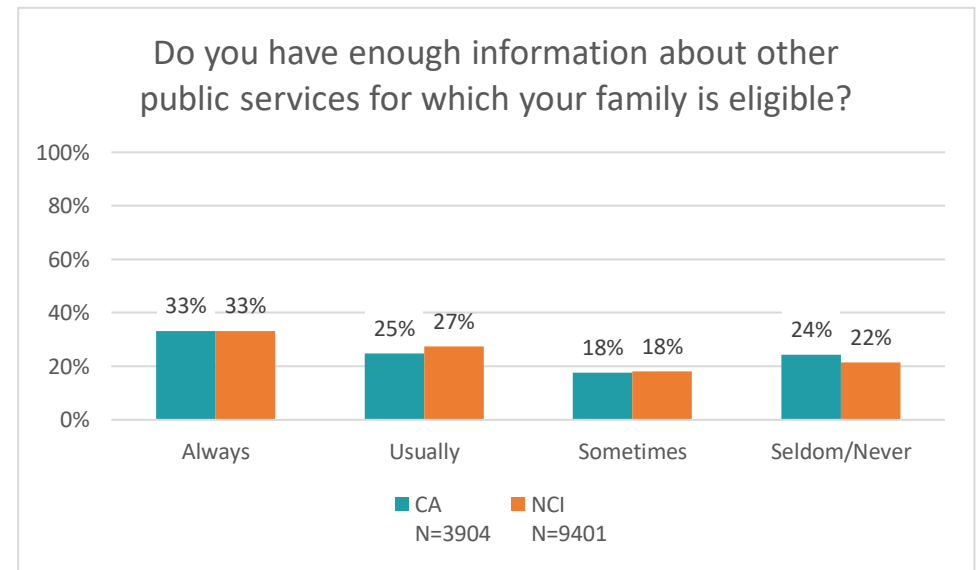
[Chart 2.](#)



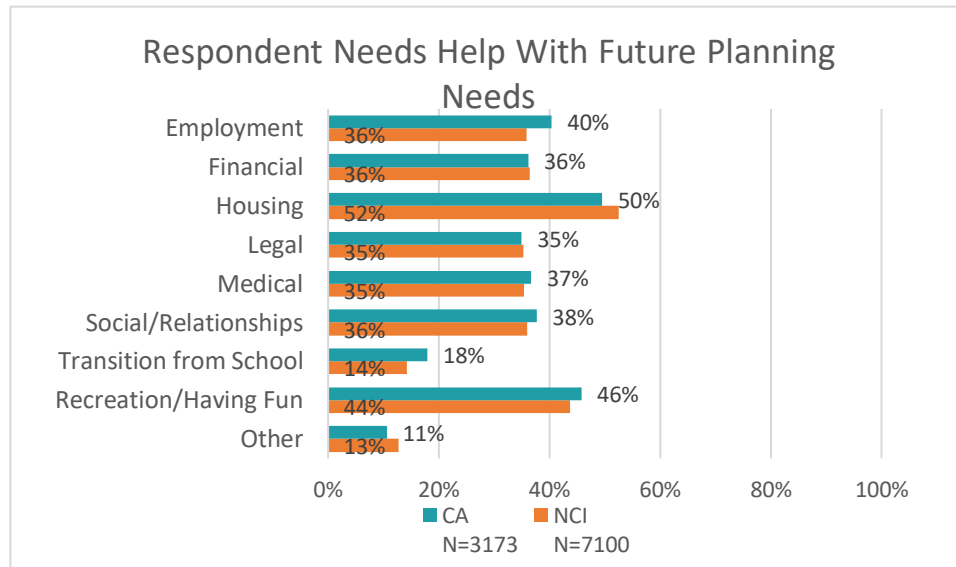
[Chart 3.](#)



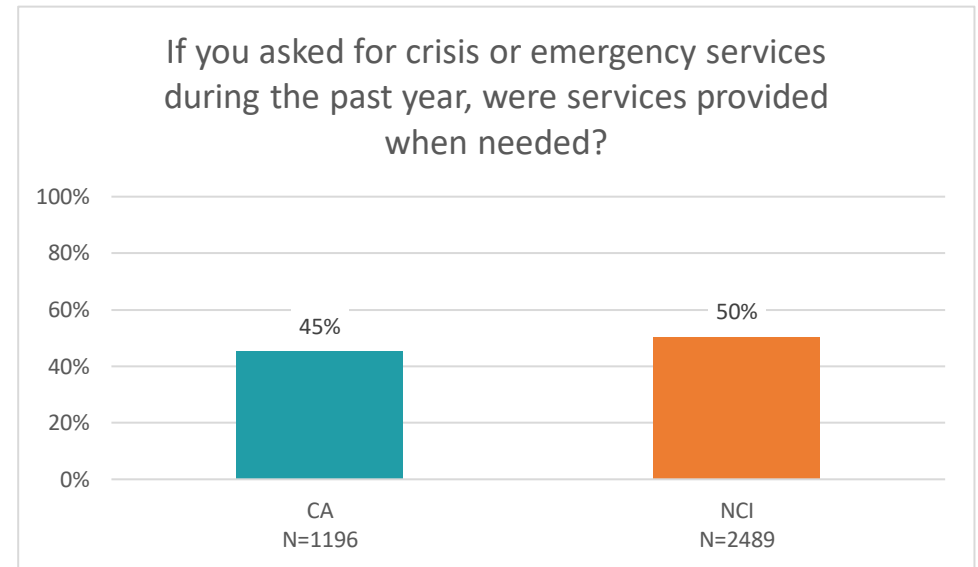
[Chart 4.](#)



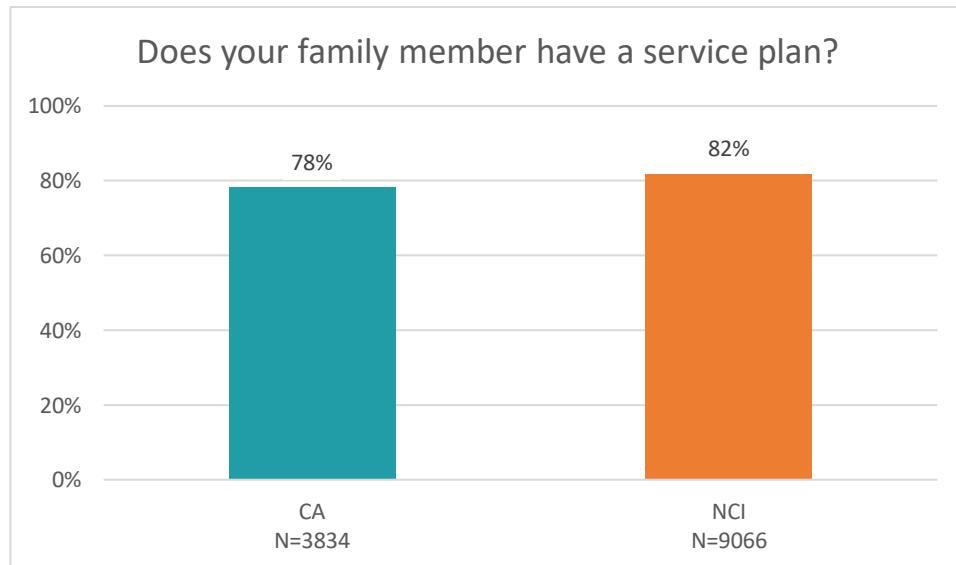
[Chart 5.](#)



[Chart 6.](#)



[Chart 7.](#)



[Chart 8.](#)

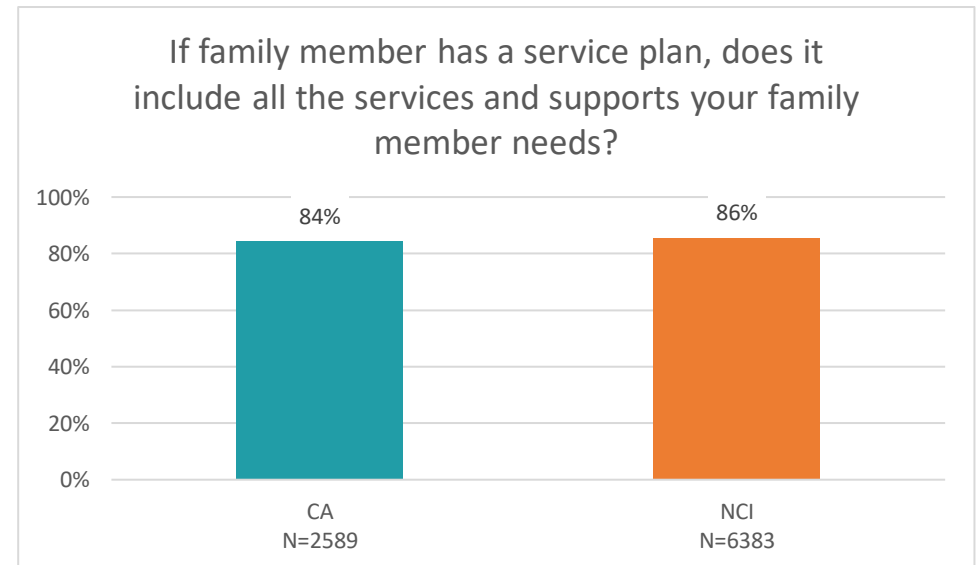


Chart 9.

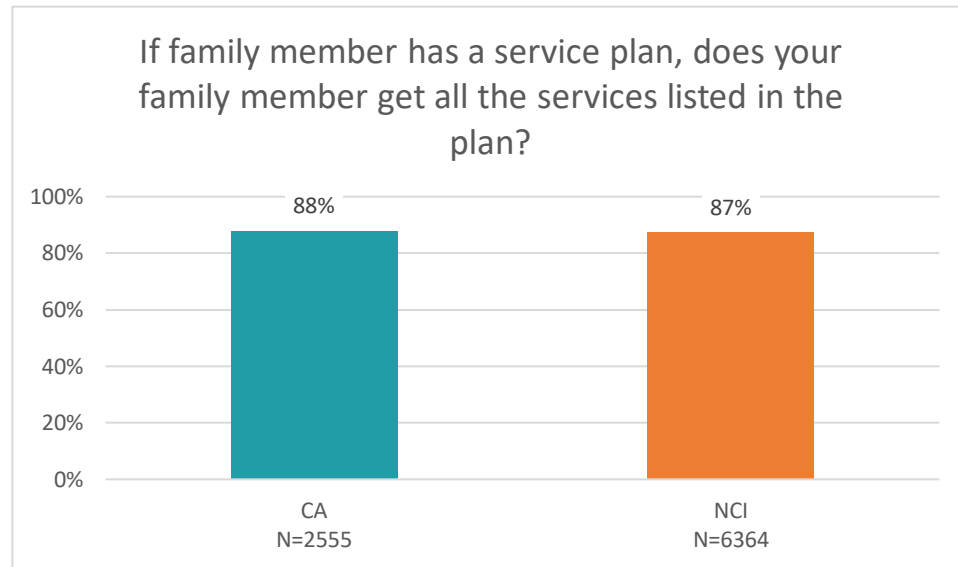


Chart 10.

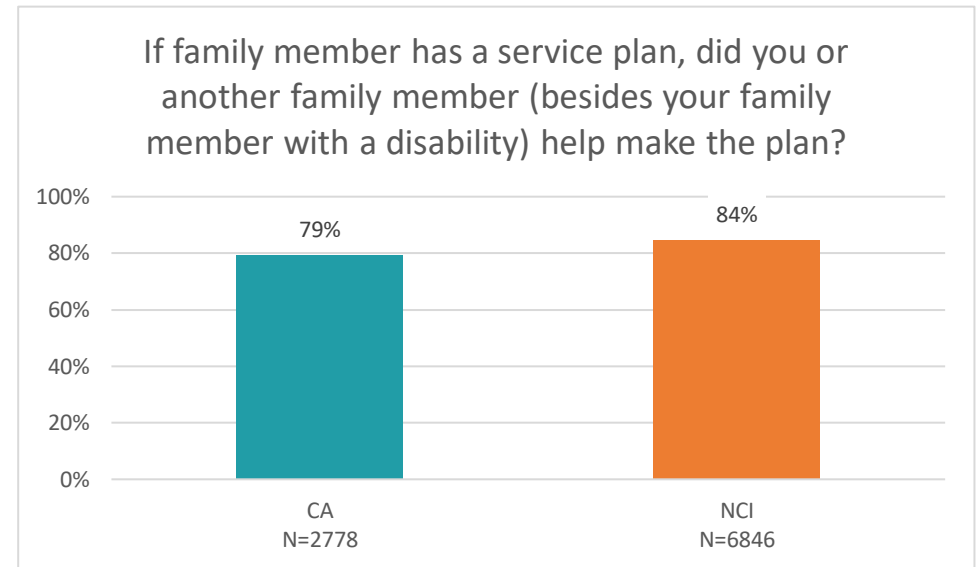


Chart 11.

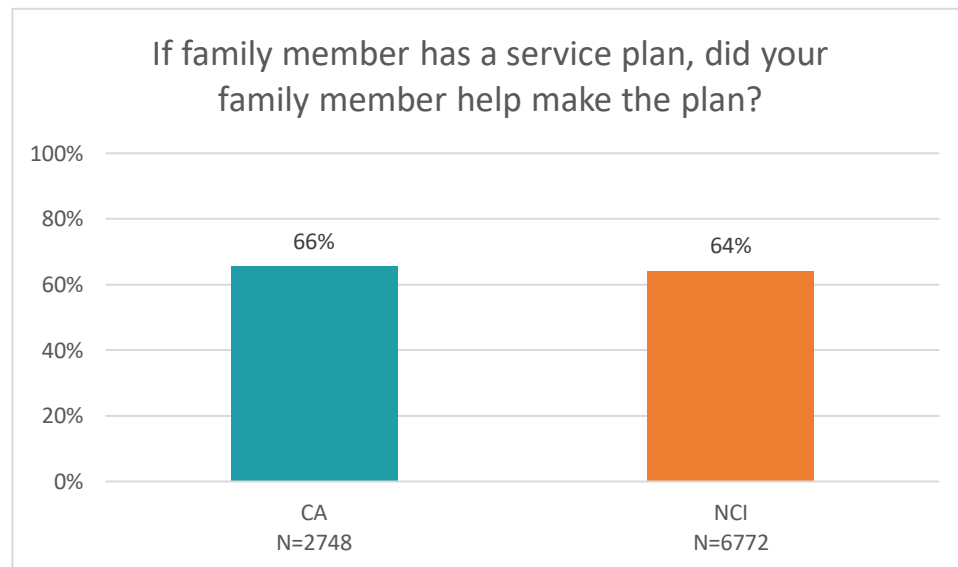
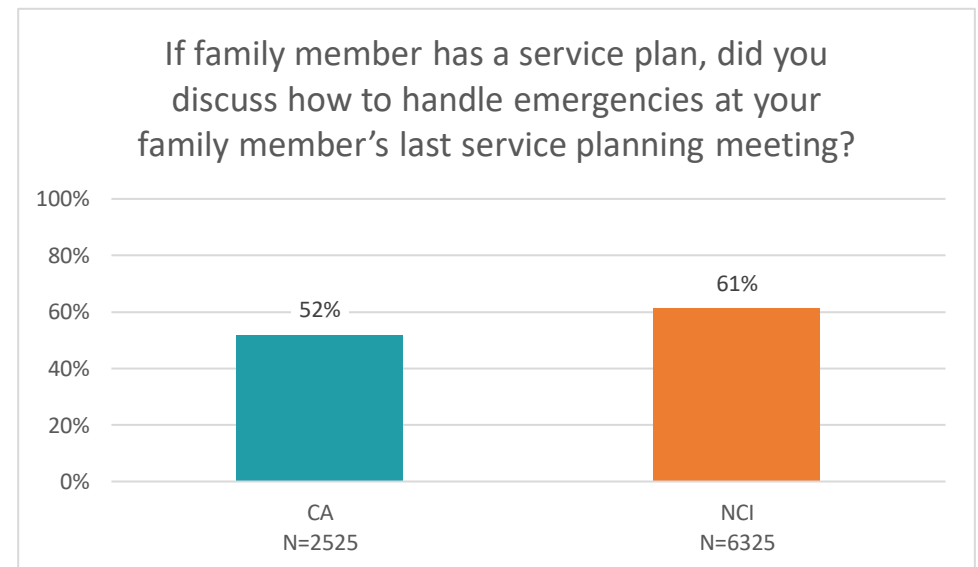
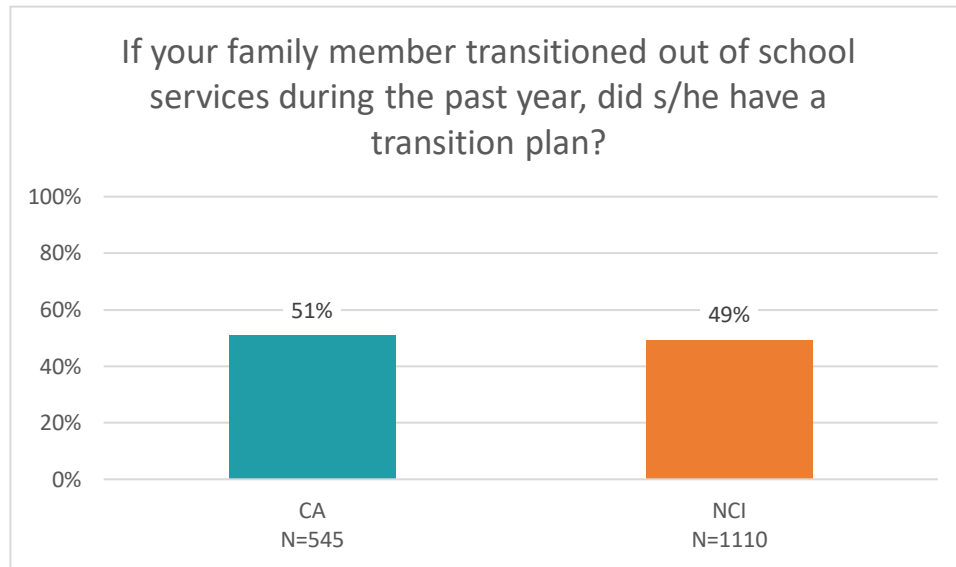


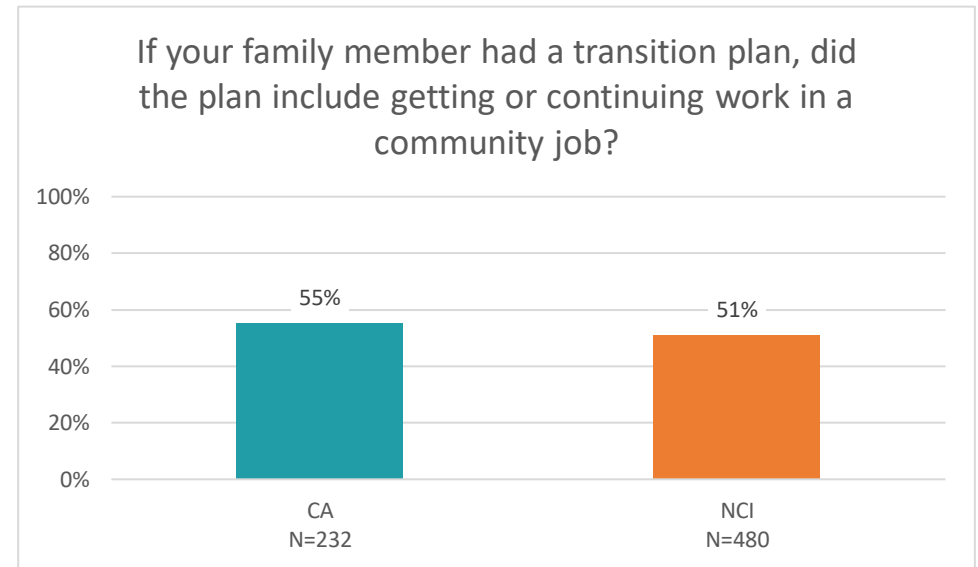
Chart 12.



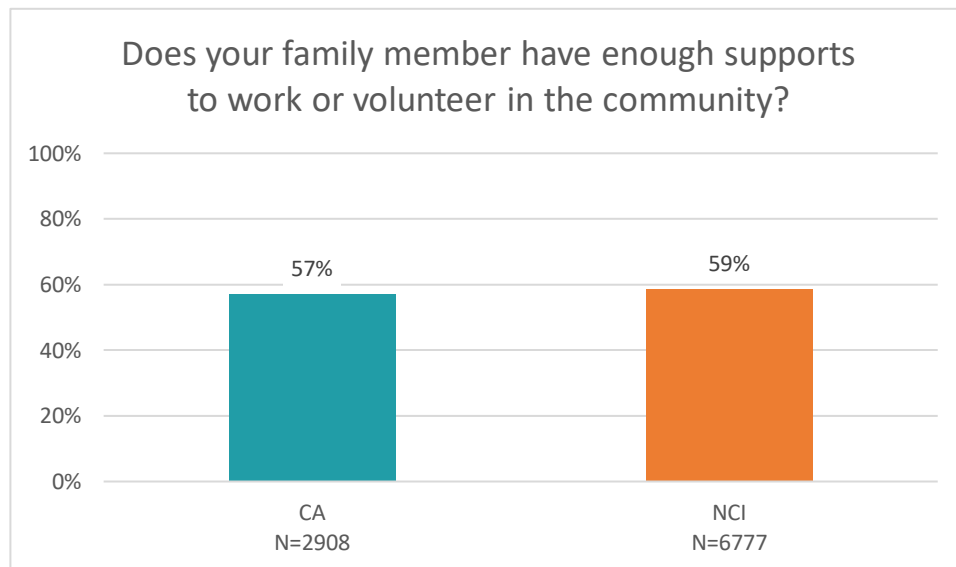
[Chart 13.](#)



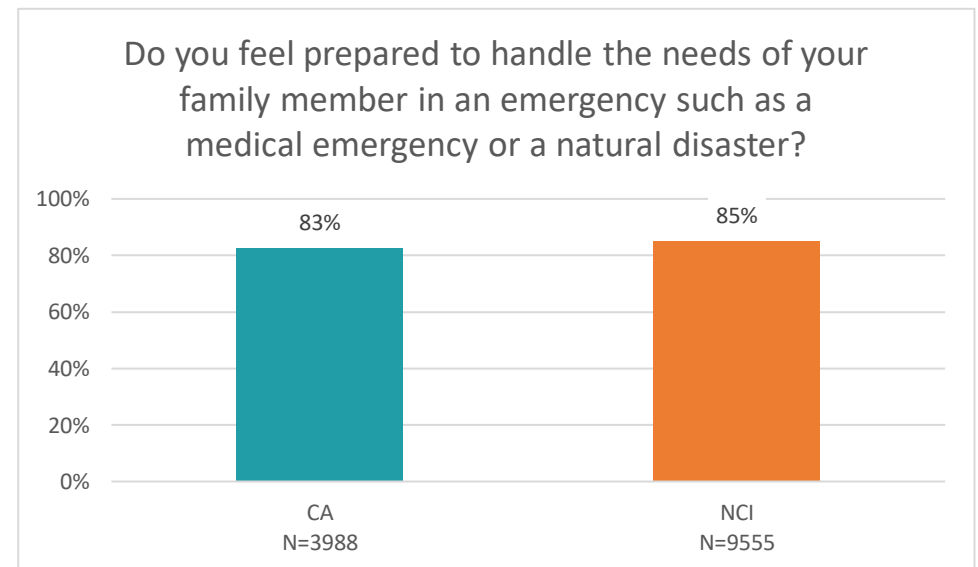
[Chart 14.](#)



[Chart 15.](#)



[Chart 16.](#)



*Tables for Information and Planning*



Table 24. Information and Planning—Always Responses

		Always	Usually	Sometimes	Seldom/Never	N
Do you get enough information to take part in planning services for your family member?	CA	35%	31%	21%	13%	4,181
	NCI	37%	34%	18%	10%	10,139
Is the information you get about services and supports easy to understand?	CA	39%	35%	20%	6%	4,255
	NCI	35%	39%	21%	6%	10,236
Does the case manager/service coordinator respect your family's choices and opinions?	CA	66%	23%	8%	3%	4,384
	NCI	68%	23%	7%	3%	10,493
Do you have enough information about other public services for which your family is eligible?	CA	33%	25%	18%	24%	3,904
	NCI	33%	27%	18%	22%	9,401

Table 25. Respondent Needs Help With Future Planning Needs

		Yes
Employment	CA	40%
	NCI	36%
Financial	CA	36%
	NCI	36%
Housing	CA	50%
	NCI	52%
Legal	CA	35%
	NCI	35%
Medical	CA	37%
	NCI	35%
Social and Relationships	CA	38%
	NCI	36%
Transition from School	CA	18%
	NCI	14%
Recreation, Having Fun	CA	46%
	NCI	44%
Other	CA	11%
	NCI	13%
N	CA	3,173
	NCI	7,100

Table 26. Information and Planning—Yes Responses

		Yes	No	N
If you asked for crisis or emergency services during the past year, were services provided when needed?	CA ▼	45%	55%	1,196
	NCI	50%	50%	2,489
Does your family member have a service plan?	CA	78%	22%	3,834
	NCI	82%	18%	9,066
<b><i>If your family member has a service plan...</i></b>				
Does it include all the services and supports your family member needs?	CA	84%	16%	2,589
	NCI	86%	14%	6,383
Does your family member get all the services listed in the plan?	CA	88%	12%	2,555
	NCI	87%	13%	6,364
Did you or another family member (besides your family member with a disability) help make the plan?	CA ▼	79%	21%	2,778
	NCI	84%	16%	6,846
Did your family member help make the plan?	CA	66%	34%	2,748
	NCI	64%	36%	6,772
Did you discuss how to handle emergencies at your family member's last service planning meeting?	CA ▼	52%	48%	2,525
	NCI	61%	39%	6,325
If your family member transitioned out of school services during the past year, did s/he have a transition plan?	CA	51%	49%	545
	NCI	49%	51%	1,110
If your family member had a transition plan, did the plan include getting or continuing work in a community job?	CA	55%	45%	232
	NCI	51%	49%	480
Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?	CA	57%	43%	2,908
	NCI	59%	41%	6,777
Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?	CA	83%	17%	3,988
	NCI	85%	15%	9,555

## Access and Delivery of Services and Supports

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

*Charts for Access and Delivery of Services and Supports*

Chart 17.

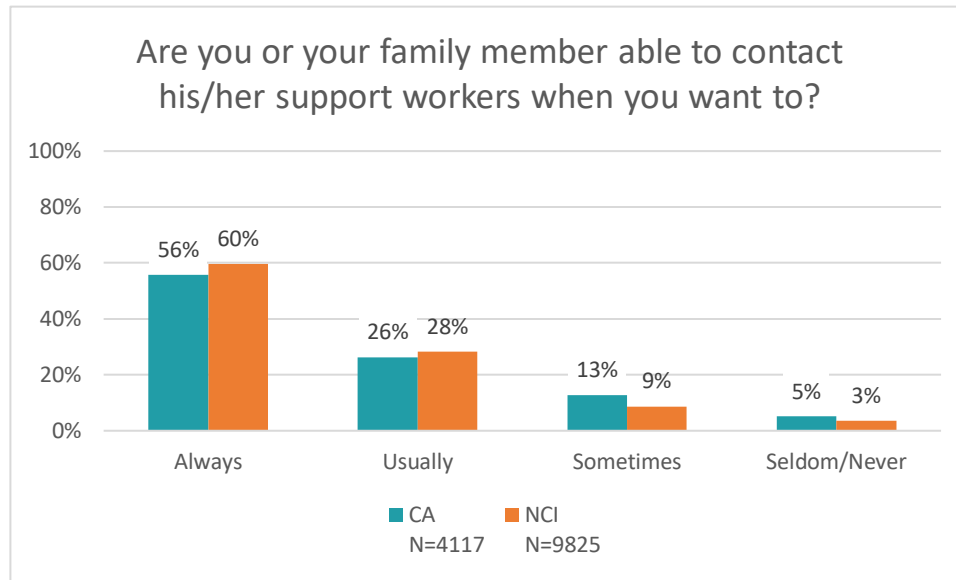


Chart 18.

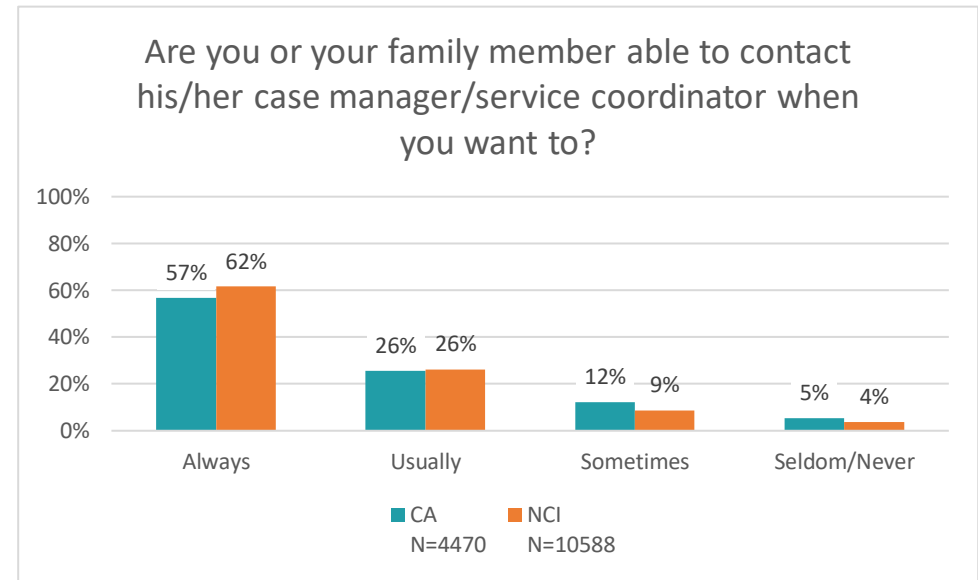


Chart 19.

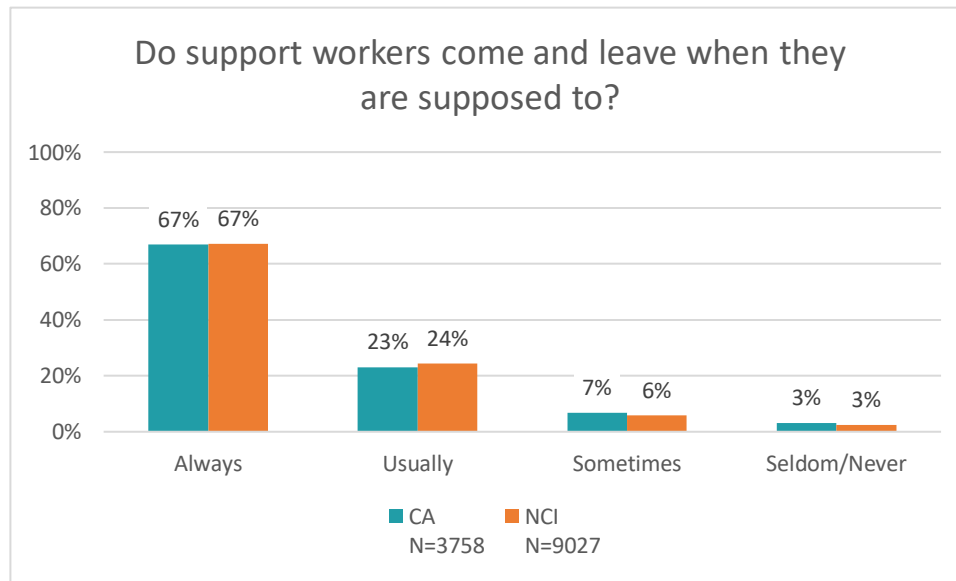


Chart 20.

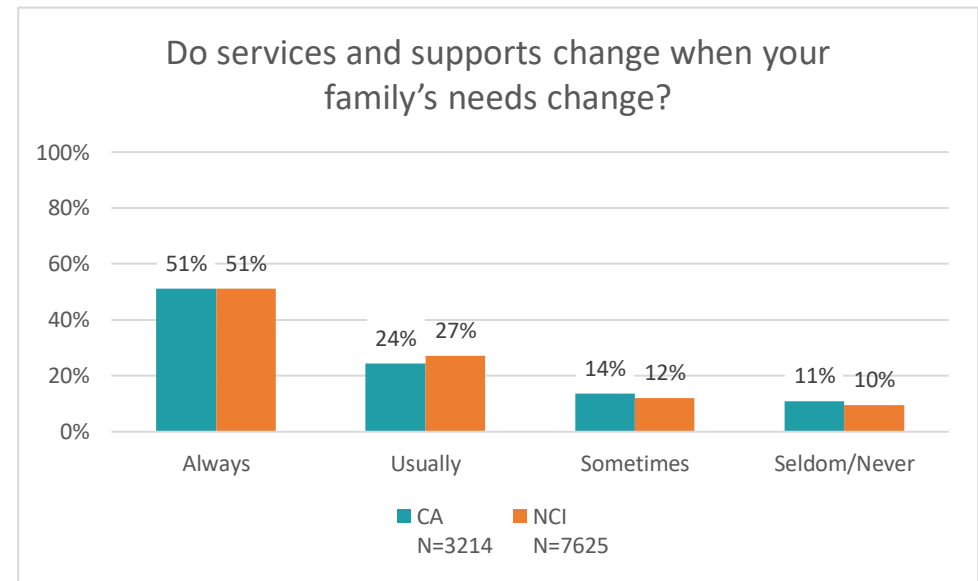


Chart 21.

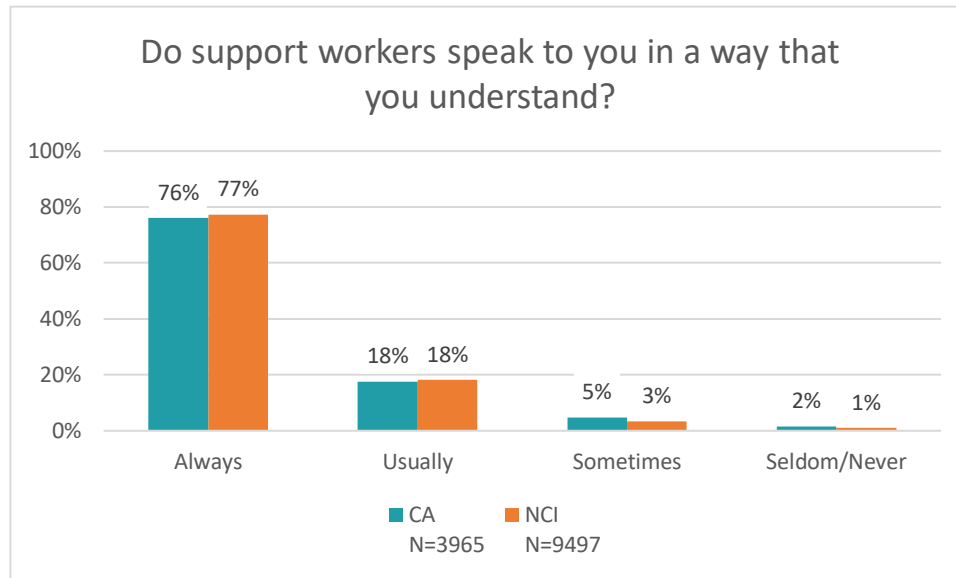


Chart 22.

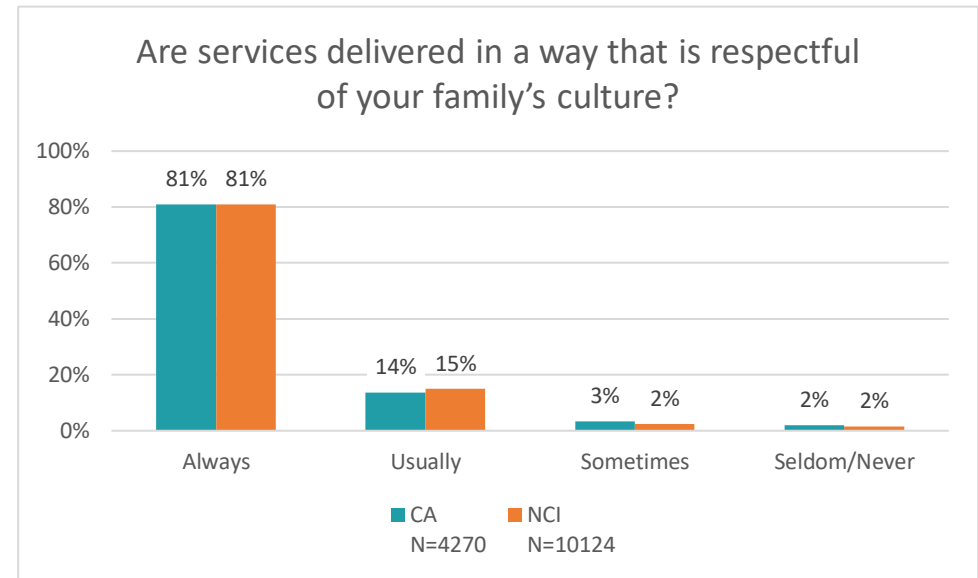


Chart 23.

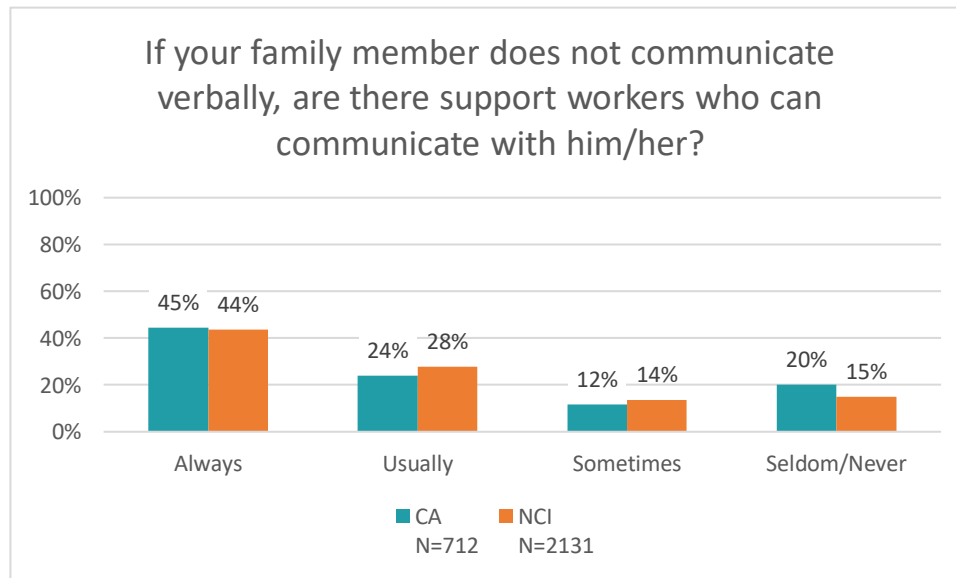


Chart 24.

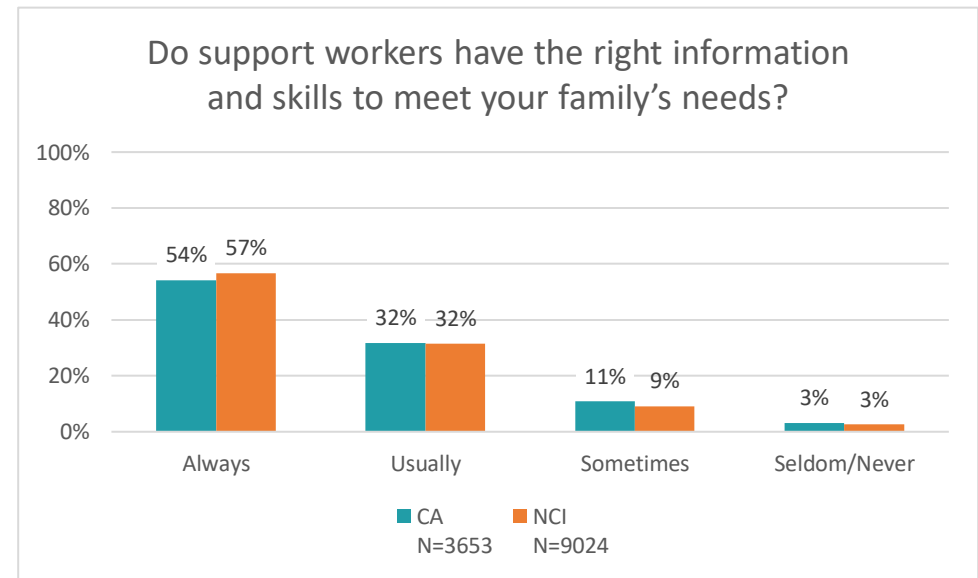


Chart 25.

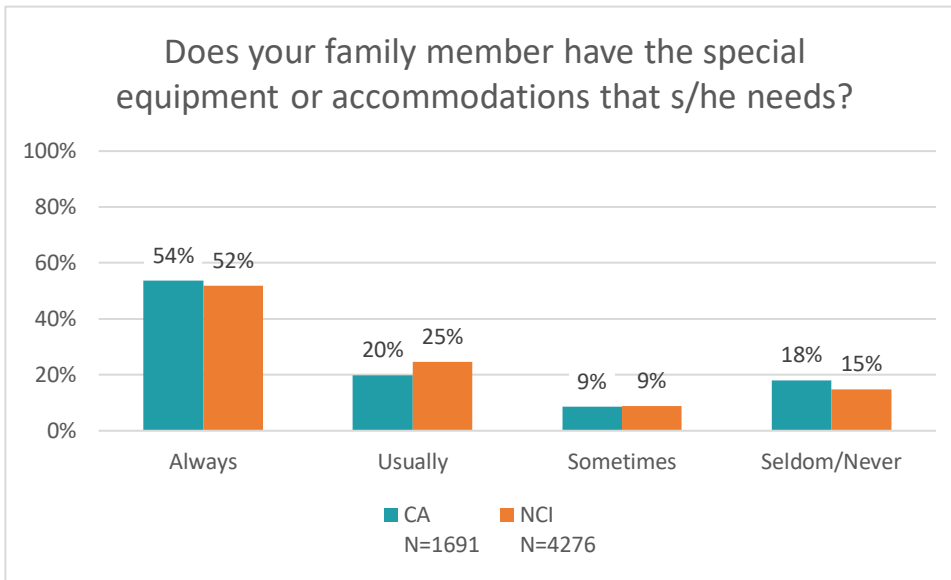


Chart 26.

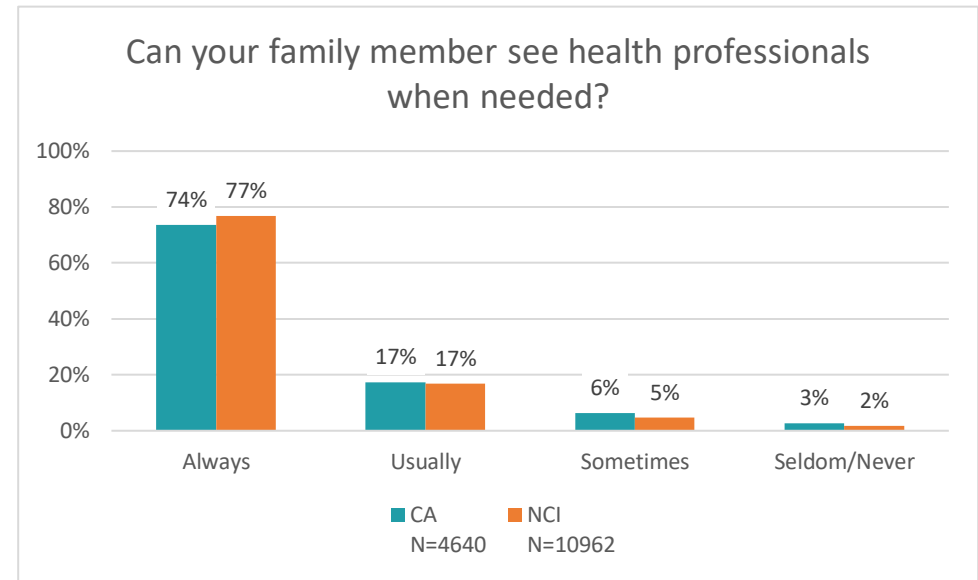


Chart 27.

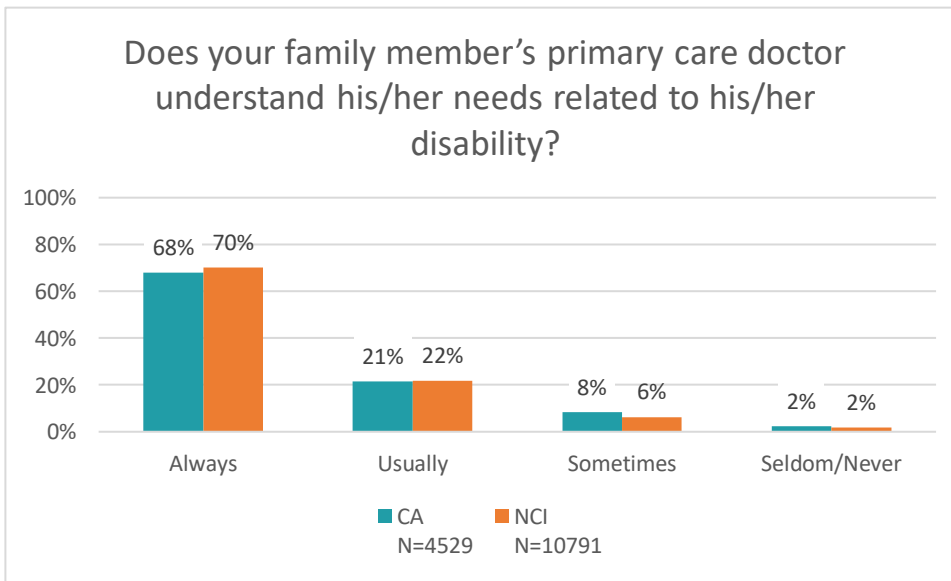


Chart 28.

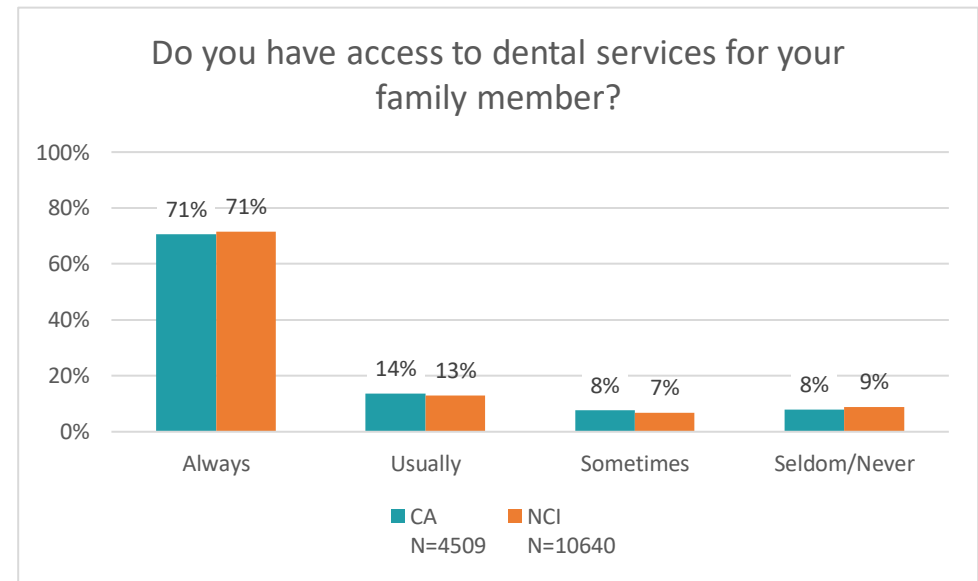




Chart 29.

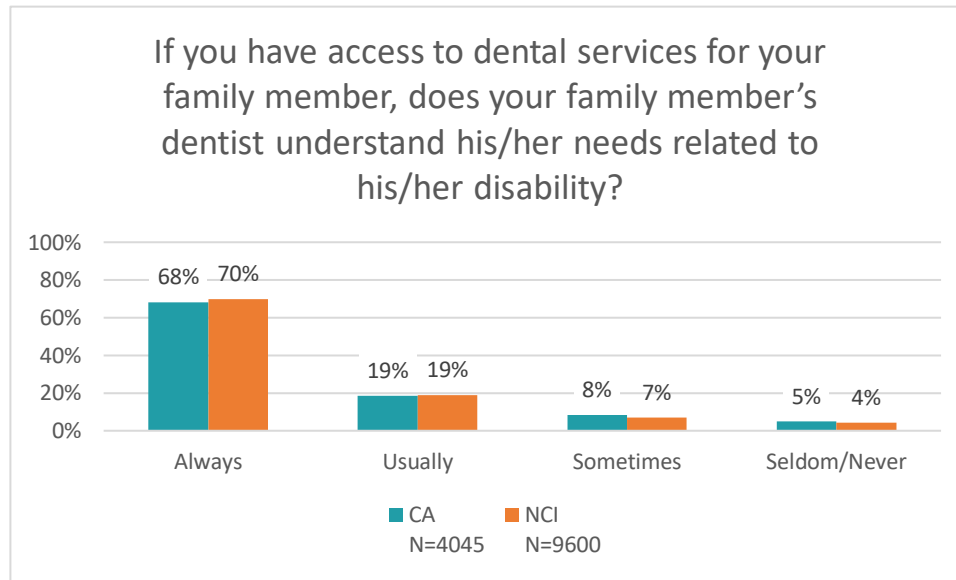


Chart 30.

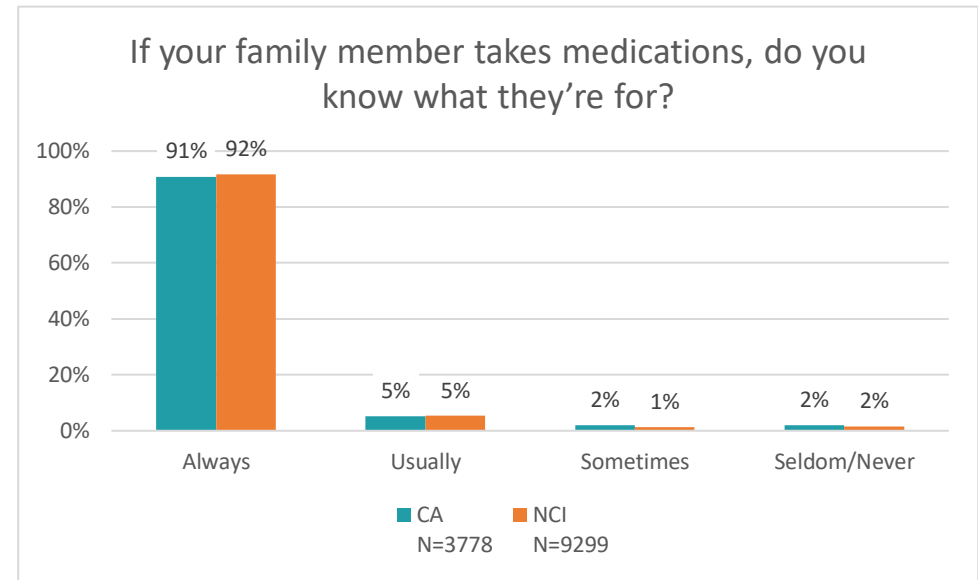


Chart 31.

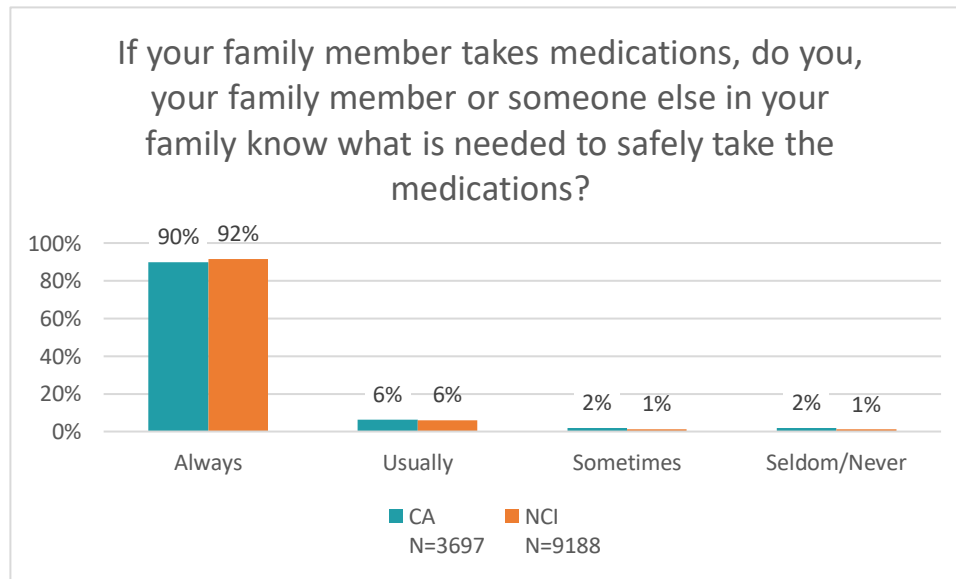


Chart 32.

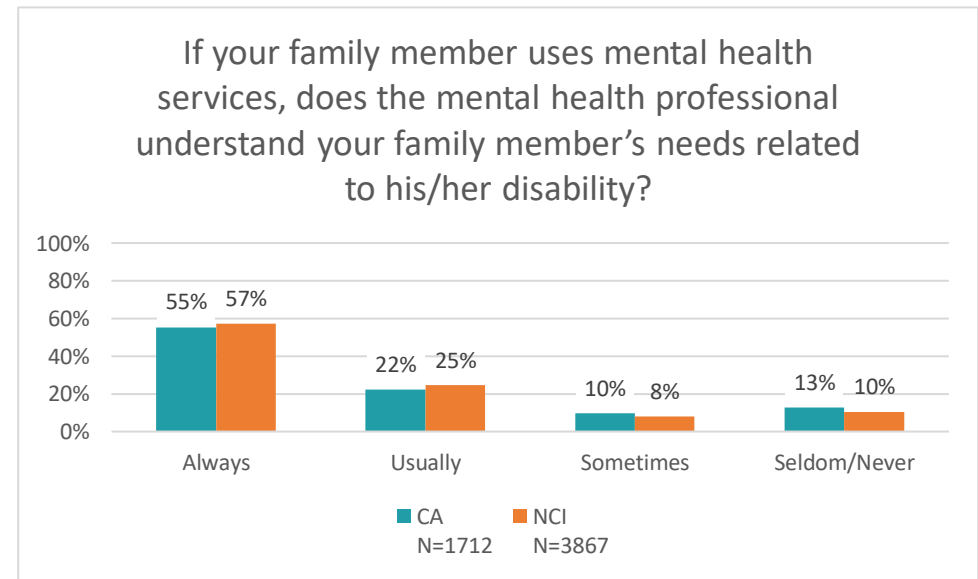


Chart 33.

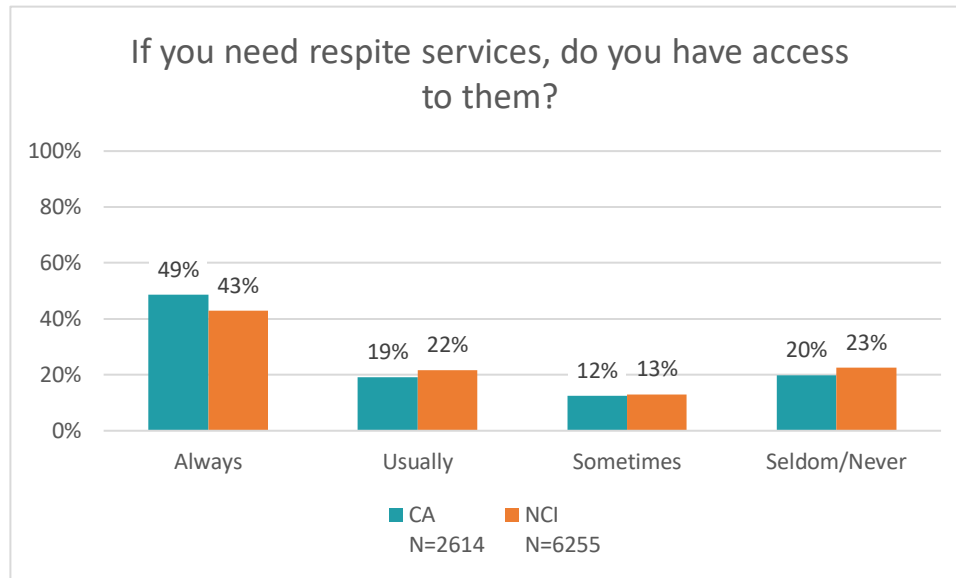


Chart 34.

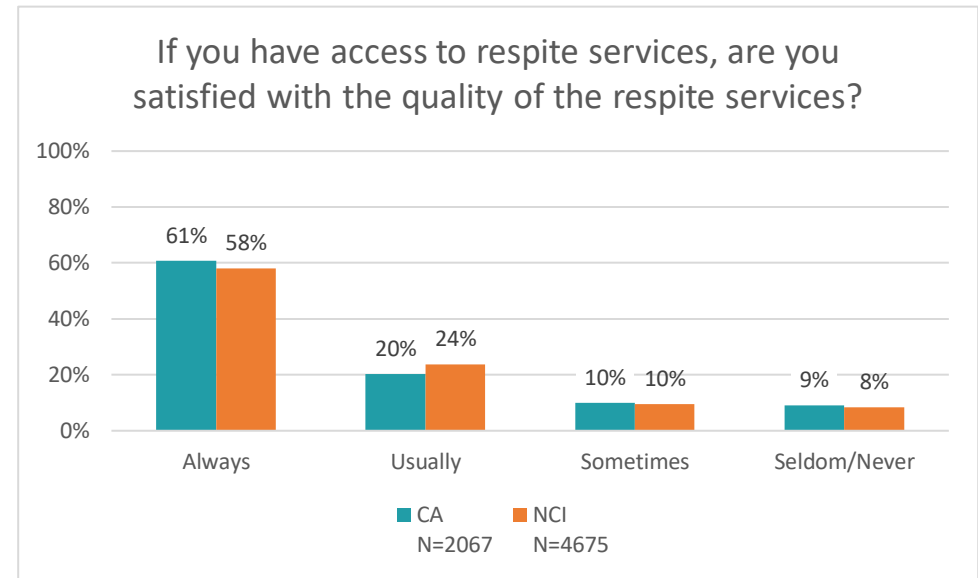


Chart 35.

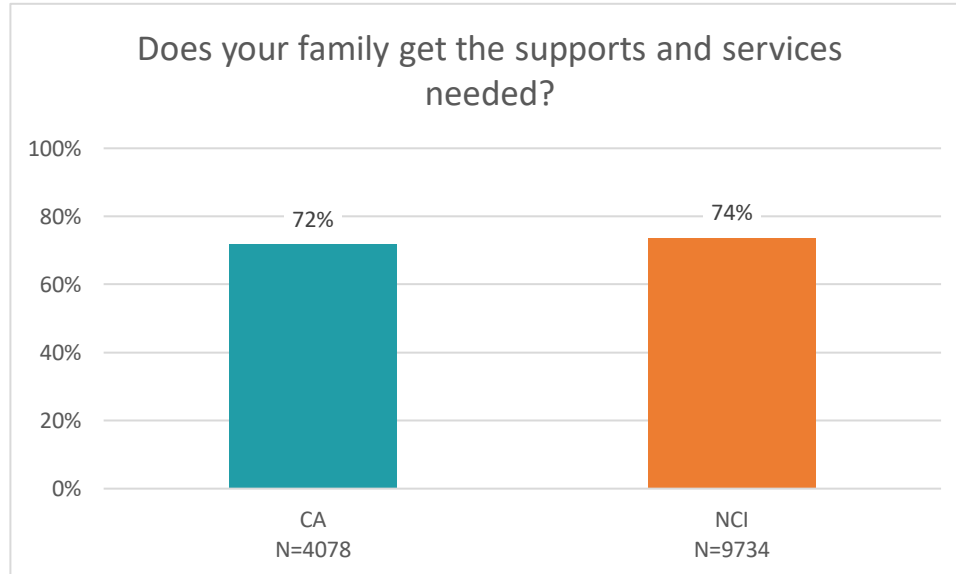
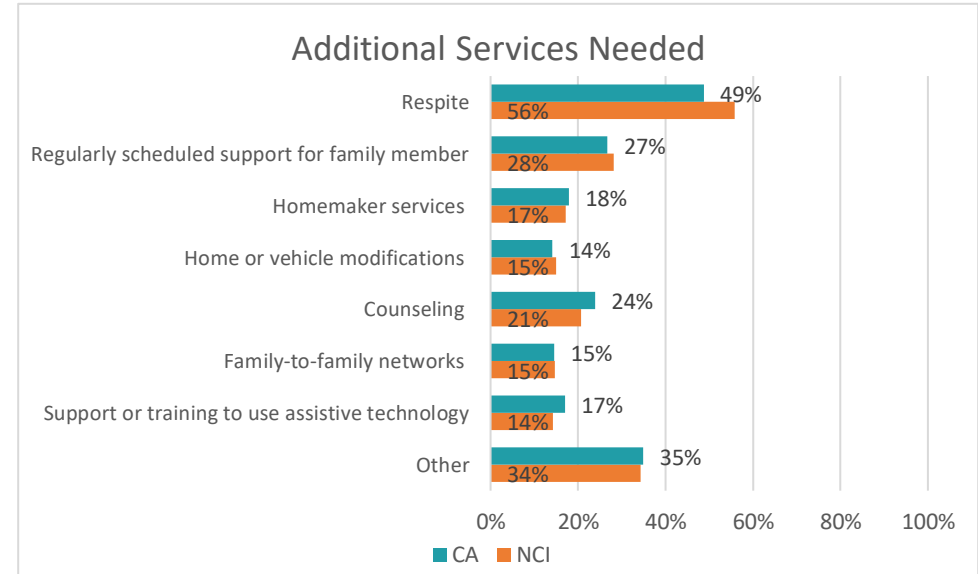


Chart 36. \*



\*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

*Tables for Access and Delivery of Services and Supports*

Table 27. Access and Delivery of Services and Supports—Always Responses

		Always	Usually	Sometimes	Seldom/Never	N
Are you or your family member able to contact his/her support workers when you want to?	CA	56%	26%	13%	5%	4,117
	NCI	60%	28%	9%	3%	9,825
Are you or your family member able to contact his/her case manager/service coordinator when you want to?	CA	57%	26%	12%	5%	4,470
	NCI	62%	26%	9%	4%	10,588
Do support workers come and leave when they are supposed to?	CA	67%	23%	7%	3%	3,758
	NCI	67%	24%	6%	3%	9,027
Do services and supports change when your family's needs change?	CA	51%	24%	14%	11%	3,214
	NCI	51%	27%	12%	10%	7,625
Do support workers speak to you in a way that you understand?	CA	76%	18%	5%	2%	3,965
	NCI	77%	18%	3%	1%	9,497
Are services delivered in a way that is respectful of your family's culture?	CA	81%	14%	3%	2%	4,270
	NCI	81%	15%	2%	2%	10,124
If your family member does not communicate verbally, are there support workers who can communicate with him/her?	CA	45%	24%	12%	20%	712
	NCI	44%	28%	14%	15%	2,131
Do support workers have the right information and skills to meet your family's needs?	CA	54%	32%	11%	3%	3,653
	NCI	57%	32%	9%	3%	9,024
Does your family member have the special equipment or accommodations that s/he needs?	CA	54%	20%	9%	18%	1,691
	NCI	52%	25%	9%	15%	4,276

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

		Always	Usually	Sometimes	Seldom/Never	N
Can your family member see health professionals when needed?	CA	74%	17%	6%	3%	4,640
	NCI	77%	17%	5%	2%	10,962
Does your family member's primary care doctor understand his/her needs related to his/her disability?	CA	68%	21%	8%	2%	4,529
	NCI	70%	22%	6%	2%	10,791
Do you have access to dental services for your family member?	CA	71%	14%	8%	8%	4,509
	NCI	71%	13%	7%	9%	10,640
If you have access to dental services for your family member, does your family member's dentist understand his/her needs related to his/her disability?	CA	68%	19%	8%	5%	4,045
	NCI	70%	19%	7%	4%	9,600
If your family member takes medications, do you know what they're for?	CA	91%	5%	2%	2%	3,778
	NCI	92%	5%	1%	2%	9,299
If your family member takes medications, do you, your family member or someone else in your family know what is needed to safely take the medications?	CA	90%	6%	2%	2%	3,697
	NCI	92%	6%	1%	1%	9,188
If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?	CA	55%	22%	10%	13%	1,712
	NCI	57%	25%	8%	10%	3,867
If you need respite services, do you have access to them?	CA▲	49%	19%	12%	20%	2,614
	NCI	43%	22%	13%	23%	6,255
If you have access to respite services, are you satisfied with the quality of the respite services?	CA	61%	20%	10%	9%	2,067
	NCI	58%	24%	10%	8%	4,675

Table 29. Access and Delivery of Services and Supports—Yes Responses

		Yes	No	N
Does your family get the supports and services needed?	CA	72%	28%	4,078
	NCI	74%	26%	9,734

Table 30. Additional Services Needed \*

		Needs Service
Respite	CA	49%
	NCI	56%
Regularly scheduled support for family member	CA	27%
	NCI	28%
Homemaker services	CA	18%
	NCI	17%
Home or vehicle modifications	CA	14%
	NCI	15%
Counseling	CA	24%
	NCI	21%
Family-to-family networks	CA	15%
	NCI	15%
Support/training to use family member's assistive technology	CA	17%
	NCI	14%
Other	CA	35%
	NCI	34%

\*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

## Choice, Decision Making and Control

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

*Charts for Choice, Decision Making and Control*



Chart 37.

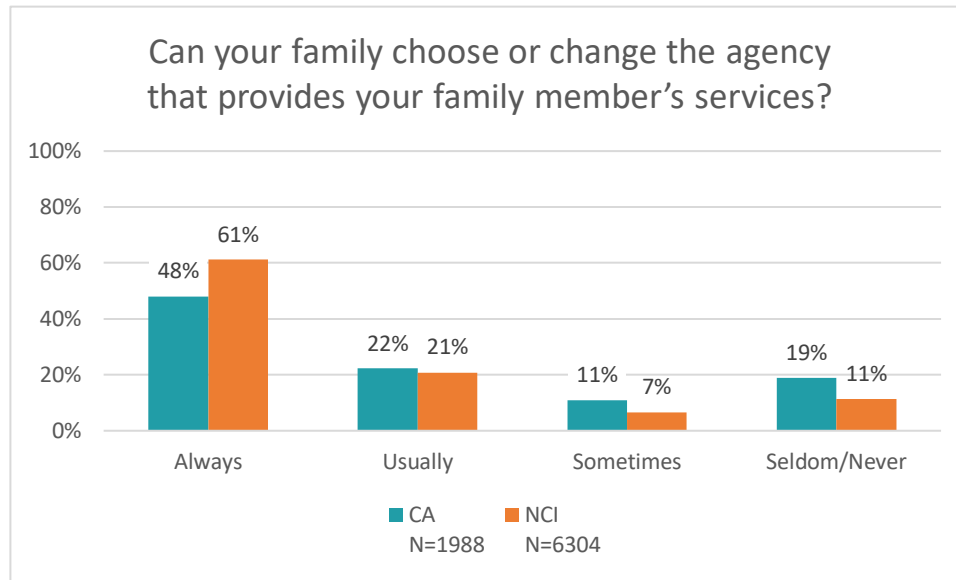


Chart 38.

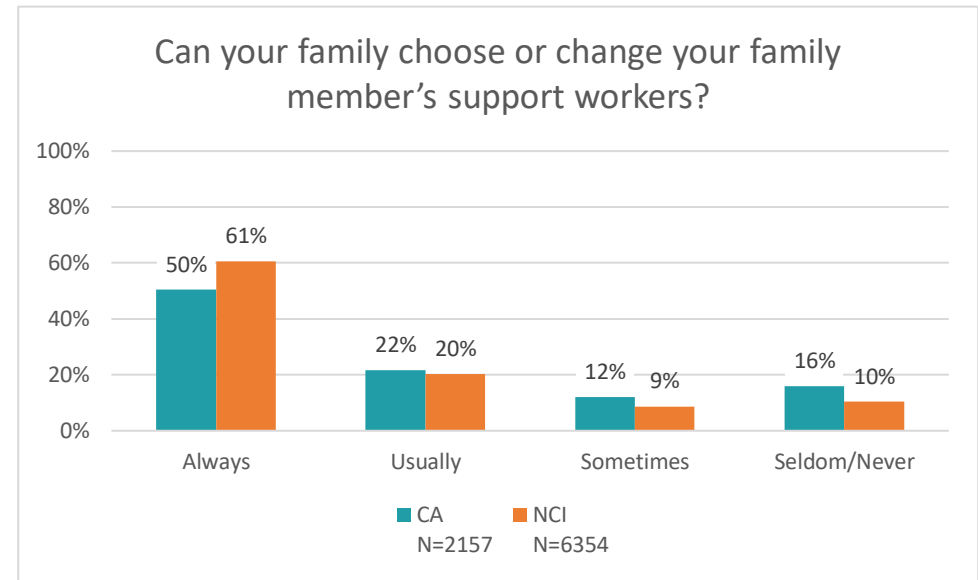


Chart 39.

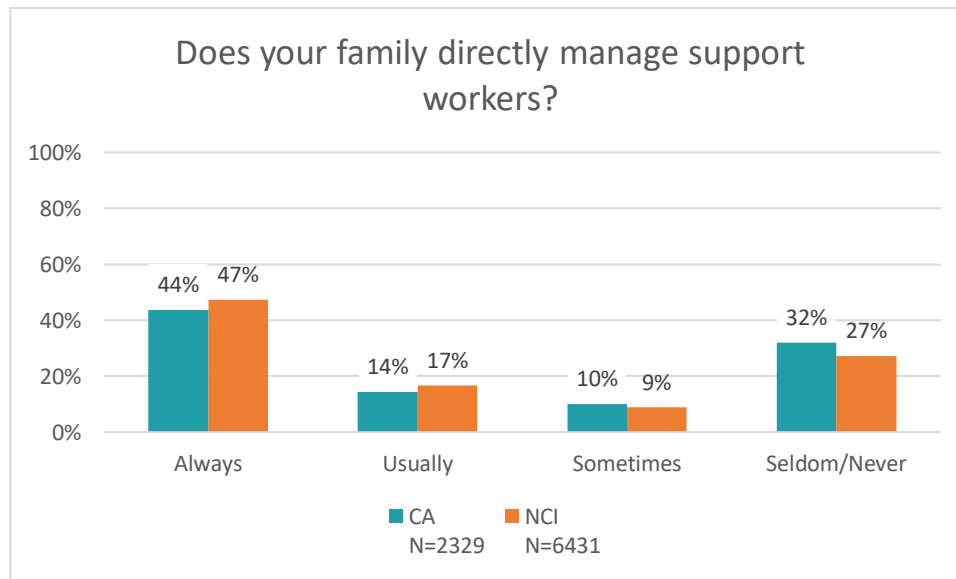


Chart 40.

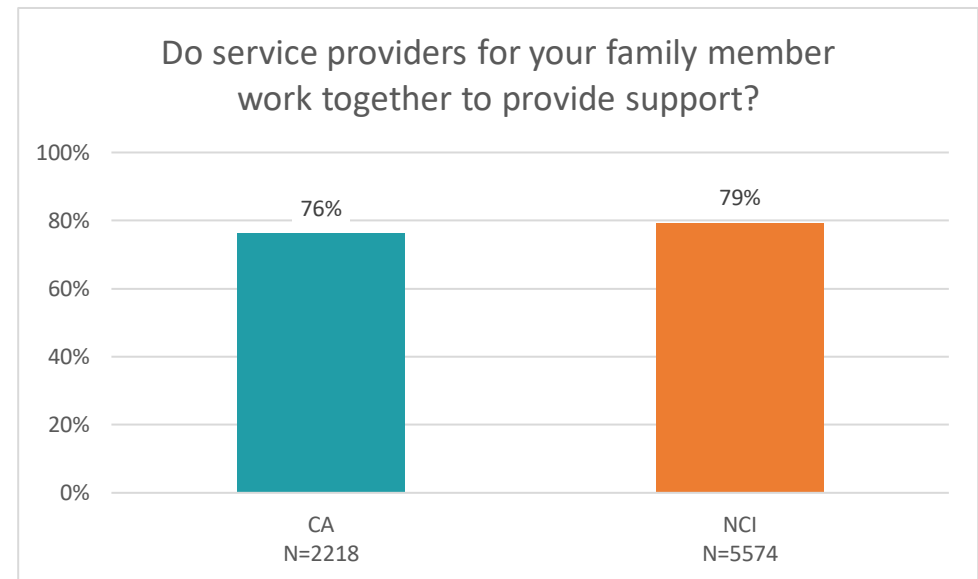
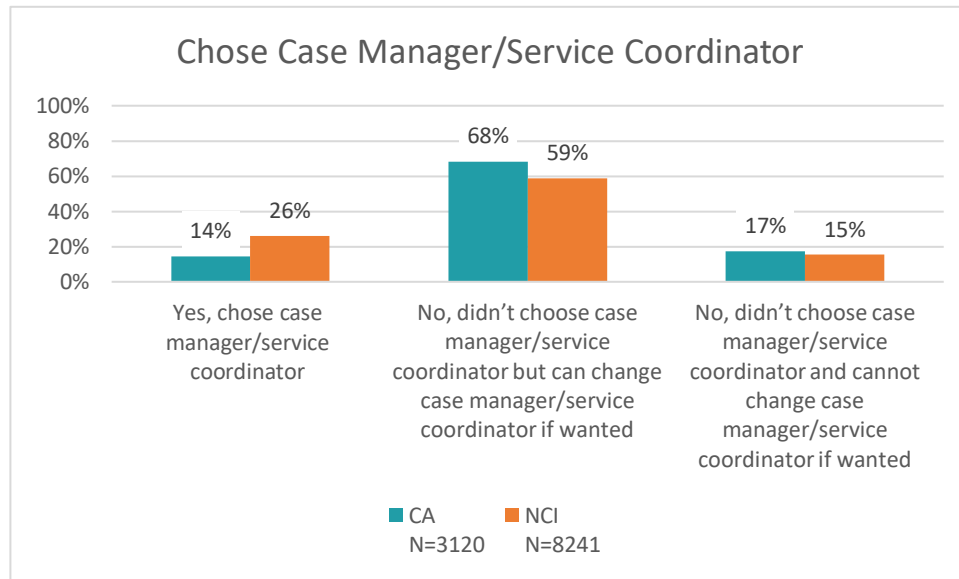


Chart 41.



*Tables for Choice, Decision Making and Control*

Table 31. Choice and Control—Always Responses

		Always	Usually	Sometimes	Seldom/Never	N
Can your family choose or change the agency that provides your family member's services?	CA ▼	48%	22%	11%	19%	1,988
	NCI	61%	21%	7%	11%	6,304
Can your family choose or change your family member's support workers?	CA ▼	50%	22%	12%	16%	2,157
	NCI	61%	20%	9%	10%	6,354
Does your family directly manage support workers?	CA	44%	14%	10%	32%	2,329
	NCI	47%	17%	9%	27%	6,431

Table 32. Choice and Control—Yes Responses

		Yes	No	N
Do service providers for your family member work together to provide support?	CA	76%	24%	2,218
	NCI	79%	21%	5,574

Table 33. Family member, or someone else in your family chose case manager/service coordinator

	Chose Case Manager/ Service Coordinator	
Yes, chose case manager/service coordinator	CA ▼	14%
	NCI	26%
No, didn't choose case manager/service coordinator but can change case manager/service coordinator if wanted	CA ▼	68%
	NCI	59%
No, didn't choose case manager/service coordinator and cannot change case manager/service coordinator if wanted	CA ▼	17%
	NCI	15%
N	CA ▼	3,120
	NCI	8,241

## Involvement in the Community

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

*Charts for Involvement in the Community*

Chart 42.

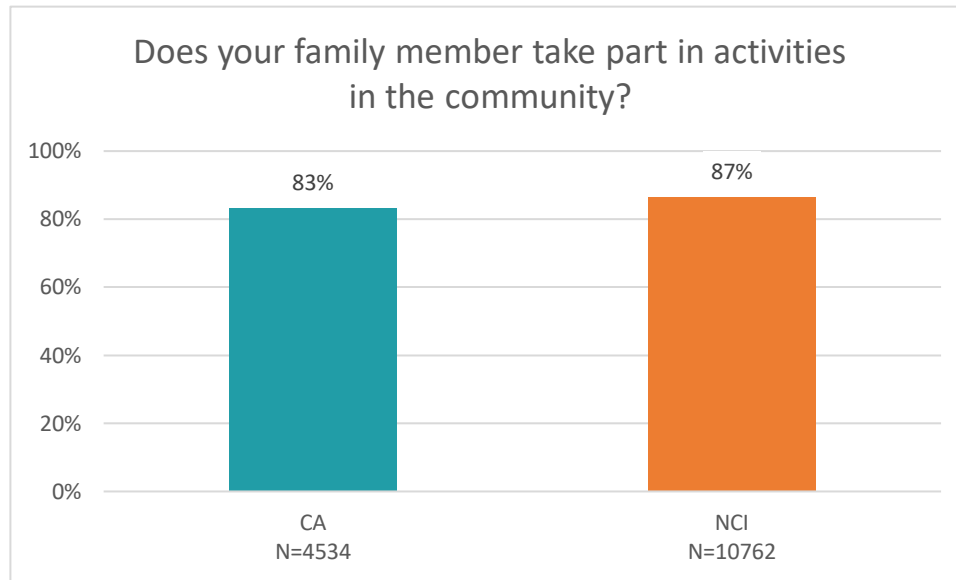


Chart 43. \*

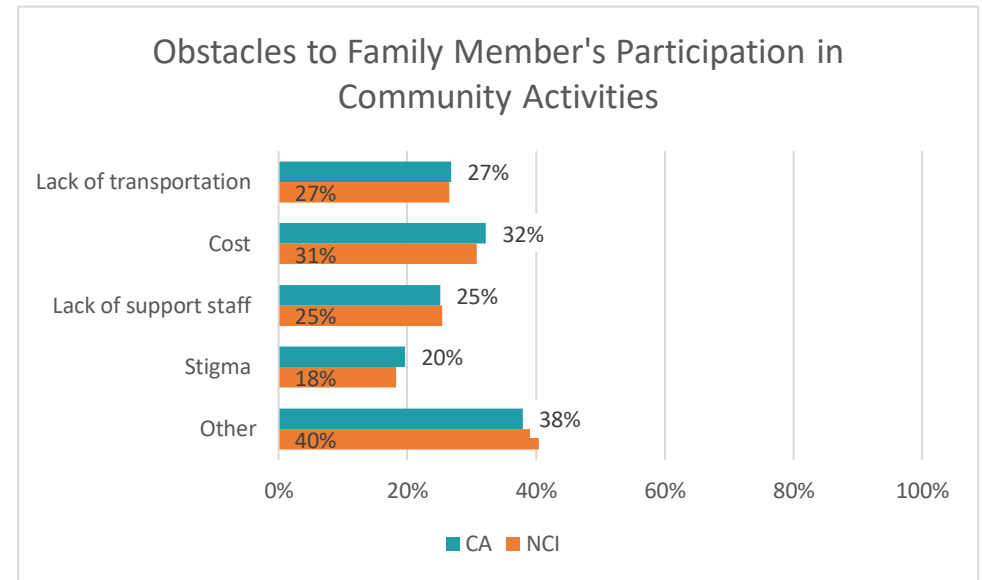


Chart 44.

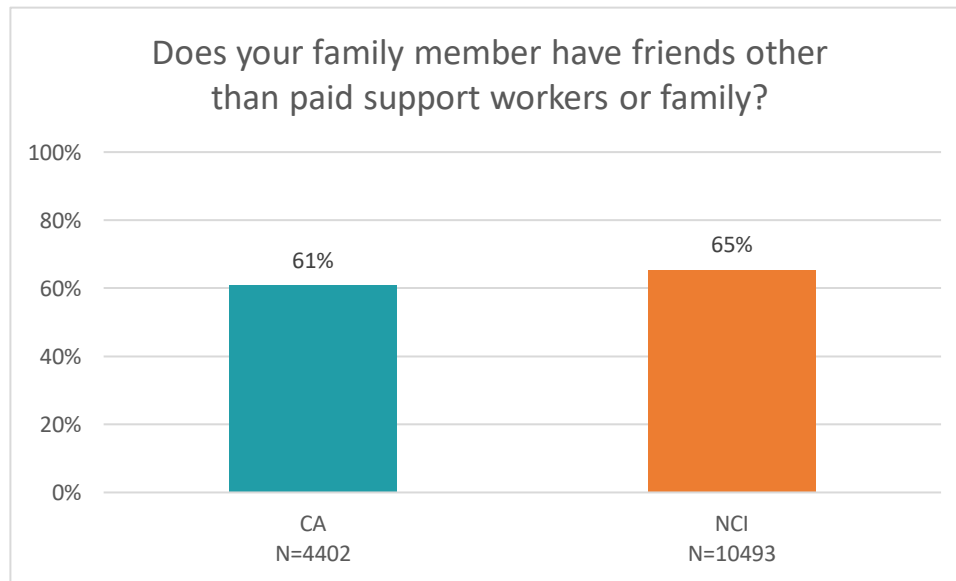
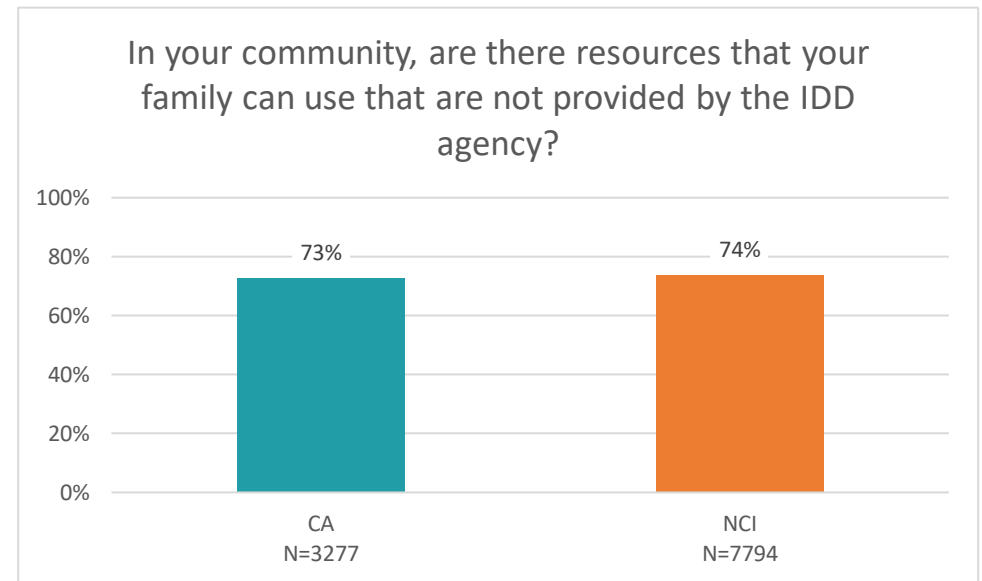


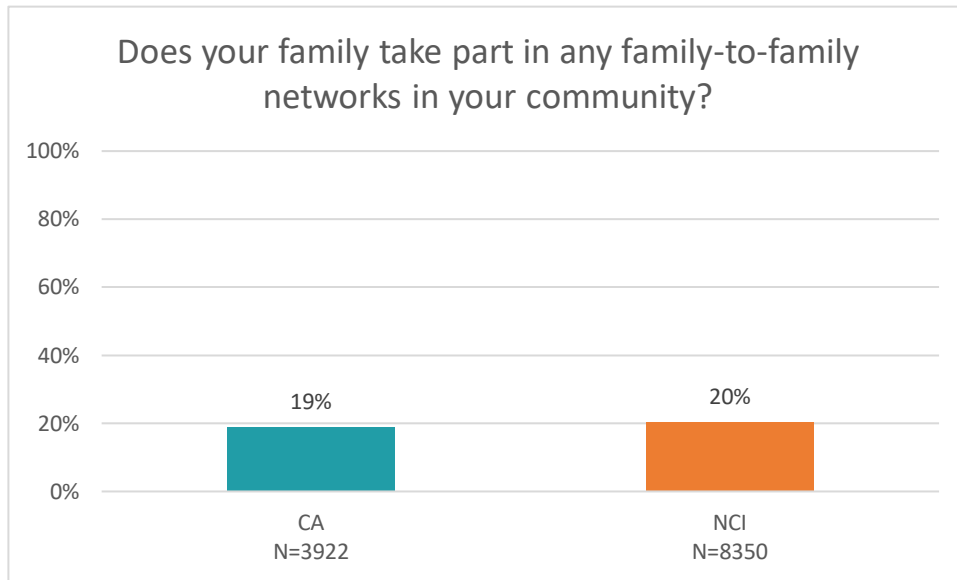
Chart 45.



\*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown



Chart 46.



*Tables for Involvement in the Community*

Table 34. Involvement in the Community

		Yes	No	N
Does your family member take part in activities in the community?	CA	83%	17%	4,534
	NCI	87%	13%	10,762

Table 35. Obstacles to Family Member's Participation in Community Activities \*

		Obstacles /Barriers
Lack of transportation	CA	27%
	NCI	27%
Cost	CA	32%
	NCI	31%
Lack of support staff	CA	25%
	NCI	25%
Stigma	CA	20%
	NCI	18%
Other	CA	38%
	NCI	40%

\*Categories are not mutually exclusive and N may differ by category; therefore, N is not shown

Table 36. Involvement in the Community—Yes Responses

		Yes	No	N
Does your family member have friends other than paid support workers or family?	CA	61%	39%	4,402
	NCI	65%	35%	10,493
In your community, are there resources that your family can use that are not provided by the IDD agency?	CA	73%	27%	3,277
	NCI	74%	26%	7,794
Does your family take part in any family-to-family networks in your community?	CA	19%	81%	3,922
	NCI	20%	80%	8,350

## Satisfaction With Services and Supports

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

*Charts for Satisfaction With Services and Supports*

Chart 47.

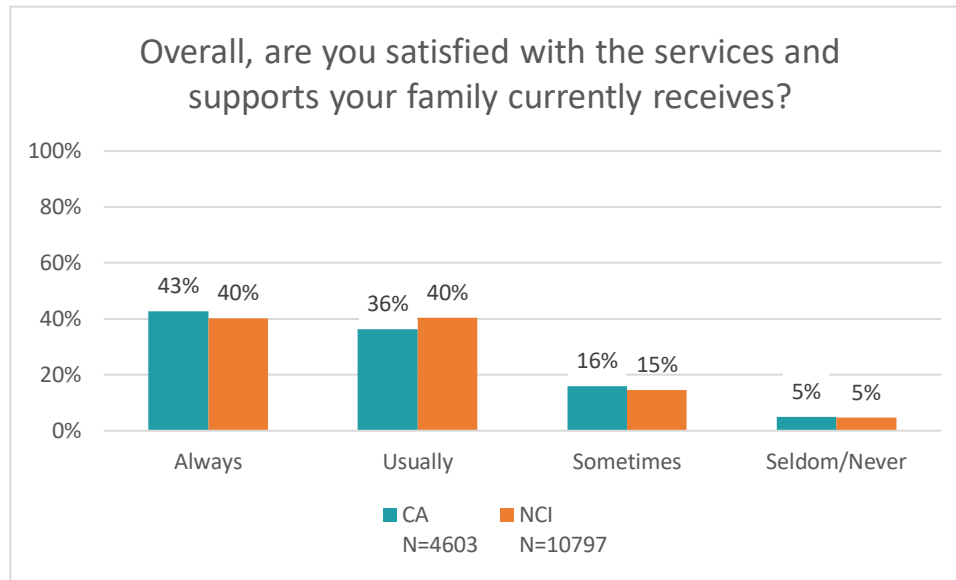


Chart 48. \*

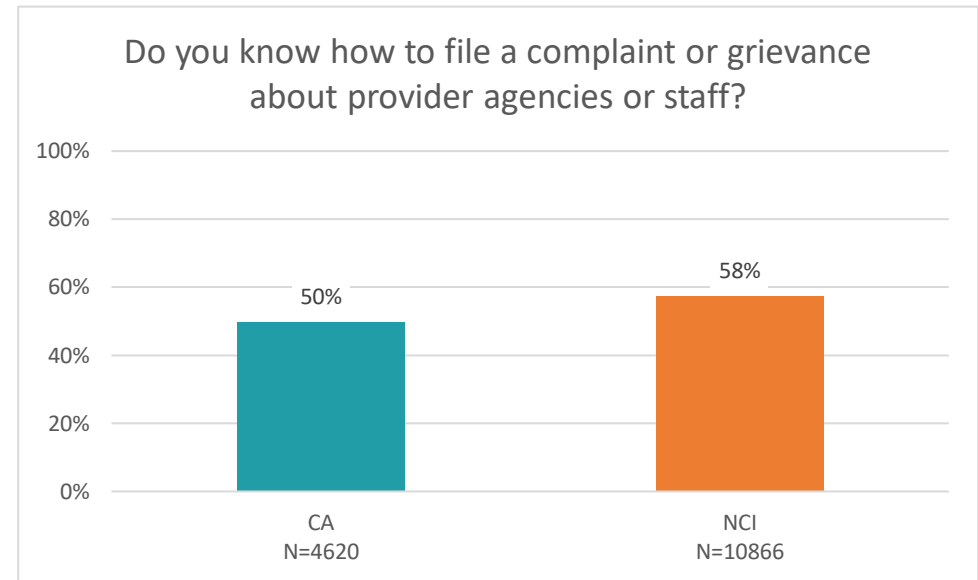


Chart 49.

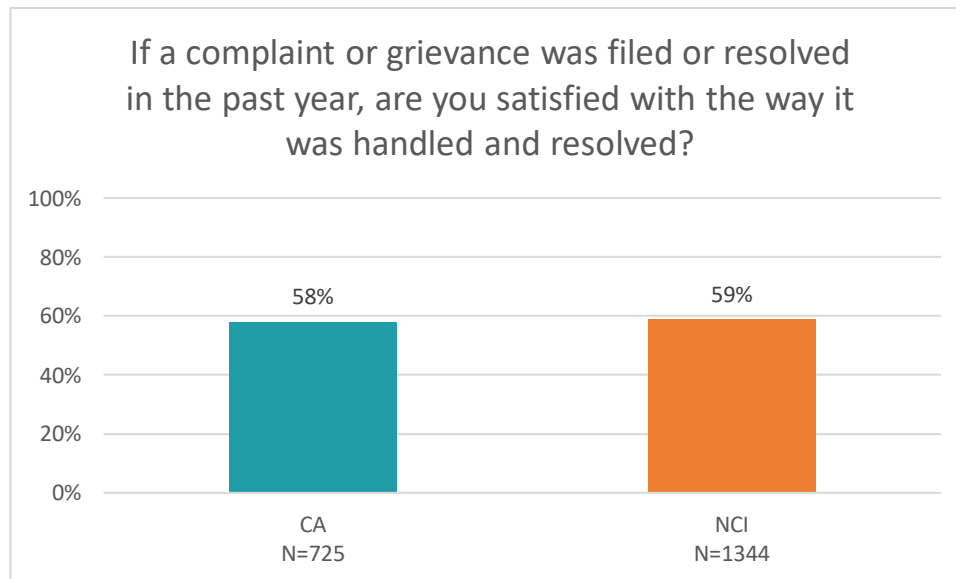
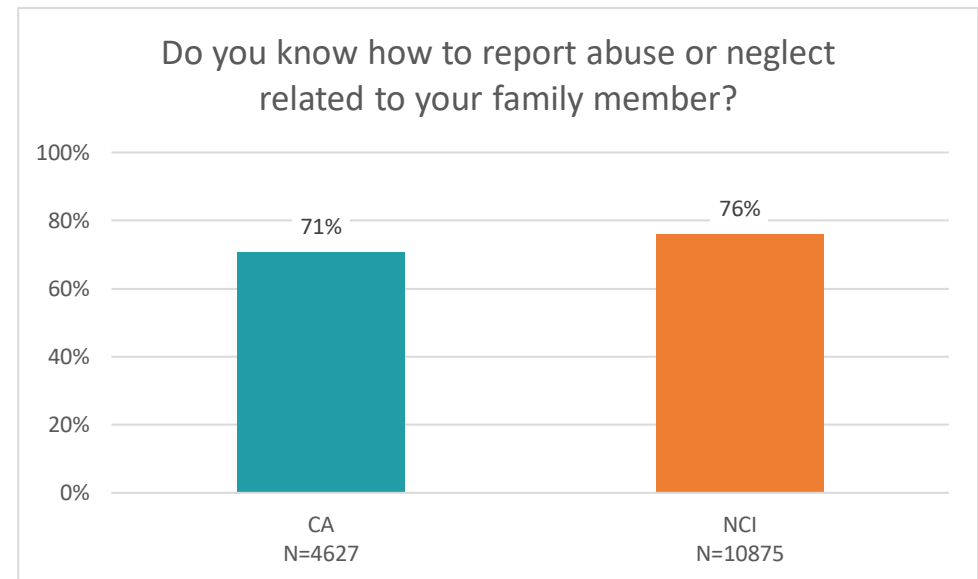
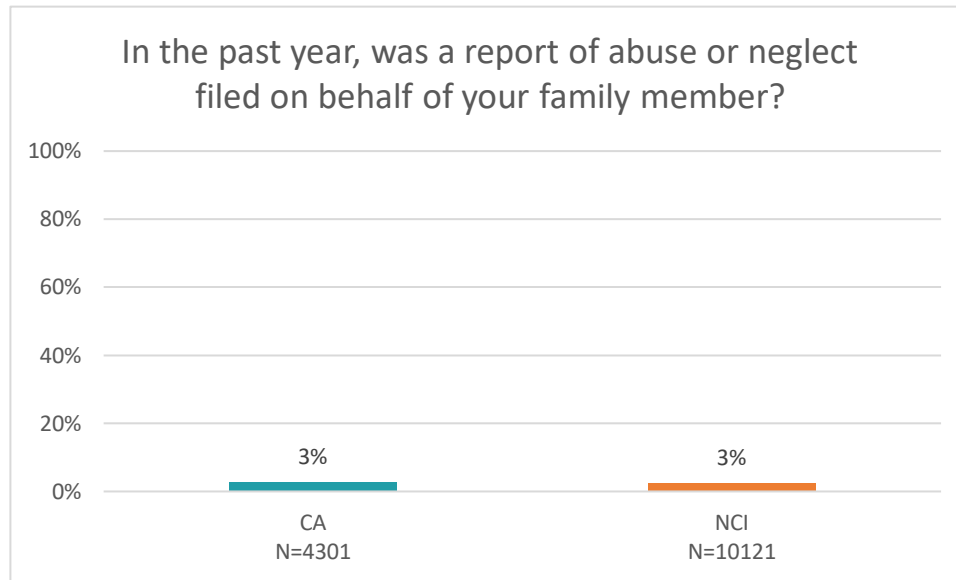


Chart 50. \*

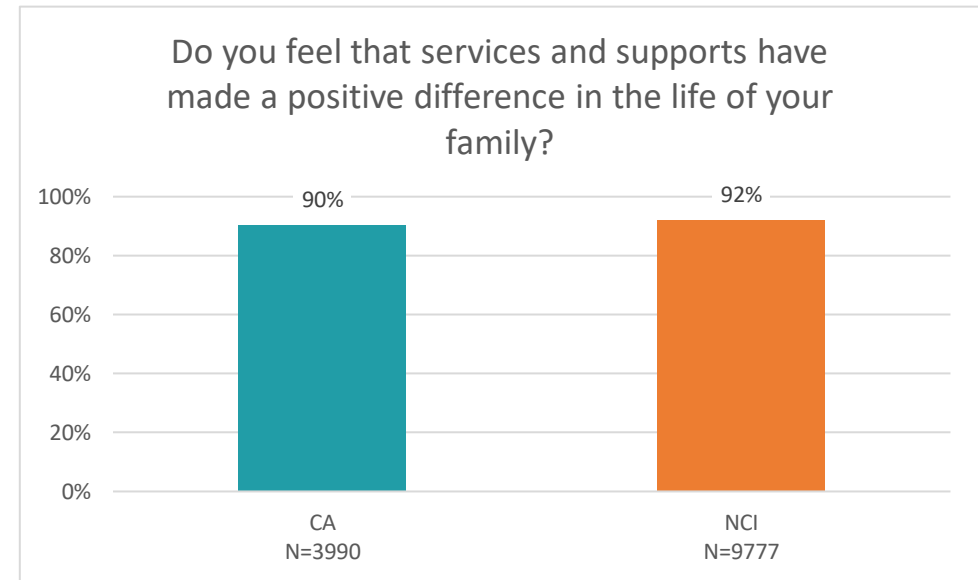


\*For this question, 'No' and 'Don't know' responses were combined.

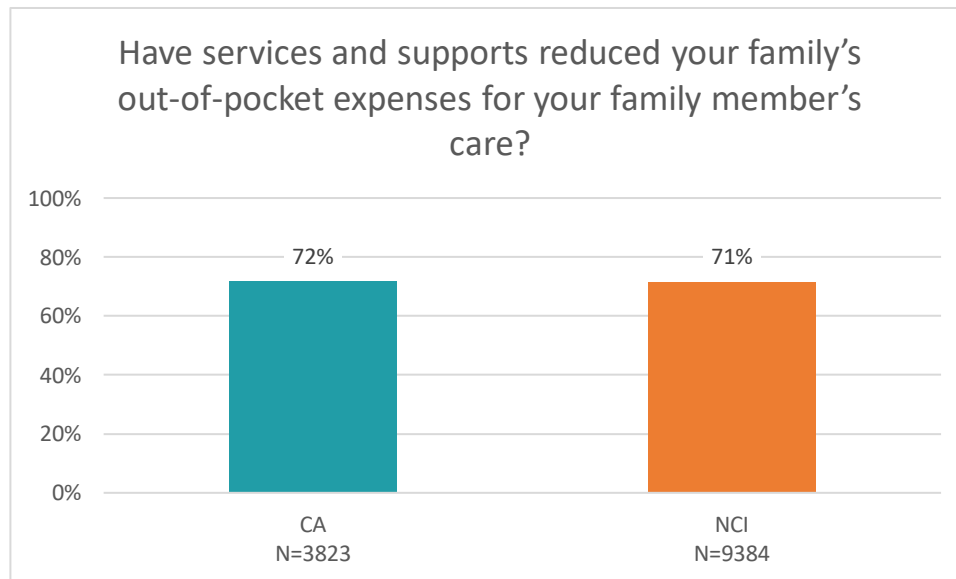
[Chart 51.](#)



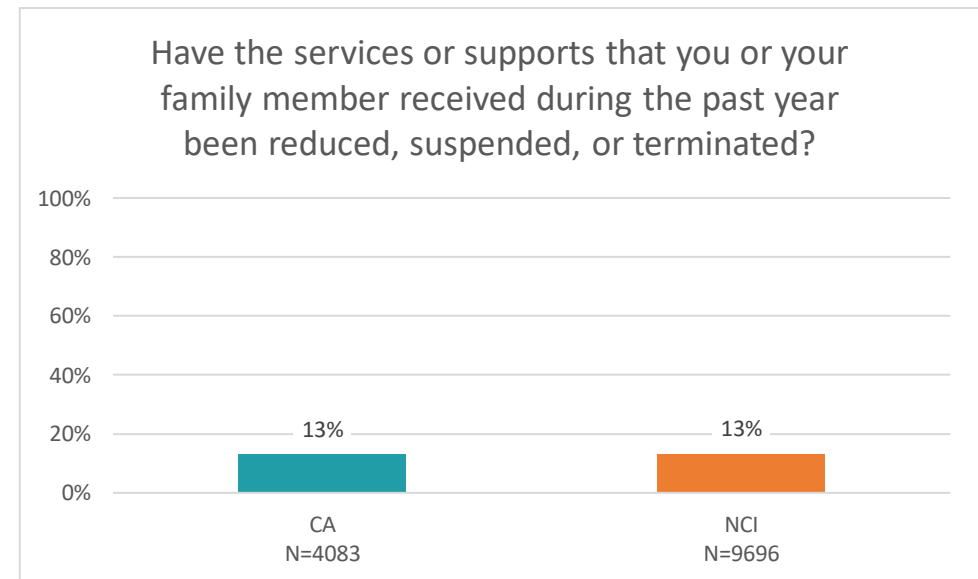
[Chart 52.](#)



[Chart 53.](#)

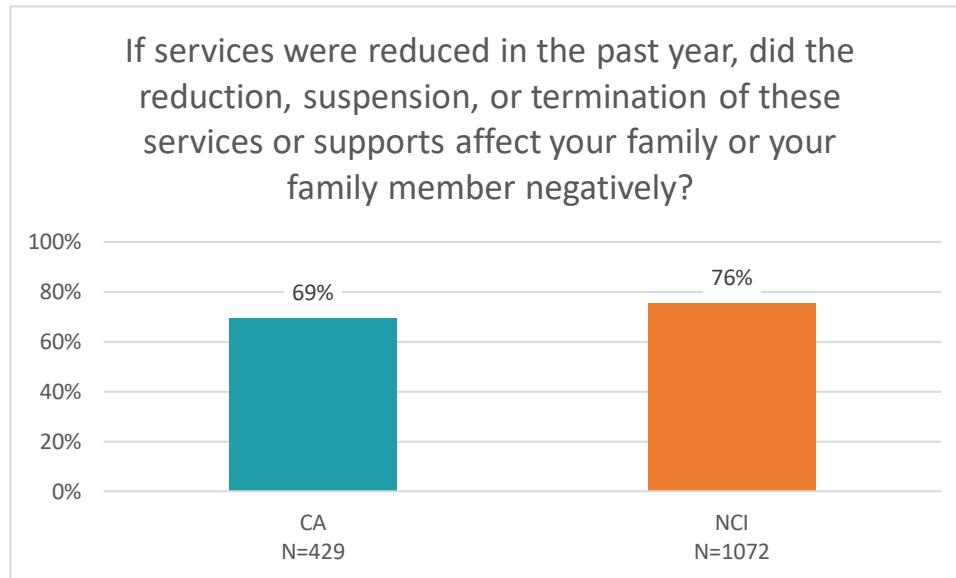


[Chart 54.](#)

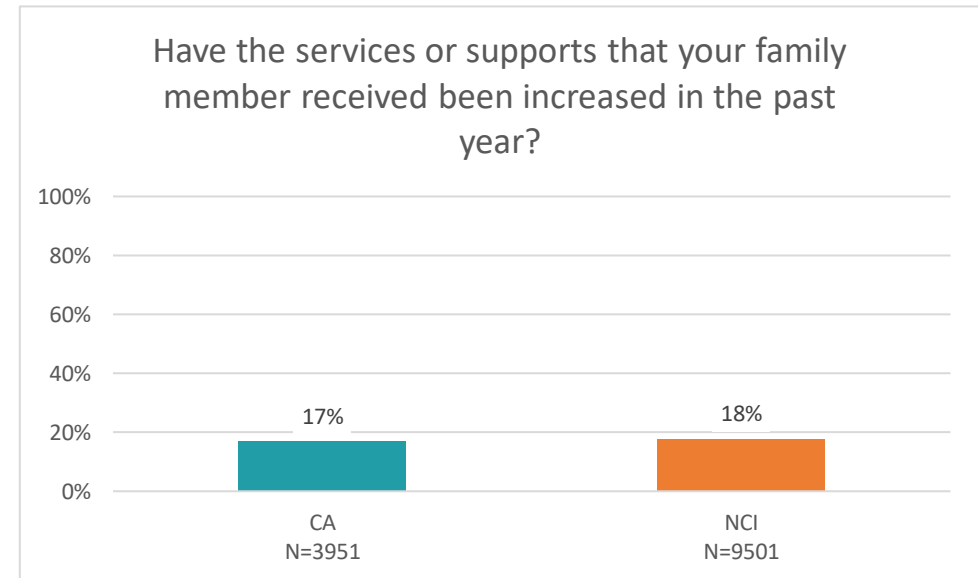




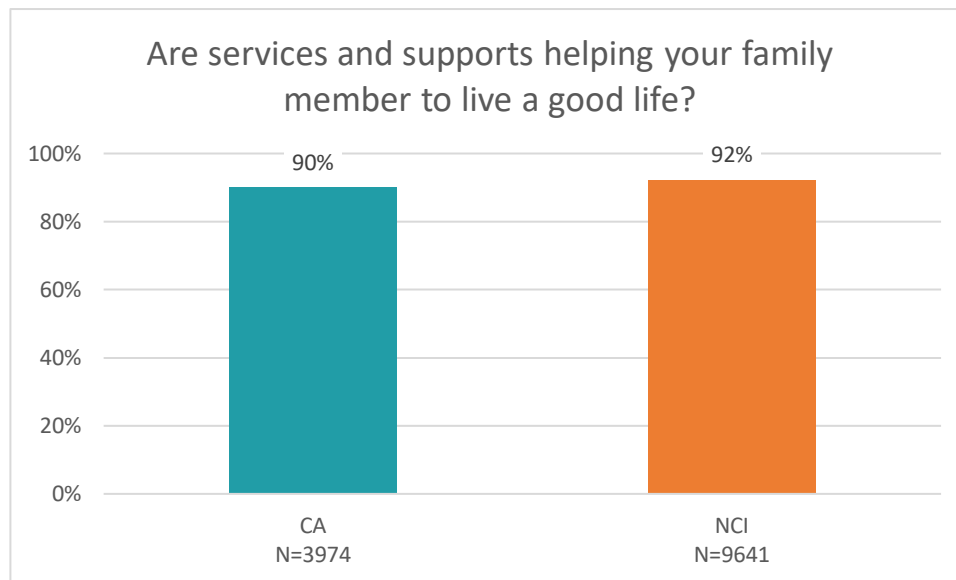
[Chart 55.](#)



[Chart 56.](#)



[Chart 57.](#)



*Tables for Satisfaction With Services and Supports*

Table 37. Satisfaction—Always Responses

		Always	Usually	Sometimes	Seldom/Never	N
Overall, are you satisfied with the services and supports your family currently receives?	CA	43%	36%	16%	5%	4,603
	NCI	40%	40%	15%	5%	10,797

Table 38. Satisfaction—Yes Responses

		Yes	No	N
Do you know how to file a complaint or grievance about provider agencies or staff? *	CA	50%	50%	4,620
	NCI	58%	42%	10,866
If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled and resolved?	CA	58%	42%	725
	NCI	59%	41%	1,344
Do you know how to report abuse or neglect related to your family member? *	CA	71%	29%	4,627
	NCI	76%	24%	10,875
In the past year, was a report of abuse or neglect filed on behalf of your family member?	CA	3%	97%	4,301
	NCI	3%	97%	10,121

\*For this question, 'No' and 'Don't know' responses were combined.

Table 39. Satisfaction—Yes Responses (continued)

		Yes	No	N
Do you feel that services and supports have made a positive difference in the life of your family?	CA	90%	10%	3,990
	NCI	92%	8%	9,777
Have services and supports reduced your family's out-of-pocket expenses for your family member's care?	CA	72%	28%	3,823
	NCI	71%	29%	9,384
Have the services or supports that you or your family member received during the past year been reduced, suspended, or terminated?	CA	13%	87%	4,083
	NCI	13%	87%	9,696
If services were reduced in the past year, did the reduction, suspension, or termination of these services or supports affect your family or your family member negatively?	CA ▲	69%	31%	429
	NCI	76%	24%	1,072
Have the services or supports that your family member received been increased in the past year?	CA	17%	83%	3,951
	NCI	18%	82%	9,501
Are services and supports helping your family member to live a good life?	CA	90%	10%	3,974
	NCI	92%	8%	9,641