



2019-20 Adult Family Survey (AFS)

Regional Center Report

San Andres Regional Center



Contents

Quality Assessment Project and National Core Indicators™	7
What is NCI?.....	7
What is the NCI Adult Family Survey?.....	7
What is included in this report?.....	7
Important Note on COVID-19	8
Demographics	9
Demographics of Family Member Receiving Services	10
Table 1. More Than One Person Living in the Home Has IDD.....	11
Table 2. Family Member’s Age.....	11
Table 3. Family Member’s Gender	11
Table 4. Family Member’s Race and Ethnicity	12
Table 5. Family Member’s Disabilities (not mutually exclusive)	12
Table 6. Family Member’s Disabilities (continued).....	12
Table 7. Family Member’s Health Conditions.....	13
Table 8. Family Member’s Health Conditions (continued)	13
Table 9. Family Member’s Preferred Means of Communication.....	13
Table 10. Family Member’s Preferred Language	14
Table 11. Family Member’s Preferred Language (Continued)	14
Table 12. Family Member’s Preferred Language (Continued)	14
Table 13. Family Member Has Legal Court Appointed Guardian or Conservator	15
Table 14. Guardian or Conservator Relationship to Family Member	15
Table 15. Family Member’s Highest level of Education.....	15
Table 16. Family Member’s Activities in the Past Two Weeks Included <i>Individual Paid Job in the Community</i>	16
Table 17. Family Member’s Activities in the Past Two Weeks Included <i>Paid Small Group Job in a Community-based Setting</i>	16

Table 18. Family Member’s Activities in the Past Two Weeks Included <i>Paid Work in a Community Job That Primarily Hires People With Disabilities</i>	16
Table 19. Family Member’s Activities in the Past Two Weeks Included <i>Unpaid Activity in the Community</i>	17
Table 20. Family Member’s Activities in the Past Two Weeks Included <i>Paid Activity in a Facility-based Setting</i>	17
Table 21. Family Member’s Activities in the Past Two Weeks Included <i>Unpaid Activity in a Facility-based Setting</i>	17
Table 22. Family Member’s Activities in the Past Two Weeks Included <i>School</i>	17
Table 23. Family Member’s Activities in the Past Two Weeks Included <i>Stays at Home</i>	18
Table 24. Family Member’s Activities in the Past Two Weeks Included <i>Other Activities</i>	18
Table 25. Family Member’s Support Needs for Self-Injurious, Disruptive, and/or Destructive Behaviors	18
Table 26. Family Member’s Level of Help Needed With Personal Care Activities (e.g., bathing, dressing, eating)	19
Table 27. Family Member’s Need for Help With Other Daily Activities (e.g., scheduling, managing money, or shopping)	19
Respondents	20
Table 28. Language Usually Spoken at Home	21
Table 29. Language Usually Spoken at Home (Continued)	21
Table 30. Language Usually Spoken at Home (Continued)	21
Table 31. Respondent’s Age	21
Table 32. Respondent’s Health	22
Table 33. Respondent’s Relationship to Family Member	22
Table 34. Respondent or Other Family Member Provides Paid Support to Family Member Receiving Services.....	22
Table 35. Number of Adults in Household (Not Including Family Member Receiving Services)	23
Table 36. Number of Children (Under 18 Years Old) in Household	23
Table 37. Respondent’s Highest Level of Education	23
Table 38. Total Taxable Household Income of Wage Earners in the Past Year	23
Table 39. Total Out-of-pocket Expenses Related to Family Member’s Care in the Past Year	24
Table 40. Services Paid for Out-Of-Pocket in The Past Year	24
Table 41. Services Paid for Out-Of-Pocket in The Past Year (Continued)	24
Table 42. Residential Designation (Urban, Suburban, or Rural)	25

Services and Supports Received	26
Table 43. Services and Supports Received From Regional Center.....	27
Table 44. Additional Services and Supports Received (Not From the Regional Center)	27
Adult Family Survey Results.....	28
Information and Planning Charts.....	29
Information and Planning Tables.....	35
Table Q1. Do you get enough information to take part in planning services for your family member?	36
Table Q2. Is information from the regional center offered in your preferred language?.....	36
Table Q3. Is the information you get about services and supports easy to understand?.....	36
Table Q4. Does the case manager/service coordinator respect your family’s choices and opinions?	36
Table Q5. Do you have enough information about other public services for which your family is eligible (for example, food stamps, SSI, housing subsidies, etc.)?	37
Table Q6. Do you need help planning for your family member’s future with respect to any of the following?	37
Table Q7. If you asked for crisis or emergency services during the past year, were services provided when needed?.....	37
Table Q8. Does your family member have an individual program plan (IPP)?.....	38
Table Q9. Does the IPP include all the services and supports your family member needs?	38
Table Q10. Does your family member get all the services listed in the IPP?.....	38
Table Q11. Did you or someone else in your family (besides your family member with a disability) help make the IPP?	38
Table Q12. Did your family member help make the IPP?.....	38
Table Q13. Did you or your family member get a copy of the IPP in your or your family member’s preferred language?.....	39
Table Q14. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member’s last IPP meeting?	39
Table Q15. If your family member left school services during the past year, did s/he have a transition plan?	39
Table Q16. If your family member had a transition plan, did the transition plan include getting or continuing work in a community job?	39
Table Q17. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?	40

Table Q18. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster? 40

Access and Delivery of Services and Supports Charts..... 41

Access and Delivery of Services and Supports Tables..... 49

Table Q19. Are you or your family member able to contact his/her support workers when you want? 50

Table Q20. Are you or your family member able to contact his/her case manager/service coordinator when you want? 50

Table Q21. Do support workers come and go when they are supposed to? 50

Table Q22. Do services and supports change when your family’s needs change?..... 50

Table Q23. Do support workers speak to you in a way you understand? 51

Table Q24. Are there support workers available who can speak to you in your preferred language? 51

Table Q25. Does your family member’s case manager/service coordinator speak your preferred language? 51

Table Q26. If your family member's case manager/service coordinator does not speak in your preferred language, is a translator provided when you speak with the case manager/service coordinator? 51

Table Q27. Are services delivered in a way that is respectful of your family’s culture? 52

Table Q28. Does your family member’s case manager/service coordinator support you in a way that is respectful to your culture? 52

Table Q29. If your family member does not communicate verbally (for example, uses gestures or sign language, or a communication aid), are there support workers who can communicate with him/her? 52

Table Q30. Do support workers have the right information and skills to meet your family’s needs? 52

Table Q31. Does your family member have the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?..... 53

Table Q32. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)? 53

Table Q33. Does your family member’s primary care doctor understand your family member’s needs related to his/her disability? 53

Table Q34. Can your family member go to the dentist when needed? 53

Table Q35. Does your family member’s dentist understand your family member’s needs related to his/her disability? 54

Table Q36. If your family member takes medications, do you know what they’re for? 54

Table Q37. 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)? 54

Table Q38. If your family member uses mental health services, does the mental health professional understand your family member’s needs related to his/her disability? 55

Table Q39. If you need respite services, how often are you able to use them? 56

Table Q40. If you have used respite services in the past year, were you satisfied with the quality of the respite services?..... 56

Table Q41. Does your family get the supports and services it needs? 56

Table Q42. If your family does not get the support and services needed, what additional services does your family need? 57

Choice, Decision Making and Control Charts..... 58

Choice, Decision Making and Control Tables..... 61

Table Q43. Can your family choose or change the agency that provides your family member’s services? 62

Table Q44. Can your family choose or change your family member’s support workers?..... 62

Table Q45. Does your family directly manage support staff? 62

Table Q46. Do service providers for your family member work together to provide support?..... 62

Table Q47. Did you, your family member, or someone else in your family choose your family member’s case manager/service coordinator? 63

Involvement in the Community Charts 64

Involvement in the Community Tables 67

Table Q48. Does your family member take part in activities in the community? 68

Table Q49. For your family member, what makes it hard to take part in activities in the community?..... 68

Table Q50. Does your family member have friends other than paid support workers or family? 68

Table Q51. 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.)? 69

Table Q52. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)? 69

Satisfaction With Services and Supports Charts 70

Satisfaction With Services and Supports Tables 75

Table Q53. Overall, are you satisfied with the services and supports your family member currently receives? 76

Table Q54. Do you know how to file a complaint or grievance about provider agencies or staff? 76

Table Q55. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled?	76
Table Q56. Do you know how to report abuse or neglect related to your family member?	76
Table Q57. Within the past year, was a report of abuse or neglect filed on behalf of your family member?	77
Table Q58. If a report of abuse or neglect was filed within the past year, did the appropriate people respond to the report?	77
Table Q59. If a report of abuse or neglect was filed on behalf of family member by someone outside of your family, were you notified of the report in a timely manner?	77
Table Q60. Do you feel that services and supports have made a positive difference in the life of your family member?	77
Table Q61. Have services helped keep your family member in your home?	78
Table Q62. Have services and supports reduced your family's out-of-pocket expenses for your family member's care?	78
Table Q63. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?	78
Table Q64. 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?	78
Table Q65. Have the services or supports that your family member received been increased in the past year?	79
Table Q66. Are services and supports helping your family member to live a good life?	79
Table Q67. Has your family member moved form a Developmental Center (DC) to the community in the past 5 years?	79
Table Q68. How long has your family member lived in the community?	80

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 2019-20 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 performance.¹ This report shows Adult Family Survey findings from San Andres Regional Center (SARC) compared to the California statewide and NCI averages. Regional centers can use this report to help guide strategic planning and monitor systemic changes.

What is NCI?

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

In 2019-20 a total of 46 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 with* the respondent and receives at least one service other than case management from the state DD agency. The survey collects demographic information on both the individual receiving services (‘family member’) as well as the person who fills out the survey (the ‘respondent’) and information on services and supports received. The survey is continually refined and tested to ensure it is valid and reliable.

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

What is included in this report?

This report includes findings from the National Core Indicators™ 2019-20 Adult Family Survey (AFS). All NCI averages are weighted.² This report includes this regional center’s Adult Family Survey data compared to California and NCI averages.

¹ Refer to the 2019-20 California Adult Family Survey Report for information about Quality Assessment Project implementation, NCI and California’s statewide results.

² NCI averages are comprised of 19,183 valid surveys collected across 14 states: AZ, CA, DE, DC, FL, GA, MD, MO, NH, NC, OK, PA, SD and WA.

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

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

Important Note on COVID-19

The 2019-20 NCI Family Survey data collection cycle began July 1, 2019 and ended June 30, 2020. Midway through data collection, in February 2020, COVID-19 began to spread across the United States. Data collection for the NCI Family Surveys continued throughout the pandemic. States begin data collection at various times throughout the year – some before the pandemic started and some after. Because the family surveys do not collect information on the date of survey completion, we cannot fully assess what impact the pandemic had on data collected at different times throughout the year. Additionally, we cannot determine whether the onset of COVID-19 impacted state samples. For instance, we do not know if certain populations were more or less likely to respond to the survey after February and we do not know whether or how responses were affected for specific questions for those who completed the survey after the pandemic began. 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.

Demographics

Demographics of Family Member Receiving Services

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

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

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

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

RC v CA v NCI	Yes	No	N
SARC	19%	81%	727
CA Average	16%	84%	14,132
Weighted NCI Average	15%	85%	18,537

Table 2. Family Member’s Age

RC v CA v NCI	Average Age	N
SARC	32.6	740
CA Average	33.4	14,378
Weighted NCI Average	34.4	18,904

Table 3. Family Member’s Gender

Standard NCI response options include “Male” and “Female”

RC v CA v NCI	Male	Female	Other	N
SARC	61%	39%	0%	745
CA Average	62%	38%	0%	14,442
Weighted NCI Average	61%	39%	n/a	18,947

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
SARC	1%	34%	2%	1%	33%	35%	1%
CA Average	2%	16%	9%	1%	43%	37%	2%
Weighted NCI Average	2%	9%	13%	1%	59%	22%	1%

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

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

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
SARC	59%	18%	37%	13%	9%	5%
CA Average	59%	20%	38%	17%	9%	6%
Weighted NCI Average	65%	23%	36%	18%	9%	7%

Table 6. 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
SARC	9%	22%	1%	15%	1%	0%	13%
CA Average	10%	22%	1%	15%	1%	1%	14%
Weighted NCI Average	10%	26%	1%	16%	1%	1%	17%

Table 7. 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
SARC	12%	22%	6%	31%	28%
CA Average	10%	18%	5%	28%	29%
Weighted NCI Average	10%	18%	5%	30%	30%

Table 8. 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	Alzheimer’s Disease or Other Dementia	Pressure Ulcers	Oral Health or Dental Problems	Sleep Apnea	Other
SARC	8%	5%	2%	11%	22%	21%
CA Average	8%	3%	2%	14%	18%	24%
Weighted NCI Average	10%	2%	2%	13%	19%	25%

Table 9. 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
SARC	78%	14%	2%	2%	4%	731
CA Average	81%	11%	2%	1%	5%	14,241
Weighted NCI Average	78%	14%	2%	2%	4%	18,721

Table 10. Family Member's Preferred Language

CA specific question

RC v CA v NCI	English	Spanish	Mandarin	Tagalog	Vietnamese	N
SARC	57%	17%	2%	2%	6%	742
CA Average	74%	14%	1%	1%	1%	14,464
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	n/a

Table 11. Family Member's Preferred Language (Continued)

CA specific question

RC v CA v NCI	Korean	Arabic	Armenian	Farsi	Hmong	N
SARC	1%	0%	0%	0%	0%	742
CA Average	1%	0%	0%	0%	0%	14,464
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	n/a

Table 12. Family Member's Preferred Language (Continued)

CA specific question

RC v CA v NCI	Khmer	Laos	Russian	ASL	Other	N
SARC	0%	0%	0%	1%	15%	742
CA Average	0%	0%	0%	1%	8%	14,464
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	n/a

Table 13. 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	Limited	Full	Has Guardianship but Level Is Unknown	N
SARC	34%	66%	n/a	n/a	698
CA Average	42%	58%	n/a	n/a	13,477
Weighted NCI Average	37%	33%	28%	2%	17,813

Table 14. Guardian or Conservator Relationship to Family Member

RC v CA v NCI	Family	Friend	State Employee or Guardianship Agency	Other	N
SARC	98%	1%	0%	0%	689
CA Average	98%	1%	0%	1%	7,433
Weighted NCI Average	96%	1%	1%	3%	10,330

Table 15. 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	High School Diploma or GED	Vocational School or Certificate Program	Some College	College Degree or Higher	N
SARC	25%	2%	32%	18%	5%	10%	7%	689
CA Average	19%	3%	35%	23%	5%	9%	6%	13,541
Weighted NCI Average	16%	3%	35%	29%	4%	7%	5%	17,923

Table 16. Family Member’s Activities in the Past Two Weeks Included *Individual Paid Job in the Community*

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

RC v CA v NCI	Yes	No	N
SARC	15%	85%	720
CA Average	13%	87%	13,877
Weighted NCI Average	14%	86%	18,302

Table 17. Family Member’s Activities in the Past Two Weeks Included *Paid Small Group Job in a Community-based Setting*

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

RC v CA v NCI	Yes	No	N
SARC	13%	87%	699
CA Average	13%	87%	13,640
Weighted NCI Average	10%	90%	17,962

Table 18. Family Member’s Activities in the Past Two Weeks Included *Paid Work in a Community Job That Primarily Hires People With Disabilities*

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

RC v CA v NCI	Yes	No	N
SARC	9%	91%	705
CA Average	8%	92%	13,538
Weighted NCI Average	7%	93%	17,895

Table 19. Family Member’s Activities in the Past Two Weeks Included *Unpaid Activity in the Community*

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

RC v CA v NCI	Yes	No	N
SARC	27%	73%	694
CA Average	27%	73%	13,697
Weighted NCI Average	28%	72%	18,038

Table 20. Family Member’s Activities in the Past Two Weeks Included *Paid Activity in a Facility-based Setting*

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

RC v CA v NCI	Yes	No	N
SARC	10%	90%	693
CA Average	12%	88%	13,642
Weighted NCI Average	13%	87%	17,991

Table 21. Family Member’s Activities in the Past Two Weeks Included *Unpaid Activity in a Facility-based Setting*

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

RC v CA v NCI	Yes	No	N
SARC	20%	80%	697
CA Average	21%	79%	13,451
Weighted NCI Average	21%	79%	17,765

Table 22. Family Member’s Activities in the Past Two Weeks Included *School*

RC v CA v NCI	Yes	No	N
SARC	24%	76%	693
CA Average	21%	79%	13,476
Weighted NCI Average	14%	86%	17,811

Table 23. Family Member’s Activities in the Past Two Weeks Included *Stays at Home*

RC v CA v NCI	Yes	No	N
SARC	47%	53%	686
CA Average	47%	53%	13,205
Weighted NCI Average	53%	47%	17,418

Table 24. Family Member’s Activities in the Past Two Weeks Included *Other Activities*

RC v CA v NCI	Yes	No	N
SARC	41%	59%	249
CA Average	46%	54%	4,949
Weighted NCI Average	44%	56%	6,499

Table 25. 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
SARC	51%	31%	18%	729
CA Average	51%	30%	19%	14,151
Weighted NCI Average	52%	31%	18%	18,570

Table 26. Family Member's Level of Help Needed With Personal Care Activities (e.g., bathing, dressing, eating)

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

RC v CA v NCI	No support needed	Some support needed	Extensive support needed	N
SARC	25%	36%	39%	743
CA Average	29%	35%	36%	14,380
Weighted NCI Average	26%	36%	38%	18,893

Table 27. Family Member's Need for Help With Other Daily Activities (e.g., scheduling, managing money, or shopping)

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

RC v CA v NCI	No support needed	Some support needed	Extensive support needed	N
SARC	8%	26%	65%	733
CA Average	9%	26%	65%	14,241
Weighted NCI Average	7%	21%	72%	18,740

Respondents

This section provides demographic information about the respondent.

Table 28. Language Usually Spoken at Home

Standard NCI response options include “English”, “Spanish”, and “Other”

RC v CA v NCI	English	Spanish	Mandarin	Tagalog	Vietnamese	N
SARC	49%	20%	3%	2%	8%	744
CA Average	68%	19%	1%	1%	1%	14,428
Weighted NCI Average	83%	11%	n/a	n/a	n/a	18,919

Table 29. Language Usually Spoken at Home (Continued)

Standard NCI response options include “English”, “Spanish”, and “Other”

RC v CA v NCI	Korean	Arabic	Armenian	Farsi	Hmong	N
SARC	2%	0%	0%	0%	0%	744
CA Average	1%	0%	0%	0%	0%	14,428
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	18,919

Table 30. Language Usually Spoken at Home (Continued)

Standard NCI response options include “English”, “Spanish”, and “Other”

RC v CA v NCI	Khmer	Laos	Russian	ASL	Other	N
SARC	0%	0%	1%	0%	15%	744
CA Average	0%	0%	0%	0%	7%	14,428
Weighted NCI Average	n/a	n/a	n/a	n/a	7%	18,919

Table 31. Respondent's Age

RC v CA v NCI	Under 35	35-54	55-74	75+	N
SARC	7%	23%	61%	9%	743
CA Average	6%	24%	60%	10%	14,371
Weighted NCI Average	4%	22%	62%	11%	18,882

Table 32. Respondent's Health

RC v CA v NCI	Excellent	Very Good	Fairly Good	Poor	N
SARC	15%	43%	32%	10%	738
CA Average	17%	45%	32%	6%	14,336
Weighted NCI Average	16%	45%	34%	5%	18,859

Table 33. Respondent's Relationship to Family Member

RC v CA v NCI	Parent	Sibling	Spouse	Grandparents	Other	N
SARC	87%	10%	0%	1%	2%	740
CA Average	86%	8%	0%	2%	4%	14,365
Weighted NCI Average	86%	7%	0%	2%	4%	18,876

Table 34. 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
SARC	45%	43%	16%
CA Average	49%	40%	13%
Weighted NCI Average	58%	32%	13%

Table 35. Number of Adults in Household (Not Including Family Member Receiving Services)

RC v CA v NCI	One	Two	Three	Four or More	N
SARC	8%	23%	42%	27%	742
CA Average	8%	27%	42%	24%	14,286
Weighted NCI Average	8%	29%	43%	20%	18,771

Table 36. Number of Children (Under 18 Years Old) in Household

RC v CA v NCI	None	One	Two	Three	Four or More	N
SARC	81%	11%	6%	2%	1%	738
CA Average	82%	11%	5%	2%	1%	14,309
Weighted NCI Average	85%	9%	4%	1%	1%	18,807

Table 37. 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
SARC	19%	16%	5%	19%	40%	728
CA Average	16%	19%	6%	23%	35%	14,224
Weighted NCI Average	11%	22%	7%	23%	38%	18,714

Table 38. Total Taxable Household Income of Wage Earners in the Past Year

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
SARC	9%	5%	9%	18%	12%	26%	21%	696
CA Average	10%	8%	11%	19%	11%	19%	22%	13,362
Weighted NCI Average	10%	7%	10%	19%	12%	20%	22%	17,697

Table 39. Total Out-of-pocket Expenses Related to Family Member’s Care in the Past Year

CA specific question

RC v CA v NCI	Nothing	\$1-\$100	\$101-\$1,000	\$1,001-\$10,000	Over \$10,000	N
SARC	31%	9%	28%	28%	4%	677
CA Average	35%	8%	28%	24%	4%	13,271
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	n/a

Table 40. Services Paid for Out-Of-Pocket in The Past Year

CA specific question. Categories are not mutually exclusive, therefore N is not shown.

RC v CA v NCI	Respite Services	Behavior Therapy	Speech Therapy	Additional Therapies	Social Skills Training	Recreational Activities and Programs
SARC	16%	5%	4%	13%	10%	41%
CA Average	13%	4%	3%	11%	6%	39%
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	n/a

Table 41. Services Paid for Out-Of-Pocket in The Past Year (Continued)

CA specific question. Categories are not mutually exclusive, therefore N is not shown.

RC v CA v NCI	Afterschool Care	Educational Expenses	Medical and/or dental expenses	Parent Training	Transportation Support	Other
SARC	8%	17%	61%	4%	40%	12%
CA Average	5%	11%	62%	2%	40%	14%
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	n/a

Table 42. 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
SARC	91%	9%	689
CA Average	90%	10%	13,188
Weighted NCI Average	78%	22%	17,567

Services and Supports Received

This section provides information about the services and supports received by the family from the regional center.³

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

Table 43. Services and Supports Received From Regional Center⁴

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	Out-of-home Respite Care	Day/Employment Supports	Transportation	Other Services/Supports	Direction/Fiscal Intermediary Services	Self
SARC	16%	32%	52%	45%	23%		22%
CA Average	12%	25%	54%	49%	20%		20%
Weighted NCI Average	15%	29%	53%	55%	25%		33%

Table 44. Additional Services and Supports Received (Not From the Regional Center⁵)

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
SARC	87%	35%
CA Average	85%	27%
Weighted NCI Average	90%	29%

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

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

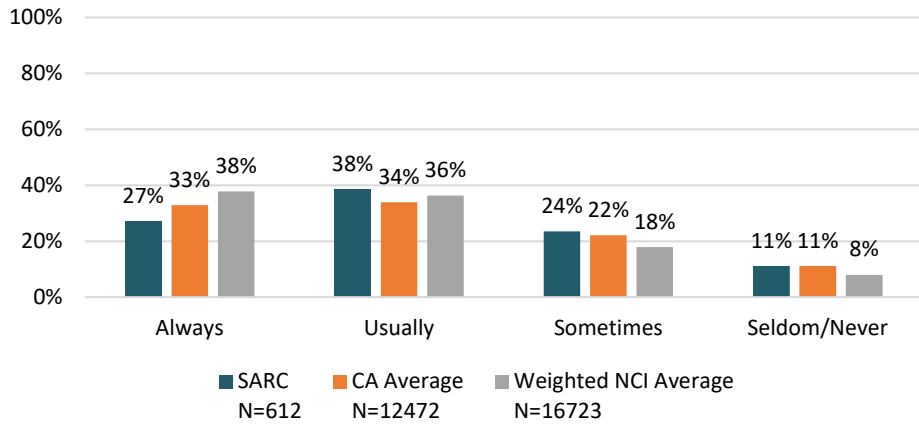
Adult Family Survey Results

Information and Planning Charts

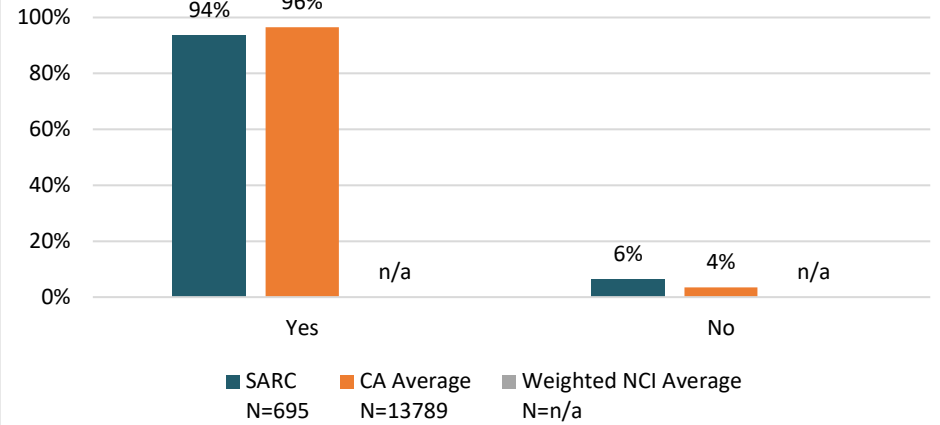
Families and family members with disabilities have the information and support necessary to plan for their services and supports.

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

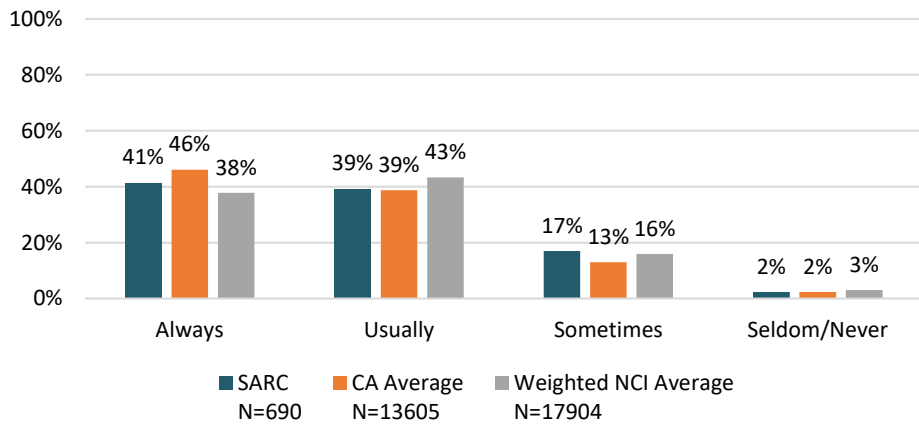
Do you get enough information to take part in planning services for your family member?



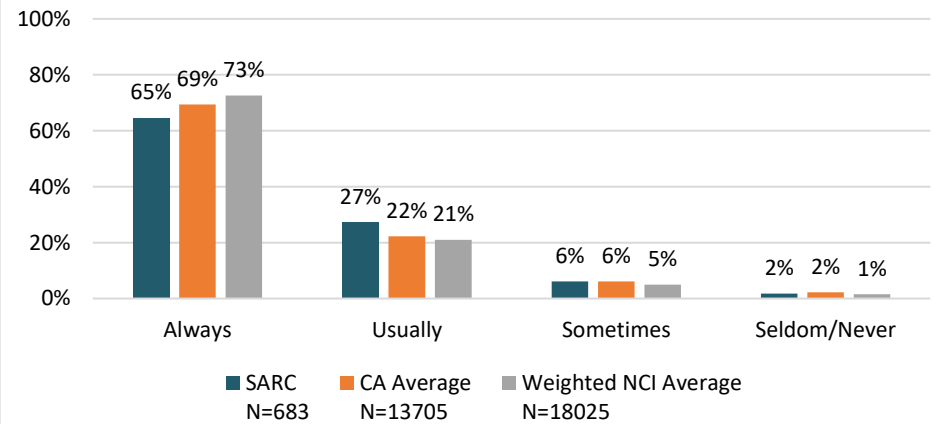
Is information from the regional center offered in your preferred language?



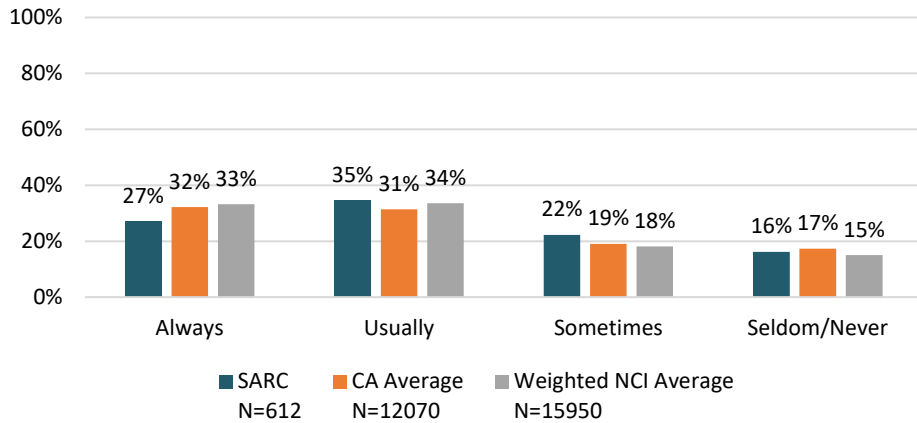
Is the information you get about services and supports easy to understand?



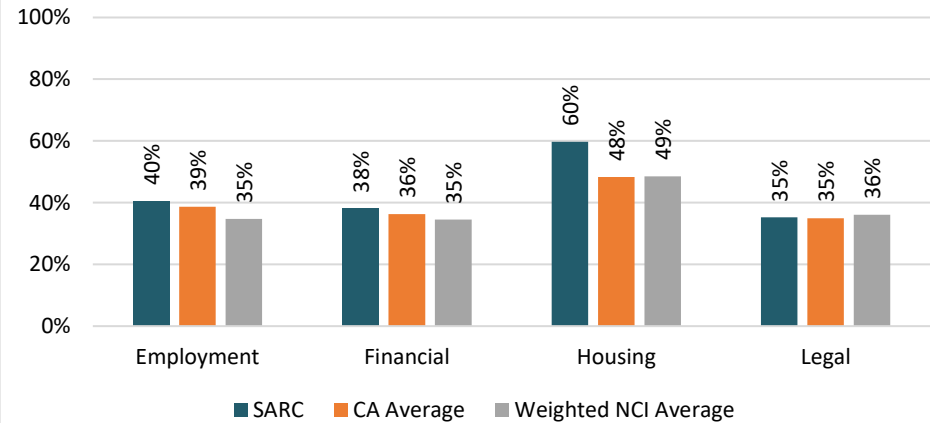
Does the case manager/service coordinator respect your family's choices and opinions?



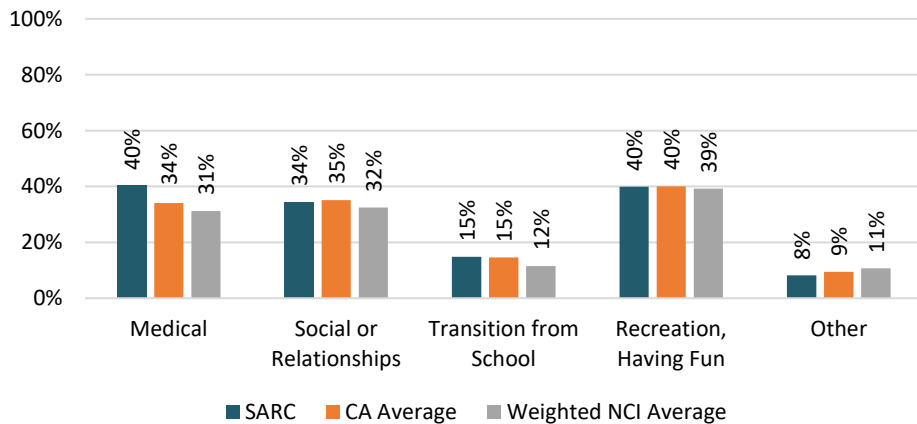
Do you have enough information about other public services for which your family is eligible?



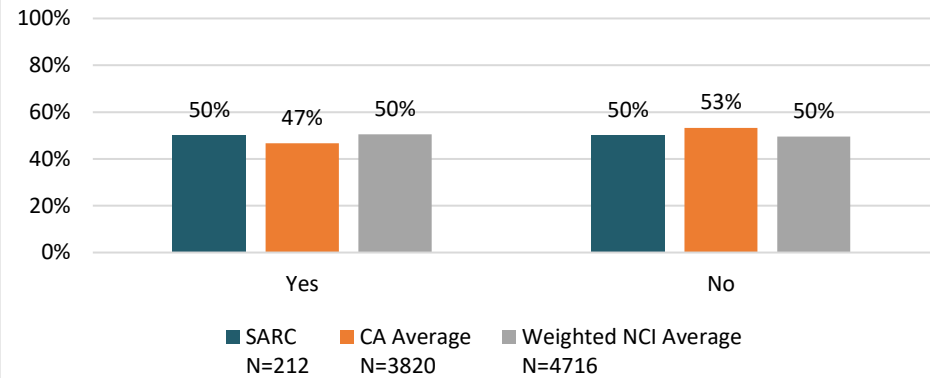
Do you need help planning for your family member's future?



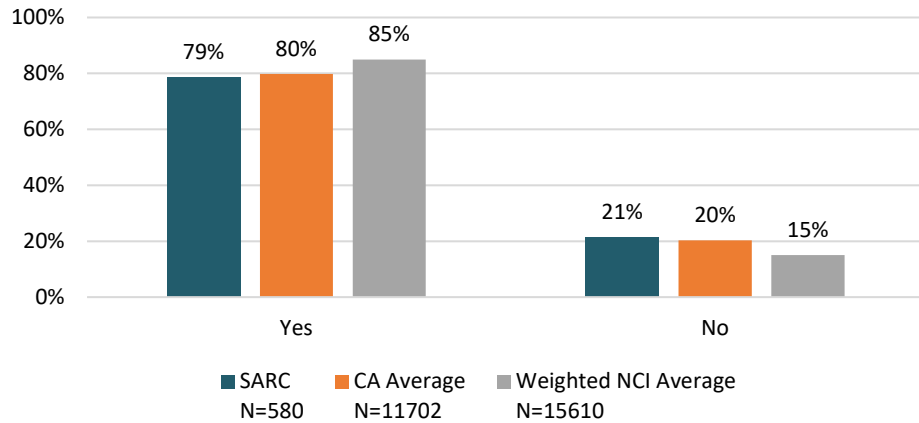
Do you need help planning for your family member's future?



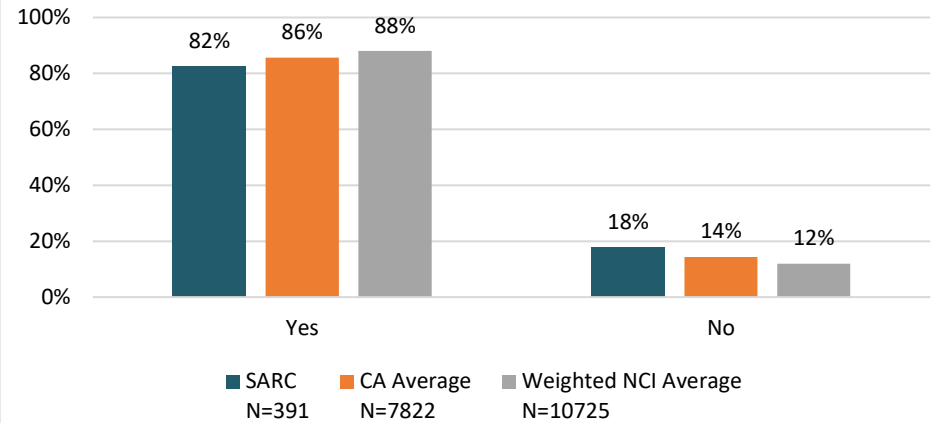
If you asked for crisis or emergency services during the past year, were services provided when needed?



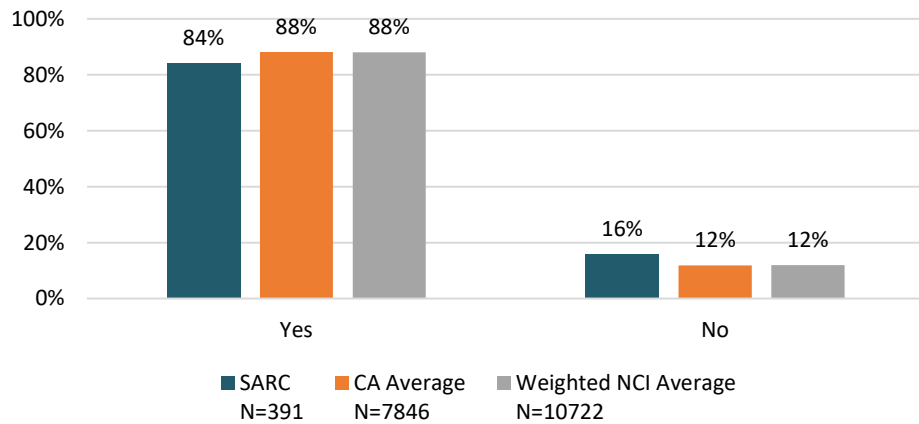
Does your family member have an individual program plan (IPP)?



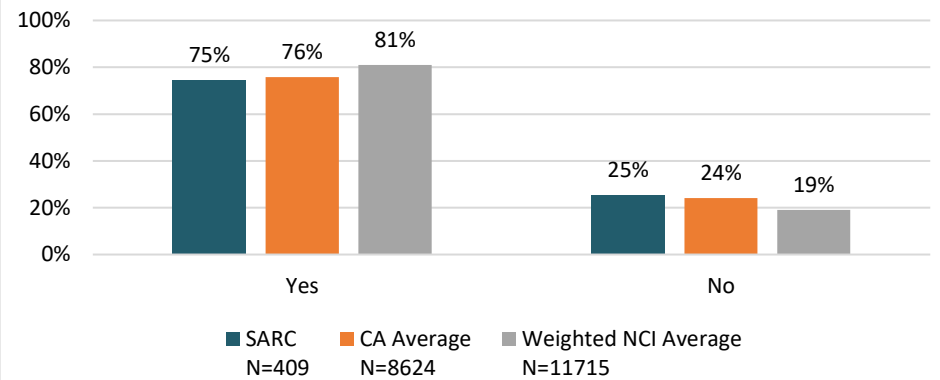
Does the IPP include all the services and supports your family member needs?

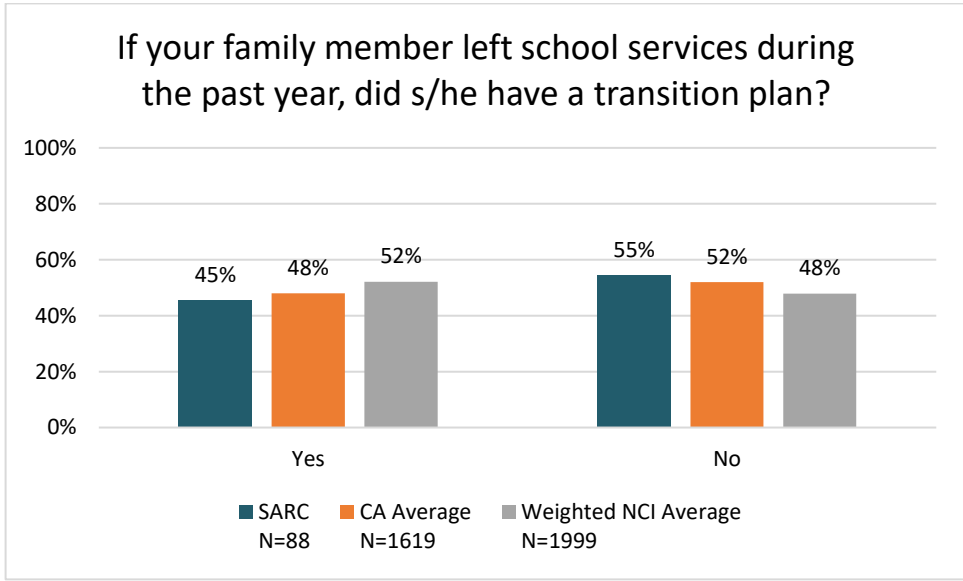
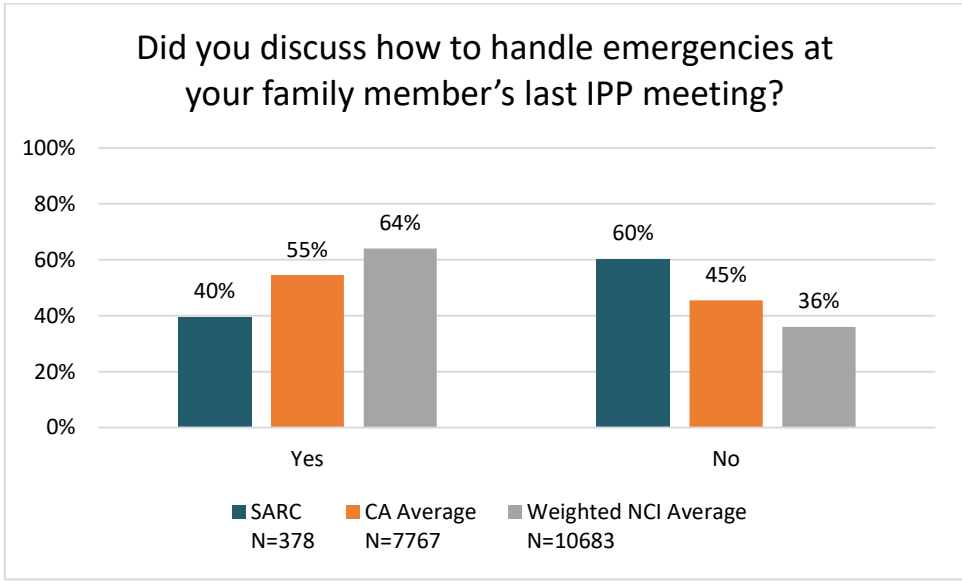
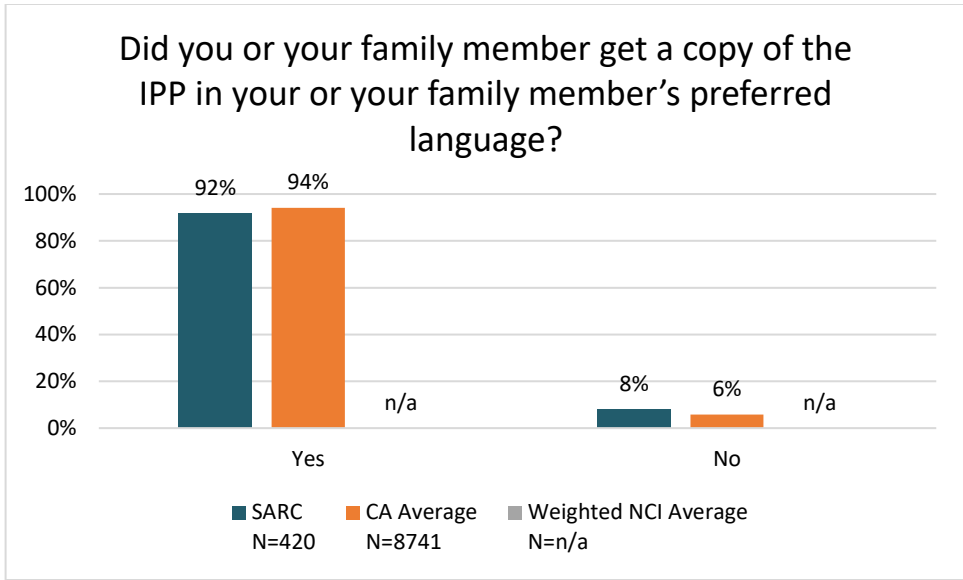
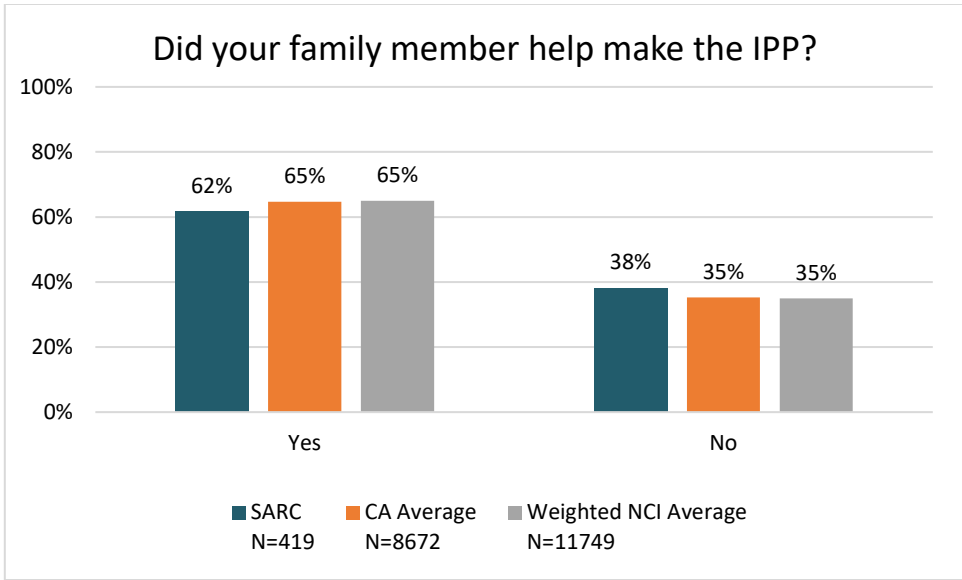


Does your family member get all the services listed in the IPP?

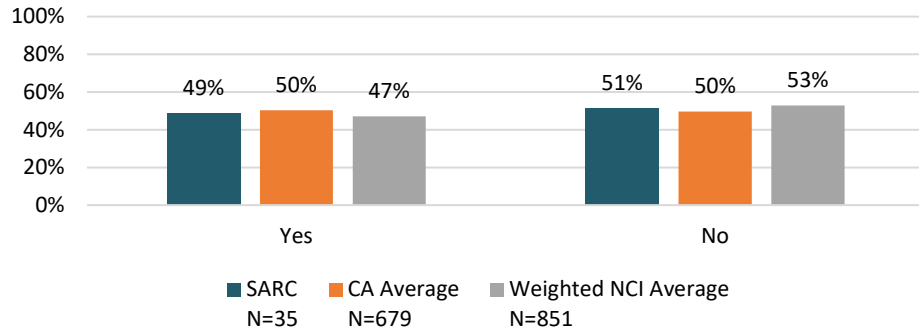


Did you or someone else in your family (besides your family member with a disability) help make the IPP?

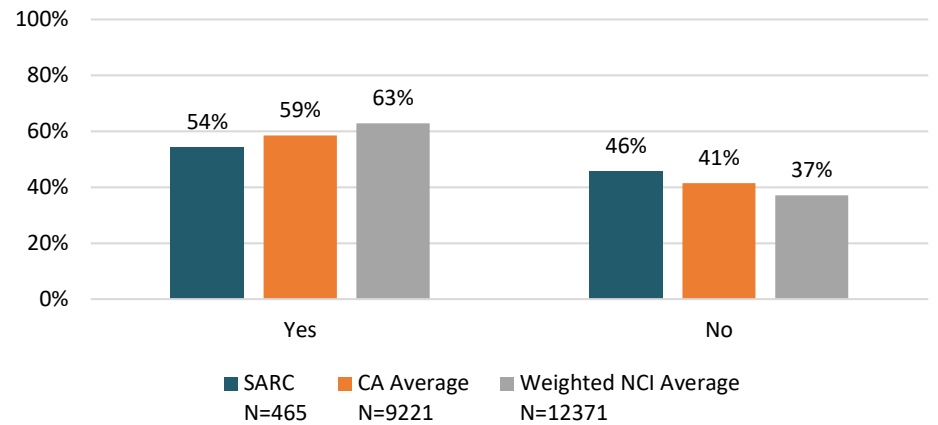




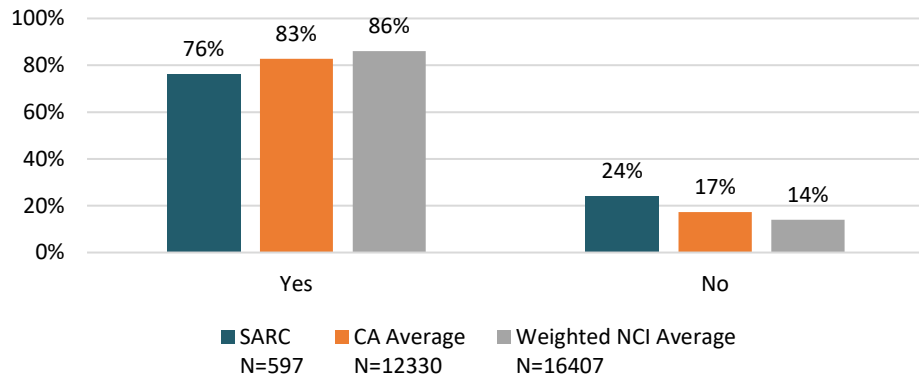
If your family member left school services during the past year and had a transition plan, did the transition plan include getting or continuing work in a community job?



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



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



Information and Planning Tables

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

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	27%	38%	24%	11%	612
CA Average	33%	34%	22%	11%	12,472
Weighted NCI Average	38%	36%	18%	8%	16,723

Table Q2. Is information from the regional center offered in your preferred language?

CA specific question

RC v CA v NCI	Yes	No	N
SARC	94%	6%	695
CA Average	96%	4%	13,789
Weighted NCI Average	n/a	n/a	n/a

Table Q3. Is the information you get about services and supports easy to understand?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	41%	39%	17%	2%	690
CA Average	46%	39%	13%	2%	13,605
Weighted NCI Average	38%	43%	16%	3%	17,904

Table Q4. Does the case manager/service coordinator respect your family's choices and opinions?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	65%	27%	6%	2%	683
CA Average	69%	22%	6%	2%	13,705
Weighted NCI Average	73%	21%	5%	1%	18,025

Table Q5. 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
SARC	27%	35%	22%	16%	612
CA Average	32%	31%	19%	17%	12,070
Weighted NCI Average	33%	34%	18%	15%	15,950

Table Q6. 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

Need future planning help with...	SARC	CA Average	Weighted NCI Average
Employment	40%	39%	35%
Financial	38%	36%	35%
Housing	60%	48%	49%
Legal	35%	35%	36%
Medical	40%	34%	31%
Social or Relationships	34%	35%	32%
Transition from School	15%	15%	12%
Recreation, Having Fun	40%	40%	39%
Other	8%	9%	11%

Table Q7. If you asked for crisis or emergency services during the past year, were services provided when needed?

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

RC v CA v NCI	Yes	No	N
SARC	50%	50%	212
CA Average	47%	53%	3,820
Weighted NCI Average	50%	50%	4,716

Table Q8. Does your family member have an individual program plan (IPP)?

RC v CA v NCI	Yes	No	N
SARC	79%	21%	580
CA Average	80%	20%	11,702
Weighted NCI Average	85%	15%	15,610

Table Q9. Does the IPP include all the services and supports your family member needs?

RC v CA v NCI	Yes	No	N
SARC	82%	18%	391
CA Average	86%	14%	7,822
Weighted NCI Average	88%	12%	10,725

Table Q10. Does your family member get all the services listed in the IPP?

RC v CA v NCI	Yes	No	N
SARC	84%	16%	391
CA Average	88%	12%	7,846
Weighted NCI Average	88%	12%	10,722

Table Q11. 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
SARC	75%	25%	409
CA Average	76%	24%	8,624
Weighted NCI Average	81%	19%	11,715

Table Q12. Did your family member help make the IPP?

RC v CA v NCI	Yes	No	N
SARC	62%	38%	419
CA Average	65%	35%	8,672
Weighted NCI Average	65%	35%	11,749

Table Q13. Did you or your family member get a copy of the IPP in your or your family member’s preferred language?

CA specific question

RC v CA v NCI	Yes	No	N
SARC	92%	8%	420
CA Average	94%	6%	8,741
Weighted NCI Average	n/a	n/a	n/a

Table Q14. Did you discuss how to handle emergencies (such as a medical emergency or a natural disaster) at your family member’s last IPP meeting?

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

RC v CA v NCI	Yes	No	N
SARC	40%	60%	378
CA Average	55%	45%	7,767
Weighted NCI Average	64%	36%	10,683

Table Q15. If your family member left school services during the past year, did s/he have a transition plan?

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

RC v CA v NCI	Yes	No	N
SARC	45%	55%	88
CA Average	48%	52%	1,619
Weighted NCI Average	52%	48%	1,999

Table Q16. If your 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
SARC	49%	51%	35
CA Average	50%	50%	679
Weighted NCI Average	47%	53%	851

Table Q17. Does your family member have enough supports (for example, support workers, community resources) to work or volunteer in the community?

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

RC v CA v NCI	Yes	No	N
SARC	54%	46%	465
CA Average	59%	41%	9,221
Weighted NCI Average	63%	37%	12,371

Table Q18. Do you feel prepared to handle the needs of your family member in an emergency such as a medical emergency or a natural disaster?

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

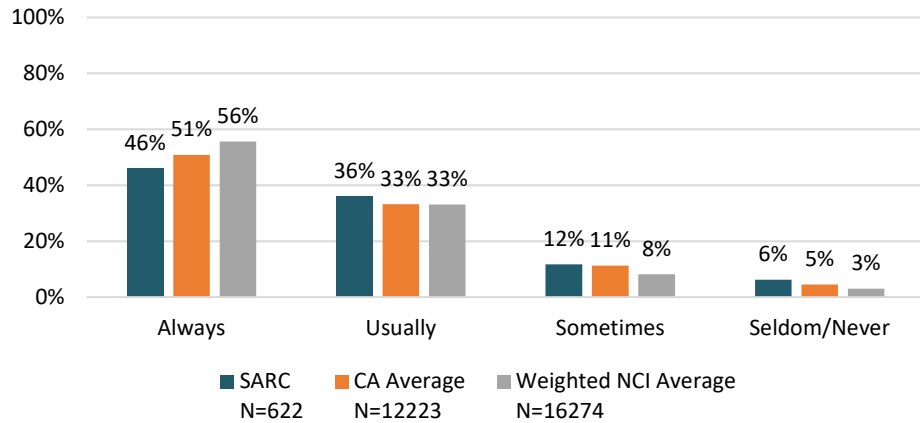
RC v CA v NCI	Yes	No	N
SARC	76%	24%	597
CA Average	83%	17%	12,330
Weighted NCI Average	86%	14%	16,407

Access and Delivery of Services and Supports Charts

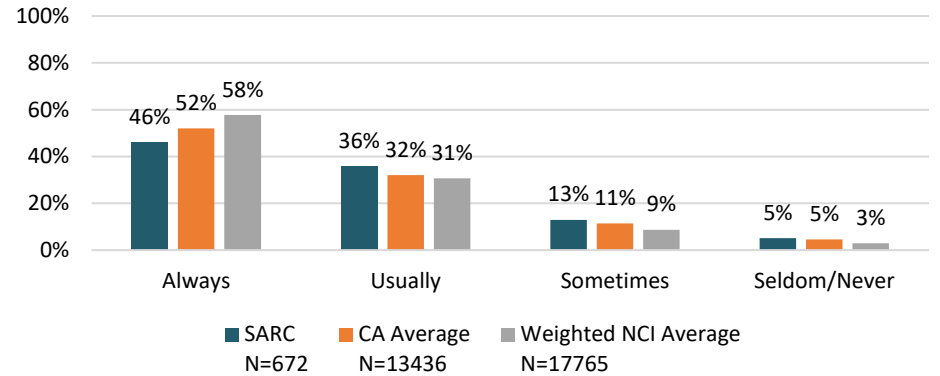
Families and family members with disabilities get the services and supports they need.

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

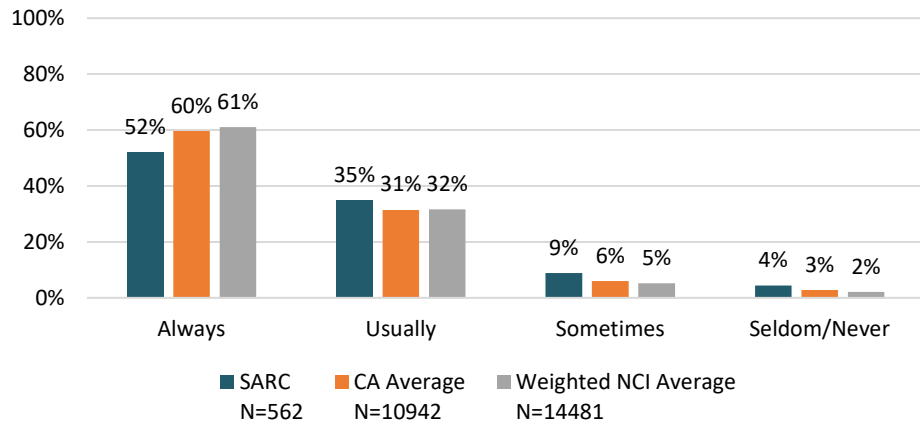
Are you or your family member able to contact his/her support workers when you want?



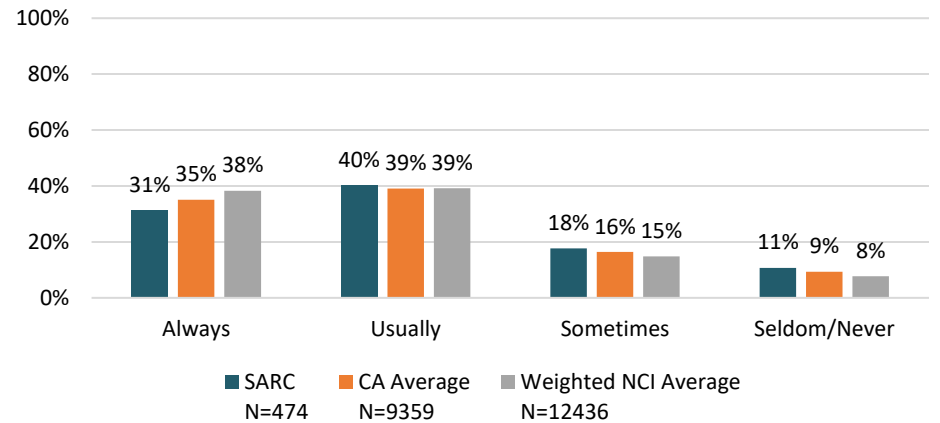
Are you or your family member able to contact his/her case manager/service coordinator when you want?



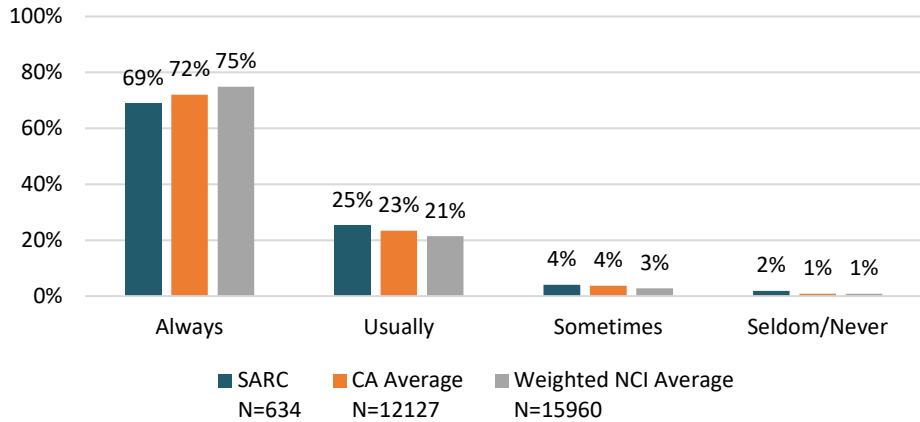
Do support workers come and go when they are supposed to?



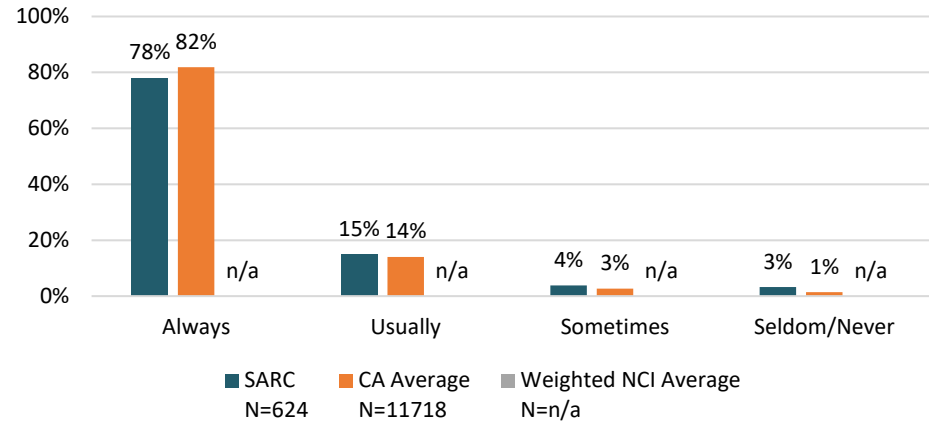
Do services and supports change when your family's needs change?



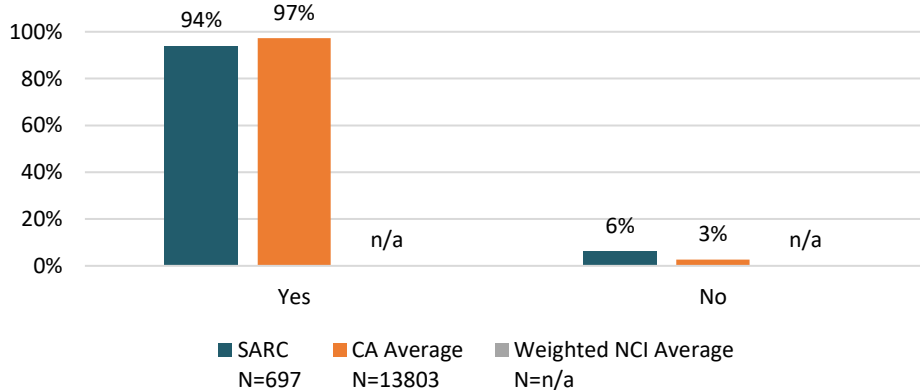
Do support workers speak to you in a way you understand?



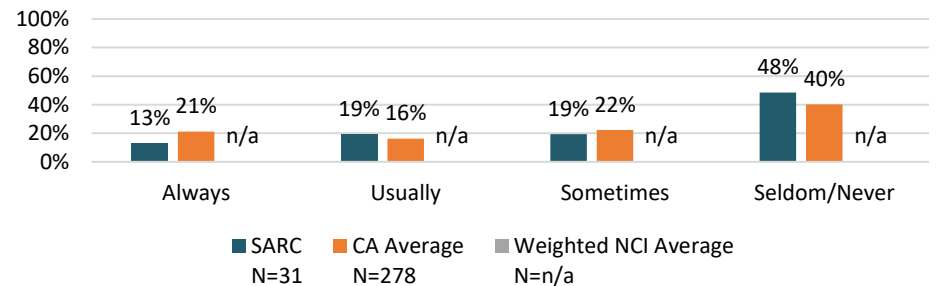
Are there support workers available who can speak to you in your preferred language?



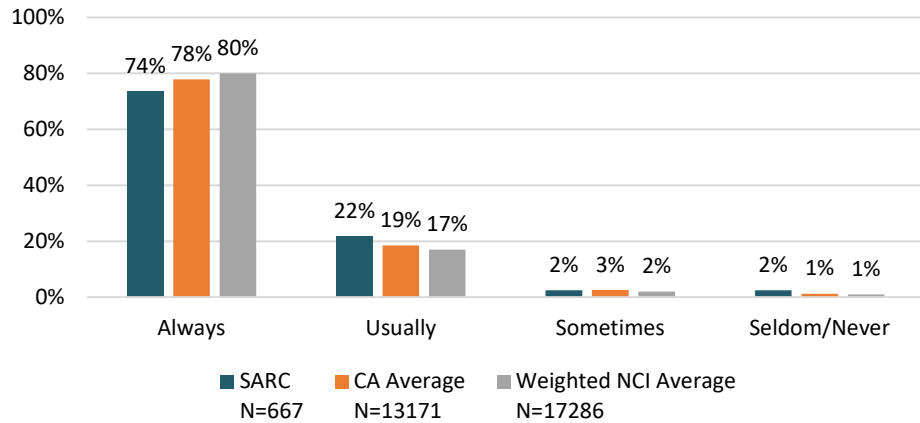
Does your family member's case manager/service coordinator speak your preferred language?



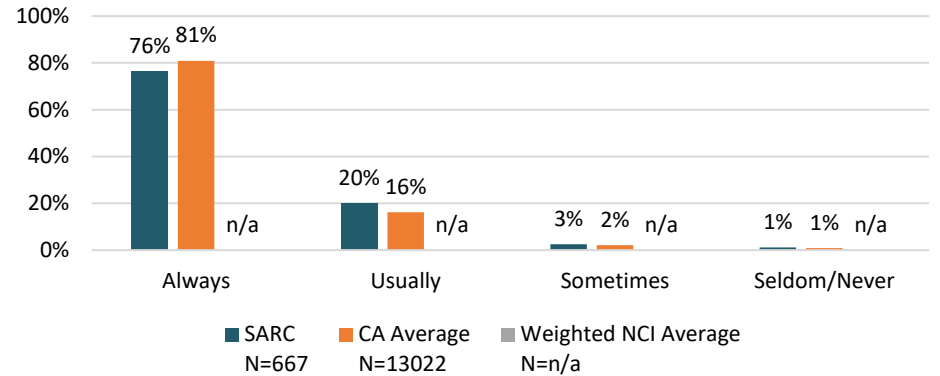
If your family member's case manager/service coordinator does not speak in your preferred language, is a translator provided when you speak with the case manager/service coordinator?



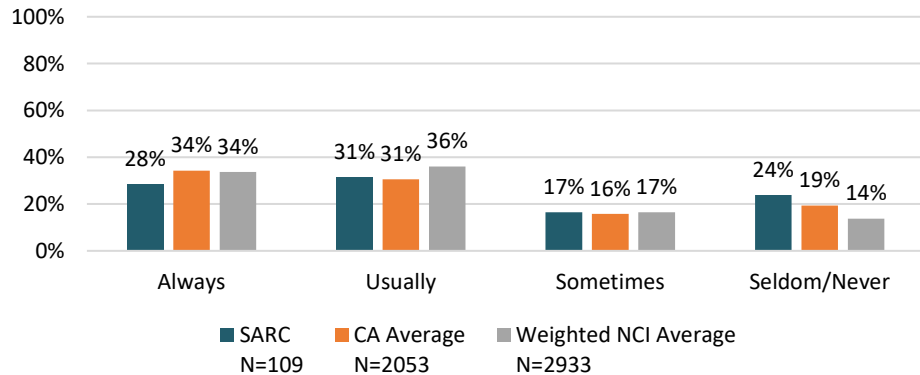
Are services delivered in a way that is respectful of your family's culture?



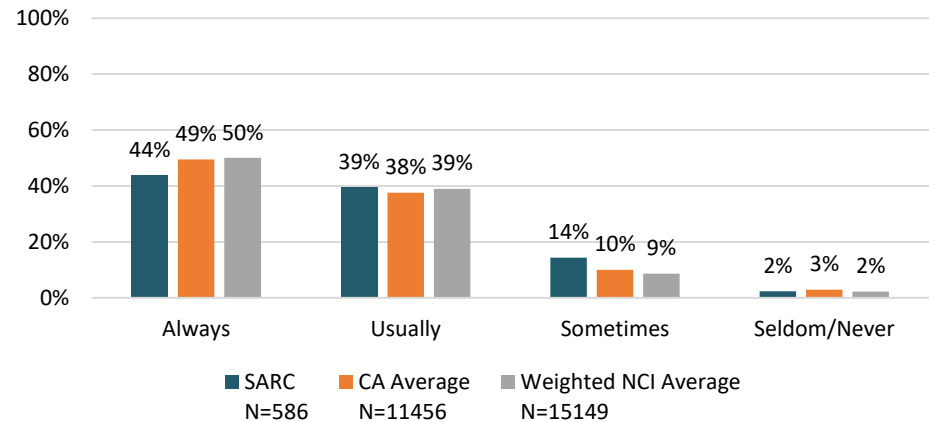
Does your family member's case manager/service coordinator support you in a way that is respectful to your culture?



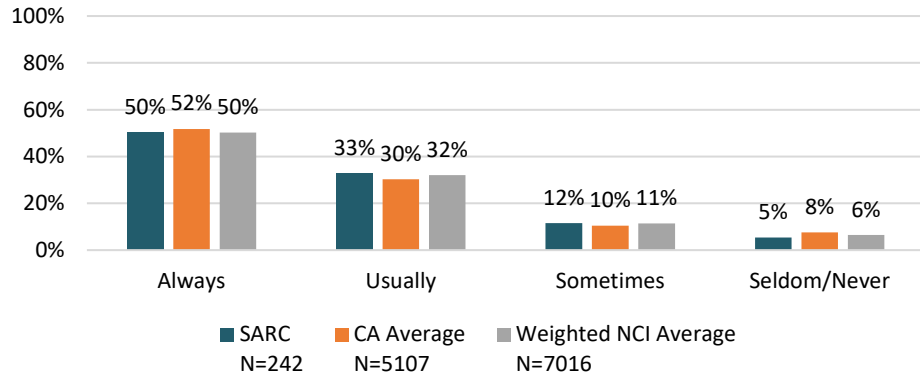
If your family member does not communicate verbally, are there support workers who can communicate with him/her?



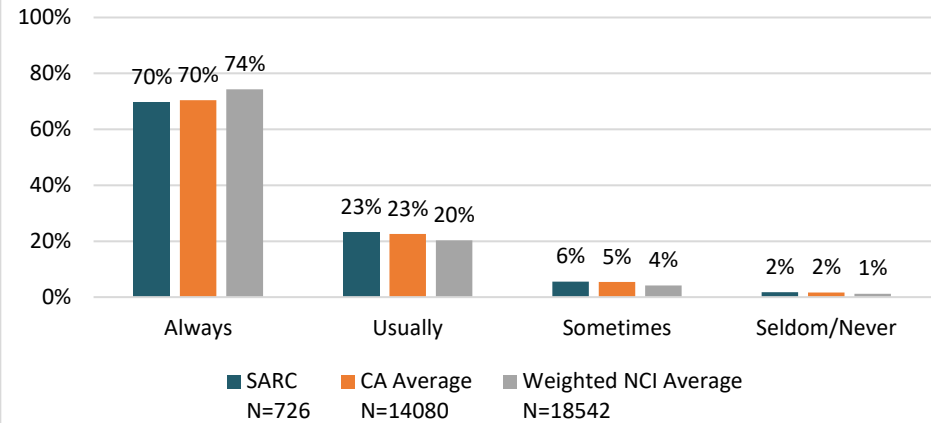
Do support workers have the right information and skills to meet your family's needs?



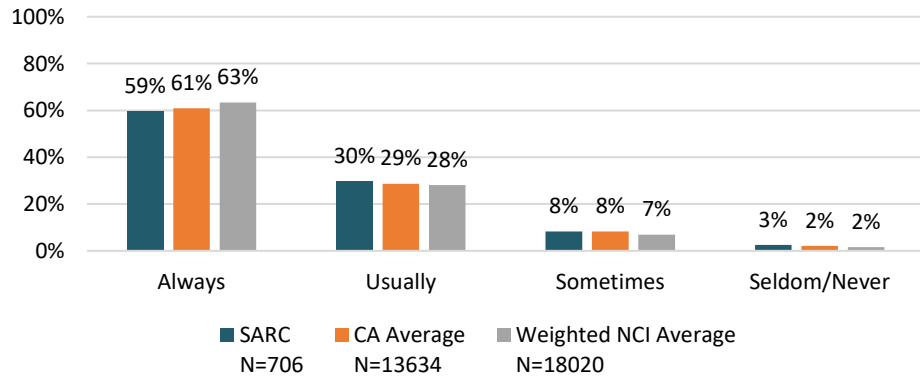
Does your family member have the special equipment or accommodations that s/he needs?



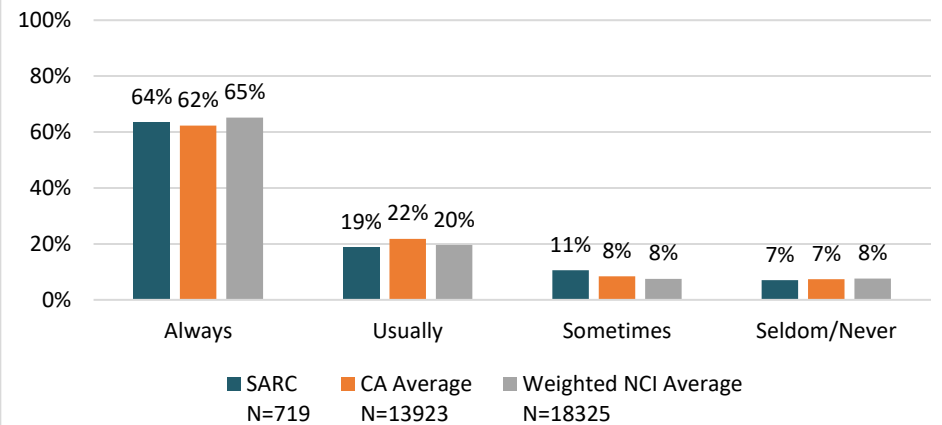
Can your family member see health professionals when needed?



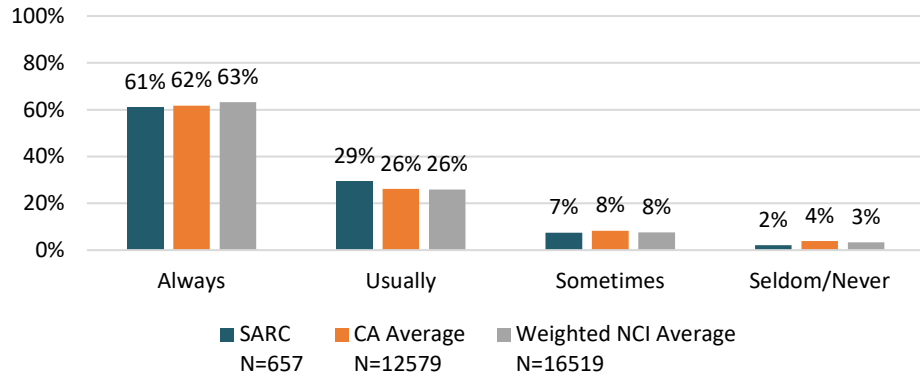
Does your family member's primary care doctor understand your family member's needs related to his/her disability?



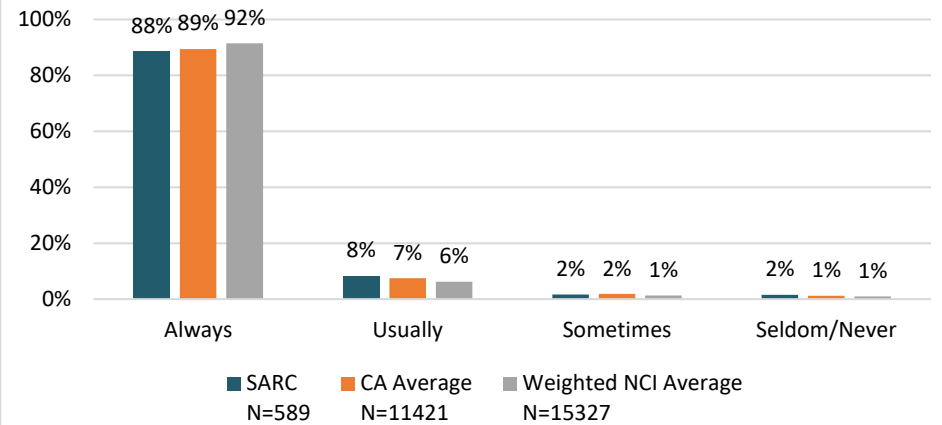
Can your family member go to the dentist when needed?



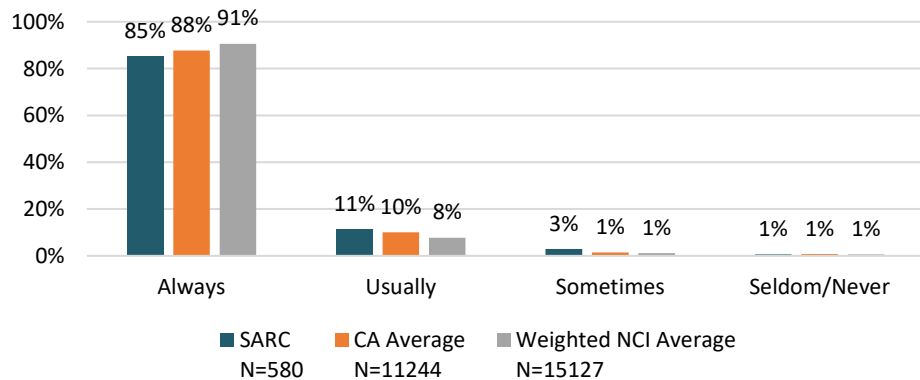
Does your family member's dentist understand your family member's needs related to his/her disability?



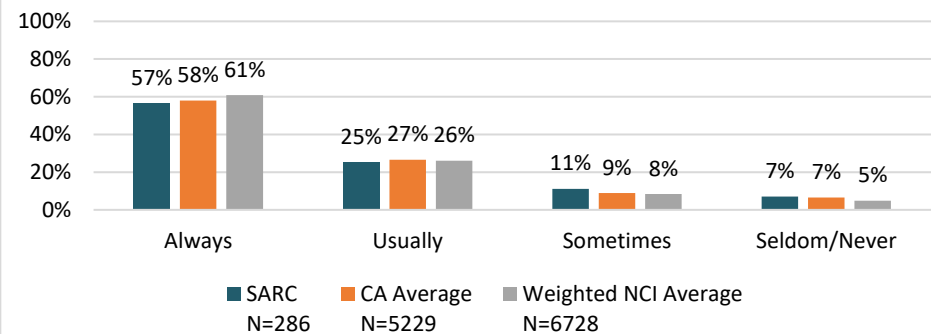
If your family member takes medications, do you know what they're for?



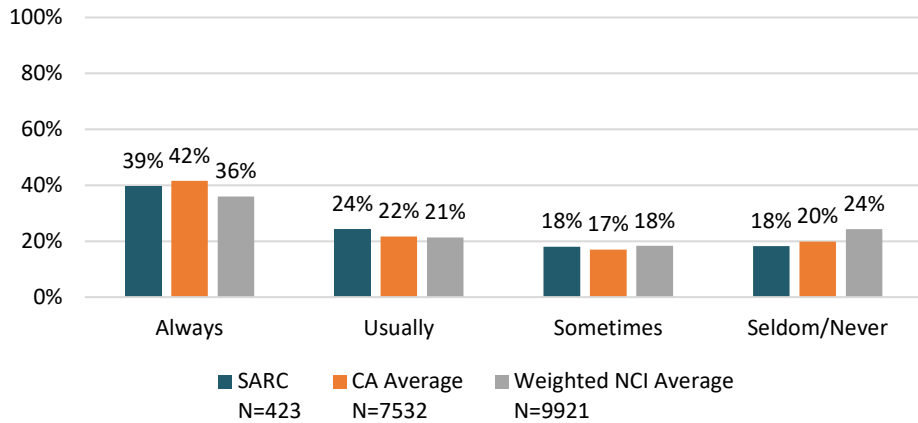
Do you, your family member, or someone else in your family know what is needed to safely take the medications?



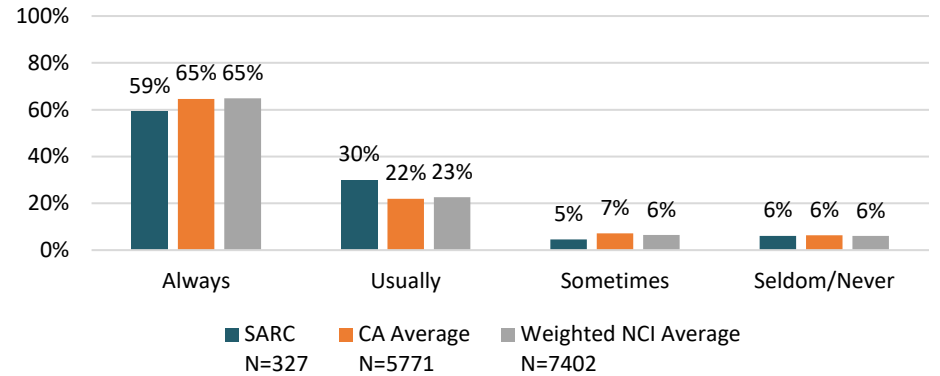
If your family member uses mental health services, does the mental health professional understand your family member's needs related to his/her disability?



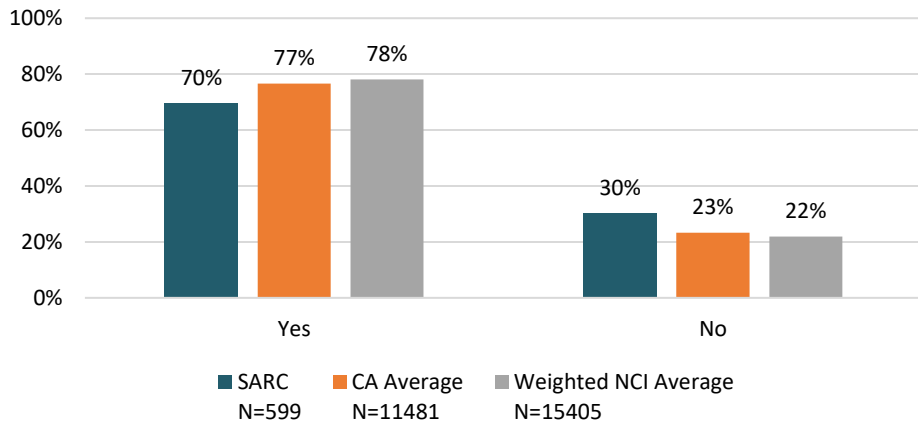
If you need respite services, how often are you able to use them?



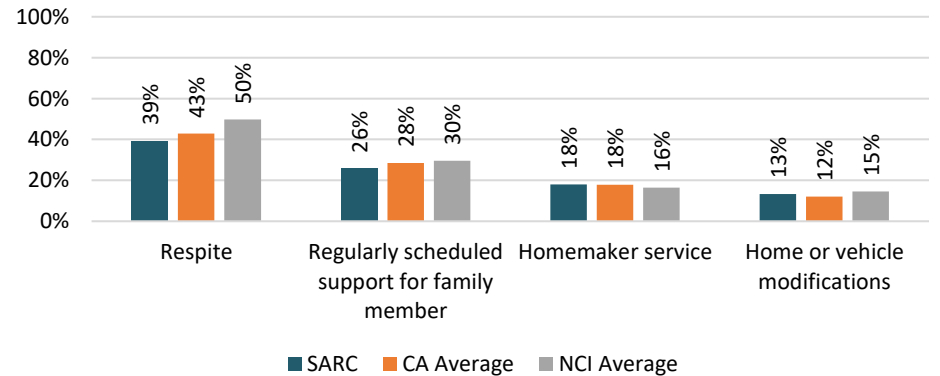
If you have used respite services in the past year, were you satisfied with the quality of the respite services?



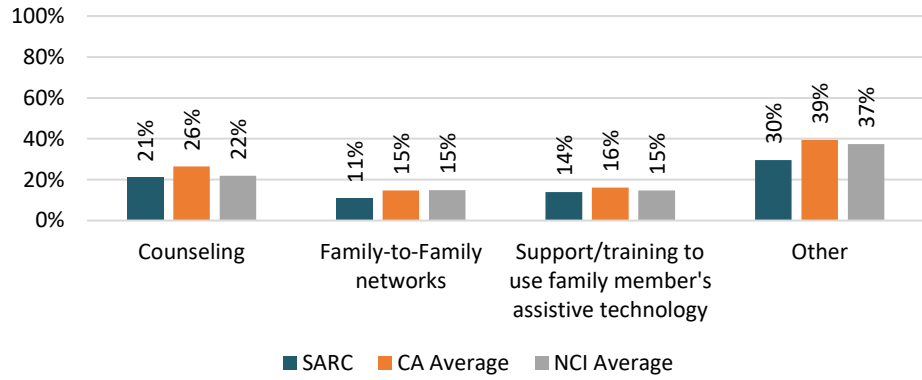
Does your family get the supports and services it needs?



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



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



Access and Delivery of Services and Supports Tables

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

Table Q19. Are you or your family member able to contact his/her support workers when you want?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	46%	36%	12%	6%	622
CA Average	51%	33%	11%	5%	12,223
Weighted NCI Average	56%	33%	8%	3%	16,274

Table Q20. Are you or your family member able to contact his/her case manager/service coordinator when you want?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	46%	36%	13%	5%	672
CA Average	52%	32%	11%	5%	13,436
Weighted NCI Average	58%	31%	9%	3%	17,765

Table Q21. Do support workers come and go when they are supposed to?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	52%	35%	9%	4%	562
CA Average	60%	31%	6%	3%	10,942
Weighted NCI Average	61%	32%	5%	2%	14,481

Table Q22. Do services and supports change when your family's needs change?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	31%	40%	18%	11%	474
CA Average	35%	39%	16%	9%	9,359
Weighted NCI Average	38%	39%	15%	8%	12,436

Table Q23. Do support workers speak to you in a way you understand?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	69%	25%	4%	2%	634
CA Average	72%	23%	4%	1%	12,127
Weighted NCI Average	75%	21%	3%	1%	15,960

Table Q24. Are there support workers available who can speak to you in your preferred language?

CA specific question

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	78%	15%	4%	3%	624
CA Average	82%	14%	3%	1%	11,718
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a

Table Q25. Does your family member's case manager/service coordinator speak your preferred language?

CA specific question

RC v CA v NCI	Yes	No	N
SARC	94%	6%	697
CA Average	97%	3%	13,803
Weighted NCI Average	n/a	n/a	n/a

Table Q26. If your family member's case manager/service coordinator does not speak in your preferred language, is a translator provided when you speak with the case manager/service coordinator?

CA specific question

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	13%	19%	19%	48%	31
CA Average	21%	16%	22%	40%	278
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a

Table Q27. 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
SARC	74%	22%	2%	2%	667
CA Average	78%	19%	3%	1%	13,171
Weighted NCI Average	80%	17%	2%	1%	17,286

Table Q28. Does your family member’s case manager/service coordinator support you in a way that is respectful to your culture?

CA specific question

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	76%	20%	3%	1%	667
CA Average	81%	16%	2%	1%	13,022
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a

Table Q29. If your family member does not communicate verbally (for example, uses gestures or sign language, or a communication aid), are there support workers who can communicate with him/her?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	28%	31%	17%	24%	109
CA Average	34%	31%	16%	19%	2,053
Weighted NCI Average	34%	36%	17%	14%	2,933

Table Q30. Do support workers have the right information and skills to meet your family’s needs?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	44%	39%	14%	2%	586
CA Average	49%	38%	10%	3%	11,456
Weighted NCI Average	50%	39%	9%	2%	15,149

Table Q31. Does your family member have the special equipment or accommodations that s/he needs (for example, wheelchair, ramp, communication board)?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	50%	33%	12%	5%	242
CA Average	52%	30%	10%	8%	5,107
Weighted NCI Average	50%	32%	11%	6%	7,016

Table Q32. Can your family member see health professionals when needed (for example, doctor, dentist, psychologist)?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	70%	23%	6%	2%	726
CA Average	70%	23%	5%	2%	14,080
Weighted NCI Average	74%	20%	4%	1%	18,542

Table Q33. Does your family member’s primary care doctor understand your family member’s needs related to his/her disability?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	59%	30%	8%	3%	706
CA Average	61%	29%	8%	2%	13,634
Weighted NCI Average	63%	28%	7%	2%	18,020

Table Q34. 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
SARC	64%	19%	11%	7%	719
CA Average	62%	22%	8%	7%	13,923
Weighted NCI Average	65%	20%	8%	8%	18,325

Table Q35. Does your family member’s dentist understand your family member’s needs related to his/her disability?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	61%	29%	7%	2%	657
CA Average	62%	26%	8%	4%	12,579
Weighted NCI Average	63%	26%	8%	3%	16,519

Table Q36. If your family member takes medications, do you know what they’re for?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	88%	8%	2%	2%	589
CA Average	89%	7%	2%	1%	11,421
Weighted NCI Average	92%	6%	1%	1%	15,327

Table Q37. 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)?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	85%	11%	3%	1%	580
CA Average	88%	10%	1%	1%	11,244
Weighted NCI Average	91%	8%	1%	1%	15,127

Table Q38. If your family member uses mental health services, does the mental health professional understand your family member’s needs related to his/her disability?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	57%	25%	11%	7%	286
CA Average	58%	27%	9%	7%	5,229
Weighted NCI Average	61%	26%	8%	5%	6,728

Table Q39. If you need respite services, how often are you able to use them?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	39%	24%	18%	18%	423
CA Average	42%	22%	17%	20%	7,532
Weighted NCI Average	36%	21%	18%	24%	9,921

Table Q40. If you have used respite services in the past year, were you satisfied with the quality of the respite services?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	59%	30%	5%	6%	327
CA Average	65%	22%	7%	6%	5,771
Weighted NCI Average	65%	23%	6%	6%	7,402

Table Q41. Does your family get the supports and services it needs?

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

RC v CA v NCI	Yes	No	N
SARC	70%	30%	599
CA Average	77%	23%	11,481
Weighted NCI Average	78%	22%	15,405

Table Q42. If your family does not get the support and services needed, what additional services does your family need?

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

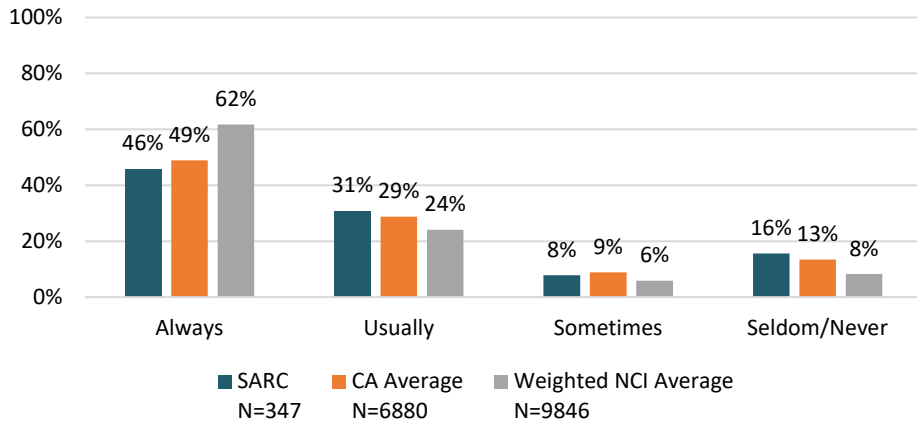
Additional Service Needed	SARC	CA Average	Weighted NCI Average
Respite	39%	43%	50%
Regularly scheduled support for family member	26%	28%	30%
Homemaker service	18%	18%	16%
Home or vehicle modifications	13%	12%	15%
Counseling	21%	26%	22%
Family-to-Family networks	11%	15%	15%
Support/training to use family member's assistive technology	14%	16%	15%
Other	30%	39%	37%

Choice, Decision Making and Control Charts

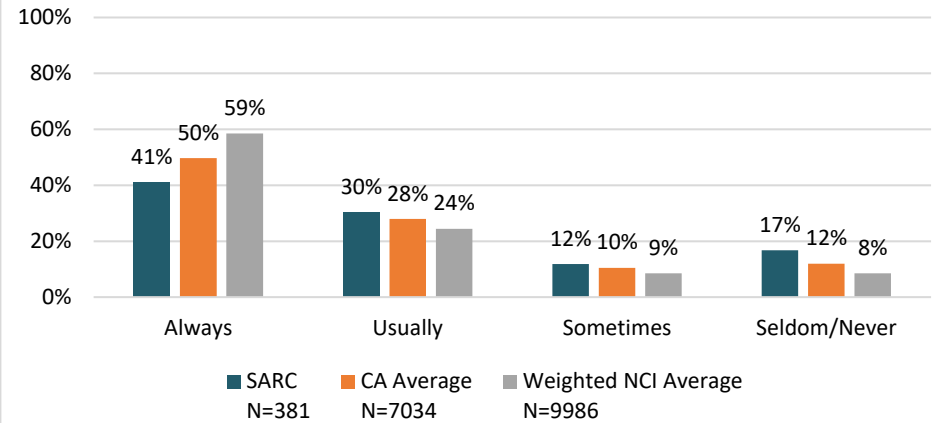
Families and family members with disabilities determine the services and supports they receive and the individuals or agencies who provide them.

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

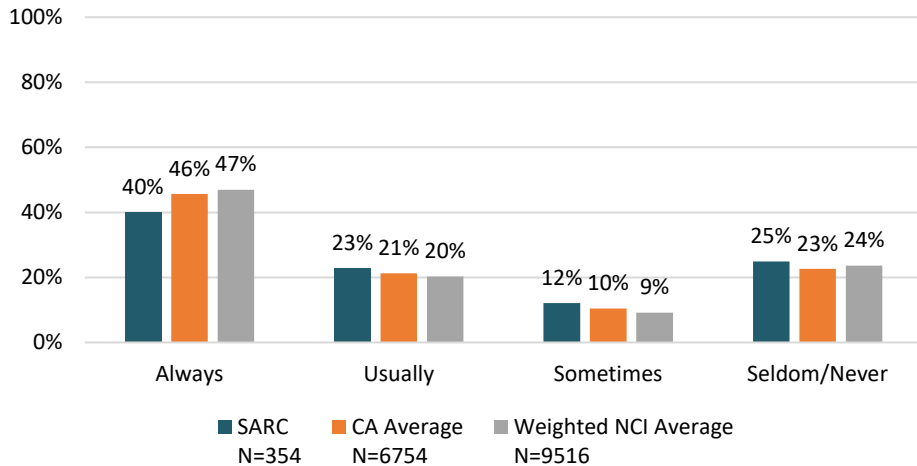
Can your family choose or change the agency that provides your family member's services?



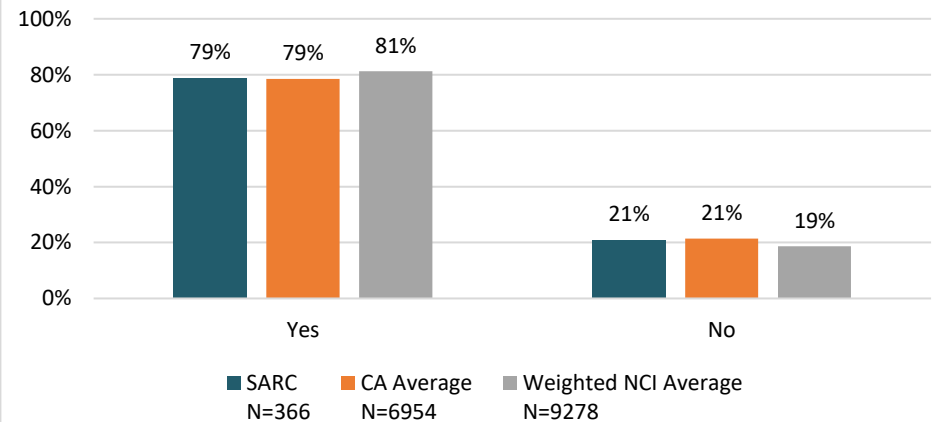
Can your family choose or change your family member's support workers?



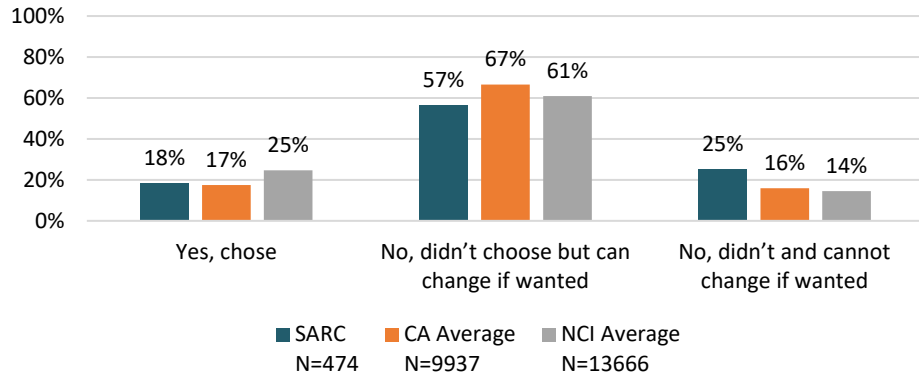
Does your family directly manage support staff?



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



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



Choice, Decision Making and Control Tables

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

Table Q43. Can your family choose or change the agency that provides your family member's services?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	46%	31%	8%	16%	347
CA Average	49%	29%	9%	13%	6,880
Weighted NCI Average	62%	24%	6%	8%	9,846

Table Q44. Can your family choose or change your family member's support workers?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	41%	30%	12%	17%	381
CA Average	50%	28%	10%	12%	7,034
Weighted NCI Average	59%	24%	9%	8%	9,986

Table Q45. Does your family directly manage support staff?

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	40%	23%	12%	25%	354
CA Average	46%	21%	10%	23%	6,754
Weighted NCI Average	47%	20%	9%	24%	9,516

Table Q46. Do service providers for your family member work together to provide support?

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

RC v CA v NCI	Yes	No	N
SARC	79%	21%	366
CA Average	79%	21%	6,954
Weighted NCI Average	81%	19%	9,278

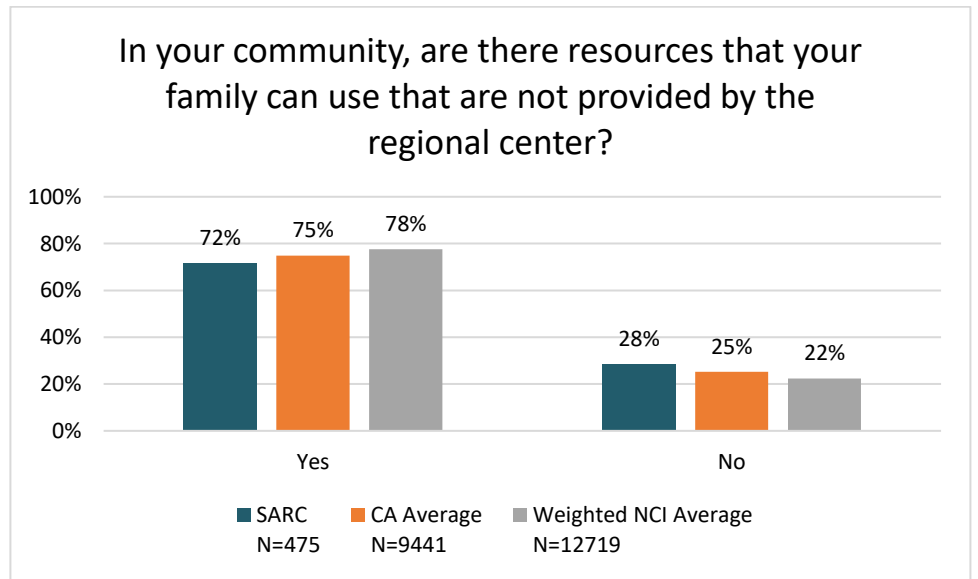
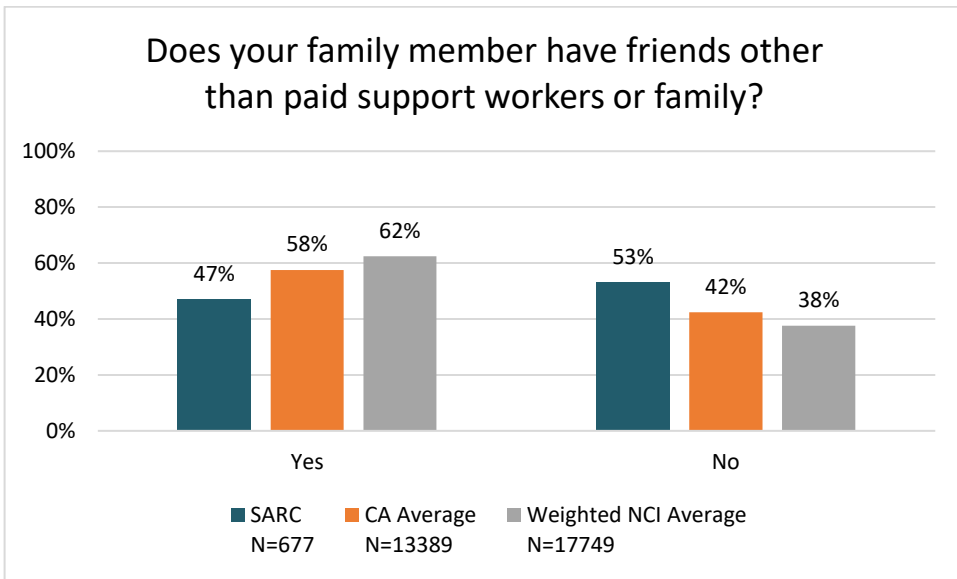
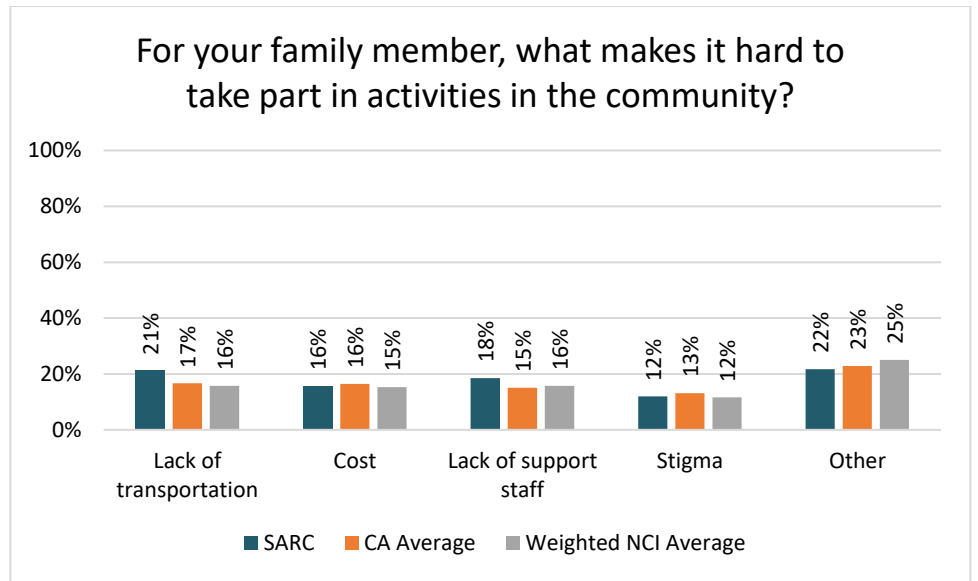
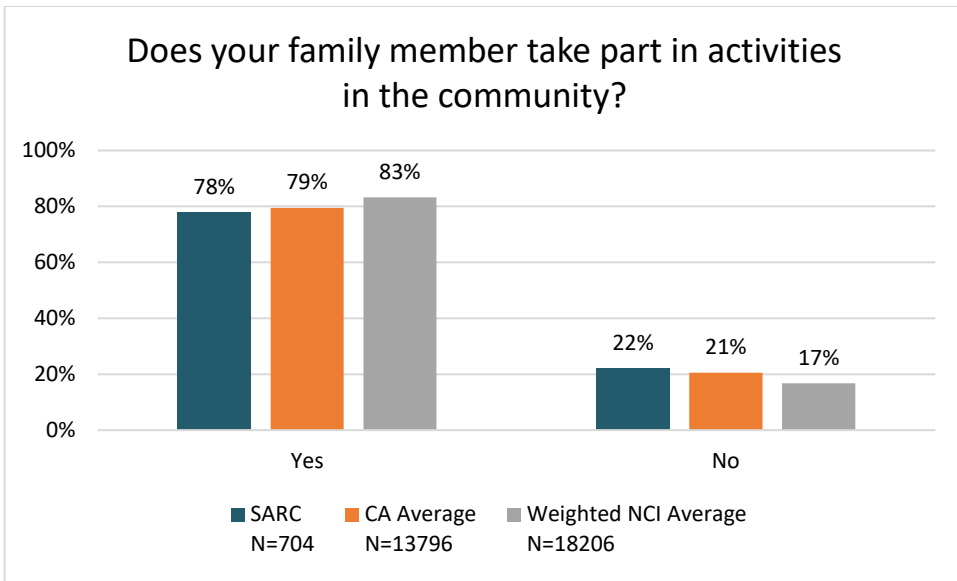
Table Q47. Did you, your family member, or someone else in your family choose your family member’s case manager/service coordinator?

Did you, your family member, or someone else in your family choose your family member’s case manager/service coordinator?	SARC	CA Average	Weighted NCI Average
Yes, chose	18%	17%	25%
No, didn’t choose but can change if wanted	57%	67%	61%
No, didn’t and cannot change if wanted	25%	16%	14%
N	474	9,937	13,666

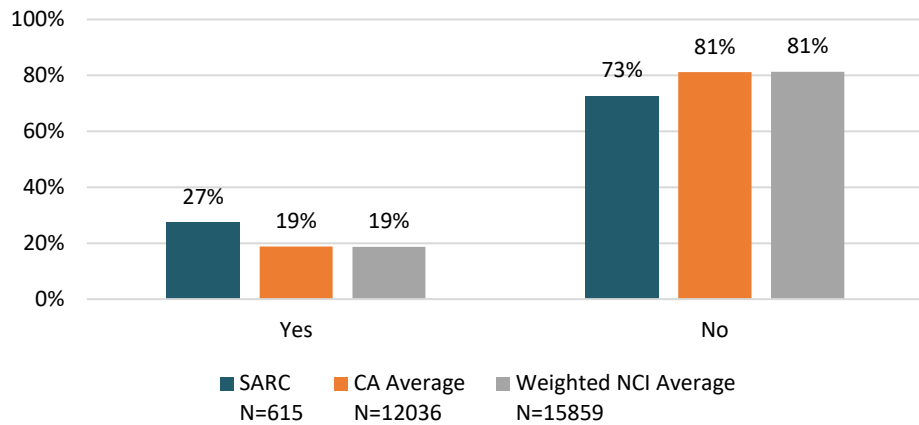
Involvement in the Community Charts

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

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



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



Involvement in the Community Tables

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

Table Q48. Does your family member take part in activities in the community?

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

RC v CA v NCI	Yes	No	N
SARC	78%	22%	704
CA Average	79%	21%	13,796
Weighted NCI Average	83%	17%	18,206

Table Q49. For your family member, what makes it hard to take part in activities in the community?

Question is rephrased from previous years; categories are not mutually exclusive, therefore N is not shown. Responses to this question might have been impacted by the COVID-19 pandemic.

What makes it hard to participate...	SARC	CA Average	Weighted NCI Average
Lack of transportation	21%	17%	16%
Cost	16%	16%	15%
Lack of support staff	18%	15%	16%
Stigma	12%	13%	12%
Other	22%	23%	25%

Table Q50. Does your family member have friends other than paid support workers or family?

RC v CA v NCI	Yes	No	N
SARC	47%	53%	677
CA Average	58%	42%	13,389
Weighted NCI Average	62%	38%	17,749

Table Q51. In your community, are there resources that your family can use that are not provided by the regional center⁶ (for example, recreational programs, community housing, library programs, religious groups, etc.)?

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

RC v CA v NCI	Yes	No	N
SARC	72%	28%	475
CA Average	75%	25%	9,441
Weighted NCI Average	78%	22%	12,719

Table Q52. Does your family take part in any family-to-family networks in your community (for example, Parent to Parent, sibling networks, etc.)?

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

RC v CA v NCI	Yes	No	N
SARC	27%	73%	615
CA Average	19%	81%	12,036
Weighted NCI Average	19%	81%	15,859

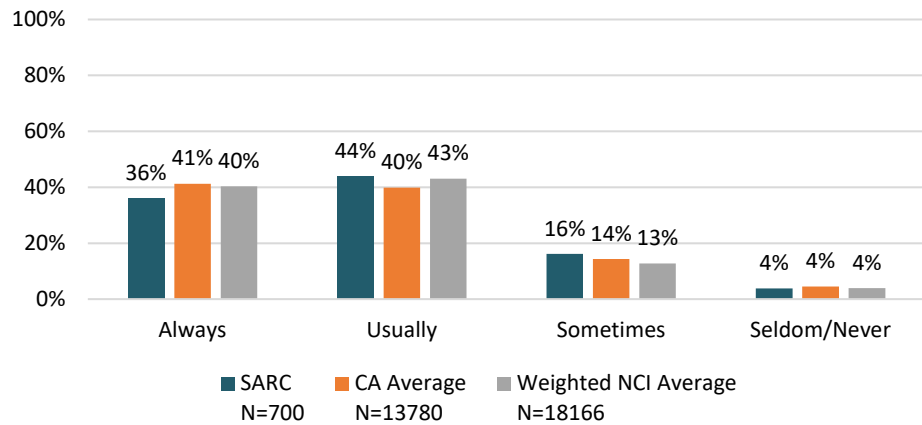
⁶ Some NCI states provide services through a statewide ID/DD agency

Satisfaction With Services and Supports Charts

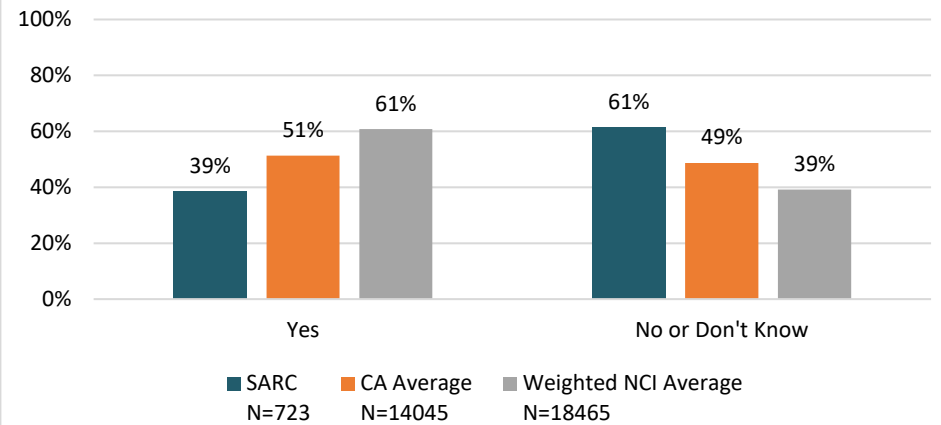
Families and family members with disabilities receive adequate and satisfactory supports.

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

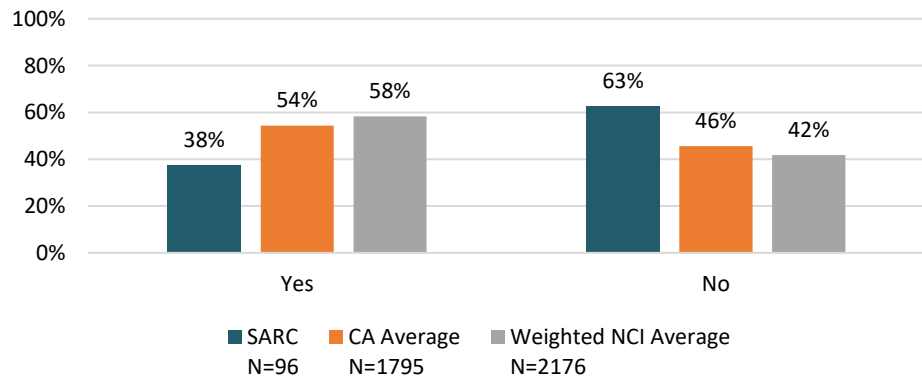
Overall, are you satisfied with the services and supports your family member currently receives?



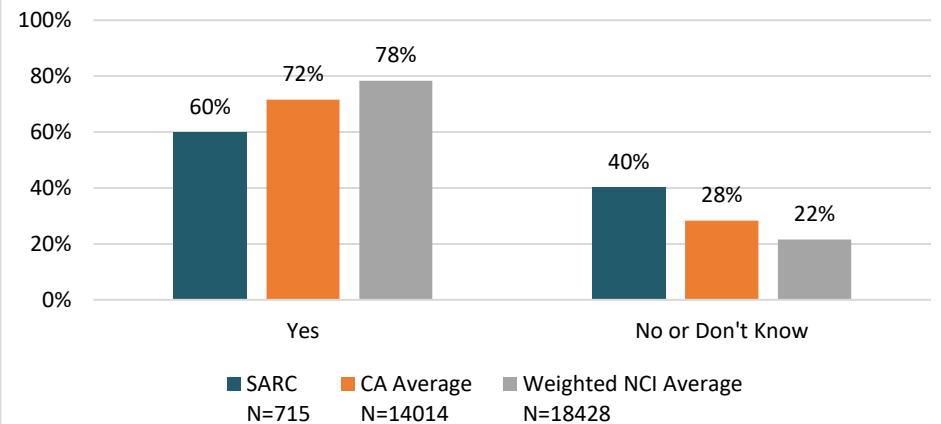
Do you know how to file a complaint or grievance about provider agencies or staff?

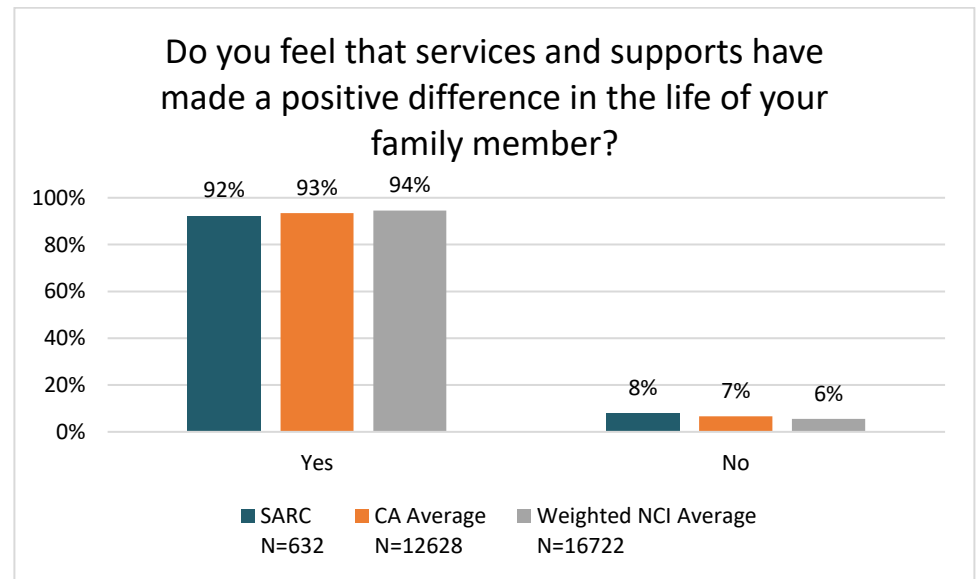
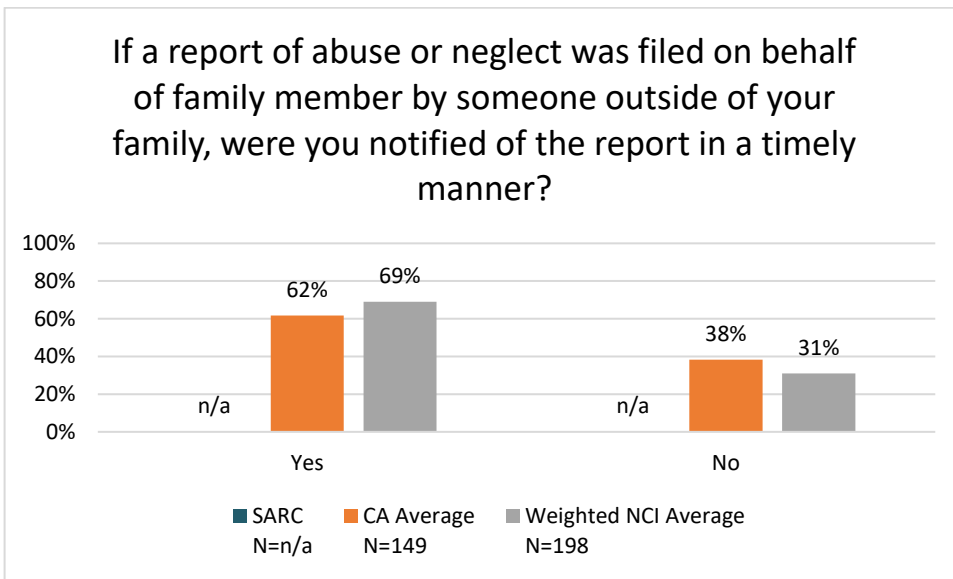
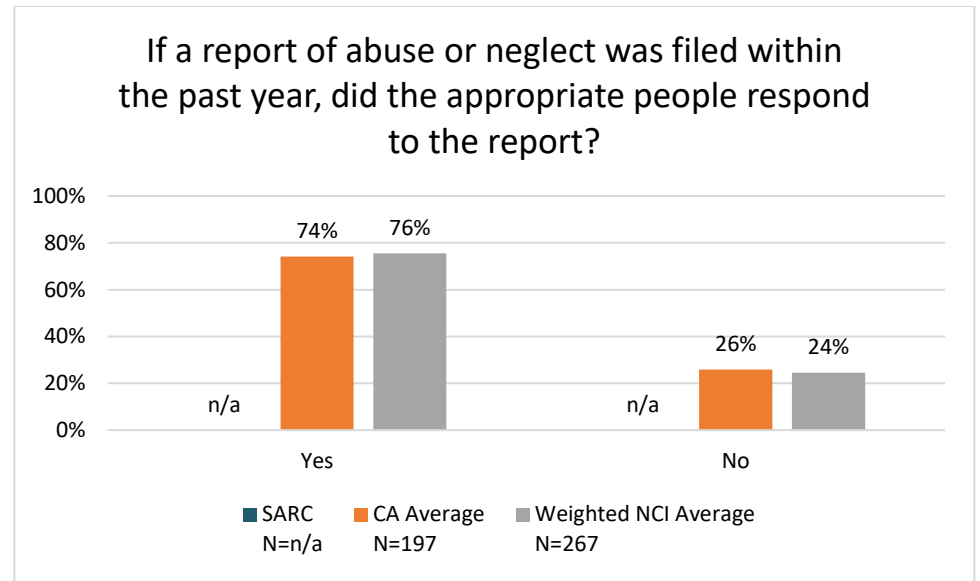
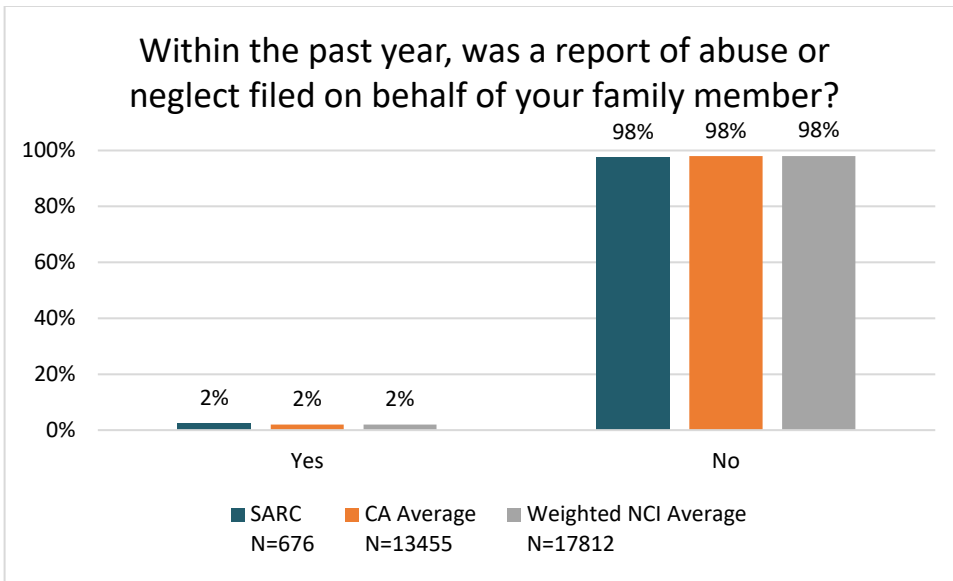


If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled?

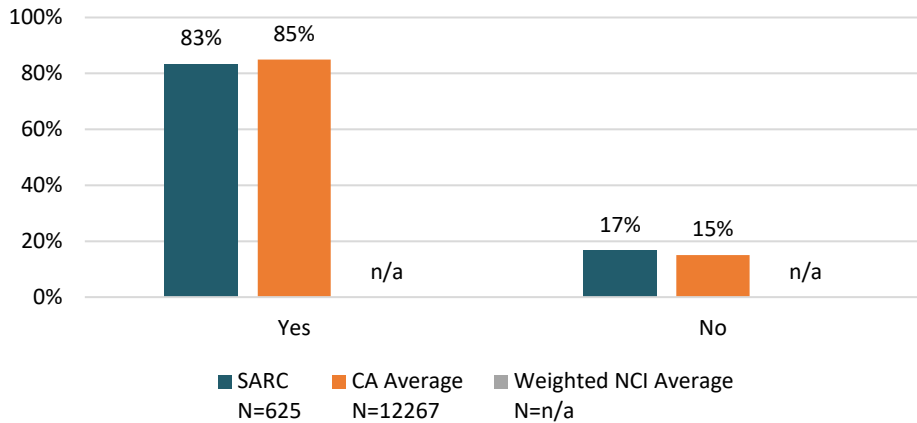


Do you know how to report abuse or neglect related to your family member?

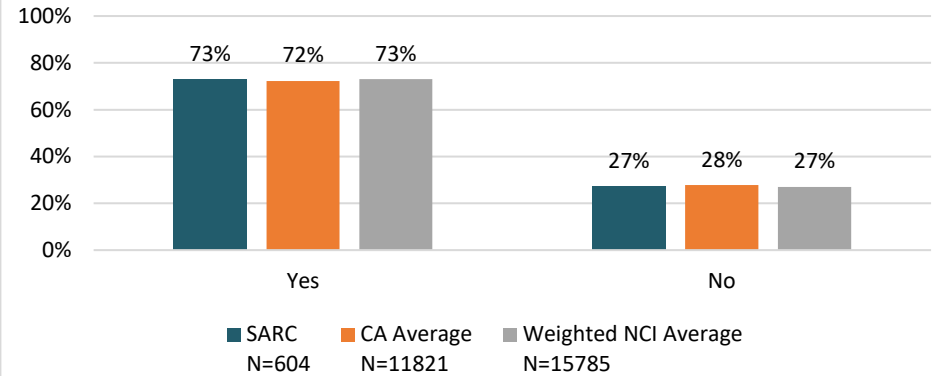




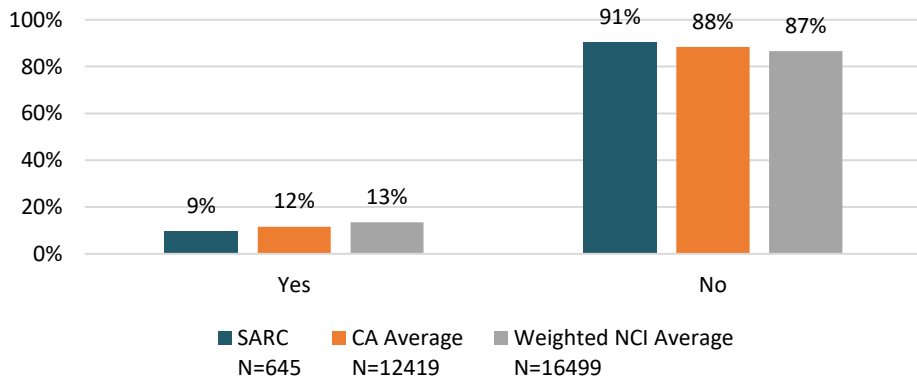
Have services helped keep your family member in your home?



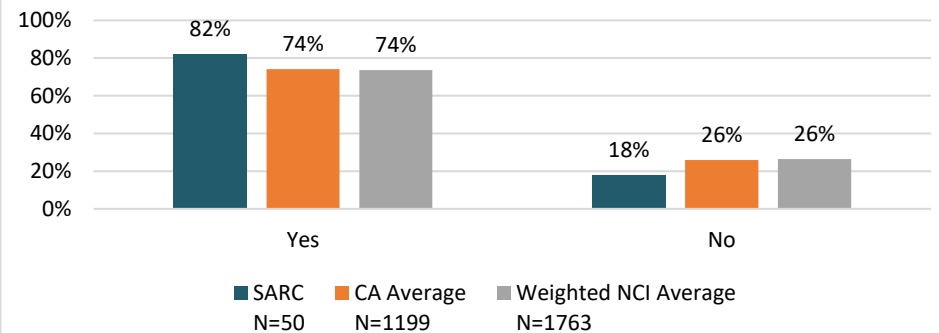
Have services and supports reduced your family's out-of-pocket expenses for your family member's care?



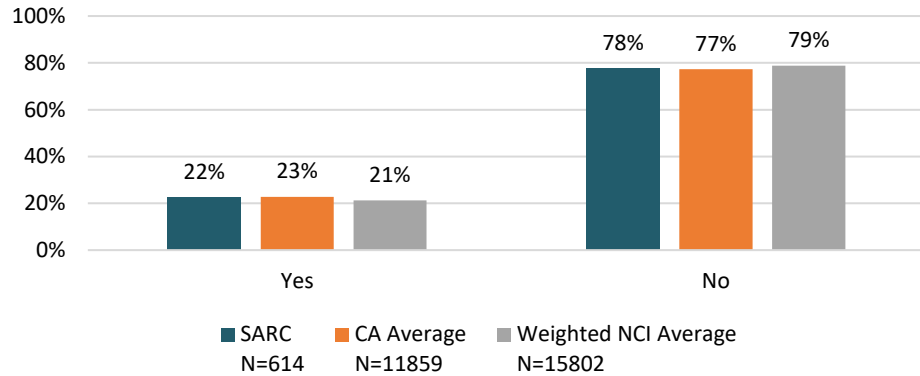
Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?



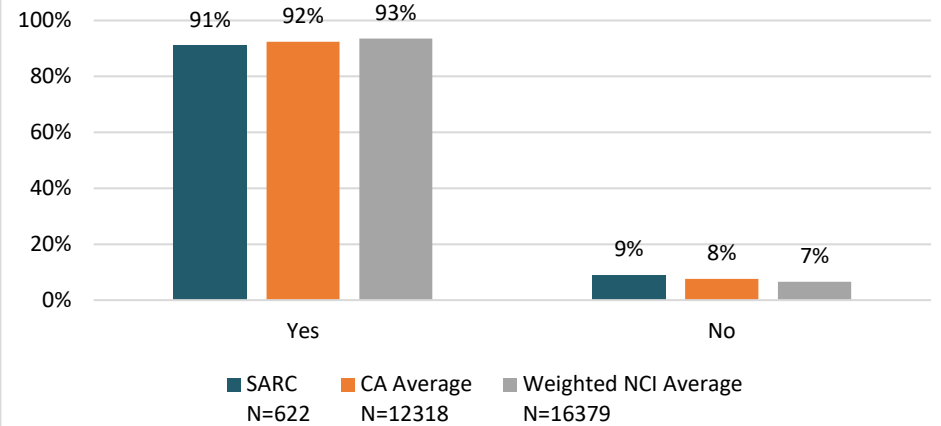
If services or supports received by the family were reduced, suspended or terminated during the past year, did the change in services affect your family member negatively?



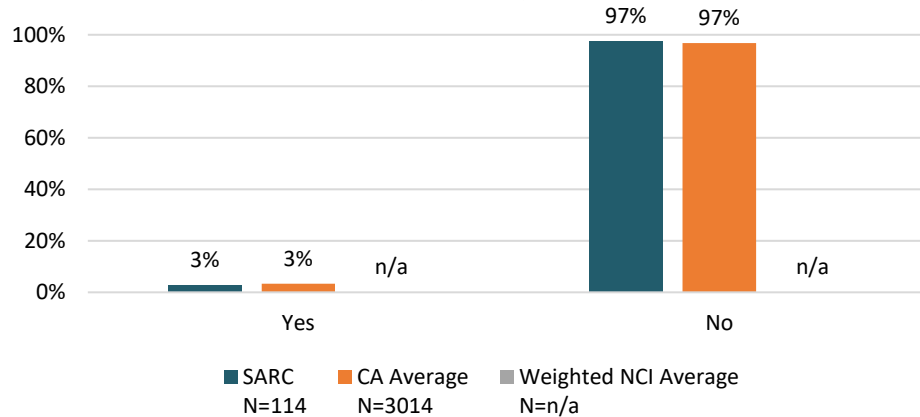
Have the services or supports that your family member received been increased in the past year?



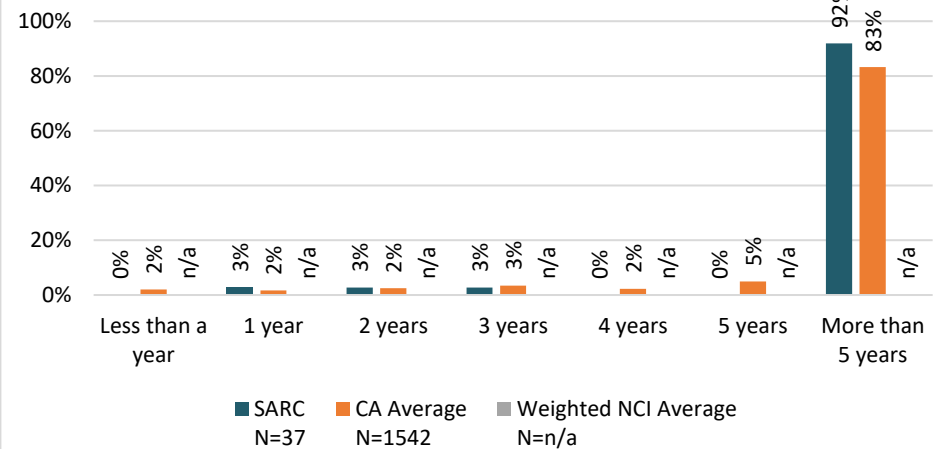
Are services and supports helping your family member to live a good life?



Has your family member moved from a Developmental Center (DC) to the community in the past 5 years?



How long has your family member lived in the community?



Satisfaction With Services and Supports Tables

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

Table Q53. Overall, are you satisfied with the services and supports your family member currently receives?

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

RC v CA v NCI	Always	Usually	Sometimes	Seldom/Never	N
SARC	36%	44%	16%	4%	700
CA Average	41%	40%	14%	4%	13,780
Weighted NCI Average	40%	43%	13%	4%	18,166

Table Q54. Do you know how to file a complaint or grievance about provider agencies or staff?⁷

RC v CA v NCI	Yes	No or Don't Know	N
SARC	39%	61%	723
CA Average	51%	49%	14,045
Weighted NCI Average	61%	39%	18,465

Table Q55. If a complaint or grievance was filed or resolved in the past year, are you satisfied with the way it was handled?

RC v CA v NCI	Yes	No	N
SARC	38%	63%	96
CA Average	54%	46%	1,795
Weighted NCI Average	58%	42%	2,176

Table Q56. Do you know how to report abuse or neglect related to your family member?⁸

RC v CA v NCI	Yes	No or Don't Know	N
SARC	60%	40%	715
CA Average	72%	28%	14,014
Weighted NCI Average	78%	22%	18,428

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

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

Table Q57. Within the past year, was a report of abuse or neglect filed on behalf of your family member?

RC v CA v NCI	Yes	No	N
SARC	2%	98%	676
CA Average	2%	98%	13,455
Weighted NCI Average	2%	98%	17,812

Table Q58. If a report of abuse or neglect was filed within the past year, did the appropriate people respond to the report?

RC v CA v NCI	Yes	No	N
SARC	n/a	n/a	n/a
CA Average	74%	26%	197
Weighted NCI Average	76%	24%	267

Table Q59. If a report of abuse or neglect was filed on behalf of family member by someone outside of your family, were you notified of the report in a timely manner?

RC v CA v NCI	Yes	No	N
SARC	n/a	n/a	n/a
CA Average	62%	38%	149
Weighted NCI Average	69%	31%	198

Table Q60. Do you feel that services and supports have made a positive difference in the life of your family member?

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

RC v CA v NCI	Yes	No	N
SARC	92%	8%	632
CA Average	93%	7%	12,628
Weighted NCI Average	94%	6%	16,722

Table Q61. Have services helped keep your family member in your home?

CA specific question

RC v CA v NCI	Yes	No	N
SARC	83%	17%	625
CA Average	85%	15%	12,267
Weighted NCI Average	n/a	n/a	n/a

Table Q62. Have services and supports reduced your family’s out-of-pocket expenses for your family member’s care?

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

RC v CA v NCI	Yes	No	N
SARC	73%	27%	604
CA Average	72%	28%	11,821
Weighted NCI Average	73%	27%	15,785

Table Q63. Have the services or supports that your family member received during the past year been reduced, suspended, or terminated?

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

RC v CA v NCI	Yes	No	N
SARC	9%	91%	645
CA Average	12%	88%	12,419
Weighted NCI Average	13%	87%	16,499

Table Q64. 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?

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

RC v CA v NCI	Yes	No	N
SARC	82%	18%	50
CA Average	74%	26%	1,199

RC v CA v NCI	Yes	No	N
Weighted NCI Average	74%	26%	1,763

Table Q65. Have the services or supports that your family member received been increased in the past year?

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

RC v CA v NCI	Yes	No	N
SARC	22%	78%	614
CA Average	23%	77%	11,859
Weighted NCI Average	21%	79%	15,802

Table Q66. Are services and supports helping your family member to live a good life?

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

RC v CA v NCI	Yes	No	N
SARC	91%	9%	622
CA Average	92%	8%	12,318
Weighted NCI Average	93%	7%	16,379

Table Q67. Has your family member moved form a Developmental Center (DC) to the community in the past 5 years?

CA specific question

RC v CA v NCI	Yes	No	N
SARC	3%	97%	114
CA Average	3%	97%	3,014
Weighted NCI Average	n/a	n/a	n/a

Table Q68. How long has your family member lived in the community?

CA specific question

RC v CA v NCI	Less than a year	1 year	2 years	3 years	4 years	5 years	More than 5 years	N
SARC	0%	3%	3%	3%	0%	0%	92%	37
CA Average	2%	2%	2%	3%	2%	5%	83%	1,542
Weighted NCI Average	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a