

2021-22 Adult Family Survey (AFS)

Regional Center Report

Golden Gate Regional Center (GGRC)



Contents

Quality Assessment Project and National Core Indicators®	10
What is NCI®-IDD?	10
What is the NCI-IDD Adult Family Survey?	10
Important note on Impact of COVID-19	11
What is included in this report?	11
Demographics	13
Demographics of Family Member Receiving Services.....	14
Table 1. More Than One Person Living in the Home Has IDD	15
Table 2. Family Member’s Age.....	15
Table 3. Family Member’s Gender	16
Table 4. Family Member’s Race and Ethnicity.....	16
Table 5a. Family Member’s Disabilities.....	17
Table 5b. Family Member’s Disabilities (continued).....	17
Table 6a. Family Member’s Health Conditions.....	18
Table 6b. Family Member’s Health Conditions (continued).....	18
Table 6c. Family Member’s Health Conditions (continued)	19
Table 7. Family Member’s Preferred Means of Communication	19
Table 8a. Family Member’s Preferred Language.....	20
Table 8b. Family Member’s Preferred Language (Continued)	20
Table 8c. Family Member’s Preferred Language (Continued).....	21

Table 9. Family Member Has Legal Court Appointed Guardian or Conservator	21
Table 10. Guardian or Conservator Relationship to Family Member	22
Table 11a. Family Member’s Highest level of Education	22
Table 11b. Family Member’s Highest level of Education (continued)	22
Table 12. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	23
Table 13. Family Member’s Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)	23
Table 14. Family Member’s Need for Help with Other Daily Activities (for example, scheduling, managing money, or shopping).....	24
Demographics of Respondents.....	25
Table 15a. Language Usually Spoken at Home.....	26
Table 15b. Language Usually Spoken at Home	26
Table 15c. Language Usually Spoken at Home	27
Table 16. Respondent’s Age.....	27
Table 17. Respondent’s Health.....	28
Table 18. Respondent’s Relationship to Family Member.....	28
Table 19. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services.....	29
Table 20. Number of Adults in Household (Not Including Family Member Receiving Services).....	29
Table 21. Number of Children (Under 18 Years Old) in Household	30
Table 22. Respondent’s Highest Level of Education.....	30
Table 23. Total Taxable Household Income of Wage Earners in the Past Year	31
Table 24. Residential Designation (Urban, Suburban, or Rural)	31

Services and Supports Received	32
Table 25a. Services and Supports Received From Regional Center	33
Table 25b. Services and Supports Received From Regional Center (continued).....	34
Table 26. Additional Services and Supports Received (Not From the Regional Centers).....	34
Adult Family Survey Results.....	35
Information and Planning.....	36
Table 27. Do you get enough information to take part in planning services for your family member?	37
Table 28. Is the information you get about services and supports easy to understand?	38
Table 29. Do you get information about services and supports in your preferred language?	39
Table 30. Does the case manager/service coordinator listen to your family's choices and opinions?	40
Table 31. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?.....	41
Table 32a. Do you need help planning for your family member's future with respect to any of the following?	42
Table 32b. Do you need help planning for your family member's future with respect to any of the following? (continued)	43
Table 33. Has your family learned about alternatives to conservatorship?.....	44
Table 34. Does your family member have an individual program plan (IPP)?	45
Table 35. Does the IPP include all the services and supports your family member needs?.....	46
Table 36. Did you or someone else in your family (besides your family member with a intellectual/developmental disabilities) help make the IPP?.....	47
Table 37. Did your family member help make the IPP?	48
Table 38. Do you feel like your family had enough say or input in making the plan?.....	49
Table 39. Did your family member leave school services and begin adult services during the past 12 months?.....	50

Table 40. If your family member left school services during the past year, did they have a transition plan?	51
Table 41. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?	52
Access and Delivery of Services and Supports	53
Table 42. Does your family member get all the services listed in the IPP?.....	54
Table 43. Does your family get the supports and services it needs?	55
Table 44a. What additional services does your family need?.....	56
Table 44b. What additional services does your family need? (continued).....	57
Table 45. Do services and supports change when your family's needs change?	58
Table 46. Does your family member have enough supports to work or volunteer in the community?	59
Table 47. Does your family member have the special equipment or accommodations they need?.....	60
Table 48. If you need respite services, how often are you able to get them when needed?.....	61
Table 49. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?	62
Table 50. Are you or your family member able to contact their support workers when you want?	63
Table 51. Are you or your family member able to contact their case manager/service coordinator when you want?	64
Table 52. Do service providers for your family member work together to provide support?	65
Table 53. Are services delivered in a way that is respectful of your family's culture?	66
Table 54. Does your family member use technology in their everyday life to help them do things on their own?.....	67
Table 55. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?	68
Table 56. How well does the internet work in your home?.....	69
Workforce (New in 2021-2022)	70

Table 57. Do support workers come and go when they are supposed to?	71
Table 58. Do support workers speak to you in a way you understand?	72
Table 59. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?.....	73
Table 60. Do support workers have the right information and skills to meet your family’s needs?.....	74
Table 61. Do your family member’s support workers change too often? Is there too much “turnover” of support workers?	75
Table 62. Is there always a staff person available to support your family member when support is needed?.....	76
Choice, Decision Making and Control	77
Table 63. Can your family choose or change the agency that provides your family member’s services?.....	78
Table 64. Can your family choose or change your family member’s support workers?	79
Table 65. Can someone in your family directly manage support staff?.....	80
Table 66. Did you, your family member, or someone else in your family choose your family member’s case manager/service coordinator?	81
Community Connections	82
Table 67. Does your family member do things in the community?.....	83
Table 68. For your family member, what makes it hard to do things and activities in the community?	84
Table 69. Does your family member have friends other than paid support workers or family?	85
Table 70. In your community, are there resources that your family can use that are not provided by the regional center (for example, recreational programs, community housing, library programs, religious groups, etc.)?	86
Table 71. Does your family take part in any family-to-family networks in your community?	87
Health, Welfare, and Safety (New in 2021-22)	88
Table 72. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?	89

Table 73. Does your family member's primary care doctor understand your family member's needs related to their intellectual/developmental disability?.....	90
Table 74. Can your family member go to the dentist when needed?	91
Table 75. Does your family member's dentist understand your family member's needs related to their intellectual/developmental disability?.....	92
Table 76. If your family member takes prescription medications, do you know what they're for?	93
Table 77. Do you, your family member, or someone else in your family know what is needed to safely take prescription medications (when it should be taken, how much to take, and the potential side effects)?	94
Table 78. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)?	95
Table 79. If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability?.....	96
Table 80. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?	97
Table 81. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?	98
Table 82. Have you talked about how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your family member's case manager/service coordinator?	99
Table 83. Do you know how to file a complaint or grievance about provider agencies or staff?.....	100
Table 84. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?	101
Table 85. Do you know how to report abuse or neglect related to your family member?	102
Table 86. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?	103

Table 87. If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?	104
Family Satisfaction.....	105
Table 88. Overall, are you satisfied with the services and supports your family member currently receives?	106
Table 89. Do you feel that services and supports have made a positive difference in the life of your family member? ...	107
Table 90. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?..	108
Table 91. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?	109
Table 92. 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?	110
Table 93. Have the services or supports that your family member received been increased in the past 12 months?	111
Table 94. Are services and supports helping your family member to live a good life?	112
COVID-19 Supplement	113
Table 95. Were your family member's services and supports changed, canceled, or reduced during COVID time?	114
Table 96. If yes, are those changes still in effect (still part of your family member's life)?	115
Table 97. If some or all of your family member's services have reopened or restarted: Did your family get enough information about the services reopening/restarting?.....	116
Table 98. If some or all of your family member's services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions?	117
Table 99. If staff support your family member in your family member's home: Do you feel that the staff follow recommendations to keep the household safe and healthy?	118
Table 100. Do you feel that the people in your household have the personal protective equipment (PPE) they need to stay healthy and safe when going out in the community?	119

Table 101. In preparation for the future, have you made or updated an emergency plan with your family member's case manager or with other staff?.....	120
California Specific Questions	121
Table 102. Total Out-of-pocket Expenses Related to Family Member's Care in the Past Year	122
Table 103a. Services Paid for Out-Of-Pocket in The Past Year	123
Table 103b. Services Paid for Out-of-pocket in the Past Year	124
Table 104. Does your regional center keep you informed, in your preferred language, about programs or services it offers? (For example, updates about new programs or services they offer)	125
Table 105. Did you get a copy of your family member's IPP in your preferred language?	126
Table 106. Do the support workers speak to you in your preferred language?	127
Table 107. Does your family member's case manager/service coordinator speak to you in your preferred language? ..	128
Table 108. If your support workers and/or case manager/service coordinator do not speak to you in your preferred language is a translator provided when needed?	129
Table 109. Does your family member's case manager/service coordinator support you in a way that is respectful to your culture?	130
Table 110. Do support workers for your family members provide services in a way that is respectful of your culture? ..	131
Table 111. Do you believe your plans for how to handle your family members needs during a natural disaster (such as a wildfire or earthquake) will be effective?	132
Table 112a. What else do you need to make an effective plan?.....	133
Table 112b. What else do you need to make an effective plan? (continued).....	134
Table 112c. What else do you need to make an effective plan? (continued)	135
Table 113. Do you know what to do if you disagree with your regional center about services and/or eligibility? (For example, how to request a Fair Hearing)	136

Quality Assessment Project and National Core Indicators®

This report contains regional center level results from California’s statewide National Core Indicators Adult Family Survey data collection from fiscal year 2021-22 in accordance with Welfare and Institutions Code (WIC), Section 4571. WIC, Section 4571 directs the Department of Developmental Services (DDS) to collect accurate, reliable, and valid consumer and family satisfaction measures as well as individual outcome data. In California, data from this project will be used to review and benchmark statewide and regional center developmental disability service system performance¹. Regional centers can use this report to help guide strategic planning and monitor systemic changes.

What is NCI®–IDD?

The National Core Indicators® – Intellectual and Developmental Disabilities (NCI®-IDD) 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 2021-22, a total of 48 states, the District of Columbia and 22 sub-state entities participated in NCI-IDD.

What is the NCI-IDD Adult Family Survey?

The NCI-IDD 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 in addition to case management from the Regional Center² (RC). The survey collects demographic information on both the individual receiving services (‘family member’) as well

¹ Refer to the 2021-22 California Adult Family Survey Report for information about Quality Assessment Project implementation, NCI and California’s statewide results.

² NCI Averages include states that provide services through a central IDD Agency

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.

Please note that while the term “case manager” is used throughout this report, the same role may also be referred to as “service coordinator” or “supports coordinator” depending on the state.

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.

Note: All Californians with an intellectual or developmental disability as defined by California law have both a civil right and an individual entitlement to receive services from the California Department of Developmental Services. As a result of these requirements, all eligible individuals are enrolled in California’s service system, and California establishes no waiting list for services. This impacts comparability between California NCI-IDD survey results and the NCI-IDD survey results of other states.

Important note on Impact of COVID-19

The 2021-22 NCI-IDD Adult Family Survey (AFS) data collection cycle began July 1, 2021 and ended June 30, 2022. California began data collection December 2021. As COVID-19 variants continued to impact communities across the United States, states were impacted in various ways throughout the year. Because the surveys do not collect information on the date of survey completion, these data cannot fully assess what impact the pandemic had on data collected at different times throughout the year. While these data will serve as an important baseline, and meaningful way for states to understand the overall impact of services on families of individuals being served, these data should be read with caution. To help better understand the overall impact of COVID-19 on families, NCI-IDD added a state optional COVID-19 Supplement to all NCI-IDD Surveys. The COVID-19 Supplement is intended to support the understanding of the experience of people with intellectual/developmental disabilities and their families at the beginning of the COVID-19 pandemic, and their interactions with services during that time. Last year’s Adult Family survey COVID-19 Supplement can be found [here](#).

What is included in this report?

This report includes this regional center’s Adult Family Survey data compared to the CA Statewide, and NCI-IDD Average.

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

If there are fewer than 20 respondents to a question, the data are shown as “n/a”, however, data are included in the statewide average.

This report also contains questions that California specifically requested be added. These questions are noted as “CA specific question” and for which there is no NCI-IDD comparison data. For those questions, the NCI-IDD Average is reported as “n/a”.

Demographics

Demographics of Family Member Receiving Services

This section provides demographic information about the respondent.

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

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

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

RC v CA v NCI	Yes	No	N
GGRC	16%	84%	399
CA	18%	82%	7,752
NCI	16%	84%	11,521

Table 2. Family Member's Age

RC v CA v NCI	Average Age	N
GGRC	36.3	390
CA	34.2	7,446
NCI	34.6	11,350

Table 3. Family Member's Gender

For "Other", the percentages for CA and Weighted NCI Average are non-zero even though they are displayed as a rounded-down 0%.

RC v CA v NCI	Male	Female	Other	N
GGRC	58%	41%	0%	394
CA	59%	40%	0%	7,692
NCI	59%	41%	0%	11,563

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.

RC v CA v NCI	American Indian or Alaska Native	Asian	Black or African American	Pacific Islander	White	Hispanic or Latino	Other	Prefer Not to Say
GGRC	1%	38%	7%	1%	35%	21%	3%	2%
CA	2%	15%	8%	1%	38%	41%	2%	3%
NCI	2%	10%	10%	0%	54%	27%	2%	2%

Table 5a. Family Member's Disabilities

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.

RC v CA v NCI	Intellectual Disability	Mood Illness or Psychiatric Disorder	Autism Spectrum Disorder	Cerebral Palsy	Limited or No Vision	Severe or Profound Hearing Loss
GGRC	67%	18%	35%	16%	7%	6%
CA	61%	21%	38%	16%	8%	5%
NCI	66%	24%	38%	17%	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.

RC v CA v NCI	Brain Injury	Seizure Disorder or Neurological Problem	Chemical Dependency	Down Syndrome	Prader-Willi Syndrome	Fetal Alcohol Spectrum Disorder	Other
GGRC	7%	26%	1%	13%	1%	1%	16%
CA	8%	23%	1%	14%	1%	1%	16%
NCI	8%	26%	0%	15%	1%	1%	18%

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.

RC v CA v NCI	Cardiovascular Disease	Diabetes	Cancer	High Blood Pressure	High Cholesterol
GGRC	7%	15%	4%	26%	27%
CA	8%	17%	4%	26%	28%
NCI	9%	16%	4%	26%	28%

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.

RC v CA v NCI	Dysphagia	Pressure Ulcers	Alzheimer's Disease or Other Dementia	Oral Health or Dental Problems	Sleep Apnea
GGRC	6%	0%	3%	11%	19%
CA	6%	1%	2%	12%	17%
NCI	8%	2%	2%	12%	18%

Table 6c. Family Member's Health Conditions (continued)

Added conditions in 2021-22 are denoted with an asterisk (*); 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.

RC v CA v NCI	Asthma*	Other Pulmonary Diagnosis (e.g., COPD, bronchitis, emphysema)*	Chronic Kidney Disease*	Long-term Health Problems Associated with COVID-19 (also known as Long COVID)*	Other
GGRC	15%	5%	4%	0%	26%
CA	18%	5%	3%	1%	26%
NCI	18%	5%	3%	1%	26%

Table 7. Family Member's Preferred Means of Communication

RC v CA v NCI	Spoken	Gestures or Body Language	Sign Language or Finger Spelling	Communication Aid or Device	Other	N
GGRC	82%	10%	1%	3%	5%	395
CA	82%	10%	1%	1%	5%	7,859
NCI	81%	11%	1%	1%	5%	11,701

Table 8a. Family Member's Preferred Language

CA specific question. The standard NCI-IDD Adult Family Survey responses are limited to: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and other. California adds additional language responses to their survey tool; the NCI-IDD Average for "Other" captures the additional languages in the standard tool.

RC v CA v NCI	English	Spanish	Chinese (including Mandarin, Cantonese, and Hokkien)	Tagalog	Vietnamese	American Sign Language (ASL)	N
GGRC	69%	10%	9%	2%	2%	0%	404
CA	70%	17%	1%	1%	1%	0%	7,930
NCI	81%	10%	1%	0%	1%	1%	11,797

Table 8b. Family Member's Preferred Language (Continued)

CA specific question. The standard NCI-IDD Adult Family Survey responses are limited to: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and other. California adds additional language responses to their survey tool; the NCI-IDD Average for "Other" captures the additional languages in the standard tool.

RC v CA v NCI	Arabic	Armenian	Farsi	Hindi	Hmong	N
GGRC	0%	0%	0%	0%	0%	404
CA	0%	0%	0%	0%	0%	7,930
NCI	n/a	n/a	n/a	n/a	n/a	11,797

Table 8c. Family Member's Preferred Language (Continued)

CA specific question. The standard NCI-IDD Adult Family Survey responses are limited to: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and other. California adds additional language responses to their survey tool; the NCI-IDD Average for "Other" captures the additional languages in the standard tool.

RC v CA v NCI	Japanese	Khmer	Korean	Laotian	Russian	Other	N
GGRC	0%	0%	0%	1%	0%	8%	404
CA	0%	0%	0%	0%	0%	9%	7,930
NCI	n/a	n/a	n/a	n/a	n/a	7%	11,797

Table 9. 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.

RC v CA v NCI	No Guardianship/ Conservatorship	Limited	Full	Has Guardianship/ Conservatorship but Level Is Unknown	N
GGRC	43%	26%	24%	6%	380
CA	44%	26%	25%	5%	7,257
NCI	35%	20%	41%	4%	10,936

Table 10. Guardian or Conservator Relationship to Family Member

RC v CA v NCI	Family	Friend	Regional Center Employee or Guardianship Agency	Other	N
GGRC	95%	1%		0% 4%	194
CA	96%	1%		1% 3%	3,732
NCI	95%	1%		0% 4%	6,416

Table 11a. Family Member's Highest level of Education

RC v CA v NCI	Did Not Complete High School (and Not Currently Enrolled)	Currently Enrolled in High School	High School Certification	N
GGRC	23%	3%	38%	375
CA	19%	3%	34%	7,410
NCI	17%	3%	34%	11,202

Table 11b. Family Member's Highest level of Education (continued)

RC v CA v NCI	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
GGRC	18%	5%	8%	5%	375
CA	26%	4%	8%	6%	7,410
NCI	31%	4%	6%	4%	11,202

Table 12. 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.

RC v CA v NCI	No Support Needed	Some Support Needed	Extensive Support Needed	N
GGRC	55%	26%	18%	375
CA	51%	30%	19%	7,535
NCI	53%	30%	17%	11,315

Table 13. Family Member's Level of Help Needed with Personal Care Activities (for example, bathing, dressing, eating)

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

RC v CA v NCI	No Support Needed	Some Support Needed	Extensive Support Needed	N
GGRC	25%	38%	37%	392
CA	27%	36%	37%	7,717
NCI	26%	37%	37%	11,583

Table 14. Family Member's Need for Help with Other Daily Activities (for example, 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.

RC v CA v NCI	No Support Needed	Some Support Needed	Extensive Support Needed	N
GGRC	8%	25%	67%	394
CA	8%	27%	65%	7,719
NCI	6%	23%	71%	11,569

Demographics of Respondents

This section provides demographic information about the respondent

Table 15a. Language Usually Spoken at Home

The standard NCI-IDD Adult Family Survey tool includes: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and Other. California adds additional language categories to their survey tool; the NCI-IDD Average for “Other” captures the additional languages in the standard tool.

RC v CA v NCI	English	Spanish	Chinese (Including Mandarin, Cantonese, and Hokkien)	Tagalog	Vietnamese	American Sign Language (ASL)	N
GGRC	61%	13%	12%	4%	2%	0%	400
CA	64%	24%	2%	1%	1%	0%	7,945
NCI	77%	15%	1%	1%	1%	0%	11,803

Table 15b. Language Usually Spoken at Home

The standard NCI-IDD Adult Family Survey tool includes: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and Other. California adds additional language categories to their survey tool; the NCI-IDD Average for “Other” captures the additional languages in the standard tool.

RC v CA v NCI	Arabic	Armenian	Farsi	Hindi	Hmong	N
GGRC	0%	0%	0%	0%	1%	400
CA	0%	0%	0%	0%	0%	7,945
NCI	n/a	n/a	n/a	n/a	n/a	11,803

Table 15c. Language Usually Spoken at Home

The standard NCI-IDD Adult Family Survey tool includes: English, Spanish, Chinese (including Mandarin, Cantonese, and Hokkien) Tagalog (including Filipino), Vietnamese, American Sign Language (ASL), and Other. California adds additional language categories to their survey tool; the NCI-IDD Average for “Other” captures the additional languages in the standard tool.

RC v CA v NCI	Japanese	Khmer	Korean	Laotian	Russian	Other	N
GGRC	0%	0%	0%	1%	0%	7%	400
CA	0%	0%	1%	0%	0%	6%	7,945
NCI	n/a	n/a	n/a	n/a	n/a	5%	11,803

Table 16. Respondent’s Age

RC v CA v NCI	Under 35	35-54	55-74	75 and Older	N
GGRC	7%	18%	60%	15%	399
CA	9%	25%	55%	11%	7,933
NCI	6%	24%	59%	12%	11,803

Table 17. Respondent's Health

RC v CA v NCI	Excellent	Very Good	Good	Fair	Poor	N
GGRC	14%	32%	34%	18%	2%	404
CA	11%	30%	37%	18%	3%	7,942
NCI	11%	32%	37%	17%	2%	11,820

Table 18. Respondent's Relationship to Family Member

For "Spouse", the percentages for CA and Weighted NCI-IDD Average are non-zero even though they are displayed as a rounded-down 0%.

RC v CA v NCI	Parent	Sibling	Spouse	Grandparent	Other	N
GGRC	86%	8%	1%	1%	6%	399
CA	84%	7%	0%	2%	6%	7,799
NCI	86%	7%	0%	2%	5%	11,679

Table 19. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services

Responses are not mutually exclusive, therefore N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	No One in Family Provides Paid Support	Respondent Provides Paid Support	Other Family Member Provides Paid Support
GGRC	49%	35%	20%
CA	49%	39%	16%
NCI	52%	36%	15%

Table 20. Number of Adults in Household (Not Including Family Member Receiving Services)

RC v CA v NCI	One	Two	Three	Four or More	N
GGRC	8%	28%	40%	24%	393
CA	8%	26%	40%	26%	7,777
NCI	8%	27%	44%	22%	11,632

Table 21. Number of Children (Under 18 Years Old) in Household

RC v CA v NCI	None	One	Two	Three	Four or More	N
GGRC	86%	9%	3%	1%	0%	394
CA	81%	12%	4%	2%	1%	7,806
NCI	84%	10%	4%	2%	1%	11,678

Table 22. Respondent's Highest Level of Education

RC v CA v NCI	No High School Diploma or GED	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
GGRC		15%	16%	6%	16%	46% 389
CA		18%	20%	6%	21%	35% 7,762
NCI		13%	23%	7%	21%	36% 11,603

Table 23. Total Taxable Household Income of Wage Earners in the Past Year

Please note: Respondents did not respond if they were a public guardian/administrator, or if they represent a financial institution or guardianship agency. Does not include state/federal benefits such as SSI, SSDI etc.

RC v CA v NCI	No Earned Income	Up to \$15,000	\$15,001-\$25,000	\$25,001-\$50,000	\$50,001-\$75,000	Over \$75,000	Prefer Not to Say	N
GGRC	12%	5%	10%	16%	12%	22%	22%	379
CA	14%	8%	9%	17%	12%	17%	23%	7,604
NCI	12%	8%	9%	18%	12%	18%	22%	11,376

Table 24. Residential Designation (Urban, Suburban, or Rural)

RC v CA v NCI	Urban or Suburban (In or Near a City or Large Town)	Rural (Outside of a City or Town)	N
GGRC	97%	3%	379
CA	88%	12%	7,094
NCI	78%	22%	10,853

Services and Supports Received

This section provides information about the services and supports received by the family from the regional center³(RC).

³ Some NCI states provide services through a statewide ID/DD Agency

Table 25a. Services and Supports Received From Regional Center ⁴

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. Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Financial Support	In-Home Support	Out of home respite care	Self-Direction or Fiscal Intermediary Services
GGRC	20%	33%	25%	24%
CA	17%	35%	23%	21%
NCI	16%	38%	24%	32%

⁴ Some NCI states provide services through a statewide ID/DD Agency

Table 25b. Services and Supports Received From Regional Center (continued)⁵

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. Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Day or Employment Supports	Transportation	Mental or Behavioral Health Care or Other Treatments or Therapies
GGRC	48%	36%	21%
CA	44%	36%	22%
NCI	44%	43%	26%

Table 26. Additional Services and Supports Received (Not From the Regional Centers)⁶

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. Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Social Security Payments (SSI/SSB)	Services or Supports from Other Agencies or Organizations
GGRC	83%	36%
CA	82%	26%
NCI	87%	31%

⁵ Some NCI states provide services through a statewide ID/DD Agency

⁶ Some NCI states provide services through a statewide ID/DD Agency

Adult Family Survey Results

Information and Planning

Families have the information and support needed to take part in planning supports and services for their family member receiving services and supports from the state developmental disabilities system.

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

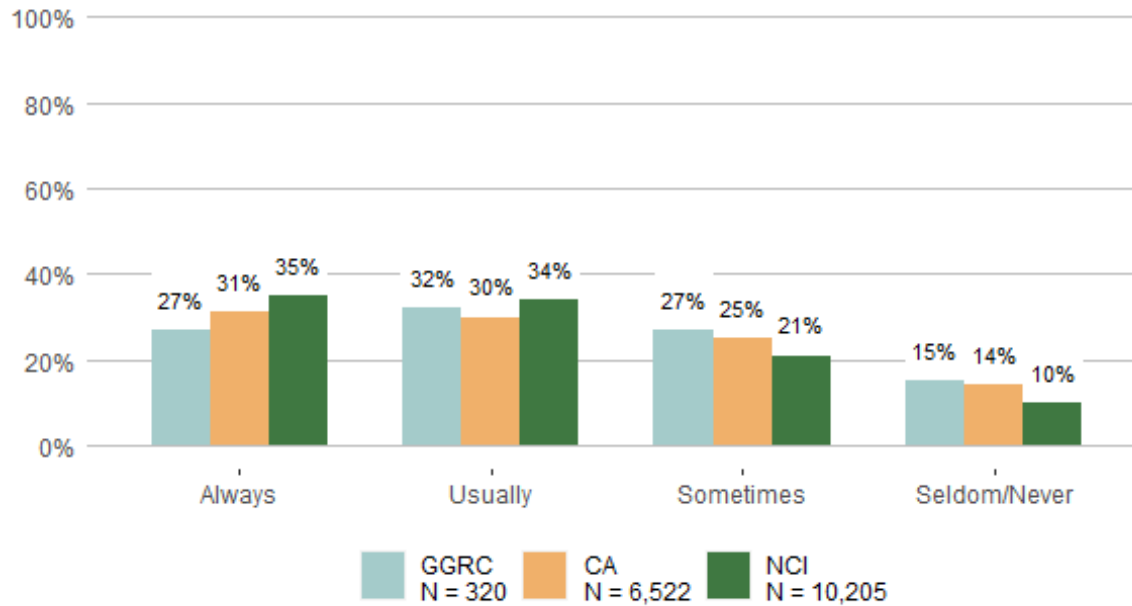


Table 27. Do you get enough information to take part in planning services for your family member?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	27%	32%	27%	15%	320
CA	31%	30%	25%	14%	6,522
NCI	35%	34%	21%	10%	10,205

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

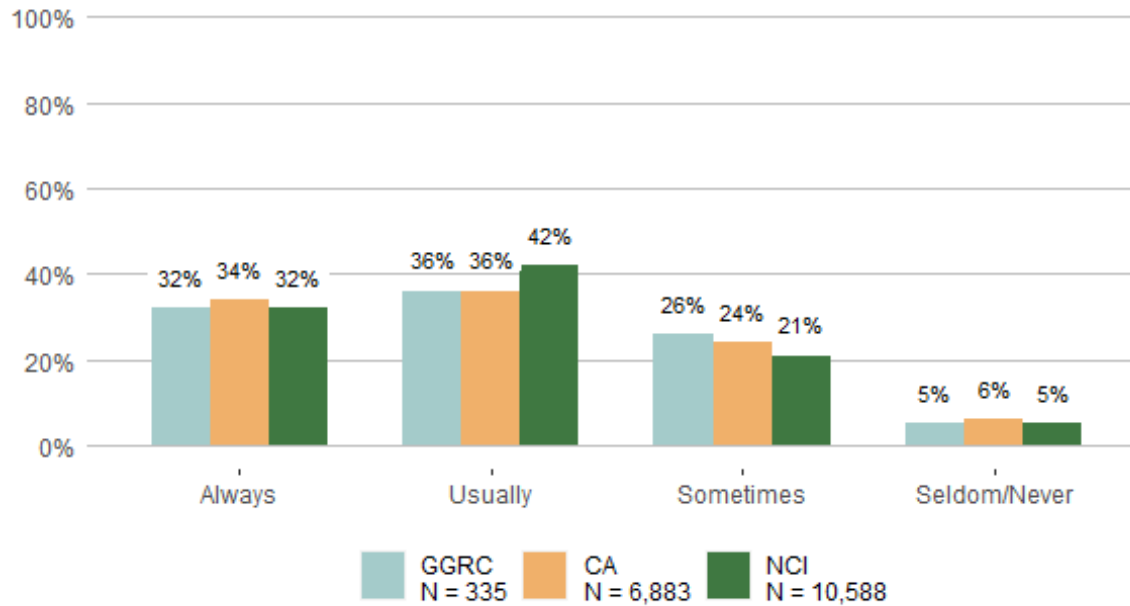


Table 28. Is the information you get about services and supports easy to understand?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	32%	36%	26%	5%	335
CA	34%	36%	24%	6%	6,883
NCI	32%	42%	21%	5%	10,588

Do you get information about services and supports
in your preferred language?

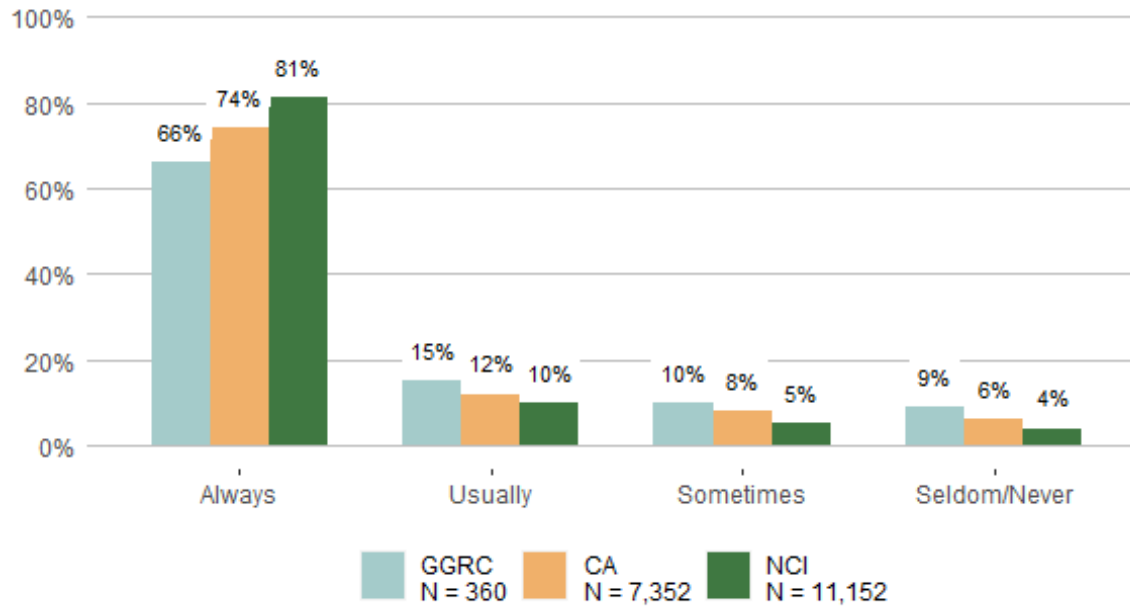


Table 29. Do you get information about services and supports in your preferred language?

New question in 2021-22

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	66%	15%	10%	9%	360
CA	74%	12%	8%	6%	7,352
NCI	81%	10%	5%	4%	11,152

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

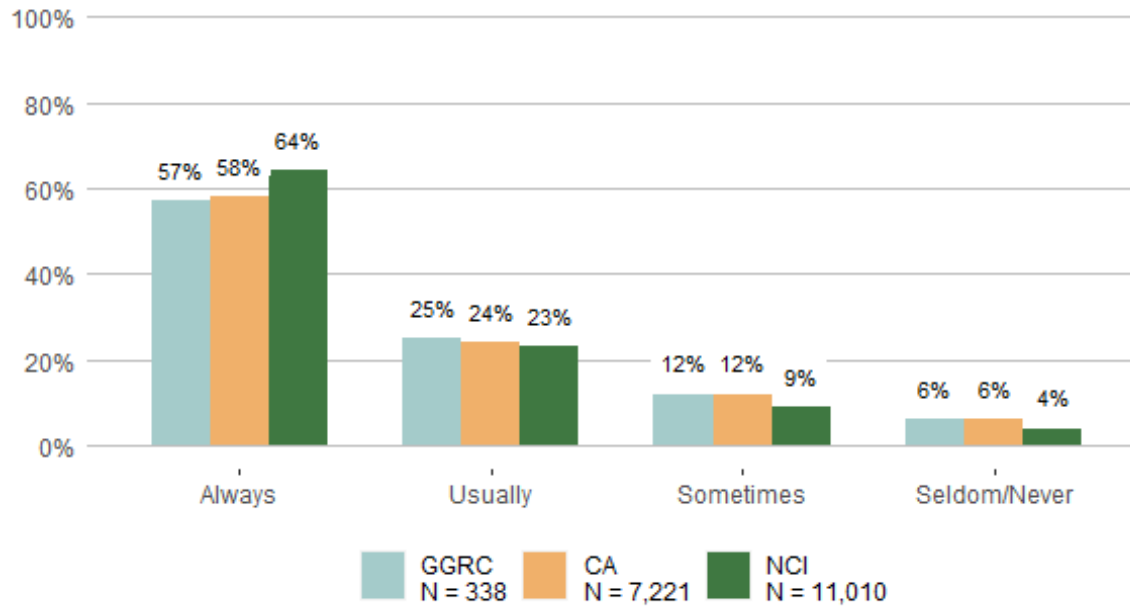


Table 30. Does the case manager/service coordinator listen to your family's choices and opinions?

Question changed in 2021-22

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	57%	25%	12%	6%	338
CA	58%	24%	12%	6%	7,221
NCI	64%	23%	9%	4%	11,010

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

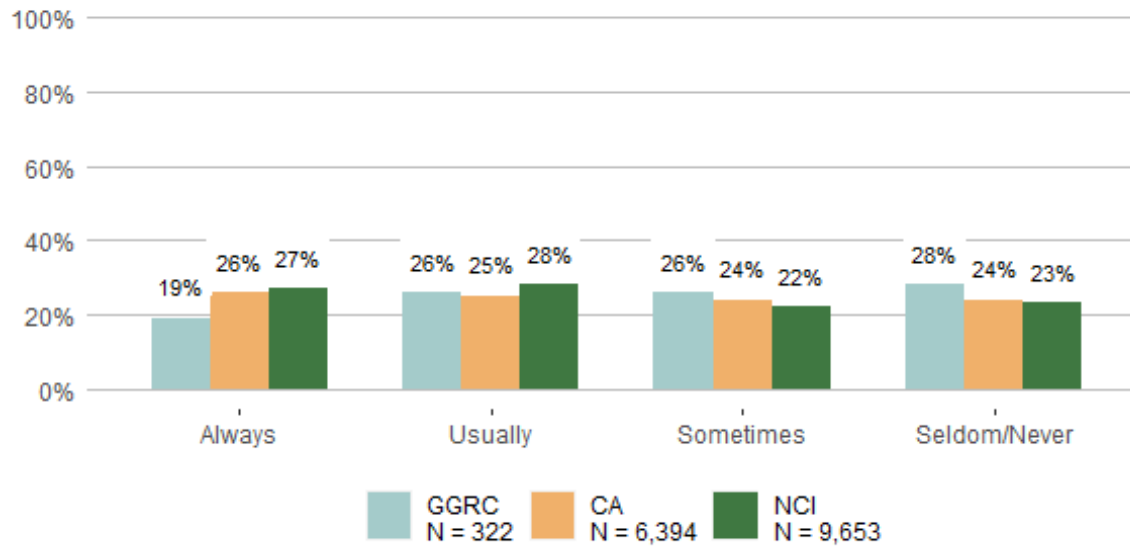


Table 31. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	19%	26%	26%	28%	322
CA	26%	25%	24%	24%	6,394
NCI	27%	28%	22%	23%	9,653

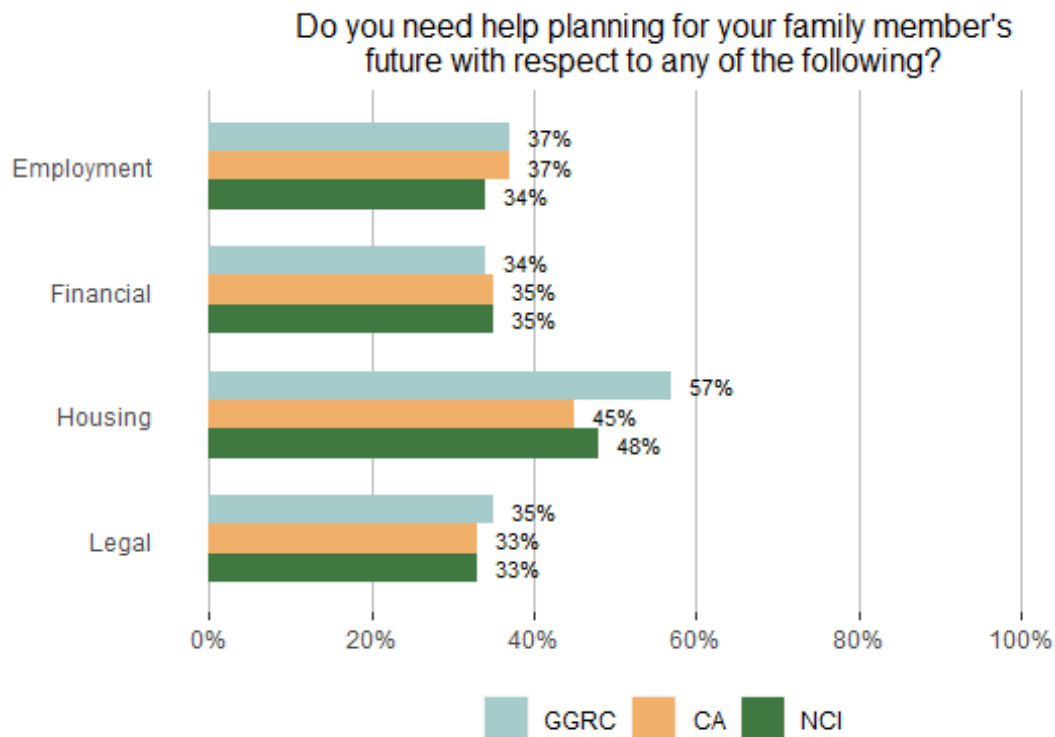


Table 32a. Do you need help planning for your family member's future with respect to any of the following?

Categories are not mutually exclusive, therefore N is not shown

RC v CA v NCI	Employment	Financial	Housing	Legal
GGRC	37%	34%	57%	35%
CA	37%	35%	45%	33%
NCI	34%	35%	48%	33%

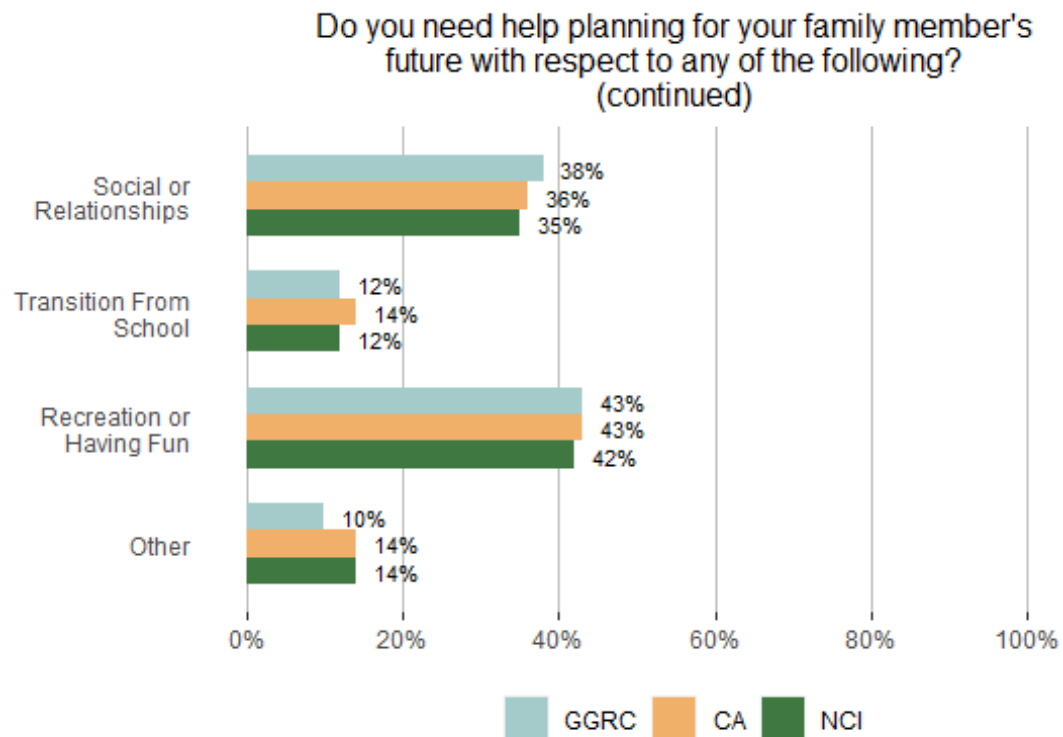


Table 32b. Do you need help planning for your family member's future with respect to any of the following? (continued)

Categories are not mutually exclusive, therefore N is not shown

RC v CA v NCI	Social or Relationships	Transition From School	Recreation or Having Fun	Other
GGRC	38%	12%	43%	10%
CA	36%	14%	43%	14%
NCI	35%	12%	42%	14%

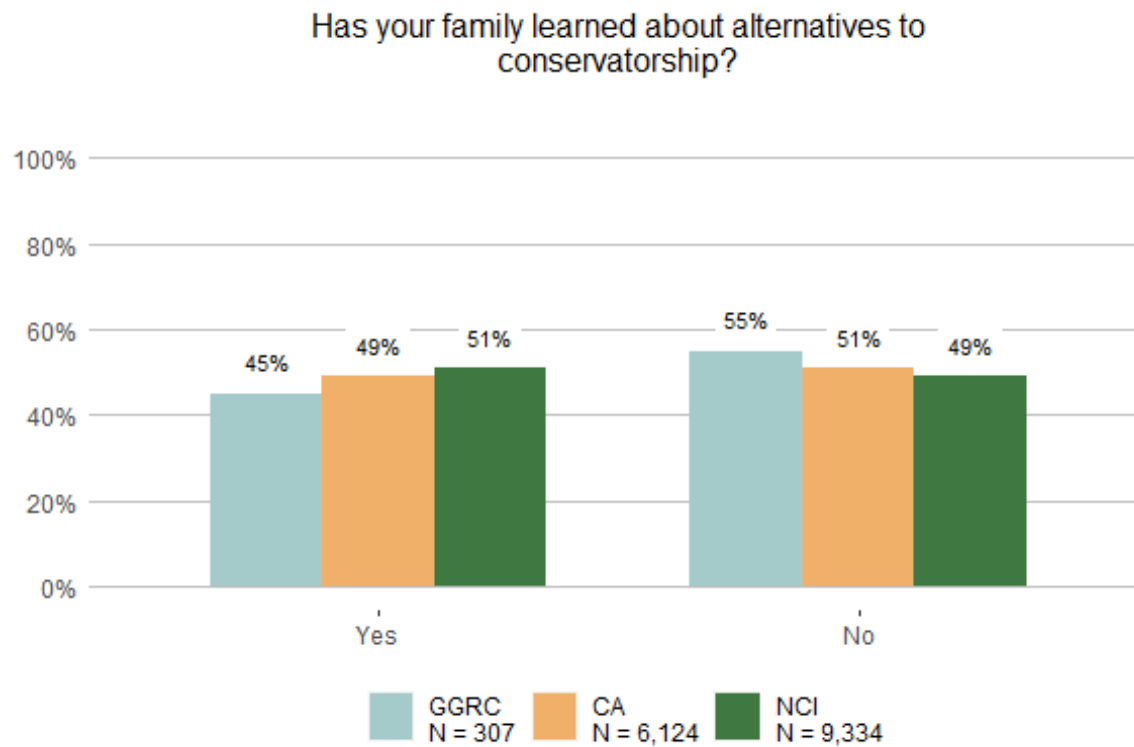


Table 33. Has your family learned about alternatives to conservatorship?

New question in 2021-22

RC v CA v NCI	Yes	No	N
GGRC	45%	55%	307
CA	49%	51%	6,124
NCI	51%	49%	9,334

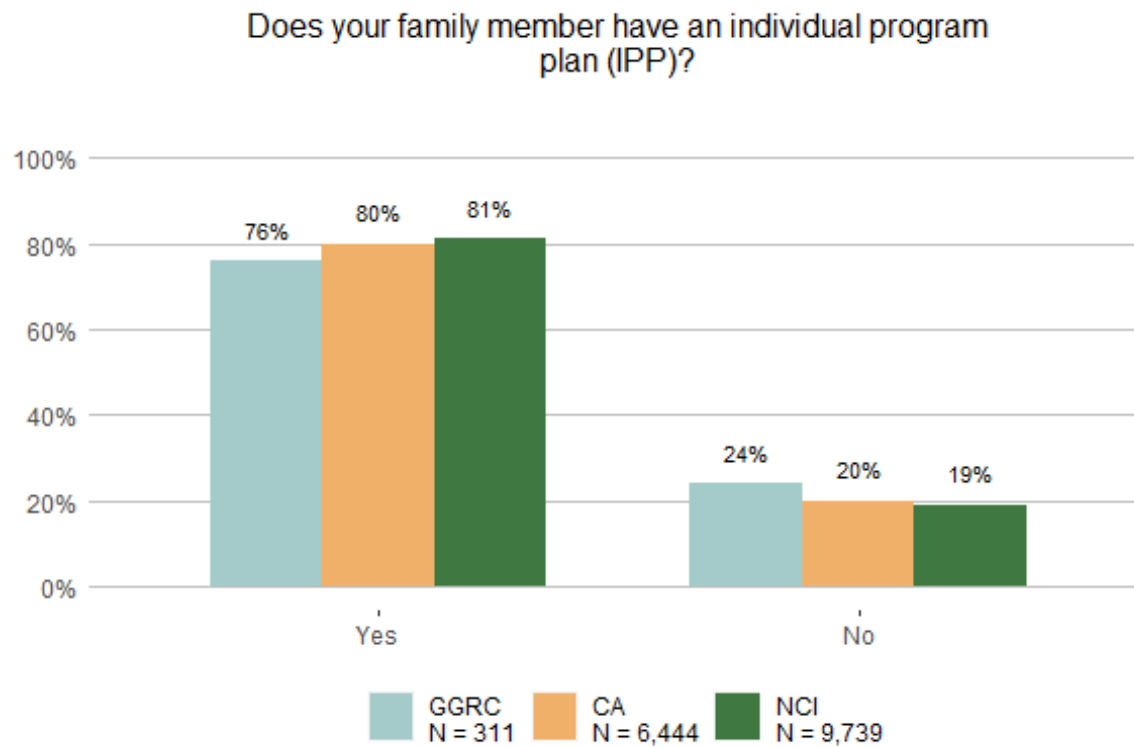


Table 34. Does your family member have an individual program plan (IPP)?

RC v CA v NCI	Yes	No	N
GGRC	76%	24%	311
CA	80%	20%	6,444
NCI	81%	19%	9,739

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

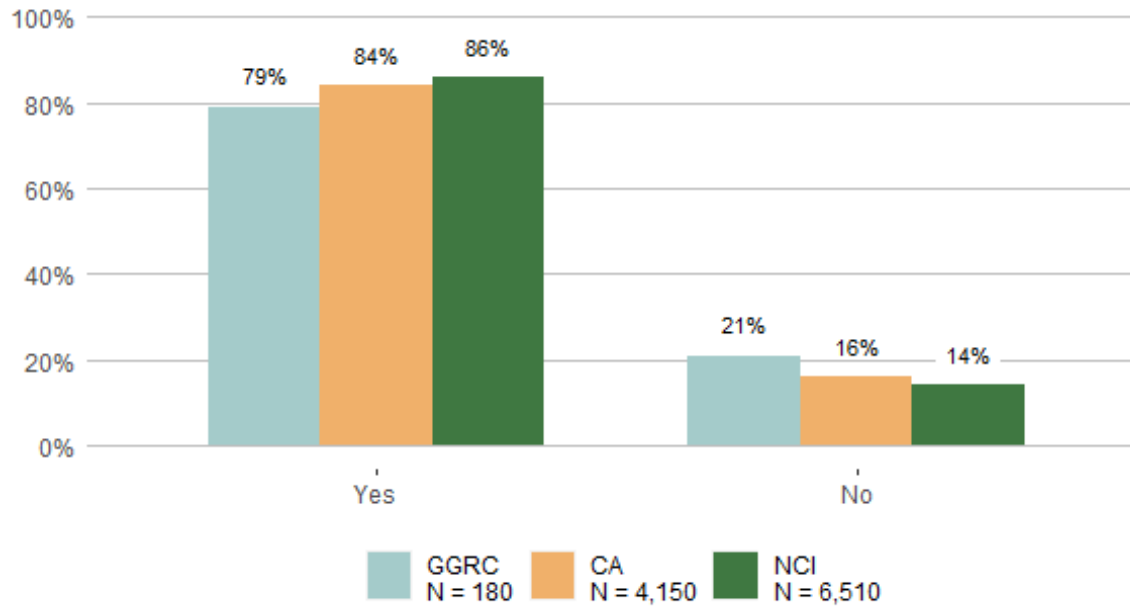


Table 35. Does the IPP include all the services and supports your family member needs?

RC v CA v NCI	Yes	No	N
GGRC	79%	21%	180
CA	84%	16%	4,150
NCI	86%	14%	6,510

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

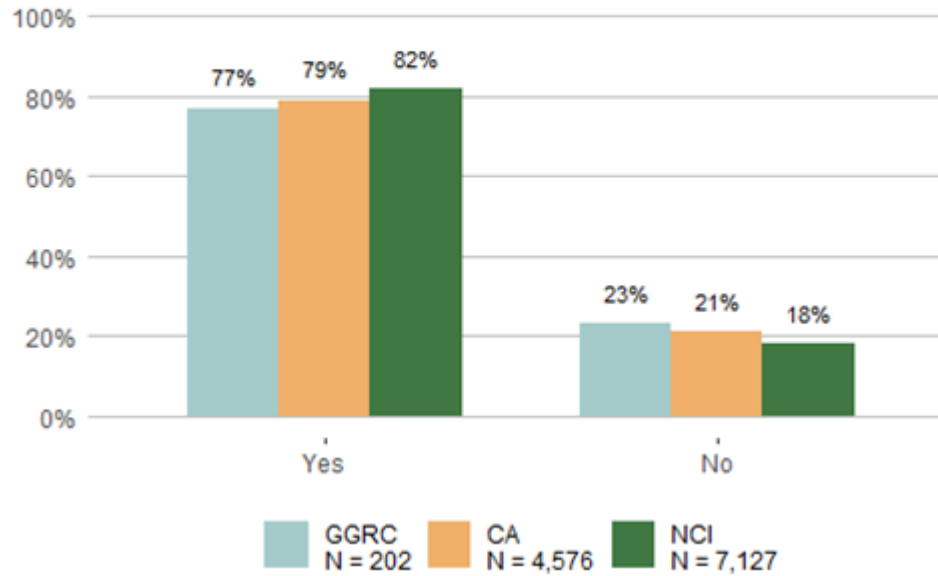


Table 36. Did you or someone else in your family (besides your family member with a disability) help make the IPP?

RC v CA v NCI	Yes	No	N
GGRC	77%	23%	202
CA	79%	21%	4,576
NCI	82%	18%	7,127

Did your family member help make the IPP?

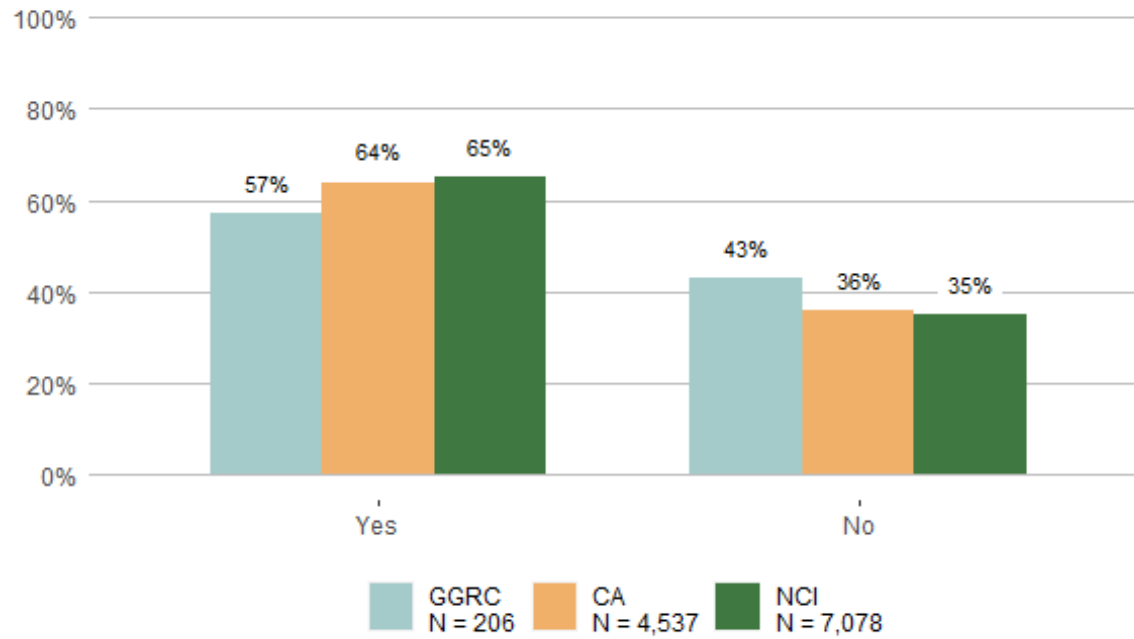


Table 37. Did your family member help make the IPP?

RC v CA v NCI	Yes	No	N
GGRC	57%	43%	206
CA	64%	36%	4,537
NCI	65%	35%	7,078

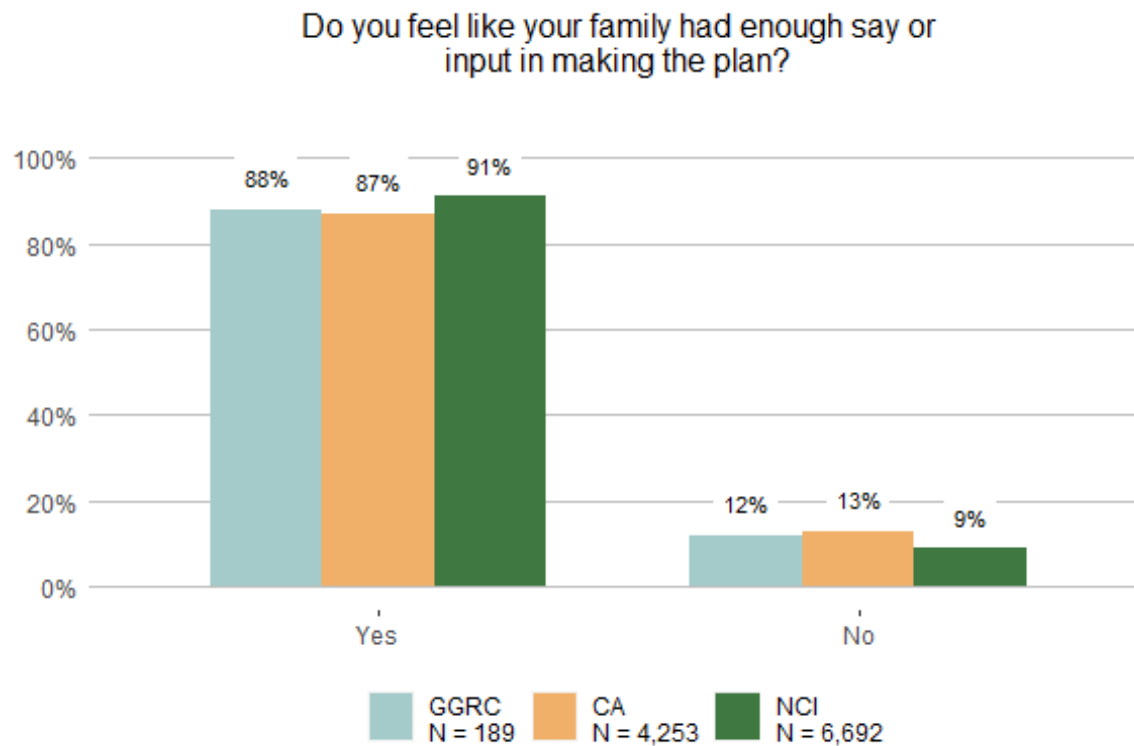


Table 38. Do you feel like your family had enough say or input in making the plan?

New question in 2021-22

RC v CA v NCI	Yes	No	N
GGRC	88%	12%	189
CA	87%	13%	4,253
NCI	91%	9%	6,692

Did your family member leave school services and begin adult services during the past 12 months?

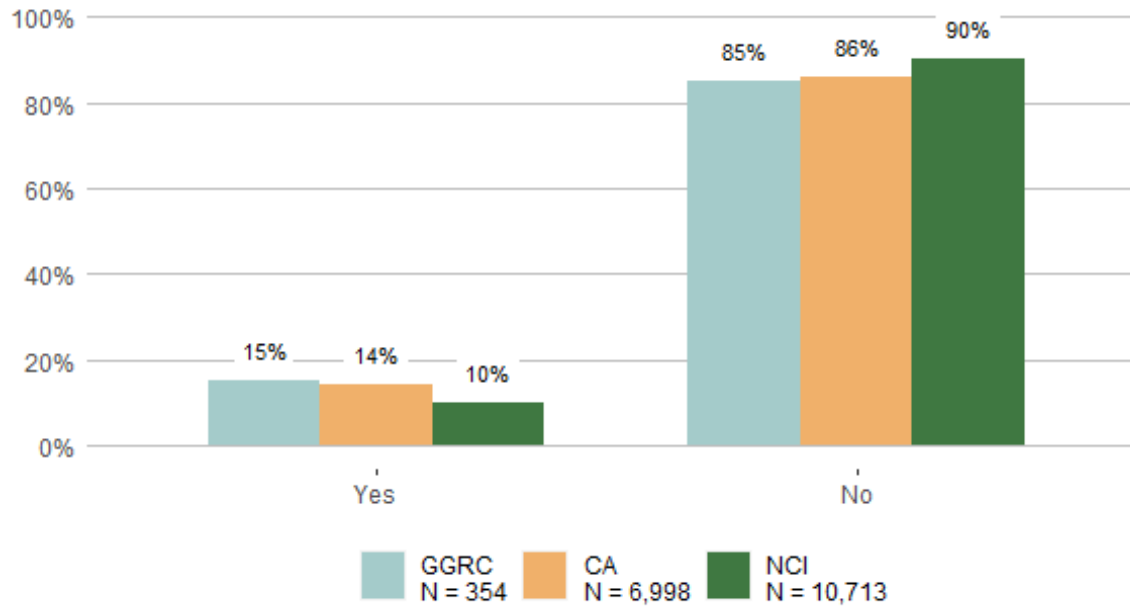


Table 39. Did your family member leave school services and begin adult services during the past 12 months?

New question in 2021-22

RC v CA v NCI	Yes	No	N
GGRC	15%	85%	354
CA	14%	86%	6,998
NCI	10%	90%	10,713

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

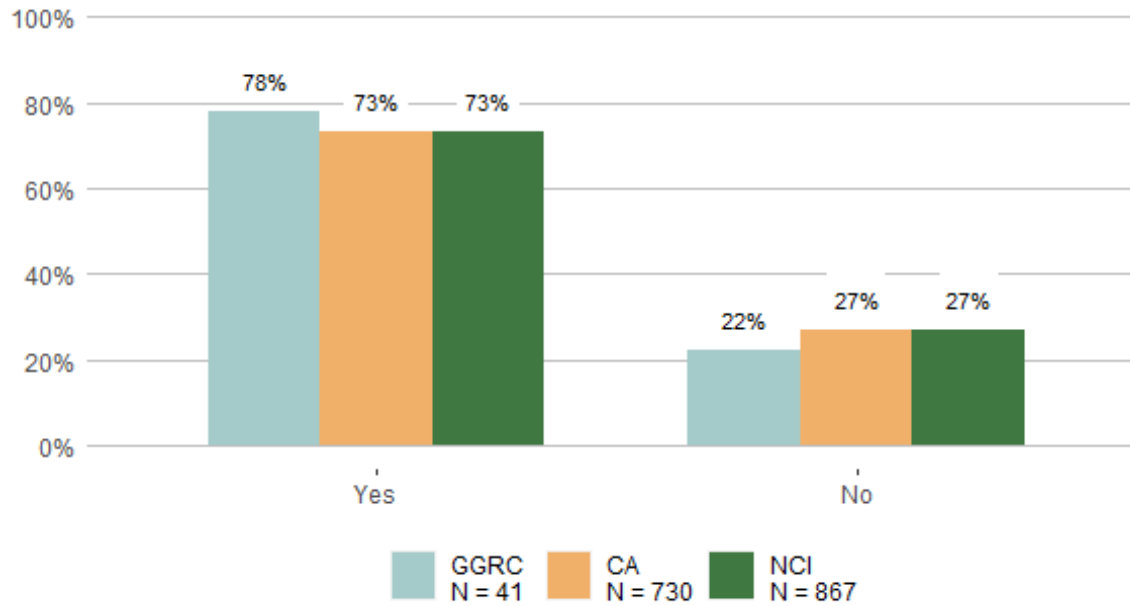


Table 40. If your family member left school services during the past year, did they have a transition plan?

RC v CA v NCI	Yes	No	N
GGRC	78%	22%	41
CA	73%	27%	730
NCI	73%	27%	867

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

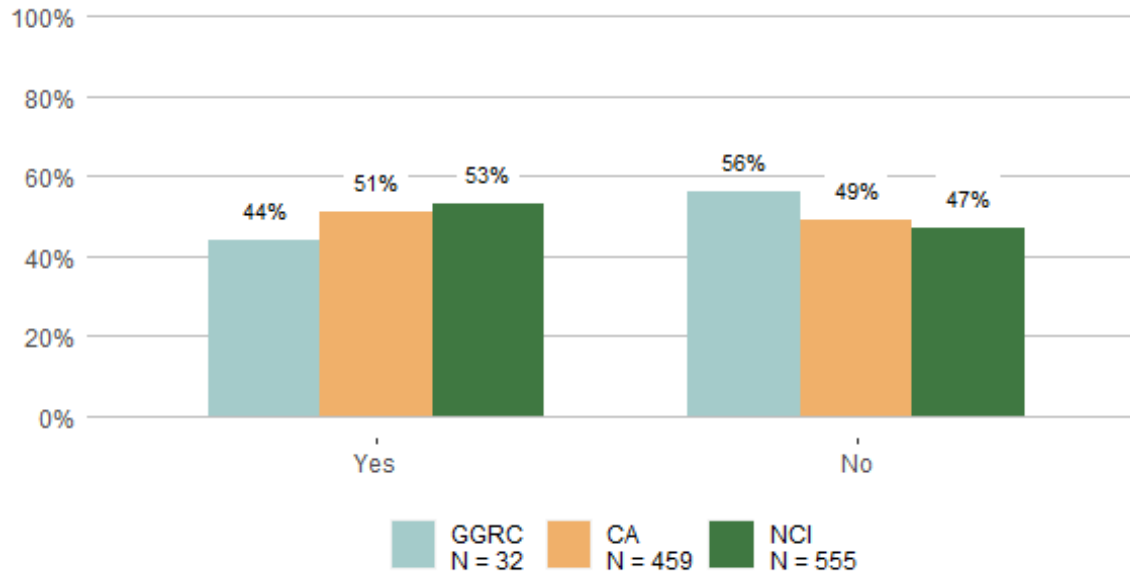


Table 41. If family member had a transition plan, did the transition plan include getting or continuing work in a community job?

RC v CA v NCI	Yes	No	N
GGRC	44%	56%	32
CA	51%	49%	459
NCI	53%	47%	555

Access and Delivery of Services and Supports

Families receive services and supports that are appropriate to the needs of the family and the family member receiving services and supports from the state developmental disabilities system.

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

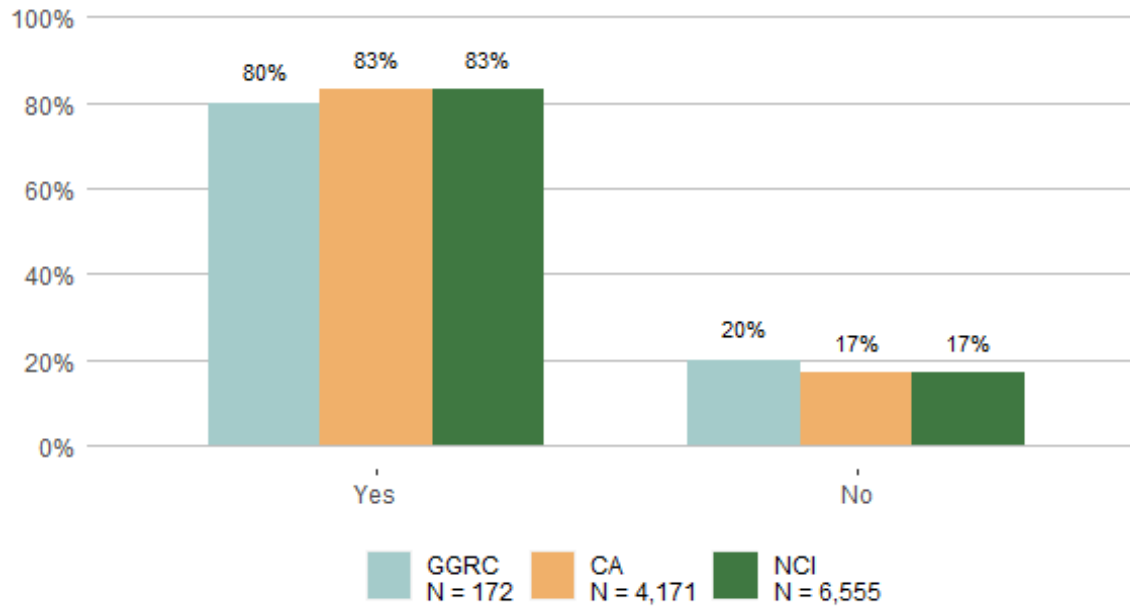


Table 42. Does your family member get all the services listed in the IPP?

RC v CA v NCI	Yes	No	N
GGRC	80%	20%	172
CA	83%	17%	4,171
NCI	83%	17%	6,555

Does your family get the supports and services it needs?

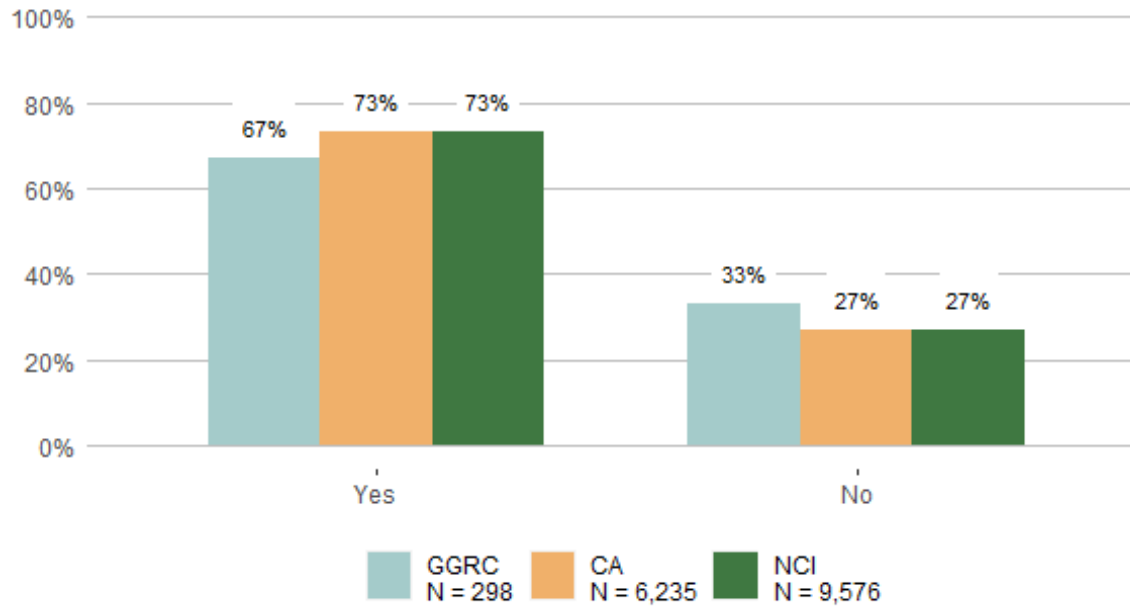


Table 43. Does your family get the supports and services it needs?

RC v CA v NCI	Yes	No	N
GGRC	67%	33%	298
CA	73%	27%	6,235
NCI	73%	27%	9,576

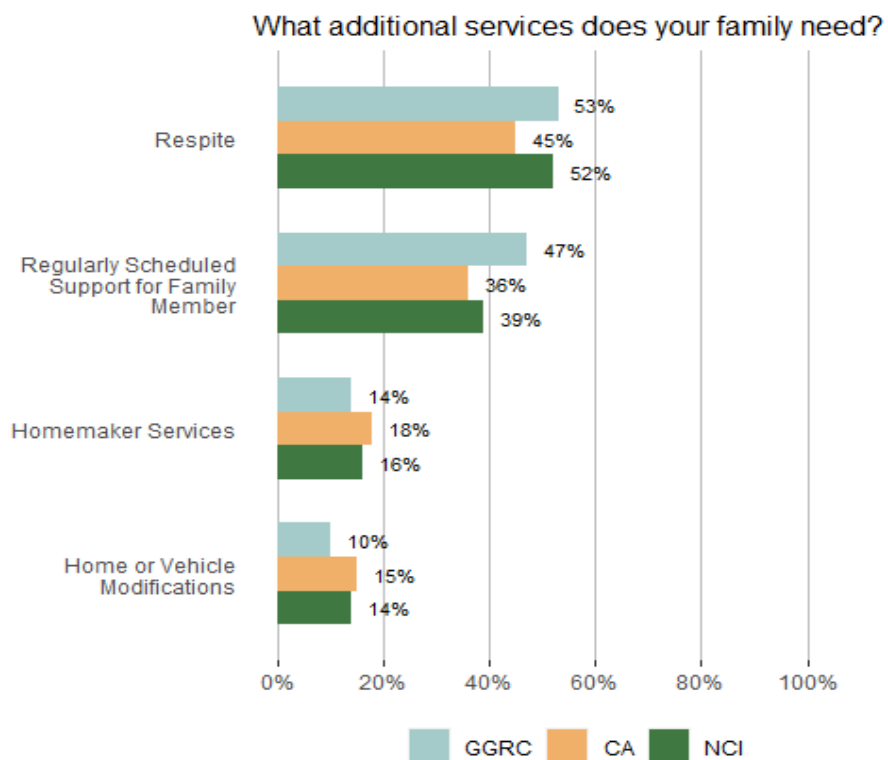


Table 44a. What additional services does your family need?

RC v CA v NCI	Respite	Regularly Scheduled Support for Family Member	Homemaker Services	Home or Vehicle Modifications
GGRC	53%	47%	14%	10%
CA	45%	36%	18%	15%
NCI	52%	39%	16%	14%

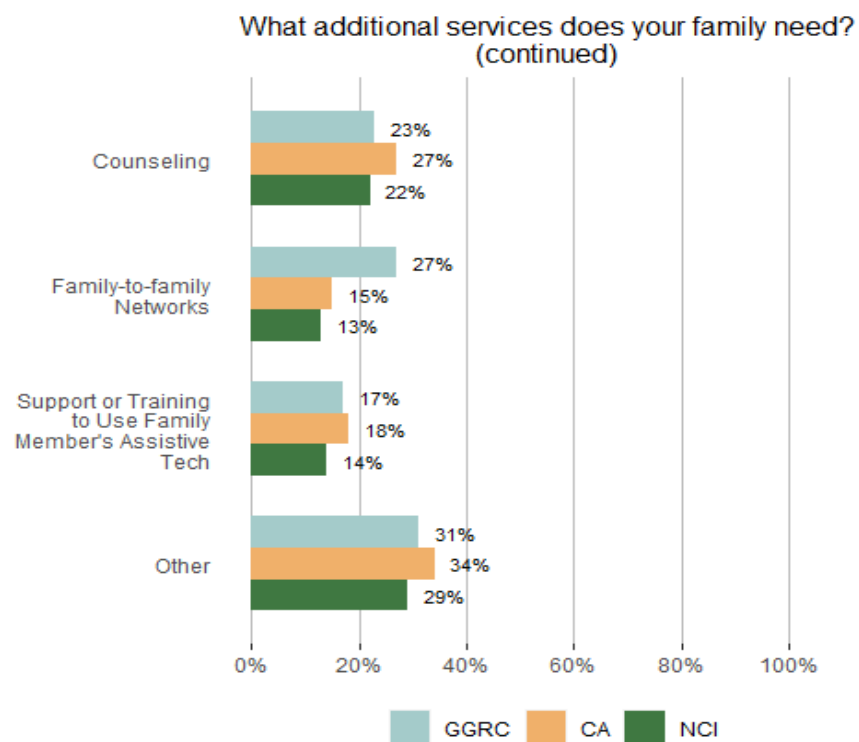


Table 44b. What additional services does your family need? (continued)

RC v CA v NCI	Counseling	Family-to-family Networks	Support or Training to Use Family Member's Assistive Tech	Other
GGRC	23%	27%	17%	31%
CA	27%	15%	18%	34%
NCI	22%	13%	14%	29%

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

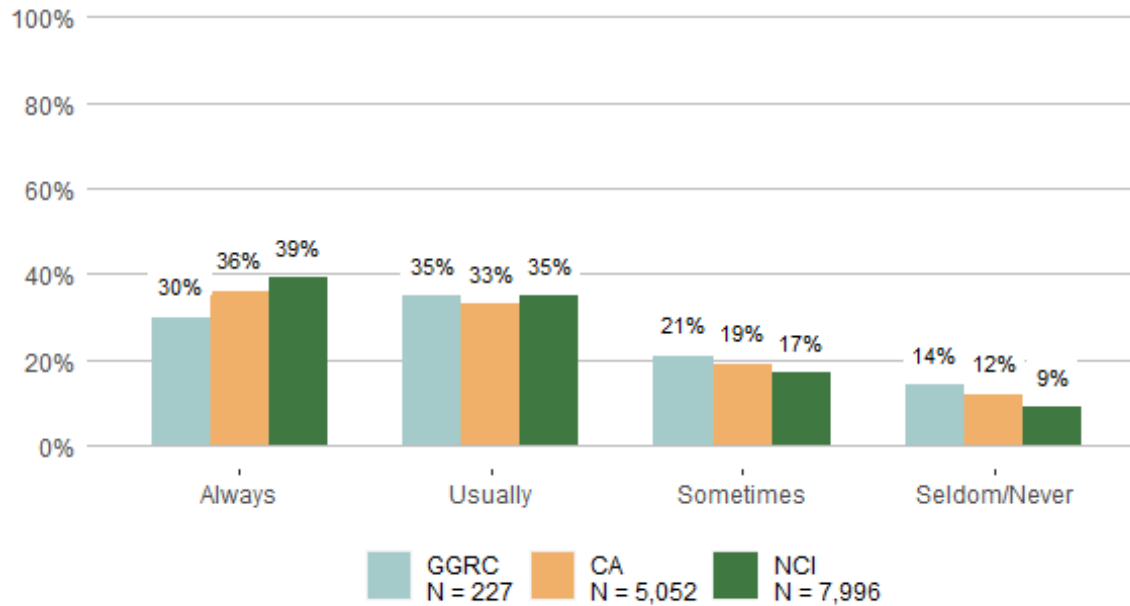


Table 45. Do services and supports change when your family's needs change?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	30%	35%	21%	14%	227
CA	36%	33%	19%	12%	5,052
NCI	39%	35%	17%	9%	7,996

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

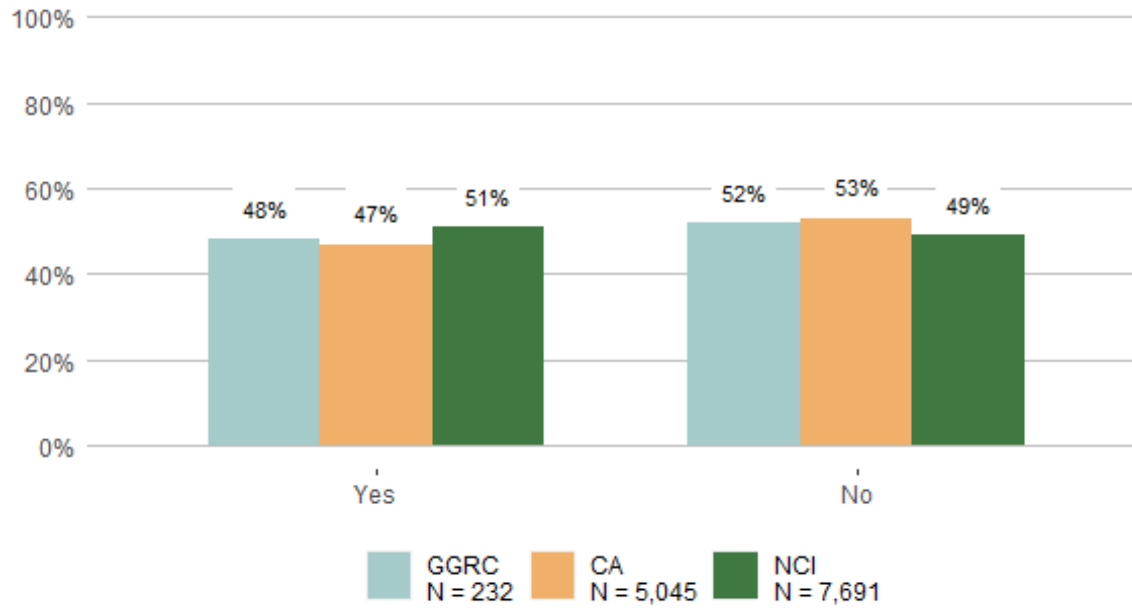


Table 46. Does your family member have enough supports to work or volunteer in the community?

RC v CA v NCI	Yes	No	N
GGRC	48%	52%	232
CA	47%	53%	5,045
NCI	51%	49%	7,691

Does your family member have the special equipment or accommodations they need?

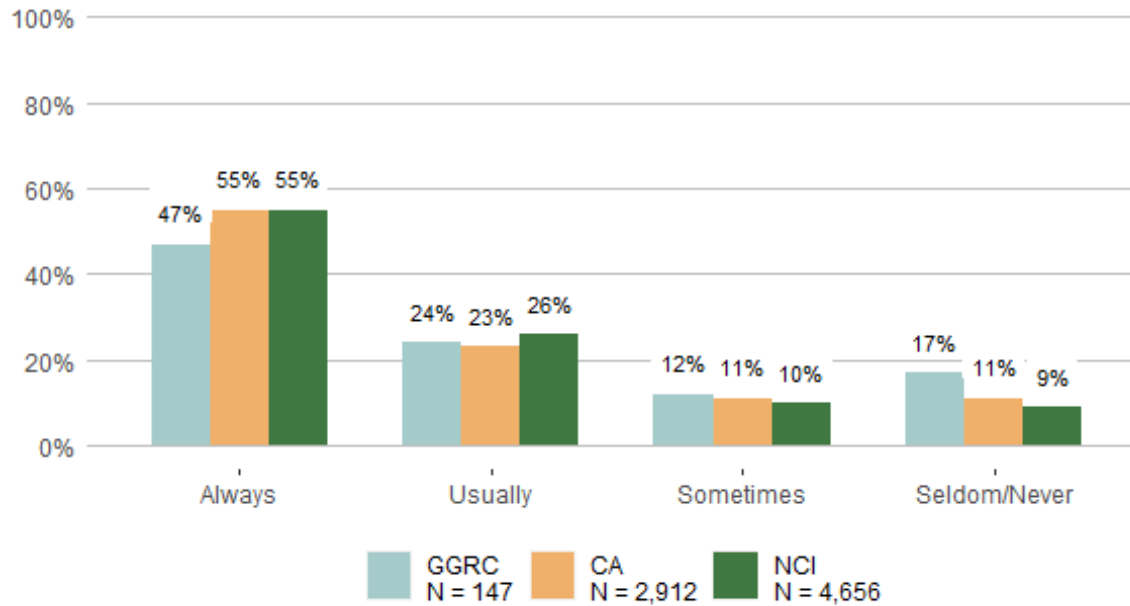


Table 47. Does your family member have the special equipment or accommodations they need?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	47%	24%	12%	17%	147
CA	55%	23%	11%	11%	2,912
NCI	55%	26%	10%	9%	4,656

If you need respite services, how often are you able to get them when needed?

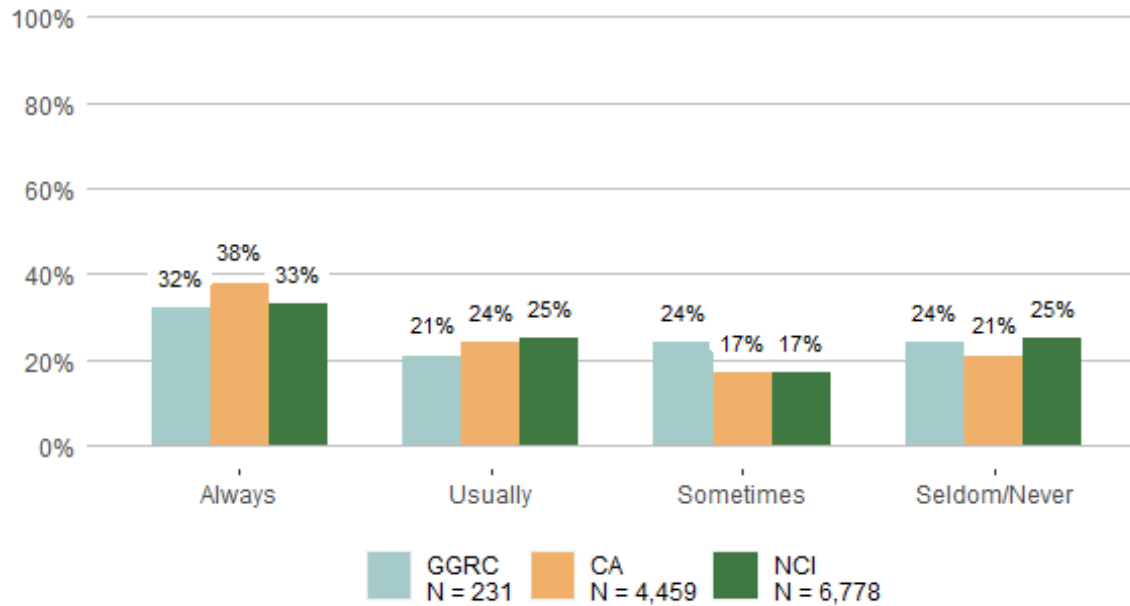


Table 48. If you need respite services, how often are you able to get them when needed?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	32%	21%	24%	24%	231
CA	38%	24%	17%	21%	4,459
NCI	33%	25%	17%	25%	6,778

If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?

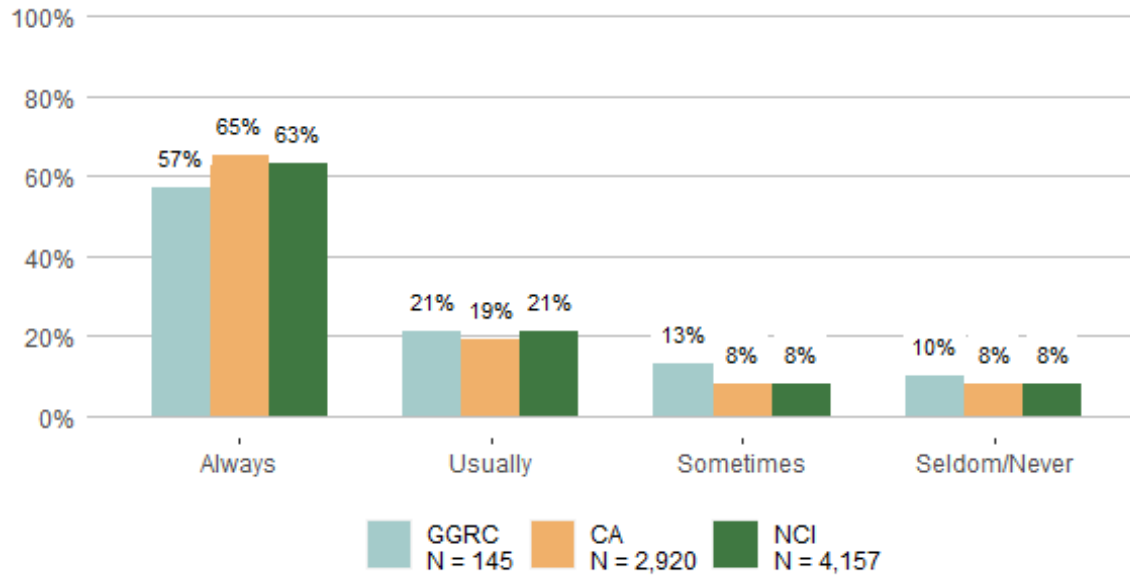


Table 49. If you have used respite services in the past 12 months, were you satisfied with the quality of the respite services?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	57%	21%	13%	10%	145
CA	65%	19%	8%	8%	2,920
NCI	63%	21%	8%	8%	4,157

Are you or your family member able to contact their support workers when you want?

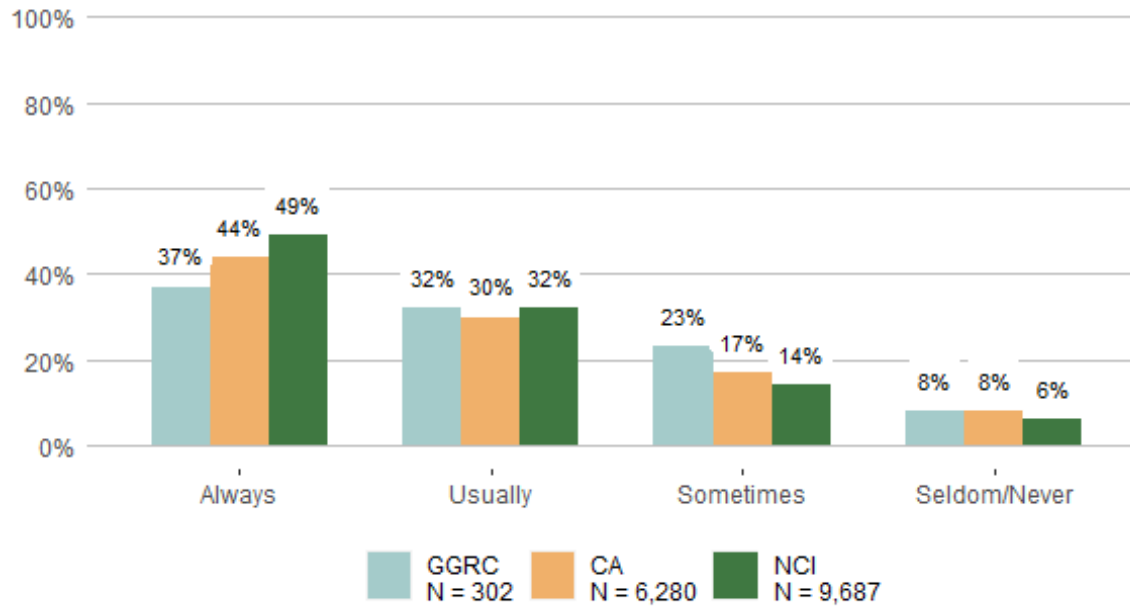


Table 50. Are you or your family member able to contact their support workers when you want?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	37%	32%	23%	8%	302
CA	44%	30%	17%	8%	6,280
NCI	49%	32%	14%	6%	9,687

Are you or your family member able to contact
their case manager/service coordinator when you
want?

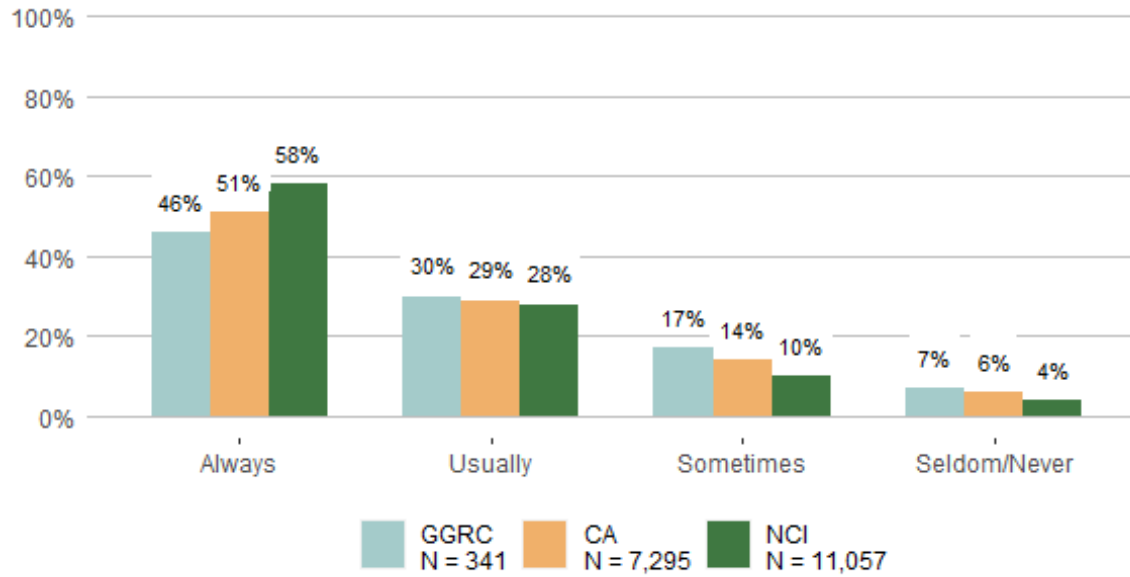


Table 51. Are you or your family member able to contact their case manager/service coordinator when you want?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	46%	30%	17%	7%	341
CA	51%	29%	14%	6%	7,295
NCI	58%	28%	10%	4%	11,057

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

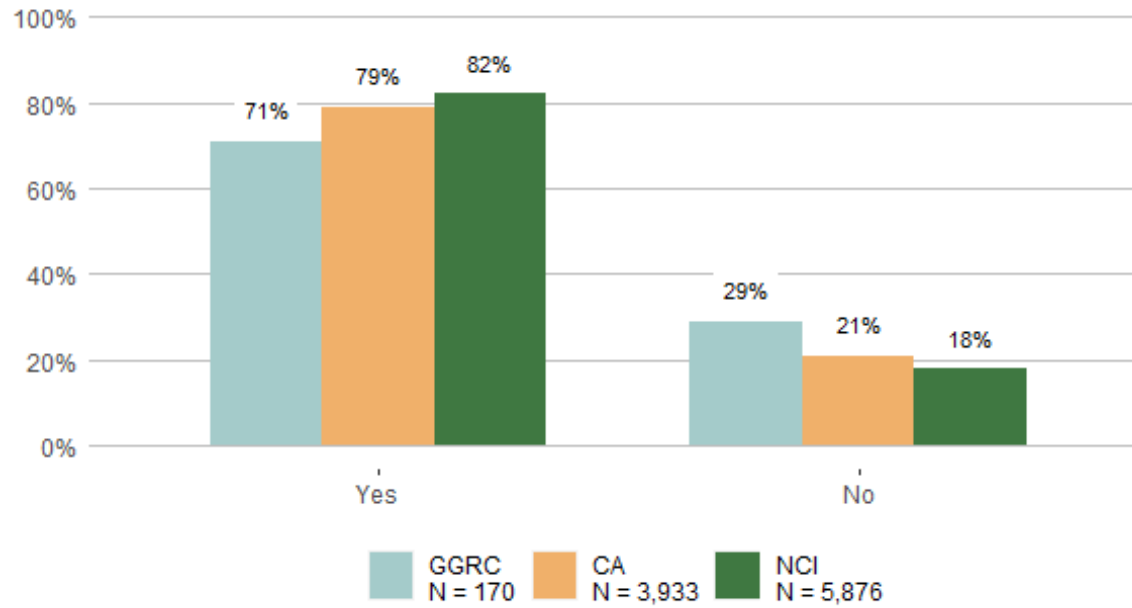


Table 52. Do service providers for your family member work together to provide support?

RC v CA v NCI	Yes	No	N
GGRC	71%	29%	170
CA	79%	21%	3,933
NCI	82%	18%	5,876

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

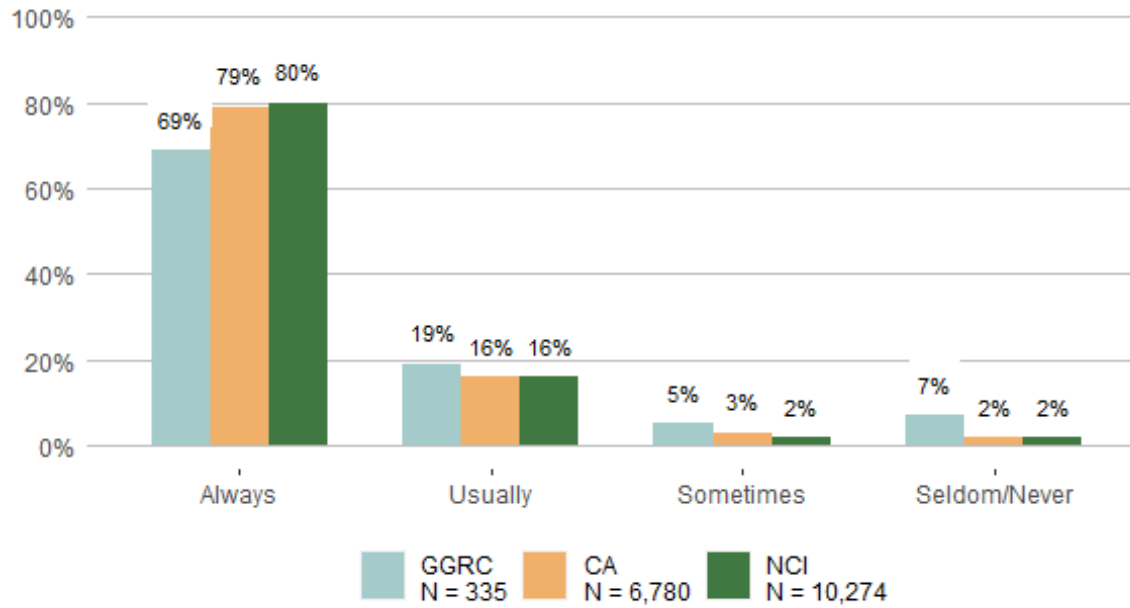


Table 53. Are services delivered in a way that is respectful of your family's culture?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	69%	19%	5%	7%	335
CA	79%	16%	3%	2%	6,780
NCI	80%	16%	2%	2%	10,274

Does your family member use technology in their everyday life to help them do things on their own?

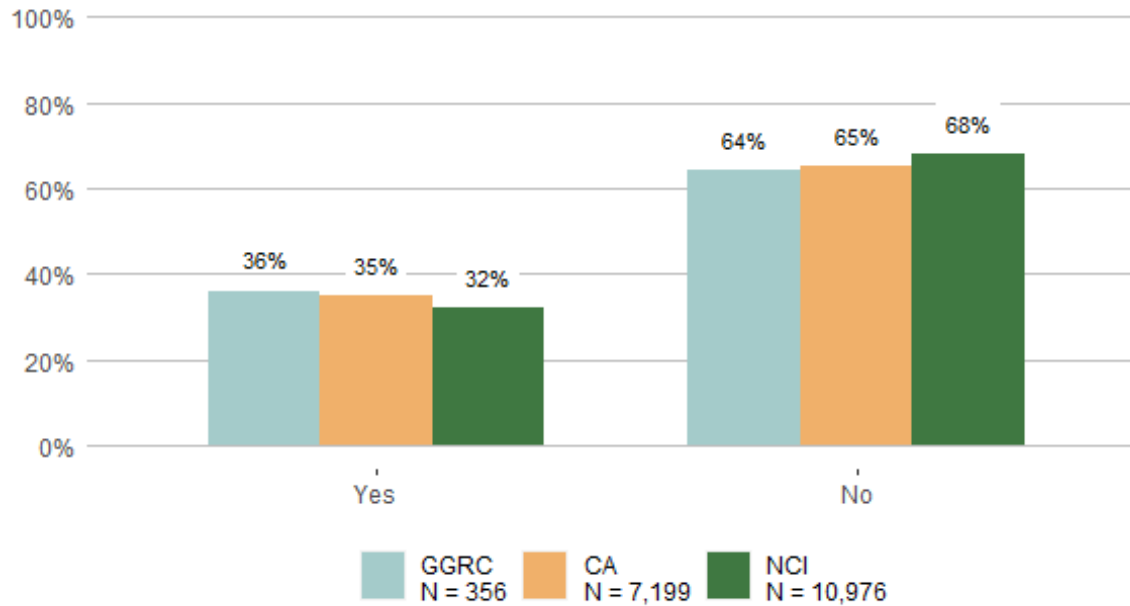


Table 54. Does your family member use technology in their everyday life to help them do things on their own?

New question in 2021-22

RC v CA v NCI	Yes	No	N
GGRC	36%	64%	356
CA	35%	65%	7,199
NCI	32%	68%	10,976

Is there a computer, tablet (for example an iPad),
or smartphone that your family can use in your
home?

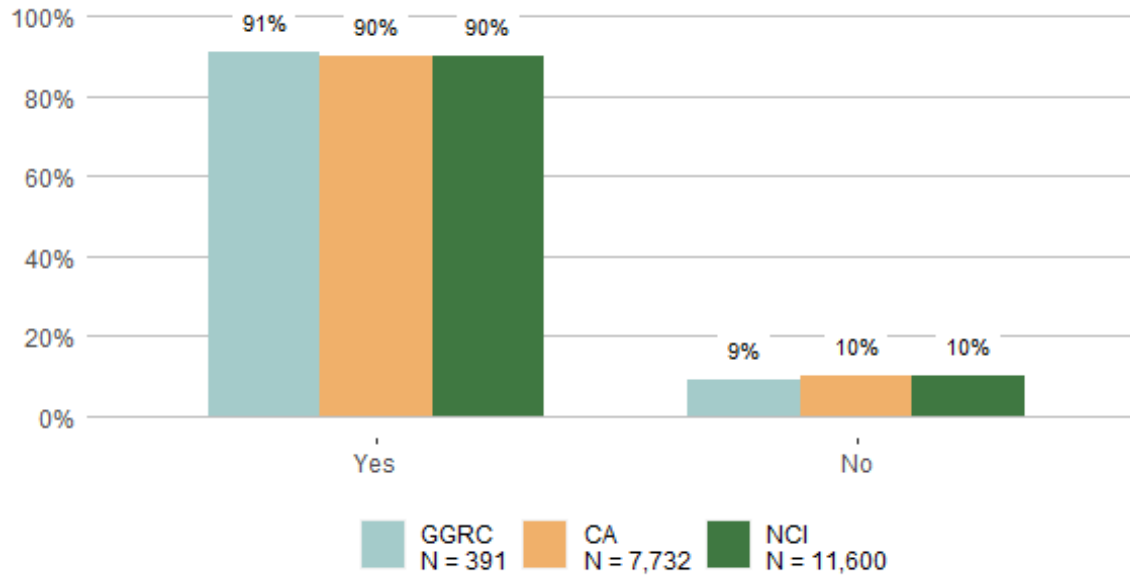


Table 55. Is there a computer, tablet (for example an iPad), or smartphone that your family can use in your home?

New question in 2021-22

RC v CA v NCI	Yes	No	N
GGRC	91%	9%	391
CA	90%	10%	7,732
NCI	90%	10%	11,600

How well does the internet work in your home?

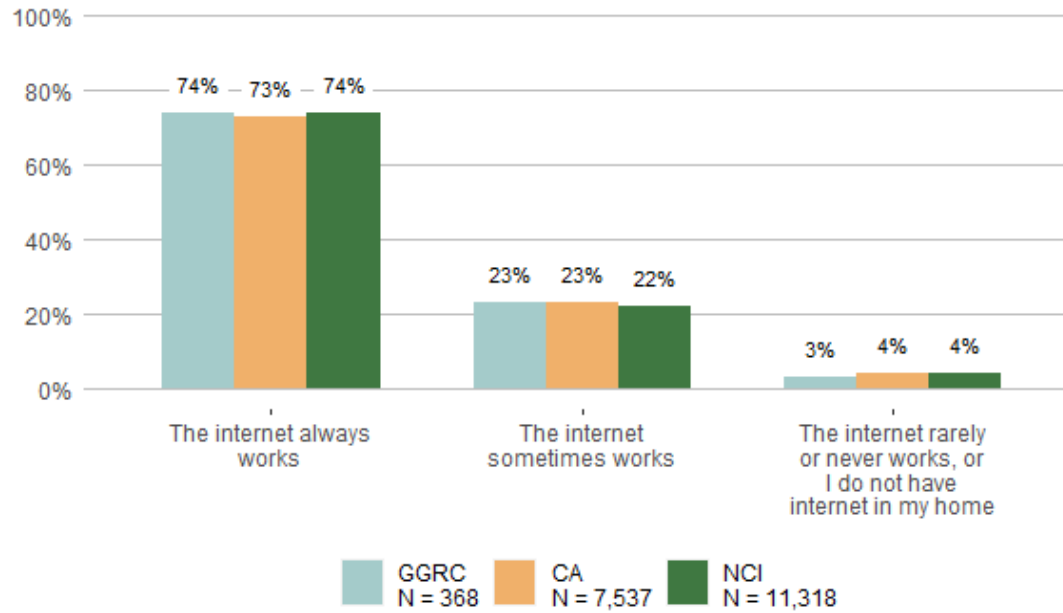


Table 56. How well does the internet work in your home?

New question in 2021-22

RC v CA v NCI	The internet always works	The internet sometimes works	The internet rarely or never works, or I do not have internet in my home	N
GGRC	74%	23%	3%	368
CA	73%	23%	4%	7,537
NCI	74%	22%	4%	11,318

Workforce (New in 2021-2022)

There is stable and sufficient workforce to meet demand. People are supported by staff who demonstrate respect for what is important to the person in their day-to-day life. Staff have the right skills to support people.

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

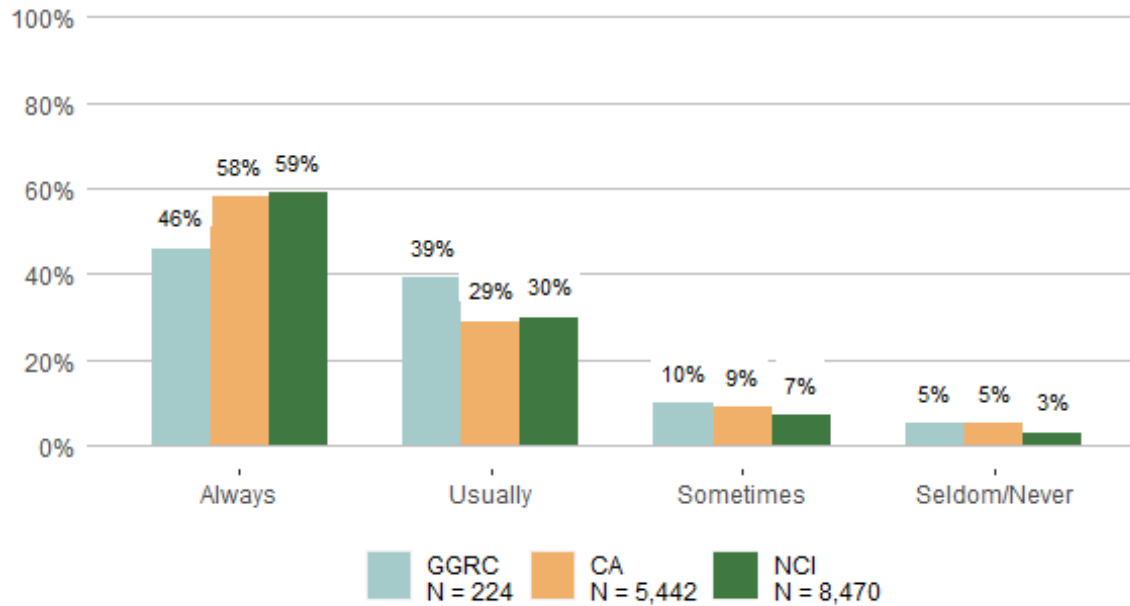


Table 57. Do support workers come and go when they are supposed to?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	46%	39%	10%	5%	224
CA	58%	29%	9%	5%	5,442
NCI	59%	30%	7%	3%	8,470

Do support workers speak to you in a way you understand?

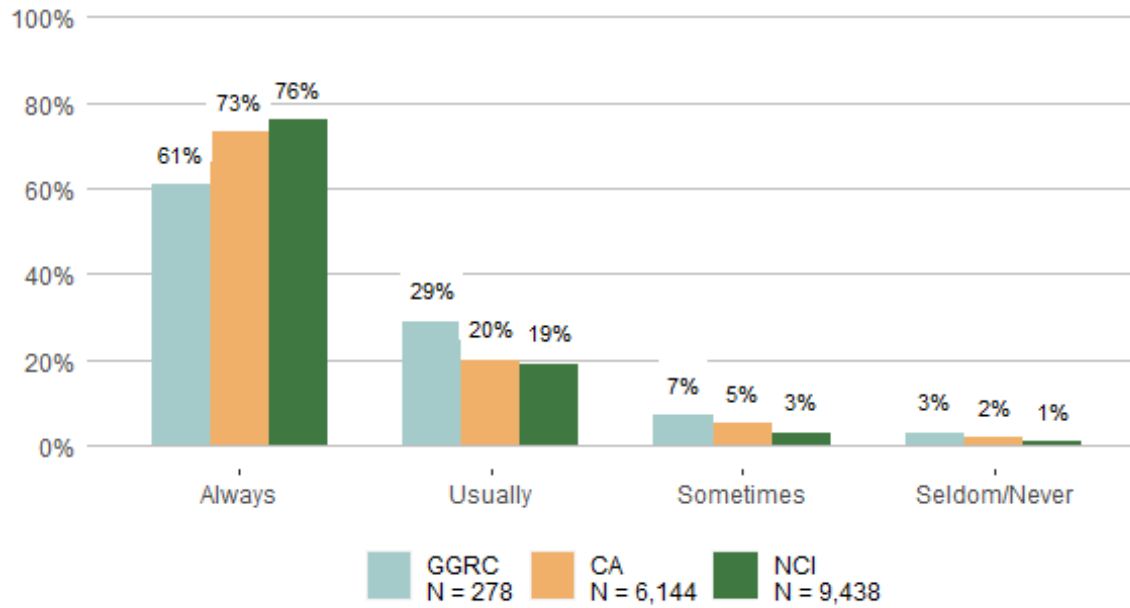


Table 58. Do support workers speak to you in a way you understand?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	61%	29%	7%	3%	278
CA	73%	20%	5%	2%	6,144
NCI	76%	19%	3%	1%	9,438

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

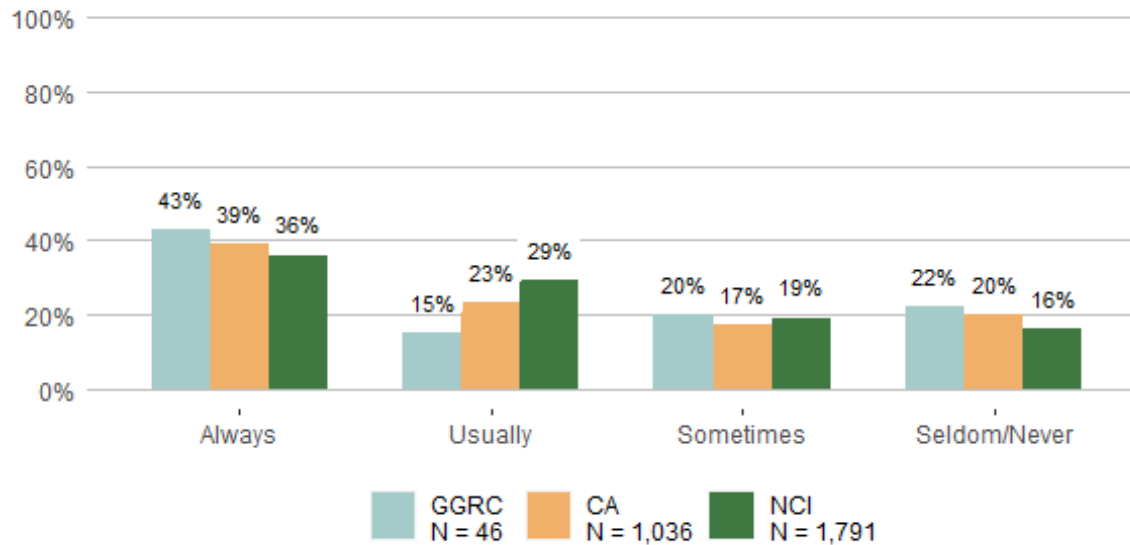


Table 59. If your family member does not communicate verbally (for example, uses gestures, sign language, or a communication aid), are there support workers who can communicate with them?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	43%	15%	20%	22%	46
CA	39%	23%	17%	20%	1,036
NCI	36%	29%	19%	16%	1,791

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

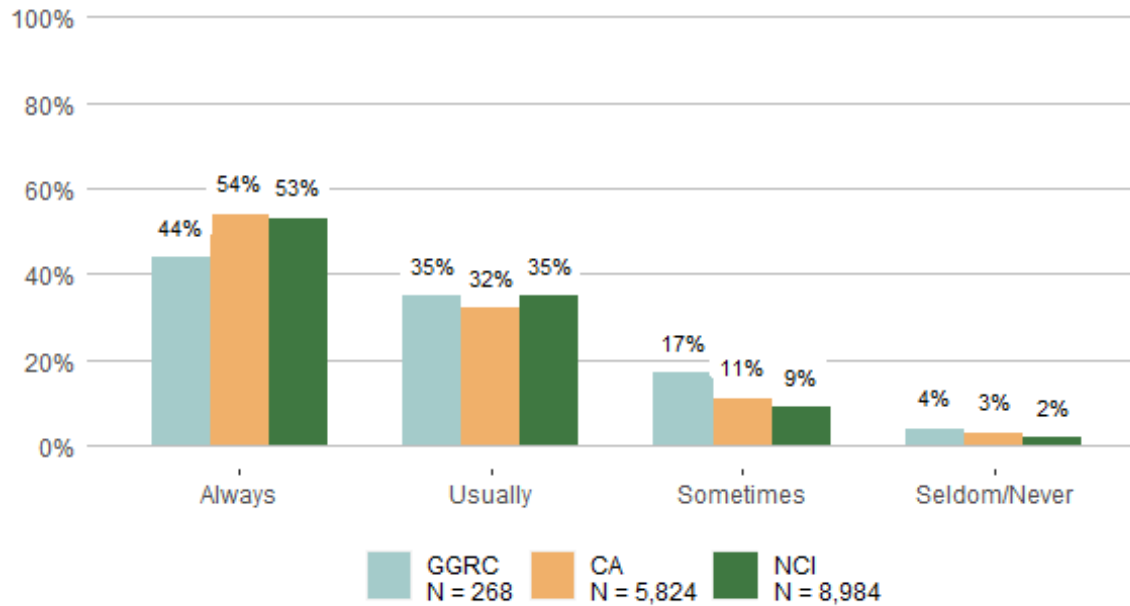


Table 60. Do support workers have the right information and skills to meet your family's needs?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	44%	35%	17%	4%	268
CA	54%	32%	11%	3%	5,824
NCI	53%	35%	9%	2%	8,984

Do your family member's support workers change too often? Is there too much "turnover" of support workers?

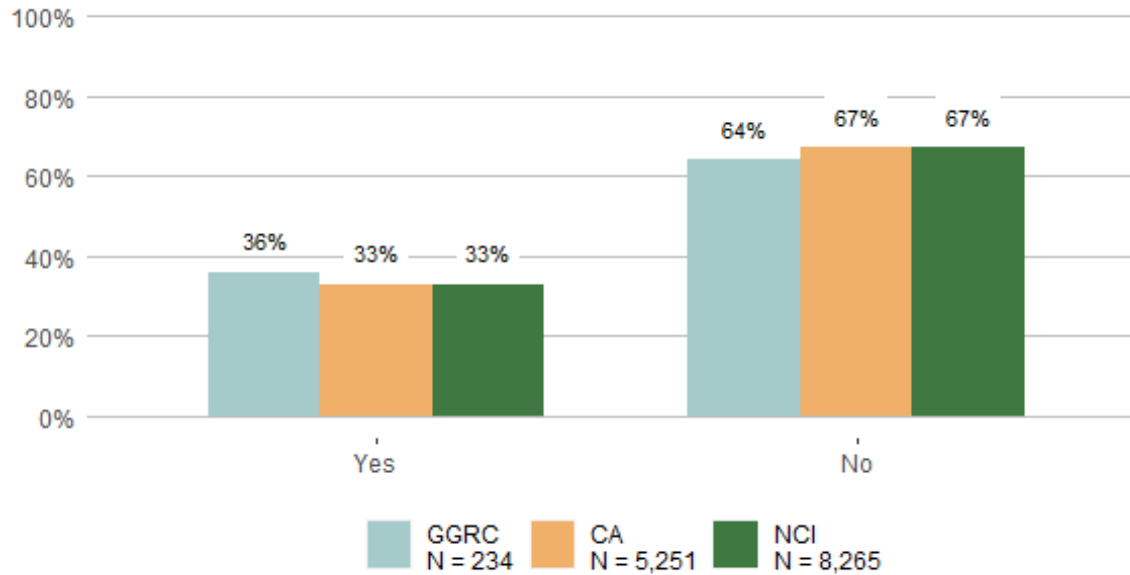


Table 61. Do your family member's support workers change too often? Is there too much "turnover" of support workers?

New question in 2021-22

RC v CA v NCI	Yes	No	N
GGRC	36%	64%	234
CA	33%	67%	5,251
NCI	33%	67%	8,265

Is there always a staff person available to support your family member when support is needed?

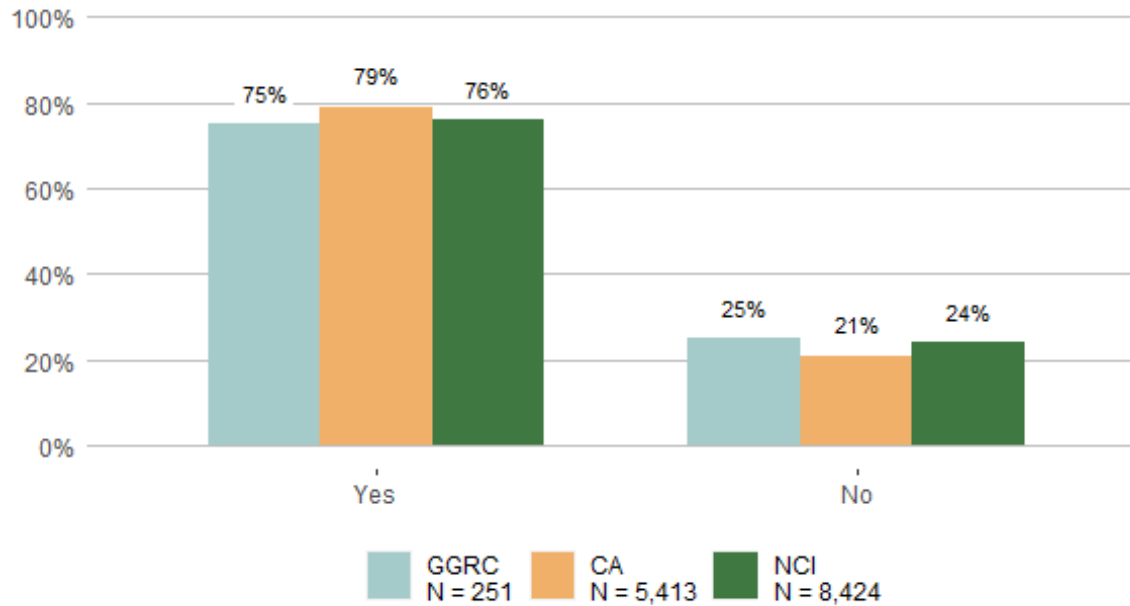


Table 62. Is there always a staff person available to support your family member when support is needed?

New question in 2021-22

RC v CA v NCI	Yes	No	N
GGRC	75%	25%	251
CA	79%	21%	5,413
NCI	76%	24%	8,424

Choice, Decision Making and Control

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

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

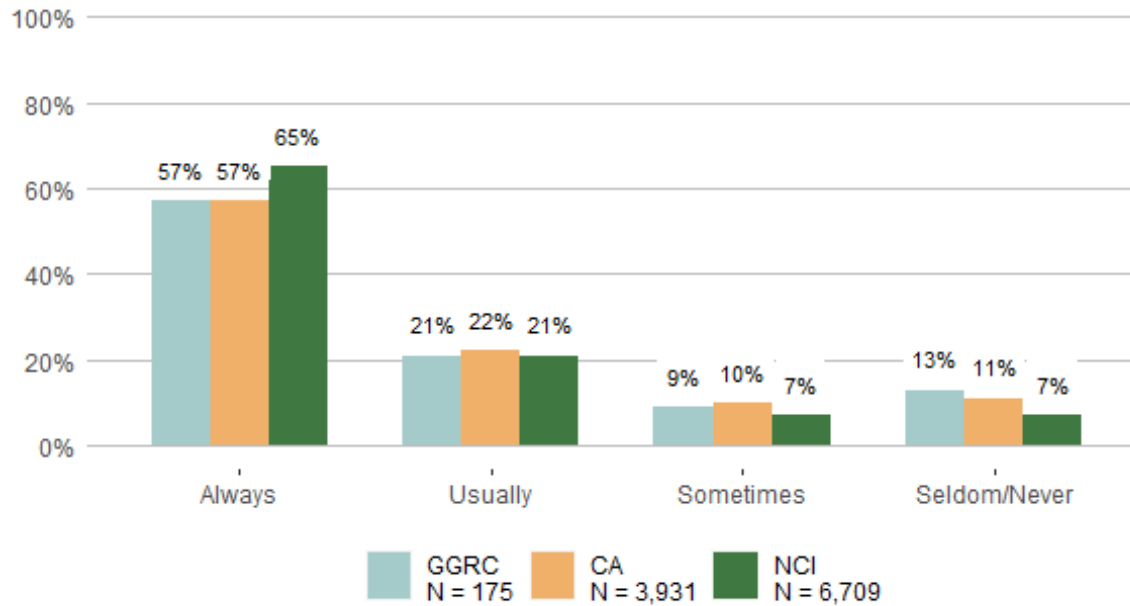


Table 63. Can your family choose or change the agency that provides your family member's services?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	57%	21%	9%	13%	175
CA	57%	22%	10%	11%	3,931
NCI	65%	21%	7%	7%	6,709

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

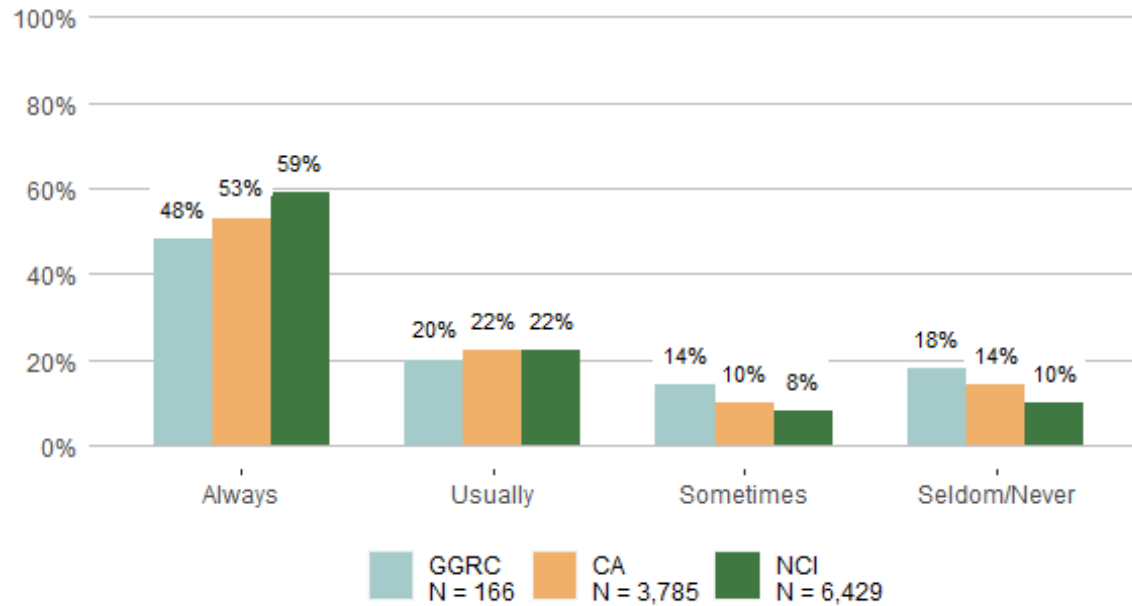


Table 64. Can your family choose or change your family member's support workers?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	48%	20%	14%	18%	166
CA	53%	22%	10%	14%	3,785
NCI	59%	22%	8%	10%	6,429

Can someone in your family directly manage support staff?

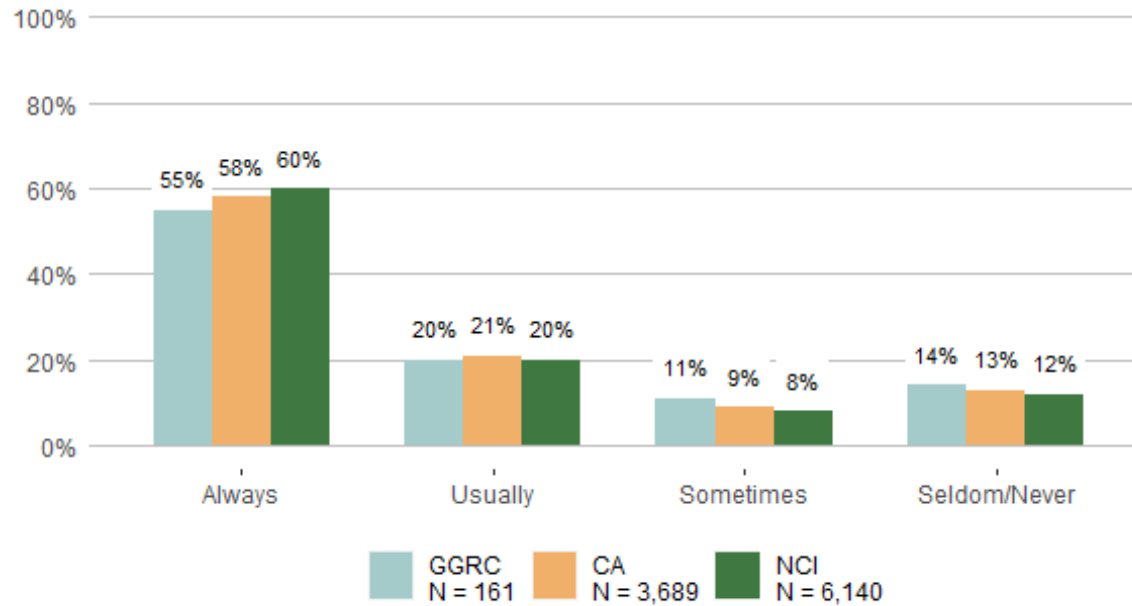


Table 65. Can someone in your family directly manage support staff?

Question changed in 2021-22

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	55%	20%	11%	14%	161
CA	58%	21%	9%	13%	3,689
NCI	60%	20%	8%	12%	6,140

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

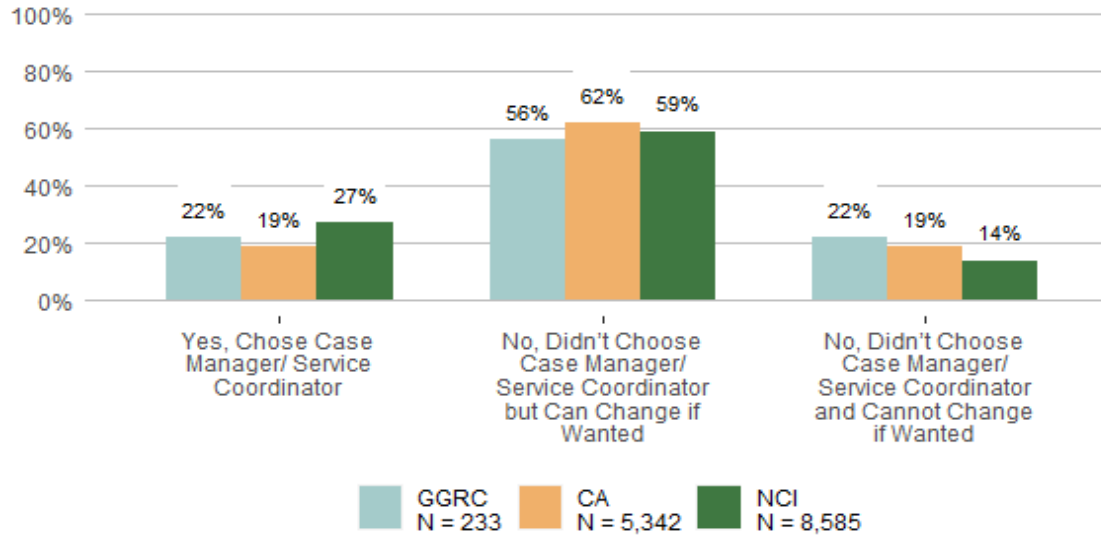


Table 66. Did you, your family member, or someone else in your family choose your family member's case manager/service coordinator?

RC v CA v NCI	Yes, Chose Case Manager/ Service Coordinator	No, Didn't Choose Case Manager/ Service Coordinator but Can Change if Wanted	No, Didn't Choose Case Manager/ Service Coordinator and Cannot Change if Wanted	N
GGRC	22%	56%	22%	233
CA	19%	62%	19%	5,342
NCI	27%	59%	14%	8,585

Community Connections

Family members receiving services and supports from the Regional Center are meaningfully engaged as members of their communities and have strong relationships. Families can use supports in their community.

Does your family member do things in the community?

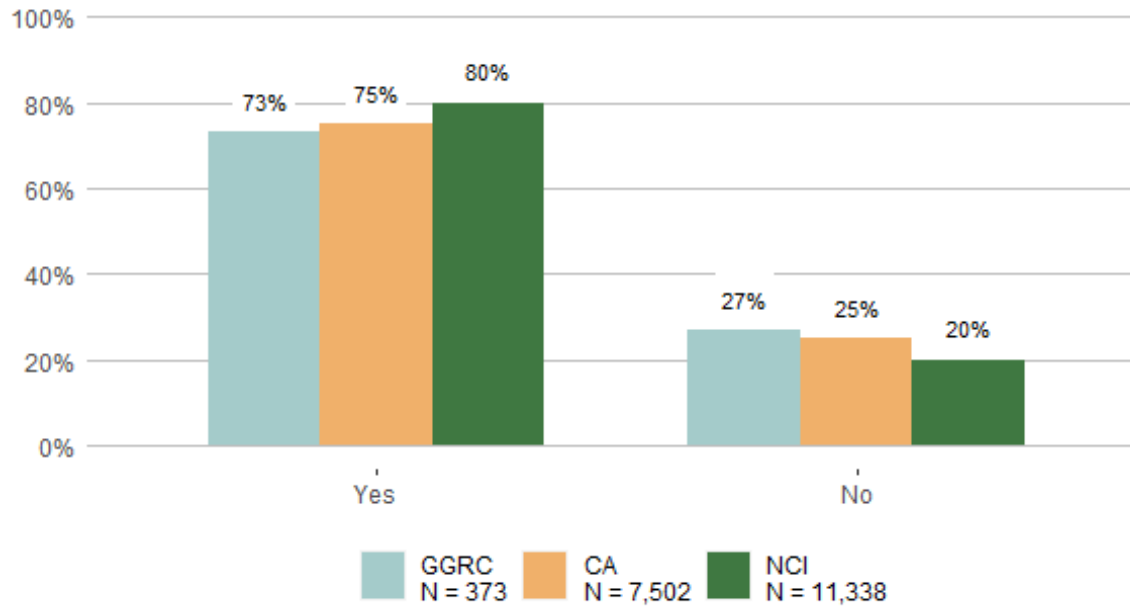


Table 67. Does your family member do things in the community?

RC v CA v NCI	Yes	No	N
GGRC	73%	27%	373
CA	75%	25%	7,502
NCI	80%	20%	11,338

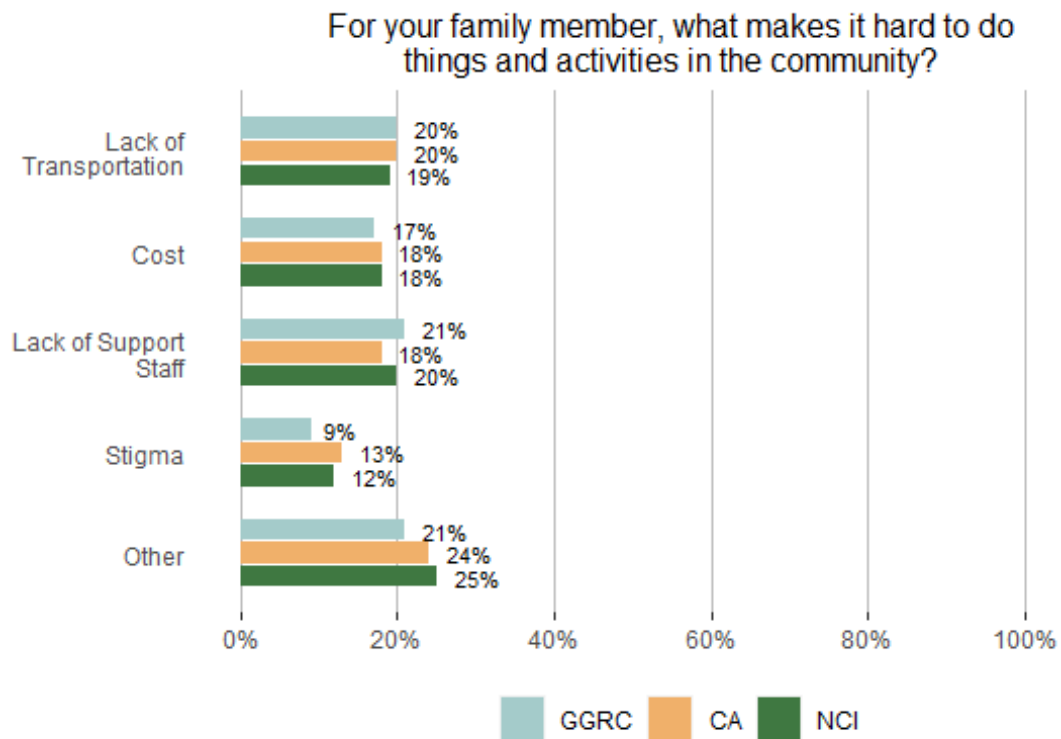


Table 68. For your family member, what makes it hard to do things and activities in the community?

Categories are not mutually exclusive, therefore N is not shown.

RC v CA v NCI	Lack of Transportation	Cost	Lack of Support Staff	Stigma	Other
GGRC	20%	17%	21%	9%	21%
CA	20%	18%	18%	13%	24%
NCI	19%	18%	20%	12%	25%

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

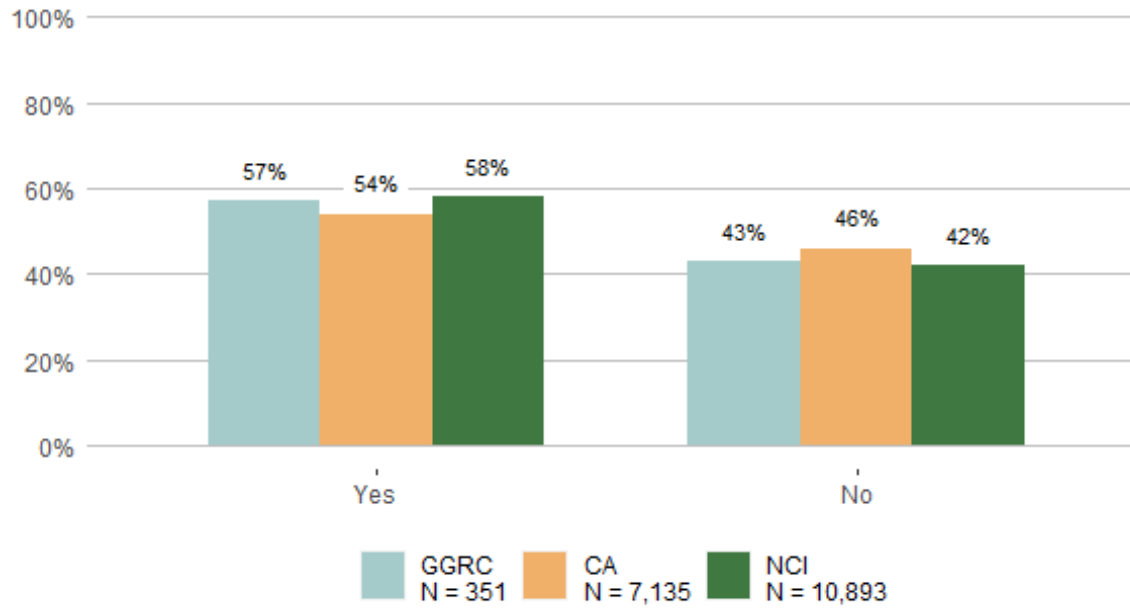


Table 69. Does your family member have friends other than paid support workers or family?

RC v CA v NCI	Yes	No	N
GGRC	57%	43%	351
CA	54%	46%	7,135
NCI	58%	42%	10,893

In your community, are there resources that your family can use that are not provided by the regional center (for example, recreational programs, community housing, library programs, religious groups, etc.)?

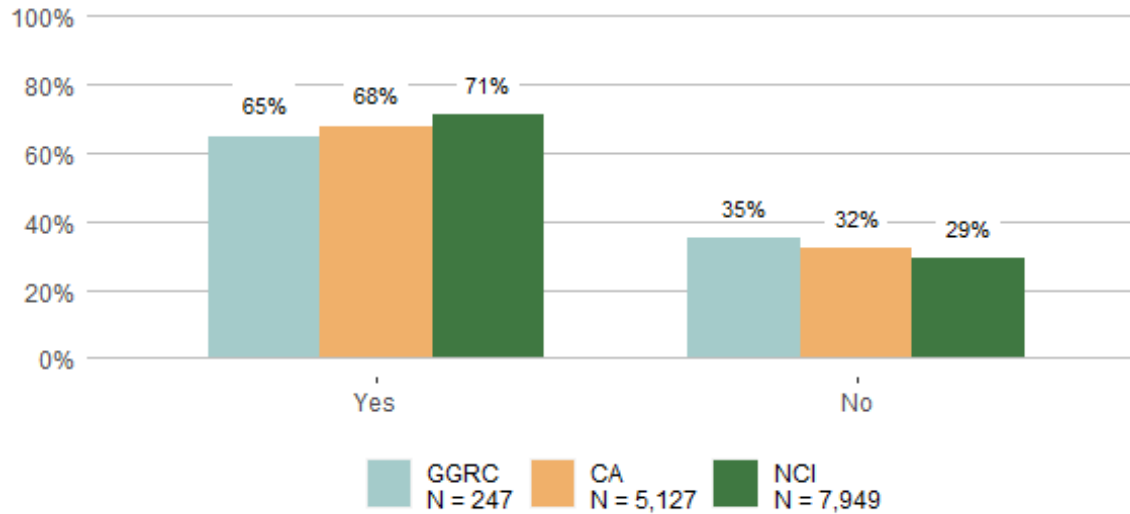


Table 70. In your community, are there resources that your family can use that are not provided by the regional center (for example, recreational programs, community housing, library programs, religious groups, etc.)?

RC v CA v NCI	Yes	No	N
GGRC	65%	35%	247
CA	68%	32%	5,127
NCI	71%	29%	7,949

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

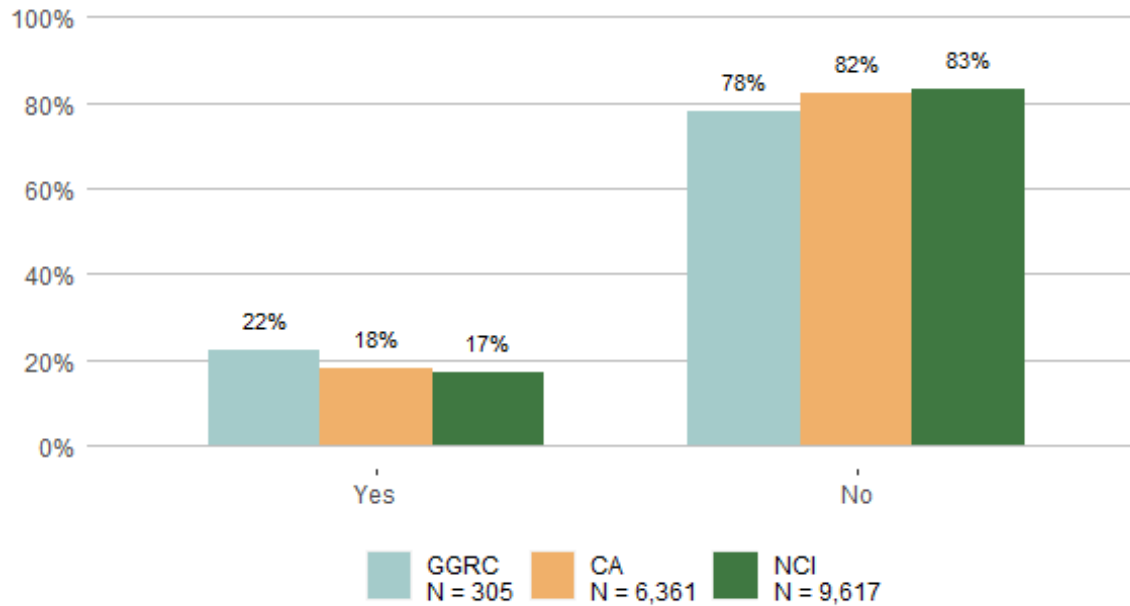


Table 71. Does your family take part in any family-to-family networks in your community?

RC v CA v NCI	Yes	No	N
GGRC	22%	78%	305
CA	18%	82%	6,361
NCI	17%	83%	9,617

Health, Welfare, and Safety (New in 2021-22)

Families are supported to ensure the health, welfare, and safety of their family member receiving services and supports from the Regional Center.

Can your family member see a primary care provider
(doctor, registered nurse, etc.) when needed?

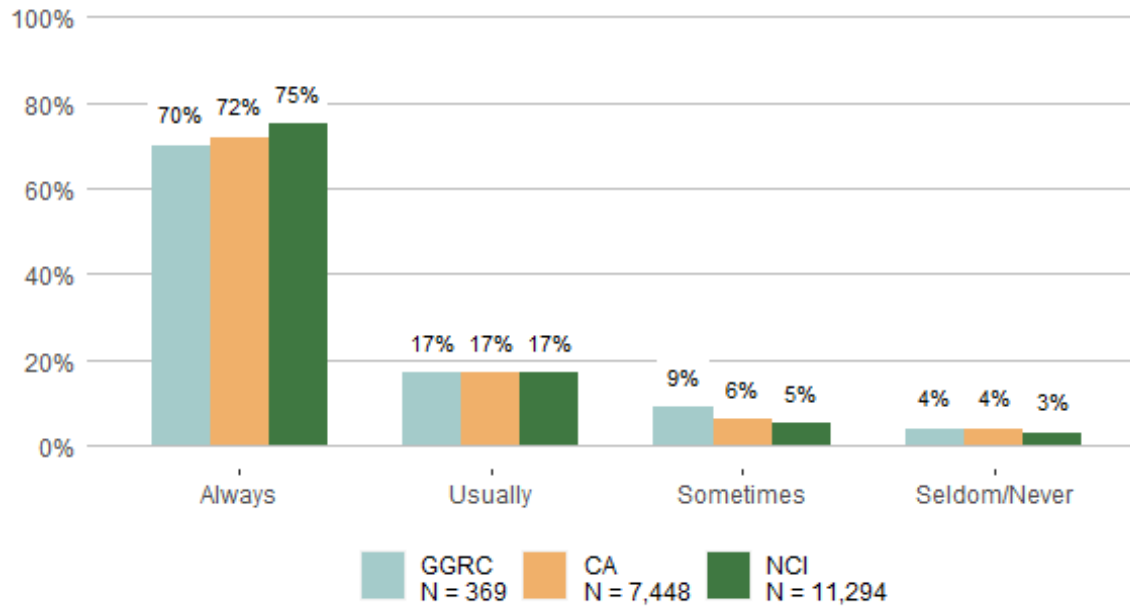


Table 72. Can your family member see a primary care provider (doctor, registered nurse, etc.) when needed?

New question in 2021-22; responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	70%	17%	9%	4%	369
CA	72%	17%	6%	4%	7,448
NCI	75%	17%	5%	3%	11,294

Does your family member's primary care doctor understand your family member's needs related to their disability?

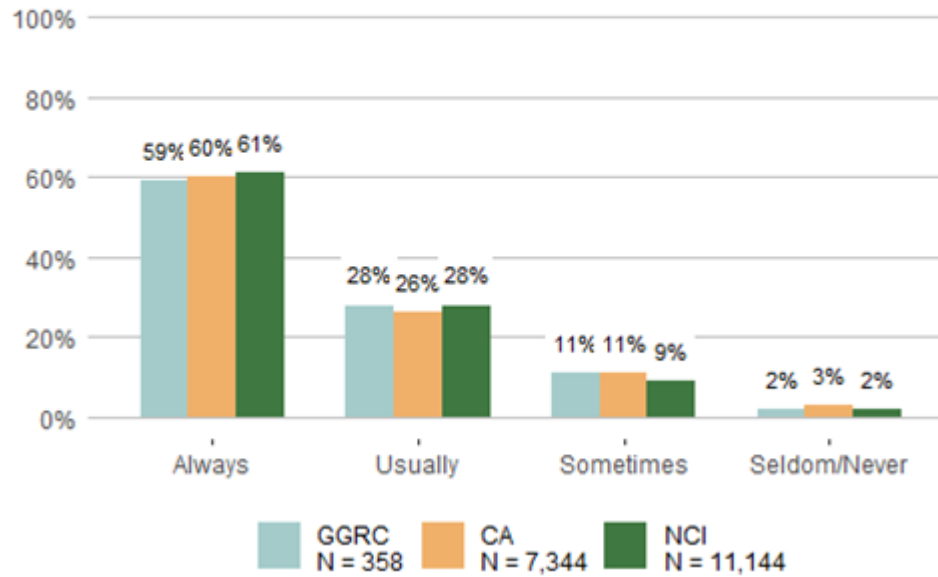


Table 73. Does your family member's primary care doctor understand your family member's needs related to their disability?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	59%	28%	11%	2%	358
CA	60%	26%	11%	3%	7,344
NCI	61%	28%	9%	2%	11,144

Can your family member go to the dentist when needed?

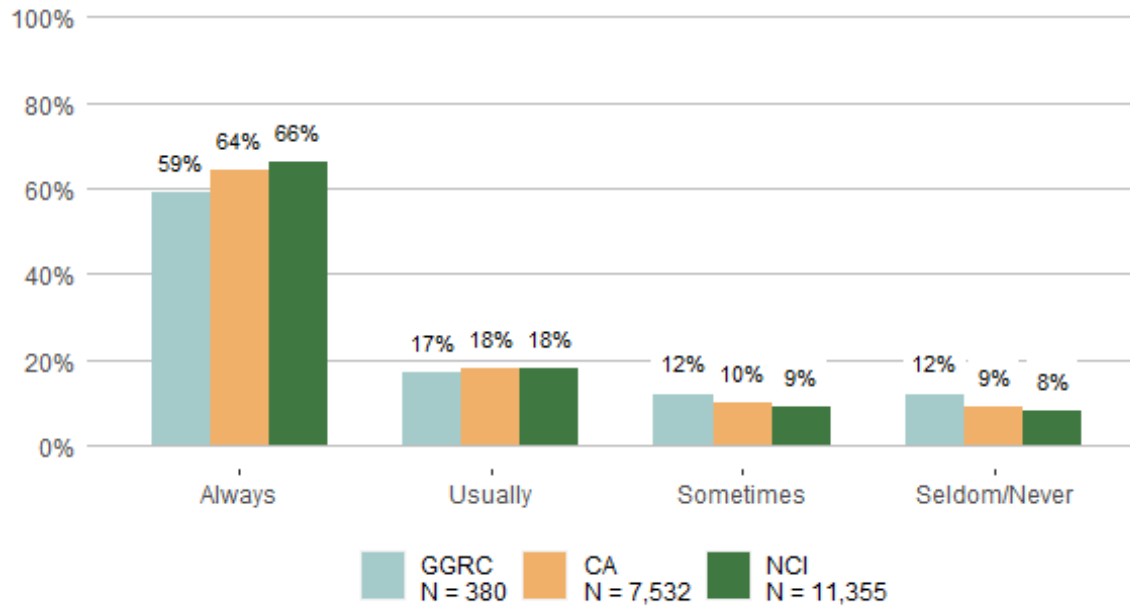


Table 74. Can your family member go to the dentist when needed?

Responses to this question might have been impacted by the COVID-19 pandemic.

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	59%	17%	12%	12%	380
CA	64%	18%	10%	9%	7,532
NCI	66%	18%	9%	8%	11,355

Does your family member's dentist understand your family member's needs related to their disability?

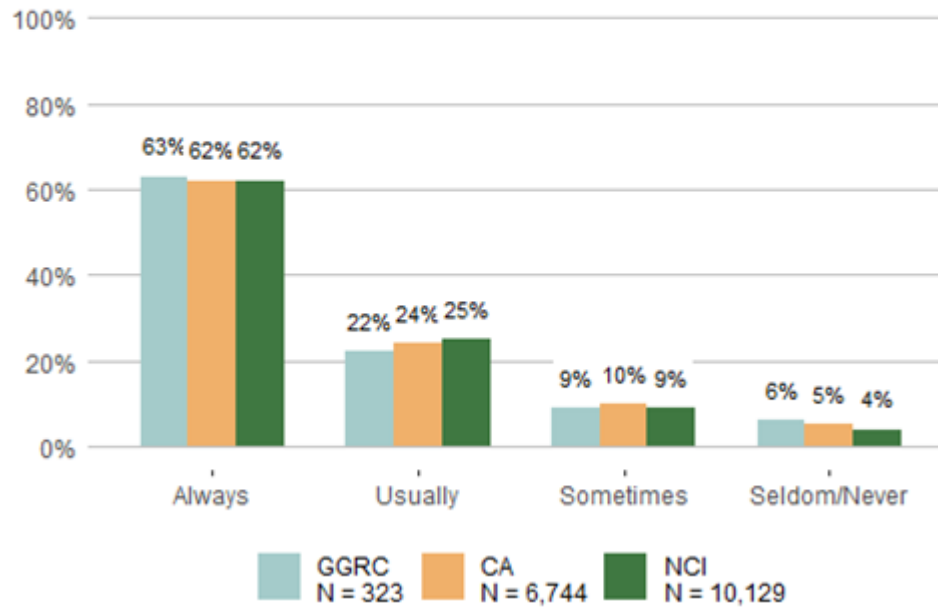


Table 75. Does your family member's dentist understand your family member's needs related to their disability?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	63%	22%	9%	6%	323
CA	62%	24%	10%	5%	6,744
NCI	62%	25%	9%	4%	10,129

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

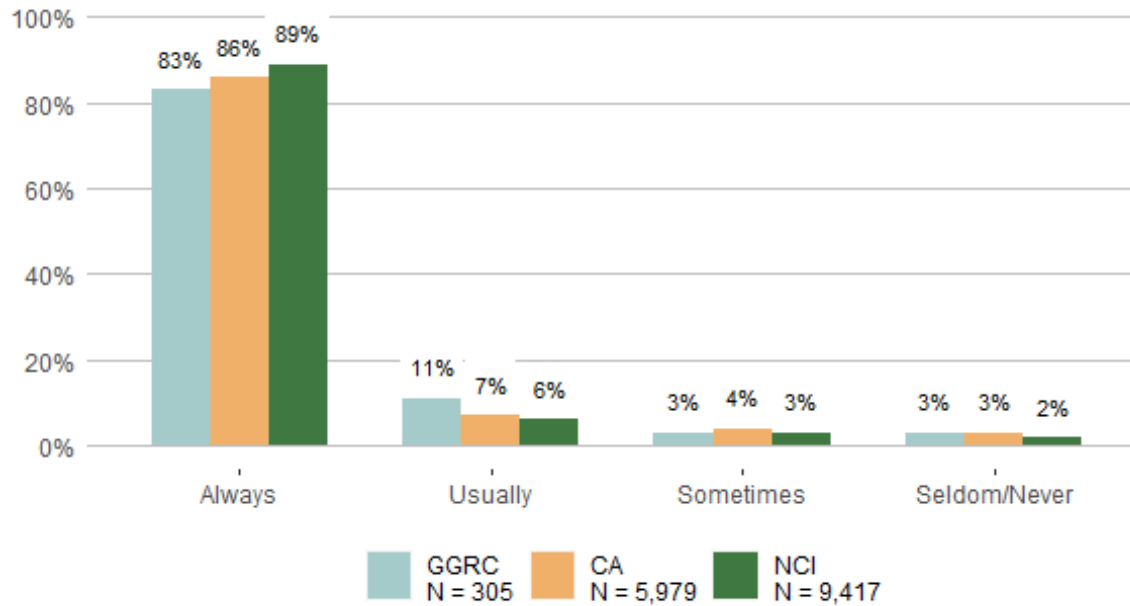


Table 76. If your family member takes prescription medications, do you know what they're for?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	83%	11%	3%	3%	305
CA	86%	7%	4%	3%	5,979
NCI	89%	6%	3%	2%	9,417

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)?

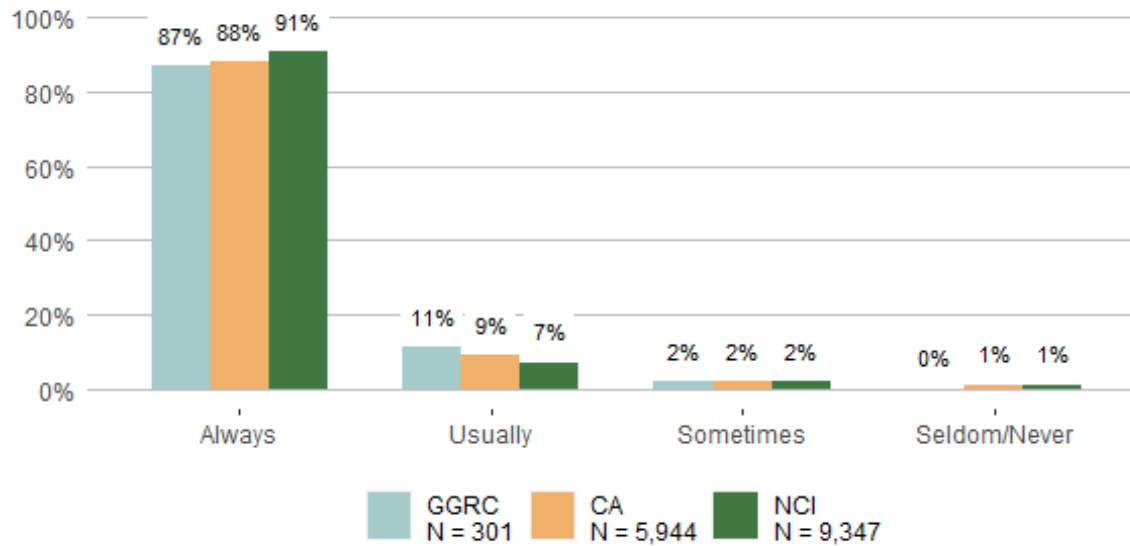


Table 77. Do you, your family member, or someone else in your family know what is needed to safely take prescription medications (when it should be taken, how much to take, and the potential side effects)?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	87%	11%	2%	0%	301
CA	88%	9%	2%	1%	5,944
NCI	91%	7%	2%	1%	9,347

Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)?

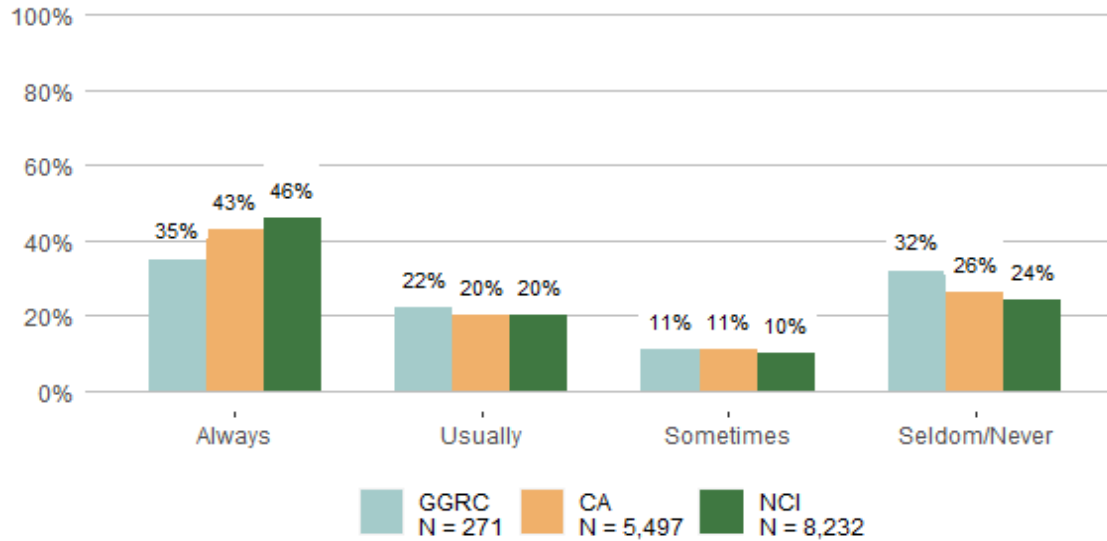


Table 78. Can your family member get mental or behavioral health supports when needed? (Like see a therapist, go to group counseling)?

New question in 2021-22

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	35%	22%	11%	32%	271
CA	43%	20%	11%	26%	5,497
NCI	46%	20%	10%	24%	8,232

If your family member uses mental health services,
does the mental health professional understand
your family member's needs related to their
disability?

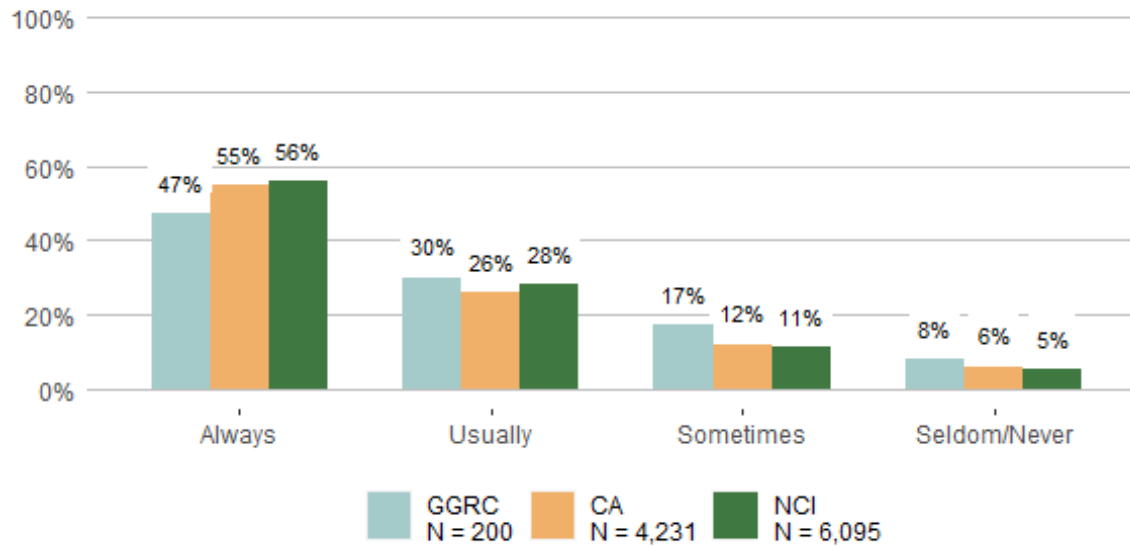


Table 79. If your family member uses mental health services, does the mental health professional understand your family member's needs related to their disability?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	47%	30%	17%	8%	200
CA	55%	26%	12%	6%	4,231
NCI	56%	28%	11%	5%	6,095

If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

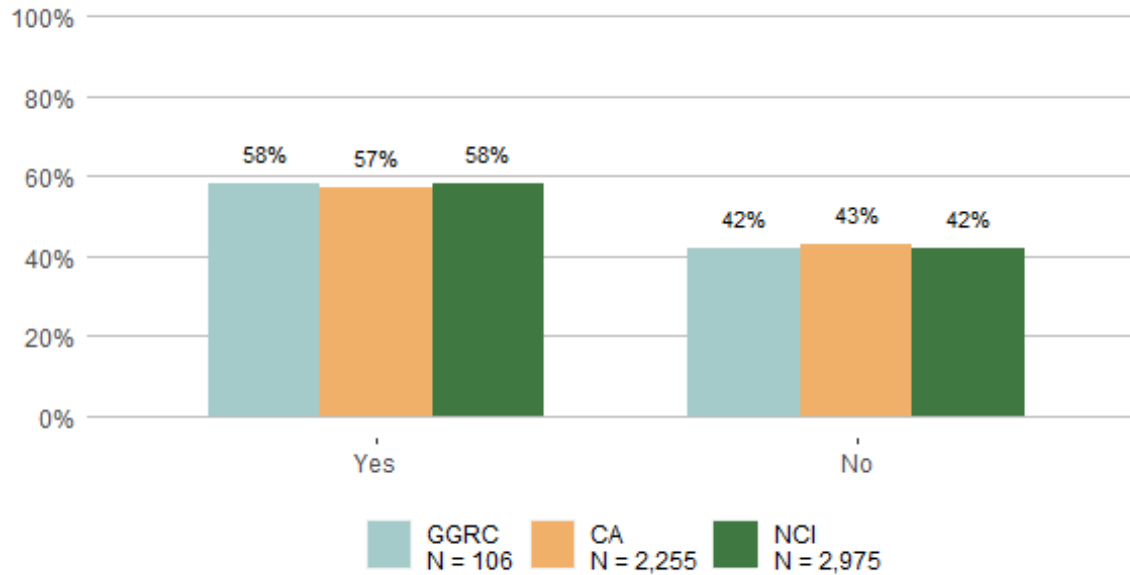


Table 80. If you asked for crisis or emergency services during the past 12 months, were services provided when needed?

RC v CA v NCI	Yes	No	N
GGRC	58%	42%	106
CA	57%	43%	2,255
NCI	58%	42%	2,975

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

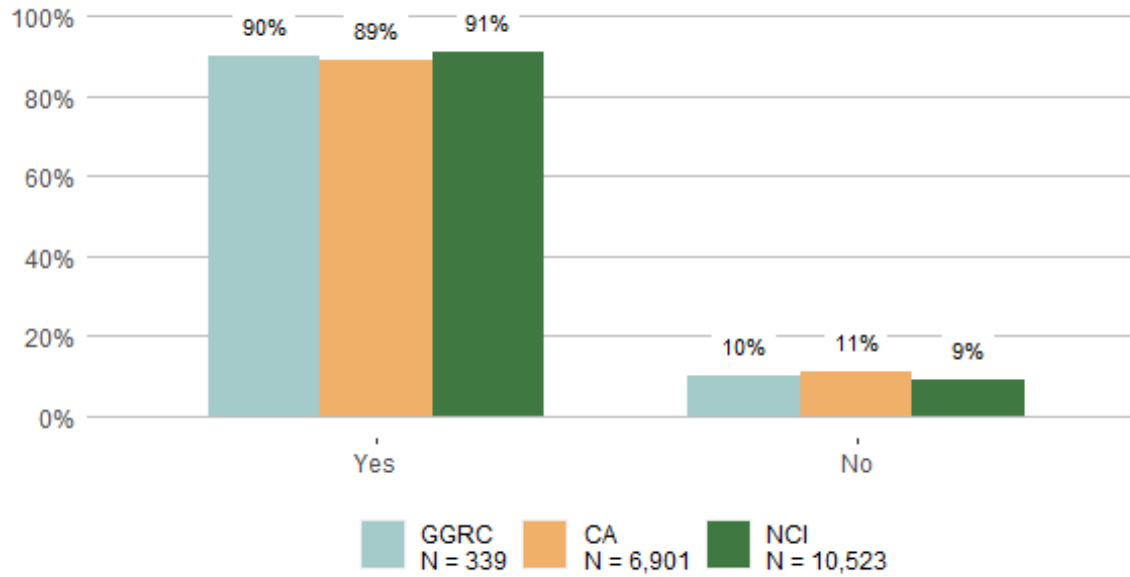


Table 81. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or natural disaster?

RC v CA v NCI	Yes	No	N
GGRC	90%	10%	339
CA	89%	11%	6,901
NCI	91%	9%	10,523

Have you talked about how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your family member's case manager/ service coordinator?

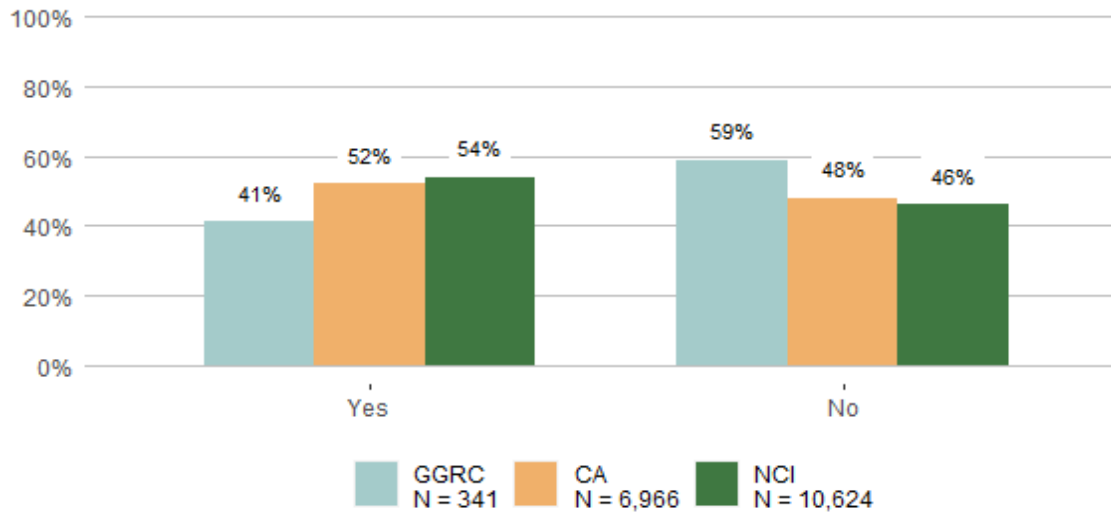


Table 82. Have you talked about how to handle emergencies (such as a medical emergency, pandemic or natural disaster) with your family member's case manager/service coordinator?

New question in 2021-22

RC v CA v NCI	Yes	No	N
GGRC	41%	59%	341
CA	52%	48%	6,966
NCI	54%	46%	10,624

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

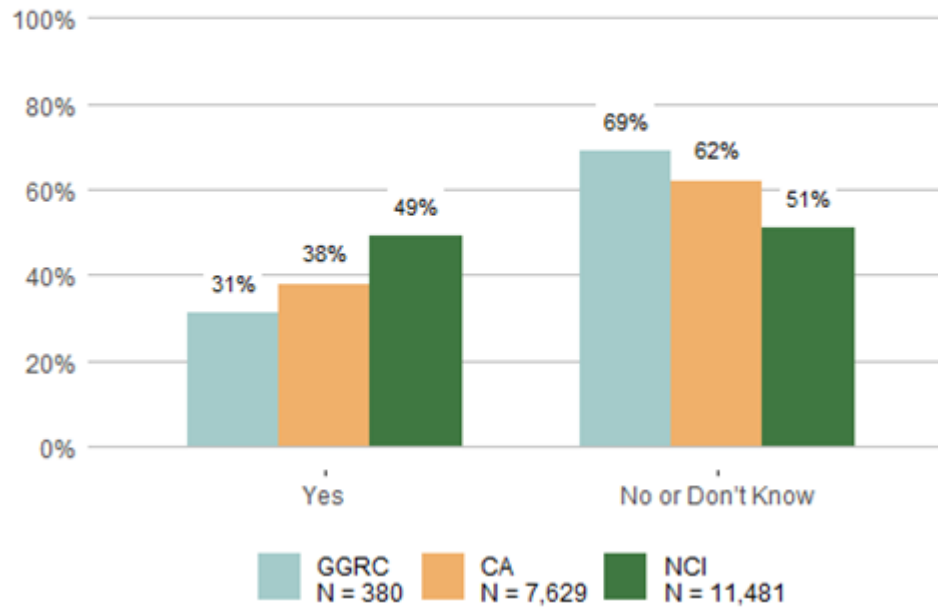


Table 83. Do you know how to file a complaint or grievance about provider agencies or staff?

RC v CA v NCI	Yes	No or Don't Know	N
GGRC	31%	69%	380
CA	38%	62%	7,629
NCI	49%	51%	11,481

If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

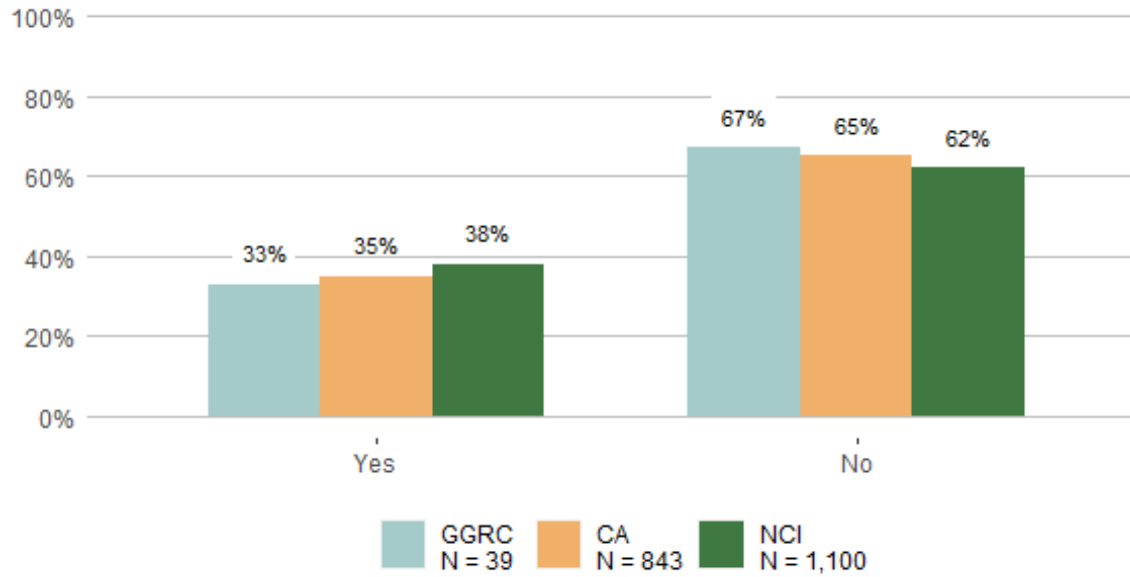


Table 84. If a complaint or grievance was filed or resolved in the past 12 months, are you satisfied with the way it was handled?

RC v CA v NCI	Yes	No	N
GGRC	33%	67%	39
CA	35%	65%	843
NCI	38%	62%	1,100

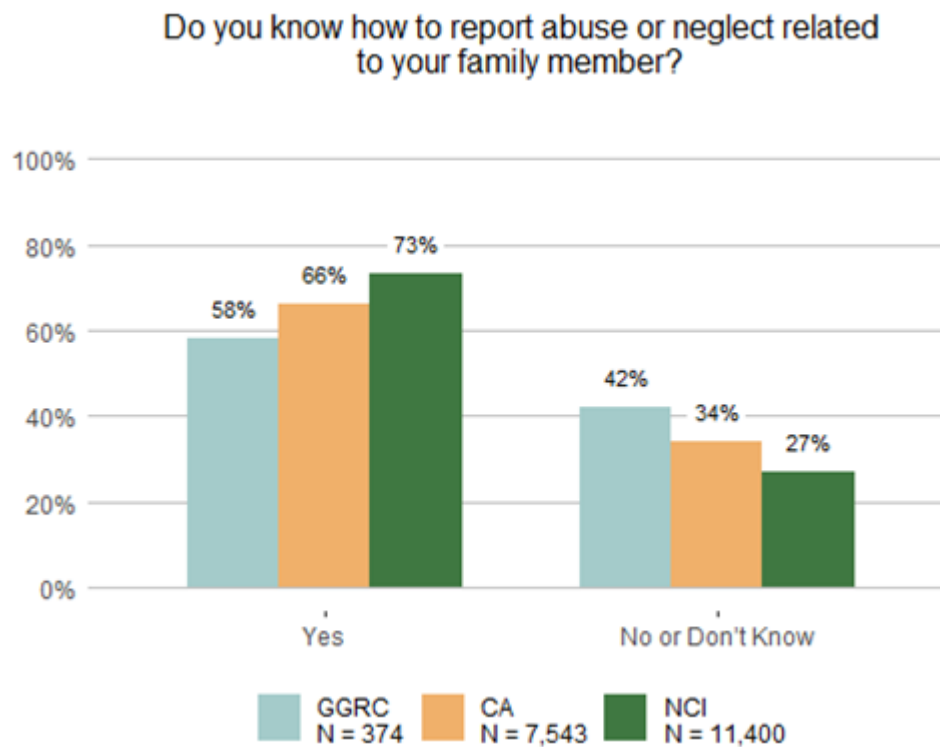


Table 85. Do you know how to report abuse or neglect related to your family member?

RC v CA v NCI	Yes	No or Don't Know	N
GGRC	58%	42%	374
CA	66%	34%	7,543
NCI	73%	27%	11,400

Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

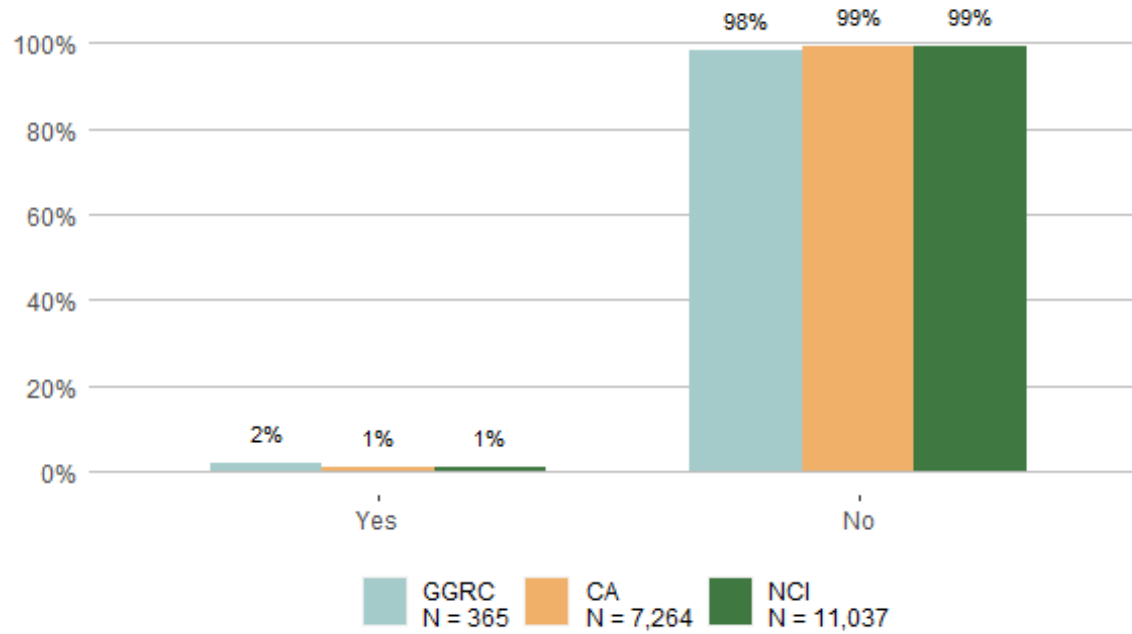


Table 86. Within the past 12 months, was a report of abuse or neglect filed on behalf of your family member?

RC v CA v NCI	Yes	No	N
GGRC	2%	98%	365
CA	1%	99%	7,264
NCI	1%	99%	11,037

If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?

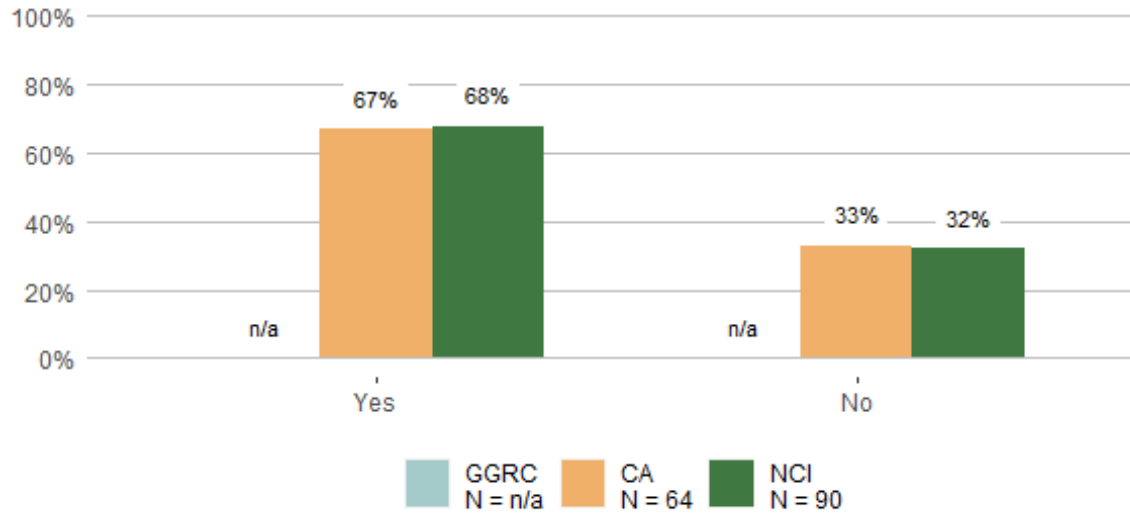


Table 87. If a report of abuse or neglect was filed on behalf of family member, if someone other than you or another family member reported abuse or neglect in the past 12 months, were you notified of the report in a timely manner?

RC v CA v NCI	Yes	No	N
GGRC	n/a	n/a	n/a
CA	67%	33%	64
NCI	68%	32%	90

Family Satisfaction

Services and supports lead to better lives for people with intellectual/developmental disabilities and their families.

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

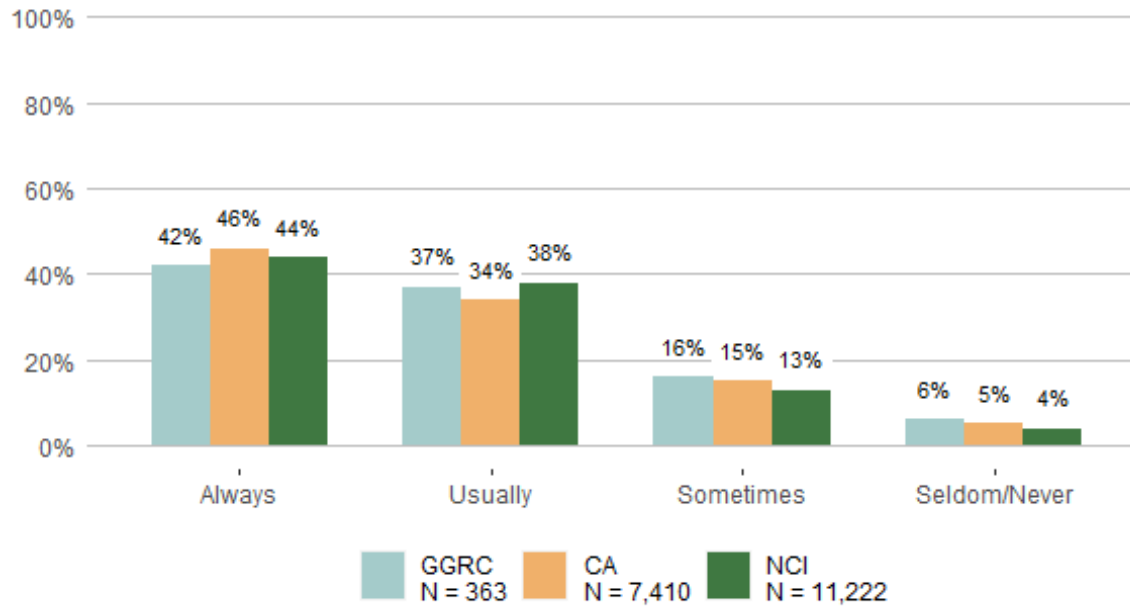


Table 88. Overall, are you satisfied with the services and supports your family member currently receives?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
GGRC	42%	37%	16%	6%	363
CA	46%	34%	15%	5%	7,410
NCI	44%	38%	13%	4%	11,222

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

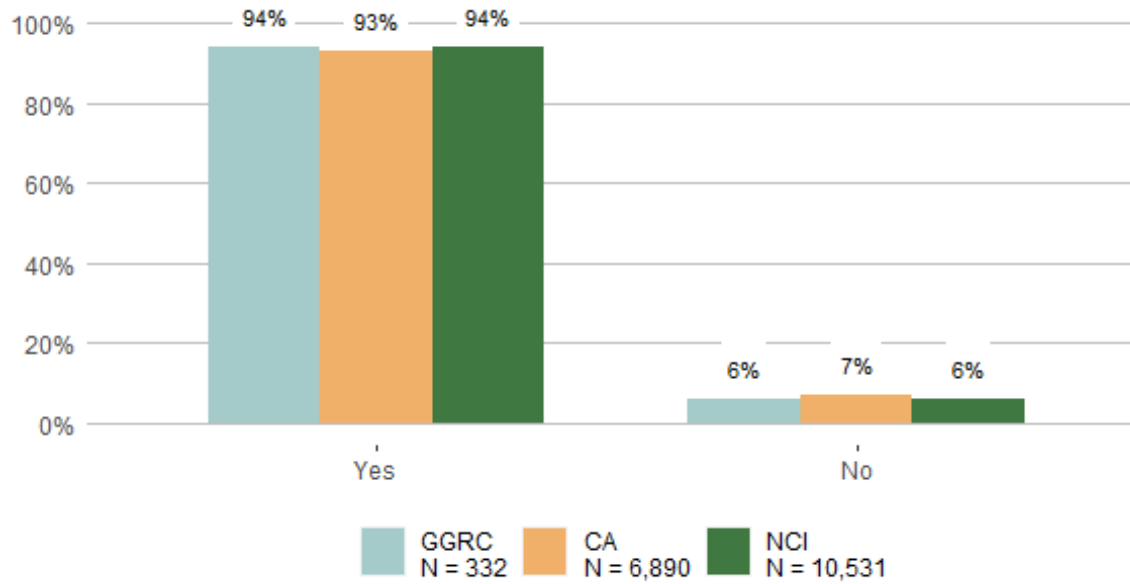


Table 89. Do you feel that services and supports have made a positive difference in the life of your family member?

RC v CA v NCI	Yes	No	N
GGRC	94%	6%	332
CA	93%	7%	6,890
NCI	94%	6%	10,531

Have services and supports reduced your family's out-of-pocket expenses for your family member's care?

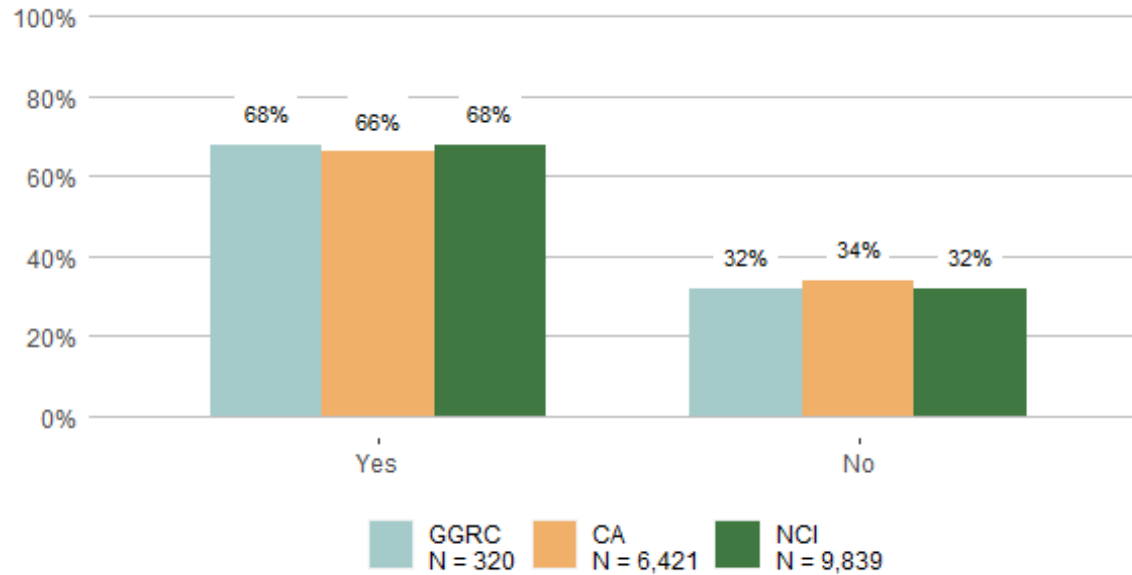


Table 90. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?

RC v CA v NCI	Yes	No	N
GGRC	68%	32%	320
CA	66%	34%	6,421
NCI	68%	32%	9,839

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

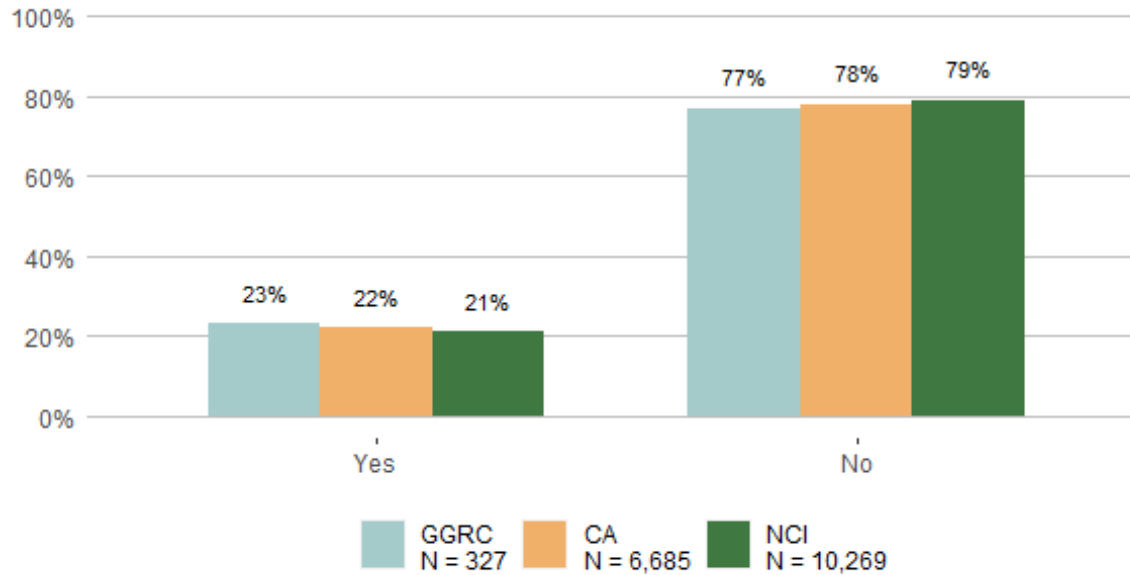


Table 91. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?

RC v CA v NCI	Yes	No	N
GGRC	23%	77%	327
CA	22%	78%	6,685
NCI	21%	79%	10,269

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?

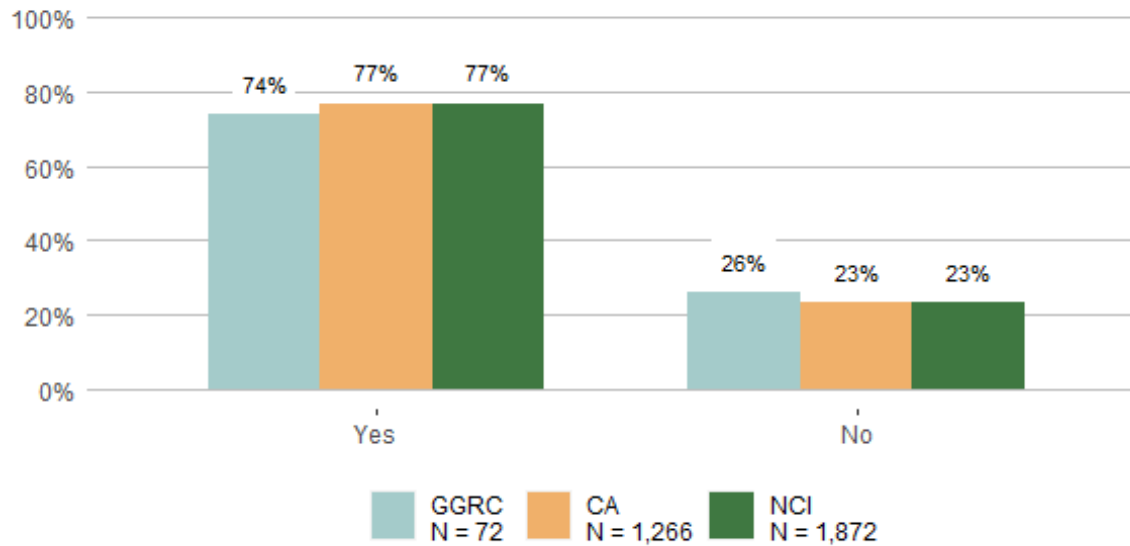


Table 92. If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?

RC v CA v NCI	Yes	No	N
GGRC	74%	26%	72
CA	77%	23%	1,266
NCI	77%	23%	1,872

Have the services or supports that your family member received been increased in the past 12 months?

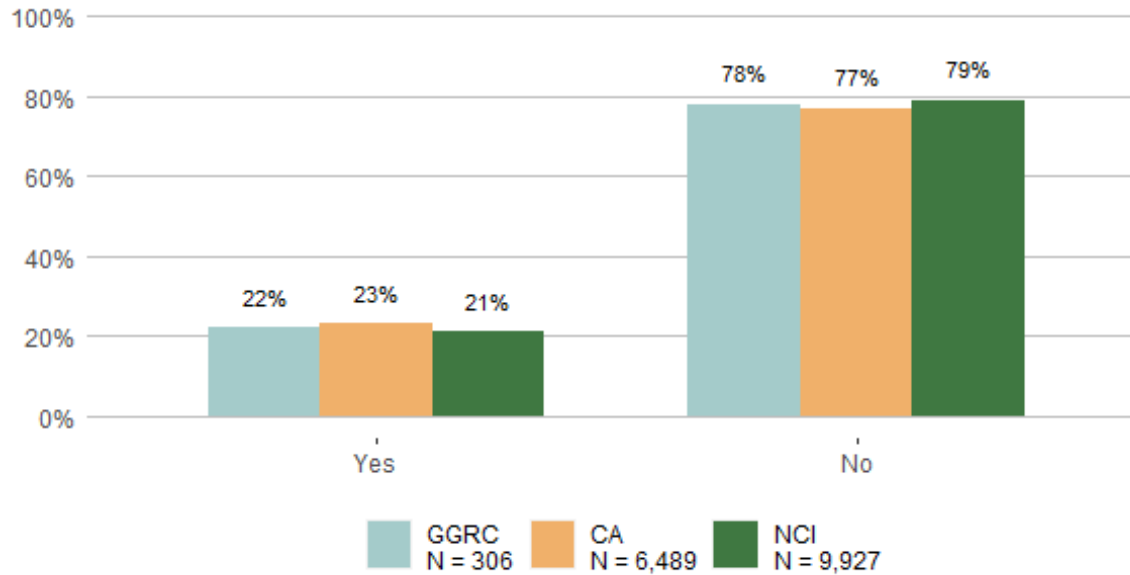


Table 93. Have the services or supports that your family member received been increased in the past 12 months?

RC v CA v NCI	Yes	No	N
GGRC	22%	78%	306
CA	23%	77%	6,489
NCI	21%	79%	9,927

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

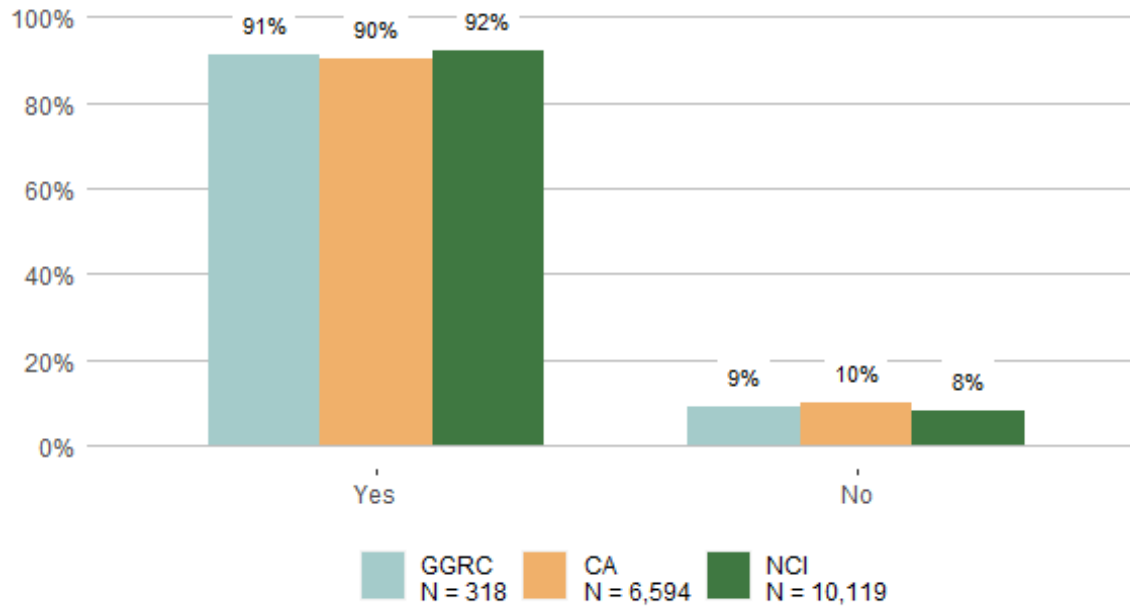


Table 94. Are services and supports helping your family member to live a good life?

RC v CA v NCI	Yes	No	N
GGRC	91%	9%	318
CA	90%	10%	6,594
NCI	92%	8%	10,119

COVID-19 Supplement

The COVID-19 Supplement is intended to support an ongoing understanding of the continuing effects of the pandemic on people's lives and services. Note: the COVID-19 Supplement was state optional, one state chose not to administer the Supplement.

Were your family member's services and supports changed, canceled, or reduced during COVID time?

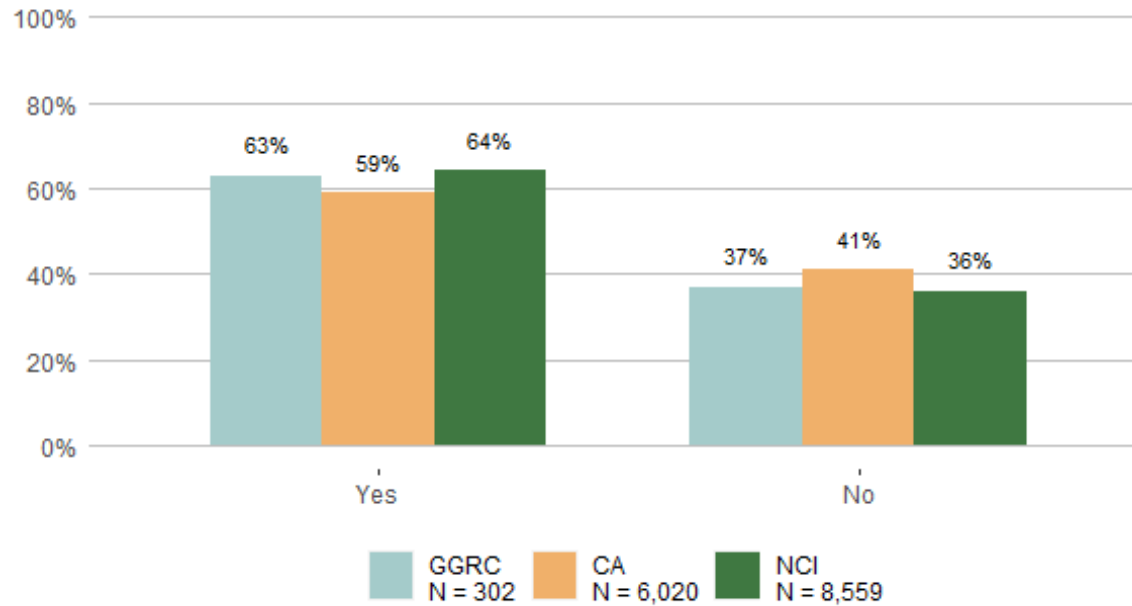


Table 95. Were your family member's services and supports changed, canceled, or reduced during COVID time?

RC v CA v NCI	Yes	No	N
GGRC	63%	37%	302
CA	59%	41%	6,020
NCI	64%	36%	8,559

If yes, are those changes still in effect (still part of your family member's life)?

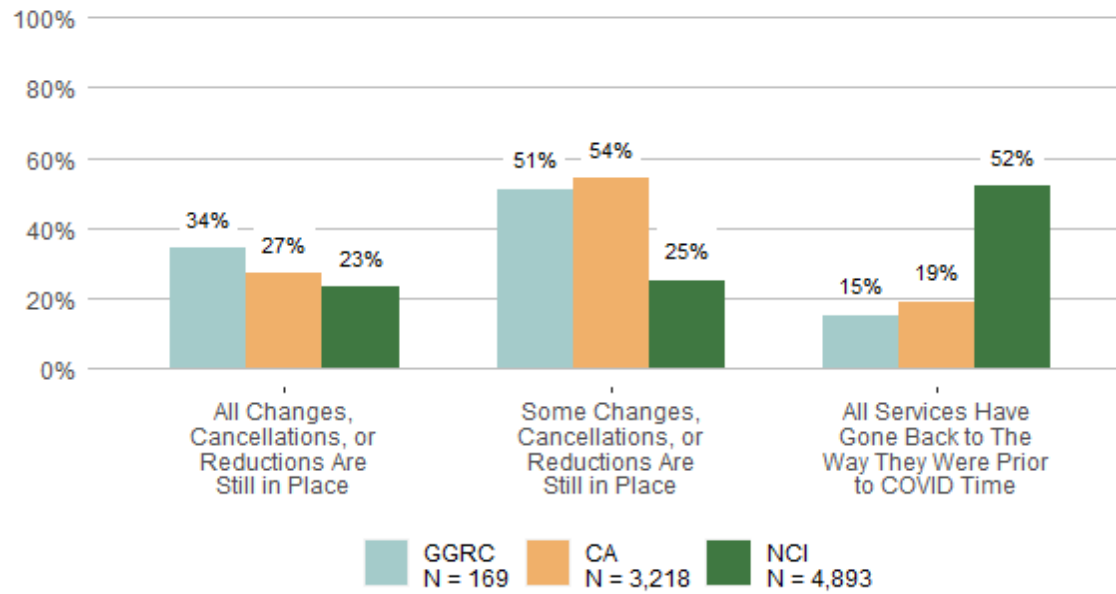


Table 96. If yes, are those changes still in effect (still part of your family member's life)?

RC v CA v NCI	All Changes, Cancellations, or Reductions Are Still in Place	Some Changes, Cancellations, or Reductions Are Still in Place	All Services Have Gone Back to The Way They Were Prior to COVID Time	N
GGRC	34%	51%	15%	169
CA	27%	54%	19%	3,218
NCI	23%	25%	52%	4,893

If some or all of your family member's services have reopened or restarted: Did your family get enough information about the services reopening/restarting?

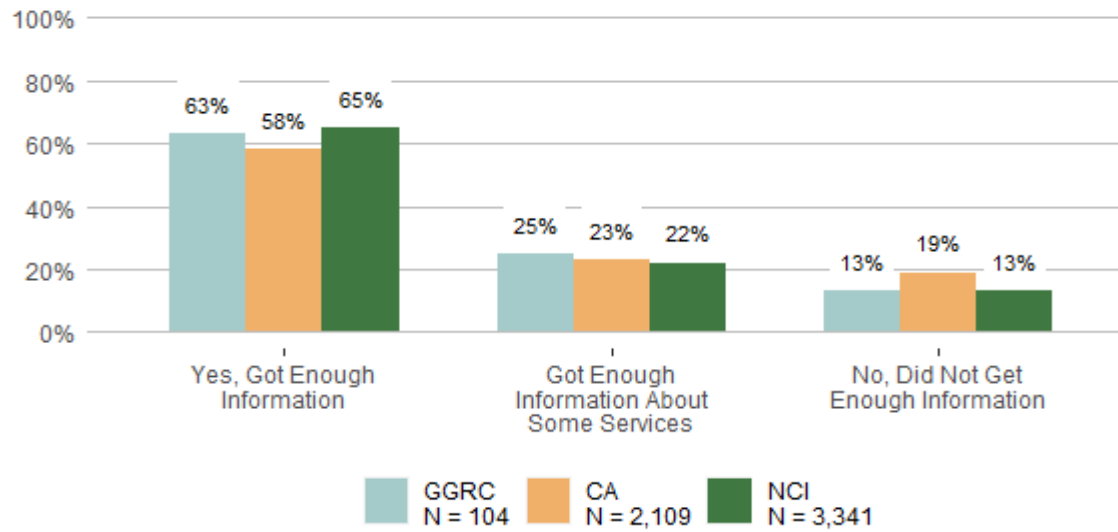


Table 97. If some or all of your family member's services have reopened or restarted: Did your family get enough information about the services reopening/restarting?

RC v CA v NCI	Yes, Got Enough Information	Got Enough Information About Some Services	No, Did Not Get Enough Information	N
GGRC	63%	25%	13%	104
CA	58%	23%	19%	2,109
NCI	65%	22%	13%	3,341

If some or all of your family member's services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions?

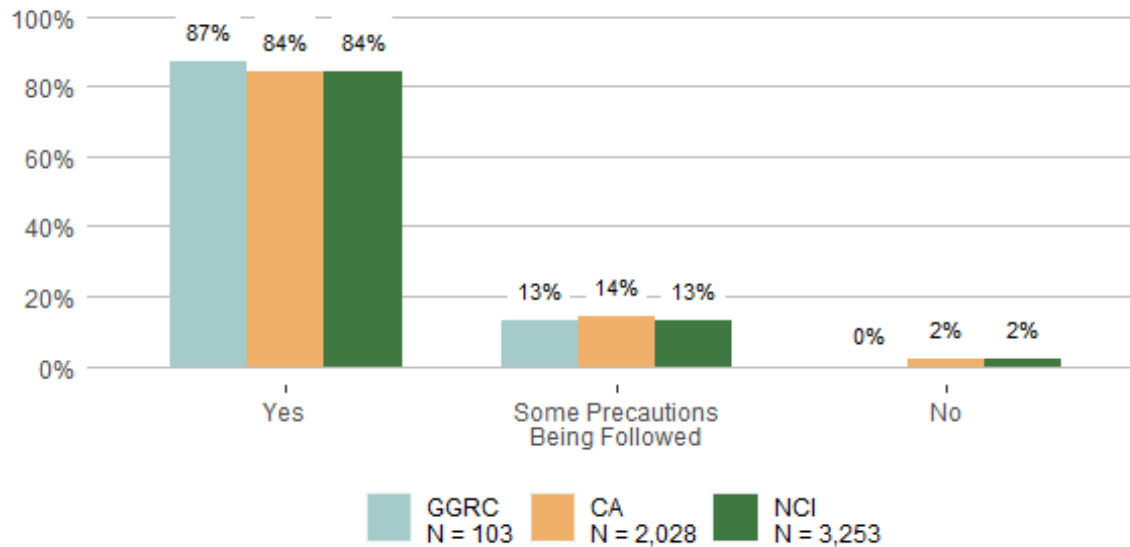


Table 98. If some or all of your family member's services have reopened or restarted: Do you feel that service providers are following COVID-19 safety precautions?

RC v CA v NCI	Yes	Some Precautions Being Followed	No	N
GGRC	87%	13%	0%	103
CA	84%	14%	2%	2,028
NCI	84%	13%	2%	3,253

If staff support your family member in your family member's home: Do you feel that the staff follow recommendations to keep the household safe and healthy?

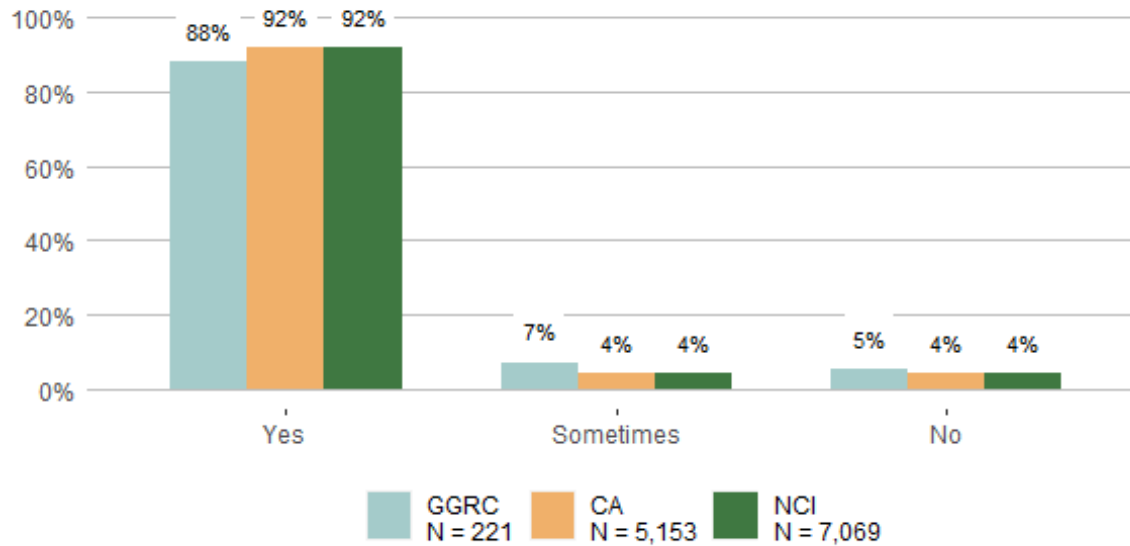


Table 99. If staff support your family member in your family member's home: Do you feel that the staff follow recommendations to keep the household safe and healthy?

RC v CA v NCI	Yes	Sometimes	No	N
GGRC	88%	7%	5%	221
CA	92%	4%	4%	5,153
NCI	92%	4%	4%	7,069

Do you feel that the people in your household have the personal protective equipment (PPE) they need to stay healthy and safe when going out in the community?

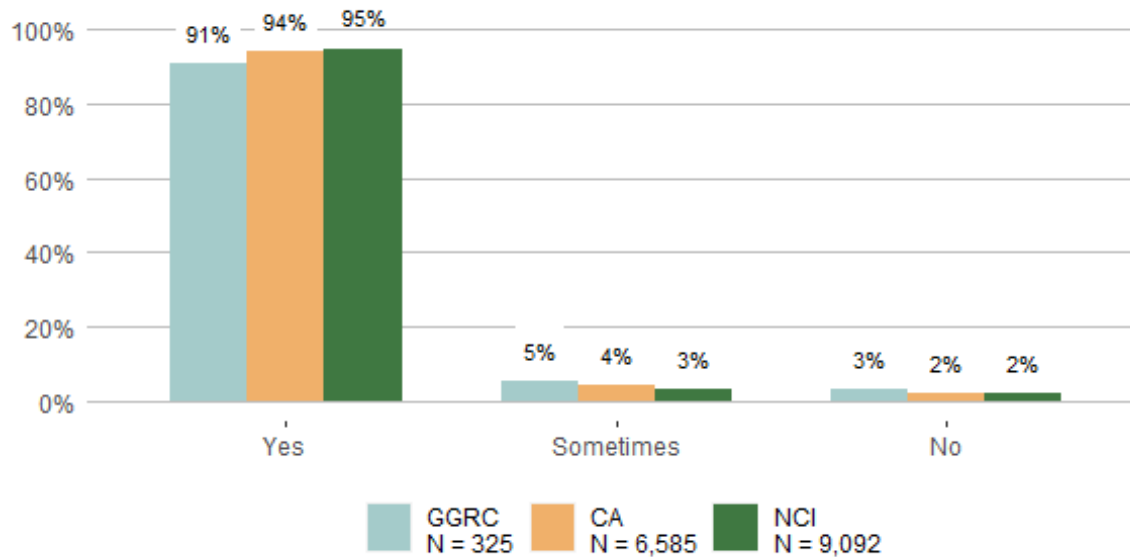


Table 100. Do you feel that the people in your household have the personal protective equipment (PPE) they need to stay healthy and safe when going out in the community?

RC v CA v NCI	Yes	Sometimes	No	N
GGRC	91%	5%	3%	325
CA	94%	4%	2%	6,585
NCI	95%	3%	2%	9,092

In preparation for the future, have you made or updated an emergency plan with your family member's case manager or with other staff?

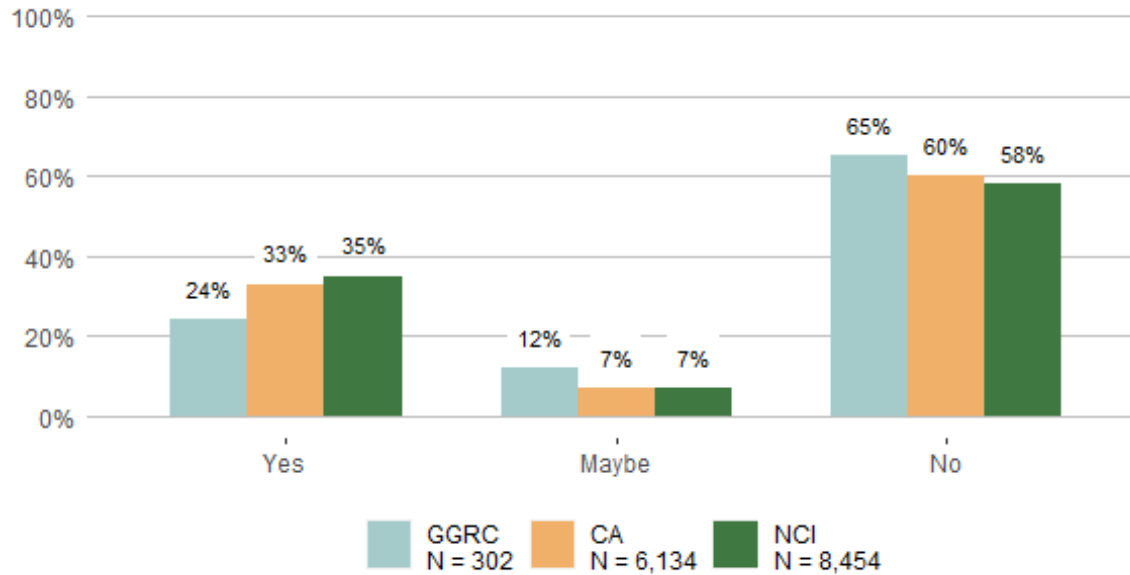


Table 101. In preparation for the future, have you made or updated an emergency plan with your family member's case manager/service coordinator or with other staff?

RC v CA v NCI	Yes	Maybe	No	N
GGRC	24%	12%	65%	302
CA	33%	7%	60%	6,134
NCI	35%	7%	58%	8,454

California Specific Questions

Total Out-of-pocket Expenses Related to Family Member's Care in the Past Year

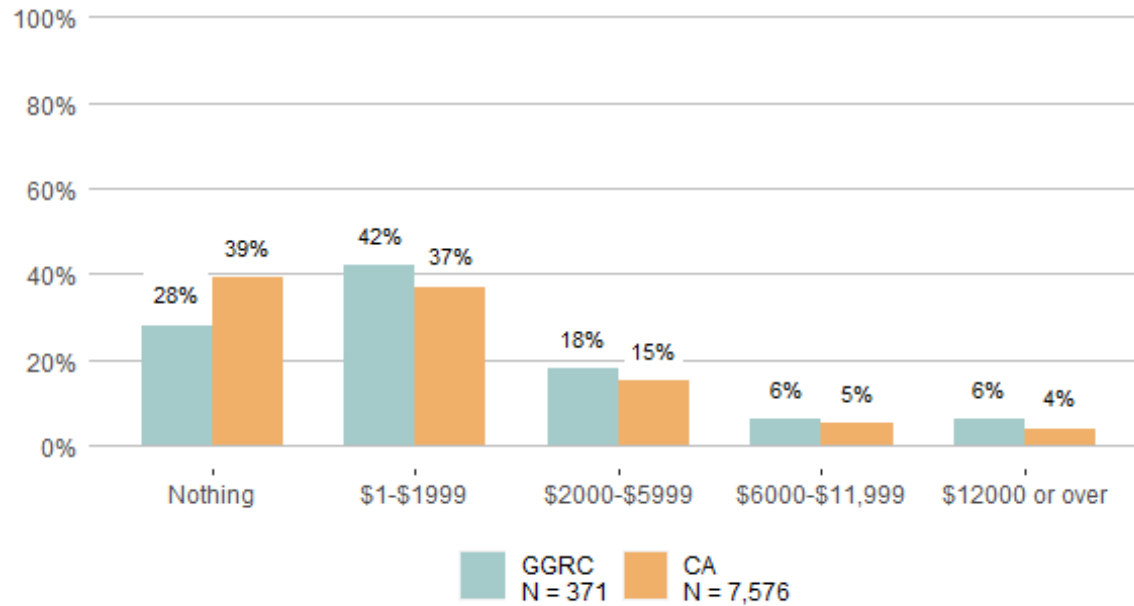


Table 102. Total Out-of-pocket Expenses Related to Family Member's Care in the Past Year

RC v CA	Nothing	\$1-\$1999	\$2000-\$5999	\$6000-\$11,999	\$12000 or over	N
GGRC	28%	42%	18%	6%	6%	371
CA	39%	37%	15%	5%	4%	7,576

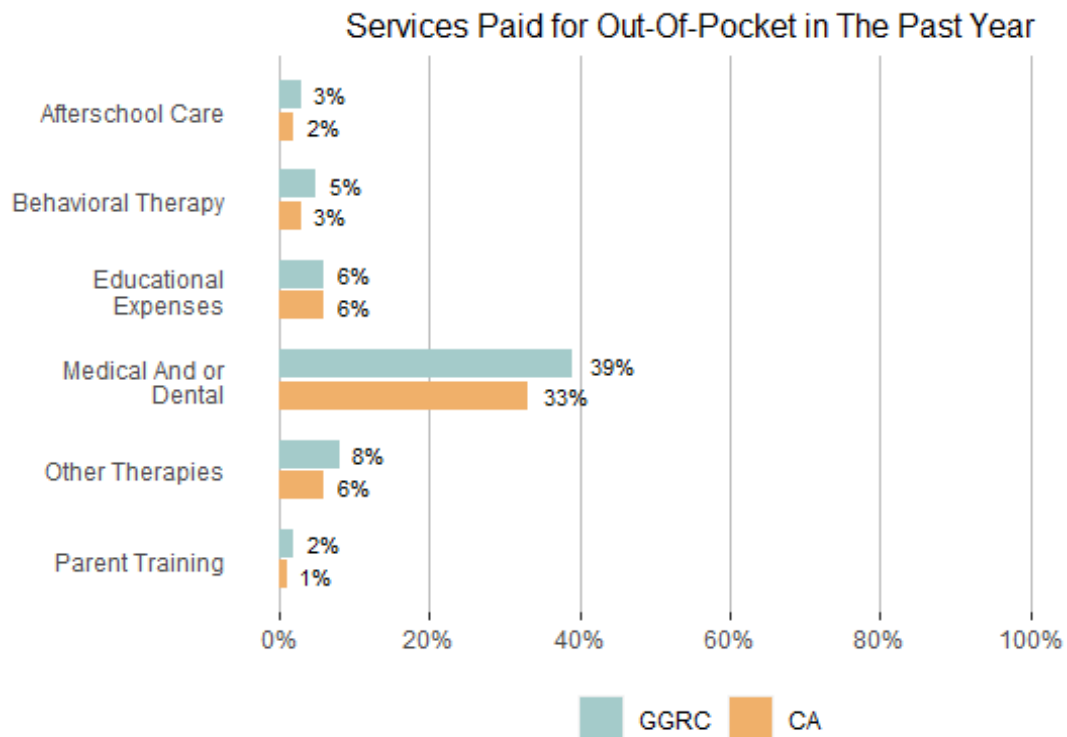


Table 103a. Services Paid for Out-Of-Pocket in The Past Year

Categories are not mutually exclusive, therefore N is not shown.

RC v CA	Afterschool Care	Behavioral Therapy	Educational Expenses	Medical And or Dental	Other Therapies	Parent Training
GGRC	3%	5%	6%	39%	8%	2%
CA	2%	3%	6%	33%	6%	1%

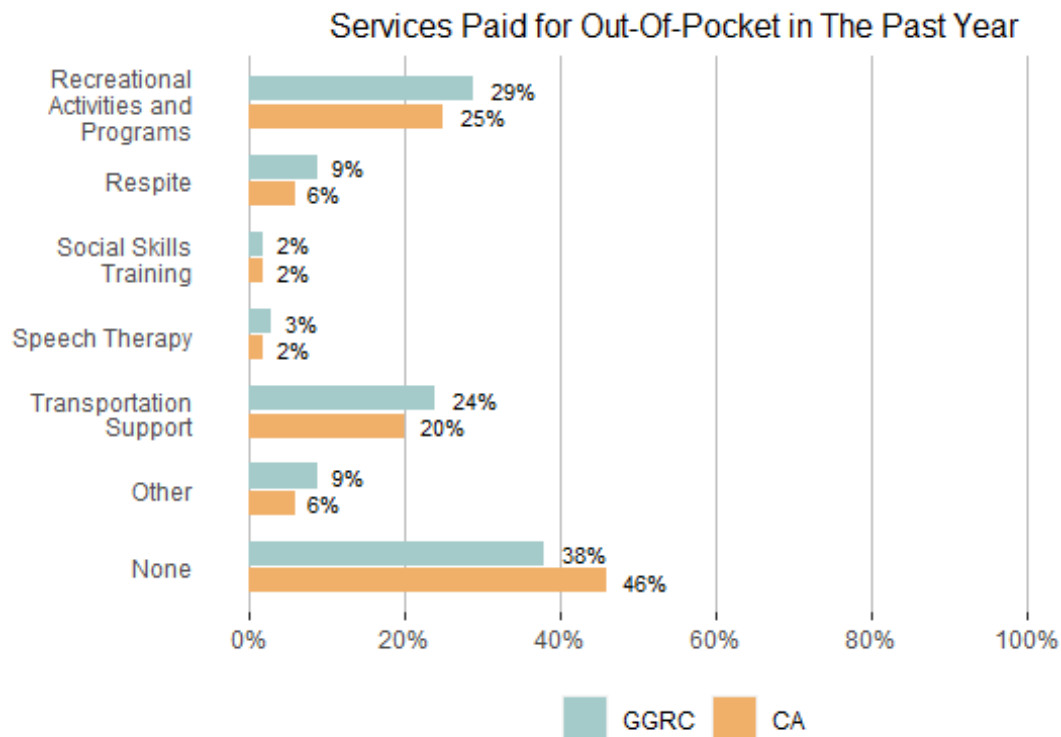


Table 103b. Services Paid for Out-of-pocket in the Past Year

Categories are not mutually exclusive, therefore N is not shown.

RC v CA	Recreational Activities and Programs	Respite	Social Skills Training	Speech Therapy	Transportation Support	Other	None
GGRC	29%	9%	2%	3%	24%	9%	38%
CA	25%	6%	2%	2%	20%	6%	46%

Does your regional center keep you informed, in your preferred language, about programs or services it offers? (For example, updates about new programs or services they offer)

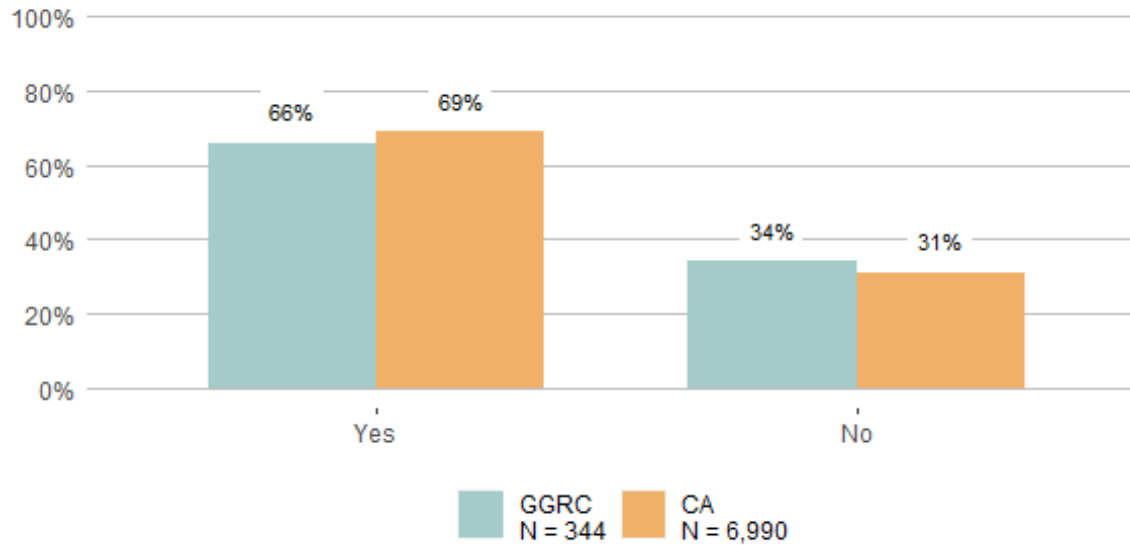


Table 104. Does your regional center keep you informed, in your preferred language, about programs or services it offers? (For example, updates about new programs or services they offer)

RC v CA	Yes	No	N
GGRC	66%	34%	344
CA	69%	31%	6,990

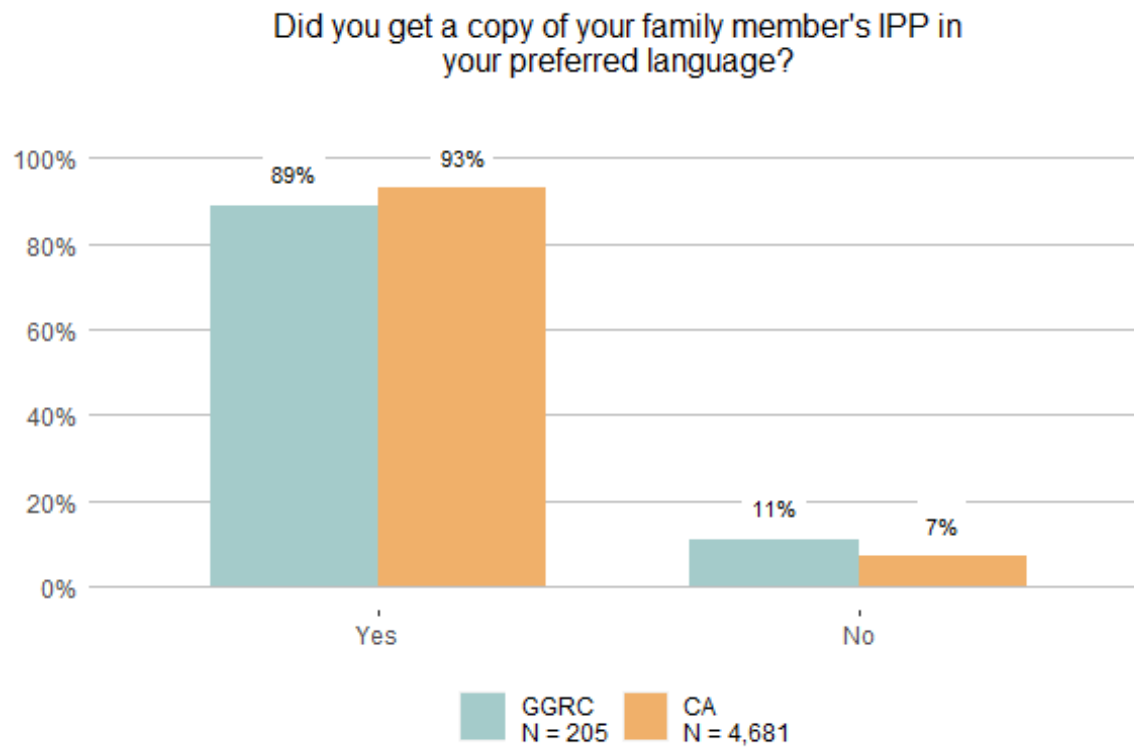


Table 105. Did you get a copy of your family member's IPP in your preferred language?

RC v CA	Yes	No	N
GGRC	89%	11%	205
CA	93%	7%	4,681

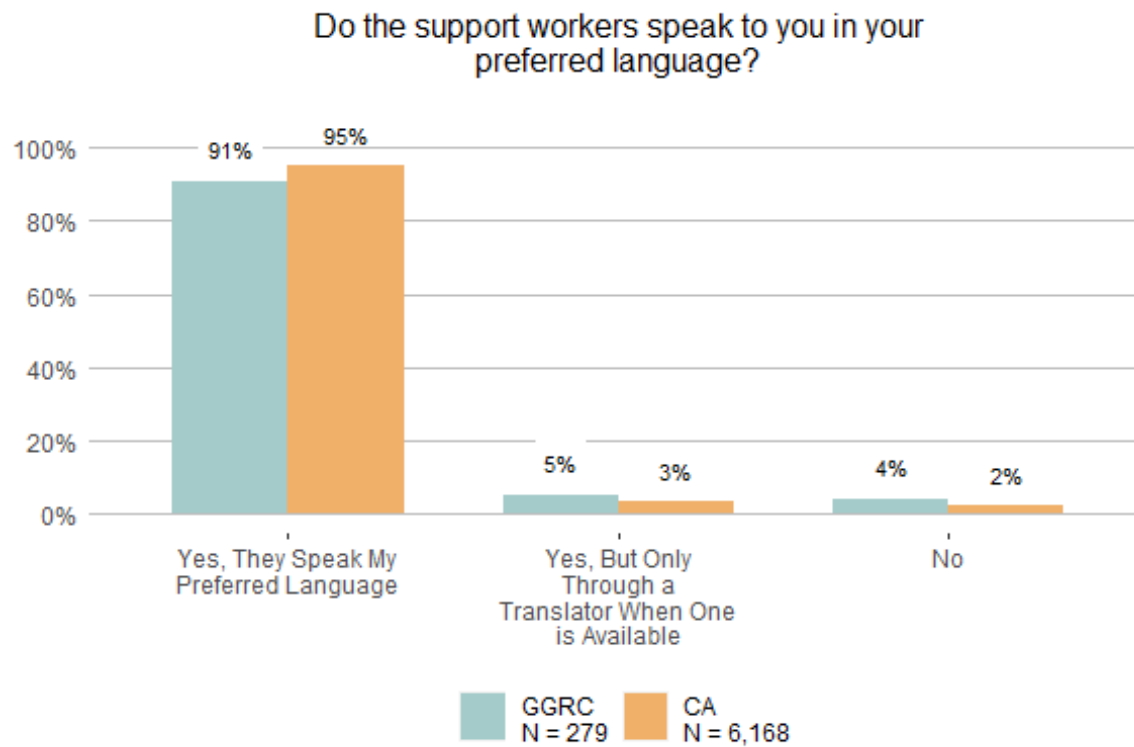


Table 106. Do the support workers speak to you in your preferred language?

RC v CA	Yes, They Speak My Preferred Language	Yes, But Only Through a Translator When One is Available	No	N
GGRC	91%	5%	4%	279
CA	95%	3%	2%	6,168

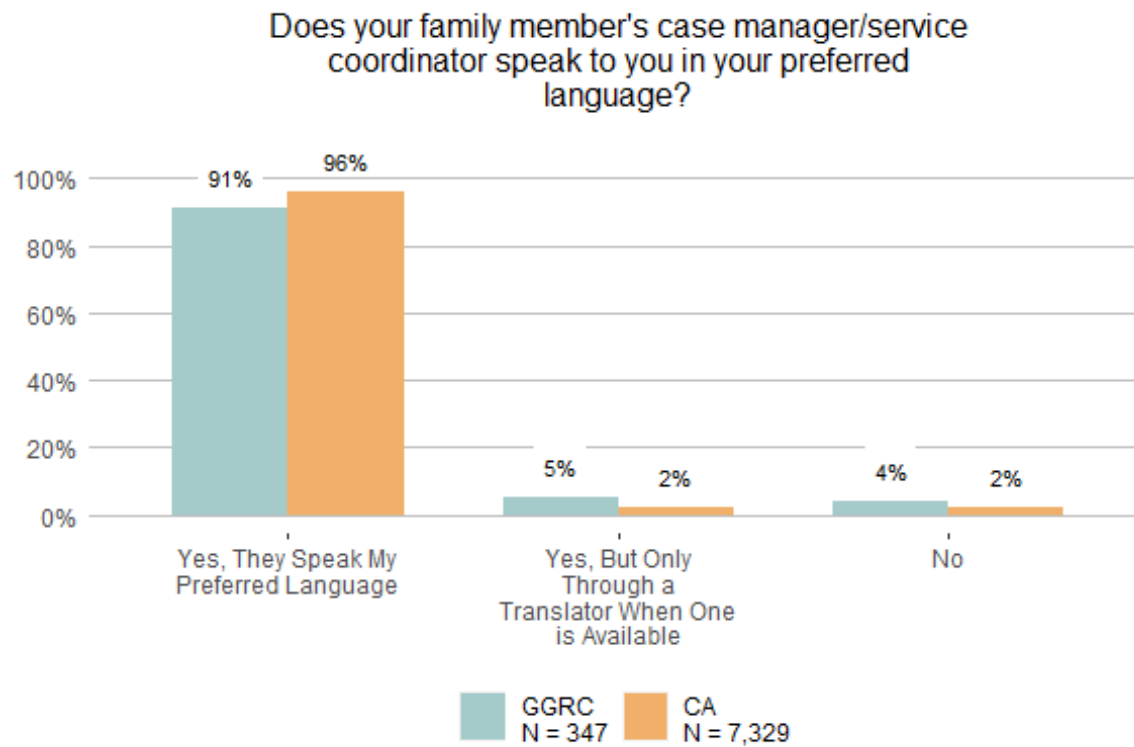


Table 107. Does your family member's case manager/service coordinator speak to you in your preferred language?

RC v CA	Yes, They Speak My Preferred Language	Yes, But Only Through a Translator When One is Available	No	N
GGRC	91%	5%	4%	347
CA	96%	2%	2%	7,329

If your support workers and/or case manager/
service coordinator do not speak to you in your
preferred language is a translator provided when
needed?

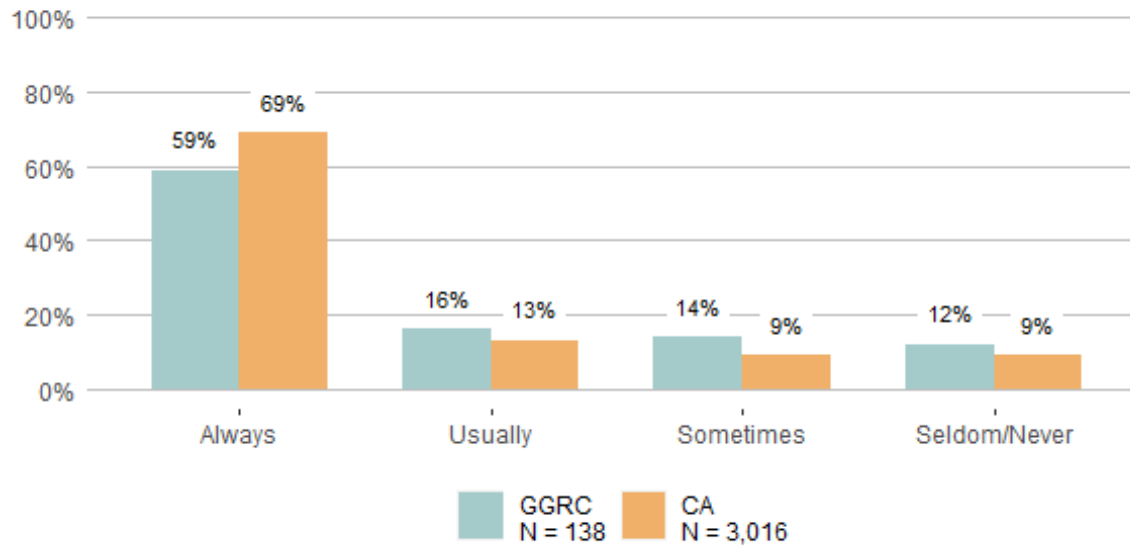


Table 108. If your support workers and/or case manager/service coordinator do not speak to you in your preferred language is a translator provided when needed?

RC v CA	Always	Usually	Sometimes	Seldom/Never	N
GGRC	59%	16%	14%	12%	138
CA	69%	13%	9%	9%	3,016

Does your family member's case manager/service coordinator support you in a way that is respectful to your culture?

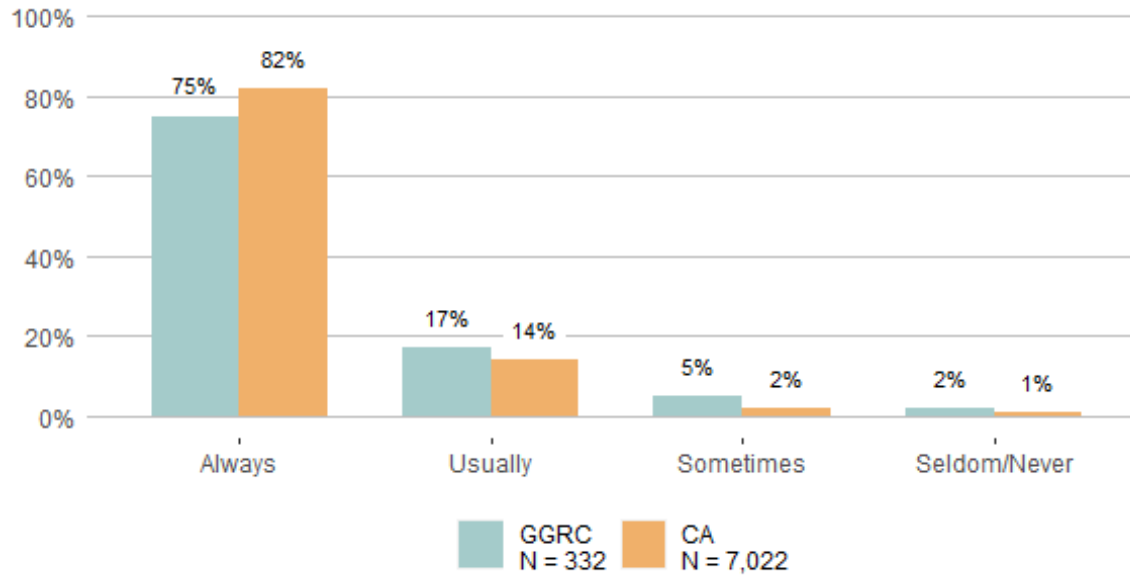


Table 109. Does your family member's case manager/service coordinator support you in a way that is respectful to your culture?

RC v CA	Always	Usually	Sometimes	Seldom/Never	N
GGRC	75%	17%	5%	2%	332
CA	82%	14%	2%	1%	7,022

Do support workers for your family members provide services in a way that is respectful of your culture?

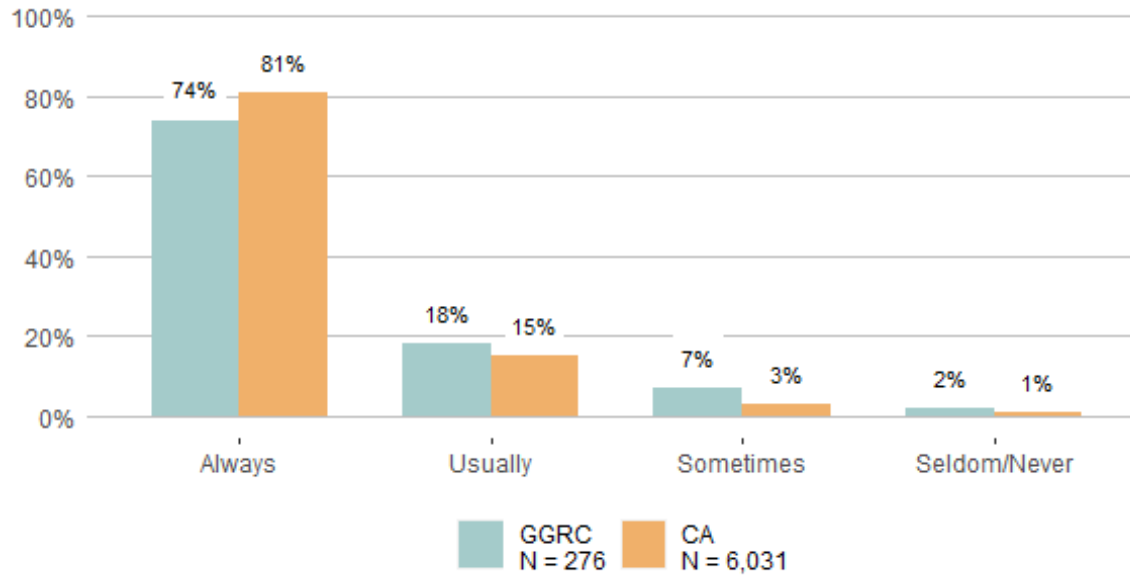


Table 110. Do support workers for your family members provide services in a way that is respectful of your culture?

RC v CA	Always	Usually	Sometimes	Seldom/Never	N
GGRC	74%	18%	7%	2%	276
CA	81%	15%	3%	1%	6,031

Do you believe your plans for how to handle your family members needs during a natural disaster (such as a wildfire or earthquake) will be effective?

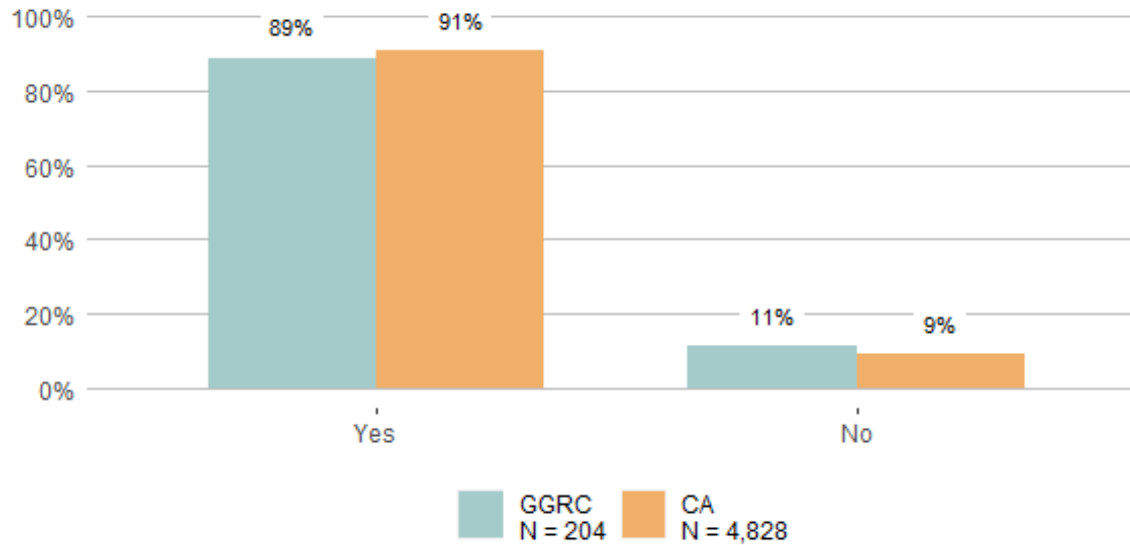


Table 111. Do you believe your plans for how to handle your family members needs during a natural disaster (such as a wildfire or earthquake) will be effective?

RC v CA	Yes	No	N
GGRC	89%	11%	204
CA	91%	9%	4,828

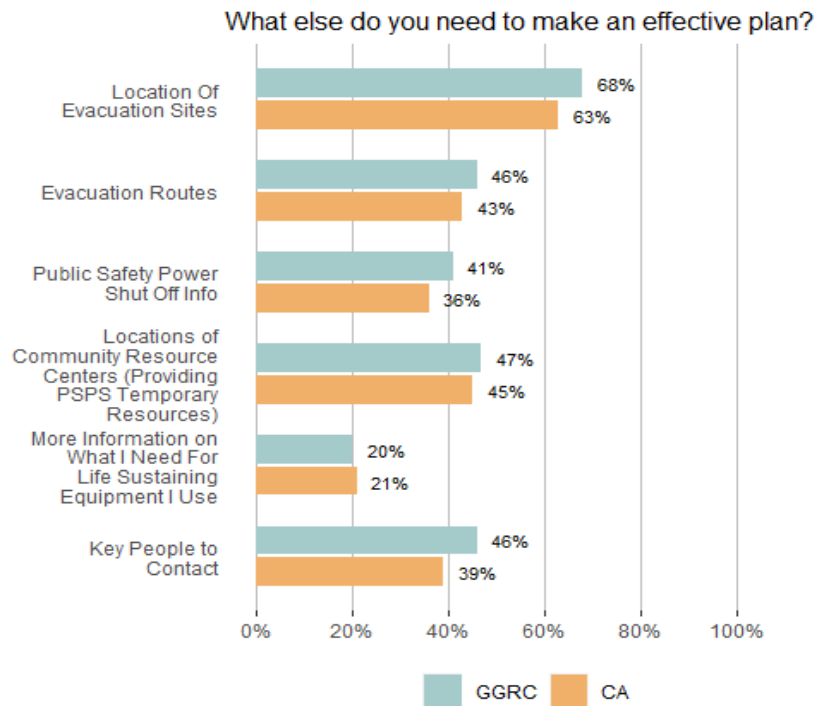


Table 112a. What else do you need to make an effective plan?

Categories are not mutually exclusive, therefore N is not shown.

RC v CA	Location Of Evacuation Sites	Evacuation Routes	Public Safety Power Shut Off Info	Locations of Community Resource Centers (Providing PSPS Temporary Resources)	More Information on What I Need For Life Sustaining Equipment I Use	Key People to Contact
GGRC	68%	46%	41%	47%	20%	46%
CA	63%	43%	36%	45%	21%	39%

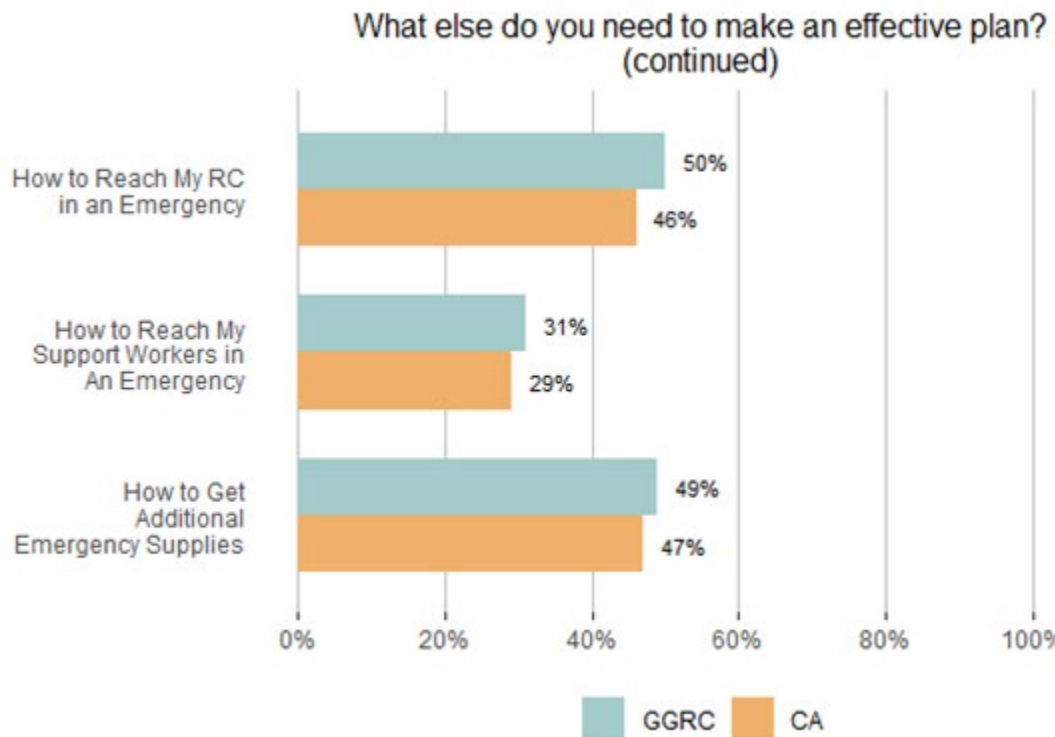


Table 112b. What else do you need to make an effective plan? (continued)

Categories are not mutually exclusive, therefore N is not shown.

RC v CA v NCI	How to Reach My RC in an Emergency	How to Reach My Support Workers in An Emergency	How to Get Additional Emergency Supplies
GGRC	50%	31%	49%
CA	46%	29%	47%

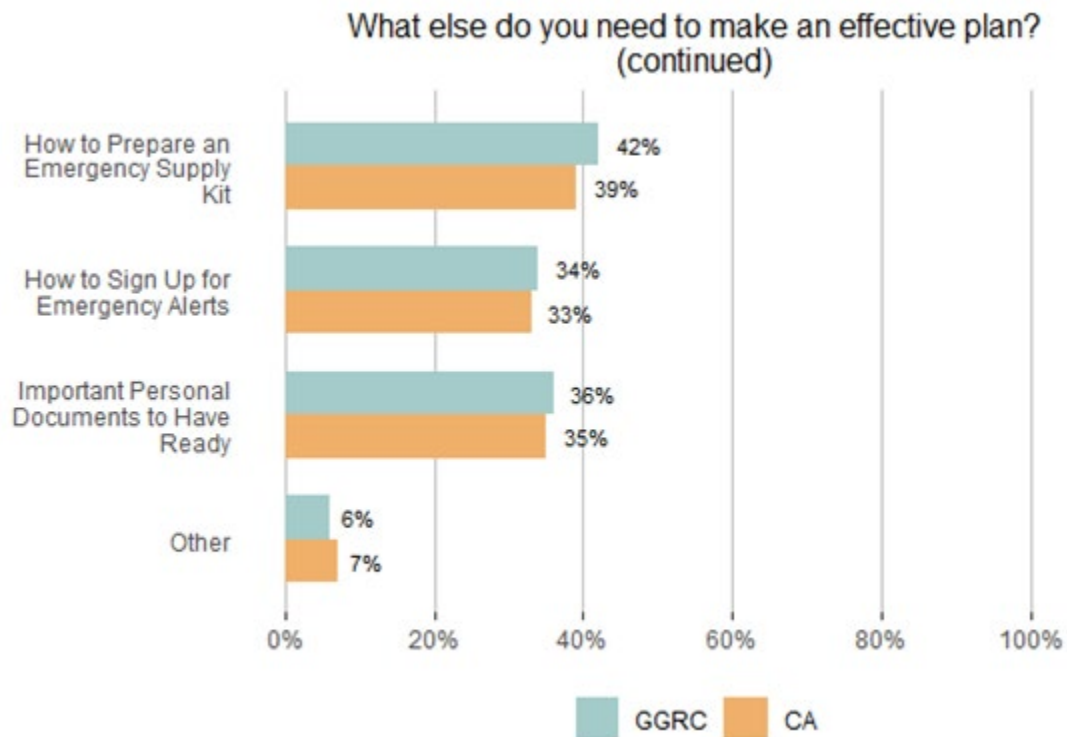


Table 112c. What else do you need to make an effective plan? (continued)

Categories are not mutually exclusive, therefore N is not shown.

RC v CA	How to Prepare an Emergency Supply Kit	How to Sign Up for Emergency Alerts	Important Personal Documents to Have Ready	Other
GGRC	42%	34%	36%	6%
CA	39%	33%	35%	7%

Do you know what to do if you disagree with your regional center about services and/or eligibility?
(For example, how to request a Fair Hearing)

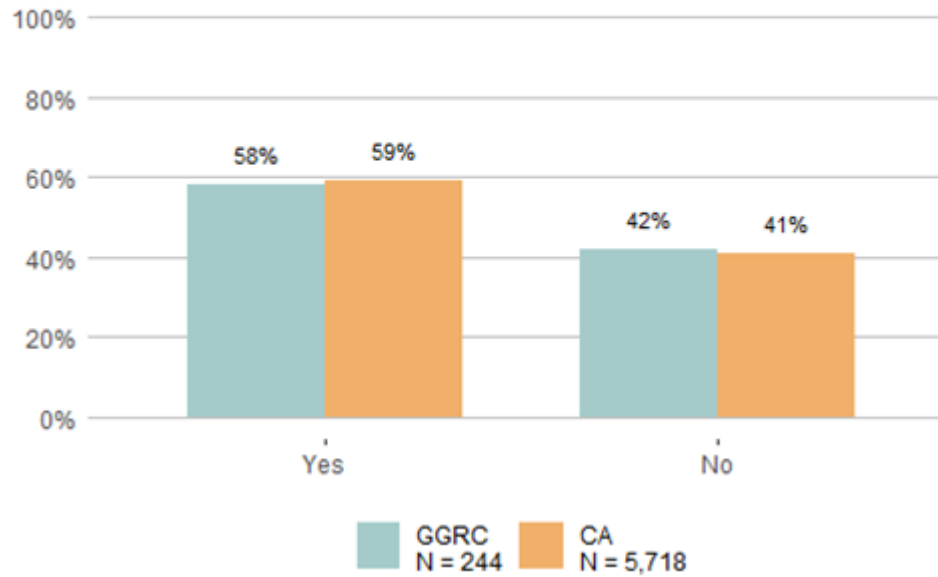


Table 113. Do you know what to do if you disagree with your regional center about services and/or eligibility? (For example, how to request a Fair Hearing)

RC v CA	Yes	No	N
GGRC	58%	42%	244
CA	59%	41%	5,718